



The Leeds Centre for
Reproductive Medicine

SPERM DONATION FOR RECEIPIENTS

Welcome

This booklet has been written to help fully inform you of the purpose and techniques of this procedure. Please ask for clarification and let us have your comments and suggestions for future editions. It is important that you read and understand all the material as our intention is to keep the risk of an error in treatment at its minimum.

HOW TO CONTACT US!!

Address:

The Leeds Centre for Reproductive Medicine
Leeds Teaching Hospitals NHS Trust
Seacroft Hospital, York Road
Leeds, West Yorkshire LS14 6UH

Telephone:

- ❖ Monday to Friday (8.00am to 5.00pm):
 - Administrative queries: **0113 206 3100**
 - Clinical queries: **0113 206 3100**
- ❖ Saturday, Sunday & Bank Holidays (8.00am to 12.00pm):
 - Clinical queries only: **0113 206 3102**
- ❖ When in emergency:
 - During working hours ring The Centre on the direct line or go to a local Accident and Emergency department
 - Outside the above hours please ring the St James's Hospital switchboard: **0113 2433144**
You will be put through to the duty person for The Leeds centre for Reproductive Medicine or go to a local Accident and Emergency department

Fax: 0113 206 3120

Email: leedsrmenquiries@leeds.nhs.uk

Website address: www.leedsreproductivemedicine.co.uk

Ethnic Minority Languages: We will be pleased to organise a session (with prior notice) for an official translator / interpreter (if available) to translate the contents of this booklet.

1. Patient Support Group

On line internet support and information is available. The website is run by current and ex-patients who have had similar experiences and who are prepared to share their experiences. They will also be able to get information regarding groups in your locality. We recommend that you contact the support group for your own benefit and that of others. Please contact The Leeds Centre for Reproductive Medicine (The Centre) for the address.

2. Should we consider the use of donated sperm?

The purpose of this leaflet is to help potential donors explore the implications of donating sperm using several methods of treatment ranging from the simpler methods such as DI to the more complicated, such as IVF and/or ICSI with donated sperm. This booklet is certainly not meant to replace the opportunity for you to discuss the questions with a counsellor. It may however help to remind you of those discussions, so that you can explore them further. You should not feel under pressure when making up your mind.

3. Who needs Sperm Donation (DI)?

Broadly the recipients are female partners of men suffering from

- a) azoospermia (absence of sperm)
- b) sub-fertility due to genetic causes
- c) Couple's suffering from dominant hereditary diseases
- d) Same-sex couples and single women

4. What causes male sub-fertility?

There are the following common causes:

- a) Genito-urinary infections e.g. Chlamydia, mycoplasma and several other related infections
- b) Undescended or delayed descent of testes
- c) Low or no sperm in the ejaculate after vasectomy and reversal of vasectomy
- d) Genetic causes (some may be hereditary)
- e) Diseases requiring removal of the testis e.g. cancers
- f) Diseases requiring chemotherapy or radiotherapy
- g) Hypothalamic and pituitary disorders
- h) Systemic diseases such as cystic fibrosis, thalassaemia and many others

• Genetic or hereditary male sub-fertility:

The incidence of chromosomal abnormalities is approximately 13.7% in men with no sperm in the ejaculate and 4.6% in men with low sperm counts. The incidence in men with normal sperm counts is 0.5%. This information is not relevant to the offspring if they have been conceived with donated sperm.

• Normal chromosome pattern:

This for every man is 46XY. There are 22 pairs of normal chromosomes (total 44) called the 'autosomes' and these are responsible for the general characteristics and bodily functions. The 23rd pair are the sex chromosome and in men this is expressed as XY, where X codes for female development and Y codes for development as a male. Females have two X-chromosomes and hence an XX pattern. In males the Y chromosome is the dominant one and this dictates development of the baby as a male.

• Abnormal patterns:

1. In the majority of men, there is no abnormality of chromosome numbers i.e. the total numbers are normal as 46XY, but a structural aberration of the sex chromosome exists with either missing or modified genetic information on the Y chromosome. This chromosome is responsible for testicular development and sperm formation. In the event of loss of genetic material or its modification, men may have genetically determined low sperm counts and sub-fertility. We do not yet know all forms of gene deletions or mutations although active research is bringing more new information forward at a considerable pace.
2. In couples undergoing ICSI treatment with their own sperm, the same Y chromosome will be passed on to the sons and there may be a risk of passing the defect to the male child whose future fertility may be affected. This problem would not occur if donor sperm is used.
3. In some men, there is an extra sex chromosome giving a pattern of 47XXY or 47XYY. The ICSI success rate in this case is also very low and variable. This problem would also not occur if donor sperm is used.
4. If there is an abnormality with the main 22 pairs of chromosomes, then the success rates after ICSI are also lower, there is an increased risk of miscarriage and, in ongoing pregnancies there will be a risk of congenital abnormality and/or mental retardation. This problem too would be bypassed if donor sperm is used.

Regulation of sperm donation:

Human Fertilisation and Embryology Act

Human Fertilisation and Embryology Act was passed by parliament in 1990 and became law on 1st August 1991. Simultaneously a statutory Human Fertilisation and Embryology Authority (HFEA) were established for the regulation of all treatments and research pertaining to human eggs, sperm and embryos. This authority licenses centres, its staff and regularly inspects the centres for compliance with the law and the HFEA Code of Practice. By law every HFEA Licensed Centre is required to report every treatment cycle and its outcome to the HFEA. This information is then analysed and published periodically on the HFEA website (www.hfea.gov.uk).

HFEA register

The Authority keeps a confidential register of identifying information on all patients and their treatments, donors and recipients and children born after all licensed treatments. This register was set up on 1st August 1991 and contains above information from that date onwards. From 1st of October 2009 the HFEA requires your permission to disclose either your identifying or non-identifying information to named researchers who approach the HFEA and have their research approved by the authority. Your consent will be requested when you are registered with the HFEA.

Using Donor Eggs, Sperm or Embryos

Identifying information about donors is held on the HFEA register and may be given to any child born from a donation once they are eighteen years old (*if the donor is registered as identifiable*).

A donor conceived person aged 16 and over is entitled to apply to the HFEA and access non identifying information that the HFEA holds about the donor. Sixteen year olds who intend to enter an intimate physical relationship can submit a joint application to establish whether they are genetically related.

From the 1st of October 2009 the HFEA permits centres to release non identifying information to recipient couples about their donors. This includes information about the screening tests performed before donation as well as personal non identifying information such as hobbies, likes and dislikes, professional qualifications and a personal message written by the donor.

We encourage couples to tell the child or children if donated gametes had been used. This we advise should be done at an appropriate time in their lives. Information, support and implication counselling is available within the clinic to help guide them through this process. External support is also available for them-see [useful addresses](#).

If you would wish to seek information about your child's donor or genetically related donor-conceived siblings you may find counselling, or similar support services, on the implications of receiving such information beneficial and highly advisable.

Legal Parenthood

The law defines the legal mother as the woman who gives birth and her partner as the father irrespective of the source of sperm or embryos created with donated sperm unless the couple are legally separated or the husband/partner can prove that he did not consent to treatment. The donor has no parental rights or responsibilities.

Both partners of a recipient couple must provide written consent to the use of donated sperm/embryos in the treatment of their partner.

Under the current law, there is no need for the recipient couple to disclose the use of donor sperm/embryos to the Registrar of Births. Therefore you will not expect to be named at any stage.

Unmarried couples concerned about parental responsibility are advised to seek independent legal advice.

Welfare of Future Children

The law states that 'a woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for a father), and of any other child (other children in the household or the family) who may be affected by the birth'.

This applies to every woman whether or not she is resident in or a citizen of the United Kingdom. It is the statutory duty of every centre to have a written procedure for assessing the welfare of the potential child and that of any other child who may be affected.

Factors considered in assessment include:

1. the couple's commitment to having and bringing up a child
2. ability to provide a stable and supportive environment for the child/children
3. couple's medical history and that of their families
4. both partner's health (including their ages) and consequent future ability to look after or provide for a child's needs
5. ability to meet the needs of the children in the event of a multiple birth
6. risk of harm e.g. that of inherited disorders, transmissible disease or abuse, multiple birth, neglect or abuse
7. risk a new born may put on the existing child in the family

It is our statutory duty to identify the person/s who will have the parental responsibility and who will be responsible for the raising of the child. Where necessary, we obtain reports from the general practitioner, other medical specialists, authorities and agencies e.g. social workers, police etc for information to ensure that the child would not be at risk. When treating single women or those in a lesbian relationship we ask the couple to identify a father figure to ensure that the child's/children's right for both paternal and maternal nurturing will be met.

Donors' rights

The donor has the right to change his mind up to the point the sperm or embryos have been placed in the recipient. Embryos created using the donated sperm can only be stored for a patient with the consent of the donor. On the other hand, the donor has no rights once sperm or embryos have been transferred to the recipient.

Limitation to the number of pregnancies with each donor

Legally in the UK, eggs or sperm from any one donor can be used to produce a maximum of TEN children or TEN families. In reality, this possibility is mostly with sperm donors and extremely unlikely for egg donors. However, donors may set a lower limit should they wish to do so.

Sibling pregnancies

In the event of a pregnancy, the recipient couple have the choice of purchasing more sperm from the same donor and storing it so that they can have a genetic sibling/s for their child at a later stage. When ever requested and for this purpose, we try to conserve sperm after the TEN pregnancy limit has been reached.

Consents

As stated above, we can only advise you with respect to the current law and the changes that we can envisage. You are advised to seek more specific and independent legal advice if you are concerned about how a retrospective change in the law might affect your legal position.

All donors are asked to sign appropriate consent forms after they have read the information booklets, have discussed the medical/ ethical issues with the doctors/nurses/counsellor, and are satisfied that their questions have been answered fully. Consents are obtained prior to storage.

Your consent advises us of your informed choice. You always reserve the right to change your mind until but not after the sperm, has been transferred to the recipient. It is however important that all issues are thoroughly considered beforehand so that sudden and unexpected changes that you may later regret are avoided.

Training – All of your eggs, sperm and embryos will be first and foremost used in your treatment or stored for future use.

In all treatment cycles, there are some unfertilised eggs, supernumerary sperm or embryos. Embryos that are not growing at the desired rate or have abnormalities in the appearance of their cells are not suitable for freezing as they are very unlikely to implant and become babies and if frozen they are also very unlikely to survive the freezing and thawing process. These cells are normally allowed to perish.

We request that you permit use of these cells for training in the laboratory. Training of new and young scientists and learning / incorporating new skills for an improvement in our success rates form an essential part of our service. Once these cells (eggs, sperm and embryos) have been used for training, they are always humanely discarded.

Confidentiality

All information regarding your treatment is strictly confidential and subject to both the HFE Act and the Data Protection Act. We may communicate with your general practitioner, referring consultant and other carers only with your written consent.

Once the information has been disclosed to unlicensed individuals it can no longer be controlled by the HFE Act although it will still be under the Data Protection Act and General Law of Confidentiality. At your GP's practice, information will be accessible to other GPs and staff. When changing GPs, your medical records will be transferred to your new GP practice without our involvement or written named consent from you.

From time to time your notes may be inspected by HFEA members for audit, by Commission of Health Improvements (CHI), individuals working for Patient Safety Agency (PSA) and National Care Standards Commission.

You have a right to decline consent when we may need to see your passport for identification. We may also need to consider the reasons for your refusal to consent in our assessments.

We advise you to keep your G.P. informed. They are your primary carers, will also be committed to confidentiality. Sometimes patients request their GP to keep written information regarding sperm donation separate from the practice notes so that this information is not freely available to all the staff in their surgery. You may request them but they may not be obliged to do so.

5. How are the Donors selected?

Donors undergo the procedure voluntarily and for altruistic reasons. The HFEA provides guidance on financial reimbursements to the donor, which covers expenses for travel and loss of earnings (SEED REVIEW: details can be accessed from the ACU staff and the HFEA website). Some patients choose to have a 'known donor' such as a brother of the male partner. This is acceptable after careful implication counselling.

6. Implication counselling

Free counselling services with a trained counsellor are routinely available to all upon request. It can be carried out in The Centre or away from the unit in the Department of Clinical Psychology which you may find less stressful. All counsellors are HFEA licensed. Appointments can be made directly by yourselves or via The Centre. If you require an interpreter, you are advised to give sufficient notice for an independent interpreter to be arranged.

The counselling is entirely confidential and private between you and the counsellor and will not be judgmental or prejudicial. The counsellor is also HFEA licensed and has a statutory duty to give essential information that may affect the Welfare of future or existing children to the team. This is exceptional.

The effect of sperm donation on the donor, his partner and any existing children is carefully discussed. Wherever possible the partner's participation and agreement is sought before proceeding with the donation. If the children of the donor are of an appropriate age the donor is also asked to discuss the matter with his children.

For donors:

All donors undergo consultation with the doctors, infertility nurses and counselling with our psychologist. This is to ensure that all aspects of medical treatment, legal and emotional implications have been discussed and considered. The effect of such a procedure on the donor, his partner and any existing children is carefully discussed. Wherever possible the partner's participation and agreement is sought before proceeding with the donation. If the children of the donor are of an appropriate age the donor is also asked to discuss the matter with his children.

For recipients:

The following counselling is available:

Support: This is to discuss the social and emotional aspects of sub-fertility, help you at times of distress or confusion and minimise the potential impact of treatment outcome to you and your partner.

Implications: When using donor sperm/embryos, you will be asked to see the counsellor to discuss the implications of your treatment. It is best performed when you have read our information booklets, so that you can concentrate on specific issues that are relevant to you.

Therapeutic: The counsellor can help you to devise coping strategies, and to understand your feelings and experiences.

Assessment: Whenever there is a concern that you may not have understood any issues relevant to the welfare of any children, the team may refer you for an assessment by the counsellor.

7. Screening of Donors

The donors are seen by a doctor in The Centre. They have to be 18 to 45 years in age, of normal intelligence, in good health and with no past or family history of severe physical, mental or genetic disease. They are required to undergo a medical examination and details are asked about their personal, medical and family history. A donor may not be accepted whenever a risk is envisaged to him, his existing children or to the future child. All donors have a responsibility to advise the centres of any new developments that may affect the well-being of future children or those already conceived/born after donation.

All donors are carefully screened according to current guidelines and best practice. Please be advised that it is possible that a donor-conceived person who is disabled as a result of an inherited condition that the donor knew about, or ought reasonably to have known about, but failed to disclose, may be able to sue the donor for damages.

Which tests are performed?

Genetic Testing:

- **Chromosome analysis:** All prospective sperm donors have an analysis performed of their chromosomes.
- **Screening for Cystic Fibrosis:** In addition, we routinely test for **cystic fibrosis**. The screening will be performed **for only the 12 commonest gene mutations** in the Caucasian and Northern European populations. These mutations account for 85% of all varieties known to medicine to date. Exclusion of these mutations reduces the risk of being a carrier for cystic fibrosis to about 1% for these populations. In other population's e.g. Asians, the incidence of cystic fibrosis is much lower than that among Caucasians. Whilst all 12 mutations known to be common in the Caucasian and Northern European populations are excluded, the risk of being a carrier among the Asian donors cannot be accurately determined.

It is very important for the recipient couples to understand that not all known gene mutations are screened for and that there may be others that are not yet known. Hence the likelihood of developing this illness is minimised as far as is possible with this screening but has not been completely eliminated.

For non-caucasian donors, additional genetic screens may be carried out to determine prevalent genetic disorders in that population e.g.

- i) Thalassaemia for Chinese, Asian and Eastern Europeans
- ii) Sickle cell disease for black and Asian population
- iii) Tay Sach's disease for Jews

Viral screening:

- **Hepatitis B, C and HIV:** All sperm donors are screened for HIV, hepatitis B and hepatitis C. This must be repeated six months after the donation before the sperm can be used for any recipient, as it is possible for a donor to have been exposed to HIV infection, test negative but the test become positive within the following six months.
- **STD's including Syphilis & Gonorrhoea:** All sperm donors are screened for Syphilis, Chlamydia and Gonorrhoea.
- **Cytomegalovirus (CMV):** This virus commonly infects people and in normal circumstances gives a minor flu like illness. However it can become activated in pregnancy and can harm the baby. It is a very common infection in the normal population and many of us are exposed to it during our lifetime. We screen all donors and use CMV negative donors only for CMV negative recipients. On the other hand, CMV positive recipients can have gametes from both negative and positive donors.

8. What is the risk of a congenital abnormality?

The risk of a congenital abnormality after treatment using donor sperm is believed to be the same as for natural conception in a normal couple that is approximately 1 - 2%. GPs and those responsible for the obstetric care routinely advise the recipient couples about prenatal diagnostic tests as appropriate.

9. How are the Donors matched to the Recipients?

Physical characteristics such as height, weight, body build, hair colour, complexion, eye colour, race and blood group etc are recorded. We try to provide an acceptable match. There are fewer donors and detailed matching is significantly more difficult now. Matching for ethnic origin and rhesus blood group is always performed. Exceptions are always discussed and agreed with the recipient couple in advance. There may be a delay if a perfect match is desired and sometimes it may be impossible e.g. for religion & caste.

10. Freezing of Embryos

Please read this section if you are undergoing an IVF cycle with donor sperm.

Please note that the decisions regarding freezing, storing and discarding embryos formed with donated sperm **must** comply with written consents of both the **donor** and recipient. This includes for how long embryos can be stored and whether or not they can be used after the death or mental incapacitation of the donor or recipient. It is also possible for either donor or recipient to withdraw consent to storage, in which case the embryos have to be allowed to perish.

During treatment, we discuss the outcome of fertilisation and quality of embryos with the recipient. We usually advise embryo freezing only if there are at least three suitable embryos. The embryos can be kept frozen for 5 years (up to a maximum of 10 years in certain circumstances) from the date of freezing.

You have a responsibility for any embryos stored at The Centre. You must advise us of any change of address, personal circumstances, or if you want to change any consents.

11. Research

Research is carefully regulated and centres have to obtain specific research licences for the projects that they conduct or take part in. From time to time we are involved in research projects and we will provide relevant information to you if appropriate.

12. Treatment methods that may be used in recipients

Fertility drugs such as Clomifene citrate is commonly used to encourage the development of eggs within a follicle and then to ovulate (release of the egg). The use of these fertility drugs encourages multiple eggs to develop simultaneously and hence increases your chance of a conception. As multiple eggs are released the risk of a multiple pregnancy also increases. In order to protect you from a high order multiple pregnancy (e.g. more than twins) or from excessive stimulation of the ovary we try to limit the number of mature follicles that we will be happy to treat you with to three. Through vaginal scanning you will be monitored for the growth rate of the follicles, number of follicles, and development of the lining of the uterus and advised of the optimum time for intra-uterine insemination (IUI).

You may be advised or you may wish to undergo a natural cycle without any medication.

Artificial Insemination - (ICI and IUI)

This is a relatively simple method of treatment, which may be appropriate if the female partner's investigations show no abnormality. Sperm can be placed in the cervix (as a thawed semen preparation) - often referred to as ICI - or directly into the womb (as a washed culture of spermatozoa) - usually referred to as Intra Uterine Insemination (IUI). Normal sexual intercourse can continue unless you are advised otherwise. IUI is more successful than ICI because the sperm is carefully prepared so that only good actively motile sperm are placed in the uterus with a much shorter distance to travel.

The precise timing of insemination is important. You may be required to monitor your own cycle using an ovulation predictor kit, which you can purchase from the hospital and they are also available from the chemist. They operate by measuring a hormone in the urine and will indicate when the ovulation is likely to take place - ovulation usually occurs within the next 24 - 36 hours. You may also be scanned from the 10th day of your cycle. A decision regarding the timing of insemination will be taken based on the size of your follicle containing the egg and the time your urine shows a colour change. We will advise you as to when you should come in for the insemination.

Super-ovulation & Intrauterine Insemination - (SO & IUI)

The pregnancy rate in women who fail to conceive with in the first year can be increased by using a combination of hormonal stimulation of the ovary and intra-uterine insemination. We have a separate information booklet regarding this method of treatment, which describes this method in detail.

IVF with donor sperm: This may be necessary when both male and female factor sub-fertility has been identified. See IVF booklet for detail.

IVF & ICSI with donor sperm: Sometimes the sperm does not survive the freeze-thaw process well and therefore the IVF procedure is combined with injection of the sperm into the egg (intra-cytoplasmic sperm injection or ICSI).

13. Nurse consultation:

Once the doctors have taken your history, your screening tests have been obtained and if the results are normal, a nurse consultation appointment is arranged when you would sign your consents with the nurse's assistance, any outstanding tests are arranged, appropriate matching detail is recorded and appointments for you to see the embryologist are made. These appointments can be made sequentially on the same day so that you do not have to make repeated visits to the unit unless necessary. This is also an opportunity for you to discuss any outstanding concerns that you may have.

14. Success rates

Our annual report contains the clinical pregnancy rates and live birth rates after 'DI'. Please ask to see the annual reports of our previous centres if you are interested.

Glossary of terms

Ovary: Female gonad responsible for development of the eggs and female sex hormones.

Eggs: Specialised female cell that develops in the ovary

Sperm: Specialised male cell that develops in the testis

Gametes: A name for eggs and sperm

Fertilisation: A term for the process by which the sperm enters the egg and its genetic material joins that of the egg.

Cleavage: A term for growth of the egg after fertilisation with an increase in cell numbers by division.

Embryos: A term for the growing ball of cells after fertilisation. Capable of developing into a human being.

Blastocyst: An advanced 5-6 day old embryo containing a large ball of cells that has divided to define parts that will form the placenta and the foetus. It contains a cavity of fluid. At this stage the embryo is ready to hatch and embed into the lining of the womb.

USEFUL ADDRESSES:

In addition to the counselling facilities that exist at The Centre you are advised to visit the HFEA website for information.

Androgen Insensitivity Support Group

2 Shirburn Avenue, Mansfield NG18 2BY
01623 661749

British Agency for Adoption & Fostering

Skyline House, 200 Union Street, London SE1 01Y
0207 593 2000

British Fertility Society (National Society for Healthcare Professionals)

16 The Courtyard, Woodlands, Bradley Stoke, Bristol BS32 4NQ
01454 642211
www.bfs.co.uk

British Infertility Counselling Association (BICA)

96 Divisional Street, Sheffield, S1 4GE
01342 843880
www.bica.net

Childlink Adoption Society

10 Lion Yard, Tremdoc Road, London SW4 7NQ
0207 498 1933

Cot Death Foundation

14 Halkin Street, London SW1X 7DP
0207 235 1721

COTS (Childlessness Overcome by Surrogacy)

Loandhu Cottage, Gruids, Lairg, Sutherland, Scotland IV27 4EF
01549 402401

Daisy Network (premature menopause support group)

PO Box 293, High Wycombe, Bucks, HP15 7SH

Department of Health Social Care Group

Wellington House, 133-155 Waterloo Road, London SE1 8UG
0207 972 4347/4084

Department of Health & Social Services

Child Care Branch, Dundonald House, Upper Newtownards Road, Belfast B24 3SF
01232 520000

Donor Conception Network

PO Box 265, Sheffield S3 7YX
0208 245 4369
www.dcnetwork.org

Human Fertilisation & Embryology Authority (HFEA)

Finsbury Tower, 103-105 Bunhill Row, EC1Y 8HF, London
0207 291 8200

www.hfea.gov.uk

Infertility Network UK

National support organisation with newsletters & helpline.
Charter House, 43 St Leonards Road, Bexhill on Sea, E Sussex TN40 NJA
01424 732361
www.infertility.uk

International Social Service of the UK

Cranmer House, 39 Brixton Road, London SW9 6DD
0207 735 8941

Miscarriage Association

c/o Clayton Hospital, Northgate, Wakefield WF1 3JS
01924 200700

Multiple Births Foundation

Hamm House, Hammersmith Hospital, Du Cane Road, London W12 0HS
020 8383 3519

National Endometriosis Society

50 Westminster Palace Gardens, Artillery Row, London SW1P 1RL
020 7222 2776

Turner Syndrome Support Society

1/8 Irving Court, Hardgate, Clydebank G81 6BA
01389 380385
turner.syndrome@tss.org.uk
www.tsss.org.uk

Twins & Multiple Births Association (TAMBA)

PO Box 30, Little Sutton, South Wirral L66 1TH
01732 868000

Verity (National PCOS Support Group)

Graystone Centre, 28 Charles Square, London N1 6HT
veritymembs@aol.com
enquiries@verity-pcos.org.uk
www.verity-pcos.org.uk

The details of other useful contacts can be obtained from ACU staff. Please do not hesitate to discuss any aspect of this information booklet with us.
We wish you good luck.

Mrs Vinay Sharma