Law Reform Committee

Inquiry into Access by Donor-Conceived People to Information about Donors

March 2012

PARLIAMENT OF VICTORIA

Inquiry into Access by Donor-Conceived People to Information about Donors

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Committee Members

This Inquiry was conducted during the term of the 57th Parliament.

The members of the Law Reform Committee are:

Mr Clem Newton-Brown, MP (Chair)

Ms Jane Garrett, MP (Deputy Chair)

Mr Anthony Carbines, MP

Mr Russell Northe, MP

Mrs Donna Petrovich, MLC

Staff

For this Inquiry, the Committee was supported by a secretariat comprising:

Executive Officer: Dr Vaughn Koops

Research Officer: Ms Amie Gordon

Research Officer: Ms Vathani Shivanandan

Administrative Officer: Ms Helen Ross-Soden

The Law Reform Committee

The Victorian Parliament Law Reform Committee is constituted under the *Parliamentary Committees Act 2003*, as amended.

The Committee comprises five members of Parliament drawn from both houses and all parties.

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.

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Terms of Reference

Referred by the Legislative Assembly on 10 February 2011.

That under s 33 of the *Parliamentary Committees Act 2003*, the Law Reform Committee is required to inquire into, consider and report no later than 30 June 2012 on donor-conceived persons and, further to the interim report of the Law Reform Committee of the 56th Parliament, the Committee is asked to consider:

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; and

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

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Chair’s Foreword

While the Committee considered many issues during the course of this Inquiry, the key questions that emerged were essentially ethical: should a donor-conceived person have the right to access information about his or her donor? Should a donor-conceived person have this right even if the donor was assured that he would remain anonymous? What role, if any, should the State of Victoria have in facilitating access to information about the identity of parties to donor-conception?

Currently, people who were conceived from gametes donated after 1998 are entitled under legislation to obtain identifying information about their donors when they reach adulthood. People conceived from gametes donated between 1988 and 1997 can only access identifying information about their donors with the donor’s consent. However, people conceived from gametes donated prior to 1988 have no legislated right to obtain identifying information.

Consequently, the Committee was asked to consider appropriate measures to reconcile conflicts between the contemporary practice that requires disclosure of information to donor-conceived people, and an historical tradition that did not.

Many donor-conceived people who are unable to obtain information about their donors experience considerable distress and anguish. They are denied information about their identity, which is a right that most of us take for granted. Their ability to access information is constrained as a result of decisions made by adults – their parents, the donor, and medical professionals – before they were conceived.

On the other hand, donors were acting altruistically in making their donations, and were promised anonymity. While most of the donors the Committee received evidence from empathised with their donor-offspring and recognised their need to know the identity of their donor, some donors opposed the release of identifying information. These donors were concerned about how their family relationships would be affected should information about their identity be released to their donor-offspring. However, some donors desired contact from their donor-offspring.

When the Committee commenced this Inquiry, it was inclined toward the view that the wishes of some donors to remain anonymous should take precedence – as they made their donation on that basis – and that identifying information should only be released with a donor’s consent.

Upon closer consideration, however, and after receiving evidence from a diverse range of stakeholders – donor-conceived people, donors, parents, medical and counselling professionals, department representatives, and academics – the Committee unanimously reached the conclusion that the state has a responsibility to provide all donor-conceived people with an opportunity to access information, including identifying information, about their donors.

The Committee believes that providing all donor-conceived people with the opportunity to access identifying information about their donors, regardless of their date of conception, is consistent with the first guiding principle found in the Victorian legislation regulating donor-conception – that the welfare and interests of persons born as a result of assisted reproductive treatment procedures are paramount. It is also consistent with comparable situations, such as adoption, where Victorian legislation retrospectively allowed adopted people to access identifying information about their birth parents.

However, the Committee also recognises the importance of ensuring that there will be no unreasonable interference in donors' lives should donor-conceived people have access to identifying information. Consequently, one of the Committee's recommendations is that donors, and donor-conceived people, have the ability to place a veto on contact from each other.

It is also important that donors, and all of the people affected by donor-conception, have comprehensive counselling and other support services available to them. The Committee has made several recommendations in this regard.

On behalf of the Law Reform Committee, I wish to thank the individuals and groups who contributed to the Inquiry by providing submissions and appearing at public hearings. I particularly wish to thank those people who shared their personal experiences about their involvement in donor-conception. Their courage should be commended.

I would like to thank my fellow Committee members – Deputy Chair Ms Jane Garrett MP, Mr Anthony Carbines MP, Mr Russell Northe MP, and Mrs Donna Petrovich MLC – for their thoughtful contributions to the Inquiry, and for their collegial and constructive approach to the work of the Committee.

Finally, I would like to thank the staff of the Committee for their ongoing dedication to the work of the Committee and for their excellent work towards this report: the Executive Officer, Dr Vaughn Koops; the Research Officer, Ms Amie Gordon; and the Administrative Officer, Ms Helen Ross-Soden. Ms Vathani Shivanandan also assisted the Inquiry as Research Officer in its initial stages.

Mr Clem Newton-Brown MP
Chair

Executive Summary

Chapter One: Introduction

This Inquiry is concerned with the rights of donor-conceived people to access information about their donors. Currently, donor-conceived people have different rights in this regard, depending upon the date of donation of the gametes from which they were conceived.

Assisted reproductive procedures help people to conceive a child through a means other than sexual intercourse. Donated gametes are often used in these procedures where partners have had difficulty conceiving, when a person carries a hereditary disease or genetic abnormality, or when women without male partners wish to have children. This is referred to as donor-conception. There are likely several thousands of donor-conceived people who were conceived in Victoria prior to 1988, and more than 5500 have been born since then. Many of these people will be unaware that they are donor-conceived.

The Committee heard views from a wide range of individuals and organisations in the course of this Inquiry, through submissions and public hearings. This report has been informed by the evidence of donors, donor-conceived persons, recipient parents, academics, and representatives from government agencies, fertility clinics, medical associations and support groups.

Chapter Two: A history of donor-conception in Victoria

Victoria was one of the leading international sites for the development of assisted reproductive technologies such as IVF during the 1970s and into the 1980s. Victoria was also the first Australian state, and the first jurisdiction in the world, to enact legislation regulating assisted reproductive treatment. This legislation – the *Infertility (Medical Procedures) Act 1984* – came into effect in 1988. The legislation has been significantly amended twice, with the *Infertility Treatment Act 1995* effective from 1 January 1998, and the current *Assisted Reproductive Treatment Act 2008* coming into effect on 1 January 2010.

Prior to 1988, donor-conception was unregulated, and was entirely in the hands of the medical profession. A culture of secrecy was pervasive in the early days of donor-conception, despite contemporaneous changes to adoption laws to eliminate secrecy. Donors and recipient parents were required to sign anonymity contracts agreeing that they would not seek to discover each other's identity. Parents undergoing treatment were advised not to disclose the manner of their child's conception to their child or to others, and clinics attempted to match the physical characteristics of the donor and the prospective father, so that the child would not look too different from the father.

Donor-conception practices in Victoria have evolved significantly over time to encourage far greater openness. Legislation regulating donor-conception has incrementally introduced provisions allowing donor-conceived people to access information about their donors, with the *Infertility (Medical*

Procedures) Act 1984 allowing post-1988 donor-conceived people to obtain identifying information with the donor's consent, and the *Infertility Treatment Act 1995* introducing the right for all post-1998 donor-conceived people to obtain identifying information about their donor in all cases.

Chapter Three: Access by donor-conceived people to information about donors

Not all donor-conceived people want to know who their donors are, or desire more information about their donors. However, donor-conceived people who want to know who their donors are can experience distress when they are unable to obtain information about them. This distress may be exacerbated when a donor-conceived person learns of the circumstances of their conception later in life.

Under current legislation in Victoria, rights for access to information by donor-conceived people are determined by the date at which the gametes used in their conception were donated. People conceived from gametes donated before 1 July 1988 have no rights to access information about their donors under legislation, although they may obtain information through a voluntary register. People conceived from gametes donated between 1 July 1988 and 1 January 1998 are entitled to receive non-identifying information about their donors, and identifying information with their donors' consent. People conceived from gametes donated after 1 January 1998 are entitled to obtain non-identifying and identifying information about their donors. Legislative change will be required to provide people conceived from gametes donated prior to 1 July 1988 with access to identifying information about their donors.

There are a number of arguments in favour of providing access to identifying information to all donor-conceived people in Victoria. These include: providing for communication of medical information between donor-conceived people and their donors; ensuring that donor-conceived people are able to exercise their rights under the *Charter of Human Rights and Responsibilities Act 2006*; and ensuring that the principle articulated in the *Assisted Reproductive Treatment Act 2008*, that "the welfare and interests of persons born or to be born as a result of treatment procedures are paramount", is applied. On the other hand, donors were promised anonymity when making donations prior to 1 January 1998, and providing donor-conceived people with access to identifying information may constitute an unreasonable breach of donors' privacy.

On balance, the Committee determined that the right of a donor-conceived person to have access to identifying information about his or her donor is paramount. The Committee therefore recommends that the Victorian Government introduce legislation to allow all donor-conceived people to obtain identifying information about their donors. However, in order to provide some assurance to donors and donor-conceived people that they will not consequently experience unreasonable interference in their lives, the Committee also recommends that both parties be able to lodge a contact veto to prohibit contact with each other.

Chapter Four: Donors’ access to information

Donors have a wide range of views on whether donor-conceived people should have access to identifying information. The Committee heard from donors who were happy to have identifying information provided to donor-conceived people and others who did not want identifying information shared with others. Some donors were worried about the effect that contact with their donor-offspring would have on their families and careers.

Under current legislation in Victoria, donors who provided gametes prior to 1 July 1988 have no right to access identifying or non-identifying information about their donor-offspring. They may obtain information from the voluntary register (if other parties have also volunteered information), and may obtain non-identifying information from the treatment clinic, if it is still operating. Donors who provided gametes after 1 July 1988 are able to obtain non-identifying information about their donor-offspring from the central register, and identifying information with the consent of their offspring (or if that person is a minor, his or her parents or guardians).

The Committee determined that all donors should be provided with access to non-identifying information about any person conceived from their gametes. The Committee considered that providing all donors with a mechanism to obtain identifying information about their donor-offspring was not necessarily in the interests of the donor-conceived person, as evidence suggests that it is preferable that donor-conceived people learn of their status from their parents. In the Committee’s view, existing arrangements for donors’ access to identifying information should remain. The Committee also recommends that a mechanism be introduced to allow medical information to be passed from a donor to their donor-offspring, if a significant genetic or hereditary risk to the donor-conceived person exists.

Chapter Five: Access to information about donor-conceived siblings

A number of donor-conceived people expressed an interest in knowing more about their donor-conceived siblings. Some donor-conceived people also expressed concerns about forming relationships with people in their age group, fearing that they may discover their partner or spouse is their half-sibling. Some donor-conceived people find it difficult to form relationships for this reason, even though the likelihood of forming such a relationship is low.

Donor-conceived people are not currently entitled to receive any information about their half-siblings. The only mechanism through which contact can be made is the voluntary register, which requires the participation of both (or all) of the half-siblings.

The Committee recommends that non-identifying information about half-siblings be made available to donor-conceived people. This would provide some means for donor-conceived people to assure themselves that a person they formed a relationship with was not related to them.

Access to identifying information on half-siblings should not be provided to donor-conceived people. The Committee recommends that a mechanism be introduced to allow medical information to be passed from a donor-conceived person to his or her half-siblings should a significant genetic or hereditary risk to the half-sibling exist.

Chapter Six: Counselling and support services

Contact between donor-conception stakeholders – including donor-conceived people, their parents, half-siblings, and donors – is still very new and uncharted territory. All parties will feel vulnerable throughout this process, and will struggle to determine the appropriate way to proceed. It is important that particularly leading up to and during this process, comprehensive counselling and support services be available to these people and their families. The arrangements that were in place when the former Infertility Treatment Authority was responsible for providing these services (up until the end of 2009) were far superior to the limited and fragmented services currently available.

While it operated, the Infertility Treatment Authority was responsible for managing the donor registers, and provided a range of related services. These included donor-linking and counselling services for those seeking information about their donor or donor-conceived offspring, and operating a letterbox service. The letterbox service allowed donor-conception stakeholders to communicate and gradually develop a relationship before revealing their identities to each other.

The introduction of the *Assisted Reproductive Treatment Act 2008* in 2010 dramatically changed the services available, by transferring the donor registers to the Registry of Births, Deaths and Marriages, and conferring a limited counselling role on a section within the Department of Human Services. The Committee heard much evidence to suggest that these changes have markedly reduced the services available to donor-conception stakeholders, and have made it difficult and confusing to access those services.

It would be preferable that all donor-conception stakeholders are able to access the information, counselling and support services that they require through a single agency with relevant expertise.

Chapter Seven: Protection and management of records

Victoria has had reliable and centralised donor-conception records from 1988 onwards, as since this time, clinics and doctors have been required to provide details about donor-conception procedures to be recorded on the central register. However, pre-1988 donor-conception records are held in disparate locations, and some may be inaccessible, incomplete, inaccurate, or may no longer exist. In addition, where these records are held privately, they are legally able to be destroyed at any time.

As donor-conception records are a type of identity record, they should be protected and preserved indefinitely. To ensure that all donor-conception records are accessible, it is critical that they all be held and managed centrally. Ideally, the managing agency would be the same agency that is responsible for providing counselling and support services to donor-conception stakeholders.

It is important that information in donor-conception records is verified before it is released. Where there are gaps and uncertainties in the records, a DNA matching facility could assist to overcome these. It is also desirable that a national donor-conception register be established, and the Victorian Government could play a role in championing the development of consistent donor-conception legislation in all Australian states and territories.

Chapter Eight: Other issues in donor-conception

In the course of this Inquiry, a number of issues were raised that do not fall within the Committee's Terms of Reference. The Committee did not make findings or recommendations on these issues, but considers that it is important to note the issues raised. These include:

- the number of families who should be permitted to use gametes donated by a single donor;
- the 'reasonable expenses' that donors should be entitled to receive, if any;
- whether potential donors should be subject to police checks before they are accepted as donors;
- whether the importation of gametes from overseas should be banned; and
- whether the legislation should be amended to clarify that a donor does not have the right to make decisions about embryos resulting from his or her gamete donation.

Table of Recommendations

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Glossary

AFRS	the Adoption and Family Records Service, predecessor of FIND
AID	assisted insemination by donor
ANZICA	Australian and New Zealand Infertility Counsellors Association
ART	assisted reproductive treatment; the use of procedures such as IVF or artificial insemination to achieve pregnancy
BDM	the Victorian Registry of Births, Deaths and Marriages
DC	donor-conceived
DHS	the Victorian Department of Human Services
DI	donor insemination; the same procedure as assisted insemination by donor
donor	a person who has donated gametes
donor-conceived offspring (or donor-offspring)	term used to describe a donor-conceived person in relation to their donor
donor-conceived person	a person conceived with the use of donated gametes (either egg or sperm, or both)
embryo	an egg that has been fertilised by a sperm and has undergone one or more cell divisions
FIND	Family Information Networks and Discovery, a unit within the DHS
FSA	Fertility Society of Australia
FTE	full-time equivalent (employees)
gametes	reproductive cells – that is, sperm or eggs (oocytes)
identifying information	information from which a person’s identity may be ascertained; would generally include their full name, date of birth and current address
ITA	Infertility Treatment Authority

IVF	in vitro fertilisation; where eggs and sperm are combined in the laboratory for fertilisation outside the body, and the resultant embryo(s) are replaced in the uterus
NHMRC	National Health and Medical Research Council
non-identifying information	non-specific information from which a person's identity is unlikely to be able to ascertained; may include information such as their gender, month of birth, year of birth, interests and physical characteristics
PILCH	Public Interest Law Clearing House
PROV	Public Record Office Victoria
recipient parents	people who have used donated gametes (sperm and/or eggs) to conceive a child
RTAC	Reproductive Technology Accreditation Committee
SRACI	Standing Review and Advisory Committee on Infertility
VARTA	Victorian Assisted Reproductive Treatment Authority
VICG	Victorian Infertility Counsellors Group
VLRC	Victorian Law Reform Commission

Chapter

1

Chapter One: Introduction

On 10 February 2011, the Legislative Assembly of the 57th Parliament passed a motion that further to the interim report of the Law Reform Committee of the 56th Parliament, the Committee inquire into, consider and report no later than 30 June 2012 on donor-conceived persons, with the same terms of reference provided to the previous Committee. In particular, the Committee was asked to consider:

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; and

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

1.1 Background

Donor-conceived people are persons who have been conceived with the use of donated gametes – donated sperm, a donated oocyte (egg), or both. The term ‘donor-conception’ is used in this Report to refer to circumstances where assisted reproductive treatment has involved the use of donor gametes to conceive.

A large focus of this report is on donor-conceived people who were conceived with gametes donated prior to 1988. In this time period, the use of donated sperm was much more common than the use of donated oocytes – egg donation did not become a common practice until the early 1990s – so the vast majority of donors were men. However, this Report also considers arrangements surrounding donor-conception for people conceived after 1988, and examines current structures for the provision of services and information to donor-conceived people.

One of the main challenges for the Committee in considering the range of issues addressed in this Inquiry is that different rights currently apply to donor-conceived people, their families, and donors, depending on the date that the gametes used to conceive them were donated. The Committee has considered these and other issues, and recommends a range of measures the Victorian Government can undertake to improve access to information and services for all participants in donor-conception.

1.1.1 What is assisted reproduction?

'Assisted reproduction' refers to procedures that are used to assist a person to conceive a child other than through intercourse. Some people may provide their own sperm and eggs for an assisted reproductive procedure, whereas other people may need to use sperm and/or eggs (gametes) obtained from a donor. The donor may be someone that the recipient knows, or may be a person previously unknown to the recipient. Donated gametes are often used when partners have had difficulties conceiving, or when a person carries a hereditary disease or genetic abnormality, or when women without male partners wish to have children.

The most common assisted reproductive treatment procedures include:

- **Insemination with donor sperm** (also referred to as artificial insemination, donor insemination or assisted insemination): where a male partner is infertile, or where there is no male partner, donated sperm can be artificially inserted into the woman's vagina or uterus, using a needleless syringe or a catheter. This usually occurs in a clinical setting with the assistance of medical staff, where the donated sperm has been frozen and screened, but can also occur through private arrangements at home, using fresh semen from a known donor;[1]

- **In vitro fertilisation (IVF)**: in IVF, a woman's egg and a male's sperm are mixed in a laboratory. If fertilisation occurs successfully and the resulting embryos appear normal, they are transferred into the uterus of the woman;[2]

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[1] Monash IVF, *Guide to getting started handbook*, Monash IVF, Melbourne, 2003, p. 28; Victorian Law Reform Commission, *Assisted reproductive technology & adoption*, Final report, VLRC, Melbourne, 2007, p. 18.

[2] Monash IVF, *Guide to getting started handbook*, Monash IVF, Melbourne, 2003, p. 30.

- **Gamete intra-fallopian transfer (GIFT)**: allows fertilisation to take place in the woman's body. Eggs are collected from a woman's ovaries and, together with previously collected sperm, are inserted directly into the woman's fallopian tube using a fine plastic tube. This type of treatment is becoming less common;[3] and

- **Intracytoplasmic sperm injection (ICSI)**: involves the direct injection of a single sperm into the substance (cytoplasm) of the egg in a laboratory, with the resultant embryo transferred to the woman's uterus. The microinjection procedure used in this procedure is a newer technique (used since 1992), and is employed for more severe forms of male infertility or after a cycle with poor fertilisation.[4]

While IVF was originally developed to assist women whose fallopian tubes were blocked or damaged, as assisted reproductive technology has developed it has been used to overcome many other causes of infertility, such as endometriosis, unexplained (idiopathic) infertility and reduced sperm count.[5]

In addition to donor insemination, donor gametes have often been used in IVF and GIFT treatments. With the development of the ICSI procedure, donor sperm is now used less frequently for couples where the male partner has low fertility, although single women and lesbian couples continue to rely on the use of donor sperm to conceive.[6]

1.1.2 Numbers of donor-conceived people and donors

The Committee was not able to obtain accurate figures on the numbers of people born through donor-conception, and the number of donors, from the period prior to 1988. Monash IVF noted that 848 births occurred during this period at the Queen Victoria Medical Centre, although those records do not distinguish between single and multiple births (i.e. twins or triplets), so there were likely more children born during this period.[7] Monash IVF noted that 264 individual donors were recorded during this period, along with 158 "ejaculate numbers", which likely included multiple donations from single donors, so that the number of donors who donated at the Queen Victoria Medical Centre in this period is certainly less than 422.[8]

Melbourne IVF told the Committee that records for thousands of donor-recipients prior to 1988 are held in storage at the Royal Women's Hospital, but that less than 100 donors were recorded there.[9] The

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[3] Ibid, p. 29.

[4] Ruth McNair, *Outcomes for children born of A.R.T. in a diverse range of families*, Victorian Law Reform Commission, Melbourne, 2004, p. 36; Monash IVF, *Guide to getting started handbook*, Monash IVF, Melbourne, 2003, p. 30.

[5] Monash IVF, *Guide to getting started handbook*, Monash IVF, Melbourne, 2003, p. 10.

[6] Victorian Law Reform Commission, *Assisted reproductive technology & adoption*, Final report, VLRC, Melbourne, 2007, p. 28.

[7] Maria Gabbe, Scientist, Monash IVF, *Personal communication*, 17 October 2011.

[8] Ibid.

[9] Joanne McCann, Operations Manager, Melbourne IVF, *Transcript of evidence*, Melbourne, 10 October 2011, p. 13.

Committee was also told that, at a rough estimate, there were around 150 donors at the Prince Henry's Hospital during this period.[10]

While the Committee was not able to obtain reliable estimates of the number of donor-conceived children and donors from the period prior to 1988, it is likely that thousands of children were born through sperm donation during this period, and that there were around 500 donors. This does not include 'fresh' sperm inseminations that may have occurred outside Victoria's major infertility facilities during this period.

By contrast, the numbers of donor-conceived people and donors after 1988 are relatively certain, as the *Infertility (Medical Procedures) Act 1984*, introduced in 1988, established a central register to record donors and births from 1988 onwards. For the period 1988 to 1998, 586 donors (236 egg donors and 350 sperm donors) and 2712 birth registrations were recorded (2402 from sperm donation).[11]

From 1998 to 30 June 2011, the central register received around 2787 birth notifications from clinics (1453 from sperm donation) and 1299 donors were recorded (848 egg donors and 451 sperm donors).[12] Table 1 summarises births and donors over the period 1988 to 30 June 2011.

Table 1: Numbers of donor-conceived births and donors recorded on the central register, 1988 to 1998 and 1998 to 2011.[13]

Time period	Child conceived with donation from…				Donors		
	sperm	eggs	embryo / sperm & egg	**total**	sperm	egg	**total**
1988 to 1998	2402	269	41	**2712**	350	236	**586**
1998 to 2011	1453	1146	188	**2787**	451	848	**1299**

1.1.3 Donor-conceived people's awareness of the manner of their conception

The Committee heard evidence that very few donor-conceived people born prior to 1988 are likely to be aware of the manner of their conception. More surprisingly, and despite the fact that donor-conceived people born between 1988 and 1998 could potentially be approached for consent to release identifying information to their donor, the Committee also heard

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[10] Gab Kovacs, *Transcript of evidence*, Melbourne, 10 October 2011, p. 33.

[11] Infertility Treatment Authority, *Annual report 2009: twelfth and final report*, ITA, Melbourne, 2009, p. 18.

[12] Ibid; Victorian Assisted Reproductive Treatment Authority, 'A statistical snapshot of the donor registers in Victoria for 2010-2011', VARTA, Melbourne, 2011, viewed 23 Nov 2011, <www.varta.org.au>, p. 2.

[13] Infertility Treatment Authority, *Annual report 2009: twelfth and final report*, ITA, Melbourne, 2009, p. 18; Victorian Assisted Reproductive Treatment Authority, 'A statistical snapshot of the donor registers in Victoria for 2010-2011', VARTA, Melbourne, 2011, viewed 23 Nov 2011, <www.varta.org.au>, p. 2.

evidence that most of these donor-conceived people are also unaware of their status:

> The Institute of Family Studies did a wellness study on Australian families and they had about 2500 families they studied, which gave us a control group to compare to. We then identified 120 DI [donor insemination] families and also contacted them. I rang every one of them up and spoke to them. One of the things I asked them on the phone, when again I thought it had to be a tactical phone call because I did not know whether the children knew or whether they did not know, but I managed to talk to 120 people and of those 120, only 40 of the children had been told about their donor conception; two thirds were not told.
>
> Despite the fact that all these couples were counselled, mainly by Helen Kane, Helen was our social worker most of the time, counselled the couples, told them how important honesty was and they should tell them and two thirds have not told them, which means there are not that many children out there who know and the percentage of those who even know who really want to chase up the donor seems to be fairly small.[14]

A number of studies suggest that this circumstance is not unusual, and that children conceived through donor-conception are typically not informed of the manner of their conception.[15] Studies conducted with the parents of donor-conceived children born around or prior to 1988 show that most had decided not to disclose information about the conception to the child. For example:

- a longitudinal study of European assisted reproduction families found that, of 94 sets of parents with donor-conceived children, just eight (8.6%) had told their child by the time he or she was twelve years old.[16] Most parents had decided never to tell their children that they were donor-conceived, with 65 (69.9%) indicating this intention;[17]

- a study in the Netherlands found that around 80 per cent of couples whose children were conceived through donor insemination (DI) in 1980 and in 1996, respectively, decided not to inform their child about the nature of his or her conception;[18] and

- in the United States, a study of 27 married heterosexual couples who had used DI to conceive revealed that nearly three-quarters of the sample had not disclosed to their child and did not plan to, although

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[14] Gab Kovacs, *Transcript of evidence*, Melbourne, 10 October 2011, p. 30.

[15] Maggie Kirkman, 'Genetic connection and relationships in narratives of donor-assisted conception', *Australian Journal of Emerging Technologies and Society*, vol. 2, no. 1, pp. 1-21, 2004, p. 2.

[16] S Golombok, A Brewaeys, M.T. Giavazzi, D Guerra, F MacCullum and J Rust, 'The European study of assisted reproduction families: the transition to adolescence', *Human Reproduction*, vol. 17, no. 3, pp. 830-840, 2002.

[17] Ibid, p. 836.

[18] D van Berkel, L van der Veen, I Kimmel and E te Velde, 'Differences in the attitudes of couples whose children were conceived through artificial insemination by donor in 1980 and 1996', *Fertility and Sterility*, vol. 71, no. 2, pp. 226-231, 1999.

> 85% had told at least one other person about conception via the use of DI.[19]

The issue of disclosure to donor-conceived people is discussed throughout this Report. The Committee notes that while there are likely thousands of donor-conceived people who may potentially be affected by any change to legislation, it is probable that only a fraction of these people are actually aware that they are donor-conceived.

1.2 Context of the Inquiry

The *Assisted Reproductive Treatment Act 2008* currently regulates assisted reproductive treatment in Victoria. In Chapter Two, the Committee reviews the history of the legislation, and examines how there came to be three groups of donor-conceived people in Victoria with different rights to access information about their donors.

There have been a number of reviews of Victorian and Australian assisted reproduction legislation over the past few years, each of which have considered some of the issues explored in this Report, and are summarised below.

1.2.1 Victorian Law Reform Commission Report

From 2002, the Victorian Law Reform Commission (VLRC) undertook a review of the laws then governing the use of assisted reproductive technology and adoption, including the *Infertility Treatment Act 1995.*[20] The VLRC conducted extensive research and undertook substantial public consultation over four years, releasing a final report in June 2007 which included 130 recommendations for law reform in this area. While considerably broader than the Committee's Inquiry, the VLRC's report considered and commented on some of the matters with which this Inquiry is concerned.

Many of the VLRC's recommendations were incorporated into the legislation that was subsequently passed by the Victorian Parliament – the *Assisted Reproductive Treatment Act 2008* – which came into effect on 1 January 2010, and remains in effect today. The VLRC's recommendations and key aspects of the *Assisted Reproductive Treatment Act 2008* are discussed in Chapter Two.

1.2.2 Australian Senate Committee Report

On 16 June 2010, the Australian Senate issued terms of reference to its Legal and Constitutional Affairs References Committee (LCAR Committee)

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[19] S Leiblum and A Aviv, 'Disclosure issues and decisions of couples who conceived via donor insemination', *Journal of psychosomatic obstetrics and gynecology*, vol. 18, no. 4, pp. 292-300, 1997.

[20] Victorian Law Reform Commission, *Assisted reproductive technology & adoption*, Final report, VLRC, Melbourne, 2007, p. 18.

for inquiry and report into matters regarding past and present practices of donor-conception in Australia, including consideration of the rights of donor-conceived individuals.[21] The LCAR Committee's report and recommendations are discussed in Chapter Two.

While the LCAR Committee in principle supported donor-conceived individuals having a right to information about their biological heritage, it did not make a specific recommendation regarding the issue of whether donor-conceived individuals should be granted retrospective access to identifying information about their donors.[22]

1.2.3 Law Reform Committee Interim Report

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. The Committee was requested to provide an interim report to the Parliament by September 2010 (prior to the conclusion of the 56th Parliament in November 2010), and to provide a final report by 2011.[23] On 15 September 2010, Mr Johan Scheffer MLC, the Chair of the Committee in the 56th Parliament, tabled the Law Reform Committee's Interim Report.[24]

The Interim Report made two recommendations:[25]

> **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 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.

To the Committee's knowledge, the Government has not yet taken any steps to implement Recommendation 1 from the Interim Report. Recommendation 2 was implemented by the Legislative Assembly of the 57th Parliament when it referred the terms of reference of the current Inquiry to the Law Reform Committee, on 10 February 2011, for report by 30 June 2012.

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[21] Senate Standing Committee on Legal and Constitutional Affairs, *Donor conception practices in Australia*, Parliament of Australia, Final report, 2011, p. 1.

[22] Ibid, p. 102.

[23] Ms Sue Pennicuik MLC, *Parliamentary debates*, Legislative Council, 23 June 2010, p. 2974.

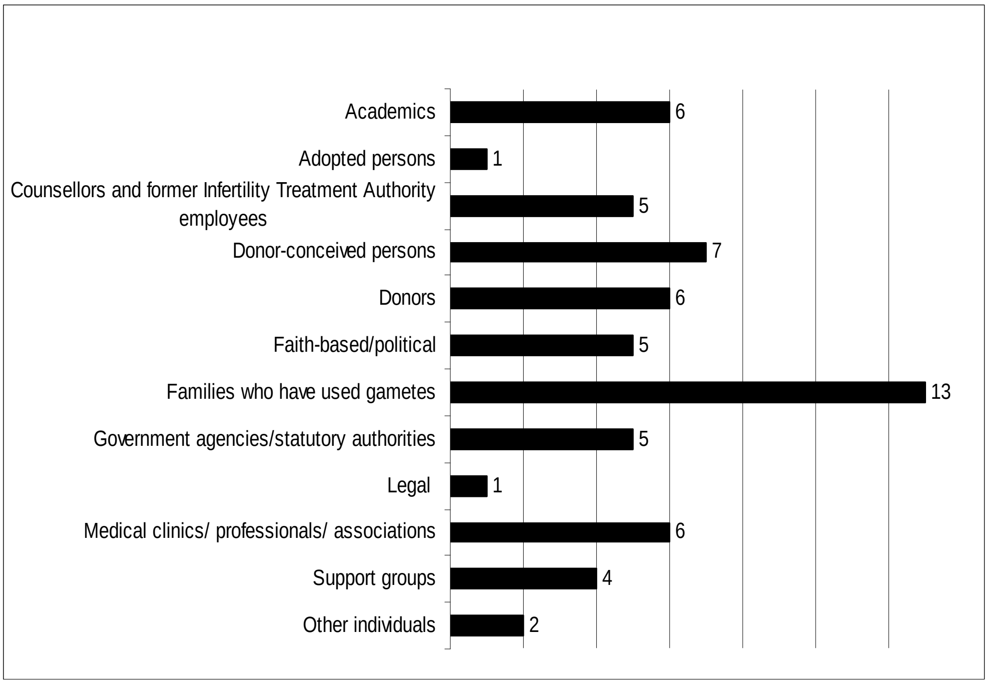
[24] Mr Johan Scheffer MLC, *Parliamentary debates*, Legislative Council, 15 September 2010, p. 4722.

[25] Law Reform Committee, *Inquiry into access by donor-conceived people to information about donors: interim report*, Parliament of Victoria, Melbourne, 2010, p. ix.

1.3 Inquiry process

In June 2011, the Committee advertised the Inquiry's Terms of Reference and called for written submissions in Victorian and national newspapers. The Committee received a total of 77 submissions[26] (see Appendix One), of which 61 were from unique persons or organisations.[27] Figure 1 provides a breakdown of the types of organisations and persons who made submissions to the Inquiry.

Figure 1: Unique submissions to the Inquiry by type



The Committee convened six public hearings between September and December 2011. Details of the hearings are set out in Appendix Two. The Committee heard evidence from a total of 51 witnesses: 20 individuals, and 31 witnesses representing 14 organisations. Witnesses included donors, donor-conceived people, parents of donor-conceived people, and academics, as well as representatives from government agencies, fertility clinics, medical associations and support groups.

Many individuals and organisations contributed to this Inquiry by making written submissions and participating in the public hearings. The Committee is grateful to these people for sharing their views and experiences, and would like to express particular appreciation for those persons who shared their personal, and often emotional, stories.

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[26] 36 submissions had been previously received during the Interim Inquiry, and an additional 41 submissions were received following the June 2011 call for submissions.

[27] Several persons who made a submission to the current Inquiry also made a previous submission to the Interim Inquiry.

1.4 Outline of the Report

Chapter Two reviews the history of donor-conception in Victoria, and the key aspects of the legislation regulating assisted reproductive technology, as it has evolved from 1988 to the present. Chapter Two also discusses how the practices around donor-conception have changed over time.

In Chapter Three, the Committee considers the differing rights that donor-conceived people currently have to access information about their donors. This Chapter describes some of the experiences of donor-conceived people who wish to access information about their donor, considers issues surrounding the retrospective release of information, and ultimately recommends that all donor-conceived people should be able to access identifying information about their donor.

Chapter Four considers the issue of donors' access to information about their donor-conceived offspring. This Chapter explores the perspective of donors and, in recommending that current arrangements be retained, notes the overriding theme that the welfare of the donor-conceived person is paramount.

In Chapter Five, the Committee considers the question of whether donor-conceived people should be able to access information about their half-siblings. In considering this issue, the Committee is mindful that many donor-conceived people, especially those conceived prior to 1988, are unaware that they were conceived with the use of donor gametes.

Chapter Six considers the importance of counselling and support services for donor-conceived people and other donor-conception stakeholders. This Chapter reviews the arrangements that were in place when the Infertility Treatment Authority was responsible for providing these services (up until the end of 2009), and recommends that these services be restored and be accessed through one central agency.

Chapter Seven reviews the status and state of donor-conception records, and recommends centralising the records and introducing mechanisms to add and verify information where records are missing, incomplete, or ambiguous.

In Chapter Eight, the Committee briefly discusses some issues that were raised in evidence, but fall outside the Inquiry's Terms of Reference.

Chapter

2

Chapter Two:
A history of donor-conception in Victoria

One in six Australian couples experience infertility, with the causes of infertility shared roughly equally between men and women.[28] Infertility is a common condition, but the increasing use of assisted reproductive treatment is allowing more women to conceive in a greater range of circumstances. Various forms of assisted conception contribute to a significant proportion of births, accounting for two per cent of all births in Australia and New Zealand in 2000.[29]

Victoria was the first Australian state, and the first jurisdiction in the world, to enact legislation regulating assisted reproductive treatment. Prior to the *Infertility (Medical Procedures) Act 1984* there was no regulation of infertility treatment, and no requirement that doctors and clinics keep records of donors. Consequently, there will always be uncertainty about the number of women who were treated for infertility, and the number of children who were conceived through the use of donated gametes, prior to 1988.[30] It is estimated that several thousand children were conceived with the use of donor gametes prior to 1988.[31] Since 1988, more than 5,500 donor-conceived children have been born in Victoria.[32]

In this Chapter, the Committee describes some of the developments in donor-conception, including legislative changes, over past decades. This Chapter then describes some of the characteristics of donor-conception in Victoria, and explores how donor-conception practices have changed over time.

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[28] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 37; Monash IVF, *Guide to getting started handbook*, Monash IVF, Melbourne, 2003, p. 12.

[29] Maggie Kirkman, 'Genetic connection and relationships in narratives of donor-assisted conception', *Australian Journal of Emerging Technologies and Society*, vol. 2, no. 1, pp. 1-21, 2004, p. 2.

[30] Victorian Law Reform Commission, *Assisted reproductive technology & adoption*, Final report, VLRC, Melbourne, 2007, p. 28.

[31] For example, the Committee heard that Melbourne IVF would likely have "thousands" of records for pre-1988 donor-conceived persons conceived through the Royal Women's Hospital (Joanne McCann, Operations Manager, Melbourne IVF, *Transcript of evidence*, Melbourne, 10 October 2011, p. 13), which does not include persons conceived through the Queen Victoria Medical Centre and Prince Henry's Hospital programs. The Donor Conception Support Group of Australia Inc. also referred to the "thousands of donor conceived people" born before legislation was in place (Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010, p. 19).

[32] Victorian Assisted Reproductive Treatment Authority, 'A statistical snapshot of the donor registers in Victoria for 2010-2011', VARTA, Melbourne, 2011, viewed 23 Nov 2011, <www.varta.org.au>.

2.1 The origins of assisted reproductive treatment in Victoria

Artificial insemination by donor has been practised for more than a century, occurring since at least the late nineteenth century.[33] Victorian clinics and doctors in private practice have been performing insemination with donor sperm since at least the early 1960s, and there are reports of instances of insemination using fresh donor semen occurring in private medical practice as early as just after the Second World War.[34] The Royal Women's Hospital in Melbourne commenced its donor sperm insemination program in 1976.[35]

More advanced techniques for assisted reproduction in humans were developed during the 1970s, drawing upon knowledge about in vitro fertilisation (IVF) obtained through scientific work with mammals.[36] Victoria was one of the leading international sites for development of these technologies throughout the 1970s, with the first IVF pregnancies in Melbourne reported in 1973 – although these pregnancies failed after less than one week.[37] The first successful IVF pregnancy leading to a live birth occurred in the United Kingdom, when physicians utilised a woman's natural menstrual cycle to obtain an egg, rather than using fertility medication for this purpose.[38] The world's third IVF baby, Candice Reed, was born in Melbourne in 1980.[39]

The Victorian IVF team subsequently made significant progress with the development of IVF technologies and techniques, with the Monash group establishing "repeatable and successful" treatments for human infertility, and training many clinicians and scientists from around the world.[40] The number of live births from IVF treatment increased substantially over this early period, both nominally, and as a proportion of all pregnancies (see Table 2).

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[33] Maggie Kirkman, 'Genetic connection and relationships in narratives of donor-assisted conception', *Australian Journal of Emerging Technologies and Society*, vol. 2, no. 1, pp. 1-21, 2004, p. 2.

[34] Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Issues paper on donor gametes in IVF*, Melbourne, 1983, p. 4.

[35] Melbourne IVF, *Submission no. 32*, 9 August 2010, p. 2.

[36] Jean Cohen, Alan Trounson, Karen Dawson, Howard Jones, Johan Hazekamp, Karl-Gosta Nygren and Lars Hamberger, 'The early days of IVF outside the UK', *Human Reproduction*, vol. 11, no. 5, pp. 439-459, 2005, p. 445.

[37] David de Kretser, P Dennis, B Hudson, J Leeton, A Lopata, J Talbot and C Wood, 'Transfer of a human zygote', *Lancet*, no. 2, pp. 728-729, 1973.

[38] Jean Cohen, Alan Trounson, Karen Dawson, Howard Jones, Johan Hazekamp, Karl-Gosta Nygren and Lars Hamberger, 'The early days of IVF outside the UK', *Human Reproduction*, vol. 11, no. 5, pp. 439-459, 2005.

[39] Ibid, p. 443.

[40] Ibid, p. 445.

Table 2: Number and outcome of completed IVF pregnancies, Australia, 1980-1983[41]

Pregnancy outcome	Year pregnancy completed			
	1980	**1981**	**1982**	**1983**
Biochemical pregnancy	6	12	19	28
Ectopic pregnancy	-	1	6	15
Spontaneous abortion	5	12	21	41
Stillbirth	-	-	-	4
Live birth	1	11	30	97
All IVF pregnancies	**12**	**36**	**76**	**185**

In the early days of fertility treatment, fresh donor sperm was frequently used.[42] During the 1980s, the use of frozen semen was increasingly employed. Over time, the practice of freezing semen has allowed donations to be screened for disease and genetic abnormalities, and to be stored for long periods of time.[43]

In the late 1970s and into the 1980s, the Queen Victoria Medical Centre, the Royal Women's Hospital, and Prince Henry's Hospital were the major clinics carrying out donor-conception procedures in Melbourne.[44]

2.2 Regulation of assisted reproductive treatment

The interest of the state in assisted reproductive treatment arose in the context of these emerging, cutting-edge technologies developed by physicians and scientists based in Victoria. Victoria was the first Australian state, and the first jurisdiction in the world, to enact legislation to regulate the use of assisted reproductive technologies, when it passed the *Infertility (Medical Procedures) Act 1984*. This Act drew upon recommendations from two reports of a Committee formed to consider issues surrounding the use of IVF technologies (the "Waller Committee").

At this time, the Victorian Parliament also amended the *Status of Children Act 1974* to clarify that a person born as a result of an assisted reproductive procedure was, for all legal purposes, the child of the woman who gave birth to that child and her husband, and that where donated

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[41] Ibid, p. 440.

[42] Lyndon Hale, IVF Directors Group, Fertility Society of Australia, *Transcript of evidence*, Melbourne, 8 September 2011, p. 14.

[43] David de Kretser, *Transcript of evidence*, Melbourne, 17 October 2011, pp. 3-4.

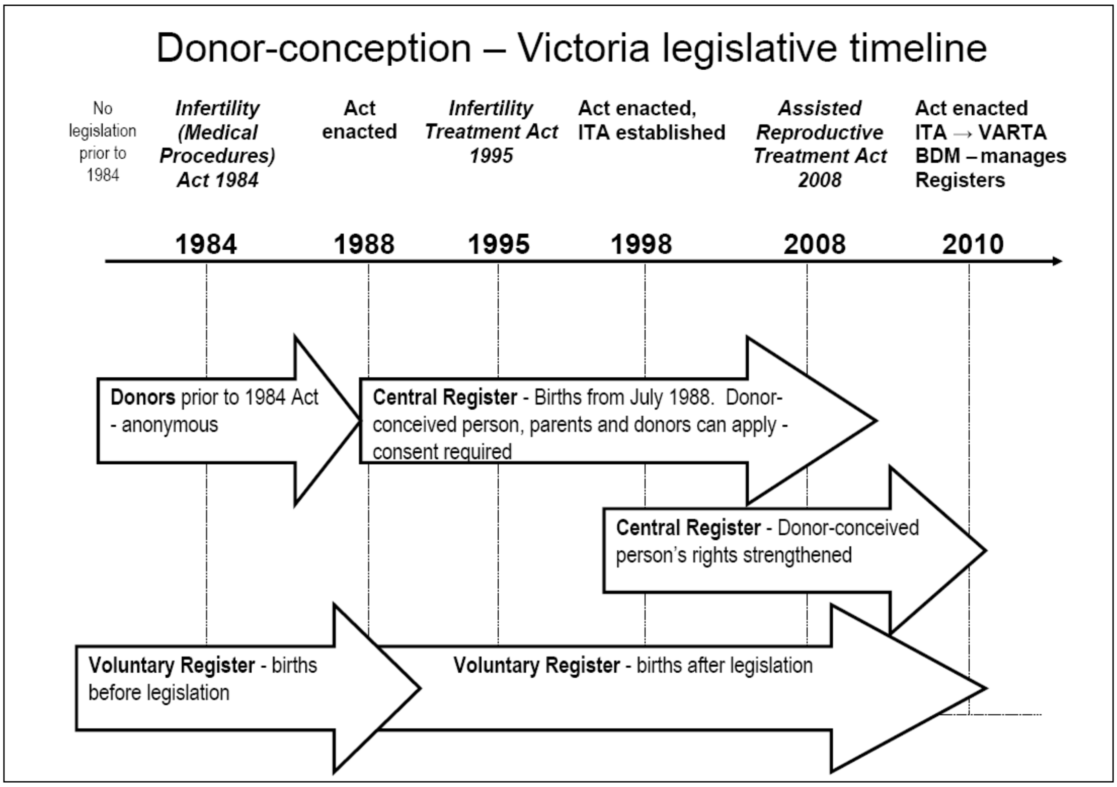
[44] Kate Bourne, *Submission no. 35*, 11 August 2010; Barbara Burns, *Submission no. 9*, 3 August 2010; Kate Dobby, *Submission no. 33*, 10 August 2010; Victorian Infertility Counsellors Group, *Submission no. 22*, 6 August 2010.

gametes were used, the donor had no rights or responsibilities as a result of that donation.[45]

While the *Infertility (Medical Procedures) Act 1984* and the legislation that followed had a substantial focus on the regulation of assisted reproductive technologies, it also introduced mechanisms for sharing information between relevant parties to donor-conception.

Legislation regulating assisted reproductive technologies has been significantly amended on two occasions, with the *Infertility Treatment Act 1995* effective from 1 January 1998, and the *Assisted Reproductive Treatment Act 2008* coming into effect on 1 January 2010 (see Figure 2).

Figure 2: Historical timeline of legislation pertaining to donor-conception in Victoria[46]



2.2.1 The Waller Committee

In May 1982, the Victorian Government established the Committee to Consider the Social, Ethical and Legal Issues Arising From In Vitro Fertilization, chaired by Professor Louis Waller (the "Waller Committee"). The Waller Committee's mandate was:

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[45] See the *Status of Children (Amendment) Act 1984* (Vic). For current provisions in this regard, see Parts II and III of the *Status of Children Act 1974* (Vic).

[46] Louise Johnson, Paper presented at the *Donor-Linking Symposium*, Melbourne, 2011.

> To consider whether the process of in vitro fertilization (IVF) should be conducted in Victoria and, if so, the procedures and guidelines that should be implemented in respect of such processes in legislative form or otherwise.[47]

The Waller Committee released two reports on the subject of IVF. Its first Interim Report, issued in September 1982, was limited to consideration of what it described as the "most common" IVF situation – where a husband and wife were seeking fertility treatment using their own gametes.[48] The Waller Committee recommended that this type of IVF treatment should be allowed, and that legislation should be enacted to authorise hospitals as centres in which IVF programs of this type could be conducted.[49]

The Waller Committee's second report specifically considered the use of donor gametes in IVF, and also considered the use of donor gametes more broadly. The Waller Committee recommended that the use of donor sperm and eggs be permitted in the Victorian community, but proposed some changes to donor-conception practices. In particular, the Waller Committee noted that it should be possible for every person to discover some information about their origins, and recommended that comprehensive information regarding donors should be maintained in a register.[50]

The Waller Committee stated that the Health Commission and hospitals conducting IVF programs should maintain registers that recorded and preserved information about donors and pregnancies, so that it would remain possible in the future for identifying information to be able to be provided to children born as the result of the successful use of donor gametes in IVF. The Waller Committee noted the growing view that honesty and integrity are crucial to the creation of nurturing families. It also noted that legislation had been passed in a number of jurisdictions providing for adopted children to discover some information about their backgrounds.[51]

The Waller Committee did not determine what kinds of information, beyond non-identifying information, a donor-conceived person enquiring about their genetic background should be entitled to receive. The Waller Committee did suggest, however, that over time community attitudes to the provision of identifying information to donor-conceived children may change, stating that it believed:

> … that the view and attitudes of the Victorian community on this subject may well develop, and develop rapidly in light of further experience in adoption, AID, and other forms of genetic variations in parenting.[52]

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[47] Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Interim report*, Melbourne, 1982, p. 2.

[48] Ibid, pp. 26-27.

[49] Ibid, pp. 35-36.

[50] Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Report on donor gametes in IVF*, Melbourne, 1983, pp. 26-28.

[51] Ibid.

[52] Ibid.

A draft bill was prepared based on the recommendations in the Waller Committee’s reports, and the resulting *Infertility (Medical Procedures) Act 1984*, the first legislation in the world to regulate assisted reproductive treatment, came into effect on 1 July 1988.

2.2.2 *Infertility (Medical Procedures) Act 1984*

The *Infertility (Medical Procedures) Act 1984* established a licensing system for assisted reproductive treatment, requiring a hospital to seek Ministerial approval in order to carry out this class of procedure.[53] Consequently, IVF procedures could only be carried out at approved hospitals.[54] Furthermore, artificial insemination could not be carried out by someone who was not a medical practitioner.[55]

The Act required that approved hospitals maintain a register recording details of each gamete donor, and of any children born as a result of a procedure.[56] Hospitals were required to forward this information to the Health Commission, for inclusion on a central register.[57] Similarly, medical practitioners carrying out artificial insemination procedures were required to keep a written record of details of the donor and children born, and provide a copy of these records to the Health Commission.[58]

The Act also introduced compulsory counselling, requiring that a medical practitioner must not carry out an IVF or artificial insemination procedure unless satisfied that the woman seeking treatment and her husband had received counselling from an approved counsellor.[59] In addition, gametes provided by a donor could not be used unless the donor and his or her spouse (if any) had received counselling from an approved counsellor.[60]

Finally, the Act established a Standing Review and Advisory Committee on Infertility (SRACI), whose functions included advising and reporting to the Minister on matters and procedures relating to infertility.[61] The Act did not contain any direct reference to the welfare or best interests of children born as a result of treatment procedures.

2.2.3 *Infertility Treatment Act 1995*

2.2.3.1 Report of the Standing Review and Advisory Committee on Infertility

Between May 1990 and October 1991, SRACI completed a three-volume report on the *Infertility (Medical Procedures) Act 1984*. The third volume of

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[53] *Infertility (Medical Procedures) Act 1984* (Vic), section 7.
[54] Ibid, sections 10-13.
[55] Ibid, section 17.
[56] Ibid, section 19.
[57] Ibid, sections 19(3) & 22.
[58] Ibid, section 21.
[59] Ibid, sections 10-13 & 18.
[60] Ibid, sections 11-13.
[61] Ibid, section 29.

the report presented recommendations for revisions and amendments to the Act, in the form of a "plain English" version of proposed legislation to replace the existing Act. In its letter to the Minister for Health enclosing the draft, SRACI noted, regarding access to information from the central register:

> The whole Committee proposes that any person born as a result of the use of donated gametes may, upon reaching the age of 18, obtain identifying information about the gamete donor from the central register. This recommendation is based on the clear belief that the interests of such a person in discovering his or her genetic parent or parents should be accorded primacy.[62]

The wording in SRACI's letter, and in the draft legislation comprising the third volume of its report,[63] is ambiguous in that it is not clear whether the provision for donor-conceived people to obtain identifying information about their donor was intended to be prospective only, or whether it was intended that *all* donor-conceived people with information recorded on the central register should have access to identifying information.

SRACI's draft legislation formed the basis for the *Infertility Treatment Bill 1995*, which was introduced in the Victorian Legislative Assembly on 3 May 1995. The bill provided only for a prospective right to identifying information about donors. In debate around the bill, several members of the Legislative Assembly suggested that the legislation should provide a retrospective right to access information, and foreshadowed the issue returning to Parliament for further consideration. Mr John Thwaites MP, member for Albert Park, noted that adoption legislation had taken the step of allowing retrospective access to information:

> We have retrospectively applied provisions affecting the communication of information to adopted children, something the bill does not address. We are applying this provision dealing with children born through IVF prospectively. … Although the legislation is an important first step, it may well be that Parliament will have to consider whether to take the next step, which the adoption legislation has taken, and allow children to gain that information, even though it would be retrospective.[64]

Mr Murray Thompson MP, member for Sandringham, noted the importance of access to genetic history for people born prior to legislation being in place:

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[62] Standing Review and Advisory Committee on Infertility, *Report on matters related to the review of post-syngamy embryo experimentation – Part III: Recommendations for amendment of the Infertility (Medical Procedures) Act 1984*, SRACI, Melbourne, 1991, p. 6.

[63] Draft section 22 reads: "A person born as a result of the use of any donated gamete or gametes who, upon reaching the age of 18, requests identifying information about the donor must be given that information by the Chief General Manager after that person has received appropriate counselling." Ibid, p. 22.

[64] Mr John Thwaites MP, *Parliamentary debates*, Legislative Assembly, 30 May 1995, p. 1922.

> Many Victorians were born as a result of the experimentation by doctors involved in the reproductive technology process through the late 1970s and during the 1980s prior to the intervention of legislation. It is important that these people have the opportunity of discovering their genetic heritage from a central register compiled from donor information records … Professor Louis Waller is very supportive of this approach.[65]

However, the bill was passed with prospective operation only. The *Infertility Treatment Act 1995* came into effect on 1 January 1998.

2.2.3.2 Key aspects of the *Infertility Treatment Act 1995*

The *Infertility Treatment Act 1995* included four guiding principles, which Parliament expressly intended be given effect in administering the Act. They were, in descending order of importance, that:

- the welfare and interests of any person born or to be born as a result of a treatment procedure are paramount;
- human life should be preserved and protected;
- the interests of the family should be considered; and
- infertile couples should be assisted in fulfilling their desire to have children.[66]

Thus the Act recognised the welfare and interests of donor-conceived people as being paramount. Consistent with this, and as recommended by SRACI, the Act brought an end to anonymous gamete donations in Victoria. Under the Act, when a donor consented to the use of his or her gametes, he or she had to be advised in writing of the right of a person conceived from the gametes to obtain identifying information about the donor. A donor-conceived person conceived from gametes donated after the commencement of the *Infertility Treatment Act 1995* (or his or her descendant) could obtain identifying details about his or her donor at the age of 18, or at a younger age with the consent of his or her parent or guardian.[67]

The *Infertility Treatment Act 1995* was silent on whether people who were conceived from gametes donated prior to the introduction of the Act were able to obtain identifying information about their donor, so the requirement for donor consent continued to apply for those people born under the *Infertility (Medical Procedures) Act 1984*. Nor did the *Infertility Treatment Act 1995* provide any mechanism for pre-1988 donor-conceived people to obtain information about their donor.

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[65] Mr Murray Thompson MP, *Parliamentary debates*, Legislative Assembly, 1 June 1995, p. 2112.

[66] *Infertility Treatment Act 1995* (Vic), section 5.

[67] Ibid, sections 17, 79 & 87.

The *Infertility Treatment Act 1995* established the Infertility Treatment Authority (ITA), whose functions included to administer the compilation and storage of donor-conception records, to manage access to those records, and to license and oversee the regulation of infertility treatment providers.[68] Licensed centres and approved doctors were required to provide information to the ITA every six months regarding all donor treatment procedures, including details of persons born, donors, and women who underwent the procedure and their spouses.[69] The ITA was required to record this information in a central register.[70]

The Act also established a voluntary register, to allow donors, donor-conceived people, their parents and descendants, and relatives, to voluntarily record identifying details or additional information not included on the central register, such as photographs and messages.[71] Information on the voluntary register could only be released in accordance with the wishes of the person who registered the information.[72] The voluntary register was also held and administered by the ITA.

An amendment to the Act in 2001 established an additional part of the voluntary register, for people associated with donor-conception procedures where the donor's consent for the use of his or her gametes was given prior to 1 July 1988.[73] Prior to this amendment, there was no formal mechanism for people who were parties to a donor treatment procedure that occurred before 1988 (whether as donors, recipients, or donor-conceived people) to record or share information.

2.2.4 *Assisted Reproductive Treatment Act 2008*

2.2.4.1 The Victorian Law Reform Commission report

In 2002, the then Attorney-General, the Hon. Rob Hulls MP, requested that the Victorian Law Reform Commission (VLRC) conduct an inquiry into the laws governing the use of assisted reproductive technology and adoption, including the *Infertility Treatment Act 1995*.[74] The terms of reference for the inquiry were broad, and included a request that the VLRC take into account the social, ethical and legal issues related to assisted reproduction and adoption, with particular regard to the rights and best interests of the children.[75]

The VLRC conducted extensive research and undertook substantial public consultation over four years, releasing a final report in June 2007 that included 130 recommendations for law reform in this area. The recommendations responded to new developments in reproductive

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[68] Ibid, section 122.
[69] Ibid, sections 64, 65 & 66.
[70] Ibid, section 68.
[71] Ibid, section 82.
[72] Ibid, section 92F.
[73] *Infertility Treatment (Amendment) Act 2001* (Vic), Part 7A.
[74] Victorian Law Reform Commission, *Assisted reproductive technology & adoption*, Final report, VLRC, Melbourne, 2007, p. 18.
[75] Ibid.

technology, and sought to recognise the relationship between changing family structures and evolving community attitudes and IVF legislation.

The Attorney-General subsequently announced that the Victorian Government would implement almost all of the recommendations, subject to working through practical implementation issues.[76] Parliament passed the resultant bill, which incorporated many of the VLRC's recommendations, and the *Assisted Reproductive Treatment Act 2008* came into effect on 1 January 2010, and remains in effect today.

2.2.4.2 Changes introduced by the *Assisted Reproductive Treatment Act 2008*

The *Assisted Reproductive Treatment Act 2008* did not make any substantive changes to the rights of donor-conception stakeholders (donors, donor-conceived people and their families) to access information about each other. As under the *Infertility Treatment Act 1995*, donor-conceived people born from donations where donor consent was given after 1 January 1998 are entitled to obtain identifying information about their donors upon turning 18 years of age.[77] New gamete donations are not permitted unless the donor provides his or her consent to this condition.[78]

The *Assisted Reproductive Treatment Act 2008* also introduced a mechanism to allow a donor-conceived person to obtain identifying information about his or her donor prior to age 18 without the consent of the parent or guardian. This can occur where a counsellor has counselled the donor-conceived person, and provides written confirmation that the person is sufficiently mature to understand the consequences of the information being disclosed to him or her.[79]

While the Act did not substantially alter the rights of people to access information, it introduced significant changes to the process by which donor-conception stakeholders are able to seek information, and the support available to them. Changes introduced by the Act in this regard included:

- changing the name of the Infertility Treatment Authority (ITA) to the Victorian Assisted Reproductive Treatment Authority (VARTA);

- removing management of the central and voluntary registers from ITA/VARTA and transferring the registers to the Registry of Births, Deaths and Marriages; and

- removing ITA/VARTA's function of providing counselling and donor-linking services.

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[76] Victorian Law Reform Commission, 'Assisted Reproductive Technology & Adoption', viewed 20 January 2012, <http://www.lawreform.vic.gov.au/>.
[77] *Assisted Reproductive Treatment Act 2008* (Vic), section 59.
[78] Ibid, section 19.
[79] Ibid, section 59(a)(ii).

The impact of these changes was profound, and is discussed in detail in Chapter Six.

The Act also introduced a requirement that where a child is conceived through a donor treatment procedure, the Registrar of Births, Deaths and Marriages must mark the child's birth entry to note that he or she is donor-conceived. When issuing a birth certificate to a donor-conceived person (but not to a third party, such as a parent), the certificate must include an addendum stating that further information is available about the entry.[80] The rationale for this requirement is to provide a means by which, even if donor-conceived persons' parents do not tell them that they were donor-conceived, they still have the opportunity to learn about the circumstances of their conception.

Finally, the *Assisted Reproductive Treatment Act 2008* limits the use of donated gametes from a single donor to the creation of ten families (including the donor's own family).[81] Previously, there was no legislated limit on the number of families who could make use of a donor's gametes. The Act also provides that a donor's consent must specify the number of women on whom treatment procedures using the donor's gametes may be carried out, so that the donor can choose to limit the number of families able to be created to less than ten.[82]

2.2.5 National Health and Medical Research Council Ethical Guidelines

There is no federal legislation governing the use of assisted reproductive technology. However, the National Health and Medical Research Council (NHMRC) has issued ethical guidelines for clinical practice and research involving assisted reproductive technology. The NHMRC is Australia's peak body for supporting health and medical research, for developing health advice for the Australian community, health professionals and governments, and for providing advice on ethical behaviour in health care and in the conduct of health and medical research.

The NHMRC first issued guidelines relating to assisted reproductive technology in 1992. These were replaced by the *Ethical guidelines on assisted reproductive technology* in 1996, which stated that all medical clinics offering assisted reproductive treatment (ART) services must obtain accreditation from a recognised accreditation body and that such accreditation would include consideration of compliance with the NHMRC guidelines.[83] The Reproductive Technology Accreditation Committee (RTAC), established by the Fertility Society of Australia, is the relevant accreditation body.

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[80] Ibid, section 153, which inserts a new section 17B into the *Births, Deaths and Marriages Act 1996* (Vic).

[81] *Assisted Reproductive Treatment Act 2008* (Vic), section 29.

[82] Ibid, section 17(b).

[83] 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, p. 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*. These guidelines were revised in 2007 to reflect the enactment of the *Prohibition of Human Cloning for Reproduction and the Regulation of Human Embryo Research Amendment Act 2006* (Cth).[84] The 2007 revision of the Guidelines currently applies in Australia.

The Guidelines are not legally binding. However, clinics providing ART in Victoria are required to be registered with VARTA under the *Assisted Reproductive Treatment Act 2008*,[85] and in order to obtain registration, they must hold current accreditation from RTAC.[86] One of the criteria that must be met by an organisation seeking accreditation from RTAC is to demonstrate compliance with the NHMRC guidelines.[87]

The Guidelines contain a number of provisions that relate to the rights of donor-conceived people to access information about their donors, including that:

- the welfare of people who may be born as a result of the use of ART is paramount (guideline 5.1);
- the privacy of all persons involved in ART procedures should be respected (guideline 5.6);
- persons conceived using ART procedures are entitled to know their genetic parents (guideline 6.1); and
- ART clinics must not release identifying information to another person without the consent of the person to be identified (guideline 6.13).

The Guidelines also state that gametes from one donor should be used in a limited number of families, although they do not specify a particular number in this regard.[88]

2.2.6 Australian Senate Committee Report on donor-conception practices in Australia

On 16 June 2010, the Australian Senate issued terms of reference to its Legal and Constitutional Affairs References Committee (LCAR Committee)

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[84] Reproductive Technology Accreditation Committee, *Code of practice for assisted reproductive technology units*, Fertility Society of Australia, revised October 2010, 2010, p. 7.

[85] *Assisted Reproductive Treatment Act 2008* (Vic), section 7.

[86] Ibid, section 74.

[87] Reproductive Technology Accreditation Committee, *Code of practice for assisted reproductive technology units*, Fertility Society of Australia, revised October 2010, 2010, p. 8.

[88] 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, p. 27, guideline 6.3.1.

for inquiry and report into matters regarding past and present practices of donor-conception in Australia.[89] The LCAR Committee was asked to conduct its inquiry with particular reference to a number of matters, including the conduct of clinics and medical services, and the rights of donor-conceived individuals.[90]

The LCAR Committee's report was tabled in the Senate on 10 February 2011. The key recommendations made by the LCAR Committee were:

- a recommendation that state and territory governments create separate but uniform legislative regimes which prohibit donor anonymity, place a limit on the number of families that one donor is able to assist, provide rights of access for donor-conceived individuals to identifying and non-identifying information about their donor and siblings, and include protection for the welfare and interests of donor-conceived children;[91]

- a recommendation that donors should be able to assist a maximum of four families (in addition to their own) Australia-wide;[92] and

- a recommendation that the Australian Government (through the Standing Committee of Attorneys-General) do everything possible to ensure the establishment of a national donor-conception register.[93]

The LCAR Committee chose to not make any specific recommendation on the issue of whether donor-conceived individuals should be granted retrospective access to identifying information about their donors.[94] The LCAR Committee stated that in principle, it supported the rights of donors to maintain the anonymity that they were guaranteed, but it also supported donor-conceived individuals having a right to information about their biological heritage.[95]

The LCAR Committee did note that the Victorian legislation provides donor-conceived individuals with differing rights of access to information (dependent upon when their donor provided consent to his or her gametes being used), and considered that such an "arbitrary 'line in the sand'" approach was unsatisfactory.[96]

2.2.7 Reference to the Law Reform Committee

Prior to the passing of the *Assisted Reproductive Treatment Bill 2008*, the issue of retrospective access by donor-conceived people to information about donors was debated in the Legislative Council. Ms Sue Pennicuik

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[89] Senate Standing Committee on Legal and Constitutional Affairs, *Donor conception practices in Australia*, Parliament of Australia, Final report, 2011, p. 1.
[90] Ibid.
[91] Ibid, pp. xi, Recommendation 3.
[92] Ibid, pp. xvi, Recommendation 29.
[93] Ibid, pp. xi, Recommendation 5.
[94] Ibid, p. 96.
[95] Ibid.
[96] Ibid.

MLC, Member for the Southern Metropolitan Region, 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.[97] The motion was defeated, but the Government proposed that the issue be referred to the Law Reform Committee for further consideration.[98] The *Assisted Reproductive Treatment Act 2008* was assented to on 11 December 2008. However, the matter was not referred to the Law Reform Committee at that time.

Consequently, on 23 June 2010, Ms Pennicuik brought a motion that the issue be referred to the Law Reform Committee. This motion was passed, and the Committee was requested to provide an interim report to the Parliament by September 2010 (prior to the conclusion of the 56th Parliament in November 2010), and to provide a final report by 2011.[99] On 15 September 2010, Mr Johan Scheffer MLC, the Chair of the Committee in the 56th Parliament, tabled the Law Reform Committee's Interim Report.[100]

On 10 February 2011, the Legislative Assembly of the 57th Parliament passed a motion that further to the interim report of the Law Reform Committee of the 56th Parliament, the Committee inquire into, consider and report no later than 30 June 2012 on donor-conceived persons, with the same terms of reference provided to the previous Committee.

2.2.8 Debates surrounding access to identifying information

While public discussion around the ability of donor-conceived people to access information about their donors has become more prominent over the past decade or so, the Committee notes that debate on whether donor-conceived people should be entitled to know the identity of their donor has been active since the early 1980s. In 1984, when the first proposed legislation to regulate assisted reproductive treatment was being debated in the Victorian Parliament, several Members of Parliament raised concerns that the *Infertility (Medical Procedures) Bill 1984* did not go far enough to protect the interests of donor-conceived children. Mr Lieberman MP, the Member for Benambra, commented:

> The only other question I raise is the one of donor ova and donor sperm and where the true parental background of the child will not be known to anyone. The House had enormous difficulty in considering the Adoption Bill to allow for an adopted child to gain knowledge of its background and there is not adequate provision in this Bill to cover that situation with regard to the offspring of an in vitro fertilization programme.

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[97] Ms Sue Pennicuik MLC, *Parliamentary debates*, Legislative Council, 2 December 2008, p. 5456.

[98] Mr Gavin Jennings MLC, Minister for Environment and Climate Change, *Parliamentary debates*, Legislative Council, 4 December 2008, p. 5449.

[99] Ms Sue Pennicuik MLC, *Parliamentary debates*, Legislative Council, 23 June 2010, p. 2974.

[100] Mr Johan Scheffer MLC, *Parliamentary debates*, Legislative Council, 15 September 2010, p. 4722.

> Although the Bill endeavours to cover that question in part, it does not go far enough and that is a matter that may cause the legislation to come back to Parliament for further clarification and qualification.[101]

Mr Shell MP, the Member for Geelong West, also commented:

> A child born through the in vitro fertilization programme should, on the attainment of adulthood, have the same access to information as what an adopted child has and be subject to the same conditions provided in the adoption legislation.[102]

Mr McNamara MP, the Member for Benalla, predicted that the same issues would arise in donor-conception as had arisen at that time in adoption:

> Honourable members have recently dealt with the adoption issue and the identity problems of adopted children who do not know who their natural parents are. The in vitro fertilization programme will raise the same types of issues.[103]

Eleven years later, when the *Infertility Treatment Bill 1995* was being debated in Parliament, a number of Members expressed concern that the proposed legislation would not allow donor-conceived children who were already born to access identifying information about their donor.[104] For example, Mrs Garbutt MP, Member for Bundoora, commented:

> … I am concerned about the silence regarding children already born as a result of these procedures. They are the only children in the state without access to information about their genetic backgrounds. At a minimum, everybody needs information for health and medical purposes. Our experience with adoption shows that people are desperate to know about their parents and families.
>
> We should learn from our experience of people who have searched for decades to find their natural parents even though they have had good relationships with their adoptive parents. Their need to know is most compelling.
>
> The Adoption Act allows retrospectivity, and reuniting families has been successful. Donors are in a similar position to relinquishing mothers, who in earlier days were guaranteed that their names would never be passed on, but society has changed. We have learned a lot. Changes in the Adoption Act allow for retrospectivity. There have been few problems and it has worked well. It has been hailed as landmark legislation.

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[101] Mr Louis Lieberman MP, *Parliamentary debates*, Legislative Assembly, 2 November 1984, p. 1815.

[102] Mr Hayden Shell MP, *Parliamentary debates*, Legislative Assembly, 2 November 1984, p. 1816.

[103] Mr Patrick McNamara MP, *Parliamentary debates*, Legislative Assembly, 2 November 1984, p. 1817.

[104] See Dr Denis Napthine MP, *Parliamentary debates*, Legislative Assembly, 30 May 1995, p. 1926; Mr John Thwaites MP, *Parliamentary debates*, Legislative Assembly, 30 May 1995, p. 1922; Mr Murray Thompson MP, *Parliamentary debates*, Legislative Assembly, 1 June 1995, p. 2112; Mrs Lorraine Elliott MP, *Parliamentary debates*, Legislative Assembly, 1 June 1995, p. 2113.

> However, the bill is silent on retrospectivity … The government must bite the bullet on this issue. It cannot allow this small group of people to reach maturity and to be the only people in Victoria … who do not know about their backgrounds. The government must face up to the issue and take some action.[105]

The Committee notes the tendency over time for donor-conception legislation in Victoria to incrementally introduce provisions facilitating access by donor-conceived people to information about their donors, with the *Infertility (Medical Procedures) Act 1984* providing post-1988 donor-conceived people with the ability to obtain identifying information with the donor's consent, and the *Infertility Treatment Act 1995* introducing the right for all post-1998 donor-conceived people to obtain identifying information about their donor in all cases.

2.3 Donor-conception practices

2.3.1 Donor-conception practices before 1988

Prior to the *Infertility (Medical Procedures) Act 1984*, which came into effect in July 1988, assisted reproductive treatment procedures carried out in Victoria were unregulated. In the 1980s, the Royal Women's Hospital, Queen Victoria Medical Centre and Prince Henry's Hospital were the main infertility treatment clinics in Melbourne, and each made use of donor gametes as necessary according to the provision of specific treatments.[106] Anecdotal evidence indicates that there were also physicians independent of these hospitals that were providing donor insemination services to patients privately.[107] At this time, the institutions and physicians providing assisted reproductive treatments individually determined the procedures they would use.

In general, a culture of secrecy surrounded donor-conception, despite contemporaneous debates about the rights of adopted people to have access to information about their birth parents. Donors were told they would be anonymous, and recipient couples were advised to keep the matter secret from their families, peers, and children. The medical profession and donors sought to assist couples who would otherwise have been unable to conceive children and were acting in what they believed to be the best interests of all parties involved. The secrecy surrounding donor-conception was thought to be necessary to maintain the integrity of the family unit. At the time, little consideration was given to possible repercussions for the donor-conceived children.

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[105] Mrs Sherryl Garbutt MP, *Parliamentary debates*, Legislative Assembly, 30 May 1995, pp. 1930-1931.

[106] Lauren Burns, *Submission no. 3*, 29 July 2010, p. 9; Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Issues paper on donor gametes in IVF*, Melbourne, 1983, p. 5.

[107] Helen Kane, *Submission no. 16*, 6 August 2010, p. 3.

2.3.1.1 Donor recruitment

The Waller Committee reported in 1983 that at that time, sperm donors were being recruited in a number of ways:

> Among the methods employed are advertisements in student newspapers published in universities and colleges of advanced education, personal approaches by doctors involved in infertility programmes to students and to the fertile husbands of patients in such programmes. Many donors are medical students engaged in clinical training in hospitals with AID [assisted insemination by donor] clinics, or in the medical schools of the universities with which the hospitals are affiliated.[108]

The Committee received evidence from donors through the course of this Inquiry that reflected some of these recruitment methods, including:

- a man who was a medical student in Melbourne in the 1970s and donated after attending a lecture at which students were asked to consider donating sperm for infertile couples;[109]

- a man who was a full-time university student, as was his wife, with both attempting to support themselves and two infant children on a research grant and a student allowance respectively, for whom the $100 fee for providing donations was a welcome income supplement. This man provided donations to the Royal Women's Hospital in 1977;[110]

- a man who responded to a call in the press in the mid-1980s for sperm donors and consequently donated at Prince Henry's Hospital;[111] and

- a man who had been a blood donor for years who had recently become a father and wanted to help people who were having difficulties conceiving, who donated sperm at Prince Henry's Hospital in the late 1980s.[112]

Prior to 1988, donors were not given a choice as to whether they wished to be anonymous. While practices may have varied slightly between clinics, it appears to have been a uniform requirement that in order to be accepted as a donor, the person had to agree that they would not seek the identity of any children born as a result of their donation.[113]

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[108] Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Issues paper on donor gametes in IVF*, Melbourne, 1983, p. 5.
[109] Name withheld, *Submission no. 1*, 20 July 2010.
[110] Michael Linden, *Transcript of evidence*, Melbourne, 10 October 2011, p. 41.
[111] Ian Smith, *Transcript of evidence*, Melbourne, 10 October 2011, p. 37.
[112] "John", *Transcript of evidence*, Melbourne, 17 October 2011, p. 81.
[113] See Appendix Three; Donor Conception Support Group of Australia Inc, *Submission no. 39*, 26 July 2011, p. 2; Fertility Society of Australia, *Submission no. 66*, 12 August 2011, p. 2.

The medical profession at this time considered it critical that donors were anonymous. For example, Ian Johnston, the Head of the Royal Women's Hospital's Reproductive Biology Unit and the founding President and Honorary Life Member of the Fertility Society of Australia, wrote in the 1980s of recruiting sperm donors that:

> … an occasional person will not be considered if he seems unusually interested in the progeny that may be produced from his semen. The absolute anonymity of the donor is considered essential in this country and all donors must be prepared to donate semen without any follow up on its use or results.[114]

It is interesting to note that Johnston's statement suggests that donor anonymity was considered to be crucial not for protection of the donor's privacy, but rather for the integrity of the family who made use of the donated gametes.

Many donors were told that their donations would be confidential, and would have no effect on their future lives.[115] They received little or no counselling about their donation, and were not encouraged to think about the consequences.[116] In some cases, donors were not definitively told that their gametes would be used to conceive children, but were rather led to believe that their donation may only be used for medical research:

> My enduring impression was that the donor program was administered in a somewhat obfuscatory, if not intentionally misleading manner. For instance, despite my contract stating so, it was never unequivocally confirmed to me that my sperm would definitely be used to produce children. In fact, on one occasion in a rather offhand way I was verbally informed that it might only be used for research purposes instead.[117]

Examples of consent forms provided to donors in this context are provided in Appendix Three.

It also appears that clinics did not generally inform donors from this time period that their gametes had resulted in the birth of children.[118] For example, the Committee heard from one man who was a sperm donor in the 1980s, who received a letter from the ITA in November 2009, informing him that 15 children had resulted from his donations, born between 1985 and 1993. This was the first time this man received any notification that he had donor-conceived children.[119]

The lack of follow-up by clinics also raises a concern that many, if not most, donors from this period will not have updated their contact details

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[114] I Johnston, 'The donor', in *Artificial Insemination by Donor*, Wood, Leeton and Kovacs (eds.), Brown Prior Andersen, Melbourne, 1981.
[115] See, for example, Name withheld, *Submission no. 1*, 20 July 2010.
[116] Helen Kane, *Submission no. 46*, 9 August 2011, p. 2.
[117] Michael Linden, *Transcript of evidence*, Melbourne, 10 October 2011.
[118] Fertility Society of Australia, *Submission no. 66*, 12 August 2011, p. 2.
[119] "Alex", *Transcript of evidence*, Melbourne, 5 December 2011, p. 2.

and medical information on the clinic's records since the time of their last donation, which may be more than 30 years ago.

2.3.1.2 Parents of donor-conceived children

In the early days of donor-conception practices, the medical profession encouraged parents of donor-conceived children not to reveal the circumstances of their child's conception, and to treat the child as if he or she was the biological child of both parents.[120]

The Committee received a submission from the mother of a donor-conceived child born before 1988, who is not aware that he was donor-conceived. The mother explained that:

> He does not know the truth of his conception. … At the time of his conception and later his birth we were overjoyed. We gave little thought to the consequences. As time went by I began to have deep reservations about this secret which we were keeping from him. … I also felt that as my husband and I had divorced, I did not want to tell him without my ex husband consenting. … Every few years the issue arises for me again and keeps rearing its ugly head. There is a nagging feeling there that he has the right to know.[121]

These kinds of concerns appear to be common for parents of donor-conceived children who accepted advice to not tell their children about their conception, although some subsequently chose to tell their children, even though it seemed unlikely that they would be able to find out more about their donors.[122]

Secrecy in the early days of donor-conception was encouraged and facilitated by clinics and treating physicians matching the physical characteristics of the donor with those of the recipient's husband, so that the child would not look too different from the father. The Waller Committee noted in 1983 that up until that time, treating physicians had endeavoured to match the physical characteristics of donors to the spouse of the recipient.[123]

2.3.1.3 Record-keeping

The Committee heard evidence that prior to the introduction of legislation, there was some variation in the way that records regarding donor-conception procedures were kept.[124] There was no requirement that

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[120] Helen Kane, *Submission no. 46*, 9 August 2011, p. 2.

[121] Name withheld, *Submission no. 2*, 28 July 2010.

[122] For example, see Barbara Burns, *Submission no. 9*, 3 August 2010, p. 1.

[123] Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Report on donor gametes in IVF*, Melbourne, 1983, p. 17.

[124] Helen Kane, *Submission no. 16*, 6 August 2010, p. 3; Melbourne IVF, *Submission no. 32*, 9 August 2010, p. 2.

records be maintained, and sometimes they were destroyed, particularly where doctors were carrying out insemination in private practice.[125]

In some cases, records may be incomplete and unreliable – names may be misspelled, and information may be missing.[126] Some records from this time period may be in the possession of the private doctor who carried out the procedure, and some are the property of the hospital where the treatment took place. As there was no central repository for the records, they are currently retained by individual clinics, physicians, or the Public Record Office Victoria.

The Committee heard a range of views on the quality and accuracy of records pertaining to donor-conception prior to 1988. The Committee was told that in some cases, donors were encouraged to use pseudonyms when providing sperm, or rarely, that treatments were conducted using sperm from both a donor and the recipient's spouse (known as "sperm mixing").[127]

While the Committee heard that a proportion of documents may be incomplete or erroneous, two of the key records holders – Melbourne IVF and Monash IVF – told the Committee that their records were generally reliable.[128] The Committee was also informed that, generally, records from Prince Henry's Hospital (now held by the Public Record Office Victoria) and the Queen Victoria Hospital were accurate. Ms Louise Johnson, Chief Executive Officer of VARTA, told the Committee that although some records were now destroyed, many were in good condition:

> The quality of records prior to legislation is mixed; however, there is a vast number of records kept at major centres that are in good condition. … In some cases there may be gaps and no records may exist, particularly where treatment was carried out by private doctors, and the records that were kept at the Queen Victoria Medical Centre have been destroyed. … Having viewed a number of records, I know there are substantial records in good condition.[129]

The quality, and completeness, of doctors' records for procedures conducted in private practice is unknown. Even if the information contained in records from before 1988 is accurate, substantial effort may still be required to identify donors, as during the intervening decades donors are likely to have changed residence, or moved interstate or internationally. Furthermore, some donors may have since died.

In 1983, the Waller Committee noted that the state plays an important role in record-keeping, and that as it was then being practiced, assisted

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[125] Helen Kane, *Submission no. 16*, 6 August 2010, p. 3; Monash IVF, *Submission no. 26*, 6 August 2010, p. 4.

[126] Kate Bourne, *Submission no. 35*, 11 August 2010, p. 3; Helen Kane, *Submission no. 16*, 6 August 2010, p. 3.

[127] Kate Dobby, *Transcript of evidence*, Melbourne, 8 September 2011, pp. 26-27.

[128] Melbourne IVF, *Submission no. 32*, 9 August 2010, p. 7.

[129] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 38.

reproductive treatment procedures effectively involved 'deceiving' the state:

> The State is the record keeper of the significant biological facts in the community. This role is to be carefully guarded; it is expressed in legislation such as the Registration of Births, Deaths and Marriages Act 1958 … As now practiced, AID often involves a series of clear breaches of this registration legislation and deception of the State.
>
> The community's concerns for accurate information requires that these records be as truthful, comprehensive and permanent as possible.[130]

The Waller Committee's comments and recommendations led to the inclusion of record-keeping requirements in the *Infertility (Medical Procedures) Act 1984*.

2.3.2 Practices after the introduction of the *Infertility (Medical Procedures) Act 1984* (1988-1997)

As described above, the *Infertility (Medical Procedures) Act 1984* introduced requirements for record-keeping, and mandated counselling of donors and donor gamete recipients.

2.3.2.1 Donor counselling

The Waller Committee had argued in its 1983 report that counselling for donors was critical:

> Each prospective donor must receive comprehensive information about the implications of gamete donation, including the use to be made of the donated material, and the consequences of its successful use in an IVF programme. In particular the donor must be fully and clearly informed of three matters. First, [the donor will have no legal relationship with the child]. Second, the donor shall be told that some information about her or his genealogical background, medical history and personal characteristics may be transmitted to the recipients of the gametes, any child or children born as a result of the donation … Thirdly, the donor shall be advised that there can be no guarantee of permanent, complete anonymity.[131]

While the *Infertility (Medical Procedures) Act 1984* included a requirement for the counselling of donors (and their spouses, if they were married),[132] the legislation did not specify that the matters mentioned by the Waller Committee should be addressed in the counselling and, in particular, did not mandate that donors be advised that "there can be no guarantee of permanent, complete anonymity." To the contrary, most clinics appear to have emphasised to donors that only non-identifying information would be

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[130] Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Issues paper on donor gametes in IVF*, Melbourne, 1983, p. 11.

[131] Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Report on donor gametes in IVF*, Melbourne, 1983, pp. 19-20.

[132] *Infertility (Medical Procedures) Act 1984* (Vic), sections 13(5) & (6).

released to donor-conceived children, and that they would remain anonymous.[133]

2.3.2.2 Parents of donor-conceived children

However, the *Infertility (Medical Procedures) Regulations 1988* did set out several prescribed matters to be addressed in the counselling of a couple undergoing assisted reproductive treatment, including "matters relating to the longer term interests of any child born as a result of a relevant procedure."[134] The regulations did not go so far as to specifically require the recipient couple to be counselled about telling their child the circumstances of his or her conception.

Despite the Waller Committee's earlier recommendation that less emphasis should be placed on matching physical characteristics,[135] it appears that at least through the late 1980s, clinics continued to try to match donor characteristics with the husband of the recipient. An information brochure about artificial insemination by donor from Prince Henry's Hospital in 1989 states that:

> In selecting a donor for a patient we try to select one whose main characteristics resemble that of her husband. This ensures that a child by AID is comparable with a natural child that the couple may have produced.[136]

The Waller Committee had also recognised the importance of impressing on donor gamete recipients the need to tell their children about the manner of their conception:

> All members of the Committee agree on the importance of counselling the couples in an IVF programme using donor gametes about the value of honesty in the family they are seeking to establish.[137]

Despite this recommendation, and despite the requirement in the *Infertility (Medical Procedures) Act 1984* that couples be counselled prior to receiving treatment, it appears that even in the late 1980s medical professionals may not have impressed upon parents the need to inform their children about their conception. The Prince Henry's Hospital information brochure states in this regard:

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[133] Standing Review and Advisory Committee on Infertility, *Annual Report to the Minister for Health for the calendar year ended 31 December 1989*, SRACI, Melbourne, 1990; Standing Review and Advisory Committee on Infertility, *Report on matters related to the review of post-syngamy embryo experimentation – Part III: Recommendations for amendment of the Infertility (Medical Procedures) Act 1984*, SRACI, Melbourne, 1991.

[134] *Infertility (Medical Procedures) Regulations 1988* (Vic), Schedule 3, clauses 1.9, 2.5 and 3.5.

[135] Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Report on donor gametes in IVF*, Melbourne, 1983, p. 17.

[136] Standing Review and Advisory Committee on Infertility, *Annual Report to the Minister for Health for the calendar year ended 31 December 1989*, SRACI, Melbourne, 1990, Appendix 20.

[137] Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Report on donor gametes in IVF*, Melbourne, 1983, p. 28.

> Another dilemma which faces prospective AID patients is whether to tell the child, relatives or friends about the nature of the pregnancy. Most patients at present decide not to tell the child, and therefore usually keep it a secret from everybody. However, as attitudes change, maybe sometime in the future, it may become popular to be open about donor insemination pregnancies.[138]

Research has confirmed that many parents from this time period (and earlier) did not tell, and may still not have told, their children that they were donor-conceived.[139] In a study undertaken in 1998, 134 couples who had undergone donor-conception treatment at a Melbourne clinic between 1976 and 1997 were asked whether they had told their child about the circumstances of their conception. Of those couples, 84 (62%) had not yet told their children that they were donor-conceived. Of the 84 couples who had not yet told their children, 30 (22% of the total number of couples surveyed) had decided that they did not ever intend to tell.[140]

2.3.2.3 Record-keeping

As the *Infertility (Medical Procedures) Act 1984* introduced requirements for record-keeping in assisted reproductive treatment procedures, records from this period are much more comprehensive and reliable than records of donor-conception treatments that occurred prior to 1988. In addition to maintaining their own register, clinics and doctors performing donor-conception treatments were required to provide to the Health Commission details of gamete donors and children born as a result of procedures, every six months, for inclusion in the central register.[141]

2.3.3 Practices after the introduction of the *Infertility Treatment Act 1995* (1998 - present)

The *Infertility Treatment Act 1995* made a fundamental change to donor-conception practices, by mandating that anonymous donations were no longer allowed.

From the commencement of the *Infertility Treatment Act 1995* on 1 January 1998, doctors and clinics were required to inform donors that information about the donor (including identifying information) would be passed on to the Infertility Treatment Authority for inclusion on the central register, and that any children conceived from their donation could obtain identifying information about the donor at the age of 18, or at a younger age with the consent of the child’s parent or guardian. The child and his or her parent or guardian were also entitled to obtain non-identifying

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[138] Standing Review and Advisory Committee on Infertility, *Annual Report to the Minister for Health for the calendar year ended 31 December 1989*, SRACI, Melbourne, 1990, p. 6.

[139] Louise Johnson and Helen Kane, 'Regulation of donor conception and the "time to tell" campaign', *Journal of Law and Medicine*, vol. 15, no. 1, pp. 117-127, 2007, p. 118.

[140] Jenny Blood and HWG Baker, *Parents of donor conceived children: the experience of telling*, unpublished paper, 1998, cited in Victorian Law Reform Commission, *Assisted reproductive technology & adoption*, Final report, 2007, p. 211.

[141] *Infertility (Medical Procedures) Act 1984* (Vic), sections 19, 21 & 22.

information about the donor. The *Infertility Treatment Regulations 1997* specified that this issue must be covered in counselling with the donor, prior to the donor consenting to the use of his or her gametes.[142]

Other matters required to be covered in pre-consent counselling of donors included:[143]

- the motivation for donating gametes, zygotes or embryos;
- the possible impact of donation on the donor's children;
- the possible impact of donation on the donor's spouse;
- any issue or concern raised by the donor or his or her spouse in relation to the donation;
- in the case of a known donor, the impact on the donor's relationship with the recipients; and
- the general requirements of the *Infertility Treatment Act 1995*.

These practices have essentially continued from the introduction of the *Infertility Treatment Act 1995* until present.

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[142] *Infertility Treatment Regulations 1997* (Vic), reg. 7(b)
[143] Ibid, reg. 7

Table 3: Donor-conceived people’s access to information about their donor under current legislation.

Donor-conceived person	Source for information	Information that can be obtained
Person conceived from gametes donated before 1 July 1988	**Fertility clinic at which mother was treated**	The fertility clinic (Monash IVF or Melbourne IVF) can, at its discretion, provide **non-identifying information** about the donor.
		The fertility clinic can, at its discretion, try to locate and contact the donor, and seek the donor’s consent to release **identifying information** to the donor-conceived person. If the donor cannot be located or will not provide consent, the clinic will not release identifying information.
		If the person was conceived through the Prince Henry’s Hospital donor program, he or she will not be able to obtain any information about the donor. These records are held by the Public Record Office Victoria, and are not accessible.
	Voluntary register	If the donor is registered on the voluntary register, the donor-conceived person can obtain **non-identifying and/or identifying information** from the voluntary register, in accordance with the donor’s wishes.
		However, the donor must be aware of the voluntary register, and must have registered, for this to occur.
Person conceived from gametes donated between 1988 and 1997	**Central register**	A donor-conceived person, regardless of their age, can obtain **non-identifying information** about their donor.
		A donor-conceived person over the age of 18, or with a parent or guardian’s consent if under 18, can apply for **identifying information** about their donor. This information will only be provided if the donor consents to its release.
	Voluntary register	Additional **non-identifying information** may be obtained through the voluntary register, if the donor has lodged information. The donor must be aware of the voluntary register, and must have registered, for this to occur.
Person conceived from gametes donated after 1 January 1998	**Central register**	A donor-conceived person, regardless of their age, can obtain **non-identifying information** about their donor.
		A donor-conceived person aged 18 years and over can obtain **identifying information** about their donor.
		A donor-conceived person who is under 18 years can obtain **identifying information** about their donor with a parent or guardian’s consent, or with a written opinion from a counsellor that they are sufficiently mature to understand the consequences of the information being disclosed to them.
	Voluntary register	Additional **non-identifying** information may be able to be obtained through the voluntary register, if the donor has lodged such information. The donor must be aware of the voluntary register, and must have registered, for this to occur.

Chapter

3

Chapter Three: Access by donor-conceived people to information about donors

Knowledge about parentage and heredity often forms a substantial part of a person’s sense of identity, and donor-conceived people who want this information, but are unable to obtain it, experience significant stress and frustration. Where people learn as youths or adults that they are donor-conceived, and are consequently forced to evaluate who they are through newly perceived relationships, the stress and frustration of not being able to find out more about their donor can be exacerbated. Unlike their parents, their donor, or the treating physician, the children are passive participants in donor-conception, and have had no influence on agreements made between those parties, even though they are substantially affected by those agreements.

In this Chapter, the Committee considers what information donor-conceived people should be able to obtain about their donors. First, the experiences of donor-conceived people are described, followed by an overview of the current arrangements for access to information. The Committee then reviews arguments for and against the provision of identifying information to donor-conceived people. Finally, recommendations on these issues are presented.

3.1 The experience of donor-conceived people who seek donor information

During the course of this Inquiry, the Committee heard from a number of donor-conceived people about the importance of being able to access information about their donors. The majority of donor-conceived people expressed their desire to have access to identifying information about their donors as well as non-identifying information. In particular, donor-conceived people told the Committee that it was important for them to know the name of their donor, even if this did not lead to actual contact:

> And at its heart, I believe this inquiry is about people. It is not about forcing people into unwanted relationships, it's about giving people like Narelle [Grech] or myself the knowledge we need to complete our sense of identity and normalising the rights of older donor-conceived people to match the

> standards we set for other Victorians, such as adopted people or younger donor-conceived people.[144]

The Committee heard how distressing it could be for people to learn as adults that they were donor-conceived, and of the upheaval this could cause to their sense of identity, and to their sense of belonging in their families:

> There's quite a bit of research that supports the fact that the later people are told about their donor conception can lead to all sorts of psychosocial or social problems or issues about identity, there's fear and risk of forming consanguineous relationships and this again goes to knowing about genetic siblings.[145]
>
> To find out that I was donor-conceived at age 20 was absolutely devastating. I cannot describe a more traumatic experience to go through because by the time you reach age 20 you've got through that angsty teenage period of wondering who the hell am I, that sort of growing up stage, and you seem to be developing a better idea of who you are and where you fit in the world, and then to have that completely demolished is, like I said, absolutely devastating. There was only a really short period of time between me discovering that I was donor-conceived and then actually coming into contact with Michael, but during that period I went through stages — it's described frequently, people talk about grief and loss, it's a process of grieving, what I knew to be who I thought I was, and then redeveloping a sense of identity with this new information that I had. So knowing that people who I thought were my family members were no longer my biological family members, so attributes that I thought I'd inherited from my dad's side of the family I could no longer rely on that position. I also felt like a bit of a fraud, to be honest. I had been overseas and visited people who were my dad's family members and stayed in their houses on the basis that I was their relative, and I felt guilty that, you know, I felt like they'd been duped because I wasn't related to them. I mean, in some sense I guess that's sort of a bit nonsensical but that was my feeling at the time.[146]

The traumatic effect on a person discovering that a parent is not genetically related to him or her has been documented in studies of adopted people, where there are obvious parallels with donor-conceived people:

> In his study of adopted adults, Triseliotis (1973) found that, without exception, all those informed of their adopted status later in life or by third parties were resentful and upset. For many, this betrayal of trust caused irreparable damage to family relationships.[147]

Even when people were aware from a young age that they are donor-conceived, certain events in their lives could change their

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[144] Lauren Burns, *Transcript of evidence*, Melbourne, 12 September 2011, p. 46.
[145] Sonia Allan, *Transcript of evidence*, Melbourne, 21 November 2011, p. 4.
[146] Myfanwy Cummerford, *Transcript of evidence*, Melbourne, 17 October 2011, p. 38.
[147] Ken Daniels and Karyn Taylor, 'Secrecy and openness in donor insemination', *Politics and the life sciences*, vol. 12, no. 2, pp. 155-170, 1993, p. 161.

perspective on the importance of knowing their donors, and their genetic heritage. Mr Damian Adams told the Committee that, although he was always curious to know who his father was, his desire to know the ‘missing’ component of his heredity became more urgent when he became a father:

> The single biggest thing in my life that has shaped my perspective on being donor-conceived was the birth of my own children. It was after my daughter was born. … I came to think about how if she ever grew up not knowing who I was that was a concept that I just could not bear to think about and how that would have devastated me, and then I came to realise how that actually resembled my own life and that for no reason or fault of my own I had been deprived of the exact same thing that I had with my daughter. What should have been an extremely happy and joyous time in my life became extremely dark, and it has left me scarred for life.[148]

All of the donor-conceived people from whom the Committee received evidence expressed that they had no desire to force a relationship on a donor, if the donor did not wish to have contact. This has also been the experience in adoption, where the preference of birth-parents not to meet or form relationships with their children is almost always respected. Counsellors and other people who have worked with donor-conceived people affirmed that, in the majority of cases, donor-conceived people would respect a donor’s desire not to meet them:

> … one of our experiences with the donor-conceived people is that they want the right [to make contact with their donor] — at least if someone tries to make contact with the donor and gives them that chance to have contact with their donor, it's when the doors are shut and you're told: no, you don't have a right to that information about you. I think that is the hardest thing — not wanting to speak on behalf of them, but our experience is that that's the hardest thing for them. If you at least try and do what you can to help them and make contact with the donor, when the donor says no they feel that at least that's been made and maybe it's opened up the possibility for future contact.[149]

The Committee also heard of the frustration experienced by many donor-conceived people who weren’t able to access information, either through the voluntary register or by approaching clinics or physicians. For some donor-conceived people, knowing that information about their genetic origin existed, but that they were prevented from accessing it, was very disheartening:

> I've been actively speaking out about donor conception for a number of years, and it's taken its toll on me emotionally and within my family. It's personally quite taxing to have to recount my story and to have to plead for information that I feel I should already have. The lack of control around this is very disempowering, the secrecy and withholding of information about who I am and my conception leads me to feel like a second-class citizen. I

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[148] Damian Adams, *Transcript of evidence*, Melbourne, 5 December 2011, p. 19.

[149] Marianne Tome, Victorian Infertility Counsellors Group, *Transcript of evidence*, Melbourne, 12 September 2011, p. 24.

> believe that the truth will set me free, so to speak, and I ask for access to my records for this reason. I want answers so that I can move forward in life without these feelings of loss and grief and I don't think anyone should have to endure this, especially when the records do exist.[150]
>
> I felt really disempowered and disenfranchised and I felt like a second-class citizen because I knew that that information was sitting in a filing cabinet and I wasn't entitled to access it. That made me incredibly angry, and still makes me angry today to hear from counsellors that they've got this information and it's on the computer and that my friend Narelle [Grech], who is associated with that clinic, isn't allowed to do anything with that information.[151]

Some witnesses drew the Committee's attention to the concept of "genealogical bewilderment" to help explain the experiences of donor-conceived people.[152] This term was originally used in the context of an adopted person's sense of identity and place within their family and society, and describes a person's desire to know more about his or her genealogical parent or parents:

> Despite a child's development being shaped by social as much as biological factors, knowledge of one's immediate genetic heritage is … considered integral to the self-identity of most people. Once donor-conceived individuals discover they are not biologically related to their parent(s), some feel a sense of "lost identity" and a corresponding desire to know more about their donor. This has been referred to as "genealogical bewilderment."[153]

A number of witnesses also described their feelings of loss and grief upon learning that they are donor-conceived and, following that, upon learning that there were few means for them to seek to make contact with their donor.[154] Ms Narelle Grech articulated the concept of "disenfranchised grief", where a person is not able to adequately express their feelings about not knowing their donor:

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[150] Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, p. 34.

[151] Myfanwy Cummerford, *Transcript of evidence*, Melbourne, 17 October 2011, p. 39.

[152] Sonia Allan, *Transcript of evidence*, Melbourne, 21 November 2011, p. 2; Sonia Allan, 'Psycho-social, ethical and legal arguments for and against the retrospective release of information about donors to donor-conceived individuals in Australia', *Journal of Law and Medicine*, vol. 19, pp. 354-376, 2011, p. 357; Ken Daniels and Karyn Taylor, 'Secrecy and openness in donor insemination', *Politics and the life sciences*, vol. 12, no. 2, pp. 155-170, 1993; Nicholas Tonti-Filippini, *Submission no. 45*, 9 August 2011, p. 2; VANISH Inc, *Submission no. 8*, 3 August 2010, p. 5.

[153] Sonia Allan, 'Psycho-social, ethical and legal arguments for and against the retrospective release of information about donors to donor-conceived individuals in Australia', *Journal of Law and Medicine*, vol. 19, pp. 354-376, 2011, p. 358.

[154] Lauren Burns, *Submission no. 3*, 29 July 2010, p. 4; Lauren Burns, *Transcript of evidence*, Melbourne, 12 September 2011, pp. 41-42; Myfanwy Cummerford, *Transcript of evidence*, Melbourne, 17 October 2011, p. 38; Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, p. 34; Narelle Grace Grech, *Submission no. 18*, 6 August 2010, p. 5; Angela Karavidas, Manager, Family Information Networks and Discovery (FIND), *Transcript of evidence*, Melbourne, 21 November 2011, p. 21; Mariaelisa Tumino, Former manager, Family Information Networks and Discovery (FIND), *Transcript of evidence*, Melbourne, 21 November 2011, p. 11; VANISH Inc, *Submission no. 8*, 3 August 2010, p. 8.

> … disenfranchised grief … is a theory that Kenneth Doka put forward, [defined] as: "Grief that persons experience when they incur a loss that is not, or cannot, be openly acknowledged, publicly mourned or socially supported." I think this theory applies to myself and other donor-conceived people because we can't publicly mourn the loss, or I can't publicly mourn the loss of my biological father and my paternal family as I already have a dad, who society regards as being all that I need.[155]

It became clear to the Committee during the course of this Inquiry that a number of donor-conceived people experience considerable anguish and sadness about not knowing, and having no effective mechanism through which to seek to know, the identity of their donor.

Finding 1: Some donor-conceived people suffer substantial distress when they are unable to obtain information about their donor, and/or if told of their donor-conceived status later in life.

Some parents of donor-conceived people also told the Committee that the lack of access to information about donors discouraged them from telling their children that they are donor-conceived. For example, the Committee heard from Ms Barbara Burns, who struggled for many years with the question of whether to tell her children that they are donor-conceived:

> After nearly a quarter of a century of keeping the secret, in 2005, I told my 2 girls that they were donor conceived. Jane was 24 and Lauren was 21. This means they were conceived prior to the Victorian cut-off date of 1988. I thought about it for a long time before actually getting the courage to speak. … Many parents, like me, as they and their donor conceived children get older, are finding the burden of the secret of their children's conception a heavy weight. They want to speak as they believe that it is very wrong to keep such fundamental information from their child. However they are rightly afraid of making a bad situation even worse. 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.[156]

These kind of concerns appear to be common for parents of donor-conceived people who accepted advice to not tell their children about their conception.[157] The Committee considers that the lack of access to information about donors may be a significant bar to parents telling their donor-conceived children about the manner of their conception.

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[155] Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, p. 35.
[156] Barbara Burns, *Submission no. 9*, 3 August 2010, p. 1.
[157] See, for example, Name withheld, *Submission no. 2*, 28 July 2010.

3.2 Current access to information

Access to information about a donor by a donor-conceived person is principally determined by the date at which the donor provided consent for his or her gametes to be used. There are currently three groups of donor-conceived people in Victoria with differing rights to access information about their donor, based on the date of consent:

- **Pre-1988** donor-conceived people, whose donor consented to the use of their gametes prior to 1 July 1988. These people currently have no rights to access any information about their donor, and limited avenues to pursue information;

- **1988-1997** donor-conceived people, whose donor consented to the use of their gametes between 1 July 1988 and 31 December 1997. People in this group have the right to obtain non-identifying information about their donor, and to obtain identifying information with donor consent; and

- **Post-1998** donor-conceived people, whose donor consented to the use of their gametes after 1 January 1998. These people have the right to obtain non-identifying and identifying information about their donor.

The rights of each of these groups of donor-conceived people, and the basis for the differing rights, are explored in further detail below.

3.2.1 The donor registers

There are two donor registers maintained under legislation in Victoria – a central register, containing information about donors, donor-conceived people, and recipient parents compiled in accordance with Victorian regulation,[158] and a voluntary register, which records personal information voluntarily lodged by a donor, a donor-conceived person, or a recipient, or a relative or descendant of one of these people.[159] Both registers are held and managed by the Registry of Births, Deaths and Marriages (BDM). Table 4 provides an overview of the registers and who is able to access information held on each of them. Each register is explained in further detail below.

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[158] *Infertility (Medical Procedures) Act 1984* (Vic), section 22; *Infertility Treatment Act 1995* (Vic), section 68.

[159] *Infertility Treatment Act 1995* (Vic), section 82.

Table 4: Content of and access to donor registers[160]

	Applies to donations made	Right to information
Central Register	From 1 July 1988 to 31 December 1997	Consent of person to whom the information relates is required for the release of identifying information.
	From 1 January 1998 to present	A donor-conceived person aged 18 years and over can obtain identifying information about their donor. A donor can only obtain identifying information about a donor-conceived person with the consent of the person born, or their parents if the person is under 18 years.
Voluntary Register	Before 1 July 1988	Information provided voluntarily and exchanged in accordance with the contributor's wishes.
	After 1 July 1988	Information additional to that contained in the central register may be lodged and exchanged in accordance with the contributor's wishes.

3.2.1.1 Central register

The *Infertility (Medical Procedures) Act 1984*, which came into effect on 1 July 1988, required that the then Health Commission maintain a central register, to contain details provided by doctors and clinics performing assisted reproductive treatments where donor gametes were used.[161] Information recorded on the central register includes various identifying and clinical information (such as names and birthdates), information about the number of other recipients and children born, and physical characteristics, occupation, interests, and limited ancestry of the donor (see Appendix Four, Table 2).[162]

The *Infertility (Medical Procedures) Act 1984* provided that a donor-conceived person could access non-identifying information about their donor held on the central register, and could obtain identifying information if the donor consented to its release. This remains the situation for 1988-1997 donor-conceived people.[163]

The *Infertility Treatment Act 1995* maintained the existence of the central register, but introduced new rules to apply to information about donors who consented to the use of their gametes after the commencement of the *Infertility Treatment Act 1995*, from 1 January 1998. These donors were required, at the time of making their donation, to consent to identifying

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[160] Adapted from Victorian Law Reform Commission, *Assisted reproductive technology & adoption*, Final report, VLRC, Melbourne, 2007, p. 149.

[161] *Infertility (Medical Procedures) Act 1984* (Vic), sections 19, 21 & 22.

[162] Ibid, sections 19 & 22, and *Infertility (Medical Procedures) Regulations 1988* (Vic), reg. 9(1).

[163] *Assisted Reproductive Treatment Act 2008* (Vic), section 59.

information being released to their donor-offspring upon request.[164] Consequently, donor-conceived people conceived from gametes donated after 1998 will be able to obtain identifying information about their donors by applying to the central register.

A post-1998 donor-conceived person can apply to the central register for identifying information about their donor once they are 18 years of age. A donor-conceived person under the age of 18 can apply for identifying information with the consent of his or her parent or guardian, or with written confirmation from a counsellor that the person has received counselling and is sufficiently mature to understand the consequences of the disclosure.[165]

3.2.1.2 Voluntary register

The voluntary register was created in 1998 and is maintained separate to the central register. The voluntary register allows donor-conception stakeholders and their relatives to exchange information outside the central register system. Pre-1988 donor-conception stakeholders can lodge information with the voluntary register.[166] The voluntary register also allows donors, donor-conceived people, their parents, and relatives to voluntarily record identifying details or additional information that is not included on the central register, such as photographs and messages.[167] As of 21 October 2011, 353 people were registered on the voluntary register, with pre-1988 conditions applying to 125 of these people.

Table 5: Parties recorded on the voluntary register[168]

Parties recorded on the voluntary register		Pre-1988
Donors	156	58
Recipient parents	135	16
Donor-conceived persons	62	49
Total	**353**	**125**

Information on the voluntary register is only released by BDM in accordance with the wishes of the person who registered the information. There is no fee to lodge an application to the voluntary register.

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[164] *Infertility Treatment Act 1995* (Vic), section 17.

[165] *Assisted Reproductive Treatment Act 2008* (Vic), section 59.

[166] *Infertility Treatment (Amendment) Act 2001* (Vic), Part 7A. This Part was inserted into the *Infertility Treatment Act 1995* in 2001 to expand the voluntary register to cover pre-1988 donor-conception stakeholders.

[167] *Infertility Treatment Act 1995* (Vic), section 82.

[168] Births Deaths and Marriages Victoria, *Supplementary evidence*, 21 November 2011, p. 3.

3.2.2 Pre-1988 donor-conceived people

Donor-conceived people whose donors provided consent to the use of their gametes prior to 1 July 1988 currently have no legal mechanism to access information about their donor. The *Assisted Reproductive Treatment Act 2008* is silent on the rights of these donor-conceived people, and consequently their access to information about donors is at the discretion, and dependent on the resources, of individual clinics and doctors who carried out donor treatments.

For this group of people, there are two means by which they can attempt to find out information about their donor.

3.2.2.1 Voluntary register

One approach available to a person seeking information on their donor is to lodge an application with BDM for inclusion on the voluntary register. If the donor has also registered, or at some later point registers, a ‘match’ will occur and BDM will provide each party with information that the other person has consented to release. This may be identifying information, or non-identifying information such as physical characteristics, interests, family information, or any other information that the person wishes to share.[169] For parties to donor-conception prior to 1988 there are currently 49 donor-conceived persons, 16 recipient parents and 58 donors recorded on the voluntary register.[170]

The effectiveness of the voluntary register as a means to facilitate contact is, of course, dependent on participation of all the relevant parties. However, as discussed in Chapter Two, the Committee heard that most donor-conceived people from the period prior to 1988 (and a significant proportion of people from the period prior to 1998) are unlikely to be aware that they are donor-conceived. Furthermore, many donors may not be aware of the voluntary register, and so will not register, even if they would otherwise be inclined to do so. Many pre-1988 donors would not have been contacted by the clinic at which they donated since the time of their donation, some decades previously, and may not be aware of developments such as the creation of the voluntary register.

BDM is empowered by legislation to publicise the establishment and purpose of the voluntary register from time to time,[171] but has not to date undertaken any advertising or public awareness campaigns aimed at informing pre-1988 donors of the existence and purpose of the voluntary

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[169] See Births Deaths and Marriages Victoria, 'Voluntary register application', viewed 2 December 2011, <http://online.justice.vic.gov.au>.

[170] As at 21 November 2011 - Births Deaths and Marriages Victoria, *Supplementary evidence*, 21 November 2011, p. 3.

[171] *Assisted Reproductive Treatment Act 2008* (Vic), section 71(2).

register. The Committee was told, however, that BDM was considering publicising the voluntary register towards the end of 2011.[172]

BDM takes the view that it cannot write to donors directly (or via the clinic at which the donor donated) to inform them of the voluntary register.[173] In 2010, BDM refused a specific request from a pre-1988 donor-conceived person to write to her donor for this purpose, on the basis that the legislation does not authorise BDM to take such action (see Case Study 2).

3.2.2.2 Treating doctor or clinic

Another means for attempting to obtain information is for the donor-conceived person to approach the doctor or clinic who provided the fertility treatment to their mother. The doctor or clinic may hold records of the treatment, including the donor's name and details. In this case, on request by a donor-conceived person, the doctor or clinic may attempt to make contact with the donor, and seek their consent to release information to the donor-conceived person.

A fortuitous combination of factors is required to fall into place in order for this approach to be successful. BDM has access to records from Prince Henry's Hospital, but will not approach donors to obtain consent for the release of information for people conceived from gametes donated prior to 1988, and Monash IVF only recently commenced making such approaches. Some treating doctors may still possess their medical files, and may access them on request, but this is entirely at their discretion. By contrast, Melbourne IVF has for some time been providing some donor-linking services for pre-1988 donor-conceived people, assisting between five and ten pre-1988 donor-conceived people per year.[174]

The Committee heard that Melbourne IVF will assist donor-conceived individuals to contact their pre-1988 donors, and has not refused any request from a donor-conceived person seeking information about a pre-1988 donor. In each case, Melbourne IVF made contact with the donor.[175] Melbourne IVF takes the view that because it provided treatment to women who conceived using donor gametes, it has a responsibility to the donor-conceived offspring.[176] The Committee commends Melbourne IVF for adopting this approach.

Nevertheless, the Committee regards this set of circumstances as highly problematic. A key impetus for the current Inquiry was concern about

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[172] Births Deaths and Marriages Victoria, *Supplementary evidence*, 21 November 2011, p. 3. The Committee was informed that BDM has "developed a communication strategy to raise awareness of the existence and purpose of the Voluntary Register, particularly targeting sperm donors from the pre-legislative period (i.e. prior to 1 July 1988). BDM anticipates that this strategy will commence roll out towards the end of 2011."

[173] Erin Keleher, Manager of Strategic Projects, Registry of Births, Deaths and Marriages, *Transcript of evidence*, Melbourne, 21 November 2011, p. 26.

[174] Marianne Tome, Victorian Infertility Counsellors Group, *Transcript of evidence*, Melbourne, 12 September 2011, p. 25.

[175] Joanne McCann, Operations Manager, Melbourne IVF, *Transcript of evidence*, Melbourne, 10 October 2011, p. 19.

[176] Ibid, p. 21.

people having differential access to information about their genetic origins based simply on the year of their birth. The Committee has further ascertained that even for people in the same circumstance (that is, those conceived from gametes donated prior to 1988) there is differential access to information depending on the place of their mother's treatment, or the record-keeping practices of individual doctors.

The following two case studies illustrate the inconsistencies in access to information for donor-conceived people from this period.

Case Study 1: Lauren Burns.[177]

"I found out I was donor-conceived when I was 21, without ever suspecting that my dad was not my biological father. … Initially I was told that my donor would have forgotten about me, definitely wouldn't want to know me; in fact, finding out about my existence would have negative impacts and potentially even ruin his life. There is a perception that donors must be protected from donor-conceived people … and the way the debate is framed about potential impacts on past donors suggests the very existence of donor-conceived people is somehow toxic and an embarrassment, which is quite hurtful to us. …

After meeting with the then Governor of Victoria [her mother's treating doctor], he agreed to write to my donor on my behalf and in fact my donor responded within days. … Anyway, finding out about my existence didn't ruin my biological father, Ben, and his three children's lives; in fact, they responded in the opposite way to which I had been warned. They were very welcoming and after writing letters and speaking on the phone we all met in person and have been in touch since that day. Before we met I was extremely nervous and on the day it was quite overwhelming to be surrounded by people that looked like me. Afterwards I think my overarching feeling was one of relief, relief to finally be able to trace the origins of my looks, personality and interests and this had the effect of soothing the endless whirring of questions which had been like a splinter in my brain."

Case Study 2: Kimberley Springfield.[178]

"Ms Springfield was conceived following a donor treatment procedure at Monash IVF. After discovering that Monash IVF held medical records identifying her biological father, Ms Springfield wrote to the doctor who facilitated her conception requesting that he write to her biological father, 'to initiate exchange of information and potentially ask for consent to release identifying information.' The doctor refused Ms Springfield's request for him to act as an intermediary on the basis that her biological father had 'elected' to remain anonymous.

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[177] Lauren Burns, *Transcript of evidence*, Melbourne, 12 September 2011, pp. 41-42.
[178] Public Interest Law Clearing House, *Submission no. 62*, 12 August 2011, pp. 3-4.

Ms Springfield subsequently wrote to Monash IVF requesting that it assist her by acting as an intermediary to facilitate contact between her and her biological father. Monash IVF refused Ms Springfield's request for the same reason given by the doctor.

In May 2010, [law firm] Corrs wrote to the Registrar of Births, Deaths and Marriages (Registrar), Ms Helen Tritias, requesting that she write to Ms Springfield's biological father to inform him of the existence and purpose of the Voluntary Register. In the event that the Registrar did not have access to Ms Springfield's biological father's identifying information we requested that the Registrar ask Monash IVF to forward such a letter to Ms Springfield's biological father. In making this request Corrs referred to the intended purpose of the Voluntary Register and the Registrar's power pursuant to section 71(2) of the ART Act which provides that, 'The Registrar may from time to time publicise the establishment and purpose of the Voluntary Register.'

In June 2010, Corrs received a letter from the Registrar declining Ms Springfield's request because the Registrar's view was that she lacked power under the ART Act to write to donors directly.

In September 2010, Ms Springfield applied to the Victorian Civil and Administrative Tribunal (VCAT) for a review of the Registrar's decision. Although Ms Springfield's application was dismissed by VCAT on the basis that it lacked jurisdiction to review the Registrar's decision, Senior Member Billings found that:

> *There appears to me to be some force in Mr Hanks' [Ms Springfield's Counsel's] submission that at least this [sending a letter through an intermediary] would be within the Registrar's power but I do not need to decide the scope of the Registrar's powers to decide whether VCAT has jurisdiction.*

As a result of the refusals from the doctor responsible for Ms Springfield's conception, Monash IVF and the Registrar in relation to Ms Springfield's request for each to act as an intermediary by contacting her biological father to ask him whether he would consent to the release of identifying information (and, in the case of the Registrar, simply to inform him of the presence of the Voluntary Register), Ms Springfield has not been able to advance any potential contact with her biological father."

The lack of regulation concerning pre-1988 donor-conceived people has resulted in ad hoc responses to requests for assistance and information. In some cases, clinics have elected not to facilitate contact with donors because, in their view, the agreement between the clinic and the donors was that the donor would remain anonymous, and because they are concerned that making contact with a donor in such circumstances could constitute a breach of privacy. Other clinics regard making an approach to a donor on behalf of a donor-conceived person as an ethical matter, and do not regard contact by the clinic as raising privacy concerns. Treating doctors, where they have access to the relevant information, may hold a similar range of views.

Finding 2: Current arrangements for access to information by people conceived from gametes donated prior to 1988 are confusing, inconsistent, and applied in a haphazard manner. Outcomes differ depending on the treating clinic, and/or the treating physician, from which a person's parents received treatment.

3.2.3 1988 to 1997 donor-conceived people

3.2.3.1 Central register

Where a donor provided consent to the use of their gametes after 1 July 1988, both identifying and non-identifying information about that donor will be recorded on the central register. A person who was conceived from gametes donated between 1 July 1988 and 31 December 1997 is entitled to obtain non-identifying information about their donor, and can do so by applying to BDM. They can also apply for identifying information about their donor, but BDM will only release such information with the donor's consent.

The Committee notes that although the legislation changed as of 1 January 1998, the use of gametes donated prior to that date continued to be permitted until 31 May 2006.[179] This means that some children born after 1 January 1998 do not have the automatic right to access identifying information about their donor, but are rather included within the group of 1988 to 1997 donor-conceived people.

3.2.3.2 Voluntary register

While the voluntary register is available to all donor-conceived people, people conceived from donations made after 1988 would likely seek identifying and non-identifying information through the central register. As the voluntary register is available to a broader range of people, such as relatives of donors and donor-conceived people, it may be used to facilitate the exchange of information between siblings and other relatives. Exchange of information between people other than donors and donor-conceived people is discussed in Chapter Six, and below.

3.2.4 Post-1998 donor-conceived people

3.2.4.1 Central register

Any person who was conceived using gametes donated from 1 January 1998 is entitled to obtain identifying information about their donor.[180] If the person is under 18 years of age, they must have the consent of a parent or guardian, or must have a counsellor declare in writing that they have counselled the person, and the person is sufficiently mature to understand the consequences of the information being disclosed to him or her.[181]

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[179] Infertility Treatment Authority, *Conditions for licence: applications for licences by hospital and day procedure centres*, ITA, Melbourne, 2006, section 5.10.

[180] *Assisted Reproductive Treatment Act 2008* (Vic), section 59.

[181] Ibid, section 59(a).

In addition, any post-1998 donor-conceived person, regardless of their age, can obtain non-identifying information held on the central register about their donor.[182] Similarly, the parent of a donor-conceived person can obtain non-identifying information about the donor.[183]

3.2.4.2 Voluntary register

The voluntary register does not necessarily offer any additional information for post-1998 donor-conceived people, as they are able to access identifying information about their donor through the central register. However, the voluntary register can allow the parents of donor-conceived children to obtain information about the donor, and potentially make contact with the donor, particularly when the donor-conceived child is still young. The voluntary register also allows recipient parents who have used gametes from the same donor to make contact with each other, if they are all registered.

For example, the Committee received a submission from Ms Shelley Sandow, a single mother of a daughter who was conceived using donor sperm and a donor egg, through Melbourne IVF. Her daughter was born in 2008. Ms Sandow joined the voluntary register after her daughter was born, and quickly made a link with her sperm donor and another family that had used the same sperm donor and have a son around the same age as Ms Sandow's daughter. Ms Sandow used the then ITA's letterbox service to exchange letters with the donor and the other family, and has gone on to pursue further contact, which she hopes to foster and continue, as she believes it is in the best interest of all involved.[184]

The voluntary register can also enable donor-conceived siblings to make contact with each other – it is the only way that this can occur directly.

3.2.4.3 The state of legislation applying to post-1998 donor-conceived people

The Committee recognises that Victoria has been a world-leader in developing and updating its legislation regulating assisted reproductive treatment and access to information by parties to donor-conception, insofar as the legislation applies prospectively. For a person conceived from gametes donated after 1998, the legislation requires that identifying information be released to that person on request (and if the person is a child, with the consent of his or her parents or a counsellor). Parents of a donor-conceived child may only receive identifying information about the donor with the donor's consent, and similarly, donors can only receive identifying information if their donor-offspring consents, or if he or she is a child, if the parent consents. All parties to donor-conception (including descendants) are entitled to receive non-identifying information.

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[182] Ibid, sections 56 & 57.
[183] Ibid.
[184] Shelley Sandow, *Submission no. 7*, 3 August 2010.

In the Committee's view, these arrangements sufficiently acknowledge the rights of all parties to information, and sufficiently ensure that the rights and desires of the donor-conceived person are paramount.

Finding 3: Current legislative arrangements pertaining to rights of access to information by people conceived from gametes donated after 1998 are satisfactory.

3.3 Considerations around the retrospective release of information

To date, most changes to legislation surrounding access to information for parties to donor-conception have been prospective – that is, applying only from a certain date after the legislation is introduced. If the Parliament is to grant people born prior to 1988 access to identifying or non-identifying information about their donors, legislation with retrospective effect will likely have to be introduced.

3.3.1 Non-legislative means for providing access to information

As noted above, in some cases donor-conceived people have been able to obtain information – including identifying information – about their donors in the current legislative environment. Melbourne IVF, for example, has taken the view that it is not a breach of privacy for it to approach former donors with requests to provide information to donor-conceived people. Other medical institutions have taken the view that the agreements they have with donors precludes them from making contact for this purpose.

Further advice would be required to determine whether any legal repercussions could arise from contact between a clinic and a donor if a donor decided to take legal action – whether, for example, a donor could subsequently initiate a compensatory action for a breach of privacy or contract. In its submission to the Inquiry, Monash IVF suggested that donors could potentially take legal action if retrospective access to identifying information was granted to donor-conceived people:

> Donors who consented at a time when anonymity was guaranteed (i.e. pre-1988 and pre-1995) may find retrospective access to identifying information about them confronting. This would likely be viewed as changing the conditions on the contract they agreed upon and may open the door for litigation.[185]

The Committee notes that a significant proportion of donor-conception records from the 1980s and earlier are held by the Public Record Office Victoria (PROV). Under current arrangements, no donor-conceived person is able to obtain identifying information about their donor from these records – as BDM (who is the Responsible Agency for these records, and

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[185] Monash IVF, *Submission no. 26*, 6 August 2010, pp. 1-2.

therefore is able to access them) will not contact or seek consent from a donor for release of information held by PROV. This issue is discussed further in Chapter Seven.

The Committee also notes that under current arrangements, no person conceived from gametes donated prior to 1998 can obtain identifying information about their donor without their donor's consent.

For these reasons, amendment or alteration to any of the current arrangements in order to allow all donor-conceived people increased access to information, and in particular identifying information, regardless of when they were conceived, will require the introduction of new legislation.

Finding 4: The introduction of measures to provide all donor-conceived people with access to identifying information will require legislative change.

3.3.2 The donor-conceived person's 'right' to know

Opinions expressed to the Committee about the extent of a donor-conceived person's 'right' to know information about their donor were diverse, and tended to encompass a number of related, but distinct, themes. These ranged, for example, from the need for people to have access to relevant medical information about their donors,[186] or non-identifying information, to the need to know the name of the family from which the donors came,[187] family history,[188] or the opportunity to contact, and possibly know, the donor him- or herself.[189] A separate, but closely related issue, is the right of a person to *know that they are donor-conceived*.[190]

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[186] Damian Adams, *Submission no. 4*, 30 July 2010, p. 2 & 3; Sonia Allan, *Submission no. 5*, 2 August 2010, pp. 1, 2 & 12; Sonia Allan, 'Psycho-social, ethical and legal arguments for and against the retrospective release of information about donors to donor-conceived individuals in Australia', *Journal of Law and Medicine*, vol. 19, pp. 354-376, 2011; Agnes Bankier, *Submission no. 38*, 25 July 2011, p. 1; Lauren Burns, *Submission no. 3*, 29 July 2010, p. 3; Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, p. 40; Narelle Grech, *Submission no. 67*, 15 August 2011, pp. 1-2; Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 39; Gordon Ley, *Submission no. 44*, 8 August 2011, p. 1; Kimberley Turner (Springfield), *Submission no. 50*, 11 August 2011, p. 1; VANISH Inc, *Submission no. 8*, 3 August 2010, p. 3; Victorian Equal Opportunity and Human Rights Commission, *Submission no. 74*, 1 September 2011, p. 8; Victorian Infertility Counsellors Group, *Submission no. 64*, 12 August 2011, p. 3; Christine Whipp, *Submission no. 31*, 9 August 2010, p. 1.

[187] Damian Adams, *Submission no. 4*, 30 July 2010, p. 2; Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, p. 44 & 45; Leigh Hubbard, Chair, VANISH Inc, *Transcript of evidence*, Melbourne, 17 October 2011, p. 14; Rosalie Hudson, Ad Hoc Interfaith Committee, *Transcript of evidence*, Melbourne, 12 September 2011, p. 6; Susan Hurst, *Submission no. 14*, 5 August 2010, p. 2.

[188] Damian Adams, *Submission no. 4*, 30 July 2010, p. 6; Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, p. 45; Office of the Victorian Privacy Commissioner, *Submission no. 58*, 12 August 2011, p. 2; Kimberley Springfield, *Submission no. 20*, 6 August 2010, p. 1; Victorian Assisted Reproductive Treatment Authority, *Submission no. 19*, 6 August 2010, p. 7; Victorian Infertility Counsellors Group, *Submission no. 64*, 12 August 2011, p. 3.

[189] Damian Adams, *Submission no. 4*, 30 July 2010, p. 6; Sonia Allan, *Submission no. 5*, 2 August 2010, p. 11; Sonia Allan, *Submission no. 37*, 18 July 2011, p. 6; Australian

In her discussion of these issues, academic Vardit Ravitsky identified four types of claims within arguments in favour of donor-conceived people's right to know about their donors:

> The medical aspect points towards the right to know one's full medical history and to know medically relevant genetic information about the donor. The identity aspect points towards the right to personal information about the donor as a person (narrative information) that would assist offspring in overcoming identity issues. The relational aspect points towards the right to know the full identity of the donor in order to contact him or her and attempt to establish a relationship. Finally, the parental disclosure aspect relates to the right to know the truth about the circumstances of one's conception as trumping parents' right to privacy.[191]

Although Ravitsky suggested that identifying information is only necessary where a donor-conceived person seeks a relationship with his or her donor, the Committee heard that knowing the donor's name is important in the 'identity' aspect as well – that being able to name the donor is important for forming a person's narrative about themselves, even if a relationship with the donor does not eventuate. This could be the case, for example, where a donor-conceived person seeks information on family ancestry in order to understand his or her own identity.

3.3.2.1 The 'right' to medical information

The importance of providing donor-conceived people with access to relevant medical information about their donors was raised in a number of submissions.[192] The importance of sharing this kind of information has the potential to flow both ways, however, as donor-conceived people may also need to pass medical information to their donors. This could be particularly important where a hereditary disease or genetic abnormality is identified in either the donor or the donor-conceived person.

Family Association, *Submission no. 68*, 15 August 2011, p. 4; Lauren Burns, *Submission no. 3*, 29 July 2010, p. 5; David Fixler, Public Interest Law Clearing House, *Transcript of evidence*, Melbourne, 8 September 2011; Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, p. 39; Narelle Grace Grech, *Submission no. 18*, 6 August 2010, p. 3; Rosalie Hudson, Ad Hoc Interfaith Committee, *Transcript of evidence*, Melbourne, 12 September 2011, p. 6; Merrilyn Mannerheim and Jo Moffat, *Submission no. 41*, 4 August 2011, p. 1; Romana Rossi, *Submission no. 25*, 6 August 2010, p. 2; Mariaelisa Tumino, Former manager, Family Information Networks and Discovery (FIND), *Transcript of evidence*, Melbourne, 21 November 2011, p. 15.

[190] Damian Adams, *Submission no. 4*, 30 July 2010, p. 3; Roger Clarke, *Transcript of evidence*, Melbourne, 17 October 2011, p. 59; Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, p. 39; Narelle Grech, *Submission no. 67*, 15 August 2011, p. 2; Caroline Lorbach, National Consumer Advocate, Donor Conception Support Group of Australia Inc, *Transcript of evidence*, Melbourne, 17 October 2011, p. 45 & 53; Name withheld, *Submission no. 2*, 28 July 2010, p. 2.

[191] Vardit Ravitsky, '"Knowing where you came from": the rights of donor-conceived individuals and the meaning of genetic relatedness', *Minnesota Journal of Law, Science and Technology*, vol. 11, no. 2, pp. 665-684, 2010, p. 668.

[192] Sonia Allan, *Submission no. 37*, 18 July 2011, p. 18; Agnes Bankier, *Submission no. 38*, 25 July 2011, p. 1; Myfanwy Cummerford, *Submission no. 53*, 11 August 2011, p. 1; Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, p. 40; Name withheld, *Submission no. 29*, 9 August 2010, p. 2; Victorian Equal Opportunity and Human Rights Commission, *Submission no. 74*, 1 September 2011, p. 8.

The Committee was told that VARTA was aware of three cases in the year to September 2011 where a donor or a donor-conceived person had a serious disease, but was not able to contact other parties to advise them of the condition.[193] In some cases, upon receiving this kind of information, clinics have considered that donor-conceived people were entitled to be informed of the medical information, even if they were not aware of the manner of their conception, such as in the circumstances described in Case Study 3.

Case Study 3: Passing on medical information[194]

"We [the Royal Women's Hospital] had contact from one of our donors who had donated pre-1988 and who had four offspring who were all aged about 29 or 30. This situation arose about four years ago, so they are all in their early 30s now. He developed a heart condition which put him at risk of fainting and even sudden death and there was a 50 per cent chance that any offspring would have inherited this condition. So it was potentially a quite serious condition. You can do a medical screening test for it to see if you have inherited it, and if you have, then you can have either appropriate medication or intervention such as a pacemaker to try to prevent your dropping dead.

We thought this was a serious enough risk that we should try to contact his four [donor] offspring to let them know of this risk to their health and recommend that they have an investigation of their heart status. Because they would not necessarily have known of their donor conception, we chose to go back to each of their parents and ask if we could have their permission to talk to the children – the four offspring all in different families – about this issue. It took us four years to work through that process, because back then when these couples had been treated it was not usual for you to tell your children they were donor-conceived. In fact secrecy was the norm. … In all these cases the adult children did not know they were donor-conceived.

It took a lot of negotiating with the couples involved to discuss with them whether they would tell their children this. In one particular case, where the 30-year-old son was a pilot, there was a huge resistance to telling him because they thought it was going to tear the family apart for him to find out at this late stage that he was donor-conceived. It was four years from when we started to when he was actually told of this risk. He was tested and he does have a heart anomaly. He is a pilot, not of a big plane but a little plane, so it was a very serious medical condition."

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[193] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 39.

[194] Penelope Foster, Fertility Society of Australia, *Transcript of evidence*, Melbourne, 8 September 2011, p. 11.

The Committee also heard evidence from Ms Narelle Grech, who was diagnosed with Stage 4 bowel cancer in May 2011:

> Not only do I not have access to my records, earlier this year in May I was diagnosed with Stage 4 bowel cancer following an emergency surgery at Royal Melbourne Hospital. The first thing the doctors and surgeons asked me was: is there any family history of cancer in your family? You can imagine how upsetting it was to not only be told of this diagnosis but to then have to wonder whether I've inherited this from my paternal family. I must say that my sister and I both were really angry and upset and in tears about this at the hospital. I'm sure there was no family history of illness at the time that T5 [the donor] donated but who is to say he simply did not know this at the time? What if he or someone else has developed cancer since 1981? What if he died from cancer himself? What about mental health implications? I'm not sure that the questions around health in the early days were as thorough as they are now. What if my eight half siblings are also at risk of cancer? What if they have children whose aunty has bowel cancer? It's really quite important that they should know this if they're at risk. It's believed that in most cases where a person is diagnosed with bowel cancer under the age of 30 that there is a genetic link.[195]

The Committee notes that as time passes, the number of donor-conceived people who may benefit from the provision of medical information about their donors will only increase, particularly as medical knowledge of the influence of genes on disease develops. The extreme detriment to some individuals that may potentially be avoided through the sharing of relevant medical information presents a strong case for this to occur.

The Committee heard, however, that while many donor-conceived people considered that medical information was important, it was usually not their main reason for wanting to find out more information:

> I expect that as my generation of donor conceived people ages there will only be an increase in the instances of serious medical complications, the knowledge of which will be of vital importance to our biological family members. The case of my good friend Narelle Grech is a poignant reminder of just how serious and important the outcome of this inquiry is. … I would like to stress however that this issue is much greater than one of needing medical information. It is about our natural desire and inalienable right to know our own identity and family. I remain unconvinced that there is any compelling argument explaining why we should have to wait any longer to obtain information of such fundamental importance.[196]

3.3.2.2 The ‘right’ to non-identifying information

Donor records hold various amounts of non-identifying information, depending on the date they were produced, and on the institution in which they were created. The views of most of the witnesses, and in most of the submissions received by the Committee, were that at a minimum,

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[195] Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, p. 39.

[196] Myfanwy Cummerford, *Submission no. 53*, 11 August 2011, p. 1.

donor-conceived people should be entitled to receive non-identifying information about their donor. For example, the Acting Commissioner for the Victorian Equal Opportunity and Human Rights Commission, Ms Karen Toohey, told the Committee that where a donor's consent was not provided to release identifying information, a donor-conceived person should receive at least non-identifying information.[197]

The Committee heard that in some cases, non-identifying information was all that the donor-conceived person wanted:

> As donor-conceived persons often want non-identifying information, some may not want to have direct contact with the donor; they may just want non-identifying information. They may want to know about medical history, for example, or what the donor looks like but not actually have that contact.[198]

However, most of the donor-conceived people that presented to the Committee, and a number of other witnesses, preferred that both identifying and non-identifying information should be accessible.

The release of non-identifying information about donors is relatively unproblematic, as long as a person with appropriate powers is responsible for accessing original donor records and, if necessary, redacting identifying information from them. The Committee heard that some clinics already release non-identifying information to donor-conceived people, and if they are in contact with a donor who does not want to be identified, will request that he (or she) provide further non-identifying information.[199]

3.3.2.3 The 'right' to identifying information about donors

Most of the submissions to the Inquiry supported the proposition that identifying information about donors should be made accessible to donor-conceived people. The Committee was struck by the compelling arguments in favour of releasing information, put forward by donor-conceived people, their families, donors, and some professionals, described at the beginning of this Chapter. Various witnesses and submissions also suggested that the 'right' to access identifying information could be found in law.

Charter of Human Rights and Responsibilities Act 2006

The submission received from the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) notes that the *Assisted Reproductive Treatment Act 2008* engages a number of rights provided in the *Charter of*

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[197] Karen Toohey, Acting Commissioner, Victorian Equal Opportunity and Human Rights Commission, *Transcript of evidence*, Melbourne, 10 October 2011, p. 4.

[198] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 39.

[199] Maria Gabbe, Donor Coordinator, Monash IVF, *Transcript of evidence*, Melbourne, 17 October 2011; Rachael Varady, Donor Program Manager, Melbourne IVF, *Transcript of evidence*, Melbourne, 10 October 2011.

Human Rights and Responsibilities Act 2006 (the Charter).[200] The VEOHRC explained that the following Charter rights are relevant for donor-conceived people:[201]

> Recognition and equality before the law, which protects the right of all Victorians, including children, to enjoy their human rights free from discrimination. This right is engaged when donor-conceived children are provided with different rights to obtain information about their donor parent and siblings based on when they were conceived.
>
> Privacy and reputation, which provides protection from unlawful or arbitrary interference with privacy or family life, including any "unjustified interference with personal and social individuality and identity." …
>
> Freedom of expression, including the freedom to seek, receive and impart information and ideas of all kinds, whether within or outside Victoria.
>
> Protection of families. The Charter recognises that families are the fundamental group unit of society and are entitled to be protected by society and the State. The right to family protection is not only a parental right, but also a right of the child.
>
> Protection of children, because "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".
>
> Cultural rights, including the child's right to practice their religion, enjoy their culture and use their language. … This right may be engaged where a donor-conceived person is denied information about their donor's background and heritage.

Several other submissions raised one or more of these Charter rights in the context of access to identifying information about donors, and suggested that the failure to provide all donor-conceived people with access to that information breaches the Charter.[202]

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[200] Victorian Equal Opportunity and Human Rights Commission, *Submission no. 74*, 1 September 2011.

[201] Ibid, pp. 6-7.

[202] Damian Adams, *Submission no. 4*, 30 July 2010; Eric Blyth, *Submission no. 43*, 8 August 2011; Kate Bourne, *Submission no. 35*, 11 August 2010; Barbara Burns, *Submission no. 9*, 3 August 2010; Lauren Burns, *Submission no. 3*, 29 July 2010; Myfanwy Cummerford, *Submission no. 12*, 4 August 2010; Kate Dobby, *Submission no. 33*, 10 August 2010; Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010; Helen Kane, *Submission no. 16*, 6 August 2010; Gordon Ley, *Submission no. 44*, 8 August 2011; Merrilyn Mannerheim and Jo Moffat, *Submission no. 41*, 4 August 2011; Monash IVF, *Submission no. 26*, 6 August 2010; Public Interest Law Clearing House, *Submission no. 27*, 6 August 2010; Romana Rossi, *Submission no. 25*, 6 August 2010; Kimberley Springfield, *Submission no. 20*, 6 August 2010; Nicholas Tonti-Filippini, *Submission no. 45*, 9 August 2011; Victorian Assisted Reproductive Treatment Authority, *Submission no. 19*, 6 August 2010; Victorian Equal Opportunity and Human Rights Commission, *Submission no. 74*, 1 September 2011; Victorian Infertility Counsellors Group, *Submission no. 22*, 6 August 2010; Christine Whipp, *Submission no. 31*, 9 August 2010.

Assisted Reproductive Treatment Act 2008

The *Assisted Reproductive Treatment Act 2008* includes five overarching principles, with Parliament's stated intention being that they are given effect to in administering the Act, in carrying out functions under the Act, and in the carrying out of activities regulated by the Act.[203] The first guiding principle listed is:

> The welfare and interests of persons born or to be born as a result of treatment procedures are paramount.[204]

This principle was also enunciated in the preceding legislation, the *Infertility Treatment Act 1995*, which listed a number of guiding principles, with the above provision listed first in a descending order of importance.[205] The *Assisted Reproductive Treatment Act 2008* does not assign a hierarchy of importance to its guiding principles, although it also includes the provision that:

> … children born as the result of the use of donated gametes have a right to information about their genetic parents.[206]

A number of witnesses and submissions drew the Committee's attention to these sections of the *Assisted Reproductive Treatment Act 2008*, and suggested that if applied consistently, the Act would require that donor-conceived people be able to access identifying information about their donors.

Many submissions to the Committee stated that denying donor-conceived people access to identifying information about their donors violates the Act's guiding principles. As several submissions pointed out, if the rights of the donor-conceived person are indeed paramount, they will take precedence over interests of other parties, such as the right of a donor to maintain his or her privacy.[207]

The term "paramount" in relation to the welfare of donor-conceived children is also employed in the NHMRC's *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research 2007*, discussed below.

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[203] *Assisted Reproductive Treatment Act 2008* (Vic), section 5.
[204] Ibid, section 5(a).
[205] *Infertility Treatment Act 1995* (Vic), section 5(2).
[206] *Assisted Reproductive Treatment Act 2008* (Vic), section 5(c).
[207] Ad Hoc Interfaith Committee, *Submission no. 70*, 16 August 2011; Damian Adams, *Submission no. 4*, 30 July 2010; Sonia Allan, *Submission no. 5*, 2 August 2010; Eric Blyth, *Submission no. 43*, 8 August 2011; Lauren Burns, *Submission no. 3*, 29 July 2010; Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010; Narelle Grace Grech, *Submission no. 18*, 6 August 2010; Susan Hurst, *Submission no. 14*, 5 August 2010; Institute for Judaism and Civilization Inc, *Submission no. 72*, 19 August 2011; Name withheld, *Submission no. 60*, 12 August 2011; Rainbow Families Council, *Submission no. 17*, 6 August 2010; Shelley Sandow, *Submission no. 7*, 3 August 2010; Ian Smith, *Submission no. 55*, 11 August 2011; Kimberley Springfield, *Submission no. 20*, 6 August 2010; TangledWebs Inc, *Submission no. 21*, 6 August 2010; Victorian Equal Opportunity and Human Rights Commission, *Submission no. 74*, 1 September 2011.

United Nations Convention on the Rights of the Child

The United Nations General Assembly adopted the Convention on the Rights of the Child (UNCROC) in 1989. Australia made significant contributions during the drafting of UNCROC, and ratified it in 1990.[208] It is the most widely ratified human rights treaty in the history of international human rights law. While UNCROC has no legal status in Victoria, it is a significant document by which to ascertain the rights of children, given its near universal acceptance.[209]

Many submissions considered that denying access to identifying information about donors contravenes UNCROC, 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 by 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.[210]

Ms Narelle Grech, a donor-conceived person, stated in her submission that "agreements made by consenting adults failed to recognise the donor-conceived person's inherent right to a true identity as is now enshrined in the UN Convention on the Rights of the Child."[211] Several other submissions shared the view that the current legislation contravenes UNCROC.[212]

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[208] John Tobin, *The Convention on the Rights of the Child: the rights and best interests of children conceived through assisted reproduction*, Victorian Law Reform Commission, 2004.

[209] Ibid, p. 2.

[210] UNICEF, 'Fact sheet: a summary of the rights under the Convention on the Rights of the Child', viewed 17 August 2010, <http://www.unicef.org/crc/files/Rights_overview.pdf>.

[211] Narelle Grace Grech, *Submission no. 18*, 6 August 2010, p. 5.

[212] Ad Hoc Interfaith Committee, *Submission no. 70*, 16 August 2011; Damian Adams, *Submission no. 4*, 30 July 2010; Sonia Allan, *Submission no. 5*, 2 August 2010; Australian Christian Lobby, *Submission no. 56*, 12 August 2011; Australian Family Association, *Submission no. 68*, 15 August 2011; Kate Bourne, *Submission no. 35*, 11 August 2010; Myfanwy Cummerford, *Submission no. 12*, 4 August 2010; Romana Rossi, *Submission no. 25*, 6 August 2010; Kimberley Springfield, *Submission no. 20*, 6 August 2010; TangledWebs Inc, *Submission no. 21*, 6 August 2010; Nicholas Tonti-Filippini, *Submission no. 45*, 9 August 2011; Victorian Equal Opportunity and Human Rights Commission, *Submission no. 74*, 1 September 2011.

The VEOHRC's submission noted that the Charter's protection of children provision reflects Australia's obligations under UNCROC.[213] The VEOHRC suggested that it is necessary to reassess the limitations currently placed on the rights and interests of those born from donor-conception procedures prior to 1998:

> If the test for eligibility to access information about a donor is to be truly consistent with the rights of children under the Convention and the Charter (and reflect the guiding principles of the ART Act), the date at which gametes were donated and prior assurances of anonymity would not be the sole consideration as to whether access to information should be granted. As such, there is a need to reassess whether the limitations on the rights and best interests of those born as a result of such procedures are reasonable, justifiable and proportionate, taking into account the nature of the right, the purpose of the interference, and applying the least restrictive means of limiting the right.[214]

Comparison with adoption legislation

A number of witnesses drew parallels between the circumstances of donor-conception and adoption. This comparison is pertinent, because in 1984 the Victorian Parliament passed legislation allowing adopted people unqualified access to identifying information about their birth parents. Witnesses noted that as with donor-conception, birth parents were formerly counselled that they should not expect to have contact with their offspring, and that consequently, at the time the *Adoption Act 1984* was introduced:

- there were concerns that birth parents' privacy would be compromised by allowing adopted people to have access to identifying information;
- there were concerns that adopted people would find and approach birth parents who didn't necessarily wish for contact; and
- there were concerns about the repercussions for birth parents' families, relationships and careers.

These concerns were shared in a number of jurisdictions where similar changes to adoption laws were contemplated. However, in jurisdictions where legislation has been amended to permit access to identifying information about birth parents, there is very little evidence of deleterious effects on birth parents or adopted people. Professor E. Wayne Carp stated, in his review of adoption law changes in the U.S., Great Britain, and Australia, that:

> What is clear from this survey of international adoption disclosure systems is that there exists a vast gap, especially between the articulated *fear* by birth parents and adopted adults that their privacy would be invaded and

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[213] Victorian Equal Opportunity and Human Rights Commission, *Submission no. 74*, 1 September 2011, p. 9.

[214] Ibid.

> their families disrupted if adopted adults were given the right to access their birth records and the *reality* that few or no offences were committed.[215]

Some witnesses suggested that similar circumstances apply in both donor-conception and adoption, and that if access to identifying information was granted, the actual harm done to donors and their families would be far less than feared.[216]

Other witnesses argued, however, that there were key differences between adoption and donor-conception that rendered comparison problematic, including that:

- a single donor could have up to ten or more children, whereas birth parents typically have far fewer;[217]
- birth parents had considered the consequences of their actions to a greater extent than donors;[218]
- adoption records were more accurate than donor records;[219] and
- adopted people tended to want to meet their birth mothers, and not birth fathers.[220]

By and large, the Committee considers the circumstances of adoption and donor-conception analogous with regard to access to identifying information about birth parents / donors. In the Committee's opinion, the accuracy or otherwise of a proportion of records does not justify preventing donor-conceived people from having access to identifying information. Nor does the Committee agree that it is necessarily the case that all birth parents consider the outcomes of their actions to a greater extent than donors – and, in any case, as birth parents and donors grow older, their views on the outcomes of their actions may well have changed over time.

However, the Committee acknowledges the fact that, in most cases, a donor may have many more offspring than a birth parent is an important difference between donor-conception and adoption. Although evidence from adoption demonstrates that unwanted contact rarely occurs between adoptees and birth parents, even small amounts of contact from each of ten donor children, for example, could prove overwhelming for a donor and his or her family. This may warrant different approaches to managing

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[215] E. Wayne Carp, 'Does opening adoption records have an adverse social impact? Some lessons from the U.S., Great Britain, and Australia, 1953-2007', *Adoption Quarterly*, vol. 10, no. 3-4, pp. 29-52, 2007, p. 49. (Italics in original).

[216] See, for example, Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010, pp. 14-17.

[217] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 39.

[218] Helen Versey, Privacy Commissioner, Office of the Victorian Privacy Commissioner, *Transcript of evidence*, Melbourne, 8 September 2011, p. 50.

[219] Ibid.

[220] Gab Kovacs, *Transcript of evidence*, Melbourne, 10 October 2011, p. 32.

access to identifying information and contact in donor-conception, as compared to adoption.

Finding 5: The circumstances of donor-conception and adoption with regard to a person’s right to identifying information are largely comparable.

NHMRC Ethical guidelines

Another important resource for understanding contemporary views on the rights of donor-conceived people to identifying information about their donors is the National Health and Medical Research Council’s (NHMRC’s) *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research 2007*. Clinics are required to comply with these guidelines, and obtain accreditation with the Reproductive Technology Accreditation Committee of the Fertility Society of Australia, in order to register for practice with VARTA in Victoria. While the Guidelines accept that there will be disagreement about the appropriate balancing of various rights for parties to assisted reproductive technologies, the Guidelines claim that “In these guidelines, AHEC [the Australian Health Ethics Committee] has recognised that the welfare of people who may be born as a result of the use of ART is paramount.”[221]

The Guidelines specify the following principles, and that the following information must be provided by clinics to donor-conceived people:

> People conceived using donated gametes are entitled to know their genetic parents. On request, clinics must arrange for either a medical practitioner, or an appropriately qualified health professional, to provide at least the following information, to a person conceived through ART procedures, provided that he or she has either reached the age of 18 years or acquired sufficient maturity to appreciate the significance of the request (including any implications for his or her younger siblings):
>
> - all medical and family history information as specified in paragraph 6.10;
> - identifying information about the gamete donor (subject to paragraph 6.1); 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 (see paragraph 6.1.3).[222]

While the Guidelines state that donor-conceived people are ‘entitled’ to know their genetic parents, in practice the Guidelines privilege consent by donors above this ‘entitlement’. Although it is not explicitly stated that the Guidelines should only be applied prospectively, they do state that:

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[221] 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, p. 9.

[222] Ibid, p. 25.

> Working with relevant professional organisations, clinics should use forums for public information to encourage people who were donors before the introduction of these guidelines, and those previously conceived using donated gametes, to contact the clinic and register their consent to being contacted by their genetic children or genetic siblings and half-siblings, respectively.[223]

This suggests that a donor-conceived person's 'entitlement' to identifying and other information is superseded by a donor's failure to consent to the release of information. By extension, this also suggests that the view of the NHMRC is that welfare of a donor-conceived person, while paramount, is not dependent on access to identifying information about their donor.

While the Committee accepts that the Guidelines reflect the views of the majority of institutions within the ART industry, the Committee notes that in the evidence it has received, the welfare of some donor-conceived people is in fact intimately tied to their ability to access identifying information about their donor. This observation has led the Committee to question whether a nominal adherence to the 'paramount' welfare of donor-conceived people, while retaining a practical adherence to the pre-eminence of consent, is a sustainable contention.

3.3.2.4 The 'right' to contact donors

The issues discussed above are principally focused on the provision of different kinds of information to donor-conceived people, which is an activity over which the state can exert some control. The purpose of providing this kind of information is also clear – to assist a donor-conceived person to understand their medical or genealogical history, and to know something about the identity of an otherwise unknown biological parent. The quality of information provided in this context is not dependent on the cooperation or consent of all parties.

By contrast, contact between donors and their donor-conceived offspring will *only* tend to be successful with the cooperation and consent of all parties. The state cannot force people to form friendships or other relationships – at best, the state could only compel people to meet.

While most of the donor-conceived people the Committee received evidence from would like to meet their donors, all of them expressed their intention that they would honour a donor's wish not to make contact.

The Committee is aware that, by granting donor-conceived people access to identifying information about donors, there may be cases where a donor-conceived person may attempt to contact a donor or his or her family against the donor's wishes. In this case, the Parliament may consider whether it is appropriate that mechanisms be introduced whereby donors and donor-conceived people can opt out of contact with one another. This matter is discussed below.

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[223] Ibid, p. 26.

3.3.2.5 The 'right' to know the manner of one's conception

Prior to 2010, disclosure to a person that they are donor-conceived was at the discretion of that person's parents, although from 1998, the state could facilitate disclosure under the *Infertility Treatment Act 1995*, which required the consent of an adult donor-conceived person to a donor's request for identifying information. As described in Chapter Two, however, the *Assisted Reproductive Treatment Act 2008* introduced in 2010 a mechanism for disclosure by the state – if a person's parents have not informed the person of the manner of his or her conception, the person may discover this if he or she ever requests a certificate of birth. Upon its introduction to the Parliament, the *Assisted Reproductive Treatment Bill 2008* did not contain this provision, and in the second reading speech then Attorney-General, the Hon. Rob Hulls MP, said:

> … it is not appropriate to record such information on a birth certificate or mandate telling children of the manner of their conception. This is better achieved through non-legislative means.[224]

Ultimately, however, the Parliament agreed to an amendment to provide appended information to a donor-conceived child should they request a birth certificate, noting that this information would not be disclosed to third parties (as it may be if this information was recorded on the certificate itself).

As discussed above, it can be very distressing for a person to discover as an older child or as an adult that he or she is donor-conceived. This discovery can have a significantly adverse effect on the donor-conceived person's relationship with his or her parents, and the extended family. The Committee also notes evidence from studies of adoption that indicate this trauma can be exacerbated where the revelation is made by third parties, such as, presumably, the state government.

The Committee holds the view that where a person is aware that he or she is donor-conceived, and wishes to contact his or her donor, it is in that person's interests that the state provide identifying information to assist his or her desire for knowledge. The Committee also holds the view that in the majority of cases, it is in the interests of a donor-conceived person to be told by his or her parents of the manner of his or her conception. The Committee cannot be certain, however, that it is in the best interests of a donor-conceived person for the state (or any third party) to circumvent that person's parents, and reveal that he or she is donor-conceived. If the state were to do so, the Committee would be concerned that the state's actions would undermine the parental relationship that the donor-conceived person would ideally rely upon when considering his or her place in the world.

However, the Committee does not believe it is appropriate to repeal existing mechanisms by which the state may inform a donor-conceived person of his or her status. The Committee notes that since at least 1988,

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[224] Hon. Rob Hulls MP, Attorney-General, *Parliamentary debates*, Legislative Assembly, 10 September 2008, p. 3439.

most, if not all recipient parents have been counselled that it is in their children's interest to know about the manner of their conception. Furthermore, all recipient parents should be aware of provisions in law active since 1988 that have the potential to lead to their child discovering that he or she is donor-conceived, such as the potential for a donor to seek consent from a donor-conceived person for identifying information.

Legislation has consistently, and increasingly, provided incentives for parents to tell their donor-conceived children about their conception. Given the Committee's view that it is ultimately in a donor-conceived person's best interests to be told by their parents, the Committee recommends that these existing provisions be retained in legislation, so that incentives for parents to tell their children about the circumstances of their conception remain in place.

There is a substantial and growing body of evidence suggesting that early disclosure to donor-conceived people of the facts of their conception is generally preferable. Arguments and observations from studies in favour of early disclosure include:

- that disclosure helps avoid secrets within families that can, over time, lead to tensions between family members;[225]

- that children who have been told that they are donor-conceived at a young age are well-adjusted;[226]

- that disclosure can have a positive effect on the child / parent relationship;[227]

- that disclosure in adolescence or later can be disruptive,[228] and disclosure when the donor-conceived person is an adult can cause

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[225] Ethics Committee of the American Society for Reproductive Medicine, 'Informing offspring of their conception by gamete donation', *Fertility and Sterility*, vol. 81, no. 3, pp. 527-531, 2004; SJ Hahn and M Craft-Rosenberg, 'The disclosure decisions of parents who conceive children using donor eggs', *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, vol. 31, pp. 283-293, 2002; A Rumball and V Adair, 'Telling the story: parents' scripts for donor offspring', *Human Reproduction*, vol. 14, pp. 1392-1399, 1999; R Snowden, 'The family and artificial reproduction', in *Philosophical ethics in reproductive medicine*, Bromham, Dalton and Jackson (eds.), Manchester University Press, Manchester, 1990.

[226] Ethics Committee of the American Society for Reproductive Medicine, 'Informing offspring of their conception by gamete donation', *Fertility and Sterility*, vol. 81, no. 3, pp. 527-531, 2004; New York State Taskforce on Life and the Law, *Assisted reproductive technologies: analysis and recommendations for policy*, Health Education Service, Albany, NY, 1998.

[227] Ethics Committee of the American Society for Reproductive Medicine, 'Informing offspring of their conception by gamete donation', *Fertility and Sterility*, vol. 81, no. 3, pp. 527-531, 2004; S Golombok, A Brewaeys, M.T. Giavazzi, D Guerra, F MacCullum and J Rust, 'The European study of assisted reproduction families: the transition to adolescence', *Human Reproduction*, vol. 17, no. 3, pp. 830-840, 2002; R Snowden, 'The family and artificial reproduction', in *Philosophical ethics in reproductive medicine*, Bromham, Dalton and Jackson (eds.), Manchester University Press, Manchester, 1990.

[228] Ethics Committee of the American Society for Reproductive Medicine, 'Informing offspring of their conception by gamete donation', *Fertility and Sterility*, vol. 81, no. 3, pp. 527-531, 2004; AM McWhinnie, 'Children from assisted reproductive technology: the

feelings of mistrust, frustration, and hostility towards his or her family;[229] and

- that there are advantages to early disclosure so that the child can absorb the information over time.[230]

The weight of evidence, and contemporary professional counselling and practice, suggests that early disclosure to a child that they are donor-conceived is beneficial not only to the child, but to his or her family as well. Evidence also suggests that it is best for parents to disclose this information to their child or children.

Finding 6: All donor-conceived people should be aware of the manner of their conception. A person's parents should be principally responsible for informing that person of his or her donor-conceived status.

3.3.3 Donors' right to privacy

While the Committee heard compelling evidence that donor-conceived people should be provided with identifying information about their donors, most witnesses and submissions also acknowledged the importance of considering the donor's right to privacy, and the circumstances and agreements that applied when donors provided their gametes in the past. It is likely that all donors prior to 1988 provided gametes with the expectation that their identity would not be disclosed to recipient parents, or any children conceived. These and other issues are discussed below.

3.3.3.1 Assurances of anonymity

Several submissions noted that pre-1988 donors were assured anonymity at the time of making their donation, and considered that this promise

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psychological issues and ethical dilemmas', *Early child development and care*, vol. 163, pp. 13-23, 2000; A Rumball and V Adair, 'Telling the story: parents' scripts for donor offspring', *Human Reproduction*, vol. 14, pp. 1392-1399, 1999; AJ Turner and A Coyle, 'What does it mean to be a donor offspring? the identity experiences of adults conceived by donor insemination and the implications for counselling and therapy', *Human Reproduction*, vol. 15, pp. 2041-2051, 2000.

[229] Ethics Committee of the American Society for Reproductive Medicine, 'Informing offspring of their conception by gamete donation', *Fertility and Sterility*, vol. 81, no. 3, pp. 527-531, 2004; AM McWhinnie, 'Children from assisted reproductive technology: the psychological issues and ethical dilemmas', *Early child development and care*, vol. 163, pp. 13-23, 2000; AM McWhinnie, 'Gamete donation and anonymity: should offspring from donated gametes continue to be denied knowledge of their origins and antecedents?', *Human Reproduction*, vol. 16, pp. 807-817, 2001; AJ Turner and A Coyle, 'What does it mean to be a donor offspring? the identity experiences of adults conceived by donor insemination and the implications for counselling and therapy', *Human Reproduction*, vol. 15, pp. 2041-2051, 2000.

[230] Ethics Committee of the American Society for Reproductive Medicine, 'Informing offspring of their conception by gamete donation', *Fertility and Sterility*, vol. 81, no. 3, pp. 527-531, 2004; KD Pruett, 'Strange bedfellows? reproductive technology and child development', *Infant Mental Health Journal*, vol. 13, pp. 312-318, 1992; A Rumball and V Adair, 'Telling the story: parents' scripts for donor offspring', *Human Reproduction*, vol. 14, pp. 1392-1399, 1999.

should be honoured.[231] Most of these submissions considered that if a donor-conceived person was seeking identifying information about his or her donor, the donor should be contacted discreetly by an intermediary, and asked whether he or she would consent to identifying information being released. If the donor did not wish to release identifying information, then those wishes should be respected. One submission suggested that in this case, the donor should be asked to provide detailed non-identifying information to provide to the person seeking information.[232] Only two submissions, including one received from the Australian Medical Association (Victoria), considered that donors' right to privacy meant that they should not be contacted at all, even to ask whether they would consent to a request for information.[233]

Melbourne IVF stated in its submission that the right of a donor-conceived person to access information about their genetic background should not override the donor's right to privacy and control over the release of his or her personal information. In particular, Melbourne IVF expressed the view that it has a strong obligation to protect the privacy of its donors and respect the circumstances under which the donations were made.[234] This view was shared by the Victorian Privacy Commissioner, the Victorian Infertility Counsellors Group, the Fertility Society of Australia, and IVF practitioners Professor Gab Kovacs and Professor David de Kretser.[235]

The Committee understands and commends the rationale behind this position, held principally by medical professionals and clinics in the assisted reproductive treatment industry, that agreements between clinics and donors to maintain confidentiality should not be breached. The Committee acknowledges that effective practice by the medical profession depends on the maintenance of trust between it and its clients, and that this trust may be undermined if agreements with clients are not upheld.

The Committee notes, however, that one of the key considerations in the context of this Inquiry is whether the anonymity agreements between clinicians and donors were in fact appropriate, and consequently, the extent to which Parliament should have a role in upholding them.

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[231] Anonymous (confidential), *Submission no. 15*, 30 July 2010; Australian Medical Association (Victoria), *Submission no. 71*, 18 August 2011; David de Kretser, *Submission no. 54*, 11 August 2011; Fertility Society of Australia, *Submission no. 66*, 12 August 2011; Gab Kovacs, *Submission no. 40*, 3 August 2011; Melbourne IVF, *Submission no. 32*, 9 August 2010; Name withheld, *Submission no. 1*, 20 July 2010; Name withheld, *Submission no. 13*, 5 August 2010; Office of the Victorian Privacy Commissioner, *Submission no. 58*, 12 August 2011; Victorian Assisted Reproductive Treatment Authority, *Submission no. 19*, 6 August 2010.

[232] Fertility Society of Australia, *Submission no. 66*, 12 August 2011.

[233] Anonymous (confidential), *Submission no. 15*, 30 July 2010; Australian Medical Association (Victoria), *Submission no. 71*, 18 August 2011.

[234] Melbourne IVF, *Submission no. 32*, 9 August 2010.

[235] David de Kretser, *Submission no. 54*, 11 August 2011; Fertility Society of Australia, *Submission no. 66*, 12 August 2011; Gab Kovacs, *Submission no. 40*, 3 August 2011; Office of the Victorian Privacy Commissioner, *Submission no. 58*, 12 August 2011; Victorian Infertility Counsellors Group, *Submission no. 64*, 12 August 2011.

3.3.3.2 Donors' views

Nine donors provided submissions and/or attended public hearings during the course of this Inquiry. These donors expressed a range of views on whether identifying information should be accessible to donor-conceived children, and under what circumstances. All but one of the donors empathised with the circumstances of donor-conceived people, and supported providing at least non-identifying information to them:

> The deliberations and decisions that you [the Committee] have to make really in the end need to focus on what is in the best interests of the children. It is all very well for the donors to be concerned about what is going to happen. I read a submission from one similarly anonymous donor who was awfully frightened about the effect on his family. It was so sad to read that. He was saying, 'I couldn't possibly have any contact: it would ruin my life and my family'. I think it is unlikely that is going to happen, and with good counselling and support and a proper process it need not happen. I suspect that most donors are not mad and most children are not troublesome, or no more troublesome than everyone else's children are.[236]
>
> One thing is very clear for me. That is that the interests and well being of the children – all of them – are paramount. Regardless of what the legal framework was at the time of my being a sperm donor, I believe that I do have responsibilities to the children born as a result of my sperm donations. At the least, these children have a right to know what my part of their genetic heritage is – more if they want more.[237]

Six of the donors that the Committee heard from were open to, or indeed hoped for, contact from their donor-offspring.[238] The remaining three donors were opposed to any release of identifying information about them.[239] One of these donors feared contact with persons who may have been conceived using his gametes, as he believed it would be distressing to both himself and his family:

> 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.[240]

This donor, and another donor who emphatically opposed the release of identifying information, also feared that they may become the subjects of 'fishing expeditions' by donor-conceived people seeking their donors, or

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[236] "Alex", *Transcript of evidence*, Melbourne, 5 December 2011, p. 4.

[237] Ian Smith, *Submission no. 55*, 11 August 2011, p. 2.

[238] "Alex", *Transcript of evidence*, Melbourne, 5 December 2011; Roger Clarke, *Transcript of evidence*, Melbourne, 17 October 2011; Michael Linden, *Transcript of evidence*, Melbourne, 10 October 2011; Name withheld, *Submission no. 1*, 20 July 2010; Paul Ruff, *Submission no. 24*, 6 August 2010; Paul Ruff, *Transcript of evidence*, Melbourne, 5 December 2011; Ian Smith, *Submission no. 55*, 11 August 2011; Ian Smith, *Transcript of evidence*, Melbourne, 10 October 2011.

[239] "John", *Transcript of evidence*, Melbourne, 17 October 2011; Anonymous (confidential), *Submission no. 15*, 30 July 2010; Name withheld, *Submission no. 13*, 5 August 2010.

[240] Name withheld, *Submission no. 13*, 5 August 2010, p. 2.

that their donor-status may be revealed and publicised through the internet, such as through social networking.[241]

The Committee heard evidence from two men who had not yet revealed to their families that they had donor-conceived children. One of these men supported a donor-conceived person's right to have identifying information about him, while the other did not. While both men empathised with the desire for some donor-conceived people to have identifying information, they were also concerned about the possible effect on their families if contact was made:

> The main consideration for myself is that my own three children do not know that I had any involvement in this program. How they would feel, I'm not sure, but I can see how at least one of them might react hurt. I think they would find it puzzling that there had been this secrecy. I've discussed this with my wife and we both agree that really we don't want to have to face this at this time.[242]

Two men had told their families that they were donors, but had not yet had contact from any of their donor-offspring.[243] Three of the donors from whom the Committee received evidence had been in contact with one or more of their donor-offspring, and all had found the experience positive:

> This has been a bizarre experience for me. At first I was overwhelmed and felt saddened, maybe by the … loss, not knowing or being around this person as she lived her life. … It has been very good to know the [donor-conceived] person and we get on very well and have a lot of surprising connections and similar interests. My children are very positive and I have enjoyed knowing her.[244]
>
> As it has transpired, [meeting my donor-offspring] was a very intense period in my life of course and my partner's life, my wife's life, and for her son because I just entered the relationship a couple of years previously and Lia's son was developing this father/son relationship with me as far as it could go in a stepfather/stepson relationship and that got disrupted to a certain extent, and similarly my relationship with Lia underwent a change, a bit of tension. But that makes it sound like you do not want to do this kind of thing but ultimately you have got to work your way through that. I am sure it has happened in the adoption sphere as well. There are challenges you have to confront, relationships that need to be reconfigured or taken on board. I do not think it is any reason not to enable these reunions, let's call them, to happen. Ultimately the relationship is an ongoing one. I have a good relationship with Myfanwy and Michael. I probably have, given the age differences, as much to do with them as I do with my other children

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[241] Anonymous (confidential), *Submission no. 15*, 30 July 2010; Name withheld, *Submission no. 13*, 5 August 2010.

[242] "John", *Transcript of evidence*, Melbourne, 17 October 2011, p. 79.

[243] Paul Ruff, *Transcript of evidence*, Melbourne, 5 December 2011; Ian Smith, *Submission no. 55*, 11 August 2011; Ian Smith, *Transcript of evidence*, Melbourne, 10 October 2011.

[244] Name withheld, *Submission no. 1*, 20 July 2010, p. 1.

> from my previous marriage. I think on a balance it has actually worked out quite well, despite any hiccups along the way.[245]

Most of the donors revealed that they had often wondered what had become of their donor-offspring. Two of these men actively desired contact with their donor-offspring, although both told the Committee that they did not want to force themselves into their donor-offspring's lives, for fear of causing them distress.[246] Ms Kate Bourne, Senior Community Education Officer, VARTA, told the Committee:

> Donors also have needs and interests in knowing who they are related to. Many donors have also spent years wondering about the people they helped to create. Most do not know the outcome of their donation and who was born. How old are they? And what gender? They wonder if they are healthy and happy, if they look alike or have characteristics in common, and question if they were well loved and looked after. Binding them to consents they signed many years ago, forbidding them to request information about the people they helped create is also unjust. They deserve to be asked what their current wishes are rather than automatically assuming they will prefer to remain unknown.[247]

The Committee also heard evidence that while donors agreed that they would remain anonymous at the time they made their donations, many will now have matured, and may have changed their views on their donor-offspring. Professor Ken Daniels, who has conducted research on these issues for many years, told the Committee that the tendency was for donors to become more open to the release of identifying information to donor-conceived people with the passage of time:

> Yesterday I was presenting some research, and I am involved in two pieces of research about donors and their views. In one particular study which looked at donors we had recruited through King's College Hospital in London we were able to go back to the records and see what their views were about openness or anonymity. When we went back 18 years later we found that 37 per cent of them had changed their minds and 75 per cent of that 37 per cent had been towards openness. The reasons that they gave for changing their minds were that they were older, that they had children of their own, that there had been a whole lot of media coverage and that they could understand the needs of offspring more. Again, it goes back to this issue of who we are recruiting, because their attitudes are going to flow through. The second piece of research is one that has not been published yet; it is under review. It is the largest study of donors undertaken in the world — 164 who joined up with the Donor Sibling Registry. These were all donors who were recruited anonymously, and now 94 per cent, I think it is, from memory, are willing to be open and contactable.[248]

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[245] Michael Linden, *Transcript of evidence*, Melbourne, 10 October 2011, p. 50.

[246] Paul Ruff, *Transcript of evidence*, Melbourne, 5 December 2011; Ian Smith, *Submission no. 55*, 11 August 2011; Ian Smith, *Transcript of evidence*, Melbourne, 10 October 2011.

[247] Kate Bourne, *Submission no. 35*, 11 August 2010, p. 3.

[248] Ken Daniels, *Transcript of evidence*, Melbourne, 5 December 2011, p. 5.

Ms Bourne also told the Committee that many donors were in fact open to being contacted, and to providing information:

> It is often argued that as donors did not give consent to the release of information; this should be respected and that legal impediment takes precedence over donor-conceived people's right to access information. Many argue that donors have a right to anonymity; however, do we really know this is what donors really want? Surely it is courteous to ask them rather than presume their wishes have remained unchanged in the many years since they donated. In my experience from contacting many donors (including donors who donated prior to the 1988 legislation when I worked at Melbourne IVF) in fact many in do not necessarily wish to remain unknown. Donors, in my professional experience, have been only too willing to give information and make themselves available to be contacted and appreciate the genuine need for this information by the people they helped create. Most have been expecting they would be contacted as they anticipated a need for more information about them.[249]

Clearly, the Committee heard a diverse range of views from donors on whether identifying information should be released to donor-conceived people. The Committee is not able to determine the extent to which these views are representative of all donors, given the tendency in the past to regard gamete-donation as a practice requiring discretion and secrecy. The Committee notes that similar issues, in terms of representativeness, also pertain for the views heard from donor-conceived people and recipient parents.

Finding 7: Donors have a wide range of views on the desirability of allowing the release of identifying information about them to their donor-offspring. Most donors empathise with the needs of donor-conceived people, but some express concern about the potential for their family life to be affected should identifying information about them be released.

3.3.3.3 The donor's right to privacy

One of the strongest arguments in favour of preserving the anonymity of donors is that any measures to release identifying information to third parties could be a breach of privacy. The right to privacy is enshrined in the *Charter of Human Rights and Responsibilities 2006*:

> 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; and
>
> (b) not to have his or her reputation unlawfully attacked.[250]

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[249] Kate Bourne, *Submission no. 35*, 11 August 2010, pp. 2-3.

[250] *Charter of Human Rights and Responsibilities Act 2006* (Vic), section 13.

However, as noted in the VEOHRC's submission, the right to privacy is qualified; while this right will be breached if there is an "unlawful" or "arbitrary" interference with a donor or donor's family's right to privacy and reputation, the VEOHRC suggests that "it is less likely that carefully crafted and well adapted legislative limitations on privacy would limit donors' privacy rights under the Charter".[251] Several other submissions also expressed the view that providing donor-conceived children with identifying information would not be an arbitrary interference with the donor's right to privacy.[252]

In addition, a number of submissions argued that anonymity agreements entered into by donors cannot be binding on donor-conceived people.[253] According to Ms Lauren Burns, a pre-1988 donor-conceived person, the concept of anonymous donors was created by the fertility industry, to minimise confusion around the parental obligations of biological parents, and to protect recipients of donor gametes from donors attempting to claim parental rights.[254] Anonymity was promised by a private contract between the clinic and the donor, and it appears that the donor-conceived person was not mentioned in these contracts. In an example contract provided by Ms Burns, the anonymity clause reads:

> I understand that the identity of my recipient shall not be disclosed to me, nor shall you voluntarily reveal my identity to any recipient.[255]

Ms Burns and others considered that such an agreement could not be binding on the person conceived, as that person was not a party to the contract, and the relevant clause does not mention the donor-conceived person, but rather the recipient of the donated gametes (i.e. the donor-conceived person's parents).

Furthermore, the Donor Conception Support Group of Australia stated in its submission that some donors who donated gametes during this time have indicated that they would have been happy to be identifiable, but this was never an option that was open to them. They were required to donate on condition of anonymity, or not at all.[256]

Nevertheless, the Committee heard that it was generally understood by all parties to donor-conception that donations were to be provided anonymously. In these circumstances, donors were under the expectation

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[251] Victorian Equal Opportunity and Human Rights Commission, *Submission no. 74*, 1 September 2011, p. 6.

[252] Damian Adams, *Submission no. 4*, 30 July 2010; Sonia Allan, *Submission no. 5*, 2 August 2010; Eric Blyth, *Submission no. 43*, 8 August 2011; Lauren Burns, *Submission no. 3*, 29 July 2010; Myfanwy Cummerford, *Submission no. 12*, 4 August 2010.

[253] Damian Adams, *Submission no. 4*, 30 July 2010; Australian Christian Lobby, *Submission no. 56*, 12 August 2011; Lauren Burns, *Submission no. 3*, 29 July 2010; Institute for Judaism and Civilization Inc, *Submission no. 72*, 19 August 2011; Gordon Ley, *Submission no. 44*, 8 August 2011; TangledWebs Inc, *Submission no. 21*, 6 August 2010.

[254] Lauren Burns, *Submission no. 3*, 29 July 2010.

[255] Ibid, p. 16.

[256] Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010.

that no identifying information about them would be released without their consent at that time or in the future:

> [Professor Kovacs] is correct in that the anonymity was emphasised, that was part of the deal; that is what I understood when I signed up. In fact technically the document I signed was largely concerned with medical information about me and my physical characteristics, genetic characteristics and so on.[257]
>
> Back in the 1980s, I was a sperm donor at Prince Henry's Hospital in St Kilda Road, at their Andrology Unit there, and I participated for a number of years there and of course went into the program with full anonymity, and that was understood.[258]

Consequently, if any action is contemplated to abrogate the right to privacy of donors, the Government and Parliament must be assured that the abrogation is not “arbitrary”. Furthermore, given that donors currently possess protection from interference due to their anonymity, consideration should also be given as to whether any protections should be offered if that privacy was removed.

Finding 8: If current arrangements permitting donor anonymity are changed to allow the release of identifying information, measures to protect donors and donor-conceived people from unreasonable interference in their private lives should be considered.

3.3.4 Weighing rights and interests

As the preceding discussion demonstrates, there are a wide range of views on the merits or otherwise of providing donor-conceived people with access to identifying information about donors. A proportion of donors, no doubt, do not want their families to know that they donated gametes, and fear the consequences to these relationships if this information is revealed. Some donors, and in some cases their spouses or families, also fear the repercussions of contact, and worry that their donor-offspring may intrude unreasonably on their lives if their identity is revealed. These fears are real, and it is possible that some of them may be realised, although the Committee notes that the experience of adoption suggests that the actual incidence of ongoing distress due to contact with previously unknown offspring is low.

While the release of identifying information to donor-conceived people may *potentially* cause discomfort and distress to donors (although this will not always be the case), it is certain that donor-conceived people are *actually* suffering from their lack of knowledge about donors. Although debates about the consequences of releasing identifying information often focus on the suffering that donors may experience, the fact is that many donor-conceived people are already suffering, in some cases quite profoundly, from not having access to this information. In the Committee’s

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[257] Ian Smith, *Transcript of evidence*, Melbourne, 10 October 2011, p. 37.
[258] Roger Clarke, *Transcript of evidence*, Melbourne, 17 October 2011, p. 56.

view, the burden of suffering under current arrangements falls predominantly on the donor-conceived person.

This is the case despite applicable legislation, and national ethical guidelines, stating that the welfare of the child is paramount. The Committee has struggled to reconcile how the welfare and interests of a donor-conceived person can be in law both paramount *and* subordinate to donor anonymity, as is currently the case. The *Adoption Act 1984* also states that "In the administration of this Act, the welfare and interests of the child concerned shall be regarded as the paramount consideration."[259] Notably, however, provisions of the *Adoption Act 1984* allow adopted people access to identifying information about their birth parents.

One of the more persuasive arguments in favour of retaining donor anonymity is the observation that donors understood and agreed that their donations would be provided anonymously. In this context, it has also been argued that overturning these agreements would constitute a breach of privacy for the donor. Similar arguments were also raised when changes to adoption arrangements were being contemplated in the 1980s. The Committee notes, for example, comments on proposed changes to adoption law in 1980 by Professor David Hambly, Faculty of Law, Australian National University:

> In recommending that its [the Statute Law Revision Committee] proposals for a tightly restricted process for access to birth information should only apply to adoptions occurring after the proposals are brought into effect, the Committee says that "any retrospective legislation changes giving access to information would be a breach of a fundamental term of the agreement, namely confidentiality." … To the extent that this argument has legal overtones, I do not think it is convincing. I do not think it is appropriate to describe an adoption as a contract or bargain; nor do I think it is tasteful. Even if the arrangement of the adoption were loosely regarded by the parents as being in the nature of an agreement – and this would be an incorrect description of its legal effect – one can understand the feelings of an adult adopted person who responds: "You may say there was a bargain, but I was not party to it and I do not feel bound by it and yet it purports to decide a matter which is of profound importance to me." But more fundamentally than that, we are not really dealing with commercial bargains that need to be strictly enforced. We are dealing with a much more complex matter of human relationships in a rapidly changing society. It seems to me that it is arid to regard the parent-child relationship as an inflexible bargain or contract, just as it is unreal to regard marriage or divorce in this way. When changes in divorce law are being debated, nobody argues that they should apply only to future marriages, so as to avoid improper interference with the terms of existing marriage contracts.[260]

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[259] *Adoption Act 1984* (Vic), section 9.

[260] Prof. David Hambly, 'The legal situation', Paper presented at the *In search of self-identity - access to information*, Harper (ed.) National Council for the Single Mother and her Child, Collingwood Education Centre, Melbourne, 1980, pp. 30-31.

A perplexing aspect of arrangements surrounding donor-conception in the 1970s and 1980s is that, during a period of intense debate about the appropriateness of anonymity in adoption, this very practice was being perpetuated in donor-conception. Donor anonymity was not being promoted in an environment devoid of examination or reflection, however, as legislators at the time drew attention to incongruities between donor-conception practice and adoption (as described in Chapter Two).

The Committee notes that all donors were legal adults at the time they provided gametes. Thus, all donors were able to consider possible repercussions of their actions, including the effect on third parties (such as any offspring, or their future families, for example), prior to consenting to participate in the donor programs. Donor-conceived children were not, of course, afforded the opportunity to consent to this process.

One of the key observations for the Committee while considering the relative rights of donors to anonymity, and of donor-conceived people to information, was that while donors may experience distress from the release of identifying information, that distress will flow from decisions that the donor made as a legal adult. While some donors told the Committee that they were shocked when they discovered that their donations had led to the conception of an *actual* child, this was in fact a repercussion of sperm donation that they should have reasonably anticipated. Furthermore, given contemporaneous debates about adoption, donors could also have reasonably anticipated that at some time, their donor-offspring may become curious about their biological heritage.

The distress experienced by donor-conceived people, by contrast, flows from decisions that were made by other people, through no fault, and by no agreement, of their own. As discussed at the beginning of this Chapter, discovering that one is donor-conceived can be a confronting and traumatic experience. While the Committee does not believe it is the role of the state to reveal to a person that they are donor-conceived, due to the trauma that such a revelation can inflict, the Committee believes the state should have a role in assisting a person to overcome trauma.

All of the parties to arrangements that led to the conception of that person – the donor, the clinics, the recipient parents, and the state – share this responsibility. Evidence received by the Committee strongly indicates that the provision of identifying information may provide, for some donor-conceived people, a means to cope with the trauma of discovery. Evidence from research also suggests that the social and psychological disruption experienced by an adolescent or adult donor-conceived person when he or she learns the facts of his or her conception is exacerbated when that person desires to know more information about his or her donor, but is unable to.[261] For this reason, the state and other parties have a

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[261] Ken Daniels, GM Lewis and W Gillet, 'Telling donor-conceived offsrping about their conception: the nature of couples' decision-making', *Social Science and Medicine*, vol. 40, pp. 1213-1220, 1995; Ethics Committee of the American Society for Reproductive Medicine, 'Informing offspring of their conception by gamete donation', *Fertility and Sterility*, vol. 81, no. 3, pp. 527-531, 2004; SJ Hahn and M Craft-Rosenberg, 'The

responsibility to facilitate that process, where requested by the donor-conceived person.

Finding 9: All donor-conceived people should have access to identifying information about their donors.

3.4 Proposals for change

In the Committee's view, legislation should be introduced to the Victorian Parliament to allow all donor-conceived people to access identifying information about their donors. This should include people conceived from gametes donated prior to 1998 – that is, *all* people born from donor-conception conducted in the state of Victoria should be able to access identifying information about their donors.

The Committee's view is that provisions of the *Assisted Reproductive Treatment Act 2008* asserting that the "welfare and interests" of donor-conceived people are paramount are appropriate, and that in pursuing this principle, some autonomy must be given to donor-conceived people to determine how their welfare and interests may be satisfied. Consequently, while the Committee believes that all donor-conceived people should have the right to obtain identifying information about their donors, the Committee is also aware that not all donor-conceived people may desire identifying information – for some, obtaining non-identifying information may be sufficient. Access to non-identifying information is discussed below. There may also be occasions when a donor-conceived person, or both that person and his or her donor, would feel more comfortable exchanging information anonymously, or through an intermediary. In the majority of cases, it is likely that the donor-conceived person will not wish to cause undue distress to a donor.

The Committee's view is that mechanisms should be introduced to facilitate multiple forms of contact between donor-conceived people and their donors.

Recommendation 1: That the Victorian Government introduce legislation to allow all donor-conceived people to obtain identifying information about their donors.

Most of the people who could be substantially affected by legislative changes to provide access to identifying information about donors are already legal adults. However, as some people conceived from gametes donated prior to 1998 may still be minors, the Committee believes that provisions should be introduced to provide them with access to identifying information about their donors, with certain conditions, prior to age 18. The Committee believes that it would be appropriate to adopt the same conditions attached to access to identifying information for people conceived from gametes donated after 31 December 1997 – namely, that

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disclosure decisions of parents who conceive children using donor eggs', *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, vol. 31, pp. 283-293, 2002.

identifying information be provided to a child if the child's parent or guardian has provided consent, or if an approved counsellor has provided counselling to the child and advised, in writing, that the person is sufficiently mature to understand the consequences of the disclosure.

Recommendation 2: That, in implementing Recommendation 1, the Victorian Government require that a child applying for identifying information about his or her donor only be provided with that information if:

1) the child’s parents have consented to the application; or
2) a counsellor has provided counselling to the child and has confirmed in writing that the person is sufficiently mature to understand the consequences of the disclosure.

3.4.1 Counselling and donor-linking requirements

A recurrent theme in the submissions and evidence heard by the Committee is that it is critical that any change to existing arrangements is accompanied by counselling being made available, particularly where donor-conceived people will seek contact with donors.[262] Parties involved in donor-linking previously (donor-conceived persons, recipient parents and donors) typically reported feeling vulnerable throughout the linking process and were often unsure of what is appropriate. The Victorian Infertility Counsellors Group noted that counselling is helpful in assisting donors recognise the motivations behind donor-conceived persons wanting access to information about them:

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[262] Sonia Allan, *Submission no. 5*, 2 August 2010; Australian Family Association, *Submission no. 68*, 15 August 2011; Australian Medical Association (Victoria), *Submission no. 71*, 18 August 2011; Agnes Bankier, *Submission no. 38*, 25 July 2011; Eric Blyth, *Submission no. 43*, 8 August 2011; Kate Bourne, *Submission no. 35*, 11 August 2010; Barbara Burns, *Submission no. 9*, 3 August 2010; Lauren Burns, *Submission no. 3*, 29 July 2010; Ken Daniels, *Submission no. 75*, 9 September 2011; David de Kretser, *Submission no. 54*, 11 August 2011; Kate Dobby, *Submission no. 33*, 10 August 2010; Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010; Fertility Society of Australia, *Submission no. 66*, 12 August 2011; Narelle Grace Grech, *Submission no. 18*, 6 August 2010; Helen Kane, *Submission no. 16*, 6 August 2010; Gab Kovacs, *Submission no. 40*, 3 August 2011; Merrilyn Mannerheim and Jo Moffat, *Submission no. 41*, 4 August 2011; Melbourne IVF, *Submission no. 32*, 9 August 2010; Monash IVF, *Submission no. 26*, 6 August 2010; Murdoch Children's Research Institute, *Submission no. 52*, 11 August 2011; Name withheld, *Submission no. 34*, 11 August 2010; Name withheld, *Submission no. 36*, 17 August 2010; Name withheld, *Submission no. 13*, 5 August 2010; Office of the Victorian Privacy Commissioner, *Submission no. 58*, 12 August 2011; Rainbow Families Council, *Submission no. 17*, 6 August 2010; Damien W Riggs, *Submission no. 23*, 6 August 2010; Romana Rossi, *Submission no. 25*, 6 August 2010; Shelley Sandow, *Submission no. 7*, 3 August 2010; Ian Smith, *Submission no. 55*, 11 August 2011; Kimberley Springfield, *Submission no. 20*, 6 August 2010; Nicholas Tonti-Filippini, *Submission no. 45*, 9 August 2011; VANISH Inc, *Submission no. 8*, 3 August 2010; Victorian Assisted Reproductive Treatment Authority, *Submission no. 19*, 6 August 2010; Victorian Infertility Counsellors Group, *Submission no. 22*, 6 August 2010; Christine Whipp, *Submission no. 31*, 9 August 2010.

> 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 identifying information (eg medical information) or initiating contact with the donor conceived person (usually via email or letter).[263]

Melbourne IVF made similar comments, based on the donor-linking it has undertaken for pre-1988 donor-conceived people:

> It has been Melbourne IVF's experience that donors may initially be reluctant to respond to contact from the Clinic. However, once they speak with a counsellor and understand why the donor conceived individual wishes to make contact with them, that the release of any information is voluntary and the options available to them (eg can provide information only without identifying themselves) most donors agree to participate.[264]

Regardless of the measures introduced to facilitate the exchange of information between donor-conceived people and donors, it is vital that they and their families are able to access appropriate counselling as they explore and negotiate new relationships. The Committee's view is that at certain points during the process for access to information, counselling for the donor-conceived person should be compulsory, and strongly recommended for donors. Recommendations for arrangements surrounding counselling and contact are discussed below, and in Chapter Six.

Recommendation 3: That, with the introduction of the legislation described in Recommendation 1, the Victorian Government require donor-conceived people to attend counselling prior to obtaining identifying information about donors.

3.4.2 Contact vetoes

Contact vetoes have been employed in an adoption context in Australia, as a means of safeguarding the opening up of previously closed adoption records.[265] In New South Wales, the *Adoption Information Act 1990* (NSW) provided adopted adults with the right to receive copies of their original birth certificates, and information that would allow them to identify their birth parents. It also gave birth parents the right to access the certificate of adoption and information enabling them to identify the child who was adopted.[266] Contact vetoes were introduced in the *Adoption Information Act*

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[263] Victorian Infertility Counsellors Group, *Submission no. 22*, 6 August 2010, p. 4.

[264] Melbourne IVF, *Submission no. 32*, 9 August 2010, p. 7.

[265] The Committee notes, however, that contact vetoes have not been employed in an adoption context in Victoria.

[266] E. Wayne Carp, 'Does opening adoption records have an adverse social impact? Some lessons from the U.S., Great Britain, and Australia, 1953-2007', *Adoption Quarterly*, vol. 10, no. 3-4, pp. 29-52, 2007, p. 46.

1990 (NSW) to provide some assurance to each party to an adoption that they would not endure unwanted contact from the other. Contact vetoes were not sought by most adopted people and birth parents following introduction in New South Wales, but where they were in place there was a very high level of compliance by relevant parties. In the two years following introduction of the legislation, only one case of an arguable breach occurred.[267]

3.4.2.1 Justification for use

While the Committee considers that donor-conceived people should have the right to know the identity of their donor, the Committee is also cognisant of the need to minimise any negative effects that the release of identifying information may have on donors and their families. The Committee recognises that for the most part, donors acted altruistically in making their donations, and many relied on the promise of anonymity that was made to them. Many donors will have their own children, and some may not have told their partner or their children that they previously donated their gametes. The majority of donors will have had no further contact from the clinic at which they donated since the time of making their donations, which may be some 25 or 30 years previously.

The Committee has also heard evidence that some donors may have a large number of donor-offspring. This is a key difference between donor-conception and adoption – a single donor may potentially have many more offspring than a birth parent. Ms Helen Kane, former Manager of the ITA's Donor Registers Service, advised that in some cases, donor records indicate that there may be as many as 30 half-siblings conceived from one sperm donor's donations.[268] It could be quite overwhelming if all of these donor-conceived people wished to make contact with their donor. Consequently, some witnesses (including donor-conceived persons) recommended that a mechanism be introduced in conjunction with allowing access to identifying information that would allow donors to prevent unwanted contact with their donor-offspring:

> I think that there should be a distinction between an information veto and a contact veto. I think donors who don't want contact, that's absolutely within their rights, and I respect that, and every donor-conceived person I've ever spoken to also respects that and is conscious of not wanting to intrude upon a donor or invade their life in any way. … I think the Committee should make a broad policy decision that we should have access to this information but in coming up with a system that is also sensitive towards donors perhaps we may look at things like a contact veto, for example.[269]

With these considerations in mind, the Committee believes that it is appropriate that donors, and donor-conceived people, should have the option of lodging a contact veto. This would not prevent a donor's offspring from accessing identifying information about them, but would prohibit

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[267] Ibid.
[268] Helen Kane, *Submission no. 46*, 9 August 2011, p. 2.
[269] Lauren Burns, *Transcript of evidence*, Melbourne, 12 September 2011, p. 44.

donor-offspring from attempting to make contact with the donor. A contact veto could be enforced through legislated penalties which would apply if the veto was breached.

The Committee is aware that the introduction of contact vetoes will have the effect of constraining people’s ability to freely associate with certain other people. The Committee believes, however, that this constraint is an appropriate measure to complement removing the right of donors to prevent their identity from being revealed to their donor-offspring.

3.4.2.2 Features of contact vetoes

Contact vetoes should only be made available to donor-conceived people whose ability to access identifying information about their donors will be affected by Recommendation 1, above, and their respective donors, who will lose the ability to maintain their anonymity. The Committee notes that, since 1998, donors and recipient parents have freely agreed to exchange identifying information, and consequently the Committee sees no justification for constraining the rights of either of these parties to contact one another.

Activating a contact veto is a significant act that would affect the rights of the other party. For this reason, the Committee recommends that the person activating a contact veto receive counselling to ensure he or she is aware of the consequences of the act. This is explored further in Chapter Six.

The Committee also considers that a veto should not last for an indefinite period of time, as a person who places a veto should be required to periodically consider whether they wish the veto to remain in place. The Committee heard evidence from Professor Ken Daniels, an academic who has conducted research on donor-conception issues and has been involved with donor linking, that requiring vetoes to be renewed every five years provides an appropriate balance between the interests of all parties.[270] Therefore the Committee recommends that contact vetoes lapse after a period of five years if not renewed by the applicant, and that provision be made for applicants to have the ability to withdraw a contact veto at any time.

The Committee believes that ‘blanket’ or pre-emptive contact vetoes should not be permitted. A donor should only have the opportunity to lodge a contact veto once they have been notified that a donor-conceived person is seeking identifying information about them. If the donor chooses to place a contact veto, the Committee considers that veto should only apply in relation to the specific donor-offspring who is seeking information. If another donor-conceived offspring later seeks identifying information, the donor should again be contacted and be required to lodge a separate contact veto applying only to that second person.

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[270] See Ken Daniels, *Transcript of evidence*, Melbourne, 5 December 2011, p. 4.

Recommendation 4: That, with the introduction of the legislation described in Recommendation 1, the Victorian Government introduce provisions for contact vetoes that may be lodged by a donor or a donor-conceived person following counselling, with the following features:

- that contact vetoes only be available to people conceived from gametes donated prior to 1998, and the donors of those gametes;
- that donors may only lodge a contact veto after they have been informed that a donor-conceived person has lodged an application for identifying information about them;
- that a veto prohibits contact between the donor and the donor-conceived person;
- that suitable penalties be established for breach of a veto;
- that a veto lapses within five years if not renewed by the person who lodged it; and
- that the person who lodged a veto may withdraw it at any time.

3.4.2.3 Protecting donors' or donor-conceived people's families

The Committee recognises that circumstances may arise where, subsequent to identifying information being released, a party to donor-conception may act inappropriately, by initiating and continuing to make unwanted contact with another party. As described above, the Committee believes that donors and donor-conceived people should have the option of lodging a contact veto, if they wish to. However, the unwanted behaviour may extend to other family members of either a donor or a donor-conceived person. In this circumstance, the Committee believes that rather than employing contact vetoes, the appropriate measure for a person who is subject to unwanted contact would be to make use of the usual protections available in such a situation. That is, the person who is being subjected to unwanted contact can apply for a personal safety intervention order against the other person.

The *Personal Safety Intervention Orders Act 2010* provides a regime to enable a person to obtain an order to prevent a specific person from engaging in "prohibited behaviour".[271] Prohibited behaviour is defined as any of assault, sexual assault, harassment, property damage or interference, or making a serious threat.[272] The Act also defines stalking,[273] which is likely to be the behaviour most relevant to donor-conception parties.

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[271] *Personal Safety Intervention Orders Act 2010* (Vic).
[272] Ibid.
[273] Ibid.

3.4.3 Contact preference form

The Committee believes that the introduction of contact vetoes will provide reassurance to donors and donor-conceived people who are concerned about, or fearful of, contact with each other. However, the Committee also recognises that as a legally enforceable measure, contact vetoes form a very blunt instrument to prevent contact with others. The Committee is aware that many donors empathise with their donor-offspring, even if they do not desire contact, and may not wish to make use of a contact veto.

In Oregon, USA, concerns about the effects on birth mothers of opening adoption records retroactively led to the legislature introducing a 'contact preference form' for birth parents. The form permitted the birth parent to indicate one of three options – "I would like to be contacted", "I would prefer to be contacted only through an intermediary", and "I prefer not to be contacted at this time", and for the form to be presented to the adopted person by an intermediary.[274] Although the preferences expressed had no legal weight, the form provided an opportunity for birth parents to express their contact wishes prior to any independent contact with them.

The Committee believes that the introduction of provisions for contact preference forms will complement the introduction of contact vetoes, offering donors an opportunity to informally communicate their preferences for contact.

Recommendation 5: That, with the introduction of the legislation described in Recommendation 1, the Victorian Government introduce provisions for donors to lodge a contact preference form for presentation to a donor-conceived person.

3.4.4 Transition period

The Committee's recommendations, if implemented, will result in substantial changes to the rights of donor-conceived people, and of donors, under the law. These changes may also encourage recipient parents to tell their children about their conception – the Committee received evidence from a number of parents indicating that a major reason why they had not told their children was that they knew no information would be accessible, and that this could be very frustrating to their child:

> … the main reason I have not told [my son that he is donor-conceived] 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 of his origins, when legislation won't allow him that access.[275]

While many donor-conceived people will likely be anxious to obtain identifying information as soon as possible, it is crucial that sufficient opportunity be provided to inform all affected parties of proposed changes

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[274] *House Bill 3194, 1999* (Oregon Legislative Assembly).
[275] Name withheld, *Submission no. 2*, 28 July 2010, p. 1.

to legislation, and arrangements surrounding access to information on donors. Consequently, the Committee recommends that a suitable period of time pass before legislation becomes effective, during which new legislative arrangements can be adequately publicised.

Recommendation 6: That the Victorian Government introduce the measures proposed in Recommendation 1 through Recommendation 5 following a period of time sufficient to publicise and inform the Victorian community of retrospective changes to donor-conception arrangements.

3.4.5 Access to non-identifying information

While the Committee believes that all donor-conceived people should be able to access identifying information about their donors, the Committee also recognises that not all may wish to do so.[276] Some donor-conceived people may only desire non-identifying information about their donors. As noted above, the release of non-identifying information about donors will not breach the donor's right to privacy. The Committee is also cognisant that access to non-identifying information about donors may also be of interest to the parents of donor-conceived people, and could assist those parents to reveal information about their children's conception to them.

Currently, people conceived from gametes donated after 1988, and their parents, are able to access non-identifying information about their donors, without the donor's consent. The Committee believes this capacity should be extended to people conceived from gametes donated prior to 1988 and their parents.

The Committee notes that it should be possible, under current legislation, for clinics, physicians and government agencies (such as PROV) to release non-identifying information about donors. Disclosure of non-identifying information is unlikely to breach any anonymity agreements entered into with donors, and is also unlikely to breach any provision of privacy legislation. Consequently, the Committee recommends that the Victorian Government encourage all persons, agencies and organisations that currently hold information on donor-conception to release non-identifying information, on request, to donor-conceived persons, their parents, and descendants.

Recommendation 7: That the Victorian Government encourage organisations, agencies and persons holding information on donor-conception to release, upon request, non-identifying information about a donor to a donor-conceived person, his or her parents, and his or her descendants.

As no privacy issues are likely to arise through introduction of this measure, the Committee believes that Recommendation 7 should be introduced immediately. The Committee notes that access to this information by parents may also be of assistance should they decide to

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[276] See, for example, Amy Corderoy, *Submission no. 77*, 26 October 2011.

reveal the circumstances of their child's conception prior to the introduction of measures to provide access to identifying information.

Currently, the right of people conceived from gametes donated after 1988 to access non-identifying information about their donors is articulated in the *Assisted Reproductive Treatment Act 2008.* While access to non-identifying information can be achieved through a policy response, over time the Committee believes that people conceived from gametes donated prior to 1988 should also have the right to obtain non-identifying information about donors articulated in legislation.

3.4.6 Age at which access to information is permitted

The *Assisted Reproductive Treatment Act 2008* currently provides that people conceived from gametes donated after 31 December 1997 can access identifying information about their donor at the age of 18. These people can also access identifying information at a younger age with the consent of a parent or guardian, or with a counsellor's written opinion that they are mature enough to understand the consequences of the disclosure.[277]

Mr Damian Adams, a donor-conceived person, suggested that the age at which a donor-conceived person is able to access information about their donor should be substantially lowered:

> … the current practice of only allowing donor offspring access to identifying information once they reach the age of 18 may cause irreparable damage as the vital identity construct window has passed. And as such it would be prudent to recommend that the age at which an offspring is able to access such information should be substantially lowered. This is supported by reports that less damage occurs when a child is told of their conception at an early age … and that it is certainly more beneficial to occur before the identity construct window of adolescence occurs … So not only should a child be told of their conception at an early age, but they should have access to the identity of their progenitor from a much earlier time point than what is currently allowed to ensure that the welfare of the child is appropriately protected.[278]

Dr Sonia Allan, and the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) similarly advocated that the age for access should be lowered, with Dr Allan recommending 16 years of age as appropriate, and the VEOHRC recommending "an age of sufficient maturity".[279]

The Committee did not receive sufficient evidence on this matter to be able to recommend, with confidence, that allowing access to identifying information by people under the age of 18 would significantly improve outcomes for the child. The Committee notes, however, that

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[277] *Assisted Reproductive Treatment Act 2008* (Vic), section 59.
[278] Damian Adams, *Submission no. 4*, 30 July 2010, p. 3.
[279] Sonia Allan, *Submission no. 5*, 2 August 2010, pp. 21-22; Victorian Equal Opportunity and Human Rights Commission, *Submission no. 74*, 1 September 2011, pp. 10-11.

Recommendation 2 of this report provides for children under the age of 18 to obtain identifying information about their donor with their parents' consent, or upon advice from a counsellor that the person is sufficiently mature to understand the consequences of disclosure. In the Committee's view, these provisions are sufficient to provide children access to identifying information prior to their eighteenth birthday.

Table 6: Donors’ access to information about donor-offspring under current legislation.

Donor	Avenue to seek information	Information that can be obtained
Donated pre-1988	**Fertility clinic at which the donor donated**	The fertility clinic may provide **non-identifying** information – the sex and number of offspring.
		If the donor wishes to obtain **identifying information**, the fertility clinic will refer the donor on to the voluntary register, as a possible avenue to obtain identifying information.
	Voluntary register	If a person conceived from the donor’s gametes is registered on the voluntary register, the donor can obtain **non-identifying and/or identifying information** from the voluntary register, in accordance with the donor-conceived person’s wishes.
		However, the donor-conceived person must know that they are donor-conceived, be aware of the existence of the voluntary register, and have registered, for this to be an option.
Donated 1988 or later	**Central register**	A donor can obtain **non-identifying information** about their donor-conceived offspring.
		A donor can apply for **identifying information** about their donor-conceived offspring. This information will only be provided if the donor-conceived person consents to its release.
	Voluntary register	Additional **non-identifying information** may be able to be obtained through the voluntary register, if the donor-conceived person has lodged such information.
		The donor-conceived person must know that they are donor-conceived, be aware of the existence of the voluntary register, and have registered, for this to be an option.

Chapter
4

Chapter Four:
Donors' access to information

A separate issue to the right of donor-conceived people to access information about their donor is the question of the extent to which donors should be able to access information about, and potentially initiate contact with, their donor-conceived offspring. There are three aspects to this issue:

- the right of a donor to obtain non-identifying information about their donor-offspring;
- the right of a donor to seek and obtain identifying information about their donor-offspring; and
- the ability of a donor to pass on medical information to their donor-offspring.

The question of a donor's right to information is a difficult one, particularly because many donor-conceived people are unaware that one or both of their parents are not biologically related to them. Consequently, a donor seeking information about their donor-offspring could result in a donor-conceived person discovering the manner of their conception, if the donor-conceived person's consent was sought to release the information, or if the donor was to make contact with the donor-conceived person.

4.1 Donor perspectives

The Committee heard evidence from a number of donors in the course of the Inquiry. While several expressed curiosity about their donor-offspring, and regret that they might not ever have the opportunity to meet and develop relationships with their genetic children, they did not necessarily consider that they should have a right to identifying information about their offspring.

For example, the Committee heard from Mr Ian Smith, a pre-1988 donor who is the biological father of nine children, seven of whom are donor-conceived. He has not met any of them, but has had preliminary contact with one of them through the voluntary register. Mr Smith expressed the view that he would like to have contact with his offspring:

> I have got my own children now, they have grown up and I know that I have seven other children who are half of me. I would dearly love to know

> something about them, to at least meet them once, but I may never do so. If I had the opportunity to do so, yes, I certainly would wish to.[280]

However, Mr Smith also emphasised that he considers the needs and interests of the children conceived from his donations to be paramount:

> You have got to protect them [donor-conceived people] is my view … the interests of the children … is in my mind paramount …
>
> Say hypothetically, if the legislation were to change and it would allow me to make contact with those people, I personally would be very reticent in initiating that in as much as I do want to, I would love to meet those people, but it comes from my philosophy that they are at the core of this and it is their human rights that are paramount.[281]

Mr Michael Linden, another pre-1988 donor, has five donor-conceived children, two of whom he has met and has an ongoing relationship with, and three further female children about whom he only has non-identifying information. Mr Linden also expressed a desire to know about and connect with his biological children:

> … as far as these missing children are concerned, I feel there is no difference between my circumstance and that of the relinquishing parent in the context of adoption. My need to connect with them and my curiosity about their whereabouts and how their lives have transpired is of the same order I believe and likewise should not be summarily negated because I somehow gave them away.[282]

At the same time, Mr Linden shared Mr Smith's view about respecting the needs and wants of donor-offspring:

> The extent of the relationship which I am prepared to offer any of my three children who might come forward will be as much as they themselves want and need to have. It is their call; not mine.[283]

The Committee heard from other donors who expressed similar views to those of Mr Linden and Mr Smith – their primary concern was for the needs of their donor-offspring, not their own needs.[284] Similarly, in the experience of the Infertility Treatment Authority (ITA), the majority of donors do not want to disrupt recipient families:

> … at present the majority of donors with whom the ITA has contact respect the privacy of the recipient families and have no intention of applying for information about the person conceived with their gametes. Instead, they

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[280] Ian Smith, *Transcript of evidence*, Melbourne, 10 October 2011, p. 38.
[281] Ibid, p. 50.
[282] Michael Linden, *Transcript of evidence*, Melbourne, 10 October 2011, p. 42.
[283] Ibid, p. 43.
[284] Roger Clarke, *Transcript of evidence*, Melbourne, 17 October 2011, p. 4; Paul Ruff, *Transcript of evidence*, Melbourne, 5 December 2011, p. 10.

> are willing to make themselves available should the child or young adult wish to make contact in the future.[285]

Another pre-1988 donor, "Alex", was clear in his view that donor-conceived people have the right to know who their donor is, but he did not feel the need to make contact with them:

> I do not want any information. I am not here searching for my children. If they want to have some contact with me, I am happy for them to have some contact with me, but I do not need to contact my children.[286]

4.2 Donors' current rights of access to information about donor-conceived offspring

4.2.1 Pre-1988 donors

4.2.1.1 Non-identifying and identifying information

Donors who donated gametes prior to 1988 currently have no right to access or request any information about their donor-offspring.

The only avenue through which a pre-1988 donor can seek to obtain identifying information about, or potentially make contact with, their donor-offspring is to lodge an application to the voluntary register held by the Registry of Births, Deaths and Marriages (BDM). If one of the donor's offspring also registers, the voluntary register will recognise a match, and depending on the wishes of each party, identifying or non-identifying information may be shared between the respective parties.[287] Non-identifying information obtained by the donor will depend on what information his or her donor-offspring has chosen to provide, but may include details such as physical characteristics, interests, occupation, and family information.[288]

It may also occur to donors to contact the clinic at which they made their donation, to seek the clinic's assistance to make contact with their donor-offspring. On receiving a request from a donor, the clinic may, at its discretion, provide non-identifying information about the donor's offspring. For example, the Committee was told that Melbourne IVF has been contacted by pre-1988 donors wanting to know how many donor-offspring they have, and their sex, and that Melbourne IVF had provided that

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[285] Victorian Law Reform Commission, *Assisted reproductive technology & adoption*, Final report, VLRC, Melbourne, 2007, p. 154.

[286] "Alex", *Transcript of evidence*, Melbourne, 5 December 2011, p. 5.

[287] *Assisted Reproductive Treatment Act 2008* (Vic), sections 71 & 72.

[288] See Births Deaths and Marriages Victoria, 'Voluntary register application', viewed 2 December 2011, <http://online.justice.vic.gov.au>.

information to them.[289] Monash IVF also confirmed that it has been contacted by pre-1988 donors seeking information:

> I've had a number of donors call in just out of the blue saying: I used to be a donor in 1975 or 1978, or whatever. And I can look it up and say: yes, your donations were used, you have x number of children, this is where you go, you go and get information on the voluntary register, this is the only way you're going to be able to know which children you've fathered …[290]

Counsellors employed by Melbourne IVF and Monash IVF advised the Committee that if they were to receive an enquiry from a donor who wished to initiate contact with, or obtain identifying information about, their offspring, the counsellor would refer the donor on to BDM, who would be able to explain the process of lodging an application with the voluntary register. Neither counsellor was aware of any approach made by a pre-1988 donor to either clinic seeking to make contact with their offspring.[291]

4.2.1.2 Passing on medical information

Currently, the only circumstance in which a treating clinic will attempt to make contact with a donor-conceived person is if a donor advises that they have a significant medical condition that could have been passed on to the offspring. In this case, the clinic would attempt to make contact with the offspring, generally via their parents, to alert the donor-conceived person to the possibility that they may also have, or have a propensity to develop, the condition.[292] An example of this situation was explored in Case Study 3 (page 54).

4.2.2 Post-1988 donors

4.2.2.1 Non-identifying information

All donors who consented to the use of their gametes after 1 July 1988 currently have the right to obtain from the central register non-identifying information about their donor-offspring, regardless of the age of the offspring.[293] The only non-identifying information available will be the donor-offspring's sex and year of birth.[294]

Donors may also be able to obtain additional non-identifying details about their donor-offspring by applying to the voluntary register.

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[289] Joanne McCann, Operations Manager, Melbourne IVF, *Transcript of evidence*, Melbourne, 10 October 2011, p. 16; Rachael Varady, Donor Program Manager, Melbourne IVF, *Transcript of evidence*, Melbourne, 10 October 2011, p. 16.

[290] Maria Gabbe, Donor Coordinator, Monash IVF, *Transcript of evidence*, Melbourne, 17 October 2011, p. 32.

[291] Rita Alesi, Victorian Infertility Counsellors Group, *Transcript of evidence*, Melbourne, 12 September 2011, pp. 29-30; Marianne Tome, Victorian Infertility Counsellors Group, *Transcript of evidence*, Melbourne, 12 September 2011, pp. 29-30.

[292] See Joanne McCann, Operations Manager, Melbourne IVF, *Transcript of evidence*, Melbourne, 10 October 2011, p. 19.

[293] *Assisted Reproductive Treatment Act 2008* (Vic), sections 56 & 57.

[294] *Assisted Reproductive Treatment Regulations 2009* (Vic), schedule 5.

4.2.2.2 Identifying information

Post-1988 donors are able to obtain identifying information about their donor-offspring, if the person about whom information is sought consents to it being released (or where the person is younger than 18 years of age, if their parent or guardian provides consent).[295] The right of donors to obtain identifying information with consent was first introduced in the *Infertility (Medical Procedures) Act 1984*, at the time of the central register coming into operation, and that right has been maintained in each of the subsequent acts regulating assisted reproductive treatment.[296]

4.2.2.3 Passing on medical information

Post-1988 donors do not currently have a direct avenue to pass on important medical information to their offspring. There are two options that they could pursue to attempt to do this. The first is that the donor could apply to the central register for identifying information, and if the donor-conceived person consents, pass the medical information on directly to the person. BDM will not act as an intermediary to pass information on, and if the donor-conceived person does not agree to their identifying details being released, they will not discover the medical information through this avenue.

The second option for a donor to provide medical information to donor-offspring is to lodge the information on the voluntary register. If the donor-conceived offspring are aware that they are donor-conceived, they can apply to the voluntary register and access the medical information, without the need to make direct contact with the donor. However, a donor-conceived person who is unaware of his or her donor-conceived status, or of the existence of the voluntary register, will not discover the information through this means.

4.2.3 Experience to date with donors seeking access to information

At present, if a post-1988 donor applies to the central register for identifying information about their donor-offspring, BDM will send a letter to the donor-conceived person (or their parents, if the person is under 18), advising of the application and seeking the person's consent to release the information. As discussed in Chapter One, it is apparent that the majority of donor-conceived people have not been told that they are donor-conceived, particularly those conceived before changes to the legislation in 1998 provided for a donor-conceived person's right to know the identity of their donor.

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[295] *Assisted Reproductive Treatment Act 2008* (Vic), sections 56 & 58.

[296] See the *Infertility (Medical Procedures) Act 1984* (Vic), section 22 and the *Infertility (Medical Procedures) Regulations 1988* (Vic), reg. 13 and schedule 8; *Infertility Treatment Act 1995* (Vic), sections 76 & 77; *Assisted Reproductive Treatment Act 2008* (Vic), sections 56 & 58.

4.2.3.1 Applications for identifying information

Until the end of 2009, the ITA managed the donor registers (the central register and the voluntary register) and provided donor-linking services. The ITA established the Donor Registers Service in 2005, in anticipation of the oldest donor-conceived children on the central register (born in 1988) reaching 18 years of age in 2006, and so becoming eligible to request identifying information about their donor, and their donor being able to seek identifying information about them.[297] A request from either party for identifying information would require the ITA to contact the other party to seek their consent to release the identifying information.

Between 1 January 2007 and 31 October 2009 the ITA received few requests from donors for identifying information, with only seven requests made during this period (see Table 7). The donor registers were transferred to BDM with effect from 1 January 2010, and as at 30 June 2011, BDM had only received one request from a donor for identifying information.[298] As at the end of June 2011, 1,885 donors are recorded on the central register.

Table 7: Donors' requests for identifying information about donor-offspring

Time Period	Applications by donors	Total number of donors on central register
1 Jan 2007 – 31 Dec 2007	3[299]	1,238[300]
1 Jan 2008 – 30 June 2009	3[301]	1,535[302]
1 July 2009 – 31 Oct 2009[303]	1[304]	1,577[305]
1 Jan 2010 – 30 June 2010	1[306]	1,663[307]
1 July 2010 – 30 June 2011	0[308]	1,885[309]

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[297] Helen Kane, *Submission no. 46*, 9 August 2011, pp. 2-3.

[298] Victorian Assisted Reproductive Treatment Authority, *Annual report 2010*, VARTA, Melbourne, 2010, p. 22.

[299] Infertility Treatment Authority, *Annual report 2008*, ITA, Melbourne, 2008, pp. 20-21.

[300] Ibid.

[301] Infertility Treatment Authority, *Annual report 2009: twelfth and final report*, ITA, Melbourne, 2009, pp. 18-19.

[302] Ibid.

[303] Note that as of 1 January 2010, management of the donor registers was transferred from ITA to BDM. Applications to the registers that were received after 31 October 2009 were not processed by the ITA because of the required time for counselling, but were instead transferred to BDM as of 1 January 2010. See Victorian Assisted Reproductive Treatment Authority, *Annual report 2010*, VARTA, Melbourne, 2010, p. 21.

[304] Ibid.

[305] Ibid, p. 20.

[306] Ibid, p. 22.

[307] Ibid, p. 20.

[308] Victorian Assisted Reproductive Treatment Authority, 'A statistical snapshot of the donor registers in Victoria for 2010-2011', VARTA, Melbourne, 2011, viewed 23 Nov 2011, <www.varta.org.au>, p. 3.

[309] Ibid.

4.2.3.2 The Infertility Treatment Authority’s experience

During the period in which the ITA managed the donor registers, a number of donors (both pre- and post-1988) contacted the ITA. Ms Kate Dobby, the then Registers Officer for the Donor Registers Service, spoke about the motivations of the donors who approached the ITA:

> … they were wanting contact with their donor-conceived offspring. … They were trying to find out what happened. They were told things at the time, and maybe it is at the back of their mind and they have suddenly done something or they have had a health crisis. … most of the times it was some sort of specific life situation occurring that made them do this, but it had always been at the back of their mind.[310]

As noted above, some of the inquiries received by the ITA were from post-1988 donors applying to the central register for identifying information about their donor-offspring. Some of these requests were in relation to offspring who had not yet reached 18 years of age. In these cases, the ITA was required by the legislation to contact the parents of the donor-conceived child, to seek their consent to releasing the identifying information.[311]

Even in situations where a donor-conceived person had reached 18 years of age, however, the Committee heard that the ITA’s practice was to make initial contact with the person’s parents. The ITA adopted this approach in order to establish whether or not the person was aware that they were donor-conceived before the ITA made direct contact with them. It also provided parents who had not told their children about the manner of their conception with an opportunity to tell their children themselves, rather than have their children learn about their conception by receiving a letter from the ITA.[312]

Figure 3 shows the text of a letter sent by the ITA to a donor-conceived person born under the *Infertility (Medical Procedures) Act 1984* following an application from a donor who wished to pass on key medical information. In this case, the ITA had made initial contact with the person’s parents, to establish whether the donor-conceived person had been informed that they were donor-conceived. The parents had not at that stage told their child, but proceeded to do so before the ITA made direct contact with the person.[313]

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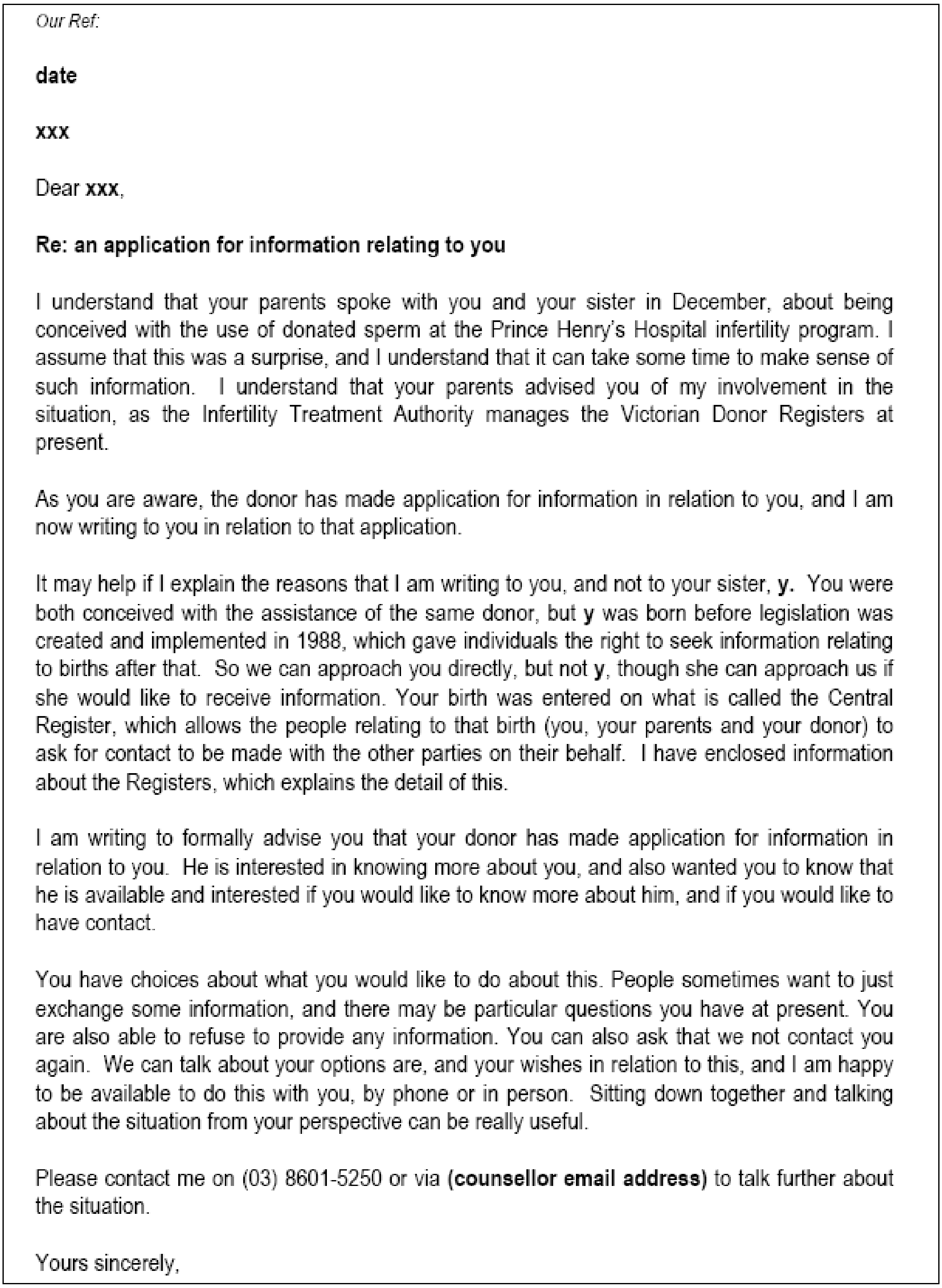
[310] Kate Dobby, *Transcript of evidence*, Melbourne, 8 September 2011, p. 27.
[311] *Infertility Treatment Act 1995* (Vic), sections 76 & 77.
[312] Helen Kane, *Transcript of evidence*, Melbourne, 12 September 2011, p. 13.
[313] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Personal communication*, 16 September 2011.

Figure 3: Sample letter from the ITA to a person born under the *Infertility (Medical Procedures) Act 1984* following an application from a donor to provide medical information[314]



Our Ref:

date

xxx

Dear **xxx**,

Re: an application for information relating to you

I understand that your parents spoke with you and your sister in December, about being conceived with the use of donated sperm at the Prince Henry's Hospital infertility program. I assume that this was a surprise, and I understand that it can take some time to make sense of such information. I understand that your parents advised you of my involvement in the situation, as the Infertility Treatment Authority manages the Victorian Donor Registers at present.

As you are aware, the donor has made application for information in relation to you, and I am now writing to you in relation to that application.

It may help if I explain the reasons that I am writing to you, and not to your sister, **y.** You were both conceived with the assistance of the same donor, but **y** was born before legislation was created and implemented in 1988, which gave individuals the right to seek information relating to births after that. So we can approach you directly, but not **y**, though she can approach us if she would like to receive information. Your birth was entered on what is called the Central Register, which allows the people relating to that birth (you, your parents and your donor) to ask for contact to be made with the other parties on their behalf. I have enclosed information about the Registers, which explains the detail of this.

I am writing to formally advise you that your donor has made application for information in relation to you. He is interested in knowing more about you, and also wanted you to know that he is available and interested if you would like to know more about him, and if you would like to have contact.

You have choices about what you would like to do about this. People sometimes want to just exchange some information, and there may be particular questions you have at present. You are also able to refuse to provide any information. You can also ask that we not contact you again. We can talk about your options are, and your wishes in relation to this, and I am happy to be available to do this with you, by phone or in person. Sitting down together and talking about the situation from your perspective can be really useful.

Please contact me on (03) 8601-5250 or via **(counsellor email address)** to talk further about the situation.

Yours sincerely,

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[314] Letter provided to the Committee by Louise Johnson, Ibid.

In the ITA's experience, donors generally did not want their donor-offspring to learn about their conception in a negative way, and were happy for the ITA to take the approach of contacting parents first rather than directly contacting the donor-conceived person.[315] This is consistent with evidence that the Committee heard from donors, who were primarily concerned with the wellbeing and interests of their offspring, rather than their own interests.

4.2.3.3 Registry of Births, Deaths and Marriages

The central register is currently managed by the BDM. If a post-1988 donor wishes to seek identifying information about their donor-offspring, he or she can lodge an application to the central register.

Upon receiving an application from a donor, BDM will send a letter directly to the donor-conceived person, advising them of the donor's application and seeking their consent to release identifying information about them to the donor.[316] This would occur without the support of counselling for the donor-conceived person, as BDM does not provide counselling services (discussed further in Chapter Six), and only refers those people who make an application for identifying information (in this case, the donor) for counselling, as opposed to those who are the subject of an application.[317]

4.3 Considerations around donors' access to information

The Committee believes that the current legislative arrangements that allow a post-1988 donor to obtain identifying information with the consent of his or her donor-offspring are appropriate. Donors have had the right to seek information about their donor-offspring since 1988, and the Committee is reluctant to recommend removing this right in the absence of compelling evidence that it has done any harm. The Committee notes that these legislative provisions may also provide an incentive for parents to disclose to their donor-conceived children the manner of their conception.

In the context of this Inquiry, a key issue for the Committee is to consider whether it is appropriate for these arrangements to be applied retrospectively, to pre-1988 donors. The range of issues for donors' access to identifying information is similar to those faced for donor-conceived people's access to identifying information, particularly as:

- donors have differing rights to seek identifying information about their donor-offspring, depending on whether they made their donations before or after 1988;
- because post-1988 donors have the right to seek identifying information about their donor-offspring, under the current system, a post-1988 donor-conceived person may discover that they are

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[315] Helen Kane, *Transcript of evidence*, Melbourne, 12 September 2011, p. 14.
[316] Erin Keleher, Manager of Strategic Projects, Registry of Births, Deaths and Marriages, *Transcript of evidence*, Melbourne, 21 November 2011.
[317] Ibid.

donor-conceived in an impersonal and potentially traumatic manner, with no counselling support; and

- there is no established mechanism to ensure that important medical information about a donor is passed on to a donor-conceived person who may have, or be at risk of developing, a serious medical condition.

4.3.1 Historical basis for the right of donors to seek identifying information

As described in Chapter Two, the first Victorian legislation regulating matters around donor-conception, the *Infertility (Medical Procedures) Act 1984*, was based in large part upon recommendations made by the Committee to Consider the Social, Ethical and Legal Issues Arising From In Vitro Fertilization, chaired by Professor Louis Waller (the “Waller Committee”), in 1982 and 1983. While the Waller Committee specifically highlighted the ethical right of a child to know its genetic background, it did not comment on any right of a donor to seek information about his or her offspring, beyond non-identifying information:

> The Committee recommends that non-identifying information about the recipients shall be offered to the donor whose gametes are used in an IVF programme. The donor shall also be advised, if he or she so chooses, of the results of any successful use of the gametes. That is, information of a non-identifying kind will be provided about any child born as a result of the use of the donated gametes.[318]

Nevertheless, the *Infertility (Medical Procedures) Act 1984* provided both donors and donor-conceived offspring with the right to obtain identifying information about each other, if the other party provided consent to the information being released.

The ability for donors to seek identifying information about their offspring was maintained in the *Infertility Treatment Act 1995*. Where a donor applied to the ITA for identifying information about his or her donor-offspring, the *Infertility Treatment Act 1995* expressly required the ITA to “make reasonable efforts” to find the person whose consent was required (i.e. the donor-conceived person, or a parent if the person was under 18 years of age).[319] The Act also provided that before seeking consent, the ITA had to advise the person whose consent was required that he or she may need counselling, and provide the names of approved counsellors with whom that person could speak.[320]

In debate in the Victorian Parliament around the proposed *Assisted Reproductive Treatment Bill 2008*, the question was raised as to why the

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[318] Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Report on donor gametes in IVF*, Melbourne, 1983, p. 25.

[319] *Infertility Treatment Act 1995* (Vic), section 77(3).

[320] Ibid, section 77(4).

provision for donors to seek identifying information was retained in the bill, particularly in view of the recommendation of the Victorian Law Reform Commission (VLRC) (discussed further below) that donors' rights to information should not form part of the bill.[321] The justification provided by the government was simply to maintain the status quo:

> The reason why it is retained in this provision and organised within the principles of the other provisions of the existing arrangements of the act is because of the fact that it is current practice.
>
> The government decided, on balance, to maintain that existing practice and cover it by the application of the law.[322]

4.3.2 Potential disruption of families

In the Committee's view, a key difference between pre-1988 donors and recipient parents on the one hand, and people conceived from donor gametes prior to 1988 on the other, is that donors and recipient parents were adults who made a conscious decision to donate, or receive, gametes. While the Committee heard that in some cases donors may not have been cognisant of the consequences of their actions, or may not have been adequately informed and counselled at the time of making their donation, all should have been aware of the possibility that their donation would lead to the conception of a child. All donors should have also understood that there was no expectation at that time that they would subsequently be able to contact those children.

Donor-conceived children were not, of course, party to decisions made by their parents or donors, and could not consent to their mode of conception. The Committee is also aware that many (if not the majority) of those donor-conceived people are unaware of the manner of their conception, as their parents have not revealed this to them.

If current arrangements for donors to seek identifying information were retrospectively applied, situations may arise in which a person who is over 18 could find out that they are donor-conceived by receiving a letter out of the blue from BDM. This is obviously a less than ideal way for someone to receive such life-altering news, and could cause the person and their family significant trauma.

Mr Ian Smith, a pre-1988 donor, commented on the importance of protecting donor-conceived people and ensuring that they do not find out in an inappropriate way about their donor-conception:

> So I would say that that must be dealt with very carefully. From the donor-conceived people who I have spoken to, many of them have been told in their 20s the truth of their conception, it is a huge shock. So to have

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[321] Ms Sue Pennicuik MLC, *Parliamentary debates*, Legislative Council, 2 December 2008, p. 5537.

[322] Mr Gavin Jennings MLC, Minister for Environment and Climate Change, *Parliamentary debates*, Legislative Council, 2 December 2008, p. 5537.

> that just come out of the blue and to have somebody contact you and say: Hi, I am actually your father, that could be very, very disruptive. I think whatever you do, you have to avoid that sort of outcome.[323]

However, Ms Barbara Burns, the mother of two donor-conceived children, expressed the view that the right to seek identifying information should be retained and extended to pre-1988 donors. Ms Burns advocated an open approach, despite the potential for disruption to families:

> Of course it is going to be a shock if parents have not told their children, and it is an extremely hard question to answer. … In my opinion, I think they [donors] should be allowed to [obtain identifying information about their donor offspring]. As I said, I basically think the secrets have to stop. There is no use trying to protect people; it just does not work. As I said, I recognise the possibility that many donor children will find out anyway many years in the future through incompatible blood or DNA, through going through their parents' papers. … I think they should have that right. I believe that most would not [exercise the right]; in fact I believe nearly all would not. I think with adoption they have that right and I do not think there have been any great problems. Originally the donation was altruistic and they do not want to hurt their children. I think they would be very responsible. Yes, I do think so. … One of the other reasons was that the post-1988 donors have the right to contact their children. The best thing with the law is to keep it as simple as possible. We do not know what the future circumstances will be. As I said, you might be protecting one group but you are causing great hardship to another group. That was my conclusion. We did think about it for quite a while, but I would opt for the truth and no more concealment and cover-ups. That is what I would choose.[324]

The Committee considers it imperative to ensure that the state does not facilitate causing trauma to donor-conceived people and disruption to their families. The Committee believes that the best way for children to find out that they are donor-conceived is for their parents to tell them.

The Committee also recognises that the approach previously taken by the ITA when handling requests from donors seeking identifying information about their offspring was sensitive and appropriate, and that taking such an approach – contacting the person's parents first and encouraging them to tell their children about their conception, and providing counselling support for all parties – would help to minimise negative repercussions from revealing that a person is donor-conceived.

4.3.3 Supporting donor-conceived people's right to know their origins

As noted in Chapter One, the Committee heard evidence to suggest that most donor-conceived people, particularly those born before 1998 – when

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[323] Ian Smith, *Transcript of evidence*, Melbourne, 10 October 2011, p. 50.
[324] Barbara Burns, *Transcript of evidence*, Melbourne, 5 December 2011, pp. 14-15.

the *Infertility Treatment Act 1995* came into effect – are unaware that they are donor-conceived.[325]

One argument that can be put forward in support of a donor's right to seek identifying information about their offspring is that retaining this right (and potentially extending the right to pre-1988 donors) may result in more donor-conceived people discovering the circumstances of their conception, which many consider to be a fundamental human right.[326] While the number of donors who actually apply for identifying information is low (only eight since 1 January 2007), the fact that donors are able to do so may encourage parents to tell their children about their conception.

The Committee agrees that it is a fundamental human right for a person to know this kind of information about their conception, and notes that this is reflected in the United Nations *Convention on the Rights of the Child*, which Australia has ratified, and which provides that:

> States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference.[327]

However, the Committee does not believe that allowing pre-1988 donors the right to seek identifying information about their donor-offspring is the most appropriate or effective way to ensure that donor-conceived people discover the circumstances of their conception. Given the low numbers of donors that have to date sought identifying information about their donor-offspring, donors' hesitance to initiate contact, and the continued reluctance of parents to tell their children about their conception despite post-1988 donors' current right to seek identifying information, it is unlikely that a significant number of donor-conceived people would learn about their conception by extending this right to pre-1988 donors.

The Committee believes that the state should take an educational and supportive approach to encourage parents to be open with their children. The Committee is also hopeful that if its recommendations in Chapter Three regarding allowing all donor-conceived people access to identifying information about their donors are implemented, parents will be encouraged to tell their children about their conception.

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[325] See, for example, Penelope Foster, Fertility Society of Australia, *Transcript of evidence*, Melbourne, 8 September 2011, p. 11; Louise Johnson and Helen Kane, 'Regulation of donor conception and the "time to tell" campaign', *Journal of Law and Medicine*, vol. 15, no. 1, pp. 117-127, 2007, p. 118; Helen Kane, *Submission no. 46*, 9 August 2011, p. 2.

[326] See, for example, Barbara Burns, *Submission no. 9*, 3 August 2010, pp. 1-2; Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, p. 39; Michael Linden, *Transcript of evidence*, Melbourne, 10 October 2011, p. 44; Romana Rossi, *Submission no. 25*, 6 August 2010, p. 1.

[327] *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990), article 8(1).

4.3.4 Rights of donors

4.3.4.1 Right of donors subject to the best interests of donor-offspring

VANISH, an organisation that provides search and support services for people in the adoption community, the donor-conception community, and Forgotten Australians, expressed the view that both donors and donor-conceived people are entitled to information about each other:

> Knowledge about the other party is a basic human right and should not be compromised by the wishes of either party, if they do not want to be contacted. All those involved are adults and those not wanting contact can simply make their wishes known. Not wanting contact is insufficient reason for either party to be denied information about the other.[328]

However, most of the opinions that the Committee heard on this topic did not endorse donors having an unconditional right to seek or obtain identifying information about their donor-offspring. Most stakeholders considered that the primary consideration should be the interests and wellbeing of the donor-conceived children, and that the wishes of the donors should be secondary.

Focusing on the needs of donor-conceived children rather than donors is consistent with the first of the guiding principles of the *Assisted Reproductive Treatment Act 2008*, which states that:

> The welfare and interests of persons born or to be born as a result of treatment procedures are paramount.[329]

Placing primary importance on the welfare of donor-offspring is also consistent with the provisions of the *Charter of Human Rights and Responsibilities Act 2006* and the United Nations *Convention on the Rights of the Child*, as discussed in Chapter Three.

Professor Ken Daniels, an academic who has been involved in research and policy advice for governments around the world in the area of donor-conception, and who has assisted in linking donor-offspring and donors, expressed the view that the decision to seek contact should be made by the offspring rather than the donor:

> I have always believed that this should be driven by the offspring. I have concerns that donors could get in touch. I have had one situation that has gone disastrously wrong in terms of a contact. That was a person living in Australia who had been donor to children in New Zealand. His needs were such as to potentially damage the offspring. That is all I need to say. Unfortunately I had not been given enough background by the referring

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[328] VANISH Inc, *Submission no. 8*, 3 August 2010, p. 4.
[329] *Assisted Reproductive Treatment Act 2008* (Vic), section 5(a).

> doctor to be aware of this until we were suddenly in a situation and it blew up.[330]

The Committee also notes that the VLRC, in reaching its position regarding donor-initiated contact (discussed further below), stated that it did not consider donors to be in the same position as the birth parents of an adopted child:

> We do not believe that donors should be treated in the same way as birth parents of an adopted child. Donors have never been regarded as parents of the children conceived and have never had relationships with the children that would justify enabling them to initiate contact.[331]

4.3.5 The Victorian Law Reform Commission's recommendations

In its 2007 report on assisted reproductive technology and adoption, the VLRC discussed the issue of donor access to information about donor-offspring and, in particular, considered whether donors should have the right to request identifying information about their offspring, leading to the offspring being contacted to seek their consent.

The VLRC noted that the current right of donors to request identifying information has been subject to considerable debate, with arguments both in support of, and against, its retention.[332] After considering the competing arguments, the VLRC took the position that donors should not have the right to apply for identifying information about a person conceived with their gametes,[333] explaining that making contact should be up to the donor-conceived person:

> The commission believes that once a donor-conceived person reaches adulthood, she or he should be the only party able to apply for information on the central register. The donor registers have been established for the benefit of donor-conceived people, who should have ownership of the process of information exchange.[334]

The VLRC considered that the removal of the donor's right to seek identifying information should occur with retrospective effect, with a window period of 12 months to allow any donors who had already donated gametes to make an application under the existing provisions. The VLRC considered that after that time, no donor should be able to seek identifying information about their offspring.[335]

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[330] Ken Daniels, *Transcript of evidence*, Melbourne, 5 December 2011, p. 6.

[331] Victorian Law Reform Commission, *Assisted reproductive technology & adoption*, Final report, VLRC, Melbourne, 2007, p. 154.

[332] Ibid, pp. 153-155.

[333] Ibid, pp. 154, Recommendation 86.

[334] Ibid, p. 154.

[335] Ibid, pp. 154-155.

In the VLRC's view, the most appropriate way for children to discover that they are donor-conceived is for them to be informed by their parents. The VLRC considered that the state should not play a role in informing them, whether as "the result of an application by the donor, by letter, or by some sort of annotation on the child's birth certificate."[336]

The VLRC's recommendations in this regard were not incorporated into the *Assisted Reproductive Treatment Act 2008*, which was enacted subsequent to the release of the VLRC's report. In addition to retaining the donor's right to seek identifying information about his or her donor-offspring, the *Assisted Reproductive Treatment Act 2008* also introduced a requirement that where a child is conceived through a donor treatment procedure, the Registrar of Births, Deaths and Marriages must mark the child's birth entry to note that he or she is donor-conceived. When issuing a birth certificate to a donor-conceived person born after 1 January 2010, the certificate must include an addendum stating that further information is available about the entry, with the intention that this will enable the person to discover the circumstances of his or her conception.[337]

4.3.6 The Committee's view

The Committee agrees with the view of many of the witnesses, and much of the evidence put before it, that the preferable state of affairs is for donor-conceived people to know how they were conceived. The Committee also agrees with the VLRC's view that the best way for donor-conceived people to find out about their origins is for their parents to tell them. The Committee does not agree, however, with the VLRC's recommendation that provisions that currently apply for donor access to identifying information about children conceived after 1988 should be removed. Nor does the Committee agree with the VLRC's position that the state should have no role in informing children that they are donor-conceived, except where a donor wishes to pass on information about a genetic disease to his or her donor-offspring.

Since 1988, recipient parents should have been aware that the donor of gametes for their child is entitled to seek their consent, or the consent of their child when she or he is aged 18 or older, for identifying information about the child. Consequently, recipient parents should have been aware since that time that their child may potentially learn of the manner of their conception independently of the parents. Despite this knowledge, and despite a tendency in counselling services to recommend recipient parents tell their children that they are donor-conceived, it appears only a minority of parents do so. A child conceived by donor gametes after 1988 and traumatised by unexpected contact from a donor is arguably not a victim of the donor's curiosity, but of their parents' inaction.

The Committee does not believe it would be fair, in this circumstance, to remove the rights of donors (which both donors and recipient parents

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[336] Ibid, p. 155.

[337] *Assisted Reproductive Treatment Act 2008* (Vic), section 153, which inserts a new section 17B into the *Births, Deaths and Marriages Act 1996* (Vic).

understood at the time of their treatment), simply for the purpose of ensuring that the state has no role informing donor-conceived people of their origins. The Committee notes that to the contrary, recent legislation has enhanced the role of the state in ensuring that donor-conceived people are aware of their origins.

4.3.7 The need to pass on medical information

4.3.7.1 The importance of passing on medical information

Donors may become aware some time after making their donation that they have a medical condition that can be passed on to offspring. In these situations, it may be critical that the offspring be advised that they may have, or may develop, a serious medical condition.

There is currently no requirement or mechanism in the *Assisted Reproductive Treatment Act 2008* for information about heritable genetic diseases or genetic abnormalities to be passed on to people who may be affected by this information. For example, if a donor informs BDM that he or she has learnt of or been diagnosed with a condition that may have a genetic link, BDM is neither required, nor able, to contact the people born as a result of the donation, or their parents.[338]

The importance of current medical information for donor-conceived people is not merely theoretical – the reality of its importance was demonstrated in evidence heard by the Committee. For example:

- Narelle Grech, a donor-conceived person, was diagnosed with stage IV bowel cancer in 2011, at 28 years of age. There is no history of cancer on the maternal side of her family, and it is believed that a person who is diagnosed with bowel cancer before the age of 30 has likely inherited it through their genes. Had Ms Grech known of a family history of cancer, it would have been possible to undertake testing at a younger age and potentially have diagnosed and treated the cancer at an earlier stage.[339]

- "Alex", a pre-1988 donor, recently discovered that his father had a potentially fatal hereditary disorder. Alex does not have the disorder, but is currently awaiting the results of tests to determine whether he could have passed it on to his offspring. If so, it would be imperative to advise his donor-offspring of the possibility that they have the disorder, as it can be treated relatively easily if diagnosed early.[340]

The Committee also heard evidence from Dr Penelope Foster, of the Fertility Society of Australia, who is also the director responsible for donor services at the Royal Women's Hospital, about a situation involving a pre-1988 donor with a serious medical condition. Case Study 3 (Chapter

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[338] Victorian Assisted Reproductive Treatment Authority, *Submission no. 76*, 12 August 2011, p. 6.

[339] Narelle Grech, *Submission no. 67*, 15 August 2011, p. 1.

[340] "Alex", *Transcript of evidence*, Melbourne, 5 December 2011, p. 3.

Three, page 54) describes how the Royal Women's Hospital dealt with that situation.

4.3.7.2 Mechanism to pass on medical information

The Committee considers that the issue of passing on medical information is distinct from the question of whether donors should be able to seek identifying information about their offspring. The Committee recognises the importance of informing donor-conceived people of possible serious medical conditions that may affect them, but considers that information of this nature should be conveyed to them independently of the donor.

The VLRC also discussed the issue of passing on medical information in its report on assisted reproductive technology and adoption. When the VLRC issued its report, the ITA was still responsible for managing the donor registers. The VLRC proposed that the only circumstance in which it should be possible for a donor to prompt the ITA to contact people conceived with their gametes would be where a donor becomes aware of a medical condition which may have been transmitted to the child. In these circumstances, the VLRC suggested, donors should be encouraged to provide the relevant information to the ITA to be passed on to the donor-conceived person. Likewise, any clinics becoming aware of relevant genetic information about a donor should inform the ITA.

The VLRC considered that the ITA should pass medical information on directly to the donor-conceived person, unless they are under the age of 18, in which case the ITA should inform their parents. The VLRC also suggested that the ITA should offer the donor-conceived person counselling about the significance of the information at the time of offering the information to the person.[341]

The Committee agrees with the VLRC's recommendations in this regard, and considers that the need for a donor-conceived person to be informed of important medical information outweighs the possible trauma of that person finding out that he or she is donor-conceived. In this regard, the Committee notes the importance of appropriate support and counselling being provided to the donor-conceived person and their family.

4.4 Proposals for change

4.4.1 Identifying information

After weighing all of the above considerations, the Committee concludes that donors should not have the right to seek identifying information about donor-offspring conceived prior to the commencement of the *Infertility (Medical Procedures) Act 1984*; that is, pre-1988 donors should not retrospectively gain a right to seek identifying information about their donor-offspring.

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[341] Victorian Law Reform Commission, *Assisted reproductive technology & adoption*, Final report, VLRC, Melbourne, 2007, p. 154.

The Committee understands, and is sympathetic to, the desire of donors to know the identity of their donor-offspring. However, the Committee's primary concern is to ensure to the greatest extent possible that the welfare and interests of the donor-conceived child is paramount, rather than the interests of the donor or the recipient parents.

While some donors may feel that knowledge of their donor-conceived children is important, the identity of a donor's offspring is not central to a donor's self-identity. The donor knows who his or her family is, and where he or she came from. While the donor may not have properly understood the consequences of his or her actions at the time of donating, the donor still made a decision to donate gametes, whereas the offspring had no choice in the matter.

The Committee accepts that some donors have a strong wish to know who their offspring are and would like to have the opportunity to meet them, but the Committee considers that the potential damage that could result from the donor initiating contact with a person conceived before 1988 outweighs other considerations. The Committee also recognises that few donors would wish their offspring to discover that they are donor-conceived in a negative way, and most would not want to exercise a right to seek identifying information about them.

Accordingly, the Committee considers that provisions in the *Assisted Reproductive Treatment Act 2008* allowing donors to seek identifying information about their offspring once the offspring reach 18 years of age should be retained, applying only to donors seeking information about children conceived from gametes donated after 1988.

Finding 10: Current provisions of the *Assisted Reproductive Treatment Act 2008* allowing donors to seek identifying information about children conceived from gametes donated after 1988 should not be extended retrospectively to allow donors to seek identifying information about children conceived from gametes donated prior to 1988.

The Committee considers that the legislation should retain the right for both recipient parents and donors of children conceived from gametes donated after 1988 to seek identifying information about each other through the central register. These donors and recipient parents are currently able to obtain identifying information about each other, subject to the other party providing their consent, and undergoing counselling.[342] The issue of counselling and support for these parties in making contact with each other will be discussed further in Chapter Six.

4.4.2 Non-identifying information

The Committee's view is that the current right of donors who provided gametes after 1988 to obtain non-identifying information about their donor-offspring should be retained. Donors should have the right to know

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[342] *Assisted Reproductive Treatment Act 2008* (Vic), sections 56 & 58.

how many donor-offspring have been conceived from their donations, their sex, and their year of birth. This is consistent with the NHMRC's ethical guidelines, which provide that:

> Gamete donors are entitled to some information about the recipients of their gametes and the offspring born (in particular, to prepare them for future approaches by their genetic offspring). Clinics may provide gamete donors, on request, with nonidentifying information about gamete recipients, including the number and sex of persons born.[343]

The Committee notes that although clinics currently provide donors who provided gametes before 1988 with basic non-identifying information about their donor-offspring, donors do not possess this right under legislation. As with non-identifying information about donors, discussed at Recommendation 7, there are unlikely to be any legal barriers to providing all donors with access to non-identifying information held by agencies and organisations that hold information on donor-conception. Similarly, the Committee recommends that the Victorian Government encourage all agencies and organisations that currently hold information on donor-conception to release non-identifying information about a donor-conceived offspring, on request, to his or her donor. Over time, as the Committee suggested in Recommendation 7, it would be preferable for donors to have rights to access non-identifying information articulated in legislation.

Recommendation 8: That the Victorian Government encourage organisations, agencies and persons holding information on donor-conception to release to a donor, upon request, non-identifying information about his or her donor-conceived offspring.

4.4.3 Passing on medical information

The Committee believes that donors should be encouraged, but not compelled, to pass on important medical information that may affect their donor-offspring. Currently no parent is compelled to disclose medical information to their offspring, and consequently the Committee believes voluntary disclosure is consistent with existing practice. The Committee recommends that this information should be passed on to the donor-conceived person independently of the donor. Ideally, VARTA should perform this role, in a similar manner to the way in which the ITA previously initiated contact with donor-offspring.

Contact for the purpose of passing on medical information should only be initiated when that information pertains to a significant potential genetic or hereditary risk to the donor-conceived person. As VARTA, or a comparable agency, may not possess expertise assessing risk in these cases, the Committee suggests that a body with appropriate expertise be engaged to

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[343] 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, pp. 29, para. 6.12.

determine the medical case for initiating contact. The Committee suggests that the Patient Review Panel could be responsible for this function, and that, if required, the Panel be empowered to draw upon independent analysis when making decisions on these matters. Alternatively, another appropriate body with relevant expertise regarding hereditary medical conditions could be established to perform this function.

Recommendation 9: That the Victorian Government introduce a mechanism for medical information from a donor to be provided to a donor-conceived person, where there is evidence of hereditary or genetic disease or risks to the health of the donor-conceived person.

Table 8: Donor-conceived persons' access to information about donor siblings under current legislation (from 1 January 2010) and preceding legislation (before 1 January 2010).

Time period	Avenue to seek information	Information that can be obtained
Before 1 January 2010	**Infertility Treatment Authority**	Previously, a donor-conceived person could obtain **non-identifying information** about donor-conceived siblings – their sex, and their year and month of birth.
	Voluntary register	If a person conceived from the same donor's gametes (a half-sibling) was registered on the voluntary register, the donor-conceived person could obtain **non-identifying and/or identifying information** from the voluntary register, in accordance with the half-sibling's wishes.
		However, the half-sibling must have been aware that they are donor-conceived, aware of the existence of the voluntary register, and have registered, for this to be an option.
1 January 2010 to present	**Voluntary register**	Currently, the voluntary register is the only avenue for a donor-conceived person to seek information about their donor siblings.
		If a person conceived from the same donor's gametes (a half-sibling) is registered on the voluntary register, the donor-conceived person can obtain **non-identifying and/or identifying information** from the voluntary register, in accordance with the half-sibling's wishes.
		However, the half-sibling must be aware that they are donor-conceived, be aware of the existence of the voluntary register, and have registered, for this to be an option.

Chapter
5

Chapter Five: Access to information about donor-conceived siblings

Many donor-conceived people will have a number of half-siblings who were conceived from the same donor's gametes. Because of the limited numbers of gamete donors, it has been, and remains, usual practice for gametes from the same donor to be used to assist a number of women to conceive. Until the introduction of the *Assisted Reproductive Treatment Act 2008* on 1 January 2010, there was no legislated limit on the number of women who could receive fertility treatment using the same donor's gametes, and no limit on the number of children who could be conceived. The *Assisted Reproductive Treatment Act 2008* limits the use of one donor's gametes to producing ten families.[344]

The Committee heard that in some cases, a single donor may have assisted the conception of a considerable number of children. According to Ms Helen Kane, former Manager of the Donor Registers Service previously operated by the Infertility Treatment Authority (ITA), for example, donor records show that in some cases there may be as many as 30 half-siblings conceived from one donor.[345]

Donor-conceived people currently have a limited ability to access information about their donor-conceived siblings, or their donor's other children. This is a cause of concern and distress for some donor-conceived people, who worry that they may inadvertently form a relationship with a person who is their half-sibling. Some donor-conceived people also feel a sense of loss that they have close biological relatives whose identities they may never know.

5.1 Current rights of access to information

Donor-conceived people, except for those who were conceived prior to 1988, are entitled to some non-identifying information about their donors. However, there is no such entitlement for donor-conceived people to

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[344] The *Assisted Reproductive Treatment Act 2008* (Vic) restricts the use of donor gametes to produce ten families. Section 29(1) provides that: "A person must not carry out a treatment procedure using gametes, or an embryo formed from gametes, produced by a donor if the person knows the treatment procedure may result in more than 10 women having children who are genetic siblings, including the donor and any current or former partner of the donor". The penalty for a breach of this section is 240 penalty units or 2 years imprisonment or both.

[345] Helen Kane, *Submission no. 46*, 9 August 2011, p. 2.

information regarding half-siblings who were conceived using the same donor's gametes, and who will be close biological relatives.

Currently, the only process by which a donor-conceived person can seek to access any information about, or seek to make contact with, their donor-conceived siblings is by applying to the voluntary register held by the Registry of Births, Deaths and Marriages (BDM).

5.1.1 Voluntary register

As explained in Chapter Three, the voluntary register provides a mechanism for anyone associated with a donor-conception – including all donor-conceived people – to voluntarily register non-identifying and identifying information about themselves, and to provide instructions as to what information can be accessed by connected parties.[346] The person lodging the application chooses what non-identifying information to record, which may include details such as physical characteristics, interests, occupation and family information.[347]

If a donor-conceived person applies to the voluntary register, and a half-sibling is also registered, the register will automatically recognise a match based on both parties having the same donor code. A BDM officer will then contact each of the matched parties to inform them that there has been a match, and to confirm their instructions in relation to the release of their information to the other party.[348] Information on the voluntary register can only be released in accordance with the wishes of the person who registered the information.[349]

There is no fee to lodge an application to the voluntary register. As at 21 October 2011, there were only 62 donor-conceived persons recorded on the voluntary register, 49 of whom were conceived from gametes donated prior to 1988.[350] As noted in Chapter One, there are likely thousands of donor-conceived people who were conceived in Victoria from gametes donated prior to 1988.

5.1.2 Clinics

Melbourne IVF and Monash IVF have both received requests for assistance from pre-1988 donor-conceived people who wished to find out who their donor-conceived siblings are. Neither clinic will contact siblings, however, because many donor-conceived people from this time period would not be aware that they are donor-conceived.[351] Unless there is a

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[346] *Assisted Reproductive Treatment Act 2008* (Vic), sections 71 & 72.

[347] See Births Deaths and Marriages Victoria, 'Voluntary register application', viewed 2 December 2011, <http://online.justice.vic.gov.au>.

[348] Erin Keleher, Manager of Strategic Projects, Registry of Births, Deaths and Marriages, *Transcript of evidence*, Melbourne, 21 November 2011, p. 25.

[349] *Assisted Reproductive Treatment Act 2008* (Vic), section 72.

[350] Births Deaths and Marriages Victoria, *Supplementary evidence*, 21 November 2011, p. 3.

[351] Marianne Tome, Victorian Infertility Counsellors Group, *Transcript of evidence*, Melbourne, 12 September 2011, p. 30.

medical reason to contact a sibling, a clinic will refer the donor-conceived person to the voluntary register as the means by which contact with siblings could potentially be made.[352]

Melbourne IVF indicated that they would inform the person seeking information of the year of birth and the sex of donor-siblings, but would not provide other details.[353] Melbourne IVF indicated that it complies with the National Health and Medical Research Council's *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research* (Ethical Guidelines), which provide that a clinic should only release identifying information about a sibling if the sibling has registered their consent:

> When a clinic is approached by a person who was conceived using donated gametes and who now seeks identifying information about his or her genetic siblings or half-siblings, it should check its register of consent for the release of such information … and proceed as follows:
>
> - If consent has been registered by the siblings concerned, the information may be released.
>
> - If consent has not been registered, clinics should not release identifying information or contact the siblings.[354]

The Ethical Guidelines are silent on the question of releasing non-identifying information about donor-conceived siblings.

5.2 Proposed changes

5.2.1 Non-identifying information

5.2.1.1 Concerns about forming relationships with siblings

A significant issue for some donor-conceived people is the concern that they may unknowingly form a romantic relationship with a half-sibling. Although this may seem unlikely to occur, the possibility is a real fear for many donor-conceived people:

> … it has been argued that the threat arising from consanguinity risks poses the greater challenge to the emotional and social wellbeing of some donor-conceived individuals. Crashaw describes how some donor-conceived individuals question "whether their attraction to someone may be 'genetic sexual attraction', and that an otherwise innocent statement such as 'you look just like so-and-so' carries a very different significance to those

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[352] Ibid.

[353] Rachael Varady, Donor Program Manager, Melbourne IVF, *Transcript of evidence*, Melbourne, 10 October 2011, pp. 20-21.

[354] 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, p. 30, para. 6.13.2.

> personally affected by donor conception". She makes the point that "the living experience with regard to consanguinity does not necessarily reflect the statistical risk".[355]

In her overview of issues surrounding donor-conception, Dr Sonia Allan noted that many donors in prior decades had donated multiple times, sometimes at more than one clinic, so that in some cases there may be up to 30 half-siblings related to one donor. Dr Allan suggested that the risk of forming a consanguineous relationship in this context cannot simply be dismissed.[356]

Even if it is unlikely that two siblings would enter into a romantic relationship, given the numbers of donor-conceived people, there are many studies that demonstrate people's inclination to misapprehend risk.[357] Although the statistical chances of donor-conceived siblings entering into romantic relationships are not great, a donor-conceived person's perception of risk may have a real and significant effect on his or her ability to form intimate relationships with others.

The Committee heard that the provision of non-identifying information about siblings, such as birth month, year, and sex, could provide donor-conceived people with a means to assure themselves that a potential partner is not a sibling.

5.2.1.2 Release of non-identifying information to donor-conceived people

Ms Helen Kane, former Manager of the ITA's Donor Registers Service, explained that the ITA previously provided non-identifying information about half-siblings to donor-conceived people, and that this was a simple way of allaying their concerns:

> Once again, one of the crucial things with the consanguinity problem is that what we routinely gave all donor-conceived people was a list of siblings by gender, by month and year of birth, because it meant they could eliminate the people within their own network because there are issues, that fear, that: how could I know I wasn't marrying my brother? It doesn't identify anybody but in fact you know that if your new boyfriend was born in that month you might just ask him a few questions and if he wasn't, you don't have to worry. In fact, it's a very simple, simple thing. … I think that has consequences for the donor-conceived person because the fear is real. When fresh sperm was used, that meant lots of women had lots of pregnancies at the same time so that meant that you actually have, are

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[355] Sonia Allan, 'Psycho-social, ethical and legal arguments for and against the retrospective release of information about donors to donor-conceived individuals in Australia', *Journal of Law and Medicine*, vol. 19, pp. 354-376, 2011, p. 360.

[356] See Sonia Allan, *Submission no. 5*, 2 August 2010, p. 12.

[357] Paul Slovic (ed.) *The perception of risk: risk, society and policy series*, Earthscan Publications, London, 2000.

> likely to have, a group of children all conceived within weeks of each other in the same geographical area.[358]

Ms Kane and others pointed out that one of the effects of the changes introduced by the *Assisted Reproductive Treatment Act 2008* and the transfer of the donor registers to BDM is that information about half-siblings is no longer available to donor-conceived people. Currently, BDM is not even able to inform donor-conceived people of the number of donor-conceived siblings they have.[359]

The Committee believes that this is not an acceptable situation. Donor-conceived people must be able to have access to basic, non-identifying information about their donor-conceived siblings on request, including:

- the number of donor-conceived siblings;
- their sex; and
- their year and month of birth.

The provision of non-identifying information would provide a means by which donor-conceived people could obtain some general information about the context of their conception, and importantly, provide a means by which donor-conceived people could assure themselves that they were not entering into intimate relationships with their half-siblings. The release of non-identifying information would be extremely unlikely to do any harm to half-siblings, but may substantially improve at least one aspect of a donor-conceived person's life.

Non-identifying information about donor-conceived siblings should be compiled by the agency that manages information about donor-conception in Victoria. This information should be released to a donor-conceived person upon their request. The Committee also believes that there should be no age restriction on the acquisition of non-identifying information about half-siblings by donor-conceived people, similar to the Committee's position in Recommendation 7, that non-identifying information about donors be made available to all donor-conceived people.

If the Committee's recommendations in Chapter Six are implemented, VARTA would be the appropriate agency to provide this information to donor-conceived people.

Recommendation 10: That the agency managing the donor registers be empowered to release to a donor-conceived person, upon request, non-identifying information about his or her donor-conceived siblings.

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[358] Helen Kane, *Transcript of evidence*, Melbourne, 12 September 2011, p. 20. See also Victorian Assisted Reproductive Treatment Authority, *Submission no. 19*, 6 August 2010, p. 6.

[359] Helen Kane, *Transcript of evidence*, Melbourne, 12 September 2011, p. 13.

5.2.1.3 Release of non-identifying information to parents

In Chapter Three, the Committee recommended that non-identifying information about donors should also be released to the parents of a donor-conceived person on request. The Committee suggested that this information may assist parents when they contemplate sharing information about their child's conception. Given the concern expressed by some donor-conceived people about the risks of forming consanguineous relationships, the Committee also believes that parents may be assisted in discussing donor-conception with their children if they have access to information about their child's half-siblings.

Recommendation 11: That the agency managing the donor registers be empowered to release to the parents of a donor-conceived person, upon request, non-identifying information about that person's donor-conceived siblings.

5.2.2 Identifying information

In addition to being concerned about the possibility of forming a consanguineous relationship, people who are aware that they are donor-conceived may also feel a sense of loss at not knowing, and not having an opportunity to form relationships with, their donor-conceived siblings. For example, Ms Narelle Grech, a pre-1988 donor-conceived person, is aware that she has donor-conceived siblings and considers them to be family:

> With regards to my eight half siblings, there are three girls that were born the same year as me. … Three boys born the year following and two girls born in 1985. I consider them to be my family, and I feel a loss for not being able to know who they are.[360]

Ms Grech told the Committee that she often wonders about her donor-conceived siblings, and believes that she should have the right to know them:

> 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? Recently, with the wonder of Facebook, I was pointed to a friend of a friend whom they said reminded them of me. To anyone else they might laugh and go along their day. For me it meant looking at this person's profile and analysing everything about them. Looking for physical similarities and comparing interests, ages and so on. I think there might be something in this link, but what am I to do? Do I approach this person and potentially open up a Pandora's box for them? Don't they deserve to know the truth

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[360] Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, p. 35.

> about their own identity if they are DC? And what about me? Shouldn't I be able to know my own siblings?[361]

The Committee understands the desire of donor-conceived people to know who their half-siblings are, and empathises with Ms Grech and others.

The Committee also notes, however, that if donor-conceived people were allowed to seek identifying information about their half-siblings, many would be reluctant to initiate contact with them. For example, Ms Myfanwy Cummerford, a pre-1988 donor-conceived person, indicated to the Committee that although she would like to know who her half-siblings are, if she did have the right to identifying information about her half-siblings, she may choose not to exercise that right:

> I don't think it's going to be possible, to be honest, but I would like to know who my half-sisters are. Honestly, I couldn't say that if I got that information whether I would make the approach. I think I would rather it came from them, but I would like the ability to know who they are.[362]

While the Committee understands the desire of some donor-conceived people to know the identity of, and potentially develop relationships with, their half-siblings, the Committee does not consider that it is appropriate to allow donor-conceived people to seek access to identifying information about their half-siblings. The Committee has similar concerns to those discussed in Chapter Four, in relation to whether pre-1988 donors should be able to seek identifying information about their donor-offspring. Allowing donor-conceived people to seek identifying information about their donor-conceived siblings could cause trauma to those siblings who are unaware that they are donor-conceived, and consequently cause significant disruption to their family relationships.

The Committee agrees with Dr Sonia Allan's suggestion that the primary focus should be on allowing donor-conceived people access to information about their donor, particularly given the central importance of identifying information about the donor to the donor-conceived person's self-identity:

> … the first issue is where a donor-conceived individual knows that they're donor-conceived and they want information about their genetic parent, and I think that's definitely the first point that needs to be addressed.
>
> It is a slightly different issue to say that they also want information or to be able to exchange the information with their siblings, I don't know whether that would be possible at the forefront because … there are so many donor-conceived people who don't know that they are donor-conceived so it would be very difficult to have that information and contact them without them knowing that they were donor-conceived. I suppose the focus should

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[361] Narelle Grace Grech, *Submission no. 18*, 6 August 2010, pp. 3-4.
[362] Myfanwy Cummerford, *Transcript of evidence*, Melbourne, 17 October 2011, pp. 40-41.

> be, at least primarily, on the donor-conceived individual knowing the donor or information about their donor.[363]

In Chapter Three, the Committee argued that providing the right for a donor-conceived person to access identifying information about their donor ensures that the interests and welfare of the child are treated as paramount, in accordance with current legislation. By contrast, providing donor-conceived people with the right to access identifying information about their siblings would potentially privilege the interests and welfare of one child over another. Consequently, the Committee does not believe that donor-conceived people should be provided with identifying information about their siblings.

Recommendation 12: That the voluntary register remain the only means for donor-conceived people to seek identifying information about their donor-conceived siblings.

As discussed in Chapter Three, the Committee anticipates that if its recommendations to allow donor-conceived people to access identifying information about their donors are implemented, parents who have not told their children about the circumstances of their conception will be encouraged and supported to do so, with the result that more donor-conceived siblings will be able to connect with each other through the voluntary register (or indeed, possibly through contact with their donor).

If a match is made between siblings through the voluntary register, however, the parties should have access to support and intermediary services to assist them in negotiating their new relationship, as Professor Ken Daniels suggested:

> I do believe … that such information sharing and contact [between donor-conceived siblings] needs to be facilitated by trained and experienced professionals, again social workers or counsellors. Such facilitation would include working with the significant networks in the offspring's lives e.g. parents, siblings and grandparents. This is a process I have been involved in in New Zealand and linking of this kind has led to very positive and helpful and positive relationships being established. It also potentially provides for a supportive environment in which contact occurs.[364]

The support and counselling needs of all donor-conception stakeholders is discussed in more detail in Chapter Six, together with the Committee's recommendations on this issue.

5.2.3 Passing on medical information

As discussed in Chapter Four, situations may arise where it is necessary for important medical information about a donor to be passed on to his or her donor-conceived offspring. Often the existence of a genetic or heritable

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[363] Sonia Allan, *Transcript of evidence*, Melbourne, 21 November 2011, p. 3.
[364] Ken Daniels, *Submission no. 75*, 9 September 2011, p. 2.

medical condition will become apparent as the donor ages. The Committee recommended that a mechanism be introduced through which information about significant heritable medical conditions could be provided to donor-conceived people.

However, the Committee also recognises that there may be situations in which medical information about a hereditary condition that a donor-conceived person has identified should be passed on to his or her donor-conceived siblings (and potentially to the donor) at the initiation of the donor-conceived person. This may be the case where, for example, the donor has not provided the information because they are deceased, because the condition has not manifested in the donor, or because their records no longer exist and they are unaware that they have donor-conceived offspring.

The Committee considers that the same principles that it has recommended apply to donors should also apply in regard to donor-conceived people providing notification of medical information.

Recommendation 13: That the Victorian Government introduce a mechanism for medical information from a donor-conceived person to be provided to that person’s donor-conceived siblings where there is evidence of hereditary or genetic disease or risks to the health of the donor-conceived person.

Chapter

6

Chapter Six: Counselling and support services

A recurrent theme raised in submissions and evidence received by the Committee was the importance of counselling and support services for donor-conception stakeholders – donor-conceived people, donors, recipient parents, and their families. These services are particularly critical when stakeholders are thinking about seeking contact with each other for the first time, and in the early stages of developing relationships with each other.

The Committee heard multiple concerns expressed about the limited services currently available, and their fragmented delivery. Many submissions and witnesses recommended returning to a model like the one that existed when the Infertility Treatment Authority (ITA) was responsible for managing the donor registers and for providing all related services.

In this Chapter, the Committee reviews the counselling and support arrangements that existed when the ITA was responsible for providing these services (prior to the introduction of the *Assisted Reproductive Treatment Act 2008*), describes services currently available, and points out the shortcomings of current arrangements. The Committee then makes recommendations on services that should be offered, and suggests how these could best be provided.

6.1 Donor-conception stakeholder services before 2010

The ITA was established by the *Infertility Treatment Act 1995*, and commenced operations in 1998.[365] Professor Louis Waller, who had previously chaired the Victorian Government's Committee on the Social, Ethical and Legal Issues arising from IVF in the early 1980s, and was Chair of the Standing Review Advisory Committee on Infertility, was the first Chairperson of the ITA.[366]

Statutory responsibilities of the ITA included compiling and keeping records relating to donor-conception, and administering access to those records – that is, managing the central and voluntary registers – as well as

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[365] *Infertility Treatment Act 1995* (Vic), Part 9.
[366] Infertility Treatment Authority, *Annual report 1999*, ITA, Melbourne, 1999, p. 8.

performing a regulatory role in regard to licences and approvals under the *Infertility Treatment Act 1995*.[367]

The ITA provided services related to managing the registers, including undertaking donor-linking and providing ongoing counselling for those seeking information about their donor or donor-conceived offspring. The ITA also provided a letterbox service, acting as an intermediary to allow donor-conceived persons, donors and recipient parents to discreetly communicate before they were ready to reveal identifying information to one another, or meet. The ITA also engaged in communications and public relations regarding its work and assisted reproduction.[368]

The ITA operated from 1 January 1998 until it became the Victorian Assisted Reproductive Treatment Authority (VARTA) on 1 January 2010. At that time, staff and members of the ITA were transferred to VARTA, and the functions of the authority changed to have a much greater focus on public education.[369]

6.1.1 Management of the donor registers

The *Infertility (Medical Procedures) Act 1984* came into effect in 1988, and applied to all children conceived from gametes donated after this date. The first of these children, born in 1988, would have become legal adults in 2006. The *Infertility (Medical Procedures) Act 1984* provided that when these children became legal adults, they would be able to apply for and obtain identifying information about their donor if their donor consented to the release of information, and likewise, their donor would be able to seek identifying information about them.[370]

In 2005, the ITA employed a counsellor, and created the Donor Registers Service.[371] The central register and the voluntary register had been administered by the ITA for several years prior to 2005, but the role of the ITA in service provision had been fairly basic, with private counsellors used to perform the counselling requirements of the *Infertility Treatment Act 1995*.[372] A more comprehensive system was introduced in anticipation of increased requests for information that the ITA was likely to receive from 2006 onwards, when the first children born under the *Infertility (Medical Procedures) Act 1984* reached adulthood.

Ms Helen Kane, who was employed as a counsellor by the ITA, told the Committee that the Donor Registers Service established by the ITA was modelled on information access systems used in adoption:

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[367] *Infertility Treatment Act 1995* (Vic), section 122.
[368] Infertility Treatment Authority, *Annual report 1999*, ITA, Melbourne, 1999, p. 16.
[369] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 36.
[370] *Infertility (Medical Procedures) Act 1984* (Vic), section 22; *Infertility (Medical Procedures) Regulations 1988* (Vic), reg. 12 and section 8.
[371] Helen Kane, *Submission no. 46*, 9 August 2011, pp. 2-3.
[372] Ibid, p. 3.

> We proceeded to set up a Service which reflected my experience of working with access to information in adoption, and the sound practice model in place in that field at that time, i.e. an interview with the applicant, the release of information, the discussion of options and wishes, and assistance in acting on these, with the provision of counselling and support to whoever was affected by this. This included the adult adopted person, the parents when requested, the birth family, and siblings. The non-identifying exchange of information … was an essential part of that service. It meant that people could take gentle steps forward, according to comfort, and make their own decisions in the process.[373]

The ITA employed two donor-linking counsellors, one at 0.8 full-time equivalent (FTE) and one at 0.4 FTE.[374] A Donor Registers Officer was also employed at 0.4 FTE.[375]

The role of the Donor Registers Officer included maintaining the registers and associated information relating to births occurring as a result of the use of donor gametes, responding to information enquiries about the registers, and releasing information to donors, recipient parents and donor-conceived people in accordance with the legislation.[376] The role of the counsellors is detailed below.

6.1.2 Counselling and donor-linking

Donor-linking counsellors at the ITA's Donor Registers Service offered counselling to all donor-conception stakeholders – donor-conceived people, recipient parents, and donors. The ITA built up extensive experience in linking donor-conceived people with their donors. From 2006 to 2009, the ITA undertook 43 'outreaches' (that is, contacting donors as an intermediary) following applications to the central register by recipient parents or young donor-conceived adults seeking information about their donors.[377] Many of the donors who were contacted had provided gametes under the *Infertility (Medical Procedures) Act 1984* (that is, they had consented to the use of their gametes between 1988 and 1997), and had been told that identifying information about them would not be released without their consent. The ITA also performed a small number of outreaches to donor-conceived people, through their parents, at the request of donors.

The Committee heard that donor outreaches made by the ITA were successful in most cases:

> In all but a very few cases the donor agreed to release information to the applicants. This usually resulted in the exchange of letters forwarded to

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[373] Ibid.

[374] Kate Bourne, *Submission no. 35*, 11 August 2010, p. 7; Kate Bourne, Senior Community Education Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 41.

[375] Helen Kane, *Transcript of evidence*, Melbourne, 12 September 2011, p. 18.

[376] Kate Dobby, *Submission no. 33*, 10 August 2010, p. 1.

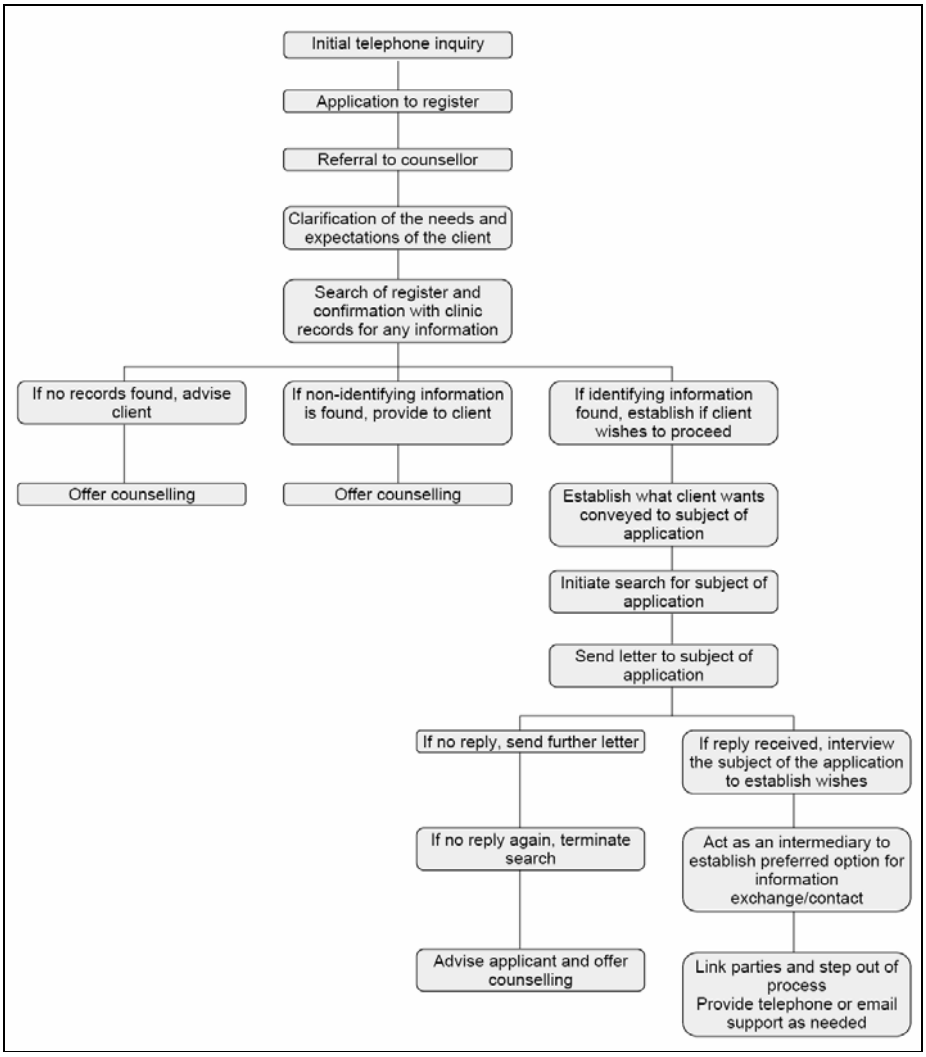
[377] Victorian Assisted Reproductive Treatment Authority, *Submission no. 19*, 6 August 2010, pp. 5-6.

> each party using the Authority as an intermediary to protect privacy. In time some chose to exchange identifying details and correspond directly, and some later met in person. We found that while donors might have had some initial reservations about being contacted, with sensitive counselling and discussion these were usually able to be resolved.[378]

6.1.2.1 Donor-linking procedures used by the ITA

The procedure that the ITA followed upon receiving an inquiry is outlined in the flow chart below (Figure 4).

Figure 4: ITA process on receiving an inquiry from a donor-conception stakeholder about the donor registers[379]



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[378] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 39.

[379] Based on a diagram used in a presentation by Louise Johnson, Paper presented at the *Donor-Linking Symposium*, Melbourne, 2011.

When an application for identifying information was made to the central register, the ITA was required to locate and contact the person whose information was being sought (generally a donor, but potentially also a donor-conceived person or their parents), in order to seek their consent to release identifying information.[380] The ITA was able to obtain approved access to the confidential Victorian register of electors, which contains dates of birth and therefore provided some assurance that the correct person was contacted, and so sought to ensure protection of their privacy.[381]

When the correct person had been located, a donor-linking counsellor would send a letter to the person by registered mail, explaining why they were being contacted, and explaining the motivation of the person seeking contact. The letter would also inform the person that the counsellor was available, and invite the person to make contact with the ITA to discuss the matter further. An example of the type of letter that the ITA would send is provided in Figure 5 below.

Most of the outreaches made by the ITA were to donors, following an application for information by a donor-conceived person or a recipient parent (see Appendix Four, Table 1). Before making contact with the donor, the counsellor would discuss the needs and expectations of the person seeking information, and would prepare information to convey to the donor. This included the person’s reasons for requesting information, personal non-identifying information about themselves that they wished to share, and short and long term hopes in relation to information exchange. The person also prepared a list of questions for the counsellor, which the counsellor used in discussion with the donor in the event that he was reluctant to give consent, but was prepared to provide specific non-identifying information. This procedure allowed the donor to obtain an appreciation of the motivations behind the request for information, and provided sufficient information for him or her to contemplate how to respond. The counsellor also offered a letterbox service if the donor was not comfortable providing identifying details immediately, but was open to commencing a dialogue with the other party.

The ITA was not able to directly contact pre-1988 donors unless they were on the voluntary register – to do so would have been a breach of privacy, as there was no legal basis for the ITA to access their records. Such records, if they existed, were held by the doctor or clinic that treated the donor-conceived person’s mother, or in the case of Prince Henry’s Hospital records, by the Public Record Office Victoria (PROV). If approached by a person who was conceived with gametes donated before 1988, the ITA would provide counselling to that person, and could assist them to approach the treating doctor.

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[380] Infertility Treatment Authority, *Annual report 2008*, ITA, Melbourne, 2008, p. 20. This was the case for all applications made pursuant to the *Infertility (Medical Procedures) Act 1984* (Vic), which requires consent for the release of identifying information.

[381] Kate Dobby, *Submission no. 33*, 10 August 2010, p. 3.

Figure 5: Sample letter to a donor as a result of an application to the central register by donor-conceived sisters, under the *Infertility (Medical Procedures) Act 1984*[382]

Our Ref:

Date

x

Dear **x**

I am writing to you in relation to a request for information which has been made to the Infertility Treatment Authority by a young woman and her twin sister **(appropriate details inserted)** who were conceived at Prince Henry's Institute of Medical Research, with the use of donated sperm.

The Infertility Treatment Authority is responsible for the management of the information registers which relate to donor conception in Victoria, and you will find enclosed detailed information about this. When a birth is recorded at the clinic concerned, we are provided with information about both the parents and donor, and this is entered on the relevant Central Register. As a result, we have an entry on the 1984 Central register which lists you as the donor concerned with the conception of these young women who were born in **(insert date).**

People who are conceived as a result of sperm donation are able to make application for information about the donor, and this is what has occurred. In this instance, the young women are interested in more information about you including medical and family history. They do not want to meet you or to have direct contact with you. They are grateful for your generous gift and want to thank you. **(Wishes of applicants provided in letter, letters tailored to situation)**

Your privacy is very important to us, and I have enclosed our Privacy Statement for your information. Because of our responsibilities under the legislation to seek consent around release of identifying information, we have been given special access to the Victorian Electoral Rolls, and we have located you through that. No other organisation or person has been involved it our attempt to locate you, and so your privacy has been protected.

No doubt this enquiry comes as a surprise to you. There are choices available to you, and no obligation to agree to the request. Please give me a call, on 8601 5250, so that we can discuss the situation, and your wishes in relation to it. I can also be contacted by email on **(details provided)**. Please note, that I am available **(details provided).**

Yours sincerely

Y
Donor Linking Counsellor
Enc

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[382] Letter provided to the Committee by Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Personal communication*, 16 September 2011.

During the period in which the ITA was responsible for managing the donor registers, 62 contacts were made between parties on the voluntary register.[383] The ITA also facilitated more than 43 applications to the central register for identifying information.[384]

6.1.2.2 The importance of counselling during donor-linking

Former employees of the ITA told the Committee that the availability of counselling was critical to successfully linking parties involved in donor-conception.[385] VARTA also described the important role that counselling and mediation played in connecting donor-conceived people or recipient parents with the donor:

> 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 for meeting them. All parties 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 or advice before committing themselves to making an application.
>
> Risks can be mitigated if counselling is provided for applicants and donors … Counselling could provide an opportunity to explore the implications and potential outcomes of proceeding with an application/providing consent and the motivations and expectations of each person. Counselling could also outline different options for information exchange or contact between parties, setting boundaries and clear communication.[386]

VARTA noted that counselling was usually able to alleviate a donor's concerns about being contacted by their donor-offspring:

> While some donors may have had some initial reservations about being contacted, with sensitive counselling in which the counsellor relayed the motivations, and the short- and long-term aims of the applicant and discussed the concerns of the donor and their family, these were usually able to be resolved.[387]

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[383] Victorian Assisted Reproductive Treatment Authority, *Annual report 2010*, VARTA, Melbourne, 2010, p. 21.

[384] See Appendix Four. Data is only available from 1 January 2007 – it is unknown how many applications for identifying information were received by the ITA prior to this.

[385] Kate Bourne, Senior Community Education Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 41; Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 39; Helen Kane, *Transcript of evidence*, Melbourne, 12 September 2011, p. 18.

[386] Victorian Assisted Reproductive Treatment Authority, *Submission no. 19*, 6 August 2010, p. 6.

[387] Ibid.

The Committee heard that donor-linking counselling provided by the ITA was highly valued by those who received it. In evidence before the Committee, Mr Roger Clarke, a donor, spoke highly of counselling provided by the ITA before he met Riley, who was conceived from his gametes and wanted to meet him. Mr Clarke was reassured by the counselling and support offered by the ITA, and has since developed a close relationship with Riley. Mr Clarke's story is set out below (Case Study 4).

Case Study 4: Roger and Riley[388]

"Back in the 1980s, I was a sperm donor at Prince Henry's Hospital in St Kilda Road, at their Andrology Unit there, and I participated for a number of years there and of course went into the program with full anonymity, and that was understood. However, at the time you had to complete a form of about six pages that was headed: non-identifying information. … The last question on that form … simply said: would you be prepared at any stage to meet your offspring? You could tick the box yes or no, and I had no hesitation whatsoever in ticking the yes box. Yes, I would be quite happy to meet any offspring that might come about.

… We need to fast forward 19 years and I had a call from VARTA [the ITA] that an application had been made by one of my offspring, and would I be prepared to meet him? … I went through the process that VARTA had adopted to allow the parties to engage, and this was very, very sensitively done. It was a program where counselling was offered, I had a very long counselling session with one of the counsellors at VARTA, explored my motives. I suppose the bottom line was they were prepared to erect a safety net in case this newly created relationship might fail, and that offered me some reassurance."

6.1.2.3 Other counselling provided by the ITA

The ITA also offered other counselling services to donor-conception stakeholders. For example, the ITA made counselling available to people who were contemplating making an application to the donor registers. The ITA counsellors were able to offer insight and support by drawing on their experience with previous linkages.[389]

The Donor Registers Service was also able to provide specialised counselling, support and referral for people for whom there were no records, or incomplete records, including pre-1988 donor-conceived people.[390]

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[388] Roger Clarke, *Transcript of evidence*, Melbourne, 17 October 2011, pp. 59-61.

[389] Kate Bourne, Senior Community Education Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 41.

[390] Kate Dobby, *Submission no. 33*, 10 August 2010, p. 3.

6.1.3 The ITA letterbox service

A key component of the range of services offered by the ITA was the letterbox service. This provided an effective intermediary step in the donor-linking process to allow donor-conception stakeholders to develop a connection with one another at a gradual pace and to determine whether they wanted to have further contact. Ms Kate Bourne explained how the letterbox service worked:

> It [was] a beautifully simple system. Often people would not want to release identifying information straight off – either the donor-conceived person or the donor. Both of them were quite nervous and apprehensive when they did not know the other person. Often it was very useful to be able to offer them a secure way of passing on information privately to the other person in a way that did not reveal those details. They could put whatever they liked [in their letters]; we did not read them. It was still private; we did not vet them. If they had wanted it, it was a secure way of passing [on] photos or letters. In the course of time, perhaps once they had exchanged letters, they might then include a mobile phone number or their full name and contact details.[391]

The letterbox service was used not only by donor-conceived people wishing to make contact with their donors, but also by recipient parents wanting to make contact with the donor and with other families who had used the same gamete donor.[392] An example of the value placed on the letterbox service by those who have used it, and the benefits that it provided, is provided in Case Study 5 below.

Case Study 5: Letterbox service.[393]

"When my daughter was two I decided I wanted to write to her donor to thank him and ask some questions. I was not after identifying information as I felt that was my daughter's decision to make when she is mature enough. I was able to make contact through the Infertility Treatment Authority and the process took about a year. I sent my letter by registered post to ITA to forward to the donor, and received a lovely handwritten letter back answering all my questions. … When I decided to contact my daughter's donor the entire process was organised through ITA – a one-stop shop. …

Approximately 40 families used the letterbox arrangements provided by ITA and it took the ITA about five minutes per week to forward them. … I think ITA was providing an excellent service and it was completely unnecessary to fragment these roles."

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[391] Kate Bourne, Senior Community Education Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 42.

[392] See, for example, Shelley Sandow, *Submission no. 7*, 3 August 2010.

[393] Name withheld, *Submission no. 29*, 9 August 2010, attachment entitled 'Letterbox arrangements associated with donor registers'.

6.1.4 Education and public campaigns

As 2006 approached, the first of the children born under provisions of the *Infertility (Medical Procedures) Act 1984* were about to become legal adults. The ITA saw a need for more resources and support to be offered to encourage and assist parents to tell their children of their donor-conception origins.

The ITA conducted qualitative research, involving interviews with parents, donor-conceived young adults and counsellors, and used this research to inform a three-year *Time to Tell* public information and education campaign to provide information and support for family members affected by donor-conception.[394] This research, and the campaign that followed, were intended to inform practice as donor-conceived people, their parents, and donors began to seek information about each other. The public information and education campaign dovetailed with the commencement of the Donor Registers Service, and the provision of support services for young donor-conceived people, parents and donors.

6.2 Donor-conception stakeholder services after 2010

The *Assisted Reproductive Treatment Act 2008*, which came into effect on 1 January 2010, introduced significant changes to counselling and support arrangements for donor-conception stakeholders. The major changes brought about by the Act were that the ITA became the Victorian Assisted Reproductive Treatment Authority (VARTA), and that two key functions of the ITA – management of the donor registers and providing counselling services – were transferred to the Registry of Births, Deaths and Marriages (BDM) and the Adoption and Family Records Service (now FIND) at the Victorian Government's Department of Human Services (DHS), respectively. Under the new arrangements, VARTA's main focus is the provision of public education and community consultation.

6.2.1 Purpose of the changes introduced by the *Assisted Reproductive Treatment Act 2008*

During debate in Parliament on the *Assisted Reproductive Treatment Bill 2008*, Mr Jennings, the member for the South-Eastern Metropolitan Region, explained that the basis for removing management of the donor registers and associated counselling services from the ITA was to allow the birth and genetic information of a donor-conceived person to be treated separately from the infertility or treatment needs of his or her parents. The intention was to 'normalise' donor-conception, and BDM was considered to be the most appropriate agency to manage the registers.[395] This change

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[394] Infertility Treatment Authority, *Annual report 2006*, ITA, Melbourne, 2006, p. 17.

[395] Mr Gavin Jennings MLC, Minister for Environment and Climate Change, *Parliamentary debates*, Legislative Council, 2 December 2008, pp. 5515-5516.

followed a recommendation from the Victorian Law Reform Commission's (VLRC's) *Report on Assisted Reproductive Technology and Adoption*.[396]

Changes introduced by the *Assisted Reproductive Treatment Act 2008* did not encompass all of the changes recommended by the VLRC regarding management of the donor registers. While the VLRC did recommend that the registers should be moved from the ITA, it did not recommend that BDM should manage the registers, but rather suggested that an independent agency connected with BDM should be established, which would operate in a similar way to the Adoption Information Service (predecessor of the Adoption and Family Records Service and FIND), and to which the donor registers would be transferred.[397] The VLRC report also expressly recommended that the agency managing the registers should provide donor-linking and counselling services.[398]

The Committee heard that the VLRC's recommendation to remove management of the donor registers from the ITA may have been inadequately informed. Ms Helen Kane advised the Committee that:

> At no point did the Law Reform [Commission] look at what had been set up at the ITA from 2005, because it postdated the review on which it based its report. We were politically naïve at the ITA, and did not press forward with up to date information about what the Registers Service was achieving. And there were no complaints in all the years that we ran the service, and so did not come to the attention of the Minister for Health, who funded the service, and appeared to have forgotten we existed.[399]

6.2.2 Donor treatment registers

6.2.2.1 Role of BDM in managing the donor registers

BDM's operations are governed by the *Births, Deaths and Marriages Act 1996*, among other legislation. BDM's primary function is record-keeping, and its main statutory roles are to:

- record all births, adoptions, marriages and deaths occurring in Victoria;
- register domestic/caring relationships for people who reside in Victoria;
- register name changes for people who were born in or reside in Victoria; and

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[396] Victorian Law Reform Commission, *Assisted reproductive technology & adoption*, Final report, VLRC, Melbourne, 2007.
[397] Ibid.
[398] Ibid, p. 158.
[399] Helen Kane, *Submission no. 46*, 9 August 2011, p. 3.

- provide certificates of the above events to individuals.[400]

As noted above, on 1 January 2010, the management of the central and voluntary registers was transferred from the ITA to BDM. No other functions relating to donor-conception were conferred onto BDM.

In contrast with the former ITA, the only service that BDM offers to donor-conception stakeholders is the provision of information, without associated support services. The *Assisted Reproductive Treatment Act 2008* requires that a person seeking to access identifying information held on the central register or the voluntary register receives counselling before information can be released.[401] The legislation also requires that counselling is offered to a person who is seeking non-identifying information.[402] BDM does not have any counsellors to discuss the implications of making an application to the donor registers with people using the service.[403] Therefore, when a person applies to access information held on one of the registers, BDM refers the applicant to FIND for counselling. BDM will not release identifying information to an applicant unless FIND has confirmed that the person has received counselling.[404]

6.2.2.2 Voluntary register

When a person lodges an application to the voluntary register, BDM will confirm the person’s donor code, and enter the data into the register. The donor code is then matched with records that have the same donor code (if any), and a BDM officer will contact each of the matched parties to inform them that there has been a match, and to confirm their instructions in relation to the release of their information to the other party.[405] BDM will only release information from the voluntary register with the consent of the person to whom the information relates.

If the matched parties have requested identifying information about each other, BDM will refer each of them to a mandatory counselling session with FIND. Once BDM has received written confirmation from FIND that both parties have attended counselling, BDM will post a Statement of Information to each party, with the details that each person has consented to releasing.[406]

If the matched parties have requested non-identifying information, BDM offers them the opportunity to attend a counselling session with FIND, but

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[400] *Births, Deaths and Marriages Act 1996* (Vic), section 6.

[401] *Assisted Reproductive Treatment Act 2008* (Vic), section 61.

[402] Ibid.

[403] Victorian Assisted Reproductive Treatment Authority, *Submission no. 76*, 12 August 2011, p. 4.

[404] Births Deaths and Marriages Victoria, *Supplementary evidence*, 21 November 2011.

[405] Erin Keleher, Manager of Strategic Projects, Registry of Births, Deaths and Marriages, *Transcript of evidence*, Melbourne, 21 November 2011, p. 25.

[406] Ibid.

counselling is not mandatory. BDM posts a Statement of Information with non-identifying details to each party by registered post.[407]

As shown in Table 9, while the ITA was responsible for managing the voluntary register, 62 links were made between parties on the register.[408] Since the voluntary register was transferred to BDM on 1 January 2010, a further 14 parties on the voluntary register have been matched as at 30 June 2011.[409]

Table 9: Links made through the voluntary register to 31 Oct 2009 (until transfer to BDM)[410]

Links	Pre-1988 parties	Post-1988 parties	Total
Donor and donor-conceived individual	12	1	**13**
Donor and recipient	5	25	**30**
Donor-conceived and donor-conceived (half-sibling)	2	0	**2**
Recipient and recipient	0	13	**13**
More complex links that may be across different voluntary registers and may involve more than two parties	across both registers	across both registers	**4**
Total links on voluntary registers			**62**

6.2.2.3 Central register

There are currently 5,499 donor-conceived people and 1,885 gamete donors recorded on the central register. Table 10 provides a breakdown of these numbers in terms of children conceived from sperm donation and egg donation, and donors who donated either sperm or eggs.

Table 10: Donor-conceived births and donors recorded on the central register as at 30 June 2011[411]

	Sperm donation	Egg donation	Both sperm & egg donation	Total
Clinic notifications of donor-conception births[412]	3855	1415	229	**5499**
Registered donors by type	801	1084	N/A	**1885**

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[407] Ibid.

[408] Victorian Assisted Reproductive Treatment Authority, *Annual report 2010*, VARTA, Melbourne, 2010, p. 21.

[409] Ibid, p. 22. Based on data included in Victorian Assisted Reproductive Treatment Authority, 'A statistical snapshot of the donor registers in Victoria for 2010-2011', VARTA, Melbourne, 2011, viewed 23 Nov 2011, <www.varta.org.au>, p. 2.

[410] Victorian Assisted Reproductive Treatment Authority, *Annual report 2010*, VARTA, Melbourne, 2010, p. 21.

[411] Based on data included in Victorian Assisted Reproductive Treatment Authority, 'A statistical snapshot of the donor registers in Victoria for 2010-2011', VARTA, Melbourne, 2011, viewed 23 Nov 2011, <www.varta.org.au>, p. 2.

[412] This number is based on notifications made by clinics. Births resulting from gamete donations in private arrangements are not notified to the central register.

A total of 1,282 donor-conceived children were registered on the central register between 1 July 1988 and 26 September 1993, all of whom are now over the age of 18 years and are eligible to apply for information about their donor.[413]

Since 1 January 2007, however, there have been just 61 applications for identifying information made to the central register.[414] Thirteen per cent of these applications have been made by donors, 21 per cent by donor-conceived individuals, and 66 per cent by recipient parents.[415] There have also been a small number of applications for non-identifying information.

When an application is made to the central register, BDM follows a similar process as when dealing with an application to the voluntary register. After receiving the application, BDM will write to the person about whom identifying information is sought, seeking their consent to release the information. This could be a pre-1998 donor, a post-1998 donor (if the application is made by recipient parents), a post-1988 donor-conceived person over the age of 18, or if the donor-conceived person is under 18, their parents.

A sample of a letter that BDM would send to a donor seeking their consent to release identifying information is set out at Figure 6 below, and can be compared to the sample of a letter that the ITA would have sent to a donor in similar circumstances (see Figure 5 above). As with an application to the voluntary register, identifying information will only be released if the person seeking the information has attended a counselling session with FIND.

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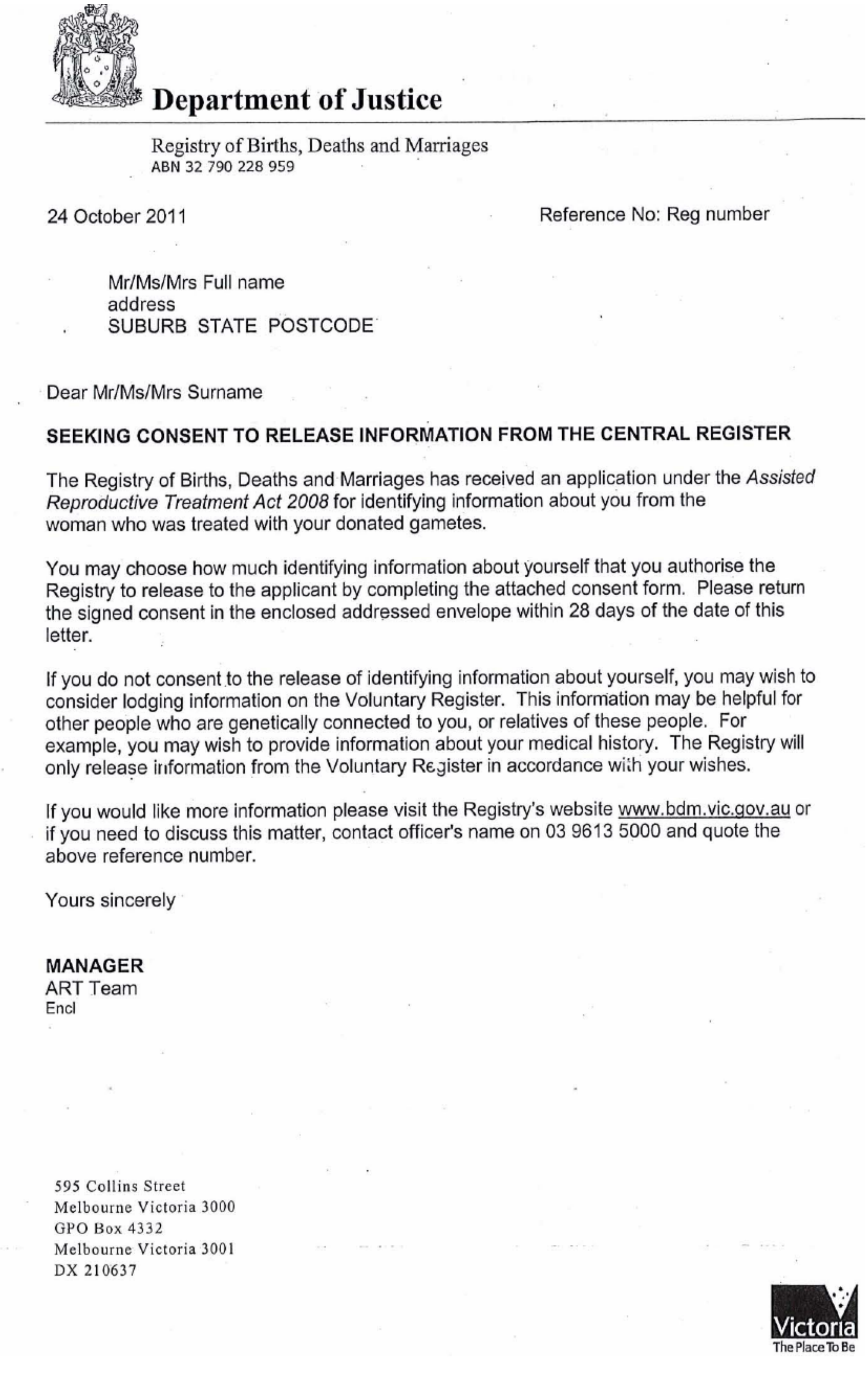
[413] Victorian Assisted Reproductive Treatment Authority, 'A statistical snapshot of the donor registers in Victoria for 2010-2011', VARTA, Melbourne, 2011, viewed 23 Nov 2011, <www.varta.org.au>, p. 2. The number of donor-conceived persons over the age of 18 will have increased by the time of publication of this report.

[414] Applications were also made before this date, but data is not available prior to 1 January 2007.

[415] For more detailed information about the number of applications, see Table 1 in Appendix Four.

Figure 6: Sample letter from BDM to a person who is the subject of an application to the central register



Department of Justice

Registry of Births, Deaths and Marriages
ABN 32 790 228 959

24 October 2011

Reference No: Reg number

Mr/Ms/Mrs Full name
address
SUBURB STATE POSTCODE

Dear Mr/Ms/Mrs Surname

SEEKING CONSENT TO RELEASE INFORMATION FROM THE CENTRAL REGISTER

The Registry of Births, Deaths and Marriages has received an application under the *Assisted Reproductive Treatment Act 2008* for identifying information about you from the woman who was treated with your donated gametes.

You may choose how much identifying information about yourself that you authorise the Registry to release to the applicant by completing the attached consent form. Please return the signed consent in the enclosed addressed envelope within 28 days of the date of this letter.

If you do not consent to the release of identifying information about yourself, you may wish to consider lodging information on the Voluntary Register. This information may be helpful for other people who are genetically connected to you, or relatives of these people. For example, you may wish to provide information about your medical history. The Registry will only release information from the Voluntary Register in accordance with your wishes.

If you would like more information please visit the Registry's website www.bdm.vic.gov.au or if you need to discuss this matter, contact officer's name on 03 9613 5000 and quote the above reference number.

Yours sincerely

MANAGER
ART Team
Encl

595 Collins Street
Melbourne Victoria 3000
GPO Box 4332
Melbourne Victoria 3001
DX 210637

Victoria
The Place To Be

If the application is for non-identifying information only, BDM will offer the applicant the option of attending a counselling session with FIND, and will release the non-identifying details to the applicant.

6.2.3 Counselling

6.2.3.1 Family Information Networks and Discovery (FIND)

FIND’s role in current service arrangements for donor-conception stakeholders is to offer counselling to individuals who apply to the central and voluntary registers for information, on referral from BDM.

FIND is a service area within DHS, and was formerly known as the Adoption and Family Records Service. FIND’s functions include assisting people to access personal and family information, records and support about past wardship and adoption.[416] FIND has significant experience in providing information and search services, and mediating contact for those affected by adoption (including the adopted person, and the birth and adoptive parents).[417] FIND has a team of ten case managers, three of whom have received training to provide counselling for donor-conception stakeholders.[418]

When BDM receives an application to the voluntary register or the central register seeking identifying information, it notifies FIND that the applicant will contact FIND to arrange their counselling session.[419] BDM will also offer a counselling referral to FIND where an applicant is seeking non-identifying information, and will similarly notify FIND that they might expect the person to contact FIND. This is the only stage at which a donor-conception stakeholder can be referred to FIND for counselling, as he or she is not able to approach FIND for counselling without a referral from BDM.[420]

During the counselling session, the FIND case manager asks the applicant about their expectations regarding the information that they are seeking, what they might learn from it, and what they might not obtain from the information. The aim of the session is to help the applicant to manage his or her expectations.[421]

FIND provides a single session of counselling. FIND advised the Committee that in most cases, one counselling session has been adequate. FIND has had two applicants make further contact after their counselling session, seeking additional information, and FIND has been able to answer their questions over the phone.[422]

Since 1 January 2010, BDM has referred 28 applicants to FIND for counselling. Of these, 20 were gamete recipients (19 sperm recipients and

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[416] Mariaelisa Tumino, Former manager, Family Information Networks and Discovery (FIND), *Transcript of evidence*, Melbourne, 21 November 2011, pp. 11-12.
[417] Ibid, p. 12.
[418] Ibid, p. 13.
[419] Ibid, p. 12.
[420] Ibid, p. 13.
[421] Ibid, p. 12.
[422] Ibid, p. 13.

one egg recipient), three were donor-conceived people, three were sperm donors, and one was an egg donor.[423]

6.2.3.2 Counselling by fertility clinics

Until recently, Melbourne IVF was the only clinic to assist pre-1988 donor-conceived people seeking information about their donor. Melbourne IVF provides linkage counselling with the aim of tracing the donor based on information kept on Melbourne IVF records, and providing information and support to both the donor and the offspring. This information can identify the donor if the offspring has requested identifying information and the donor is willing to provide it.[424]

Relatively few people have accessed these services through Melbourne IVF, with just five to ten pre-1998 donor-conceived people assisted per year.[425] However, Melbourne IVF told the Committee that it has not refused any request, and in each case has made contact with the donor-conceived person's donor.[426]

Melbourne IVF also provides support to recipient parents who wish to make contact with their donor, either to provide the donor with information about their donor-conceived child, or to ask the donor for information. Melbourne IVF does not provide assistance to donor-conceived individuals wanting to make contact with their donor-conceived siblings, nor to donors wishing to initiate contact with their donor-offspring.[427]

Ms Helen Kane commented on the success of the donor-linking and counselling services provided by Melbourne IVF:

> The infertility program at the Women's Hospital, now as Melbourne IVF, developed a practice in relation to assisting donor conceived people conceived prior to the 1984 legislation to seek contact with their donor. This has been highly successful, and demonstrates that it is possible to do this in a way that acknowledges the needs of all, even when legislation does not exist to guide the process.[428]

Monash IVF has recently started providing a similar service for pre-1988 donor-conceived people for whom it holds donor records. Although in the past Monash IVF had refused requests from donor-conceived people for

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[423] As at 21 November 2011 – see Erin Keleher, Manager of Strategic Projects, Registry of Births, Deaths and Marriages, *Transcript of evidence*, Melbourne, 21 November 2011, p. 12. The Committee notes that the numbers provided by FIND add up to 27 applicants, rather than 28.

[424] Victorian Infertility Counsellors Group, *Submission no. 22*, 6 August 2010, p. 3.

[425] Marianne Tome, Victorian Infertility Counsellors Group, *Transcript of evidence*, Melbourne, 12 September 2011, p. 25.

[426] Joanne McCann, Operations Manager, Melbourne IVF, *Transcript of evidence*, Melbourne, 10 October 2011, p. 19.

[427] Melbourne IVF, *Submission no. 32*, 9 August 2010.

[428] Helen Kane, *Submission no. 16*, 6 August 2010, p. 5.

assistance, in 2011 it provided donor-linking assistance to two pre-1988 donor-conceived people.[429]

6.2.4 Education and regulation

As noted above, VARTA's main role is to deliver public education on a range of issues pertaining to assisted reproductive treatment.[430] VARTA is staffed by four full-time equivalent employees, and a Chief Executive Officer.[431] As well as public education, VARTA has a range of other responsibilities, such as registering clinics that provide assisted reproductive treatment, monitoring compliance with licences, authorising the import and export of gametes from Victoria, and promoting research into the causes of infertility.[432] VARTA's education role includes providing education about assisted reproductive treatment procedures and the best interests of children born as a result of treatment procedures, and highlighting research about fertility and infertility.[433]

VARTA has continued the *Time to Tell* campaign commenced by the ITA, to support and encourage parents to tell their children that their family was formed through donor-conception (or through surrogacy). VARTA also provides access to support resources and information on its website in the form of brochures and podcasts, and holds *Time to Tell* seminars for parents and health professionals (such as counsellors and educators).[434]

VARTA does not provide any counselling or information to donor-conception stakeholders. If VARTA receives an enquiry from an individual seeking information about a person connected to them through donor-conception, VARTA will explain in general terms what applying to the donor registers involves, and will refer the individual on to BDM.[435]

6.2.5 Interaction between the agencies

As VARTA, FIND and BDM all provide related but separate services to donor-conception stakeholders, it is important that they communicate and share information with each other. VARTA has developed information brochures for both BDM and FIND to use in their respective roles of providing information and counselling to donor-conception stakeholders. BDM, FIND and VARTA meet on a quarterly basis to discuss matters of

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[429] Marianne Tome, Victorian Infertility Counsellors Group, *Transcript of evidence*, Melbourne, 12 September 2011, p. 25.

[430] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 37.

[431] Victorian Assisted Reproductive Treatment Authority, *Annual report 2011*, VARTA, Melbourne, 2011, p. 11.

[432] *Assisted Reproductive Treatment Act 2008* (Vic), section 100.

[433] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 37; Victorian Assisted Reproductive Treatment Authority, *Submission no. 19*, 6 August 2010, p. 1.

[434] Victorian Assisted Reproductive Treatment Authority, *Annual report 2011*, VARTA, Melbourne, 2011, p. 7.

[435] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 37.

interest in relation to the operation and function of each organisation. Discussions do not include the exchange of information about any specific application to the registers, or any associated provision of counselling.[436]

FIND counsellors attend VARTA's *Time to Tell* seminars, which are held approximately every six months, and have also started attending a regular counsellors' meeting between VARTA and IVF counsellors, so that they can improve their knowledge of issues relating to donor-conception.[437] A representative from BDM also attends and speaks at the *Time to Tell* seminars, to educate the public about the donor registers.[438]

BDM has also recently requested that one of their staff sit in on one of FIND's counselling sessions, and the agencies are currently in the process of organising this.[439]

6.2.6 Shortcomings of the current service arrangements

The Committee received evidence from several sources that the current system is not meeting the needs of donor-conception stakeholders. Many people expressed concern, through submissions and in public hearings, that services previously offered by the ITA are no longer available, and noted that VARTA (formerly the ITA) was particularly well-placed to provide these services, given that prior to 2010 it had accrued almost 15 years of experience in dealing with issues surrounding donor-conception:

> The Infertility Treatment Authority (ITA) was in the best position to manage such requests for information and it was a sad day when I learned that they would be closed down. I was part of the Donor Registers Reference Committee for a number of years and felt that Helen Kane and the team there were working extremely well to educate the public, inform clinics and maintain the varied registers. They had built a great wealth of knowledge and expertise that was much needed for such a complex practice. It still dumbfounds me as to why the government chose to put it to a stop. I am seriously concerned about the implications of having lost such an intrinsically supportive body.[440]

A number of issues raised in submissions and during public hearings regarding current service arrangements are discussed below.

6.2.6.1 Lack of counselling and support

One of the major shortcomings of the current service arrangements is the limited counselling available to donor-conception stakeholders. FIND

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[436] Ibid, p. 36; Erin Keleher, Manager of Strategic Projects, Registry of Births, Deaths and Marriages, *Transcript of evidence*, Melbourne, 21 November 2011, p. 29.

[437] Mariaelisa Tumino, Former manager, Family Information Networks and Discovery (FIND), *Transcript of evidence*, Melbourne, 21 November 2011, p. 13.

[438] Erin Keleher, Manager of Strategic Projects, Registry of Births, Deaths and Marriages, *Transcript of evidence*, Melbourne, 21 November 2011, p. 29.

[439] Mariaelisa Tumino, Former manager, Family Information Networks and Discovery (FIND), *Transcript of evidence*, Melbourne, 21 November 2011, p. 16.

[440] Narelle Grace Grech, *Submission no. 18*, 6 August 2010, p. 7.

provides only one information session to a person who is referred by BDM for counselling. There is no capacity for a donor-conception stakeholder to approach FIND directly seeking counselling services – only those people who apply to BDM seeking access to information on one of the registers, and who are consequently referred on to FIND, are able to access FIND's services.[441]

The limited availability of counselling has a number of ramifications. Firstly, there is no opportunity for counselling for a person who is considering whether to apply to the registers for information:

> There is inadequate support for people considering making an application to the Registers. This is a big step for people to take and they often require very sensitive information and support. They need to consider such issues as what register do I apply to, what information can I request / am I entitled to, what do I hope to achieve from my application, is this the right time for me to apply.[442]

Another major limitation is that there is no counselling offered to a person who is the subject of an application for information.[443] A person who receives a letter from BDM as a result of an application to the central register – a donor, a donor-conceived person, or recipient parents if the donor-conceived person is under 18 – is not provided with any counselling or support, despite the fact that the letter may come as a shock to them, and they may not be adequately prepared to consider all of the repercussions of their decisions. VARTA provided an illustrative example of what could happen under current arrangements, where a donor applies for identifying information about their donor-offspring, and the donor-offspring is over 18 years of age:

> … BDM may be required to seek consent from a donor-conceived young adult on receiving an application from a donor for identifying information. This young adult may not be aware that they are donor-conceived and so learn they are donor-conceived as a result of the application. In seeking consent from the donor-conceived person to release information to the donor, BDM is not in a position to provide counselling support to assist the young adult to come to terms with the revelation that their Dad (or Mum) is not their biological parent. The donor-conceived person will also need information regarding the reasons and wishes of the donor in making the application. Under the existing service model, there is also no capacity for BDM to refer the young adult to FIND for discussion and support about the application and potential issues associated with providing consent.
>
> As a result, there is no clear pathway of support for a donor-conceived adult. They may not be able to discuss issues with their parents and

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[441] Mariaelisa Tumino, Former manager, Family Information Networks and Discovery (FIND), *Transcript of evidence*, Melbourne, 21 November 2011, p. 13.

[442] Kate Bourne, *Submission no. 35*, 11 August 2010, p. 6.

[443] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 39.

> community counsellors have little experience in dealing with these issues. This puts the donor-conceived person in a difficult position.[444]

Similarly, there is no opportunity for a person other than an applicant to seek counselling – for example, a partner or child of a donor or of a donor-conceived person. Although these people may also need specialised support to consider a situation that affects their family and themselves, they cannot currently access such support.

Finally, there is no counselling or specialised support available where a person applies for information from one of the registers but is unable to obtain it. This may occur, for example, when:

- a pre-1988 donor-conceived person lodges an application to the voluntary register, but no other related person has lodged information on the voluntary register, so there is no match;
- a 1988-1998 donor-conceived person seeks identifying information about their donor, but BDM cannot locate the donor and so consent to release the identifying information cannot be obtained; and
- a 1988-1998 donor-conceived person seeks identifying information about their donor, but the donor refuses to consent to the release of identifying information.

The lack of support available in these and other circumstances is of concern to the Committee, as various participants may benefit from counselling support to cope with the disappointment of finding they are unable to access information.[445] In the second and third examples above, the donor-conceived person seeking the information will simply be advised by a letter from BDM of the circumstances preventing the release of information. A sample letter of the type that BDM would send to a donor-conceived person where the donor has refused to consent to the release of identifying information is provided at Figure 7 below.

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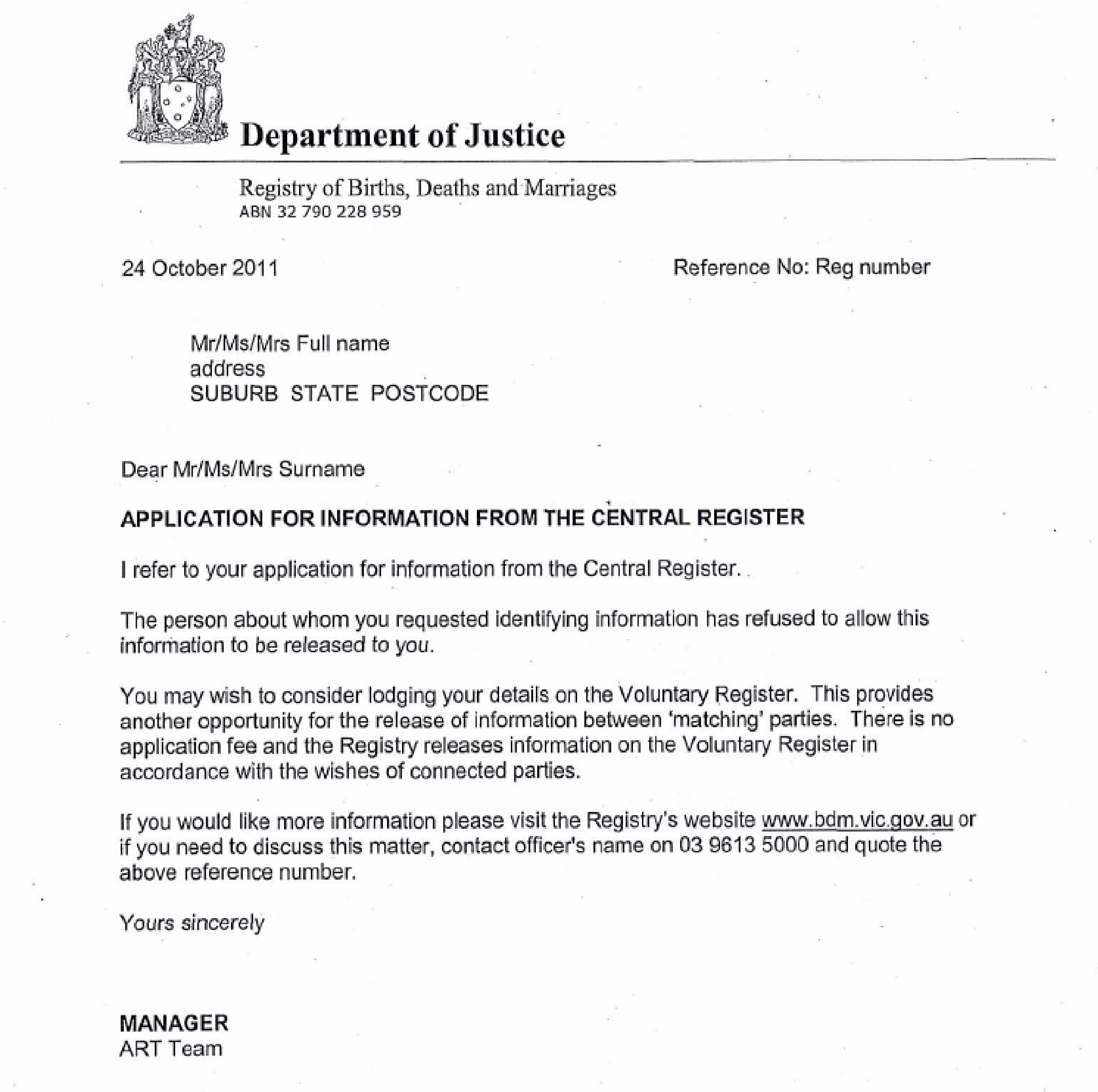
[444] Victorian Assisted Reproductive Treatment Authority, *Submission no. 76*, 12 August 2011, p. 2.

[445] Victorian Assisted Reproductive Treatment Authority, *Submission no. 19*, 6 August 2010, p. 5.

Figure 7: Sample letter from BDM to an applicant to the central register, advising that the person about whom information is sought has refused to consent to its release



Department of Justice

Registry of Births, Deaths and Marriages
ABN 32 790 228 959

24 October 2011 Reference No: Reg number

Mr/Ms/Mrs Full name
address
SUBURB STATE POSTCODE

Dear Mr/Ms/Mrs Surname

APPLICATION FOR INFORMATION FROM THE CENTRAL REGISTER

I refer to your application for information from the Central Register.

The person about whom you requested identifying information has refused to allow this information to be released to you.

You may wish to consider lodging your details on the Voluntary Register. This provides another opportunity for the release of information between 'matching' parties. There is no application fee and the Registry releases information on the Voluntary Register in accordance with the wishes of connected parties.

If you would like more information please visit the Registry's website www.bdm.vic.gov.au or if you need to discuss this matter, contact officer's name on 03 9613 5000 and quote the above reference number.

Yours sincerely

MANAGER
ART Team

6.2.6.2 No donor-linking services

In contrast to the ITA model – where there was an opportunity to explore the motivations of the applicant, and convey these to other parties when they were contacted to ask if they would consent to releasing identifying information – the current system does not allow for the person who is the subject of an application to gain any insight as to why the other party is seeking information about them. This makes it difficult for the person to decide whether or not they should agree to release identifying information – as well as the initial shock of receiving the letter, a person may be apprehensive in the absence of any personal contact or reassurance as to the applicant's motives.

In the ITA's experience, understanding why the other person wanted information was crucial to the decision-making of the person who was contacted:

> The request for consent to release identifying information was usually quite unexpected and came as a shock. While the applicant may have deliberated about making an application, the person contacted as a result of the application might not have thought through the implications of giving consent to their information being released. To make such a decision, they usually wanted to know the motivation behind the application, the short and long-term goals of information exchange or contact and how the applicant wanted to begin this process.[446]

With sensitive counselling and information about why the applicant is seeking contact with them, a person may feel much more comfortable about making contact, especially if they understand that contact can proceed at a gradual pace.

There is also no counselling or support available to an applicant after information has been released to them, whether as a result of an application to the voluntary register or to the central register. If identifying details are released, the person must decide on their own as to how they will proceed – BDM does not provide any assistance or support to the person in making contact with the other party. This is not ideal, as VARTA points out:

> All parties are usually anxious about beginning contact even if they initiated the application. All parties are usually unclear as to what is the appropriate or the correct 'etiquette' between donor-conceived people, donors, and recipient parents. Usually, a small amount of early support is sufficient to reduce this apprehension and give guidance as to the appropriate roles and boundaries for each party.[447]

Furthermore, under the current model, no intermediary services are made available to donors, donor-conceived people, or their parents, so that it is not possible for relationships to develop slowly from initial non-identifying contact. There is no letterbox service available, so there is no way for parties to exchange information and letters without immediately revealing their identity to the other party. Ms Kate Bourne, former donor-linking counsellor at the ITA, explained the important role that an intermediary can play in assisting a relationship to develop:

> … many clients find it useful to communicate via an intermediary. The donor-linking counsellor prepares a list of questions formulated by the donor-conceived person to pose to the donor that are of significant importance to them if the donor is not prepared to give consent to releasing their full identity. For example, the donor may be prepared to answer these and might write a letter which is then forwarded on by the donor-linking

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[446] Victorian Assisted Reproductive Treatment Authority, *Submission no. 76*, 12 August 2011, p. 3.

[447] Ibid, pp. 5-6.

> counsellor, rather than providing identifying details immediately. This enables the parties to get to know each other safely. Donors are often initially suspicious about releasing information until they feel they can trust the other person. Donor-conceived young people are often quite wary about having direct contact with their donor until they get to know them. For these reasons, parties often prefer to get to know each other by writing until they do not feel like strangers and feel comfortable and safe enough to meet …
>
> This contact through an intermediary may appear to be quite involved but in practice the role of the donor-linking counsellor is to convey the wishes of each party to the other to get the arrangement going and then retreat into the background and only re-enter momentarily, if there are concerns, and again retreat as soon as possible. This model closely reflects sound adoption linking practice.[448]

6.2.6.3 Limited services for pre-1988 donor-conception stakeholders

There are limited support services currently available for pre-1988 donor-conceived people, and for pre-1988 donors. As mentioned above, and in Chapter Three, if a pre-1988 donor-conceived person is seeking information about their donor, and the donor is not on the voluntary register, the only avenue for the donor-conceived person is to approach the fertility clinic that provided treatment to his or her mother. Melbourne IVF provides donor-linking services to pre-1988 donor-conceived people who request its assistance, but as Melbourne IVF itself points out, it would be preferable for these services to be provided by a central agency:

> Assisted Reproductive Treatment clinics are able to provide donor linkage services to their patients without a change to legislation in the way that Melbourne IVF currently does. However, this may limit the access to information for donor conceived individuals and their donors, as it relies on private clinics to undertake what is essentially a free service and would be dependent on the clinics being able to carry out their own investigation to locate a donor. Clinics would require greater access to information to assist in locating donors and would need to be adequately funded to provide such a service. A comprehensive community education program would also need to be established to raise awareness of the availability of donor linking services for those born before 1988.
>
> A second and more appropriate option for providing donor linkage for those born before 1988 is that donor linkage is provided by a central service that has access to the registers and information held by the clinics. This centralised service should work in much the same way as The Infertility Treatment Authority (ITA) previously functioned where they would provide outreach to donors on behalf of donor conceived individuals, supporting both parties to make contact or share information in a way that is most comfortable for all parties.[449]

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[448] Kate Bourne, *Submission no. 35*, 11 August 2010, p. 5.
[449] Melbourne IVF, *Submission no. 32*, 9 August 2010, p. 8.

The Committee notes that the managers of counselling services at Melbourne IVF and Monash IVF respectively noted that fertility clinics have commercial pressures that may affect clinic policy and practices:

> I think they've advocated that the clinics are responsible for that [maintaining their own records], and I thought that was great that they were taking responsibility for that, but I just wonder in the long-term how that would work just with commercial pressures.[450]
>
> That's right and businesses change and our one's a commercial business as well and interests can shift over time so I think having something consistent is really important.[451]

The Committee also heard that there may be issues of trust if records are left in the hands of clinics to manage, as well as issues of inconsistency between clinics:

> A point that came up by Monash IVF, the recommendation made that donor records be managed by clinicians, what assurances do donor-conceived people have that the records will be protected? Maybe it's slightly different with the bigger clinics, like Monash IVF and Royal Women's who have perhaps better record keeping practices, but with smaller clinics we know that records have been destroyed. If those records are maintained by clinics, how can we ensure that donor-conceived people can be assured that their records are not going to be destroyed, are managed correctly, and also the symbolic aspect of it in that if the records are maintained by clinicians they're not maintained by a neutral agency.[452]

The shortcomings associated with clinics providing counselling services for pre-1988 donor-conception stakeholders include:

- the range and types of services provided depends on the clinic, and may vary between clinics;
- services provided by the clinic are not regulated, and so there may be some mistrust of the clinics by donor-conception stakeholders;
- if the clinic that provided the treatment no longer exists and its records are not now held by another clinic (for example, many records from the former Prince Henry's Hospital), no services will be available; and
- clinics do not have access to the confidential Victorian register of electors, which makes locating and contacting donors and protecting their privacy more difficult.

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[450] Marianne Tome, Victorian Infertility Counsellors Group, *Transcript of evidence*, Melbourne, 12 September 2011, p. 25.

[451] Rita Alesi, Victorian Infertility Counsellors Group, *Transcript of evidence*, Melbourne, 12 September 2011, p. 25.

[452] Myfanwy Cummerford, *Transcript of evidence*, Melbourne, 17 October 2011, p. 35.

6.2.6.4 Limited information exchange between agencies

One of the problems resulting from distributing responsibilities formerly possessed solely by the ITA between three agencies, is that limitations to information available to each agency constrains the quality of services they can provide. While the Committee notes that BDM, FIND and VARTA have undertaken efforts to minimise the effect of these constraints, limitations on each agency's capacity to share relevant information hampers their respective efforts to provide comprehensive services to clients.

For example, FIND does not have access to the central and voluntary registers, and there is no provision in the *Assisted Reproductive Treatment Act 2008* to allow BDM to release information to FIND about an application to the central register or voluntary register. This means that FIND's case managers receive no information about the content of an application prior to a counselling session, including whether the person they will be seeing is a donor, a donor-conceived person, or a recipient parent.[453] Nor will the counsellor know in advance of the session which legislative regime the person falls under, or whether they are a stakeholder of a pre-1988 procedure. Ms Kate Bourne explained the implications of this:

> As [FIND] is a separate body from the Registry, due to privacy restrictions, the Registry is not able to communicate the particular situation of the applicant to the [FIND] counsellors. Therefore the counsellors are not able to be given any background information about the person or … the person the applicant is linked to … They are not in a legal position to convey to the other party the motivations and aims of making the application. This means the counselling provided can then be generic only and not truly 'donor-linking' as the counsellor is unable to work effectively as a facilitator/mediator to broker an arrangement that is acceptable to both parties. This is a highly unsatisfactory situation for the applicant and the outreached party. This means that the person who has been contacted as the result of an application has no information upon which to make their decision whether to consent to release information. The applicant is also not informed of the preferred wishes of the person they want to contact to guide them as to their preferences.[454]

Similarly, FIND counsellors are unable to give information to BDM regarding the outcomes of counselling. If a person who is counselled has particular wishes as to how they would like information exchange or contact to proceed, this cannot be passed on to BDM.[455] FIND simply provides notification to BDM that the counselling session has taken place, without further detail.[456]

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[453] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 40.

[454] Kate Bourne, *Submission no. 35*, 11 August 2010, p. 6.

[455] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 40.

[456] Erin Keleher, Manager of Strategic Projects, Registry of Births, Deaths and Marriages, *Transcript of evidence*, Melbourne, 21 November 2011, p. 25.

FIND described another problem relating to the limited feedback it is able to provide to BDM in regards to a counselling session. The *Assisted Reproductive Treatment Act 2008* provides that the person to whom an application is made (that is, BDM) may disclose the requested information to the applicant's doctor, rather than directly to the applicant, if they have concerns that disclosure of the information may affect the physical or mental health or wellbeing of the applicant.[457] Whilst FIND is able to recommend to BDM that the disclosure should be made to the applicant's doctor, based on the counselling session with the applicant, BDM ultimately makes the decision, without supporting details from FIND. Further, if BDM decides that the information should be released to the applicant's doctor, the doctor is not provided with any accompanying assessment by FIND as to why FIND might have recommended this. The doctor is left to guess as to why the information was released to them rather than directly to the applicant.[458]

6.2.6.5 Current system is disjointed and difficult to navigate

Ms Helen Kane, the former Manager of the ITA's Donor Registers Service, expressed the view that the current system for accessing information about donors is complex and poorly integrated, and should be streamlined.[459] This view was echoed in several submissions that expressed concern about the difficulty and confusion experienced by people attempting to navigate the current system, due to different areas of responsibility being sited within separate organisations, rather than all services being provided by a 'one stop shop' such as the former ITA.[460] For example, Ms Lauren Burns, a donor-conceived person, expressed the view that:

> The splintering of different areas of responsibility under three different organisations makes it more difficult for people to know where they should be seeking information, and means some people will be shunted between organisations.[461]

As pointed out by VARTA, the division of functions, and the lack of provision for the three agencies to share information, means that an applicant to the donor registers will often have to discuss these sensitive matters with a number of staff across different agencies.[462]

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[457] *Assisted Reproductive Treatment Act 2008* (Vic), section 65.

[458] Mariaelisa Tumino, Former Manager of FIND, *Personal communication*, 3 January 2012.

[459] Helen Kane, *Submission no. 16*, 6 August 2010.

[460] Kate Bourne, *Submission no. 35*, 11 August 2010; Lauren Burns, *Submission no. 3*, 29 July 2010; Kate Dobby, *Submission no. 33*, 10 August 2010; Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010; Fertility Society of Australia, *Submission no. 66*, 12 August 2011; Narelle Grace Grech, *Submission no. 18*, 6 August 2010; Melbourne IVF, *Submission no. 32*, 9 August 2010; Name withheld, *Submission no. 29*, 9 August 2010; Victorian Assisted Reproductive Treatment Authority, *Submission no. 19*, 6 August 2010; Victorian Infertility Counsellors Group, *Submission no. 22*, 6 August 2010.

[461] Lauren Burns, *Submission no. 3*, 29 July 2010.

[462] Victorian Assisted Reproductive Treatment Authority, *Submission no. 76*, 12 August 2011, p. 4.

6.3 Proposed changes to current arrangements

The Committee notes Ms Helen Kane's comments as to the necessary elements of an effective system for supporting and counselling donor-conception stakeholders:

> What is required, if equality is acknowledged for all donor conceived people, is a system which has the capacity to locate information, confirm it, provide counselling, and provide an outreach/mediation service to the parties concerned.
>
> It requires recognition of the rights of the donor conceived person to seek information, and for respect of the needs of the donor, as well as the family, to be involved in making decisions in the present, based on new circumstances.[463]

The changes that the Committee proposes below are aimed at ensuring that the system for support and counselling of donor-conception stakeholders has these important characteristics.

6.3.1 Justification for change

6.3.1.1 Shortcomings of the current system

As discussed above, there are a number of shortcomings to the current service model. In summary, the limits to the counselling and support services currently available include that there is:

- no capacity for self-referrals for counselling – so that:
    - no counselling is available for people who are considering making an application for identifying information; and
    - no counselling is available for other related parties (eg. relatives of the person who is applying for information);
- no capacity for ongoing counselling;
- no counselling available for a person who is the subject of an application for identifying information;
- no counselling or support available for a person who applies for identifying information but is unable to obtain it;
- no counselling or support available for someone once they have received identifying information, but may be unsure how to proceed;
- no capacity for the exchange of non-identifying information through a letterbox service; and

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[463] Helen Kane, *Submission no. 16*, 6 August 2010, p. 2.

- limited support and services for pre-1988 donor-conception stakeholders.

In addition, as also discussed above, the limits to the exchange of information between the agencies (particularly BDM and FIND) causes problems, and the division of responsibilities between BDM, FIND and VARTA makes the system disjointed and difficult for donor-conception stakeholders to navigate.

6.3.1.2 Purpose of the changes introduced by the *Assisted Reproductive Treatment Act 2008* has not been achieved

As mentioned above, the changes introduced by the *Assisted Reproductive Treatment Act 2008* – specifically, the transfer of management of the donor registers to BDM – were made with the intended purpose of de-stigmatising and normalising donor-conception.[464] It does not appear that Parliament's intention was also to reduce the availability of services to donor-conception stakeholders by making these changes, but this has clearly been a consequence of the changes.

The Donor Conception Support Group of Australia Inc. (DCSG) commented that the ITA's management of the registers did not make donor-conceived people feel stigmatised, and that the transfer of the registers to BDM has not normalised donor-conception:

> We understand the desire to try to normalise donor conception as it is something that our group has been working towards for over 15 years. We also understand the desire to try and prevent parent's infertility from prevailing on the donor conceived child/adult: this is something of which the members of our group who are parents of donor conceived children are acutely aware. The DCSG has spoken to donor-conceived people who have had contact with ITA and none of them have expressed any concern that the issues of infertility have clouded their discussions with ITA. The main reason why donor conceived people have felt different to other people is that they have been treated differently by society and this different treatment has been encouraged by legislation. The alienation felt by donor conceived people could be diminished by giving them the right to have access to identifying information about their genetic parentage.
>
> We feel that the moving of the registers from the management of ITA has done nothing to normalise donor conception but has in fact put further hurdles in front of families and donor conceived persons.[465]

A donor-conceived person, Ms Lauren Burns, made similar comments:

> The government made a presumption that people were feeling stigmatised by dealing with the Infertility Treatment Authority and would feel more 'normal' dealing with Births Deaths Marriages (BDM). This presumption was

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[464] Victorian Law Reform Commission, *Assisted reproductive technology & adoption*, Final report, VLRC, Melbourne, 2007.

[465] Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010, pp. 19-20.

> not based on consultation with donor conceived people as there was no grass roots discontent with the previous service model. In fact, the ITA was recognised as providing world's best practice.[466]

The general view of the stakeholders from whom the Committee heard was that the current system diminishes support for donor-conceived people, and the previous system was far preferable. For example, Monash IVF made a recommendation that the legislative arrangements should:

> Follow the model of donor linking counselling services as previously offered by the Infertility Treatment Authority which has a system that reflected the complex and long-term needs of this population; unlike the ART Act 2008, which actually diminishes the type of support offered to these people, further disenfranchising them.[467]

6.3.2 Proposed changes to services

6.3.2.1 All services to be provided by one agency

Evidence received by the Committee during the course of this Inquiry suggests that current institutional arrangements for access to information by donor-conception stakeholders could be considerably improved. In particular, the fragmentation of service provision between three agencies appears to have had a detrimental effect on information services to donor-conceived people, their parents, donors, and their families. The Committee heard from a number of people and organisations that the model of service delivery formerly practiced by the ITA was far superior to current arrangements. Consequently, the Committee believes that it is critical that donor-conception stakeholders are able to access all relevant information services through one agency. The same agency that manages the donor registers should provide all associated counselling and donor-linking services, in addition to providing education and running public campaigns about donor-conception.

Having a single agency responsible for all of these services will allow donor-conception stakeholders to easily access the information and support that they need. It will remove any confusion as to which is the appropriate agency to approach, and will eliminate current problems associated with the limits on information-sharing between FIND and BDM.

Recommendation 14**:** That the Victorian Government introduce legislation to empower one agency to provide all services relating to the provision of information, linking and counselling services related to donor-conception, including management of the donor registers, a letterbox service, education and public campaigns.

When the ITA was providing donor-linking services, it had an arrangement with the Victorian Electoral Commission that it could access date of birth

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[466] Lauren Burns, *Submission no. 3A*, 6 August 2010.
[467] Monash IVF, *Submission no. 26*, 6 August 2010, p. 2.

details on the register of electors – which are not available to the general public – in addition to names and addresses. This assisted the ITA to ensure that they were contacting the correct person when an application was made to the central register:

> If you do not have that, you have to write to a number of people with the same name until you find the right person. Obviously if they have similar names they might be related and this increases the risk of a breach of privacy. When you write your letter, you need to make very sure that you are reaching the right person.[468]

The Committee believes it is important that the agency referred to in Recommendation 14 (hereafter referred to as "the agency") providing services to donor-conception stakeholders has access to these details on the register of electors, for reasons of efficiency and maintaining privacy.

Recommendation 15: That the agency referred to in Recommendation 14 be granted access to the Victorian register of electors in order to conduct its functions.

In the Committee's view, it is important that the agency providing information and counselling services has relevant experience and expertise around donor-conception issues, or experience that translates to the donor-conception field.

Several people expressed concern to the Committee that BDM is not the most appropriate organisation to be managing the donor registers. While BDM is highly experienced in record-keeping and information management, BDM staff do not have sufficient experience dealing with donor-conception issues, and may not have an appreciation of the sensitivities and emotional issues often involved with seeking information from the donor registers. This is illustrated by the experience of a parent who, together with her same-sex partner, has a daughter conceived with donor sperm, recounted in Case Study 6.

Mr Ian Smith, a pre-1988 donor, also commented on the transfer of responsibility from VARTA (then the ITA) to BDM:

> Without being at all critical of BDM, I think that system is not working as well as it did with VARTA. … I had some experience with that. The contact from the young woman who is one of my biological children occurred under VARTA and the process was done really well. It was really thorough, it was really careful. BDM is just not set up, as I understand it, to do that as well and I think that is really unfortunate because it will potentially not lead to some good outcomes. It will make it hard for people.[469]

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[468] Kate Bourne, Senior Community Education Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 43.

[469] Ian Smith, *Transcript of evidence*, Melbourne, 10 October 2011, p. 39.

Case Study 6: Dealings with the Registry of Births, Deaths and Marriages.[470]

"One of the great benefits of the ITA handling the registers was that its staff, its CEO, its board, were peopled by experts in the relevant field: infertility counsellors, lawyers in the fields, reproductive medicine specialists, infertility nurses, etc. … The ITA was capable of handling inquiries with tact, delicacy and compassion as well as with a view to what could be done. My encounters with the Registry have been the antithesis of such qualities.

In a recent encounter with the Registry, I approached them for information about applying for identifying information about the man who helped us to have a child. … I was told, in the course of several distressing conversations with the Registry staffer, quite a few startling pieces of misinformation and was, ultimately, disgusted and dismayed by the way my inquiry was handled. Again, this is in my view a systemic problem, produced by a profound confusion of roles which has, at its basis, the misunderstanding of the Registry's proper function as well as a profound lack of education about why these situations, of people applying for information about the genetic parenthood of their children, should not be treated as just another bureaucratic job. … The care and management of the Registers is not simply a bureaucratic function that can be undertaken by any bureaucracy. It involves much more than that. We leave it to the Registry at its great peril, and people's lives will be affected as mine and my family's have been."

The Committee considers that VARTA is the agency best placed to provide all services related to donor-conception. Key former staff from the ITA are currently employed at VARTA, and VARTA has the necessary connections and expertise in the donor-conception field. Ms Helen Kane, former Manager of the Donor Registers Service at the ITA, indicated to the Committee that it is not too late to re-establish the ITA model:

> It is less than two years since the ITA Donor Registers Service was dismantled. It is not too late to go back, and recreate that service, within VARTA. The expertise has not entirely disappeared as yet, and the support within the field was very strong, and the good will no doubt continues to exist.
>
> The service needs to be able to assist parents, donors, the donor conceived persons, siblings, and the professionals working with all of these. It needs to be able to access whatever information exists and to use that within the legal framework, to locate the other parties, to set up agreements and information exchanges, to establish direct contact if desired, and to provide counselling to deal with the challenges, and the disappointments.
>
> … The Registers Officer at ITA had extraordinary gifts in searching, locating, and connecting, information for the applicants to the Register. The counselling and linking processes we provided at ITA was second to none,

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[470] Name withheld, *Submission no. 34*, 11 August 2010, pp. 3-5.

> and were seen as groundbreaking. The disappointments were many for the people concerned, but we were able to provide a good service, which left them feeling that at least they had been heard. We did not have one single complaint in the 4-5 years of the Service.[471]

Recommendation 16: That VARTA assume the responsibilities of the agency referred to in Recommendation 14.

6.3.2.2 Management of the donor registers

BDM currently uses databases for all applications to the voluntary and central registers, which allows for the automatic matching of data.[472] In order to effectively manage the donor registers, ownership of and responsibility for these databases should be transferred to the agency that has responsibility for facilitating contact between donor-conception stakeholders, and for the provision of counselling services. These and related matters are discussed in detail in Chapter Seven.

Recommendation 17: That the Victorian Government introduce legislation to transfer ownership of, and responsibility for, the donor register databases currently held by the Victorian Registry of Births, Deaths and Marriages to the agency referred to in Recommendation 14.

6.3.2.3 Counselling and donor-linking

A recurrent theme in submissions and evidence was the vital importance of specialist, ongoing counselling for all donor-conception stakeholders, especially in the early stages of linking, leading up to contact.[473] It is the

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[471] Helen Kane, *Submission no. 46*, 9 August 2011, p. 4.

[472] Erin Keleher, Manager of Strategic Projects, Registry of Births, Deaths and Marriages, *Transcript of evidence*, Melbourne, 21 November 2011, p. 24.

[473] See Sonia Allan, *Submission no. 5*, 2 August 2010; Australian Family Association, *Submission no. 68*, 15 August 2011; Australian Medical Association (Victoria), *Submission no. 71*, 18 August 2011; Agnes Bankier, *Submission no. 38*, 25 July 2011; Eric Blyth, *Submission no. 43*, 8 August 2011; Kate Bourne, *Submission no. 35*, 11 August 2010; Barbara Burns, *Submission no. 9*, 3 August 2010; Lauren Burns, *Submission no. 3*, 29 July 2010; Ken Daniels, *Submission no. 75*, 9 September 2011; David de Kretser, *Submission no. 54*, 11 August 2011; Kate Dobby, *Submission no. 33*, 10 August 2010; Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010; Fertility Society of Australia, *Submission no. 66*, 12 August 2011; Narelle Grace Grech, *Submission no. 18*, 6 August 2010; Helen Kane, *Submission no. 16*, 6 August 2010; Gab Kovacs, *Submission no. 40*, 3 August 2011; Merrilyn Mannerheim and Jo Moffat, *Submission no. 41*, 4 August 2011; Melbourne IVF, *Submission no. 32*, 9 August 2010; Monash IVF, *Submission no. 26*, 6 August 2010; Murdoch Children's Research Institute, *Submission no. 52*, 11 August 2011; Name withheld, *Submission no. 34*, 11 August 2010; Name withheld, *Submission no. 13*, 5 August 2010; Office of the Victorian Privacy Commissioner, *Submission no. 58*, 12 August 2011; Rainbow Families Council, *Submission no. 17*, 6 August 2010; Damien W Riggs, *Submission no. 23*, 6 August 2010; Romana Rossi, *Submission no. 25*, 6 August 2010; Shelley Sandow, *Submission no. 7*, 3 August 2010; Ian Smith, *Submission no. 55*, 11 August 2011; Kimberley Springfield, *Submission no. 20*, 6 August 2010; Nicholas Tonti-Filippini, *Submission no. 45*, 9 August 2011; VANISH Inc, *Submission no. 8*, 3 August 2010; Victorian Assisted Reproductive Treatment Authority, *Submission no. 19*, 6 August 2010; Victorian Infertility Counsellors Group, *Submission no. 22*, 6 August 2010; Christine Whipp, *Submission no. 31*, 9 August 2010.

Committee's opinion that donor-conception stakeholders should have access to comprehensive counselling and support services, in accordance with VARTA's observation that:

> … it is important that a counselling service is comprehensive, that it can be linked with public education initiatives, that all the parties have a chance to apply for information – those born prior to the legislation as well as those born after the legislation – and that the counselling, support and information are available to not only the person applying but also the other party where an outreach is made to see whether they are prepared to provide consent.[474]

As noted in Chapter Three, it is critical that adequate counselling support be provided to accompany changes recommended by the Committee to allow access to identifying information about donors by donor-conceived people. It is essential that those donors who are contacted in regard to their donor-offspring, and who would previously have had no expectation that their donor-conceived offspring might make contact, have access to support and counselling to assist them in dealing with this unexpected experience. The availability of counselling may also be important during the period that changes in access to information are promoted, prior to implementation. Donors, donor-recipients, donor-conceived people and their families may all benefit from the availability of counselling as they contemplate the potential effect of legislative change on their lives.

Without being prescriptive, the Committee considers that the counselling and donor-linking services provided by the agency referred to in Recommendation 14 should essentially follow the model of the services previously provided by the ITA, illustrated in Figure 4 (page 122). This would include the agency making counselling and support services available to:

- any person who is considering making an application to the donor registers;
- relatives of donor-conceived people, donors, and recipient parents, where requested;
- any person who is the subject of an application for information;
- any person who applies for identifying information but is unable to obtain it;
- any person who has received identifying information about another party but is unsure of how to proceed; and
- all donor-conception stakeholders, including pre-1988 stakeholders.

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[474] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 41.

The Committee considers that a donor-conceived person who is seeking identifying information about their donor should be required to attend a counselling session before the application progresses. Similarly, because post-1988 donors have the right to seek identifying information about their donor-offspring, the Committee considers that they also should be required to attend a counselling session before the donor-conceived person is contacted to seek consent to release the information.

A donor-conceived person who is contacted to seek their consent to releasing identifying information should be strongly encouraged to attend a counselling session with VARTA, as should a donor who is the subject of an application for identifying information. If the donor wishes to lodge a contact veto, the donor should be required to attend a counselling session, and asked to provide reasons as to why he or she wishes to place the veto, so that these reasons can be conveyed to the donor-conceived person.

The Committee believes that support from counsellors should be made available to stakeholders throughout the linking process, and that the agency referred to in Recommendation 14 should have the ability to act as an intermediary for the parties.

Recommendation 18: That the agency referred to in Recommendation 14 offer comprehensive and ongoing counselling and support services, in association with managing the donor registers, to all donor-conceived people, recipient parents and donors, and their relatives, and that counselling be compulsory for:

- a donor-conceived person who is seeking identifying information about his or her donor;
- a donor who is seeking identifying information about his or her donor-conceived offspring; and
- a donor or donor-conceived person who applies to lodge a contact veto.

Although donor-conceived people will have the right to obtain identifying information, it is not the Committee’s intention that identifying information about the donor should be released immediately upon request. The Committee’s preference is that the agency referred to in Recommendation 14 should be available as an intermediary to assist the parties to exchange information at a pace with which they are comfortable, and assist those parties to agree on an appropriate time at which identifying information be provided. Ultimately, however, it is the Committee’s view that if a donor-conceived person would like to obtain identifying information about their donor, they should be able to receive that information without unreasonable delay.

The Committee recognises that there may be some donors who will wish to avoid providing identifying information, either due to personal preference, or because they have concerns about the effect of revealing that information on their family and/or career. The Committee notes, however, that the system of contact vetoes, and contact preferences, outlined in Recommendation 4 and Recommendation 5, should provide adequate protection to donors in all but the most extraordinary of circumstances.

Therefore, the Committee recommends that there should be a mechanism to allow the release of identifying information to a donor-conceived person, an appropriate length of time after that person's donor has been identified and contacted by the agency referred to in Recommendation 14. The period of time after which identifying information must be released to a donor-conceived person should be consistently applied by the agency to all applicants, and should be sufficient to allow the donor to obtain counselling and carefully consider his or her options for further communication.

During the interval between a donor-conceived person applying for and receiving identifying information, the agency should undertake to offer counselling to all parties about options for engagement with one another.

Recommendation 19: That the Victorian Government introduce a mechanism by which identifying information about a donor can be released directly to a donor-conceived person, in appropriate circumstances.

6.3.2.4 Letterbox service

As discussed above, at present no agency offers a means for donor-conception stakeholders to communicate via an intermediary letterbox service. Due to the lack of provision in the *Assisted Reproductive Treatment Act 2008* for sharing information, a letterbox service that enables the secure transmission of non-identifying information from one party to another is not currently possible.[475]

Many consider the letterbox service previously provided by the ITA to have been an essential service, as it allowed parties to exchange correspondence in a neutral environment and enabled a relationship to develop between them at a gradual and comfortable pace.[476] Several witnesses and submissions specifically called for a letterbox service to be reinstated.[477]

The Committee notes that FIND currently provides a letterbox service to parties involved in adoption, but not for donor-conception stakeholders.[478] One submission to the Inquiry argued that making a letterbox service

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[475] Ibid, p. 40.

[476] See, for example, Shelley Sandow, *Submission no. 7*, 3 August 2010.

[477] Australian Medical Association (Victoria), *Submission no. 71*, 18 August 2011; Kate Bourne, *Submission no. 35*, 11 August 2010; Lauren Burns, *Submission no. 3*, 29 July 2010; Kate Dobby, *Submission no. 33*, 10 August 2010; Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010; Fertility Society of Australia, *Submission no. 66*, 12 August 2011; Helen Kane, *Submission no. 16*, 6 August 2010; Name withheld, *Submission no. 29*, 9 August 2010; VANISH Inc, *Submission no. 8*, 3 August 2010; Victorian Assisted Reproductive Treatment Authority, *Submission no. 19*, 6 August 2010; Victorian Infertility Counsellors Group, *Submission no. 22*, 6 August 2010.

[478] Mariaelisa Tumino, Former manager, Family Information Networks and Discovery (FIND), *Transcript of evidence*, Melbourne, 21 November 2011, p. 15.

available for adopted persons, but not for donor-conceived persons, is discriminatory.[479]

The letterbox service was highly valued by those who used it, and did not require a significant amount of time and effort on the part of the ITA to operate it. The Committee considers that a letterbox service is a valuable service, and should be available to donor-conception stakeholders.

Recommendation 20: That the agency referred to in Recommendation 14 provide a letterbox service for donor-conception stakeholders, based on the service previously provided by the ITA.

6.3.2.5 Education and public campaigns

The Committee acknowledges that VARTA (and the former ITA) have done some excellent work providing educational resources for donor-conception stakeholders, particularly through the *Time to Tell* campaign. The Committee believes that the agency referred to in Recommendation 14 should continue this important work, and should integrate education with the other services that it will provide if the Committee's recommendations in this Chapter are implemented. VARTA should continue to play an important role in providing education and resources around assisted reproductive treatment and infertility more generally.

If the Committee's recommendations for change throughout this Report are implemented, an educational campaign will be needed to inform stakeholders of changes to their rights, and to the system for seeking access to identifying and non-identifying information. In particular, pre-1998 donors will need to be advised that their identifying details can now be released, regardless of whether they provide consent. Information will also need to be disseminated about the contact veto system, and about the services that will be offered by the agency to donor-conception stakeholders.

Recommendation 21: That if the Committee's recommendations are implemented, VARTA conduct a public information and awareness campaign advising the public of relevant changes in the provision of information to donor-conception stakeholders, particularly targeting pre-1998 donors.

The Committee notes that anecdotal evidence suggests many donor-conceived people, especially those conceived before 1988, are unaware of the circumstances of their conception. As discussed in Chapter Three, the Committee considers that these people have a fundamental right to know the circumstances of their parentage. Changing legislation to allow pre-1998 donor-conceived people to access identifying information, as recommended in Chapter Three, may encourage parents to tell their children about their conception:

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[479] Name withheld, *Submission no. 29*, 9 August 2010.

> I think it may also help encourage families to be honest with their children and also help donors to come forward and be honest with their families as well. We know there is a lot of secrecy that has surrounded this issue for a long time, and while we have the Time to Tell seminar and that sort of thing, it is very targeted at telling young children now. It is not so much targeted at adults, like people from my generation. A lot of them still do not know, and I would not know if it was not for the fact that these things are very hard to keep secret. It was passed down the family. It is not something that was deliberately told to us, and I think that is the same for a lot of families. I think that public awareness and bringing out the openness and honesty in a real sense would help families, donor-conceived people, donors and all of their families just to bring it out into the light and be able to talk about it.[480]

However, parents who have not told their children will require support and resources to assist them in doing do. The Committee believes that VARTA will have an important role to play in providing support to these parents, and in encouraging them to tell their children about their conception.

Recommendation 22: That VARTA continue its education and public campaigns role, with a particular focus on encouraging and supporting the parents of older donor-conceived children to tell their children about the circumstances of their conception.

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[480] Kimberley Turner, *Transcript of evidence*, Melbourne, 5 December 2011, p. 28.

Chapter
7

Chapter Seven:
Protection and management of records

7.1 Current status of records

During the course of the Inquiry, the Committee heard a range of concerns expressed about the integrity, vulnerability and accessibility of pre-1988 donor-conception records. A significant proportion of these records were created prior to the introduction of legislation regulating donor-conception, and the processes, content, and ownership of those records is very much contingent on when they were made, where, and by whom. While these types of records are nowadays regarded as a type of identity document, in many cases they were created as, or functioned as, medical records, or agreements between parties involved in donor-conception to not seek one another out.

Consequently, donor-conception records are held in diverse locations, and by a diverse range of agencies and individuals – by the clinic at which the fertility procedure was carried out, or by the successor to the original fertility clinic, by the Public Record Office Victoria (PROV), and (anecdotally) by practising or retired physicians, or their families. There may also be cases where records have been destroyed or lost, particularly where the records were created by a physician in private practice.

Where records are held privately, they are not currently protected under any legislation, and are legally able to be destroyed at any time. The Committee also heard that pre-1988 records from one of the former major fertility clinics were destroyed in the past.[481]

In this Chapter, the Committee considers how to best ensure that records are managed appropriately, with a view to ensuring that information is preserved, is accurate, and is accessible to those entitled to access it.

7.1.1 History of fertility clinics in Victoria

As mentioned in Chapter Two, in the late 1970s and into the 1980s, the Queen Victoria Medical Centre, the Royal Women's Hospital, and Prince Henry's Hospital were the major clinics carrying out donor-conception

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[481] Kate Dobby, *Transcript of evidence*, Melbourne, 8 September 2011, p. 30; Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 38.

procedures in Victoria.[482] In addition, some doctors were providing donor insemination services to patients privately.[483]

Today, two of the main clinics in Victoria that perform assisted reproduction and donor-conception procedures are Melbourne IVF and Monash IVF.

7.1.1.1 Melbourne IVF

Melbourne IVF is a privately-owned, for-profit fertility clinic, with seven locations throughout Victoria. Melbourne IVF has a long-standing relationship with the Royal Women’s Hospital, originating from its Reproductive Biology Unit, and was founded in 1989.[484] Melbourne IVF currently provides some of its fertility treatment services through the Reproductive Services Unit of the Royal Women’s Hospital.[485] Melbourne IVF also has day hospitals and performs diagnostics, and deals with all types of fertility and IVF issues.[486]

7.1.1.2 Monash IVF

The Queen Victoria Medical Centre's clinical IVF program was Monash University’s IVF program, and is now called Monash IVF (previously the Infertility Medical Centre, and before that, the Melbourne Family Medical Centre). Monash IVF is also a for-profit fertility business, and has Victorian clinics at the Epworth Hospital in Richmond, the Monash Day Surgery in Clayton and five regional clinics throughout Victoria.[487]

7.1.1.3 Queen Victoria Medical Centre

The Queen Victoria Hospital was established in 1896. In 1973, the Melbourne Family Medical Centre (Monash University’s IVF program) was established at the Queen Victoria Hospital, and was then the largest donor insemination clinic in Australia.[488] In 1977, the hospital amalgamated with McCulloch House and was renamed the Queen Victoria Medical Centre. During the 1980s, some IVF patients in the Queen Victoria Medical Centre program had their treatments carried out at the Epworth Hospital.[489]

In 1987, the Queen Victoria Medical Centre merged with Moorabbin Hospital, and relocated to the Monash Medical Centre at Clayton. In 1991 it was involved with yet another merger, this time with the Prince Henry's

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[482] Lyndon Hale, IVF Directors Group, Fertility Society of Australia, *Transcript of evidence*, Melbourne, 8 September 2011, p. 14.

[483] Standing Review and Advisory Committee on Infertility, *Issues paper on donor gametes in IVF*, SRACI, Melbourne, 1983, p. 4.

[484] IVF Success, 'Our network', viewed 2 February 2012, <www.ivfsuccess.com.au>.

[485] Melbourne IVF, 'IVF Clinic Parkville', viewed 12 January 2012, <www.mivf.com.au>.

[486] Andrew Othen, Managing Director, Melbourne IVF, *Transcript of evidence*, Melbourne, 10 October 2011, p. 12.

[487] Monash IVF, 'History of IVF', viewed 21 January 2012, <www.monashivf.com>.

[488] JF Leeton and A Asche, 'Artificial insemination by donor - and beyond', *Medico-Legal Society Proceedings*, 1981, p. 78.

[489] Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Report on donor gametes in IVF*, Melbourne, 1983, p. 4.

Hospital, to form the Monash Medical Centre, a multi-campus teaching hospital.[490]

7.1.1.4 Prince Henry's Hospital

The Prince Henry's Hospital opened as a hospital for the sick poor in 1876, and from 1885, it was situated on St Kilda Road. The Medical Research Centre was incorporated in 1990 and renamed the Prince Henry's Institute of Medical Research.[491] In 1987, the Prince Henry's Hospital was amalgamated with the Queen Victoria Medical Centre and Moorabbin Hospital to form the Monash Medical Centre, which opened in 1992.[492]

7.1.2 Pre-1988 records

For donor-conception records created prior to 1988, there were (and still are) no legislative requirements or consistent procedures around their collection and retention. The management of these records was at the discretion of the clinics and the doctors who provided the treatment. There is no obligation on clinics or doctors who hold pre-1988 donor records to retain those records – they are subject only to the *Health Records Act 2001* (Vic), which requires that records are retained for seven years from the most recent patient consultation.[493] Records held by private institutions are maintained according to NHMRC guidelines and industry standards and practices, and internal institutional policies. Records held by PROV, however, are protected by privacy provisions under the *Public Records Act 1973* (Vic), and are unlikely to be destroyed.

According to the Victorian Assisted Reproductive Treatment Authority (VARTA), who previously managed the donor registers as the Infertility Treatment Authority (ITA), the quality of pre-1988 records is mixed, but there is a large number of records kept at the major centres that are in good condition:[494]

> One of our roles as the Infertility Treatment Authority was to license the IVF clinics, and we used to inspect records on a regular basis as part of an audit process. Sometimes donors who were used prior to legislation were also used after legislation, so we did inspect records. Having viewed a number of records, I know there are substantial records in good condition.[495]

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[490] The Australian Women's Register, 'Queen Victoria Hospital 1896 - 1977', viewed 12 January 2012, <www.womenaustralia.info>.

[491] The Encyclopedia of Melbourne Online, 'Prince Henry's Hospital', viewed 19 January 2012, <www.emelbourne.net.au>.

[492] Ibid.

[493] *Health Records Act 2001* (Vic), Schedule 1, Principle 4.2.

[494] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 38.

[495] Ibid.

Pre-1988 records held by the clinics are physical paper records (that is, they are not in electronic format).[496] This means that accessing and extracting information from these records will tend to be a labour-intensive process, at least until such time as they may be compiled in electronic format.

While a large number of records held by clinics and PROV are in good condition, the Committee heard that there may be gaps in some of the records – some may be incomplete or inaccurate, or have deteriorated over time. As noted above, in some cases, records may no longer exist, particularly where treatment was carried out privately by doctors.[497] The Committee also heard there may be some rare instances where information in records has been altered or tampered with.[498]

7.1.2.1 Queen Victoria Medical Centre records

VARTA advised the Committee that records that were kept at the Queen Victoria Medical Centre have been destroyed.[499] However, Monash IVF holds some records previously held by Queen Victoria Medical Centre, as Ms Maria Gabbe, Donor Coordinator at Monash IVF, explained:

> Monash IVF donor records came from the Melbourne Family Medical Centre [at the Queen Victoria Medical Centre] which were specifically dealing with donor insemination, and then later on a few of these may have been part of Monash IVF's IVF Program because that's merged there a little bit towards the end.[500]

7.1.2.2 Royal Women's Hospital records

The Committee heard that the Royal Women's Hospital always maintained information regarding donors and donor treatments.[501] Melbourne IVF confirmed that records dating back to before the formation of Melbourne IVF in 1989 remain in storage at the Royal Women's Hospital, with Melbourne IVF able to access them as required:

> Because Melbourne IVF was born out of the doctors that stemmed out of the reproductive services at the Women's Hospital, the records primarily were kept at the Women's Hospital and they remain in storage at the Women's Hospital. So anything beyond the starting point of Melbourne IVF is all stored at the Women's Hospital, which we have access through our

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[496] Rita Alesi, Victorian Infertility Counsellors Group, *Transcript of evidence*, Melbourne, 12 September 2011, p. 26; Marianne Tome, Victorian Infertility Counsellors Group, *Transcript of evidence*, Melbourne, 12 September 2011, p. 26.

[497] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 38.

[498] Kate Dobby, *Transcript of evidence*, Melbourne, 8 September 2011, pp. 30, 31; Maria Gabbe, Donor Coordinator, Monash IVF, *Transcript of evidence*, Melbourne, 17 October 2011, p. 28.

[499] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 38.

[500] Maria Gabbe, Donor Coordinator, Monash IVF, *Transcript of evidence*, Melbourne, 17 October 2011, p. 29.

[501] Melbourne IVF, *Submission no. 32*, 9 August 2010, p. 7.

> contract with them. So that information is accessible on a daily basis to us.[502]

Thus, pre-1988 records from the Royal Women's Hospital are held in one location and for the most part, should be reasonably secure, complete, and accurate.

Melbourne IVF noted that while information held in the records, such as address and marital status, would have been relevant to the donor at the time of donation, further investigation would be required to determine contemporary information about donors, based on the information in the records.[503] This caveat will apply to all pre-1988 records, regardless of where the procedure was undertaken.

7.1.2.3 Prince Henry's Hospital records

Around 1,500 women received donor-conception treatment through Prince Henry's Hospital in the 1980s and during the first couple of years after the *Infertility (Medical Procedures) Act 1984* came into effect, prior to the closure of the clinic.[504] These recipient and donor insemination records were preserved and, in November 2006, were transferred to PROV.[505]

Ms Lauren Burns was conceived before 1988 through the Prince Henry's Hospital program and spent some years tracking down donor records, seeking the identity of her biological father. According to Ms Burns, the records from Prince Henry's Hospital are physical paper records, and they feature a treatment register:

> The Central Treatment Register contains the name of each donor insemination recipient (commissioning mother), together with the name and date of birth of the donor whose sperm she received. I know that the Central Treatment Register dates back to at least July 1980 (possibly further), because it records the birth of my older sister in this month and year. The existence of the Central Treatment Register should ensure the completeness of the Prince Henry's Records. Furthermore, the Central Treatment Register contains records of half siblings by identifying which recipients received sperm from the same donor. However it may only contain enough information to be able to contact the parents of half siblings, rather than the siblings themselves, since the name of the donor conceived child may not be recorded.[506]

In response to a suggestion that some doctors may have themselves provided sperm donations, Professor Gab Kovacs, who was formerly the

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[502] Joanne McCann, Operations Manager, Melbourne IVF, *Transcript of evidence*, Melbourne, 10 October 2011, p. 13.

[503] Melbourne IVF, *Submission no. 32*, 9 August 2010, p. 7.

[504] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 38.

[505] Infertility Treatment Authority, *Annual report 2009: twelfth and final report*, ITA, Melbourne, 2009, p. 4.

[506] Lauren Burns, *Submission no. 3*, 29 July 2010, p. 9.

head of the Prince Henry's artificial insemination program, confirmed that the clinic had a high standard of practice and record-keeping:

> I ran the Prince Henry's service; we had a very tight ship. I think what they are talking about is some decades ago, there were some private practitioners and donor insemination with fresh sperm where it was very informal and with the source of the semen there is no paper trail. But on Prince Henry's, Henry Burger was the director of the clinic. David de Kretser set it up. So nothing more needs to be said. The propriety of the clinic was very clear. Everything was recorded … every single donation is recorded and every single pregnancy recorded.[507]

Monash IVF also holds a small number of Prince Henry's Hospital pre-1988 records, as Prince Henry's infertility treatment program was sold to Monash IVF, and records of current patients were transferred to Monash IVF.[508] Records of former patients remained with Prince Henry's Hospital, before being transferred to PROV.[509]

7.1.2.4 Accessing records at the Public Record Office Victoria

PROV has a legislative mandate to take permanent public records into custody.[510] As a public hospital, Prince Henry's Hospital was considered to be a "public office" within the meaning of the *Public Records Act 1973*. Records that were created by Prince Henry's Hospital are therefore public records able to be held by PROV.[511]

In 2004, Prince Henry's Hospital approached PROV and, after conducting an assessment of the records, PROV issued a disposal authority declaring the "Sperm Donor Files", "Index to Sperm Donor Codes" and "Patient Files" to be permanent records. The transfer of these records to PROV was completed in November 2006.[512]

The records transferred from Prince Henry's Hospital to PROV have been declared 'closed' records, under section 9(1) of the *Public Records Act 1973*. This means that these records are not accessible by the general public, but can be accessed by the agency that created the records, or the agency which currently exercises the function described by the records, referred to in the legislation as the "Responsible Agency".[513]

PROV advised the Committee that the ITA was the Responsible Agency for the Prince Henry's Hospital records until the establishment of VARTA, and the Registry of Births, Deaths and Marriages (BDM) is currently the Responsible Agency:

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[507] Gab Kovacs, *Transcript of evidence*, Melbourne, 10 October 2011, pp. 33-34.
[508] Rita Alesi, Victorian Infertility Counsellors Group, *Transcript of evidence*, Melbourne, 12 September 2011, p. 23.
[509] Public Record Office Victoria, *Personal communication*, 22 December 2011.
[510] *Public Records Act 1973* (Vic), section 8A.
[511] Public Record Office Victoria, *Personal communication*, 22 December 2011.
[512] Ibid.
[513] Ibid.

> The Responsible Agency became the Registry of Births, Deaths and Marriages (BDM) in February 2011, following the receipt of a letter from the Registrar of Births, Deaths and Marriages advising that with the commencement of the *Assisted Reproductive Treatment Act 2008* on 1 January 2010, the Victorian Assisted Reproductive Treatment Authority was no longer responsible for access to and maintenance of the donor register and that this responsibility had passed to BDM.[514]

Despite BDM's designation as the Responsible Agency, it is not possible for BDM to use the records proactively to contact pre-1988 donors, for example, at the request of a donor-conceived person seeking information about the donor:

> If you were born prior to the legislation and your mother was treated at Prince Henry's Institute for Medical Research, you could only make an application to the voluntary register through the Registry of Births, Deaths and Marriages. The Infertility Treatment Authority and the Registry of Births, Deaths and Marriages explored the scope to proactively use these records, and under the legislation that is not possible. If your mother was treated at the Royal Women's Hospital, for example, it may be possible for a treating doctor to actually seek contact with the donor and see whether the donor is prepared to provide consent to release non-identifying information to a young person making an inquiry. The problem is that the legislation does not enable the Registry of Births, Deaths and Marriages to proactively make that same inquiry in relation to the Prince Henry's Institute records.[515]

This places pre-1988 donor-conceived people whose mothers received treatment at Prince Henry's Hospital at a disadvantage, compared with those who were conceived through the Royal Women's Hospital. The Committee heard a stark illustration of this, with Ms Narelle Grech recounting her efforts to learn the identity of her biological father.

Ms Grech has known since she was 15 years old that she is donor-conceived. At that age, she contacted her mother's treating doctor, Professor Gab Kovacs, formerly of Prince Henry's Hospital, who had access to the relevant Prince Henry's treatment records, as they had not yet been transferred to PROV. Based on the records, Professor Kovacs identified three people who could potentially be Ms Grech's donor, all of whom had the same first initial and surname. Professor Kovacs apparently wrote to each of these people at their last known address, as well as their addresses from the phone book.[516] However, no response was received from Ms Grech's donor.

Ms Grech approached Professor Kovacs again some years later, and requested that he again attempt to make contact with her donor. Ms Grech

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[514] Ibid.

[515] Louise Johnson, Chief Executive Officer, Victorian Assisted Reproductive Treatment Authority, *Transcript of evidence*, Melbourne, 8 September 2011, p. 38.

[516] Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, p. 33; Gab Kovacs, *Transcript of evidence*, Melbourne, 10 October 2011, pp. 26-27.

told the Committee that Professor Kovacs informed her that he had sought the advice of the Prince Henry's Ethics Committee, and they determined that it would be a breach of the donor's privacy to attempt to contact him again, so no further attempts at contact were made.[517]

Since that time, the records relating to Ms Grech's conception have been transferred to PROV, and are no longer accessible by Professor Kovacs. Professor Kovacs advised the Committee that he recently lodged a freedom of information request seeking access to the notes that he and others from his team had written, which includes identifying information about donors, but this request was rejected on the basis that:

> … I cannot get information, it is not my information, it is other people's, third party's information and therefore freedom of information does not apply and I cannot get access to those notes, even though I wrote a lot of them or my team wrote a lot of them.
>
> Now we actually have no way of getting to the notes. That is a special problem for the Prince Henry's conceived offspring.
>
> … There is no other record anywhere else. All the records were kept in the clinic histories and are now locked up by the Public Records Office.[518]

As Professor Kovacs can no longer access Ms Grech's records, and BDM is not legally able to use them to make contact with Ms Grech's donor, it appears that there is currently no possible avenue for Ms Grech to follow in seeking to discover the identity of her biological father. Other people conceived through the Prince Henry's Hospital program would be in the same position as Ms Grech.

7.1.2.5 Private doctors' records

In addition to the three main fertility clinics described above, some doctors provided donor insemination treatments from their private consulting rooms, particularly in the early days of donor insemination.

Ms Helen Kane, former Manager of the ITA's Donor Registers Service, advised that in the course of receiving inquiries and applications for information from the central register, the ITA was continually increasing its knowledge of what had actually happened in donor-conception practices, who had provided the services, where they were provided, and what the quality of the records was:[519]

> … the history of her [Kate Dobby] managing the registers and setting up the registers, that was before I was employed, was of actually sussing out, working out, because the parents would say where they had their treatment so we knew about private clinics, we knew about the doctors and the doctors who were providing donor insemination in their private rooms. …

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[517] Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, p. 33.
[518] Gab Kovacs, *Transcript of evidence*, Melbourne, 10 October 2011, pp. 24-25.
[519] Helen Kane, *Transcript of evidence*, Melbourne, 12 September 2011, p. 14.

> There are practical issues which relate to the way the records have been kept. Private doctors in their private practices, as well as doctors within public and private hospitals, have all provided donor treatments since well before the 1940s, with a huge increase in the 1970s and into the 1980s. There was enormous variation in the way that the records were kept but, most importantly, they were not all kept at the time, or were destroyed when medical practices closed down. We're all aware of at least one of those private suburban practices where the records were literally destroyed.
>
> … The doctors were not breaking any laws with what they were doing, it was more not understanding the information and the importance of what they held in their records.[520]

While Ms Kane considered that there would be very few 'pockets' of privately held records around Victoria,[521] she also suggested that it would be desirable to have a mechanism to require that private records be handed over to a central authority, as such records do exist, and it would resolve issues for doctors who are still holding onto them:

> What would be really lovely is if you actually made it possible to get those [records held privately by individual doctors] because they do exist. Because one of the quandaries is – I assume it's a quandary for the doctors too – these are private patient records and, yes, there are doctors with records in their garage. But if in fact you actually had a way of them handing over those records, I would imagine some easing of concerns on their part too.[522]

7.1.3 Post-1988 records

7.1.3.1 Central register

The Committee did not hear of any significant concerns from witnesses regarding the quality and completeness of post-1988 records, as prescribed information regarding post-1988 procedures has been maintained on the central register (see Table 2 of Appendix Four). For procedures undertaken since commencement of the *Infertility (Medical Procedures) Act 1984*, hospitals and doctors providing donor-conception services have been required to keep registers recording details of donor-conception procedures, and have been required to pass on information to the government agency managing the central register (variously the Health Commission, the Infertility Treatment Authority, and now BDM) for inclusion in the central register.[523]

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[520] Ibid, pp. 14-15.
[521] Ibid, p. 15.
[522] Ibid, p. 14.
[523] See *Infertility (Medical Procedures) Act 1984* (Vic), sections 19, 21 & 22; *Infertility Treatment Act 1995* (Vic), Part 7; *Assisted Reproductive Treatment Act 2008* (Vic), Part 6.

7.2 Measures to protect and manage records

7.2.1 Records to have protected status

A number of submissions expressed concern about the possibility of pre-1988 donor records being destroyed, and the impact that this may have on donor-conceived people. There were calls to attempt to locate donor records, and accord them protected status to prevent their destruction.[524]

In the Interim Report released by the Law Reform Committee during the 56th Parliament, the Law Reform Committee recommended 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.[525]

The Committee is unaware of any action taken by the Government to date to implement this recommendation. The Committee believes that it is important that these records, which contain vital information relating to the identity of donor-conceived people, should be protected and preserved.

The Committee notes that a proportion of these documents are currently held by PROV and by private clinics. Records held by PROV are unlikely to be destroyed, and records held by clinics are preserved in accordance with the NHMRC Guidelines, which require clinics to make:

> - arrangements to ensure transfer of records to a suitable person or location when a clinic closes or a practitioner ceases to practise (such arrangements should ensure that records stay with the gametes and embryos to which they relate); and
> - provision to keep records indefinitely (or at least for the expected lifetime of any persons born).[526]

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[524] Ad Hoc Interfaith Committee, *Submission no. 70*, 16 August 2011; Australian Christian Lobby, *Submission no. 56*, 12 August 2011; Australian Family Association, *Submission no. 68*, 15 August 2011; Agnes Bankier, *Submission no. 38*, 25 July 2011; Eric Blyth, *Submission no. 43*, 8 August 2011; Kate Bourne, *Submission no. 35*, 11 August 2010; Barbara Burns, *Submission no. 9*, 3 August 2010; Lauren Burns, *Submission no. 3*, 29 July 2010; David de Kretser, *Submission no. 54*, 11 August 2011; Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010; Fertility Society of Australia, *Submission no. 66*, 12 August 2011; Helen Kane, *Submission no. 16*, 6 August 2010; National Health and Medical Research Council, *Submission no. 48*, 10 August 2011; Office of the Victorian Privacy Commissioner, *Submission no. 58*, 12 August 2011; Kimberley Springfield, *Submission no. 20*, 6 August 2010; TangledWebs Inc, *Submission no. 21*, 6 August 2010; Nicholas Tonti-Filippini, *Submission no. 45*, 9 August 2011; VANISH Inc, *Submission no. 8*, 3 August 2010.

[525] Law Reform Committee, *Inquiry into access by donor-conceived people to information about donors: interim report*, Parliament of Victoria, Melbourne, 2010, p. ix.

[526] 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, p. 49.

While these arrangements ensure that these records will be preserved in the medium term, the Committee's view is that donor records should be regarded as a species of identity record, and as is the case with identity records administered by the state, all such records should be preserved indefinitely. The Committee notes that the NHMRC Guidelines do not, in fact, *require* indefinite storage of these documents.

A more urgent consideration, however, is the status of donor-conception records held privately, or by bodies that are not subject to the NHMRC Guidelines or PROV practices. The Committee believes it is critical that these records be preserved. Consequently, the Committee recommends that measures be introduced to ensure that all records that provide a means to identify parties to donor-conception (that is, donors, donor-recipients, and donor-conceived people) are preserved indefinitely.

Recommendation 23: That the Victorian Government introduce legislation to provide that destruction of, falsifying or tampering with, any records that identify parties to donor-conception is an offence.

7.2.2 Centralisation and management of records

7.2.2.1 Centralisation of donor-conception records

The Committee received several submissions advocating that all donor-conception records should be held and managed by a central authority.[527] Under a centralised approach, all those who currently hold pre-1988 donor-conception records (clinics, doctors and PROV) would be required to provide those records, either in original or copied form, to a central agency. The central agency should also be responsible for managing the donor registers, so that they would hold and deal with information relating to both pre- and post-1988 donor-conceptions.

The advantages of holding all donor-conception records and information centrally, rather than having them disbursed across a number of bodies as they are currently, include that:

- common record management protocols and indexes would be easier to implement;
- auditing and identification of gaps in records would be simpler;
- it would be easier to ensure consistency in access to records; and

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[527] Sonia Allan, *Submission no. 5*, 2 August 2010; Australian Medical Association (Victoria), *Submission no. 71*, 18 August 2011; Barbara Burns, *Submission no. 9*, 3 August 2010; David de Kretser, *Submission no. 54*, 11 August 2011; Office of the Victorian Privacy Commissioner, *Submission no. 58*, 12 August 2011; Shelley Sandow, *Submission no. 7*, 3 August 2010; Kimberley Springfield, *Submission no. 20*, 6 August 2010; Nicholas Tonti-Filippini, *Submission no. 45*, 9 August 2011; Victorian Infertility Counsellors Group, *Submission no. 22*, 6 August 2010.

- there would be a single point of access for people seeking information.

Ms Rita Alesi, Manager of Counselling Services at Monash IVF, endorsed the suggestion that records should be centralised, and suggested that a central system would assist with meeting challenges with records:

> I like the idea of having a central register because there is uniformity and consistency across all the sites and everyone has access to the same level of rights and I think then there's a system in place to deal with all sorts of challenges. One of the biggest challenges that I've been facing is accessing records but the records have either been tampered with, information is missing or information, if it is intact, is actually very minimal. … So the information where there has been details crossed out, and I can think of some historically where there's a name and address, it's actually been cut out.[528]

On the other hand, the Committee heard that clinics may have reservations about handing their records over to a central agency. For example, Dr Lyndon Hale of the Fertility Society of Australia, who is a practitioner at Melbourne IVF, stated that:

> We, as an organisation, would think that we have a duty of care, given the treatment we offered in the past. If it is going to become more common, then that is part of the skill set that we expect our counsellors and doctors to have. The Fertility Society as well as the clinics … would think we are at the forefront of where this is all going and that, therefore, we are the experts and should be providing the advice.[529]

Dr Hale's colleague, Dr Penelope Foster, agreed with him, noting that Melbourne IVF, as one of the original care providers for women who have had fertility treatment, feels a duty to provide donor-linking services to donor-conceived children resulting from the program, and to absorb the cost associated with this.[530] However, Dr Hale and Dr Foster also noted that one of the key considerations should be ensuring that the organisation that holds the information has staff with sufficient skills to provide effective linking services:

> I think there are two issues. One is of course information and who provides the counselling to link in, and it is quite difficult to separate them. They probably belong together, so if you give one body the information but do not provide them with the staff and the skills to use that information properly, I think there is a risk that we are running a very poor service with very bad outcomes.[531]

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[528] Rita Alesi, Victorian Infertility Counsellors Group, *Transcript of evidence*, Melbourne, 12 September 2011, p. 25.

[529] Lyndon Hale, IVF Directors Group, Fertility Society of Australia, *Transcript of evidence*, Melbourne, 8 September 2011, p. 16.

[530] Penelope Foster, Fertility Society of Australia, *Transcript of evidence*, Melbourne, 8 September 2011, p. 16.

[531] Ibid, p. 13.

As discussed in Chapter Six, the Committee considers that all counselling and donor-linking services for donor-conception stakeholders should be provided by a single agency rather than by individual clinics. The Committee believes that VARTA has the requisite knowledge, experience and skills to be able to provide these services competently. While the Committee recognises the view of some clinics that it is their responsibility to provide donor-linking services to former patients, the Committee is also cognisant that it would be very difficult to ensure consistency and continuity in access to information, and to provide commensurate service to people across multiple clinics.

The Committee also notes that IVF clinics, as for-profit corporations, may over time find the economic cost of providing donor-linking services to pre-1988 donor-conceived people burdensome, and difficult to justify within a business model.

Furthermore, while many records are held by existing clinics, a substantial proportion of records from closed institutions – such as the Prince Henry's Hospital records – are not currently accessible. If the State Government is to provide equal access to donor-conception records to all donor-conceived people, an existing or new government agency or authority would likely need to take possession of, and assume responsibility for, records currently held by PROV. This body would likely also need to take possession of records provided to it by private medical practitioners (if any). In this circumstance, it would likely be more efficient, and achieve economies of scale, if a single body was responsible for the provision of all information and counselling services pertaining to donor-conception.

As privacy issues are involved – clinics would risk committing a breach of their duty of confidentiality to patients if they simply handed records, or copies of records, over to a third party – legislative change will be required in order to secure the transfer of documents to the central agency. Previously, the ITA determined it could not make contact with pre-1988 donors – therefore, in order to preserve the donor's confidentiality, only the treating doctor or clinic was able to make contact. Centralising all records would remove such patient confidentiality concerns, and would enable all donor-conceived people access to the same, consistently applied, impartial services provided by one central agency.

Recommendation 24: That the Victorian Government introduce legislation to require that persons or organisations that hold records containing information on pre-1988 donor-conception provide copies of the records to a central agency, and in the case of PROV, that pre-1988 donor-conception records be transferred to a central agency.

Ms Lauren Burns, a pre-1988 donor-conceived person, suggested that private doctors' records could be sought through a publicised call for records, in conjunction with approaching specific identified doctors:

> Other records of donor insemination carried out by private doctors could be requested via a publicised amnesty system, with the option for dealing with this situation on a case-by-case basis, if a donor-conceived person who

> wishes to make an enquiry can name the doctor who performed the donor conception.[532]

The Committee agrees that a combination of a campaign advertising legislative changes and targeted approaches to individual doctors should be employed to facilitate the centralisation of pre-1988 donor-conception records.

Recommendation 25: That the legislative changes proposed in Recommendation 24 be advertised in a public campaign targeting the medical profession.

Recommendation 26: That the agency referred to in Recommendation 24 approach individual doctors who are known to have provided donor insemination services and obtain copies of records held by them, if any, containing information on parties to donor-conception.

7.2.2.2 Central agency

As discussed in Chapter Six, since 1 January 2010 the central register and the voluntary register have been held and maintained by BDM. Prior to that, the ITA was responsible for managing the donor registers. Based on the evidence received, and as discussed in Chapter Six, the Committee is of the view that donor-conception stakeholders' access to information and support has declined since the transfer of the central and voluntary registers from the ITA to BDM, and the subsequent fragmentation of services to donor-conceived people, donors, and donor-recipients.

It is critical that information from donor-conception records is readily accessible by those who are providing counselling to donor-conception stakeholders. The Committee recommended in Chapter Six that VARTA should be responsible for providing all counselling and support services for donor-conception stakeholders. If this recommendation is implemented, it follows that for VARTA to be able to provide these services effectively, it must have ready access to the donor registers. In this regard, several submissions and witnesses suggested that VARTA is the agency best suited to managing the registers and information about donors and donor-conceived people, and advocated that VARTA should be reinstated as the authority to manage the donor registers:[533]

> Ever since this change was put in place our group has been receiving calls asking if there is any way that the registers can revert to VARTA. VARTA

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[532] Lauren Burns, *Submission no. 3*, 29 July 2010, p. 10.

[533] Damian Adams, *Submission no. 4*, 30 July 2010; Lauren Burns, *Submission no. 3*, 29 July 2010; Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010; Helen Kane, *Submission no. 16*, 6 August 2010; Name withheld, *Submission no. 34*, 11 August 2010; Romana Rossi, *Submission no. 25*, 6 August 2010; Ian Smith, *Submission no. 55*, 11 August 2011; VANISH Inc, *Submission no. 8*, 3 August 2010; Victorian Infertility Counsellors Group, *Submission no. 22*, 6 August 2010.

> as we, and many others, have said was a "one stop shop"; a place where people could go to have all their questions answered, to get help in accessing information and if necessary access counselling. VARTA also provided a much appreciated service of being a "letter box drop" so that parties involved in donor conception could communicate with each other without meeting or invading the other's privacy.[534]
>
> Previously, I know you have heard it said before, the Infertility Treatment Authority had a very comprehensive counselling service that sat alongside the keeping of that information and that was effective, but now that has been separated, that can cause a problem I guess in terms of the information that is available.[535]

The Committee recognises that BDM has particular experience and expertise in indexing and managing data, and in providing access to, and ensuring security of, confidential information. However, the Committee also recognises the efficiencies and convenience that would result from allocating authority to a central agency for the management of donor records, in conjunction with providing counselling and support services to donor-conception stakeholders. The Committee believes that VARTA is the appropriate body to manage pre-1988 donor-conception records, as well as the central and voluntary registers, in particular to ensure that it is able to access all records relevant to its activities. The Committee notes that, provided that the central agency's access to records is assured, storage and management of donor-conception records could be subcontracted to another agency, such as BDM.

Recommendation 27: That the Victorian Government introduce legislation to transfer responsibility for the central and voluntary registers from the Victorian Registry of Births, Deaths and Marriages to the agency described in Recommendation 14.

7.2.2.3 The role of the voluntary register

As described in previous chapters, the voluntary register currently allows information to be exchanged outside the central register system, which is particularly important for pre-1988 donor-conception stakeholders who are not currently recorded on the central register. There is no fee to apply to the voluntary register for information.

Although the Committee has recommended that all donor-conceived people should have the right to access identifying information about their donor (see Chapter Three), the Committee believes that there will continue to be a role for the voluntary register. However, its purpose will likely become limited to enabling the exchange of non-identifying information, and to facilitating voluntary contact between donor-conception stakeholders other than donors and donor-conceived people. For example,

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[534] Donor Conception Support Group of Australia Inc, *Submission no. 39*, 26 July 2011, p. 4.

[535] Joanne McCann, Operations Manager, Melbourne IVF, *Transcript of evidence*, Melbourne, 10 October 2011, p. 20.

the voluntary register may facilitate contact between a donor and recipient parents (particularly before a donor-conceived child reaches 18 years of age), between recipient parents who have children conceived from the same donor's gametes, and between half-siblings.

7.2.3 Gaps in the records

The Committee heard evidence from several witnesses that there are issues with some pre-1988 records – some may have been destroyed, some are missing information (for example, they may contain only a donor name, without any further information such as a date of birth), and some may in fact record a false name for the donor. For example, Ms Maria Gabbe, the Donor Coordinator at Monash IVF, advised that:

> I'm assuming we have the file of every single donor that's come through Monash IVF, which sits in a filing cabinet behind my desk, so we have the files on the donors and those files, the early files, they are very incomplete. Some of them don't have dates of births, some of them have definitely no addresses, some of them didn't even have names because they've been cut out of the files, the signatures have been removed, and all I have is one small piece of paper. The information they were asked to give in those days was very minimal.[536]

During the Committee's public hearings, the Privacy Commissioner suggested that the existence of inaccurate data in donor-conception records may potentially lead to harm if, for example, a person was wrongly identified as a donor.[537] However, generally witnesses agreed that the incompleteness of data should not prevent information from being accessible where it does exist, but emphasised that it is vital to ensure that where information is released, it is correct.[538]

While recognising the possibility that some records pertaining to pre-1988 donors have been lost or are incomplete, submissions argued that this should not be a reason to prevent people from obtaining information where records do exist.[539] The release of even small amounts of information may be valued by donor-conceived people. In its submission, VARTA observed that:

> In general, donor-conceived people are aware of the difficulties in accessing old records and that records may be incomplete or destroyed.

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[536] Maria Gabbe, Donor Coordinator, Monash IVF, *Transcript of evidence*, Melbourne, 17 October 2011, p. 28.

[537] Helen Versey, Privacy Commissioner, Office of the Victorian Privacy Commissioner, *Transcript of evidence*, Melbourne, 8 September 2011, p. 47.

[538] Kate Dobby, *Transcript of evidence*, Melbourne, 8 September 2011, p. 31; Helen Versey, Privacy Commissioner, Office of the Victorian Privacy Commissioner, *Transcript of evidence*, Melbourne, 8 September 2011, p. 47.

[539] Lauren Burns, *Submission no. 3*, 29 July 2010; Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010; Helen Kane, *Submission no. 16*, 6 August 2010; Gordon Ley, *Submission no. 44*, 8 August 2011; VANISH Inc, *Submission no. 8*, 3 August 2010; Victorian Assisted Reproductive Treatment Authority, *Submission no. 19*, 6 August 2010.

> 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.[540]

The Committee believes that donor-conceived people should be entitled to any information available about their donor, provided that appropriate steps have been taken to verify the accuracy of information prior to its release. Where uncertainty about the accuracy of records cannot be resolved, the person to whom the information is released should be made aware of any caveats as to its reliability.

The Committee heard suggestions from witnesses about measures that could be taken to ensure that information is as complete and accurate as possible, and to facilitate the availability of information where records are not available. The key suggestions in this regard were that the voluntary register should be maintained; that advertising should be conducted to encourage donors to come forward voluntarily to provide information; and that a DNA database should be implemented to assist matching those people whose records are incomplete.[541] The Committee notes that the first two of these suggestions are already available, or practised, in Victoria. However, there is currently no public facility providing DNA testing to confirm donor matches.

7.2.3.1 DNA matching

The Committee notes that the Legal and Constitutional Affairs References Committee, a Committee of the Australian Senate, which released a report on donor-conception practices in Australia in February 2011, recommended that:

> … any voluntary registers [established by an Australian state or territory] incorporate a DNA databank, to enable donors and donor conceived individuals to have their details placed on the register for possible matching, in circumstances where records relating to their identities have been destroyed.[542]

A number of submissions proposed that the State Government provide a facility to facilitate DNA matching for people whose records were incomplete.[543] Ms Marianne Tome, of the Victorian Infertility Counsellors

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[540] Victorian Assisted Reproductive Treatment Authority, *Submission no. 19*, 6 August 2010, p. 4.

[541] Damian Adams, *Submission no. 4*, 30 July 2010, p. 7; Sonia Allan, *Transcript of evidence*, Melbourne, 21 November 2011, p. 8.

[542] Senate Standing Committee on Legal and Constitutional Affairs, *Donor conception practices in Australia*, Parliament of Australia, Final report, 2011.

[543] Damian Adams, *Submission no. 4*, 30 July 2010; Sonia Allan, *Submission no. 5*, 2 August 2010; Kate Bourne, *Submission no. 35*, 11 August 2010; Lauren Burns, *Submission no. 3*, 29 July 2010; David de Kretser, *Submission no. 54*, 11 August 2011; Kate Dobby, *Submission no. 33*, 10 August 2010; Helen Kane, *Submission no. 16*, 6 August 2010; VANISH Inc, *Submission no. 8*, 3 August 2010; Victorian Infertility Counsellors Group, *Submission no. 22*, 6 August 2010.

Group, and Manager of Counselling Services at Melbourne IVF, commented on the potential role of DNA matching in this regard:

> We've talked about Prince Henry's. One of the things we did also think about is sometimes because of the inaccurate or just the missing information we may not be absolutely sure that this is the donor for this donor-conceived person, so we feel there needs to be a DNA bank where they can help connect and make sure we are getting the correct linking.[544]

DNA paternity or maternity testing is performed by comparing between ten and fifteen different areas of the child's and parent's DNA (called *loci*). These areas are recorded numerically, so that each person's DNA profile is comprised of up to 30 numerical values (as humans have two sets of chromosomes, and thus two values for each area of DNA). If at least one of these values matches between two people at each of the loci, there is usually a probability in excess of 99.999% that they are parent and child. If any of the loci do not match, the two people will not be parent and child.[545]

Given the relatively limited quantity of data that must be recorded for each person, maintenance of a DNA matching register by an agency, such as VARTA, would likely not be excessively resource-intensive. The Committee considers that it would be relatively unproblematic to integrate a DNA matching facility with the voluntary register, provided that adequate arrangements were made to ensure that private information is protected and secure. The Committee also believes that DNA matching would provide a useful tool to facilitate contact between people who desire contact with each other. Consequently, the Committee recommends that options be examined to incorporate a facility for DNA matching into the voluntary register.

Recommendation 28: That the Victorian Government provide a facility within the voluntary register for DNA matching.

In most cases, if a donor or donor-conceived person wishes to place information for DNA matching on the voluntary register, the Committee believes that those people should be responsible for obtaining their own genetic profile from market providers. However, where donor-conception records are incomplete, ambiguous or unavailable, the Committee believes that the state should offer a concession on the cost of genetic testing, if that person wishes to place information on the voluntary register. This would provide a mechanism through which the state could facilitate (but not guarantee) contact between donors and donor-conceived people in circumstances where, through no fault of their own, records are deficient or incomplete. Concessional, or free, DNA testing should not be offered to parties to donor-conception in circumstances where available records clearly indicate the identities of both parties.

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[544] Marianne Tome, Victorian Infertility Counsellors Group, *Transcript of evidence*, Melbourne, 12 September 2011, p. 28.

[545] Chang Ling Lee, 'Numerical expression of paternity test results using predetermined indexes', *American Journal of Clinical Pathologists*, vol. 73, no. 4, pp. 522-536, 1979.

The Committee notes that, as the *Status of Children Act 1974* (Vic) ensures that no legal relationship exists between donors and their donor-offspring, DNA testing lodged with the voluntary register would not have to comply with requirements of the *Family Law Act 1975* (Cth), and so could ordinarily be obtained at less cost than legally admissible parental testing evidence.

Recommendation 29: That where records for donors or donor-conceived people are unavailable, incomplete, or ambiguous, the Victorian Government offer a concession for DNA testing if that person wishes to lodge DNA matching data on the voluntary register.

7.3 Development of a national register

A number of submissions to the Inquiry suggested that a national register for donor-conception should be developed to ensure consistent practice for all parties to donor-conception across Australia.[546] These submissions also noted that regulation of donor-conception and access to information across Australian jurisdictions was inconsistent. One submission noted that at the moment, there is nothing to prevent a donor from making donations in multiple states or territories, which means there is no effective mechanism to track how many families a donor has contributed to, and no national mechanism for donor-conceived people to identify genetic siblings from other states and territories.[547] Witnesses who supported development of a national register argued that it would assist in addressing this issue.

This issue was one of several considered by the Australian Senate's Legal and Constitutional Affairs References Committee (LCAR Committee), during the course of its Inquiry into donor conception practices in Australia. The LCAR Committee noted that there "was a high level of dissatisfaction about the differences in legislation and regulation between the states in the management of donor conception data",[548] and that evidence suggested that some clinics may not be complying with NHMRC guidelines in the management of donor registers.[549] Consequently, the LCAR Committee recommended that there should be a centralised, national register:

> Recommendation 5: The committee recommends that the Australian Government, through the Standing Committee of Attorneys-General, do everything possible to ensure the establishment, as a matter of priority, of a national register of donors, and that such a national register should also include information about donor conceived individuals.[550]

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[546] Sonia Allan, *Submission no. 5*, 2 August 2010; Australian Family Association, *Submission no. 68*, 15 August 2011; Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010; Narelle Grace Grech, *Submission no. 18*, 6 August 2010; Name withheld, *Submission no. 29*, 9 August 2010; Name withheld, *Submission no. 2*, 28 July 2010; TangledWebs Inc, *Submission no. 21*, 6 August 2010.

[547] Name withheld, *Submission no. 29*, 9 August 2010.

[548] Senate Standing Committee on Legal and Constitutional Affairs, *Donor conception practices in Australia*, Parliament of Australia, Final report, 2011, p. 94.

[549] Ibid.

[550] Ibid, p. 104.

Over time, a national register, or the ability to share information across jurisdictions, would likely improve the regulation of donor-conception nationally, and would assist donor-conceived persons to obtain information about their biological relatives. However, establishment of a national register would require substantial work to alter and align legislation pertaining to donor-conception in all of the states and territories. For example, four Australian jurisdictions – Queensland, Tasmania, the Northern Territory, and the Australian Capital Territory – currently have no legislation to regulate donor-conception. In view of this, the LCAR Committee also recommended that, in the absence of a national register, each state and territory introduce its own centralised register for donor-conception.[551]

While there is merit in pursuing the development of a national register, the Committee notes that many issues in donor-conception are still subject to vigorous debate, and that even jurisdictions that have regulated donor-conception practices for some time – such as Victoria – continue to refine legislation periodically. The Committee anticipates that the recommendations for legislative change it has made in this Report will provide a model for regulation that could guide the development of legislation in other jurisdictions. The Victorian Government may be able to provide considerable assistance to other jurisdictions in this regard if it was to provide regular reports to an appropriate body, such as the Council of Australian Governments (COAG) or the Standing Committee of Attorneys-General (SCAG), on progress with the development and implementation of legislative change.

Recommendation 30: That the Victorian Government provide regular reports to an appropriate inter-jurisdictional body, such as the Standing Committee of Attorneys-General or the Council of Australian Governments, on progress with the development and implementation of reforms to donor-conception legislation.

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[551] Ibid.

Chapter

8

Chapter Eight: Other issues in donor-conception

During the course of the Inquiry a number of issues were raised concerning donor-conception and legislation regulating assisted reproductive treatment that were not encompassed by the Committee's Terms of Reference. Some of these issues are discussed in this Chapter. While the Committee believes it is important to note the range of issues raised in the course of this Inquiry, it has not elected to make findings or recommendations on issues that fall outside the Terms of Reference.

8.1 Limits on children conceived from one donor's gametes

Prior to the introduction of the *Assisted Reproductive Treatment Act 2008,* there was no legislated limit on the number of families who could use gametes from the same donor. The *Assisted Reproductive Treatment Act 2008* introduced a ban on the use of donated gametes to produce more than ten families, providing that it is an offence for a person to carry out a donor-conception procedure if they know that the procedure may result in more than ten women having children who are genetic siblings. This limit includes any children conceived by the donor and his or her present or former partner/s.[552]

The Committee received six submissions expressing concern with this provision, suggesting that the maximum number of families should be reduced.[553] 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 gametes from the same donor.[554] A limit of five families was also recommended in a submission received from a family who used donated gametes to conceive a child.[555] This is currently the number allowed under New South Wales' *Assisted Reproductive Technology Act 2007*.[556]

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[552] *Assisted Reproductive Treatment Act 2008* (Vic), section 29.

[553] Australian Family Association, *Submission no. 68*, 15 August 2011; Agnes Bankier, *Submission no. 38*, 25 July 2011; Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010; Narelle Grace Grech, *Submission no. 18*, 6 August 2010; Name withheld, *Submission no. 29*, 9 August 2010; Shelley Sandow, *Submission no. 7*, 3 August 2010.

[554] Donor Conception Support Group of Australia Inc, *Submission no. 10*, 4 August 2010, p. 23.

[555] Name withheld, *Submission no. 29*, 9 August 2010.

[556] *Assisted Reproductive Technology Act 2007* (NSW), section 27(1).

As described in Case Study 7, the Committee heard from a donor who recently discovered that he has 15 donor-conceived children, in addition to his three natural children. While this donor made his donations prior to 1988, under the current legislated limit of ten families, it is still possible that one person could be the biological parent of many children.

Case Study 7: "Alex"[557]

"I am a donor. My donations were made at Prince Henry's Institute over a period of a year or two in the early to mid-1980s.

… I would have been in my 30s. My wife and I had just had our first child, and we had some friends who were having difficulty conceiving. That was the way I became a donor – because of having experienced the miracle of birth and the difficulties that other people were having. That was my motivation for becoming a donor. I cannot recall much by way of counselling happening at the time from the point of view of thinking through the consequences of what I thought at the time was helping in the process of other people conceiving. Certainly the understanding was that it was entirely anonymous and there would be no contemplation of responsibility or contact with the children. I think that was the philosophy at the time.

… I then stopped donating. I heard nothing and then – I think as a result of some publicity – I got in touch with the Infertility Treatment Authority who were encouraging donors to say whether or not they would be prepared to have the information shared with the donor-conceived people, so I registered. I think that is very important, so I registered. There was then a silence of some months or years; I am not quite sure how long. Then a letter arrived, 'Dear Alexander' – only my mother calls me Alexander – 'You have 15 children'. I found that rather stunning for a variety of reasons. It is rather a lot. … I have 15 children as a result of donations and another three as a result of my wife and I, so that is 18 children.

The first thing I would say is that 15 is rather a lot. I do not know if it is a good idea for people to have 15 children conceived naturally or with several partners or through donation. I do not know if the terms of reference extend that far, but all of the difficulties that come out of donor conception are multiplied significantly by the numbers. I think it is daunting, and I think as a practice it is not a good idea for people to have so many children.

… I have three children conceived naturally. The odds increase substantially of them coming into contact or having a relationship with a half-brother or half-sister. … I have not had any contact, and apparently none of the children have sought to have any contact. I am comfortable with that. If people do not want to have any contact, that is fine. Imagine if they all did, though? I struggle to give my three natural children appropriate time. Imagine if another 15 turned up on the doorstep?"

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[557] "Alex", *Transcript of evidence*, Melbourne, 5 December 2011, pp. 2-3.

During the course of this Inquiry the Committee did not specifically consider what, if any, limits should be placed on the number of children that could be conceived from gametes contributed by one donor. The Committee notes, however, that donors are now able to specify the maximum number of families they would like their gametes to contribute to.[558] Clinics should also now be informing donors when children are born after being conceived from their gametes. This should mean that future donors will not be unprepared if they are approached by people conceived from their gametes. From the perspective of access to information, the Committee believes that the key issue is that the donor is aware of, and has some control over, the number of children that are conceived from his or her gametes, as is currently the case.

8.2 Reimbursement for donor expenses

Some witnesses suggested that current practices for reimbursement of expenses to donors were effectively payment for services, and felt that the commercial nature of this transaction may one day be hurtful to donor-conceived children. A recipient parent with a daughter conceived by sperm donation in Victoria suggested to the Committee that the travel costs currently provided by clinics to donors should be reduced or eliminated:

> The positive aspect of donor issues in Australia is that it is for altruistic reasons. I would hate to see Australia adopt the American pattern where young males and females are paying for their college tuition by donating sperm and eggs. However, eliminating or reducing the travel fees given to donors could still improve this system. Some clinics are providing up to $100 in travel assistance; indeed donors have mentioned this is enough to entice them to donate. It could be hurtful for a donor-conceived child to find out this was the reason their donor donated. A blood donor does not get paid for travel expenses so why should a sperm or egg donor? If it is deemed necessary to pay donors travel expenses then I recommend it is organised through a scheme such as Victoria's DHS' VPTAS scheme. The first $100 is reimbursed only to health care card holders who had to travel over 100km for medical treatment, and then there is a choice of submitting your bus/train ticket for reimbursement or receiving 40c per km driven. This would mean there is a uniform approach to claiming travel expenses and would stop poor students donating for a bit of cash.[559]

The *Prohibition of Human Cloning Act 2008* prohibits commercial trading in human eggs, sperm, or embryos – it is an indictable offence punishable by imprisonment for up to 15 years under that legislation to give, offer, receive, or offer to receive valuable consideration for the supply of a human egg, sperm or embryo.[560] However, the *Prohibition of Human Cloning Act 2008* does provide that reasonable expenses may be paid,

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[558] *Assisted Reproductive Treatment Act 2008* (Vic), section 17(1)(b).

[559] Name withheld, *Submission no. 29*, 9 August 2010.

[560] *Prohibition of Human Cloning Act 2008* (Vic), section 17.

including expenses relating to collection, storage and transport of the egg, sperm or embryo.[561]

There is considerable variation between the 'reasonable expenses' for which fertility clinics in Melbourne offer compensation to sperm donors. Melbourne IVF's policy is to provide $250 per donation:

> Can I be paid to be a sperm donor?
>
> In Australia, donating sperm is a generous gift, and it's illegal to take payment for it. You can, however, have your travel or parking expenses reimbursed – either by the recipient if they are known to you, or by the clinic at which you donate.
>
> Clinic recruited donors will be reimbursed by Melbourne IVF for their time spent attending appointments. $250 per donation will be reimbursed in two lump sums; $160 after completing donations and the final $90 on completion of the post-quarantine blood tests. Most men who donate average between 5 and 10 donations in total.[562]

Monash IVF provides an allowance of $90 per donation, based on ten donations being made:

> Compensation for Reasonable Medical and Travel Expenses
>
> An allowance of $90 per donation is payable to cover reasonable travelling expenses, car parking, time off work etc, however this is paid in three amounts. Initially, $400 is paid by cheque after the fifth donation. This is to cover the time you spent in counselling, medical consultation and for the first 5 donations. A further $200 is paid after the tenth donation. Finally, you will receive a final $300 payment when the 6 month quarantine blood tests have been finalized, and the donated sperm is available for use.[563]

City Fertility, another clinic providing fertility services in Melbourne, uses sperm donations obtained through Sperm Donors Australia, who offer a total of $300 per donation, as follows:

> Will I get paid?
>
> While it is illegal in Australia to pay for human sperm (under the Human Tissue Act 1982), we are able to compensate you by way of a lump sum for any expenses you incur. Once you have completed the initial screening process we are able to reimburse you as follows:
>
> Payment 1: $150 per sample, after each donation.
>
> Payment 2: $150 per sample – already donated (paid after the final 6 month blood test).

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[561] Ibid.

[562] Melbourne IVF, 'Become a sperm donor', viewed 14 February 2012, <mivf.com.au>.

[563] Monash IVF, 'Donor sperm program', viewed 20 January 2012, <www.monashivf.com>.

> There are no fees for your clinic appointments or medical check-up or blood tests.[564]

None of these three clinics provide information on their websites regarding the compensation that they offer for the reasonable expenses of egg donors.

The Committee did not receive sufficient evidence to ascertain whether current reimbursements to donors for expenses are paid at an appropriate level.

8.3 Police checks on donors

A recipient parent with a five-year-old daughter conceived by sperm donation in Victoria suggested that all prospective donors should be required to undertake a police check:

> Donors in all states should be subject to police checks. Imagine the affect on a donor-conceived child if they find their donor spent time in prison for a serious crime.[565]

The *Assisted Reproductive Treatment Act 2008* does not require or recommend that a person undergo any criminal or police records checks prior to being accepted as a gamete donor. However, the Committee notes that the *Assisted Reproductive Treatment Act 2008* does require that in order for a woman to undergo an assisted reproductive treatment procedure (including donor insemination), she and her partner, if any, must have undergone a criminal records check.[566]

While donors are unlikely to have the same influence on the day-to-day development of children conceived from their gametes as parents will, the Committee notes that current provisions of the Act do provide a means through which contact between the child and the donor can be facilitated. It is perhaps inconsistent, then, that the recipient parent of a child is subject to a criminal records check when the donor, who may also eventually have contact with that child, is not.

As the Committee did not receive sufficient evidence on this issue to determine whether criminal records checks should be introduced for donors, and as this issue is not directly relevant to the Inquiry Terms of Reference, the Victorian Government may wish to review conditions for criminal records checks for donors (or for recipient parents) as it considers changes to other aspects of current legislation.

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[564] Sperm Donors Australia, viewed 14 February 2012, <www.spermdonorsaustralia.com.au>.

[565] Name withheld, *Submission no. 29*, 9 August 2010.

[566] *Assisted Reproductive Treatment Act 2008* (Vic), sections 10(1)(a) & 11(c). The Committee also notes that this requirement was the subject of some debate at the time it was proposed for inclusion in the legislation – see *Parliamentary debates*, Legislative Council, 4 December 2008, at pp. 5424-5425.

8.4 Importation of gametes from overseas

The Australian Family Association (AFA) suggested that the importation of gametes into Victoria from overseas should be prohibited.[567] The AFA viewed this as an urgent issue related to the right of donor-conceived people to know the identity of their biological parents and other relatives.

The Committee recognises that the use of imported gametes may make it more difficult for donor-conceived people to obtain information about, and potentially make contact with, their donors. However, the Committee notes that at present, the *Assisted Reproductive Treatment Act 2008* prohibits the movement of donor gametes and embryos produced from donor gametes into or out of Victoria, unless the Victorian Assisted Reproductive Treatment Authority (VARTA) has provided written approval to such import or export.[568] This includes gametes imported from overseas. The *Assisted Reproductive Treatment Act 2008* also requires that the names of all donors are provided to the central register for births and pregnancies, and where the outcome of a procedure is unknown.[569]

8.5 Donor rights to decisions about embryos

Section 32 of the *Assisted Reproductive Treatment Act 2008* prohibits storing embryos except in particular circumstances, and states:

> (1) A person must not cause or permit an embryo to be placed or remain in storage.
>
> Penalty: 240 penalty units or 2 years imprisonment or both.
>
> (2) Subsection (1) does not apply if:
>
> (a) the person is a registered ART provider; and
>
> (b) it is intended to transfer the embryo to the body of a woman in a treatment procedure in accordance with this Act; and
>
> (c) the persons who have produced the gametes from which the embryo has been formed have consented to its storage for the purpose of later transfer.
>
> (3) A consent under subsection (2)(c) –
>
> (a) must be in writing; and
>
> (b) must be given as soon as practicable after the consent has been given, to the registered ART provider storing the embryo.

Monash IVF suggested that section 32(2)(c) is a source of inconsistency in the *Assisted Reproductive Treatment Act 2008*, as it provides donors with rights over embryos that are, in fact, formed from gametes from two parties:

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[567] Australian Family Association, *Submission no. 68*, 15 August 2011, pp. 3-4.
[568] *Assisted Reproductive Treatment Act 2008* (Vic), section 36(1).
[569] Ibid, sections 51 & 52.

> Section 32, (2c) states that the persons who have produced the gametes from which the embryo has been formed have consented to its storage for the purpose of later transfer. This consent deals with the EMBRYO, not the gametes. 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?[570]

Monash IVF recommended that the wording of the legislation should be amended to state that a donor only has rights to make decisions about gametes prior to insemination:

> Once an egg is inseminated it should then be considered the legal property of the couple undergoing IVF treatment and any decision making regarding the fate of any embryos should be that of the couple who are the recipients of that donation.
>
> If donors wish to set conditions to their donation (such as the number of families they wish to help create) then this should be very clearly stated in writing prior to the act of the donation, all parties counselled about the implications of such conditions, and all be in agreement with those conditions before proceeding with treatment.[571]

The Australian Medical Association (Victoria) noted that it supported Monash IVF's recommendation, and suggested that any change to the legislation must ensure that donors are adequately informed that their ability to withdraw consent for the use of their gametes ceases at the point of insemination.[572]

The Committee notes that these concerns with current legislation fall outside the issues the Committee was required to examine in its Terms of Reference for this Inquiry. The Committee notes that, should the Victorian Government wish to alter consent provisions for embryos, there may be an opportunity to do so if legislation concerning the Committee's recommendations for access to information for donor-conceived people is introduced to Parliament.

Adopted by the Law Reform Committee
14 March 2012

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[570] Monash IVF, *Submission no. 26*, 6 August 2010, p. 7.
[571] Ibid, pp. 7-8.
[572] Australian Medical Association (Victoria), *Submission no. 71*, 18 August 2011, p. 3.

Bibliography

Allan, S, 'Psycho-social, ethical and legal arguments for and against the retrospective release of information about donors to donor-conceived individuals in Australia', *Journal of Law and Medicine*, vol. 19, pp. 354-376, 2011.

Births Deaths and Marriages Victoria, 'Voluntary register application', viewed 2 December 2011, <http://online.justice.vic.gov.au/CA256902000FE154/Lookup/BDMApplication_Forms/$file/ART_VoluntaryRegApp.pdf>.

Blood, J and Baker, H, *Parents of donor conceived children: the experience of telling*, unpublished paper, 1998.

Carp, EW, 'Does opening adoption records have an adverse social impact? Some lessons from the U.S., Great Britain, and Australia, 1953-2007', *Adoption Quarterly*, vol. 10, no. 3-4, pp. 29-52, 2007.

Cohen, J, Trounson, A, Dawson, K, Jones, H, Hazekamp, J, Nygren, K-G and Hamberger, L, 'The early days of IVF outside the UK', *Human Reproduction*, vol. 11, no. 5, pp. 439-459, 2005.

Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Interim report*, Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, Melbourne, 1982.

Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Issues paper on donor gametes in IVF*, Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, Melbourne, 1983.

Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, *Report on donor gametes in IVF*, Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, Melbourne, 1983.

Convention on the Rights of the Child, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990).

Daniels, K, Lewis, G and Gillet, W, 'Telling donor-conceived offsrping about their conception: the nature of couples' decision-making', *Social Science and Medicine*, vol. 40, pp. 1213-1220, 1995.

Daniels, K and Taylor, K, 'Secrecy and openness in donor insemination', *Politics and the life sciences*, vol. 12, no. 2, pp. 155-170, 1993.

de Kretser, D, Dennis, P, Hudson, B, Leeton, J, Lopata, A, Talbot, J and Wood, C, 'Transfer of a human zygote', *Lancet*, no. 2, pp. 728-729, 1973.

Ethics Committee of the American Society for Reproductive Medicine, 'Informing offspring of their conception by gamete donation', *Fertility and Sterility*, vol. 81, no. 3, pp. 527-531, 2004.

Golombok, S, Brewaeys, A, Giavazzi, MT, Guerra, D, MacCullum, F and Rust, J, 'The European study of assisted reproduction families: the transition to adolescence', *Human Reproduction*, vol. 17, no. 3, pp. 830-840, 2002.

Hahn, S and Craft-Rosenberg, M, 'The disclosure decisions of parents who conceive children using donor eggs', *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, vol. 31, pp. 283-293, 2002.

Hambly, PD, 'The legal situation', Paper presented at the *In search of self-identity - access to information*, P. Harper (ed.) National Council for the Single Mother and her Child, Collingwood Education Centre, Melbourne, 1980.

Infertility Treatment Authority, *Annual report 1999*, Infertility Treatment Authority, Melbourne, 1999.

Infertility Treatment Authority, *Annual report 2006*, Infertility Treatment Authority, Melbourne, 2006.

Infertility Treatment Authority, *Conditions for licence: applications for licences by hospital and day procedure centres*, Infertility Treatment Authority, Melbourne, 2006.

Infertility Treatment Authority, *Annual report 2008*, Infertility Treatment Authority, Melbourne, 2008.

Infertility Treatment Authority, *Annual report 2009: twelfth and final report*, Infertility Treatment Authority, Melbourne, 2009.

IVF Success, 'Our network', viewed 2 February 2012, <http://www.ivfsuccess.com.au/our-network>.

Johnson, L, Paper presented at the *Donor-Linking Symposium*, Melbourne, 2011.

Johnson, L and Kane, H, 'Regulation of donor conception and the "time to tell" campaign', *Journal of Law and Medicine*, vol. 15, no. 1, pp. 117-127, 2007.

Johnston, I, 'The donor', in *Artificial Insemination by Donor*, C. Wood, J. Leeton and G. Kovacs (eds.), Brown Prior Andersen, Melbourne, 1981.

Kirkman, M, 'Genetic connection and relationships in narratives of donor-assisted conception', *Australian Journal of Emerging Technologies and Society*, vol. 2, no. 1, pp. 1-21, 2004.

Law Reform Committee, *Inquiry into access by donor-conceived people to information about donors: interim report*, Parliament of Victoria, Melbourne, 2010.

Lee, CL, 'Numerical expression of paternity test results using predetermined indexes', *American Journal of Clinical Pathologists*, vol. 73, no. 4, pp. 522-536, 1979.

Leeton, J and Asche, A, 'Artificial insemination by donor - and beyond', *Medico-Legal Society Proceedings*, 1981.

Leiblum, S and Aviv, A, 'Disclosure issues and decisions of couples who conceived via donor insemination', *Journal of psychosomatic obstetrics and gynecology*, vol. 18, no. 4, pp. 292-300, 1997.

McNair, R, *Outcomes for children born of A.R.T. in a diverse range of families*, Victorian Law Reform Commission, Melbourne, 2004.

McWhinnie, A, 'Children from assisted reproductive technology: the psychological issues and ethical dilemmas', *Early child development and care*, vol. 163, pp. 13-23, 2000.

McWhinnie, A, 'Gamete donation and anonymity: should offspring from donated gametes continue to be denied knowledge of their origins and antecedents?', *Human Reproduction*, vol. 16, pp. 807-817, 2001.

Melbourne IVF, 'Become a sperm donor', viewed 14 February 2012, <http://mivf.com.au/fertility-treatment/ivf-donor-program/sperm-donation>.

Melbourne IVF, 'IVF Clinic Parkville', viewed 12 January 2012, <http://mivf.com.au/fertility-clinic-locations/ivf-clinic-parkville>.

Monash IVF, *Guide to getting started handbook*, Monash IVF, Melbourne, 2003.

Monash IVF, 'Donor sperm program', viewed 20 January 2012, <http://www.monashivf.com/Services/Donor_Programs1/Donor_Sperm_Program.aspx>.

Monash IVF, 'History of IVF', viewed 21 January 2012, <http://www.monashivf.com/About_Monash_IVF/History_of_IVF.aspx>.

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.

New York State Taskforce on Life and the Law, *Assisted reproductive technologies: analysis and recommendations for policy*, Health Education Service, Albany, NY, 1998.

Pruett, K, 'Strange bedfellows? reproductive technology and child development', *Infant Mental Health Journal*, vol. 13, pp. 312-318, 1992.

Ravitsky, V, '"Knowing where you came from": the rights of donor-conceived individuals and the meaning of genetic relatedness', *Minnesota Journal of Law, Science and Technology*, vol. 11, no. 2, pp. 665-684, 2010.

Reproductive Technology Accreditation Committee, *Code of practice for assisted reproductive technology units*, Fertility Society of Australia, revised October 2010, 2010.

Rumball, A and Adair, V, 'Telling the story: parents' scripts for donor offspring', *Human Reproduction*, vol. 14, pp. 1392-1399, 1999.

Senate Standing Committee on Legal and Constitutional Affairs, *Donor conception practices in Australia*, Parliament of Australia, Final report, 2011.

Slovic, P (ed.) *The perception of risk: risk, society and policy series*, Earthscan Publications, London, 2000.

Snowden, R, 'The family and artificial reproduction', in *Philosophical ethics in reproductive medicine*, D. Bromham, M. Dalton and J. Jackson (eds.), Manchester University Press, Manchester, 1990, 70-78.

Sperm Donors Australia, viewed 14 February 2012, <http://www.spermdonorsaustralia.com.au/will-i-get-paid>.

Standing Review and Advisory Committee on Infertility, *Issues paper on donor gametes in IVF*, Standing Review and Advisory Committee on Infertility, Melbourne, 1983.

Standing Review and Advisory Committee on Infertility, *Annual Report to the Minister for Health for the calendar year ended 31 December 1989*, Standing Review and Advisory Committee on Infertility, Melbourne, 1990.

Standing Review and Advisory Committee on Infertility, *Report on matters related to the review of post-syngamy embryo experimentation – Part III: Recommendations for amendment of the Infertility (Medical Procedures) Act 1984*, Melbourne, 1991.

The Australian Women's Register, 'Queen Victoria Hospital 1896 - 1977', viewed 12 January 2012, <http://www.womenaustralia.info/biogs/AWE0049b.htm>.

The Encyclopedia of Melbourne Online, 'Prince Henry's Hospital', viewed 19 January 2012, <http://www.emelbourne.net.au/biogs/EM01188b.htm>.

Tobin, J, *The Convention on the Rights of the Child: the rights and best interests of children conceived through assisted reproduction*, Victorian Law Reform Commission, 2004.

Turner, A and Coyle, A, 'What does it mean to be a donor offspring? the identity experiences of adults conceived by donor insemination and the implications for counselling and therapy', *Human Reproduction*, vol. 15, pp. 2041-2051, 2000.

UNICEF, 'Fact sheet: a summary of the rights under the Convention on the Rights of the Child', viewed 17 August 2010, <http://www.unicef.org/crc/files/Rights_overview.pdf>.

van Berkel, D, van der Veen, L, Kimmel, I and te Velde, E, 'Differences in the attitudes of couples whose children were conceived through artificial insemination by donor in 1980 and 1996', *Fertility and Sterility*, vol. 71, no. 2, pp. 226-231, 1999.

Victorian Assisted Reproductive Treatment Authority, *Annual report 2010*, Victorian Assisted Reproductive Treatment Authority, Melbourne, 2010.

Victorian Assisted Reproductive Treatment Authority, *Annual report 2011*, Victorian Assisted Reproductive Treatment Authority, Melbourne, 2011.

Victorian Assisted Reproductive Treatment Authority, 'A statistical snapshot of the donor registers in Victoria for 2010-2011', Victorian Assisted Reproductive Treatment Authority, 2011, viewed 23 Nov 2011, <http://www.varta.org.au/secure/downloadfile.asp?fileid=1004724>.

Victorian Law Reform Commission, 'Assisted Reproductive Technology & Adoption', viewed 20 January 2012, <http://www.lawreform.vic.gov.au/inquiries/art-adoption>.

Victorian Law Reform Commission, *Assisted reproductive technology & adoption*, Final report, Victorian Law Reform Commission, Melbourne, 2007.

Legislation

Victoria

Adoption Act 1984 (Vic).

Assisted Reproductive Treatment Act 2008 (Vic).

Assisted Reproductive Treatment Bill 2008 (Vic).

Assisted Reproductive Treatment Regulations 2009 (Vic).

Births, Deaths and Marriages Act 1996 (Vic).

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

Health Records Act 2001 (Vic).

Infertility (Medical Procedures) Act 1984 (Vic).

Infertility (Medical Procedures) Regulations 1988 (Vic).

Infertility Treatment (Amendment) Act 2001 (Vic).

Infertility Treatment Act 1995 (Vic).

Infertility Treatment Regulations 1997 (Vic).

Parliamentary Committees Act 2003 (Vic).

Personal Safety Intervention Orders Act 2010 (Vic).

Prohibition of Human Cloning Act 2008 (Vic).

Public Records Act 1973 (Vic).

Status of Children (Amendment) Act 1984 (Vic).

Status of Children Act 1974 (Vic).

Commonwealth

Family Law Act 1975 (Cth).

Prohibition of Human Cloning for Reproduction and the Regulation of Human Embryo Research Amendment Act 2006 (Cth).

New South Wales

Adoption Information Act 1990 (NSW).

Assisted Reproductive Technology Act 2007 (NSW).

International

House Bill 3194, 1999 (Oregon Legislative Assembly).

Appendix One:
List of Submissions

Submissions received in the 56th Parliament

	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	6 August 2010
4	Mr Damian Adams	30 July 2010
5	Dr Sonia Allan	2 August 2010
6	Name withheld	3 August 2010
7	Ms Shelley Sandow	3 August 2010
8	VANISH Inc	3 August 2010
9	Ms Barbara Burns	3 August 2010
10	Donor Conception Support Group of Australia Inc	4 August 2010
11	Name withheld	4 August 2010
12	Ms Myfanwy Cummerford	4 August 2010
13	Name withheld* **This submission was resubmitted in 2011 as submission 47*	5 August 2010
14	Ms Susan Hurst	5 August 2010
15	Anonymous (confidential)	30 July 2010
16	Ms Helen Kane	6 August 2010
17	Rainbow Families Council	6 August 2010
18	Ms Narelle Grech	6 August 2010
19	Victorian Assisted Reproductive Treatment Authority (VARTA)	6 August 2010
20	Ms Kimberley Springfield	6 August 2010
21	TangledWebs Inc	6 August 2010
22	Victorian Infertility Counsellors Group	6 August 2010
23	Dr Damien W. Riggs	6 August 2010
24	Mr Paul Ruff	6 August 2010
25	Ms Romana Rossi	6 August 2010
26	Monash IVF	6 August 2010
27	Public Interest Law Clearing House	6 August 2010
28	Ms Sarah Nichols	6 August 2010
29	Name withheld	9 August 2010

	Name of individual or organisation	Date received
30	Name withheld	9 August 2010
31	Ms Christine Whipp	9 August 2010
32	Melbourne IVF* **This submission was resubmitted in 2011 as submission 59*	9 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 (confidential)	17 August 2010

Submissions received in the 57th Parliament

	Name of individual or organisation	Date received
37	Dr Sonia Allan	18 July 2011
38	Professor Agnes Bankier	25 July 2011
39	Donor Conception Support Group of Australia Inc	26 July 2011
40	Professor Gab Kovacs	3 August 2011
41	Ms Merrilyn Mannerheim and Ms Jo Moffat	4 August 2011
42	Name withheld	8 August 2011
43	Professor Eric Blyth	8 August 2011
44	Mr Gordon Ley	8 August 2011
45	Associate Professor Nicholas Tonti-Filippini	9 August 2011
46	Ms Helen Kane	9 August 2011
47	Name withheld* **This submission was submitted in 2010 as submission 13*	10 August 2011
48	National Health and Medical Research Council (NHMRC)	10 August 2011
49	TangledWebs Inc	10 August 2011
50	Ms Kimberley Turner (Springfield)	11 August 2011
51	Ms Barbara Burns	11 August 2011
52	Murdoch Children’s Research Institute	11 August 2011
53	Ms Myfanwy Cummerford	11 August 2011
54	Professor David de Kretser	11 August 2011
55	Mr Ian Smith	11 August 2011
56	Australian Christian Lobby	12 August 2011
57	Ms Romana Rossi	12 August 2011
58	Office of the Victorian Privacy Commissioner	12 August 2011

	Name of individual or organisation	Date received
59	Melbourne IVF* **This submission was submitted in 2010 as submission 32*	12 August 2011
60	Name withheld	12 August 2011
61	VANISH Inc	12 August 2011
62	Public Interest Law Clearing House	12 August 2011
62A	Public Interest Law Clearing House – supplementary submission	14 September 2011
63	Ms Lauren Burns	12 August 2011
64	Victorian Infertility Counsellors Group	12 August 2011
65	Reproductive Technology Council Western Australia	12 August 2011
66	Fertility Society of Australia	12 August 2011
67	Ms Narelle Grech	15 August 2011
68	Australian Family Association	15 August 2011
69	Anonymous (confidential)	16 August 2011
70	Ad Hoc Interfaith Committee	16 August 2011
71	Australian Medical Association (AMA) (Victoria)	18 August 2011
72	Institute for Judaism and Civilization Inc	19 August 2011
73	Miss Maria Ann Kolovrat	8 August 2011
74	Victorian Equal Opportunity and Human Rights Commission	1 September 2011
75	Professor Ken Daniels	9 September 2011
76	Victorian Assisted Reproductive Treatment Authority (VARTA)	12 August 2011
77	Ms Amy Corderoy	26 October 2011

Appendix Two: List of Witnesses

Public hearing, 8 September 2011
Room G1, 55 St Andrews Place, East Melbourne

Witness(es)	Organisation
Mr David Fixler	Public Interest Law Clearing House (PILCH)
Dr Lyndon Hale, IVF Directors Group Dr Penelope Foster	Fertility Society of Australia
Ms Kate Dobby	Individual
Ms Kirsten Mander, Chairperson Ms Louise Johnson, Chief Executive Officer Ms Kate Bourne, Senior Community Education Officer	Victorian Assisted Reproductive Treatment Authority (VARTA)
Ms Helen Versey, Privacy Commissioner Mr Scott May, Policy and Compliance Officer	Office of the Victorian Privacy Commissioner

Public hearing, 12 September 2011
Legislative Council Committee Room, Parliament House, Spring Street, East Melbourne

Witness(es)	Organisation
Associate Professor Rosalie Hudson Associate Professor Nicholas Tonti-Filippini	Ad Hoc Interfaith Committee
Ms Helen Kane	Individual
Ms Marianne Tome Ms Rita Alesi	Victorian Infertility Counsellors Group
Ms Narelle Grech Ms Lauren Burns	Individuals

Public hearing, 10 October 2011 Legislative Council Committee Room, Parliament House, Spring Street, East Melbourne

Witness(es)	Organisation
Ms Karen Toohey, Acting Commissioner Ms Skye Rose, Senior Legal Adviser	Victorian Equal Opportunity and Human Rights Commission
Mr Andrew Othen, Managing Director Ms Joanne McCann, Operations Manager Ms Rachael Varady, Donor Program Manager	Melbourne IVF
Professor Gab Kovacs	Individual
Mr Ian Smith Mr Michael Linden	Individuals

Public hearing, 17 October 2011 Room G1, 55 St Andrews Place, East Melbourne

Witness(es)	Organisation
Professor David de Kretser	Individual
Mr Leigh Hubbard, Chair Mr Gary Coles Ms Lauren Burns	VANISH Inc
Ms Rita Alesi, Counselling Manager Ms Maria Gabbe, Donor Coordinator	Monash IVF
Ms Myfanwy Cummerford	Individual
Ms Caroline Lorbach, National Consumer Advocate Ms Leonie Hewitt Ms Genevieve Hewitt	Donor Conception Support Group
Mr Roger Clarke Ms Susanne Pinder-Clarke	Individuals
Reverend Dr Gerald Gleeson, Member of NHMRC's Australian Health Ethics Committee Mr Matthew Sammels, Director of Health and Research Ethics Section	National Health and Medical Research Council (NHMRC)
John* **The name of this witness has been changed to protect his identity.*	Individual

Public hearing, 21 November 2011
Legislative Council Committee Room, Parliament House, Spring Street, East Melbourne

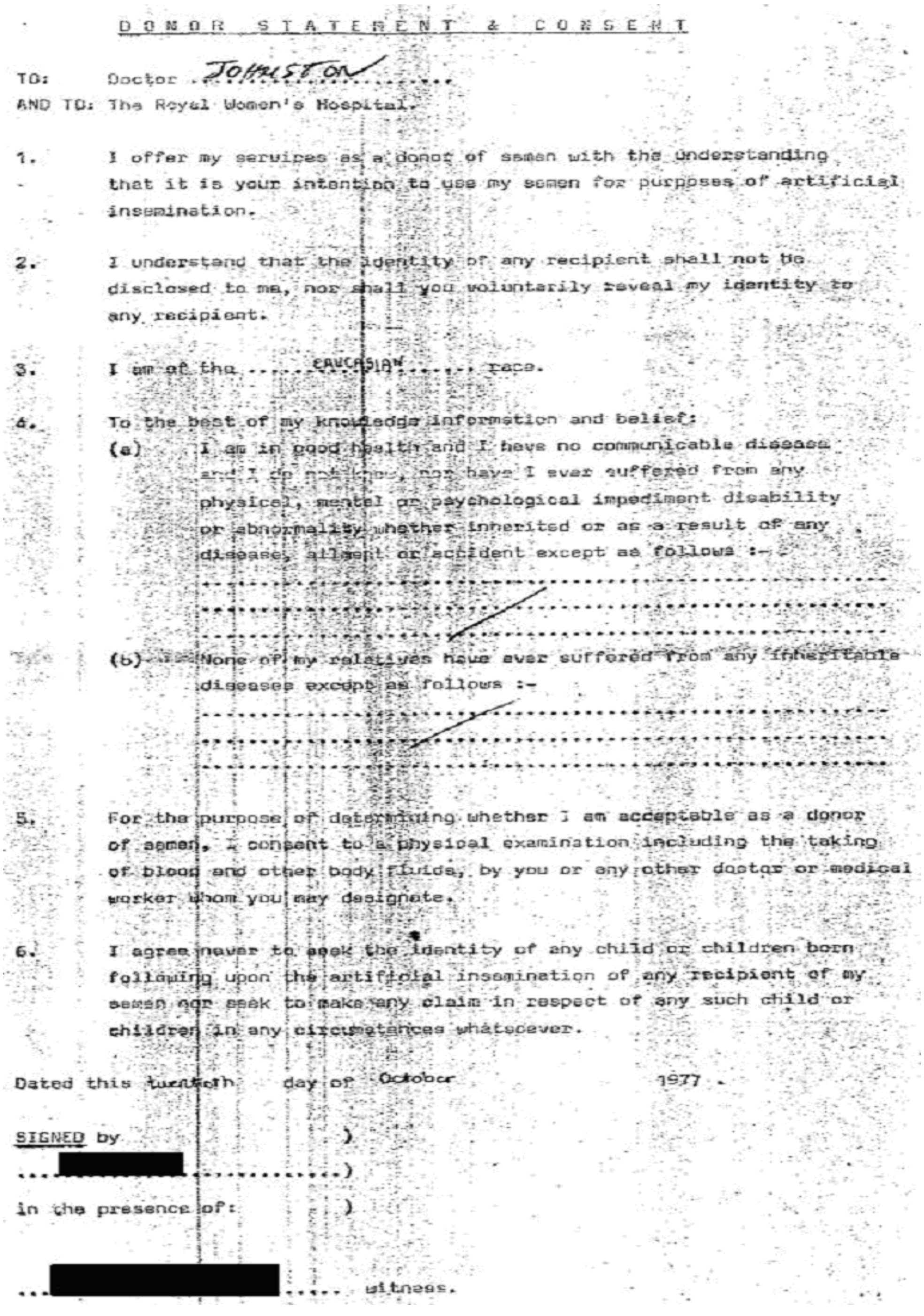
Witness(es)	Organisation
Dr Sonia Allan	Individual
Ms Mariaelisa Tumino, former Manager, Family Information Networks and Discovery (FIND) Ms Angela Karavidas, Manager, Family Information Networks and Discovery (FIND) Mr Keith Smith, Manager of Children, Youth and Families (Southern Region)	Department of Human Services
Ms Erin Keleher, Manager of Strategic Projects	Registry of Births, Deaths and Marriages

Public hearing, 5 December 2011
Room G3, 55 St Andrews Place, East Melbourne

Witness(es)	Organisation
Alex* **The name of this witness has been changed to protect his identity.*	Individual
Professor Ken Daniels	Individual
Mr Paul Ruff	Individual
Ms Romana Rossi Ms Barbara Burns	Individuals
Mr Damian Adams	Individual
Ms Kimberley Turner (Springfield)	Individual

Appendix Three: Sample donor consent forms[573]

Donor statement and consent form from the Royal Women's Hospital, 1977



DONOR STATEMENT & CONSENT

TO: Doctor JOHNSTON

AND TO: The Royal Women's Hospital.

1. I offer my services as a donor of semen with the understanding that it is your intention to use my semen for purposes of artificial insemination.

2. I understand that the identity of any recipient shall not be disclosed to me, nor shall you voluntarily reveal my identity to any recipient.

3. I am of the ....CAUCASIAN........ race.

4. To the best of my knowledge information and belief:

   (a) I am in good health and I have no communicable disease and I do not know, nor have I ever suffered from any physical, mental or psychological impediment disability or abnormality whether inherited or as a result of any disease, ailment or accident except as follows :-

   ....

   ....

   ....

   (b) None of my relatives have ever suffered from any inheritable diseases except as follows :-

   ....

   ....

   ....

5. For the purpose of determining whether I am acceptable as a donor of semen, I consent to a physical examination including the taking of blood and other body fluids, by you or any other doctor or medical worker whom you may designate.

6. I agree never to seek the identity of any child or children born following upon the artificial insemination of any recipient of my semen nor seek to make any claim in respect of any such child or children in any circumstances whatsoever.

Dated this [illegible] day of October 1977.

SIGNED by)

...[redacted]...............)

in the presence of:)

...[redacted]..... witness.

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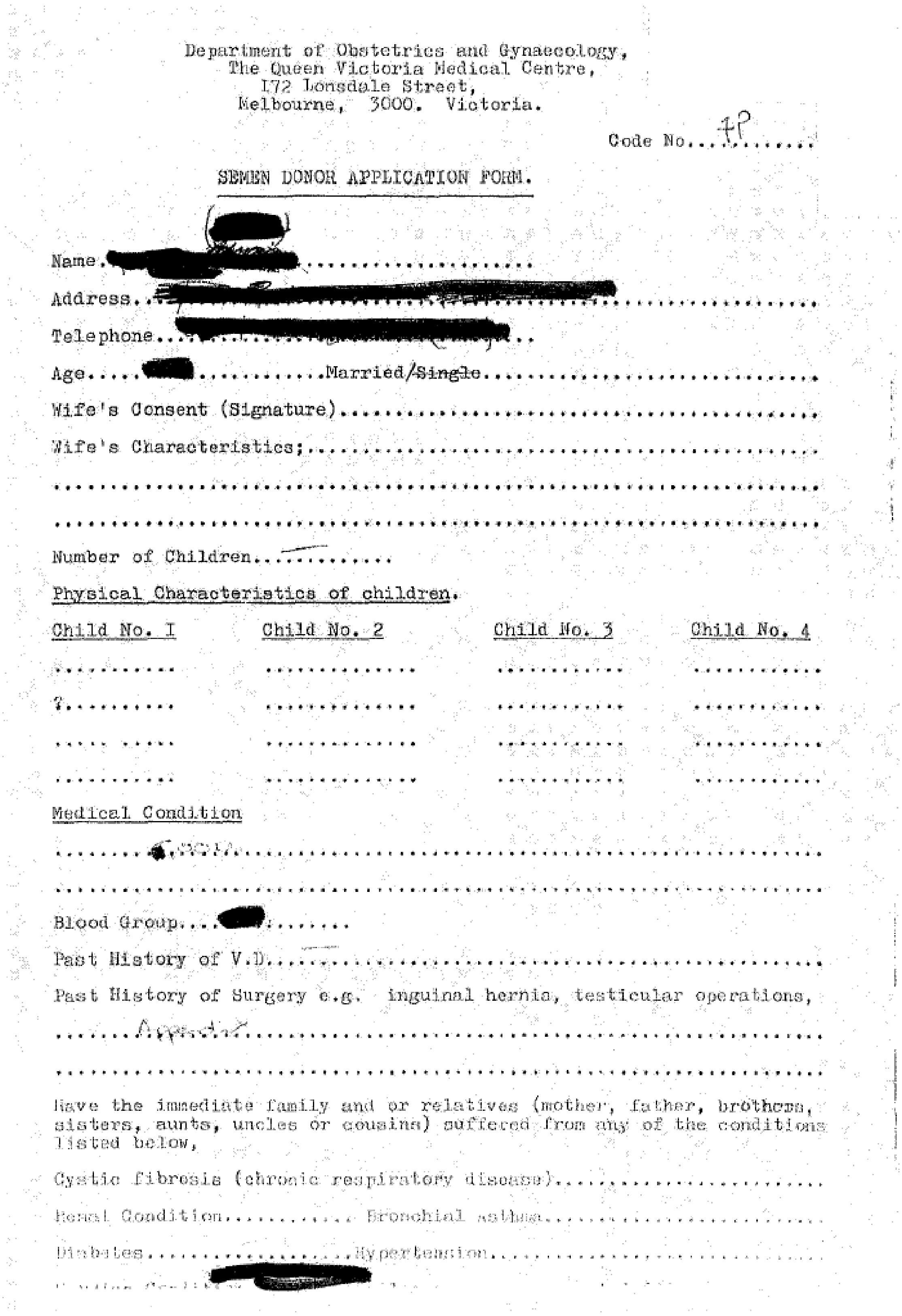
[573] The consent forms included in Appendix Three were provided by Sonia Allan, *Submission no. 37*, 18 July 2011.

Donor statement and consent form from the Queen Victoria Medical Centre (page 1)



Department of Obstetrics and Gynaecology,
The Queen Victoria Medical Centre,
172 Lonsdale Street,
Melbourne, 3000. Victoria.

Code No...4P........

SEMEN DONOR APPLICATION FORM.

[redacted]

Name.[redacted]......................

Address..[redacted]..

Telephone..[redacted]..

Age....[redacted]............Married/~~Single~~................................

Wife's Consent (Signature)..

Wife's Characteristics;..

....

....

Number of Children..............

Physical Characteristics of children.

Child No. I	Child No. 2	Child No. 3	Child No. 4
....	....	....	....
?.........	....	....	....
....	....	....	....
....	....	....	....

Medical Condition

........[redacted]ood...

....

Blood Group....[redacted]........

Past History of V.D...

Past History of Surgery e.g. inguinal hernia, testicular operations,

.......Appendix...

....

Have the immediate family and or relatives (mother, father, brothers, sisters, aunts, uncles or cousins) suffered from any of the conditions listed below,

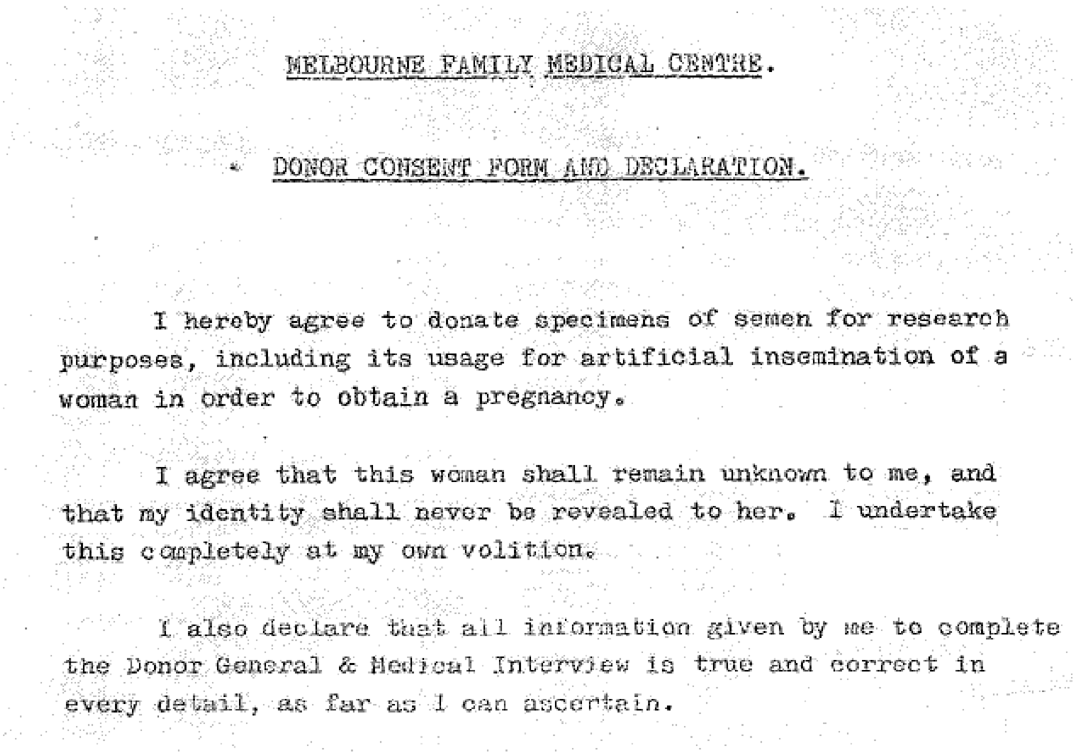
Cystic fibrosis (chronic respiratory disease).......................

Renal Condition............. Bronchial asthma.........................

Diabetes.....................Hypertension..............................

[illegible] [redacted]

Donor statement and consent form from the Queen Victoria Medical Centre (page 3)[574]



MELBOURNE FAMILY MEDICAL CENTRE.

DONOR CONSENT FORM AND DECLARATION.

I hereby agree to donate specimens of semen for research purposes, including its usage for artificial insemination of a woman in order to obtain a pregnancy.

I agree that this woman shall remain unknown to me, and that my identity shall never be revealed to her. I undertake this completely at my own volition.

I also declare that all information given by me to complete the Donor General & Medical Interview is true and correct in every detail, as far as I can ascertain.

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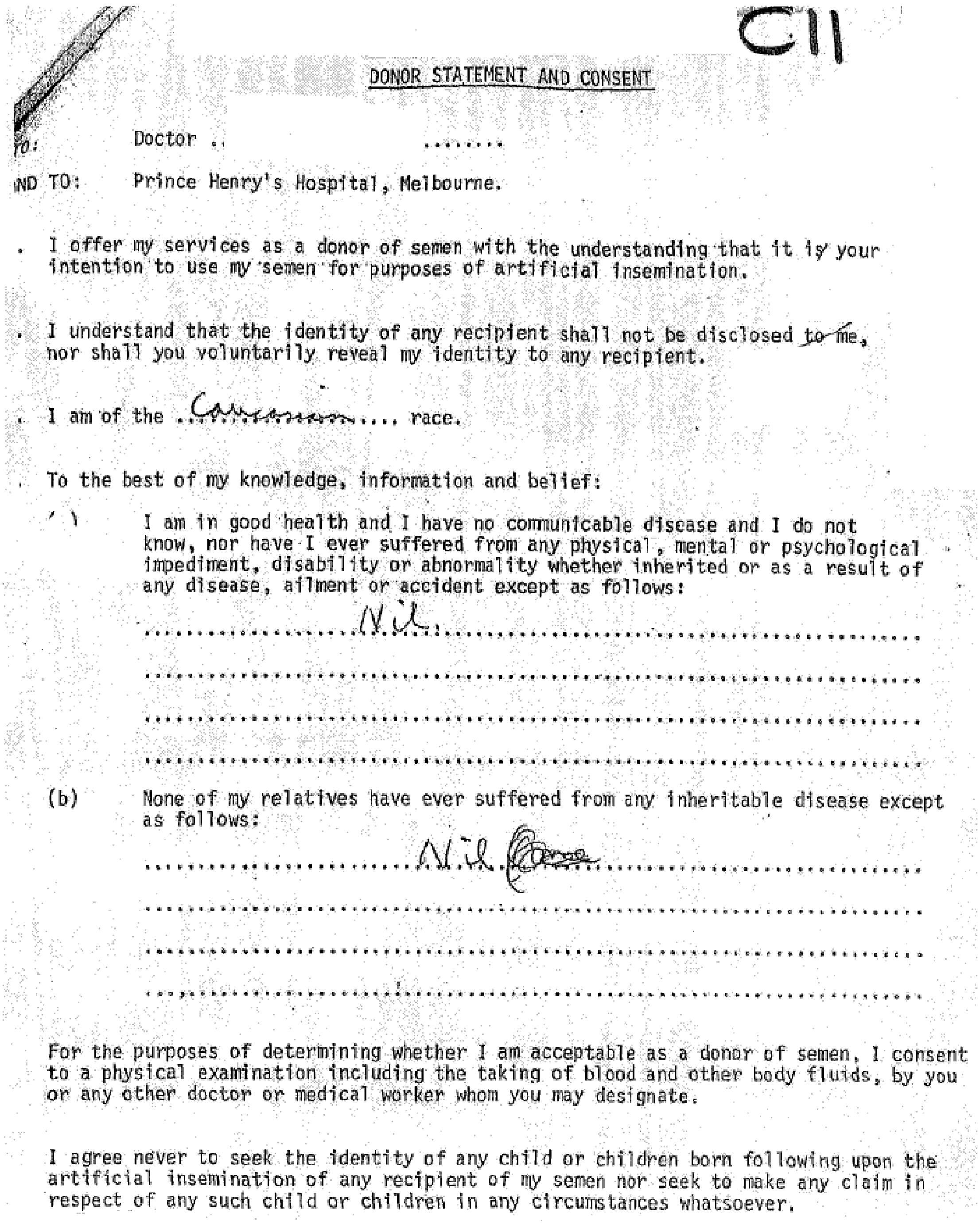
[574] Page 2 of the consent form is omitted, as it contains donor details.

Donor statement and consent form from Prince Henry's Hospital



C11

DONOR STATEMENT AND CONSENT

TO: Doctor .. ..

ND TO: Prince Henry's Hospital, Melbourne.

. I offer my services as a donor of semen with the understanding that it is your intention to use my semen for purposes of artificial insemination.

. I understand that the identity of any recipient shall not be disclosed to me, nor shall you voluntarily reveal my identity to any recipient.

. I am of the ..Caucasian.... race.

. To the best of my knowledge, information and belief:

(a) I am in good health and I have no communicable disease and I do not know, nor have I ever suffered from any physical, mental or psychological impediment, disability or abnormality whether inherited or as a result of any disease, ailment or accident except as follows:

Nil.

(b) None of my relatives have ever suffered from any inheritable disease except as follows:

Nil

For the purposes of determining whether I am acceptable as a donor of semen, I consent to a physical examination including the taking of blood and other body fluids, by you or any other doctor or medical worker whom you may designate.

I agree never to seek the identity of any child or children born following upon the artificial insemination of any recipient of my semen nor seek to make any claim in respect of any such child or children in any circumstances whatsoever.

Appendix Four:
Central register data

Table 1: Applications to the central register by applicant and time period

	Applications for identifying information[575]	**1984 central register**	**1995 central register**	**Total**
1 July 2010 – 30 June 2011[576]	Donors	0		**0**
	Donor-conceived individuals	3		**3**
	Recipient parents	9		**9**
1 January 2010 – 30 June 2010[577]	Donors	1		**1**
	Donor-conceived individuals	2		**2**
	Recipient parents	3		**3**
1 July 2009 – 31 October 2009[578]	Donors	0	1	**1**
	Donor-conceived individuals	1	0	**1**
	Recipient parents	0	4	**4**
1 January 2008 – 30 June 2009[579]	Donors	1	2	**3**
	Donor-conceived individuals	4	0	**4**
	Recipient parents	4	15	**19**
1 January 2007 – 31 December 2007[580]	Donors	2	1	**3**
	Donor-conceived individuals	3	0	**3**
	Recipient parents	4	1	**5**
TOTAL				**61**

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[575] A small number of applications for non-identifying information have also been made, but consistent data are not available for these across the entire time period, so only applications for identifying information are tallied here.

[576] Victorian Assisted Reproductive Treatment Authority, 'A statistical snapshot of the donor registers in Victoria for 2010-2011', VARTA, Malbourne, 2011, viewed 23 Nov 2011, <www.varta.org.au>, p. 3. Note that the numbers for applications for identifying information include applications for both identifying and non-identifying information. This data does not distinguish the 1984 and 1995 central registers, as they were merged into one central register from 1 January 2010.

[577] Victorian Assisted Reproductive Treatment Authority, *Annual report 2010*, VARTA, Melbourne, 2010, p. 22. Again, the numbers for applications for identifying information include applications for both identifying and non-identifying information.

[578] Ibid, p. 21.

[579] Infertility Treatment Authority, *Annual report 2009: twelfth and final report*, ITA, Melbourne, 2009, p. 19.

[580] Infertility Treatment Authority, *Annual report 2008*, ITA, Melbourne, 2008, p. 21.

Table 2: Information recorded on the central register[581]

Information about a child born as a result of a donor treatment procedure	Date of birth Sex Name and address of place of birth
Information about the woman on whom the donor treatment procedure was carried out	Birth name Unique patient identifier Date of birth Place of birth (suburb or town)
Information about the partner (if any) of the woman on whom the donor treatment procedure was carried out	Birth name Unique patient identifier, if applicable Date of birth Place of birth (suburb or town)
Information about the donor treatment procedure	The outcome of the treatment procedure – whether a birth, a pregnancy or unknown
Information about the donor treatment procedure – if carried out by a registered ART provider	Name of registered ART provider Address of registered ART provider
Information about the donor treatment procedure – if it was carried out by a doctor other than on behalf of a registered ART provider	Name of doctor Address of doctor The doctor's Medical Practitioners Board of Victoria Registration Number
Information about the donor of the gametes, or each donor of the embryo used in the donor treatment procedure	Any other name by which the donor has been known Sex Unique donor identifier In the case of a donor embryo, the embryo reference number Date of birth Place of birth (suburb or town and country) Whether the donor has donated gametes, other than to the registered ART provider or doctor who carried out the treatment procedure Date of the donor's consent to use the gametes or embryos in a treatment procedure Number of women who have children conceived using the donor's gametes or from an embryo formed from the donor's gametes, including the donor and any current or former partner of the donor

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[581] *Assisted Reproductive Treatment Regulations 2009* (Vic), Schedule 5.

	Number of children born as a result of treatment procedures carried out by the registered ART provider or the doctor using the donor's gametes or embryo Any genetic abnormality of the donor (if known) Hair colour Eye colour Build Height Blood group Marital status Occupation Education Interests Father's country of birth (if known) Mother's country of birth (if known) Paternal grandfather's country of birth (if known) Paternal grandmother's country of birth (if known) Maternal grandfather's country of birth (if known) Maternal grandmother's country of birth (if known)