



bmt infonet

bmt infonet

In this issue...

- The Truth about Stars...2
- Advances in Cord Blood Transplantation...3
- BMT InfoNet...
We're with you every step of the way4
- Celebrate Life Silk Scarf.....4
- Symposium Highlights...5
- NMDP6
- 2009 Calendars6
- NMDP6
- Order Form7

bmt infonet

Editor: Susan K. Stewart

To subscribe, contact:

BMT InfoNet

2310 Skokie Valley Rd., Suite 104

Highland Park, IL 60035

888-597-7674 (toll free)

847-433-3313

847-433-4599 (fax)

help@bmtinfonet.org

www.bmtinfonet.org

ISSN 1525-6855

©2008 BMT InfoNet

This issue of Blood and Marrow Transplant Newsletter is sponsored by Teva

Newsletter

Chemobrain! Is It Real?

Chemobrain. We've all heard the term. It refers to changes in the way many transplant survivors, and others undergoing cancer treatment, think and process information. The technical term for the problem is cognitive dysfunction and was the subject of neuropsychologist Dr. Christina Meyers' presentation at the Celebrating a Second Chance at Life survivorship symposium hosted by BMT InfoNet and the National Marrow Donor Program in Dallas, Texas this past September.

"Chemobrain occurs in a majority of cancer patients on active therapy," says Meyers "and persists in a substantial number of patients after treatment is discontinued. It can be caused by the cancer itself, the treatment and/or other complications such as anemia, infection or graft-versus-host disease."

There are several components of cognitive dysfunction. Working memory, the amount of new information that can be learned at one time, may be diminished. Retrieving previously learned information may be inefficient. The ability to focus on a task or do several tasks at one time may be more difficult. However, reasoning and problem-solving tend not to be affected.

These changes can have a significant impact on a person's daily life, says Meyers. A person may become overwhelmed when more than one thing is happening at the same time, like multiple conversations. They may become easily distracted, miss key points in conversations and have trouble meeting deadlines. Performing daily tasks requires increased effort – there is no autopilot for tasks that once were routine.

So how can these problems be corrected?

The first step is to identify and correct any medical problems that may be causing the condition. These include hormonal changes, thyroid problems or borderline anemia.

In some cases, drug therapy may be appropriate.

"I think our clinic hands out more Ritalin® than any school district in the United States," jokes Meyers, "but, in fact, people who experience fatigue, attention and focus problems may really benefit from this type of medication."

Behavioral and life style changes can also improve the problem.



Christina Meyers

"Relaxation training to focus attention and exercise can help with attention," says Meyers. "I'm not talking about going to the gym and wearing yourself out, but mild exercise on a daily basis."

Daily planners or PDAs are extremely useful for people with cognitive problems. "Create a daily list of tasks, prioritize those that are most important and do them first. Have an end of day checklist to be sure tasks were accomplished, and use devices with audible alerts, like PDAs, to help you keep organized and on task."

Conserving your energy can help focus and memory problems. "Pace yourself, organize tasks around the hours of day when you are most energetic, delegate tasks whenever possible, take frequent breaks and aggressively manage sleep problems," says Meyers.

There are a number of strategies or tricks you can use to combat forgetfulness. "If you tend to forget where you parked your car, park in the same place every day or write

The Truth About Stars: Stories of Hope

by Sara Patterson

Star light, star bright,
First star I see tonight,
I wish I may, I wish I might,
Have the wish I wish tonight

For years, many of us have been wishing upon falling stars. It's amazing how a simple childhood rhyme can speak volumes to the oldest of souls. For a falling star is not simply a night time wonder- rather it is a unique combination of particles and gases that are providing the most spectacular array of light in the midst of an overwhelming darkness. When we wish upon a falling star, we wish for something we are hoping for—and that hope is the reason we are all here today.

At the age of 15, I entered the world of cancer with a diagnosis of acute myelogenous leukemia. After enduring two rounds of intensive chemotherapy, we soon learned that without a bone marrow transplant, my odds of long term survival were slim to none. My diagnosis was grim, but my hope was strengthened when we found out that my brother, Adam, was a perfect match.

Two weeks after my sixteenth birthday, I received the gift of hope and a gift of life—and ten years later, I can stand before you as a healthy vibrant young woman who has survived a bone marrow transplant.

My fascination with stars began upon being discharged from the hospital, when my oncologist gave me a shooting star pin with the number "88" on the back, indicating that I was the 88th BMT they had done. My doctor called his BMT patients his shooting stars. To him, the transplant patients were the ones who, in the midst of bleak circumstances, shined the brightest and gave him hope.

From diagnosis, through the transplant, in transition to long term survivorship there is a certain amount of strength that's required of bone marrow transplant patients. One of the key strengths that we find is hope.



**We are all rare lights.
We are surviving and
we are shining.**

Hope is a vital part of the bone marrow transplant process. For many of us, the chemotherapy brought us to our lowest, sickest point, and for many of us, hope was what we clung to.

The hope we live with every day is made up of many things. Often the hardest ingredient of hope is patience. Patience, for many of us, has continued to be a learning process.

I met Tom a few years after my own transplant. Tom was tall and quiet. He played high school baseball and always had on a different team's cap to show his enthusiasm. When Tom's leukemia relapsed, he found himself living in the practice of patience. He needed a bone marrow transplant and remained on the transplant list for many months. The longer he waited, the more hope he had that he would one day find that perfect match, the more hope he had that he would be out there playing baseball again soon.

For Kristy, she had her match right away. Her sister fit perfectly. Kristy is 16 and, according to her sister, she has the attitude to prove it. After the

transplant, Kristy was thrilled to return to her world of hair, shopping, and boys. But she started to develop some odd symptoms and soon learned she had chronic GVHD. Disappointed, she grows in hope and endures this new struggle in patience. She is always hoping that new methods to deal with her chronic GVHD will soon be discovered.

As time tests our patience, community strengthens us as we wait. And community is the second ingredient of hope. Indeed, community can be one of the most powerful and beautiful components of hope.

A friend of mine, Cathy, was recently divorced when she was diagnosed with leukemia. Cathy's sons lived states away and her friends seemed to disappear. At first, she turned to a local cancer community group for financial help. It was there that she found activities and events that allowed her to meet others who understood and could offer a helping hand. When I met Cathy, I had a hard time believing that her frowning face would ever crack a smile. When I saw Cathy the day before she finally entered the BMT unit, smiling was all she could do—she knew she had a community of hope supporting her throughout the process.

Perhaps the most important ingredient of hope lays not in the struggles of patience or the camaraderie of community, but rather, it is found in the attitude towards life that we carry with us every day. So I submit to you that the third ingredient of hope is Joy.

For without joy, we cannot celebrate the small moments in life or fully celebrate our moments of triumph.

The purest moment of joy I have ever seen was on a little boy's face, Jon, when he received his make-a-wish gift...a puppy. Jon had already endured one transplant and at eleven years old he would have rather been out playing than face another one. Jon loved to spend his days in the hospital playing Nintendo and using his IV pole as a skate-board. When Jon was at his

continued on page 3



Advances in Cord Blood Transplantation

Bone marrow and stem cell transplants are a life-saving procedure for many patients with blood disorders such as lymphoma and leukemia. However, many patients who could benefit from a transplant do not have a matched bone marrow or stem cell donor.

Umbilical cord blood has been increasingly used as an alternative source of stem cells for transplantation. Cord blood, however, is used more often in children rather than adults because many cord blood units do not have enough stem cells for adults and adolescent patients.

Doctors are testing different methods to make this life-saving therapy available to more patients. One method being studied is called StemEx®.

StemEx® is a technique that increases the number of cord blood stem cells in the laboratory before transplanting the cells into the patient. Higher numbers of these cells may increase the chance for successful engraftment following a cord blood transplant. A study called ExCell®

is underway at twenty five transplant centers in the US, Europe and Israel to test the effectiveness of this technique in a larger group of patients.

Who may be eligible for the study?

Patients (ages 12-55 years) with blood disorders including acute myelogenous leukemia (AML), acute lymphocytic leukemia (ALL), chronic myelogenous leukemia (CML), myelodysplastic syndromes (MDS), Hodgkin's disease (HD), or non-Hodgkin's lymphoma (NHL), who are candidates for a stem cell transplant from an unrelated donor may be eligible. Further eligibility criteria will be determined by investigators at each transplant center.

A list of transplant centers who are enrolling patients in the StemEx® study can be found at www.StemExStudy.com.

Other approaches

The StemEx® study is one of several techniques being investigated to make cord blood transplant a viable option for more patients. Another technique involves transplanting adults with more than one unit of cord blood, while a third approach combines a single unit of cord blood with a second unit that has been manipulated in the laboratory to increase the number of stem cells available for transplant.

Cord Blood Webcast

Dr. Patrick Stiff of Loyola University Medical Center discussed advances in cord blood transplantation and new techniques to make it available to more patients on webcast hosted by BMT InfoNet in September. You can listen to that webcast on BMT InfoNet's web site at bmtinfonet.org/webcastcord.

continued from page 2

weakest though, he received his puppy who was "sterilized" enough to enter the BMT unit - and no, they did not put the puppy in the autoclave. The joy that that puppy brought was what provided Jon the inspiration he needed to face his second transplant.

We all have those moments of joy in our lives, every day. We all know the joy that came with taking off our mask in public... or removing that hat for the very last time. We all know the joy that comes with the news of a match and the hug of a friend. Joy is what helps us endure, makes us reach out, and continues to build us in our journey of hope.

Hope requires many ingredients, but what we hope for is so powerful. Our hope comes from our own continuing stories of survival. Our hope comes from the inspiration of others who have gone before us. Our hope is for the

cures that our stories will someday bring to others.

A shooting star is merely a meteor that is struggling against the earth's atmosphere. It is within that struggle against the darkness that the meteor produces such a beautiful and rare light.

I, like many of you, have had many rare lights in my life.

For Tom and Jon, their struggles here on earth ended but the light that their lives produced still brings joy to many. Indeed, the inspiration of their stories have inspired thousands to donate time and money towards research and support efforts.

For Kristen and Cathy, they are still facing the initial challenges of survivorship through physical and emotional struggles. They are still learning to shine.

For myself and other long-term survivors, we are trying to shine brightly

so that those who come after us will see that there is hope after a transplant.

We are all rare lights. We are surviving and we are shining.

The truth about stars is that they function as far more than viewing pleasure. Some provide direction. Some provide light and warmth. Some provide a mystical feeling of hope as they go shooting across the night sky. No matter what happens in life, no matter our function, we are still stars... still part of a larger constellation of hope."

Star light, star bright,
First star I see tonight,
I wish I may, I wish I might,
Have the wish I wish tonight

My wish for you and for those who will follow this path after us is that they will see our larger constellation of hope and aim for the stars.



BMT InfoNet...We're with you every step of the way

Dear Friends –

In 1990, two women had a vision: to provide comfort and hope to families facing a stem cell transplant, and to arm them with information that would help them make informed decisions during treatment.

The women – one a nurse, the other the consumer advocate – were both bone marrow transplant survivors. They had experienced firsthand the fear and frustration that many patients feel when overwhelmed by a deadly diagnosis and the prospect of a risky medical procedure.

Back in those days, when the internet was in its infancy and transplants were rare, there was no information about stem cell transplantation written in a language that patients could understand.

So with little more than a powerful idea and a will to help others, BMT InfoNet was born. It was the first and only organization to provide written information and emotional support – sometimes in the wee hours of the night – to transplant patients who were gripped with fear and uncertainty. And ever since, BMT InfoNet has been the trailblazer in advocating on behalf of bone marrow, stem cell and cord blood transplant patients and their families.

With generous support from people whose lives have been touched by transplant, BMT InfoNet now serves more than 10,000 families annually. Whether it's our comprehensive, easy-to-read books, our Caring Connections program that puts patients in touch with transplant survivors, our survivorship symposia or our knowledgeable staff who will track down answers to even the most complex questions, BMT InfoNet fulfills a vital need.

To continue these unique and important services, **BMT Infonet needs your support.** Will you help?

Please use the envelope in this newsletter to make a contribution – big or small – to help BMT InfoNet support transplant patients in 2009.

“What an incredible resource! When I thought I had no one to turn to for help, I found BMT InfoNet. Your book about transplants and the patient, caring staff person who answered each of my many questions helped lessen my worries and fears. Thanks for all you do!”

Togetherwe can provide a ray of hope for thousands of families next year.

On behalf of the BMT InfoNet staff, I wish you a joyous holiday season and a healthy New Year!

Sue Stewart

You can also donate online through BMT InfoNet's secure web site: www.bmtinfonet.org/survive.html

Wear the Gift of Life



Treat yourself or someone you love to a beautiful piece of wearable art, designed by a talented stem cell transplant survivor.

The lovely, pure silk **Celebrating Life** scarf featured to the left was designed by award winning artist Jim Egan, while recovering from his stem cell transplant for myelodysplasia.

“It has several meanings for me,” says Jim. “The bird of paradise symbolizes the beauty of restored life, and the stained glass execution symbolizes the spiritual aspect of the transplant experience. The background itself symbolizes the dawning of renewed hope.”

This 36” square pure silk scarf will provide warmth under your fall/winter coat and is a beautiful design element to enhance a suit jacket, blouse or sweater. It is suitable for framing as well.

What an inspiring gift for you and others on your holiday list!

Proceeds from the sales of the scarf will help support the many important programs offered by BMT InfoNet to bone marrow, stem cell and cord blood patients and their families.

Celebrate the holiday season by wearing this inspiring piece of art! Use the order form on page 7 or phone 888-597-7674 to place your order. Or order online at <http://bmtinfonet.org/scarf2009.html>.

\$32 plus shipping and handling. Order soon. Supplies are limited.





Symposium Highlights Challenges and Victories After Transplant

More than 250 people assembled in Dallas, Texas for the **Celebrating a Second Chance at Life** survivorship symposium September 20-21, 2008. Transplant survivors from as far away as India, South America and Australia participated in the symposium which was designed to help survivors and their families learn how to “live well” after transplant.

“The weekend was incredibly beneficial to me especially during this difficult period in my recovery,” says David Mejia, a Denver resident who recently underwent a transplant for multiple myeloma. “I’m grateful to the staff and volunteers for providing invaluable information that was well-organized, addressed the important post-transplant topics, and provided the right amount of detail. I plan to share some of this knowledge with my fellow survivors in Denver.”

“An amazing group of experts” is how one attendee described the presenters who provided in-depth information on chemobrain, fatigue, caregiver challenges, preventing post-transplant complications, emotional challenges after transplant, insurance issues, sexuality, chronic graft-versus-host disease, fertility and hormone replacement therapy. Survivors, spouses, parents and other family members shared their own experiences and expertise with each other during formal networking groups, where new friendships were forged and tips on managing

post-transplant problems were exchanged.

“The most valuable part of the conference was meeting with others going through the same thing I am,” commented one survivor. “I found out I am not alone.”

The weekend marked the “new birthday” of two survivors, one of whom celebrated her first anniversary post-transplant, and a second who celebrated her 12th. Another survivor used the opportunity to travel to Texas to meet her stem cell donor for the first time.

“There was a special energy at the symposium that comes when people who have faced a great challenge in their lifetime meet together, laugh together, even cry together,” says Sue Stewart, Executive Director of BMT InfoNet. “Everyone had something to learn and something to teach one another. It was a unique and powerful experience for everyone involved.”

“This symposium was the result of a lot of hard work and dedication by BMT InfoNet staff, our co-host the National Marrow Donor Program, our corporate sponsors and the transplant centers who helped fund and staff the event,” says Stewart. “We are most grateful for their support.”

If you were unable to attend the symposium, don't despair! Thanks to a grant from Otsuka, all of the presentations are now available for viewing on BMT InfoNet's web site at www.bmtinfonet.org/dallas2008



New Resources from the NMDP Office of Patient Advocacy



In 2007, the NMDP facilitated nearly 3,700 marrow and cord blood transplants for patients who do not have matching donors in their family. However, many patients who have a blood-related cancer or other disease for which a bone marrow or cord blood transplant (also called a BMT) is a treatment option do not receive the transplant they need. The NMDP has created a new online tool, MatchView, to help patients explore unrelated marrow and cord blood transplant as one of their treatment options.

MatchView allows patients to enter their Human Leukocyte Antigen (HLA) typing and view the number of potential matches (donors and cord blood units) on the NMDP Registry. To use MatchView, patients need HLA typing results for HLA-A, -B, and -DRB1. The matches are called potential because a transplant center must follow up to see if the potential donors and cord blood units are suitable and available.

MatchView also includes information to help patients and caregivers

- Understand HLA matching
- Understand the steps in the search and transplant process

The purpose of MatchView is to increase patients' access to information on transplant as a treatment option. It can also help facilitate discussions between patients and their physicians regarding unrelated transplant and the appropriate next steps, if transplant is an option.

MatchView can be found on the NMDP's Web site, at: www.marrow.org/matchview

Share Your Story

Transplant patients and families indicate that it is valuable to hear about the transplant experiences of others. To address this need, the National Marrow Donor Program's Office of Patient Advocacy uses stories and quotes from transplant patients, their caregivers and

family members in the majority of our publications.

If you are interested in sharing more about your transplant experience, contact us at patientinfo@nmdp.org, and we will e-mail you a form that asks questions such as:

- How did you get information about transplant and treatment options
- Talk about your support system following the transplant
- What was most helpful to your recovery during your treatment?
- Discuss some milestones that were important to you during the first 100 days after transplant.

Although not all patient and family stories will be used, your story will go on file for potential future publications. Your story could be used in conjunction with patient advocacy, donor recruitment, or other NMDP initiatives that work to give all patients the best possible chance to receive the life-saving transplant they need.

Just in time for the New Year Celebrating Life 2009 Calendar

BMT InfoNet is pleased to offer a full year of hope for 2009: an inspiring wall calendar that celebrates the lives of twelve people who underwent a bone marrow, stem cell or cord blood transplant.

Each month of the calendar introduces you - with a color photo and essay - to a survivor who is active and full of life. Our survivors are from different parts of North America, have different ethnic backgrounds, are different ages and had different diagnosis. The **Celebrating Life** calendar shares their uplifting stories with you.

At \$12 each, they are a perfect gift for friends and family while supporting the work of BMT InfoNet.

To order copies, phone 888-597-767
or visit our website
www.bmtinonet.org/calendar2009



Order Our BMT InfoNet Publications

Celebrating Life 2009 Calendar

A 12 month, full-color wall calendar that celebrates the lives of 14 transplant survivors through colorful photographs and essays. \$12 (includes shipping & handling within the U.S.). Call for discounts on quantities of 50 or more.

Bone Marrow and Blood Stem Cell Transplants:

A Guide for Patients

A 200-page handbook that explains, in clear, concise language, what is involved in undergoing a transplant with bone marrow, blood stem cells or cord blood stem cells from a donor. \$9.85 + shipping and handling. Also available in Spanish.

Autologous Stem Cell Transplants:

A Handbook for Patients

A 165-page handbook that explains in clear, concise language, what is involved in undergoing a transplant using the patient's own marrow or stem cells. \$9.85 + shipping and handling.

Across the Chasm: A Caregiver's Story

The story of a young woman's experience caring for her husband during his transplant. \$9.85 + shipping and handling.

Mira's Month

A colorfully illustrated book designed to be used with children whose parent is about to undergo a transplant. \$5.00 + shipping and handling.

Celebrating Life Silk Scarf

\$32 plus shipping and handling

Finding the Money: A Guide to Paying Your Medical Bills

A practical, easy-to-read 137-page book that provides tips on how to organize and pay your medical bills, and how to raise funds to pay for bills not covered by insurance. \$12.00 + shipping and handling.

A Guide to Protecting Your Health After Transplant: Recommended Tests and Procedures

A booklet that outlines the specialized care transplant survivors require for long-term health management. Separate versions available for patients recovered from an allogeneic transplant (transplant using bone marrow, blood stem cells or cord blood from a donor) or autologous transplant (transplant using the patient's own marrow or stem cells). FREE.

Resource Directory

Lists nearly 100 organizations that provide information, counseling and financial support to transplant patients. \$1.50 (includes free shipping)

Helpful Hints for Caregivers

A flyer with tips on how to be an effective caregiver and how to minimize the associated stress. FREE.

Order Your Books Today!

NAME _____

ADDRESS _____

CITY _____

STATE/PROVINCE _____ ZIP CODE _____

COUNTRY _____

PHONE _____

EMAIL _____

Item	Qty	Unit Price	Total
Bone Marrow & Blood Stem Cell Transplants			
Bone Marrow & Blood Stem Cell Transplants (Spanish)			
Autologous Stem Cell Transplants			
Across the Chasm			
Finding the Money			
Mira's Month			
A Guide to Protecting Your Health—Allogeneic*			
A Guide to Protecting Your Health—Autologous*			
Celebrating Life 2008 Calendar			
Resource Directory			
Caregiver Hints			
Celebrating Life Silk Scarf			
		Subtotal	
		Shipping	
		TOTAL	

*These guides will be shipped separately from CIBMTR.

Check here to receive our newsletter electronically by U.S. Mail
Method of Payment:

Check Visa Mastercard American Express Discover

Card# _____

Expires _____

BOOK PRICES

BONE MARROW AND BLOOD STEM CELL TRANSPLANTS: A GUIDE FOR PATIENTS (ENGLISH AND SPANISH)

AUTOLOGOUS STEM CELL TRANSPLANTS: A HANDBOOK FOR PATIENTS

ACROSS THE CHASM: A CAREGIVER'S STORY

QUANTITY	PRICE/BOOK
1-4	\$9.85
5-9	\$8.95
10+	\$8.25

FINDING THE MONEY: A GUIDE TO PAYING YOUR MEDICAL BILLS	\$12 EACH
MIRA'S MONTH	\$5 EACH
CELEBRATING LIFE SILK SCARF	\$32 EACH
CELEBRATING LIFE 2009 CALENDAR (INCLUDES SHIPPING WITHIN THE U.S.)	\$12 EACH
RESOURCE DIRECTORY (INCLUDES SHIPPING WITHIN THE U.S.)	\$1.50 EACH

Shipping & Handling Within U.S.:

Total Books	Total Shipping
1 to 4	\$5.00
5 to 9	\$10.35
10 to 14	\$12.95
15 to 19	\$14.25
20 to 24	\$17.00
25 to 29	\$19.10
30+	Call
To Canada & Mexico	Total Shipping
1 to 3	\$9.00
4+	Call
To Europe	Total Shipping
1 to 3	\$11.00
4+	Call

For shipping outside the US or on larger quantities phone us toll-free at 888-597-7674 or e-mail help@bmtinfonet.org for prices.

Send this form to: BMT InfoNet
2310 Skokie Valley Rd., Suite 104
Highland Park, IL 60035
847-433-3313 847-433-4599 (fax)
help@bmtinfonet.org

Or order online at www.bmtinfonet.org

continued from page 1

down the location in a daily planner. If you have trouble keeping up with your medications, use a pill box to help you remember which pills to take and when. Use direct deposit for your paycheck, appliances with automatic shut-off and phones that store phone numbers. Have a “memory station” in your home – a place where you always put important items like car keys so that they can be easily found.

What doesn't work is repetitive tasks, says Meyers. “It's very trendy these days to do Sudoku games, cross word puzzles or video games to make yourself more sharp. While stimulating the brain is good, it doesn't help with the kinds of memory problems people with “chemobrain” experience. For example, if you try to do Sudoku or video games to help with your word retrieval difficulties, it won't work. You'll get better at the game, but not at retrieving words from your memory.”

For most survivors, the chemobrain effect lessens over time, but for some it may persist for years. For people who are unable to manage the problem on their own, a consultation with a neuropsychologist may be in order. The American Academy of Clinical Neuropsychology can help you identify a qualified provider in your area. Contact them at 734-936-8269 or <http://theaacn.org>

Issue #74

Inside: Chemobrain! Is It Real?

Address Service Requested

www.bmtinfonet.org
847-433-3313 or toll-free 888-597-7674
Highland Park, Illinois 60035
2310 Skokie Valley Road – Suite 104
Blood & Marrow Transplant Information Network

NON-PROFIT ORG.
US POSTAGE
PAID
WINNETKA IL
PERMIT NO. 228