

December, 2011

Dear Friends of the nbmtLINK:

In January the nbmtLINK will be celebrating its 20th anniversary!

It's difficult to believe how fast time has passed since the LINK was "born" in 1992 in the vacant bedroom of my daughter Amy. People have asked me why I started the nbmtLINK. The simple answer is that after working for 10 years as Associate Director for the Children's Leukemia Foundation of Michigan, during the mid-80's, the medical world was turning more and more to bone marrow transplants as a treatment option. Back then, as far as I knew and searched, there were few, if any, nationally available resources, booklets or support programs, specifically designed for BMT patients, caregivers, and their families.




Then the inspiration to create the nbmtLINK came to me in response to the plight of a woman named Sandy. Sandy was diagnosed with leukemia and needed to leave her 2-year-old child behind in Michigan to receive a lifesaving BMT in Seattle. Sandy was emotionally distraught, not knowing whether she would ever be able to see her daughter again. These thoughts lingered while she spent weeks recovering, in great need of support through this isolating and uncertain time.

As a mother, I identified with Sandy's plight and wanted to ensure that others going through transplant would have the support, strength, and hope for survival. Thus, the nbmtLINK's mission was created "to help patients, caregivers, and families cope with the social and emotional challenges of BMT from diagnosis through survivorship by providing vital information and personalized support services."

Today, as more and more people receive lifesaving bone marrow/stem cell transplants, there is a growing need to continue to provide these important psychosocial services. The nbmtLINK has helped thousands of patients, survivors, caregivers, and families over the past 20 years, and **we couldn't have done it without you! We continue to rely on your kindness, generosity, understanding, and identification with those that need help, like Sandy, before, during, and after treatment, and especially for those dealing with the long term effects of BMT.**

Please consider making a generous contribution this year-end to commemorate the nbmtLINK's 20th Anniversary and to honor all of the patients, survivors, caregivers, and families that we have served and have yet to serve. You can make your donation right now online at www.nbmtlink.org and click on give TODAY!

Thank you,



Myra Jacobs
Founding Director



Outstanding National Telephone Conference LINKS Patients, Survivors, and Caregivers Coping with Chronic Graft versus Host Disease

On November 1, 2011, the nbmtLINK convened a telephone conference for over 100 BMT patients, survivors, caregivers, and health care professionals from around the U.S. Speakers included Mary Flowers, MD, Professor of Medicine, University of Washington, Director, Long Term Follow Up, Fred Hutchinson Cancer Research Center, Seattle, WA; Sandra Mitchell, PhD, CRNP, Research Scientist, Outcomes Research Branch, Applied Research Program Division of Cancer Control and Population Sciences, National Cancer Institute, Bethesda, MD; and Ellen Frank, PhD, BMT Survivor coping with cGvHD, Boston, MA. We also wish to thank our program sponsors: The Meredith A.

Cowden Foundation and The Leukemia & Lymphoma Society. cGvHD continues to be one of the most serious after effects of BMT, and many patients consider cGvHD to be worse than the disease for which they receive the transplant.

The positive response to this program demonstrates the ongoing need for focused cGvHD education and support. A Podcast of the telephone conference will soon be accessible as a free download from the nbmtLINK's website: www.nbmtlink.org. Another telephone conference is being planned for 2012. ♦

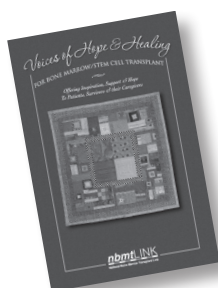
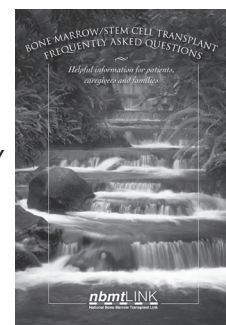
New Booklet is Coming! Become a Book Sponsor!

In our continuing effort to provide quality and up-to-date information for patients, caregivers, families, and health care professionals and to reach out to the Spanish-speaking population, the nbmtLINK is publishing a new **bi-lingual resource**, *Bone Marrow/Stem Cell Transplant-Frequently Asked Questions—Helpful Information for Patients, Caregivers, and Families*. The nbmtLINK is very grateful to City of Hope for generously providing the booklet's translation into Spanish.

Patients and families often have many questions when considering transplant as a treatment option. They are concerned about the risks and costs associated with their care

and need unbiased information to help them make informed decisions. *Frequently Asked Questions* will discuss the answers to 20 pertinent questions and will include a comprehensive resource listing.

The booklet is scheduled to be available in spring 2012. If you are interested in becoming a booklet sponsor, please contact Myra Jacobs at myrajacobs@nbmtlink.org. Becoming a sponsor enables you to have your name or name and logo printed in the booklet and to obtain a number of free copies, depending on your level of sponsorship. ♦



Voices of Hope & Healing Booklet Now Available!!

The latest booklet from the nbmtLINK includes a collection of inspirational stories, poems, and practical advice from BMT survivors, caregivers, and their families. This patchwork of "voices"

serves as a source of support and warming comfort.

Both the original online interactive version and the new booklet are available to read, download, or order on the nbmtLINK website: www.nbmtlink.org. ♦

Dynamic Outreach to the BMT Community

The goal of the Dynamic Outreach to the BMT Community initiative is to ensure that every BMT patient, caregiver, and family member is aware of the educational and support services offered through the nbmtLINK and the network of allied patient advocacy organizations.

As is stated in the textbook, **Chronic Graft versus Host Disease, Interdisciplinary Management** by Georgia B. Vogelsang and Steven Z. Pavletic, in the chapter on 'Patient Advocacy, Education and Psychosocial Support...' "A critical responsibility of transplant professionals includes providing information about different types of advocacy organizations and the characteristics and benefits of each. Assisting a patient to identify and access

appropriate resources empowers the patient and the support network to seek the services that meet their psychosocial, and treatment-related needs."

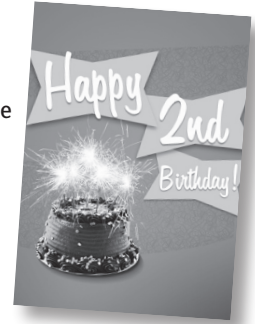
The nbmtLINK is accomplishing this outreach through in-service visits or telephone conferences with BMT health care professionals at various medical centers around the country. Recently, nbmtLINK provided in-service visits to UCSF, Stanford, City of Hope, Mt. Sinai, Memorial Sloan-Kettering Cancer Center, and Vanderbilt Ingram Cancer Center. We are very grateful for the support of Amgen, Inc. and Ortho Clinical Diagnostics for helping us launch this important effort. ♦

Celebrating Second Birthdays — Hope for BMT Survivors

Celebrating Second Birthdays recognizes the progress and accomplishments of the BMT survivor and family. It acknowledges and honors over 500 BMT survivors with a specially designed “re-birthday” card during the month of their transplant anniversary. Survivors appreciate the recognition as is reflected poignantly in the following response:

Thank you so much for the remembrance; it is especially meaningful, as you are the only one who remembers...

If you are interested in signing up to be recognized on your BMT anniversary, please email cindygoldman@nbmtlink.org or sign up on our website: www.nbmtlink.org. ♦



The New Normal Video Soon Available as DVD!

Through the generosity of Mr. Harry Pearce, former Vice Chair of General Motors and a BMT survivor, and the General Motors Foundation, the nbmtLINK will be creating a DVD of its EMMY award-winning video *The New Normal*. Originally produced in 2001 by Sue Marx Films, Inc. the video features six transplant survivors, their caregivers, and families who share their

remarkable stories from diagnosis to transplant to their “new normal” lives, providing encouragement and inspiration. This timeless video focuses on the significance of survival and reaching your “new normal.” Videos may still be ordered at www.nbmtlink.org. ♦

Thank you to our LINK Partner Sponsors!

Many of the major U.S. transplant centers and transplant-related organizations have recognized the nbmtLINK’s work by becoming a LINK Partner, providing annual support for our publications and programs. In exchange, each LINK Partner receives a number of free copies of our booklets and other educational materials, recognition on promotions and publications, and a listing on the nbmtLINK’s website with a hyperlink to their center or organization’s website. The nbmtLINK wishes to thank the following for their leadership and LINK PARTNERSHIP!

Barbara Ann Karmanos Cancer Institute
City of Hope
Dana-Farber/Brigham and Women’s Cancer Center
Duke Medicine Adult Bone Marrow and Stem Cell Transplant Program
Fred Hutchinson Transplant Program at Seattle Cancer Care Alliance
Froedtert Hospital and the Medical College of Wisconsin
Henry Ford Transplant Institute
Loyola University Medical Center
Mayo Clinic Cancer Center
Memorial Sloan-Kettering Cancer Center

The Blood and Marrow Transplant Program at Northside Hospital
Oregon Health & Science University
Roswell Park Cancer Institute
University of Michigan Comprehensive Cancer Center
The University of Nebraska Medical Center and The Nebraska Medical Center
Vanderbilt Ingram Cancer Center
American Society for Blood and Marrow Transplantation
The Leukemia & Lymphoma Society
Meredith A. Cowden Foundation
Be the Match

If your center or organization would like to be added to this list of distinguished LINK partners, please contact Myra Jacobs, Founding Director, myrajacobs@nbmtlink.org or 800-546-5268.

We are also very grateful for the generosity of the following pharmaceutical companies, foundations, and transplant-related organizations:

Amgen, Inc.
Center for International Blood and Marrow Transplant Research (CIBMTR)
Centocor Ortho Biotech
DeRoy Testamentary Foundation
Frank M. Ewing Foundation

General Motors Foundation
Lula C. Wilson Trust
Ortho-Clinical Diagnostics
Sinai Medical Staff Foundation
Winship Cancer Institute of Emory University