



Volunteer Spotlight: Matthew Neil



Matthew Neil

In 2005, Matthew Neil thought he had strep throat and went to see his doctor. Matthew's white blood count was low, and to his dismay, he was diagnosed with Acute Myelogenous Leukemia (AML). In March of 2006, he

received an unrelated bone marrow transplant at Loyola University Medical Center in Chicago, IL.

This was a difficult time for Matthew. Rather than spending time with friends and getting ready for college, he was hospitalized and had to cope with transplant side effects such as a loss of appetite and fatigue. He felt like he was in the "twilight zone."

Fast forward three years later, Matthew is feeling well now. He is in his junior year of college studying Biology/Pre-Med. He always thought about going into the medical field and, because of his transplant,

Matthew is considering becoming an oncologist.

This past February, Matthew joined 14 other transplant survivors and caregivers in an nbmtLINK training program to become a Peer Support Volunteer. He wanted to become a volunteer to give back and use what he has been through in a positive way. "I have had a lot of great experiences, and I want to share them with others," he stated. He looks forward to helping other young adults facing transplant and giving them support when they are unable to see friends and must remain in a sterile environment. Matthew said his experience as a Peer Support Volunteer has been rewarding.

Matthew highly encourages people, especially those from diverse ethnic backgrounds, to consider becoming a marrow donor, as "There is someone that needs help." He tells young transplant patients and survivors to remember "It's a new life; it's not going to be like before...Keep going!" ♦

Interview with Keren Stronach, *Survivorship Guide* Author



Keren Stronach, MPH, is the author of the nbmtLINK's upcoming *Survivorship Guide for Bone Marrow/Stem Cell Transplant, Coping with Late Effects*. Keren is a two-time BMT survivor and has been facilitating a group for young adults with cancer for the last twelve years. She serves on the board of the National Bone Marrow Transplant Link and has spoken at public forums locally

and nationally. Keren shares with us her thoughts about the new publication and her survivorship experience:

nbmtLINK: Why did you want to write this *Survivorship Guide*, focusing on the long-term effects of transplant?

KS: I was relatively well-informed about the transplant process while I was going through it. However, I had very little information about what to expect after transplant, and the little information I was given did not reflect my experience. So, I just muddled my way through, coping as best as I could, piecing together a new life that could accommodate ongoing immuno-suppression, GVHD, infertility, and changed stamina and life goals.

Over the course of the last 14 years, I have, through trial and error, learned to cope with many of these

challenges. I decided to write this *Guide* in order to share some information and coping methods that I found useful. I hope that by sharing the collective experiences and wisdom of survivors, we can all benefit by learning about what lies ahead and how others have coped.

nbmtLINK: What was the most surprising thing about your life post-transplant?

KS: I think that the biggest surprise is the realization that I have the strength and resilience to construct a life that I find worthwhile and meaningful even though it is so very different than the life I once conceived for myself.

nbmtLINK: What has been the most difficult challenge that you've had to overcome post-transplant?

KS: Re-aligning my perception of myself to accommodate who I am now. I found it very hard to let go of who I was – strong, athletic, resilient – and learn to identify with my new self – mortal, slightly fragile, and more cautious.

nbmtLINK: What is your next project?

KS: I'd like to publish a couple of children's books. I have written two stories about being a little person for my daughter who has a type of dwarfism. She loves the stories and has taken their messages to heart. I'd love to publish them so that other children who have a difference can enjoy them as well. And then, the road is wide open.

To order a copy of the *Survivorship Guide*, please visit our website at www.nbmtlink.org or call 800-546-5268. ♦

Coming Soon: New Publication

The nbmtLINK is currently finishing a new inspirational publication, *Voices of Hope and Healing: Inspiration and Reflection for Bone Marrow/Stem Cell Transplant Patients*. The primary purpose of this publication is to provide empathy and support for individuals undergoing transplant in communities around the country. *Voices* is a collection of stories, poems, and original artwork from BMT survivors and their family members. This publication will act as a collage of support, helping individuals feel less isolated through this connection to those that have been through the transplant process. The publication will be available online in early 2010; a print version will be available in the Spring. For your reading pleasure, we've included an excerpt from this upcoming publication:

What Cancer Has Given Me

By Martha Nielsen

I was diagnosed with Non-Hodgkin's lymphoma in 2003 and had 10 cycles of 3 different chemotherapy regimens followed by an autologous stem cell transplant and 23 days of radiation in 2004. Many people who hear my cancer story seem surprised when I say that if I had the chance to go back and erase the whole experience, I wouldn't do it. Here are my top ten reasons:

- #10 I have had 3 major surgeries since my transplant. Any time I got worried about the outcomes or the expected long recovery times, I can just say to myself, "Hey, it's not a terminal illness!"
- #9 Like most women, I wasted years of my life wishing my hair was thicker and curser and most certainly a more interesting color. Now, after going without any hair at all for 14 months, I am quite happy with exactly what I've got.
- #8 Like many people, I also spent a lot of time worrying about my weight and wishing I didn't enjoy food so much. Having to literally force myself to eat for a time after my transplant has made me realize that enjoying food is a wonderful gift that makes life far more pleasurable.
- #7 Cancer taught me that getting old, with all of its changes and infirmities, looks a whole lot better if you think you're not going to get to do it.
- #6 I have learned there are many, many ways to provide support and comfort to another person and not all of them require words. Now when I don't know what to say, I understand that just being there is enough.
- #5 Cancer pointed out to me that the vast majority of the activities I frantically try to fit into every day are really not very important after all.
- #4 One of the hardest lessons cancer taught me was how to be a gracious receiver. For me, the secret to that was realizing that refusing to be a receiver deprives another person of the joy that giving brings.

[To be continued...]

To read Martha's top 3 reasons, please stay tuned for the debut of *Voices of Hope & Healing!* ♦

Staff Spotlight: Cindy Goldman



Cindy Goldman

Cindy Goldman, Patient & Caregiver Support Coordinator, joined the nbmtLINK in September of 2008. Cindy is a licensed professional counselor (LPC) in the state of Michigan, as well as a nationally certified counselor (NCC). She holds her Master of Education in Counseling and Development from Clemson University. Prior to the nbmtLINK, Cindy worked for Hospice of Michigan in both grief support services and spiritual care. At the nbmtLINK, Cindy stays busy with the psychosocial outreach efforts to patients, caregivers, and families by coordinating programs such as Celebrating Second Birthdays; assisting with the Peer Support Volunteer Program; and providing professional support services as needed through supportive phone calls and referrals. The nbmtLINK warmly welcomes Cindy to its staff. ♦

Bone Marrow/Stem Cell Transplant: The Future of Survivorship



Denise Lillvis, Patti Lee, Myra Jacobs, Dr. Stephanie Lee, Dr. Ellen Frank, & Dr. Steven Pavletic

The nbmtLINK hosted an elegant event in Washington, D.C. on December 1st for survivors, family members, and health professionals. Our Mistress of Ceremonies, Patti Lee, welcomed everyone to this special event. Ms. Lee's father, Jack, is a 70 year old BMT survivor, so she was able to relate her perspective as a caregiver to the audience. Dr. Robert Hartzman, Director of the C. W. Bill Young Marrow Donor Recruitment and Research Program, provided opening remarks. He was followed by Dr. Ellen Frank, a BMT survivor and nbmtLINK board member. Dr. Frank shared her personal story about her struggles in the post-transplant years and inspired fellow survivors in their journey. Our featured speakers were Dr. Steven Pavletic of the National Cancer Institute and Dr. Stephanie Lee of the Fred Hutchinson Cancer Research Center. Drs. Pavletic and Lee discussed the importance of increasing our knowledge about the late effects of transplant, particularly chronic Graft Versus Host Disease, and what the research community is doing to address these challenges.

At the close of the evening, Denise Lillvis and Myra Jacobs of the nbmtLINK talked about the need for increased resources for BMT survivors and their caregivers, as well as what attendees can do to help support these individuals. Afterwards, guests joined our speakers for an elegant wine tasting conducted by sommelier Amanda Weaver-Page. And, all guests received commemorative pins specially designed by Karen Koltonow, a BMT survivor, to mark the occasion.

The nbmtLINK wishes to extend a special thank-you to our event sponsors for making this evening possible:

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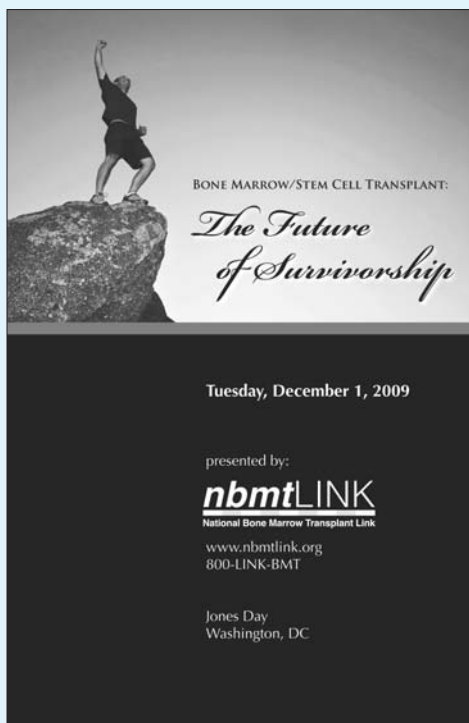
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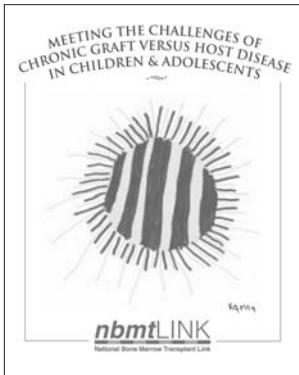
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New Webcasts for Parents and Guardians of BMT Survivors with cGvHD

This fall, the nbmtLINK launched two new webcasts on *Meeting the Challenges of Chronic Graft Versus Host Disease (cGVHD) in Children and Adolescents*, available at www.nbmtlink.org/webcasts. Both webcasts were co-sponsored by the National Marrow Donor Program.



Part I, “The Medical Aspects and Management of cGVHD in Children and Adolescents,” features Kristin Baird, MD, of the Pediatric Oncology Branch, National Cancer Institute, National Institutes of Health and Kimberly Thormann, MA, CPNP, of Children’s Memorial Hospital. This webcast provides an overview of stem cell transplants and the prevention and development of cGVHD. It also reviews symptoms and health maintenance options recommended to maintain and improve the well-being of children living with cGVHD.

Part II, “Families Coping with Chronic Graft Versus Host Disease (cGVHD) in Children & Adolescents” is presented by Lynn Hardesty, MSS, LICSW, BCD, of Children’s National Medical Center. This webcast provides parents and other family members with practical advice on how to cope with cGVHD. Three parents of children living with cGVHD offer their perspectives on the disease and provide practical advice for parents before and after transplant. ♦

The National Bone Marrow Transplant Link is very grateful to the following LINK Partners, whose support is essential to our mission. For information on how your institution can become a LINK Partner, please contact Denise Lillvis at deniselillvis@nbmtlink.org.

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