

# Information for donor conceived individuals on the Assisted Reproductive Technology Act 2007

## The Assisted Reproductive Technology Act 2007

In NSW a number of children are born every year as a result of ART treatment using donated gametes (sperm and ova). Until recently there was no process to support the disclosure of information about the people involved in this process and many gamete donors were anonymous. This has created a situation in which many individuals are unable to identify a biological parent and obtain information about their genetic heritage and background, which has been distressing for some and occasionally created medical and social dilemmas for both individuals and their parents.

The *Assisted Reproductive Technology Act 2007* (ART Act) and Assisted Reproductive Technology Regulation 2014 (ART Regulation) were developed to address this issue and a range of other matters in the area of ART.

The ART Act establishes a Central ART Donor Register (Register) to contain information about donors and children born as a result of ART treatment using donated gametes. Information on the Register, including identifying information about the donor, can be accessed by individuals conceived using donated gametes once they turn 18 years of age. Parents of children conceived using donated gametes, donors and other offspring of donors are also able to access certain information on the Register.

## When did the Register start?

The Register commenced on 1 January 2010, the day the ART Act commenced. Since that date it has been mandatory for ART providers to provide details about the birth of each child born as a result of ART treatment using donated gametes, and the donor, to the Register within two months of the birth.

This means that if conception, using donated gametes, occurred on or after 1 January 2010 information about the donor is included on the Register once a child is born.

The ART Act also establishes a Voluntary Register to contain information about children born as a result of ART treatment using donated gametes prior to the commencement of the ART Act on 1 January 2010.

## What information is included on the Register?

The Register includes the following information about each donor:

- the donor's full name,
- the residential address of the donor,
- the date and place of birth of the donor,
- the ethnicity and physical characteristics of the donor,
- any medical history or genetic test results of the donor or the donor's family that are relevant to the future health of:
  - a person undergoing ART treatment involving the use of the donated gamete;
  - any offspring born as a result of that treatment;
  - any descendants of any such offspring;
- the name of each ART provider who has previously obtained a donated gamete from the donor and the date on which the gamete was obtained, and
- the sex and year of birth of any offspring of the donor.

The Register includes the following information about every child born as a result of ART treatment using donated gametes:

- the full name, sex and date of birth of the child, and
- the name of the woman who gave birth to the child, and
- the full name, date and place of birth of the donor of the gamete.

The information on the Register reflects the circumstances of the donor, and any offspring of the donor, as at the time the donor donated his or her gametes, unless the donor or offspring provides updated information.

## Who can access information on the Register?

### Adult donor conceived individuals are entitled to have access to:

- a) the full name of the donor,
- b) the residential address of the donor,
- c) the date and place of birth of the donor,
- d) the ethnicity and physical characteristics of the donor,
- e) any medical history or genetic test results of the donor or the donor's family that are relevant to the future health of:
  - i) a person undergoing ART treatment involving the use of the donated gamete, or
  - ii) any offspring born as a result of that treatment, or
  - iii) any descendent of any such offspring,
- f) the name of the ART provider who provided the above information for the Register; and
- g) the sex and year of birth of each other offspring of the donor.

### Other adult offspring of the donor (not through donation) are entitled to have access to:

- a) the sex and year of birth of each other offspring of the donor.

### Parents of a child born through donation are entitled to have access to:

- a) the ethnicity and physical characteristics of the donor,
- b) any medical history or genetic test results of the donor or the donor's family that are relevant to the future health of:
  - i) a person undergoing ART treatment involving the use of the donated gamete, or
  - ii) any offspring born as a result of that treatment, or
  - iii) any descendent of any such offspring,
- c) the sex and year of birth of each other offspring of the donor.

### The Donor is entitled to have access to:

- a) The sex and year of birth of each offspring of the donor.

The information on the Register reflects the circumstances of the donor, and any offspring of the donor, as at the time the donor donated his or her gametes, unless the donor or offspring provides updated information.

### Will identifying information about donor conceived individuals be given to the donor or other offspring of the donor?

If you are a donor conceived individual who is over the age of 18, you can give your written consent to the disclosure of other information, including identifying information about yourself, to:

- the donor; and or
- other offspring of the donor.

The disclosure of identifying information about yourself may result in the donor, or, other offspring of the donor contacting you. You should therefore consider the issue carefully before providing further information about yourself to the Register. A counsellor may be able to assist you in determining whether or not it is appropriate for you to consent to allowing the donor or other offspring of the donor to have access to identifying information about yourself. You are responsible for any costs incurred in seeking counselling.

If you provide additional information to the Register, you can also revoke your consent in writing for that information to be released in which case the information will be removed from the Register.

### **Counselling**

It is recommended that you consider seeking counselling before you apply to access information on the Register. The ART provider who provided the ART services or an independent counsellor may be able to assist you with counselling services. You are responsible for any costs incurred in seeking counselling.

## **What if I was conceived before 1 January 2010?**

### **The Voluntary Donor Register**

The ART Act also established a Voluntary Donor Register for the inclusion of information about donors who donated gametes prior to 1 January 2010 and individuals born prior to 1 January 2010 as a result of ART treatment using donated gametes.

The Voluntary Donor Register only holds information about donors and donor conceived offspring that has been voluntarily provided to the Register by those donors and donor conceived individuals.

### **What information can be included on the Voluntary Donor Register?**

Donors may provide any or all of the following information to the Secretary, NSW Health for inclusion in the Voluntary Register:

- a) the full name of the donor,
- b) the residential address of the donor,
- c) the date and place of birth of the donor,
- d) the ethnicity and physical characteristics of the donor,
- e) any medical history or genetic test results of the donor or the donor's family that are relevant to the future health of:
  - i) a person undergoing ART treatment involving the use of the donated gamete, or
  - ii) any offspring born as a result of that treatment, or
  - iii) any descendent of any such offspring,
- f) the sex and year of birth of each other offspring of the donor,
- g) the name of the ART provider to whom the gamete was provided
- h) the date on which the gamete was provided.

Individuals, conceived prior to 1 January 2010 as a result of ART treatment using donated gametes, may provide any or all of the following information to the Secretary, NSW Health for inclusion in the Voluntary Register:

- a) the sex, full name, residential address and date and place of birth;
- b) any medical history or genetic test of the child or the child's family that are relevant to the future health of the donor or any descendants of the donor.

### **Who can access information on the Voluntary Register?**

Information on the Voluntary Register will only be disclosed in accordance with the consent of the person who provided the information to the Voluntary Register.

This means, that if a donor or donor conceived individual wants to include their information on the Voluntary Register, they must advise the Secretary, NSW Health as to who can have access to their information.

### **Can I remove my information from the Voluntary Register?**

Yes. If you have provided information to the Voluntary Register, and you later change your mind, you can have the information removed from the Voluntary Register by notifying the Secretary, NSW Health in writing.

### **I was conceived before 1 January 2010, can I find out information about my donor?**

If you were conceived before 1 January 2010, you will be only be able to access information about your donor if the donor has provided his or her information to NSW Health for inclusion on the Voluntary Register and has consented to that information being provided to you.

If the Voluntary Register does not contain information about your donor, the ART provider who provided the ART treatment may be able to assist you in contacting the donor.

In providing information for the Voluntary Register you may be able to provide additional information that assists in matching donor and offspring information such as a clinic's donor code or the name of the ART provider who undertook the procedures.

However, it is important to remember that the reliability of information on the Voluntary Register and of records kept by the ART provider cannot be guaranteed. You may wish to consider genetic testing to confirm biological links.

**Contact details**

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