

## Bone Marrow Registry

### What is a bone marrow registry?

A bone marrow registry collects information on individuals willing and able to donate bone marrow and gathers the donor information into a database. When a patient is in need of a bone marrow transplant, the registry database is searched to find available donors who match the patient. Registry staff then contact the matching donor and arranges for the donation, which delivers life-saving cells to the patient. During this process, registry staff provide support to the patient, to the caregivers, and to the family. Bone marrow registries also support research to advance the science so more diseases can be treated with a bone marrow transplant, advocate for legislation and policies to maintain and improve patient access to care, and provide clinical education for health care professionals.

### Who benefits from bone marrow donations?

Each year, approximately 18,000 people, ages 0-74 in the United States are diagnosed with life-threatening illnesses where a bone marrow transplant from a related or unrelated matched donor is the best treatment option.<sup>1</sup> A bone marrow transplant replaces a patient's diseased blood-forming cells with healthy cells. Doctors look for a marrow donor with a human leukocyte antigen (HLA) tissue type that closely matches the patients. HLA are proteins, or markers, that the immune system uses to recognize the cells that belong in the body and those that do not. Because tissue type is inherited, you might expect that a family member would be the best match. However, only 30% of patients will have a relative who matches and is able to donate.<sup>1</sup>

A bone marrow transplant is used for patients with the following conditions:

#### Leukemias and lymphomas

- Acute myelogenous leukemia
- Acute lymphoblastic leukemia
- Chronic lymphocytic leukemia
- Chronic myelogenous leukemia

- Juvenile myelomonocytic leukemia
- Hodgkin lymphoma
- Non-Hodgkin lymphoma

## Bone marrow diseases

- Severe aplastic anemia
- Fanconi anemia
- Paroxysmal nocturnal hemoglobinuria
- Pure red cell aplasia
- Amegakaryocytosis/congenital thrombocytopenia

## Inherited immune system disorders

- Severe combined immunodeficiency
- Wiskott-Aldrich syndrome

## Hemoglobinopathies

- Beta thalassemia major
- Sickle cell disease

## Inherited Metabolic Disorders

- Krabbe disease
- Hurler syndrome
- Adrenoleukodystrophy
- Metachromatic leukodystrophy

## Myelodysplastic syndromes and myeloproliferative disorders

## Multiple myeloma and other plasma cell disorders

## Familial erythrophagocytic lymphohistiocytosis and other histiocytic disorders

## Other malignancies or cancers

## Why are bone marrow donations needed?

Bone marrow transplantation has been a life-saving therapy for more than 30 years and for many patients a transplant offers the only cure. Most (70%) patients who need a transplant do

not have a fully-matched donor in their family.<sup>i</sup> They depend on bone marrow registries to find a matching donor. A well-matched donor is important to the success of a transplant. Even with more than 35 million potential marrow donors available worldwide, it is harder for patients of racially and ethnically diverse backgrounds to find a match. Because tissue type is most likely to match someone of the same race and ethnicity, donors of these racial and ethnic heritages are especially needed:

- American Indian or Alaska Native
- Asian
- Black or African-American
- Hispanic or Latino
- Native Hawaiian or Other Pacific Islander
- Multiple race

Today's researchers are improving transplantation to increase survival, reduce complications, and possibly treat more diseases.

## How do I join a bone marrow registry?

The National Marrow Donor Program has managed the largest and most diverse marrow registry in the world for the past 30 years. You can register to join the registry at <https://join.bethematch.org>. The registration process will consist of a series of questions about your medical history to see if you meet basic qualifications. If you meet the basic qualifications, you will be asked to swab your cheek to provide a sample of your DNA. Your DNA will be added to the registry for potential matching with a patient. When you are matched with a patient, you will be contacted to donate. It could be weeks, months, or years before you are contacted to donate.

The [Gift of Life Marrow Registry](#) is an international public bone marrow and blood stem cell registry that facilitates transplants for children and adults. At Gift of Life, you can register to join the registry and order a cheek swab kit. Your DNA will be added to the registry for potential matching with a patient. When you are matched with a patient, you will be contacted to donate. It could be weeks, months, or years before you are contacted to donate.

## How do I acquire a free buccal (cheek) swab kit from a bone marrow registry?

You can get a free buccal swab kit by mail from <https://join.bethematch.org>, through a cheek swab at a Be The Match event, or from [Gift of Life](#).

## Where can I find more information about bone marrow donation and registration?

[National Marrow Donor Program](#)

[Gift of Life Marrow Registry](#)

[Health Resources and Services Administration](#)

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[Frequently Asked Questions \(FAQ\) | Blood Stem Cell \(hrsa.gov\)](#)