# Health and guardianship law: Changes to anonymity for donors and donor-conceived children under Victorian law (Editorial)

# Health and guardianship law

## Editor: Dr Malcolm Smith

## CHANGES TO ANONYMITY FOR DONORS AND DONOR-CONCEIVED CHILDREN UNDER VICTORIAN LAW

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### Donor Conception in Victoria and recent changes

When assisted reproductive technology (ART) practices were first developed, it was commonplace for gamete donors to remain anonymous when their genetic material was used by others in an ART procedure. However, it is now well established that donor-conceived children should have access to information concerning their biological parent(s). Recent legislative reform in Victoria advances this further, by implementing significant changes concerning the anonymity of donors and donor-conceived children. The *Assisted Reproductive Treatment Amendment Act 2016* (Vic) updates the statutory framework relevant to ART in Victoria (the *Assisted Reproductive Treatment Act 2008* (Vic)),[1] by abolishing donor anonymity in Victoria, irrespective of when donation occurred. This is a bold move given that prior to 1998, gamete donors in Victoria donated on the basis that they would remain anonymous.

Victoria has been at the forefront of developments in law and policy concerning ART, both nationally and internationally, particularly in relation to prioritising the welfare and interests of children conceived using donated gametes. Such developments have included, for example: establishing a central register to lodge information concerning donors and donor-conceived people; removing anonymity in donation (from 1998 onwards); creating reciprocity in information concerning donated gametes, in terms of enabling *donors* to also obtain information concerning their donor conceived offspring via the central register; and providing community education and awareness in relation to matters concerning donor conception.[2] The most recent legislative changes in Victoria follow a long path of reform on this issue. And notably, parliamentary debate surrounding the passage of the Bill and the changes to anonymity emphasised the importance of the guiding principles outlined within the *Assisted Reproductive Technology Act 2008* (Vic), particularly the requirement to prioritise the welfare of any prospective children conceived by way of ART services.[3] This recent change in law therefore places the rights of donor conceived people to obtain information about their biological parent(s), over the anonymity of donors.

The amending legislation will be fully operative from 1 March 2017, and although this change in law means that the anonymity of all Victorian gamete donors will be abolished, there are provisions within the legislation that seek to preserve the privacy of donors who do not wish for certain information to be disclosed. For example, the legislation allows relevant parties (including donors and donor-conceived children) to limit the information that will be divulged. This is referred to as a "contact preference statement" which might, for example, indicate that the donor does not want

[1] For an overview of the statutory framework relevant to ART in Victoria, see MK Smith, "Regulating Assisted Reproductive Technologies in Victoria: The Impact of Chancing Policy Concerning the Accessibility of In Vitro Fertilisation for Pre-Implantation Tissue Typing" (2012) 19 JLM 820.

[2] See L Johnson and H Kane, "Regulation of Donor Conception and the 'Time to Tell' Campaign" (2007) 15 JLM 117; L Johnson, K Bourne and K Hammarberg, "Donor Conception Legislation in Victoria, Australia: The 'Time to Tell' Campaign, Donor-Linking and Implications for Clinical Practice" (2012) 19 JLM 803.

[3] See Sonia Allan and Damian Adams, "All Donor-conceived People in Victoria Now Have the Right to Donor Information", BioNews (29 February 2016) <http://www.bionews.org.uk/page_621487.asp>.

contact with, or wishes to limit contact with, their genetic child.[4] Similar provisions also exist that relate to the contact preferences of donor conceived children.[5] A penalty can apply if a contact preference is not followed.

### *Implications for donor conception in Australia and beyond*

Some have argued that the recent changes to the law in Victoria are disrespectful to gamete donors and immoral,[6] particularly because of the fact that prior to 1998 gamete donors in Victoria did not expect that their information would be disclosed. One argument put forward to support such an assertion is that those who donated at a time when anonymity was assured were "cheated" into donating and, most likely, would not have donated their gametes had they been aware that anonymity would not remain.[7] There are clearly difficult ethical issues that arise in relation to donor conception. However, for quite some time now it has been recognised that donors should not remain anonymous, so that donor-conceived children have rights to obtain information about their genetic and medical history, as well as identifying information about their donor(s). Current national ethical guidelines relevant to ART seek to prioritise such a right, stating:

> 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.[8]

Moving forward, it is clear that gamete donors in Australia must expect that their personal information might be disclosed to those conceived using their genetic material. However, this will not help a number of Australians in obtaining information about their genetic origins in circumstances where they were conceived outside of Victoria during a time when anonymous donation practices were adopted as the norm. It is not clear whether other Australian jurisdictions might enact retrospective laws that permit access to information concerning donor conception, in the same way that Victoria has. Some have argued in favour of such a move.[9] Despite this, it is likely that there are a number of practical hurdles to such an approach in some other Australian States and Territories, which might limit the success of such a move. For example, despite calls for the introduction of a *national* ART donor register,[10] in those jurisdictions where no central register exists or where there is no specific ART legislation, key information concerning donors and donor offspring might not be held directly by the State. Where this is so, key information is likely to be held by different organisations such as fertility clinics or other service providers. Where information is not held by the State, it is likely to prove more difficult for donors and donor-conceived children to track down the source of such historical information. In turn, this dilutes the likely success of such a law in establishing its key aim – that being to prioritise the welfare and interests of donor-conceived children in securing access to information about their genetic origins. Nevertheless, given the ethical and moral significance of

[4] See *Assisted Reproductive Treatment Act 2008* (Vic), s 63C (as amended).

[5] *Assisted Reproductive Treatment Act 2008* (Vic), s 63I (as amended).

[6] See Guido Pennings, "Disrespectful and Immoral: Retrospective Legislation on Donor Anonymity", *BioNews* (14 March 2016) <http://www.bionews.org.uk/page_627606.asp>.

[7] Pennings, n 6.

[8] National Health and Medical Research Council, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (NHMRC, 2007) [6.1].

[9] See D Adams and C Lorbach, "Accessing Donor Conception Information in Australia: A Call for Retrospective Access" (2012) 17 JLM 608.

[10] See, eg, B Bennett, "Time for a National Approach to Donor Conception in Australia" (2011) 19 JLM 7.

donor-conception practices, it can be argued that the legislative changes in Victoria provide an impetus for other States, such as Queensland, to reconsider how donor-conception practices are regulated moving forward.

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