# **Gift of Life Media Fact Sheet**

Holly saved Lola's life

# ABOUT GIFT OF LIFE MARROW REGISTRY

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, with field staff in New York City and Los Angeles.

When he was 22 years old, Feinberg was diagnosed with leukemia. On learning that finding a match would be extremely difficult, he was advised to prepare his bucket list and do what he could with his remaining time.

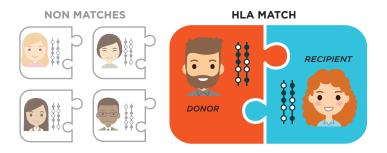
Because tissue type is inherited, like hair and eye color, a patient's best chance of finding a genetic match lies with those of similar ethnicity. Feinberg was of Eastern European descent and at that time the registry was not diverse and potential matching donors from that background were not prevalent. Unwilling to accept this advice, 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. Gift of Life operates the only registry-integrated stem cell collection center in the world, making it possible to bring donors to collection faster at a time when every moment counts.

## **ABOUT 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 biological father – meaning that there is a 25% chance of inheriting the same HLA as a sibling. If a donor does not have a match within the family, the search moves to the worldwide registry. Seventy-five percent of patients search the registry in the hopes of finding a donor.



Genetic heritage is important to the process. As the HLA 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.

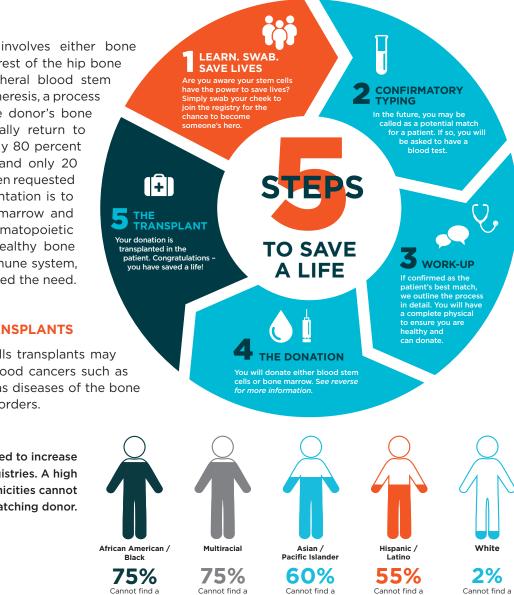
#### **ABOUT TRANSPLANTATION**

Transplantation using a donor involves either bone marrow collected from the iliac crest of the hip bone while under anesthesia or peripheral blood stem cells (PBSC) collected through apheresis, a process similar to donating platelets. The donor's bone marrow or stem cells will naturally return to pre-donation levels. Approximately 80 percent of today's donations are PBSC, and only 20 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 new immune system, free from the conditions that caused the need.

## **CONDITIONS TREATED BY TRANSPLANTS**

Bone marrow and blood stem cells transplants may be used to treat or cure many blood cancers such as leukemia and lymphoma, as well as diseases of the bone marrow 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.



#### **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 with field staff in New York City, Los Angeles
- 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

matching donor

matching donor

matching donor

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## **GIFT OF LIFE FIRSTS**

- First registry to recruit donors with a cheek swab at drives
- First registry to recruit donors online
- First registry to use mobile, paperless registration
- First registry-integrated stem cell collection center

# **FACTS & STATISTICS**

- Blood cancer is diagnosed in a child or adult every 3 minutes in the United States, affecting 176,200 people in 2019
- Blood cancer kills more children than any other form of cancer every year
- Each year approximately 20,000 people in the United States need a marrow transplant
- Eighty percent of donations are from peripheral blood; 20 percent are marrow aspirations from the posterior pelvic bone
- One in every 200 Americans will have a transplant within their lifetime using marrow, stem cells or cord blood
- There is a 1 in 4 chance of matching a sibling
- Only 30% of matches are found within the family; 70% of donors are strangers found on the registry

- Matching factors are inherited, so donors and recipients are usually from similar ethnicity and race
- There is an urgent need to increase diversity in the registries: 55% of Latinos, 60% of Asian Americans, 75% of African Americans and 75% of multi-racial individuals cannot find a donor
- New cases of leukemia, lymphoma and myeloma are expected to account for 10 percent of the estimated 1,762,450 new cancer cases diagnosed in the United States in 2019
- Over time there is a 10 percent chance of being called back as a possible match
- 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 donor 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.

# **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 it is needed. Help us get everyone involved, swabbed and cured! 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**

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

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