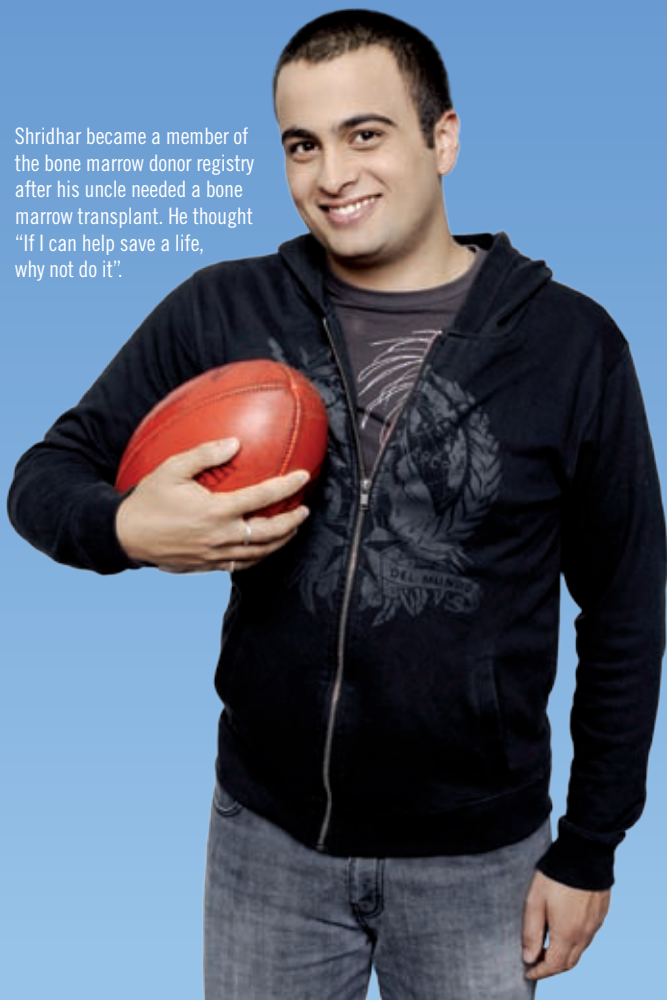


Joining the bone marrow registry

Shridhar became a member of the bone marrow donor registry after his uncle needed a bone marrow transplant. He thought "If I can help save a life, why not do it".



ABMDR
Australian Bone Marrow Donor Registry



Australian Red Cross
BLOOD SERVICE

The Australian Bone Marrow Donor Registry is a list of people who may be willing to donate bone marrow or blood 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/stem cell donor requires careful consideration and we hope that this brochure will assist you in making an informed decision.

Donor information

Each year thousands of people are diagnosed with leukaemia or other life threatening blood disorders. A bone marrow/blood stem cell transplant is the only possible treatment for many of these people to save their lives.

70% of people will not find a match within their family and rely on a search of donors on the bone marrow registry.

Searching the same ethnic group as the patient greatly increases the chance of finding a match, so your ethnic background is important. Please indicate your family background on the consent form at registration (for example Italian or Chinese).

Are you an eligible donor?

You can join the registry if you are between 18 and 40 years of age and in good health.

You may be asked to donate about 470ml of blood which will be screened for viruses or other infections. You will be asked if you have lived in or visited England, Wales, Scotland, Northern Ireland, Channel Islands, Falkland 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. This is because of the possible risk of variant Creutzfeldt-Jakob disease, the human version of 'mad cow disease' and you may be told that you cannot register because of this.

You will also be asked to indicate at registration whether you wish to be contacted in the future for ethically approved research.

Once you've registered

After you have filled out the registration forms, you will have a simple blood test to determine your tissue type which is the information that is used to match donors with patients. On recruitment, a sample of your blood will be stored in case more detailed HLA typing is needed later.

You usually won't be contacted by the ABMDR unless identified as a potential match for a patient. Potential donors are retired from the registry on their 60th birthday.

No bone marrow/blood stem cells will be taken at this time.

If you join the ABMDR, you may help save the life of any person in need of a transplant.

Can you be a donor for a friend?

It is natural to want to help a friend who needs a bone marrow/blood stem cell transplant, but unfortunately it is not possible to register with the ABMDR for a specific person. The ABMDR will be searched to find a match for your friend. If a match cannot be found on the Australian registry, the international registries will be searched and a possible match may be found from the pool of potential donors worldwide.

In the same way, if you join the ABMDR, you may be found to help save the life of any person in need of a transplant.

Donor selection

Your tissue type is entered into a national database, which is then linked to the worldwide registries. When a patient needs a donor, their tissue type is compared with all potential donors on the registries worldwide. If you then match with a patient you will be contacted by the ABMDR and asked to confirm your commitment to be a donor and provide another blood sample to confirm this match. In Australia, only 1 in 1,500 donors will be asked to donate stem cells in any year.

Your health and wellbeing before and after donation are very important to us. If you are chosen to become a donor, 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 state capital cities. You would not be required to travel interstate or overseas.

You can change your mind

Participation in the ABMDR is voluntary and you may withdraw at any time. Deciding to donate your 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, the patient's own bone marrow is destroyed in preparation for receiving the donated stem cells. At this point the patient will die unless healthy bone marrow is transplanted. It is therefore very important that you let us know well before this 'point of no return' if you have any concerns regarding donation.

Collection of your bone marrow/blood stem cells

There are two ways you can donate your bone marrow/blood stem cells. The actual donation method best for you will be assessed by a medical specialist prior to your blood stem cell donation but ultimately you will be able to choose the method of collection.

1. Peripheral blood stem cell 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 Granulocyte Colony Stimulating Factor (G-CSF) is injected under the skin daily for 4 days prior to the collection. 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 to your body. This procedure is performed at a hospital or blood donor centre, does not require a general anaesthetic and takes approximately 3 to 4 hours. After the procedure you may leave but another donation the following day may be necessary if not enough cells are collected.

What are the risks? G-CSF is usually well tolerated, although during the course of the injections, you may have bone pain and some flu-like symptoms, which usually respond to paracetamol.

G-CSF is also used to treat patients. 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 donors is unknown. There have been some rare side effects which have been reported and these will be discussed in more detail if you match a recipient.

2. Bone marrow donation

Blood stem cells found in the bone marrow can be collected under general anaesthetic. Using a needle and syringe, 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 one or two units of blood. This blood is stored and may be returned to you after the collection.

The time needed for complete recovery varies, but generally you can go home the same or next day, and resume your normal activities after two or three days. Normal bone marrow will re-grow rapidly to replace the collected bone marrow.

What are the risks? The risks for donating stem cells by this method are the same as those with any procedure involving a general anaesthetic. The chance of a serious complication is very low.

Some people may experience nausea and/or local pain and discomfort for several days.

How the transplant is performed

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

There is no cost to you

We just ask you give some of your time. The ABMDR will cover all medical and hospital expenses related to the stem cell donation. Incidental expenses associated with donation such as travel to and from hospital and accommodation if necessary, will be paid for. 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's condition changes. Other types of blood products may also be requested for that patient such as a normal blood donation or white blood cell donation which is collected by a cell separator machine. It is highly unlikely that you would be asked to donate to more than one recipient 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. Please refer to the ABMDR privacy policy on the website abmdr.org.au

Can you contact the patient who receives your stem cells?

You may receive progress reports on the patient after transplant. Donors and patients are not encouraged to meet, although if both parties agree and provide written consent, contact can be made.

How else can you help?

Following chemotherapy or stem cell transplantation patients often develop very low platelet counts. Platelets are needed to control bleeding. You may be able to become a platelet donor. For more information contact the blood service when you next donate or visit donateblood.com.au

When you should 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.

Thanks to a generous donor Vanessa is healthy and enjoying life



For more information or to make an appointment to join the registry call the Australian Red Cross Blood Service on **13 14 95** or visit **abmdr.org.au**

