

### Introduction

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

Donor sperm may be needed because of fertility problems; for example donor sperm may be needed when there is a significant male factor contributing to fertility problems and also for treatment of same sex couples. 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. 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 when donating at one of the four NHS Scotland Fertility Centres. We are asking for your help to support patients who need donor sperm.

### Would you be a suitable sperm donor?

We aim to develop a diverse sperm bank and are looking for donors from all nationalities, religions, ethnicities and cultures to meet the demands of people who use this service. We are looking for sperm donors who understand what it means to pass on their genes to children born from donated sperm. You must be aged between 18 and 45 years and have a normal sperm assessment. You need to be able to provide a personal and biological family history (including grandparents) and there should be no significant illnesses or inherited diseases. You need to be able to commit to weekly donations over 2-3 months.

### Who cannot be a sperm donor?

To ensure the wellbeing of future offspring and to meet the requirements of the Human Fertility and Embryology Authority (HFEA), we are unable to accept donors who:

- Are unable to provide a biological family history
- Have a genetic abnormality that could lead to a serious physical or mental condition in their offspring
- Are identified as being at increased risk of infections that can be transmitted through their donation
- Cannot provide the required documentation to verify their identity

Please note that the law limits the number of families created from each donor and so we cannot accept a donor who has previously donated at another centre.

### What do I need to think about before donating?

Sperm 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 a sperm donor. A member of the donor team will get in touch with you to advise of the next step.

### Donor Profile and Health Questionnaire

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









### Clinic Appointments

You will have a number of appointments which may be via video call/phone call or in person at your recruiting centre where you will meet members of the donor team. Depending on the recruiting centre, the order of appointments and the staff you will meet may vary. The overall process however is standardised and a summary of the different stages of donor recruitment is outlined below.

At your first appointment, we require photographic ID (i.e. driving licence or passport) to confirm your identity. If your appearance or details change over time (e.g. through deed poll or through medical/surgical treatment) then there will be a requirement to re-confirm your identity.

A member of the donor team will provide you with all relevant information about sperm donation and discuss with you the implications of sperm 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 biological family history) and carry out a physical examination.

### **Blood and Urine 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 urine sample 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 disease and thalassaemia), as well as to carry out genetic screening. Genetic screening includes chromosome analysis and testing for abnormalities in the Cystic Fibrosis gene 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.

The samples taken for the above testing will be sent to various laboratories, including laboratories in hospitals and also at the Scottish National Blood Transfusion Service. A sample of your blood (serum) sample may be retained and stored by one or more of these laboratories for testing of any new infections that may emerge in the future or for repeat testing to confirm initial results.

If your test results indicate an infection or a genetic abnormality, you will usually be unsuitable to donate sperm, depending on the results. Even if successfully treated, some past infections e.g. syphilis, will be detectable for life, so that donation will not be possible. If this is the case, you will be given your results and you will be referred for genetic counselling or further investigation and/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 usually has no implications 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 a sperm donor, after taking into account the rest of your medical and personal history.





All sperm donations are stored for at least three months and you are then re-tested for infections (including hepatitis B, hepatitis C, hepatitis E, HIV, HTLV, Syphilis, CMV, Chlamydia and Gonorrhoea). If the results are satisfactory, your donations can be released for the treatment of patients. Rescreening for these infections is required every 3 months during donation. New emergent infections/new regulations may also require testing for additional infections.

### Semen Analysis and Test Freeze

There are minimum requirements for sperm quality that need to be met to ensure samples are suitable for use in treatment of patients.

You will be asked to produce a semen sample to assess the quality of your sperm. We assess the sperm count, motility (how they swim) and their shape. Your sample will undergo freezing and thawing to assess sperm survival.

### **Test results**

We will give you the results of all your screening tests and if you still meet the criteria to become a donor, we will advise you of your next appointment. If any of these test results are abnormal, we will offer you counselling and refer you to the relevant medical staff.

### **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 a sperm donor. You will be able to talk through some of the procedures or ethical aspects of sperm donation to help you make an informed decision.

If you have a partner, we would strongly encourage discussing this with them to check if they support your decision to donate your sperm 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 sperm. 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.

### Do you discuss my history/results with others?

All donors/patients making use of NHS services can be assured of confidentiality at all times. In order to ensure safe and effective management of donors/patients it is important to be able to have input from various colleagues within the NHS to ensure the care offered is optimised for the individual. Therefore, the information you provide to a given member of staff may be shared as required and in confidence within the team, or with specific experts e.g. if a second opinion about a particular condition may be required to ensure that you receive the best care. Information about you, including personally identifiable data that will include your gender history, will be collected, stored and shared with relevant colleagues (including the Scottish National Blood Transfusion Service (SNBTS)) involved in the management of your donation as required by regulations and to ensure safety of the donation, ensuring confidentiality at all times.





### Can I be sued for any reason?

Providing you are open and honest about your personal and biological 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 biological family's medical history when you donated sperm. 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 to my sperm donations if I die or lose mental capacity?

By consenting to become a sperm donor you are agreeing to donations being stored and used if you die or lose mental capacity. If you do not want your sperm (or embryos created with your sperm) to be used in the event of your death or mental incapacity, you can record this as a restriction on the relevant HFEA consent form. Please note however that centres can only act on donation restrictions relating to death or mental incapacity if they are made aware of a donor's death or mental incapacity.

### 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. Common reasons include poor sperm quality at initial analysis, poor sperm survival after freezing and thawing or testing positive for an infection. Sperm quality can vary for a number of reasons including illness, stress and lifestyle changes (e.g. smoking, diet, alcohol consumption).

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 sperm and agree to donate, you will need to sign legally binding consent for the storage and use of your sperm. By law, donor sperm can be stored for up to 55 years. Any embryos created from such donations, can also be stored for a further 55 years from when they are created. You may consent to a shorter storage period. At the end of the storage period, or at an earlier time point if the donation is no longer required, 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 and each Centre that will be using your sperm in treatment, the storage facility (SNBTS) 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 children can be born from my donation?

By law, donated sperm can be used to create up to ten families from each donor. This number can be lower if you wish. You should be aware that there is no limit to the number of children within each family due to the possibility of multiple births (e.g. twins, triplets) or siblings.

### What are my rights and legal responsibilities?

As long as the sperm donation and any treatment using the donated sperm is carried out in a HFEAlicensed clinic, sperm 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 <u>www.hfea.gov.uk</u>.





### Can I change my mind?

You have the right to vary or withdraw consent up until your donated sperm has been used for treatment, or embryos created using your sperm have been transferred for treatment. You can also vary or withdraw your consent for training/research (if you have consented for these purposes) if your donation is still available for use for such purposes.

### What happens with my personal information?

The law requires donors to register both non-identifying and identifying information. Recipients of donor sperm 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 (this may result in the disclosure of your gender history)
- 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-todate 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 from the HFEA Register.

Donors must consent to the disclosure of information to ensure the welfare of the donor, the potential offspring and the recipients.

### **Sperm Donations**

Once accepted as a sperm donor, you can make sperm donations by appointment at the fertility centre using our dedicated facility. Before each donation appointment, you need to abstain from ejaculation for a minimum of 2 days and ideally not more than 7 days. The quality of each donation is checked before being frozen for storage.

You will be rescreened for a number of transmissible infections every 3 months during the time you are donating. You will also need to return to the fertility centre to be rescreened up to 6 months after your last donation. After the quarantine period and repeat testing, sperm donations are released for patient treatment and may be transferred to a centralised storage centre facility at the Scottish National Blood Transfusion Service.





### Why I Might Be Contacted in the Future (after rescreening)

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 sperm donations. Although we aim to store enough donations for patients returning for donor-conceived siblings, there may be times when further donations are required.
- 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 (including gender history) may be inferred, which could include the donor or a donor-conceived person.

### Thank you

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

