Talking with Your Employer

When you make the decision to donate marrow, you'll want the understanding and help of your support network—including your employer. It's critical to inform your direct supervisor early on of your decision to donate to gain his or her full support and ensure the most flexibility in your schedule for appointments, the donation and recovery time.

When speaking about donation, listen to and address your supervisor's concerns to provide the best experience for both of you. This guide covers some of the questions your supervisor might have and talking points you can use when responding. This honest dialogue will help secure the work support you need during your life-saving journey.

Donation Basics

Q: What is marrow donation, and what are you being asked to do?

- Marrow donation is the process of giving my healthy blood-forming cells to replace a patient's unhealthy cells.
- There are two methods of donation: peripheral blood stem cell (PBSC) and bone marrow collection. The patient's doctor chooses the donation method that is best for the patient.
- PBSC donation is a nonsurgical procedure that takes place at a blood center or outpatient hospital facility that is contracted by Be The Match.
 - The PBSC donation procedure is called apheresis and is similar to plasma donation; however, PBSC donation typically takes longer.
 - If I'm requested to donate PBSC,
 I will be given injections of medication for five days in a row before the donation, and
 I may experience flu-like symptoms during this time. My donation happens on the fifth day.
- Marrow donation is a same-day surgical outpatient procedure that takes place in a hospital operating room.
 - I will receive anesthesia, then doctors will withdraw marrow from my pelvic bone.

Q: How did you get selected to be a marrow donor?

- I joined the Be The Match Registry®, the world's largest database of unrelated volunteer marrow donors. I am one of more than 11 million people on the registry, and any one of us may be identified as a match for a stranger in need of a transplant.
- The organization matches volunteer donors like me with thousands of patients with blood cancers like leukemia and lymphoma, sickle cell anemia or other life-threatening diseases. A marrow transplant may be the only treatment option that could save their life.

Q: Why is being a match for a patient so important?

- Seventy percent of patients who need a transplant don't find a match within their own family and depend on Be The Match to find an unrelated donor. I may be the best match to help this patient.
- Matching a patient and donor is more complex than simply matching blood types. It's based on many factors, the most important being their human leukocyte antigen (HLA) type. HLA are proteins—or markers—found on most cells in the body.

CONVERSATION TIPS:

Consider sharing with your direct supervisor where and why you joined the registry in the first place. This might help him or her understand your motivation for wanting to help someone you don't even know.

TIME COMMITMENT

Q: How will the donation process affect your work schedule?

- If I am asked to donate, I may have to take some time off from work. The time commitment for the donation process is generally 20-30 hours over a 4-6 week period.
- I will have to participate in an information session and appointments for blood tests, and complete a physical exam—all of these activities ensure that donation is safe for me and the patient.

CONVERSATION TIP:

Speak with your donor contact representative about your schedule. They can help you determine a plan that you can share with your direct supervisor to put them at ease.

Q: Is the time commitment for the two types of donation the same?

- In general, the overall time commitment for both marrow and PBSC donation is the same.
- If I am asked to donate PBSC, there is more of a time commitment before the donation due to time spent at appointments to receive my medication injections.
- If I am asked to donate marrow, I will need more recovery time after the donation.

Q: Will you need to take time off for the donation process all at once?

- The time commitment for donation may spread out over several weeks, depending on a number of factors including travel time for me, the patient's condition and more. Because of this, I will need some flexibility in my schedule.
- The appointments leading up to and the actual donation may change due to the condition of the patient.
- If the patient needs more treatment before their transplant, my donation could be postponed. If the patient is responding well to other treatments, he or she may decide not to move forward with transplant and my donation could be cancelled.

CONVERSATION TIP:

Brainstorm ways to cover your work projects or shifts while you're out. Your direct supervisor likely will appreciate the consideration.

Q: Where will you need to go for your appointments and the donation?

- To ensure that the procedure is safe for donors, Be The Match only works with hospitals and facilities that are experienced in collecting marrow or PBSC. If there is not an available participating facility nearby, I will need to travel.
- I may be asked to travel for the donation or any of the steps of the donation process. Travel is primarily based on the needs and timeline of the patient.
- I will not be traveling to the patient's location for donation. My cells are hand carried, by courier, to the patient's location after my donation.

CONVERSATION TIP:

Start by sharing that nearly 40 percent of donors travel by air for the donation and stay one or more nights in a hotel. This will help your direct supervisor understand how common it is to travel during the donation process.

COMPENSATION

Q: Will you take PTO/vacation time for these appointments?

The discussion of paid time off (PTO) versus leave without pay will be unique to each donor depending on your job, your direct supervisor and the policies of your organization. In place of talking points, the following tips will equip you to prepare for this important conversation.

CONVERSATION TIP:

Before you discuss this topic with your direct supervisor, check your employee policy about leave for medical reasons. Some states have legislation requiring employers to give workers time off for donation without using sick time or vacation. To see donor leave statutes by state, visit BeTheMatch.org/StateStatutes.

CONVERSATION TIP:

If your organization doesn't have a paid donor leave policy, your supervisor might ask you to take PTO or vacation time for appointments and the actual donation. If you don't have paid time off as part of your employment, your supervisor might expect you to take leave without pay. If this becomes a significant barrier to your donation, please contact your donor contact representative to discuss resources that may be available to you.

Q: Are you getting paid for donation?

• Be The Match is a volunteer program. If I am asked to donate, I will not be compensated to help save someone I don't know.

RECOVERY AND PHYSICAL LIMITATIONS

Q: How soon will you be able to return to work after donation?

- Recovery times for marrow and PBSC procedures are different, so it ultimately depends on what I am asked to donate.
- If I donate PBSC, I should be able to return to work, school and any other activities in one to two days, depending on my job responsibilities. However, the median time to full recovery is one week (seven days).
- If I donate marrow, I should be able to return to work, school and any normal activities within one to seven days. If possible, it's recommended that I work a half day upon returning to work, and increase my schedule as I am able. If my job involves physical labor or heavy lifting, more recovery time may be necessary. The median time to full recovery for a marrow donation is 20 days.

Q: Are there any activities you should avoid when you return to work?

- If I donate PBSC, it is recommended that I:
 - 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; however, it's OK to fly as a passenger.
- If I donate marrow, it is recommended that I:
 - Avoid heavy lifting, bending or exercise, as well as lifting more than 10 lbs. during the first week.
 - Allow time between periods of heavy activity throughout the day during the first week.

ABOUT BE THE MATCH

Q: How can you be sure that Be The Match is a legitimate organization?

- A leader in the field of marrow and cord blood transplantation, Be The Match was founded in 1987 and has facilitated more than 60,000 transplants to give patients a second chance at life.
- The U.S. government has entrusted Be
 The Match to operate the C.W. Bill Young
 Cell Transplantation Program, the federal
 program supporting bone marrow and cord
 blood donation and transplantation.
- Be The Match is the hub of a global transplant network. The organization's standards are designed to ensure that patients and donors receive high-quality care and that government requirements are met.

CONVERSATION TIP:

Share the "Celebrating Be The Match" video with your employer to give a brief summary of the history of Be The Match.
Visit BeTheMatch.org/CelebrateVideo.

Q: Can I speak to someone at Be The Match about your donation, or get formal documentation?

 Yes, I can authorize my donor contact representative to speak with you; however, please know that they will not be able to provide specific details about my case due to confidentiality. Also, you can visit <u>BeTheMatch.org</u> for comprehensive information about the donation process and time commitment asked of donors.

CONVERSATION TIP:

It's your choice to authorize your donor contact representative to speak with your direct supervisor. This step may help address additional concerns and strengthen support for your decision.

Q: Be The Match sounds great! How can our organization get involved?

- There are many ways that our organization can get involved, including:
 - Host a marrow registry drive at our office.
 Visit <u>BeTheMatch.org/Donor-Drive</u> for scheduling information.
 - Give a financial gift. Visit <u>BeTheMatch</u>.
 <u>org/Giving</u> for information about how our
 organization can support Be The Match
 through monetary contributions and
 workplace giving programs.
 - Volunteer for Be The Match. Visit
 <u>BeTheMatch.org/Volunteer</u> for
 information about how employees can
 volunteer with Be The Match.
 - Help tell my donation story as a way to encourage others to join the Be The Match Registry, and show how our organization supports employees' personal causes.

ADDITIONAL DONOR RESOURCES

- Visit <u>BeTheMatch.org/DonorToolkit</u> and click on "Talking with Your Employer" for more resources, including an introductory letter to your employer from Be The Match explaining the need for donors and what is involved in the process.
- If your employer is interested in establishing a paid donor leave policy at your organization, contact your donor contact representative for more information.