



The Meredith A. Cowden Foundation Honors the nbmtLINK & Announces the 2015 National GvHD Symposium for Patients & Professionals

The Meredith A. Cowden Foundation honored nbmtLINK Executive Director, Myra Jacobs, as the 2014 Honorary Chair and Guest Speaker at its “Six Courses for a Cure” event held this past August in Cuyahoga Falls, Ohio. The event raised funds to help support the Cowden Foundation’s GvHD Symposium, which is scheduled for April 24, 2015 at the Embassy Suites in Independence, Ohio.

The 2015 symposium, presented by The Cowden Foundation, in conjunction with the Cleveland Clinic, Case Comprehensive Cancer Center, and University Hospitals of

Cleveland, is a unique one-day conference consisting of two tracks: one designed for physicians and other health care professionals; the other, offering topics of interest to bone marrow transplant (BMT) survivors, their families and caregivers. Both tracks will focus on cutting-edge research and the latest treatment protocols.

For more information, please call Shawna Hofstetter at 216-410-6005 or contact her at shawna@cowdenfoundation.org. ♦



Myra Jacobs and Dr. Steven Pavletic

Myra Jacobs Invited to NIH Meetings

Myra Jacobs, M.A., Executive Director of the nbmtLINK, was invited to attend two outstanding National Institutes of Health (NIH) meetings in September. The Scientific Program: Advances in the Practice of Stem Cell

Transplantation delivered information about the current state-of-the-art of allogeneic stem cell transplantation, the result of two decades of clinical research at the NIH Clinical Center. The sessions covered such topics as stem cell donation, transplantation in malignant and nonmalignant

conditions, late effects, and future directions of NIH research.

The Survivorship Program: Patient and Caregiver Perspectives described relevant topics pertaining to allogeneic stem cell transplantation, as experienced by survivors and caregivers in the past two decades of clinical research at the NIH Clinical Center. The program focused on the benefits and challenges that those survivors and their families face following treatment. This session highlighted the perspective of survivors and caregivers after they experience allogeneic stem cell transplantation and to inform other survivors, families, and health care providers of the many aspects of survivorship during re-integration into community and life roles. ♦

nbmtLINK Widens Its Reach

After planning and organizing for over a year, the Santa Cruz Bone Marrow Transplant Support Group held our first meeting the evening of October 16. I was both excited and apprehensive. Twenty patients and caregivers attended the meeting and several others said they’ll plan to come in the future. What struck me most about the group was how much we who have been down this road all needed to come together to give and receive support from one another. Yet, until that October evening, I don’t believe that the understanding and support of the myriad issues BMT post-transplant patients face existed in the Santa Cruz area ... and quite likely is not present in many other locales as well.

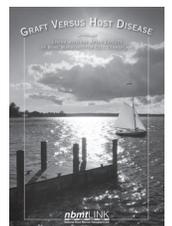
With all of the recent advancements in research in the

bone marrow/stem cell transplantation field, patients are living longer and, therefore, encountering chronic issues associated with survivorship, including daily fatigue, cognitive dysfunction, pain, myriad medical complications, psychological and financial challenges. And, unique to BMT – dealing with chronic graft versus host disease.

To think about where we go from here can be overwhelming. As so many others have, we will look to the National Bone Marrow Transplant Link for supportive programs and services ... and for encouragement. We are grateful to have formed a core group of people who are dedicated to making our efforts “fly.” The process is an evolving one. It is exciting, and I am privileged to be part of this endeavor. ~ Jim Engelman ♦

Last Call for GVHD Book Sponsors!

There is still time for you to be counted among the sponsors of the LINK’s upcoming book on Chronic Graft versus Host Disease for BMT patients, caregivers, families, and health professionals. To honor an individual, memorialize a loved one, pay tribute to a friend, physician or caregiver, or simply to be recognized as a supporter of the nbmtLINK, please contact Cindy Goldman at 248-358-1886 or cindygoldman@nbmtlink.org. Organizations, Private Foundations, Corporations & Businesses are also invited to be sponsors. ♦



Cindy Goldman, MEd, LPC, at the Heart of the nbmtLINK Programs



Educating and informing people about the transplant process is an important part of nbmtLINK's mission and contributes to the psychosocial support of patients and their caregivers. Cindy Goldman, a nationally certified counselor (NCC) has been matching up patients and families with booklets,

resourceful information, survivorship programs such as Celebrating Second Birthdays, or a peer support volunteer for supportive telephone calls. Cindy trains the volunteers who interact with the patients and families who want to speak with someone who has been through a BMT or may be struggling with post-transplant issues. Our Peer Support On-Call Program helps both the volunteers and

the recipients of the calls.

In addition, Cindy manages the nbmtLINK Website and Facebook page where specialized groups, such as BMT survivors dealing with chronic Graft vs. Host Disease (cGvHD), can find nbmtLINK and one another. In cooperation with the National Institutes of Health, she coordinates a cGvHD Telephone Education Support Group that provides an opportunity to learn more about how others are coping and about treatments that are working to alleviate symptoms. When BMT patients are seeking information and support, an email announcing a new resource, a telephone support group, or a Survivorship Guide available on our website, are just some examples of the types of support they will find at the heart of nbmtLINK's programs. ♦

Thank you to our nbmtLINK Partner Sponsors

Through their annual support of the nbmtLINK's publications and programs, many major transplant centers, transplant-related organizations, corporations and foundations from across the country have recognized the value of our work. As annual funders, each of these nbmtLINK Partners 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 acknowledge and thank the following organizations for their exceptional leadership as LINK PARTNERS:

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The Blood and Marrow Transplant Program at Northside Hospital
Oregon Health & Science University Knight Cancer Institute
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Thomas Jefferson University & Kimmel Cancer Center
University of Michigan Comprehensive Cancer Center
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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 248-358-1886.