

This information is provided as extra details on HLA matching and reading it is entirely optional. You do not need to understand this to register with the ABMDR or to donate. If you have any questions your donor coordinator will be happy to answer them or explain this material in more detail.

Bone marrow transplantation, like most areas nowadays has a lot of technical terms and abbreviations that make it easier for people who work in the field every day to communicate. For someone new to the area this can be a little daunting. We have tried to use as much plain language as possible in these documents, but sometimes it is better to use the technical terms, as they more accurately describe the item. The first abbreviation that you should learn is “haemopoietic stem cell” (HSC). Haemopoietic means “the formation of blood cells” and “stem” means something from which other things can be derived. So HSCs are the cells from which all blood in the body is created – they are found predominantly in the bone marrow. We don’t like to use the term “bone marrow” when talking about these cells, as people often associate bone marrow with the more specific collection of HSCs from the hip bones. That is just one way to collect HSCs. Another common way to collect HSCs is through a peripheral blood stem cell (PBSC) collection (similar to a blood donation) or from the umbilical cord blood (both of these are good sources of HSCs).

Step 1: Joining the ABMDR

When you enrol with the ABMDR, blood samples taken at the time are sent to a “tissue typing” laboratory. The laboratory will perform preliminary testing on your blood sample. The laboratory is looking for specific “markers” (antigens) that appear on most of your body’s cells. These markers identify these cells as belonging to you. Your body uses this

information to determine “friend or foe” and generally the immune system will attack anything not marked as yours. In a blood stem cell transplant it is very important because these cells are involved in creating the immune system. If the match is not close the transplanted immune system can actually attack the recipients existing cells. This can be very severe and is known as graft versus host disease (GvHD). So the key indicator to the success of an HSC transplant is matching, and although you are probably not aware of it there are computer systems and dedicated transplant and search coordinators throughout the world constantly trying to match recipients to the best possible registered donors.

Everyone has two sets of these specific markers (antigens) also know as human leukocyte antigens (HLA) which are inherited – one set from your mother and one from your father. When the laboratory looks at these HLA markers, they can do it at several levels of resolution. Generally we continue to refer to “antigens” as low resolution and high resolution as “alleles” which are antigens more specifically typed.

The HLA markers that are initially assessed when looking for a donor are called HLA-A, HLA-B and HLA-DR. Remembering that there are two possibilities at each locus, means that there are 6 antigens or alleles that we are trying to match. Some transplant doctors may look at 8, 10 or even 12.

Your preliminary typing information is entered into the ABMDR computer database which is searched on behalf of patients in need of a HSC transplant. When the patient’s tissue type is entered into the ABMDR computer system, a list of matched potential donors is generated.

Step 2: You are identified as a “preliminary match”

It is not uncommon to be identified as a preliminary match with a patient. This means that the typing information on the database shows that you are a potential match to a patient (often matching at 5 out of 6 or 6 out of 6 antigens). If this occurs, normally additional testing will be required (preliminary typing is generally done at an antigen or low resolution level). In most cases the laboratory will still have your sample from registration and will use this. But in some cases this might not be the case and you will be contacted by the ABMDR donor coordinator asking you to come in for a blood test. The result of your more detailed typing is entered into the ABMDR computer database and compared with the patient's type. The result of this test is usually available in 2 - 4 weeks.

Step 3: You are identified as a potential donor

After the additional typing, you may be identified as a potential donor. The donor coordinator will contact you and make an appointment for the collection of a blood sample for “confirmatory typing”. The main purpose of the confirmatory typing is to act as a double check that the earlier typing was correct. This is generally done in a different lab to the initial typing. Other tests such as cellular assays (mixing patient and donor white blood cells to see if they react) may be performed to select the best possible matched donor for the patient. About 50 - 100 ml of blood is collected at this stage. As the search process proceeds it is more likely that you may be selected as a HSC donor. But at this stage the transplant centre is probably still considering other options. “Dropping out” at this stage is completely acceptable. However it is important to understand that there is a possibility

that the next call you get from the donor coordinator could be to inform you that you have been selected as a donor.

At this stage, it is especially important that you notify the ABMDR of any change of address or other contact details, any travel plans that you have or any time that you may not be available to donate. It would probably be a good idea to seriously consider how you feel about donation at this time and take the opportunity to discuss it with family members. If you have any concerns or doubts about going ahead with donation, the donor coordinator will be happy to discuss them with you. We do not want you to feel pressured in any way to proceed with the donation, but it does make it easier for everyone if you think about the issues and let the donor coordinator know earlier rather than later to avoid disappointment for patients and their family and to allow time to pursue the search for the patient.

The process of preparing a patient for transplant can be very difficult and time consuming. One of the major factors in this is the patients' condition which can vary considerably (generally patients can only be transplanted when they are relatively healthy, or in remission). This means that there may be a long period before you hear from us again but the donor coordinator will contact you as soon as we hear from the transplant centre. As a precaution, you are deferred from normal blood donation for a period of six months. This is done just in case you are asked to donate HSCs.

If you are found to match with a patient but the patient is not ready to proceed to transplant, you may be “held” for this patient for a further six months.