



*Accelerating
the
Search
for a
Cure*

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MYELOMA FOCUS

Newsletter of the

MMRF

Multiple Myeloma Research Consortium (MMRC) Launched

The Multiple Myeloma Research Foundation (MMRF) announces the launch of the Multiple Myeloma Research Consortium (MMRC), the first research model of its kind that brings together leading academic institutions to speed the development of new myeloma therapies.

The MMRC was developed in partnership with the myeloma research community and founded by MMRF President Kathy Giusti as an extension of the MMRF's mission. The MMRC and the MMRF will work hand in hand to pursue an ultimate goal -- a cure for myeloma.



The MMRC Leadership Team: (L-R) William Dalton, PhD, MD; Rafael Fonseca, MD; Kathy Giusti, President/Founder MMRC and MMRF; Keith Stewart, MD, ChB; Kenneth Anderson, MD

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Chicago Awards Dinner Huge Success



(L-R) Event Chairs Philip and David Purcell join MMRF President Kathy Giusti, mistress of ceremonies Bonnie Hunt and keynote speaker General Norman Schwarzkopf

Purcells Help
Chicago Event Surpass Goal,
Raise Over \$950,000

On Thursday, April 21st, the Multiple Myeloma Research Foundation held its fourth Chicago Awards Dinner. The event raised more than \$950,000 for myeloma research. "Chicago truly is our second home," said MMRF President Kathy Giusti. "Due to the generosity and support of this community, we are moving faster to a cure than ever before."

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Welcome Letter

Families Funding Research

Dear Friends,

We have an amazing new ally in the fight to cure multiple myeloma. The launch of the Multiple Myeloma Research Consortium (MMRC) and its swift success, as highlighted in this newsletter, should give us all more hope than ever before that we truly are on track toward discovering a cure.

In just a few months, the MMRC has laid the groundwork necessary to identify new molecular targets for multiple myeloma, validate new drugs against these targets and expedite clinical trials. It has done this by integrating the leading myeloma centers around a national tissue bank, data bank and scientific cores.

At the heart of these achievements, the creation of the MMRC tissue bank addresses the greatest previous obstacle to myeloma research by now allowing researchers access to a centralized repository of high-quality, well-annotated tissue, needed to fast-track the development of new, lifesaving myeloma therapies. The Bank has already accrued over 150 bone marrow samples matched with peripheral blood.

I know that these amazing accomplishments indicate the critical role the MMRC will continue to play in expediting the testing of new myeloma therapies, and I am thrilled to share these successes with those who may benefit from them the most.

Sincerely,



(L-R) Sheri Lyons, Jill Walsh and Doug and Donna Wingate

When Sheri (Wingate) Lyons' mom was diagnosed with multiple myeloma in 1998, she and her sister, Jill (Wingate) Walsh, sought out as much information as they could find. Their research took them to the MMRF, but their hope remained guarded. Their mother was told she had advanced Stage III myeloma, and as Sheri puts it, "Seven years ago there wasn't a lot of positive information out there."

Years later, with their mother's cancer in remission after 2 successful stem cell transplants, and after watching the awareness and knowledge about myeloma grow exponentially thanks to the MMRF, the Wingate Family is more grateful and hopeful than ever before. Inspired by Tim Young and his family (also of the Albany, NY area), who had lost a father to multiple myeloma and were honoring his memory with an annual fundraising golf tournament, the Wingates decided to put their hope and love to work in a similar way.

"Dance for a Cure" was thus born 2 years ago, bringing the Wingates' family, friends, co-workers and doctor's office contacts together for an evening of music and dance. It features a hometown favorite band, The Burners UK, and is opened by MOJO Lightning, which includes one of Donna's doctors, Fred Shapiro, MD, who plays in the band. Since its first year, the event has raised over \$46,000 for myeloma research and has grown to include even more patient families and local contacts. Sheri explains "the enthusiasm and momentum has been building steadily, and it's exciting to know that by coming together for an evening of fun, we're making a real difference in the future of myeloma research and treatments."

After years of living with the realities of multiple myeloma, the Wingate Family's advice to the many newly diagnosed patients and families is, "to become knowledgeable and educate yourself. There is more reason than ever before to be hopeful." It's that hope, spirit and drive that helped Donna make it through her treatments, and today make the Wingate Family such an inspiration and invaluable contributor to myeloma research.

Fundraising

continued from page 1

Chicago Awards Dinner

The evening featured keynote speaker General Norman Schwarzkopf, longtime friend of the MMRF and recipient of the 1999 MMRF Leadership Award for his role in raising the visibility and awareness of cancer. Diagnosed with prostate cancer in 1994, he has been an important spokesperson for cancer awareness and research, and an inspirational voice for thousands of cancer patients and advocates. Paraphrasing a quote by President Theodore Roosevelt, Schwarzkopf remarked, “The credit belongs to the woman who is actually in the arena ... who spends herself in a worthy cause; who at best knows in the end the triumph of high achievement, and who at the worst, if she fails, at least fails while daring greatly.” He concluded that, “We all need to join Kathy Giusti in the arena.”

The MMRF also welcomed back as mistress of ceremonies, Chicago-born Bonnie Hunt, actor, director and producer of hit comedy shows like “Life With Bonnie” and recently seen in the hit movie “Cheaper by the Dozen”. While her witty humor was present throughout the evening, Bonnie realized the seriousness of bringing attention to multiple myeloma and other cancers. Bonnie also shared her life experience at Northwestern University Hospital, where she served as an oncology nurse while pursuing her acting and comedic career.



Dinner Chair Brian Feltzin (middle), Managing Partner of Sheffield Asset management LLC, friends and family with Hunt and Schwarzkopf



Dinner Chair Robert Parkinson, Chairman and CEO of Baxter International, Inc. and wife Betty with Schwarzkopf and Hunt



Schwarzkopf with Dinner Chair John Jordan, Chairman and CEO of Jordan Industries, Inc.

Special Thanks To:

Event Chairmen:

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David Purcell, Continental Advisors, LLC

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MMRC Research

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The Need for the MMRC Leadership Team

In recent years, we have seen the emergence of new therapies -- such as Velcade and Revlimid -- that now offer patients more treatment options than ever before. Despite these strides, myeloma remains an incurable disease.



(L-R) Robert Knight, MD, Celgene; Julian Adams, MD, PhD, Infinity; David Schenkein, MD; Millennium; Paul Richardson, MD, DFCI; Leif Bergsagel, MD, Mayo Clinic

As a lead funder of myeloma research, the MMRF was in a unique position to identify barriers to developing breakthrough therapies so urgently needed. Though these challenges are multi-faceted, advances have generally been impeded by four key challenges: **1)** Fostering collaboration between academic institutions; **2)** Creating a critical mass of patients and tissue samples; **3)** Determining optimal targets for myeloma and drugs active against these targets; **4)** Conducting early-stage clinical trials with a focus on correlative science.

The MMRC was created to rapidly address these challenges and to explore opportunities in the most promising areas of myeloma research. Developed in partnership with PricewaterhouseCoopers, and with the help of the scientific community, the MMRC focuses on concrete milestones while shortening the timeline. The result is a new research model that will accelerate drug development to a pace only once imagined.

"Our goal is to rapidly drive therapies to patients because the need is so urgent," said Ken Anderson, MD, chair of the MMRC Leadership Team. "We now have an optimal model for drug development that will allow us to do just that."

A New Model for Rapid Drug Development

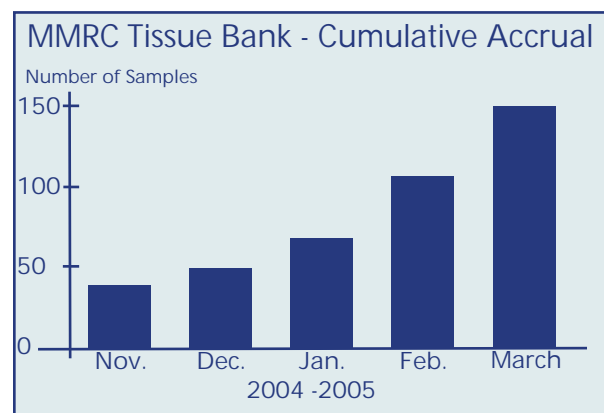
The MMRC brings together as the Consortium, the world's leading research institutes -- Dana-Farber Cancer Institute, H. Lee Moffitt Cancer Center & Research Institute, Mayo Clinic, and University Health Network (Princess Margaret Hospital) - - to conduct innovative research in three cutting-edge research cores. The heart of this integrated model is the MMRC Tissue Bank.

Centralized Tissue

A scarcity of high-quality tissue poses one of the greatest obstacles in developing new, targeted therapies. This challenge is even greater in uncommon cancers like multiple myeloma because tissue samples are both limited in number and scattered throughout the country. With the creation of the MMRC Tissue Bank, we are now well on our way to accruing the significant volume of high-quality tissue samples necessary to advance research efforts.

The MMRC Tissue Bank integrates patient bone marrow aspirates and peripheral blood samples with corresponding genomic and clinical data. This will enable researchers to identify and validate optimal molecular targets for myeloma and drugs active against these targets. To guarantee samples are of the highest quality, the MMRC requires that all samples be uniformly collected, analyzed and stored in adherence with government-regulated Good Laboratory Practice (GLP).

"Researchers now have access to the significant volume of high-quality bone marrow biopsies and peripheral blood samples needed to truly fast-track the clinical development of new myeloma therapies," said Rafael Fonseca, MD, chair of the MMRC Tissue Bank.



MMRC Research

Supporting this invaluable resource is the MMRC Data Bank, a state-of-the-art data management system that integrates information generated by the Consortium's research efforts into one common interface. *"The establishment and integration of this extraordinary collaboration is sure to result in scientific advances beyond the scope of any one institution and the development of new drugs in record speed," said David Parkinson, MD, Amgen Inc.*

Integrated Research Cores

Spanning the most cutting-edge areas of myeloma research, the Consortium's research efforts will be conducted in multi-site research cores:



Led by Rafael Fonseca, MD, Mayo Clinic, **The Genomics Core** analyzes myeloma tissue to identify molecular targets that play a role in the onset and progression of myeloma. The Core also analyzes samples collected from patients enrolled in MMRC clinical trials to advance our understanding of why some drugs are effective in treating some myeloma patients, but not others.



Led by Leif Bergsagel, MD, Mayo Clinic, **The Validation Core** validates new and existing targets for myeloma and new and combination therapies active against these targets. Robust validation of both targets and potential drugs is key to developing therapies that effectively treat the disease.



Led by Paul Richardson, MD, Dana-Farber Cancer Institute, **The Clinical Trials Core** supports clinical trials of novel new drugs and combination therapies with a focus on correlative science. As trials are completed, the Consortium will collaborate with industry partners to fast-track these therapies through the clinical trials process to patients in need.

Standardized Processes

The Consortium has successfully developed uniform template documents to streamline the clinical trials process. These include an Informed Consent Form (ICF), Clinical Trials Agreements (CTA) and Case Report Forms (CRF).

MMRC Drug Development Projects

The MMRC facilitates cutting-edge research in the most promising areas of myeloma and is particularly focused on the development of novel, targeted therapies. "The Consortium will accelerate the testing of new therapies and provide a greater understanding of myeloma," said Keith Stewart, MD, a member of the MMRC Leadership Team. "Taken together, these efforts will result in a faster discovery of a cure for the disease."

Projects currently underway include:

- ▶ The creation and maintenance of an extensively characterized panel of myeloma cells lines -- an invaluable resource for the Consortium and industry partners, as the Consortium pursues drug screening projects.
- ▶ A pioneering study to identify and validate optimal screening methods to detect patients who exhibit a t(4;14) and express FGFR3-a poor prognostic indicator for myeloma.
- ▶ A phase I clinical trial of a new targeted therapy in patients with relapsed or refractory myeloma.

Myeloma Patients- You Can Make A Difference!

Patients frequently ask how they can do more to advance myeloma research. In response, the MMRC has developed a program that will allow you to make a difference in myeloma. If you are being treated at one of the following MMRC Member Institutions, the MMRC encourages you to provide tissue to the MMRC Tissue Bank.

- Dana-Farber Cancer Institute
- H. Lee Moffitt Cancer Center & Research Institute
- Mayo Clinic Cancer Center
- University Health Network (Princess Margaret Hospital)

If you are interested in participating, please email **Alicia Sable-Hunt, RN -- the MMRC's nurse specializing in myeloma research -- at sablehunt@themmrc.org for details.**

Education

Educational Program Calendar

May 19-20, 2005

Boston, MA

Chairs:

Drs. Kenneth Anderson and
Paul Richardson
Dana-Farber Cancer Institute

June 9-10, 2005

Seattle, WA

Chair: Dr. William Bensinger
Fred Hutchinson Cancer
Research Center

June 23-24, 2005

Chicago, IL

Chair: Dr. Steven Rosen
Northwestern University

September 30, 2005

New York, NY

Chair: Dr. Sundar Jagannath
St. Vincent's Comprehensive
Cancer Center

November 17-18, 2005

Tampa, FL

Chair: Dr. Melissa Alsina
H. Lee Moffitt Cancer Center
and Research Institute

For more information, please
contact the MMRF at
203-972-1250.

Registration is available online
at
[multiplemyeloma.org/medical_](http://multiplemyeloma.org/medical_programs)
programs

MMRF Institutional Insights

The MMRF kicked off the 2005 Institutional Insights Series on March 4th at Johns Hopkins School of Medicine in Baltimore, MD. The esteemed panel spoke to patients and professionals about the latest research being done. Dr. Ivan Borrello of Johns Hopkins, also a MMRF grant recipient, chaired the program. Other faculty included Drs. Carol Ann Huff, Nikhil Munshi, David Roodman and Mohamad Hussein, who provided updated information on myeloma research and treatment options. The MMRF expresses its gratitude to the Baltimore and Washington D.C. area for participating in this program.



The Johns Hopkins
Institutional Insights
Faculty: (L-R)
Dr. David Roodman,
Dr. Mohamad Hussein,
Dr. Nikhil Munshi,
Dr. Carol Ann Huff and
Dr. Ivan Borrello

Dr. David Roodman answers
questions from a patient.



The MMRF Thanks
the following
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CHIRON

MILLENNIUM

You Need To Know

WEBCAST

CME Accredited Updates from IMW/ASCO

The MMRF is pleased to webcast key highlights from the IMW and the ASCO Annual Meeting. From the International Myeloma Workshop (IMW) in Sydney, the webcast features **Drs. Douglas Joshua**, Royal Prince Alfred Hospital; **Vincent Rajkumar**, Mayo Clinic; **Paul Richardson**, Dana-Farber Cancer Institute; and from ASCO, **Sundar Jagannath**, St. Vincent's Comprehensive Cancer Center. The latest advances in treating multiple myeloma will be discussed.

To register and to view audio presentations, transcripts and downloadable slides, please visit
www.multiplemyeloma.org/medical_programs

Patients' Perspective

View the Multiple Myeloma Patients' Perspective Webcast Today! See Myeloma Mentors Jim Bond, Torrance Campbell, Bruce Holmberg and Angie Minnick as featured speakers in Multiple Myeloma: Patients' Perspective - A one-hour live audio and video broadcast delivered right to your computer.

To view the online video program visit
www.webcast.ey.com/mmrif

2005 Blood Cancer Advocacy Day

Sponsored by the MMRF and
The Lymphoma Research Foundation

Join hundreds of blood cancer
patients and their families on

June 14-15, 2005 in Washington, D.C.

If you are interested in becoming and advocate,
please contact **Bruce Holmberg** at
bpholmberg@comcast.net.

TELECONFERENCE

Listen In! Updates from IMW/ASCO

The MMRF, in collaboration with CancerCare, is pleased to provide you with highlights from the International Myeloma Workshop (IMW) and the Annual Meeting of the American Society of Clinical Oncology (ASCO). Listen to the live teleconference on May 26 from 3:00 pm ET to 4:00 pm ET. Speakers include **Drs. Philip Greipp**, Mayo Clinic and **Seema Singhal**, Robert H. Lurie Comprehensive Cancer Center of Northwestern University, who will discuss the most promising findings in myeloma research presented at the meetings.

For more information and to register, please visit
www.multiplemyeloma.org/medical_programs

CASE STUDIES

New Great Debates CME Case Study Program May 31st!

This cutting-edge CME program is a series of on-line interactive case studies developed by two top myeloma researchers providing two treatment options for a patient case. Each case will update hematologists, oncologists and other health care professionals on the latest research and treatment developments. Case 1, entitled The Incorporation of New Therapeutic Agents for Relapsed/Refractory Patients, will be available online beginning May 31, 2005 and features **Drs. Nikhil Munshi**, Dana-Farber Cancer Institute and **James Berenson**, Institute for Myeloma and Bone Cancer Research.

CLINICAL TRIALS MONITOR

For the latest cutting-edge treatments for myeloma visit the MMRF's Clinical Trials Monitor (CTM) at www.myelomatrials.org, the most comprehensive database of myeloma trials found anywhere!

For information on how to post a clinical trial, please contact Stefanie Kasven at kasvens@themmrif.org.

Industry Update

Velcade® Fully Approved for Use in Relapsed Myeloma Positive Clinical Results Reported Across the Disease Spectrum

The MMRF is excited to announce that the FDA has approved Millennium Pharmaceutical's supplemental New Drug Application for Velcade® (bortezomib) for Injection, which expands the current labeling to include the treatment of myeloma patients who have received at least one prior therapy. While initial accelerated approval for relapsed and refractory myeloma was granted in May 2003, the additional indication as second-line therapy means that Velcade is now fully approved to treat relapsed myeloma. Velcade is the only drug therapy that has demonstrated a significant survival advantage as compared to a standard therapy in relapsed myeloma.

The approval was based on data from the Phase III APEX study, which compared single-agent Velcade to a traditional myeloma therapy, high-dose dexamethasone. In the Velcade arm, 45% of second-line patients achieved a complete or partial response versus 26% in the high-dose dexamethasone arm. The study demonstrated a significant survival advantage with Velcade in patients who had received one to three prior therapies. Importantly, this pronounced survival advantage was also observed when data from patients receiving Velcade as second-line therapy was analyzed separately. The safety profile of Velcade in the phase III APEX study was consistent with the phase II SUMMIT trial.

The Emerging Role of Velcade

Positive clinical results from studies of Velcade across the disease spectrum were presented at the 10th Annual

International Myeloma Workshop in Sydney, suggesting its emerging role as a cornerstone of myeloma therapy.

These data build on the promising results reported at the ASH meeting in December. For example:

- Investigator-initiated studies of five different Velcade-containing regimens being evaluated as front-line therapy showed overall response rates of up to 95% and high complete and near complete response rates of up to 32%. Stem cell harvest and future transplant were not compromised. Side effects were found to be manageable and included gastrointestinal, hematologic, neurologic, and musculoskeletal effects; fatigue, malaise, or weakness; skin rashes and fever. Positive results from these studies have led to three large, international, randomized, Phase III trials.
- In relapsed and refractory myeloma, overall response rates of more than 60% have been achieved with Velcade in combination with therapies such as Doxil® (liposomal doxorubicin, Ortho-Biotech)/Thalomid® (thalidomide, Celgene Corp.), melphalan/Revlimid® (lenalidomide, Celgene).



Millennium Launches New Phase IV Retreatment VELCADE Trial

Millennium Pharmaceuticals announced the launch of EVEREST, a phase IV, open-label study assessing the efficacy, safety and tolerability of retreatment with VELCADE for injection in multiple myeloma patients. This is a clinical trial for patients who have previously responded to VELCADE and relapsed following a treatment-free remission. Further information is available through MMRF's Clinical Trials Monitor at www.myelomatrials.org.

The MMRF & VELCADE

- 2000 : Velcade introduced at MMRF Research Roundtable
- 2001 : MMRF Program Grant Funded Velcade Phase II Clinical Trial
- 2002 : Basic Velcade Research via Six MMRF Senior/Fellows Grants
- 2002 : MMRF Funded Accrued trials on Clinical Trials Monitor
- 2003 : MMRF Continuing Medical Education Programming on Velcade
- 2004 : Velcade Novel Combinations (Program MMRF Grant)

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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.

Industry Update

Revlimid® Studies Unblinded Early Statistically Significant Difference In Time-to-Progression Seen

The MMRF is excited to report that in March, the two ongoing pivotal phase III trials of Revlimid® (lenalidomide, Celgene Corp.) in patients with relapsed and refractory myeloma were unblinded early because they exceeded the primary efficacy endpoint of time-to-disease progression. In both trials, there was a strong, statistically significant difference in time-to-progression between patients receiving Revlimid plus dexamethasone -- who had not yet reached the primary endpoint -- and those receiving dexamethasone alone (see table). Interim clinical data from the trials were presented at the 10th International Multiple Myeloma Workshop in Sydney, Australia, in April.

	US Study (MM-009)		International Study (MM-010)	
	Revlimid + Dex (n=170)	Dex (n=170)	Revlimid + Dex (n=176)	Dex (n=176)
Median time-to-progression	Not reached after >15 mos.*	5 mos.	Not reached after >11 mos.*	5 mos.
Overall response rate	51.3%†	22.9%	47.6%†	18.4%
Complete response rate	19.5%	3.8%	9.1%	1.2%
Incidence of deep vein thrombosis (DVT)	11.2%	2.9%	4.7%	2.9%

*Statistically significant difference between treatment arms (P 0.00001)

† Statistically significant difference between treatment arms (P 0.001)

Response rates achieved with the combination were about 50% -- more than double that seen with dexamethasone alone. Together, these data confirm a significant clinical benefit for patients receiving Revlimid plus dexamethasone.

In both trials, patients treated with the combination had an increase in side effects compared with patients receiving dexamethasone alone. These adverse events were generally manageable and included anemia, thrombocytopenia, neutropenia, fatigue, neuropathy, and constipation. An increased risk of deep-vein thrombosis (DVT) was also seen with the combination.

The MMRF & Revlimid

2001 : MMRF Funded Phase II Trial via Program Grant

2002/2003 : Accrued Trials on MMRF Clinical Trials Monitor

3000 hits to CTM for Revlimid Trials

MMRF Continuing Medical Education Programming on Revlimid

2004 : Revlimid Novel Combinations (MMRF Program Grant)

Research

Targets Award Winners

The MMRF is pleased to announce the following distinguished grant recipients, who will receive a combined total of \$400,000 toward research focused on identifying and validating molecular targets that have strong therapeutic potential.

Each of these grantees were awarded funding following a two-phased review process. The first phase invited researchers to submit a short proposal on validation of a molecular target for myeloma treatment. A subset of researchers were then invited to present their proposal before a panel of reviewers and their peers, from which the three award recipients were selected. The MMRF enthusiastically supports the early target identification and validation work of these researchers, which will lead to a more complete understanding of the targets that strongly influence the course of multiple myeloma and be critical to developing novel effective treatments.



James E. Bradner, MD, Broad Institute of Harvard and MIT
Project Title: Selective inhibition of HDAC6 in the treatment of multiple myeloma

Abstract: Dr. Bradner's research will investigate how to block HDAC6, a gatekeeper that allows elimination of toxic proteins and prevents the permanent death of myeloma cells in patients on bortezomib (Velcade). His lab discovered the only drug against HDAC6, called tubacin, and has recently proven that this drug kills myeloma cells in Petri dishes and that when tubacin and bortezomib are combined, myeloma cells are killed more effectively. Dr. Bradner will use his funding to investigate over 10 more potent versions of tubacin that he has identified and bring the best candidate into the clinic.



Robert Z. Orlowski, MD, PhD, University of North Carolina at Chapel Hill

Project Title: The immunoproteasome as a target for multiple myeloma therapy

Abstract: Dr. Orlowski has identified a novel inhibitor of a specific myeloma proteasome called the immunoproteasome, which prevents the removal of unwanted and damaged proteins needed for myeloma cell death and remission. This agent killed myeloma cells but spared other cells in laboratory studies, while non-specific inhibitors like bortezomib caused death in all of them. These and other findings suggest that the immunoproteasome is a novel, distinct therapeutic target whose inhibition could help patients with myeloma while causing fewer side effects. Dr. Orlowski's new funding will examine the utility of this new class of drugs.



Allan M. Weissman, MD, Center for Cancer Research, NCI-Frederick

Project Title: Targeting ERAD and UPR in multiple myeloma

Abstract: Dr. Weissman's research will investigate endoplasmic reticulum-associated degradation (ERAD), a process by which myeloma cells destroy excess antibodies and proteins in order to survive. By blocking this process, Dr. Weissman believes myeloma cell death can occur, as has happened in studies of mice. He will use his funding to apply these findings to human myeloma as a step toward new therapeutics for treatment.



Ask The Expert

In this issue's **Ask the Expert**, we are pleased to feature our panel of nurses and nurse practitioners who provide their perspective on the management of neuropathy. Our faculty panel presented at the Novel Treatment Strategies for Multiple Myeloma symposium during the Oncology Nursing Society 30th Annual Congress, held in April in Orlando, FL. The symposium was supported by an unrestricted educational grant from the MMRF.

Peripheral neuropathy is a problem in the function of the nerves outside the brain and spinal cord that causes pain, numbness, tingling or muscle weakness. "Neuropathy can be a complication of the disease itself, such as when monoclonal proteins deposit on peripheral nerves or when myeloma involves the spinal cord," notes Ms. Faiman. "It also can be a result of prior treatments." The myeloma drugs most commonly associated with neuropathy include thalidomide (Thalomid®, Celgene), bortezomib (Velcade®, Millennium), vincristine (part of the VAD regimen) and high-dose melphalan.

Our panelists agree that myeloma patients need to be assessed for neuropathy as part of their initial workup and then on a regular basis, particularly if they are starting a therapy that may cause neuropathy. According to Mr. Tariman, neuropathy is often hard to assess because it is so subjective. "Patients may not realize they are experiencing neuropathy, so we describe the symptoms," notes Ms. Colson. Patients may not recognize symptoms such as burning, coldness or cramping as being due to neuropathy.

Treatments for neuropathy are varied and include use of vitamins and supplements, medications, and non-drug therapies (see chart). "If a patient will be starting a therapy that may cause neuropathy, we might suggest certain vitamins and supplements as a prophylactic measure," notes Ms. Swift. This is because there is some evidence suggestive of a protective effect of these supplements on nerve tissue. Various medications are used to help control symptoms. If the neuropathy is severe, a drug dose may be reduced or it may be held and then restarted at a lower level.

"Neuropathy is a very challenging situation," notes Mr. Tariman. "However, our primary goal is to do what we can to get patients through their treatment to get their myeloma under control."

Treatment Options for Neuropathy		
Treatment	Examples	Usage
Vitamins/Supplements	B vitamins, Folic acid, Vitamin E, Amino acids (ie, glutamine, acetyl L-carnitine, alpha-lipoic acid)	To potentially help protect nerve fibers
	Magnesium, Potassium, Tonic water	For cramping
Medications	Anticonvulsants, such as Gabapentin (Neurontin®) or Carbamazepine (Tegretol®)	For stabbing pain
	Antidepressants, such as Amitriptyline (Elavil®) or Sertraline (Zoloft®)	For burning, shooting, or tingling pain
	Pain medications, such as Over-the-counter pain relievers, Narcotics or Lidocaine patches	For mild or severe pain
Non-drug therapies	Exercise, Massage, Cocoa butter, Acupuncture, Physical therapy, Relaxation techniques, Capsaicin cream (Zostrix), etc.	For symptom relief



Kathleen Colson, RN, BS, BSN
Dana-Farber Cancer Institute



Beth Faiman, RN, MSN, CNP, AOCN
Cleveland Clinic Taussig Cancer Center



Regina Swift, RN, BSN
Institute for Myeloma and Bone Cancer Research



Joseph Tariman, RN/APN, MN, APRN-BC, OCN
Northwestern University Medical Faculty Foundation



Fundraising

MULTIPLE MYELOMA
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MMRF Race for Research San Francisco

This year's MMRF Race for Research 5K walk/run included 750 participants who came together on Saturday, April 9th at the Crissy Field Golden Gate National Recreation Area to run, walk, and show their support for myeloma research. This year's race was a huge success, raising over \$200,000 for multiple myeloma.

Special thanks to Jack Aiello, the top individual fundraiser, and Laura Wilson and the Wilson Family, for being the top team fundraiser. Corporate and family teams were out in full force, Kosan Biotechnology with 80 participants, Scios with 30 participants and The Yellow Team with over 50 participants.

Thanks to all Bay Area organizers, participants and volunteers who made the day such a great success!



Team Velocity 11 takes time to pose for a photo.



The Yellow Team smiles for the camera.



SAVE THE DATE:

MMRF Race for Research coming to a city near you!

Boston, MA
Saturday, May 21, 2005

Cleveland, OH
Sunday, June 12, 2005

New Canaan, CT
Saturday, June 18, 2005

Seattle, WA
Saturday, July 9, 2005

Chicago, IL
Saturday, September 24, 2005

Minneapolis, MN
Sunday, September 25, 2005

Philadelphia, PA
Saturday, October 8, 2005

Atlanta, GA
Sunday, October 23, 2005

Washington, DC
Saturday, November 12, 2005

For more information visit
www.mmrfce.org or contact Elissa Iuso
at 203-652-0219 or iuso@themmrf.org.

Fundraising

Community Fundraisers

MMRF Spin-a-Thon

Stephanie Carpenter, a San Francisco Bay Area friend and myeloma family member, hosted the first-ever **MMRF Spin-a-Thon**, on April 6th at her local gym, the Bay Club of Marin.

The event included 39 participants riding stationery spin bikes and making minimum donations of \$50 each. As Stephanie says, "the event quickly grew from this simple concept and 'spun' into something more." With so many people offering to make additional contributions and donations of their time and services, Stephanie was also able to organize a silent auction leading up to the event, raising a combined total of close to \$12,000 for myeloma research.

"It's amazing how many people wanted to give and how generous they were," Stephanie says. She's already working on the next Spin-a-Thon and thinks it's an idea that could easily catch on in any local community. "If you are looking for a way to help make a difference, planning an event like this is one of the most fun and rewarding things you can do."

Friends Together Gala



(L-R): Dr. Michael Lado, Christine Cardillo, Dianne Deutsch, Dr. John Foley and Marie Kenny.

The 2nd **Friends Together Gala** was held on Saturday, April 2nd at the Crocker House in New London, CT. In total, \$56,000 was raised through this grassroots social event. Thank you to this year's honorees: Dr. Mel Goldstein, Dr. Michael Lado and the evening's emcee, Dr. John Foley. Special thanks to event organizer Christine Cardillo and the event chairs, Dianne Deutsch and Jennifer Hough.

Start Your Own Fundraiser
It's As Easy As



Visit www.grassroots.multiplemyeloma.org
to get started today.

Golf Anyone?

Join a Tournament Near You and
Support the MMRF

Monday, June 13, 2005
Milford, CT

Links for Life Golf Tournament

Great River Golf Club
Contact Rich Carter at linksforlife@optonline.net
or (203) 353-1022.

Saturday, June 18, 2005
Averill Park, NY

4th Annual Albert G. Young Memorial Golf Tournament

Burden Lake Country Club
Contact Tim Young at tbbyoung@aol.com
or (518) 286-2212.

Monday, July 25, 2005
Beverly, MA

Bruce Figurido Memorial Golf Tournament

Beverly Golf and Tennis Club
Contact Louis Malaquias at lmalaquias@comcast.net.

Monday, July 25, 2005
Hardyston, NJ

Marc Mayer Memorial Golf Tournament

Wild Turkey Golf Club
Contact Brian Mayer at mayerb@mcginnsmith.com
or (212) 219-2083.

Thursday, August 25, 2005
Harrisburg, PA

2nd Annual Alexander R. Rich, Jr. Multiple Myeloma Charity Golf Tournament

Dauphin Highlands Golf Course
Contact Geoffrey Rich at garadvertising@comcast.net
or (717) 272-1450.

Monday, September 19, 2005
West Babylon, NY

1st Annual Barbara Claus Memorial Golf Tournament

Bergen Point Golf Club
Contact Denise Veracka at dveracka@contourmortgage.com or (516) 843-0218.

Spring Appeal

Help The MMRF Create A World Without Multiple Myeloma

Keep an eye out in your mail for the MMRF's 2005 Spring Appeal mailing. Please read it thoroughly to learn how far we have come in the fight against multiple myeloma since our founding in 1998.

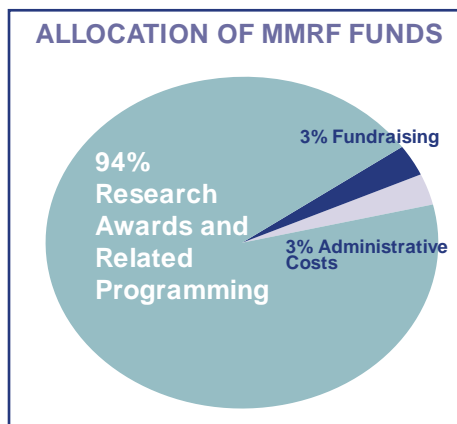
With the generous support of thousands of donors the MMRF:

- ▶ ignited innovative research by funding more than 100 grants at 56 institutions worldwide
- ▶ played a vital role in accelerating the development of lifesaving therapies such as Velcade and Revlimid
- ▶ currently funds more than 20 new compounds in pre-clinical testing and Phase I, II and III clinical trials that show promise in treating patients at all stages of the disease.

Taking our focus on research to the next level, the MMRF is now acting aggressively on the innovative advances now taking place in the areas of genomics, proteomics and cutting-edge technology through our exciting new initiative, the

Scientific Agenda. The Scientific Agenda will enable us to rapidly advance our understanding of the disease and bring new therapies to patients who urgently need them.

We apply 100% of every donation from our Spring Appeal directly to myeloma research. By contributing to the appeal you are personally helping us create a world without multiple myeloma.



Planned Giving

This year, you can establish a personal legacy of giving and help create a future without multiple myeloma. Consider making a planned gift to the MMRF and help it succeed in its mission to accelerate the search for the cure.

Regardless of the size of your estate, you can help. Many friends of the MMRF who may not be in the position to make an immediate cash gift see planned giving as an attractive way to leave a lasting legacy of hope to myeloma patients.

Your gift can be structured to address your personal objectives in meeting the financial needs of your loved ones. Choosing the most appropriate planned giving option and leaving a legacy of hope to myeloma patients is easy. Just follow these three steps.

Planning Strategies



Scott Santarella
Executive Director
MMRF
51 Locust Avenue, suite 201
New Canaan, CT 06840
(203) 972-1250
www.multiplemyeloma.org

- 1 Go to the Planned Giving section of the MMRF web site to review a variety of planned giving options to find one that is right for you and your loved ones.
- 2 Pick the gift type that best meets your personal planning objectives. Discuss your plan with your loved ones and your financial and estate planning advisor.
- 3 Contact Brian Porter at porterb@themmrf.org or 203-652-0206 to discuss your plans and request any additional information you need to make an informed decision.

It's so easy to get started. You, your loved ones and the thousands of myeloma patients who stand to benefit from your generosity will be grateful for your thoughtful act of kindness.

Volunteer Recognition

Beth and Stu Compton

Beth and Stu Compton have watched the MMRF change and grow significantly since they first met with Executive Director, Scott Santarella, in 2000. Scott had come to the Bay Area to meet with their myeloma patient support group and tell them about a new foundation being launched by Kathy Giusti and Karen Andrews. Immediately impressed by Scott's enthusiasm and the goals he shared for the foundation's future, Beth, who had recently been through a grueling, but successful double stem cell transplant and radiation therapy, knew instantly that she wanted to be involved.

"Being diagnosed with this disease changed my life. I was fortunate enough to have successful treatments, but I had to give up a career that I loved -- working with children with special needs. That was my soul, and once I was well enough, I needed something to fill the void; my desire to help make a difference was stronger than ever before." Volunteering for the MMRF, as she and her husband Stu, have done now for over 5 years, has been one of the many ways, she has chosen to devote her renewed energy and enthusiasm for life.



Beth and Stu Compton

As the co-leader of the San Francisco 5K Walk/Run Race for Research, Beth helped to raise over \$180,000 this year for myeloma research. In addition, she is an active recruiter for Blood Cancer Advocacy Day and also continues to be involved with San Francisco based myeloma support groups. Beth points out that her work for the MMRF couldn't be done

without the help of her husband who, as she says, "is my right hand man and does all my (literal and figurative) heavy lifting for me when it comes to these events." Both Beth and Stu also rely on the support and dedication of their daughters, Anastacia and Jodi, whom Beth refers to as "my computer tutors, editors, and biggest cheerleaders."

The Comptons hope that their volunteer efforts can be an inspiration to others.

They have watched in awe as family and friends who participate in the 5K are able to raise thousands of dollars and bring along hundreds of supporters each year. It's this contagious spirit that they believe will truly help the MMRF, and make the biggest difference in helping to find a cure.



MMRF Exclusive Acorn Jewelry Order Form



Name: _____ Phone: _____ Email: _____

Address: _____ City: _____ State: _____ Zip: _____

Relation to Myeloma: Patient Patient Family Member Patient Friend Nurse Clinician

Order total: Necklace (@ \$125 each) \$ _____ Bracelet (@ \$125 each) \$ _____ Earrings (@ \$50 pair) \$ _____
Large Pin (@ \$125 each) \$ _____ Small Pin (@ \$50 each) \$ _____ SUBTOTAL \$ _____

Tax (please add 6% sales tax to all orders within state of CT): \$ _____ GRAND TOTAL: \$ _____

Payment By Credit Card: Visa Mastercard Amex Card# _____

Signature: _____ Exp. Date ____/____/____

Please make all checks payable to the MMRF.
Please return to: MMRF, 51 Locust Avenue, Suite 201, New Canaan, CT 06840. Fax: 203-972-1259
Visit www.jewelry.multiplemyeloma.org to order online today.



MMRF
51 Locust Avenue, Suite 201
New Canaan, CT 06840

Accelerating the Search for a Cure

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Permit No. 58

Chicago Awards Dinner Huge Success



MMRF Executive Director, Scott Santarella with Event Chairs Philip Purcell, Chairman and CEO of Morgan Stanley and son David, Founder and Managing Partner of Continental Advisors LLC



Dinner Chairs and RoundTable Healthcare Partners' Executives Robert DeBaun, Lester Knight and Joseph Damico with Bonnie Hunt and General Norman Schwarzkopf