

# GIFT OF LIFE FACT SHEET

# ABOUT GIFT OF LIFE MARROW REGISTRY

The Gift of Life Marrow Registry is a public bone marrow registry in the United States, founded in 1991 by Jay Feinberg, a marrow transplant recipient and leukemia survivor. The organization is a 501(c) (3) nonprofit corporation, and is an accredited member of the World Marrow Donor Association. Headquarters are located in Boca Raton, Florida.

Sebastian's life When he was 22 years old, Feinberg was diagnosed with leukemia. He was told that finding a match would be extremely difficult, and was advised to prepare his bucket list and do what he could with his remaining time. Because tissue type is inherited, like hair and eye color, a patient's best chance of finding a genetic match lies with those of similar ethnicity. Feinberg was of Eastern European descent and at that time the registry was not diverse and potential donors who shared his background were low in numbers. Unwilling to accept that there was so little chance, he and his family launched a four-year, international search for a matching donor, registering over 60,000 people and finding hundreds of matches for other cancer patients - but not Feinberg. As his time was running out, one final drive was held, and the last person tested that day turned out to be his perfect match. The lengthy struggle to find a donor inspired Feinberg and his family to pay it forward and start the Gift of Life Marrow Registry.

Today, the organization continues its mission to cure patients suffering from blood cancer. Donors can be searched by transplant centers and physicians around the world.

#### **DONOR-PATIENT MATCHES**

Matches between the donor and patient are identified by immune system factors called Human Leukocyte Antigens (HLA).

Blood type does not matter for this kind of match.

The more closely the HLA are matched, the more likely a transplant will be successful. Half of the antigens are inherited from the mother and half from the father. There is a 25% chance of matching each sibling. If a donor does not have a match within the family, the search moves to the worldwide registry.

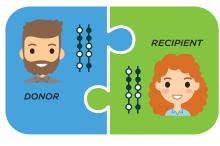
More than 70% percent of patients search the registry in the hopes of finding a donor.

Genetic heritage is important to the process. As antigens have been passed down for centuries, unique combinations have developed within various ethnic groups, therefore two people from the same ethnicity are more likely to share a matching HLA type.

#### **NON MATCHES**



#### **HLA MATCH**



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Brooke saved

#### **ABOUT TRANSPLANTATION**

Transplantation using a donor involves either peripheral blood stem cells (PBSC) collected through apheresis, a process similar to donating platelets, or bone marrow collected from the iliac crest of the hip bone while under anesthesia. The donor's stem cells or bone marrow naturally return to pre-donation levels. Approximately 90 percent of today's donations are PBSC, and only 10 percent bone marrow, which is often requested for children. The goal of transplantation is to fully replace the patient's bone marrow and immune system with healthy hematopoietic stem cells that will form new, healthy bone marrow that generates a fresh immune system, free from the conditions that caused the disease.

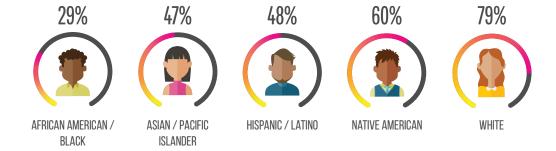
## Swab your cheek to CONFIRMATORY **TYPING** join the registry. If you're a match for a patient, you will be asked to have a blood test. STEPS THE TRANSPLANT Your donation is **TO SAVE** transplanted into the patient. A LIFE Take a physical to ensure you are healthy and can donate. THE DONATION You will donate either blood stem cells or bone marrow.

#### **CONDITIONS TREATED BY TRANSPLANTS**

Blood stem cell and bone marrow transplants may be used to treat or cure many blood cancers such as leukemia and lymphoma, as well as diseases of the bone marrow, sickle cell disease, and inherited immune disorders.

#### PERCENT ABLE TO FIND A MATCHING DONOR

There is an urgent need to increase diversity in the registries. A high percentage of many ethnicities cannot find a matching donor.



#### **GIFT OF LIFE AT A GLANCE**

- The cost to add a new donor to the registry is \$60
- Donors are not paid, nor do they incur a cost for donating
- Only bone marrow registry founded and headed by a transplant recipient, Jay Feinberg
- Accredited member of World Marrow Donor Association, serving 52 countries
- Headquartered in Boca Raton, Florida
- Campus Ambassadors at more than 100 universities in the United States
- As a registered 501(c)(3), nonprofit organization, Gift of Life receives no government funding and relies on charitable contributions to further its lifesaving mission

#### **GIFT OF LIFE FIRSTS**

- First registry to recruit donors with a cheek swab instead of a blood sample at drives
- First registry to recruit donors online
- First registry to use mobile, paperless registration
- First registry-integrated stem cell collection center
- First registry to create a smart phone app for registration
- First registry with an integrated, in-house stem cell collection center

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### **FACTS & STATS**

- Approximately every 3 minutes, one person in the United States is diagnosed with Blood Cancer, affecting 186,400 people in 2021
- Leukemia accounts for more than 25% of all cancers in children, and is the second leading cause of cancer deaths in children under 20 years of age
- Approximately 20,000 Americans need a marrow transplant every year
- 90% of donations are from peripheral blood stem cells
- 10% of donations are marrow, usually for children
- One in every 200 Americans will have a transplant within their lifetime using marrow, stem cells or cord blood
- Only 30% of matches are found within the family; 70% of donors are strangers found on the registry

- There is a 1 in 4 chance of matching a sibling
- Matching factors are inherited, so donors and recipients are usually from similar ethnicity and racial background
- There is an urgent need to diversify the registry: Only 29% of African Americans/Blacks, 47% of Asians/Pacific Islanders, 48% of Hispanics/Latinos, and 60% of Native Americans are able to find a matching donor
- New cases of leukemia, lymphoma and myeloma make up 9.8% of the nearly 1.9 million new cancer cases diagnosed in 2021
- Over time, there is a 10 percent chance of being called as a possible match from Gift of Life's registry
- Over 85 percent of transplants are from donors aged 18 to 35 years old

#### **HOW TO JOIN THE REGISTRY**

Every person has the potential to save the life of someone with blood cancer. Joining is simple – it only takes two minutes and no blood is drawn. Donors must be 18 to 35 years old, in general good health and a U.S. citizen. Donors remain in the registry until age 61.

New donors swab the inside of their cheeks and complete a registration questionnaire. The swabs are tested by a lab for genetic markers, which are entered in the registry where they can be searched to find matches for patients in dire need of a transplant.

To join the registry, order a testing and registration kit online at <u>giftoflife.org/register</u> or join in person by visiting a registration drive. For a calendar of upcoming drives and their locations, visit <u>giftoflife.org/events</u>.

Only U.S. citizens 18 and older may join the Gift of Life Marrow Registry. Citizens of other countries can contact their local bone marrow registry to volunteer as a donor. **Contribute:** Gift of Life receives no government funding. Contributions help add new donors to the registry and support Gift of Life's mission: finding a donor for every patient in need, whenever and wherever they are needed. Visit giftoflife.org/contrib.

Gift of Life is happy to provide additional information and statistics about bone marrow and peripheral stem cell donation, images, quotes and interviews.

#### **CONTACT INFORMATION**

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#### OTHER WAYS TO GET INVOLVED

**Volunteer:** Gift of Life has a highly active and friendly community of volunteers across the U.S., who help in many ways, including staffing donor recruitment drives, 5ks and fundraising drives, organizing community events, and other opportunities. Contact Gift of Life's Volunteer Coordinator, 561-982-2900.



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