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

Scientific & Clinical News

The 2013 Annual Meeting of the American Society of Hematology (ASH) presented the myeloma community with a record number of posters and oral presentations. Perhaps the most eagerly anticipated presentations were those on new drug candidates with novel mechanisms of action. The ever-growing arsenal of weapons to fight myeloma gives us all hope that we'll soon have a combination therapy to cure this disease. In our ASH Highlights, we feature the most important news about novel agents, new drugs, stem cell transplant, and maintenance therapy. ***PAGE 5***

The International Myeloma Foundation (IMF) Black Swan Research Initiative® (BSRI®) is moving into high gear in the new year. "Building on remarkable progress made by the BSRI team during the last months of 2013, our game-changing approach to finding a cure for myeloma has hit key scientific goals ahead of schedule," writes Dr. Brian Durie, IMF Chairman, in his update. Additionally, the work is attracting significant financial support from both industry and private partners. ***PAGE 4***

A Social Media Team of myeloma patients and support group leaders sponsored by the IMF was on the ground in December 2013 at the ASH conference, attending educational events, medical symposiums, and poster presentations about myeloma research. Using Twitter, blogs, and digital images, the team sent live reports daily to the myeloma patient and caregiver community, keeping those unable to attend the conference in the loop. ***PAGE 6***

Special Events

Laughter rocked the house at the **IMF's 7th Annual Comedy Celebration benefiting the Peter Boyle Research Fund** on November 9, 2013. More than 1,000 guests gathered at the Wilshire Ebell Theatre in Los Angeles in support of the Black Swan Research Initiative®. The star-studded comedy lineup included Ray Romano, the evening's host; Ray's *"Everybody Loves Raymond"* co-star, Patricia Heaton; the show's creator and executive producer, Phil Rosenthal; and Phil's wife, Monica Horan, who also co-starred on the show. Among the evening's highlights was a transcendent acoustical performance by legendary singer-songwriter David Crosby. ***PAGE 18***

Education & Awareness

The IMF Advocacy Team has been working internationally, nationally, and on the state level to advance causes important to myeloma patients. Arin Assero, Vice President, Global Advocacy, led the second meeting of the Global Myeloma Alliance (GMA) at ASH 2013 and traveled to South Korea to educate patients on advocacy. In the US, the IMF advocacy team worked to advance oral anticancer treatment access legislation in several states, and partnered with Congressman Brian Higgins (D-NY) to reintroduce the national Cancer Drug Coverage Parity Act. ***PAGE 12***

Special Meetings

The IMF, in conjunction with myeloma associations in Norway and Denmark, hosted patient meetings in both countries. Each meeting welcomed more than 200 attendees, including myeloma physicians, patients, and family members. The meetings featured presentations from the local patient associations, local myeloma experts, Dr. Ola Landgren of the US National Cancer Institute, and the IMF's Nadia Elkebir, Director Europe/Middle East, Medical Education & Patient Liaison. ***PAGE 15***

The IMF's Nurse Leadership Board (NLB), comprised of nurses from leading myeloma centers, held its ninth annual meeting in October 2013. The meeting highlighted NLB members' work to improve the nursing care and self-care of patients with myeloma over the past year, and provided an opportunity to plan for 2014. The meeting was co-chaired by NLB members Beth Faiman, PhDc, MSN, APRN-BC, AOCN, Cleveland Clinic Taussig Cancer Institute, Multiple Myeloma Program, and Sandra E. Kurtin, RN, MS, AOCN, ANP-C, Arizona Cancer Center. ***PAGE 11***

Support Groups

The IMF's network of support groups has grown to include more than 140 groups in the US. The IMF's dedicated Support Group Team is committed to nurturing them all with a wide variety of resources, guidance, and the communication tools to help them succeed in the 21st century. Support groups can access a rich trove of educational content on the IMF website, and can benefit from unequaled creation and hosting of their own local websites, courtesy of the IMF. ***PAGE 17***

Also in this issue...

This issue of *Myeloma Today* is supported by Celgene Corporation,
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A Message from the President

Dear Reader,

In recent months, I've had the pleasure to meet with scientific investigators of the Black Swan Research Initiative® (BSRI®) as they gathered together from Italy, Spain, Germany, and the US, to share research, brainstorm ideas, and chart the next steps on our path to curing myeloma.

As you can imagine, it was such a thrill to be in the room listening to these brilliant researchers discuss and debate the next steps for BSRI. As I listened to the presentations and the passionate exchanges that followed, I was reminded that this amazing and critically important project is really a natural extension of the IMF and the core values we've embodied since Day One: a focus on myeloma patients, collaboration, out-of-the-box thinking, and a global vision.

The Black Swan Research Initiative began with a big idea and a small team; it's now quickly grown into a myeloma game-changer. BSRI's start is so similar to how the IMF began. We were just three people with a big idea, and a clear vision of what we wanted to do. We also had the creativity and the ability to bring the people together and work collaboratively. When I look at where we are now, 23 years later, I am so proud and thankful to the hundreds of thousands of people around the world who work with us, believe in us, and share our vision. Together we are making miracles happen!

Today, the IMF's global vision resonates around the world. In October, Arin Assero, Vice President, Global Advocacy, traveled to South Korea where she shared with myeloma patients the strategies that are the most effective to ensure access to the best treatments. Arin has spearheaded a new group, the Global Myeloma Alliance, building an international team whose members are working in tandem to increase the strength of their voices.

In 2006, our out-of-the-box thinking led us to bring myeloma patients to the annual meeting of the American Society of Hematology (ASH) – which had always been considered to be a doctors-only affair. Since then, an IMF team of patients and support group leaders have attended ASH each year, sharing their unique perspectives on Twitter, Facebook, blogs and videos to keep the myeloma community abreast of all the breaking news as it happens! *(Editor's note: See article on Support Group Leaders at ASH 2013 on page 6.)* Other organizations talk about breaking down barriers between patients and the medical community – the IMF actually does it, giving patients access to important studies and researchers once considered off-limits.

Our focus on patients takes many forms, and education has always been a cornerstone of the IMF and is of vital importance. Technology today enables us to live-stream events from ASH, Patient & Family Seminars, and meetings of the International Myeloma Working Group (IMWG). We deliver the latest news about treatments and research directly to the entire global myeloma community. It's imperative for myeloma patients to learn about the latest advances in treatment and research – our information empowers them and provides much needed hope in the fight against myeloma.

Ultimately, the IMF is about collaboration – we bring people together. We collaborate in many ways, and a great example of this is the IMWG. This group of 165 of the world's top myeloma experts comes together to set the standards for optimum patient treatment. To date, they have published 133 guidelines in the most prestigious medical journals; these guidelines are of paramount importance for myeloma doctors everywhere.

In the 23 years since our founding, the IMF has been fueled by a passionate belief in the power of collaboration, out-of-the-box thinking, patient focus and a global vision. We truly believe that these values are leading us to a cure for myeloma.

Warmly,

Susie Novis

Susie Novis, President

The IMF at ASH 2013
IMWG Conference Series & Web Interviews

IMWG Myeloma Experts Debate the Latest Trends in Treatment (Video Archive)

The International Myeloma Working Group (IMWG) Conference Series, "Making Sense of Treatment," was broadcast live on December 9, 2013 from the 2013 Annual Meeting of the American Society of Hematology in New Orleans. During this webcast, myeloma experts Dr. Brian G.M. Durie, Chairman and Co-founder of the IMF, Dr. Joseph Mikhael, Dr. Ola Landgren and Dr. Antonio Palumbo tackled the key questions currently facing myeloma doctors and patients. Archived here: **tinyurl.com/IMWG2013ASH**

IMF Web Interviews

The IMF brings you video interviews with myeloma experts from the 2013 annual meeting of the American Society of Hematology (ASH). This exciting convergence of 20,000 health care professionals from around the world occurred December 7-10 in New Orleans, Louisiana. More than 100 IMF video interviews feature discussions of the latest clinical updates in myeloma research, therapies, and practice strategies. Archived here: **tinyurl.com/IMFinterviews2013ASH.**

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BLACK SWAN RESEARCH INITIATIVE MOVES INTO HIGH GEAR

by Brian G.M. Durie, MD
IMF Chairman

The International Myeloma Foundation (IMF) Black Swan Research Initiative® (BSRI®) is moving into high gear in 2014.

Building on remarkable progress made by the BSRI team during the last months of 2013, our game-changing approach to finding a cure for myeloma has hit key scientific goals ahead of schedule. Additionally, the work is attracting significant financial support from both industry and private partners.

BSRI is the IMF's signature research project – a multinational consortium of leading myeloma experts who are studying and harnessing new technologies and myeloma treatments. The linchpin to these studies is the quest for determining when zero Minimal Residual Disease (MRD-Zero™) has been achieved, and this is where the most thrilling breakthroughs have occurred.

Professors Alberto Orfao and Bruno Paiva from Spain presented results of an automated, ultra-sensitive technique for MRD testing at an investigator meeting held in New Jersey in October 2013. The "multiple" in multiple myeloma refers to the frequency of myeloma occurring in different patches or areas of bone. Based on this, they came up with a cocktail of eight antigens that identify myeloma regardless of its state or location in the body.

To eliminate another common variable – the human observer – a computer software program was developed to analyze the read-out from the new test. The sensitivity of the test is one part in 100,000, and perhaps even lower.

We Can Analyze Hundreds of Thousands of Events

At a follow-up BSRI meeting held before last December's annual meeting of the American Society of Hematology (ASH) in New Orleans, excitement about the new test was palpable. With this new test, "we can analyze hundreds of thousands of events, maybe millions," said Dr. Vincent Rajkumar of the Mayo Clinic. "No one person can do that."

In early 2014, BSRI investigators will host a workshop in Spain to train others to run the Multicolor Flow Cytometry test, as the new technique is called. Once trained, those researchers will return to their own countries to teach others. The next step is achieving consensus on the test, then incorporating the flow cytometry testing into clinical trials so that the testing may be validated prospectively.

Dr. Rajkumar predicted that in two to three years the software will be able to be run anywhere globally. "It's why the Black Swan Research Initiative can change the world."

To some of the investigators on the team, it already has changed. Prof. Jesús San Miguel asked a provocative question during the discussion of this new testing protocol at the meeting in New Orleans: "My question is – how many patients are already cured?" He was referencing the concept espoused by BSRI that finding the pathway to a cure requires systematic evaluation and validation every step of the way.

The new cytometry test may soon identify patients who have indeed been cured – which in turn would pave the way for successfully replicating their particular portfolio of treatments. Cross correlations will prove very important in establishing a more finalized MRD testing panel. A key aspect of MRD testing and validation is to compare the flow and molecular methods, such as the Sequenta DNA method. Imaging and molecular testing will round out BSRI's testing protocol.

Five Major Objectives to Achieve Our Goals

There are five major objectives to achieve our goals:

1) Establish a standardized definition for MRD-Zero accepted by the International Myeloma Working Group (IMWG);
2) Standardize the new MRD tests;
3) Validate MRD-Zero in retrospective datasets;
4) Integrate standardized/automated/validated MRD-Zero testing into trials at different disease stages; and
5) Use MRD-Zero for treatment decisions to achieve cure.

Our timeline to accomplish all of this is approximately three years. But progress may be swifter than we imagine. Leading up to the next BSRI investigator meeting in spring 2014, the team is working to establish a chain of publications that will establish a new definition of myeloma, including ultra-high risk.

We must also better understand the nature of resistant subclones to achieve MRD-Zero.

And, of course, alongside our scientific efforts we are cultivating the financial support for the costly clinical trials and labor-intensive research required to find answers to our questions. This is crucial if we are to accelerate BSRI's efforts to find a cure for myeloma.

Fortunately, support for our efforts has been forthcoming – a sign we are on the right path.

Multi-Year Collaboration with Onyx Pharmaceuticals

Last December, the IMF was thrilled to announce the start of a multi-year collaboration with Onyx Pharmaceuticals, Inc., an Amgen subsidiary. Onyx is BSRI's inaugural industry partner and we are grateful for their early and enthusiastic support.

The IMF is equally appreciative of the support given by generous individuals, such as IMF Board of Directors member John O'Dwyer and his wife Dorothy. The couple are BSRI Founding Donors and, taking his commitment a step further, John has kindly agreed to serve in the important role of Chairman of the BSRI donor campaign. The O'Dwyers are also joined by Andrew and Laurie Kuzneski in the BSRI campaign.

We are indebted to Loraine Boyle, whose Peter Boyle Research Fund – named in honor of her late husband – turned its focus this year to Black Swan at the 2013 IMF 7th Annual Comedy Celebration. Private donors have committed more than $625,000 to the initiative so far. And IMF

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HIGHLIGHTS FROM THE 2013 AMERICAN SOCIETY OF HEMATOLOGY ANNUAL MEETING

by Debbie Birns
IMF Hotline Coordinator

The 2013 annual meeting of the American Society of Hematology (ASH) presented the myeloma community with a record number of posters and oral presentations. Many of them have enriched the ongoing debates about early treatment, continuous therapy, treatment of the elderly and of high-risk disease, and current best options for up-front and relapse therapy. The high number of presentations on disease biology and new tests to monitor, analyze, and quantify myeloma cells broadens our understanding of drug resistance and response to therapy. Perhaps the most eagerly anticipated presentations were those on new drug candidates with novel mechanisms of action. The ever-growing arsenal of weapons to fight myeloma gives us all hope that we'll soon have a combination therapy to cure this disease.

Previously approved agents

Revlimid® (lenalidomide)

The most important presentation on myeloma at this ASH meeting, and probably one of the most important presentations in any area of hematology, was the MM-020/IFM 07-01 study. The principal investigator and presenter was Dr. Thierry Facon (University Hospital, Lille, France) (abstract 2). The oral presentation was given in a huge plenary session and reported the results of a 1,600-patient, 3-arm trial comparing 1) the combination of Revlimid and low-dose dexamethasone for 18 cycles to 2) Rev/dex given until disease progression, to 3) melphalan, prednisone, and thalidomide (MPT, standard therapy in Europe) in newly diagnosed patients who were aged 65 or older and who were not candidates for stem cell transplant. Not only did Rev/dex given until disease progression significantly improve overall survival (OS) and progression-free survival (PFS) rates, there were fewer adverse effects with Rev/dex than with MPT, and a lower rate of second primary malignancies (SPMs) among patients who received Rev/dex (0.4%) than among those who received MPT (2.2%). This presentation not only demonstrates the superiority of Rev/dex over MPT, forcing the hematology community to question the use of melphalan as frontline therapy in non-transplant-eligible patients, but also, and perhaps more importantly, emphasizes the significant remission and survival benefit of continuous therapy.

Dr. Maria-Victoria Mateos (University of Salamanca, Spain) also presented the results of a large study for older, non-transplant-eligible, newly diagnosed patients in which a Velcade® based triplet combination and Rev/dex were studied. The Spanish trial, which is ongoing, compares sequential vs. alternating administration of Velcade, melphalan, and prednisone (VMP) and Rev/dex (403). Although both sequential and alternating approaches provide good responses, even among patients with high-risk cytogenetics, there is a trend toward improved PFS and OS in the alternating group. Dr. Mateos's theory is that response may improve when the plasma cell is exposed early to different agents. The final results of this trial will be reported next year.

Other important studies that reinforced the benefits of continuous Revlimid therapy were presented by Dr. Neha Korde (National Cancer Institute, Bethesda, Maryland) on the combination of Kyprolis® (carfilzomib), Revlimid, and dexamethasone followed by "extended dosing" with Revlimid (538), and the follow-up study of last year's MM-015 trial, in which Dr. Meletios Dimopoulos (Alexandra Hospital, Athens, Greece) evaluated the results of next-line therapy ("PFS2") for patients in the 015 trial who had relapsed (405). In Dr. Korde's study, which is ongoing and will be evaluated later for long-term follow-up, 27 of the 43 evaluable patients have thus far had either near-complete remission (nCR), complete remission (CR), or stringent complete remission (sCR), and all 27 are minimal residual disease (MRD) negative, a marker for long PFS and OS. Dr. Dimopoulos's follow-up study of the comparison of MP, MPR, and MPR-R provided several important insights: Revlimid provided a durable, progression-free interval even when the impact of second-line therapy was taken into account, confirming the clinical benefits of continuous therapy with Revlimid; the benefit of MPR-R was apparent regardless of subsequent therapy; and long-term treatment with Revlimid did not affect the efficacy of subsequent therapy.

Revlimid was featured prominently in combination therapy trials presented at this year's meeting. Many are mentioned in the discussion of the other agents in the combination, below. One of particular note that does not involve another novel or experimental therapy is the BIRD regimen (Biaxin, Rev, dex), which was the topic of Dr. Nilanjan Ghosh's (Johns Hopkins, Baltimore, Maryland) poster (1960), a retrospective study of the

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BSRI PROGRESS REPORT — continued from page 4

members have begun earmarking proceeds from their fundraising events for BSRI. The proceeds from October 2013's Miracles for Myeloma 5K run in New Jersey, for example, will fund Bruno Paiva's study of Minimal Residual Disease in myeloma.

This is all great. We want as many members of the myeloma community as possible to participate – researchers, patients, caregivers and friends. Anyone who can contribute whatever they can, be it research, financial support, or raising awareness of our work, is welcome. By pulling together, collaborating, and expanding our minds to consider possibilities never thought of before, I am certain we will find a pathway to achieving a cure for myeloma. **MT**

Patients and Caregivers at ASH 2013

A team of myeloma patients, caregivers, and support group leaders from around the country joined the approximately 20,000 healthcare professionals attending the recent 55th Annual Meeting and Exposition of the American Society of Hematology (ASH) in New Orleans, Louisiana. Their participation at the conference was sponsored by the International Myeloma Foundation (IMF).

At ASH, these patient advocates were brought up to date on the latest in myeloma treatment and research. In turn, they reported the news to the myeloma patient community back home, using social media tools like blogs, Twitter, video, and Facebook.

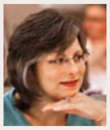
Held December 7-10 at the Ernest N. Morial Convention Center, ASH is the premier hematology conclave in the world. Some 300 companies, publishers, and nonprofit organizations were on hand along with the IMF.

Robin Tuohy
Senior Director, Support Groups

Robin Tuohy is caregiver to her husband, Michael, who was diagnosed with multiple myeloma in 2000 at the age of 36. But her outreach to myeloma patients extends beyond her home: as IMF's Senior Director of Support Groups, Robin acted as tour guide through the various programs at ASH for a group of 12 myeloma patients and support group leaders. She was especially moved by the holistic approach of many of the ASH presentations. "I love that we are treating the patient as a person and not the disease. This is critical for long-term survival."

Jerry Walton
Founder and Co-Leader,
Southeastern Virginia MM Support Group

Jerry Walton is a 33-year Navy veteran who retired from active duty in 1998 in Virginia Beach, VA. He taught math in a local public school until June 2007, the year after he was diagnosed with smoldering multiple myeloma. A visit to an IMF Patient & Family Seminar changed Jerry's life, inspiring him to start the Southeastern Virginia Multiple Myeloma Support Group. Jerry was excited to attend this year's ASH meeting and sees a benefit to SG leaders' "inclusion in the worldwide myeloma 'team' created by the IMF" – namely, the close connection forged with staff and group leaders who can help each other improve their own knowledge about myeloma.



Linda Huguelet
Co-Leader,
Chattanooga MM Networking Group

Linda Huguelet, who was diagnosed with myeloma in April 2010 at age 46, co-leads the Chattanooga Multiple Myeloma Networking Group with her husband, Jack. Linda has always been interested in the annual ASH meetings, typically following the results on the IMF website. This year she attended the event for the first time and shared the experience by blogging and tweeting daily, focusing on maintenance therapy and the emerging antibody treatments. She emerged "amazed" by the researchers' passion and the level of interest from their colleagues. "I couldn't wait to get home to share the knowledge I gathered, convey the experiences from this massive conference, and spread the excitement I feel."

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use of BIRD after patients have progressed on Rev/dex. Dr. Ghosh found that the addition of Biaxin to Rev/dex can salvage a subset of patients who have become refractory to Rev/dex, particularly if they had a previous response to that combination (although one patient who was primary refractory to Rev/dex had a complete response to BIRD).

The results of another noteworthy trial with a Revlimid-based combination therapy, Revlimid/Cytoxan® (cyclophosphamide; called "Endoxan" in Europe)/prednisone for patients with relapsed/refractory disease (287) was presented by Dr. Inger Nijhof (University of Utrecht, The Netherlands). All of the patients in this trial were refractory to Revlimid. Nevertheless, 67% of the patients had at least a partial response (PR) to this combination, with a median OS of 15.5 months.

Velcade® (bortezomib)

Perhaps the most important new information about Velcade is that "more is more." Two important presentations, one from Dr. Maria-Victoria Mateos (1968), and one from Dr. Pieter Sonneveld (Utrech Medical Center, The Netherlands) (404), demonstrate that OS is improved both with higher cumulative doses of Velcade (Mateos) and as both induction before and maintenance therapy after stem cell transplant (Sonneveld). We also learned that for patients with AL amyloidosis, Velcade is more effective given twice weekly rather than once weekly (1981, Sachchithanantham).

Dr. Jacob Laubach (Dana-Farber Cancer Institute, Boston, Massachusetts) presented data demonstrating that Velcade does not cause congestive heart failure (3187), which can be a problem with Kyprolis, a newer proteasome inhibitor. Although we know that about 23% of patients who are refractory to Velcade can benefit from Kyprolis, we also learned that some patients who are refractory to treatment with Kyprolis may subsequently benefit from Velcade-based therapies (1994, Alagappan).

Dr. Craig Reeder (Mayo Clinic, Scottsdale, Arizona), in his 5-year follow-up study of long-term survival in newly diagnosed patients treated with Velcade/Cytoxan/dexamethasone (also known as "CyBorD" or CBD) (3192), reports that 80% of the good-risk patients are still alive, as are 50% of those with high-risk disease. Velcade-based regimens are frequently used as front-line therapy, and we know of their benefit for patients with high-risk genetic mutations and renal dysfunction. In Europe, frontline Velcade is most frequently combined either with melphalan and prednisone or with thalidomide and dexamethasone, while in the US, Velcade/Rev/dex and Velcade/Cytoxan/dex are the most common Velcade-based therapies. Dr. Shaji Kumar (Mayo Clinic, Rochester, Minnesota) retrospectively analyzed the outcomes of newly diagnosed patients at the Mayo Clinic treated with either VRD or VCD to compare the benefit, toxicities, and cost of each combination (3178). He concluded that while these two excellent regimens provide similar PFS, OS, and tolerability, VCD is less costly than VRD, and cost is an issue of great importance in this era of soaring medical bills and limited resources.

Pomalyst® (pomalidomide)

Not surprisingly, there were many studies of the newest immunomodulatory agent, Pomalyst, in various disease settings. For European patients, the most important Pomalyststudy presented was the MM-003 trial, which will be presented to the European Medicines Agency (equivalent to the FDA in the United States) for approval of Pomalystin the treatment of relapsed and refractory myeloma. There were four presentations on the Pom/dex vs high-dose dex MM-003 study in relapsed/refractory myeloma (Dimopoulos, 408; Prof. Jesús San Miguel, University of Navarra, Pamplona, Spain 686; Katja Weisel, University of Tuebingen, Germany 3198; and Kevin Song, Vancouver General Hospital, Canada 2939), all of which demonstrated the superiority of Pom/dex over high-dose dex alone, even among older patients (Weisel) and among patients with high-risk genetics

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(Dimopoulos). In addition, to address an issue dear to patients' hearts, one study demonstrated improved quality of life with pom/dex over high-dose dex (Song).

Other pomalidomide highlights include Dr. Xavier Leleu's (University of Nantes, France) sub-analysis of the IFM 2010-02 study of pom/dex for relapsed/refractory patients (689). He looked at a cohort of patients with the high-risk genetic features deletion 17p and/or t(4;14) (689). His results demonstrate that patients with 17p- had a significantly longer duration of response to Pom/dex therapy than did those with t(4;14).

Dr. Giovanni Palladini (University of Pavia, Italy) reported on a pioneering study of pom/dex as treatment for relapsed/refractory AL amyloidosis (288), in which there was a 70% overall response rate (ORR; the percent of patients who have responded with at least a 50% drop in their monoclonal protein) to the regimen among a group of heavily pretreated patients.

Both Dr. Paul Richardson (Dana-Farber Cancer Institute, Boston, Massachusetts) and Dr. Joseph Mikhael (Mayo Clinic, Scottsdale, Arizona) presented data from early-phase trials with the novel combination of Pomalyst, Velcade, and dexamethasone for relapsed and refractory disease. A maximum tolerated dose (MTD) has been established, and response rates are high among all patients, including those who are refractory to Revlimid. There is currently a large, ongoing, randomized, prospective phase III trial comparing PVD with VD (MM-007).

Another innovative US trial with pomalidomide is Dr. Tomer Mark's (Weill-Cornell Medical Center, New York, New York) study of a combination known as "ClaPD," Biaxin® (clarithromycin), Pomalyst, and dex. Based on the same rationale as the BIRD regimen, it is still ongoing, with interim OS and PFS twice that which is achieved with pom/dex alone.

Kyprolis® (carfilzomib)

The trial of a new combination therapy that generated the most excitement at this ASH was the Kyprolis, Pomalyst, and dex regimen for patients with relapsed and refractory disease. Interim results of the phase II portion of the study were presented by Dr. Jatin Shah (MD Anderson Cancer Center, Houston, Texas) (690). There are now 82 patients enrolled, all of whom are heavily pretreated and refractory to Revlimid. The ORR is 70%, a most encouraging figure in this population of patients. If all the patients who have responded even minimally are counted (this is called the "clinical benefit response," or "CBR"), the response rate is 83%. Moreover, the responses are durable, with a median of 17.7 months. Median OS has not been reached at 18 months. These are outstanding results, making it clear that car/pom/dex is a big addition to the anti-myeloma arsenal.

Other Kyproliscombinations that are in trials and are producing excellent results are Kyprolis/thalidomide/dex, also called "carthadex," for newly diagnosed myeloma (Sonneveld, 688); Kyprolis/melphalan/prednisone for older, non-transplant-eligible patients (Moreau, 1933); and "car-BIRD" (now there's a visual for you), which is Kyproliswith the Biaxin/Rev/dex regimen, in newly diagnosed patients (Mark, 3216). In this clinical trial, patients are given the drugs in sequence: Kyprolisand dex, then BIRD, and finally Revlimid extended therapy until disease progression. It is too early to know if this sequence of drugs is superior or inferior to a combination, but we will follow the results with interest as they are reported.

New agents not yet approved by the FDA

Monoclonal antibodies

Among the as-yet unapproved agents for treating myeloma, those generating the most interest are the anti-CD 38 monoclonal antibodies, daratumumab (known as "dara")

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Nick Menedis
Co-Founder,
Columbus Multiple Myeloma Support Group

Nick Menedis was diagnosed with multiple myeloma in 2006. Along with his wife Sandy, he founded the Columbus, Ohio myeloma support group. Today Nick is in remission, on maintenance therapy and eagerly attended ASH with the IMF for the first time. He took in so much information that by the convention's close, he blogged, "I need a cup of coffee and a shower." He urged his fellow patients to "take care and know there are a lot of people working in your interest with the support of the IMF."

Michael Tuohy
Co-Founder, Co-Leader,
Connecticut Multiple Myeloma Fighters

Michael Tuohy was diagnosed with multiple myeloma in 2000 at the age of 36. The following year, with the IMF's help, he and his wife Robin started the first myeloma support group in Connecticut. Michael's focus at this year's ASH was the benefit of maintenance therapy. Having attended eight annual ASH gatherings, he returns home from each having gained "more hope that myeloma will be cured. Yes, I am using the word 'cure' because the IMF is leading the fight and I know they will accomplish that goal."

Cindy Ralston
Founder, Kansas City MM Support Group

Within a year of finding the IMF following her 1995 diagnosis, Cindy Ralston started the Kansas City MM Support Group. There, newly diagnosed patients contact her, "hungry for information and support." Cindy assures them that many other myeloma patients are living full and active lives. "Knowledge is power and the IMF does an excellent job of providing patients with all the tools they need to understand their disease."

Teresa S. Miceli, RN, BSN, OCN
Member, IMF Nurse Leadership Board
Nurse liaison for the IMF Support Group Leaders

Teresa Miceli, a member of the IMF Nurse Leadership Board, has been a nurse at the Mayo Clinic in Rochester, MN, in the Bone Marrow Transplant program and has worked with myeloma patients since 1991. She became affiliated with the Multiple Myeloma Sharing Sessions in Rochester in 2007 and three years later became the acting meeting facilitator. "There is so much to learn and discuss as a group," she says of her ASH experience, having recently attended her fourth annual conference. "It is an inspiring experience."

Cynthia Chmielewski
Member, Philadelphia MM Networking Group

Cynthia Chmielewski is proud to be a Jersey Girl. She was born and raised in the Trenton area and attended Rutgers University, where she earned degrees in Psychology and Elementary/Special Education. Then, after suffering for two years with debilitating back pain, Cynthia's doctors told her that she had myeloma. Today, she's in partial remission thanks to novel therapies and demonstrates her appreciation by giving back to the myeloma community. "The passion I felt during the presentations of medical research abstracts and at the satellite events held throughout the ASH conference was contagious."

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Yelak Biru
Co-Leader, North Texas MM Support Group

Yelak Biru has been associated with the North Texas Myeloma Support Group for the last 17 years and served as co-leader of the group for 12. Yelak attended ASH excited to learn about advances in research and the latest clinical trials. He shared information – via blogs and tweets – on the IMF Satellite Symposium on "Providing Best Options for Myeloma Treatment in 2013" and the IMF's Black Swan Research Initiative®. Yelak returned from ASH impressed with "the accessibility of these world-renowned doctors and researchers that have dedicated their lives to myeloma."

Anne Pacowta
Regional Director, Support Groups

Anne Pacowta was introduced to the IMF when her husband Jack was diagnosed with myeloma. A local support group was crucial to their understanding of the disease, so following Jack's retirement they moved to Florida and started their own support group in Jacksonville with the help of the IMF. Now Florida Regional Director of Support Groups, Anne attended ASH for the first time this year and returned "encouraged and enlightened" about "new treatments, new ways to use existing treatments, more pharmaceutical companies investing in myeloma research, and the IMF's Black Swan Research Initiative."

Jack Aiello
Co-Leader, San Francisco Bay Area
MM Support Group

Jack Aiello had three young children – ages 10, 14, and 16 – when he was diagnosed with stage III multiple myeloma. That was in 1995, when Jack was 45. Soon thereafter, he attended a local support group meeting and realized how important it was for him to see someone living and breathing with myeloma. Today, he is proud to help facilitate the San Francisco Bay Area Myeloma Support Group. To help share crucial knowledge with other patients, Jack first attended ASH seven years ago and "was energized by all the great research being done. I learned so much at that first meeting and haven't missed an ASH conference since."

IMF-sponsored Social Media Team of myeloma patients and support group leaders at the 2013 ASH in New Orleans.

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and SAR650984 (known – out of necessity – as "sar"). Dr. Inger Nijhof gave an oral presentation (277) that provided the preclinical background for anti-CD 38 immunochemotherapy of myeloma, demonstrating what happened in the laboratory when dara was added to Revlimid or Velcade in myeloma cell lines. Her elegant slides demonstrated how the effects of dara + Velcade are additive (1+1 = 2), while those with dara plus Revlimid are synergistic (1+1 = 3).

Dr. Joseph Mikhael presented what may well be the most exciting information on a new drug for myeloma at this meeting when he reported the results of a phase I dose escalation study with sar for patients with relapsed, refractory hematologic malignancies expressing the CD 38 antibody (284). This was a dose-escalation study in patients who had had a median of 6 prior therapies. All the myeloma patients had had Revlimid and Velcade, and many had already had Kyprolisand Pomalyst. There have been responses – including a CR! – even at very low doses in this single-agent dosing study. With few adverse side effects, MTD has not been found, nor has a recommended phase II dose (RP2D). We are eager to hear more about this drug as it progresses through the next phases of clinical trials.

A report on a study of the first monoclonal antibody conjugate drug (a monoclonal antibody and a cytotoxic agent rolled into one) used to treat myeloma patients was another ASH highlight. Dr. Kevin Kelly (University of Texas Health Science Center, San Antonio, Texas) presented the phase IIA study of BT062 (not well known as indatuximab ravtansine) in combination with Rev/dex for relapsed refractory myeloma patients (758). Fifty percent of the 12 patients on treatment were Revlimid-refractory, but Dr. Kelly reported responses across all dose levels in the 9 patients evaluable for response, including 1 PR, 1 VGPR, 5 PRs, and 2 patients with stable disease. Thus all 9 patients demonstrated CBR.

Oral proteasome inhibitor MLN9708

The oral proteasome inhibitor farthest along in clinical trials is MLN9708 (or, by its generic name, ixazomib). Three myeloma notables, Dr. Paul Richardson (535), Dr. Shaji Kumar (1944), and Dr. Jatin Shah (1983) all had presentations relating to trials with this new agent. Dr. Richardson's phase I/II study was with the all-oral frontline combination of twice-weekly MLN9708, Revlimid, and dexamethasone for newly diagnosed, transplant-eligible patients. Seventy-five percent of the patients reached sCR, and there was a high rate of MRD negativity by flow cytometric testing. However, Dr. Richardson feels that the high rate of adverse events with twice-weekly MLN9708 in this regimen suggests that once-weekly dosing will be tested in other trials, and that the twice-weekly regimen should only be used in selected patients.

Dr. Kumar presented the results of a phase II single-agent trial of weekly MLN9708 in patients with relapsed myeloma who were not refractory to Velcade. If patients didn't respond after 2 cycles to single-agent MLN9708, dexamethasone was added. Twenty of the 32 patients evaluated needed to have the added dex. Half of the patients had at least minimal response, and all patients are still receiving therapy after one year. MLN9708 is now in trials with Cytoxan and dexamethasone, and is also in phase III trials with Rev/dex in both the newly diagnosed and relapsed/refractory settings. We will undoubtedly hear much more about this new oral agent in the coming year.

KSP inhibitor ARRY-520

Among the many new drugs to fight myeloma with novel mechanisms of action, ARRY-520 (filanesib), is a rising star in the treatment firmament for myeloma. Dr. Jonathan Kaufman, on behalf of Dr. Sagar Lonial (Emory Clinic in Atlanta, Georgia), was one of several researchers who presented data from trials with this KSP (kinesin spindle protein) inhibitor. In a phase II trial with ARRY-520 given as a single agent every other week to patients with relapsed/refractory disease, patients were defined as "triple refractory,"

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meaning that they were unresponsive to IMiDs® (immunomodulatory drugs), proteasome inhibitors, and dexamethasone. Dr. Kaufman's presentation highlighted the discovery that patients with high levels of AAG (alpha-1 acid glycoprotein, which binds many drugs and some hormones in the serum) do not respond to ARRY-520. Patients who had low levels of AAG, however, responded to ARRY-520 independent of prior exposure to all types of myeloma therapy. The discovery of a serum marker that identifies non-responders raised questions about using AAG to best define who should and should not get filanesib, and also about potential ways to lower the AAG level as pretreatment for the drug.

Reports on early-phase trials of ARRY-520 in combination with other agents included Dr. Ajay Chari's (Emory Clinic, Atlanta, Georgia) poster on a phase I trial of ARRY-520 with Velcade and dexamethasone in relapsed/refractory disease (1938); and Dr. Jatin Shah's presentation of the results of another phase I study testing the combination of ARRY-520 and Kyprolis (1982).

HDAC inhibitors

There were many studies looking at the efficacy and safety of new histone deacetylase (HDAC) inhibitors ACY-1215, panobinostat, and quisinostat. ACY-1215, known by its generic name rocilinostat, is a selective HDAC 6 inhibitor, and seems to have fewer side effects than its predecessors, pan-HDAC inhibitors vorinostat and panobinostat. Dr. Noopur Raje (Massachusetts General Hospital, Boston, Massachusetts) presented the interim results of a phase II study of ACY-1215 and Velcade (759). Dr. Raje pointed out that HDAC 6 inhibition is not only able to overcome Velcade resistance, but is also active in killing myeloma cells. There were no grade 3 or 4 toxicities with the combination, and no maximum tolerated dose (MTD) has been reached. The interim results are encouraging, and dose expansion will continue. ACY-1215 is also in a phase I trial in combination with Revlimid and dex in patients with relapsed and refractory disease. The results of that study were reported by Dr. Andrew Yee (Massachusetts General Hospital, Boston, Massachusetts) (3190). In that early trial, dosing cohorts are still being accrued, and there are currently 16 patients on study, 100% of whom have at least stable disease or better.

Dr. Richardson presented his phase II data on the combination of panobinostat and Velcade in relapsed/refractory myeloma. The ORR was 35%, with durable responses. We await the results of the randomized phase III study of panobinostat/Velcade/dex vs. Velcade/dex.

An oral HDAC inhibitor is being studied in early trials in France. Dr. Philippe Moreau (University Hospital, Nantes, France) presented his data on the phase I dose escalation study of quisinostat in combination with Velcade and dex. The MTD has been established, side effects were manageable, and the ORR was 88%.

Selective inhibitor of nuclear export (SINE)

Oral KPT330, or selinexor, belongs to an interesting new class of drugs that cause tumor suppressor proteins to remain in the nuclei of myeloma cells and thus lead to both cell death and heightened sensitivity to other cytotoxic drugs. Dr. Shaun Rosebeck (University of Chicago, Chicago, Illinois) presented a laboratory study of the effects of KPT330 alone and in combination with Velcade on myeloma cell lines (279). Dr. Christine Chen (Princess Margaret Hospital, Toronto, Canada) presented data on a phase I study of selinexor in patients with advanced relapsed/refractory myeloma or Waldenström's macroglobulinemia (1942). Dose escalation is continuing, but prolonged responses have already been seen in myeloma patients on the study.

Stem cell transplant

Two studies of note in this category are those of Dr. Suzanne Lentzsch (Columbia University Hospital, New York, New York) (3180) and Prof. Antonio Palumbo, MD (University of Torino, Italy) (763). Dr. Lentzsch's study of Rev/dex alone vs. Rev/dex with autologous stem cell transplant (ASCT) was designed to help answer the question, "Is autotransplant still necessary in the age of novel therapies?" Her data in a randomized trial of newly diagnosed patients demonstrate that these two options are equivalent. With three years of follow-up, the ORR, PFS, and OS of the two arms of the study show the same results. It will be important to watch the survival data mature in the coming years, when we will be better able to determine whether ASCT is an unnecessary remnant of the past or a vital option for myeloma patients.

Maintenance therapy

Without doubt, the liveliest debate in the oral sessions occurred after Dr. Michel Attal (Purpan Hospital, Toulouse, France) presented his follow-up analysis of the IFM 2005-02 trial of maintenance therapy with Revlimid after stem cell transplant (406). His demonstration of the overlapping survival curves of patients with and without Revlimid maintenance therapy, and his insistence that the risks of second primary malignancies (SPMs) following Revlimid maintenance outweigh the benefits of doubled PFS, sent a flock of angry doctors to the microphone, including Drs. Phil McCarthy (of the Cancer and Leukemia Group B or "CALGB" study), Sundar Jagannath, Evangelos Terpos, Shaji Kumar, Meletios Dimopoulos, Gareth Morgan, and Paul Richardson, among others. These experts pointed out that Dr. Attal's study is an outlier among all the maintenance trials.

As if to quell the debate, the next speaker, Dr. Preet Paul Singh (Mayo Clinic, Rochester, Minnesota) presented his meta-analysis of four maintenance trials (407), including the one that Dr. Attal had just presented. Although he does not yet have all the data from the fourth study, Dr. Singh stated that there is a trend toward OS benefit with maintenance therapy. He remarked that the four studies are heterogeneous, that high-risk status of patients was not uniformly reported, that there is no data on quality of life, and that there is no data on the patients who received Revlimid as therapy when they relapsed after transplant.

Dr. Francesca Gay (University of Torino, Italy) presented a randomized trial in which patients all received induction therapy with Rev/dex, then were randomized to receive either ASCT or MPR (melphalan, prednisone, and Revlimid). Each arm was then randomized to Revlimid maintenance therapy or observation. OS was similar for MPR and ASCT; Revlimid maintenance therapy significantly improved PFS and OS in both arms of the trial. **MT**

2014 IMF RESEARCH GRANTS

Susie Novis and Dr. Robert Kyle

The International Myeloma Foundation (IMF) presented its 2014 Research Grant awards at a ceremony held during the 55th annual meeting of the American Society of Hematology (ASH) in December 2013. Fittingly, the awards followed a reception at which patients described what it is like to live with myeloma. Following the moving patient presentations, Susie Novis, IMF President, introduced Dr. Robert Kyle, who presented the awards.

For nearly 20 years, the IMF has funded promising clinical investigators in the field of multiple myeloma (MM) from around the world through donations from private individuals and IMF Member Fundraisers. Senior Research Grants are $80,000. Junior Research Grants are $50,000.

2014 Brian D. Novis Senior Research Grants

Three 2014 Brian D. Novis Senior Research Grants were awarded. The winners are:

A Brian D. Novis Senior Research Grant for 2014 was awarded to **Fotis Asimakopoulos, PhD** (University of Wisconsin, Department of Medicine, Hematology and Oncology, Madison, Wisconsin). Dr. Asimakopoulos's study is entitled "TPL kinase regulates macrophage-tumor cell interactions in the myeloma niche: biological and clinical implications."

Roman Hájek, MD (University of Ostrava, Department of Internal Medicine, Ostrava, Czech Republic) also received a 2014 Senior Research Grant. Dr. Hajek's study is entitled "Dynamics of microRNA and cell free DNA profiles during multiple myeloma progression."

The third recipient of a Senior Research grant is **Manoj Pandey, PhD** (Pennsylvania State University, College of Medicine, Hershey, Pennsylvania). Dr. Pandey's study is entitled "Gambogic acid: a potential therapeutic agent for multiple myeloma and associated bone loss."

2014 Brian D. Novis Junior Research Grants

Six 2014 Brian D. Novis Junior Research Grants were awarded. The winners are:

Elke De Bruyne, PhD (Vrije Universiteit Brussel, Hematology and Immunology, Jette, Belgium) received a grant for her work entitled "Study of the epigenetic regulation of multiple myeloma cells within the bone marrow microenvironment." This grant was supported by IMF fundraising event "Coach Rob's Benefit Bash and Golf Tournament."

Sham Mailankody, MD (National Cancer Institute, National Institutes of Health, Bethesda, Maryland) received a grant for his study entitled "High throughput sequencing of multiple myeloma and its precursor state, smoldering myeloma." Dr. Mailankody's grant was supported by the IMF fundraising event "Miles for Myeloma 5K," which was sponsored by the Philadelphia Multiple Myeloma Networking Group, the Central New Jersey Support Group, and the Northern New Jersey Support Group.

A research grant was awarded to **Laura Oliva, PhD** (Fondazione Centro San Raffaele, Milano, Italy) for her study entitled "Exploiting the stress of amyloidogenic light chain production as a therapeutic target." Dr. Oliva's grant was supported by the IMF fundraising event "Music Against Myeloma."

Bruno Paiva, PhD (Fundación para la Investigación Médica Aplicada Clínica, Pamplona, Navarra, Spain) was awarded a grant for his study entitled "Phenotypic and molecular characterization of circulating tumor cells and minimal residual disease myeloma cells: understanding disease dissemination and chemoresistance." Dr. Paiva's grant was supported by IMF member fundraising event "Miracles for Myeloma 5K" in honor of Sheree Pask and Frank Guarino.

A research grant was awarded to **Jinsheng Weng, PhD, MD** (MD Anderson Cancer Center, Houston, Texas) for his study entitled "Development of human tumor antigen specific T cells against multiple myeloma." Dr. Weng's study was supported by the "J.C. Golf Tournament" IMF member fundraiser.

Brian White, PhD, Washington University in St. Louis, St. Louis, Missouri, was awarded a grant for his study entitled "Mechanisms of clonal progression in multiple myeloma." Dr. White's project was supported by IMF member fundraiser "The Carolyn Czerkies Charity Golf Outing."

2014 IMF-Japan Awards

In addition to the 2014 Brian D. Novis Research Grants, awards were presented by IMF-Japan to investigators working in the field of multiple myeloma.

Aki Horinouchi Research Grant

This annual grant was instituted in 2002 by IMF-Japan in memory of its founder, Aki Horinouchi. This year, it was awarded to **Dr. Masahiro Hiasa** (University of Tokushima Graduate School, Tokushima, Japan) for his study entitled "Development of novel anti-myeloma agents with anabolic actions."

IMF-Japan Special Research Grants

Yoichi Imai, MD, PhD (Tokyo Women's Medical University, Tokyo, Japan) was awarded a Special Research Grant for his study entitled "Elucidation of calcineurin as a novel oncogene in multiple myeloma and development of calcineurin-targeted therapy for multiple myeloma." Ajay Nooka, MD (Emory University School of Medicine, Atlanta, Georgia) was also awarded a Special Research Grant. **MT**

NLB NINTH ANNUAL MEETING

By Diane Moran
Senior Vice President, Strategic Planning

The International Myeloma Foundation's Nurse Leadership Board (NLB), comprised of nurses from leading myeloma centers, convened in New Jersey in October 2013 for the NLB's ninth annual meeting. The meeting was co-chaired by Beth Faiman, PhDc, MSN, APRN-BC, AOCN, Cleveland Clinic Taussig Cancer Institute, Multiple Myeloma Program, and Sandra E. Kurtin, RN, MS, AOCN, ANP-C, Arizona Cancer Center.

The Nurse Leadership Board's mission is to improve the nursing care and self-care of patients with myeloma. The 2013 meeting highlighted the incredible work our members had done to achieve our mission.

The co-chairs of our meeting were each recently published in the prestigious peer-reviewed *Journal of the Advanced Practitioner in Oncology*. Sandra E. Kurtin co-authored a review on the use of novel agents – proteasome inhibitors and immunomodulatory agents – in the treatment of myeloma. Beth Faiman published an article on health policy implications for the under-insured and uninsured that discussed myeloma patients.

Sandra Kurtin

Beth Faiman

We were proud to promote three of our former associate members to full NLB membership based on their proven commitment to NLB activities. The newly promoted full NLB members are Sandra E. Kurtin (Arizona Cancer Center), Beth Finley-Oliver (Moffitt Cancer Center), and Kim Noonan (Dana-Farber Cancer Institute). In addition to these promotions, we welcomed four accomplished guest attendees who will be candidates for associate membership.

We also recognized the work our members have done to directly educate myeloma patients and healthcare providers during the past year. Our members have led education sessions at the IMF 2013 Support Group Leaders Summit, Patient & Family Seminars, and Myeloma Center/Regional Community Workshops throughout the country. Members contributed to IMF publications, including *Understanding Clinical Trials*, *Understanding Adherence*, and *Myeloma Today*. Additionally, NLB nurses speak on monthly teleconferences with support group leaders and have led *Living Well with Myeloma* teleconferences, open to the entire myeloma community. The NLB nurses are very dedicated to make the time to educate and support patients through IMF programs, in addition to their fulltime nursing and research schedules!

Importantly, the ninth annual meeting of the NLB provided the nurses with the opportunity to chart their course for the coming year. NLB members are currently working on three major efforts: a research project on health maintenance practices, development of an electronic survivorship care plan tool, and a continuum of care project. Each NLB nurse serves on one of these three project teams. When a project is completed, the team begins work on a new issue – our members' work for myeloma patients never stops. Members from each project team also serve on one of our three task forces, which are: publications, patient education, and nurse education. This ensures that we get important updates about each project to all of our key audiences.

During the annual meeting, we discussed upcoming publications, including a special supplement that has since been published in the December 2013 issue of the *Clinical Journal of Oncology Nursing*, called *Hematopoietic Stem Cell Transplantation: A Clinical Guide to Care of the Multiple Myeloma Patient*. Additionally, in the coming months, NLB members Beth Faiman and Tiffany Richards will publish an article on the use of innovative agents in myeloma treatment in the *Journal of the Advanced Practitioner in Oncology*.

Beth Faiman summed up her impressions of the meeting: "Each year I come to the Nurse Leadership Board annual meetings, I am inspired and energized by my nurse colleagues who are so very passionate about helping myeloma patients. They dedicate so much effort and personal time to work on our NLB projects. It's so invigorating to collaborate with these dedicated nurse leaders who are there because they want to be! This meeting was a huge success, and I look forward to accomplishing the next projects we undertake."

The meeting gave us a lot to look forward to, and our nurse leaders left feeling inspired and ready to tackle their next projects.

Thank you to Beth and Sandra for organizing such a successful meeting! **MT**

IMF INSPIRES PATIENT ADVOCATES IN SOUTH KOREA

By Arin Assero
IMF Vice President, Global Advocacy

During the last week of October, I had the pleasure of being a guest speaker at the annual multiple myeloma seminar in Seoul, South Korea hosted by the Korean Blood Cancer Association (KBCA) and the Korean Multiple Myeloma Working Party (KMMWP), a division of the Korean Society of Hematology (KSH). This was the second time that the International Myeloma Foundation (IMF) had the honor of participating in this meeting to address myeloma patients in Korea, and the opportunity to meet with the team of dedicated physicians and members of the KBCA staff.

More than 250 patients and family members listened to presentations by the KMMWP on transplant, clinical trials, frontline therapy, and relapse. Fortunately, they were also excited to learn about advocacy, which is where I came in. While it has no direct translation in the Korean language, I explained that the word advocacy applies to many activities that meet the dictionary definition of "the act or process of supporting a cause." This can mean educating others about the disease, raising myeloma awareness in the community, or telling your story as a patient to the media or policymakers to illustrate the need for continued innovation in blood cancer research and access to treatment for patients in Korea.

IMF Vice President, Global Advocacy, Arin Assero (center) with the KBCA executive team & staff.

The message seemed to resonate with the audience as many patients approached me after the meeting to thank me for my participation and compassion for patients in Korea. I also learned that there is a lot of online advocacy activity already happening through a myeloma patient group affiliated with KBCA, the Korean Federation of Multiple Myeloma Patients (KFMMP). I had the opportunity to meet with them and learn more about their organization and discuss ways in which we may collaborate to improve the circumstances for patients in Korea. My hope is that there will be much more to report on that effort in the near future.

Arin Assero with Nurse Ko, Hope Medical Information Center

(left to right) Ms. Jung Suk Park, Director, KBCA, Arin Assero, Dr. Sung Soo Yoon (Chairman, KMMWP), Mr. Tae Pyong Chang (Chairman, KBCA), Ms. Jung Hee Lee (Assistant Manager, KBCA), Mr. Ivan Lee (KBCA Volunteer/interpretor), Dr. Chang Ki Min (Seoul Saint Mary's Hospital), Dr. Hyeon Seok Eom (National Cancer Center), Mr. Chul Hwan Lee (Executive Director, KBCA)

A brief history of the KBCA: The Korean Blood Cancer Association is a nonprofit organization that was established in December 1995 in Seoul, South Korea with the mission of supporting patients through education, consulting, support programs, and financial assistance. The association offers various programs that are

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ADVOCATES FROM 10 COUNTRIES

GLOBAL
MYELOMA
ALLIANCE

On December 6, 2013, in conjunction with the 55th annual meeting of the American Society of Hematology (ASH) in New Orleans, LA, the Global Myeloma Alliance met for its second face-to-face discussion about the critical issues facing patients internationally and the best way to move forward as a coalition to address those issues.

Represented at the meeting were organizations from 10 countries including the IMF, Myeloma Canada, Myeloma UK, AEAL of Spain,

Steve Roach and Brian Rosengarten, Myeloma Foundation Australia

Eric Low, Myeloma UK

Alfonso Aguarón, AEAL, Spain

Steve Roach, Australia and Varda Shoham, AMEN, Israel

SOUTH KOREA — continued from previous page

similar to ours at the IMF and they are run by a compassionate group of patients and social workers. KBCA also started the Hope Medical Information Center, which is run by nurses and social workers, and offers support programs to patients and their families. It is the only center of its kind in Seoul where patients can come to learn, meet other patients, get emotional support, and participate in programs including patient mentoring, medical information sessions, yoga therapy, mind healing, and nutritional/cooking classes, to name a few. I was very impressed with the number of classes and programs offered and how they aim to treat the whole patient, physically, mentally, emotionally, and spiritually.

While we may come from very different parts of the world, it was quite clear that the passion and dedication that we have for the myeloma community is the same from one side of the world to the other, and we will all continue to work tirelessly to support patients and their families battling myeloma.

I'd like to sincerely thank the staff at KBCA, Hope Center, and the members of the KMMWP for their hospitality, their compassion for patients and for the amazing opportunity to be a part of their outstanding work! **MT**

CONVENE IN NEW ORLEANS

KBCA of Korea, Myeloma Foundation of Australia, Slovakia Myeloma Patient Society, AIL of Italy, AMEN of Israel, the MAX Foundation, and the San Francisco Bay Area Myeloma Support Group,

Through our collaborations and sharing best practices amongst patient groups, the alliance will be able to effectively and efficiently create programmatic solutions for the most critical issues facing myeloma patients on a global scale. **MT**

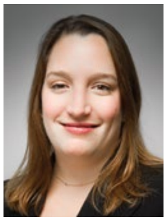

Francine Gendron & Aldo Del Col, Myeloma Canada


Mei Ching Ong and Erin Schwartz, The MAX Foundation


Steve Roach, Myeloma Australia and Nadia Elkebir, IMF Director of Europe/Middle East


Arin Assero and Meghan Buzby of IMF with Francine Gendron and Aldo Del Col, Myeloma Canada

SPOTLIGHT ON US ADVOCACY



IMF, PEAC win bipartisan support for new Senate legislation

By Johanna Gray
Federal Government Affairs Consultant

The International Myeloma Foundation and its advocates were hard at work in Washington, DC in 2013. They partnered with Congressman Brian Higgins (D-NY) to reintroduce the Cancer Drug Coverage Parity Act in May. The bill would create parity in how private insurers cover intravenous and oral anticancer treatments, which will greatly reduce patients' out-of-pocket costs for oral drugs. As of mid-January 2014, we have 67 bipartisan cosponsors for the bill.

Additionally, we are thrilled to announce that Senators Al Franken (D-MN) and Mark Kirk (R-IL) introduced companion legislation in the Senate in December 2013. The Senate bill is S.1879, the Cancer Treatment Parity Act. Now that bills have been introduced in both chambers, we plan to increase our advocacy efforts to build awareness of the issue and support for the bills among Congressional offices. To learn more about the bills and take action to encourage your Congressional representatives to co-sponsor the bills, please visit peac.myeloma.org.

IMF leads efforts to help patients access affordable treatments

By Zina Cary
National State Affairs Consultant

Despite early predictions to the contrary, the 2013 state legislative cycle was successful for multiple myeloma patients in states across the country. Massachusetts, Utah, Oklahoma, Nevada, Florida, Rhode Island and California passed laws that require insurers to charge patients taking oral anticancer treatments the same out-of-pocket amount as those receiving intravenous or injected anticancer treatments. As of December 2013, the total number of states to pass Oral Anticancer Treatment Access legislation is 27, plus the District of Columbia.

The IMF has championed this issue at the state and federal level for many years. In the summer of 2012, the IMF launched the State Patients Equal Access Coalition (SPEAC), which not only brought together and organized the efforts of national partner groups around the oral anticancer treatment access issue, but also ensured that the cancer patient's voice was front and center in New Jersey, Illinois, and Nevada, as they implemented health care reform.

Going into the 2014 state legislative cycle, which starts in January, the IMF will continue its work with SPEAC and will also lead campaigns in South Carolina and Kentucky to pass oral anticancer treatment access bills. **MT**

For more information, visit the websites.

PEAC
PATIENTS EQUAL ACCESS COALITION
peac.myeloma.org

SPEAC
STATE PATIENTS EQUAL ACCESS COALITION
speac.myeloma.org

ROME PATIENT & FAMILY SEMINAR: AIL PACIENTE MIELOMA AND IMF

By Susie Novis
IMF President

The 2013 Rome Seminar was held on September 28th in a new medical center. Over 300 people were in attendance for this annual meeting. We were very honored to once again be able to collaborate with AIL (Associazione Italiana contro le Leucemie-linfomi e mieloma) on this important meeting. Myeloma experts from across Italy participated as faculty in this seminar, including Prof. Giuseppi Avvisati (Roma), Mario Boccadoro (Torino), Maria Teresa Petrucci (Roma), Patrizia Tosi (Rimini), Luca Baldini (Milano), Alessandro Corso (Pavia), and Sara Bringhen (Torino), and Brian Durie (Los Angeles). We were so fortunate to have such an esteemed panel of experts presenting the most up-to-date information about the advances in the treatment for myeloma.

I was fortunate to be able to open the seminar with a presentation on how to cope with hearing the diagnosis, and move from being terrified to being an empowered and informed patient. I want to thank Mike Katz for letting me use many of the slides from his presentation on this important topic. And a very special thank you to Adolpho Marafini for providing the translation to my presentation!

Dr. Durie was the first presenter and he spoke about how myeloma is diagnosed – the various testing that can determine how active the myeloma is and what effect it may be having on the bones, and ultimately to determine what stage the patient is in. He noted how effective and helpful a PET scan can be in diagnosing myeloma activity. PET/CT and MRI are used in the diagnosis and treatment of myeloma and to assess how active the myeloma is after therapy. These tests lead to determining what stage the patient is in, and if treatment is needed at that time or if it is better to watch and wait.

Dr. Brian Durie, who was a presenter at AIL's annual myeloma seminar in Rome, chatted with two nuns in attendance.

He noted that the most important thing to remember is that every patient is different and each patient will respond differently. There is no "one size fits all" when it comes to deciding what the appropriate treatment should be. He showed how myeloma differs genetically between patients as well as evolves within an individual patient over time. As always, Dr. Durie noted how important it is to have hope and move forward in a positive way, to have confidence in the treatment.

There were many questions from the attendees and all of a sudden we were on "Italian time"! All good though and the panel was kept quite busy answering many important questions on a wide range of topics. One interesting comment from a patient was that he developed a plasmacytoma on his hip, in the exact spot where he kept his cell phone in his pocket. A truly alarming story was from a man who was part of a military team that assisted in atomic experiments. He is one of the 400 men working on this program who were diagnosed with myeloma. Of those 400 men, he is the only survivor.

Next, Dr. Sara Bringhen from Torino presented treatment for elderly patients. Melphalan and prednisone plus thalidomide (MPT) is still used in a subset of patients. Another therapy used for this subset of patients is standard VMP and they are also using Velcade® sub Q. Revlimid® (lenalidomide) is another option and she discussed with the attendees the various side effects that each of the therapies can cause and how best to manage them to allow the maximum benefit from the treatment.

Myeloma experts received many questions from the audience at the Rome meeting.

Dr. Francesca Patriarca from the University of Udine presented what a typical therapy would be for a young patient. One of the options may be to use VTD followed by cyclophosphamide + G-CSF and then move onto an auto transplant followed by thalidomide maintenance. She asked the question "Is ASCT always needed?" It seems that for Dr. Patriarca, the answer is yes, and in her view this treatment strategy has become the gold standard of treatment for the younger patients. They have a better quality of life and a recent survey showed that there is no plateau at this time. Having access to new drugs and using them before and after ASCT have definitely increased overall survival.

In young patients, VTD is currently being used as initial therapy before the patient has either one or two ASCT followed by consolidation maintenance.

After a very active lunch break, (and bless the Italians, the wonderful buffet included wine) we returned to the meeting to hear Dr. Luca Baldini, from Milano, present information on new therapies. He began by showing how drugs make their way from the lab into clinical trials and then hopefully on to approval, and noted how sometimes this process can take up to 18+ years. He then showed the history of the IMiDs® starting with thalidomide to lenalidomide and then pomalidomide – how one drug opens the door for the next generation in the same class. He showed the same for the proteasome inhibitors starting with the backbone of this class, Velcade and Velcade sub Q. He then showed a whole new class of drugs that included elotuzumab, a monoclonal antibody (MAb) and noted that it can take 10 years for a new drug to be incorporated into mainstream treatment.

The next talk was by Dr. Alessandro Corso from Pavia, whose talk was on clinical trials. He showed the progress we've made in the treatment for myeloma especially since 1999 with the approval of thalidomde, and then the next blockbuster drug Velcade. He gave a very nice overview of what a clinical study is, the classification of clinical studies, the experimental studies and observational studies, and how review of these studies may be

CONTINUES ON PAGE 16

UPDATES FROM AROUND THE GLOBE

Debut of Asia Pacific Multiple Myeloma Expert Roundtable

by Dan Navid
IMF Vice President, Global Affairs

On October 27, 2013, the International Myeloma Foundation (IMF) joined forces with Janssen's Academy for Cancer Education in Shanghai to host the first ever Asia Pacific expert session on myeloma. Key opinion leaders from Australia, China, Taiwan, Japan, Korea, Singapore, Thailand, Vietnam, and the US discussed new myeloma developments in Asia. The session also served to jump-start interactions among hematologists in the region.

Participants of the Asia Pacific Multiple Myeloma Expert Roundtable meeting

Speakers, including IMF International Myeloma Working Group (IMWG) members Dr. Wen Ming Chen, Dr. Wee-Joo Chng, Dr. James Chim, Dr. Jian Hou, Dr. Jonathan Kaufman, and Dr. Shaji Kumar, addressed the "Era of Novel Agents" and the management of adverse effects from novel agent treatment. Other topics included depth-of-response issues for myeloma treatment, risk-adaptation in myeloma management and patient care.

In Shanghai, the IMF also convened ad hoc sessions of the Asian Myeloma Network (AMN) in preparation for the launch of an AMN Clinical Trials Group at the December 2013 annual meeting of the American Society of Hematology (ASH), and a meeting of the IMF Chinese Myeloma Working Group to plan 2014 training activities.

Report from Norway and Denmark

by Nadia Elkebir
Director Europe/Middle East
Medical Education & Patient Liaison

The International Myeloma Foundation, in conjunction with local myeloma associations in Norway and Denmark, hosted patient meetings in each country in late October 2013. Each meeting welcomed over 200 attendees! I was impressed with the attendance and the informative programs offered at each meeting. Norway's annual meeting, held in Oslo, welcomed physicians, patients, and family members. The IMF has worked closely with the Norwegian myeloma patient association, Blodkreft Foreningen, for quite some time.

We are very pleased to be forging even stronger bonds with this organization, as Tone Hansen, president of Blodkreft Foreningen, is joining the IMF's Global Myeloma Alliance (GMA). The IMF founded GMA in June 2013 to strengthen the voice of the myeloma community internationally, bringing groups together to improve the quality of life for patients around the world through advocacy, support for new drug approvals, and expanded access to treatment.

Nadia Elkebir welcome attendees

In addition to talks from Blodkreft Foreningen representatives and me, the Norwegian meeting featured medical presentations from myeloma specialists Drs. Nina Gulbrandsen, Fredrik Schjesvold, and Ann Kristin Kvam. The audience listened attentively, and engaged the physicians in a lively Q&A following their presentations.

Just a few days after the meeting in Norway, I attended a Danish Patient & Family Seminar in Middelfart, Denmark. The IMF hosted this meeting in conjunction with Danish patient association, Dansk Myelomatose Forening, which is run by two myeloma patients, Ole Dalriis and Bibi Roe.

The 210 patients and family members in attendance heard presentations from several Danish myeloma specialists.

Additionally, both the Danish and Norwegian meetings featured presentations from renowned physician and researcher Dr. Ola Landgren, head of the Multiple Myeloma Section at the National Cancer Institute in the U.S. Dr. Landgren is one of the myeloma specialists working closely with IMF Chairman Dr. Brian Durie on the IMF's Black Swan Research Initiative to find a cure for myeloma.

Tone Hansen, president of Norway's Blodkreft Foreningen

Both the Danish and Norwegian meetings included opportunities for patients to learn from informative medical presentations and to connect with and support each other. We are looking forward to working closely with the local myeloma associations to plan next year's meetings! **MT**

A full house in Oslo, Norway

A DAY IN ROME — continued from page 14

retrospective and prospective. The development of a new drug includes:

- Discovery of a compound
- Preclinical phase
- Clinical research – phase I/II/III/IV

He then outlined what the purpose is of each phase of a clinical trial. Clinical research must follow good clinical practice, and the respect of good clinical practice needs the controls of authoritative societies like the FDA and EMEA.

- Phase I – dose-finding – maximal dose with less toxicity
- Phase II – needs – Ethical Committee, promoter, researcher, regulatory agencies AIFA, EMEA, NICE

To give you an idea of how hard it is to bring a new drug to market, out of 5,000 drugs only five will make it to market and into mainstream treatment. We also need patients to participate in these trials; without patient participation, no new drugs would ever become possible. The advantages to being in a clinical trial are many. Participating in a clinical trial allows patients to get tomorrow's drugs today!

The final speaker of the day was Dr. Patrizia Tosi, who previously worked in Bologna but has relocated and is now working in Rimini. Her topic was on supportive care. She gave a very nice and helpful overview on what patients can do to overcome the side effects often associated with novel therapies such as bortezomib, thalidomide, and lenalidomide. She outlined each drug and the common side effects patients experience, and how best to deal with them.

The novel therapies have given patients the ability to experience long-term remissions. The management of side effects has become extremely important to enable patients to get the maximum benefit and stay on therapy. Bone disease remains a problem for myeloma patients and using bisphosphonates along with radiotherapy and orthopedic intervention can be quite helpful. She noted that kyphoplasty can be used to alleviate the pain and disability from a compressed vertebra. Bisphosphonates continue to be a very important therapy for bone disease and having regular dental checkups to make sure there are no signs of osteonecrosis of the jaw is extremely important.

Another debilitating side effect can be anemia, and she noted that erythropoietin (EPO) can be helpful in overcoming this.

Pain control is another extremely important part of supportive care. She noted that the following drugs that can be very helpful in alleviating pain: tramadol, morphine patch, peridural catheter, etc.

After a very full day filled with lots of wonderful information, the remainder of the meeting was an open question-and-answer session. No one hesitated to jump up, grab the mic and ask their question!

The day ended with a collective feeling that even though we were tired from such an active day, we all learned a lot not only from the experts but from each other! We left feeling empowered and with the commitment to stay in touch. A huge thank you to the outstanding faculty for their time and expertise, and to Maria Rita Grattarola and her wonderful team at AIL. Ciao, and see you next year! **MT**

Newly diagnosed? You are not alone.

The IMF is here to help you. Myeloma can very often be treated successfully, and many patients live long and productive lives after being diagnosed. We encourage you to learn as much as possible and to seek the best care. We are here to help you do that, while we work toward better treatments and a cure.

Improving Lives • Finding the Cure®

IMF Hotline

800-452-CURE (2873) *in the US and Canada*

818-487-7455 *worldwide*

email: **hotline@myeloma.org** *web:* **myeloma.org**

IMF'S WEBSITES HELP SUPPORT GROUPS REACH PATIENTS

by Robin Tuohy
Senior Director, Support Groups

The International Myeloma Foundation's network of support groups has grown to include more than 140 groups in the US. In 2013, a record 23 new local support groups were established! Whether a support group is just launching or has been around for a while, the IMF's dedicated Support Group Team is committed to nurturing them all with a wide variety of resources, guidance and the communication tools to help them succeed in the 21st century.

Support groups can access a rich trove of educational content on the IMF website (myeloma.org), such as teleconference replays; archived webcasts from the most newsworthy hematology and cancer meetings; the latest options in treatment therapies and side effect management; and "Ask Dr. Durie" videos, in which IMF Chairman Dr. Brian Durie answers patients' questions.

Miko Santos

But in addition to the IMF website, local groups also find it extremely useful to supplement the IMF site with their own website in order to allow them to post local information. That's where the IMF steps in, offering unequaled website creation and hosting. IMF Web Producer Miko Santos works with local support group leaders to build customized websites to keep myeloma patients informed when and where a group meets, when special events and speakers are scheduled, and even how they might participate in private message boards for confidential patient-to-patient conversations. To date, the IMF has built or adapted 48 websites. Here's a snapshot of two of them:

San Diego, California

The IMF hosts a website for the **San Diego Multiple Myeloma Support Group**. Miko worked with this group to adapt a site that had been previously built. Although group co-leader Debbie Dyer is a software engineer, she says she really appreciates Miko's help on the website. "It's extremely helpful to work with Miko, who knows the technology of the site already." Working with Miko leaves Debbie and her fellow co-leaders Tom Tucker and Eric Wolf free to focus on their other important work for the group.

These three, who took the helm of the 180-member group in 2013, say they are also grateful to Kelly Cox, Director, Support Groups & Regional Community Workshops at the IMF, for his guidance. When a former leader had to step back, says Debbie, "Kelly recognized that we needed support. He stepped up to the plate, coming to every meeting and helping to identify our new co-leaders – he really helped keep us going and we're now re-invigorated."

The San Diego support group co-leaders are currently creating a manual for potential future leaders, something they were encouraged to do at the IMF's 2013 Support Group Leaders Summit. With continuing support from the IMF, this large support group is well positioned to keep helping patients far into the future.

Visit the San Diego Multiple Myeloma Support Group website: **sandiego.myeloma.org**

Bismarck, North Dakota

One of the newest support group websites was created by the IMF for the **North Dakota Multiple Myeloma Support Group**, founded by Shirley Jonas this year. Shirley marveled at how smoothly the creation went: "I told Miko the features that I thought would be most beneficial for our group and I couldn't believe it when he had the website up within a day of our conversation!"

Shirley believes the website will help patients newly diagnosed with myeloma. "I remember searching for a local website when I was diagnosed, and there wasn't anything. I'm glad that now, when newly diagnosed myeloma patients in my area search for 'myeloma,' they'll be able to find a local resource for support right away."

Since there was no local myeloma group when Shirley was diagnosed, she and her husband Rod traveled all the way to Florida to attend the IMF's Boca Raton Patient & Family Seminar. With the help of Sue Enright, Midwest Regional Director of Support Groups at the IMF, the North Dakota Myeloma Support Group is up and running.

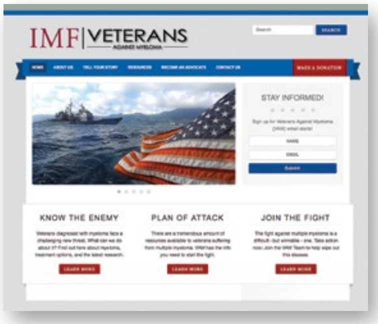
"I am so grateful that the IMF was there to get our group going," says Shirley Jonas. "They keep supporting me, allowing me to provide a place for all North Dakota patients to connect and learn."

Sue describes Shirley as a "powerhouse leader." She should know – she founded her own local support group after her husband was diagnosed with myeloma. Sue recalls attending her first support group meeting: "I realized the value of having a place where patients and caregivers can meet, learn, and support one another."

Visit the North Dakota Multiple Myeloma Support Group website: **northdakota.myeloma.org** MT

IMF launches new veterans website

The IMF has long been a resource for information about myeloma for veterans like Jerry Walton (pictured), a 33-year Navy veteran who founded the Southeastern Virginia Multiple Myeloma Support Group. Now that effort kicks up a notch with the launch of the IMF's new **Veterans Against Myeloma (VAM)** website. The site provides links to relevant Veterans Administration information, such as state veterans assistance offices and national veterans service organizations. Email alerts will notify VAM readers about breaking news and articles of interest. If you're a veteran and find this resource useful, please pass it on to others you know who may be going through a similar experience. Visit the site at **veterans.myeloma.org**



INTERNATIONAL MYELOMA FOUNDATION

7th Annual Comedy Celebration

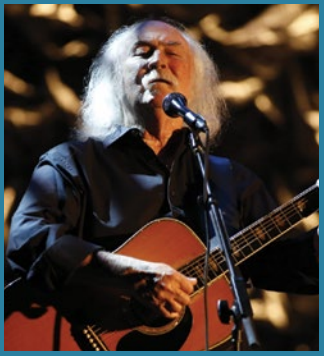
benefiting the Peter Boyle Research Fund and supporting the Black Swan Research Initiative®

A Night of Stars, Laughter, and Compassion

Laughter rocked the house Saturday night at the International Myeloma Foundation's 7th Annual Comedy Celebration benefiting the Peter Boyle Research Fund and supporting the Black Swan Research Initiative®. Nearly 1,100 guests gathered at Los Angeles's Wilshire Ebell Theatre to honor the late actor, who died in 2006 after a four-year battle with myeloma.

The Annual Comedy Celebration began in 2007, when event Chair Loraine Boyle, IMF Board member and wife of the late actor Peter Boyle, reached out to IMF co-founders Susie Novis and Dr. Brian Durie with a profound desire to make a difference in the lives of people coping with multiple myeloma. Loraine established the Peter Boyle Research Fund, calling upon her and Peter's friends to join her in raising awareness and money to find a cure. They answered her call without hesitation, and have been donating their time and talents to our cause ever since.

Ray Romano, the evening's host, set the comic tone for Saturday night's show with observations about growing old. "I will be your friend if you're a doctor," he said. "I'm at a party and they introduce me to an orthopedic doctor, oh forget it. I'm going to invite him camping right there." He was joined onstage by his *Everybody Loves Raymond* co-star, Patricia Heaton, Monica Horan, another *Raymond* alum, and the show's creator, Phil Rosenthal, who reminisced about working with Peter Boyle. CBS president Les Moonves suggested casting the film star – someone Rosenthal said he never imagined would consider acting in a television comedy.



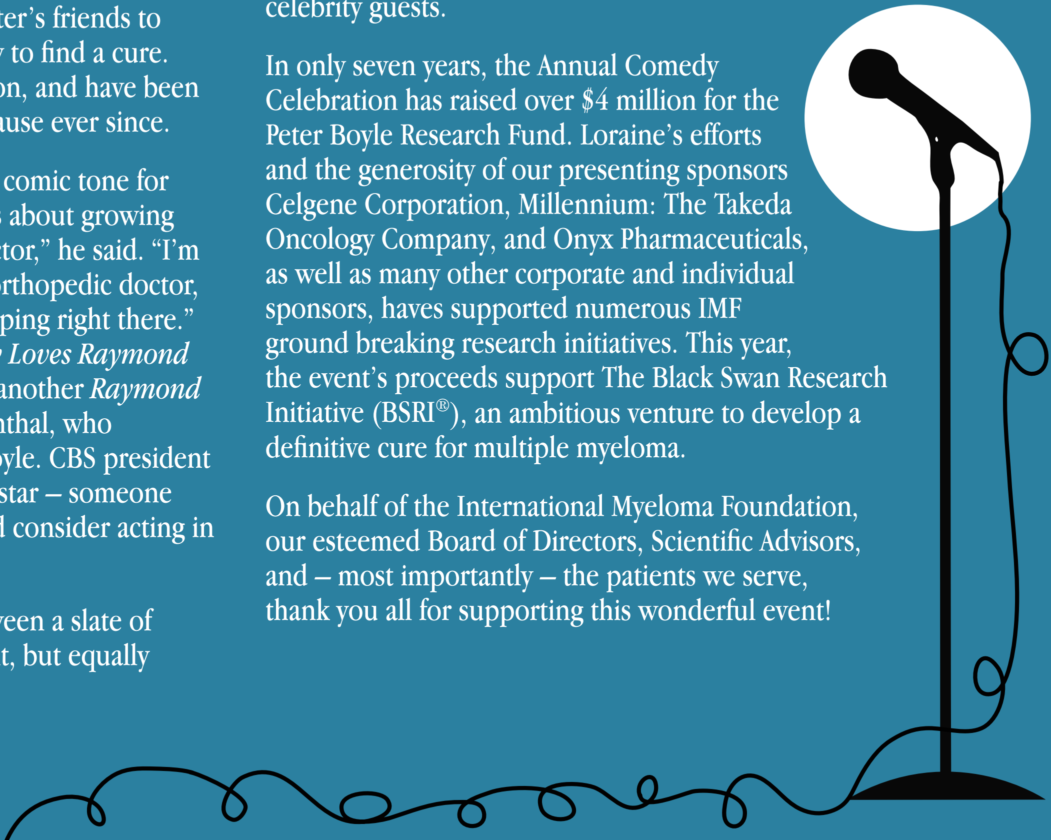
Romano offered non-stop patter in between a slate of comedians offering distinctively different, but equally hilarious, brands of comedy. Deon Cole, Jackie Hoffman, Andy Kindler, Larry Miller, Bruce Vilanch, and Justin Willman had guests laughing for two hours straight. Rock icon David Crosby closed the show with a spine-tingling performance that filled the auditorium with acoustical bliss.

The event – complete with red carpet and paparazzi – also featured a dazzling silent auction with more than 100 items including a guitar autographed by Pete Townsend of The Who, fantastic travel packages, an assortment of Hollywood and sports memorabilia, and gift baskets from high-end boutiques and restaurants.

After the show, the main dining room of the 1920's style Ebell Club was transformed into a lounge-chic after-party for VIP guests, who sipped champagne and sampled desserts while chatting and schmoozing with friends, colleagues, and members of the cast and other celebrity guests.

In only seven years, the Annual Comedy Celebration has raised over $4 million for the Peter Boyle Research Fund. Loraine's efforts and the generosity of our presenting sponsors Celgene Corporation, Millennium: The Takeda Oncology Company, and Onyx Pharmaceuticals, as well as many other corporate and individual sponsors, haves supported numerous IMF ground breaking research initiatives. This year, the event's proceeds support The Black Swan Research Initiative (BSRI®), an ambitious venture to develop a definitive cure for multiple myeloma.

On behalf of the International Myeloma Foundation, our esteemed Board of Directors, Scientific Advisors, and – most importantly – the patients we serve, thank you all for supporting this wonderful event!

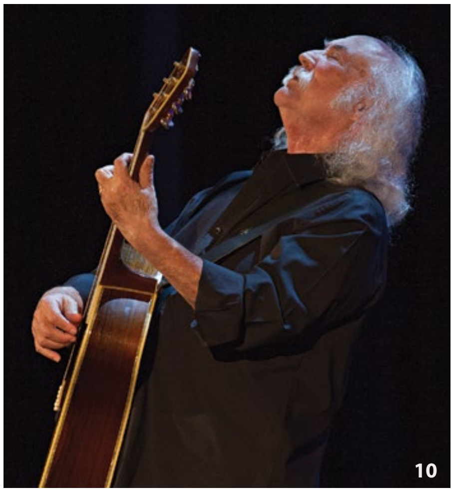


7th Annual Comedy Celebration

THE SHOW!

More than 1,000 guests attended the sold-out comedy and music show. Many thanks to all the talented performers who gave our guests a night of laughter and fond memories!

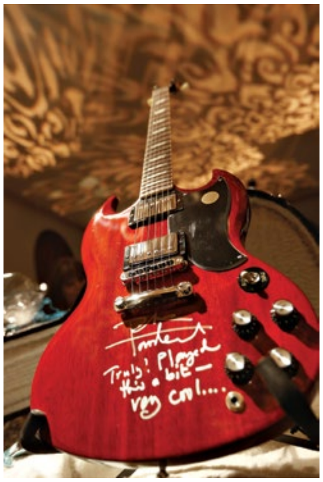
(1) The sold-out theater just before the show begins; (2) Bruce Vilanch; (3) Comedic Magician Justin Willman on stage with IMF Chairman Dr. Brian G.M. Durie; (4) Our host, Ray Romano; (5) Deon Cole; (6) Andy Kindler; (7) Jackie Hoffman; (8) Executive Producer Phil and Monica Rosenthal share memories of Peter Boyle with Ray Romano and Patricia Heaton; (9) Larry Miller; (10) David Crosby



7th Annual Comedy Celebration

Auction and Party

The event welcomed more than 1,000 guests, including celebrities and entertainment industry executives, myeloma patients, caregivers, doctors, and representatives from our pharmaceutical partners. The 7th Annual Comedy Celebration raised nearly $550,000, bringing the total raised for the Peter Boyle Research Fund to more than $4 million.



Above – Photos from the cocktail party, silent auction, and post-show champagne reception

Below (L-R) – John Crowley & Deborah Doss with Carol & Benson Klein; Igor & Cindy Sill; Mike & Susie Katz with Joelle Frank & Larry Klurfeld

7th Annual Comedy Celebration


1

Red Carpet

The event's red carpet was buzzing with excitement as our celebrity guests came out in support of the Peter Boyle Research Fund. In addition to the evening's comedic cast members, we welcomed many familiar faces from *Everybody Loves Raymond*, as well as some new friends to the IMF.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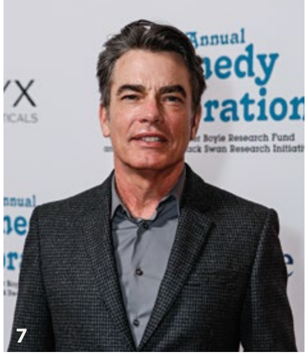
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(1) David Crosby with event chair Loraine Boyle, Susie Novis, and Dr. Brian Durie; (2) Ray Romano; (3) Alex Meneses; (4) Phil and Monica Rosenthal with their daughter Lilly; (5) Deon Cole; (6) Larry Miller; (7) Peter Gallagher; (8) Loraine Boyle with Bruce Vilanch; (9) Jackie Hoffman; (10) Andy Kindler; (11) Renee Auberjonois; (12) Maggie Wheeler; (13) Kimberly Alexander; (14) Justin Willman with Susie Novis and Dr. Brian Durie; (15) Howard Hesseman


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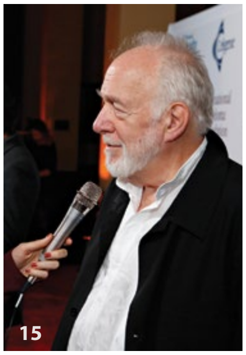
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The team from Presenting Sponsor **Celgene**

The team from Presenting Sponsor ***Millennium: The Takeda Oncology Company***

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, Millennium: The Takeda Oncology Company, and Onyx Pharmaceuticals. Please see next page for a full list of event sponsors. Their participation made the event the huge success that it is and we thank them all.

The team from Presenting Sponsor ***Onyx Pharmaceuticals***

The team from Ruby Sponsor ***Novartis***

Ray Romano with the team from Topaz Sponsor ***Sanofi***

7th Annual Comedy Celebration

Event Sponsors

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Susie Novis &
Dr. Brian G.M. Durie

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Member Events

IMFers RAISE FUNDS TO SUPPORT RESEARCH

By Suzanne Battaglia

International Myeloma Foundation (IMF) members are raising funds to support essential multiple myeloma research while also raising awareness. Fundraisers are taking place all across the country! Most of these activities start with a call to the IMF and one simple question – "What can I do?" Those who become involved find their efforts to be not only fulfilling but also incredibly empowering. The IMF's FUNdraising program is fun and easy, and brings with it the satisfaction of knowing that YOU are making a difference in many lives.

The two articles that follow demonstrate the flexibility you have in choosing an event that will be both fun and valuable in fundraising and raising public awareness in your community. If you have resources for a large community outreach effort and lots of help, you can plan a marathon, walk, golf tournament, or carnival. To plan a smaller-scale event, consider putting a twist on something you normally might do, such as a bake sale, garage sale, holiday party or, like one member, a dance-a-thon with friends at your local gym.

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 web and social media outlets. Please contact me at sbattaglia@myeloma.org or 800-452-CURE (2873) to chat about any ideas you might have.

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…

First Annual 5K Draws a Crowd Ready for Miracles

More than 500 participants showed up to raise awareness of myeloma in Clark, New Jersey at the first annual Miracles for Myeloma 5K on October 5th.

Event organizers Sheree Pask, her husband Ron Pask, and Gina Klemm had estimated a turnout of only 150 for the event. But this year's 5K, which also raised money for the International Myeloma Foundation, was so much more successful than they'd anticipated that they are already planning a second annual "Miracles" event in 2014.

Miracles for Myeloma committee, including organizers Sheree Pask, Ron Pask, and Gina Klemm

Sheree Pask and Gina Klemm with photo of Frank Guarino

Sheree Pask was diagnosed with myeloma in 2007, and, sadly, Gina lost her brother Frank Guarino to myeloma in December 2012, just 18 months after he was diagnosed. The two met at the preschool that Gina's children had attended and where Sheree Pask still teaches.

"My brother was an avid runner since high school," Gina said, explaining her choice of tribute. "He was so proud of his accomplishments as a runner. He even discussed wanting to complete a 5K to raise money to find a cure for multiple myeloma."

Sheree had also wanted to plan a fundraiser, specifically a race, to benefit the IMF. In a collaboration that seemed "meant to be," the event organizers came together to bring Frank's dream and Sheree's vision to fruition.

Pask family

According to the organizers, the IMF was crucial in supporting their efforts. Ron Pask, who worked closely with the IMF, cited Suzanne Battaglia and the IMF team as "an important support network. Suzanne helped us find grants, sponsorships and get a website set up. She was always available on the other end of the phone or answering emails immediately."

To raise myeloma awareness, the event organizers recruited myeloma medical professionals to speak before the 5K. "This wasn't just a race," Sheree Pask explained. "It was an opportunity to educate people and help them understand the positive advances we've been seeing in the myeloma world."

Throughout the day, support from the community for Gina's family, the Pasks and all of the local patients was evident. "I can't describe the warmth that I feel when I look at the picture of my entire extended family together at our 5K event," said Gina. "It is overwhelming."

Ann McNeill, IMF Nurse Leadership Board member and nurse practitioner at Hackensack University Medical Center, educated participants before the 5K. Dr. Mecide Gharibo, myeloma specialist at Rutgers Cancer Institute of New Jersey, also spoke.

Gina Klemm and her family

Sheree Pask recounted how "one newly diagnosed woman came and formed a huge team with her friends. I could see how important it was to have this big gathering of her friends around her. It was amazing to look around and see all these groups of people supporting each other – how wonderful to know that this event was the reason all of these people gathered."

Miracles for Myeloma also included a Remembrance Path with white balloons in memory of those lost to myeloma and maroon balloons in honor of myeloma patients. The Remembrance Path echoed the sentiment of the event – a tribute to Frank and others lost to myeloma, and a place to come together to support family and friends suffering from myeloma.

Ron, Sheree and Gina expect the planned-for second annual Miracles for Myeloma to top this year's event in size and impact. Sheree foresees an annual gathering that not only brings the local community together but will also "benefit others beyond our community, as well.

Sheree Pask and Suzanne Battaglia

"When you get that exhilarating, wonderful feeling seeing everyone come together, it makes you realize you did it right."

Dancing Queens Honor Friends

The women who attend aerobics classes and the instructors who guide them at the Busy Body Fitness Center in Boca Raton, Florida are more than just fitness devotees: they're like a family. Their friendship extends outside of class to birthday parties, baby showers, wedding celebrations – even a trip to see "Mamma Mia" on a party bus!

Dance-a-thon instructors, including Meryl Coughlin, second from left, and participants in action

Dance-a-thon instructors and event attendees

After the group lost two of its members – Patti Tyrie and Angela Chadwick – to myeloma over the course of a year, Busy Body instructor Meryl Coughlin and class member Chrissie Ciletti decided to honor their friends at the place they loved and thrived, with a Dance-a-Thon fundraiser at the gym that was their home-away-from-home.

Gym members, family, and friends attended the October 5th event, which was conceived to heighten myeloma awareness and raise funds for the International Myeloma Foundation. Highlights of the day included dances to songs that Patti and Angela loved, such as "Mamma Mia," and the drawing of raffle prizes by 15-month-old Grace Patricia, a granddaughter that Patti never got to meet.

Coughlin credits support from the IMF and advice from IMF Director of Member Events Suzanne Battaglia with helping make the fundraising portion of the event a success. "I thank her and all her 'elves' for their efforts, even during vacation hours."

Coughlin and her fellow organizers now have some advice of their own for event planners: look at activities they already love doing when thinking about planning their own fundraisers. **MT**

Calendar of Upcoming Events

January 27, 2014

Gayla's Celebration – Traverse City, MI
Contact: Gayla Elsner at gelsner9@gmail.com

April 26, 2014

Miles for Myeloma 5K – Philadelphia, PA
Contact: http://philadelphia.myeloma.org/miles-for-myeloma/

May 17, 2014

JC Golf Tournament – St. Cloud, MN
Contact: boloz@charter.net

June 7, 2014

Carolyn Czerkies Memorial Golf Outing – Naperville, IL
Contact: czak16@aol.com

September 27, 2014

Miracles for Myeloma 5K – Clark, New Jersey
Contact: miracles4mm@comcast.net

October 19, 20, 2014

Coach Rob's Benefit Bash & Golf Tournament – Apopka, FL
Contact: rbradford@crothall.com

November 1, 2014

Texas Hold 'em Benefit Poker Bash – San Jose, CA
Contact: Jack Aiello – jackaiello@comcast.net

Staff Updates

NEW IMF TEAM MEMBERS

Sharon Chow

Development Assistant

Sharon Chow recently graduated from the University of California, Davis with a B.S. in Environmental Toxicology. While studying at UC Davis, she interned at Rite Aid pharmacy and at the Pediatric Emergency Room and Operating Room at UCD Medical Center in Sacramento. In addition to medical internships, she was the Public Relations Officer for the Nursing Club at UC Davis and a member of Alpha Phi Omega, a community service fraternity. After graduating, she worked in advertising in San Francisco before moving to the Los Angeles area.

Sharon is the newest addition to the IMF family. As the development assistant for the IMF Development Team, she helps with administrative support and participates in all fundraising activities, including donor relations, direct mail, and special events. Sharon is excited to start her professional path with IMF. Sharon can be reached at schow@myeloma.org.

Annabel Reardon

Meeting Coordinator

Annabel Reardon has extensive experience in event planning and departmental management. She honed her skills while working for the award-winning Seven Stars Bakery in Providence, Rhode Island, where she created and managed both the Catering and Farmers Market departments. Prior to that, she taught English and managed the Foreign Teacher program at the Swaton School of English in Uijeongbu, South Korea.

No stranger to the IMF, Annabel has previously worked on planning various IMF events and meetings, coordinating all logistical details. Currently, she plans and manages national and international meetings the IMF holds and attends, and manages the auction for the IMF's Annual Comedy Celebration. Annabel says she returned to the IMF because she has always valued working for a non-profit.

She holds a degree in International Hospitality Management from Northern Arizona University and studied International Management at the London Metro University. Annabel can reached at areardon@myeloma.org

News & Notes

ONCE AGAIN IMF SCORES HIGHEST RATING FROM CHARITY NAVIGATOR

IMF has been awarded Charity Navigator's highest rating for the ninth year. The rating, according to Charity Navigator CEO Ken Berger, indicates that the IMF operates in an ethical and fiscally responsible manner.

A 4-star rating is the highest rating a charity can receive from the organization and earning it places the IMF in the "Exceptional" category, meaning the IMF "exceeds industry standards and outperforms most charities in its cause."

"This is a reflection of the amazing professionalism of our talented team, which works so hard to ensure excellence in all of the IMF's programs," said IMF President Susie Novis.

Charity Navigator works to promote "a more efficient and responsive philanthropic marketplace, in which givers and the charities they support work in tandem to overcome our nation's and the world's most persistent challenges."

Shop for the Cure

Shop with the leading merchants on the Internet, receive the same price as anyone else visiting their sites, and support the IMF at the same time! Visit the merchants using the links at shop.myeloma.org and, if you make a purchase, a percentage goes to support the IMF. Please remember that the IMF receives a donation only if you use the links on the shop.myeloma.org page, so please bookmark this page to ensure that when you are shopping your purchases are properly credited. E-commerce vendors include **Amazon, Macy's, Walmart, iTunes, 1-800-Flowers, Hotwire, The Sharper Image, Omaha Steaks, Dollar** and **Thrifty Car Rental**, and many others. Keep checking back as we regularly add new stores to our mall. Thanks for your support!

Free Teleconference to Kick Off Myeloma Awareness Month!

Living Well with Myeloma Teleconference Series

"Chemo Brain – Is It Real?"

Thursday, March 13, 2014 at 4:00 PM PT / 7:00 PM ET

Speaker:

Pamela Joyce Shapiro, PhD

Assistant Professor, Department of Psychology

Temple University

Duration: 60 minutes (including Q&A)

Slides will be available on the IMF website

Pre-register today. It's FREE. Go to **chemobrain.myeloma.org**


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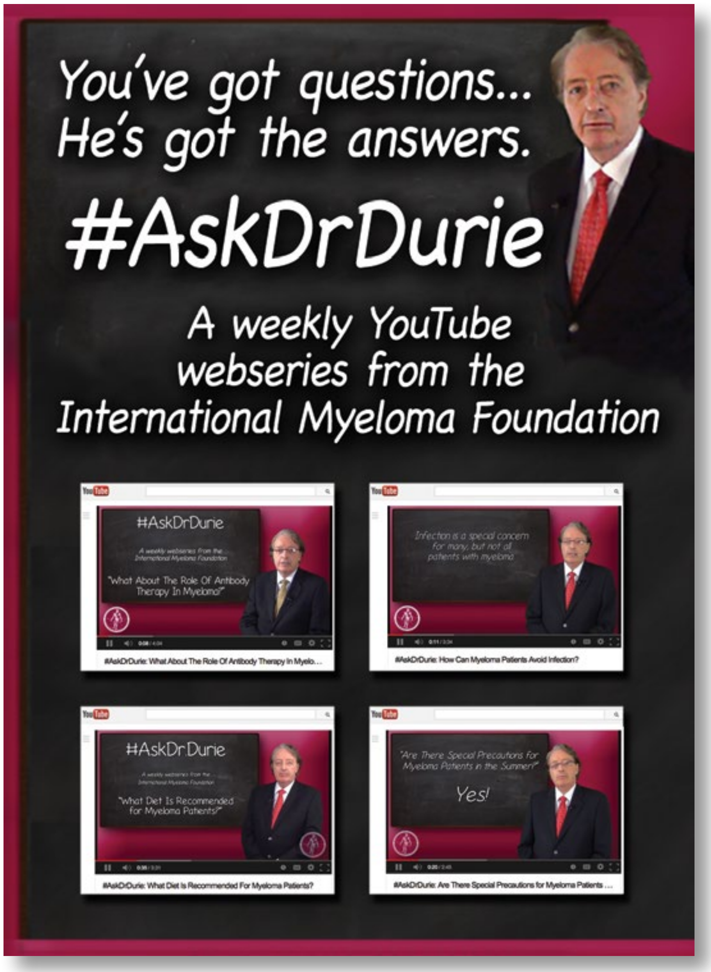
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He's got the answers.

#AskDrDurie

A weekly YouTube
webseries from the
International Myeloma Foundation

#AskDrDurie
A weekly webseries from the International Myeloma Foundation
"What About The Role Of Antibody Therapy In Myeloma?"
#AskDrDurie: What About The Role Of Antibody Therapy In Myelo…

Infection is a special concern for many, but not all patients with myeloma
#AskDrDurie: How Can Myeloma Patients Avoid Infection?

#AskDrDurie
A weekly webseries from the International Myeloma Foundation
"What Diet Is Recommended for Myeloma Patients?"
#AskDrDurie: What Diet Is Recommended For Myeloma Patients?

"Are There Special Precautions for Myeloma Patients in the Summer?"
Yes!
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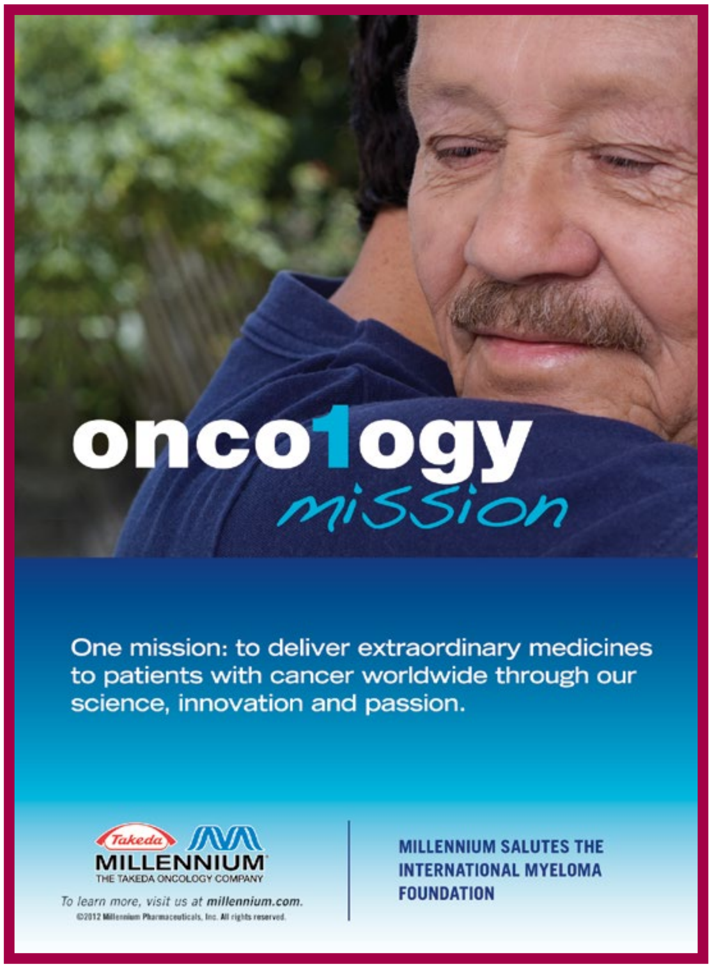
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2014 IMF Calendar of Events

Feb 1	IMF Myeloma Center Workshop (MCW) – Denver, CO
Feb 28-Mar 1	IMF Patient & Family Seminar (PFS) – Boca Raton, FL
March 8	IMF Regional Community Workshop (RCW) – Portland, OR
March 13	Living Well with Myeloma Teleconference Series – *"Chemo Brain – Is It Real?"**
April 26	IMF Regional Community Workshop (RCW) – Norfolk, VA
May 16-17	IMF Patient & Family Seminar (PFS) – Atlanta, GA
June 9-11	2014 International Myeloma Working Group (IMWG) Summit – Milan, ITALY
June 10	Robert A. Kyle Lifetime Achievement Award Presentation– Milan, ITALY
June 14	IMF Myeloma Center Workshop (MCW) – Minneapolis, MN
July 25-27	IMF Support Group Leader Summit – Dallas,TX
Aug 22-23	IMF Patient & Family Seminar (PFS) – Los Angeles, CA
Oct 10-11	IMF Patient & Family Seminar (PFS) – Short Hills, NJ
Dec 5-8	56th Annual Meeting & Exposition of the American Society of Hematology (ASH) – San Francisco, CA
Dec 5	IMF Satellite Symposium at ASH – San Francisco, CA

The IMF is proud to work with our global partners. We thank them for supporting our international meetings.
For more information about upcoming events, please visit **calendar.myeloma.org** *or call* **800-452-CURE** *(2873).*
For information on activities in Australia, Canada, Israel, Japan, or Latin America, please visit:
Australia **www.myeloma.org.au** • *Canada* **myelomacanada.ca** • *Israel* **amen.org.il** • *Japan* **myeloma.gr.jp** • *Latin America* **mielomabrasil.org**

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* Pre-register for this FREE teleconference on the IMF website: myeloma.org. This 60-minute, Living Well Series teleconference starts at 4 p.m. Pacific/7:00 p.m. Eastern.