

Joining the Registry Q&A

Q: Why is there a need for people to join the Be The Match Registry®?

A: Thousands of patients with blood cancers like leukemia and lymphoma, sickle cell disease and other life-threatening diseases are in need of a blood stem cell or bone marrow transplant and depend on the Be The Match Registry to find a donor. Patients need donors who are a genetic match—and even with a registry of millions, many patients cannot find a match. Donors with diverse ethnic backgrounds are especially needed.

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

A: A blood stem cell or bone marrow transplant is a life-saving treatment for people with blood cancers like leukemia and lymphoma, sickle cell disease and other life-threatening diseases. First, patients undergo chemotherapy and sometimes radiation to destroy their diseased marrow. Then, a donor's healthy blood-forming cells are transplanted directly into the patient's bloodstream, where they can begin to function and multiply.

For a patient's body to accept these healthy cells, the patient needs a donor who is a close genetic match. Seventy percent of patients don't have a fully matched donor in their family and depend on the Be The Match Registry to find an unrelated bone marrow or umbilical cord blood donor.

Q: How do I become a blood stem cell or bone marrow donor?

A: The first step to becoming a donor is to join the Be The Match Registry. Doctors around the world search the registry to find a match for their patients. If a doctor selects you as a match for a patient, you may be asked to donate bone marrow or cells from circulating blood (called peripheral blood stem cell, or PBSC, donation).

Q: Why is there an age limit for joining the registry?

A: Currently, people who want to join the registry need to be between the ages of 18 and 40. Our age limits for unrelated donors are in place for a few reasons:

- Scientific Studies: Patients receiving cells from younger donors have a better longterm survival rate.
- **Selection History**: Two-thirds of the time, physicians select donors between the ages of 18 and 35. Young adult donors have the healthiest, most robust blood stem cells, which produce the best results for patients.
- **Donation Safety**: The safety of our donors is very important to us—and the older donors get, the greater their chances are of experiencing health complications.

Find out more about our age requirements.

Please note: Age guidelines are different for related donors (those donating to a sibling, child or parent). Learn more on our <u>Related Donor Services page</u>.

Q: Why does a person have to be 18 to join? Can my parent sign the consent for me?

A: An individual must be 18 to join because donation is a medical (for peripheral blood stem cell donation) or surgical (for marrow donation) procedure, and the person undergoing the procedure must legally be able to give informed consent.

A guardian or parent cannot sign a release or give consent for someone under age 18 because unrelated marrow donation is a voluntary procedure and is not directly beneficial or life-saving to the volunteer donor.

If you're under 18, pre-register today so that you can join the registry on your 18th birthday.

Q: If I'm older than 40 and can't sign up to be donor, how else can I help?

A: We value your commitment to our mission, and you definitely have an important role to play as a supporter. You can <u>create an account and join the Be The Match community</u> as a Champion, which will give you access to members-only content and news about our lifesaving work, as well as allow you to connect with other members.

You also can get involved by <u>fundraising</u>, <u>hosting a donor registration drive</u>, <u>volunteering</u> or <u>spreading the word</u>.

Q: How do I use the registration swab kit to collect a cheek cell sample?

A: When you join the registry, you'll use our registration kit to take a swab of your cheek cells. We'll tissue type the sample you provide and use the results to match you to patients.

If you join in person at a donor registry drive, the Be The Match representatives can explain how to use the swab kit. If you join online, you'll receive a kit with instructions in the mail.

Q: What is my commitment if I join?

A: When you join the Be The Match Registry, you make a commitment to:

- Be listed on the registry until your 61st birthday, unless you ask to be removed
- Consider donating to any searching patient who matches you
- Update us if your address changes, you have significant health changes or you change your mind about being a donor
- Respond quickly if you're contacted as a potential match for a patient

You have the right to change your mind about being a donor at any time. Donating is always voluntary.

If you decide you don't want to donate, let us know right away. That way, we can continue the search for another donor without dangerous delays for the patient.

Q: If I join the Be The Match Registry, how likely is it that I'll donate to someone?

A: We cannot predict the likelihood that an individual member will donate because there is so much diversity of tissue types in the population. However, doctors request donors in the 18-35 age group nearly 75% of the time. That's because research shows cells from younger donors lead to more successful transplants.

Every person who joins the registry gives patients hope, and new patient searches begin every day. You may never be identified as a match for someone, or you might be one of a number of potential matches. But you may also be the only one on the registry who can save a particular patient's life.

Q: Does race or ethnicity affect matching?

A: Ethnic heritage is a very important factor. Patients are most likely to match someone of their own ethnicity. Today, the registry isn't diverse enough to help every patient. Adding more ethnically diverse members increases the likelihood that all patients will find a lifesaving match.

Members of these backgrounds are especially needed:

- Black or African American
- American Indian
- Asian, including South Asian
- Hispanic or Latino
- Multiracial

Q: What's the donation process like?

A: Adult donors may be asked to donate in one of two ways:

- Peripheral blood stem cell (PBSC) donation, used about 80% of the time, involves removing a donor's blood through a sterile needle in one arm. The blood is passed through a machine that separates out the cells used in transplants, and the remaining blood is returned through the other arm. The process is similar to donating plasma.
- Bone marrow donation, used about 20% of the time, is a surgical procedure in which liquid marrow is withdrawn from the back of the donor's pelvic bones with special, hollow needles. General or regional anesthesia is always used for this procedure, so donors feel no needle injections and no pain during marrow donation. Many donors feel some pain in their lower back for a few days afterward.

Q: Can I get tested to see if I'm a match for a specific patient or family member?

A: When you join the Be The Match Registry, you make a commitment to consider donating to any searching patient who matches you. As a volunteer, you're never under any legal obligation to donate, and your decision is always respected. However, because a late decision not to donate can be life-threatening to a patient, please think seriously about your commitment before deciding to join our registry.

If you want to be tested only for a specific patient, you'll need to have your testing done privately. You can contact the patient's transplant center or transplant doctor for more information.

Q: I've already been tested for a family member. How can I add my results to the Be The Match Registry?

A: To join the registry, get a copy of your human leukocyte antigen (HLA) tissue typing lab report and contact the donor center in your area. You'll need to fill out a health history form to verify you meet medical guidelines. You'll also need to sign a consent form agreeing to be listed on the Be The Match Registry. Once you're listed on our registry, we'll contact you if you're identified as a possible match for a patient.

Q: I think I may have already joined. How can I verify that I'm on the registry?

A: If you're unsure whether you joined, contact us at 1 (800) 627-7692.

