



About AusCord and Public Cord Blood Banking



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What is AusCord?

AusCord is the national network of public cord blood banks in Australia. It comprises three cord blood banks – the **BMDI Cord Blood Bank** in Melbourne operated by a consortium comprising the Royal Children’s Hospital, the Fight Cancer Foundation and the Murdoch Childrens Research Institute; the **Queensland Cord Blood Bank At The Mater** in Brisbane, operated by Mater Misericordiae Limited; and the **Sydney Cord Blood Bank**, operated by the Sydney Children’s Hospitals Network.

What is cord blood and how is it collected?

‘Cord blood’ is the blood left behind in the umbilical cord and placenta after a baby is born. Cord blood is rich in blood stem cells that can generate all blood cell types. It can be used in transplantation to treat many serious blood and related disorders such as leukaemia, immune disorders and bone marrow failure in children and adults.

Cord blood can be collected after the umbilical cord has been cut following either a vaginal or Caesarean birth. A needle is inserted into the umbilical cord vein attached to the placenta and the blood is drained into a collection bag. The procedure for delivery is never altered for the collection of cord blood. The cord blood may be collected either before or after the placenta has been delivered.

What are my options for collection and storage of cord blood?

In Australia there are two options:

1. Donation to an **AusCord public cord blood bank**. If this option is chosen, donated cord blood is made available to all patients in need of a blood stem cell transplant in Australia or overseas. No fee is charged for storage. You and your baby will have no further rights in, or ownership of this cord blood, and only in special circumstances may your baby’s cord blood be made available for use by your baby or another family member, provided that it has not previously been released.
2. Storage in a **private cord blood bank** for potential use only by your baby or other family members. Private banks charge a fee for their services. Further information about private cord blood banking is available online or through your obstetrician.
AusCord does not provide private storage.

Alternatively, you are free to choose not to have your cord blood collected, in which case the placenta and umbilical cord will simply be discarded according to usual hospital procedures.

If you choose to donate cord blood bank, you may also consent to:

1. The bank using the cord blood and your blood samples for validation, quality control or development of techniques for cord blood banking, and/or
2. The release of de-identified cord blood and your blood samples, and/or any associated information, for research approved by a registered human research ethics committee.

Conditions on collection and donation of cord blood

There are some reasons you may not be able to donate your baby's cord blood to a public cord blood bank:

- Medical factors relating to your health, that of the baby or other family members
- Availability of collection staff at the time of delivery
- Technical factors affecting cord blood collection – for example, delayed cord clamping reduces the volume of cord blood available for collection. The volume of cord blood collected is critical for successful transplantation.

You should **NOT** agree to donate if:

- You are HIV (AIDS) positive
- You carry the hepatitis B or C virus
- You have injected drugs not prescribed by a doctor or dentist within the last 5 years
- You have been paid for having sex in the last 12 months, or
- You have had sex with a bi-sexual man in the last 12 months

Are there additional requirements if I agree to donate cord blood?

If the cell count in the cord blood collection is sufficiently high to make it suitable for banking you will be asked to:

- Provide a personal and family health history
- Answer and sign a maternal declaration about your health history
- Give a blood sample around the time of the baby's birth. In some cases, such as if you have recently travelled to an area where malaria occurs, we will ask you to have another blood test six months after the birth of your baby
- Provide follow-up information about your and your baby's health approximately six months after delivery
- Give permission for cord blood bank staff to contact you in the future about the health of your child
- Give permission for cord blood bank staff to review your and your baby's medical records
- Allow the cord blood bank to store a sample of your and your baby's blood for relevant future testing

Why is it necessary to collect all this information?

We are required to collect this information by the regulatory bodies that oversee the safety of blood and cell products for use in patients. In Australia this is the 'Therapeutics Goods Administration' and there are similar agencies in each country to which cord blood may be sent. The information is collected for the protection of the vulnerable patients needing transplants, both to prevent the transmission of blood-borne infections and to ensure that inherited disorders of the blood and immune systems, which may not be evident at birth, are not passed on to the patient via the stem cells in the cord blood. We need to meet all safety requirements before releasing cord blood for transplantation. We acknowledge that the information collected may be very personal and detailed but without this information we will not be able to bank your baby's cord blood. If you wish to access your information in the future or have questions relating to the information we collect, you may contact the CBB to which you donated (See contact details at the end of the document).

What testing will be performed on my and my baby's blood?

- Blood Count (numbers of various kinds of blood cells)
- ABO Blood grouping of red blood cells (blood typing)
- Tissue typing (white blood cell grouping) to enable cord blood matching with potential patients
- Tests for some inherited blood disorders such as thalassaemia
- Tests for exposure to infections such as HIV (AIDS), hepatitis B and C, HTLV and syphilis
- Depending on your travel history, additional testing (e.g. for malaria) may be undertaken

If we identify clinically significant health concerns you and/or your GP will be contacted for further follow-up.

Are there any risks involved?

The risks of donating cord blood are associated with you having a blood sample collected. These risks are momentary discomfort, potential local bruising and rarely local infection. There is no risk to your baby as cord blood collection does not commence until after the cord has been cut. **Your baby will not require a blood sample to be taken.**

Will I incur expenses?

You will not incur expenses, nor will you be paid for cord blood donation.

Are there any benefits to me, my baby or my partner?

There is no direct benefit to you, your partner or your baby, but your donation supports the growth of the AusCord inventory of cord blood units available for patients with life-threatening disorders worldwide. Your donation may also contribute to biomedical research that has been approved by a registered human research ethics committee, or for quality control purposes.

Will my decision about cord blood banking affect my or my baby's care?

Participation is completely voluntary. Whether you donate cord blood or decline to participate will not in any way affect your or your baby's care.

Can I change my mind?

You are free to withdraw your agreement to donate up until 30 days after the birth of your baby.

Is my privacy and that of my baby protected?

Yes. Other than as required by law, all information identifying you and your baby will be kept confidential and is not passed on to persons outside the AusCord network other than you, your doctor and other health professionals involved in your or your baby's health care. All information related to your cord blood donation and your medical and family history is allocated a unique number. The information reported to Donor Registries and Transplant Centres is identified only by this unique cord blood number.

The records that link your and your baby's information to the cord blood donation are kept securely, indefinitely by the cord blood bank to allow for any required follow up and notification of abnormal results to you and/or your doctor.

AusCord will only use or disclose your personal information for the primary purposes for which it was collected (as set out above) or as permitted or required by law.

If we provide your details to a third party acting on behalf of AusCord for these purposes, the third party will be subject to a confidentiality agreement and must only use your personal information for the purposes for which it was provided.

All information collected by AusCord is stored securely. All electronic records are stored in Australian Data Centres. Where information is stored by a third party, AusCord requires them to comply with the National Privacy Act.

Information on the use of the cord blood will only be published or disclosed to other people in a way that will not identify you or your baby. No identifying information is exchanged between the cord blood bank and transplant centre, or between a cord blood donor and recipient.

By law, a positive test result for HIV/AIDS, HTLV I and II, hepatitis B and C and syphilis must be reported to the relevant State or Territory health authority.

How do I contact my local AusCord Cord Blood Bank?

BMDI Cord Blood Bank (Melbourne):

Ph.: 03 9345 5834

Fax: 03 9345 4194

Email: cord.rch@rch.org.au

Queensland Cord Blood Bank at the Mater:

Ph.: 07 3163 2665

Fax: 07 3163 2345

Email: qcbb@mater.org.au

Sydney Cord Blood Bank:

Ph.: 02 9382 0371

Fax: 02 9382 0372

Email: enquiries@scbb.com.au

www.abmdr.org.au/public-cord-blood-donation

