

Patient Information – Information for Embryo Donors

What is this leaflet about and who is it for?

This leaflet is about embryo donation and has been designed for patients who have completed a cycle of In vitro Fertilisation (IVF) treatment and have embryos remaining in storage that they no longer wish to use for their own treatment. In such circumstances it is possible to donate these embryos to other couples/individuals who are unable to conceive using their own gametes (eggs or sperm).

Who is suitable for embryo donation?

- Female partner between 18 and 35 when embryos were created
- Male partner between 18 and 45 when embryos were created
- No history of transmissible disease
- No personal or family history of inheritable disorders
- No higher risk of transferring a prion-related disease
- Two or more embryos in storage but this will depend on quality of embryos and method used for freezing.

What does the donation process involve?

You will be required to complete a detailed questionnaire (one for each partner) about your own and family history. These questionnaires will be reviewed by our team and if suitable, an initial appointment will be arranged with our team to answer questions and organise the blood tests. We test for:

- HIV, Hepatitis B, Hepatitis C and Hepatitis E
- Cytomegalovirus, Syphilis
- Human T Cell Lymphotropic Viruses (HTLV 1 & 2)
- Blood Group
- Karyotype (your genetic make-up)
- Cystic Fibrosis (to see if you are a carrier)

Other tests may be required depending on a potential donor's ethnic group for conditions such as Tay-Sachs (Eastern European Jewish), sickle cell anaemia (African / Afro-Caribbean) and β -thalassaemia (Mediterranean / Middle Eastern / Asian).

These blood tests are all taken at the same time and only require one needle to be inserted into the arm. Screening may not be 100% effective and you must tell us in future if you become aware of heritable illness.

If blood tests are satisfactory an appointment with our counsellor would be arranged to discuss the implications of embryo donation. Following this there would be an appointment to complete the necessary consent forms and provide us with proof of identification. At this appointment each of you will also be given a form to take home with you to write a little bit about yourself. This form provides the only freely accessible, personal information about you to any resulting child and can be very beneficial in order for that child to understand their own personality, likes and dislikes etc.

Important considerations

As previously mentioned, we require a number of blood tests to be taken. It is worthwhile bearing in mind that your results may not all be negative, for example we may find out that you are a cystic

fibrosis carrier. If any irregularities were found in either of your blood tests, we would inform you and invite you for an appointment to discuss this.

You should also be aware that donors no longer retain their anonymity. Any child born as a result of your donation can apply for your personal details such as your name, date of birth and last known address. These details will be held on a register at the Human Fertilisation and Embryology Authority (HFEA) and are accessible to a child born of donation from their 18th birthday.

The increasing popularity of direct-to-consumer DNA testing has made it possible for donors and donor-conceived people to become identifiable to each other outside of the current, managed system of information provision. This can happen if they, or a close family relative, sign up to such a service that allows for genetic matching. Many people undergo these DNA tests to learn more about their family heritage, however it has introduced the possibility of a donor or donor-conceived person (or a close relative) being matched with one another.

What will the embryo recipients be told about us?

Only non-identifying information can be given. Physical characteristics such as height, hair colour and eye colour as well as blood group are given so as to try and obtain as close a match as possible or one that is acceptable to the recipient. The recipients may also be given other non-identifying information about you, such as hobbies or interests.

Can we find out what has happened to the embryos?

You can request to be informed whether a child has been born as a result of your donation. You can be told the sex of the child and the year of birth. We may be able to treat more than one patient with your embryos depending on how many you have in storage.

Will we have any responsibility towards a child born as a result of your donation?

No. You will not be legally or financially responsible for any child born as a result of your donation. You will have no legal claim to them and they will have no legal claim to you.

What happens if we change our minds?

You can remove your consent to donate your embryos at any time prior to them being used for treatment. If you would like to withdraw or amend your consent, you can do so by contacting your fertility clinic who would be able to provide you with the necessary forms. There are currently very few embryos available for recipients so thank you very much for considering embryo donation and for reading this document. If we can provide any additional information, please do not hesitate to contact your unit.

Where can I find out more information?

Human Fertilisation & Embryology Authority (HFEA)

The authority that regulates and monitors all licensed fertility treatments.

Website: <https://www.hfea.gov.uk/>

SEED Trust

A national support group, for people who have conceived through donation and those considering being donors.

Website: <https://seedtrust.org.uk/>

Next steps

After reading this leaflet, if you wish to go ahead with embryo donation, please contact your clinic.