THE
Michael H. Flanagan
FOUNDATION
146 COUNTY ROAD, BARRINGTON, RHODE ISLAND 02806

SAVE THE DATE IN 2008!

Saturday September 27th

Mount Hope Farm, Bristol, Rhode Island

A Casual Night From Sunset to Starlight
The Michael H. Flanagan Foundation's 6th Fall Benefit

Details to follow…

For further information about The Michael H. Flanagan Foundation please contact: www.mikesfoundation.org or write to:
The Michael H. Flanagan Foundation
146 County Road, Barrington RI 02806

NEWSLETTER DESIGN BY CARRIE SIEGEL, WWW.CARRIESIEGEL.COM

COURAGE INTEGRITY FAITH

THE
Michael H. Flanagan
FOUNDATION

SPRING 2008 VOLUME NUMBER 6

IMAGINE being the first one in your family to be attending college and soon after you are diagnosed with leukemia. When every penny counts how do you prioritize .....dreams or health? Imagine being married with a six year old daughter and watching your wife's health fail so much with her diagnosis that you need to become her caregiver. Your extended family lives in Ireland and you cannot afford after school care so that you can work to pay the bills.

For seven years a base of individuals, friends and family have supported The Michael H. Flanagan Foundation so that we can help people such as these. It is our mission to provide comfort to leukemia and bone marrow transplant patients and their families. Although based in the New England area we have reached out as far as Texas and Ohio. The Michael H. Flanagan Foundation's low overhead, quick turnaround, lack of "red tape" and attention to needs, allow patients with leukemia and their families to receive support services rapidly and in a caring, personal manner. We are proudest of our ability to receive donations on a Friday and directly benefit patients on Monday. This year we funded 30 financial grants, up from 17 last year and distributed over 60 Comfort Bags.

The Foundation instituted three new offerings this year. One being a Hospitality program in the Oncology Clinic Waiting Rooms at Tufts Medical Center. Two coffee stations were provided by the Foundation so that patients there for hours upon hours can have a complimentary cup of coffee or tea while waiting. The oncology clinic manager, Kathy DelGrosso, indicated that over 2, 831 patients have been seen since October and annually they average about 9,000. Think of all the people whose difficult day has been made a bit brighter by that small gesture. Tufts Medical Center embraced and recently decided to continue this worthwhile project. The second new offering is the "Jacki ", an alternative to the hospital Johnny . The "Jacki " is a comfortable shirt jacket made for patients to wear with ease while going through chemo. It offers a bit of dignity to those who are in hospital beds all day with lines for IV's. See the article inside for a full explanation. The Foundation also provided Miriam Hospital in Providence, RI with funds to purchase and install four computers in their patient waiting area and education rooms. The response from patients and families about the availability of this resource has been extremely positive. See article inside for this as well.

Our helping of more and more individuals and families means that leukemia is still very present. The doctors, nurses and social workers we team up with at each hospital are so thankful that we are a readily available resource to their patients. Those who have been touched by the Foundation are grateful for your support and unwavering dedication to provide some measure of comfort to their difficult diagnosis. I thank each one of you who has contributed in any way to the continuing success of our Foundation.

We look forward to seeing you all on **Saturday, September 27th** at our **Fall Benefit** to thank you in person for all that you do to keep our work moving forward. Have a safe and happy spring.

Warmest Regards, Christine

OUR MISSION

The mission of the Michael H. Flanagan Foundation is to comfort bone marrow transplant patients and their families. Through the Foundation, it is our goal to enhance the patients' quality of life.

The Michael H. Flanagan Foundation is a 501 c (3) charitable organization.

COMPUTERS AT MIRIAM HOSPITAL

The computers are currently being used in the patient waiting area,as well as in the education room by our teaching nurses and pts., and in our phone triage office for our nurse practioners. The response from pts. and families about the availability of this resource has been extremely positive. Pts/families have been utilizing the computers as a education tool regularly. They are looking up more info about their diagnosis as well as support programs that are online. This has made time in the waiting area more productive as they wait for treatment. This is also happening in the teaching/education room. we are able to access up to date info while we are teaching pts./families about chemotherapy. The computers have been a great addition for our patients.

IN MEMORY OF HELEN V. MURPHY

Thank you to the following individuals for their thoughtful donations, inspired by Helen's husband John who was so touched by the Comfort Bag she received while at Rhode Island Hospital.

Lora Hendrickson
Donna Treworgy
Bruce Campbell
Sunetra Rojanarungtawee
Lorraine Williams
Robert and Shirley Straight
Janet & Frederick Demagistris
David & Linda Allen
David & Meg Carroll
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Marie O. Broadfoot
Paul O'Connor
Rosemary McBride
Patsy A. Cunningham
Normand & Maria Bergeron
Douglas H. Smith
Brenda & Newton Schiebel
Scott & Bonnie Dittrich
Richard & Susan Desilets
Judith & Raymond Maccarone, Jr.
Maureen Depot
Joyce & Al Kratt
Mary Hames
Denis & Linda Costellese

IN MEMORY OF HEATHER CARRIE CARBONE BRASSELL

Remo and Maureen Guarnieri
Her Friends at Franklin Medical Center Medical Records
Brad and Lisa Tatreau
Sullivan Electric & Pump, Inc.
Nancy Kingsley
Frank and Suzanne Moroz
Ken Russell
Linda Russell
Jason Vivier
Jen Vivier
Scott Russell
Community YMCA in Greenfield Board of Directors, Executive Director and Staff
Jean McNally
Nancy and Leslie Lapoint
Rosalie A. Pratt
Marion and Walter Boyd
Medfield Public Library
Maryann Silva
Samuel Williams
Betty Miles
Walker and Betty Miles
Kristen Miles Allen
Stephen Miles
Julie-Anne Miles
Eleanor Campbell
Heather Campbell
Catherine and Daniel Brassell
Jim Whalen
Maura McNicholas
Cynthia Page
Health Information Management Dept.
Margo Frobel; Caritas Norwood Hospital
Helen Geirin
Marilyn Moroz
Arvid E. Opry
Alex and Mary Philippone
David and Sally Ahearn
Howard and Rosemary Natenshon
Ann Larsen

HEATHER

During Michael's stay on the BMT Unit at Tufts Medical Center, he developed a friendship with a lovely young woman. Her name was Heather and she was admitted to the unit for transplant during the summer of 2001. She and Michael were the only two patients in their 20's and they quickly developed a friendship via telephones. They developed a unique bond as each knew what the other was experiencing and they could share the frustrations of being 23 and confined to one room. Because of face masks and isolation, Michael and Heather never really saw one another, however, that didn't seem to matter. They exchanged notes and gifts and poems and music. Before long Heather was discharged and she made sure that Michael would have her large corner room on the unit.

Heather was married the following spring and in lieu of favors, she and her husband made a donation to Michael's foundation. During her five years after transplant, Heather traveled the world with her husband, but she struggled with the side effects of graft vs. host disease. Last March Heather's family called with the news that she died from complications. Again, Heather and her family asked that all memorial donations be made to Michael's foundation. Heather was like a twinkling star with her enthusiasm and positive energy. We will always be grateful for her friendship with Michael.

THE NEELY HOUSE 10TH ANNIVERSARY

In October of 2007 the **Cam Neely Foundation for Cancer Care** commemorated the 10th anniversary of The Neely House. As they wrote in their Homefront News publication, "The Neely House is the only in-hospital temporary home and support network in New England for cancer patients and their families." During these ten years, the Neely House has welcomed more than 4,000 families. Mike and Kathy Flanagan lived at the Neely House for the 6 months that Michael was hospitalized and it did become a home away from home. The generosity of Cam and Scott Neely and their family served as an inspiration and Michael's Foundation supports and complements their hard work. Kathy and Mike were honored to attend the evening event that commemorated the 10th anniversary.

Each November, the Neely Foundation hosts a major fundraiser in Boston. This year, Executive Director Scott Neely asked Kathy and Mike if they would participate in a video to be shown at the benefit. A talented and dedicated crew came to their home in Swansea and taped some of their reflections and comments about their stay in Boston. Several families participated in the video and the end product provided a glimpse into the impact of the Neely House on the families and patients who live there. It is a gift that makes all the difference.

Since opening the Neely House, the Cam Neely Foundation for Cancer Care also developed a Stem Cell Transfusion Center at Tufts Medical Center. Their current projects include The Michael Neely Center for Brain Tumor Care and the construction of the Pediatric Bone Marrow Transplant Unit in the Floating Hospital for Children.

"FLANAJAM 2"

THE SWANSEA OPEN

On Saturday , October 27, 2008, "Friends of Mike" sponsored their first charity golf tournament. The Friends of Mike is a group of classmates from the Case High School class of 1996 and Tyler Borges is their fearless leader. The event took place on the championship course at Swansea Country Club and 18 foursomes participated.

The weather was stormy in surrounding communities, but the rain held off until all players finished their round and were comfortable in the clubhouse. At the end of play, all enjoyed lunch and a very successful raffle. The generous donations by businesses and individuals added to the fun of the day.

The tournament raised more than $4,000 for the Michael H. Flanagan Scholarship. Thank you to all who weathered the wet and soggy afternoon. Special thanks to Tyler and Jessica Borges and the hardworking committee who pulled it all together.☆

A Journey to a NEW LIFE

The following piece is an interview conducted by Susan Garland, LICSW, a clinical social worker on the oncology department at Rhode Island Hospital. At one of our Foundation meetings, Susan offered to create this piece to show one aspect of how the Foundation touches the lives of patients diagnosed with leukemia. This inspiring patient, Pat Lucy, volunteered to share her story alongside her daughter's journal entries.

On February 6, 2006, Pat Lucy attended her first appointment at the Cancer Center at Rhode Island Hospital. It was at this time that she learned from her oncologist, Dr. Butera she had been diagnosed with Acute Myeloid Leukemia (AML). Despite feeling fatigued in the proceeding weeks, this news was nonetheless unexpected and surprising. Together with her family, Pat began her journey through diagnosis, treatment and ultimately a bone marrow transplant. Reflecting back almost 1 _ years, Pat shared her thoughts/memories of this time with me.

In early February 2006, Pat was admitted to RIH for her induction chemotherapy. She would spend the next 5 weeks at RIH. Within a couple of days, Pat received a comfort bag from the Flanagan Foundation that gave Pat much respite and pleasure during a difficult time. Pat's daughter Kelly visited her mother daily in the hospital and began to chronicle Pat's progress in the journal that came with the comfort bag. Pat has generously shared some of these entries with me to pass on to all who have made the generosity of the Michael H. Flanagan Foundation possible.

SUSAN: What was it like hearing from the doctor that the diagnosis was acute leukemia?

PAT: My first thought was did I hear him right – leukemia? My husband was with me – it was unsettling. It was overwhelming. I kept thinking one step at a time. I didn't have a lot of time to think – I did think how did I get leukemia? My husband asked Dr. Butera. "Where did it come from?" Dr. Butera said, "We all would be millionaires it we knew – only God knows". I still get chills when I think of his answer.

THURSDAY, FEB 9TH Pat's daughter Kelly writes in the journal: "Dr. Butera and Dr. Zakai performed Mom's biopsy in her room. She had little to no discomfort in the procedure and said both Dr's were wonderful throughout. She had quite a few "visitors" throughout the day—the nurse who gave her information on the clinical trial, new members of Dr. Butera's team (interns) and Susan, an oncology social worker. Mom was given a bag full of goodies from a local leukemia foundation named after a 19 year old young man who battled leukemia. These "little" things mean so much and do so much to brighten our spirits!"

"Mom slept a bit finally and ate a great dinner. After a long day of visitors, I knew she was tired and needed a good night's sleep. We ended our day around 7:30 pm with many expectations for another great day tomorrow."

SUSAN: How did you cope with the difficult chemotherapy treatment course?

PAT: I felt comforted by all the nurses and their care. I kept thinking I feel like this now, but it will pass – it is something I just have to get through. After treatment I did feel nauseous and discouraged.

THURSDAY, FEBRUARY 16TH Kelly writes: "Mom had a tough night last night. She was sick pretty much into the morning and wasn't feeling much better when her Dr. team came on early in the am. Dr Butera immediately advised his nurse team to administer a new nausea medicine, Zofran. – When I arrived @ 11:00 am, Mom was just going to sleep. They brought her in another pint of blood and administered more Zofran. Mom slept for about 1 hour and 45 minutes. When she woke, she was feeling better and had some energy. I gave her a mini pedicure & asked if she was ready to walk for a while. She was ready! Together we cruised the halls and walked around both nurses' stations. We sat for a while in the small waiting area where it was nice & cool.

SUSAN: How did you manage your long admission to RIH? (Pat remained admitted to RIH from 2/6 – 3/13).

PAT: This was troubling – I tried to get through it the best I could – a lot of thoughts went through my mind. I felt claustrophobic, it helped to get out of the room, walking and talking with visitors and staff. My doctors were kind and gentle to me. I enjoyed the art cart when the woman brought it around – it was uplifting. The staff felt like family to me and I felt like family to the other patients. We talked about so many things- not just the cancer. We laughed - I would look forward to seeing my new friends when I walked in the hallway.

SUSAN: What was your reaction to receiving the comfort bag?

PAT: I was in awe – wow – I was thinking – this is all for me? Everything was so helpful and useful, especially the CD player – I listened to Bon Jovi!!

MONDAY, FEB. 20TH Kelly writes: "President's Day! A holiday so there was not much activity today within the hospital. Mom was feeling a bit tired and her mouth was extremely sore today. She had some trouble trying to eat so they gave her just some tuna salad on wheat bread. She was able to pick off baby pieces and swallow it. She was advised to try and drink at least 3 shakes a day to supplement her diet - - as long as we find some chocolate ones, we'll be good to go!

Mom & I had a great day talking about the old days and our future days! She's rearranging her house in her mind as she has so much time to think and is looking forward to doing projects she hasn't done in quite a few years!

After receiving some platelets, Mom felt a bit better. There's so much running through her mind right now – she's got a lot to do when she's out of here! Goodnight Grammy!!"

MONDAY, MARCH 13 Kelly writes: "Today's the day! I told Mom to tell Dr. Butera that if he has anything but good news not to come into her room. Luckily he has a sense of humor!

We waited patiently for Dr. Butera to arrive. Just prior to noon, Dr. Butera came in to say that he was contacting the pathologist to get the tests read and that he expected to have the results within 2 hours. More waiting...

Just about 1:30pm Dr. Butera came into Mom's room. He was smiling but saying nothing... Finally, Dr. Butera said he had some good news....

Mom was in Remission!!!

We never wanted to hear these four words as much as I did today! We all cried – tears of joy and our doctor couldn't stop smiling.

Mom sobbed – as she thanked Dr. Butera for everything he had done. He in turn, commended her for the job she did over the past 5 weeks. It was such a great moment!

After all the paperwork and red tape had been completed, we drove away from the hospital just about 4:00pm...."

Pawcatuck here we come.....

SUSAN: What advice would you give patients beginning their journey through treatment?

PAT: I would advise patients to try and be patient – to listen and learn about the disease and treatment. Try to be understanding especially of the doctors – they are here for our benefit. If something is bothering you let someone know. Believe when the doctors tell one step at a time – try not to rush ahead.

SUSAN: How have you changed because of all you have undergone since February 2006?

PAT: I have learned to put myself first now – I am more assertive and take care of myself. I speak up for myself and have more confidence. I feel so much comfort in my life now...what would have been easy to be down everyday never knowing what would come next, my spirit was always positive through the love of my family- my husband Dick, my children Kelly, Eric and Paul, and Peg, my guardian angel- I love you all. You really gave me so much to live for.

Following Pat's first admission to RIH in 2006, Pat underwent additional chemotherapy treatment before undergoing an autologous bone marrow transplant at Roger Williams Hospital. This means that Pat received her own bone marrow/stem cells back. Pat's leukemia remains in remission and Pat returns to the RIH Cancer Center on a regular basis for follow up visits with her doctors. Pat and her husband continue to live with her husband in Pawcatuck, Ct.

Thank you Pat and Kelly for sharing with us your thoughts and experiences following your initial diagnosis and treatment. ☆

What is a JACKI®?

The Jacki® is a jacket with special features that makes the wearer more comfortable through any phase of Leukemia Treatment and Recovery. It is very warm, comfortable and has pockets for holding the drains. It also has Velcro for radiation and exams and no metal fasteners for testing. The Jacki® should allow you to dress at home and stay warm all day without having to change at the doctor's office for tests, exams, (except X-rays). The Jacki® minimizes the hours spent in the standard hospital garment sometimes referred to as a "Johnny". It provides a patient and hospital friendly incognito style that restores dignity and lets you feel more like a person than a patient. Additionally, this unique jacket is intended for home recovery and allows you to perform your daily functions while feeling and looking more like yourself.

SOME OF THE SPECIAL COMFORT FEATURES INCLUDE:

- Soft materials
- Available in different colors and fabrics
- Easy opening Velcro buttons
- Cozy and warm
- Stylish
- Provides step in entrance when pulling over the head is not an option
- Allows you to dress yourself one-handed
- Sleeves provide both opening & closure over intravenous lines
- Velcro fasteners allow easy arm access for blood pressure or taking blood samples
- Helps your sense of well-being
- Enhances morale and self confidence

One of the nurse managers at Tufts Medical Center requested that we pilot these to see how patients would use them since they were originally designed for Breast Cancer patients. One of our thank you notes reads, "Thank you for the Jacki all star shirt. I used it last time I had chemo. I will take it every time with me as I use it as a night jacket. It is so warm and cuddly. Thank you again....". Founder of the Jacki, Cathy McGrath worked with us to make a male/unisex version as well, calling it the All-Star shirt. It looks like a baseball jersey, ready to be decorated with patches from a favorite team if they'd like. These have been distributed based on need and under the discretion of nurses and social workers. The patients who receive them can't believe they can keep them!☆

ABOUT CORPORATE MATCHING

Corporate matching can make your gift go twice as far and is an easy way for people to increase the impact of their personal contributions to The Michael H. Flanagan Foundation. Check with your company about its matching gift policy. Many employers will provide a form for you to complete and send to us.

THE MICHAEL H. FLANAGAN FOUNDATION
would like to acknowledge the following hospitals and individuals who contribute to the success of our mission.

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Larisa Patacchiola, LICSW,OSW-C
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Dan MacLellan, BSN, RN
Assistant Nurse Manager
Bone Marrow Transplant Unit

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Oncology Clinical Social Worker

Diane Passantino, LICSW
Oncology Clinical Social Worker

Marita Headley, BSN,RN
Clinical Manager of Oncology Unit

THE MIRIAM HOSPITAL

Kathy Higginbotham, MSW, LICSW
Oncology Clinical Social Worker

Margaret Smith, MSW, LICSW
Oncology Clinical Social Worker

Karen Weavill, Annual Giving Officer
The Miriam Hospital Foundation

THANK YOU

Thank you for your generous support in this year's Campaign For Comfort. We raised over $20,000! This list includes gifts received and processed between April 1, 2007 and April 1, 2008. 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 401.247.7763 or email www.mikesfoundation.org and accept our sincere apologies.

Susan & Christopher Abadi
Antone Aguiar Jr.
Harvey & Maureen Anderson*
In memory of Shawn Luvendan
Karen & Steven Angelone
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Cynthia & Frank Sailes*
Robert & Beverly Trenholm*
** in memory of Don Dettlinger, Sr.*