Tissue Typing for your bone marrow / stem cell Transplant

Information for patients and relatives and consent form
Information about your treatment

Introduction
This leaflet explains the work of the Transplant Immunology and Immunogenetics Laboratory and the laboratory tests that might be used in your treatment. The laboratory is sometimes called the Tissue Typing Laboratory. Our main function is to do tests that allow transplantation to be carried out safely between a donor and recipient. The tests include genetic DNA testing. The laboratory stores DNA from patients and donors.

What is HLA typing (tissue typing)?
To help with your treatment, we do a test called HLA typing (also known as ‘tissue typing’) on a blood sample. Human Leukocyte Antigens (HLA) are markers found on the surface of cells in the blood and other places around the body. There are many different forms of HLA and each person has only a limited number. We inherit HLA from our parents in a combination called our ‘HLA type’ or ‘tissue type’.

Reducing the risk of rejection
When cells or tissues are transplanted from one person to another, the donor HLA type can be recognised by the patient’s body as ‘different’. If this happens then the patient’s immune system may respond by trying to destroy the transplanted cells. This is called ‘rejection’. We do HLA typing to match the donor and recipient and so reduce the risk of rejection.

Reducing the risk of Graft versus Host Disease (GvHD)
Stem cells from a donor can themselves recognise the patient’s HLA as different. When this happens it can cause graft versus host disease (GvHD). By HLA typing and then matching the recipient with a donor the risk of GvHD is reduced.
Choosing a related donor

The most likely place to find an HLA matched donor is amongst siblings (brothers and sisters who have the same mother and father). Siblings have a 1 in 4 chance of being matched. For this reason, if your doctor decides that a stem cell transplant is the best treatment for you, they will first ask if it is possible to test any brothers and sisters. Other family members can also be tested if there are no HLA matched siblings.

As well as helping us with a patient’s treatment, HLA typing family members can also give information about the genetic relationships of the patient and those family members.

Matched unrelated donors (MUDs)

If there is not an HLA identical match in the family, then a stem cell transplant may be possible from a matched unrelated donor (MUD). This is because people who are not related may happen to be a good match by chance. Throughout the world there are large registries of HLA typed volunteers who are willing to donate stem cells for a matched patient.

Other laboratory tests that may be done after transplant

After the transplant, donor stem cells move to the bone marrow where they multiply and produce new blood cells. By comparing stored (pre-transplant) DNA with DNA made from a blood sample after the transplant, we can see what proportion of your new blood cells come from the donor’s transplanted stem cells. This information is used by the doctors to see how well the transplant is progressing.
Use and storage of samples from patients or relatives

**What we will do with your samples**

For the treatment we will use a small amount of DNA from some of your blood cells to HLA type you and will store your DNA in case further testing is necessary.

In order to maintain the high quality of our tests, we need to continually assess our test procedures. This is for the benefit of all patients and is called “Quality Assurance”. In addition to using samples for the treatment, we may also use surplus portions of your stored samples for quality assurance. Samples used in this way are anonymous.

**What we could also do with your samples if you agree by signing the consent form at the end of this leaflet**

We would like you to consider giving your consent for your samples to be used for the purposes described in 1 and 2 below.

Please note that your (or your relative’s) treatment will not be affected whether you do or do not consent to the use of samples as described.

1. Sometimes it can be very useful to test surplus portions of stored samples to help us with the diagnosis and treatment of other patients. Samples used in this way are anonymous.

2. Similarly, surplus portions of your stored samples may be useful to carry out ethically-approved medical research studies that may help patients now and in the future. Samples used in this way are anonymous.

Please complete the consent form at the back of this leaflet so that we can record your wishes either way. If you change your mind at any time in the future you can let us know and we will change your records.
How to contact us

If you have any questions about this information, please contact:

**Dr Susan Fuggle or Dr Martin Barnardo at:**
Transplant Immunology and Immunogenetics Laboratory
Oxford Transplant Centre
Churchill Hospital
Oxford OX3 7LJ

Tel: 01865 226102

Useful websites

Anthony Nolan Trust: www.anthonynolan.org.uk

British Transplant Society: www.bts.org.uk

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

Human Tissue Authority: www.hta.gov.uk

NHS Blood and Transplant: www.uktransplant.org.uk
I, ............................................................................................................................... (please print your name) have read and understood the information in “Tissue Typing for Your Bone Marrow/Stem Cell Transplant – Information for Patients and Relatives and Consent Form” and have had the opportunity to talk to hospital staff about storage and use of my samples.

1. Surplus portions of my stored samples may be used to help with the diagnosis and treatment of other patients.
   - [ ] I agree
   - [ ] I do not agree

2. Surplus portions of my stored samples may be used to carry out ethically-approved medical research studies.
   - [ ] I agree
   - [ ] I do not agree

3. I give my consent for this period of time:
   - [ ] Indefinitely
   - [ ] 5 years
   - [ ] 10 years
   - [ ] ......................... years

Signature ...........................................................................................................................................

Today's date ................................................... Date of birth ......................................................