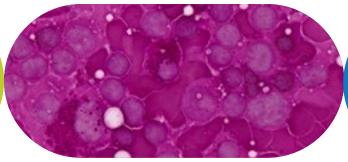


Talking with your parents

Talking with your parents about donation can be challenging—especially if you're not sure how they're going to react. Listen to and talk with them about their concerns. It's important to tell them the facts, as they may have heard myths or may not know anything at all about donation. They may be thrilled that you've been identified as a match and still concerned for your safety.

Because you are over the age of 18, your medical and donation information must be discussed directly with you and is only available to you.

We encourage you to involve your parents in the conversation, knowing NMDP℠ is bound by confidentiality guidelines to protect your information.

The questions below are some of the most commonly asked questions from parents of potential donors like you. Use the information below to prepare yourself for your conversation.

Donation basics

Q: What did you join?

- I joined the NMDP Registry℠, the world's most diverse listing of volunteer blood stem cell donors.
- I am one of more than 41 million U.S. and international potential donors on the registry.
- NMDP matches volunteer donors like me with thousands of patients with blood cancers like leukemia and lymphoma, sickle cell anemia or other life-threatening diseases.
- For many people with blood cancers like leukemia and lymphoma, and other life-threatening diseases, a blood stem cell transplant may be the best treatment option that could save their life.

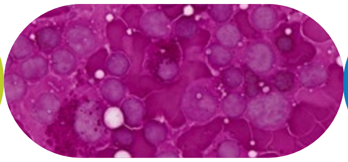
Conversation tip: Tell your parents where and why you joined the registry in the first place. Did you have a friend who needed a transplant? Did you hear about the urgent need to help find donors for patients who share your ethnic background? Is helping another person what you've always believed in? This might help them understand your motivation.

Q: Why do you want to donate?

- I decided to join the registry and pledged to help save the life of any searching patient. I can help give a patient a second chance at life and hopefully more time with their family.
- I made a promise to patients and their families, and I want to follow through with my commitment.
- Seventy percent of patients don't have a fully matched donor within their own family and depend on NMDP to find a donor. They depend on NMDP to find a genetically matched donor. I would want someone to help us if we were in the same situation.
- Matching a patient is more complex than simply matching blood types. I could be the only person on the registry that can help this specific patient. Doctors match donors and patients 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. Because the markers are inherited, patients are more likely to match someone who shares their ethnic background.w

Conversation tip:

- Tell your parents 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.
- Your HLA is inherited from your parents. They have contributed to your uniqueness, allowing you to match the patient.
- Your parents might ask you for more information about the patient. It's ok to tell them what you do know about the patient and that identities are kept confidential to protect both the donor and the patient.



Q: What is involved in donation?

- There are two methods of donation: peripheral blood stem cell (PBSC) and bone marrow. 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 experienced and participates in PBSC collections for NMDP.
  - For five days leading up to donation, I will be given injections of a drug called filgrastim to increase the number of blood-forming cells in my bloodstream.
  - My blood will be 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 me through the other arm. This process is called apheresis.
  - This method of donation is similar to the method used for plasma donation. However, PBSC donation typically takes longer than a plasma donation. If I donate in one day, it could take up to eight hours. If I donate over the course of 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 receive anesthesia and feel no pain during the donation.
  - Doctors use a needle to withdraw liquid marrow from both sides of the back of my pelvic bone.
  - The marrow replaces itself completely within 4–6 weeks.
- After donation, my collected cells are immediately transported by a trained courier who hand carries my cells to the patient's location for transplant.

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

- In order to be able to donate enough peripheral blood stem cells (PBSC) for a transplant, more of my cells need to be moved out of my marrow and into my bloodstream so they can be collected by apheresis. One way to do this is by receiving filgrastim (Neupogen®) injections for five days leading up to donation.
- Filgrastim is commonly used to treat cancer patients to boost their blood cell counts.

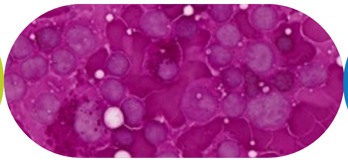
Your donor contact representative is a good resource for more information about filgrastim.

Q: Is donating safe?

- NMDP takes all the necessary precautions to ensure the safety and well-being of their donors. NMDP has the NMDP Donor and Patient Safety Monitoring Committee, that ensures safe and effective processes and procedures are used in donation.
- There are many steps involved in the donation process to ensure donating is safe for me. hese steps include completing a health history questionnaire, physical exam and blood tests.

Q: How does a blood stem cell transplant work?

- First, patients undergo chemotherapy and sometimes radiation to destroy their diseased bone marrow. Then the donor's healthy blood-forming stem cells are given to the patient, where they can begin to function and multiply, replacing the recipient's entire blood and immune system.
- For a patient's body to accept these healthy cells, the patient needs a donor who is a close genetic match based on their human leukocyte antigen (HLA) type.



Q: I've never heard of this organization. Are you sure it's legitimate?

- NMDP was founded in 1987 and has facilitated more than 120,000 transplants to give patients a second chance at life. NMDP facilitates more than 6,200 transplants each year and is a leader in the field of cellular therapy.
- 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 that connects more than 470 leading centers worldwide, including donor centers and transplant centers. They have standards designed to ensure that patients and donors receive high quality care and that government standards are met.

Time and cost

Q: How much time will this take away from school or your job?

- I may have to take some time off. The time commitment for the donation process is generally a total of 20–30 hours over a 4–6 week period. That includes phone calls, an information session, appointments for blood tests, a physical exam and the actual donation. All of these activities ensure that the donation is safe for me and the patient.
- Some states and some employers will cover wages for time away from work for donation. I'm going to talk with my boss and look at the statutes for our state. If my employer does not offer paid time off for donation, NMDP may be able to help through their donor financial assistance program. In most cases, NMDP is able to reimburse my lost wages due to donation-related activities, such as the physical exam, donation itself, and recovery. If lost wages for my companion are a concern, they may be able to help with that as well.
- I'm going to talk to my instructors, research my school and instructors' policies for missed classes, and review my course syllabus for key dates.

Conversation tip: Speak with your donor contact representative about your schedule. They can help you determine a plan that you can share with your parents to put them at ease. They can also help you find resources that may be helpful to you.

Q: Do you have to travel?

- To ensure the procedure is safe for donors, NMDP only works with hospitals and facilities that are experienced in collecting PBSC and marrow, so if there is not a facility near me, I may need to travel.
- All travel, meals and hotel expenses are covered by NMDP for me and one companion.
- NMDP will coordinate all the travel arrangements.
- Travel is based on the needs and timeline of the patient and the donor.
- I will not be traveling to the patient's location for donation. My cells are transported to the patient's location right after my donation.

Q: Can I come with you when you donate?

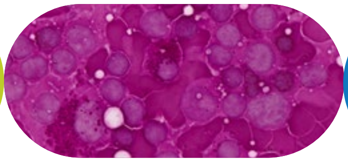
- I am encouraged to bring one companion along with me to the donation. Expenses are covered for me and one companion. The role of my companion is to support me before, during and immediately following my donation.

Q: Do we have to pay for this?

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

Q: Is this going to affect our family's insurance plan?

- No. I will get a card from NMDP that acts as an insurance card for all medical appointments related to donation. My insurance will not be involved.



Health concerns

Q: What are the side effects and risks associated with PBSC donation?

- If I donate PBSC, I 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.
- Common side effects of PBSC donation include bruising at the needle site, numbness or tingling and chills. These will go away shortly after the donation is completed.
- Most PBSC donors report full recovery within 7–10 days of donation. My donor contact representative will follow up with me until I report a full recovery.

Q: What are the side effects and risks associated with marrow donation?

- If I donate marrow, I can expect to feel some soreness in my lower back for a few days after donation or longer. Most marrow donors experience some pain, fatigue and stiffness following the donation. My marrow returns to normal levels within a few weeks.
- Most donors are back to their normal routine in a few days and most feel fully recovered within 21 days. My donor contact representative will follow up with me until I report a full recovery.
- Some donors said the experience was more painful than they expected, others, less painful.
- The vast majority of donors say it was worth it to help save someone's life, and they would do it again.

Conversation tip: You can always speak with your donor contact representative for more detailed information on health concerns, side effects and risks. You may also visit You're A Match: A Donor's Online Guide to Donation at nmdp.org/donationguide.

Q: Will you be able to have children after you donate?

- Donation does not impact my ability to have children.

Support

Q: What can I do to support you?

- You can support and be proud of my decision to move forward in the process. I have researched the process and am educated about the side effects and risks. I am willing to help this patient in need.
- You can be my advocate throughout the process. There may be moments when I'm anxious, excited or uncomfortable. You can be there for me, offering encouragement and reassurance, as well as helping me with daily tasks when needed.
- You can help spread the word about the opportunity to save someone's life. For people with life-threatening blood cancers like leukemia, lymphoma, sickle cell and other diseases, a cure exists—but they need their genetic match to join the registry. Help make sure every patient gets the transplant they need. Encourage others to join the registry, or consider making a financial contribution to help more people find their cure.

Q: Who is making sure that your needs as the donor are being met?

- My donor contact representative is here to answer any questions I might have. All donor contact representatives are professionals trained to advocate for, screen and educate potential donors about the donation process.
- NMDP has a Donor Advocacy Program that represents the rights of all NMDP donors.
- You. Help me come up with questions to ask about the donation process. I would like your support throughout the donation experience, registry, or consider making a financial contribution to help more people find their cure.

Q: Our cultural/religious beliefs do not support donation. I cannot support your decision.

- I understand religious and cultural beliefs play an important role in our lives. However, most religious groups support donation.

Conversation tip: Offer to set up a meeting with your religious leader and your parents to discuss your unique opportunity to help save someone's life.