Tiana (right) donated blood stem cells to Donna

You're a Match

A Donor's Guide to Donation

nmdp℠

FIND CURES. SAVE LIVES.

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


Amy Ronneberg,
Chief Executive Officer

You could be someone's cure

When you joined the NMDP Registry^{SM}, you joined knowing one day you might be a match for a patient with a blood cancer like leukemia or lymphoma or another life-threatening blood disorder.

That time is now: A doctor has identified you as a match for their patient who needs a life-saving transplant.

We have the rare opportunity to work together to potentially give someone a second chance at life and we are profoundly grateful for the time and effort you have already devoted to NMDP^{SM}. Thank you for considering becoming a marrow or peripheral blood stem cell (PBSC) donor.

This guide will help you learn more about the donation process and how the NMDP team works closely with you on the details and supports you throughout the donation journey.

Becoming a donor is an important commitment and we know there is a lot to think about throughout this process. We're here for you every step of the way. Your representative will work with you to answer your questions and 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. Whatever decision you make will be respected.

You could be someone's cure. We deeply appreciate your commitment to saving a life.

Amy Ronneberg

AMY RONNEBERG
CHIEF EXECUTIVE OFFICER

This guide will explain:

- Why you have been called
- Steps of the donation process and blood tests involved
- Your time commitment
- Risks and side effects
- Two different methods of donation
- 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 REPRESENTATIVE:

DONOR CENTER REPRESENTATIVE CONTACT INFORMATION:

MY GRID DONOR ID NUMBER:

COLLECTION CENTER OR APHERESIS CENTER:

NOTES:

NMDP
1 (800) MARROW-2

500 N 5TH St.
Minneapolis, MN 55401-1206

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

Table of contents

BECOMING A DONOR

PBSC DONATION

MARROW DONATION

AFTER YOUR DONATION

PATIENT EXPERIENCE

The donor and patient testimonials throughout this guide are selected and 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 to make an informed decision to donate.

Statistics in this guide are derived from data captured by NMDP through December 2020. This data represents unrelated donors from the United States who donated for the first time in the years 2007 to 2024.

Ketan, marrow donor, with his wife and two children

Becoming a donor

"We were initially very shocked that I was a match for someone so soon after joining. My wife had been on the registry for years before I joined and was so supportive when I got the call."

–KETAN, MARROW DONOR,
WITH HIS WIFE AND TWO CHILDREN

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 NMDP Registry, you agreed to consider donating cells from your marrow or blood to possibly help any patient in the world. You gave a blood or tissue sample when you joined. That sample was tested to determine your tissue type and the test results were listed on the Registry.

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

If you agree to donate, blood-forming cells collected from your marrow or bloodstream (which are PBSCs) will be transplanted into the patient to replace their marrow. A marrow or PBSC transplant can often help patients with leukemia, lymphoma, sickle cell disease and other life-threatening diseases live longer, healthier lives.

A transplant requires carefully matching the tissue type of the donor and the patient. Tissue type is inherited, so 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:

- Complete a Health History Screening Questionnaire
- Learn more about the process
- Make an informed decision about donating

"Donating is such a small investment for such a large return. I equate it to me giving a single dollar—and that dollar is worth a million dollars to the person receiving it."

**–KAWIKA,
MARROW DONOR**

Understanding your involvement

Health History Screening Questionnaire

The Health History Screening Questionnaire that you may have done at an earlier stage was helpful in establishing your suitability for donation. To assess your current state of health and suitability, we need to do a Health History Screening Questionnaire in preparation for the physical exam. The Health History Screening Questionnaire must be completed within 12 weeks of the donation date. If more than 12 weeks have passed, the Health History Screening Questionnaire will need to be completed again.

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 ensure donating would not pose any undue risk to you or the patient.

The typical time commitment for the donation process is 20–30 hours spread out over a four-to-six-week period. This does not include travel time, which may include air travel and staying overnight in a hotel. The majority of donors are likely to travel during the donation process, whether within or out of state.

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

- Scheduling
- Patient's condition
- Travel requirements

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 associated with 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 a range of emotions. These may include stress or anxiety about the process, excitement about the opportunity to help a patient, disappointment over delays or cancellation or sadness about the patient's situation. All of these feelings are normal and we are here to help support you with our donor counseling services. Because of the strong emotions a donor may experience, donating may not be appropriate for everyone. Our Donor Services social worker is here to support you throughout your donation journey. For more information, please reference the **Donor Support Services** section (next page).

"When Emily found out she would have to travel to the NMDP collection center in Seattle, to help a man battling a rare blood cancer, she didn't hesitate. "I have had no reservations about the entire thing," she said. "This has been, literally, the easiest decision and process I've ever been through in my entire life and I'd do it again."

–EMILY, PBSC DONOR

SUITABLE DONOR
A donor who has been evaluated and determined to meet all medical guidelines as defined by NMDP to ensure the donor is healthy enough to move forward with donation.

Donor support services

Donor counseling

Going through the donation process can be challenging for a variety of reasons. If at any point you would like to process your thoughts or feelings, we have a licensed counselor available to support you. The counselor can help you to identify and resolve personal, social and emotional challenges related to donation. The counselor can also suggest coping strategies to improve your quality of life.

Donor Connect

Our Donor Connect program partners you with a trained mentor who has gone through the process of donating marrow or PBSC to a patient. No matter where you are in the donation process, past donors are available to connect with you by phone or email. They can answer your questions and provide tips from their own donation experience.

Donor Community

Our Donor Community is a closed Facebook group that connects registry members called as a potential match with donors who have gone on to donate either marrow or PBSC. The goal of the Donor Community is to provide a space for community and support as well as educate members. For information on how to join the Donor Community, please reach out to your donor center representative.

> "I received all the support I could ask for from my family; all of them told me to do it and keep going with the donation process. They told me they were very proud of me."
>
> **–GRACE (SECOND FROM RIGHT), MARROW DONOR, WITH HER FAMILY**

“A year and a half after his stem cell donation, Levi was able to contact, then meet, his recipient, Amanda, for the very first time. “There is not that big of a gap between somebody you love dearly and a stranger. Our paths crossed from this experience and now we’ll be connected forever.”

–LEVI, MARROW DONOR

Donor Advocacy Program

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

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 Registry.

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

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

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.

To learn more from past NMDP donors about how valuable family and friend support is throughout the donation process, visit our Donor Testimonial Library on our website. NMDP created toolkits to help you navigate talking about blood stem cell donation with the key people in your life. Feel confident in sharing your reasons for donating and answering any questions with the donor toolkits. You can find these resources on our website.

Toolkits include:

- Talking with your spouse or partner
- Talking with your parents
- Talking with your friends
- Talking with your employer
- Talking with your children
- Talking with your educators

CONTACT THE DONOR ADVOCACY PROGRAM:
Call toll-free
1 (800) 526-7809 ext. 8710
or send an email to
advocate@nmdp.org

If you don't have support from your friends or family, you can work with your donor center representative for support during the donation process. We welcome all donors to join our private Donor Community on Facebook or request a donor mentor through our Donor Connect program. Further details on these resources and how to access them can be found in the Donor Support Services section (page 11).

Expense

NMDP covers the cost of exams, medical care, transportation and other expenses related to donation. Donors are reimbursed or have the option of a cash advance or gift card to cover any additional out-of-pocket expenses. 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.

Some 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. Your representative can help you work with your employer or discuss other financial resources that may be available to you.

We cover 100% of donor expenses

Medical

- Lab tests
- Appointments
- Donation procedure

Travel (+1 companion)

- Accommodations
- Transportation
- Mileage
- Parking
- Meals

Personal

- Childcare
- Pet boarding

Professional

- Lost wage reimbursement

Plus, we'll consider covering any expenses not listed here on a case-by-case basis.

The steps leading to donation

When Camille, PBSC donor, got the call she was a match for someone, she was very shocked. She was getting married three weeks after the donation date and was concerned about the time commitment. Despite the reservations from her family, Camille worked with NMDP to make sure the donation worked within her schedule and went on to donate.

The steps to prepare for marrow or PBSC donation are generally the same for all donor centers, but 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 voluntary participation in research studies
5. Receive a physical exam
6. Give blood samples

Marrow donation	PBSC donation
1. Autologous blood donation, if required	1. Receive filgrastim or an FDA-approved similar
2. Pre-op appointment, if required	2. Apheresis procedure
3. Marrow donation	3. Follow-up with donor center representative
4. Follow-up with donor center representative	

AUTOLOGOUS BLOOD DONATION
The process of a donor donating blood prior to a marrow donation that will be stored and saved for use during or after the donation.

FILGRASTIM AND ITS FDA-APPROVED SIMILARS
Filgrastim is also known as G-CSF (granulocyte-colony stimulating factor) or by the trade name Neupogen®, Nivestym®, Zarxio®, Granix® and Releuko®. It is given by injection to donors who have agreed to donate peripheral blood stem cells (PBSCs). Filgrastim stimulates the marrow to make more blood-forming cells and moves them from the marrow into the bloodstream so that they can be collected by apheresis.

NOTE: Donating PBSC for unrelated transplants is done under an FDA (U.S. Food and Drug Administration) regulated clinical research study. Therefore, if you are requested for a PBSC donation, you will be asked to sign a study-specific consent form before beginning the donation process. Please see the PBSC Donation section (page 25) of this guide for more information. Your donor center representative will discuss details of the study with you during the information session and consent process. If you choose not to donate PBSC, you may be asked to donate marrow.

Information session

You will have an information session with your donor center representative to learn about the donation process. This session is designed to make sure 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 any 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 marrow or PBSC. We want you to be fully informed and read about both types of donations. You will be informed which donation procedure is being requested and why.

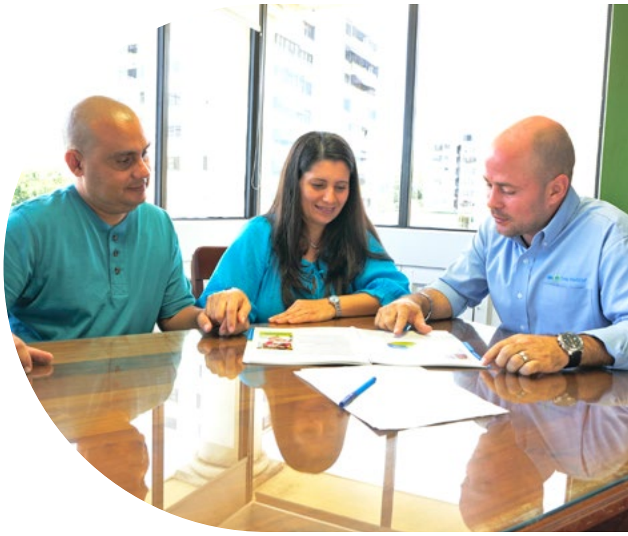
If you do not wish to donate using the requested method but would consider donating using the other method, tell your donor center representative.

At the information session, you will:

- Learn about the donation process and the risks and side effects associated with both marrow and PBSC donation
- Review the proposed donation schedule
- Receive 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
- Learn about additional research in which you may be asked to participate
- Receive more details about the expenses NMDP will cover related to your donation
- Learn about the life, health and disability support NMDP provides for donation
- Discuss the possibility of receiving updates on your recipient's condition after transplant as well as corresponding with your recipient

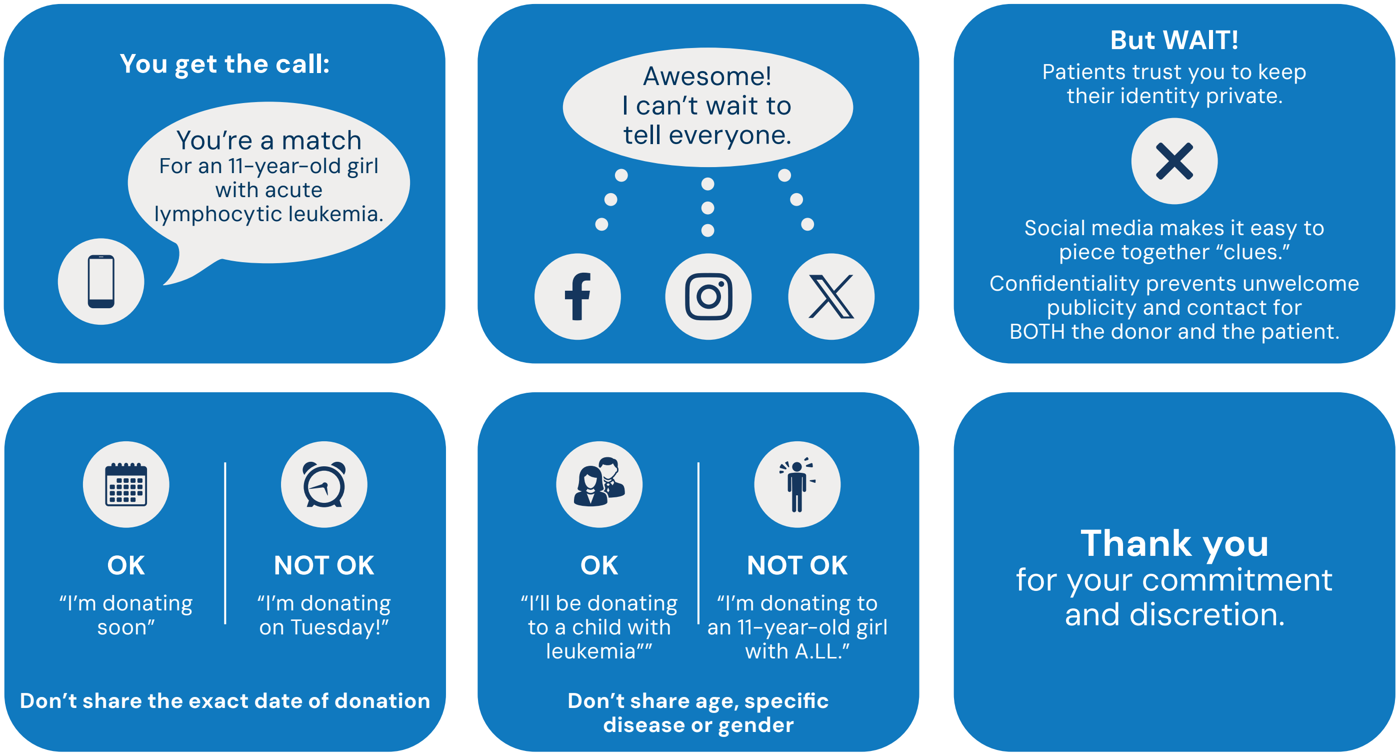
If further assistance is requested, you have access to someone in our Donor Advocacy Program. For more information about this program, see page 12.

Please ask your donor center representative if you'd like to speak with someone who has already donated. We welcome all donors to join our private Donor Community on Facebook or request a donor mentor through our Donor Connect program. Further details on these resources and how to access them can be found in the **Donor Support Services** (page 11) section.



> "The information session happened both by phone and in person. I remember there were a lot of questions, but I already made up my mind that I was going to donate."
>
> **–ELIZABETH, PBSC AND MARROW DONOR, WITH DAVID, NMDP REPRESENTATIVE**

Guidelines for social media sharing



You get the call:

You're a match
For an 11-year-old girl with acute lymphocytic leukemia.

Awesome!
I can't wait to tell everyone.

But WAIT!
Patients trust you to keep their identity private.

Social media makes it easy to piece together "clues."

Confidentiality prevents unwelcome publicity and contact for BOTH the donor and the patient.

OK
"I'm donating soon"

NOT OK
"I'm donating on Tuesday!"

Don't share the exact date of donation

OK
"I'll be donating to a child with leukemia""

NOT OK
"I'm donating to an 11-year-old girl with A.LL."

Don't share age, specific disease or gender

Thank you
for your commitment and discretion.

Share the excitement, but share with care

Confidentiality

NMDP is committed to protecting the privacy of both patients and donors. It is the law to keep donor and patient information private. 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.

If you would like to share your donation experience on social media, we support that; however, we ask you to respect the confidentiality guidelines shown above. For an online version of the Guidelines for Social Media Sharing infographic shown above, visit **nmdp.org/socialmediaguidelines**.

Please see the Communication and Contact with Your Recipient section (page 52) of this guide for more information on communication and confidentiality.

Consent to donate

Feel free to ask questions about donating during your information session. 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 or 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 (page 55) of this guide for more information on the transplant process.

> "The way I look at it is being sore for a couple days and a few doctors appointments is nothing compared to helping ... somebody else enjoy another holiday with their family. I think it's really worth it in that regards."
>
> **–RYAN, PBSC DONOR**

The NMDP℠ Biorepository collects paired donor-recipient blood samples. They send them to researchers studying transplant outcomes data to learn more about how matching and other factors affect transplant outcomes.

Consent to participate in research

If you decide to become a donor, you will be invited to participate in research studies. The purpose of our research is to help future patients in need of a transplant and to ensure donor safety. You may also be asked to participate in research studies your patient is enrolled in. These studies are conducted by the patient's transplant center. Participation in research is voluntary. You may choose not to participate in research studies and still donate.

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

- To allow information related to your donation to be added to our research database
- To donate a blood sample for research to be stored in our Research Sample Repository
- To be involved in additional research projects

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 examining practitioner is not involved with the care of the patient—this is to assure you that your welfare is their only concern. The exam is not a substitute for the routine health care you receive from your personal doctor.

The exam will include:

- A review of medical history
- 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 31 for more information.
- Blood tests (complete blood count, chemistry/metabolic profiles, infectious disease markers and sickle cell testing). Each blood collection for testing takes a few teaspoons of blood.
- A pregnancy test if you are a woman of child-bearing potential. Pregnancy testing is required to be repeated prior to donation.
- Other tests may be required by the doctor, such as a chest X-ray, electrocardiogram (EKG) or an urinalysis.

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. At this time, we may also find that you are only able to donate marrow or PBSC, but not both. This is for your safety.

If more than 12 weeks pass between the exam and the donation, you may be asked to repeat some of the initial steps. For example, giving blood for additional/repeat testing, repeating your physical exam and/or completing your Health History Screening Questionnaire. This may include a phone call to review information from your first exam. It will depend on how much time has passed between your first exam and the scheduled donation. Keep in mind that a current physical exam must be completed within six months of the donation date.

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

Before donation and on the day of donation, you will need to give several blood samples.

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 a 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.

"I am just so excited to be able to donate. It's a dream come true here for me."

–MITCH, PBSC DONOR AND NMDP EMPLOYEE

If more than 30 days have passed from the time of your most recent infectious disease testing until the day of donation, federal regulations 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. Your marrow collection center may ask for you to donate your own (autologous) blood based on their internal policy and/or the amount of marrow requested by the patient's doctor. If required, your donor center representative will arrange for you to donate and store it in advance. If you have not been asked to donate your own blood and in the very rare event that a transfusion is needed, an allogeneic (not your own) blood transfusion will be given.

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

Complete blood count (PBSC donors only)

You receive injections of filgrastim for five days before donating PBSC. This blood test is required on the fifth day you receive filgrastim, which is also your donation day. 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.

Research samples (optional)

If you agree to participate in the 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 and to ensure donor safety. Research done with these blood samples is intended to improve the outcomes for future patients and donors.

Cleared to donate

After you have been cleared to donate, your donor center representative will contact you to confirm scheduling details. You will not travel to the patient's location to donate but, depending on the patient's treatment timeline and where you live, you might be required to travel to donate. Your donation will take place at a hospital or apheresis center. You are encouraged to bring one companion with you to the donation. Expenses are covered for you and that companion. The role of your companion is to support you before, during and immediately following your donation. A trained courier will accompany the marrow or PBSC to the patient's location, which could be anywhere in the world.

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 the treatment begins, he or she will likely die within a short amount of time.

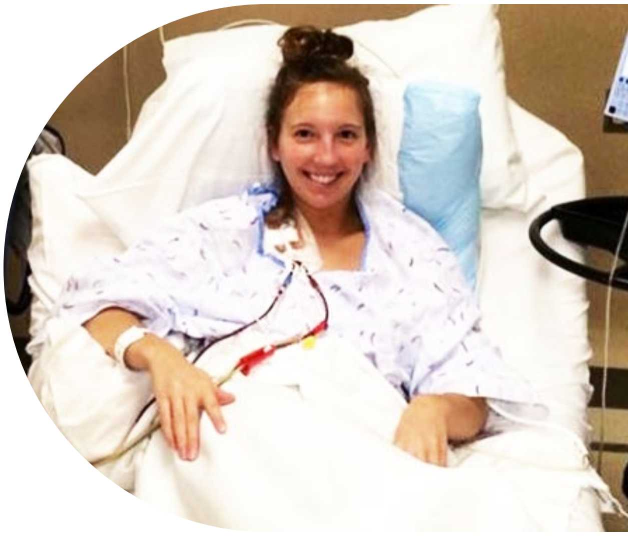
Cryopreservation

In some cases, the doctors treating the patient may request that your cells be cryopreserved before they are infused into the patient. Your coordinator will let you know if the request is for cryopreserved cells and you will be given the opportunity to give your verbal consent to having your cells cryopreserved. In these cases, cells will be infused when the patient is ready for transplant.

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. We realize how difficult it can be and appreciate your patience. 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 have been found.



"Being given the opportunity to donate and potentially save someone's life was a truly amazing experience. Everyone I came into contact with during my donation process was delightful and very accommodating. Each individual was willing to work with what I could do given my busy schedule at the time."

–AMY, PBSC DONOR

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

Joey, PBSC donor

PBSC donation

> “Being on this registry and helping others in this very small, simple way ... could make a world of difference to both the person that you’re helping and yourself.”
>
> **–JOEY, PBSC DONOR**

Peripheral blood stem cell donation

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. The donation will take place in a hospital or apheresis center with experience collecting PBSCs for NMDP.

So that you are able to donate enough PBSCs for a transplant, more of the cells need to be moved out of the marrow and into the bloodstream. One proven way to do that is by taking is by taking filgrastim or an FDA-approved similar (Nivestym, Zarxio, Granix, or Releuko), drugs 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.

Use of filgrastim and its FDA-approved similars

Filgrastim and FDA-approved similars stimulate the marrow to make more blood-forming cells and move them from the marrow into the bloodstream so that they can be collected by apheresis. This process has been in place since the mid-1990s to aid in PBSC donation. The data we collect from donors helps establish if there are any positive or negative effects from receiving filgrastim or filgrastim similars. Based on available data from approximately 45,000 donors who have received filgrastim, no late-appearing risks have been found.

Donors receiving filgrastim or its FDA-approved similars should not take aspirin because it affects the normal blood clotting process. Donors can take non-aspirin products (such as Tylenol®, Motrin® or Advil®) instead. Because filgrastim may cause spleen enlargement, donors should also avoid strenuous activity, vigorous exercise, heavy lifting and contact sports during filgrastim injections and up to one week following donation.

PBSC studied under a protocol with the FDA

The process of donating PBSCs is under a clinical research study reported to the 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 or FDA-approved similar injections.

Huy Pham, MD, medical director at NMDP Seattle Collection Center

“They told me I was going to get some shots and I got the shots over five days. I don’t like needles, so it wasn’t very fun—but it also wasn’t so bad. And the worst of it, for me, was that I had some aches and pains some nights. Other than that, I got to sit down for five hours during the donation and just relax. It was something I like to do anyway.”

–DEREK, PBSC DONOR

“My bones were sore for a couple of days, not a big deal. Donating was not hard at all. The price that I paid doesn’t compare to the benefit of saving someone’s life.”

–AUSTIN, PBSC DONOR

Preparing to donate PBSC

Day one

It is recommended that the first dose of filgrastim or FDA-approved similar be given in a clinical setting. On the first visit, you will be weighed and your vital signs will be monitored. Typically, the injection(s) 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.

You will be observed for at least 15 minutes following the first dose. 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, you will be treated as necessary and observed for at least another 45 minutes. Less than 1% of donors have an allergic reaction, which may include skin rash or shortness of breath.

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

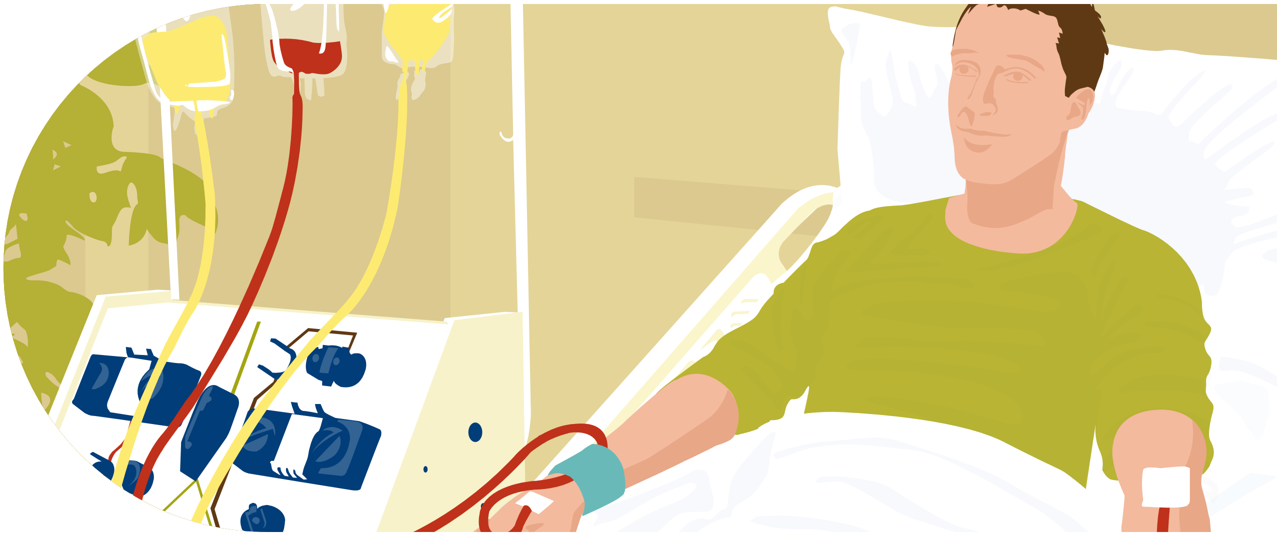
Days two, three and four

The following three doses may be administered by a health care professional in the donor’s home, workplace or other location, such as a donor center or medical clinic. In limited circumstances, those doses may be self-administered. Your donor center representative will discuss the scheduling options with you. Before each daily injection, you will have your temperature, pulse and blood pressure checked. The dose may be adjusted as needed based on the symptoms you report.

Day five

Your fifth and final dose of filgrastim or an FDA-approved similar will be given at the blood collection center or hospital where your donation will take place. Blood will be drawn to measure your complete blood cell count. After this, you will begin donating.

(In rare cases, a two-day collection may be needed. If so, a sixth dose may be necessary to help ensure we meet the cell dose requested by the transplant center.)



The PBSC donation process

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

98% of all PBSC donations are completed in one apheresis session, which may take up to eight hours. The remaining 2% of donations are completed in two apheresis sessions, which may take four to six hours on two consecutive days.

Risks and side effects of filgrastim and similars

Fewer than 1% (0.6%) of PBSC donors experience serious side effects.* The data 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 late-appearing risks have been found.

PBSC donors receive injections of a drug called filgrastim for five days leading up to donation.

Common side effects of filgrastim

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

Less common side effects of filgrastim

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

Rare side effects and risks of filgrastim

- Shortness of breath and chest pain (1 in 3,000)
- Bleeding of the spleen (1 in 5,000)
- Bleeding in the head (1 in 5,000)
- Blood vessel swelling (1 in 14,000)

To learn more about filgrastim injections and PBSC donation from Jeff, an NMDP PBSC donor, visit: nmdp.org/jeffvideo

Side effects of filgrastim usually disappear 48 to 72 hours after the last dose of the drug. Most PBSC donors report full recovery within seven days of donation. Until then, donors can take non-aspirin products (e.g., acetaminophen or ibuprofen) such as Tylenol, Motrin or Advil for their discomfort. Donors should not take aspirin for 14 days before and after donation because it decreases the normal blood clotting process. Some collection centers have different practices regarding pain control. Your representative will notify you if your center follows different guidelines. Donors should avoid heavy lifting for one week, strenuous activity for two weeks and contact sports for one week after the donation.

---

*Pulsipher MA, Chitphakdithai P, Logan BR, et al. Lower risk for serious adverse events and no increased risk for cancer after PBSC vs BM donation. Blood. 2014; 123(23): 3655–3663.

Risks and side effects of the PBSC donation procedure

Aaron, PBSC donor, proudly showing his blood stem cells after his donation was complete

While donating PBSC, some donors experience tingling around the mouth, fingers and toes and mild muscle cramps. This is caused by the anticoagulant (blood thinner) used in the apheresis procedure. These symptoms are treated with calcium replacement (oral or intravenous (IV)) or by slowing down the procedure. These symptoms will subside shortly after the donation. Rarely, some donors may need to continue calcium or other electrolyte replacement for several days after donation.

Following completion of PBSC donation, your platelet counts may be low for three to five days. Platelet loss may cause blood to take longer than normal to clot. Donors who experience platelet loss might bruise more easily.

Donors can take non-aspirin products (e.g., acetaminophen or ibuprofen) such as Tylenol, Motrin or Advil as needed, but they should not take aspirin because it could prolong bleeding. Donors should not take aspirin for 14 days before and after donation because it decreases the normal blood clotting process. Some collection centers have different practices regarding pain control. Your representative will notify you if your center follows different guidelines. Donors should avoid heavy lifting and contact sports and strenuous activity until one week after the donation.

Common side effects of PBSC donation

- Bruising at needle site
- Decrease in blood platelet count
- Numbness or tinging

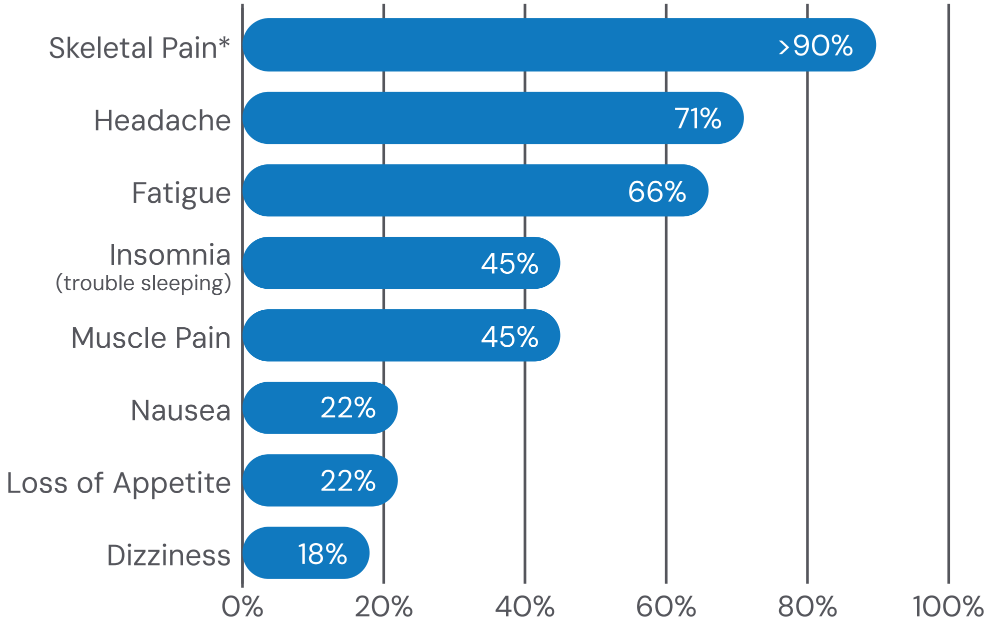
Less common side effects of PBSC donation

- Lightheadedness
- Nausea

Rare side effects and risks of PBSC donation

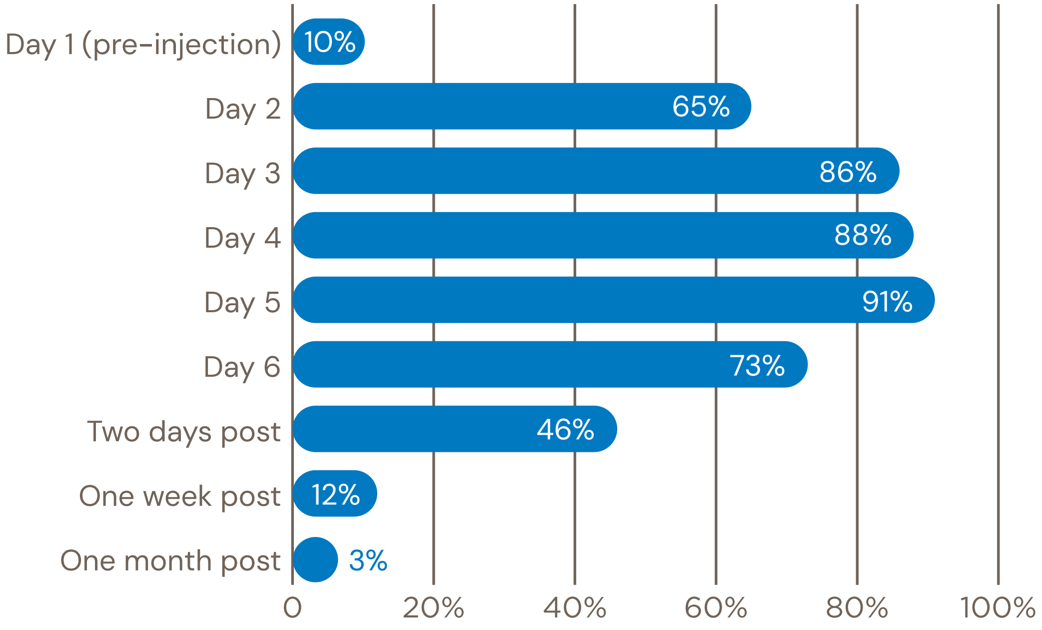
- Chills
- Fainting due to lowered blood pressure
- Infection
- Nerve injury

Common side effects reported during filgrastim/similars injections and donation



*Skeletal pain presents in at least one of the following sites: back, bone, headache, hip, joints, limbs and/or neck

Donors experiencing pain* from filgrastim/similars injections



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

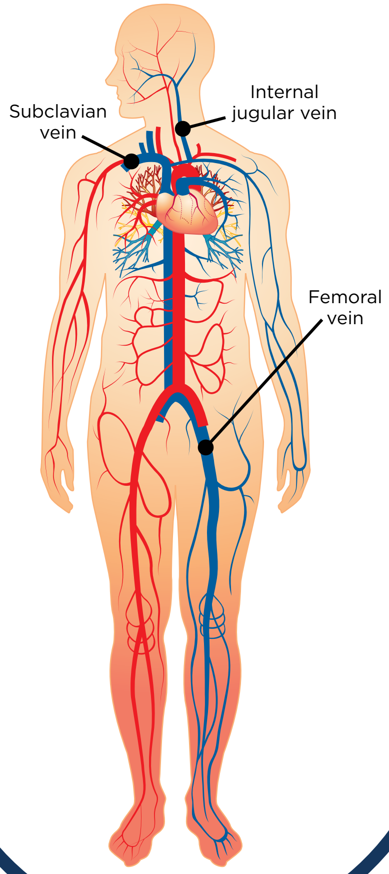
Central venous line

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 experience of NMDP, 19% of women and 3% of men require a central line placement. Of those who require a central line, 59% have the line placed in the internal jugular (neck) vein, 36% in the femoral (groin) vein and 5% in the subclavian (shoulder/chest area) vein.



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.

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 minimizes the potential for risks and complications.

Side effects and risks:

- There is about a 1% risk of partial collapse of the lung from insertion of a subclavian line under the collar bone area.
- There is a less than 1% risk that the central line may not function properly during the procedure. This is not a serious complication but may require removal and replacement of the central line.
- Bleeding can occur where the central line is inserted.
- Air embolism (air bubble in the blood stream) is a rare complication that may occur when the central line is inserted, removed or in use if air enters the line.
- 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.

For more information on what to expect after PBSC donation, see page 41 in the **After Your Donation** section of this guide (page 41).

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

Chase, marrow donor

Marrow donation

> “When I played college basketball, the constant banging in a basketball game hurt more than donating. If I was called to donate again, I would 100% do it every single time.”

–CHASE, MARROW DONOR

Marrow donation

Marrow donation is a surgical procedure that takes place in the operating room of a hospital that participates in marrow collections for NMDP. You will be given either general or regional anesthesia to block the pain. Typically, the hospital stay is from early morning to late afternoon, but occasionally donors may need to stay overnight for observation. The donation will take place in a hospital that is experienced and participates in marrow collections for NMDP.

Tips to prepare you for your hospital visit

- Do not use aspirin or any medication containing aspirin (e.g., Bayer®, Excedrin® or Anacin®) for at least two weeks before and after the donation, unless instructed otherwise by your health care provider. Aspirin can prolong bleeding.
- Use only acetaminophen or ibuprofen products (e.g., Tylenol, Motrin or Advil) for headaches 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.
- Arrange transportation home after donation as you will not be authorized to drive. Let NMDP staff know if you need assistance arranging transportation.

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

"One of the greatest things I have taken from this experience is that when you donate, you are not only changing the life of the recipient but the life of the community around them."

**–RACHEL,
MARROW DONOR**

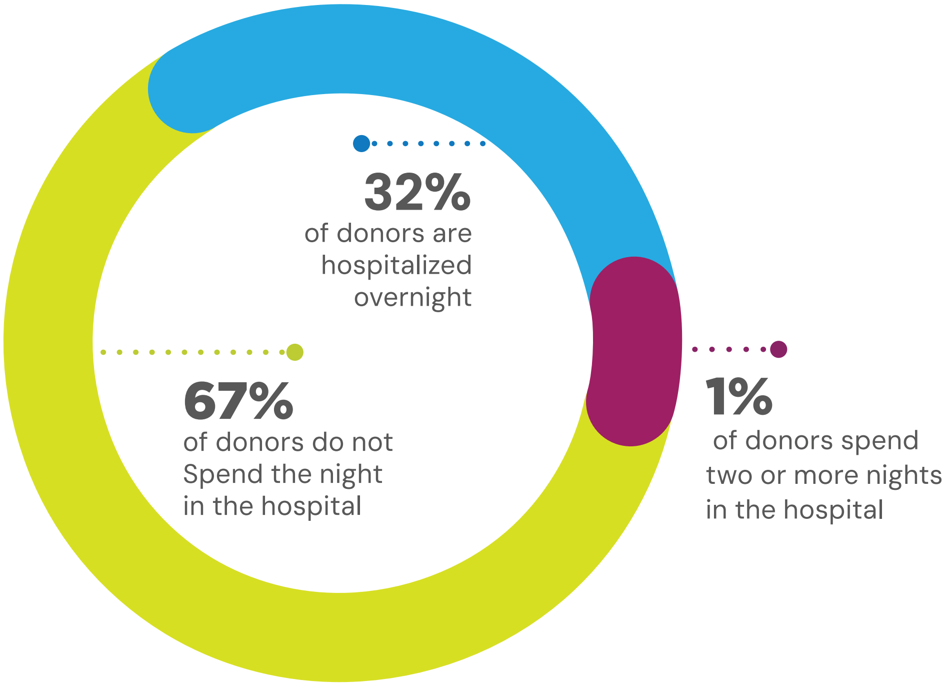
At the hospital

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. Each hospital's visitor policy is different; however, you will need to identify a support person to be available during the donation process and drive you home afterward. 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.

> "My donation didn't feel real until the morning of my procedure when they started the prep work. Talking through the procedure with my doctor and nurse really helped calm my nerves."
>
> **—AMANDA, MARROW DONOR, GIVING HER MOTHER A HIGH FIVE BEFORE HER DONATION**

HOSPITAL STAY



Please note that the time you will spend in the hospital is determined by the individual hospital's policy as well as your condition.

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 routine surgical procedures.

General anesthesia

If general anesthesia is used, you will be unconscious during the donation. General anesthesia is used for about 98% of NMDP marrow donations. The average time under anesthesia is less than two hours.

Anesthetic medication is delivered in the operating room through an IV. A breathing tube will be placed in your throat after you are asleep and you will be monitored closely by an anesthesiologist for the entire procedure.

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. Often, medication can be given to manage these side effects if they do occur.

Regional anesthesia

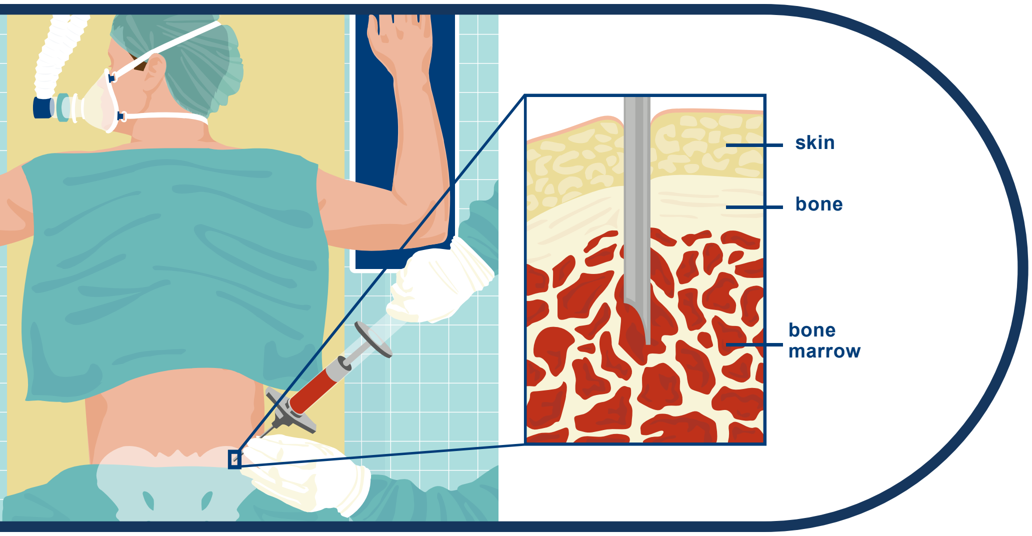
There are two types of regional anesthetic: spinal and epidural. With both, medication is injected in the lower back between the vertebrae of the spine. This medication blocks sensation in the affected area. In addition, you may be given a sedative to help you relax but you will remain aware of your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

Zalika (left) spent years suffering from sickle cell disease until Tinisha (right) became her marrow donor.



During marrow donation, marrow is collected from both sides of your pelvic bone.

The marrow donation procedure

During the 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 1/4 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 marrow is collected. The average amount of marrow and blood donated is about 1.5 liters. 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 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 (e.g., acetaminophen or ibuprofen) such as Tylenol, Motrin or Advil for minor pain until symptoms have resolved. 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 said it was 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 (2.4%) of donors experience serious complications due to the procedure.*

NMDP wants to ensure 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.

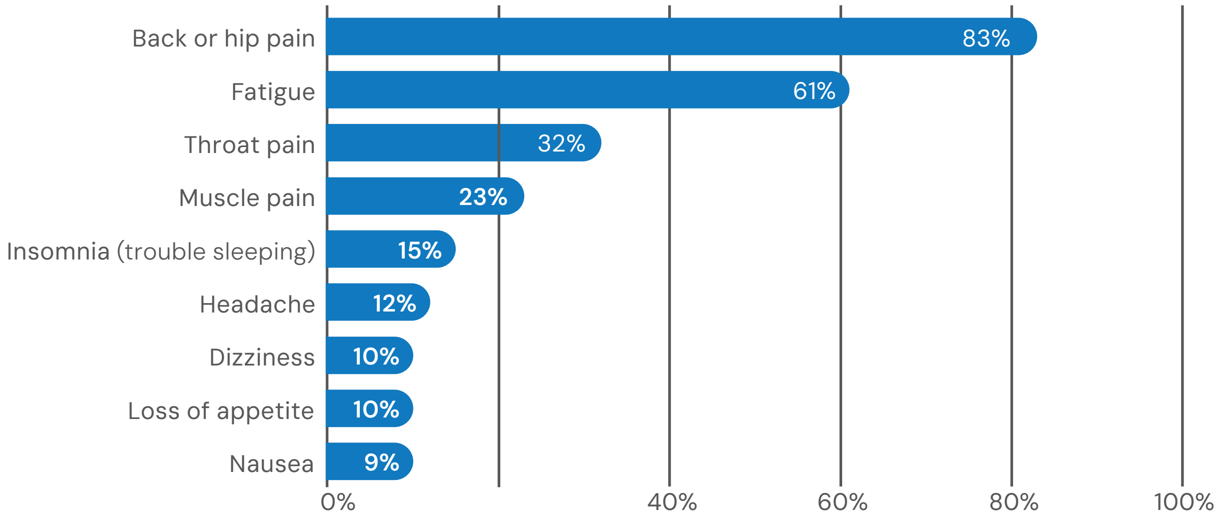
"I describe the procedure to our donors and discuss possible side effects and complications, but most importantly, I thank them for the beautiful gift they are giving to a stranger in need."

–WOLFGANG RENNERT, MD, COLLECTION CENTER MEDICAL DIRECTOR AT MEDSTAR GEORGETOWN UNIVERSITY HOSPITAL

---

*Pulsipher MA, Chitphakdithai P, Logan BR, et al. Lower risk for serious adverse events and no increased risk for cancer after PBSC vs BM donation. Blood. 2014; 123(23): 3655–3663.

Common side effects of marrow donation reported two days after donation



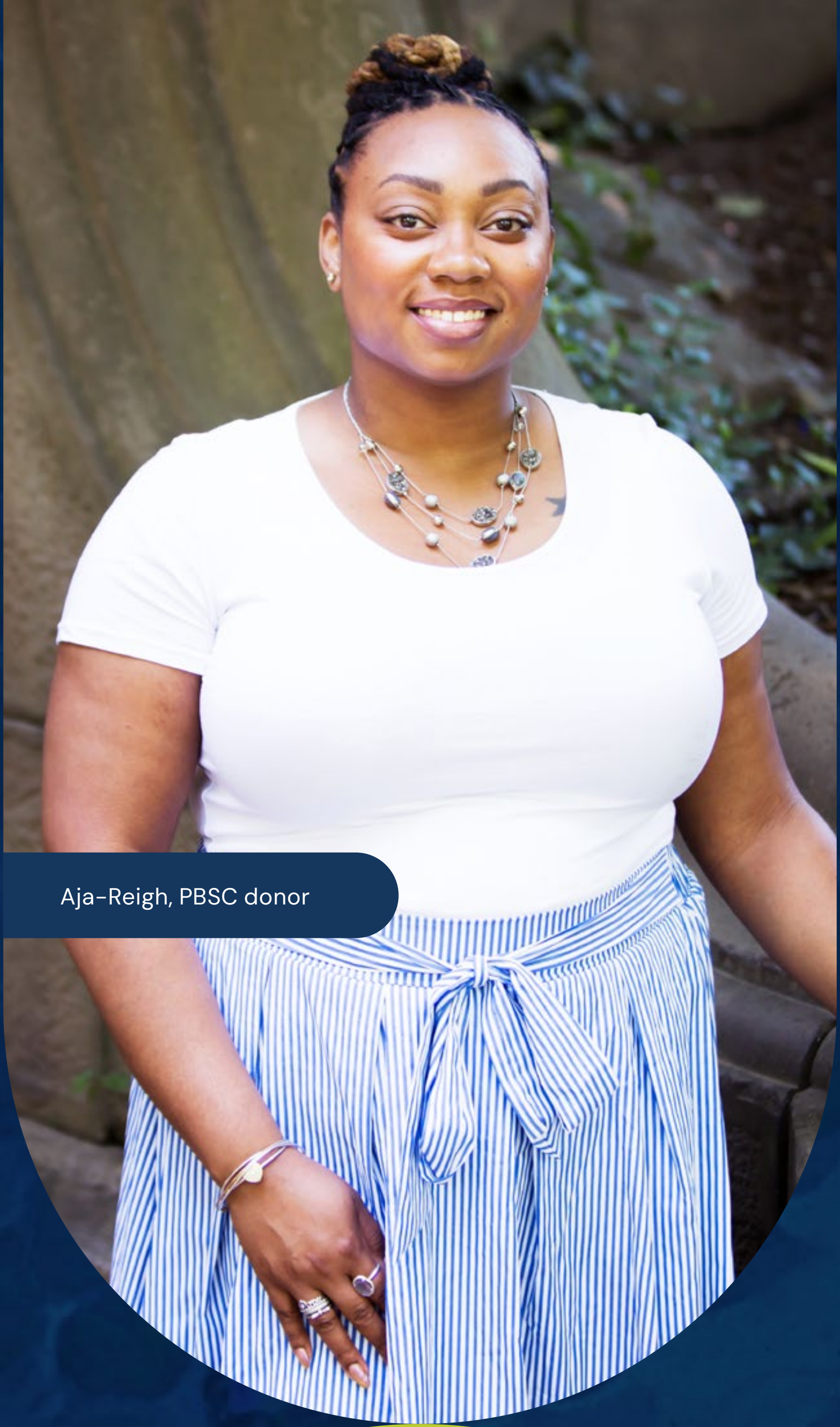
Recovery when you leave the hospital

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 the **After Your Donation** section (next page) on page 46 of this guide.

To learn more about marrow donation from the perspective of real NMDP donors, visit our Donor Testimonial Library on our website.

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


Aja-Reigh, PBSC donor

After your donation

> “My donation was not painful. I definitely would donate again because it felt like I was making an important step in helping someone live a healthier and possibly longer life.”

–AJA-REIGH, PBSC DONOR

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 46.

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 or FDA-approved similar injections that you will receive to increase the number of PBSCs in your bloodstream. These side effects disappear shortly after the donation, usually within one to two days after the last dose. 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
- Symptoms of a possible head bleed: severe headache, blurred vision, nausea, numbness and tingling in the face or extremities and memory changes
- Temperature of 100.5 degrees Fahrenheit (38 degrees 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 INFORM EMERGENCY PROVIDERS THAT YOU RECEIVED FILGRASTIM OR AN FDA-APPROVED FILGRASTIM SIMILAR AND DONATED PBSC. BRING A COPY OF THE SELF-CARE INSTRUCTIONS TO THE EMERGENCY ROOM.

Activity recommendations and limitations

“The day after [donation], I didn’t really feel that bad. There was a little bit of aching in my bones ... but I felt pretty much 100% 24 hours later.”

–DAVID, PBSC DONOR

Use of pain medications

- Use non-aspirin products (e.g., acetaminophen or ibuprofen) such as Tylenol, Motrin or Advil for minor pain until symptoms have resolved.
- Do not use aspirin unless specifically instructed to by your doctor; aspirin decreases the blood’s ability to clot and increases the risk of bleeding.

Hydration and dietary recommendations

- 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 10 glasses of water) for the next several days.
- Do not drink alcoholic beverages for the next 24 hours.

Care of needle sites

After your donation, you will be provided with self-care instructions to follow at home. 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 10 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.

General recommendations

- Return to light activities the next day, if you feel well enough.
- If you feel lightheaded or dizzy, lie down immediately and 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 one week.
- Do not participate in contact sports for one week.

Work and school recommendations

- You should be able to return to work, school and any other activities the next day or as soon as you feel recovered.
- 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 okay to fly as a passenger).

Recovery time

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

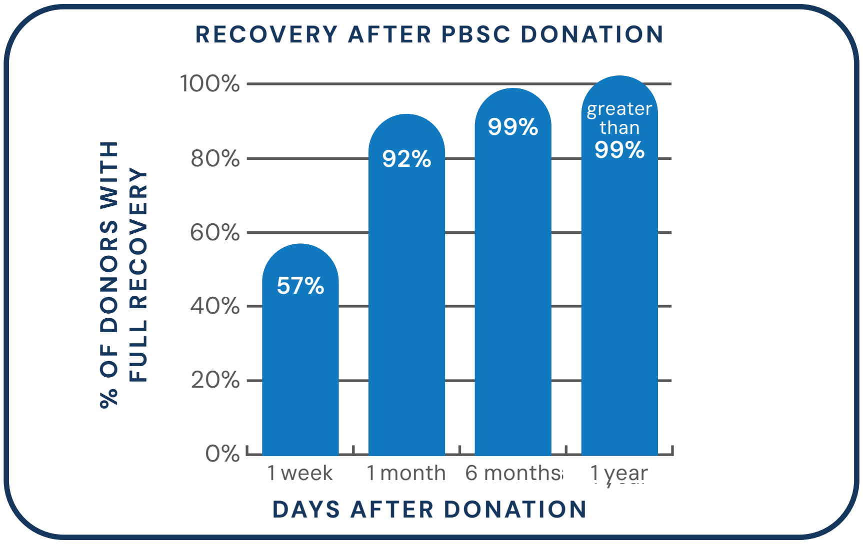
NOTE: Median time is defined as the middle number in a range of numbers.

Pregnancy recommendation

While there are no adequate or well-controlled studies of pregnant women, it is recommended that donors wait to try to get pregnant until filgrastim or its FDA-approved similar is no longer in the bloodstream. Both men and women should wait at least 48 hours after the last dose of filgrastim to conceive a child.

Filgrastim and its FDA-approved similars and Fertility

Filgrastim similars are not known to negatively affect human female or male fertility. Granulocyte colony stimulating factors like filgrastim similars have been studied and demonstrated to be safe and effective when used for fertility preservation and to support embryo implantation during in vitro fertilization. In studies done prior to marketing, filgrastim similars had no observed effect on the fertility of male or female rats or on gestation at doses up to 500 mcg/kg, which is approximately fifty times higher than the dose used in stem cell mobilization of healthy donors. Additional information can be found in the individual drug inserts which are accessible to the public online.



RECOVERY AFTER PBSC DONATION

Abdus Salam, MD, medical director of Apheresis Associates of Northern Virginia (AANoVA), and his team ensure donors are comfortable and safe throughout the donation process.

THE FOLLOWING PAGES OFFER INFORMATION ABOUT WHAT TO EXPECT AFTER MARROW DONATION.

PBSC donors, please skip to page 50 to continue reading about what to expect after your donation.

Marrow donors

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, hips 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 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 could last a few weeks.

Symptoms that require medical attention—marrow donors

- Temperature of 100.5 degrees Fahrenheit (38 degrees 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 INFORM EMERGENCY PROVIDERS THAT YOU DONATED BONE MARROW. BRING A COPY OF THE SELF-CARE INSTRUCTIONS TO THE EMERGENCY ROOM.

Activity recommendations and limitations

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 medication 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 medication may cause nausea; report any side effects to your donor center representative.
- Do not use aspirin products (e.g., Bayer, Excedrin, Anacin) for two weeks after the donation unless instructed by your doctor. Aspirin decreases the blood's ability to clot and increases the risk of bleeding. You may take non-aspirin products (e.g., acetaminophen or ibuprofen) 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.

Hydration and dietary recommendations

- Have a snack before you leave the hospital or collection center and eat a well-balanced meal the evening after your donation.
- Adequate hydration is a critical element in your recovery. Drink plenty of fluids (eight to 10 glasses of water) for the next several days.
- Do not drink alcoholic beverages for the next 24 hours.
- In general, your diet should:
  - Be well balanced
  - Be high in iron-rich foods such as green leafy vegetables and red meat*

***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. Adequate hydration is crucial to your recovery.

"I was very nervous heading into the donation but felt proud that my bone marrow was going to be able to save someone's life. We all have fears and obstacles, but we need to remember the reason we registered and hopefully make the right decision to help someone in need."

–JOSÉ, MARROW DONOR

“I was under anesthesia and not awake during the procedure. I was in the hospital at 5 a.m. and out by 11 a.m. For about a week and a half, I was a little sore, like I had fallen down. And time wise, it was nothing—especially compared to other things I've done, like being on the high school swim team with the grueling training before and after school.”

–SAMANTHA, MARROW DONOR

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.).
- Do not shower for 24 hours after donation.
- Take only showers for the first week 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 on page 46.

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 trouble 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/walking 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 activities such as jogging or running.

Through week four:

- Avoid contact sports.

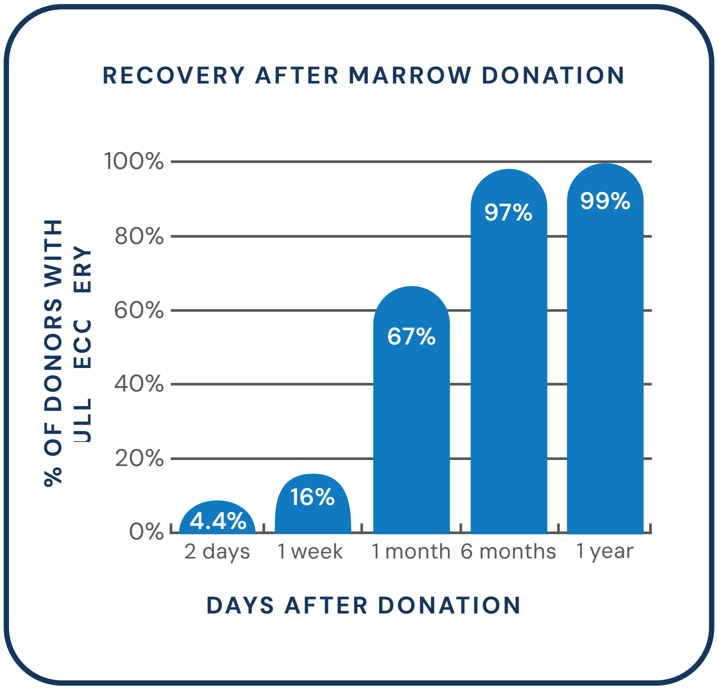
Work and school recommendations

- 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.

Recovery time

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

NOTE: Median time is defined as the middle number in a range of numbers.



RECOVERY AFTER MARROW DONATION

To learn more about the recovery experiences of real NMDP donors, visit our [Donor Stories Library]

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

PBSC and marrow donors

In 2015, JP donated bone marrow to a young boy. In 2022, she found out she was a match for a second time. JP has donated both PBSC and marrow and says she would do it again in a heartbeat!

What to expect after donation

We care very much about your safety and want to know about the details of your recovery. Your donor center representative will contact you 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.

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. We understand there may also be emotional challenges with donation; please see the Donor Support Services section (page 11) for more resources and support.

Requests for subsequent donations

After the transplant, the recipient 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

About 10% 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 and marrow. Recovery and side effects following a second donation of marrow or PBSC are 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 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.

Expense reimbursement

Out-of-pocket expense reimbursement (e.g., food and mileage) may take up to 30 days after your request has been received by NMDP. If you have additional questions about your reimbursement, reach out to your coordinator.

Cole, PBSC donor, showing off his cells after finishing donation

Updates about your recipient

If your recipient's transplant center is in the U.S., your donor center should be able to give you a brief update about your recipient's condition around these times:

- 9 months after transplant
- 12 months after transplant
- 18 months after transplant
- 30 months after transplant

However, each country has different rules about providing updates. If your recipient is at a transplant center in another country, you may never receive an update (or updates) on your recipient.

Even if you do get an update about your recipient, it might not be as much information as you'd like. If you want to know more, you may be able to send an anonymous correspondence to ask how the recipient is doing. The rules about anonymous communication are different in each country, but in most cases, sending a letter is a possibility (see page 52).

Talk to your donor center representative to find out what you should expect for updates and if you can send an anonymous letter.

If you are able to get updates or if you choose to contact your recipient anonymously, there is a chance that you'll receive bad news about your recipient—your recipient might not have survived. Hearing this news could be upsetting to you. Please feel free to talk with your donor center representative about how you'd feel if you received bad news about your recipient.

“It’s a gift, I wanted it to remain a gift.”

–TRACEY (MIDDLE), PBSC DONOR, ON HER DECISION TO REMAIN ANONYMOUS, PICTURED WITH HER SISTERS

Communication and contact with your recipient

NMDP is committed to protecting the confidentiality of donors and recipients. It is the law to keep donor and patient information private. The NMDP Registry coordinates transplants around the world. In some regions, contact between donors and recipients is never allowed.

Guidelines for anonymous communication

During the first year after transplant, some transplant centers allow donors to send anonymous communication to their recipients. Talk to your donor center representative to find out if this is an option for you. If it is, NMDP will help you exchange electronic correspondence (e.g. email, scanned copies of handwritten letters/cards) anonymously. Keep in mind there are many reasons your recipient might not respond. Before you send anything, consider how you'll feel if you don't hear back.

If you do reach out, it's important to understand the rules for anonymous and confidential communications. All correspondences are reviewed first by your donor center representative, then by NMDP and finally by the recipient's transplant center to make sure identifying information is not shared. These rules are designed to protect both you and your recipient.

Think about ways to express yourself without using—or even hinting at—specific names or places that could give away your location or identity.

Laila met her donor, Kenton, for the first time at the NMDP Gala.

Avoid the following:

Names

No personal names are allowed, including:

- Nicknames for donor, recipient, family members, pets, etc.
- Local artists, groups or performers
- Sports team references (names, logos, etc.) of any kind
- Donor center or collection center name, staff, doctors
- Employer or school/teacher names

Locations

Nothing more specific than country, including landmarks

Organizations or causes

that you are part of, such as a local community group or club

Personal dates

Such as your birthday or anniversary

Photographs

The policies for communicating with your recipient vary by country. During the first year after transplant, transplant centers in most countries allow anonymous communication between donors and recipients. Starting at one year post-transplant, most centers allow direct contact between donors and recipients if both consent. However, some centers have a two-year or more waiting period and some do not allow direct contact between donors and recipients at any time.

“One year after his donation, Bopper received the contact information for his recipient, Andy. Today, they are close friends. “We stay in contact at least once a week,” stated Bopper. “I try to involve him in a lot of things that are going on in my life because, since then, he is a part of my life.”

– BOPPER, PBSC DONOR

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. 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 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 them.

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

Kari with her son, Justin, transplant recipient

Patient experience

Life after Justin’s transplant has been great. Justin gets to go back to school and socialize. He hated the way people treated him because he was sick. Now he gets to be a regular kid with his friends.”

–KARI WITH HER SON, JUSTIN, TRANSPLANT RECIPIENT

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, they have already been diagnosed with a very serious or life-threatening disease and have learned that a blood stem cell transplant may be the best, or only, treatment option. The patient's doctor is evaluating transplant options and they turned to the NMDP 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 NMDP 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.

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.

Step 3:
If the patient is not already at a transplant center, a doctor will refer the patient 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 to travel far distances; some even have to relocate with their caregivers to be closer to their transplant center.

Valerie 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 blood stem cell donor. She received her transplant six years later at the age of 17.

CORD BLOOD
A source of blood-forming cells used in transplantation; the blood collected from the umbilical cord and placenta after a baby is born.

Cord blood contains a high concentration of blood-forming cells.

“I realize I can never repay her for what she’s done, but I can sure say thank you … I can say you are awesome a lot. I can say you are fabulous a lot. Black girl magic. You are it.”

– DONNA (RIGHT),
PBSC RECIPIENT

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

Patients need more testing to find out if donors or cord blood units from the preliminary search are a suitable match. A transplant center may test several potential donors or cord blood units to find the best option for the patient. If a potential donor appears to be a good match, they must be contacted to be sure they are healthy, willing and able to donate.

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 test to make sure that you do not have an infection or disease that could be passed on to the patient. 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 weakens the patient’s immune system so it won’t reject the donor’s cells. If the patient is prepared for transplant and does not receive the transplant, the consequences are usually life-threatening.

For many patients, 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 a few days to weeks. The length and strength of this treatment depends on the patient’s disease, their age, any previous treatments the patient may have had and whether their disease is active.

How the patient receives the donor's cells

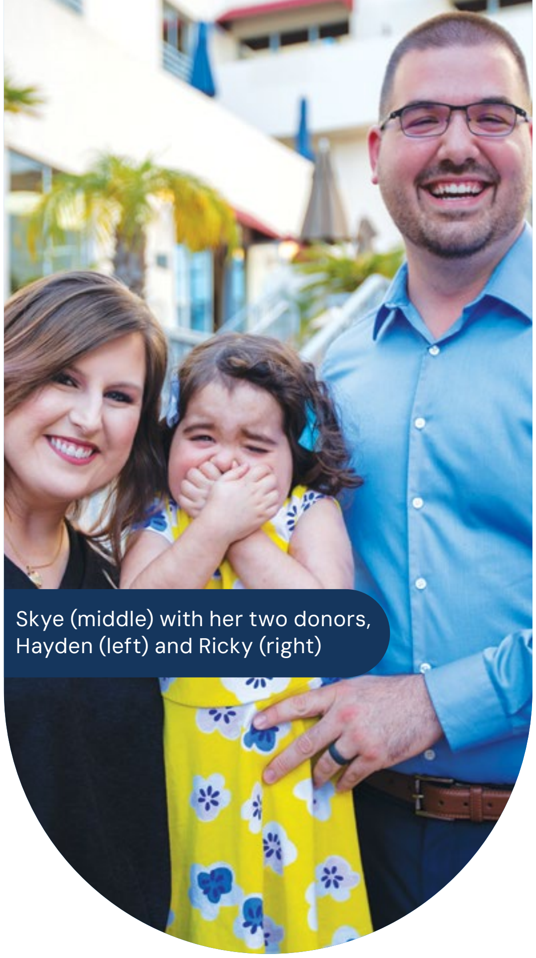
Transplant day usually comes one or two days after the patient completes the pre-transplant treatment. Patients sometimes refer to transplant day as Day Zero or their "second birthday".

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

The transplant is not surgery. The cells in the bags are put into the patient's body through an IV line, much like a blood transfusion. The patient will be awake to receive the donated cells. 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 patient's bloodstream to settle in their 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.

> "What you are doing is so incredible. It is so important and means the world to the patient who you are donating to. Bone marrow cannot be produced, we cannot go to a factory and ask them to produce bone marrow for us. The only source for bone marrow is human beings."
>
> **– KYLE,**
> **TRANSPLANT RECIPIENT**



Skye (middle) with her two donors, Hayden (left) and Ricky (right)

Recovery after transplant

The days before engraftment are high risk for a transplant 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. Infections are serious and can even be life-threatening.

Over time, the donated cells the patient received start to engraft. The recipient's blood cell counts begin to increase and their 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 recipient's recovery.

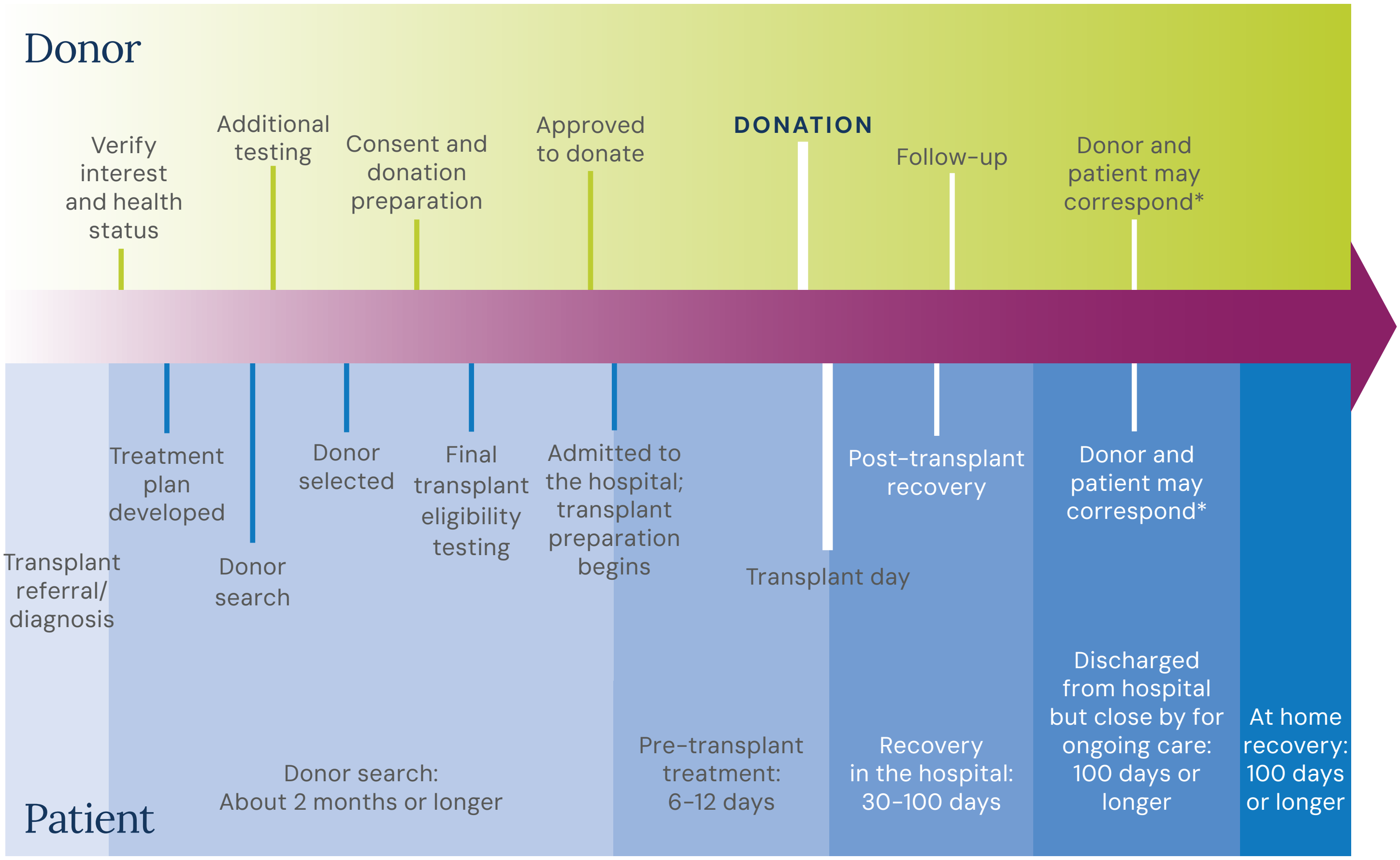
The recipient will stay in or near the hospital during early recovery—generally 100 days or more. In the first months after transplant, the recipient's focus will be on recovery: eating well, avoiding infections, taking medications, getting care from his or her doctor and following other guidelines to stay healthy. Many recipients 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.

Watch the story of transplant recipient [Gary and donor Tim]

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. Transplant delays are common and can change the donation and transplant timeline.



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

*See pages 52–53 for guidelines for communicating with and contacting your recipient.

Transplant outcomes

"I told Kyle: Everyone gets knocked down sometimes; it takes a superhero to get back up … every time."

– KAWIKA (LEFT), MARROW DONOR, WITH KYLE, HIS RECIPIENT

NMDP has impacted more than 130,000 lives since 1987 through cell therapy.

It's hard to know how any one patient will do after transplant. 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

For every 10 people who receive an unrelated donor transplant, usually four to eight of those recipients are alive two to three years after transplant.

Younger patients and people who have a blood disease that isn't cancer tend to do better than older patients and people with blood cancers.*

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

While this may sound discouraging, remember that without a transplant, many patients don't have another chance for a cure and do even worse. All donors provide hope for a cure!

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 NMDP and searching patients, thank you for considering becoming a marrow or PBSC donor.

**Donor and Patient Safety Monitoring Report (2017).*

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

Glossary

ALLOGENEIC TRANSPLANT
Any marrow or peripheral blood stem cell (PBSC) transplant in which the cells come from another person rather than the patient. The donated cells can come from a related or unrelated donor.

ANESTHESIA
Drugs used to block the pain 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 peripheral blood stem cells (PBSCs) 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 NMDP membership criteria, including experience, staff and facilities to collect peripheral blood stem cells (PBSCs) and white blood cells through apheresis.

AUTOLOGOUS BLOOD DONATION
The process of a donor donating blood prior to a marrow donation that will be stored and saved for use during or after the donation.

AUTOLOGOUS TRANSPLANT
A marrow or peripheral blood stem cell (PBSC) transplant in which the patient's own cells are used.

NMDP REGISTRY
A confidential national database of potential volunteer marrow donors established and maintained by NMDP.

BLOOD-FORMING CELLS (ALSO CALLED BLOOD STEM CELLS)
Cells found in the marrow and blood that can grow into red blood cells, white blood cells or platelets.

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

BONE MARROW TRANSPLANT (BMT)
A medical treatment to replace a patient's damaged marrow with blood-forming cells from healthy marrow or peripheral blood stem cells (PBSCs) of the donor.

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.

CHEEK SWAB (ALSO CALLED BUCCAL SWAB)
A swab used to collect cells from the inside of the cheek. These cells are used to determine a person's tissue type when joining the registry.

CLEARED TO DONATE
The time at which the information session is complete and the Donation Consent Form is signed. All required medical evaluations have been completed, results have been reviewed by a physician and the donor is deemed medically suitable to donate.

COLLECTION CENTER
A hospital that meets NMDP membership criteria—including experience, staff and facilities—to perform allogeneic stem cell transplantation.

CORD BLOOD
A source of blood-forming cells used in transplantation; the blood collected from the umbilical cord and placenta after a baby is born. Cord blood contains a high concentration of blood-forming cells.

Glossary (Continued)

CRYOPRESERVATION
A procedure for storing tissues or blood products at extremely low temperatures. All cord blood units are cryopreserved, as are blood stem cells used in autologous transplants. Blood stem cells for allogeneic transplants are sometimes cryopreserved, as are some cell and gene therapies.

ENGRAFTMENT
When marrow or peripheral blood stem cells (PBSCs) given to the patient during the transplant start to grow and make blood cells.

FILGRASTIM AND ITS FDA-APPROVED SIMILARS
Filgrastim is also known as G-CSF (granulocyte-colony stimulating factor) or by the trade name Neupogen, Nivestym, Zarxio, Granix and Releuko. It is given by injection to donors who have agreed to donate peripheral blood stem cells (PBSCs). Filgrastim stimulates the marrow to make more blood-forming cells and moves them from the marrow into the bloodstream so that they can be collected by apheresis.

GENERAL ANESTHESIA
Drugs used to temporarily put the donor into a deep sleep so he or she doesn'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 (PBSCs) attack the patient's body. GVHD can be mild or severe and is sometimes life-threatening.

HLA (HUMAN LEUKOCYTE ANTIGEN) MARKERS
Proteins or markers found on almost all cells of the body, making up the main part of each person's tissue type.

INFECTIOUS DISEASE MARKERS (IDMS)
Indicators in a person's blood that show if a person currently has, or has had, an infectious disease.

INFECTIOUS DISEASE TESTING
Tests performed on a sample of the donor's blood to determine whether their marrow or peripheral blood stem cells (PBSCs) could transmit an infectious disease to the patient.

INFORMED CONSENT
The process of getting permission before conducting a medical procedure or research study. Informed consent includes:

- Explanation of the medical procedure, risks and benefits
- Agreement to participate
- Opportunity to ask questions and receive answers
- Written indication that the participant understands and agrees to the information provided

A person can provide informed consent at the age of 18.

MARROW DONATION
A surgical procedure during which a person donates some of their liquid marrow from the back of their pelvic bone for a patient undergoing marrow transplant. The donor's marrow typically replaces itself within four to six weeks.

NMDP
NMDP is dedicated to ensuring all patients who need a transplant receive access to this potentially life-saving treatment. Headquartered in Minneapolis, Minn., the nonprofit organization:

- Manages the NMDP 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 CELLS (PBSCS)
Blood-forming cells that are found in the circulating bloodstream.

PERIPHERAL BLOOD STEM CELL (PBSC) DONATION
Blood-forming cells are collected from a donor's circulating blood through an apheresis procedure following five days of receiving filgrastim injections. The cells are then transplanted into a patient.

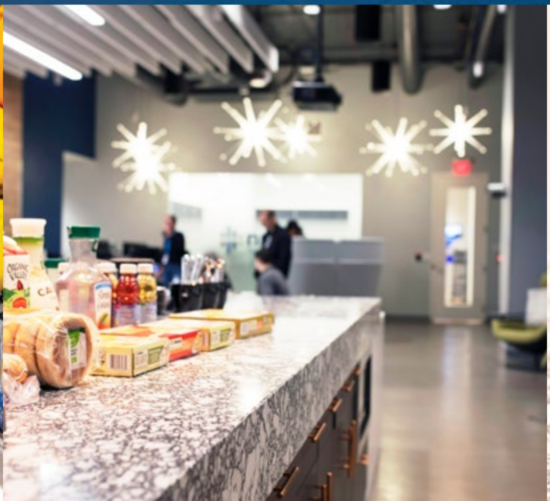
REGIONAL ANESTHESIA (SPINAL AND EPIDURAL)
Drugs used to temporarily numb a large area of the donor's body so they don't feel pain during the marrow donation procedure. The donor is awake but sedated to make them feel sleepy and less anxious.

RELAPSE
The return of signs and symptoms of an illness or disease.

SUITABILITY
A donor who has been evaluated and determined to meet all medical guidelines as defined by NMDP to ensure the donor is healthy enough to move forward with donation.

TRANSPLANT CENTER
A hospital that meets NMDP membership criteria—including experience, staff and facilities—to perform allogeneic stem cell transplantation.

NMDP Seattle Collection Center



Notes:

Bree (left), PBSC donor, with Kwincy, her recipient

FIND CURES. SAVE LIVES.

1 (800) MARROW-2
1 (800) 627-7692

nmdp.org

NMDP is entrusted to operate the C.W. Bill Young Cell Transplantation Program, including the NMDP Registry.

NMDP IRB Approved