

#### **Donating to the Public Cord Blood Bank**

### What does it entail?

The process involves collecting the blood present in the placenta and umbilical cord after the birth of your baby. This blood contains stem cells, which have the property of enabling patients with serious illnesses, such as leukemia, to rebuild their blood system.

# **Benefits**

You and your child will not receive any benefits from your donation. However, there may be a health benefit for the person receiving the cord blood.

# A few criteria to register

- Be in good health;
- Be 18 years of age or older;
- Register before the 36th week of pregnancy;
- Be pregnant with one fetus only;
- Know the medical and genetic history of your biological parents and those of the child's father or genitor.

## Registration

- First, read this Consent to cord blood donation.
- Once well informed, if you want to pursue cord blood donation, fill the online registration form.

## Your qualification

You will be contacted by a Héma-Québec representative before your delivery to fill out a qualification questionnaire about your medical history and risk behaviours. This is to ensure the safety of the product and protect the health of the recipient.

- In the event that you do not qualify, the representative will explain the reasons for your exclusion.
- If you qualify, the collection process will be arranged with the hospital staff where you will be giving birth.

### During delivery

The cord blood collection will be performed by the physician following the birth of your child, after the umbilical cord has been cut and before the placenta is expelled. This collection will not interfere with the delivery.

Effective date: 02-05-2022 ENR-03305[2] Page 1 of 5



### Qualification of your donation

The collected cord blood is sent to Héma-Québec's Public Cord Blood Bank and will go through a qualification process.

If your donation qualifies:

- The cord blood is frozen and banked;
- A Héma-Québec representative will contact you within seven (7) days of your donation to fill out a second qualification questionnaire and collect samples of your blood.

### Other uses of your donation

On rare occasions, your cord blood donation could be used for educational or quality control of the product purposes, or as a reactive agent for blood tests at Héma-Québec.

Alternatively, if the cord blood does not qualify, it could be used for research purposes if you consent to this. The section "Donating Cord Blood for Research" below explains what it entails.

Otherwise, your cord blood donation will be destroyed if it does not qualify.

# Blood tests

Héma-Québec's laboratories will perform several tests.

On the cord blood:

- HLA typing;
- Screening for certain hemoglobin abnormalities;
- ABO and Rh blood group analysis;
- Microbial detection test.

On your blood samples:

- HLA typing, if required;
- ABO and Rh blood group analysis;
- Screening for blood-borne infectious diseases:
  - Hepatitis B and C;
  - Syphilis;
  - Human immunodeficiency virus (HIV);
  - Cytomegalovirus (CMV);
  - Human T-lymphotropic virus (HTLV I/II);
  - West Nile virus (WNV);
  - Chagas disease, if required.

Effective date: 02-05-2022 ENR-03305[2]



You will be notified of any positive or indeterminate result on any of these tests while ensuring confidentiality. You will be invited to provide Héma-Québec with your physician's contact information so he or she can, if necessary, perform proper medical follow-up.

- The banking process will be stopped.
- In the case of a disease that must be reported, the results will be sent to the Québec Public Health Authorities.

### Preservation of samples

Samples of your blood and the cord blood will be preserved for as long as the cord blood is banked:

- For subsequent recipient compatibility tests;
- For analysis in the event of new transmissible and genetic disease screening tests, as well as other tests as needed.

## Risks

There is no risk to you or your child since cord blood is collected after you give birth and the umbilical cord is cut.

The volume of collected blood that you must provide for the donation to quality is low (approximately two tbsp); this is not harmful to your health. You may feel some discomfort associated with the collection of blood samples (for example, bruising, pain or redness at the puncture site).

### Questions

If you have any specific questions and would like to speak with a Héma-Québec representative:

- call 514-832-5000, extension 5253 or 1-800-565-6635, extension 5253
- write to: <a href="mailto:cordblood@hema-quebec.qc.ca">cordblood@hema-quebec.qc.ca</a>

### Consent

Your participation in the Public Cord Blood Bank and your cord blood donation are entirely voluntary. You can withdraw your consent and terminate your participation at any time without consequence.

You will not receive any compensation for your donation.

You provide your consent for yourself and your child for the collection, preparation, preservation and release of the cord blood.

This cord blood will be available for any patient in Québec, Canada and worldwide.

You understand that your cord blood may not be available if a member of your family needs it in the future.

Effective date: 02-05-2022 ENR-03305[2]



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#### Personal information collected by Héma-Québec

Your consent to participate in the Public Cord Blood Bank allows Héma-Québec to collect:

- Information related to your pregnancy and delivery from your medical record;
- Information contained in your child's medical record.

Only the information required by Héma-Québec is collected. All the information collected about you and your child by Héma-Québec is kept confidential and secure and retained indefinitely. The information linking you to your child and the cord blood product will also be retained indefinitely.

Your personal information will never be disclosed, except to access your hospital medical record regarding the pregnancy and the delivery.

Héma-Québec may disclose relevant medical information to national and international cord blood registries. In such cases, the information will be kept anonymous and identified only through the use of a unique identifier.

With the intention of continuously improving its knowledge in the field of live donations, Héma-Québec may use the information collected for educational, research and statistical purposes or to communicate with you.

You have the right to consult your medical record to verify the information collected and have it rectified if necessary.

#### **Donating Cord Blood for Research**

## **△** What does it entail?

If your cord blood donation does not qualify to be banked, it is still valuable for research purposes in the field of cord blood transplantation, to better understand blood diseases, viral infections stem cells, and to study its components to allow new product development.

As a partner of Héma-Québec in the field of cord blood research, the CHU Sainte-Justine Cord Blood Research Bank will act as a coordinator for all research projects on cord blood that are of interest for various research centers.

## **5** Ethical approval of projects

For a research project to benefit from cord blood units unqualified for banking, it must have been approved by the Héma-Québec Research Ethics Board.

Héma-Québec distributes the cord blood for research projects that are duly approved ethically and scientifically.

The cord blood used for research will be destroyed once the research has been completed.

## **△** Confidentiality of your information

Héma-Québec protects your personal information. It will not be disclosed to the research teams. The cord blood unit will be identified with a unique identifier that will be kept confidential at Héma-Québec. Héma-Québec may provide researchers with anonymous data on your

Effective date: 02-05-2022 ENR-03305[2] Page 4 of 5



health status for the purposes of qualifying the sample for their research project. However, it will be impossible for the researcher to identify you.

The results of the research may be the subject of a publication or a communication by the researcher. At no time will it be possible to identify you.

In order to verify the proper conduct of the research and ensure your protection, your research file could be reviewed by the Héma-Québec Research Ethics Board.

### **A** Risks and benefits

Donating for research does not pose any additional risk to your health or that of your child.

These scientific advances will benefit the population as a whole.

There is no benefit to you or your child and you will not be compensated for your participation. However by consenting for research, you will help researchers better understand stem cell transplantation, improve existing treatments and support the development of new treatments.

#### **△** Consent

Your support of cord blood research is entirely voluntary and you can withdraw your consent at any time without prejudice.

The research results could contribute to the creation of commercial products from which you will not receive any financial benefit.

### **≜** Questions

For more information about admissible research projects, please contact the staff of Sainte-Justine University Hospital Cord blood research unit at 514-345-4931, extension 3625 or the administration office of the Héma-Québec Research Ethics Board at 514-832-5000, extension 5370, or free of charge at 1-888-666-4362, extension 5370.

Please go back to the website to fill in the registration form and certify that you have read this consent document in order to agree to a cord blood donation as per the above mentioned conditions.

Effective date: 02-05-2022 ENR-03305[2] Page 5 of 5