Committee Secretary
Senate Legal and Constitutional Committee
PO Box 6100
Parliament House
Canberra ACT 2600
Australia

Phone: +61 2 6277 3560
Fax: +61 2 6277 5794
Email: legcon.sen@aph.gov.au

To the Senate Committee Inquiry into Donor Conception,

I am writing in regard to the *Inquiry into Donor Conception in Australia* currently being convened by the Senate Legal and Constitutional Committee of the Australian Parliament.

As a legal academic and researcher who has for a number of years worked on these particular issues I make below specific comments which focus upon donor conceived individuals having access to identifying and non-identifying information about their donors and siblings. It is my suggestion that a national register be set up to enable this and I propose a number of models for how this may be achieved.

I do not address the issue of donors wishing to contact or be given any significant information about the children who have been conceived as a result of their donations. I here note however that it is my view that this should only occur where the donor conceived child has given permission.

My focus is the individuals who, as a result of medical technologies, have been conceived using donor sperm, oocytes or embryos and who deserve to choose whether or not they wish to know more about their genetic heritage. In order to make such choices it is imperative that disclosure of their donor conception be made and that they have access to information should they want it.

I thank you for the opportunity to present my views.

Dr Sonia Allan

SUBMISSION TO SENATE COMMITTEE INQUIRY INTO

DONOR CONCEPTION ACCESS TO GENETIC INFORMATION AND DONOR IDENTIFICATION

Prepared by:

Dr Sonia Allan[1]

PhD(Law); LLB(Hons) BA(Psych)(Hons);
Grad. Dip Legal Practice (NSW); GCHE.
Senior Lecturer, Adelaide Law School, University of Adelaide.

Correspondence concerning this submission may be sent to sonia.allan@adelaide.edu.au

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[1] Some of the information in this submission is taken from a submission made to the Commonwealth Attorney General in 2007 by Sonia Allan and Michael Williams titled *Assisted Reproductive Technology: Access to Genetic Information and Donor Identification, Proposal for a Federal Register for Donor Conceived Individuals*.

EXECUTIVE SUMMARY

This submission focuses upon access to information about donor conception *by donor conceived individuals*. It details concern that many people who were (or will be) conceived using donor insemination or ART do not have access to information about their donor and/or siblings born to other families that share the same donor. In particular the submission examines:

- the inconsistency between state and territory laws in Australia which impedes equal access to information across Australia—noting that many donor-conceived individuals do not have access to information at all;
- the importance of access to information for donor-conceived individuals (in relation to issues of self-identity, medical history, and the risk of meeting and forming relationships with biologically related donors or donor-conceived individuals);
- international models for voluntary and compulsory registries which are aimed at addressing issues of access to information by donors and donor-conceived individuals;
- proposed models for an Australian National Register;
- the age that donor conceived individuals should be able to access information;
- counselling; and
- a brief consideration of ways to facilitate disclosure.

It recommends that:

- a national register should be established that holds identifying and non-identifying information of donors and donor conceived individuals to facilitate those donor conceived individuals who wish to know about their genetic heritage and/or biological siblings
- all future use of donor gametes and/or embryos should involve compulsory reporting of identifying and non-identifying information about the donor to the register;
- in relation to information that is already held on record at clinics, hospitals and doctors surgeries:
    - the preferred position is that all information currently held on record that is identifying and non-identifying be added to the register—regardless of when that information was gathered. (I.e. that legislation requiring disclosure act retrospectively);

    - that if the preferred position is not adopted, that all non-identifying information that is held should be added to the register—regardless of when that information was gathered;
- the register should also provide for voluntary registration of information by donors and donor conceived individuals where records might have been destroyed, are not available or were not adequately kept; and
- the age that donor conceived children should be able to access information be sixteen, but that donor conceived individuals should be permitted to access the information earlier if they do so under the guidance of a counsellor, youth worker, parent, guardian or other responsible adult;
- counselling be made available on an ongoing basis to parents, donors and donor conceived individuals should they need it; and
- that the inquiry also consider the question of how to facilitate disclosure so that donor conceived individuals may choose whether they wish to access information about their genetic heritage.

i. INTRODUCTION

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. 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.'[2] 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.

Given these 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. Donor support groups estimate the figure to be closer to 60,000.[3] Of great concern therefore is that the identity of many donors remains unknown due to the secrecy that has surrounded donor conception and that many thousands of donor conceived individuals are denied access to information about their genetic heritage.

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[2] 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.

[3] See for example the Donor Conception Support Group, http://www.dcsg.org.au/legislation/inquiry.html at 24 July 2010.

ii. AUSTRALIAN STATE AND TERRITORY LAWS

The Australian approach to regulating (or not regulating) donor conception differs across jurisdictions. Each state and territory has exhibited divergent methods for recruiting donors, storing and using their sperm and assessing which infertile couples are appropriate to receive donor conception. 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 doctors performing donor conception. 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 donor-conceived individuals, when informed of their donor-conceived status and curious for information about their donor, to be informed by the clinics at which they were conceived that such information has been destroyed. For other donor-conceived individuals the information still exists, however they are unable to access it. This is clearly a result of inconsistent legislation regarding access to information across Australia.

Currently, four Australian states have legislation that governs access to information concerning donor conception[4] however South Australia does not maintain a registry and information is difficult at best to obtain. The remaining states and territories refer to the National Health and Medical Research Council (NHMRC) guidelines and recommendations for ethical practice.[5] 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. **The lack of information available in the other states and territories and thus the inequity within Australia depending on where one was conceived is striking.** 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.

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[4] *Human Reproductive Technology Act 1991* (WA); *Assisted Reproductive Treatment Act 2008* (Vic); *Assisted Reproductive Technology (Clinical Practices) Act 1988* (SA); *Assisted Reproductive Technology Act 2009* (NSW).

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

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

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**[6] 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.
Victoria	*Assisted Reproductive Treatment Act 2008* (Vic)	**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	**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

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[6] 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
		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.	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 will be 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.
South Australia	*Reproductive Technology (Clinical Practices) Act 1988* (SA)	South Australian legislation and regulations require record keeping. While there is no right to access identifying information, such access is possible if all parties consent. However, there is no central register that holds this information, and donor conceived individuals must 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
Tasmania, **Northern Territory** **ACT**	NHMRC Ethical Guidelines on the Use of Assisted Reproductive in Clinical Practice and Research	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.*	NONE

STATE	LEGISLATION/ REGULATIONS/ GUIDELINES	ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION	VOLUNTARY REGISTER
Queensland	(2007)	*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; they should therefore be encouraged to tell their children about their origins.* *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.	

It is difficult to justify a situation in which some people born as a result of the use of ART have a right to access to information about their biological parentage because they were conceived in a particular state at a particular time, but those conceived in other states or territories or prior to the introduction of legislation are not entitled and do not have access to such information. This is particularly relevant as donor-conceived individuals face a number of concerns in relation to not having access to information.

iii. The importance of access to information for donor-conceived individuals

Whilst there are divergent perspectives on whether an individual has an ethical or legal 'right' to know their genetic background, several countries (including Sweden, Austria, Switzerland, The Netherlands, Norway, the UK, Finland and New Zealand) and some of the Australian jurisdictions discussed above (South Australia, New South Wales, Victoria and Western Australia) provide for access to information. Such access has been based on arguments concerning the importance for all donor-conceived individuals to know about their genetic heritage. Of major significance is that:

> 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**?[7]

With respect to the welfare of children, domestic and international law regulating the conduct of governments, courts and private organisations broadly adopt the principle that 'the best interests of the child' shall be paramount. This is enshrined in the United Nations *Convention on the Rights of the Child* ('CROC'), which Australia and 191 other countries have ratified. Article 7 of CROC further states that children have a right to know the identity of their parents. It is also argued that this includes knowing about one's genetic heritage to:

- gain a fuller sense of self-identity,
- have access to medical information about donors, and
- avoid the chance of engaging consanguineous relationships with unknown relatives.

GAINING A FULLER 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

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[7] S. Ramsey (1998) *Keeping Secrets and Telling Stories*. Opening Address at Donor Issues Forum, organised by the South Australian Council on Reproductive Technology, Adelaide, 30 May.

that societies such as Australia's place great weight on 'blood relations [as] … the basis of kinship'.[8] 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 that they are not biologically related to their parent(s) many feel a sense of 'lost identity' and a corresponding desire to know more about their donor. This desire often exists independently of the love and affection individuals feel from their non-biological parent(s) and the fact their relationship is strong.

Similar to adopted children wanting to meet their biological parents,[9] donor-conceived individuals feel a strong need to connect with their donor in order to obtain a fuller sense of self-identity. Of major concern then is that individuals told late in life about their adopted or donor-conceived status may experience psycho-behavioural difficulties. For example, where it is too late to meet their biological parents, such individuals may experience a great sense of loss. Calls for openness in adoptive situations have been thus been encouraged. It is here argued that the same openness and access to information should be afforded to donor-conceived individuals.

Also while there is evidence to suggest that donor-conceived individuals undergo a 'fracturing' in their identity due to knowledge of their status such difficulties are typically related to feelings of frustration at being denied information about their donor. There may be a deeper appreciation of the relationship with the parents that have reared them based on an acute awareness of how much they were wanted by their parents who endured fertility treatment in order to give birth to them. On the other hand, such feelings coexist with a strong desire to know one's donor and frustration at being denied information.

In studies conducted to evaluate the consequences of 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, '[t]hese sentiments suggest that identity is related to genetic inheritance in some way', and that a fuller sense of

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[8] HD Grotevant, N Dunbar, JK Kohler, and AML Essau, 'Adoptive Identity: How Contexts Within and Beyond Families Shape Developmental Pathways', (2000) 49(4) *Family Relations 379* as cited in Dr Ruth McNair, *Outcomes for Children Born of A.R.T. in a Diverse Range of Families* (2004), 39.

[9] Noting that whilst 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.

identity for a donor-conceived person may only be achieved through access to details about their donor.'[10]

ACCESS TO MEDICAL INFORMATION

The importance of having access to information concerning a biological parent's medical history (for example whether or not there is a familial history of heart disease, diabetes, cancer, mental health issues, and so on) is undeniable, and therefore will not be discussed in great detail. Suffice to say that donor-conceived individuals who are denied access to such information are placed at risk as a result of not being informed about their genetic heritage.

AVOIDING THE CHANCE OF CONSANGUINITY BY FORMING RELATIONSHIPS WITH UNKNOWN RELATIVES

There is also a strong desire by donor-conceived individuals to know whether they have half-siblings, and frustration at not being able to meet them. Of major concern is also that they may unknowingly form relationships with siblings or possibly their unknown donor. Such a risk is significant within Australia. While it has been claimed in international reports that one way to avoid half-siblings forming relationships was through the restriction of a donor to one donation, it is clear that this is not the approach to donor conception in Australia. In many clinics and doctor's surgeries, donors are likely to have donated multiple times. Some donors may also have donated at multiple clinics.

The risk of siblings (and/or donors) forming relationships with related individuals is 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. Tasmania is a primary example of this. There the population is around 500,000 and donor conception occurred for years without proper retention of records or information about donors is suppressed. In one prominent clinic in Launceston run by the late Dr Lachlan Hardy-Wilson, and later by Dr Timothy Sutton, multiple donor conceptions were performed throughout the 1980s with no retention of any details relating to donors. Given that Launceston has only around 100,000 people, the statistical probability that persons involved in donor conception (either offspring or donors) form

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[10] Dr Ruth McNair, *Outcomes for Children Born of A.R.T. in a Diverse Range of Families* (2004), 43.

relationships unknowingly is not insignificant. The American Institute of Marriage and Families reinforces the issues raised by such a situation, stating:

> Since many children close in age could be conceived from the same sperm donor and live in relative proximity to the sperm bank, and since sharing half your genetic make-up with someone might make them seem especially 'familiar' and attractive (especially if you did not know they were your blood relation) the fear of unknowingly dating a half-sibling is not unfounded.[11]

Donor-conceived individuals and their donors are clearly placed at a significant risk when forming relationships as they lack the necessary information to avoid such a situation.

The issue further presents legal difficulties for donors and donor-conceived individuals. The Commonwealth *Marriage Act* makes unlawful marriages between an individual and their parent, and an individual and their half-sibling. The effect of this provision is to invalidate the marriage because such relationships fall under a prohibited category within the Act. However, 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. 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 regards 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 with the possibility of being connected.

Finally, 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. The existence of a voluntary federal register in which identifying and/or non-identifying information is made available donor-conceived individuals would thus not only assist such individuals in addressing issues related to identity; enable access to information about medical history; but also ensure that relationships with blood relatives are avoided. Giving all donor-conceived individuals access to information about their donors and siblings requires a mechanism for collecting and retaining this information. The mechanism suggested here (i.e. a donor registry) is illustrated by first considering a number of international models.

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[11] Elizabeth Marquardt (on behalf of the Commission for Parenthood's Future), *The revolution in parenthood: the emerging global clash between adult rights and children's needs* (2005), 38.

iv. INTERNATIONAL MODELS

In their article ‘Donor-Conceived People’s Access to Genetic and Biographical History: An Analysis of Provisions in Different Jurisdictions Permitting Disclosure of Donor Identity’,[12] Eric Blyth and Lucy Frith provide comprehensive information about countries (and/or states—including those Australian states mentioned above) that require gamete or embryo donors to agree to the disclosure of their identity to any offspring. The author refers the inquiry to that article for discussion of the various systems that have been implemented in those countries. Suffice to say here that Australia lags behind these nations in its recognition for the need for donor conceived individuals to have information about genetic heritage. Some nations have had such laws for over twenty years whilst others have more recently recognised this need. This is illustrated in Table Two.

Table Two: Other Jurisdictions that Require Disclosure of Identity of Donor[13]

Jurisdiction	Legislation	Date of implementation
Sweden	Lag om insemination (Law on Insemination) 1984 (replaced by Genetic Integrity Act 2006)	18 March 1985
Austria	Fortpflanzungsmedizingesetz. 275 Bundesgesetz.	1 July 1992
Switzerland	Federal Act on Medically Assisted Procreation of 18 December 1998 – FF 1996 III, 197 (LPMA)	1 January 2001
The Netherlands	Wet donorgegevens kunstmatige bevruchting, 2002	1 June 2004
Norway	Act on Biotechnology 2003	1 January 2005
UK	Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004 (and Human Fertilisation and Embryology Act 2008 – due to be implemented during 2009)	1 April 2005
New Zealand	Human Assisted Reproductive Technology (HART) Act 2004	22 August 2005
Finland	Act on Assisted Fertility Treatments (1237/2006)	1 September 2007

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[12] Eric Blyth and Lucy Frith, ‘Donor-Conceived People’s Access to Genetic and Biographical History: An Analysis of Provisions in Different Jurisdictions Permitting Disclosure of Donor Identity’ (2009) 23(2) Int. Jnl. of Law, Policy and the Family, 174-191.

[13] Information contained in this table is from the article listed above (ibid).

In all jurisdictions, since the inception of their respective legislation, a prospective donor is required to consent to the release of her or his identity to any offspring who requests this information and such consent is secured in advance of the collection and use of gametes or embryos.[14] Information is then held on a registry that may be accessed by donor conceived individuals.

Australia may draw upon such models (and of course those that exist in its own states of Victoria and Western Australia) when considering the approach that should be taken on a national level here. However, as discussed above and below, it is important that in setting up a national register in this country that we recognise the injustice of denying people access to *any* information that is available about their genetic heritage. As such, the preferred position of this submission is to provide donor conceived individuals access to ***all identifying and non-identifying information that is in fact held by clinics, hospitals and/or doctors*** **regardless of when conception took place. It is argued here that to preserve the secrecy with which their conception might have taken place is not acceptable.**

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[14] Blyth and Firth, above n12.

v. PROPOSED MODEL FOR AUSTRALIAN NATIONAL REGISTER

Federal legislation in Australia does not regulate ART per se[15] however federal law is relevant to the legal definitions of family relationships.[16] The Commonwealth has responsibility for determining disputes between parents and other significant figures in the child's life, and can make orders about where a child will live, who a child will have contact with and about decision making in relation to that child. The relevant provisions regarding who is a parent of a child born as a result of artificial conception procedures (and therefore responsible for support and maintenance in relation to that child) are contained in *the Family Law Act*.[17] It is not proposed here that any amendments be made to alter the status of donors in relation to their parental status under relevant federal legislation. **It is proposed that a national register be established where donor-conceived individuals can access information about their genetic relations (donors and siblings) at a central location—regardless of where in Australia a person was born or conceived.** This register could take a variety of forms:

1) A *compulsory* register in which all identifying and non-identifying information held regarding donations be reported to the register irrespective of the date of conception. This model would mirror the approach taken in the 1980s in Australia towards releasing information about the genetic heritage of adoptees retrospectively. There are some sound legal arguments that in spite of past practice which ensured donors anonymity that retrospective release of identifying information can and should also be the case for donor conceived children.[18] As stated above, whilst some records have been destroyed, other clinics or places in which donor conception has occurred have extensive records concerning donor identity, the number of donations made and the resultant children conceived and born as a result of such donations. To deny access to this information is argued by many donor conceived individuals to be unacceptable. The individuals born as a result of

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[15] Department of Human Services (DHS) 2004. It is however noted that at the 2003 meeting of the Council of Australian Governments (COAG) there was an indication of Federal and State governments' desire to work towards uniform legislation across Australia to standardise the regulation of ART (FSA 2004), although this has not to date occurred.

[16] Victorian Law Reform Commission, *Assisted Reproduction and Adoption: should the current eligibility criteria be changed? Consultation Paper.* (2003).

[17] *Family Law Act 1975* (Cth), s60H.

[18] For an extensive legal analysis of these arguments in the United States context see Thomas K. Sylvester 'A Case Against Sperm Donor Anonymity' (2007), http://donorsiblingregistry.com/legal.pdf at 22 July 2010.

donor conception were not party to any agreement concerning secrecy and it is the donor conceived individual that is most affected by not having the choice to know about their genetic heritage if they wish to find out. If the right to access information about genetic heritage is seriously recognised, then retrospective release of information needs also to be considered.

2) A *compulsory* register in which all non-identifying information held regarding donations is reported to the register, with voluntary registration of identifying information for donations made prior to a specified date; and compulsory registration of information for all future donations.

This option would enable donor-conceived individuals across Australia to access non-identifying information recorded in the past which is still in existence. *It would also facilitate siblings contacting each other, as they would not be reliant on a donor coming forward voluntarily to enter his/her name on the register.* As difficult questions could arise about arrangements and understandings that may have been made at the time when the records were created, records that are of an identifying nature would only be submitted voluntarily (ie. with the consent of the donor or donor-conceived person).

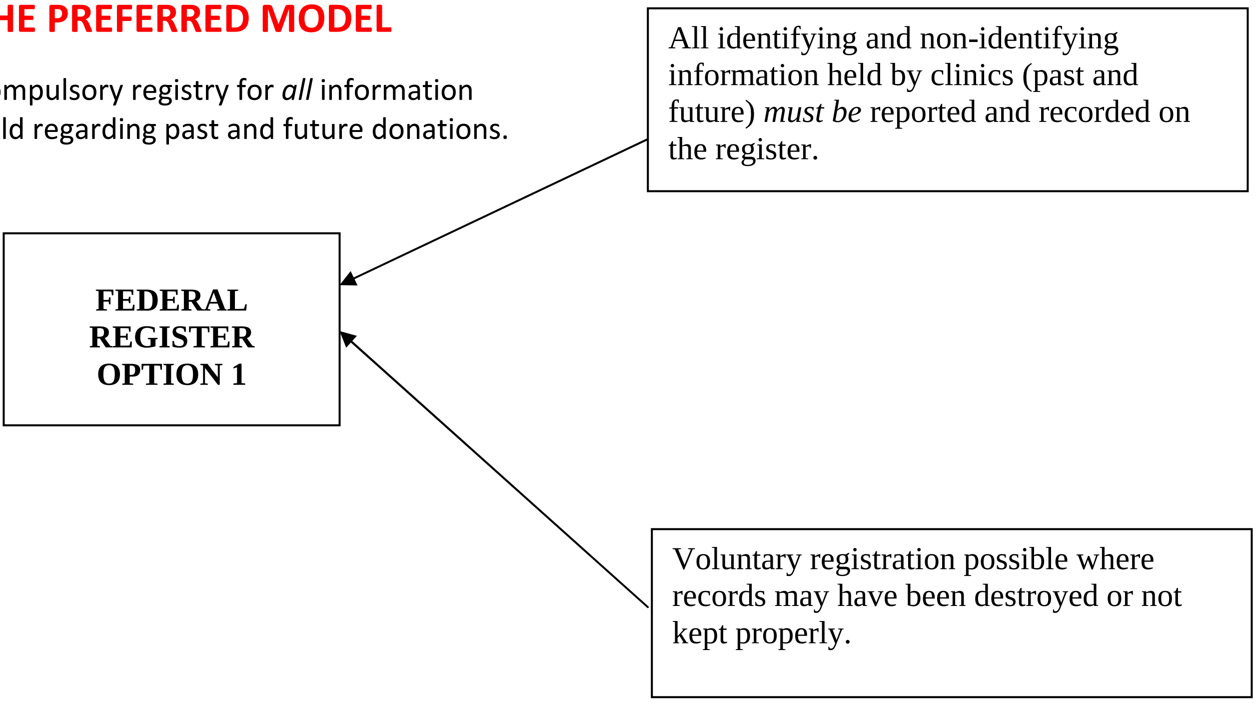
3) A national *voluntary* register for all identifying and non-identifying information for donations made prior to a specified date; compulsory registration of information for all future donations. Under this model it would be voluntary to place information for all donations made prior to a specified date. However information (both identifying and non-identifying) relating to all future donations would be recorded on the register compulsorily. This model mirrors that of the New Zealand and United Kingdom registries described above and as stated is unacceptable for use in Australia. Specifically it is a complete contradiction to recognise that donor conceived individuals have a need and a right to information about their genetic heritage and then to leave the access to information to chance—where information and records are held they must be released.

The suggested Federal Registry for Donors and Donor-conceived individuals could be housed at and maintained by the Family Court; The Federal Magistrates Court; or The National Health and Medical Research Council (NHMRC). Information held by the state based registries could be transferred to the Federal Registry.

The three models are represented diagrammatically as follows:

THE PREFERRED MODEL

Compulsory registry for *all* information held regarding past and future donations.



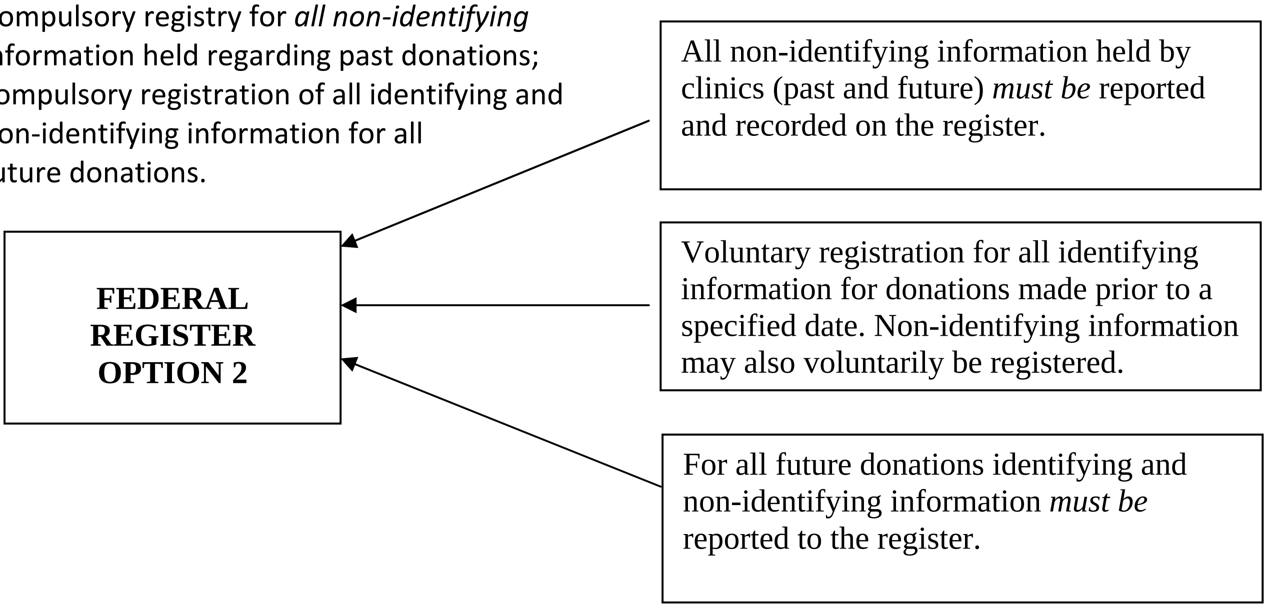
FEDERAL REGISTER OPTION 1

All identifying and non-identifying information held by clinics (past and future) *must be* reported and recorded on the register.

Voluntary registration possible where records may have been destroyed or not kept properly.

THE ALTERNATIVE

Compulsory registry for *all non-identifying* information held regarding past donations; compulsory registration of all identifying and non-identifying information for all future donations.



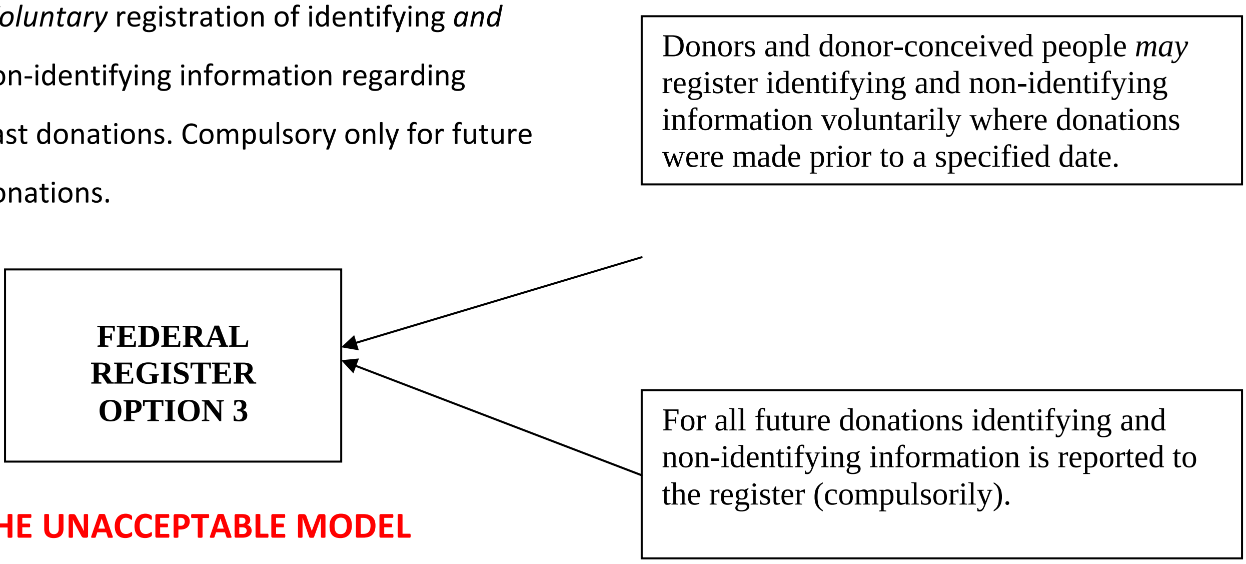
All non-identifying information held by clinics (past and future) *must be* reported and recorded on the register.

Voluntary registration for all identifying information for donations made prior to a specified date. Non-identifying information may also voluntarily be registered.

For all future donations identifying and non-identifying information *must be* reported to the register.

FEDERAL REGISTER OPTION 2

Voluntary registration of identifying *and* non-identifying information regarding past donations. Compulsory only for future donations.



Donors and donor-conceived people *may* register identifying and non-identifying information voluntarily where donations were made prior to a specified date.

For all future donations identifying and non-identifying information is reported to the register (compulsorily).

FEDERAL REGISTER OPTION 3

THE UNACCEPTABLE MODEL

It is contradictory to recognise a need for and right to information and then leave access to existing information to the chance of voluntary registration. Information that exists must be released to the registry regardless of when the donor conception took place.

Age that Donor Conceived Individual May Access Information

In addition to the above discussion this submission notes that access to such information is important for individuals prior to the age of eighteen.

A number of international jurisdictions (Finland, New Zealand, Norway, Switzerland, the UK), that require identifying information to be held on the donor, 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 information may be requested, requiring instead that the donor-conceived person has 'achieved sufficient maturity'.[19]

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.

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[19] United Nations Committee on the Rights of the Child, 1998.

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.

Ensuring Disclosure of Donor Conception

Finally, 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 may in itself play a part in facilitating parental disclosure there may be other ways to encourage disclosure. It has already been suggested above that counselling should be available to parents and families to facilitate this process. In addition, whilst the registration of births falls to the states and territories in Australia, 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 shortcomings[20] 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. As such matters require far more analysis than that which is possible in this submission no recommendation is made about which approach (if any) regarding disclosure on birth certificates is most acceptable. **Rather I call for the recognition of such issues as an adjunct to the main thrust of this submission which is the need and right of donor conceived individuals to access information about genetic heritage. In order to make a choice about accessing such information donor conceived individuals must know about the method of their conception in the first place.**

v. 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. The Federal Government of Australia should correct the anomalies faced by donor-conceived individuals in Australia by setting up a national register for donors and donor-conceived individuals. Options and models have been provided to illustrate how such a registry may run. It is not a difficult task, just one that has been ignored for far too long.

This submission therefore calls for compulsory registration of both identifying and non-identifying information for all donor conceptions in the future. It also calls for 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

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[20] 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.

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. Of the above models proposed, it is therefore Model 1 that is preferred. However, should Model 1 not be accepted, Model 2 which advocates the compulsory registration of non-identifying information recorded in the past and still in existence should be implemented.

Both Model 1 and Model 2 are possible given that 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.[21] Nonetheless, it must also be noted that for the large number conceived through donor conception before the implementation of ethical guidelines 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. Such voluntary registration must therefore also be facilitated through the suggested national register.

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. 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

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[21] 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.