



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



Dr. Brian G.M. Durie (Chairman, IMF Board of Directors; Cedars-Sinai Comprehensive Cancer Center, Los Angeles, CA) discussed the 53rd annual meeting and exposition of the American Society of Hematology (ASH). ASH had an impressive total of 712 myeloma-related presentations. Dr. Durie summarizes *ASH 2011 Highlights*, which covers some of the most interesting research in multiple myeloma presented at this major medical meeting. **PAGE 4**



Dr. Robert A. Kyle (Chairman, IMF Scientific Advisory Board; Mayo Clinic, Rochester, CA) presents summaries of projects supported by the 2012 IMF Research Grant awards. For the past 17 years, the IMF Research Program has been funding promising clinical investigators from around the world in an effort to improve outcomes for myeloma patients. The IMF-funded research has led to many publications, enabled investigators to become established in the field, made important contributions to understanding the biology of myeloma, and supported the development of better therapies. **PAGE 6**



Dr. Shaji K. Kumar (Mayo Clinic, Rochester, NY), the lead investigator of a multicenter study conducted by the IMF's International Myeloma Working Group (IMWG) on the risk of progression and survival in multiple myeloma patients who have relapsed following therapy with immunomodulatory drugs (IMiDs) and VELCADE® (bortezomib). The IMWG study data establish a context and provide an important reference point for comparing the results of ongoing clinical trials of newer drugs for multiple myeloma. Such data can aid the development of better therapies by identifying the most promising treatments currently in clinical trials. **PAGE 7**

Supportive Care



IMF's Nurse Leadership Board (NLB) has developed a Survivorship Care Plan that examines specific aspects of long-term care. In this edition of *Myeloma Today*, we offer a condensed version of the manuscript published by the *Clinical Journal of Oncology Nursing*® (CJON). Topics include renal insufficiency, long-term effects of MM on renal function, the impact of kidney dysfunction, and supportive care and monitoring recommendations. **PAGE 9**

IMF Hotline Coordinators answer a question about subcutaneous (SQ) administration of VELCADE® (bortezomib), which is now approved by the FDA. Instead of having a port put in and receiving the drug intravenously (IV), patients can get Velcade as an injection given under the skin – what we commonly call a “shot.” Clinical trial results indicate that SQ Velcade’s efficacy is comparable to that of IV Velcade, with SQ Velcade causing significantly less peripheral neuropathy (PN). SQ Velcade may be considered for MM patients who have pre-existing PN or who are at risk of developing PN. **PAGE 11**



Special Event

The 2012 Boca Raton IMF Patient & Family Seminar is described by a patient from the perspective of a 14-year journey with MM. Tom Callahan, who has attended several IMF seminars over the years, was one of over 350 patients and family members from across the country who participated in the Boca Raton meeting. Some were new to the IMF and the world of myeloma; others, like Tom, believe that we should never stop learning about this disease and its treatment options. **PAGE 13**



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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.

Upcoming P&F Seminars

- Los Angeles, CA**
August 10-11, 2012
- Boston, MA**
August 24-25, 2012

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

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A Message from the President

Dear Reader,

Educating patients and doctors about multiple myeloma (MM) has been the mission of the International Myeloma Foundations (IMF) for 21 years. Today, we can reach out globally more efficiently than ever before. And as I'll show you, today myeloma awareness is not just a nicety, it's a crucial necessity.

In order to amplify that message for the 2012 Myeloma Awareness Month in March, the IMF launched the "Tell One Person" campaign. Patients, caregivers, friends and family members pledged to tell one person (or more!) who hadn't heard of the disease the basics about myeloma.

We got the ball rolling on our social media channels by posting a daily myeloma fact on Twitter and Facebook. Our energetic and enthusiastic followers broadcast these facts daily to their own Twitter followers and Facebook friends, turning up the volume on our Myeloma Awareness Month message. The IMF's Facebook page-views grew by a factor of 90!

So what's so important about raising myeloma awareness? After all, isn't "raising awareness" the mantra of every advocacy group in the world?

Of course it is, but in the case of a relatively unknown disease like myeloma, patients pay a particularly high price for ignorance, especially when that ignorance extends to the medical community.

We only have to read the comments we receive to see what happens when myeloma awareness is absent.

"Doctors kept insisting my mom had osteoporosis, when it was myeloma," wrote one woman.

Another caregiver wrote that her husband visited "ten different doctors to find the source of his back pain before one of them recognized the symptoms of myeloma."

But there is another reason it has become vital to tell the world about myeloma: Younger and younger people are being diagnosed. Traditionally, myeloma was thought to be a disease that only affected the elderly. When myeloma symptoms appear in younger patients, doctors who aren't up-to-date on the latest information about myeloma are not able to recognize it for what it is.

Case in point is a young man from Ohio who wrote on our Facebook page. He was just 17 years old when he was diagnosed with myeloma. For two critical years, his complaints of back pain were dismissed by doctors as "growing pains."

Also in March, the IMF Hotline team received a call from a nursing student from the Midwest who was diagnosed with myeloma. She is just 22 years old, well below the typical profile. Her local doctors recommended a treatment so complex that a myeloma expert has since called it "drastic." But after contacting the IMF Hotline, she was able to get advice from IMF Chairman Dr. Brian Durie to seek a second opinion at a major medical center familiar with myeloma. The newest treatments for myeloma are both more tolerable and more effective, a

perfect example of why "awareness" is so important.

We may celebrate Myeloma Awareness Month in March each year, but why wait? Spreading the word – whether through social media or Support Group meetings or flyers posted in a doctor's office – could prompt an accurate diagnosis and early treatment for those who do not yet know they have the disease. Proper diagnosis, treatment, and monitoring are key to a good outcome. And while we all strive to do our best for today's patients, please know that the IMF continues the search for the cure.

Warmly,



Susie Novis, President



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!

Help the IMF learn more about MM patients

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

BEST OF ASH 2011 RECAP: WHAT PATIENTS NEED TO KNOW



By Dr. Brian G.M. Durie

The 53rd annual meeting and exposition of the American Society of Hematology (ASH) took place December 10-13, 2011, in San Diego, California. ASH 2011 brought the greatest number of abstracts on multiple myeloma (MM) ever published in the meeting's history, 712 abstracts to be exact. While no single abstract made headlines, taken collectively they offer ample evidence

of a year of significant steps forward in understanding, prognosticating, imaging, treating, and monitoring this disease. To better categorize the meeting's highlights, we turn to the IMF's 10 STEPS TO BETTER CARE™ as a framework.

1. Know What You're Dealing With

Several important abstracts were presented in the general category of diagnosis and disease definition, notably a series of studies from the Mayo Clinic (Rochester, MN, USA) that examine outcomes among various subgroups of patients.

Shaji Kumar examined the outcomes of patients in the US, Europe, and Korea who became refractory to both Velcade® (bortezomib) and an immunomodulatory (IMiD) agent. He points out that these "double refractory" patients have a poor prognosis no matter where they are treated. Patients in the US are likely to have more therapies both before and after they become refractory.



Vishal Rana's study looking at the reasons for early mortality among those who died within 12 months of diagnosis concludes that advanced age, poor performance status, high ISS stage, and high levels of serum calcium are predictors of early death. Identifying these factors up front will enable doctors to design risk-adapted, appropriate therapy.



Soo-Mee Bang retrospectively examined outcomes in patients over 70 years of age, concluding that exposure to novel agents has improved their overall survival, although it still lags behind that of younger patients.

Prashant Kapoor's analysis of survival among patients 45 years of age or less at the time of diagnosis in the era of novel therapies concludes that younger patients not only benefit from the survival advantage granted by their youth and general good health, but from exposure to novel agents, as opposed to their historical controls.



Another significant presentation in this category was the follow-up on the study of therapy for high-risk smoldering multiple myeloma (SMM) by Maria-Victoria Mateos. Dr. Mateos's longer-term data now indicate that time to progression to active MM was significantly prolonged in the group of patients with high-risk SMM that was treated with nine cycles of Revlimid® (lenalidomide) and dexamethasone followed by Revlimid maintenance. Only two patients developed second primary malignancies (SPM) in the treated group, and both malignancies were confirmed to have originated before the start of Rev/dex therapy. While there is a trend

to improved overall survival in the treated group, it is too early to fully assess overall survival benefit, and therefore it is too early to change clinical practice based on these trial results.

2. Tests You Really Need

Data in the category of valuable prognostic tests includes the new heavy/light chain assay, genetic studies, imaging, and flow cytometry. Of particular note is the identification of cereblon, an IMiD-binding protein that corresponds to response to treatment with IMiD therapies.

Elena Zamagni's prospective study confirms that PET-defined CR is an independent prognostic factor in MM patients treated with up-front novel therapies and autologous stem cell transplant (ASCT). Jens Hilgess reports that the number of focal lesions on whole-body MRI has prognostic value after ASCT, but not at diagnosis. Whole-body MRI is not able to discern focal lesions with active MM cells as opposed to osteolyses without active MM.

The serum heavy/light assay, which Heinz Ludwig describes as a "simple test," is able to measure the relationship between clonal and non-clonal protein in the blood. It increases diagnostic accuracy by allowing the measurement of paraproteins that cannot be measured via other techniques, especially in the case of IgA, which tends to migrate to the beta region with serum protein electrophoresis. It can also identify those patients who are not in true CR, despite evidence to the contrary with immunofixation electrophoresis (IFE).

Herve Avet-Loiseau compared data from whole exome sequencing and cytogenetics and discovered that there was no significant correlation between recurrent chromosomal changes and gene mutations. There was also no correlation between the number of genetic mutations and cytogenetic risk. In his study of chromosomal abnormalities in MM patients >65 years, he discovered a much lower incidence of t(4;14) in this group, but no significant difference in the occurrence of del(13) or del(17p). As in younger patients, both t(4;14) and del(17p) negatively affect PFS and OS in elderly patients.

Roberto Pessoa Magalhaes performed a novel flow cytometric analysis of patients with long-term disease control. He reported that these patients have increased numbers of cytotoxic T-cells and CD56 natural killer (NK) cells.

3. Initial Treatment Options

Survival continues to improve for newly diagnosed patients. Better induction therapy improves survival. Jesús San Miguel's 5-year follow-up data on the VISTA trial (VP vs. VMP) demonstrated an overall survival benefit of 13 months, with a 31% reduced risk of death for those on VMP vs. MP. Although VMP did not overcome cytogenetic risk, patients who relapsed on VMP and went on to other therapy still did better on their second therapy than those on MP did. There was no increased risk of second malignancies with VMP.

Philippe Moreau of the IFM presented data on the PK and PD of subcutaneous (SQ) Velcade, demonstrating that it has similar pharmacokinetics and pharmacodynamics to intravenous (IV) Velcade.

Ruben Niesvizky's UPFRONT study comparing VD, VTD, and VMP in nearly 500 newly diagnosed patients age >65 years in the community practice setting demonstrated that there is added toxicity and no significant benefit to triplet therapy in an elderly population. There were increased rates of hematologic toxicity with melphalan added to Velcade and dexamethasone, and thalidomide increased the incidence of peripheral neuropathy. Similarly, Rachid Baz's retrospective study of doublets vs. triplets of novel agents indicated that patients without high-risk cytogenetics had no difference in OS regardless of whether they had two-drug or three-drug regimens. Those with high-risk cytogenetics, however, had worse survival with the intensive three-drug regimens than with two-drug combinations.

4. Supportive Care and How to Get It

Data in this category include details about peripheral neuropathy (PN), venous thromboembolism, renal impairment, and the risk factors for the development of second primary malignancies (SPMs). Paola Tacchetti reviews the experience with Velcade- and thalidomide- induced PN. An interesting new finding is the correlation between the likelihood of PN and deregulated expression of genes (GEP) involving nervous system function from assessment of bone marrow plasma cells from patients with VTD-induced PN.

5. Transplant: Do You Need One?

Transplant, even in this age of highly effective novel therapies, is still of great value in MM and will remain part of the standard of care for younger patients. Two studies that tip the balance toward high-dose therapy and transplant were Antonio Palumbo's randomized comparison of MPR vs. transplant (MEL200) and Lijun Dai's trial of len/dex with and without ASCT. Both studies conclude that although toxicities are higher with high-dose melphalan and ASCT, the data does suggest improved progression-free (Palumbo) and overall (Dai) survival.

Several studies examined the timing, route of administration, and cost of mobilizing stem cells with plerixafor (Mozobil®), demonstrating that it can be given at a more convenient schedule, administered intravenously as well as by injection, and that, though costly, it causes fewer problems than cyclophosphamide and thereby reduces hospitalization and overall healthcare costs.

6. Response Assessment

Bruno Paiva identified a group of patients who require special monitoring and novel treatment strategies after stem cell transplant.

7. Consolidation and/or Maintenance

The notion of continuous therapy for MM has gained credence as the result of several studies examining the role of consolidation and maintenance therapy. PFS was doubled in Antonio Palumbo's follow-up data on the MM 015 MPR-R trial. In Maria-Victoria Mateos's trial using VT or VP

maintenance after VTP or VMP, both VT and VP improved the complete response rate from 24% before to 42% after maintenance. The IFM data on up-front VRD followed by ASCT, VRD consolidation, and Revlimid maintenance led to an impressive stringent complete response (sCR) rate of 38%.

8. Monitoring without Mystery

Saad Usmani provided compelling data on the utility of MRI and PET in predicting PFS and OS. Former IMF research grant recipient Marco Ladetto presented data on the impact of minimal residual disease (MRD) detected by real-time quantitative polymerase chain reaction, and concluded that careful monitoring of increases in MRD can lead to tailored treatment for those most at risk of relapse. In these patients, it is crucial to make response as complete as possible.

9. Relapse: Do You Need A Change in Treatment?

Assessment of relapse with Velcade and IMiDs were the topics of two important studies. Carlos de Larrea identified a sub-group of Velcade-treated patients with poor prognosis due to DNA methylation, while Enrique Ocio concluded that if a patient is resistant to one IMiD, another IMiD can be effective and should be tried.

10. New Trials

Probably the richest sources of new information at ASH this year were the sessions on results of new drugs in clinical trials. The most promising include the two drugs likely to be approved by the FDA in the next calendar year, carfilzomib and pomalidomide. In Andrzej Jakubowiak's phase I/II frontline trial of carfilzomib in combination with Revlimid and dexamethasone, 100% of patients had \geq VGPR after 4 cycles, with 71% of patients in CR after 4 cycles, and 79% in nCR/CR after 12 cycles. All patients were able to mobilize and harvest stem cells for future transplant successfully. The IFM and Dana-Farber data with pomalidomide and dexamethasone in relapsed and refractory MM were also impressive. Other very promising results were from the studies of the monoclonal antibody elotuzumab in combination with Revlimid and dexamethasone; bendamustine, an old drug finding new life in combination with Revlimid or Velcade; and the novel proteasome inhibitors MLN9708, given orally, and marizomib, given intravenously. Perhaps most disappointing were the long-anticipated results of two studies of the HDAC inhibitor vorinostat (Zolinza®), which showed only minimal benefit and significant toxicities.

In Closing

This overview of the year's ASH highlights also serves as an introduction to the forthcoming International Myeloma Working Group (IMWG) publications, which will update older guidelines and provide new ones in line with the newly presented data. We thus anticipate a year of outstanding contributions to the guidelines for better understanding and management of MM, and a year that will bring two new agents to the armamentarium of approved drugs to fight it. **MT**

Editor's Note: The full text of ASH 2011 Multiple Myeloma Highlights, which cites specific abstracts, can be viewed or downloaded from the IMF website myeloma.org. Please also visit the Blogs section to read about the experiences of patients and caregivers whose ASH attendance was sponsored by the IMF.



2012 IMF RESEARCH GRANTS



By Dr. Robert A. Kyle – Mayo Clinic, Rochester, MN

For the past 17 years, the 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-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 of better therapies.

We are certain that the work of the recipients of the 2012 IMF research grants will continue to contribute significantly to the field of myeloma.

The IMF grants are funded by donations from private individuals. Junior Research Grant projects are funded in the amount of \$50,000 and Senior Research Grant projects are funded at \$80,000.

The presentation ceremony for the 2012 IMF Research Grant awards took place during the 53rd annual meeting and exposition of the American Society of Hematology (ASH) in San Diego, California.



Brian D. Novis Senior Research Grants

A Brian D. Novis Senior Grant for 2012 was awarded to **Nancy L. Krett, PhD**, of Northwestern University, Chicago, Illinois. Her project deals with the identification of gene networks regulated by glucocorticoids in multiple myeloma (MM). Glucocorticoids in the form of dexamethasone or prednisone are a cornerstone of MM treatment, but little is known about the mechanisms which induce cell death or induce resistance to therapy. Glucocorticoids have an impact on cell-signaling networks as an enhancer with the chromatin landscape providing cell specificity. Dr. Krett plans to combine her current expression data sets with chromatin mapping and a high-throughput transcription factor interaction screen to show the primary functional targets of glucocorticoids. This may provide the basis for the development of targeted therapies for patients with glucocorticoid resistance.

The role of C/EBP- β as a potential target will be explored by **Suzanne Lentzsch, PhD** currently at Columbia College of Physicians and Surgeons in New York City, New York. She has identified C/EBP- β as a critical factor regulating growth of multiple myeloma (MM) cells. This protein interacts with the bone marrow microenvironment and results in the induction of growth of MM cells and destruction of bone. If the hypothesis is confirmed, it will provide a novel treatment approach for targeting both the myeloma tumor cell and the osteoclasts which destroy bone.

The third Brian D. Novis Senior Grant recipient, **David Smith, PhD**, of West Virginia University, Morgantown, West Virginia, will study specific inhibitors of ubiquitin-dependent proteasomal degradation. VELCADE® (bortezomib) is a 20S proteasome inhibitor and is an important first-line drug for multiple myeloma (MM). However, it has dose-limiting side effects such as peripheral neuropathy (PN). Furthermore, MM patients often subsequently relapse and become resistant to bortezomib. It is likely that PN develops because all proteasome functions require the 20S inhibitor which regulates most cellular dependent degradation. Dr. Smith has recently discovered a new regulatory site in the proteasome that is needed

for ubiquitin-dependent degradation. He plans to generate inhibitors at this site that will specifically block ubiquitin-dependent functions while allowing the 20S proteasome inhibitor to function normally. Theoretically, these novel proteasome inhibitors may be less toxic and more effective for treatment of MM.

Brian D. Novis Junior Research Grants

Brian D. Novis Junior Research Grants were awarded to four investigators. **Antonia Cagnetta, MD**, of Dana-Farber Cancer Institute in Boston, Massachusetts, will investigate the role of NAD (Nicotinamide adenine dinucleotide) and NAD dependent enzymes in multiple myeloma (MM). NAD is a coenzyme involved in many cellular functions including energy metabolism, reactive oxygen species scavenging, DNA repair and control of gene expression. The stores of intracellular NAD are continuously replenished. Nicotinamide phosphoribosyltransferase (Nampt) is the rate-limiting enzyme in the NAD salvage pathway. It plays a pivotal role in controlling the activity of several cellular enzymes. It is found in solid tumors and hematologic malignancies, but the role of this enzyme in malignancies is poorly understood. It has been shown that the intracellular depletion of NAD has an anti-tumor effect and the Nampt inhibitor, FK866, may induce tumor cell death. Based on the reported effects of FK866, Dr. Cagnetta will study the mechanism of action and the effect of this novel agent against MM cells. She will determine whether FK866-induced cell death involves apoptosis, autophagy or cell necrosis. In addition, she will determine whether NAD depletion produced by FK866 will affect the production of VEGF as well as IL-6, which is a key cytokine in the growth of MM cells.

Ulf Krause, MD, of Texas A&M University in Temple, Texas, will study the effect of glycogen-synthetase-kinase3 β (GSK3 β) inhibition and its role in multiple myeloma-induced bone disease. Many patients with multiple myeloma (MM) develop bone lesions which may result in skeletal pain and/or fractures. These changes are often irreversible even when successful chemotherapy has controlled the MM. Bisphosphonate treatment does not result in bone repair. He has shown that inhibition of GSK3 β

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RELAPSED MULTIPLE MYELOMA AFTER THERAPY WITH IMiDS AND BORTEZOMIB

Myeloma Today in conversation with Dr. Shaji K. Kumar

Dr. Kumar, you were the lead investigator of a multicenter study conducted by the IMF's International Myeloma Working Group (IMWG) on the risk of progression and survival in multiple myeloma (MM) patients who have relapsed following therapy with immunomodulatory drugs (IMiDs) and bortezomib.

Over the past ten years, the introduction of novel agents to the treatment of multiple myeloma (MM) has changed the treatment paradigm. We have seen a significant improvement in survival of MM patients with the use of the proteasome inhibitor Velcade® (bortezomib), and immunomodulatory drugs (IMiDs) thalidomide and Revlimid® (lenalidomide). But patients eventually become resistant to available therapies, so newer therapies must be developed.

There are several promising newer drugs in development, some in single-arm clinical trials. As the safety and efficacy of these newer drugs is being evaluated for treatment of MM, we need to have a sense of what we can expect from these agents for the MM patients who have become resistant to currently available therapies. The benchmark to which we compare the trial results of a newer drug is the expected outcome in patients who relapse following current therapies. The questions are always, "What are we gaining? Does this drug offer something new? Are we making progress?"

Relapsed MM has been studied previously, but these data are no longer reflective of the current practice of widespread use of novel agents. The IMF's International Myeloma Working Group (IMWG) saw a need for a better understanding of the outcome of MM patients who have relapsed after therapies with bortezomib, thalidomide, and/or lenalidomide.

Please tell us about the patients you evaluated.

Similar to what is often seen in large multicenter clinical trials, we evaluated patients from different geographical regions. We reviewed medical records from large cancer centers across the United States, Europe, and Asia. In this regard, the IMWG is an ideal forum for such a study because it is a collaborative effort of MM specialists from around the globe.

We identified 300 patients with measurable relapsed disease who were refractory to bortezomib and had also relapsed and/or were refractory, intolerant, or ineligible to receive an IMiD. We took into consideration either thalidomide or lenalidomide, not both, due to the availability (or lack thereof) of IMiDs in different parts of the world. MM treatment patterns vary across the globe, mostly dictated by access to different drugs.

Because our goal was to use the data to assess future clinical trials, we excluded from our study patients who would typically be ineligible for participation in clinical trials. We developed uniform data collection forms to be used at all the study sites. The data were sent for analysis to Cancer Research And Biostatistics (CRAB) in Seattle, Washington. It took us approximately a year to collect and process the data, then another six months to prepare the manuscript that was published in *Leukemia*.



Shaji K. Kumar, MD
Mayo Clinic
Rochester, NY

What did the analysis show?

From the 300 patients with MM enrolled in the study, our analysis is based on the 286 patients for whom complete data were available. The 286 patients were treated at nine cancer centers: 107 patients from three sites in the US, 115 patients from five sites in Europe, and 64 patients from one site in Asia. The patients range in age from 30 to 85 (median age 58 years) at diagnosis. The median estimated follow-up for the entire group was 5.8 years from diagnosis. It took approximately 3.5 years for patients we studied to become resistant to both types of novel agents, but please keep in mind that we were specifically focused on the patient population already resistant to both bortezomib and one of the IMiDs, so this number is clearly biased toward the shorter timeframe. For example, patients who reached the point of drug resistance at 7 years may not have been included in this study.

We examined the patients' data from the point that they became resistant to bortezomib and one of the IMiDs. Of all the patients studied, 188 had relapsed on bortezomib while others had either not responded or had relapsed within 60 days of discontinuing the bortezomib. Among the 205 patients who were refractory to or ineligible for treatment with thalidomide, 135 patients had relapsed on therapy and/or were refractory, and 69 patients were considered intolerant to thalidomide due to toxicity. Among the 79 patients who were refractory to or ineligible for treatment with lenalidomide, 70 had relapsed on therapy and/or were refractory, and 9 were intolerant.

We analyzed responses based on whether or not patients received a regimen containing bortezomib, lenalidomide or thalidomide. The response rate to the first treatment regimen was 24% among the 106 patients treated with a regimen containing bortezomib, lenalidomide or thalidomide compared with 25% among the 107 patients receiving a regimen not containing one of these three drugs. Interestingly, bortezomib and the IMiDs continued to be used in the subsequent regimens in a significant proportion of patients.

Is it possible to draw any conclusions based on the study data?

The results of the IMWG study demonstrate significant differences between different parts of the world in terms of the treatment patterns both in the setting of initial therapy as well as relapsed disease, mostly dictated by the availability and patient access to different drug therapies.

It is important to understand the clinical course of patients who have become refractory to one or more therapies. Our study enrolled patients with measurable disease at the point at which they would be considered refractory to bortezomib plus at least one of the IMiDs. These drugs can be used in combination with a variety of agents, giving rise to multitude of regimens, so detailed information regarding specific drug combinations is not available at this time.

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GRANTS — continued from page 6

by a GSK3 β inhibitor will stimulate marrow stromal cells and decrease myeloma bone disease. These inhibitors also induce apoptosis of the MM cells. The GSK3 β inhibitors should synergize with bisphosphonate therapy resulting in a reduction of bone disease in patients with MM.

Charitha Madiraju, PhD, of Sanford-Burnham Medical Research Institute in La Jolla, California, will identify inhibitors of the ubiquitin-conjugating enzyme (UBC13). Dr. Madiraju hopes that new UBC13 inhibitors will have a synergistic action with bortezomib and other novel agents for the treatment of multiple myeloma (MM), and will eventually yield new medicines to improve treatment outcomes for MM patients.

Eyal Zcharia, PhD, of the Bruce Rappaport Faculty of Medicine, Technion University, Haifa, Israel, will study heparinase and its role in the treatment of multiple myeloma (MM). Heparinase is a heparin sulfate-degrading enzyme that promotes the growth of MM cells. Heparinase correlates with myeloma tumor vascularity as well as affecting MM cell invasion of bone. Heparinase is the only heparin sulfate-degrading endoglycosidase and is involved in the progression of malignancy. It is hypothesized that drugs designed to block heparinase function in vivo will inhibit disease progression. Dr. Zcharia and colleagues have generated a novel chemically-modified non-anticoagulant heparin (HI-2 = SST0001) that binds to heparinase and inhibits its enzymatic activity. This compound produced impressive results in preclinical models of MM. The investigation plans to develop second-generation compounds. They have elucidated the crystal structure of heparinase which allows for the rational design of heparinase inhibitors. This may lead to the design of novel, unique heparinase inhibitors. **MT**

IMF-Japan Research Grants

In addition to the 2012 Brian D. Novis Research Grants, three awards were presented by IMF-Japan to investigators working in the field of multiple myeloma.

The Award in Aki's Memory*

"Identification of Genes for Molecular Targeting Therapy Against Side Population Cells of Multiple Myeloma"

Dr. Hiroyuki Tagawa

Dept. of Hematology, Nephrology, and Rheumatology
Akita University Graduate School of Medicine
Akita City, Akita, JAPAN

The Special Award in Sugi's Memory

"The Research for Prevention of Symptomatic Multiple Myeloma"

Dr. Ai Kotani

Medical Science Division
Tokai University Institute of Innovative Science and Technology
Hiratsuka City, Kanagawa, JAPAN

The Award of IMF-Japan

"Fat Fraction Analysis of Multiple Myeloma Using 3T-MRI"

Dr. Miyuki Takasu

Graduate School of Biomedical Sciences
Hiroshima University
Higashi-Hiroshima City, Hiroshima, JAPAN

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



Jim Omel, co-leader, Grand Island MM Support Group, Nebraska

Multiple myeloma treatment has come a long way since I was diagnosed in 1997, when there was only a three-year median life expectancy. But there's still much to do. We need a cure; we need research. The IMF is a leader in funding that research.

At the 2012 IMF Research Grant award presentation ceremony, three of the myeloma patients in attendance spoke about the impact this disease had on them and how research has extended their lives.

Michael Tuohy, who was diagnosed at age 36, talked about how myeloma research helped make him an 11-year survivor. In that time, he saw his lovely daughter, who



was only seven years old when he was diagnosed, graduate from high school. His son, who was two at the time of Michael's diagnosis, has now been inducted into the National Junior Honor Society. Michael is co-founder and co-leader of the Connecticut Multiple Myeloma Fighters Information Group.

Mike Katz, a 22-year myeloma survivor and a co-leader of two myeloma support groups in and near New York City, said he would not be alive today if it



were not for myeloma research. Mike is currently enrolled in a clinical trial, and he spoke of all the treatments he has received throughout the years, the life and death importance of research that produces new anti-myeloma treatments, and how thrilled he is to have become a grandfather.

Mary Ming-Mosley was told she'd be dead in two years after she was diagnosed with myeloma at age 49. She is now a 19-year survivor, a grandmother of five, and a co-founder of the Inland Valley Multiple Myeloma Support Group in California.



I watched the faces of the award recipients as they listened to the stories shared by Michael, Mike, and Mary. I have no doubt that as they work in their labs they will remember and be inspired by these three remarkable patients. **MT**



SURVIVORSHIP CARE PLAN

Renal complications in multiple myeloma and related disorders

Page Bertalotti, RN, BSN, OCN

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

Elizabeth Bilotti, RN, MSN, APRN, BC

The John Theurer Cancer Center at HUPC
Multiple Myeloma Division
Hackensack, NJ

Kathleen Colson, RN, BSN, BS

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Deborah Doss, RN, OCN

Dana-Farber Cancer Institute
Boston, MA

Beth Faiman, MSN, APRN-BC, AOCN

Cleveland Clinic Taussig Cancer Institute
Multiple Myeloma Program
Cleveland, OH

Charise Gleason, MSN, NP-BC, AOCNP

Emory University Winship Cancer Institute
Atlanta, GA

Bonnie Jenkins, RN

University of Arkansas Medical School
Little Rock, AR

Kathy Lilleby, RN

Fred Hutchinson Cancer Research Center
Seattle, WA

Patricia A. Mangan, APRN, BC

Abramson Cancer Center at the University of Pennsylvania
Philadelphia, PA

Ann McNeill, RN, MSN, APN

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Multiple myeloma (MM) patients are living longer due to therapeutic options not available a decade ago. To address the evolving needs of MM patients and the nurses who work with them, the IMF's Nurse Leadership Board (NLB) has developed a Survivorship Care Plan that examines specific aspects of long-term care. The full manuscript was published by the *Clinical Journal of Oncology Nursing*® (CJON) in August, 2011, as a supplement to Volume 15, Number 4.

The IMF-NLB recommendations provide an overview rather than an in-depth examination of possible issues. In this edition of *Myeloma Today*, we offer a condensed version of the CJON manuscript chapter prepared by Beth Faiman, Patricia Mangan, Jacy Spong, Joseph Tariman, and other members of the IMF-NLB.

Renal Insufficiency

A serum creatinine level of 2 mg/dL or greater (normal range: 0.7–1.4 mg/dL) is used to define renal insufficiency. Kidney dysfunction is one of the common clinical features of symptomatic MM at diagnosis or it may occur during the course of the disease.

Chronic insults to the kidneys from treatment or MM itself, or from other illnesses, can have a negative effect on renal function and increase the risk for additional complications. These include bone loss, myelosuppression, infection, and anemia.

Identification of patients at risk for kidney damage is essential. The IMF-NLB has developed recommendations for screening renal function, identifying risk factors, and selecting appropriate therapies and supportive care measures to manage renal complications in patients with MM.

Long-Term Effects of MM on Renal Function

Pathogenesis of renal insufficiency in MM: By the time many patients have been diagnosed with MM, mild to moderate kidney damage may have already occurred. Cast nephropathy is the most common cause of damage to the kidneys as a result of myeloma protein deposition. This is also called “myeloma kidney.”



Beth Faiman



Patricia Mangan



Jacy Spong



Joseph Tariman

ATN: Acute Tubular Necrosis (ATN) can be caused by dehydration in the presence of kappa or lambda light chains. The use of loop diuretics (e.g. furosemide) may contribute to cast formation and increased serum creatinine levels. Hypercalcemia, NSAIDs (e.g. ibuprofen), or aminoglycoside antibiotics can cause decreased blood flow to the kidneys and result in kidney damage.

AL: Amyloidosis (AL) is a rare disease characterized by the deposition of amyloid fibrils that consist of monoclonal light chains in various tissues of the body. Systemic AL leads to organ dysfunction as amyloid fibrils are deposited in the heart, kidneys, nervous system, or gastrointestinal tract. The pathologist will stain tissue with “congo red” dye to confirm the diagnosis of AL.

LCDD: Light Chain Deposition Disease (LCDD) occurs when kappa or lambda light chains become deposited in the kidney. The diagnosis of LCDD requires a kidney biopsy. The pathologist will perform immunofluorescence and electron microscopy. Treatment of LCDD and AL is similar to MM.

Impact of Kidney Dysfunction

Relapsed MM: The advent of novel therapies offers options to treat patients at the time of relapse even in the setting of decreased renal function. Velcade® (bortezomib), thalidomide, and doxorubicin alone or in combination with steroids generally are well tolerated. Revlimid® (lenalidomide) can be given to patients with renal insufficiency or renal failure with dose modifications. Cyclophosphamide and melphalan also generally are well tolerated by patients with renal insufficiency, but the dose of melphalan may be reduced based on the clinician's judgment.

Additional risk factors: All MM patients should be monitored for kidney disease. Diabetes mellitus is the number one cause of kidney failure in the general population.

Hypertension is both a cause and a complication of chronic kidney disease and should be treated carefully. Weight control, exercise, smoking cessation, and medications for blood pressure may prevent or slow the progression to kidney failure in patients with MM. The greater the patient's age, the greater the risk for developing renal insufficiency, necessitating dose reductions for renally cleared drugs.

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Bone Complications: The kidneys play an important role in maintaining healthy bone mass by maintaining calcium and phosphorus levels in the blood. Bone loss associated with chronic renal disease can begin many years before symptoms appear. Older adult patients, postmenopausal women, and patients with MM in general are at increased risk for osteoporosis, which progresses as renal function worsens.

Newly diagnosed, eligible for transplantation: Frontline therapy for transplantation-eligible MM patients with decreased renal function includes regimens that contain thalidomide, Revlimid, Velcade, dexamethasone, vincristine, doxorubicin, liposomal doxorubicin, and cyclophosphamide. ASCT is well documented as an effective treatment for patients with newly diagnosed MM as well as for those with relapsed/refractory disease. Transplantation may be considered in patients receiving dialysis, but morbidity and mortality are higher.

Newly diagnosed, not eligible for transplantation: Alkylating agents such as melphalan may be administered to MM patients who are not considered candidates for transplantation. A combination of melphalan, prednisone, and Velcade has been shown to be an effective upfront therapy for patients newly diagnosed with MM, including those with impaired renal function.

Supportive Care Recommendations

Bisphosphonates are potent inhibitors of bone resorption that promote bone formation. Aredia® (pamidronate) and Zometa® (zoledronic acid) both are indicated to decrease fracture risk in patients with MM, but their effects on patients differ. Aredia and Zometa should be given cautiously, particularly in patients with uncontrolled MM.

When renal function has stabilized, serum creatinine levels should be evaluated at baseline and prior to each infusion of bisphosphonates. Dose reductions may be needed, and longer infusion times of pamidronate currently are recommended for patients with reduced creatinine clearance. Patients who are receiving bisphosphonates also should be given 1,000 mg/day of calcium and 400 IU/day of vitamin D. However, calcium supplementation is contraindicated in patients with hypercalcemia.

Anemia may be present in patients with moderate to severe renal dysfunction. If blood loss is not found, and the anemia is not considered to be related to treatment or disease progression, assessing serum erythropoietin, iron, folic acid, and vitamin B12 levels may identify the type of anemia. The use of ESAs (erythropoiesis – stimulating agents) to manage anemia in renal disease is accepted; however, their use in MM remains controversial, with one study suggesting that ESAs may have a negative effect on survival.

Individuals undergoing dialysis can benefit from many of the available novel treatment strategies; supportive care considerations in the dialysis-dependent patient differ from those of the nondialysis-dependent patient with chronic renal insufficiency.

Monitoring

Patients' myeloma and renal function must be closely monitored. Although the frequency of testing depends on the degree of renal failure as well as patients' response to therapy, testing CBC and chemistry laboratory parameters on a monthly basis is reasonable. Additional assessment, such as serum and urine protein electrophoresis, serum beta-2 microglobulin,

24-hour urine for protein electrophoresis, and serum free light chain (sFLC) assay may also be necessary.

Conclusion

Renal insufficiency in patients with MM should be assessed at initial diagnosis and regularly throughout therapy. Preventive measures should be initiated at diagnosis and throughout the course of the disease. Prompt intervention and identification of the underlying cause of renal failure may allow a patient's renal function to improve or even resolve, provide patients with more therapeutic options, and offer the potential for improved survival and quality of life.

Additional Information

Please visit the IMF website myeloma.org to view or download the full CJON manuscript, and contact the IMF Hotline at TheIMF@myeloma.org or 800-452-CURE (2873). And, as always, we encourage patients and caregivers to communicate with their medical teams. **MT**

DR. SHAJI K. KUMAR — continued from page 7

One of the most striking findings of this IMWG study has been the response rates seen in the study population with the first regimen used after the patients became refractory to the novel therapies. We found that older drugs such as alkylators were the most commonly used drugs in patients who stopped responding to the newer therapies. Patients relapsing after novel agents can achieve clinically meaningful response with delayed transplant as with early transplant.

We also found that a novel agent can be used again in patients who initially responded but then stopped responding to it. Bortezomib has been shown to have activity in re-treatment, and lenalidomide has activity in patients who are refractory to thalidomide.

In contrast to older studies, we did not see a progressive decline in response rates and duration of response, but this may be in part due to more treatment options being available now as compared to an era when alkylators and steroids were standard treatment for MM. But despite the initial responses of relapsed and refractory patients, the study data highlight the poor overall outcome among patients who are no longer responding to the existing newer therapies.

Given the limitations of our study, such as the exclusion of trial-ineligible patients and those refractory to an individual novel agent, the IMWG investigation provides valuable insights into the natural history of MM after it becomes nonresponsive to the novel therapies.

The IMWG study data establish a context and provide an important reference point for comparing the results of ongoing clinical trials of newer drugs for MM. Such data can aid the development of better therapies by identifying the most promising treatments currently in clinical trials.

An ongoing study is recruiting additional patients to extend the current analyses. **MT**

Editor's Note: Dr. Kumar's research at the Mayo Clinic focuses on studying the disease biology and developing new drugs for treatment of MM, as well as identifying synergistic combinations of different drugs that can result in better treatment responses and improved patient outcome.

Supportive Care

IMF HOTLINE COORDINATORS ANSWER YOUR QUESTIONS

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

To submit your question online, please email TheIMF@myeloma.org.

My doctor has talked to me about Velcade infusions as part of my myeloma therapy. I have read that the drug is now approved for subcutaneous administration. How does this compare to receiving Velcade intravenously?

VELCADE® (bortezomib) is the first in a class of drug called proteasome inhibitors. Bortezomib was first shown to have remarkable benefit in the treatment of relapsed and refractory multiple myeloma (MM). Intravenous (IV) bortezomib was subsequently approved by the FDA for the treatment of newly diagnosed MM, alone and in combination with other agents. Thus, IV bortezomib is available throughout the disease course for patients with MM, from those who are newly diagnosed to those whose disease has become refractory to and/or relapsed on previous therapies. IV bortezomib may be injected through either a peripheral or central intravenous line.

Subcutaneous (SQ) bortezomib was recently FDA approved for the treatment of MM. This means that now, instead of having a port put in and receiving the drug directly into a vein, patients can visit their doctor's office and get bortezomib as an injection given subcutaneously (under the skin) – what we commonly call a “shot.” It is an option for all situations.

The data that led to FDA approval arose from a French (IFM) clinical trial of 222 patients with relapsed MM led by Dr. Philippe Moreau. Patients were assigned to either IV or SQ administration of bortezomib and received the drug for 12 weeks (four 3-week cycles). The overall response rate for SQ bortezomib was 43%, and for IV bortezomib 42%. The complete response rate for SQ bortezomib at 12 weeks was 7%, while for IV bortezomib it was 8%. The progression-free survival, that is, the time from study entry to disease progression, was 10.2 months for SQ bortezomib and 8.0 months for IV bortezomib. These results all indicate that SQ bortezomib's efficacy is comparable to that of IV bortezomib.

The clinical trial data on the two methods of administering bortezomib began to diverge only in the area of peripheral neuropathy (PN), a common side effect of bortezomib. Patients who received SQ bortezomib had an incidence of PN of any severity (rated on a National Cancer Institute-designed scale of 1-4, with 1 being least and 4 being most severe) of



(l to r) Paul Hewitt, Judy Webb, Debbie Birns, and Missy Klepetar

38%, while those who received IV bortezomib had a 53% incidence of any grade of PN. Only 6% of the patients who received SQ bortezomib had PN of grade 3 or 4, while 16% of the IV bortezomib patients had grade 3 or 4 PN.

While changing the administration of IV bortezomib from twice-to once-weekly and/or lowering

the dose has been effective in halting or preventing PN, SQ administration is an additional factor that must be considered for MM patients with pre-existing PN or for those who are at risk of PN. Since there are few really effective options for treating PN once the nerve damage has occurred, patients MUST be proactive about avoiding neuropathy. Prevention is your best protection. Those who have pre-existing neuropathy from another disease, such as diabetes, or who have PN from the myeloma itself, should be especially cautious and should discuss with their oncologists the best dose, schedule, and route of administration of bortezomib before they start treatment with it.

Injection sites for SQ bortezomib are rotated between the thigh and abdomen. Some patients experience redness, swelling, itching, and/or pain at the injection site; 6% of patients in the clinical trial had such reactions. The median time for these reactions to resolve in the clinical trial was 6 days. Patients who have an injection site reaction must report it to their healthcare team for evaluation. The most commonly reported side effects in the clinical study comparing IV and SQ bortezomib occurred in approximately the same percentage of patients no matter how they received the drug, with the exception of PN.

We urge you to be vigilant about reporting any and all problems you are experiencing while receiving treatment. Whether or not they are related to therapy, your nurses and doctors need to know about them to help you maintain quality of life and to make your therapy most effective.

The IMF Hotline welcomes your questions via phone at 800-452-CURE (2873) or email at info@myeloma.org. The Hotline blog is accessible via the IMF website myeloma.org. As always, the IMF urges you to discuss these and all other medical issues thoroughly with your doctor. **MT**

Myeloma Manager™ Personal Care Assistant™

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



Do you have a question?

Perhaps you would like to order a publication? Are you thinking about registering for a Patient and 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



SPOTLIGHT ON ADVOCACY

IMF's advocates take action



By Meghan Buzby

New Jersey becomes 15th state to pass oral chemotherapy access legislation

The oral chemotherapy access bill, A.2666 / S.1834 was signed by Governor Chris Christie on January 17, 2012, making New Jersey the 15th state to pass this legislation into law. This is a tremendous victory for all cancer patients in New Jersey who now have access to all anti-cancer medications regardless of the method of delivery. We would like to thank all of our advocates who made this possible. Our special thanks go to Paula Van Riper and Elizabeth Bilotti, RN, MSN, APRN, BC. Paula, the leader of the Central New Jersey Support Group, testified in June before the Assembly



Health Committee. Elizabeth, who works with myeloma patients at the John Theurer Cancer Center at Hackensack University Medical Center, is a member of the IMF's Nurse Leadership Board and testified in October before the Senate Budget and Appropriations Committee.

IMF's support group leader makes huge impact at press conference in Delaware

Josephine Diagonale, the leader of the Delmarva Multiple Myeloma Support and Networking Group, addressed legislators, supporters, and members of the press at a January 25 press conference held to announce the introduction of the Delaware Cancer Treatment Access Act (HB 265).

HB 265, a bi-partisan bill introduced by a group of legislators (Representatives Deborah Hudson, Ruth Briggs King, Bryon Short, and Senators Patricia Blevins and Liane Sorenson), would require health insurance plans in Delaware that cover cancer treatments to provide coverage for orally administered anti-cancer medications on a basis no less favorable than coverage for intravenously administered or injected anti-cancer medications.



Josephine Diagonale helps to introduce HB 265 (the Delaware Cancer Treatment Access Act) with bill sponsor Representative Deborah Hudson

Josephine explained to the crowd how the diagnosis of cancer brings patients face-to-face with their own mortality. But with help from family, friends, doctors, nurses, spiritual advisors, and medical researchers dedicated to discovering new drugs that prolong life, cancer patients find within themselves the tenacity and warrior spirit to persevere.

"Cancer patients form a band of brothers and sisters who are focused on a cure," she asserted. "And this means having access to all chemotherapy available to us without regard to the particular delivery system. Imagine having to choose between incurring a large financial burden for oral

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Capitol Hill Bulletin

By Johanna Gray

HR 2746 – The Cancer Drug Coverage Parity Act

Introduced in August 2011, the Cancer Drug Coverage Parity Act will ensure that patients will have equal and appropriate access to all cancer treatments, whether the treatments are oral or intravenous drugs. Currently, many patients have significantly higher out-of-pocket costs for oral treatments (i.e. pills) than they do for intravenous treatments. This legislation is a high priority for the IMF and, if signed into law, would require private insurers to provide equal coverage of both forms of anticancer drugs. Congressman Brian Higgins (D-NY) introduced the bill, which now has 15 bipartisan cosponsors.

We need your help! Please visit our action center at www.advocacy.myeloma.org to learn how to ask your Representative in Congress to cosponsor HR 2746. Additionally, we are collecting stories from patients who faced challenges in getting insurance coverage for their oral chemotherapy treatments. If you had to pay significantly more out-of-pocket for oral chemotherapy drugs than you would have for intravenous drugs, or if you faced challenges in getting insurance coverage for oral chemotherapy drugs, please contact Johanna Gray jgray@dc-crd.com or 202-484-1100. With your help, we can guarantee that cancer patients have fair and equal access to all types of treatments.

President Obama releases FY2013 budget

On February 13, 2012, President Obama released his budget proposal for the 2013 fiscal year. Congress does not have to adhere to this budget, but it tends to provide a starting place for discussions when working on spending bills. In the budget proposal, the White House kept the funding for the National Institutes of Health (NIH) at last year's level, which is approximately \$30 billion. Many anticipate that advocates will lobby Congress to invest more in medical research and, hopefully, Congress will increase the NIH budget next year. The Centers for Disease Control and Prevention (CDC) cancer control programs are also being funded at last year's levels with no increases. Instead of funding those programs directly through the CDC budget, it appears that the President's budget proposal transfers money from the Prevention and Public Health Fund created during health reform to cover those cancer control programs. This may upset advocates who support prevention programs and who could pressure Congress to change the source of funding for these programs. While we are pleased that the President did not recommend cutting the NIH and CDC budgets, the IMF will advocate for increasing their budgets as Congress works on the appropriations legislation to fund the agencies.

The IMF Advocacy Voice: Get Fired Up! Raise Your Voice! Get Out There and Take Action!



We are fighting for oral parity laws in 16 states. Is your home state one of them? Find out and sign up at www.advocacy.myeloma.org. We need YOUR voice so that no patient suffers cost discrimination. Sign up TODAY at advocacy.myeloma.org!

2012 BOCA RATON IMF PATIENT & FAMILY SEMINAR

A long-term survivor's perspective



By Tom Callaghan

WHAM!! "I'm sorry You say I have what? What the heck is multiple myeloma?" You go to the hospital, fearing you might have to undergo back surgery and then, out of the blue, you're slammed with the news that you have some kind of advanced bone marrow cancer. Trembling, you then summon the courage to choke out the words: "How much time do I have?" The uncomfortable response is something like: "Maybe three years, depending on your response to treatment."

So it was that my thus-far-14-year journey with multiple myeloma (MM) began.

As diverse as we are, and as unique as our stories can be, all of us myeloma patients share a common experience upon diagnosis. Like others who are similarly afflicted, we scramble for information and knowledge about this heretofore unfamiliar disease, and for the best available treatment options. Together with our loved ones, we burn up the internet in desperate search for knowledge and direction, and then, confused and overwhelmed, we turn to second and third opinions from the best clinicians we can find. Transplant or drugs? What are the risks of clinical trials? What new drugs might be in the pipeline, and which of them in combination could create an optimal response? And why is it that certain protocols work well for some patients and not for others? Complicated stuff, to say the least.

Thank God for the International Myeloma Foundation. Over the past two decades, under the incredibly dynamic and dedicated leadership of Susie Novis and Dr. Brian Durie, the IMF has grown exponentially

into the grassroots juggernaut it is today: as the relentless sponsor of cutting-edge research and leading educational resource for patients and caregivers alike.

Recently, I had the privilege of attending the two-day IMF Patient & Family Seminar

in Boca Raton, Florida. Over 350 patients and family members from across the country participated in the meeting, and I know all would enthusiastically agree that the experience was profound and immensely rewarding. Some were new to the IMF and the world of MM; others, like me, believe that we should never stop learning about this disease and its treatment options.

Apart from being one of the most beautifully and professionally conducted conferences (of any type!) that I have ever attended, the IMF Patient & Family Seminar afforded us the unique opportunity to hear

and interact directly with the foremost accomplished and heralded professionals in the field of MM. The impressive faculty consisted of world-renowned experts, such as Dr. Ken Anderson (Dana-Farber Cancer Institute, Boston, Massachusetts), Dr. Brian Durie (Cedars-Sinai Oschin Cancer Center, Los Angeles, California), Dr. Asher Chanan-Khan (Mayo Clinic Cancer Center, Jacksonville, Florida), Dr. Bart Barlogie (University of Arkansas Myeloma Institute, Little Rock, Arkansas), and Dr. Shaji Kumar (Mayo Clinic, Rochester, Minnesota).

We listened to presentations and asked questions about issues ranging from a coherent explanation of the disease, an array of new drugs and effective combinations, the efficacy of and best candidates for transplant, the promise of ongoing clinical trials, management of the disease, and lifestyle and quality of life issues. Each presentation – as well as the interactive panel discussions between doctors and patients – was illuminating and compelling, and an affirming source of increased hope for all of us. As ever, knowledge is power.

Specifically, it seemed there was something for everyone. Dr. Kumar expounded in a very understandable way on the range of best therapies for elderly MM patients. For those considering the option of transplant, whether as front-line therapy or at a later time, Dr. Barlogie, a renowned transplant pioneer and specialist, offered his views on the most effective therapies for patients opting for autologous stem cell transplant (ASCT). Dr. Anderson gave a marvelous presentation on the exact nature of the disease itself, the development of therapies over the years leading to present research outcomes, recent advances in genetic profiling affecting therapy decision-making, and promising new and ongoing clinical trials. Dr. Durie then concluded with a comprehensive and illuminating talk on the management of bone disease, including how best to monitor bone lesions, particularly through increased utilization of Positron emission tomography (PET) scans. Dr. Durie went on to highlight the benefits of vertebroplasty and balloon kyphoplasty, and then discussed the advantages of bisphosphonate therapy, but with a cautionary note on how best to manage the risk of osteonecrosis of the jaw (ONJ) associated with Aredia® (pamidronate disodium) and Zometa® (zoledronic acid).

Finally, sharing stories and experiences in fellowship with other patients and caregivers is another extraordinary benefit that cannot be overstated. I have attended several IMF Patient & Family Seminars over the years, and the camaraderie is simply unsurpassed.

If you haven't yet attended one of these remarkable IMF events, you should by all means go for it! **MT**



Dr. Ken Anderson with Brian & Cindy Feltsen



Patients and caregivers at the Boca Raton Patient & Family Seminar

IMF WELCOMES NEW MEMBERS TO ITS BOARD OF DIRECTORS

Prof. Dr. Mario Boccardo
Oncology Division,
University of Torino
Torino, Italy



Prof. Mario Boccardo began his career in multiple myeloma (MM) research and treatment in 1978 as a post-doctoral fellow working with Prof. Benjamin Van Camp, one of the earliest researchers in the field of MM. Following this, Prof. Boccardo was

appointed as assistant professor in the Department of Medicine and Experimental Oncology in the department of Prof. Alledandro Pileri, a noted researcher in the area of MM. In the early 1980s, Prof. Boccardo spent two years as a visiting investigator at the Arizona Cancer Center in Tucson, where he worked with Prof. Brian Durie and Prof. Sydney Salmon, co-developers of the Durie/Salmon Staging System for MM.

Prof. Boccardo created the Italian Myeloma Study Group, the first research consortium in Italy and one of the first in Europe. Under his direction, the Italian Myeloma Study Group has conducted a series of pivotal clinical trials, spanning more than two decades and representing a remarkable collective contribution to the MM community. Prof. Boccardo is a member of numerous professional societies both in Europe and in the United States. Since 2000, he has held the title of Professor and Head of the Hematology Section of the Oncology Division at the University of Torino. Prof. Boccardo has been honored by the IMF's Robert A. Kyle Lifetime Achievement Award for his body of work in the field of MM.

Andy Kuzneski, III
President, Berkshire Securities Corp.
President, Greyhawk Capital, Inc.
Principal, Kuzneski Financial Group



Mr. Kuzneski is currently active in the insurance, investment, and banking industries. He is a Principal at Kuzneski Financial Group (an insurance broker) and President of Greyhawk Capital (a provider of equity

capital and advice to seed and early stage growth companies). He is also President and board member of Berkshire Securities (a private investment company that has invested in Pennsylvania-based community and regional banks for over 30 years). Mr. Kuzneski serves on the boards of Berkshire Securities, VIST Financial (a publicly-traded financial holding company), First National Bank of Santa Fe (New Mexico) and its insurance subsidiary, and FastFreight Expeditors (a specialty trucking and logistics firm he co-founded). He has also served on the boards of numerous non-profit organizations, some of which he co-founded.

Andy graduated *cum laude* from the University of Pennsylvania's Management & Technology Program, simultaneously earning a finance degree from Wharton and a computer science degree from the School of Engineering and Applied Science. After graduation, he was a software developer and then formed his own startup, ArtWatch International, which grew to become one of the largest manufacturers of character watches in the US.

Prof. Dr. Heinz Ludwig
Center of Oncology and Hematology
Wilhelminenspital
Vienna, Austria



Prof. Dr. Heinz Ludwig is Director of the Department of Medicine, Center of Oncology, Hematology and Palliative Care, at Wilhelminenspital, Vienna. Since 1990, under his leadership, the center has become one of the leading centers in Austria. In addition to his dedication

to clinical work, Prof. Dr. Ludwig has an accomplished career in scientific research. His research interests encompass a broad field of therapeutics in hematology and medical oncology. In particular, his research focuses on the biological and clinical aspects of multiple myeloma (MM) as well as pathophysiology and treatment of cancer-related anemia.

Presently, Prof. Dr. Ludwig is a member of the National Health Counsel and president of the Austrian Forum Against Cancer. Furthermore, he is a member of editorial advisory boards of several scientific journals and a former president of the European Society for Medical Oncology (ESMO) and member of the board of international directors of the American Society of Clinical Oncology (ASCO). Beyond that, Prof. Dr. Ludwig is a corresponding member of the American Association for Cancer Research (AACR). He has contributed to several clinical studies and organized investigator-sponsored trials. For his scientific contributions, Prof. Dr. Ludwig has been honored by the IMF's Robert A. Kyle Lifetime Achievement Award and the Golden Cross of Merit from the Republic of Austria. **MT**

ADVOCACY — continued from page 12

chemotherapy or going without treatment. This is a life or death situation for many. Imagine having to make this choice in today's economy, when you have kids to raise or have kids aspiring to have a college education. The financial stresses associated with cancer can be overwhelming."

Josephine emphasized that access to oral chemotherapy increases patients' quality of life, mobility, and freedom. She urged legislators in Delaware to pass HB 265 to allow all cancer patients access to all anti-cancer medications regardless of how they are delivered. "Adding my voice to the Delaware legislators and other supporters of this bill was an honor and a privilege. This bill would allow us all to focus on our primary battle—the battle to live productive and meaningful lives."

The IMF is leading the coalition effort in support of HB 265. We gathered more than 10 national and local patient advocacy organizations to work collaboratively towards the passage of this bill. As of the writing of this article, a hearing is scheduled for March 14, 2012, in the Economic Development, Banking, Insurance and Commerce Committee. The IMF is working tirelessly to make Delaware the 16th state to pass this into law! **MT**

How to contact the IMF Advocacy Team



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UPDATES FROM ASIA

By Dan Navid

Training Doctors from China

There are likely more multiple myeloma (MM) patients in China than anywhere else in the world. And the number of cases is increasing, due perhaps to environmental factors and certainly to better diagnosis. While leading Chinese physicians are world-renowned and are active members of the IMF's International Myeloma Working Group (IMWG), there is a pressing need to enhance the capacity of Chinese hematologists to better diagnose and treat a growing epidemic of Chinese MM patients.

As previously reported in *Myeloma Today*, the IMF has entered into a cooperative agreement in late 2010 with the Chinese Health Promotion Foundation, a unit under the Chinese Ministry of Health. The main purpose of this accord was to assist in the training of Chinese physicians.

At the December 2011 annual meeting and exposition of the American Hematology Society (ASH) in San Diego, the IMF was able to implement two important actions as part of this process of education.

The first was undertaken in cooperation with Xian-Janssen, the company providing VELCADE® (bortezomib) to MM patients in China. A briefing session was held for some 45, mostly young, first-time Chinese participants to the ASH conference. This activity, the first of its kind, provided the new ASH attendees with a roadmap to the maze of upcoming sessions and events. IMF's medical experts explained how the ASH conference functioned and highlighted the key sessions and presentations likely to be of special interest to the Chinese physicians. The lively question and answer period that followed the briefing demonstrated that the IMF's session was well received and much appreciated.

The second was a more traditional roundtable table discussion with the Chinese key opinion leaders in the field of MM, held in cooperation with Celgene-China, the makers of REVLIMID® (lenalidomide) and THALOMID® (thalidomide). At this event, some 15 Chinese experts met with IMF counterparts to review priorities for education and training in the coming three years. The findings of the meeting, including the need for in-country courses and seminars as well as "preceptorships" abroad will be incorporated into the IMF-China program for 2012-2014.

IMF's Asian Myeloma Network meets at ASH



Under the Chairmanship of Dr. Brian Durie, IMF's Asian Myeloma Network (AMN) held its most recent meeting upon the occasion of the December 2011 annual meeting and exposition of the American Hematology Society (ASH) in San Diego.

Comprised of members from China, Hong Kong, Chinese Taipei, Japan, Korea, Singapore and Thailand, the AMN serves to advise the IMF on its Asian program and to implement certain regional projects.

The first AMN regional activity, the Asian Myeloma Data Base, was the main focus of discussion at this meeting. Data on some 4,000 patients

from the seven participating countries and territories has been collected and analyzed. An abstract on the findings will be released later in 2012.

The group also discussed priorities for further action, including launching pan-Asian clinical trials. The work of the AMN continues via correspondence with the next formal meeting scheduled for Shanghai in May 2012.

Landmark agreement signed in Shenzhen, China

On 25 February 2012, the IMF and Xian-Janssen, a pharmaceutical company of Johnson and Johnson, agreed to a three-year program of cooperation for physician training and myeloma patient support in China. IMF President Susie Novis signed this agreement with Sandy Mu, Vice President of Xian-Janssen, at a ceremony in Shenzhen in advance of a conference for Chinese physicians.



The signing of the agreement between IMF President Susie Novis and Xian Janssen VP Sandy Mu.

The agreement provides for cooperation in the designation of Chinese centers of excellence for MM training and research, for the development of training programs and awareness raising actions in China, and for "preceptorships" for Chinese physicians abroad.



A toast is shared between IMF and Xian-Janssen following the signature of the cooperative agreement. From left to right: Xin Bian, Brian Durie, Sandy Mu, Dan Navid, Susie Novis, and Ming Liu.

Susie Novis noted that "sign-

ing the agreement was significant because it shows the long-term commitment on both sides to work together to promote the myeloma cause in China." And Ms. Mu remarked that the IMF's prestige and expertise would provide a tremendous boost to the Chinese medical community and that Xian-Janssen was proud to be able to partner with the IMF in this important effort.

Annually, the IMF and Xian-Janssen will agree upon specific projects to be funded and implemented under this program. The next actions in 2012 will include a training program in Shanghai in May for some 200 Chinese hematologists. A session of the IMF Asian Myeloma Network (AMN) will also be convened at this time.



Meeting's faculty and organizers

CONTINUES ON PAGE 16

IMF Staff Updates



Aimee Martin

Grassroots Liaison

Aimee Martin earned her degree in Government and Economics at Connecticut College in 2007. Since graduating, she has been travelling the country working on advancing legislative and ballot measures in California, Maine, New Jersey, and Maryland. In each of those states, Aimee created volunteer action teams that continue to be active and successful.

Having experienced the impact of cancer on members of her own family, Aimee has joined the IMF's advocacy team to help improve the lives of people living with multiple myeloma (MM). She will contribute her knowledge of grassroots lobbying and organizing by developing action teams to help pass oral parity laws in every state in the US, thereby improving access to quality care for MM patients while raising MM awareness across the country.



Chelsea Proctor

Executive Assistant

Chelsea Proctor graduated from the University of Southern California with a Bachelor of Arts degree in International Relations in 2009. Her studies fueled Chelsea's desire to devote her career to finding solutions to social and economic challenges.

Chelsea's professional experience includes work with a Los Angeles-based community foundation and, most recently, with a major private equity firm. At the firm, she managed circulations, legal filings for new web content, production updates, and site-wide promotions. Chelsea was also responsible for the creation and management of process flow documents, and providing administrative coordination to senior executive teams. She is excited to support members of the IMF team as they work to serve the multiple myeloma community. **MT**

Letters to the IMF

At age 58, my life began again on 8/16/2011. I now consider the day I was diagnosed with multiple myeloma (MM) to be my new birth date. I woke up feeling lousy, but I pressed on to work. By noon, I was headed to the emergency room. After being admitted to the hospital, I learned of my diagnosis. It was mindboggling and difficult to conceptualize.



As I began my journey with MM, I found my strength and independence replaced by interdependence, caring support, and love and compassion beyond my wildest imagination. Family and friends took time out of their busy schedules, co-workers sent gifts and offered words of encouragement, and my sons have been there for me every step of the way.

It was after I got all my affairs for dying in order that I found myself ready to start truly living. Cancer is a part of my life now, but it does not define it. All the wonderful moments I experience on a daily basis are simply priceless. I'd like to express my heartfelt thanks to the IMF and all the myeloma researchers, clinicians, and supporters of those of us who are living with MM. Where would we be without you?

Celinda Lovett

I recently had the need for a brochure on multiple myeloma for a patient of mine who speaks and reads Russian. We obtained a pamphlet from your website which was excellent and answered all the patient's questions and concerns.

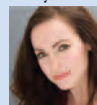
Just wanted to let you know that your foundation is providing an excellent service. Thank you for being a resource to my practice in providing patient care and understanding.

Mary M. Klix, MD

Your web site is great!!! On it, I found a lot of help while dealing with my mom who is battling this awful cancer. Thank you all for doing what you do... all of you are ANGELS.

Karen Higgins

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



Marya Kazakova – Publications Editor

International Myeloma Foundation

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mkazakova@myeloma.org

INTERNATIONAL — continued from page 12

Following the signature ceremony, an expert session was held to discuss key issues for physician training. IMF Chairman Dr. Brian Durie spoke about the work of the IMF; Prof. Robert Orłowski of the MD Anderson Cancer Center and the IMF's IMWG member spoke about MM treatment and the MD Anderson experience in building a successful MM center; and Prof. Irene Ghobrial of the Dana-Farber Cancer Institute spoke about new MM therapies and the global cooperative research work at her center.

The IMF's IMWG members Prof. Wen-Ming Chen of Beijing Chaoyang Hospital and Prof. Jian Hou of Changzheng Hospital in Shanghai completed the panel and led discussions amongst the Chinese physicians.

Second Singapore National Patient Forum

On 2 March 2012, the second National Patient Forum was held in Singapore in cooperation with the IMF. Seventy-five local MM patients and caregivers attended.

Building upon the inaugural session held last year, the Forum featured several expert presentations from leading physicians, as well as

patient testimony. IMF President Susie Novis opened the session with words of encouragement and stressed that there were many resources available to assist patients with MM. IMF Chairman Dr. Brian Durie presented the 10 Steps to Better Care™ which was provided in a Chinese translation for distribution to the participants.



Susie Novis with meeting co-chair David Ong and his wife



Dan Navid with Dr. Satish Kumar of the Singapore General Hospital

Further presentations were given on Future Treatment Options in Singapore by Dr. Wee Joo Chng, Current Treatment and Side-effects by Dr. Satish Kumar, Myeloma and Bone Health by Dr. Naresh Kumar, and Acupuncture and Peripheral Neuropathy by Dr. Qin Xiudi. **MT**

IMFERS RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY



By Suzanne Battaglia

In 2011, IMF members raised over \$395,000 to support essential multiple myeloma (MM) research. This impressive sum is the result of neighborhood garage and bake sales, community marathons and walks, party and entertainment events, golf and other sports tournament, and countless other fundraisers.

Most of the fundraising and MM awareness events start with a phone call to the IMF and one simple question – “What can I do?” Those who became involved found their activities to be not only fulfilling but also incredibly empowering.

The moneys raised over the past year by individuals like you are supporting cutting-edge projects funded by the IMF Brian D. Novis Research Grant program. This past December, six talented researchers were awarded donor-funded grants. Some were funded through one-time events, while others were supported by funds raised over a span of years. Member Events responsible for funding the 2012 IMF Brian D. Novis Research Grants include:

- **ANNUAL “JC” GOLF TOURNAMENT** – When Janet “JC” Jackson, who was beloved by all, passed away from MM, her husband and friends organized an annual golf tournament to honor her memory. They have already funded several research projects with the proceeds of this event.
- **ANNUAL CAROLYN CZERKIES MEMORIAL GOLF OUTING** – This year marked the fourth tournament and the second research grant funded by The Czerkies Family in honor of their mother. Craig Czerkies and his brothers are committed to helping the myeloma community until the cure is found.
- **MILES FOR MYELOMA 5K** – Organized by three separate Support Groups in the Tri-State area (Philadelphia MM Networking Group, Central New Jersey MM Support Group, and Northern New Jersey MM Support Group), this event has now funded three research grants. In 2011, the 5K was attended by well over 600 people, who came out in support of the MM community regardless of the pouring rain.
- **COACH ROB’S BENEFIT BASH & GOLF TOURNAMENT** – The first Coach Rob research award was presented in honor of Chris Hollyer, a patient who for many years managed the MM list serv, and thereby helped countless other patients, including Rob Bradford. Rob’s event, which includes a Monte Carlo Night on Sunday and a golf tournament on Monday, has now funded three grants.
- **TROOPER BENSON RESEARCH FUND** – IMF Board of Directors member Benson Klein and his wife Carol have been supporters of MM research for many years. Together with Nancy Krett, the powerhouse trio raises funds in several different ways each year – through the Trooper Benson Research Fund, a ladies’ Afternoon Tea event, and a bridge tournament.
- **GARY C. HEUER MEMORIAL GOLF TOURNAMENT** – Nancy Heuer lost her son to MM at a very young age. To honor Gary, who was an avid golfer, Nancy has organized an annual golf event, which has now

held its 10th tournament. It took Nancy 10 years to be able to fund a full grant. This is a true measure of dedication!

Join us in working together toward our common goal... a CURE. Our FUNdraising program is fun and easy, and brings with it the satisfaction of knowing that YOU are making a difference in many lives. Choose an established event model or create your own. No idea is too large or too small! The IMF provides you with tools and assistance to make your event a success, and promotes your efforts through our website and social media outlets.

Become a part of making miracles happen! Please contact me, Suzanne Battaglia, at sbattaglia@myeloma.org or 800-452-CURE (2873) to chat about any ideas you might have. Here are some examples of recent events...

Jack Aiello’s Poker Bash

Jack Aiello has hosted an annual Dinner & Texas Hold ‘Em Poker Tournament fundraiser for the last seven years. The idea was the result of some brainstorming with a dear friend whose birthday falls close to Jack’s. “We have now known each other for more than 30 years, and this seemed like a great way to share the celebration of our birthdays with a lot of friends while doing something to benefit a good cause,” said Jack. “In addition, my third transplant took place on my birthday in November 1998, so for me the day has a double significance. It’s both my birthday and my re-birthday!”



Jack, who helps lead the San Francisco Bay Area MM Support Group, was diagnosed with MM more than 17 years ago. He persevered through a lot of difficult MM therapies during the first 7 years, including two autologous transplants plus an allogeneic transplant with his sister as donor. “I continued to deal with medical issues for a couple of years after my third transplant, including graft-versus-host disease (GVHD), but for the last 10 years I have been in a good remission and have not required any treatment.”

It was at a support group meeting in 1995 that Jack first met another MM patient. He provided Jack with some resources, including referring him to the IMF. The next year, Jack experienced his first IMF Patient & Family Seminar. “I guess what’s kept me involved with the IMF is that the memory is still fresh in my mind. It just doesn’t seem like it was so long ago that I was overwhelmed by a disease I had never heard of. I am fortunate to be able to give back, both in terms of sharing knowledge with fellow patients and raising funds to support the IMF, an organization whose focus is always on the patient.”

Matt Jacob’s Letter Campaign

In his professional life, Matt Jacobs was a very successful information technology specialist, dedicated to his business of running large databases for Fortune 500 companies. His diagnosis with MM in June 2004 came as a

MYELOMA 200 – CLOSER TO A CURE

Progress in multiple myeloma (MM) research and new approaches to treatment are improving outcomes for people diagnosed with MM, but there is much more to be done. The IMF is celebrating our 21st year providing myeloma patients, caregivers, physicians, nurses, and researchers the tools they need to fight this disease.

In honor of this tremendous achievement, we have re-launched one of our most successful fundraisers, MYELOMA 200 – CLOSER TO A CURE. Participating in the M200 Challenge is easy: for every \$200 you give or raise, you will be entered in a drawing to win a fabulous vacation getaway for two, for 7 days and 6 nights, at the beautiful Four Seasons Costa Rica at Peninsula Papagayo. The prize includes airfare on American Airlines and a \$400 gift certificate toward spa treatments. To participate, all you have to do is register online at M200.myeloma.org or contact Suzanne Battaglia at sbattaglia@myeloma.org or 800-452-CURE (2873).

Teamwork makes everything possible. Start your M200 Fundraising Team and help the IMF reach a goal of \$200,000 raised for our Research, Education, Support, and Advocacy Programs. The M200 Challenge will continue until April 30, 2012. Anyone can participate, and by helping us reach our goal of \$200,000 you help ensure that everyone wins! **MT**



MEMBER EVENTS — continued from page 17

huge shock that led to a new perspective on life. He decided to retire and dedicate himself to helping others.

Besides fundraising, Matt is involved with hospital visitations and is very active in his local support group. A big believer in the importance of being an educated patient, he soon found himself as a sought-after resource for fellow MM patients in his support group. He has helped others navigate the maze of health insurance matters, as well as apply for Social Security and disability. A veteran of several clinical trials, Matt also keeps up to date on MM research.

Another way Matt wanted to help the larger MM community was to use his vast network of personal and professional relationships to raise funds to benefit the IMF. Every year, Matt initiates a letter-writing campaign sharing his personal experience and information about MM, and soliciting donations. "It is very rewarding to see how many positive responses I receive," said Matt. "The generosity of donors, old and new, is very gratifying. To date, we have raised more than \$25,000 to support myeloma research. Obviously, I have a vested interest in raising funds for research, as it is clearly the way to a cure. Anything I can do to help is truly a labor of love." **MT**

UPCOMING MEMBER EVENTS

April 28, 2012

Miles for Myeloma 5K – West Chester, PA
Contact: Karen Horan karen.horan@verizon.net

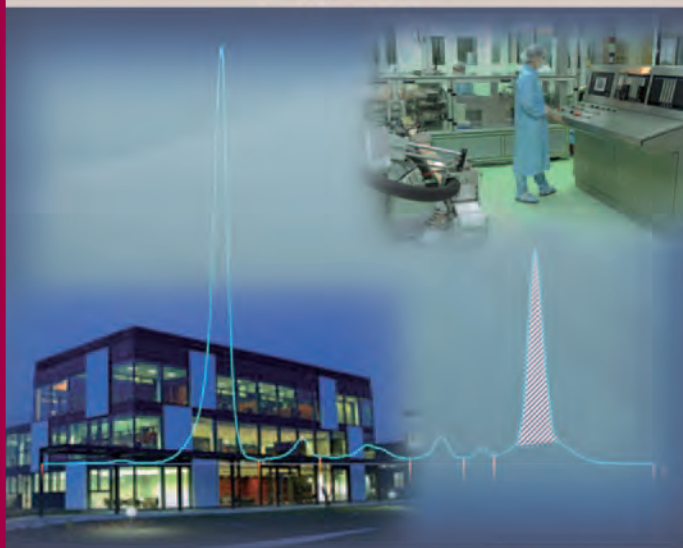
May 19, 2012

JC Golf Tournament – St. Cloud, MN
Contact: Bob Zins or boloz@charter.net or 320-291-2130

June 9, 2012

Carolyn Czerkies Memorial Golf Outing – Naperville, IL
Contact: Craig Czerkies czak16@aol.com or 630-721-0557

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MOST PATIENTS WITH MULTIPLE MYELOMA STILL

RELAPSE

The overall 5-year survival for patients with multiple myeloma has improved over the past 10 years.¹ However, myeloma remains a largely incurable disease, and almost all patients will relapse.²

**PROGRESS HAS BEEN MADE, BUT NEW
THERAPIES ARE URGENTLY NEEDED.**

References: 1. National Cancer Institute. *Surveillance Epidemiology and End Results*. seer.cancer.gov/csr/1975_2007/browse_csr.php?section=18&page=sect_18_table.06.html#table1. Accessed April 6, 2011. 2. Chanan-Khan AA, Ivan Borrello J, Lee KP, et al. Development of target-specific treatments in multiple myeloma. *Br J Haematol*. 2010;151(1):3-15.

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oncology
mission

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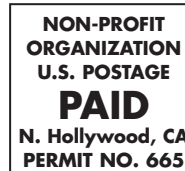


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2012 IMF Calendar of Events

- May 3-5 Oncology Nursing Society (ONS) annual conference – New Orleans, LA
May 5 Myeloma Center Workshop (MCW) at the Myeloma Institute for Research and Therapy (MIRT) – Little Rock, AR
May 11-13 IMF-China Physician Training Conference & Asian Myeloma Network (AMN) meeting – Shanghai, CHINA
May 19 IMF Regional Community Workshop (RCW) – Indianapolis, IN
May 26 MüUC/IMF Regional Community Workshop (RCW) – Münster, GERMANY
May 30 CMG/IMF Regional Community Workshop (RCW) – Brno, CZECH REPUBLIC
June 2-4 American Society of Clinical Oncology (ASCO) annual meeting – Chicago, IL
June 7 AF3M/IMF Patient & Family Seminar (PFS) – Paris, FRANCE
June 9 WüUC/IMF Patient & Family Seminar (PFS) – Würzburg, GERMANY
June 10 Koblenz SG/IMF Regional Community Workshop (RCW) – Koblenz, GERMANY
June 11-13 International Myeloma Working Group (IMWG) Summit III – Amsterdam, THE NETHERLANDS
June 12 Robert A. Kyle Lifetime Achievement Award Dinner – Amsterdam, THE NETHERLANDS
June 14-17 European Hematology Association (EHA) 17th congress – Amsterdam, THE NETHERLANDS
June 16 Munich SG Patient & Family Seminar (PFS) – Munich, GERMANY
June 17 Leipzig SG/IMF Regional Community Workshop (RCW) – Leipzig, GERMANY
June 20 Berlin SG/IMF Regional Community Workshop (RCW) – Berlin, GERMANY
June 23 MLÖ/IMF Patient & Family Seminar (PFS) – Vienna, AUSTRIA
July 27-29 IMF Support Group Leaders' Annual Summit – Dallas, TX
Aug 10-11 IMF Patient & Family Seminar (PFS) – Los Angeles, CA
Aug 18 IMF Regional Community Workshop (RCW) – San Antonio, TX
Aug 24-25 IMF Patient & Family Seminar (PFS) – Boston, MA
Sept 12 DMG/IMF Patient & Family Seminar (PFS) – Nyborg, DENMARK
Sept 15 Myeloma Center Workshop (MCW) at Emory University – Atlanta, GA
Sept 15 TUC/IMF Patient & Family Seminar (PFS) – Trondheim, NORWAY
Sept 16 UH/IMF Patient & Family Seminar (PFS) – Oslo, NORWAY
Sept 21-22 CMG/IMF Patient & Family Seminar (PFS) – Lazne Belorad, CZECH REPUBLIC
Sept 22 AIL/IMF Patient & Family Seminar (PFS) – Catania, ITALY
Sept 24 AIL/IMF Patient & Family Seminar (PFS) – Turin, ITALY
Sept 30 HUC/IMF Patient & Family Seminar (PFS) – Heidelberg, GERMANY
Oct 5 Myeloma Center Workshop (MCW) at UNC/Duke University – Raleigh-Durham, NC
Oct 27 6th Annual Comedy Celebration – Los Angeles, CA
Nov 3 IMF Regional Community Workshop (RCW) – Sacramento, CA
Nov 10 Myeloma Center Workshop (MCW) at Mayo Clinic – Scottsdale, AZ
Dec 8-11 American Society of Hematology (ASH) annual meeting – Atlanta, GA

The IMF is proud to work with our global partners.

Additional events will be posted online and in later editions of Myeloma Today as dates are finalized.

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

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