

Patient Information – Information for Prospective Egg Donors

Introduction

Thank you for taking time to consider becoming an egg donor. There is currently a shortage of egg donors in Scotland and supply does not meet demand, but you could help change this.

Donation is a generous and positive act and if you decide to become a donor, you will be helping people have children when they otherwise could not.

What is egg donation?

Egg donation is when an individual goes through part of the IVF process in order to have some of their eggs collected, which can then be donated to others to help them have a child. In many cases, people donate to someone they know, such as a family member or friend who may be unable to use their own eggs. Others donate to help someone they don't know have a much-wanted baby.

Why do some people need donated eggs for treatment?

There are many reasons why a couple may need donated eggs, including:

- infertility as a result of cancer treatment or early menopause
- when there is a risk of passing on a serious genetic illness to their children
- when a same-sex male couple wish to have a child

By using donated eggs, couples have the option of using their partner's sperm or donor sperm to create a much-wanted family.

As with other types of donation, motivation to help others in this way is a truly altruistic act and there will be no financial compensation or expenses paid when donating at one of our four NHS Scotland fertility centres. We are asking for your help to support our patients who need donor eggs and also to support our amazing NHS service.

Who can donate eggs?

Egg donors must

- Be under 36 years of age on the day of egg collection
- Have a Body Mass Index (BMI) of less than 30
- Be a non-smoker
- Have no personal or family history of inherited illness or disability
- Screen negative for certain infections or genetic disorders
- Have a good egg reserve (assessed by an ultrasound scan and blood test)

What do I need to think about before donating?

Egg donors provide a wonderful gift to people who long for a child but it is important to be aware that this can have an impact on other people too. This includes the people who receive your donations in treatment, children born from your donations, and you and your own family.

Legally and socially, the person or couple who receive your donation will be the parent(s) of any child born as a result of your donation. The child inherits your genes, therefore any child of theirs will be genetically related to you. You should think about how you feel about this now and try to

imagine how you might feel in the future. You will be given an appointment to speak with one of our counsellors so you have the opportunity to explore potential concerns or implications.

Screening

First Contact and Initial Questionnaire

Once you have read and understood the information provided you will be asked to complete an initial questionnaire. This allows us to determine if you may be suitable to become an egg donor. A member of the donor team will get in touch with you to advise of the next steps.

Donor Profile and Health Questionnaire

This form is used to gather detailed information about you and your family's medical history. This can be used to assess your suitability to go to the next stage of the process.

Clinic Appointments

You will have a number of appointments which may be via video call/phone call at your recruiting centre where you will meet members of the team. Depending on the recruiting centre, the order of appointments and the staff you will meet may vary. All consent, screening and information will be standard and a summary of the different stages of donor recruitment is outlined below.

At your first appointment, we require photographic ID (e.g. driving licence or passport).

A member of the team will provide you with all relevant information about egg donation and discuss with you the implications of egg donation. You will have the opportunity to ask questions about the process so that you can make an informed decision when completing the consent forms.

A doctor will review the information you have given (including family history) and carry out a physical examination.

Blood and swab Tests

Blood samples are taken to test for the potential presence of a number of infections that may be transmissible through donations, such as hepatitis B, hepatitis C, hepatitis E, Human Immunodeficiency Virus (HIV), Human T-cell Lymphotropic Virus (HTLV), Syphilis and Cytomegalovirus (CMV). A vaginal swab is also required to test for Chlamydia and Gonorrhoea.

Blood samples are also taken to check your blood group, to test for blood disorders (e.g. sickle cell and thalassaemia), as well as to carry out genetic screening. Genetic screening includes chromosome analysis and Cystic Fibrosis testing as a minimum. Additional tests may be needed depending on your background.

Further tests may be required depending on your personal and travel history, or due to regulatory changes or new emergent infections. A sample of your blood sample may be retained for testing of any new infections that may emerge in the future or for repeat testing to confirm results.

If your test results indicate an infection or a genetic abnormality, you will usually be unsuitable to donate eggs, depending on the results. If this is the case, you will be given your results and you will be referred for further investigation or treatment to your GP/specialist, if necessary.

Past infection with CMV is very common, affecting up to 80% of the UK population. This virus usually causes a mild flu-like illness. If test results suggest that you have had CMV this has no implication for your current personal health and you will still be able to donate, as long as there is no current

active infection. Your donations will usually be used for recipients who also test positive for past CMV infection.

If you test positive for Chlamydia or Gonorrhoea you will be referred for treatment and deferred from donation. You can be retested after 6 months and if the results are negative (i.e. the infection has cleared), you may be suitable to become an egg donor, taking into account the rest of your medical and personal history.

Ultrasound

An ultrasound scan (transvaginal) and blood test (AMH test) will be done to check your potential to donate eggs (ovarian reserve).

Test results

We will give you the results of all your screening tests. If you still meet the criteria to become a donor, an appointment with a counsellor will be arranged. If any of these test results are abnormal, we will offer you counselling and refer you to the appropriate specialist.

Counselling appointment

An appointment with one of our fertility counsellors will give you the opportunity to discuss all implications or any concerns you may have about becoming an egg donor. You will be able to talk through some of the procedures or ethical aspects of egg donation to help you make an informed decision.

If you have a partner, we would strongly encourage discussing this with them to support your decision to donate your eggs for the treatment of others. They are welcome to accompany you at your counselling appointment.

Does travelling abroad affect whether or not I can become a donor?

It depends on where and when you travel. We will ask you for information about travel within the last year or travel that may have put you at risk of subclinical infections that can persist (e.g. malaria). Geographical risks of transmitting specific diseases (e.g. Zika virus) change frequently; we will assess the risk at the time of your donation and will advise you accordingly.

Do you contact my GP?

It is a legal requirement for clinics to confirm that there is no known reason why you might not be suitable to donate eggs. You will be asked to sign a consent form to allow us to contact your GP to ask for relevant information. All information will be treated confidentially.

Can I be sued for any reason?

Providing you are open and honest about your personal and family medical history, this is highly unlikely to occur. A donor-conceived person born with an abnormality could successfully sue for damages if it is proven that you withheld relevant facts about your personal and/or family's medical history when you donated eggs. It is important to inform us of any inherited conditions or physical or mental illnesses that affect you or anyone in your family, and this includes any new diagnosis after completing donations.

What happens if I'm not accepted as a donor?

If we have been unable to accept you as a donor, you will be given a full explanation for this decision.

We will provide you with your screening results and organise a referral to your GP or a specialist, if appropriate.

Consent and Legal Information

If you are suitable to donate eggs and agree to donate, you will need to sign legally binding consent for the storage and use of your eggs. By law, donor eggs can be stored up to 55 years. You may consent to a shorter storage period. At the end of the storage period, samples that have not been used will be allowed to perish.

Information about you and your donations will be held confidentially by the recruiting fertility centre, storage facility and the Human Fertilisation and Embryology Authority (HFEA). The HFEA is the body that regulates fertility treatment in the UK. It keeps a confidential register of information about donors, patients and their treatments. This is designed to protect all parties, including donor-conceived children.

How many times can I donate?

The maximum times you can donate is 3.

What are my rights and legal responsibilities?

Eggs donors in the UK have no legal obligation to any child born as a result of their donation. You will not be a legal parent and will not be named on a birth certificate; you will not be asked to financially support a child and neither will you have any rights over how a child will be brought up. If you want to find out more, please visit www.hfea.gov.uk.

Can I change my mind?

You have the right to vary or withdraw consent up until your donated eggs have been used for treatment or for training/research (if you have consented to the latter). If you would like to withdraw your consent your fertility clinic would be able to advise you of the process.

What happens with my personal information?

The law requires donors to register both non-identifying and identifying information. Recipients of donor eggs and a donor-conceived person (from the age of 16 years) can find out non-identifying information about their donor, including:

- Physical description (height, weight, eye/hair/skin colour)
- Year and country of birth
- Ethnic group (including that of the donor's parents)
- Whether the donor was adopted or donor-conceived (if they are aware of this) – we are only able to accept donors if they are able to provide a detailed medical history of their biological family
- If the donor had any genetic children when they registered, the number and their gender
- Occupation, religion and interests (if supplied)
- Marital status at the time of donation
- Details of screening tests and medical history
- Skills
- Reason for donating and a goodwill message for the future children
- Pen portrait (donor's description of themselves) – identifiable information will be removed from this and from the good will message.

At 18 years old (or 16 if intending to marry), a donor-conceived person can obtain their donor's identifying information:

- Full name (and any previous names)
- Date of birth
- Town or district of birth

- Last known postal address (or address at the time of registration).

The HFEA would notify you before information is released, so it is important to ensure you provide up-to-date contact information. Donors may request information from the HFEA about the number, gender and year of birth of children born as a result of their donations. This is done via the Application for Information form from the HFEA Register.

What can donors find out about children born from their donation?

Donors cannot be given any information that could potentially identify the children conceived from their donation. However, donors can be informed of:

- The number of children born from their donation
- Their gender
- Their year of birth

Egg Donation

The process for donating your eggs is exactly the same as the early stages of IVF treatment.

- Medication taken as a daily injection or nasal spray will suppress your natural hormone production. This will give your doctor complete control of the fertility process.
- You'll have an ultrasound scan to check your natural cycle is fully suppressed. If it is, you'll start hormone treatment (usually gonadotrophins) to boost the number of eggs your body produces.
- Two days before your eggs are due to be collected, you'll be given a hormone injection to help the eggs mature.
- Your eggs will be collected whilst you are sedated. The procedure takes around half an hour and you may feel a little sore or bruised.
- If you have any reactions to the fertility drugs, it is very important that you let your clinic know straight away.

After the egg donation

Donating your eggs is generally very safe; most people won't experience any health problems beyond slight discomfort of the IVF treatment. After you have donated your eggs it is important to allow a short period of time for your recovery.

- You may experience some pain and discomfort
- You should rest for the next 24 hours and if needed, take regular pain relief like paracetamol and drink plenty of fluids
- You will need someone to take you home
- You will not be allowed to drive for 24 hours
- If you had previously been taking oral contraception, you can start this again but also use condoms for a period of time until this becomes effective

We will call you within a few days to ensure you are feeling well and you should expect a period-like bleed 7-10 days after your eggs have been donated.

In some very rare cases, women develop ovarian hyperstimulation syndrome (OHSS). This is a serious reaction to fertility drugs which happens about a week after your eggs have been collected. Symptoms include:

- Swollen stomach and stomach pains

- Nausea
- Vomiting
- Breathlessness
- Fainting
- Reduced volume of urine

It is important to tell your clinic if you experience any of these symptoms so that they can monitor and provide care if required.

Why I Might Be Contacted in the Future

There may be a number of reasons why we may wish to contact you in the future:

- To ask if you are willing to provide further egg donations.
- To invite you to participate in research, if you consent to being contacted for this purpose.
- If a child born as a result of your donations has been found to have a hereditary condition, we would notify you, with your consent.

DNA Testing and Matching Websites

With the growing availability and use of DNA testing and matching websites, it is possible that donors and donor-conceived people, and/or their close genetic relatives, may become identifiable. This could be through intentional searching or inadvertently when the donor or donor-conceived person is using these services for another purpose, such as researching their historic family ancestry, ethnicity, or seeking genetic health information.

People who are not aware that they are donor-conceived may become aware of this for the first time through their use of direct-to-consumer DNA testing and matching services. Neither the donor nor the donor-conceived person themselves necessarily need to be signed up to such a service for a genetic link, and possibly their identity, to be inferred.

If a donor or donor-conceived person's close genetic family members have opted into genetic matching services, but not the donor or donor-conceived person themselves, then it is still possible (in combination with information from other sources) that other wider genetic relationships may be inferred, which could include the donor or a donor-conceived person.

Thank you

Thank you for taking time to consider becoming an egg donor. We really appreciate your interest and we look forward to hearing from you.