

Both blood and blood stem cells from your bone marrow are replenished within two to three weeks.

## What are the risks involved in donating blood stem cells?

### Method One: Stimulated peripheral blood stem cell donation

The apheresis procedure is commonly used in a variety of situations, for example, plasma and platelet donations. The risks associated with this procedure are minimal, you may however experience some discomfort during the procedure, including feeling light-headed, nauseous or cold. A nurse will be continually monitoring your donation and you should report any discomfort so that appropriate steps can be taken to alleviate these symptoms.

The long-term side-effects of G-CSF, the drug used to stimulate the production of stem cells, are unknown at this time. You should have your blood tested each year, and we will send a letter to remind you to make an appointment with your family doctor.

### Method Two: Bone marrow stem cell donation

Any surgical procedure carries inherent risks, however for a bone marrow donation these risks are considered very low. There are some risks associated with anesthesia, and these vary with the type of anesthesia. Infection at the site of the bone marrow collection is very rare and can be treated with antibiotics. Nerve, bone or other tissue damage is also very rare and may require additional medical treatment. Most donors experience fatigue, pain at the donation site, bruising and lower back pain for a few days to several weeks; donors may also have discomfort when walking, standing or sitting. The recovery period varies from donor to donor. All of these risks will be explained to you by the physician collecting the bone marrow. We encourage you to make a list of questions before your meeting with the collection physician to get all the answers you need to feel comfortable in proceeding.

## What are the short-term side effects?

If you're donating peripheral blood stem cells, the possible short-term side effects from the drug used to stimulate the production of blood stem cells 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 will normally subside 24 to 48 hours after making your donation.

Following the peripheral stem cell donation, you will be released from the hospital on the day of the procedure and should be able to return to work the day after your donation.

If you're donating bone marrow, most donors experience fatigue, pain at the donation site, bruising and lower back pain for a few days to several weeks. Donors may also have discomfort when walking, standing or sitting.

Many bone marrow donors are released from the hospital the day of the procedure. Most donors need to take several days off

work and avoid strenuous activity for at least two to three weeks, which is approximately how long it takes to regenerate the donated bone marrow.

## What will it cost me to be a donor?

Joining the Canadian Blood Services Stem Cell Registry is free and the costs associated with the medical examination and the donation will be covered by Canadian Blood Services, the transplant centre, or your provincial health card.

Canadian Blood Services Stem Cell Registry will discuss with you the details about the expenses that may be reimbursed if you are asked to donate.

## What is the outlook for patients who receive blood stem cell transplants?

Outcomes depend on many factors including the level of compatibility between the donor and the patient, the stage of the disease, the type of disease, the age of the patient and other factors. There are not any guarantees for the patient, but a transplant may be the best hope of returning to good health.

## Do people on the Canadian Blood Services Stem Cell Registry ever get to know the individuals they are helping?

Exchange of information between donor and patient is not permitted for at least one year. After a year, some registries will allow correspondence, while other registries never permit the exchange of information. You can reach out to us one year following the transplant and we will let you know about the policy of your patient's transplant centre.

## What if I move?

It is very important that you let us know when your contact information changes. This can be done by calling us toll-free at **1 888 2 DONATE** (1.888.236.6283) or visiting our website [blood.ca/change-your-address](http://blood.ca/change-your-address). We also appreciate being advised if your health status has changed in any way, as it may affect your eligibility to donate.

## What if I no longer wish to donate blood stem cells?

You are free to decline to donate at any point in the process and your decision will remain entirely confidential. You should be aware that there is a serious risk of death to the patient if you decide to decline after the patient's radiation or chemotherapy treatment has begun. You will be told in advance exactly when the patient will start this treatment and given every opportunity to decline before that date.

## Withdrawing from the Canadian Blood Services Stem Cell Registry

Your participation in the Canadian Blood Services Stem Cell Registry is voluntary. You may withdraw at any time by calling

**1 888 2 DONATE** (1.888.236.6283). If you withdraw, Canadian Blood Services will no longer attempt to match you with a patient in need and your samples will be discarded. All personal information collected up to the date of your withdrawal all remain in the stem cell registry but no further information about you will be collected.

## How do I join the Canadian Blood Services Stem Cell Registry?

**Step 1:** Read this pamphlet. Being an informed donor is a vital part of the donation process. It is important that you read and understand the information in this pamphlet. If you have any questions before proceeding, please call us at **1 888 2 DONATE** (1.888.236.6283).

**Step 2:** Read the Privacy Notice to Stem Cell Registry Participants so you understand what personal information we collect from you when you join. The privacy notice also explains how your personal information is used and disclosed by Canadian Blood Services.

**Step 3:** Complete the Stem Cell Registry Health, Screening and Consent to Participate, form which will help Canadian Blood Services determine your eligibility to join the stem cell registry.

**Step 4:** Swab your cheek. A buccal swab involves brushing your inner cheek with a special swab to collect cells that can be tested for certain antigens, which can be used to determine your compatibility (or match you) with a patient waiting for a stem cell transplant. Full instructions are included in the swabbing kit.

**Step 5:** Confirmation of eligibility. You will receive either a telephone call from a Canadian Blood Services representative to discuss your eligibility, or a letter confirming that you will be added to the registry.

Further compatibility testing may be required to determine if you are a match with a specific patient, or if a new compatibility test is identified as being important in the matching process and your buccal swab was not previously tested for this new compatibility test.

## What if I still have questions?

If you still have questions after reading this pamphlet, feel free to contact us anytime at **1 888 2 DONATE** (1.888.236.6283) and we will be happy to help you.



# Canadian Blood Services Stem Cell Registry information for new registrants

## Stem Cells for Life

## What you must know to join Canadian Blood Services Stem Cell Registry?

The Canadian Blood Services Stem Cell Registry maintains a database of volunteer donors willing to donate stem cells to any patient who requires a stem cell transplant and is responsible for coordinating donor searches on behalf of Canadian and international patients. Fewer than 25 per cent of patients who need stem cell transplants find a compatible donor within their own family. The rest rely on those who have volunteered to anonymously donate blood stem cells to any patient in need.

Because the Canadian Blood Services Stem Cell Registry is part of an international network of donor registries, we can also search more than 36 million individuals in 80 registries worldwide<sup>1</sup>. This international cooperation significantly increases the odds of finding a matched donor for any patient, anywhere in the world.

**Important note:** If you were registered with the OneMatch Stem Cell and Marrow Network you are already part of the Canadian Blood Services Stem Cell Registry. You do not need to register again. If you are uncertain about your registration status, contact us at **1 888 2 DONATE** (1.888.236.6283) or visit **blood.ca**.

## Who is eligible to join Canadian Blood Services Stem Cell Registry?

You are eligible to join if you are between 17 and 35 years old and meet certain health criteria. The upper age limit for stem cell donation is 60 years and registrants remain on the registry until their 60th birthday. This is to ensure the well-being of donors and patients.

Health problems that could make you ineligible include some heart conditions, cancer, blood diseases, insulin-dependent diabetes and infectious diseases such as HIV/AIDS, hepatitis B and C.

There are also height and weight restrictions in place to protect both donors and patients. People who do not meet the program's height/weight criteria may be at a higher risk of complications during the donation procedure.

A person's best chance of finding a matching donor is within his or her own ethnic group. As such, it is important that potential donors added to the registry reflect Canada's rich ethnic diversity. It is also important for the future of Canadian Blood Services Stem Cell Registry to attract young potential donors that will remain on the registry for longer periods of time.

## Can I be tested specifically for my relative?

The Canadian Blood Services Stem Cell Registry is responsible for identifying and matching unrelated donors. If you would like to be tested specifically for your relative, please contact your relative's transplant team.

## Can I be tested specifically for my friend?

It is extremely unlikely that two friends will share the same genetic profile. A patient's best chance for a match lies with the potential donors who are already on the Canadian Blood Services

Stem Cell Registry or another international registry worldwide. You must be willing to donate to any patient and you must meet the program's eligibility requirements to join the registry.

## What are blood stem cells?

Blood stem cells are immature cells that can reproduce the entire blood and immune system, including:

- Red blood cells to carry oxygen in your body,
- White blood cells to fight infection and
- Platelets to help blood to clot.

Bone marrow is a rich source of stem cells, but stem cells can also be found in circulating blood (also known as peripheral blood) and umbilical cord blood. The Canadian Blood Services Stem Cell Registry donors may be asked to donate stem cells from bone marrow or peripheral blood depending on which product the patient requires.

## What is a blood stem cell transplant?

In a blood stem cell transplant, a patient's diseased bone marrow is replaced with healthy stem cells from a donor. To prepare for the transplant, the patient is usually given high doses of radiation and/or chemotherapy to destroy the diseased bone marrow. At this point, stripped of the ability to build life-giving blood cells, the patient is extremely vulnerable. They will not survive unless the donor proceeds with the donation. Once the healthy blood stem cells are collected from the donor, they are given intravenously to the patient as soon as possible.

## What diseases are treated with blood stem cell transplants?

A variety of diseases and disorders are treated with blood stem cell transplants including diseases such as leukemia, aplastic anemia, inherited immune system and metabolic disorders.

## What do you mean by a “match”?

Donors and patients are matched according to the compatibility of inherited genetic markers called Human Leukocyte Antigens (HLA). These antigens are inherited from your parents. A patient's physician will compare the patient and donor antigens to determine the best match possible for a patient in need of a transplant. Up to 12 antigens are considered important in the matching process.

## Is there a matching donor for every patient who needs a blood stem cell transplant?

Even with millions of potential donors on registries worldwide, a stem cell match isn't always available. Some patients have uncommon antigens and/or antigens that are very specific to a certain ethnicity. In these instances, even with everyone's best efforts, it may be difficult or impossible to find a donor. It is for this reason that the Canadian Blood Services Stem Cell Registry is committed to recruiting donors from diverse ethnic backgrounds.

## Height/weight chart

This chart displays the maximum weight for someone to join the Canadian Blood Services Stem Cell Registry

Height		Maximum weight at enrollment	
ft/in	cm	lbs	kgs
4'10"	148	191	87
4'11"	150	198	90
5'	153	204	93
5'1"	155	211	96
5'2"	158	218	99
5'3"	161	225	103
5'4"	163	233	106
5'5"	166	240	109
5'6"	168	247	113
5'7"	171	255	116
5'8"	173	263	120
5'9"	176	270	123
5'10"	178	278	127
5'11"	181	286	130
6'	183	295	134
6'1"	186	301	137
6'2"	188	310	141
6'3"	191	321	146
6'4"	194	328	149
6'5"	196	339	154
6'6"	199	345	157
6'7"	201	355	162
6'8"	204	363	165
6'9"	206	374	170
6'10"	209	381	173
6'11"	211	392	178

UBMDC0501 Appendix 1: height/weight chart

## What if I'm a match?

Being a potential match is an exciting experience, but it is still only a first step. You may be required to provide a new buccal swab and will be required to provide a blood sample to determine the full extent of your compatibility with the patient. You will also need to complete a health screening questionnaire and be tested for transmissible diseases to confirm your health status and eligibility to proceed.

If you are selected to donate, you will be contacted by a Canadian Blood Services Stem Cell Registry team member who will guide you through each step of the process, including the donation method and dates requested. You will be required to complete a physical examination and routine medical tests at the hospital (collection centre) where you will donate. These tests may include a chest X-ray and electrocardiogram, as well as blood and urine analyses, and are intended to ensure that you are healthy and it's safe for you to donate. The collection physician will also review the donation method with you and ensure you understand the risks and benefits of the procedure. During this time, you should address any questions or concerns you have with the collection physician.

If you agree to proceed, the patient will be notified, and the preparatory procedures for the patient, such as radiation and chemotherapy, will begin. If you decline or are unable to proceed with the donation once this intensive treatment has begun, it is very unlikely that the patient will survive.

## How do I donate blood stem cells?

You will donate your blood stem cells through one of the two methods described below. The transplant centre will request the stem cell product that is most suitable for the patient.

### Method One: Stimulated peripheral blood stem cell donation

One way to donate blood stem cells is through your circulating blood (also called peripheral blood). To increase the number of blood stem cells in your blood, you will receive injections of a drug called granulocyte colony stimulating factor (G-CSF) every day for four to five days. The blood stem cells are then collected using a non-surgical procedure called apheresis. During this procedure, blood is drawn through a needle and passes through a machine that separates the blood stem cells from the blood and returns the blood to you through another needle. The procedure can take four to six hours and may require a second donation the following day to ensure enough stem cells are collected.

### Method Two: Bone marrow stem cell donation

Bone marrow stem cell donation is a surgical procedure performed under general anesthetic. The collection physician will use special, hollow needles to withdraw liquid marrow from the iliac crest, which sits at the back of your pelvic bones. Normally about 1,000 milliliters of marrow is harvested. The volume of the collection can range from about 500 milliliters up to 1,500 milliliters, depending on your size and the size of the patient. The procedure usually lasts from 45-90 minutes. The collection includes blood along with the stem cells from your bone marrow.

<sup>1</sup>Current numbers can be viewed on [www.wmda.info](http://www.wmda.info).