



Stem
cell

Donor
Registry

GUIDE FOR THE
POTENTIAL DONOR



HÉMA-QUÉBEC

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INTRODUCTION

According to your tests results, it is possible that you might be compatible with someone who needs a bone marrow transplant. This is a unique opportunity for you to offer your help.

You might be asked to donate some of the healthy stem cells in your bone marrow to someone who needs them in the treatment of a serious illness. Stem cell transplants have become an increasingly important treatment for a variety of diseases. In 1989, the year the Registry was established, only 17 unrelated bone marrow donations were performed in Canada. Today, thanks to advances in medicine and the growth of the Registry's donor database, well over 100 Canadians donate bone marrow each year.

Some donors from the Registry may occasionally be asked to donate stem cells using another donation procedure called stimulated Peripheral Blood Stem Cell (PBSC) collection. This type of donation is discussed on page 11.

As you may know, locating compatible donors can be a scrupulous process. There is a less than 30% chance that a potential transplant patient has a brother or sister able to donate stem cells. The search for an unrelated donor is even more challenging. Thanks to your generosity, a transplant patient might be given a very special second chance.

This guide gives you an idea of what to expect should you decide to donate. In the following pages you will find information on:

- The steps taken by a donor in preparation for the donation procedure
- The bone marrow or PBSC collection procedure
- The recipient's preparation and recovery
- The post-donation period

There is quite a bit of information included in this guide, so please take your time to read it carefully. If possible, review this guide before the teleconference with your counsellor.

First, let's explain a few terms that you will encounter in this guide:

Blood stem cells: Cells in the body that can grow into red cells, white cells or platelets. These cells are found primarily in bone marrow, and in smaller numbers in the bloodstream.

Collection: Process of collecting stem cells through bone marrow or PBSC donation.

Collection centre: The facility where you will go to make your bone marrow or PBSC donation. We have two designated collection centres in Québec: C.H. Maisonneuve-Rosemont in Montreal and the C.H.A.Enfant-Jésus in Quebec City. Your collection procedure will be scheduled at the centre closest to your home.

Counsellor: The person from Héma-Québec trained especially for the Registry who will guide you through the entire process.

Transplant centre: The hospital where the patient is being treated. It may be in Canada or in another country.

Work-up: The process used to prepare you for the collection of bone marrow or PBSC.

PREPARING FOR YOUR DONATION

The steps leading up to your donation may be spread over several weeks or even months. It is called the work-up period. The average time for a donor work-up is five to seven weeks.

Remember, your health and the potential recipient's health are our top priorities and will not be compromised for the sake of convenience. If the work-up is taking what you consider to be an exceptionally long time, or if you feel pressured due to time constraints, please talk with your counsellor.

If you are chosen to give your stem cells, let's find out what will be involved in the work-up process.

DONOR INTERVIEW WITH THE COUNSELLOR

Now that you are a potential donor for a patient, you will be asked to participate in an interview with the Héma-Québec counsellor. This interview, which will be conducted by telephone, helps ensure you are fully informed and counselled on the 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 forget and with whom you can discuss your decision.

Here are some of the topics that will be discussed:

- Blood and medical tests
- Confidentiality policies
- A review of expenses for which you will be compensated
- Health insurance policy for donors from the Registry
- The possibility of a second donation request.

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 counsellor. Please feel free to ask any questions during this interview or at any other point throughout the work-up process. Your questions help us improve our donor information and services. Once the interview is complete, we will suggest that you take a few days to think about all you have heard before you decide whether or not you wish to proceed.

PHYSICAL EXAMINATION AND INTERVIEW WITH THE COLLECTION CENTRE STAFF

If you decide to continue with the process, your Héma-Québec counsellor will work with you to schedule a complete physical examination at the Collection centre. The examination will consist of:

- A medical history and general physical examination
- Blood and urine tests
- An ECG (electrocardiogram) and a chest X-ray for donors aged 40 and over.

If you are a female donor, it is important that you inform the collection centre physician if you may be pregnant.

The collection centre physician will meet you in person to review the collection process. He will be discussing:

- The need for anesthetic (bone marrow donors only)
- The collection procedure
- The risks associated with the procedure
- The possibility of autologous blood donation (bone marrow donors only (see "Autologous Blood Donation" on page 5)
- Iron supplements, which kind is recommended, if and when you should take them and for how long
- The recovery period and side effects.

If you are being asked to donate bone marrow, you will probably have questions about hospital procedures, such as the admitting process, which ward you will be staying on before and after the procedure, visiting hours, how you will feel after the anesthetic and how the intravenous line feels. You should discuss these and any other related questions with the collection centre staff.

Do not forget to:

- Ask about any medications you might be taking, confirming when and if you need to stop taking the medication
- Ask whether you can smoke and drink in the days preceding and following the procedure, if applicable
- Ask about the timing of the procedure and menstrual cycles, if applicable.

Again, write any questions down in advance. Do not feel that some questions are too foolish. Now is your chance to ask.

INTENT TO DONATE FORM

After you complete your physical examination and interviews, you will be asked if you wish to proceed with the donation process. If you answer yes, you will sign the INTENT TO DONATE form. This form acknowledges that you have had the opportunity to ask questions and review written material about the donation. Your signature on this form indicates your intent 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 potential recipient will be notified that there is a willing donor. Preparatory procedures for the patient, such as radiation and chemotherapy, will begin.

Seven to ten days before your donation, the recipient 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 recipient will survive.

For this reason, approximately two weeks before your donation, we recommend that you adhere to the following guidelines. Advise us of any changes in your health (e.g., a bad cold)

Remember that certain activities may put you at risk for transmissible diseases and affect your eligibility to donate. These include:

- Having a new sexual partner
- Having sex with someone who is considered at high risk for AIDS or other transmissible diseases
- Body piercing (including ear piercing)
- Getting a tattoo.

Protect your health and physical condition by avoiding unnecessary risks.

BLOOD DONATION AND COLLECTION

Once you have been contacted as a possible bone marrow match, we ask that you stop making any more blood/plasma/platelet donations. As part of the process to match donors with recipients, several blood samples will be collected from you over the upcoming weeks.

Once you have donated your marrow and you feel you are ready to resume donating blood/plasma/platelets, please contact your blood donor centre for information.

The following is a list of the tests and requirements for your blood samples:

Pre-collection samples: Many donors are asked for pre-collection samples of blood. When such specimens are requested, they are usually for the purpose of cross-matching for blood products needed by the recipient after transplant. Blood samples may also be used to determine if your stem cells have engrafted or "taken" in the recipient after the transplant.

Transmissible disease testing: Your blood will be tested for infectious diseases such as HIV (AIDS), hepatitis, syphilis, CMV (cytomegalovirus), WNV (West Nile virus) and HTLV (human T-cell lymphotropic virus). All of these tests are done in strict confidence. The testing is performed because these diseases could be transmitted to your recipient. If more than 30 days pass from the time of your first transmissible disease test until the date of your collection, these tests will need to be repeated. You will then be asked to give another blood sample. Positive results will be reported to the public health department where required by provincial law.

Research samples: Some transplant centres have research projects. If the Registry is approached to collect research blood samples from you, we will advise you accordingly. You may either provide informed consent or you may decline to participate in the research.

AUTOLOGOUS BLOOD DONATION

The collection centre physician will make a recommendation, if necessary, regarding your need for an autologous blood donation. Generally, the larger the potential recipient, the larger the amount of bone marrow you will be asked to donate and the more important an autologous blood unit would be for the collection procedure. If you decide to donate an autologous unit of your blood before the bone marrow collection, it will be carefully labelled and stored until after the donation. Following the bone marrow collection you will receive your own stored blood through a transfusion.

COSTS ASSOCIATED WITH THE DONATION

The costs associated with your work-up and donation will be covered by the Registry (Héმა-Québec), the transplant centre and your provincial medical service or health plan (in most provinces). Your Héმა-Québec counsellor will advise you about expenses for which you may be reimbursed. You will need to submit receipts for these items.

The Registry does not routinely reimburse donors for lost wages. We will supply you with a letter to your employer explaining your important role in the upcoming transplant. Many organizations have provided paid time off for the bone marrow donations. Ask your employer if your company has a policy, or would consider a policy, for such donations.

CONFIDENTIALITY

The Canadian Unrelated Bone Marrow Donor Registry and its international registries and transplant centres maintain strict donor and patient confidentiality standards. During the interview with your Héმა-Québec counsellor, these policies will be discussed with you.

Please be aware of the following:

- Specific information about your recipient will not be made available prior to the donation.
- Exchanging or sending photographs is not permitted.
- Correspondence may be shared following your donation, but it must not contain the donor or recipient's name, city or country of residence, employer, or any other identifying information including a personal signature. Your counsellor can facilitate the exchange of correspondence after the donation.

Please note: Some transplant centres have policies that NEVER permit the exchange of any correspondence between donor and recipient.

- Media interviews about your donation may compromise confidentiality. The Registry has a policy regarding such interviews that will be reviewed with you during the work-up process. To protect the confidentiality of patients and donors, we ask that donors respect this policy and decline media interviews before and after the donation. If you have questions, please do not hesitate to contact your Héმა-Québec counsellor.

- Information on the recipient's condition or direct communication between donor and recipient will not be permitted until at least one year after the donation for Canadian and American donors and recipients, and then only if both parties agree to it in writing.

Please note: certain registries and transplant centres insist on a longer waiting period (e.g. two years); others never permit the release or exchange of personal information.

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

Please note: Once a donor is found, some transplants never take place.

Although you prepare both physically and emotionally to donate, donations are occasionally cancelled. This can happen for many reasons.

- Your recipient's condition may deteriorate, no longer making him an acceptable candidate for transplant; in some cases, the recipient may pass away before the transplant can take place.
- Your recipient 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.

BONE MARROW COLLECTION

After you complete the steps described in the previous section, and your potential recipient's condition is ready to receive your healthy bone marrow, you will prepare for your hospital stay. As mentioned earlier, your bone marrow will be collected at the collection centre nearest your home, either at the C.H. Maisonneuve-Rosemont for the Montreal area or the C.H.A. Enfant-Jésus for the Quebec City area. Once the donation has taken place, a representative of the transplant centre will transport your bone marrow by hand to the patient who may be in Canada or another country.

YOUR HOSPITAL STAY

Each collection centre has its own hospital policies. You can expect to be admitted to hospital mid-to-late afternoon on a weekday. You will spend the night in hospital and your bone marrow will be collected early in the morning. You will usually be discharged the day after the collection.

The hospital assigns you a room and will attempt to make your stay as comfortable as possible. You may have a roommate during your stay. Individual hospital policies, as well as your condition, determine the time you will 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 makeup or nail polish
- remove eyeglasses or contact lenses.

You will need an intravenous line (IV) to give you fluids both during and following the collection procedure. The IV will be started in your arm or hand by a nurse 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.

ANESTHESIA

Bone marrow collection is a surgical procedure performed under anesthetic. You will have to fast for at least 8 hours before the procedure. With general anesthetic you are unconscious and have no awareness of the surgical procedure or any other sensations. You will receive the anesthetic intravenously; however, most patients will also breathe the anesthetic after they are asleep. Because a breathing tube is placed in your throat while you are asleep, you may have a sore throat when you awake. This will disappear once you start to drink fluids. Nausea and vomiting are also common after general anesthetic. Medication can be given to control and sometimes prevent it. Most anesthesiologist select general anesthetic for bone marrow collection procedures, however some collections are performed using spinal anesthetic, which leaves the donor awake but numb from the abdomen down. Either technique has specific advantages and disadvantages.

The ultimate choice of anesthetic will be made by the anesthesiologist in consultation with you and the collection centre physician. Do not be afraid to state your own preference for anesthetic. During the collection procedure, your vital signs, including your heart rate and rhythm, blood pressure, temperature, breathing will be monitored. Current monitoring methods make anesthesia safer than ever. The risk of serious complication resulting from anesthesia is only one in 10,000. Some difficulties may include bradycardia (a slowing of the hearth rate), apnea (temporary interruption of breathing) or hypotension (very low blood pressure) during donation. Prompt attention to these abnormalities by the anesthetist has consistently produced immediate reversal and recovery. Temporary high fevers, allergic reactions or inability to urinate may also result from anesthesia. However, these reactions are uncommon and the risks of anesthesia are considered to be minimal. Do not hesitate to ask questions to the anesthesiologist.

THE COLLECTION PROCEDURE

As you lie on your stomach, under anesthetic, the physician will insert a large hollow needle through your skin into the cavity of the rear hip-bone (iliac crest) where a large quantity of bone marrow is located. 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 an inch long (one to two centimetres) through the skin on your lower back. The incisions are small enough that no stitches are needed. Other physicians simply insert a needle into the skin without making incisions. In either case, a hollow needle is inserted and multiple puncture sites are made along the top edge of the hip-bone (just above the buttocks, approximately where your belt would lie). 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 average amount of blood and bone marrow collected is 1,000 millilitres or one litre. However, the volume of the collection can range from about 500 millilitres (if your potential recipient is a child) up to 1,500 millilitres. This may sound like a large amount, but the average collection represents about 5% 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.

Following the collection, the bone marrow cells will first be filtered to remove any fat and bone particles and then mixed with an anti-coagulant. The bone marrow will then be placed in a sterile blood transfusion bag, transported by a representative of the transplant centre, and given intravenously to the recipient in a process similar to routine blood transfusion.

RISKS OF THE COLLECTION

The Collection centre physician will explain to you the risks of the collection and will answer your questions or concerns. However, the following is some general information regarding the 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. However, antibiotics may produce adverse reactions or hypersensitivity.

Tissue injury can occur to the bone, nerves, or muscles surrounding the collection site. Such injuries 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. It is estimated that there is a 0.1 to 0.3% chance (1 to 3 in 1,000) of experiencing a major complication and a 6 to 12% chance of a less severe complication.

RECOVERY PERIOD

When the collection procedure is complete, you are taken to a recovery area until the anesthetic 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 or get out of bed until you are wide 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. Pain medication, such as Extra Tylenol, 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 is on hand to provide treatment and answer your questions. If you are suffering from ongoing nausea, or if your dressings need 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 not to soak in the tub for the next few days, and to shower instead. If the dressings 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 Héma-Québec counsellor.

RECOVERING FROM YOUR BONE MARROW DONATION

In the days following your donation:

- Keep your legs raised whenever possible.
- Take an iron supplement, if recommended. 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 before you absolutely need it.
- Use only over-the-counter acetaminophen products for pain medication 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 a recovery period that could last 2 weeks.

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. Some donors found the procedure less painful than they had 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 anesthetic (for a day or so)
- Light-headedness (for a day or so).

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

Your counsellor and, in some cases, a staff member from the collection centre will telephone you to follow up on your hospital experience. We also suggest that you return to your family doctor approximately two weeks after the bone marrow collection to ensure that your blood counts have returned to an adequate level.

You should also be aware that emotional reactions may occur for several months, especially if the transplant is not successful and you receive bad news about your recipient.

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. Because of the intensity of emotions a donor may experience, donation may not be appropriate for everyone. Professional counselling is available for any donor who is having trouble dealing with the outcome of the transplant.

It is always important to remember the value of your gift. In cases where the recipient does not survive, you can be comforted by the fact that you gave the recipient's family peace of mind that everything was done to try and save the life of their loved one. This in itself is a true gift.

DONOR SURVEYS

Your health and well-being are our greatest concern and for this reason you will be asked to complete a series of surveys throughout the donation process. A list of these surveys follows:

- **Pre-donation:** One questionnaire to be completed at least one week before you are scheduled to donate.
- **Immediately post-donation:** One questionnaire to be completed within 48 hours of donating (via telephone) to monitor your health.
- **Second donation:** One questionnaire asking whether or not you would like to be contacted if your recipient requires an additional donation.
- **Two weeks post-donation:** One questionnaire to be completed two weeks after the donation to monitor your recovery.
- **Recovery:** If you are not feeling back to normal, a follow-up questionnaire (via telephone) until you are fully recovered and have resumed your pre-donation level of activity.

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

You could be asked to consider a second donation for your original recipient at any time after your donation. However, you will not be approached to donate for a different patient during the first year after the donation as your file will be "on hold" for the original patient.

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.

STIMULATED PERIPHERAL BLOOD STEM CELL COLLECTION

Until the past few years, bone marrow was the most common source of stem cells for transplantation. However, there are other sources of stem cells that are beneficial to patients. One of these is stimulated Peripheral Blood Stem Cells. (PBSC)

PBSC refers to stem cells that circulate in the bloodstream. Under normal circumstances, there are too few of these cells to provide a useful quantity for transplant purposes. However, it has been shown that the administration of granulocyte colony stimulating factor (G-CSF) to healthy individuals increases the number of cells in the bloodstream where they can then be collected in large quantities.

It appears that in some clinical situations, a stimulated PBSC transplant offers advantages over a bone marrow transplant. In such cases, the donor may be asked to consider such a request from the patient's transplant physician. PBSC donations may also be requested in situations where a donor is asked to donate a second time to the same patient. For example, if the second donation is requested soon after the first donation, the donor's bone marrow might not provide enough stem cells, hence the request for a stimulated PBSC donation.

The procedure used to collect PBSC is different than the procedure used to collect bone marrow. You will receive a subcutaneous injection of G-CSF every day for four or five days. These injections will be given to you in your leg, arm or abdomen. The G-CSF can be administered by collection centre staff, by your family doctor or by yourself, reducing the need for disruption to your schedule during the period leading up to the collection itself. If your family doctor will administer the injections, you will be given a prescription for G-CSF during your meeting with collection centre staff.

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.

The stem cells will be collected using a procedure called apheresis. During the procedure, blood is drawn through a needle in the donor's arm and passed through a centrifuge. The centrifuge separates the stem cells from the blood and returns the blood to the donor through the same needle. Apheresis is a closed-system procedure, which means the donor's blood will never leave the sterile tubing on its journey through the centrifuge. The apheresis collection usually lasts three to five 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.

RECOVERING FROM A STIMULATED PBSC DONATION

The apheresis procedure used to collect the PBSC is a safe and commonly used technique. Héma-Québec plasma donors may undergo apheresis up to 26 times a year. The long-term side effects (more than 10 years) of G-CSF, the drug used to stimulate the production of stem cells, are unknown at this time. The collection centre physician performing the apheresis will provide all the information and answer your questions. You will sign a consent form agreeing to the procedure at the hospital. Possible side effects related to both procedures (bone marrow collection and PBSC collection) are listed in the following table:

SIDE EFFECTS

BONE MARROW

Fatigue
Pain at collection site (hip bone)
Pain walking
Back pain
Sore throat
Pain sitting
Pain climbing stairs
Nausea
Headache
Pain at IV site
Vomiting
Fever
Bleeding at collection site
Fainting

Other minor side effects were reported including hypotension, syncope, severe post spinal headache, excess pain, minor infection. Most donors feel completely recovered within two to four weeks.

Major and life-threatening complications are very rare, with a frequency estimated at 0.1 to 0.3%. Life-threatening complications that have been reported include nonfatal cardiac arrest, aspiration pneumonia, pulmonary embolus, intravenous thrombosis, ventricular tachycardia and cerebral infarction. The main risk categories are those associated with anaesthesia, infection, mechanical injury, transfusion and other risks associated with conditions previously undiagnosed in the donor.

PBSC WITH G-CSF

Bone pain
Headache
Myalgia
Fatigue
Insomnia
Nausea
Other flu-like symptoms
Sweating
Anorexia
Chills
Fever
Local reaction at injection site
Skin reaction
Vomiting
Allergy
Increasing of spleen volume was observed in 10 to 15% of cases.

Common side effects are most of the time related to the G-CSF. Bone pain, the most common, is usually mild to moderate, A painkiller like Extra Tylenol is usually enough to calm the discomfort. On the haematological side, there is a decrease on the platelets and white cells count. Everything comes back to normal approximately after a month.

Major side effects are rare and include stroke, anaphylaxis, arterial thrombosis, idiopathic thrombocytopenia purpura and splenic rupture (6 cases reported in the literature, no death).

The apheresis procedure can also cause side effects and minor complications. The most significant of these is that inadequate venous access may require placement of a central line in a minority of donors. Complications from central line placement are uncommon, but include pneumothorax, hemorrhage and infection.

RECIPIENT PREPARATION

As soon as you accept to donate your stem cells, many tests are carried out to ensure that the intended recipient is physically capable of undergoing a transplant. Tests of the recipient's heart, lungs, kidneys and other vital organs are also used to develop a baseline against which post-transplant tests can be compared to determine if any organ functions have been altered.

A recipient first undergoes several days of chemotherapy and/or radiation that destroy bone marrow and cancerous cells to make room for your healthy stem cells. Before this treatment, a small flexible tube called a catheter is inserted into a large vein in the recipient'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 recipients during this period is much stronger than dosages administered to those who are not undergoing a transplant.

THE TRANSPLANT FROM A RECIPIENT'S POINT OF VIEW

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

Complications may develop such as:

- Infection
- Liver disease
- Bleeding
- Graft versus Host Disease (a condition in which the donor's stem cells recognize the recipient 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, walking, sitting up in bed for long periods of time, reading, talking or even watching TV may require more energy than the recipient has.

There can also be tremendous emotional and psychological stress for the recipient and their family. First, a patient undergoing a transplant is already traumatized by the news that they have 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 recipients are finally able to leave their room, they must be required to wear gloves, a mask and a gown 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 bone marrow and PBSC transplant recipients, and this can lead to further feelings of anger or resentment. For many recipients, it is unsettling to be totally dependent on others for survival. The 18 to 25 days spent waiting for a donated tissue to engraft, blood counts to return to safe levels and side effects to disappear can also increase the emotional stress on the recipient and their family. In many cases, it can take as long as one year for the recipient's bone marrow to function normally. Medical staff must closely monitor recipients during that time. Readmission to 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.

CHANCES OF A SUCCESSFUL TRANSPLANT

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

Leukemia and other cancer

The transplant allows higher doses of chemotherapy to be given to the patient, offering a better chance of eliminating the disease.

Aplastic anemia

The transplant replaces absent or abnormal bone marrow.

Immunodeficiency

The transplant can provide a brand new immune system for 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 potential recipient. The recipient may suffer fatal complications from the transplant or perhaps their 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.

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.

During the 12 months following your donation, you will be temporarily excluded from the Registry. If the recipient fails to engraft, relapses with the original disease or has complications after the transplant, the transplant centre may ask you for a second donation. The Héma-Québec counsellor will advise you. You are always free to reconsider the request and to decline.

DO THE RECIPIENT AND DONOR EVER MEET?

As mentioned earlier, there are specific policies concerning the right to privacy of the donor and recipient. When you complete the one-year post donation survey, you will be asked if you would like to be sent a "Consent to Release Donor's Personal Information" form (if this is allowed by the transplant centre's policy).

If program policies permit, and if both parties sign consent forms to release personal information, then the donor and recipient's identities may be revealed and the two parties may meet or communicate directly.

In some situations, both the donor and the recipient have been very eager to meet. Often, however, the recipient declines to have personal contact with the donor, or vice versa. Some recipients 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 in life.

Do not forget that life after a transplant can be both exhilarating and worrisome. On the other hand, it's 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 recipient has recovered. It can take a long time for the recipient to come to terms with these difficulties. We mention this because a few of our donors have expressed frustration with the fact that they are not permitted to make contact with their recipient sooner. Both the donor and recipient may feel a special bond even though there has been no direct contact. There may be strong emotions associated with the donation process. However, we caution donors to remember that an individual's desire for privacy must be honoured.

If the recipient dies and his family indicates that they would like to exchange information with you, and if program policies permit, you may be contacted by Registry staff to see if you'd like to release your personal information.

In Canada, approximately 25% of donors have received correspondence from their unrelated recipients. Please be aware that most bone marrow donors and recipients never meet.

IS IT WORTH IT?

The reasons to donate stem cells are as varied as the donors themselves. But there are common traits shared by all potential donors. Like you, they are caring, compassionate individuals who are prepared to offer help to those around them rather than looking the other way.

In the name of all patients waiting for a stem cell transplant, we thank you for your generous gift.

TIPS TO PREPARE YOURSELF FOR YOUR HOSPITAL STAY

- Do not take 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 (Tylenol) for relief from a headache or other minor pain.
- Past bone marrow donors suggest packing a few carefully chosen items such as loose fitting clothes (jogging suit/sweat pants to accommodate swelling and tenderness at the collection site) to wear home from the hospital. Donors from out of town who are staying overnight should also pack personal items such as a comb, brush, slippers, razor, toothpaste and toothbrush.
- Share any concerns with your physician and nurses. If you have a specific concern about your hospital stay, symptoms, comfort, privacy or any other issue, do not hesitate to let them know. They want to help make your bone marrow donation experience as pleasant as possible.
- Have your Héma-Québec counsellor's phone number handy and do not hesitate to call should you require assistance.
- Expect unexpected delays. Although everyone involved would prefer to proceed according to schedule, delays are often unavoidable. There may be a wait to see the physician, for the collection to be done, to get back to your room after the procedure, with the IV in after the operation or to be discharged. Your patience throughout your hospital stay is greatly appreciated.
- Bring some reading material to help pass the time during your recovery.
- If you are feeling nauseous, ask the nurse for medication to relieve your symptoms.
- Ask the nursing staff for assistance if you want to get up and walk around after the donation. Although you might be stiff and sore, many donors report feeling better if they are able to move around. Do not get up for the first time without assistance as your blood pressure may be low following surgery and you may feel faint.
- You may want to have a pillow in the car to cushion your lower back on the trip home.
- Have ice packs available for your arrival back home
- **CELLULAR TELEPHONES ARE NOT PERMITTED IN THE HOSPITAL ENVIRONMENT.**

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 a bone marrow collection.

<u>MEAT AND ALTERNATIVES</u>	<u>APPROXIMATE IRON CONTENT</u>	
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 g
Chilli 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
<u>FRUITS AND VEGETABLES</u>		
Prune juice	125 mL (1/2 cup)	7.9 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 (1/2 cup)	1.2 mg
Raisins	50 mL (1/4 cup)	1 mg
Brussels sprouts	125 mL (4)	0.9 mg
Strawberries (fresh)	125 mL (1/2 cup)	0.8 mg
Blueberries (fresh)	125 mL (1/2 cup)	0.7 mg
<u>BREADS AND CEREALS</u>		
Cream of wheat (enriched)	125 mL (1/2 cup)	7.9 mg
Whole grain and 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)	0.9 mg
Oatmeal (cooked)	125 mL (1/2 cup)	0.8 mg