



# Newsletter

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## Celebrating a Second Chance at Life

*A symposium for transplant survivors and their loved ones*

**Dallas, Texas • September 20-21**

More than 200 survivors of a bone marrow, stem cell or cord blood transplant will converge on Dallas, Texas September 20-21 for a two day educational forum on living well after transplant. Transplant experts from around the country will address issues ranging from how to protect your health after transplant, to coping with the psychological challenges that affect transplant survivors and their loved ones.

"I'm excited about the opportunity to learn and network with other survivors at the symposium," said Michelle Worman, who was transplanted for chronic myelogenous leukemia in 1996, and now hosts an on-line chat room (bmtsupport.org) for patients, survivors and caregivers. "I know the information we learn from the experts and from each other will be very powerful."

The symposium will kick off Saturday, September 20, 2008 with a presentation by Jeff Chell MD, chief executive office of the National Marrow Donor Program, who will highlight the

progress made in transplantation over the past decade.

His talk will be followed by presentations on how to manage your health long-term, emotional challenges post-transplant, and chronic fatigue. Separate networking sessions for survivors and family members will follow. The evening will conclude with dinner and entertainment by Dallas-based *Vocal Trash* – a high energy, a cappella vocal group that delights audiences of all ages.

On Sunday, a series of workshops will address the unique needs of pediatric and adult survivors. Topics will include learning and memory problems after transplant, caregiver challenges, insurance questions, chronic graft versus host disease, sexuality post-transplant, infertility, and hormone replacement therapy. The day will end with an Ask the Experts session, where a panel of transplant experts will answer questions from the audience on any transplant-related topic.

You can register online at: [bmtinfonet.org/dallas2008](http://bmtinfonet.org/dallas2008)

or at 888-597-7674. You can also use the registration form on page 7. A \$75 registration fee for the two-day session includes snacks, dinner and entertainment on Saturday, and breakfast and substantial snacks on Sunday. A discounted hotel rate of \$99/night has been arranged with the Doubletree Hotel at the Galleria where the conference will take place. Scholarships are available for survivors and family members who can not afford the registration fee. Phone 888-597-7674 for details. Social workers attending the conference can earn 7.5 continuing education units (CEUs).

"We're very grateful to our sponsors for their support of this program," says Susan Stewart, executive director of BMT InfoNet. "The symposium will provide participants with new tools to handle post-transplant issues and new friends who share common concerns. This is a unique opportunity to meet and learn from others who understand the challenges of surviving after transplant, and have practical information to share."

**SATURDAY, SEPTEMBER 20, 2008**

**Welcome**

Susan Stewart, BMT InfoNet

**Look How Far We've Come**

Jeff Chell MD, National Marrow Donor Program

**Protecting Your Health Long Term (adult)**

Sergio Giralt MD, UT MD Anderson Cancer Center  
Brian Berryman MD, Medical City Dallas Hospital;  
Baylor University Medical Center  
Madhuri Vusirikala MD, UT Southwestern Medical Center

**Protecting Your Health Long Term (pediatric)**

Robert Krance MD, Texas Children's Hospital  
Gretchen Eames MD, Cook Children's Hospital

**Riding the Emotional Roller Coaster of Survival (adult)**

Karen Syrjala PhD, Fred Hutchinson Cancer Research Center

**Riding the Emotional Roller Coaster of Survival (pediatric)**

Susan Parsons MD, Tufts-New England Medical Center

**Give me a Break! Managing Fatigue after Transplant**

Lillian Nail RN PhD, Oregon Health & Science University

**Stories of Hope**

Sara Patterson MA

**Survivor, Spouse, Parent and Other Family Member Networking Groups**

**Dinner Reception/Entertainment**

**SUNDAY, SEPTEMBER 21, 2008**

**Continental Breakfast**

**Chemobrain! Is it Real?**

Christina Meyers PhD, UT MD Anderson Cancer Center

**Learning and Memory Problems after Transplant (pediatric)**

Daniel Armstrong PhD, University of Miami

**Caregiver Challenges (adult)**

Michelle Bishop PhD, University of Florida

**Caregiver Challenges (pediatric)**

Susan Parsons MD, Tufts-New England Medical Center

**Male Sexuality Post-Transplant**

Leslie Schover PhD, UT MD Anderson Cancer Center

**Female Sexuality Post-Transplant**

Leslie Schover PhD, UT MD Anderson Cancer Center

**Navigating the Insurance Maze**

Joanna Morales, Esq., Cancer Legal Resource Center  
Patricia Martin RN BSN, Wellpoint, Inc.

**Chronic Graft-versus-Host Disease**

Paul Shaughnessy MD, Texas Transplant Institute  
Steven Pavletic MD, National Cancer Institute

**Hormone Replacement Therapy after Transplant: Is it right for me?**

Hillary Boswell MD, Women's Specialists of Houston

**The Unique Needs of Young Adult Survivors**

Sage Bolte, MSW, Life with Cancer, Inova Health System

**Fertility Options After Transplant**

Hillary Boswell MD, Women's Specialists of Houston

**Ask the Experts Panel (both adult & pediatric)**

A panel of experts from several transplant programs

**Closing Ceremony**

**THANKS TO OUR SPONSORS**

**Blood & Marrow Transplant Information Network (BMT InfoNet)**  
National Marrow Donor Program Office of Patient Advocacy  
(NMDP OPA)

**American Society for Blood & Marrow Transplantation (ASBMT)**  
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Baylor Charles A. Sammons Cancer Center, Dallas, TX  
BMTSupport.org

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Cook Children's Medical Center, Fort Worth, TX  
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University Medical Center, Lubbock, TX

**US Department of Health & Human Services, Health Resources and Services Administration, Department of Transplantation**  
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# New Tool for Controlling Mouth Sores

High dose chemotherapy and radiation given to patients before their transplant often cause painful mouth and throat sores. The sores typically appear 4-8 days after treatment, and can make eating difficult or impossible.

A new tool is on the market to protect against painful mouth sores. Caphosol®, when used in combination with fluoride treatments, reduces the frequency, intensity and duration of mouth and throat sores in patients undergoing chemotherapy and radiation prior to transplant, according to a study published in *Bone Marrow Transplantation*.<sup>1</sup>

The study, conducted at Tufts New England Medical center, randomly assigned 95 stem cell transplant patients to receive

either fluoride treatments alone, or fluoride treatments with Caphosol® prior to transplant. Most patients had leukemia, lymphoma, Hodgkin's disease, multiple myeloma, or myelodysplasia. Little over half underwent an autologous stem cell transplant (using their own stem cells) and the remainder had an allogeneic transplant (using donor stem cells).

Patients in the Caphosol® group experienced, on average, 3.5 fewer days of mouth sores (mucositis) than the group receiving fluoride treatments alone. The Caphosol® group reported nearly five fewer days of mucositis-related pain than the fluoride-only group. The amount of morphine required by patients to control the pain was significantly less in the Caphosol® group than in the fluoride-

only group (35.54 mg versus 122.78 mg) and some in the Caphosol® group required no morphine at all.

Caphosol® is an oral rinse with no known adverse side effects or drug interactions. The study authors acknowledge that the data is derived from a relatively small number of patients with various diseases, who were treated with different combinations of chemotherapy and radiation. They note, however, that the study results are similar to other prior studies of Caphosol®.

<sup>1</sup> Papas, A et al: A prospective, randomized trial for the prevention of mucositis in patients undergoing hematopoietic stem cell transplantation, *Bone Marrow Transplantation* (2003) 31, 705-712.

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## Publications available from BMT Infonet

### **Bone Marrow & Blood Stem Cell Transplants: A Guide for Patients** (also available in Spanish) (2006)

### **Autologous Stem Cell Transplants: A Handbook for Patients** (2008)

These guidebooks, often referred to as "the bible" by patients, walk the reader through a transplant, clearly explaining each step of the procedure. Included are chapters on choosing a transplant center, preparing for transplant, managing side effects, coping with emotional stress, pain management, nutrition, caregiving, pediatric transplants, and long-term survivorship issues.

Choose **Bone Marrow & Blood Stem Cell Transplants: A Guide for Patients** if you are considering an allogeneic transplant (a transplant using donor marrow, stem cells or cord blood). It also includes information on finding and being a donor. If you are considering an autologous transplant (a transplant using your own marrow or stem cells) choose **Autologous Stem Cell Transplants: A Handbook for Patients**. \$9.85 plus shipping.

### **Across the Chasm: A Caregiver's Story**

Many fine books have been written by transplant survivors, but **Across the Chasm** offers a unique glimpse of the transplant experience as seen through the eyes of a caregiver. The book chronicles a 27-year-old woman's day to day life as she struggled to care for her husband, raise a young child and maintain her sanity. With humor and candor, she offers a vivid picture of the emotions and challenges caregivers face. \$9.85 plus shipping

### **Mira's Month**

**Mira's Month** is a colorfully illustrated book designed for use with young children whose parent will undergo a transplant. It discusses the questions children have and the feelings they often experience during this stressful time. Written by a transplant patient, the book comforts children by assuring them that they are not alone, and offers tips to help them cope with their sadness. \$5.00 plus shipping.

### **Resource Directory for Transplant Patients**

In this guide you'll find nearly 100 organizations that provide information, emotional support and/or financial assistance to transplant patients. \$1.50

### **Finding the Money: A Guide to Paying Your Medical Bills**

This practical, easy-to-read guide provides tips on how to assess what your transplant and after care will cost, how to organize and pay your medical bills, and how to raise funds to pay for bills not covered by insurance. \$12.00 plus shipping.

### **Helpful Hints for Caregivers**

A free flyer with helpful tips for managing caregiver stress. No charge in quantities of 50 or less.

You can order these publications online at

[www.bmtinfonet.org/books.html](http://www.bmtinfonet.org/books.html)

or by phoning 888-597-7674.



# New Resources from the NMDP Office of Patient Advocacy

## Online Financial Tool

The NMDP facilitates more than 3,600 unrelated bone marrow and cord blood transplants (BMT) each year. While this life-saving treatment is often the only treatment option or cure for people suffering from chronic and/or fatal diseases, transplant is an expensive and complex procedure. Furthermore, patients aren't always aware of the additional expenses of BMT, such as relocation costs, co-payments, prescriptions, and childcare, until well into the transplant process. Often, patients and their families are left with the numerous additional costs long after the transplant.

To help patients plan for the additional expenses of BMT, the National Marrow Donor Program's (NMDP) Office of Patient Advocacy created an online financial tool, entitled *Planning for Additional Transplant Expenses*. This resource is free, confidential, and assists patients and their families by:

- Calculating a family's existing costs and income
- Identifying important costs the family may incur throughout the transplant process
- Helping promote financially-specific discussions with family, caregivers, transplant center staff and financial advisors
- Generating customized financial reports for the patient
- Linking patients directly with additional financial information and resources



The online financial tool can be found on the NMDP's Web site, at: [www.marrow.org/planahead](http://www.marrow.org/planahead)

## Talking Transplant: A New Online Resource for Healthcare Professionals

*Talking Transplant* is a new online resource for medical interpreters and other professionals who help transplant patients and families overcome language and cultural barriers. Ten lessons are currently available through *Talking Transplant*, including supporting glossaries, print materials and audio files. These resources are designed to meet the needs of medical interpreters and other professionals in the following ways:

- Increase their comfort and familiarity with the transplant process
- Build their capacity to meet the needs of transplant patients and families
- Clarify the important role they provide with facilitating access to care and information

*Talking Transplant* is also a valuable resource for anyone who wants to simply learn more about

the transplant process in easy-to-follow modules.

*Talking Transplant* is free, and is available on the NMDP's Web site, at:

<http://www.talkingtransplant.org/>

## Patient Survivorship Conferences: Webcasts Available Online

Living Now: A Survivors' Conference on Life after Transplant was held in San Francisco, Calif., and Philadelphia, Pa., in June 2007. The conference was designed for adult bone marrow or cord blood transplant survivors, caregivers, family members and health care professionals who were interested in learning the latest in post-transplant research and information.

Living Now drew almost 200 attendees. The conference proved to be a success, as nearly 90% of attendees ranked the presentations as very informative. Topic highlights include:

- Your Post-Transplant Roadmap
- For Better and for Worse: Survivorship and Quality of Life after Transplant
- Relationships and Intimacy after Transplant: For People with and without Partners
- Cancer and the Law

These Webcasts are free and are available online at: [www.marrow.org/PATIENT/Support\\_Resources/Living\\_Now\\_Recordings/index.html](http://www.marrow.org/PATIENT/Support_Resources/Living_Now_Recordings/index.html)



# Someone You Should Know....

## Frank Martinez

On a small laminated card in his pocket, Frank Martinez carries three quotes: Emily Dickinson on hope; Thomas Edison on success; and Maya Angelou who says that “people will forget what you say, they will forget what you do, but they never will forget how you make them feel.” Frank’s life embodies that.

***“Being a survivor shows people that I am living proof that all their hard work can pay off.”***

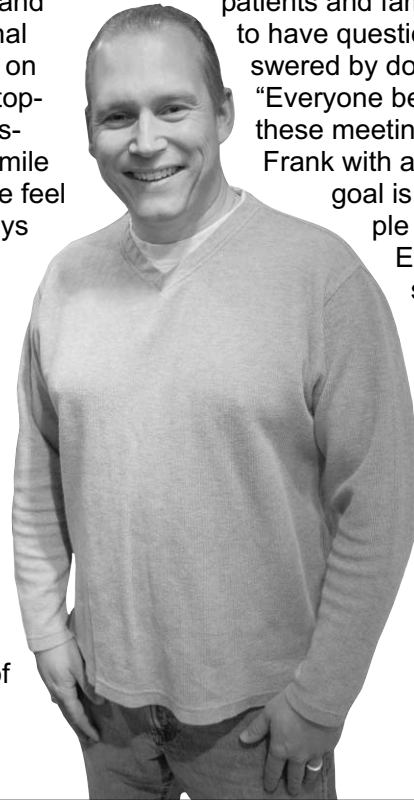
Transplanted in 1995 for acute myelogenous leukemia, Frank now lives life to the fullest. First it should be said that Frank has a light side. His carefree moments are spent with his wife and son indulging in his passion for old cars. The 1970 Cutlass, 1967 Corvette and 1969 Z28 are his hall-of-famers. The Martinez family enjoys car museums, car shows, car movies – just about anything related to cars capture their interest.

At work, Frank’s goal is to improve the quality of life for his customers. He not only finds mortgages for people of all income levels, but offers mortgage planning and educational seminars on financial topics. “A customer’s smile makes me feel good,” says Frank.

Frank is the first leukemia survivor to be president in the 60 year history of the Leukemia Research Foundation (LRF), based in the Chicago area. He takes his role as survivor and president seriously.

“Being a survivor shows people that I am living proof that all their hard work can pay off,” explains Frank.

He also founded and is head of A La Vida, the Hispanic chapter of the LRF. A La Vida means “To Life”. Through A La Vida, Frank hosts a Town Hall meeting where patients and families gather to have questions answered by doctors. “Everyone benefits from these meetings,” says Frank with a smile. “My goal is to get people involved. Everyone has something to add – we can all help each other.”



## Caring Connections – Your Chance to Give Back

If you went through your transplant thinking “how can I ever repay people for the kindness they’ve shown” then here’s your opportunity. BMT InfoNet’s *Caring Connections* program links patients who are about to go through transplant with survivors who can provide emotional support.

“The goal of the program is not to provide medical information, but comfort and encouragement,”

says Sue Stewart, executive director of BMT InfoNet. “There is nothing like hearing directly from someone who has ‘walked the walk’ and understands the fears and questions you have.”

Each year, nearly 500 people ask for peer support through the program. “We link not only patients about to go through transplant, but caregivers, donors and other family members whose lives are being

affected by the patient’s transplant.” Stewart explains.

Volunteers must be good listeners, says Stewart. “This is not a forum to share war stories. Our volunteers know how to listen to people, validate their concerns, and provide encouragement.”

Patients, caregivers and family members are matched with others who had a similar transplant

Continued on back page



# Celebrating Life 2009 Calendar

Are you looking for a wall calendar that speaks joy and hope? Then look no further.

BMT InfoNet is pleased to offer a full year of hope for 2009: a stunning calendar that celebrates the lives of twelve people who underwent a bone marrow, blood stem cell or cord blood transplant. Each month introduces you to a transplant survivor who is active and embraces life.

What a perfect gift for the holiday season and a great way to support the work of BMT InfoNet. At \$10 plus shipping, they make wonderful gifts for you, your family and friends. They are sure to inspire you throughout the new year.

To order copies, phone 888-597-7674 or visit our website [www.bmtinfonet.org/calendar2009](http://www.bmtinfonet.org/calendar2009)



## Thanks to our calendar sponsors:

- |   |   |
|---|---|
| Abbott  | Loyola University Health System                       |
| American Society for Blood and Marrow Transplantation             | Memorial Sloan-Kettering Cancer Center                |
| The Center for International Blood and Marrow Transplant Research | Texas Children's Cancer Center                        |
| Otsuka America Pharmaceuticals Inc                                | The University of Alabama at Birmingham               |
| Dana-Farber/Brigham and Woman's Cancer Center                     | The University of Chicago Medical Center              |
| Duke Children's Hospital & Health Center                          | University Hospitals/Ireland Cancer Center            |
| Emory Winship Cancer Institute                                    | University of Minnesota Children's Hospital, Fairview |



**Registrant:** \$75 (includes dinner on Saturday, breakfast on Sunday, and food/beverages at breaks)  Scholarship needed for survivor unable to afford fee

First Name: \_\_\_\_\_ Last Name: \_\_\_\_\_ Age: \_\_\_\_\_

Mailing Address: \_\_\_\_\_ Relationship to the survivor:

City: \_\_\_\_\_ State: \_\_\_\_\_ ZIP: \_\_\_\_\_  \$75 I am the survivor

Phone: \_\_\_\_\_ Work or Cell #: \_\_\_\_\_  \$75 Spouse/Partner of survivor

Email: \_\_\_\_\_  \$75 Parent

**Workshop Selections:** Enter 4 workshop codes that you would like to attend on Sunday (see below)  \$75 Sibling of survivor

\$75 Child of an adult survivor

\$75 Health Care Professional

\$75 Health Care Professional with CEUs

\$75 Other (specify) \_\_\_\_\_

**Selection #1:** \_\_\_\_\_ **Selection #2:** \_\_\_\_\_ **Selection #3:** \_\_\_\_\_ **Selection #4:** \_\_\_\_\_

**Workshop Selections:** Enter the workshop codes for each attendee

- |  |  |
|--|--|
| <b>A</b> Chemobrain! Is it real? - Adults                                      | <b>H</b> Chronic Graft-versus-Host Disease                                 |
| <b>B</b> Learning and Memory Problems in Children after Transplant - Pediatric | <b>I</b> Fertility Options after Transplant                                |
| <b>C</b> Caregiver Challenges - Adults   | <b>J</b> Hormone Replacement Therapy after Transplant: Is it right for me? |
| <b>D</b> Caregiver Challenges - Pediatric                                      | <b>K</b> Navigating the Insurance Maze                                     |
| <b>E</b> The Unique Needs of Young Adult Survivors                             | <b>L</b> Ask the Experts Panel - Adults                                    |
| <b>F</b> Female Sexuality Post-Transplant                                      | <b>M</b> Ask the Experts Panel - Pediatric                                 |
| <b>G</b> Male Sexuality Post-Transplant  |  |

**Other family members who will be attending with you:**  Scholarship needed for family member(s) unable to afford fee

Name # 1 First Name: \_\_\_\_\_ Last Name: \_\_\_\_\_ Age: \_\_\_\_\_

Same address as Registrant

Mailing Address: \_\_\_\_\_ Relationship to the survivor:

City: \_\_\_\_\_ State: \_\_\_\_\_ ZIP: \_\_\_\_\_  \$50 I am the survivor

Phone: \_\_\_\_\_ Work or Cell #: \_\_\_\_\_  \$50 Spouse/Partner of survivor

Email: \_\_\_\_\_  \$50 Parent

**Workshop Selections:** Enter 4 workshop codes that you would like to attend on Sunday (see above)  \$50 Sibling of survivor

\$50 Child of an adult survivor

\$75 Health Care Professional

\$75 Health Care Professional with CEUs

\$75 Other (specify) \_\_\_\_\_

**Selection #1:** \_\_\_\_\_ **Selection #2:** \_\_\_\_\_ **Selection #3:** \_\_\_\_\_ **Selection #4:** \_\_\_\_\_

Name # 2 First Name: \_\_\_\_\_ Last Name: \_\_\_\_\_ Age: \_\_\_\_\_

Same address as Registrant

Mailing Address: \_\_\_\_\_ Relationship to the survivor:

City: \_\_\_\_\_ State: \_\_\_\_\_ ZIP: \_\_\_\_\_  \$50 I am the survivor

Phone: \_\_\_\_\_ Work or Cell #: \_\_\_\_\_  \$50 Spouse/Partner of survivor

Email: \_\_\_\_\_  \$50 Parent

**Workshop Selections:** Enter 4 workshop codes that you would like to attend on Sunday (see above)  \$50 Sibling of survivor

\$50 Child of an adult survivor

\$75 Health Care Professional

\$75 Health Care Professional with CEUs

\$75 Other (specify) \_\_\_\_\_

**Selection #1:** \_\_\_\_\_ **Selection #2:** \_\_\_\_\_ **Selection #3:** \_\_\_\_\_ **Selection #4:** \_\_\_\_\_

**History:** Tell us about the survivor  Does not apply

Survivor's Name: \_\_\_\_\_ Year of most recent transplant: \_\_\_\_\_

Hospital where transplant performed: \_\_\_\_\_ Diagnosis: \_\_\_\_\_

Type of Transplant:  Autologous (used your own bone marrow or stem cells)  Related Donor transplant  Unrelated Donor transplant

**Payment:** Make checks payable to BMT InfoNet c/o CONDOR Registration Services

Check  VISA  MasterCard  Discover  American Express

**Total Amount Due:** \_\_\_\_\_

Credit Card/Check #: \_\_\_\_\_ Expiration Date: \_\_\_\_\_

Name (as it appears on card): \_\_\_\_\_ Verification Code: \_\_\_\_\_

Signature: \_\_\_\_\_ Billing ZIP: \_\_\_\_\_

Please let us know if you have special needs that we must make accommodations such as wheel chair accessibility, assistance for the blind or hearing impaired, etc.

**Special Needs & Dietary Restrictions:** \_\_\_\_\_

Send form and payment to: BMT InfoNet c/o CONDOR Registration Services · P.O. Box 3348 · Huntsville, AL 35810 · Phone: (256)852-4490 · Fax: (256)852-6838

Continued from page 3

experience. "In most cases we match people by disease, age and type of transplant," explains Stewart. "We can often match people by other criteria that are important to some patients such as gender, religious background, whether or not there were children in the household at time of transplant, etc."

BMT InfoNet currently has more

than 800 volunteers in the *Caring Connections* program, but there is a need for more.

"People usually want to speak with someone who has been through a transplant within the past few years, since treatments change so rapidly," says Stewart. "We have an ongoing need for people who have been transplanted with 'mini'

or reduced intensity transplants, people who were over 60 at the time of transplant, and people transplanted for rare diseases."

If you would like to volunteer with the *Caring Connections Program* complete the registration form online at [www.bmtinfonet.org/survivor.html](http://www.bmtinfonet.org/survivor.html) or phone 888-597-7674.

Issue #73

## Inside: Celebrating Life Survivorship Symposium

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