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Information guide and registration

HÉMA-QUÉBEC PUBLIC
CORD BLOOD BANK

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Introduction

You have heard about the storage of cord blood and its use in treating various health problems. The information concerning this practice comes from a variety of sources (media, physician or other) and is often complex.

This document provides information about the history of cord blood use and cord blood banks, cord blood transplants and research in progress in this field. It provides information about how you can contribute to the Public Cord Blood Bank. It also contains a section on the most frequently asked questions. With this information, you will be able to make an informed decision about contributing your child’s cord blood to the bank.

If after reading this document you would like to contribute to the Public Cord Blood Bank, simply complete the forms provided in the pouch of this document and send them to Héma-Québec as quickly as possible.

Enjoy your reading!
One of the primary roles of bone marrow is to produce the various components of blood, using certain cells known as “hematopoietic stem cells.” Bone marrow cells, which are essential to life, include red blood cells, white blood cells and platelets. Certain children and adults who suffer from diseases that affect these cells, such as leukemia, certain types of anemia, osteopetrosis, immune system deficiencies and certain metabolic disorders, may benefit from a stem cell transplant, which will enable their body to start producing normal blood cells. For the past 20 years, stem cell transplantation has been a preferred treatment, although it does entail certain inconveniences.

As the stem cell must come from a compatible donor, the primary source for such a donor is the family. However, the chance of finding a compatible donor in the family is about 25%.

The second source for compatible donors is the international Unrelated Stem Cell Donor Registry. The probability in finding a compatible donor through this registry, within six month ranges, is from 10% to 60%, depending on the recipient’s ethnic origin. Moreover, waiting periods may occasionally be lengthy, with the resulting risk that the patient may deteriorate or even die. Bone marrow transplant also involves certain physical inconveniences for the donor when the marrow is collected.

Research has been conducted to help overcome these inconveniences. It has been demonstrated that blood from the umbilical cord and the placenta (cord blood), which can be collected with no risk after the birth of a child, can be used instead of bone marrow for transplants.
Since the practice was first introduced, cord blood has been transplanted into thousands of patients with most encouraging results.

The results of various studies confirm the advantages of using cord blood rather than bone marrow:

1) Cord blood can be collected at no risk to the mother or the newborn.

2) It is easier to find compatible cord blood for a patient than a donor with compatible bone marrow. This means that transplants can be offered to a larger number of patients.

The major constraint involved in using cord blood is the number of stem cells contained in a regular collection. Cord blood can generally be used for transplant in an individual weighting less than 50 kg.

Héma-Québec founded the Public Cord Blood Bank to collect, process and store stem cells contained in cord blood. The object is to increase the accessibility of cord blood to Quebecers of various ethnic backgrounds who are waiting for stem cell transplants. The cord blood is collected in certified hospitals working in partnership with Héma-Québec.

### Important dates

<table>
<thead>
<tr>
<th>Year</th>
<th>Location</th>
<th>Accomplishment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1988</td>
<td>France</td>
<td>First successful transplant of cord blood for a child suffering from Fanconi’s anemia by Dr. Eliane Gluckman.</td>
</tr>
<tr>
<td>1992</td>
<td>New York</td>
<td>Founding of the first cord blood bank by Dr. Pablo Rubinstein.</td>
</tr>
<tr>
<td>1996</td>
<td>Hôpital Sainte-Justine</td>
<td>The practice of transplanting cord blood into patients suffering from various hematological and immune illnesses started.</td>
</tr>
</tbody>
</table>
Transplantation and research

To date, it has been demonstrated that stem cells can be kept frozen for more than 15 years without losing the properties that are important for transplantation. They are used to replace stem cells in people who essentially suffer from leukemia, anemia or an immune system deficiency. The recipient experiences no pain when hematopoietic stem cells are transplanted since they are received as a blood transfusion.

Individuals who require a stem cell transplant receive a treatment intended to destroy their own bone marrow, which is normally the source of their health problem. Once the bone marrow is destroyed, stem cells from bone marrow, peripheral blood or cord blood can be transplanted. During the entire period, they must remain isolated in a room until the transplant has been successfully completed and the new bone marrow is producing sufficient white blood cells to defend their system against the surrounding bacteria.

Considering the hope generated by the stem cells identified in cord blood, research is ongoing. Current knowledge about stem cells remains at a preliminary stage. Québec research centres are contributing to current initiatives by the scientific community to increase their knowledge with respect to the effective and safe use of cord blood for transplantation.
If you decide to donate your child’s cord blood after birth, this precious donation takes three steps.

**Registration**

The first step involves registering. This will take you about 10 minutes. Before contacting a representative of the Public Cord Blood Bank, here are a few items you can verify on your own. Future mothers who want to participate must:

- be in good health
- be 18 years of age or older
- register before the 36th week of their pregnancy
- be pregnant with one foetus only (no twins or more)
- know the genetic or medical history of their biological parents and those of the father’s parents

If you satisfy these criteria and wish to register, complete the registration form and the two consents included. Some partner hospitals have special research project you could also register in case your cord blood donation does not qualify.

If you would like to ask a Héma-Québec nurse specific questions, contact the Public Cord Blood Bank at 514-832-5000, extension 253 or 1-800-565-6635, extension 253.

**Selection process**

A selection process has been developed for future mothers who wish to donate cord blood in order to ensure their safety, that of their unborn child and of the individual receiving the transplant. It is also important to identify behaviors that place the future mothers at risk and illnesses that could endanger the safety of the future recipient.

A nurse from Héma-Québec will contact you around your 25th week of pregnancy in order to complete a qualification questionnaire with you. This will take approximately 30 minutes.

You may expect to be excluded. The Héma-Québec Public Cord Blood Bank consulting nurse will explain this decision to you. You may be excluded for the following reasons:

- multiple pregnancy (twins or more)
- hepatitis contracted after the age of 10
- active infectious diseases
- cancer
- blood diseases
- hereditary genetic diseases
- you are using certain medications
- premature delivery (before 34th week)

**The donation**

It takes three to five minutes to collect the cord blood and there is no danger for the infant or the mother. This is done after the child is born, once the umbilical cord has been cut and before the placenta is expelled. The mother and newborn will experience no effects.

The cord blood is collected as follows:

1. After your child is born, the umbilical cord is cut and your child will receive the usual care provided.
2. Following this, your physician will collect the blood contained in the portion of the cord that is still attached to the placenta.

3. This will be done before the placenta is expelled (in utero).

4. The blood bag containing the cord blood will be identified by means of a label with a unique number in order to ensure the safety of the product and to track it.

5. The information contained in your medical file concerning your pregnancy and your delivery will be transmitted to Héma-Québec. The same applies for the information contained in your child’s file.

6. The pouch containing the cord blood will then be sent to the Héma-Québec Public Cord Blood Bank.

7. Tests will be conducted to qualify the cord blood.

8. If the blood satisfies the standards, it will be frozen until it is used.

9. Blood tests will be performed on the samples taken from you at the hospital in the seven days following the donation:
   - HLA typing
   - screening for hepatitis B
   - screening for hepatitis C
   - screening for HIV
   - screening for syphilis
   - screening for cytomegalovirus
   - screening for West Nile Virus
   - Chagas’ disease

Your family physician will be notified confidentially and as quickly as possible of any positive or inconclusive result for a test to identify a disease that must be reported. Your physician will contact you and note the information in your medical file so that it can be monitored. Moreover, in the case of a disease that must be reported, the results will also be sent to the Québec Public Health Authorities.

10. Screening for certain genetic diseases (sickle cell anemia, thalassemia) and a blood type analysis will be performed on the cord blood.
Steps in the selection process

1. Returning documents to Héma-Québec
   The registration and consent forms must be completed and returned as soon as possible in order to continue the selection process.

2. Interview with a nurse
   A Héma-Québec nurse will contact you to complete a qualification questionnaire and answer all of your questions.

3. Self-exclusion
   If your pregnancy ends before 34 weeks, or if you are pregnant of more than one child, it will not be possible to collect the cord blood.

4. Donation
   The physician will collect the cord blood after your child is born, the cord cut and before the placenta is expelled. The nurse will see that your donation is sent to Héma-Québec properly.

5. In the days following the birth and the donation
   If your cord blood qualifies for banking, a Héma-Québec nurse will call you to review a portion of the questionnaire and make an appointment to take blood samples.

6. Héma-Québec reserves the right to communicate with you for medical reason regarding your health, your child’s health or the recipient’s health.

For more information:
Héma-Québec
Public Cord Blood Bank
Phone: 1-800-565-6635 or 514-832-5000, ext. 253
E-mail: sangdecordon@hema-quebec.qc.ca
What is umbilical cord blood?

During a pregnancy, the placenta and the blood it contains serve as a link and means for carrying all of the nutritional elements required from the mother to the child. After birth, the mother naturally eliminates the placenta, the umbilical cord and the blood they contain. In the past, the placenta, the umbilical cord and the blood were considered biological waste. Since the discovery of stem cells in umbilical cord blood, this cord blood can be collected and stored for transplantation.

What is a stem cell?

Cells in bone marrow and blood all come from certain parent cells, known as hematopoietic stem cells. These stem cells are capable of renewing themselves and changing in order to produce the components of blood: red blood cells, white blood cells and platelets. This phenomenon is known as “hematopoiesis” (this word comes from the Greek words haima, or blood, and poiesis, creation) and all of the cells that make up the bone marrow and blood are “hematopoietic tissue.” This is why we refer to “hematopoietic transplants;” this expression includes bone marrow transplants as well as hematopoietic stem cell transplants from other sources: cord blood (also called placental blood) and stem cells from blood (also called peripheral stem cells). In all cases, the product that is injected into the recipient is called the “transplant.”

When were these cells discovered?

The potential of stem cells was discovered in the early 1980s. This discovery led to innovations in clinical treatments in stem cell regenerative medicine. Following these studies, the first successful human transplant of stem cells from umbilical cord blood was performed in 1988. Since that time, thousands of cord blood transplants have been performed throughout the world, primarily on children.
What are the advantages of cord blood as a treatment?

Since the immune system cells contained in cord blood are immature, they are less likely to attack the other healthy cells in the recipient’s body in the case of a transplant. This reduces the illnesses resulting from the transplant (graft versus host) and makes the transplant procedure more tolerable for the patient.

What are the disadvantages of transplanting cord blood?

The volume of cord blood depends on the weight of the newborn. As a result of this small volume, it can be used for transplant in people weighing less than 50 kg, most of whom are children. Certain adults may undergo cord blood transplants successfully. Research is continuing efforts to maximize the use of the stem cells contained in cord blood.

Are there any risks to the child or the mother?

Donating cord blood is completely safe and there is no risk to either the mother or the child. The donation has no effect on the health of the child or the mother’s birthing experience since the blood is collected after the child is born. If a problem occurs during the delivery, the physician will not collect the cord blood. In this case, the placenta, the umbilical cord and the cord blood will be disposed of, in keeping with the usual procedures.

What is a public cord blood bank?

It is a place where blood donations from the umbilical cord are frozen. A public bank stores cord blood donations for any individual who needs this donation for treatment. By taking part, you increase the chances of survival of all Quebecers who need blood stem cell transplants.

What is a private cord blood bank?

Private banks store the cord blood solely for family members, for a fee, strictly as insurance against the eventuality of a future illness.

How long have cord blood banks existed?

The first cord blood bank was founded in New York in 1992. Following that, almost 50 public banks have been founded throughout the world, in addition to more than 100 private banks.

Why do we need a cord blood bank?

In the case of people suffering from serious illnesses, such as leukemia, the bone marrow produces only abnormal cells. If chemotherapy or radiation therapy do not eliminate these abnormal cells, it will be necessary to give these people healthy stem cells so that they can re-build their entire blood system. This is referred to as a “hematopoietic stem cell transplant.”

The stem cells required for this kind of transplant may come from a compatible family member. However, if no one in the family is compatible for a bone marrow transplant, an unrelated donor will be identified from among those listed in the international Unrelated Stem Cell Donor Registry or the Public Cord Blood Bank. For the general public, the probability of identifying a compatible donor depends on the ethnicity of the recipient and may be as low as 1 in 750,000 for the stem cell registry and 1 in 50,000 for the Public Cord Blood Bank. Thus, increasing the cord blood donations in the bank, for all ethnic groups, increases the chances of identifying a compatible donor.
Where is the cord blood donated?

Cord blood donations will be collected at hospitals that have been certified by Héma-Québec. It is possible to check the list of hospitals that have been certified by Héma-Québec by contacting a member of the Public Cord Blood Bank team or by visiting our Web site: www.hema-quebec.qc.ca.

Is the cord blood donation handled in a confidential manner?

All information collected about you and your child will be treated confidentially. No information exchange will occur between the donor and the recipient of cord blood. Only authorized persons have access. Cord blood is identified by a unique code number attached to your file. The information collected about you and your child will be kept indefinitely. You have the right to review your record to verify the information and make changes if necessary.

Does Héma-Québec require consent to collect cord blood?

Yes. No cord blood is collected without written consent.

Can I make a directed donation?

If a member of your family is suffering from a health problem that could be treated by a cord blood transplant, making a directed donation is possible. In this case, the cord blood will be kept for the member of your family who will need it soon. Above all, you must discuss this with the patient’s physician, who will be able to take the steps required with Héma-Québec for this type of donation. Since 1996, Héma-Québec has been storing cord blood donations for family members (brother, sister, father or mother of the child) that can be treated through the transplantation of stem cells. There is no cost for either the parents of the donor or for the recipient of a transplant.
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