

You're a Match:

A Donor's Guide to Donation



The information in this guide is also available
online at **[BeTheMatch.org/donationguide](https://www.BetheMatch.org/donationguide)**.

On front cover

Top row from left: Lydia, donor, with her recipient, Teresa; Randy, donor, with his recipient, Luke
Bottom row from left: Tom, donor, with his recipient, Joey; Adam, donor, with his recipient, Lamar



From left to right: Dr. Miller, Dr. Chell and Dr. Confer

Dear Registry Member:

When you joined the Be The Match Registry®, operated by the National Marrow Donor Program® (NMDP), you learned that one day you may be called to donate to a patient who could benefit from a transplant. A doctor has identified you as a possible match for a patient. We deeply appreciate the time and effort you have already given to Be The Match® and thank you for considering becoming a marrow or peripheral blood stem cell (PBSC) donor.

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

Your donor center representative will work with you to answer your questions. You will be the one to make the final decision to become a donor. You may agree to more testing to get ready to donate, or you can say you prefer not to donate at this time. We will respect your decision either way.

Thank you again for the personal commitment you have already given to Be The Match and for considering becoming a donor.

JOHN MILLER, M.D., PH.D.
Vice President and
Senior Medical Director

JEFFREY W. CHELL, M.D.
Chief Executive Officer

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Chief Medical Officer

This guide 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
- What to expect after donation
- Transplant from the patient perspective
- Resources available to you

Contact names and numbers

If at any time you have questions or concerns about the donation process, please contact your donor center representative.

Donor center name: _____

Donor center representative: _____

My donor ID number: _____

Collection center or apheresis center: _____

Notes: _____



Be The Match Registry,
operated by the National Marrow Donor Program

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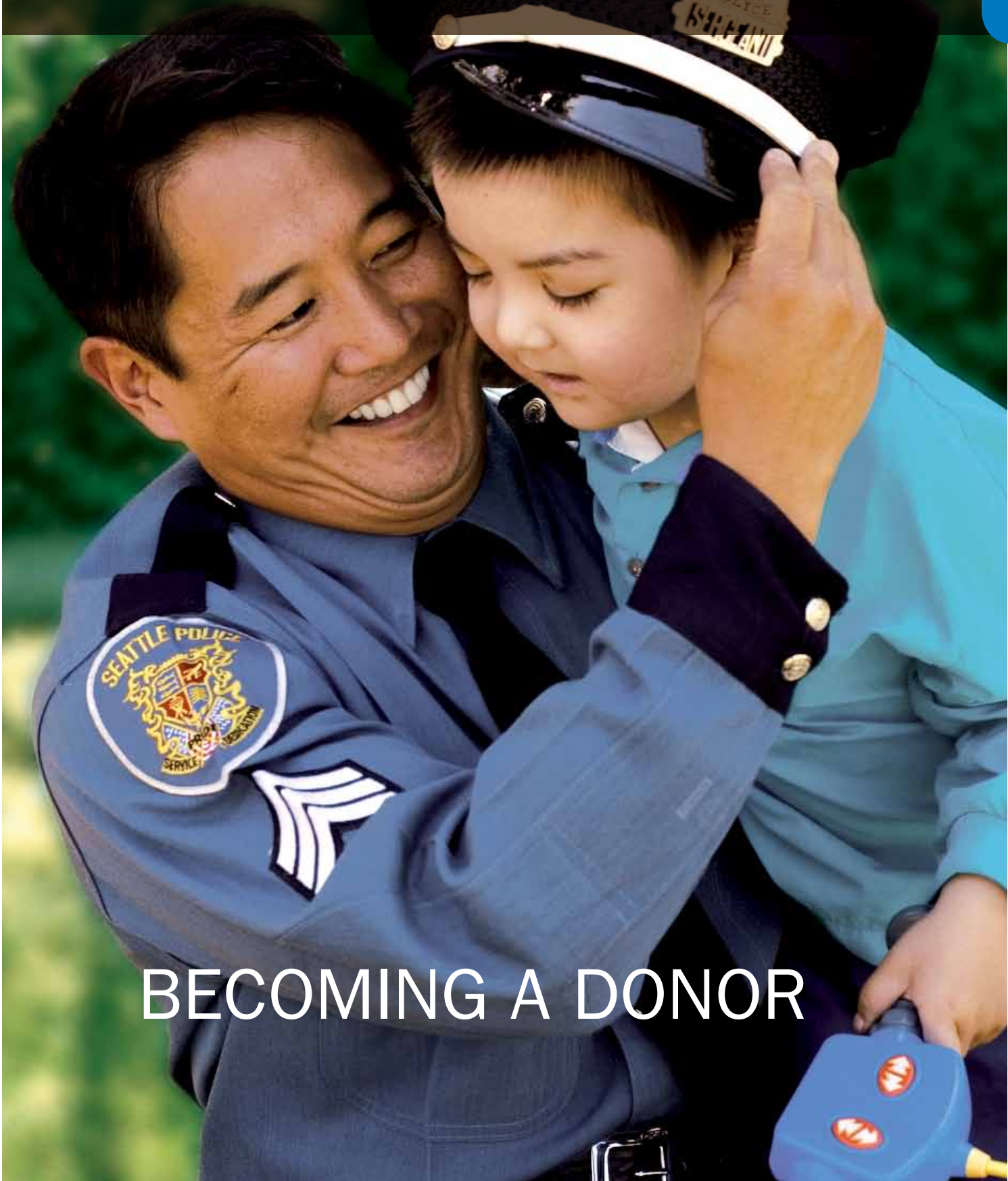
Thank you

Glossary.....

The donor and patient testimonials throughout this guide are selected donor and patient experiences and they may not be representative of all donor and patient experiences.

The references to online content within this guide are supplemental to the information in this book. The additional web content is not necessary to review in order to make an informed decision to donate.

In 2002, Randy (left) donated to Luke (right). Luke was a year old when he was diagnosed with leukemia and received his transplant.



BECOMING A DONOR

Why you have been asked to donate

You have been identified as a possible donor for a patient who seeks a marrow or peripheral blood stem cell (PBSC) transplant. When you joined the Be The Match Registry, you agreed to consider donating cells from your marrow or blood to possibly help any patient in the world who may benefit from a transplant. You gave a sample when you joined. That sample was tested to determine your tissue type, and the test results were listed on the Be The Match Registry.

Now, a doctor searching the registry has identified you as a possible match for a patient who needs a transplant.

If you agree to donate, blood-forming cells collected from your bone marrow or bloodstream (which are PBSCs) will be transplanted into the patient to replace his or her damaged marrow. A marrow or PBSC 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
- Make an informed decision about donating



“I joined Be The Match Registry when I was 19. But I never thought I’d be a match for someone since my Irish, Korean, and Jewish background isn’t exactly common and usually matches occur with a shared ethnicity.”

—Victoria, PBSC donor

Understanding your involvement



Lori was one of the first waves of people to join Be The Match Registry. But she found herself worried when she donated to a 5-year-old back in 1987. She thought, “what if this doesn’t work for him?”

Time commitment

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

The time period from your information session until the day of the donation could be as short as three weeks or as long as several months. The average time commitment for the donation process is 30 to 40 hours of your time over a four to six week period.

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

Physical risks and discomforts

Some parts of the donation process can be uncomfortable. These may include blood tests, injections and side effects from the donation 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 guide dealing with the donation process.

Emotional risks and benefits

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 patient, disappointment over delays or cancellation, or sadness about the patient’s situation. Because of the strong emotions a donor may experience, donating may not be appropriate for everyone.



Erma, marrow donor,
and her son, Irving

Family and friend support

It is important to include your family and friends in your donation decision. They can provide you with emotional support, as well as help you through the donation process. We encourage you to include a family member or friend in the information session to help you talk through your questions or concerns.

Expense

There will be no cost to you for exams, medical care, transportation or other expenses related to donation. Most expenses associated with donating are covered by the patient or the patient's insurance. Sometimes by mistake, a donor receives a medical bill. You are not expected to pay the bill. 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 PBSC donation. Additionally, some states have laws requiring employers to provide paid donor leave. If paid time off is an issue for you, please tell your donor center representative. They can help you work with your employer or discuss other resources that may be available to you.

The steps leading to donation



The steps to prepare for marrow and PBSC donation are generally the same for all donor centers. Some details of scheduling may vary. You and your donor center representative will discuss the specifics of your donation plan.

The general steps are:

1. Participate in an information session
2. Learn whether you are being asked to donate marrow or PBSC
3. Sign the Consent to Donate form
4. Consider participation in research studies
5. Receive a physical exam
6. Give blood samples

Marrow donation

1. Autologous blood donation
2. Marrow donation
3. Follow-up with donor center representative

PBSC donation

1. Receive filgrastim
2. Apheresis procedure
3. Follow-up with donor center representative

“It’s hard to describe when you know there’s somebody out there who needs you and you don’t know who it is. With every step of the process, I became more invested. It was a really special day for me, the day I donated marrow.”

—Randy, marrow donor

Note: Donating PBSC is done under a research study. Therefore, if you are requested for a PBSC donation, you will be asked to sign a research consent form before beginning the donation process. Please see the *PBSC donation* section of this guide for more information.

Information session

You will have an information session—in person or by phone—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 donation procedure and its possible side effects.

You will be given detailed information about what to expect. Please ask questions at this session to ensure that your concerns are addressed. We encourage you to include a family member or friend. 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 PBSC. We want you to be fully informed and read about both types of donations. The patient's doctor asks for the type that is best for the patient. You will be informed which donation procedure is being requested and why.

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

At the information session, you will:

- Learn about the donation process and the risks and side effects associated with both marrow and PBSC donation.
- Be offered the services of a 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.
- Get information about the patient's disease and chance of successful transplant (based on the experience of other recipients) and the possibility of being asked to donate again.
- Review the proposed donation schedule.
- Learn about the life, health and disability insurance the NMDP provides for donation.

Please ask your donor center representative if you'd like to speak with someone who has already donated.



You will have an information session—in person or by phone—with your donor center representative to learn about the donation process.



The NMDP is committed to protecting the privacy of both patients and donors. We ask for your cooperation in maintaining this confidentiality.

Confidentiality

The NMDP is committed to protecting the privacy of both patients and donors. We ask for your cooperation in maintaining this confidentiality. This promise of confidentiality protects patients and donors from unwelcome publicity or contact, including pressure to donate or requests for payment.

To help keep donor and patient identities private, identification (ID) numbers are given to each person. These ID numbers protect donor and patient 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.

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

Consent to donate

After your information session, you will be offered an opportunity to ask questions and will be asked if you are interested in donating. If you agree to donate, you will be asked to confirm your decision to donate by signing the Consent to Donate form. Make sure all your questions have been answered before you sign the form.

The consent form says that you have reviewed the written material about marrow and PBSC donation and were able to ask questions. **Signing this form means you agree to continue in the process, and it is your intention to donate.**

If you are unwilling or unable to donate, or you are undecided, please tell your donor center representative as soon as possible.

IMPORTANT: You have the right to decide not to donate at any time. However, if you change your mind after you've signed the consent form, it could cause dangerous delays for the patient. **Additionally, if you change your mind after the patient has begun treatment to prepare for transplant, the patient will likely die within a short amount of time if he or she does not receive the transplant.** Please see the *Patient experience* section of this guide for more information on the transplant process.

Consent to participate in NMDP research

If you decide to become a donor, you will be invited to participate in NMDP research studies. The purpose of our research is to help future patients in need of a transplant and to ensure donor safety. Participation in research is voluntary. You may choose not to participate in the NMDP research studies listed below and still donate. NOTE: At this time, donating PBSC is only done under a research study. If you choose not to participate in PBSC donation research, you may be asked to donate marrow.

If you decide to participate in one or more of these studies, you will be asked to sign a research consent form for each:

- To allow information related to your donation to be added to the NMDP research database
- To donate a blood sample for research to be stored in the NMDP Research Sample Repository
- To participate in long-term donor follow-up

Your donor center representative will tell you more about the different studies. You will have time to ask questions and talk to your family and friends before making your decision.

Physical exam

If you decide to continue, a physical exam will be scheduled for you.

The exam will:

1. Assess your suitability as a marrow or PBSC donor by making sure you do not have any medical conditions that pose a risk to you or the patient if you donate.
2. Take place at a clinic or hospital. The doctor who examines you is not involved with the care of the patient. 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 NMDP Repository collects paired donor-recipient blood samples that are prepared and sent to researchers studying transplant outcomes data to learn more about how matching and other factors affect transplant outcomes.

The NMDP Research Sample Repository contains more than 22,000 related and unrelated paired transplant recipient and donor (or cord blood) samples.



“I went in for further testing and I asked a lot of questions.”

—Tom, marrow donor

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 donation procedure. If your veins are not suitable for a PBSC donation, a central venous line will be needed. See page 27 for more information.)
- Blood tests (complete blood count, chemistry/metabolic profiles, and sickle cell testing)
- A pregnancy test if you are a woman of child-bearing potential (must be repeated within 15 days of donation)

Your donor center medical director will review the exam results and confirm that you are healthy and suitable to donate. Any abnormal findings reported from the tests listed above will be discussed with you confidentially. If any findings show a risk of harm to you or the patient, you will be informed and may not be able to donate.

If more than eight weeks pass between the exam and the donation, you will need an “interval physical exam.” This may include a phone call to review information from your first exam. It may also include more blood tests or another complete exam. It depends on how much time has passed between your first exam and the scheduled donation.

Please note: A woman who becomes pregnant during any stage in the process will not be allowed to donate.

Blood samples

Before you donate, and on the day of donation, you will need to give several blood samples. This may require two to four more appointments that will be scheduled by your donor center representative. The following section explains why the blood samples are needed.

PRE-DONATION SAMPLES. You may be asked to give additional blood samples before the marrow or PBSC donation. The patient’s doctor uses these samples to perform final matching and other tests.

INFECTIOUS DISEASE MARKERS. To determine whether your donation could transmit any disease to the patient, a sample of your blood will be tested for the following infectious diseases:

- Human immunodeficiency virus (HIV, the AIDS virus)
- Hepatitis viruses
- Syphilis
- CMV (cytomegalovirus)
- Human T-lymphotropic virus
- Chagas
- West Nile virus

These are routine tests that are also performed whenever anyone donates blood. You will be informed if any test results are abnormal. All test results are strictly confidential, however some abnormal results, such as HIV or syphilis, must be reported to state health departments.

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

AUTOLOGOUS BLOOD DONATION (MARROW DONORS ONLY). Some marrow donors may require a blood transfusion during or after the marrow donation to replace blood that is collected along with the marrow. We recommend that you receive your own (autologous) blood. Your donor center representative will arrange for you to donate and store in advance any autologous blood that is recommended.

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 procedure will decide if and when you will receive an autologous transfusion.

COMPLETE BLOOD COUNT (PBSC DONORS ONLY). This blood test is required on the first and fifth day you receive filgrastim. 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 drug that moves blood-forming cells used for transplant from your marrow into your bloodstream. You receive injections of filgrastim for five days before donating PBSC.



“When I was called, it was exciting, but a little nerve-racking, too, because I hadn’t really looked into the process. I was told I was a potential match for a sixteen-year-old boy, so I went in for more testing. A week later, I learned I was a perfect match.”

Craig, PBSC donor



Six years after Vivek joined the registry he was called as a match for a 38-year-old woman with leukemia. He donated to her in 2008 and again in 2009.

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 transplant. Research done with these blood samples is intended to improve the outcomes for future patients.

Cleared to donate

After you have been cleared to donate, your donor center representative will contact you to confirm scheduling details. Your donation will take place at a hospital or apheresis center. You will not travel to the patient's location to donate. A trained courier will transport the marrow or PBSC to the patient's location.

PLEASE NOTE: Once you have been cleared to donate, the patient will be told that their donor is ready. The patient will begin treatment to prepare for the transplant. This treatment typically includes chemotherapy and/or radiation. **It is important for you to know that if the patient does not receive a transplant after this point, he or she will likely die within a short amount of time.**

Delay or cancellation

You should be prepared for the possibility that your donation 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 and there are many possibilities for the delay or cancellation, such as:

- The patient's condition could get worse, requiring additional treatment or transplant may no longer be an option.
- 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 identified, and a closer matched donor may be found.

PBSC DONATION

In June 2006 Teresa (right) was diagnosed with leukemia and told that she needed a bone marrow transplant. Fortunately, Teresa found her match in Lydia (left) and received her transplant in 2006.



Peripheral blood stem cell donation



Jeff donating PBSC.

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

In order to be able to donate enough PBSC for a transplant, more of the cells need to be moved out of the marrow and into the bloodstream. One proven way to move PBSC from the marrow into the bloodstream is by taking filgrastim, a drug given by injection each day for five days before the PBSC donation. Filgrastim is commonly used to treat cancer patients to boost their blood cell counts.

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. Also, filgrastim may cause spleen enlargement so donors should also avoid heavy lifting and contact sports during filgrastim injections and up to one week following donation.

PBSC studied under a protocol with the FDA

The National Marrow Donor Program (NMDP) is studying the use of PBSC for transplant under a clinical research study reported to the U.S. Food and Drug Administration (FDA). A clinical research study includes a written set of instructions for how a donation will be carried out. It is an important, scientific way to evaluate the safety and effectiveness of the procedure for both donors and recipients. As part of the study you will be asked questions about your symptoms each day of the filgrastim injections.

To watch a video animation of the PBSC donation process, scan this code with your smart phone or visit BeTheMatch.org/PBSCvideo.





“I went in for my first Neupogen® injection (Note: Neupogen is a brand of filgrastim). They drew some blood and did another pregnancy test. Took my vitals and the nurse went over what to expect. I got my injections in the arms, nothing more than a little shot. I get allergy injections in my arms every four weeks, so this was nothing new to me. This stung just a tinge more than an allergy shot, but no big deal.”

—Mandi, PBSC donor

Preparing to donate PBSC

Day one

The first injection of filgrastim should be given at a donor center or medical clinic. On the first visit, you will be weighed and your vital signs will be monitored. Also, blood will be drawn to measure your complete 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 15 minutes following the first injection. If after 15 minutes there are no signs of an allergic reaction to the filgrastim, no further observation is required. If a reaction occurs within the first 15 minutes, the donor will be treated as necessary and observed for at least another 45 minutes. Less than one percent of donors have an allergic reaction, which may include skin rashes or shortness of breath.

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

Day two, three and four

The following three injections 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 filgrastim dose will be adjusted if needed based on the symptoms you report.

Day five

Your fifth and final injection of filgrastim will be given at the blood collection center or hospital where your donation will take place. You will begin donating about an hour after receiving filgrastim.



To read about Mandi's PBSC donation experience, scan this code with your smart phone or visit BeTheMatch.org/Mandi.

The PBSC donation process



Jay donating PBSC.

Donating PBSC is done through a standard process called apheresis. 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 PBSC, some platelets, and some white blood cells. Plasma and red blood cells are returned to your body through the other arm while the PBSC are put into a collection bag. All the tubing used in the machine is sterile and used only once for your donation.

Seventy-five percent of all PBSC donations are completed in one apheresis session, which may take up to eight hours. The remaining 25 percent of donations are completed in two apheresis sessions, which will take four to six hours each.



“I’m not going to lie, the side effects of the shots felt like getting the flu. So that wasn’t too pleasant.”

—Patrick, PBSC donor

Risks and side effects of filgrastim

The NMDP started using filgrastim to stimulate the release of PBSC into a healthy donor’s bloodstream to aid in donation in the 1990s. Less than 1 percent (0.6 percent) of donors experience serious side effects. The data the NMDP collects from donors helps establish if there are any positive or negative effects from receiving filgrastim. Based on available data from healthy people who have received filgrastim, no long term risks have been found to date.

Common side effects of filgrastim	Less common side effects of filgrastim	Rare side effects and risks of filgrastim
• Headache	• Allergic reactions	• Shortness of breath and chest pain (1 in 3,000)
• Bone or muscle pain	• Rapid heart rate	• Bleeding of the spleen (1 in 5,000)
• Nausea	• Dizziness	• Bleeding in the head (1 in 5,000)
• Trouble sleeping	• Shortness of breath	• Blood vessel swelling (1 in 5,000)
• Tiredness	• Itching or rash	
• Decrease in blood platelet count	• Eye swelling	

Side effects of filgrastim usually disappear one or two days after the last dose of the drug. Most PBSC donors report full recovery within seven to ten days 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 two days after donation because it decreases the normal blood clotting process. Donors should avoid heavy lifting and contact sports until one week after the donation.

Risks and side effects of the PBSC donation procedure

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 treated with calcium replacement or by slowing down the procedure.

Platelet loss may cause blood to take longer than normal to clot. Donors who experience platelet loss might bruise more easily.

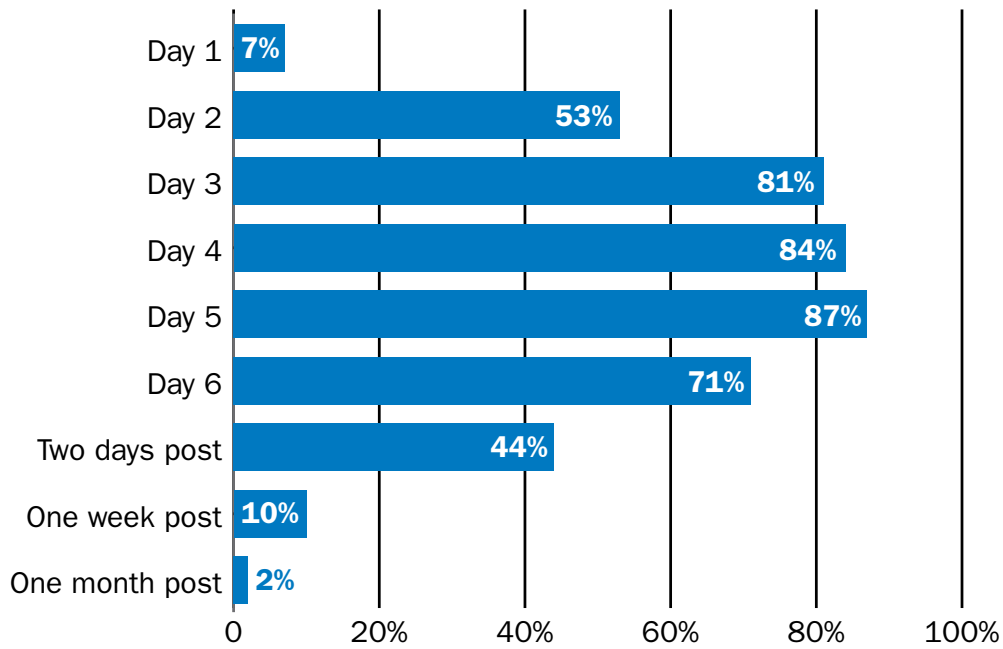
Donors can continue to take acetaminophen or ibuprofen as needed, but they should not take aspirin because it could prolong bleeding.



Cheryl begins the PBSC donation process.

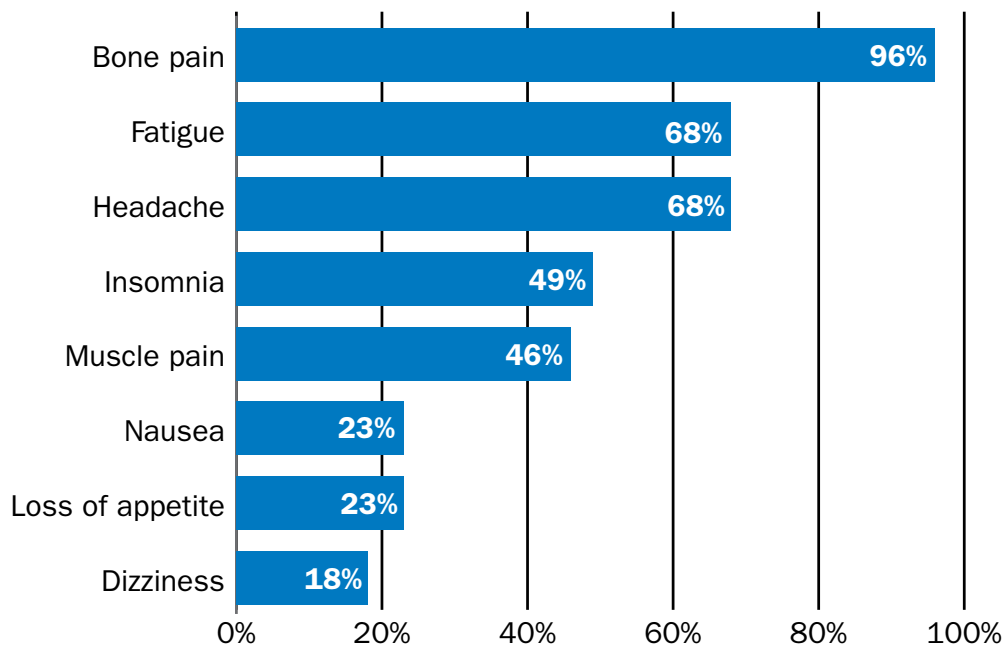
Common side effects of PBSC donation	Less common side effects of PBSC donation	Rare side effects and risks of PBSC donation
<ul style="list-style-type: none"> • Bruising at needle site 	<ul style="list-style-type: none"> • Lightheadedness 	<ul style="list-style-type: none"> • Fainting due to lowered blood pressure
<ul style="list-style-type: none"> • Numbness or tingling 	<ul style="list-style-type: none"> • Nausea 	<ul style="list-style-type: none"> • Infection
<ul style="list-style-type: none"> • Chills 		<ul style="list-style-type: none"> • Nerve injury
<ul style="list-style-type: none"> • Decrease in blood platelet count 		

Donors experiencing pain* from filgrastim injections



*Pain reported in one or more of the following sites: Back, bone, joint, limb, neck and/or hip.

Common side effects reported during injections and donation



Central venous line

If you do not have suitable arm veins, you will 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 in the groin, internal jugular vein in the neck or subclavian vein in the chest. It provides an alternate way to access your veins and enables the apheresis procedure to be performed. In the hospital, a physician will insert the central line. Local anesthesia, such as lidocaine, 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 do not agree to have a central line placed, you will most likely be asked to donate marrow instead.

Based on the NMDP's experience, 19 percent of women and 3 percent of men require a central line placement.

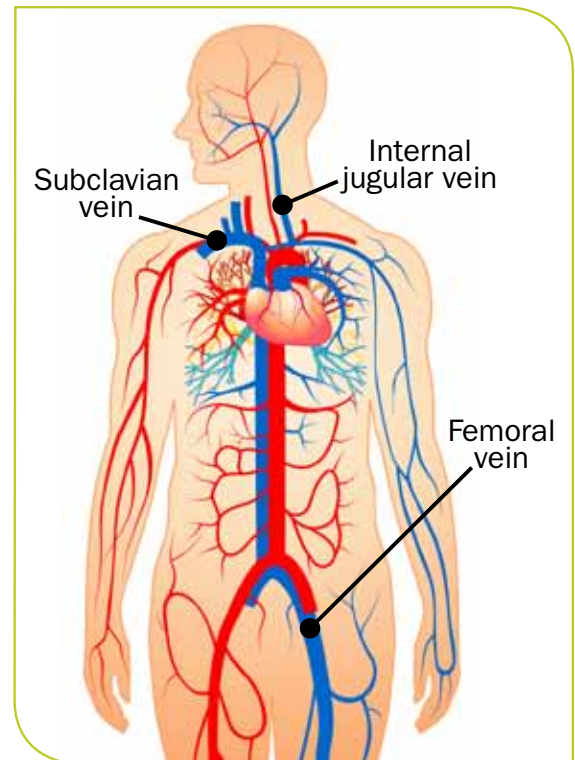
Possible side effects and risks from a central line

The risk of serious complications from the use of a central line for PBSC donations is small. Central lines for PBSC donors will remain in place for only one or two days, which minimize the potential for risks and complications.

Side effects and risks:

- One common risk is that the catheter may not function properly during the procedure. This is not a serious complication, but may require removal of the catheter.
- There is about a 1 percent risk of partial collapse of the lung from insertion of a subclavian line under the collar bone area.
- Bleeding can occur where the central line is inserted.
- Air embolism is a rare complication that may occur when the catheter is inserted, removed or in use if air enters the line connected to the catheter.
- Infection at the insertion site of the central line is rare.

If a central line is needed, you will be given additional information regarding possible risks of placement and be asked to sign a separate consent form.



A central venous line is a sterile tube that is inserted into one of the larger veins—the femoral vein in the groin, internal jugular vein in the neck or subclavian vein in the chest.

“With small veins in one arm, I donated PBSC through my jugular vein by a central line. I was glad I’d scheduled a day off post donation as the fatigue was fairly strong.”

—Tami, PBSC donor and NMDP employee



MARROW DONATION

Tom (left) who joined the registry in 2000, donated marrow to Joey (right) in 2004 when she was diagnosed with leukemia.

Marrow donation

Marrow donation is a surgical procedure that takes place in a hospital operating room. 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. The donation will take place in a hospital that is experienced and participates in marrow collections for the National Marrow Donor Program (NMDP).

Tips to prepare you for your hospital visit

- Do not use aspirin or any medication containing aspirin (e.g., Bayer®, Excedrin®, Anacin®) for at least two weeks before the donation. Aspirin can prolong bleeding.
- Use only acetaminophen or ibuprofen products (e.g., Tylenol, Motrin, Advil) for headache or other minor pain. Specific recommendations vary depending on where your donation takes place.
- Leave all valuables, including jewelry, at home.
- Do not eat or drink anything after midnight on the evening prior to your donation. This is very important because if you do, the donation will be rescheduled.

Pack the following:

- Loose fitting clothes to wear home from the hospital (to accommodate tenderness at the incision sites)
- 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 for the trip home
- Personal identification and emergency contact information



In 2006, Caden (right) was diagnosed with a rare genetic disorder that left him without an immune system. That same year, Karen (left) joined the registry and was identified as Caden's match. Karen went on to donate to Caden in 2007.



To watch a video animation of the marrow donation process, scan this code with your smart phone or visit [BeTheMatch.org/marrowvideo](https://www.BeTheMatch.org/marrowvideo).

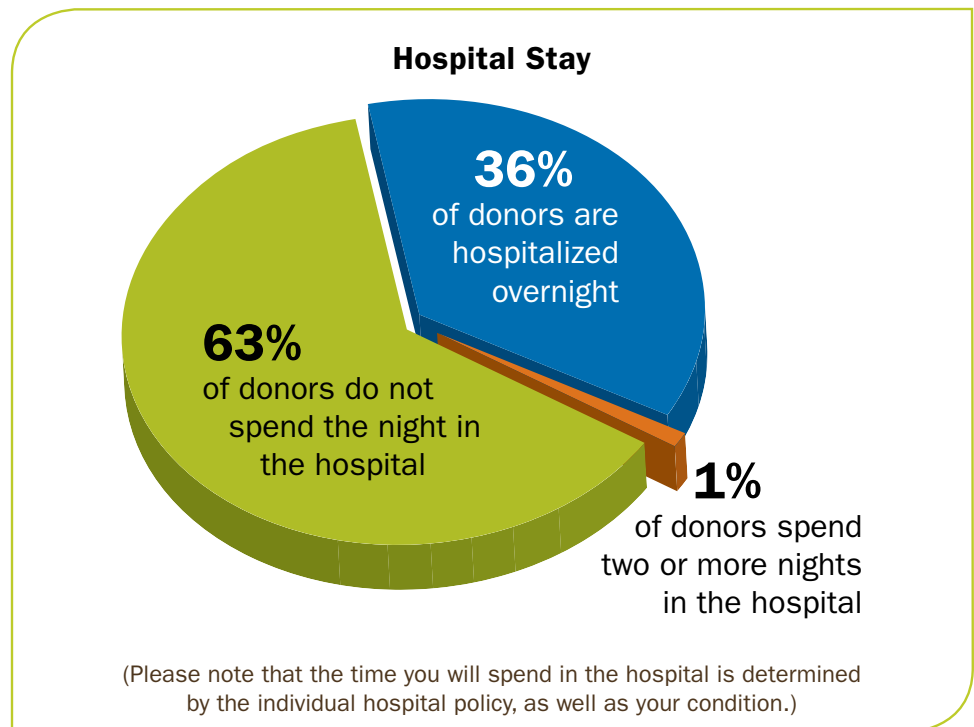
At the hospital



Linda in the hospital before her marrow donation procedure. Linda went on to donate to a 40-year-old male with non-Hodgkin lymphoma.

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 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 make your marrow donation procedure as comfortable as possible. Also, please be aware that delays may occur.



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 96 percent of NMDP marrow donors. The average time of anesthesia is about two hours.

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

“The evening of the donating and the couple days after were painful, but the hospital staff were really caring and the recovery went fast.”

Alan, marrow donor



Alan (front) turned out to be the best match for a young girl, Clarissa (back), who was diagnosed with a rare blood disease. Alan donated marrow to Clarissa in 2007.



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.

“People ask me a lot of questions about how bad bone marrow donation hurt. But you are under anesthesia during the procedure. It hurts some when you are awake, but let me put it this way: I had the procedure on Thursday and was back at work on Monday.”

—Tom, marrow donor

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 hospital collection team is on hand to provide treatment and answers to your questions. Be sure to report anything that concerns you.

Your donor center representative will let you know who to contact if your condition changes after you are discharged from the hospital. Depending on the distance you need to travel to return home, your donor center representative 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:

- Back or hip pain
- Fatigue
- Muscle pain
- Headache
- Bruising at the incision sites

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 of donors experience a full recovery. A small percentage (1.3 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.

“The marrow collection was a cinch. I had a sore back—similar to a strain—but I went for a walk the day after the collection to loosen up. I donated on a Friday and rode my bike to work on Monday.”

—Mary,
marrow and PBSC donor



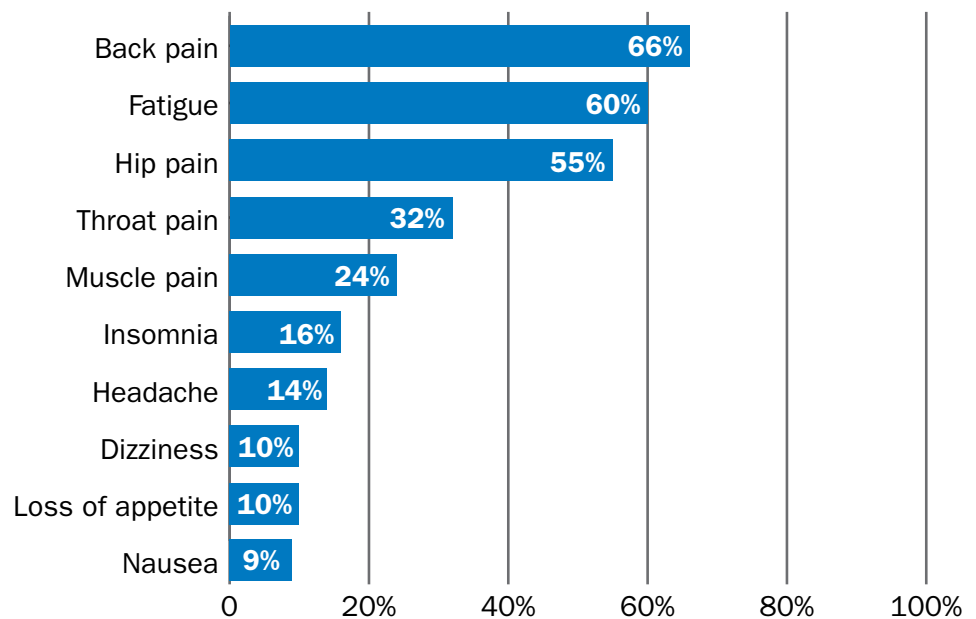
Mary, two-time donor and now an NMDP employee, with her children, whose cord blood was also donated.



“After my marrow donation, when I was ready to leave the hospital, they told me to be sure and pick up my prescription of pain pills. I said okay, but I felt fine. Later on that night, I understood why they told me to take the pills. I did feel a little discomfort. It wasn’t pain; it was stiffness. It lasted for a couple of days and I was able to go back to work afterward.”

—Erma, marrow donor

Common side effects of marrow donation reported two days after donation



Recovery when you leave the hospital

Before you are discharged, your hospital collection team will provide you with self-care instructions for you to follow at home. If you are unsure of any of the instructions, be sure to ask for clarification. Following these instructions is important to your recovery. It is also important to share the information you receive about your care and recovery with your family and friends and to accept their offers to help.

For more information on what to expect after marrow donation, see page 42 in the *After your donation* section of this guide.



AFTER YOUR DONATION

Lori (behind) donated marrow to Jason (in front) when he was just five years old.

PBSC donors

This section offers information about what to expect after donation. If you are a peripheral blood stem cell (PBSC) donor, see below. If you are a marrow donor, see page 42

Possible symptoms or complications

You may experience headaches, or bone or muscle aches for several days before donation. These are side effects of the filgrastim injections that you will receive to increase the number of PBSC in your bloodstream. These side effects disappear shortly after the donation. It is also common to experience some pain and bruising at the injection sites.

Symptoms that require medical attention—PBSC donors

- Increased redness, bleeding, swelling or pain at the needle sites
- Temperature of 100.5° Fahrenheit (38° Celsius) or higher
- Muscle weakness, swollen lymph glands or severe headache within two weeks of donation
- Severe skin rash or flare-up in pre-existing skin conditions such as eczema
- Abdominal pain
- Inflammation in the eyes

Contact your donor center representative or apheresis center if you experience any of these symptoms.

In the event of a life-threatening emergency, call 911 and/or take a copy of these instructions to the Emergency Room.



In 1999, Adam (right) joined the Be The Match Registry. In 2005, Adam donated PBSC to Lamar (left) who was diagnosed with Leukemia in 2004.



“After the donation, the day after I didn’t really feel that bad. There was a little bit of aching in my bones still at that time but I felt pretty much 100 percent 24 hours later.”

David, PBSC donor

Use of pain medications

- Use acetaminophen or ibuprofen products such as Tylenol, Motrin or Advil for minor pain
- Do not use aspirin unless specifically instructed to use aspirin by your doctor; aspirin decreases the blood’s ability to clot and increases the risk of bleeding

Care of needle sites

(If a central line was placed, you will receive a separate set of instructions)

- Keep the bandage on for at least four hours
- If the needle site bleeds, apply firm pressure and raise your arm up straight into the air until bleeding stops (usually five to ten minutes)
- Cold washcloths or ice packs can be used to help reduce swelling, bruising, and bleeding at the needle site during the first 24 hours*
- After the first 24 hours, use a warm, moist washcloth or warm pack

* Note: Do not leave cold pack on longer than 20 minutes at a time and do not reapply for at least an hour.

Physical activity recommendations and limitations

General recommendations

- Return to light activities within 60 to 90 minutes after donation, if you feel well enough
- If you feel lightheaded or dizzy, lie down immediately, raise your feet above your head by resting them on a cushion or chair

Exercise recommendations

- Avoid strenuous activity for the rest of the day after donation
- Do not perform heavy lifting or pulling for seven days
- Do not participate in contact sports for seven days

Work and school recommendations

- Wait 24 hours before operating heavy machinery, climbing ladders or working from heights
- Wait three days before piloting a plane or working as flight crew (it's OK to fly as a passenger)

Dietary recommendations after donation

- Have a snack before you leave the apheresis center and eat a well-balanced meal the evening after your donation
- Drink plenty of fluids (eight to ten glasses of water) for the next 24 hours
- Do not drink alcoholic beverages for the next 24 hours

Recovery time

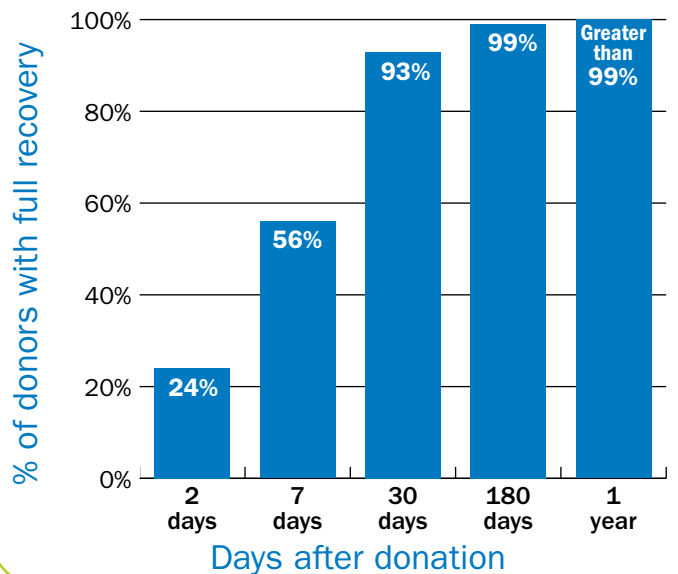
The median time to full recovery for a PBSC donation is one week (seven days).

Pregnancy recommendation

Female donors wishing to become pregnant should consult with their personal physician before becoming pregnant. While there is no adequate or well controlled studies in pregnant women, waiting to become pregnant until the next menstrual cycle after the last dose of filgrastim is recommended.

Similarly, on the absence of clinical data, male donors should wait two days following the last dose of filgrastim to conceive a child.

Recovery after PBSC donation



The following pages offer information about what to expect after marrow donation. PBSC donors, please skip to page 46 to continue reading about what to expect after your donation.

Marrow donors

“After my donation, I had to stay in the hospital a few days because I got an infection. I understand this complication is uncommon, but it did happen to me.”

Jackie, marrow donor



After several years of being listed on the registry, Jackie (right) was selected as the match for Paizley (left). Paizley was born with Sickle cell disease, an illness that gave her chronic lowerback pain and made her tired all the time.

Possible symptoms or complications after donation

- 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 incision sites after the procedure

It is normal to experience some pain, bruising and stiffness during the first week after donation. You may feel more tired than usual and run a low-grade fever the first week. Some clear or pink fluid drainage can be expected. It is common to experience small, hard lumps in the incision area. These lumps might take a few weeks to dissolve.

Symptoms that require medical attention—marrow donors

- **Temperature of 100.5° Fahrenheit (38° Celsius) or higher**
- **Increased redness, bleeding, swelling, drainage or pain at the incision sites**
- **Muscle weakness or severe headache within two weeks of donation**
- **Pain more than 14 days after the donation**

Contact your donor center representative or collection center if you experience any of these symptoms.

In the event of a life-threatening emergency, call 911 and/or take a copy of these instructions to the emergency room.

Use of pain medications

The soreness at the incision sites should go away in about one week. To help ease discomfort:

- Take pain medication as directed. Donors are usually advised to take pain medications around the clock for the first 24 hours after donation.
- Take your pain medication before you absolutely need it and be aware that some pain medications may cause nausea; report any side effects to your donor center representative.
- Do not use aspirin during the first week after the donation unless instructed to use aspirin by your doctor. Aspirin decreases the blood's ability to clot and increases the risk of bleeding. You may take acetaminophen or ibuprofen products such as Tylenol, Motrin or Advil.

Expect the pain to decrease each day. Please call your donor center representative if the pain medication does not ease your discomfort, if your pain is getting worse instead of better, or if you require a refill of your pain medication prescription.

Care of incision sites

- Check incision sites each day for bleeding or increasing redness. Clear or pink fluid drainage is normal.
- Keep the incision sites dry the night after the procedure.
- If you have bandages: 24 hours after the surgery, you may remove the bandages and replace with an adhesive bandage. You may apply some antibacterial ointment before you cover the incision sites with an adhesive bandage. These sites need to be kept clean and covered for three days after the procedure. Note: Showering before you remove the bandage and letting the warm water soak the bandage a bit will help the bandage peel off easier.
- If you have steri-strips: Do not remove the steri-strips—they will work themselves off within several days.
- Do not sit in water until the incisions are healed (no baths or Jacuzzi® tubs, pools, lakes, etc).
- Take only showers for the first two to three days to decrease the risk of infection. Apply a clean adhesive bandage to the incision sites daily after you shower. Blot the area dry with a towel but avoid rubbing.
- If bleeding occurs, apply firm pressure for five minutes, followed by an ice pack. If the bleeding does not stop after 10 minutes of constant, direct pressure, contact a medical professional as directed above.



Valerie (back) was only 11 years old when she learned she had aplastic anemia and had a life expectancy of no more than five years. She underwent several years of intense medical procedures as she waited for a matching donor. She received a transplant from Julie (front) six years later.



“The first week after the surgery I was just sore. I felt that I had worked out too hard at the gym, like I had a bruise in my back. The next week it got better and it continued to get better. After about 2 or 3 weeks I felt nothing at all.”

—Jennah, marrow donor

Physical activity recommendations and limitations

General recommendations

- Do not expect to return to pre-donation activities for about two to three weeks, maybe longer for more strenuous activities
- Plan to take at least a few days off from work, perhaps more if your job is physically demanding
- You may experience difficulty climbing stairs, lifting objects or bending over; do not push yourself to do any of these activities for several days
- Take several rest periods during the day; keep your legs elevated whenever possible
- Keep moving/walk regularly to prevent stiffness
- If you feel lightheaded or dizzy when changing positions, be careful and scale back activities as needed
- Carry a small pillow with you to improve your comfort when sitting
- Get plenty of sleep

Exercise recommendations

Through week one:

- Avoid heavy lifting, bending or exercise
- Avoid lifting more than 10 lbs
- Allow time between periods of heavy activity throughout the day

Through week two:

- Avoid strenuous activity such as jogging or running

Through week four:

- Avoid contact sports

Work and school recommendations

- You should be able to return to work, school and any other activities within one to seven days
- If possible, work a half day upon returning to work, and increase your schedule as you are able
- If your job involves physical labor or heavy lifting, more recovery time may be necessary

Dietary recommendations

In general, your diet should:

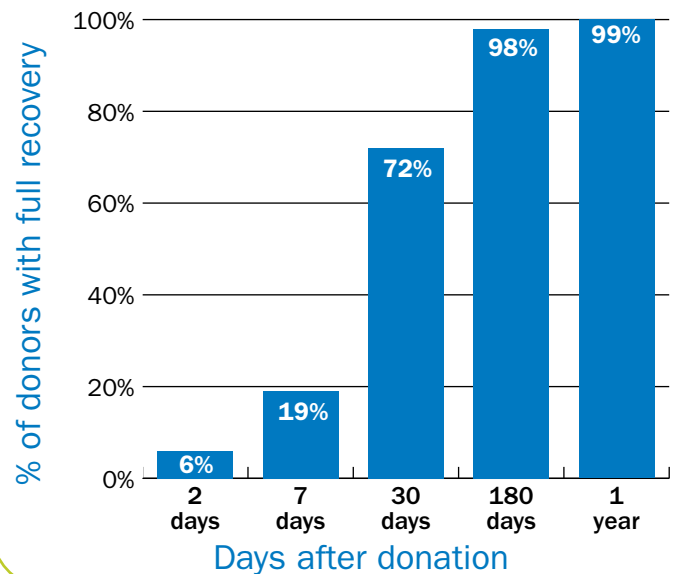
- Be well balanced
- Be high in iron-rich foods such as green leafy vegetables and red meat*
- Include eight to ten glasses of water per day; avoid alcohol and caffeine

*Note: Vitamin C taken with iron-rich foods increases iron absorption. The physician may want you to take iron supplements; specific instructions will be given if supplements are recommended.

Recovery time

The median time to full recovery for a marrow donation is 21 days.

Recovery after marrow donation



PBSC and marrow donors



Cheryl holds her PBSC collection bag before it is physically carried by a trained courier to the transplant center.

Benefits to you

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

Post donation follow-up

For most 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.

We care very much about your safety and want to know about the details of your recovery. Your donor center representative 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. You will be contacted on a regular basis until you report a full recovery.

After that, if you chose to participate in the National Marrow Donor Program's (NMDP) long-term donor follow-up study, the NMDP or your donor center representative will contact you by phone every other year for up to ten years to ask health-related questions. This phone call would take about five to ten minutes. For complete information about the long-term donor follow-up study, contact the NMDP at LTFDU@nmdp.org or (800) 526-7809 ext. 4365.

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.

Requests for subsequent 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:

- T-cells (a type of white blood cell)
- PBSC
- Marrow
- Whole blood
- Platelets

Less than 10 percent of marrow and PBSC donors have donated again for the same recipient. Currently, the most common type of second donation is T-cells (collected by apheresis) followed by PBSC, marrow and whole blood. Recovery and side effects following a second donation of marrow or PBSC appear to be very similar to the first donation.

If you are asked for a second donation, your medical suitability will be evaluated. You are free to say yes or no to the request. Your decision, whether or not to donate, will not affect your standing as a valued donor.

What to do if you receive a medical bill related to your donation

Sometimes by mistake, donors receive a medical bill. You are not expected to pay the bill. **If you receive a bill related to your donation, please do not set it aside, throw it away, or pay the bill.** Instead, call your donor center representative for assistance. They will ask you for a copy of the bill and they will make sure the bill gets resolved. At no time should you have to pay out of your own pocket for medical expenses related to the donation process.

Updates about your recipient

Your recipient's transplant center may provide up to three updates within the first year after transplant. Many transplant centers provide updates about the recipient's condition at or around these times:

- One month after transplant
- Six months after transplant
- One year after transplant

Your donor center representative will let you know if an update on your recipient's health is available. It is important to understand that some transplant centers do not provide updates. Your donor center representative will let you know what you can expect. You should be prepared for the possibility that you may never receive updates on your recipient.

There is also the chance that you will receive unpleasant news about your recipient. Your recipient may suffer a setback or may not survive. We realize hearing this news might be upsetting. Please feel free to contact your donor center representative to discuss your reaction to news about your recipient.



“I was initially encouraged to hear my recipient was out of the hospital and doing great at the three month mark, but she ultimately didn't survive. My continued hope is that she and her family enjoyed some extra time together.”

*Tami, PBSC donor
and NMDP employee*



Chris (right) joined the registry in 1996 and went on to donate in 2002 to Nancy (left) who was diagnosed with leukemia in 2000.

Communication and contact with your recipient

The NMDP is committed to protecting the confidentiality of donors and recipients. It is the law to keep donor and patient information private. The NMDP coordinates transplants around the world. In some regions, contact between donors and recipients is not ever allowed.

Guidelines for anonymous communication

During the first year after transplant, some transplant centers allow donors to send anonymous communication to their recipients. If anonymous contact during the first year is allowed, we will help you exchange letters, cards or small gifts anonymously. Your donor center representative and the recipient's transplant center will check what you send to be sure no identifying details are shared. There is no guarantee that you will get a response.

Anonymous contact means that you cannot include any information that could reveal your name or location. See the detailed guidelines below:

Okay to send	Do not send
Your gender	Names, including initials, nicknames or made up names for yourself, your recipient, friends or family
Your age	Your city, state, geographical region or country – including mention of a landmark, such as the Golden Gate Bridge
Your general profession, such as teacher, but not the name of your employer	Your specific job title, such as Marketing Representative for Target Corporation
Description of your donation experience, without mentioning the name of the center or hospital	The name, location or number of your donor center or hospital
Greeting cards	On greeting cards - the name, address, country of the greeting card publisher, a currency (such as dollars) or a barcode
	Photographs
Small gifts of appreciation	Gifts of high monetary value or gifts that are easily broken
Non-perishable food or candy	Perishable food, such as fruit or baked goods
CDs, tapes and DVDs, in the original wrapping with seals unbroken	Personally mixed or recorded CDs, tapes or DVDs
	Gifts that might imply the location of the sender, such as a CD by a local artist



To see if you can pick out what is okay to send to your recipient and what is not, play the *What Can I Send* game. Scan this code with your smart phone or visit [BeTheMatch.org/guidelinesgame](https://www.BeTheMatch.org/guidelinesgame).



“I have met my recipient, and we’ve corresponded a lot. I’m pleased to report that he’s doing quite well.”

Barbara, PBSC donor and NMDP employee

Contact the Donor Advocacy Program:

Call toll-free
(800) 526-7809
EXT. 8710
or send an email to
advocate@nmdp.org.

Direct contact

Some centers may allow direct contact between donor and recipient one or more years after the transplant. Contact may occur only if both donor and recipient agree. Both donor and recipient must sign a consent form.

Often, both donor and recipient want to communicate and possibly meet. Many donors have met their recipients and reported a good experience with this. Other donors had a more difficult time and reported sharing little in common with their recipient.

Sometimes, the recipient and/or donor choose not to have any personal contact. It is a highly personal decision. You should be prepared for the possibility that you might not learn your recipient’s identity or have any contact with him or her.

Donor advocacy program

Your donor center representative can answer your questions and help with any issues you face. If you need further help, the NMDP Donor Advocacy Program is available.

The Donor Advocacy Program represents the interests, rights, needs and expectations of persons who are or may become volunteer marrow or PBSC donors through the NMDP.

The Donor Advocacy Program provides education and assistance to donors in the following areas:

- Information about the life, disability, and medical insurance coverage for donors
- Potential risks, side effects and complications related to the donation process
- Informed consent
- Financial assistance
- Donor/recipient contact issues
- Paid donor leave
- Unusual circumstances
- Confidentiality
- Donor satisfaction/concerns about your experience as a donor



PATIENT EXPERIENCE

“I’m alive and well today because I had a transplant,” Betsy says (pictured here with her daughters). “I would hope that my donor knows that he’s given me life, and that’s the most generous gift anyone could give me.”

The patient experience

As you move through the steps of the donation process, you may be interested in what the patient who will be receiving your donation is experiencing. At this point, he or she has already been diagnosed with a very serious or life-threatening disease and has learned that a stem cell transplant may be the best, or only treatment option. The patient's doctor has determined that there are no matching donors in the patient's family and they turned to the Be The Match Registry to find an unrelated donor.

The steps of the search for a donor

Step 1: Patient's doctor asks for a preliminary search of the registry

In a preliminary search, the patient's human leukocyte antigen (HLA) tissue type is compared to the HLA types of millions of Be The Match Registry members like you.

HLA are proteins—or markers—found on most cells in the body. The immune system uses these markers to recognize which cells belong in the body and which do not. A close HLA match between patient and donor is the most important factor in selecting a donor for a patient.

Step 2: Patient's doctor reviews the preliminary search results

The doctor receives a list of potential donors and cord blood units that **may** be a match for the patient. These early results may show many or few potential matches. Further testing is needed to find out which, if any, of the potential donors or cord blood units are the closest possible match for the patient.

Step 3: If the patient is not already at a transplant center, his or her doctor will refer them to one

At the transplant center, the transplant team will evaluate the patient's health, disease stage and other factors to decide if transplant is a good treatment option for the patient. Many patients have significant travel to their transplant center due to the need for specialized transplant care. Some patients and their caregivers even need to relocate for the duration of their transplant so they are closer to their transplant center.



Betsy was diagnosed with leukemia and received a bone marrow transplant in 2005.

To read about Betsy's transplant experience, scan this code with your smart phone or visit BeTheMatch.org/Betsy





Ashante was working toward a doctorate and ready to take a job as a counselor and case manager when she learned she had severe aplastic anemia and needed a bone marrow transplant. Ashante received her transplant in 2009.

Step 4: Patient’s transplant center asks for additional testing of one or more potential donors

Further testing is needed to find out whether potential donors or cord blood units listed on the preliminary search results are suitable matches for the patient. A transplant center may test several potential donors or cord blood units to find the closest match for the patient. If a potential donor appears to be a good match, he or she must be contacted to be sure he or she is healthy, willing and able to donate.

Treatment during search

A patient’s health can change while he or she is waiting for a donor to be found or for transplant to take place. For example, a patient may get a severe infection or the disease may come back. Sometimes the patient’s doctor decides it is in the patient’s best interest to delay the transplant. It is important for the patient to be as healthy as possible when they have their transplant to give the best chance of recovery.

Step 5: Transplant doctor selects a suitable donor

YOU ARE AT THIS STEP. The transplant doctor has selected you as a potential donor for the patient. If you agree to donate, you will undergo tests to ensure that you do not have an infection or disease that could be passed on to the patient through the transplant. The tests also make sure donating will not be too risky for you.

Preparing the patient for transplant

Once it is confirmed that a donor is ready to donate, the patient will receive pre-transplant treatment of chemotherapy—with or without radiation. This treatment destroys diseased cells in the patient’s body. The treatment also destroys the blood-forming cells in the patient’s bone marrow to make room for the new cells and destroys his or her immune system so it cannot reject the donor’s cells. If the patient is prepared for transplant and does not receive the transplant, the consequences are usually life-threatening.

The doses of chemotherapy and radiation therapy are much higher than would be used to treat the same disease in a patient who was not getting a transplant. While these higher doses may cause more severe side effects, they may also destroy more disease cells.

The chemotherapy may last six to twelve days. The length and strength of this treatment depends on the patient's disease, his or her age, any previous treatments the patient may have had and whether his or her disease is active.

Some patients get pre-transplant treatment that use smaller doses of chemotherapy and less intense or no radiation. This treatment is called a reduced-intensity or non-myeloablative transplant. This option makes transplants possible for patients who might not be able to tolerate the standard, high-dose regimen.

How the patient receives the new cells

Transplant day usually comes one or two days after the patient completes the pre-transplant treatment. Patients sometimes refer to transplant day as Day Zero or their “second birthday.”

The donation date depends on the patient's health and when he or she will be ready for transplant. On the scheduled date, the donor will donate the marrow or PBSC. A trained courier brings the donated cells to the patient's transplant center within one to two days after they have been donated, and the patient receives the donated cells. The donated cells arrive in blood bags, just like the ones used to collect blood from blood donors.

The cells in the bags are infused (put into the recipient's body) through an intravenous (IV) line, much like a blood transfusion. The recipient will be awake to receive the donated cells; no surgery is involved in the transplant process. The infusion process takes about one hour, sometimes longer, depending on the volume of cells.

The donated cells “know” where they belong in the recipient's body. They move through the recipient's bloodstream to settle in his or her bones. This is where the donated cells will begin to grow and produce new red blood cells, white blood cells and platelets. This is called engraftment.



“I expected the day of my transplant to be a big, happy party day, but instead it was very quiet. I was out of it, because I'd had a lot of chemo and was sedated. Once they brought the bag of marrow cells in, they hooked me up, and I fell asleep.”

“Now, I'm feeling back to normal in some ways, but it's only been a few months. I still need to stay home and rest a lot. I'm not doing the physical things that I used to do, because my body's not there yet.”

*Matthew,
transplant recipient*



Mark (right) was a recent high school graduate when he suffered from a relapse of leukemia and learned he would need a bone marrow transplant. Guy (left) donated marrow to Mark in 2004.

To watch a video of Mark and Guy talking about their donor and patient experiences, scan this code with your smart phone or visit BeTheMatch.org/MarkandGuy.



Recovery after transplant

The period before engraftment is a time of especially high risk for a recipient. Until the donated cells start to grow and make new blood cells, the recipient will have low counts of all types of blood cells. This means the recipient can get an infection easily and infections during this time can be serious, even life-threatening. This is caused by the chemotherapy before the transplant. It is also caused by some drugs the recipient takes after the transplant to prevent graft-versus-host disease (GVHD), a disease where the immune cells from the donated marrow (the graft) attack the body of the transplant recipient (the host).

Over time, the donated cells the patient received start to engraft. The recipient's blood cell counts begin to increase and his or her immune system becomes stronger (although it will be weaker than usual for many months). The transplant essentially gives the recipient a new blood and immune system. Engraftment is an important milestone in the transplant recovery.

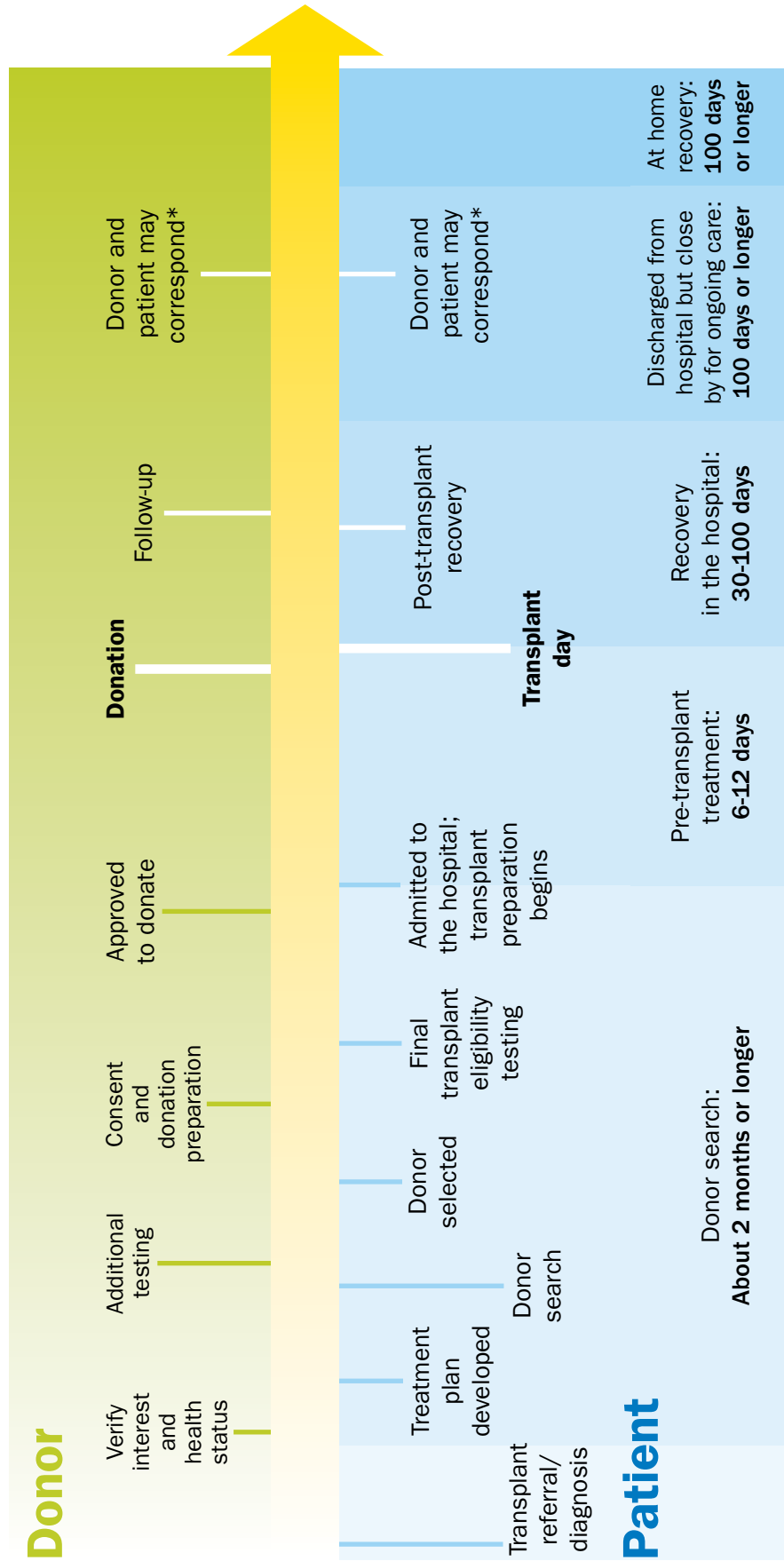
The recipient will stay in or near the hospital during early recovery—generally 100 days or more. In the first months after transplant, the recipient's focus will be on recovery: eating well, avoiding infections, taking medications, getting care from his or her doctor and following other guidelines to stay healthy. Many survivors say recovery takes at least a full year. However, a recipient may feel better more quickly or more slowly. In time, the recipient will probably be ready to return to work or school and other activities.

Donor and patient timeline

The timeline on the next page is designed to give you an idea of how the donation process impacts the patient's transplant process. The donor events are listed on the top half of the chart, while the patient events and timeline are listed on the bottom half.

It is important to remember that the transplant timeline varies based on the patient, type of disease, disease stage for the patient and the patient's transplant center. Postponements of transplants are common and can alter the donation and transplant timeline.

Donation and transplant timeline



Timeline created in conjunction with the University of Minnesota Blood and Marrow Transplant Program

*During the first year after transplant, some transplant centers allow anonymous communication between donors and recipients. One or more years after transplant, some centers allow direct contact between donors and recipients if both consent. Some centers do not allow contact between donors and recipients at any time.

Transplant outcomes



Steve (left) donated marrow to Ryan (right). They met for the first time in 2011.

Since 1987, the National Marrow Donor Program (NMDP) has facilitated more than 43,000 transplants for patients who did not have a suitable donor in their family.

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

- Disease being treated
- Stage of the disease
- Recipient's age and general health
- Degree of match between the donor and recipient

In general, younger recipients do better than older recipients. 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, the overall survival rates for recipients (two to three years after transplant) are generally in the 30 to 60 percent range.

Without a transplant, many of these diseases are incurable with poor long term-survival.

Thank you!

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

On behalf of Be The Match and your local NMDP representatives, thank you for considering becoming a marrow or PBSC donor.

Glossary

Allogeneic transplant

Any bone marrow/peripheral blood stem cells (PBSC) transplant in which the cells come from another person rather than the patient's own cells. The donated cells can come from a related or unrelated donor.

Autologous transplant

A bone marrow/peripheral blood stem cells (PBSC) transplant in which the patient's own cells are used.

Anesthesia

Used to block the pain before and during the marrow donation procedure. There are two types of anesthesia used in marrow donation: general and regional.

Apheresis

A procedure where blood is continually drawn from a donor's arm and circulated through a machine that removes the requested cells such as stem cells or white blood cells while the rest of the blood is returned to the donor.

Apheresis center

A medical clinic, hospital or blood center that meets National Marrow Donor Program (NMDP) membership criteria, including experience and facilities to collect peripheral blood stem cells (PBSC) and white blood cells through apheresis and to care for donors before and after the donation procedure.

Autologous blood donation

The process of donating blood prior to a scheduled surgery that will be stored and saved for use during or after the donor's surgery.

Blood forming cells (sometimes called blood stem cells)

Cells found in the bone marrow and blood that can grow into a red blood cell, a white blood cell or a platelet.

Bone marrow transplant (BMT)

A medical treatment to replace a patient's damaged bone marrow with healthy marrow/peripheral blood stem cells (PBSC). There are two types of transplants: allogeneic and autologous.

Bone marrow

A spongy tissue inside of large bones where the body's blood cells (red cells, white cells and platelets) are made.

Central venous line

A sterile, flexible tube that is inserted into one of the larger veins—the femoral vein in the groin, internal jugular vein in the neck or subclavian vein in the chest. It provides an alternate way to access a donor's veins and enables the apheresis procedure to be performed.

Collection center

A hospital that meets National Marrow Donor Program (NMDP) membership criteria, including experience and facilities to collect marrow and care for marrow donors before and after the donation procedure.

Engraftment

Marrow/peripheral blood stem cells (PBSC) given to the patient during the transplant start to grow and make blood cells.

Filgrastim

Filgrastim is also known as GCSF (granulocyte-colony stimulating factor) or by the tradename Neupogen®. It is given by injection to donors who have agreed to donate peripheral blood stem cells (PBSC). Filgrastim stimulates the bone marrow to make more blood stem cells and moves them from the marrow into the bloodstream so that they can be collected by apheresis.

General anesthesia

Medicine used to temporarily put the donor into a deep sleep, so they don't feel pain during the marrow donation procedure.

Graft versus host disease (GVHD)

A condition where some of the transplanted donor marrow or peripheral blood stem cells (PBSC) attack the patient's body. GVHD can be mild or severe and is sometimes life-threatening.

HLA (Human Leukocyte Antigen) markers

Proteins on white blood cells that make each person's tissue unique. The HLA markers are important in matching patients and donors for a marrow or peripheral blood stem cell (PBSC) transplant.

HLA (Human Leukocyte Antigen) type (sometimes called tissue type)

A person's markers include HLA A, B, C and DR proteins.

Infectious disease markers (IDMs)

Elements in a person's blood which indicate if a person has had an infectious disease.

Glossary *(Continued)*

Infectious disease testing

Tests performed on a sample of the donor's blood to determine whether their marrow or peripheral blood stem cells (PBSC) could transmit disease to the patient.

Marrow donation

A surgical procedure by which a person donates a portion of their bone marrow from the pelvic bone for a patient who has diseased marrow and needs a bone marrow transplant. The donor's marrow typically replaces itself within 4 to 6 weeks.

National Marrow Donor Program

The National Marrow Donor Program (NMDP) is dedicated to ensuring all patients who need a transplant receive access to this potentially life-saving treatment. Headquartered in Minneapolis, the nonprofit organization:

- Manages the Be The Match Registry®
- Facilitates transplants worldwide
- Conducts research
- Provides education and support to patients, donors and health care professionals

The U.S. government has entrusted the NMDP to operate the *C.W. Bill Young Cell Transplantation Program* and serve as a single point of access to potential donors for a global network of hospitals, blood centers, public cord blood banks, laboratories and recruitment centers.

Peripheral blood stem cell (PBSC)

Peripheral blood circulates through the bloodstream in the body. Some blood stem cells are found in the peripheral blood.

Peripheral blood stem cell (PBSC) donation

Blood stem cells are collected from a donor's circulating blood through an apheresis procedure following five days of receiving filgrastim injections. The PBSC is then transplanted into a recipient.

Regional anesthesia (spinal and epidural)

Medicine used to temporarily numb a large area of the donor's body so they don't feel pain during the marrow donation procedure. The donor is awake, but sedated to make them feel sleepy and less anxious.

Registry

The Be The Match Registry is a confidential national database of potential volunteer marrow donors established and maintained by the National Marrow Donor Program (NMDP).

Transplant center

A hospital that meets National Marrow Donor Program (NMDP) membership criteria, including experience, staff and facilities to perform allogeneic stem cell transplantation.



The information in this guide is also available online at **BeTheMatch.org/donationguide.**

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The National Marrow Donor Program is entrusted to operate the C.W. Bill Young Cell Transplantation Program, including the Be The Match Registry®.

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