Submission to the Victorian Parliament Law Reform Committee

Inquiry into access by donor-conceived people to information about donors

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The Privacy Commissioner wishes to acknowledge the work of Scott May (Policy and Compliance Officer) in the preparation of this Submission.

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1. Introduction

1. The Privacy Commissioner is on leave and has delegated all of her powers and functions to me under section 61(1) of the Information Privacy Act 2000 (Vic).

2. Donor conception has a long and proud history in Victoria. Thousands of Victorians have been donor-conceived since the technology's introduction. The practices in the late 1970s and early 1980s continue to impact on donor-conceived individuals today. The prevailing view of that earlier time was one of confidentiality, secrecy and anonymity occurring in what was an unregulated sphere and perhaps without a full appreciation of the impact such arrangements would have on the lives that were being created.

3. With the wisdom of experience, this jurisdiction passed the Assisted Reproductive Treatment Act 2008 (Vic) (‘ART Act’) which now strictly regulates the practice of assisted reproductive technology and deals in a considered, upfront manner with how information will be both provided and accessed in the donor-conceived sphere.

4. However, there still remains the unresolved question of those individuals conceived in an earlier time where such regulation did not exist. Those donor-conceived individuals conceived using gametes donated prior to 1988 do not have any legal right to access (even non-identifying) information about their donors. On both sides of the ledger are two equally valid rights – the right of donor-conceived individuals to obtain and know information about his or her parents and lineage, and the right of privacy of donors who were assured and promised confidentiality and secrecy at the time of donation.

5. Of course, there is no easy answer where fundamental human rights conflict. A balance is required, and this submission supports options that hopefully achieve such a balancing act to the satisfaction of both donors and donor-conceived individuals.

2. Issues relating to access to identify information about donors (and siblings), regardless of date of donation

a. The privacy rights of donors and the rights of donor conceived persons

6. It is important to note the prevailing circumstances of donors in the pre-1988 world. Generally, donors entered into donation arrangements with the medical provider directly and were assured confidentiality, and similarly agreed not to seek the identity of children conceived. Donors were commonly young, receiving inadequate counselling and unaware of the magnitude of their donation, and often compensated with medical treatment, STD testing, money or course credits.2

7. It is equally vital to note the strong interest in donor-conceived individuals being able to obtain information about their donors. Obtaining one's own personal information is in fact a privacy right in itself.3 Information relating to the donor's medical and genetic history, and a person's right to know their genealogy, are extremely important concepts for donor-conceived individuals, and one that individuals with known parents may take for granted. The information sought by donor-conceived persons may appear routine – a photograph or simply an answer to the question of 'what is

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1 See, for example, Victorian Parliament Law Reform Committee, Inquiry into access by donor-conceived people to information about donors, Interim Report (Sep 2010) p 8 (Donor statement and consent form from 1997).

2 Ibid, p 29.

3 See Information Privacy Act 2000 (Vic), Sch 1, Information Privacy Principle (IPP 6)
he/she like?" It is possible that denial of such information could affect the physical or mental health of a donor conceived person, although it is noted that due to advances in genetic testing for heritable disease this appears less the case than previously.5

b. Open access to all records by approved persons

8. One possible option for change is to release donor-identifying information solely on request from approved individuals, similar to the regime of access to birth details by adopted people. In my view, such an option (whilst potentially easiest to administer) contains significant drawbacks.

9. Firstly, such a decision would basically abrogate the right to privacy that donors were legally assured of. Unilateral and retrospective alteration of the privacy rights of donors by Parliament would be a significant step. Donors were assured confidentiality and entered into the legal arrangement with the hospital and/or doctor on that basis, in what in effect was a contractual arrangement between the donor and the fertility clinic in question. There is the potential loss of confidence in medical treatment facilities being able to assure their patients confidentiality if such an arrangement can be overridden by statute at a later date.

10. Secondly, it is important to note the ‘variation’ of the nature of the records as they stand.6 It is extremely common that older records are, by their nature, less accurate than recent records with a modern focus on data quality and recordkeeping standards. As collection was ‘entirely within the discretion of medical clinics and doctors’ with ‘significant variation in the way records were maintained’,7 the information contained within such records is likely to be incomplete and inaccurate. Access to such information may in fact raise more questions than it answers and if inaccurate could potentially mislead donor-conceived individuals.

c. The balancing act – releasing information on consent

11. In my view, the best option for balancing the rights of both donors and donor-conceived individuals is essentially similar to that recommended by the Victorian Law Reform Commission (VLRC) being:

‘Donors (are) to be contacted and asked to consent to the release of information only upon request for information by a donor-conceived person.’8

12. This approach is to be preferred to that of recontacting all donors and asking all donors to re-consent to identification. As pointed out by the Victorian Assisted Reproductive Treatment Authority (VARA), that option would be time consuming as it would require donors to be contacted regardless of whether an application is received.9 It is entirely possible that whilst some donor-conceived individuals may have a strong need for information about their donor, other donor-conceived

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4 Eric Blyth, ‘Information on genetic origins in donor-assisted conception: is knowing who you are a human rights issue?’, Human Fertility, 2002, p 188
6 Above n 1, p 33
7 Ibid.
8 Victorian Law Reform Commission, Assisted Reproductive Technology and Adoption – Final Report, June 2007, p 158 (Recommendation 97)
9 Above n 1, p 30.
individuals may not. It would be somewhat impractical to seek the consent of donors to release information about them in the absence of a specific request in the future.

13. Secondly, such a procedure would replicate the provisions for access to information by donor-conceived people conceived using gametes donated between 1 July 1988 and 31 December 1997.¹⁰

14. Additionally, a consent-based procedure may in fact increase the data quality and accuracy of information to be made subsequently available to donor-conceived individuals. Donors could, during any consensual-based release policy, be afforded the opportunity to check to ensure that the information to be provided to the donor-conceived individual is accurate and correct, and potentially add further information if they wish. Such an opportunity could actually result in better information provision for donor conceived persons.

i) A note of caution

15. Firstly, it should be noted that any proposed contact itself will be a form of privacy imposition, albeit a lesser one than disclosure of one’s personal information, but an imposition nonetheless. Donors who were assured confidentiality at the time of donation would not ordinarily expect contact from any authority purporting to gain their consent to disclose their personal information to a donor-conceived individual. Donors, for example, may not have informed their families of their past donation(s). Great care needs to be taken in initiating contact with any donors who were assured confidentiality.

16. Data quality issues may also be considerable when making initial contact with donors. For example, contact details will need to be carefully verified and contact made in a confidential, appropriate fashion. The possibility of an individual being wrongly identified as a donor and being sent requests for consent to release their information could be quite stressful for the recipient involved.¹¹

17. Secondly, gaining proper, informed consent from donors for any release of the donor’s personal information is vital. It is fundamentally important that donors are in a position to provide truly voluntary and informed consent as to how their personal information will be disclosed to donor-conceived individuals. This will include, at a minimum, explaining:

- that the decision to consent to disclosure is a voluntary one;
- what precise types of personal information of the donor is proposed to be disclosed;
- who will receive the information (presumably the donor-conceived individual);
- whether the donor wishes to receive contact from the donor-conceived person and if so, how that is to occur, and
- explanation of the impacts (positive and negative) a decision to consent to disclosure may have on the donor.¹²

18. It may be necessary that donors receive some level of counseling before providing consent. This is particularly the case with pre-1988 donations, given the possibility that contact from any authority may be quite an unexpected event for the donor, and

¹⁰ Assisted Reproductive Treatment Act 2008 (Vic) s 59(b)(ii).
¹¹ For example, see above n 1, p 33
¹² See Privacy Victoria, *Guidelines to the Information Privacy Principles Ed 2, 2006 p 14-17*
the donor may not have had the opportunity to fully consider the ramifications of a request.

d. **Taking steps to preserve donor related information**

19. I note that Recommendation 1 of the Interim Report was that 'pending further inquiry and report, the Victorian Government considers as a matter of urgency whether measures should be taken to ensure that existing and unprotected donor records are preserved'.

20. I believe this point, to my knowledge, has not yet been addressed. Although usually privacy principles oblige destruction of information where it is no longer needed for any purpose, the situation with donor-conceived individuals is somewhat different to the routine case. There is a clear public interest and purpose in ensuring that the information in question is retained and not destroyed. Rather, the main question surrounds the level of access to be provided to donor-conceived individuals. One possible option would be to compel transfer of existing (old) records from various hospitals and practices to a central authority (such as the Registry of Births, Deaths and Marriages which is now managing the Central and Voluntary Registers).

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13 Above n 1, p 35.
14 Information Privacy Act 2000 (Vic), Sch 1, Information Privacy Principle 4.1