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Myeloma Today

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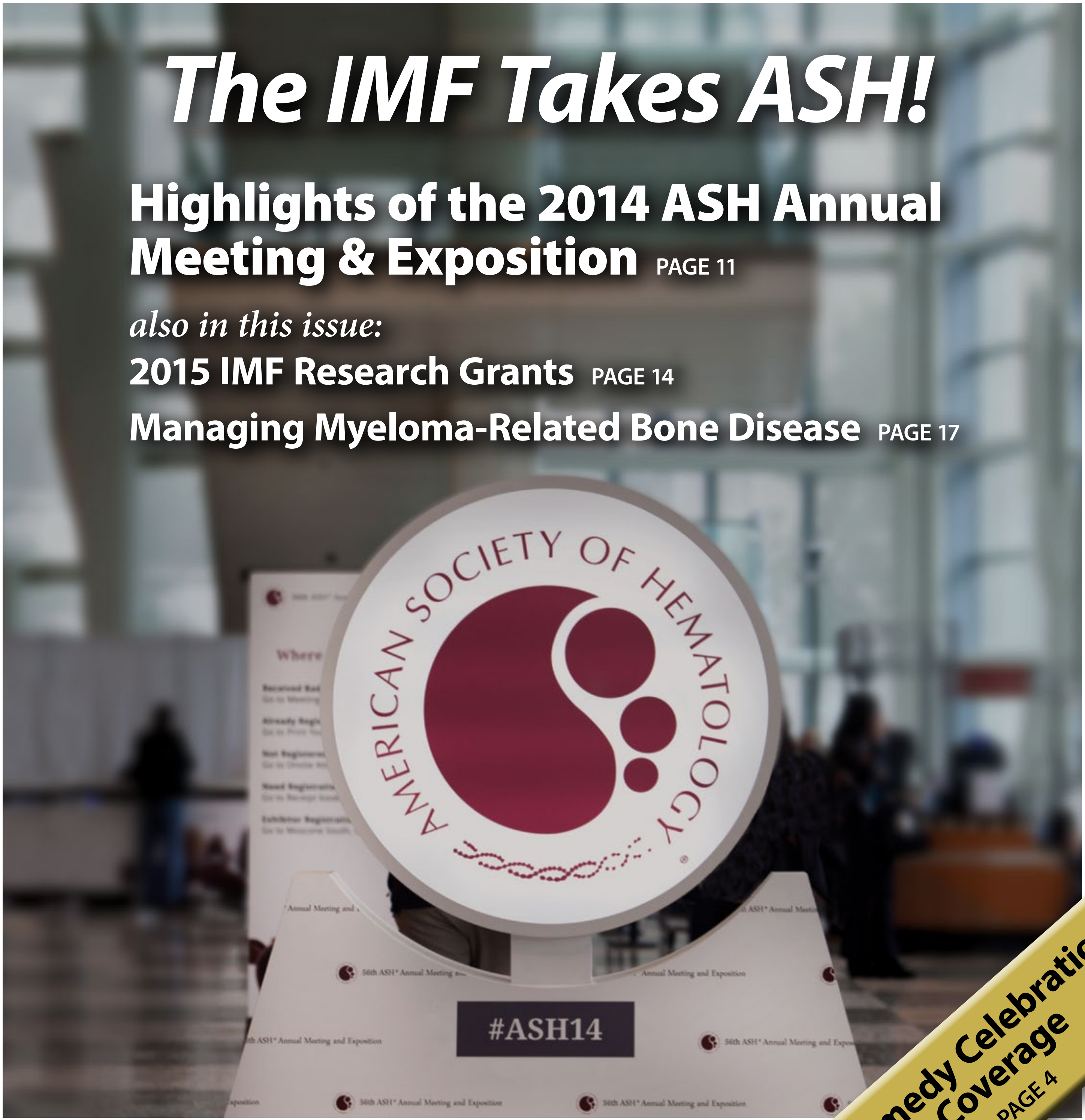

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A Message from the President

Dear Reader,

In 2015, the IMF celebrates its 25th anniversary. Quite a milestone! We founded the IMF with just three people and a very good idea: to find a cure for myeloma, and empower people through education. The three people were Dr. Brian G.M. Durie, Brian Novis and me, sitting talking over a cup of coffee. Well… as they say, "We've come a long way baby!" Today the IMF is a global organization with over 350,000 members in 140 countries. This truly is reflective of us being "One Myeloma Nation."

Our four pillars remain education, research, support, and advocacy. This is a landmark year for the IMF and I'd like to share with you some of our plans for 2015 in our four areas of focus.

Research

Since 1994, the IMF has been funding the most promising research in the field of myeloma. In 2013, the IMF officially launched the Black Swan Research Initiative®, an ambitious effort to develop the first definitive cure for myeloma. Led by IMF Chairman Dr. Brian G.M. Durie, the team of international myeloma experts is moving quickly to bridge the gap from long-term remission to cure. In 2015, an innovative, ultra-sensitive myeloma test developed with IMF support will be incorporated into global clinical trials. Researchers will be able to measure with extreme precision whether elusive cancer clones remain after treatment, a key step to eradicating myeloma completely.

Since 1995 we've consistently awarded both Junior and Senior grants to support research projects in top institutions around the world, and to date the IMF has awarded 106 grants. These grants are very important for many reasons; they bring new people into the field and keep researchers working in myeloma.

Education

IMF Patient & Family Seminars and Regional Community Workshops will be held across North America, Latin America, Europe, Asia, and Australia. These educational meetings bring up-to-date information to the myeloma community regarding diagnosis, treatment, management of myeloma, and the advances we're making toward the cure. The IMF's education program includes a vast library of publications available in 20 languages, covering a range of key topics literally from A to Z. We also provide education to doctors, nurses, and other healthcare professionals.

In the US we'll hold Patient & Family Seminars in Boca Raton, FL, Redwood City (San Francisco Bay Area), CA, Los Angeles, CA, and Stamford, CT. Regional Community Workshops (half-day meetings) will be held in, Denver, CO, San Diego, CA, Dallas, TX, Seattle, WA, Charlotte, NC, Edina, MN, Chicago, IL, and Richmond, VA. Mark your calendar to attend one or more of these amazing educational meetings!

Support

The IMF "Hotline" the first service of its kind for myeloma patients, started operation 20 years ago. Today, this service is known as the IMF InfoLine. Our trained and compassionate coordinators answer nearly 5,000 calls and emails from patients and caregivers around the world. They directly address a multitude of myeloma-related questions and concerns, and also link callers to other resources for support and assistance. The IMF's support group team led by Robin Tuohy along with Kelly Cox, Ann Pacowta, Nancy Bruno, and Sue Enright works with over 140 groups across the US and one new group in Jamaica! The highlight for the team is the annual Support Group Leaders Summit which is held each year in Dallas, TX. This summit brings together the IMF Support Group Leaders from around the country. They represent the entire range of support groups, from large established groups with 100+ members to newly formed groups. This program provides an arena for Support Group Leaders to discuss successes, opportunities, and challenges they face and increase understanding of their support group leader role.

Advocacy

In 1998, the IMF took a major step forward into the advocacy arena. In that banner year, we joined other cancer organizations from across the nation and were an active participant in the "March on Washington." We urged legislators to fund cancer research, improve access to treatment, and address the environmental impact on the causes of cancer. That was a seminal moment for the IMF, and from that point on we've been leading the charge, ensuring patients have access to the treatments they need when they need them. The IMF also formed and leads the Global Myeloma Action Network, comprised of organizations from 28 countries to ensure patients have equal access to the best available treatments.

I'm asking you to join us in helping make our dream a reality. Let's make 2015 the year that some patients are able to achieve a cure, that coverage for the best cancer treatments is no longer an issue, and that patients and their families around the world are empowered and not alone. We are… One Myeloma Nation.

Warm regards,

Susie Novis

Susie Novis, President

This free issue of *Myeloma Today*© (Volume 15, Number 1) is dated January 15, 2015. *Myeloma Today*© is a quarterly (Spring, Summer, Fall, and Winter) publication of the International Myeloma Foundation, located at 12650 Riverside Drive, Suite 206, North Hollywood, CA 91607 USA

INTERNATIONAL MYELOMA FOUNDATION

8th Annual Comedy Celebration

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

featuring a one-night-only performance of **celebrity autobiography**

Big Laughs, Big Success

Laughter rocked the Wilshire Ebell Theatre in Los Angeles on Saturday, November 8, 2014. Guests and stars gathered in support of the IMF's 8th Annual Comedy Celebration benefiting the Peter Boyle Research Fund and supporting the Black Swan Research Initiative®. Host Ray Romano was joined by his *Everybody Loves Raymond* co-stars Patricia Heaton and Doris Roberts, as well as Danny DeVito, Rhea Perlman, Lesley Nicol, Howard Hesseman, Rita Wilson, and Alex Meneses, among others. The actors and comedians presented a special one-night only version of "Celebrity Autobiography," performing hilarious readings of segments of stars' autobiographies before an audience of more than 1,100. The performers had the audience in stitches and the event raised more than $600,000 for critical myeloma research – we'd call that a big success!

The event – complete with red carpet and paparazzi – also featured a dazzling auction that brought much excitement for auction winners. IMF supporters will travel in style to one of several European destinations, including the Vatican, Paris, and Austria, some with airfare included. There were more than a dozen kid-friendly packages including huge Hello Kitty Gift Baskets, some great family destinations, passes to Southern California's best theme parks, and even a teddy bear handcrafted and donated by a myeloma patient. Sports fans augmented their collections with memorabilia signed by some of baseball and basketball's greatest players. Two fabulous autographed guitars were auctioned off – one signed by all members of the Rolling Stones!

After the Celebrity Autobiography 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.

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 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.

In only eight years, the Annual Comedy Celebration has raised more than $4.5 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, have supported numerous IMF groundbreaking research initiatives. This year, the event's proceeds support the Black Swan Research Initiative, an ambitious research project 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! **MT**

THE SHOW!

More than 1,000 guests roared with laughter as our lineup of celebrity performers read excerpts from the autobiographies of famous Hollywood stars in a special performance of Celebrity Autobiography.


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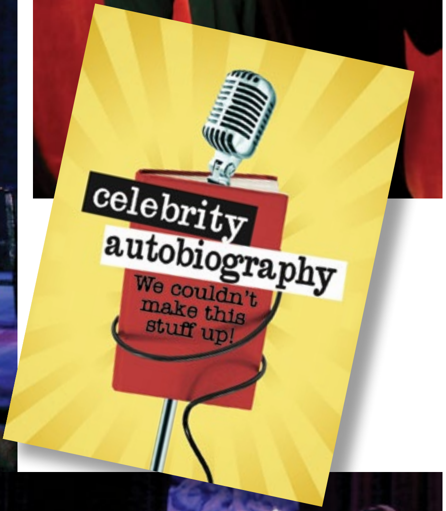


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1. Rita Wilson and Alex Meneses
2. Gene Pack
3. Ray Romano
4. Gene Pack, Dayle Reyvel, Howard Hesseman, Rhea Perlman, Laraine Newman
5. Danny DeVito and Howard Hesseman
6. Danny DeVito, Rhea Perlman, and Lucy DeVito
7. Doris Roberts
8. Lesley Nicol
9. Rita Wilson
10. Patricia Heaton


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Auction and Party

More than 400 VIP guests gathered before and after the show to peruse the evening's silent auction offerings and enjoy atmosphere with friends. The Annual Comedy Celebration has raised well over $4.5 million in funding for the Peter Boyle Research Fund supporting the IMF's groundbreaking Black Swan Research Initiative.

Top row: Guests enjoying the event's silent auction and post-show VIP reception
Middle Row, left to right: Lesley Nichol and Carol Klein, Dr. Brian Durie with Kristi Willette, John O'Dwyer
Bottom Row, left to right: Matthew Robinson with Susie Novis and Dr. Durie, Carol Klein, Loraine Boyle, Cathleen Zilner, and Laurie Kuzneski

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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1. Loraine Boyle 2. Susie Novis and Dr. Durie 3. On the red carpet 4. Rhea Perlman, Lucy DeVito, Danny Devito 5. Laraine Newman 6. Doris Roberts 7. Patricia Heaton 8. Dayle Reyfel and Eugene Pack 9. Patricia Heaton, Dr. Durie, and Lesley Nichol 10. Alex Meneses 11. Rita Wilson and Ray Romano 12. Loraine Boyle, Susie Novis, Rhea Perlman, Lucy DeVito, Danny DeVito, and Dr. Durie

Event Sponsors

The IMF's partners in the pharmaceutical industry turned out in force! We were pleased to see so many of our friends at 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 the 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.

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IMWG Issues New Guidelines for Early Diagnosis of Multiple Myeloma

by Brian G.M. Durie, MD

THE LANCET

The IMF's research division, the International Myeloma Working Group (IMWG), has issued updated criteria for the diagnosis of multiple myeloma. Published in the journal *Lancet Oncology*, the new guidelines are a result of years of study and collaboration by the IMWG's more than 180 myeloma researchers worldwide. The guidelines allow for the diagnosis of myeloma to be made in patients without symptoms and before organ damage occurs, using validated biomarkers associated with the near inevitable development of clinical symptoms.

"This step forward has many important implications," said IMF Chairman Dr. Brian G.M. Durie, "not the least of which is the expectation that earlier treatment will lead to better outcomes." This is the central idea of the IMF's signature Black Swan Research Initiative®, in which early treatment is coupled with close assessment of residual disease to determine which therapeutic approach will ultimately achieve cure.

The IMWG's updated criteria represent no less than "a paradigm shift in myeloma," said Dr. S. Vincent Rajkumar, lead author of the *Lancet Oncology* article, in a video interview about the new guidelines. "We are now willing to treat myeloma before symptoms happen." In addition to improving outcomes, the new guidelines will improve the quality of life for patients with asymptomatic smoldering multiple myeloma (SMM) who have an "ultra-high" risk of progression to full-blown disease.

"Finally, instead of enduring the frustrating hurry-up-and-wait approach, these patients will be able to receive early diagnosis and treatment," said IMF President Susie Novis. "For patients in this situation, the new IMWG guidelines offer tremendous relief. This is an endorsement of moving forward with the effective new myeloma treatments we have today." **MT**

Surprise Rejection of Panobinostat for Approval at ODAC Hearing

On November 6, the Oncologic Drugs Advisory Committee (ODAC) hearing convened in an optimistic fashion with many in the myeloma community expecting there would be a recommendation for approval of panobinostat, an HDAC inhibitor used in combination with Velcade® and dexamethasone. Publicly available data indicated a 3.9 months progression-free survival (PFS) or remission duration benefit with the three-drug panobinostat combination in patients who had been treated with 1–3 prior therapies. Note was made of significant toxicities, including low blood platelet levels (56.7%), diarrhea (25.4%), and fatigue (24.6%). However, going into the hearing, it was felt that the benefits outweighed these types of toxicities. From the myeloma patient perspective, there was the hope that panobinostat would be added to the myeloma treatment armamentarium. IMF staff and team members were at the ODAC hearing to affirm the continued unmet need for new drugs to treat myeloma.

Unfortunately, the presentation by Barry Miller (FDA Senior Clinical Analyst) dashed these hopes and expectations rather quickly. Miller pointed out that "missing data" was the main reason the FDA staff asked for the ODAC review. A large amount of data was unavailable or "censored," often because patients withdrew from the trial. The question was "Why?" Did the patients withdraw for incidental reasons (minor problems, trial logistics, etc.) or major toxicities, or even unexpected on-trial deaths?

As pointed out by Dr. James E. Liebmann (ODAC panelist from University of Massachusetts Memorial Medical Center), there was a disparity in "on-treatment deaths" in the panobinostat arm of the trial. The uncertainties about "censoring" apparently had led to four separate estimates of the PFS duration: 3.9 months (the duration reported); but also 2.2. months; 3.7 months, and 1.9 months. The FDA's own analyses gave a PFS difference of 2.2. months (9.9 months versus 7.7 months): rather disappointing compared to the 3.9 months provided by Novartis and their Independent Review Committee (IRC). IRC member Dr. Paul Richardson was unable to explain the reasons for the censoring to the satisfaction of the ODAC reviewers. Dr. Richard Pazdur (Director, FDA Office of Hematology and Oncology Products) himself raised the issue of censoring as an important concern.

FDA U.S. Food and Drug Administration
Protecting and Promoting *Your* Health

Ultimately, Dr. Richard Pazdur summarized what appeared to be the prevailing opinion of the ODAC reviewers. "PFS is not the question, there's clearly some benefit... The question is what is the magnitude of benefit and does it warrant the toxicity."

This perspective reflected the vote of 5–2 against a recommendation to the FDA to approve panobinostat. Dr. Liebmann also summarized the difficulties faced by the panel when confronted, as they were, by patient advocates,including a woman who had benefitted for five years on panobinostat. He said, "First, this is a very difficult decision... this agent does have some activity... and can be useful in this disease. But I think the toxicity outweighed the marginal benefit in PFS." He went on to say that we should not give up on the drug or class of drugs, and certainly this is the case. Although it seems very unlikely that the FDA will go against the ODAC recommendation, it may still be possible that Novartis can answer the questions that were raised.

This is certainly a wake-up call for the myeloma community. What are the expectations for new drugs moving forward? Do we need to set the bar higher and try to achieve a much greater benefit, especially in the setting of important toxicities? My sense is that all involved will be recalibrating and setting their sights on longer remissions and lesser side effects – key needs for myeloma patients everywhere. We will keep you posted as many new drugs move forward in trials and hopefully give the benefits we all want to see. **MT**

Highlights of the 2014 ASH Annual Meeting & Exposition

by Debbie Birns
IMF Medical Editor

Treatment updates

The 56th annual meeting and exposition of the American Society of Hematology (ASH) took place in San Francisco at the Moscone Center from December 6–9, 2014. More than 35,000 hematologist/oncologists from around the globe attended the meeting.

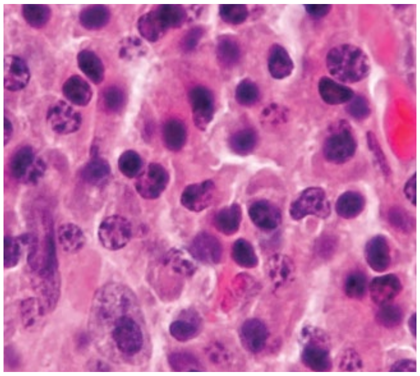
Each year's growing number of myeloma-related oral and poster presentations at ASH gives testimony to the robust research climate in myeloma. Although this year's ASH was not one that featured major breakthroughs in myeloma, the 855 myeloma-related presentations demonstrated steady progress on the research side in understanding myeloma's complex and evolving biology. On the clinical side, presentations at ASH demonstrated the ever-expanding arsenal of tools available to diagnose, treat, and monitor patients effectively. Of particular note were the presentations on a wealth of combination therapies that are moving us closer to a cure.

Combination studies with approved agents

Kyprolis (carfilzomib)

Perhaps the most highly anticipated myeloma oral presentation at this year's ASH was that of Dr. Keith Stewart (Mayo Clinic, Scottsdale, Arizona) on the ASPIRE clinical trial, an international, 792-patient, randomized, phase III study comparing Kyprolis® (carfilzomib)/Revlimid® (lenalidomide)/dexamethasone (KRD) to Revlimid/dexamethasone (RD) in patients with relapsed and refractory myeloma (abstract #79). To no one's surprise, progression-free survival (PFS) in the KRD arm was 26.3 months versus 17.6 months for those randomized to receive RD. Although overall survival (OS) was not reached in either group, there has been a trend for longer OS among patients treated with KRD. This large, international study demonstrated that the KRD regimen has an acceptable safety profile and is highly effective, suggesting that it may take its place as a potential new standard of care for relapsed/refractory myeloma.

Other notable presentations featuring Kyprolis combination therapies were those of Dr. Antonio Palumbo (University of Torino, Torino, Italy) who studied weekly Kyprolis/Cytoxan® (cyclophosphamide)/dexamethasone (KCD) (#175); Dr. Tomer Mark (Weill Cornell Medical Center, New York City, New York), who presented data on frontline Kyprolis/dex followed by stem cell harvest and consolidation with Biaxin® (clarithromycin), Revlimid, and dexamethasone (BiRd) (#4761); and Dr. Cara Rosenbaum (University of Chicago, Chicago, Illinois), who presented a poster on a phase Ib/II study of Kyprolis/Pomalyst® (pomalidomide)/dexamethasone (KPD) for patients who have already been treated with Revlimid and may be refractory to it, but who have either never been treated with a proteasome inhibitor or are still responding to it after treatment (#2109). All three studies were small, but explored new territory in the use of carfilzomib with positive results.



Velcade (bortezomib)

There were no fewer than 129 presentations at ASH that included combination therapies with Velcade® (bortezomib). Among the standouts were two 5-year follow-ups of VTD vs. TD (Velcade/thalidomide/dex vs. thalidomide/dex). The first, an oral presentation by Dr. Michele Cavo (University of Bologna, Bologna, Italy), compared

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ASH 2014 HIGHLIGHTS — continued from page 11

VTD and TD as induction therapy before, and consolidation therapy after, double autologous stem cell transplant (#196). Long-term follow-up demonstrated a significant PFS advantage at second relapse (PFS2) among patients in the VTD group. There was no statistically significant difference in OS between the two groups because most of the patients on the TD arm were treated with Velcade at relapse.

The second presentation, a poster by Dr. Laura Rosinol (University of Barcelona, Barcelona, Spain), was a long-term follow-up of a comparison of three different induction approaches (VTD, TD, or combination chemotherapy) prior to autologous stem cell transplant (#3457). Like Dr. Cavo's study, this PETHEMA/GEM study concluded that VTD induction results in longer PFS when compared to the other regimens. Like the Italian study as well, this study found no significant OS advantage for any of the three arms, and found that high-risk patients had a significantly shorter OS after relapse no matter which induction therapy they had received.

Two Velcade studies of note were designed for older, newly diagnosed, transplant-ineligible patients. The first was an oral presentation by Dr. Maria-Victoria Mateos (University of Salamanca, Spain) on alternating vs. sequential use of VMP (Velcade/melphalan/prednisone) and RD (#178). This study demonstrated equivalent results with the two treatment approaches, leaving the choice of sequential versus alternating VMP and RD for the doctor and patient to determine according to each patient's needs and preference. The second was the poster presented by Dr. Elizabeth O'Donnell (Massachusetts General Hospital, Boston, Massachusetts), a study of "RVD lite" (#3454), with 15 mg of Revlimid on days 1-21, once-weekly standard-dose subcutaneous Velcade, and once-weekly dexamethasone at 20 mg. This gentler version of RVD for older patients was well tolerated and, given patients' ability to stay on the regimen, may improve clinical benefit as well.

Revlimid (lenalidomide)

Of the many abstracts in which Revlimid was featured, the follow-up on last year's plenary session pick, the FIRST clinical trial with continuous RD versus MPT and defined-duration RD in newly diagnosed, transplant-ineligible patients, was most eagerly anticipated. Dr. Cyrille Hulan's (University Hospital Center Nancy, Vandoeuvre-les Nancy, France) oral presentation on the effect of age on efficacy and safety of RD (#81) looked at the sub-groups of patients younger and older than 75 years, and concluded that continuous RD was effective and increased PFS and interim OS regardless of age.

There were several trials with the combination of RD plus an experimental agent, such as monoclonal antibodies daratumumab, SAR650984, and elotuzumab or the HDAC inhibitor panobinostat. (Several of these will be discussed below, under the sub-heading of New Agents.)

A study that is sure to be of interest to those who are familiar with dexamethasone was presented by Dr. Evangelos Terpos (National and Kaposdistrian University of Athens, Athens, Greece) in a poster entitled "The Combination of Bortezomib and Lenalidomide (VR) Consolidation Post-ASCT, in the Absence of Dexamethasone and Bisphosphonates, Improves Response Rates and Bone Metabolism in Newly Diagnosed Patients with Multiple Myeloma" (#3462). The title says it all.

Pomalyst (pomalidomide)

Pomalyst (pomalidomide) was featured in two notable oral presentations. Dr. Rachid Baz (H. Lee Moffitt Cancer Center, Tampa, Florida) presented the results of a randomized phase II study comparing Pomalyst/cyclophosphamide/dex (PCD) to pom/dex (PD) in patients with relapsed/refractory myeloma (#303). PCD resulted in improved responses and PFS compared to PD.

The second oral presentation, which immediately followed the first, was by Dr. Martha Lacy (Mayo Clinic, Rochester, Minnesota). Dr. Lacy's study looked at the combination of Pomalyst/Velcade/dex (PVD) in Revlimid-refractory patients (#304), and concluded that over 80% of the patients who were refractory to lenalidomide responded to PVD.

Studies with experimental agents

Ixazomib

Ixazomib, an oral proteasome inhibitor also known as MLN9708, was the subject of several important presentations, including one from Dr. Shaji Kumar (Mayo Clinic, Rochester, Minnesota) on a phase II study of long-term ixazomib maintenance therapy after induction therapy with ixazomib/RD (IRD) (#82). The results indicate that maintenance with ixazomib for up to 1.5 years was generally well tolerated and improved responses following IRD. There is an ongoing phase III trial of ixazomib in the maintenance setting.

Ixazomib is also being evaluated for patients with relapsed/refractory AL amyloidosis. Dr. Giampaolo Merlini (University of Pavia, Pavia, Italy) presented a phase I study of the long-term outcome of ixazomib/dex in patients with vital organ dysfunction (#3450), concluding that

weekly ixazomib/dex was generally well tolerated, produced hematologic responses in 43% of patients (who had at least a very good partial response or VGPR), and that these patients also had organ response and improved PFS. All (100%) of patients who had not had prior therapy with a proteasome inhibitor had organ response to ixazomib, which is most welcome news.

Elotuzumab

Dr. Saad Usmani (Levine Cancer Institute, Charlotte, North Carolina) presented a poster on early data from a study of the combination of monoclonal antibody to SLAM-F7, elotuzumab, with RVD (Revlimid/Velcade/dex) for newly diagnosed patients with high-risk myeloma (#4762). While elotuzumab has been impressive in combination with RD in relapsed/refractory disease, this combined approach with four drugs to aggressively attack high-risk disease up front is a new direction in myeloma. Although efficacy data were not presented, it was encouraging to see that the regimen is safe and well tolerated, and that the study is ongoing in phase II. We will watch this maturing study with interest in the year to come.

Anti-CD38 monoclonal antibodies

Highly anticipated studies on two promising monoclonal antibodies with single-agent efficacy were presented in succession by Drs. Thomas Martin (University of California, San Francisco, California) and Torben Plesner (Vejle Hospital, Vejle, Denmark). Single-agent efficacy means that in early trials, these monoclonal antibodies produced responses in patients without the addition of dexamethasone or other drugs. Dr. Martin presented data on a dose escalation study of SAR650984 (SAR) in combination with Revlimid and dexamethasone in relapsed/refractory disease (#83). Almost all of the enrolled patients had already been exposed to Revlimid and/or pomalidomide, and 85% were refractory to an IMiD®-based therapy. Almost all had also relapsed after a prior proteasome inhibitor (PI)-based regimen. The overall response rate (ORR, response of at least 50% drop in monoclonal protein or better) for all patients was 64.5%. Even for patients who were refractory to both IMiD-based and PI-based therapies, the ORR was 52.4%. Responses were rapid and deepened with continuing therapy, and adverse events were few. More encouraging news followed when Dr. Plesner presented data on a safety and efficacy study of daratumumab (dara) in combination with RD in relapsed/refractory myeloma (#84). All patients on the trial had at least some degree of response to dara/RD, and 75% of the patients had at least a 50% drop in monoclonal protein. Moreover, the combination was well tolerated.

And others…

Other new agents in early studies with promising data in relapsed/refractory myeloma included Dr. Heinz Ludwig's (Wilhelminen Cancer Research Institute, Vienna, Austria) poster on targeted agent NOX-A12 in combination with Velcade and dexamethasone (#2111); Dr. Jacob Laubach's (Dana-Farber Cancer Research Institute, Boston, Massachusetts) poster on hypoxia-targeted TH-302 and dexamethasone (TborD), with or without Velcade (#2142); and Dr. Marc Raab's (University of Heidelberg, Heidelberg, Germany) oral presentation on a study of pan-kinase inhibitor LGH447 (#301). We will follow these agents as their data matures and they move through later-phase studies.

A new and interesting line of research in myeloma was presented by Dr. Michael (Luhu) Wang (MD Anderson Cancer Center, Houston, Texas) in his early study of a cancer vaccine, PVX-410, to treat patients with smoldering disease (#4737). There were several other ASH presentations on the treatment of smoldering multiple myeloma (SMM), including a meta-analysis of 12 clinical trials in which SMM patients with varying degrees of risk of progression to active disease were allocated to treatment (#4771, presented by Jayanthi Vijayakumar of the University at Buffalo, Buffalo, New York). Eight of the trials included OS data, and were included in the analysis. In all eight trials, patients who were treated for SMM had reduced mortality and better PFS compared to the observation group. Patients treated with anti-myeloma therapy and bisphosphonate therapy had a better OS and PFS than did the observation only group, whereas treatment with bisphosphonate therapy alone did not impact either OS or PFS.

Several studies looked at groups of patients who are at high risk, such as those who are obese and/or have Type 2 diabetes (T2D), those with high-risk cytogenetics, the elderly, and those with renal impairment, all of whom present unique challenges to the clinician. Not only does obesity/T2D predispose a person to developing myeloma (#2044), we now have studies that demonstrate that obesity increases the risk of progression of MGUS to active myeloma (#2061) and also shortens OS (#2048). This news certainly heightens the resolve to remove pounds we put on over the holidays as we begin the new year.

Finally, in news to those who have expressed an interest in the use of medical marijuana to treat pain and nausea associated with therapy, a poster presented by Dr. Maria Victoria Barbado (University of Seville, Seville, Spain) reports favorably on the preclinical use of cannabinoids as anti-myeloma agents (#4724). Not only did the treatment shrink tumors and promote survival in mice, they were probably also very relaxed. **MT**

2015 IMF Research Grants

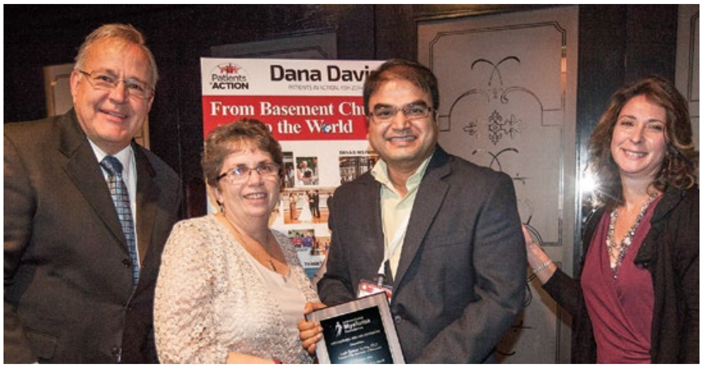
For 20 years, the International Myeloma Foundation (IMF) has funded the most promising research in the field of myeloma by investigators from around the world. The IMF presented its 2015 Research Grant awards at a ceremony held during the 56th Annual Meeting and Exposition of the American Society of Hematology (ASH) in December 2014.

The awards reception offered the researchers a rare opportunity to mingle with myeloma patients, the potential beneficiaries of these scientists' hard work. Lively conversation between members of both groups ensued. Dr. Hiroyuki Takamatsu, a grant awardee for his work on minimal residual disease (MRD) monitoring in myeloma, explained his research to myeloma patient Michael Tuohy.

"We will decipher the mechanisms of 67LR-dependent apoptosis," said Dr. Takamatsu, "and based on novel molecular mechanisms, we will suggest the ideal combination to kill multiple myeloma cells."

Michael, who was attending ASH as a member of the IMF team's support group representatives, recounted the conversation in a blog post about the evening. "Now that's what a patient loves to hear – kill those myeloma cells!" he wrote. "As a matter of fact, each night when I take my oral therapy, my wife and I say those exact words."

Senior Research Grants are funded at $80,000; Junior Research Grants are $50,000. The IMF research program is supported through donations from private individuals and IMF Member Fundraisers.



2015 IMF Brian D. Novis Senior Research Grants

Claire M. Edwards, PhD (University of Oxford, United Kingdom) was awarded a grant for her project entitled "Caloric restrictions and bone marrow adiposity in myeloma." To find new treatments, it is essential to understand how myeloma develops and progresses. Dr. Edwards and colleagues have shown that a high fat diet promotes the development of myeloma, suggesting that fat cells are important. They will investigate the role of fat cells in myeloma progression, and whether caloric restriction can reduce tumor burden and bone disease. This project will identify whether fat cells control the growth of myeloma cells and represent a new therapeutic target.

Yang Yang, MD, PhD (University of Alabama at Birmingham) was awarded a grant for a project entitled "The role of myeloma cell-derived Runx2 in myeloma metastasis: focus on bone microenvironment." Tumor bone metastatis occurs in 90% of patients with myeloma, but the mechanisms driving the spread to bone remain unclear. Recent work in Dr. Yang's laboratory suggests that Runx2 in myeloma cells can stimulate the cells to secrete soluble factors that create a receptive environment in bone for tumor cells homing to, surviving, and growing in new bone sites. The knowledge gained from this project might help predict outcome and develop new treatments.

2015 IMF Brian D. Novis Junior Research Grants

Francesca Cottini, MD (Dana-Farber Cancer Institute, Boston, Massachusetts) was awarded a grant for her project entitled "Targeting the kinase STK4 to treat myeloma." Myeloma cells are abnormal plasma cells with defective genes. Dr. Cottini and colleagues have identified a mechanism in myeloma which prevents the killing of gene-damaged myeloma cells by inhibiting the Hippo pathway. They discovered that a kinase switch turns off Hippo, thereby favoring cancer proliferation. The researchers will study and validate drugs which block this kinase, restore Hippo in myeloma, and lead to myeloma cell death. These agents therefore represent promising novel therapies.

Tarun K. Garg, PhD (University of Arkansas for Medical Science, Little Rock, Arkansas) received a grant for a project entitled "Myeloma cells modulate ICAM3 to evade natural killer cell-mediated lysis." Dr. Garg and colleagues are treating myeloma patients with specialized immune cells that have been activated and grown in large numbers (ENK). They are studying myeloma cell lines which are not killed by ENK. One molecule, ICAM3, is less abundant in one of the resistant cell lines. The researchers will study if ICAM3 is also decreased on the other three resistant lines and in patients' myeloma cells in order to determine which patients benefit most from this therapy.

Patricia Maiso, PhD (Clinical University of Navarra, Spain) received a grant for a project entitled “Role of hypoxia in myeloma: new therapeutic approaches targeting minimal residual disease and drug resistance.” Most myeloma patients relapse despite achieving complete response after conventional treatment. Identifying the specific mechanisms that maintain the survival of myeloma tumor cells and cause relapse is essential to developing new therapeutic interventions. Dr. Maiso and colleagues believe that one of the principal causes of tumor cell maintenance is the hypoxic environment within the bone marrow, which helps keep a low percentage of tumor cells that are able to restart the disease.

Amit Kumar Mitra, PhD (University of Minnesota at Minneapolis) received a grant for a project entitled “Identifying tumor response heterogenity using single-cell transcriptomics.” Recent studies have demonstrated the presence of subpopulations of proteasome inhibitor (PI)-resistant myeloma cells within heterogeneous primary tumor cell populations. The goal of this project is to use a gene-based model to identify residual PI-resistant tumor subclones within bulk tumors from newly diagnosed myeloma patients using single-cell targeted high-throughput gene expression analysis. This research will continue toward the development of novel treatment strategies specifically targeted at drug-resistant tumor subclones early in myeloma therapy.

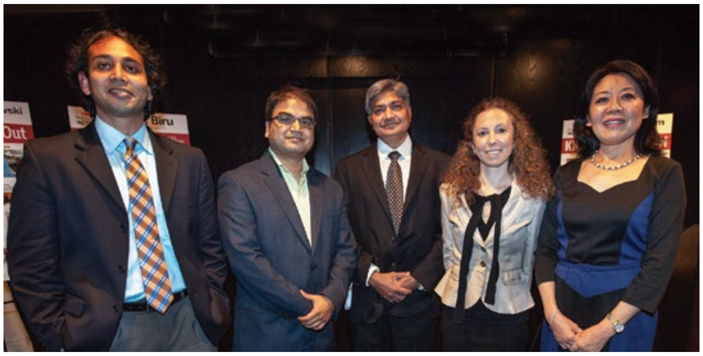
2015 IMF-Japan Research Grants

In addition to the 2015 Brian D. Novis Research Grants, three awards were presented by IMF-Japan.

Hideto Tamura MD, PhD (Nippon Medical School) is the recipient of the Aki Horinouchi Research Grant for his study entitled “The role of SLAM family molecules and immunotherapy with SLAM-directed chimeric antigen receptor (CAR)-engineered T-cells in myeloma.” To determine the target of T-cell immunotherapy, this study will focus on SLAM family members and analyze the expression of the molecules in human myeloma cell lines and in myeloma cells from patients as well as immune cells. Dr. Tamura and colleagues will analyze the functions of SLAM family members, especially their proliferative potential and drug resistance, and determine whether they are associated with the pathophysiology of myeloma.

Hirofumi Tachibana, MD, PhD (Kyushu University) received a Special Research Grant for his study entitled “Elucidation of the molecular mechanism on a novel apoptotic cell death-inducing pathway in myeloma cells.” This study will compare ASO-qPCR with a next-generation sequencing method, the LymphoSIGHT™, which employs consensus primers and high-throughput sequencing to amplify and sequence all rearranged immunoglobin gene segments present in a myeloma clone, as well as with multiparameter flow cytometry for MRD detection in autografts, peripheral blood, and bone marrow cells to assess sensitivity, specificity, and simplicity of these methods. Researchers will design optimal treatments for patients with myeloma based on chromosomal abnormalities, GEP, and MRD.

Hiroyuki Takamatsu, MD, PhD (Kanazawa University Graduate School of Medical Sciences) received a Special Research Grant for his study entitled “Minimal residual disease monitoring in myeloma using next-generation sequencing.” Pathological studies demonstrate that abnormal expression of 67LR is correlated with the poor prognosis. This study will focus on molecular mechanism of 67LR-dependent eNOS/cGMP pathway activation. Moreover, to screen the agents that potentiate the 67LR-dependent cell, researchers will use the inhibitors array system. Based on these methods, they will decipher the mechanisms of 67LR-dependent apoptosis and, based on novel molecular mechanisms, they will suggest the ideal combination to kill myeloma cells. **MT**



Willette Foundation Presents IMF with Significant Donation in Support of Black Swan Research Initiative®

The IMF is proud to announce the receipt of a generous contribution in support of our signature research project, the Black Swan Research Initiative®. Kristi Willette has donated $75,000 to the IMF in the name of her late husband, Chick C. Willette.

“We are dedicated in our desire to assist your work in the discovery of a cure for multiple myeloma,” said Kristi Willette, who heads the Willette Charitable Foundation. The IMF is deeply grateful for the financial support from individuals like Kristi, along with IMF board member John O’Dwyer and his wife Dorothy O’Dwyer, as well significant industry sponsorship from Onyx Pharmaceuticals, The Binding Site, and others.

“Not only do these donations provide vital support for our global investigative team’s research,” said Dr. Brian Durie, IMF Chairman and leader of the Black Swan Research team, “they also tell us that we’re on the right track, and that our ideas about how best to chart a path to a cure for myeloma ring true.”

Transplant at Relapse: Is It Valuable?

An update from the International Workshop on Salvage Stem Cell Transplantation for Multiple Myeloma

by Brian G.M. Durie, MD

On October 27, more than two dozen experts from around the world gathered in Minneapolis, Minnesota, to assess the current landscape for autologous stem cell transplant (ASCT) as an option for myeloma patients who have relapsed. "Salvage" transplant offers an effective treatment choice for patients who have had a positive prior response to transplant.

During this era of novel therapies, salvage transplant has become an overlooked option. Presentations at the meeting, held under the auspices of the American Society of Blood and Marrow Transplantation (ASBMT), the Blood and Marrow Transplant Clinical Trials Network (BMT CTN), the National Marrow Donor Program (NMDP), and the International Myeloma Foundation (IMF), suggest that it is time to take a second look at the uses and recommendations for salvage transplant – both the name, perhaps, and the process.

We know that transplant has clear benefits as a high-dose consolidation therapy for patients in the frontline setting, as described in the 2011 publication in the journal *Blood*, "International Myeloma Working Group (IMWG) consensus approach to the treatment of multiple myeloma patients who are candidates for autologous stem cell transplantation." The Minnesota workshop provided an opportunity to re-examine of the merits of second transplants as well.

The workshop was co-chaired by Dr. Sergio Giralt (Memorial Sloan Kettering Cancer Center) and Dr. Ed Stadtmauer (University of Pennsylvania School of Medicine, Abramson Cancer Center) representing the Center for International Blood & Marrow Transplant Research (CIBMTR) and the BMT CTN, and myself, representing the IMF and the International Myeloma Working Group (IMWG). Other organizing committee members were Drs. Hari Parameswaran, Phillip McCarthy, and Marcelo Pasquini.

Two of the key presentations during the workshop were:

Dr. Stadtmauer's excellent overview of the role of salvage ASCT. The data from the International Bone Marrow Transplant Registry (IBMTR) were compared with other reported studies. Outcomes correlated with the length of the first remission with ASCT, as well as the depth of response with both the first and second (salvage) transplants. To put the results in perspective with regard to other potential therapies for relapse patients, average remissions were about 1 year and subsequent overall survivals approximately 2–4 years.

Prof. Gordon Cook's (University of Leeds, United Kingdom) presentation of the results of his Myeloma X Trial. Salvage ASCT with melphalan 200 mg/m^2 was compared with simply Cytoxan® (cyclophosphamide) by mouth (400 mg/m^2 once/week for 3 months). Starting in 2008, 174 patients were randomized. The full results were published recently in *Lancet Oncology*. It was very helpful to see the benefit of salvage ASCT in this randomized setting. The data also confirmed the importance of length of prior remission and depth of response.

After breaking into four work groups, workshop participants presented their ideas and recommendations, which included:

- A need to summarize current knowledge;
- Risk stratification of patients at relapse;
- Assessment of the role of minimal residual disease (MRD) measurement after ASCT in the relapse setting;
- Studies of ASCT at different time points;
- A need for comparative effectiveness research (ASCT at relapse versus other options).

With priorities agreed upon by all of the workshop participants, the meeting concluded with a commitment to prepare guidelines promptly under the auspices of the IMWG and also to set up several planned studies. The IMF team of Lisa Paik, Diana Wang, and myself were very pleased to be in attendance and will be working closely with the transplant team members to ensure rapid progress to achieve the planned outcomes. In addition, follow-up meetings will occur as feasible at the Annual Meeting of the American Society of Hematology (ASH), the IMWG Summit and other venues. **MT**

Managing Myeloma-Related Bone Disease

Living Well with Myeloma: Expert advice from Dr. Matthew Drake

The International Myeloma Foundation (IMF) works with leading healthcare experts to bring critical information and advice to the myeloma community through its "Living Well with Myeloma" teleconference series.

The goal of the "Living Well with Myeloma" teleconference series is to deliver expert information on a range of health and wellness issues that can improve patients' lives. Each year since 2010, the IMF has hosted at least three teleconferences in the series on topics ranging from stress management and chemo brain to infection prevention and nutrition.

The most recent teleconference in the series provided expert advice on managing myeloma-related bone disease. Hosted by the IMF, the teleconference featured Matthew Drake, MD, PhD, of Mayo Clinic in Rochester, Minnesota.

Dr. Drake specializes in bone metabolism and endocrinology. He has authored dozens of research publications focused on bone biology, bone loss, and treatment of bone-related issues in cancer patients. Dr. Drake is also a member of the International Myeloma Working Group (IMWG), a collaborative research initiative of the IMF focused on improving myeloma treatment options for patients.

Bone disease is extremely common in myeloma, affecting 80%–90% of myeloma patients, and the issues associated with it are often severe, making Dr. Drake's "Living Well with Myeloma" teleconference particularly important.

Bone remodeling

"On average, adults replace their skeleton about every seven years through the bone remodeling process," Dr. Drake said. He explained that bone remodeling is a balance of bone resorption, the breaking down of bone, and bone formation. "This process is coupled, so wherever bone is scooped out, in the normal process, bone is reformed in order to maintain a strong, healthy skeleton."

The cells that break down bone are called osteoclasts, and the cells involved in building new bone are called osteoblasts.

Bone loss in myeloma

"Research done over the past 10 to 15 years has shown that signals from myeloma cells disrupt the normal processes of osteoclasts and osteoblasts," said Dr. Drake. His explanation of how myeloma disrupts the normal process of bone remodeling and why that can lead to bone disease was illuminated with slides that included graphics and illustrations. (For links to the audio recording and slides from Dr. Drake's teleconference, please see the end of this article.)

Signals from myeloma cells can increase the activity of the bone-resorbing cells, osteoclasts, as well as suppress the normal activity of the osteoblasts which replace that bone. Because of signals from myeloma cells, osteoblasts are unable to come in and rebuild that bone to match the rate of resorption.

This imbalance in the process of bone remodeling leads to bone loss, which can be seen as lesions in specific locations and as osteoporotic bone loss throughout the skeletal system.

Consequences of myeloma-related bone disease

"The risk of fractures is markedly increased in patients with multiple myeloma," said Dr. Drake.

Myeloma-related bone loss can lead to fractures and other severe issues that result in pain and diminished quality of life. Therefore, it is important for myeloma patients to be aware of the potential issues and treatment options.

Consequences of myeloma-related bone disease can include:

- Fractures
- Spinal cord compression and/or collapse
- Hypercalcemia (high calcium levels in the blood)
- Bone pain
- Diminished quality of life
- Decreased survival

CONTINUES ON PAGE 18

DR. DRAKE/BONE DISEASE — continued from page 17

Treatment options and managing their side effects

There are several treatment options available to address myeloma-related bone loss, bone pain, and further bone damage.

Bisphosphonate therapy: Bisphosphonates inhibit the bone resorption process. There are currently two pharmaceutical therapies approved by the US Food and Drug Administration (FDA) to treat myeloma-related bone loss. Pamidronate (Aredia®) and zoledronic acid (Zometa®) are bisphosphonates that are administered intravenously. An oral bisphosphonate, clodronate, is available in some other countries, but is not as effective as the intravenous (IV) bisphosphonates.

The "Living Well with Myeloma" teleconference recording and Dr. Drake's slide presentation include more information about how bisphosphonates work and data supporting their use.

While bisphosphonates can be effective in treating bone loss, they also may come with side effects. During the teleconference, Dr. Drake discussed steps patients and their doctors can take to manage these side effects.

Bisphosphonate side effects can include:

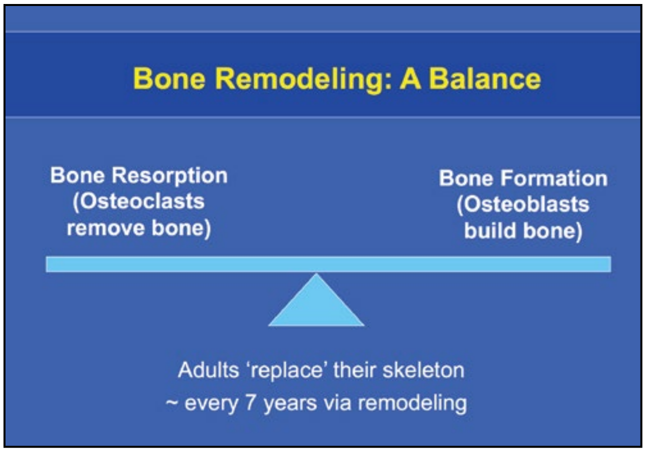
- Flu-like symptoms, which can be managed with acetaminophen taken before and after bisphosphonate infusion.
- Osteonecrosis of the jaw (ONJ), which can be managed with excellent oral hygiene, avoiding invasive dental procedures, managing bisphosphonate use around any necessary invasive dental procedures, and antibiotics and pain control.
- Lower-leg fractures, which are very rare and may be prevented by detecting thickened bone on x-rays. It is important that patients tell their doctors if they develop new thigh pain, groin pain, or metatarsal foot fractures.
- Kidney damage, which is another rare complication and can be managed by monitoring kidney function prior to each bisphosphonate infusion and staying well hydrated on the day of infusion and days following an infusion.

There are several additional treatment options to address bone disease.

Radiation therapy: Radiation therapy can treat localized bone pain, spinal cord compression, and other issues, but is typically used sparingly because it decreases bone marrow function, may injure healthy bone marrow, and may cause toxicity to other organs, according to Dr. Drake.

Surgical procedures: Surgical procedures are also used to treat myeloma-related bone disease, and can be especially important in treating issues in the spine. According to Dr. Drake, "Spine lesions are very common and problematic in multiple myeloma." Spine lesions can be very painful and lead to height loss from vertebral collapse. This can result in changes in posture, which puts pressure on other bones, and even lack of space for the lungs. Surgical procedures can address these issues. A procedure called vertebroplasty can relieve pain from spinal compression fractures and the closely related procedure, kyphoplasty, can also improve vertebral height.

Additional treatment options: Bone disease should also be addressed with non-therapeutic and non-surgical methods. Dr. Drake recommended avoiding activities with high fracture risk, such as lifting heavy items while bending.

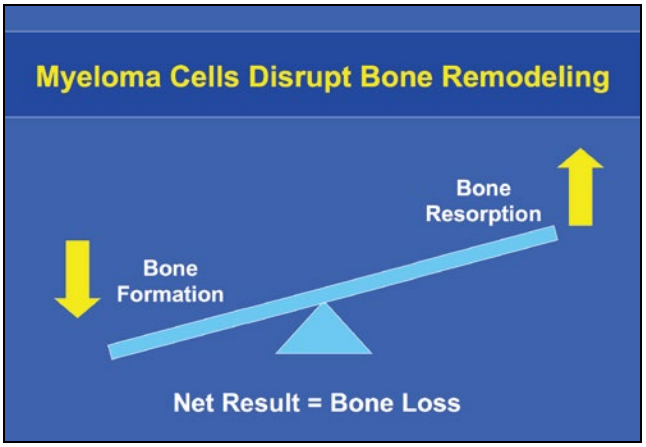


Bone Remodeling: A Balance

Bone Resorption
(Osteoclasts
remove bone)

Bone Formation
(Osteoblasts
build bone)

Adults 'replace' their skeleton
~ every 7 years via remodeling



Myeloma Cells Disrupt Bone Remodeling

Bone
Resorption

Bone
Formation

Net Result = Bone Loss

Dr. Drake also discussed the role that diet and nutrition play in treating myeloma-related bone disease. He noted that it is important to monitor calcium and vitamin D levels, and adjust intake as necessary to be within optimal levels.

Looking to the future: There are several new therapeutics being evaluated in clinical trials. Denosumab is currently being evaluated in a late-stage clinical trial in myeloma patients, and earlier-stage trials are evaluating therapeutics including BHQ880 and ACE-011. There are also clinical trials in progress that are evaluating how best to use bisphosphonates to avoid some of their potential side effects.

Conclusion

There are a number of options available now to help patients manage myeloma-related bone disease, with even more on the horizon. Dr. Drake stresses that effective treatments are available, and it is important for patients to discuss bone-related issues with their physicians. He also recommends that patients and their doctors review the "International Myeloma Working Group Recommendations for the Treatment of Multiple Myeloma-Related Bone Disease," which were published in the *Journal of Clinical Oncology* in June 2013 and can be found on the IMF website at http://bit.ly/1BNIyEk.

The audio recording of the "Living Well with Myeloma" teleconference featuring Dr. Drake is available online at http://bit.ly/1xl6fj3. Dr. Drake's slide set is available at http://bit.ly/11l4ghR. All other "Living Well with Myeloma" teleconference recordings are archived on the IMF website at http://bit.ly/1yeSRNv. **MT**

Dr. Brian Durie honored with the Distinguished Alumni Award from Mayo Clinic

The IMF congratulates its Chairman and Co-Founder Dr. Brian G.M. Durie on being honored with the Distinguished Alumni Award from Mayo Clinic. Dr. Durie, who completed residencies and fellowships at Mayo Clinic, was honored at a ceremony in October 2014 for his "exceptional contributions" to the field of myeloma.


Dr. Morie Gertz presents award to Dr. Brian Durie

"It is an honor to receive Mayo Clinic's Distinguished Alumni Award," said Dr. Durie. "The time I spent learning and practicing at Mayo Clinic was invaluable in shaping my career and my focus on myeloma. I am indebted to the researchers I worked with during those years for their insight, collegiality, and support."

Each year since 1981, Mayo Clinic's Board of Trustees has given Distinguished Alumni Awards to individuals who have been recognized nationally, and often internationally, in their fields of medicine. Dr. Durie is only the second person to be honored for his work in blood cancer, following myeloma pioneer Dr. Robert Kyle. He was nominated for the Distinguished Alumni Award by Mayo Clinic's Dr. Morie Gertz.

"I am extremely proud of Dr. Durie, as is the IMF," said Susie Novis, IMF President and Co-Founder. "This is truly a well-deserved honor and recognizes Dr. Durie's substantial contributions to the body of myeloma knowledge, which benefit the entire myeloma community. The work he does will continue to have a major impact on myeloma treatment, management, and, most importantly, the cure for this disease."

Dr. Durie serves as the Chairman of the IMF's International Myeloma Working Group (IMWG) and leads the IMF's Black Swan Research Initiative®, a collaborative research initiative to find a cure for myeloma.

Dr. Durie won the Leukemia Society of America Scholar award in 1976, and was also the US Hematologic Research Foundation Annual Awardee. In 2002, he won the Society of Nuclear Medicine and Molecular Imaging's annual first-prize award for Best Clinical Medicine Study for his paper on whole-body FDG/PET scanning in myeloma. Dr. Durie received the 2006 Robert A. Kyle Lifetime Achievement Award, an award from the IMF that honors a physician whose body of work in the field of myeloma has made significant advances in research, treatment, and care of myeloma patients. In 2009, Dr. Durie won the Waldenström's Research Award in recognition of his many contributions to the field of multiple myeloma. In 2011, Dr. Durie was awarded the Joseph Michaeli Award from Weill Cornell Comprehensive Cancer Center for outstanding contributions to the treatment of myeloma.

Dr. Durie has authored more than 400 research papers, 16 book chapters, and five books on myeloma and related conditions. He co-created the Durie/Salmon Staging System, which is used worldwide for evaluating patients with myeloma. Dr. Durie is also a marquee member of "Who's Who in America" and "The Best Doctors in America." **MT**

"Making Sense of Treatment" with the IMWG

Drs. Brian Durie, Ola Landgren, Joseph Mikhael, and Antonio Palumbo took time during the busy 56th annual meeting and exposition of the American Society of Hematology (ASH) to sit down and debate the latest hot topics in myeloma treatment for the International Myeloma Working Group (IMWG) Conference Series: "Making Sense of Treatment." Their overview of the ASH oral presentations and posters included high risk smoldering myeloma, frontline therapy, the current role of minimal residual disease, the state of transplant recommendations, maintenance and continuous therapy options, the latest in imaging, and relapse and new drugs. The individualized replays are available on the IMF website myeloma.org – just click on the IMF TV dropdown menu and select "IMWG Conference Series."

Don't miss the "Best of ASH 2014" teleconference!

If you could not participate in the live "Best of ASH 2014" teleconference, you can still listen to Dr. Brian Durie discuss the latest news coming out of the ASH meeting in December 2014. This 60-minute IMF teleconference is followed by a 30-minute Q&A session and includes key information that myeloma patients and caregivers need to know. The recording is archived on the IMF website myeloma.org.

IMF interviews myeloma experts at ASH

In addition to the IMWG Conference Series – "Making Sense of Treatment" – the IMF team filmed more than 40 interviews with scientists and clinicians presenting their findings at the ASH meeting. These webcasts are reports on the current status of some of the most interesting research in myeloma. Please be aware that at the time of posting, in some cases, the interviewees are reporting on interim data from incomplete clinical trials. Therefore not all the data presented are final results, and it is possible that results will be different when the data has matured with long-term follow-up. None of this research has yet been peer-reviewed and published in a medical journal. Videos are posted on the IMF website myeloma.org – use the IMF TV dropdown menu and select "Webcasts from Medical Meetings" before clicking on "Webcasts from ASH 2014." **MT**

The Challenge of Coping with Fatigue

IMF InfoLine coordinators answer your questions

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

by Debbie Birns
IMF Medical Editor

I am responding to treatment, but I feel utterly exhausted, to the point that I can't get anything done. Why do I have this overwhelming lack of energy? Is there anything that can be done to make it better?

The overwhelming sense of exhaustion that you're feeling is one of the most common problems facing cancer patients in general, not just myeloma patients, and it is often the most difficult to deal with. Pain, peripheral neuropathy, low blood counts, and GI issues can all be addressed and treated by your doctors, but fatigue is much more difficult to wrap one's therapeutic arms around. How can your doctor measure and treat something that's nebulous, complex, and multifactorial? How is fatigue (other than fatigue caused by anemia) assessed and quantified?

Defining the problem

Both myeloma itself and the treatments for myeloma can cause fatigue. Myeloma-related fatigue can be the result of anemia (low red blood cell count), high levels of cytokines (proteins released by white cells in response to infection or inflammation that in turn signal other immune system cells), and/or persistent pain. Effective treatment for myeloma can and should address and relieve each of these factors.

Fatigue is a known side effect of all the novel therapies and older chemotherapy agents used to treat myeloma. Patients commonly report fatigue that is cumulative, increasing in severity over the duration of treatment. Treatment-related side effects such as infection, nausea and vomiting, insomnia, mood changes, diarrhea or constipation, and loss of appetite can heighten fatigue and weakness. But fatigue can still be a problem in the absence of these other side effects. Although we can't pinpoint exactly why the novel therapies are causing fatigue, we do know that even the novel agents kill healthy cells along with malignant ones. The body must expend extra energy to repair those healthy cells, further depleting a cancer patient of energy reserves.

What can be done?

You can help yourself and your healthcare providers understand and manage your fatigue more effectively if you report and describe it. Unless your fatigue is entirely related to anemia, your doctor can't do a laboratory test to diagnose it. Your doctor must rely upon your reports to help understand the sources of your fatigue and find ways to manage them.

Because anemia is common among myeloma patients – 60%-70% of patients are anemic at diagnosis – and is easy to diagnose and treat, it is the first thing a doctor will test for in a patient who reports fatigue. If the patient is newly diagnosed or is not currently undergoing treatment, initiating therapy for myeloma can often restore the proper function of the bone marrow, where new red and white blood cells and platelets are made, and thus restore the red blood cells' ability to transport oxygen. If the patient is currently undergoing anti-myeloma therapy, the anemia may be caused by one or more of the treatments, and the doctor may need to reduce the treatment dose, discontinue the treatment temporarily until the hemoglobin count improves, or discontinue the medication entirely, depending upon the severity of the anemia and how well it responds to dose reduction.

Many myeloma patients are also being treated for other medical problems and/or are taking other medications that can cause fatigue. Among the drugs that are known to cause fatigue are treatments for high blood pressure, high cholesterol, gastrointestinal reflux, anxiety disorders, muscle spasms, depression, glaucoma, edema, insomnia, nausea, and allergies. Treatments for pain, an all-too common companion to myeloma-related bone disease, can also cause fatigue. You must let your doctor know all the medications you're taking and watch out for drug interactions and proper dosing. Many drugs, such as the antibiotic clarithromycin (Biaxin®), can increase the bioavailability of other drugs you take and make them – and their side effects – more potent.

Poor nutrition can also contribute to fatigue. You need to consume enough calories with enough vitamins and minerals to meet your body's needs. If the body's ability to absorb and digest all available nutrients is impaired (for example, by vomiting or diarrhea), you may have to eat more and better food than you did before your diagnosis and treatment. As a guide, you need 15 calories for every pound of your weight each day to remain stable. It's also vital to drink plenty of fluids to flush out the kidneys and reduce the side effects of medications.

Although it seems counterintuitive, curtailing your activities is the last thing you should do to combat fatigue. Frequent light exercise (such as walking) can reduce stress, improve mood, help build and maintain bone and muscle tissue, increase endurance, and reduce fatigue.

Although there are few over-the-counter medications that are known to reduce fatigue, a Mayo Clinic study published in 2012 demonstrated that

2000 mg daily of American ginseng over an 8-week period did seem to help patients who were currently being treated for cancer and were suffering from fatigue. Patients with fatigue who were not currently receiving therapy for cancer did not respond as well. If your fatigue is severe enough to interfere with your ability to perform the normal activities of daily living, such as showering, dressing, and preparing a light meal, then your doctor may prescribe a medication to keep you more active during the day.

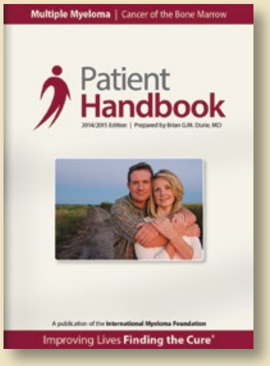
The key to managing your fatigue is good communication with your healthcare team. Pay attention to the time of day when your fatigue is worst, to any new medications you're taking or any increased dosages, to emotional stressors, to the presence of physical pain, to sleep disturbances, to dietary changes, or to any other changes that could affect your energy level. You need to accurately note and report to your doctor any factors that you think may be adding to your fatigue.

For further information on causes and management of fatigue, see the IMF publication *Understanding Fatigue*. This booklet is available in electronic format on the IMF website myeloma.org and also as a hard copy publication. All IMF publications are free of charge. As always, the InfoLine team at the IMF is here to help you develop effective communication strategies with your healthcare team. **MT**

Editor's Note: We encourage you to visit myeloma.org for up-to-date information about myeloma, and to contact the IMF with your myeloma-related questions and concerns. IMF InfoLine specialists can be reached at 800-452-CURE (2873) in the US and Canada, or 818-487-7455 from abroad. To submit your question electronically, please email InfoLine@myeloma.org. The InfoLine consistently provides callers with the best information about myeloma in a caring and compassionate manner. The InfoLine is staffed by Paul Hewitt, Missy Klepetar, and Judy Webb. Phone lines are open Monday through Friday, 9 a.m. to 4 p.m. (Pacific).

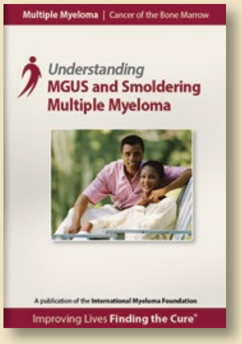
New and Updated IMF Publications

We are pleased to announce that several 2015 editions of IMF publications are now available via web and in hard copy.



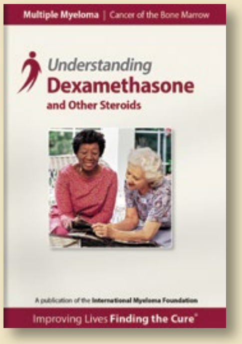
Patient Handbook

It is vital for you to learn as much as possible about myeloma and its treatments so that you are empowered to make good decisions about your care with your doctor. The IMF's *Patient Handbook* provides an excellent general overview of myeloma. One of the most daunting aspects of being diagnosed with myeloma is learning about – and understanding – an unfamiliar disease that is quite complicated. Patients and their loved ones often feel as if they are in a world where their old vocabularies no longer work. The IMF's *Patient Handbook* is meant to be your guide through this "new world," and to furnish you with the tools to understand and better manage your myeloma. Prepared by Dr. Brian G.M. Durie, the *Patient Handbook* focuses on what to do when myeloma is first discovered, the tests you really need, initial treatment options, and supportive care and how to get it.



Understanding MGUS and Smoldering Multiple Myeloma

The IMF's *Understanding* series of booklets is designed to acquaint you with treatments and supportive care measures for myeloma. We organize our information according to the 10 Steps to Better Care®, which takes you from diagnosis (Step 1) through clinical trials and how to find them (Step 10). Information about monoclonal gammopathy of undetermined significance (MGUS, pronounced "EM-gus") and smoldering multiple myeloma (SMM) belongs in Step 1: Get the Correct Diagnosis. Neither MGUS nor SMM are active myeloma disease states. However, both are precursor states to active myeloma. It is therefore important to understand if, when, and how active myeloma might evolve and what monitoring and/or interventions are appropriate.

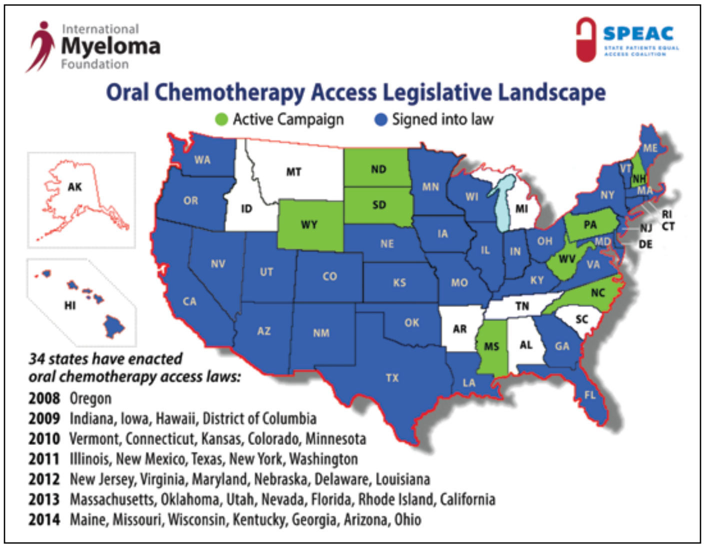


Understanding Dexamethasone and Other Steroids

This booklet is devoted to an important component of almost all myeloma therapies: the steroid dexamethasone. It fits into the 10 Steps to Better Care schema in initial treatment options (Step 3) and relapse (Step 9). Dexamethasone (which is sometimes called "dex" for short) is a synthetic adrenocortical steroid, also known as glucocorticosteroid or corticosteroid. Dexamethasone is also known by the brand names Decadron®, Dexasone®, Diodex®, Hexadrol®, and Maxidex®. It is one of the most frequently used medications in the treatment of myeloma.

The *Patient Handbook*, as well as the many booklets in the *Understanding* series, are available on the IMF website myeloma.org, where you will find a wealth of information. To order hard copies of IMF publications, call 800-452-CURE (2873) toll-free in the United States and Canada, or 818-487-7455 worldwide, or send an email to TheIMF@myeloma.org. For help with a general understanding of myeloma and its treatments, the IMF InfoLine is here to help you at the telephone numbers listed above, or at InfoLine@myeloma.org. We look forward to hearing from you. **MT**

Spotlight on Advocacy



34 states have enacted oral chemotherapy access laws:

2008	Oregon
2009	Indiana, Iowa, Hawaii, District of Columbia
2010	Vermont, Connecticut, Kansas, Colorado, Minnesota
2011	Illinois, New Mexico, Texas, New York, Washington
2012	New Jersey, Virginia, Maryland, Nebraska, Delaware, Louisiana
2013	Massachusetts, Oklahoma, Utah, Nevada, Florida, Rhode Island, California
2014	Maine, Missouri, Wisconsin, Kentucky, Georgia, Arizona, Ohio

Oral Parity: Advocacy in Action

Taylor Patton
IMF Advocacy Associate

Oral parity remains an important initiative within the International Myeloma Foundation and across the US, with several campaigns running at the state and federal level. If enacted, these laws could provide hundreds of thousands of cancer patients with access to the medications they need to remain in good health. To date, 34 states plus the District of Columbia have passed oral parity initiatives, leaving 16 states remaining without the benefits that these laws provide.

To support the passage of oral parity legislation, the IMF is working with other patient advocacy organizations, including the Leukemia and Lymphoma Society (LLS) and the American Cancer Society (ACS). The IMF leads the State Patients Equal Access Coalition (SPEAC), a collection of these like-minded organizations that support each other in these efforts. Currently, SPEAC has active campaigns running in Mississippi, New Hampshire, North Dakota, Pennsylvania, South Dakota, West Virginia, and Wyoming.

IMF Advocacy Associate Ray Wezik traveled to West Virginia on November 17 to meet with state legislators in order to gather support for the introduction of an oral parity bill for 2015. Ray explained that these meetings are often crucial to the success of the campaign. "Discussing the issue with legislators face-to-face is an important first step on the road to oral parity. We met with so many legislators, and they were all so receptive." Ray met with 12 legislators in all, including Sen. Mike Hall, Sen. Ron Stollings and Delegate Don Perdue.


West Virginia Capitol Building, Charleston, WV

It takes a great deal of work to generate the momentum behind the legislation as a bill is moved forward until it is passed into law, and the patient perspective is always invaluable. Without patients' voices and stories, it is hard for policy makers to know the intricacies of how an issue affects their constituents. Speaking with legislators directly, such as Ray did on behalf of myeloma patients in West Virginia, helps strengthen our effort.

Many patients in other states with oral parity laws in place were very active in sharing their stories as well, and not only with their representatives. Local news affiliates are often eager to speak to residents about issues that affect them directly, and to broadcast those stories on radio and television. The same applies to local newspapers, as most have a section set aside for special interest pieces. With legislative sessions scheduled for early 2015, many media outlets will be looking for subjects. This presents an excellent opportunity for patients and advocates to share their stories about oral parity. Finally, social media outlets are often excellent tools for a patient's story to reach thousands of people through a network of friends and colleagues. Try it out; you may be surprised with how far your story can go!

2014: A Look Back

Ray Wezik
IMF Advocacy Associate

As 2014 comes to an end, we look back on the amazing things that have been accomplished. The year was incredibility fruitful and positive, with a number of notable milestones in state and federal policy work, as well as Myeloma Awareness Month (MAM) proclamations. As we say goodbye to 2014, we can envision how we can make 2015 even better.

On the federal policy front, the IMF's main focus has been House Resolution (HR) 1801, the Cancer Drug Coverage Parity Act introduced by Congressman Brian Higgins (D-NY26). HR 1801 is the federal version of oral parity legislation that would create a seamless framework across the country for drug cost parity and negate the need for the current patchwork of legislation that exists in 34 states plus the District of Columbia. In 2014, the IMF and its advocates drummed up support for HR 1801 and added 26 more co-sponsors, bringing the grand total to 92. Especially impressive is that these co-sponsors were brought on during a tense election year, when it was challenging to get anything done in Washington.

In addition to HR 1801, the IMF achieved success with HR 528 to make March "National Myeloma Awareness Month." It was introduced by Rep. Spencer Bachus (R-AL6) and was referred to the committee on oversight and government reform. While the resolution has not gotten past committee, having the resolution introduced is considered an acknowledgment by Congress of the importance of myeloma awareness. The resolution has 10 co-sponsors, and the IMF hopes to reintroduce a similar bill in 2015.

On the state level, oral parity remained a primary issue for the IMF advocacy team in 2014. Oral parity as a legislative policy initiative is fairly new, having come into being only in 2008. Since that time, more than half of the states have enacted some form of the model legislation, which is an extraordinary feat. In 2014, the IMF saw seven additional states join the ranks of those with laws on the books, bringing the total number to 34 states plus the District of Columbia. The seven new states are Maine, Missouri, Wisconsin, Kentucky, Georgia, Arizona, and Ohio.

In order to finish the job in the last 16 states, the States Patient Equal Access Coalition (SPEAC), which the IMF leads, started eight new oral parity campaigns in the remaining states of Wyoming, North Dakota, South Dakota, Pennsylvania, New Hampshire, North Carolina, Mississippi, and West Virginia. Early meetings in West Virginia and South Dakota, two states the IMF leads directly, have shown there to be strong interest by state legislators on introducing and sponsoring a bill for oral parity.

Myeloma Awareness Month is a big event for the myeloma community. In 2014, our dedicated patient advocates ensured that 47 towns, cities, counties, or states declared March 2014 to be Myeloma Awareness Month.

In 2014, the IMF added more advocacy associates to the team and, together with our dedicated patient advocates, we plan on making 2015 a landmark year.

Raise Your Voice, Raise Awareness

Are you a myeloma patient, caregiver, family member, or friend? Do you want to help raise awareness of myeloma? Try getting a Myeloma Awareness Month proclamation for your city or state! Partnering with your city and state is a great way to reach thousands of people, and the process is easy and doesn't require a lot of resources. Simply contact your mayor or governor's office and explain who you are and what myeloma is, and how the disease affects you and your family. If you need assistance with navigating the process, planning outreach activities around your city's Myeloma Awareness Month, or articulating some talking points, please contact a member of the IMF Advocacy team at advocacy@myeloma.org. **MT**

MARCH IS

MYELOMA

AWARENESS MONTH

What is Multiple Myeloma?

- Second most common blood cancer
- Affects 750,000 people worldwide

What are the symptoms?

- Bone pain
- Anemia
- Extreme fatigue

What we do:

- Advocate for needs of the myeloma community
- Foster collaborative research
- Empower people through education
- Provide support for patients and families

Call the IMF InfoLine at 800.452.2873 or visit us at myeloma.org

Updates from Around the Globe

KBCA holds annual myeloma patient seminar

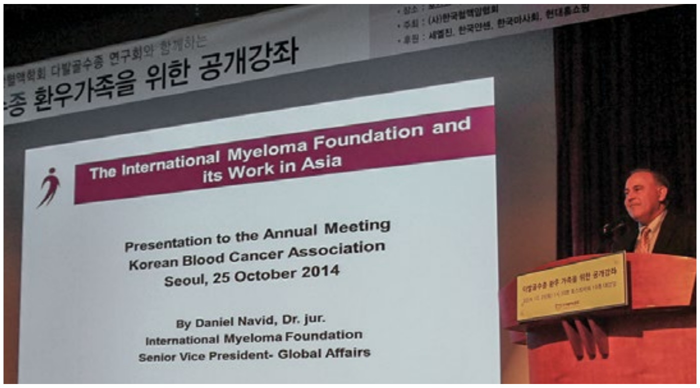
The Korean Blood Cancer Association (KBCA) held a most successful patient support workshop on October 25, 2014. More than 200 myeloma patients and family members gathered in Seoul to hear presentations by several of the leading Korean hematologists.

The annual meeting was chaired by Dr. S.S. Yoon, President of the Korean Myeloma Working Group, and member of the IMF Asian Myeloma Network. To open the session, words of welcome were provided by Mr. Y.H. Bae, Chairman of the Korean Federation of Multiple Myeloma Patients. Then Daniel Navid, IMF's Senior Vice President, Global Affairs, was invited to deliver a keynote address to mark the recent affiliation agreement between the KBCA and the IMF, which was signed into effect last June in Milan.

Mr. Navid took the opportunity to stress that myeloma sufferers in Korea are not alone. He reported on the work of the IMF throughout the world to support myeloma patients and presented information about myeloma incidence in Asia, highlighting the work of the IMF Asian Myeloma Network (AMN). Mr. Navid underlined the leading role being played by Korean experts in moving forward the IMF's Asian capacity. The presentation concluded with some thoughts about future cooperation between the KBCA and the IMF, building upon the IMF's expertise in physician education and support to patients and their families.

A series of expert presentations were then provided:

- What is Multiple Myeloma? (by Dr. S.K. Park)
- Introduction to Amyloid (by Dr. K.H. Kim, member of IMF Asian Myeloma Network)
- Chemotherapy of Transplantation/Non-Transplantation (by Dr. S.M. Bang)
- Management of Complications and Side Effects of Treatment (by Dr. H.J. Kim)
- Treatment of Relapsed Patients and the Introduction of New Drugs (by Dr. H.S. Eom)



Dan Navid speaks on behalf of the IMF

The conference next turned to a lively question and answer session. The questions amply demonstrated that the Korean patients have a very sophisticated grasp about the science of myeloma, reflecting very well on the work of the KBCA over the years to spread the myeloma message.

Finally, discussion was directed to review the results of a survey of myeloma patients in Korea recently undertaken by the Nielsen company, sponsored by Jansen Korea. The survey gathered information on matters such as patient symptoms, the nature of initial diagnosis and advice received, the various steps or phases patients passed through before being referred to hematologist/oncologist (e.g., the length of time from first symptom to effective treatment) and then the kinds and stages of treatment provided (e.g., injections, oral medication, transplantation, radiation therapy, others). The information gathered showed that while the Korean experience is improving, there are still grounds for further improvement. In addition, there are some significant problems in the area of reimbursement for novel agent treatment and concerns about delays in the approval process for new treatments in Korea, with some of the more recent novel agents not being available as yet on the Korean market.

The IMF is pleased to continue to work with the KBCA and with the expert hematologists in the Korean Myeloma Working Group to address problems of patient support and access to the latest treatment options.

KBCA team and volunteers with IMF's Dan Navid

Speakers at the KBCA patient meeting

IMF co-hosts meetings in Norway and Denmark

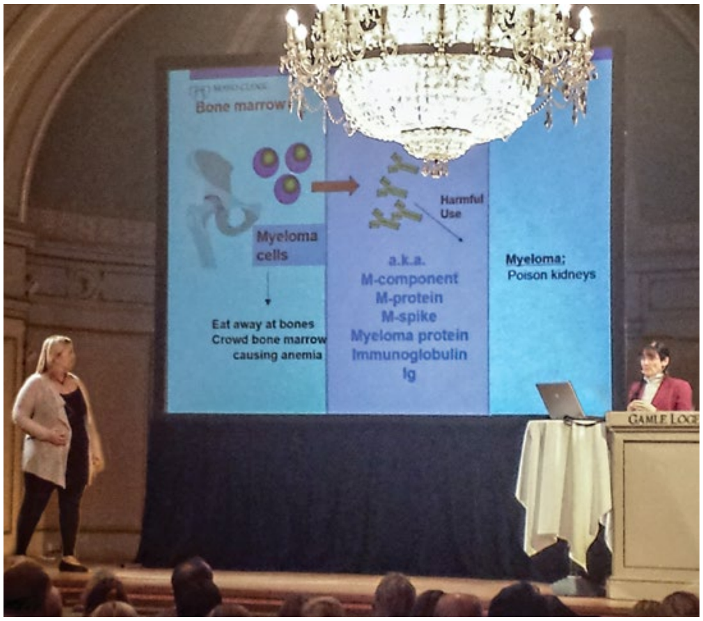
The first week of November 2014 saw the IMF co-hosting three Patient & Family Seminars in Norway and Denmark, where leaders of the patient associations from those countries gathered to discuss the latest in myeloma news and treatments. It was an opportunity for the IMF to make patients aware of its resources and bring the global myeloma community even closer together. Nadia Elkebir (IMF Director, Europe and the Middle East) proudly represented the IMF at the meetings.

The Patient & Family Seminar in Trondheim took place on November 1. The meeting was moderated by Dr. Anders Waage (Norwegian University of Science and Technology, Trondheim) and Dr. Angela Dispenzieri (Mayo Clinic, Rochester, Minnesota) was an invited speaker. Monitoring myeloma, novel therapies, treating complications of the disease, and potential preventative measures were discussed. Patients were very appreciative to have a myeloma specialist from abroad come to Trondheim. In fact, there was such a demand for attendance that the meeting hit capacity at 200 participants, and some had to be turned away.

Other presentations delivered during the seminar included:

- Pain and Physical Activity with Myeloma (by Janne Anita Sundfaer, Nurse)
- Awareness and Coping (by Tone Hansen, Chairman of Blodkreftforeningen)
- Clinical Studies in Norway for Patients Diagnosed with Myeloma (by Dr. Waage)
- Learning and Mastery Groups for Patients Diagnosed with Myeloma (by Turid Almvik, Nurse)
- Emotional and Physical Effects of Recurrence (Celgene representative)

In addition to the educational presentations, time was set aside for patients to ask questions and share their stories. Tone Hansen, who is the leader of the Blodkreftforeningen (Norwegian patient association) and an excellent psychologist, had a very uplifting influence on the participants.



Dr. Nina Gulbrandsen and Dr. Angela Dispenzieri

On November 4, a second Patient & Family Seminar in Norway was held in Oslo, with 208 participants in attendance. Some were newly diagnosed with myeloma and this was their first patient meeting, so the first presentation on diagnosis by Dr. Nina Gulbrandsen (Professor and Chief Physician, Oslo University, Rikshospitalet) proved to be of much interest. Other presentations included Dr. Fredrik Schjesvold's "Current Treatment for Newly Diagnosed Patients and Treatment at Recurrence," Tone Hansen's "Awareness and Coping," Celgene's "Emotional and Physical Effects of Recurrence," and Dr. Waage's "The Norwegian Research Center: Jebsen's Centre for Myeloma." There was also ample opportunity for patients to share their stories.

On November 5, Celgene held a physician meeting in Oslo, which Nadia Elkebir attended representing the IMF. Approximately 50 physicians took part, including some of the speakers who were part of the faculty at the Oslo Patient & Family Seminar. Dr. Dispenzieri repeated her presentation of "Diagnosis and Treatment of Myeloma," which created a lively discussion during the Q&A section.

On November 6, a physician meeting was held at Odense University Hospital in Denmark. Approximately 40 physicians attended, many of whom work with Syddansk Universitet's Dr. Niels Abildgaard. Dr. Dispenzieri presented "Virotherapy in Multiple Myeloma – The Mayo Experience" and engaged in yet another lively discussion.

The final event of the week was the Patient & Family Seminar in Denmark. Held on November 7 in Middelfart, it drew 210 participants in person plus an additional virtual contingent via live-streaming. The event opened with a beautiful biblical song sung by the attendees, followed by Ole Dalriis (Chairman of the Danish Myeloma Foreningen, DMF) and Bibi Moe officially welcoming the IMF, and Nadia Elkebir introducing the day's activities.

Dr. Abildgaard moderated the meeting and translated for Dr. Dispenzieri, who presented "Monitoring and Management of Myeloma Treatment." The Danish patients are clearly educated about their disease, as their questions were thoughtfully formed.

The outpouring of gratitude toward the IMF at the meetings in Norway and Denmark demonstated the strength of the relationships with Blodkreftforeningen and the DMF, and we are already eagerly anticipating next year's joint events! **MT**

IMF Support Group Leaders at ASH 2014

The International Myeloma Foundation (IMF) provided a unique opportunity for 12 Support Group Leaders and members to attend the 56th American Society of Hematology (ASH) Annual meeting December 6–9 in San Francisco, California. Robin Tuohy, IMF Senior Director of Support Groups, coordinated ASH activities for the team. Leaders came from across the US to attend ASH presentations on myeloma research, the IMF's educational events, and more. They shared their perspectives on ASH with their local communities and with the entire global myeloma community through blogs, Twitter, and Facebook.

The Leaders' time in San Francisco was filled with early mornings, late nights, learning, studying, listening, collaborating, and sharing. The volume of new information they learned might have been overwhelming at times, but the experience left the support group team inspired.

"The more I have learned about myeloma and new developments, the more hopeful I feel," said Cindy Ralston of the Kansas City (Missouri) Multiple Myeloma Support Group. "The ASH conference pumps you full of hope!"

Data presentations

The official ASH meeting program provided the support group leaders with an opportunity to see and hear more than 850 myeloma-related presentations. The team spent hours in the ASH exhibit hall reviewing many posters detailing myeloma clinical trials. They also attended several oral presentations, including the prestigious Ham-Wasserman Lecture, presented by Jesús San-Miguel, MD, PhD (University of Navarra, Pamplona, Spain).

The IMF organized sessions for the support group leaders to discuss and digest all of the information they learned at the ASH presentations, including working breakfasts each morning. Debbie Birns, IMF Medical Editor, joined one meeting to review key data from ASH presentations from the previous days. Because there were so many simultaneous presentations, the team divided, conquered, and shared to learn the most information possible.

IMF events and opportunities

Before the ASH presentation hall opened each morning and after its doors closed each evening, the IMF hosted several events where the support group team had the opportunity to interact with the doctors and researchers whose work was featured during the ASH meeting.

On December 5, the Leaders were also able to attend the IMF-hosted satellite symposium to educate physicians on the latest in myeloma treatment strategies. The presentation, "Critical Issues Need Answers: Providing Best Options for Myeloma Treatments in 2014," drew more than 1,000 doctors who listened to top myeloma researchers present interactive case discussions with "point-counterpoint" sessions.

On December 6, the IMF hosted a meeting for the International Myeloma Working Group (IMWG), a research initiative of the IMF comprised of more than 180 myeloma researchers from around the globe. Four support group leaders had the opportunity to attend and listen to elite myeloma researchers provide updates on current and proposed projects that may shape the course of myeloma treatment in the years to come.

"Witnessing the top myeloma researchers discuss their projects brought me great hope," said Linda Huguelet. "It's so refreshing to see so much collaboration. This meeting and all of the ASH activities reinforced how

confident I am that a cure for myeloma is a definite possibility! This is something that wasn't even talked about in 2010 when I was diagnosed. This is amazing progress in a short period of time."

Later that night, the IMF hosted the Brian D. Novis Senior and Junior Research Grant Awards Ceremony, a highlight for many members of the support group team. This event provided an opportunity to meet some of the brightest myeloma researchers from around the world and two members of the IMF's support group team had an opportunity to share their stories.

Yelak Biru described his journey from "a scared, young, 25-year-old patient to 'older,' well informed myeloma survivor of almost two decades." He said, "Telling my story at the reception to help put a face to myeloma was exhilarating." Cynthia Chmielewski also discussed her evolution as a myeloma patient, to one who seeks out knowledge and shares it with nearly 3,000 people following her on social media.

"The Brian D. Novis Research Grant Awards Ceremony is one of my favorite events at ASH," said Michael Tuohy. "At the reception I had the pleasure of speaking with one of the grant winners, who told me about his project to target and kill myeloma cells. Now that's what a patient loves to hear – kill those myeloma cells! As a matter of fact, each night when I take my oral therapy, my wife and I say those exact words."

The IMF capped off an exciting few days at the ASH meeting with "Making Sense of Treatment: The International Myeloma Working Group (IMWG) Conference Series," held on December 8. The Leaders watched the live webcast from their hotel in San Francisco as IMF Chairman Dr. Brian G.M. Durie moderated and joined IMWG members Drs. Joseph Mikhael, Ola Landgren, and Antonio Palumbo tackle the key questions facing myeloma doctors and patients in light of the latest research presented at ASH.

Leaders' reports and reach

The Support Group Leaders wrote dozens of blog posts and shared hundreds of updates on Twitter and Facebook discussing their time at the ASH, reaching a combined total of more than 32,000 people.

The social media analytics company Symplur reports that IMF's social media team members were among the "top ten" by numbers of tweets during the ASH meeting. Top ten out of more than 20,000 people attending the ASH conference!

"As the IMF's Susie Novis says, 'Knowledge is power!'" said Robin Tuohy. "It is so important to our support group team that we spread the information we are so privileged to learn at ASH to all myeloma patients."

Sharing the knowledge they gained at ASH with tens of thousands of people around the world, the dedicated team of Support Group Leaders does indeed empower the global myeloma community. **MT**

Meet the Leaders

Jack Aiello co-facilitates the San Francisco Bay Area Myeloma Support Group. He is a nearly 20-year myeloma survivor.

Yelak Biru co-leads the North Texas Myeloma Support Group and is a 16+ year myeloma survivor who was diagnosed at the age of 25.

Cynthia Chmielewski traveled from New Jersey to attend the ASH annual meeting for the fourth time with the IMF. She shares all she learns with her more than 2,000 Twitter followers.

Linda Huguelet co-leads the Chattanooga (Tennessee) Multiple Myeloma Networking Group. Diagnosed with myeloma in 2010, she is back in remission following a relapse.

Gail McCray, a myeloma survivor in near-complete remission since 2008, co-leads the Southside Atlanta (Georgia) Myeloma Support Group. A certified Community Health Educator, she was excited to attend ASH for the first time.

Teresa Miceli is meeting facilitator for the Multiple Myeloma Sharing Sessions in Rochester, Minnesota and a nurse and transplant coordinator at Mayo Clinic. She is also a member of the IMF's Nurse Leadership Board.

Jim Omel is a physician and co-leader of the Central Nebraska Myeloma Support Group. Diagnosed with myeloma in 1997, he is involved in advocacy work with a range of organizations, including the US Food and Drug Administration (FDA). During ASH, Jim was most interested in learning about and reporting on myeloma genomics, pathways, and measurement of MRD through flow cytometry.

Cindy Ralston, a founder of the Kansas City Multiple Myeloma Support Group, was diagnosed with MGUS in 1995, and by 1996 was told she had smoldering myeloma.

Michael Tuohy was diagnosed with myeloma in 2000 at the age of 36 and in 2001, co-founded the first myeloma support group in Connecticut, the Connecticut Multiple Myeloma Fighters.

Robin Tuohy, IMF Senior Director of Support Groups, led the support group team during ASH. She co-founded the Connecticut Multiple Myeloma Fighters with her husband Michael.

Tom Swick, diagnosed with myeloma in 2007, is chairman of the Orange County (California) Multiple Myeloma Support Group. He attended ASH for the first time and was most interested in learning about and reporting on new drugs in development.

Jerry Walton, a 33-year Navy veteran, founded the Southeastern Virginia Multiple Myeloma Support Group after he was diagnosed with myeloma in 2006.

IMFers Raise Funds to Benefit Myeloma Community

by Suzanne Battaglia
IMF Director, Member Events

Friends of the IMF are raising funds to support essential 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 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 stories that follow demonstrate the flexibility you have in choosing an event. 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 small event, consider putting a twist on something you normally might do, such as a bake sale, garage sale, holiday party, or 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.

Celebrating a Union, Raising Funds for Research

When Manuel R. Arevalo was diagnosed with multiple myeloma in the mid-1990s, his family didn't have the internet in their household. To research the disease, Mr. Arevalo's daughter, Denise, went to the library. There, she found only a one-paragraph definition, which "broke my heart," she recalled. The entry said that life expectancy for those diagnosed was approximately five years.

Denise's father did live for five years with myeloma, and Denise lived with him as a full-time caretaker. "He was really, really dear to me," she said. "I was closer to my father than anyone else in my life…I moved in with him when it became clear that he couldn't do it on his own. He was trying so, so hard to do it himself, but I just had to be there."

In 2014, as Denise was planning her wedding to Tom, she wanted to find a way to acknowledge her father. Once again, she turned to research. This time the internet provided a wealth of information on myeloma and the organizations dedicated to research, awareness, and a cure. That is how Denise found the IMF.

"The IMF has a personal touch, and that is suited to my father's personality. That's what I really wanted," Denise said of the IMF. Denise and Tom turned their wedding into a fundraiser for the IMF, and set up a donation page on the IMF website.

"It's not like we're 20 years old getting married and we need silverware and dishes. We're already blessed in our lives. We don't need more things…but what I think the world still needs is research for cancer – and particularly the cancer that my father had," Denise said.

Tom runs a nonprofit boys' camp and understands the importance of charity. Most importantly, though, he understood how personal this cause was to his bride. Denise and Tom were married on August 31, 2014 in Marina Del Rey, California. With the help of their guests, the couple raised approximately $6,000 for the IMF.

"I wanted it to be something uplifting. For me, it was all about celebrating my love for my father," Denise said.

Red Rock Canyon Bike Ride

Douglas Kinkade has been an avid cyclist for years, often participating in charity bike rides for cancer. But in 2013, while attending the IMF Patient & Family Seminar in Boca Raton, Florida in his role as an Onyx representative, Doug was inspired to combine his passion for cycling with a worthy cause and create his own race towards a cure – this time for myeloma.

"I've been involved in oncology for 20 years, and I think one of the most important things for a patient to do is to become one's own advocate," Doug said. "The IMF does an excellent job at helping with that. At the seminar I was looking through the IMF literature and I was really impressed. I wanted to organize an event that we could do at Onyx."

With the company's representatives spread across the country, Doug figured the best way to involve the most participants was to plan a bike ride around Onyx's 2014 annual national meeting in Nevada. About 30 members of the Onyx family joined the bike ride, raising approximately $4,000 for the IMF.

"Everybody wanted to help. The outpouring of people who wanted to do it was remarkable," he said. But riding through the desert of Red Rock Canyon, Doug "definitely got some looks" from those who didn't know how challenging the 30-mile ride would be. There was a lot of climbing involved, and that is not easy to do on a bike. But "everybody made it, and everybody made it safely!" he said. Members of the team's "pit crew" made sure everyone stayed hydrated and had fun.

Since then, Doug has been encouraged to make this an annual event, so he has begun thinking about where to organize a ride for 2015. "The big focus is to try to make it a better fundraiser. The idea is to make it something that everybody can do."

Doug may have been the brainchild behind the Red Rock Canyon Bike Ride, but he credits his Onyx co-workers, Steve Vickers and Mike Kacer, as being "instrumental" in setting things up and participating in the ride. "And I couldn't ask for better help from the IMF… It's a really great resource for everyone who has been touched by myeloma." **MT**

Staff Update

Stanley M. Baratta

Executive Vice President, Development

The IMF is pleased to welcome its newest team member, Stanley Baratta, IMF Executive Vice President, Development. A nationally recognized senior development executive for 25 years, Stanley has raised more than $200 million for major nonprofit education and charitable institutions.

"I am thrilled to join the International Myeloma Foundation at such an exciting time in the organization's history," said Stanley. "This year, the IMF will celebrate its 25th anniversary as the leading myeloma research and patient education and advocacy organization in the world. With the Black Swan Research Initiative®, the IMF is poised to cure this disease and change the lives of so many."

The beneficiaries of Stanley's extensive development expertise have included the Flying Tigers Historical Organization, the Ronald Reagan Presidential Library, and the Zimmer Children's Museum.

From 2008–2012, he was National Campaign Executive Director for the Pacific Aviation Museum in Pearl Harbor, Hawaii, and before that, he served for three years as President of the Sherman Oaks Hospital Foundation. This followed his five-year tenure as Vice President of Development and Community Affairs for the Weingart Center Association, the largest homeless support agency west of the Mississippi, where he led a multimillion-dollar capital campaign to create the first adult education center on Los Angeles's Skid Row.

Stanley brings tremendous experience from his years of development work on behalf of a wide range of institutions that include Brandeis University, the United Jewish Fund, the University of Judaism, the Weizmann Institute of Science, the Anti-Defamation League, Shaare Zedek Medical Center, and the Jewish National Fund.

His community service work includes serving as a member of the Board of Directors of the Beverly Hills Performing Arts Center, the Hollywood Classics Channel, the Los Angeles Jewish Symphony and the Wings Over Camarillo Air Show.

Stanley is a graduate of Antioch University. He was also awarded a Certificate in Jewish Communal Service from Hebrew Union College. He and his wife, Karen, live in Southern California and are the proud parents of Kate, Spencer, and Grayson.

"I'm proud to be affiliated with such a dynamic, innovative organization," he said, "and I look forward to leading a very successful development effort on its behalf."

Stanley Baratta can be reached at sbaratta@myeloma.org **MT**

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Shop through shop.myeloma.org 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. The IMF receives a donation only if you use the links at myelmoa.org, so use this page to ensure that when you are shopping your purchases are properly credited. Keep checking back as we regularly add new e-commerce vendors to our mall. Thanks for your support!

Mambo for Myeloma

IMFers are trying to come up with the next big fundraising and awareness challenge for multiple myeloma. One cool idea we've seen from our members is **Mambo for Multiple Myeloma**. Here's how it works:

Take videos of yourself, friends, or family members dancing in honor of myeloma research – any solo or group dance moves work! Mention that it is for **multiple myeloma** (we don't want it confused with melanoma). Upload your video to YouTube and tag it as Mambo for Multiple Myeloma, then share it on the Mambo for Multiple Myeloma Facebook page. Challenge others to do the same.

Can't do a video? No problem! Just take a dance move photo and post it to the Mambo for Multiple Myeloma Facebook page. Want to help spread the word? Help raise myeloma awareness by "liking" the page and sharing it. (Or, if you just want to support the campaign, simply visit mambo.myeloma.org and make a donation.)

Do your dance today and help spread awareness, and let us know if you've started your own "challenge" idea in your community!


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2015 IMF Calendar of Events

Feb 13-14	IMF Patient & Family Seminar (PFS) – Boca Raton, FL
March 7-8	IMF Next Generation Flow Workshop – Tokyo, Japan
March 7	IMF Regional Community Workshop (RCW) – Denver, CO
March 14	IMF Regional Community Workshop (RCW) – San Diego, CA
March 27-28	IMF Patient & Family Seminar (PFS) – San Francisco (Redwood City), CA
April 11	IMF Regional Community Workshop (RCW) – Dallas, TX
April 23-26	40th Annual Congress of the Oncology Nursing Society (ONS) – Orlando, FL
May 15	IMF Next Generation Flow Workshop – Beijing, China
May 16	IMF Clinical Conference and Chinese Myeloma Working Group (CMWG) meeting – Beijing, China
May 29-June 2	51st Annual Meeting of the American Society of Clinical Oncology (ASCO) – Chicago, IL
June 6	IMF Regional Community Workshop (RCW) – Charlotte, NC
June 8-10	International Myeloma Working Group (IMWG) Summit – Vienna, Austria
June 11-14	20th Congress of the European Hematology Association (EHA) – Vienna, Austria
June 20	IMF Regional Community Workshop (RCW) – Edina, MN
Aug 21-22	IMF Patient & Family Seminar (PFS) – Los Angeles, CA
Sept 12	IMF Regional Community Workshop (RCW) – Chicago (North Shore), IL
Sept 24-26	15th International Myeloma Workshop (IMW) – Rome, Italy
Oct 16-17	IMF Patient & Family Seminar (PFS) – Stamford, CT
Oct 24	IMF Regional Community Workshop (RCW) – Richmond, VA
Dec 5-8	57th American Society of Hematology (ASH) Annual Meeting and Exposition - Orlando, FL

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 **myeloma.org.au** • *Canada* **myelomacanada.ca** • *Israel* **amen.org.il** • *Japan* **myeloma.gr.jp** • *Latin America* **mielomabrasil.org**

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