

# Share Life

A publication for people interested in marrow and blood cell donation.

## How the NMDP Helps Patients in Need

The National Marrow Donor Program® (NMDP) helps people who need a life-saving marrow or blood cell transplant. We connect patients, doctors, donors and researchers to the resources they need to help more people live longer and healthier lives. To achieve our mission, we:

- **Search** our Registry – the largest listing of volunteer donors and cord blood units in the world
- **Support** patients and their doctors throughout the transplant process
- **Match** patients with the best donor or cord blood unit using innovative science and technology

## How Can You Become a Marrow or Blood Cell Donor?

We want you to have all the information and support you need to make a committed decision. To qualify as a volunteer marrow donor, you must:

- Be between 18 and 60 years old and meet health guidelines
- Take a blood test to determine your tissue type
- Be listed on the NMDP Registry, which is strictly confidential
- Update your contact information if there is a change in your address, health status or willingness to donate

## Other Ways You Can Help

In addition to joining the NMDP Registry, there are many ways you can help a patient in need of a transplant:

- Tell friends and family about the need for donors.
- Donate frequent flyer miles to help patients to travel to receive treatment.
- Make a financial contribution through The Marrow Foundation®. Contributions can be sent to :

**The Marrow Foundation**  
400 Seventh St. N.W.  
Suite 206  
Washington, D.C. 20004

## Getting the Chance to Save a Life!

As a veteran police officer in a large city, there are not a lot of things that can bring a tear to Randy Yamanaka's eye. But when Randy talks about attending Luke Do's third birthday party, that all changes.

"To see him playing in the sunshine at his birthday party was absolutely joyous for me," said Randy. "I cannot describe that feeling in words."

In 2002, Luke was diagnosed with leukemia when he was just 18 months old. After chemotherapy, blood transfusions and experimental drugs did not stop the leukemia, doctors told his parents that Luke's only hope to survive was to have a bone marrow transplant. However, he would need a matching donor.

The best chance to finding a matching donor is from a sibling. However, Luke's sister did not match. His family then turned to the National Marrow Donor Program (NMDP) to search for a matching unrelated donor.

### Getting the Call

Six years earlier, Randy joined the NMDP volunteer donor Registry during a recruitment drive at his place of employment. He gave a blood sample, which was tested to determine his HLA tissue type. Those results were then stored on the NMDP's international Registry of more than 5.5 million donors.

When Luke's doctors searched the NMDP's computerized Registry, Randy's



Randy (donor, left) and his recipient, Luke

tissue type was a match. "I got this phone call telling me that I was a match for a patient, and that I had to come in for more testing," Randy said. "It was quite an awesome phone call to receive." On March 18, 2002, Randy donated marrow to Luke.

"I was ready. I felt an absolute calm on the day of my marrow collection," Randy said. "The discomfort was minimal, but I did feel some nausea from the anesthesia. My recipient was this brave little boy who lived two states away from me ended up to be his miracle match."

## More Diverse Donors Needed on the Registry

Because one's tissue type is inherited, patients are most likely to match someone of their same racial and ethnic background. The NMDP is working to increase the diversity of the Registry to improve the chance of finding a donor for all patients.

There is continuing need to recruit more donors who identify themselves as: African American or Black, Asian, American Indian or Alaska Native, Native Hawaiian or Other Pacific Islander, Hispanic or Latino, or mixed race.

# ABCs of Marrow and Blood Cell Transplants

## What is a marrow or blood cell transplant?

A marrow or blood cell transplant is a potentially life-saving treatment for patients with leukemia, lymphoma and other blood diseases. A transplant replaces a patient's unhealthy blood cells with healthy blood-forming cells from a volunteer donor. Patients who do not have a matched donor in their family may search the NMDP donor Registry for a donor. The three sources of blood-forming cells are marrow, blood-forming cells collected from the blood (PBSC donation) and umbilical cord blood.

## Who covers the expenses of becoming a donor and the actual donation?

The blood test performed to add you to the Registry identifies your HLA tissue type. The cost for the test is generally \$65 to \$95, depending on the donor center and the laboratory that completes the test. Some donor centers cover part of the cost of the testing for donors of whole blood or blood components. After the initial testing, all medical expenses are covered by the patient or the patient's insurance.

## How are patients matched with donors?

Blood samples from adult donors or cord blood units are tested, and the tissue type is added to the NMDP Registry. Doctors can search this Registry when they need to find a donor whose tissue type matches their patient's.

## How does a person's race or ethnicity affect matching?

Because tissue type is inherited, patients are most likely to match someone of their same race and ethnicity. There is a special need to recruit more donors who identify themselves as: Black or African American, American Indian or Alaska Native, Asian, Native Hawaiian or Other Pacific Islander, Hispanic or Latino and multiple race.

## How are blood-forming cells collected?

**Marrow donation** is a surgical procedure performed in a hospital. While the donor receives anesthesia, doctors use special, hollow needles to withdraw liquid marrow from the donor's pelvic bones. Many donors receive a transfusion of their own previously donated blood. A donor's marrow is completely replaced within four to six weeks.

**PBSC donation** takes place at an apheresis center. To increase the number of blood-forming cells in the bloodstream, donors receive daily injections of a drug called filgrastim for five days

before the collection. The donor's blood is then removed through a sterile needle in one arm, passed through a machine that separates out the cells used in transplantation, and the remaining blood is returned through the other arm.

**Cord blood** is collected from the umbilical cord after a baby's birth. The cord blood is taken to a cord blood bank where it is tested. Cord blood units that meet eligibility standards are frozen and stored for future use. The collection does not pose any health risk to the mother or baby, and does not affect the birth process in any way.

## Does donating hurt? What are the side effects?

Marrow donors can expect to feel some soreness in their lower back for a few days or longer. Donors also have reported feeling tired and having some difficulty walking. Most donors are back to their usual routine in a few days. Some may take two to three weeks before they feel completely recovered.

PBSC donors report varying symptoms including headache, bone or muscle pain, nausea, insomnia and fatigue while receiving injections of filgrastim. These effects disappear shortly after collection. During the collection, donors may experience a tingling feeling or chills. These effects go away shortly after donating.

## How does a patient receive a transplant?

After a patient undergoes chemotherapy and/or radiation treatment to destroy their diseased marrow, the healthy donor cells are given directly into the patient's bloodstream. The cells travel to the marrow, where they begin to function and multiply.

## Would I travel to donate to the patient?

The NMDP makes every effort to arrange for the donation to be at an NMDP collection center or apheresis center closest to the donor. However, there are times when travel is required. After the donation, the marrow or blood-forming cells are then transported to the patient by a specially trained courier.

## Will I ever meet the recipient of my marrow or blood cells?

Volunteer unrelated marrow or blood cell donation is an anonymous process. For the first year post-transplant, the donor and recipient communicate only in writing through the NMDP. If both the recipient and donor wish to meet after one year, NMDP coordinators can assist in that process.

## Patients Are Counting on Committed Donors Like You to Help Save a Life

We will need your current contact information if you ever match a patient. Patients and their families are counting on you.

It is terribly disappointing to a family to learn that a donor is no longer available.

- Some potential donors can not be located.
- Some have a change in their health.
- Some are no longer interested.

Delays in finding a donor are dangerous to the patient. A patient's condition can worsen if time is wasted trying to locate donors who are no longer available.

If your contact information or health has changed, it is extremely important that you notify us so we can update your file.

If you no longer wish to be listed on the

Registry, it is important that you let us know. No one will question your decision or try to change your mind. Removing yourself from the Registry saves patients from dangerous delays, disappointment and false hope.

To update your contact information, ask questions or remove yourself from the Registry, visit [www.marow.org](http://www.marow.org) or call 1 (800) MARROW-2.

# Steps of Marrow and Blood Cell Donation



- 1 Join the Registry.** Volunteers must be between the ages of 18 - 60 and meet the health guidelines. Volunteers should be committed to helping any patient. To join, you complete a short health questionnaire and sign a form stating that you understand what it means to be listed on the Registry. Then, a small blood sample is taken to find your tissue type. This information is added to the Registry.
- 2 Stay committed and available.** Doctors search the Registry to find a donor whose tissue type matches their patient's. If you are chosen, your donor center will contact you. If you agree, more testing will be scheduled.
- 3 Attend an information session.** You will meet with staff from your donor center to learn about the donation process, risks and side effects. You are free to bring a friend or family member. You will also be told which source of blood-forming cells is being requested — either collected from the marrow or from the circulating blood (known as a PBSC donation). You will then decide whether or not to donate.
- 4 Receive a physical exam.** If you agree to donate, you will be given a physical exam to discover if donating would pose any special risks to you or the patient.

## Marrow Donation



- 5 Marrow donation is a surgical procedure.** While you receive anesthesia, doctors use special, hollow needles to withdraw liquid marrow from the back of your pelvic bones. Many donors receive a transfusion of their own previously donated blood.
- 6 Side effects and recovery.** You can expect to feel some soreness in your lower back for a few days or longer. Most donors are back to their normal routine in a few days. Your marrow is completely replaced within four to six weeks.
- 7 Follow-up.** Your NMDP donor center coordinator will follow up with you until you are able to resume normal activity. You will also receive annual calls for long-term follow-up.

## PBSC Donation



- 5 PBSC donation takes place at an apheresis center.** To increase the number of blood-forming cells in the bloodstream, donors receive daily injections of a drug called filgrastim for five days before the collection. Your blood is then removed through a sterile needle in one arm and passed through a machine that separates out the blood-forming cells. The remaining blood is returned to the donor.
- 6 Side effects and recovery.** You may experience headache, or bone or muscle aches for several days before collection. This is a side effect of the filgrastim injections that you received to increase the number of blood-forming cells in the bloodstream. These effects disappear shortly after the collection.
- 7 Follow-up.** Your NMDP donor center coordinator will follow up with you until you are able to resume normal activity. You will also receive annual calls for long-term follow-up.

*The National Marrow Donor Program® helps people who need a life-saving marrow or blood cell transplant. We connect patients, doctors, donors and researchers to the resources they need to help more people live longer and healthier lives.*

**For more information visit [www.marrow.org](http://www.marrow.org)  
1 (800) MARROW-2**

NATIONAL MARROW DONOR PROGRAM®

3001 Broadway St. N.E., Suite 500

Minneapolis, MN 55413-1753

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*Creating Connections. Saving Lives.™*

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## Creating Connections. Saving Lives.

Each year, more than 35,000 people are diagnosed with life-threatening diseases for which a marrow or blood cell transplant may offer the only chance for a cure. These diseases affect people from all racial and ethnic backgrounds, but patients from diverse backgrounds face a greater challenge in finding matching donors.

Only 30 percent of patients in need of a marrow or blood cell transplant find a matched donor in their family. The other 70 percent may turn to the National Marrow Donor Program® (NMDP) to search for an unrelated donor.

Since it began operations in 1987, the NMDP has facilitated more than 20,000 marrow or blood cell transplants for patients who do not have matching donors in their families.



Randy (donor, left)  
and his recipient, Luke