



MYELOMA TODAY

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A Publication of the International Myeloma Foundation

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

Scientific & Clinical News



Dr. Cristina Gasparetto (Duke University Medical Center, Durham, NC), who specializes in multiple myeloma both in clinical practice and in the laboratory, talks about the current role of transplantation in myeloma. She discusses autologous stem cell transplantation (ASCT) and allogeneic stem-cell transplantation (allo-SCT) and, as an author of the recent International Myeloma Working Group (IMWG) consensus statement regarding the current status of allo-SCT, Dr. Gasparetto shares the findings recently published in the *Journal of Clinical Oncology*. **PAGE 7**



Dr. Matthew T. Drake (Mayo Clinic, Rochester, MN), an endocrinologist whose primary interest is in metabolic bone disease, talks about myeloma bone disease, and its diagnosis and monitoring. He explains how biochemical markers of bone metabolism may be helpful in assessing both bone formation and resorption in myeloma. Dr. Drake also addresses osteonecrosis of the jaw (ONJ), the effect of novel drugs on myeloma bone disease, the development of a new osteoclast inhibitor, and the use of bisphosphonate therapy in myeloma. **PAGE 8**



Dr. Joseph Mikhael (Mayo Clinic, Scottsdale, AZ), whose clinical practice is dedicated to plasma cell disorders, is also an educator and an investigator of many clinical trials, primarily in relapsed myeloma. Dr. Mikhael speaks about clinical trial design, the process of new drug development, and the patient factors to be considered when selecting individualized anti-myeloma therapy. He also offers a glimpse into the promising myeloma drugs currently in the development pipeline that should become available to patients in the near future. **PAGE 8**

Profiles in the News



Robert Reeves was diagnosed with myeloma at age 72. An athlete with a passion for running and cycling, Bob biked 150 miles for charity a year following his diagnosis. He had a stem cell transplant at age 74. A regular caller to the IMF Hotline during his eight years of living with myeloma, Bob has coped with multiple tumors, radiation, surgery, treatments that worked and those that didn't, side effects of myeloma therapy, and the loss of a wonderful wife of 54 years to cancer. Bob shares what has helped him on his journey that might also be of benefit to you. **PAGE 8**

Supportive Care



IMF Hotline Coordinators

respond to a question about vitamin D deficiency. People at risk for vitamin D deficiency include those who have inadequate sun exposure, inadequate dietary intake, severe liver disease, kidney problems, antiepileptic medications, or malabsorption due to health issues. Because vitamin D deficiency is linked to more advanced stage of myeloma at diagnosis (portending poorer outcome), and to other health problems, maintaining adequate levels through supplementation is an important new aspect of myeloma care. **PAGE 11**



Greg Pacini, a licensed professional counselor and certified group psychotherapist with more than 30 years experience, talks about the difference between stress and stressors, suffering and pain, and the nature of discomfort. Greg offers tools and suggestions that, with awareness and practice, can help us learn to master our emotions and manage difficult feelings, during the holidays and beyond. He also addresses the challenge faced by individuals who put everyone else first while having a hard time honoring their own needs and asking for help. **PAGE 12**

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2011 IMF Calendar of Events **BACK COVER**



LOOKING FOR A LOCAL MYELOMA SUPPORT GROUP?

Please visit our website at www.myeloma.org
or call the IMF at **800-452-CURE** (2873).

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IMF Regional Community Workshops

Dear Kelly,

Thank you for the wonderful day at the IMF Regional Community Workshop in Raleigh/Durham, NC. It was so uplifting, positive, and entertaining. We walked away with some more hope and were very pleased to learn of the upcoming new drugs, clinical trials, etc. This has been a very daunting year and a half. It is people like you who really help people like us. Again, thanks.

Ed and Nancy Brooks

We enjoyed the Kansas City Area IMF Regional Community Workshop in Overland Park, KS. Besides learning to live with myeloma, I am learning so much more about the disease. Since I don't fit the "typical profile," I feel as if I am going in many different directions to gather as much information as possible. Since I found out there is a myeloma support group in Kansas City, I will attend the next meeting in November. Thanks for all you do for myeloma patients!

Sherry Kennedy

Thank you for the fabulous IMF Regional Community Workshop you organized in Denver, CO. My family and I were really impressed with the content and quality of the presentations. There is nothing like hearing directly from the medical specialists who deal with multiple myeloma on a daily basis. Not only did we come away with additional knowledge, but my kids said they came away with more hope. Knowledge may be power, but hope is eternal. I think we are all better prepared for whatever may face us in the future. I look forward to seeing you at the next support group meeting. Thanks again.

Malena Garst

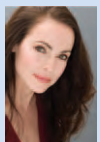
Multiple myeloma support groups

Kelly,

Thank you so very much for the most informative meeting our Inland Valley Multiple Myeloma Support Group has had in a very long time. You and the nurse who spoke to our members were so clear, precise, and forthcoming with important information. We send you both a big thank you from our group!

Mary Ming-Mosley

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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mkazakova@myeloma.org

How to Start a Myeloma Support Group

- ▶ Secure a location for the meeting as soon as practical. Consider parking availability and handicap accessibility. Some suggestions are hospitals, community centers, libraries, and churches.
- ▶ Pick a date and time convenient to you, taking into consideration the best time for others to come to the meeting. Groups typically meet for two hours, and on a monthly basis.
- ▶ Compose a letter that you can send to doctors, clinics, hospitals, and patients and family members informing them of the group. Ask the office of your local oncologist to inform their patients about your group and post your flyer in their office.
- ▶ List your group's meeting date, time, and place in your local newspaper's health section (free). Involve local radio and TV media to help create awareness of your group.

How the IMF can assist you

- ▶ Provide direction and ongoing assistance in starting your myeloma support group.
- ▶ List your support group on the IMF website.
- ▶ Create a basic website for the group.
- ▶ Design a flyer for the group.
- ▶ Mail out a flyer to patients in the area to help with outreach.
- ▶ IMF staff can visit and provide you with free IMF publications and information.
- ▶ Provide you with an annual DVD of an IMF Patient & Family Seminar.
- ▶ Offer free IMF Patient & Family Seminar registration for support group leaders.
- ▶ Access to specific website exclusively for IMF Support Group Leaders, as well as the Support Group Leader Listserv.
- ▶ Invite you to the IMF Annual Support Group Leader Retreat.



Currently there are over 100 myeloma support groups that meet regularly. If there is not one in your area, we will be happy to help you initiate one.

International Myeloma Foundation: Celebrating

1990 1992 1993 1994 1995 1996 1997 1998 2000

- International Myeloma Foundation begins operations
- Toll-free hotline (800-452-CURE) established in the United States



- IMF hosts first Clinical Conference on Myeloma
- IMF's first Gala fundraiser for myeloma research
- First edition of *Myeloma Today* published



- IMF begins distributing free info packs
- IMF attends the American Society of Hematology (ASH) annual meeting for the first time
- IMF hosts first Patient & Family Seminar



- IMF opens Myeloma Center in Vienna, Austria



2010 Brian D. Novis Grant Recipients

- IMF awards first Brian D. Novis Research Grant

- First Patient Seminar outside the USA held in the UK
- IMF's website, www.myeloma.org, goes live



- IMF opens offices in the UK



- IMF begins advocacy initiatives



- IMF hosts first Think Tank to advance myeloma research
- IMF's tenth anniversary Gala raises \$500,000 for the IMF's research and educational programs.

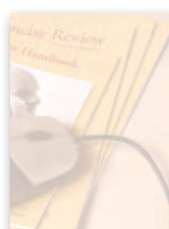


Dear Reader,

The International Myeloma Foundation, the first myeloma organization in the world, was founded 20 years ago with the firm belief that no one should ever have to face multiple myeloma alone. Since 1990, families like yours have come to depend on the important work that the IMF does not only to improve their quality of life in the short term, but also to ultimately find the cure. The IMF has become the leading international gateway for information and resources in the fight against myeloma, serving more than 195,000 members – patients, families, caregivers, and healthcare professionals – in 113 countries. As we mark our 20th anniversary, we celebrate the many achievements in the myeloma community but remain committed to the work that remains to be done to put the end to this disease, focusing our efforts in four key areas:



EDUCATION



Education is one of the strongest weapons in the fight against myeloma, and an independent survey has rated the IMF as the number one patient resource for up-to-date information on treatments and clinical trials, as well as its publications and educational seminar programs. The IMF has held more than 200 educational patient meetings in 16 countries. The IMF produces publications that address myeloma treatment options, clinical trials, and quality of life issues. Materials are available in 16 languages, and this extensive library of pamphlets, booklets, and tip cards is available free of charge. The complimentary IMF Info Pack, a compilation of these resources, is distributed annually to more than 20,000 patients, caregivers, and healthcare professionals. The IMF's quarterly newsletter *Myeloma Today* has more than 15,000 print subscribers, as well as a web view and pass-along rate independently estimated at an additional 60,000 readers. The *Myeloma Minute*, a frequently distributed e-mail newsletter with more than 16,000 subscribers, presents up-to-the-minute information about myeloma and IMF services.

The IMF is strongly committed to educating healthcare professionals. The Nurse Leadership Board (NLB) was founded by the IMF in 2006 in order to continually improve the care of myeloma patients through the education of nurses. Their first guidelines, *Managing the Side Effects of Novel Agents for Multiple Myeloma*, was published in the *Clinical Journal of Oncology Nursing*, June 2008. In 2010, for the 4th consecutive year, the NLB presented a Satellite Symposium at the Annual Congress of the Oncology Nursing Society (ONS). As myeloma patients are increasingly living longer and achieving extended disease-free periods as a result of novel drug therapies, the NLB's Long-Term Care Survivorship Plan is addressing the need for effective management of treatment-related side effects and other survivorship issues. The Satellite Symposium at ONS was attended by a "standing room only" audience of 625 oncology nurses. Also in 2010, the nurses of the NLB educated their colleagues at 11 accredited in-person meetings and through a series of accredited webinars, and provided patient and caregiver education at four IMF Patient & Family Seminars, 10 IMF Regional Community Workshops, and 12 educational conference calls. Another outstanding 2010 accomplishment of the NLB is the first ever myeloma textbook for nurses. Joseph D. Tariman served as the textbook's editor and, along with nine NLB colleagues, contributed chapters to the book. The textbook, published by the ONS a mere year after its conceptualization, has been extremely well-received.



RESEARCH

The IMF's collaborative research initiatives continue to lead the way as the myeloma community enters the era of "tailored treatment," with new approaches aimed at customizing each myeloma patient's treatment to his or her specific needs. As our research successes continue, we are making important strides toward myeloma becoming a chronic disease, and moving closer and closer to a cure.

The IMF's International Myeloma Working Group (IMWG) of 140 experts from around the world are pursuing their mission to conduct basic, clinical, and translational research in a collaborative manner to improve patient outcomes, and to provide scientifically valid and critically-appraised consensus opinions on the diagnosis and treatment of myeloma and related disorders. To date, IMWG members have had more than 30 papers published in the most prestigious peer-reviewed medical journals,

20 years of service to the myeloma community

2001 2002 2003 2005 2006 2007 2009 2010



• First Scientific Advisors Retreat leads to publication of first management guidelines for multiple myeloma

• IMF introduces the Myeloma Matrix to track drugs of interest from Phase I clinical trials through FDA approval
• Susie Novis testifies before a Senate appropriations sub-committee on Labor & HHS

• IMF launches Bank On A Cure® the first-ever comprehensive databank of myeloma patient DNA



• The International Staging System (ISS) developed by the International Myeloma Working Group of the IMF is published



• New response criteria for assessing treatment benefit published by the International Myeloma Working Group
• IMF establishes the Nurse Leadership Board to develop broad recommendations for nursing care for myeloma patients



• Bank On A Cure research is honored as the "Best of ASH" by the American Society of Hematology Scientific Committee
• Celebrating Peter Boyle benefit (later renamed Annual Comedy Celebration) takes place

• The IMF unveils the Cancer Patient Statement of Principles to guide the IMF's efforts in advocacy



• IMF achieves 20th Anniversary, remaining the oldest and largest myeloma charity in the world
• IMF hosts the 1st Annual International Myeloma Working Group Summit in Barcelona



including numerous myeloma guidelines and consensus statements, as well as genetic publications linked to the IMF's Bank on a Cure® research initiative. In 2010, the IMWG held its inaugural Myeloma Summit, a first-of-its-kind meeting, in order to identify, support, and implement the most promising research to prevent onset of active disease, improve treatment, and find a cure for myeloma.

In keeping with our efforts to make research more efficient and collaborative, the IMF has initiated the new Global Clinical Trials Network (GCTN). And, with more than 100 grants awarded since 1994, the IMF's Brian D. Novis Research Grants Program continues to fund junior and senior projects. (The 2011 IMF Brian D. Novis Research Grant recipients and their projects will be profiled in the Spring 2011 issue of Myeloma Today.)



SUPPORT

The IMF offers support to all myeloma patients, and their families and caregivers, through its toll-free Hotline 800-452-CURE (2873), as well as via e-mail, with National Cancer Institute (NCI) trained specialists who respond to over 4,300 phone calls and over 3,600 e-mails each year. The IMF also provides blogs and online listservs for the myeloma community.

The IMF web site www.myeloma.org receives an average of 70 million "hits" per year, serving as a touchstone for everything the IMF has to offer and providing 24-hour access to news and information on myeloma, as well as our comprehensive publications, videos, and blogs. The site is multilingual and offers multi-media webcasting and downloads.

With a network of more than 100 myeloma support groups, the IMF seeks to ensure that patients and families have access to support and information in their local communities. IMF representatives frequently visit the groups and offer guidance as needed. In 2011, the IMF will host the 12th annual myeloma Support Group Leaders Summit, an opportunity for Leaders to learn from each other, stay abreast of new advances in myeloma treatment from invited speakers and have the opportunity to discuss the many issues they encounter as leaders. They leave feeling renewed and empowered with new information to share with their group members.



ADVOCACY

By building relationships and fostering meaningful change, the IMF is committed to supporting the needs of everyone touched by myeloma. The IMF serves as a strong voice on behalf of our constituents in favor of protecting and increasing myeloma research budgets, improving access to quality care, advocating for appropriate and early Food and Drug Administration (FDA) approvals, strengthening clinical trials, and ending the disparities in insurance coverage that affect patient care. The IMF's online Advocacy Action Center www.advocacy.myeloma.org is a "one stop shop" for individuals who want to communicate with their elected representatives on issues the IMF is tracking. The IMF provides information on key federal- and state-level initiatives that will have a significant impact on the lives of myeloma patients and the cancer community at large, as well as tools needed to become proactive in these efforts and be an effective advocate.

In closing, as the IMF marks our 20th Anniversary, I can't help but remember how it all began... with three people in a London coffee shop – Dr. Brian Durie, Brian Novis, and me – with an idea to create something that didn't exist, an organization dedicated to helping myeloma patients. Brian Novis and Brian Durie, two remarkable men, put their heart and souls into making the IMF what it is today. The passion they shared has made a world of difference in the lives of tens of thousands of patients around the world. Their passion has only grown stronger over the last 20 years, and it is shared by everyone here at the IMF. Our commitment to you is unwavering – you are not alone – and together we will find a cure for myeloma.

Susie Novis

Susie Novis, President



The content for the News & Notes section of *Myeloma Today* is drawn from a long list of publications based on inquiries received by the IMF Hotline and the interests expressed by our readers. To submit your inquiries or suggestions, please email MKazakova@myeloma.org.

ASH/ASCO clinical practice guideline on the use of ESAs has been updated

The clinical practice guideline of the American Society of Hematology (ASH) and the American Society of Clinical Oncology (ASCO) for use of erythropoiesis-stimulating agents (ESAs) in adult patients with cancer has been updated. Based on data published between January 2007 and January 2010, the Update Committee recommends that clinicians treating patients undergoing myelosuppressive chemotherapy who have hemoglobin (Hb) less than 10 g/dL discuss the potential harms and benefits of ESAs, and compare these with potential harms and benefits of red blood cell (RBC) transfusions. Individual preferences for assumed risk should contribute to shared decisions on managing chemotherapy-induced anemia. The Committee cautions against ESA use under other circumstances. If used, ESAs should be administered at the lowest dose possible and should raise Hb to the lowest concentration possible to avoid transfusions. ESAs should be discontinued after 6 to 8 weeks in nonresponders. ESAs should be avoided in cancer patients not receiving concurrent chemotherapy, except for those with lower risk myelodysplastic syndromes. Caution should be exercised when using ESAs with chemotherapeutic agents in diseases associated with increased risk of thromboembolic complications.

MGUS follow-up and early diagnosis and prevention of myeloma-related complications

Monoclonal gammopathy of undetermined significance (MGUS) is associated with a long-term risk of progression to multiple myeloma or related malignancy. In a retrospective study, investigators reviewed 116 patients from southeastern Minnesota seen at Mayo Clinic (Rochester, MN) between 1973 and 2004 who were diagnosed with MGUS that subsequently progressed to myeloma. The findings suggest that routine annual follow-up of MGUS may not be required in low-risk patients. Future studies are needed to determine the optimal frequency of monitoring in higher-risk MGUS patients.

Phase 3 VISTA study results highlight CR as an important treatment goal

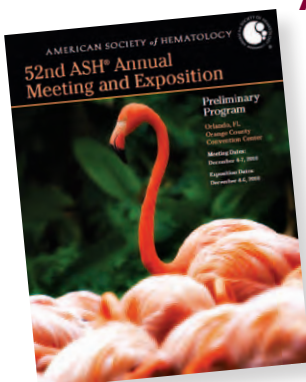
Analysis of the phase 3 VISTA study results show that superior outcomes are associated with complete response (CR) in newly-diagnosed multiple myeloma patients treated with non-intensive therapy. The phase 3 VISTA study of bortezomib (Velcade®) plus melphalan-prednisone (VMP) versus melphalan-prednisone (MP) as initial therapy in myeloma patients ineligible for high-dose therapy demonstrated that VMP was superior to MP across all efficacy end points. After nine 6-week cycles of therapy, the investigators assessed the participating patients using the European Group for Blood and Marrow Transplantation (EBMT) criteria. CR was associated with significantly longer time-to-progression (TTP), time to next therapy, and treatment-free interval when compared to partial response (PR). There was no significant difference in overall survival (OS); similar differences were seen with CR versus very good partial response (VGPR). Quality of response improved with prolonged VMP treatment. CR duration appeared similar among patients with "early" (cycles 1-4) and "late" (cycles 5-9) response; the same conclusion was reached regarding patients receiving 9 or fewer than 9 cycles of bortezomib within VMP. In conclusion, the Phase 3 VISTA investigators report that CR is an important treatment goal and support prolonged VMP therapy to achieve maximal response. **MT**

Help the IMF learn more about myeloma patients

Whether you are a myeloma patient or a caregiver who can provide information on behalf of a patient, you can help the IMF by participating in our latest Myeloma Patient Survey. No personal identifying information is gathered as part of the survey. All responses are anonymous. Please visit at <http://survey.myeloma.org>.

ASH 2010 Multiple Myeloma Highlights for Patients

The 52nd annual meeting of the American Society of Hematology (ASH) took place December 4–7 in Orlando, FL. An overview of the myeloma highlights from the ASH meeting will appear in the Spring 2011 issue of *Myeloma Today* (Volume 8, Number 6). In the meantime, please visit the IMF website www.myeloma.com to view webcasts from ASH, take part in an interactive presentation on continuous therapy in myeloma, and access the video from the IMF co-sponsored symposium, Key Myeloma Questions for 2010: Latest Developments in Diagnosis, Prognosis, and Treatment.



THE CURRENT ROLE OF TRANSPLANTATION IN MULTIPLE MYELOMA

Myeloma Today in conversation with Dr. Cristina Gasparetto

Please tell us about your medical background and how you came to work in myeloma.

I received my medical training at the Sapienza University of Rome, Italy. My residency in Internal Medicine was at Duke University Medical Center, followed by residency in Hematology and Bone Marrow Transplant, also at Duke. During my first year at Duke, I was called to a consultation with a young woman who had just been diagnosed with multiple myeloma. At that time, the treatment options available to myeloma patients were very limited. She was a candidate for a transplant and, as she struggled with the decision, I wanted to help her with the best recommendations I could give. This led me to do a lot of reading about myeloma. I knew at that point that I wanted to make myeloma the focus of my medical career. I spent the last two years of my fellowship doing myeloma research in the laboratory.



Cristina Gasparetto, MD
Duke University Medical Center
Durham, NC

Do you currently work both in the lab and in the clinic?

Before my work at Duke University Medical Center, when I first came to the US from Italy, it was on a scholarship. I worked in the lab at Memorial Sloan-Kettering Cancer Center, where I focused my research on stem cells and growth factors for stem cell mobilization. I was involved with a lot of pre-clinical studies. At that time, the dendritic cell vaccine was introduced for other cancers, and I thought it would be interesting to explore this avenue in myeloma. When I joined the faculty, I kept my laboratory work going, even though it was difficult to do both clinical and lab work simultaneously. I love my clinical work because I really love working with patients and participating directly in their care, which was why I became involved with translational research and clinical trial development.

Currently, what is your primary focus?

I have always been interested in transplantation, both in terms of my laboratory research and in terms of working with patients with hematologic malignancies who could be candidates for high-dose chemotherapy and stem-cell transplantation. I am involved both with laboratory and clinical research, following my interest in developing immunotherapy approaches to treating myeloma, particularly in conjunction with stem cell transplantation. My current lab research projects include the development of dendritic cell vaccines and antibody therapies. Clinical studies include a recently approved trial involving vaccination with autologous dendritic cells pulsed with idiotype protein following high-dose chemotherapy and autologous stem cell transplant (ASCT). Upcoming trials include novel antibody therapies. I am also an investigator on several other clinical trials for myeloma, including non-myeloablative allogeneic transplantation, high-dose sequential chemotherapy and ASCT, and transplantation of partially HLA-matched unrelated cord blood.

How would you assess the current role of transplantation in myeloma?

For now, myeloma remains an incurable disease, and we have only three options to offer our patients – chemotherapy, transplantation, and novel agents. Since we have not yet cured anybody, I don't think that any one

option has clearly surpassed the other treatment approaches.

Some doctors see the novel agents – thalidomide, lenalidomide (Revlimid®), and bortezomib (Velcade®) – as substitutes for a transplant, while I see novel agents as a way to improve upon transplant. In my opinion, the real question is, “What is the best sequential way to tackle myeloma?”

Our goal must be not to simply achieve complete remissions (CR), but to achieve a CR with good depth and durability. As with other approaches to myeloma therapy, the major failure of transplant is relapse, but transplant patients usually experience longer periods of progression-free survival (PFS) and often have longer periods of time off therapy. This also helps them avoid developing significant toxicity-related issues and/or drug resistance.

Over the past decade, I have acquired a lot of experience with transplants in myeloma. ASCT is not a perfect solution to myeloma, but I think it remains a valid option, particularly for younger patients. In transplant, one approach is a short course of powerful induction therapy; the other approach is to continue therapy with consolidation and maintenance. The second choice requires us to continue therapy longer – we cannot stop after just a few cycles. Younger patients may not wish to spend much of the rest of their lives receiving anti-cancer therapy, so a more aggressive transplant approach may be the right choice for these individuals. Others may not be able to tolerate the toxicity of therapy that goes on for a prolonged period of time.

This is why I tailor therapy to each individual patient. Some patients prefer to “go for the cure” while others decide that it is more appropriate to control the disease without attempting to cure it. Plus, given the heterogeneity of myeloma, what is a reasonable goal for one patient may not be for another.

You are a member of the IMWG, which recently published a paper on allogeneic transplantation. Please tell us about that consensus statement.

The IMF's International Myeloma Working Group (IMWG) consensus statement regarding the current status of allogeneic stem-cell transplantation (allo-SCT) as a treatment option for myeloma was published in October by the Journal of Clinical Oncology. The IMWG reviewed the results from prospective and retrospective studies of allo-SCT in myeloma. Allo-SCT, which uses cells from a compatible donor, is a treatment with a potential to cure myeloma due to the graft-versus-myeloma (GVM) effect, and because the donor cells are free from myeloma contamination. However, given the high treatment-related mortality rates with allo-SCT, and the increasing survival rates being achieved with other anti-myeloma therapies and supportive care, allo-SCT should only be recommended in the context of clinical trials until it is made safer and more effective for patients with myeloma. The promising results of reduced-intensity conditioning (RIC) transplantation in low-grade lympho-proliferative disorders

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BONE DISEASE IN MULTIPLE MYELOMA

Myeloma Today in conversation with Dr. Matthew T. Drake

Please tell us about your medical background.

The 2010 annual meeting of the American Society of Clinical Oncologists I studied biology at Harvard and worked at the Massachusetts General Hospital with a group interested in bone biology, so my interest in bone started in college. I received my medical degree and completed my doctoral work in Molecular and Cell Biology at Washington University (St. Louis, MO). Subsequent to that, I did my residency and fellowship in Internal Medicine/Endocrinology at Duke University (Durham, NC), followed by two more years there as a Postdoctoral Fellow. In 2006, I came to Mayo Clinic (Rochester, MN) as a Postdoctoral Clinical and Research Fellow in Endocrinology. Since 2007, I have been Senior Associate Consultant (Endocrinology) and Assistant Professor of Medicine (College of Medicine) at Mayo Clinic.

Recently you were invited to join the IMF's International Myeloma Working Group (IMWG).

How did you develop an interest in myeloma?

Endocrinology can be subdivided into several sub-specializations, and my primary interest is in metabolic bone disease. It was not until I came to Mayo in 2006 that I started to work in myeloma. Clinically, I spend about a quarter of my time seeing patients with metabolic bone diseases, including myeloma and MGUS (monoclonal gammopathy of undetermined significance).

In brief, please describe myeloma bone disease.

In a healthy individual, there is a balanced continuous process of removal of old bone by osteoclasts and replacement with new bone by osteoblasts. This process is normally well coupled, so that on average we completely replace our skeletons every 6-7 years. In a number of bone diseases, there is increased bone breakdown (resorption), but myeloma bone disease is rather distinct from other bone diseases because it also involves decreased bone formation (remodeling). In myeloma, there is both increased activation of osteoclasts and suppression of osteoblasts. Thus in myeloma, bone is being destroyed at an accelerated rate *and* not being then actively rebuilt.

How is myeloma bone disease diagnosed and assessed?

In myeloma, bone scans can be misleading because they are based on the bone formation process. However, in myeloma, the bone building cells are not working properly. As a result, it is easy to underestimate the extent of myeloma bone disease. Thus in myeloma, plain X-rays and MRIs are more accurate than bone scans.

What other options are there?

In myeloma, biochemical bone turnover markers of bone metabolism may be helpful in assessing both bone formation and resorption, and may provide useful information on myeloma disease activity in bone. Bone turnover markers have also been used for the early diagnosis of bone lesions, for evaluating the extent of myeloma bone disease, and to measure response to anti-myeloma therapies. However, there has been no consensus for the use of bone turnover markers in myeloma. The recent IMWG report, published in *Leukemia*, summarizes the current data for the use of markers of bone remodeling to assess the extent of myeloma bone disease and to monitor bone turnover during anti-myeloma treatment, proposes markers that may have a role in caring for patients with



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myeloma, and presents novel markers that may be of interest in the future.

Is there a correlation between myeloma bone disease and the myeloma itself?

It does not appear that the myeloma cells are the direct cause of bone loss, but they affect the bone cells that, in turn, cause the bone loss. In general, patients who have more extensive myeloma tend to have more bone damage. Approximately 85-90% of myeloma patients have some sort of lytic (destructive) bone disease as a complication of their myeloma. The majority of myeloma patients have bone lesions that result in skeletal-related events (SREs).

It is also known that patients with MGUS, even those who never progress to myeloma, are at a higher risk for osteoporotic fractures than individuals who do not have MGUS. I think it is reasonable for MGUS patients to have their baseline bone mineral density determined.

Patients with MGUS or myeloma may experience fractures, radiation or surgery to bone, spinal cord

compression, and hypercalcemia (elevated calcium levels in the blood). Bone lesions rarely heal even in those myeloma patients who have achieved a complete remission (CR). Without therapy for their bone disease, more than half of myeloma patients with stage III disease will experience at least one SRE over the span of two years. On average, patients who do not have myeloma bone disease have a better prognosis than those who do.

Please give us some examples of bone markers and their use in myeloma.

Bone markers help assess bone turnover. In myeloma the bone resorption markers are more useful than the bone formation markers in assessing bone disease, and they have also been shown to correlate with stage of myeloma. The bone resorption markers that appear to be more useful in myeloma include urinary NTX, serum CTX, and serum ICTP. In my practice, I frequently use the serum CTX marker with myeloma patients because it's a simple blood test done fasting in the morning, and it gives me a some sense of whether the disease is active or not, especially if I track the patient over an extended time.

What about anti-resorptive therapy?

Biochemical bone turnover markers have been used in studies of myeloma patients to monitor response to bisphosphonate therapy, and in studies aimed at determining those patients who would most benefit from bisphosphonate therapy to decrease bone resorption. Data from such studies demonstrate that while the majority of patients have a good clinical response to bisphosphonate therapy and decrease their bone resorption markers, there are some myeloma patients who do not respond to, or who stop responding to bisphosphonate therapy over time.

How would you assess the risk of ONJ?

With improved recognition of osteonecrosis of the jaw (ONJ), and improved dental care, the risk of developing ONJ has significantly decreased. The rate of ONJ is currently about 2-4%. In addition to our heightened awareness and improved dental care efforts up front, we look forward to studies aimed at determining if decreased cumulative bisphosphonate

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CLINICAL TRIALS IN MULTIPLE MYELOMA

Myeloma Today in conversation with Dr. Joseph Mikhael

Please tell us about your medical background and current affiliations.

I graduated from medical school at the University of Ottawa in Canada. My internal medicine residency at the Ottawa General Hospital was followed by hematology training in Toronto, along with a masters' degree in education at the University of Toronto - Ontario Institute for Studies in Education (OISE). In 2004, I completed a two-year multiple myeloma fellowship at Princess Margaret Hospital in Toronto, primarily under the guidance of Dr. Keith Stewart. From 2004 until starting at Mayo Clinic in January 2008, I was a staff hematologist and education coordinator for hematology at Princess Margaret Hospital.

I am a consultant hematologist at the Mayo Clinic in Scottsdale, Arizona. I specialize in plasma cell disorders: myeloma, amyloidosis, and Waldenstrom's macroglobulinemia. I am currently the principal investigator (PI) of many clinical trials, primarily in relapsed myeloma. My clinical research interests also include the transformation of MGUS to myeloma, pharmaco-economics, and supportive care in cancer. I am currently the PI of the prECOG study evaluating the use of lenalidomide (Revlimid®) in patients with renal insufficiency.

In addition, I continue to be heavily involved in education. I am an assistant professor at the Mayo College of Medicine, the Vice-Chair of Education for the division of Hematology-Oncology, the program director of the Hematology-Oncology Fellowship Training Program, and the Vice-Chair of the Graduate Education Committee at Mayo Clinic (Arizona).

How did you develop an interest in myeloma?

I was influenced by my mentor, Dr. Stewart, and I was fascinated by the complexity of this disease and by how much better we could make our patients with the novel therapies, which is what got me interested in myeloma research.

Do you work both in the clinic and in the lab?

One of the benefits of working at Mayo Clinic (Arizona) is that we have three of the best myeloma researchers – Keith Stewart, Rafael Fonseca, and Leif Bergsagel. With them in the lab, I am able to split my time between clinical research and clinical practice, as well as continue my work in education. My research work in myeloma is all clinical, be it therapeutic trials or supportive care. I follow up on what Drs. Stewart, Fonseca, and Bergsagel do in the lab. My role in the bench-to-bedside paradigm is to help bring some of what they learn in the lab into the clinic setting.

What is your approach to myeloma research?

It is a three-step process. A better understanding of myeloma leads to better drugs for this disease, which leads to better survival for patients. This requires getting samples from patients and having a sophisticated mouse model, which we have at Mayo. We can give mice myeloma, then test new drugs or test blood levels to gain knowledge about how this disease changes over a rapid period of time. This enables us to understand the pathways of the disease, so that drugs can be developed to counteract those pathways. When a new drug is developed, my role is to design clinical trials for the specific group of myeloma patients who are most likely



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to benefit from that particular drug. If the drug is shown to be effective, we hope that in the long run it will also be shown to improve patient survival.

What is your assessment of the current range of myeloma therapies?

There has been a major shift in the field of myeloma. Not long ago, a doctor might have said, "My standard treatment for myeloma is X." We had very few bullets for the gun, and when the bullets ran out, they ran out. Doctors now have an arsenal of weapons to help patients fight myeloma. The reason for this is the research that has allowed us to understand myeloma on a molecular level.

How does one select the best treatment?

There are several factors to be considered, both for the disease and for the patient. We have learned that there are as many as six types of myeloma. To keep things simple, I'll break it down into the three major groups: standard-risk, intermediate-risk, and high-risk disease. We treat patients differently depending

on which risk group their disease belongs to. We also consider several patient factors. Does the myeloma patient have kidney or other organ involvement? Does the patient live far away from a medical facility and, therefore, prefer an oral therapy to an intravenous one? Does the patient have specific symptoms that may eliminate some treatment options while pointing us in a different direction? We individualize the treatment based both on myeloma features and patient features.

What new treatments might become available for myeloma in the near future?

I would separate those into two categories: promising new versions of the older drugs as well as completely new mechanisms of drugs. Both of those development pipelines are very deep. Currently, the three major anti-myeloma drugs on the market are thalidomide and lenalidomide, which belong to the same drug family, and bortezomib (Velcade®). In both drug families, there are new drugs being developed.

The next-generation drug in the thalidomide and lenalidomide family that's showing a lot of promise is pomalidomide, which seems to be very well tolerated and is not associated with peripheral neuropathy (PN). It is soon to begin phase III clinical trials. Similarly, there are several next-generation proteasome inhibitors being developed. The front-runner seems to be carfilzomib, which is already under phase III investigation. In the US, it is likely to be the next drug to receive FDA approval for myeloma. The other drugs in the bortezomib family that are being developed for myeloma are either not associated with PN, can be given less frequently, or are administered orally. So the outlook in this category is very promising. In addition, there may be as many as 20 drugs being developed that are completely new to myeloma but could become a big part of what we will be able to offer patients in the near future.

Currently, drug development is less about directly attacking the plasma cell (the key cell in myeloma) and more about interrupting the bone marrow microenvironment. We know that in myeloma the communication between the cells and their environment is very sophisticated, so we are trying to make it harder for the myeloma cells to thrive.

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GASPARETTO / TRANSPLANTATION — continued from page 7

renewed the interest in allo-SCT as a treatment option for myeloma. However, no definite conclusions could be drawn as to whether allo-RIC was even of benefit. Future studies of allo-SCT in myeloma should aim at improving the graft-versus-myeloma (GVM) effect while reducing the morbidity and mortality of allo-SCT.

DRAKE / BONE DISEASE — continued from page 8

phonate dosing and decreased dosing frequency will further decrease the incidence of ONJ.

What about denosumab, a bisphosphonate currently in clinical trials?

Denosumab is a potent new osteoclast inhibitor. It targets the same cells but uses a completely different mechanism of action than the bisphosphonates Zometa® (zoledronic acid) and Aredia® (pamidronate). It has a much shorter duration of action, staying in the bones approximately 3-6 months, not 5-10 years like we believe some other bisphosphonates do. Also, it does not seem to have an adverse effect on renal function. In a recent study of 1776 patients with solid tumors or myeloma who had not previously received intravenous bisphosphonates, those who were randomized to receive 120 mg of subcutaneous denosumab attained results similar to the patients who received intravenous zoledronic acid every 4 weeks. Denosumab also reduced urinary NTX levels by more than 80% within the first month. However, in the subgroup of patients with myeloma (approximately 10% of the total study population), denosumab was associated with significantly worse survival. As a result, the FDA did not approve the drug for treatment in myeloma. Further studies are needed to evaluate the safety and efficacy of denosumab in myeloma.

What is the effect of novel anti-myeloma agents on bone markers?

The effect of novel drugs – thalidomide (Thalomid®), lenalidomide (Revlimid®), and bortezomib (Velcade®) – on bone metabolism in

Any closing comments?

The survival of patients with myeloma has improved significantly over the past decade. Not only are many patients living longer, but many also have good quality of life. The overall outlook is encouraging, and it continues to improve. **MT**

myeloma has been evaluated in several studies. The available data indicate that immunomodulatory drugs have more effect on osteoclast activity than on osteoblast activity. Two clinical phase II trials have studied the effect of thalidomide on bone metabolism in myeloma. One study of relapsed/refractory patients showed that after six months of therapy with thalidomide plus dexamethasone (TD) there was a significant reduction of serum levels of some bone markers. The other study of newly diagnosed myeloma patients showed that the combination of TD and zoledronic acid (Zometa®) for four months produced a significant reduction of urinary NTX and serum CTX in patients who responded to therapy. There is limited data on the effects of lenalidomide on myeloma bone disease. Studies have shown that bortezomib may decrease bone resorption and increase bone formation, but data suggest that the beneficial effect of bortezomib may be reduced when it is combined with other anti-myeloma agents.

What do you anticipate in your field in the near future?

Better understanding bone disease and the bone marrow microenvironment, the area within the bone where myeloma cells grow, is crucial to controlling and/or curing myeloma. Clinical trials are needed before biochemical markers of bone remodeling become part of the routine clinical care of myeloma patients. There are ongoing studies with breast cancer patients and in patients with other forms of cancer and bone metastases, and trials in myeloma are anticipated in the future. **MT**

MIKHAEL / CLINICAL TRIALS — continued from page 9

Also, it is important to remember that we are not looking for one silver bullet. We are learning to combine drugs, old and new, to increase efficacy and lessen toxicity. This approach also helps us counter drug resistance. There is such a complex nature to the growth and development of myeloma that we have not been able to shut it down with a single drug. One patient might have more than one type of myeloma growing in them simultaneously, and a strategic combination approach appears to be most successful at limiting the disease. Some of these therapies are only available in the context of a clinical trial.

So who is the best candidate for entering a clinical trial?

Clinical trials are available to patients at all stages of myeloma, and we encourage all patients to consider participating if there is one available to them. There is no down side. Clinical trials are not using people as guinea pigs. Clinical trials are providing patients an opportunity to be treated with either a validated therapy or a therapy that's undergoing validation. Patients always have the option to opt for standard therapy later on. Of course, as with all other important decisions, it is very important to have clear and honest discussions with the healthcare provider and the team running the trial.

Any closing comments?

Our management of myeloma – the ability to diagnose, treat, and monitor

this disease – has improved tremendously. We can now detect the disease at a much lower level than ever before, both at initial diagnosis and at relapse, and we can run tests that help us stratify the patients. The use of newer drugs and drug combinations is resulting in longer and deeper remissions for many patients. Another important point is that supportive care continues to get better. We don't just treat the myeloma, we are continuing to get better at treating the whole patient.

I consider myself an optimistic realist and, overall, the future looks very optimistic. Although myeloma is still not curable, we have seen a tripling in the average patient survival rates. Dramatic progress has been made in the field in the last decade, and our understanding of myeloma has improved significantly in the last three years. But our successes notwithstanding, we all share a very strong drive to find better and longer-lasting therapies.

In the meantime, I would stress the importance of myeloma patient education. This is a very complex disease, and knowledge IS power. While scientists and clinicians seek to better understand the disease and to develop better treatments, I would encourage all patients to take a participatory role in their own care in partnership with their healthcare providers. **MT**

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 Nancy Baxter, Debbie Birns, Paul Hewitt, and Missy Klepetar. The phone lines are open Monday through Friday, 9AM to 4PM (Pacific Time). To submit your question online, please email TheIMF@myeloma.org

I have read several articles about vitamin D supplementation. As a multiple myeloma patient, I am curious if vitamin D deficiency plays a role in myeloma?

Vitamin D is a hormone produced by the skin when it is exposed to ultraviolet B radiation from sunlight. It can also be ingested from dietary sources (vitamin D-fortified dairy products, fatty fish, eggs, and meat) and oral supplements. Vitamin D is essential for the metabolism of calcium and for skeletal health.

According to studies published in the Archives of Internal Medicine in 2007 and the Journal of the American Geriatric Society in 2009, higher vitamin D levels have also been associated with increased longevity.

People at risk for vitamin D deficiency include those who have inadequate sun exposure, inadequate dietary intake, severe liver disease, kidney problems, or malabsorption because of one of a number of gastrointestinal issues. Certain antiepileptic medications can also cause low levels of vitamin D. The Centers for Disease Control reports that the percentage of Caucasian adults who have adequate levels of vitamin D declined to approximately 30% in 2001-2004. During the same period, only 5% of African-Americans had sufficient levels of vitamin D.

Vitamin D deficiency has played a prominent role in the medical press of late, and has been linked to a host of illnesses including colon, breast, and prostate cancer, vascular disease, infectious conditions, autoimmune diseases, osteoporosis, type 2 diabetes, obesity, and cognitive decline. Not surprisingly, vitamin D deficiency also plays a role in the clinical presentation and prognosis of myeloma.

In the March 2009 article in the American Journal of Hematology entitled "Impact of vitamin D deficiency on the clinical presentation and prognosis of patients with newly diagnosed multiple myeloma," Drs. Ng, Kumar, Rajkumar, and Drake of the Mayo Clinic report on 148 newly diagnosed patients whose vitamin D levels were tested within 14 days of diagnosis. They found that ISS (International Staging System) stage increased in parallel with vitamin D deficiency, suggesting that vitamin D deficiency "may portend poorer outcomes in subjects with MM." Vitamin D deficiency occurred in 16% of patients with stage I, 20% of patients with stage II, and 37% of patients with stage III myeloma.

Patients who were vitamin D deficient had higher levels of C-reactive protein (CRP), a marker of systemic inflammation, and of creatinine, a marker of kidney dysfunction. High levels of both CRP and creatinine in newly diagnosed myeloma patients have been shown to predict poorer outcome and survival. Contrary to their original hypothesis, however, the researchers did not find that lower levels of vitamin D correlated with skeletal morbidity (increased lytic lesions, long bone fractures, or vertebral compression fractures) at the time of diagnosis. This finding does not, however, preclude the possibility that low levels of vitamin D may play a role in the subsequent development of new skeletal lesions or in the progression of bone disease following diagnosis.

The Mayo authors conclude by asserting the need for larger population-based studies to confirm their research and more fully assess the role of vitamin D deficiency in disease progression, overall survival, and quality of life in



patients with newly diagnosed myeloma.

At the Los Angeles IMF Patient & Family Seminar in August 2010, Dr. Robert Kyle stated that all myeloma patients should have their calcium and vitamin D levels checked. Population reference ranges for vitamin D vary widely depending on ethnic background, age, geographic location, and season, so they cannot be given as a blanket statement. Kennel et al at Mayo make the following recommendations:

- Measurement of the total 25(OH)D level is the preferred means of assessing vitamin D stores in the body.
- Adequate vitamin D intake cannot be maintained by diet alone; vitamin D supplementation is safe and inexpensive. Revised dietary reference intakes from the Institute of Medicine are in process.
- Supplementation should be with vitamin D3 in general, but vegans and vegetarians will better absorb vitamin D2.
- If a patient is severely vitamin D deficient, a "loading dose" of 50,000 IU of vitamin D orally once weekly for 2-3 months, or 3 times weekly for 1 month, may be necessary. For mild to moderate deficiency, a shorter treatment interval or lower dose may be effective.
- Regardless of initial vitamin D therapy, a maintenance/prevention dose of 800-2,000 IU daily will be needed to avoid recurrent deficiency.
- Both vitamin D3 and vitamin D2 should be taken with a meal containing fat to ensure maximum absorption.

In addition to the above recommendations, Dr. Brian Durie of the IMF urges follow-up testing of vitamin D levels to ensure adequate supplementation and absorption, particularly at the time of relapse. If the hematologist/oncologist who treats you is in doubt about assessing and maintaining adequate levels of vitamin D, Dr. Durie stresses the need for a referral to an endocrinologist who deals with bone issues to evaluate your situation and make recommendations.

Myeloma patients should be closely monitored throughout the course of their treatment, not only for levels of M-protein and blood counts, but also for levels of serum calcium and serum creatinine, both closely related to vitamin D levels. These tests should be routinely performed as components of the metabolic panel. It is important to note that the United States Department of Agriculture (USDA) table of Dietary Reference Intakes states that "patients on glucocorticoid therapy may require additional vitamin D." Glucocorticoids, of course, include such medications as dexamethasone, prednisone, and methylprednisolone, common components of myeloma treatment.

Until further research is done on vitamin D levels in myeloma patients, we cannot automatically make the assumption that patients' outcomes will improve if they achieve a normal level of vitamin D. What we do know, however, is that vitamin D deficiency is linked to more advanced stage at diagnosis (portending poorer outcome), and to a host of other health problems. Maintaining adequate levels of vitamin D is thus an important new aspect of myeloma care.

As always, we urge you to discuss this and all other medical issues thoroughly with your doctor, and to call the IMF Hotline, 800-452-CURE (2873), for help with your questions. . **MT**

HOPE, STRESS, MYELOMA & THE HOLIDAYS

Myeloma Today in conversation with Greg Pacini, MS, LPC, CGP

On November 19, 2010, the IMF held a teleconference on Hope, Stress, Myeloma & the Holidays. The event, which was part of the IMF's quarterly Living Well with Myeloma conference call series, was moderated by Susie Novis, IMF President. This was the final installment of the call series for 2010, and featured guest speaker Greg Pacini. Greg has been a friend of the IMF for many years. He holds a master's degree in guidance and counseling, and is a Licensed Professional Counselor and Certified Group Psychotherapist with more than 30 years experience, including 20 years focused on support of the chronically and terminally ill, their caregivers, and the medical professionals who serve them. Greg is in private practice in St. Louis, MO, and speaks locally and nationally. Greg's book, Journey Beyond Diagnosis, takes a compassionate look at the vast landscape of an illness experience, offering assistance to survivors, caregivers, and medical professionals alike.



Greg Pacini, MS, LPC, CGP

In your professional opinion, what are the biggest holiday stress factors for myeloma patients and their loved ones?

It could be something small. It could be something more significant like whether you have the strength to do the things you wish this holiday season. It could be a physical issue or how you feel emotionally, something with relationships or even financial. Let's start by talking about the difference between stress and stressors, suffering and pain, and about discomfort in general. As we do that, we'll focus on hope.

A stressor is an event in the physical world that has the potential to stress us. Stressors trigger reactions within us, usually accompanied by uncomfortable thoughts or feelings, which can affect our behavior. We are constantly exposed to stressors, but whether or not we become uncomfortable is based on our response. What is stress for one person may not be for another. For example, one might react to a snow storm by saying, "Look, it's snowing! It makes me feel peaceful." and another might say, "It's snowing, and I hate it because it's going to take me 45 minutes longer to drive home." The stressor is the snow, but one person experiences peace while another experiences the discomfort of stress.

How do you define the difference between emotional pain and suffering?

Pain is a part of the human experience. It can be physical, emotional, mental, or spiritual. The pain you feel from a medical treatment or from witnessing a loved one in pain is real and it's happening in the moment. Suffering comes from a thought like, "I'll probably feel as bad at New Year's as I did at Thanksgiving." Suffering is thinking about pain that might happen or has happened. Suffering is optional.

How do we manage difficult feelings during the holidays?

We have an absolute right to whatever we feel. Emotions are neither right nor wrong. Honoring our difficult emotions is as important as those that feel good. Feelings are simply guideposts. With practice, we can shift emotions to feel something different, if only for a moment. We can learn to master our emotions instead of allowing them to master us.

The first thing to do in dealing with any emotion is to Acknowledge it: "I'm sad. I'm scared. I'm angry." The second step is to Accept it. If you are in remission and the tests are good, but you still feel anxious, say to

yourself, "It's reasonable that I feel this way." When we accept what we feel, we stop struggling within ourselves. We then move forward more naturally with right Action.

We can regulate our emotional discomfort. For example, we can use doorways as cues. Walk into the kitchen, and notice how you feel. Get into the car, and notice what you're thinking. Walk into the doctor's office, and notice your reaction. If you are not in physical pain but find yourself in discomfort, I invite you to shift out of that. If you have ever felt hope, strength, love, or joy, you are clearly capable of them. Those emotions are simply not being accessed now.

How does one transition from fear to hope?

I like to quote the writer Lu Xun, "Hope is like a path in the countryside: originally there was no path -- yet, as people are walking all the time in the same spot, a way appears." Neuroscientists tell us that the brain acts exactly this way. When we persist in a

particular set of thoughts or feelings, the brain creates neuropaths to support those thoughts or feelings. If we frequently entertain thoughts that are hopeful, the mind creates a network of nerve cells to support those thoughts and feelings and, pretty soon, there's a path there of hope or of joy or of love.

Now, what I'm learning about how this works at the cellular level, is that when we feel fearful or angry or sad, neuropeptides associated with those emotions are released, landing on the cells and leaving less space for neuropeptides related to hope. This explains why, if you've been sad for a long time, it's difficult to start feeling hopeful. On the other hand, if we begin to experience hope, the cell says, "We've got to start making room for hope." The more we make room for hope, the less space there is for the neuropeptides associated with sadness. It takes awareness and practice, but this is something we can regulate. The more we practice it, the easier it becomes to experience emotions that feel better.

One teleconference participant asked about referring to her disease as "my myeloma." What are your thoughts on "owning" the disease?

There's nothing wrong with referring to it as "my myeloma" if your body contains it. But I don't know that your spirit or your thoughts or your emotions have to. There's information available about using visualization to release illness, and some people have had good results with visualizing their body without disease. The body responds to our thoughts, which in a sense, are visualizations. It's probably more useful to say "I have an illness." Between you and me, and the quietness of your own spirit, consider thinking, "I am releasing this illness."

Another caller asked about her guilt associated with having trouble orchestrating the perfect holidays.

You can attempt to influence the situation. Let people know in advance that you're going through a difficult time and how important it is for you to enjoy the holidays together. "Let's make a choice. We can talk about the sad stuff or we can put that on hold. We can laugh, hold each other, and make this a special time." It's not about not feeling, it's about choosing.

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Nurse Leadership Board

REPORT FROM NLB VI

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The IMF Nurse Leadership Board (NLB) was founded as a partnership with multiple myeloma nurses to gain insights into their unmet needs and to address them and those of their patients by accomplishing the following objectives:

- Provide insights into the needs of myeloma nurses and their patients.
- Identify and implement key nurse and patient education programs.
- Facilitate information flow between the IMF, oncology nursing organizations, and patients.

The NLB, which is made up of experienced specialty oncology nurses, published the first comprehensive guidelines – *Managing the Side Effects of Novel Agents for Multiple Myeloma* – for nurses who work with myeloma patients receiving thalidomide, lenalidomide (Revlimid®), and/or bortezomib (Velcade®) therapy. The NLB consensus guidelines, published in the June 2008 as a supplement to the *Clinical Journal of Oncology Nursing*, with 70,000 prints in circulation, continue to be immeasurably valuable to the general nursing community involved in myeloma care.

The NLB is currently completing work on the Survivorship Care Plan, their second major paper. Publication is projected for the second quarter of 2011. The Survivorship Care Plan will cover the key topics of renal complications, sexuality and sexual dysfunction, bone disease and bone health, functional mobility and safety, and health maintenance. This project was initiated at NLB III, a prior assembly of the NLB membership. On November 6, 2010, the NLB gathered in Jersey City, NJ, for the sixth meeting of the full membership – NLB VI. This occasion also marked the fourth anniversary of the Board's inaugural meeting in November 2006.

NLB members Elizabeth Bilotti, RN, MSN, APRN, BC (John Theurer Cancer Center at HUMC), Teresa Miceli, RN, BSN, OCN (Mayo Clinic – Rochester), and Joseph Tariman, PhD, MN, APRN, BC (Northwestern University) served as NLB VI Faculty Facilitators.

After an early breakfast, the meeting was convened at 8:30 a.m. with welcome remarks by Diane Moran, RN, MA, EdM (Sr. Vice President, Strategic Planning, IMF). Diane continued with an overview and update of IMF program and initiatives. This was followed by a review and update of activities and developments by NLB and its members in 2010:

- Authored the FIRST myeloma textbook for nurses, with Joseph D. Tariman as editor. Published by the ONS, the textbook is being extremely well received.



At NLB VI, nurses celebrate the 4th anniversary of the founding of the IMF Nurse Leadership Board

- Participated as faculty at the annual Oncology Nursing Society (ONS) meeting.
- Presented at a meeting by IMF-Japan.
- Presented at a meeting of the Canadian Association of Nurses in Oncology.
- Conducted patient focus groups for IMF.
- Conducted a series of accredited nurse education teleconferences/webinars.
- Conducted educational teleconference during Myeloma Awareness Week.
- Worked with elected government officials on oral drug parity and access issues.
- Presented on various patient education topics as speakers at twelve IMF myeloma support group conference calls.
- Presented at four IMF Patient & Family Seminars.
- Participated in ten IMF Regional Community Workshops.
- Developed and conducted myeloma patient advisory boards.

After an impressive recap, the group moved forward with its NLB VI agenda. The meeting's first presentation was made by Elizabeth Bilotti, who addressed the development of an interactive web-based Survivorship Care Plan Tool to help patients, caregivers, and healthcare practitioners improve symptom management, decrease patient distress, and enhance patient quality of life. Next, Joseph Tariman spoke about clinical trials that are shaping the future landscape of myeloma therapy.

After a break, Teresa Miceli presented the guidelines for optimal management of transplant patients. Next, Joseph Tariman talked about the structure and scope of a projected nurse-led clinical research study – a clinical trial that will focus on a common disease-related issue. The morning session concluded with a scientific update of myeloma presented by IMF Chairman Dr. Brian G.M. Durie, whose insightful talks are always an essential aspect of NLB gatherings. Dr. Durie discussed cutting-edge diagnostic testing for myeloma

CONTINUES ON PAGE 15

UPDATES FROM AROUND THE GLOBE

Myeloma initiatives in Japan

IMF-Japan carries out an extensive program of work on behalf of myeloma patients in Japan, including regional and national seminars, intervention with health care authorities regarding risk assessment and access to treatment, provision of myeloma publications, an extensive website, and the issuance of research grants.

On October 31, IMF-Japan hosted an extremely successful patient and family seminar in Fukuoka, the capital city on Kyūshū Island in southern Japan. The event was attended by more than 200 myeloma patients and family members. The IMF leadership was delighted to be able to assist in this event.



Masahiro Fukuda, Dr. Brian GM Durie, Dan Navid, (seated) Midori Horinouchi, Susie Novis, Kyoko Joko



IMF President Susie Novis assisted in the seminar via an innovative "Talk Show" session, being interviewed by IMF-Japan Vice President Kyoko Joko about her personal experience and about the role of caregivers. IMF Chairman Dr. Brian Durie joined in an expert

panel and delivered a lecture about innovations in myeloma management. International Myeloma Working Group (IMWG) member Dr. Hiroyuki Hata presented an introductory talk on myeloma and treatment options.

New treatment options are now becoming increasingly available in Japan. As part of the IMF Asia Program, work is being pursued with commercial partners in Japan to publicize and promote these new treatment options, as well as to develop educational programs for Japanese physicians in order to enhance application of these treatments.



The convening of the biannual International Myeloma Workshop (IMW) in Kyoto in 2013 will provide an excellent focus for this expanded effort in Japan and throughout the Asian region.

Editor's Note: For more information, please contact Dan Navid at dnavid@myeloma.org or +41-21-825-5546, or Kyoko Joko at BZR13060@nifty.ne.jp.

IMF-Japan annual seminar in Toyama

The 2010 IMF-Japan annual seminar on myeloma was held at Toyama International Conference Center in Toyama City, on November 21. More than 150 patients and family members from all over Japan attended the educational meeting. Seminar presentations included a lecture by Dr. Shinsuke Iida on the fundamentals of myeloma, talks from the two 2011 Aki Award research grant recipients Drs. Hiroshi Yasui and Yusuke Furukawa, and breakout sessions by Dr. Chihiro Shimazaki and Dr. Akiyoshi Miwa. As a special gift to the medical professionals, patients and caregivers expressed their thanks in letters decoratively arranged on a board as petals of tulips, the popular product of Toyama prefecture. All participants look forward to getting together again at the 2011 IMF-Japan annual seminar in Tokyo.



IMF co-sponsored activities in Germany

IMF Scientific Advisor Dr. Bart Barlogie (Little Rock, AR, USA) is heading several patient and doctor meetings in Germany, co-sponsored by the IMF in December 2010. IMF Scientific Advisor Dr. Hermann Einsele (Würzburg University Clinic, Würzburg) is hosting Dr. Barlogie and Dr. Niklas Zojer (Wilhelminenhospital, Vienna, Austria) for an Interactive Patient Seminar on December 18. Two days prior to that, Dr. Barlogie will be hosted by the Stuttgart Myeloma Support Group and Dr. Hans-Günther Mergenthaler (Karolinenhospital, Stuttgart) at a meeting for both patients and doctors. In addition, Dr. Barlogie will make presentations for colleagues at the Heidelberg University Clinic in Berlin, and the Münster University Clinic. Dr. Barlogie studied medicine in Heidelberg and completed his residency in Münster.



Dr. Bart Barlogie

Earlier this year, the IMF co-sponsored four patient meetings in Germany. Two were held in Berlin and co-sponsored by Elke Schutkowski of the Berlin Myeloma Support Group. On May 9, Dr. Igor-Wolfgang Blau of the Benjamin Franklin campus of Berlin Charité hosted Drs. Einsele, IMF Scientific Advisor Dr. Hartmut Goldschmidt (Heidelberg University Clinic) and Hans Salvender (Hamburg-Altona Asklepios Clinic) for a full day of lectures and discussion. On September 5, Dr. Christian Jakob (St. Hedwig Clinic, Berlin) hosted IMF Scientific Advisor Dr. Orhan Sezer (Hamburg-Eppendorf University Clinic) and Dr. Martin Kropff (Münster University Clinic).



Dr. Hermann Einsele, Paul Becker, Dr. Ralph Naumann, Dr. Hartmut Goldschmidt, Gregor Brozeit, Dr. Robert Weide, and Harald Eberwein in Koblenz

The latest news and

International Affiliates

UPDATES FROM AROUND THE GLOBE — continued from page 14



Dr. Harmut Goldschmidt engages in group discussion at the Koblenz patient meeting

studies from the annual European Hematology Association (EHA) congress were highlighted at a patient meeting in Koblenz on June 13. Coming just a day after the end of the EHA congress, Dr. Ralph Naumann of Koblenz hosted Drs. Einsele and Goldschmidt as well as Dr. Robert Weide

of Koblenz. The Koblenz Myeloma Patient Support Group leaders Paul Becker and Harald Eberwein co-sponsored the meeting.

Albrecht Reissman, founder and leader of the Leipzig Myeloma Support Group and Dr. Dietger Niederwieser (Leipzig University Clinic) organized a patient meeting



Leipzig Support Group Founder Albrecht Reissman moderates questions at the Leipzig patient meeting



on June 19. In addition to Dr. Niederwieser, Dr. Wolfram Pönisch, a member of the Leipzig faculty who spearheaded many of the key studies on bendamustine, also spoke.

Dr. Dietger Niederwieser at the Leipzig patient meeting



Drs. Salvender and Blau speak to patients and caregivers in Berlin



Dr. Martin Kropff addresses Berlin patients and caregivers



Dr. Christian Jakob and Dr. Orhan Sezer take questions from the audience

Editor's Note: The IMF plans another full slate of meetings in Germany for 2011. For more information, please contact Gregor Brozeit at greg.brozeit@sbcglobal.net.

PACINI / HOPE, STRESS, HOLIDAYS — continued from page 12

You talk about the Type C personality. Would you explain this to our readers?

Everyone has heard about Type A and Type B personalities. Some researchers suggest that there is also a Type C personality, and I've seen this in my own work. The Type C personality tends to put everybody else first and has a hard time honoring their own needs and asking for help. We need to love ourselves first. Being self-loving is not the same as being selfish. When we give to others without attending to our own needs, a level of resentment may build up that can have numerous consequences, including taking a toll on our bodies. When we come forward with our needs, people may rally to us in ways that we didn't expect. And when our needs are being met, service to others flows without effort.

Any closing comments?

I wish your readers well, and I hope that the concepts I've shared will help support them through the holidays and beyond. **MT**

NLB — continued from page 13

and evaluated new anti-myeloma therapies that might be forthcoming in the near future.

After lunch, NLB participants separated into several breakout sessions. When the membership reassembled, Diane Moran and Taskforce Team Leaders reviewed the future goals of NLB's standing taskforces. More breakout sessions followed, this time dedicated to taskforce planning. The fast-paced changes in the myeloma field require frequent updating of the existing NLB educational materials, both for nurse and patient audiences. Currently, consideration is also being given to developing a new slide deck specifically for nurse practitioners. After a brief recap of Day 1 activities, the meeting was adjourned until the next day.

Day 2 started with a question and answer session about the prior day's activities. After breakout sessions to discuss NLB project initiatives, Team Leaders reported on progress to the fully assembled participants. Standing Status was reported by Taskforce Leaders and, after final remarks by Diane Moran about NLB VI accomplishments and future steps, the very productive meeting came to a close. **MT**

SPOTLIGHT ON ADVOCACY



By Christine Murphy

Wrap up of IMF advocacy priorities

Below is a summary of some of the legislative issues the IMF followed in 2010. As you can see, we were successful on many important issues, such as ensuring access to clinical trials and declaring September Blood Cancer Awareness Month. Over 3,000 messages were sent to Congress this year from myeloma advocates. Your commitment to the mission helped to

ensure our success on many legislative issues in 2010 and IMF thanks you for all of your efforts on behalf of myeloma patients.

September designated as Blood Cancer Awareness Month

Representatives Walther Jones (R-NC) and Betsy Markey (D-CO) sponsored a resolution (H. Res. 1433) designating September 2010 as Blood Cancer Awareness Month. H. Res. 1433 highlighted the impact that the blood cancers have in the United States each year and encouraged greater support for blood cancer research and education. Because of the efforts of IMF advocates, we met our goal of obtaining at least 100 cosponsors to ensure that the resolution moved through the legislative process and ultimately passed the House.

President signs Improving Access to Clinical Trials Act

On October 5th, the President signed the Improving Access to Clinical Trials Act (HR 2866/S 1674) into law. This important legislation changes the eligibility requirements for Supplemental Security Income (SSI) and Medicaid so that compensation of up to \$2,000 for participating in clinical trials won't be considered income in SSI and Medicaid determinations.

Health insurance reform signed into law

The Patient Protection and Affordable Care Act transforms significant portions of the health care environment. Below are the provisions that will improve the quality of life for all myeloma patients.

1. Access to Clinical Trials - Health insurance plans are required to provide coverage for routine costs associated with participation in clinical trials. This was a huge win for myeloma patients as many patients have had to decline participation in trials due to plans refusing to pay for the same costs they would reimburse for a patient that is going through non-clinical trial treatment.

2. Eliminates the Medicare "donut hole" - The bill provides a \$250 rebate to Medicare beneficiaries who reach the Part D coverage gap in 2010. The beneficiary coinsurance rate in the Medicare Part D coverage gap is gradually phased down from 100% to 25% by 2020. For brand-name drugs, pharmaceutical manufacturers will provide a 50% discount on prescriptions filled in the Medicare Part D coverage gap beginning in 2011, in addition to federal subsidies of 25% of the brand-name drug cost by 2020 (phased in beginning in 2013). For generic drugs, manufacturers will provide federal subsidies of 75% of the generic drug cost by 2020 for prescriptions filled in the Medicare Part D coverage gap (phased in beginning in 2011). Finally, the bill will reduce the out-of-pocket amount that qualifies an enrollee for catastrophic coverage.

3. Eliminates Annual and Lifetime Caps on Insurance Coverage - Lifetime limits are eliminated in all health insurance. Annual limits are restricted in new plans until 2014, after which they would be prohibited in all health insurance plans.

4. Eliminates "Pre-Existing Conditions" as a Barrier to Health Insurance - This year children with pre-existing conditions can no longer be denied health insurance coverage. Beginning in 2014, pre-existing condition discrimination will become a thing of the past for everyone with health

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

Introducing the all NEW A.C.E. training program!

The IMF's new and improved **A.C.E.** training program – Advocates for Cancer policy Education – is designed for everyone. Choose an activity level that matches your personality and schedule. Learn when to act, what to say, who to contact, why it's important, and how to go about making a difference. The IMF Advocacy Team will provide you with the tools and preparation you need to help fight for issues that affect YOU and the myeloma community.

To find out how you can become an A.C.E. Advocate and to learn about the advocate levels, please visit our new A.C.E. webpage by clicking the Advocacy tab at www.myeloma.org.

Take the first step and sign up NOW for the Myeloma Action Network to stay informed of critical issues affecting the myeloma community. Visit www.advocacy.myeloma.org



Level 1:
Grassroots Guru



Level 2:
Meeting Master



Level 3:
All-Star Advocate

insurance including myeloma patients. Additionally, adults who are uninsured because of pre-existing conditions now have access to affordable insurance through a temporary subsidized high-risk pool.

The IMF honored in the congressional record

Representative Brian Higgins (D-NY) honored the work of the IMF and raised awareness of multiple myeloma through his statement in the May 25th edition of the Congressional Record. Representative Higgins stated what myeloma is, who is affected, and its prevalence in the statement. He recognized the IMF for its dedication to improving the quality of life for patients and caregivers while working toward prevention and cure for myeloma. He also noted his bill, the Cancer Drug Coverage Parity Act (HR 2366), which eliminates disparities for cancer patients whose insurance coverage has differences in the way oral and intravenous chemotherapy therapies are covered. The IMF has been proactively involved in helping to fight for this legislation.

Final FY 2011 cancer funding on hold until after 2010 elections

At the time of writing this article, fiscal year (FY) 2011 funding for cancer programs has not yet been finalized. A Continuing Resolution (CR) that allows the federal government to continue functioning, largely at current spending levels, is in effect until lawmakers rejoin the battle over FY 2011 appropriations. Congress is expected to continue debate on FY 2011 appropriations when they return for a lame duck session on November 15th.

In both the House and Senate versions of the Labor, Health and Human Services, and Education (LHHS) Appropriations bills, the National

Institutes of Health (NIH), the National Cancer Institute (NCI), and the Centers for Disease Control and Prevention (CDC) all received increases in funding. In the House LHHS bill, the NIH received \$32 billion (a \$1 billion increase over FY 2010). The NCI was allocated \$5.265 billion, \$162 million more than FY 2010. The Senate LHHS Appropriations bill included the same allocation for the NIH as the House bill. The Senate allocation for the NCI is \$5.257 billion. This amount is \$153 million above the FY 2010 funding level. For the Geraldine Ferraro Blood Cancer Program at the CDC, the Senate included \$5 million for the program in FY 2011 (an increase of \$300,000). It is unclear if these programmatic increases will hold as the FY 2011 appropriations process continues to drag into the lame duck session and potentially into the New Year.. **MT**

How to contact the IMF Advocacy Team



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WHAT DO YOU GET AT AN IMF PATIENT & FAMILY SEMINAR?

Education • Access to Experts • Camaraderie

Topics Covered

- *What's New in Myeloma?* • *Ask-the-Expert*
- *Managing Side Effects* • *How to be a Better Patient*
- *Frontline Therapy* • *Transplant* • *Bone Disease*
- *Maintenance Therapy* • *Relapse* • *Novel Therapies*



Regional Community Workshops (RCW)

If you cannot get to a P&F Seminar, consider attending a Regional Community Workshop. These half-day meetings provide Education, Access to Experts, and Camaraderie. Registration is free but you must register. It's a great way to learn from myeloma experts, as well as share experiences and gain strength from others in the IMF family. Find more details about the next RCW near you at our website.

Go to our website
www.myeloma.org
and click on the
“meetings & events” tab
for more details, the most
up-to-date faculty, hotels
and registration information.



A WONDERFUL SUCCESS STORY... 8 YEARS AND COUNTING

By Robert Reeves

I was diagnosed with myeloma in September 2002, at age 72. My family and I were in shock and wondered what the future would be like. One of my sons reached out to the IMF for a packet of information that we found to be most educational.

A tumor was found on my C2 vertebra. After several treatments, the doctors became concerned because the tumor had destroyed a part of that vertebra. Radiation was halted and surgery performed – a metal plate was installed on the back of my head with rods down my neck that were attached to other fused vertebra. Radiation was resumed after the surgery, and I completed a total of 26 treatments.

I have been an athlete all my life and my latest passions were running and cycling. One of the events I really enjoyed was the MS150 bike ride (75 miles a day for 2 days for a total of 150 miles cycled) to raise money for multiple sclerosis research. In September 2003, I did the South Carolina MS150, riding from Columbia to Myrtle Beach. My wonderful wife insisted that I take it easy, so I only cycled 50 miles per day. I wore a neck brace part of the time, but I completed the 150.

Following the radiation therapy, Zometa® infusions were begun (and have continued to this day). My M-protein levels were monitored, and remained high, but my oncologist did not think additional treatment was required at that time. I continued to keep in contact with the IMF, especially Hotline Coordinators Nancy Baxter and Debbie Birns, to make sure that my treatment plan made sense. When my M-protein levels began increasing in September 2003, the doctors recommended a VAD treatment plan. I called the IMF and learned about dexamethasone plus thalidomide as a potential solution, and that is what we went with. While a 54% decrease in the mutated M-protein was achieved in the first month, when the thalidomide dosage reached 200 mg per day, the peripheral neuropathy (PN) got very bad. As a result, the thalidomide dosage was gradually reduced to 50 mg during the second month. At the lower dosage, I had no PN while the treatment remained just as effective.



low ever since. In 2006 or 2007, I was once again talking with the IMF Hotline Coordinators and they asked about my light chains, which I knew nothing about. Measuring light chains was not part of my routine blood work. The test was performed after a discussion with my doctor and we discovered the lambda free light chains were high and the kappa free low. The levels ranged from 100 to 400 for several years yet it was felt that no treatment was required because every 6 months CT scans were being performed of my spine, chest, abdomen, and pelvis, and everything was stable. In 2007 and 2008, I grew a tumor on both a rib and my sternum, and was treated with radiation. In February 2008, my wonderful wife of 54 years died with a brain tumor.

In January 2010, a CT scan showed tumors in my lumbar and thoracic areas. I was hospitalized, and a decision was made to treat the tumors with radiation. During treatment, more tumors were discovered on my right shoulder and the back of my head. The shoulder was treated with radiation but the head was not because of the brain. It was also suggested that, if I am growing tumors, the light chain should be treated. I discussed my situation with IMF Hotline Coordinator Paul Hewitt, who confirmed that treatment was necessary.

In March 2010, bortezomib (Velcade®) treatment was begun. After the second dose (2.5 mg), I was very sick for a week. However, the light chain measurement went from 383 to 53, so my response to the drug was excellent. Treatment was resumed in April at the lower dosage of 1.4 mg, administered twice a week for two weeks, followed by a week off, and I had very little adverse reaction at that dosage. After about 8 weeks, the tumor on the back of my head was gone, leaving a sunk-in place but it is not a problem. The light chains have continually gone down and are now at 3.1 (as of November 19). For me, bortezomib has been very effective.

I have been very fortunate, and I hope that what has helped me on my journey might also be of benefit to you:

1. Since my diagnosis, I have relied on all the programs and services provided by the IMF. The published materials are excellent and the personal contact with the Hotline Coordinators has been invaluable, and I know that the IMF and the Hotline could not exist without all the doctors, researchers, and other staff involved. Thank God for all those wonderful people. When a cure is found it will be because of their dedication and hard work.
2. I have doctors who work with me in adjusting the treatment plans so they meet my needs. I've consulted with a myeloma specialist and communicate freely with my healthcare team, asking questions and expressing my preferences.



Robert Reeves (center) with his daughter and a friend at a 50-mile bike ride to aid the homeless.

On July 1, 2004, at age 74, I had a stem cell transplant. At that hospital, I was the oldest person to receive a transplant for myeloma. The results were excellent, and my M-protein levels have been

CONTINUES ON NEXT PAGE

Support Groups

PEOPLE HELPING PEOPLE

You are never alone in your battle against myeloma

The Delaware & Neighboring Maryland Multiple Myeloma Support & Networking Group

Josephine C. Diagonale had microscopic hematuria, the presence of blood cells in the urine. In November 2007, her urologist recommended a CT scan, which revealed bone lesions. Josephine and her husband, Jim Mulvihill, turned to the Internet and discovered myeloma as a potential cause of Josephine's test results. This was confirmed by the oncologist.

Jim is a retired research scientist (chemistry) and is currently working in anthropological genetics as an avocation, and Josephine is a former educator who has her own business in consulting and management development. In addition, Josephine had been facilitating meditation classes, including at the local Wellness Center, and has been working in what is often referred to as the energy awareness and healing field for the past 12 years.



Josephine C. Diagonale & Jim Mulvihill

"Given our backgrounds, the myeloma diagnosis did not come as a surprise to me and my husband. What was a surprise was the dexamethasone! It was part of my frontline therapy, along with lenalidomide (Revlimid®)," says Josephine. "We've done a lot of reading on myeloma – the IMF educational materials are terrific! – and we pretty much knew what to expect every step of the way. But with myeloma there are always surprises. So, in essence, I quickly formed my own 'support group': My husband has been enormously helpful, both emotionally and in terms of contributing a wealth of scientific knowledge, and I have a wonderful oncologist who listens to me. I work with alternative healthcare practitioners. My close friends and colleagues have been supportive."

Earlier this year, Josephine decided that it was time to offer to others the support that has been of benefit to her. "After living with myeloma for three years, I have reached the point of being comfortable with going public, and I have experience and a skill set that can be of service to others." Josephine will lead the newly founded Delaware & Neighboring Maryland Multiple Myeloma Support & Networking Group, beginning with the group's first meeting on January 15, 2011.

"Our first meeting will be in the format of an open discussion, with an opportunity to introduce ourselves to one another and to discuss the mission of the group. Certainly, education will be a major aspect of the group as we move forward, with several speakers

already confirmed for future meetings, but our purpose is to be there for each other in emotional ways, too. The group will be a supportive forum to share our stories. After all, myeloma is not the only thing that defines us."

Starting January 15, 2011, the Delaware & Neighboring Maryland Multiple Myeloma Support & Networking Group will meet on the third Saturday of each month from 1:30 p.m. to 3:30 p.m. at The Eden Hill Medical Center, 3rd floor conference room, 200 Banning Street (off Rt. 8), Dover, DE 19904. For more information, please contact Josephine C. Diagonale at mmsupportde@comcast.net or 302-233-8229. We hope to see you there! **MT**

REEVES / SUCCESS STORY — continued from page 13

3. Numerous experiences with the medical advice and treatment I have received, as well as the information provided by the IMF, have made me realize how essential it is for patients to be proactive about their medical options. I know that the medical professionals do the best they can, but patients need to educate ourselves to keep up with what is happening.

4. As myeloma patients, we all have our moments of struggle. As difficult as it may be at times, I believe it is essential to try to find and maintain a positive outlook.

This story would not have been possible without the dedication, skills, and caring attitude of the medical professionals who have been with me every step

of the way. In fact I owe my life to the surgeon, oncologists, radiologists, nurses, technicians, and others who have cared for me during the last 8 years. And to live in a country where all this is possible is awesome!

I am very fortunate to have responded well to the treatments I have received. I continue to do my best to take good care of myself. I usually walk 3-5 miles a day, and ride the stationary bike in my basement 8-12 miles (as I have not ridden outside this year because of the concern of what a fall might do). My adventure with myeloma continues and, while this is most definitely a challenging journey, LIFE IS STILL GOOD. **MT**



Robert Reeves in 2004 at age 74, shortly after a stem cell transplant

Member Events

IMF MEMBERS RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY



By Suzanne Battaglia

In 2010, the IMF is proud to mark its 20-year anniversary of service to the myeloma community. Our membership is a network of people like you, from across the country and around the globe. Many IMF members are raising money for myeloma research and educational 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 myeloma. By

organizing an event in your community, you are also raising public awareness and helping those whose lives have been touched by this disease. You want to do something in your community, but deciding on what to do and how to do it can be confusing. That's where we come in! The IMF's Fundraising program is here to help you every step of the way. We make it as easy as possible for you to be involved, whether or not you have any previous experience with such activities.

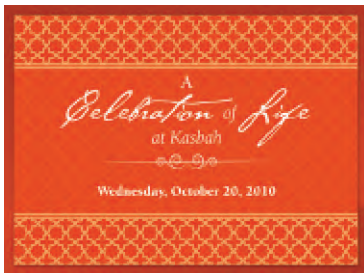
FUNdraising is fun and easy to do, and brings with it the satisfaction of knowing that YOU have made a difference in many lives. We are grateful to all IMFers who contribute their

time, imagination, and hard work to benefit the myeloma community. Our FUNdraising program provides you with the tools, assistance, and expertise to make your event a success. Choose an established event model or create your own – no idea is too large or too small. 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). I am here to chat with you about any ideas you might have. Be part of making miracles happen!

Here is just a sampling of some past and upcoming events...



A Celebration of Life at Kasbah



On October 20, A Celebration of Life at Kasbah honored the lives of three myeloma survivors – Neil Hamburger (diagnosed February 1999), Spencer Rubin (diagnosed February 2008), and IMF Board member Allan M. Weinstein (diagnosed September 2002), all friends or

family of Nancy Nashban, who helped organize the evening. Held at the Intercontinental Montelucia Resort & Spa in Paradise Valley, AZ, the event's Andalusian/Moroccan theme was inspired by the venue's gorgeous style.



Phyllis & Allan M. Weinstein

The evening featured cocktails, tapas, a Mediterranean buffet, live music, and Flamenco and belly dancers. Plus, a silent auction offered guests an opportunity to win some amazing prizes. Each of the honorees spoke to the crowd, sharing his personal story of survival. "It was a spectacular event, at a fantastic venue, with great food, and terrific continuous entertainment," said Allan. "We had close to 150 guests, many of

whom told me it was the best event they had attended. Everyone enjoyed the party, and we were able to raise myeloma awareness while raising a lot of money for the IMF."

Afternoon Tea

On October 3, co-chairs Carol Klein and Nancy Moses hosted their fourth Afternoon Tea at The Four Seasons Hotel in Washington, DC. The popular event, organized in support of the IMF's myeloma research programs by

two dynamic women whose husbands live with myeloma, brings together the local philanthropic community for a lovely afternoon reception, high tea service, a guest speaker, and opportunity drawings.

In addition to being exceptionally successful at raising funds for myeloma research, Carol and Nancy continue to be highly successful at increasing awareness of myeloma by garnering local press coverage and by educating more and more people about the disease at each event. This year's Afternoon Tea special guest was Emme, the plus-size supermodel



Carol Klein, Emme, and Nancy Moses



(l to r) Elaine Stein, Judy Lapidus, Judy Goozh, Benson Klein, Beverly Kressin, and Penny Bender

and lymphoma survivor, who spoke from the heart about her experience with cancer. To date, almost 700 women have attended the Afternoon Tea to share the camaraderie, learn about myeloma, and maybe even go home with one of the donated luxury prizes from the event's opportunity drawing. Thanks to the generosity of sponsors and participants, the 2010 Afternoon Tea event raised \$40,000 to continue its tradition of supporting significant myeloma research through the IMF's grants program.

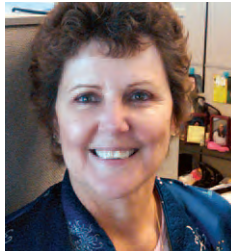


(l to r) Michelle Napoli, Laura Napoli, Lori Klein, and Abby Napoli

Member Events

Casual Week at Blue Shield

Susan Snook, who works in the small groups department of Blue Shield, was diagnosed with myeloma in 2009. A few months after her diagnosis, she attended an IMF Patient & Family Seminar and experienced for herself that the work of the IMF is closely related to her own interest in promoting myeloma awareness and raising funds for research to help find a cure. Fortunately, Blue Shield is always supportive of its employees' fundraising efforts on behalf of a good cause, offering matched (and doubled!) contribution for every dollar their employees raise for an organization of their choice.



Su decided to coordinate a Casual Week, and was very gratified to see more than 30 coworkers sign up to contribute \$10 each in order to be able to dress casually for the entire work week. During her fundraising event, Su also sold IMF burgundy bracelets and distributed informative TipCards about the IMF and myeloma. After Blue Shield contributed \$20 for each of Su's Casual Week participants, Su's final fundraising tally exceeded \$1000!

"Having myeloma has been a very difficult experience, but everyone at work has been very supportive," says Su. "Of course, I don't know how I would get through any of this without the help of my family. I am very thankful for all the help and support I continue to receive from those around me. And I just try to do my part in spreading myeloma awareness, and sharing the message with my fellow cancer patients to never give up!"

Casual Day in LA

Carol Yee is not a myeloma patient. She is not a myeloma caregiver either. In fact, when she first learned about the IMF and its programs and services, she had never known anyone with myeloma. Carol found out about myeloma and the work of the Foundation from an IMF staffer who attends the same exercise facility. "I was so impressed with the IMF that I wanted to find some way to be of help to the organization and the people it serves," says Carol. "I started doing some volunteer work for the IMF, including at its annual Gala, and I found the experience so gratifying that I wanted to organize an event of my own to raise funds for myeloma research. I work in the investment field, and my company has a Casual Day program, so this was the natural choice for my first fundraiser. Participants were asked to donate at least \$10 and up and, in the end, we were able to make a nice contribution to the IMF. I feel so strongly that whenever you have an opportunity to be helpful, and are capable of doing so, that's exactly what you should do. You don't need to know someone with myeloma to want to help people who are battling this disease." **MT**



Making your holiday gift list?

Double your dollars with every purchase at the 2010 IMF Holiday Boutique. With every gift you buy, you make a donation to the IMF to support myeloma education, research, support and advocacy. Two gifts in one! It's easy to find the Holiday Gift Boutique on our website.

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IMF Holiday Boutique

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SUPPORT IS JUST A CALL AWAY
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There are many ways that you can help. Make any donation today.

Newly Diagnosed
We have a hotline. The IMF hotline is here to help you. Myeloma can be scary, but we're here to help you understand it and to provide you with the information you need to make the best decisions for you and your family.

Publications
We offer free publications to help you stay up to date on the latest news about myeloma.

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.

www.myeloma.org

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1. Greipp et al. *Journal of Oncology* 2005; 23:3412-3420
2. Kyrtsolis et al. *Seminars in Hematology* 2009; 46:110-117
3. Dispenzieri et al. *Leukemia* 2009; 23:215-224

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2011 IMF Calendar of Events

Feb 7	IMF Patient & Family Seminar – Barcelona, SPAIN	June 8	Robert A. Kyle Lifetime Achievement Award Dinner – London, UK
Feb 25-26	IMF Patient & Family Seminar – Boca Raton, FL	June 9-12	European Hematology Association (EHA) – London, UK
Mar 11-12	IMF Patient & Family Seminar – San Francisco, CA	June 10-11	Eastern Cooperative Oncology Group (ECOG) – Boston, MA
April 13-16	Southwest Oncology Group (SWOG) – San Francisco, CA	July 15-16	IMF Patient & Family Seminar – Dallas, TX
Apr 28-May 1	Oncology Nursing Society (ONS) – San Diego, CA	July 29-31	IMF Support Group Leaders' Summit – Dallas, TX
May 3-6	International Myeloma Workshop (IMW) 13 – Paris, FRANCE	Aug 26-27	IMF Patient & Family Seminar – Philadelphia, PA
June 3-7	American Society of Clinical Oncology (ASCO) – Chicago, IL	Oct 12-15	Southwest Oncology Group (SWOG) – Chicago, IL
June 7-9	International Myeloma Working Group (IMWG) Summit II – London, UK	Dec 9-13	American Society of Hematology (ASH) – San Diego, CA

Additional events/meetings will be posted in later editions of *Myeloma Today* as dates are finalized.
For more information, please visit www.myeloma.org or call 800-452-CURE (2873).
IMF–Latin America, IMF–Japan and IMF–Israel events are not included above.

Thank you for your continued support of the IMF.