Improving Lives • Finding the Cure

MYELOMA TODAY

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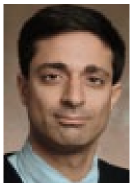
A Publication of the International Myeloma Foundation

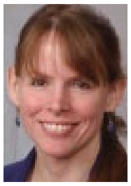
Dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure.

Scientific & Clinical News

Dr. Thomas G. Martin (Associate Director, Myeloma Program, University of California San Francisco) discusses Kyprolis™ (carfilzomib), the agent recently approved by the U.S. Food and Drug Administration (FDA) for the treatment of patients with myeloma who have received at least two prior therapies, including bortezomib and an immunomodulatory agent (IMiD), and have demonstrated disease progression on or within 60 days of completion of the last therapy. For these patients, Kyprolis is now available outside the clinical trial setting. ***PAGE 5***



Dr. Sagar Lonial (Winship Cancer Institute of Emory University, Emory University School of Medicine, Atlanta, GA) discusses panobinostat, a highly potent histone deacetylase inhibitor (HDACi) that is part of a new class of anticancer agents currently in clinical development in myeloma. HDACi target the enzyme histone deacetylase (HDAC), which is involved in the deacetylation of cellular proteins that play important roles in epigenetic regulation of gene expression. Additionally, inhibition of HDAC6 is known to enhance myeloma cell death. ***PAGE 6***



Dr. Martha Q. Lacy (Mayo Clinic, Rochester, MN) discusses pomalidomide, which is currently in an ongoing pivotal phase III clinical trial comparing pomalidomide plus dexamethasone versus dexamethasone alone. Other pomalidomide studies are also underway or in development. In addition to being very active in myeloma, pomalidomide is very well tolerated. Pomalidomide does not appear to be associated with much peripheral neuropathy (PN), which can be an issue with other agents, and patients with PN are not necessarily excluded from pomalidomide trials. ***PAGE 6***

Supportive Care

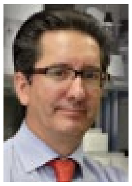
IMF Hotline Coordinators answer a question about Kyprolis™ (carfilzomib), a "next-generation" proteasome inhibitor, which became the newest agent approved by the US Food and Drug Administration (FDA) for the treatment of patients with myeloma on July 20, 2012. Kyprolis is now approved for patients who have received at least two prior therapies, including bortezomib and an immunomodulatory (IMiD) agent, and who have demonstrated disease progression on or within 60 days of the completion of the last therapy. ***PAGE 7***

Special Meetings

The IMF's **Nurse Leadership Board (NLB)** recently held its eighth meeting, co-chaired by Sandra Kurtin and Joseph Tariman. The two-day event was held June 30 through July 1 in New York City, and served as an opportunity for the Board to work on current NLB projects, including nurse-led clinical research, a transplant guidelines manuscript, the Survivorship Care Plan (SCP) online resource tool, a patient education publication focused on oral therapies, and a paper providing an update on proteasome inhibitors and immunomodulatory (IMiD) agents. ***PAGE 8***

The **2012 IMF Support Group Leaders' Summit** brought together myeloma support group leaders from across the US and from Canada to share wisdom, camaraderie, hope, and humor. Myeloma patients and caregivers look to support groups for guidance and strength. But who do support group leaders turn to when they need the same? Once a year, the IMF Support Group Leader Summit makes it possible for these remarkable individuals to turn to each other during this valuable annual program. The 2012 Summit was the 13th Summit to be held. ***PAGE 10***

Special Event

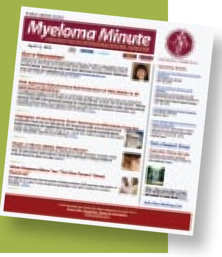


Prof. Jesús San-Miguel, the recipient of the 10th Robert A. Kyle Lifetime Achievement Award, was honored for his lifetime body of work in myeloma on June 12, 2012. Prof. San-Miguel is Professor of Medicine, Head of the Haematology Department at the University Hospital of Salamanca, and Director of the Biomedical Research Institute of Salamanca, Spain. He is a member of the Scientific Advisory Board of the IMF, the MMRF, Carreras Foundation, and a board member of the Spanish Hematology and Genome Foundations. ***PAGE 4***

Also in this issue…

Sign up for the *Myeloma Minute*

This free IMF weekly e-mail newsletter presents up-to-the-minute information about myeloma research, treatment, support, and the myeloma community. To join the mailing list go to myeloma.org, email TheIMF@myeloma.org, or call 800-452-CURE (2873) or 818-487-7455.



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A Message from the President

Dear Reader,

There is never a dull moment at the International Myeloma Foundation, and this past summer was one of the most action-packed in our 22-year history! Between Memorial Day and Labor Day, we have hosted two major research meetings, three Patient & Family Seminars, two Regional Community Workshops, and the Annual Support Group Leader Summit. We also launched an iPad app, held two teleconferences, one webinar, and one live webcast, testified (successfully) for the approval of a new drug for use in myeloma therapy, redesigned the look of our publications, published several new editions, and attended three major medical conferences.

But of all the things we did this summer, what I'm most proud of and excited to tell you about is a truly innovative and very exciting program that the IMF developed and conducted in August – the *International Myeloma Working Group (IMWG) Master Class*. This new project is an intensive educational course designed for clinicians who are specializing in myeloma. Utilizing special designated funding for this, we developed a training course for young clinicians in China. The inaugural Master Class was comprised of seven young and incredibly bright doctors from seven of the top hospitals in China.

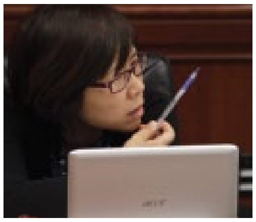
Dr. Brian G.M. Durie put together an outstanding and really exciting program – as novel as the novel therapies they would be discussing! The program covered two intensive weeks, beginning with Dr. Durie presenting Diagnosis/Baseline Testing. Our wonderful visiting myeloma experts, who flew in to teach selected "Steps" from 10 Steps for Better Care™, included Drs. Joseph Mikhael – Tests/Treatment, Bob Vescio – Bone Disease, Vincent Rajkumar – Response Assessment, Bill Bensinger – Transplant, and Shaji Kumar – Relapse/Clinical Trials. The course ended as it began, with a presentation by Dr. Durie, this time on Myeloma Monitoring. All this was immediately followed by an exam!

I can't begin to express how proud I am of all the people who made this program happen: the hours they put in and the dedication of the faculty to be here to teach and spend time with our visiting clinicians, to ensure that they could go home with new and powerful information that will dramatically change the lives of thousands of myeloma patients. The IMF is already working on the next series of IMWG Master Classes for doctors here in the US and abroad. We can never lose sight of the fact that we are a global community and it is our mission to reach out and help people no matter where they live! The most exciting news is we're having amazing results, and you'll be able to read about them in upcoming issues of *Myeloma Today*.

Warmly,

Susie Novis

Susie Novis, President



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PROFESSOR JESÚS SAN-MIGUEL IS RECIPIENT OF THE TENTH ROBERT A. KYLE LIFETIME ACHIEVEMENT AWARD

The Award

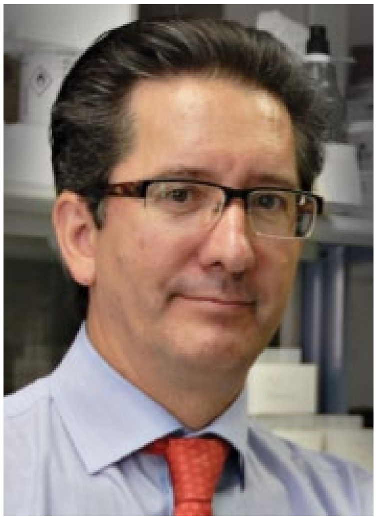
The IMF bestowed the first annual Lifetime Achievement Award in 2003, and this award has since become known by the name of its first recipient, Dr. Robert A. Kyle. The IMF's Robert A. Kyle Lifetime Achievement Award was established to honor individuals whose lifetime body of work furthers the ultimate goal of finding a cure for myeloma. When Dr. Kyle was first approached about receiving the award, his response to Susie Novis was, "I'm not done yet!"

Dr. Kyle is a founding member of the International Myeloma Foundation's Board of Directors and has remained chairman of its Scientific Advisory Board throughout the foundation's 22-year history. Dr. Kyle is a sought-after presenter at IMF clinical conferences and workshops, and is the most frequently requested speaker at IMF Patient & Family Seminars. Through IMF programs, Dr. Kyle has helped thousands of myeloma patients and their families around the world. His guidance and encouragement are as important to the IMF today as when the IMF first began.

In his more than 40 years at Mayo Clinic, Dr. Kyle has never wavered from his commitment to the needs of patients with multiple myeloma. Dr. Kyle's dedication and compassion has gained him recognition the world over as a pioneer and respected leader in the advancement of myeloma research, clinical treatment, and education. His humility, sense of humor, and caring nature are among the many reasons for which the IMF named this award in his honor.

The Robert A. Kyle Lifetime Achievement Award has been presented to Dr. Bart Barlogie (2004), Dr. Kenneth C. Anderson (2005), Dr. Brian G.M. Durie (2006), Prof. Heinz Ludwig (2007), Prof. Mario Boccadoro (2008), Prof. Jean-Luc Harousseau (2009), Prof. Joan Bladé (2010), and Prof. Douglas E. Joshua (2011).


In addition to Dr. Robert A. Kyle, on hand were several past KLAA winners, including Prof. Douglas E. Joshua, Dr. Brian G.M. Durie, Prof. Heinz Ludwig, and Prof. Joan Bladé.



TENTH ANNUAL INTERNATIONAL MYELOMA FOUNDATION
ROBERT A. KYLE
LIFETIME ACHIEVEMENT AWARD

The 2012 Recipient

Prof. Jesús San-Miguel

Prof. Jesús San-Miguel is Professor of Medicine, Head of the Haematology Department at the University Hospital of Salamanca, and Director of the Biomedical Research Institute of Salamanca, Spain.

Prof. San-Miguel studied medicine at the University of Navarra, Spain. He completed his residency in Haematology/Internal Medicine at the University Hospital of Salamanca. In 1980, after obtaining his PhD, he undertook a post-doctoral fellowship at the Leukaemia Unit of Hammersmith Hospital, Royal Postgraduate Medical School, London, UK.

He is a member of the Scientific Advisory Board of the IMF, the MMRF, Carreras Foundation, and a board member of the Spanish Hematology and Genome Foundations. Prof. San-Miguel is member of the editorial board of several scientific journals, and was Associated Editor of *Haematologica*. He has served as Vice Director of the Cancer Research Center in Salamanca, and as Chairman of the Spanish Myeloma Group (GEM) as well as the European Association. Prof. San-Miguel was Board Councillor and Chairman of the Scientific Committee for the 9th Congress of the European Haematology Association (EHA) and President for the 15th EHA Congress.


Prof. Jesús San-Miguel receives his award from Dr. Robert A. Kyle


Dr. Brian G.M. Durie congratulates Prof. Jesús San-Miguel's wife, Pilar, and son, Dr. Inigo San-Miguel

Prof. San-Miguel organized the International Myeloma Workshop (IMW) held in Salamanca in 2003. He has received numerous prizes, including the Waldenström Award, and the Spanish prizes in both Oncology and Translational Research. Prof. San-Miguel has published more than 500 original papers in international journals. His areas of interest include multiple myeloma, the biology of leukaemic cells and their prognostic implications, and minimal residual disease (MRD).

The Tenth Robert A. Kyle Lifetime Achievement Award was presented to Prof. San-Miguel in Amsterdam on June 12, 2012. **MT**

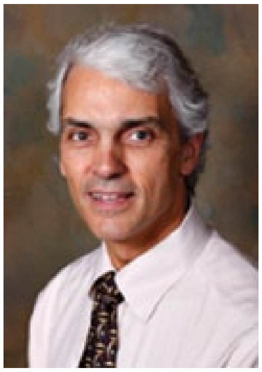

Prof. Jesús San-Miguel is toasted Dr. Robert A. Kyle

UPDATE ON NEW DRUGS

Kyprolis™ (carfilzomib)

The largest trial of Kyprolis™ (carfilzomib) was a phase II clinical trial known as the 003 study. Two hundred and sixty-six patients with relapsed multiple myeloma who had received at least two prior therapies including bortezomib and an immunomodulatory agent (IMiD), thalidomide or Revlimid® (lenalidomide), were enrolled in the open-label, single-arm, multicenter clinical trial, and 257 patients were evaluable for response. The 003-A1 phase IIb study was published in the medical journal *Blood*, the medical journal of the American Society of Hematology (ASH), the first peer-reviewed publication of full data results.

The primary endpoint of the trial was overall response rate (ORR), defined as partial remission (PR) or better. The ORR was 23.7% among evaluable patients and 22.9% among the total patient population enrolled in the study. The median duration of response was 7.8 months. The most common treatment-emergent side effects reported in this study were fatigue (49%) and anemia (46%). The most common Grade 3/4 side effects were thrombocytopenia (29%) and anemia (24%). The most common side effects of any grade possibly related to carfilzomib were fatigue (37%) and nausea (34%).



Thomas G. Martin, MD
Associate Director,
Myeloma Program
University of California
San Francisco,
San Francisco, CA

The patients in the study had received a median of five prior anti-myeloma regimens. The more treatments a patient receives, the tougher the myeloma becomes. In a less heavily pretreated patient population, those who have had on average two prior anti-myeloma regimens, the response rate jumps up into the 40%-50% range, which is a very robust response.

Here at University of California San Francisco, we have been involved with four clinical trials of carfilzomib, including the 003 study, and there are several more trials in development. Data has consistently shown that carfilzomib is a very active agent in myeloma, and that it works well in the relapse/refractory setting. We have seen response rates of 18%-19% even in patients who are refractory to both bortezomib and lenalidomide. These patients have very limited treatment options, so the availability of carfilzomib to treat their advanced disease is very important. Most of the patients tolerate the therapy quite well. If anything, when it comes to side effects, there's much less incidence and severity of peripheral neuropathy.

Carfilzomib continues to be studied in several clinical trials, including:

- A global phase III clinical trial, known as ASPIRE, is evaluating the combination of lenalidomide and low-dose dexamethasone with or without carfilzomib in patients with relapsed myeloma who have received one to three prior therapies. In this setting the response rates are even better.
- A phase III clinical trial, known as FOCUS, is evaluating single-agent carfilzomib in patients with relapsed and refractory myeloma who have received three or more prior therapies.
- A global head-to-head phase III clinical trial, known as ENDEAVOR, is evaluating the combination of carfilzomib and low-dose dexamethasone versus the combination of bortezomib and low-dose dexamethasone.
- A phase I/II clinical study being conducted by Ono Pharmaceutical Co. Ltd. is evaluating Kyprolis in Japanese patients with relapsed/refractory myeloma.
- Carfilzomib in combination with panobinostat is a new study we are getting ready to open here at UCSF.

On July 20, based on clinical trial response data, the U.S. Food and Drug Administration (FDA) granted accelerated approval of carfilzomib for the treatment of patients with myeloma who have received at least two prior therapies including bortezomib and an IMiD), and have demonstrated disease progression on or within 60 days of completion of the last therapy. For these patients, Kyprolis™ (carfilzomib) is now available outside the clinical trial setting. **MT**

Editor's Note: The IMF appreciated the opportunity to participate at the recent Oncologic Drugs Advisory Committee (ODAC) hearing. IMF Vice President Diane Moran and IMF Director of Support Groups Robin Tuohy, along with her husband Michael who is a myeloma patient, presented dramatic and powerful testimony demonstrating the dire need to approve new drugs such as Kyprolis. A tip card and an *Understanding Kyprolis* booklet are available both in hard copy and as electronic file on the IMF website.

CONTINUES ON PAGE 6

The Emerging Role of Kyprolis™ in the Treatment Paradigm

Dr. Brian G.M Durie, IMF Chairman of the Board, and Dr. Tom Martin of the University of California San Francisco (UCSF) discussed the emerging role of Kyprolis™ (carfilzomib) in the treatment paradigm during a teleconference held by the IMF on August 22. To access the audio recording, as well as the presentation slides from this teleconference, go to the IMF website myeloma.org, click on the Webcasts tab and select Teleconferences from the dropdown menu.

Onyx Pharmaceuticals 360™

Onyx 360 is a comprehensive support and services program designed to help patients and caregivers navigate the treatment journey, including reimbursement and payment support, treatment support, and referrals to third-party organizations for day-to-day and emotional support.

ONYX 360™
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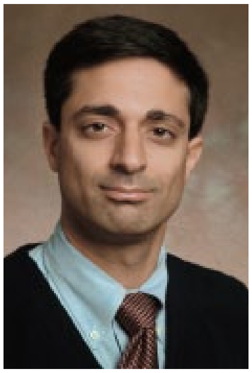
UPDATE ON NEW DRUGS

Panobinostat

Although FDA-approved novel anti-myeloma agents have improved response rates in recent years, newer approaches and treatment options are needed for patients with multiple myeloma (MM) whose disease relapses. MM patients who are refractory to bortezomib and an immunomodulatory drug have limited treatment options and a poor prognosis.

Histone deacetylase inhibitors (HDACi) are a new class of anticancer agents that are currently in clinical development in MM. HDACi target the enzyme histone deacetylase (HDAC), which is involved in the deacetylation of cellular proteins that play important roles in epigenetic regulation of gene expression. Additionally, inhibition of HDAC6 is known to enhance MM cell death in the context of proteasome inhibition via the blockade of the accessory aggresome pathway for protein degradation.



Sagar Lonial, MD
Winship Cancer Institute
of Emory University
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Atlanta, GA

Panobinostat (LBH589) is a highly potent HDACi, which has demonstrated anti-tumor effects in preclinical studies. Panobinostat has encouraging potential as a therapeutic anti-MM agent due to its ability to modulate a variety of biological pathways essential in MM biology. The clinical efficacy of panobinostat is currently under investigation in several clinical trials.

Clinical responses were observed in a phase I study of patients with relapsed or relapsed/refractory MM who were treated with panobinostat and bortezomib (Velcade®). Even patients with bortezomib-refractory disease showed responses.

PANORAMA 2 is a phase II single-arm study of panobinostat in combination with bortezomib and dexamethasone in 55 heavily pretreated patients with relapsed and bortezomib-refractory MM. Most (64%) enrolled patients had received prior autologous stem cell transplant (ASCT). The primary endpoint of the first phase of treatment, which consists of eight 3-week cycles of oral panobinostat, intravenous bortezomib, and oral dexamethasone, is overall response.

Eighteen patients achieved at least partial response (PR) for an overall response rate of 33% (1 near complete response and 17 PR), and 13 patients achieved minimal response (MR) for a clinical benefit rate of 56%. Three patients achieved a very good partial response (VGPR).

The 18 patients who demonstrated clinical benefit continued to four 6-week cycles of panobinostat, bortezomib, and dexamethasone, and two have completed 12 or more cycles. Ten patients are continuing treatment and 28 are in follow-up.

Available data demonstrate that panobinostat synergizes with bortezomib in recapturing responses in heavily pretreated, bortezomib-refractory patients with MM. This drug combination is generally well tolerated and is a promising treatment for patients with bortezomib-refractory disease.

A better understanding of the panobinostat mechanisms of action and its targets is needed to identify the best possible combination therapies to improve outcomes in patients with MM. **MT**

Pomalidomide

At the Mayo Clinic, we have conducted a series of phase II clinical studies with pomalidomide and dexamethasone, at different doses and schedules, which showed that pomalidomide is quite active in patients with relapsed multiple myeloma (MM). All of the clinical trials have used pomalidomide in combination with low-dose dexamethasone.

Martha Q. Lacy, MD
Mayo Clinic
Rochester, MN

The first trial studied pomalidomide at a dose of 2 mg daily for 28 days continuously, with dexamethasone 40 mg once a week, in patients with relapsed MM. We were impressed with the response rates, which were initially 63% and 65% with longer follow-up. The duration of response was over a year. Interestingly, there were patients in that group who were refractory to lenalidomide (Revlimid®) but responded to pomalidomide. This made us want to study pomalidomide in other settings.

The second trial we conducted studied pomalidomide in patients who were refractory to lenalidomide. The third trial we conducted studied pomalidomide in patients who were dual-refractory to both lenalidomide and bortezomib (Velcade®).

By the time we were reporting data on the second and third cohorts that we had studied, Dr. Paul Richardson (Dana-Farber Cancer Institute, Boston, MA) and colleagues reported data consistent with our findings. Their study used pomalidomide at 4mg per day, so we went back and looked at the different patient populations at different pomalidomide doses.

Our next study of pomalidomide was at 4 mg per day for 21 days of a 28-day cycle in 120 newly diagnosed MM patients. This is our most recent cohort and these patients have not yet been evaluated. We finished accrual in February and we will be analyzing the data in approximately two months. We plan to report the data at the next meeting of the American Society of Hematology (ASH) in December of this year.

There is currently also an ongoing pivotal phase III clinical trial accruing patients for a study comparing pomalidomide plus dexamethasone versus dexamethasone alone. We are also accruing relapsed MM patients who have had at least one prior regimen and are refractory to lenalidomide (but not refractory to bortezomib) for a clinical trial of pomalidomide, bortezomib, dexamethasone (PVD) – the pomalidomide plus dexamethasone combination with once-a-week bortezomib. Once the correct dosing for PVD is identified, this may lead to future phase III regulatory clinical trials comparing PVD to VD (bortezomib plus dexamethasone).

In addition to being very active in MM, pomalidomide is very well tolerated. The major side effect is neutropenia, which is seen in approximately one third of patients, but we simply adjust the dose to a tolerable level in these patients. Pomalidomide does not appear to be associated with much peripheral neuropathy (PN), which can be an issue with other agents, and patients with PN are not necessarily excluded from pomalidomide trials. Also, DVT risk is low with pomalidomide, between 0% and 3%, which is a very favorable profile.

Pomalidomide is now being submitted to the Food and Drug Administration (FDA) for consideration of accelerated approval based on the merits of phase II clinical studies. We are hoping for approval so pomalidomide becomes available to MM patients outside the clinical trial setting, but this is beyond our control.

At present, for the majority of patients, myeloma is a relapsing and remitting disease that must be managed chronically. We are very excited to be adding pomalidomide to our armamentarium of anti-myeloma agents. **MT**

WHAT YOU NEED TO KNOW ABOUT KYPROLIS™

The IMF Hotline 800-452-CURE (2873) consistently provides callers with the best information about myeloma in a caring and compassionate manner. The Hotline is staffed by Debbie Birns, Paul Hewitt, Missy Klepetar, and Judy Webb. The phone lines are open Monday through Friday, 9 a.m. to 4 p.m. To submit your question online, please email TheIMF@myeloma.org.

I am very excited about the recent FDA approval of carfilzomib. What can you tell me about this new drug and how it can help me with my myeloma?


Paul Hewitt, Judy Webb, Debbie Birns, and Missy Klepetar

The first thing you need to know is that KYPROLIS™ is the registered brand name of carfilzomib, a so-called "next-generation" proteasome inhibitor. (The first proteasome inhibitor was bortezomib, also known as VELCADE®.) Carfilzomib has been featured in past issues of *Myeloma Today* as a promising agent in clinical trials. As of July 20, 2012, carfilzomib became the newest agent approved by the US Food and Drug Administration (FDA) for the treatment of multiple myeloma, and the drug is now known as Kyprolis.

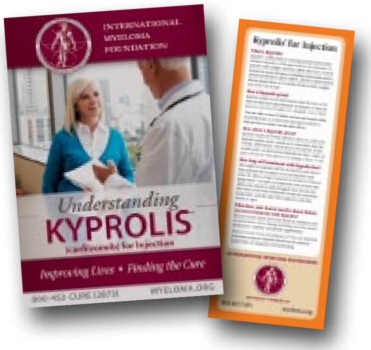
Kyprolis was approved by the FDA for the treatment of patients with myeloma who have received at least two prior therapies, including bortezomib and an immunomodulatory (IMiD) agent – either thalidomide or lenalidomide (REVLIMID®) – and who have demonstrated disease progression on or within 60 days of the completion of the last therapy.

Kyprolis is administered by intravenous infusion over 2-10 minutes, at a dose of 20 mg for every square meter of body mass (mg/m^2) for the first cycle, escalating to 27 mg/m^2 for subsequent cycles. A cycle is four weeks (28 days) in length, with Kyprolis given on days 1 and 2, 8 and 9, and 15 and 16. Days 17-28 are rest days. Patients in clinical trials with carfilzomib were treated for a maximum of 12 cycles, unless their myeloma progressed while they were being treated or they had unacceptable side effects.

Normally, drugs are approved based on data from phase III randomized trials. However, the clinical trial data from the phase II single-arm clinical trials of carfilzomib were so positive that Onyx Pharmaceuticals, the manufacturer of Kyprolis, submitted the phase II data to the FDA for consideration of early review and approval. The FDA required that the Oncology Drug Advisory Committee (ODAC) convene on June 20, 2012. ODAC reviewed the data on carfilzomib, evaluated questions about risks and benefits, and heard public comments from patients, physicians, and representative organizations.

Myeloma patient, support group leader, and dear friend of the IMF, Dr. Jim Omel was among the members of ODAC who convened at the meeting to consider whether or not to recommend FDA approval of carfilzomib. IMF's own Robin Tuohy (Director of Support Groups) and Diane Moran (Senior Vice President, Strategic Planning), along with much beloved patients Michael Tuohy and Amy Wolverton, gave moving and compelling testimony at the ODAC meeting that helped convince the committee members to recommend approval of carfilzomib. The final vote was 11 in favor of approval, 0 opposed. The FDA approved carfilzomib/Kyprolis for the treatment of myeloma – a full week ahead of the anticipated announcement!

Researchers who perform clinical trials keep careful records of all the side effects (called "adverse events") that their trial patients experience, and these are reported to the FDA. The "events" may be related to the drug, unrelated to the drug, or possibly but not definitely related to the drug. As part of the approval process, the FDA and its advisory committees must decide if the benefits of a drug outweigh the potential for serious side effects. The most common side effects of Kyprolis (occurring in at least 30% of patients), from most commonly to least commonly reported for the 526 patients who participated in phase II clinical trials, included fatigue, anemia (low red blood cell count), nausea, thrombocytopenia (low platelet count), shortness of breath, diarrhea, and fever. These side effects are discussed, with management tips, in the IMF's new publication, *Understanding Kyprolis (carfilzomib) for Injection*. If your doctor prescribes Kyprolis for you, be sure to also check the IMF's Kyprolis Tip Card on the IMF website or call us at 800-452-CURE (2873) to request these publications.


INTERNATIONAL MYELOMA FOUNDATION
Understanding KYPROLIS (carfilzomib) for Injection
Improving Lives • Finding the Cure
800-452-CURE (2873)
myeloma.org

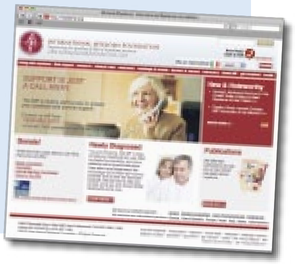
Onyx Pharmaceuticals has also created a program – "Onyx 360" – to help all patients taking Kyprolis as well as their caregivers. Onyx 360 is staffed by a network of oncology nurse advocates who are there to help guide you through all aspects of Kyprolis treatment. You can reach them from 9:00 a.m. to 8:00 p.m (Eastern Standard Time) at 855-ONYX-360 (855-669-9360) or visit their website at onyx.com/therapies/patient-access/onyx-360. Onyx 360 staff can link you directly to the Chronic Disease Fund, Cancer Support Community, and the IMF Hotline.

As always, we encourage you to visit our web site for the best and most up-to-date information about myeloma, now organized into The 10 Steps to Better Care™, and to call the IMF Hotline at 800-452-CURE (2873) with all your myeloma-related questions and concerns. **MT**

Do you have a question?

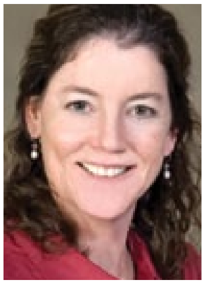
Perhaps you would like to order a publication? Are you thinking about registering for a Patient & Family Seminar or Regional Community Workshop? Would you like to download the Myeloma Manager™? All this and *MORE* is possible on the IMF website.

myeloma.org



Nurse Leadership Board

REPORT FROM NLB VIII MEETING


Sandra Kurtin,
RN, MS, AOCN, ANP-C

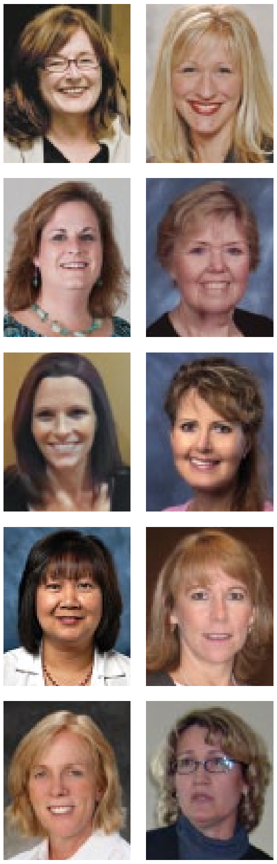

Joseph Tariman,
PhD, ANP-BC

The 8th International Myeloma Foundation (IMF) Nurse Leadership Board (NLB) meeting was held June 30 through July 1 in New York City, NY. The IMF-NLB consists of nurses from the leading institutions caring for multiple myeloma (MM) patients across the US *(please see sidebar)*. The two-day NLB VIII event served as an opportunity to review the execution of completed projects, work-in-progress status, and future activities planning. NLB VIII was co-chaired by Sandy Kurtin and Joseph Tariman.

Day 1

Diane Moran, IMF Senior Vice President of Strategic Planning, opened NLB VIII with an update highlighting some of the many accomplishments of the NLB over the last year:

- NLB's ONS Satellite Symposium "Multiple Myeloma: The Patient Journey Through Survivorship" – attended by 600+ participants.
- NLB delegates participated as faculty at four 2012 IMF Patient & Family Seminars (PFS).
- NLB speaker participation is standard for all IMF Regional Community Workshops (RCWs) and Myeloma Center Workshops (MCW), with 11 workshops to have taken place by the end of 2012.
- NLB's Teresa Micelli took part in the 2012 IMF Support Group Leader Summit.
- NLB members led four Support Group Teleconferences, with six more scheduled by year's end.
- Beth Finley-Oliver, Page Bertolotti, and Kim Noonan took part in an educational video presentation on Velcade SQ.
- Beth Faiman, Sandy Kurtin, and Kathy Lilleby have contributed entries to the *Oh Nurse!* Blog on the IMF website.
- Beth Faiman led the Myeloma Awareness Month Teleconference.
- NLB members contribute content to each issue of *Myeloma Today*.
- Beth Faiman received the 2012 Excellence in Medical Oncology Award from the Oncology Nursing Society (ONS).
- Sandra Rome received the 2012 Distinguished Alumni Award from the UCLA School of Nursing.
- Page Bertolotti co-chaired the Ambulatory Clinical Practice, Education, and Advancement Task-force Group of the Outpatient Divisional Practice Council.
- Kathy Colson was a contributing author published in *The Oncology Nurse* May/June 2012 issue.
- Beth Faiman published 11 manuscripts in 2011-2012.
- Sandra Rome published 5 articles in peer journals.
- Sandy Kurtin published 14 peer-reviewed journal articles and 9 oncology chapters.



- Charise Gleason, a member of working group with ASCO, is completing the outpatient febrile neutropenia manuscript and guidelines, plus has a chapter on peripheral neuropathy in press with Dr. Sagar Lonial. She is co-author of multiple papers and abstracts in 2012, including ASCO and EHA.
- Joseph Tariman received his PhD, becoming the first PhD on the NLB! He is the author of many published articles and editor of *Multiple Myeloma: A Textbook for Nurses*.

Joseph Tariman followed with an update on myeloma research, drug approvals, and potential upcoming drug approvals for 2012. These topics are covered in all issues of *Myeloma Today* and the IMF's weekly e-newsletter *Myeloma Minute*. In addition, up-to-date information is always available via the IMF website or by calling the IMF Hotline 800-452-CURE (2873).

CONTINUES ON PAGE 14

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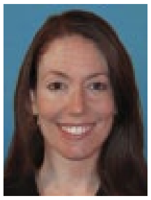
SPOTLIGHT ON ADVOCACY



By Meghan Buzby

Coalition for Cancer Drug Coverage Parity Converges in Washington, DC

In June 2012, the Patients Equal Access Coalition (PEAC) headed to The Hill in Washington, DC, to support the Cancer Drug Coverage Parity Act (HR 2746) introduced by Representative Brian Higgins (D-NY 27th). The International Myeloma Foundation (IMF) and volunteers from seven other PEAC member organizations held nearly 30 meetings with representatives and senators to encourage support of our efforts in improving insurance coverage for oral chemotherapy. The IMF thanks the more than 100 advocates from across the country who participated, contacting nearly 100 different legislators by phone or email.

At the time of publication, HR 2746 has 49 co-sponsors. If your Representative has not yet signed on as a supporter, please send an email through the IMF's web-based Action Center today at advocacy.myeloma.org!

PEAC, founded by the IMF in 2010, is a patient-focused coalition working to ensure that cancer patients have equal and appropriate access to all cancer treatments. For more information on PEAC, please visit peac.myeloma.org.

IMF Advocates Add Their Voices to the 'One Voice Against Cancer' Campaign

Close to 100 advocates met with hundreds of US senators and representatives in early July 2012 to request increased funding for cancer research and prevention at the 13th annual One Voice Against Cancer (OVAC) Lobby Day in Washington, DC. Thank you to Anthony Sibert, a multiple myeloma patient and California Inland Empire support group leader, and Geri Smith-Benjamin, a myeloma patient from Arlington, VA. Anthony and Geri were among the advocates asking members of Congress to support continued medical research.

OVAC is a collaboration of 40 national nonprofit organizations representing millions of Americans with cancer. It is one of the leading cancer coalitions in the nation's capital and delivers a unified message to Congress on the need for increased cancer-related appropriations. The IMF has been a member since 2001.

The Supreme Court Upholds the Affordable Care Act

On March 26, 2012, the United States Supreme Court began hearing arguments contesting the constitutionality of the Affordable Care Act (ACA). On June 28, the Supreme Court announced its decision.

The ACA requires that all citizens have health insurance coverage after 2014 or pay a fine, referred to as the "individual mandate." Several individuals sued the government, arguing that it is unconstitutional for Congress to pass a law requiring individuals to purchase something that they don't want to purchase. The Supreme Court ruled that the individual mandate is indeed constitutional, meaning that the government can require people to purchase health insurance. In essence, this means that the entire law is upheld and all of the provisions will remain intact and go into effect as outlined in the law.

The IMF supports the provision prohibiting insurance companies from denying coverage or raising premiums because of pre-existing conditions. A diagnosis of cancer, including myeloma, is considered a pre-existing condition and without this protection in ACA, many patients and their families would have difficulty obtaining health insurance. These protections go into effect in 2014.

The IMF also supported the provision that removes annual limits and lifetime caps on benefits. Today patients who reach this limit have to pay out-of-pocket for any additional costs. After 2014, myeloma patients will not have to worry about reaching limits on their benefits annually or over the course of their lifetime.

Most plans with Medicare prescription drug coverage (Part D) have a coverage gap called a "donut hole." This means that after you and your drug plan have spent a certain amount of money for covered drugs, you must pay all costs out-of-pocket for your prescriptions up to a yearly limit. Once you have spent up to the yearly limit, your coverage gap ends and your drug plan helps pay for covered drugs again. In 2010, Medicare provided seniors with a one-time rebate of $250 to help cover their prescriptions when they reach the donut hole. You also get a 50% discount on expensive brand name drugs in the donut hole and in 2020, the entire donut hole will be closed and you will no longer have this coverage gap.

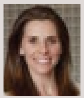
Additionally, the Supreme Court decision means that the insurance exchanges will also remain intact and continue to be implemented over the next 1-2 years. Plans offered through the exchanges must include a minimum set of benefits called essential health benefits (EHB) and it's up to each state to set the benchmark plan that describes those benefits. The IMF is advocating on the state level to include oral cancer drugs as part of the benchmark plan's prescription drug benefit and now after the Supreme Court decision, they will continue these efforts.

The IMF Advocacy Voice:

Get Fired Up! Raise Your Voice! Get Out There and Take Action!

We have over 2100 advocates signed up for our Action Network. It's time for you to join us in our fight for cancer patients everywhere. Sign up ***TODAY*** at advocacy.myeloma.org! **MT**

How to contact the IMF Advocacy Team



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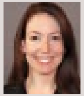

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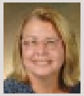

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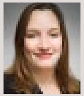

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2012 IMF SUPPORT GROUP LEADERS' SUMMIT

Myeloma Support Group Leaders Gather in Dallas to Share Wisdom, Camaraderie, Hope, and Humor

By Abbie Rich, IMF Web Producer

And So We Begin

Myeloma patients and caregivers look to support groups for guidance and strength. But who do support group leaders turn to when they need the same? Once a year, the IMF Support Group Leader Summit makes it possible for these remarkable individuals to turn to each other to answer questions like "How do you keep people attending support group meetings when they start feeling better?" or "When a leader leaves or dies, how do we rebuild the group from the ground up?"

The IMF is grateful to have corporate sponsors whose generosity underwrites the Summit and ensures that our support group leaders have access and transportation to this valuable annual program. They fund this meeting in full, and without their support the Summit would not be possible.

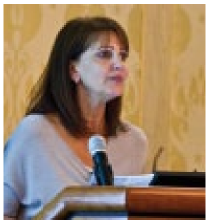
We thank our sponsors for their support of the Summit!

- Amgen
- Bristol-Myers Squibb
- Celgene
- Diplomat Pharmacy
- Marx Family Foundation
- Millennium: The Takeda Oncology Company
- Onyx
- Sanofi

The 2012 Support Group Leader Summit was the 13th Summit to be held, but this was only the second Summit I have attended in my 10 years with the IMF. Last year's Summit was such an inspiring and emotionally moving experience for me, I was eager to return this year.

It was wonderful to see everyone again and to meet the new group leaders. These are truly amazing people. Almost all of them are patients or caregivers themselves, although we also have some social workers and nurses in the group. They could have turned inward after receiving a diagnosis of myeloma, but instead turned outward and have committed themselves to helping others. And there were so many new leaders!

The Summit started with a welcome from Susie Novis, who identified a couple of leaders in attendance who had participated in the very first Summit! She then introduced Dr. Brian G.M. Durie, who gave us a medical update on myeloma. For a myeloma specialist, these are very exciting times, with new drugs and other developments improving outcomes for patients. Dr. Durie talked about the FDA approval of Kyprolis™ (carfilzomib) and drugs currently in the pipeline – pomalidomide, elotuzumab, and panobinostat. The IMF's International Myeloma Working Group (IMWG), made up of 160 of the world's top myeloma experts, is working on new strategic concepts involving early disease, frontline therapies, supportive care, maintenance, and how to identify and manage plasma cell leukemia (PCL) and extramedullary plasmacytoma (EMP). He talked about so many positive developments that my head began to swim!



Next up was the incredible IMF Advocacy Team. (To read their latest report, please turn to page 9 of *Myeloma Today* or visit the Advocacy Action Center on the IMF website.) The third presentation was by Debbie Birns, a 10-year veteran of the IMF Hotline. She talked about monitoring myeloma, and making sense of tests and results. Debbie advised against comparing results with other patients. She also pointed out that no human body is in a steady state – test results may vary by 15% without necessarily being cause for concern. Patterns of results over time are more important than any single test result. It is a good idea to get copies of your test results and refer to the IMF's publication *Understanding Your Test Results* for a clear and concise explanation of this topic, or call the IMF Hotline at 800-452-CURE (2873).

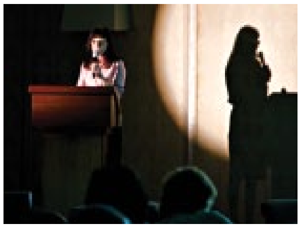
Mixing and Mentoring

IMF's longtime meeting facilitator Alan Kumamoto asked each of the group leaders to share a tip or challenge with the Summit participants. The responses from the nurses, patients, caregivers, and social workers who lead various groups resonated around the room. If you are curious to learn more about the inner workings of support groups, please read my full blog entry on the IMF website.

After a long and educational first day, wine and appetizers were served in the foyer of the ballroom, giving us a chance to talk with each other, which is always fun. So much fun that it wasn't hard at all to follow Alan Kumamoto's final instruction of the day: "I want you to make three new friends tonight."

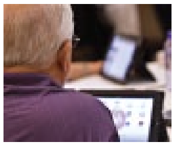
During the delicious dinner, we toasted the FDA approval of Kyprolis and our good fortune to have another drug in the myeloma treatment armamentarium. After we had consumed enough food to make us happily quiet, the IMF Advocacy Team presented their Second Annual Academy Awards of Advocacy to leaders who had taken the time to testify or work on behalf of the Oral Parity efforts. And then it was off to our rooms to watch the opening ceremony of the Olympic Games in London.

A BIG Surprise



On Saturday morning, Susie started the day with a HUGE surprise. With lowered lights and musical fanfare, people rushed into the room with tables loaded with white boxes… and Susie announced that the IMF, thanks to funding by Celgene, Millennium, Onyx, and Sanofi, was giving each of the support groups an iPad fully loaded with all the materials group leaders need to more effectively do their wonderful work.

The room exploded with excitement! (One group leader, Paula van Riper, declared she felt as though she was on Oprah.) One necessary part of business took place next, with the leaders signing agreements that the iPads belong to the group, and are to be passed on to a new leader if the current leader steps down. An iPad lesson followed, led by Kelly Cox and Thomas Shin from the IMF. Everyone spent the next couple of hours learning how to use these new tools.



Facilitating with Hope

This session was led by Greg Pacini, MS LPC CGP, a counselor who works with people living with chronic illness. Almost all of our group leaders are patients or caregivers themselves, and he told them that letting their groups see that you are a human being with good days and not-so-good days is important. He talked about the challenges of losing group members. He talked about his own experience facilitating a group in which he carried the pain of the members into his own life. "I was taking a little bit of everyone's pain with me. But I let it go because it does not belong to me. If I take someone's pain, my message to them is that they cannot handle it themselves. You are not powerful. But we are all powerful." He reminded us to acknowledge difficult emotions, to accept them, and to hold on to hope.

Working Lunch with Dr. Durie

This very popular segment of the Summit gives support group leaders an opportunity to ask random questions of Dr. Durie. There were many questions and he answered all of them in-depth, and I only have the space to share with you the gist of a few of the points he made.

The first topic that came up was the problem of infection. Dr. Durie said to pay attention to fever, and have it checked out right away. Plan ahead. If it happens on Friday night, you need to have a number you can call. Travel with antibiotics in case you spike a fever while in transit. Carry a list of medications with you with your doctor's number or email on it. If you encounter a doctor who does not understand what spiking a fever means in MM, carry a summary letter from your own doctor explaining what it means.

What about taking the vaccine for shingles? Ask if the vaccine is live because MM patients should NOT take live vaccines. If a family member gets the vaccine and then comes down with a pseudo version of chicken pox, it's best to avoid them for at least two weeks.

A transplant-eligible patient wanted to know if he should have a transplant. Dr. Durie said that it is not mandatory. VRD studies are showing that around half of the patients can have a complete remission without transplant. If in complete remission, which lasts on average about two years, you can have stem cells harvested but there would be no rush to transplant for two years. More definitive information about transplant is needed.

Neuropathy remains the biggest problem we don't yet know how to deal with consistently. We have topical treatments for it, including a cream containing capsaicin. Teresa Miceli, a nurse from the Mayo Clinic, suggested that the antidepressant Cymbalta® (duloxetine) had been found to relieve the symptoms of chemotherapy-induced peripheral neuropathy.

An Educational Emotional Dinner

Saturday was capped by a wonderful dinner that gave us all the chance to get to know more about some of the leaders. All the newbies were invited to introduce themselves to the group.

The newest leaders in the room were Ray and Gail from Lubbock, TX. They came to learn about starting and maintaining a support group, and said they learned a lot and met wonderful people.

Malcolm is off to a good start with more than 20 members in his newly established group in Encino, CA.

CONTINUES ON PAGE 12

SGLS — continued from page 11

Tom went to his first support group meeting a week after being diagnosed, and he shared how important it was to meet vibrant people who were long-term survivors. That was five years ago and he just recently took over as leader for a group in Orange County, CA.

Teresa had 29 people show up to her first meeting in Spokane, WA.

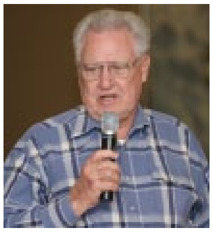
Lorelei from Canada arrived to the Summit without her baggage but maintained the sunniest attitude throughout the weekend.

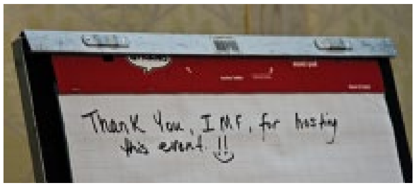
David and Sandy got matching "Have Faith" tattoos after myeloma entered their lives, and they now lead a group in Charlotte, NC.

Joe, a leader of the group in Atlanta, GA, turned me into a sobbing mess by singing Amazing Grace in a beautiful baritone.

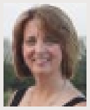
Many touching moments were shared throughout the weekend, and several participants spoke about what the experience of the Summit meant to them. I think it is safe to say that these are some of the best people I have ever met. I felt honored to be in their presence. **MT**

Editor's Note: For the full text of the blog by Abbie Rich, IMF Web Producer, please visit sglsummit2012.myeloma.org.





How to contact the IMF Support Group Team



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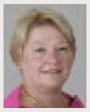

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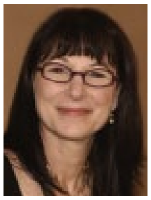
Gregor Brozeit – ***European Programs***
email: greg.brozeit@sbcglobal.net

UPDATES FROM AROUND THE GLOBE

IMF attends patient and doctor meetings in Japan: July 6-8, 2012



By Susie Novis, IMF President

The International Myeloma Foundation has a long history with our friends and colleagues in Japan, and this collaboration is very important to us. So it was an honor to return to Japan this summer for a series of important meetings in Kyoto.

Kyoto is the site of the 14th International Myeloma Workshop (IMW) meeting to be held in April 2013, so it was especially helpful to have a preview of the city and International Conference Center (ICC) venue. The ICC is a large center and well capable of hosting the IMW meeting. However, it will certainly be a challenge to organize all the myeloma scientific activities next year in a city known for the Cherry Blossom Festivals, which occur during the same month and always attract many visitors.

During our time in Kyoto in July 2012, the IMF was honored to participate in the 37th Annual Meeting of the Japanese Myeloma Society (JMS), which was attended by more than 500 physicians from across Japan. The focus on myeloma by the JMS extends back to the mid-1980s. The scientific part of this meeting lasted two days and, in addition to esteemed faculty from Japan, included several renowned guest speakers from abroad: Dr. Antonio Palumbo from Italy, and Drs. Brian Durie, Ola Landgren, and Paul Richardson from the US. Dr. Durie, Chairman of the IMF, was the keynote speaker, highlighting current developments in myeloma research and practice.

A unique aspect of these physician meetings is the overlap with the IMF Japan Patient & Family Seminar. Myeloma experts make presentations to the patients and patients can listen to the JMS scientific sessions. A new feature this year was that eight of the myeloma specialists from Japan set aside individual "one-on-one" consultation times for Japanese patients. More than 300 patients attended and were able to take advantage of a broad range of sessions including four special "commentary" sessions about bone disease, renal problems, novel therapies, and key questions from 2012.

For me, it is thrilling to witness how the hard work of our friends ensures that IMF Japan continues to flourish and create its own blend of activities and support for myeloma patients throughout the country. For those of you who do not know how our wonderful relationship began, I would like to tell you a story of partnership, shared vision, and joint commitment to improve the lives of myeloma patients and their families.

It all began with Aki Horinouchi and Mike Katz, two myeloma patients, one from Japan and one from the United States. Aki and Mike met online and became good "virtual" friends. Both were in the prime of their lives. They were savvy businessmen with successful careers, both had families, and both were shocked to be diagnosed with a disease neither of them had heard of previously – I'm sure that many of you can relate!

After his diagnosis, Mike dedicated himself to volunteering for the IMF and helping his fellow patients, and was invited to become a member of the IMF Board of Directors. In 1997, Aki decided that he wanted to do something for myeloma patients in Japan, so he came to Los Angeles to visit us at the IMF. That was when Aki made the commitment to start the IMF-Japan. He translated our patient education materials, created the Japanese website, and began organizing the very first local seminar for myeloma patients. IMF-Japan is the oldest of all the national IMF affiliates with a long record of service to patients and their family members in Japan.

We were thrilled with Aki's dedication and accomplishments and, in recognition of all his work, the IMF presented him with the Francesca Thompson Outstanding Service Award. Of course he was in Japan and we were in the US, so we had get creative. The award was presented during an IMF patient seminar, with Aki and his wife Midori on the speaker phone. It all worked out just great!

A lot has happened since then, but the memory of Aki remains strong and vibrant. It was wonderful for us to spend time with Midori, who continues to help lead and inspire IMF Japan. And we are so proud of Kyoko Joko, the current chair of the IMF Japan Board, who has done a remarkable job of both carrying on the work of Aki and Midori while initiating many new and impressive programs.

But I think that for all of us the most exciting development of the past few years has been the progress made in the treatment for myeloma. We have seen more and more new drugs join the arsenal of anti-myeloma therapies, and the improvements in patient responses and quality of life are impressive. Patients are experiencing longer and longer remissions, and cure is now a word that we can actually think about using! Maybe not today, but certainly soon.

Myeloma researchers are collaborating on a wide variety of cutting-edge projects, both in the lab and in the clinic. The work being done is unprecedented in any other disease. The impressive accomplishments of the International Myeloma Working Group (IMWG) – a research division of the IMF comprised of 160 doctors from 30 countries – cannot be overstated. The IMWG's mission is to identify, support and implement the most promising research to prevent onset of active disease, improve treatment and find a cure for myeloma. I can assure you that they are doing their job! The IMF is very proud that Prof. Kazuyuki Shimizu, the president of next year's IMW in Kyoto, is such an active and important member of the IMWG.

It is an exciting time for myeloma work in Japan. As our weekend in Kyoto drew to a close, I reflected on an amazing and rewarding visit, and began to look forward to the exciting events of 2013, when we return for the 14th IMW. There will be a strong IMF presence at the IMW, with a special focus on myeloma in Asia. IMF-Japan will also organize a patient seminar during the conference, the first time that this has occurred at the IMW. I know that the Workshop will be a huge success and will bring us all even closer to our common goal of putting an end to myeloma. As the beautiful aroma of the cherry blossoms always reminds me -- anything is possible and life is beautiful. **MT**

NLB — continued from page 8

The subject of therapy adherence and self-management in myeloma is a very important one, and it was discussed in a presentation made by NLB's Sandy Kurtin. Low adherence rates are problematic in most chronic diseases, not just in malignant conditions. To quote Dr. C. Everett Koop, who served as thirteenth Surgeon General of the United States from 1982 to 1989, "Drugs don't work in patients who don't take them."

After a much-needed coffee break, participants reconvened to hear Dr. Brian G.M. Durie present an update on the work of the International Myeloma Working Group (IMWG). Next, Sandy Kurtin led a manuscript-writing mini-workshop. Developing a manuscript as a group presents both challenges and opportunities. The opportunities reflect the experiences and insights of a large group, and the mentoring and sharing that takes place. The challenge is to channel the enthusiasm and diversity into a cohesive work.

Next, NLB members turned their attention to team projects. After presentations to the general membership, the remaining part of the day was dedicated to breakout working sessions, with continued planning and content development for each of the established group projects.

- **Nurse-led Clinical Research:** led by Charise Gleason and Joseph Tariman, with the participation of four additional NLB team members. The final protocol is to be submitted through the Emory institutional review board (IRB) with the support of Dr. Sagar Lonial. A draft protocol was submitted for review by the group, which then assigned sections to individual group members. A timeline is in place.
- **Transplant Guidelines:** led by Teresa Miceli, with the participation of six additional NLB team members. Draft manuscript underwent review and edits by the Transplant Guidelines team, followed by a review during the NLB VIII by the entire NLB. Work continues according to plan, with an established timeline for publication submission.
- **Survivorship Care Plan (SCP) Online Resource Tool:** led by Tiffany Richards, with the participation of five additional NLB team members. The concept of the SCP tool has evolved to align with new IMF technology. This will provide an interactive format for the SCP work published in two *Clinical Journal of Oncology Nursing (CJON)* supplements, and will integrate the numerous resources available on the IMF website. The team is moving forward with planning and implementation of the next steps in accordance with the identified timeline. Sandy Kurtin will be leading this effort in the next phase of development.

The day concluded with team members reconvening and reporting back on their projects to the entire group.

Day 2

The day's sessions opened with remarks by Diane Moran. Next, the group continued to review the transplant manuscript and provide feedback to the project team. Plans were made for continued work on the manuscript, with another opportunity scheduled for the entire membership to review the final draft before submission for publication.

The Clinical Trials Taskforce activity update was presented by Joseph Tariman. This taskforce has completed its mission and members were reassigned to other projects.

The Patient Education Taskforce activity update was presented by Teresa Miceli. The team has produced three separate slide sets for patients, which are being used extensively in IMF's educational programming, including IMF Patient & Family Seminars, Regional Community Workshops and Myeloma Center Workshops, as well as IMF webcasts. New slide decks for 2013 are under development.

The Nurse Education Taskforce is chaired by Charise Gleason, with four other NLB members on the team. They are reviewing and updating slide deck modules.

The Publications Taskforce met to outline several opportunities for publication. Sandy Kurtin and Beth Faiman continue to support the Transplant Manuscript Team in finalizing their publication. Elizabeth Bilotti and Sandy Kurtin will submit a review paper providing an update on proteasome inhibitors and immunomodulatory agents to be published in *The Journal of the Advanced Practitioner in Oncology* in November/December 2012. Beth Faiman and Tiffany Richards will follow this with a review of other classes of novel agents in the subsequent issue. Additional opportunities for publication were identified and a timeline for follow-up calls was established.

The Adherence Taskforce is a new project led by Sandy Kurtin and Joseph Tariman, with three other NLB members on the team. The group has outlined a publication focused on oral therapies used in the treatment of myeloma. Additional opportunities for deliverables relative to oral therapies were also discussed.

Progress has continued since NLB VIII with follow-up teleconference calls. It is truly remarkable how much these dedicated Board members are able to accomplish above and beyond their commitment to their respective myeloma centers and the dedication to the patients they work with. We extend our heartfelt gratitude to NLB VIII co-chairs Joseph and Sandy, and the entire nurse faculty of the NLB! **MT**

Living Well With Multiple Myeloma

TELECONFERENCE

Getting to the Source: Acute and Chronic Pain

On September 27, Arizona Cancer Center nurse practitioner Sandy Kurtin will discuss managing acute and chronic pain in the myeloma patient. Kurtin, who has been a nurse for 27 years, is known for her motto, "knowledge is only powerful if shared." Register for the teleconference at livingwell.myeloma.org. All Living Well With Multiple Myeloma teleconferences are archived on the IMF website for replay.

New Design, New Materials

IMF publications now have a fresh new look. Making timely information on myeloma treatments available in a format that is easy to read and understand is an ongoing commitment for the IMF.

The new edition of *Understanding Velcade® (bortezomib) for Injection* booklet is filled with the most up-to-date information on Velcade® Sub Q. This booklet was the first to carry our new design, and is available for viewing or downloading from the IMF website myeloma.org, or can be ordered from the IMF as a printed copy.

The IMF library of publications has also added a brand new title. The *Understanding Kyprolis™ (carfilzomib) for Injection* booklet discusses the recently FDA-approved drug Kyprolis, the results of clinical trials with Kyprolis, how and when it is administered, its possible side effects, and how to manage them. Like all IMF publications, it is available free of charge, either online or as a printed copy.

Don't Miss Out!

Make your reservations for 2013 IMF Patient & Family Seminars now. These popular educational events have limited seating capacity and fill up fast.

What you get at an IMF Patient & Family Seminar:

- ***Education***
- ***Access to Experts***
- ***Camaraderie***

In 2013, don't miss your opportunity to attend an education-packed IMF Patient & Family Seminar in Boca Raton (FL), San Francisco Bay Area (CA), Chicago (IL) or Philadelphia (PA). For dates, please see the IMF calendar on the back cover.

New Myeloma Trials Open for Enrollment

Two new phase III myeloma studies are enrolling approximately 1,400 patients worldwide. The studies are designed to see whether the investigational drug elotuzumab (formerly known as HuLuc63) in combination with Revlimid® (lenalidomide) and dexamethasone is more effective than lenalidomide plus dexamethasone alone.

Elotuzumab is a monoclonal antibody that targets CS1, a cell surface glycoprotein highly expressed on myeloma cells but minimally expressed on normal cells. The "ELOQUENT 1" study is recruiting previously untreated patients who are not candidates for stem cell transplant. "ELOQUENT 2" is for patients with documented progression from their most recent line of therapy.

Both studies are open label, which means both the study doctor and patient know which medications the patient is on. Information on the trials is available on the IMF website myeloma.org or at clinicaltrials.gov, a service of the US National Institutes of Health (NIH). You are welcome to call the IMF Hotline 800-452-CURE (2873) with your questions.

50 Cancers Approved for Coverage by 9/11 Health Fund

In June, the IMF welcomed a federal ruling that will add 50 types of cancer, including multiple myeloma, to those illnesses covered by the $4.3-billion fund established by Congress after the terrorist attacks of September 11, 2001. The decision came as a vindication for those who have claimed that their cancers were caused by their exposure in the aftermath of the attacks.

Rescue workers and volunteers, as well as people with covered cancers who lived, worked, or attended school in Lower Manhattan between September 11, 2001, and May 30, 2002, would be able to apply for compensation for their economic losses, pain, and suffering. Survivors of patients who have died may also apply.

"This country owes a debt of gratitude to the heroic first responders who, instead of running away from dangerous ash clouds that enveloped the streets of New York, ran toward them in the hopes that they would be able to help save lives," said Dr. Brian Durie, co-founder and chairman of the IMF. "This decision ensures health coverage for all affected by this tragedy."

The cancers will be officially added to the list of covered illnesses after a period of public comment and review. The new rules would also apply to responders at the Pentagon and in Shanksville, PA. **MT**

Share your thoughts

Be an active reader and viewer. Share your thoughts and questions about any article, video, or blog that appears on the IMF website myeloma.org by clicking on the comments tab, and join the discussion on matters of importance to everyone touched by myeloma. Your input can help others.

Our site features webcasts and interviews from the premier meetings for MM patients and healthcare professionals, as well as webinars and teleconferences that cover a broad range of topics.

You can subscribe to blogs by doctors, nurses, patients, caregivers, and others in order to receive email notification when a new posting is made. We hope you find this new capability helpful.

The IMF has a social community

Join the IMF's active social community, on both twitter and facebook.

Find us on facebook at www.facebook.com/myeloma

Follow us on twitter @IMFmyeloma

We already consider you part of the family… Now, let's be friends!

Help the IMF learn more about MM patients

Please help the IMF learn more about MM 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.

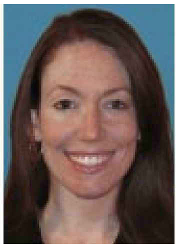
IMF Staff Updates

Lisa Paik

The IMF's Lisa Paik has been promoted to Senior Vice President, Clinical Education & Research Initiatives. Lisa joined the IMF in June 2001 as Director of Meeting Services, bringing with her extensive public relations and special events planning experience. Previously, Lisa was an Executive with Ogilvy Public Relations in Washington, DC. At Ogilvy, she specialized in consumer education programs and disease-awareness campaigns. At the IMF, Lisa currently oversees the IMF's research grant awards process, as well as all of the Foundation's CME & CE programs. She is the point person for the Health Medical companies accrediting clinical meetings and coordinates workshops for the International Myeloma Working Group (IMWG), a collaborative group of leading myeloma specialists. Lisa can be reached at lpaik@myeloma.org.

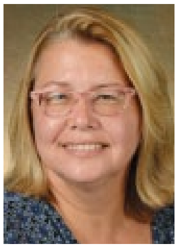
Arin Assero

The IMF's Arin Assero has been promoted to Vice President, Global Advocacy. Arin joined the IMF in 2007 to lead the Myeloma Mobile national awareness campaign, a cross-country effort to educate the general public and empower the myeloma community. In 2009, Arin initiated an advocacy program based on the IMF's newly established Cancer Patient Statement of Principles. Arin launched the IMF's Legislative Action Center, an integral part of our grassroots network. Arin and her team led the formation of the Patients Equal Access Coalition (PEAC), which collaboratively represents patients, healthcare professionals, care centers, and industry to ensure that cancer patients have equality of access (and insurance coverage) to all approved anticancer regimens regardless of their method of delivery. Reach Arin at aassero@myeloma.org.



Meghan Buzby

The IMF's Meghan Buzby has been promoted to Director of US Advocacy. As part of the advocacy team, Meghan manages the IMF's US federal and state policy issues and initiatives, focused on prevention, innovation, access, and approval of treatments. She currently maintains and operates the State Patients Equal Access Coalition (SPEAC). Within one year of joining the IMF in 2010, Meghan expanded our grassroots program to more than double the number of advocates from the year before. She brought to the IMF over eight years of marketing and communications experience, having specialized in strategic planning in a variety of different industries. Meghan earned her Bachelor's degree from Towson University, and holds an MBA from Loyola University Maryland. Meghan can be reached at mbuzby@myeloma.org.



Zina Cary

The IMF welcomes Zina Cary as our National State Affairs Consultant to help broaden our effort of increasing access for patients to all anti-cancer treatments. Zina has served as National Director of State Affairs for The Leukemia & Lymphoma Society (LLS), spearheading LLS campaign efforts in state legislatures around the US. She has worked in the health advocacy arena for more than 19 years, holding such positions as Director of Government Affairs for the National Health Council, National Field Coordinator for Families USA, Health Care & Consumer Advocate for the Vermont Public Interest Research Group, and Legislative Analyst for Assemblyman Richard N. Gottfried, Chair of the NY State Assembly Health Committee. Zina can be reached at zcary@myeloma.org.

SAVE THE DATE

INTERNATIONAL MYELOMA FOUNDATION

6th Annual

Comedy Celebration

benefiting the Peter Boyle Research Fund

Hosted by **Ray Romano**

Featuring

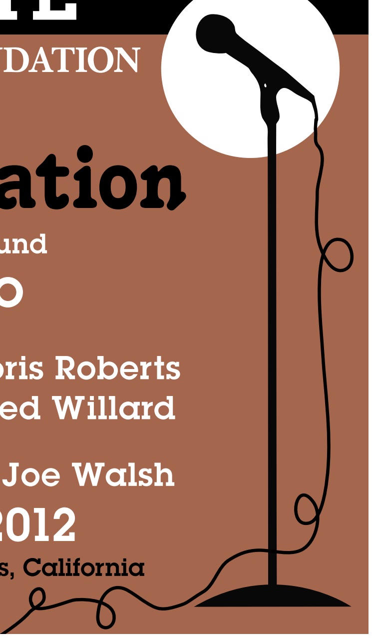
Jeff Garlin
Judy Gold
Gilbert Gottfried
Dom Irrera
Jay Johnson
Doris Roberts
Fred Willard

and a special musical performance by **Joe Walsh**

Saturday, October 27, 2012

The Wilshire Ebell Theatre & Club in Los Angeles, California

All performers subject to availability. Additional performers to be announced.



Sneak Peek of Auction Items

- 4-Night Stay in Hawaii at the Grand Wailea Resort
- 3-Night Stay in Belize at the Maruba Resort Jungle Spa
- 2-Night Stay in Paris at the Hotel le Bristol
- Four VIP Tickets to The Daily Show and Meet & Greet with Jon Stewart
- Alec Baldwin Meet & Greet and two tickets to his spring Broadway play "Orphans"

Visit us at comedy.myeloma.org or
follow us at facebook.com/myeloma or
@IMFComedy for program updates.

IMFers RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia

2012 promises to be a very successful year for IMF members who are raising funds to support essential multiple myeloma (MM) research while also raising MM awareness. Fundraisers as diverse as neighborhood garage and bake sales, community marathons and walks, parties and entertainment events, sports tournaments and countless other events are taking place across the country. Most of these events start with a phone call to the IMF and one simple question – "What can I do?" Those who became involved find their activities to be not only fulfilling but also incredibly empowering.

Our FUNdraising program is fun and easy, and brings with it the satisfaction of knowing that YOU are making a difference in many lives. Choose an established event model or create your own. ***No idea is too large or too small!*** *The IMF provides you with tools and assistance to make your event a success, and promotes your efforts through our website and social media outlets. Please contact me, Suzanne Battaglia, at sbattaglia@myeloma.org or 800-452-CURE (2873) to chat about any ideas you might have.*

The moneys raised by individuals like you help support cutting-edge MM research funded by the IMF. Become a part of making miracles happen! Join us in working together toward our common goal... a CURE.

Here are some examples of recent events…

4th annual "IT" Fashion Show

Darlene Ritz and Suzanne Battaglia

Produced by the Art Institute of California-San Diego, the 4th annual "IT" Fashion Show took place on May 25, 2012. The show was preceded by a VIP reception for sponsors. "The goal is to raise awareness about Ai's fashion programs, to showcase our very talented students' work, and through ticket sales to donate funds to our charities of choice," said Jaye Brown, Academic Director of Fashion Programs. This year, the Ai event benefitted the IMF in memory of Mary Kaye Ritz, whose sister Darlene Ritz is a fashion instructor at the school.

Mary Kaye Ritz

Mary Kaye Ritz lived in Hawaii with her husband, and worked as a journalist for the religion and spirituality "beat" of the local newspaper. In March 2009, she saw a doctor for an infection in her foot, and he noted a protein spike in her blood test results. Having previously seen myeloma patients, he quickly referred Mary Kaye to a hematologist, and the MM diagnosis was confirmed. It was a shock to the entire family.

"Being a faith-based person, Mary Kaye embraced every aspect of her life and faced the cancer diagnosis with strength and a positive attitude," said Darlene. "We come from a very close-knit family of six sisters and Mary Kaye also had the support of her wonderful husband of almost 30 years and their two sons." Darlene wanted to do something to help, and Mary Kaye suggested she get in touch with the IMF. In 2010, Darlene organized a successful fundraiser with Ai students. In 2012, the school stepped forth to honor Mary Kaye and support Darlene at their major fashion show event of year. "I am so fortunate to be working with such caring individuals who continue to contribute to the cause. My sister was a fighter and we are carrying the fight in her memory."

Attending the fashion show and meeting Darlene was a wonderful experience for me, and witnessing first-hand the dedication of the staff and students was truly inspiring!

Be Bold Be Bald

A group called Small Army for a Cause has launched a campaign at beboldbebald.org that gets individuals or teams to commit to wearing a bald cap on November 2nd, just for one day, and get others to sponsor them. The IMF is one of the beneficiaries involved. There are so many ways to support the fight against myeloma, and this is an easy way to get involved in a national campaign without having to organize your own fundraising event. Be Bold Be Bald is also a great way to raise awareness of MM.

Coach Rob's 7th Annual Benefit

October 28-29, 2012 • Shingle Creek Golf Club, Orlando, FL

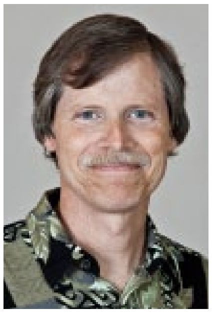
Coach Rob's 7th Annual Benefit Bash & Golf Tournament is a two-day fundraising event, featuring a dinner, auction, and casino night on Sunday, followed by a golf tournament on Monday. If you live near Orlando or plan to be in the area and wish to take part in this wonderful event, please visit coachrobscharities.com, or contact Rob Bradford at rbradford@crothall.com or 407-739-6268.

Vehicle Donation

There is a free, convenient service for converting that extra car, truck, or RV into a tax deductable donation benefiting the International Myeloma Foundation. V-Dac has been providing vehicle donation services to non-profit organizations since 2003, offering the highest return to charities while providing donors with an easy vehicle donation experience. V-Dac will make sure your vehicle is properly handled so you get your tax deduction and the IMF gets the benefit of your donation.

Letters to the IMF

Support Group Leader Summit



Energizing. Life-changing. Hopeful. All adjectives that can be used to describe my experience at the 2012 IMF Support Group Leader Summit. I must admit that I was reluctant to attend this year's meeting. Thank God the IMF's Support Group Director, Robin Touhy, encouraged me to go!

It was an amazing experience! I was impressed with updates provided by Dr. Brian Durie and a half dozen or more medical experts. But as exciting as all of this was, the human side of the gathering made the biggest impression on me. What a wonderful, selfless group of dear friends I made over the course of the weekend!

Even though it was my first Summit, I knew a number of the leaders from visits I had made around the country to their groups to share my story with their members. And I knew most of the IMF staff from our trips together to American Society of Hematology (ASH) meetings in New Orleans, Orlando and, most recently, San Diego. We all worked hard, spending the weekend learning and sharing ideas together.

Sure, the primary goal of the Summit was to bring back lots of ideas and information to our respective support groups. But in one short weekend, I was able to turn dozens of former acquaintances into what I hope will be life-long friends.

It was an experience I will never forget!

Pat Killingsworth
Nature Coast (Florida) MM Support Group

We had a fantastic time at the 2012 IMF Support Group Leader Summit. Meeting other leaders, getting great ideas, and learning from each other were only parts of the experience. The lectures gave us up-to-date information, and we came home better educated about myeloma and what we can do as leaders to help fellow patients in our support groups. We left with more Knowledge, Support, HOPE and a great outlook for the future! And there is a Future!

We want to thank everyone who made this weekend so special!

Kathy & Jeff Cartwright
Southwest Illinois/Northeast Missouri
MM Support Group

I want to thank the IMF staff for all of your efforts to make the Support Group Leader Summit outstanding. In my humble opinion, I think it was one of the very best.

Paula Van Riper
Central New Jersey MM Support Group

Myeloma Center Workshops

After being diagnosed with multiple myeloma in June of 2006, and undergoing two stem cell transplants, I have been in remission since 2008. Although I do not require cancer therapy at this time, my wife and I still feel that keeping up with myeloma education is important. We are members of the Arkansas MM Support Group that meets in Texarkana, and we recently attended the Myeloma Center Workshop (MCW) at the Myeloma Institute for Research and Therapy (MIRT) in Little Rock, AR. We came to the workshop hoping to get a better understanding of the status of myeloma research and treatment. What we learned at the meeting about the genetics of myeloma and cutting-edge testing and monitoring of the disease left us very optimistic about what the future holds.

Jim Blackburn

Hotline

I am a nine-year veteran of multiple myeloma who recently relapsed for the first time. My physician recommended a course of treatment with which I did not feel entirely comfortable. I wanted to explore other options, so I turned to the IMF Hotline for information and assistance.

Paul Hewitt answered my call and proved to be not only very knowledgeable, but also very helpful in pointing me toward other useful sources of information. With his advice and assistance, I believe that I was able to make an informed decision that I can live with. Many kudos to Paul and to the IMF for providing this wonderful service.

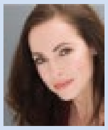
George R. Horn

Advocacy Webinar

The IMF Advocacy Webinar training was excellent! I loved the materials and plan on sharing the slides with members of my support group. I am hopeful that this will encourage them to take part in future webinars and teleconferences, and I know that it will get them (and their family and friends) to complete the postcards for oral drug parity that's so important to us patients. I appreciate all you do to further the education of myeloma patients and their loved ones.

Carlene Pratt
Inland Valley MM Support Group

If you would like to share your thoughts with the IMF or with readers of *Myeloma Today*, or if you wish to suggest or contribute future content for this newsletter, please contact:



Marya Kazakova – Editor-in-Chief, Publications
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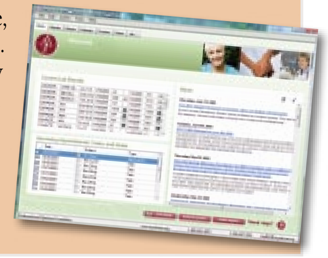
Myeloma Manager™ Personal Care Assistant™

We are pleased to offer you, free of charge, the Myeloma Manager™ software, v4.0.2. Designed and developed by the IMF specifically to help patients and caregivers battling multiple myeloma, the Myeloma Manager™ provides a tool to capture laboratory results and display and print tables and charts to show how those results change over time. We hope that you will find it useful.

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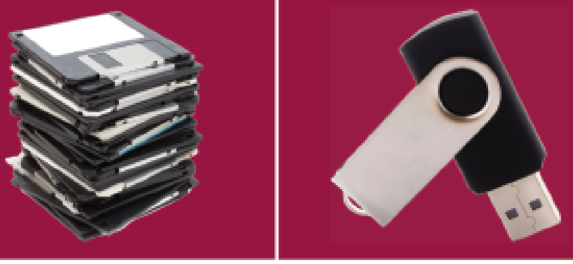


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Improving Lives • Finding the Cure

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

2012 / 2013 IMF Calendar of Events

2012

Sept 12	DMG/IMF Patient & Family Seminar (PFS) – Nyborg, DENMARK
Sept 15	Myeloma Center Workshop (MCW) at Emory University – Atlanta, GA
Sept 15	TUC/IMF Patient & Family Seminar (PFS) – Trondheim, NORWAY
Sept 16	UH/IMF Patient & Family Seminar (PFS) – Oslo, NORWAY
Sept 21-22	CMG/IMF Patient & Family Seminar (PFS) – Lazne Belorad, CZECH REPUBLIC
Sept 22	AIL/IMF Patient & Family Seminar (PFS) – Catania, ITALY
Sept 24	AIL/IMF Patient & Family Seminar (PFS) – Torino, ITALY
Sept 30	IMF Patient & Family Seminar (PFS) – Heidelberg, GERMANY
Oct 5	Myeloma Center Workshop (MCW) at UNC/Duke University – Raleigh-Durham, NC
Oct 27	6th Annual Comedy Celebration – Los Angeles, CA
Nov 3	IMF Regional Community Workshop (RCW) – Sacramento, CA
Nov 17	Myeloma Center Workshop (MCW) at Mayo Clinic – Scottsdale, AZ
Dec 8-11	American Society of Hematology (ASH) annual meeting – Atlanta, GA

2013

March 1-2	IMF Patient & Family Seminar (PFS) – Boca Raton, FL
March 10-11	IMF Patient & Family Seminar (PFS) – Redwood (SF Bay Area), CA
August 9-10	IMF Patient & Family Seminar (PFS) – Chicago, IL
August 23-24	IMF Patient & Family Seminar (PFS) – Philadelphia, PA

The IMF is proud to work with our global partners.
For more information about upcoming events, please visit myeloma.org or call 800-452-CURE (2873).
IMF–Latin America, IMF–Japan and IMF–Israel events are not included above.