

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 manages and recruits donors who are willing to donate their bone marrow or blood stem cells to a transplant patient.

The ABMDR is linked to a worldwide network of similar donor registries that can be searched for these patients.

The decision to become a bone marrow or blood stem cell donor requires careful consideration. We hope this brochure will help you to make an informed decision.

Why donation is important

Bone marrow is the soft tissue found inside bones. Bone marrow produces stem cells that in turn generate red blood cells, white blood cells and platelets. If bone marrow is damaged or destroyed by disease such as leukaemia or other blood disorders, a stem cell transplant from a matching donor is the only possible treatment for many of these people to save their lives.

The donation has to come from a person who matches the patient. Searching for a donor from the same ethnic group as the patient greatly increases the chance of finding a match, so your ethnic background is important.

Are you an eligible donor?

You can join the registry if you are aged between 18 and 45 years, in good health and meet the eligibility criteria. To join, you need to live in Australia and be prepared to donate anonymously to any patient anywhere in the world.

You will be asked to complete a donor enrolment form, which includes questions about ethnicity and to confirm your eligibility.

Please indicate your family background on the enrolment form (for example, southern European or northern Chinese).

Your tissue type, which is a way of making sure that you are compatible with patients, will be determined using a sample of your blood taken at the time of enrolment. A sample will also be stored in case more detailed tissue typing is needed later.

At the time you apply to become a donor on the register, the Australian Red Cross Blood Service may also ask you if you would like to become a blood donor and make a blood donation.

Once you've enrolled

The ABMDR won't usually contact you unless you are identified as a potential match for a patient.

Your name will stay on the register for as long as you wish, however, donors are retired from the registry on their 60th birthday.

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

Donor selection

Your tissue type is entered into a national database, which is 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 match with a patient, ABMDR will ask you to confirm your commitment to be a donor and to provide another blood sample to confirm this match.

In Australia, only one in 1,500 potential donors will be asked to donate bone marrow or 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 bone marrow or stem cells donation will assess you medically and answer your questions. Donation occurs in one of the major hospitals in the state capital cities. You will not be required to travel overseas.

Can you be a donor for a friend?

It is natural to want to help a friend who needs a bone marrow or blood stem cell transplant, but it is highly unlikely that two friends share the same genetic profile. The best hope for any patient lies with the millions of donors who are already listed on stem cell registries worldwide. The ABMDR and international registries will be searched to find a match for your friend. 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 anywhere in the world.

No bone marrow or blood stem cells will be taken at enrolment.

You can change your mind

Deciding to donate your bone marrow or stem cells is an important decision. Participation in the ABMDR is voluntary and you may withdraw at any time.

There are many reasons donors may change their mind, such as poor health, the time involved or concern about the risks. However, there is a 'point of no return' for the transplant patient. About a week before the donation, the patient's own bone marrow is destroyed in preparation for receiving the donated bone marrow or stem cells. At this point the patient will die unless healthy bone marrow or stem cells are transplanted as their own bone marrow will never grow back. Therefore, it is very important that you let us know well before this point if you have any concerns regarding donation.

Research and quality assurance

A small amount of your sample may also be used for quality assurance projects to ensure the proper functioning of the ABMDR and associated laboratories.

The ABMDR believes in the importance of scientific and medical research. This research can be helpful in understanding bone marrow transplantation and the ways in which cells and genes work, as well as the causes and treatment of leukaemia and other diseases.

For these reasons, at enrolment and other key stages of the donation, you will be asked if you wish to take part in ethically approved research.

If you consent to this, your blood samples and other information that does not identify you, may be made available to researchers and laboratories for research that the ABMDR ethics committee has approved. The researchers and laboratories may also store and share samples for future research.

Collection of your bone marrow or blood stem cells

If you are matched and agree to donate, there are two ways you can donate your bone marrow or stem cells. A medical specialist will assess the donation method that is best for you, but 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 four days before 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, which is performed at a hospital or blood donor centre, does not require a general anaesthetic and takes about 3-4 hours. You may leave after the procedure, but you may be asked to give another donation the following day if not enough cells have been collected.

What are the risks?

G-CSF is usually well tolerated, but you may have bone pain and some flu-like symptoms during the course of the injections. These symptoms 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. Rare side effects have been reported in donors, and these will be discussed in more detail with you if you match a recipient.

2. Bone marrow donation

Blood stem cells found in the bone marrow can be collected under general anaesthetic. The marrow is extracted from the pelvic bone cavity using a needle and syringe. This procedure can take up to two hours.

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 using 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, local pain and discomfort for several days.

To join the ABMDR, you must be willing to help any person who needs a bone marrow transplant.

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

The ABMDR will cover all medical and hospital expenses related to the stem cell donation. We just ask that you give some of your time.

The ABMDR will also pay for incidental expenses associated with donation, such as travel to and from hospital and accommodation.

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

Life after donation

Donors are temporarily deferred from the registry for two years after donation but they remain available for the same patient during this period. Donors are automatically reactivated after this period.

The ABMDR wants to make sure that you are fine after donation. For this reason, we will contact you within 72 hours of collection and weekly until you are fully recovered and have resumed your normal activities.

You will also receive a phone call at three months and an annual telephone call for up to 10 years to check your general condition. If you have donated peripheral blood stem cells, you will be asked to see your general practitioner (GP) at a designated date after the donation.

If any abnormal findings are identified in follow-up tests, you will be referred to your GP or a relevant physician.

Can you donate again?

You may be asked to donate bone marrow or stem cells a second time 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 cells, which are 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.



Privacy and confidentiality

The ABMDR recognises the importance of respecting your privacy and protecting the confidentiality of you and your family's personal and health information that is collected and stored. We need this information to ensure safe matching of potential donors and to maintain the quality of the registry database.

We work closely with the Australian Red Cross Blood Service (Blood Service) and a network of health professionals and organisations, including registries in other countries. We do not provide information that would identify you to persons outside the ABMDR, the Blood Service or the health professionals involved in your care.

If you are identified as a potential match, the information provided to other registries and treating doctors is solely to enable them to confirm your suitability as a match. If the match is confirmed and you agree to donate, only the hospital and health professionals involved in the collection process will know your identity.

More detailed information on our Privacy Policy is on our website – www.abmdr.org.au.

If you have any questions about protecting your privacy, please ask us.

Can you contact the patient who receives your stem cells?

Protecting donor and patient anonymity and confidentiality is a priority for the ABMDR and our centres.

We know you may need information that can help you better understand why you have been selected to be a donor. The person looking after you can provide specific de-identified information for this purpose.

The ABMDR also understands that you might want to know about the patient's progress after the transplant. You can ask the team looking after you for an update on the patient's clinical condition. This update will not include any identifiable or personal information about the patient, and can be given to you 30 days and 12 months after transplantation.

The ABMDR allows anonymous communication between you and the patient. This can include correspondence or exchange of gifts, but no personal details such as name, date of birth or address may be disclosed. Ask the team looking after you for more information.

While the ABMDR discourages direct contact between donors and patients, we recognise that you and the patient may decide that, after receiving counselling about the implications of this decision, you want to release details to the other party. If you want to release your personal details you need to wait two years after the donation and then you will need to sign a consent form. Ask the team looking after you for more information.

How else can you help?

Patients often develop very low platelet counts after chemotherapy or stem cell transplantation. 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 address and telephone numbers
- your personal details e.g. last name changes
- your health that may prevent you from donating permanently or temporarily, including pregnancy
- your commitment to remain on the ABMDR

For more information, call **13 14 95** or visit abmdr.org.au

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