

# **GIFT OF LIFE FACT SHEET**

#### ABOUT GIFT OF LIFE MARROW REGISTRY

The Gift of Life Marrow Registry is a public blood stem cell and 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.

At age 22, Feinberg was diagnosed with leukemia. He was told it would be nearly impossible to find a matching donor and was advised to prepare his bucket list and do what he could in his remaining time. Because matching factors are inherited, matches are usually found with someone of similar genetic heritage. But, at the time, the registry had few potential donors from Feinberg's Eastern European background, so his chances were poor. His family would not take "no" for an answer and launched a four-year grassroots search that spanned the world. More than 60,000 volunteers were tested, hundreds of matches found for others, but none for Jay. As his health was declining, one last, hopeful drive was held, and the last person to be tested that day turned out to be his perfect donor. The lengthy struggle to find this one-in-a-million match inspired the Feinberg family to pay it forward and start the Gift of Life Marrow Registry.

CITE OFT

Graeme saved Grant's life

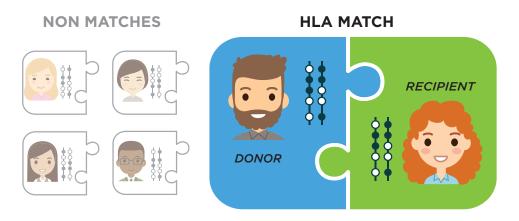
Today, the organization continues its mission to cure patients battling blood cancer. Donors can be searched by transplant centers and physicians around the world.

### **DONOR-PATIENT MATCHES**

Matches between donor and patient are identified by immune system factors called Human Leukocyte Antigens (HLA). Blood type doesn't 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.



#### **ABOUT TRANSPLANTATION**

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

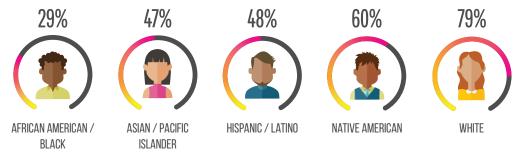
#### **CONDITIONS TREATED BY TRANSPLANTS**

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



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

## PERCENT ABLE TO 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 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 160 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 to create a smart phone app for registration
- First registry with an integrated, in-house stem cell collection center

## **FACTS & STATS**

- Approximately every 3 minutes, one person in the United States is diagnosed with Blood Cancer, affecting 187,740 people in 2024
- 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 patients must search the registry hoping to find a match

- There is a 1 in 4 chance of matching a sibling
- Matching factors are inherited, so donors and recipients are usually from similar ethnic 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 9.4% of the nearly 2 million new cancer cases diagnosed in 2024
- 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 three 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 marrow registry to volunteer as a donor.

#### **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.

**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 marrow and peripheral stem cell donation, images, quotes and interviews.

#### **CONTACT INFORMATION**

Gift of Life Marrow Registry 5901 Broken Sound Pkwy NW, Suite 600 Boca Raton, FL 33487

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