

The HART Register and You

Human Assisted Reproductive Technology

INTERNAL AFFAIRS



Te Tari Taiwhenua

What is the Human Assisted Reproductive Technology (HART) register?

One of the purposes of the Human Assisted Reproductive Technology Act 2004 is to establish a register so that donor offspring (i.e. people born from donated embryos, sperm or eggs) can find out about their genetic origins. The Department of Internal Affairs Births, Deaths and Marriages division (BDM) has the responsibility for establishing and maintaining that register.

Who will be named on the register and how do their details get into the register?

The details of donor, donor offspring and their guardians will be held on the register about fertility treatment that has taken place at a fertility clinic. The way the data is collected depends on when the embryos or cells were donated. For donations made prior to 22 August 2005, people can choose whether to provide their details for inclusion on the register*. For donations made on or after this date that result in a birth, fertility clinics will provide to BDM details of the donors, offspring and guardians.

*Donor offspring must be over 18 years of age to provide their details, or 16 or 17 with the approval of the Family Court. Guardians can provide the details of donor offspring under 18 years old.

The diagram over the page shows how data feeds into the register.

Who can see the registered information?

The register is a closed register, which means that generally only the people named on the register can access the information, or their guardians if the offspring is under 18 years old. BDM will require identity documentation to verify an applicant's eligibility to access information from the register.

The HART Act restricts the release of some information, depending on when the donation was made and who wants to access it. Refer to the BDM website www.bdm.govt.nz or call BDM (Freephone 0800 22 52 52) for specific details of who can access what type of information. In some circumstances medical professionals can request information from the register.

As a donor offspring what sort of information might I be able to find out about my donor?

If BDM holds the information and if you have the right to access it, you will be able to receive the donor's personal details as well as information about the donor's physical attributes, family history, ethnicity and cultural affiliation. If the donor is Māori, you may be able to find out the donor's whānau, hapū and iwi affiliations.

Is BDM the only holder of Human Assisted Reproductive Technology information?

No. Fertility clinics will continue to hold information about people who use their services, and it may be possible to obtain donor/offspring information from the clinic that carried out the original treatment.

BDM will provide a single point for collecting and providing access to information on donors and donor offspring relating to donations made prior to 22 August 2005. Fertility clinics will not be providing BDM with any information relating to these births.

Fertility clinics will initially hold more information than BDM for births which resulted from donations made on or after 22 August 2005. Clinics will provide basic donor information to BDM following a birth and will send more detailed information after 50 years.

How does information get into the HART Register?

For embryos, sperm or eggs donated prior to 22 August 2005 (voluntary registration)

■ Donor

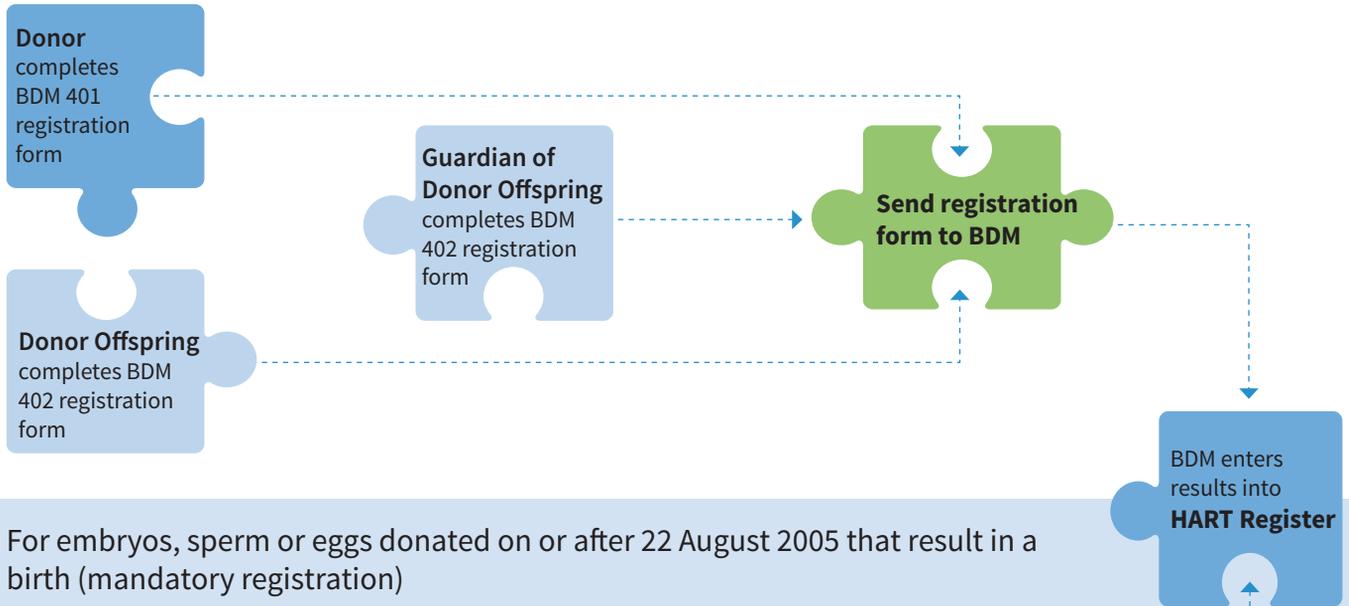
- Donation prior to 22.8.05
- Optional to register your details

■ Guardian of offspring under 18

- Donation prior to 22.8.05
- Optional to register your details and the offspring's details

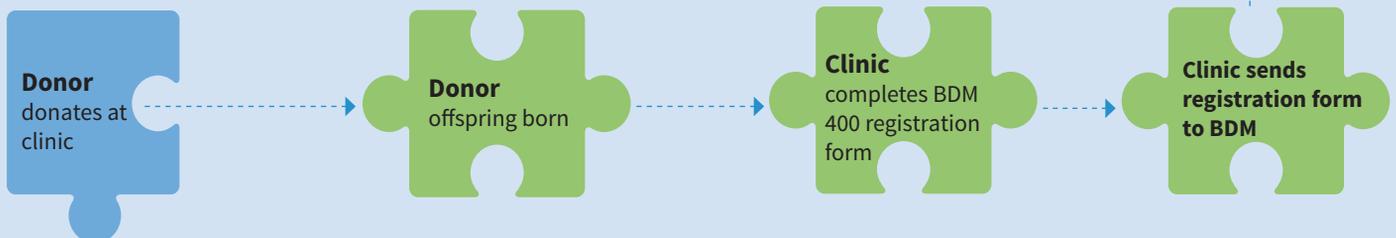
■ Donor offspring over 18

- Donation prior to 22.8.05
- Optional to register your details



For embryos, sperm or eggs donated on or after 22 August 2005 that result in a birth (mandatory registration)

- Donation on or after 22.8.05
- Fertility clinics provide to BDM details of donors, donor offspring and guardians



Is BDM likely to be able to match donors and donor offspring?

For donations made prior to 22 August 2005 BDM can only be sure of a link by matching the donor identifier of a donor to one or more donor offspring, where both parties have provided information to BDM. Fertility treatment in NZ commenced in the late 1970's and during the early years information concerning donors was not usually kept, so there will be some people for whom a link is not possible. The more people who register their details with BDM, the higher the chance will be of making a link. Where a birth occurs from a donation made after 22 August 2005, fertility clinics will provide information to BDM that links the donor and donor offspring.

How will donors and donor offspring be advised that a link has been made?

When BDM receives a registration that links a donor and donor offspring each party will be advised that a link has been made. Parties can then apply to access information about their donor/offspring / siblings* who share the same donor from BDM or fertility clinics. When identifying information is released concerning either the donor or donor offspring, the other party will be advised. Parties may choose to confirm the genetic link through DNA testing.

If I am accessing donor / offspring / sibling information, should I get counselling?

Counselling is recommended for people considering accessing information about their donor, offspring or siblings who share the same donor. A counsellor may also be able to advise on the usefulness of DNA testing. People may choose to approach the fertility clinic where the treatment took place, or speak to an independent counsellor. The person seeking the counselling is responsible for any cost incurred.

*Under the HART Act, the term 'siblings' refers to donor offspring who share the same donor.

Can people listed on the register restrict information given out about them?

Yes. The legislation allows for the release of non-identifying information or identifying information. People on the register can advise BDM whether they give consent to information being released, or want restrictions placed on the release of their information. Consent or the restrictions can be withdrawn at any time by the individuals concerned.

If I am a donor offspring, can I find out if I have any siblings related to the same donor?

Yes, however for births that occurred from donations made prior to 22 August 2005, BDM will only be able to make a match if the relevant people have chosen to be listed on the register. If a link is established between one donor and several offspring records, that information will be available as long as each party has consented or not imposed any restrictions on the release of their information.

There is no cost to donors, offspring or guardians to list data on the register. There is a fee for an individual to check if there is any information recorded about them, and there is a further fee for printouts of the recorded information for people who are entitled to access that information. Further details are listed on the access forms.

Keeping personal details up to date

It is important that the information held by BDM and the fertility clinics is as up-to-date as possible. If you are a donor, donor offspring or the guardian of a donor offspring, please update your details (e.g. change of address) at any time using the registration form. The form asks you to advise whether you are providing new information or updating existing information. There is no charge for advising BDM of changes to your details.

Where can I get HART registration forms?

- From the BDM website www.bdm.govt.nz
 - From the BDM contact centre, Freephone 0800 22 52 52
 - From a BDM customer services office in Auckland, Manukau, Wellington or Christchurch. The addresses are available from the website or the contact centre
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More Information

- For more information on the register, email Births, Deaths and Marriages: bdm.nz@dia.govt.nz
 - Contact the Ministry of Justice for information on the HART Act: justice.govt.nz
 - View the HART Act and regulations at www.legislation.govt.nz
 - For information about fertility treatment; counselling or donations contact a local fertility clinic. Your GP may be able to provide more information
 - To find a counsellor, contact your GP, local fertility clinic or look under Counselling Services in the Yellow Pages
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Postal Address

HART Team
Births, Deaths & Marriages
(HART)
PO Box 10526
Wellington 6143

