

Patient Frequently Asked Questions

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Q: What are blood stem cells?

A: Blood stem cells are one type of stem cells. Stem cells are any of the cells in your body that grow into other types of cells. Blood stem cells grow into red blood cells, white blood cells and platelets. Each of these cells are important for your body. Red blood cells carry oxygen to all parts of your body. White blood cells help the body fight infection, and platelets help control bleeding. A healthy body makes new blood stem cells. You cannot survive for long without healthy blood stem cells.

Q: Where do blood stem cells come from?

A: The cells used in blood stem cell transplants can come from three sources:

- **Bone marrow** makes blood stem cells for the body. Bone marrow is a spongy tissue found inside larger bones. Doctors remove the bone marrow from a donor's hip bone in a surgical procedure using sterile needles and syringes. The donor's body replaces the donated bone marrow in four to six weeks.
- **Peripheral blood stem cells (PBSC)** are stem cells found in the bloodstream. Normally, the bone marrow releases only a small number of stem cells into the bloodstream. To increase the number of cells, a donor is given shots. The stem cells are taken from the blood using a process called apheresis. In apheresis, a needle is placed in the donor's vein, usually in his or her arm. The donor's blood passes through a machine that removes the stem cells from the donor's blood. The rest of the blood returns to the donor. The donor's body replaces the donated stem cells in two to three weeks.
- **Umbilical cord blood** is taken from the umbilical cord and placenta after a baby is born. This blood contains large numbers of blood stem cells. The donated cord blood is frozen and stored at a cord blood bank for future use.

Q: Does the National Marrow Donor Program (NMDP) use stem cells taken from embryos or fetuses?

A: No. The NMDP only uses adult stem cells for transplant. Stem cells from umbilical cords are considered to be adult stem cells. This is because the babies are full-term and have developed beyond the embryonic stage.

Q: What is a blood stem cell transplant (bone marrow transplant)?

A: A blood stem cell transplant is a standard treatment option for many patients with life-threatening blood, immune system or genetic disorders. This kind of transplant replaces your unhealthy blood stem cells with healthy ones.

Q: What are the steps in a blood stem cell transplant?

A:

- **Preparation:** To prepare for a transplant, you will get chemotherapy, radiation therapy or a mix of both. This is usually given over several days. The goal of the

treatment is to kill your unhealthy cells.

- **Transplant:** The healthy stem cells are given to you through a vein. This is like a blood transfusion.
- **Recovery:** The transplanted cells begin to grow and make the red blood cells, white blood cells and platelets your body needs. This is called engraftment, and typically takes three to four weeks.

Q: How long will I have to stay in the hospital?

A: You'll stay in the hospital until your doctor feels you are well enough to leave. The length of time you stay can last for several weeks, but depends on your transplant center and your condition before, during and after transplant. Ask your doctor when you might be able to go home or move to a hotel near the transplant center. Your transplant team will continue to watch you closely until they feel you are ready to go home and regular doctor.

Q: Are there different types of blood stem cell transplants?

A: There are two basic types of blood stem cell transplants. A transplant might use stem cells from a donor or yourself:

- **Autologous transplants** use blood stem cells that are taken from your marrow or blood and frozen. You get chemotherapy, radiation therapy or a mix of both. Then, your stem cells are given back to you through a vein. Whether or not an autologous transplant is an option for you depends on your disease and other factors. Autologous transplants may be used to treat patients with diseases such as Hodgkin's disease, non-Hodgkin's lymphoma, multiple myeloma and some solid tumors.
- **Allogeneic transplants** use blood stem cells from a matching donor. The donor can be either related or unrelated to you. Related donors are usually a brother or sister. If you cannot find a matching family member, your doctor can search for a match in the National Marrow Donor Program's Registry. The Registry lists more than five million potential donors and more than 28,000 umbilical cord blood units.

(See *How do I find a matching donor?* below to learn more about how donors are matched with patients.)

Q: Who needs a blood stem cell transplant?

A: Each year more than 30,000 people are diagnosed with life-threatening diseases for which a marrow or blood stem cell transplant may be a treatment option. About 75% of the patients who receive a transplant through the National Marrow Donor Program (NMDP) have some form of leukemia, including:

- Acute lymphocytic leukemia (ALL)
- Acute myelogenous leukemia (AML)
- Chronic myelogenous leukemia (CML)

A transplant might also be a treatment option if you have:

- Inherited (congenital) immune system disorders

- Severe aplastic anemia
- Hodgkin's disease
- Myelodysplastic syndromes
- Non-Hodgkin's lymphoma

Q: What is a cord blood transplant?

A: A cord blood transplant uses blood stem cells taken from the blood in a newborn infant's umbilical cord. The blood in the umbilical cord and placenta contains large numbers of blood stem cells. Cord blood is taken from the umbilical cord and placenta after a baby is born. The donated cord blood is frozen and stored at a cord blood bank for future use. The stored cord blood is called a cord blood unit. Doctors search the NMDP Registry of donors and cord blood units to find a match for their patients who need a transplant.

If you have questions about a cord blood transplant for yourself, discuss them with your doctor. Your doctor will look at many factors to decide whether cord blood transplant is a good option for you.

Q: What is a non-myeloablative transplant?

A: Non-myeloablative transplants use a milder treatment to prepare for transplant than standard transplants. They are also called reduced intensity transplants or mini-transplants.

With a standard transplant, patients are prepared for transplant with very strong chemotherapy, radiation therapy or a mix of both. This treatment kills unhealthy cells, such as cancer cells. It is also very hard on the body. Because of this, standard transplants are not an option for some patients. Older age and some medical problems can rule out standard transplants.

Non-myeloablative transplants may be an option for patients who can't have a standard transplant. Non-myeloablative transplants use a milder treatment before transplant to kill some of the unhealthy cells. The immune system grown by the transplanted stem cells may then kill the rest of the unhealthy cells. Non-myeloablative transplants are still a newer treatment. Results so far seem to show this is a good treatment for some patients. It will take time to learn whether these patients stay healthy for many years.

Q: How do I decide if a transplant is the right treatment for me?

A: It is important to think about both the risks and the benefits of a transplant. A transplant doctor can answer your questions and help you decide if a transplant is a good option.

A blood stem cell transplant has serious risks. Some patients suffer from life-threatening problems as a result of their transplant. These problems can include serious infections and graft-versus-host disease (GVHD). GVHD is a disease where the transplanted stem cells attack the patient's body.

On the other hand, a transplant may be your best hope for a cure or a longer life. You, your doctor and your family need to consider many things, including:

- Your disease stage
- Your age
- Your overall health
- Other treatment options

Q: How many blood stem cell transplants have been done and how well do they work?

A: The NMDP has helped more than 15,000 patients get unrelated transplants using unrelated donors since 1987. Thousands more have had transplants either using their own blood stem cells or a related donor's. The chances the transplant will work are different for each patient. How well the transplant works depends on many things, such as:

- The disease being treated
- The stage of the disease
- The patient's age and general health
- How well the donor matches the patient

Other things can also make a difference. Please talk with your doctor about your own situation.

Q: Could I catch a disease from my donor?

A: Blood stem cell donors and cord blood units are carefully screened and tested. These tests are done to reduce the risk that a donor could pass a disease to a transplant patient. Before they are approved to donate, donors:

- Are tested for infectious diseases such as AIDS and hepatitis.
- Answer questions about their health history. This helps doctors find risks that the donors have an infectious or hereditary disease.
- Are checked by doctors for signs of disease.

The NMDP keeps up to date with medical information. Sometimes new or rare diseases such as West Nile virus or severe acute respiratory syndrome (SARS) become public concerns. When this happens, the NMDP uses available methods to watch for these diseases. If a donor shows signs of disease, in some cases he or she will not be allowed to donate. In other cases, where the risk to the patient is considered small, it may be up to the transplant doctor and patient to decide whether or not to use that donor.

Blood stem cell donations are carefully screened, similar to donations of whole blood. Even so, donated whole blood cannot be guaranteed 100% free of infectious diseases. In the same way, the risk that donated blood stem cells carry a disease cannot be

completely eliminated.

Q: Where do I go to receive a stem cell transplant?

A: Hospitals that do stem cell transplants are called transplant centers. There are many transplant centers in the United States and around the world. Here are some questions to ask that may help you find the right transplant center:

- Does your health plan have rules about which transplant centers are covered? Contact your health plan to find out about your insurance coverage.
- Did your doctor recommend a transplant center for you?
- Does the transplant center do unrelated allogeneic donor transplants? Some centers do only related donor or autologous transplants.
- Has the transplant center done transplants for many patients with the same disease as you?
- Has the transplant center cared for many patients in your age group? Some centers work mostly with adults or mostly with children.

Many transplant centers that do unrelated donor transplants also work with the National Marrow Donor Program (NMDP).

Q. How much does a transplant cost?

A. An unrelated donor stem cell transplant is expensive. Many health plans cover at least part of the cost, but they don't always cover the cost for a donor search. In the United States, you can also check with state and federal programs such as Medicaid and Medicare to find out if you qualify for these government health benefits. If they can pay for your transplant often depends on the state or territory where you live, as well as your disease. For help understanding your health plan, you can call your health plan, your employer or county human services office.

When you get to a transplant center, ask your transplant coordinator to put you in touch with someone who can help you with insurance and money matters. You can also call the NMDP's Office of Patient Advocacy with your questions. In the United States, call toll-free at 1 (888) 999-6743. Outside the United States, call (612) 627-8140.

Q: How do I find a matching donor?

A: A well-matched donor is important to the success of your transplant. To find a matching donor, doctors draw blood to test for your human leukocyte antigens (HLA). HLA antigens are proteins found on most cells in your body. Your immune system uses HLA antigens to recognize which cells belong in your body and which do not. Doctors look for a donor who matches your HLA antigens. Transplant centers test for at least six antigens.

Because HLA antigens are inherited, someone from your own family may be your closest match. However, 70% of patients do not have a matching donor in their family. If you do not have a related donor, your doctor can search the NMDP Registry for an unrelated donor. The NMDP Registry includes more than five million

volunteer donors and more than 28,000 umbilical cord blood units.

Even with so many possible donors, not everyone finds a perfect match. Some patients find a good match in a few weeks or months. Others may not find a donor for years, and some never find a match.

Your doctor may want to do a mismatched donor transplant if there is no perfect match for you. Your doctor will decide if this is an option based on your age, your disease and how quickly you need a transplant. Transplant centers vary on how much of a mismatch they allow. NMDP standards allow marrow or peripheral blood stem cell (PBSC) transplants if five of six HLA antigens match and cord blood transplants if four of six match.

Q: Should I have my family members and friends tested?

A: To find a match, doctors look at HLA antigens on your cells. (See How do I find a matched donor? above for more about what HLA antigens are.) Because you inherit half of your HLA antigens from your mother and half from your father. Therefore, each brother and sister who has the same parents as you has a 25% chance of matching you. It is very unlikely that any other family members will match you. It is also unlikely that a friend or neighbor will match you. Your doctor can tell you more about who should be tested and how this can be done.

If your friends and family members are willing to be donors for anyone, not just for you, they may be able to join the NMDP Registry. To learn more, call 1 (800) 654-1247.

Q: Who do I contact to find out what is happening with my donor search?

A: Contact your transplant center coordinator or doctor. They will keep you up to date on how your search is going. You can call the NMDP's Office of Patient Advocacy (OPA) if you have general questions about the unrelated donor search process. In the United States, call the OPA toll free at 1 (888) 999-6743. Outside the United States, call (612) 627-8140. The OPA has interpreters available at these numbers.

Q: Will I ever meet my donor?

A: You will not know who your donor is at the time of your transplant. The NMDP follows strict confidentiality standards to protect the privacy of both you and your donor. According to these standards, you and your donor cannot learn each other's identities for at least the first year after your transplant. Some centers do not ever allow you and your donor to learn each other's identities.

After your transplant, the NMDP may help you and your donor communicate without knowing each other's names. For example, you may be able to send cards and letters through the transplant center and donor center coordinators. They will check the letters to be sure no identifying details are shared. These rules vary from center to center. Some centers do not allow you and your donor to have any kind of contact at all.

After one year, many centers allow you to meet your donor if you and your donor both sign release forms. In this case, the NMDP will let you know how to contact each other.

Some centers do not allow you to have contact with your donor at any time.

Q: How can the NMDP's Office of Patient Advocacy help me?

A: The National Marrow Donor Program's Office of Patient Advocacy (OPA) is a free resource for you and your family.

The OPA can help you:

- Understand the process of the donor search and unrelated donor stem cell transplant
- Answer questions about your health insurance coverage and transplant costs
- Find a transplant center that meets your treatment needs

Services from the OPA are free. You can contact the OPA Monday to Friday, 8 a.m. to 5 p.m. Central time.

Call the OPA

- Inside the United States, call 1 (888) 999-6743. This call is toll-free in the United States.
- Outside the United States, call (612) 627-8140. This call may have long-distance or international charges.

Interpreters Are Available

If you need information in another language, the OPA can help. You will need to tell us -- in English -- what language you speak. It will take four to eight minutes for an interpreter to join the call. Please stay on the line.
