
 When I found out that umbilical cord blood could save someone's life, **donating my cord blood to a public bank was an easy decision.** 

*– Nathaly, two-time cord blood donor  
with Canadian Blood Services' Cord Blood Bank*



**Canadian  
Blood  
Services**

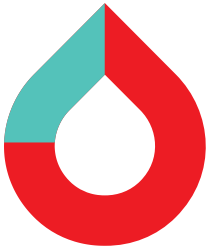
BLOOD  
PLASMA  
STEM CELLS  
ORGANS  
& TISSUES

**Did you know that after a baby is born, the blood left in the umbilical cord and placenta is rich in lifesaving stem cells?**

## **Cord blood can treat over 80 diseases and disorders including leukemia, yet it is often discarded as medical waste.**

Canadian Blood Services' Cord Blood Bank collects and stores donated cord blood for future use by patients in need of an unrelated stem cell transplant.

Half of all stem cell transplant patients in Canada are unable to find a stem cell donor.



**Fewer than 25%**  
of patients find a matching donor within their own family

**The other ~75%**  
must rely on unrelated donors to save their lives

A diverse national public cord blood bank means a better chance of finding a match for a patient in need.

## **Donating cord blood is free, easy and poses no risk to the mother or baby.**

Cord blood can be donated at four locations:

### **The Ottawa Hospital General Campus**

Ottawa Ontario

### **William Osler Health System at Brampton Civic Hospital**

Brampton Ontario

### **Alberta Health Services' Lois Hole Hospital for Women**

Edmonton Alberta

### **BC Women's Hospital and Health Centre**

Vancouver British Columbia

Visit our website to learn more about translation and interpretation services in other languages.

You could be the donor who saves someone's life.

**Registering is easy, visit [blood.ca/donatecord](http://blood.ca/donatecord)**

**Together, we are Canada's lifeline**

## **PERMISSION TO COLLECT Umbilical Cord Blood**

This Permission to Collect form contains information about donating your baby's cord blood to the public cord blood bank managed by Canadian Blood Services (the "Cord Blood Bank"), including the possible benefits and risks. Choosing not to donate your baby's cord blood will not have any impact on you or your family's medical care. If you donate your baby's cord blood to the Cord Blood Bank, your baby's cord blood cannot be transferred to a private cord blood bank.

### **What are cord blood stem cells?**

Umbilical cord blood contains blood stem cells. Cord blood stem cells are immature cells that develop into these cells in the bloodstream:

- Red blood cells to carry oxygen in your body
- Platelets to help blood to clot
- White blood cells to fight infections

### **What can cord blood stem cells be used for?**

The Cord Blood Bank collects, tests and stores cord blood stem cells to make them available for any patient in need of a stem cell transplant in Canada or worldwide. Occasionally, the Cord Blood Bank may use cord blood stem cells for other uses such as quality assurance (e.g. validation, training and quality control), product improvement and research if you have given the Cord Blood Bank your consent for research ("Other Uses"). Please see further information on Research Option below.

### **How are cord blood stem cells collected?**

After your baby is born, the umbilical cord is clamped then cut and the placenta, or "afterbirth," is delivered and then transferred to the Cord Blood Bank staff at the hospital. Your physician or midwife is voluntarily helping the Cord Blood Bank with the collection of cord blood based upon the consent you give for the collection. The cord blood is collected from the umbilical cord into a sterile bag and it is checked for eligibility for storage with the Cord Blood Bank. You may ask to have the placenta and/or umbilical cord returned to you if requested.

### **Determining if your baby's cord blood is eligible for the Cord Blood Bank**

At the hospital, the Cord Blood Bank will determine if your baby's cord blood is eligible.

If your baby's cord blood contains enough cord blood stem cells, the cord blood is eligible for the Cord Blood Bank. The cord blood will be transferred to the Cord Blood Bank manufacturing facility for further assessment. Before you leave the hospital, a Cord Blood Bank staff member will speak with you about consent to store your baby's cord blood for future transplant use. This includes asking questions about your medical history and general health. You will be asked to provide a blood sample which will be tested for HIV, hepatitis and other infectious diseases that can pass from one person to another. If you require IV (intravenous) fluid during labour, we may ask that you provide a blood sample at that time.

If your baby's cord blood is not eligible, depending on where you deliver, it may be

- discarded,
- transferred to the Cord Blood Bank manufacturing facility to be used for Other Uses, or
- returned to your hospital, to be dealt with according to approved hospital policies (e.g. Research). Questions about how your hospital will handle the returned cord blood should be directed to a hospital representative.

### **Storage and Transplantation**

Once your baby's cord blood arrives at our manufacturing facility, we will start testing and preparing the cord blood stem cells for storage. The results of this testing will help us determine if your baby's cord blood stem cells can be stored for future transplant use.

## PERMISSION TO COLLECT Umbilical Cord Blood

If at any time, we determine that your baby's cord blood stem cells may not be stored, your baby's cord blood and any blood samples may be discarded. Some cord blood units may be used for Other Uses.

### Research Option

If at any time, the Cord Blood Bank determines that your baby's cord blood stem cells may not be stored for future transplant use, they could still be used for biomedical research under the Cord Blood Bank's research program. In addition, during the process of preparing cord blood stem cells for storage, by-products (such as red blood cells) are removed from the cord blood and can be used for research rather than being discarded. Mark the Research Opt-In box so that the Cord Blood Bank may use or distribute your baby's cord blood and by-products for biomedical research under the Cord Blood Bank's research program. For more information about the Cord Blood Bank's research program and examples of research that may be done with cord blood, see Canadian Blood Services' information pamphlet on biomedical research at [www.blood.ca/cordblood](http://www.blood.ca/cordblood).

You may be asked to participate in research by a hospital researcher who is not associated with the Cord Blood Bank, whether or not you mark the Research Opt-In box below.

### Costs and Reimbursements

There is no cost to donate your baby's cord blood. There is no reimbursement for any part of your cord blood donation.

### Potential Benefits

Your donation may give a patient with a life-threatening disease a chance for a healthy life.

### Potential Risks and Discomforts

There are no significant risks related to the donation of cord blood. The collection of umbilical cord blood will not affect the delivery or the care of you or your baby. The cord blood is collected from the umbilical cord after delivery of your baby. If blood samples are taken from you for testing, the amount of blood taken is small (about three tablespoons) and will not affect your health. There is a small risk of slight pain and bruising at the site where the blood is taken, lightheadedness, possible fainting and, rarely, infection.

### Personal Information

You give the Cord Blood Bank staff permission to review the medical records of you and your baby to see if your baby's cord blood stem cells may be eligible for storage. The purpose of this review is to identify whether you or your baby have any diseases or medical conditions that could be passed on to a patient who may receive the cord blood stem cells. Information about the collection, use and disclosure of personal information is in our Privacy Notice.

### Where can I get more information?

For more information about Canadian Blood Services' Cord Blood Bank:

- Visit our website at [www.blood.ca/cordblood](http://www.blood.ca/cordblood)
- Call 1 888 2 DONATE (1-888-236-6283)
- Email [cordblood@blood.ca](mailto:cordblood@blood.ca)

Speak to your health care provider if you have any questions or concerns about cord blood donation.

### Withdrawing from the Cord Blood Bank

Your participation in the Cord Blood Bank is voluntary. You may withdraw at any time by calling 1 888 2 DONATE (1-888-236-6283). Your baby's cord blood stem cells will be discarded if they have not already been used for transplantation or Other Uses. The personal information Canadian Blood Services collected up to the date of your withdrawal will remain in the Cord Blood Bank but no further information about you or your baby will be collected, used or disclosed. We will use your personal information to contact you for safety reasons, if necessary.

Maternal Hospital ID Label

## PERMISSION TO COLLECT Umbilical Cord Blood

**Ethnic Background:** This information helps match a potential donor and a patient in need of a stem cell transplant. Please select the heritage that you and the baby's father most identify with on the chart below.

Please select only one ethnicity for yourself and one for the baby's father.

	Arab	Asian- Central	Asian-North	Asian- Northeast	Asian-South	Asian- Southeast	Black- African	Black- Caribbean	Black-Other	Caucasian	Chinese	Filipino	First Nations	Hispanic	Inuit	Jewish- Ashkenazi	Jewish- Sephardic	Metis	Pacific Islander	Multi-ethnic	Unknown	Prefer Not to Say	
Mother																							
Father																							

### Permission to Collect

I have read and understand the information about cord blood donation. I have had the opportunity to ask questions and I am satisfied with the answers to the questions. I have had access to an independent health care provider (e.g. my physician or midwife) for any questions or concerns regarding the donation of my baby's cord blood.

By signing this form, I voluntarily consent to the collection of my baby's cord blood after delivery for the purposes described in this form; to have a blood sample taken from me; to allow staff to review my medical record and my baby's medical record; to the collection, use and disclosure of my personal information and my baby's personal information as described in the Privacy Notice. I understand how I may withdraw my consent.

I understand that I may be asked to participate in research by a hospital researcher who is not associated with the Cord Blood Bank, whether or not I mark the Research Opt-In box below.

By marking the box below, I voluntarily agree to allow Canadian Blood Services to use or distribute my baby's cord blood, if it is not eligible for storage, and by-products to researchers for the purposes of biomedical research under the Cord Blood Bank's research program. I have read Canadian Blood Services' pamphlet on biomedical research and have had the opportunity to ask questions. I understand that Canadian Blood Services will not notify me if the cord blood unit is used for biomedical research and I will not receive results of any research using my baby's donated cord blood under the Cord Blood Bank's research program. I understand that research results will be posted on the Canadian Blood Services website.

**RESEARCH OPT-IN** (mark the box if you agree to the research option)

\_\_\_\_\_  
(Mother's printed name)

\_\_\_\_\_  
(Mother's signature)

\_\_\_\_\_  
(Date form signed)

\_\_\_\_\_  
(Mother's postal code)

\_\_\_\_\_  
(Mother's telephone number)

\_\_\_\_\_  
(E-mail, optional)

#### For CBB Use Only:

**Change of Information:**      Name     Address     Postal Code     Phone Number

Verification of information discrepancy from maternal hospital unique ID label to documented information by mother:

CBU Unique ID Number

# **PRIVACY NOTICE**



## **To Blood Donors, Stem Cell Registry Participants and for Canadian Blood Services' Cord Blood Bank**

At Canadian Blood Services we are committed to protecting your personal information. This notice explains how we collect, use and disclose the personal information we collect from blood (e.g., whole blood, plasma, platelets) donors and prospective donors, participants in the Canadian Blood Services Stem Cell Registry ("Stem Cell Registry") and participants in the Canadian Blood Services' Cord Blood Bank ("Cord Blood Bank"). If you are a cord blood donor, the following includes your baby's personal information, as applicable.

### **What personal information we collect**

Canadian Blood Services may collect the following personal information:

- Contact and demographic information, including contact information for your healthcare provider, as applicable;
- Responses to social and health questions;
- Post-donation information and your donation history, including information pertaining to your ineligibility to donate, if applicable;
- Test results from your blood, cord blood or buccal swabs, as applicable. These test results may include those for blood groups, including human leukocyte antigen (HLA) typing, and transmissible infection markers; and
- Health information from you or your healthcare provider, as required.

### **How we use your personal information**

Canadian Blood Services uses your personal information to assess your eligibility to participate in Canadian Blood Services' donation programs, to assess and match your compatibility with patients in need, and to ensure the quality and safety of blood, blood products, cord blood and stem cells. Your personal information may also be used to:

- Contact you if you are identified as a potential match for a patient, as applicable;
- Send you a buccal swab kit, if required;
- Contact you about relevant health matters, as applicable;
- Contact your healthcare provider, as required;
- Contact you regarding other opportunities to participate in our programs;
- Contact you in the event of blood shortages;
- Make our programs better and more efficient, to educate and train staff and others;
- Manage your accounts and respond to your inquiries;
- Honour you at Canadian Blood Services award ceremonies and to recognize your contributions as a donor or participant;
- Enable your participation in contests, promotions, surveys, and chats;
- De-identify your personal information: de-identification is the process of removing personal identifiers such as name, address, and phone number;
- Perform research that has been ethically approved;
- Maintain the safety of our workplace;
- Access your test results in the event of accidental contact with your donation or samples, as applicable;
- Contact you about opportunities to participate in research;
- Contact you for fundraising purposes. If you wish to be removed from our fundraising contact list, please call 1 888 2 DONATE (1.888.236.6283);
- Comply with legal and regulatory requirements; and

# PRIVACY NOTICE



- Other purposes as permitted or required by law or for other reasonable purposes.
- **Cord Blood Bank participants only:** contact you after delivery to inquire about your baby's health.

Canadian Blood Services does not sell your personal information.

## **Who we share your personal information with**

Your personal information may be shared with:

- Public health authorities;
- Other Canadian blood operators to ensure the safety of the blood supply system;
- Your healthcare provider regarding relevant health matters, as applicable;
- Canadian hospitals to coordinate your donation, as applicable;
- Canadian hospitals and registries, and international registries, as applicable, for matching purposes. We will only refer to you using a unique identifier when information is disclosed;
- Researchers, provided the research has been ethically approved and meets legal and regulatory requirements;
- Auditors from Canadian Blood Services' accreditation and regulatory bodies; and
- Others as permitted or required by law.
- **Stem Cell Registry participants only:** if you are identified as a potential match for a patient and we are unable to locate you, your contact information and date of birth will be disclosed to the Royal Canadian Mounted Police so they can attempt to locate you.

## **Protecting Your Personal Information**

Access to your personal information is limited to those who need access to it to perform their specific duties in relation to Canadian Blood Services. We may use third party service providers, including service providers outside of Canada. In some cases, those service providers may collect your personal information directly from you and your personal information may be subject to their privacy policies. All providers are contractually obligated to protect your personal information and to only collect, use and disclose the personal information they require for the purposes of providing these services for, or on behalf of, Canadian Blood Services.

## **Accessing or Correcting Your Personal Information**

To access or request corrections to your personal information, please visit our Privacy/Legal page at [blood.ca](http://blood.ca). Canadian Blood Services offers an online Change Your Address form for revising your contact information and at any time you may update your contact information through: calling 1 888 2 DONATE (1.888.236.6283) Email: [feedback@blood.ca](mailto:feedback@blood.ca) or our online chat feature on [blood.ca](http://blood.ca).

## **How to Contact Us**

For questions or concerns about this notice, please contact Canadian Blood Services Privacy and Compliance: Toll Free: 1.877.262.9191 Email: [privacy@blood.ca](mailto:privacy@blood.ca).

If you feel your concerns have not been addressed by Canadian Blood Services, you have the right to contact your provincial Information & Privacy Commissioner or Ombudsman.

# CANADIAN BLOOD SERVICES' CORD BLOOD BANK INFORMATION FOR CORD BLOOD DONATION FOR BIOMEDICAL RESEARCH



**This handout contains information about donating cord blood to Canadian Blood Services' Cord Blood Bank ("Cord Blood Bank") for biomedical research.**

Biomedical research on cord blood may increase our knowledge about blood stem cell transplantation and the processes for collection, manufacturing and storage of cord blood. Some researchers are studying stem cells from cord blood to determine or develop new treatments for diseases. Other researchers may use cord blood for research (not related to stem cells) that might lead to improvements in future medical care.

## ***When will cord blood donated to the Cord Blood Bank be used for research under the Cord Blood Bank's research program?***

Cord blood may be found unsuitable for storage if it does not meet the eligibility requirements of the Cord Blood Bank. Sometimes your baby's cord blood may be stored but later found to be unsuitable for transplantation. If at any time, the Cord Blood Bank determines that your baby's cord blood cannot be stored or used for transplantation, it could still be distributed to researchers in Canada and worldwide, to be used for biomedical research under the Cord Blood Bank's research program.

When preparing your baby's cord blood stem cells for storage, components are removed from your baby's cord blood. These components, also known as by-products, include for example, red blood cells. The components that are not used during the preparation of the blood stem cells for storage could be distributed for biomedical research under the Cord Blood Bank's research program rather than being discarded.

Under the Cord Blood Bank's research program, donated cord blood will be distributed for use in biomedical research **only** if:

- You have given your consent for your baby's cord blood to be used;
- Your baby's cord blood is found to be unsuitable for storage or for use in transplantation;
- Your baby's cord blood meets certain research criteria; and;
- The research project that will use your baby's cord blood has been approved.

Canadian Blood Services may provide your baby's cord blood or by-products to an approved research project on a cost recovery basis.

## ***How do I consent to donate my baby's cord blood for biomedical research under the Cord Blood Bank's research program?***

You must mark the Research Opt-In box on the Permission to Collect form if you want your baby's cord blood to be used for biomedical research. Otherwise your baby's cord blood may be discarded.

## ***Will the care my baby and I receive be affected if I do not donate my baby's cord blood to the Cord Blood Bank's research program?***

Your donation is completely voluntary. Your participation in the biomedical research program of the Cord Blood Bank has no effect on the care you or your baby receive.

## ***Are there any risks if I donate my baby's cord blood for biomedical research under the Cord Blood Bank's research program?***

There is no health risk to you or your baby if you donate your baby's cord blood for biomedical research under the Cord Blood Bank's research program. 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. Information that directly identifies you is replaced by a unique code. This way, the researchers will not know who donated the cord blood.



# CANADIAN BLOOD SERVICES' CORD BLOOD BANK INFORMATION FOR CORD BLOOD DONATION FOR BIOMEDICAL RESEARCH



## ***Are there any benefits if I choose to donate my baby's cord blood for biomedical research under the Cord Blood Bank's research program?***

Though neither you nor your baby will directly benefit from donating your baby's cord blood, the cord blood is used in scientific and medical research to help patients in the future. Cord blood may be useful for developing drugs, medical and/or commercial products to treat diseases. The products may be developed and sold to the public, but you will not own any rights to the product or receive any financial benefit from them.

## ***What kind of biomedical research will my baby's cord blood be used for under the Cord Blood Bank's research program?***

Examples of cord blood biomedical research include:

- Improvements to current clinical practices that use cord blood
- Improvements to cord blood collection, manufacturing and storage
- Study of stem cell biology
- Discovery of other clinical and non-clinical uses of stem cells from cord blood
- Production of stem cell lines that could be maintained for many years and used for a variety of research purposes
- Development of drugs, medical and/or commercial products to treat human diseases

Canadian Blood Services must approve all research projects under the Cord Blood Bank's research program. The Canadian Blood Services Research Ethics Board will also review all projects. In addition, researchers must receive ethics approval from their own institutions and, if applicable, other advisory groups who supervise research.

If you donate your baby's cord blood, you cannot choose what kind of research or which research project your baby's cord blood may be used for.

Find more information about research projects using donated cord blood under the Cord Blood Bank's research program on the Canadian Blood Services website at [www.blood.ca/researchcordblood](http://www.blood.ca/researchcordblood).

## ***How will the research results be disclosed?***

The results of biomedical research using cord blood distributed under the Cord Blood Bank's research program may be presented at meetings or in publications, but your identity or that of your baby will not be disclosed. You will not be contacted about any research results presented or published. The Canadian Blood Services website has information about ongoing research projects and general results of completed research.

## ***What if I want to withdraw my consent for biomedical research under the Cord Blood Bank's research program?***

Donating your baby's cord blood is completely voluntary. You may withdraw your consent at any time. Call 1 888 2 DONATE (1-888-236-6283) and we will send you a form titled *Withdrawal of Consent to Participate in the Canadian Blood Services' Cord Blood Bank*. Complete the form and return it to Canadian Blood Services.

Please note, most cord blood distributed to researchers under the Cord Blood Bank's research program will be shipped within 48 hours of collection. If your baby's cord blood has not already been used for biomedical research it will be discarded. If your baby's cord blood has already been used for biomedical research under the Cord Blood Bank's research program, the cord blood sample and research results may not be withdrawn.

## ***What if I have questions about the Cord Blood Bank's research program?***

Call 1 888 2 DONATE (1-888-236-6283) or go to our website at [www.blood.ca/researchcordblood](http://www.blood.ca/researchcordblood) for more information.