

The Australian Bone Marrow Donor Registry (ABMDR) is bound by the Federal Government's Privacy Amendment (Private Sector) Act 2000. The Legislation includes National Privacy Principles that set out how the private sector organisations should collect, use, keep secure and disclose personal information.

The principles also give individuals a right to know what information an organisation holds about them and the right to amend it if it is incorrect. There are special provisions for sensitive information, which includes health information.

Under this Act an organisation must have a policy document outlining its information handling practices and make the document available to anyone on request.

The Privacy Act gives you a number of rights including the following:

- ◆ You must be told why personal information is being collected and whether it can be given to anyone else.
- ◆ You have the right to request access to the information held about you and if necessary to have it corrected so that it is accurate, complete and up to date.
- ◆ You have the right to have your personal information stored securely and protected from unauthorised access or misuse.
- ◆ You have the right to know how your personal information will be used.

If you believe your privacy has been infringed you can make a complaint.

Collection of donor and recipient information

The ABMDR collects information from you (as a donor) in order to protect both your health and safety and the safety of the stem cell products. The ABMDR also collects information from you (as a recipient) in order to accurately search for an appropriate donor for unrelated stem cell transplantation.

What information we hold about you

The ABMDR holds personal information supplied by you or by a medical professional. In addition, we hold test results. This information may include details such as contact information of you and your nominated secondary contact, tissue typing information, results on infectious disease testing, your medical history and other medical tests.

The ABMDR is a national organisation and information is stored in the National Office as well as state based centres.

Disclosure of your information

Your information will be used to perform medical assessments and to maintain contact with you. Donor and recipient information will be accessed by ABMDR staff, donor centres, tissue typing/search centres, collection and apheresis centres, medical and scientific personnel involved in searching, matching and collecting hematopoietic stem cells, as well as personnel involved in the transplant and follow-up. As a donor, your personal information, which means your identity, will not be provided to any personnel involved in the transplant.

In some instances it may also be necessary for the ABMDR to release personal information to insurers and/or regulatory auditors. The insurers and auditors

will be required to hold this information in confidence.

Access to information

Should you wish to see what information we hold about you, you may be asked to submit a written request to the ABMDR Executive Officer. Proof of identity will be required to ensure information is not disclosed to the wrong person. Some information may not be immediately available but we will attempt to deal with requests quickly.

Storage and security of information

Security systems control access to record storage areas and electronic information is password protected. All staff and volunteers are bound by the Australian Red Cross Blood Service (ARCBS) Confidentiality Policy and the ABMDR Guidelines.

Making a complaint

If you believe that your privacy has been infringed, your concerns may be taken up with relevant donor centre, tissue typing/search centre, collection centre or apheresis centre. If you are not satisfied with the centre's response you can contact the ABMDR Executive Officer, and if you are still not satisfied you can refer your complaint to the Federal Privacy Commissioner.