



Canadian
Blood
Services

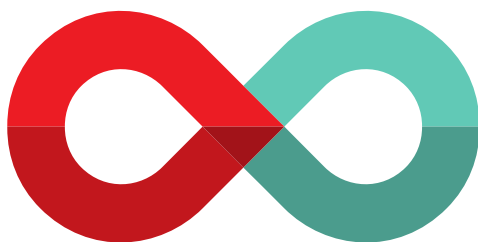
BLOOD
PLASMA
STEM CELLS
ORGANS
& TISSUES

Guide for Potential Unrelated Donors

Canadian Blood Services
Stem Cell Registry



Danny,
stem cell
donor



Tom,
stem cell
recipient

**This guide is intended
for potential unrelated
donors to give you an
idea of what to expect
should you decide to
donate stem cells**

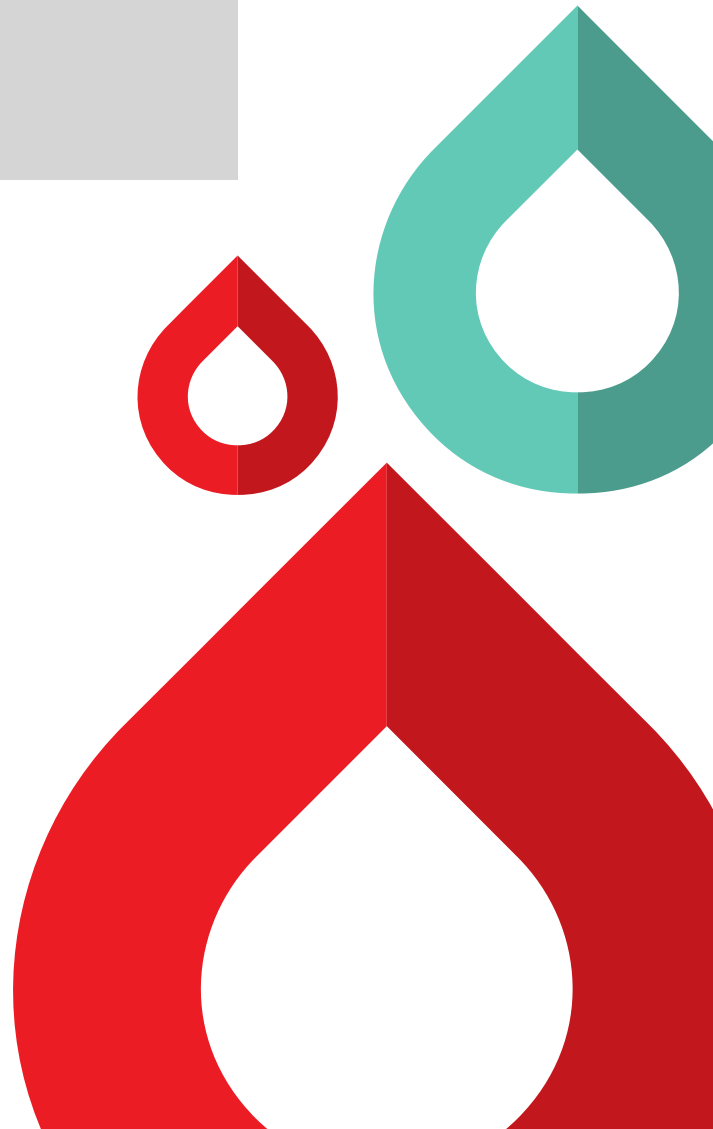


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Introduction

CONGRATULATIONS! You've been identified as a potential unrelated match for someone who needs a stem cell transplant. This is a unique opportunity for you to give a patient a second chance at life.

You are being asked to consider donating some of the healthy stem cells in your bone marrow or peripheral (circulating) blood to someone you do not know, who needs stem cells in the treatment of a serious illness or disorder.

This guide gives you an idea of what to expect should you decide to donate stem cells.

Fewer than 25 per cent of patients who need a stem cell transplant have a compatible donor within their own families. Locating a suitable unrelated donor can be a lengthy and complex process. Advances in medicine and the growth of the Canadian Blood Services Stem Cell Registry donor base, has made it possible for hundreds of Canadians to donate stem cells each year to someone they do not know.

There is a lot of information included in this guide, so please take your time and read carefully. After reviewing this information, if you have any questions or concerns, please contact a Stem Cell Registry Case Manager at 1-866-233-2445.

First, here is an explanation of a few terms that you will come across:

Bone Marrow: The tissue found in the soft center of bones. It manufactures blood cells, including red blood cells, white blood cells, and platelets.

Case Manager: A Registered Nurse at Canadian Blood Services Stem Cell Registry who will guide you through the entire donation process.

Collection: The process of collecting stem cells through a bone marrow or PBSC donation.

Collection Centre: The facility where you will go to make your bone marrow or PBSC donation and where you will undergo a physical examination to ensure you're healthy to donate stem cells. There are designated "Collection Centres" located in hospitals across Canada. Your physical examination and collection procedure will be scheduled at the Centre closest to your home. In some cases, the nearest Collection Centre may be in another province and you will be asked to travel to this Centre.

Verification Typing: The collection of blood samples to determine whether you are the best match for a patient.

Donor Leukocyte Infusion (DLI): Leukocytes are white blood cells, also referred to as T-cells.

Peripheral Blood Stem Cells (PBSC): Refers to stem cells that circulate in the peripheral blood. Normally, there are too few of these cells to provide a useful quantity for transplant purposes. However, when a healthy donor is given a drug called granulocyte colony stimulating factor (G-CSF), the number of stem cells are mobilized to increase significantly in the peripheral blood.

Stem Cells: Specifically, hematopoietic blood stem cells which are immature cells that can become either red blood cells (which carry oxygen), white blood cells (which fight infection) or platelets (which help to stop bleeding). Bone marrow is a rich source of these cells, but they can also be found in your blood system and in umbilical cord blood.

Transplant Centre: The hospital where the patient is being treated. It may be in Canada or in a different country.

Work-up: The process used to prepare you for the stem cell collection, includes a medical assessment at the Collection Centre as well as the collection of additional blood samples for infectious disease testing. Begins when you have been identified as the best match and ends when you have fully recovered from the donation.

Personal Information: Personal Information, which includes personal health information, is information that may be used to identify you. It includes such details as your name, address, date of birth, health status and compatibility testing.

Confidentiality

Canadian Blood Services Stem Cell Registry and its affiliated national and international registries and Transplant Centres maintain strict donor and patient confidentiality standards.

If you are selected as the best match, your Case Manager will review the confidentiality policy in more detail. However, please be aware of the following to ensure confidentiality is maintained for both you and the patient:

- Specific information about your patient will be kept confidential (*see “Life After Donation”*).
- The exchange or sending of photographs or gifts is not permitted.
- Correspondence may be shared immediately following your donation, however any identifying information will be removed.
- Media interviews may compromise confidentiality. The Canadian Blood Services Stem Cell Registry policy regarding interviews will be reviewed with you. To protect the confidentiality of patients and donors, we ask that donors respect this policy and decline media interviews, before and after the donation. As well please refrain from publishing information yourself about the donation through the internet, social media or other means. If you have any questions, please contact your Case Manager.

- Information on the patient's condition will not be available until at least three months after the transplant. Given the confidential nature of the transplant process and depending on the policy of the Transplant Centre or International Registry, we may be limited or prohibited from providing any patient information. Your Case Manager will determine what information is available to you, if any.
- Direct communication between donor and patient is not permitted until at least one year after the last donation, and then only if both parties agree.

These policies can be disappointing for donors who wish to learn more about their patient and vice-versa. However, these policies exist out of respect for the privacy of donors and patients. Each participant, whether a donor or patient, reacts in a unique way to this life-altering experience. Confidentiality policies ensure your right to privacy in making the decision to donate, just as they ensure the patient's right to privacy during and after recovery.

- The patient's condition may deteriorate, and he or she may no longer be an acceptable candidate for transplant.
- In some cases, the patient may pass away before the transplant can take place;
- The patient may respond to more conventional treatments and/or may decide not to have a transplant;
- The search for the best possible match may continue after you have been selected as a donor, and a more compatible donor may be found.

Please note: Certain registries and Transplant Centres insist on a longer waiting period (i.e. two years); others never permit the release or exchange of personal information.

Your Verification Typing

While it may have been a few months or even a few years since you joined the Stem Cell Registry, you are in a unique position to potentially help someone in need. You have been identified as a potential match for a patient, who is not related to you, and now we need to assess your health and do further typing of your blood "to verify" if you are indeed the best match for this patient. This involves collecting personal information about you, including:

- A health assessment interview by a Canadian Blood Services Registered Nurse (Case Manager) to determine if you are in good health;

- Collection of blood samples for a variety of tests, including further compatibility testing and infectious disease testing.

Why are blood samples required?

There are a number of DNA markers called Human Leukocyte Antigens (HLA), which are known to be important when matching a patient to a donor. When you joined the Canadian Blood Services Stem Cell Registry, your compatibility testing may not have been as detailed as today's more sophisticated typing methods. As well, Transplant Centres may now want to match up to 12 of these markers.

Prior to any blood samples being collected for testing please tell staff if you are allergic to latex or to the powder used in medical gloves.

The Transplant Centre will test your blood to determine how closely you match the patient. The Transplant Centre will make the final donor selection based on the needs of the patient.

The Transplant Centre may store a portion of your blood sample indefinitely for further testing, which may include compatibility testing, blood grouping and/or infectious disease testing related to donor selection and testing related to the donation/transplant process.

In addition, a portion of the blood samples will be tested by Canadian Blood Services (and in some cases, the Transplant Centre as well) for infectious diseases which may include hepatitis, syphilis, Human T-Lymphotropic Virus (HTLV), Human Immunodeficiency Virus (HIV), Cytomegalovirus (CMV), West Nile Virus (WNV), Chagas' Disease and other factors to make sure that your donation is as safe as possible.

All personal information that is collected during the Verification Typing process may be shared as described in the next section.

Sharing Your Personal Information

Canadian Blood Services may share personal information from your health assessment interview and your infectious disease test results with your Collection Centre, other stem cell registries and Transplant Centres in order to identify you as a potential stem cell donor for a particular patient.

The Transplant Centres may share the results from its compatibility testing, and infectious disease testing and any other further testing with Canadian Blood Services so that your Stem Cell Registry file is accurate and complete.

The potential patient of your donation may be advised of any transmissible disease risk so that they may make an informed decision about accepting this risk, however your identity will not be made known to them.

Finally, positive infectious disease test results may be reported to the appropriate public health authority.

Information on AIDS/HIV Virus

AIDS is caused by a virus known as HIV. HIV can be spread when body fluids such as semen, blood or vaginal fluids from a person with the virus enter the bloodstream of someone else.

HIV Risks

There are certain activities that put individuals at an increased risk for contracting and/or spreading HIV. You are considered at risk if:

- You are a male who has had sex with another male within the past 12 months ;
- You have used a needle to inject illegal drugs into yourself within the past 5 years;
- You have taken money or drugs for sex within the past 5 years;
- You regularly receive blood products;
- You have had sex with someone who has done any of the things listed above;
- You have been in jail for longer than 72 hours in the past 12 months.

Definition of Sex

Sex refers to any of the following activities:

- Vaginal intercourse (contact between penis and vagina);
- Oral sex (mouth or tongue on someone's vagina, penis or anus);
- Anal intercourse (contact between penis and anus).

How long will it take to collect the blood samples?

The blood sample collection process will take less than 15 minutes. It's important to bring one piece of ID, preferably your provincial health card to your appointment. You may eat and drink before having the samples collected. After the samples are collected, they will be packaged and sent to the following sites:

- The Transplant Centre where DNA testing will be performed to determine compatibility; and
- A Canadian Blood Services regional laboratory where infectious disease testing will occur.

What are my chances of being asked to donate stem cells?

At this point there is simply no way of knowing, as there are many variables involved in finding and selecting a suitable unrelated donor for a patient.

How long do I wait before I find out if I am a match?

The donor selection process can take up to two months.

The Transplant Centre may have identified a number of potential unrelated donors and may wish to review all the test results carefully before making a final selection. The donor selection process can take up to two months.

After approximately two months, you will be given a status update either by telephone or mail. There are three possible outcomes:

1. You may be released from the search. This can occur because you are not the best match for the patient, or the patient's condition may have changed so that a stem cell transplant is no longer an option.
2. You may be asked to remain "On Hold" for this particular patient for a period of time. After the "On Hold" period passes, you will either be released or asked to donate.
3. You may be selected as the best match and will be asked to donate stem cells.

This may seem like a long time to wait to hear if you are a suitable match for a patient. However, conducting these tests is essential in selecting the best donor for the patient, which will ultimately offer the best outcome for the patient.

What happens if I am asked to donate?

If the Transplant Centre decides that you are the best match for this patient, you will begin the work-up process. At this point, you will:

- Be provided with detailed information by a Case Manager who will also guide and support you throughout the entire donation process;
- Meet with a Collection Centre physician who will conduct a physical examination to ensure that you meet all the health criteria for unrelated donors. This physician will also ensure you understand the risks and benefits of this procedure.

If the patient is in urgent need of the transplant, the work-up can be completed in as little as two weeks. Usually, however, the process takes five to seven weeks. You should also be aware that sometimes the patient's condition could change, which can cause your donation to be delayed, sometimes for a number of months, or longer.

Which type of donation will I be asked to make?

The Transplant Centre will request the stem cell product most suitable for the patient. Depending on the request, you may be asked to give bone marrow or peripheral blood stem cells as a first donation, and possibly leukocytes as an additional donation.

What Should or Shouldn't I Do Now?

A request to proceed to "Work-up" may come at any time. To allow us to proceed quickly, please keep these points in mind:

- **Do not** proceed with any whole blood donations until a decision regarding your suitability as a stem cell donor for this particular patient has been made;
- Let us know if you will be out of town for an extended period – one week or greater;
- Advise us of any changes in your health.

The following activities may make you temporarily ineligible to donate stem cells:

- Having a new sexual partner;
- Having sex with someone who may have participated in an activity that is considered high-risk for AIDS or HIV;
- Body piercing;
- Getting a tattoo.

Preparing for Your Donation

When you receive the telephone call advising that you are a match for a patient, you may be ready to pack your bag and head to the nearest hospital to make your donation. While such enthusiasm is welcome, it is important to understand what to expect should you decide to proceed with a stem cell donation. The steps in the process leading up to your donation may be spread over several weeks or even months, depending on the patient's condition, the schedules of the Collection Centre and Transplant Centre, as well as a number of other factors. The preparation for the collection, called the work-up period could be as short as two weeks or as long as several months. The average time for a donor work-up is five to seven weeks.

Remember, your health and the patient's health are our top priorities and will not be compromised for the sake of convenience. If you feel the work-up is taking a long time, or you feel pressured due to time constraints, please talk to your Case Manager.

Now, let's find out what is involved in the work-up process.

Interviews with your Case Manager

During the initial phone call informing you that you have been selected as the best match for the patient, your Case Manager will ask questions about your health which are based upon the blood stem cell regulations and standards. The personal information that you provide during the interview may be shared with your Collection Centre, other stem cell registries and Transplant Centres so that they can determine your suitability to donate. The potential patient of your donation may also be advised of any transmissible disease risk, but your identity will not be made known to them.

The final decision about a donor's suitability is made by the Transplant Centre physician.

A telephone information session will also be scheduled with your Case Manager. This session will focus on ensuring you are fully informed and counselled about the stem cell collection procedure and its potential effects on you. We encourage you to have your partner, spouse or a close friend join you so that you have someone who can ask any questions you may forget, and with whom you can discuss your decision.

Some of the topics that will be discussed include:

- The type of donation being requested;
- Required blood and medical tests;
- Confidentiality policies;
- A review of expenses for which you will be compensated;
- Health insurance benefit for donors;

- The possibility of cryopreservation of a portion of your donation and
- The possibility of a second donation request (see *“Donating More Than Once”*).

We encourage you to note any questions you may have at the end of this guide and to have the list ready for your interview with your Case Manager. Your questions help us to improve the information and enhance the services we provide to donors.

Interview with the Collection Centre Staff

At the Collection Centre you will undergo a complete physical examination.

Everyone involved wants to be sure that your donation will not be of risk to you or the patient. The examination may consist of the following:

- A medical history and general physical examination;
- Blood and urine tests;
- An ECG (electrocardiogram);
- A pregnancy test for females.

The Collection Centre physician will also review the following information with you during your medical assessment:

- The collection procedure
- The risks associated with the procedure including the short-term and long-term side effects from Granulocyte Colony Stimulated Factor (G-CSF)
- The need for anesthetic (bone marrow donors only)
- The possibility of donating autologous blood (bone marrow donors only – (see *“Autologous Blood Donation”*)
- Iron supplements
- The recovery period and side-effects.

At this time, make sure you ask about the following:

- Any medications you might be taking, confirming when and if you need to stop taking the medication;
- Whether you can smoke and drink in the days preceding and following the procedure.

Again, write any questions down in advance. Remember, there is no such thing as a silly question! Use this opportunity to ask questions and make sure you are comfortable with the answers.

Intent to Donate Form

You will be asked to review and sign the *Intent to Donate* form.

This document acknowledges that you had the opportunity to ask questions and review written material about the donation. Your signature on this form indicates your intention to donate. It is **NOT** a consent to the procedure itself. You have the right to decline to donate at any time. **HOWEVER**, once you sign the *Intent to Donate* form, the patient will be notified that there is a willing donor.

Preparatory procedures for the patient, such as radiation and chemotherapy, will begin.

Seven to 10 days before your donation, the patient will begin high-dose chemotherapy and radiation therapy to prepare for the transplant.

If you decline or are unable to donate once this intensive treatment has begun, it is very unlikely that the patient will survive.

For this reason, approximately two weeks before your donation, we ask that you adhere to the following guidelines.

- Advise your Case Manager of any changes to your health (e.g. a cold, flu, etc.);
- Avoid dental work, immunizations or any invasive procedure for two weeks prior to donating;
- Protect your good health and physical condition – avoid unnecessary risks. (See *What Should or Shouldn't I Do Now*).

Blood Donation and Collection

If you are a regular Canadian Blood Services blood donor, thank you. At this time, please stop making any more blood, plasma or platelet donations. As part of the matching process, several blood samples will be collected from you over the next few weeks. **These samples will be used for the following:**

1. **Pre-Collection Samples:** Pre-collection blood samples may be collected and sent to the Transplant Centre for the purpose of crossmatching for blood products needed by the patient after transplant. They may also be used, following the transplant to determine engraftment. If more than 30 days pass from the time these samples were collected until the date of your stem cell donation, additional samples may be collected.

The Transplant Centre may store a portion of your pre-collection blood samples indefinitely for further testing, which may include compatibility testing blood grouping and/or infectious disease testing related to the donation/transplant process.

2. **Infectious Disease Testing:** Your blood will be tested by Canadian Blood Services for infectious diseases such as HIV (AIDS), hepatitis, syphilis, CMV (cytomegalovirus), West Nile Virus (WNV) HTLV, and Chagas' Disease. This testing is performed because these diseases could be transmitted to your patient. Canadian Blood Services may share your infectious disease test results with your Collection Centre, other stem cell registries and Transplant Centres so that they can determine your suitability to make the donation. The potential patient of your donation may also be advised of any transmissible disease risk, in order to make an informed decision about accepting any risk but your identity will not be made known to them. Positive infectious disease test results may also be reported to the appropriate public health authority.

If more than 30 days pass from the time of your first infectious disease tests until the date of your collection, these tests will need to be repeated. You will then be asked to give additional blood samples.

3. **Research Samples:** Some Collection Centres and Transplant Centres are studying the cells and plasma of donors and patients. This research may contribute to increase the number of successful transplants as well as improve the methods of matching unrelated donors and a patient. If the Registry is approached to collect research blood samples from you, we will discuss your participation in the voluntary research. You may either provide informed consent or you may decline to participate in the research.

Once you've made your stem cell donation and feel ready to resume your blood, plasma or platelet donation, please contact a Canadian Blood Services Information Nurse at **1 888 2 DONATE** (1.888.236.6283) to confirm your eligibility and, if applicable, to schedule an appointment.

Autologous Blood Donation

Donors may be required to donate and store their own blood before a bone marrow collection procedure, this is called an autologous blood donation. The Collection Centre physician will discuss the advantages and disadvantages of making autologous donations before donating bone marrow.

Costs Associated with the Donation

The costs associated with your work-up and donation will be covered by Canadian Blood Services, the Transplant Centre or your Provincial Medical Health Plan. Your Case Manager will advise you about expenses for which you may be reimbursed. You will need to submit receipts for these items.

The Donation Experience

Your Hospital Stay

Each Collection Centre has its own hospital policies and procedures. Your Case Manager will provide you with general information. However, when visiting the Collection Centre, ask about their policies and procedures. Whether donating bone marrow or PBSC, most Collection Centres will schedule a same-day stay for the procedure. If you donate bone marrow, some Collection Centres may have you stay overnight before discharging you the following morning.

Tips to Prepare you for your Hospital Stay

- Do not use aspirin, ibuprofen (Motrin, Advil), indomethacin or any other anti-inflammatory drugs for at least two weeks before the collection (these can prolong bleeding).
- Use only acetaminophen products (e.g. Tylenol) for relief from a headache or other minor pain.
- Pack a few carefully chosen items such as loose-fitting clothes (a jogging suit/sweat pants which will accommodate swelling and tenderness at the collection site) to wear home from the hospital after a bone marrow donation. If you are from out of town and are staying overnight, remember to pack personal items such as a comb, brush, slippers, razor, toothpaste and toothbrush.
- Share any concerns with your physicians and nurses. If you have a specific concern about your hospital stay, your symptoms, your comfort, your privacy or some other issue, do not hesitate to let them know. The hospital staff want to help make your donation experience as pleasant as possible.
- Have your Case Manager's telephone number handy and call if you require assistance.
- **Expect unexpected delays.** Although everyone involved would prefer to proceed according to schedule, delays are often unavoidable. You may have to wait to see the physician, wait for the collection to be done, wait to get back to your room after the procedure, wait with the intravenous (IV) line in after the operation or wait to be discharged. Your patience throughout your hospital stay is greatly appreciated.

Bone Marrow Collection

Arrival at the Collection Centre

The hospital assigns you a room, which you may be sharing, and will make your stay as comfortable as possible. Individual hospital policies, as well as your condition, determine the time you stay in hospital.

Just before going to the operating room, you must:

- Wear a hospital gown;
- Empty your bladder;
- Remove all jewellery and hairpins;
- Remove any dentures or partial plates;
- Remove any make-up or nail polish;
- Remove eyeglasses or contact lenses.

You will need an IV line to give you fluids both during and following the collection procedure. The IV will be started in your arm or hand. An IV nurse will usually start it in your room. You will then be taken to the holding area of the operating room.

In the holding area you will wait, along with several other patients waiting for surgery, until the operating room is ready. Once in the operating room, the anaesthesiologist may have you breathe into an oxygen mask. However, you will fall asleep from a medication given to you through your IV.

Anesthesia

Bone marrow collection is a surgical procedure performed under anesthesia. You will receive the anesthetic intravenously, however most patients will also breathe the anesthesia after they are asleep. Because a breathing tube is placed in your throat while you are asleep, you may have a sore throat after you wake up. This will disappear once you start drinking fluids. Nausea and vomiting are also common after general anesthesia. Medication can be given to control and sometimes prevent it. Most anesthesiologists select general anesthesia for bone marrow collection procedures, however some collections are performed using spinal anesthesia, which leaves the donor awake but numb from the abdomen down. Either technique has specific advantages and disadvantages. The ultimate choice of anesthesia will be made by the anesthesiologist in consultation with you and the Collection Physician.

The Collection Procedure

As you lie on your stomach, under anesthesia, the physician will insert a large hollow needle through your skin into the cavity of the iliac crest which sits at the back of the pelvic bone. The bone marrow, a thick, red liquid, is found in the sponge-like interior of the pelvic bone. Depending on the procedure used by the collection team, some physicians will make several small incisions less than two centimetres long through the skin on your lower back. The incisions are small enough that no stitches are needed. Multiple puncture sites are made along the top edge into the cavity of the iliac crest where a hollow needle is inserted. The physician then attaches a syringe to the hollow needle and draws out the bone marrow. The physician repeats this process until the appropriate amount of bone marrow is

collected. The collection team places bandages or dressings over the collection sites. The amount of bone marrow collected depends on the size of the patient and your concentration of bone marrow cells. Much of what is collected is actually blood that is withdrawn along with the bone marrow. The volume of the collection can range from about 500 millilitres up to 1,500 millilitres. This may sound like a large amount, but the average collection represents about five per cent of your total bone marrow. Your body will automatically replenish the donated bone marrow within two to three weeks. The collection procedure usually takes from 45 to 90 minutes.

The bone marrow will then be placed in a sterile blood transfusion bag, transported by a representative from the Transplant Centre, and given intravenously to the patient in a process similar to a routine blood transfusion.

Risks of the Collection

The vast majority of donors recover without incident. Infection can occur at the site of the bone marrow collection or the IV-line insertion. Prompt treatment with antibiotics usually cures the infection. Injury can occur to the bone, nerve, or muscles surrounding the collection site. If any injuries occur, they may require additional medical or surgical treatment or physical therapy. Any surgical procedure carries inherent risks, however for a bone marrow donation; these risks are considered very low.

Recovery Period

When the collection procedure is complete you are taken to a recovery area until the anesthesia wears off. The nurse in the recovery room will check your blood pressure and pulse. The nurse will also check the pressure dressing on your hip-bone. You will not be allowed to eat food or get out of bed until you are fully awake, and the anesthetic has worn off. When you are fully awake, and your condition is stable, you will be taken back to your room. The IV line will remain in your arm or hand until you are drinking well, and your blood pressure is normal. You may feel very sleepy from the anesthetic. The areas from which the bone marrow was removed will probably be sore and tender. A pain medication, such as Tylenol 3, is usually enough to relieve the discomfort. Later in the day, you will be encouraged to walk, eat and drink. During your stay, hospital staff will closely monitor your condition. Be sure to report anything that concerns you. If you experience complications of any sort, the hospital staff are on hand to provide treatment and answer your questions. If you are suffering from ongoing nausea, or if your bandage needs changing, do not hesitate to ask the staff for help.

Discharge from the Hospital

You will be given a prescription for pain medication in case you need it. It is recommended that you refrain from taking a shower or bath for 24 hours following discharge from the hospital. The medical staff will also advise you to shower, rather than soak in the tub for the

next few days. If the bandages fall off, they do not have to be replaced unless you are still experiencing slight bleeding from the collection sites. Should you notice any unexpected redness, tenderness, acute pain or drainage from the collection sites, please contact the Collection Centre and your Case Manager.

If you are discharged from the hospital on the same day as the procedure, you will not be permitted to drive yourself home due to the lingering effects of the anesthetic. Donors usually have a companion drive them home or they travel by taxi. You will also need to have a companion stay with you overnight. If you are from out of town, you will be asked to stay in the vicinity overnight. Depending on the policy at your Collection Centre, you might be asked to return to the hospital the next day for a follow-up assessment to check your hemoglobin (iron level in your blood), to inspect the collection sites, and if necessary, to change the dressings. Sometimes companions are given instructions on how to change dressings.

Recovering from your Bone Marrow Donation

In the days following your donation:

- Keep your legs raised whenever possible;
- Take an iron supplement if recommended and take it with Vitamin C (e.g. orange juice) for better absorption. * See the Guide to Iron Content of some foods listing at the back of the booklet. Be aware that this may cause constipation.
- Increasing your fluid intake and eating high-fibre foods such as grains, fruits and vegetables may be helpful. If constipation occurs, over-the-counter laxatives are effective;
- Take your pain medication as directed;
- Use only acetaminophen products (e.g. Tylenol) as these products will not prolong bleeding;
- You may experience difficulty climbing stairs, lifting objects or bending over; do not push yourself to do any of these activities for several days;
- Do not over-exert yourself; you will be more tired than usual;
- Do not expect to return to your sports activities immediately or to strenuous activities for at least two to three weeks;
- Your bruises may continue to expand for several days after the procedure;
- You may experience muscle pain and fatigue in your back and legs;
- You are likely to be stiff and sore in the lower back area where the bone marrow was collected;
- Plan to take at least a few days off work.

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. Some donors have compared the feeling after donation to the pain experienced after falling on your tailbone; one donor describes it as “more like the muscle pain you feel after doing hard work in the backyard.” Another donor said it was difficult to vacuum for four to five weeks. Some donors found the procedure less painful than they expected.

The recovery period varies considerably from donor to donor. Approximately half the donors experience some of the following:

- Difficulty climbing stairs (for a week or two);
- Nausea and sore throat, especially with general anesthesia (for a day or so);
- Light-headedness (for a day or so).

A limited number of donors experience a headache, vomiting, fever, pain at the site of the IV and pain from the bandage, but these usually subside within a few days. Only a few donors report fainting and prolonged bleeding at the site of the donation. No adverse long-term effects are expected, other than small scars that may form at the bone marrow collection sites.

Your Case Manager and, in some cases, a staff member from the Collection Centre, will contact you by telephone to follow up on your hospital experience. We also strongly encourage that you visit your family doctor approximately two weeks after the bone marrow collection to ensure that your blood counts have returned to an adequate level.

Peripheral Blood Stem Cell (PBSC) Collection

With the administration of granulocyte colony stimulating factor (G-CSF) to a healthy individual, the number of peripheral blood stem cells increases significantly, making PBSC a viable option for transplantation.

Granulocyte Colony Stimulating Factor (G-CSF)

In preparation for your PBSC donation, you must increase the number of stem cells in your peripheral blood. This is done by receiving injections of G-CSF, also known as Filgrastim, every day for four or five days just prior to the scheduled donation date. You will receive a subcutaneous injection of G-CSF in your leg, arm or abdomen. The G-CSF may be given by Collection Centre staff if you live in the same city, by your family doctor, or you may receive instructions on how to self-administer the injections.

Once the required set of injections is complete, a blood test will be performed to ensure there is an adequate number of stem cells in your peripheral blood. If the stem cell count is still too low, you may be asked to receive an additional dose of G-CSF to further stimulate the release of stem cells.

You may experience side-effects from using the G-CSF. These can include:

- Bone pain occurring in the breastbone, shoulder blades, bottom ribs, hips or lower back. The pain is usually mild to moderate and usually lasts for a few days. Increased discomfort may occur three or four days after the injections begin;
- General muscle pain;
- Headaches (usually mild) and flu-like symptoms;
- Redness or pain at the injection site.

Once the injections of G-CSF are completed, the side-effects will diminish or disappear within 24 to 48 hours. If you experience severe pain that is not controlled by medication, contact the Collection Centre immediately.

Arrival at the Collection Centre

Before arriving for your donation, you should eat a light breakfast and avoid caffeinated beverages. Once you arrive at the Collection Centre, you should empty your bladder as you will be unable to get up once you are connected to the apheresis machine.

The Collection Procedure

Your stem cells will be collected using a procedure called apheresis. During the procedure, blood is drawn through a needle and passes through a centrifuge. The centrifuge separates the stem cells from the blood and returns the blood to you through another needle.

Apheresis is a “closed system”, which means your blood will never leave the sterile tubing on its journey through the centrifuge. The apheresis collection usually lasts for three to six hours. In some cases, you may need to be scheduled for two collections (depending on the amount of PBSC requested by the Transplant Centre). These collections would take place on two consecutive days.

Risks of the Collection

The long-term side-effects of G-CSF, the drug used to stimulate the production of stem cells, are unknown at this time.

Apheresis is considered a safe procedure. 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. After your donation, you may experience some localized bruising after the needles are removed.

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.

Recovery Period

When the collection procedure is complete, you may be asked to remain for a few minutes to ensure there is no excessive bleeding when the needles are removed. You may also be encouraged to take a walk and have a light refreshment. Be sure to report anything that concerns you. If you experience any sort of complication, let hospital staff know so that appropriate treatment can be provided.

Discharge from the Hospital

You'll be discharged the same day of the procedure and will not be permitted to drive yourself home. You may have a companion drive you home or take a taxi. If you live alone, you should have someone stay with you overnight. If you're from out of town, you will be asked to stay in the vicinity overnight. Travel restrictions may apply for 24 to 48 hours after the procedure. Check with the Collection Centre regarding their policies.

Recovering from your PBSC Donation

In the days following your donation:

- Use only acetaminophen products (e.g. Tylenol)
- Do not over-exert yourself; you may be more tired than usual;
- Your sports and any other strenuous activities may be restricted – check with the Collection Centre for their recommendations;
- If you have bruises, they may continue to expand for several days after the procedure;
- You should be able to return to work the day after your donation.

Your Case Manager and, in some cases, a staff member from the Collection Centre, will contact you by telephone to follow up on your donation experience.

After the Donation

Emotional Reactions

Your donation may be a life-changing experience for you. In addition to causing the temporary disruption of your daily physical routine, the process may produce intense emotions, ranging from general distress to post-donation elation or blues, to the contemplation of the patient's (or your own) mortality. Professional counselling is available through your family doctor if you are having trouble dealing with the outcome of the transplant. If the transplant is not successful, it can be difficult. As one donor said, "Although I was very sad, I felt good that the transplant had given the patient and his family hope." Another donor commented, "When I got the news, I was immobilized for the rest of the day. It took two weeks before my grief wasn't excruciating."

It is always important to remember the significance and value of your gift. In cases where the patient does not survive, you can be comforted by the fact that you gave the patient's family peace of mind that everything was done to try and save the life of their loved one. The donation in itself is a true gift. A bone marrow donor, Blair Wiley, eloquently describes his donation experience in the following excerpt:

“Why is that a Question?”

*The chance of it [life],
the hope of it,
the realization of it.
All are worthwhile.
To give it a shot.
To go down fighting.
To break free and to tell others.
That it is so worthwhile to be alive!
Only you can provide this for them.
You are growing the magic in your body.
You've been taking care of it for all these years.
Now just give it away!
You'll get over it quickly.
But you'll never be the same.
Just ask any mother.
Just ask any marrow donor.
Mothers give life.
Marrow donors give time.*

Donor Surveys

Your health and well-being are very important to us, and for this reason you will be asked to complete a series of surveys. As part of these surveys, you will be asked to provide personal information. Canadian Blood Services Stem Cell Registry uses these donor surveys to help identify opportunities to improve the quality of services provided by the Stem Cell Registry and Collection Centres.

Please assist us by completing all of the surveys. Your responses are crucial to helping us improve the experience for you and for future donors.

At your one-year donation anniversary you will receive a “One-Year Post-Donation” questionnaire in the mail. You will be asked, among other things, if you wish to have your file re-activated. If you indicate “yes”, and you continue to meet the eligibility criteria, your tissue typing results will be made available for future patients requiring transplants.

Donating More than Once

Some donors have asked if they can donate more than once. If you meet the physical health and age requirements, there is no medical reason why you cannot donate a second time. If the patient fails to engraft or only partially engrafts after the first transplant, or if the patient relapses with the original disease or has complications after the transplant, the Transplant Centre may request a second donation. This may involve bone marrow, PBSC or even leukapheresis (a process in which the donor's white blood cells are collected using an apheresis machine).

If you are approached to consider another donation, you are always free to decline even if you have already provided a donation. Your case manager will review the request with you and encourage you to speak with your family about it.

Additional donations may be required a few months or a few years following the first donation. If at any time after your donation, you wish to have your name removed from the availability list, please contact your Case Manager.

You will never be asked to make a third stem cell donation (bone marrow or PBSC).

Patient Preparation

Before the stem cell transplant, many tests are carried out to ensure that the patient is physically capable of undergoing a transplant. Tests of the patient's heart, lungs, kidneys and other vital organs are used to develop a "baseline" against which post-transplant tests can be compared to determine if any organ functions have been altered.

A patient first undergoes several days of chemotherapy and/or radiation that destroys bone marrow and any cancerous cells and makes room for your healthy stem cells. Before this treatment, a small flexible tube called a catheter is inserted into a large vein in the patient's chest just above the heart. This tube enables the nursing staff to administer drugs and take blood samples painlessly without inserting needles each time.

The dosage of chemotherapy and/or radiation given to a patient during this period is much stronger than dosages administered to those who are not undergoing a transplant. Patients may become weak, irritable and nauseous.

The Transplant from a Patient's Point of View

The transplant takes place one to two days after the end of high-dose chemotherapy and/or radiation. The patient receives the stem cells just as he or she would receive any blood transfusion. Because the transplant is not a surgical procedure, it can take place in the patient's hospital room. Patients are checked frequently for signs of fever, chills, hives and chest pains during the transfusion.

Complications may develop such as:

- Infection;
- Liver disease;
- Bleeding;
- Graft-versus-host disease (a condition in which the donated stem cells (graft) recognize the patient (host) as foreign and begin to attack certain organs such as the skin, liver and intestines);
- Mouth sores (this makes eating and swallowing uncomfortable, and patients often require pain medication such as morphine to reduce the discomfort).

These complications create considerable discomfort that can usually be controlled by medication. In some cases, the patient may not have the energy for walking, sitting up in bed for long periods of time, reading, talking or even watching TV. There can also be tremendous emotional and psychological stress for the patient and his or her family.

First, a patient undergoing a transplant is already traumatized by the news that he or she has a life-threatening disease. While the transplant offers hope for recovery, the prospect of undergoing a long, difficult medical procedure can be frightening, and unfortunately there is no guarantee of success. Secondly, patients undergoing a transplant often feel quite isolated. They are normally kept in a private room, sometimes with special filtering equipment to purify the air because their immune system cannot fight germs at this point. The number of visitors may be restricted, and visitors may be asked to wear gloves, masks, and other protective clothing to stop the spread of bacteria and viruses while visiting. When patients are finally able to leave their room, they may be required to wear a protective mask, gown and gloves as a barrier against infection. They must also avoid crowds and large gatherings to reduce the risk of infection.

Helplessness is a common feeling among stem cell transplant patients and this can also lead to feelings of anger or resentment. For many patients, it is unsettling to be totally dependent on others for survival. The 18 to 25 days spent waiting for the donated stem cells to engraft, for blood counts to return to safe levels, and for side-effects to disappear can also increase the emotional stress for the patient and his or her family. In many cases, it can take as long as a year for the patient's bone marrow to function normally. Medical staff must closely monitor patients during that time. Readmission to the hospital is not uncommon in the first three months. Even patients with a positive outcome may have side-effects and complications for the rest of their lives.

Life After Donation

Chances of a Successful Transplant

Your donation can benefit the patient in different ways depending on the diagnosed disease.

- **Leukemia and other cancers:** The transplant replaces bone marrow destroyed during chemotherapy and/or radiation treatment.
- **Aplastic anemia:** The transplant replaces absent or abnormal bone marrow.
- **Immunodeficiency:** The transplant can provide a brand-new immune system to the patient.
- **Enzyme deficiency:** The transplant provides the missing enzymes or replaces the defective ones.

It is not possible to predict the chances of a successful transplant for your patient. The patient may suffer severe complications from the transplant, or perhaps his or her disease may not be cured by the procedure. You have no control over the success of the transplant, so it is important that you do not feel personally responsible.

Do the Patient and Donor Ever Meet?

As mentioned earlier, there are specific policies concerning the right to privacy of the donor and patient. If program policies permit, and if both parties agree, then the donor and patient identities may be revealed, and the two parties may meet or communicate directly.

In some situations, both the donor and the patient have been very eager to meet. Often, however, the patient declines to have personal contact with the donor, or vice-versa. Some patients prefer to wait several years because their condition may still be unstable, or it may just be too overwhelming for them to speak with the person who has offered them a second chance at life.

Don't forget that life after a transplant can be both exhilarating and worrisome. On the one hand, it is wonderful to be alive after being so close to death. However, there is always the worry that relapse will occur. Sometimes words or events can trigger unpleasant memories of the transplant experience long after the patient has recovered. It can take a long time for the patient to come to terms with these difficulties. We mention this because a few donors have expressed frustration that they are not permitted to make contact with their patients sooner. Both the donor and patient may feel a special bond even though there has been no direct contact. There may be strong emotions associated with the donation process. We caution donors to remember that an individual's desire for privacy must be honoured.

If the patient dies and his or her family indicates that they would like to exchange information with you, and if program policies permit, you may be contacted by Stem Cell Registry staff to see if you would like to release your personal information. Please be aware that most stem cell donors and patients never meet.

Please note: *Certain registries and Transplant Centres have policies that NEVER permit the exchange of personal information between donor and patient.*

Privacy / Access to Your Personal Information

Throughout this guide, we have described the collection, use and disclosure (sharing) of your personal information for the purpose of voluntarily donating your stem cells to an unrelated patient who needs them in the treatment of a serious illness or disorder.

Canadian Blood Services may collect, use or disclose your personal information for additional purposes as follows:

- We may use your personal information to contact you about participating in voluntary research, to enquire about your health after the donation, or to send you post donation surveys.
- In the event of accidental exposure to your blood, we may access your test results to determine risk to that individual.
- We may use your personal information, such as a positive test results for a transmissible disease and/or your responses to the health assessment questionnaire, to protect the safety of blood, blood products, stem cells and the blood supply, and for that purpose we may also share it with other Canadian blood operators.
- We may use your personal information to comply with legal and regulatory requirements or to fulfill any other purposes prescribed by law.
- For the purpose of protecting your health, we tell your physician that you have been chosen to donate, and we may review aspects of your medical history with him or her. We also inform your physician once you have donated.
- If you require follow-up tests or treatment, following donation, we may request that your physician share with us specific information about your health from your follow-up appointments.
- On your request, we will share information explaining your planned absence or need for any special considerations with your employer.
- To make travel arrangements, arrange for you to have medical care before or after the donation, or pay expenses incurred, we may need to use your personal information or share certain personal information with travel agents, nursing care providers or others.
- We may also share your personal information with regulatory or accreditation bodies, provided they agree to keep it confidential, or with others as authorized or required by law.

Canadian Blood Services is committed to protecting the privacy and security of your personal information and respects your right to access and request correction of your personal information.

How to Contact Us:

You may contact our Privacy and Access to Information Office for more information about our privacy and access practices, or to request access to or correction of your personal information as follows:

In Writing:

Canadian Blood Services
Privacy and Access to Information Office
1800 Alta Vista Drive
Ottawa, ON K1G 4J5

Website: www.blood.ca

By phone:

1.613.739.2483
1.877.262.9191 (toll free)

By e-mail:

Privacy Office - privacy@blood.ca
Access to Information Office - ati@blood.ca

Is it Worth it?

The reasons for wanting to donate bone marrow or PBSC are as varied as the donors themselves. But there are common traits shared by all potential donors. Potential donors are caring, compassionate individuals who are prepared to offer help to those around them rather than looking the other way.

A quote from the mother and father of a six-year-old boy who received an unrelated bone marrow transplant:

“When all else has failed and you feel there is no hope, there is the Canadian Blood Services Stem Cell Registry. For our family it meant a chance to keep our son with us. It gave us back our hope and it gave us the strength to believe. Then it gave us our miracle. It gave us a perfect match and it gave him a new life. Most of all, it gave us a happy, healthy boy who has an appreciation for life greater than his years’ who teaches us to love life and enjoy each day to its fullest. Our family and friends, though we don’t know the donor, are sure we will never receive a greater gift in our lifetime than the one a perfect stranger gave to Dylan, for he or she gave Dylan life.”

As you have read, your donation is a potentially lifesaving procedure for the patient, but how will it affect you? One donor expressed these sentiments:

“Most people never have the chance to try and save someone else’s life... to run into the burning building, scale a mountain, crawl into a car wreck. Donating stem cells gave me the feeling that maybe I am that kind of person. Someone who cares about their fellow man. Stem cell transplants in general are not front-page news. I think most of the people who

volunteer and never match are heroes. They are reaching out to their neighbours and saying, 'I do care'."

In 1997, a bone marrow donor, Blair Wiley, summed up his feelings about the act of donating in a heartfelt piece entitled "Who's Better Off?" We have included some excerpts.

"Who's Better Off?"

When you donate bone marrow, who's better off?

Sure, you'll give someone else a chance at life.

This may last a short time or a long time.

*But every precious moment, every day, week, month,
or year is so worth it to them and to their families.*

But what about you, the donor?

What did you have to give up to give someone borrowed time?

*You get one heck of a medical adventure,
if you want to look at it like that.*

*You get to experience the greatest thrill
known to mankind – the thrill of helping.*

*You get the certainty-for-life that you did a wonderful,
miraculous thing, whether it was just to give some hope for a
while or to give life for years on end, or somewhere in between.*

You are about to give a very special gift ... the gift of hope.

On behalf of the Canadian Blood Services Stem Cell Registry and the patients we serve,
THANK YOU!

A Guide to the Iron Content of Some Foods

The Collection Centre may recommend that you increase the amount of iron in your diet before and after your donation.

ALTERNATIVES APPROXIMATE IRON CONTENT

Pork liver (cooked) 90 g (3 oz)	26.1 mg
Beef kidney (cooked) 90 g (3 oz)	11.8 mg
Beef or chicken liver (cooked) 90 g (3 oz)	8 mg
Baked beans with pork 250 ml (1 cup)	4.9 mg
Chili with beans 250 ml (1 cup)	4.5 mg
Corned beef 90 g (3 oz)	3.9 mg
Liverwurst 60 g (2 oz)	3.2 mg
Pumpkin or sesame seeds 50 ml (1/4 cup)	3.2 mg
Beef, pork, veal, ham (roasted) 90 g (3 oz)	3 mg
Split peas (cooked) 125 ml (1/2 cup)	2.4 mg
Chick peas (cooked) 125 ml (1/2 cup)	2.2 mg
Sunflower seeds 50 ml (1/4 cup)	2 mg
Almonds 50 ml (1/4 cup)	2 mg
Lentils (cooked) 125 ml (1/2 cup)	1.7 mg
Chicken or Turkey (roasted) 90 g (3 oz)	1.5 mg
Egg 1 large	1.1 mg
Prune juice 125 ml (1/2 cup)	5.5 mg
Dates (pitted) 125 ml (1/2 cup)	2.8 mg
Prunes (cooked) 125 ml (1/2 cup)	2.4 mg
Spinach (cooked) 125 ml (1/2 cup)	2.1 mg
Apricots (dried) 3 medium	1.4 mg
Broccoli (cooked) 180 g (1 stalk)	1.4 mg
Tomato juice 125 ml (1/4 cup)	1.2 mg
Raisins 50 ml (1/4 cup)	1 mg
Brussel sprouts 125 ml (4)	.9 mg
Strawberries (fresh) 125 ml (1/2 cup)	.8 mg
Blueberries (fresh) 125 ml (1/2 cup)	.7 mg
Cream of wheat (enriched) 125 ml (1/2 cup)	7.9 mg
Whole grain & enriched dry cereal 200 ml (3/4 cup)	4.5 mg
Pasta (cooked) 250 ml (1 cup)	2.4 mg
Granola 125 ml (1/2 cup)	1.8 mg
Rice (cooked) 250 ml (1 cup)	1.4 mg
Bran muffin or date square 1	1.3 mg
Whole grain or enriched bread 2 slices	1.2 mg
Brown rice 250 ml (1 cup)	.9 mg
Oatmeal (cooked) 125 ml (1/2 cup)	.8 mg

Questions You Would Like to Ask Your Case Manager and/or the Collection Centre:

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