

Proposed Amendments about the right to obtain information under the Assisted Reproductive Treatment Act 1988

An amendment to the *Assisted Reproductive Treatment Act 1988* ("the ART Act") passed by the South Australian parliament in 2019 will commence operation on 7 November 2021 to mandate the establishment of the donor-conception register (DCR). Further amendments to the ART Act are now proposed to ensure effective and optimal functioning of the DCR. This fact sheet provides information relating to how the current amendment Bill proposes to treat information and the release of information (including previously confidential information).

Proposed changes to the ART Act

Fertility clinics operating in South Australia have provided donor conception services to families who need help conceiving since the late 1970's.

Under the current system, if a person wants to access information about their donors, donor siblings, or donor-conceived offspring they must seek this information from the fertility clinic responsible for the treatment.

Many donor-conceived people born in South Australia currently face barriers to accessing historical details from fertility clinics about their genetic heritage including details of their donor and any genetic siblings conceived through the same donor.

The South Australian Government will establish a donor conception register (DCR) to operate from November this year and is proposing to progress legislative changes to the *Assisted Reproductive Treatment Act 1988* (ART Act) to:

- ensure the effective and optimal operation of the DCR;
- provide all donor-conceived people with the right to access identifying information about their donor (with retrospective effect);
- ensure the DCR can operate retrospectively to include historical donor conception information; and
- ensure all donor-conceived people have the option to have donor information included in their birth certificate.

These changes were recommended through a 2017 review of the *Assisted Reproductive Treatment Act 1988* which was the result of extensive community consultation.

Donor conception provided before 2004 was provided under conditions of anonymity. Donors and recipient parents who were treated at that time were advised that donor identities could never be revealed.

Donor Conception: Access to Information

The donation of gametes (sperm or eggs) and embryos, has been integral to the provision of some assisted reproductive treatment. It has meant that people who may not have otherwise had children, were able to use donated materials from others in order to do so.

From the time that donor-conception was introduced as a means to assist such people, there has been discussion, and increasing recognition, that people born as a result of the use of donated gametes or embryos, may desire further information about their donor and/or genetic relatives.

Over time, as donor-conceived people have grown, the psycho-social and medical impacts, for some, of being denied information have also become apparent. There has been a growing recognition worldwide, and increasing legislative reforms in some countries, to provide opportunities for people involved in donor-assisted conception, to access information. Notably this includes recipients, donors, donor-conceived people and their genetically related siblings and half-siblings, recognising that all parties involved may wish to exchange information and may desire varying levels of contact.

Information Release in Other Jurisdictions

In Australia registers operate in New South Wales, Western Australia and Victoria. In 2016 Victoria made legislative changes to allow all donor-conceived people to access identifying information about their donors.

The following international jurisdictions have various systems requiring information recording and release: Argentina; Austria; Croatia; Finland; New Zealand; Norway; Netherlands; Sweden; Switzerland; Washington State (U.S.); United Kingdom; Uruguay.

Registers vary across jurisdictions in relation to who operates them, who may access information, when such access may occur, the information available, the date from which people may access information, the conditions under which information will be released, and whether there are any support services provided to people accessing information or about who information is being released.

Societal Changes

Secrecy in donor conception was the norm from the inception of the fertility industry in the late 1970's until the early 2000's. Donors and parents who used the donations rarely told others about their experience and prior to 2004, all parties, whether they wanted it or not, were guaranteed lifelong anonymity. As society has become more open, this practice has changed. It is now accepted that this view to secrecy is against the best interest of a donor conceived person and the idea of increased communication and openness of information has increasing support.

It is now widely accepted that knowledge of one's heritage and biological links plays a significant role in the development of a person's identity and self-esteem, and it also enables access to important medical, and genetic information for family planning and avoiding formation of consanguineous relationships.

While these considerations tip the balance in favour of release of information to donor conceived people, balancing the interests of donors who were promised anonymity and their interests in privacy is also a necessary consideration for the register.

In addition the ready availability of direct to consumer genetic testing websites that match genetic relatives raise significant questions about donors' ability to rely on anonymity into the future. Many donor-conceived people have turned to these services with great success.



What the Bill proposes in relation to Access to Information

The Bill recognises the change in societal expectations around confidentiality and what is in the best interest of a donor conceived person and proposes to allow for a donor conceived person (18 years or above) to access information about themselves contained within a centrally maintained register.

Understanding how these changes will work helps to understand the way in which interests are balanced under the proposal, and support provided for all parties.

Contact preferences

All parties will be able to lodge contact preferences through a Statement of Wishes. This will be provided to the party who is seeking information to ensure they are aware of how best to make contact, or not. Support services will be available through the contact process.

It is currently not proposed to impose a punishment should a contact preference be breached. This is because it is not considered consistent with the best interests of the person born as a result of donor conception. The ART Act provides that the welfare of the person born as result of the provision of assisted reproductive treatment is to be of paramount importance and a fundamental principle in the operation of the Act. The Act is not considered to be the appropriate place to criminalise or make it an offence to make contact with another through the DCR when there is existing legislation available to control or restrain contact between individuals should it become harassment.

A contact veto would allow a donor or donor conceived person to nominate that they do not want contact from their offspring or donor and impose penalties for any breaches.

One of the intentions in the establishment of the DCR and a principle underpinning the proposed changes is to normalise donor conception, to validate a person's donor conception story and to encourage openness about the practice. Penalties for breaches of contact preferences and contact vetos are not aligned with these principles.

The South Australian Government considered the issue of contact vetos in the context of adoptions in 2017. At that time changes to the *Adoptions Act 1988* were being considered and the decision was made that no adoption veto system of any kind would be adopted in South Australia.

There will be a four month time period implemented during which a donor will be advised (if found) by the support service that their information is being sought. This will give donors time to lodge contact preferences. It will also provide an opportunity to those who require time to adapt to the news that they have donor offspring, to advise family members, and to seek any support that is needed.

If a donor is unable to be found during the four month period, their information will nevertheless be released to their donor offspring after that time.

Because of this proposal the support service will play an integral role in mediating the release of information for those who donated prior to 2004 under conditions of anonymity.

Support Services

Support will be provided to donors and their families through the process of being identified. These services will include counselling and other support.

What would this change mean for:

A Donor Conceived person

The proposed changes to the ART Act are intended to provide all donor-conceived people with the right to access identifying information about their donor (including if they were conceived prior to 2004).

The type of information that the donor conceived person will be able to access about the donor includes:

- The donor's full name, date of birth and nominated contact address (if known);
- Any Statement of Wishes about contact preferences provided by the donor available on the register;

The register will also facilitate sharing information between siblings.

A verification process will be required prior to the release of information and it is important to note that whilst historical records will be included in the DCR, due to previous record keeping practices there may be gaps in information. Please refer to the Fact Sheet: The State of Donor Conception Records in SA for further information.

A Donor

Since 2004, in order to provide a donation, donors have been required to consent to the release of identifying information to any donor-conceived people born from their donation. It is intended that the information contained within these records will be used to create the DCR and be available upon request following appropriate verification.

If you donated prior to 2004, you may have done so under the belief that you would remain anonymous. However, we are proposing to ensure that all donor-conceived people have access to identifying information about their donors regardless of when the donation was made or when the person was conceived. This means the lifelong guarantee of anonymity provided to donors will be removed. It is proposed that this will be done without the consent of the donor.

Your information will be recorded in the DCR and made available to a relevant party if requested following appropriate verification, disclosure processes and the giving of contact preferences (see below).

You will be also be able to access identifying information about your donor-offspring through the register with their consent (or if under 18 years their parents' / legal guardians' consent).

How will donor's privacy be protected after these changes are made?

The South Australian Government recognises that it is crucial to balance the rights of those who wish to find out about their genetic relatives and the rights to privacy for those who may have their anonymity lifted.

South Australia is proposing to adopt a model similar to that which is in place for adoptions which will ensure that all parties have access to comprehensive support services. If information about a donor is requested the support service will attempt to make contact in the first instance to inform the donor that their information is being sought by their donor-offspring and to assist the donor in navigating this information with their family.

In line with time periods that have been adopted in Victoria, the donor will have a four month period before a disclosure is made to the donor-offspring to allow for time for searching to be undertaken and for the donor to tell their families and to seek support if needed.

Donors and donor-conceived people will have the right to lodge a Statement of Wishes which will contain information about the persons contact preferences and reasons for wanting (or being open to) contact or not wanting contact. The support service will be able to facilitate the exchange of the Statement of Wishes.

A parent or legal guardian of a donor conceived person under the age of 18

It will be possible for access to be granted in circumstances where the donor conceived child is under the age of 18 if the parents or legal guardian of a donor conceived child (under the age of 18) **and** the donor agree. There will also be the opportunity for recipient parents of donor-siblings to agree to exchange information. To facilitate this each party will be required to provide a consent notice to the Minister (via the DCR) which will allow any party to the consent notice to access relevant information contained within the DCR.

The consent notice may be revoked at any time by either party.

A descendant of a donor conceived person

If you are the descendent of a person born as a consequence of ART then you will also be entitled to access information contained in the DCR relating to that treatment. This includes donor information regardless of whether or not the donor consents to the disclosure of the information.

Consultation and Feedback

We strongly encourage both donor-conceived people and donors to provide their comments and feedback on these proposed changes during the consultation period.

For more information

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