INQUIRY INTO INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS

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SUBMISSION TO THE NSW LEGISLATIVE ASSEMBLY'S COMMITTEE ON LAW AND SAFETY INTO

INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS

Prepared by:

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The Chair, Committee on Law and Safety, Parliament House, Macquarie Street, SYDNEY, NSW 2000

15 December 2011

Dear Mr Barilaro and members of the Committee,

I thank you for your letter dated 20 October 2011, inviting me to make a submission to your current inquiry into the inclusion of donor details on the Register of Births, Deaths and Marriages (RBDM). As a legal academic and researcher who has for a number of years worked on these particular issues I am grateful for the opportunity to contribute to your inquiry.

I acknowledge that the impetus to this inquiry was a District Court decision to remove a sperm donor's details from the RBDM, and that this register is separate to the 'central register' maintained by the NSW Department of Health upon which details of donors are held. The latter register was set up to assist the exchange of information on donor conceived people, with donors and offspring having the opportunity to access information about each other for those donations made after 2010.

Your inquiry however, raises a number of issues that go beyond simply where information is and should be stored. In particular, why information should be released and surrounding issues need to be considered.

As such, my submission will address:

- 1. The history of donor conception in Australia;
- 2. The current state of law with regards to
 - a. Legal parentage of donor-conceived individuals; and
 - b. the recording and release of information about donors to donor-conceived individuals across Australia;
- The call for a national register of donors or in the alternative a central register in all states and territories – (The Senate Committee Inquiry, 2010);
- The issue of retrospective release of information about donors to donor conceived individuals;
- 5. The need to separate the issue of *information release* from issues of *legal parenthood*, and *contact*;

6. Specific issues raised by your inquiry, including examination of the form in which information might be held at the NSW RBDM.

Having considered these issues, it is my submission that, given the complexities surrounding information exchange, all information about donors and donor-conceived individuals should be held at the Central Register. I would suggest that this should include a shift to add to that register all information about donors who donated sperm, eggs or embryos prior to 2010, including the opportunity for those who 'donated' outside of the clinic system to add their names to the register. Nonetheless, the RBDM might play an important role in *notifying* donor-conceived individuals that such information exists as without knowledge that they are donor-conceived, they may not then make a choice about whether they wish to access such information.

Again, I thank you for the opportunity to express by thoughts, and do hope they are helpful to your inquiry.

Kind regards,

Dr Sonia Allan

i. INTRODUCTION

History of Donor Conception in Australia

The use of donor sperm to achieve pregnancy has reportedly existed for centuries. However, since the early 1950s its existence became better known and from the 1970s its use greatly increased. Technological advances further increased the occurrence of donor conception in Australia with the first in-vitro fertilisation ('IVF') procedure in Australia occurring in 1979, and the first IVF baby born in June 1980. Since then numerous assisted reproductive technologies (ART) and practices have been developed (including gamete intra-fallopian transfer ('GIFT'), zygote intra-fallopian transfer ('ZIFT'), intracytoplasmic single sperm injection ('ICSI'), and surrogacy). All of these may involve the use of donor oocytes, embryos or sperm, and take place within the clinic system with ART specialists, counsellors and other professional staff involved in the process using ART to attempt to conceive a child.

Private arrangements amongst certain parties have also existed throughout the history of donor conception. This is often referred to as 'known' donations, and involves a man agreeing to donate his sperm to a woman or female couple. In these instances, the woman may inseminate herself outside of the clinic system, or sexual intercourse may occur for the purposes of conceiving a child. Generally the latter (i.e. sexual intercourse between parties) would fall outside of what is referred to as ART.

The use of ART in Australia continues to increase—for example, the Australian Institute of Health and Welfare ('AIHW') Perinatal Statistics Unit 2008 report states '[t]here were 10,522 babies born to women who had fertility treatment in 2006. This was a 5% increase on 2005.'¹ Whilst the majority of treatments involve the use of fresh or frozen non-donor gametes (eggs and sperm), there were 354 live births following embryo transfers which involved oocytes/embryo donation and 278 live deliveries of children who were conceived using donor insemination in 2006. These figures do not include DI cycles undertaken in hospitals or private clinics that are not fertility clinics. They also do not include the situation in which 'known donors' are used.

¹ YA Wang, JH Dean, T Badgery-Parker & EA Sullivan, *Assisted reproduction technology in Australia and New Zealand 2006*, (2008). Assisted reproduction technology series no. 12. AIHW cat. no. PER 43. Sydney: AIHW National Perinatal Statistics Unit.

Given the recorded figures, if at an estimate there has been an average of 600 births per year since the early 70s in which donor gametes were used to conceive, this would amount to approximately 20,000 donor conceived individuals living in Australia. However, donor support groups estimate the figure to be closer to 60,000² if one includes those individuals that were conceived with the assistance of a GP or outside of the clinic system.

Secrecy Surrounding Donor Conception of the Past

In most jurisdictions in Australia, both identifying and non-identifying information about donors remains unknown to both the recipient parents and the donor-conceived individual in particular due to the secrecy that surrounded donor conception in the past. Such secrecy was often closely linked to family angst about infertility, and doctors trying to assist such families to have children. Recipient parents were told they should not seek information about the donor, whilst donors were told they should not seek information about the recipient parents or the resultant child.

Where heterosexual couples were involved, it has been reported that it was often easier for parents simply not to tell the resultant child they were donor conceived either because of their shame about their own battles with infertility, their fears of being rejected by the resultant child, or because despite their desire to tell their child, they were frustrated by having no way of imparting further information about the donor.

The secrecy does not appear at all to have been ill intended—that is, all involved may have believed that what they were doing was best for the donor-conceived individual. However, we are learning, as some of the donor-conceived individuals born to these families are now reaching adulthood, and having families of their own, that the effects of such secrecy, and being denied access to information about their genetic heritage, have had significant negative impacts for some donor-conceived individuals.

Changing Families

History has seen significant changes to laws surround access to assisted reproduction and openness. With changing laws which allowed access to ART through the clinic system (and therefore a safer environment for women as they were able to access screened sperm), single

² See for example the Donor Conception Support Group, <u>http://www.dcsg.org.au/legislation/inquiry.html</u> at 24 July 2010.

women, and same-sex couples moved to increasingly utilising ART as a means of family building. The laws in all states and territories have moved to recognise both members of the couple as legal parents, giving them equal status to heterosexual couples who had used ART to conceive a child. (These laws are discussed further below, but it is here noted that in all cases these laws are intended and work to ensure that the people who are parenting the child are recognised as the *legal* parents and therefore have all rights and responsibilities for that child).

Evidence shows that same-sex families have been much more open with their donorconceived children about the method of conception, and that outcomes for children have been very positive. The earlier children are told, and the more information they have, the better they fair.

However, despite the growing acceptance of ART as a way to assist people to build families, many continue to be frustrated by lack of access to information about the 'donor' and/or 'donor siblings' of the donor conceived individual. That is, despite a desire to be open, in most jurisdictions in Australia, access to information has been difficult to say the least. There has therefore been a move towards encouraging disclosure and away from secrecy amongst all families that access ART.

The issues therefore faced by families of all types across Australia are of concern. Moreover, the denial of information about genetic heritage for many thousands of donor conceived individuals impacts upon them, and of course generations to come. The need for information is further discussed below. However, first, I will turn to an exposé of the current state of law in Australia.

ii. AUSTRALIAN STATE AND TERRITORY LAWS

LEGAL PARENTAGE OF CHILDREN WHERE ART HAS BEEN USED

Every jurisdiction in Australia has legislation the object of which is to provide legal certainty regarding the status of children and their parents.³ Such legislation was introduced in all jurisdictions in the 1970s to address the stigmatisation of children born to women who were not married and to remove notions of 'illegitimacy'. There have been significant social changes since the inception of these Acts. Forty years later it is now common place that Australian families come

³ Artificial Conception Act 1985 (WA); Family Relationships Act 1975(SA); Parentage Act 2004 (ACT); Status of Children Act 1996 (NSW); Status of Children Act (NT); Status of Children Act 1974 (Tas); Status of Children Act 1978; and Status of Children Act 1974 (Vic).

in 'all shapes and sizes'. Children may be parented by their biological parent(s) or they may have adoptive parents, foster parents, or live in blended families. The people who parent them may be heterosexual, gay, lesbian, bisexual or transgender (GLBT). They may be single, married, in heterosexual de facto or same-sex relationships. Whilst the law has been slow to recognise *legal* parentage in some of these circumstances it is now the case that changes to laws in federal and state/territory jurisdictions recognise and in some instances facilitate same-sex parenting.

THE IMPORTANCE OF RECOGNISING LEGAL PARENTAGE

Legal recognition of parents gives rise to a set of rights and responsibilities (or obligations) under the law that serve to protect and maintain children. Children who do not have their parentchild relationship recognised may have reduced rights and/or entitlements than other children within the community. For example, without legal recognition of a non-biological parent a child may be left in the predicament where one of its primary carers may not legally

- make decisions about medical treatment for the child;
- appoint a testamentary guardian for the child;
- bring about legal proceedings on behalf of the child;
- make decisions or meet legal obligations concerning schooling or employment for children under 17 years of age;
- be entitled to be party to child protection hearings; or
- be entitled to be present if the child is being questioned by police.

In addition, the child may not be able to lay claim to the co-parent's estate if adequate provision in a will has not been made or the co-parent dies intestate (without a will).⁴

RECOGNITION OF LEGAL PARENTAGE: HETEROSEXUAL COUPLES AND SINGLE WOMEN

Historically, the law in all jurisdictions has made provision for legal parentage in circumstances in which ART was used for heterosexual married or de facto couples, and for single women or where a woman underwent ART without her husband's consent.

⁴ For detailed discussion of the impacts upon children in these circumstances see Queensland Government, *Review of the Legal Status of Children Being Cared for by Same-Sex Parents* (August 2009); Victorian Law Reform Commission, *Assisted Reproductive Technology and Adoption* (March 2007); John Tobin, *The Convention on the Rights of the Child: The Rights and Best Interests of Children Conceived Through Assisted Reproduction* (2004) viii (Occasional Paper Commissioned by Victorian Law Reform Commission).

In all jurisdictions it was generally provided that the woman giving birth to a child is that child's legal parent. When, with the consent of her husband, a married woman had undergone artificial insemination using donor sperm, the husband was presumed to be the father of the resulting child and the donor was presumed not to be the father. When the procedure involved an ovum or embryo transfer (whether or not the woman's ovum or the husband's sperm was used) the woman's husband was presumed to be the father.

In all instances, the sperm or egg donor (if any) was presumed not to be a legal parent of the child, and has 'no rights and incurs no liabilities' in respect of the child unless he later became the husband of the child's birth mother.

Similarly, where donor sperm was used for the artificial insemination of an unmarried woman, or of a married woman without the consent of her husband, the law provided that the donor 'has no rights and incurs no liabilities'.

Thus, in the case of heterosexual married or defacto couples, and single women, who had used ART to assist them to conceive a child, full legal parenting status was given to them over the resulting donor-conceived individual. The difficulties described above regarding the need to recognise the people who were actually parenting the child as its legal parents were resolved.

RECOGNITION OF SAME-SEX CO-PARENTS

Although parenting orders under the *Family Law Act 1975* (Cth) created similar entitlements in some of these areas for same-sex parented families, they did not create equal entitlements for children within these families. It was recognised that parenting orders could be changed, only last until a child turns 18, are subject only to the terms of the order,⁵ and may not overcome the issues concerning succession.

In addition, arguments that it was discriminatory to require certain parents to attend court and pay for such orders to be made, when in other family structures parental status and the accompanying legal rights and responsibilities were (and continue to be) presumed under the law were made. For example, Tobin identified that 'prohibition against discrimination is a fundamental principle of international law and a guiding principle under the international *Convention on the Rights of the Child*'.⁶ He emphasised that states must therefore ensure and respect the rights

⁵ Family Law Act 1975 (Cth), s61D.

⁶ Tobin, above n4, viii.

under the Convention of each child without discrimination of any kind irrespective of the child's status.⁷ This would include his or her status as a child living with parents of the same-sex. The Convention further provides that States must take all appropriate measures to ensure a child is protected from all forms of discrimination on the basis of the status of his or her parents, which would extend to their sexual orientation.⁸ 'It is not necessary that the discrimination be intended, it need only be shown that the effect of the treatment is to undermine the enjoyment of a right.'⁹ The Australian Human Rights Commission report 'Same-Sex Entitlements: National Enquiry into Discrimination Against People in Same-Sex Relationships, Financial and Work Related Entitlements and Benefits' (2007) echoed that denial of same-sex parenting is discriminatory and that it leads to injustices for children. Numerous reports and inquiries around the country concerning same-sex parenting across Australia have found the same.¹⁰

It was also increasingly recognised that children reared in same-sex families have positive family experiences and outcomes.¹¹ Notably, in a recent review of research and literature on the matter, Short et al found:

it is family *processes* (such as the quality of parenting and relationships within the family) that contribute to determining children's wellbeing and 'outcomes', rather than family *structures*, per se, such as the number, gender, sexuality and co-habitation status of parents. The research indicates that parenting practices and children's outcomes in families parented by lesbian and gay parents are likely to be at least as favourable as those in families of heterosexual parents, despite the reality that considerable legal discrimination and inequity remain significant challenges for these families.¹²

For these reasons, and to remove discrimination against GLBT individuals and same-sex couples, all jurisdictions in Australia have moved to amend their laws. The amendments are further described below.

⁷ Ibid, 28.

⁸ Ibid.

⁹ Ibid.

¹⁰ Queensland Government, Review of the Legal Status of Children Being Cared for by Same-Sex Parents (August 2009); Human Rights and Equal Opportunity Commission, *Same-sex: Same Entitlement* (May 2007); Victorian LRC, Assisted Reproductive Technology and Adoption (March 2007); New South Wales Law Reform Commission, *Relationships* (June 2006); and Tasmanian Law Reform Institute, *Adoption by Same-Sex Couples* (May 2003).

¹¹ Dr Ruth McNair, Outcomes for Children Born of ART in a Diverse Range of Family Types (2004).

¹² Elizabeth Short et al., Lesbian, Gay, Bisexual and Transgender (LGBT) Parented Families: A Literature Review Prepared for the Australian Psychological Society (2007).

FEDERAL SAME-SEX PARENTING LAWS

In 2008 the Federal Government changed 85 laws to give same-sex couples in a de facto relationship or registered relationship the same rights as de facto opposite-sex couples. Of relevance to this discussion specifically are changes to the *Family Law Act 1975* (Cth) (FLA) which mean that Federal law now recognises many more same-sex couples and their child/ren as a family. They include:

- the recognition of a consenting female de facto partner as the parent of a child born to a woman as a result of an artificial conception procedure;¹³
- provision that the gamete donor is not a parent of the resulting child for the purposes of the FLA;¹⁴
- the extension of parental status to a person whose de facto partner has adopted a child with their consent;¹⁵ and
- clarification that transfer of parentage by state and territory courts for surrogacy families alters parentage under the FLA.¹⁶

<u>The provisions apply to children born before, as well as after, the amendments</u> and have been adopted in various other federal Acts. Same-sex parents are now also recognised for the purposes of child support; parenting orders; superannuation; tax; child care and family benefits (including Medicare and the Pharmaceutical Benefits Scheme); recognition of extended family members of both parents as family members of the child/ren; and other recognitions of family formation which are relevant to consent giving regarding stored human embryos and witness protection.¹⁷ Same-sex families are protected from discrimination on grounds of 'family responsibilities', by the *Sex Discrimination Act 1984*.

¹³ Family Law Act 1975, s60H(1)).

¹⁴ Family Law Act 1975, s60(H)(1)(d).

¹⁵ *Family Law Act 1975,* s60HA.

¹⁶ *Family Law Act 1975,* s60HB.

¹⁷ See Law Officers Act 1964 ; Customs Act 1901; Service and Execution of Process Act 1992; Witness Protection Act 1994; Export Market Development Grants Act 1997 ; Family Law Act 1975 ; Sex Discrimination Act 1984 ; Research Involving Human Embryos Act 2002.

Whilst the changes to the federal laws are not without their shortcomings,¹⁸ they do generally enhance access to justice for children born into non-traditional families.

AUSTRALIAN STATE/TERRITORY REGULATION OF SAME-SEX PARENTING

As the changes to Federal law did not affect any State/Territory responsibilities all jurisdictions have also moved to amend their laws.

Following numerous inquiries and law reform reports across Australia,¹⁹ all Australian jurisdictions presume the same-sex partner of a birth mother who has used ART to conceive is a legal parent of a child born.²⁰ This is an irrebuttable presumption in all jurisdictions, provided consent was given to the birth mother undergoing ART.²¹ All jurisdictions provide for the same-sex co-parent to be entered on the child's birth certificate.

Surrogacy parentage (which may include same-sex male partners) reforms across Australia have been less uniform. Whilst altruistic surrogacy arrangements are possible in all jurisdictions except South Australia only Victoria,²² Queensland²³ and the Australian Capital Territory²⁴ make provision for transfer of legal parentage to the commissioning person/couple regardless of sexual orientation.²⁵ Western Australia, whilst allowing for transfer of legal parentage in relation to surrogacy agreements limits such transfer to two people 'of opposite sexes who are married or in a de factor relationship with each other'.²⁶ The other jurisdictions do not prohibit surrogacy, but they do not provide for transfer of legal parentage (for anyone) by way of parenting orders. Nonetheless, the laws do demonstrate a trend towards according parental status in surrogacy

¹⁸ For a detailed discussion of the provisions see Jenny Millbank, 'Defacto Relationships, Same-sex and Surrogate Parents: Exploring the Scope and Effect of the 2008 Federal Relationship Reforms' (2009) *23 Australian Journal of Family Law* 21.

¹⁹ Queensland Government, Review of the Legal Status of Children Being Cared for by Same-Sex Parents (August 2009); Human Rights and Equal Opportunity Commission, *Same-sex: Same Entitlement* (May 2007); Victorian LRC, Assisted Reproductive Technology and Adoption (March 2007); New South Wales Law Reform Commission, *Relationships* (June 2006); and Tasmanian Law Reform Institute, *Adoption by Same-Sex Couples* (May 2003)..

 ²⁰ Status of Children Act 1996 (NSW), s14(1A); Status of Children Act 1974 (Vic), s13; Artificial Conception Act 1985 (WA), s6A; Status of Children Act (NT), s5DA; Parentage Act 2004 (ACT), s11(4); Status of Children Act 1974 (Tas), 10C(1A); Status of Children Act (Qld), s19C-19E.

²¹ Ibid.

²² Assisted Reproductive Treatment Act 2008 (Vic); Status of Children Act 1974 (Vic).

²³ Surrogacy Act 2010 (Qld).

²⁴ Parentage Act 2004 (ACT).

²⁵ Note: Each jurisdiction has other criteria that must be met before entering into a surrogacy agreement (for example age of surrogate, counselling, gestational versus partial surrogacy) discussion of which is beyond the scope of this paper.

²⁶ Surrogacy Act 2008(WA), ss19(1)(i) & (2).

families through 'state-based post-birth court sanctioned transfer processes.'²⁷ This was confirmed in January 2009 when the Standing Committee of Attorneys General issued a discussion paper calling for a harmonious approach in particular relating to parentage transfer in such arrangements.²⁸

REGULATION OF ART AND LAWS REGARDING INFORMATION ABOUT DONORS

Of course, with the recognition of a non-biological parent as a legal parent of a donorconceived individual, the dilemma concerning secrecy or denial of information about the individual's genetic heritage has arisen. This is not to say that recognition of legal parentage should not have occurred however, as such recognition is fundamental to family functioning, and the child's well-being. Rather, the issue concerning information, is a separate one, which has increasingly been recognised as a matter that needs rectification.

Here, the law has not been uniform. The Australian approach to regulating (or not regulating) donor conception differs across jurisdictions. Each jurisdiction has exhibited divergent methods for recruiting donors, storing and using their sperm and assessing which infertile couples are appropriate to receive donor conception.

With regards to information collection and dissemination, while the various jurisdictions today purport to follow ethical codes of conduct in the documentation and retention of identifying information and the medical history of sperm donors, this has not always been the case. The retention of information on donors has traditionally been within the sole discretion of medical clinics and the doctors performing ART. State and territory legislation specifies a period in which medical records must be retained but, after this period, information on donors may be destroyed. It is therefore common for many donor-conceived individuals, when informed of their donor-conceived status and curious for information about their donor, to be informed by the clinics, or GP that performed the artificial insemination, that such information has been destroyed. For other donor-conceived individuals the information still exists, however they are unable to access it. This is a result of inconsistent legislation regarding access to information across Australia.

For donor-conceived children conceived outside of the clinic system (i.e. through known donation'), access to information is completely reliant on the parties to that arrangement

²⁷ Millbank, above n18.

²⁸ Standing Committee of Attorneys-General Joint Working Group, A Proposal for a National Model to Harmonise Regulation of Surrogacy (January 2009).

maintaining and giving information themselves. That is, unless the known donor was entered onto the birth certificate, his information may not have been recorded anywhere. Further, brought to our attention by way of changes to the law that recognise legal parentage for same-sex couples, is that even where a known donor was originally recorded on the birth certificate this information might be removed. Of course, this simply equates to the situation where he was never put on there in the first place—recognising that only two legal parents may be recorded on the birth documents. The dilemma is, in all circumstances (for all families), where that donor's information should be recorded to ensure the donor-conceived individual may access it if they wish to.

SPECIFIC LAWS REGARDING INFORMATION RECORDING AND RELEASE

Currently, four Australian states have legislation that governs access to information concerning donor conception²⁹ however South Australia does not maintain a registry and information is difficult at best to obtain.

All states and territories (including those without legislation) refer to the National Health and Medical Research Council (NHMRC) guidelines and recommendations for ethical practice.³⁰ Whilst the states that have legislation make some (differing) provisions for donor-conceived children to access identifying or non-identifying information about their donors and/or any related siblings they are piecemeal and depend upon when a person was conceived. This is illustrated in Table 1, which details state and territory positions, highlights the differences between them regarding access to information and donor registries, and illustrates the complexities of registers where they do exist.

²⁹ Human Reproductive Technology Act 1991 (WA); Assisted Reproductive Treatment Act 2008 (Vic); Assisted Reproductive Treatment Act 1988 (SA); Assisted Reproductive Technology Act 2009 (NSW).

³⁰ NHMRC Ethical Guidelines on the Use of Assisted Reproductive in Clinical Practice and Research 2004 (Revised as at 2007).

STATE	LEGISLATION/ REGULATIONS/ GUIDELINES	ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION	VOLUNTARY REGISTER
Western Australia	Human Reproductive Technology Act 1991 (WA)	Compulsory Register: Identifying Information People conceived after 2004 may access identifying information when they turn 16 about their donor. People conceived prior to 2004 may access non-identifying information that is held on the register. (Noting that information has only been held on the central register since 1993). Many people will have to approach the clinic involved in their conception and access to information will depend on clinic's record keeping and policies.	Voluntary Register ³¹ A 1999 report reviewing the Act considered that donor offspring should be able to obtain information about their origins, including identifying information. Consequently, a voluntary register exists to facilitate the exchange of identifying information. Such information is entered on the Voluntary Register if a person completes a properly signed and witnessed written registration form. Access is based on the mutual consent between donors and donor-conceived individuals. Related donor-conceived offspring may also have access to identifying information about each other if they have all consented. This may be done without identifying the donor.

Table One: Access to information: state and territory regulations and registries.

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³¹ NB. Although the WA voluntary register may include details of people involved in donation since ART started in Western Australia (circa the early 1970s) its operations are influenced by whether the donation was made before or after the *Human Reproductive Technology Act 1991* came into operation, on 8 April 1993 as central records have only been stored since April 1993. The only records available before that time are those held by the fertility clinics and medical practitioners that provided such services. Because detailed records were not always kept in the early days of ART the registry notes that it is very difficult to match records for donors and donor offspring where donations were made before the early 1980s.

STATE	LEGISLATION/ REGULATIONS/ GUIDELINES	ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION	VOLUNTARY REGISTER
Victoria	Assisted Reproductive Treatment Act 1988 (SA)	 Mandatory Registers Maintained by the Victorian Registry of Births, Deaths & Marriages: Date of consent of the donor determines which register information is held on, and therefore access to information: 1984 Central Register: Infertility (Medical Procedures) Act 1984. Information that identifies any person may only be released with the consent of the person about whom it relates. 1995 Central Register: Infertility Treatment Act 1995 Donor consented from January 1st 1998 onwards. Information that identifies the donor is available when donor conceived person turns 18 years of age – subject to counseling requirements. The donor conceived person must consent to information being released to the donor requested. **NB. Victoria is currently undergoing an inquiry regarding retrospective release of information (Victorian Law Reform Committee) 	Voluntary Registers Voluntary registers have been set up to enable information exchange by people not governed by the legislation. There were two registers kept when held by the former Infertility Treatment Authority, defined again by changes in legislation: *Post-1988 Voluntary Register *Pre-1988 Voluntary Register However, Victorian Registry of Births, Deaths & Marriages now only refers to 'the Voluntary Register'.
New South Wales	Assisted Reproductive Technology Act 2007 (NSW) Assisted Reproductive Technology Regulation 2009	From 1 January 2010 identifying information has been held on a register maintained by the NSW Department of Health. Donor conceived individuals may access this information when they turn 18. Those conceived prior to 1 January 2010 need to contact the clinic in which they were conceived for non-identifying information if such records still exist.	A voluntary register is also to be maintained by the NSW Department of Health. Information will only be disclosed in accordance with the consent of the person who has entered information upon the register.

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STATE	LEGISLATION/ REGULATIONS/ GUIDELINES	ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION	VOLUNTARY REGISTER
South Australia	Assisted Reproductive Treatment Act 1988 (SA)	South Australian legislation requires record keeping. Changes to the Act in 2010 include that the Minister <u>may</u> keep a register of donors of human reproductive material used in assisted reproductive treatment and resulting in the birth of a child (the donor conception register). The law provides the register must contain, in relation to each donor on the register— (a) the donor's full name and nominated contact address; and (b) the full name and nominated contact address of the person to whom assisted reproductive treatment using the donor's human reproductive material was provided; and (c) the full name of any child born as a consequence of such assisted reproductive treatment (if known); and (d) any other information required by the regulations, and other information that the Minister thinks fit. However, the use of the word 'may' means that such a register is not compulsory. To date, there is no central register that holds this information. (The Health Department states that they are working on developing one). The status quo remains that donor conceived individuals must therefore contact the clinic/hospital/surgery where they were conceived. Donor-conceived individuals may access non-identifying information when they reach the age of 16, but again this is reliant on information actually being held by clinics.	NONE

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STATE	LEGISLATION/ REGULATIONS/ GUIDELINES	ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION	VOLUNTARY REGISTER
Tasmania, Northern Territory ACT Queensland	NHMRC Ethical Guidelines on the Use of Assisted Reproductive in Clinical Practice and Research (2007)	 These guidelines state: '6.1 Persons conceived using ART procedures are entitled to know their genetic parents. Clinics must not use donated gametes in reproductive procedures unless the donor has consented to the release of identifying information about himself or herself to the persons conceived using his or her gametes. Clinics must not mix gametes in a way that confuses the genetic parentage of the persons who are born. 6.1.1 Clinics should help potential gamete donors to understand and accept the significance of the biological connection that they have with the persons conceived using their gametes. Donors should be advised that the persons conceived are entitled to knowledge of their genetic parents and siblings. 6.1.2 Clinics should help prospective recipients to understand the significant biological connection that their children have with the gamete donor. Recipients should be advised that their children are entitled to knowledge of their genetic parents and siblings. 6.1.3 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.' There is however no evidence that the guidelines are implemented and no oversight of clinics with respect to ensuring identifying information is made available. Donor conceived individuals must contact the clinic to see if they hold any information (non-identifying) and whether they will release that information. 	NONE

iii. The importance of exchanging information for donorconceived individuals, recipient parents, and donors

There are numerous arguments that support the call for access to information by donorconceived individuals about their donors. I refer the Committee to the 2010 Senate Legal and Constitutional Affairs Committee Inquiry into Donor Conception Practices (Report 2011); and also to the attached article (in Appendix 1) written by myself which detail some of the arguments for and against such release.

In summary, these arguments include (but are not limited to) the following:

- The number of affected individuals who are demanding information is increasing as donorconceived individuals enter adulthood, and some have families of their own; Similarly, there are potentially tens of thousands of individuals who are yet to reach adulthood, or are yet to be conceived in those jurisdictions that do not have legislation that requires information recording and release, who may in the future call for information about their donors;
- 2. Whilst academic literature has increasingly emphasised that relations based on blood are less important in shaping a child's development than previously thought, some donor-conceived individuals report that on discovering they are not biologically related to their parent(s), that they feel a sense of "lost identity" and a corresponding desire to know more about their donor.³² This has been referred to as "genealogical bewilderment";³³
- 3. The curiosity about their donor and the propensity for donor-conceived individuals to search for information is not related to the desire to escape negative family issues; rather, most donor-

³² Turner A and Coyle A, "What Does it Mean to be Donor Offspring? The Identity Experience of Adults Conceived by Donor Insemination and the Implications for Counselling and Therapy" (2000) 15(9) *Human Reproduction* 2041; Jadva V, Freeman T, Kramer W and Golombok S, "Experiences of Offspring Searching for and Contacting their Donor Siblings and Donor" (2010) 20 *Reproductive BioMedicine Online* 523 at 524.

³³ Turner and Coyle, n 32; Wellisch E, "Children without Genealogy: A Problem with Adoption" (1952) 13(1) *Mental Health* 41; Sants H, "Genealogical Bewilderment in Children with Substitute Parents" (1964) 37(2) *British Journal of Medical Psychology* 133. Such bewilderment may be particularly acute for people who discover later in life that they were donor-conceived.

conceived individuals report positive relationships with their parents.³⁴ On the other hand, such feelings coexist with a strong desire to know about one's donor and frustration at being denied information;³⁵

- 4. There is great importance for having access to information concerning a biological parent's medical history (eg whether or not there is a familial history of heart disease, diabetes, cancer, mental health issues, and/or other heritable diseases).³⁶ Donor-conceived individuals who are denied access to familial medical histories are placed at increased risk as a result of not having access to information about their genetic heritage. This becomes very significant as people age. A donor who donated in the 1970s or 1980s, when donor-conception was shrouded in secrecy, may not until more recently have become aware that they are a carrier of certain diseases. Similarly, a donor-conceived individual may become aware of a heritable condition, but has no way presently to notify their donor(s) or half-siblings conceived using the same donor gametes. As there is no linkage for either the donor to the donor-conceived person, or vice versa, or to donor-conceived siblings, in most jurisdictions of Australia, alerting relevant parties to health information is problematic. This may have ramifications not just for the person unaware of such information but for generations to come. (On the other hand, the release of medical information raises issues about health privacy and confidentiality which are generally protected in Australia. These issues, along with the numerous exceptions to maintaining "health privacy", are discussed in my paper – see Appendix 1);
- 5. Some donor-conceived individuals report the fear of unknowingly forming relationships with siblings or possibly their unknown donor.³⁷ While the actual probability of such an occurrence is unknown (as the actual number of donor-conceived individuals is unknown), such a risk
 - may be significant within Australia, given the small population and the significant number of donor-conceived individuals in existence;

³⁴ Mahlstedt PP, LaBounty K and Kennedy WT, "The Views of Adult Offspring of Sperm Donation. Essential Feedback for the Development of Ethical Guidelines within the Practice of Assisted Reproductive Technology in the United States" (2010) 93(7) *Fertility and Sterility* 2236.

³⁵ Turner and Coyle, n 32; Dennison M, "Revealing Your Sources: The Case for Non-anonymous Gamete Donation" (2008) 21(1) *Journal of Law and Health* 1 at 13.

³⁶ Centers for Disease Control and Prevention (CDC), "Awareness of Family Health History as a Risk Factor for Disease" (2004) 53(44) Morb Mortal Wkly Rep 1044.

³⁷ Senate Legal and Constitutional Affairs References Committee, Submission 156 (M Crawshaw) p 7.

- may have legal ramifications see for example, the *Marriage Act 1961* (Cth) which makes unlawful marriages between an individual and their parent, and an individual and their half-sibling; ³⁸
- may result in children being born to couples who are related, and therefore an increased risk of genetic or chromosomal difficulties in those children;³⁹
- 6. The law, across Australia, and within jurisdictions, is discriminatory as it depends not only upon *where* a donor-conceived individual was born but also upon *when* a donation took place, as to whether they can access information about their genetic heritage;
- 7. Parents of donor-conceived individuals are prevented from being able to provide their children with information that many actually desire to impart;
- It is not necessarily the case that past donors wish to remain anonymous.⁴⁰ The Donor
 Conception Support Group quoted in their submission to the Senate Committee a former sperm donor who stated:

I was a sperm donor during 1997-1998. [M]y donations were during the period when [d]onors had to sign away any future contact. This was a condition of participation and I only wanted to help people – but at the back of my mind was the hope that the rules would change to allow the resultant children to trace their donor fathers, if they wished to do so.⁴¹

Similarly, the Victorian Assisted Reproductive Treatment Authority (VARTA) stated that the belief that secrecy was paramount to protect all parties to the arrangement was based on myths:

[T]hat donors would not want to be contacted, that parents would not want to know more about their donor, and that donor-conceived individuals would not want information about their donor if they really loved their parents.⁴²

³⁸ Marriages Act 1961 (Cth), s 23(1)(b), makes marriages involving "prohibited relationships" void. Section 23(2)(a)-(b) states that "marriages between an individual and their parent and an individual and their sibling, including half siblings" are "prohibited relationships".

³⁹ Bennett RL, Motulsky AG, Bittles A et al, "Genetic Counseling and Screening of Consanguineous Couples and Their Offspring: Recommendations of the National Society of Genetic Counselors" (2002) 11(2) *Journal of Genetic Counseling* 97. The authors, in recognising the risk associated with forming consanguineous relationships, recommend genetic counselling and screening for consanguineous couples and their offspring. Donor-conceived individuals who are unaware of their relatedness to others would not have the opportunity to undergo such counselling/screening.

⁴⁰ Senate Legal and Constitutional Affairs References Committee, Submission 73 (Rainbow Families Council) p 2; Submission 122 (Donor Conception Support Group) p 139.

⁴¹ Senate Legal and Constitutional Affairs References Committee, Submission 122 (Donor Conception Support Group) p 74.

⁴² Victorian Assisted Reproductive Treatment Authority.

VARTA stated that "donors do not forget they have donated and often wonder about the people they helped to create. Who are they? Are they healthy? Are they happy? Are they loved?"⁴³

9. As access to assisted reproduction is opened up, and our country celebrates and recognises the many different family formations, so too should it facilitate the access of those families to information. This is vital, as such information is at risk of being lost or destroyed, eg as clinics or doctors' surgeries close.

iv. The Senate Committee Report

In the February 2011 report on its inquiry into the past and present practices of donor conception in Australia,⁴⁴ the Australian Senate Legal and Constitutional Affairs References Committee (the Senate Committee) made 32 recommendations concerning matters relating to:

- donor conception regulation and legislation across federal and State jurisdictions;⁴⁵
- the conduct of clinics and medical services with regard to payment for donors,⁴⁶ managing data relating to donor conception,⁴⁷ and provision of appropriate counselling and support services;⁴⁸
- the number of offspring born from each donor with reference to the risk of consanguineous relationships;⁴⁹ and
- the rights of donor-conceived individuals.⁵⁰

⁴³ Victorian Assisted Reproductive Treatment Authority, n 86.

⁴⁴ Senate Legal and Constitutional Affairs References Committee, *Donor Conception Practices in Australia* (2011) p 1.

⁴⁵ Senate Legal and Constitutional Affairs References Committee, pp 103-104, Recommendations 1, 2 and 3.

⁴⁶ Senate Legal and Constitutional Affairs References Committee, p 107, Recommendation 22.

⁴⁷ Senate Legal and Constitutional Affairs References Committee, p 105, Recommendation 12.

⁴⁸ Senate Legal and Constitutional Affairs References Committee, pp 107-108, Recommendations 25-27.

⁴⁹ Senate Legal and Constitutional Affairs References Committee, p 108, Recommendations 28 and 30.

⁵⁰ Senate Legal and Constitutional Affairs References Committee, pp 103-104, 107, Recommendations 3, 4 and 19.

Significantly, the Senate Committee recommended that jurisdictions which do not already have legislation in place should, "as a matter of priority", introduce legislation to regulate donor conception, ⁵¹ and that the "Australian Government pursue all available policy and political options ... to ensure that nationally consistent legislation relating to donor conception is developed". ⁵² In addition, <u>17 recommendations related to the preservation, recording and release of records concerning identifying and non-identifying information</u>⁵³ about donors to donor-conceived individuals. ⁵⁴ These included a call for the establishment, "as a matter of priority", of a national register of donors⁵⁵ and that this central register should operate according to principles which provide for donor-conceived individuals to be able to access identifying information about their donor.⁵⁶ In the alternative they called for state based registers underpinned again by uniform legislation.

I note that the recommendations and report left a number of issues open for further debate, including whether the legislation should provide for the retrospective release of identifying and non-identifying information about donors to donor-conceived individuals.⁵⁷ This is a matter that NSW will need to address given that it already provides a central register for donor conceived

⁵¹ Senate Legal and Constitutional Affairs References Committee, p 103, Recommendation 1.

⁵² Senate Legal and Constitutional Affairs References Committee, p 103, Recommendation 2.

⁵³ Identifying information would include the donor/donor-conceived person's name, date of birth and address; nonidentifying information might include education (level and qualifications); eye colour; hair colour; height; weight; marital status; number of children (if any); sex; year of birth; place of birth; nationality/culture with which the donor identifies; religion (if any); reason for becoming a donor; number of offspring born through other donations; identity of other offspring born through other donations; interests/hobbies/sporting activities; anything else the donor considers central to their personality. (It is difficult to delineate some of the information as identifying or non-identifying as some information in combination might lead to the identification of a person, but alone would be considered nonidentifying.)

⁵⁴ Senate Legal and Constitutional Affairs References Committee, pp 103-109, (see Recommendations 3, 5-14, 19-21, 25, 31-32).

⁵⁵ Senate Legal and Constitutional Affairs References Committee, p 104, Recommendation 5.

⁵⁶ Senate Legal and Constitutional Affairs References Committee, pp 104-105, Recommendation 9. Arguably, such a register would also enable donors to receive information about their offspring, and donor-conceived siblings to receive information about each other.

⁵⁷ See Senate Legal and Constitutional Affairs References Committee, p 114 at [7.26]: "In the absence of authoritative evidence about the legal and ethical implications of retrospectively removing donor anonymity, the committee chooses not to make any specific recommendation about retrospectivity."

individuals post 2010. Again, I refer you to the article that I have provided to you in Appendix 1, for further discussion of these issues. However, I here note that it is my position that given that the call for information has been made most loudly by those donor-conceived individuals who are already in existence, and who are denied access to information that already exists the issue of retrospectivity must be resolved for them in a positive manner.

v. Differentiating between information and contact

I would here like to note that I see a need to differentiate between the legal consideration of providing <u>information</u> about donors to donor-conceived individuals, and the issue of whether these individuals would like to pursue a <u>relationship or some kind of contact</u> with each other.

Where contact is desired by all parties, positive relationships may be formed. However it is reported that 'donor linking' (i.e. linking a donor-conceived individual, the recipient parents, the donor, and/or donor-conceived siblings) works best when excellent counselling and other support systems are in place to adequately support transitions to such relationships (see Victorian Assisted Reproductive Treatment Association for their work and experience).

However, the law should also provide for situations where the parties do not wish to have contact or to form a relationship. That is, some donor-conceived individuals (and/or their families) may want information about the donor, but do not wish to establish a relationship with him/her/them. In other instances, a donor may not wish to have contact with the resultant offspring. Exchanging information in these instances should not also necessitate or obligate contact between the parties. In these circumstances, I advocate allowing for information release, but also providing for what is referred to as a 'contact veto' – which would therefore protect the privacy of the person (and their extended family) that does not wish to be contacted. That is, whilst identifying and non-identifying information would be made available to the donor-conceived individual so that their needs regarding identity formation, knowledge about their heritage, medical history, etc. are addressed, a relationship with the donor may not follow unless all parties agreed (and underwent the necessary counselling).

There is also the consideration of situations in which known donations have occurred. In such situations, where there has been no relationship with the child, similar issues to those above stated arise. However, it is clear that there are many 'parenting' situations that go beyond the 'twoparent' families recognised at law for 'legal parentage' purposes. Known donors may in fact be very involved with the offspring; more than one couple may share the parenting of a child (for example, a same-sex male couple and a same-sex female couple), and so on. In all of these situations, it is equally important for the donor-conceived individual to have access to information about his/her donor and any donor-siblings. However, as with other family situations across Australia where conflict arises about parenting of the child and/or contact is at issue, it is my position that where the parties cannot agree these matters should properly be decided by the Family Law court. Contact in these circumstances falls outside of the scope of my submission, which recognises that family dynamics and personal situations are many and varied. I do not intend to suggest that such issues may be resolved by providing an opportunity for donor-conceived individuals to access information about their donors. Rather, I simply advocate that donor-conceived individuals should have a legal right to know of their method of conception and to have access to identifying and nonidentifying information about their donor.

For further discussion of the contact veto system, please again see Appendix 1.

vi. Where should information be held?

The recording and release of information relating to donor conception is not a simple matter. A donor's sperm may be used to by a number of families, and siblings may also wish to share and exchange information. It is my submission that simply recording a donor's information at the RBDMs would not be sufficient.

Support in relation to the collection and release of information is essential for donor-conceived individuals, recipient parents, and donors. In addition, the linking that needs to occur should donors and donor-conceived individuals and/or donor-conceived siblings wish to move to contacting each other is complex. To provide an example, we have seen that moving information to the RBDM in Victoria (in an effort to treat such information as part of the birth record), has been criticised for moving from a system that supported such complexities by way of donor linking programs, counselling and support services (through the central register once held at the former

Infertility Treatment Authority), to one which is disconnected and failing donor-conceived individuals. Victoria is currently considering whether a return to the old system is warranted, or whether adding/changing services provided by their RBDM are necessary.

I submit that

- all records should be held at the same central register for donor conception as already in existence for donor conceived individuals post 2010;
- support services should be provided for donor-conceived, recipient parents and donors in relation to the collection and release of such information; and
- 'contact vetos' may be placed at this register.

However, I think that fundamental to access to information is the need for donor-conceived individuals to have knowledge of their conception – and this is where the role of the RBDM is crucial.

That is, as it is the contention of this submission that donor conceived individuals have both a need and a right to know information about their genetic heritage it is important to address the issue of disclosure. Whilst legislative change removing donor anonymity has in itself played a part in facilitating parental disclosure there may be other ways to encourage disclosure. Counselling should be available to parents and families to facilitate this process. In addition, it is suggested that the inquiry should give consideration to how birth registration and certification may serve to identify a child's genetic heritage.

In Victoria, s153(1) of the Assisted Reproductive Treatment Act 2008 (Vic) provides for the birth certificate of a donor-conceived child to be annotated with the text 'donor conceived' where a 'birth registration statement' specifies that the child was conceived by a donor treatment procedure. Other approaches include:

- recording both the individual's genetic and social parentage on the birth certificate of a donor conceived person;
- the issue of a separate certificate to a donor-conceived person alerting them to the possibility
 of information held on the Register of Information; placing a code or symbol on the birth
 certificate of a donor-conceived person; the annotation of birth certificates of all individuals to
 indicate the existence of information held on the register; or

 the issue of two certificates to all people – a 'Certificate of Birth', identifying an individual's legal parentage and a 'Certificate of Genetic Heritage', indicating where an individual's genetic and legal parentage are different.

None of these proposals are without shortcomings⁵⁸ and some are more problematic than others. It might be argued in the alternative that it would be unacceptable (or traumatic) for a person to find out that they were donor conceived by way of application for a birth certificate if their parents have not told them about their conception. Similarly having a different birth certificate or a birth certificate that is marked in some way when compared to those of non donor conceived people might result in a donor conceived individual feeling stigmatised or resenting that information about their conception may be known to others when they, for example, use their birth certificate to open a bank account, get a driver's licence or any of the many other things for which birth certificates must be shown.

Whilst such matters require far more analysis than that which is possible in this submission I do believe that at a minimum an annotation to the birth certificate should exist because in order to make a choice about accessing information about their donors, donor conceived individuals must know about the method of their conception in the first place.

Further Considerations:

Age that Donor Conceived Individual May Access Information

In a number of international jurisdictions (Finland, New Zealand, Norway, Switzerland, the UK) eligibility to request disclosure of the donor's identity is conferred when the donor-conceived person reaches the age of eighteen. This age however may be adjusted in some circumstances. For example, in New Zealand a donor conceived person may apply to the Family Court from age sixteen to be treated as an eighteen year old, although the court will need to be satisfied that it is in the individual's best interests to receive the information requested.

In other jurisdictions the age is lower. For example, in Austria it is fourteen years, and in the Netherlands and Western Australia it is sixteen years. Sweden alone specifies no age at which the

⁵⁸ For a detailed critique see E. Blyth, L. Frith, C. Jones, J. Speirs, 'The Role of Birth Certificates in Relation to Access to Biographical and Genetic History in Donor Conception' (2009) 172 *International Journal of Children's Rights* 207–33.

information may be requested, requiring instead that the donor-conceived person has 'achieved sufficient maturity'.⁵⁹

In Western Australia, a donor conceived individual younger than sixteen years may learn her or his donor's identity, providing that the donor consents and the young person's parent(s) consent on the young person's behalf. Similarly in Victoria, a donor conceived individual that has not yet turned eighteen may learn his or her donor's identity providing the donor consents and the request is made via the young person's parent(s). Pursuant to the *Assisted Reproductive Treatment Act 2008* (Vic), parental or guardian consent will not be required if the young person has received appropriate counselling and the counsellor judges the individual to be 'sufficiently mature' to understand the consequences of seeking the information.

It is recommended here that access to identifying and non-identifying information be available to donor conceived individuals from the age of sixteen. Access to such information from a younger age should also be possible with the guidance/support of an adult – this may include a counsellor, youth worker, parent, guardian or other responsible adult.

Counselling

Counselling in relation to donor conception should be available on an ongoing basis and not only occur prior to conception. It should be readily available for recipient parents, donors and offspring. Given that this submission recommends total disclosure and access to information it should be available to assist parents in telling their children about how they were conceived, helping the family address any issues they face in relation to donor conception, and for the donor conceived. It should also be made available to donors to support them in recognising that their donation has resulted in the life of another person who may wish to access information about their genetic heritage. Of course, should all of the parties involved wish to move to also establishing some kind of relationship, they should be supported in doing so – recognising here the complexities again that arise given the many families (and individuals within them) that may be involved.

⁵⁹

United Nations Committee on the Rights of the Child, 1998.

viii. CONCLUSION

The issues faced by donor-conceived individuals concerning information about their genetic heritage and any siblings they may have, are of great importance. Inconsistency amongst states and territories with regards to access to such information creates an unjustifiable position in Australia. Whilst the author has called for the Federal Government of Australia to correct the anomalies faced by donor-conceived individuals in Australia by setting up a national register for donors and donor-conceived individuals, and the Senate Committee recommended that such a register be devised, this submission calls for New South Wales to address the issues faced by donorconceived individuals in their state.

This submission calls for compulsory registration of both identifying and non-identifying information for all donor conceptions regardless of when the donation took place. That is, registration of all identifying and non-identifying information held by clinics, hospitals and doctors surgeries about past donations. It is noted that opponents of disclosing identifying donor information argue that donor privacy should be respected. However the right to privacy does not and should not trump a person's ability to know important information about their genetic heritage. Whilst retrospective release of information is controversial, it is not impossible. There is already a precedent set by the release of identifying information in the adoption context, and the possibility of 'contact vetoes' as per this model. (See Appendix 1).

Records of information relating to the parties to ART should have been created by all IVF clinics in response to directives from the NHMRC and the Fertility Society of Australia.⁶⁰ Nonetheless, it must also be noted that for the large number conceived through donor conception before the implementation of ethical guidelines or the legislation in New South Wales which encouraged the retention of records and disclosure of donor identity, the only mechanism to achieve such outcomes is to also provide the opportunity to *voluntarily register information* to promote information-sharing between donors, offspring and/or siblings. **The New South Wales voluntary registry should also be maintained.**

There is of course an important function for the Register of Births Deaths and Marriages to play. Donor-conceived individuals cannot make a decision about whether or not they wish to

⁶⁰ Parliament has power to enact legislation with retrospective effect if it chooses, and modern statutes often contain specific provisions allowing for the prospective and retrospective operation of other provisions within the legislation.

access information about themselves unless they know they are donor conceived. It is my submission therefore that the RBDMs should annotate the birth certificate of a donor conceived individual to alert them to the fact that further information that they may wish to obtain is held on the Central Register. Knowing such notation will be given to the donor-conceived individual may encourage parents to disclose. As such, it is also my submission that NSW works towards ensuring that adequate counselling and support services are made available to recipient parents, donors and donor-conceived individuals in the move towards openness and sharing of information.

In Australia there are thousands (possibly tens of thousands) of individuals who have been donor conceived. Some of those individuals may wish to know about their genetic heritage, as might their children and generations after them. They deserve the right to choose. It is not acceptable to maintain or protect the secrecy that was involved in some of their conceptions. The law needs to be changed to provide them, and future donor conceived individuals, access to identifying and non-identifying information about their donors and their biological siblings.

I thank you for the opportunity to make this submission and look forward to seeing positive changes to the law come to fruition.

Kind regards,

Dr Sonia Allan

SUMMARY OF RECOMMENDATIONS:

- New South Wales must address the issues faced by donor-conceived individuals in their state regarding access to information about their donors.
- Compulsory registration of both identifying and non-identifying information for all donor conceptions regardless of when the donation took place should occur (including registration of all identifying and non-identifying information held by clinics, hospitals and doctors surgeries about past donations).
- All records should be held at the same central register for donor conception as already in existence for donor conceived individuals post 2010.
- Support services should be provided for donor-conceived, recipient parents and donors in relation to the collection and release of such information; and
- 'Contact vetos' may be placed at this register.
- The New South Wales voluntary registry should also be maintained and encourage known donors, and donors where records may have been destroyed to place their information on this register.
- The NSW RBDMs should annotate the birth certificate of a donor conceived individual to alert them to the fact that further information that they may wish to obtain is held on the Central Register.
- Access to identifying and non-identifying information should be made available to donor conceived individuals from the age of sixteen. Access to such information from a younger age should also be possible with the guidance/support of an adult – this may include a counsellor, youth worker, parent, guardian or other responsible adult.

APPENDIX 1

Psycho-social, ethical and legal arguments for and against the retrospective release of information about donors to donor-conceived individuals in Australia

Sonia Allan*

In the February 2011 report on its inquiry into the past and present practices of donor conception in Australia, the Australian Senate Legal and Constitutional Affairs References Committee called for the introduction of legislation to regulate donor conception in all jurisdictions that do not have it in place "as a matter of priority". It further called for the establishment, "as a matter of priority", of a national register of donors to enable donor-conceived individuals to access identifying information about their donor. The Senate Committee left open the question as to whether the legislation and central register should have retrospective effect. This article focuses upon that question. It shows that arguments concerning the privacy, confidentiality and anonymity of some donors who may wish to remain anonymous are outweighed by the manifest injustice faced by donor-conceived individuals who are denied access to such information, as well as their families and donors who wish to exchange this information.

INTRODUCTION

In the February 2011 report on its inquiry into the past and present practices of donor conception in Australia,¹ the Australian Senate Legal and Constitutional Affairs References Committee (the Senate Committee) made 32 recommendations concerning matters relating to:

- donor conception regulation and legislation across federal and State jurisdictions;²
- the conduct of clinics and medical services with regard to payment for donors,³ managing data relating to donor conception,⁴ and provision of appropriate counselling and support services;⁵
- the number of offspring born from each donor with reference to the risk of consanguineous relationships;⁶ and
- the rights of donor-conceived individuals.⁷

Significantly, the Senate Committee recommended that jurisdictions which do not already have legislation in place should, "as a matter of priority", introduce legislation to regulate donor conception,⁸ and that the "Australian Government pursue all available policy and political options ...

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⁷ Senate Legal and Constitutional Affairs References Committee, n 1, pp 103-104, 107, Recommendations 3, 4 and 19.

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¹ Senate Legal and Constitutional Affairs References Committee, Donor Conception Practices in Australia (2011) p 1.

² Senate Legal and Constitutional Affairs References Committee, n 1, pp 103-104, Recommendations 1, 2 and 3.

³ Senate Legal and Constitutional Affairs References Committee, n 1, p 107, Recommendation 22.

⁴ Senate Legal and Constitutional Affairs References Committee, n 1, p 105, Recommendation 12.

⁵ Senate Legal and Constitutional Affairs References Committee, n 1, pp 107-108, Recommendations 25-27.

⁶ Senate Legal and Constitutional Affairs References Committee, n 1, p 108, Recommendations 28 and 30.

⁸ Senate Legal and Constitutional Affairs References Committee, n 1, p 103, Recommendation 1.

The retrospective release of information about donors to donor-conceived individuals in Australia

to ensure that nationally consistent legislation relating to donor conception is developed".⁹ In addition, 17 recommendations related to the preservation, recording and release of records concerning identifying and non-identifying information¹⁰ about donors to donor-conceived individuals.¹¹ These included a call for the establishment, "as a matter of priority", of a national register of donors¹² and that this central register should operate according to principles which provide for donor-conceived individuals to be able to access identifying information about their donor.¹³

The recommendations and report left a number of issues open for further debate, including whether the legislation should provide for the retrospective release of identifying and non-identifying information about donors to donor-conceived individuals.¹⁴ Given that the call for information has been made most loudly by those donor-conceived individuals who are already in existence, and who are denied access to information that already exists, the issue of retrospective release of identifying and non-identifying and non-identifying information about donors whose donations predate legislative intervention, and who, at the time of their donation, may have been told that their anonymity would be preserved.

The article begins with an examination of principles of statutory law regarding whether it is possible for legislation to be enacted retrospectively. This is important as, without the power to legislate retrospectively, the question of whether such legislation should be enacted is a moot point. It is shown that governments do, in fact, have such power. The psycho-social, ethical and legal arguments for and against the retrospective release of information about donors to donor-conceived individuals are then analysed, followed by a consideration of the balancing exercise required by the principles of statutory interpretation and drafting. The final section provides a conclusion. It is argued that while not all donor-conceived individuals may want information, all donor-conceived individuals should be given the choice. The "rights" and "interests" of donor-conceived individuals to access identifying and non-identifying information about their donors, along with those of families and donors who wish to be able to share information with them, should prevail. Nonetheless, the issues raised in relation to parents who fear disclosing their child's donor-conceived status, or by donors in relation to privacy, confidentiality and contracts for anonymity, require sensitivity and thought in how a program that provides for the release of information would occur. The article leaves open the opportunity for more detailed discussion of each of the issues presented.

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⁹ Senate Legal and Constitutional Affairs References Committee, n 1, p 103, Recommendation 2.

¹⁰ Identifying information would include the donor/donor-conceived person's name, date of birth and address; non-identifying information might include education (level and qualifications); eye colour; hair colour; height; weight; marital status; number of children (if any); sex; year of birth; place of birth; nationality/culture with which the donor identifies; religion (if any); reason for becoming a donor; number of offspring born through other donations; identity of other offspring born through other donations; interests/hobbies/sporting activities; anything else the donor considers central to their personality. (It is difficult to delineate some of the information as identifying or non-identifying as some information in combination might lead to the identification of a person, but alone would be considered non-identifying.)

¹¹ Senate Legal and Constitutional Affairs References Committee, n 1, pp 103-109 (see Recommendations 3, 5-14, 19-21, 25, 31-32).

¹² Senate Legal and Constitutional Affairs References Committee, n 1, p 104, Recommendation 5.

¹³ Senate Legal and Constitutional Affairs References Committee, n 1, pp 104-105, Recommendation 9. Arguably, such a register would also enable donors to receive information about their offspring, and donor-conceived siblings to receive information about each other.

¹⁴ See Senate Legal and Constitutional Affairs References Committee, n 1, p 114 at [7.26]: "In the absence of authoritative evidence about the legal and ethical implications of retrospectively removing donor anonymity, the committee chooses not to make any specific recommendation about retrospectivity."

DOES THE LEGISLATURE HAVE THE POWER TO PASS RETROSPECTIVE LEGISLATION?

Legislation is retrospective if it has effect in relation to a matter arising before it was enacted or made.¹⁵ Another, slightly more complex, definition is that a statute is retrospective when it "takes away or impairs any vested right acquired under existing laws, or creates a new obligation, or imposes a new duty, or attaches a new disability in respect to transactions or considerations already past".¹⁶

In the absence of a clear statement to the contrary, the courts have frequently declared that an Act will be assumed not to have retrospective operation.¹⁷ That is, there is a "presumption against retrospectivity". The presumption is based upon the idea that one should not *imply* retrospectivity as doing so may have negative impacts upon people who in the past acted according to the law as it was at that time. However, the presumption is rebuttable: it can be excluded by a clear statement to the contrary within an Act of Parliament, or where a court can spell out a necessary intendment that the Act is to operate retrospectively.¹⁸ "Well-reasoned arguments against too ready an acceptance of the presumption against retrospectivity" have also been recognised.¹⁹ For example, Pearce and Geddes cite Adam J in *Doro v Victorian Railways Commissioners* [1960] VR 84 who said (at 86):

The strength of the presumption against retrospectively in any particular case, and accordingly the ease or difficulty with which it may be overcome, must ... depend on the nature and degree of the injustice which would result from giving a statute a retrospective operation. Where palpable injustice would result, the presumption should be given its fullest weight. In such a case it is but common sense to require the clearest indication of legislative intention that such an unjust result was intended. On the other hand, where to give retrospective operation to a statute might be considered to work some injustice to one party, but is clearly required to rectify a manifest injustice to others, there would, on principle, seem little reason for giving much weight to the presumption. In such a case, where the legislature used language which is apt to give to its statute retrospective operation, it would be a matter of conjecture to presume that it preferred the interests of the one to the others.

The presumption against retrospectivity also does not imply that the Parliament cannot or should not make laws that have retrospective operation.²⁰ As noted, a clear statement that a statute is to act retrospectively is enough to make the provisions contained in the Act retrospective.

In *R v Kidman* (1915) 20 CLR 425 Isaacs, Higgins, Gavan Duffy, Powers and Rich JJ (Griffith CJ dissenting) held that the Commonwealth had power to pass retrospective legislation. Higgins J stated (at 451):

The ... Parliament, admittedly, has power to make its laws retroactive; and I know of no instance in which a Legislature created by the ... Parliament has been held to have overstepped its powers by making legislation retroactive. [While] there are plenty of passages that can be cited showing the inexpediency, and the injustice ... of legislating for the past, of interfering with vested rights, and of making acts unlawful which were lawful when done ... these passages do not raise any doubt as to the power of the Legislature to pass retroactive legislation, if it see fit.

The constitutional validity of retrospective legislation has also been affirmed in *Millner v Raith* (1942) 66 CLR 1, *Polyukhovich v Commonwealth* (1991) 172 CLR 501 and *Tuitupou v Minister for*

¹⁸ Pearce DC and Geddes RS, Statutory Interpretation in Australia (6th ed, Butterworths, Sydney, 2006) p 314.

¹⁹ Pearce and Geddes, n 18, p 315.

²⁰ Pearce and Geddes, n 18.

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Allan

¹⁵ Greenberg D (ed), Craies on Legislation: A Practitioner's Guide to the Nature, Process, Effect and Interpretation of Legislation (8th ed, Sweet & Maxwell, London, 2004) p 389.

¹⁶ L'Office Cherifien des Phosphates Unitramp SA v Yamashita-Shinnihon Steamship Co Ltd (The Boucraa) [1993] 3 WLR 266 at 273 (Sir Thomas Bingham MR).

¹⁷ Maxwell v Murphy (1957) 96 CLR 261 at 267 (Dixon CJ); Fisher v Hebburn Ltd (1960) 105 CLR 188 at 194 (Fullagher J); Geraldton Building Co Pty Ltd v May (1977) 136 CLR 379.

The retrospective release of information about donors to donor-conceived individuals in Australia

Immigration and Multicultural Affairs (2000) 60 ALD 361.²¹ The only qualification upon such power has been that, where retrospective legislation deprives someone of a property right, it must do so upon just terms.²²

There is therefore no impediment to the legislature passing retrospective legislation allowing the release of identifying and non-identifying information about donors to donor-conceived individuals if it sees fit. The passing of retrospective legislation is, however, not commonly done, and further examination must be made of the possible injustices to one party (some donors) who are required to rectify a manifest injustice to others (donor-conceived individuals, donors who wish to release their information, and parents who wish to tell their children).

ARGUMENTS FOR AND AGAINST THE RELEASE OF IDENTIFYING AND NON-IDENTIFYING INFORMATION TO DONOR-CONCEIVED INDIVIDUALS

This section examines arguments for and against the retrospective release of information about donors to donor-conceived individuals. It examines arguments posited in relation to donor-conceived individuals, their parents, and donors. In relation to each of these parties, it considers the psycho-social, ethical and legal arguments as they arise.

Donor-conceived individuals

Number of individuals affected and demand for information increasing

It has been estimated that there are between $20,000^{23}$ and $60,000^{24}$ donor-conceived individuals in Australia. The number of people who may be affected due to lack of information about their genetic heritage, including donor-conceived individuals, their families, and generations to come, using either estimate, is therefore significant.²⁵

As donor-conceived individuals enter adulthood, and some have families of their own, the call for information has increased. Similarly, there are potentially tens of thousands of individuals who are yet to reach adulthood, or are yet to be conceived in those jurisdictions that do not have legislation that requires information recording and release, who may in the future call for information about their donors. As access to assisted reproduction is opened up, and our country celebrates and recognises the many different family formations, so too should it facilitate the access of those families to information. This is vital, as such information is at risk of being lost or destroyed, eg as clinics or doctors' surgeries close. In his submission to the Senate Committee, Mr Richard Egan of FamilyVoice Australia said:

[Y]ou need to collect the data before clinics go out of business. Some of it will be very patchy going back to the 1970s and so on, but we need to get that information into a central registry before it is too late. Some people may not start looking for their donor father until they are 30 or 40, so these things come up at different times in people's lives. [There is] an absolute right to know.²⁶

Genealogical bewilderment: A sense of identity

Academic literature has increasingly emphasised that relations based on blood are less important in shaping a child's development than previously thought. However, it is also the case that societies such

²³ Senate Legal and Constitutional Affairs References Committee, n 1, p 2.

²⁴ Senate Legal and Constitutional Affairs References Committee, n 1, p 2.

²⁵ However, the actual number of donor-conceived individuals in Australia is unknown, as most jurisdictions have not kept central registers or have not required specific information to be entered on birth records about the method of conception. In Victoria, there were 4,821 donor-conceived individuals and 1,663 donors on that State's register in 2010: see VARTA, *Annual Report 2010* (2010). This would not include private arrangements, or individuals conceived before the central register began in 1988.

²⁶ Commonwealth, Senate Committee, Hansard (29 October 2010) pp 19-20 (Mr Richard Egan, Family Voice Australia).

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²¹ In relation to delegated legislation.

²² Georgiadis v Australian and Overseas Telecommunications Corp (1994) 179 CLR 297; Australian Constitution Act 1901 (Cth), s 51(xxxi).

as Australia's place great weight on "blood relations [as] ... the basis of kinship".²⁷ Despite a child's development being shaped by social as much as biological factors, knowledge of one's immediate genetic heritage is thus 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.²⁸ This has been referred to as "genealogical bewilderment".²⁹

Similar to adopted children wanting to meet their biological parents,³⁰ some donor-conceived individuals may feel a strong need to connect with, or have detailed information about, their donor in order to obtain a more complete sense of self-identity.³¹ The desire often exists independently of the love and affection that individuals feel from their non-biological parent(s) and the fact that their relationship is strong. There may in some instances be a deeper appreciation of the relationship with the parents who have reared them based on an acute awareness of how much they were wanted by parents who endured fertility treatment in order to give birth to them.³² The curiosity about their donor and the propensity for donor-conceived individuals to search for information is not related to the desire to escape negative family issues; rather, most donor-conceived individuals report positive relationships with their parents.³³ On the other hand, such feelings coexist with a strong desire to know about one's donor and frustration at being denied information.³⁴

In studies conducted to evaluate the consequences of non-disclosure for an individual's sense of identity, some respondents described feeling as though they were "freaks" or "products of experiments" or that they were in some way "incomplete". McNair writes:

These sentiments suggest that identity is related to genetic inheritance in some way, and a fuller sense of identity for a donor-conceived person may only be achieved through access to details about their donor.³⁵

There is evidence to suggest that donor-conceived individuals undergo a "fracturing" in their identity due to knowledge of their status. However, such difficulties are typically related to feelings of frustration at being denied information about their donor and not about being donor-conceived per

³⁰ While it has been suggested that the issues faced by adopted children are distinct from donor-conceived individuals because the latter do not undergo the trauma of knowing they were "abandoned" at birth, the sense of "lost identity" is reportedly the same.

³¹ Turner and Coyle, n 28; Wellisch, n 29; Sants, n 29.

³² Mahlstedt PP, LaBounty K and Kennedy WT, "The Views of Adult Offspring of Sperm Donation. Essential Feedback for the Development of Ethical Guidelines within the Practice of Assisted Reproductive Technology in the United States" (2010) 93(7) *Fertility and Sterility* 2236; Golombok S, Brewaeys A, Bish A et al, "Families Created by New Reproductive Technologies: Quality of Parenting and Social and Emotional Development of Children" (1995) 66 *Child Development* 285.

³³ Mahlstedt, LaBounty and Kennedy, n 32.

³⁴ Turner and Coyle, n 29; Jadva et al, n 28 at 524; Dennison M, "Revealing Your Sources: The Case for Non-anonymous Gamete Donation" (2008) 21(1) *Journal of Law and Health* 1 at 13.

³⁵ McNair, n 27, p 43.

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²⁷ Grotevant HD, Dunbar N, Kohler JK and Essau AML, "Adoptive Identity: How Contexts Within and Beyond Families Shape Developmental Pathways" (2000) 49(4) Family Relations 379, cited in McNair R, Outcomes for Children Born of ART in a Diverse Range of Families (Victorian Law Reform Commission, Melbourne, 2004) p 39.

²⁸ Turner A and Coyle A, "What Does it Mean to be Donor Offspring? The Identity Experience of Adults Conceived by Donor Insemination and the Implications for Counselling and Therapy" (2000) 15(9) *Human Reproduction* 2041; Jadva V, Freeman T, Kramer W and Golombok S, "Experiences of Offspring Searching for and Contacting their Donor Siblings and Donor" (2010) 20 *Reproductive BioMedicine Online* 523 at 524.

²⁹ Turner and Coyle, n 28; Wellisch E, "Children without Genealogy: A Problem with Adoption" (1952) 13(1) *Mental Health* 41; Sants H, "Genealogical Bewilderment in Children with Substitute Parents" (1964) 37(2) *British Journal of Medical Psychology* 133. Such bewilderment may be particularly acute for people who discover later in life that they were donor-conceived.

se.³⁶ Of major concern, then, is that there are a significant number of Australian donor-conceived individuals who continue to be denied access to information.

Access to medical information

The importance of having access to information concerning a biological parent's medical history (eg whether or not there is a familial history of heart disease, diabetes, cancer, mental health issues, and/or other heritable diseases) is undeniable.³⁷ Donor-conceived individuals who are denied access to familial medical histories are placed at increased risk as a result of not having access to information about their genetic heritage. This becomes very significant as people age. A donor who donated in the 1970s or 1980s, when donor-conception was shrouded in secrecy, may not until more recently have become aware that they are a carrier of certain diseases. Similarly, a donor-conceived individual may become aware of a heritable condition, but has no way presently to notify their donor(s) or half-siblings conceived using the same donor gametes. As there is no linkage for either the donor to the donor-conceived person, or vice versa, or to donor-conceived siblings, in most jurisdictions of Australia, alerting relevant parties to health information is problematic. This may have ramifications not just for the person unaware of such information but for generations to come.

On the other hand, the release of medical information raises issues about health privacy and confidentiality which are generally protected in Australia. These issues, along with the numerous exceptions to maintaining "health privacy", are discussed below in relation to donors' privacy and confidentiality.

Fear and risk of forming consanguineous relationships

Some donor-conceived individuals report the fear of unknowingly forming relationships with siblings or possibly their unknown donor.³⁸ While the actual probability of such an occurrence is unknown (as the actual number of donor-conceived individuals is unknown), such a risk may be significant within Australia, given the small population and the significant number of donor-conceived individuals in existence. While it has been claimed in international reports that one way to avoid half-siblings forming relationships was by restricting a donor to one donation, it is clear that this is not, and has not been, the approach to donor conception in Australia.³⁹ In many clinics and doctors' surgeries, donors are likely to have donated multiple times. Some donors may also have donated at multiple clinics, and across jurisdictions. The risk of siblings (and/or donors) forming relationships with related individuals may be more acute in States and Territories with small populations, where donor conception has been practised with inadequate record-keeping, or where information is retained but unavailable.⁴⁰

Entering consanguineous relationships has legal ramifications. The Marriage Act 1961 (Cth) makes unlawful marriages between an individual and their parent, and an individual and their

³⁶ Dennison, n 34 at 13; Ravitsky V, "Knowing Where You Come From: The Rights of Donor-conceived Individuals and the Meaning of Genetic Relatedness" (2010) 11(2) *Minnesota Journal of Law, Science & Technology* 655 at 670, referring to Warnock M, "The Good of the Child" (1987) 1 *Bioethics* 141 at 151.

³⁷ Centers for Disease Control and Prevention (CDC), "Awareness of Family Health History as a Risk Factor for Disease" (2004) 53(44) Morb Mortal Wkly Rep 1044.

³⁸ Senate Legal and Constitutional Affairs References Committee, n 1, Submission 156 (M Crawshaw) p 7.

³⁹ In Victoria, the maximum number of families is 10: Assisted Reproductive Treatment Act 2008 (Vic), s 29. In New South Wales, the number is five: Assisted Reproductive Technology Act 2007 (NSW), s 27(1). In Western Australia, the number is five: Human Reproductive Technology Act 1991 (WA) (see Western Australian Government Gazette, "Human Reproductive Technology Directions (WA)" (30 November 2004) p 5434 at [8.1]). In Queensland, South Australia, Tasmania, the Northern Territory and the Australian Capital Territory, the NHMRC Guidelines cover the issue and provide that "clinics must take all reasonable steps to reduce the numbers of genetic relatives created through donor gamete programs to protect donor conceived people, and donors, from having too many genetic siblings or too many offspring, respectively": National Health and Medical Research Council, Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research (2004) at [6.3]. A number of submissions to the Senate Committee noted concerns that, despite limiting numbers, the inconsistent registration of donors between States prevents a person from accurately knowing the number of families a donor has assisted: Senate Legal and Constitutional Affairs References Committee, n 1, p 73 at [5.16].

⁴⁰ New South Wales Law Reform Commission, Artificial Conception: Human Artificial Insemination, Discussion Paper 11 (1984).

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half-sibling.⁴¹ The effect of this provision is to invalidate the marriage because such relationships fall under a prohibited category within the Act.⁴² How can donor-conceived individuals avoid breaking the law by forming unions with their siblings or donors if they cannot identify them? State criminal law also makes incest between individuals and their parents and half-siblings a punishable offence.⁴³ While such an offence requires knowledge of blood relations, if half-siblings were unwilling to separate upon discovering their biological connection, this places them in an uncertain position with regard to the legality of their relationship. The chances of such situations occurring would be greatly lessened if donor-conceived individuals and donors were able to obtain information about each other, including the possibility of being related.

Beyond the legal difficulties, there is also the chance that such relationships would bear children, leading to genetic or chromosomal difficulties in those children due to having genetically related parents.⁴⁴ The fear of this occurring causes great distress for some donor-conceived individuals.⁴⁵

Psycho-social and ethical dilemmas also exist. Most importantly, 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. Crashaw⁴⁶ 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 personally affected by donor conception".⁴⁷ She makes the point that "the living experience with regard to consanguinity does not necessarily reflect the statistical risk".⁴⁸

Inconsistency in providing for access to information to some but not all donor-conceived individuals

The law in four Australian jurisdictions does, in fact, require the recording and release of identifying and non-identifying information to donor-conceived individuals.⁴⁹ However, it depends on where and when a donor-conceived individual was conceived as to whether they can access information about their genetic heritage.

Those conceived in Western Australia post-2004;⁵⁰ Victoria post-1998⁵¹ (or post-1984 with donor's consent);⁵² New South Wales post-1 January 2010;⁵³ and South Australia since 2010⁵⁴ (or

⁴³ See eg Crimes Act 1958 (Vic), s 44(2), (4).

⁴⁴ Bennett RL, Motulsky AG, Bittles A et al, "Genetic Counseling and Screening of Consanguineous Couples and Their Offspring: Recommendations of the National Society of Genetic Counselors" (2002) 11(2) *Journal of Genetic Counseling* 97. The authors, in recognising the risk associated with forming consanguineous relationships, recommend genetic counselling and screening for consanguineous couples and their offspring. Donor-conceived individuals who are unaware of their relatedness to others would not have the opportunity to undergo such counselling/screening.

⁴⁵ Commonwealth, Senate Committee, Hansard (3 November 2010), oral evidence of donor-conceived individuals.

⁴⁶ Retired Senior Lecturer in Social Work, University of York; Former Infertility Counselling Service; Co-Chair of PROGAR (Project Group on Assisted Reproduction).

⁴⁷ Senate Legal and Constitutional Affairs References Committee, n 1, Submission 156 (M Crawshaw) p 7.

⁴⁸ Senate Legal and Constitutional Affairs References Committee, n 1, Submission 156 (M Crawshaw) p 7.

⁴⁹ Regarding storage of information, see eg Human Reproductive Technology Act 1991 (WA), s 45; Assisted Reproductive Technology Act 2008 (Vic), ss 19, 49, 50; Assisted Reproductive Technology Act 2007 (NSW), s 33; Assisted Reproductive Treatment Act 1988 (SA).

⁵⁰ Human Reproductive Technology Act 1991 (WA), s 49.

⁵¹Assisted Reproductive Treatment Act 2008 (Vic), s 59(a)-(b).

⁵² Assisted Reproductive Treatment Act 2008 (Vic), s 59(b)(ii).

⁵³ Assisted Reproductive Technology Act 2007 (NSW), s 37.

⁵⁴ Assisted Reproductive Treatment Act 1988 (SA), s 16; Assisted Reproductive Treatment Regulations 2010 (SA), reg 4(c).

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⁴¹ Marriages Act 1961 (Cth), s 23(1)(b), makes marriages involving "prohibited relationships" void. Section 23(2)(a)-(b) states that "marriages between an individual and their parent and an individual and their sibling, including half siblings" are "prohibited relationships".

⁴² Marriages Act 1961 (Cth), s 23(1)(b).

post-1988 with donor's consent)⁵⁵ may have access to identifying and non-identifying information about their donors. Non-identifying information is available in Western Australia to donor-conceived individuals conceived pre-2004, although such information has been on the central register only since 1993.⁵⁶ In South Australia, donor-conceived individuals may access non-identifying information at the age of 16.⁵⁷ However, in South Australia there is no central registry and access has been reliant on information being held by clinics. Donors may also voluntarily place information on the register in Victoria, Western Australia and New South Wales but all have been maintained from different dates⁵⁸ and the availability of such registers is not widely known.

The remaining States and Territories refer to the National Health and Medical Research Council (NHMRC) Guidelines for ethical practice, which from 2004

- recognise that persons conceived using assisted reproductive treatment (ART) procedures are *entitled to know their genetic parents*;
- require the donor to consent to the release of identifying information about herself or himself;
- emphasise the significance of the biological connection that donors have with the persons conceived using their gametes; and
- require donors to be advised that the persons conceived are *entitled to knowledge of their genetic* parents and siblings.⁵⁹

However, the NHMRC Guidelines are not law, and do not link in to any central registry to ensure that information is maintained and made available to donor-conceived individuals. Submissions to the Senate inquiry also indicated that clinics vary in the assistance given to donor-conceived individuals in accessing information.

That the law varies across States and Territories in a federal system is not unusual. However, given that there is recognition of the need for, and entitlement to, information nationwide (via legislation or the NHMRC Guidelines), the argument for legally mandated retrospective release of information in relation to the national inconsistencies gains force. The Senate Committee called for the entitlement to information by donor-conceived individuals to be mandated across all Australian jurisdictions. It asked the States and Territories to consider further the retrospective release of such information.⁶⁰ In doing so, the States and Territories must recognise that allowing the law to continue to deny a subset of donor-conceived individuals access to the very information that is recognised as essential to all donor-conceived individuals would be inconsistent and therefore unacceptable.

Analogy with adoption

Psychologists have drawn many parallels between the experiences of donor-conceived individuals and adoptees, particularly in relation to the problems described above that some individuals experience in relation to genealogical bewilderment as a result of being denied access to information,⁶¹ and the secrecy that in the past shrouded both practices. Similarly, the Canadian Supreme Court of British

⁵⁹ National Health and Medical Research Council, n 39.

⁶⁰ Senate Legal and Constitutional Affairs References Committee, n 1, p 96 at [7.26]: "The committee urges the States and Territories to further consider the issue of retrospectivity in the creation of any national register (including seeking and obtaining legal advice, as considered appropriate)."

⁶¹ Turner and Coyle, n 28.

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⁵⁵ Reproductive Technologies (Clinical Practices) Act 1988 (SA).

⁵⁶ Human Reproductive Technology Act 1991 (WA). The Act came into operation on 8 April 1993 and central records have only been stored since April 1993.

⁵⁷ Reproductive Technologies (Clinical Practices) Act 1988 (SA).

⁵⁸ For example, while the Western Australia voluntary register includes details of people involved in donation since ART started in Western Australia (circa the early 1970s), its operations are influenced by whether the donation was made before or after the *Human Reproductive Technology Act 1991* (WA). The only records available before the commencement date of that Act are those held by the fertility clinics and medical practitioners that provided such services. Because detailed records were not always kept in the early days of ART, the registry notes that it is very difficult to match records for donors and donor offspring where donations were made before the early 1980s.

Columbia has held that the circumstances of adoptees and those of donor offspring, with regard to the need to know and have connection with one's roots, are closely comparable.⁶² The Senate Committee report recognised numerous submissions that drew this analogy.⁶³ It said:

[A]ll States and Territories have legislation which sets out the rights that adopted people have to information about their birth parents ... All State and Territory legislation provides adopted people with the right to identifying information about their biological parents, including their original birth certificate. However, legislation is not consistent between States and Territories and, additionally, not all adoption legislation in Australia is retrospective. For example, in South Australia and Queensland, birth parents and adopted people may veto the release of identifying information, and any contact, if the adoption was finalised prior to the commencement of the relevant legislation in those States.

With respect, this is not quite correct. All laws in Australia were passed with retrospective effect. The possibility of contact and/or identifying information vetoes does not negate the retrospectivity of the law. Rather, it gives the relinquishing parent the option to "opt out" of the retrospective system. Some jurisdictions only provided the option to "opt out" in relation to contact. Victoria does not allow any vetoes at all. South Australia is the only State that allows for information vetoes.

In Queensland, the identifying information and contact vetoes applied only to adoptions that occurred prior to 1991. However, in 2010 Queensland enacted the *Adoption Act 2009* (Qld), which retrospectively removed the option of placing a veto on identifying information. Acting Child Safety Minister, Karen Struthers, said at the time:

No longer will we have the most restrictive adoption laws in the country ... Under the new Act, which will come into force on February 1, 2010, adopted people and birth parents will have the right to identifying information regardless of when the adoption took place. The new laws balance people's right to information about their birth parents or son or daughter who was adopted, with the right of others to maintain their privacy. Currently more than 3000 Queenslanders affected by an adoption that occurred before 1991 are prevented from obtaining identifying information about their birth parents or son or daughter who was adopted. The new Act will give these people the right to access information about their own identity or that of a son or daughter for the first time. The new laws will make it possible for people to access identifying information about their birth parents but still requires them to respect another person's privacy if they do not wish to be contacted.⁶⁴

The Explanatory Memorandum of the Queensland Bill states that people's privacy would be protected via enabling contact vetoes, and placing fines for breach of such vetoes. It provides:

[T]his retrospective removal of their rights must be balanced with the benefits that arise by allowing other parties to those adoptions access to information about their identity, family and heritage. The change in the law also ensures that parties to adoptions are treated equally, regardless of when the adoption occurred, as there is no longer any entitlement to object to the release of identifying information.⁶⁵

Similarly, Western Australia previously allowed for both contact and information vetoes; however, information vetoes were removed. In this jurisdiction, a person who wishes to gain access to information that was previously restricted by an information veto, and where a contact veto is in place, is required to be interviewed by an approved counsellor and to sign an undertaking not to contact the vetoer. Breach of the undertaking imposes penalties of \$10,000 and 12 months in prison. The purpose of counselling in these instances is to ensure that the rights of all involved parties are fully understood and that people are made aware of some of the issues which may arise in the search and reunion process.⁶⁶

⁶² Pratten v British Columbia (Attorney General) 2011 BCSC 656 at [3]. This case is discussed further below.

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⁶³ Senate Legal and Constitutional Affairs Reference Committee, n 1, p 84.

⁶⁴ Queensland Government, *New Adoption Laws for Queensland* (1 January 2010), <u>http://www.mysunshinecoast.com.au/</u> <u>articles/article-display/new-adoption-laws-for-queensland,16035</u> viewed 8 May 2011.

⁶⁵ Adoption Bill 2009 (Qld), Explanatory Memorandum, pp 19-20, <u>http://www.legislation.qld.gov.au/Bills/53PDF/2009/</u> AdoptionB09Exp.pdf viewed 8 May 2011.

⁶⁶ Australian Institute of Health and Welfare, Adoptions Australia 2006-2007 (2008).

In 1992 the New South Wales Law Reform Commission detailed the reasoning for retrospective release of information about adoptees in New South Wales. In relation to the retrospective enactment of legislation, it reiterated that there is no legal principle preventing legislation from having retrospective operation.⁶⁷ It recognised that the law relating to information about adoption needed to deal fairly with many different people and situations and that a further complication existed:

[T]he law has to deal with the consequences of adoptions that took place over a long period of time – from the 1920s to the mid-1970s – and over that period there were major changes in adoption law and practice. The degree of secrecy that prevailed at the time of the adoption, the amount of information supplied to the parties, and the information available from existing records, all vary considerably according to the period in which the adoption took place, the agency which arranged the adoption, and other factors. It is a difficult task to design a law that will deal appropriately with all the people and situations involved in this complex picture.⁶⁸

The New South Wales Law Reform Commission concluded that, in passing retrospective laws in New South Wales that allowed identifying information release to adoptees, there had in fact been a weighing up of the competing interests of different groups of people affected by adoption, namely adopted people, birth parents, adoptive parents and other relatives:

[T]he view that prevailed was that the law should enable adopted persons and birth parents to have the right to information, even though this did mean a change from the position as it was when the adoption order was made. The interests of those who felt threatened by the new law were acknowledged by a number of measures, notably the contact veto system.⁶⁹

The Victorian Adoption Network for Information and Self Help Inc (VANISH) noted that, despite the initial anxiety surrounding the retrospective release of information regarding adoption, it is now well accepted that it is normal for adopted people to want information about their birth parents.⁷⁰ That some jurisdictions provide the option for vetoes pertaining to contact to be placed does not diminish the force of arguments that advocate information release.

The Australian Institute of Health and Welfare (AIHW) reported in 2008 that in 2006-2007 there were 2,851 applications made in relation to adoptions, 83% of which were for identifying information. In that year, there were 80 contact vetoes lodged. The vast majority of information applications (both identifying and non-identifying) were made by the adopted person, being 73%, while 15% were lodged by birth parents, and 7% by other relatives. Nine in ten adopted persons seeking identifying information were aged 25 years and over, and over two-thirds were aged 35 years and over.⁷¹ The AIHW also noted that over the years, the number of applications for information far exceeded the number of vetoes lodged against contact or the release of identifying information.⁷²

Clearly the analogy can be drawn with donor-conceived individuals. Australia is seeing an increased call for identifying and non-identifying information as donor-conceived individuals reach their late twenties and onwards. These are the donor-conceived individuals conceived in the 1970s and 1980s. They call for a system similar to that implemented for adoption. As Mr Egan of FamilyVoice Australia commented during the Senate Inquiry:

[I]f legislation establishing a national register was retrospective, contact vetoes could be put in place the way they are in adoption cases; [n]o-one wants to force themselves on someone else, but they do have a right to know where they come from, who they are, who their relatives are and so on. That should include the ability to track donor siblings so you know who your brothers and sisters are. That seems to me a fundamental human right. That is the "right to know" stuff.⁷³

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⁶⁷ New South Wales Law Reform Commission, Review of the Adoption Information Act 1990, Issues Paper 7 (1992) at [3.14].

⁶⁸ New South Wales Law Reform Commission, n 67 at [3.1].

⁶⁹ New South Wales Law Reform Commission, n 67 at [3.16].

⁷⁰ Commonwealth, Senate Committee, Hansard (3 November 2010) pp 65-70 (Mr Cole, VANISH).

⁷¹ Australian Institute of Health and Welfare, n 66, p 27.

⁷² Australian Institute of Health and Welfare, n 66, p 30.

⁷³ Commonwealth, Senate Committee, Hansard (29 October 2010) pp 19-20 (Mr Egan, Family Voice Australia).

It must also be recognised that some of those donor-conceived individuals, donors and recipients who seek information might not wish to forge relationships. Many simply desire information. It is here emphasised that the law in Queensland was changed retrospectively to address the issues faced by more than 3,000 Queenslanders affected by the previous legislation, and yet the number of donor-conceived individuals denied information in Australia runs into the tens of thousands.

Human rights arguments

It is also relevant to recognise arguments that place the issue of access to information by donor-conceived individuals about their donors within a human rights framework. Such arguments have existed for some time. In 1998, Ramsey stated:

Principles from the domain of human rights can provide an important framework for responding to one of the most pressing challenges confronting reproductive technology ... access by donor offspring to information about their origins ... [P]ut at its most succinct, from a human rights perspective, one might ask the question – how can one argue against the basic human right to know one's genetic identity?⁷⁴

Australia's obligations under a number of international treaties support this. Particularly relevant "rights" are discussed in the following sections.

United Nations Convention on the Rights of the Child

Arguably the Articles of the *Convention on the Rights of the Child* (the Convention) which are most applicable to the issue of donor conception are Arts 7 and 8. Article 7 specifies that every child has a right to know and be cared for by their parents as far as possible.⁷⁵ With respect to this Article, the *Implementation Handbook for the Convention on the Rights of the Child* stated:

[A] reasonable assumption is that, as far as the child's right to know his or her parents is concerned, the definition of "parents" includes genetic parents (for medical reasons alone this knowledge is of increasing importance to the child) *and* birth parents, that is the mother who gave birth and the father who claimed paternity through partnership with the mother at the time of birth (or whatever the social definition of father is within the culture: the point being that such social definitions are important to children in terms of their identity). In addition, a third category, the child's psychological parents – those who cared for the child for significant periods during infancy and childhood – should also logically be included since these persons too are intimately bound up in children's identity and thus their rights under Article 8.⁷⁶

While a non-biological parent(s) is considered the *legal* parent(s) of a donor-conceived child in Australia, and it is not argued here that this should be otherwise, this should not preclude that child having information about their genetic parent(s). Obligations under Art 7 of the Convention support this, noting that as early at 1994, the United Nations Committee on the Rights of the Child highlighted the possible contradiction between Art 7 of the Convention and the policy of the state party in relation to artificial insemination, "namely in keeping the identity of sperm donors secret".⁷⁷

Article 8 states that every child has a right to preserve her or his identity, including nationality, name and family relations as recognised by law without unlawful interference. Denying a donor-conceived individual access to information about their genetic heritage may contravene this right by denying them access to important information that can help in the development of identity and preserve family relations. With respect to this Article, the Implementation Handbook noted:

The concept of "children's identity" has tended to focus on the child's immediate family, but it is increasingly recognized that children have a remarkable capacity to embrace multiple relationships. From the secure foundation of an established family environment, children can enjoy complex and subtle relationships with other adults and with a range of cultures, to a much larger degree than may be

⁷⁷ Norway CRC/C/15/Add.23 at [10].



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⁷⁴ Ramsey S, "Keeping Secrets and Telling Stories", opening address at Donor Issues Forum organised by the South Australian Council on Reproductive Technology, Adelaide, 30 May 1998.

⁷⁵ United Nations Convention on the Rights of the Child, opened for signature 20 November 1989, [1991] ATS 4 (entered into force 2 September 1990).

⁷⁶ Hodgkin R and Newell P, UNICEF Implementation Handbook for the Convention on the Rights of the Child (3rd ed, 2007) p 105.

recognized. Thus children's best interests and senses of identity may be sustained without having to deny them knowledge of their origins, for example after reception into state care, through "secret" adoptions or anonymous egg/sperm donations and so forth.⁷⁸

The message is clear that, pursuant to the above Articles, secrecy and anonymity are not in the best interests of the child. Other Articles in the Convention are also relevant.

Article 2 requires states parties to take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions or beliefs of the child's parents, legal guardians or family members. The status of a child's parent as "recipient" or "donor" should not therefore preclude the child from having information about their genetic heritage. It could be deemed discriminatory to deny donor-conceived individuals information about their genetic heritage when other children in Australia have access to such information.

Article 3(1) provides that "In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration". The best interests of the child include having access to information about their biological heritage for their own psychological health and wellbeing and the development of their identity, as well as for the avoidance of consanguineous relationships and knowledge of genetic siblings and parent(s).

Article 13 provides that the child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds. Denying donor-conceived individuals the right to seek and receive information about their genetic heritage may therefore contravene this right.⁷⁹

Universal Declaration of Human Rights

Article 7 of the Universal Declaration of Human Rights, the overarching foundation for a growing number of national laws, international laws and treaties, should also be noted. It gives rise to arguments that may support information release by recognising that all are equal before the law and are entitled without any discrimination to equal protection of the law.⁸⁰ Denying a subset of donor-conceived individuals access to information about their genetic heritage treats them differently, and therefore it is submitted unequally, to other Australian children. Most children are granted access to information about their genetic heritage via their birth certificates, or other means within the law. The Family Court of Australia has the power to order DNA testing when trying to determine genetic parentage pursuant to issues governed by the *Family Law Act 1975* (Cth).⁸¹ As noted above, some States provide for information release to donor-conceived individuals, while others do not. That some donor-conceived individuals born at a certain time and/or in a certain State or Territory do not have access to information clearly places them in an unequal position to other donor-conceived individuals in Australia. While such inequality may also be found in South Australia with regard to adoptees who may be denied access to identifying information about their birth parent(s) as a consequence of the veto system,⁸² the rest of the States and Territories have recognised this as an injustice.

Local human rights charters

Reference to human rights arguments is not confined to international law or treaties. For example, in its submission to the Senate Committee inquiry into donor conception, the Public Interest Law Clearing House argued that the issue of access by donor-conceived individuals to donor information in Victoria raised a number of complex human rights issues, given that State's *Charter of Human Rights*

⁷⁸ Hodgkin and Newell, n 76, p 142.

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⁷⁹ The exercise of this right may be subject to certain restrictions as provided by law and are necessary (i) for respect of the rights or reputations of others; or (ii) for the protection of national security or of public order, or of public health or morals. The "right to privacy" of donors may be raised in relation to (i) and is discussed further below.

⁸⁰ Universal Declaration of Human Rights, GA res 217A (III), UN Doc A/810 at 71 (1948).

⁸¹ Family Law Act 1975 (Cth), s 69W.

⁸² Adoption Act 1988 (SA), s 27.

and Responsibilities Act 2006 (Vic).83 It said:

On the one hand, the denial of access to donor identifying information may be inconsistent with ... [provisions of the *Charter of Human Rights and Responsibilities Act 2006* (Vic)] including the freedom of expression (including freedom to seek and receive information of all kinds), the right to recognition and equality before the law, the protection of families and children, and cultural rights. On the other hand, the right of donors to privacy and reputation may be impinged upon if access to donor identifying information is too freely available. A balance must be struck between the rights of donors and donor-conceived individuals.

The balancing process is considered further below.

Parents of donor-conceived individuals

Parents being unable to provide information to their children

The current state of law also affects parents of donor-conceived individuals. Such parents are prevented from being able to provide their children with information that many actually desire to impart. For example, during the Senate Committee inquiry, the Victorian Infertility Counsellors Group submitted:

Up until the [Assisted Reproductive Treatment Act 2008 (Vic)], fertile women had to travel interstate to seek treatment and did therefore not come under Victorian legislation [which provides for information recording and release]. These women and their children therefore do not have the same access to information about their donor origins as do donor conceived offspring in the rest of the Victorian community. These women find it particularly difficult not to be able to provide their children with up to date and accurate information about their donor, often only having a few lines of information to share with their child. A retrospective national register would assist in rectifying this inequality.⁸⁴

Issues of equity are again apparent. Parental interests and desire to be open and able to provide their child with information about that child's genetic heritage are clearly denied. Parents are also affected in other ways. They may "wish to thank the donor for helping them become a family and/or may wonder what they are like and what their child has inherited".⁸⁵ They may also wish to be able to refer to the donor by a name when telling their children about the method of conception, rather than referring to her or him as "donor". Without laws mandating the retrospective release of information, parents are unable to do so, or to share information within their families.

Parental curiosity about donor-conceived siblings and donors

In 2009, researchers from the United Kingdom's Cambridge University Centre for Family Research recruited 791 parents via the Donor Sibling Registry⁸⁶ in order to study why parents seek information about their donor-conceived children's donor-conceived siblings and donors.⁸⁷ The study found that parents' principal motivation for searching for their child's donor siblings was curiosity. In relation to their search for their donor, their primary reason was to enhance their child's sense of identity.⁸⁸ A total of 11% of parents who had found their child's donor siblings had found 10 or more, with one parent finding 55.

An overwhelming majority of parents reported positive experiences in contacting and meeting their child's donor siblings and donor. Very few negative experiences were reported: 2% (8) reported

⁸⁸ Freeman et al, n 87.

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⁸³ Senate Legal and Constitutional Affairs References Committee, n 1, Submission 125 (Public Interest Law Clearing House) p 8.

⁸⁴ Senate Legal and Constitutional Affairs References Committee, n 1, Submission 68 (Victorian Infertility Counsellors Group) p 46 at [3.58].

⁸⁵ Victorian Assisted Reproductive Treatment Authority, Time to Consent? Information Pamphlet (2008).

⁸⁶ The Donor Sibling Registry is a United States-based international registry that facilitates contact between donor conception families who share the same donor.

⁸⁷ Freeman T, Jadva V, Kramer W and Golombok S, "Gamete Donation: Parents' Experiences of Searching for their Child's Donor Siblings and Donor" (2009) 24(3) *Human Reproduction* 505. The parents consisted of 39% lone mothers, 35% lesbian couples and 21% heterosexual couples. A totals of 91% (717) of parents lived in the United States, 5% (37) in Canada and 1% (8) in the United Kingdom; other countries of residence included Austria, Germany, Ireland, Spain, Sweden, Australia, New Zealand and Israel.

negative experiences in contacting their child's donor siblings for themselves and 1% (2 parents) reported negative experiences for their child.⁸⁹ Parents frequently described feeling excited and happy on their child's behalf when they found donor siblings, and viewed the addition of such relationships to their children's lives as "enriching", "wonderful" and "fun".⁹⁰ Most parents reported that the impact of searching for both their child's donor siblings and their child's donor had a "neutral" or "positive" impact on their relationship with their child.⁹¹ The study concluded that having access to information about a child's donor origins is important for some parents and has potentially positive consequences.⁹²

Such results support the release of information. In particular, they show that "kinship relationships are based on both direct and indirect genetic connections and shared understandings and experiences, out of which new concepts of the family are being defined and negotiated".⁹³

As a nation, Australia recognises and embraces diversity, and supports varying family types. We should do so for the extended family connections that are being newly defined in relation to donor conception.

Parental fear of telling

Some parents, however, may have fears associated with disclosing that their child was donor-conceived. Some may have kept a secret for a long time, and feel they are now unable to tell, they may fear rejection, or that they will lose the child (or adult) they love.⁹⁴ Many parents received treatment when the culture of secrecy was strong, and may genuinely feel that they are protecting their children and their families, or are shamed by their battle with infertility.⁹⁵ Daniels stated that "confidence is required in order to resist potential stigma and view donor conception as a way to build families in a positive manner".⁹⁶

While the Cambridge University study described above illustrates that many of these fears may not become reality, some parents who conceived in the time where secrecy was emphasised may need significant support in telling their children and in accepting their offspring's desire for information. Nonetheless, when parents find the courage to tell, many describe feeling a sense of relief in telling their children, and in that they have been able to "pass the baton" to the donor-conceived individual, recognising that the information rightly belongs to them.⁹⁷

Donors

Donors do not necessarily wish to remain anonymous

It is not necessarily the case that past donors wish to remain anonymous.⁹⁸ The Donor Conception Support Group quoted in their submission to the Senate Committee a former sperm donor who stated:

⁹⁴ Daniels K, "Donor Gametes: Anonymous or Identified" (2007) 21(1) Best Practice and Research Clinical Obstetrics and Gynaecology 113.

95 Daniels, n 94.

96 Daniels, n 94 at 122.

⁹⁷ Victorian Assisted Reproductive Treatment Authority, *Time to Tell Seminar*, public communications by parents and donor-conceived individuals (7 May 2011).

⁹⁸ Senate Legal and Constitutional Affairs References Committee, n 1, Submission 73 (Rainbow Families Council) p 2; Submission 122 (Donor Conception Support Group) p 139.

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⁸⁹ Freeman et al, n 87 at 511.

⁹⁰ Freeman et al, n 87 at 511.

⁹¹ Freeman et al, n 87 at 509.

⁹² Freeman et al, n 87 at 509.

⁹³ Dr Tabitha Freeman, research associate at the Centre for Family Research, University of Cambridge, quoted in When Parents Seek Siblings of Their Donor-conceived Children (2009), <u>http://www.disabled-world.com/news/research/donor-conceived-children.php</u> viewed 9 May 2011.

I was a sperm donor during 1997-1998. [M]y donations were during the period when [d]onors had to sign away any future contact. This was a condition of participation and I only wanted to help people – but at the back of my mind was the hope that the rules would change to allow the resultant children to trace their donor fathers, if they wished to do so.⁹⁹

Similarly, the Victorian Assisted Reproductive Treatment Authority (VARTA) stated that the belief that secrecy was paramount to protect all parties to the arrangement was based on myths:

[T]hat donors would not want to be contacted, that parents would not want to know more about their donor, and that donor-conceived individuals would not want information about their donor if they really loved their parents.¹⁰⁰

VARTA stated that "donors do not forget they have donated and often wonder about the people they helped to create. Who are they? Are they healthy? Are they happy? Are they loved?"¹⁰¹

At a seminar held in Victoria, Australia, aimed at educating parents about how to tell their children they were donor conceived, one donor stated:

At the time of my donations, made in the early 80s, I don't think I understood what I was doing. I don't think I gave truly informed consent, as I was simply asked to sign a form, and had a brief discussion with the people who worked at the clinic about what had to be done from there. I don't believe I had a contract with anyone. I think I was told that it was anonymous, but this wasn't explained, and having seen an ad in the paper, and having known an infertile couple, I just wanted to help people. It was not until I had my own children that it began to dawn on me. I then one day received a letter from the ITA [Infertility Treatment Authority], stating I had helped to conceive seven (7) other children. They are out there somewhere, they might not know, I have so many questions, and fear I will never know, they will never know.¹⁰²

Studies have also shown that donors who may once have wished for anonymity may at a later date wish to meet the donor-conceived individuals and that their thoughts on the matter may change over time.¹⁰³ Some studies have also indicated that the majority of donors agree to the release of medical records;¹⁰⁴ however, there is yet to be a system put into place that ensures these records are updated and that vital information is disseminated to offspring and recipient parents. There does not seem to be a blanket refusal, as such, to share information.

As seen below, arguments made against release of information about donors often centre on a "donor's right to privacy and confidentiality" and/or the contract for anonymity that was made. However, as such privacy, confidentiality and anonymity were mandated by the medical profession at the time of donation, one may question the perpetuation of secrecy and denial of information in an age where the entitlement for information has been established. In reviewing the retrospective release of information, we must not assume that donors wish to remain anonymous. For many donors, particularly in jurisdictions where there were no registers and no legislation, they were not given any choice. Legislation providing for the retrospective release of information could provide an "opt out" for donors who do not wish to be contacted by allowing contact vetoes.

¹⁰⁴ Robinson JN, Forman RG, Clark AM, Egan DM, Chapman MG and Barlow DH, "Attitudes of Donors and Recipients to Gamete Donation" (1991) 6(2) *Human Reproduction* 307; Mahlstedt PP and Probasco KA, "Sperm Donors: Their Attitudes Toward Providing Medical and Psychosocial Information for Recipient Couples and Donor Offspring" (1991) 56(4) Fertil Steril 747.



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⁹⁹ Senate Legal and Constitutional Affairs References Committee, n 1, Submission 122 (Donor Conception Support Group) p 74.

¹⁰⁰ Victorian Assisted Reproductive Treatment Authority, n 85.

¹⁰¹ Victorian Assisted Reproductive Treatment Authority, n 85.

¹⁰² Donor, Victorian Assisted Reproductive Treatment Authority, n 97.

¹⁰³ Crawshaw MA, Blyth ED and Daniels KD, "Past Semen Donors' Views about the Use of a Voluntary Contact Register" (2007) 14(4) Reprod Biomed Online 411; Daniels K, Blyth E, Crawshaw M and Curson R, "Short Communication: Previous Semen Donors and Their Views Regarding the Sharing of Information with Offspring" (2005) 20(6) *Human Reproduction* 1670.

Privacy and confidentiality

Arguments against the retrospective release of identifying information often raise issues of the donor's right to privacy and confidentiality.¹⁰⁵ For example, in their submission to the Senate Committee inquiry, the Fertility Society of Australia (the body that represents fertility doctors and clinics Australia-wide) suggested that retrospectivity would be a "grievous violation" of the privacy of donors who previously entered into confidential agreements in good faith.¹⁰⁶ Privacy is a contentious and complicated subject. Like the "rights" discussed above in relation to arguments for information to be released to donor-conceived individuals, the *International Covenant on Civil and Political Rights*¹⁰⁷ gives rise to obligations to recognise a basic human right to privacy premised on the autonomy and dignity of the individual. Such arguments support caution in any consideration to release personal (and identifying) information.

Nonetheless, while a "right to privacy" is recognised to some degree in Australian law, the "right to privacy" is not absolute. This is illustrated by a statement made by the Australian Law Reform Commission in its 2008 report on privacy:

[A]s a recognised human right, privacy protection generally should take precedence over a range of other countervailing interests, such as cost and convenience. It is often the case, however, that privacy rights will clash with a range of other individual rights and collective interests, such as freedom of expression and national security. Although the ALRC often heard emphatic arguments couched in the language of rights, international instruments on human rights, and the growing international and domestic jurisprudence in this field, all recognise that privacy protection is not an absolute. Where circumstances require, the vindication of individual rights must be balanced carefully against other competing rights.¹⁰⁸

In fact, there are clear exceptions to the protection of private and/or confidential information in Australia.¹⁰⁹ Examples of the ability to release information exist in many areas of the law: there exists statutory provision for the release of identifying information in relation to the reporting of communicable diseases;¹¹⁰ suspected child abuse;¹¹¹ supply of certain drugs, or supply of drugs of addiction to registered addicts;¹¹² reportable deaths (to the coroner);¹¹³ illness affecting driving

¹⁰⁸ Australian Law Reform Commission, For Your Information: Australian Privacy Law and Practice, Report 108 (2008) p 104.

¹⁰⁹ Skene L, "Genetics and Artificial Procreation in Australia" in Meulders-Klein M-T, Deech R and Vlaardingerbroek P, *Biomedicine, the Family and Human Rights* (Springer, Australia, 2002) p 110.

¹¹⁰ Public Health and Wellbeing Act 2008 (Vic), s 127; Public and Environmental Health Act 1987 (SA), s 30; Health Act 1911 (WA), ss 276, 300; Public Health Act 1997 (Tas), ss 48, 49, 61 and 50(1)(c); Public Health Act 2010 (NSW), ss 54, 55, s 56(4); Notifiable Diseases Act 1981 (NT), s 8(1)(b); Public Health Act 2005 (Qld), ss 70-73; Public Health Act 1997 (ACT), s 102.

¹¹¹ Public Health Act 2005 (Qld), ss 158, 191-193; Child Protection Act 1999 (Qld), s 148; Commission for Children and Young People and Child Guardian Act 2000 (Qld), s 20; Children, Youth and Families Act 2005 (Vic), ss 182, 184; Children, Young Persons and their Families Act 1997 (Tas), ss 13, 14; Children's Protection Act 1993 (SA), s 11; Family and Community Services Act 1972 (SA), s 73; Children and Young Persons (Care and Protection) Act 1998 (NSW), ss 23, 27; Community Welfare Act 1983 (NT), s 14(1); Care and Protection for Children Act 2007 (NT), ss 23, 26; Children and Young People Act 2008 (ACT), ss 356, 362; Children and Community Services Act 2004 (WA), ss 101, 124B.

¹¹² See eg Poisons Regulations 1965 (WA), reg 51FE.

¹¹³ See eg Coroners Act 2003 (Qld), ss 8, 17; Coroners Act 2008 (Vic), ss 4, 10-13.

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¹⁰⁵ The terms "privacy" and "confidentiality" are commonly used interchangeably; however, while related, they are not identical concepts in law. Privacy may include physical privacy, and also privacy that relates to information about a person. Information privacy laws regulate the handling of personal information through enforceable privacy principles. Confidentiality relates to information only.

¹⁰⁶ Senate Legal and Constitutional Affairs Reference Committee, n 1, Submission 106 (Fertility Society of Australia) p 11.

¹⁰⁷ International Covenant on Civil and Political Rights, opened for signature 16 December 1966, 2200A (XXI) (entered into force 23 March 1976). Article 17 pertains to privacy. This Covenant is contained in the Human Rights Commission Act 1986 (Cth), Sch 2. The ALRC noted the preamble to the Privacy Act 1988 (Cth): "the legislation was intended to implement, at least in part, Australia's obligations relating to privacy under the ICCPR. The Privacy Act, however, is concerned with information privacy only, and therefore is not a full implementation in domestic law of the meaning of Art 17." See Australian Law Reform Commission, Protecting a Right to Personal Privacy, <u>http://www.alrc.gov.au/publications/</u>74.%20Protecting%20a%20Right%20to%20Personal%20Privacy%20/background?print viewed 10 May 2011.

ability;¹¹⁴ and impairment affecting a registered health professional's ability to practise.¹¹⁵ By analogy, the health issues relating to non-disclosure of donor information arguably outweigh the need to keep such information private.

Beyond the recognition of health-related examples, it has already been shown that the retrospective release of identifying information to adoptees regarding their biological parent(s) is also provided for in all States and Territories,¹¹⁶ noting that South Australia is the only State that continues to allow for information vetoes to be placed.¹¹⁷

There also exists common law authority in a number of other contexts where private information may be disclosed. In the context of breach of confidence, the law provides that private information may be released in circumstances where the withholding of information would lead to iniquity.¹¹⁸ That is:

[I]f the subject matter is the existence or real likelihood of the existence of an iniquity in the sense of a crime, civil wrong or serious misdeed of public importance, and the confidence is relied upon to prevent disclosure to a third party with a real and direct interest in redressing such crime, wrong or misdeed.¹¹⁹

In the law of negligence there is also precedent that recognises a "public interest" exception to the general duty of confidentiality which may enable a doctor to release information to avoid a serious risk to a third party, eg where a person's sexual partner has HIV and the person is at risk of infection.¹²⁰

In relation to genetic information, the Australian Law Reform Commission's report entitled *Essentially Yours: The Protection of Human Genetic Information in Australia* recommended:

Privacy laws should be harmonised and tailored to address the particular challenges of human genetic information. Among other things, this will require extending privacy protection to genetic samples as well as genetic information. However, the familial dimension of genetic information also requires acknowledgment – for example, doctors should be authorised to disclose personal genetic information to a genetic relative where disclosure is necessary to lessen or prevent a serious threat to an individual's life, health, or safety.¹²¹

The *Privacy Act 1988* (Cth) was amended in 2006 to permit health professionals to use or disclose genetic information whether or not a patient gives consent in circumstances where there is a reasonable belief

that the use or disclosure is necessary to lessen or prevent a serious threat to the life, health or safety (whether or not the threat is imminent) of an individual who is a genetic relative of the individual to whom the information relates.¹²²

¹¹⁶ Adoption Act 1993 (ACT); Adoption Act 2000 (NSW); Adoption of Children Act 1994 (NT); Adoption Act 2009 (Qld); Adoption Act 1988 (SA); Adoption Act 1988 (Tas); Adoption Act 1984 (Vic); Adoption Act 1994 (WA).

¹¹⁹ Corrs Pavey Whiting & Byrne v Collector of Customs (Vic) (1987) 14 FCR 434 at 455-456 (Gummow J); Smith Kline & French Laboratories (Aust) Ltd v Department of Community Services and Health (1990) 22 FCR 73 at 110-111 (Gummow J); British American Tobacco Australia Ltd v Gordon (No 3) [2009] VSC 619.

¹²⁰ BT v Oei [1999] NSWSC 1082.

¹²¹ Australian Law Reform Commission, *Essentially Yours: The Protection of Human Genetic Information in Australia, Report* 96 (2003) Vol 1, p 35.

122 Privacy Act 1988 (Cth), Sch 3.



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¹¹⁴ See eg Motor Vehicle Act 1959 (SA), s 148.

¹¹⁵ See eg Health Professions Registration Act 2005 (Vic), s 36.

¹¹⁷ Adoption Act 1988 (SA), s 27(B).

¹¹⁸ Attorney-General v Guardian Newspapers Ltd (No 2) [1990] 1 AC 109 at 282 (Lord Goff); Gartside v Outram (1856) 26 LJ Ch (NS) 113 at 114 (Wood VC) ("there is no confidence as to the disclosure of iniquity"); Beloff v Pressdram [1973] 1 All ER 241 at 260; Castrol Australia Pty Ltd v EmTech Associates Pty Ltd (1980) 51 FLR 184 at 213-214; A v Hayden (1984) 156 CLR 532.

Guidelines developed by the National Health and Medical Research Council on the use and disclosure of genetic information by private health care professionals were released in 2009,¹²³ and include provisions that where such information needs to be released:

- reasonable steps should be taken to obtain consent (Guideline 3);
- specific ethical considerations must be taken into account when making a decision about whether or not to use or disclose genetic information without consent (Guideline 2);
- where practicable, the identity of the patient should not be apparent (Guideline 6);
- disclosure to genetic relatives should be limited to genetic information necessary to convey the increased risk, and should avoid disclosing the identity of the patient (Guideline 7); and
- disclosure without the consent of the patient should generally be limited to people no further removed than third-degree relatives (Guideline 8).

It is clear that release of information is possible. Further, the national privacy protection legislation and the National Privacy Principles recognise that information may be released where the use or disclosure of such information is *required or authorised by or under law*.¹²⁴ Given that the call for information is not just one based on a desire to know medical history or information about heritable diseases, it is possible that the legislature chose to pass laws that simply allow for the release of information without having to meet any of the above "exceptions". Such laws would not lead to contravention of the privacy legislation; in fact, they would enable doctors to confidently and legally release information about donors to donor-conceived individuals without fear that they were breaching privacy or confidentiality obligations.

Contracts for anonymity

The Senate Committee reported having received a limited number of submissions that did not support the retrospective release of identifying information about donors because, in the past, sperm donors often signed or had a verbal contract which assured the donor of anonymity.¹²⁵ For example, the Canberra Fertility Centre was "emphatically opposed to any retrospective legislation ... as it would seem unfair to donors who donated under the impression they would remain anonymous".¹²⁶ The Senate Committee noted potential legal difficulties in relation to contracts for anonymity that

unlike the abolition of anonymity in adoptions, in which the States or Territories were generally involved through public hospitals or State-run institutions, the committee understands that donating gametes often involved a contract between the donor and a private clinic or medical practitioner. While little evidence was presented to the committee on this issue specifically, the committee is concerned about any contractual or other legal obligations that exist between donors and clinics which, if breached, may potentially leave the States and Territories or ART clinics open to claims for compensation.¹²⁷

However, if a law was passed retrospectively to make void any anonymity clause in a contract for donor conception, it is unclear how clinics would be open to claims for compensation. The alleged "anonymity" clause in the contract could not be enforced. As stated above, retrospective legislation may "take away or impair any vested right acquired under existing laws, or create a new obligation, or impose a new duty, or attach a new disability in respect to transactions or considerations already past".¹²⁸

Even without such legislation, it may be argued that any such contracts may be void for public policy reasons. For example, there is overseas precedent where a contract for anonymity between a

¹²³ National Health and Medical Research Council and the Office of the Privacy Commissioner, Use and Disclosure of Genetic Information to a Patient's Genetic Relatives under Section 95AA of the Privacy Act 1988 (Cth) (2009).

¹²⁶ Senate Legal and Constitutional Affairs References Committee, n 1, Submission 48 (Canberra Fertility Centre) p 7.

¹²⁷ Senate Legal and Constitutional Affairs Reference Committee, n 1, p 96 at [7.25].

¹²⁸ L'Office Cherifien des Phosphates Unitramp SA v Yamashita-Shinnihon Steamship Co Ltd (The Boucraa) [1993] 3 WLR 266 at 273 (Sir Thomas Bingham MR).

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¹²⁴ Privacy Act 1988 (Cth), s 14.

¹²⁵ For example, see Senate Legal and Constitutional Affairs References Committee, n 1, Submission 48 (Canberra Fertility Centre) p 7; Submission 106 (Fertility Society) p 11.

private clinic and a donor was held to be so. In *Johnson v Superior Court* 95 Cal Rptr 2d 864 (2000), an 11-year-old donor-conceived girl, Brittany Johnson, won the right to information from a California cryobank about her donor father. Although the parents had received a guarantee that sperm was screened for heritable disease, at age six Brittany Johnson developed a genetic kidney disease inherited from her biological father. The contract between the sperm bank and the donor prohibited disclosure under *any* circumstances. The court held that obtaining important genetic and medical information for donor offspring would, in some circumstances, require the disclosure of the sperm father's identity, and that "a contract that completely forecloses the opportunity of a child conceived by artificial insemination to discover the relevant and needed medical history of his or her genetic father is inconsistent with the best interests of the child" (at 875). On the issue of privacy, the court held that the father's right to privacy was limited and was outweighed by compelling state interests in disclosure. It noted (as discussed above in relation to Australian law) that privacy rights are not absolute and must be balanced against other interests (at 875).

However, there is also the question of exactly what, if anything, the "contract" for anonymity provided. That is, samples of written "contracts" that existed in a number of jurisdictions from the 1970s and 1980s, including donor statement and consent forms which the donors were required to sign, and recipient consent forms deserve closer scrutiny.

The "anonymity clause" in the form used by the Melbourne Royal Women's Hospital in 1977 stated:

I understand that the identity of any recipient shall not be disclosed to me nor shall you reveal my identity to any recipient.¹²⁹

This clause *does not* preclude or prohibit release of information to donor-conceived children (or anyone other than the recipient). The form further required the donor to agree

never to seek the identity of any child or children born or any recipient of my semen, nor shall I seek to make any claim with respect to such child or children in any circumstances whatsoever.

Again, however, this *does not* prohibit a donor-conceived individual from seeking information about their donor. It would have been impossible to bind a non-existent party (a potential, but not as yet existing child) to the contract for anonymity. Forms from the Queen Victoria Medical Centre, Victoria, similarly required the donor to agree that the woman to whom his semen was provided to make pregnant "would remain unknown" to him, and that the donor's "identity shall never be revealed to her".¹³⁰ Again, there was no restriction, or agreement, that the donor would remain unknown to the child conceived as a result of using his sperm. In these instances, the argued contract therefore does not protect the identity of a donor insofar as the donor-conceived individual is concerned. Nor would it leave medical clinics open to liability if they released such information to the donor-conceived individual or to, eg, a donor register, as the donor did not sign anything stating that this was prohibited, or even a condition of his agreement/consent to provide sperm.

Recipient contracts were likewise similar. For example, a form used in New South Wales at the Westmead Hospital¹³¹ stated:

We understand that the identity of the donor will not be disclosed to us, nor shall we directly or indirectly seek his identity.

This does not prohibit the donor-conceived individual from doing so.

Nonetheless, arguments that raise the spectre of "injustice" or "fairness" are valid, and the above-mentioned privacy and confidentiality issues still need be resolved. For those who donated and who wish to remain anonymous, it may appear an injustice to release their information. The Senate Committee urged the States and Territories to further consider the matter and, where necessary, to seek expert legal advice. Within the present article's scope a call for further analysis is also made. However, while it is beyond the scope of this article to delve further into the issues of contract law, it

¹³¹ The form was kindly provided to the author by a recipient parent.



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¹²⁹ The form was kindly provided to the author by a donor.

¹³⁰ The form was kindly provided to the author by a donor-conceived individual.

is certain that arguments based purely upon alleged contracts for anonymity do not in themselves close the matter of retrospectivity. Nor do they seem to reflect what, in fact, those "contracts" contained. In any case, if there were anonymity clauses in other contracts, the legislature has the power to make such anonymity clauses void.¹³²

Risk of donors refusing contact

The final argument against retrospective release of information raised in one submission to the Senate Committee inquiry was that "[i]t may also be devastating to a child or the recipient parents if their attempt at contact with the donor was rebuffed".¹³³ This, again, does not in itself have the force of the arguments raised in favour of information release, and, with respect, seems a rather weak argument in itself. It must be emphasised that not all donor-conceived individuals want *contact* with the donor. Some, however, do want information. Some donors wish they could provide information, or know about the offspring they helped to conceive. The frustration and/or devastation faced by some donor-conceived individuals who desire information but are currently denied it may outweigh the risk of having an attempt at contact rebuffed. This, of course, is an unknown, but to draw on the adoption analogy again, devastation has not been the experience when information was made accessible.

BALANCING THE INTERESTS, RIGHTS AND INJUSTICES

The above discussion illustrates that, in deciding about the retrospective release of identifying and non-identifying information about donors to donor-conceived individuals, the balancing of "rights", "interests" and/or the potential injustices that may be suffered by the respective parties is called for. This is different to finding that the "rights" or "interests" accorded to any of the parties involved in donor conception are *erroneous*.¹³⁴ Rather, as illustrated above, the legislature may pass retrospective legislation when it sees fit, the only exception being that, where this relates to the acquisition of property, it must be done so upon just terms. Retrospective legislation may be enacted even where such legislation may result in injustice to one party – in this instance, some (but arguably not all) donors. This is so because retrospectivity may serve to rectify a manifest injustice to others – donor-conceived individuals, their families and donors who wish to release information.

Human rights discourse similarly requires the weighing of benefits and detriments in relation to the competing rights being served.¹³⁵ The Public Interest Law Clearing House submitted that a human rights-based approach to access to donor information provides a helpful framework for addressing and balancing these concerns in a nuanced way. Other jurisdictions have, in fact, taken a "rights"-based approach.

In July 2002, the English High Court held in *Rose v Secretary of State for Health* [2002] 2 FLR 962 that donor anonymity contravenes donor-conceived individuals' right to "respect for private and family life" guaranteed by Art 8 of the *European Convention on Human Rights 1950*. While the court did not rule upon whether there had been a breach of Art 8 in the case before it, Scott Baker J was clear that the applicants' request to obtain information about their genetic fathers "goes to the very heart of their identity" and was an essential element of "private life" protected by the Convention. He stated (at [47]):

 134 Cf Senate Legal and Constitutional Affairs References Committee, n 1, Submission 20 (Office of the Information Commissioner Queensland) p 3: "[I]f donors provided sperm or eggs on the understanding that their identities would remain confidential, that should not be overridden by any new laws without evidence that the presumptions of benefit are shown to be erroneous or that any detriment that is shown to arise overrides the benefits of the policy to an extent where it becomes desirable to change the rules." It is argued here that the view that the laws must be shown to be *erroneous* is incorrect.

 135 See eg the European Court of Human Rights approach to determining whether any state interference with a right is valid. Generally, the court takes the approach that (i) the interference must be proscribed by law and must be unambiguous (*Sunday Times v United Kingdom* (*No 2*) (1991) 14 EHRR 229); (ii) the aim of the interference must be legitimate (*Campbell v United Kingdom* (1993) 15 EHRR 137); and (iii) the interference in all the circumstances "must be necessary in a democratic society" (*Smith v United Kingdom* (2000) 29 EHRR 493).

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¹³² L'Office Cherifien des Phosphates Unitramp SA v Yamashita-Shinnihon Steamship Co Ltd (The Boucraa) [1993] 3 WLR 266 at 273 (Sir Thomas Bingham MR).

¹³³ Senate Legal and Constitutional Affairs References Committee, n 1, Submission 48 (Canberra Fertility Centre) p 7.

It is to my mind entirely understandable that [ART] children should wish to know about their origins and in particular to learn what they can about their biological father or, in the case, of egg donation, their biological mother. The extent to which this matters will vary from individual to individual. In some instances ... the information will be of massive importance. I do not find this at all surprising bearing in mind the lessons that have been learned from adoption. A human being is a human being whatever the circumstances of his conception and an [ART] child is entitled to establish a picture of his identity as much as anyone else.

In the 2011 case of Pratten v British Columbia (Attorney General) 2011 BCSC 656 the Supreme Court of British Columbia balanced the rights of parties involved in donor conception, pursuant to the Canadian Charter of Rights and Freedoms (the Charter). In Pratten, it was asserted that the law preventing access to information was contrary to the Charter through the failure to enact any legislation to provide donor offspring with rights and opportunities to know the origins that most Canadians take for granted (at [4]-[6]). It was argued that it was unfair and discriminatory to recognise the needs of adoptees to learn about their biological parents and roots, but to ignore the very same needs of individuals who are donor offspring and experience the same sense of loss and incompleteness as adoptees (at [3]). The court held, pursuant to s 15(1), that "anonymity is not in the child's best interests" (at [247]) and that "[m]ore significantly ... donor offspring are the victims of stereotypical thinking about their circumstances and needs" (at [248]). It said (at [254]): "Strong and positive relationships with social parents do not satisfy or eliminate the desire and need of donor offspring to know where they came from, and their need to know their origins is just as powerful and real as those of adoptees." It held that there was "a violation of the rights of ... donor offspring" (at [259]) and ordered that the Province of British Columbia draft and enact legislation to comply with the Charter. The case is currently on appeal on the basis of constitutional issues raised by the judgment.

In some European countries donor anonymity is also prohibited on human rights grounds. Sweden became the first nation to eliminate sperm donor anonymity in 1984, Austria passed anti-anonymity legislation in 1992 partly based upon an interpretation of Art 7 of the *United Nations Convention on the Rights of the Child*, and that same year, Switzerland incorporated a new constitutional Article ensuring a child's "access to data concerning his lineage".¹³⁶ In all instances the right of the child to know its genetic heritage was seen to outweigh any argument for donor anonymity.

Nonetheless, in its report the Senate Committee stated:

[W]hile many submissions and witnesses framed the issues surrounding donor conception in terms of the rights of donor-conceived individuals or the rights of donors, some research in related areas of public policy suggests that an approach that focuses on "rights" may not be of great assistance in this context.¹³⁷

The Senate Committee cited the Australian Law Reform Commission's report into the protection of human genetic information in Australia which considered analogous issues relevant to genetic parentage testing and cautioned:

[T]his is not an area in which it is especially useful to draw on the language of "rights" – whether that be a child's "right" to know his or her biological parentage, or a man's "right" to know who are his biological offspring. This is an area that requires a careful balancing of *interests* of mothers, fathers and children in different biological and social relationships with each other. To privilege the interest of one party by accepting a claim to an absolute right fails to give adequate regard to the interests of others involved in the equation.¹³⁸

Arguably, the ALRC/AHEC report was not suggesting that "rights"-based arguments should be rejected altogether, but rather that such language is not particularly useful when used in absolutes

¹³⁸ Australian Law Reform Commission, *Essentially Yours: The Protection of Human Genetic Information in Australia, Report* 96 (2003) Vol 2, pp 861-862 (emphasis in original).



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¹³⁶ Frith L, "Gamete Donation and Anonymity: The Ethical and Legal Debate" (2001) 16 Human Reproduction 818 at 818.

¹³⁷ Senate Legal and Constitutional Affairs References Committee, n 1, p 88.

without considering other arguments or interests involved. As such, rather than rejecting rights-based arguments, it may be preferable to engage in the balancing of *both* the rights and interests of the parties involved.

Using the language of "interests" still leads to an exercise where one must determine whose interests prevail or how any or all of the interests may be accommodated. Much of the debate surrounding the retrospective release of information assumes there can be conflicts of interest between the parties involved. If a donor-conceived person wishes to identify their donor, and the donor wants to keep their identity a secret, the law cannot satisfy both. The interests are competing, and the law must choose between them, or in addressing the interests it must seek a compromise. There is clear precedent that shows that the law can, and does, balance such interests, and at times makes a compromise. For example, it was shown above in relation to the New South Wales legislation on adoption that there was a weighing up of the competing *interests* of different groups of people affected by adoption and

the view that prevailed was that the law should enable adopted persons and birth parents to have the right to information, even though this did mean a change from the position as it was when the adoption order was made. The interests of those who felt threatened by the new law were acknowledged by a number of measures, notably the contact veto system.¹³⁹

The contact veto system was therefore the compromise.

What seems most significant is that consideration is given to *all* arguments for and against retrospectivity, be they "rights"-based or "interests"-based, and that engagement in a balancing process is undertaken. In passing retrospective legislation, we need to consider what injustice (if any) will arise, and whether it is outweighed by the manifest injustice that the legislation serves to correct. Given the strength of arguments above in favour of those donor-conceived individuals who are denied access to information about their genetic heritage, and their families and donors who wish to impart/exchange such information, it is argued here that, on balance, donor-conceived individuals' rights and interests outweigh any possible injustice that may arise in relation to those donors who may wish to remain anonymous. Contact vetoes may, however, provide a compromise so that those donors, who wish to, may protect their privacy by preventing contact by their genetic offspring.

CONCLUSION

In making their recommendations, the Senate Committee recognised the need for disclosure of information relating to donor conception to donor-conceived individuals, their donors and their extended families. While not all donor-conceived individuals may wish to access such information, the growing view is that the information must be available should they choose to do so. Access to such information is important to a significant number of individuals for reasons including, but not limited to, identity formation, a need to know about biological heritage and medical history, a fear of forming consanguineous relationships, and a desire by some to connect with biologically related siblings and/or donor(s).¹⁴⁰ There are human rights arguments that support the release of information, and the number of donor-conceived individuals already in existence who are affected by the secrecy that surrounded donor conception in the past is significant. There are also arguments made by both donors and recipient parents for such information to be released. On the other hand, privacy, confidentiality and contracts for anonymity issues are used by others to claim that information should remain closed to those donor-conceived individuals who were not protected by any laws at the time of their conception.

The Senate Committee recommended that the States and Territories consider further the issue of retrospectivity. This article has attempted to highlight the complexities and legal arguments that need weighing when trying to establish whether retrospective legislation, while potentially serving an "injustice" to some donors, may in fact be required to rectify the manifest injustice faced by

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¹³⁹ New South Wales Law Reform Commission, n 67 at [3.16].

¹⁴⁰ Herz R and Mattes J, "Donor Shared Siblings or Genetic Strangers: New Families, Clans, and the Internet" (2011) 20(10) *Journal of Family Issues* 1.

donor-conceived individuals, their families and donors who do wish for information to be released. It is apparent that, as those conceived in the 1970s and 1980s reach adulthood, the call for such information is increasing. Tens of thousands of Australians are affected. Australia has in recent decades moved to right many injustices, and in doing so as a nation celebrates different family types and recognises them at law – with the best interests of the child at the forefront. This is an opportunity to lift the veil of secrecy that has surrounded donor conception for donor-conceived individuals, their families, donors and generations to come. There is no shame in making, or helping people to make, families. The call for information from those brought into being by such "family-making practices" should not be ignored.

That said, should retrospective legislation be passed, it does not have to, nor should it, occur in a way that is insensitive to the needs of all people affected by this issue. Long notice periods, counselling, and sensitivity to peoples' personal and familial situations would, of course, be warranted. The contact veto system is a way of further protecting people's privacy, while recognising the need for, and entitlement to, information for donor-conceived individuals, their families and generations to come.

In conclusion, while highlighting the psycho-social, ethical and legal issues relevant when considering retrospective release of identifying and non-identifying information to donors, this article cannot in itself resolve them. It does, however, indicate that both "rights"- and "interest"-based arguments support the view that the manifest injustice suffered by donor-conceived individuals who wish to know their genetic heritage but are denied such information, outweighs the arguments put forth by some about donor anonymity, privacy and confidentiality. The law allows for retrospective legislation to be passed. The Australian legislatures need to act to preserve the information already held and to enact legislation that enables access to information by donor-conceived individuals nationwide, regardless of when they were born.



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