



Improving Lives • Finding the Cure®

MYELOMA TODAY

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

Scientific & Clinical News



The 54th Annual Meeting and Exposition of the American Society of Hematology (ASH) brought its usual bounty of more than 700 oral presentations, posters, and publications on myeloma. Here, we present the highlights of this year's most important takeaways from myeloma presentations. These studies deepen our knowledge of drugs, molecules, and antibodies that hold promise for the future, improve testing, imaging, monitoring, transplant, and treatment of the disease, and broaden the understanding of myeloma biology. **PAGE 4**

Myeloma patients, caregivers, and support group leaders from around the country



joined the thousands of hematologists and healthcare professionals attending the recent ASH annual meeting, the premier hematology conclave in the world. These patient advocates were brought up-to-date on the latest research, therapies, and tools available to myeloma patients. In turn, they reported the news to the myeloma patient community back home. Here, they share their experiences and impressions with *Myeloma Today* readers. **PAGE 5**

Since 1994, the IMF Research Grants Program



has been funding promising clinical investigators from around the world in an effort to improve outcomes for patients with myeloma. The IMF-funded research has led to many publications, enabled investigators to become established in the field of myeloma, and made important contributions to understanding the biology of this disease, as well as supported the development of better therapies. Read about the investigations undertaken by the recipients of the 2013 IMF research grants. **PAGE 8**



Dr. Rafat Abonour is Professor of Medicine and Professor of Pathology and Laboratory Medicine, as well as Director of IU Melvin and Bren Simon Cancer Center Adult Clinical Research Office at the Indiana University School of Medicine. He is a member of the myeloma committee at the Eastern Cooperative Oncology Group, and part of the Academic Myeloma Consortium. Dr. Abonour was the first doctor to treat a patient with Car-Pom-d, a combination of Kyprolis® (carfilzomib), Pomalyst® (pomalidomide), and dexamethasone. **PAGE 9**

Education & Awareness



The IMF's Nurse Leadership Board has published a report on the subcutaneous (SQ) administration of Velcade® (bortezomib) in patients with myeloma, which is increasingly becoming a standard of care for maintenance patients. The NLB discusses current Velcade use, experiences with administration, dosing and side effect management, and office dynamics in clinical practice. NLB members emphasized the continued need for nurse education around Velcade SQ administration and side effect management. **PAGE 10**



IMF Hotline Coordinators discuss Pomalyst® (pomalidomide) capsules, the newest oral immunomodulatory drug (IMiD®). Pomalyst in combination with dexamethasone was approved by the US Food and Drug Administration on February 8, 2013. Pomalyst is a thalidomide analogue indicated only for patients with relapsed/refractory myeloma who have received at least two prior therapies including Revlimid® (lenalidomide) and Velcade® (bortezomib), and have demonstrated disease progression on or within 60 days of completion of the last therapy. **PAGE 11**

Patient Experience



Jameca Barrett was told she had stage III myeloma in 2003, at age 26, after months of misdiagnosis. At that time, she was the youngest patient with myeloma in the Metro-Atlanta Area of Georgia. She spent three months in the hospital before she was strong enough to start myeloma therapy. In the summer of 2004, Jameca was ready for an autologous transplant. She has been in remission ever since. In her story, Jameca shares her struggles and successes, and how becoming a myeloma advocate helped her help others in her community. **PAGE 17**

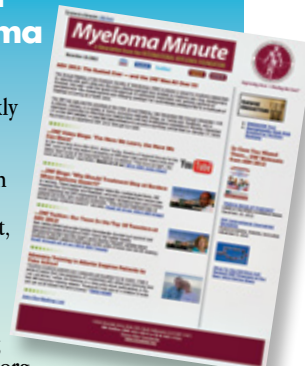
Also in this issue...

- Dear Reader** by IMF president Susie Novis **PAGE 3**
- Spotlight on Advocacy** **PAGE 13**
- Letters to the IMF** **PAGE 14**
- Updates from Around the Globe** **PAGE 15**
- Support Groups** **PAGE 18**
- Member Events** **PAGE 20**
- News & Notes** **PAGE 22**
- IMF Calendar of Events** **BACK COVER**

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To join the mailing list go to myeloma.org, email TheIMF@myeloma.org, or call 800-452-CURE (2873) or 818-487-7455.



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A Message from the President

Dear Reader,

2013! Sounds almost like something out of a science fiction novel. Yet it's our world today. So many changes happening at warp speed, and we're all suffering from information overload. Change is a good thing, but the speed at which things happen can be overwhelming. We're constantly being bombarded with news. The internet is both a dream come true and at times your worst nightmare. Facebook, Twitter, TV, radio (yes, some people do listen to the radio), newspapers, books, e-books, and on and on.

And that's just the world around us. Now let's think about the evolving world of myeloma. When things happen at what seems like warp speed in medicine, that's a good thing! That's what is happening today in myeloma. More new drugs are available today than ever before, and more new drugs are in the pipeline. More information, more choices = more challenges, and more stress. No one wants to make the wrong decision. My head is spinning just writing this!

How does someone make the right decision? Whether you're a patient, physician, or nurse this is the challenge. That's where the IMF comes in. For 22 years we have been – and still are – the go-to organization for the entire myeloma community: patients, doctors, and nurses, and the world at large. We provide the most accurate and up-to-date information to our global community. People have coined a phrase about the IMF. They say (and I agree) we provide "truth in treatment!"

Making treatment decisions that are right for you as a patient can be, and often is, daunting. Here's what we're doing in this ever-changing landscape to ensure that each person has access to what they need:

We're focusing on our ever-evolving community. We want to hear from you. We want to know you better. In this ever-changing world here are some things we want to know.

As a patient –

- Who are you?
- How old are you?
- Where do you live?
- How old were you when you were diagnosed?
- How long ago were you diagnosed?
- What treatment are you currently on?
- What is your biggest issue/challenge?

As a physician –

- Where is your practice?
- How many myeloma patients do you see?
- How do you keep current on treatment advances?
- How do you like to receive information?

As a nurse –

- Where do you work?
- How many myeloma patients are seen in your institution/office?
- How do you keep current on myeloma management?
- How do you like to receive information?

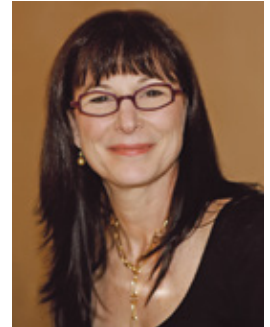
Please take a moment to answer these questions by going to our website to access either the patient survey at survey.myeloma.org or the doctors and nurses survey profsurvey.myeloma.org. This information is vital to ensure we address the needs of our rapidly evolving community.

We'll keep you posted on what we learn!

Warmly,



Susie Novis, President



View the Boca Raton Patient & Family Seminar on the Web!

The IMF has kicked off the 2013 Myeloma Awareness Month by live streaming our signature Patient & Family Seminar from Boca Raton, Florida. The webcasts of the March 2nd sessions are now archived on the IMF website myeloma.org. Click on the **webcasts** tab to watch myeloma experts discuss and answer questions about clinical trials, new drugs, and what the future holds for myeloma patients.

Panelists include IMF Chairman and Co-Founder Dr. Brian G.M. Durie, Dr. Sagar Lonial, Dr. Paul G. Richardson, and Dr. Robert A. Kyle. **MT**



What you get at an IMF Patient & Family Seminar

- **Education**
Get up-to-date, vital information.
- **Access to Experts**
Get one-on-one access to the experts with time to ask questions about your treatment options.
- **Camaraderie**
Share your experiences and gain strength from others in the IMF family.

Go to our website myeloma.org and click on the "Seminars and Meetings" tab for the most up-to-date faculty and registration information.

Upcoming Seminars

San Francisco Bay Area, CA
May 10-11

Chicago, IL
Aug 9-10

Philadelphia, PA
Aug 23-24

ASH 2012 – SUMMARIES OF MULTIPLE MYELOMA PRESENTATIONS

The 54th Annual Meeting and Exposition of the American Society of Hematology (ASH) was held December 8–11 in Atlanta, Georgia. ASH 2012 brought its usual bounty of more than 700 oral presentations, posters, and publications on multiple myeloma (MM). These studies continue to deepen our knowledge of drugs that have by now become familiar names, and of new molecules and antibodies that hold promise for the future. Our ability to test, image,

identify, monitor, and treat MM, and our understanding of its biology, grow ever better. We once again turn to the IMF's 10 Steps to Better Care® as a framework for highlighting this year's most important takeaways. Please go to ash.myeloma.org in order to view our filmed interviews with presenters from ASH and/or accompanying presentation slides, and to view the complete text of the IMF's ASH 2012 Multiple Myeloma Highlights publication.

Step 1. Know What You're Dealing With.

Improved Survival

Dr. Shaji Kumar (Mayo Clinic, Rochester, MN) presented *Continued Improvement in Survival in MM and the Impact of Novel Agents*, and encouraging poster presentation documenting the continued improvement in overall survival (OS) in MM. Dr. Kumar's data indicates a median OS of 7.3 years among patients in the time period from 2006-2010, an improvement of nearly double that calculated for the period 2001-2005. The data are particularly impressive for older patients, and are due to the impact of novel agents.

MDS/ALL Pre-Treatment

Dr. Neha Korde (National Cancer Institute, National Institutes of Health, Bethesda, MD) presented *Early Myelodysplastic Changes Present in a Substantial Proportion of MGUS and SMM Patients*. A population-based study of 5,652 Swedish patients demonstrates an 8-fold increase in the likelihood of developing myelodysplastic syndrome (MDS) and acute leukemia among patients with monoclonal gammopathy of undetermined significance (MGUS) and smoldering MM (SMM).

Dr. Linsey Roeker (Mayo Clinic, Rochester, MN) presented *Development of MDS and Acute Leukemias in Patients with MGUS*. Dr. Roeker used a data base of 17,315 MGUS patients and also determined that patients with plasma cell disorders carry an inherent risk of MDS.

Step 2. Tests You Really Need.

Step 6. Response Assessment: Is Treatment Working?

Step 8. Keeping Track of the Myeloma: Monitoring Without Mystery.

Genomics/FISH

Dr. Leif Bergsagel (Mayo Clinic, Scottsdale, AZ) presented *Promiscuous Cryptic Rearrangements of MYC Locus Cis-Dysregulate MYC Expression and Are Present in the Majority of Patients with Hyperdiploid Myeloma*. Dr. Bergsagel's research identifies the MYC gene locus and its association with progression of MGUS to active MM.

Dr. Benjamin Hebraud (Hôpital Purpan, Toulouse, France) presented *1p22 and 1p32 deletions are Independent Prognosis Factors in Young Patients with Myeloma*. This important study highlights the cytogenetic abnormalities in chromosome 1 that have an impact on prognosis in MM.

Cereblon

Dr. Steven Schuster (Mayo Clinic, Scottsdale, AZ) presented *Cereblon Expression Predicts Response, Progression-Free and Overall Survival after Pomalidomide and Dexamethasone Therapy in MM*. We first learned about cereblon (CRBN) at ASH 2011, and the five abstracts presented at ASH 2012 deepened our knowledge of this direct protein target for immunomodulatory drugs (IMiDs®). Dr. Schuster demonstrates the potential utility of testing for CRBN in the clinical setting.

Circulating Plasma Cells

Dr. Malek Faham (New York University Clinical Cancer Center, New York, NY) presented *Detection of MM Cells in Peripheral Blood Using High-Throughput Sequencing Assay*. A cohort of MM patients was assessed using a highly sensitive new technique to see if minimal residual disease (MRD) could be detected in peripheral blood rather than in the bone marrow. This new assay was able to identify myeloma clonotypes in peripheral blood MM cells in 93% of patients.

Dr. Bruno Paiva (Hospital Universitario de Salamanca, Salamanca, Spain) presented *Phenotypic, Functional, and Circadian Characterization of Peripheral Blood Multiple Myeloma Circulating Tumor Cells (CTCs)*. Dr. Paiva studied the movement of CTCs from the bone marrow to the peripheral blood. CTCs are quiescent, non-proliferative cells, and like hematopoietic stem cells, they are modulated by the circadian rhythm, peaking during patients' resting hours to colonize other sites in the bone marrow. These may be the cells involved in metastasis.

Hevylite®

Dr. Mark Drayson (University of Birmingham, Birmingham, UK) presented *Immunoglobulin Heavy/Light Chain Measurements During Monitoring Provide Prognostic Information of Relapse After Therapy in MM*. The researchers studied IgA MM patient samples from the MRC IX trial, and presented data suggesting that immunoglobulin heavy/light chain assay (HLC) ratios may be better markers of residual disease in IgA patients than electrophoretic methods, and that normalization of both FLC and HLC ratios may be more valuable for them than the prognostic value of stringent complete response (sCR).

PET

Dr. Saad Usmani (University of Arkansas for Medical Sciences, Little Rock, AR) presented *18-FdG Pet Focal Lesion and Avidity Suppression as Early as Day 7 Post-Induction Chemotherapy Predicts for Superior Outcome in Newly Diagnosed MM Patients Treated with TT3 Trials*, a study of the PET scans of patients treated at UAMS, which determined that changes in lesions could be seen very early, and that prognosis could be determined by the number of lesions that were PET-avid on day 7 post-initiation of therapy.

Step 3. Initial Treatment Options.

Kyprolis® (carfilzomib)

Dr. Pieter Sonneveld (Erasmus University, Rotterdam, The Netherlands) presented abstract 333: *Carfilzomib Combined with Thalidomide and Dexamethasone Is a Highly Effective Induction and Consolidation Treatment in Newly Diagnosed Patients with MM Who Are Transplant Candidates*. This phase II study was conducted to determine the safety, effectiveness, maximum tolerated dose, response rate (RR), and progression-free survival of 50 newly diagnosed patients. After transplant and consolidation, the overall RR was 90%, and the CR rate was 35%.

Dr. Joseph Mikhael (Mayo Clinic, Scottsdale, AZ) presented *Results from the Phase II Dose Expansion of Cyclophosphamide, Carfilzomib, Thalidomide,*

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and Dexamethasone (CyClone) in Patients with Newly Diagnosed MM. The rationale for this quadruple regimen is based on the worldwide availability and minimal toxicity of the drugs. Treatment was for four cycles prior to stem cell harvest. The regimen was highly effective and well tolerated.

Dr. Antonio Palumbo (University of Torino, Torino, Italy) presented *Carfilzomib, Cyclophosphamide, and dexamethasone (CCd) for Newly Diagnosed MM Patients*.

This study evaluated induction and maintenance therapy with CCd in patients over 65 years of age or transplant ineligible. CCd was given for 9 cycles, followed by carfilzomib monotherapy maintenance until disease progression. 100% of patients had at least a partial response (PR) by the end of cycle 9.

Dr. Neha Korde (National Cancer Institute, National Institutes of Health, Bethesda, MD) presented *Phase II Clinical and Correlative Study of Carfilzomib, Lenalidomide, and Dexamethasone (CRd) in Newly Diagnosed MM Patients*. Minimal residual disease (MRD) status by flow cytometry revealed that all 10 nCR/SCR patients (of the 45 patients in the study) are MRD negative. Severe toxicities were limited, and responses were rapid and deep.

Velcade® (bortezomib)

Dr. Antonio Palumbo (University of Torino, Torino, Italy) presented *Overall Survival Benefit for Bortezomib-Melphalan-Prednisone-Thalidomide Followed by Maintenance with Bortezomib-Thalidomide (VMPT-VT) Versus Bortezomib-Melphalan-Prednisone (VMP) in Newly Diagnosed MM Patients*. Dr. Palumbo posed this study as “the best experimental therapy versus the best standard of care.” He was particularly interested in the synergy between a proteasome inhibitor and an IMiD that was introduced in the experimental arm. The 4-drug regimen provided better disease control, but may be too toxic for patients older than 75 years.

Dr. Gunjan Shah (Tufts Medical Center, Boston, MA) presented *Subcutaneous (SQ) Bortezomib in Combination Regimens in Newly Diagnosed Patients with MM or Systemic AL Amyloidosis*, a retrospective study of 19 newly diagnosed patients with MM or AL, and determined that with the use of SQ Velcade in combination regimens, only 5% of patients required dose reductions of Velcade for thrombocytopenia.

Dr. David Simpson (North Shore Hospital, Auckland, New Zealand) presented *Once-Weekly SQ Bortezomib with Cyclophosphamide and Dexamethasone Is Well-Tolerated and Effective as Initial Treatment in Symptomatic MM*. All newly diagnosed patients at this institution were treated with CyBORd. Patients who proceeded to transplant were given VTD consolidation for four cycles. Treatments were well tolerated, and responses improved with each cycle of treatment.

MLN 9708

Dr. Shaji Kumar (Mayo Clinic, Rochester, MN) presented *A Phase I/II Study of Weekly MLN9708, an Investigational Oral Proteasome Inhibitor, in Combination with Lenalidomide and dexamethasone in Patients with Previously Untreated MM*. MLN9708 is the first oral proteasome inhibitor. At the time of Dr. Kumar’s presentation, 92% of study patients had achieved ≥PR. Two phase III trials are currently enrolling patients, one for newly diagnosed and one for relapsed/refractory myeloma.

Step 4. Supportive Care.

Infections

Dr. Cecilie Blimark (Sahlgrenska University Hospital, Gothenburg, Sweden) presented *MM and Infections, a Population-Based Study Based on 9,610 MM Patients*. The infection rate of patients in the Swedish Cancer Registry was compared to almost 38,000 healthy controls. It was determined that MM patients’ rate of infection increased in the age of novel therapies, necessitating trials of prophylactic measures.

Bisphosphonate Therapy

Dr. Noopur Raje (Massachusetts General Hospital, Boston, MA) presented *Bone Marker-Directed Dosing of Zoledronic Acid for the Prevention of Skeletal Complications*

Patients and Caregivers at ASH 2012

Several myeloma patients, caregivers, and support group leaders from around the country joined the approximately 18,000 healthcare professionals attending the recent 54th Annual Meeting and Exposition of the American Society of Hematology (ASH) in Atlanta, Georgia. Their participation at the conference was sponsored by the International Myeloma Foundation (IMF).

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

Held December 8-11, 2012, at the Georgia World Congress Center, ASH is the premier hematology conclave in the world. Some 300 companies, publishers, and nonprofit organizations were on hand in the state-of-the-art exhibit hall, the IMF and its members among them.



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

Teresa is a registered nurse with more than 20 years experience, and a veteran in the area of transplantation at the Mayo Clinic in Rochester, Minnesota. Teresa is an international speaker on myeloma, a member of the IMF’s Nurse Leadership Board (NLB), and a facilitator of the myeloma support group in Rochester.

While Teresa’s role at ASH was to interpret the information being presented “to further the advocates’ knowledge and perspective,” she actually credits those patients with broadening her own perspective. “I’m honored to have been a part of this marvelous experience. Four days in a group of people filled with energy, passion, and a drive to further the science of myeloma,” is how she describes it.



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

Jack, who was diagnosed with myeloma in 1995, recalls: “I enjoyed watching debates among myeloma experts. But if even they disagree about treatment and maintenance regimens, how are the patients to know what’s best for us? While we might get frustrated not having definitive answers, we must keep in mind that this is a lot better than NOT having therapy options. 18 years ago, I was given a choice between only two available treatments. ASH 2012 was educational and inspirational, and I’m already looking forward to ASH 2013 in New Orleans!”



Yelak Biru
Co-Leader, North Texas MM Support Group

Yelak was diagnosed with myeloma at age 26, more than 15 years ago. While the very word “cancer” frightened his family, Yelak tackled his condition with his typical positive outlook. “I was happy it was me and not someone else I loved who had myeloma,” he says. “I knew if anyone can fight the disease and cope with its treatments, I can. ASH is an annual gathering that gives ongoing hope to people like me. My goal, when I was first diagnosed, was to live five years. Fifteen years after diagnosis, my goal now is to wait for The Cure.”



Nancy Bruno
Co-Leader, Atlanta MM Support Group Leader
IMF Southeast Regional Director of Support Groups

“Myeloma was a foreign term to us when my husband Mike was diagnosed in 1998,” says Nancy. “Doctors told him he had two to three years to live. Now there is so much good news from the myeloma researchers, which makes this an exciting time for today’s patients. I am looking forward to sharing the information and the hope with others.”

CONTINUES ON PAGE 6

CONTINUES ON PAGE 7

in Patients with MM. The final results of the Z-MARK study, which used levels of urinary N-telopeptide, a marker of bone resorption, to determine if patients could receive zoledronic acid (ZA) every three months instead of monthly show that it is feasible and safe to give bisphosphonate therapy every three months, although we don't yet know if urinary N-telopeptide is the best marker to use.

Second Primary Malignancy (SPM)

Dr. Vaishali Sanchorawala (Boston University School of Medicine, Boston, MA) presented *Risk of Second Primary Malignancies in Patients with AL Amyloidosis Treated with Lenalidomide*. While longer follow-up may be necessary to ascertain the results of this post hoc study, it appears that the use of Revlimid therapy following melphalan does not increase the risk of SPMs in AL amyloidosis patients.

Dr. Guillemette Fouquet (Hopital Claude Huriez, Lille, France) presented abstract 2964: *Efficacy and Safety Profile of Longterm Exposure to Lenalidomide in Relapsed MM*. None of the patients with more than three years exposure to lenalidomide had a SPM. 62% of patients remained on lenalidomide beyond three years, reflecting a good safety and tolerability profile.

Step 5. Transplant.

There were not many oral sessions on transplant in MM at ASH 2012, but many poster presentations brought forth new ideas for tweaking conditioning regimens and assessing risk in transplant patients. We highlight three important studies, two of them concerning allogeneic transplant and a third assessing the role of Velcade in high-risk patients undergoing autotransplant.

Allogeneic Transplant

Dr. Mauricette Michallet (Centre Hospitalier Lyon Sud, Pierre Benite, France) presented *Allogeneic Hematopoietic Stem Cell Transplantation in First-Line High-Risk MM Patients*. Much discussion has taken place among researchers around the concept of treating high-risk MM patients with allo transplant as a front-line therapy rather than waiting for late relapse. This important study demonstrated significantly improved PFS and OS among the patients treated with auto/mini-allo followed by IMiD therapy with Velcade plus donor lymphocyte infusion (DLI) when compared to patients who received auto/mini-allo alone.

Dr. William Bensinger (Fred Hutchinson Cancer Research Center, Seattle, WA) presented abstract 3064: *Lenalidomide Is Effective Therapy for Relapse after Allogeneic Stem Cell Transplant for MM*. Because a prior study using Revlimid as maintenance therapy post-allo transplant had caused unacceptable rates of graft versus host disease (GVHD), there had been a general feeling that Revlimid was not an option following allo transplant. This study demonstrated the efficacy of Revlimid given to patients who have relapsed following allo transplant, and that it is possible to capitalize on the new immune system generated by the donor's cells without causing high rates of GVHD.

Autotransplant

Dr. Michele Cavo (Bologna University School of Medicine, Bologna, Italy) presented *Impact of Bortezomib Incorporated into Autotransplantation on Outcomes of MM Patients with High-Risk Cytogenetics*, an analysis of patients enrolled in four European studies. The analysis of patients treated with induction regimens containing Velcade before single or double autotransplant revealed that Velcade incorporated into either single or double autotransplant significantly increases duration of CR throughout the treatment program. More mature data is needed for OS follow-up.

Step 7. Consolidation and/or Maintenance.

Dr. Laura Rosinol (Hospital Clinic de Barcelona, Barcelona, Spain) presented *Maintenance Therapy after Stem Cell Transplantation for MM with Bortezomib/Thalidomide vs. Thalidomide vs. alfa2b-Interferon*. All patients in this Pethema/GeM randomized trial were given VTD induction followed by autotransplant. Results of the maintenance phase of the trial demonstrate that while PFS was significantly longer with VT than with the other two maintenance regimens, OS was not significantly different among the three arms at a median follow-up of almost three years, nor was the incorporation of Velcade able to overcome the impact of poor-risk cytogenetics.

Step 9. Treatment at Relapse.

Step 10. New Clinical Trials.

As is always the case at ASH, there were many presentations involving therapies new and old to treat relapsed/refractory MM, which remains a highly active area of study. The following look to be most promising.

Pomalyst® (pomalidomide)

There were seven presentations on combination therapies with Pomalyst for relapsed/refractory MM, all with excellent results:

- pomalidomide + carfilzomib + dexamethasone
- pomalidomide + cyclophosphamide + prednisone
- clarithromycin + pomalidomide + dexamethasone
- pomalidomide + dexamethasone
- pomalidomide + cyclophosphamide + dexamethasone
- pomalidomide + bortezomib + dexamethasone.

Monoclonal Antibodies

In addition to the by now well known first monoclonal antibody used in MM, elotuzumab, there were presentations on early studies of daratumumab (anti-CD 38), BT062 (anti-CD 138), tabalumab (anti-BAFF), and lorvotuzumab mertansine (anti-CD 56). Daratumumab is the most exciting of these promising antibodies, having demonstrated early single-agent activity at ASH 2011.

Proteasome Inhibitors

Two new oral proteasome inhibitors deserve mention here, MLN9708 and ONX0912 (or oprozomib).

Dr. Giampaolo Merlini (Amyloidosis Research and Treatment Center, Fondazione IRCCS Policlinico San Matteo, University of Pavia, Pavia, Italy) presented *MLN9708, a Novel, Investigational Oral Proteasome Inhibitor, in Patients with Relapsed or Refractory Light-Chain AL Amyloidosis*. Previously treated patients who had CR or better after three cycles of MLN9708 remained on single-agent MLN9708; those who had <PR were given MLN9708 with dexamethasone weekly. The overall response rate was 60%, and aside from thrombocytopenia, side effects were mild.

Dr. Michael Savona (Sarah Cannon Research Institute, Nashville, TN) presented *A Phase Ib Dose-Escalation Study of Split-Dose Oprozomib in Patients with Hematologic Malignancies*. This study of ONX0912 in heavily pretreated patients has not reached MTD, and thrombocytopenia was the only grade 3-4 adverse event. There was one PR and one minimal response (<PR) in patients with MM.

HDAC Inhibitors

Dr. Noopur Raje (Massachusetts General Hospital, Boston, MA) presented the preliminary data from the first-in-humans study, *Rocilinostat (ACY-1215)*,

CONTINUES ON NEXT PAGE

a *Selective HDAC6 Inhibitor, Alone and in Combination with Bortezomib in MM*. At the second dose level, researchers are seeing responses, and there have been no dose-limiting toxicities or serious side effects.

There were several abstracts on panobinostat, including one from **Dr. Paul Richardson** (Dana-Farber Cancer Institute, Boston, MA), *PANORAMA 2: Panobinostat Combined with Bortezomib and Dexamethasone in Patients with Relapsed and Bortezomib-Refractory MM*. Dr. Richardson's study combines panobinostat with Velcade and dexamethasone in patients refractory to Velcade to see if the drug combination can restore bortezomib sensitivity. One third of these Velcade-refractory patients had >PR, and median OS had not been reached at 8.1 months.

Other New Drugs

Dr. Shaji Kumar (Mayo Clinic, Rochester, MN) presented data from a trial of a novel CDK inhibitor dinaciclib (SCH727965) in patients with relapsed MM, which demonstrates encouraging single-agent activity. Ongoing studies are evaluating different dosing schedules and combination therapy with proteasome inhibitors.

Dr. Wenming Chen (Chaoyang Hospital of Capital Medical University, Beijing, China) presented data from a study that is particularly interesting because it is the first drug developed for MM in China. Recombinant circularly permuted TRAIL (CPT) is a novel targeted therapy for the treatment of relapsed or refractory MM.

Dr. Heinz Ludwig (Wilhelminenhospital, Vienna, Austria) presented data from a trial of bendamustine-bortezomib-dexamethasone (BBD) in a heavily pretreated relapsed/refractory MM patient population. Bendamustine, an alkylating agent marketed in the US for CML as Treanda®, is well tolerated and shows significant activity.

Dr. Jatin Shah (MD Anderson Cancer Center, Houston, TX) presented on ARRY-520, a kinesin spindle protein inhibitor that uses a novel mechanism of action for MM cells and has no cross-resistance with other anti-MM drugs. All patients on the study were "triple refractory" (to Velcade, Revlimid, and dexamethasone) and had at least two prior lines of therapy. The overall response rate with single-agent ARRY-520 was 16%, and 22% with dexamethasone added.

Dr. Nikhil Munshi (Dana-Farber Cancer Institute, Boston, MA) presented early evidence of anabolic bone activity of single-agent BHO880, a fully human anti-DKK1 neutralizing antibody, in previously untreated patients with high- and intermediate-risk SMM. There is preliminary evidence of increased vertebral strength at 6 months with quantitative computed tomography.

Dr. Aaron Rapoport (Greenebaum Cancer Center, University of Maryland, Baltimore, MD), who works extensively with genetically engineered autologous T-cells, presented two studies:

Data from *Combination Immunotherapy after ASCT for MM using MAGE-A3/Poly-ICIC Immunizations Followed by Vaccine-Primed and Activated Autologous T-Cells* shows that T-cell infusions were well tolerated with no ≥ grade 3 toxicity.

Adoptive Transfer of Gene-Modified T-Cells Engineered to Express High-Affinity TCRs for Cancer-Testis Antigens NY-ESO-1 or Lage-1 in MM Patients Post ASCT was the first study using gene engineered cells (GEC) in MM. It has been established that using GEC after autotransplant is safe, well tolerated, and effective. A study using GEC without autotransplant is being planned.

• • •

In Summary

There was much to learn at ASH 2012, and we have much to look forward to in the coming months and years as our knowledge of MM and the tools to treat it continue to expand. **MT**



Cindy Chmielewski
Member, Philadelphia MM Networking Group

Cindy was diagnosed in 2008, and she quickly assumed an active role in the myeloma community. She reaches out to fellow patients and others via Twitter using the appropriate handle "@MyelomaTeacher" to pass along research news, identify noteworthy articles on the subject, and create an online community of those interested in learning as much as they can about this disease. "I have learned to live with myeloma," says Cindy. "And I try to help others deal with this unpredictable, unique disease."



Pat Killingsworth
Co-Leader, Nature Coast MM Support Group

Pat first began treatment for myeloma six years ago. After a relapse a year ago, he underwent "nine long months" of drug therapy and is now once again in remission. Pat is a medical writer and he has written three books about myeloma. Whenever his health allows, he travels across the country speaking to patients, nurses, and physicians. His story stresses the importance of patient education – and lots of hope. Pat is also a frequent blogger. "Attendance at ASH armed me with a lot of valuable information to pass along to others."



Jim Omel, MD
Co-Leader, Central Nebraska MM Support Group

A full-time caregiver for his wife, who is afflicted with multiple sclerosis, Dr. Omel was diagnosed with myeloma in 1997. In 2000, he retired from active medical practice and began a new role as patient advocate. He served on the National Cancer Institute (NCI) advocacy board Director's Consumer Liaison Group (DCLG), as well as on NCI's Board of Scientific Advisors (BSA). Dr. Omel represented patients on the U.S. Food and Drug Administration (FDA) Oncologic Drugs Advisory Committee (ODAC) during review of carfilzomib (Kyprolis™) leading to its approval. His role as co-leader of the his support group is augmented with efforts on behalf of the Alliance Cooperative Group, CIBMTR, Moffitt Cancer Center, and his local hospital board.



Cindy Ralston
Kansas City Metro MM Support Group Leader

Prior to her 1996 diagnosis, Cindy had never heard of myeloma. "Thankfully, I found the IMF," she says. That same year she helped start the Kansas City Metro MM Support Group, and she has been an active member of the myeloma community ever since. A long-term myeloma survivor, Cindy was one of the many success stories present at ASH. "Like myeloma support groups, ASH gives hope to so many people," says Cindy. "With the help of the IMF, our community continues to grow and offer more and more support to myeloma patients."



Paula Van Riper
Leader, Central New Jersey MM Support Group

"At ASH 2012, I had a first-hand opportunity to learn about cutting-edge myeloma research," says Paula, a 13-year myeloma veteran. "The IMF's Myeloma Symposium, which kicked off the conference, had more than 700 doctors in attendance! The scientific data could be quite dense, but Teresa Miceli helped us understand more fully the information we were gleaming from the presentations. The conference was a wealth of hope and inspiration. I am immensely grateful to the IMF for making sure that patients have access to the latest information on myeloma." **MT**

Editor's Note: The complete text of the IMF's ASH 2012 *Multiple Myeloma Highlights* digital publication is available for at ash.myeloma.org, and a printed copy can be requested by emailing theIMF@myeloma.org or calling 800-452-CURE (2873).

2013 IMF RESEARCH GRANTS

For the past 18 years, the International Myeloma Foundation (IMF) Research Program has been funding promising clinical investigators from around the world in an effort to improve outcomes for patients with multiple myeloma (MM). The IMF funds several research grants, including the Brian D. Novis Research Award, which honors the IMF's founder Brian Novis, who died of myeloma in 1992. The IMF grants are provided through donations from private individuals, and are presented annually.

The IMF-funded research has led to many publications, enabled investigators to become established in the field of MM, made important contributions to understanding the biology of MM, as well as supported the development



2013 Brian D. Novis Senior Research Grants

A Brian D. Novis Senior Research Grant for 2013 was awarded to **Manoj Pandey, PhD**, of Pennsylvania State University, College of Medicine, Hershey, Pennsylvania. The purpose of Dr. Pandey's study is to delineate the biological significance of NF-κB inhibition in MM cells using a novel NF-κB inhibitor gambogic acid (GA). Bone marrow microenvironment promotes MM cell growth and resistance to conventional therapies. Activation of nuclear factor (NF)-κB has been associated with the pathogenesis of MM; therefore, NF-κB would be a potential target to prevent MM. This study will provide the framework for clinical evaluation of GA, alone and in combined therapies, to improve patient outcome in MM.

Another Brian D. Novis Senior Research Grant for 2013 awarded to **Jetze J. Tepe, PhD**, of Michigan State University, East Lansing, Michigan. Current myeloma treatment often involves proteasome inhibition, but nearly all patients (~97%) become resistant and/or intolerant within months to years following treatment. Dr. Tepe's research investigates the mechanism of a new type of proteasome regulation by TCH-compounds, which are highly effective against myeloma in cell culture and in vivo, and act additively with and overcome resistance to Velcade® (bortezomib).

2013 Brian D. Novis Junior Research Grants

A Brian D. Novis Junior Research Grant for 2013 was awarded to **Antonia Cagnetta, MD**, of Dana-Farber Cancer Institute, Harvard Medical School, Boston, Massachusetts. Dr. Cagnetta was also a recipient of a Brian D. Novis Junior Research Grant for 2012. Despite recent advances with new drugs, MM remains an incurable disease. Used as single agent, new agents have shown marked antitumor activity, but the number of patients with relapsed and refractory disease remains high. The combination of these agents with other classes of drugs offers great promise to improve patient outcome. This year, Dr. Cagnetta will study in vitro and in vivo effect of a combination therapy with new compound FK866 and Velcade (bortezomib) and provide the rationale for advancement of this combination into clinical development.

Brenda De Keersmaeker, MsC, PhD, of Vrije Universiteit Brussel, Brussels, Belgium, proposes that a main target in the road towards cure is the eradication of residual disease, for instance by specific immune cells. Dr. Keersmaeker's research project involves the preclinical evaluation of a new MM immunotherapeutic strategy integrating two major recent developments. The first is the introduction of Revlimid® (lenalidomide), a drug with immunomodulatory properties. The second is MM immunotherapy, which could boost the immune system towards killing tumor cells.

of better therapies. We are certain that the work of the recipients of the 2013 IMF research grants will continue to contribute significantly to the field of myeloma.

The IMF grants are funded by donations from private individuals: Senior Research Grant projects are funded in the amount of \$80,000 and Junior Research Grant projects are funded at \$50,000. The presentation ceremony for the 2013 IMF Research Grant awards took place during the 54th annual meeting and exposition of the American Society of Hematology (ASH) in Atlanta, Georgia.

Thang Van Nguyen, PhD, California Institute of Technology, Howard Hughes Medical Institute, Pasadena, California, aims to identify binding partners of cereblon (CRBN) using proteomic technologies and to assess the effects of immunomodulatory drugs (IMiDs®) on the ubiquitination and degradation of CRBN substrates. A recent study, aiming to investigate the role of CRBN in MM, reported that CRBN is required for the anti-myeloma effects of IMiDs in vitro and that MM cell lines, isolated for resistance to IMiDs, carry deletions in the CRBN gene, suggesting that formation of an IMiD-CRBN complex accounts for the therapeutic effect of IMiDs in MM. Dr. Nguyen's research will provide insights critical for understanding how IMiDs modulate myeloma disease biology.

Els Van Valckenborgh, PhD, of Vrije Universiteit Brussel, Brussels, Belgium, will investigate how the tumor cells regulate the generation, expansion, and function of myeloid-derived suppressor cells (MDSC). In myeloma it has been demonstrated that the immune system is not working efficiently, resulting in the development and growth of tumor cells. Several cell types exist that influence the immune system in a negative way, including MDSC. Understanding these mechanisms will help researchers better understand myeloma development and to develop new therapies to improve the treatment of patients.

2013 IMF Special Research Grant

The recipient of the 2013 IMF Special Research Grant is **Juan Du, MD, PhD**, of the Myeloma and Lymphoma Center, Shanghai Changzheng Hospital, Shanghai, China). Her project aims to establish a new prognostic model for myeloma in the novel agent era based on the ISS, FISH, and serum FLS (sFCL). Myeloma is a heterogeneous disease with variable disease course, response to therapy, and survival outcome. This variability derives from heterogeneity in both myeloma cell biology and multiple host factors. Therefore, identifying myeloma patients in risk groups with prognosis at diagnosis and relapse is critical for understanding disease outcome and optimizing treatment strategies. Dr. Du will explore incorporating ISS, FISH, and sFCL as a novel, well validated, and easily applied risk stratification model.

2013 IMF-Japan Research Grants

In addition to the 2013 Brian D. Novis Research Grants, two awards were presented by IMF-Japan to investigators working in the field of multiple myeloma.

Aki Horinouchi Research Grant

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

Tetsuro Sasada, MD, PhD

"Development of Novel Immunotherapy Against Multiple Myeloma"

Department of Immunology and Immunotherapy
Kurume University School of Medicine – Kurume, Japan

IMF-Japan Special Research Grant

Masaki Ri, MD, PhD

"Pursuit of Mechanisms Responsible for Bortezomib Resistance and the Way To Conquer It in Multiple Myeloma"

Department of Medical Oncology and Immunology
Nagoya City University Graduate School of Medical Sciences – Nagoya, Japan

MT

MYELOMA TODAY IN CONVERSATION WITH DR. RAFAT ABONOUR

Please tell us about your background in myeloma.

I received my medical degree at the University of Damascus in Syria. For my residency and fellowship, I came to the University of Wisconsin in Madison. I started seeing patients with myeloma and developed relationships with them that contributed to my interest in this disease. That was in the years before bisphosphonates, when we were seeing patients' bones crumble from the myeloma. There was a clear need develop treatments, and to help myeloma patients maintain a better quality of life.

For the past 18 years, I have been at the Indiana University (IU) School of Medicine. When I came to IU, there was really no myeloma program here. So, about 12 years ago, I started building one. At the time I was the only physician here working in myeloma, but now there are five of us. At IU, I am now Professor of Medicine and Professor of Pathology and Laboratory Medicine, as well as Director of IU Melvin and Bren Simon Cancer Center Adult Clinical Research Office.

I am a member of the myeloma committee at the Eastern Cooperative Oncology Group (ECOG), one of the largest clinical cancer research organizations in the United States, and I am part of the CORE Science Solutions (CSS) Academic Myeloma Consortium (AMyC). This consortium is an innovative research model that combines expertise in the operational components of oncology clinical research with a group of key opinion leaders in myeloma treatment and translational research. Being able to conduct clinical trials quickly enables us to bring a new standard of care to the management of patients with myeloma.

Speaking of clinical trials, please tell us about the Car-Pom-d.

In the past, we were satisfied if our patients had a partial response (PR) to treatment. But now we have in our arsenal amazing novel drug combinations that are resulting in complete remissions (CR) for many patients. There are patients in my practice who have had myeloma for more than 20 years, but not many of them, which I think will change soon.

Unfortunately, most patients eventually become refractory to the therapies that had previously worked well for them. So the question we asked ourselves at AMyC was, "Can we come up with a novel combination?" We had previous experience combining immunomodulatory drugs (IMiDs[®]) with a proteasome inhibitor, so it was obvious to us that a newer-generation IMiD plus a newer-generation proteasome inhibitor will be successful.

I was lucky to treat the very first patient with a combination of Kyprolis[®] (carfilzomib), Pomalyst[®] (pomalidomide), and dexamethasone (Car-Pom-d). This patient had very aggressive refractory disease. Today, more than a year and a half after enrolling in our Car-Pom-d clinical trial, this patient is still doing extremely well.

We completed the phase I component of the clinical trial successfully, establishing the safe dose of both Kyprolis and Pomalyst, and presented the data at the 2012 Annual Meeting of the American Society of Hematology (ASH) in December. Even in phase I, we saw a significant response rate. We have now moved on to phase II component of the trial, and I have many patients taking part, with most of them having significant responses to this therapy. Not only are we achieving CR, but we are achieving lasting remissions with minimal toxicity.



*Rafat Abonour, MD
IU Melvin and Bren Simon Cancer Center
Indiana University School of Medicine
Indianapolis, IN*

Which side effects have you seen with Car-Pom-d?

Some of the side effects we've seen in the first cycle were fluid retention and congestive heart failure, but for the most part these side effects were managed successfully in the outpatient setting, although a couple of patients were hospitalized for 2-3 days. We have not seen peripheral neuropathy or blood count drops significant enough to require transfusions. After the first cycle, we are seeing the majority of patients doing well, without the need for dose reduction.

What is next for Car-Pom-d?

Car-Pom-d is a very exciting combination that is active in multiply treated and refractory patients. Several academic centers are involved in the study and we are accruing patients rapidly. Given the limited side effects we have observed, the natural progression of this combination therapy would be to use it earlier in the disease course in order to get more patients into a good remission quickly. Car-Pom-d as frontline therapy for myeloma would be a reasonable and important question for us to answer.

Where do you see the field of myeloma research heading?

What I find incredibly encouraging is the level of collaboration among myeloma researchers. AMyC is just one example of this. Major myeloma institutions are working together to tackle the challenges we are facing on the way to finding a cure. We need more and better combination therapies, using different classes of drugs together to overcome disease resistance and produce more complete responses. In many trials, CR is associated with improved survival of patients with myeloma, and the more patients we are able to have achieve enduring CRs, the closer we get to a cure. We also need to better define minimal residual disease (MRD) in myeloma, and arrive at a better classification of this disease and better techniques to identify patients. This is very important. Myeloma is not created equal. Each patient is different. And there is a small subset of patients who have very ugly myeloma, and we need to find a way to better identify and treat their disease.

In my opinion, retrospective analysis is not the best way to study myeloma. Designing large prospective trials may be a more productive way to discover better treatments. This is such an exciting time in myeloma and my overall outlook is very optimistic. We are seeing incredible and lasting responses like never before. I do believe this will one day get us to the home run of a cure.

Besides myeloma research, you are also involved in raising myeloma awareness. Please tell us about that.

One important thing to acknowledge is that most members of the myeloma community are very educated about their disease. The IMF has done an excellent job in facilitating this. Many of my patients attend IMF seminars and workshops, giving them a better understanding of myeloma and its treatments. A strong network of support groups is also instrumental in keeping patients connected and informed.

Every fall since 2005, I set off on a two-day trek crisscrossing Indiana to raise awareness of myeloma and funding for research. I am an avid runner and marathoner, so initially the event consisted of a day of running and a day of cycling, but now it is two days of bike riding. I spend most of my summer training. If I'm not on call, I'm on the road getting ready.

CONTINUES ON PAGE 12



SUBCUTANEOUS VELCADE® (BORTEZOMIB)

Overview and Introduction

On December 4th, in conjunction with the 2012 American Society of Hematology (ASH) Annual Meeting, nine members of the International Myeloma Foundation (IMF) Nurse Leadership Board (NLB) gathered to discuss subcutaneous (SQ) administration of Velcade® (bortezomib) in patients with multiple myeloma (MM). The NLB is a committee of nurses from leading MM treatment centers who develop recommendations in nursing care for MM patients. The resulting NLB report, which appears in an abridged format below, shares highlights from the December 4th discussion, as well as practice recommendations.

Velcade is a proteasome inhibitor indicated for the treatment of patients with MM. It was first approved by the US Food and Drug Administration (FDA) in 2003 as an intravenous (IV) formulation, and was approved for SQ administration in January 2012 after a pivotal phase III investigation demonstrated that Velcade SQ was noninferior to Velcade IV in terms of efficacy in patients with relapsed MM. Velcade SQ also appeared to offer an improved safety profile with a reduction in the incidence and severity of peripheral neuropathy.

Current Velcade Use

Over the past year, approximately 80% of patients have converted from Velcade IV to Velcade SQ. All board members currently administer Velcade SQ and have witnessed increasing use in their own practices and practices in their surrounding communities since FDA approval. In some instances, clinical protocols have been amended to include Velcade SQ as a routine component of care. The point at which Velcade SQ is introduced into the treatment cycle varies from institution to institution. Some institutions start newly diagnosed patients on Velcade SQ, with the idea that they would rather start patients on a therapy with the least risk for neuropathy; while others prefer to initiate newly diagnosed patients on Velcade IV and then will later switch to Velcade SQ. This may be influenced by the fact that Velcade SQ approval was based on a clinical trial that focused on MM patients with relapsed disease.

Often patients are risk-stratified for Velcade SQ use (e.g., patients who are at greater risk for neuropathy, older patients, and patients on maintenance therapy are more likely to receive SQ administration). Data specific to high-risk MM patients receiving Velcade SQ is limited, thus, these patients generally receive IV therapy. Many patients who start on Velcade IV may be changed to the SQ route once their health care providers become familiar with the FDA approval, efficacy, and safety profile for Velcade SQ. Other factors that may influence the use of Velcade SQ include patient preferences. For example, patients who dislike injections and patients who mention aesthetic concerns

regarding skin changes are more likely to prefer the IV formulation. Overall, most patients are happy to try a new modality and are open to using Velcade SQ. In fact, secondary to patient-focused education, MM patients are beginning to request Velcade SQ from their providers, even in practices where IV use is standard.

Experiences with Administration

Members agreed that patients on Velcade SQ remained on therapy longer than IV patients, but noted that while this could be a factor of a superior Velcade SQ therapeutic index, it could also result from the weekly dosing schedule that is often associated with Velcade SQ.

Injection site irritation is one of the most common challenges with Velcade SQ. Members offered a series of recommendations that have been successful in their practices for improving SQ administration and mitigating injection site irritation including: calibrating needle size to the amount of SQ fat, ensuring that the drug is room temperature before it is administered into the body, offering the Velcade IV formulation (1 mg/mL instead of 2.5 mg/mL) split between two SQ injections, and using the air-sandwich technique.

Dosing and Side Effect Management

Because data have shown that a once weekly schedule of Velcade in maintenance patients is as efficacious as twice weekly dosing, and can result in less neuropathy and hematologic toxicity, many maintenance patients receive Velcade on a once weekly basis. Members commented that patients who have lost response to Velcade on a once weekly schedule are, however, often able to regain response when they are transferred to twice weekly dosing. In fact, at signs of disease progression several members first consider augmenting patients' treatment schedules before they consider adding another agent or switching patients to different therapy.

In addition to changes to enhance efficacy, dose alterations can be used to improve tolerability. Members had significant experience dose-reducing Velcade to mitigate side effects, though most typically do not go below 1 mg/m². In the rare instances that the 0.7 mg/m² dose is used it is administered in patients with liver disease and severe neuropathy. Members emphasized that while Velcade SQ causes significantly less neuropathy than Velcade IV, neuropathy can and does occur in SQ patients. As such, it is important for nurses to continue to assess patients for neuropathy at every visit, even when they are on the SQ formulation.

Patients with MM can experience cytopenia as a result of the progression of their disease, or as a side effect of Velcade therapy. Therefore, members are cautious

CONTINUES ON PAGE 12

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WHAT IS POMALYST® (POMALIDOMIDE) AND HOW IS IT USED?

What is Pomalyst® (pomalidomide) and how is it used?

Pomalyst® (pomalidomide) is a capsule taken by mouth. Pomalyst is the newest oral immunomodulatory drug (IMiD®). IMiDs can modify or regulate the functioning of the immune system. Since myeloma is a cancer of certain cells in the immune system, IMiDs are particularly effective anti-myeloma agents. Pomalyst is chemically related to Thalomid® (thalidomide), which came into use against myeloma in the early 2000s, and Revlimid® (lenalidomide), which was approved by the FDA in 2006, but Pomalyst has been enhanced to be more effective.

Pomalyst in combination with dexamethasone, an oral adrenocortical steroid, was approved by the US Food and Drug Administration (FDA) on February 8, 2013. Pomalyst is a thalidomide analogue indicated only for patients with relapsed/refractory myeloma who have received at least two prior therapies including Revlimid and Velcade® (bortezomib), and have demonstrated disease progression on or within 60 days of completion of the last therapy. FDA approval was based on response rate. Clinical benefit, such as improvement in survival or symptoms, has not been verified.

The IMF organizes our educational information according to the 10 Steps to Better Care®, from diagnosis (Step 1) through clinical trials and how to find them (Step 10). Information relevant to each step along the way, including guidelines for testing, treating, transplanting, assessing response, managing side effects, monitoring, and treating relapsed disease, is available on the IMF website under the appropriate step on the path to better care. Pomalyst fits into the 10 Steps to Better Care schema in:

- Step 4 – Supportive Care (managing side effects)
- Step 9 – Relapse: Do you need a change in treatment?
- Step 10 – New clinical trials.

Pomalyst is swallowed with water once a day as a whole capsule, taken two hours before or after a meal. Pomalyst is given orally at 4 mg per day on days 1 to 21 of repeated 28-day cycles until disease progression. The recommended dose of dexamethasone is 40 mg per day on days 1, 8, 15, and 22 of each 28-day cycle. Pomalyst capsules are manufactured in 1 mg, 2 mg, 3 mg, and 4 mg strengths. Your doctor will determine if it is necessary and/or appropriate to treat you with less than the recommended 4 mg dose.

Data from the large, randomized, international phase III MM-003 clinical trial for 455 patients with relapsed/refractory myeloma was presented at the December 2012 American Society of Hematology (ASH) meeting in Atlanta, Georgia. This trial was designed to compare the combination of 4 mg of Pomalyst given for 21 days of a 28-day cycle plus low-dose dexamethasone at 40 mg of dexamethasone given once every week (20 mg weekly for patients older than 75 years), with high-dose



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

dexamethasone at 40 mg days 1-4, 9-12, and 17-20 in a 28-day cycle (20 mg for patients older than 75 years). Patients had to have been previously treated with at least two consecutive cycles of Velcade and Revlimid, either alone or in combination, and to have had disease progression while on therapy or within 60 days of completing their last myeloma therapy. At a pre-specified time point, interim overall survival (OS) was assessed and was determined to be significantly longer with Pomalyst plus low-dose

dexamethasone vs. high-dose dexamethasone. The Data Safety Monitoring Board for the study recommended immediate cross-over of patients on high-dose dexamethasone to Pomalyst plus low-dose dexamethasone.

At the same ASH meeting, Dr. Martha Lacy of the Mayo Clinic in Rochester, Minnesota, summarized the phase II data on 345 patients with relapsed/refractory myeloma who had been treated at Mayo in six sequential phase II trials with differing doses of Pomalyst plus a weekly 40-mg dose of dexamethasone. Across all six trials, partial response (PR, defined as at least a 50% or reduction in monoclonal protein) or better was seen in 34% of patients. At the 4-mg dose in patients refractory to both Velcade and Revlimid, 29% had a confirmed response rate greater than PR. Pomalyst plus low-dose dexamethasone was active and well tolerated even in heavily pretreated patients and in those with high-risk myeloma.

One of the most important discoveries about Pomalyst during lab studies is that it harms the developing fetuses of laboratory animals. Because Pomalyst is similar in chemical structure to thalidomide, which is known to harm human fetuses, Pomalyst should never be taken by pregnant women and women who are capable of becoming pregnant.

Pomalyst is present in the semen of male patients who take it, so they must also comply with mandatory contraceptive measures.

Because of the embryo-fetal risk, Pomalyst is available only through a restricted program under a Risk Evaluation and Mitigation Strategy (REMS) called "POMALYST REMS." Prescribers and pharmacists must be certified with the program; patients must sign an agreement form and comply with the requirements. You or your physician must report any suspected fetal exposure to Pomalyst to the FDA via the MedWatch program at 800-332-1088 and also to Celgene Corporation at 888-423-5436.

Female patients of child-bearing potential and all male patients are required to complete a monthly phone survey. Doctors must check monthly pregnancy tests, limit prescriptions to a 28-day supply, and report any pregnancies to the FDA.

Because many drugs are excreted in human milk and because of the potential for adverse reactions in nursing infants from Pomalyst, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

CONTINUES ON PAGE 12

Nurse Leadership Board

NLB — continued from page 10

about dose-reducing Velcade before they are able to determine the underlying cause of cytopenia. If cytopenia is thought to occur secondary to Velcade in patients who are clinically not requiring maximal therapy, then dose reduction is an option, but if cytopenia is related to disease progression then they treat through the cytopenia and offer support. If patients are experiencing cytopenia as an effect of disease progression, dose reduction of Velcade is not common due to the concern for further progression of disease.

Herpes virus reactivation has been associated with Velcade use, occurring in 6-11% of newly diagnosed and relapsed refractory patients. While it is recommended that patients on Velcade receive prophylactic antiviral therapy, members noted that there are many patients being treated with Velcade SQ who are not receiving antiviral medication. Members shared several cases of Velcade patients who developed shingles while on therapy and stressed the importance of Velcade patients receiving prophylactic antivirals, regardless of the mode of administration.

Members agreed that educational strategies about Velcade side effects that target nurses are needed.

Office Dynamics

Nurse practitioners and nurses are influential not only in caring for patients but also in changing clinical practice. While physicians ultimately

decide which drugs they want to prescribe, nurse practitioners and nurses have considerable influence over the types of drugs that are used, the type of administration that is chosen, and how long patients will remain on a particular therapy.

Members mentioned the convenience of treating Velcade SQ patients in the office in “injection rooms” separate from the area where other patients receive infusions. While this strategy can work in many of the patients on Velcade SQ, nurses must first carefully assess where patients are in their disease, the pace of their disease, the length of time that they have been on therapy, their tolerability to therapy, and their comorbidities. It is important that all patients receive appropriate face time with caregivers during their appointments. One practice that distributed nurses into teams according to tumor type (e.g., HCC team, MM team, lung team) found that allowing nurses to develop expertise in a particular disease has made a dramatic difference in the quality of patient care.

Closing Statement

Overall, members stated that Velcade SQ is increasingly becoming a standard of care for maintenance patients. While the NLB is pleased to report that neuropathy is less prevalent with SQ administration, it is important to evaluate all patients for neuropathy development. Members emphasized the continued need for nurse education around Velcade SQ administration and side effect management. **MT**

Education & Awareness

HOTLINE – POMALYST — continued from page 11

Cases of acute myelogenous leukemia have been reported in patients receiving Pomalyst in clinical trials, although none of these were patients in myeloma trials.

No formal drug interaction studies have been conducted with Pomalyst, which is primarily metabolized by CYP1A2 and CYP3A enzyme systems. Pomalyst is also substrate of P-glycoprotein (P-gp). You should not take Pomalyst with drugs that are strong inhibitors of CYP1A2, CYP3A, or P-gp. Cigarette smoking may reduce Pomalyst exposure due to CYP1A2 activation. Patients should be aware that smoking may reduce the efficacy of Pomalyst. Any concerns or questions about possible drug interactions should be discussed with your doctor and pharmacist.

DR. ABONOUR — continued from page 9

I have cycled approximately 1,400 miles for myeloma. I am often joined by patients and caregivers for various segments of the trek. Some run and some cycle, and it's been an amazing experience to share with them. When I started my work in myeloma, it would have been impossible to imagine myeloma patients running and cycling. It has been very rewarding to see the scientific advances being made in myeloma, but it is no less exciting to see my patients enjoying longer and more active lives thanks to the improvements in myeloma therapies and supportive care. **MT**



Pomalyst is metabolized in the liver. Pomalyst and its metabolites are excreted by the kidneys. The influence of kidney and liver impairment on the safety, efficacy, and pharmacokinetics of Pomalyst has not been evaluated. The following patients should not take Pomalyst:

- Patients whose serum creatinine is >3.0 mg/dL
- Patients whose serum bilirubin is >2.0 mg/dL
- Patients whose AST/ALT is $>3.0 \times$ ULN

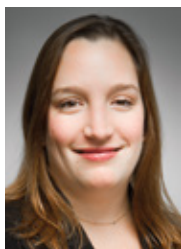
Patients must be aware of these and other warnings and precautions before taking Pomalyst. Speak with your doctor or nurse if you notice any changes in your health. Being a “good patient” doesn’t mean suffering in silence; it means accurately and promptly reporting any problems or changes in your health to your healthcare providers so that they can take appropriate steps.

For a more comprehensive overview of Pomalyst, please read the IMF’s new *Understanding Pomalyst® (pomalidomide) capsules* booklet, available on the IMF website myeloma.org or by calling 800-452-CURE (2873). **MT**

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

SPOTLIGHT ON ADVOCACY

Cancer Coverage Parity Act: New Year, New Congress



by Johanna Gray
Federal Government Affairs Consultant

The IMF supports the passage of the Cancer Drug Coverage Parity Act that will ensure that cancer patients have equal access to all types of approved anticancer medications, whether or not they are patient administered (such as a pill) or physician administered (such as intravenously). The IMF and the Patients Equal Access Coalition (PEAC) had a very productive 2012 and we're already off to a great start with our advocacy efforts in the new Congress.

Last year's hill days and grassroots efforts resulted in a total of 53 bipartisan co-sponsors for the Cancer Drug Coverage Parity Act in the House of Representatives, and we identified a Senate champion to introduce companion legislation in the Senate. With the start of a new Congress, we now have a two-year cycle to work to get this much-needed legislation passed and signed into law. Our first goal is to have the bill reintroduced in the House, with as many of last year's cosponsors as possible, and introduced for the first time in the Senate with both a Democrat and Republican original sponsor.

The more than 20 coalition members convened on January 31st for an in-person meeting to strategize our advocacy efforts for the next year. The group updated all of our fact sheets and materials, identified goals for the year, and discussed how to further build the coalition's membership. Beyond introduction, our goals include building co-sponsorship, and moving the legislation through the committee process. We will also seek to add members to the coalition so that the broadest possible group of stakeholders is advocating in support of the bill. After a productive morning, the Coalition members headed over to Capitol Hill and met with five House and 11 Senate offices. The advocates were well received and we are one step closer to confirming our original Senate cosponsors.

State Patients Equal Access Coalition: Cancer Coverage under the ACA



by Zina Cary
National State Affairs Consultant

January was not only the wind-down for the professional football season, it was also the kickoff for the majority of state legislative sessions. During the 2013 legislative session, the IMF's State Patients Equal Access Coalition (SPEAC) will focus its efforts on three target states: New Jersey, Illinois and Nevada.

New Jersey and Illinois launched their sessions in the second week of January and Nevada's session began on February 4th. To support these efforts, professional legislative counsel is being retained in each state.

In all three instances, the IMF is leading coalitions of state-based cancer organizations to influence coverage for cancer patients in each state's health insurance marketplace, as part of implementation of the Affordable Care Act (ACA). Top policy priorities include making sure patients have

equal access to oral chemotherapy treatments and other therapies and diagnostics, and that services are affordable for all patients, regardless of which plan they choose. The IMF has held coalition meetings and calls in each state and is submitting letters to and scheduling legislative visits with key policymakers, to share the IMF's position on a range of issues involving coverage for cancer patients.

Any IMF volunteers interested in becoming involved in these target states are encouraged to contact IMF's Grassroots Liaison, Aimee Martin, at amartin@myeloma.org.

ASH 2012 Advocate Lunch & Learn: A Patient's Perspective



by Jim Mahoney
Member of the Northern Atlanta Support Group

Like most readers of Myeloma Today, I am a patient with myeloma. My journey started more than seven years ago with a routine physical and a diagnosis of smoldering multiple myeloma (SMM). I went through the usual drill – staging, bone density testing, bone scans, blood work, and yes, the bone marrow aspiration – until things ramped up four years later and I had a stem cell transplant. Today, two years post-transplant, my journey continues.

In December 2012, I participated in my first official IMF Advocacy training session, held at the Hard Rock Cafe in Atlanta, Georgia. This training session took place concurrently with the annual meeting and



exposition of the American Society of Hematology (ASH). There were about 50 aspiring advocates in attendance – patients, caregivers, and others who wanted to learn more about advocacy. In one way or another, we all shared the same journey. We were there because each of us cares deeply about every person coping with myeloma. As a member of the Northern Atlanta Support Group, I knew a few of the attendees, but was thrilled about all the new people I met. Connecting with others and knowing that I am not alone gave me a sense of peace.

Arin Assero, IMF Vice President of Global Advocacy, started the day by reminding us that myeloma is not specific to the US. There are patients all over the world living each day with the same disease. Then we spent some time talking about the Affordable Care Act (ACA) and how we as patients will be affected by it.

Meghan Buzby, IMF Director of US Advocacy, put the key points in non-technical language so we could really understand the upcoming healthcare changes. My head was swimming – the ACA is not an easy document to understand. Aimee Martin, our Grassroots Liaison, then took the conversation to a lighter level by teaching us the “10 Steps to Building

CONTINUES ON PAGE 14

ADVOCACY — continued from page 13

a Better Relationship with Our Legislators” and how to use the IMF Advocacy Action Center website advocacy.myeloma.org. The most interesting part for me was learning how to research our legislators right from the website, and what a huge difference this makes when asking them to support issues important to us.

So what am I going to do with all I learned? I am going to eat this advocacy elephant one bite at a time: My legislators, who sponsored the Cancer Coverage Parity Act in 2011, will hear from me when the bill is re-introduced in 2013. Why? Because I support the bill that will help many patients gain access to treatments that are currently unavailable to them because of the antiquated benefit design surrounding oral chemotherapy treatments. Want to learn more? Go to the IMF website. What can you do? Sign up – it only takes a click – and join the fight. We can all do this.

I found the IMF Advocacy training session to be so engaging that I was shocked we had been together almost four hours. I learned that there are many people advocating on our behalf daily. Doctors and nurses talk to the insurance companies, and drug companies and researchers work to get us what we need for today and tomorrow. Terrific folks at the IMF support us behind the scenes to ensure we are provided every opportunity to receive the best treatment available, and I am glad they are there to advocate on my behalf and to make it so easy to advocate on my own behalf. **MT**

The IMF Advocacy Voice:

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

With redistricting based on the 2010 census and changes from the 2012 elections, do you know who your current legislators are? Visit the Action Center's Elected Officials section at advocacy.myeloma.org to learn who they are and what committees they serve on to start building your new relationship today.

How to contact the IMF Advocacy Team



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Letters to the IMF

IMF Advocacy Training Session

I will start by saying that we want/love to attend any and every event that brings us up-to-date on the treatment of multiple myeloma. But when we attended the IMF's training session for myeloma advocates in December, what we encountered was so much more than an update.

Cancer is a disease that redefines who a person is. The attitude we take along on our journey with this diagnosis can provide us with an opportunity unlike anything else in our lifetime. We have met patients, caregivers, medical professionals, and many others who have a role in the fast-evolving progress of beating myeloma.

But the surprise of the IMF's event was that we had an opportunity to meet people who are advocates on our behalf, behind the scenes. What we witnessed shows us how we can also become better advocates on our own behalf and on behalf of those we love so dearly. We learned how easily we are able to reach out to our representatives through the website. The entire presentation was given with the ease of a group of old friends getting together to talk about the changes in their lives. As everyone in the room introduced themselves, it became very apparent that this group of folks included a LARGE number of long-term survivors. Not that long ago this would have been unimaginable.

The event's presenters were knowledgeable and moved rapidly through a mountain of information. If we hadn't been there, we could not have imagined that the topic of health reform could be that interesting, but it WAS... I personally went to work on Monday morning sharing my insight of the many topics discussed at this conference.

Now that we understand what is going on behind the scenes, I cannot thank the IMF enough for all the work you are doing. By the end of the day, we were committed to becoming more involved and to getting others involved, too. This is our opportunity to help improve healthcare for all.

Thank you again,
Tony & Nancy Monti

Do you have a question?

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

myeloma.org



UPDATES FROM AROUND THE GLOBE



Myeloma in Asia

by Dan Navid
IMF Senior Vice President, Global Affairs

The work of the International Myeloma Foundation (IMF) in Asia continues to expand with several exciting new initiatives scheduled in the coming months.

Talks are now underway with commercial partners to launch the first IMF Asian Myeloma Network (AMN) clinical trials. Myeloma is a growing health problem in Asia, with an incidence that is approaching that in western countries, but with a much larger population base. The IMF established the AMN in March 2011 and it remains the only organization of its kind in the region. Composed of myeloma experts from seven territories in Asia, the initial focus of the network was the development of a unified data base to assess the incidence of myeloma in Asian countries as a key step in the designing of region-specific treatment management tools and strategies.

Building upon the very successful IMF Asian Myeloma Data Base project, multi-national, multi-center clinical trails are now being developed in key Asian markets. It is anticipated that these will provide important new data for myeloma research, as well as allow an important number of Asian patients access to new therapies that are otherwise unavailable.

The International Myeloma Workshop (IMW) being held in Kyoto in April is the first Asian venue for this event. The IMW will provide a great opportunity to advance the IMF's work in the Asian region. Amongst other activities in Kyoto, the IMF will convene a session of the AMN, a training program for Chinese physicians, a patient forum with IMF-Japan, as well as help convene a session of the IMW on Myeloma in Asia.

Finally, training activities for China continue to grow. The first IMF Myeloma Master Class, the exciting new educational program designed to help physicians around the globe learn about the newest thinking in myeloma diagnosis and treatment, brought seven young physicians from different institutions in China to Los Angeles to study for two weeks under the tutelage of American myeloma expert Dr. Brian G.M. Durie. The second Master Class for Chinese physicians will be held in Los Angeles and San Francisco in May 2013, while the third IMF Chinese Myeloma Working Group conference and patient forum will also be held in May in Guangzhou, China.

Reports about these initiatives and further information about the IMF's Asian program will be provided in upcoming issues of *Myeloma Today*.



IMF in Europe

by Gregor Brozeit
IMF European Programs

The Fall of 2012 was a busy time for the IMF in Europe. We cosponsored and participated in eight patient education meetings and three physician education meetings with partners in Germany, Eastern Europe, and Scandinavia. These meetings featured several myeloma experts from the United States.

In September, IMF Chairman Dr. Durie and IMF President Susie Novis participated in the annual patient and family seminar in Heidelberg, Germany. Hosted by International Myeloma Working Group



(IMWG) member Prof. Hartmut Goldschmidt of the University of Heidelberg, the Heidelberg seminar is the longest-running myeloma patient meeting held in Europe and regularly attracts more than 200 persons.

Also in September, IMWG member Dr. Morie Gertz of the Mayo Clinic headlined two patient and family seminars drawing more than 150 attendees in Nyborg, Denmark, and 90 persons in Trondheim, Norway. The Nyborg seminar was organized by the IMF and Ole Dallris, leader of the Danish national support group (DMG), and Prof. Niels Abildgaard, chair of the Danish Myeloma Study Group. This was the second annual seminar cosponsored by all three groups.

Dr. Gertz presented his popular myeloma lecture, "Weeds in the Garden," which was enthusiastically received by the audience. Additional speakers included Dr. Peter Gimsing from Copenhagen and Dr. Niels Anderson Frost from Aarhus. Attendees had the opportunity to ask individual questions to every speaker.

The Trondheim myeloma seminar was the first ever held in the city and the second meeting the IMF has cosponsored in Norway. Prof. Anders Waage of the University of Trondheim and chair of the Norwegian Myeloma Study Group split the bill with Dr. Gertz, who reprised his talk from Nyborg.

The 2012 annual seminar in the Czech Republic, held in the spa resort Lazne Belohrad, was a two-day event. Loosely modeled on the IMF's Patient & Family Seminar format used in the United States, the seminar was hosted by IMWG member and chair of the Czech Myeloma Group Prof. Roman Hajek from the University of Ostrova. More than 130 people from throughout the Czech Republic participated. Program included an overview of myeloma, research and treatment updates, pain management, nutrition, and legal issues affecting patients.

On September 28-29, the IMF cosponsored its first patient and family Seminar in Slovakia with the Slovak Myeloma Society (SMS), led by caregiver Miroslav Hrianka and Dr. Zdenka Štefániková. The SMS had held annual seminars in the past, but this was the first with IMF participation. The meeting was held in the northern Slovak spa resort of Liptovský Jan, just south of the Polish border. More than 125 persons attended, participating in lectures and discussions held by Dr. Jan Straub from Prague, the Czech Republic. The meeting also included time for physical exercise and walks in the hills surrounding the resort.

In October 2012, Dr. Bart Barlogie of the University of Arkansas was sponsored by the IMF to give three medical lectures in Scandinavia and one patient meeting in Germany. He provided the keynote speech at the

CONTINUES ON PAGE 16

INTERNATIONAL — continued from page 15

annual Myeloma Norway (the Norwegian myeloma study group) meeting in Oslo and the semi-annual meeting of the Danish Myeloma Study Group in Odense. In between, he squeezed in two lectures at Skane University in Lund, Sweden. Hosted by IMWG member Prof. Ingemar Turesson, Dr. Barlogie gave separate lectures to physicians and nurses. The highlight for the attendees of all meetings was the extensive time he provided to engage in discussions. Dr. Barlogie finished his tour by speaking at a patient meeting with host Dr. Hans Salwender at the Hamburg-Altona Asklepios Clinic. More than 125 attendees were treated to comparative views of myeloma treatment in Germany and Arkansas.

In Germany, two more patient meetings were held in Berlin and Leipzig, where the IMF has developed strong ties with local support groups and now co-hosts multiple patient meetings per year. The third 2012 meeting in Berlin was held at the Berlin Charité Benjamin Franklin Campus, the former hospital of the US Army, and attracted more than 80 attendees to hear lectures by host Dr. Wolfgang Blau and guest Prof. Hermann Einsele from the University of Würzburg, a member of the IMWG and chair of the DSMM, one of the German myeloma cooperative groups.

Sadly, this meeting was the last attended by the founder of the Berlin support group, Elke Schutkowski, who lost her battle with myeloma just two weeks after the meeting. She was a pioneer among myeloma support group leaders, building relationships with the three major myeloma clinics in Berlin and forging cooperation between doctors and clinics that serve the patients in the region.

In November 2012, the IMF's last European meeting of the year was held in Leipzig. Albrecht Reissman, Leipzig support group founder and leader, co-hosts two meetings per year with the IMF. This meeting featured Dr. Christian Jakob from St. Hedwig Clinic in Berlin, as well as Drs. Luisa Montavani-Löffler and Christoph Schimmelpfennig, and attracted more than 130 participants.

The IMF's 2013 participation is both patient and physician meetings in Europe is already underway, with an annual hematology conference



(left to right) Gregor Brozeit, Albrecht Reissman, Dr. Luisa Montavani-Löffler, Dr. Christoph Schimmelpfennig, and Dr. Christian Jakob

having been held in Turkey in February, with Dr. Brian Durie as invited faculty. In April, three patient meeting will be held in Germany: the Dresden Regional Community Workshop (RCW) will be hosted by Dr. Christoph Röllig at the Dresden University Clinic on April 13; the Tübingen RCW will be hosted by Dr. Katja Weisel at the Tübingen University Clinic on April 15; the Cologne RCW will be hosted by Prof. Christof Scheid at the University of Cologne Clinic on April 17. Dr. Robert Kyle of Mayo Clinic has been invited to speak at all three meetings in Germany. **MT**



Attendees at the 6th Leipzig patient meeting held on November 17, 2012.

Myeloma UK Chief Executive Receives OBE

On February 1, 2013, Myeloma UK Chief Executive, Eric Low, received his Order of the British Empire from His Royal Highness Prince Charles at Buckingham Palace. Eric was awarded the OBE for services to charity in the Queen's Birthday Honours List 2012.

Eric has been involved in the field of myeloma for more than 15 years, working at the headquarters of the International Myeloma Foundation (IMF) in the United States before returning to the UK to found a similar organization in 1997.

Under Eric's direction Myeloma UK has grown and developed and is the only UK cancer organization dealing exclusively with myeloma. The organization currently employs 34 staff members and provides a broad range of services. Today, Myeloma UK reaches more than 12,000 people affected by myeloma.



Eric has helped ensure that myeloma patients in the UK are able to access novel treatments through advocating solution-oriented approaches to the way drugs are made available on the National Health Service (NHS). He is an active member of a number of myeloma and cancer-related boards, steering groups and committees.

"It was an honour to be presented my OBE by Prince Charles, which I accepted very much on behalf of the myeloma community," said Eric Low on receiving the award. "Together, we have achieved many great things over the past 15 years, but there is still much vital work to be done. I am humbled by the congratulations and acknowledgements I have received and thank everybody who has taken the time to do so." **MT**

MYELOMA TODAY IN CONVERSATION WITH JAMECA BARRETT

Tell us about your life before myeloma.

I have always lived in Atlanta, Georgia. In 2003, I was 26 years old, married for one year, and working as an IT specialist. My work involved a lot of travel with my team, which was something I enjoyed doing. I have always been extremely close to my family and very involved in my church.

When and how were you diagnosed?

Professionally, I was between jobs, which also meant I did not have health insurance. When I started having flu-like symptoms that were so bad I couldn't even hold down a glass of water, I went to the emergency room. They gave me a couple of prescriptions and sent me home, but I still couldn't keep anything down.

A week later, on Thanksgiving Day, my Mom and Dad came over and instantly knew something was wrong. Once again, I went to the nearest emergency room. This time, I was admitted to the hospital because my kidneys had started to shut down. I was treated for the kidney problem and discharged.

After three days at home, all the symptoms returned. Instead of going back to the same hospital, I went to a local community clinic. Next thing I knew, they were transferring me by ambulance to Grady Memorial Hospital, the largest hospital in the state of Georgia. My blood test revealed a calcium level was so high I should have been in a coma. They also performed some imaging tests, which confirmed the diagnosis of Stage III myeloma. At that time, I was the youngest patient diagnosed with myeloma in the Metro-Atlanta Area.

How did you cope with your diagnosis and treatment?

I was kept in the hospital for three months before I was well enough to start the myeloma therapy. Next came chemotherapy with vincristine, adriamycin, and dexamethasone (VAD), which had me back in the hospital for five days every 28 days for three to four months.

In my personal life, my husband chose not to stay by my side through the journey. But I have a strong faith, and a very close-knit family and community of supporters. My father and mother have been right by my side, and all the love and support I received helped me enormously.

I choose to take on the challenge of finding a reason to be thankful for each day, no matter how difficult the day. Every day of living is a win against cancer. In the summer of 2004, I had an autologous transplant at Emory University under the care of Dr. Sagar Lonial.

I have been in remission ever since, but I still have myeloma and this fact is never out of my consciousness. I have continued to experience back pain due to spinal compressions and losing three inches of height. I am now planning to undergo a surgical procedure on my spine.

You were the IMF Advocate of the Month in January 2013. Why did you decide to become involved?

As soon as I was discharged from the hospital in 2003, I started attending local myeloma support group meetings. Although I was in a wheelchair, I looked so young that everyone assumed my mother was the patient, not me. The support group was very helpful during that period of my life, but I became overwhelmed when new friends relapsed or lost their battle with



myeloma. I was trying my hardest to live with myeloma without living in fear of it. I am committed to being part of the myeloma community, so I had to find a different way to contribute.

From my own experience, I understood some of the issues with health insurance because it was challenging for me to find employment after my diagnosis. Due to the myeloma, I could no longer perform the same type of work and needed to change my career path. When I attended an IMF Patient & Family Seminar, I learned about the advocacy program and knew it would be a good fit for me. Being a myeloma advocate gives me a way to attack myeloma – by educating the public about the life-changing impact that healthcare policy

has on cancer patients. As a myeloma survivor, I am excited about making a difference in the lives of others. I can help empower patients, young and old. Many of us have decades of life ahead and the action we choose to take now may have an impact on how those years unfold.

What message do you have for other patients?

Becoming involved with the myeloma community not only benefits others going through the same struggles, but it is also a way to empower ourselves. For example, due to my age at diagnosis, young patients reach out to me because they are inspired by my story. But at the same time, their stories inspire me and give me strength.

I recall a particularly challenging morning, one of those days when everything that could go wrong does and at the wrong time. I had to pull my car over and just cry. But later in the day I received an email from a young lady who was diagnosed with myeloma last year at age 22, and she was having a down day, too. We talked on the phone and our conversation was a blessing for each of us.

We all need each other, and whether we are typical or atypical of the larger myeloma patient population, we are all part of one whole. And all of us need to make our voices heard. I encourage everyone to find their own way to express and share their myeloma experience with others.

It is also important to find a way to make a contribution to the world. I organize monthly business-to-business networking events and fundraisers for local and national charitable causes, and I am building an event-planning business that requires clients to support non-profit organizations as part their events. And, of course, I am very proud to call myself a myeloma advocate. **MT**

Improved Patient Access to Cancer Research Articles

A new patient advocacy initiative is making cancer research more available to patients and caregivers. Sponsored by the American Society of Clinical Oncology (ASCO) and its Conquer Cancer Foundation, the patient ACCESS initiative provides free access to medical research articles published in ASCO's *Journal of Clinical Oncology* (JCO) and *Journal of Oncology Practice* (JOP). ASCO foresees patients and caregivers bringing relevant articles to their doctors as well as improving their own knowledge about cancer therapies. To obtain an article, visit the jco.ascopubs.org or jop.ascopubs.org website.

PEOPLE HELPING PEOPLE

You are never alone in your battle against myeloma

The IMF is often asked by patients if we know of support groups in their areas where they can meet others dealing with myeloma. There is a worldwide network of more than 150 myeloma support groups that hold regular meetings for members of the myeloma community, and we encourage you to seek them out. In the United States alone, there are 126 myeloma support groups, and more groups are forming every year. In 2011 and 2012, seven new myeloma support groups were founded across the country. Although the IMF does not sponsor these groups, we support their efforts and conduct annual summits for myeloma support group leaders. The members of the IMF's Support Group Team also crisscross the country visiting groups in person. Featured below are the myeloma support groups recently visited by our team.



Cincinnati, Ohio

by Robin Tuohy
Senior Director, Support Groups
rtuohy@myeloma.org

The Cincinnati Area Multiple Myeloma Networking Group was founded in January 2007 by Bill Jackson. A remarkable characteristic of this group is its nature to share the workload with its leaders; this group formed a committee so that there was divided responsibility for the tasks of running it. When the leader underwent myeloma treatment and was taking care of his health, the group continued to run smoothly. The group is now led by Hugh Shaffer and Maryanne Brennan.



Members of the Cincinnati support group attend the October 2012 IMF Regional Community Workshop.

This is a bonded group of caring individuals. The meetings include occasional speakers, but always reserve time for a Q&A session, where members learn from and support each other. An average of 30 members are present at every meeting. On my recent visit to the group, each member gave a brief overview of who they are, when they were diagnosed, and what treatments they're currently on. On the lighter side, group members always start off each meeting with a funny story or joke. Whether you are a patient or caregiver, the camaraderie shared at meetings and the long-term friendships that have been built among the group members contribute to the feeling that you are with people who understand what you are going through in your journey with myeloma.

Sharing experiences helps patients gain knowledge on treatments, side effects, clinical trials, and more. Since we are not doctors or nurses, we are careful to remind group members that myeloma is a very individual disease, and what may work for one patient may not for another. It is imperative for patients to have conversations with their healthcare team to ensure they understand "their" myeloma and its treatment plan. If they learn something new at a support group meeting, the best thing to do is to discuss this on their next appointment with their hematologist-oncologist. To give patients a better understanding of myeloma, I refer them to the IMF website and to read Dr. Brian Durie's 10 Steps to Better Care[®], a unique IMF tool for diagnostic and treatment information.

The Cincinnati Area Multiple Myeloma Networking Group is a hands-on, knowledgeable, and active support group and it was a pleasure to be included in their meeting.

The Cincinnati Area Multiple Myeloma Networking Group meets on the third Thursday of every month from 6:30 to 8:00 p.m. at The Cancer Support Community, 4918 Cooper Road, Blue Ash, OH 45242. For more information, please visit the group's website cincy.myeloma.org or contact Hugh Schaffer at hugh69marie@gmail.com or 513-289-5842, or Maryanne Brennan at maryanne_brennan@hotmail.com or 513-871-3973.



East Texas

by Kelly Cox
Director, Support Groups & RCWs
kcox@myeloma.org

The East Texas Multiple Myeloma Support Group has been operational since 2007. The group is led by remarkable and well-informed individuals, Joe & Millie Denton and Ed & Carolyn Evans. The leaders and participants work unbelievably hard, collaboratively, to make their meetings meaningful. They encourage participation and reach out to their communities with support. This is one of the most extraordinary, active support groups that I have ever visited.

Community outreach plays a vital role in this group's functions; members reach out to local physicians with information about their group to ensure that the oncologists and their staff inform the patients they treat of the support and education this group provides. Patients and caregivers in the surrounding areas of Long View need never feel that they are alone or without a plethora of educational resources and support.

Group members actively solicit a variety of speakers (doctors, nurses, and technical experts locally and from across the country) to attend the group meetings to discuss treatment options and effective therapeutic strategies. On my visit, there were three presentations, one from a local doctor and two (a nurse and oncologist) staff members from University of Arkansas. There was an excellent Q&A session following the presentations, followed by a group discussion. It was a lively and comfortable gathering.

The East Texas Multiple Myeloma Support Group started with two people and now has a roster of about 100 members. This growth is thanks to the incredible community outreach of this group and the level of support the members offer to those affected by myeloma. Approximately 25 active members (around 90% of whom are myeloma patients) attend each group meeting.

The East Texas Multiple Myeloma Support Group meets on the second Saturday of each month from 11:00 a.m. to 1:00 p.m. at the Gardens of Gladewater, 108 Lee Street, Gladewater, Texas 75647. For more information, please contact Joe and Millie Denton at 903-858-2332, or Ed and Carolyn Evans at 903-839-4653 or through the group website at easttexas.myeloma.org.



Columbia, South Carolina

by Nancy Bruno
Southeast Regional Director, Support Groups
nbruno@myeloma.org

On my visit to the Columbia Multiple Myeloma Support Group, I had the opportunity to witness firsthand a knowledgeable and supportive environment for patients, families, and caregivers. The group was founded in March of 2009 by Karen Davies. Karen has been battling both myeloma and lung cancer for the last five years. Her co-leader, Susan Mandel, was diagnosed with myeloma at around the same time as Karen. Both co-leaders are presently in remission and on maintenance therapy.

Support Groups

Karen and Susan lost their fathers to blood cancers, and both expressed strong convictions to contribute to patient support and education. These leaders are extremely well-informed and as a result, participants of this group are very up-to-date on myeloma and its treatment options.



Columbia group members with IMF's Nancy Bruno during the February 2013 meeting

During my visit, the meeting discussion was lively. After my presentation, each group member in attendance (which includes 10-15 active members, on average) discussed their own treatment status. An important topic of conversation at the meeting was effects of treatment, particularly recent experiences with peripheral neuropathy. Attendees also took this gathering opportunity to discuss risk associations and family relations.

The Columbia support group is a well-informed and well-organized group, led by two extraordinary myeloma patients. It was a pleasure and privilege for me to be involved in their discussions and in such a supportive environment.

The Columbia Multiple Myeloma Support Group meets from 1:00 to 3:00 p.m. on the second Saturday of every other month. The group meets at the Jewish Community Center, 306 Flora Drive, Columbia, SC 29223. For more information, contact Susan Mandel at jacoosie@earthlink.net.



Madison, Wisconsin

by Sue Enright
Midwest Regional Director, Support Groups
senright@myeloma.org

The Madison Multiple Myeloma Support Group has been active since 1999! This group was founded by Chuck Koval, a former University of Wisconsin professor, myeloma patient, and active member of the myeloma community. In addition to founding the support group, Chuck was also co-founder of the annual Wisconsin Multiple Myeloma Conference. Chuck passed away in 2009, and the Conference continues to honor his memory with the "Chuck Koval Spirit Award," which is presented each year to an individual who has demonstrated significant contributions to myeloma patients.

In 2007, when Chuck retired from his role as group leader, Jayne Schwartz, a caregiver who worked alongside Chuck, stepped in to lead the group. Jayne is a thoughtful and organized group leader; she is well-informed and up-to-date on research publications and support materials. Jayne ensures group members are informed of upcoming events and is a strong believer of "sharing time," whereby members learn from each other's experiences. Jayne also brings in guest speakers to give members the latest information on myeloma, treatment, side effects, and survivorship.

This support group is one of the longest running groups at the IMF. There are around 20-30 active members participating in monthly meetings, and attendees are eager to learn about the disease and to share information on treatment and experiences with each other.

During my recent visit to the group, I talked with members about the IMF and its four pillars: Research, Education, Support, and Advocacy. In my presentation, I also emphasized all of IMF's learning resources, including its website, teleconferences, seminars and webinars, workshops, educational materials and publications, advocacy initiatives, and its highly trained, wonderfully knowledgeable team of Hotline Coordinators. We also discussed and distributed "Postcards for Parity," which will be used to advance the federal and Wisconsin oral chemotherapy parity bill.

When my husband, Rob, was diagnosed in 2006, the IMF referred us to the Madison Multiple Myeloma Support Group, which was the first myeloma support meeting we ever attended. Chuck was the first myeloma patient Rob ever spoke with. This group is near and dear to our hearts and it's great to still see all of the work and support it continues to provide.

The Madison Multiple Myeloma Support Group meets on the third Tuesday of each month from 3:30 to 5:30 p.m. at UW West Clinic, 451 Junction Road, WI 53717. For more information, please contact Jayne Schwartz at schwartzdon@sbcglobal.net or 608-244-2120.



Boca Raton, Florida

by Anne Pacowta
Florida Regional Director, Support Groups
apacowta@myeloma.org

The Boca Raton Multiple Myeloma Support Group was founded in November 2011 by Dawn Toimil. Shortly thereafter, Gail Young began leading the group alongside Dawn. The two leaders are still complementing each other beautifully. Gail is a dedicated myeloma survivor with experiences with a stem cell transplant and various therapies. Dawn not only has previous support group experience through her battle with breast cancer and treatment in the 1990s, but also displays such motivation to truly understand myeloma.

Both leaders work very hard to emotionally support their group members and keep each of them educated and updated on treatment and support. These leaders have been able to secure many interesting speakers for the group's meetings, including various medical experts, dietitians, and pharmaceutical representatives. They always include frank and honest discussions about myeloma in their meetings, but also cover topics outside of myeloma (e.g., yoga, happiness, legal matters). Open discussions are warmly encouraged and supported.



Co-leaders
Dawn Toimil
and Gail Young

At my visit, I was so welcomed. I noted a friendship and camaraderie among members; they enthusiastically self-educate and share their information with the group. I congratulate the Boca Raton Multiple Myeloma Support Group for completing their first year of serving the needs of the local myeloma community, as well as its successful and continued growth.

The Boca Raton Multiple Myeloma Support Group meets the first Monday of the month from 6:00 to 8:00 p.m. at James Rutherford Community Center, 2000 Yamato Rd, Boca Raton, FL 33431. For more information, please contact Dawn Toimil at dawn8992@yahoo.com or 561-901-5938, or contact Gail Young at alghyoung@comcast.net or 561-637-4682. **MT**

Editor's Note: If you are looking for a myeloma support group in your area, or wish to start a new group, the IMF can help. Please contact Robin Tuohy at rtuohy@myeloma.org or 203-206-3536.

A Support Group Blooms in Staten Island

The New York borough of Staten Island, which was hard hit by Hurricane Sandy, now has its own group. The Staten Island Multiple Myeloma Support Group held its first meeting on January 9, 2013. "The response has been amazing," says Laura Mooney, who founded the group with her husband Charles. "Nothing beats meeting in person with others who are going through the same thing." The group meets on the second Wednesday of each month from 7:00 to 9:00 p.m. in the Fountain Room of the Hilton Garden Inn, 1100 South Avenue, Staten Island, NY 10314. For more information, contact Laura and Charles Mooney at simyeloma@gmail.com, or 718-390-7008 or 718-524-6970.

IMFers RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY



By Suzanne Battaglia

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

The IMF’s FUNdraising program is fun and easy, and brings with it the satisfaction of knowing that YOU are making a difference in many lives.

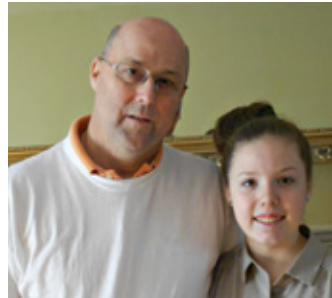
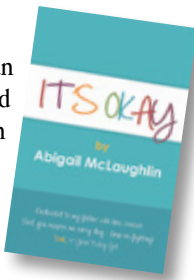
Choose an established event model or create your own. No idea is too large or too small! The IMF provides you with tools and assistance to make your event a success, and promotes your efforts through our website and social media outlets. Please contact me, Suzanne Battaglia, at sbattaglia@myeloma.org or 800-452-CURE (2873) to chat about any ideas you might have.

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

Here are some examples of events...

“It’s Okay”

Abigail McLaughlin is a 14-year-old high school freshman who lives with her parents, brother Mathew (23), and sister Julia (19), in Fall River, Massachusetts. When Abby was in the sixth grade, her father was diagnosed with myeloma. “I was 11 years old when my Dad told me he had cancer,” recalls Abby. “It was really scary news. I was so worried about him, but talking with my Mom helped me feel less anxious about it. I think that’s when I first had an idea to write about it.”



Stephen and Abby McLaughlin

Abby and her family made certain that she continued all her extracurricular activities to keep her from dwelling on Stephen’s illness. “I love to dance and cheerlead, so that is how I kept myself busy and happy. For someone else it could be playing sports that keep you healthy and make you sleep better at night. Writing, drawing, or another creative hobby could also be a great way to express how you feel.

Reading is great! Anything active, creative, or imaginative that takes your mind off being sad is a good thing.”

Shortly thereafter, Abby learned that her next assignment in school would be to write a children’s book. “My father is an inspiration to me,” says Abby. “Writing the book helped me cope with his myeloma diagnosis, and I also really wanted to help other kids whose families are dealing with cancer.”

Abby’s father learned about his daughter’s book shortly after his transplant. “She did it all on her own!” says Stephen McLaughlin. “My wife found out about it from the school, brought it home, and showed it to me. I was amazed.” Since then, the book has been published by the IMF and has reached across the world, far beyond the McLaughlin Family. “My wife and my kids are all phenomenal people. They had a hard time with my diagnosis and treatment but their support has been outstanding throughout, and that’s what kept me going on the down days. To learn that my daughter has been thinking of other kids while dealing with her own challenges, I’m simply overwhelmed.”

Go Fly a Kite!

Suzanne Novick’s daughter Debbie, and her grandchildren Sam and Hannah, have been beside her with their love and support during the entirety of her five-year fight with myeloma.

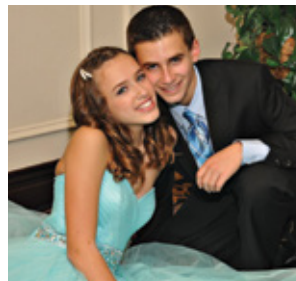
“Though Sam and Hannah were a mere six and seven years of age at the time of my diagnosis, they have known the battle I am



(left to right) Suzanne Novick with daughter Debbie, grandchildren Hannah and Sam, their father Mark, and her husband Jeff

waging to survive this most insidious disease,” says Suzanne. “Given their close proximity and the very frequent time we spent together, they have been privy to all of the trials and tribulations that have ensued.”

Suzanne endured eight rounds of chemotherapy before she reached her first remission, followed by a stem cell harvest and transplant, then radiation to her spine, followed by surgery on the thoracic spine. “Finally, after a remission that lasted 16 months, I entered a phase III clinical trial in hopes of attaining another remission. This was realized after approximately 18 cycles of treatment. But yet again the disease relapsed and, at present, I am undergoing more radiation. I have worn a wig, spent three months in a brace for my back and had central lines implanted for infusions of all sorts. Each progression has had its significant challenges, but the best ‘medicine’ has always been the love and nurturing of my family.”



Hannah and Sam

Sam and Hannah are now respectively 12 and 13 years old, and have just become a Bar and Bat Mitzvah. “In my mind, they have truly reached ‘adulthood,’” shares Suzanne. “I mean this in

CONTINUES ON NEXT PAGE

Member Events

not only the religious vein, but also in their mature understanding of what an illness such as myeloma means in terms of its devastation to life and limb." As their Mitzvah Project, the children raised money for the IMF's myeloma research program through the Multiple Expressions Virtual Kite Creation website. For every kite created, Celgene Corporation has agreed to make a donation (up to a maximum of \$25,000 per year) to the IMF, to benefit the Foundation's myeloma research program.

Sam and Hannah set up a booth at their temple, brought their laptops and encouraged the children to create kites online, assisting the younger children with making kites and sending messages of encouragement to someone with myeloma. With their own money, they purchased the burgundy awareness bracelets from the IMF and gave each individual who came to the booth a bracelet, informed them about the illness, and explained the purpose of making the kite. "At last count, I am the proud recipient of 22 kites," adds Suzanne. "More importantly, there are now children and adults who are better educated about the need for research to find cures for myeloma and other diseases. Sam and Hannah are a beautiful example of how we can all help in the battle to find a cure for myeloma. And we need all of the help that we can get. I could not be more proud of my grandchildren's contribution, and I'd like to encourage everyone to... Go Fly a Kite!"

Each kite created at multipleexpressions.com is a gift to someone you wish to support and establishes a contribution to the IMF's myeloma research program.

Tracy's Run for Terry

Tracy Finegan is a wife and mother of two young boys, Liam and Declan, and she is the daughter of Theresa (Terry) Ann Kushman, who was diagnosed with myeloma in August 2010. Although Terry lost her battle to complications of myeloma in September 2012, Tracy has chosen to remain a proactive advocate of myeloma research in order to improve outcomes for others who are battling the same disease as her mother.



Terry Ann Kushman with daughter Tracy Finegan and grandsons Liam and Declan

"My Mom was a true friend, a loving daughter, a special sister, and the truest example of someone who could laugh at herself," says Tracy. "She had a way with the little things. A card in the mail, a package sent, flowers dropped off. Mom took on the burden of worry so that others could be carefree. She made sacrifices so others had opportunity. Her life was filled with family and friends. My sister and I have always said mom showed us how to be a good mother. She was sensitive, thoughtful, and a good listener. We think of her every day, miss her, and feel her presence. She had a fighting spirit and a positive outlook on life. My Mom said it best - Every night I thank the universe for my blessings. I ask for guidance, too. Mostly, I just take time to appreciate my children, family, grandchildren, and my home. Everything else has only a fraction of the importance of these gifts."

On November 18, 2012, Tracy ran the Philadelphia marathon, her sixth, in honor of her mother. Ten years after running her prior five marathons, Tracy finished the run in an impressive 4 hours and 28 minutes and raised more than \$7,000 for the IMF's research program. "I had my Mom's picture pinned to my marathon bib, and my sons wore t-shirts designed for my Mom over their coats (as it was chilly out). When my emotions were raw, that's when I felt closest to my Mom. I fought hard to the finish line, but if she could fight myeloma then I can run a marathon. Before she passed away, my Mom expressed how proud she was of me for raising funds for research and also raising myeloma awareness, so I knew as I ran that my Mom was taking every step with me. And I knew why I was running - so no other family has to go through the pain of losing a loved one to myeloma. I truly believe that together we can wipe out this deadly disease." **MT**



Tracy Finegan at the Philadelphia marathon in November 2012



The IMF Earns 4-star rating from Charity Navigator

The IMF has once again earned a 4-star rating, the highest possible, from Charity Navigator!

Only 9% of all charities have received consecutive 4-star ratings for three or more years. The IMF has received a 4-star rating for every full fiscal year reviewed, nine in total. Charity Navigator is an independent organization with a team of analysts that rate non-profits based on how efficiently they use donor support, how well they sustain programs and services over time and their level of commitment to good governance, best practices and openness with information. The IMF is proud to receive the top rating again. For more information, please visit charitynavigator.org.

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New IMF Publications Help Patients Understand Pomalyst®

Pomalyst® (pomalidomide) is the newest in the line of anti-myeloma agents called immunomodulatory drugs, or IMiDs®, agents that can modify or regulate the functioning of the immune system. The IMF's Understanding Pomalyst® (pomalidomide) capsules booklet and Tip Card feature information on Pomalyst: how it works; the results of clinical trials and ongoing research; how and when to take it; and potential side effects and their management.

IMF Teleconference: "What's NEW with Novel Therapies?"



Dr. Brian G.M. Durie (Cedars Sinai Samuel Oschin Cancer Center, Los Angeles, California) and Dr. Sagar Lonial (Winship Cancer Center, Emory University, Atlanta, Georgia) discuss the latest information about the recently FDA

approved Pomalyst® (pomalidomide) capsules, as well as Subcutaneous (SQ) Velcade® (bortezomib), Kyprolis® (carfilzomib), and more in a free 90-minute teleconference entitled "What's NEW with Novel Therapies?" To listen to the audio recording or view the slide presentation, please visit myeloma.org and select "teleconferences" from the "webcasts" dropdown menu.

New Clinical Trial Opens under Direction of NLB's Beth Faiman



Enrollment is open for a new clinical trial at the Cleveland Clinic led by IMF Nurse Leadership Board (NLB) member Beth Faiman, PhDc, MSN, APN-BC, AOCN, of the Cleveland Clinic Taussig Cancer Institute. "Glutamine in Preventing Peripheral Neuropathy in Patients with Multiple Myeloma Receiving Bortezomib" is a randomized phase II trial that studies glutamine in preventing peripheral neuropathy (PN) in patients with myeloma who are receiving Velcade (bortezomib). Glutamine may help prevent PN in patients receiving chemotherapy.

IMF's Link to Amazon.com Helps Support Myeloma Research

amazon.com When you purchase items using the IMF link amazon.myeloma.org, Amazon.com will contribute funds to myeloma research and education. As one IMF donor puts it: "I buy everything from refrigerator filters to televisions to garage storage on Amazon.com. And I go through the IMF link, so we get a percentage of everything I spend." Music to our ears!

Paperwork Hurdle Stalls 9-11 Myeloma Coverage

The 9/11 compensation fund has been in the news again. According to the New York Times, the first 15 compensation awards were given out – but none to cancer patients. The stumbling block to those who might qualify for compensation under the \$2.8-billion fund? Paperwork. Sheila Birnbaum, the special master of the fund, said she had not awarded money for cancer yet because she had not received completed applications. Of the 16,000 people who have registered, only 2,500 have submitted eligibility forms, and, of those, only 190 have submitted compensation

forms and many lack documentation. Staff advice is apparently available, and myeloma patients need to work through these details in as timely a manner as possible, as the fund expires in 2016.

NLB and Senior Research Grant Winner Included in 14th IMW



The IMF's Nurse Leadership Board (NLB), which is made up of nurses from the leading centers treating myeloma patients in the US, will have a poster at the International Myeloma Workshop (IMW), a biennial event held this year April 3-7 in Kyoto, Japan. This is the third consecutive IMW at which the NLB will have a poster. Also recently announced was the IMW's acceptance of a poster presentation by 2012 Brian D. Novis Senior Grant winner Dr. Nancy Krett. Congratulations to all!

Dr. Brian G.M. Durie on NPR's "Morning Edition"



IMF Chairman Brian G.M. Durie, MD, was interviewed for National Public Radio's "Morning Edition," with more than 12 million listeners tuning in. The story about the changing landscape of myeloma treatments aired February 18. The availability of targeted cancer drugs, "really has changed the whole landscape for both the doctor and the patient," Dr. Durie told NPR correspondent Richard Knox. Also featured in the report was myeloma patient Don Wright, who was diagnosed with myeloma in 2003 only days after completing his first marathon at the age of 62. In the 10 years since his diagnosis, Don has run a total of 70 marathons in all 50 states.

Share your thoughts

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

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

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

The IMF has a social community

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

Find us on  at www.facebook.com/myeloma

Follow us on  @IMFmyeloma

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

Share your stories – we want to help!

The IMF is working to help patients across the US who are having trouble getting the oral chemotherapy treatments they are prescribed. We know privately insured (not Medicare) patients may face high out of pocket co-pays associated with oral therapies. If you are having difficulties accessing oral drug treatments, please share your story with us by emailing Aimee Martin at amartin@myeloma.org or calling 800-452-CURE (2873).



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

2013 IMF Calendar of Events

- | | | | |
|-------------|--|------------|--|
| March 23 | Medical Center Workshop (MCW) at Mayo Jacksonville – Jacksonville, FL | June 11 | Robert A. Kyle Lifetime Achievement Award Presentation – Stockholm, SWEDEN |
| April 3-7 | 14 th International Myeloma Workshop (IMW) – Kyoto, JAPAN | June 13-16 | European Hematology Association (EHA) Annual Congress – Stockholm, SWEDEN |
| April 13 | IMF Regional Community Workshop (RCW) – Nashville, TN | June 15 | Medical Center Workshop (MCW) – Minneapolis, MN |
| April 13 | Regional Community Workshop (RCW) – Dresden, GERMANY | June 22 | IMF Regional Community Workshop (RCW) – Cincinnati, OH |
| April 15 | Regional Community Workshop (RCW) – Tübingen, GERMANY | July 13 | IMF Regional Community Workshop (RCW) – Spokane, WA |
| April 17 | Regional Community Workshop (RCW) – Cologne, GERMANY | July 26-28 | IMF Support Group Leader Summit – Dallas, TX |
| April 20 | IMF Regional Community Workshop (RCW) – Milwaukee, WI | Aug 9-10 | IMF Patient & Family Seminar (PFS) – Chicago, IL |
| April 25-27 | Oncology Nursing Society (ONS) Annual Congress – Washington, DC | Aug 23-24 | IMF Patient & Family Seminar (PFS) – Philadelphia, PA |
| May 10-11 | IMF Patient & Family Seminar (PFS) – San Francisco Bay Area, CA | Oct 5 | IMF Regional Community Workshop (RCW) – St. Louis, MO |
| May 14-18 | Guangzhou International Myeloma Conference – Guangzhou, CHINA | Nov 9 | 7 th Annual Comedy Celebration – Los Angeles, CA |
| May 18 | IMF Regional Community Workshop (RCW) – Grand Rapids, MI | Dec 6-9 | 55 th Annual Meeting & Exposition of the American Society of Hematology (ASH) – New Orleans, LA |
| June 1-3 | American Society of Clinical Oncology (ASCO) Annual Meeting – Chicago, IL | | |
| June 10-12 | 2013 International Myeloma Working Group (IMWG) Summit – Stockholm, SWEDEN | | |

The IMF is proud to work with our global partners.

For more information about upcoming events, please visit myeloma.org or call 800-452-CURE (2873).

For information on activities in Latin America, Japan, or Israel, please visit:

Latin America mielomabrasil.org • Japan myeloma.gr.jp • Israel amen.org.il