Celebrating 15 Years of Service!

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National Bone Marrow Transplant Link

UpDate

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BMT Caregivers' Guide, Second Edition

Melanie Goldish, Mother of BMT survivor Travis and "super Sib" Spencer

As difficult as it is, the quicker we can snap ourselves into the reality of "what is"—what we're dealing with—the better we can focus our energy, resources, and creativity to decide on the best course of action for our child and family. We can't choose the fact that this "event" has happened—that our child needs a transplant; that this is "happening to us"—yet we CAN choose how to respond.

Erin Gentry, Caregiver for her mother Martha

Time is a funny thing in the transplant world. It is what you are fighting so desperately for more of, and yet what often passes monotonously in waiting rooms in anticipation of the next set of "results." But time is all about how you choose to fill it. [My mother and I] unexpectedly found ourselves with time for leisurely conversations and with bonafide excuses to "goof off" in whatever ways we could invent. We had the kind of time to spend together that grown children and their parents rarely get. Despite the hard, scary and ugly moments, we both remember this time as one of the greatest gifts the transplant process gave us. (Yes, it does give gifts!)

Kay Forsht, Caregiver for her husband Woody

Twenty-five years ago if this had been in my horoscope, I would have said I couldn't do it. Of course, I wish this had never happened to the person I love most, but I've been privileged to have the opportunity to witness my husband's strength, his hope, his faith, his courage, and his determination. Being his caregiver is really just another way to say to him, "I love you!"

The highly anticipated second edition of the *Caregivers' Guide for Bone Marrow/Stem Cell Transplant: Practical Perspectives* was published this fall. It is the *only* booklet worldwide that specifically celebrates and supports BMT caregivers.

The role of the BMT caregiver is filled with enormous challenges. Studies have shown that the caregiver role is critical to the health, adjustment, and quality of life of the BMT survivor. Yet, the physical, emotional, and social impact of the disease and BMT treatment on the family often go unacknowledged. In fact, caregivers experience the same, if not more distress than the survivors themselves, and are usually less likely than the survivors to get the help they need.

The practical advice and words of encouragement, wisdom, and hope offered by BMT "care-vivors" in this booklet will help sustain countless numbers of other BMT caregivers as they embark upon this difficult journey. The nbmtLink is proud to offer this valuable resource to the BMT community.

Copies of the Caregivers' Guide are available to order online at www.nbmtlink.org or by calling 1-800-546-5268. The publication of this booklet was made possible through the support of the National Marrow Donor Program, LINK Partners, and book sponsors.

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Watch for Webcast on BMT Caregiving

The first nbmtLINK Webcast, co-sponsored by the National Marrow Donor Program (NMDP), is currently in production and will be available on our Web site, www.nbmtlink.org soon. We are honored to introduce Michelle Bishop, PhD, Research Assistant Professor in the Departments of Medicine and of Clinical and Health Psychology at the University of Florida, Gainesville in a presentation entitled, *For Better **and** For Worse: Impact of Cancer and BMT on Spouse-Caregivers.*

A licensed clinical health psychologist, Dr. Bishop has 12 years of experience helping patients and families with the psychosocial aspects of acute and chronic illness and its treatment, particularly cancer and blood and marrow transplantation (BMT). She served as the project coordinator of the largest study to date of the long-term quality of life (QOL) of BMT survivors and their spouses and has conducted an in-depth follow up study of those couples. Dr. Bishop has received several awards for her research and has presented her work at a variety of state and national meetings.

GUIDE DE RESSOURCES
POUR LA GREFFE
DE CELLULES SOUCHES

nbmtLINK

Resource Guide *en français!*

The *Resource Guide for Stem Cell Transplant Including Bone Marrow, Peripheral Blood, and Cord Blood* has been translated into French. Last year the LINK was approached by Yvan Rousseau, RN, BScN, MBA, Stem Cell Transplant Program Coordinator at McGill University Health Center in Montreal. Yvan wanted to make this important educational resource available to the hospital's French-speaking patients. This booklet is now available to our French-speaking friends around the world! Call 800-546-5268 for additional information.

Educational Outreach

Survivorship: Facing Forward, a three-part evening series held in the Spring in Troy, Michigan, provided information regarding the physical and emotional aftereffects of transplant, resources for survivors, and maintaining health and moving forward after transplant. Speakers included Muneer Abidi, MD, Karmanos Cancer Center; Anthony Opipari, MD, PhD, University of Michigan Medical School; Linda Diaz, ACSW, LMSW, Birmingham Maple Clinic; Marta Metz, LMSW, MPH, Henry Ford Health System; Jessica Monczka, RD, CNSD, University of Michigan Health System; and Gail Elliott Evo, William Beaumont Hospitals. During the final session, a panel of survivors and caregivers shared their very moving stories about coping with the challenges of transplant.

Bone Marrow/Stem Cell Transplant*: *The New Normal, an all-day forum in Boston was convened on May 19, 2007 and co-sponsored with The Leukemia & Lymphoma Society, Massachusetts Chapter, under the direction of Leah Sherman, Patient Services Manager. Speakers included David Avigan, MD, Director, Hematology Malignancy/Bone Marrow Transplant Program at Beth Israel Deaconess Medical Center in Boston and health professionals from Tufts-New England Medical Center, Dana Farber Cancer Institute, and Cancer*Care.*

These programs were made possible through the generosity of our sponsors: Blue Cross Blue Shield of Michigan; DeRoy Testamentary Fund; the McCarty Cancer Foundation; Sinai Medical Staff Foundation; Michigan Society of Hematology Oncology; My Friends Care; Wright and Filippis; Amgen; Comerica; Pall Medical; and the Amercian Society for Blood and Marrow Transplantation.

Telephone Education and Support for cGvHD Patients

Chronic Graft versus Host Disease (cGvHD) is one of the most difficult long-term complications following allogeneic transplant. It is associated with "decreased quality of life, impaired functional status, and the continued need for immuno-suppressive medication and difficulties that arise from this need." (National Institutes of Health).

Since 2006, the nbmtLINK has recognized the unique circumstances and issues associated with cGvHD by offering telephone education and support groups for individuals living with the disease. In October 2007, the nbmtLINK and The Leukemia & Lymphoma Society, Michigan Chapter, co-sponsored the fourth cGvHD group facilitated by staff from the National Institutes of Health: Sandra Mitchell, CRNP, MScN, AOCN, Predoctoral Fellow; Kate Castro, RN, MS, AOCN, and Steven Z. Pavletic, MD, Head, GVH and Autoimmunity Unit, Experimental Transplantation and Immunology Branch, National Cancer Institute.

As a response to the many requests from support group participants for a follow-up session, the first cGvHD Alumni Group was held in September. The group reunited previous members to discuss "***Emerging Chronic GvHD Treatments.***" Heartfelt appreciation and thanks go to Kate, Sandra, and Dr. Pavletic for their commitment to these groups. To participate in future groups please contact nbmtLINK at 800-546-5268 or email info@nbmtlink.org.

This program would not have been possible without the generous support of The Leukemia & Lymphoma Society, Michigan Chapter, DeRoy Testamentary Fund; Lula C. Wilson Trust; Sinai Medical Staff Foundation; Therakos, Inc.; and the William G. and Myrtle E. Hess Charitable Trust.

The National Bone Marrow Transplant Link is very grateful to the following list of LINK Partners, whose support is essential to its mission of helping patients, as well as their caregivers, families, and the health care community, meet the many challenges of bone marrow/stem cell transplant by providing vital information and support services.

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Dana-Farber/Brigham and Women's Cancer Center

Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance
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Karmanos Cancer Center
Mayo Clinic
Memorial Sloan-Kettering Cancer Center
OHSU Center for Hematologic Malignancies
University of Michigan Comprehensive Cancer Center
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