

PROTECTING YOUR PRIVACY OUR PRIVACY POLICY



WHO ARE WE?

The Australian Bone Marrow Donor Registry (ABMDR) is a non-profit organisation that manages the processes of recruiting volunteer bone marrow and blood stem cell donors, searching and selecting donors for patients in need of transplant and following up donors after donation. We support the members of the global network of stem cell registries by collecting and distributing information to enable the best decision to be made for both the donor and the patient. We receive funding support from the Commonwealth and state and territory governments.

ABMDR is committed to providing high-quality services to support this important and life-saving work. We acknowledge

the great generosity and commitment of our volunteer donors. As a fundamental part of this commitment, we recognise the importance of protecting the privacy and confidentiality of the information that we collect about you, your health and your family.

If you have any questions about our Privacy Policy please do not hesitate to ask our staff or contact us.

As well as being an important professional and ethical commitment to you, we are required to comply with Commonwealth, state and territory privacy

laws. The Commonwealth privacy law is the Privacy Act 1988. Under these laws, we are required to comply with a number of Privacy Principles. The core Principles are the Australian Privacy Principles (APPs) under the Privacy Act. A copy of these Principles can be found on Australian Information Commissioner's website – www.oaic.gov.au.

OUR KEY PARTNERS

We work closely with the Australian Red Cross Blood Service (Blood Service), AusCord (the Australian network of public cord blood banks), hospital tissue typing and transplant units and members of the global network of stem cell registries. The Blood Service stores the blood and other tissue samples on our behalf.

Our network includes:

- **Australian Red Cross Blood Service bone marrow donor centres:** The donor centres manage the register of donors and handle all stages of the donation process, including recruitment, counselling and advocacy to the donors.

- **Tissue typing laboratories:** These centres provide tissue typing services on patients and donors. They provide expert advice on tissue typing matters and a dedicated search coordinator who manages searches on behalf of patients requiring family and unrelated donor searches.
- **Transplant centres:** These centres provide transplant services for Australian patients needing bone marrow transplantation. They care for the patients and, via the local search coordinator, initiate the search for matched donors through the ABMDR.
- **Collection and apheresis centres:** These centres collect the blood stem cells from the volunteer ABMDR donors before transplant. In collaboration with the donor centres, the staff counsel the donors before the collection, perform a physical assessment and ensure the donor is well before discharge.
- **AusCord cord blood banks:** These blood banks manage the donation of umbilical cord blood units. They counsel the mothers who are donating cord blood, and collect, process, store and release cord blood units for public use.

WHAT PERSONAL AND HEALTH INFORMATION DO WE COLLECT, STORE AND USE?

During all stages of the donation and transplantation process, it is essential that we are able to identify you, know your relevant medical history (and your family's medical history), keep records of tests and tissue typing, and are able to contact you. When collecting cord blood from your baby, information will need to be collected about your baby and your baby's parents.

This information will include:

- Personal details, including your name, address, date of birth, sex, ethnic background, your contact details and details of next of kin and/or other persons to contact if we need to find you.
- Your relevant medical history (and your family's medical history), including information to determine whether we might need to exclude you or a sample from the registry.
- The results of blood and other tests required to assess and determine if you and/or the sample can be included in the registry (these tests may include testing for particular conditions including infectious diseases, hepatitis and HIV/AIDS).
- Details of your doctor and hospitals and other relevant health professionals involved in your health care.

Generally, we will collect this information directly from you and, where required, from your doctor, other health professionals and hospitals involved in your health care, your family members or carer. If we need to get information from other people, we will ask your permission to do so.

We may collect this information in a variety of ways including completion of forms, or via telephone, email, text messaging or fax. You may also provide this information to us through our website, a mobile device or an app.

It is important that the information we hold about you remains accurate and up to date. Please let us know of any changes in your contact and other personal details. Our staff may need to confirm your current address and contact details with you from time to time for this purpose.

WHAT DO WE DO WITH THE INFORMATION?

The information we hold about you will be used to determine your suitability for inclusion in our registry. We enter information about you and your tissue type and other relevant health information in our databases and update this information as required, keeping in touch with you.

It is essential that we are able to identify you and the sample(s) linked to you so that we can:

- Ensure the accuracy of the databases.
- Contact you and your doctor if the information collected identifies a health issue that you need to know about.
- Maintain the safety and integrity of the clinical information we have collected.

This identifying information is also shared with the Blood Service and, where relevant, AusCord as it is essential for the safe testing, tissue typing, storage and management of your sample. The Blood Service may use this information to determine your suitability as a blood donor.

HOW WILL YOU USE MY INFORMATION?

When authorised organisations ask for information from our registers to see if there is a potential match for a transplant, we do not disclose information that would identify you. If a likely match is identified, we and/or the Blood Service will contact you to see if you wish to proceed as a donor for the proposed transplant.

In rare circumstances, due to legislative requirements or a court order (e.g. subpoena), we may be required to disclose information about you to regulators, law enforcement bodies or other parties without your prior knowledge or consent. Subject to any legal constraints, we will use reasonable steps to let you know of these requests.

We respect and protect your privacy. We do not disclose your identity to anybody, other than the Blood Service or, where relevant, AusCord, without your knowledge and agreement.

HOW DO WE STORE AND PROTECT THE INFORMATION WE HOLD ABOUT YOU?

We store your information at our premises and in electronic systems under our control. As noted earlier in this policy, identifying information about you will also be stored in systems operated by the Blood Service and the AusCord cord blood banks. Only de-identified information is provided to other international registries.

We will take appropriate steps to protect the security of the information we hold about you, including protection against unauthorised access, virus or other electronic intrusions, fire, theft or loss. Our electronic records holding information about you are protected by a security password. Our staff are bound by strict requirements regarding protection of the privacy and confidentiality of your information as a condition of their contract with us.

CAN I SEE WHAT INFORMATION YOU HOLD ABOUT ME?

Under Australian privacy law, you have the right to see the information we hold about you. This right includes correcting any errors in the information. Please contact us if you wish to see this information. There may be a fee to cover the costs of providing copies of this information to you.

RESEARCH, EDUCATION AND QUALITY IMPROVEMENT

The ABMDR is involved in research programs, professional development and other educational activities as part of our commitment to supporting high-quality community education, donor recruitment, tissue testing, matching, transplantation and after care of donors and recipients. We may use the information we hold about you and your linked sample to assist with this research and education. **However, this information will not identify you unless we have received your agreement to do so.**

HOW LONG DO WE KEEP THE INFORMATION?

Participation in the donor registry is voluntary. If you advise and confirm that you no longer wish to participate in the registry, we will remove you from our register of active donors. However, for safety reasons and to comply with legislative and medico-legal requirements, identifying information about you will need to be retained by us and information relating to tests will need to be retained by the Blood Service and tissue typing laboratories.

In keeping with international practice and for safety and quality reasons, we retire donors from our register when they reach their 60th birthday.

If you have any questions or concerns about our privacy policy and management of your information, please let our staff know and they will be happy to address your concerns. If our staff do not resolve your concerns, or you have a complaint about our privacy management, please advise us by calling (02) 9234 2405 or emailing abmdr.admin@abmdr.org.au. We will do our best to address your complaint within 30 days of receiving it. If you are not satisfied by our response, you have a right to make a complaint to the Commonwealth or state/territory Privacy Commissioner and we can provide you with their contact details.

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For more information visit abmdr.org.au

