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Tissue typing for potential family stem cell or bone marrow donors

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Bone Marrow Transplant Unit

Information for Patients

Introduction

If you are reading this leaflet, your family member has been diagnosed with a serious blood disorder, and their doctors feel that a bone marrow or stem cell transplant may help him or her. In these cases it is usual for the doctors to ask the patient's family if they would be willing to have blood samples taken to see if they might be suitable donors. This can be done here in the hospital where the patient is being treated or, if you live out of the area, at your GP practice.

It is important to read this leaflet and understand the implications of giving a blood sample before you make an appointment. If you attend to have the blood test we will assume that you are willing to be a donor for your family member.

All information you give us will be treated in the strictest confidence.

Why do I need this blood test?

The blood test will tell us your tissue type, For a transplant to take place, your tissue type needs to match that of your family member. Matching is based on your human leukocyte antigen (HLA) tissue type. Your HLA is part of what makes you 'you' – your individual genetic characteristics.

Your sample of blood will only be compared with your relative's blood and will not be tested for compatibility with anyone else.

Where do we get our individual tissue types from?

Tissue types are inherited from our parents. These can combine in many different ways. This means that there are millions of different tissue types. However, if a person inherits the same HLA combination from their parents, they could be a suitable donor for a sibling.

If a close HLA match cannot be found, then a haploidentical (haplo) transplant maybe an option. A haplo tansplant uses a family member whose tissue type is half-matched to yours. Children are always a half-match for their biological parents, and vice versa. Siblings have a 50% chance of being a half-match for each other.

It is important to point out that if you are the same blood group as your family member, this does not mean that you will be a suitable match. In fact, you could have a different blood group to your family member and still be a suitable match.

Why is tissue type important in transplantation?

If the tissue types of the donor and the patient are carefully matched, this will give the greatest chance of the transplantation being successful. If the tissue types are identical this will reduce the risk of rejection. The doctors will consider which is best for the patient: a full sibling match (if there is one), a donor match (from outside the family) or a haplo match.

What are my chances of being a suitable match?

You have a 1 in 4 chance of being an identical match with one of your full siblings. However, if you are a half-sibling you will not be a match.

In some families, more than one sibling can be a suitable HLA match. Therefore, more than one sibling could be a suitable match to donate bone marrow or stem cells. In this situation, a decision will be made about who will be the most suitable donor to use.

With haplo matches most parents, children and siblings of the patient are matches.

Do I have to be in good health to be a donor?

Yes, there are strict rules that mean that if you have certain health problems you cannot be a donor. In that case it would not be worth having the test done.

Do you have, or have you had:

Cancer of any form	Yes / No
Serious heart disease	Yes / No
A stroke	Yes / No
Epilepsy	Yes / No
Problems with your bone marrow or immune system	Yes / No
HIV, Hepatitis, TB infection	Yes / No
Are you currently being treated for any medical condition?	Yes / No
Have you ever been told that you cannot give blood?	Yes / No

Frequently asked questions

When do I get the results?

The results of the test are usually available after two to four weeks, and we will write to you with the results.

What happens if I am not a match?

If none of the patient's siblings is a match, it may be possible for us to find an unrelated donor from international registers of potential donors or consider haplo matches.

What happens next if I am a match?

You will be invited to attend an appointment at the hospital. At this appointment you will be counselled to make sure that you are aware of the implications of donation to both you and your family member. Once you have had all your questions answered you will be asked to sign a consent form to confirm that you are happy to proceed with the donation process.

Whilst you are at the clinic, we will assess your general health by performing a detailed examination and doing various tests, including blood tests, X-rays and an ECG (heart tracing).

Within 28 days of this appointment you will be asked to attend for a procedure to collect either your bone marrow or stem cells.

How are bone marrow or stem cells collected?

There are two ways of collecting cells from adult donors: **a peripheral blood stem cell collection** or a **bone marrow collection**. Both procedures are done as day cases.

What is peripheral blood stem cell collection?

Before the stem cell collection takes place, you will be given five daily injections of a growth factor called G-CSF. This helps the stem cells to leave the bone marrow, where they are made, and circulate in the blood stream.

Stem cell collection is carried out using a cell-separating machine. The procedure takes between three and four hours.

What is bone marrow collection?

This is performed under a general anaesthetic (whilst you are asleep). The bone marrow will be taken from the back of your pelvis.

This information about bone marrow and stem cell collection is very brief. If you would like more detailed information, please ask.

Regulation of transplantation

Transplantation is a carefully regulated process, and all transplant units must be licensed by the Human Tissue Authority (HTA). Further information is available on the HTA website:

www.hta.gov.uk

Contact numbers

If you have any questions or concerns please contact us:

Leicester Royal Infirmary

Cellular Therapy Centre

Monday to Friday 9am to 5pm

Telephone: 0116 258 5124

Bone Marrow Transplant Unit

24 hours, seven days a week

Telephone: 0116 258 5698

Sources of further information and support

Macmillan Information and Support Centre

Osborne Building, Leicester Royal Infirmary

Telephone: 0116 258 6189

Email: uhl-tr.cancerinformationcentre@nhs.net

Sue Young Cancer Support

Helen Webb House

35 Westleigh Road

Leicester LE3 0HH

Telephone: 0116 223 0055

Website: www.sueyoungcancersupport.org.uk

Macmillan Cancer Support

Freephone: 0808 808 00 00

Website: www.macmillan.org.uk

Leukaemia Care

Telephone: (24 hours) 08088 010 444

Website: www.leukaemiacare.org.uk

Blood Cancer UK

Telephone: 0808 2080 888

Website: www.bloodcancer.org.uk

Lymphoma Action

Telephone: 0808 808 5555

Website: www.lymphoma-action.org.uk

Myeloma UK

Infoline: 0800 980 3332

Website: www.myeloma.org.uk

Other information

If any other members of the family want to look into joining the Bone Marrow Register, the following may be of interest:

Anthony Nolan

UK blood cancer charity and bone marrow register.

Website: www.anthonynolan.org

Telephone: 0303 303 03 03

DKMS

Charity with a key mission to register blood stem cell donors.

Website: www.dkms.org.uk

Telephone: 020 8747 5620

Health information and support is available at www.nhs.uk or call 111 for non-emergency medical advice
Visit www.uhleicester.nhs.uk for maps and information about visiting Leicester's Hospitals.
To give feedback about this information sheet, contact uhl-tr.informationforpatientsmailbox@nhs.net

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

إذا كنت ترغب في الحصول على هذه المعلومات بلغةٍ أُخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો.

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email uhl-tr.equalitymailbox@nhs.net

We are a research hospital and you may be asked to take part in research

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