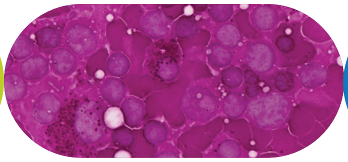


Talking with your parents

Discussing donation with your parents can be challenging, especially if you're unsure how they will react. It's important to listen to their concerns and provide them with accurate information. They may have heard myths or have little knowledge about the donation process. While they might be excited that you've been identified as a match, they may also be concerned about your safety. Involving your support system as early as possible is crucial.

Since you're over 18, your medical and donation information is confidential and can only be shared directly with you. However, we encourage you to involve your parents in the conversation, keeping in mind that NMDP^{SM} is bound by confidentiality guidelines to protect your information.

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

Donation process

Q: What is the donor list you joined?

- I joined the NMDP Registry^{SM}, 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.

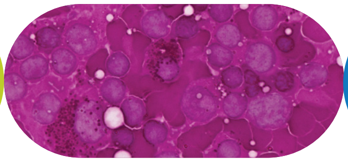
Conversation tip: Tell your parents where and why you joined the registry. Did you have a friend who needed a transplant? Did you hear about the urgent need to help find donors for patients who share your ethnic background? (Patients from ethnically diverse backgrounds can face greater challenges in finding a donor.) 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 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 depend on NMDP to find a suitable unrelated donor. Imagine if someone in our 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 human leukocyte antigen (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:

- 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 type is inherited from your parents. They have contributed to your uniqueness, allowing you to match 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) 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'll 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'll 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.

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

- While the overall time commitment for both marrow and PBSC donation is similar, there are some differences in the timing and nature of commitments.
- If I'm asked to donate PBSC, for five days leading up to donation, I'll receive injections of a drug called filgrastim. This medication increases the number of blood-forming cells in my bloodstream. This could affect my participation in sports or other activities before the donation.
- If I'm asked to donate marrow, more recovery time is needed after the donation.

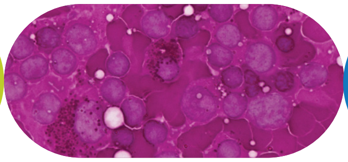
Conversation tip: Your donor specialist is a good resource for more information about filgrastim.

Q: Is donating safe?

- NMDP takes all necessary precautions to ensure the safety and well-being of its donors. They have a dedicated NMDP Donor and Patient Safety Monitoring Advisory Group, that oversees and ensures the use of safe and effective processes and procedures throughout the donation journey.
- There are several steps involved in the donation process to ensure it's safe for me. These steps include completing a health history questionnaire, undergoing a physical exam and performing blood tests.

Q: How does a blood stem cell transplant work?

- First, patients receive chemotherapy and sometimes radiation to destroy their diseased bone marrow. Then, the donor's healthy blood-forming stem cells are infused into the patient. These cells travel to the bone marrow, where they begin to function and multiply, effectively replacing the patient's entire blood and immune system.
- For the patient's body to accept these healthy cells, it is crucial to find a donor who is a close genetic match based on their HLA type.



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

- Founded in 1987, NMDP is a leader in cell therapy, helping find cures and save lives for patients with blood cancers and disorders.
- The U.S. Congress has entrusted NMDP to operate the C.W. Bill Young Cell Transplantation Program, the federal program supporting the national blood and marrow registry of the United States.
- NMDP serves as the hub of a global transplant network. The organization's standards are designed to ensure that both patients and donors receive high-quality care and that all government requirements 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-to-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.
- **Time away from work:** 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.
- **Time away from school:** 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 specialist 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.
- Travel is based on the needs and timeline of the patient and donor.
- All travel, meals and hotel expenses are covered by NMDP for me and one companion.
- NMDP will coordinate all travel arrangements.
- I don't need to travel to the patient's location for donation. My cells will be transported to the patient's location right after my donation.

Q: Can I come with you when you donate?

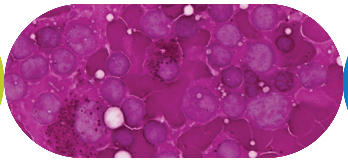
- I'm encouraged to bring one companion with me to the donation. Expenses for both my companion and me are covered. The role of my companion is to support me before, during and immediately following the donation.

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. Travel expenses and other non-medical costs are also included in this coverage. The only potential cost to me might be the 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 and muscle aches for several days leading up to the donation. These side effects are due to the filgrastim injections and typically subside shortly after the procedure.
- Common side effects of PBSC donation include bruising at the needle site, numbness or tingling and chills. These symptoms usually resolve quickly once the donation is complete.
- Most PBSC donors report full recovery within seven to 10 days after the donation. My donor specialist will follow up with me to ensure I have fully recovered.

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 the donation, which may last longer. Most marrow donors experience some pain, fatigue and stiffness following the procedure. However, my marrow will return to normal levels within a few weeks.
- Most donors are back to their normal routine within a few days, and the majority feel fully recovered within 21 days. My donor specialist will follow up with me until I report a full recovery.
- Some donors found the experience more painful than they anticipated, while others found it less so.
- Despite the discomfort, 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 specialist for more detailed information on health concerns, side effects and risks. You may also read about matching blood stem cell donors at nmdp.org/DonationGuide.

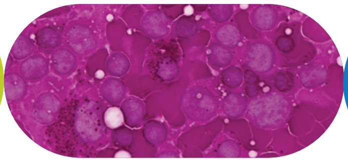
Q: Will you be able to have children after you donate?

- 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 with the donation process. I've thoroughly researched the process and am well-informed about the side effects and risks. I'm committed to helping this patient in need.
- You can be my advocate throughout the journey. There may be moments when I'm anxious, excited or uncomfortable. Your presence and support will be invaluable, offering me encouragement and reassurance, as well as helping with daily tasks when needed.
- You can also help spread the word about the life-saving opportunity that blood stem cell donation provides. 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 that every patient gets the transplant they need by encouraging others to join the registry or by considering a financial contribution to support more people in finding their cure.



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

- My donor specialist is here to answer any questions I might have. All donor specialists are professionals trained to advocate for, screen and educate potential donors about the donation process.
- The NMDP Donor Advocacy Program protects the rights of all donors. Additionally, donors have access to a team of social workers for free consultations, NMDP Donor Connect—a peer-to-peer support program that connects donors with past donors and mentors who share their experiences and provide support—and the NMDP Donor Community on Facebook, where I can ask questions and receive support from others who have been through the same process.
- You. Help me come up with questions to ask about the donation process. I would like your support throughout the donation experience.

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

- I understand religious and cultural beliefs play a significant role in our lives. However, many religious groups support donation and view it as an act of compassion and helping others.

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.