SPERM DONATION FOR RECIPIENTS

Welcome
This booklet has been written to help fully inform you of the purpose and techniques of treatment. 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 8BU

Mrs M Moroney
Consultant Obstetrician & Gynaecologist
Nobles Hospital
Douglas
Isle of Man IM4 4RJ

Telephone:
❖ Monday to Friday (8.30am to 5.00pm):
  ➢ Secretary 650330

❖ EMERGENCY PROCEDURE
If you have an urgent enquiry during normal office hours contact Mrs Moroney's secretary using the telephone number above. Out of hours in an emergency contact the gynaecological SHO on-call at Noble’s Hospital via the hospital switchboard 650000. Alternatively, contact the St James's Hospital switchboard 0113 243 3144 and ask for the duty IVF member of staff who can then be contacted and will return your call. There is someone available 24 hours a day who will be able to help in an emergency.

❖ Leeds Centre of Reproductive Medicine
  ➢ Reception 0113 206 3111
  ➢ Clinical enquires 0113 206 3102
  ➢ Embryology enquiries 0113 206 3103

Website address: www.leedsreproductivemedicine.co.uk
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 is 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:

  a. 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.

  b. 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.

  c. Some men have 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.

  d. 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.
5. Regulation of sperm/egg donation:

We suggest you visit the website of the Human Fertilisation & Embryology Authority and look at "What you need to know about donating sperm, eggs or embryos" www.hfea.gov.uk

1) Human Fertilisation and Embryology Act

The Human Fertilisation and Embryology Act was passed by Parliament in 1990 and became law on 1st August 1991. Simultaneously the Department of Health established The Human Fertilisation and Embryology Authority (HFEA) 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 analysed periodically and published on the HFEA website (www.hfea.gov.uk).

a. HFEA registers:

The Authority keeps a confidential register of identifying information on all patients, their treatments, donors, recipients and children born after HFEA licensed treatments. This register was set up on 1st August 1991 and contains above information from that date onwards. From the 1st 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.

b. 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 18 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 hold about the donor. 16 year olds who intend to enter into an intimate physical relationship can submit a joint application to establish whether they are genetically related.

From the 1st 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 and their results as well as personal non-identifying information such as hobbies, likes/dislikes/ professional qualifications and a personal message written by the donor.

We encourage couples to tell the child/children if donated gametes have been used. This should be done at an appropriate time in their lives.

Information, support and implications counselling is available within the clinic to help guide you through this process. External support is also available-see useful addresses.

2) 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 eggs or embryos created with donated eggs unless the husband/partner can prove that he did not consent to treatment. The sperm donor has no parental rights or responsibilities.

Both partners of a recipient couple must provide written consent to the use of donated sperm/eggs/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/eggs/embryos to the Registrar of Births. Therefore the donor or you will not expect to be named at any stage.

3) Welfare of Future Children

The HFEA Act 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 supportive parenting), 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 Future Child and that of any other existing child who may be affected by treatment.

4) Factors considered in assessment include:

i. the couple's commitment to having and bringing up a child

ii. ability to provide a stable and supportive environment for the child/children

iii. couple's medical history and that of their families

iv. both partner's health (including their ages) and consequent future ability to look after or provide for a child's needs

v. ability to meet the needs of the children in the event of a multiple birth

vi. risk of harm e.g. that of inherited disorders, transmissible disease or abuse, multiple birth, neglect or abuse

vii. 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 single sex 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.

5) Donors’ rights
An egg/sperm donor has the right to change her/his mind up to the point the sperm/embryos have been placed in the recipient. Embryos created using donated sperm/eggs can only be stored for a patient with the consent of the donor. On the other hand, the donor has no rights once sperm/embryos have been transferred to the recipient.

6) 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.

7) 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.

8) 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 and recipients 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 each donation cycle.

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

9) Confidentiality
All information regarding your treatment is strictly confidential and subject to both the HFEAct 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 to communicate with specific people or agencies, in which we may 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 egg and 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.

We request photographic evidence of your identity (e.g. passport) which we will photocopy and along with a photograph of yourself placed in your notes, so that as treatment proceeds we can confirm your identity.

10) Treatment for same sex couples and single women:
This is considered on an individual basis after careful consideration of the Welfare of the Future Child/Children (see below).

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 centre 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.

**Which tests are performed?**

**Genetic Testing:**

- **Chromosome analysis:** All prospective sperm donors have an analysis performed of their chromosomes.

- **Screening 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 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%. GP’s 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 10 years 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

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 your local 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. Mrs Moroney will liaise with the Leeds centre and advise you as to when you should attend for the insemination.

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

The pregnancy rate in women who fail to conceive with in the first three treatment cycles can be increased by using a combination of hormonal stimulation of the ovary and intra-uterine insemination. 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).

IVF/ICSI with donor sperm

This may be necessary when both male and female factor sub-fertility has been identified. See IVF/ICSI booklet for detail.
13. Success rates

The Leeds Centre of Reproductive Medicine Annual Report contains the clinical pregnancy rates and live birth rates after 'DI'.

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 Leeds Centre you are advised to visit the HFEA website for information.

HFEA (Human Fertilisation and Embryology Authority)
21 Bloomsbury Street, London, WC1B 3HF
Tel: 020 7291 8200
Website: www.hfea.gov.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.