



NATIONAL MARROW DONOR PROGRAM®

Creating Connections. Saving Lives.™



Confirmatory Typing

for Blood Stem Cell Donation

You are a Possible Match for a Patient in Need of a Transplant

Thank you for being part of the National Marrow Donor Program's (NMDP) volunteer donor Registry. When you signed up to be a volunteer donor, you gave a blood sample. That sample was tested and your tissue type was stored on our computerized Registry. Now, a doctor searching the Registry has chosen you as a possible donor for a specific patient.

We are sharing this information with you to help you make your decision about whether or not you want to go forward.

If you choose to go forward, more testing is needed to see if you are the best donor for the patient. This additional testing is called confirmatory typing.

STEPS OF CONFIRMATORY TYPING

1

You are contacted by the donor center staff and given more information.

2

You are given the chance to express your interest about continuing as a potential donor.

3

You answer questions about your health history.

4

You give your consent to move forward for more testing.

5

You may or may not be requested to give an additional blood sample.

On the cover:

At left, Bob (donor) and his daughter, Teagan; top right, Mary H. (donor) and family; bottom right, Randy (donor) and his recipient, Luke.

Steps of Donation

Join the NMDP Registry as a Committed Donor

- Answer a short health history questionnaire
- Give a blood sample for HLA testing
- Results are stored on the NMDP Donor Registry and searched by physicians every day
- More than 5.5 million volunteers have joined the Registry

Confirmatory Typing

- A request to come in for more testing to see if a potential match is the best donor for the patient
- About 8% (1 in 12) of donors who reach this stage go on to donate

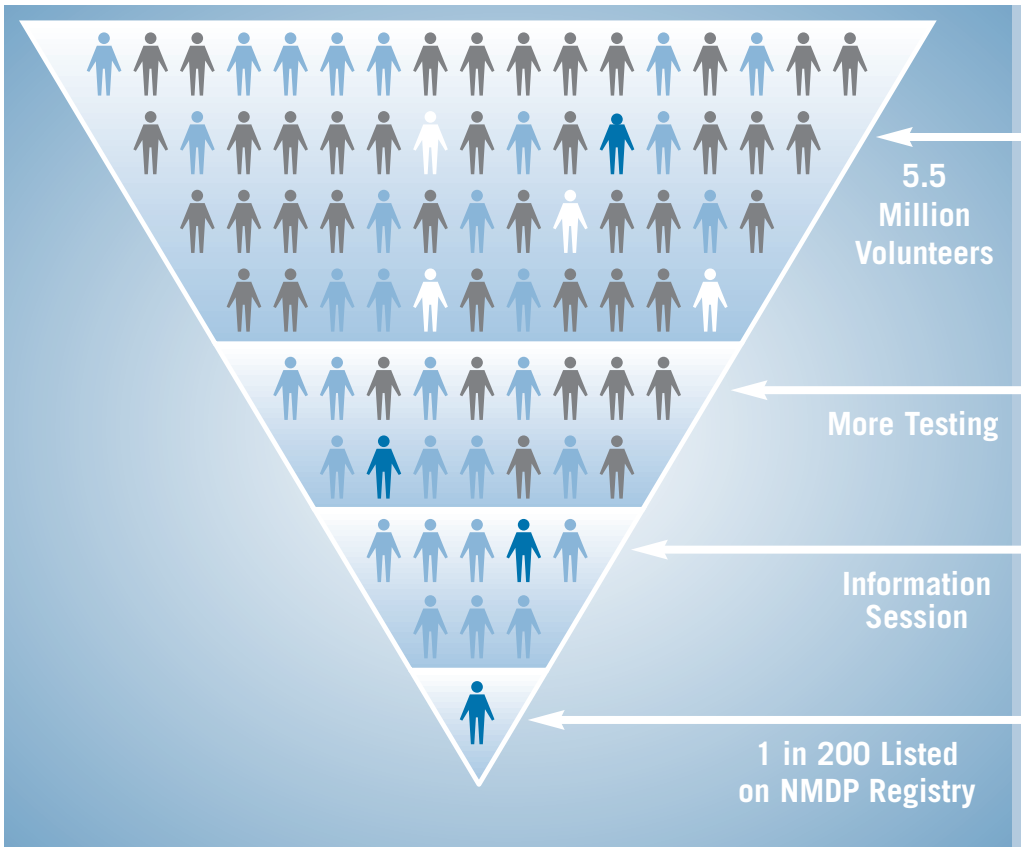
Workup

The process that a matched donor goes through to make sure he or she is healthy enough to donate marrow or blood stem cells. Workup includes:

- Information session
- Physical exam
- Blood samples for testing and screening

Donation

- Donor found to be healthy and given clearance to donate by the doctor
- The NMDP has facilitated more than 20,000 transplants
- One in 200 volunteer donors listed on the NMDP Registry will go on to donate



About Blood Stem Cells

Blood stem cells are produced in your bone marrow. Blood stem cells can grow into red blood cells, white blood cells and platelets.

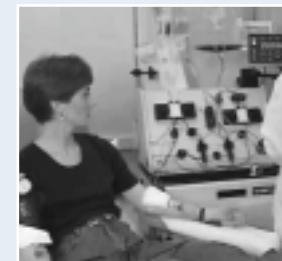
The three sources of the cells used for transplant are:

- Marrow
- Peripheral blood stem cells (PBSC)
- Blood collected from the umbilical cord after a baby is born

The transplant physician chooses the source of blood stem cells that is best for the patient.



MARROW



PBSC



CORD BLOOD

THREE SOURCES OF BLOOD STEM CELLS

Though Many Are Called for Confirmatory Typing, Few Go on to Donate Marrow or PBSC

About eight percent of donors called for confirmatory typing go on to donate. It is important that all possible donors are ready for more testing and are willing to donate if chosen.

If you agree to donate, the patient's doctor will ask for a specific type of blood stem cell donation — either bone marrow or peripheral blood stem cells (PBSC). The doctor chooses which is best for the patient. You are not asked to make a choice about the type of donation.

It's Your Decision

The decision to participate in confirmatory typing is up to you. You should know that there is no cost to you to donate. Any medical expenses will be covered by the National Marrow Donor Program or the patient's insurance. If you are unwilling or unable to participate for any reason, please tell staff at your donor center. Time is important, so let your donor center know as soon as you make a decision.

Time Frame for Confirmatory Typing

It can take from one week to 60 days for the patient's doctor to get the results and make a decision. The patient's condition also affects how long the process can take.

Time is important, so let your donor center know as soon as you make a decision.

8%

About eight percent of donors called for confirmatory typing go on to donate. It is important that all possible donors are ready for more testing and are willing to donate if chosen.



You will talk with staff from your donor center to learn about the donation process, risks and side effects. This session will last about 90 minutes.

What Happens after Confirmatory Typing?

The donor center staff will contact you to let you know the outcome of your confirmatory typing.

If you **are not chosen** to move forward, you may be called for another patient in the future. Please stay on the Registry and remain committed. Your confirmatory typing results will be added to your tissue typing, which may increase your chances of being selected in the future.

If you **are chosen**, you may be asked to donate right away or to wait until the patient is ready. Each case is different, and the timing for your donation will be based on what is best for you and the patient. Once this is determined, you will proceed to **workup**.

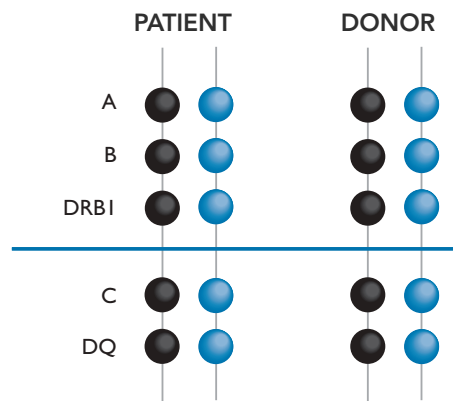


If you agree to donate, you will be given a physical exam to identify if donating would pose any special risks to you or the patient.

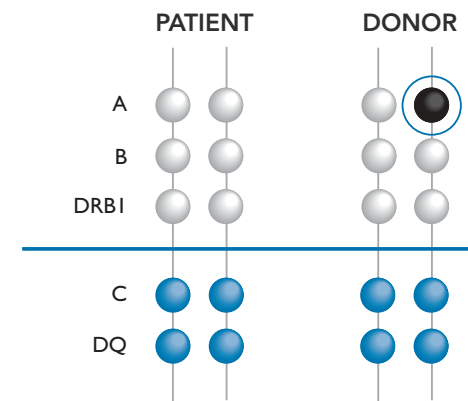
What is a Match?

- Human leukocyte antigens (HLA) are proteins found on most of your body's cells. These antigens help identify your tissue type. Your immune system uses HLA antigens to recognize which cells belong in your body and which do not. The HLA proteins are important in matching patients and donors for a blood stem cell transplant.
- You have two sets of tissue type markers compared in the matching process. One set is inherited from your mother, the other from your father.
- When a transplant center looks at the match level, it is looking at how alike the tissues of the patient and the donor are to each other. The NMDP requires at least a 5 of 6 antigen match for marrow and peripheral blood stem cell transplants.
- Most transplant centers look at more than six HLA antigens to select a donor. This means the transplant center is looking at other HLA antigens along with A, B and DRB1. These other antigens are C and DQ.
- In some cases, a 5 of 6 or a 9 of 10 match between a patient and a donor is suitable to use for a transplant.

A. 6 of 6 Match / 10 of 10 Match



B. 5 of 6 Match / 9 of 10 Match



- **Example A** shows the patient's antigens (A, B, DRB1, C and DQ) all match the donor's antigens. The 6 of 6 match means that there is a perfect match at A, B, DRB1. A 10 of 10 match means there is a perfect match at A, B, DRB1, C and DQ.
- **Example B** shows that one of the patient's A antigens does not match one of the donor's A antigens. Therefore, this is a 5 of 6 match or a 9 of 10 match.

RESEARCH

More Information is Available

This information is designed to help you make an informed decision to consider becoming a marrow or blood stem cell donor. If you would like more information about marrow or blood stem cell donation, visit our Web site at www.marrow.org.

The NMDP is committed to supporting research to improve transplant outcomes for patients and donors. You may be asked to participate in this research as part of the donation experience.

Workup

The workup process involves a series of steps to see if you are willing, healthy and ready to donate marrow or PBSC.

Steps of Workup

- **Participate in an information session**
You will talk with staff from your donor center to learn about the donation process, risks and side effects. This session will last about 90 minutes. You are free to bring a friend or family member. Blood stem cells can be collected from your marrow or from your circulating blood (PBSC donation). After the information session, you will then decide whether or not to donate.
- **Sign a consent form**
This will show that you understand what will take place during the donation process and the risks of donation.
- **Receive a physical exam**
If you agree to donate, you will be given a physical exam to identify if donating would pose any special risks to you or the patient.
- **Give blood samples to be tested for infectious diseases**
Some diseases can be transmitted to a patient through donation. Testing for these infectious diseases is an important step in determining your eligibility.

If the workup process shows that donating would not pose any special risk to you or the patient, you will proceed to donation. A marrow or blood stem cell transplant can help patients with life-threatening diseases live longer, healthier lives.

There are Two Types of Donation Procedures



Marrow Donation

Marrow donation is a surgical procedure that takes place in a hospital. 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 after the procedure.

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 work in a few days. You should be back to your normal physical routine in a few weeks. Your marrow is completely replaced within four to six weeks.



PBSC Donation

PBSC donation takes place at an apheresis center. Apheresis centers may be located in a blood center or a hospital.

To increase the number of blood stem cells in the bloodstream, you will receive daily injections of a drug called filgrastim for four days before the collection and a fifth injection on the day of your collection.



Your blood is then removed through a sterile needle in one arm and passed through a machine that separates out the blood stem cells. The remaining blood is returned to you through the other arm.

Side Effects and Recovery

You may experience headaches, or bone or muscle aches for several days before collection. These are side effects of the filgrastim injections that you received to increase the number of blood stem cells in the bloodstream. These side effects disappear shortly after the collection.

Follow up

After you donate marrow or PBSC, your donor center will call you to see how you're doing. They will keep in touch until you feel back to normal. Most donors are back to work in a few days and back to their normal physical routine in a few weeks. Your marrow is completely replaced within four to six weeks. The NMDP and your donor center staff care about your safety and want to know about your recovery.

Your Donor Center is There to Help You

More information will be given to you if you want. You will also get more information if you go on to workup. You may speak with a donor advocate at any time to help you make your decision.

Privacy

The NMDP must keep information about donors and patients private and confidential. It is the law. This policy protects donors and patients from unwelcome attention or contact. This could include pressure to donate or requests for payment.

To help keep information private, donors and patients are given identification (ID) numbers. These ID numbers let doctors share important medical information without using names or addresses. This high level of privacy is kept at all stages of the process.

Patients are told only the age and sex of their donor. Donors are told only the patient's age, sex and disease.

Glossary

Blood Stem Cells

Young cells that can grow into red blood cells, white blood cells and platelets. Blood stem cells are produced in the bone marrow. The three sources of the blood stem cells used for transplant are: marrow, peripheral blood stem cells (PBSC) and blood collected from the umbilical cord after a baby is born.

Bone Marrow Transplant (BMT)

The process of giving healthy marrow to a patient whose marrow is damaged or diseased.

Collection Center

A hospital associated with the NMDP that has experience to collect bone marrow and care for donors before and after the donation procedure.

Confirmatory Typing

A stage of testing to make sure that a potential donor is the best match for a patient.

Donor Center

An organization associated with the NMDP that recruits and manages volunteer donors listed on the Registry.

Match

In a marrow or blood cell transplant, the match refers to how much alike the donor's and patient's tissue types are.

Registry

The NMDP donor Registry is a confidential national database of potential volunteer donors and cord blood units established and maintained by the National Marrow Donor Program.

Workup

The process that a matched potential donor goes through to make sure he or she is healthy and ready to donate marrow or blood stem cells. Workup includes a detailed information session with donor center staff, a physical examination and collection of blood samples for testing and screening for infectious disease markers.

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