# YOU HAVE THE POWER TO GIVE LIFE

: Learn how to donate your baby's cord blood today. Ottawa • Brampton • Edmonton • Vancouver

## JUST 5 EASY STEPS FOR CORD BLOOD DONATION...

- STEP 1 Read this Information Kit.
- **STEP 2** Print and fill in the forms.
- **STEP 3** Give completed forms to your healthcare provider or to your hospital RN on day of delivery.
- **STEP 4** Your baby's cord blood will be collected in hospital by a qualified professional.
- **STEP 5** If your baby's cord blood unit qualifies, a nurse will visit you before you leave the hospital for a second consent, blood work and a health questionnaire.





#### WHAT TESTS ARE REQUIRED?

Canadian Blood Services Cord Blood Bank is required to perform certain tests on your baby's cord blood and your blood to determine eligibility for storage such as:

- genetic markers to match the donor to the patient
- human immunodeficiency virus (HIV, the virus that causes AIDS)
- Hepatitis B and C viruses (HBV and HCV)
- Human T-lymphotropic virus (HTLV), syphilis and West Nile Virus (WNV)

#### HOW IS MY PRIVACY PROTECTED?

Canadian Blood Services is committed to protecting your privacy and personal information. Please read our privacy notice for more information at blood.ca/cordblood

#### WHAT WILL MY BABY'S CORD BLOOD BE USED FOR?

The Canadian Blood Services Cord Blood Bank collects, tests and stores cord blood to make it available for any patient in Canada or world-wide in need of an unrelated stem cell transplant. Occasionally, cord blood may be used for other purposes such as quality control or process and product improvement. Depending upon which hospital your baby's cord blood is collected, cord blood that is not eligible for storage may be:

- used and/or distributed for research purposes by the Canadian Blood Services Cord Blood Bank with your consent,
- returned to the hospital, where it may be used and/or distributed for research purposes, with your consent, or
- discarded.

#### HOW ELSE CAN I HELP?

## There are many ways you and your family and friends can help:

- Register to donate stem cells. If you are between 17 and 35, you can join a network of donors for those in need. Find out more at blood.ca/stem-cells
- Make a blood donation. If you are 17 years of age or older you can donate whole blood, platelets or plasma. Find out more at blood.ca
- Become a volunteer: blood.ca/volunteers

Maternal Education and Recruitment program provided through the generous support of Bayer Inc.



#### CANADIAN BLOOD SERVICES CORD BLOOD BANK

#### Visit blood.ca/cordblood



# GIVE LIFE TWICE BY DONATING CORD BLOOD



Thank you for considering donating to the Canadian Blood Services Cord Blood Bank. Umbilical cord blood is a medically proven

source of blood stem cells that can help save a life. Find out more about donating cord blood today at blood.ca/cordblood.

#### WHAT IS THE CANADIAN BLOOD SERVICES CORD BLOOD BANK?

#### The Canadian Blood Services Cord Blood Bank:

- recruits healthy, volunteer mothers delivering at a designated collection hospital;
- collects, tests and stores eligible blood stem cells from the umbilical cord and placenta;
- makes eligible cord blood units available for any patient in Canada or world-wide in need of an unrelated stem cell transplant;
- collects donations at no charge to you. The Canadian Blood Services Cord Blood Bank is not affiliated with a private cord blood bank. To reserve donated cord blood for your family's use, please make those arrangements directly with a private cord blood bank.

#### WHERE CAN I DONATE MY BABY'S CORD BLOOD?

**OTTAWA:** The Ottawa Hospital, Civic Campus or General Campus

**BRAMPTON - GTA:** William Osler Health System, Brampton Civic Hospital

**EDMONTON:** Alberta Health Services' Lois Hole Hospital for Women

**VANCOUVER:** BC Women's Hospital & Health Center

#### DO I QUALIFY TO DONATE TO THE CANADIAN BLOOD SERVICES CORD BLOOD BANK?

#### You can donate if you are:

- healthy (mother and baby) with no medical conditions that could be passed on to a patient
- 18 years of age or older, with your signed consent
- not delivering before 34 weeks in your pregnancy
- not having twins or triplets (or more)
- fluent in English or French
- delivering at one of the five designated collection hospitals

Speak to your health care provider to see if you are a candidate for cord blood donation.

Are there any risks to my baby or myself? The Canadian Blood Services Cord Blood Bank does not interfere with the natural process of the delivery of your baby. The risks to your health and your baby's health are very low, as blood stem cells are collected from the umbilical cord/placenta after delivery of your baby.

#### HOW DO I DONATE MY BABY'S CORD BLOOD?

#### There are just 4 easy steps:

**STEP 1:** Talk to your healthcare provider. They will give you the information needed. Or, download the information kit from our website, blood.ca/cordblood.

**STEP 2:** Fill out the consent form. Give it to your healthcare provider or bring it with you on your day of delivery. Tell your nurse or healthcare provider of your intent to donate.

**STEP 3:** Cord blood collection. The cord blood will be collected in a designated hospital by a qualified professional.

**STEP 4:** If your baby's cord blood unit qualifies, a nurse may visit you to collect additional information before you leave the hospital which includes a second consent, blood work and a questionnaire.

## WHAT ARE CORD BLOOD STEM CELLS?

Cord blood stem cells are immature cells that give rise to the cells found in the bloodstream: red blood cells to carry oxygen in your body, platelets for blood clotting and white blood cells for fighting infections.



**Introduction:** Canadian Blood Services' National Public Cord Blood Bank is building a public umbilical cord blood bank that reflects the ethnic diversity of Canada. With the help of hospital physicians, midwives and/or nurses, Canadian Blood Services' National Public Cord Blood Bank collects, tests, stores and distributes donated human umbilical cord blood.

Maternal Hospital ID Label

The following information is provided to you to explain the purpose of the program, including what you will be asked to agree to as a voluntary participant and the potential risks and benefits. Choosing not to participate in the program will not have any impact on you or your family's medical care. You are encouraged to contact the National Public Cord Blood Bank at 1 888 2 DONATE (1-888-236-6283) to ask questions at any time.

Why donate umbilical cord blood? Umbilical cord blood contains blood stem cells. Blood stem cells produced by your baby before birth circulate through the baby's body, the umbilical cord and placenta. <u>After your baby is born</u>, the umbilical cord is cut and the placenta, or "afterbirth," is delivered. The blood stem cells collected from the placenta and/or umbilical cord can be used to treat people with diseases such as leukemia, bone marrow failure and other serious disorders. The cord blood donated to the National Public Cord Blood Bank can be used for any patient who might need it for transplantation, in Canada or around the world. There are private companies that also bank cord blood for direct family use for a fee, but they are not publicly available for use by others in need. Private banks are not affiliated with Canadian Blood Services and you must contact them directly if this option interests you. Once your baby's cord blood has been collected by the National Public Cord Blood Bank, it cannot be transferred to a private bank.

**Description:** You are being asked to permit your physician, midwife and/or the National Public Cord Blood Bank staff to collect your baby's cord blood that remains in the placenta and its attached umbilical cord <u>after your baby is born</u>. In collecting the cord blood, your physician or midwife is voluntarily assisting Canadian Blood Services with the collection of cord blood based upon the consent granted by you for the collection. The collection of the umbilical cord blood will not affect the delivery or the care of you or your baby. After collection, your baby's cord blood unit and your samples, if any, will be sent to the National Public Cord Blood Bank manufacturing facility to start the process of testing and preparing the cord blood for storage. The cord blood unit and blood samples are then placed in a secure location until all screening tests are complete. The results of these tests will help us determine if your baby's cord blood can be stored.

**Privacy:** You are also being asked to permit the National Public Cord Blood Bank staff to review (before or after collection) the medical records of you and your baby to see if your baby's cord blood will meet the requirements for storage. We also need to collect certain personal information about you and your baby, including the health assessment from your physician, and the results of any laboratory tests that may have been completed. 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. If a condition or disease is present, we will not proceed with further collection, testing or storage of your baby's cord blood for the purpose of transplantation. For further information about the collection use and disclosure of personal information please review the accompanying Privacy Notice.

CBU Unique ID Number



Assessment, Storage and Transplantation: Your baby's cord blood must meet certain minimum requirements for storage for patients in need. If all requirements are met, a staff member will return to speak with you after you have rested from your delivery. The staff member will discuss with you the 'Informed Consent' form specific for storage for transplantation, ask questions related to your medical history and general health, and discuss storing your baby's cord blood with the National Public Cord Blood Bank. Also at that time, you will be asked to provide a blood sample which will be tested for HIV, hepatitis and other transmissible diseases. If you require intravenous fluid during your labour, we may ask that you provide a blood sample for transmissible disease testing at the same time as the intravenous insertion. Any positive test results will be given to you and your physician, as per Canadian Blood Services' policy, and will also be reported to the appropriate public health authorities.

**Research Opt-in**: Cord blood may be found unsuitable for storage if the amount of blood collected is too small or it does not meet the specific requirements of the National Public Cord Blood Bank. In addition, sometimes your baby's cord blood may be stored but later found to be no longer bankable. If your baby's cord blood cannot be banked or used for transplantation, it could still be used for biomedical research, rather than being discarded. In addition, during the process of preparing cord blood stem cells for banking, components (such as red blood cells) are removed from the cord blood. These by-products could be used for research rather than being discarded. If you wish to donate for biomedical research your baby's cord blood, in the event that it is unsuitable for storage or transplantation, and its by-products, you must provide your consent by ticking the research opt-in box at the end of this form. For more information regarding the research option and the type of research that may be done with cord blood, please consult the accompanying information pamphlet on biomedical research. You may also contact CBS National Call Center at 1 888 2 DONATE (1-888-236-6283) if you have questions about research or to be put in contact with the local researcher.

**Discarding Cord Blood:** In the event that your baby's cord blood is determined unsuitable for storage or transplantation, and if you have not consented to donate for biomedical research; your baby's cord blood and any blood samples will be discarded, unless they are used for quality assurance purposes. If you consent to donate your baby's cord blood to biomedical research but it is determined unsuitable for this purpose, your baby's cord blood will also be discarded.

<u>Costs and Reimbursements</u>: There will be no cost to you to participate in the program. There will be no reimbursements to you for any aspect of your cord blood donation. In the event that research with your baby's cord blood leads to material that is patentable or that has commercial value, you will not own or have any financial interest in them.

**Potential Risks and Discomforts**: The National Public Cord Blood Bank does not interfere with the natural process of the delivery of your baby. There are no significant risks related to participating in the National Public Cord Blood Bank as blood stem cells are collected from the umbilical cord/placenta after delivery of your baby. If blood samples are drawn from you for infectious disease testing, the amount of blood drawn is small (total of 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.



<u>Potential Benefits</u>: Though neither you nor your baby will directly benefit from the donation, it may provide a patient with a life-threatening disease with a chance for a healthy life. If you consent to the use of your baby's cord blood for biomedical research, you may also benefit from the knowledge that your participation will further research and help others in the future.

<u>Withdrawing from the National Public Cord Blood Bank</u>: Your participation in the National Public Cord Blood Bank is voluntary and may be withdrawn at any time by calling 1 888 2 DONATE (1-888-236-6283). Your baby's cord blood will be discarded if it has not already been used for transplantation, quality assurance or biomedical research purposes. A "Withdrawal of Consent to Participate in the Canadian Blood Services' National Public Cord Blood Bank" form will be provided to you for completion and return.

The personal information that has been collected by Canadian Blood Services up to the date of your withdrawal will remain in the National Public 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. Please know that choosing not to participate will not have any impact on you or your family's medical care in any way.

**<u>Ethnic Background</u>**: The National Public Cord Blood Bank must reflect the ethnic diversity of Canada. Since certain genetic markers are common in some populations, Canadian Blood Services is asking mothers donating their baby's cord blood to therefore select the background that you and your baby's father most identify with.

This information helps in the matching process between a potential donor and a patient in need and allows OneMatch to ensure that it is meeting the needs of Canadian patients. The chart on the following page may be used as a guideline to assist you.

**Instructions:** Please complete the chart and sign the consent on the following page and either (1) return to your health care professionals, who will send a copy to the hospital where you will deliver your baby, or (2) bring with you to the hospital at time of delivery. The hospital will keep a copy on your medical chart and provide a copy to Canadian Blood Services.



Please select only one ethnicity for yourself and one for the baby's father.																					
	Arab	Asian- Central	Asian-North	Asian- Northeast	<u> </u>	Asian- Southeast	Black- African	Black- Caribbean	Black-Other	Caucasian	Chinese	Filipino	First Nations	Hispanic	Inuit	Jewish- Ashkenazi	Jewish- Sephardic	Metis	Pacific Islander	 Unknown	Prefer Not to Disclose
Mother																					
Father																					

Maternal Hospital ID Label

## CONSENT

<u>About this Consent:</u> By signing this form, you freely and voluntarily consent to the collection of your baby's cord blood after delivery. You are giving consent based on the verbal and written information provided to you with the understanding that you are medically and physically qualified to participate. Please keep a copy of this signed consent form for your records.

I have read and understood the information provided on cord blood donation and have had the opportunity to ask questions which have been answered satisfactorily. I have also read and understood the Privacy Notice for the National Public Cord Blood Bank and consent to the collection, use and disclosure of my personal information and my baby's personal information, including my medical record and other personal health information, for the purposes outlined therein. I understand how I may withdraw my consent.

I voluntarily agree to allow my physician, midwife or National Public Cord Blood Bank staff to collect my baby's cord blood for the purposes described in this "Permission to Collect" form. I also consent for a blood sample to be taken from me, for staff to review my medical record and my baby's medical record, and to interview me for health screening purposes, if applicable.

In addition, by ticking the box below, I voluntarily agree to allow my baby's cord blood, if it is not suitable for banking, and by-products, to be distributed by Canadian Blood Services to researchers in Canada and internationally for the purpose of conducting biomedical research. I acknowledge that I have read the Canadian Blood Services' pamphlet on biomedical research and have had the opportunity to ask questions. I understand that I will not be notified if the cord blood unit is used for biomedical research nor will I receive results of any research performed using my baby's donated cord blood unit. I understand that research outcomes will be posted on Canadian Blood Services website.

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



#### 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 <u>www.blood.ca/privacy</u>.

#### Purpose:

Canadian Blood Services manages the OneMatch Stem Cell and Marrow Network and the National Public Cord Blood Bank.

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 Registry 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, email address, address, date of birth, health status, test results and 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 storage;
- 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 programs 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;
- Send you materials such as e-newsletters and e-magazines about Canadian Blood Services with the option to unsubscribe if you do not wish to receive them;
- Support our education and training activities;



- Perform quality control testing 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; and
- 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 and the blood supply;
- Canadian transplant centres and international registries. We will only refer to you or your baby 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 be used to select your baby's donated cord blood unit for transplant. We may 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: Ontario: http://www.ipc.on.ca



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

The purpose of this handout is to provide information regarding donating cord blood to Canadian Blood Services' National Public Cord Blood Bank for biomedical research. You are encouraged to contact the National Public Cord Blood Bank at 1888 2 DONATE (1-888-236-6283) to ask questions at any time.

Biomedical research on cord blood will increase our knowledge about current blood stem cell transplantation practices as well as the processes for collecting, manufacturing and storing cord blood. In addition, stem cells obtained from cord blood are being investigated in the development of new treatments for many diseases. Such stem cell research provides hope for more safe and effective medical therapies in the future. Other biomedical research, which does not relate to stem cells, may also be undertaken with cord blood and lead to new discoveries that may improve medical care in the future.

#### Who can donate cord blood?

Healthy pregnant women, 18 years of age or older, can donate cord blood with their signed consent. Additionally, a mother qualifies to donate her baby's cord blood if neither she nor her infant has any diseases or medical conditions that could be passed on to a patient who receives a cord blood stem cell transplant.

Mothers reaching 34 weeks or later in their pregnancy may consider donating their baby's cord blood. A mother must deliver at one of our designated collection hospitals in order to donate her baby's cord blood to the National Public Cord Blood Bank.

#### What happens if I do not donate my baby's cord blood?

Cord blood that is not donated to the National Public Cord Blood Bank is normally discarded, unless other personal arrangements have been made.

## Will cord blood donated to the National Public Cord Blood Bank be used for research?

The donated cord blood will be distributed to researchers for use in biomedical research **only** if:

a) Your baby's collected cord blood is found to be unsuitable for banking or for use in transplantation;

b) You have given your consent for your baby's cord blood to be used for biomedical research;

c) There is a research program associated with your hospital collection site, **and**;

d) A research project, to which your baby's cord blood can be distributed to, has been approved.

Cord blood may be found unsuitable for banking if the amount of blood collected is too small or it does not meet the specific requirements of the National Public Cord Blood Bank. In addition, sometimes your baby's cord blood may be banked but later found to be unsuitable for transplantation. If your baby's cord blood cannot be banked or used for transplantation, it could still be distributed to researchers in Canada and worldwide to be used for biomedical research, rather than being discarded.

In addition, when preparing your baby's cord blood stem cells for storage (banking), 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 discarded during the preparation of the blood stem cells for storage could be distributed for biomedical research rather than being discarded.

Your baby's cord blood or by-products will be provided by Canadian Blood Services to an approved research project on a cost recovery basis.

## How do I donate my baby's cord blood to biomedical research?

To authorize the National Public Cord Blood Bank to distribute your baby's cord blood to researchers, you are being asked to provide consent to donate for biomedical research by ticking the Research Opt-In box in the Permission to Collect form. Indicating your consent to donate your baby's cord blood to biomedical research will not necessarily lead to its distribution to a researcher. Your baby's cord blood may be distributed for biomedical research if it meets certain research criteria and if the requirements described above are met. Otherwise your baby's cord blood will be discarded.

# Will the care my baby and I receive be affected if I choose not to participate in the biomedical research program?

Participation in the biomedical research program is entirely voluntary. Your participation in the biomedical research program of the National Public Cord Blood Bank will have no effect on the care you or your baby will receive.

## Are there any risks in donating my baby's cord blood for biomedical research?

The collection of umbilical cord blood will not affect the delivery of your baby or the care of you and your baby. There is no health risk to you or your baby related to donating your baby's cord blood for biomedical research. Canadian Blood Services will disclose only minimal information about you and your baby's gender and the criteria we used to determine that your baby's cord blood was unsuitable for banking. Cord blood donated for biomedical research purposes will have personal identifiers removed and replaced by a unique code. In this way, the researchers will not know who donated the cord blood. If you would like

to know more about the National Public Cord Blood Bank's privacy policy, please consult the attached Privacy Notice as well as the website at <u>www.blood.ca/privacy</u>.

## Are there any benefits if I choose to donate my baby's cord blood for biomedical research?

Though neither you nor your baby will directly benefit from donating your baby's cord blood for biomedical research, the donated cord blood will allow scientific and medical research to help other patients in the future. Your baby's cord blood may help the research community learn more about how to improve the clinical applications of cord blood, as well as how to improve the collection, processing and storage of cord blood. Cord blood and derived stem cells may be useful for developing drugs, medical and/or commercial products to treat human diseases. The products may be patentable or have commercial value but you will not own or have any financial interest in them.

## What kind of biomedical research will my baby's cord blood be used for?

Biomedical research involving cord blood is ongoing and covers a range of studies. The Canadian Blood Services website posts information about the research projects being carried out with cord blood donated for biomedical research to the National Public Cord Blood Bank. For details please visit <u>www.blood.ca/researchcordblood</u>. However, when consenting to donate your baby's cord blood for biomedical research, you cannot specify what kind of research or which research project your baby's cord blood may be used for.

All research projects must be approved by Canadian Blood Services and undergo ethics review by the Canadian Blood Services Research Ethics Board. In addition, researchers must obtain ethics approval from their own institutions, as well as from other research oversight bodies as appropriate.

Some common examples of cord blood biomedical research purposes are:

- To improve current clinical practices that use cord blood
- To improve cord blood collection, manufacturing and storing processes
- To study stem cell biology
- To determine other clinical and non-clinical uses of stem cells from cord blood
- To produce stem cell lines that could be maintained for many years and that could be distributed to several researchers to be used for various research purposes
- To develop drugs, medical and/or commercial products to treat human diseases

## What if I have questions regarding the biomedical research program?

You can call us at 1 888 2 DONATE (1-888-236-6283) and we will be happy to answer any of your questions about donating your baby's cord blood for biomedical research. You can also look at our website www.blood.ca/researchcordblood for information about the biomedical research program and about the research that is carried out using cord blood donated to the National Public Cord Blood Bank.

## What if I want to withdraw my consent for biomedical research?

Your choice to donate your baby's cord blood for biomedical research is completely voluntary and your consent may be withdrawn at any time by calling 1 888 2 DONATE (1-888-236-6283). A "Withdrawal of Consent to Participate in the Canadian Blood Services' National Public Cord Blood Bank" form will be provided to you for completion and return. If your baby's cord blood has not already been used for biomedical research it will be discarded. Please note that most cord blood distributed to researchers will be shipped within 48 hours of collection. Depending upon when you withdraw your consent, the cord blood may have already been used for biomedical research. If your baby's cord blood has already been used for biomedical research, the research sample and derived research findings may not be withdrawn.

#### Will the research results be disclosed?

The results of biomedical research studies may be presented at meetings or in publications. Neither your identity nor that of your baby is disclosed as personal identifiers are removed and replaced by a unique code and thus researchers do not have access to the information. You will not be contacted regarding any research results published or presented but you will be able to check Canadian Blood Services website (www.blood.ca/researchcordblood) for information regarding both ongoing research projects and the general results of completed research studies.

## How do I donate my baby's cord blood to the National Public Cord Blood Bank?

If you are delivering at one of the designated hospitals, please talk with your health care provider, doctor or midwife during your prenatal visits about your interest in donating your baby's cord blood. They will provide you with information about the National Public Cord Blood Bank and whether cord blood collected at your hospital are distributed to biomedical research.

On the day of delivery, simply arrive with your signed "Permission to Collect" form and let your nurse know of your intent to donate your baby's cord blood for storage, transplantation and biomedical research. For online access to the "Permission to Collect" form and related information, please visit <u>www.blood.ca/cordblood</u>.

#### Does it cost money to donate cord blood?

There is no cost to donate cord blood to the National Public Cord Blood Bank either for transplantation or for biomedical research. All cord blood donations to the National Public Cord Blood Bank are made through the generosity of donor families.

> CANADIAN BLOOD SERVICES NATIONAL PUBLIC CORD BLOOD BANK