



# MYELOMA TODAY

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A Publication of the International Myeloma Foundation

Dedicated to improving the quality of life of myeloma patients while working towards prevention and a cure.

## Scientific & Clinical News



**Dr. Brian G.M. Durie**, co-founder and chairman of the IMF, discusses some of the myeloma-related news coming out of the 51st annual meeting of the American Society of Hematology (ASH) that may offer new approaches to treating multiple myeloma. Presentations covered both elderly and younger patients and, for the first time, ASH studies investigated treating the disease in every possible setting, from smoldering (pre-symptomatic) myeloma to long-term continuous therapy with and without stem cell transplants, and onto promising new regimens for patients who no longer respond to existing drugs. **PAGE 5**



**The 2010 IMF Research Grant award recipients** are announced and their investigative projects summarized. Research being funded by the IMF in 2010 includes a promising project by senior investigator **Aaron Schimmer, MD, PhD, FRCPC (Canada)**, as well as work by junior researchers **Xin Li, PhD (USA)**, **Eline Menu, PhD (Belgium)**, **Steffan Nawrocki, PhD (USA)**,



**Ariosto Silva, PhD (USA)**, and **Vyacheslav Yurchenko, PhD (USA)**. In addition, the 2010 Aki Award, instituted in memory of IMF Japan founder Aki Horinouchi, is funding the work of **Junya Kuroda, MD, PhD**. **PAGE 7**



**Dr. Brian G.M. Durie** answers questions about the role of **Freelite™** and **Hevlyte™** serum assays in myeloma. Freelite assays, which measure free lambda and free kappa immunoglobulin light chains, are used for the detection of oligosecretory (sometimes called “non-secretory”) myeloma and for assessment of patients with MGUS (monoclonal gammopathy of undetermined significance), as well as for monitoring disease progression and for evaluating treatment response in these patients. The utility of Freelite is now being explored in myeloma patients who have a regular M component. Hevlyte, a new assay currently being assessed for its usefulness in managing myeloma, allows a direct look at the heavy chains of the serum M spike. Clinically, the new test is potentially very important because it can actually measure M proteins when they are of low concentration or when they are hidden by other protein bands. **PAGE 9**

### LOOKING FOR A LOCAL MYELOMA SUPPORT GROUP?

If you are interested in joining a support group, please visit our website at [www.myeloma.org](http://www.myeloma.org) or call the IMF at 800-452-CURE (2873).

## Supportive Care



**IMF Hotline Coordinators** answer a question about myeloma patients being diagnosed with hypothyroidism, which occurs when the thyroid gland produces insufficient levels of thyroid hormone.

Classic signs and symptoms of hypothyroidism are explained, as well as a possible link between thyroid dysfunction and the use of thalidomide and Revlimid® (lenalidomide) in myeloma. **PAGE 16**

## Profiles in the News



**RL Schrag**, a communication professor for 36 years, is also a painter, sculptor, husband, and the father of two adult children. But it is not from his perspective as a mature college professor, but rather as a young artist, that he revisits the experience of his autologous stem cell transplant. Currently in remission, he shares finding beauty in being a myeloma patient through becoming an insightful observer as he moved through the various stages of the transplant journey. **PAGE 21**

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**2010 IMF Calendar of Events** **BACK COVER**

### Myeloma Today Gala Supplement

On November 7th, 2009, almost 1,200 guests packed the Wilshire Ebell Theatre in Los Angeles for the IMF's 3rd Annual Comedy Celebration benefiting the Peter Boyle Memorial Fund.

Co-chairs Loraine Boyle and Amy & Steve Weiss rounded up an exceptional cast of celebrity comedians to come out in support of the IMF award-winning research program and patient services. The event was hosted by Ray Romano with Jimmy Kimmel, and featured appearances from Jason Alexander, Brad Garrett, Doris Roberts, Bob Saget, Fred Willard, and a special musical performance by Tenacious D with Jack Black and Kyle Gass.

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# A Message from the President

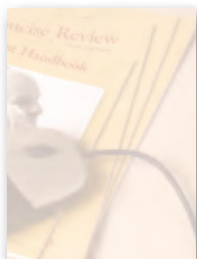
## Dear Reader,

As 2009 draws to a close, the first question is “WHERE DID IT GO?!” This has been an incredibly busy year, and I’m pleased to report that the IMF has been very productive on all fronts. So, I would like to take this opportunity to share with you what we’ve accomplished in our four main areas of focus.



### Research:

As the myeloma community entered the era of tailored treatments, with new approaches aimed at customizing each patient’s treatment to his or her specific needs, the successes of the IMF’s International Myeloma Working Group (IMWG) will soon make it possible for myeloma to be managed as a chronic disease. The IMWG consists of 110 investigators from around the world who have joined together to advance the science and other clinical aspects of myeloma. To date, IMWG members have had 26 papers published in the most prestigious peer-reviewed medical journals with more papers currently pending. In June 2010 they will meet for a “Summit” where they will focus on 5 key areas: epidemiology, diagnostic testing, molecular approaches for assessment of biology, diagnosis and treatment, new drugs, and updating the Myeloma Management Guidelines. The IMF’s innovative research program has a strategic plan to make myeloma truly a chronic disease and bring us to the cure.



### Education:

Since the founding of the IMF 19 years ago, the way people get information has changed dramatically. From having very few outlets in the past, today’s patients have a myriad ways to obtain the information they seek. Millions use the Internet as their “go to” resource, some prefer publications in hard copy, others want to talk to an actual person and utilize the IMF Hotline, and others prefer to attend a seminar. However, we’re finding that a majority uses a mix of all of the above – and that’s great. This year the IMF held numerous Patient & Family Seminars and Regional Community Workshops across the U.S. and around the world. Patients and their families learned about the advances in myeloma treatment and management from world experts and also learned from each other. The exchange of information and personal experiences is such an empowering and positive experience – one that just can’t be beat. This year, we continued to enrich the content available through our website. Over 1 million visits to the website and over 6 million page views is something we’re proud of, continuing to provide information for patients, family members, doctors, nurses, healthcare providers, and other interested parties. We reported on ground breaking news, conducted interviews, wrote articles, disseminated published papers from the International Myeloma Working Group and from the Nurse Leadership Board, produced videos – lots of videos – from interviews with Key Opinion Leaders on key topics (and in multiple languages, too!), to educational videos for patients, clinicians and nurses. And our library now has over 100 publications in various languages on a wide

variety of topics far too many to name. It’s no wonder that the IMF is the number one resource for information about myeloma in the world!



### Support:

The IMF works with over 100 Support Groups and I’m so proud of the work that they do to reach out in their communities to help others with myeloma. The IMF’s 3 Support Group Coordinators criss-crossed the country visiting Support Groups to ensure that they had what they needed – everything from a place to hold their meetings, supplying them with materials, as well as securing outstanding speakers to keep them abreast of advances in myeloma treatment and research. And we held the 10th Annual Support Group Leaders Retreat, which brought together Leaders from groups across the country.



### Advocacy:

In 2009 the IMF launched a new initiative to support and advance myeloma legislation and priority policies. The Cancer Patient Statement of Principles lies at the center of this effort, focusing on prevention, innovation, equality of access and insurance coverage, early approval of new treatments and access to experimental treatments for patients who have exhausted all other possibilities. This initiative will educate and inform potential myeloma advocates about the legislative process and public policy to ensure positive changes for myeloma patients and their families. We also established an on-line Advocacy Action Center, a “one-stop-shop” for federal legislative and regulatory information that helps IMF members quickly and effectively communicate with their Congressional Members on issues the IMF is tracking. To join the Myeloma Action Network, receive advocacy updates, and see the IMF’s public policy statements, please visit [www.myeloma.org](http://www.myeloma.org) and click on the Advocacy tab.

One of the events that helps make IMF programs and services possible is the Annual Comedy Celebration benefiting the Peter Boyle Memorial Fund. More than 1,200 guests congregated at Los Angeles’ historic and elegant Wilshire Ebell Theatre & Club on November 7 to raise money in support of the IMF. To read more about it, please see the special supplement to this issue of Myeloma Today.

As always I welcome your thoughts and comments. The IMF would not be where we are today without your belief in and support of our programs.

Warm regards,

Susie Novis





## IMF bracelets

My relationship with the IMF began more than four years ago when my Dad was diagnosed with multiple myeloma and myelodysplasia. He was over 80 years old and living in Ohio, far from my home on the West Coast. Being an only child and having a medical background, I was frustrated not to be able to go to his medical appointments. I did contact his doctors a few times but not enough to help my Dad like I really wanted to. So I went to the Internet and found the IMF, and your invaluable information became a source of support for me. I eventually brought my Dad home to Seattle and cared for him the last two years of his life.



In February of 2009, my good friend Sandy Evanick was also diagnosed with myeloma. Shortly after Sandy's diagnosis, I ordered the IMF burgundy bracelets for friends, family, and members of our Bunco Club and to wear as a reminder to pray for her daily. There are now about 60 of us who wear the bracelets to support Sandy's ongoing recovery from a stem cell transplant and as a sign of support for the IMF.

I am including a photo of some of us with our bracelets. Sandy's husband made a blow up of it for her hospital room and she got so much comfort from knowing she wasn't forgotten.

**Diana Woodward**

## IMF Myeloma Manager

I was very pleased that I was able to bring a printed copy of my Myeloma Manager, with the last two years of my blood work, when I attended the Myeloma Canada Patient & Family Seminar in Calgary. Dr. Donna Reece was able to really see the trends I was speaking of and, in just five minutes of time, was able to make an educated decision on what I should do. An excellent reason right there to use the Myeloma Manager program, especially given that I was asking for her time when she was anything but prepared for such a question. I came away feeling much heartened by what she was able to tell me based on what she could see on the spread sheet.

So, my heartfelt THANK YOU to the IMF for developing the Myeloma Manager!!!

**Beth Hamilton**



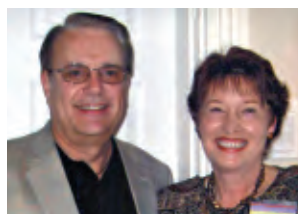
## IMF patient meetings

Thank you for the wonderful IMF meeting in Minneapolis, MN. Everyone was so approachable and supportive. I learned much at the seminar, and I appreciate the tremendous work that goes into presenting an event like that. I am also grateful for the Hotline; the IMF coordinators have been very helpful to us. My husband's high-risk multiple myeloma has been especially difficult on the heels of colorectal cancer. Blessings to you all!



**Maureen Carroll and the IMF's Lisa Paik**

**Maureen Carroll**



From the first IMF Patient & Family Seminar that we attended in St. Louis in 1999, one year after our myeloma diagnosis, to our recent attendance at the Cincinnati IMF Regional Community Workshop in October, we continue to be grateful to the IMF for all you do to educate people with myeloma and the general public about this incurable (for now) cancer, as well as the latest research and treatments.

The free-of-charge Regional Community Workshop was a day-long version of the IMF Patient & Family Seminar weekend format. We missed having the breakout sessions that are such a key part of Patient & Family Seminars, but we got to listen to two Regional Community Workshop presenters (a myeloma doctor from Indianapolis and a nurse from the Cleveland Clinic who is a member of the IMF Nurse Leadership Board), and we appreciate all the information included in their sessions. We also appreciate having the opportunity to spend time with other myeloma patients and their family members. Whether we are newly diagnosed or long-term survivors, it always helps to know that we are not alone on our journey.

In the 10+ years since the myeloma diagnosis we have attend all IMF educational patient meetings within a reasonable driving distance of our home. Both of us have learned so much from the myeloma experts we have met at the IMF meetings. Over the years, it has become clear to us that this disease changes over time, as does the range of available treatments, so it is essential to keep current with all the developments in the field. Just when you think you have finally become well-versed in myeloma, something changes. So there is never a point when one can say that there is nothing left to learn. The continuing education and the camaraderie are invaluable to those of us who plan to keep on "keeping on" and the IMF is a key resource for both.

**Chuck & Mary Anne Martz**



**Participants at the Cincinnati Regional Community Workshop**



## STUDIES PRESENTED AT ASH MAY OFFER NEW APPROACHES TO TREATING MULTIPLE MYELOMA

By Brian G.M. Durie, MD

Aptium Oncology

Cedars-Sinai Comprehensive Cancer Center, Los Angeles, CA

### Introduction

The 51st annual meeting of the American Society of Hematology (ASH) was held December 5 through 8 in New Orleans, LA. This important conference for the hematology community was especially exciting for the myeloma research community. Presentations covered both elderly and younger patients and, for the first time, ASH covered all stages of multiple myeloma. Studies investigated treating the disease in every possible setting, from smoldering (pre-symptomatic) myeloma to long-term continuous therapy with and without stem cell transplants, and onto promising new regimens for patients who no longer respond to existing drugs.

A large number of abstracts, nearly a quarter of the presentations submitted this year to the annual meeting of the American Society of Hematology (ASH), were for multiple myeloma, with one being presented at the prestigious plenary session. This plenary abstract dealt with the role of Velcade® (bortezomib) combinations in the frontline setting, assessing both induction and maintenance in a randomized fashion.

A new aspect of this year's ASH meeting was the focus on treatment or understanding of the disease from its earliest stages on. Below, I will briefly highlight some of the myeloma-related news coming out of the ASH meeting which appeared to generate the most interest and enthusiasm among those present at the meetings. A more detailed report is being prepared by IMF medical writer Lynne Lederman, PhD, which should be available shortly in print and on the IMF website [www.myeloma.org](http://www.myeloma.org).

*"This has been one of the most exciting medical meetings for myeloma in recent years. We believe patients with myeloma and related blood cancers will have more treatment options that could lead to a better quality of life."*

– Susie Novis, IMF president and co-founder

In addition, interviews with 55 major presenters at the ASH meeting are also available on the IMF website [www.myeloma.org](http://www.myeloma.org).

### Educational symposia

The IMF's symposium – the Super Friday Workshop – took place on December 4. This year, the speakers included S. Vincent Rajkumar (Mayo Clinic, Rochester, MN), Mario Boccadoro (University of Torino, Italy), Philippe Moreau (Nantes, France – leader of the French myeloma study group, IFM), and Robert Orlowski (MD Anderson, Houston, TX). This particular educational session takes a practical approach to the management of myeloma, illustrating for the audience how to integrate the use of the novel agents into the management of myeloma. This is increasingly important as we now have three major novel agents in myeloma – Thalomid® (thalidomide), Revlimid® (lenalidomide), and Velcade – with several promising new agents in the development pipeline. How do practicing clinicians introduce these agents into their day-to-day practice? The Super Friday Workshop reviewed how patients should be diagnosed and staged, the different myeloma prognostic categories, the role of cytogenetics and genetic profiling in identifying the best treatment for patients, the

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### ASH 2009 – IMF ADVOCACY BOOTH



By Arin Assero

Director, Communications & Public Policy

Along with the IMF's coalition partners, the MDS Foundation (MDSF) and Tackle Cancer Foundation (TCF), the IMF brought our Cancer Patient Statement of Principles to the 2009 meeting of the American Society of Hematology (ASH) in New Orleans. The principles emphasize equal insurance coverage, prevention research, continued innovation,

early approvals, and expanded access to experimental drugs. Since the launch of our national advocacy initiative and the introduction of our principles at the annual meeting of the American Society of Clinical Oncology (ASCO) in May of this year, the IMF has gained support of myeloma patients nationwide, built an active legislative campaign (see <http://www.capwiz.com/myeloma>), and secured bi-partisan support for state and federal initiatives that address the issues raised by this program.

The ASH meeting was the perfect platform for our patient advocates to inform researchers, clinicians, industry, and the media about the issues they face while living with an incurable-but-treatable cancer. Such one-on-one interaction of the patients and the medical professionals working in

*"As part of the broader IMF mission, we are leading a coalition of blood cancer organizations in calling for improved access to research and resources, as well as equitable insurance coverage and reimbursement for patients with hematologic malignancies until cures are found. The IMF's Cancer Patient Statement of Principles initiative hosted a booth at ASH, and this inaugural effort was quite successful."*

– Brian G.M. Durie, MD

myeloma helps build support for our joint cause, the ultimate cure of this disease. Patient advocates were also able to attend ASH sessions to learn about new treatments in the pipeline for treating myeloma.

One of the IMF patient advocates spent much of his time at ASH blogging from the IMF Statement of Principles booth. "The IMF has been working hard to organize the cancer community and to lobby Congress to help cancer patients," he says. "I am so blessed to be healthy enough to learn and share anything and everything I can with my fellow myeloma patients. It is a responsibility I take very seriously." And this is a responsibility we at the IMF take seriously too as we move ahead to help assure not only continuing research and development of new treatments, but that patients have ready access to those treatments. Attendance at ASH was one small but critical step in this effort. **MT**

## ASH PRESENTATIONS — continued from page 5

integration of novel agents along with autologous transplant for younger patients, drug combinations, maintenance, and the approach to relapsed/refractory disease.

There was also an important educational session put on by ASH that took place on Saturday afternoon and Sunday morning. Speakers Jesus San Miguel (University of Salamanca, Spain), Antonio Palumbo (University of Torino, Italy), and Keith Stewart (Mayo Clinic, Scottsdale, AZ) talked about the treatment of younger and older patients and relapsed/refractory disease.

The educational symposia at ASH are just as important as the scientific presentations of new study results. The hematologist-oncologist clinicians need guidance on how to best use the novel drugs to treat their myeloma patients. Often, because of time constraints, researchers presenting results from their studies cannot put the data into a comprehensive context. But the clinician needs to know how those results stack up against other results from other studies being presented, or against the results that have already been published. Discussions that look at both the older and the newer results in the context of day-to-day management of patients are a

key component of ASH.

### Smoldering myeloma

Treating patients before they show any symptoms is controversial, but a study at the University of Salamanca in Spain of Revlimid in smoldering myeloma is an important first step toward reconsidering how patients are treated at the earliest stages of this cancer. The phase I/II study from Maria-Victoria Mateos, MD, demonstrated for the first time that early intervention treatment before clinical symptoms occur may delay the onset of active myeloma (abstract #614). In the observation-only arm of this randomized study where patients are watched closely but not treated, 50% of patients with high-risk smoldering myeloma progressed to active myeloma in 19 months, including the classic symptoms of bone disease. However, in 45 patients who began and continued active treatment with Revlimid at this early stage, no disease progression was observed after a median follow-up of 16 months. It is an innovation to introduce the use of an agent, in this case Revlimid, at the earliest time point to see if early treatment reduces the complications of myeloma – such as bone disease

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## ASH 2009 – A PATIENT'S PERSPECTIVE



By Jack Aiello

The 2009 meeting of the American Society of Hematology (ASH) was the fourth year I've attended this important annual gathering. The 25,000 attendees from all over the world included clinicians practicing in the field of hematology/oncology, lab researchers, scientists, and representatives from pharmaceutical companies. Many results are presented from a broad range of clinical trials and research centers.

As I tried to gather my notes in order to share my impressions of ASH with fellow patients and caregivers who read Myeloma Today and/or visit the IMF website, I found myself looking at a veritable alphabet soup of combination treatments that comprise the current approach to myeloma therapy. VTD, RTD, VCDx, VRDx, VPM, and more! While there is still no “best” treatment for all patients, what we currently have are options for many. If myeloma experts are still debating treatment approaches of sequential “more gentle” (low-dose) therapies as opposed to the “kitchen sink” (three- and four-drug combinations) mentality, it's no wonder that the overall treatment picture is so difficult for most of us patients to truly understand. And with so many treatment choices, it now appears that the role of transplantation in myeloma has evolved as a treatment option rather than the gold standard it once was.

And questions extend beyond treatment combinations to issues of dosage levels and maintenance. A few years ago, we saw the recommended dosage level of dexamethasone get reduced from 40mg on days 1-4 to 40mg just once per week. Today, other “standard” dosage levels are being tested (e.g. bortezomib being given just once/week instead of twice). “Maintenance” (not a great word because it may well be treatments that continue to improve response) has become a more important topic as

patients are living longer with myeloma. Also, on the front end of the myeloma process, treatments for MGUS and “smoldering” myeloma that may potentially delay the onset of disease are being evaluated.

New drugs in development continue to produce good trials results. Personally, I'm always grateful to see toxicity results, both hematologic (e.g. pulmonary embolism, neutropenia) and non-hematologic (e.g. peripheral neuropathy), presented as part of every trial and dose-escalation results. And high-risk myeloma, which accounts for about 25% of patients, now appears to be successfully overcome in some patients with the use of novel agents and/or transplantation.

I appreciated having the opportunity to listen to myeloma experts presenting their findings at ASH, and found the following remarks most interesting:

- “I can't really tell you which triple regimen [VTD, RTD, VCDx, or VRDx] is better than the other. And do these justify that the ‘kitchen sink’ or ‘sequential’ treatment approach is better?” - Ann Morbacher (USA)
- “The goal for treating a young patient (< 65-70yo) should be long-term survival (10-20 yrs) with good quality of life.” - Jesus San-Miguel (Spain)
- “Consider dose-reduction as the patient ages.” - Mario Boccadoro (Italy)

For someone like myself, diagnosed with Stage III multiple myeloma 15 years ago, the myeloma world has made incredible strides, especially since about 2000. While there continue to be many unanswered questions, the bottom line is that there are now many more effective treatments (perhaps with maintenance) for myeloma, providing patients with better opportunities to manage their disease. For me personally, even though I've been in complete remission for the last eight years without treatment, I know enough to expect my myeloma to return one day. As such, I'm grateful for the enormous progress that continues to be made developing new myeloma treatments, both for the newly diagnosed patients and for those like me. **MT**

## 2010 IMF RESEARCH GRANT RECIPIENTS ANNOUNCED

The recipients of the 2010 IMF Research Grant awards were announced at the gathering of the Foundation's Scientific Advisors, held at the 51st annual meeting of the American Society of Hematology.

For the past 15 years, the IMF's research program has been funding promising clinical investigators from around the world in an effort to improve outcomes for myeloma patients. The 2010 IMF grant award presentations took place during the 51th annual meeting and exposition of the American Society of Hematology (ASH). Susie Novis (president and co-founder of the IMF), Dr. Brian G.M. Durie (chairman and co-founder of the IMF), Dr. Robert A. Kyle (chairman of the IMF Board of Scientific Advisors), and many IMF Scientific Advisors from around the globe were on hand during the research grants award presentation ceremony.

The IMF grants are funded by donations from private individuals. Junior investigators receive funding in the amount of \$50,000. Senior investigators are funded at \$80,000. Over the years, the IMF research grant program has led to many publications, enabled investigators to become established in the field of myeloma and made important contributions to understanding the biology of myeloma and developing better therapies. We are certain that the work of the recipients of the 2010 IMF research grants will continue to contribute significantly to the field of myeloma.

### 2010 Brian D. Novis Senior Research Grants



**"Development of the antihelminthic flubendazole as a novel therapeutic agent for the treatment of multiple myeloma"**

**Aaron Schimmer, MD, PhD, FRCPC**  
Princess Margaret Hospital  
Ontario Cancer Institute  
Toronto, ON, Canada

This project takes the unique approach of studying drugs approved by the FDA for other diseases to assess if they have unrecognized anti-myeloma activity. Any such drug can have an accelerated approval for myeloma use if significant anti-myeloma activity is demonstrated. Dr. Schimmer and colleagues have already identified that flubendazole, a drug used for intestinal worms, has anti-myeloma activity. The research team aims to advance the clinical development of flubendazole for myeloma by identifying biomarkers for use during a clinical trial and develop a Phase I clinical trial for this compound in patients with relapsed and refractory myeloma.

### 2010 Brian D. Novis Junior Research Grants



**"Mesenchymal cell cytotherapy for multiple myeloma"**

**Xin Li, PhD**  
Myeloma Institute for Research and Therapy  
Winthrop P. Rockefeller Cancer Institute  
University of Arkansas for Medical Sciences  
Little Rock, AR, USA

Induction of myeloma bone disease is mediated through increased production of pro-osteoclastogenic and anti-osteoblastogenic factors in

myelomatous bones, as well as due to potential abnormal properties of bone marrow mesenchymal stem cells (MSCs). Preliminary in vitro experiments by Dr. Li and colleagues showed that MSCs from normal bone marrow directly inhibit osteoclast formation and stimulate osteoblast differentiation, suggesting that these cells affect bone remodeling and myeloma cell growth via interaction with the host osteoclasts and osteoblasts. These findings have led to formulation of an overall hypothesis that, in contrast to patient MSCs, normal MSCs can help control myeloma directly and indirectly by preventing bone loss and stimulating bone formation. The research project will determine the direct effects of MSCs on osteoclasts and osteoblasts, shed light on molecular mechanism by which MSCs affect osteoclastogenesis and osteoblastogenesis. This can lead to new approaches to the treatment of myeloma bone disease.



**"Characterization and preclinical evaluation of NKT cells in multiple myeloma" \***

**Eline Menu, PhD**  
Vrije Universiteit Brussel (VUB)  
Brussels, Belgium

One strategy to target multiple myeloma is using a patient's immune system to target the tumor. However, myeloma cells can evade the immune system. Therefore, new drugs are being studied that can activate the immune system and enhance anti myeloma activity. In this project, Dr. Menu and colleagues will use the ST33MM mouse model to test a new activator of NKT (natural killer T-lymphocytes) cells preclinically. They will first characterize the NKT population in these mice and test their functionality against ST33MM cells and a CD1d transduced ST33MMvt cell line. They will then compare the efficiency of a new analogue in its capacity to activate NKT cells and reduce myeloma burden both in vitro and in vivo. This study will provide a potential new approach for immunotherapy in myeloma.



**"Reolysin: a novel reovirus-based therapy for multiple myeloma" \*\***

**Steffan Nawrocki, PhD**  
The University of Texas  
Health Sciences Center  
San Antonio, TX

The proteasome inhibitor bortezomib (Velcade®) is an important new drug for the treatment of myeloma. Based on this success, novel combination therapies with bortezomib are being tested for efficacy and for their potential in circumventing drug resistance in myeloma. The reovirus is a naturally occurring virus that is non-pathogenic and has been reported to preferentially replicate in cancer cells, but not in normal tissue. This observation prompted the development of the reovirus-based anticancer agent Reolysin®, which has already demonstrated promise in early preclinical and clinical studies. However, the mechanism by which Reolysin induces tumor cell death remains unclear. Myeloma cells have

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## 2010 GRANT RECIPIENTS — continued from page 7



Dr. J. Carew accepted the award on behalf of Dr. Nawrocki

remarkably high rates of protein synthesis to produce large amounts of immunoglobulins. Therefore, it has been suggested that these cells may be hypersensitive to endoplasmic reticular (ER) stress. Dr. Nawrocki and colleagues hypothesize that Reolysin preferentially induces the accumulation of viral products in myeloma cells and that this selectively stimulates ER stress-mediated cell death. Since abnormal protein accumulation can trigger cancer cell death, the simultaneous induction of different types of protein buildup (ubiquitin-conjugated and viral) may be a promising anticancer strategy. Moreover, the high protein synthesis rates of myeloma cells (compared with low protein synthesis rates of normal cells) may render them uniquely sensitive to proteotoxicity-mediated cell death. Dr. Nawrocki will investigate this possibility by evaluating the benefit of a bortezomib and Reolysin combination therapeutic strategy. The knowledge gained from this research will be rapidly translated into a clinical trial and has the potential to significantly impact myeloma therapy.



### “Bone marrow microenvironment and multiple myeloma chemotherapy optimization”

**Ariosto Silva, PhD**

H. Lee Moffitt Cancer and Research Institute  
Tampa, FL, USA

While systemic chemotherapy for myeloma is often initially quite successful, tumor sites that are resistant to therapy invariably remain as minimum residual disease (MRD) even after high-dose treatment. The mechanisms of resistance to chemotherapy include both micro-environmental and cellular factors such as (1) regional hypoxia in bone marrow resulting in decreased drug effectiveness due to absence of intermediate oxygen free radicals, (2) environmentally mediated resistance (EMDR) due to signaling between tumor cells and extracellular matrix (ECM), bone marrow stromal cells (BMS), and endothelial cells (EC), and (3) phenotypic resistance through upregulation of xenobiotic metabolism or DNA repair pathways. Dr. Silva and colleagues will examine these complex systems using an approach characterized as “integrated mathematical oncology” in which mathematical models are combined in an iterative way with in vivo and in vitro experiments. Ultimately, through understanding of the dynamics that govern emergence of chemotherapy resistance in myeloma, this research project will explore alternative treatment strategies based on understanding these dynamics to slow the evolution and growth of resistant phenotypes.



### “MMSET and epigenetic control in t(4;14) myelomas” \*\*\*

**Vyacheslav Yurchenko, PhD**

Rockefeller University  
Laboratory of Lymphocyte Signaling  
New York, NY, USA

The overexpression of IgH enhancer/promoter driven genes such as cyclin D1, cyclin D3, or c-maf is likely to contribute to myeloma cell

proliferation. Recent findings suggest an important role of histone methyltransferase MMSET (Multiple Myeloma SET domain protein) in malignant progression of myeloma. In about 15% of all myeloma cases, the t(4;14) translocation brings MMSET gene under the control of the  $\mu$  enhancer followed by increased, as compared to healthy plasma cells, expression of the protein. It is not currently known how the increased expression of MMSET in plasma cells is translated into myeloma development and/or progression. Provided that MMSET acts as a transcriptional co-repressor and histone methyltransferase, Dr. Yurchenko and colleagues propose that the developmental program of normal and neoplastic plasma cells is regulated by this enzyme. Specifically, they hypothesize that deregulation of MMSET in plasma cells contributes to the disease initiation and/or progression. The goal of this research project is to establish the role of MMSET-dependent genetic program in normal plasma cell differentiation and myelomagenesis in mice. To achieve this goal, this project aims to define the role of MMSET in normal plasma and myeloma cell development and to identify the genetic network directly controlled by MMSET in B cells.

## 2010 IMF Aki Horinouchi Research Grant



### “Novel anti-myeloma therapy by targeting molecular signaling regulated by galectin family proteins” \*\*\*\*

**Junya Kuroda, MD, PhD**

Division of Hematology and Oncology  
Kyoto Prefectural University  
Kyoto, Japan

Because myeloma cells acquire the chemo-resistant phenotype not only by cell intrinsic molecular abnormalities but also by the support of extracellular bone marrow (BM) components, it is essential to development new agents simultaneously targeted for those two divergent but mutually interacting, abnormal molecular signaling networks for myelomagenesis. To this purpose, Dr. Kuroda and colleagues are currently investigating the molecular signaling modulation which is specifically responsible for chemo-resistance of myeloma cells in tumor microenvironment model consisted of BM stromal cells, cytokines, and extracellular matrix. Preliminary data suggest that several members of galectins, a family of animal lectins that show affinity for b-galactosides (such as galectin-3 or galectin9), play important roles for myeloma cell survival, the resistance to cellular insults, cell adhesion, or deregulated cell proliferation in BM microenvironment.

## MT

\* This grant is funded by Michael McKean in honor of Lee Grayson.

\*\* This grant is funded by Carol Klein and Nancy Moses through their annual Afternoon Tea event.

\*\*\* This grant is funded by the Multiple Myeloma Networking Group, the Central New Jersey Multiple Myeloma Support Group, and the Northern New Jersey Multiple Myeloma Support Group.

\*\*\*\* This annual myeloma research grant was instituted in 2002 by IMF Japan in memory of its founder, Aki Horinouchi.

## THE ROLE OF FREELITE™ AND HEVYLITE™ SERUM ASSAYS IN MYELOMA

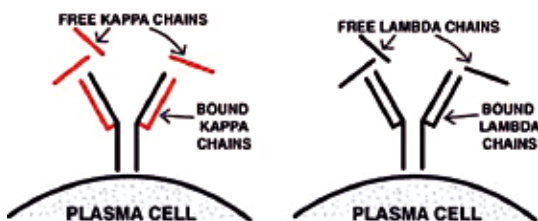
*Myeloma Today* in conversation with Dr. Brian G.M. Durie

### Would you please bring us up to date on the use of Freelite™ serum free light chain assays in multiple myeloma?

For several years now, Freelite™ serum free light chain assays, which measure free lambda and free kappa immunoglobulin light chains, have been used for the detection of oligosecretory (sometimes called “non-secretory”) multiple myeloma and for assessment of patients with MGUS (monoclonal gammopathy of undetermined significance), as well as for monitoring disease progression and for evaluating treatment response in these patients. Patients with oligosecretory myeloma do not have the typical M protein spike in either blood or urine, and Freelite has been an effective tool in diagnosing and monitoring such patients.

### Is Freelite also applicable to myeloma patients who have the M spike?

This potential application of Freelite is still being explored. For example, baseline levels of Freelite have prognostic significance with higher levels indicating more aggressive disease. Freelite is currently used as part of myeloma clinical trials being conducted in different settings, and we hope that the data will clarify the utility of Freelite in patients who are not oligosecretory. In other words, if a myeloma patient has a regular M component, it is the spike that should be measured and monitored. However, with the introduction of novel anti-myeloma therapies, more and more patients are having a complete response (CR) or a very good partial response (VGPR) assessed using the serum and/or urine M component. When patients have a very low level of disease, they still have low levels of measurable free light chains. So the question we are now addressing is the utility of Freelite for quantitative assessment of minimal residual disease. It is useful to apply Freelite for monitoring in this setting. For example, this test gives an earlier indication of disease relapse.



When immunoglobulin molecules are produced by the plasma cells in the bone marrow, the heavy chains (G, A, M, D, or E) and the light chains (kappa or lambda) are produced separately. The kappa and lambda molecules are bound to the heavy chains and intact immunoglobulins are assembled, then transported to the surface of the plasma cell. Free kappa and lambda light chains are produced in excess, and the Freelite test quantifies the free kappa and free lambda light chain concentrations.



Brian G.M. Durie, MD  
Aptium Oncology  
Cedars-Sinai Comprehensive  
Cancer Center  
Los Angeles, CA

### Are there pros and cons to using Freelite to assess minimal residual disease?

It is useful because we can get some measurable numbers. But, at the very low levels of free light chains, there is fluctuation and this up and down bounce can be disconcerting to patients and physicians alike. So it is important for patients to keep in mind that they are being monitored at such low levels of disease that, even with the numbers fluctuating, the test results are usually way below where one needs to take any action.

The key question is what are the situations where such monitoring is actually useful? One example of this is the normalization of the Freelite Ratio in a responding patient – when a patient has a normal serum or urine spike plus the Freelite ratio tests as normal. This is part of the definition of stringent CR (sCR) – the absence of the M spike, the immunofixation is negative, the bone marrow is normal, and the Freelite ratio is normal. This is a definitive endpoint

which is part of the International Myeloma Working Group (IMWG) uniform response criteria and now being prospectively evaluated as part of ongoing trials.

### So how is Freelite being used in the ongoing myeloma clinical trials?

In all the different protocols and trials, the studies are looking at the differences between sCR and CR with an abnormal Freelite Ratio. Freelite might turn out to be the best way to identify best response, but there is no final answer yet. This is an ongoing process, with bits of data coming out sequentially.

Another area of study is to look at patients who have Bence Jones myeloma when the monoclonal light chain protein present in urine. Is it possible to replace the 24-hour urine collection to measure the urine light chains with a blood test to check the level of serum light chains? The urine collection is more precise, so this remains our recommendation at present. There just isn't the same security with the serum test because of the fluctuating numbers. At this time we can say that even though the serum test might reduce the frequency of the urine test, the 24-hour urine collection remains the standard test.

### What can you tell us about the new Hevylite™ assay?

Hevylite™ is a new assay currently being assessed for its usefulness in managing myeloma, which allows us to look directly at the heavy chains of the serum M spike. For example, if you have IgG myeloma, the Hevylite test looks at IgG kappa. Clinically, the Hevylite test is potentially very important because it can actually measure M proteins when they are of low concentration or when they are hidden by other protein bands. For

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### What is the current availability of the Hevylite test?

**Have there been any Freelite/Hevylite news coming out of the 2009 annual meeting of the American Society of Hematology (ASH)?**

The diagram illustrates the structure of an antibody. It shows a Y-shaped molecule composed of two light chains (red) and two heavy chains (blue). Labels with arrows point to the 'Light chain' and 'Heavy chains'. A detail view on the right shows a 'Heavy chain epitope' as a small red and blue structure.

Target epitopes (in black) for Hevylite antibodies are on the constant regions between the heavy and light chains of immunoglobulin molecules.

Editor's Note: To learn more about Freelite, please see the Understanding Serum Free Light Chain Assays brochure published by the IMF or visit [www.thebindingsite.com](http://www.thebindingsite.com), and stay tuned for upcoming data from the IMF and the IMWG about the use of Freelite and Hevlyte serum assays in myeloma.

**The IMF publishes a comprehensive library of informative myeloma resources. Used by patients, caregivers, healthcare professionals, and anyone needing a reliable source of up-to-date information regarding the disease, these publications are critical to a better understanding of myeloma.**



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The content for the News & Notes section of *Myeloma Today* is drawn from a long list of publications based on inquiries received by the IMF Hotline and the interests expressed by our readers.

### **AOSW survey shows cancer costs negatively impact focus on recovery**

A survey conducted by the Association of Oncology Social Work (AOSW) demonstrates that financial hardships often complicate or compromise a patient's battle against cancer. Money issues reduce patients' compliance with their cancer treatment even though treatment is key to their recovery. According to the study, 87% of patients with catastrophic/major financial burdens due to cancer treatment say costs have a negative impact on their ability to focus on recovery, 68% of patients experience financial hardship due to medical bills, 66% of patients with major financial challenges suffer depression/anxiety, 55% of patients surveyed say the stress of dealing with costs negatively affects their ability to focus on their recovery, 54% of patients and caregivers with a major/catastrophic financial burden said that it has become more difficult to afford treatment for cancer in the past year, 40% of patients reported depleting their savings, almost 30% reported dealing with bill collectors, 29% of patients delay filling prescriptions due to financial pressures, and 22% skip doses.

The survey results of interactive datasets are part of an ongoing effort by the AOSW to increase understanding and support for people with cancer and their families. Although most patients report experiencing cost-related psychosocial stresses that social workers are adept at helping manage, only 34% of patients surveyed report actually utilizing a social worker as a resource. In fact, only about half feel comfortable speaking with health professionals about financial issues. Study findings show that nearly all cancer patients, including those with blood cancers such as multiple myeloma, consider effectiveness before all other factors when determining their treatment plan and rank the cost of treatment last in their decision-making process when initially diagnosed. Study statistics were based on 169 cancer patients, 131 caregivers, and 153 social workers. Patient and caregiver results are presented in aggregate. The survey was developed by Kelton Research in conjunction with Millennium: The Takeda Oncology Company under the guidance of the AOSW.

For more information, please call the IMF at 800-452-CURE (2873). Our Hotline Coordinators are here to answer your questions and help guide you to available resources. CancerCare's new "Door to Door" initiative, which offers grants to individual patients with myeloma to help with costs of transportation to and from medical care, is detailed below. The IMF is also actively involved in advocacy efforts that bring the voices of the myeloma community to the current debate on health care reform and related issues.

### **Possible genetic link between environmental toxins and myeloma**

Newly published data may provide a possible genetic link between environmental toxins and bone disease, the characteristic feature of multiple

myeloma. Once considered a "rare disease of the elderly," myeloma is increasingly being diagnosed in patients under 45 years old, including some of the early responders to the 9/11 World Trade Center site. Now a published study may help explain why.

The study from researchers with the IMF gene bank, Bank on a Cure®, identified several changes in DNA sequences called SNPs (single nucleotide polymorphisms) that are associated with a risk of bone disease in myeloma. Further analyses showed that many of these DNA changes may be involved with the way the human body responds to certain environmental toxins, providing a possible link between myeloma and the environment. The findings were published in the journal *Leukemia* on August 6, 2009.

Dr. Brian G.M. Durie, lead author of the study and Chairman of the IMF said: "This is a hypothesis-generating study. While the functional role of many SNPs is still uncertain, this study is supportive of the notion that genetic factors affecting toxin breakdown may be related to the development of myeloma. This gives us an important starting point for further studies."

The findings may help explain a widely reported study in the *Journal of Occupational and Environmental Medicine* that found more cases of myeloma among younger responders to the 9/11 World Trade Center site than would normally be expected. The findings are also supportive of a study published earlier this year that suggests a link between certain pesticide exposures in agricultural workers and a precursor to myeloma. Previous studies have also shown an increased risk for myeloma among firefighters, and the IMF has issued guidelines for firefighters for the prevention and treatment of this disease.

"Multiple myeloma is not a familiar cancer to patients or even to many doctors, but taken together, these studies say it should not be overlooked," said Susie Novis, President and Co-founder of the IMF. "While multiple myeloma cannot be cured, it can be treated with new, targeted therapies including REVLIMID®, VELCADE® and THALOMID®. These studies tell us it is critically important for medical practitioners to know the possible risk factors for myeloma along with the early warning signs so they will be alerted to test for it."

### **The importance of bone marrow examination in determining complete response**

Dr. Cheng E. Chee and colleagues from Mayo Clinic in Rochester, MN, have studied the importance of bone marrow (BM) examination in determining complete response (CR) to therapy in patients with multiple myeloma. The current definition of complete response in myeloma includes a requirement for a BM examination showing less than 5% plasma cells in addition to negative serum and urine immunofixation. There have been suggestions to eliminate the need for BM examinations when defining complete response. The investigators evaluated 92 patients with myeloma who achieved negative immunofixation in the serum and urine after therapy and found that 14% had BM plasma cells more than or equal

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## SPOTLIGHT ON ADVOCACY

### IMF Launches Major New Advocacy Initiative

By Christine Murphy



**D**id you know that your Congressional Members make decisions each and every day that impact your health? *It's true!* Each year the United States Congress determines how much of the federal budget will be dedicated to medical research and makes policy decisions that may affect how you obtain treatment for myeloma.

A strong advocacy program is essential to supporting and advancing myeloma legislation and priority policies. The IMF has just launched a whole new advocacy initiative and is actively looking for myeloma advocates to "join the team." The involvement of myeloma patients and their loved ones in addition to myeloma doctors, nurses, and researchers in the legislative process are vital to IMF's mission of improving the quality of life of myeloma patients while working toward prevention and a cure.

IMF's new advocacy initiative is designed to:

- **EDUCATE** and inform YOU and other potential myeloma advocates like you about the public policy and legislative process
- **ENCOURAGE** involvement in our government to bring about change for myeloma patients, and
- **ENSURE** positive change in health policy for myeloma patients and their families.

If you are a myeloma patient, a caregiver, a doctor, nurse, researcher, or know someone affected by myeloma, we need your help! **To make a difference, you need to make your voice heard.**

There are three important actions you can take today to join the IMF in our fight.

#### Take Action: Write Your Elected Officials

Your Congressional Members want to hear from you! Members of Congress are most responsive to people from their own states and communities, and they need to hear from myeloma advocates about the priorities and



concerns of the myeloma community. Unless they hear directly from myeloma advocates, policymakers will fail to address the concerns of the myeloma community. Policymakers must have your input to be aware of the needs in their communities and the ramifications of changes in policy. A well-informed, articulate, passionate myeloma advocate can be a valued resource to elected officials and their staff, raise issues of importance to the myeloma community, and help craft and implement necessary legislative solutions.



The IMF has recently created an online Advocacy Action Center on the IMF website as a "one stop shop" for federal legislative and regulatory information so that myeloma advocates can quickly and effectively communicate with their Congressional Members on issues the IMF is tracking for you.

By visiting the IMF Advocacy Action Center at [www.capwiz.com/myeloma/home](http://www.capwiz.com/myeloma/home), you can

send messages to your legislators directly from the site on issues of importance to the myeloma community.

The Advocacy Action Center also includes such features as:

- **Template Letters** you can personalize and send via e mail or fax to your Members of Congress on crucial policy issues.
- **Sponsor Track** attaches information on relevant bill sponsorship on the bio pages of Members of Congress.
- A **Vote Scorecard** lists every Member of Congress and how they voted on bills of interest to the myeloma community.
- **Congress Today** provides daily schedules of House and Senate activity, including committee hearing schedules.
- **Tell a Friend** enables users to send Alerts, Votes, and other legislative-related information to one or more other potential myeloma advocates.
- A searchable **Guide on National and Local Media** includes newspapers, magazines, and TV networks and stations in your area; users can use this information resource to send e mails, faxes or printed letters to newspaper journalists, radio talk show hosts, and television commentators.

#### Educate Yourself: Learn More about Myeloma Advocacy Issues & Legislation

Want to learn more about the issues and legislation important to the IMF and the myeloma community? The IMF produces statements and letters aimed at decision-makers on a variety of public policy issues that the IMF supports including access to clinical trials, funding for myeloma research, and health care reform.

To keep myeloma advocates informed of moving legislation in Congress, the IMF will be drafting advocacy updates twice a month on issues and legislation important to the myeloma community. The email newsletter *Myeloma Minute* and the quarterly publication *Myeloma Today* will also include advocacy updates. These updates, along with the IMF's public policy statements, can be viewed online on the IMF Advocacy page at [www.myeloma.org](http://www.myeloma.org).

## Get Involved: Sign Up for the Myeloma Action Network

By becoming a member of the Myeloma Action Network you will help the IMF to focus our “email alerts” directly to you and other myeloma advocates who reside in a specific state or district represented by legislators we need to target. These alerts provide strategic information to affect key policy issues of interest to the IMF and the myeloma community. To receive the email alerts, we need you to sign up on the IMF Advocacy Action Center at [www.capwiz.com/myeloma/home](http://www.capwiz.com/myeloma/home).

The new Advocacy website page on the IMF website features more information to keep myeloma advocates informed – as well as how to conduct a Congressional visit. Other key elements of the new advocacy website at IMF include:



### Cancer Patient Statement of Principles

The IMF developed the *Cancer Patient Statement of Principles* to:

- Focus and establish the fundamental advocacy priorities being addressed by the IMF.
- Inform myeloma patients, colleague organizations, government officials, the media, and the public about the IMF's public policy concerns.

- Provide a continuing framework for the IMF to review and report on actions that address current and past policy concerns.

The *Cancer Patient Statement of Principles* focuses on the key areas of prevention, innovation, access, and early approvals which will be the driving force behind the IMF's advocacy efforts with the United States Congress. The *Cancer Patient Statement of Principles* can be downloaded from the Advocacy section of the IMF's website at [www.myeloma.org](http://www.myeloma.org). Also, the Principles make excellent “leave behinds” when meeting with Members of Congress.

### Advocacy Toolkit

The IMF Advocacy Toolkit has been developed as an introductory guidebook that outlines the role of the myeloma advocate in health policy advocacy, explains the public policy and legislative process, and provides tips and resources regarding how you can help bring about change. The toolkit includes information such as:

- 1) How a Bill Becomes a Law;
- 2) Building Relationships with Legislators;

- 3) Do's and Don'ts in Government Relations;
- 4) a Glossary of Legislative Terms; and,
- 5) a Guide to Legislative Staff Titles.

You can download your own Advocacy Toolkit directly from the Advocacy section of the IMF's website at [www.myeloma.org](http://www.myeloma.org) or you can contact the IMF (*see below*) and ask us to send you an IMF Advocacy Toolkit.

### Advocacy Partnerships

One of the best ways to achieve success is to join forces with other organizations with shared interests and goals. The IMF leverages its resources by collaborating with others in the cancer community to promote legislative and regulatory issues of mutual interest and priority. The Advocacy Partnership webpage on the IMF Advocacy site outlines the different coalitions that the IMF actively participates on issues that impact the myeloma community.

### Public Policy Web Resources

In addition to the information myeloma advocates will find on the website, IMF has also included a list of great on-line resources on health policy and advocacy. This list includes links to federal government sites; sites specializing in health policy and funding; media, journals, and related sites; and additional state and local resources.

Advocacy is more than just understanding the issues. The involvement of myeloma patients and their caregivers – i.e., people like YOU – is vital to the success of IMF's grassroots efforts. It only takes you 5 minutes to start to get involved and make YOUR voice count. Can one person help bring about change? Absolutely! Engaging myeloma advocates in health policy advocacy is essential to ensuring that IMF's priorities are addressed by Congress. By using the IMF's resources such as the new Advocacy Action Center, the Cancer Patient Statement of Principles, and the Advocacy Toolkit, YOU and other myeloma advocates have the tools necessary to be effective health policy advocates.

The IMF is here to help whether you need answers to your questions or to give you the information and tools you need to become a successful myeloma advocate. Should you have any questions or want more information on how to help the IMF's new advocacy initiative, please feel free to contact Christine Murphy at IMF's Government Affairs office in Washington, DC or Arin Assero at IMF's headquarters in North Hollywood, California. Contact information for Christine and Arin is included below.

**MT**

#### Christine Murphy

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## NEWS & NOTES — continued from page 11

to 5%. Adding a requirement for normalization of the serum-free light chain ratio to negative immunofixation studies did not negate the need for BM studies; 10% with a normal serum-free light chain ratio had BM plasma cells more than or equal to 5%. It was also found that, on achieving immunofixation-negative status, patients with less than 5% plasma cells in the BM had improved overall survival compared with those with 5% or more BM plasma cells. This information is very helpful in assessing the best ways to implement response criteria within ongoing clinical trials.

Study confirms association between ESAs and DVTs or PEs  
A study published by the Journal of the National Cancer Institute has confirmed that erythropoiesis-stimulating agents (ESAs), such as Procrit® (epoetin alfa) and Aranesp® (darbepoetin alfa), are associated with an increased risk of deep vein thrombosis (DVT) or pulmonary embolism (PE). The association between ESAs and venous thromboembolism was observed in previous meta-analysis but the new finding is significant because the data is from community clinical settings, not a short-term study. The new analysis included data from more than 50,000 patients aged 65 years or older, including those with more advanced cancer or high-risk status, who therefore might not have been candidates for clinical trials. Results demonstrated that more patients who received an ESA developed DVT or PE, compared with patients who did not. Overall survival was similar in both groups.

### Novel proteasome inhibitor shows promise

A recent study demonstrated that a novel proteasome inhibitor NPI-0052 triggers apoptosis in multiple myeloma cells resistant to bortezomib (Velcade®). In a laboratory setting, combining NPI-0052 and lenalidomide (Revlimid®) was shown to induce synergistic anti-myeloma activity in vitro using myeloma cell lines or patient cells. In animal tumor model studies, low-dose combination of NPI-0052 and lenalidomide is well tolerated, significantly inhibits tumor growth, and prolongs survival. Taken together, the study provides the preclinical rationale for clinical protocols evaluating lenalidomide together with NPI-0052 to improve patient outcome in myeloma.

### CancerCare launches “Door to Door” initiative

CancerCare’s new “Door to Door” initiative provides grants to individual patients with multiple myeloma to help with costs of transportation to and from medical care. The grants of up to \$600 per year cover costs such as car fuel, taxi, bus, or train fare. The program is funded in part by a generous grant from Millennium: The Takeda Oncology Company.

Founded in 1944, CancerCare is a national non-profit organization with a track record of providing financial assistance to people facing cancer. In 2008, CancerCare launched a separate organization, the CancerCare Co-Payment Assistance Foundation, to help cancer patients cover the cost of their health insurance co-payments for certain types of treatments.

To receive a “Door to Door” transportation grant, patients must meet eligibility criteria and complete an application form. To obtain an application, please visit [www.cancercare.org](http://www.cancercare.org) or call 800-813-HOPE (4673).

### Help the IMF learn more about myeloma patients

Please help the IMF learn more about myeloma patients by completing the latest online Myeloma Patient Survey at <http://survey.myeloma.org>. You can complete this survey either as a patient or as a caregiver on behalf of a patient. All responses will be anonymous. No personal identifying information will be gathered.

### AMEN Scientific Advisor is co-recipient of a 2009 Nobel Prize

The 2009 Nobel Prize in Chemistry is shared by researchers Ada Yonat, Thomas Steitz, and Venkatraman Ramakrishnan for their work on the atomic structure of the ribosome. Dr. Yonat is the first Israeli woman to be awarded a Nobel Prize. She is a professor at the Weizmann Institute of Science and is a member of the scientific advisory board of AMEN, the Israeli Association of Myeloma Patients. AMEN translates IMF materials into Hebrew and disseminates them to the myeloma community in Israel, sets up support groups, and participates in conferences focused on myeloma education and research. Dr. Yonat is actively involved with the organization and has never missed an anniversary meeting of AMEN. The IMF joins AMEN in congratulating Dr. Yonat and her colleagues for their impressive achievement.

### RSS feed now available

A new look and a new feature are now available from the same trusted source of information for the National Cancer Institute (NCI) Center for Cancer Research (CCR) clinical trials at the National Institutes of Health (NIH) in Bethesda, Maryland. You can sign up to receive the RSS information feed by visiting the <http://bethesdaclinicaltrials.cancer.gov> website and clicking on the orange RSS button near the upper right corner of the page. CCR conducts more than 150 clinical trials at the NIH. While on the Home Page, clicking on the “All cancer types” link will take you to a page where you can select “Multiple Myeloma” from the list of diseases to narrow your search for information of interest to members of the myeloma community. **MT**

**Imagine Moving Forward** is the theme of the IMF’s myeloma bracelet. Wear one in honor, celebration, or in memory of a loved one. When people ask you about it, you’ll have a perfect opportunity to spread the word about multiple myeloma. These bracelets are only \$1 each in sets of 10. Youth bracelets are available, so everybody in your family who has been touched by myeloma can wear one! Order bracelets online at our website [www.myeloma.org](http://www.myeloma.org), or contact Suzanne Battaglia at [SBattaglia@myeloma.org](mailto:SBattaglia@myeloma.org) or 800-452-CURE (2873).



## ASH PRESENTATIONS — continued from page 6

and kidney problems – and improves survival. These are only preliminary data and it will take us some time to see the full impact of this type of early intervention, but obviously it is an exciting new approach.

### Ongoing active therapy

A study from Antonio Palumbo, MD, at the University of Torino, Italy, (abstract #613) showed that “ongoing active therapy” may be a new option for patients with myeloma. This is the first study to show benefit from continuing treatment as long as the patient continues to respond, and it may be a first step toward revising current standards of care. The three-arm study compared patients treated with a standard combination of melphalan-prednisone (MP), to patients treated with melphalan-prednisone plus Revlimid (MPR) who remained on ongoing active treatment with Revlimid (MPR-R). The interim data analysis focusing upon the comparison of MP versus MPR followed by Revlimid maintenance (MPR-R) presented at ASH demonstrated a 77% overall response rate for MPR-R, and a 50% reduction in risk of disease progression, versus patients treated with limited duration MP. This is the highest risk reduction reported for any phase III study in this patient group. The presentation concluded, “MPR-R (ongoing active therapy) can be considered a new standard of treatment for elderly patients.” These interim results are extremely encouraging, and we certainly look forward to further analyses at the next medical meeting as the trial progresses to assess the full value of this new regimen.

### Velcade combinations

Of further note, a whole series of studies presented at ASH this year indicated benefits using a wide range of Velcade combinations. These included three-drug combinations such as Velcade-Revlimid-dexamethasone, Velcade-cyclophosphamide-dexamethasone, Velcade-thalidomide-dexamethasone, and the four-drug combination Velcade-Cytosan®-Revlimid-low-dose dexamethasone (“Evolution” trial). The longer-term follow-up of the Velcade-melphalan-prednisone combination (“VISTA” trial) was also presented and continued to show an overall survival benefit. We thus now have several very active Velcade combination protocols. The next step is to sort through these combinations to determine which will confer the most benefit in the short-term and ultimately in terms of long-term survival. An additional aspect discussed was the use of Velcade in a once weekly schedule, which showed promise in terms of both equivalent efficacy and reduced neurotoxicity. This approach resulted in quite a bit of discussion among attendees.

### Pipeline drugs and combinations

We have come a long way in treating myeloma, but a study from the IMF’s International Myeloma Working Group (IMWG) looks at what happens when patients no longer respond to the available treatments. This makes a powerful case for continuing innovation in treatment development, while it gives us an important benchmark we can use to evaluate new drugs as they come along (abstract #2878).

Some of the most exciting ASH presentations for the future treatment of myeloma are the results of studies of new drugs. Carfilzomib (a new proteasome inhibitor), pomalidomide (the third generation IMiD, after thalidomide and lenalidomide), elotuzimab (with lenalidomide) and vorinostat

(which can enhance the efficacy of both lenalidomide and bortezomib) are showing efficacy in the treatment-resistant patient population. These new drugs are being studied as single agents, with steroids, as well as in combinations that include existing drugs such as Velcade and Revlimid. There are indications that patients will respond to the new drugs even when they no longer respond to other drugs in the same class (abstracts #301-306, #429, #430).

### Novel combinations versus transplant

A study which caught attention was the randomized study comparing MPR versus high-dose melphalan with autologous stem cell transplant. These results demonstrated that oral drugs in the MPR arm had a 91% progression-free survival at 12 months, identical to that seen in the transplant arm of the study. This raises the possibility that at some point novel combinations could substitute for autologous stem cell transplant in the myeloma treatment paradigm. Obviously further follow-up and additional studies are required to evaluate this type of approach.

### Side effects and predicting outcome

Studies from the IMWG and the IMF gene bank, Bank On A Cure®, suggest a combination of chromosome abnormalities coupled with stage of the disease are a better predictor of outcome when evaluated together than either factor alone (abstract #743). A second study finds specific genetic changes may be responsible for side effects of treatment such as neuropathy, making it possible to build a data base that anticipates adverse events (abstract #1800). Another interesting presentation showed that kidney toxicity, which is important in myeloma, can be reversed with the use of Revlimid and dexamethasone. There were also a number of presentations on new supportive care drugs, including a new type of drug for the treatment of bone disease, ACE-011, which has a unique mechanism of action in enhancing bone repair.

### Myeloma setting the stage for new treatments for other cancers

What is happening in myeloma research is feeding into developments in other areas of hematologic malignancy. Multiple myeloma has been setting the stage for new treatments for a range of cancers, and several presentations at ASH highlighted this fact. Revlimid, developed for use in myeloma and also approved for use in myelodysplastic syndromes (MDS), is now the subject of Phase III studies in a variety of cancers including diffuse large B-cell lymphoma, chronic lymphocytic leukemia, and pivotal studies in mantle cell lymphoma (abstracts #206, #944, #1676, #1679). Likewise, Velcade is approved in mantle cell lymphoma and is also the subject of Phase II studies in follicular lymphoma (abstracts #933, #1661). The results achieved in myeloma are stimulating broader interest and serving as a model in hematologic malignancies overall.

### Conclusion

I hope that this brief overview gives you a flavor of what is coming out of ASH. While myeloma cannot be cured at present, using new therapies in combination and in sequence can provide the potential for long-term remissions with a good quality of life for patients. **MT**

## Supportive Care

### IMF HOTLINE COORDINATORS ANSWER YOUR QUESTIONS

The IMF Hotline 800-452-CURE (2873) is staffed by Paul Hewitt, Missy Klepetar, Nancy Baxter, and Debbie Birns. The phone lines are open Monday through Thursday, 9am to 4pm, and Friday, 9am to 2pm (Pacific Time). To submit your question online, please email [TheIMF@myeloma.org](mailto:TheIMF@myeloma.org).

**I have heard that many myeloma patients have been diagnosed with hypothyroidism. What is it? Why does it occur in myeloma patients? Is it treatable?**

Hypothyroidism occurs when the thyroid gland produces insufficient levels of thyroid hormone. It commonly presents as a general slowing in physical and mental activity, but often the signs of this disease are subtle and hard to pinpoint. Classic signs and symptoms are lethargy, cold intolerance, puffiness, decreased sweating, constipation, slow heart rate, hoarseness, and coarse skin.

There have been several case studies, including one by Badros et al in the *American Journal of Medicine* (2002;112:412-413) that document the incidence of hypothyroidism in multiple myeloma patients being treated with thalidomide. Badros et al found that 14% of patients on thalidomide treatment were subclinically hypothyroid (in other words, they had no outward symptoms, but their laboratory tests showed low thyroid hormone) at three months of therapy. They further suggested that thyroid dysfunction might contribute to some of the known side effects of the drug, such as fatigue, constipation, and bradycardia (slow heart rate).

More recently, there have been reports that Revlimid® (lenalidomide), which is chemically analogous to thalidomide, also causes hypothyroidism. The percentage of patients who developed the problem while receiving Revlimid in clinical trials was 6.8%.



Paul Hewitt, Missy Klepetar, Nancy Baxter, and Debbie Birns

Researchers haven't pinpointed the exact mechanism by which thalidomide and Revlimid affect the thyroid gland. It may be due to the direct toxic effects of the drugs on the gland, or to autoimmune damage to the gland due to deregulations of cellular chemicals called cytokines.

If the patient is responding well to anti-myeloma therapy with either thalidomide or Revlimid and then develops hypothyroidism, he or she may continue the thalidomide or Revlimid and

concurrently receive thyroid hormone replacement therapy; symptoms of low thyroid hormone will abate as thyroid levels normalize.

Obstacles to proper management of the thyroid during thalidomide or Revlimid therapy are:

- 1) the assumption (by both patients and physicians) that the symptoms are merely side effects of the drug, and
- 2) failure to detect the occurrence of asymptomatic hypothyroidism.

Some patients diagnosed with myeloma may even have underlying hypothyroidism as a result of pre-existing viral or autoimmune thyroid disease. Patients who receive thalidomide or Revlimid should, therefore, have their thyroid function checked both *before* receiving either of these drugs and periodically during treatment. If the patient is found to be hypothyroid, then further medical review is required to be certain of the cause. **MT**

### WHAT DO YOU GET AT AN IMF PATIENT & FAMILY SEMINAR?

**Education • Access to Experts • Camaraderie**



#### Topics Covered

- **What's New in Myeloma?** • **Ask-the-Expert**
- **Managing Side Effects** • **How to be a Better Patient**
- **Frontline Therapy** • **Transplant** • **Bone Disease**
- **Maintenance Therapy** • **Relapse** • **Novel Therapies**



#### Regional Community Workshops (RCW)

If you cannot get to a P&F Seminar, consider attending a Regional Community Workshop. These half-day meetings provide Education, Access to Experts, and Camaraderie. Registration is free *but you must register*. It's a great way to learn from myeloma experts, as well as share experiences and gain strength from others in the IMF family. Find more details about the next RCW near you at our website.

Go to our website  
**[www.myeloma.org](http://www.myeloma.org)**  
and click on the  
"Seminars and Meetings"  
tab for more details, the  
most up-to-date faculty, hotels  
and registration information.







# Nurse Leadership Board

## NLB REPORTS ON SURVIVORSHIP CARE PLAN PROGRESS

### Myeloma Today in conversation with Beth Faiman and Teresa Miceli

*Over the past decade, advances in anti-myeloma therapy have led to better overall survival for patients with multiple myeloma. Novel agents have become a staple in the growing array of myeloma treatment options, providing hope for extended disease-free periods and improved outcomes for patients. As more people are living longer with myeloma, members of the IMF Nurse Leadership Board (NLB) are addressing the evolving needs of myeloma survivors. The NLB Survivorship Care Plan, which is currently being prepared for publication, examines five specific aspects of long-term care for the benefit of patients and the nurses who work with them. Patient survivorship care planning allows for optimal management of emergent late-term effects and improved quality of life. The leaders of two of the five NLB teams spoke with Myeloma Today about their work. The work of other three teams will be profiled in upcoming issues.*



Beth Faiman,  
RN, MSN, CNP, AOCN  
Taussig Cancer Institute  
Cleveland Clinic  
Cleveland, OH

I am in charge of the Renal Section of the Survivorship Care Plan. For many people with myeloma, cancer and kidney disease often go hand in hand. As many as 25% to 50% of myeloma patients are affected by kidney disease at some point during their treatment. This might occur at diagnosis or at relapse. In addition, as people are living longer with myeloma, the patient population of people with renal issues is growing.

The kidneys of myeloma patients need to be evaluated and monitored with blood tests. If renal function is not monitored as diligently as it should be, serious problems might arise. It is important for both patients and nurses to be aware of what medications and procedures to avoid and how to approach treatment when renal issues are a concern. For example, patients taking Revlimid® (lenalidomide) may need to have their doses adjusted in order to protect their kidneys from possible damage.

Proper care can prevent future need for dialysis. A patient's primary care doctor can make sure that the proper kidney surveillance is taken care of. However, once the patient reaches a certain stage of kidney failure (Stage 3), the Chronic Kidney Disease Foundation recommends that the patient be followed by a nephrologist, and follow-up with blood tests may need to be done every three or six months.

In Renal Section of the Survivorship Care Plan manuscript, we recommend that patients drink lots of water and pay attention to their urination (which should be regular, with urine that is light in color) and report any changes to their healthcare team. Other health conditions, such as diabetes or high blood pressure, should be monitored and kept under control. We highly recommend that each patient develop a care plan with their providers to monitor kidney function in order to avoid unnecessary problems.



Teresa Miceli, RN BSN OCN  
Mayo Clinic  
Rochester, MN

I head the team working on the Bone Health & Bone Disease Section of the Survivorship Care Plan. This section includes guidelines on bone health maintenance, as well as the impact that bone disease has not only on acute care but also on long-term management, pain management, quality of life and lifestyle issues, prevention of further

bone damage and protections of skeletal structure, and other components that contribute to bone health or bone disease.

There are many facets of bone physiology and pathophysiology that my team is examining. The pathology of bone structure has an impact on myeloma patients' diagnosis and prognosis, functional mobility, and pain management. Our group is looking at myeloma treatment options in view of bone health and bone disease, including the benefits and cautions regarding the use of bisphosphonates. Long-term management of osteonecrosis of the jaw (ONJ) is one of the important issues being incorporated into this section of the Survivorship Care Plan.

It is important to note that bone involvement is not consistent across the board among patients with myeloma. Not all patients have bone involvement as a result of their disease, and we must reflect on this as well. Myeloma patients who do not have underlying bone-related issues but who are exercising caution when it comes to activities they enjoyed prior to their myeloma diagnosis, might not need bisphosphonates or other precautions. For example, I know a myeloma patient who enjoyed playing contact sports prior to diagnosis but ceased his activities for fear of bone fractures. This patient did not have any bone lesions or any underlying bone disease as part of his myeloma, so his risk of a fracture was no greater than that of any other person who did not have this disease. It was important for him to hear that playing a sport he had enjoyed would not put him at greater risk of a fracture than anyone in the general population. **MT**

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Cedars-Sinai Outpatient Cancer Center  
Samuel Oschin Comprehensive Cancer Institute  
Los Angeles, CA

**Elizabeth Bilotti, RN, MSN, APRN, BC, OCN**  
John Theurer Cancer Center at HUMC  
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**Kathleen Colson, RN, BSN, BS**  
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**Beth Faiman, MSN, APRN-BC, AOCN**  
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**Bonnie Jenkins, RN**  
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Meeker County Memorial Hospital  
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# Support Groups

## PEOPLE HELPING PEOPLE

You are never alone in your battle against myeloma

### Report from the 10th annual IMF Support Group Leaders Retreat

The International Myeloma Foundation's 10th annual Support Group Leaders' Retreat was held on July 17-19 in Dallas, Texas. For a decade, leaders of myeloma support groups from across North America have gathered for a weekend to share, learn, network, and just have fun. The generous sponsors who made this year's retreat possible include the Celgene Corporation, Proteolix Inc., the Marx Family Foundation, and Millennium Pharmaceuticals.



The 2009 retreat was attended by more than 50 group leaders, co-leaders, and representatives – an impressive group that included 17 new myeloma support group leaders. The format of the retreat was enhanced by the skilled facilitator Alan Kumamoto (Kumamoto Associates), a long-time friend of the IMF.

On Friday, July 17, the leaders were welcomed by the IMF staff before the start of the day's presentations. An update on myeloma clinical trials by Dr. Brian G.M. Durie and a presentation about the IMF's advocacy program were only two highlights of a very busy day. Before adjourning, Alan gave a retreat overview and explained to the participants what was in store for the weekend. At cocktails and dinner, everyone enjoyed mingling with old friends and making new ones.

On Saturday, July 18, the day's program started bright and early with Alan dividing the participants into small groups for an "icebreaker" activity. Each person got to tell "three lies and a truth" about themselves and then the others had to guess which was which. It was a fun way to start off the day that helped everyone feel like they had known each other for longer than just a few hours. The rest of the day was spent discussing group leaders issues, problem solving, suggestions and recommendations, and roles and responsibilities.

On Sunday, July 19, retreat participants got right to the nuts and bolts of support group strategic and operational planning. Leaders were divided into three groups according to the geographic regions of their groups. Leaders from the Northeast, the South, and the West were challenged to identify short-term and long-term objectives, as well as to create a plan that would support the longevity of their groups. At the end of the day, all participants shared experiences and ideas to help ensure each group's successful future.

By the end of the retreat, each group's representative had a signed "contract" as well as a commitment from the IMF support group director for their region to help the leader follow through with their plans. The IMF has already set up a new website designed specifically to enhance group leaders' sharing of information, documents, and ideas on running a myeloma support groups. As participants dispersed to travel back to their homes, many expressed their enthusiasm for next year's retreat. Now that's a sure sign of a successful and productive Support Group Leaders' Retreat!

### Myeloma Canada hosts successful conference

Myeloma Canada's fifth annual Patient, Family & Healthcare Professionals Conference was held in Calgary on September 11-12. The meeting was hosted by the Southern Alberta Multiple Myeloma Support Group in co-operation with the IMF. Faculty included Drs. Donna Reece (Princess Margaret Hospital, Toronto, ON), Morie Gertz (Mayo Clinic, Rochester, MN), Brian Durie (Cedars-Sinai Cancer Centre, Los Angeles, CA), Arthur Bradwell (University of Birmingham, UK), and Nizar Bahlis (Tom Baker Cancer Centre).

The general assembly sessions included presentations on myeloma basics, current approaches to myeloma therapy for both the newly diagnosed and for relapsed/refractory disease, promising treatment developments on the horizon, serum free light chain analysis, and understanding lab data and test results. Panel discussions and audience Q&A sessions provided additional insight into several current issues in myeloma management. In addition, IMF Director Mike Katz shared his insights about how to be a better patient and explained the helpful new Myeloma Manager tool, myeloma nurse Teresa Miceli (Mayo Clinic, Rochester, MN) talked about managing side effects. The break-out sessions provided participants with an opportunity to attend discussions of specific interest.

### New Ohio support group off to a solid start

In addition to Cincinnati, Cleveland, and Dayton, Ohio now has a new multiple myeloma support group in the Columbus area. The group's first meeting took place on September 10, with 11 people in attendance, most of them patients. The support group was formed by Nick Menedis, who was diagnosed with myeloma in 2006. "With the assistance of IMF's Robin Tuohy, we mailed invitations to myeloma patients and caregivers within an hour's drive of our meeting facility. We also posted flyers in local clinics and hospitals," says Nick. "The format of our meetings is focused on encouraging patients to talk about where they are with their disease and to address the questions that arise. Although we use a facilitator, our group is run by patients and caregivers who want to help each other to become better educated about our disease in order to take a more active role in our treatment decisions. We encourage developing a positive outlook and maintaining a good attitude. I have taken a very involved stance with my disease and I want to share with others the knowledge and resources that have helped me since my diagnosis." The group meets on the third Tuesday of each month from 6:30 p.m. to 8:00 p.m. at The Wellness Center, 10330 Sawmill Parkway, Suite 600, Powell, OH 43065. For more information, please email Nick at [IMFnick48@aol.com](mailto:IMFnick48@aol.com) or call him at 614-868-8506.

### NEW support groups invite YOU to join them

**Eau Claire, Wisconsin:** This group's first meeting took place on December 14, 2009. Meetings will continue to take place on the second Monday of each month. For more information, please contact Colleen O'Connor at [eauclairemyeloma@me.com](mailto:eauclairemyeloma@me.com) or 715-835-2303.

**Richmond, Virginia:** This group's first meeting is planned for January 2010. For more information, please contact Barbara Marx at [gobabsgo@aol.com](mailto:gobabsgo@aol.com).

**York, Pennsylvania:** This group's first meeting is planned for January 2010. For more information, please contact Sharon Berger at [yorkbergers@verizon.net](mailto:yorkbergers@verizon.net) or 717-292-5890. **MT**



## UPDATES FROM AROUND THE GLOBE

### Florence, Italy

The second annual Patient & Family Seminar of the Associazione Schirinzi A. Mario was held on October 21, 2009. The Florence meeting was the first seminar in Italy since the IMF and the Associazione Schirinzi A. Mario have formed an alliance to formally work together in the fight against multiple myeloma. Founded in April 2008, the Associazione Schirinzi A. Mario, disseminates information about myeloma through its site <http://mieloma-help.blogspot.com>, maintains an active news flow through updated press releases, provides contact information for hematology centers in Italy, organizes events to raise public awareness about myeloma, and holds seminars for patients and their families.

### Torino, Italy

On October 23, 2009, the IMF once again joined with AIL (the Italian Leukemia/Lymphoma Organization) to hold a Patient & Family Seminar in Torino. This was the eighth IMF Patient & Seminar in Italy. Rai TV, the national television network, filmed the meeting, excerpts of which aired later that day. The meeting was also covered by the Italian print media.



Prof. Mario Boccadoro

The Torino seminar began with a welcome from the Seminar Chair Prof. Mario Boccadoro, who read a letter from the esteemed Italian myeloma doctor Prof. Franco Mandelli, who sent regrets that he could not attend the seminar. Prof. Mandelli expressed his best wishes and his hopes that the attendees would make the most of the wonderful opportunity to learn about myeloma from an outstanding faculty assembled for the meeting. Before the start of the presentations, IMF President Susie Novis thanked the seminar's expert medical faculty – including Mario Boccadoro, Brian G.M. Durie, Maria Teresa Petrucci, Sara Bringhen, Federica Cavallo, Patrizia Tosi, Louisa Giaccone, Tommaso Caravita, Luca Baldini, and Benedetto Bruno – as well as her IMF colleagues in attendance, Executive Director David Girard and Director of Europe Greg Brozeit.

Seminar presentations covered a broad range of topics, including myeloma diagnosis, staging, monitoring, maintenance and supportive care, as well as the use of novel therapies in patients who will not be undergoing transplantation, treatment options after relapse, promising new drugs in the pipeline, and autologous and mini-allo transplantation. The comprehensive presentations, which made complex information accessible to the lay audience, were very well received. During the lively interactive sessions, it was interesting to note that 32% of patients had been diagnosed as a result of a routine physical exam. Also of note was the keen interest in neuropathy and fatigue, which the interactive survey revealed to be the side effects of most concern to the patients in attendance.

The seminar showcased the progress made in the field of myeloma in recent years, the profound benefits of patient education, and the growing spirit of hope for the future that is shared by both the medical and the patient communities. Susie Novis compared the seminar to a movie, which was fitting as the meeting took place in the auditorium of a movie theater. "Scene 1: the patient receives the diagnosis and it's a scary movie. Scene 2: the movie becomes a drama as the patient begins treatment and life is turned upside down. Scene 3: the doctors are excellent, the patient has access to effective new therapies, the disease goes into remission – it's a love story. The closing scene is a look into the future where there is a cure, the patient is fine, and life is good."

### Paris, France

On October 30, 2009, the IMF held its seventh Patient & Family Seminar in Paris. Once again the event was held in the beautiful Le Maison de La Americ Latine. Meeting Chair Prof. Jean-Luc Harousseau was joined by an esteemed faculty, which included Profs. Thierry Facon, Michel Attal, Philippe Moreau, and Jean Paul Fermand of France, as well as Brian G.M. Durie of the USA.



Jean-Luc Harousseau,  
Brian G.M. Durie, Susie Novis,  
and Thierry Falcon

The meeting began with a welcome from Susie Novis and the important message that knowledge is power. By attending educational seminars, participants have an opportunity to learn about the many treatment advances in myeloma available to them. Susie acknowledged the work of the Association Francaise des Malades due Myelome Multiple (AF3M), the French national myeloma advocacy group, and expressed that the IMF is honored to be able to work with them.

The seminar's medical presentations were informative and comprehensive, and the faculty's shared outlook of optimism for the future was important for the patients in attendance to hear. The IMF filmed the Paris seminar and is making the video available for viewing on the IMF website.. **MT**



### Dr. Kyle Participates in German Meetings

By Gregor Brozeit

IMF Scientific Advisory Board (SAB) Chairman Dr. Robert A. Kyle of the Mayo Clinic headlined a number of patient and doctor meetings in Germany in the summer of 2009, reaching hundreds of patients and family members and dozens of doctors.

Dr. Martin Gramatzki of the University of Kiel hosted Dr. Kyle in the first ever patient education meeting in the extreme north of Germany.

Dr. Martin Kropff of the University of Münster hosted 305 audience members – the largest IMF meeting ever held in Germany – in a patient meeting on June 13, 2009. In addition to Dr. Kyle, IMF SAB member Dr. Hartmut Goldschmidt of the University of Heidelberg also spoke to the audience covering topics including novel therapies, treatment for relapsed and refractory patients, and clinical trials in Germany.

Leipzig support group leader and founder Albrecht Reissman hosted Dr. Kyle, Dr. Dieter Niederwieser of the University of Leipzig and more than 135 patients and family members on June 15. Dr. Niederwieser also serves as the president of the European Group for Blood & Marrow Transplantation (EBMT).



Dieter Niederwieser, Robert A.  
Kyle, and Albrecht Reissman

At the Hamburg-Eppendorf University Clinic, Dr. Nicolas Kröger hosted Dr. Kyle in a speech before 50 doctors at the clinic. The final stop on Dr. Kyle's tour was a presentation for doctors hosted by SAB member Dr. Orhan Sezer of Berlin Charité Hospital, the largest hospital in Germany.

Dr. Kyle's trips to Germany over the past four years have attracted more than 1700 attendees and over 200 doctors to attend educational meetings. **MT**



## IMFERS RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia

As the International Myeloma Foundation begins its 20th year of service to the myeloma community, we reflect with pride on our effort to make the IMF your foundation, in the most inclusive way possible. Working together with IMFers across the country and around the world, our Member Fundraising campaign has blossomed into a network of people like you, raising money for myeloma research and educational programs.

By organizing an event in your community, you are extending myeloma awareness to those who have never heard of it. In addition, it lets them know there is a place to turn for the most up-to-date information and resources available to the myeloma community. You know you want to do something in your community to raise funds and public awareness about myeloma, but deciding on what to do and how to do it can be confusing. The IMF's FUNdraising program is here to make it as easy as possible for you to participate, whether or not you have any experience with fundraising or awareness activities.

FUNdraising is fun (get it?) and easy to do, and brings with it the satisfaction of knowing that YOU have made a difference in many lives. We are grateful to all IMFers who contribute their time, imagination, and hard work to benefit the myeloma community. Our FUNdraising program provides you with the tools, assistance, and expertise to make your event a success. Choose an established event model or create your own – no idea is too large or too small. Join us in working together toward our common goal... a CURE. Please contact me, Suzanne Battaglia, at [sbattaglia@myeloma.org](mailto:sbattaglia@myeloma.org) or 800-452-CURE (2873). I am here to chat with you about any ideas you might have. Be part of the progress of making miracles happen!

*Here is just a sampling of some past and upcoming events...*

### Carolyn Czerkies Charity Golf Outing



Dave Czerkies, Ed Czerkies, IMF Director Chuck Newman, Craig Czerkies, Scott Czerkies

On June 6th, the second annual Carolyn Czerkies Charity Golf Outing to Benefit the IMF took place at the Whitetail Ridge Golf Club in Yorkville, Illinois.

More than 100 golfers were present for the shotgun start to the event. Golfers' donation entitled them to greens fees, cart, driving range, lunch, drink tickets, buffet

dinner, an open bar at the post-golf gathering, and goodie bags provided by Wachovia Securities. Contests included Longest Drive and Closest to the Pin, with trophies for tournament champions. All participants, including some non-golfers, enjoyed the event and several lucky ticket buyers took home raffle prizes donated by other participants and event sponsors. The golf outing was a stunning success and the organizers are already looking forward to planning the 2010 event!

### Julie Smudz 5K Fun Run & Family Walk



On June 7th, the Julie Smudz 5K Fun Run & Family Walk took place at the Delaware State Park in Delaware, Ohio. Julie was a strong and active woman who fought hard against myeloma. Her courage and positive spirit have inspired family and friends to help raise money to defeat this disease by organizing the run/walk in honor of

Julie's healthy lifestyle. "The day was fantastic!" said Mike Smudz. "Many company sponsors and individual participants stepped up to support our event and we raised almost \$5300 for the IMF's myeloma research program. Great success!"

### Jonesboro Days

On July 4th, Darlene Jessee and members of the Northeast Tennessee Multiple Myeloma Support Group hosted a fundraiser at Jonesboro Days in Jonesboro, Tennessee. The event fit in well with the group's mission – to build

a social and emotional support network for patients with myeloma, their friends and family, and to spread awareness and disseminate medical information within the local community. The event was organized in memory



Photo above: Guerry McConnell and Darlene Jessee accepting a check from Jimmy Neil Smith, Founder and President of the International Storytelling Center

left to right: Judy and Jim Harvilla, support group leader Darlene Jessee, Melisa Jessee, and Darlene

of support group members Doug Bradford and Doc McConnell, the well-known storyteller. Doug's wife Darlene and her friends made handmade greeting cards to sell and Doc's wife Guerry donated CDs of Doc's stories and entertained guests at "Doc's front porch" at the International Storytelling Center in Jonesboro.

### Friends Of Richie III

On September 20th, 2009, Friends Of Richie III:

A Bloody Good Time benefit concert combined an evening of music with comic arts and pop culture at Hollywood's Knitting Factory. "Friends Of Richie" was first organized in 2007 to honor veteran alternative musician Richie Hass and to benefit IMF programs and services.

In 2008, "Friends Of Richie II: A Celebration Of

A Life," took place in Richie's memory as a fundraiser for the IMF. The event has now become an annual staple on the Los Angeles music scene, with an illustrious lineup of musicians Richie worked with during his long career. **MT**



Richie Hass

### UPCOMING MEMBER EVENTS

**January 30, 2010** "The Reign" Fashion Show Extravaganza – National Constitution Center • Philadelphia, PA – To purchase tickets, please call 609-254-6328 or visit [www.christinephillipsonline.com](http://www.christinephillipsonline.com)

**April 10, 2010** Fishing for a Cure: Bull Roast & Celebration in honor & memory of Bill Gunther – American Legion Post 39 • Bel Air, Maryland To purchase tickets, please contact Bill Gunther 3rd at 410-808-2457 or [Billwcg@aol.com](mailto:Billwcg@aol.com)

**April 24, 2010**

**MILES FOR MYELOMA 5K Walk/Run** – Philadelphia, PA Co-Sponsored by Philadelphia Multiple Myeloma Networking Group, Central New Jersey Support Group, and Northern Jersey Support Group For information, please contact Karen Horan at [karen.horan@verizon.net](mailto:karen.horan@verizon.net)

## LOOKING FORWARD, LOOKING BACK

### An Artist Recalls His Stem Cell Transplant

By RL Schrag

OK, it was not a stay at the spa – but in some ways that is good news. The only time I went to a spa they blasted me with a water cannon, put hot rocks on my back, and made me eat tofu-based products garnished with nuts and sprouts. Not the ideal protocol for someone with multiple myeloma. But I hadn't been diagnosed yet, what did I know? Still, a return to the spa is not high on my list of "gotta do that" as I sit here, 18 months post-transplant, in the relative comfort of remission. I would, however, like to revisit my transplant with you, particularly if yours is still waiting down the winding road to recovery.

I came to my transplant as a mature college professor. For thirty years, thousands of fresh or jaded young faces had floated in and out of my classrooms. All entered as strangers, a few left as lifelong friends. It was, and remains, a good life. But I came to my transplant as a relatively young artist. My willingness to self-identify as an "artist" was only a few years old, and my first one-man show was even younger. The distinction is important because as I moved through my transplant, my youthful inner-artist was better company than my older inner-professor. The professor tended to obsess over the details: Why are you doing that? What does that do? He leaned toward criticism and concern. My inner-artist allowed himself to be fascinated by those same interactions: I'm going to make completely new bone marrow? How cool is that! I'm going to get a shunt in my chest so you don't have to stick me with a gazillion needles every day? Neat!

I do not mean to disparage my intellectual identity. We all enter this sci-fi world of stem cell transplants in various stages of ignorance. I was fortunate to have a superb medical team attending to me. My own oncologist walked me through what to expect, and the folks over at the University of North Carolina Hospital Bone Marrow Transplant Unit kept me well informed each step of the way. My wife and I asked hundreds of questions and got in-depth answers. We all need to do that, we need to be informed participants in our treatment – otherwise we remain willfully ignorant, and that's just stupid. But I soon realized that, for



me, the constant role of "medical overseer" was proving incredibly stressful – the professor was making me nuts. I decided that I had absorbed as much about medicine as I could. It was time to look for the art.

Among the rules I have set for myself since "coming out" as an artist, is to look for art everywhere. We often stumble over beauty, not because it is hiding, but because we have grown inattentive to the exquisite in the everyday. We are inclined to find art only where someone else has placed a frame, or erected a pedestal, or thrown up a spotlight declaring, "Now that, Mildred, that there is art. That's what they call 'real beauty'." Balderdash! It's always been one of my favorite words, and is delightfully applicable here. Beauty

needs no frame to gild its particular lily. Insight needs no pedestal. As a matter of fact, if you spend enough time at contemporary art galleries you begin to suspect that the very presence of a frame or pedestal indicates more Gotcha than Goya. I recently went to a gallery in Florence, Italy,

no less, featuring the works of "Italy's best young artists." Among the displays was a small bottle filled with fingernail clippings, starkly lit. The card informed me that it was reflecting "an angst filled vortex spinning in on it- and him-self searching for a potential solution, or what we might even call a cure." I must confess, I laughed. Surely with tongues so firmly planted in cheeks these folks must have trouble breathing, not? But, I digress. The point is this: As we sharpen our appreciation for the little bits of beauty that lurk around hospital corners where sterility is king, we become attuned to the wonders that await everywhere in life.

How do we find beauty in being a patient? By looking. Carefully. By listening. Intently. By becoming the individual acting within the environment, not acquiescing to the role of "the body acted upon." By recording what we see and hear, by creating from that input, by seeking out and expressing the exquisite residing in the unexpected, we find a kind of patient beauty.

#### To My Senses, Returning After Chemo

Senses – fragile, childlike and skittish,  
Remain poised to startle into the dark forest  
That still surrounds this welcome patch of sun.  
They come back slowly, as softly as  
Pieces of a song that once you knew by heart.  
The laptop's keyboard eschews dull symbols  
Needing to be beaten, unwillingly, into words.  
Instead fingers find allies responding gently  
As you draw shy meaning out onto the page.  
Then taste enchants, swift flashes of pleasure.  
Ephemeral pastels, but pleasure nonetheless.  
Birdsong rivals violins, unstudied symphonies  
Pour from preening orchestras hidden in the hedge.  
When pain attacks it is with edges dulled  
By renewed confidence in pending ease.  
Sleep floats in on waves of soft comfort,  
Replacing torpid surrender to fatigue.  
It is neither over nor complete; but it is progress  
Every bit as riotous as the gaudy flowers,  
That paint the greening canvas of this Spring.

– RL Schrag

CONTINUES ON PAGE 22



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#### RL SCHRAG — continued from page 21

I heard a story on the radio the other day about a videographer embedded with troops in Afghanistan. He revealed that life in that chaos was more tolerable through the lens of a camera. The role of insightful observer was somehow empowering. He could walk through a firefight with a modicum of calm if he framed it through optics. I found the same to be true as I moved through the various stages of my stem cell transplant. I am sure you can do the same.

The patient information sheets provided by the hospital neglect to list some tools vital to patient comfort and empowerment: a camera, a sketchpad, pencils, pens, markers, and, of course, your laptop or other digital palette of preference. I need to point out that expertise with any of those tools is completely optional. They are simply the friends who are taking this journey with you. They let you record those moments that eventually fade from memory. My blog at <http://artisticinterloper.blogspot.com/> shows you how I used my friends to structure the wonder and artistry that I encountered during my experience. Feel free to hop over there and take a look. But that was my journey — yours awaits you, enjoy it.

No, that is not a typo. I really did say enjoy it. You are going to do it, right? It is a necessary stage on your journey back to health. You cannot get there except through this experience. So why fight it or fear it? A transplant is magical and beautiful in its potential and complexity. I remain in awe of the science and compounded genius that made it all possible. I remain profoundly grateful to the dozens of people who walked the transplant trail with me. I hope I did them justice with my words and images. Now you give it a shot. **MT**

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Or, you can mail your phones direct to the IMF:

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1 Katzmann, J.A., et al. Mayo Clinic Proc. 2006;81(12):1575-78  
2 Pratt, G. et al. Leukemia and Lymphoma, 2006;47(1):21-28

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## 2010 IMF Calendar of Events

April 15-17	Southwest Oncology Group (SWOG) meeting – San Francisco, CA	July 23-25*	IMF Support Group Leaders' Retreat – Dallas, TX
April 21	IMF Patient & Family Seminar – Paris, FRANCE	Aug 13-14*	IMF Patient & Family Seminar – Philadelphia, PA
April 27	IMF Clinical Conference – Moscow, RUSSIA	Aug 27-28*	IMF Patient & Family Seminar – Los Angeles, CA
May 13-16	Oncology Nursing Society (ONS) meeting – San Diego, CA	Sept 23-24	6th Int'l Serum Free Light Symposium – Bath, UK
May 21-22*	IMF Patient & Family Seminar – Portland, OR	October	IMF Patient & Family Seminar – Bologna, ITALY (date TBD)
June 4-8	American Society of Clinical Oncology (ASCO) meeting – Chicago, IL	October	IMF Patient & Family Seminar – Barcelona, SPAIN (date TBD)
June 8-9	International Myeloma Working Group (IMWG) summit – Barcelona, SPAIN	Oct 15-16	IMF Patient & Family Seminar – Vienna, AUSTRIA
June 9	Robert A. Kyle Lifetime Achievement Award dinner – Barcelona, SPAIN	Oct 21-23	Southwest Oncology Group (SWOG) meeting – Chicago, IL
June 10-13	European Hematology Association (EHA) meeting – Barcelona, SPAIN	Nov 5-7	Eastern Cooperative Oncology Group (ECOG) meeting – Ft. Lauderdale, FL
June 10-13	Eastern Cooperative Oncology Group (ECOG) meeting – Washington, DC	Nov 13	4th Annual Comedy Celebration – Los Angeles, CA
July 16-17*	IMF Patient & Family Seminar – Indianapolis, IN	Dec 4-6	American Society of Hematology (ASH) – Orlando, FL

Additional events/meetings will be posted in later editions of *Myeloma Today* as dates are finalized.

For more information, please visit [www.myeloma.org](http://www.myeloma.org) or call 800-452-CURE (2873).

IMF–Latin America, IMF–Japan and IMF–Israel events are not included above.

*\*Dates subject to change as this issue goes to press. Check the website for dates as they are finalized.*

*Thank you for your continued support of the IMF. Because of your contributions, we have been able to maintain the full range and quality of the programs we offer.*



# INTERNATIONAL MYELOMA FOUNDATION 3rd Annual Comedy Celebration

*benefiting the Peter Boyle Memorial Fund*

## MYELOMA TODAY Special Gala Report



On November 7th, 2009, almost 1,200 guests packed the Wilshire Ebell Theatre in Los Angeles for the IMF's 3rd Annual Comedy Celebration benefiting the Peter Boyle Memorial Fund. The annual fundraiser once again broke IMF fundraising records by bringing in

nearly \$700,000 for our award-winning research program and patient services.

The Annual Comedy Celebration began when Loraine Boyle, IMF Board member and wife of the late actor Peter Boyle, reached out to Susie Novis and Dr. Brian Durie with a profound desire to help make a difference. Having established the Peter Boyle Memorial Fund, she invited Peter's colleagues and friends to put on a comedy show in his honor to raise myeloma awareness and funds for the IMF.

This year, Amy and Steve Weiss joined the event as co-chairs. Together with Loraine, they rounded up an exceptional cast of comedians to come out in support of the IMF. As in previous years, the event was hosted by Ray Romano, this time with Jimmy Kimmel, and featured appearances from Jason Alexander, Brad Garrett, Doris Roberts, Bob Saget, Fred Willard, and a special musical performance by Tenacious D with Jack Black and Kyle Gass.

In addition to the stellar show, the IMF welcomed attendees to enjoy a pre-show cocktail party and silent auction that made a significant impact on the overall success of the event. Items up for bid in the auction included guitars signed by Sting and Meat Loaf, boxing gloves from Mohammed Ali and Sugar Ray Leonard, and a fantastic assortment of trips, memorabilia, jewelry, and more that were graciously donated for the cause.

VIP guests were also treated to a post-show champagne and dessert reception that lasted well into the night. The IMF would like to thank our presenting sponsors, Celegene and Millennium, as well as the nearly 30 additional event sponsors for their generous support.

**MT**





Attendees ranged from long-time IMF supporters to guests of the generous sponsors who made the event a tremendous success. The energy throughout the evening was one of excitement and laughter as people from different backgrounds and levels of interaction with the IMF joined together to raise money for the Peter Boyle Memorial Fund.



*(l to r) IMF President Susie Novis, Honorary Co-Chairs Louis and Alice Weiss, IMF Chairman Dr. Brian Durie, event Co-Chairs Steven and Amy Weiss*



*Susie Novis, Loraine and Lucy Boyle, Dr. Brian Durie*



*Dr. Brian Durie and Susie Novis with Mark and Donna Di Cicila*



*Kimberly Alexander, Dr. Brian Durie, Elijah Alexander, Susie Novis*



*Phyllis and Allan Weinstein*



*Doran Goldstein and Jeff Katz with Susan and Michael Katz*



*Susie Novis with Carol Klein, Sarah Klein and Dr. Brian Durie*



*Susie Novis and Dr. Brian Durie with actress Alison Sweeney*



*(l to r) Susie Novis, Blythe Danner, Loraine Boyle, Jimmy Kimmel and Dr. Brian Durie*





The IMF's partners in the pharmaceutical industry turned out in force! We were so pleased to see so many of our friends for a social occasion in support of myeloma research. We especially thank our presenting sponsors, Celgene and Millennium: The Takeda Oncology Company. Please see the inside-back cover for a full list of all of our sponsors. Their participation makes the event the huge success that it is and we thank them all.



Mark Alles and the team from **Presenting Sponsor Celgene** with Susie Novis and Dr. Brian Durie



Dr. Brian Durie and Susie Novis join representatives of Aptium Oncology, Inc. at the VIP Post-Show Champagne Reception.

(l to r) Dr. Brian Durie, Sarah Jessup, Dr. William Audeh, Paul O'Dea, Kelli O'Dea, Susie Novis, Peter Jessup



Ronny Mosston and the team from **Presenting Sponsor Millennium: the Takeda Oncology Company** with Dr. Brian Durie and Susie Novis



The team from Proteolix (now Onyx) join the festivities and visit with Dr. Brian Durie and Susie Novis.

Back row (l to r): Mai Le, Paula Boulton, Chris Molineaux, Barbara Frauman; Front row (l to r): Susan Demo, Dr. Brian Durie, Susan Monineaux, Susie Novis, Hilary Nouri



The sold-out event welcomed more than 1100 people including celebrities and their fans, entertainment industry executives, myeloma patients, doctors and pharma representatives to the Wilshire Ebell Theatre, raising almost \$700,000 for the IMF's research program. The show brought tears of laughter to everyone's eyes and enormous thanks to all the celebrities who donated their time and their humor to the event.



Clockwise from above:  
Honorary Co-Chairs Louis and Alice Weiss with event Co-Chairs Amy and Steven Weiss; Doris Roberts; Loraine Boyle, Ray Romano, Susie Novis and Dr. Brian Durie; Ray Romano on the Red Carpet; The Red Carpet Press Line; Fred Willard and Dr. Brian Durie; Jason Alexander with Susie Novis and Dr. Brian Durie



Celebrities signed our Cancer Patient Statement of Principles to show their support of the IMF's advocacy efforts.

Clockwise from top-right:  
Event Co-Chairs Steven and Amy Weiss; Actress Jenna Elfman; Musician Adam Gaynor of Matchbox Twenty; Actor Joe Manganiello; Actress Alison Sweeney; Event Co-Chair Loraine Boyle; Comedian Jimmy Kimmel



Clockwise from top-right: Musician Joe Walsh of the Eagles; Elijah and Kimberly Alexander; Actress Maggie Wheeler; Actress Jill Zarin; Musician Meat Loaf; Everybody Loves Raymond Actress Alex Meneses





INTERNATIONAL MYELOMA FOUNDATION  
**3rd Annual Comedy Celebration**  
*benefiting the Peter Boyle Memorial Fund*

THE SHOW! Thanks to all the comedians and musicians that made us laugh until we cried!



Host-extraordinaire Ray Romano



Jimmy Kimmel



Doris Roberts



In the Greenroom with (l to r)  
 Ray Romano, Bob Saget,  
 Jimmy Kimmel and Jason Alexander



Bob Saget



Brad Garret and Ray Romano



Jason Alexander

Tenacious D with Jack Black and Kyle Gass gave a performance that was the highlight of a truly hilarious evening



Fred Willard



Photos in this publication by John Heller, Craig Rucker, and James Needham



## Excerpts from some of the articles about the event

THE  
HUFFINGTON  
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IN PARTNERSHIP WITH CAUSECAST  
DECEMBER 10, 2009



**Loraine Boyle**

Posted: November 6, 2009 11:27 PM

BIO

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Bloggers' Index

## Fighting Myeloma with Laughter

In her book, "The Year of Magical Thinking", Joan Didion defined for me what it is to lose your husband. Her book helped get me through the hell of losing my husband of 29 years, Peter Boyle, who died nearly three years ago of an incurable blood cancer called myeloma... Although Peter played monsters and villains in many movies, his roots were in improvisational comedy. Laughter to fight disease made sense... Seeing these great per-

formers supporting Peter's memory makes life a little easier for me and my family... In life we do have a choice to either deal with what's given us in a positive way or else let it undermine the rest of our lives. The first way pays tribute to those whom we loved and the second leads to despair.

[http://www.huffingtonpost.com/loraine-boyle/fighting-myeloma-with-lau\\_b\\_349296.html](http://www.huffingtonpost.com/loraine-boyle/fighting-myeloma-with-lau_b_349296.html)

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## One Man's Illness Works to Myeloma's Benefit

By Danielle Berrin

As often happens with serious illness, Steve's diagnosis impelled the couple to take stock of their lives. Both are prominent players in the Hollywood community; they realized they had been incredibly fortunate, but also considerably insulated from some of life's difficult realities. "It's really kind of a wake-up call," Steve said about his diagnosis. "You dealt with all those people, you enjoyed the perks and all of that — what meaning does it have? You start to realize what is really of value in life. The Los Angeles Hollywood community is kind of a big bubble that separates us from a lot of realities. Yet when it comes to raising awareness about a cause, few people in the world can attract public

attention the way Hollywood can." "A lot of times people think celebrities are self-absorbed, and all I can say in my experience with this benefit is that

I reached out to the heads of studios, heads of networks, heads of agencies, and without fail the support was there," Amy added. Some of the comedians, Amy said, canceled paying gigs to appear at the event. "There are opportunities where you see the best and worst of people," Amy said. "For me, this was about the best of people."

[http://www.jewishjournal.com/giving/article/one\\_mans\\_illness\\_works\\_to\\_myelomas\\_benefit\\_20091115/](http://www.jewishjournal.com/giving/article/one_mans_illness_works_to_myelomas_benefit_20091115/)



From left: Lucy Boyle, Doris Roberts, Loraine Boyle, Amy and Steve Weiss at the International Myeloma Foundation's third annual Comedy Celebration.

Los Angeles Times

IMAGE

November 10, 2009 | 2:29 pm

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## Yucks = bucks: Peter Boyle memorial adds \$700,000 to myeloma fight

By Adam Tschorn

Although few people may be familiar with myeloma, you'd be hard pressed to find anyone in Hollywood who isn't familiar with the late actor Peter Boyle — the larger-than-life actor who cut a comedic swath through popular culture that included the tap-dancing monster in "Young Frankenstein" and the sitcom curmudgeon Frank Barone on "Everybody Loves Raymond," before succumbing to the blood cancer in 2006. So, for the last three years, his widow, Loraine, has leveraged the latter to battle the former, calling on her

husband's comedy connections and former co-workers to stage a comedy benefit to help battle the disease by funding the International Myeloma Foundation (IMF)... But perhaps even more impressive than the galaxy of stars that perform, is the deep bench of American comedy — and musical — talent that turn out each year in memory of Boyle and in support of the charity.

<http://latimesblogs.latimes.com/alltherage/2009/11/third-annual-comedy-celebration-benefiting-peter-boyle-memorial-fund-raises-70000-for-myeloma-battle.html>



## Ray Romano Honors his Late Co-star Peter Boyle

"It's great to honor Peter this way and to spend time with the cast members and his family," Romano said. "Fans all know him as this curmudgeon, this ornery old man, but Peter was just the opposite. He was a sweet man who

took me under his wing. It's emotional to come here and remember him this way."

<http://www.etonline.com/news/2009/11/80810/index.html>

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*Dedicated to improving the quality of life of myeloma patients while working towards prevention and a cure.*



The IMF's 3rd Annual Comedy Celebration featured some of comedy's biggest names before a sold-out crowd. The star-studded line up had the guests rolling in the aisles in hilarity.

