

Paediatric haematology

HLA typing (tissue typing)

Information for patients, relatives and carers

Introduction

This leaflet should help answer some of the questions you or those close to you may have if you or your child is hoping to receive or donate bone marrow. It is not meant to replace the consultation between you and your medical team, but aims to help you understand more about what you discussed together.

What is HLA typing?

We all inherit human leukocyte antigens (HLA) from our parents. Our HLA combination determines our tissue type. To find out the tissue type of potential bone marrow donors, we take a blood sample and analyse it to see the HLA in their white blood cells, tissues and organs. We do this twice and on separate days for safety reasons.

Why compare HLA type?

We do HLA typing before planning a bone marrow transplant (BMT). Finding a good HLA match between the person donating the marrow and the person receiving it reduces the risk of the bone marrow being rejected by their immune system.

HLA typing also reduces the risk of a disease called graft versus host disease (GvHD). This can occur when the donor cells recognise the recipient as foreign and mount a defence against the recipient's body. GvHD occurs because there are numerous antigens in the body, but to perform a bone marrow transplant only ten need to be matched. This means that there is a level of difference between all donors and recipients except for transplants performed in identical twins.

How are donors found?

Siblings of a potential recipient have a one in four chance of being a good HLA match, as long as they have the same mother or father as the person receiving the transplant. We usually test them first.

- if we find more than one good match, we will make a choice based on each person's size, blood group and whether or not they have been exposed to cytomegalovirus (CMV)
- if blood has been collected from a brother or sister's umbilical cord (directed cord donation), we will carry out another test to make sure the HLA results are accurate

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- if we identify a donor who is younger than 16, or who does not have the capacity to consent to the donation, a Human Tissue Authority (HTA) assessor will evaluate them to make sure they understand what they are agreeing to do and are not being coerced into donating. This is a legal requirement, and a transplant cannot go ahead unless HTA approval has been granted

If we cannot find a match who is a brother or sister, we will test people related to the parents in circumstances where the parents are consanguineous (married 1st & 2nd cousins for example). If necessary, we can test samples from overseas.

- if there is no match within the close or extended family, we can carry out a search for unrelated donors who are a good HLA match
- in the event of non-consanguineous parents, it is unlikely that a relative other than a sibling would prove to be a match and therefore you will not be tested to identify as a full match donor
- if there is no sibling donor available and an unrelated search does not reveal a match you will be tested to see if you could be a haploidentical donor (50 per cent match)

What happens when I become a donor?

We will take a separate sample of blood and store it with blood cells from the person who will receive the transplant. This is known as **blood chimerism**. It allows us to analyse the genetic DNA of both the potential donor and recipient to analyse the effectiveness of the transplant once it has taken place.

Your confidentiality is assured. If you are a good HLA match it does not mean you have to be a donor. It is your decision whether to go ahead, and if you change your mind you can stop at any point up until the recipient has been admitted for transplant and started chemotherapy. If you are an adult who may be a match for a child you will get your results confidentially before the recipient's parents are told.

Contact us

Your bone marrow transplant (BMT) nurse will be able to answer any questions you have. Call the BMT coordinators on 020 3312 5062 or 020 3312 3345 or 077 6699 1070

Useful websites

Anthony Nolan Trust: www.anthonynolan.org

British Transplantation Society: www.bts.org.uk

British Society for Histocompatibility and Immunogenetics: www.bshi.org.uk

Human Tissue Authority: www.hta.gov.uk

Additional patient information is available on our website:



How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). You can also email PALS at imperial.pals@nhs.net. The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to express your concerns in **writing** to:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street, London W2 1NY.

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille, or in alternative languages. Please email the communications team:

imperial.patient.information@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

Paediatric haematology4
Published: January 2024
Review date: January 2027
Reference: 832

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Consent form for HLA typing

Your name:

Your date of birth:

Your hospital number:

I.....[your name, or if you are under 16, full name of your parent or legal guardian] have read and understood the information in this (HLA typing) leaflet and have had the opportunity to discuss the use and storage of my DNA samples.

I understand that testing will be carried out to determine my HLA type and to assess the immunological compatibility for bone marrow transplantation.

I understand that in the event that I proceed with donation (or in the event of the potential recipient proceeding with BMT) my DNA will be stored and analysed to confirm the effectiveness of the transplant.

Name:.....

Signature:.....

Date:.....