

## WHAT IT MEANS TO JOIN THE REGISTRY

Once you join, if you are found to be a suitable match for a patient, you will be contacted and asked whether you consent to proceed. If you're healthy and happy to go ahead, you will be given further information about the donation procedure and have the opportunity to ask questions. You will have further blood tests (including for infectious diseases) and a comprehensive medical check-up.

Most patients will be treated with a blood stem cell donation – for the donor, this involves taking a short course of daily injections, and then blood stem cells can be filtered out of your blood. A small proportion of patients – for example, infants – can only be treated with a donation of bone marrow, which is a surgical procedure using a needle to extract cells from the pelvic bone, performed under general anaesthetic and involving a same-day or overnight hospital stay.

Before you join, it's important you understand that enrolling as a donor means:

- that the Registry collects, stores, uses and discloses personal and health information about you, in order to conduct its operations.
- that the Registry does not release a donor's name, other than for the purpose of contacting you if you are matched to a suitable potential transplant recipient.
- samples (including DNA) will be collected from you for the purpose of tissue typing and infectious disease screening. The retention, storage and sharing of these samples is required for testing, quality assurance

## USE OF MY INFORMATION FOR RESEARCH

The information held by the Registry is a valuable resource for medical researchers. De-identified information about donors, their health and tissue types can be made available for research approved by the Registry's Ethics Committee, if you consent.

Please mark which option you prefer:

I consent to the use of my information, which does not identify me, for ethically approved research.

OR

I do **not** agree to the use of my information for research.

OR

Sometimes, approved medical researchers would like to contact donors to ask them to actively participate in a study – for example, by providing an additional blood sample. In this event, the Registry would contact you first to see if you are interested and give consent. If you would like the Registry to contact you about actively participating in specific ethically approved medical research studies, please tick here.

### For Australian Red Cross Lifeblood and other recruitment staff to complete

Donor is:  An existing blood donor  A new blood donor  Not a blood donor

Blood donor ID .....

Date of ABMDR sample collection / / / / /  Place of donation .....

Recruitment staff name ..... Position/organisation .....

Signature ..... Date / / / / /

Any modifications to the form must be signed and dated.

For Registry use only – Complete IDs when detaching pages

GRID	ABMDR Donor ID	Tissue Typing Lab ID (if applicable)
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and other operational processes. Samples will only be shared with accredited health services working with the Registry.

- that the Registry is part of a worldwide network of bone marrow and blood stem cell donor registries which share information to match patients with donors around the world. Your name would not be shared with international registries, however information about your health and tissue type will be.
- no payment will be made to you other than reimbursement of some basic expenses involved in the process of becoming a donor.
- you may be matched with a patient up until you are 60, unless you advise us earlier that you would like to be removed.
- it's really important that you keep your details up to date so that we can contact you. If we can't reach you using the information you have provided to us, you agree to allow us to share your identifying information with Medicare Australia and the Australian Red Cross Lifeblood for assistance in contacting you.

Further information on the donation process and the Registry's privacy policy is available on the Registry's website, [abmdr.org.au](http://abmdr.org.au).

By signing this form below, you are agreeing that you consent to the above.

## SIGN ME UP!

I confirm that I have carefully read all of the above and informed myself about becoming a bone marrow/blood stem cell donor, and I would like to join the Australian Bone Marrow Donor Registry.

Donor name .....

Donor signature .....

Date / / / / /

Donation number (place barcode here)

# Donor enrolment

## Bone marrow/blood stem cells



## Thank You!

Stem cells from blood and bone marrow can cure many types of cancer and immune diseases. Patients can only receive donations from people who are a very close match. Some patients match very few people in the world; sometimes, you may be the only match.

The greatest need for blood stem cells typically comes from patients with leukaemia, which affects all age groups, but the best source of blood stem cells is healthy young adults.

Before you fill out this form, you should have first read our brochure or website materials (at [abmdr.org.au](http://abmdr.org.au)) to make sure you have a good understanding of the donation process. You should also talk to your family, so that they can understand and support your decision.

The questions below are a quick checklist to help you and the Registry determine if there are any risks, for you or a patient, by becoming a donor. If you have any questions about answering this checklist, please contact the Registry on [info@strengthtogive.org.au](mailto:info@strengthtogive.org.au) to discuss.

We then need to know how to contact you if you are matched to a patient; and some information about your genetic heritage – this helps decide who is the best match for a patient, and can speed up the search process.

Finally, we want to make sure you understand what joining the Registry means. You will need to consent to the Registry storing and sharing your health information with other health services we work with, in Australia and overseas. We also ask you to consider whether you would like your health information to be used for important medical research purposes.

## AM I ELIGIBLE TO JOIN?

The Registry cannot accept donors if donating could be unsafe for you or the patient. However, you can still help us spread the word and encourage others to join! To join the Registry you must meet the following criteria:

1. I have never been diagnosed with thalassaemia major, sickle cell disease, Fanconi anaemia or haemophilia
2. I have never received an organ or bone marrow transplant
3. I have never suffered a stroke or heart attack
4. I have never had a positive test for HTLV or HIV
5. I am between 18 and 35 years of age
6. I am willing to donate anonymously to anyone in the world

If you have suffered from the following conditions, you **may** be ineligible to donate – before continuing, please contact us on [info@strengthtogive.org.au](mailto:info@strengthtogive.org.au) so we can discuss the details with you.

- Cancer – this includes any past history of cancer **except** basal cell carcinoma (BCC) of the skin, squamous cell carcinoma (SCC) of the skin, and pre-cancerous conditions such as cervical abnormalities.
- Autoimmune disease – this includes serious diseases like rheumatoid arthritis, systemic lupus erythematosus, and multiple sclerosis.

By continuing, you are confirming that you are eligible to join.

For Registry use only – Complete IDs when detaching pages

GRID	ABMDR Donor ID	Tissue Typing Lab ID (if applicable)
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## ABOUT ME

Family name .....

Given name ..... Middle name(s) .....

Date of birth   /   /

Sex Female  Male  Other (please specify) .....

Sex assigned at birth (if different from above) Female  Male

Height (estimate)    (cm) Weight (estimate)    (kg)

Home phone (   )       Work phone (   )

Mobile

Email .....

Work email .....

Mailing address .....

State    Postcode

Home address (if different from mailing address) .....

State    Postcode

If you are matched to a patient, contacting you will be of critical importance. The Registry makes it easy to update your contact details; however just in case you forget to let us know of any changes, please clearly write below the details of any other means of contacting you. This could be your social media details, family member or friends' phone numbers (ask them first!), employers, etc.

Do you have a Medicare card? Yes  No

Have you ever enrolled to donate bone marrow or blood stem cells before?

No, I am a new donor.

Yes, I am registered with an overseas registry and wish to transfer.

Please write name of overseas registry: .....

Have you donated bone marrow or blood stem cells before?

No

Yes – I donated to a relative. Number of donations: .....

Yes – I donated to an unrelated patient. Number of donations: .....

## ABOUT MY FAMILY

The Registry collects information on your ethnicity as there is a strong linkage between your genetic background and your tissue type. This data helps provide the best match between donors and patients and can speed up the search process. Please tick those ethnicities that apply to your **parents and grandparents**. If your heritage is not represented, or you are unsure, please leave blank.

### Oceanian

Aboriginal Australian/Torres Strait Islander

Maori

Melanesian

Papua New Guinean

Micronesian

Polynesian

### European

North West European

Southern European

South Eastern European

Eastern European

Eastern European Jewish

### African and Middle Eastern

Arab

Middle Eastern Jewish

Other Middle Eastern

North African

Central and West African

Southern and East African

### Americas

African American

Hispanic North American

Native North American Indian

South American

Central American

Caribbean Islander

### Asian

*Mainland SE Asian*

Lao

Thai

Vietnamese

Other Mainland SE Asian (eg Burmese, Khmer)

*Maritime SE Asian*

Filipino

Indonesian

Other Maritime SE Asian (eg Balinese, Timorese, Malay)

*Chinese Asian*

Northern Chinese

Southern Chinese

Western Chinese

Taiwanese

Other Chinese Asian

*NE Asian*

Korean

Japanese

Other NE Asian (eg Mongolian)

*Southern Asian*

Indian

Pakistani

Other Southern Asian (eg Sri Lankan)

*Central Asian*

Central Asian (eg Afghan, Armenian, Georgian)

GRID

ABMDR Donor ID

Tissue Typing Lab ID  
(if applicable)

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