

Inquiry into Past and Present Practices of Donor Conception in Australia

**PILCH Submission to the Senate Standing Committee
on Legal and Constitutional Affairs**

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1. Executive Summary

PILCH welcomes the opportunity to make a submission to the Senate Standing Committee on Legal and Constitutional Affairs in relation to its inquiry into the past and present practices of donor conception in Australia.

PILCH notes that the Committee has been asked to examine (among other things):

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

This submission is concerned primarily with donor conception regulation and legislation, and with the rights of donor conceived individuals. It focuses on the legal and practical issues surrounding the inability of many donor conceived individuals to access information about their donor, including his identity, medical and psychological history and cultural background.

In summary, PILCH submits that existing legislation should be amended and/or guidelines should be implemented to improve access to, and the quality of, donor identity information. The amendment of legislation and/or drafting of guidelines should occur with consideration of the rights of all persons, including donor conceived individuals born as a result of donor treatment procedures. It is suggested that such reform could additionally recognise a special responsibility on the part of medical clinics, medical practitioners and other individuals or entities (those responsible for holding medical records) to take reasonable steps to act as intermediaries between donor conceived individuals and their donors.

PILCH's submission speaks to the Victorian legislative regime. The discussion in part 5 is informed by the human rights and fundamental freedoms protected in the *Charter of Human Rights and Responsibilities Act 2006* (Vic) (**Charter**), as it relates to donor legislation in Victoria. Although the Charter is not binding on the Federal Government, the Government is bound by international human rights, many of which are similar to those protected in the Charter.

1.1 Recommendations

In summary, PILCH makes the following recommendations:

Recommendation 1

State and territory legislation regulating access to donor information, including the *Assisted Reproductive Treatment Act 2008* (Vic) (ART Act), should be amended to improve access, by donor conceived individuals, to information identifying their donors. In particular, the ART Act should be amended to:

- (a) expressly confer power on the Registrar of Births, Deaths and Marriages (Registrar) to facilitate requests by donor conceived individuals to access**

information regarding their donors, including communicating such requests by writing to the donor;

- (b) expressly confer power on medical practitioners who are in possession of, or who are privy to, information identifying donors, to facilitate requests by donor conceived individuals to access that information, including communicating such requests by writing to the donor;
- (c) require the Registrar to bring the Voluntary Register to the attention of donors upon request by donor conceived individuals; and
- (d) specify, in the definition of the Voluntary Register, that donors may provide information regarding medical records pertaining to both physical and psychological health, medical history and cultural and racial background of the donor and his relatives.

Recommendation 2

In the absence of any legislative amendment per (a) and (b) above, guidelines should be drafted under which the Registrar or medical practitioners who are in possession of, or who are privy to, identifying information about donors, are encouraged to act as intermediaries between donors and donor conceived individuals.

Recommendation 3

Resources should be directed to awareness campaigns regarding the existence and purpose of the Voluntary Register.

Recommendation 4

Any new legislation regulating access to donor information must comply with Australia's human rights obligations.

2. About PILCH

PILCH is a leading Victorian, not-for-profit organisation. It is committed to furthering the public interest, improving access to justice and protecting human rights by facilitating the provision of pro bono legal services and undertaking law reform, policy work and legal education. In carrying out its mission, PILCH seeks to:

- ▶ address disadvantage and marginalisation in the community;
- ▶ effect structural change to address injustice; and
- ▶ foster a strong pro bono culture in Victoria; and, increase the pro bono capacity of the legal profession.

In 2009-2010, PILCH facilitated pro bono assistance for over 2,500 individuals and organisations and provided hundreds of others with legal information and referrals. In the last year, PILCH also made numerous law reform submissions on questions of public interest. PILCH has a particular interest in the promotion and protection of human rights. PILCH's referral and law reform work in this area has assisted in securing human rights and access to justice for many marginalised and disadvantaged members of the Australian community.

3. Victorian Legislative Scheme

3.1 Overview of Victorian Legislation

Since 1988, a number of acts have regulated the recording of, and access to, donor treatment information in Victoria.¹ As at the time writing, donor treatment information is governed by the ART Act. In accordance with that Act, information about donor treatment procedures is recorded in a compulsory Central Register and also in a Voluntary Register; the Registrar of Births, Deaths and Marriages maintains both Registers.

The Central Register commenced in 1988 and records information about donor treatment procedures that occurred after July 1988. The Voluntary Register was established in 2010 and contains information that donors and donor conceived individuals have voluntarily contributed. That information may relate to donor treatment procedures that were performed at any time, including prior to 1988.

When providing information to the Voluntary Register, donors and donor conceived individuals indicate the circumstances in which they consent to this information being released. The ART Act provides that the Registrar may from time to time publicise the establishment and purpose of the Voluntary Register.²

Donors, donor conceived individuals and the legal parents of donor conceived individuals may apply to the Registrar for release of information from these Registers. Before the Registrar is able to release identifying information from the Registers, two conditions must be met, namely:

- ▶ the information released must be consistent with the consent details that may apply to the particular record; and
- ▶ the donor conceived individual applicant must undergo counselling by an approved service, regarding the potential consequences of disclosure.

3.2 Effect of Victorian Legislation

Prior to 1988, a lack of regulation of information about donor treatment procedures meant that donor conceived individuals were not statutorily empowered to access identifying information about their donors. Indeed, in some cases, such information may not have been recorded or kept. Because of this, the contribution of information by donors to the Voluntary Register will, in certain circumstances, be crucial to the ability of donor conceived individuals to obtain any information about their donors.

Despite this, because of the evolution and complex nature of the Victorian legislative regime on donor treatment information, many donors may be unaware of the existence and purpose of the Voluntary Register and therefore be unable to contribute to it. This means that many donor conceived individuals will continue to be deprived of donor identifying information.

In addition, in the absence of express legislative definition, there is a lack of donor awareness of what types of information can be included on the Voluntary Register. Donors may not know that the Voluntary Register may maintain relevant medical records pertaining to the physical and psychological health and medical

¹ See, eg, *Infertility (Medical Procedures) Act 1984* (Vic); *Infertility Treatment Act 1995* (Vic); *Assisted Reproductive Treatment Act 2008* (Vic).

² *Assisted Reproductive Treatment Act 2008* (Vic) s 71(2).

history of the donor as well as information about the cultural and racial identity of the donor and his relatives. PILCH's experience assisting donor conceived individuals (referred to below in part 4 – 'Case Studies') informs its view that the kinds of information that may be included on the Voluntary Register need to be clarified. If the kinds of information that could be entered were clearly set out in legislation and/or regulations, this would assist donors in deciding whether to enter information on the Voluntary Register and, if so, what type of information to enter.

4. Case Studies

Through its pro bono referral work, PILCH has witnessed first hand the difficulties that donor conceived individuals face when attempting to access records containing information about their donors. In 2009-2010, PILCH assisted two individuals who attempted to access such information. PILCH referred these two clients to Corrs Chambers Westgarth (**Corrs**) for legal assistance.³

Client 1

In 2009, PILCH referred Client 1, a donor conceived individual, to Corrs for assistance in gaining access to records containing information about her biological father. The records were held at the Public Records Office, Victoria, and controlled by the Infertility Treatment Authority (ITA).

The ITA denied Client 1's requests to access these records. Corrs advised Client 1 of a number of legal causes of action that she might pursue to gain access to these records. Before any legal action was commenced, however, Client 1 was fortunate to gain access to her records through a personal connection.

Concerned about the ongoing difficulties faced by other donor conceived individuals, Client 1 sought ongoing legal assistance to establish a legal precedent granting other donor conceived individuals access to information regarding their donors.

On 22 September 2009, Client 1, with the assistance of Corrs, wrote to the Attorney-General, the Hon Rob Hulls MP. The letter noted that new legislation regulating donor treatment procedures was imminent but that the new legislation would not provide a substantive right of access to donor identifying information to those born as a result of donor treatment procedures prior to 31 December 1997. The letter requested that the Attorney-General consider a 'public awareness campaign directed at donor awareness of the Voluntary Register and their rights in relation to it'. It further suggested that the Government could prompt the then regulators of donor identifying information (the ITA) to facilitate requests for information by contacting donors directly, to inform them that their biological child sought donor identifying information, and of the existence of a Voluntary Register where donor identifying information could be disseminated.

On 5 January 2010, the Attorney-General responded, noting that 'any further consideration of increased access to donor information will be carried out in light of developments at the national level'.

Client 1 was successful in obtaining access to her records through non-legal means. However, other donor conceived children without a personal connection to their mother's doctor are still denied access to the relevant information.

³ These case studies have been de-identified and are used with permission.

Client 2

In 2010, PILCH referred Client 2, a donor conceived individual, to Corrs for assistance in gaining access to records containing information about her biological father. Client 2 was conceived following a donor treatment procedure undertaken by her mother at [REDACTED] in 1983.

[REDACTED] has records containing information identifying Client 2's biological father. Client 2 wrote to [REDACTED], seeking access to those records. [REDACTED] responded that it was not empowered under the relevant Act to release them to Client 2.

[REDACTED] also informed Client 2 that the name of her donor had been omitted from the records. Subsequent communication revealed that the donor's name was in fact in the records.

Client 2, with the assistance of Corrs, wrote to the Registrar of Births, Deaths and Marriages to request that the Registrar write to her donor to inform him of the existence of the Voluntary Register and the fact that he could contribute information to it. This request was refused on the basis that the ART Act does not expressly or impliedly require the Registrar to contact donors directly. PILCH and Corrs continue to assist Client 2 in her attempts to access donor identifying information.

Despite the introduction of the Voluntary Register, an absence of widespread knowledge of its existence means that only very limited information is available about donor treatment procedures. Because of this, donor conceived individuals continue to face difficulties accessing information about their donors. This may include genetic information that has health ramifications for donor conceived individuals or that prevents donor conceived individuals from entering into consanguine relationships.

5.A Human Rights-Based Approach to Donor Conception

The issue of access by donor conceived individuals to donor information raises a number of significant and complex human rights issues. For example, on the one hand, the denial of access to donor identifying information may be inconsistent with particular provisions of the Charter including the freedom of expression (including freedom to seek and receive information of all kinds),⁴ the right to recognition and equality before the law,⁵ the protection of families and children,⁶ and cultural rights.⁷ 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.⁸

A balance must be struck between the rights of donors and donor conceived individuals. PILCH submits 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. Under this approach, a human right may be subject only to such reasonable limits as can be demonstrably justified in a free and democratic society based on human dignity, equality and freedom.⁹

PILCH submits that, at present, the balance is struck too far in favour of the rights of donors, resulting in inadequate protection of the rights of donor conceived. For example, at present the Registrar, treating clinics and doctors do not have an obligation to assist donor conceived individuals by facilitating their requests for identifying information about their donors.

Accordingly, PILCH submits that new legislation and/or guidelines should be implemented which place greater importance on the rights of donor conceived individuals. In the Victorian context, the Charter prescribes that all legislation enacted must be compatible with the human rights set down in the Charter.¹⁰

PILCH urges the Government to undertake legislative reform in this area to ensure donor conceived individuals can access donor information. PILCH's recommendations are outlined below.

Recommendation 1

State and territory legislation regulating access to donor information, including the ART Act, should be amended to improve access, by donor conceived individuals, to information identifying their donors. In particular, the ART Act should be amended to:

⁴ *Charter of Human Rights and Responsibilities Act 2006 (Vic)* s 15.

⁵ *Ibid* s 8.

⁶ *Ibid* s 17.

⁷ *Ibid* s 19.

⁸ *Ibid* s 13.

⁹ *Ibid* s 7(2).

¹⁰ *Ibid* ss 28, 30.

- (a) expressly confer power on the Registrar to facilitate requests by donor conceived individuals to access information regarding their donors, including communicating such requests by writing to the donor;
- (b) expressly confer power on medical practitioners who are in possession of, or who are privy to, information identifying donors, to facilitate requests by donor conceived individuals to access that information, including communicating such requests by writing to the donor;
- (c) require the Registrar to bring the Voluntary Register to the attention of donors upon request by donor conceived individuals; and
- (d) specify, in the definition of the Voluntary Register, that donors may provide information regarding medical records pertaining to both physical and psychological health, medical history and cultural and racial background of the donor and his relatives.

Recommendation 2

In the absence of any legislative amendment per (a) and (b) above, guidelines should be drafted under which the Registrar or medical practitioners who are in possession of, or who are privy to, identifying information about donors, are encouraged to act as intermediaries between donors and donor conceived individuals.

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