

Talking with Your Educators

Starting the conversation

If you are enrolled as a student when you make the decision to donate blood stem cells, it's important to inform your instructors, advisors and coaches early on about the donation process and discuss how they can provide support. There's a time commitment associated with donation and recovery, which may impact your class attendance, school deadlines, athletic training, competitions and more. This guide covers some of the questions your instructors and coaches may have about the donation process, including talking points you can use when responding. Expressing your needs for flexibility and key steps in the process early on will help ensure support throughout the process.

Donation basics

Q: What is blood stem cell donation, and what are you being asked to do?

- Blood stem cell 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 NMDPSM.
 - 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 donor?

- I joined the NMDP RegistrySM, the world's most diverse database of unrelated volunteer blood stem cell donors. I am one of more than 41 million U.S. and international potential donors 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 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 have a fully matched donor within their own family and depend on NMDP 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 tip: Consider sharing with your instructors where and why you joined the registry in the first place. This might help them understand your motivation for wanting to help someone you don't even know.



Time commitment

Q: How will the donation process affect your class schedule? Will you miss classes, important deadlines or exam dates?

- If I am asked to donate, I may have to miss some classes or request extensions for my coursework. The time commitment for the donation process is generally 20–30 hours over a 4–6 week period, so it's likely there may be some schedule conflicts.
- As part of the donation process, 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: Before talking to your instructors, research your school and instructors' policies for missed classes, and review your course syllabus for key dates (i.e., presentations or exams). If you participate in work study, international study or have scholarships, check with your advisor to see whether absences impact eligibility for continued involvement in these programs.

Conversation tip: Suggest to your instructors potential solutions to meet key deadlines. This could include submitting coursework electronically, turning in work early or taking exams in advance.

Q: Is the time commitment for the two types of donations 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 miss consecutive classes for the donation process, or will it affect classes once in a while?

- The time commitment for donation may spread out over several weeks, depending on a number of factors including travel for me, the patient's condition and more. As a result, I may need some flexibility in my class 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 canceled.

Q: Will your appointments and donation take place nearby?

- To ensure that the procedure is safe for donors, NMDP 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.

Q: Do you have formal documentation (like a doctor's note) to verify that you've been identified as a potential donor?

 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 nmdp.org for comprehensive information about the donation process and time commitment asked of donors.





Q: How soon will you be able to return to class 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 class, work and any normal activities in one to two days. However, the median time to full recovery is one week (seven days).
- If I donate marrow, I should be able to return to class, work and any normal activities within one to seven days. It's recommended that I plan to take a few days off from school and work; perhaps more if associated activities are physically demanding. 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 class?

- 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.

Q: How soon will you be able to return to athletics?

- If I donate PBSC or marrow, there are limitations on exercise and physical activity that extend beyond the donation itself, and will impact my ability to train, practice or participate in athletics. These limitations vary depending on what I'm asked to donate.
- If I donate PBSC, it is recommended that I:
 - Avoid strenuous activity for the rest of the day after donation.
 - Avoid heavy lifting or pulling for seven days.
 - Avoid contact sports during the days leading up to donation while I receive the medication injections, and for seven days after donation.
- If I donate marrow, the restrictions are greater:
 - Through week one, it is recommended that I avoid heavy lifting, bending or exercise; avoid lifting more than 10 lbs; and allow time between periods of heavy activity throughout the day.
 - Through week two, it is recommended that I avoid strenuous activity such as jogging or running.
 - Through week four, it is recommended that I avoid contact sports





Q: How can you be sure that NMDP is a legitimate organization?

- A leader in the field of cellular therapy, NMDP was founded in 1987 and has facilitated more than 120,000 transplants to give patients a second chance at life.
- The U.S. government has entrusted NMDP to operate the C.W. Bill Young Cell Transplantation Program, the federal program supporting bone marrow and cord blood donation and transplantation.
- NMDP 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 "100,000 Transplant Story" <u>video</u> with your employer so they can learn more about NMDP.

Q: NMDP sounds great! How can our school and students get involved?

- There are many ways that our school and students can get involved, including:
 - Bring an NMDP ChaptersSM official chapter to our school. Visit nmdp.org/chapters to join a grassroots effort of students around the country working to raise funds, educate and build the NMDP Registry on their campuses. Chapter participation builds leadership skills, resumes and more.
 - Host a donor recruitment drive on our campus. Visit <u>nmdp.org/Donor-Drive</u> for scheduling information.
 - Encourage students to join the movement and help spread word of the NMDP mission through their social networks.
 - Help tell my donation story to students and the campus community through our school newspaper and other channels.

Additional donor resources

- Visit nmdp.org/DonorToolkit and click on "Talking with Your Employer" for more resources, including an introductory letter to your employer from NMDP explaining the need for donors and what is involved in the process.
- Share this letter with your instructors, coaches, advisors, dean or any other educators that may need to approve your time away from school.