Fact Sheet

I'm donor-conceived: What should I know?

A donor conception register commenced operation on 7 November 2021. Legislative amendments are now proposed to enable the inclusion of information in the register relating to private arrangements and to also enable access to information contained in the register.

What is a Donor Conception Register?

The Donor Conception Register (DCR) is an electronic register that stores available and verifiable donor conception records/information kept by South Australia's assisted reproductive treatment (ART) clinics. A draft Amendment Bill proposes to allow access to the DCR for people who seek information about their donor (genetic parent) or a person born as a result of donor conception. It is intended that the DCR will also be able to store donor information relating to private arrangements.

What information can I access and about whom when I turn 18?

Under the proposed amendments, once you turn 18 years of age you would have immediate access to non-identifying information about your genetic parent(s) (donor) and any donor-conceived siblings you may have (where the sibling's birth was registered in South Australia).

It is also proposed that once you turn 18 you would have access to identifying information about your genetic parent(s). This information may be disclosed immediately but in instances where the donation occurred prior to September 2004, disclosure may be deferred for three months[1].

With their consent you may also have access to:

- identifying information about your donor-conceived siblings aged 18 years and over
- contact details of your donor-conceived sibling's recipient parent(s).

See the ***Fact Sheet – What information is held by the register?*** for details about what is considered identifying and non-identifying information.

Accessing identifying information about your genetic parent(s) does not necessarily mean you will have contact with them. Both you and your genetic parent(s) would be able to set contact preferences in the DCR to let each other know if you are open to contact.

What information about me can be accessed and by whom?

Under the proposed amendments, your genetic parent(s) (donor), donor-conceived siblings aged 18 years and over and their recipient parent(s) would have immediate access to non-identifying information about you.

It is also proposed that once you turn 18 you could consent in the DCR to disclose your identifying information to your genetic parent(s), donor-conceived siblings aged 18 years and over, and/or the recipient parent(s) of your donor-conceived siblings. You would be able to provide the consent to disclose your information to each individual relationship.

[1] The standard timeframe for disclosure is three months, however there may be instances where an extension to this timeframe is permitted due to extenuating circumstances.

Can I add information to the DCR?

It is expected that the DCR would provide the ability for you to lodge contact preferences, specifying if you are open to contact, unsure at this time or do not wish to have contact. If you are open to contact, you would be able to specify your preferred mode of contact such as email, phone, etc. Contact preferences would be applied individually to your genetic parent(s), sibling and/or recipient parent(s) to allow you to form relationships at your own pace.

If you wish to, you could also include a biographical statement, 1-2 photos and/or a legacy video about yourself.

It is also intended that you would be able to include non-identifying information about genetic or heritable medical conditions you have been diagnosed with that would enable your genetic parent(s), donor-conceived siblings, or their recipient parent(s) to seek early medical advice or intervention that they may not know to seek otherwise.

You would also be able to set notification preferences specifying if you want the DCR to notify you when your information is accessed or medical information of genetic relatives is updated.

Will the DCR contain full and complete records?

It is unlikely that all records used to create the DCR will be full and complete, and it is expected that information gaps will remain, particularly for the older, historical records. The reasons for this include:

- provisions that required fertility clinics to keep identifying information about a donor in a different place to other information about the donor up until 2010
- clinics changing ownership or the place of business moving.

It is anticipated that the information contained in records made since September 2004 when anonymity provisions were removed, will be generally complete. All records made since 2010 are full and complete.

Records prior to September 2004 are held at various locations in South Australia. These must be assessed and verified before being transferred into the DCR. Not all of this information will be verifiable, and it may not be possible to match you with your genetic parent(s).

Unfortunately, the DCR may not answer all of the questions that donor-conceived people have about their genetic parentage, however, it will provide significant amounts of information in one central location with the added benefit of ensuring the preservation of these records.

What support is available?

Feedback has previously indicated that people want to choose if they wish to access support, and if they do, the level of support and choice of provider. The DCR will provide links to appropriate support services and offer a library of resources to help support you.

If your genetic parent(s) provided the donation resulting in your conception **prior** to September 2004, it is proposed for you to have the option of accessing an intermediary service funded by the government or you may prefer to seek your own provider that suits your personal circumstances.

If your genetic parent(s) provided the donation resulting in your conception **after** September 2004, you would be able to choose a provider that suits your personal circumstances.

What if I was conceived through a private arrangement?

Private arrangements are those made with a donor that is known to the recipient at the time of the donation. A fertility clinic may or may not be used to assist with the fertilisation procedure.

Where a private arrangement occurred and the donor was recorded on the birth registration statement submitted to the South Australian Births, Deaths and Marriages, it is proposed that the donor's information would be included on the DCR with the same access provisions.

Can I access information if I'm not 18?

Under the amendments, recipient parent(s) would be able to register and access information about your genetic parent(s) and donor-conceived siblings aged 18 years and over where these relatives consent to disclose this information to them in the DCR.

Where extenuating circumstances exist, the draft Bill proposes for the Minister for Health and Wellbeing to consider disclosing information to a donor-conceived person under the age of 18 years without parental support and where they are deemed to be of sufficient maturity.

> Refer to the ***Quick Guide – Who can access the DCR?*** for details about when identifying and non-identifying information may be disclosed.

Need more information or wish to provide feedback?

The YourSAy webpage contains further information and resources about the DCR.

Written comments and feedback on the draft Amendment Bill can be sent to health.donorconceptionregister@sa.gov.au by 5.00pm Tuesday, 6 December 2022.

For more information

Legal and Legislative Policy
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