

What is Canadian Blood Services Stem Cell Registry?

Every year, hundreds of patients across the country wait for a lifesaving blood stem cell transplant. In Canada, their search for a donor may start with family members, but less than 25% of patients find a match within their family. Canadian Blood Services Stem Cell Registry ('the Registry') recruits unrelated volunteer donors for patients needing blood stem cell transplants.

What are blood stem cells?

Blood stem cells make all the cells found in the blood, including cells important for the immune system. They are found mainly in the bone marrow but also in the blood.

How do blood stem cell donors help patients?

Blood stem cell transplants can treat over 80 diseases and disorders, including leukemia, aplastic anemia, and some inherited immune system and metabolic disorders. Patients need a stem cell transplant when their bone marrow (stem cell factory) has failed due to a life-threatening illness. A blood stem cell transplant replaces a patient's diseased bone marrow with healthy blood stem cells from a donor.

How are donors matched to patients, and how does ethnicity play a role?

Donors and patients are matched according to the compatibility of inherited genetic markers called Human Leukocyte Antigens (HLA). Patients are more likely to find a matching donor among those who share

their ethnic ancestry, which makes growing an ethnically diverse donor base extremely important.

Am I eligible to join the Registry and help patients in need?

We encourage you to join the Registry if you are:



Between the ages of 17 and 35 (research has shown that younger donors provide the greatest chance for transplant success).



In good general health; free of infectious diseases such as HIV/AIDS, or hepatitis B and C.



Have not been diagnosed with a serious health condition, including cancer, blood diseases, insulin-dependent diabetes, certain heart conditions, etc.



Willing to donate to any patient in need, in any part of the world.

I am ready to join, how do I get started?

1

Read this pamphlet and the Privacy Notice to Stem Cell Registry Participants. Be sure

you understand the information provided, what personal information you must provide and how your personal information is used, retained, and disclosed by Canadian Blood Services. If you have any questions before joining the Registry, please call us at **1 888 2 DONATE (1.888.236.6283)**. If you have questions about our privacy policy, please call us at **1.877.262.9191**, or email us at **privacy@blood.ca**.

2

Register online. If registering at a stem cell event in your community, use your smartphone's camera app to scan the QR code on your barcode label sheet to be taken directly to the online registration. If registering at home, simply visit **blood.ca/register4stem** to check your eligibility with a 2-minute health questionnaire and complete your online registration.

3

Complete your swab kit. Gently swab the inside of your cheeks to collect cells that will be tested to determine your genetic profile. Full collection instructions are included in your swab kit. Return your completed swab kit to a Canadian Blood Services representative or a volunteer at a stem cell event. If you're completing your swab kit at home, just mail your completed kit back to us at any post office or drop box, free of charge with postage included.

4

Receive confirmation you have been added to the Registry. Once we test your genetic sample, we'll officially add you to the Registry, and send you an email confirming your registration.

5

Show up for patients in need. It can take a month or years to find a match. Make sure your health and contact information are up to date so we can reach you when the time comes.

Joining the Registry means:

- You understand that stem cell donation is a treatment that may save or prolong a patient's life.
- If you decide not to donate stem cells after you have been selected as the best match for a patient, it could have serious consequences for the patient if they have already started their preparation for the transplant.
- You will keep your contact information updated so that we can reach you quickly if you are a match for a patient.
- You understand that there are two types of donation methods, peripheral blood stem cell and bone marrow donation, depending on the patient's needs.
- If selected for a patient, you'll attend medical appointments over a 4-6 week period. Appointments include:
 - Blood tests, including infectious disease testing and an additional cheek swab for further testing.
 - A physical exam by a physician who will review the donation method details with you and ensure you understand the procedure.
 - A health screening questionnaire.
 - Donating your stem cells to a patient in need.
- Joining the Registry helps match patients with an unrelated stem cell donor. If you have a family member in need of a stem cell transplant, please contact their transplant team to discuss family testing for your relative.



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Canadian Blood Services Stem Cell Registry information for new registrants



Benny,
stem cell registrant
and blood donor

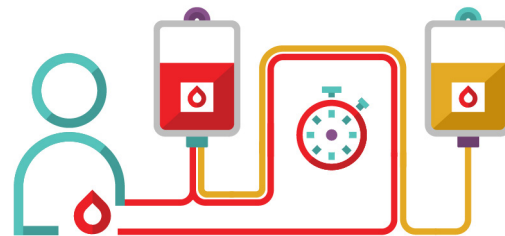
Stem Cells for Life

How do I donate blood stem cells, and what are the risks?

There are two types of methods for adult blood stem cell donation.

Peripheral blood stem cells (PBSCs)

The PBSC collection method is used approximately 80% of the time. PBSCs are collected from circulating (peripheral) blood. Since only a small number of blood stem cells are released into the bloodstream, a drug called “granulocyte colony stimulating factor” (G-CSF) is given to the donor by injection under the skin daily for 4-5 days to stimulate the production of stem cells. G-CSF has been administered to stem cell donors for over 20 years with no known long-term side effects. Short-term side effects may include mild to moderate bone pain, muscle pain, headaches, flu-like symptoms, nausea and vomiting, and redness or pain at the injection site. These symptoms usually subside 24-48 hours after your donation.



On donation day, stem cells are collected using a procedure called apheresis, where only the stem cells are separated and collected during donation. The remaining blood components are safely returned to the donor. This relatively painless, non-surgical procedure takes approximately 4-6 hours.

In some cases, a second donation is required the following day. Donors may experience some discomfort during the procedure, such as feeling light-headed, nauseous, or cold. Risks with this method are minimal, and a nurse continually monitors the donor. Donors should be able to return to work and regular activities the following day.

Bone marrow stem cells

The bone marrow collection method is used approximately 20% of the time.



This is a surgical procedure performed under general anesthesia where a physician withdraws liquid marrow from the pelvic bone using a hollow needle.

The volume of bone marrow collected is usually between 0.5-1.5 litres, and the procedure takes about 45-90 minutes. Most donors need to take a few days off work and avoid strenuous activity for at least two to three weeks while the body replenishes the donated bone marrow.

There are risks with any surgical procedure, but with a bone marrow donation, the risk of complications is low. There are some risks associated with anesthesia, and these vary depending on the type of anesthesia used. Most donors experience fatigue, pain at the donation site, bruising and lower back pain for at least a few days following the donation. Donors may also have discomfort when walking, standing, or sitting. The recovery period varies from donor to donor. Infection at the bone marrow collection site is very rare and can be treated with antibiotics. Nerve, bone, or other tissue damage is extremely rare and may require additional medical treatment.

Withdrawing from the Registry:

We know plans can change over time. If you can no longer donate, please get in touch with us at privacy@blood.ca to update your commitment.

If you withdraw, Canadian Blood Services will no longer use your personal information to match you with a patient needing a blood stem cell transplant. The personal information collected about you up to the date of your withdrawal will remain in the Registry, but no further personal information about you will be collected.

The upper age limit for stem cell donation is 60 years, you will automatically be removed from the Registry when you reach that age.

What if I still have questions?

If you still have questions after reading this pamphlet, contact us anytime at **1 888 2 DONATE (1.888.236.6283)** or visit blood.ca/stemcells for more information.

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