



# ANNUAL REPORT

2013

## **HISTORY AND MISSION OF THE BONE MARROW FOUNDATION**

For many families in crisis with a child, spouse or relative battling cancer, The Bone Marrow Foundation has come to their aid with direct financial assistance for vital costs of care not covered by medical insurance. The Foundation's founder and executive director, Christina Merrill, began this unique organization in 1992 and has since raised millions of dollars for patients nationwide.

The Bone Marrow Foundation is dedicated to improving the quality of life for bone marrow, stem cell, and cord blood transplant patients and their families by providing vital financial assistance, educational information, and emotional support programs. Transplants treat over 70 life threatening diseases including cancers and genetic disorders. The Foundation is the only organization of its kind that does not limit assistance to a specific disease, type of transplant, or age range. All of the Foundation's services are offered free to patients and their families.

## OVERVIEW OF BONE MARROW AND STEM CELL TRANSPLANTS

Each year, bone marrow and stem cell transplants save the lives of children and adults suffering from leukemia, Hodgkin's and non-Hodgkin's lymphomas, multiple myeloma, aplastic anemia, severe combined immunodeficiency, neuroblastoma, and many other cancers and genetic disorders. Since the first successful bone marrow transplant in 1968, there have been great advances in the understanding of transplantation biology and supportive care so that the procedure has evolved from a treatment of last resort to a “first line” therapy.

The National Institutes of Health have declared that “in the 21st century there will be many opportunities to extend transplantation to treat a wider range of diseases—transplantation is among the most successful and promising areas of medicine.” The advances in transplantation that have taken place since the start of the Foundation in 1992 include more donors in the National Marrow Donor Registry, the use of umbilical cord blood stem cells, and better methods of collecting marrow stem cells both for the donor and recipient. As a result, the numbers of children and adults receiving this second chance at life are greatly increasing.



This therapy is not without cost. The average transplant ranges from \$400,000 - \$500,000. This figure does not include donor testing, follow up care, living expenses, or loss of wages. According to the World Health Organization, “a diagnosis of cancer may lead not only to the loss of a source of income, but also all too frequently to exhausting the family’s remaining income and resources in seeking treatments.”

As a result of these lost wages and expensive treatments, many families struggle to meet their basic needs. According to a 2009 report issued by the American Journal of Medicine, 62% of all bankruptcies in 2007 were linked to medical expenses. This statistic is an increase of almost 16% from 2001.<sup>1</sup> For patients going through these costly medical procedures, these expenses mean that child care, rent, transportation, and even food are often just out of reach. Research also shows that patients and families need education and psychosocial intervention before and after bone marrow, stem cell, and cord blood transplantation, as well as financial support.<sup>2</sup>

The Bone Marrow Foundation was created to respond to these needs and to the critical financial and educational gaps for patient and their families.

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<sup>1</sup> Himmelstein, Thorne, Warren, Woolhandler “Medical Bankruptcy in the United States, 2007: Results of a National Study” American Journal of Medicine, 2009

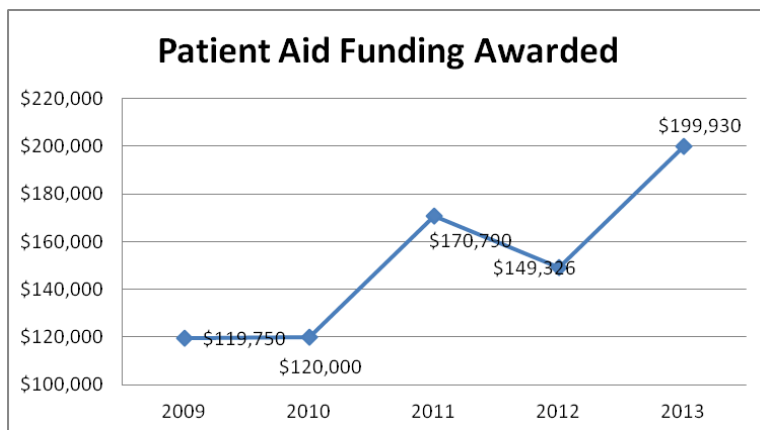
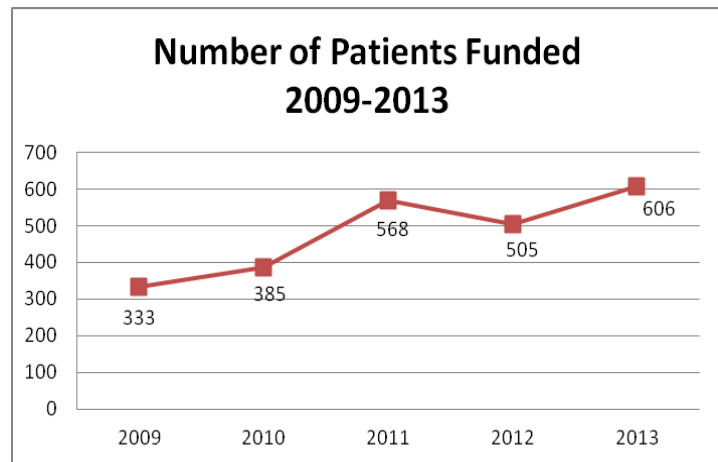
<sup>2</sup> Zabora, J. R., Smith, E., Baker, F., Wingard, J. R., & Curbow, B.: The family: the other side of bone marrow transplantation. Journal of Psychosocial Oncology, 1992

## 2013 PROGRAM OVERVIEWS AND STATISTICS

### Financial Assistance Programs

**Patient Aid Program** provides funding to help cover the costs of donor searches, compatibility testing, bone marrow harvesting, medications, home and childcare services, medical equipment, transportation, cord blood banking, housing costs, 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. The Bone Marrow Foundation offers this type of direct financial aid to bone marrow, stem cell, and cord blood transplant patients without limiting patient assistance to a specific diagnosis, type of transplant, or age range.



Over the past year, The Bone Marrow Foundation has seen an overwhelming growth in the need for assistance through our Patient Aid Program. In the 2013 fiscal year, the program awarded financial assistance to 606 patients. This figure marks a 20% increase from 2012. The Patient Aid Program saw a similar growth in total funding awarded, with \$199,930 being distributed to patients and their

families throughout the country, a 43% increase from the \$149,326 awarded in 2012.

**One-to-One Funds** assists patients and their families by creating a personal fund at The Bone Marrow Foundation. This program encourages that patient to utilize their communities, families, and friends to raise money for transplant expenses. The Foundation administers these funds directly to the patient and all expenses need to have accompanied receipts. Each donor receives an acknowledgement letter and the patient receives a listing of all donations made to their personal fund. The Bone Marrow Foundation takes a 5% fee to administer this fund.

During 2013, The Bone Marrow Foundation patients raised more than \$109,000 through the One-to-One Fund program.

**Lifeline Project** is The Bone Marrow Foundation's newest financial support program. It leverages social media outreach so that donors can make a direct and instant difference in the life of a transplant patient. Stories and pictures are posted on the Lifeline Project's website and individual donors can read these profiles and make financial contributions for the patients' care. The Lifeline Project raised more than \$3,100 for 14 patients.

### **Education and Support**

The Bone Marrow Foundation's Patient Education and Support Program continued to grow throughout 2013.

The Bone Marrow Foundation's **Medical & Educational Handbooks** provide comprehensive patient education and resources to assist patients and family members in obtaining information regarding the transplant procedure and all aspects of follow-up care. Approximately 10,000 patient education books were distributed to individuals and hospitals throughout the United States.

Because The Bone Marrow Foundation believes that patients are most healthy when they are most informed, it offers **Ask the Expert** and **SupportLine**. These two programs allow patients to interact directly with others who can offer advice and answer questions.

Ask the Expert enables individuals to pose questions concerning bone marrow, stem cell, or cord blood transplantation and to have them answered by health professionals. The individual asking the question and the Medical Advisory Board member responding to the question remain anonymous to each other, and all communications occur via the website or through the Foundation. The Foundation's Patient Program Coordinator is responsible for ensuring that only appropriate questions are directed to the expert panel and that all routine questions are answered by The Bone Marrow Foundation staff.

SupportLine serves transplant patients and their families by linking them with volunteers who have gone through the transplant process. The goal is to provide direct telephone or email support and encouragement from the unique perspective of someone who has experienced it.

In 2013, these two programs connected over 340 patients with information and support.

In addition to these programs, The Bone Marrow Foundation also continued to offer its **Peer Support Group**. This group is staffed by a medical social worker and a nurse clinician, provides patients and their family members with a monthly group setting in which to share experiences and draw support from others.

## STATEMENT OF FINANCIAL ACTIVITIES FOR 2013

### Income

Contributions	\$349,062
In-kind Contributions	\$0
Special Event Revenue	\$863,192
Investment Income	\$202
<b>Total Income:</b>	<b>\$1,212,456</b>

**Total Program Expenses**                      **\$572,288**

### Non-Program Expenses

Fundraising Expenses	\$229,183
Management/Administrative	\$53,596
<b>Total Non-Program Expenses</b>	<b>\$282,779</b>

**Total Expenses**                                      **\$855,067**

**End of the year net assets:**                      **\$737,032**

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