

# Application to lodge information on the Voluntary Register

**VR**

December 2019

## Many people are curious about others they are connected to via donor conception.

The Voluntary Register allows people who have been involved in donor conception in Victoria to voluntarily record information about themselves so it can be exchanged with people they are genetically related to.

### Who can apply?

- **Donor-conceived people** who wish to connect with donor siblings (other people conceived by the same donor) and/or their donor.
- **Parents** who wish to connect with other parents who have used the same donor and/or their child's donor.
- **Donors** who wish to connect with or provide information to their donor offspring.
- **Descendants** of donor-conceived people who want information about the donor from whom they are descended.
- **Relatives** of all the above.
- **Other people** who are connected with a donor treatment procedure that has occurred in Victoria.

Applicants may match with any of the people above. It is also possible that an applicant matches with people who are already in contact with each other as the donations of one donor can be used by up to ten women.

### What information can be lodged?

An applicant can decide what information they wish to lodge. This can include information about:

- medical history
- family tree and cultural heritage
- interests, hobbies and personality
- photographs, films, audio recordings, letters or other items
- anything else the applicant would like to share.

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### What happens after an application is lodged?

#### If there is no match

If people connected to you have not lodged information on the Voluntary Register, you will not receive a match. You will be notified by VARTA if this occurs. Over time this may change. As more people engage with the register, the chance of a match increases.

Sometimes it is not possible to link parties on the Voluntary Register if the records are poor, have been destroyed, or where there is no record of a donor code or evidence to substantiate a link between parties.

**It is important to inform VARTA of any change to your contact details, so that you can be notified if and when there is a match.**

### Matches on the Voluntary Register

If **two or more applicants are matched** on the Voluntary Register, each person will be contacted. Information will be shared in accordance with the wishes of the parties.

### Process for Voluntary Register match

- 1 Once an application to the Voluntary Register has been lodged, VARTA will check the Voluntary Register to see if there is a corresponding match.
- 2 If there is one or more matches, each party will be notified and asked to attend an information and support session at VARTA.
- 3 During the session, the implications of sharing information and/or arranging to have contact with the other people are explored to help everyone feel prepared and supported during the process.
- 4 Together with the VARTA counsellor, applicants complete a *Statement of reasons* form, outlining why they wish to connect and what they hope for in the short and long term.
- 5 These *Statement of reasons* forms are then exchanged with the other party/ies.
- 6 Each party chooses how they wish to proceed. All information exchanged, as well as any linking that takes place, will be subject to the wishes of those involved. The counsellor is available to support each party if they wish.

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### Options for linking include:

- facilitated email exchange
- setting up a non-identifying email address
- a facilitated meeting supported by the VARTA counsellor
- exchanging contact details e.g. telephone number or address.

### Fees

There is **no charge** to apply to lodge information on the Voluntary Register. VARTA provides all services associated with the lodging of information or matching without charge.

### Privacy and disclosure of information

VARTA is responsible for the management of the Voluntary Register under the *Assisted Reproductive Treatment Act 2008* (Vic) (the Act). VARTA will only collect, use and release information in accordance with the provisions of this Act, the *Privacy and Data Protection Act 2014* (Vic), the *Health Records Act 2001* (Vic) and the *Freedom of Information Act 1982* (Vic).

VARTA will use your information for:

- processing your application and carrying out donor linking services
- updating the Voluntary Register
- statistical, educational, or reporting purposes.

Your information will only be disclosed to an individual with whom you are linked in accordance with your wishes, conveyed verbally or in writing to VARTA. No other parties will have access to your information without your consent, unless VARTA is otherwise compelled by law to disclose your information.

You may request that VARTA correct information on the register or remove information from the register at any time.

### Need help or advice?

VARTA staff can assist you to complete this form.

For more information about applying to the Voluntary Register and to view VARTA's privacy policy, visit:  
[www.varta.org.au](http://www.varta.org.au) or email: [dcrs@varta.org.au](mailto:dcrs@varta.org.au)

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Office use only    IRN \_\_\_\_\_    ARN \_\_\_\_\_    Date received \_\_\_/\_\_\_/\_\_\_

### STEP 1 - YOUR DETAILS

Are you submitting a new application or updating  
an existing Voluntary Register entry?

- New application  
 Updating existing Voluntary Register entry

Title     Mr.     Mrs.     Ms.     Miss     Other

Surname

First name

Middle name

Other names used

Current postal address

Phone number

Email address

Date of birth

Gender (if comfortable to provide)

Preferred pronouns used (e.g. he, she, they)

Place of birth

Donor code (if known)

Clinic/hospital where treatment/donation occurred (if known)

Name of person treated (if known)

I am applying as a:

- donor-conceived person  
 parent of a donor-conceived person  
 donor  
 descendant of a donor-conceived person  
 relative of a donor  
 relative of a donor-conceived person  
 relative of a parent of a donor-conceived person  
 relative of a descendant of a donor-conceived person  
 other, please specify:  
\_\_\_\_\_

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### STEP 2- ALTERNATIVE CONTACT – Optional

After you have applied to the Voluntary Register and lodged information, VARTA will contact you if there is a match. If your contact details are out of date VARTA may not be able to reach you.

**Please keep your contact details up to date.**

You may wish to provide an alternative contact in case we can't reach you. Before doing so, we recommend that you ask that person whether they would be comfortable being contacted by VARTA for the purposes of your Voluntary Register application. We would contact this person only for the purpose of seeking to locate you.

**Your full name** \_\_\_\_\_

**Full name of alternative contact** \_\_\_\_\_

**Phone number** \_\_\_\_\_

**Email address** \_\_\_\_\_

**Relationship to you** \_\_\_\_\_

\_\_\_\_\_

### STEP 3- INFORMATION TO BE LODGED ON THE VOLUNTARY REGISTER – Optional

In step 3, you can choose to lodge specific information on the Voluntary Register that will only be released with your consent and in accordance with your wishes.

You can complete this section by including as much or as little information as you like, or you can leave this section blank. If you leave this section blank, and there is a match, you can decide later what information you share directly with the person you match with.

If you do choose to lodge specific information below and there is a match on the Voluntary Register, you can:

- ask VARTA to release this information to the person you have matched with, or
- exchange contact details with the person you have matched with to communicate more, or
- use the VARTA intermediary services to communicate with the person you have matched with.

#### Your reasons for applying

In this section, you may want to provide information about your main reasons for lodging information on the Voluntary Register, including your wishes, hopes and goals. Perhaps you are looking for a certain type of information about another person or wish to have contact with others to whom you are genetically related.

You can also express your preference for your information to be shared if you can't be located or in the event of your death.

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### STEP 3- Optional

## Voluntary information you may choose to add to the register

Here are some suggested details you might want to add to the register. You may also submit a hand-written letter, photographs or a personal message via video, for example. These are suggestions only. You can choose to provide as much or little information as you wish.

### Personal information

Comments can be provided below or attached to this application.

**Height**

**Build**

**Eye colour**

**Hair colour**

**Personality type**

**Interests/hobbies**

**Philosophy on life**

**Career/educational background**

**Cultural and family information**

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### STEP 3- Optional

## Lodging medical information on the Voluntary Register – Optional

Sharing medical information with people you are genetically related to can be beneficial for their health. It may, for example, alert somebody to a higher risk of a hereditary illness that they can take steps to prevent. This can help make a person aware of possible preventable medical conditions which they may have a higher chance of inheriting. Many donor-conceived people say they have valued knowing their donor's medical history because it completes their own family medical history.

### Providing medical information

You may wish to provide information about chronic medical conditions you or family members have been diagnosed with, as this type of information could be significant for a person to whom you are genetically linked.

Sometimes people find it hard to decide what kind of medical information they would like to lodge on the Voluntary Register. A list of conditions is provided below. These conditions are the types of conditions that a person may want to know about because they can be hereditary. If you belong to an ethnic or cultural group which is predisposed to a particular medical condition, you may like to mention this, including whether members of your family have experienced the condition.

If new medical conditions are diagnosed you may wish to update your Voluntary Register information. Comments can be provided on this form or attached to this application.

- |  |   |
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| <ul style="list-style-type: none"> <li>• Allergies</li> <li>• Alpha-1 antitrypsin disease (a lung and liver disease)</li> <li>• Anxiety</li> <li>• Autism</li> <li>• Bipolar disorder</li> <li>• Canavan disease (a brain disorder)</li> <li>• Cancer</li> <li>• Cataracts</li> <li>• Christmas disease (a bleeding disease)</li> <li>• Cleft lip and/or cleft palate</li> <li>• Colour blindness</li> <li>• Creutzfeldt-Jakob disease (a type of dementia)</li> <li>• Cystic fibrosis (a lung and bowel disease)</li> <li>• Deafness in childhood or young adulthood</li> <li>• Dementia (including Alzheimer's disease)</li> <li>• Depression</li> <li>• Diabetes type 1</li> <li>• Diabetes type 2</li> <li>• Down syndrome</li> <li>• Epilepsy</li> <li>• Fragile X syndrome</li> <li>• Friedreich Ataxia</li> <li>• Glaucoma</li> <li>• Haemophilia (a bleeding disease)</li> </ul> | <ul style="list-style-type: none"> <li>• Heart attack</li> <li>• Heart conditions</li> <li>• Heart malformation</li> <li>• Haemochromatosis</li> <li>• Huntington's disease (a progressive brain disease)</li> <li>• Intellectual disability or learning disorders</li> <li>• Marfan syndrome</li> <li>• Mitochondrial disease</li> <li>• Multiple miscarriages</li> <li>• Muscular dystrophy</li> <li>• Nervous system disorders</li> <li>• Neurofibromatosis</li> <li>• Phenylketonuria (PKU)</li> <li>• Polycystic kidney disease</li> <li>• Schizophrenia</li> <li>• Sickle cell anaemia</li> <li>• Spina bifida</li> <li>• Spinal muscular atrophy</li> <li>• Sudden unexplained death before age 50</li> <li>• Tay-Sachs disease</li> <li>• Thalassaemia</li> </ul> |
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### Notes and comments

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### STEP 4 - CONSENTS AND DECLARATIONS

✓ Please tick as applicable

#### Consents

- I consent to VARTA verifying the accuracy of the information provided in this application, including by communicating with nominated treatment clinics to confirm treatment details. I understand that VARTA may decide not to include some information provided if the information is inaccurate.
- I consent to VARTA using the contact details provided in this application to update my personal details held on VARTA's case management system and Central Register.
- I understand that if a match is found on the Voluntary Register and I wish to exchange identifying information, I must attend an information and support session at VARTA and complete a *Statement of reasons* form before my application can progress.
- In the event of a match, I give permission for my first name to be used in any discussion with other person(s).
- If VARTA cannot contact me, I consent to VARTA contacting my alternative contact provided in Step 2 of this form for the purposes of my Voluntary Register application.
- In the event of my death, I consent to VARTA releasing to other person/s I am linked with on the Voluntary Register:
  - All information I have lodged, including my name, date of birth and contact details.
  - Only information provided in Step 3, being non-identifying information about me.
- I agree to be contacted by VARTA in the future for the purpose of evaluation or research designed to improve VARTA's services. I acknowledge that I can withdraw my consent to be approached for this purpose at any time.
- I would like to receive VARTA newsletters and invitations to seminars via email.
- Please tick this box if you are submitting additional material (photographs, letters or other items).

Please describe any additional items you have lodged: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

#### Declaration

I declare that all statements made in this application are true and correct. I understand that it is an offence under section 38 of the *Assisted Reproductive Treatment Act 2008* (Vic), to knowingly or recklessly give false or misleading information. I understand that committing such an offence could result in a penalty.

**Your full name:** \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_/\_\_\_\_/\_\_\_\_



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### PROOF OF IDENTITY

In order to process your application, VARTA requires **certified** copies of documents verifying your identity and eligibility to make an application to the Voluntary Register. We require that you provide copies of two documents showing the use of your identity in the community, that is:

- one primary document, such as a birth certificate, an Australian driver's licence, passport, or marriage certificate
- one secondary document, such as a bank statement, ATM card, or Medicare card
- if relevant, you also need to supply evidence of change of name, such as a marriage or birth certificate
- if you are a descendant of a donor-conceived person, please provide evidence of your relationship to them e.g. birth certificate.

If you cannot supply these documents, please provide a statutory declaration confirming your identity.

### HOW TO HAVE A DOCUMENT CORRECTLY CERTIFIED

1. Take the original AND a photocopy to an authorised witness. The most common authorised witnesses are police officers, school principals, lawyers, and pharmacists. Visit the **Australian Government Attorney-General website** for a complete list of authorised witnesses: [www.ag.gov.au](http://www.ag.gov.au)
2. The authorised witness must examine the original document and write the following on the last page. *'I have sighted the original document and certify this to be a true copy of the original'.*
3. Ensure the authorised witness writes their name, date of certification, contact phone number, and profession/position number (if relevant).

If you are unable to meet the above requirements, please telephone VARTA on **(03) 8601 5250** or email [dcrs@varta.org.au](mailto:dcrs@varta.org.au)

### CHECKLIST AND SUBMISSION OF APPLICATION

**Please ensure you have completed this checklist and attached the relevant documents before submitting your application to avoid delays.**

- Your details
- Information to be lodged on the Voluntary Register
- Consents and declarations
- Proof of identity

**Please submit your completed form and supporting documents to:**

Registers Officer  
Victorian Assisted Reproductive Treatment Authority  
Level 30, 570 Bourke Street  
MELBOURNE VIC 3000

or

**Scan and email your signed application form and supporting documents to: [dcrs@varta.org.au](mailto:dcrs@varta.org.au)**

