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. Morton Coleman (Director, Center for Lymphoma and Myeloma, New York Presbyterian – Weill Cornell, New York, NY) has worked in MM for the past 45 years. Primarily focused on clinical research, Dr. Coleman was an early proponent of high-dose therapy in MM. In collaboration with colleagues, Dr. Coleman pioneered the BLT-D and BiRD protocols, and is now studying the ClaPD regimen as well as the continuous low-dose therapy approach. ***PAGE 4***

Dr. Noopur Raje (Director, Multiple Myeloma Program, Massachusetts General Hospital, Boston, MA) talks about her medical background and research interests in MM. As an example of the evolving use of existing novel therapies, she shares her thoughts and experience with subcutaneous administration of Velcade® (bortezomib), an effective part of the anti-MM arsenal that is currently FDA-approved for intravenous administration. ***PAGE 5***

Supportive Care

The IMF's Nurse Leadership Board (NLB) Survivorship Care Plan, which examines five specific aspects of long-term care, has been published by the Clinical Journal of Oncology Nursing (CJON). In this issue of Myeloma Today, we offer a summary of NLB recommendations regarding maintaining bone health. Topics of discussion include pathophysiology, risk factors, imaging and laboratory assessment, treatment, transplantation, diet, and pain management. ***PAGE 7***

Profiles in the News

Barbara Hammack shares her experience of living with MM for 20+ years. Barb was a 45-year-old single parent of two teenagers when she was diagnosed in July 1991. She is now grandmother of two boys. She experienced standard chemotherapy, transplantation, multiple rounds of maintenance protocols, and more than her share of medical issues. But she has found the resiliency of the human spirit, and she's learned "not just how to live with cancer but how to live, period." ***PAGE 11***

Robin Tuohy has been dealing with MM since her husband was diagnosed in 2000. In 2001, they founded the first MM support group in Connecticut, and the Tuohy Family has been part of the IMF family ever since. In 2005, Robin came to work for the IMF as a support group assistant. She is now IMF Director of Support Groups, and she answers questions about the program dedicated to assisting individuals and communities with local access to support, information, and a sense of collective identity. ***PAGE 14***

Also in this issue…

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A Message from the President

Dear Reader,

Earlier this month, I was having dinner at a favorite local restaurant when I struck up a conversation with the couple at the next table. After a while, the man asked what line of work I was in. When I told him that I am the president of a non-profit cancer foundation, he asked "Oh, what type of cancer?" I replied "Something you've probably never heard of – multiple myeloma" and he answered, "Myeloma? My mother has that."

A few weeks earlier, a woman walked into our headquarters in Los Angeles. She had brought her elderly father to meet with an attorney who has an office in the same building when she saw a sign that said *International Myeloma Foundation*. "My mother passed away from myeloma 22 years ago," she told us. "At that time, there were no resources available to us, and now there is this wonderful organization ensuring that patients and family members get the information they need."

For a cancer that is considered rare, it is amazing how many people's lives have been touched by it. The IMF was founded to ensure that no myeloma patient would ever have to face this disease alone. For these two people, learning about the IMF has given them new hope that something is being done to help myeloma patients fight the disease.

With early diagnosis being a key factor in survival rates, we must continue to raise awareness of myeloma and its symptoms so both patients and doctors know what to look for. That is why the IMF launched **10 Steps to Better Care**™, a unique tool for diagnostic and treatment information. **10 Steps to Better Care**™ is available on our website at 10steps.myeloma.org. The "steps" are:

1. Know what you're dealing with. Get the correct diagnosis.
2. Tests you really need.
3. Initial treatment options.
4. Supportive care and how to get it.
5. Transplant: Do you need one?
6. Response assessment.
7. Consolidation and/or maintenance.
8. Monitoring without mystery.
9. Relapse: Do you need a change in treatment?
10. New Trials: How to find them.

Linked to each "step" are supporting articles and videos that will further enhance the depth of your understanding of the subject matter. **10 Steps to Better Care**™ is just one of myriad programs that the IMF offers to help you.

Since 1993, our flagship educational program – the IMF Patient & Family Seminar – has reached tens of thousands of people around the world. This two-day conference, held four times each year, not only provides myeloma patients and their caregivers with the latest information about myeloma treatment and research, it also brings much needed hope and empowerment. Patients not only get to learn from world-renowned myeloma experts, but also from one another by sharing experiences and emotional support. I strongly encourage you to attend a seminar in 2012.

The 2012 IMF Patient & Family Seminars will be held in Boca Raton, Seattle, Boston, and Los Angeles. To register or obtain more information about these seminars or our other programs and services, please visit myeloma.org or call the IMF.

As we move into a new year, we continue to work on making great strides on the path toward finding a cure for myeloma. In the meantime, the IMF is here to help every patient, caregiver, and family member, no matter where they live. We are always here for you – in person, on the web, and via our Hotline at 800-452-CURE (2873).

On behalf of everyone at the IMF, I wish you and your family a happy holiday season and a brighter new year.

Warmly,

Susie Novis

Susie Novis, President

What do 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.

Typical Friday Topics

• *What's New in Myeloma?* • *Ask-the-Expert*
• *Managing Side Effects* • *How to be a Better Patient*

Typical Saturday Topics

• *Frontline Therapy* • *Transplant* • *Maintenance Therapy*
• *Relapse* • *Bone Disease* • *Novel Therapies*

Upcoming Patient & Family Seminars

Boca Raton, FL – February 3-4, 2012
Seattle, WA – March 23-24, 2012
Los Angeles, CA – August 10-11, 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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DR. MORTON COLEMAN SHARES AN OVERVIEW OF HIS 45-YEAR CAREER IN MM

What is your background in medicine?

My family always wished for me to become a physician. During my college years, I considered becoming a chemist but, virtually on his deathbed, my father said, "If you want to be a chemist, become a chemist, but first I wish you to be a doctor." My father died of lung cancer, which kindled my interest in oncology. The summer between my first and second year at the Medical College of Virginia, a Dr. Arnold F. Strauss hired me, a 19-year-old student, to do autopsies. At that time, I enjoyed physiology so much that I considered delaying medical school and getting a PhD, but Dr. Strauss told me, "Mort, first become a physician." After my internship and first-year residency at Grady Memorial Hospital – Emory University, I served in the Navy during the Vietnam War, partly at sea and partly at the National Naval Medical Center in Bethesda, MD. In 1967, for my second-year residency, I went to what was then New York Hospital-Cornell. Almost 45 years later, I am still here.

Morton Coleman, MD
Director, Center for Lymphoma and Myeloma
New York-Presbyterian/Weill Cornell
New York, NY

Early in my career, my interest in oncology became focused on hematological malignancies. I am now the director of the Center for Lymphoma and Myeloma at New York Presbyterian Hospital and clinical professor of medicine at Weill Cornell Medical College. It has been a very rewarding venue and career. If I had to do it all over again, I certainly would.

What contributions have you made in hematology-oncology?

One of my earliest achievement was in originating what has remained for decades the standard chemotherapy for Hodgkin's lymphoma. In multiple myeloma (MM), my first project looked at the interference of MM proteins in coagulation. This laboratory research segued to my interest in MM.

In the early 1970s, Dr. John Harley developed Triple Therapy for MM, which combined three alkylating agents: BCNU, melphalan (Alkeran®), and cyclophosphamide (Cytoxan®). Cancer and Leukemia Group B (CLGB), of which I was a committee member, did a ramdonized study. When I reviewed the data, those MM patients who had greater toxicity also had better responses, which prompted my interest in dose intensity.

At a meeting of the International Society of Hematology in Jerusalem, there was a presentation about a patient with MM who had been accidently over-treated with 10 times the normal dose of intravenous Alkeran® and went into complete remission. Not long thereafter, I learned about a patient in the US who went into complete remission also after being over-treated with Alkeran®. That spurred me to write a paper on using "super high-dose" therapy in MM. Even after multiple revisions, the *Journal of Clinical Oncology* ultimately rejected it because they thought it was too radical. As my paper was being revised and reviewed, Dr. Tim McElwain, who ultimately became a close friend, published a paper on high-dose therapy with Alkeran®, which marked the initiation of "ultra high-dose" chemotherapy and autologous transplantation in MM.

A few years ago at a medical meeting in San Diego, Dr. Brian Durie presented a paper on the use of clarithromycin (Biaxin®) in MM. Although skeptical, I tried Biaxin® in refractory MM patients who were receiving high-dose dexamethasone, and their immunoglobulin (Ig) further responded. Around that time, Dr. Bart Barlogie published a paper about the use of thalidomide in MM, so I added thalidomide to the combination. The Ig count dropped dramatically in all but one patient – almost a 100% response! We published a paper on the BLT-D (Biaxin®, low-dose thalidomide, dexamethasone) regimen in 2002 in *Leukemia & Lymphoma*, and those original observations have been sustained in the years since. These observations included increased thrombosis with immunomodulatory drugs (IMiDs), the prevention of this phenomenon with low-dose aspirin, and the use of weekly (low-dose) dexamethasone, which has since become the gold standard way to administer steroids in MM.

Two of my closest associates at Cornell, Drs. Ruben Niesvizky and Mark Tomer, collaborate on all MM projects. When lenalidomide (Revlimid®) came out, we decided to substitute it for thalidomide because we wanted to avoid the neurologic complications of thalidomide in BLT-D. The results with the BiRD (Biaxin®, Revlimid®, dexamethasone) protocol were astounding, and we still have patients on this regimen seven years later. In the process, we determined that the toxicity of lenalidomide is enhanced by renal insufficiency. We also did a case-by-case comparison of BiRD against the two-drug combination (without Biaxin®). The 3-drug combination was found clearly superior. Hopefully, just as the low-dose dexamethasone approach has finally taken hold, Biaxin® will eventually receive recognition as an effective augmenting anti-MM agent.

What are your research plans for the near future?

I am concerned that some clinical studies are simply combining many drugs together, which may necessitate the attenuation of doses in order to reduce toxicity. Instead, our approach is to use a "one-two" punch. For instance, we use carfilzomib plus dexamethasone until we get a maximum response, then consolidate immediately with the BiRD regimen. This approach uses the concepts of the Norton-Simon and the Goldie-Coldman hypotheses to design a more effective, less toxic regimen. In the lab, we are working closely with Dr. Selina Chen-Kiang, who is developing agents to arrest cell cycling, allowing synchronization for a more successful therapeutic regimen. We have now extended our observation with the BiRD regimen, substituting pomalidomide for lenalidomide. The results with the ClaPD (clarithromycin, pomalidomide, dexamethasone) protocol are extremely promising in heavily pre-treated patients.

Please tell us about the annual congress you host in New York City.

In 2000, we at Cornell inaugurated the Lymphoma & Myeloma International Congress, which I have had the privilege of chairing since inception. The Congress has grown to nearly 1,000 attendees from over 40 countries, becoming the premier forum on the latest advances in lymphoma, myeloma, and related disorders in the US. At the 2011 Congress, we honored Dr. Durie with the *Joseph Michaeli Award* for his contributions to the field of MM. IMF President Susie Novis is also a past recipient of the award for leading the way in *pro bono* activities on behalf of MM patients.

From your perspective, how would you assess the anticipated progress in MM in the near future?

Our understanding of the basic biology of MM has increased exponentially over the years. The better our knowledge of how the MM cell survives, the more capable we become in attacking disease. One day, I am sure we shall cure MM. But I believe that making MM a controllable chronic condition

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DR. NOOPUR RAJE DISCUSSES HER RESEARCH INTERESTS IN MM

Please tell us about your medical background.

I received my medical degree from B.J. Medical College, Pune University, India. I trained in internal medicine at Massachusetts General Hospital (MGH) and completed a fellowship in hematology and medical oncology at the Dana-Farber Cancer Institute in Boston, MA. Currently, I hold a faculty appointment at MGH and am an associate professor of medicine at Harvard Medical School. At MGH, I am the director of the Multiple Myeloma Program, Medical Oncology. As a hematologist/oncologist, my primary focus is in multiple myeloma (MM), both as a clinician and researcher.

What are your research interests?

We pursue laboratory and clinical research in MM with the goal of translating these efforts to the improvement of patients' lives. My research focuses on understanding the biology of MM, the biology of bone disease in MM, tumor microenvironment and its role in MM pathogenesis, the development of novel therapeutics, as well as identifying and validating novel targets.

I have been involved with investigating the role of B-cell activating factor (BAFF) in MM using a neutralizing antibody and cyclin-dependent kinase inhibitors. All of these clinical trials are backed by translational research endpoints informed by our preclinical studies with the view to validating our data.

Despite the significant progress that has been made in the treatment of MM in recent years, substantial challenges remain. This is especially true for our high-risk MM patients, and for those with advanced drug-resistant MM. To address these challenges, we must identify novel classes of anti-MM agents and incorporate them into safe and effective regimens. We must also develop more efficient algorithms to help us select the most appropriate therapeutic options for each individual patient.

Is subcutaneous administration of Velcade® an example of the evolving use of existing novel therapies?

The standard administration of bortezomib (Velcade®) is intravenous (IV) injection, but subcutaneous (SQ) administration is now being studied as an alternative in MM. Prof. Philippe Moreau and colleague have published data from a randomized, Phase III, non-inferiority study of SQ versus IV administration of bortezomib in patients with relapsed MM. They compared the efficacy and safety at the standard dose (1.3 mg/m2) and twice per week schedule. No significant differences were found in time-to-progression (TTP) and 1-year overall survival (OS), and side effects – peripheral neuropathy (PN) in particular – were significantly less common with SQ than with IV administration. The data demonstrate that SQ bortezomib is feasible, resulting in equivalent bortezomib plasma exposure and similar efficacy, but with an improved systemic safety profile compared to standard IV administration. The data support the use of SQ bortezomib administration in the clinical setting where the safety and efficacy of IV bortezomib have been established.

Noopur Raje, MD
Director, Multiple Myeloma Program,
Medical Oncology
Massachusetts General Hospital
Boston, MA

Can you tell us about the SQ bortezomib clinical experience you have had with the MM patients you are treating?

In the United States, bortezomib is currently approved for the treatment of MM via IV administration. It has been a very effective part of the anti-MM arsenal for many patients, but data show that approximately a third of MM patients being treated with IV bortezomib experience PN, which can cause pain, numbness, and/or tingling in the extremities. To manage side effects, the dosage or frequency of administration can be decreased. Once weekly instead of twice weekly administration of IV bortezomib has become common since a clinical trial demonstrated the safety and efficacy of this approach, which significantly reduces side effects, including PN.

In the SQ route of administration for bortezomib, it is injected into the fat below the skin. This is not yet approved by the US Food and Drug Administration (FDA), but an application has been submitted. Some cancer centers are now using the SQ method, and patients can inquire if their treatment facility offers it. My patients who are on SQ bortezomib are doing very well. No patient has had significant issues with it.

For a patient, SQ administration makes bortezomib delivery more quick and comfortable. But convenience is not the only factor. Importantly, the SQ administration method makes it possible for us to use bortezomib in individuals with pre-existing PN who otherwise respond well to the therapy. In addition, with SQ administration, patients may tolerate bortezomib longer, which might improve the depth and duration of their response to therapy.

Unfortunately, insurance reimbursement remains an issue because SQ bortezomib is not yet FDA-approved. Of course, once the SQ route is approved, the next step would be to determine if combining weekly and SQ bortezomib administration can maintain efficacy while further reducing side effects. I would also be cautious about using SQ bortezomib in combination approaches as data to that effect are lacking.

Thank you. Any closing comments?

The outlook for patients with MM has improved significantly with the use of the immunomodulatory drugs thalidomide and lenalidomide (Revlimid®), and the proteasome inhibitor bortezomib. The progress continues, with advances being made in the discovery and development of new drug classes, the introduction of next-generation agents, and our ability to effectively treat MM with existing novel agents while reducing the potential for side effects and being watchful of the patients' quality of life. Overall, we are looking at the very realistic goals of further improving outcomes and expanding treatment options for patients with MM.

Editor's Note: Dr. Raje is a member of the American Medical Association (AMA), America Society of Hematology (ASH), American Society of Clinical Oncology (ASCO), and American Association of Cancer Research (AACR). She is also an *ad hoc* reviewer for several journals, including *Blood*, *Clinical Cancer Research*, *Leukemia*, and the *American Journal of Hematology*. Dr. Raje is the recipient of several awards and has published extensively in the field of MM research. **MT**

MAINTAINING BONE HEALTH

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 has been published by the *Clinical Journal of Oncology Nursing*® (CJON) in August 2011 as 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 Teresa Miceli, Kathleen Colson, Beth Faiman, Kena Miller, Joseph Tariman, and other members of the IMF-NLB.

Bone Health

Up to 90% of MM patients develop osteolytic bone lesions at some time in the course of their disease. Clinical implications include fractures, pain, spinal cord compression, hypercalcemia, and renal dysfunction. Management of bone disease in MM is an integral part of the treatment paradigm.

Pathologic fractures and other skeletal events can lead to poor circulation, blood clots, muscle wasting, compromised performance status, and decreased survival. Clinicians can identify patients at risk and provide recommendations to reduce and manage bone complications. Preventive and therapeutic interventions include diagnostic monitoring, dietary counseling, medication administration, and surgical procedures.

Pathophysiology

Normal bone formation is initiated by osteoblasts, and bone resorption is initiated by osteoclasts. Osteoprotegerin is a cytokine that inhibits production of osteoclasts, maintaining the balance between bone resorption and formation. Osteolytic lesions found with MM are caused by rapid bone turnover, which occurs as a result of increased resorption that is not accompanied by a comparable increase in bone formation.

Bone destruction in MM is believed to result from an interaction of bone marrow stromal cells and MM tumor cells within the microenvironment of the bone marrow. Bone pain and the incidence of pathologic fracture are high among MM patients as a result of osteolytic bone lesions and bone turnover related to excess cytokine levels. Common locations of fracture include the vertebral bodies, flat and long bones, the extremities, and pelvis.

Assessment

The severity of bone disease and number of lesions at the time of diagnosis help classify patients considered high-risk. The "Durie/Salmon PLUS" staging system integrates the quantification of bone lesions by magnetic resonance imaging (MRI) and positron-emission tomography (PET) into a new generation of anatomic and functional MM staging to better define the treatment plan for patients newly diagnosed with early disease.

Imaging is an important tool for diagnosis and monitoring of MM bone disease. Bone scans are not the technique of choice because the degree of bone disease may be underestimated. A complete skeletal survey, the standard method of imaging in MM patients, detects fractures, tumors, or degenerative changes in the bone. Metastatic bone survey, the gold standard for assessing MM bone disease, is able to identify the lytic disease where at least 30% of the trabecular bone has been destroyed, however this technique does not demonstrate response to therapy. These limitations have led to the use of CT, PET, and MRI, which can be helpful in discerning suspicious lesions or areas of focal bone destruction. MRI may reveal the presence and progression of disease and provide prognostic information for patients with nonsecretory or oligosecretory MM. PET scans are useful in detecting bone disease, marrow infiltration, and extramedullary disease.

Laboratory tests to assess bone include calcium, vitamin D, fractionated alkaline phosphatase, and creatinine. A variety of markers are used to monitor bone resorption in MM; these markers can also predict the development of new skeletal events. Endocrine evaluation that includes thyroid, parathyroid, and testosterone levels may be indicated.

Risk Factors

MM therapies may adversely affect bones. Plus, MM patients can have comorbid conditions that may place them at risk for poor bone health, and pharmacotherapy for those conditions may contribute to osteoporosis and risk of fracture.

The use of glucocorticoids (dexamethasone or prednisone) is a staple in MM therapy. Steroids kill MM cells directly and may enhance the efficacy of other drugs when used in combination. However, steroid use may inhibit or kill osteoblasts, stimulating bone resorption, inhibiting calcium absorption, and increasing calcium excretion. Steroid use is also associated with avascular necrosis or osteonecrosis.

Osteoporosis risk factors include gender, age, family history, small or thin frame, and low levels of sex hormones. Potentially modifiable causes

(CONTINUES ON NEXT PAGE)

DR. MORTON COLEMAN — continued from page 4

is no less an achievement. Survival of MM patients used to be measured in months to years; now hopefully it can be measured in years to decades!

MM doesn't have to stop an individual from living a full and rich life. Some diseases, while not curable, are treatable. For example, while we cure the most aggressive high-grade forms of lymphoma, we do not cure low-grade lymphomas, yet those patients live long and rewarding lives.

We are now applying the concept for metronomic (continuous low-dose) therapy, which we originally developed in lymphoma and leukemia, to MM. For example, we daily alternate thalidomide with lenalidomide, thereby reducing the potential for hematologic and neurologic toxicities. Chronic lymphocytic leukemia (CLL) patients are doing remarkably well on metronomic therapy, and it might work equally well in maintenance therapy for MM.

So the outlook is good for patients with MM?

In MM, almost all patients will have a good response to therapy whether they are newly diagnosed or pretreated, and the median survival will almost certainly continue to increase. But there is a small segment of the MM patient population who are poor responders, and they are our main challenge. But for the vast majority of MM patients, the outlook is much better than in years past. Our increasing understanding of the molecular basis of cancer will continue to enable us to better tailor individualized therapy. I expect even more significant progress to be made in MM in the next five years.

Editor's Note: Dr. Coleman has served as member or chairman of numerous medical and scientific organizations and committees and has received many awards and recognitions. A named professorship at Weill Cornell Medical College has been established in his honor. **MT** include nutritional deficits, chronic medical conditions, inactivity, smoking, alcohol abuse, and certain medications.

Renal disease is a common complication in MM. Patients with renal osteodystrophy experience increased risk of fractures and resultant joint and bone pain. Kidneys have a significant role in bone mass by maintaining calcium and phosphorus levels in the blood.

Gonadal failure can be a natural part of aging or therapy-related, and can affect both men and women. Postmenopausal women are at higher risk of osteoporosis and fractures, because the loss of estrogen results in a higher rate of bone loss.

Diabetes (Types 1 and 2) carries an increased risk of fracture. The mechanism for bone loss in diabetes is not well understood. MM patients undergoing treatment with high-dose steroids have an increased risk of developing steroid-induced diabetes.

Cardiovascular disease and osteoporosis association in men is not well understood and may be a culmination of comorbid conditions that place a person at risk for both conditions.

Major depressive disorders occur more frequently in those diagnosed with cancer. The association of depression, osteoporosis, and risk of fracture is unclear. Physiologically, hormone levels that promote osteoclastic function and decrease osteoblastic function are elevated in those who have major depressive disorders. Secondary risk factors may play the greatest role because an association exists between depression and unhealthy behaviors. In addition, antidepressants have been implicated in increased risk of fractures.

Bone Marrow Transplantation

Bone loss is common following autologous and allogeneic bone marrow transplantation. Few long-term studies are available, and the mechanism is not completely understood. One small study of 29 patients who underwent autologous bone marrow or peripheral blood transplantation following high-dose chemotherapy did not have significant osteopenia despite high-dose steroids, prolonged inactivity, and decreased estrogen levels. This was a follow-up study of patients five years post-transplantation, so these unexpected results may be due to recovery of endocrine function during that time. Further studies are needed before making any conclusions.

Treatment

Treatment of active MM with effective therapies helps manage MM-related bone disease. For patients with bone involvement but no bone-related pain, systemic therapy is often the primary treatment choice. Adjuvant therapies include localized radiation, surgical interventions, and the use of agents that inhibit bone resorption. For each patient, all factors should be considered when developing an individualized treatment plan.

Novel agents used in MM may positively affect bone metabolism. Several studies demonstrate that bortezomib (Velcade®) may increase osteoblast activity. Thalidomide may halt receptor activator of NF-kB ligand (RANKL)-induced osteoclast formation. Lenalidomide (Revlimid®) decreases osteoclast formation and activity. Thalidomide plus dexamethasone reduces bone resorption. The combination of bortezomib, thalidomide, and dexamethasone reduces bone resorption and the RANKL/osteoprotegerin ratio. As the understanding of MM bone biology develops, more targeted therapies should emerge.

Bisphosphonates inhibit bone resorption, are effective in the management of hypercalcemia of malignancy, decrease risk of fractures, and may decrease pain. In the US, the bisphosphonates administered to MM patients include pamidronate (Aredia®) and zoledronic acid (Zometa®). An anti-MM effect has been demonstrated for zoledronic acid. Pamidronate may also have an anti-MM effect. The International Myeloma Working Group (IMWG) suggests that using pamidronate or zoledronic acid decreases the risk of skeletal-related events, but the optimal duration of therapy is unknown. Side effects include flu-like symptoms, a small but increased risk of osteonecrosis of the jaw (ONJ), and renal impairment.

Radiation to affected areas of bone is a useful modality for some MM patients, providing local pain and tumor control as well as preventing or treating fractures. Radiation may be curative for solitary bone plasmacytomas. The use of radiation should be limited as it may cause permanent bone marrow damage and compromise organ function within the treatment areas.

Surgical procedures can stabilize bone to control pain and prevent or treat fractures. Two surgical techniques specific to the spine are Kyphon® Balloon Kyphoplasty and percutaneous vertebroplasty. Both are minimally invasive and may provide immediate pain relief in some patients, along with improvements in functional stability and spine stabilization.

Emerging treatments include the human monoclonal antibody denosumab, which is approved for use in preventing skeletal-related events in solid tumors and indicated for the management of postmenopausal osteoporosis. Not approved in the US for MM, denosumab is currently in clinical trials, as are Dickkopf-related protein 1 (DKK1) inhibitors.

Diet

Patients are encouraged to eat well-balanced diets. Most nutritional supplements are safe in moderation; however, based on preclinical evidence, vitamin C interferes with the ability of bortezomib to kill human cancer cell lines in culture. Alpha lipoic acid, often recommended for peripheral neuropathy, has been shown to interfere with anti-MM effects of bortezomib. Preclinical research demonstrated tumor cell death caused by bortezomib may be negated by the use of green tea. Although no clinical evidence exists, the IMF-NLB recommends avoidance of vitamin C, alpha lipoic acid, and green tea on the day of bortezomib therapy.

Vitamin D and calcium are required for bone health. Supplementation is advised for all patients with osteopenia or osteoporosis, particularly if they are receiving bisphosphonates. In older adults, maximizing serum vitamin D levels is associated with improved muscle strength, resulting in a 20% decreased risk of fracture.

Evidence shows that increased levels of vitamin K reduce the risk of fracture. Phytoestrogens, found naturally in plant-based products such as soy, may act as a safe hormone replacement therapy for postmenopausal women.

Smoking and use of alcohol (>2 drinks/day) are both associated with impaired absorption of calcium in the intestine. Consumption of excess or insufficient amounts of protein, vitamin A, and phosphorus may have positive or negative effects on bone health, depending on their renal effects.

Pain Management

Damage to bones as a result of MM often causes pain, which can be debilitating. Control of MM bone pain can be challenging because it usually occurs when patients change position or walk ("incident pain"). All patients must have effective pain management. Three main types of analgesia are used to treat bone pain and other types of pain related to MM: nonopioid analgesics, opioid analgesics, and adjunct medications. Uncontrolled pain may result in immobility and muscle and bone wasting, in turn leading to increased risks of complications.

Additional Information

For more information, please contact the IMF Hotline at TheIMF@myeloma.org or 800-452-CURE (2873), or visit the IMF website myeloma.org. And, as always, we encourage patients and caregivers to communicate with their medical teams. **MT**

REPORT FROM THE NLB VII MEETING

Beth Faiman

Teresa Miceli

Shaji Kumar, MD

NLB VII, the 7th meeting of the International Myeloma Foundation (IMF) Nurse Leadership Board (NLB) was held September 24–25 in Las Vegas, NV. The two-day event opened with remarks by Diane Moran, IMF Senior Vice President of Strategic Planning, who updated the attendees on IMF's 2011 activities and, along with NLB VII co-chair Teresa Miceli, also presented a brief review of NLB's 2011 accomplishments.

The IMF-NLB consists of 20 nurses from the leading institutions caring for multiple myeloma (MM) patients across the US. This Board of experienced MM nurses has accomplished a lot in a relatively short time since the first NLB gathering five years ago. At NLB VII, the Board reviewed past work and planned the execution of projects for next year. Here are just some highlights of IMF-NLB activities in 2011:

- The IMF-NLB has held four popular live and recorded teleconferences-webcasts.
- The IMF-NLB presented a Satellite Symposium at the annual meeting of the Oncology Nursing Society (ONS) – *Long-Term Survivorship: The IMF Nurse Leadership Board's Guidelines for Multiple Myeloma Patients* – which was attended by more than 750 nurses.
- The IMF-NLB presented a poster – *Long-Term Care Guidelines for Patients with Myeloma* – at the prestigious biannual International Myeloma Workshop (IMW), which was held in Paris, France.
- The IMF-NLB published the Survivorship Care Plan for Multiple Myeloma in ONS' *Clinical Journal of Oncology Nursing*®.
- Nine IMF-NLB nurse leaders authored the first ever textbook on MM for nurses, which was edited by IMF-NLB member Joseph Tariman.
- IMF-NLB delegates participated as faculty at every IMF Patient & Family Seminar and Regional Community Workshop.
- IMF-NLB members have contributed updates and/or supportive care articles to every issue of *Myeloma Today*.
- IMF-NLB member Bonnie Jenkins led an inspiring session at the annual IMF Support Group Leaders' Summit.
- The new "Oh, Nurse!" blog premiered on myeloma.org and has so far featured seven entries by seven IMF-NLB members.
- IMF-NLB member Kena Miller met with 10 legislators in Albany in support of the oral chemotherapy parity bill and helped articulate the importance of patient access to treatments.

NLB VII continued with co-chair Beth Faiman presenting a research update on a variety of topics, including the new paradigms in MM treatment, the benefits of continuous/maintenance therapy, the low risk of secondary primary malignancies, less neuropathy with once-weekly or subcutaneous administration of bortezomib, comparisons between 3- and 4-drug combinations, "ultra high risk" MM subpopulation studies, bone health and the benefits of zoledronic acid, and new agents in development. The discussion of drugs in development for MM was particularly exciting, as there are so many promising new drugs in the pipeline: carfilzomib, pomalidomide, vorinostat, panobinostat, denosumab, elotuzumab, perifosine, temsirolimus, and others. The presentation made clear that MM is a disease with active research, with new dosing and administration regimens leading to long-term survival and increases in progression-free survival (PFS), overall survival (OS), and quality of life.

The next update was presented by guest speaker Dr. Shaji Kumar, a myeloma expert and member of the International Myeloma Working Group (IMWG). Dr. Kumar talked about the diagnosis and management of high-risk smoldering MM, the role of early transplant, maintenance vs. consolidation, testing, risk stratification, minimizing peripheral neuropathy, the best clinical trial designs, and integrating new and existing drugs into new combinations. This session made clear the scope of progress that has already been made in the field of MM and the significant advances currently underway.

Next, the discussion turned to practical matters. The group worked on increasing the utility of the IMF-NLB web portal, which was originally created to enhance communication among members and facilitate complex teamwork requiring joint effort. Later, the group focused on the manuscript development process as presented by medical writer Lynne Lederman, PhD. The IMF-NLB is currently drafting *Guidelines for Managing MM Patients Undergoing Stem Cell Transplant*. In addition, with the assistance of IMF Board of Directors member Michael Katz, the IMF-NLB is working on developing the *Survivorship Care Plan Online Tool*.

Charise Gleason gave a presentation about nurse-led clinical research, which will lead to the

CONTINUES ON NEXT PAGE

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I am inspired by Harold Dozier's story in the Fall 2011 issue of Myeloma Today, as well as cyclist Andy Sninsky's letter to the IMF. I was diagnosed with stage III multiple myeloma in 1992, and have cycled 328 miles over four days each of the last five years in the American Cancer Society Pan Ohio Hope Ride (POHR). Funds raised enable patients and families to access leading myeloma and other cancer treatments by staying for free at one of over 35 Hope Lodges in the US. I plan to cycle 328 miles again in July 2012. Other myeloma patients cycle with me.

Like Harold, I have had many treatment protocols and side effects. After diagnosis, I continued normal activities, worked full-time until my firm's required retirement age, and continue to exercise daily. My leading advocate, caregiver, and wife of 41 years, Kathleen, and I have shared our survival story and empowerment views with 62 groups, many of which are IMF support groups. Other patients and caregivers inspire us.

Jim Bond

I just wanted to thank you for sending IMF informational brochures to our multiple myeloma support group. We had a table at a LLS blood cancer conference this past weekend to promote our support group, and while there were not many myeloma patients in attendance, there were lots of nurses and health care professionals who took our IMF brochures as well as our support group flyers. The nurses were very appreciative to have good myeloma brochures to share with their patients. We should have ordered more – we just had no idea they were going to be so popular! Thanks again for all you do to support the IMF, and for helping us get useful myeloma information to the people who need it. Knowledge is power!

Sue VanDuyn

The IMF is our "bible" for MM. You have all the information regarding our disease that we need. The IMF Hotline coordinators offer the most current and relevant information to both the newly diagnosed patients and the long-term survivors. And their kindness, patience, and knowledge are a real comfort to us. The IMF is clearly an organization dedicated to taking care of MM patients and families.

Our MM support group in Stillwater, MN, has been in operation since 2004, beginning in my home with just a few people. Over the past seven years, we have outgrown that cozy surrounding and now count 54 MM patients and caregivers as members. Usually, we meet once a month in the large conference room at the Family Means Center. But for our October 2011 meeting, we enjoyed some leisure time together by chartering a cruise on a paddlewheel boat. With 52 of our patients and caregivers in attendance, we spent three hours on the beautiful St. Croix River, and everyone had a wonderful time.

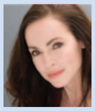
We are a FAMILY that does just what the definition suggests. We nurture each other and share information and education. But most of all we share hope. And we are living and enjoying life.... one day at a time.

Karl Vollstedt and Barb Davis

Thank you for sending me *Myeloma Today*. For the past 20 years, I have followed with great admiration your efforts to update physicians interested in this disease, as well as to educate MM patients and their families. Special thanks to Susie Novis, whose perseverance, charm, and courage helps make this possible. I thank you from the bottom of my heart.

Esther Aghai, MD

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:



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NLB — continued from page 8

generation of evidence-based nursing recommendations to enhance patient management and care. The rest of the day was spent with members separating into groups for breakout sessions in order to continue planning and content development for their respective team projects.

Day 2 of NLB VII started with opening remarks by Diane Moran, who presented the goals and agenda for the remainder of the meeting. The group discussed emerging progress ideas that came out of the previous day's breakout sessions. Next, the team leaders of IMF-NLB taskforces presented updates on the work of their groups.

The Patient Education Taskforce, led by Teresa Miceli, is updating patient education materials with information from the Survivorship Care Plan and effectively disseminating this information to patients, caregivers, and patient advocacy groups. In 2011, the taskforce presented this information at four IMF Patient & Family Seminars and 10 Regional Community Workshops, plus 12 support group teleconferences. Future updates will include new MM medications such as pomalidomide, carfilzomib, and denosumab.

The Nurse Education Taskforce, co-led by Charise Gleason and Beth Faiman, is working on key educational messages for the community oncology nurse audience and developing educational materials for various forums, such as teleconferences, webcasts, and national and regional meetings.

The Publication Taskforce, led by Tiffany Richards in 2011 and Elizabeth Bilotti in 2012, reviewed a list of suggested MM blog topics, in addition to the group's ongoing projects. The Clinical Trials Taskforce, led by Joseph Tariman, proposed several activities for consideration and discussed which projects could be feasibly undertaken.

The Clinical Trials Taskforce, led by Joseph Tariman, is developing separate sets of educational materials for nurse and patient communities. The materials available in print format for publication and as slides for meeting presentations will help nurses and patients better understand the treatment opportunities available within the context of clinical trials. IMF-NLB members are also preparing to conduct a nurse-led research project in 2012.

In her closing remarks, Diane Moran touched on the role of emotional intelligence in the nursing profession and noted that emotional competencies are not mere innate talents, but learned capabilities that must be developed to achieve outstanding performance. She acknowledged the amazing productivity of NLB VII and the impressive accomplishments of IMF-NLB members in 2011, but noted that the Board's work has just begun, with much more expected in 2012. **MT**

ASH 2011 interviews and webcasts

The 53rd annual meeting of the American Society of Hematology (ASH) was held December 10-13, 2011, in San Diego, CA. This important event for medical professionals brings together clinicians and scientists from around the world, including a large contingent of multiple myeloma (MM) clinicians and researchers.

In keeping with the IMF's commitment to help you stay up-to-date on the latest MM therapies and discoveries, the IMF brings you highlights from the meeting in the form of session webcasts and interviews with key MM experts. As these videos become available, the IMF is posting them on our website myeloma.org, along with presentation abstracts and slides (where available).

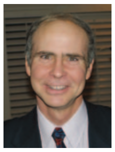
The webcasts taped at the meeting are reports on the current status of some of the most interesting research in MM. Please be aware that, at the time of posting, in some cases the interviewees are reporting on interim data from incomplete clinical trials. Therefore, not all the data presented are final results, and it is possible that results will be different when the data has matured with long-term follow-up. None of this research has yet been peer-reviewed and published in a medical journal.

Boca Raton IMF Patient & Family Seminar features stellar faculty

Emphasizing education, advocacy and support, the IMF Patient & Family Seminars empower patients and provide invaluable information to the MM community. The seminar is structured as a two-day format, covering a broad range of topics, and featuring world-renowned MM specialists as faculty.

In 2012, the first Patient & Family Seminar of the year brings together a stellar line-up of doctors, and registrations for the event are expected to reach capacity soon. Don't miss this opportunity to have your questions answered by these highly sought-after MM experts

Dr. Brian Durie
Cedars-Sinai Comprehensive Cancer Center
Los Angeles, CA



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There is no charge for a *Myeloma Today* subscription, although we ask our members to consider making a tax-deductible contribution to the IMF to support our efforts in putting together this outstanding publication.

IMF staff updates

After 10 years as an IMF Hotline Coordinator, helping thousands of MM patients and their loved ones, the inimitable Nancy Baxter has retired.

Over the years, many have benefited from Nancy's compassionate nature and depth of knowledge about MM. We are extremely grateful to have had her as part of the IMF team for such a long time. Countless letters and comments from patients and caregivers have confirmed what a difference Nancy has made in their lives. We will all miss her terribly.

The IMF's toll-free Hotline is one of our longest-running programs, and one of our most important, providing callers with the best information about MM 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., and you can either dial 800-452-CURE (2873) or "Click-to-Call" via the IMF website myeloma.org. Your questions can also be submitted via email TheIMF@myeloma.org.

Share your thoughts

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

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

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

The IMF has a social community

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

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

Follow us on twitter @IMFmyeloma

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

HANGIN' IN: 20+ YEARS OF LIVING WITH MYELOMA!

By Barbara Hammack

I would like to share my multiple myeloma (MM) journey with others who are traveling this rocky road. We are all marvelous survivors; whether you are just starting to deal with MM, or are someone with a few years under your belt. You are all so very important to me.

My incredible journey started one quiet Sunday night in July 1991 when my doctor called a few days after my annual check-up. "I've been following some protein levels in your blood work," he said gently. "And I want you to see a hematologist."

The first oncologist I saw refused to be straight with me; I told him I was a single parent of two teenagers and needed to know what was going on. But he still tried to sugar-coat the reality of what he suspected I had. He said that I "probably" had "smoldering multiple myeloma" that didn't require treating yet, but needed to be followed every three months. I hurried over to the medical library at the National Institutes of Health (NIH) – I live just outside of Washington, DC – and read that most people with MM were African-American men in their 70's. As a 45-year-old Caucasian woman, this was clearly not my demographic! Then I learned that the statistics for surviving MM were from 7 to 14 months.

I went into complete denial. I felt perfectly healthy; had a job I loved, a good man in my life, and frankly, was just too busy to be bothered by any kind of serious illness. I considered it then – and still do – as a real nuisance in my life.

In 1993, I learned from the oncologist that my IgG had climbed from 3100 to 5500, but he still did not recommend treatment. I decided it was time for a second opinion. My primary doc set me up with a consultation where I was told quite emphatically that I needed an immediate bone marrow transplant. It was hard to grasp that I could have gone from "no treatment yet" to needing such a harrowing procedure. I sought out a different oncologist. In just one month between consults, my IgG had climbed to over 7000.

My new oncologist started me on the only chemo available then: Alkeran® (melphalan) and prednisone. I responded immediately, and moved on to transplant in 1994. They had just begun using stem cells along with the bone marrow; with no other option to extend my life, it was a no-brainer. I achieved remission, but there were still traces of MM cells in my marrow until 2000. I've been on and off a maintenance protocol since then.

Fast forward to July 2011, the 20th anniversary of this terrible diagnosis. To tell you the truth, I have no idea why I have been so fortunate in surviving for so long. For sure, I have not had wildly aggressive disease. Over the past 20 years, by far my biggest lesson has been to just keep hangin' in. I have had my share of medical issues over the past decade; including a near-fatal attack of meningitis in 2005 and a broken femur in 2007. While neither incident was directly blamed on MM, my docs and I agree that surely the disease played some role in these events. I also had shingles a year after my transplant and suffer from post-herpetic neuralgia, a chronic condition that has permanently damaged a nerve in my back that limits my activities.

I've learned so much over the years, not just how to live with cancer but how to live, period. After all, cancer is but one of life's indignities. None of us will escape pain and sorrow in our lives. None of us make it much past 35 without having something rattle our very being. Eventually, we must learn how to navigate the minefield that is "adulthood."

I have found the resiliency of the human spirit. I have survived the death of my parents, the loss of the love of my life, and then, my diagnosis with MM. I was able to work until 1999 when chronic pain forced me to retire, but I still try to do something each day that brings me pleasure; from solving a hard crossword puzzle to enjoying my two grandsons to having lunch with a dear friend or simply hangin' with my family. Some days are better than others, but that's just life.

As for myeloma, I've learned that there is no "right answer" when it comes to treatment. There is no real consensus of what one "must do." This means that each of us has to weigh ALL considerations when deciding which path to pursue and, if one option doesn't work, there will be a Plan B, C, D, and probably even E. What is critical is to believe in and OWN whatever decision we make at each step of the way. It does no good to be looking over your shoulder at the path not taken.

As for statistics, I am NOT a fan. I've surpassed every benchmark and I have no plan of giving up. No one knows my "expiration" date, so why agonize about dying from MM when I am still able to live with it. A quote from Maya Angelou expresses how I try to live my life: "We spend precious hours fearing the inevitable. It would be wise to use that time adoring our families, cherishing our friends, and living our lives."

I've been blessed to witness MM morph into what is for some folks, myself included, a chronic disease that can be managed successfully for many years. My goal is to keep hangin' in, waiting for the next thing to come along to keep me hangin' in even longer. **MM**

Editor's Note: Barbara Hammack is an active member of the MM listserv, where she participates under the moniker "Boogie Barb."

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.

UPDATES FROM AROUND THE GLOBE

IMF Europe: Looking Back, Looking Forward

By Gregor Brozeit

Since March 2006, IMF Europe has sponsored or cosponsored 96 multiple myeloma (MM) patient or doctor educational meetings in 9 European nations. Every meeting has featured national, regional, and local clinicians and/or researchers who discussed the latest strategies to treat MM. Top MM experts from the US have participated in European meetings sponsored or cosponsored by the IMF, including Drs. Robert Kyle, Brian Durie, Bart Barlogie, Morie Gertz, and David Vesole.

In 2011, IMF Europe organized or participated in 22 patient and doctor meetings. Prof. Kyle headlined five meetings, including the IMF's first patient meeting in Denmark, a Danish study group meeting, a German patient and family seminar, as well as two doctor meetings in Germany. In addition, Professors Hermann Einsele (Germany) and Mario Boccadoro (Italy) participated in IMF meetings held in the US. In Europe, 11 meetings cosponsored by the IMF – eight for patients and three for doctors—were held in four countries in Fall 2011.

Czech Republic

The Czech Myeloma Group (CMG) and the IMF cosponsored the 7th annual Czech Patient & Family Seminar in Lednice on September 30, which featured Prof. Roman Hajek. More than 100 persons attended. Roman Sadzuga, founder and president of the Polish MM patient association, provided the keynote address.

CMG coordinator Iveta Mareschova attended this year's Patient & Family Seminar in San Francisco to observe how the IMF conducted its meetings. "After seeing how Susie ran the caregiver breakout session," said Iveta, "Dr. Hajek and I thought it would be a productive addition to our meeting, and we were pleasantly surprised by how well it was received. More than 40 persons attended our first caregiver session."

Italy

Two patient meetings were held in Italy in September, in Rome and in Lucca (Tuscany). Susie Novis attended the Rome meeting and Vittorio Schirinzi hosted the Lucca meeting. Vittorio is the founder of the Schirinzi Myeloma Patient Association, the IMF affiliate in Italy, and assembled a faculty of medical speakers from the Universities of Pisa, Florence, and Parma. One of the speakers, Prof. Nicola Giulini, is a past recipient of the IMF Brian D. Novis Research Grant.

Both meetings went exceptionally well. "Patients and family members, as well as individual faculty presenters all gain something positive out of these meetings," said Vittorio. "I'm very pleased with the progress we've made over the years and hope to develop a more ambitious agenda as we continue to grow."

Denmark

Ole Dallris, chairman of the Danske Myelomtose Forening (DMG) and a long-term MM patient, provides services that include phone counseling, a newsletter, and patient meetings throughout Denmark. Ole and the DMG have long been friends of the IMF, so it was the fulfillment of a long-standing desire to conduct a joint meeting. The first ever Patient & Family Seminar in Denmark was co-sponsored by the IMF and the Danish MM patient association, Danske Myelomtose Forening (DMG). Held in Nyborg, the meeting featured two of the Denmark's top MM specialists, Prof. Niels Abildgaard and Dr. Peter Gimsing, with Prof. Kyle from the US joining the faculty as a special guest. On the following day, Prof. Kyle was the keynote speaker of the semi-annual meeting of the Danish Myeloma Study Group, a gathering of 60-70 of the top hematologists in Denmark.

Germany

Hosted and organized by Prof. Hartmut Goldschmidt, IMWG member and chair of the German Multiple Myeloma Study Group (GMMG), the 11th annual Myeloma Days combined an annual patient meeting with a semi-annual GMMG meeting. This was Prof. Kyle's third speaking engagement at the event.

The annual Heidelberg patient meeting, the oldest and largest MM patient event in Germany, was attended by more than 220 persons this year, including 70 newly diagnosed MM patients. Prof. Kyle provided the keynote address with a historical overview of MM research and treatment. The other faculty members were drawn from the University of Heidelberg and the German Cancer Research Center (DKFZ). Under the leadership of Prof. Goldschmidt, the university and the DKFZ share resources for MM clinical and basic research. Each faculty member participated in two breakout sessions each in order to allow more participants to meet different experts in smaller settings. "The Heidelberg meeting went very well," said Prof. Kyle. "The patients asked a lot of pertinent questions."

Immediately following the Heidelberg meeting, Prof. Kyle spoke to students participating in an international course for oncology management at the University of Ulm. His tour concluded with a lecture to 65 University of Freiburg hematology faculty hosted by Prof. Monika Engelhardt.

On October 23, Prof. Goldschmidt joined Dr. Igor Wolfgang Blau at the Berlin Charité Benjamin Franklin campus as speakers for the second Berlin patient meeting in 2011 cosponsored by the Berlin MM patient support group and IMF Europe. Elke Schutkowski, founder and leader of the Berlin group said, "We have a very sophisticated group of patients and family members, and they value the excellent speakers we have been able to attract."

On October 29, Dr. Christian Langer hosted a patient meeting at the University of Ulm, with more than 160 attendees. The distinguished faculty included Prof. Donald Bunjes and Prof. Einsele, as well as Dr. Jens Hillengass, arguably the top expert in MM imaging in Germany.

The November 19 patient meeting was the second event cosponsored by the IMF and the Leipzig MM patient support group this year. Speakers included Drs. Luisa Montavani Löffler, Monika Keller, and Dr. Christoph Schimmelpfennig. With a packed house of more than 100 attendees, IMF Europe culminated a successful year of meetings.

CONTINUES ON NEXT PAGE

THE IMF WELCOMES NEW MM SUPPORT GROUPS

Arkansas

The Arkansas MM Support Group meets on the 1st Friday of each month from 10:00 a.m. to 12:00 noon at First Presbyterian Church in Texarkana. For more information, please contact Andy Shoptaw at jewellshoptaw@live.com or 870-773-0273 or 903-826-7993.

Delaware

The Delmarva MM Support & Networking Group also serves areas of Maryland and Virginia. The group meets on the 3rd Saturday of each month from 1:30 to 3:30 p.m. at The Eden Hill Medical Center in Dover. For more information, please contact Josephine Diagonale at mmsupportde@comcast.net or 302-233-8229.

Florida

The Boca Raton MM Support Group meets the 1st Monday of the month from 6:00 to 8:00pm at James Rutherford Community Center. For more information contact Dawn Toimil at dawn8992@yahoo.com or 561-901-5938, or Gail Young at alghyoung@comcast.net or 561-637-4682.

The Nature Coast MM Support Group meets the 3rd Wednesday of the month from 6:00 to 7:30 p.m. at the Oak Hill Partners Club at Oak Hill Hospital in Brooksville. For more information, please contact Dianne Terry at dianne_mm@tampabay.rr.com or 352-621-0672, or Richard Blustein at blustein22@aol.com or 352-428-4536.

Indiana

The IU Simon Cancer Center offers "First Mondays," a community-wide support program open to cancer patients and their families. "First Mondays" meets the 1st Monday of each month from 5:00 to 7:30 p.m. in Indianapolis. For more information, please contact Stephanie White at swhite9@iuhealth.org or 317-948-2538.

Louisiana

The North Louisiana MM Support group meets on the 3rd Saturday of each month from 11:00 a.m. to 1:00 p.m. at the University Worship Center in Shreveport. For more information, please contact Pete or Carolyn Petty at cfpett@gmail.com or 318-518-2693 or 318-797-6620.

INTERNATIONAL — continued from previous page

Plans for 2012

In addition to patient and doctor meetings, IMF Europe has been focused on fulfilling the ever-growing demands for informational materials and online resources. MM support groups remain scarce in most countries, but tend to be well connected with community resources where they exist, and IMF Europe remains committed to assisting them in every way possible.

The IMF's Myeloma Manager™ Personal Care Assistant™ software tool, designed specifically to help patients and caregivers battling MM track and understand their lab results, has been translated into German, French, Spanish, and Italian. It will be disseminated in these languages in 2012, while additional versions are being prepared in Danish, Norwegian, and Swedish.

Also in 2012, the IMF will be re-launching free electronic newsletters in German, French, Spanish, and Italian.

Please feel free to contact me at greg.brozeit@sbcglobal.net with questions, suggestions, or requests for additional information. **MT**

Michigan

The Greater Grand Rapids MM Support & Networking Group meets on the 3rd Monday of each month at 5:30 p.m. for supper, with meeting directly following from 6:00 to 7:30 p.m. at Gilda's Club in Grand Rapids. For more information, please contact Sue & Harold Van Duyn at hsvanduyn2@aol.com or 616-669-0781.

North Carolina

The Charlotte Area MM Support group (CAMMS) meets the 1st Saturday of each month from 10:00 a.m. to 12:00 noon at the Carmel Presbyterian Church. For more information, please contact Sandy or David Hirsch at shirsch48@gmail.com or704-840-6740.

Ohio

The Toledo Area MM Support & Networking Group meets the 3rd Tuesday of each month from 2:00 to 4:00 p.m. at the Perrysburg Way Public Library in Perrysburg. For more information, please contact Inge Lanzenberger at inge1028@gmail.com.

Tennessee

The Nashville MM Support Group meets on the 3rd Wednesday of each month from 11:00 a.m. to 12:30 p.m. at Gilda's Club. For more information, please contact co-facilitator Kelly Fields Owens, LMSW, at kelly.owens@vanderbilt.edu or 615-322-4887.

Texas

The Kingwood Area MM Support Group meets on the 3rd Saturday of each month from 10:00 a.m. to 12:00 noon at the YMCA in Kingwood. For more information, please contact Mike Boyd at mboyd4814@gmail.com or 281-360-9267.

How to contact the IMF Support Group Team

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PEOPLE HELPING PEOPLE

You are never alone in your battle against myeloma

By Robin Tuohy, IMF Director of Support Groups

How did myeloma enter your life and what is your background with the IMF?

My husband Michael was diagnosed with multiple myeloma (MM) in 2000 at age 36. The IMF was there for me and my family – and continues to be there for us – so we've now been involved with the IMF for more than a decade. Michael and I founded the first MM support group in Connecticut in 2001, soon after meeting the IMF while attending Advocacy Days in Washington, DC. Our kids started supporting the IMF when they were still quite little, beginning with a lemonade stand, and my daughter Ally just recently held an event to raise myeloma awareness and benefit the IMF as part of her senior project in high school. In early 2005, I came to work for the IMF as a support group assistant. In the summer of 2007, our family hit the road with the MYELOMA MOBILE, an awareness project to help educate and empower patients and their families in local communities across the United States. The IMF is more than a place where I work – it is family to us.

I'm very humbled to be a part of the most knowledgeable and caring organization I've ever had the pleasure to work for. The IMF is truly dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure. Together with the other members of the IMF 's support group team, I am committed to assisting individuals and communities by reaching out to patients, their families, friends, and healthcare workers.

Would you tell us about the IMF's work with MM support groups?

Through a global community of IMF-assisted support groups, the IMF seeks to ensure that MM patients, their caregivers, family members, and friends have local access to support, information, and a strong sense of collective identity. From my personal experience, I know how important such resources are to those of us who are dealing with MM.

The IMF currently supports 120 MM groups in the United States, plus many groups abroad. There is now a worldwide network of more than 150 MM support groups, and I am happy to report that our ranks are continuing to grow. In the last year or so, the IMF has facilitated the formation of 11 new groups in the US alone *(please see box for more info)*. More groups are also being formed abroad.

Tell us about these groups and how the IMF supports them.

The power of psychosocial support for cancer survivors has been well-documented. Support groups that hold regular meetings can help increase knowledge, decrease anxiety, and create a sense of community. IMF-assisted MM groups are disease-specific, and many participants find that this is extremely helpful to creating a network of support. Although the IMF does not sponsor these groups, we are dedicated to overseeing the needs of each group and its leaders. Each group has a unique personality and identity that reflects its members and their experiences with MM. The objectives of each group vary, so the IMF is here to assist in many ways.

We help develop outreach letters and flyers, promote the groups through the IMF website and our publications, and assist with mailing to local patients, caregivers, oncologists, and hospitals. We provide direction and ongoing guidance in starting, maintaining and sustaining a group. The IMF provides free educational publications, an annual DVD of an IMF Patient & Family Seminar, and a basic template to help the group develop a website.

The IMF forms and maintains relationships with MM support group leaders and members. Our staff has personally visited almost all of the US-based groups. In the US, the IMF's support group team, which includes me and three regional directors, has attended all IMF Patients & Family Seminars as well as Regional Community Workshops. In addition, the IMF holds annual Support Group Leaders' Summits. In July 2011, we held the twelfth such Summit.

How do the Support Group Leaders' Summits benefit the groups?

The IMF's 12th annual Support Group Leaders' Summit took place in Irving, TX. A total of 76 support group leaders representing 50 groups attended the Summit. While many leaders had attended prior Summits, there were 33 leaders who attended for the first time in 2011.

In the course of the Summit, participants are updated on the latest information about myeloma treatment and care, and are provided with new leadership tools and approaches. The program is designed to help leaders further enhance the experience for their support groups back home. Ultimately, all IMF programs and services are designed to benefit the patient. This is the case with IMF's research, education, advocacy, *and* support programs.

As support group leaders, my husband and I attended the Summit in 2001, and from that day forward have felt a bond with MM group leaders all over the world – people walking in our same shoes, trying to learn all they can about MM, helping others in their local communities.

The relationships we formed at the 2001 Summit have continued to grow stronger through the years. "If One can Make a Difference; Two can Make a Miracle"… We all strive to be a part of the Miracle!

In what other ways does the IMF support the group leaders?

We maintain a web-based "extranet" so MM support group leader have a place to post and share documents, ideas, information, pictures, etc. It is a great way for leaders to start conversations with one another, as well as share practical tips and emotional support.

In 2011, the IMF implemented a brand new program for group leaders, a monthly teleconference. Leaders are able to dial in and talk about any challenges they may have, share success stories, ideas for planning, etc. This is a fantastic new program that has already become a hit among the group leaders.

Any closing comments?

The IMF and our support group team are very excited for 2012, with an eye on launching several new and unique programs geared to support the MM groups specific to the IMF. I encourage every individual whose life has been touched by myeloma to seek out a group in their area. If such a group does not yet exist, please consider starting one. It takes dedication and perseverance, but can be an extremely rewarding experience.

The IMF's support group team is dedicated to assisting individuals and communities. We reach out to patients, their families, friends, and healthcare workers. And we invite you to reach out to us. The IMF is always here for you. **MT**

SPOTLIGHT ON ADVOCACY

IMF's First Congressional Briefing

With the country's ongoing deficit crisis and looming budget cuts, the IMF thought it was the opportune time to illustrate areas where the US remains the world's leader – science and medicine. What better way to highlight the importance of biomedical research than myeloma?

On October 25th, the IMF Advocacy team headed to the capitol to host our first ever congressional briefing – Why Investment in Biomedical Research is Necessary: A Case Study on Myeloma. Not only was this a wonderful opportunity to underscore the importance of continued funding for cancer research at the NCI at levels that support innovation, but it was also a way to raise awareness of the disease and educate members of congress as well as their staff.


Congresswoman Jackie Speier gives remarks

We were very fortunate to have our event open with remarks from Congresswoman Jackie Speier (D-CA), a champion for research and innovation. Congresswoman Speier serves as co-chair of the Congressional Biomedical Research Caucus, a 78-member bipartisan caucus dedicated to educating and advancing life science issues throughout Capitol Hill. Through her leadership of this caucus and her personal office, she has been a very strong advocate for cancer research. We can't thank her enough for her tremendous leadership and support of our cause.


Dr. Ola Landgren discusses advances in MM research

Our key note speaker, Dr. Ola Landgren, Chief of the Multiple Myeloma Section and Senior Investigator, the National Cancer Institute (NCI) at the National Institute of Health (NIH), discussed his ongoing research aimed at the treatment, causation, diagnostics, prognostics, and natural history of multiple myeloma and its precursor condition MGUS (monoclonal gammopathy of undetermined significance).

Dr. Landgren spoke of the advancements in treatment, as well as the expanded knowledge and understanding of the disease that has come as a result of this research. While discussing his work, Dr. Landgren made a point that resonated with the entire audience. He said, "We would never send an early breast cancer patient home and tell them to come back when it metastasizes." It was an eye opening statement and a brilliant example of why it is crucial to fund this research at the NCI.

In addition to Dr. Landgren, our panel included Dr. Barbara Klencke (Onyx Pharmaceuticals) and Michael Katz (patient advocate, 21-year myeloma survivor, member of the IMF Board of Directors). Dr. Klencke gave a brief overview of the development and FDA approval process of carfilzomib, a promising new treatment for myeloma. She talked about the discovery process and the research that goes into the development of drugs like carfilzomib. This helped our audience understand that none of it would be possible without research efforts at the NIH. Work by Dr. Landgren and other researchers at institutes funded by the NIH makes possible an improved understanding of what causes myeloma and how to treat the disease effectively.

Carfilzomib is just one example of the results of NIH research. We are at the cusp of many new discoveries in cancer. Now is the time to invest in and translate those discoveries into effective treatments and cures.


Dr. Barbara Klencke and Mike Katz lead the "Living with Myeloma Thanks to Next-Generation Treatments" panel discussion,

Mike Katz, a 21-year survivor of myeloma, took to the podium to conclude the morning session. Putting a face on myeloma is imperative when telling our story on Capitol Hill. Just about everyone has been touched by cancer and could either see themselves or the face of their loved ones in Mike's that day. Patients like Mike are the reason why doctors like Dr. Landgren and Dr. Klencke are so dedicated to their research.

Mike's message was simple: "Biomedical research is hope for the future for me, my fellow patients, and our families." When Mike was diagnosed at age 37, he was a father of three young children, and he thought his life was over. Twenty-one years later, Mike has seen his three sons graduate from college and his first three grandchildren born.

The investment in research means everything to patients – it means LIFE. We thank Congresswoman Speier, Drs. Landren and Klencke, and Mike Katz for their participation in what turned out to be a very successful briefing. We'd also like to thank Onyx Pharmaceuticals for providing the IMF with an educational grant that made this briefing possible.

Update on the Cancer Coverage Parity Act of 2011

In August, US Representative Brian Higgins (D-NY) introduced HR 2746, the Cancer Coverage Parity Act of 2011. This important piece of legislation requires health insurance coverage of oral anticancer drugs on terms no less favorable than the coverage provided for intravenously (IV) administered anticancer medications.

Our thanks go to each of the more than 250 advocates who wrote over 300 letters to their Representative to help eliminate the disparity in coverage between oral and IV chemotherapy. In addition, many advocates met face-to-face with their Representative to ask for his or her co-sponsorship of HR 2746. We are happy to share that your initiative and hard work is paying off!

At the time of publication, HR 2746 is now co-sponsored by Representatives

CONTINUES ON PAGE 16

Investing In The Future

THE HOPE SOCIETY

For nearly 21 years, the IMF has been the center of education and support for multiple myeloma (MM) patients and family members who rely on our services. In a similar way, the IMF depends on its donors to help continue and improve upon those services.

During the summer of 2009, the IMF introduced *The Hope Society*, a sustained giving program that allows members to contribute monthly or quarterly gifts to the IMF. In two years, *The Hope Society* has grown to include over 150 members who have contributed more than $40,000 toward the IMF's research, education, support, and advocacy programs.

Susan Gannon joined *The Hope Society* in December 2009. Diagnosed with MM three years earlier, she first learned about the IMF's research and education programs while attending an IMF Patient & Family Seminar near her hometown of Houston, Texas. She became an active supporter of the IMF soon after, often making more than one contribution in the same year. "I believe the more we can contribute to the area of myeloma research, the better my chances are," she says.

Susan believes that by participating in the program as a monthly donor, she is investing in the research that has already made a difference in her life as a myeloma patient. "The progress made thus far in treatment success is due largely to research that has been funded by the IMF," she explains. "It's a little selfish," she continues, "I support the IMF because I'm trying to save my own life."

Members of *The Hope Society* make a huge impact on the continuation of the IMF's mission, and becoming a member is simple. To set up your own recurring gifts for the IMF, please contact Randi Lovett at rlovett@myeloma.org or 800-452-CURE (2873).

Membership Level	*Giving Range*
Member $35 to $149 annually	$5 – $12 Monthly $10 – $37 Quarterly
Supporter $150 to $499 annually	$13 – $41 Monthly $38 – $125 Quarterly
Friends' Circle $500 to $999 annually	$42 – $83 Monthly $126 – $250 Quarterly
Associate's Circle $1,000 to $4,999 annually	$84 to $208 Monthly $251 – $1,250 Quarterly
Partner's Circle $5,000 to $10,000 annually	$417 – $833 Monthly $1,251 – $2,499 Quarterly

ADVOCACY — continued from previous page

Joe Baca (D-CA), Jeff Fortenberry (R-NE), Barney Frank (D-MA), Rush Holt (D-NJ), and Steve Israel (D-NY). **MT**

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

Please help us pass HR 2746, the Cancer Coverage Parity Act of 2011. Write to your US Representative today. Visit www.advocacy.myeloma.org and click on the Action Alert "Help Eliminate the Disparity in Coverage for Chemotherapy" under the Issues & Legislation tab.

Become an IMF advocate to stay informed of critical issues affecting the myeloma community and legislation at both federal and state levels to help resolve them. Make a positive change in your life and the lives of ALL cancer patients in the US. ***Sign up TODAY at advocacy.myeloma.org!***

How to contact the IMF Advocacy Team

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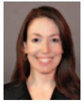


Meghan Buzby – *Grassroots Liaison*
phone: 410-252-3457 *email:* mbuzby@myeloma.org
email: mbuzby@myeloma.org

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**

IMFERS RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia

IMF members are people like you, from across the country and around the globe, and many are raising money for multiple myeloma (MM) research and education programs that have an impact on the lives of patients and family members worldwide.

Being involved is very fulfilling and empowering. Join us in our search for a cure for MM by organizing an event in your community to raise public awareness and help those whose lives have been touched by this disease. Deciding what to do and how to do it can be confusing, and that's where we come in. The IMF is here to help you every step of the way, making it as easy as possible for you to be involved!

Our FUNdraising program is fun and easy, and brings with it the satisfaction of knowing that YOU have made a difference in many lives. Choose an established event model or create your own – ***no idea is too large or too small*** *– and we provide you with the tools, assistance, and expertise to make your event a success.*

We are grateful to all who contribute their time, imagination, and hard work to benefit the MM community. Join us in working together toward our common goal... a CURE. Please contact me, Suzanne Battaglia, at sbattaglia@myeloma.org or 800-452-CURE (2873) to chat about any ideas you might have. Be part of making miracles happen!

Here is a sampling of past events. . .

Car Raffle

Mario Bonacorsi presents check for $8,000 to IMF representative Robin Tuohy

Mario Bonacorsi was diagnosed with MM in 2006. "Two years later, in 2008, I had an autologous transplant," said Mario. "Unfortunately, the remission didn't last, so I had an allogeneic transplant in 2009. Another bump in the road followed, but I'm doing well on my current drug regimen." Mario is semi-retired, but has maintained a part-time business of selling cars as well as locating cars for customers to purchase. As a member of the Barre Rotary Club in Vermont, Mario decided to organize a fundraiser that united many of interests and benefited both local charities and the IMF.

Mario found a sports car he felt would work for the fundraiser, a red 2004 Mazda Miata MX-5 Convertible. Together with friends and family, he sold 250 raffle tickets at $100 each and raised an impressive $25,000. "Almost everyone knows someone with cancer so, even in this economy, people want to help. We ended up selling raffle tickets to people as far away as Colorado and Georgia! After deducting costs, we were able to donate $5,000 to local charities and $8,000 to the IMF."

2004 Mazda Miata MX-5 LS Convertible 1.8Ltr 5Spd 56K Miles

Exceptionally clean, well maintained car from Texas! No winters, garage kept, like new!

Black leather seats, Bose premium sound, CD, cruise, tilt, power windows, power locks, power steering, theft system, privacy glass, AC, alloy wheels.

Only 250 Tickets Sold at $100 Each!!

Raffled by The Barre Rotary Club

IMF's Robin Tuohy attended the local MM support group meeting for the check presentation ceremony. When Robin asked Mario how he'd like to see the money he raised be directed, he simply said, "I'd like the money to support the search for a cure. I'm glad we could raise funds for the IMF's MM research program. Hopefully, we will find a cure in my lifetime. Yes, my reasons for supporting MM research are very personal, but any advances we make will also help others who are dealing with the same disease."

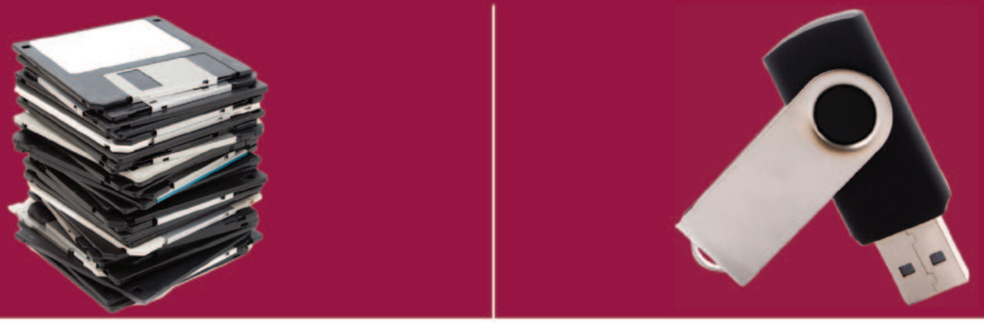
Fall Bocce Classic

Dick Bloom was diagnosed with MM in 2008 as a result of routine blood tests. "I was 61 years old and I had no idea that anything was wrong. I felt fine," said Dick. "Since then, I've been on and off different drug cocktails. In the meantime, I did a stem cell collection, just in case. Otherwise, my wife Lisa and I try to live life just we did before. We spend six months a year in Florida with our two sons and our grandkids. The rest of the time, we live in Dayton, OH."

Lisa Bloom is of Italian descent and is a member of the Italian-American Club in Dayton. For years, Dick has enjoyed the game of Bocce, an ancient ball game played as far back as in the Roman Empire. In fact, at one point Dick ran an annual Bocce tournament with more than 100 teams participating. "We are surrounded by a community of caring people who have been very supportive of us, and Lisa and I decided that it would be a good idea to organize a one-day Bocce tournament, with the proceeds going to support the IMF and MM research." That is how the Fall Bocce Classic was born.

On September 24, almost 90 players came together for the second annual Fall Bocce Classic to support the Bloom Family and the IMF. "Unfortunately, just before the event, a second member of our club was diagnosed with MM, and it started to hit home for a lot more people. There were now two of us with this obscure form of cancer so, in addition to fundraising, we placed a lot of emphasis on raising myeloma awareness."

Dick and Lisa plan to continue the Fall Bocce Classic next year and hope to attract even more people to the tournament. "Bocce is a very competitive game, but one of the neat things about it is that just about anyone can play: male, female, young, old. The winning team included a 12-year-old, and he was the one who won the very last game. The tournament is a great way to show support for cancer research and have a lot of fun, too." **MT**

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2012 IMF Calendar of Events

Feb 3-4	IMF Patient & Family Seminar – Boca Raton, FL
March 23-24	IMF Patient & Family Seminar – Seattle, WA
May 3-6	Oncology Nursing Society (ONS) annual conference – New Orleans, LA
June 1-5	American Society of Clinical Oncology (ASCO) annual meeting – Chicago, IL
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
July 27-29	IMF Support Group Leaders' Annual Summit – Dallas, TX
Aug 10-11	IMF Patient & Family Seminar – Los Angeles, CA
Oct 13	6th Annual Comedy Celebration – Los Angeles, CA
Dec 8-11	American Society of Hematology (ASH) annual meeting – Atlanta, GA

Additional events/meetings will be posted in later editions of *Myeloma Today* as dates are finalized.
For more information, please visit myeloma.org or call 800-452-CURE (2873).

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