



NATIONAL MARROW DONOR PROGRAM®

Creating Connections. Saving Lives.®



Now That You Are a Match

What you need to know about becoming a donor

Dear donor:

Thank you for considering becoming a marrow or blood cell donor.

Becoming a donor is a serious commitment. This notebook will explain the process so you can make an informed decision about whether or not you will donate.

This notebook will explain:

- Why you have been called
- Various steps and blood tests involved
- Your time commitment
- Risks and side effects
- Two different ways you may be asked to donate
- Resources available to you

Your National Marrow Donor Program® donor center coordinator will work with you to answer your questions.

You make the final decision about becoming a donor. You may agree to more testing to get ready to donate, or you can say no. We will respect your decision either way.

Thank you again for considering becoming a donor.



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On the cover:

Mary, two-time donor, with her children, who donated their cord blood;

Lamar (left), recipient, with his donor, Adam (right);

Randy (left), donor, with his recipient Luke (right);

Ramiro (left), donor, with his recipient, Danielle (right).

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Why you have been asked to donate

You have been identified as a possible donor for a patient who needs a marrow or blood cell transplant. When you joined the National Marrow Donor Program® (NMDP) Registry, you agreed to consider donating cells from your marrow or blood to possibly help any patient in the world. You gave a sample when you joined. That sample was tested to find your tissue type, and the test results were listed on a computerized Registry.

Now, a doctor searching the Registry has chosen you as the best match for a patient who needs a transplant.

If you agree to donate, blood-forming cells collected from your bone marrow or bloodstream will be transplanted into the patient to replace his or her damaged marrow. A marrow or blood cell transplant can often help patients with leukemia, lymphoma and other life-threatening diseases live longer, healthier lives.

A transplant requires carefully matching the tissue type of the donor and the patient. Because tissue type is inherited, a patient's brother or sister usually has the best chance of matching. If a match cannot be found within the patient's family, the search is started to find an unrelated donor, like you.

Now that you have been identified as a possible donor, you will be asked to:

- Learn more about the process
- Consider your commitment
- Make an informed decision about donating

This notebook is produced using data gathered from actual experiences of NMDP donors.

A doctor searching the Registry has chosen you as the best match for a patient who needs a transplant.

Becoming a donor requires a commitment of your time.

There are several steps involved in becoming a donor.

Understanding your commitment if you agree to donate

Time commitment

Becoming a donor requires a commitment of your time. There are several steps involved to make sure you are the best donor for the patient. These steps include going to an information session, keeping appointments for additional blood tests and a physical exam—all before the actual donation. The tests are needed to assure that donating would not pose any undue risk for you or the patient.

The time from your information session until the day of the donation (called the “workup” period) could be as short as three weeks or as long as several months. The average time for a donor workup is four to six weeks.

Your time commitment may spread out over a number of weeks, depending upon a number of factors, including:

- Scheduling
- Patient’s condition
- Travel time for you
- A variety of other factors

(Filling out the chart in Appendix II or Appendix III with your donor center representative will give you an idea of the time frame for your specific situation.)

Physical commitment

Some parts of the donation process can be uncomfortable. These may include blood tests, injections and side effects from the collection procedure. While serious risks are extremely rare, it is likely that you will experience some side effects from donating. These will be described in detail during the information session and in the sections of this notebook dealing with the collection process.

Emotional commitment

Becoming a donor is an important life event that can cause strong emotions. These may include stress or anxiety about the process, excitement or joy about the opportunity to help a recipient, disappointment over cancellation, or sadness about the patient’s situation. Because of the strong emotions a donor may experience, donating may not be appropriate for everyone.

Expense

Most expenses associated with donating are covered by the patient or the patient’s insurance. There will be no cost to you for exams, transportation or expenses related to your donation. If you ever receive a bill related to your donation, call your donor center representative right away.

Many employers provide paid time off for donation. Ask your employer if your company has a policy for marrow or blood cell donation. Your donor center coordinator can also connect you with a donor advocate if this is an issue for you.

The steps leading to donation

The steps for marrow and blood cell donation are generally the same for all NMDP donor centers. Some details of scheduling may vary. You and your donor center coordinator will discuss the steps followed by your donor center.

The general steps are:

- Attend an information session at your donor center
- Sign Consent to Donate Form
- Sign Research Database and Research Sample Repository Consent Form
- Receive a physical exam
- Give blood samples

Marrow donation

- Autologous blood donation
- Marrow donation
- Follow-up with coordinator

Peripheral Blood Stem Cell (PBSC) donation

- Receive filgrastim
- Apheresis procedure
- Follow-up with coordinator

Information session

You will have an information session — in person or via the telephone — with your donor center representative to learn about the donation process. This session is designed to make sure that you are fully informed about the procedure and its possible side effects.

You will be given detailed information about the donation experience. Please ask questions at this session. You are free to bring a friend or family member with you. The decision to become a donor is an important one. Having someone with you can be helpful.

The patient's doctor is asking for a specific type of blood cell donation — either bone marrow or peripheral blood stem cells (PBSC). We want you to be fully informed and read about both types of collections. The patient's doctor asks for the source that is best for the patient. You do not get to choose the collection procedure. You will be informed which collection procedure is being requested and why.

If you do not wish to donate the product that is requested, but would consider donating the other product, tell your donor center representative.

Some parts of the donation process can be uncomfortable. These include blood tests, injections and side effects from the collection procedure.

There is no cost to you. Check with your employer about paid time off to donate.

You and your donor center coordinator will discuss the specific routine followed by your donor center.

At the information session:

- You will watch a video about donation.
- You will learn about the donation process and the risks and side effects associated with both marrow and PBSC donation.
- You may be able to speak with someone who has already donated. You will also be offered the services of a local volunteer donor advocate to support you through the decision-making process. The donor advocate knows about the donation procedure, but is not part of the patient's transplant team. This is to assure that your welfare is the advocate's only concern.
- You will also get information about the patient's disease and chance of successful transplant (based on the experience of other patients) and the possibility of being asked to make a second donation.
- You may be presented with possible collection dates.
- You will also get information about the life, health and disability insurance the NMDP provides for donors.



You will have an information session, either in person or via the phone.

You will be given detailed information about the donation experience. Please ask questions at this session.

Confidentiality

The NMDP is committed to protecting the privacy of both patients and donors. This promise of confidentiality protects patients and donors from unwelcome publicity or contact. This could include pressure to donate or requests for payment.

To help keep patient and donor identities private, identification (ID) numbers are given to each person. These ID numbers protect patient and donor identities (such as name and address) but still allow important medical information to be shared. This high level of privacy is maintained during all stages of the donation and transplant process.

Patients are told only the age and sex of their donor. Donors are only told the age and sex of the patient and the patient's disease.

Talking with your personal doctor

You may want to talk to your own doctor before making your decision. Before you do, check with your donor center representative. You might need approval from the center in order to have this visit paid for.

Consent to donate

After your information session, you will be asked to confirm your decision to donate by signing a Consent to Donate form. Make sure all your questions have been answered before you sign the form.

The form says that you have reviewed the written and/or video material about marrow and blood cell donation and were able to ask questions. **Signing this form means you agree to continue with the workup, and it is your intention to donate.**

If you are unwilling or unable to donate, or you are not sure of your commitment, please tell someone at your donor center as soon as possible.

Important: You have the right to decide not to donate at any time. If you change your mind about donating after the workup process has begun, it could cause dangerous delays for the patient.

If you change your mind after the patient has begun chemotherapy and/or radiation treatment to kill his or her own marrow, the recipient may die if he or she does not receive the transplant.

Consent to participate in NMDP research

If you decide to become a donor, you may be invited to participate in NMDP research. The purpose of research is to help future patients in need of a transplant and donors. Participation is voluntary. You may choose not to participate in NMDP research and still donate. If you choose to participate in research, you will be asked to sign a consent form to 1) allow information related to your donation to be added to the NMDP research database and 2) to donate a blood sample for research to be stored in the NMDP Research Sample Repository. You may choose to participate in both of these research activities or just one.

The NMDP protects the privacy of donors and patients.

There is a possibility that you will never learn the identity of your recipient.

Donating is voluntary. You have the right to decide not to donate at any time.

You may choose not to participate in NMDP research and still donate.



After your information session, you will be asked to sign a Consent to Donate Form.



You will have a physical examination to confirm that you are healthy and eligible to donate.

Physical exam

If you decide to continue with the workup process, your donor center coordinator will schedule a physical exam for you.

The exam will:

1. Assess your suitability as a marrow or blood cell donor by making sure you do not have any medical conditions that pose a risk of harm to you or the patient if you donated.
2. Take place at a clinic or hospital. The doctor who examines you is not involved with the care of the recipient. This is to assure you that your welfare is the doctor's only concern. The exam is not a substitute for the routine health care you receive from your personal doctor.

The exam will include:

- A health history.
- An electrocardiogram (EKG) to check your heart.
- A chest X-ray.
- A urinalysis.
- An assessment of the veins in your arms. (This is done to see if your veins are suitable for the PBSC collection procedure. If your veins are not suitable for a PBSC collection, a central venous line will be needed.)
- Blood tests.
- A pregnancy test if you are a woman of child-bearing age.

Your donor center medical director will review the exam results. Any abnormal findings will be discussed with you confidentially. If any findings show a risk of harm to you or the patient, you will not donate.

Sometimes delays occur due to the patient's health. If more than eight weeks have passed between the exam and the donation, you will need an "interval physical exam." This exam may include a phone call with the doctor who did your first exam. It may also include more blood tests or another exam. It depends on how much time has passed between your first exam and the scheduled donation.

Blood samples

Before you donate, and on the day of collection, you will need to give several blood samples. These samples are sent to various centers and labs for testing. The samples cannot all be collected at the same time. You may have to make several trips (typically, two to four) to have blood drawn. The following section explains why the blood samples are needed.

If any findings show that you or the recipient could be harmed by your giving marrow or blood cells, you will not donate.

You may have to make several trips (typically, two to four) to have blood drawn.

Pre-collection samples. You will be asked to give additional blood samples before the marrow or blood cell collection. These samples are used to perform final tissue matching and other tests.

Infectious disease markers. To determine whether your marrow or blood cells could transmit any disease to the patient, a sample of your blood will be tested.

You will be tested for the following:

- Human Immunodeficiency Virus (HIV, the AIDS virus)
- Hepatitis viruses
- Syphilis
- CMV (cytomegalovirus)
- Human T-lymphotropic virus

These are routine tests performed whenever anyone donates blood. You will be informed if any disease, or history of disease, is found. All test results are strictly confidential. Some positive results must be reported to state health departments.

If more than 30 days have passed from the time of your first infectious disease testing until the date of collection, NMDP Standards require repeating the infectious disease tests. You will then need to give another blood sample.

Autologous blood donation (marrow donors only). Most marrow donors require a blood transfusion during or after the marrow donation to replace blood that is collected along with the marrow. PBSC donors do not need a transfusion. The NMDP recommends that you receive your own (autologous) blood. Your donor center will probably arrange for you to donate one or two units (pints) of blood in proportion to the amount of marrow you will donate.

The amount of marrow the transplant center requests is based on the patient's weight and how much you can safely donate. NMDP Standards further specify that no more than 1,500 ml (about three pints) can be donated. The larger the patient, the more marrow you will be asked to donate, and the more autologous blood you will need.

Your donor center representative will give you more information about the autologous blood donation. Your blood will be labeled and stored until your marrow donation. The doctor in charge of your donation will decide if and when you will receive your autologous units.

Complete blood counts and chemistry tests (PBSC donors only). These blood tests are required during the preparation process before the donation(s). These small samples of blood are drawn from a vein in your arm and are used to monitor your response to filgrastim. Filgrastim is a growth factor used to move the cells used in transplantation from your marrow into your bloodstream. You receive injections of filgrastim for five days before donating PBSC.

Several routine blood tests will be performed.

Most marrow donors require a blood transfusion during or after the marrow collection to replace blood that is collected along with the marrow.

Research samples (optional). If you agree to participate in the NMDP Research Sample Repository, a blood sample will be drawn from your arm. This sample may be paired with the patient's blood sample for future studies on transplantation. Research done with these blood samples is intended to improve the outcomes for future patients and donors.

After you have been cleared to donate, the collection will be scheduled.

The collection may be delayed or canceled.

The search for the best possible donor may continue after you have been selected, and a better donor may be found.

Cleared to donate

After you have been cleared to donate, a date for the collection will be set. It will take place at an NMDP collection center or apheresis center. You will not travel to the patient's location to donate. A trained courier will transport the marrow or blood cells to the patient's location.

Please note that once you have been cleared to donate the patient will be told that a donor is ready. The transplant date will be set and the patient will begin treatment to get ready for the transplant. This treatment typically includes chemotherapy and/or radiation treatment to kill the patient's damaged marrow cells.

It is important for you to know that if the patient does not receive a transplant after this point, he or she may die.

Delay or cancellation

You should be prepared for the possibility that your collection could be rescheduled or canceled. It can be disappointing after all you've done to get ready. It's important to remember that it's not your fault.

Possible reasons for delay or cancellation include:

- The patient's condition could get worse. If the patient isn't strong enough, a transplant may no longer be an option, either temporarily or permanently.
- The patient may respond to alternative treatments and/or decide not to have a transplant.
- The search for the most suitable donor may continue after you have been selected, and a more suitable donor may be found.

Marrow donation

Marrow donation is a surgical procedure that takes place in an operating room. The donation will be scheduled at the NMDP hospital nearest to your home. You will be given either general or regional anesthesia to block the pain. Typically, the hospital stay is from early morning to late afternoon, or occasionally overnight for observation.

Tips to prepare you for your visit to the hospital

- Do not use aspirin or any medication containing aspirin for at least two weeks before the collection. Aspirin can prolong bleeding.
- Use only acetaminophen or ibuprofen products (e.g., Tylenol, Motrin, Advil) for headache or other minor pain. Ask your collection physician about other drugs.
- Ask your donor center coordinator if you will be sharing a room or have a private room so you will know what to expect.
- Leave all jewelry at home.
- Do not eat or drink anything after midnight on the evening prior to your collection. This is very important as failure to do so may cause the collection to be rescheduled.

Pack the following:

- Loose fitting clothes to wear home from the hospital (to accommodate tenderness at the collection site).
- Personal items such as a comb, brush, slippers, razor, toothbrush, toothpaste, etc.
- A book or magazine to help pass the time.
- A pillow to cushion your lower back during the car ride home.

At the hospital

In most cases, the hospital will schedule a same-day admission and discharge for your marrow donation procedure.

Some hospitals routinely plan for an overnight hospital stay. Your NMDP donor center representative will guide you through the process and will be available the day of your marrow donation.

- If you have a specific concern about your hospital stay — your symptoms, your comfort, your privacy or some other issue — tell the hospital staff. They want to help make your marrow collection procedure as comfortable as possible.
- Be aware that delays may occur.

Marrow donation is a surgical procedure that takes place in an operating room.



Use only acetaminophen or ibuprofen products (e.g., Tylenol, Motrin, Advil) for headache or other minor pain.



In most cases, the collection center will schedule a same-day admission and discharge for your marrow collection procedure.

Hospital Stay

(Please that the time you will spend in the hospital is determined by individual hospital policy, as well as your condition.)

- 50% of donors spent fewer than 15 hours in the hospital.
- 40% of donors spent 16-37 hours in the hospital.
- 10% of donors spent 38 or more hours in the hospital.

Anesthesia

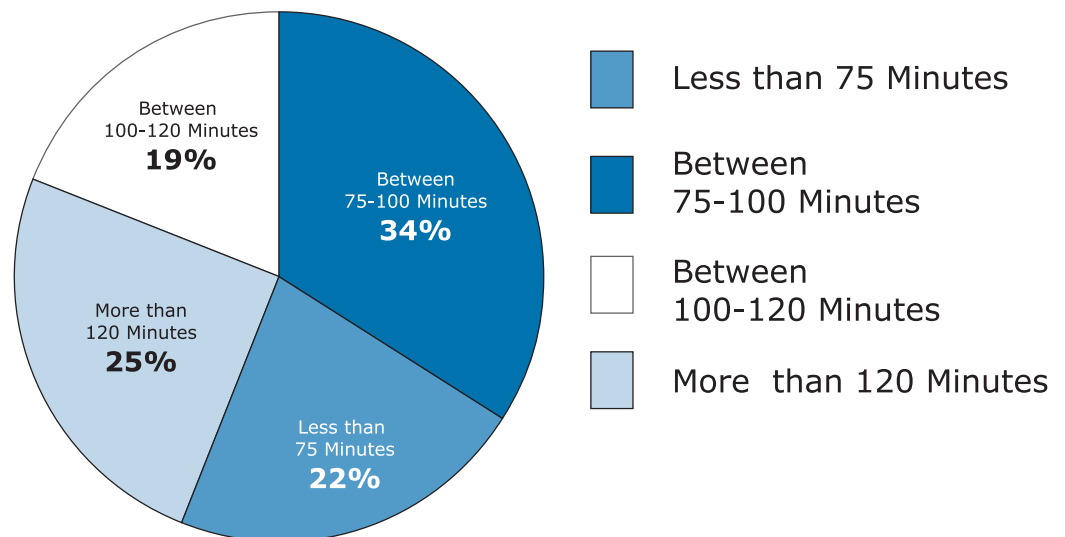
You will be given either general or regional anesthesia to block the pain before and during the actual marrow donation. A doctor or nurse will discuss the options with you and recommend which type of anesthesia is best in your situation.

While serious side effects are rare, the risk of an adverse reaction to anesthesia during marrow donation is similar to that of other surgical procedures.

General anesthesia

If general anesthesia is used, you will be unconscious during the donation. General anesthesia is used for about 75 percent of NMDP marrow donors. The average time of anesthesia is about two hours.

Average Time of Anesthesia During Marrow Donation



Anesthetic medication is delivered through a tube into a vein. After you are unconscious, you may also breathe an anesthetic gas. This requires the placement of a breathing tube in your throat.

Common side effects of general anesthesia include:

- Sore throat (caused by the breathing tube)
- Mild nausea and vomiting

Please bring any side effects to the attention of medical staff. Medication can be given to control and sometimes prevent these side effects.

Regional anesthesia

There are two types of regional anesthetic: spinal and epidural. With both, medication is injected in the lower back between the vertebrae of the spine. This medication blocks sensation in the affected area. In addition, you may be given a sedative to help you relax, but you will remain aware of your surroundings during the donation.

While donors who have regional anesthetics report fewer instances of nausea or vomiting, (as with general anesthesia) other side effects have been reported.

Common side effects of regional anesthesia

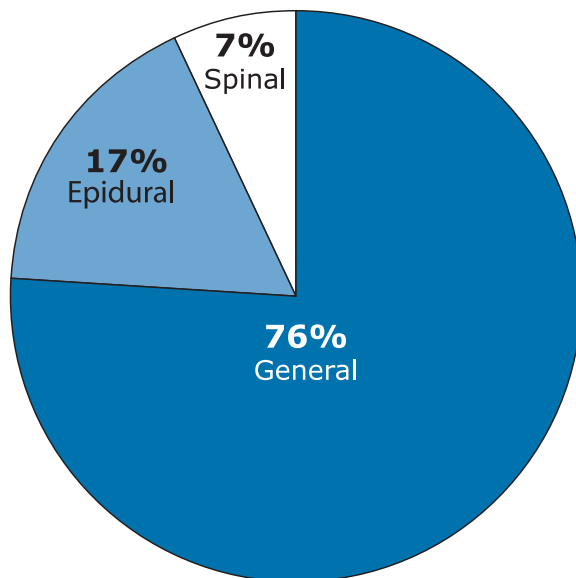
- A decrease in blood pressure (Intravenous fluids are given to reduce this effect).
- Some donors have reported having a headache after the procedure, sometimes lasting a few days.

There are two types of regional anesthetic: spinal and epidural.



With general anesthesia, you will be unconscious.

Type of Anesthesia Received During Marrow Donation





Marrow is collected from the rear of the pelvic bones using hollow needles.

The donation does not weaken your immune system. The marrow naturally replaces itself within a few weeks.



You will be observed in the recovery room.

Marrow donation procedure

During the marrow donation, you will be lying on your stomach. While the donation varies slightly from hospital to hospital, generally, the doctors make several small incisions through the skin over the back of the pelvic bones.

The incisions are less than one-fourth inch long and do not require stitches. The doctor will insert a special hollow needle through these incisions over the rear of the pelvic bone. A syringe is attached to the needle to draw out the marrow.

The process is repeated until the appropriate amount of the marrow is collected. The average amount of marrow and blood donated is about one quart. If the patient is a child or a baby, less marrow is needed.

The amount of marrow donated is only a fraction of the body's total marrow. The amount donated does not weaken your own immune system. The marrow naturally replaces itself within a few weeks.

When the marrow donation is complete, a bandage is placed over the site and you will be moved to a recovery area.

Recovery at the hospital

In the recovery area, you will be observed until the anesthesia wears off. When you are fully alert and physically stable, you will be returned to your room. Check with the hospital staff about having visitors. Most donors go home the same day or the next morning.

During your stay, hospital staff will closely monitor your condition, which will likely involve collecting additional blood samples.

In rare instances, a small tube may need to be inserted into a donor's bladder to drain urine. If you experience any medical complications, the collection team is on hand to provide treatment and answers to your questions. Be sure to report anything that concerns you.

Your donor center coordinator will let you know who to contact if your condition changes after discharge. Depending on the distance you need to travel to return home, your donor center coordinator will discuss options for the timing of your return trip.

Risks and side effects of marrow donation

Common side effects of the marrow donation procedure include:

- Lower back pain
- Fatigue
- Stiffness when walking
- Bleeding at the collection site

Discomfort and side effects vary from person to person. Most marrow donors experience some pain, fatigue and stiffness following the donation.

You may take a non-aspirin pain reliever. Moving around a bit may also help relieve the stiffness and soreness. You should ask for help from the nursing staff the first time you get up to walk around after the donation.

Some donors said the experience was more painful than they expected, others, less painful. Some donors describe the pain as similar to achy hip bones or falling on their buttocks. Others say it feels more like a strained muscle in the back. The ache may last a few days to several weeks.

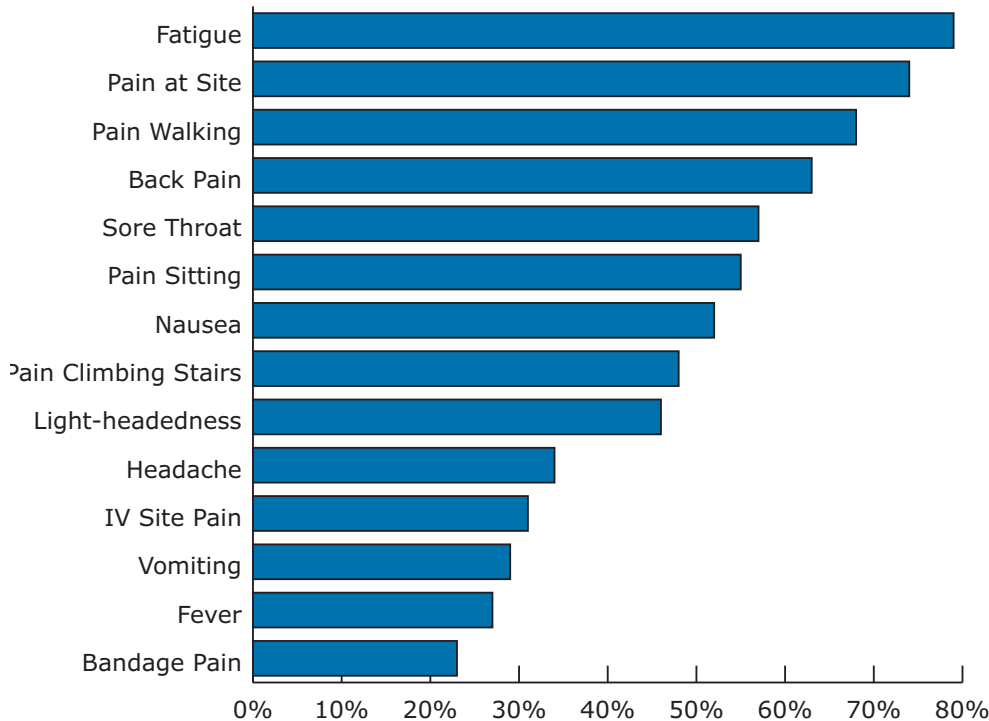
The majority (more than 98.5 percent) of donors experience a full recovery. A small percentage (1.34 percent) of donors experience a serious complication due to anesthesia or damage to bone, nerve or muscle in their hip region.

The NMDP wants to assure donor safety, but no medical procedure is risk-free. The risk of death during marrow donation is extremely low, but each donor should be aware that this risk is present.

Some donors said the experience was more painful than they expected, others, less painful.

Use only non-aspirin products (such as Tylenol, Motrin or Advil) as these products will not prolong bleeding.

Common Side Effects of Marrow Donation Reported in First 72 Hours



Recovery when you leave the hospital

- You are likely to be stiff and sore in your lower back.
- You may experience muscle pain and/or muscle fatigue in your back and/or legs.
- You may be more tired than usual for several days to weeks.
- You may experience bruising at the collection site after the procedure.
- For a few days, keep your legs raised whenever possible.
- 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 expect to return to pre-collection activities for about two to three weeks, maybe longer for more strenuous activities.
- Do not over-exert yourself.
- Plan to take at least a few days off from work, perhaps more if your job is physically demanding.
- Use only non-aspirin products (such as Tylenol, Motrin or Advil) as these products will not prolong bleeding.
- Take your pain medication before you absolutely need it. Be aware that some pain medications may cause nausea. Report any side effects to your coordinator.
- Take an iron supplement, if prescribed.
- Share the information you received about your care and recovery with your loved ones. Accept their offers to help.

PBSC donation

Peripheral blood stem cell (PBSC) donation is another way to collect blood-forming cells for transplantation. The same blood-forming cells (sometimes called blood stem cells) donated from the marrow are also found in the circulating (peripheral) blood.

In order to be able to donate enough blood-forming cells for a transplant, more of the cells need to be moved out of the bone marrow and into the bloodstream.

PBSC studied under a protocol with the FDA

The NMDP is studying PBSC donations and transplants under a clinical research study reported to the U.S. Food and Drug Administration (FDA). A clinical research study has a written set of instructions for how a donation will be carried out. It is an important scientific way to evaluate the effectiveness of the procedure for both donors and recipients.

One proven way to move stem cells from the bone marrow into the bloodstream is by taking filgrastim, a drug given by injection each day for five days before the donation.

Donors receiving filgrastim should not take aspirin because it decreases the normal blood clotting process. Donors can take non-aspirin products (such as Tylenol, Motrin or Advil) instead.

Preparing to donate PBSC

Day one

The first injection of filgrastim must be given at a donor center or medical clinic. On the first visit, you will be weighed and have blood tests done to measure your white blood cell count. Typically, the injection is given just under the skin in the upper arm, the abdominal area or the thigh. The visit will take about 30 to 60 minutes, excluding any travel time.

You will be observed for 20 to 60 minutes for any signs of an allergic reaction to the filgrastim. Less than one percent of donors have an allergic reaction, which may include skin rashes or shortness of breath.

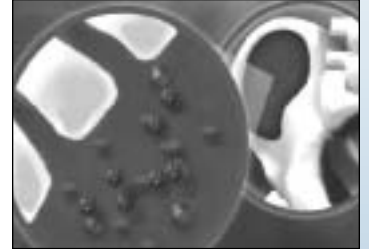
You should call your NMDP donor center representative to discuss any symptoms you may be experiencing from the filgrastim. The representative will also check in with you throughout the process.

Days two to four

The following three doses may be given at your place of work, your home, at a donor center or a medical clinic. Before each daily injection, you will have your temperature, pulse and blood pressure checked. The amount of the filgrastim injection will be adjusted if needed. A licensed medical professional will administer each dose.

Day five

After receiving the fifth and final dose of filgrastim you will donate your blood cells at the donor center or hospital outpatient unit via a process called apheresis.



PBSC collection involves collecting blood-forming cells from the bloodstream.

Before each injection, you will have your temperature, pulse and blood pressure checked.



The first injection of filgrastim must be given at a donor center or medical clinic.



The apheresis machine collects blood-forming cells, platelets and some white blood cells.

The PBSC donation process

During apheresis, a needle will be placed into each of your arms. Blood will be removed from a vein in one arm and passed through tubing into a blood cell separator machine. The blood is spun at high speed and the cells separate into layers.

The machine collects blood-forming cells, platelets, and some white blood cells. Plasma and red blood cells are returned to your body through the other arm while the blood-forming cells are put into a collection bag. All the tubing used in the machine is sterile and used only once for your donation.

If only one apheresis donation is done, it may take up to eight hours. If two donations are done on separate days, each collection will take four to six hours.

Side effects of filgrastim

Common side effects of filgrastim

- Headache
- Bone or muscle pain
- Nausea
- Trouble sleeping
- Tiredness

Side effects of filgrastim usually disappear one or two days after the last dose of the drug. Most PBSC donors report full recovery within one week of donation.

Until then, donors can take non-aspirin products (such as Tylenol, Motrin or Advil) for their discomfort. Donors should not take aspirin for 48 hours after donation because it decreases the normal blood clotting process.

Less common side effects of filgrastim

- Allergic reactions
- Rapid heart rate
- Dizziness
- Shortness of breath
- Itching or rash
- Eye swelling
- Skin rashes

Rare side effects of filgrastim

- Bleeding of the spleen

Less than 1 percent (0.7 percent) of PBSC donors experience serious side effects. As of July 2004, the NMDP is aware of four healthy non-NMDP donors worldwide who donated for family members and developed pain and bleeding from the spleen while receiving filgrastim. In two of those cases the spleen was removed. All four donors recovered.

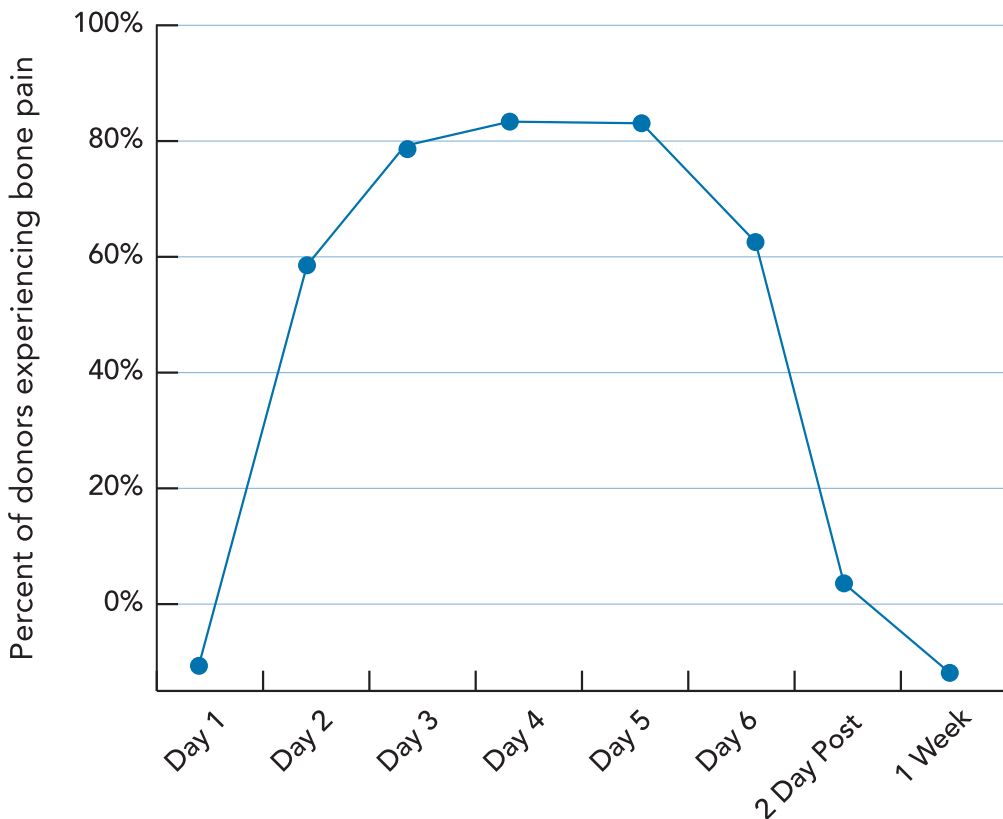
The NMDP estimates there is a 1 in 10,000 risk of bleeding from the spleen when taking filgrastim.

Long-term effects of filgrastim

Filgrastim is commonly used to treat cancer patients. The use of filgrastim to stimulate the release of blood-forming cells into a healthy donor's bloodstream is fairly new. There is, therefore, no data yet available about the long-term safety of filgrastim. The NMDP started using filgrastim to aid in transplants in the 1990s. Since then, no NMDP donors have reported any long-term complications from filgrastim injections.

Most PBSC donors report full recovery within one week of donation.

Donors Experiencing Bone Pain Following Filgrastim Injections



Common side effects of the PBSC donation procedure

Common side effects for PBSC donation may include:

- Bruising at needle site
- Numbness or tingling
- Chills

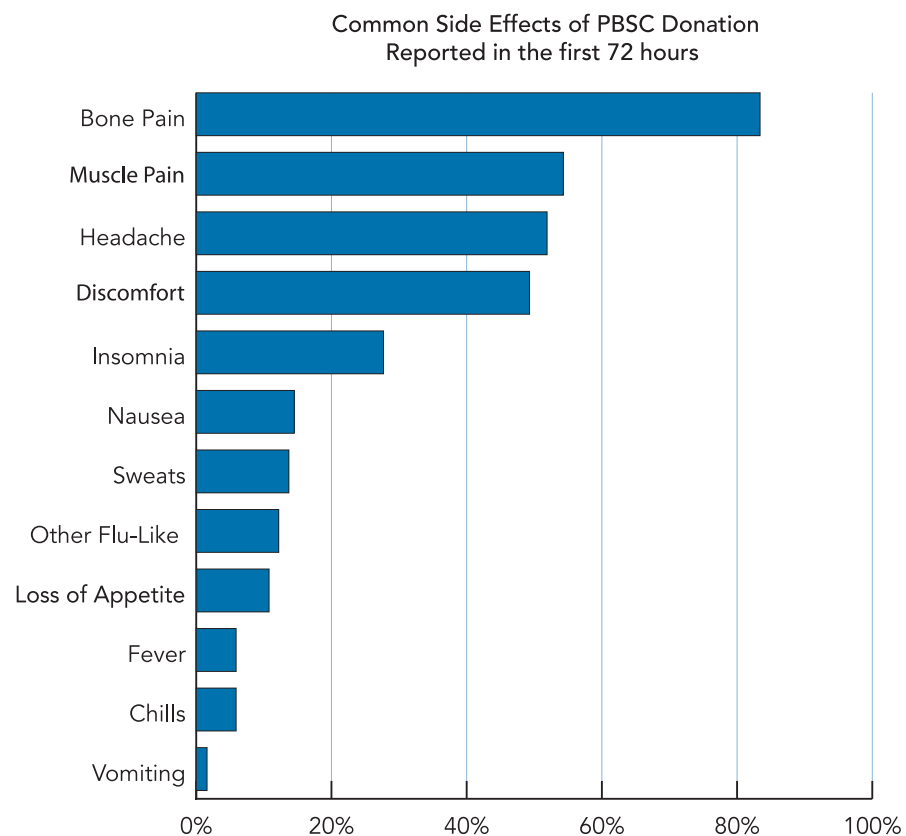
Some donors experience tingling around the mouth, fingers and toes and mild muscle cramps. This is caused by the anti-coagulant (blood thinner) used in the apheresis procedure. These symptoms are easily treated by slowing down the procedure or giving the donor calcium.

Less common side effects for PBSC donation

- Decrease in blood platelet count
- Lightheadedness
- Nausea

Platelet loss may cause blood to take longer than normal to clot. Donors who experience platelet loss might bruise more easily and should avoid heavy lifting for 24 hours.

Donors can continue to take acetaminophen or ibuprofen as needed, but they should not take aspirin because it could prolong bleeding.



Rare side effects for PBSC donation

- Fainting due to lowered blood pressure
- Infection
- Nerve injury

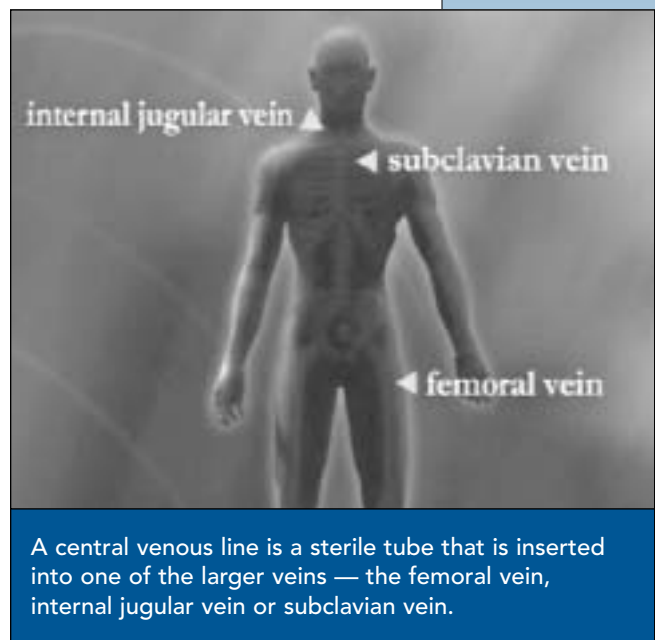
Central venous line

If you do not have suitable arm veins, you may be asked if you are willing to have a central venous line placed for the donation.

A central venous line is a sterile tube that is inserted into one of the larger veins – the femoral vein, internal jugular vein or subclavian vein. It provides an alternate way to access your veins and enables the apheresis procedure to be performed. In a hospital, a physician will insert the central line. Local anesthesia, such as novocaine, is used. If a two-day donation is needed, you will stay overnight in the hospital. The central line is removed at the end of the PBSC donation procedure.

Such a line will be placed only with your consent. If you decline to have a central line placed, you will most likely be asked to donate marrow.

Based on the NMDP's experience, 18 percent of women and 3 percent of men require a central line placement.



Possible side effects from a central line

The risk of serious complications from use of a central line is small.

There is about 1 percent risk of partial collapse of the lung from insertion of a subclavian line under your collar bone area. Bleeding can occur where the central line is inserted or into the chest area.

You will receive additional information about possible risks of central line placement. You will also be asked to sign a separate consent form for the central line placement.

Based on the NMDP's experience, 18 percent of women and 3 percent of men require a central line placement.

Benefits to you

Donation does not directly benefit you in any way. However, your donation may directly help the patient and may provide information on the value of marrow or PBSC transplantation in the future.

Post-donation, follow-up and testing

For most NMDP donors, the marrow or PBSC donation procedure goes smoothly, and they return home the same day of the donation. Some marrow donors remain in the hospital overnight and return home the next day.

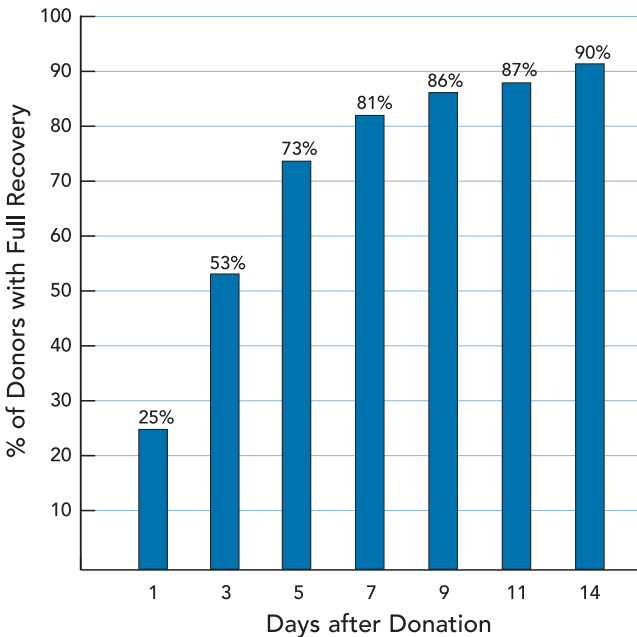
The NMDP and your donor center staff care very much about your safety and want to know about the details of your recovery. Your donor center coordinator will contact you on a regular basis after donation to ask about your physical condition. It is important to report any and all symptoms you experience.

If at any time in the weeks, months and years after donation you experience physical problems that might be related to the donation, be sure to contact your donor center as soon as possible.

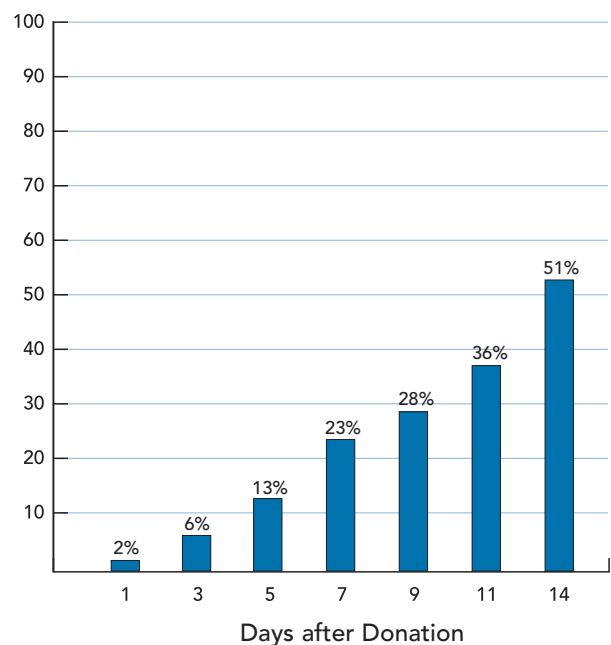
At one month, six months and yearly after donation, your donor center representative will contact you to assess your current health. A representative from the donor center will be contacting you on a regular basis until you report full recovery, then once per year for a check-up.

A representative from the donor center will be contacting you on a regular basis until you report full recovery, then once per year for a check-up.

Recovery after PBSC Donation



Recovery after Marrow Donation



Nine percent of marrow and PBSC donors have given one or more additional blood donations for the same patient.

Requests for additional blood donations

After the transplant, the patient may need additional blood donations to boost his or her recovery. You may be asked to consider making an additional donation of:

- White blood cells
- Platelets
- Whole blood

You have the right to say either yes or no to donating these blood products.

Requests for a second marrow or PBSC donation

If the patient suffers a major setback, he or she may need a second marrow or PBSC donation. Some NMDP donors are asked to consider a second donation. If this happens, your medical safety for a second donation will be fully evaluated. You will also have the freedom of choice to say yes or no to the request. Your decision whether or not to donate will not affect your standing as a valued NMDP donor.

Nine percent of marrow and PBSC donors have given one or more additional blood donations for the same patient. Currently, the most common type of second donation is donor lymphocytes collected by apheresis, followed by PBSC, marrow and whole blood. Recovery and side effects following a second donation appear to be very similar to the first donation.

Transplant outcomes

Since 1987, the National Marrow Donor Program has facilitated more than 25,000 transplants for patients who did not have a tissue-matched donor in their family.

It is difficult to predict the outcome for an individual patient. How well a transplant works depends on many factors, including:

- The disease being treated
- The stage of the disease
- The patient's age and general health
- The degree of match between the donor's and patient's tissue type

In general, younger patients do better than older patients. Leukemia patients who receive their transplants when their disease is in remission do better than those patients who are transplanted when their disease has relapsed.

For a matched, unrelated donor transplant, overall survival rates (two to three years after transplant) currently range from 30 to 60 percent.

Without a transplant, survival rates range from 0 to 15 percent.

Communication between donors and patients

The NMDP is committed to protecting the confidentiality of both donors and patients. The NMDP facilitates transplants around the world. In some countries, contact between donors and recipients is not allowed. Some transplant centers may allow anonymous communication, managed through the center. Anonymous communication must not include any identifying information, such as names, addresses or other contact information.

Some centers may allow direct contact between donors and patients one or more years after the transplant — if both parties agree to the contact. The NMDP may be able to assist in the process.

In some cases, both donor and patient are very eager to meet. Often, however, either the recipient or donor chooses not to have any personal contact.

You should be prepared for the possibility that you may never learn the identity of your recipient or have any contact with him or her.

Thank you

We hope the information in this notebook is helpful to you. If you have any questions, please ask your donor center coordinator.

On behalf of the National Marrow Donor Program and your local NMDP representatives, thank you for considering becoming a marrow or blood cell donor.

Some centers may allow direct contact between donors and patients one or more years after the transplant — if both parties agree to the contact.

Time commitment worksheet for marrow donation

Required step	Appointment time and location	Approximate time required
Information session		
Physical exams Initial exam		
Collection center (If done separately)		
Interval exam (If necessary)		
Intent to donate		
Blood samples Research samples		
Pre-collection samples		
Autologous donation		
Infectious disease markers		
Marrow collection/ Hospital stay		

Time commitment worksheet for PBSC donation

Required step	Appointment time and location	Approximate time required
Information session		
Physical exams Initial exam		
Collection center (If done separately)		
Interval exam (If necessary)		
Consent form		
Blood samples/ Research samples		
Pre-collection samples		
Infectious disease markers		
Filgrastim injections 1. _____ 2. _____ 3. _____ 4. _____ 5. _____		
Apheresis collections 1. _____ 2. _____		

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To learn how you can help make life-saving transplants a reality for patients, visit **marrow.org**

The National Marrow Donor Program® helps people who need a life-saving marrow or cord blood transplant. We connect patients, doctors, donors and researchers to the resources they need to help more people live longer and healthier lives.

Entrusted to operate the C.W. Bill Young Cell Transplantation Program