

## Donor identification

Victorian legislation gives rights to *all* donor-conceived people

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On Tuesday, 23 February 2016, the state parliament of Victoria passed legislation that will enable *all* donor-conceived people the opportunity to receive identifying information about their sperm, oocyte or embryo donor(s).¹ Referred to as "Narelle's Law", the passing of the legislation honours the memory of a donor-conceived woman who died in 2013 from hereditable bowel cancer. Narelle Grech had searched for her donor for 15 years, and had engaged in extensive lobbying, alongside many others, to create legal change for donor-conceived people to know their biological heritage (Tomazin, 2013).

The model adopted in Victoria is a world first in its application to donor conception. It mirrors the approach taken in Australian states in the 1980s in which legislation was enacted to enable adoptees access to information about their genetic heritage, regardless of when they were born, subject to the ability of persons to place a contact veto (Allan, 2011a; 2011b). Similarly, donor-conceived people will be given access to identifying information, regardless of

when a donor donated or when the donor-conceived person was born, subject to people about whom information will be released being able to place a "contact preference statement".<sup>2</sup>

This article examines these world-first laws. The second section of this article outlines the reasons why information release has been deemed warranted. The third section considers the passage of the Victorian law. The article then details how the Victorian law will operate and the requirements for information release. The concluding discussion highlights laws around the world that have increasingly moved to support information release. It is shown how the Victorian laws are very progressive and may provide a model approach for future release of information around the world.

# Why are the changes to the law important?

The history of donor insemination is one that has been shrouded in secrecy (Allan, 2012a). Such secrecy and the resulting anonymity of

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donors has historically been underpinned by the stigma of infertility, the presence of a doctor using an instrument to inseminate the woman, and the implications of donor conception for marriage—including questions of whether the act was adulterous. Donor conception was regarded as against natural law by religious leaders and subsequently condemned. Legal issues regarding inheritance and legal parentage were also raised. More recently, calls to maintain anonymity also seem to reflect the market view that if anonymity is removed, supply may be reduced. Such reasons, however, focus primarily (if not often solely) on the adults involved in the process, or the profit that the fertility industry could make.

In contrast, the decision to release identifying information to all donor-conceived people has centered on the number of increasingly well-known reasons that focus on the people born of such arrangements, including factors relevant to their identity, medical history, risk and/or fear of forming consanguineous relationships, as well as other reasons beyond these. In Australia, as in other jurisdictions around the world, calls for donor identification reform have grown as donor-conceived people have reached adulthood, and have expressed the impact that anonymity has had on them in relation to such matters.

#### **Identity**

Self-identity involves the "Who am I?" questions that many people ask at various stages of their life. In childhood they may include questions about "Where do I come from?". In adolescence they may be asked as one develops a sense of individual self. In adulthood, as relationships are formed, marriage occurs and children and grandchildren are born, the questions become relevant in a generational sense, giving a broader picture of who a person is and their identity within and across generations.

Questions regarding biological heritage may therefore involve a desire to know more about oneself. For donor-conceived people such questions are in this sense similar to those asked by those in the general population. However, such questions are made more complex in that donor-conceived people have parent(s) who have reared them but are also the genetic offspring of a sperm and/or egg donor(s). Answering the question becomes more difficult simply because of this fact.

Further compounding such complexity is that there may be a stronger sense of "lost identity" for some donor-conceived people when they are denied access to information due to

systems of anonymity (Turner & Coyle, 2000). There is also evidence to suggest that some donor-conceived people who have been told of their conception later in life may undergo a "fracturing" in their identity due to knowledge of their status, and feel significantly deceived about who they are (Dennison, 2008; Ravitsky, 2010).

Perhaps most clear is that, while the small amount of existing research points to varied feelings regarding donor conception and outcomes for families (Golombok et al. 2011; McNair, 2004; Wise & Kovacs, 2014), reasons for searching for information almost always include the desire to know and understand more about the donor, and about oneself.

#### **Medical history**

Knowing about familial medical history is also important. In fact, knowing familial history of heart disease, diabetes, cancer, mental health issues and/or other heritable diseases is undeniable and strongly encouraged in the present day (Centers for Disease Control and Prevention, 2004).

Donor-conceived people who are denied access to familial medical histories may be placed at increased risk as a result of not having access to information. This becomes very significant as people age. There are many conditions which develop later in life, and a donor who donated in the 1970s or 1980s, when donor conception was shrouded in secrecy, may not have been aware that they are a carrier of these diseases.

Similarly, a donor-conceived person may become aware of a heritable condition, but in an anonymous regime has no way to notify their donor(s) or half-siblings conceived using the same donor gametes. This may have ramifications not just for the person unaware of such information but for generations to come. This was clearly the case for Narelle Grech, mentioned above. Early screening for her, if she had known she was at risk, may have led to early treatment and prevented her death. In addition, it is known that she has at least eight genetic half-siblings, who perhaps if warned, could undergo screening and early treatment if needed.

#### Consanguineous relationships

Another significant driver in the search for information for some donor-conceived people is the fear of unknowingly forming relationships with siblings or possibly their unknown donor (Senate Legal and Constitutional Affairs References Committee, 2011). While the probability of such an occurrence is unknown,

such a risk may be significant within smaller populations, or where there are no controls on the number of families for which the same donor's gametes may be used (NSW Law Reform Commission, 1984). Although one way to avoid half-siblings forming relationships is to restrict a donor to one donation or to one recipient family, it is clear that this is not, and has not been, the approach to donor conception in most jurisdictions.<sup>3</sup>

The reality is that a significant number of donors are likely to have donated multiple times. Some may also have donated at multiple clinics and in a number of jurisdictions. In many circumstances, donor sperm was used by specific clinics to assist families in a particular area at a particular time. There is good evidence in areas of Australia that multiple half-siblings were born within a small time frame to a variety of families all living in the same vicinity, and a number of stories are emerging in which donor-conceived people have found they went to school with their half-siblings.4

Entering consanguineous relationships may have negative legal ramifications.5 There is also the chance that such relationships would bear children, leading to the risk of genetic or chromosomal abnormalities (Bennett et al., 2002). The fear of this occurring can cause great distress for some donor-conceived people.6 The threat of consanguinity may thus also affect the emotional and social wellbeing of some donor-conceived people (Senate Legal and Constitutional Affairs References Committee, 2011). The chances of such situations occurring and/or the fear of forming consanguineous relationships would be greatly reduced if donor-conceived people and donors were able to obtain information about each other.

#### Openness, honesty, and equality

There are other reasons beyond those above that drive some donor-conceived people to search for information. Some report simply wanting to know a name for their donor; others wish to say thank you; while others want to know whether they have any half-siblings. Cutting across all of these reasons is a desire for openness, honesty and an end to secrecy and lies that have formed the foundation of the donor-conceived person's life. Simply put, donor-conceived people call for an end to secrecy and anonymity, and an opportunity to choose for themselves whether to pursue access to information about their donor and/or further contact.

Similarly, there have been many recipient parents and donors who have also called for release of information and an end to secrecy



(Allan, 2011a). They too wish to be open and honest with the people who are most affected by donor conception practices and to end the secrecy, which they feel they have been forced to maintain. Donors also report wondering about the offspring they have helped to create, and have themselves actively engaged in searching (Allan, 2011a; Adams and Lorbach, 2012).

### Passage of the law in Victoria

#### **History of the Victorian Laws**

Victoria is renowned for its early recognition of the interest donor-conceived people may have regarding information about their donors. A number of inquiries held in the early 1980s, chaired by Professor Louis Waller, led to the establishment of the first Central Register for information in the world (Waller, 1982; Waller, 1983a; Waller, 1983b; Waller, 1984). However, changes to laws over time have meant that different people have had different rights to access information in the same state. People conceived with sperm donated before 1988 were not granted access to information; those conceived with sperm donated between 1988 and 1998 were granted access to nonidentifying information, but only to identifying information if the donor consented;7 and those conceived with sperm donated after 1 January 1998 were granted both identifying and nonidentifying information when they turned 18, as the law required the donor to consent to such release prior to donation.8 While a voluntary register was also established to allow people to register their desire to share information if they fell outside of the laws that allowed for access, such a register proved not to be the solution people wanted.

Calls for changes to the laws were ongoing and spanned many years.

#### Increasing calls for change

In February 2011, following a federal inquiry into donor conception, the Australian Senate Legal and Constitutional Affairs Committee handed down a report in which it made 17 recommendations (among others) that related to the preservation, recording and release of records concerning identifying and nonidentifying information about donors to donor-conceived people (Senate Legal and Constitutional Affairs Committee, 2011). These included a call for the establishment of a national register of donors to provide donor-conceived people access to identifying information about their donor. The Senate committee's report left a number of issues open for further debate, including whether the recommended legislation should provide for the retrospective release of information about donors to donor-conceived people. The federal government responded to the Senate committee's recommendations that while it agreed in principle with many of the recommendations, it ultimately fell to the states to regulate assisted reproduction. Each state/territory was therefore called upon to further consider and/or act on the Senate's recommendations.

At the time, a state inquiry on donor conception had been underway in Victoria. The Victorian Law Reform Committee had commenced in the 56th parliament, in 2010, and an interim report recommended it proceed into the 57th parliament, which it did in 2011-12. Many people came forward and continued the call for information release.

I undertook to research the issue of retrospectivity, putting forward to committee(s) that, under Australian law, there was no impediment to passing laws that would grant access to information for all donorconceived people (Allan, 2010; Allan, 2011a). Instead, it needed to be recognised that such laws are not to be passed lightly, and would only be acceptable after consideration of the possible injustices to one party (some donors who many not want their information released) and whether these are outweighed by the need to rectify injustice to others (donorconceived people denied information, donors who wanted an end to anonymity and parents who wished to share information with their children). It was to this end that I also explored the question of "contact vetos" as a way to balance the rights of donor-conceived people to access information with the right to privacy of any donor about whom such information would be released, ultimately concluding that this would be a fair and balanced approach.

The legal issues raised, however, were complex—there were issues regarding the rights and interests of donor-conceived people to information, the right to privacy of donors, whether there existed a contract for anonymity, how to balance human rights when such rights may conflict, the comparison between the approach taken for the release of information to adoptees and that which might be taken for donor-conceived people and, of course, whether and, if so, how information could be released (Allan, 2011a). To explore such issues further, it was necessary to call upon experts in relevant areas of law and practice, as well as donor-conceived people, recipients and donors, to draw on their experiences, and to research and write articles examining each specific issue raised in more detail (Adams & Lorbach, 2012; Allan, 2012a; Blyth, Crawshaw, Frith, & Jones, 2012; Cahn, 2012; Chisholm, 2012; Rees, 2012; Tobin, 2012; Johnson, Bourne, & Hammarberg, 2012). The outputs of such research were provided to the Victorian inquiry.

The inquiry received a total of 77 written submissions, with the majority (52 submissions) supporting the release of information to all donor-conceived people. Public hearings conducted by the Victorian Law Reform Committee also reflected preferential support for full release of information to all donorconceived people.

The committee, however, said it was most significantly influenced in its decision making by the evidence given by donor-conceived people, the recipient parents and donors. Some told stories of devastation and grief, others tales of successful relationships being forged between donors and their offspring. Mostly, there were consistent and heartfelt appeals for equality, truthfulness and openness in the law. It also became apparent that while not all donor-conceived people may want information, and/or contact with their donor, having the personal choice was of utmost importance. It was their lived experience that demonstrated the need for change.

Considerations concerning donor anonymity, and the balancing of interests of donors who had been promised anonymity and were opposed to information release also weighed heavily on the committee. While such donors did not appear to be in the majority,9 their interests in privacy needed also to be respected.

Ultimately the committee chairman, Clem Newton Brown, said:

When the Committee commenced this Inquiry, it was inclined toward the view that the wishes of some donors to remain anonymous should take precedence—

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as they made their donation on that basis—and that identifying information should only be released with a donor's consent. Upon closer consideration, however, and after receiving evidence from a diverse range of stakeholders—donor-conceived people, donors, parents, medical and counselling professionals, department representatives, and academics—the Committee unanimously reached the conclusion that the state has a responsibility to provide all donor-conceived people with an opportunity to access information, including identifying information, about their donors.

#### However,

the Committee also recognised the importance of ensuring that there will be no unreasonable interference in donors' lives should donor-conceived people have access to identifying information. Consequently, one of the Committee's recommendations is that donors, and donor-conceived people, have the ability to place a veto on contact from each other. It is also important that donors, and all of the people affected by donor-conception, have comprehensive counselling and other support services available to them.

As such, the Victorian Law Reform Committee inquiry resulted in recommendations that all records in Victoria be opened, upon request by a donor-conceived individual for information about their donor, regardless of when they were conceived, pursuant to adopting the suggested contact veto system (Victorian Law Reform Committee, 2012).

Narelle Grech lived to see the handing down of the committee's report but not the final changes to the law.

#### **Interim changes**

The changes to Victorian laws were moved forward by Labor MPs Jane Garrett and Anthony Carbines, who introduced a private member's bill to parliament in 2014. However, full enactment of the Victorian Law Reform Committee's recommendations were initially forthcoming. While the laws again changed in Victoria on 29 June 2015 to allow all people conceived with gametes donated in the state before 31 December 1997 to access non-identifying information, they would allow access to identifying information only if the donor gave his or her consent. 10 The law as it applied to those born between 1988 and 1998 was therefore extended retrospectively to apply to all people conceived with donated gametes prior to 1998. The extension of the law also applied to donors seeking information about the donor-conceived offspring.

The two-tiered system, however, retained differential treatment based upon whether a person was conceived with sperm donated preor post-1998. Great disappointment among the donor-conceived community, their parents and donors ensued. Nevertheless, they continued to speak with government, appeared in the media and shared their stories in the hope that there would be further change. A young aeronautical engineer, Lauren Burns, was profiled on a popular documentary, *Australian Story*, sharing her incredible journey of seeking her donor father (Australian Broadcasting Corporation, 2014); Sarah Dingle, a reporter and NSW donor-conceived person

whose records were tampered with to remove the donor code—thus destroying her chances of finding information—made public her plight (The Sydney Morning Herald, 2014); many other lived experiences were again shared (e.g. see Fuss, 2014; Howie, 2014).

#### The new laws

In 2015, with an election due, the Victorian Labor Party made an election promise that it would give full effect to the Law Reform Committee's recommendations if they gained power. Donor-conceived people, recipients and donors continued to share their stories. A national conference held in 2015 in Victoria, and a subsequent campaign about being donor-conceived (Are You Donor Conceived Campaign, 2015), further drew attention to the issues they faced. It remained the case that unless laws were changed, people born in Victoria had unequal access to information. The lack of equal treatment was seen as unacceptable.

Following the Labor Party's success at the ballot poll, and further public debate, a Bill to rectify such inequality was introduced into the Legislative Assembly in late November 2015,11 where it was passed with a free vote of 56 to 27. It moved to the Legislative Council in February 2016, and again was shown bipartisan support via another free vote. The Bill was read into law. Emphasis in the passage of the bill was given to honouring the guiding principles of the Victorian ART Act, that "the welfare and interests of persons born or to be born as a result of treatment procedures are paramount"



and that "children born as the result of the use of donated gametes have a right to information about their genetic parents". 12 Donor-conceived people, their parents, donors, children and their supporters watched from the galleries. Members of Narelle Grech's family were also there to see the passing of the laws.

The Victorian Minister for Health, Jill Hennessy, made the following pertinent statements:

We believe all donor-conceived people should have the right to know about their genetic heritage, no matter when their donors donated ... If this information is available, it shouldn't be kept from them. (Premier of Victoria, 2016)

The new laws will come into force on 1 March 2017.13

#### How the Victorian law will work

Understanding how the Victorian law will work is integral to understanding the way that the system balances interests and also provides for support for all.

#### **Information release**

As noted above, the changes to the Victorian law will enable persons born as a result of the use of gametes donated before 1 January 1998 to obtain identifying information about their donor(s).14 This gives those persons equal rights to all donor-conceived people in Victoria to access information. The new laws also allow for the provision of information to a person descended from a person born as a result of a donor treatment procedure irrespective of when the gametes used in that treatment procedure were donated.15 If the applicant is a child, the disclosure will be made if the applicant's parent or guardian has consented to the making of the application or a counsellor has provided counselling to the applicant that has established that the applicant is sufficiently mature to understand the consequences of the disclosure.16

In order to balance the privacy interests of people about whom information will be released, including donors, donor-conceived people and any other children of the donor, the law enables such people to lodge a contact preference statement detailing the sort of contact (if any) they would be willing to engage in.17 The applicant for information must give an undertaking to comply with the contact preference before any information is released.<sup>18</sup> There is a maximum penalty of approximately \$7,500 if this undertaking is breached. (Contact preferences are further detailed below.)

#### Registers

Central and Voluntary Registers will continue to be maintained but their management will be transferred from the Registrar of Births, Deaths and Marriages to the Victorian Assisted Reproductive Treatment Authority (VARTA)—a government authority established under the ART Act 2008 (Vic.). 19 The Act specifies what information must be kept on the Central Register, including but not limited to identifying information about the donor of gametes, the number of births resulting from the use of donated gametes and other prescribed information. The Central Register will also hold results of any genetic testing undertaken to establish relatedness.20

The Voluntary Register will continue to allow the following persons to place information on the voluntary register and express wishes for contact: persons born as a result of donor treatment procedures; the descendants of persons born as a result of donor treatment procedures; donors; women who have undergone donor treatment procedures and their partners, if any; and the relatives of all such persons. This may be particularly important when records have been destroyed. In addition, there is new provision for a person to enter any photograph, toy, jewellery or other item approved by VARTA onto the Voluntary Register.<sup>21</sup> The law will continue to provide for counselling before the disclosure of information in the Voluntary Register.<sup>22</sup>

#### Provision of information to the **Central Register**

Registered ART providers will be required to report the information specified within the ART Act, relevant to pre-1998 donor conception, to VARTA for inclusion in the register.<sup>23</sup> In addition, persons other than registered ART providers may report information they hold about pre-1988 donor treatment procedures to VARTA.<sup>24</sup> Persons who forward information under the law will not be liable for prosecution of an offence, or to a civil action, for providing the information.25

VARTA will have access to records transferred to the Public Records Office from the Prince Henry's Institute of Medical Research that relate to persons born as a result of pre-1988 donor treatment procedures.26 In addition, if VARTA believes on reasonable grounds that a person other than a registered ART provider is in possession of or has control of relevant records, VARTA may request the person to locate and give the records to VARTA.27 If within 90 days such records are not produced, VARTA may apply to the magistrates' court for



a production order to provide the records, or copies of them, to VARTA.

The law provides that it is not a reasonable excuse for a person to fail to comply with a production order on the grounds of medical professional privilege or on the grounds that complying with the order would constitute unprofessional conduct or a breach of professional ethics.28

VARTA will be able to amend or correct information, or create a new entry, in the Central Register if there are inconsistencies, or pursuant to results of genetic testing, or when other information comes to light; for example, under a production order to amend or correct information or create a new entry in the Central Register.29

#### Insufficient information about donor: DNA testing

If an application has been made by a person born of a pre-1998 donor treatment procedure and there is insufficient information to determine whether a person whose name is entered on the Central Register is the donor of gametes used in the procedure, VARTA may, for the purposes of establishing a genetic link, request that the person undergo genetic testing at a place specified by VARTA; consent to the comparison of the results of that genetic testing with a DNA profile or genetic test results relating to the applicant; and consent to the results of the comparison being given to VARTA.30

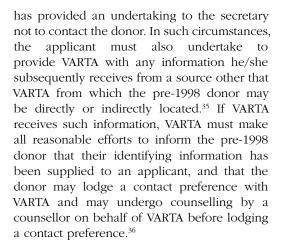
VARTA will also have authority, under a new section 56M, to request genetic test results of an adult blood relative of a suspected donor if the suspected donor person cannot be located,

is deceased, is considered missing, or VARTA considers there are exceptional circumstances justifying a request of the adult blood relative. An example of what may constitute "exceptional circumstances" is where the applicant is diagnosed with a hereditary terminal illness and wishes to identify their donor in order to notify any donor siblings of the potential to inherit the same illness. In such circumstances VARTA must make all reasonable efforts to give notice of the intended request to the person whose name is on the Central Register. That person may apply within 28 days for a review of the decision to the Victorian Civil and Administrative Tribunal.

#### Disclosure of information

Before disclosing information, VARTA must be satisfied that a person whose name is on the Central Register and a donor-conceived person are related.31 If VARTA intends to disclose information under the Act relating to a pre-1998 donor, or to a donor-conceived person, VARTA must make all reasonable efforts to inform them that an application for identifying information has been made and by whom. The person will then be informed that he or she may lodge with VARTA a contact preference<sup>32</sup> and that they may undergo counselling before lodging a contact preference.<sup>33</sup>

Where the applicant is a donor-conceived person, information about a donor will generally be released within four months. This includes if the donor cannot be located within four months of the application being made, or if the donor is deceased, 34 provided the applicant



VARTA is provided with the discretion to delay the disclosure of a pre-1998 donor's identifying information for a further period of up to four months in exceptional circumstances.<sup>37</sup> This discretion applies both where the pre-1998 donor is served with notice38 and where VARTA is not required to give notice to the pre-1998 donor.39

#### Contact preferences for pre-1998 donors

In relation to donors, the new law provides that if an application is made for the disclosure of the identifying information about a pre-1998 donor, the donor may lodge with VARTA:

- **a** written statement setting out the donor's wishes about being contacted by the applicant for the disclosure of the information;40 and/or
- a written statement setting out the donor's wishes about the donor's child being contacted by the applicant for the disclosure of the donor's information.41

A contact preference may state either that the pre-1998 donor does not wish to be contacted by the applicant, or that the donor wishes contact with the applicant to occur only in a specified way (e.g., via email, letter, phone call or intermediary).

A contact preference may also be lodged regarding a pre-1998 donor's child (i.e., a child legally recognised as the donor's child) and may similarly state that the donor does not wish for the child to be contacted by the applicant or that the donor wishes contact between the child and the applicant to occur only in a specified way. In the case of a contact preference regarding a donor's child, VARTA may have regard to the child's wishes, and whether the donor's wishes are reasonable in the circumstances.42

A contact preference must be in an approved form and must be lodged with VARTA before any contact between the donor and the applicant to whom the contact preference relates has taken place. If a donor chooses not to lodge a contact preference prior to the release of identifying information to the applicant, the donor can still lodge a contact preference at a later date provided there has been no contact between the donor and the applicant.

Once a contact preference has been lodged, the new laws require VARTA to give the applicant a copy of a contact preference as soon as practicable after its being lodged.<sup>43</sup> VARTA must also keep records of contact preferences lodged.

#### Amendment of a contact preference

A contact preference may be amended by written notice to VARTA provided there has been no contact between the donor and applicant to whom the contact preference relates.<sup>44</sup> VARTA must again, as soon as practicable, notify the applicant to whom the amended contact preference relates of the amendment and its particulars.

#### Withdrawal of a contact preference

A pre-1998 donor may withdraw by written notice a contact preference. A donor may not lodge a subsequent contact preference in relation to the applicant if there has been contact between the applicant and the donor.<sup>45</sup> VARTA must as soon as practicable after the contact preference is withdrawn, notify the applicant.

#### Expiration of contact preference

A contact preference lodged continues in force for five years from the date it is lodged or five years after it is extended (which may be done via written request). <sup>46</sup> In the case of the contact preference relating to a child, it expires on the day the child turns 18 years of age.

Before a contact preference expires VARTA is required to make all reasonable efforts to give the pre-1998 donor who lodged the contact preference written notice as to when the contact preference will expire and that it may be extended. VARTA must, as soon as practicable after a contact preference expires or is extended, notify the applicant to whom the contact preference relates.

#### Contact preferences lodged by donorconceived people

Victoria's new laws will also continue to allow for the release of information about donorconceived people to their donor. However, the



new law also provides that if an application is made for the disclosure of the identifying information of a donor-conceived person, the person or, if the person is a child, the person's parent or guardian may also lodge a contact preference statement.<sup>47</sup>

Note, if the donor-conceived person is a child, VARTA may have regard to the child's wishes in relation to the lodgement of the contact preference, and if the child's wishes are different to the wishes of the parent or guardian, comply with the wishes of the parent or guardian only if VARTA considers it reasonable in the circumstances.<sup>48</sup>

Contact preferences in relation to donor-conceived people must again be in the prescribed form and must be lodged prior to any contact occurring.<sup>49</sup> There is also a requirement that VARTA offer counselling before the contact preference is lodged. Contact preferences again remain in force for five years and may be extended for a further five years.<sup>50</sup> They may also be amended or withdrawn in writing. As soon as practicable after a contact preference expires or is withdrawn, VARTA must notify any applicant to whom the contact preference relates.

If the preference is lodged by the parent or guardian of a donor-conceived person and is in force on the day on which the donor-conceived person turns 18 years of age, the contact preference expires six months after that person turns 18 years of age.<sup>51</sup> Before the contact preference expires, VARTA must make all reasonable efforts to give the donor-conceived person written notice as to when the contact preference will expire. The person may amend<sup>52</sup> or withdraw the contact preference,

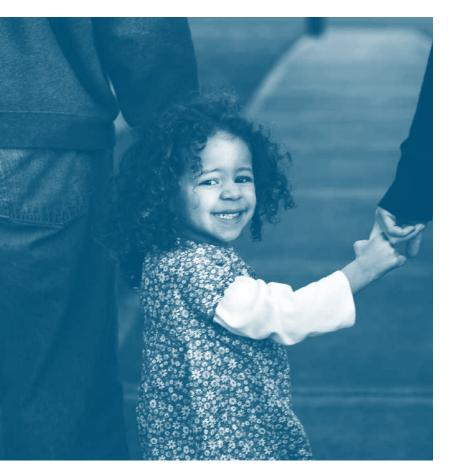
or withdraw the contact preference and lodge another contact preference.53

#### Requirements for counselling

Section 61 of the ART Act (Vic.) sets out the requirements for counselling prior to the disclosure of information recorded on the Central Register. These requirements will be maintained under the new law. Information may be disclosed to a person who makes an application under the Act only if in the case of the disclosure of non-identifying information the Registrar has offered the person counselling by a counsellor; or in the case of identifying information—the Registrar is satisfied the person has received counselling, from a counsellor, about the potential consequences of disclosure of information from the Central Register.

#### Notification of donor-conceived status

To promote greater openness, Victoria implemented an addendum provision to the birth certificate of donor-conceived people born after 1 January 2010, which records the status "donor-conceived" on the register, and states that further information is available about them on the Victorian Registry of Births, Deaths and Marriages.<sup>54</sup> People born post 2010 will continue to be alerted to the fact of their



donor conception on application for a birth certificate. Parents have been encouraged, and supported, via various educational seminars led by VARTA to disclose the use of donor conception to their children.55 The new law does not address further notification of pre-2010 donor-conceived children of their status.

#### Discussion

As donor-conceived people have grown, entered adulthood and, for some, had their own families, the call for information about their donors has become more prominent. There has been increasing understanding of the importance of such information and recognition of the injustice in its denial. A growing number of jurisdictions allow for access to identifying information about donors and prohibit anonymity. This now includes legislation in the Australian states of New South Wales,<sup>56</sup> Victoria,<sup>57</sup> Western Australia<sup>58</sup> and South Australia<sup>59</sup>; and the countries of Austria;<sup>60</sup> Croatia;<sup>61</sup> the Netherlands;<sup>62</sup> Norway;<sup>63</sup> Finland;<sup>64</sup> New Zealand;<sup>65</sup> Sweden;<sup>66</sup> Switzerland;<sup>67</sup> the United Kingdom,<sup>68</sup> Uruguay,<sup>69</sup> Argentina<sup>70</sup> and Ireland.<sup>71</sup> In these jurisdictions the donor-conceived person who knows they were donor-conceived and wishes to obtain information about their donor(s) may turn to a special register,72 to the clinic73 or hospital74 that assisted in their conception, or apply for judicial approval<sup>75</sup> to access information about their donor(s), and possibly siblings. Donors and recipient parents in some jurisdictions may also be able to obtain some information under these laws.

Four jurisdictions-Victoria, Ireland, Croatia Argentina-also require entry of information about the method of conception on the birth register. Victoria and Ireland explicitly state that such information will be provided to the donor-conceived person on application for their birth certificate at age 18. Croatia mandates disclosure by parents to the child regarding its donor-conceived status no later than age 18, although how such a provision will be enforced is unclear.

In Germany, Supreme Court recognition has been given to donor-conceived people's rights to access identifying information about their donor, at any age.76

Other nations, including the United States, Canada and Denmark, have seen a greater move to offering open identity gamete donation, albeit those nations still also offer anonymous donors<sup>77</sup> (Allan, in press).

There has been added controversy in respect to whether the move to recognise a right to access information should only be prospective or whether people conceived in the past, when donor anonymity was "guaranteed" by clinicians, should also be given access to information (Allan, 2012b; Pennings, 2012).

One other jurisdiction, Switzerland, provided for retrospective access to information in 2001. There, a register of donor information for children born post 2001 was established, but the law also provides that those born before 2001 can apply to clinics for information—who are obliged to release it. Unfortunately, retrospective access has proven difficult in Switzerland as many files held by clinics were lawfully destroyed pursuant to other laws that only required holding records for 10 years.

Two other nations have allowed for donors to consent to the release of their information for past donations. In the Netherlands, legislation introduced in 2004 allowed access to information for all donor-conceived people conceived after that date; however, all donors that donated prior to that date were also asked to consent to release of information. A voluntary DNA register exists for those not able to access information otherwise. Similarly, laws and practices introduced in the United Kingdom in 2005 to ban anonymity also allowed for people who donated between 1991 and 2005 to "reregister" so as to give their consent to release of information. This again may have provided access for some but not all those searching for information.

Victoria, in comparison, has thus taken a very progressive step. It has recognised that once it is agreed that access to identifying information about donors should be granted to donorconceived people, it should be granted equally to all. Victoria has adopted a model to allow this to occur. It is the first in the world to recognise rights to access identifying information about donors to donor-conceived people, to move to protect records, to hold all such information on a central register, to allow for further searching for information where records are incomplete (either by orders to produce records, or DNA testing, or both), and to apply the contact veto/preference system to donor-conception to balance the right to information with the right to privacy in circumstances in which a person may not wish to have, or wishes to limit, contact. Detailed consideration of such laws illustrates the careful system that has been put in place.

The passing of such legislation continues to mark the tides of change as access to information by donor-conceived people about their donors is increasingly recognised as a fundamental right, including in relation to donations of the past.

#### **Endnotes**

- 1 Assisted Reproductive Treatment Amendment Act 2015 (Vic.)
- 2 Assisted Reproductive Treatment Amendment Act 2015 (Vic.), s 2 inserts the following definition into Assisted Reproductive Treatment Act 2008 (Vic.) s 3: "Contact preference is defined as a written statement lodged under section 63C or 63I". (Hereafter "ART Amendment Act 2015" and "ART Act 2008").
- 3 Some jurisdictions limit the number of families to which a donor may donate. For example, in Victoria, the maximum number of families is 10: ART Act 2008 (Vic.), s 29. In New South Wales, the number is five: Assisted Reproductive Technology Act 2007 (NSW), s 27(1). In Western Australia, the number is five: Human Reproductive Technology Act 1991 (WA) (see "Human Reproductive Technology Directions (WA)", Western Australian Government Gazette (30 November 2004) p. 5434 at [8.1]).
- 4 See, for example, the story of Bridgette Reynolds, reported in James Purtill, "A Daughter's Search for her Anonymous Sperm Donor", RMR1084, *JJJ Hack*, <www.abc.net.au/triplej/programs/hack/a-daughter's-search-for-her-anonymous-sperm-donor-father/7201012> (accessed 23 May 2016).
- 5 For example, the Australian *Marriages Act 1961* (Cth), s 23(1)(b), makes marriages involving "prohibited relationships" void. Section 23(2)(a)–(b) states that "marriages between an individual and their parent and an individual and their sibling, including half siblings" are "prohibited relationships". State criminal law also makes incest between individuals and their parents and half-siblings a punishable offence: e.g. see *Crimes Act 1958* (Vic.), s 44(2), (4).
- 6 Commonwealth, Senate Committee, Hansard (3 November 2010), oral evidence of donor-conceived individuals
- 7 Infertility (Medical Procedures) Act 1984 (Vic.), ss 20 and 23.
- 8 Infertility Treatment Act 1995 (Vic.), s 17 (repealed);
  ART Act 2008 (Vic.), s 57 (application for information on Central Register), s 58 (with respect to parents of a person born as result of donor or donor treatment procedure), s 59 (person born as result of donor treatment procedure) and s 60 (person descended from person born as result of donor treatment procedure).
- 9 Notably there are more than 120 donors on the voluntary register in Victoria, and many donors supported information release.
- 10 ART Act 2008 (Vic.), s 59
- 11 Assisted Reproductive Treatment Amendment Bill 2015 (Vic.)
- 12 ART Act 2008 (Vic.), s 5
- 13 Reference to the provisions of the amended ART Act 2008 (Vic.) as it will be after this date are noted below according to whether the provision is a "new section" or is "amended").
- 14 ART Act 2008 (Vic.) s 59 (amended)
- 15 ART Act 2008 (Vic.) s 60 (amended)
- 16 ART Act 2008 (Vic.) s 59 (amended)
- 17 ART Act 2008 (Vic.) new sections 63C and 63I
- 18 ART Act 2008 (Vic.) new section 63G

The changes to the Victorian law will enable persons born as a result of the use of gametes donated before 1 January 1998 to obtain identifying information about their donor(s).

As donor conceived people have grown, entered adulthood and, for some, had their own families, the call for information about their donors has become more prominent.

- 19 Note: the registers are currently held by Births, Deaths and Marriages but will be transferred to VARTA to enable them to administer the registers and provide counselling, search and support services in the one location.
- 20 ART Act 2008 (Vic.) new sections 53(ac)-53(ae)
- 21 ART Act 2008 (Vic.) s 71 (amended)
- 22 ART Act 2008 (Vic.) s 73
- 23 ART Act 2008 (Vic.) s 52A (amended)
- 24 ART Act 2008 (Vic.) s 52B (amended)
- 25 ART Act 2008 (Vic.) s 52B (amended)
- 26 The Prince Henry Institute was the location of many early donations
- 27 ART Act 2008 (Vic.) new section 56B. Note VARTA, however, must not request records under that section from the legally recognised child of a donor unless the donor consents to VARTA making the request or the child has previously initiated contact with VARTA. This protection has been included in recognition that the child may not know that his/her parent is a donor.
- 28 ART Act 2008 (Vic.) new section 56I
- 29 ART Act 2008 (Vic.) s 54A (amended)
- 30 ART Act 2008 (Vic.) new section 56L
- 31 As defined in ART Act 2008 (Vic.) new section 56N (4) and (5)
- 32 Pursuant to ART Act 2008 (Vic.) new section 63C
- 33 ART Act 2008 (Vic.) new section 62
- 34 ART Act 2008 (Vic.) new section 63
- 35 ART Act 2008 (Vic.) new section 63A
- 36 ART Act 2008 (Vic.) new section 63A(2)
- 37 New section 63B
- 38 Pursuant to new section 62(2)
- 39 Pursuant to new section 63
- 40 Pursuant to new section 63C(1)(a)
- 41 ART Act 2008 (Vic.) new section 63C(1)(b). Note: Reference to the "donor's child" in s 63C(1)(b) is to a child for whom the donor is the legally recognised
- 42 ART Act 2008 (Vic.) new section 63C(1)(b)
- 43 ART Act 2008 (Vic.) new section 63C
- 44 ART Act 2008 (Vic.) new section 63E
- 45 ART Act 2008 (Vic.) new section 63F
- 46 ART Act 2008 (Vic.) new section 63D
- 47 ART Act 2008 (Vic.) new section 63I
- 48 ART Act 2008 (Vic.) new section 63I(2)
- 49 ART Act 2008 (Vic.) new section 63I 50 ART Act 2008 (Vic.) new section 63K
- 51 ART Act 2008 (Vic.) new section 63L
- 52 ART Act 2008 (Vic.) new section 63M
- 53 ART Act 2008 (Vic.) new section 63N
- 54 ART Act 2008 (Vic.) ss 153, 17B(2)
- 55 The Victorian Assisted Reproductive Treatment Authority runs yearly Time To Tell seminars, and has developed numerous resources to assist people in talking to children about the use of a donor to create their family. See further <www.varta.org.au/events/ time-tell-seminar>.
- 56 Assisted Reproductive Technology Act 2007 (NSW)
- 57 Infertility (Medical Procedures) Act 1984 (Vic.); Infertility Treatment Act 1995; Infertility Treatment Regulations 1997; ART Act 2008 (Vic.)

- 58 Human Reproductive Technology Act 1991 (WA)
- 59 Assisted Reproductive Treatment Act 1988 (SA) s 16; Assisted Reproductive Treatment Regulations 2010 (SA) reg 8.4(c).
- 60 Fortpflanzungsmedizingesetz. 275 Bundesgesetz,
- 61 Zakon O Medicinski Pomognutoj Oplodnji (Law on Medically Assisted Reproduction, 12 July 2012) (Croatia), No: 71-05-03 / 1-12-2, Article 15(2)
- 62 Wet donorgegevens kunstmatige bevruchting, 2002
- 63 Act on Biotechnology, 2003
- 64 Act on Assisted Fertility Treatments (1237/2006)
- 65 Human Assisted Reproductive Technology (HART) Act 2004
- 66 Lag om insemination (Law on Insemination) 1984 (replaced by Genetic Integrity Act 2006)
- 67 Federal Act on Medically Assisted Procreation of 18 December 1998 - FF 1996 III, 197 (LPMA)
- 68 Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004
- 69 Law Regulating Human Assisted Reproductive Techniques (22/11/2013 No 19.167)
- 70 Código civil y comercial de la nación (Civil and Commercial Code of the Nation), Title V, Ch2, approved by Law 26,994
- 71 Children and Family Relationships Act 2015 Act No. 9 of 2015, s 25(1)
- 72 Australian states of New South Wales, Victoria, Western Australia; countries of Croatia; Finland; Ireland; The Netherlands; New Zealand; Switzerland; United Kingdom.
- 73 Austria, Switzerland (pre-2001)
- 74 Sweden
- 75 Argentina, Uruguay
- 76 Supreme Court of Germany decision XII ZR 201/13, summary, available at <bit.ly/29n1sKa>
- 77 For detailed discussion of all of the above jurisdictions and their laws, see Allan (in press).

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Access to information by donor-conceived people about their donors is increasingly recognised as a fundamental right, including in relation to donations of the past.