

Annual Report 2016

In the United States, approximately every four minutes someone is diagnosed with a blood cancer or blood disorder such as leukemia, lymphoma, multiple myeloma or myelodysplastic syndromes. Bone marrow, stem cell and cord blood transplantation—which infuses healthy stem cells into the bloodstream of a patient—is commonly used to treat these and other diseases and disorders. In fact, since the first successful bone marrow transplant in the 1960s, the procedure has evolved from a treatment of last resort to a first line therapy for more than 70 life-threatening diseases.

Since its founding in 1992, The Bone Marrow Foundation has been dedicated to improving the lives of bone marrow, stem cell and cord blood transplant patients and their families. The Foundation's wide-ranging portfolio of programs provide vital financial assistance, educational information and emotional support to patients and their families. Our programs make a tremendous difference in the lives of patients, supporting them every step of the way, from diagnosis through survivorship.

The Bone Marrow Foundation is the only organization of its kind that serves transplant patients and their families throughout the country regardless of their geographic location, age, race, or type of disease. All of the Foundation's services are provided free of charge to patients and their families.

PROGRAMS AND ACCOMPLISHMENTS

A diagnosis of cancer or another life-threatening disease can be a devastating experience for indivduals and families. The physical, emotional, logistical and financial burdens are often overwhelming for both patients and their families. That's where The Bone Marrow Foundation steps in—supporting patients and their families every step of the way during the transplant process, providing them with the financial assistance, resources and educational materials they need to help allay their fears, understand the challenges they face and make effective decisions about their treatment and its aftermath.

The Bone Marrow Foundation serves as a comprehensive resource for anyone facing a bone marrow, stem cell or cord blood transplant. Our programs and services provide financial, educational and emotional support to patients and families through every step of the transplant process and beyond. As the number of patients who receive these life-saving treatments increases each year, The Bone Marrow Foundation is committed to expanding our programs and outreach to meet the growing demand for our services.

The Lifeline Fund: A Patient Financial Assistance Program

Our flagship program, Lifeline provides financial support to eligible individuals and families who are preparing for and undergoing a bone marrow, stem cell or cord blood transplant. The individuals who seek the Foundation's support often lack the financial resources necessary to afford not only life-saving treatment, but also the often overlooked living and ancillary expenses that accompany treatment. Funding from The Bone Marrow Foundation's Lifeline Fund helps to cover the myriad costs associated with transplants, such as donor searches, compatibility testing, bone marrow harvesting, medications, home and child care services, medical equipment, transportation, cord blood banking, housing and other expenses associated with the transplant. Health insurance often does not cover these vital support services, and many patients cannot afford them on their own.

In 2016, The Lifeline Fund awarded a total of \$458,750 in direct financial aid to 1,167 patients, helping them meet their ongoing expenses while preparing for and undergoing transplants.

One-to-One Funds

The Foundation's One-to-One Funds Program offers patients a personalized way to reach out to family, friends and social media for support before, during and after their transplant. Originally launched as a crowdfunding program, One-to-One Funds has helped nearly 200 patients raise over \$3 million in recent years, including more than \$550,000 during this year alone.

Responding to the evolving needs of patients and families—as well as recent technological advances—The BMF is now redesigning and expanding the One-to-One Funds program. Now called CareLines and CareTracker, this innovative new platform will include four distinct modules, each of which can be used by interested patients and families either alone or in combination:

- **Crowdfunding:** The new One-to-One Funds platform will continue to offer patients a quick and easy way to reach out to family, friends and social networks for financial support. The Foundation works closely with each participating patient to set up a One-to-One Funds profile and to promote it through social media and/or more traditional means. All contributions to One-to-One Funds are tax-deductible and do not affect a patient's medical insurance or other benefits.
- **Journaling:** This new module will allow patients to rally support from family and friends around the world and share updates about their treatment. Patients will be able to share updates, photos and videos with their community, and others can leave messages of support for the patient.
- Volunteer Calendar: This program component will provide a simple and effective way for patients to keep track of appointments and organize support from their community members. Patients and/or caregivers can reach out for help with day-to-day tasks such as meal preparation, child and pet care, transportation to appointments and other errands. Supportive community members can easily utilize the calendar to volunteer for specific tasks, allowing the patient to focus on getting better.
- Medical Note Pad: This feature encourages medication compliance and education, providing patients and their caregivers with the tools to understand their medication regimen and to support their communications with the medical team. Patients will have access to a virtual pill box to keep track of their current medications along with a description of their medicines. Learning about their medications is one of the most effective ways to improve adherence. Patients will be able to monitor how they are feeling and possible side effects.

Medical and Educational Handbooks

As part of our education and support programs, in 2000 The Bone Marrow Foundation developed patient handbooks to assist individuals and their families facing a bone marrow, stem cell or cord blood transplant. The handbooks contain in-depth information regarding the transplant process and all aspects of follow-up care for both autologous and allogeneic transplants. To date, the Foundation has distributed 50,000 copies of these handbooks to patients at more than 200 hospitals and transplant centers across the country.

Building on the success and popularity of our existing handbooks—and responding to feedback from patients, family members, the medical community and social workers—The Bone Marrow Foundation has recently created a revised version. Entitled "The Comprehensive Guide for the Transplant Journey", this book contains wide-ranging information covering every aspect of the transplant procedure—from diagnosis through survivorship—empowering patients and families to make informed choices regarding treatment options. In response to requests from health care professionals, patients and families, the Foundation has also created a dedicated pediatric transplant journey section of the book, which addresses a critical gap in patient education by targeting school-aged transplant patients. To meet the needs of the widest possible audience, all handbooks are available as hard copies as well as through our website, and were produced in both English and Spanish.

Scholarship Fund

Our newest program, the Scholarship Fund help make educational aspirations a reality for bone marrow, stem cell or cord blood transplant survivors. Transplants affect all aspects of life and often prohibit the pursuit of educational opportunities. To address this, The Bone Marrow Foundation has created a new program to offer survivors a future where their hopes and dreams remain intact. Funds may be used to cover the cost of tuition, books, living expenses, supplies or homebound educational equipment. During 2016, the Foundation awarded our first five grants through the Scholarship Fund.

Ask the Expert

The Bone Marrow Foundation's Medical Advisory Board comprises more than 100 medical professionals, many of whom are renowned experts in the field of bone marrow, stem cell or cord blood transplantation. Our Ask the Expert program allows patients and families to benefit from our Medical Advisory Board's wealth of expertise by having their most pressing questions answered by qualified and experienced health profesisonals. The individual asking the question and the advisory board member remain anonymous to each other, and all communications occur via the Foundation. During 2016, our Ask the Expert program linked 202 patients with qualified medical professionals, who responded to questions about transplantation and related issues.

SupportLine

Recognizing that talking or corresponding with someone who has gone through a bone marrow, stem cell or cord blood transplant can help new patients understand what to expect during and after the process, our SupportLine program links transplant patients and their families with volunteers who have gone through the transplant experience themselves.

Clinical Care Counseling

Through this program, The Bone Marrow Foundation provides confidential individual and family supportive counseling, financial guidance and resource referrals to individuals and families. Trained counselors are available in person or by telephone to help patients, family members and caregivers navigate the transplant process.

Survivorship Program

Responding to the needs of transplant survivors—who have told us they experienced feelings of extreme isolation in the weeks and months following the procedure—The Bone Marrow Foundation designed and launched a dedicated support program for this population. Our Survivorship Program addresses the ongoing need for emotional and social support through weekly telephone or in-person meetings, provides education about transplant and side-effect related issues and helps survivors create a healthy new life. The return to "normal" life takes a different path for each person, yet the ability to share common experiences with others can provide significant support and encouragement during the process of returning to school or work and adjusting to post-transplant life.

STATEMENT OF FINANCIAL ACTIVITIES FOR 2016

\$ 852,387

Income

End of Year Net Assets

Contributions \$ 841,567 Special Event Revenue (Net) \$ 726,932 **Investment Income** \$ 110 **Total Income:** \$ 1,568,609 **Program Expenses** Direct Financial Assistance Distributed \$ 777,826 (Lifeline, One-to-One Funds, Scholarships) Other Program Expenses \$ 366,718 **Total Program Expenses** \$ 1,144,544 **Non-Program Expenses** Fundraising \$ 285,380 Management/Administrative \$ 82,587 **Total Non-Program Expenses** \$ 367,967 **Total Expenses** \$ 1,512,511

PATIENT STORIES



Naomi was diagnosed with aplastic anemia in 2013, when she was six years old.

She received a bone marrow transplant in 2014, with her older brother as her donor. Unfortunately, Naomi suffered a relapse and underwent a second transplant in 2017, again with her brother as her donor.

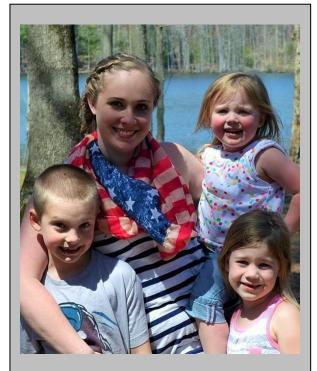
During her ordeael, Naomi's parents turned to The BMF's One-to-One Funds program to raise funds to help them meet their ongoing expenses.



Originally from Venezuela, Jesus was diagnosed with acute lymphoblastic leukemis (ALL) in August of 2011, while attending the University of Arizona. He responded well to treatment and in 2014 moved to New York to pursue a masters degree at New York University.

Shortly after Jesus moved to New York, he suffered a relapse and underwent a cord blood transplant in August of 2015.

During and after his long medical ordeal, The Bone Marrow Foundation has been a source of constant support for Jesus. He initially raised money through our One-to-One Funds program and later received a grant from The Lifeline Fund. Later, he became one of the first recipients of a grant through The BMF's Scholarship Fund, which enabled him to resume his studies at NYU.



Stephanie is the mother of three children and the wife of a U.S. Navy sailor. She was diagnosed with chronic myelogenous leukemia (CML) in May of 2016 and received an unrelated allogeneic stem cell transplant in September of that year.

During her illness and recovery, Stephanie turned to The Bone Marrow Foundation for assistance to help cover the cost of housing so that her family could stay nearby while she was hospitalized, and to ensure that her parents could stay with her when her husband was deployed on military duty. The Bone Marrow Foundation awarded Stephanie a grant through our Lifeline Fund and also helped her raise money through our One-to-One Funds program.



Aunesti was born with sickle cell disease, a hereditary blood disorder. As a result of this disease, she has also developed avascular necrosis (AVN), which has caused her to develop brittle bones due to low oxygen in her blood.

She has also endured bullying at school, which resulted in a pain crisis that kept her in the hospital for six weeks.

At 11 years old, Aunesti underwent an allogeneic, unrelated bone marrow transplant. The Bone Marrow Foundation helped Aunesti's mother cover the transplant-related costs while she is unable to work by awarding her a grant from The Lifeline Fund and also helping her raise additional funds through our One-to-One **Funds** program.

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