



*Accelerating  
the  
Search  
for a  
Cure*

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# MYELOMA FOCUS

Newsletter of the

## MMRF

### Boston Event Raises \$600,000

**B**ob Kraft knows a little something about the value of teamwork and its payoff, even against unfavorable odds. His New England Patriots emerged as champions due to the relentless effort and focused goal of every player on the team. As he kicked off the Multiple Myeloma Research Foundation's Boston Awards Dinner on April 3<sup>rd</sup> at the Fairmont Copley Plaza, Kraft likened this team ethic to the championship teamwork involved in finding a cure for myeloma.



(L-R) Sportscaster Steve Burton, former New England Patriot Ron Burton and Superbowl Champion Patriots Owner Bob Kraft

That night, the MMRF together with the Dana-Farber Cancer Institute (DFCI), Millennium Pharmaceuticals, honorary chairs, sponsors, patients, and families teamed up to raise over \$600,000 for myeloma research.

Steve Burton, sports commentator for WBZ TV in Boston, served as the evening's Master of Ceremonies and paid tribute to myeloma team leaders along with 550 attendees. Steve joined Dr. Ken Anderson in presenting his father, Ron Burton, former New England Patriot and myeloma patient, with the MMRF Public Awareness award.



(L-R) Mark Levin, CEO of Millennium and his wife Becky

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### President Bush Signs Blood Cancer Bill



Dr. Kenneth Anderson and Kathy Giusti with President Bush

**O**n May 14, 2002, President Bush signed into law the Hematological Cancer Research Investment and Education Act that was passed by the House during the Blood Cancer Coalition Advocacy Days 2002 in June. The signing was the result of the hard work and advocacy efforts of the Multiple Myeloma Research Foundation, the Leukemia & Lymphoma Society and the Lymphoma Research Foundation. The new law will enhance and coordinate federal support for blood cancer research and education programs for patients and the public.



# Welcome Letter

## Families Funding Research

**D**ear Friends,

Thanks to the efforts of several committed advocates and extraordinary leaders, including Senator Kay Bailey Hutchison (R-TX), Senator Barbara Mikulski (D-MD) and Geraldine Ferraro, blood cancer patients and families had reason to celebrate last month. The passage of the Hematological Cancer Research Investment and Education Act of 2002, signed into law on May 14th, represents an important step in the national commitment to fight blood cancers and an improved standing of the public/private partnership working to find a cure.

The new law allows the National Cancer Institute (NCI) to enhance its support of hematological research to a level more consistent with blood cancer incidence rates.

The MMRF looks forward to working with the NCI to identify myeloma research studies the agency will fund under this new law and those studies that private sources (like the MMRF) will continue to support. We plan to work with our NCI partners to ensure the most efficient distribution of research dollars in order to have the greatest impact on patients' lives and treatment discoveries.

Our work with Congress continues as well. In order for the NCI to proceed with the full charge of this law, we need to insure that adequate funds will be allocated for its purposes through the ongoing Congressional appropriations process.

With your continued help and support we truly are making a difference. Thanks again to everyone who made this success possible.



**Sen. Kay Bailey Hutchison (R-TX) and Geraldine Ferraro**

**L**ouisa Ayoub was a "dynamo of energy and love." She touched lives with her spirit and generosity as she continues to do now through a generous donation to fund an MMRF research grant.

Born in Cairo, Egypt in 1926, it was there that Louisa met and married Sam Ayoub, a business leader in the banking and airline industry. They came to the United States together in 1958 and eventually settled in Atlanta, where Sam was appointed as a senior executive at the Coca-Cola Company.



**Louisa Ayoub**

Shortly after her husband's death in 1997, Louisa was diagnosed with multiple myeloma. She was treated in Atlanta and remained stable for several years. As her treatments became less effective, she went to Connecticut to be closer to her family and to meet with Dr. Sundar Jagannath in New York City. Sadly, Louisa's options were running out and she passed away earlier this year.

Louisa and her family had been in contact with the MMRF since the onset of her illness and "had a great appreciation for Kathy Giusti's tireless work to find a cure, as well as for information and advice received from the foundation," according to her brother, Frank Elmasry. In appreciation of this work, Louisa made a generous bequest to fund a research grant through MMRF, "in hopes for a breakthrough that could help others."



**The MMRF Thanks**  
the following corporations for  
their support of Myeloma Focus



**CTI, HGS, Millennium, Ortho Biotech**

# MMRF GALA REPORT

## Boston Event a Huge Success

continued from page 1



Steve Burton and Donna Zaccaro

The MMRF Advocacy Award was then presented to Geraldine Ferraro for ensuring that Congress support the growing needs of myeloma research. Ferraro was presented the award by her daughter, Donna Zaccaro, herself a myeloma advocate and member of the MMRF Board.

Kathy Giusti presented the Corporate Leadership Award to Mark Levin of Millennium Pharmaceuticals for the company's investment and leadership in developing new therapies to treat multiple myeloma. Mark Levin said that "the partnership between the MMRF and Millennium is more than a business relationship, it is a shared mission and an alliance built on a common purpose that will change the lives of patients the world over."



Geraldine Ferraro and Ron Burton



Mel Stottlemyre



Richard Grasso

## NY Yankees and NYSE Support the MMRF

**T**he MMRF will return to New York City for its second annual summer fundraiser and an evening hosted by Mel Stottlemyre, Pitching Coach of the New York Yankees, and his wife Jean. As longtime friends and supporters of the Foundation, Mel and Jean have continued to demonstrate their commitment to finding a cure.

The event will take place at New York's St. Regis Hotel on Thursday, June 13<sup>th</sup> and will also honor Geraldine Ferraro with the MMRF Public Awareness Award and the Celgene Corporation with the Corporate Leadership Award.

Keith Olbermann, Emmy Award-winning News and Sports commentator, will serve as the evening's Master of Ceremonies. Keith is the current anchor of "**Speaking of Sports**" and "**Speaking of Everything**."

Honorary Chairs include Richard Grasso, CEO, New York Stock Exchange and Ed Randall, ESPN Radio Host. Dinner Chairs include Chris Blackwell, Judy and Paul DeWinter, Amy Cavers, Sol J. Barer, PhD, Angela Macropoulos, Ken Makovsky and Donna Zaccaro.



# McCARTY FOUNDATION AND MMRF

## Fighting Side-by-Side for a Cure

**K**athy Giusti and Craig McCarty met five years ago at a multiple myeloma fundraising roundtable and became instant friends. Craig, who had recently been diagnosed with multiple myeloma, was gifted from his son, Darren McCarty, an NHL star and Detroit Red Wing, with the McCarty Cancer Foundation. Kathy was forming the MMRF at the time. Their mutual bold approach to raising research funds and resolute support from their family members laid the basis for what is now a solid partnership in the fight to cure multiple myeloma.

After Craig's death in 1999, Darren and Craig's wife Roberta took over leadership of The McCarty Cancer Foundation. At its annual "Gathering for the Goal" fundraiser, the McCarty Foundation honored the strong partnership of Kathy and Craig by presenting Kathy with its Humanitarian Award. The award, which recognizes those who make a difference

in the lives of cancer patients, was a "fitting honor" for Kathy, said Roberta. Darren said that he could "not think of anyone who has done more over the last five years to raise awareness of myeloma and funding for myeloma research than Kathy." Craig and Kathy's friendship and the close-knit goals of the their respective organizations have led to significant milestones in the fight to cure myeloma.



Kathy accepting Humanitarian Award from Detroit Red Wing, Darren McCarty

The McCarty Cancer Foundation has funded over \$3 million in myeloma research and co-sponsors the MMRF Senior Research Awards. It has become an important resource for patients and families by hosting regular support groups in both Detroit and Ontario and by sponsoring national fundraising events and advocacy initiatives.

For more info on the McCarty Cancer Foundation go to [www.cancerfoundation.org/mcf/](http://www.cancerfoundation.org/mcf/)

## Barit Fashions 4 A Cure



(L-R) Bruce, Ashley and Jerra Barit

**A**shley Barit, a 21-year-old senior at Canisius College in New York, took charge once again to organize the Fourth Annual "Fashions 4 A Cure" fashion show in honor of her mother, Jerra Barit. Ashley first launched the show in 1999, shortly after her mother was diagnosed with multiple myeloma. This year's return to the runway featured adult and children's fashions from **Ann Taylor** and **The Children's Place**. The event raised \$19,000 in support of multiple myeloma research.



Models prepare for the show

# MMRF Race for Research

## San Francisco 5K Walk/Run Raises \$180,000 for Research



Scott Santarella of the MMRF and Dick Brewer, CEO of SCIOS



Runners rally at starting line



**M**ore than 400 participants joined Dick Brewer, President and CEO of SCIOS, Myrtle Potter, COO of Genentech, and Kathy Giusti to raise awareness of and funds for multiple myeloma research at San Francisco's Crissy Field on April 14<sup>th</sup>.

A combination of dedicated planning, enthusiastic support and Golden Gate sunshine helped to make the San Francisco MMRF Race for Research 5K Walk/Run a huge success.

MMRF wishes to extend a special thanks to Beth Compton and Ron Anker for their incredible organization and coordination on the local level and to Melissa Nafzgar for her planning role with SCIOS. The event proved that everyone has the potential to make a big difference. John Peckham and Beth Compton, both patients, personally raised over \$8,000 each!

## Join Us July 20<sup>th</sup> for the MMRF Race for Research - Seattle

**J**oin James A. Bianco, MD, President and CEO of CTI, Inc. for the Seattle MMRF Race for Research 5K Walk/Run. The event begins at 9:00 AM July 20<sup>th</sup> at Sand Point Magnuson Park. Dr. Bianco will be joined by co-chair John Schwartz, co-owner of Schwartz Brothers Restaurants, and honorary chair Jeff Nelson, pitcher for the Seattle Mariners.



5K Chair James A. Bianco, MD

For more information, contact  
Craig Robertson at  
robertsonc@themmrf.org  
203-972-1250.

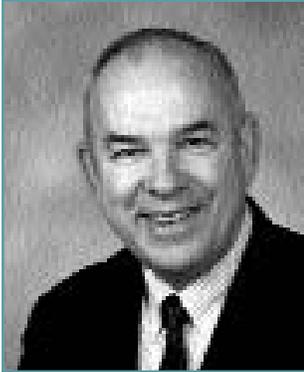
### Upcoming Events

September 8, 2002  
Boston, MA  
Myelothon - 1:00 PM  
Boston Commons

September 21, 2002:  
Chicago, IL  
MMRF Race for Research 5K  
Walk/Run - 10:00 AM  
Grant Park

September 28, 2002:  
Goshen, CT  
Miles Conquer Myeloma 5K  
Walk/Run - 9:00 AM

# ASK THE EXPERT



Dr. Philip Greipp, Mayo Clinic

This month's **Ask the Expert** features the MMRF's Scientific Advisor, Philip Greipp, MD, Director of Hematology Research at the Mayo Clinic in Rochester, MN.

**Q:** Dr. Greipp, my doctor has recommended that I start thalidomide therapy because it appears to be effective in myeloma. Can you tell me if it has any side effects?

Yes, thalidomide has demonstrated efficacy in myeloma and it is currently under investigation for use in myeloma. If your doctor has recommended thalidomide, he or she feels that the benefit you will obtain from this agent outweighs any possible side effects you might experience. A typical starting dose is 200 mil-

ligrams per day, but a lower dose may minimize early side effects.

Side effects that may occur with use of thalidomide include constipation, dizziness, drowsiness, dry skin or rash, peripheral edema (swelling in the legs, ankles, or feet) and neuropathy, a disorder of the nerves that can result in abnormal sensations (such as burning or tingling) in the hands and feet. Not everyone will experience these side effects. If they occur, there are several things you can do to minimize many of them, and most are manageable (see table below). Report any symptoms to your doctor.

**Q:** I heard that Zometa® is a new drug for myeloma bone disease. What are the advantages of this agent over Aredia®?

Both Aredia (pamidronate, Novartis) and Zometa (zoledronic acid, Novartis) are bisphosphonates -- drugs that inhibit bone destruction. Both are used to treat bone complications associated with a variety of tumor types, including myeloma. Both agents are administered once a month. They are equally effective at preventing bone destruction, and at 9 months, both are associated with a similar reduction in bone pain and fractures. Studies are ongoing to determine the efficacy of Zometa over a longer period of time. Both have a similar safety profile. The main differences are in their potency and administration. Zometa is more potent, so it can be administered in a shorter period of time (15 minutes versus 2 to 4 hours with Aredia); thus, it may be more convenient.

Side Effect	Strategy
Constipation	Easily managed with adequate fluid intake and use of a stool softener and mild laxatives.
Drowsiness	Usually improves after thalidomide is taken for several weeks or the dose adjusted. Can be minimized by taking thalidomide on an empty stomach at bedtime.
Dizziness	Patients should sit upright for a few minutes if they have been lying down before they stand up. If severe, may require dose adjustment.
Dry Skin/ Rash	Itching can be managed with antihistamines or topical steroids. If rash is severe, thalidomide should be stopped and can be restarted at a lower dose (50 mg to 100 mg) with close monitoring.
Peripheral Edema	Often short-lived and managed with elastic stockings, foot elevation, or occasionally, dose reduction.
Neuropathy	May be related to long-term use of the drug and/or previous exposure to large doses of chemotherapy. Symptoms may resolve if therapy is discontinued when they first appear. The dose may be reduced if symptoms are mild.



# Medical Corner

## Report from ASCO 2002

The 38<sup>th</sup> annual meeting of the American Society for Clinical Oncology (ASCO) was held on May 18-21 in sunny Orlando. In this issue, we present the highlights of the Poster Session and the Educational Session in multiple myeloma.

Preliminary data from the Phase II study of PS-341

### Preliminary Phase II Data Show PS-341 Active in Majority of Patients

(Millennium Pharmaceuticals, Inc.) in relapsed and refractory myeloma generated much excitement at ASCO. In this study, PS-341 (also known as MLN341 or LDP-341) stabilized or reduced M protein in the majority of study participants.

The 24-week Phase II study included 202 patients who had progressive disease despite having received at least two prior therapies. Results from the first 78 patients - who had received an average of five prior regimens - are shown in the table on the right. Altogether, 77% of the 70 patients who could be evaluated experienced a reduction or stabilization in their M protein, an indicator of tumor burden. Twenty percent achieved a greater than 90% reduction in M protein. Equally exciting was the fact that the majority of patients did not experience disease progression during the study. Side effects were manageable and predictable.

A Phase III trial comparing PS-341 and high-dose dexamethasone in patients with relapsed or refractory myeloma has just been initiated.

Response	# Patients (%)
Complete or partial:	
> 90% reduction	14 (20%)
> or = 75% reduction	7 (10%)
> or = 50% reduction	6 (9%)
> or = 25% reduction	6 (9%)
Stable disease	21 (30%)
Progressive disease	12 (17%)
Not evaluable	4 (6%)

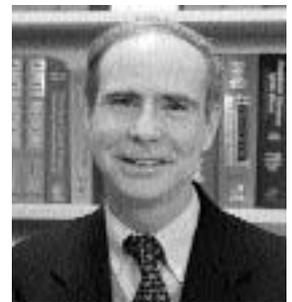
Total 77%

Novel

### Advances in Basic Science and Clinical Practice

#### Biologically-based Therapies: A New Treatment Model

Kenneth C. Anderson, MD (Dana-Farber), began the session by discussing the role of novel biologically-based therapies in myeloma. According to Dr. Anderson, these types of approaches are needed to overcome resistance to current therapies and improve patient outcome. "Novel biologically-based therapies target the mechanisms that support myeloma cell growth and survival in the bone marrow and represent a new treatment model in myeloma."



**Dr. Ken Anderson**

The bone marrow microenvironment plays a key role in promoting growth, survival, drug resistance and migration of myeloma cells. The close contact between myeloma cells and normal cells -- particularly bone marrow cells -- plays a critical role in the progression of the disease. These cells interact via molecules on their surface and fit together like a lock and key. Referred to as cell adhesion molecules, they allow myeloma cells to interact with bone marrow cells, stimulating the production of growth and survival factors for myeloma cells, as well as protecting them from apoptosis (programmed cell death). Later, the loss of certain adhesion molecules allows myeloma cells to escape into the blood where they can spread to other organs.

The interaction between cells triggers a variety of reactions within the cells that lead to the production of myeloma growth and survival factors. Novel therapies under investigation in myeloma, such as thalidomide and the immunomodulatory drugs (IMiDs™, Celgene), the proteasome inhibitor PS-341, (Millennium) and arsenic trioxide (Trisenox™, Cell Therapeutics), interfere with these reactions in a variety of ways and thus inhibit myeloma growth and induce cell death. Preliminary studies indicate that two other agents may act in a similar manner and may prove effective in myeloma. These agents include TRAIL (also known as Apo2 ligand, Immunex /Genentech) and PTK787 (Novartis).

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# Medical Corner

## Transplantation in Myeloma



Dr. Nikhil C. Munshi

**N**ikhil C. Munshi, MD (Dana-Farber) presented the current state-of-the-art of transplantation in myeloma and discussed strategies being implemented to improve outcome. High-dose therapy and autologous stem cell support is safe and effective, resulting in responses that are superior to standard chemotherapy. Various methods to improve this response, such as tumor cell purging or intensifying the regimen with other chemotherapy

drugs or total body irradiation, have not been more effective. These include the use of dexamethasone, thalidomide with or without dexamethasone, IMiDs, bisphosphonates and immune-based therapies, such as vaccines.

Tandem (double) transplants appear to be superior in a certain subset of patients, but longer follow-up is necessary to confirm. Older patients and patients with renal failure are no longer automatically excluded from receiving a transplant, but are considered on an individual basis.

The safety of allogeneic transplants has improved in recent years, but the most promising avenue in this respect is the use of the mini-transplant (non-myeloablative transplant). New approaches for maintenance of remissions achieved following transplantation are under investigation. (See box below.)

### Strategies for Maintenance of Remissions Following Transplantation

- Dexamethasone
- Thalidomide +/- Dexamethasone
- Interferon- $\alpha$
- Other novel agents
  - IMiDs
- Bisphosphonates
- Immune-based therapies
  - Vaccines

According to Dr. Munshi, transplantation may be considered as a "first step" in treatment in some settings. "The bottom line is although transplantation doesn't always cure the disease, it achieves distinctly defined endpoints. It increases survival by almost double or more, and it decreases the tumor burden so that other newer therapies, such as immune-based therapies, can be used to eliminate the remaining tumor cells."

## Mini-transplants Promising

Results of a recent study of mini-transplantation in 32 myeloma patients (Maloney, et al) with a median follow-up of 1 year:

- ✓ 53% of patients achieved a complete response
- ✓ 31% achieved a partial response
- ✓ Overall survival was 81%

## New Advances in Myeloma Bone Disease



Dr. James R. Berenson

James R. Berenson, MD (Cedars-Sinai Medical Center) discussed novel insights and therapies for myeloma bone disease, the major cause of symptoms in myeloma. Loss of bone structure occurs because bone-destroying cells (osteoclasts) are stimulated as a result of the interaction between myeloma cells, normal cells in the bone microenvironment and the osteoclasts themselves.

Bisphosphonates, such as pamidronate and zoledronic acid (Aredia<sup>®</sup> and Zometa<sup>®</sup>, Novartis), reduce the skeletal complications of myeloma bone disease and help relieve symptoms, dramatically improving patient's lives. Recent studies in the laboratory suggest that bisphosphonates also have potential anti-myeloma effects. Kyphoplasty, a new surgical procedure for treating spinal compression fractures, also dramatically improves pain and functional ability.

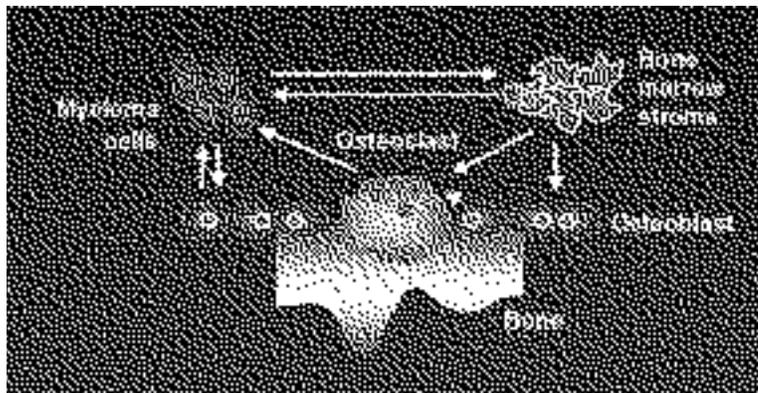
Recent studies have identified a variety of factors that stimulate osteoclasts and have pinpointed the ways that the different

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# Medical Corner

## Myeloma Bone Disease

cell populations interact in the bone marrow to cause bone loss in myeloma. As a result, several new agents that inhibit bone loss are entering clinical trials. According to Dr. Berenson, two new agents -- osteoprotegerin (OPG) and RANK-Fc -- inhibit a key interaction between osteoclasts and myeloma cells and have been shown to reduce bone destruction in animal models. In a recent Phase I trial, a single dose of OPG reduced bone resorption and was well tolerated. The proteasome inhibitor PS-341 may also reduce bone resorption in a similar manner, and the cholesterol-lowering statin drugs may have an effect on bone as well.



Factors (cytokines) released by myeloma cells stimulate bone-destroying osteoclasts directly and indirectly via their action on other cells.

## Industry Update

### Celgene Presents Preclinical Data on IMiDs™ and SelCIDs™

Celgene Corporation recently reported preclinical data on their IMiDs (immunomodulatory drugs) and SelCIDs (selective cytokine inhibitory drugs) at the American Association for Cancer Research (AACR) meeting. The data show that both types of drugs have significant anti-tumor activity in animal models of solid tumors. IMiDs are orally available analogs of thalidomide that are more potent and have an improved safety profile in comparison with the parent compound. In addition to their anti-tumor activity, the IMiDs were shown to enhance the effectiveness of an experimental cancer vaccine. Celgene has two IMiDs in clinical trials: Revimid™ and Actimid™. Both are in Phase I/II trials in myeloma and Revimid is also being evaluated in solid tumor cancers.

### Marketing Application for Thalomid® Accepted for European Review

Celgene Corporation's marketing application for Thalomid as a treatment for relapsed or refractory myeloma has been accepted for review by the European regulatory agency. If and when approved, Thalomid would be authorized for use in all member states of the European Union. Celgene will be conducting an

additional trial in patients with early stage myeloma before it submits its application to the U.S. Food and Drug Administration (FDA) for use in myeloma.

### Dendreon Receives Orphan Drug Status for Mylovenge™

The FDA has granted Mylovenge, Dendreon Corporation's therapeutic vaccine for myeloma, orphan drug status. This designation is designed to encourage development of new therapies for diseases that affect fewer than 200,000 people in the U.S. Mylovenge is currently in Phase II clinical trials in myeloma and other disorders. Early trials suggest that the agent is safe, and may stimulate the immune system and cause disease regression or stabilization.

### Phase II Trial of Progen's PI-88 Initiated

Progen Industries (Australia) recently announced that a multi-center Phase II multiple myeloma trial of PI-88, their anti-cancer compound, is under way. A third patient was recently enrolled in the trial at the Mater Misericordiae Hospital in Newcastle. PI-88 acts by inhibiting angiogenesis and tumor metastasis and is administered as an injection under the skin.

# MMRF Research Roundtable

## B-Cell Biology: Insight into the Initiation of Myeloma

The eighth MMRF Research Roundtable session was unique in that it was the first such meeting entirely devoted to the subject of plasma cells and their relationship to the origination and development of multiple myeloma. The session brought together clinicians and researchers from academia, industry and the National Cancer Institute to help better understand the control of generation of plasma cells (the normal counterparts of myeloma cells) in order to gain insight into how myeloma and other B cell cancers potentially arise.



Roundtable co-chair  
Dr. Chen-Kiang

One of the key findings of plasma cell research is that the stages of normal plasma cell differentiation that are relevant to the initiation of myeloma are now becoming more precisely defined. By identifying genetic events associated with myeloma, we are already beginning to provide more accurate diagnosis and staging of the disease as well as important prognostic information. The identification of these genetic events may also eventually lead to targeted therapies for myeloma.



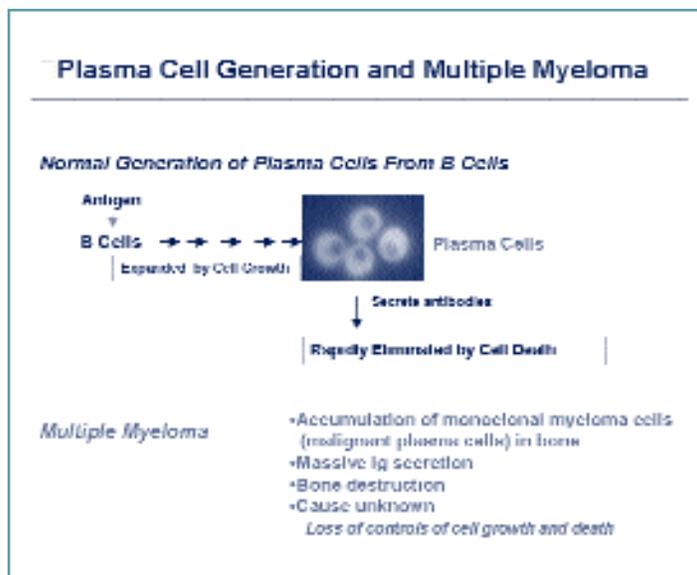
Roundtable co-chair  
Professor MacLennan

The Roundtable took place March 16-18 in New York City, and was co-chaired by Selina Chen-Kiang, PhD (Weill Medical College of Cornell University, NY) and Ian C.M. MacLennan, MD, PhD (University of Birmingham, England). The session was funded by the MMRF with support from Amgen, Celgene, Genta and Human Genome Sciences.

According to Dr. Chen-Kiang, the roundtable capitalized on the emerging knowledge of plasma cell generation that has taken place within the past year. "Researchers have come away with new insights into the checkpoints that are present in the generation and function of normal plasma cells," she noted. In addition, key genetic abnormalities have been identified that may contribute to the initiation and progression of myeloma, as well as various B cell cancers.

In addition, several of the factors present in the bone microenvironment that are crucial for the survival of normal plasma cells and malignant myeloma cells have now been identified.

This has been taken one step further by looking at ways to make the bone microenvironment "inhospitable" to myeloma cells. Several novel therapeutics that act in this way, such as thalidomide and its derivatives (Celgene), the proteasome inhibitor PS-341 (Millennium Pharmaceuticals), osteoprotegerin (OPG, Amgen), and Genasense™ (Genta) are being evaluated in clinical trials in myeloma.



### Roundtable Sponsors

Amgen  
Celgene  
Genta  
Millennium

# MMRF CLINICAL TRIALS MONITOR (CTM)

## Your Top Source for Myeloma Clinical Trials

The recently launched MMRF Clinical Trials Monitor (CTM) database has been very well received by members of the myeloma community. Over a recent 3-month period, 3,400 individuals conducted a search: 60% were patients, 30% were family or friends, and the remainder were health care professionals and researchers. The type of trial most often searched is the Novel Drug category, where information on over 30 trials of cutting-edge therapies can be found.

CTM provides access to the most current information about open myeloma clinical trials. CTM is updated on a monthly basis and currently lists over 50 trials, mainly single institution and pharmaceutical trials not listed elsewhere.

To learn about the latest Multiple Myeloma clinical trials, simply go to:  
<http://www.multiplemyelomatrials.org>

Trials Posted on CTM	Contact Information
<p><b>A multicenter, controlled, parallel-group, randomized, open-label study to evaluate the efficacy and safety of two Revimid™ (CDC 501) dose regimens when used alone or in combination with dexamethasone for the treatment of subjects with relapsed or refractory myeloma.</b>  <a href="http://www.multiplemyeloma.org/ClinicalTrials/CTM-68.html">www.multiplemyeloma.org/ClinicalTrials/CTM-68.html</a></p>	<p>Dana-Farber Cancer Institute (MA)            Kathy Kelly, RN            617-632-6303  <a href="mailto:kakelly1@partners.org">kakelly1@partners.org</a></p>
<p><b>A Phase II exploratory study of combination PS-341 and thalidomide in refractory myeloma.</b>  <a href="http://www.multiplemyeloma.org/ClinicalTrials/CTM-53.html">www.multiplemyeloma.org/ClinicalTrials/CTM-53.html</a></p>	<p>University of Arkansas for Medical Sciences (AK)            Kathryn Bailey, CCRP            501-296-1503, ext. 1441  <a href="mailto:BaileyKathrynL@uams.edu">BaileyKathrynL@uams.edu</a></p>
<p><b>A randomized study of low-dose thalidomide and dexamethasone vs. dexamethasone, with or without biaxin, for treatment of newly diagnosed myeloma.</b>  <a href="http://www.multiplemyeloma.org/ClinicalTrials/CTM-19.html">www.multiplemyeloma.org/ClinicalTrials/CTM-19.html</a></p>	<p>NY Presbyterian Hospital/Weill Medical College of Cornell University (NY)            Dr. Ruben Niesvizky            212-746-3964</p>
<p><b>Randomized Phase III study of dexamethasone with or without Genasense™ (Bcl-2 antisense oligonucleotide) in patients with relapsed or refractory myeloma.</b>  <a href="http://www.multiplemyeloma.org/ClinicalTrials/CTM-25.html">www.multiplemyeloma.org/ClinicalTrials/CTM-25.html</a></p>	<p>Studies conducted at multiple sites.            908-286-9800  <a href="mailto:ClinicalTrials@genta.com">ClinicalTrials@genta.com</a></p>
<p><b>Phase II evaluation of FTI (R115777) in treatment of advanced myeloma.</b>  <a href="http://www.multiplemyeloma.org/ClinicalTrials/CTM-40.html">www.multiplemyeloma.org/ClinicalTrials/CTM-40.html</a>  <a href="http://www.multiplemyeloma.org/ClinicalTrials/CTM-57.html">www.multiplemyeloma.org/ClinicalTrials/CTM-57.html</a></p>	<p>Mayo Clinic (MN), Deb Schott            507-538-1521  <a href="mailto:schott.debra@mayo.edu">schott.debra@mayo.edu</a>            H. Lee Moffitt Cancer Center (FL)            Dr. Melissa Alsina            813-903-6886  <a href="mailto:AlsinaM@moffitt.usf.edu">AlsinaM@moffitt.usf.edu</a></p>
<p><b>A Phase II Study of Gleevec™ (Imatinib mesylate, formerly known as STI-571) in patients with relapsed and refractory myeloma.</b>  <a href="http://www.multiplemyeloma.org/ClinicalTrials/CTM-41.html">www.multiplemyeloma.org/ClinicalTrials/CTM-41.html</a></p>	<p>Mayo Clinic (MN), Deb Schott            507-538-1521  <a href="mailto:schott.debra@mayo.edu">schott.debra@mayo.edu</a></p>
<p><b>An open-label, Phase I study to assess the safety and efficacy of MRA (humanized anti IL-6 antibody) given as monotherapy to patients with myeloma.</b>  <a href="http://www.multiplemyeloma.org/ClinicalTrials/CTM-50.html">www.multiplemyeloma.org/ClinicalTrials/CTM-50.html</a></p>	<p>University of Arkansas for Medical Sciences (AK)            Kathryn Bailey, CCRP            501-296-1503, ext. 1441  <a href="mailto:BaileyKathrynL@uams.edu">BaileyKathrynL@uams.edu</a></p>

# MMRF INSTITUTIONAL INSIGHTS



**INSTITUTIONAL  
INSIGHTS**  
ON MYELOMA

The MMRF recently held Institutional Insights conference at the Myeloma Institute for Research and Therapy at the University of Arkansas for Medical Sciences and also at the Cleveland Clinic.

Topics included prognostic indicators and risk categories in multiple myeloma, bisphosphonates and the bone marrow micro-environment, and the role of high-dose chemotherapy and stem-cell transplantation.

The MMRF would like to thank all the experts and attendees for their support, especially the Chairs, Dr. Guido Tricot, Division Head of the Myeloma Institute for Research and Therapy at the University of Arkansas and Dr. Mohamad Hussein, Director of Multiple Myeloma Programs at the Cleveland Clinic Taussig Cancer Center.



The MMRF at the University of Arkansas  
(L-R) Dr. Robert Vescio, Dr. Brian Van Ness, Tammy Smith, Dr. Bart Barlogie, Loren Feingold, Dr. Nikhil Mushi and Dr. Guido Tricot



The MMRF at the Cleveland Clinic  
(L-R) Dr. Philip Greipp, Dr. Isador Lieberman, Gabriele Schmitt, Dr. Jose Cruz, Tammy Smith and Dr. Mohamad Hussein

## DATES TO REMEMBER

### June 6, 2002

Teleconference: Novel Therapies and Clinical Trials in Multiple Myeloma. Ken Anderson, MD, Dana-Farber Cancer Institute. 3-4 PM EST. Hosted on the MMRF Web site for one year.

### June 13, 2002 New York, NY

New York City Awards Dinner  
Contact Scott Santarella:  
santarellas@themmrf.org or (203) 972-1250

### June 21 & 22, 2002 Stanford, CA

Institutional Insights on Myeloma  
Stanford University Medical Center

### July 20, 2002 Seattle, WA

MMRF Race for Research 5K Walk/Run

### Sept. 21, 2002 Chicago, IL

MMRF Race for Research 5K Walk/Run

### Sept. 24, 2002 Philadelphia, PA

Institutional Insights on Myeloma in collaboration with University of Pennsylvania Medical School

### October 3, 2002 New York, NY

Institutional Insights on Myeloma

### October 4-5, 2002 New York, NY

Research Roundtable on targeted therapeutics

### November 2, 2002 Greenwich, CT

MMRF "Friends for Life" Fall Gala

### Continual Programs:

MMRF Webcast

<http://multiplemyeloma.org>

Past Myeloma Teleconferences

[www.multiplemyeloma.org/events/teleconference.html](http://www.multiplemyeloma.org/events/teleconference.html)

### \*Institutional Insights on Myeloma

For more information on Institutional Insights Programs: [www.multiplemyeloma.org/events/seminars.html](http://www.multiplemyeloma.org/events/seminars.html) or call (203) 972-1250

# YOU NEED TO KNOW

## Patient Assistance Programs

**M**any pharmaceutical companies have assistance programs to guide patients through the maze of insurance coverage and to help them obtain needed medications. The following are such programs set up specifically for Procrit® (epoetin alfa, Ortho Biotech), Thalomid® (thalidomide, Celgene), and Zometa® (zoledronic acid, Novartis).

### Procrit Reimbursement Line and Patient Assistance Hotline

PROCRIline™, the Procrit Reimbursement and Patient Assistance Hotline, can determine if a patient is financially and medically eligible for one of the Procrit patient assistance programs. Patients who qualify for the patient assistance program financially and medically receive a PROCRIline card and then can have prescriptions filled at a local pharmacy. PROCRIline also assists in verifying insurance benefits, answers many Procrit coding questions and provides support with appeals.

#### How Do I Contact PROCRIline?

You or your doctor can call the toll free Procrit Reimbursement and Patient Assistance Hotline at 1-800-553-3851, Monday through Friday from 9 AM to 8 PM EST. You can also get more information on Procrit patient assistance and reimbursement programs at [www.procritline.com](http://www.procritline.com).

### Thalomid Therapy Assistance Program

The Therapy Assistance Program helps patients obtain Thalomid. The primary goal is to find third party benefits, if available. If none are available, the program will assess eligibility for free drugs based on income and assets. The program can also provide assistance with insurance claim appeals and supplies letters of medical necessity when needed.

#### How Do I Contact Them?

Your doctor will need to call 1-888-4-CELGENE (1-888-423-5436), prompt 3, to request an application form. The form will be faxed to your doctor, who will then fill out the application with you. Both of you will need to sign it. Your doctor then faxes the completed application to Celgene and your coverage options will be assessed based on your income and insurance

information. The company's goal is to provide a response within 48 hours.

### ZOMETA Assistance Program for Patients (ZAPP)

ZAPP provides assistance regarding insurance benefits and issues and helps identify sources of coverage for Zometa. For patients who do not have insurance coverage, the Novartis patient assistance program provides full assistance for Zometa to qualified patients based on income and other eligibility criteria.

#### How Do I Contact Them?

Patients, health care providers and caregivers can call the ZOMETA Reimbursement Support line at 1-866-4-ZOMETA (1-866-496-6382), Monday through Friday, 9 AM to 8 PM EST. A reimbursement specialist will help with questions regarding insurance coverage and determine if you are eligible for assistance. If so, your doctor can fill out the necessary paperwork.

If you or someone you know is having difficulty obtaining other prescribed medications, try contacting the manufacturer directly. The following Web sites may be helpful:

#### Directory of Prescription Drug Patient Assistance Programs

<http://www.phrma.org/searchcures/dpdpap>

Prescription Drug Assistance Programs Provides information on public and private programs that offer discounted or free medication, as well as Medicare health plans that include prescription coverage  
<http://www.medicare.gov/Prescription/Home.asp>



## CONTRIBUTING EDITORS

Kathy Giusti  
Scott Santarella

MEDICAL WRITER  
Marie Recine

PRODUCTION  
backofficenyc

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EXECUTIVE DIRECTOR  
Scott Santarella

The Multiple Myeloma  
Research Foundation  
3 Forest Street  
New Canaan, CT 06840  
Telephone (203) 972-1250  
Fax (203) 972-1259  
E-mail: [themmrf@themmrf.org](mailto:themmrf@themmrf.org)  
Visit our web site at  
<http://www.multiplemyeloma.org>

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.

## Donna Zaccaro



Donna Zaccaro

**D**onna Zaccaro's media career spans 20 years since her early beginnings managing press coverage for her mother, Geraldine Ferraro, during several political campaigns. Her portfolio includes running a marketing and communications consulting firm, worked on a major network television news show and currently heads up an independent film and television production company.

It didn't take long for Donna's journalistic instinct to kick in when she learned of her mother's multiple myeloma diagnosis in 1998. Within days, the then-producer of NBC's **Today Show**, used every resource available and quickly identified Dr. Kenneth Anderson as the leading multiple myeloma specialist and Kathy Giusti, at the Multiple Myeloma Research Foundation, as the primary source of information on the disease. "It became clear that they were the people I needed to talk to in order to better understand my mother's diagnosis and the disease itself."

As an accomplished producer and a Harvard Business School graduate, Donna quickly assembled a team that would help answer the questions left unanswered by her mother's initial diagnosis. She quickly recognized that the information she had uncovered, needed to be brought to the nation's attention. She produced a feature **Today Show** segment on Kathy Giusti and the MMRF focusing on the search for a cure for multiple myeloma. The program successfully launched awareness of the disease into the national press, bringing needed attention from policy-makers and funding sources.

Since orchestrating her mother's public announcement on national television, **NBC**, in print, the **New York Times** and producing the **Today Show** segment, Donna has remained committed to building awareness of multiple myeloma as a member of the MMRF Board. "There are so many stories that can make a difference." Among these include the fact that blood cancers are second only to lung cancer in claiming the lives of cancer patients, and that myeloma is the third fastest growing cancer. More can be done to highlight the prevalence of myeloma in the African American population, since this population is affected more frequently.

While her mother's celebrity has brought recognition to myeloma, Donna suggests that it doesn't always take a well-known person to compel press coverage, policy-maker attention, and research funding. "There is no doubt that there has been an increase in attention because of my mother's willingness to be a spokesperson for patients, but individual stories can often be just as poignant, if not more so."

Through her role on the MMRF Board, Donna hopes to ensure that everyone's story can be shared.



# MEET OUR NEW COLLEAGUES

## MMRF Development Director



Craig Robertson

Craig comes to the MMRF with over eight years of non-profit development experience and a commitment to the cause of curing multiple myeloma. "I am absolutely thrilled to be a part of the Multiple Myeloma Research Foundation team. It is an honor to work with a group of individuals who have accomplished so many great things in such a short period of time and I look forward to building on the development strategies that have made the Foundation such a tremendous success. I am committed to doing everything in my power to speed up the search for a cure."

The Multiple Myeloma Research Foundation is pleased to welcome Craig Robertson as its new Director of Development. In his new role, Craig is responsible for planning and implementing the MMRF's fundraising efforts, including special events, major gifts and annual appeals. He will also assist with the formulation of development strategy, including identification of new funding sources, corporate sponsors and foundation partnerships.

Craig began his development career with the upstate New York chapter of the Muscular Dystrophy Association (MDA). He soon became District Director of Central and Western New York where he oversaw hundreds of fundraising events and in just over two years raised more than \$2,000,000.

Craig then served as MDA's Regional Coordinator for two years, overseeing five district offices in Connecticut and downstate New York. Craig guided them to their most successful fundraising years. He became Regional Director of the MDA's Connecticut and New York district offices in 1999 where he oversaw fundraising and development efforts, directed the association's array of health care and program services and coordinated the annual Jerry Lewis Labor Day Telethon. In addition to these duties, Craig served on several national training and development task forces within different cities, working with local and regional development staff to improve their local fundraising events and programs.

Craig helped raise over \$13,000,000 in his eight-year career with the MDA and coordinated five Labor Day Telethons that raised over \$25,000,000.

Craig graduated cum laude from Niagara University with a Bachelor of Arts in Political Science. He resides in Middletown, CT with his wife of four years, Kristie.

## MMRF Summer Interns

Carolyn Y. Shih, M.D.

Carolyn Shih, a multiple degree graduate student at Columbia University, scheduled to receive her Medical, Public Health and Business Administration degrees in May 2003, will join the MMRF this summer as an intern. She will be working directly with Kathy Giusti to develop a 3-year strategic business plan for the foundation.

Carolyn's experience includes a fellowship with the National Cancer Institute's (NCI) Lab of Clinical Pharmacology, where she quantified drug levels and developed models for predicting effective therapeutic levels for cancer patients. In addition to her medical and business background, she is conversant in Mandarin, Taiwanese and Spanish along with being both a concertmaster and soloist in the piano and violin.

Scott Stransky

Scott Stransky, soon to be a sophomore at MIT and majoring in Mathematics and Computer Science. Scott returns to the MMRF this summer to assist with the office's information technology systems. He will be working with a database design expert to help create a customized informational database that will improve the way the MMRF is able to communicate with physicians and patients.

Scott began working as a volunteer with the MMRF two years ago, and was recognized for his computer skills and willingness to take on several tasks. His previous work included the creation of new databases, web site consulting, donation processing, event organization and information technology system maintenance.

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## **Cancer Bill Signed by President Bush**

**Research Investment and Education Act Becomes Law**

**On May 13<sup>th</sup> President Bush signed the Hematological Cancer Research Investment and Education Act that was passed by the House at Advocacy Days 2002 in June. The legislation will intensify and coordinate federal support for blood cancer research and education programs for patients and the public.**



(L-R) Rep. Phil Crane, Rep. Jim McGovern, Sen. Barbara Mikulski, Sen. Kay Bailey Hutchison, President George W. Bush, Geraldine Ferraro, Patricia Hamel, NIH Director Elias Zerhouni, NCI Director Dr. Andrew von Eschenbach