



# Share Your Story Guide



An NMDP<sup>SM</sup> guide to sharing the NMDP mission through your own personal story.

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## Share your story guide

Purpose: The purpose and needs of this kit are to enable recruitment ambassadors, NMDP Chapter members, patients, donors, NMDP partner volunteers, coaches, players, and all volunteers to share information accurately on their social media. By providing social posts, do and don'ts, guidelines, and talking points, we can better ensure our NMDP brand is shared appropriately by volunteers.

## Who is NMDP

### Our Mission

At NMDP, we believe each of us holds the key to curing blood cancers and blood disorders. Our vision is to create a world where every patient can receive their life-saving cell therapy. Your support helps push the boundaries of what is possible.

### What we do

We save lives through cell therapy. When a patient receives cell therapy, their diseased or damaged cells are replaced by healthy ones. The process might use a patient's own cells or those from a donor. At NMDP, we harness the power of cell therapy to treat or cure blood cancers and other blood disorders.

### Partners: a global movement to save lives

NMDP strives to deliver world-class service to transplant centers, donor centers and NMDP BioTherapies<sup>SM</sup> partners by providing decision-making tools, high-quality products and research data to deliver clinical excellence and advance standards of care for patients and donors. As a member of the World Marrow Donor Association, NMDP collaborates across an extensive global ecosystem of experts and organizations.

## NMDP at a glance

At NMDP, we believe each of us holds the key to curing blood cancers and disorders. As a global nonprofit leader in cell therapy, we work tirelessly to find cures and save lives through blood stem cell transplants and other cell therapies.

The generosity of our partnerships and philanthropic community is critical to moving our mission forward. Together with your support we are expanding access to treatment and helping patients live longer, healthier lives through groundbreaking research. We are continuing to grow the world's most diverse registry of blood stem cell donors and we're breaking down barriers to treatment so every patient can receive the cell therapy they need.

## We're here for patients every step of the way.

### Patient and donor support

NMDP provides one-on-one support for both donors and patients at every step of the transplant journey. Our comprehensive services include patient education, counseling, transplant navigation support, our NMDP Peer Connect program and much more—completely free of charge.

We also know that financial costs continue to be the number one burden or barrier reported by patients who come to us needing a transplant. \*

In 2023, we provided \$5.5 million in patient assistance grants. Much of this critical lifeline is funded through philanthropy and the generous support of our community and volunteers like you.

## How to share the NMDP mission and your connection

Before you begin sharing your connection to NMDP, we want to ensure you have the information you need to correctly share what it means to be an NMDP Registry member. When recruiting registry members, it is critical you understand the request you are making as well as helping the person joining understand the commitment to the registry.

In this section, you will be able to review our NMDP key messages, find answers to frequently asked questions, understand the two ways to donate, the donation process, who pays for the travel and expenses for the donor and more. Refer to this section often as there will be many questions from people when they are asked to join the registry.

## NMDP Registry requirements

You can join the NMDP Registry if you are:

- Between the ages of 18-40
- A resident of the United States or one of its territories or freely associated states
- Able to meet our medical guidelines

## Two ways to donate



# Donating blood stem cells

## Two ways to donate

If you're a match, you'll be asked to provide blood samples for further testing. Blood work is typically done locally, but travel will likely be required for donation.

The entire donation process takes an average of 20–30 hours spread out over 4–6 weeks, exclusive of travel.

### Most donors (90%) are asked to provide blood stem cells collected from circulating blood.

These peripheral blood stem cells (PBSC) are donated during a process that's similar to giving plasma or platelets.

- Nonsurgical outpatient procedure
- Typically back to regular routine in 1–2 days
- Requires 5 days of shots leading up to donation to increase the production of blood-forming cells

### Some donors (10%) are asked to provide blood stem cells collected from bone marrow.

Marrow donation is done while under general anesthesia. Doctors use a needle to withdraw liquid marrow (where the body's blood-forming cells are made) from the pelvic bone.

- No pain during donation
- Outpatient procedure
- Typically back to regular routine in 2–7 days



NMDP<sup>SM</sup> pays for all donation-related costs, including travel costs for you and a companion, medical appointments, lost wages, childcare, pet care and more.



Scan the QR code to learn more.

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Who pays for all of this?



## We cover 100% of donor expenses

<b>Medical</b>	<ul style="list-style-type: none"><li>• Lab tests</li><li>• Appointments</li><li>• Donation procedure</li></ul>	
<b>Travel</b> (+1 companion)	<ul style="list-style-type: none"><li>• Accommodations</li><li>• Transportation</li><li>• Mileage</li><li>• Parking</li><li>• Meals</li></ul>	
<b>Personal</b>	<ul style="list-style-type: none"><li>• Childcare</li><li>• Pet boarding</li></ul>	
<b>Professional</b>	<ul style="list-style-type: none"><li>• Lost wage reimbursement</li></ul>	

Plus, we'll consider covering any expenses not listed here on a case-by-case basis.

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## What do I say if someone isn't sure about joining the registry?

Joining the registry often feels like a big commitment to people. Below you will find some suggestions of things to say to someone who is not sure yet if they want to join the registry. As you are sharing your story and recruiting others to the register, it is important you ensure they understand what they are signing up for and that being a committed donor is critical for patients in need. While this list is not comprehensive, it does highlight many phrases you should use when talking about their decision to join.

- “You could be a patient’s best match—their only hope for a cure. When you register, you’re committing to donating to any patient in the world, even if you’re joining on behalf of a specific person.”
- “If you match, you have the right to change your mind. But because a decision not to donate can be life-threatening to the patient, please think seriously about your commitment before joining the registry.”
- “It’s ok if you’re on the fence or still have questions—let’s talk this through.”
- “It’s ok if now is not the time—NMDP will be here for you when you’re ready.”
- “Maybe you’d prefer to donate your time; we’d love for you to volunteer with us. We have many ways to engage through fundraising, advocacy and recruitment.

## Facts to know when asking people to join the registry

- Once you’ve returned your swab kit, it’ll take six to eight weeks to be added to the registry. After that, you could be called for a patient anytime: in two months, one year or longer.
- Keep your contact information up to date so we can find you quickly if you are a possible blood stem cell donor match and make sure to add an alternate contact to your account.
- When you are called as a possible match, it’s important that you respond quickly. If you are a potential match, you will be asked to provide blood samples or go through additional testing. Blood work is typically done locally, but travel will likely be required for donation.
- It costs you nothing to join the registry or donate! NMDP pays for all donation-related costs, including travel costs for you and a companion, medical appointments, lost wages, childcare, pet care and more.
- If needed, NMDP can talk to your family, professors, coaches and/or employers to explain the commitment.
- We are serious about safeguarding your privacy. When you join, you will give us a cheek swab sample. The sample and information about your tissue type are identified by a unique code and kept separate from your personal identifying information (like your address, phone number and email).



- Creating an account post-swabbing is critical as this helps NMDP stay in touch with you and your alternate contact. Without that information, you could match, and we would not be able to get in touch with you.

## Frequently asked questions

### ***How do blood stem cell transplants help patients?***

When a patient with a blood cancer or disorder receives a blood stem cell transplant, the donor's healthy cells travel to the patient's bone marrow and start producing new cells. These new cells enter the patient's bloodstream, replacing the diseased cells.

### ***How does the donor registration process work?***

It begins with a simple cheek swab, which allows us to add your genetic type to the registry. If you are a match for a patient, we will contact you; you may need to go through additional testing. We will walk you through everything you need to know about the blood stem cell donation process and discuss the schedule. You will then undergo a physical exam and give blood samples to make sure that donation is safe for you and the patient.

### ***What is the likelihood of being called as a match?***

We cannot predict the likelihood that an individual member will match with a patient or donate because there is so much diversity of tissue types in the population. However, doctors request donors in the 18-35 age group nearly 80% of the time. That is because research shows cells from younger donors lead to more successful transplants.

### ***Can I say no if I get called to donate?***

You could be a patient's best match—their only hope for a cure. When you register, you are committing to donating to any patient in the world, even if you are joining on behalf of a specific person. If you match, you have the right to change your mind. But because a decision not to donate can be life-threatening to the patient, please think seriously about your commitment before joining the registry.

### ***What happens to my personal information?***

We're serious about safeguarding your privacy. When you join, you will give us a cheek swab sample. The sample and information about your tissue type are identified by a unique code and kept separate from your personal identifying information (like your address, phone number and email). We will only use that personal info for things such as matching you with patients, sending you membership materials or sharing other ways you can support our mission. That is all outlined in the consent form you will sign while registering. We never share your name, contact info or genetic type with any government agencies or companies beyond our clinical partners.

### ***If I can't donate blood, can I still donate blood stem cells?***

Guidelines for donating blood stem cells are not the same as those for donating blood. Requirements for donating blood stem cells exist to protect your health and the health of transplant patients. If you are a match for a patient, we will discuss your health history further and arrange for a thorough physical exam.

### ***How does donation work?***

There are two ways to donate blood stem cells. If confirmed as the best match for a patient, you will donate either peripheral blood stem cells (PBSC) or bone marrow. See the two ways to donate section on page 6 in this guide.

## How to share your story

This is where the fun begins. Now that you are equipped with the proper information and facts, it is time to start sharing this mission and why it is important to you. There are many ways to share the NMDP mission, and we hope that each person will share in the way that is most comfortable for them. For some that will be word of mouth, for others email and of course there is always social media. Regardless of how you choose to share your story, ensuring you are sharing accurate information as well as following guidelines is critical to our mission.

We do have social media guidelines; you will find those below. In addition, you will find templates to use to share your story online.

We have provided some sample caption ideas to use when sharing your story on social media, as well as guidance on how to add your personalized join code. If you're interested in using personalized templates or have any questions, please contact your local NMDP representative.

### Social media usage

Sharing your story on social media is an easy way to motivate others to join NMDP's mission to save lives just like you. We recommend using a mix of photos and videos. Consider sharing your volunteer experience in social media groups or networking groups where other members share your interests or identities. Utilize these connections to build organic relationships with people who may want to get involved with NMDP as well. If possible, consider contacting members of your community who have larger social media followings to amplify your reach.

When sharing your story or encouraging people to join the NMDP cause, use these guidelines on social media platforms.

- Include your personalized join keyword name (URL or text-to-join code) in every social post.
- Add your URL to your Instagram bio so it can be accessed easily.
- If comfortable, set your account to "public." Otherwise, tagging organizations, using hashtags or any mentions will not be seen by the public, nor will they be shareable.
- Always use the hashtag **#NMDP** to add to the growing set of inspiring posts being shared every day.
- Tag **@nmdp\_org** whenever possible so NMDP can engage and re-share.
- Tag friends and family who you think would want to get involved. Tag Search the internet for apps to help schedule social media posts in advance. Some are free to use and can help you stick to your plan.
- Let your friends know how many people have joined on your behalf already to encourage other people to sign up.

## Social Media Content Ideas

Highlighting various stages of your volunteer experiences can effectively inform others about what it means to join the registry and what it looks like to volunteer with NMDP.

Questions to consider while making content:

- When did you first hear about NMDP?
- What made you decide to volunteer?
- What's your favorite part about volunteering with NMDP?
- When, where, and why did you decide to join the registry?
- What did it mean to you to sign up?
- What would you tell others who have either never heard of NMDP or who are uncertain about joining the registry?

## Caption Ideas

Authenticity is key when thinking about how to caption your social media post. Please be mindful and avoid sharing personally identifiable information mentioned on page (14). Below are sample captions.

- You can impact lives when you volunteer with NMDP!
- I joined the NMDP Registry. And you should too! Text (*insert keyword*) to 61474 to learn more.
- Recently, I volunteered with NMDP to tell people about the NMDP Registry and how they can join! You can too by texting (*insert keyword*) to 61474. We are proud and thankful to have you volunteer to further our mission, and we appreciate your enthusiasm. Before posting about NMDP on social media, please review the Do's and Don'ts guidance below.

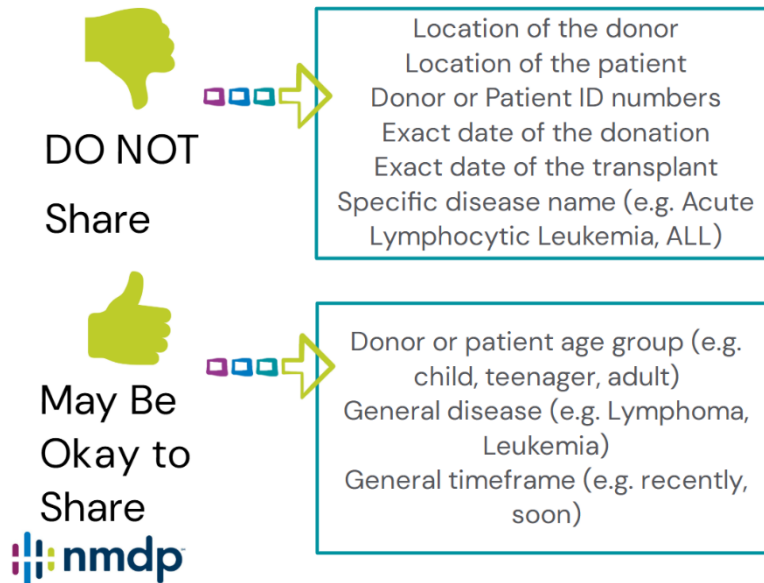
## Social media dos and don'ts

### Do:

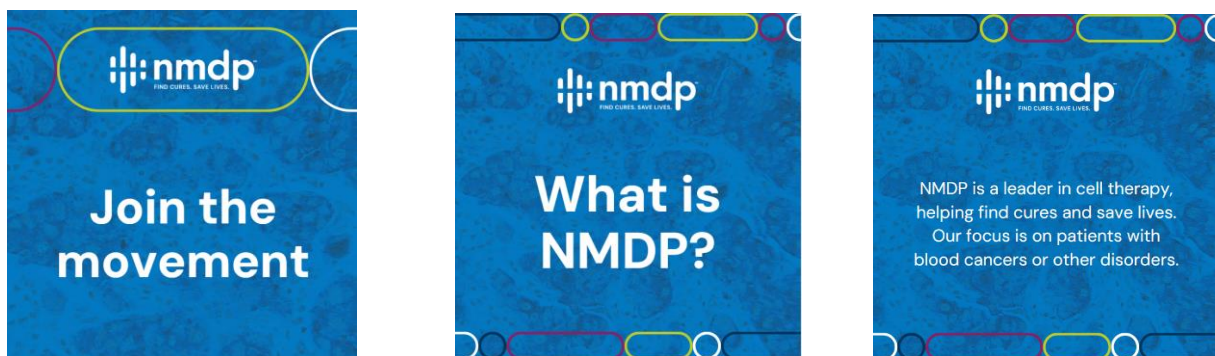
- Share your volunteer experience with NMDP on social media! When posting, please ensure you accurately reflect your role as a volunteer. We recommend you use the following format: your name, NMDP volunteer role
- Example: Sue, NMDP volunteer courier and James, NMDP volunteer live drive events
- Protect the confidentiality of our patients, donors, their families, our staff, other volunteers, etc.
- Encourage your connections to follow us on social media or become a volunteer with NMDP!

### Don't:

- Share personally identifiable information about NMDP patients, donors or their families.
- Share photos of patients, donors, their families or NMDP staff at volunteer events, unless authorized by your volunteer coordinator.
- Share personally identifiable information about NMDP staff, customers, suppliers, vendors, network members or other businesses we work with.



### Social media post templates



We've compiled a list of ready-to-use [social media templates](#) for you to share your volunteer experience.

## Texting and Emailing

- Reach out to friends and family personally to let them know how easy it is to join the registry! Don't forget to include your personalized referral (join) code in each communication.
- Email people you know and include why this is important to you and what motivated you to host a virtual NMDP event. You can attach a patient or donor video to drive your message home. Sometimes videos might be too big to share in an email, so you can link out to a video on YouTube.
- Send the email multiple times over the next few weeks and share additional information each time.
- Text your join link or text-to-join number out! Include a short message about why this is important to you and what motivated you to host a virtual drive.

## Solicitations on behalf of NMDP

NMDP does not authorize volunteers to take any action that will bind, obligate or significantly affect NMDP and our business activities. Examples of such actions are public statements to the media, coalition or lobbying efforts with other organizations or any agreements involving contractual or other financial obligations.

We know our volunteers have many ideas about how to connect with the community and fulfill our mission of saving lives. Before doing any outreach for donation of goods, services or dollars, contact your volunteer coordinator to verify NMDP's standard practices and methods of communication.

## Statements to the media

During your volunteer work with us, you may have contact with members of the media (such as television, radio, newspapers, online or magazine outlets). If this happens, direct any inquiries to your volunteer coordinator so they can provide the media representative with up-to-date, accurate information that reflects the mission of NMDP.