

# The Michael H. Flanagan Foundation

Volume Number 3

Spring 2005

## Our Mission

The mission of the Michael H. Flanagan Foundation is to comfort leukemia and bone marrow transplant patients and their families.

Through the Foundation, it is our goal to enhance the patients' quality of life.

*"Many persons have a wrong idea of what constitutes true happiness.*

*It is not attained through self gratification, but through fidelity to a worthy purpose."*

Helen Keller

So much to think about and reflect upon as I look back at all the **Michael H. Flanagan Foundation** has accomplished after another year. As I started to write this letter I thought of the John Mellencamp song "Everyone Needs A Hand to Hold On To". Then it struck me that we have been providing those "hands" for patients and their families to hold onto for the past four years. A simple statement, but one that has had a real impact. The Foundation has made those patients -battling the horrible disease of cancer and living through bone marrow transplants- a little less lonely. I am so proud of all that has been accomplished for others because of your tremendous support.

You should know...

...the foundation is sponsoring an education series at Tufts-NEMC for bone marrow transplant patients and their families that will be free, open to the New England community, and include top doctors, nurses, staff and caregivers covering a wide variety of topics. (Info inside)

...Over the course of this past year we were able to provide over 40 comfort bags, which have been upgraded to canvas tote bags with the name of the Foundation on them. This was done in order to make a sturdier bag and also to remind the patient of the foundation should any needs arise.

...Fifteen patient grants were funded, two additional dvd/ver tape players, an x-box system, continued expansion of the video/dvd library, and a blender for making the patients smoothies was requested and delivered.

Each hospital we work with, whether it is Tufts-NEMC, or the Lifespan family of Rhode Island Hospital and Miriam Hospital, has a wonderful group of people that are so grateful for all that we are able to do.

The funding for these items and our current capital project of the North 8 family room at Tufts-NEMC is possible thanks to you and the success of our Fall Benefit. Our third annual "Evening under the Stars" this past October was a tremendous success. I heard that there was a drop of rain here and there but must admit that I was so amazed at the incredible turnout, great music and food that I honestly didn't notice! Maybe the bits of mud here and there were a clue and I apologize for any ruined shoes. Nonetheless, we are so proud to announce that we raised over \$41,000. The Silent Auction gave way to amicable bidding over many unique items including jewelry donated by Diane Stratton, an original Altamira lamp, a Boys and their Bait package donated by Laura and Peter Ramsden, hand finished Adirondack chairs and a hand knit afghan, golf, golf, and more golf...Loon Mountain ski house, PC basketball gear, and much more. Once again, we would also like to extend our deep appreciation to Richard and Sandi Oster and Ed Arseneault for the amazing greenery and torches...it made the setting remarkable. Taste of Curiosity Catering Company of Barrington did another outstanding job with the evening's food and drinks...sushi bar, potato bar and martini bar and more, and our addition of a band this year was well received. The band, Power of Love, continued to play on after their time was over but refused to be paid. Rather they wished the money to be spent on a comfort bag. Power of Love was sensational; and will be back again this year.

Thanks to everyone who supports this special foundation. Together we have been so fortunate to have touched the lives of so many.

Take care,

Christine Griffin

*Save The date...  
for the 4th. Annual  
"Evening under the Stars"*

Saturday, October 1, 2005

Courage



Integrity



Faith

### Michael Flanagan and his Foundation

*Janice Maienza RN MSN Clinical Educator Tufts-New England Medical Center*

Michael came to our unit in May, 2001 and stayed with us until November. During this time, Michael had two stem cell transplants. What is a stem cell transplant? Hematopoietic stem cells are the very early cells that live in our bone marrow. These stem cells grow and divide, eventually becoming our blood and immune system. Michael got his new stem cells by having someone donate their bone marrow in one instance and their blood (peripheral stem cells) in another.

Receiving stem cells is like having a blood transfusion. It is a relatively simple procedure. It's what happens before and after that causes the complications. In order for Michael to accept his new marrow, he got very high doses of chemotherapy. And while he waited for his new marrow to engraft or take root in his own body, he had no immune system. During this time he was susceptible to infection and had to be protected in a safe room with special filters and rules for all who entered.

I am telling this because I would like you to understand the tremendous contributions this young man made to the nurses and entire health care team at Tufts-New England Medical Center. We learned so much from Michael. Imagine being a 23 years old, young and robust, confined to one room for 6 months. Every body fluid is measured and every symptom investigated. Privacy is respected but compromised.

After a while, Michael had enough. He taught us what was necessary and what was unnecessary, and yes, some things he could actually do himself. He wanted his private time and asked us to respect that. His friends visited and he tried hard to sustain these relationships. He played his guitar with his Dad and enjoyed his many CD's. His family brought him movies and magazines and provided comfort in every way. He talked to his family and told them what he wanted and how to live on if the transplants were unsuccessful. For 6 months, we learned from this wonderful family how to cope and grieve when losing your son, brother, uncle.

So now we have his Foundation and comfort bags that we give to all patients coming in for transplant or beginning chemotherapy for leukemia. These canvas bags are full of many thoughtful items - many of which are based on Michael's experience. Have you ever had a painful mouth? Michael did and now there is chapstick in the bag along with a soft toothbrush. Have you ever had a bad GI flu? Michael had this symptom for weeks and now there is soft toilet tissue and Kleenex in the bag. Have you ever just wanted to get away from it all? Michael did. He listened to his music. Now there is a CD player with inspiring CD's. There is a comforting eye pillow in every bag. There is an 800 minute phone card to call your friends and family. Michael's Foundation also trained 8 nurses to become Reiki practitioners. And there are videos. Michael has given us DVD players, monitors and hundreds of DVD movies, TV series (including Sex and the City) and books on tape.

Have you ever missed an important birthday or holiday due to illness? Michael did. Michael's Foundation just recently funded a

Hanukkah celebration for a young woman's little girl. His Foundation bought Hanukkah gifts for every day and our social worker help her Mom shop through the many catalogs brought in by friends and staff. It was this Mom's final celebration.

The mission of the Foundation is "to comfort bone marrow transplant patients and their families". Michael taught us and continues to teach us how.

### NEW PEOPLE:

We would like to take this opportunity to thank Judith Kahn, LICSW for her tremendous support and belief in Michael's foundation. Judith worked very closely with our family during Michael's hospitalization at Tufts New England Medical Center. Judith is now at Dana Farber Hospital. We will miss her and we wish her the very best in her new endeavors.

And what better time to welcome the new members of our Boston team. Out three new members include **Tim Cummings**, LICSW, Director of Social Services, **Nandini Narayanan**, LICSW, Hematology-Oncology and Bone Marrow Transplant Social Worker, and **Patricia Rowe**, Director of the Cam Neely House for Cancer Patients and their families. Their time, effort and contributions are invaluable.

### Introducing Dr. Hans Klingemann

Dr. Klingemann is a graduate of the University of Marburg Medical School in Germany. After his residency at the University of Würzburg-Germany, he was an oncology fellow at the Fred Hutchinson Cancer Research Center in Seattle. From 1987 to 1997, he served as attending physician in the Division of Hematology and was a member of the Leukemia/Bone Marrow Transplant Program of British Columbia-Vancouver, Canada. During that time he headed the Transplantation Biology Laboratory at the Terry Fox Laboratory.

Between July 1997 and June 2004, Dr. Klingemann was the Coleman Foundation Professor of Medicine and Director of the Section of Bone Marrow Transplant & Cell Therapy at Rush University Medical Center in Chicago. He was also the Medical Director of the Sramek Center for Cell Engineering at the same institution. Since July 2005 he is the Director of the Bone Marrow and Hematopoietic Cell Transplant Program at Tufts-New England Medical Center in Boston.

### PATIENT EDUCATION SERIES 2005

Tufts-New England Medical Center is offering a 15 lecture education series open to any person diagnosed with Leukemia, Lymphoma or Multiple Myeloma. The Michael H. Flanagan Foundation is proud to sponsor this program. The sessions are open to patients, loved ones and family members and they are free of charge. Amgen is kindly providing lunches at each session. The series is designed to offer vital information that will empower, help you cope and transform your experience through treatment and recovery. Our team at Tufts-New England Medical Center has worked tirelessly to offer this education series and we are privileged to have speakers who are not only experts but compassionate caregivers who are on the front line. *"see upcoming workshops on page 6"*



### TEAM IN TRAINING

On September 12, 2004 Elena Maltese-Blount completed her first Team in Training Triathlon. The proceeds of this event benefit leukemia/lymphoma research. Elena knew Michael through his sister Katie as they shared an apartment in graduate school. Elena now lives in New York City where she works on Broadway in the performing arts. Elena and so many others trained with her team and coach for months. The actual triathlon took place in Narragansett, Rhode Island and included swimming, biking and running. Michael's name was on the back of her shirt. She completed the race in 6 hours and she and her team raised \$75,000 for leukemia/lymphoma research.

Great effort Elena!!

\* To learn more about The Team In Training efforts contact [www.teamintraining.org](http://www.teamintraining.org)

### NEWS FROM RHODE ISLAND HOSPITAL SOCIAL WORK

by Diane Passantino, LICSW and Susan Garland, LICSW

Beginning last summer we were delighted to welcome the Michael Flanagan Foundation to Rhode Island Hospital. As Social Workers, we have a deep appreciation for the struggles and victories experienced by patients with leukemia.

We are humbled as we share in our patient's journey and marvel at their extraordinary resiliency and strength.

We are fortunate to have the opportunity to present newly diagnosed patients with the comfort bags. Our patients have been so appreciative and touched by this gesture of caring. Often patients will comment how connected they feel to Michael's legacy.

In addition, Michael's foundation have donated a DVD and X-box to the oncology unit. One patient in particular, who was admitted for a period of two months without resources to purchase entertainment, used these gifts almost daily.

Michael's foundation has assisted patients with emergency funds for critical needs such as transportation.

### COMFORT BAG

The MHFF signature Comfort Bag continues to make a difference. The bags are given to patients at Tuft's New England Medical Center in Boston as they prepare for bone marrow transplant. In addition we are now including patients who are newly diagnosed with leukemia and we have extended our reach to the LifeSpan Hospitals in Rhode Island. Most receive treatment at the Miriam or Rhode Island Hospitals. The patients and families frequently express their reaction to the gift and we have received many touching messages of gratitude. One letter came from a patient's daughter shortly after he died from leukemia. Her Dad was an accomplished musician and found joy and some peace using his CD walkman and listening to his favorite classical music.

### CLOSER TO HOME

In the Spring 2004 newsletter we were exploring the possibility of serving patients and families close to home. Presently the foundation is offering grants and Comfort Bags to patients and families at the Miriam and Rhode Island Hospital Cancer Centers. Our Life Span teams includes Kathy Higginbotham, LICSW and Margaret Smith LICSW from Miriam Hospital and Diane Passantino, LICSW and Susan Garland, LICSW from Rhode Island Hospital. These dedicated professionals have made out transition into Rhode Island a very smooth one.

We are grateful for their effort and their belief in our work.

For further information about

The Michael H. Flanagan Foundation please contact:

Christine Griffin, Director or Kathleen Flanagan, Assistant Director  
15 Rumslick Drive, Barrington, RI 02806  
[ChristineGriffin@cox.net](mailto:ChristineGriffin@cox.net)

## THE MHFF GIFT of COMFORT

**A CD walkman with recording CD's...**...a way to relax, listen to music, listen to books, block out the continuous sound of the HEPA filter and to close your eyes and meditate during difficult procedures and tests

**A phone card with 800 minutes...**...stays in touch with family and friends without the worry of outrageous hospital phone bills

**A Turtle-Fur fleece hat...**...stay warm, look adorable and let this specially designed hat wick the perspiration away from you when those high temperatures finally break

**A colorful eye pack...**...soothe your dry eyes by warming or cooling your eye pack and escape for a peaceful nap

**A journal...**...or maybe a sketch book, just a place to put your thoughts or maybe leave them there. A good way to communicate when you don't feel like talking...or maybe you are a poet or artist

**A funny read...**...nothing too heavy, just a few silly thoughts to help you cope on those frustrating days, laughing can be so therapeutic

**Personal hygiene items...**...and not just any items, each one has been tested and approved just for your comfort, all very soft, no alcohol or scents, and they feel sooooo good...moisturizer, lip balm, extra soft tissue, soft nail file, extra soft toothbrush, moisture rich soap, and lots of baby wipes...be comfortable

**Playing cards...**...help to pass the time and a good way to spend hours with friends when you don't feel like talking...on occasion there might be an exchange of money, but you did not hear that from us

**Your own little creature-friend...**...last but not least is a small, soft, travel-friendly creature just for you. Might sound silly but silly can be good. It can be comforting to know that this soft little lizard is very versatile...it can be held or squeezed, or it can just be there for a distraction... but it is always there with you, a room-mate. And your little companion is small enough to travel when you have to leave your room & venture to unknown places in the hospital.



This gift of approximately 17 items is presented to each new admission on the Bone Marrow Transplant Unit and Leukemia induction patients. The gift is in keeping with the mission of the foundation. It is only one piece of our work, and we feel it is an important one.

# Thank You.

Thank you for your generous support. This list includes gifts received and processed between April 1, 2004 and April 1, 2005. Gifts received after will be included in next year's listing. Great care has been taken to ensure accuracy of all names. If an error has been made, please let us know by calling 401.267.7763 or email [ChristineGriffin@cox.net](mailto:ChristineGriffin@cox.net) and accept our sincere apologies.

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# Thank You.

## Continued

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### My Teachers

Walking with you on this  
journey, You teach me so much.  
In every moment you impart  
your wisdom.

I have learned from you that...

It is through fear that courage is  
born, it through despair that  
peace finds its wings, it is in  
the midst of hopelessness that  
the tiniest flicker of hope shines  
brightest.

It is in vulnerability that your  
heart opens to unconditional  
friendships and love, it is in the  
face of uncertainty that you are  
moved to embrace faith.

It is through tears that smiles  
sometimes taste the sweetest, it  
is also through loss that we may  
gain liberation and wholeness.

It is through surrender that you  
trust that the journey has its  
hidden miracles, its gifts.

It is through our shared journey  
that we receive each other's love  
with humility, with grace.

I thank you for being my  
teachers every day.

~ Nandini Narayanan, LICSW,  
oncology social worker TUFTS-NEMC

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It is not how much we do, but how much love  
we put in the doing.

It is not how much we give, but how much love  
we put in the giving.

--Mother Teresa

### Fall Benefit Auction Item Contributors

Thank you to all who contributed ...a success thanks to your generosity.

Altamira Lighting	Chris and Gwyn Veglas
David and Jennifer Boland	Jim Veglas
Rhode Island Philharmonic	TPC Boston
New Leaf Salon	Fall River Country Club
Providence College	Sakonnet Golf Club
Joe Brum	Rhode Island Country Club
Mike and Kathy Flanagan	Carnegie Abbey
Taglia	Steve Healy
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Liquors	Jill DiPippo
Katherine Healy	Mystic Seaport
Cowan Plastics	New England Aquarium
Gina Perry and Nathan Duarte	Museum of Science
Diane Stratton	Foxwoods Grand Pequot Tower
Caroline Ballou	Providence Children's Museum
Laura and Peter Ramsden, Foley Fish	Roger Williams Zoo
Steve Flanagan	Newport Mansions
Taste of Curiosity	Taste of Curiosity
Christine and Steve Griffin	Power of Love
Cappuccino Bakery	

# "I'M TOO YOUNG FOR THIS"

## YOUNG ADULTS WITH CANCER SYMPOSIUM

SATURDAY APRIL 9, 2005

authored by Tim Cummings, LICSW  
Director of Social services Tufts-NEMC

### MUSEUM OF SCIENCE BOSTON

On Saturday April 9th close to 100 young adults attended a symposium at the Museum of Science in Boston. The symposium, which is the second of its kind in Boston in the last 3 years, focused on issues impacting young adults who have been touched by cancer in some way. Most who attended were cancer survivors, however, there were many who were young adult caregivers, family members, friends or partners of people diagnosed with cancer. The symposium was planned and organized by individuals from various institutions and organizations within the greater Boston area and was offered free of charge. Those involved in planning and supporting the symposium included: Tufts-New England Medical Center, The Wellness Community of Greater Boston, Dana-Farber Cancer Institute, The Lymphoma & Leukemia Society, The American Cancer Society, Massachusetts General Hospital, The SAMFund for Young Adult Survivors of Cancer, The Young Survivors Coalition and The New England Coalition for Cancer Survivorship.

The full day symposium included two keynote speakers, both of whom are young adult cancer survivors. Gerylun Lucas, author of "Why I Wore Lipstick to My Mastectomy" spoke in the morning and gave a touching and often humorous account of her cancer journey and what it was like for her to be diagnosed with breast cancer in her 20's. Matthew Zachary, who was diagnosed with brain cancer in his early 20's, and who is now a songwriter, pianist and recording artist, spoke about his experiences with cancer and of how it's changed his life. He also entertained the symposium participants

with a number of his original compositions.

There were ten workshops offered including: Couples and Cancer, Being Single and Having Cancer, Issues in the Workplace, Fertility and, Young Men and Cancer among others. Educational and support information was available as well as the chance to meet with, and get information from, representatives from the various institutions and organizations who were involved. Doug Ullman from the Lance Armstrong Foundation was in attendance, as was a film crew from NBC's Dateline program, which may include parts of the Becoming Your Own Best Advocate workshop in a segment that they are doing on one of the attendees, Erin Zammert. Erin, an associate editor at Glamour Magazine, was diagnosed with cancer at 23 and has written a book, *My (So Called) Normal Life*, about her experiences.

The initial feedback from the attendees was very positive with numerous comments about the importance of offering an opportunity for people with cancer, in this age group and who are often at a crossroads in their lives regardless of having a diagnosis of cancer, to come together to share their thoughts, feelings and triumphs. There is a need to know that you are not alone in your cancer journey and that there is strength and hope in coming together with others who are on the same path. The hope is to make this symposium an annual event, which will grow, drawing from the entire New England area.



Tufts-New England Medical Center

The Michael H. Flanagan Foundation  
is proud to sponsor

### PATIENT EDUCATION SERIES 2005

An educational series open to any person diagnosed with Leukemia, Lymphoma or Multiple Myeloma. The series offers 15 lectures with vital information that will empower, help you cope and transform your experience through treatment and recovery.

The sessions are open to patients, loved ones and family members. Referrals will be served.  
The series is free of charge; a RSVP is requested.

Please Join Us!

Time: 12-1:30 PM

Location: Atrium 8002 Conference Room  
Tufts-New England Medical Center

For more information and to RSVP please call  
Nandini Narayanan, LICSW, Hematology/Oncology  
& Bone Marrow Transplant Social Worker:  
(617)36-9222 or  
via email [nnarayanan@tufts-nemc.org](mailto:nnarayanan@tufts-nemc.org)

### 2005 PATIENT EDUCATION SERIES TOPICS & DATES

**March 24** *Understanding Hematological Cancers*

Guest Speaker:  
Hans Klingemann, M.D., Ph.D.,  
Director, Bone Marrow and  
Hematopoietic Cell Transplantation

**March 31** *Under the Microscope: The Pathologist's Role and Perspective*

Guest Speaker:  
Stephen P. Naveh, M.D., Ph.D.,  
Pathologist-in-Chief

**\* April 7** *Surviving and Thriving Through Treatment: Managing the Side-effects of Treatment and Transplant*

Guest Speakers:  
Nancy Cook-Lynn, R.N., N.P.  
Leah Wilson, R.N., N.P.

**April 14** *Finding Hope and Meaning: The Emotional Journey*

Guest Speaker:  
Tim Cummings, LICSW, Director,  
Psychosocial Services,  
Cancer Center, Tufts-NEMC

**April 21** *The Mind-Body Connection: Risk, Guided Imagery & Relaxation Techniques*

Guest Speakers:  
Janice Mastura, R.N.,  
Clinical Nurse Educator &  
Nandini Narayanan, LICSW

**April 28** *Learn and Be Prepared for Radiation Therapy*

Guest Speaker:  
Julie Mignone, M.D.  
Radiation Oncology

**May 5** *Why Transplant? Enhancing Your Knowledge of Bone Marrow Transplant*

Guest Speaker:  
Kelle Sprague, M.D.,  
Asst. Director, Bone Marrow Transplant,  
Asst. Prof. of Medicine, Tufts University

**May 12** *What is Reduced Intensity Treatment?*

Guest Speaker:  
Geoffrey Chan, M.D., Director,  
Bone Marrow Transplant Registry,  
Asst. Prof. of Medicine, Tufts University

**May 19** *Understanding the Many Types of Lymphoma*

Guest Speaker:  
Francis M. Foss, M.D.,  
Asst. Prof. of Medicine, Tufts University,  
Director of Lymphoma,  
Director, Pathophysiology & Experimental  
Therapeutics

**May 26** *Advances in Power: Knowledge and Research in Hematological Cancers*

Guest Speaker:  
Andrew Khan, M.D.,  
Asst. Director Bone Marrow Transplant,  
Asst. Prof. of Medicine, Tufts University

**June 2** *The Patients' Journey: Walking in Your Shoes*

Paul Patients

**\* June 9** *The Family Caregivers Journey*

Paul Campaigne

**June 16** *Community Resources: Leukemia & Lymphoma Society, Wellness Community and American Cancer Society*

Guest Speakers:  
Leah Sherman, Patient Servs. Mgr. LLSL,  
Harris Sherman, Psy.D.,  
Program Director, Wellness Community,  
ACS Representative

**June 23** *The Nitty-Gritty of Coordinating a Bone Marrow Transplant (BMT)*

Guest Speakers:  
Dah Black, R.N., B.S.N., O.C.N., IBMT  
Coordinator & Debra Hase, IBMT  
Adm. Coordinator

**June 30** *Spiritual Restoration: Gaining Strength and Healing from Inside*

Guest Speaker:  
Mary Fitzgerald, Chaplain, Tufts-NEMC

\* Please Note:  
Meeting room change from Atrium 8002 to Atrium 7002