



Lillian saved Daisy's life (right)

**SEE PAGE 6**  
FOR DAISY'S STORY

Daisy is now a healthy young girl who loves tutoring children and creating art

**There is a CURE for blood cancer**  
and it's inside of you!





## Offering help and hope for curing blood cancer

**G**ift of Life Marrow Registry helps children and adults suffering from leukemia, lymphoma, other cancers and genetic immune disorders find matching donors for lifesaving blood stem cell and marrow transplants. The organization began in 1991, with one family's search to save their son's life.

Jay Feinberg, a 23-year-old from New Jersey, was diagnosed with a cancer called Chronic Myelogenous Leukemia. Chemotherapy only worked for Jay temporarily. Doctors said that a bone marrow or stem cell transplant offered the possibility of a cure, but they thought he had little chance of finding a matching donor.

It is natural to think that a family member would be a perfect donor, but due to genetics, there is only a 30 percent chance that a sibling will be a match. Seventy percent of patients in need of a transplant must search the worldwide bone marrow donor registry. Because the factors that determine a compatible match between a donor and recipient are inherited, like hair and eye color, the best chance of a match is with someone from the same ethnic background. Jay's family is Jewish, and because there were few Jewish donors in the registry at that time, his doctors felt it was unlikely there would be a donor for him.

The Feinberg family was not willing to accept this as the final word. They launched a grassroots campaign to find that one person who matched Jay's tissue type and could save his life. Hundreds of recruitment drives were organized and over 60,000 potential donors joined the registry. Matches were identified for many other patients in need, but none for Jay. In a final, hopeful effort as Jay's health was declining, one last drive was organized. In May 1995, the very last donor tested at that drive turned out to be Jay's match, Becky, and he received a successful transplant two months later – a cure for his leukemia, the gift of life.

Jay's search took four long years. Feeling that no one should struggle for years to find a donor, he was determined to help others in similar circumstances. Jay devotes his life to increasing the number of volunteer donors in the registry, counseling patients and their families, and setting the high standards for quality that have become the trademark of Gift of Life.



Becky saved Jay's life

Today, Gift of Life is an international medical resource, highly regarded for its unique and vital work. A member of the international collaborative, Bone Marrow Donors Worldwide, and an associate registry of the National Marrow Donor Program, Gift of Life ranks fifteenth in size out of seventy-five stem cell registries in fifty-two countries, and is the only registry founded and managed by a transplant recipient.

Gift of Life has now adopted a bold call to action, a plea to society to help us get everyone, whether that's getting them involved, getting them swabbed to join the registry, or getting them cured. We changed the odds for Jewish cancer patients – from only a 5 percent chance of finding a donor, to a 75 percent chance – and we ask you to help us improve the chances for the Latino/Hispanic community: our goal is to find a matching donor for every patient who needs one – regardless of when, where, or who they are.

As a volunteer donor, you could help save the life of a child, a mother, a father, or a grandparent. Every patient deserves a second chance at life, and we invite you to join the registry!



## Why the marrow registry matters to **Latinos**

**L**atino and Hispanic families face the same challenge today that Jay Feinberg faced in 1991: because so few people with Latin ethnicity are registered as donors, 55 percent of Latino/Hispanic cancer patients never find the matching donors who can save their lives.

The Latino population in the United States is known to have higher rates of certain blood cancers than the general population. The only known cure for many of these cancers is a bone marrow or peripheral blood stem cell (PBSC) transplant, making the worldwide bone marrow registry a lifesaving resource for the Latino/Hispanic community.

Scientific studies have shown that cancer is the leading cause of death in the Hispanic population of the United States, and Latino/Hispanic children have higher rates of leukemia than other ethnic groups. Hispanic adult men and women have higher incidences of certain types of leukemia and lymphoma than other populations.

We know from experience that potential donors for patients are out there, but the only way to match a donor with a patient in need is through the registry. This is why joining the registry is so important. Once a donor has joined the registry, if they are a match for a child or adult with cancer, either today or in the future, Gift of Life can call and offer them the chance to save a life.

Every one of us wants the best chance at life for our children, family, friends, and community members. Joining the registry gives you the opportunity to offer someone a second chance at life.



## Blood Cancer in the Latino/Hispanic community

Statistics from national sources are presented with the term “Hispanic” only, stats for “Latinos” are not collected separately.

- Leukemia is the most common cancer in children, accounting for one third of childhood cancers.<sup>1</sup>
- Hispanic children and adolescents have higher rates of leukemia than all other racial and ethnic groups in the US.<sup>1</sup>
- Hispanic children and adolescents have lower leukemia survival rates than non-Hispanic white children.<sup>1</sup>
- Childhood cancer is the second leading cause of death among Hispanic children ages 1 to 14 years.<sup>2</sup>
- Cancer is the leading overall cause of death among the Hispanic population.<sup>3</sup>
- Hispanic men and women have the highest rates of developing acute lymphocytic leukemia.<sup>3</sup>
- Hispanic men and women have the second highest rates of lymphoma, after non-Hispanic whites.<sup>3</sup>
- Cancer survival remains lower among Hispanics than for non-Hispanic whites.<sup>1</sup>
- Regular screening can detect cancer at an early stage and improve treatment success for some types of cancer.<sup>1</sup>

Sources: 1) American Cancer Society, Cancer Facts & Figures for Hispanics/Latinos 2015-2017  
2) North American Association of Central Cancer Registries  
3) Centers for Disease Control and Prevention



Participants at The David Project/AJC Latinos and Jews United summit helped save lives by joining the Gift of Life Bone Marrow Registry

## Joining the registry is easy!

Just swab the inside of your cheek and fill out the registration information



**A FAST and EASY  
way for a chance  
to save a life!**

**T**oday joining the registry as a volunteer donor takes only two minutes and is incredibly easy. All you need to do is swab the inside of your cheek in four spots, seal the swabs in a special envelope, and complete the registration information. Your swabs will be sent to a lab to test the tissue type and add you to the registry.

The bone marrow registry can be searched by physicians and transplant centers around the world. If you are found at a match for a patient, now or in the future, Gift of Life will call you to offer you the chance to save someone's life!

If you choose to donate, the organization will be right there for you through the entire process, answering all your questions and making sure you are well taken care of!

Your personal information will remain anonymous and is protected by Gift of Life's robust security measures.

To order a swab kit, complete with instructions, visit <https://es.giftoflife.org/register> or alternatively fill out the form below or visit a donor registration drive near you. To check the calendar of drives and other events, visit <https://es.giftoflife.org/events>

### Swab Kit Order Form

Name (first, last)

Male  Female

Address

City, State, Zip

Email

Cell Phone

Date of Birth

Today's Date

Thank you for your interest in joining the Gift of Life Bone Marrow Registry! Please complete this form and we will mail you a cheek swab kit which you use at home and send back to us for testing.

Signature

Mail this form to: Gift of Life Marrow Registry, 800 Yamato Road, Suite 101, Boca Raton, FL 33431

GIFT OF LIFE **HUGE STATISTICS**Over 262,000  
registered donorsOver 2,000  
VolunteersOver 10,000 donor  
recruitment drivesOver 13,000  
donor-recipient  
matchesOver 3,000  
marrow  
transplantsOver 135 student  
interns on college  
campuses nationwideConducted donor  
searches for over  
85,000 patients117 hospitals  
and cancer  
centersServe patients in  
45 countries on  
6 continents

# What is bone marrow donation and how does it work?

## The miracle of transplantation can give a patient the chance for a cure

One in 200 Americans will receive a bone marrow or peripheral blood stem cell (PBSC) transplant in their lifetime. Only 30 percent of patients will find a matching donor within their families, with 70 percent seeking an unrelated matching donor in the worldwide bone marrow registry.

A transplant can be either bone marrow or PBSC. Today, about 80 percent of transplants are PBSC which is collected through a process similar to donating platelets. Bone marrow makes up 20 percent of transplants, and is often requested for young children, and is drawn under general anesthesia from the hip bone. Both bone marrow and PBSC regenerate naturally on their own – there is no permanent change to the donor.

The donated cells are infused into the recipient, where they migrate on their own into the bone marrow areas and begin the work of creating new blood cells and immune system. The goal is to completely replace the patient's immune system with a healthy new system, free of the disease.

### WHAT CONDITIONS ARE HELPED BY TRANSPLANTATION?

Every four minutes, someone is diagnosed with leukemia, lymphoma or another blood disorder such as sickle cell anemia. Transplants can offer the hope of a cure for many such conditions, including a range of blood cancers, inherited immune system

disorders, bone marrow disorders, metabolic disorders, and some other malignant diseases.

### HOW DOES TRANSPLANTATION WORK?

The goal of a bone marrow or PBSC transplant is to give the patient a new immune system free of disease and with the strength to fight off any remaining cancer cells in the body. The donor and recipient must have matching tissue types, called human leukocyte antigens, or HLA.

**Someone cares,  
and there is  
hope for a cure!**

When a matching donor is found, the patient is prepared by a regimen of chemotherapy and radiation therapy to remove his or her bone marrow and immune system, and destroy as many cancer cells as possible. The donated marrow or PBSC is infused into the patient, and the cells migrate on their own into the bone marrow cavities to begin growing new marrow and creating new blood and immune system cells. This recovery process is called engraftment.

### WHY ARE GENETICS SO IMPORTANT?

The transplant can only work if the genetic HLA factors of the donor and recipient match. Every cell in the body has markers called antigens on its surface

to help cells recognize each other. If a cell doesn't have the correct antigens, the immune system sees it as an enemy and destroys it before it can cause an infection. In a healthy person, this is how the body fights off the millions of bacteria and viruses encountered every day.

If the HLA factors of a donor and recipient don't match, the new immune system will see the patient's cells as enemies and attack them as if they were invaders. Making a good match between donor and recipient is crucial for the transplant to be successful.

### WHY DOES ETHNICITY MATTER?

HLA factors are determined by the DNA and are inherited from parents, like hair and eye color. The best chance of finding a donor with matching HLA is within the same ethnic group.

The need for donors of Latino and Hispanic ancestry to join the registry is urgent. Currently, 55 percent of Latino/Hispanic patients who need a lifesaving transplant are unable to get one due to the shortage of volunteer donors from these communities. The situation is even worse for people of mixed race as their HLA profile can be rare. More than 75 of multi-racial patients are unable to find donors.

Adding new donors to the registry is Gift of Life's primary mission, to ensure that every person who needs a transplant can have one, when it is needed.

# Daisy, 11, received a lifesaving bone marrow transplant as baby

Today she's a healthy young girl who loves tutoring children and creating art

Daisy shown here as the flower girl at Lillian's wedding. They both immediately felt a special bond.



**D**aisy was only a baby in 2007 when she was diagnosed with a rare, life-threatening immune system condition. With constant fevers and infections, much of her first year was spent in the hospital, with her frightened and worried family praying that a cure would be found.

Violeta, Daisy's mother, remembers those days in the hospital clearly. She said, "We were scared and felt so worried about her – she suffered so much. Yet we placed our faith and belief in God."

Daisy's doctors felt certain she could be cured with a bone marrow or peripheral blood stem cell transplant. This would result in a complete replacement of the immune system, creating a new one that would function normally and be free of the disease.

Daisy's family felt hopeful that this cure would work for their little girl, but worried that there may not be a matching marrow donor for her. For the transplant to be a success, a donor with matching tissue type had to be found.

As they waited for the transplant search to answer their prayers, a young woman named Lillian received a phone call from the Gift of Life Marrow Registry. She had registered as a volunteer bone marrow donor while she was in college, but never expected to receive a call that she was a match for a patient in need.

"I was in shock when I got the call," said Lillian. "I never thought twice about helping this little girl and her family. She was one year old, her parents hardly knew her – I couldn't let them lose their daughter."

Daisy received treatments to prepare her for the transplant, and in another part of the country, Lillian went to a donation center for her bone marrow to be collected.

Once she received the transplant, Daisy began to recover. Her new bone marrow created a healthy immune system, and for the first time in her life she was free of infections and fevers.

In 2010, Daisy was introduced to Lillian in person at the Gift of Life Annual Gala in New York, where they immediately felt a special bond. Regulations prevent donors and recipients from learning each other's identities for the first year after transplant, so this meeting was an emotional and happy occasion for all.

"Lillian is like a member of our family, a compassionate person with a big heart," said Violeta. "Daisy was the flower girl at her wedding, and even though she is now busy with two little girls of her own, we talk and text each other and share pictures."

Daisy is now a healthy and happy 11-year-old in fifth grade. She loves helping her teacher tutor the fourth graders, and she also loves cooking, animals and creating arts and crafts. "When she was little she wanted to be a doctor, maybe because she had spent so much time with them," said Violeta. "Now she wants to be a teacher, but she also talks about being an artist or becoming a veterinarian – like every 11-year-old she has many ideas for the future."

Thanks to a young woman willing to become a volunteer bone marrow donor, Daisy now has a full, active and healthy life, and a long future ahead of her.

# The Saul & Theresa Esman Foundation Sponsors a New Latino Initiative

**T**he Saul and Theresa Esman Foundation has provided generous support in the amount of \$216,000 to Gift of Life during 2016. Working with the Foundation, Gift of Life will expand its outreach to underrepresented ethnic minority groups, particularly the Latino/Hispanic community. This group has a particularly difficult time finding matching donors in public registries. With over 2.2 million Latino/Hispanic residents in South Florida, Gift of Life is ideally positioned to lead a comprehensive outreach program in the region. Targeted donor recruitment drives will be set up in densely populated Latino/Hispanic communities across South Florida to provide both education and the opportunity to join the registry.

In addition to increasing diversity in the registry, the Foundation has also recognized the importance of the Campus Ambassador Program and provided funding for the Annual Symposium, which brings students from across the country to Gift of Life's headquarters in Boca Raton, where they immerse themselves in the science behind saving lives and learn valuable knowledge about hosting bone marrow recruitment drives on their campuses. On August 9, 2016 Foundation Executive Director – and longtime friend of Gift of Life – Murray Levin



Saul & Theresa Esman Foundation

announced that the Foundation plans to continue funding the symposium indefinitely.

Mr. Levin gave a heartwarming speech about his personal interest in and relationship with Gift of Life. He said that when he first learned about the organization he “could not believe that someone would send a courier to hand carry donated transplant tissues across the country to save the life of one human being.”

Jay Feinberg expressed thanks to Mr. Levin, Ms. Esman and their Foundation. “This grant in support of the CAP Symposium ensures that we’ll be able to prepare college students for their internships for years to come,” he said.



Esman Foundation Executive Director Murray Levin speaking at the CAP Symposium

*Our thanks to Murray Levin and the Saul & Theresa Esman Foundation for their heartfelt and generous support.*



*This has been the single greatest privilege of my young life. I would urge anyone to grasp the gravity of how greatly their decision to join the registry could impact a stranger's life for the better. Don't think twice – do it!*

—DONOR ERIC



*It is humbling to have the ability to help someone in this way. It was just as much a gift to me to be able to help someone else.*

—DONOR CATHERINE



*As soon as I had the opportunity to join the registry, I did it without hesitation. If it can save someone's life, it must be done.*

—DONOR GABRIEL



*With Gift of Life, I was able to donate stem cells and actually see that I've saved someone's life. That's just incredible to me.*

—DONOR LAURA



## Professional Sports Community Partners

**G**ift of Life is grateful for the support and increased visibility offered by professional sports teams in 2016, including the New York Mets, Miami Dolphins and Los Angeles Galaxy. Through a long partnership with the Mets, donors and recipients are introduced for the first time and have the pleasure of attending a game in a suite at the stadium. The Miami Dolphins recognized Gift of Life during National Cancer Awareness Month in October, and the LA Galaxy featured Gift of Life as their Community Partner of the Day during their playoff game on October 30.

## HUGE Stats

- 55% of Latino and Hispanic patients who need a bone marrow transplant cannot find a donor. Together, we can change those odds.
- Over 75% of multi-racial patients do not have a matching donor. Join the registry and you may get the chance to save someone's life!
- Someone cares, and there is hope for a cure. You can find help with Gift of Life.
- Hispanic children and adolescents have higher rates of leukemia than all other racial and ethnic groups in the US.

Source: American Cancer Society, Cancer Facts & Figures for Hispanics/Latinos 2015-2017

## Ball & Chain Offers FREE Appetizers

**J**oin us to learn more about Gift of Life on April 20 at the Ball & Chain restaurant in Little Havana, Miami. The Ball & Chain is an iconic nightclub from the 1930s-1950s that reemerges as a live-music venue with Cuban style food and drink. It once occupied the same space and welcomed jazz superstars like Billie Holiday, Count Basie and Chet Baker to its stage.

Latinos are currently under represented in the bone marrow registries world wide. Gift of Life is on a mission to change that. We would love to meet you and answer any questions you may have about our organization. We will have volunteers on site to swab participants who are interested on getting on the Gift of Life Marrow Registry. There will be FREE appetizers and one FREE drink ticket when you swab. We look forward to seeing you there!

**WHAT:** Gift of Life Meet and Greet Happy Hour

**WHERE:** 1513 SW 8th St, Miami, FL 33135

**DATE:** Thursday, April 20, 2017

**TIME:** 5:30pm - 7:30pm

**RSVP:** Email us at [events@giftoflife.org](mailto:events@giftoflife.org)

**MORE INFO:** [www.giftoflife.org/ballandchain](http://www.giftoflife.org/ballandchain)

**QUESTIONS?** Email Linda Barrocas at [lbarrocas@giftoflife.org](mailto:lbarrocas@giftoflife.org)

