

THE NATIONAL PUBLIC CORD BLOOD BANK PRIVACY NOTICE OUR COMMITMENT TO YOUR PRIVACY

Our Commitment:

At Canadian Blood Services we are committed to protecting the privacy and security of all personal information in our possession. We do so by following relevant laws and best practices and encourage you to read our privacy policy on our website at www.blood.ca/privacy.

Purpose:

Canadian Blood Services manages the OneMatch Stem Cell and Marrow Network which is a national program comprised of the National Public Cord Blood Bank and the Adult Registry.

The purpose of the National Public Cord Blood Bank is to recruit, collect, process and store donated cord blood for unrelated stem cell transplantation. Donated cord blood units will be listed on the OneMatch Stem Cell and Marrow Network for the purpose of finding potential matches with patients who require stem cell transplants.

What is Personal Information?

Personal information, which includes personal health information, is information that may be used to identify you or your baby. It includes such details as name, address, date of birth, health status, test results or provincial health card number.

Collection of Personal Information:

In order for you to participate in the National Public Cord Blood Bank, we will collect personal information about you and your baby from your hospital records, from the blood samples that we collect from you for compatibility and transmissible disease testing, as well as your answers to a health questionnaire. We will review our records to determine if you have ever donated or attempted to donate blood or adult stem cells or if you have joined or ever attempted to join the OneMatch Stem Cell and Marrow Network as a potential stem cell donor. We need to collect this information so that we may determine whether the cord blood collected is suitable to process and store for potential transplant into a patient. This information will be put into an electronic database which forms part of Canadian Blood Services' OneMatch Stem Cell and Marrow Network, for which the servers are located in Ottawa, Ontario. Because your personal information will be held in Ontario it may be subject to the privacy laws of Ontario, as well as any privacy laws in your own province.

If it is determined that the cord blood unit we collected is not suitable for storing, the personal information we have collected about you and your baby will remain in the OneMatch Stem Cell and Marrow Network database so that we may keep a record of individuals who have attempted to participate in the National Public Cord Blood Bank.

How Do We Use Your Personal Information?

We may use your personal information and your baby's personal information to:

- Assess your eligibility to store the cord blood unit;
- Select the cord blood unit for transplant;
- Attempt to contact you after your baby's birth to enquire about your baby's health if the cord blood unit is suitable for transplant;
- Contact you for safety reasons, if necessary;
- Contact your physician to request supporting documentation if you report problems regarding your health or your baby's health which may affect the cord blood;
- Make our services better and more efficient;
- Access your test results in the event a staff member accidentally comes into contact with your blood;
- Advise you regarding Canadian Blood Services' programs and donor events;
- Support our education and training activities;
- Perform quality control testing of equipment and process improvement;

- Protect the safety of blood, blood products and stem cells in the event your blood sample tests positive for a transmissible disease;
- Comply with legal and regulatory requirements;
- Fulfill any other purposes prescribed by law.
- Contact you about our fundraising activities. If you wish to remove your name from our fundraising contact list, please call 1 888 2 DONATE (1-888-236-6283) and ask for our National Fundraising Office.

Your Personal Information May be Shared With:

- Your physician to report any health risk;
- Public health authorities to report any positive transmissible disease test results. This information may also be shared with other Canadian blood operators to ensure the safety of blood products and the blood supply;
- Canadian transplant centres and international registries. We will only refer to you by using a unique donor number when we disclose information to the transplant program health care providers or registries;
- A third party laboratory for the purpose of performing screening tests on your baby's cord blood, provided they agree to keep it confidential;
- Accreditation or regulatory bodies provided they agree to keep it confidential; and
- Others, as authorized or required by law.

Research:

If your baby's cord blood, or its by-products, has been distributed to biomedical research with your consent, Canadian Blood Services will disclose only minimal information about you and your baby to researchers such as the date of collection, your baby's gender and the criteria we used to determine that your baby's cord blood was unsuitable for storage. Cord blood donated for biomedical research purposes will have personal identifiers removed and replaced by a unique code by Canadian Blood Services before being distributed to researchers. In this way, the researchers will not know who donated the cord blood. All research is subject to approval by Canadian Blood Services' Research Ethics Board and may also involve local review by research ethics boards where the research projects are taking place. You or your baby will not be identified in any research publication or presentation.

Withdrawing from the National Public Cord Blood Bank:

You may withdraw your consent to participate in the National Public Cord Blood Bank at any time by contacting Canadian Blood Services at 1 888 2 DONATE (1-888-236-6283). All personal information collected up to the date of your withdrawal of consent will remain in the OneMatch Stem Cell and Marrow Network database, but no further personal information about you or your baby will be collected or added to your record. Personal information about you or your baby will no longer be used to select your baby's donated cord blood unit for transplant. We will use your personal information to contact you for safety reasons, if necessary. If you withdraw, your baby's cord blood unit (if it has not already been used for quality assurance, transplantation or biomedical research), and all samples stored, will be discarded.

How to Contact Us:

You may contact our Privacy and Access to Information Office for more information about our privacy and access practices, or to request access to or correction of your personal information as follows:

In Writing:

Canadian Blood Services
Privacy and Access to Information Office
1800 Alta Vista Drive
Ottawa, ON K1G 4J5

Website: www.blood.ca

By phone:

1-613-739-2483
1-877-262-9191 (toll free)

By e-mail:

Privacy Office - privacy@blood.ca
Access to Information Office - ati@blood.ca

If you feel your concerns have not been addressed by Canadian Blood Services you have the right to contact your provincial Privacy Commissioner at:

British Columbia: <http://www.oipc.bc.ca>

Ontario: <http://www.ipc.on.ca>

Alberta: <http://www.oipc.ab.ca>