



BE  THE MATCH®

YOU'RE A
POTENTIAL MATCH.
Explore the Journey to Donation

Edward, PBSC donor,
with his wife, Andrea





A patient needs you

You've been contacted because you've been identified as a potential match for a specific patient who needs a transplant. You have the opportunity to provide hope to someone with a blood cancer like leukemia or lymphoma, or another life-threatening disease. Reach out to your donor contact representative as soon as possible to confirm your willingness to move forward.

TABLE OF CONTENTS

You're a potential match and next steps **3**

Steps of the donation process **6**

PBSC donation **8**

Marrow donation **10**

Time commitment **12**

Confidentiality **14**

Donation FAQs **16**

Glossary **20**

About us **22**



When you joined the Be The Match Registry®, you joined knowing that one day you might be a match for a patient in need of a life-saving marrow transplant. **That time is now.** A patient's doctor recently searched the registry and identified you as a potential match for their patient.

YOU'RE CURRENTLY AT ONE OF THE FOLLOWING STAGES:

- **Additional Testing:** The patient's doctor needs more information on your human leukocyte antigen (HLA) type to determine if you're a good match. Usually, additional testing is conducted on your original blood or cheek swab sample. You may be asked to provide another sample in the form of a cheek swab for additional testing.
- **Confirmatory Typing:** The patient's doctor has requested a blood sample from you to determine if you're the best match and to test for infectious diseases that could be passed along to the patient through a marrow transplant. Your donor contact representative will work with you to schedule an appointment for the blood draw.

AT EACH STAGE, YOU WILL BE ASKED TO:

- Respond with your willingness to move forward
- Sign a consent form
- Complete a health history questionnaire
- Confirm your contact information



Jeff donated PBSC to a man with lymphoma.

Visit [BeTheMatch.org/DonorVideos](https://www.bethematch.org/DonorVideos) to watch Jeff and other donors talk about their donation experiences.



It is possible to go through multiple testing stages, but not everyone is asked to do so. The process is dependent on the patient's disease and transplant timeline.

Regardless of where you are in the process, time is important. **Please call your donor contact representative right away**, even if you haven't made your decision yet. Your contact representative can help by answering questions you may have about moving forward. If you have work, school, travel or other commitments that may impact your participation, please let your representative know. They can work with you around most scheduling conflicts.

It is important to note that moving forward is up to you. You decided to join the registry because you felt strongly about saving lives. Now you need to make the decision about moving forward with testing and possibly donation. We encourage you to talk with your family and friends about your decision. Others can help you, however, the final decision is yours.

WHAT'S NEXT?

After testing, it can take up to **60 days** for the patient's doctor to review test results and make a decision about moving forward with transplant. We understand we're asking you to act urgently and wait patiently, so we will update you as soon as we hear back from the patient's doctor.

While you wait, there are many ways to prepare for donation and to stay involved.

DONOR MEDICAL GUIDELINES:

In order to help ensure the safety of donors and recipients, guidelines have been established for potential donors. You will not be able to donate if you have/had certain medical conditions. Some of those conditions include: chronic neck or back pain, some types of cancer, and some heart conditions. For more information, visit [BeTheMatch.org/MedicalGuidelines](#). These guidelines don't include every situation that would prevent a person from going on to donate, so be sure to speak with your donor contact representative to determine your eligibility.

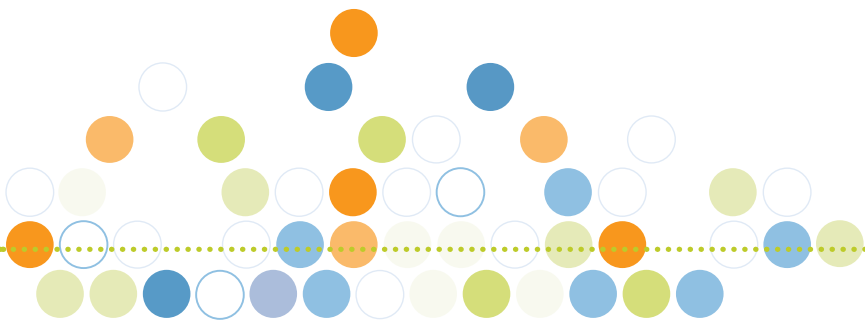
If you are NOT identified as the best match for the patient, or the patient is not ready for transplant at this time, your donor contact representative will let you know. We appreciate your commitment and will keep you informed about Be The Match® news and stories through our registry member e-newsletter. If you're looking for more ways to help, you can spread the word about Be The Match, volunteer and contribute financially. Learn more at [BeTheMatch.org/GetInvolved](https://www.bethematch.org/GetInvolved).

Because additional testing and confirmatory typing provide us with more information about your HLA type, you're more likely to be called for another patient in the future. It's important that you update us with changes to your contact information or health. You can do this by visiting [BeTheMatch.org/Update](https://www.bethematch.org/Update) or calling **1 (800) MARROW-2**.

If you ARE identified as the best match for the patient, you will participate in an information session where you will learn everything you need to know about the donation process. You may be asked to donate in a few weeks or to wait until the patient is ready. Each case is different and the timing of your donation will be based on what is best for you and the patient.

WHILE YOU WAIT:

- Keep us up-to-date: inform your donor contact representative of any health changes or travel plans.
- Spread the word about Be The Match: visit [BeTheMatch.org/Badge](https://www.bethematch.org/Badge) to post a social media badge letting everyone know that you're committed to marrow donation.
- Educate yourself further: visit [BeTheMatch.org/InTheKnow](https://www.bethematch.org/InTheKnow).
- Discuss your donation decision with family and friends: use tips and messages from [BeTheMatch.org/DonorToolkit](https://www.bethematch.org/DonorToolkit).





STEPS OF THE DONATION PROCESS

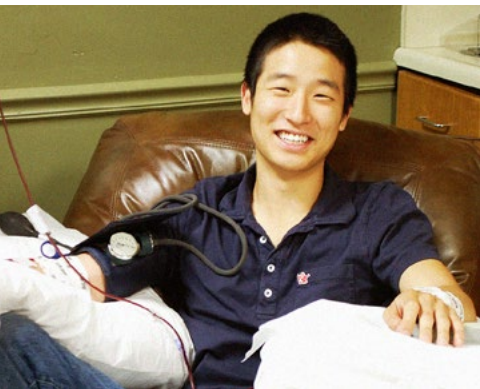
- 1. Update your health information:** You will be asked to confirm your interest and complete a thorough health history questionnaire.
- 2. Participate in an information session:** You will talk with your donor contact representative to learn about the two methods of donation, risks and side effects. This session will last about 90 minutes and is designed to make sure that you're fully informed about donation. After the information session, you will be offered the opportunity to ask questions and will be asked if you're willing to donate.
- 3. Sign a consent form:** If you agree to donate, you will be asked to confirm your decision to donate by signing the consent form.
- 4. Undergo a physical exam:** If you agree to donate, you will have a physical exam to see if donating would pose any risk to you or the patient.
- 5. Give blood samples:** To ensure that donation is safe for both you and the patient, blood samples will be requested throughout the process.
- 6. Donate:** After these steps are successfully completed, you will proceed to donation.

It's important to know you may be asked to travel for the donation or any of the steps of the donation process. Nearly 40 percent of donors travel by air and stay one or more nights in a hotel. Most travel expenses are covered by Be The Match. Medical and non-medical expenses related to your donation are also covered.

Throughout Erin's donation experience, she received support from her family, friends and her faith community. After successfully going through steps 1-5, she went on to donate PBSC to a young man suffering from leukemia.

Erin, PBSC donor (center), with family and close friends





Jeff donating PBSC

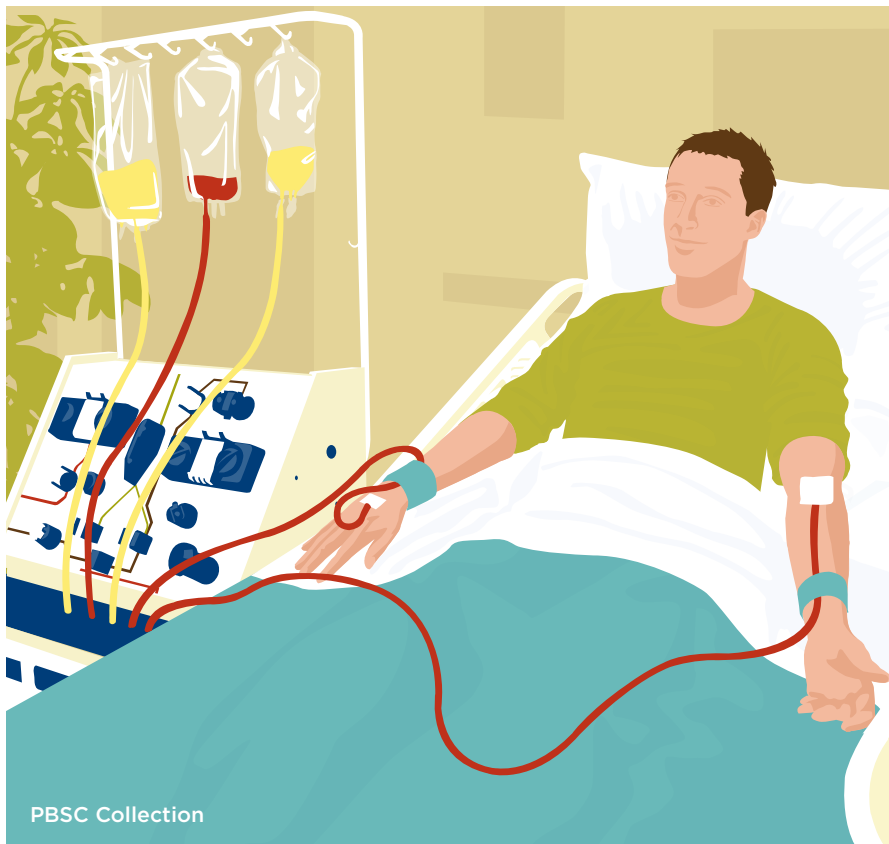
If you agree to donate, the patient's doctor will request that you donate either peripheral blood stem cells (PBSC) or marrow. The doctor chooses the donation method that is best for the patient.

PERIPHERAL BLOOD STEM CELL (PBSC) DONATION

PBSC donation is a nonsurgical procedure—called apheresis—that takes place at a blood center or outpatient hospital facility that is experienced and participates in PBSC collections for Be The Match. For five days leading up to donation, you will be given injections of a drug called filgrastim to increase the number of blood-forming cells (also called blood stem cells) in your bloodstream. Your blood is then removed through a needle in one arm and passed through a machine that separates out the blood-forming cells. The remaining blood is returned to you through the other arm. After donation, your blood-forming cells are transported to the patient's location for transplant.

SIDE EFFECTS AND RECOVERY

You may experience headaches, or bone or muscle aches for several days before donation. These are side effects from the filgrastim injections. The side effects go away shortly after the donation. Your donor contact representative will follow up with you until you report a full recovery. Most PBSC donors report full recovery within one week (seven days) of donation.



Use of filgrastim

Filgrastim stimulates the bone marrow to make more blood-forming cells and moves them from the marrow into the bloodstream so that they can be collected by apheresis. Be The Match started using filgrastim to aid in PBSC donation in the 1990s. The data Be The Match collects from donors helps establish if there are any positive or negative effects from receiving filgrastim. Based on available data from donors who have received filgrastim, no long-term risks have been found to date.



MARROW DONATION

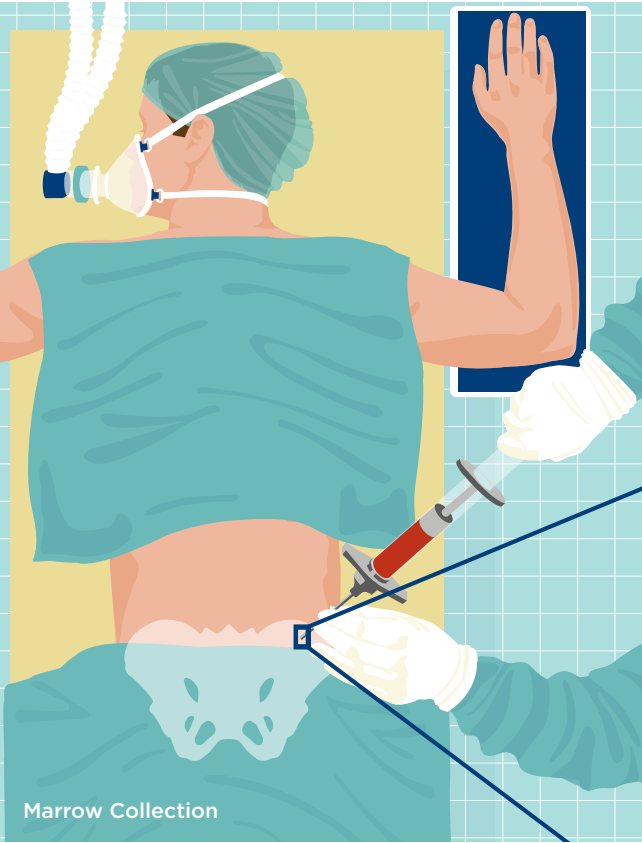
Marrow donation is a surgical procedure that takes place in a hospital operating room. Doctors use special, hollow needles to withdraw liquid marrow (where the body's blood-forming cells are made) from both sides of the back of your pelvic bone. You will be given either general or regional anesthesia to block the pain during the procedure. After donation, your liquid marrow is transported to the patient's location for transplant.

Typically, the hospital stay for marrow donation is from early morning to late afternoon, or occasionally overnight for observation. The donation will take place in a hospital that is experienced and participates in marrow collections for Be The Match.

SIDE EFFECTS AND RECOVERY

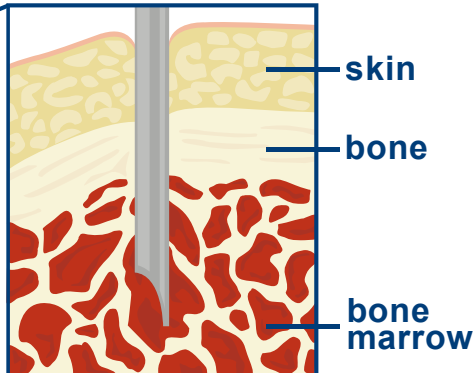
You can expect to feel some soreness in your lower back for a few days or longer. Most donors are back to their normal routine in a few days and feel fully recovered within 20 days. Your donor contact representative will follow up with you until you report a full recovery. Your marrow returns to normal levels within a few weeks.

“If I were to talk to somebody who had just gotten the phone call that they are a potential match for a patient, I would tell them to go through the whole process; to go through as far as they could go,” says Alan (left), donor to Clarissa (right). “I think that if anybody has the opportunity to save a life—save a life.”



Use of anesthesia

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

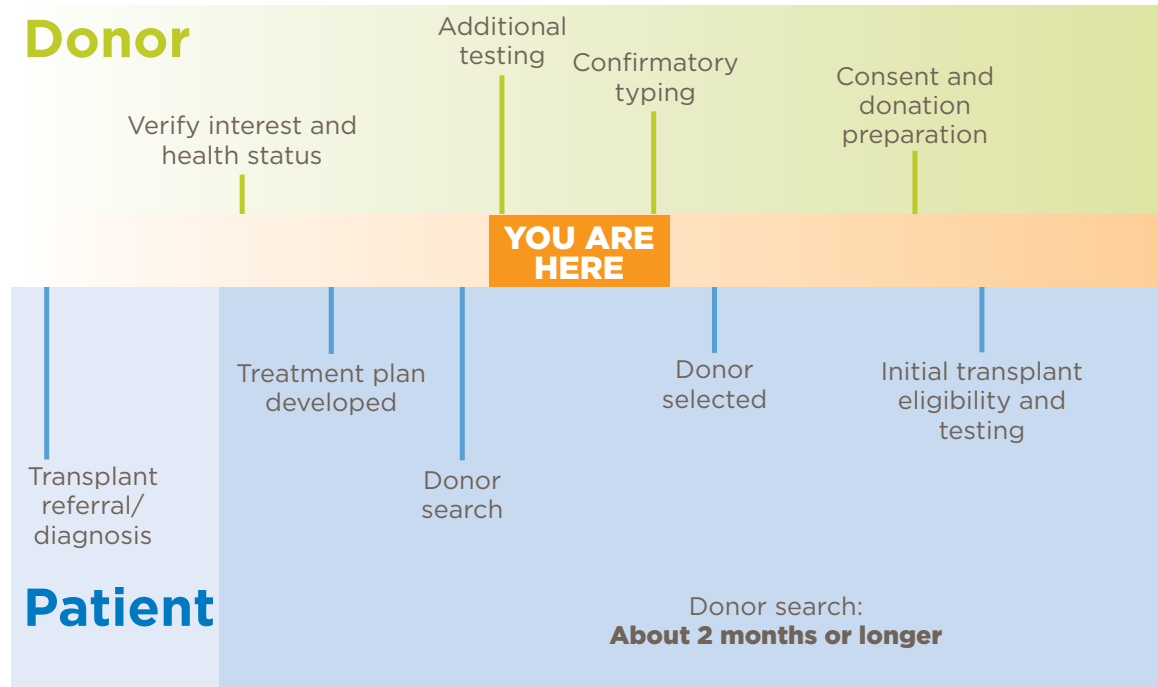


Time Commitment

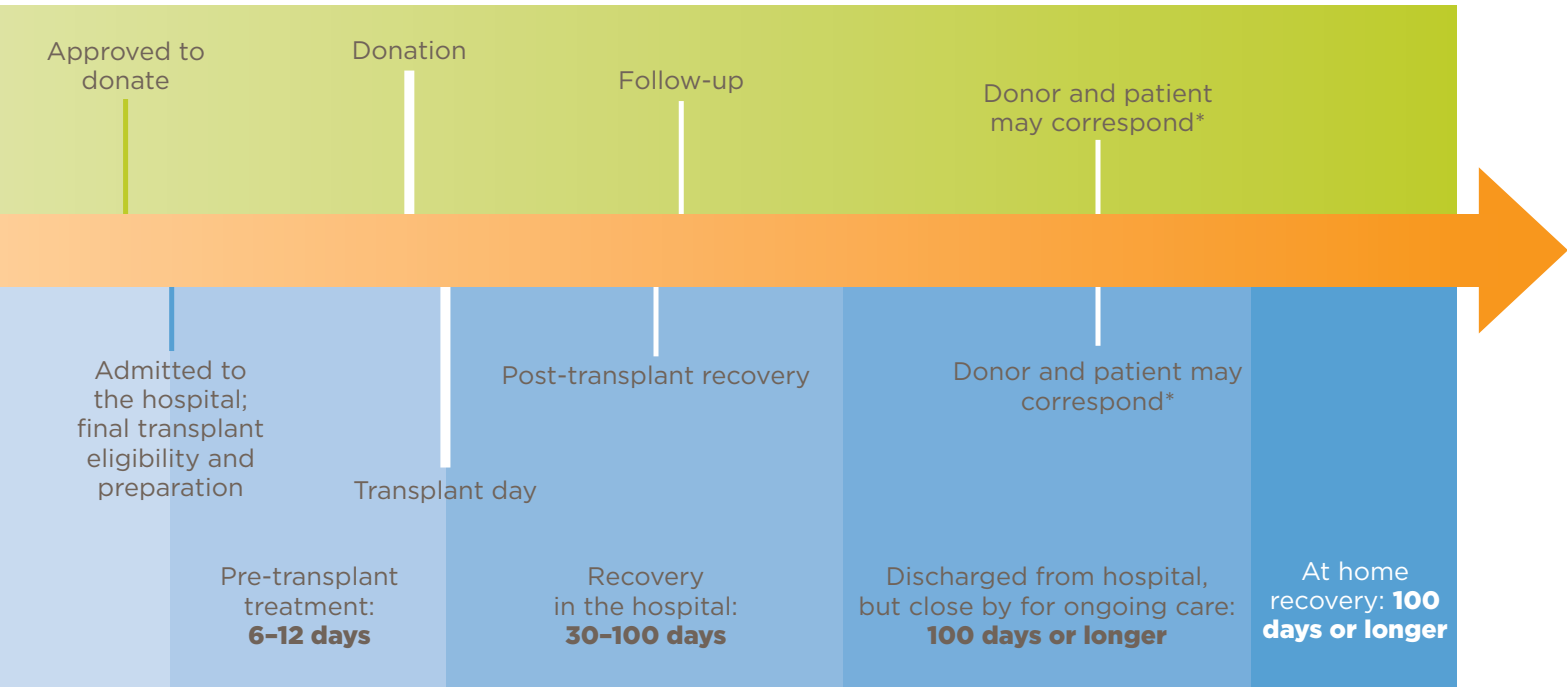
You're at the additional testing or confirmatory typing stage of the donor and patient timeline. Each stage can take up to 60 days as the patient's doctor reviews results and makes a decision. The patient's condition also affects how long the process can take. Time commitment for the donation process is generally 20-30 hours of your time during a four- to six-week period.

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

DONATION AND TRANSPLANT TIMELINE



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



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



Transplant recipient Zalika (left), was excited to meet her donor, Tinisha (right). Before the transplant, both Zalika's and Tinisha's identities were kept confidential. After waiting the required year after transplant, both women signed a consent form to release their information to each other.

CONFIDENTIALITY

Be The Match is committed to protecting the privacy of both donors and patients. We ask for your cooperation in maintaining this confidentiality. This promise of confidentiality protects donors and patients 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.

DONOR ADVOCACY

Your donor contact representative can answer your questions and help with any issues you face. If you need further help, the Be The Match Donor Advocacy Program is available. The Donor Advocacy Program represents the interests, rights, needs and expectations of persons who are or may become volunteer PBSC or marrow donors through Be The Match.

To contact the Donor Advocacy Program, call **(800) 526-7809 ext. 8710** or send an email to advocate@nmdp.org.



Zalika (left) and her donor
Tinisha (right)

DONATION FAQs

HOW IS A MATCH DETERMINED?

Doctors look for a donor who matches their patient's tissue type, specifically their HLA tissue type. HLAs are proteins—or markers—found on most cells in your body. Your immune system uses these markers to recognize which cells belong in your body and which do not. The closer the match between the patient's HLA markers and yours, the better for the patient.

HOW LIKELY IS IT THAT I WILL MATCH A PATIENT AND GO ON TO DONATE?

About one in every 12 members who complete additional typing goes on to donate for a patient. On average, one in every 540 members of the Be The Match Registry in the United States will go on to donate PBSC or marrow to a patient. Because of the vast variation in tissue types, we can't predict an individual registry member's chance of donating to a patient. Every person who joins the registry gives patients more hope of finding the match they need. The most important thing you can do as a registry member is to stay informed and committed so that if you're selected as the best match, you're ready to move forward.

IS THERE AN AGE LIMIT FOR DONATION?

Donors must be between the ages of 18 and 61 to donate. The age guidelines are in place for donor safety and to provide the best treatment for patients.

DOES IT COST ME ANYTHING TO DONATE?

All medical costs for the donation procedure are covered by Be The Match, or by the patient's medical insurance, as are travel expenses and other non-medical costs. The only costs to the donor might be time taken off from work.

WHERE DO I DONATE?

The PBSC donation procedure is done at an apheresis center, which is usually located in a blood center or outpatient hospital facility. For five days leading up to the donation, you will receive filgrastim injections. The first must be given at a donor center or medical clinic, and the fifth will be given at the location where you will undergo the donation procedure. The injections on days two through four may be given at your place of work, your home, at the donor center or a medical clinic.

Marrow donation is a surgical procedure that takes place in an operating room. The donation will be scheduled at a hospital that works with Be The Match. In some cases, the hospital may be near your home. In other cases, you may be asked to travel.

DOES DONATING INVOLVE SURGERY?

The majority of donations do not involve surgery. Today, patients' doctors most often request PBSC donations, which are nonsurgical.

The other way of donating is marrow donation, which is a surgical procedure.

In each case, donors typically go home the same day they donate.

WHAT IS BONE MARROW AND HOW DOES IT HELP PATIENTS?

Bone marrow produces blood-forming cells that grow into:

- Red blood cells, which carry oxygen to all parts of the body
- White blood cells, which help fight infection
- Platelets, which help control bleeding

A healthy blood system is always making new blood-forming cells, which are necessary for survival. If the blood-forming cells begin making many abnormal cells and not enough healthy cells, a marrow transplant to replace the blood-forming cells may be the best treatment.

A bone marrow transplant is a potentially life-saving treatment for people with blood cancers like leukemia and lymphoma, sickle cell anemia or other life-threatening diseases. First, patients undergo chemotherapy and sometimes radiation to destroy their diseased marrow. Then, a donor's healthy blood-forming cells are given directly into the patient's bloodstream, where they can begin to function and multiply.

For a patient's body to accept these healthy cells, the patient needs a donor who is a close match.

DONATION FAQs *(continued...)*

DOES DONATING HURT?

There can be uncomfortable but short-lived side effects of donating PBSC. Due to taking a drug called filgrastim for five days leading up to donation, PBSC donors may have headaches, joint or muscle aches, or fatigue. PBSC donors are typically back to their normal routine in one to two days.

Those donating marrow receive general or regional anesthesia, so they feel no pain during donation. Marrow donors can expect to feel some soreness in their lower back for one to two weeks afterward. Most marrow donors are back to their normal activities in a few days.

DOES MARROW GROW BACK?

Your marrow returns to normal levels within a few weeks. However, the amount taken does not compromise your own immune system or put your health at risk.

WHAT IS THE TIME COMMITMENT INVOLVED IN THE ENTIRE DONATION PROCESS?

Before you donate, there are several steps to make sure you're the best donor for the patient and that you're medically able to donate. These steps are spread out over the course of several weeks. PBSC and marrow donation require about the same total time commitment.

The typical time commitment for the donation process is 20-30 hours of your time over a four- to six-week period. This does not include travel time, which is defined by air travel and staying overnight in a hotel. Nearly 40 percent of donors will travel during the donation process.

HOW LONG DOES THE ACTUAL DONATION PROCEDURE TAKE?

The time needed for the actual donation depends on the donation procedure.

Ninety percent of all PBSC donations are completed in one apheresis session, which may take up to eight hours. The remaining 10 percent of donations are completed in two apheresis sessions, which may take four to six hours on two consecutive days.

The marrow donation procedure lasts about 90 minutes. In most cases, the hospital will schedule a same-day admission and discharge for your procedure—asking you to arrive in the early morning and discharging you in the late afternoon. Some hospitals routinely plan for an overnight hospital stay.

WILL I NEED TO TAKE TIME OFF WORK OR SCHOOL?

It is likely you will need to take time off from work or school. We understand you have obligations and taking time off could be difficult for you. Please speak with your donor contact representative if you need flexibility.

ARE THERE RISKS ASSOCIATED WITH MARROW DONATION?

No procedure is risk free; however, the majority of donors experience a full recovery. A small percentage (2.4 percent) of donors experience a serious complication due to anesthesia or damage to bone, nerve or muscle in their hip region.

CAN I CHANGE MY MIND?

You have the right to change your mind about being a donor at any time. Donating is always voluntary.

If you decide you do not want to donate, let us know right away. We will need to continue the search for another donor. Delays in the search may be life-threatening for the patient.

WILL I GET UPDATES ABOUT MY RECIPIENT?

Some transplant centers may provide up to three updates within the first year after transplant. However, some transplant centers do not provide updates.

During the first year after transplant, some centers allow anonymous communication between you and your recipient. Others do not.

WILL I MEET MY RECIPIENT?

Some transplant centers allow direct contact between donors and recipients one or more years after the transplant, if both you and your recipient consent. Some centers do not allow you to have contact with your recipient at any time.

HOW MANY PATIENTS SEARCH THE BE THE MATCH REGISTRY?

Every year, thousands of people of all ages are diagnosed with blood cancers like leukemia or lymphoma, sickle cell anemia or other life-threatening diseases. For many, their last hope of survival is receiving a marrow or cord blood transplant from a matching donor. Seventy percent of people do not have a match in their family and depend on the Be The Match Registry to find a donor to save their life.

GLOSSARY

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 PBSC 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 Be The Match membership criteria, including experience, staff and facilities to collect PBSC and white blood cells through apheresis.

Be The Match Registry

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

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 transplant (BMT)

A medical treatment to replace a patient's damaged marrow with blood-forming cells from healthy marrow or PBSC of the donor.

Bone marrow (also called marrow)

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

Collection center

A hospital that meets Be The Match membership criteria, including experience, staff and facilities to collect marrow.

Filgrastim

Filgrastim is also known as GCSF (granulocyte-colony stimulating factor) or by the trade name Neupogen®. It is given by injection to donors who have agreed to donate PBSC. 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/she doesn't feel pain during the marrow donation procedure.

HLA (Human Leukocyte Antigen)

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 in the past an infectious disease.

Infectious disease testing

Tests performed on a sample of the donor's blood to determine whether their marrow or PBSC could transmit an infectious disease to the patient.

Marrow donation

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

National Marrow Donor Program

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

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

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

Peripheral blood stem cell (PBSC)

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 recipient.

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.

Transplant center

A hospital that meets Be The Match membership criteria, including experience, staff and facilities to perform allogeneic stem cell transplantation.



ABOUT US

For people with blood cancers like leukemia or lymphoma, or other life-threatening diseases, a cure exists. Be The Match connects patients with their donor match for a life-saving marrow or umbilical cord blood transplant. As a member of the Be The Match Registry, financial contributor or volunteer, you provide hope to patients searching for a cure. Be The Match also provides patients and their families one-on-one support, education, and guidance before, during and after transplant.

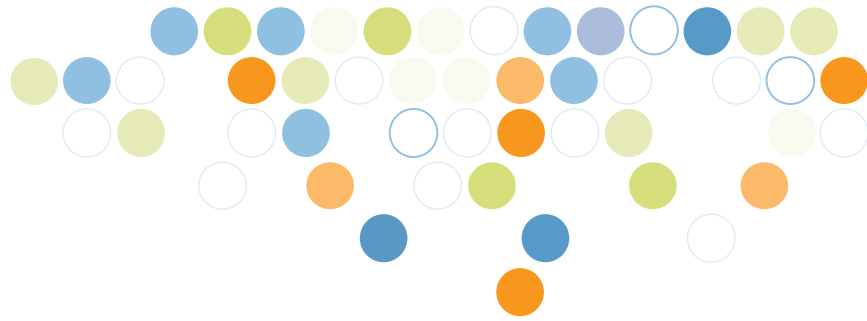
Be The Match is operated by the National Marrow Donor Program® (NMDP), a nonprofit organization that matches patients with donors, educates health care professionals and conducts research so more lives can be saved. To learn more about the cure, visit [BeTheMatch.org](https://www.BeTheMatch.org) or call **1 (800) MARROW-2**.

Johnny (left) was diagnosed with leukemia and needed a bone marrow transplant. Roymar (right) donated bone marrow to Johnny in 2010.





You've been contacted because you're a potential match for a patient. Please call your donor contact representative right away. You can find their information in the letter or email they sent to you. If you cannot find this information you may also call **1 (800) MARROW-2** and ask them to connect you with your donor center.



1 (800) MARROW-2

1 (800) 627-7692

BeTheMatch.org