



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



and albumin levels, with cytogenetics, especially fluorescence in situ hybridization. **PAGE 7**

Prof. Herve Avet-Loiseau of the Institute de Biologie in Nantes, France, discusses the impact of cytogenetics on overall and event-free survival in myeloma. Until now, there has been no large-scale analysis of molecular features linked to the International Staging System (ISS) of myeloma. In the current project, the International Myeloma Working Group is looking at combining the ISS prognostic model, which is based on $\beta 2m$ and albumin levels, with cytogenetics, especially fluorescence in situ hybridization. **PAGE 7**



delayed transplant groups. **PAGE 9**

Dr. Shaji Kumar of the Mayo Clinic in Rochester, MN, talks about the place of autologous stem cell transplantation (SCT) in the era of novel agents in myeloma. SCT has been an integral part of myeloma therapy since randomized trials demonstrated improved survival for SCT compared to conventional therapy. Investigators at the Mayo Clinic reviewed the outcome of 410 patients and studied the differences in efficacy between the upfront and

Supportive Care

IMF Hotline Coordinators answer a question about the safety of using gadolinium, a contrast agent injected into the body and taken up by active myeloma lesions, in magnetic resonance imaging (MRI) tests. An MRI test is useful in assessing the disease state of a patient with myeloma, but gadolinium is potentially toxic to the kidneys, and there has been some debate regarding the wisdom of using gadolinium in myeloma patients because many have kidneys that are compromised by their disease. **PAGE 13**



LOOKING FOR A LOCAL MYELOMA SUPPORT GROUP?

If you are interested in joining a support group, please visit our website at www.myeloma.org or call the IMF at 800-452-CURE (2873).

Profiles in the News



Daniel Navid has joined the IMF as Senior Global Analyst. He will assist in the strategic planning, implementation, and annual evaluation of an international program for the IMF that aims to enhance myeloma awareness and patient education, and improve diagnosis and access to effective therapies. **PAGE 4**



Amy Weiss has joined the IMF Board of Directors. She has committed to work on behalf of the IMF and do all she can to help find a cure for myeloma in her husband's lifetime.

Ms. Weiss is an attorney who has worked for Walt Disney Television and Columbia Tri-Star Television business affairs. In 1999, she joined Brillstein Entertainment Partners (then Brillstein-Grey Entertainment), where she works closely with top performers, writers, and producers in the entertainment industry. **PAGE 5**



Yolanda Brunson-Sarrabo was diagnosed with myeloma in 2008, when an annual blood test showed an elevated protein level. She was 37 years old. Reaching out for an expert opinion to Dr. Robert A. Kyle at the Mayo Clinic prevented Ms. Brunson-Sarrabo from starting anti-myeloma treatment prematurely. After keeping her diagnosis private even through radiation for a painful solitary plasmacytoma, Ms. Brunson-Sarrabo now shares the story of the personal and medical challenges of her myeloma experience. **PAGE 17**

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2010 IMF Calendar of Events **BACK COVER**

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A Message from the President

Dear Reader,

In this issue you will find an important article in the Education & Awareness section, "Spotlight on Advocacy." Why am I pointing this out to you? Because I want you to get involved with the IMF Campaign on Health Reform, which focuses on the most essential issues that cancer patients are facing. And, quite frankly, we need your help. This is the critical moment – when we still have the opportunity to make a change. If we let it slip by, we may not have another chance for decades. If we were in Vegas, and those were the odds, we wouldn't want to make a bet like that.

This issue is not blue or red, left or right. This is about people and our right to very basic and extremely important improvements in care.

These changes aren't going to happen on their own. We all need to come together and get involved. It's time to stop complaining and get active. If not you – who? If we're not willing to do it on our own behalf, how can we expect someone else to do it for us? The truth that is the easiest thing to do is nothing. When you do nothing you get nothing. Sadly, Congress is famous for this. This time, don't let them off the hook. They work for us, so let's get them working on what matters most to us!

Historically, change happens when average Joes and Janes (that would be you and me) decide enough is enough and come together and take action that results in significant change.

These are the essential needs for the entire cancer community, and here's what we're asking for:

- Affordable access to basic and catastrophic health care coverage for as many Americans as possible

- The elimination of "pre-existing conditions" as a barrier to health care coverage
- The elimination of annual and lifetime caps on insurance coverage
- Closing of the Medicare "donut hole"
- Continued investment in research and innovation to address the needs of those with all deadly diseases



I've been there, caring for a loved one with myeloma. I've been victimized by the system, and I've been fighting the system on your behalf ever since. Trust me, the time to act is now!

I know your strength and your passion, and I've seen how much you care. We're all highly motivated, so let's not let this moment pass. Together we can move mountains!

Warm regards,
Susie Novis

Editor's Note: To read the "Spotlight on Advocacy" column, please turn to page 11.

IMF WELCOMES DANIEL NAVID



The IMF is pleased to welcome Daniel Navid as Senior Global Analyst. Mr. Navid will assist in the strategic planning, implementation, and annual evaluation of an international program for the IMF that aims to enhance myeloma awareness and patient education, and improve diagnosis and access to effective therapies. He will oversee and participate in selected activities in areas of his expertise, and will play a definitive role

in developing partnerships with industry, national societies, and government agencies.

Mr. Navid is an American lawyer who has been based in Europe for 35 years; the first six years in Germany and the following 29 in Switzerland. He has extensive experience in the fields of international law, diplomacy, capacity building, and management in the environment, development, and health fields. Mr. Navid's most recent client has been the Fragility Fracture Network, a scientific society dedicated to supporting osteoporosis

patients, which he helped establish as an international organization in Switzerland and for which he served as interim Chief Executive Officer.

Between 2001 and 2009, Mr. Navid served as the first Chief Executive Officer for the International Osteoporosis Foundation, a nongovernmental organization with almost 200 member societies in over 90 countries. Prior to that, he served for several years as a diplomat in the United Nations, served as the First Secretary General to the Convention on Wetlands of International Importance, and worked as a legal officer and Executive Officer at the International Union for Conservation of Nature and Natural Resources. Mr. Navid has provided advisory services to numerous governments in the drafting of legislative and policy instruments including those of Cyprus, Eritrea, India, Japan, Kenya, Laos, Thailand, and Zimbabwe.

Mr. Navid received his BA degree with distinction in Political Science from the University of Michigan - Ann Arbor and his Juris Doctorate degree from Northwestern University (Chicago, IL). He is a member of the Bar of the State of Illinois and has served on the Board of several foundations and organizations in the United States and abroad. **MT**

Letters to the IMF

IMF Hotline

I wanted to send a quick note after corresponding, then speaking, with Debbie Birns of the IMF Hotline. I had written your organization hoping to get some advice not on my myeloma per se, but on the increasing number of side effects I have been experiencing, and their similarly increasing severity. I wrote to a number of organizations focused in various ways on myeloma and attendant health issues. All replied, but none with the thoroughness, patience, depth of knowledge, concern, and sheer tenacity on my behalf, as did Ms. Birns of the IMF.

I will not elaborate on information and the advice provided, except to say that these were extremely helpful and directly on point. Ms. Birns wrote to me; called saying that in order to better serve me that I should call; and took said call immediately and with full attention and professionalism. She asked numerous very relevant questions and used my answers to suggest both some specific explorations and further questions I might address, and made several recommendations for me to share with my medical providers. Ms. Birns repeatedly advised me NOT to rush off and act on information and guidance provided, but rather to fold this into conversations with the doctors and others treating me, and with whom I consult.

Following my several contacts with Debbie, and based upon information she provided for me to further research, I switched to a primary provider who is wonderful and under whose care I have also changed my entire treatment regimen to one which has elevated my life quality significantly and which, thus far, has been most effective. This would not have happened without the IMF and Debbie's pro-active approach. My contact with Ms. Birns, and therefore with the IMF, was the single best of its kind I can recall making in this or any other context. She, and your organization, are greatly to be commended, hopefully to be emulated.

David C. Miller

Dear Nancy:

Thank you so much for your prompt, thoughtful response to my questions about my husband's condition. The books you sent were great and I now understand myeloma better than I did before. It is a scary thing when you feel like you are alone in making treatment decisions and it is wonderful to know someone is out there who can help. You have no idea how much I appreciate your support.

Pat Laas

Missy,

I just wanted to thank for all your help last week. You were very patient and compassionate during a very difficult time. I also received the IMF Info Pack yesterday. I pray that this will be a success story for the books!

Nicole O'Hara

Thanks, Debbie!

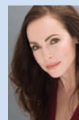
Your response was very thorough and extremely helpful, and the table you referred me to was exactly what I was looking for. It is so helpful to know the results of current research and the general consensus of the Scientific Advisory Board of the IMF. It would take me forever to find all the info on my own; I really appreciate your taking the time to provide me with such great info! I wish I had known about the IMF when I was first diagnosed. It would have saved me a lot of stress, as I ended up with an oncologist who knew very little about myeloma (I have since changed doctors). I can't believe the quality of the responses I get from the IMF Hotline to my questions – sometimes better answers than my oncologist gives. You are such a great resource and I'm so glad I found you!

Kris Grandinetti

My husband was diagnosed with myeloma three years ago, and I've taken advantage of many of the IMF's services: the website, Patient & Family Seminars, and publications. I had my first opportunity to use the IMF Hotline yesterday and talked to Paul Hewitt about something that my husband's doctor had said that scared me, but I didn't want to talk to my husband about it and scare him, or talk to the doctor in front of him. Paul was a formidable library of information, and I got exactly the pieces I needed. The information was so specific and helpful that I hope the doctors know it, too. What a resource!!!!!!

Kim McLaughlin

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:

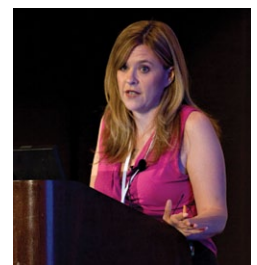


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WHAT DO YOU GET AT AN IMF PATIENT & FAMILY SEMINAR?

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.



THE IMF WELCOMES ENTERTAINMENT INDUSTRY EXECUTIVE TO BOARD OF DIRECTORS

Myeloma Today in conversation with Amy Weiss

Recently, you accepted the invitation to become an IMF Director. Why did you choose to join the Board?

I am honored by the opportunity to work on behalf of the IMF and do all I can to help find a cure for multiple myeloma in my husband's lifetime. This is a very personal mission for me.

How did myeloma enter your life?

Longevity runs in my husband's family. Steve's father is an active 92-year-old. His mother is very active. My husband's great uncle was George Burns, who lived to celebrate his 100th birthday. So I had assumed that after a couple more years of working, Steve and I would enjoy many many years together in retirement. But that was before myeloma...

In May 2008, Steve saw his internist for a routine physical. The blood test didn't look right, so the doctor repeated the test. Once again, the test showed an elevated protein level. A week later, after more extensive testing, the diagnosis of myeloma was established.

Like so many others, we had never heard of this cancer. At first, I thought the doctor said "melanoma" – the skin cancer – which was something I was familiar with. The myeloma diagnosis was such a shock, I actually passed out.

What did you do after you got your bearings?

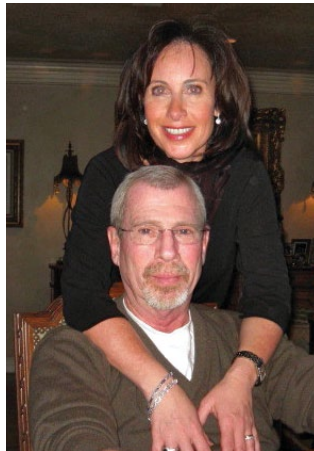
By nature, I am a very take charge person. Day and night, I searched the Internet, which turned out to be a source of both accurate and inaccurate information about myeloma, and much of it was very bleak. Quickly, I learned to filter the information I was accessing. That's why I fully appreciate the fact that the IMF is the premier source of reliable myeloma education.

Immediately after the diagnosis, Steve was reluctant to know too much, but he then became a full partner in his recovery. After learning the basics about myeloma, we proceeded to look for the best care for him. We toured two premier hospitals in the area before going to the Cedars-Sinai Medical Center, where we met Dr. Brian Durie. To us, Cedars just felt right, like a place where we were supposed to be. Plus, we noticed that the cancer center is located at the corner of Gracie Allen Drive and George Burns Road, named in honor of Steve's great aunt and uncle!

How were you introduced to the IMF?

We met IMF co-founder and president Susie Novis through Dr. Durie, who is the co-founder and chairman of the Foundation. Susie reached out to us and became our source of comfort and information. At a difficult time, the support, friendship, and caring of the IMF was there for us.

I truly believe that knowledge is power. To find a cure for myeloma, we need to raise funds for research



and we need to raise public awareness. So, when I was asked to co-chair the 2009 *Annual Comedy Celebration* supporting the IMF's research programs, I jumped at the chance before I fully realized what such a commitment would entail. In the end, the event was a huge success.

How were you able to bring in such support for the event?

I work in the entertainment industry. My husband was an agent with the William Morris Agency for many years. Steve's father, Lou Weiss, helped build the agency, having served as chairman emeritus until his retirement in 2007, after 70 years with the company.

I began my career as an attorney in New York. In 1993, I came to Los Angeles with my mother so she could receive

an experimental bone marrow transplant for her lymphoma. I was hired as an attorney by Walt Disney Television, then worked for Columbia TriStar Television business affairs. In 1999, I joined Brillstein Entertainment Partners (then Brillstein-Grey Entertainment), where I work closely with some top performers, writers, and producers in the entertainment industry. Currently, I am both a talent manager and Executive Vice President in charge of Business Affairs.

My clients Bob Saget, Meat Loaf, and Jill Zarin, as well as many of my writers, participated in the IMF benefit. Many of my friends and colleagues were there as well to support the cause. I reached out to the heads of film studios, television networks, and talent agencies. Without fail, the support was there. People flew in from all over the country, donated money and volunteered their time. Some of the comedians canceled paying gigs to appear at the event.

At present, how are you and Steve coping with his myeloma?

We had a tough Summer in 2009. But right now, knock on wood, he is feeling okay and having a relatively normal life. Steve and I have developed our new "normal" – living with myeloma – which is not perfect but we can handle it while we move towards a cure. We stay very pro-active. I have a myeloma alert on my computer and, on a daily basis, I keep up with info on new and existing drugs. I also read several myeloma blogs.

What is your vision of your continued involvement with the IMF?

I think that bringing in more members of the entertainment community to support our cause is important, both for increasing research revenue and for raising the public visibility of the myeloma community. The Gala benefit is one way to address both goals, and I would like to continue my involvement with this event, possibly expanding the program into other cities. **MT**

"When I first met Amy I knew she shared our passion to find a cure for myeloma, and that she recognized the importance of helping patients today, providing education and offering support. Amy has been a tireless worker on behalf of patients with multiple myeloma. This past November, Amy, along with Loraine Boyle, co-chaired our Annual Comedy Celebration Benefiting the Peter Boyle Memorial Fund. Her drive, capabilities and respect within the entertainment community contributed significantly to our success in raising both awareness and funding to support myeloma research. We are thrilled that she is joining our Board and we know she will continue to be a driving force in helping to raise money to find a cure."

– Susie Novis
IMF President and Co-founder

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.



IMF names Prof. Joan Bladé as recipient of the 2010 Robert A. Kyle Lifetime Achievement Award

The International Myeloma Foundation (IMF) is proud to award its prestigious *Robert A. Kyle Lifetime Achievement Award* for 2010 to Prof. Joan Bladé. The IMF's Robert A. Kyle Lifetime Achievement Award was established to honor

an individual whose lifetime body of work furthers the ultimate goal of finding a cure for myeloma, a cancer of the bone marrow. The accolade is named after Dr. Robert A. Kyle, noted physician and founder of the Myeloma and Related Diseases Research Group at the Mayo Clinic in Rochester, Minnesota. Dr. Kyle himself was the first recipient of the award in 2003. Subsequently, the award has been presented to Dr. Bart Barlogie of the Myeloma Institute for Research and Therapy in Little Rock, Arkansas in 2004, Dr. Kenneth C. Anderson of the Dana Farber Cancer Institute in 2005, and Dr. Brian G.M. Durie of the Cedars Sinai Comprehensive Cancer Center in 2006, Prof. Heinz Ludwig in 2007, Prof. Mario Boccadoro in 2008 and Prof. Jean-Luc Harousseau in 2009.

Prof. Bladé graduated from the Medical School of the University of Barcelona. In 1981 he joined the staff at the Hematology Department of Hospital Clinic, where is now the Senior Consultant and Director of the Myeloma Programs. He was co-founder of the PETHEMA Foundation, and co-founder of the Spanish Myeloma Group. Dr. Bladé chaired the group who developed the European Group and Marrow Transplantation (EBMT) response criteria, known today as the Bladé Criteria. He has published over 200 papers on both myeloma and MGUS, and he is an active member of the *International Myeloma Working Group* (IMWG).

The presentation will take place on June 9, 2010, in Barcelona, Spain. For information about sponsorship opportunities, please contact Suzanne Battaglia, at SBattaglia@myeloma.org, or (818) 487-7455.

Circulating myeloma cells and autologous stem cell transplantation

Multiple myeloma (MM) patients with a good performance status are often offered high-dose therapy (HDT) followed by autologous stem-cell transplantation (ASCT). HDT/ASCT is associated with complete response (CR) rates of up to 40%. Although a significant proportion of patients have a durable response after HDT/ASCT, others relapse relatively quickly and do not appear to benefit from the procedure, which may impact the overall survival (OS) of these patients. Researchers at the Indiana University School of Medicine and Simon Cancer Center (Indianapolis, IN) attempted to define the role of infusing mobilized myeloma cells on the survival of patients undergoing ASCT.

Investigators studied data on autograft characteristics of 303 patients who underwent ASCT between January 1999 and April 2008. The mobilization regimen was cyclophosphamide and GCSF for the majority of the patients and GCSF alone for the more recent transplants. Melphalan at 200 mg/m² was given 18 hours prior ASC infusion. In 199 patients there were no

CD38+/CD45- cells detected. Among the 104 patients with evidence of CD38+/CD45- cells the range was 0.1–10.2 x10⁶ cells/kg and there was no difference in OS in this patient group compared to the group without evidence of contaminating myeloma cells. Continuous variable analysis also did not reveal any relationship between the dose of CD38+/CD45- cells and survival. There may be a survival advantage after 40 months for those receiving CD38+/CD45- cells, however the scientific rationale is not well understood. Neither beta 2 microglobulin nor the number of plasma cells in the bone marrow were relevant in multivariate analysis. In conclusion, the presence of MM cells in the autograft does not appear to influence OS, and the inclusion of CD45 and CD38 flow cytometric analysis of mobilized stem cells may not be necessary. A video interview with Dr. Hayley Knollman of the Indiana University School of Medicine and Simon Cancer Center is available on the IMF website, www.myeloma.org.

Phase III trial in smoldering multiple myeloma at high risk of progression

Smoldering multiple myeloma (sMM) is a plasma cell (PC) disorder defined by the presence of ≥10% of PC and/or a serum M-component (MC) ≥3g/dl without end-organ damage. Recent studies have identified a subgroup of sMM patients at high risk of progression to active MM (>50% at 2 y): patients with both PC ≥10% & MC ≥3g/dl or ≥95% aberrant PC (aPC) by immunophenotyping, or abnormal FLCs. Standard of care for sMM is monitoring without treatment until disease progression. Several small studies, which did not focus on high-risk sMM, have explored the value of early treatment with either conventional agents (melphalan/prednisone) or novel drugs (thalidomide, interleukin-1b), with no clear benefit.

Researchers at Hospital Universitario de Salamanca (Salamanca, Spain) participated in a multicenter, randomized, open-label, phase III trial of lenalidomide (Revlimid[®]) plus dexamethasone (len-dex) versus no treatment in sMM patients at high risk of progression to symptomatic MM. In the first interim analysis, the Salamanca investigators presented data on the first 40 patients recruited, looking at whether early treatment prolongs the time to progression (TTP) in sMM patients at high risk of progression to active MM. These preliminary results show that in sMM patients at high risk for progression to active MM, delayed treatment is associated with early progression (median time 17.5 months) with bone disease, while so far len-dex has been able not only to prolong the TTP (without any progression so far) but also to induce complete response (CR) with a manageable and acceptable toxicity profile. A video interview with Dr. Maria-Victoria Mateos of the Hospital Universitario de Salamanca is available on the IMF website, www.myeloma.org. **MT**

Help the IMF learn more about myeloma patients

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

IMPACT OF CYTOGENETICS ON OVERALL AND EVENT-FREE SURVIVAL IN MULTIPLE MYELOMA

Myeloma Today in conversation with Prof. Herve Avet-Loiseau

Please give us a little background on the cytogenetics work of the IMWG, for which you serve as the principal investigator.

One of the projects of the International Myeloma Working Group (IMWG) is focused on the molecular classification of multiple myeloma. Until now, the prognostic impact of molecular changes in myeloma has been assessed from relatively small and/or incomplete studies, and there has been no large-scale analysis of molecular features linked to the International Staging System (ISS) of myeloma, which is a very useful staging system published by the IMWG in 2005. In the current project, the IMWG is looking at combining the ISS prognostic model, which is based on β_2m and albumin levels, with cytogenetics, especially fluorescence in situ hybridization (FISH). We believe cytogenetics to be very important in myeloma and, in order to clarify the overall impact of chromosomal abnormalities, IMWG investigators undertook a collective analysis of 9,897 patients. At the 51st annual meeting of the American Society of Hematology (ASH), which was held in December 2009, we presented our analysis to date.

In brief, what were the IMWG findings presented at ASH?

Within the 9,897 myeloma patients in the study, 2,295 patients had presence of cytogenetic abnormalities (CA); 1,713 hypodiploidy; 1,673 hyperdiploidy; 2,309 cytogenetic deletion 13; 3,226 deletion 13 FISH; 1,573 FISH t(4;14); 1,486 FISH del 17p; 1,683 FISH t(11;14); and 366 FISH t(14;16). Enrolled patients had complete clinical and treatment details available including baseline standard prognostic factors, ISS stage, as well as both progression-free survival (PFS) and overall survival (OS) information. Data was gathered from 14 studies in the U.S., Europe, Asia, and Latin America. Univariate and multivariate analyses were performed.

Each of the known adverse molecular features had a negative impact upon both PFS and OS. Among the deleterious FISH abnormalities, the t(4;14) abnormality was highly correlated with poorer outcomes. The t(4;14) abnormality combined with ISS stage also significantly enhanced predictive capability (please



Herve Avet-Loiseau, MD, PhD
 Institute de Biologie,
 Center for Research
 in Myeloma (CERM)
 Nantes, France

see figure). The best outcomes were for ISS Stage I in the presence of t(11;14), with OS 89% at 4 years. Absence of any one adverse feature correlated with 80-81% OS at 4 years for Stage I. Presence of any one adverse feature had a more variable impact and correlated with 22%-40% OS at 4 years for Stage III.

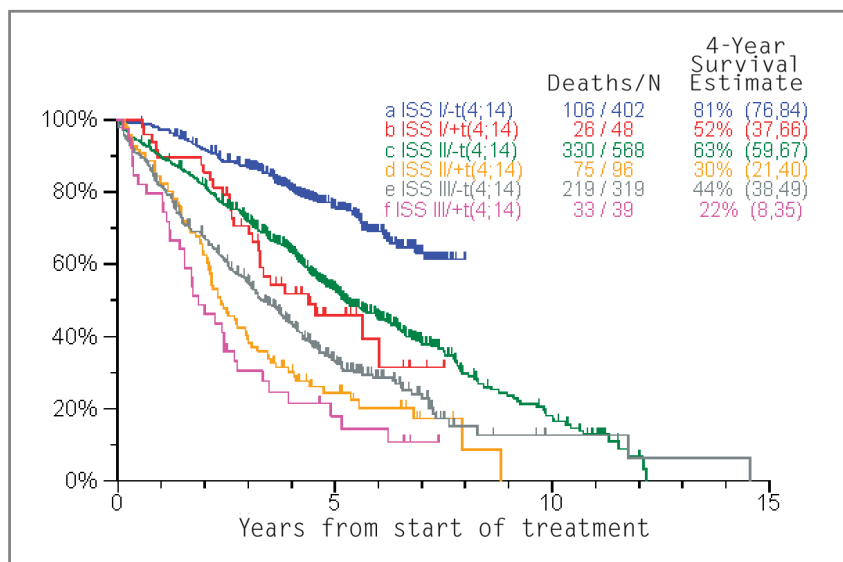
FISH improves the prognostic value of the ISS and, in combination with ISS, provides the best predictive capability. Presence of any CA, t(4;14), 17p-, hypodiploidy, and cytogenetic 13q- contribute to poorer outcomes by ISS stage. The presence of hyperdiploidy and/or t(11;14) contribute to better outcomes. The IMWG analysis confirms the correlations between abnormal molecular findings and outcomes.

Since the ASH presentation in December, what updates are you able to share with us?

The project is moving forward rapidly. We are continuing to collect cytogenetics data on myeloma patients from centers around the world and, so far, the information has been very consistent with what we presented at ASH in December. Since ASH, we have received data from Italy and the United Kingdom, and those results are being analyzed and verified by our statisticians.

Once we have the results of the analyses that are still outstanding, I will begin work on the manuscript for publication. Our goal is to propose a new staging system for myeloma that will integrate the ISS with the newer findings on chromosomal abnormalities. Combining ISS with cytogenetics yields very valuable prognostic information, not only in the setting of clinical trials but also for doctors

who see myeloma patients as part of their clinical practice. The information gleaned from cytogenetics allows us to present a more clear prognostic picture to the patient and to propose more specific treatment regimens that are more likely to successfully address the individual patient's disease. It is already clear to us that all myeloma patients would benefit from chromosomal analysis as part of their initial disease assessment. **MT**



MYELOMA TODAY IN CONVERSATION WITH DR. SHAJI KUMAR

Novel Agents for Initial Therapy of Multiple Myeloma: Comparable results with continued initial therapy and delayed transplantation at relapse versus early transplantation

Dr. Kumar, you made a presentation at the 51st annual meeting of the American Society of Hematology (ASH) about your investigation into the place of autologous stem cell transplantation in the era of novel agents in multiple myeloma. What can you tell us about this study?

Autologous stem cell transplantation has been an important part of multiple myeloma therapy since randomized trials showed improved survival with transplant compared to conventional therapy. However, the conventional treatment of myeloma has changed with the introduction of new drugs like IMiDs and proteasome inhibitors and there has been an increasing trend towards delaying transplant. While clinical trials in the pre-novel agent area have shown equivalent outcomes with early or delayed transplant, it is not clear if this holds true when the new drugs are used in the beginning. Patients treated with new drugs have had an understandable concern regarding the value of transplant once their myeloma relapses.

We studied the disease course among 410 patients seen at Mayo Clinic between 2001 and 2008. The patients included 123 (43%) individuals who received initial therapy with thalidomide-dexamethasone (TD) and 167 (57%) patients who were treated with lenalidomide-dexamethasone (LD). In 290 (71%) patients, a stem cell harvest was attempted and these patients were considered transplant eligible for this study (i.e., started on growth factor irrespective of collection success and whether or not they ended up having a transplant).

The early transplant group included 174 (60%) patients undergoing transplant within 12 months of diagnosis, and in whom the SCT was performed within 2 months of stem cell harvest. The remaining 118 (40%) patients were considered in the delayed transplant group, irrespective of whether a transplant was actually performed (45 patients from the delayed SCT group have been transplanted to date from among 68 who had a second line therapy). The median estimated time to SCT was 5.3 months among the early group compared to 39 months in the delayed group.



Shaji Kumar, MD
Mayo Clinic
Rochester, MN

At baseline, the groups were comparable for age, gender and other relevant clinical features.

What differences in efficacy did you find between the upfront and delayed transplant groups in the Mayo Clinic study?

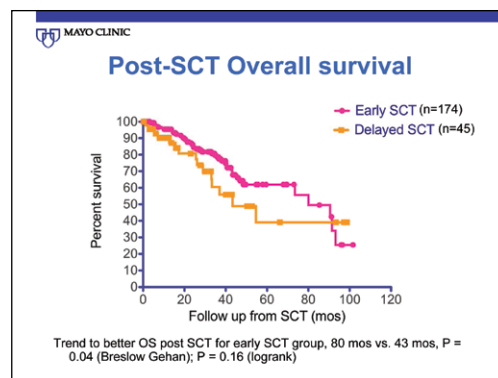
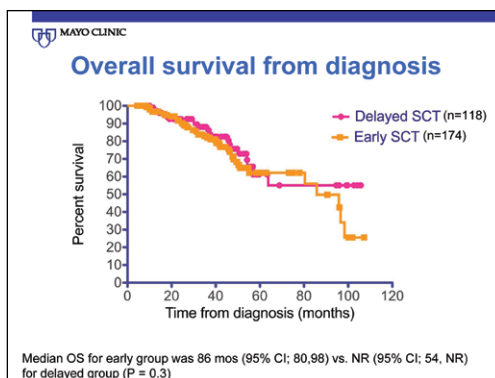
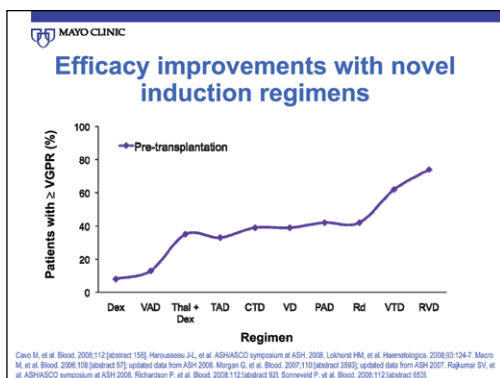
In this group of newly diagnosed patients treated with TD or LD as initial therapy, an approach of continued initial therapy and delayed transplant at the time of first relapse appears to have comparable efficacy to upfront transplant. Most importantly, the overall survival of patients was comparable whether they received the transplant in an early or delayed fashion. The time to disease progression appears comparable following transplant, likely reflecting the fact that these patients had not received previous treatment with melphalan type drugs. However, the overall survival post-SCT appears to be lower for the delayed SCT group reflecting fewer options for salvage therapy. The timing of transplant in the era of novel agents remains the top question on the mind

of both physicians and patients, and this is the first study to examine this very important question.

Did the retrospective study uncover a clear rationale when selecting early versus delayed transplant?

The rationale governing the decision to go forward with an early or delayed transplant is difficult to ascertain for any particular patient in this retrospective study. The retrospective nature of our study precludes understanding reason for the early versus delayed decision in any particular patient. Clearly, randomized prospective studies are needed to confirm these findings. Transplantations should be considered a “regimen” for myeloma therapy, not a platform to base all therapy on.

Also, it is important to note that our retrospective study did not address quality of life (QOL) issue, and this should be assessed in future studies as such consideration clearly plays an important role in the decision of early versus delayed SCT. **MT**



Support Groups

PEOPLE HELPING PEOPLE

You are never alone in your battle against myeloma

San Diego, CA

The San Diego Multiple Myeloma Support Group was founded almost 15 years ago by Fred and Virginia Gloor. The group held its first meeting with a total of five people in attendance. From those humble beginnings, the group has grown to approximately 300 patients and caregivers.



Dr. Ewa Carrier and Elliot Recht

“Our meetings are open to anyone who has questions about myeloma: patients, caregivers, family members, and friends,” says Elliot Recht, who has been part of the group since his diagnosis in 1998 and has served as its leader for the past four years. “Fred and Virginia laid the foundation for our group, and I was very fortunate to have their support when I was newly diagnosed. Now I try to carry on what they started.

I coordinate the meetings and the speakers, and send out monthly emails to our members. We have 40 to 50 people turn out to most meetings. At special meetings that feature dinner and speakers, we usually have 80 to 120 people in attendance. At our core, we are a group focused on myeloma education, and we have been able to bring in some excellent speakers to address the group. In addition, we have a number of long-term survivors among us, which is always encouraging to our new members who have been recently diagnosed.”



Dr. Ewa Carrier and James W. Huston

The group’s February meeting took place at University of California San Diego (UCSD) and featured a reception and presentations by Dr. Ewa Carrier (UCSD Moores Cancer Center) and James W. Huston (co-author of the book “100 Questions and Answers about Myeloma”). IMF’s Kelly Cox (Director of Support Groups Outreach) was also in attendance, as were 110 group members who came to enjoy the evening and hear the presentations.

Currently the group holds two meetings a year that include dinner or a reception, and Elliot is making plans to host a third educational event like the recent UCSD meeting on a regular basis. “We are very fortunate to have the IMF as one of our group’s sponsors,” adds Elliot. “And we also receive support from Celgene and Millennium Pharmaceuticals, as well as RosArt Multimedia. But we are continuing to seek new sponsors and supporters.” *[Elliot is also seeking someone to assist him with running the monthly meetings and someone who can help the group seek additional funding by writing grants. He welcomes hearing from interested IMFers.]*

In October 2009, the San Diego group was selected as a Finalist in the 2009 third annual San Diego Business Journal’s Health Care Champion

Award contest. Health Care Champions is an event that recognizes individuals and/or organizations in the County of San Diego health care industry that are making a significant impact on the quality of health care. The support group feels very lucky to have been selected, not only to be recognized, but also to be presented a Finalist award.



Group members Joanna Jones, Don and Althea Channell, and Tom Hedges

The San Diego Multiple Myeloma Support Group meets on the second Monday of every month in the Forum Meeting Room above the Wells Fargo Bank at Westfield UTC Shoppingtown in La Jolla, CA. For more information, please contact Elliot Recht at 858-273-5008 or ElliotRecht@san.rtr.com, or visit the group’s website at www.multiplemyelomasandiego.org.

Montgomery, AL

The Montgomery Area Support Group was started by Dale and Kitty Collier in March 2009. The idea to form the group came to the Colliers as a result of attending support meetings at the Arkansas Cancer Research Center. Like other patients at the Arkansas center, the Colliers went home to an area that did not have a support group specifically serving patients with myeloma and their families.



The Montgomery Area Support Group

As the Colliers promoted the existence of their group, they were able to secure some media coverage. An article appeared in the local paper, which eventually came to the attention of David Martin, who had just been diagnosed with myeloma. David and his wife Lori joined the group and, when the Colliers were moving out of the area and were looking for

CONTINUES ON PAGE 12

Support Groups

PEOPLE HELPING PEOPLE — continued from page 9

new leadership to assume responsibility, David and Lori Martin stepped up to the task.

“There is still no other dedicated myeloma support group in the Montgomery area,” says David. “In fact, we’ve had people drive as much as 100 miles to attend our meetings. Some of our gatherings can be smaller and more intimate, but every third meeting or so we bring in guest speakers and those days always draw a bigger crowd. We encourage our members to be educated about this disease, but we feel that it is equally important for people to be able to share their experiences, both medical and emotional, with others who understand exactly what they are going through. I know that myeloma varies from case to case but talking to other patients helps us understand our own experience better. It is gratifying to know that our support group is providing something that people need.”

“As a caregiver, I know that no matter how hard it might be to get to a meeting, I always feel so much better having been there. The support we share with one another is so valuable,” adds Lori. “We have patients in every age group, both newly diagnosed and long-term survivors, but I’d say many who come to our meetings have something in common – they have undergone transplantation at the myeloma center in Little Rock, AR. Some of our members had their transplants 10 to 15 years ago, so our group has a lot of positive stories to share and encouragement to offer.”

The Montgomery Area Support Group meets on the second Saturday of each month at Frazer United Methodist Church on Atlanta Highway. For more information, please call David and Lori Martin at 334-277-6824 (home, evenings) or 334-462-4183 (cell) or email them at dmartin1@ch2m.com or newtr4a@yahoo.com.

Start-up groups seek your support

Albany, GA: When Barbara Blake moved back to Georgia from Arizona, she discovered there was no myeloma support group in the Southwestern part of her home state. Barbara’s oncologist introduced her to a social worker and the two of them organized a support group that held its first meeting in the summer of 2009. The group is growing little by little, and welcomes your participation and involvement. “As a cancer warrior,

Llamada a la comunidad hispana con el mieloma múltiple

La IMF tiene el orgullo de anunciar que por primera vez en los Estados Unidos, existirá un grupo de apoyo para la comunidad hispana con el mieloma múltiple en español. La primera reunión se celebrará el primero de mayo en Los Angeles. Para más información, contacte a Betty (Mirna) Arevalo por email marevalo@myeloma.org o sin costo al 800-452-2873.

The IMF is pleased to announce that the first ever Spanish-language myeloma support group meeting in the US is scheduled to take place on May 1 in Los Angeles, CA. For more information, please contact Betty (Mirna) Arevalo at marevalo@myeloma.org or 800-452-CURE (2873).

Date/Fecha: May 1, 2010

Time/Hora: 10 AM – 12 PM

Location/Dirección:

Sheraton Universal Hotel (in the Board Room)
333 Universal Hollywood Drive, Universal City, CA 91608

I realize that every day is a blessing,” says Barbara. “As group members, we learn so much from each other and help in our own healing by sharing with others.” The SOWEGA Multiple Myeloma and Stem Cell Transplant Support Group meets on the first Thursday of each month at 5:30 PM in Albany, GA. For more information, please contact Barbara Blake at bblake5186@aol.com or 229-308-7337.

Shreveport/Bossier, LA: Donna LaRocque, whose husband Roger was diagnosed with myeloma in 2005, has started a new myeloma support group at the LSU Health Sciences Center’s Feist-Weiller Cancer Center. “I call myself an outreach program,” says Donna, who had previously started a successful myeloma support group in East Texas. The first meeting of the Shreveport/Bossier Area Multiple Myeloma Support Group was held on March 15th. For more information about upcoming meetings, please contact Donna LaRocque at donnajune@cablynx.com or 903-918-9553.

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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.

SPOTLIGHT ON ADVOCACY

Important policies and political issues that impact the myeloma community



By Christine Murphy

Since the start of the New Year, the IMF has been working hard to advance legislative policies that benefit myeloma patients. With the passage of health reform, Congress is beginning to look at other health related priorities that would benefit the myeloma community. Below are some of the issues that IMF will be focusing on throughout 2010.

Has Your U.S. Representative Cosponsored the Cancer Coverage Parity Act (HR 2366)?

Representative Brian Higgins (D-NY) introduced the Cancer Drug Coverage Parity Act of 2009 (HR 2366) on May 12th, 2009. HR 2366 eliminates the inequities for cancer patients whose insurance coverage has differences in the way oral and intravenous chemotherapy treatments are covered. The IMF needs your help to build support for this important piece of legislation. Currently HR 2366 has 5 co-sponsors (4 D, 1 R). To encourage your U.S. Representative to become a co-sponsor, please visit the Advocacy Action Center at <http://www.capwiz.com/myeloma/issues/alert/?alertid=14033126>.

President's Federal Budget Includes Funding Increases and Cuts to Myeloma Programs

On Monday, February 1st, the President released his budget for fiscal year (FY) 2011. The President's Budget includes \$32.09 billion for the National Institutes of Health (NIH), an increase of \$1 billion (3.2 percent) over the FY 2010. The proposed NIH budget includes \$5.26 billion for the National Cancer Institute, an increase of \$161 million (3.16 percent). The President's Budget also provides \$2.5 billion for the Food and Drug Administration (FDA), an increase of \$148 million (6.26 percent) over FY 2010.

While this is good news for cancer research, the President's Budget eliminated the Geraldine Ferraro Blood Cancer Program at the Centers for Disease Control and Prevention (CDC), which received \$4.7 million in FY 2010. This is an important program to the myeloma community and the IMF will work with our champions in Congress to ensure that this crucial program continues to receive funding.

House Will Introduce the 21st Century Cancer ALERT Act

In 2009, former Senator Ted Kennedy (D-MA) and Senator Kay Bailey Hutchison (R-TX) introduced S 717, the 21st Century Cancer Access to Life-Saving Early Detection, Research, and Treatment (ALERT) Act. This legislation is an update to the National Cancer Act of 1971. The ALERT Act was put on hold for health care reform and the death of Senator Kennedy. Senator Hutchison is committed to moving this legislation and will be teaming up with Senator Dianne Feinstein (D-CA) to move the ALERT Act.

Additionally, Representatives Lois Capps (D-CA) and Frank Pallone (D-NJ) intend to introduce the House companion to the ALERT Act.

IMF Campaign on Health Reform

IMF led a campaign calling on Congress to retain a sharp focus on critical elements of health reform. Essential issues of immediate importance to patients should not be lost in partisan battles. These essential issues included:

- Affordable access to basic and catastrophic health care coverage for as many Americans as possible.
- The elimination of "pre-existing conditions" as a barrier to health care coverage.
- The elimination of annual and lifetime caps on insurance coverage.
- Closing of the Medicare "donut hole."
- Continued investment in research and innovation to address the needs of those with all deadly diseases.

While many of these essential issues have been addressed in the recently passed health reform bill, IMF will be working with Congress to ensure that all of them are eventually addressed in future legislation.

Health Insurance Reform Signed Into Law

On Tuesday, March 23rd, the President signed into law the *Patient Protection and Affordable Care Act* which transforms significant portions of the health care environment and contains a number of reforms that will benefit myeloma patients. Once the underlying legislation became law, the House and the Senate passed the Health Care and *Education Reconciliation Act* (amendments to the health reform bill).

Based on IMF's campaign on health reform (listed above), below is a list of the provisions that are important to myeloma patients:

- **Access to Clinical Trials.** Health insurance plans will be required to provide coverage for routine costs associated with participation in clinical trials. This will help myeloma patients as many 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.
- **Medicare "Donut Hole" Closure.** The bill provides a \$250 rebate to Medicare beneficiaries who reach the Part D coverage gap in 2010 (Effective January 1, 2010). It also phases down gradually the beneficiary coinsurance rate in the Medicare Part D coverage gap from 100% to 25% by 2020.
- **Medicare Part D Prescription Discounts.** For brand-name drugs, pharmaceutical manufacturers will provide a 50% discount on prescriptions filled in the Medicare Part D coverage gap beginning

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SUPPORT GROUPS — continued from page 10

NEW support groups invite YOU to join them

Eau Claire, Wisconsin: For more information, please contact Colleen O'Connor at eauclairemymeloma@me.com or 715-835-2303.

Richmond, Virginia: For more information, please contact Barbara Marx at gobabsgo@aol.com.

York, Pennsylvania: For more information, please contact Sharon Berger at yorkbergers@verizon.net or 717-292-5890.

2010 IMF Annual Support Group Leaders' Retreat

This year's Support Group Leaders' Retreat will commence at 1 p.m. on July 23rd at the beautiful Four Seasons Resort & Club, Dallas at Las Colinas, in Irving, TX. The retreat will conclude at noon on July 25th. Alan Kumomoto will once again serve as facilitator. We are confident that everyone who attends the retreat will take away lots of helpful information to bring back to their group to make it even better! **MT**



IMF Welcomes Joanie Borbely

The IMF is pleased to announce that Joanie Borbely has joined our team as the Regional Co-director of Support Groups SE (South East). Joanie has been a volunteer at the IMF since its inception. She holds a degree in Speech Pathology and Audiology from Emerson College, which she applied for 10 years in private practice before moving on to a career in sales. Joanie has a long history as an advocate for the myeloma community. Located in Florida, Joanie now serves as an additional member of the IMF for the myeloma support groups in the region. She can be reached at jborbely@myeloma.org or 860-655-7107.

SPOTLIGHT ON ADVOCACY — continued from page 11

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). The bill will also reduce the out-of-pocket amount that qualifies an enrollee for catastrophic coverage.

- **Elimination of Annual and Lifetime Benefit Caps.** Both the health reform bill and the reconciliation bill include provisions that eliminate annual and lifetime caps on insurance coverage. Lifetime and annual limits on private insurance pose a considerable problem for individuals with myeloma. Patients who exceed their annual or lifetime limits have to find other ways to pay for medical costs, such as paying more out of pocket, finding new insurance, or worse curtail medical care. Lifetime limits would be eliminated in all health insurance plans – both new and existing – six months after enactment. Annual limits would be restricted in new plans until 2014, after which they would be prohibited in all new and in existing group health insurance plans.
- **Elimination of Pre-Existing Conditions as Insurance Barrier.** 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 insurance including myeloma patients. Additionally, adults who are uninsured because of pre-existing conditions will have access to affordable insurance through a temporary subsidized high-risk pool beginning this year. **MT**

Editor's Note: For more information, or to take action, please visit the IMF's Advocacy Action Center at www.advocacy.myeloma.org.

How to contact the IMF Advocacy Team



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International Myeloma Foundation
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IMF Welcomes Meghan Pullarn

We are pleased to announce that Meghan Pullarn has joined the IMF to assist with our Advocacy program. Meghan has more than 8 years of marketing and communications experience across a broad range of industries. Her focused experience is in strategic planning, copywriting, and event planning. Meghan earned her Bachelor's degree from Towson University, and holds an MBA from Loyola University Maryland.

In her new role at the IMF, Meghan will assist with the Advocacy program grassroots outreach, event coordination, and social media campaigns. She will also assist the IMF Advocacy program with its overall goal of raising visibility across the country while shaping public policy to meet the specific needs of myeloma patients.

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 Paul Hewitt, Missy Klepetar, Nancy Baxter, and Debbie Birns. The phone lines are open Monday through Friday, 9am to 4pm (Pacific Time).

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

Is the use of gadolinium in MRI a necessary part of the imaging test and is it safe?

MRI (magnetic resonance imaging) is a diagnostic test that uses magnetic energy to produce detailed two- or three-dimensional images of organs and structures inside the body. It can provide 20-30% more information than a standard x-ray (a form of electromagnetic radiation). An MRI test is useful in assessing the disease state

of a patient with multiple myeloma. It can detect the amount of myeloma cell infiltration in the bone marrow before bone destruction is evident on x-rays. An MRI is excellent for imaging of the axial skeleton (the bones of the head and neck, rib cage, and vertebral column) and can help distinguish between benign and malignant compression fractures. It can illustrate spinal cord compression as well as head and neck plasmacytomas. In myeloma, MRI is considered to be more sensitive than standard radiography.¹

Gadolinium is a contrast agent – a dye injected into the body to enhance images from the MRI. Gadolinium is a colorless, non-radioactive, water-like liquid. It is toxic but usually rapidly cleared by the kidneys. Gadolinium is taken up by active myeloma lesions. This contrast enhancement can help identify areas of myeloma involvement. However, there has been some debate regarding the wisdom of using gadolinium in myeloma patients because of potential risks. Many myeloma patients have kidneys that are compromised by their disease and their creatinine clearance is lower than in individuals with healthy kidneys. Patients with renal dysfunction who get an MRI using gadolinium dye are at risk to develop Nephrogenic Systemic Fibrosis (NSF). NSF is a systemic disease, meaning it affects multiple systems of the body or the body as a whole. Symptoms of NSF include hard, shiny, reddened or darkened patches of skin that tighten and become extremely painful; joint inflexibility; painful joints; loss of movement; yellow-colored eyes; as well as potential lung, heart, and other organ damage. This is therefore rather a serious potential side effect.

It is thus best to avoid use of gadolinium in the setting of known renal compromise. In addition, it is worthwhile to note that at the December 2009 American Society of Hematology (ASH) meeting in New Orleans, data was presented by Mariateresa Fulciniti, PhD (Dana-Farber Cancer Institute, Harvard Medical School, Boston, MA), entitled



Paul Hewitt, Missy Klepetar, Nancy Baxter, and Debbie Birns

“Gadolinium-containing contrast agent promotes multiple myeloma cell growth: implication for clinical use of MRI in myeloma” (ASH abstract 1809). Dr. Fulciniti’s collaborators included others at Dana-Farber Cancer Institute and researchers at the Myeloma Institute at the University of Arkansas (Little Rock, AR).

The investigators involved in this study of gadolinium, both in the laboratory setting and in the tissues of myeloma patients, drew the following conclu-

sion: “These results, confirming both in vitro and in vivo growth-promoting effects of Gd-containing contrast agent on multiple myeloma, suggest the need for further analysis of the mechanism of its action on myeloma cells and careful analysis of its clinical impact in multiple myeloma patients undergoing MRI evaluation.” To watch the video of Dr. Fulciniti’s IMF interview at ASH, read the abstract, and see the poster for this presentation, please visit the IMF website at www.myeloma.org.

The question thus becomes: is it possible to get sufficient information from MRI imaging without using gadolinium? The answer appears to be yes. Large groups specializing in multiple myeloma, such as the Myeloma Institute in Little Rock and others, specifically exclude gadolinium from their standard MRI sequence protocols. **The new International Myeloma Working Group (IMWG) imaging guidelines² likewise recommend imaging without gadolinium in part to avoid the risks, but also because excellent results can be obtained without gadolinium.**

In conclusion, it is possible for an imaging specialist to perform an MRI without the use of gadolinium and still get an accurate assessment of disease. This avoids any potential risks. Please discuss all of the above with your oncologist and/or radiation oncologist prior to having an MRI.

Editor’s Note: If you would like to obtain copies of the referenced papers, please contact IMF Hotline Coordinators at 800-452-CURE (2873).

¹ Engelhardt M, Kleber M, Frydrychowicz A, et al. “Superiority of magnetic resonance imaging over conventional radiographs in multiple myeloma.” *Anticancer Research*, 29:4745-4750, 2009.

² Dimopoulos M, Terpos E, Comenzo RL, et al. “International myeloma working group (IMWG) consensus statement and guidelines regarding the current role of imaging techniques in the diagnosis and monitoring of multiple myeloma.” *Leukemia*; 23:1545-1559, 2009.

UPDATES FROM AROUND THE GLOBE

Report from IMF Japan

By Daisuke Nakao

IMF Japan was founded by myeloma patient Akira Horinouchi in 1997, after he relapsed from an autologous transplant. Aki found comfort and drew strength from the IMF and its listserv (mailing list). He wanted to share with other myeloma patients in Japan the benefits that he received through his relationship with the IMF. Aki became the driving force behind IMF Japan with his commitment to reach out to people across Japan to offer support and let them know that they are not alone in their battle with this disease. Aki also inspired members to support the search for a cure by raising funds to benefit myeloma research.

Today, IMF Japan not only keeps Aki's vision and spirit alive, it continues to grow and serve more people in more ways. IMF Japan is currently being run by seven board members, headed by Midori Horinouchi, Akira's wife. The mission of IMF Japan is based on four pillars:

1. Provide accurate and timely information in Japanese
2. Connect patients and their medical teams
3. Provide for a patient community
4. Work towards a cure

IMF Japan publishes a bi-annual community magazine, "Ganbarimassyo!" which is colloquial Japanese for "Give it a try." We also host seminars and study sessions all over Japan, the latter being held in co-operation with the Japan Myeloma Study Group (JMSG). We maintain an information website, which also hosts a community bulletin board (<http://myeloma.gr.jp>). IMF Japan also provides funding for promising myeloma research and clinical trials through its annual Aki Award research grant. We also petition the national government and Diet representatives for the rapid approval of new drugs.



Susie Novis and Dr. Brian Durie being introduced to the seminar participants

Every November, IMF Japan holds its annual Patient & Family Seminar, at a different location each year to make it more accessible to members around the country. These seminars are full-day events, with a lot of talking and a lot

of studying. The faculty presenters are some of the best myeloma specialists in Japan, all belonging to the JMSG, which is headed by Dr. Shimizu, who is also on the scientific advisory board of the IMF. IMF Japan seminars are scheduled on the day following the annual meeting of the JMSG so as to make scheduling easier on the doctors.

The 12th annual seminar was held on November 21-22, 2009. Niigata City, a large port-city facing the Sea of Japan, provided a fascinating setting for the meeting. Niigata is famous for its rice and sake (rice wine).



IMF Japan's Kyoko Joko and Daisuke Nakao with Susie Novis and Dr. Brian Durie at the closing ceremonies. In the background is IMF Japan's "Thank You Doctor Tree" with letters from myeloma patients.

The 12th annual seminar was very special in a number of ways. We had a record turnout of more than 200 participants. For the first time, JMSG and IMF Japan totally integrated their respective annual events into a two-day event. The first day targeted the medical professional community (though patients were free to attend), and the second day was dedicated to patients and their families (although doctors were free to attend as well).

The first day of the event was a departure from previous JMSG annual meetings in that the role of "co-medicals" (such as nurses and pharmacists) were highlighted as key players of the medical team. Talks were given on themes such as nursing, medication control, and patient-doctor relationships, with each presentation followed by a panel discussion. I was pleased to present the patient-doctor relationship talk on behalf of IMF Japan.

The 2009 IMF Japan meeting was a momentous event for the myeloma community in Japan, but there was something even more special that weekend. IMF president Susie Novis and chairman of the board Dr. Brian Durie flew in to join us at the meeting! There was a dinner with the IMF staff on Friday, presentations on Saturday, followed by a Saturday dinner party with patients, family members, and staff, and on Sunday, a family member talk session headed by Susie. A lot of patients and family members who heard Susie and Brian talk came up to us and said that they have not been so comforted, felt so cared for in a long while. Brian and Susie, they do have a magic touch!

Brian and Susie, many thanks from all of us at IMF Japan. Together, we will continue to significantly further the cause of myeloma education and awareness in Japan. We hope to see you visiting us again soon! **MT**

National Myeloma Day in Australia

The Leukaemia Foundation of Australia is holding its inaugural National Myeloma Day on Wednesday, May 19, 2010. The event will take place across all states and territories in Australia. For more information, please email myeloma@leukaemia.org.au. A recap of the day's events will appear in the summer issue of *Myeloma Today*.

IMFERS RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia



Now in its 20th year of service to the myeloma community, the IMF continues to strive to be your foundation in the most inclusive way possible. Working with IMFers across the country and around the world, our Member Fundraising program has blossomed into a network of people like you, raising money for myeloma research and educational programs.



By organizing an event in your community, you are raising public awareness among those who have never heard of myeloma, while helping those whose lives have been touched by this disease know where to turn for the most up-to-date information and resources. You know you want to do something in your community, but deciding on what to do and how to do it can be confusing. The IMF's FUNdraising program is here to make it as easy as possible for you to participate, whether or not you have any previous experience with such activities.

FUNdraising is fun (get it?) 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 the progress of making miracles happen!

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



Liz Stafford & Greg Kurantowicz Get Married!

On September 18, 2009, IMFer Liz Stafford married her high school sweetheart Greg Kurantowicz at the Church Of Saint Timothy in West Hartford, CT. Liz has been a part of the IMF family since she was a high school student raising awareness and funds for myeloma research in honor of

her father, Jeffrey Stafford. Liz organized the first annual WAMP Swim-a-thon at the Wampanoag Country Club in 2001 along with her siblings Julianne, Christopher, and Courtney.

Throughout her college years and while she worked as an intern in the nation's capitol,



Liz and her father

Liz and the entire Stafford Family have remained committed to the WAMP Swim-a-thon tradition. Over the years, hundreds of swimmers have participated in raising funds to fight myeloma. The funds raised through the WAMP Swim-a-thon have supported cutting-edge research through IMF Brian D. Novis Grants awarded to investigators working in the field of myeloma.



The whole bridal party wore IMF bracelets in honor of Liz's father

In lieu of wedding favors, Liz and Greg made a contribution towards the Jeffrey Stafford research fund at the IMF. In fact, the entire wedding party got into the spirit with everyone wearing IMF burgundy bracelets and all the grooms-men wearing IMF ribbon pins in their lapels in honor of Liz's father. Please join us in wishing the Stafford and Kurantowicz Families all the best for many years to come!

All wedding photos courtesy of Carla Ten Eyck and Mike Romano:



Alexandra Zousmer and Joanna Share in the shirts they designed for their Misbehave for Myeloma event

Misbehave for Myeloma

On September 25, 2009, Alexandra Zousmer and her cousin Joanna Share co-hosted a myeloma fundraising event at Captain Morgan's Club, located at the legendary Wrigley Field baseball stadium in Wrigleyville, a neighborhood of Chicago, IL. Wrigley Field was built in 1914 and has served as the home ballpark of the Chicago Cubs since 1916. The Captain Morgan Club, located near the Harry Caray statue at the southeast corner of the ballpark, has a partnership with the Cubs and serves as a fan headquarters outside Wrigley Field.

When Alex and Joanna decided to organize the Misbehave for Myeloma benefit to raise funds for myeloma research in honor of Arnold Zousmer (Alex's dad and Joanna's uncle), they knew exactly what they wanted to do. "We have all heard of those stuffy charity events where you have to get dressed up and pay lots of money to have dinner with people you don't know, right? Well, we decided to spice it up a bit." For a \$30 entry fee, guests were granted access to a 3-hour open bar, as well as a silent auction and raffle with loads of great items.

More than 150 friends gathered to honor Arnold Zousmer and to support the Zousmer and Share families. In addition, 55 national and local sponsors contributed to the event's success. Together, organizers



Alexandra with her father Arnold Zousmer

CONTINUES ON PAGE 16

Member Events

MEMBER EVENTS — continued from page 15



The cousins celebrate the astounding success of their first fundraising event!

and supporters brought the total raised for myeloma research close to \$15,000! “The event was so much fun for everyone, the turnout was bigger than we ever expected, and the support for IMF was unreal!” says Alex. “My dad was smiling the whole time!”

“We cannot thank the IMF enough for their unconditional dedication to improving the quality of life of myeloma patients while working toward prevention and a cure of this life-altering disease. Myeloma research and support would not be where

it is today without the IMF,” says Joanna. “Our event did more than raise money and awareness; it raised everyone’s spirits and made my uncle and all our family members and friends very happy. The experience was awesome!!!”

The cousins are already working on their 2010 fundraiser, which promises to be even bigger and more successful than the last. If you wish to join the Zousmer and Share families on November 6, come to Harry Caray’s at 3551 North Sheffield in Wrigleyville, visit the event’s IMF web page at <http://online.myeloma.org/netcommunity/misbehaveformyeloma2010>, look for Misbehave for Myeloma on Facebook at <http://www.facebook.com/pages/Misbehave-for-Myeloma/105089836188137?ref=ts>, or call the IMF at 800-452-CURE (2873)!

TriBeCans for the Fight Against Myeloma

A philanthropic organization dedicated to helping myeloma patients by raising funds for the IMF, TriBeCans for the Fight Against Myeloma was formed by Donna Marotta, Nicole Bennett, and Melanie Lawley. The organization was the idea of TriBeCa resident Donna Marotta, whose grandmother Marie Moretti was diagnosed with myeloma in April 2009.

“My grandmother had 11 children, so I have a very large extended family, and no one else in our family has ever had cancer,” says Donna. “The diagnosis was devastating for all of us.” After rising above several difficulties associated with chemotherapy and blood transfusions, Donna is pleased to report that Marie is doing well. “Her doctors have come up with a treatment that seems to be holding the disease at bay.”



TriBeCans for the Fight Against Myeloma group members Melanie Lawley, Nicole Bennett and Donna Marotta

Beyond helping her grandmother cope with the day-to-day challenges of myeloma, Donna decided to start working toward a cure by raising funds for research: “We know that new drugs and better treatments are on their way, but money is needed to support myeloma research. It is my goal to be able to contribute to the fight against myeloma by funding scientific advances in the field.”

TriBeCans for the Fight Against Myeloma held the group’s first fundraiser – A Night of Wellness & Beauty – on March 16, 2010. The event was limited to an exclusive list of 30 guests. To ensure the success of the evening, Donna asked



Three generations of women united in their fight against myeloma: Donna Marotta with grandmother Marie Moretti and mother Eleanor Marotta

companies to donate products and friends to volunteer their time. SkinCeuticals, Arbonne, Estée Lauder, Equinox, and Lisa Stewart Jewelry were among the companies that made donations for the auction and the event goodie bags. In addition, Skincare expert Yona Gonen, Urban Nutrient’s Marie Dulev, and celebrity manicurist Elisa Ferri made presentations during the evening. The event’s success exceeded the organizers’ expectations! “We are very pleased with the outcome of our event,” says Donna. “And we are already looking forward to our next event, which we anticipate will happen in the Fall.” For more information, please look for the TriBeCans for the Fight Against Myeloma group on Facebook. **MT**

UPCOMING MEMBER EVENTS

April 24, 2010 MILES FOR MYELOMA 5K Walk/Run

Co-Sponsored by Philadelphia Multiple Myeloma Networking Group, Central New Jersey Support Group, and Northern Jersey Support Group – Philadelphia, PA

For more information, please contact Karen Horan at karen.horan@verizon.net

May 22, 2010 11th annual “JC” Golf Tournament

Wapicada Golf Course – St. Cloud, MN

For more information, please contact Bob Zins at boloz@charter.net

June 5, 2010 3rd annual Czerkies Charitable Golf Outing

Whitetail Ridge Golf Club – Yorkville, IL

For more information, please contact Craig Czerkies at czak16@aol.com

October 3, 2010 “Afternoon Tea”

Four Seasons Hotel – Washington, DC

For information and reservations, please contact Carol Klein at carol60klein@verizon.net

October 20, 2010 Coach Rob’s Charity Golf and Benefit Bash

Rock Springs Ridge Golf Club – Apopka, FL

For information and reservations, please contact Rob Bradford at rbradford@crothall.com

MYELOMA TODAY IN CONVERSATION WITH YOLANDA BRUNSON-SARRABO

When and how did myeloma first enter your life?

My first experience with cancer took place many years ago when my grandmother had breast cancer. I was very young then, but I was the eldest of my generation of cousins, and my grandmother's experience had a big impact on me.

I became very health-conscious, both in terms of being an advocate for a healthy lifestyle and in terms of getting regular health screenings. I had regular check-ups and kept an eye on my slight inclination toward anemia and my vitamin D deficiency, which has been treated with supplements. In 2005, I had a lump in my breast, which understandably caused me quite a bit of concern. Thankfully, it turned out to be benign.

Everything remained relatively normal until 2008, when my annual physical and blood test showed an elevated protein level. My doctor did not explain the possible implications of the abnormality but told me to find a hematologist. I was taking my time trying to find a blood specialist when my doctor called me to follow up a few weeks later on a Sunday evening. It was only then that I realized that something might be wrong.

The hematologist performed a bone marrow aspiration and diagnosed me with multiple myeloma. I was 37 years old.

Did you start treatment at that time?

The doctor wanted to start treatment immediately, and recommended that I take thalidomide as part of the anti-myeloma therapy. At that time, my husband and I were talking about starting a family. Taking thalidomide would put an end to our plans. We realized that we needed to seek another opinion.

My ob-gyn told me about Dr. Robert A. Kyle at the Mayo Clinic in Rochester, MN. Dr. Kyle was exceptionally nice and responsive. He reviewed my medical records and concluded that my myeloma was of the asymptomatic "smoldering" type and did not require treatment. If I had not found a myeloma specialist to review my case, I would have subjected my body to unnecessary treatment. Only in hindsight can I truly appreciate that seeking a second opinion probably added years to my life!

Have you received any treatment since?

No, not for myeloma. At one point I developed a painful solitary plasmacytoma on my sternum, which was treated with radiation. By that point, I was under the care of a local myeloma specialist who was recommended by Dr. Kyle. I also have had a small lesion for two years now, but it doesn't appear to be doing anything so my doctor and I have chosen to just keep an eye on it. Otherwise, I've remained very active in my life. I have blood tests performed every couple of months, and see the specialist if there is a shift in my numbers. Right now, if my numbers remain good, I won't need to see my myeloma doctor for another six months.

What has happened to your plans for starting a family?

That has remained a quandary for us. My husband and I have been told that trying to conceive might activate my myeloma. My doctor says that



he can't tell me not to do it. The decision is ours. I am still pretty healthy so, if we wish to proceed, this would be a good time to try to have a child. Of course, my husband worries that this might put my life on the line. We will be having a consultation with a fertility specialist to weigh the risks of our situation. And I would welcome hearing from IMFers who might have had to face a similar decision, so if anyone would like to reach out, please write to me care of the IMF.

Do you and your husband have a support network around you?

Eventually, we told our families, and we have gradually told a few friends. Some people have been supportive while others have had difficulty processing the "cancer" word. No one at work knows.

I'm a young black female. Statistics show that myeloma is highly prevalent in the African-American community, but many people are clueless to this fact. And I've not met anyone else in my situation.

In addition, my myeloma is still "smoldering". On the one hand, I have not had to deal with some of the challenges faced by patients whose disease is active. On the other hand, I feel like a ticking time bomb, living and coping with this diagnosis daily. The isolation can be a bit frightening.

Have you met any other African-Americans with myeloma?

For more than 10 years, I have worked in the fashion industry, holding various positions in production and technical departments of major fashion labels. In 2005, I penned my first book – "The Ins And Outs Of The Fashion Industry From A Fashion Insider" – about the trials and tribulations of building and maintaining a career in a very competitive and intense industry called fashion. The book's editor is also black. When I told her that I had cancer and was thinking of writing about my myeloma journey, she broke down and told me that two of her friends passed away from this disease. She is the only person of color I know who had actually even heard of myeloma.

You've remained very private about your diagnosis. Why are you now choosing to speak about it?

I'd like to share my story, especially within the black community, in hopes that I can raise awareness of myeloma and encourage people to get more regular health screenings. Being diagnosed while my disease is still smoldering has given me options I would not have had if my myeloma was active at diagnosis. And I would recommend that everyone diagnosed with this cancer seek a second opinion from a myeloma specialist – this certainly made a big difference in my case. And I do understand the type of strength that is in all of us, which helps us in times of uncertainty, as well as the hope that helps us live life a little brighter each day from our new outlook. **MT**

Editor's Note: If you or someone you know has a story to share with the readers of Myeloma Today, please contact Marya Kazakova at mkazakova@myeloma.org or 800-452-CURE (2873).

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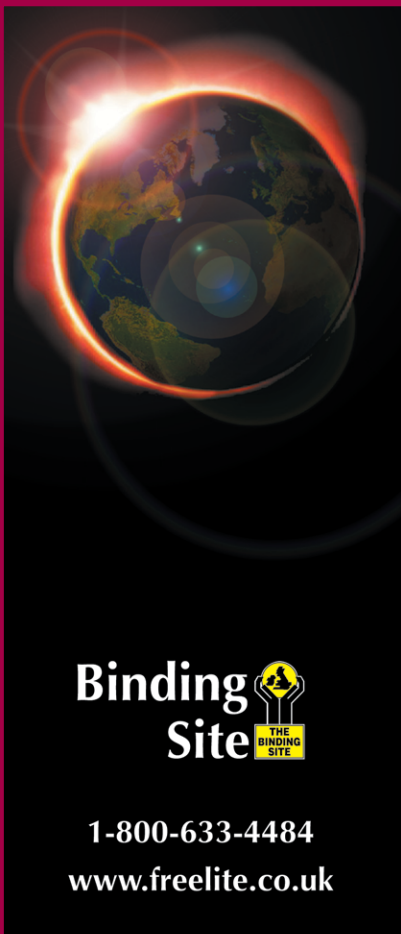
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¹ Katzmann, J.A., et al. Mayo Clinic Proc. 2006;**81**(12):1575-78

² Pratt, G. et al. Leukemia and Lymphoma. 2006;**47**(1):21-28

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2010 IMF Calendar of Events

- | | | | |
|------------|--|------------|--|
| April 21 | IMF Patient & Family Seminar – Paris, FRANCE | Aug 27-28 | IMF Patient & Family Seminar – Los Angeles, CA |
| April 27 | IMF Clinical Conference – Moscow, RUSSIA | Sept 18 | IMF Regional Community Workshop – Shreveport, LA |
| May 13-16 | Oncology Nursing Society (ONS) meeting – San Diego, CA | Sept 23-24 | 6th Int'l Serum Free Light Symposium – Bath, UK |
| May 21-22 | IMF Patient & Family Seminar – Portland, OR | Sept 25 | IMF Regional Community Workshop – Las Vegas, NV |
| June 4-8 | American Society of Clinical Oncology (ASCO) meeting – Chicago, IL | Oct 15-16 | MMHÖ/IMF Patient & Family Seminar – Vienna, AUSTRIA |
| June 8-9 | International Myeloma Working Group (IMWG) summit – Barcelona, SPAIN | Oct 16 | IMF Regional Community Workshop – Raleigh/Durham, NC |
| June 9 | Robert A. Kyle Lifetime Achievement Award dinner – Barcelona, SPAIN | Oct 18 | IMF Patient & Family Seminar – Bologna, ITALY |
| June 10-13 | European Hematology Association (EHA) meeting – Barcelona, SPAIN | October | IMF Patient & Family Seminar – Barcelona, SPAIN <i>(date TBD)</i> |
| June 10-13 | Eastern Cooperative Oncology Group (ECOG) meeting – Washington, DC | Oct 21-23 | Southwest Oncology Group (SWOG) meeting – Chicago, IL |
| July 16-17 | IMF Patient & Family Seminar – Cincinnati, OH | Oct 23 | IMF Regional Community Workshop – Kansas City, MO |
| July 23-25 | IMF Support Group Leaders' Retreat – Dallas, TX | Oct 23 | Myeloma Canada Patient, Family, & Healthcare Professionals Conference – Richmond, BC, CANADA |
| Aug 8 | IMF Regional Community Workshop – Honolulu, HI | Nov 5-7 | Eastern Cooperative Oncology Group (ECOG) meeting – Ft. Lauderdale, FL |
| Aug 13-14 | IMF Patient & Family Seminar – Philadelphia, PA | Nov 13 | 4th Annual Comedy Celebration – Los Angeles, CA |
| | | Dec 4-6 | American Society of Hematology (ASH) – Orlando, FL |

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.