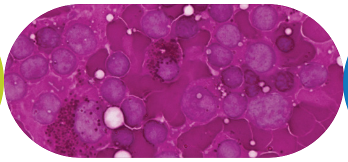


Talking with your friends and other support networks

Your friends, coworkers, family members and other support networks will likely be very curious about your donation experience. Be ready to address common myths about the donation process and clarify what it actually involves. Many of your friends may be eager to help and get involved, so consider asking them to spread the word about NMDP℠. Here are some of the most frequently asked questions from friends and supporters of potential donors like you. Use this information to prepare for your conversations:

Donation basics

Q: What donor list did you join?

- I joined the NMDP Registry℠, a global registry of potential blood stem cell donors.
- NMDP connects volunteer donors like me with thousands of patients with blood cancers like leukemia and other diseases like sickle cell.
- Every year, 12,000 patients are diagnosed with life-threatening blood cancers or diseases like sickle cell, for which a blood stem cell transplant from an unrelated donor may be their best or only hope of a cure.

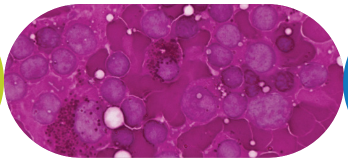
Conversation tip: Tell your friends where and why you joined the registry in the first place. Did you have a friend that needed a transplant? Did you hear about the strong need for donors from diverse racial and ethnic communities? This might help them understand your motivation.

Q: How does a blood stem cell transplant work?

- First, patients receive chemotherapy and sometimes radiation to eliminate their diseased bone marrow. Next, the donor's healthy blood-forming stem cells are infused into the patient. These cells then start to function and multiply, gradually replacing the patient's entire blood and immune system.
- For the patient's body to accept these healthy cells, it's important to find a donor who is a close genetic match, determined by their human leukocyte antigen (HLA) type.

Q: Why do you want to donate?

- I decided to join the registry and pledged to donate to any patient in need. By doing so, I can help give someone a second chance at life.
- Seventy-five percent of patients don't have a fully matched donor within their own family and turn to NMDP to find a suitable unrelated donor. Imagine if someone in your family needed a transplant and couldn't find a match.
- I've been identified as a potential match for a patient. If I'm confirmed as the best match, I'll be asked to donate. To protect both the donor and the patient, identities are kept confidential, so I have limited information about the person I might help.
- Matching a patient is more complex than just matching blood types. I could be the only person on the registry who can help this patient. Doctors match donors and patients based on several factors, with the most important being the HLA type. HLA are proteins—or markers—found on most cells in the body. Because these markers are inherited, patients are more likely to match someone from their own ancestry.



Conversation tip: Share the excitement of your donation, but **share with care**. Patients trust you to keep their identity private and social media makes it easy to piece together clues. Do not share the exact date of donation. And do not share age, specific disease or gender of patient.

Conversation tip: Tell your friends and other supporters specifically why you want to help this patient and how much it means to you. The best answer to this question is your personal motivation for donating.

Q: What is involved in donation?

- There are two methods of donation: peripheral blood stem cell (PBSC) donation and bone marrow donation. The patient's doctor decides which method is best for the patient.
- **PBSC donation** is a nonsurgical procedure that takes place at a blood center or an outpatient hospital facility experienced in PBSC collections for NMDP.
  - For five days leading up to donation, I will receive injections of a drug called filgrastim. This medication increases the number of blood-forming cells in my bloodstream.
  - During the donation, blood is drawn from one arm and passed through a machine that separates out the blood-forming cells. The remaining blood is then returned to me through the other arm. This process is known as apheresis.
  - PBSC donation is similar to plasma donation but typically takes longer. If I donate in one day, it could take up to eight hours. If the donation is split over two days, it will take 4–6 hours each day.
- **Marrow donation** is a surgical outpatient procedure that takes place in a hospital operating room.
  - I will be given anesthesia, so I won't feel any pain during the donation.
  - Doctors use a needle to withdraw liquid marrow from both sides of the back of my pelvic bone.
  - The marrow regenerates completely within 4–6 weeks.
- After the donation, my collected cells are immediately transported by a trained courier who hand-carries them to the patient's location for transplant.

Time and cost

Q: Do you get paid to donate?

- No, people join the NMDP Registry and donate voluntarily because they want to help others in need, regardless of compensation. Donation is an altruistic act.

Q: How much time is this going to take out of your life?

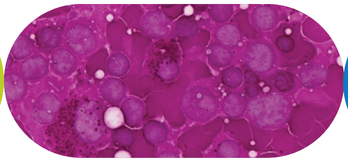
- The donation process typically requires a time commitment of 20–30 hours spread over 4-to-6-weeks. This includes phone calls, completing a health history, a physical exam and the actual donation.

Q: Will you need to travel?

- I may be asked to travel for the donation or any of the steps in the donation process. Travel is primarily based on the needs and timeline of the patient.
- If there isn't a suitable hospital or facility near me, I may need to travel. However, I will not travel to the patient's location; my cells will be transported to the patient right after my donation.

Q: Do you have to pay to donate?

- No. NMDP covers all donation-related activities, including medical and travel expenses. They can also reimburse lost wages.



Health Concerns

Q: Does donation hurt? It sounds pretty scary.

There are two methods of donation PBSC donation and bone marrow donation. Both methods are designed to be as comfortable and safe as possible for the donor.

- **PBSC donation:** This is an outpatient procedure that takes place at a blood center or hospital. For five days leading up to the donation, the donor will receive injections of a drug called filgrastim, which can cause some temporary side effects such as headaches, joint or muscle aches and fatigue. However, these side effects are generally short-lived, and most PBSC donors are back to their normal routine within one to two days.
- **Bone marrow donation:** This procedure is performed in a hospital operating room under general or regional anesthesia, so the donor will feel no pain during the donation. Doctors use a needle to withdraw marrow from the back of the pelvic bone. After the donation, one might experience some soreness in their lower back for one to two weeks, but most bone marrow donors are able to return to their normal activities within a few days.

Conversation tip: Encourage others to visit our donor testimonial library to watch past donors talk about their experience. These videos will help eliminate the myths your friends have about the donation procedure.

Q: How long will it take you to recover?

- I'm expecting to return to work, school and most other activities within one to seven days after donation.
- Most PBSC donors report they feel completely recovered within one week of donation.
- Most marrow donors report they feel completely recovered within three weeks of donation.

Support

Q: What can I do to help you while you're going through the donation process?

- Donation involves several appointments and a time commitment. You can support me in various ways, such as offering to drive me to and from my appointments; assisting with childcare, pet care or household tasks; being there to talk and offer emotional support, as the process can be emotionally challenging.

Q: How can I get involved with NMDP?

- You can help raise awareness about the importance of blood stem cell donation. For people with life-threatening blood cancers like leukemia and lymphoma or other diseases, a transplant can be a cure. Help ensure every patient has a chance at the transplant they need by making a contribution or joining the registry.
- You can also organize a recruitment drive to encourage others to join the registry. Fill out the online form on the NMDP website, and a representative will contact you.

Q: I don't think my cultural/religious beliefs support donation.

- I understand religious and cultural beliefs are deeply important. However, many religious and cultural groups support donation as a way to help others in need.
- I encourage you to learn more about the donation process and its impact and have a conversation with your religious leader to explore whether joining the registry aligns with your beliefs.