Stem Cells for Life

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





BLOOD PLASMA STEM CELLS ORGANS & TISSUES

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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



PERMISSION TO COLLECT **Umbilical Cord Blood**

Maternal Hospital ID Label

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.



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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.

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
- Call 1 888 2 DONATE (1-888-236-6283)
- Email 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

<u>Ethnic Background:</u> 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	an	Asian- Northeast	J-Sc	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.

if it is not eligible for storage, and by Bank's research program. I have r opportunity to ask questions. I unde biomedical research and I will not re	-products to researchers for the purposes ead Canadian Blood Services' pamphle rstand that Canadian Blood Services will ceive results of any research using my ba	ices to use or distribute my baby's cord blood, is of biomedical research under the Cord Blood et on biomedical research and have had the I not notify me if the cord blood unit is used for aby's donated cord blood under the Cord Blood 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 discrepa	ncy from maternal hospital unique ID lab	pel to documented information by mother:							

CBU Unique ID Number



PRIVACY NOTICE FOR CANADIAN BLOOD SERVICES' CORD BLOOD BANK

Our Commitment to Privacy:

At Canadian Blood Services we are committed to protecting the privacy and security of personal information in our possession. This Notice explains how Canadian Blood Services collects, uses, retains and discloses the personal information it collects about cord blood donors and their mothers.

What Personal Information Do We Collect?

Canadian Blood Services may collect and retain the following personal information about you and your baby when you make, or attempt to make, a cord blood donation:

- Contact information such as your name, address and telephone number;
- Date of birth for you and your baby;
- Responses to pregnancy, travel, social and medical history questions;
- Responses to questions about your donation history with Canadian Blood Services;
- Name and contact information for your health care providers;
- Health assessments and other relevant medical information from your physician and your hospital records;
- Test results from your blood samples and the cord blood donation;
- Information about your ineligibility to donate, if applicable.

How Do We Use Your Personal Information?

Canadian Blood Services collects and retains your and your baby's personal information so that we may assess your eligibility to donate cord blood and to ensure the safety of blood and blood products for recipients. Your personal information may also be used to:

- Assess whether the cord blood donation is a suitable match for a patient in need of a transplant;
- Contact you after delivery to enquire about your baby's health;
- Consult your physician if you report problems with your or your baby's health which may affect the cord blood;
- Provide you with test results or to request further tests, if required;
- Make our programs better and more efficient, including offering opportunities to provide feedback;
- Access your test results in the event of accidental contact with your blood;
- Contact you regarding new and existing programs, services, donor events and promotions;
- Train employees;
- Contact you for the purpose of fundraising. If you wish to be removed from our fundraising contact list, please call 1
 888 2 DONATE (1-888-236-6283) and ask for our National Fundraising Office.
- Comply with legal and regulatory requirements;
- Fulfill any other purposes as permitted or prescribed by law.

Who Do We Share Your Personal Information With?

Your and your baby's personal information may be shared with the following:

- Canadian transplant centres and international stem cell registries searching for stem cells for patients in need. We will
 only refer to you or your baby using a unique donor number when personal information is disclosed;
- Your health care provider to report potential health risks;
- Third party laboratories to perform screening tests on your baby's cord blood;
- Public health authorities in the case of positive transmissible disease test results;
- Other Canadian blood operators to ensure the safety of the entire blood system;
- Researchers provided the research has been approved by an independent research ethics board and meets legal and regulatory requirements;



- Auditors from Canadian Blood Services' accreditation and regulatory bodies;
- Others as permitted or required by law.

Withdrawing Your Consent from Canadian Blood Services' Cord Blood Bank

You may withdraw your consent to participate in Canadian Blood Services' Cord Blood Bank at any time. Your withdrawal must be made in writing by submitting a *Withdrawal of Consent to Participate in the Canadian Blood Services Cord Blood Bank* form. The form may be obtained by contacting Canadian Blood Services' National Contact Centre at 1 888 2 DONATE (1-888-236-6283).

All personal information collected up to the date of your withdrawal will be retained by Canadian Blood Services' Cord Blood Bank, but no further personal information about you or your baby will be collected. Your and your baby's personal information will no longer be used in searches for patients in need.

How Do We Protect Your Personal Information?

Access to your personal information is restricted to Canadian Blood Services staff who need access to this information to perform their jobs. All Canadian Blood Services employees sign confidentiality agreements.

Canadian Blood Services may use third party service providers to perform services such as donor recruitment and communication. In some cases, our service providers may process or store data outside of Canada. These service providers are contractually obligated to implement appropriate safeguards to protect personal information and to use the personal information to which they have access for the purposes of providing these services for, or on behalf of, Canadian Blood Services.

Accessing or Correcting your Personal Information

To request access to the personal information Canadian Blood Services retains about you and your baby, please visit our Access to Information page at www.blood.ca.

Canadian Blood Services offers an online <u>Change Your Address</u> form for revising your contact information and at any time you may update your contact information or contact preferences by calling 1 888 2 DONATE (1-888-236-6283).

How to Contact Us

For questions relating to cord blood donation, or enquiries about your eligibility to donate, please visit our website at www.blood.ca/cordblood or contact Canadian Blood Services' National Contact Centre:

Toll Free: 1 888 2 DONATE (1-888-236-6283)

Email: <u>feedback@blood.ca</u>

For questions or concerns about this Notice, please contact Canadian Blood Services' Privacy & Access to Information Office:

Toll Free: 1-877-262-9191 Email: 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 reserves the right to modify, amend or restate this Notice from time to time without prior notice.



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.

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 for more information.