

Patient Information

The Shropshire and Mid Wales Fertility Centre

Egg Donation

Information for Egg Donors

Shropshire and Mid Wales Fertility Centre

Address: Severn Fields Health Village, Sundorne Road, Shrewsbury SY1 4RQ. Tel:01743 261202

Introduction

This leaflet has been designed to help those who are considering donating their eggs to help other women who are unable to produce or use their own eggs have the chance of having a family.

If, after reading this leaflet, you have any further questions about donating your eggs, please feel free to speak to a member of the nursing team at the Fertility Centre (Tel: 01743 261202).

Why is egg donation needed?

Some women find it is impossible or extremely difficult to achieve a pregnancy using their own eggs. This can be due to them having low numbers of eggs remaining, poor quality eggs or certain medical conditions.

These conditions include:-

- Premature menopause (usually classed as menopause before the age of 40)
- Poor response to ovarian stimulation at previous attempts at fertility treatment.
- Infertility caused by the removal of both ovaries or from chemotherapy or radiotherapy treatment.
- Inherited disorders in the woman's family.

Women and couples who find themselves in this situation will be advised to consider using donated eggs as a possible treatment option. Eggs donated by another woman (known as the "donor") are fertilised in the laboratory using the patient's partner's sperm or donor sperm in a process known as In-Vitro Fertilisation (IVF). Embryos created using this process are transferred back into the patient, (known as the "recipient") who will hopefully go on to achieve a pregnancy and give birth to a baby. Donors may be known to the patient or may be anonymous.

Who can donate and how are donors selected?

Donors must be 35 years or younger and can come from one of two categories:

• 'Anonymous' volunteer donor

This is perhaps the best way to obtain donor eggs. Donors undergo the procedure voluntarily and for purely altruistic reasons. Expenses incurred by the donor (e.g. transport and loss of earnings) up to the value of £985 are reimbursed.

• Close relative or friend

Some patients, either for ethnic, cultural or religious reasons and others out of personal preference, choose to have a 'known donor', such as a sister or friend of the female partner.

Donors are required to undergo some diagnostic tests to determine whether they are likely to have a good egg reserve and to undergo screening to ensure they are healthy.

Egg donation and the law

Any child born as a result of an egg donation treatment will be the legal child of the recipient, not the donor. The Human Fertilisation and Embryology Authority (HFEA) keeps a register of all egg and sperm donors as well as all treatments using donated eggs or sperm.

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

Unless a known donor volunteers (e.g a friend or female family member) egg donors are anonymous from the patients who receive their eggs. A donor will not know the identity of the patients who receive their eggs and recipients of the eggs will not know the identity of the donor.

Potential recipients and patients receiving donated eggs are given information on the characteristics of the donor such as eye colour, hair colour, height, build (body mass index), ethnic origin, blood group etc and non-identifiable information about yourself that you may provide. Some donors choose to leave a non-identifiable message about themselves and the reason for donating and recipients may ask to see this if they wish.

If you want to specific extra conditions for the use of your eggs please speak to a member of staff as this may be possible but please note we cannot accept donations from anyone wishing to place restrictions on the use of their eggs based on characteristics protected under the Equality Act 2010. These characteristics include:

age disability gender (reassignment) marriage and civil partnership race religion or belief sex sexual orientation

The identity of egg 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 egg treatment will have the right to contact the HFEA at the age of 16 at which time they will be legally entitled to receive the following non-identifying information:-

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

Any child born as a result of donor egg 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 attempts to notify the donor) which will include:-

- Donors 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)

All of the above information is given by the donor prior to treatment and is held in clinic notes and on the HFEA register.

Donors have the right to access by law information about the number, gender and year of birth of any children born as a result of their donation. This information is currently available to donors as a discretionary right from the Authority.

Donors are strongly encouraged to inform the fertility unit and HFEA of any change of contact details. This is so that you can be informed if anyone requests your disclosable information in future. We shall attempt to contact you should we become aware that a request for your identifiable information has been made. Counselling is available on request.

Consent to Storage

Donated eggs are not normally frozen and are used to create embryos immediately If more embryos are created than can be used in the recipients treatment they may be frozen to use in a later treatment. You will be asked to consent to the storage of eggs and embryos created with your eggs. The donor can consent to storage for up to 55 years but can specify a shorter period if they wish without renewing consent.

The person who received your donated eggs will also consent to storage. If the period of time you consent to is different to theirs any remaining eggs/embryos will be discarded on the earlier date.

If you wish to change your consent at any point you should contact the fertility clinic so that new paperwork can be issued.

In consenting to donate eggs and embryos you are also agreeing to them being used if and stored if you were to die or lose your mental capacity. If you do not want your eggs or embryos created with your eggs to be used if this happens you need to specifically state this on your HFEA consent form. We can only act on your wishes if the clinic is told of your death or loss of mental capacity.

Are there other ways donors can be identified?

Yes. Although the fertility clinic and HFEA will continue to manage (and potentially disclose) the donor's information in line with the HFE Act donors and recipients need to be aware that it is possible for them to be identified through direct to 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.

Donor Screening and History

We will take a detailed medical, family and travel history. A general examination is performed by a doctor at the time of the pelvic ultrasound scan. We will also ask for the donor's permission to contact her GP for a more detailed medical history.

After a woman has been counselled and accepted as a potential donor she must undergo a 'screening' programme. This is done to ensure that she has no infections or genetic conditions that might be passed on to the recipient or her child.

The donor must provide blood samples to determine whether they have any infections such as Hepatitis B, Hepatitis C, Syphilis, HIV 1&2, Cytomegalovirus (CMV) & Human T-Lymphotrophic Virus (HTLV) 1&2 and their Chromosomes and Cystic Fibrosis status checked. The donor will also have to give a urine sample to test for Gonorrhea and Chlamydia.

Jews of Eastern European descent should be screened for Tay-Sachs. People of Indian, Mediterranean and Middle-Eastern descent should be screened for β Thallassaemia and people of African descent should be screened for sickle cell.

Please be aware that the screening process is not a guarantee that any child born would be healthy and free from genetic disease or that the donor is free from all infectious disease

Please consider the implication of the genetic and medical screening you will undertake and how this could affect you and any family you have if you receive any unexpected results. The implications of being tested for HIV 1&2 are discussed with the patient prior to the test being taken. The results of the tests are confidential and are only made known to the donor. Without her written permission her GP cannot even be informed.

All egg donors are required to have repeat screening three months after their egg donation and before a recipient goes on to have treatment using frozen embryos/blastocysts from that donation.

Will I be held responsible if a child born from my donation is disabled in any way?

It is the responsibility of the donor to inform us of any genetic (inheritable) diseases that are known in the family. It is essential that the Centre is informed of any such conditions as if it can be proven that the donor has knowingly misled the Centre and the recipient then the parents of any child born as a result of treatment that is affected could sue the donor for damages.

Should you become aware of any genetic or medical problems after you have donated you have a duty to inform the fertility clinic of this as it may have implications for the woman you have donated eggs to and any resulting children.

What treatment is involved for the donor?

An egg donor will basically receive the same treatment as a patient undergoing IVF, with the main difference being that the donor will not have any embryos replaced in her uterus.

Treatment involves medication to "switch off" the ovaries followed by other medication to stimulate them to produce more eggs. The doctor will decide which protocol of medication best suits you. During this time we will need to perform 3-5 trans-vaginal ultrasound scans and blood tests to determine the growth of the follicles which will contain the eggs.

The egg collection is performed under conscious intravenous sedation and pain relief. If you are an anonymous donor, the eggs are usually divided equally between two recipient couples.

We ensure that the recipient of the eggs and her partner (if she has one) are carefully counselled and that the rights of the unborn child conceived using egg donation are carefully considered.

Matching the Donor to the Recipient - in anonymous donation

As far as possible we try to match the general physical characteristics of the donor to those of the recipient. The characteristics we try to match are:-

- Height
- Weight
- Build
- Hair colour
- Eye colour
- CMV status (presence of Cytomegalovirus antibodies in the blood)
- Complexion
- Ethnic Background

We always attempt to match blood group. It is not always possible to get an exact match, but we try our best to get it as close as possible.

Will I have to pay to donate?

No. All medical expenses will be covered by the recipient or by the NHS.

Do I Get Paid to Donate?

From 1st October 2024, the donor can be compensated up to £985 to cover expenses and loss of earnings with the provision to claim an excess to cover higher expenses if the centre feels that it is a

reasonable. The centre may only provide excess expenses (such as travel, accommodation or childcare) which are reasonable; do not include loss of earnings; have been incurred by the donor in connection with the donation of gametes provided to the centre' and have been incurred by the donor solely within the United Kingdom. The centre is required to keep a record of the actual excess expenses incurred, a record of the amount reimbursed and all receipts produced by the donor linked to the donation.

How many times can a donor donate?

Every donor is limited to creating 10 family units in the United Kingdom. . Once a couple have had a baby with donated eggs they may have as many 'sibling' children using the same donor eggs as they wish, either by using embryos frozen in previous cycles or, fresh donor eggs if the donor is willing to go through another egg collection.

The ten family units limit makes it absolutely essential that you inform the Centre if you have donated eggs in the past at other Centres. Please be aware if a woman also chooses to donate eggs at a clinic outside the UK this is not counted in the 10 family rule as the HFEA only regulate this in the UK.

Donor Counselling

All volunteers for egg donation are carefully counselled by two separate members of the Fertility Centre team and are also seen by the independent counsellor. The effects of the procedure on the donor, her family and children are discussed in detail. The Centre also ensures that if the donor has a partner they participate fully and agree with the treatment.

If the donor has children who are old enough to understand the implications, we encourage her to discuss it with them also.

Confidentiality is maintained at all times, both for the donor and the recipient and the Centre will not inform the donor of the outcome of the donation. Obviously a known donor would be informed by the recipient couple.

Can I find out about the outcome of my donation?

A year following the donation the donor may ask the centre for the following information if they wish:

- The number of children born as a result of the donation
- The gender of the children born as a result of the donation
- The year of birth of the children.

You may wish to ask again in future as often embryos are frozen for future use if the first treatment was not successful or the recipient wishes to try to have a sibling for the child. Counselling and support is available at any point before, during and after donation.

The risks to the donor

There are some risks associated with donation but these are small and short term. There is a 1-2% risk of excessive ovarian stimulation (where too many eggs are produced) despite careful monitoring of injections. This is called Ovarian Hyperstimulation Syndrome (OHSS) and information about this will be available separately. If this occurs the cycle may be abandoned.

There is a small risk of pelvic infection following an egg collection (less than 1%).

What should I do if I wish to donate?

You can contact the nursing staff at the Fertility centre (Tel: 01743 261202) to arrange an appointment or for an informal chat 9am to 5pm Monday to Friday.

If you wish to know more about the drugs involved and the egg collection procedure itself please visit our website <u>www.shropshireivf.nhs.uk</u>.

The Importance of Telling Children About Their Donor-conceived Origins

Centres are now required by law to give patients undergoing treatment using donor gametes (eggs or sperm) or embryos information about the importance of telling any resulting child at an early age that they are donor-conceived. Centres are also obliged to inform patients about suitable methods for doing so.

What happens if I change my mind?

You can withdraw your consent to the egg donation up until the point where the eggs/embryos have been used without fear of financial penalty or recrimination. This could be when they are transferred to a woman, used for research or training (if you have agreed to this) or been allowed to perish. . Once donated you can change or withdraw consent up until the eggs/embryos have been used in treatment (e.g. before first treatment or if they are in storage). Please contact the fertility department if you are considering doing this.

What happens if the fertility unit think I am unsuitable to donate?

On occasion the fertility unit may consider someone unsuitable for donating eggs, for example because of your health. This will have been discussed at a multidisciplinary meeting, taking into account current equality legislation, before making this decision and we will let you know the reasons why. If you are considered unsuitable to donate you will be offered counselling.

Additional information for trans donors

Donors who are considering transitioning are advised that any information disclosed by the HFEA to anyone born as a result of their donation may reveal their gender history. If you wish, you may provide details of your acquired identity to the HFEA so they may update the register to allow anyone conceived from your donation to also know your current gender identity.

Contacting the Centre

You can contact the centre at any time if you have any worries, concerns or questions about your treatment.

The staff are available on the following number 01743 261202 option 2 Monday—Friday from 9am— 5pm.

Other Sources of Information

References HFEA <u>www.hfea.gov.uk</u>

Donor Conception Network www.dcnetwork.org

Contact details for more information

Useful telephone numbers

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.

Further information is available from;

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

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: <u>www.nhs.uk</u>

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

Information in other Formats

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

Website: www.sath.nhs.uk

www.shropshireivf.nhs.uk

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