



The Shrewsbury and
Telford Hospital
NHS Trust

Patient Information

The Shropshire and Mid Wales

Fertility Centre

Information for Donor Sperm Recipients

Shropshire and Mid Wales Fertility Centre

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Introduction

In fertility treatment donated sperm is often used in the following cases:

- A heterosexual couple where it is unlikely or impossible for them to achieve a pregnancy using the male partner's own sperm.
- A heterosexual couple where it is likely or possible that an inherited condition may be passed on to any resulting offspring by the male partner.
- A same-sex female couple hoping to achieve a pregnancy.
- A single woman hoping to achieve a pregnancy.

Donors may be known to the patient or may be anonymous.

Donated sperm can be used as a part of an intrauterine insemination cycle (DIUI) or in vitro fertilization (DIVF).

In a DIUI treatment, a sample of sperm is transferred to the uterus (womb) at the correct time in the menstrual cycle using a thin tube called a catheter.

A DIVF cycle involves using medication to stimulate the woman to produce more eggs than normal and these are collected in a medical procedure that is performed under sedation. The collected eggs are mixed with a sample of donated sperm in the laboratory and checked for fertilisation the following day. Once fertilised eggs have developed into embryos, an agreed number can be transferred back into the uterus and the remainder frozen for use in a future treatment. The sperm of some donors may only be suitable for use in intra-cytoplasmic sperm injection (ICSI) cycles where the sperm is injected directly into the egg in the laboratory.

Our regulating body, the Human Fertilisation and Embryology Authority (HFEA), keeps a register of information of those who donate their sperm, eggs or embryos for the treatment of others and of those that have had treatment using a donation. This leaflet explains why they do this and in what circumstances certain information can be disclosed.

This information booklet is designed to help patients having treatment using donated sperm to understand what is involved and its implications. Information on other aspects of treatment will be given separately.

What happens next?

Once you have been told that donated sperm is your only or best chance of becoming pregnant you will be offered the chance to talk to the Centre's independent counsellor. If you decide to continue with treatment using donor sperm, you will be contacted by the department's donor sperm coordinator. You will need to have some additional blood tests organized which will check if you have ever been exposed to a virus called Cytomegalovirus (also referred to as CMV) and your blood group (if required).

Blood group

Blood Group - This blood test is optional; you can decide if you would like to source a donor with a specific blood type that may match you or your partner (if applicable). It is not an essential test and trying to source a donor with a specific blood group may reduce the number of donors available to you. The blood type rarely has relevance for the choice of donor, just as it is rare to consider the blood type important when finding a partner if

trying to conceive under natural conditions, further information can be found on the NHS website (<https://www.nhs.uk/conditions/blood-groups/>).

Rhesus factor - You should be aware however that you may want to match the Rhesus factor (usually shown as a -ve or +ve after your blood group) in some circumstances to avoid possible problems in pregnancy. Rhesus factor is only important if your blood type is Rhesus negative and the chosen donor is Rhesus positive. In most cases no problems occur in the first pregnancy, but following pregnancies issues can arise. Pregnant women are always given a blood test so that any necessary treatment to prevent complications can be provided. Further information on Rhesus factor can be found on the NHS UK website (<https://www.nhs.uk/conditions/rhesus-disease/>), please discuss further with the donor coordinator if required.

Cytomegalovirus – This is often referred to as CMV; it is a common virus in the same family as the herpes virus that includes chicken pox and cold sores. Most people will not know if they have been previously infected with CMV as an active infection normally presents very similarly to a common cold or the flu and typically does not result in lasting effects following recovery. Following infection, most people gain immunity from the virus, these individuals will test CMV positive. A simple blood test can detect if an individual has an active infection or if they have gained immunity from a previous infection (CMV positive). If they have not gained immunity from a previous viral exposure, these individuals will test CMV negative.

If a CMV negative woman becomes infected during pregnancy, there is a risk of the foetus being infected as well, this is known as a congenital infection. The majority of children born following CMV exposure will have no health issues. However, approximately 1 in every 5 children born with the virus will develop permanent problems due to the infection. These problems include hearing loss, physical and motor impairment, seizures, autism, learning difficulties and visual impairment. It is therefore essential that we consider CMV status when sourcing donor sperm for use in assisted conception.

As CMV is a very common virus a large proportion of sperm donors have been exposed to the virus and are therefore CMV positive. If you and your partner (if applicable) test negative for CMV, it's essential to select a CMV negative donor, as CMV can be transmitted via body fluids such as semen. If either you or your partner (if applicable) test positive for CMV, we can use either a CMV negative or positive donor.

Finding a sperm donor

Your options are:

1. To use an anonymous donor that clinic staff will guide you to source either from men who have donated directly to the clinic or from an external sperm bank. If you are an NHS patient the cost of the donor sperm is often covered, depending on the area you live in. If you are funding your own treatment you will have to pay for the sperm yourself. This can be in the region of £1250 to £1800.00 per treatment. Our donor sperm coordinator will work with you to guide you through the process of donor selection. As any offspring are likely to inherit physical characteristics from the sperm donor you may wish to express preferences in terms of hair colour, skin tone etc to match that of your partner if you have one. We work closely with several sperm banks, and we will provide information regarding the companies we use once you are at the selection stage.

2. Ask a friend or relative to donate their sperm to you as a known donor. If you would like to consider using a known donor, additional information will be provided to you and the donor regarding the process. All donors, whether known to you or anonymous, must have counselling and screening as described below. The process to become a known donor can be lengthy as strict screening processes must be followed. This may take a minimum of six to nine months to complete. In addition, if you are funding your own treatment, the costs of processing a known donor would also need to be covered, which can be in the region of £2000 to £2500.

Counselling and Screening of Donors

All prospective donors are seen by a fertility doctor and scientist, as well as the Centre's independent counsellor and nursing staff. The donors are informed that any child born as a result of their donation will be the legal child of the individual/couple they have donated to. A detailed medical and family history is taken, and the donor's GP is contacted to check they have no issues relating to any health concerns of the prospective donor.

Screening tests are carried out on the donor to check their suitability and health status to reduce the risk of transmitting any illness (including certain viral and bacterial infections) from the donor to the recipient or embryo. However, the screening process does not guarantee that any child born as a result of donor treatment would be healthy and free from genetic disease or that the donor is free from all infectious disease.

Counselling of Sperm Recipients

All patients seeking treatment with donated sperm are carefully counselled by members of the fertility team and must be seen by the unit's independent counsellor. We ensure that the rights of the unborn child conceived after sperm donation are carefully considered during consultations.

The Importance of Telling Children About Their Donor-conceived Origins

Fertility centres are now required by law to give patients undergoing donor treatment information about the importance of telling any resulting child that they are donor-conceived at an early age. Centres are also obliged to inform patients about suitable methods for doing so.

The Donor Conception Network (DCN), an organisation that helps parents of donor conceived people discuss these issues with their children, has produced a series of booklets which can be downloaded at www.dcnetwork.org.

Donor Anonymity

Unless you are using a known donor, sperm donors are "anonymous". They will not know the identity of the patients who receive their donation and the recipient will not know the identity of the donor.

Patients receiving donor sperm are given information on the physical characteristics of the donor such as eye colour, hair colour, blood group, etc. Recipients can also be provided with the pen portrait provided by the donor on request. This pen portrait (if available) can provide additional information which can include their reason for donating, a good will message and a description of themselves as a person. Any information which may identify the donor will be removed.

The identity of sperm donors who donate anonymously will only be known to Centre staff and the Human Fertilisation & Embryology Authority (HFEA). Any child born as a result of donor treatment will have the right to contact the HFEA at the age of 16, at which time they will be entitled to receive the following non-identifying information about the donor:

- Physical description (height, weight, and eye, hair and skin colours)
- Year and country of birth
- Ethnic group of the donor and his parents'
- Whether the donor had any genetic children when they registered and the number and gender of those children
- Whether the donor was adopted or donor conceived (if they are aware)
- The number, gender and year of birth of any half/full siblings they may have
- Other details the donor may have chosen to supply (e.g., occupation, religion and interests)
- Marital status (at the time of donation)
- Details of any screening tests and medical history
- Skills
- Reason for donating
- A good will message
- A description of themselves as a person (pen portrait)

Any child born as a result of donor treatment will have the right to contact the HFEA at the age of 18, at which time they will be entitled to receive *identifying* information after appropriate counselling and notification to the donor which will include:

- Donor's full name (and any previous names)
- Date of birth and town or district where born
- Last known postal address (or address at time of registration)

The donor will not have any obligations towards such children. The couple being treated will be the legal parents.

Any child born as a result of donor treatment may request anonymous information about any donor conceived genetic siblings from the age of 16. From the age of 18 they can be given identifying information about genetic siblings with mutual consent.

They may also request information about the possibility of being related to the person they intend to marry or enter into a civil partnership with at any age and from the age of 16, information on the possibility of being related to a person they intend to enter into an intimate physical relationship with.

Recipients should note that up to 10 families can be created with one donor's sperm and that any child born as a result of donor treatment could have a number of genetic half siblings. Recipients should also note that the 10-family limit only applies to treatment at licensed clinics in the UK. It should also be noted that there could be additional families created if a donor has also donated overseas, or if the donor has been imported into the UK for use in treatment. Similarly, once a UK donor has reached the 10-family limit, the sperm samples from that donor can be exported to other countries, increasing the number of siblings.

As a recipient of donated sperm, you should also be aware that the donor may request the following information regarding their donation:

- The number of children born

- The gender of the children
- The year the children were born

If you give birth to a child following donor treatment you will be entitled to ask for:

- All non-identifying information about the donor
- Information about the number, gender and year of birth of your child's genetically related donor-conceived siblings

Counselling and support services are available to discuss the implications of receiving this information either through the fertility unit or independently.

Are there other ways donors can be identified?

Yes; although the fertility clinic and the HFEA will continue to manage (and potentially disclose) the donor's information in line with the Human Fertilisation and Embryology (HFE) Act, donors and recipients need to be aware that it is possible for them to be identified through direct consumer DNA testing matching services e.g., '23 and me', and that this is outside of the control of both the clinic and the HFEA. It may be possible for those not registered with a consumer DNA matching company to be traced through genetic relatives that are registered.

Things to consider

Costs

Most NHS treatments have the additional cost of the donated sperm included in their NHS entitlement. Private or self-funded patients will pay for their treatment, including any medication and the cost of the donor sperm themselves. The cost of the sperm alone can be between £1250 and £1800 per treatment. The exact cost of the sperm will be dependent on where your chosen donor is sourced. This will be explained by clinic staff during the donor matching process. Further information on the cost of fertility treatment can be found on our website www.shropshireivf.nhs.uk.

Risks

- Donor Screening

Donors are screened prior to donating to check for diseases or conditions that may be passed on to the recipient or any resulting offspring. It is, however, important to note that this screening is not a guarantee that the donor is free from all disease or inherited conditions, nor that donor treatment will result in a healthy pregnancy. The clinic and the HFEA monitor the outcomes of all fertility treatments, including donor treatments. Should there be a cause for concern with the outcomes of treatments using a particular donor (e.g., a higher-than-normal rate of miscarriage or babies born with health conditions) then the donor will be withdrawn from future treatments whilst this is investigated. On rare occasions, if embryos have already been created using a donor that is temporarily stopped from use, access to the embryos may also be placed on hold. Unfortunately, if a donor and or embryos are placed on hold, we would not be responsible for the loss of any planned treatment cycles. We would not be able to offer any refunds for costs

incurred or offer replacement treatment either for NHS funded cycles and or self-funded cycles.

It is also important to note that current screening requirements may be different to those applied to previously recruited donors as screening regulations may change over time.

Human papillomavirus or HPV, is the name of a common group of viruses. Depending on the type, HPV can live in the mouth, throat, vagina, penis, and/or anus. The virus can be transmitted easily between individuals infected and it is therefore a very common sexually transmitted infection (STI). Since HPV infection can be asymptomatic, many people may not even know that they have been infected. Most HPV infections will resolve in about 12 months as many people's bodies can fight off the virus without further problems. Despite this, health problems are more likely to occur in some individuals and especially people with a compromised immune system. One of the biggest complications of HPV is cervical cancer and other genital cancers. Screening for HPV in men is complex and it is currently not possible to screen donors for HPV prior to or during their semen donation. Therefore, the use of donor sperm carries a risk of HPV transmission and it is especially important for women presenting for treatment to be aware that they may be exposed to HPV and therefore potential cancer risk. In order to minimise the risk of HPV transmission, all sperm donors are required to provide information about previous STIs, and they also undergo a physical examination to determine if they have any symptoms of potential STIs such as genital warts or lesions. Any donor with past infection and or symptoms would not be permitted to donate. If you have any concerns of HPV transmission prior to receiving donor sperm treatment you may wish to explore the possibility of vaccination for HPV, which may be available to individuals that are not yet sexually active. It is also important to ensure compliance with the NHS cervical screening programme.

- Potential Miscarriage

The risk of miscarriage following IVF/ICSI after a positive pregnancy test alone is about 30%. Once the pregnancy sac has been seen and fetal heartbeat identified at a 7-week scan then the risk of miscarriage is significantly lower at about 5%. The risk of miscarriage after IUI is the same as a naturally conceived pregnancy.

- Risk of Ectopic Pregnancy

The risk of a tubal or ectopic pregnancy (a pregnancy that develops outside the womb) after embryo transfer (IVF/ICSI) is about 3-5%. It is possible, though very unlikely, to have a pregnancy in the womb and a tube at the same time. The risk of tubal or ectopic pregnancy after IUI is the same as a naturally conceived pregnancy.

- Risk of Abnormalities

The risk of abnormalities in babies born after IVF is likely to relate to your age and family history and that of the donor. It is thought that there is a slightly increased risk of some abnormalities in babies born as a result of the ICSI procedure (please refer to our patient information A47C for more information on this). This checklist is given to you at or before your consents appointment and information is also available on our website <https://www.shropshireivf.nhs.uk/information-leaflets/>.

Sibling sperm

Providing the sperm or embryos are available and within consented time frame, they can be used in treatment. If patients would like to use the same donor in the future, reserving sperm samples is possible if available but will incur a fee.

On some occasions, sibling sperm or samples reserved for specific patient use may be approaching their consented storage period. In these instances, patients will be contacted in plenty of time to notify them of expiry and offer the opportunity to use the samples in treatment or potentially to extend the storage (please see section below for more information).

- Donor consent to storage and use

Following a change to storage laws, fertility patients now have more time to make important decisions about their future as it enables all patients to store their eggs, sperm, and embryos for up to 55 years, providing they re consent every 10 years.

From the 1st of July 2022, donors can also store their sperm for use in other people's treatments for up to a maximum of 55 years, and they are not required to renew their consent within their original consented period. However, prior to the new storage regulations being implemented on the 1st of July 2022, automatic storage beyond ten years was not possible. If a donor gave consent to storage of their sperm and any embryos created using their sperm beyond 10 years prior to 1st July 2022, the sperm/embryos must not be stored beyond 10 years; unless the donor has been contacted, informed of the July 2022 changes to the HFEA storage regulations, and it is documented that they still agree for their sperm to remain in storage and can be used in other people's treatments or they re consent using new storage consent forms. This is because donors who consented prior to 1st July 2022 will have been informed that only patients who are prematurely infertile would be able to store beyond 10 years, and that a medical practitioner would be required to approve the storage extension. As this is no longer the case, we cannot assume that the donor would still consent to storage extension.

- It is important to know that the donor can change or withdraw consent at any point until their sperm or embryos created with their sperm have been used in treatment.
- Unfortunately, if a donor was to withdraw consent, we would not be responsible for the loss of any planned treatment cycles and or frozen embryo transfer cycles. We would not be able to offer any refunds for costs incurred or offer replacement treatment either for NHS funded cycles and or self-funded cycles.

Consent and Information Session

You will be seen by a nurse before you start treatment. During this time, you will be taken through the medical and ethical issues involved in your treatment and you will be able to ask any questions you might have. You (and your partner if you have one) will have some screening bloods taken and sign relevant paperwork.

To start the donor matching process, one of the donor sperm coordinators will contact you by phone to inform you of the process involved in sourcing a suitable donor. The telephone consultation will provide you with information about the donor banks we can use to source a

sperm donor for your treatment. When a donor match has been found and you have completed implications counselling you will be invited to a consents and information appointment. During this appointment you will receive information about potential treatment plan and sign consent forms and may have further blood tests. The nurse will explain in detail what happens in a typical treatment cycle so that you are prepared for what is involved.

During the consents session you will be asked to complete important paperwork to ensure that the partner of the woman being treated (if applicable) is recognised as the legal parent of the child. Issues can arise if the woman being treated is still legally married to someone else, other than their current partner, so it is very important you disclose this to staff if this is the case.

This leaflet only covers information specific to those using donated sperm. You will be given other information throughout your treatment which must be read along with this leaflet.

Other Sources of Information

Our website: www.shropshireivf.nhs.uk

Donor Conception Network: www.dcnetwork.org

The Seed Trust: www.seedtrust.org.uk

NHS 111 - A fast and easy way to get the right help, whatever the time. NHS 111 is available 24 hours a day, 365 days of the year.

Telephone: 111 (free from a landline or mobile)

Website: www.nhs.uk

Patient UK - Provides leaflets on health and disease translated into 11 other languages as well as links to national support/self-help groups and a directory of UK health websites.

Website: www.patient.info

Contact details for more information

Fertility nursing team 01743 261202 option 2 or call the hospital switchboard on 01743 261000 and ask to be put through to the Fertility unit. Please note the department accepts calls from 9am to 5pm Monday to Friday.

Patient Advice and Liaison Service (PALS)

We act on your behalf when handling patient and family concerns, liaising with staff, managers and where appropriate, relevant organisations to negotiate immediate or prompt solutions. We can also help you get support from other local or national agencies.

Royal Shrewsbury Hospital, Tel: 0800 783 0057 or 01743 261691

Princess Royal Hospital, Tel: 01952 282888

Information in other formats

Please contact the Fertility Unit to discuss if you need this information in another format or different language.

References

HFEA: www.hfea.gov.uk

Website: www.sath.nhs.uk

www.shropshireivf.nhs.uk

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