

Talking with your spouse or partner

It's important to involve your spouse or partner in your decision to donate, as it will significantly affect your family life. They'll likely have questions about your health and safety, the time commitment and how they can support you throughout the process. When discussing with them, make sure to listen to their concerns and explain your reasons for wanting to donate. Here are answers to some of the most common questions spouses and partners of potential donors often ask:

Donation basics

Q: What is the donor list you joined?

- I joined the NMDP RegistrySM, a global registry of potential blood stem cell donors.
- NMDPSM connects volunteer donors like me with patients with blood cancers like leukemia and other diseases like sickle cell.
- Every year, thousands of 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 spouse or partner where and why you joined the registry in the first place. Did a friend's child need a transplant? Did you hear about the urgent need to help find donors for patients who share your ethnic background? This might help them understand your motivation for wanting to donate.

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 spouse or partner 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.
- 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: What is filgrastim?

- To donate enough PBSC for a transplant, it's necessary to increase the number of cells in my bloodstream. This is achieved by moving more cells from my bone marrow into my bloodstream. One effective method is receiving filgrastim (NEUPOGEN®) injections for five days leading up to the donation.
- Filgrastim is commonly used to treat cancer patients to boost their blood cell counts.

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

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 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: Are you going to have to miss work? Can we afford this?

- I may need to take some time off. The entire donation process typically requires a total of 20–30 hours over a 4-to-6-week period. This includes phone calls, an information session, blood tests, a physical exam and the actual donation. All these steps ensure the safety of both me and the patient.
- Some states and some employers will offer paid time off for donation. I'm going to talk with my boss and look at the statutes for our state. If my employer does not provide paid time off, NMDP can assist through their donor financial assistance program. In most cases, NMDP can reimburse lost wages due to donation-related activities, such as the physical exam, the donation itself and recovery.
- If lost wages for my companion are a concern, NMDP may also provide assistance. This includes reimbursement for any missed work or lost pay for my traveling companion due to donation-related activities.

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

Q: Do you have to travel? Why can't you just donate at any medical facility?

- 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 the donor.
- All travel, meals and hotel expenses are covered by NMDP for me and one companion.
- NMDP will coordinate all travel arrangements.
- After donating, my cells are transported via courier, directly to the patient's location, eliminating the need for me to travel.

Q: What about expenses? Is this going to cost us anything?

- 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 school, work or other responsibilities.
- NMDP will cover child and pet care for any time I'm away for donation.

Q: Does this affect our family's insurance plan?

- Not at all. NMDP will give me a donor insurance card to take to all of my donation-related appointments. NMDP will be billed directly.

Q: Can I come with you? If so, how much will that cost?

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

Conversation tip: There are many factors to consider when choosing who to bring with you to the donation. While you might like to have your spouse or partner accompany you, it might be more help to you if they stay home to take care of the household while you're away.

Another family member or friend might be a more appropriate donation companion in some situations. Talk with your spouse or partner about the pros and cons of going with you to the donation. If you're interested in having your children go with you to the donation, check with your donor specialist.

Health concerns

Q: What about your health? Is this safe?

- NMDP prioritizes the safety and well-being of all donors. They have established the NMDP Donor and Patient Safety Monitoring Advisory Group to ensure that all processes and procedures are safe and effective.
- To ensure that the donation is safe for me, the process involves several important steps. These include completing a detailed health history questionnaire, undergoing a physical exam and conducting blood tests. Each of these steps is designed to thoroughly assess my health and ensure that I'm a suitable candidate for donation.

Q: How does donating impact pregnancy and breastfeeding?

- **Female donors:**
 - Donation does not impact my ability to have children.
 - If I choose to proceed with the donation process, we need to put our pregnancy plans on hold, during and for a short period after donation.
 - If I become pregnant during any stage of the process, I will not be allowed to donate.
 - It is recommended that I should consult with my personal physician after donation and before becoming pregnant. In the absence of clinical data, waiting to become pregnant until my next menstrual cycle after the last dose of filgrastim is recommended.

Conversation tip: Breastfeeding will be interrupted by donation. New moms should talk with their donor specialist for more information.

- **Male donors:**
 - Donation does not impact my ability to have children.
 - In the absence of clinical data, male donors should wait two days following the last dose of filgrastim to conceive a child.

Q: What are the side effects and risks associated with filgrastim and 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.

Q: How long does it take for you to recover from donation?

- Most PBSC donors report full recovery within seven to 10 days of donation.
- Marrow donors typically return to their normal routine within a few days and generally feel fully recovered within 21 days.
- My donor contact specialist will follow up with me until I report a full recovery.

Conversation tip: It's likely you'll need help with your daily chores while you're recovering. Talk with your spouse or partner about your daily tasks and determine how they'll be accomplished. It might be helpful to ask another family member or friend to help around the house until you can resume normal activity.

Support

Q: What can I do to support you during the donation process?

- Your support means a lot as I move forward with the donation process. I've researched the process and am well-informed about the potential side effects and risks. I'm committed to helping this patient in need.
- There may be days leading up and following the donation when I don't feel well. Your help in taking care of me and monitoring my health would be invaluable. We can review the donation materials together to ensure we're both prepared for any side effects I might experience.
- I will also need your emotional support. This process can be emotionally challenging, and I may learn information about the patient's health that could be difficult to process. If either of us needs to talk to someone, NMDP is able to provide counseling support from the social work team.
- During my recovery, I might not be able to handle all of my usual household chores for a while. I may need your help or the assistance of another family member or friend.
- You can also help by spreading the word about the life-saving opportunity that blood stem cell donation provides. For people with life-threatening blood cancers like leukemia or diseases like sickle cell, a cure exists, but they need their genetic match to join the registry. Help make sure 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 can 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 spouse or partner to discuss your unique opportunity to help save someone's life.