



**INSIDE
THIS ISSUE**

**Families Funding
Research**
Page 2

**Greenwich Gala
continued**
Page 3

Chicago Race
Pages 4

Atlanta Race
Pages 5

Annual Appeal
Page 6-7

Program Grant
Pages 8

Ask the Expert
Page 9

Medical Corner
Page 10

You Need to Know
Page 11

MYELOMA FOCUS

Newsletter of the

MMRF

Raising Over \$1 Million for the Fourth Consecutive Year

The seventh annual MMRF Friends for Life Fall Gala was held on Saturday, October 25th at the Hyatt Regency in Greenwich, CT. The event was an enormous success raising over \$1 million for the fourth consecutive year.

Sharon Osbourne, a cancer survivor and talk-show host, was honored at the event with the MMRF Spirit of Hope Award. She and her husband, Ozzy Osbourne, were joined by the Gala Corporate Chairman, Dave Burwick, Chief Marketing Officer at Pepsi-Cola North America, and Deborah Norville, Emmy-winning host of Inside Edition and the event's Master of Ceremonies. Over 750 people attended the black tie event, which has raised over \$6 million for myeloma research since 1997, our first event.



L-R: Sharon Osbourne (MMRF Spirit of Hope Award) and Deborah Norville, who served as Master of Ceremonies for the 5th year

Dave Burwick, who along with his Pepsi executive leadership team, helped secure nearly \$500,000 in support for the event, talked about the "magic" that has been woven by MMRF co-founders, Kathy Giusti and Karen Andrews. Dave spoke of how the MMRF has turned "wishing and wanting...into action and resolution" and how the "work of the MMRF has created magical results that have put us in a much better place than we were five years ago."



(L-R) Dave Burwick, Karen Andrews, Spirit of Hope Award recipient Sharon Osbourne, Ozzy Osbourne, and Kathy Giusti at the "Friends for Life Fall Gala"

Welcome Letter

Families Funding Research

Dear Friends,

Each of you is a critical player in the fight to cure multiple myeloma. As patients and families, we know that you battle everyday with the reality of disease, and that you understand, more than anyone, the importance of finding a cure. For this reason, your direct support of myeloma research is absolutely essential. You are proven fighters in your daily battles, and now we are asking you to fight with us in ours, by directly supporting the search for a cure.

Incredible progress has been made in the past few years as a result of research and investment into new drug therapies to fight multiple myeloma. Validation of our efforts has come with the success of recent therapies like Velcade. But we all know that there is more to be done and that a cure has still not been found. The MMRF is committed to ensuring that the pace of research and progress continues, and we can't do it without your help.

The National Cancer Institute funding is expected to remain flat in 2004 so now more than ever your contributions are critical.

We know that many of you rely on the MMRF for the information and services we provide. Despite this fact, last year only 5% of you supported our appeal. Help us double this percentage this year with your contribution today. When you contribute to the MMRF, you will know that every dollar you give is spent to directly support the highest quality of research.

Together, we will continue to make a difference.



Herb and Barbara Goodfriend. The MMRF thanks you!

Barbara Goodfriend was diagnosed with multiple myeloma 5½ years ago and since then has decided that she has a lot to be thankful for. Her treatment regimen has been continuous and changing and she has been lucky, she says, that “medical science has always been one step ahead of me.” Barbara knows that this is largely because organizations like the MMRF have committed themselves to making progress towards treating and curing multiple myeloma, and now she and her husband, Herb, want to show their gratitude.

“There is nothing more important to me and my family than keeping me going. We are very fortunate for all the progress that has been made in research, and we know that there is still more to do.” That's why the Goodfrends recently donated \$100,000 to the MMRF, funding a Senior Grant Award to the University of Texas MD Anderson Cancer Center. The center has been at the forefront of investigations into myeloma and the Goodfrends know that the funding is being put to very good use—supporting the type of research that Barbara has already benefited so greatly from.

The Goodfrends have also brought their friends and family into their effort to support research. Over a year ago, guests invited to their 50th wedding anniversary celebration were asked to make contributions to the MMRF in lieu of presents. As they see it, there is no better expression of love.

“We rely on the MMRF for so many of the services they provide. Supporting its cause is a small way for us to show our appreciation and to ensure that groundbreaking research continues.”

Raising Funds Fall Gala

Friends for Life Fall Gala continued

Ms. Osbourne was diagnosed with colon cancer last year and has been in remission for several months. Over the past year, she has done a great deal to make a difference in the lives of those affected by cancer, including starting her own foundation, The Sharon Osbourne Colon Cancer Foundation. "I am here to raise as much awareness as I possibly can," Osbourne told those in attendance.

The Fall Gala's success was complemented by an amazing auction of unique and impressive items and packages donated by MMRF and Pepsi supporters. Among several vacation packages auctioned were a 3-day VIP experience of the 2004 Grammy Awards (donated by Charles Ortner and the Academy of Recording Arts and Sciences); a 10-day Mediterranean Sea Odyssey (donated by Silversea Cruises); a week long Virgin Islands vacation at the Caneel Bay Resort; VIP tickets and access to Super Bowl XXXVIII (donated by Pepsi and Genesco Sports) and VIP invitations for four to the Hollywood movie premiere of Shrek 2 (donated by Wendy Ryding and DreamWorks).



Gala Partners, Robert and Carol Wolf with Scott Santarella, MMRF Executive Director



Art Rosenberg, Pepsi Committee member, enjoys the Gala with his wife



Event Chair Alan Panzer celebrates a special night with his sister (patient), Barbara (L) and wife, Judy (R)

1-800-flowers.comSM
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Celebrate the Holidays

When thinking of your loved ones this holiday season, think of the **MMRF** too, and send flowers to say how much you care. Contact 1-800-Flowers and order gifts for your family, friends and business associates and 10% of the purchase will be donated to the MMRF when you mention our code: "MMRF" during your purchase.

Raising Funds Race for Research

2nd Annual Ann Landers Race for Research

The second annual MMRF-Ann Landers Race for Research, held on September 14th at Grant Park in Chicago, IL was another huge success reporting record numbers! In total, 1,250 registered walkers and runners came out to show their support of the MMRF. In addition to raising awareness, participants and sponsors helped to raise over \$205,000 for myeloma research in the name of Ann Landers, the legendary advice columnist who lost her battle to myeloma last year.

The Chicago Race was our most successful Race for Research event to date. Our success would not have been possible without the support of our flagship sponsor, Baxter International and our honorary event chairs, Dr. Seema Singhal, Dusty Baker and Senator Dick Klemm. A very special thank you goes out to the employees from Baxter International and Hewitt Associates, the Carol King team, as well as all of our friends in Chicagoland for a tremendous team effort.



Hewitt Team in full force



Baxter International CEO Harry Kraemer and family enjoying the day



MMRF Board Members Joe Hogan and Kathy Giusti

Raising Funds Race for Research

Inaugural Race for Research – Atlanta a Big Hit!



Jerry's Team

The MMRF Race for Research-Atlanta, held on October 5th at Piedmont Park, was an enormous success. The event, in its first year, attracted over 500 participants and raised nearly \$100,000 for multiple myeloma research. Special thanks go out to our event chairs, Dr. Leonard Heffner, Hamilton Jordan and Oscar Gamble, as well as to our friends and supporters in the Southeast section of the country!



(L-R) Top Winners:
Orlando Daniels,
Shayina Fein, Jet Stigter

We would also like to thank our local sponsors, Winship Cancer Institute at Emory University, PriceWaterhouse Coopers, Stone Mountain Park, Celgene, Harry Norman, Realtors, Millennium Pharmaceuticals, Inc and the Atlanta Area Multiple Myeloma Support Group for their generosity and dedication. Be on the lookout for the second annual Atlanta race coming up next fall!



(L-R) Event Chair
Dr. Leonard Heffner and Shelly
Christie, MMRF Development
Coordinator

UPCOMING SCHEDULE Race for Research 5K Walk/Run

Sunday, April 18, 2004
San Francisco, CA

Sunday, May 2, 2004
Boston, MA

Sunday, May 22, 2004
New Canaan, CT

Sunday, June 13, 2004
Cleveland, OH

For more information about upcoming races, contact Shelley Christie at Christies@themmrf.org, or visit the MMRF's website at www.multiplemyeloma.org/events

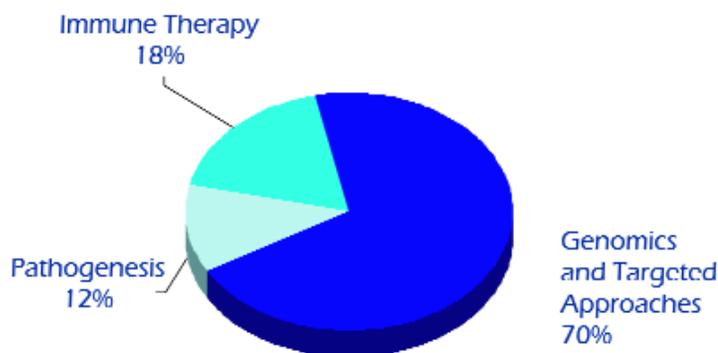
Raising Funds Annual Appeal

What a difference six years makes! When the MMRF was founded in 1998 there was limited research being done on multiple myeloma, few had even heard of the disease and little was being done to find a cure. The MMRF was founded with a simple business model: raise dollars to fund early research and put it in the hands of the world's leading myeloma scientists.

The Result:

- ◆ the MMRF is the worlds #1 private funder of myeloma-specific research.
- ◆ the MMRF has funded nearly \$15 million to 46 institutions around the world.
- ◆ the MMRF has accomplished all of this while keeping our administrative expenses at 7% or less.
- ◆ 70% of MMRF-funded grants focus on new approaches and genomics

Total MMRF Research Funding



2003 was a banner year for the MMRF and the entire myeloma community. The Food and Drug Administration (FDA) approved Velcade for multiple myeloma this was a historical development in the treatment of the disease. The MMRF worked closely with Millennium Pharmaceuticals and played a key role in bringing Velcade from bench to bedside by:

- ◆ Introducing Velcade at our Research Roundtable in 2000
- ◆ Funding a portion of the clinical research necessary to take the compound from phase II to phase III
- ◆ Rapidly accruing the clinical trials through Clinical Trials Monitor (CTM)

Today the MMRF continues to focus on new drugs and targeted approaches. With an NCI Accredited (stringent) Review process, we know that our awards fuel the most promising efforts.

The budget of the National Cancer Institute will remain level so the onus of ensuring continued progress in myeloma research will fall primarily on the MMRF.

- ◆ The MMRF is the only non-profit organization dedicated 100% to funding myeloma research
- ◆ The MMRF is the only organization committed to increasing support of myeloma research in 2003 by 10% and 2004 by 14%.
- ◆ The MMRF is the only organization directly funding new myeloma compounds

MMRF-Funded Compounds

Velcade	Anakinra	IGF1 receptor-
Revimid	FGFR3 receptor-	inhibitor
Thalomid	inhibitor	RANKL
Trisenox	HSP70	R-Etodolac
Zarnestra	HSP90	TRAIL

Your support is critical to helping us maintain this much needed pace. We need every person to get involved in this fight and support the advancement of research. Last year only 5% of the myeloma community supported our annual appeal. This year, we can double that amount with your help!

Here's How You Can Help:

- ◆ Look for the MMRF Annual Appeal Letter in your mailbox
- ◆ Complete the support form - include check, money order or credit card information
- ◆ Mail back to MMRF today

If you have not received a copy, please contact Scott Santarella at santarellas@themmrf.org and we will forward one to you immediately.

Please join us in this battle and contribute what you can. With your gift, we will continue to fund the world's most cutting edge research. An investment in the MMRF today could mean a cure tomorrow.

Raising Funds Planned Giving

MYELOMA FOCUS

Estate Gift Helps Fund Myeloma Research

In July of 2001, Mr. Grayson Harding, a myeloma patient from Falls Church, Virginia called the MMRF and said he was interested in learning more about how he could include the MMRF in his will as beneficiary of his estate. He said he was a man of simple means, but wanted his legacy to have a positive impact on making a difference by supporting research through the MMRF.

His request was a simple one to satisfy - he had his attorney add to his will the following: "I give, devise and bequeath to Multiple Myeloma Research Foundation, New Canaan, Connecticut, a non-profit corporation existing under the laws of the State

of Connecticut, my primary residence, to be used for its general objectives and purposes."

In June of 2002, Mr. Harding lost his seven-year battle with myeloma. Upon settling his estate this past June \$370,000 in proceeds from the sale of his house went directly to MMRF's 2003 grant awards in his name. We are honored and grateful for Mr. Harding's generous planned gift and are certain his legacy will live on through the research his gift will support.



How you can help

If you would like to learn more about how you too can have a lasting impact on helping others:

- ◆ Look for the MMRF Planning Strategies Brochure in your mail
- ◆ Review the brochure with your family
- ◆ Contact your attorney about what strategy will most benefit you and your loved ones
- ◆ Complete the postage paid form and return to the MMRF

FALL 2003 CORRECTIONS:

William and Annette Lifford should have been listed as a Gold Sponsors;
Carl and Susan Barash should have been listed as a Bronze sponsor

**The MMRF THANKS
Celgene, Novartis
and Millennium
Sponsors of
Myeloma Focus**



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The information herein is not intended to replace the services of trained health professionals (or to be a substitute for medical advice.) You are advised to consult with your healthcare professional with regard to matters relating to your health, and in particular, regarding matters which may require diagnosis or medical attention.

Funding Research MMRF Program Grant

\$1.5 million for Bone Disease

In October, the MMRF, the world's largest private funder of myeloma-specific research, announced that a team of researchers from the University of Pittsburgh, the University of Michigan and Columbia University is the recipient of its 2003 Collaborative Program Grant. This year, the MMRF has awarded nearly \$4.5 million in research funding, which brings total research funding to date to more than \$15 million. The grant, which provides \$1.5 million to researchers over three years, is designed to foster unique collaborations among researchers and institutions to help bring new therapies to clinic quickly.



Dr. Roodman

This Collaborative Program, entitled Program Pathogenesis and Treatment of Myeloma Bone Disease, is led by G. David Roodman, MD, PhD, Director of the Bone Biology Center of the University of Pittsburgh Medical Center, and Director of the Myeloma Program at the University of Pittsburgh Cancer Institute, and brings together

researchers with expertise in molecular biology, animal models of tumor metastases, hematology, endocrinology, bone biology and clinical trials. The research program consists of three core projects entitled:

- ◆ p62^{Zip}, a novel target for treating myeloma bone disease
- ◆ Bone microenvironmental factors and myeloma bone disease
- ◆ Pure anabolic skeletal therapy with PTH-related protein for myeloma bone disease: pre-clinical and clinical studies.

All projects will use in-vivo models of myeloma to dissect the role of the microenvironment in myeloma bone disease and the effects of anabolic agents on bone formation in myeloma. These studies will serve as a basis for two innovative phase I/II clinical trials.

According to Dr. Roodman, "Bone destruction is the major source of morbidity in patients with myeloma and causes agonizing bone pain and fractures, which severely decreases the quality of life for myeloma patients. For the first time, this program brings together experts in myeloma, bone biology and osteoporosis to focus on myeloma bone disease, which would not be possible without the support of the MMRF."

NCI Accreditation for MMRF

Award winners are selected following a rigorous peer-review process by the MMRF's esteemed Scientific Advisory Board using guidelines established by the National Institutes of Health (NIH). Earlier this year, the National Cancer Institute (NCI) approved the MMRF's research grants program, finding that it meets the same rigorous scientific standards the NCI applies to its own research grant review process. The MMRF is only the seventh private, charitable research organization in the United States to receive approval since the NCI started the program nearly 10 years ago.

Principal Investigators



Dr. Chung
University of Pittsburgh



Dr. Dempster
Columbia University



Dr. Kurihara
University of Pittsburgh



Dr. McCauley
University of Michigan



Dr. Stewart
University of Pittsburgh

ASK THE EXPERT



Paul Richardson

We are pleased to feature Paul Richardson, MD in this issue's **Ask the Expert**. Dr. Richardson is the Clinical Director of the Jerome Lipper Myeloma Center at the Dana-Farber Cancer Institute (DFCI) and Assistant Professor of Medicine at Harvard Medical School in Boston.

Dr. Richardson, what do clinical trials offer myeloma patients?

In myeloma, participation in a clinical trial is considered to be a standard of care because there are limited treatment options and, despite recent advances, it remains incurable. We now have a spectrum of clinical trials for patients at all stages of the disease—at diagnosis, early relapse, and later relapse. In fact, participation earlier in the disease process is to be encouraged in my view because it can leave other options open for the future. Also, because of improved laboratory and animal mod-

els that are more predictive of potential benefit in patients, the newer targeted therapies are increasingly likely to achieve disease response and hopefully be less toxic.

Patients who take part in a clinical trial may benefit in several ways. Patients have access to cutting-edge treatments not normally available elsewhere. In addition, by participating, patients help increase the body of knowledge about myeloma treatment and help us bring effective therapies to approval more rapidly, which in turn benefits more patients. One can look at bortezomib (Velcade™, Millennium) as an example of how about a third of patients in the pivotal study benefited and also helped achieve drug approval through their participation. So, ideally, we hope it's a win-win situation.

How can I find out more?

The MMRF Clinical Trials Monitor (CTM) is a great place to start. Individuals can search for trials open to patients at a particular stage of disease, geographic area, and type of trial.

Clinical Trials Monitor

Find the Latest Myeloma Trials!

Do you want access to the latest, cutting-edge treatments for multiple myeloma? Are you trying to find a clinical trial in your area? Look no further! Join the 20,000 visitors who have searched for clinical trials for multiple myeloma across the world at the MMRF's Clinical Trials Monitor (CTM) at www.myelomatrials.org, the most comprehensive database of myeloma trials found anywhere! Following are several trials currently posted on CTM, but check back often as new trials are added weekly.

If you are a healthcare professional who would like to post a clinical trial at www.myelomatrials.org, please contact Anne Quinn Young, Program Director, at quinnyounga@themmrf.org.

- ◆ A Multicenter Phase III Trial of Revimid (CC-5013) Plus Dexamethasone Versus Dexamethasone Alone in Previously Treated Subjects with Multiple Myeloma
- ◆ Phase II Trial of Velcade Alone and in Combination With Dexamethasone in Previously Untreated Multiple Myeloma Patients
- ◆ Phase II trial of Thalidomide With Doxil, Vincristine, and Decadron for Newly Diagnosed & Relapsed/Refractory Multiple Myeloma
- ◆ Phase I/II Trial of Arsenic Trioxide with Ascorbic Acid in the Treatment of Relapsed/Refractory Multiple Myeloma

Log on to www.myelomatrials.org today to find the clinical trial that is right for you or your patient!

MEDICAL CORNER

NCCN Guidelines

Tclinical practice guidelines developed by the National Comprehensive Cancer Network (NCCN), an alliance of 19 of the world's leading cancer centers, are a recognized standard reference for appropriate practice in the field of oncology. The guidelines are based on a review of the literature and on the expertise and clinical experience of NCCN panel members.

The NCCN guidelines help physicians identify appropriate and effective treatments for cancer patients at specific stages of their disease. They also help identify patients who are candidates for certain clinical protocols or trials.

The NCCN recently updated their Multiple Myeloma Clinical Practice Guidelines. The 2003 myeloma guidelines include the latest consensus of the panel members on strategies for an initial diagnostic workup, disease staging, initial treatment, follow-up therapy and maintenance, additional treatment, and supportive treatment for bone disease and other complications. Two important additions were made to the guidelines:

- ◆ The proteasome inhibitor bortezomib (Velcade™, Millennium Pharmaceuticals, Inc.) was added to the list of chemotherapeutic agents considered appropriate for patients with progressive or refractory myeloma who have previously been treated with standard-dose chemotherapy alone or followed by high-dose chemotherapy and stem cell transplant.
- ◆ The combination of thalidomide (Thalomid®, Celgene) and dexamethasone has been added to the list of options for the primary treatment of advanced disease. In past guidelines, thalidomide had been recommended as an option for treating progressive or refractory myeloma.

Other recommendations added to the guidelines include:

- ◆ Renal (kidney) impairment is not a contraindication for transplant.
- ◆ Patients who receive bisphosphonates regularly should have their renal function monitored.
- ◆ Vertebroplasty or kyphoplasty should be considered for symptomatic vertebral compression fractures.

MMRF Scientific Advisory Board Chairman Kenneth Anderson, MD of the Dana-Farber Cancer Institute served as Chair of the myeloma panel and was a member of the Writing Committee. According to Dr. Anderson, these guidelines establish an algorithm for patient care and identify patient settings in which protocol therapies are appropriate. "By partnering with our patients and third-party providers, outcome of protocol treatments can be carefully analyzed and ultimately lead to improved treatment strategies," he noted.

Excerpt from NCCN Treatment Guidelines

I. Primary conventional therapy

- ◆ Melphalan/prednisone (MP)
- ◆ VAD
- ◆ Dexamethasone
- ◆ Thal/Dex (insufficient data to recommend treatment duration)

II. Maintenance Therapy

- ◆ Steroids
- ◆ Interferon

III. Salvage

- ◆ Repeat primary
- ◆ conventional therapy
- ◆ Cyclophosphamide-VAD
- ◆ EDAP
- ◆ High-dose cyclophosphamide
- ◆ Thalidomide
- ◆ Bortezomib

Anderson, K.C., et al. The NCCN Multiple Myeloma clinical practice guidelines in oncology, version 1.2003.

Available at: http://www.nccn.org/physician_gls/index.html. Accessed 11/19/03. To view the most recent and complete version of the guideline, go online to www.nccn.org.

The NCCN believes that "the best management for any cancer patient is in a clinical trial." Like the MMRF, the NCCN strongly encourages participation in clinical trials.

YOU NEED TO KNOW

DATES TO REMEMBER



MMRF Webcasts from the American Society of Hematology (ASH) Annual Meeting

◆ **Webcast:** For the third straight year, the MMRF is webcasting highlights from the Myeloma Education Session, Chaired by Bart Barlogie, MD, PhD, of the University of Arkansas for Medical Sciences. In addition to Dr. Barlogie, Ken Anderson, MD, of the Dana-Farber Cancer Institute and Rafael Fonseca, MD, of Mayo Clinic, will be featured on the webcast, which will be posted on the MMRF's website on **December 9**.

Topics will include updates on prognostic indicators and genomics, bone disease, stem cell transplantation, standard and supportive care, and the cutting-edge research on novel therapies such as Velcade and Revimid.

◆ **Teleconference:** On **December 18** from 12:00-1:00PM, the MMRF will present "Update from ASH," an interactive teleconference featuring Paul Richardson, MD, of the Dana-Farber Cancer Institute and Vincent Rajkumar, MD, of the Mayo Clinic, in collaboration with CancerCare. This live, hour-long teleconference will feature commentary from two of the world's leading myeloma experts on the exciting research presented at the ASH annual meeting. Participants will also have the opportunity to ask questions. Registration information is available online at www.cancercare.org or you can call CancerCare for more information at 1-800-813-HOPE (4673).

December 6-9, 2003
San Diego, CA

45th Annual American Society
of Hematology (ASH) meeting

December 18, 2003
Teleconference
"Update from ASH"

February 5 & 6, 2004
Los Angeles, CA

Institutional Insights Physician
and Patient Seminar

March, 2004
Cleveland, OH

Institutional Insights Physician
and Patient Seminar

**For more information, please call
Sara Nichols, Program Coordinator,
at (203) 972-1250 or email at
nicholss@themmrf.org**

**Stay posted for more information
to be available online at
www.multiplemyeloma.org/events**

MMRF Institutional Insights



(L-R) Program attendee, Dr. Neil McPhail, and program faculty, Drs. Rafael Fonseca, Keith Stewart (Chair), Philip Greipp, Paul Richardson, and William Bensinger.

Dr. Keith Stewart chaired the MMRF Institutional Insights program in Toronto, Ontario on October 2-3, 2003. Partnering with the University of Toronto and the McCarty Cancer Foundation, the MMRF was pleased to bring the latest research and treatment information on multiple myeloma to over 350 attending patients and professionals. Drs. William Bensinger, Rafael Fonseca, Philip Greipp and Paul Richardson joined Dr. Stewart presenting on disease

biology and staging, contemporary therapies, stem cell transplantation, novel therapies and current clinical trials.

A special thank you to Roberta McCarty and Marion State for their time and energy in support of the Greater Toronto area myeloma community. The MMRF would also like to thank the speakers for their time in support of our programs.

If you wish to receive the handouts from this and other Institutional Insight programs, please contact Sara Nichols at nicholss@themmrf.org or call at 203-972-1250.



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Accelerating the Search for a Cure

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Greenwich Gala

Story on Page 1



L-R: Dave Burwick (CMO of Pepsi-Cola North America and Gala Corporate Chairman), Sharon Osbourne (MMRF Spirit of Hope Award), Lori Marcus (Vice President, Pepsi)



Karen Andrews and Kathy Giusti, co-founders of the MMRF, celebrate the 7th Annual Gala