

STEM CELL DONOR REGISTRY

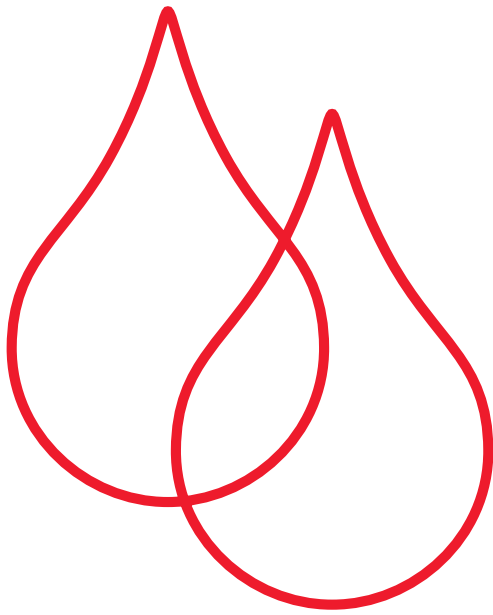
WHAT IF YOU, AND YOU ALONE, COULD SAVE A LIFE?



Decision Support

Information to Enrol in the
Stem Cell Donor Registry





WHAT IF THIS GIFT WAS FLOWING THROUGH YOUR VEINS?

Thousands of people need a stem cell transplant to survive. When treatments, such as chemotherapy, are no longer effective, a stem cell transplant is often the only chance to overcome a serious illness, for example:

- Leukemia and other cancers
- Aplastic anemia
- Primary immune deficiency
- Hemoglobin abnormality, such as sickle cell anemia or thalassemia major

WHAT IF YOU WERE TOLD THAT YOU HELD THE KEY TO THEIR RECOVERY?

Unfortunately, in three among four cases, there is no compatible donor in the family. A donation from an unrelated donor becomes the only hope.

Patients need that one person, among several million others enrolled in a worldwide registry, to find a compatible donor.

AND THAT HOPE COULD FLOURISH BECAUSE OF YOU?

Enrolling in the Stem Cell Donor Registry increases the chances that a patient will find a compatible donor.

Agreeing to donate your stem cells is offering a unique chance of survival to someone who needs it.

THIS DOCUMENT CONTAINS IMPORTANT INFORMATION REGARDING:

- Eligibility criteria and enrolment in the Stem Cell Donor Registry;
- Preparation for donating if you are called upon to be a donor;
- Types of donations possible.

Please read it carefully. It is vital that you know what is involved in the process before you enrol in the Registry and what will be expected of you if you are found to be compatible with a recipient.



Feel free to contact us if you would like to learn more before enrolling. We will be pleased to answer your questions:

By email:

donor.research.registry@hema-quebec.qc.ca

By phone:

1-800-565-6635, ext. 5279

WHO CAN ENROL IN THE REGISTRY?

TO ENROL IN THE REGISTRY, YOU MUST BE:

- **Between 18 and 35 years old.**

A transplant physician will always choose the best option for the patient. For example, if two potential donors have similar compatibility profiles, the treating physician will usually opt for the younger donor. Studies show that a younger donor increases the chances of a successful stem cell transplant.

- **In good health.**

The safety of recipients and donors is a priority for Héma-Québec. For this reason, Héma-Québec has established stringent eligibility criteria.

- **Ready to donate stem cells to anyone who needs them.**

You may feel called upon to help a particular patient who is searching for a compatible donor. You should know, however, that the likelihood that you are compatible with that person is very slim. If you decide to enrol in the Registry, you must be ready to donate to whoever needs a stem cell transplant here or elsewhere in the world.

HOW TO ENROL?

After reading this guide, you will be ready to fill out the online registration form. Based on the information you submit, a Héma-Québec adviser may contact you to obtain additional information on your health status.

Once your eligibility is confirmed, you will receive a buccal swab kit in the mail, consisting of cotton swabs to rub inside your mouth to collect cell samples.

Your samples will be analyzed in the lab to determine your genetic profile. The analyses that are done are limited and intended to assess your potential compatibility with future donors. This information, which is treated confidentially, will be stored in our Registry and made available to similar registries around the world. It will be used solely to establish compatibility between a patient waiting for a stem cell transplant and you. The information will be stored until your 60th birthday.

WHAT HAPPENS IF I AM SELECTED?

Only donors who are compatible with a recipient waiting for a stem cell transplant will be contacted. You may never be contacted, or you could be contacted in six months' time or even in 20 years. Until your 60th birthday, you could be found to be compatible with a patient and have the chance to save a life.

At that stage, Héma-Québec will contact you to check your compatibility, your eligibility to donate and your intention to proceed with the process.

YOU WILL NEED TO:

- **Provide blood samples in preparation for donating your stem cells. The samples will be used for:**
 - Compatibility testing to confirm your compatibility with the recipient;
 - Screening tests for blood-borne infectious diseases.
- **Fill out an eligibility questionnaire.**

While there is no guarantee that you will be chosen, once you have been selected for typing confirmation, you must always be ready to donate. If your compatibility with a donor is confirmed and the results of your tests are successful, we will invite you to proceed with the donation. There might be a delay of several weeks or months before the patient is ready for the transplant.



NOTE:

Some transplant centres participate in research projects. We will advise you if you are asked to take part in such projects. Your participation is voluntary: you must provide written consent if you accept to participate.

PREPARING TO DONATE

PREPARING TO DONATE CONSISTS OF THE FOLLOWING STEPS:

- A phone call with a Héma-Québec adviser
- A meeting with the collection centre (hospital)
- A medical examination and blood tests
- A period of reflection about your intention to donate
- Confirmation of your intention to donate

This preparation period can be as short as a week, for urgent cases, or extend over several months. The usual timeframe is between five and seven weeks.

Remember that your health and well-being, and those of the recipient, remain our priority. If you feel that the preparation period is much too long or that you are being rushed because the preparation period is too short, discuss this with your adviser.

CONFIRMATION OF YOUR INTENTION TO DONATE

At any time during the process, you have the right to refuse to donate.

You should know, however, that seven to ten days before your donation, the recipient will begin intensive chemotherapy and/or radiation treatments to prepare for the transplant.

From that moment on, if you change your mind or are unable to donate, the patient's life could be in danger.

COSTS ASSOCIATED WITH THE DONATION

The costs associated with preparing to donate are paid by Héma-Québec, the Québec health insurance plan and the recipient's transplant centre. Your adviser will inform you about the expenses that will be reimbursed to you. You should know, however, that the Registry does not reimburse lost wages. We will inform your employer of the important role that you are playing in the transplant process. Several companies have already planned for this eventuality.

CONFIDENTIALITY:

Héma-Québec's Stem Cell Donor Registry, the affiliated international registries and the transplant centres have stringent confidentiality criteria between donors and recipients.

The information collected on donors, which includes test results, are stored confidentially in accordance with the law. To continuously improve knowledge in the field of stem cell transplantation, Héma-Québec may use the information collected on donors for studies, research and statistics, without disclosing the donor's personal information.

TWO POSSIBLE TYPES OF DONATION

Bone marrow stem cell donation

If the recipient's health allows, we will prepare you for a stay in the collection centre. The collection will be done in your region, either at the Hôpital Maisonneuve-Rosemont for the Montréal region or at the Hôpital de l'Enfant-Jésus for the Quebec City region. Once the donation is completed, a representative from the transplant centre will send your donation to the hospital where the recipient is being treated (this may be in Canada or elsewhere in the world).

HOSPITALIZATION

With this type of donation, you could spend a night at the hospital. You will have a room assigned to you, and everything will be done to make your stay as pleasant as possible.

ANESTHETIC

Collecting stem cells from bone marrow involves surgery that is done under general anesthesia. You are therefore asleep during the procedure.

COLLECTION PROCEDURE

You will be lying on your stomach. The physician will insert a needle in the base of your back to reach the iliac crest of the pelvic bone. This bone contains a large quantity of bone marrow. The amount of bone marrow collected depends on the recipient's weight and the concentration of stem cells in your bone marrow. Following the collection, your bone marrow will be injected intravenously into your recipient, like a blood transfusion.

RISKS ASSOCIATED WITH THE COLLECTION PROCEDURE

Héma-Québec and the physician from the collection centre will explain to you the risks associated with the donation and answer your questions. Most

donors recover without any problem.

All surgical procedures carry risks, including death (extremely rare).

However, the risks associated with bone marrow donation are minimal. The estimated risk of major complications occurring is between 0.1% and 0.3% (1/1,000 to 3/1,000), while the risk of minor complications is between 6% and 12%.

AFTER THE DONATION

Once you are awake and your health status is stable, you will be brought to your room. You may feel sleepy following the anesthetic, and the needle puncture sites may be sensitive and painful. During your hospital stay, you will be monitored by the collection centre staff.

HOSPITAL STAY

You will be given a prescription for analgesics to be taken as needed to deal with the pain, and you will receive instructions and advice to ensure a good recovery.

CONVALESCENCE

The convalescence period usually lasts two weeks. Your adviser will call you in the days following your release from hospital to inquire about your health.



Stimulated peripheral stem cell donation

Another source of stem cells, stimulated peripheral stem cells, is found in your peripheral blood, i.e., your veins. Usually, the quantity of stem cells circulating in peripheral blood is not sufficient to ensure a successful transplant. However, administering a drug called “granulocyte-colony stimulating factor” (G-CSF) in healthy individuals increases the number of stem cells circulating in peripheral blood, where they can be collected in greater number.

COLLECTION PROCEDURE

The collection procedure is different from that used for bone marrow. Cells are collected by apheresis, a technique used by Héma-Québec for plasma and platelet donations. The donor's blood is removed through a needle in the arm, passes through a device that withdraws only the desired blood component (in this case, stem cells) and returns the other components to the donor.

PREPARING FOR THE DONATION

You will receive two subcutaneous injections of G-CSF once a day for four days, as well as on the morning of the donation (Day 5). This treatment is generally well tolerated. Pain in the bone is the most frequent side effect.

AFTER THE DONATION

Once the collection procedure is completed, if everything goes well and your health is stable, you can return home the same day.

CONVALESCENCE

In the first days after the donation:


- Take acetaminophen or another analgesic
- Limit activities for several days
- Rest
- Avoid sports or intense physical activity for two to three weeks
- Plan for a period of up to two weeks to convalesce

Your adviser or nurse at the collection centre will call you in the days following your donation to inquire about your health.



**WHAT IF I AM
THAT UNIQUE AND
VALUED PERSON
THAT A SERIOUSLY ILL
PATIENT HAS WAITED
FOR SO LONG?**





Each year, thousands of individuals need a stem cell transplant. For most, this is their last chance to overcome a serious illness.

By enrolling in the Registry, you are spreading the seeds of hope for all those families who are counting on us to find a compatible donor.

On behalf of everyone waiting for a stem cell transplant, **thank you for your selfless act.**

THANK YOU!

NEED MORE INFORMATION?

**WE WILL BE PLEASED TO
ANSWER YOUR QUESTIONS:**

| 1-800-565-6635, ext. 5279

| donor.research.registry@hema-quebec.qc.ca