

FREQUENTLY ASKED QUESTIONS

ABOUT REGISTRATION

I registered a few years ago, do I need to register again?

No. If you signed up as a bone marrow donor before, you should not register again. If you are not sure about whether you are registered, you must contact the donor center you think you may have joined. Below is DKMS's number, as well as those of two other bone marrow donor centers.

DKMS: 1.866.340.3567
Be the Match: 1.800.627.7692
Gift of Life: 1.800.962.7769

Please do not sign up with DKMS until you have confirmed that you are not already registered.

Why does a person have to be 18 to join? Can't my parent sign the consent for me?

An individual must be 18 because the donor must legally be able to give informed consent. A guardian or parent cannot sign a release or give consent because unrelated marrow donation is a voluntary procedure.

If I'm over 55, why can't I join?

The age limit is not meant to discriminate. We must use chronological age to determine eligibility to protect the safety of the donor and provide the best possible treatment for the patient. With age comes a small increase in the risk of side effects from anesthesia.

Can I get tested for a specific patient or family member?

When you register with DKMS you will be listed on the national registry and you must be committed to donating to ANY patient with whom you might match. If you have a family member who needs a bone marrow transplant and their doctor thinks you could be a potential match, they will generally arrange for private testing. If you wish to be tested privately for your own knowledge, you can purchase a personal kit from bonemarrowtest.com.

If I have already been tested for a family member, can I send my results to DKMS to be added to the national registry?

Yes. Contact DKMS at data@dkms.org for further information.

Can I register if I am pregnant?

Yes, but please let us know because you cannot donate during your pregnancy. We will temporarily block you on the registry until at least 6 months after you give birth. After that time, you will be reactivated and can be matched with anyone until your 61st birthday.

Do I have to be a citizen and/or a resident of the U.S.?

You do not have to be a citizen of the U.S. to register as a bone marrow donor. However, you must permanently reside in the U.S. and must be able to travel between states. If you reside outside of the U.S. you can find a donor center in your home country at www.wmda.info

ABOUT MATCHING

How are patients matched with donors?

A cheek cell sample is collected at registration. The sample is tested for the HLA tissue type and added to the national registry, which doctors can search to find a matching donor for their patient.

What is human leukocyte antigen (HLA) typing?

Human leukocyte antigen (HLA) typing is a DNA-based test used to match patients and donors for bone marrow transplants. HLA are proteins, or markers, found on most cells in your body. Your immune system uses these markers to recognize which cells belong in your body and which do not. The closer the match the better the chances the patient's body will accept the donated cells and allow them to grow and make new healthy cells.

How likely is it that I will match a patient?

We cannot predict the likelihood that you will match a patient as there is too much diversity in tissue types. There is a chance you may never be identified as a match for someone needing a transplant — or you may be the one match to save someone's life. In either case, when you register you should be prepared for the possibility of becoming a bone marrow donor.

Does ethnicity affect matching?

Your ethnic heritage is an important factor as patients are more likely to match with someone of a similar background. Increasing the diversity of the donor pool increases the likelihood that all patients will find a lifesaving match.

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What happens if I match a patient?

More testing will need to be done to determine if you are the best available match including completing a health history questionnaire, providing blood samples, and undergoing a physical exam. A DKMS representative will walk you through each step of the process and will be available to answer any questions you may have.

ABOUT DONATION

What is a bone marrow transplant?

A bone marrow or stem cell transplant is a potentially lifesaving treatment for patients fighting blood cancers like leukemia and lymphoma, as well as other blood diseases like sickle cell disease. A transplant replaces the patient's unhealthy blood stem cells with healthy ones from a donor like you. Prior to transplant, a patient undergoes high dosages of chemotherapy and possibly radiation therapy to destroy all the diseased cells in their body. During transplant, the donated cells are infused into the patient and move through the bloodstream into the bone marrow, where they begin to grow and produce new healthy blood cells through a process called engraftment.

Does it hurt?

For peripheral blood stem cell (PBSC) donation, most people will feel bone pain from the filgrastim injections for 4 days before the donation. Many people will also have muscle aches or headaches. It might feel like you are starting to catch the flu. After you donate, you will probably also feel very tired. These symptoms should go away within one to two days following the procedure. During bone marrow collection you are under anesthesia. After the procedure, donors generally feel discomfort and some pain in their lower back for one or two weeks. We check on our donors after the donation to make sure you are recovering properly. If you're not, we'll arrange and pay for any follow up care.

Do I have a choice on which donation method?

The patient's doctor decides which method is the best. There are different factors that can make one method better than the other depending on the patient's situation. Because of that, we ask our donors to be comfortable with both methods of donation.

Can I change my mind about donating?

Donating is voluntary and you have the right to change your mind at any time. However, if you decide you no longer want to be listed as a registered bone marrow donor, it is critical to let DKMS know immediately. A late decision not to donate can be life-threatening to a patient, so please think seriously before registering.

How much time does it take?

Being a bone marrow donor does require a time commitment. On average the entire process — from the first information session to the actual donation — can take 30 to 40 hours over four to six weeks.

Do I have to travel?

Although we try to schedule our donors at the collection center closest to their home, often times donors will have to travel by car, train or airplane. DKMS will arrange and pay for your transportation, as well as out-of-pocket expenses, such as your meals.

Will I get patient updates or meet my transplant recipient?

All patient information is confidential. However you might be told the patient's age, sex, and disease. Your patient's transplant center may provide up to three updates within the first year after the transplant. However, some transplant centers do not provide updates at all. Depending on the patient's hospital's policy, and if both parties are interested and willing, one year after donation the donor and patient can potentially communicate or meet. Please note that contact is subject to the confidentiality rules of the transplant center and is not always possible.

ABOUT PAYMENT

Who pays for the donation process?

The costs for the donation procedure — whether they are medical, travel, or miscellaneous expenses — are covered by the patient's medical insurance and DKMS.

Will I get paid for the time off I may need to take from work?

If you are not covered by your employer, DKMS has a financial assistance program for lost wage compensation. If you are found to be a match for a patient we can give you more information on the program to help you.