

The Australian Bone Marrow Donor Registry (ABMDR) is a list of people who may be willing to donate bone marrow/ stem cells to give a transplant patient a second chance at life.

The ABMDR is linked to a worldwide network of donor registries which can be searched for those patients. The decision to become a bone marrow/blood stem cell donor requires careful consideration and we hope that this brochure will assist you in making an informed decision.

Why do you need me?

Each year many patients are diagnosed with leukaemia or other fatal blood disorders. A bone marrow/blood stem cell transplantation is the only possible treatment for many of these patients.

The most suitable donor is a fully matched (tissue typed) family member, but only about one patient in three has such a donor. If a suitable donor is not found within the family a search for an unrelated donor is necessary.

Since tissue types can be linked to ethnic origin, people who share the same ethnic background are more likely to be compatible. For this reason, we ask you to indicate your ethnic origin (or racial group) and that of your ancestors on the consent form. For example, if your ancestors were Italian or Chinese, then please indicate this on the form even if you were born in Australia.

Am I able to be a donor?

Donors must be between 18 and 40 years of age at registration and in good health. You may be asked to donate a unit of blood (470ml) and undergo screening tests for viruses or other infections. Your registration may be affected if you have lived in or visited England, Wales, Scotland, Northern Ireland,

Channel Islands or the Isle of Man for a cumulative (total) period of 6 months or more, between 1st January 1980 and 31st December 1996 inclusive, because of the possible risk of variant Creutzfeldt-Jakob Disease (vCJD).

Donors are retired from the registry at the age of 60. The ABMDR will not normally contact you unless you are identified as a potential match for a patient, but please notify the ABMDR of any changes of address, personal details or if you feel your registration may be affected by the vCJD policy.

If I agree to help, what will happen?

You will have a blood test to establish your HLA type (or tissue type). It is not necessary to take a sample of your bone marrow to determine your tissue type.

HLA stands for Human Leucocyte Antigen. A leucocyte is a white blood cell and an antigen is a 'marker' on the surface of blood cells. The HLA type is determined by two sets of genes, one inherited from each parent. On recruitment a sample of your blood may be used for ethically approved research. For further information about research projects or if you have any concerns regarding research, the Executive Officer of the ABMDR can be contacted on (02) 9229 4464.

Can I be tested only for someone I know?

No. While you may be motivated to join because of someone close to you, it is important to realise that each year the ABMDR searches for over 1,000 patients in need of stem cell transplantation. By joining the ABMDR, you may be selected to help any patient in need, anywhere in the world.

How are donors selected?

Your tissue type is entered into a national database. When a patient needs a donor, their tissue type will be compared with all the tissue types on the registry. Only 1 in 1,000 donors will be asked to donate stem cells in any year.

What happens if I am selected as a donor?

If you match with a patient you will be contacted by the donor centre for another blood sample to confirm the match and a counselling session will be conducted to assess if you are suitable and willing to proceed to a possible stem cell donation.

Your health and wellbeing before and after donation are very important to us. Before donation an independent specialist with detailed knowledge of stem cell donation will assess you medically and answer any questions you may have. In Australia, donation occurs in one of the major hospitals in the capital cities. You would not be required to travel interstate or overseas.

Can I change my mind?

Deciding to donate stem cells is an important decision. There are many reasons why you may decline, such as poor health, the time involved or concern about the risks. There is however a 'point of no return' for the patient. About a week before the actual donation, a patient's own bone marrow is destroyed in preparation for receiving the donor's bone marrow or stem cells. These treatments can be fatal unless healthy bone marrow is transplanted. At this point, having agreed to donate, you have a moral obligation to proceed.

How is the donation collected?

Currently there are two ways a donor can donate stem cells. Details of these procedures and associated risks are below. The choice will be dictated by the patient's needs and so you may be asked to donate either bone marrow or peripheral blood stem cells. A small percentage of donors may be asked to donate both stem cells and bone marrow.

1. Bone marrow donation

Bone marrow is collected under general anaesthetic from the cavities in the posterior hipbones. Using a needle and syringe, punctures are made through the skin over each hip, and the marrow is extracted from the pelvic bone cavity. This procedure can take up to two hours. In the month before the collection you may be asked to donate 1 or 2 units of blood. This blood is stored and may be returned to you during the procedure.

The time needed for complete recovery varies, but generally you can go home the same or following day, and resume your normal activities after two or three days. Normal bone marrow will re-grow rapidly to replace the donated bone marrow. We will contact you after the donation to check on your wellbeing.

What are the risks for me?

The risks for donating bone marrow are the same as those with any general anaesthetic. The chance of a serious complication is very low but some people may experience nausea and/or local pain and discomfort for several days.

2. Peripheral blood stem cell (PBSC) donation.

Normally the number of stem cells circulating in the blood is low. To increase the number of blood stem cells, a hormone-like substance called G-CSF is

injected under the skin daily for 4 days prior to the procedure. The stem cells are then collected by a procedure called leukapheresis. During this procedure a needle is inserted into a vein in your arm and your blood passes into a cell separator machine, which selectively removes the stem cells.

The remaining blood components are immediately returned. This procedure performed at an accredited collection centre or apheresis centre, does not require a general anaesthetic and takes approximately 3 - 4 hours. After the procedure you may leave but subsequent donations may be necessary if insufficient cells numbers were collected. We will contact you after the donation to check on your wellbeing.

What are the risks for me?

G-CSF is usually well tolerated, although you may experience bone pain and some flu-like symptoms during the course of the injections, which usually respond to paracetamol. As yet no significant long term side effects have been observed with prolonged administration of G-CSF to patients but the long term effects of short treatments in normal donors is unknown.

How is the transplant performed?

About a week before the transplant the patient has chemotherapy and/or radiotherapy to destroy their diseased bone marrow. They then receive the healthy donated stem cells similar to a blood transfusion.

Is there any cost to me?

The main cost to you will be some of your time. The ABMDR will cover all medical and hospital expenses related to the stem cell donation. Incidental expenses associated with the donation such as travel to and from hospital and accommodation if necessary will be

paid directly or reimbursed by your donor centre. All your "out of pocket" expenses will be reimbursed.

Donating stem cells is voluntary and you will not receive any payment.

Can you donate again?

You may be asked to donate stem cells on a second occasion for the same patient if the first transplant did not 'take', or if the patient condition changes. Other types of blood products may also be requested for that patient such as whole blood or donor lymphocytes (white blood cells). It is highly unlikely that you would be asked to donate to more than one patient needing a transplant, although it has happened. Donors will be retired from the registry for one year and recontacted at the end of that period to see if they wish their name to be re-activated on the registry.

Confidentiality

Your details are treated confidentially and kept by the ABMDR donor centre in your state. Only your tissue type with an identifying code is entered onto the registry. This code is the only identifier released to the transplant centre. Only appropriate medical details will be passed to the transplant team involved if you agree to donate. Your personal details will not be divulged to anyone outside the Registry without your written consent. Similarly, you will not receive any identifying details of the patient.

Can you contact the patient who receives your stem cells?

You may receive progress reports on the recipient after transplant. Donors and recipients are not encouraged to meet, although if both parties agree and consent in writing, contact can be made.

How else can I help?

Following chemotherapy or bone marrow/blood stem cell transplantation patients often develop very low platelet counts. Platelets are needed to control bleeding. Sometimes patients need platelets from HLA matched (tissue typed) donors. You may be able to become a platelet donor.

Platelet donation is like a regular blood donation except that it takes a little longer and involves selective removal of platelets using a cell separator machine. There is no requirement for anaesthesia and the risk for the donor is essentially the same as for a blood donation.

When should I contact the ABMDR?

Please remember to tell us of:

- ◆ changes in your contact address and telephone numbers
- ◆ changes in your personal details e.g. last name changes
- ◆ changes in your health that may prevent you from donating permanently or temporarily, including pregnancy
- ◆ changes in your commitment to remain on the ABMDR

Participation in the ABMDR is voluntary and you may withdraw at any time.