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Committee Secretary
Senate Standing Committee on Legal and Constitutional Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

21 October 2010

Dear Secretary,

Re: Inquiry into the past and present practices of donor conception in Australia

Liberty Victoria welcomes the opportunity to contribute to the Senate Standing Committee's inquiry into donor conception practices in Australia and would like to thank the Committee for accepting this late submission.

Liberty Victoria is one of Australia's leading human rights and civil liberties organisations and works to defend and extend human rights and freedoms in Victoria.

Liberty Victoria notes that the Committee has been asked to examine the past and present practices of donor conception in Australia, with particular reference to:

- (a) donor conception regulation and legislation across federal and state jurisdictions.
- (b) the conduct of clinics and medical services, including:
 - (i) payments for donors,
 - (ii) management of data relating to donor conception, and
 - (iii) provision of appropriate counselling and support services;
- (c) the number of offspring born from each donor with reference to the risk of consanguine relationships; and
- (d) the rights of donor conceived individuals.

This submission focuses on donor conception regulation and legislation across federal and state jurisdictions and the rights of donor conceived individuals. Liberty Victoria also wishes to acknowledge that it has had the benefit of reading the PILCH submission and wish to endorse their position that any changes to the law in the area of donor conception must be undertaken through the prism of Australia's international human rights obligations.

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1. Rights of donor conceived individuals

Liberty believes that current donor conception regulation and legislation does not sufficiently protect the rights of donor conceived individuals. We are particularly concerned with the inability of donor conceived individuals to access information about their donors.

Liberty's position on donor conception is largely based on Australia's ratification of a number of important international conventions which apply to donor conceived people. We believe that by denying donor conceived individuals access to information about their donors and half-siblings, Australia is not meeting its obligation under the *United Nations Conventions on the Rights of the Child* and the *International Covenant on Civil Rights*.

United Nations Conventions on the Rights of the Child

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

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

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

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

The International Covenant on Civil and Political Rights

Article 26 All persons be guaranteed equal & effective protection under the law against discrimination on any ground such as race, colour, sex, language, religion, or other opinions, natural or social origin, property, *birth* or other status.

In 2005, a non-government report designed to further Australia's compliance with the United Nations Convention on the Rights of the Child found that:

A group of Australian children whose right to identity is not widely recognised are children born as a result of assisted reproductive technologies...In the vast majority of cases these children are entitled only to limited information about their biological and genetic background.¹

A guiding principle of Victoria's *Assisted Reproductive Treatment Act 2008* is that 'children born as a result of the use of donated gametes have a right to information about their genetic parents,' however the Act provides no means of enforcing such a right.²

Donor conceived individuals are being discriminated against on the basis of the nature of their birth and conception, in breach of Australia's international obligations.

¹ The National Children's and Youth Law Centre and Defence for Children International (Australia), 'The Non-government Report on the Implementation of the United Nations Convention on the Rights of the Child in Australia' (2005) 14

² *Assisted Reproductive Treatment Act 2008* (Vic) s 5(c).

2. Donor conception regulation and legislation

The rights of donor conceived individuals to access information regarding donors and half-siblings differs between jurisdictions. This inconsistency causes inequality, with Australians being entitled to different rights depending on where they were born.

Four Australian States have legislation governing access to information regarding donor conceptions. In Victoria, New South Wales and Western Australia, individuals now have a right to access identifying information about their donors.³ Compulsory registers exist in these States and anonymous gamete donation has been formally prohibited.⁴ In South Australia legislation exists on the topic of donor conception but does not give any right to access identifying information, in addition, the SA register is voluntary rather than compulsory. Victoria, New South Wales and Western Australia have also created voluntary registers to help those not covered by legislation to access information.

The remaining states and territories refer to the National Health and Medical Research Council (NHMRC) guidelines and recommendations for ethical practice. The guidelines state that, '[p]ersons 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.'⁵ However we are concerned that these guidelines do not do enough to ensure the rights of donor conceived individuals.

Differences also exist within jurisdictions depending on when individuals were conceived (New South Wales and Western Australia) or when the gametes leading to their conception were donated (Victoria).

For example in Victoria, under the *Assisted Reproductive Treatment Act 2008 (Vic)*, the rights of donor-conceived people vary depending on when the gametes leading to their conception were donated.

- 'Donor-conceived people can access identifying information about their donors if the person was conceived using gametes donated after 31 December 1997.'⁶
- 'Donor-conceived people can access information about their donors if they were conceived using gametes donated between 1 July 1988 and 31 December 1997 and the donor has consented to the disclosure of the identifying information.'⁷
- 'The Act does not mention people conceived using gametes donated prior to 1 July 1988 and therefore they have no right to access information about their donors under this legislation.'⁸

³ *Assisted Reproductive Treatment Act 2008 (Vic)*, *Assisted Reproductive Technology Act 2007 (NSW)* and *Human Reproductive Technology Act 1991 (WA)*.

⁴ 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 *International Journal of Law, Policy and the Family*, 174, 175.

⁵ *National Health and Medical Research Council's Ethical guidelines on assisted reproductive technology* (2007) s 6.1.

⁶ *Assisted Reproductive Treatment Act 2008 (Vic)* s 59(b)(i).

⁷ *Assisted Reproductive Treatment Act 2008 (Vic)* s 59(b)(ii).

⁸ Law Reform Committee, Parliament of Victoria, *Interim Report on the Inquiry into access by donor-conceived people to information about donors* (2010) 12.

The regulation of donor conception in Australia is complicated and piecemeal and treats donor conceived individuals unequally on the bases of when and where they were conceived.

Liberty believes that *all* donor conceived individuals should have equal access to information about their donors. Currently in jurisdictions where no register exists, individuals are dependent on the practices of clinics and physicians who may hold different information and have different policies on how long the information should be kept.

Such an approach contravenes Australia's obligations under international human rights instruments. Donor conceived individuals should not be deprived of information about their genetic origins.

Recommendation 1

Uniform legislation should be established throughout Australia to give donor conceived individuals equal rights to access information regarding their donors no matter what jurisdiction they were born in.

Recommendation 2

A national prospective compulsory register should be established to ensure information is being recorded, kept uniformly and is accessible to donor conceived individuals..

3. A National Voluntary Retrospective Register

Prior to the introduction of legislation 'the consent of donors to donate gametes was not legally required but rather was provided in a private contract between medical clinics and donors. These contracts assured donors that they would remain anonymous.'⁹ As pointed out in the PILCH submission, a balance needs to be struck between the rights of donors and donor conceived individuals.¹⁰ There are competing human rights and privacy interests pertaining to both donors and donor conceived individuals. Liberty Victoria supports the proposition put by the Fertility Society of Australia, that it would be unfair to institute 'compulsory retrospective registries, as this would be a violation of agreements entered into, in good faith, with sperm donors who have made an altruistic donation to help other families have children'.¹¹ This position is also advanced by the Queensland Office of Information Commissioner, who argues that:

If donors provided sperm or eggs on the understanding that their identities would remain confidential, that should not be overridden by 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.¹²

However, respect or recognition of the privacy of donors needs to be balanced with the rights of the child under Articles 2, 3, 7 & 8 of the *Convention on the Rights of the Child*. Liberty Victoria believes that in respect of previous donors who volunteered on the basis of anonymity, an education process aimed at those donors along with the creation of a national voluntary retrospective register could address the information vacuum prior to the mid-1990s.

A national voluntary retrospective register would enable those born prior to the introduction of legislation (conferring rights to information identifying donors) to lodge and apply for information about their donors. Such a register would only be used to help mitigate the adverse impact of previous

⁹ Law Reform Committee, Parliament of Victoria, *Interim Report on the Inquiry into access by donor-conceived people to information about donors* (2010) 25.

¹⁰ PILCH, *Inquiry into Past and Present Practices of Donor Conception in Australia*, 6 August 2010 8.

¹¹ Fertility Society of Australia, *Inquiry into Past and Present Practices of Donor Conception in Australia*, 1.,

¹² Office of the Information Commissioner Queensland, *Inquiry into Past and Present Practices of Donor Conception in Australia*, 3.

policies allowing donors to donate anonymously. However, information could only be obtained if the donor has also lodged information, or if the donor agreed to the release of information. Therefore steps would need to be taken to inform donors about the ability to lodge information with the voluntary register and to encourage them to do so. In order to achieve this end the Commonwealth Government should create an education program to facilitate donors coming forward. Such a campaign should point out the importance of donor conceived individuals access to records pertaining, not just to their identity and origin, but also to genetic physical and psychological medical history.

The *NHMRC Ethical guidelines on assisted reproductive technology* state that; '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.'¹³

A legislated provision could additionally impose a responsibility on those holding medical records (such as clinics) to take reasonable steps to act as intermediaries between donor conceived individuals and their donors. If possible, donors could be contacted and asked to consent to the release of information upon the request of a donor-conceived person.

Recommendation 3

Legislation should be enacted to help donor conceived individuals with no right to identifying information to gain information through a national voluntary retrospective register.

4. Counselling Services

Liberty Victoria concurs with PILCH's view that before a Registrar releases identifying information to donor conceived individuals, two conditions must be met: 'that information released must be consistent with the consent details that apply to the particular record; and that the donor conceived applicant must undergo counselling by an approved service, regarding the potential consequences of disclosure'.¹⁴ The Fertility Society of Australia points to complex social, emotional, and medical aspects of donor conception. It is important that donor conceived individual be prepared for what could be emotionally confronting information.

Recommendation 4

That National Voluntary Retrospective and National Compulsory Prospective Registries be accompanied by the provisions of appropriate counselling and support services.

5. Payment for donors

Liberty Victoria believes that a commercial market in donor conception should not be encouraged. This is inconsistent with a human rights approach to donor conception and the altruistic motivation in giving assistance to couples who cannot conceive. However, we believe that people should be reimbursed for any necessary medical, accommodation or travel costs associated with donor conception.

¹³*National Health and Medical Research Council's Ethical guidelines on assisted reproductive technology* (2007) s 6.1.3.

¹⁴ PILCH, above n 10, 4.

6. Conclusion.

Liberty Victoria believes that a national and non-discriminatory approach better serves the interests of both donors and donor conceived individuals than the present system ad hoc state approach. In addition we further submit that new national legislation or regulations must comply with Australia's international human rights obligations as well as consider relevant state legislation, such as the Victorian *Charter of Human Rights and Responsibilities 2006*.

Research: Jo Hambling, Liberty Victoria Intern.

Committee Member: Anne O'Rourke

Should you wish to discuss any aspect of the matters raised please contact me on

Yours faithfully

Michael Pearce SC

President.