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# 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. Robert Z. Orlowski** (The University of Texas MD Anderson Cancer Center, Houston, TX) has been working on proteasome inhibitors since the early clinical trials of VELCADE® (bortezomib), a drug that has contributed to the doubling of average survival in patients with myeloma in the past 10 years. KYPROLIS™ (carfilzomib) is a second-generation proteasome inhibitor, which was recently approved for myeloma. Dr. Orlowski discusses the ENDEAVOR clinical trial, a head-to-head comparison of progression-free survival (PFS) in patients randomized to receive a combination therapy with either Velcade or Kyprolis. **PAGE 5**



**Dr. Sagar Lonial** (Winship Cancer Institute, Emory University School of Medicine, Atlanta, GA) discusses MLN9708, an oral proteasome inhibitor currently in clinical trials. With a structure similar to VELCADE® (bortezomib), MLN9708 has a bit more potency when it comes to its ability to bind to the proteasome. In addition, even when compared to Velcade given subcutaneously (SQ), there is markedly less peripheral neuropathy (PN) with MLN9708 than with Velcade. MLN9708 also offers the convenience of an oral medication, which can be conducive to preserving quality of life of patients who are coping and living with this myeloma. **PAGE 7**

## Supportive Care



**IMF Hotline Coordinators** discuss diet for myeloma patients. Nutritional science has long wrestled with the question of how food influences the immune system. This is an extremely complex and layered field of inquiry. Researchers in myeloma and in nutritional science have not been able to determine specific guidelines for foods that will be beneficial for myeloma patients, or indeed, for any other cancer patients. There are, however, some good general guidelines. **PAGE 9**



**Sandra Kurtin, RN, MS, AOCN, ANP-C** (The University of Arizona Cancer Center, Tucson, AZ) discusses strategies for pain management in myeloma. Whether pain is acute, chronic, or breakthrough, it is one of the more complicated symptoms, affecting most aspects of life, not only physical functioning, but also social, emotional, and psychological status. Taking an active part in treating pain effectively can help patients better plan for success. **PAGE 10**



## Patient Experience



**Steven Miro** was diagnosed with myeloma during his junior year of high school. He was 17 years old. After experiencing symptoms since age 15, and being told by doctors that nothing was wrong, tumors were found on Steven's neck, head, ribs, and spine. Through chemotherapy, a stem cell transplant, and more chemotherapy, Steven continued to go to school as long as possible, and he graduated. Now 21 years old and in remission, Steven attends the Police Academy and a local community college, and hopes re-enlist in the US Army. **PAGE 14**

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## ASH 2012: The Busiest Ever

The Annual Meeting and Exposition of the American Society of Hematologists (ASH) is always a busy venue for myeloma researchers. However, this year – with the recent FDA approval of carfilzomib (Kyprolis®) and pending approval of pomalidomide – the diverse options and changing paradigm for novel therapy led to a multitude of meetings occurring at a frantic pace. The IMF has captured the activities of the 54th Annual Meeting, held December 8–11 in Atlanta, GA, in a variety of forms – including webcasts, blogs, on Twitter and Facebook, and in interviews with key investigators. A post-ASH teleconference to provide a summary will be held by the IMF on January 17, 2013. In the meantime, we invite you to experience ASH 2012 through our eyes by visiting our website [myeloma.org](http://myeloma.org) and clicking on the “webcasts” tab to view the following videos:

### “Controversies in Multiple Myeloma: Current Debates in Optimal Care”

Presentations include an overview of the treatment landscape in myeloma (Dr. Robert Z. Orlowski), defining high-risk myeloma (Dr. Ola Landgren), smoldering myeloma

(Dr. Jesús F. San Miguel), and optimal therapies for transplantation-ineligible patients (Dr. Brian G.M. Durie), plus a debate on minimal residual disease between Dr. Philippe Moreau and Dr. Jesús F. San Miguel.

### “Journalists’ Workshop with Leading Myeloma Experts”

Watch presentations from leading myeloma experts at a workshop for international journalists. The physicians discuss important myeloma topics presented at the 2012 ASH meeting, including the latest treatments in development. Speakers include Dr. Brian G.M. Durie, Dr. Paul G. Richardson, Dr. Xavier Leleu, and Dr. Robert Orlowski.

### “International Myeloma Working Group (IMWG) Conference Series: Making Sense of Treatment”

Hear the expert opinions and the latest thinking on myeloma in this second installment of the popular series of IMWG debates. This debate between world-recognized experts from the United States (Dr. Brian G.M. Durie and Dr. Paul G. Richardson) and Europe (Dr. Philippe Moreau and Dr. Antonio Palumbo) is an event you don't want to miss.

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# A Message from the President

## Dear Reader,

I sometimes like to pause during a busy day and take stock of how much has changed since the first time I heard the word myeloma over 22 years ago. Back then, we couldn't Google myeloma to find out that it wasn't skin cancer. We couldn't just take out our smart phones and navigate to the nearest cancer center or support group. There wasn't a myeloma Hotline staffed by specialists who could talk us through the most difficult days of our lives. We certainly didn't have access to the top myeloma doctors in the world to ask them our questions. And I wouldn't have been able to name three pharmaceutical companies that manufactured drugs for myeloma.

Comparing the IMF of today to the IMF at the time of our founding, it is remarkable how far we've come. Then, we were a fledgling organization trying to help people and make a difference in the world. Today we are still helping people and making a difference, but we are also recognized globally as the leader in advancing results-driven myeloma research. Through the efforts of the International Myeloma Working Group (IMWG), the Asian Myeloma Network (AMN), and more than 100 projects funded by Brian D. Novis Research Grants, the IMF produces tangible, effective outcomes that prolong the lives of myeloma patients.



Over the past 22 years, I have met and become close friends with many of those patients – wonderful, talented, smart, funny people who happen to have myeloma. I have watched in awe as they faced their diagnoses with courage and grace. Some have become Support Group Leaders, sharing their strength with their communities. Others have

become active advocates, carrying the voice of the myeloma community to their elected officials. Yet others have helped support the work we do by raising awareness and much needed funding through our Member Events program.

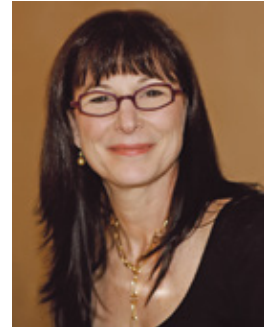
Although I am married to one, I am not an expert on multiple myeloma. I do, however, sit in an office just across the way from the IMF's four extremely knowledgeable and compassionate Hotline Coordinators. I have access to their wealth of information. And so do you. They gladly share it through the toll-free Hotline, at Patient & Family Seminars (PFS), Regional Community Workshops, Myeloma Center Workshops (MCW), and through regularly scheduled teleconferences.

In 1992, the IMF organized the first clinical conference on myeloma in Scottsdale, AZ. Since then, the topic of myeloma has gone from being a peripheral concern at the annual meeting of the American Society of Hematology (ASH) to a highly anticipated forum to announce advances in myeloma treatment and research.



In 2001, we saw the need to bring together an international body of myeloma experts so they could do something rare in research: collaborate in order to share ideas and

brainstorm on the most promising research projects. Today, the IMWG publishes the most highly recognized and most often cited work in the myeloma community. To give you an example of how influential the body of published work of the IMWG is: It was cited last year at the FDA's Oncologic Drugs Advisory Committee (ODAC) hearing on Kyprolis™ (carfilzomib). Because of the work of the IMWG, we have another new treatment option available to myeloma patients today.



And now, as an offshoot of the work of the IMWG, the IMF is once again paving the way in research with the creation of the Black Swan Research Initiative. This unique approach encourages the simultaneous exploration of multiple avenues of research, enabling us to design the protocols that will lead to the cure that much faster. But... more on the Black Swan Research Initiative later. This groundbreaking program is still very young (just a signet ring now), but in the coming months you will see and hear a lot more about this promising new initiative.



In the areas of patient support and education, the IMF was – and continues to be – the most innovative organization in the cancer community. We held the first-ever Patient & Family Seminar in 1992 because we believed from



the start that access to information and experts was key to helping patients live longer and better lives. We are proud to see that this

program has been replicated throughout the medical world. We are even more proud as the program has evolved with the creation of our Regional Community and Myeloma Center Workshops. These one-day workshops bring myeloma experts into communities and within reach of people who might otherwise have no access to them.

Created in 1993, the Info Pack – full of free publications that are often the patient's first word that there are people living with myeloma – is one of the



IMF's most enduring educational programs. Back then, producing Info Packs involved spending hours at the copier churning out as many as we could. Today, the IMF maintains a library of over 100 publications offered in thirteen languages – all for free.

We have also evolved along with technology. We launched the first myeloma-focused website in 1996. Today, the IMF website, myeloma.org, is a vast repository of



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This free issue of *Myeloma Today*© (Volume 9, Number 4) is dated December 31, 2012. *Myeloma Today*© is a quarterly (Spring, Summer, Fall, and Winter) publication of the International Myeloma Foundation, located at 12650 Riverside Drive, Suite 206, North Hollywood, CA 91607 USA.

# Dear Reader

DEAR READER — continued from page 3

information including webcasts, audio teleconferences, research publications, links to support, blogs, and so much more. The website has been reconfigured as an app for the iPad and iPhone – making the information portable and accessible away from your computer. We share important information as it happens using Facebook and Twitter. We were the first in the myeloma space to make use of the latest live-streaming technology as we brought the IMWG's Conference Series into your home or office. We are planning to use this technology to share even more information with you in the coming year.



Looking back, we never could have imagined in 1990 the scope and range of what the IMF was capable of achieving. Myeloma is a global problem; it requires a global solution. Today, the IMF is on the front lines of addressing this problem from every angle.

We are the leader in internationally collaborative myeloma research. We are the premier source of education for patient and healthcare providers alike. We are supporting patients and their families across our country and around the world. We are advocating for the needs of patients everywhere.

We are the International Myeloma Foundation and we are here for you.

Warmly,

Susie Novis, President



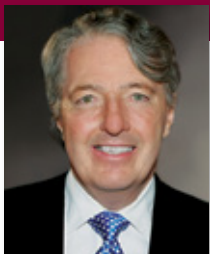
## INTERNATIONAL MYELOMA FOUNDATION DONOR APPRECIATION EVENT

February 28th • Boca Raton, FL

Join Dr. Brian G.M. Durie, IMF Chairman of the Board, and Dr. Ola Landgren, Senior Investigator and Chief of the Multiple Myeloma Section at the National Cancer Institute, as they present an update on the evolving landscape of myeloma research. Drs. Durie and Landgren will also provide an exclusive glimpse at the IMF's innovative Black Swan Research Initiative and its first project, *Sorting Out Myeloma*.

An intimate dinner in appreciation of our donors' generous support will follow.

*Minimum Annual Gift Required. Please contact Heather Cooper Ortner at [hortner@myeloma.org](mailto:hortner@myeloma.org) or 800-452-CURE*



## PROTEASOME INHIBITORS IN CLINICAL TRIALS

*Myeloma Today* in conversation with Dr. Robert Z. Orlowski

### You've had a long history with proteasome inhibitors. Please give us a brief recap.

I have been working on proteasome inhibitors for quite a long time. VELCADE® (bortezomib) was the first proteasome inhibitor that came from the laboratory to clinical trials. Initially, it was approved for use in myeloma as a single agent for patients who were both relapsed and refractory. Later, it was approved for use earlier in the disease process for patients who were either relapsed or refractory, with 1 to 3 prior therapies. Several years later, Velcade was approved in myeloma in combination with DOXIL® (doxorubicin) for relapsed/refractory disease. Finally, it was approved in newly diagnosed myeloma in combination with melphalan and prednisone. Velcade is now used in a number of combinations, most notably with REVLIMID® (lenalidomide), with thalidomide, and with CYTOXAN® (cyclophosphamide) for both upfront and relapsed disease. Velcade has been a revolutionary drug because it has improved outcomes for patients in terms of response rates, response quality, and response durability. It has been a major contributor to the doubling of average survival in patients with myeloma in the past 10 years.

When administered intravenously, one of our concerns with Velcade has been peripheral neuropathy (PN), which for some patients can be described as a numbness, tingling, or burning sensation or pain, usually starting in the toes or fingers or both. To avoid worsening of those symptoms, PN can require dose reduction or, in some patients, dose interruption.

KYPROLIS™ (carfilzomib) is a second-generation proteasome inhibitor. Like Velcade, Kyprolis inhibits the proteasome, but Kyprolis binds in a slightly different way: Velcade makes one bond between the active site of the proteasome and the drug, whereas Kyprolis makes two bonds. After a period of time, the Velcade bond lets go but Kyprolis binds and doesn't let go, making the bond irreversible. One theory is this is why Kyprolis gives a longer period of proteasome inhibition than Velcade. Another theory is that Kyprolis has a lesser toxicity because of how its chemistry differs from Velcade. This may be why there seems to be less PN with Kyprolis than with Velcade. Of course, the only way to find out for sure is to do a head-to-head clinical trial comparing progression-free survival (PFS) in patients of a similar type, who are being treated within one study.

### Is this the rationale behind the ENDEAVOR clinical trial?

Yes. Patients with 1 to 3 prior lines of myeloma treatment will be randomized to receive either Kyprolis plus dexamethasone or Velcade plus dexamethasone. The Velcade can be given intravenously or subcutaneously (SQ), which dramatically lowers the rate of PN (and slightly decreases the rate of thrombocytopenia), so both arms of this study have a likelihood of a lower side-effect profile than some of the previously available treatments. This is why it is easy to be enthusiastic about the ENDEAVOR trial.



Robert Z. Orlowski, PhD, MD  
The University of Texas  
MD Anderson Cancer Center  
Houston, TX

We hope that data from the ENDEAVOR trial head-to-head comparison will answer the questions we have about PN rates, but there is another aim to this study. Older Kyprolis clinical trials have used lower doses of the drug, usually 20 mg/m<sup>2</sup> in the first cycle, then 27 mg/m<sup>2</sup>. Later studies showed that if Kyprolis is given over a 30-minute infusion, you can safely increase the dose to 56 mg/m<sup>2</sup> and there are some suggestions that this dose may be more effective. ENDEAVOR will be the first study to compare the activity of the higher dose of Kyprolis in a large trial. And, of course, this study will compare PFS, response rates and response quality between the two drugs, as well as the overall survival (OS).

### You stated that patients enrolling in the ENDEAVOR trial must have 1 to 3 prior lines of treatment. If a patient has had upfront therapy followed by a transplant followed by consolidation, would this count as 1 or 3 lines of therapy?

That would be considered 1 line of treatment. Most clinical trials do not define lines of treatment by the number of drugs a patient gets. As long as there is no disease progression between switching treatments, one line could include induction therapy followed by transplant followed by maintenance. If there is progression between transplant and the start of maintenance, then this is considered two lines of therapy.

### The ENDEAVOR trial is a large study. When do you expect data to become available?

Yes, ENDEAVOR is a large phase III study, with approximately 200 trial sites around the world and estimated enrollment of 888 patients. How quickly the study enrolls and how well the patients do on the study will determine when data becomes available. This trial began enrollment in July 2012, so it is too early to speculate when we might expect data.

The data from the ENDEAVOR trial may lead to expanded approval of Kyprolis, which is currently approved for the treatment of patients with myeloma who have received at least two prior therapies, including bortezomib and an immunomodulatory agent, and have demonstrated disease progression on or within 60 days of completion of the last therapy. This means that currently Kyprolis is available only to patients whose disease is at a later point in its course. Expanded approval would make Kyprolis available to more patients earlier in the disease course.

The Eastern Cooperative Oncology Group (ECOG), one of the largest clinical cancer research organizations in the US, has proposed a study of Kyprolis that is currently under review by the National Cancer Institute (NCI) and the myeloma steering committee. The proposed trial for newly diagnosed patients would compare a combination of Velcade plus Revlimid and dexamethasone to a combination of Kyprolis plus Revlimid and dexamethasone. If such a study were to move forward, which could happen next year, it may provide a data set that could lead to an approval of Kyprolis for newly diagnosed patients.

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## MEDICAL UPDATES

### Promising results increase chances of early pomalidomide approval

The results of a study comparing pomalidomide plus low-dose dexamethasone versus high-dose dexamethasone alone in relapsed/refractory patients show both improved progression-free survival (PFS) and overall survival (OS). The results of study MM-003, a phase III, multicenter, randomized, open label trial indicate that the pomalidomide arm of the study shows both improved PFS and OS. Professor Jesús San Miguel, Head of the Department of Hematology at the University of Salamanca in Spain and principal investigator for the study, was clearly very encouraged by the results indicating that: “The survival results in this study build on earlier observations of high response rates for pomalidomide and dexamethasone in multiple myeloma.”

The benefit in patients who relapsed on or were refractory to (having ultimately progressed on) at least two prior therapies, including both Revlimid® (lenalidomide) and Velcade® (bortezomib) is impressive and would seem to meet the US Food and Drug Administration (FDA) criteria for filling an “unmet need” for refractory/relapsing myeloma patients. The results of the MM-003 study increase the likelihood of favorable review of pomalidomide by the FDA and potential early approval. The pomalidomide combination has, in addition, been submitted to the European Medicines Agency (EMA) with expectation of a decision in 2013. The EMA and the FDA have regular joint conference calls to review joint submissions and share data.

### Should myeloma patients get a flu shot? If so, which one?

The flu vaccine is safe for myeloma patients, and the IMF recommends that all myeloma patients receive a flu shot annually. Special considerations exist for stem cell transplant patients, those over 65, and those wondering if they might benefit from the “high-dose flu vaccine.” The National Institutes of Health’s (NIH) Center for Disease Control (CDC) recommends that stem cell transplant patients receive a flu shot six months post-transplant. The “high-dose flu vaccine” is approved for use only in people 65 years of age and older. It was developed with the knowledge that human immune defenses become weaker with age, which places older people at greater risk of severe illness from influenza. The high-dose vaccine contains four times the amount of antigen contained in the regular flu shot, to create a stronger immune response in this susceptible population. However, the potential for side effects from this higher-dose shot is greater than with the lower-dose shot. If patients 65 or older have had the flu shot before with no complications, it is probably safe for them to get the high-dose shot. Patients 65 and older who have never before had a flu shot, however, should get the regular-dose vaccine. As always, we recommend you discuss your individual situation with your doctor.

### IMWG researcher shows that FISH data enhance the value of ISS staging

In the largest collaborative International Myeloma Working Group (IMWG) study to date, chromosome FISH (fluorescence in situ hybridization) data were combined with ISS (International Staging System) staging information to develop a new and improved classification system for myeloma patients at diagnosis. Two especially interesting points

are that: 1) Low ISS stage to some extent counteracts the negative prognostic impact of t(4;14) and (17)p-chromosome changes; and 2) Autologous stem cell transplant can improve outcome for some poor-risk patients. The study appears in the October 3rd edition of the journal *Leukemia*, with IMWG researcher Herve Avet-Loiseau as lead author.

### MGUS research update

A recent paper in the journal *Blood* from the Mayo Clinic myeloma group draws attention to the fact that some patients with monoclonal gammopathy of undetermined significance (MGUS) can have renal damage from the M-component, and even complete renal failure in some instances. They propose a new name for this subtype of patient: monoclonal gammopathy of renal significance (MGRS). This draws attention to a range of clinical problems that can emerge from the effects of the M-component in serum and/or urine produced in MGUS patients. Possible neuropathy is widely recognized, but there can also be a range of autoimmune disorders affecting muscle (myositis), skin (dermatitis), blood vessel (arteritis) and even blood components resulting in, for example, acquired hemophilia or Von Willebrand’s bleeding disorders. So we need to be more aware of these clinical issues, which are significant and not undetermined, according to Dr. Brian G.M. Durie, Chairman and Co-founder of the IMF.

### Velcade SQ approved for myeloma in the European Union

The European Commission has approved the marketing authorization for the subcutaneous (SQ, under the skin) administration of Velcade® (bortezomib). The ruling was based on data from a phase III clinical trial. In the US, the Food and Drug Administration (FDA) approved Velcade SQ for treatment of myeloma in January 2012. **MT**

### Help the IMF learn more about MM patients

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

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- **Education**  
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#### Upcoming Seminars

- Boca Raton, FL**  
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- San Francisco Bay Area, CA**  
May 15-16
- Chicago, IL**  
Aug 9-10
- Philadelphia, PA**  
Aug 23-24

## PROTEASOME INHIBITORS IN CLINICAL TRIALS

*Myeloma Today* in conversation with Dr. Sagar Lonial

### Please give us a brief recap of the clinical trial history of MLN9708.

MLN9708 is an oral proteasome inhibitor. This drug has a structure similar to VELCADE® (bortezomib), but MLN9708 has a bit more potency when it comes to its ability to bind to the proteasome. MLN9708 is a reversible inhibitor that has the same boron-based “backbone” as Velcade. One of the things we learned from early phase I studies is that the half-life of MLN9708 is longer than the half-life of Velcade. The responses we saw in the phase I studies were approximately 15%, but most of the patients participating in the trial were resistant both to proteasome inhibitors and to immunomodulatory drugs (IMiDs) thalidomide and REVLIMID® (lenalidomide). These were very sick patients, with very advanced myeloma. However, when we looked at newly diagnosed myeloma patients, or patients with less advanced disease, we saw encouraging data. When MLN9708 was given weekly and combined with Revlimid and low-dose dexamethasone, the response rate was close to 100%! Clearly, MLN9708 can be very active in patients sensitive to proteasome inhibition.

### What about side effects, such as peripheral neuropathy?

There is markedly less peripheral neuropathy (PN) with MLN9708 than with Velcade. Even when compared to Velcade given subcutaneously (SQ), which greatly reduced grade 3 and grade 4 neuropathy, MLN9708 appears to be superior. It is important to realize that the rate of PN with MLN9708 is not zero, but it is lower than we have seen with either IV or SQ Velcade. I can tell you that I have a patient who had to be taken off Velcade due to grade 3 PN, and this patient has now been on MLN9708 for over two years without any neuropathy recurrence. MLN9708 has helped patients who couldn't be helped otherwise.

### Do you envision MLN9708 becoming part of available treatment regimens in myeloma?

The advantage of MLN9708 is that it would give us an oral proteasome inhibitor with much less toxicity than Velcade. MLN9708 also offers the convenience for patients of coming to the clinic less frequently, and this would be a welcome change. While we strive for improved depth of response when we treat myeloma, we also want our patients to have improved quality of life.

I think that the combination of MLN9708 plus Revlimid and dexamethasone holds the promise of a completely oral anti-myeloma regimen, and this is very exciting. Even patients who are in relapse and being treated with Velcade or KYPROLIS™ (carfilzomib) might be able to come to the clinic only once every 3 or 4 weeks.

Those of us treating myeloma are realizing that combinations of drugs are really important if we are going to try to minimize and eliminate the multiple clones that are present at the time of myeloma diagnosis. The efficacy of single-agent therapies is limited. I think we will be using more combination therapies in all settings, especially in newly diagnosed



Sagar Lonial, MD  
Winship Cancer Institute  
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disease. And if we can make treatment easier for patients, this would be a great advantage in terms of quality of life.

### How is MLN9708 administered?

MLN9708 is a capsule that can be given on a once-a-week or twice-a-week schedule, which is currently being evaluated in clinical trials, both in the relapsed setting and in the frontline therapy setting.

### Does the route of drug administration have an impact on efficacy?

It's not so much that the route of administration has an impact on efficacy, but it has an impact on quality of life. We also know that if bortezomib is absorbed over a longer period of time, the toxicity is significantly less. For example, there is less toxicity with Velcade administered SQ than with the same drug given intravenously (IV). The oral administration of MLN9708 has the potential of giving us a much longer period of absorption, with a lower “peak” effect.

### Can you overcome Velcade resistance with MLN9708?

We don't yet know the answer to this question. We know that MLN9708 gives us an oral alternative for an IV medicine, and it does so in a way that is better tolerated, with patients experiencing less nausea and less gastrointestinal (GI) toxicity. Clearly, this is a step forward.

As for overcoming resistance, let me point out that developing resistance in the first place has a lot to do with how you approach treatment and what kind of myeloma you are dealing with. Not every myeloma is the same. There are indolent myelomas, where we can potentially stay in control of the disease for greater than 10 to 12 years. But some patients have high-risk disease, and drug resistance can be a problem in such cases, so keeping in control of the disease from the very beginning is a critical step.

### So what is your approach to myeloma treatment?

At our facility, we use a number of factors to tailor how we approach maintenance therapy. For patients with high-risk disease, we use RVD followed by a single transplant, followed by aggressive maintenance. We think this is important because if you lose control of high-risk patients' myeloma, you might never get it back again.

For standard risk patients, we still use RVD as induction therapy, but may use a less intensive maintenance approach. All patients should get the best possible therapy for their disease at the time of diagnosis. It is important to have the greatest possible impact on the patients' disease at the time when their myeloma is most sensitive to treatment.

Where we differentiate approaches to treatments is in the maintenance setting. Patients with standard-risk myeloma may get maintained differently than those who have high-risk disease.

CONTINUES ON PAGE 8

## ORLOWSKI / PROTEASOME INHIBITORS — continued from page 5

### What are the other key clinical trials of Kyprolis?

The ASPIRE study of Kyprolis, Revlimid, and dexamethasone in patients with relapsed myeloma has finished enrollment. This study comparing Kyprolis, Revlimid, and dexamethasone versus Revlimid plus dexamethasone has also completed enrollment, and the data should be available in advance of ENDEAVOR results. There are other ongoing Kyprolis trials,

but the ones I've mentioned are the larger studies that may lead to new or modified indications in the US. These are exciting investigations and, since the ENDEAVOR study is still accruing, patients who are eligible to enroll should consider participating. Both arms of the ENDEAVOR trial are expected to have good outcomes with less toxicity, and that's a great thing to offer patients. **MT**

## LONIAL / MLN9708 PROTEASOME INHIBITOR — continued from page 7

### How would you describe the patient(s) who may benefit most from clinical trial participation?

Every patient at every stage of disease should be considered for a clinical trial. At our center, and at many other myeloma centers, we have trials for patients in every stage of the disease. We have induction trials, as well as trials for patients in their first relapse, as well as transplant trials. Until we can cure everyone with myeloma, we need studies to find the answer to this disease. And until we can get over that hurdle and successfully cure myeloma, we need newer and better drugs for our patients.

### What have been the key clinical trials for MLN9708?

At the 2011 annual meeting of the American Society of Clinical Oncology (ASCO), I reported on the phase I clinical trial of single-agent MLN9708 in refractory myeloma. Other trials reported at ASCO 2011 included the combination of MLN9708 with Revlimid and dexamethasone for newly diagnosed patients.

MLN9708 is now in phase III studies, including trials comparing Revlimid and dexamethasone to Revlimid and dexamethasone in combination with MLN9708 for patients who have relapsed myeloma, as well as a phase III trial in relapsed/refractory amyloidosis.

### Are you hoping to see MLN9708 approved for myeloma? What about other drugs in the pipeline?

Yes, absolutely! Recently, we saw carfilzomib receive US Food and Drug Administration (FDA) approval for myeloma. I hope that in the next few

months pomalidomide will be added to the list of approved drugs. Next, there are opportunities for approval of panobinostat and elotuzumab. These are the drugs furthest along in development. MLN9708 is currently accruing patients for phase III clinical trials and we have very high hopes for this drug.

Vorinostat, another agent that had been in development for myeloma, encountered dose and scheduling challenges. It is FDA-approved (as ZOLINZA®) for the treatment of advanced primary cutaneous T-cell lymphoma, and it is still sometimes used "off-protocol" in myeloma. I have personally treated a number of myeloma patients with the combination of vorinostat and Velcade, and these patients would not be here if not for this drug. I continue to think that this class of compounds – called histone deacetylases (HDAC) inhibitors – is important in myeloma. Unfortunately, the dose and scheduling used in vorinostat's myeloma trials were not tolerable. I hope that panobinostat, which has a similar mechanism of action, will be better tolerated. In addition, there are other HDAC inhibitors being studied that so far are not showing toxicity.

In closing, I'd like to make one general comment. Now that we have better drugs for myeloma, it is important to make those treatments more convenient for patients, so that their quality of life is preserved as they are coping and living with this disease. That's what makes MLN9708 so exciting. **MT**

## TELECONFERENCE

# A Cancer Patient's Guide to the Affordable Care Act (ACA)

**Wednesday, March 21, 2013**  
**7 p.m. (Eastern), 4 p.m. (Pacific)**

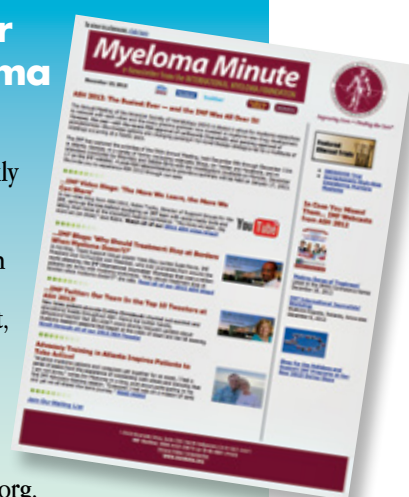
The Affordable Care Act (ACA), passed in 2010, will increase access to health coverage for Americans without health insurance and introduce new protections for people who have health insurance. To learn what the ACA means to you, please join the IMF for our first teleconference on this important topic. For dial-in information, please contact Aimee Martin at [amartin@myeloma.org](mailto:amartin@myeloma.org).



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## **IS THERE A RECOMMENDED DIET FOR MYELOMA PATIENTS?**

As you can imagine, this is a Hotline FAQ, and not one we can easily answer. Nutritional science has long wrestled with the question of how food influences the immune system. This is an extremely complex and layered field of inquiry. Researchers in myeloma and in nutritional science have not been able to determine specific guidelines for foods that will be beneficial



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

for myeloma patients, or indeed, for any other cancer patients. We have, however, gathered some good general guidelines both from myeloma experts like Dr. Brian G.M. Durie, who recently blogged and held a teleconference about nutrition, and from nutrition experts like Dr. Loch Chandler, a naturopath in Portland, Oregon, who relies on peer-reviewed scientific studies to make his recommendations, and who provided the IMF with some good nutrition guidelines for myeloma patients some years ago.

### **The DON'T's**

Dr. Durie's advice is rich in do's and don't's. His primary "don't" is "Don't eat processed foods with chemicals in them." Two easy rules to follow are: (1) don't consume artificially sweetened foods and drinks or artificial sweeteners, and (2) avoid cola drinks and diet sodas. Although it is difficult to avoid all processed foods, we should all try to avoid them to the extent possible, and to strictly limit intake of any food or drink that has questionable ingredients. Here are some substances to watch out for that you might not know about.

❖ **Acrylamide** – Many, if not most, of us are familiar with Dr. Durie's famous "Cookies" blog, in which he warns that many baked goods are rife with acrylamides, chemicals that are used in industrial processes that can also appear in food. The National Cancer Institute (NCI) fact sheet entitled *Acrylamide in Food and Cancer Risk* states that "The National Toxicology Program and the International Agency for Research on Cancer consider acrylamide to be a probable human carcinogen." Acrylamide is formed in certain foods when a protein called asparagine is heated to a temperature above 248°F (120°C) in the presence of some types of sugar. Notable among these foods are potato chips, French fries, and – sorry, Cookie Monster – many types of cookies. (Bake your own with organic ingredients at lower temperatures or look for "soft-baked" cookies at the bakery to avoid acrylamide.) Acrylamide is also present in cigarette smoke, so even those who don't smoke, but who are exposed to second-hand smoke, are at risk. For more information on acrylamide, go to [cancer.gov/cancertopics/factsheet/Risk/acrylamide-in-food](http://cancer.gov/cancertopics/factsheet/Risk/acrylamide-in-food).

❖ **4 MEI** – Another "don't" concerns the chemical 4-Methylimidazole (4 MEI), which gives many foods and beverages (think dark beers and colas) their rich caramel brown color. There is concern not only about 4 MEI as a food additive, however, but as a possible by-product of roasting (including roasted coffee beans) and grilling. A study from the National Toxicology Program (NTP) of the US Department of Health

and Human Services (HHS) published last year concluded that there was clear evidence of 4-MEI's carcinogenicity (cancer causation) and neurotoxicity (damage to the nervous system) in certain lab animals. For more information on toxicology and carcinogenesis studies of 4 MEI, go to [ntp.niehs.nih.gov/index.cfm?objectid=9B956B07-F1F6-975E-79BBCDCD57001C8](http://ntp.niehs.nih.gov/index.cfm?objectid=9B956B07-F1F6-975E-79BBCDCD57001C8).

❖ **Genetically Modified (GM) Food** – The concerns with genetically modified foods are numerous, and include the current lack of a standard way to evaluate nutritional equivalence, that is, the presence of unexpected changes in nutrients, allergenicity, and toxicity in the modified food. Another major concern with GM foods, as Dr. Durie points out, is that they are often modified to be resistant to weed-killers, enabling growers to spray carcinogenic defoliants on plants that are then saturated with them and absorb them. For an in-depth look of the pros and cons of GM foods, see WebMD's article [webmd.com/food-recipes/features/are-biotech-foods-safe-to-eat](http://webmd.com/food-recipes/features/are-biotech-foods-safe-to-eat).

### **The DO's**

If we are to avoid processed foods and can avoid GM foods—which are currently omnipresent but unlabeled—the obvious route is to eat what Dr. Durie calls "Real Food." Choose local, seasonal, organic, and unprocessed food: grass-fed beef, cold-pressed olive oil, locally grown produce, wild-caught (not farmed) fish. And, of course, the healthy "fun foods": red wine and dark chocolate, both rich in polyphenol antioxidants. Dr. Durie believes that human beings have digestive systems that are best designed for omnivores, those who eat the full range of meat, fish, eggs, fruits, vegetables, and grains.

Most nutrition experts, including Dr. Chandler, believe that the best model for dietary health is the so-called "Mediterranean Diet," which is high in vegetables, legumes (beans, lentils, split peas), fruit, nuts, unrefined (whole) grains, olive oil, fish, unprocessed cheese, yogurt, regular but moderate alcohol (a large Swedish study recommends 7-14 drinks per week as optimal), and only low levels of poultry, meat, and potatoes. This diet is not only beneficial for obesity and heart disease, but leads to a 60% reduced risk of cancer of all types.

❖ **Vegetables** – The goal should be to eat a minimum of 5 servings of fresh fruit and vegetables a day, with the optimum being 9 servings. Among the healthiest vegetables are those in the cabbage family: (in alphabetical order) arugula, bok choy, broccoli, Brussels sprouts, cabbage, cauliflower, collard greens, horseradish, kale, kohlrabi, mustard greens, rutabagas, turnips, wasabi, and water cress. They are associated with lower rates of many cancers and induce enzymes to detoxify carcinogens. The onion/garlic family of vegetables has similar effects.

❖ **Fruits** – Berries are what Dr. Chandler calls "powerhouse" fruits. According to the Aggregate Nutrient Density Index (ANDI), which

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## STRATEGIES FOR PAIN MANAGEMENT IN MYELOMA

By Sandra Kurtin, RN, MS, AOCN, ANP-C



Pain is one of the most common symptoms among cancer patients. More than 85% of cancer patients report “breakthrough pain.” If you’re someone who has suffered from pain, you know all too well that it affects most aspects of your life, not only your

physical functioning, but also your social, emotional, and psychological status. As nurses who work with myeloma patients, we understand that, too.

Pain, much like fatigue, is one of the more complicated symptoms that healthcare professionals deal with clinically. Pain is always subjective and individual, and it is highly variable. It often takes time to treat pain effectively, and that presents challenges for all of us.

In 2000, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) declared that all patients have the right to the appropriate assessment and management of their pain. Healthcare professionals now often talk about pain assessment as the “fifth vital sign”: When you come into the clinic, we measure your blood pressure, your temperature, your height, your weight... and your pain. Your “pain score” is quantified by you, and then formally assessed by us. It is a score that we’ll revisit over time, because like many of your other “vitals,” it is going to change – there are going to be different times when pain is better or worse.

Assessment of pain intensity is just a snapshot, but it’s a helpful one. Most commonly it is measured on a scale of zero to 10, and it’s best evaluated when looking at the things you do every day. How does pain affect you throughout the day and from day to day? Is it interfering with your ability to work or do the things that you enjoy?

When we talk about your pain, we’re actually looking at different categories: Acute pain, chronic pain, and breakthrough pain. Acute pain is something that, with a very sudden onset, often brings myeloma patients into clinics. **Acute pain** for myeloma patients may be a result of a pathological fracture. Blood clots can also create acute pain, as can oncological emergencies such as high blood calcium (hypercalcemia) or cord compression. Diagnostic and therapeutic interventions – bone marrow biopsies, for example – can be very uncomfortable during their limited duration. **Chronic pain** is pain that lingers over time – sometimes months, sometimes years. Chronic bone pain is something that we deal with often in myeloma,

as is soft tissue pain, or when tumors press upon organs. Peripheral neuropathy (PN) may also cause chronic pain. Some pain related to myeloma falls into both categories: Herpes zoster (“shingles”) can cause pain upon onset (acute), and that pain can also linger over time (chronic). **Breakthrough pain** is a transient increase in pain in patients treated for persistent pain, often telling us we need to re-evaluate your pain or make changes in the pain regimen.

My fellow clinicians and I try to help by assessing your acute, chronic, and breakthrough pain as best we can. This includes understanding your patient history and the specific characteristics of your pain, as well as conducting a physical exam, and perhaps additional diagnostic testing. Our ability to understand the underlying cause of your pain helps us select the best treatment for you.

Armed with the best possible understanding of your pain, we can better plan for success. Here are some of my suggestions for taking an active part in treating your pain effectively:

1. Create a “team” of family and caregivers. I call this team the Truth Squad. Your Truth Squad might see things in a way you cannot, and therefore help you and your clinicians with little pieces of information that are truly helpful. The more information we have, the better;
2. Stick with a singular pain assessment scale (usually zero to 10);
3. Incorporate a multidisciplinary approach. This might include your primary care physician, a nephrologist, an orthopedist, a radiologist, and your medical oncologist. But ultimately, one clinician should be in charge of all pain prescriptions to most effectively track your pain treatment and successes;
4. Maintain a basic working knowledge of pain modalities. Be aware of what options are out there;
5. Keep it simple. Sometimes easy solutions are the best solutions. Instead of medication, it might be a pillow in the right place, or sleeping a certain way;
6. Establish criteria for referral to a pain specialist. Pain specialists can be helpful with some of the newer technologies;
7. Identify other risks. Be aware how your age, and other illnesses or diseases you might have, can be contributing factors of your pain. Remember to look at yourself as a whole person, not just “bits and pieces.”

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## HOTLINE/RECOMMENDED DIET — continued from page 9

measures how many nutrients are present per unit measure of food, berries top the list for fruits. They have high levels of antioxidants and have been shown to reduce the growth of colon and prostate cancer cells. Tomatoes (also technically a fruit) are rich in the antioxidant lycopene, which is best absorbed when the tomatoes are cooked and eaten with fat such as olive oil.

- ❖ **Whole Grains** – As opposed to white flour, white rice, most pasta, bagels, and breads, consumption of whole grains is associated with lower cancer risk as well as lower risk of heart disease and type 2 diabetes. Whole grains promote lower insulin levels and help regulate the bowels.
- ❖ **Legumes** – Legumes are high in antioxidants, micronutrients, and fiber. They have been tested in healthy women and found to be associated with a reduced risk of breast cancer. In other studies, they have been associated with lower rates of prostate and colon cancer.
- ❖ **Healthy Fats** – Healthy fats such as fish and olive oils tend to be anti-inflammatory. Countries in which olive oil is the predominant fat have lower rates of cancer. The Omega-3 fats found in fish, flax, canola, tree nuts (particularly walnuts), and some green vegetables are also good fats. Healthy fats have been studied not only in the context of cancer prevention (most studies suggest that fatty fish are protective against cancer), but in management of cancer treatment-related side effects. They are known to improve survival in patients undergoing radiation, and have also been associated with a reduced rate of infections.

## NLB — continued from page 10

My motto – and my advice for you – is that believing is 90% of doing. Pain management is almost always “a work in progress.” One discussion, or one visit with your healthcare team, often is not enough. It takes time to keep refining a plan. There are several myeloma patients with whom I have worked for many years and, like them, I encourage you not to give up. Believing that pain is something you can control is very important. I truly believe that we all share the ultimate goal when addressing cancer pain: To enjoy life in the moment, and to be pain free. **MT**

Editor’s Note: Sandra Kurtin is a member of the IMF’s Nurse Leadership Board (NLB). Her in-depth analysis of a variety of pain management approaches, *Getting to the Source: Acute and Chronic Pain*, was part of the IMF’s Living Well with Myeloma teleconference series. The audio recording and the corresponding slides can be found at [livingwell.myeloma.org](http://livingwell.myeloma.org).

## Myeloma Manager™ Personal Care Assistant™

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



## A final word of advice

For the many myeloma patients taking dexamethasone, you should avoid carbohydrate-rich foods that elevate blood glucose levels even further than the drug does. Foods with a high glycemic index raise blood sugar quickly. They are watermelon, white bread, dried dates, baked white potatoes, parsnips, corn flakes, bagels, French fries, ice cream, potato chips, beets, scones, and high-fructose corn syrup, which is present in many processed foods, dairy products, and sugary drinks. Better choices include low glycemic index foods such as plain yogurt, apples, sweet potatoes, oatmeal, hummus, nuts, cherries, broccoli, lettuce, yams, green peas, lentils, and pinto beans.

Audio recordings and presentation slides from the IMF’s Living Well with Myeloma teleconference series are archived at [livingwell.myeloma.org](http://livingwell.myeloma.org).

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



Joseph Tariman,  
PhD, ANP-BC

## NLB member recognized as 2012 Nurse of the Year

Congratulations to IMF Nurse Leadership Board (NLB) member Joseph D. Tariman, PhD, of the Northwestern University Myeloma Program, on receiving a 2012 Nurse of the Year award from the Leukemia Research Foundation (LRF). The award was created to recognize hematology-oncology nurses who give their time, compassion, and heart each and every day. “These nurses are true heroes,” said Linda Kabot, LRF Director of Programs and Research Grants Administrator.

## Do you have a question?

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

**myeloma.org**



## UPDATES FROM AROUND THE GLOBE



### Report from Turkey

By Nadia Elkebir

The first IMF meeting in Ankara was a great beginning to what will surely be a continuing productive relationship with the local myeloma community. The event started with a presentation by Dr. Meral Beksac of Ankara University. After each case study she presented, Dr. Beksac invited input from Dr. Rafael Fonseca who traveled to Turkey from the Mayo Clinic in Arizona. I would describe the experience as a true bridge-building, with many people coming together in cooperation to make the most of this educational opportunity, and the patients clearly appreciated this. Next time, we look forward to making even more new friends in Ankara!



Dr. Mustafa Cetiner, Nadia Elkebir, and Asli Ortakmac

The Istanbul meeting was even larger than in Ankara, and left me with very vibrant memories. There was an energetic exchange of information during the Q&A with the entire faculty of physicians, with many questions posed to Dr. Fonseca. And I was very impressed with the innovative presentation by Dr. Mustafa Cetiner of the American Hospital in Istanbul. In addition, I was



happy to meet Asli Ortakmac of the Turkish myeloma website and the Istanbul myeloma support group – she is a dynamic lady and part of an incredible team!

The IMF's meetings in Turkey were a wonderful experience and I look forward to our return for future meetings and events. Dr. Fonseca expressed how pleased he was to be in Turkey and how important it is for all patients to be educated about myeloma and to keep a positive attitude as this makes a big difference in living with the disease. To further assist with this effort, the IMF is working on translating some of our educational publications into Turkish. Many thanks the team from Celgene for all their support and assistance.



### Report from Korea

By Lisa Paik and Arin Assero

On October 20, 2012, we had the honor of representing the IMF at a meeting of the Korea Blood Cancer Association (KBCA) in Seoul.

Originally established in December 1995 as the Saebitnuri Association, the KBCA is officially authorized by the Ministry of Health and Welfare to provide support and services to blood cancer patients and their families. The KBCA works collaboratively with many other organizations in Korea and abroad.

The KBCA's Board of Directors includes several distinguished hematology experts and the organization has 80 medical mentors. KBCA management

and staff includes many cancer survivors and more than 100 dedicated volunteers. We had the pleasure of getting to know Mr. Tae Pyong Chang (Chairman and President of KBCA), Mr. Chul Hwan Lee (Secretary General and co-founder of KBCA), Ms. Jung Suk Park (Director of KBCA), and Ms. Jung Hee Lee (Assistant Manager of KBCA). We also met several of KBCA's medical mentors who served as faculty for the myeloma meeting: Dr. Sung-Soo Yoon of Seoul National University Hospital, who also is Chair of the Korean Multiple Myeloma Working Party (KMMWP), Dr. Yeung-Chul Mun of Ewha Women University Medical Center (KMMWP member), and Dr. Chang-Ki Min of Seoul St. Mary's Hospital (KMMWP member).



Mr. Chul Hwan Lee (Executive Director, KBCA) and Lisa Paik

Like the IMF, the KBCA firmly believes that hope and information play an important role in helping patients navigate their journeys through cancer.



Front row (l to r): Dr. Sung-Soo Yoon (Chair, KMMWP), Lisa Paik, Mr. Tae Pyong Chang (Chairman/President, KBCA), and Arin Assero

Back row (l to r): Dr. Yeung-Chul Mun (KMMWP), Mr. Chul Hwan Lee (KBCA), and Dr. Chang-Ki Min (KMMWP)

KBCA's patient services include medical treatment support, consultation and counseling, educational meetings and seminars, free publications, and an active website and online community. KBCA also organizes social and cultural events for blood cancer patients.

The KBCA holds approximately 40 educational meetings per year for a variety of blood cancer patients, but the meeting we attended focused solely on myeloma and took place on their annual Myeloma Patient Day. As guest speakers, we addressed an audience of 200 myeloma patients and caregivers. We talked about the IMF's 22-year history, our mission, and our wide range of programs in the areas of Research, Education, Support, and Advocacy. We found the audience to be receptive, and the strong KBCA team to be clearly committed to putting patients' needs first. We were very impressed with KBCA's activities and accomplishments, and we are looking forward to increased close cooperation in the future. **MT**



## SPOTLIGHT ON ADVOCACY



By Johanna Gray

### Update on ACA Implementation: What's New and What's Next?

The summer and fall of 2012 have been very active for the implementation of the Patient Protection and Affordable Care Act (ACA) and 2013 will prove to be even more active as the federal government, states, and individuals prepare for the major reforms to be enacted in 2014.

### Supreme Court Review of the ACA

One of the most important aspects of ACA implementation in 2012 was the decision by the Supreme Court on the constitutionality of the ACA released on June 28th. In a 5-4 decision, Chief Justice John Roberts authored an opinion, which was joined by Justices Breyer, Kagan, Sotomayor, and Ginsburg, that upheld the constitutionality of the individual mandate. The Justices believe the mandate is a tax and, therefore, is constitutional and the implementation of the private insurance reforms will continue and implemented reforms will be maintained. Additionally, the Supreme Court further decided that the Medicaid expansion is constitutional. However, the federal government cannot withhold existing Medicaid funding for states as punishment for states that do not expand coverage under the new law. The Medicaid expansion to childless adults is now optional for states – they can implement it or reverse the expansion at any time. States are currently weighing whether to accept the funds under ACA and expand coverage or not. This flexibility will make it challenging for patients who are weighing their insurance options.

### Progress toward 2014 Implementation of Essential Health Benefits and Exchanges

A major provision in ACA is the establishment of insurance exchanges, which are competitive, regulated marketplaces where individuals and small groups can go to purchase health insurance in 2014 and beyond. For an insurance plan to be eligible to participate in an exchange, it must include a minimum set of coverage benefits that all new individual and small group plans will have to cover called the Essential Health Benefits or EHBs. The second half of 2012 has also included significant activity by states to implement policies to determine EHBs and establish the exchanges.

The federal government has directed states to pick a benchmark plan that currently exists in the state to define EHB for the new plans. Many states

have had public comment periods on their proposed benchmark plans, and IMF has actively advocated in 22 states for benchmark plans that are sufficient for individuals with myeloma and other cancers. In particular, IMF has advocated for a benchmark plan selection that includes parity in coverage for oral and IV/infused chemotherapy; access to more than one drug per category or class in the prescription drug formulary; and access to comprehensive diagnostic and treatment services, including a written care plan and all elements of multi-disciplinary care. To date, more than 25 states have selected a benchmark plan. IMF will continue to monitor the implementation of EHB on the state level to ensure that plans are adequate for myeloma patients.

On the Exchange front, many states are moving forward with creating their exchanges. HHS must certify each state's exchange plan in January 2013, and so it should soon become clear whether a state will set up its own exchange or leave it to the federal government to create one for the state – though an exchange will exist in each state regardless. The IMF will continue to monitor exchange creation in each state and will advocate for exchanges to be responsive to consumer needs. Open enrollment in exchanges begins on October 1, 2013, so there will be considerable activity in each state as that deadline approaches. If you'd like to keep up with what your state is doing, one great resource is [www.statereform.org](http://www.statereform.org), which has information about exchange and EHB implementation for each state.

### What does ACA mean for Medicare Beneficiaries?

Under ACA, existing guaranteed Medicare-covered benefits won't be reduced or taken away and people can choose their own doctors. The prescription drug coverage gap known as the "donut hole" (when seniors who have paid an initial amount in prescription costs have to pay for all of their drug costs until they spend a total of \$4,700 for the year, at which point coverage begins again) is closed by 2020 and seniors will have full prescription coverage under Medicare. Additionally, Medicare now covers 100% of the cost for many preventive screenings such as colonoscopy to screen for colon cancer, mammography, diabetes screening, and flu vaccinations. Seniors new to Medicare have access to a "Welcome to Medicare" preventive visit which is a one-time review of one's health as well as education and counseling about preventive services and care, and an annual visit after that to update a personalized prevention plan.

### Missouri Advocates Shine Through Postcards for Parity

By Aimee Martin

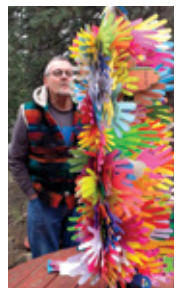
Change does not happen overnight and not without the hard work of amazing advocates. Thanks to everyone's participation we have collected over 2500 postcards. Even if you were only able to sign one card, it made a difference.



Throughout this process, there were a few states that stood out as powerhouses and I want to take this opportunity to highlight the amazing state of Missouri. John Killip, Cindy Ralston, and Kathy Cartwright helped us grow our Missouri advocates from 36 to 367 and secured our first

Missouri Representative co-sponsor by collecting over 400 postcards to date!

John Killip, Associate Dean at UMKC had his students fill out postcards and had his colleagues do the same in their classes. I was very excited to send Rep. Emanuel Cleaver from District 5 more than 160 postcards asking him to co-sponsor HR2746. In September 2011, John met with Rep. Cleaver to ask for his co-sponsorship and again this year requested his co-sponsorship just a few weeks before John had his third stem cell transplant. John, I want to deeply thank you for advocating on behalf of all patients regardless of your circumstances. Your hard work will show Rep. Cleaver how much this legislation



CONTINUES ON PAGE 16

## MYELOMA TODAY IN CONVERSATION WITH STEVEN MIRO

### Tell us a little bit about yourself.

I'm 21 years old. I have three half-siblings, two on my father's side and one on my mother's side. I'm from Jefferson County, Ohio, which is known as the birthplace of Clark Gable, Dean Martin, General Custer, Jimmy "The Greek" Snyder, and movies like "The Deer Hunter." I moved throughout the area a lot when I was young, and therefore went to six different schools, but I graduated from Buckeye Local in Rayland, Ohio. I currently attend the Police Academy and a local community college, and I love to read, write, hunt, and fish. I briefly served in the U.S. Army. Serving my nation in that way is my proudest accomplishment, but I was discharged because I have cancer. Myeloma.

### How did your myeloma diagnosis come to pass?

I started having symptoms when I was 15, but doctors kept telling me I was fine, that nothing was wrong, and that I was just "full of it," so to speak. They essentially thought I had pulled my muscles. But my junior year of high school, the pain got so bad, my mom took me to Allegheny General Hospital in Pittsburgh, Pennsylvania. There they found tumors on my neck, head, ribs and spine. They said I was lucky to have come in when I did, because it was that bad. But I was actually just glad to know what was wrong after three long years of not having any answers. Everyone in my family took it much harder than I did. I was the one keeping everyone in good spirits.

### What was your initial treatment?

After a lot of blood work and four biopsies – to make sure they had the right diagnosis – I underwent a combination chemotherapy regimen of Revlimid® (lenalidomide) and dexamethasone for a year. My senior year of high school they thought I had a relapse – which I'm not sure about. I went to The James Cancer Hospital in Columbus and underwent a stem cell transplant and had more chemotherapy under the care of Dr. Craig Hofmeister. I lost my hair during this treatment. Several family friends who were soldiers in Afghanistan at the time shaved their heads in solidarity with me. Chemotherapy is tough, but I continued to go to school as long as possible, and I graduated. I'm in remission now, for I believe close to three years. I don't keep perfect track. But I have been out of treatment for a while, and I try to stay active and fit, especially because of the requirements for the Police Academy.

### Have you met other people with myeloma in your age group?

I haven't met anyone even slightly close to my age! After my diagnosis, I met three or four myeloma patients who were in their 60s, and they were astonished to meet me. I'm pretty much a case study.

### You've made some connections between your cancer and your environment. Tell us more about that.

The area I grew up in, people often call it "Death Valley," especially doctors I've had. It's known for its coalmines and its steel mills, and so many people get sick in this area. I hope to leave one day and make my roots somewhere else, because of that.

### What are your future plans?

I would really like to re-enlist in the Army. I'm in the midst of some

paperwork, and I hope that works out. I come from a military family – several uncles are retired Army, I have a cousin who is on active duty in the Air Force, and a step brother who is currently in the first part of his contract with the Marines. I'd also like to follow in my family's footsteps and become a third generation Deputy Sheriff, which my father is right now.

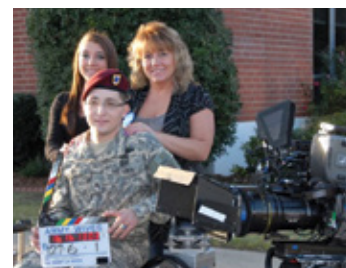
If that doesn't work out, I'd like to pursue a degree in acting. I actually have already appeared on the Lifetime series "Army Wives." It was a great experience. My character was just an extra, but I'm easy to spot throughout the episode. I liked serving in the Army more than playing someone from the Army on television, but it was really fun. The actors were very down to earth. They spent time with me and wanted to get to know me. I really appreciated that.

### Thinking of your future, where does myeloma fit into the picture?

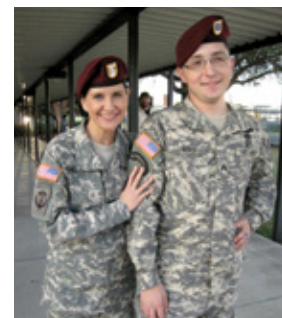
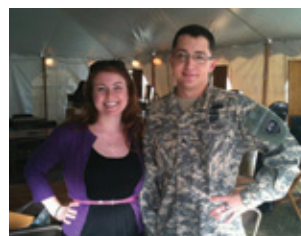
My doctors say they don't know if or when the myeloma might come back, because they haven't encountered anyone as young as I am. I think about what I might do if it comes back when I'm 30 and married with kids versus if I'm 30 and single with no kids. Right now I feel like if I were married with kids I would be more likely to fight it, but I also know that my thoughts could change over time.

I know that keeping a positive attitude is important. One of the main reasons I'm able to is because of a man named Marcus Luttrell, a retired Navy SEAL. He wrote a book called "Lone Survivor," which is about how against all odds he managed to crawl seven miles with two broken legs after his entire team was ambushed by the Taliban. He's a survivor. **MT**

Editor's Note: You can follow Steven's story further by visiting [facebook.com/StevensFight](https://www.facebook.com/StevensFight).



Steven Miro on the set of "Army Wives"



## IMFers RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY



By Suzanne Battaglia

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

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

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

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

Here are some examples of events...

### A Tribute to Dominik Zuchowicz

Friends and family of Dominik “Dom” Zuchowicz organized a memorial tribute to celebrate the life and work of the Canadian instrument-maker. The concert was sponsored by Viols of Houston, which was founded as a chapter of the Viola da Gamba Society of America (VdGSA). The founder of Viols of Houston, Barrett Sills, was the first of many Houstonians to commission an instrument from Dom. Today, Houston is the home to no fewer than twelve of Dom’s instruments, and many more reside elsewhere in Texas.



Dom

The concert was held on September 9th at Christ The King Lutheran Church in Houston, TX. Dom’s wife, Barbara Zuchowicz, participated in the tribute, and gave a moving pre-concert talk, sharing stories of Dom’s life and work,



Musicians after the tribute concert

and his courageous three-year battle with multiple myeloma. Barbara also performed with the evening’s featured artist, viol virtuoso Mary Springfels. In addition to Ms. Springfels, the concert also included performances by a number of professional musicians from the Houston and Austin areas.

“It was an evening’s of wonderful music performed by really fine musicians,” said Nancy Ellis, Artistic Director of Houston Early Music (HEM). “I am fortunate to have a beautiful seven-string bass viol made by Dom, and one of the visiting musicians played it during the concert. We had expected maybe 50 people but nearly 80 attended. Admission was pay-what-you-wish, with donations benefiting the IMF. It was an outstanding event benefiting a most worthy cause. The evening was a tremendous success, exceeding our expectations. It was a fitting tribute to a man whose life and work has meant so much to so many.”



Lion head bass viol made by Dom

### Glenda Hinson Memorial Fund

Benton Rabitsch is a fifth-grade student at Level Creek Elementary in Suwanee, GA. In May 2007, his grandmother, Glenda Hinson, lost her battle with multiple myeloma. “She was only 60,” said Benton. “Myeloma is a disease that my family and I had never even heard of until Grandma’s diagnosis. I wanted to help raise myeloma awareness and raise money for the International Myeloma Foundation.”



Glenda Hinson



Benton Rabitsch with his grandmother, Glenda

Benton’s plan to form the Glenda Hinson Memorial Fund and raise \$1,000 for the IMF’s myeloma research program became a reality when he started asking friends and family to make a tax-deductible donation. In addition to donations, Benton sold \$5 raffle tickets for a drawing to win sports memorabilia donated by the Atlanta Falcons. The drawing was held on November 2, 2012. “For me,” said Benton, “this is a great way to remember Grandma and to help with the fight to find a cure for this disease.”

### Premier Designs Jewelry Show

In September, Jordan-Brittany Cook, a consultant for Premier Designs high-fashion jewelry, hosted a fundraiser in Laurel, MD. “The timing of our fundraiser couldn’t be any better,” said Jordan. “The date coincided with the ‘Weekend to End Myeloma’ campaign to help the IMF fund research and promote awareness of this disease, and it commemorated what would have been my parents’ 29th wedding anniversary and my father’s 63rd birthday.”

Jordan’s dad was diagnosed with myeloma in 2001 and succumbed to the effects of the disease in March 2012. “At the event, I gave a presentation about myeloma to help educate the general public. I also raised money and donated part of the proceeds to help with research, so people who are diagnosed with myeloma are able to live longer and healthier lives. Helping the myeloma community is one of the many ways I continue to honor my father’s memory.” **MT**

# Member Events



## The IMF Earns 4-star rating from Charity Navigator

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

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

**Mail for the Cure** is a simple but very powerful concept with which you can make a big difference. Here's how it works: All over the country, people just like you are mailing letters to their friends and relatives asking for their support of myeloma research and other important IMF programs. We provide you with a specially coded IMF donation envelope and a letter template, which you can personalize.



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- Running or Not
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Get a Tax Benefit and a big "Thanks" from us

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## The Great Cell Phone DRIVE



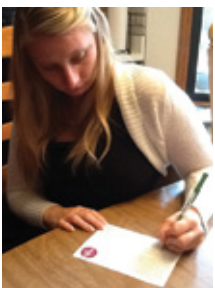
### Put your old cell phone to good use!

Donate your old cell phone and become part of finding the cure. The IMF has partnered with a cell phone recycling organization that makes a donation for every cell phone we turn in. Current cell phone models are worth up to \$20 each. Many older models are worth \$1 to \$10.

You can help the IMF continue its research and programs. You can help our environment. You can provide cell phones to underserved communities. And it's as easy as sending us your old cell phones. For more information about how to turn your old cell phone into a contribution (or how to set up an IMF collection program at your business or school), contact Kemo Lee at 800-452-CURE (2873) or [KLee@myeloma.org](mailto:KLee@myeloma.org).



*An estimated 200 million old CELL PHONES sit neglected in America's closets and drawers. Through Cell Phones For A Cure, IMF members can turn these phones into thousands of dollars in support of myeloma research.*



### ADVOCACY — continued from page 13

matters to his constituents.

Kathy took a different route to complete hundreds of postcards from concentrated areas of the state. She enrolled members of her support group and family to collect at least 25 postcards from their local communities. One great example of reaching beyond the myeloma community comes from a support group member's daughter whose church put postcards in the service programs one Sunday. The minister then asked everyone to fill out the postcard right then and return it to him on the way out of service. **MT**

### The IMF Advocacy Voice:

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

We are proud to announce that we have grown to more than 3,000 advocates since our program's inception in 2010. "We have come a long way in the past few years, successfully shaping policies to meet the needs of the myeloma community," says Arin Assero, VP Global Advocacy. "But none of our victories would have been possible without our hardworking patients and caregivers who have given their time and endless dedication to our mission. We thank ALL of you for your fearlessness and determination to improve the lives of your fellow patients."

Want to be part of the team? Sign up **TODAY** at [advocacy.myeloma.org](http://advocacy.myeloma.org)!

### How to contact the IMF Advocacy Team



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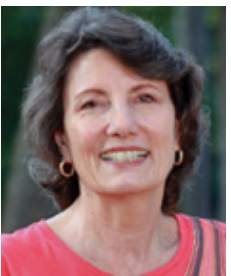




**Nadia Elkebir**  
**Director Southern Europe  
& the Middle East**

Nadia Elkebir was first introduced to the IMF several years ago when she met Susie Novis and Dr. Brian Durie at a medical meeting in Calgary, Canada. At that time, she was living in her home city of Paris, France, and working with a renowned medical scientist and professor who was also interested in myeloma. Nadia spent several years working with the professor, attending medical meetings around the world and visiting many major medical centers. But it was her desire to help others in a more “hands on” way that convinced her that it was time make a career change. It also made her a perfect fit with the IMF!

Nadia organized the 2012 Paris Patient & Family Seminar, and found the experience of gathering together patients, families, physicians, and scientists truly remarkable. “In my new role with the IMF, I hope to continue building these bridges,” she says. “I also look forward to continuing to raise awareness about the disease, as well as organize programs for medical practitioners to train and learn from each other – an ‘exchange program’... I have so many ideas!” Nadia can be reached at [nelkebir@myeloma.org](mailto:nelkebir@myeloma.org).



**Nancy Bruno**  
**Southeast Regional Director, Support Groups**

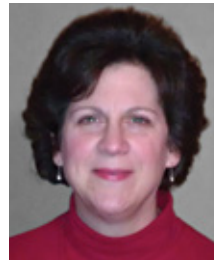
“Myeloma” was a foreign term to Nancy Bruno when her husband Mike was diagnosed in late 1998. Nancy had spent her professional career as Director of Technical Resources for National Data Corporation, managing high speed networks and large healthcare databases. Her work also included explaining complex systems to customers and support staff. “This skill has served me well in understanding myeloma research and the results from clinical trials,” she says now. “I found I was able to explain things in practical terms to patients and caregivers.”

In 1999, Nancy attended her first meeting of the IMF’s Atlanta support group. Eight years later, she became the group’s leader – a group that now includes

more than 140 myeloma patients, plus their caregivers and family members, with an average monthly attendance of 50 members.

Nancy’s husband passed away in January 2011. Although it has been a significant adjustment after 31 years of marriage, the transition has been eased by the closeness of Nancy’s family, including her three children and four grandchildren, and from comfort provided by the members of the Atlanta support group.

“The timing of my new position with the IMF fits perfectly into my journey,” Nancy says. “And this is an exciting time for the myeloma community. There is so much good news stemming from new research. I look forward to working with IMF support groups to spread all of this hope.” Nancy can be reached at [nbruno@myeloma.org](mailto:nbruno@myeloma.org).



**Sue Enright**  
**Midwest Regional Director, Support Groups**

Sue Enright was born in Casablanca, Morocco, raised in Idaho, and has lived in Wisconsin for 16 years, raising two daughters with her husband Rob, working in administration, and dedicating herself to volunteering.

When Rob was diagnosed with myeloma in 2006, Sue turned to the IMF, first online, then through its Wisconsin-based support groups. In 2008 she launched a new group in West Bend. They began with 12 members, and have since grown to more than 30 regular attendees.

Sue served on the Planning Committee for the annual Wisconsin Multiple Myeloma Conference for three years. She is also active with IMF and local advocacy (as a member of Wisconsin Coalition for Cancer Treatment Access), meeting with several Wisconsin state legislators, including a part of Wisconsin Lobby Day regarding the Oral Chemotherapy Parity Bill. Sue’s advocacy work earned her an IMF All-Star Advocates Oscar in 2011.

“The IMF has given us so much, and I look forward to giving back and helping others in any way I can,” Sue says. “Support groups are my passion, and I’m excited to begin this new chapter in my life!” Sue can be reached at [senright@myeloma.org](mailto:senright@myeloma.org). **MT**



**Best Wishes to the IMF’s Andy Lebkuecher**  
**Regional Co-Director, Support Groups Southeast**

It’s a bittersweet time for the IMF, as Andy Lebkuecher retires after 15 years of taking great care of IMF support groups.

The IMF first met Andy in 1994, when he and his wife Cathy attended their first Patient & Family Seminar, which was held in Virginia. They traveled from their home in Atlanta,

where Andy has lived since 1979, and where at the time he was working in aerospace electronics. Andy’s first Patient & Family Seminar was a profound experience, and since then he has attended at least two IMF Patient & Family Seminars every year.

In 1999, Andy and Cathy established the Atlanta Area Multiple Myeloma Support Group, which now has more than 140 patients and family members on its roster. In 2004, Andy began helping the IMF oversee its support groups – 70 in total at the time. Cathy passed away in 2006, and Andy decided he wanted to continue the amazing legacy that Cathy had established, and he formally became the IMF Regional Director of Support Groups in the

Southeast. Thanks to Andy’s hard work, passion, and dedication, myeloma support groups across the Southeast have grown and prospered and are an integral part of the network of 150 support groups that the IMF is proud to foster and support.

“I’m moving on with mixed emotions, because I love what I do and the IMF has been a significant part of my life,” Andy says. “But I use the phrase ‘Mother Nature and Father Time may have caught up with me.’ Fresh blood and new minds should only help us move on to new levels.”

Andy looks forward to sharing an active life with his new wife, Juanita, with hopes of traveling, tinkering around the home, and spending time with his three children and three grandchildren. But the IMF community will never stray far from his mind, or his heart. “Through my years with the IMF, I now have a greater appreciation for people wanting to help others,” he says. “And what I will remember most is how I was always welcomed by support groups, how much they appreciated the updates and information I presented. They are wonderful people who I will always hold dearly in my heart.”

After months of misdiagnosis, it was discovered that I had the first of my five vertebral compression fractures. I was finally diagnosed with myeloma in February 2011. Six months later, I had an autologous stem cell transplant. The local IMF Support Group provided a wonderful combination of information and emotional support and, as I recovered, I felt the need to give something of myself. This is not totally altruistic. I want to spend time focusing on things other than myself and my physical condition.

When I saw the offer for advocacy training through the IMF, it was an opportunity to do something of value that I can feel good about. The process felt like a challenge to me, as I have never met with a legislator. However, I felt prepared thanks to the information provided to me by IMF's Aimee Martin. I contacted Congressman Scott Rigell's district office in Virginia Beach, hoping to encourage his co-sponsorship of pending federal oral parity legislation (HR 2746).

Together with Jerry Walton, leader of my support group, I visited with the Congressman's District Director, Shannon Kendrick. We asked for support and co-sponsorship of HR 2746, and we felt that Shannon listened carefully to what we had to say. She was visibly taken back by the co-pay cost for Revlimid® (lenalidomide), a drug so many myeloma patients take as part of their treatment. The information we presented has been forwarded to the aide who deals specifically with healthcare issues, and we are hoping that the Congressman will become the 55th co-sponsor on HR 2746.

What I took away from the experience is that it's important for us patients to be heard. Our advocacy efforts are worth pursuing, and I would be glad to participate again in the future.

**Tom Glass**

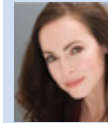
Thank you for the advocacy training, coordination, and motivation! Well done to Tom Glass for his leadership and to the IMF for making advocacy a front-burner item, and for helping constituents to effectively carry the ball on such important issues. Tom invited me to join him at the scheduled meeting to provide compelling examples of support group members who had been severely impacted by myeloma pill expenses, including some who had turned down doctor-recommended therapies due to the high cost under their insurance coverage. Tom's leadership resulted in a very effective session with Congressman Scott Rigell's District Director, in which the need for federal oral parity legislation (in addition to previously passed state oral parity legislation) was emphasized.

**Jerry Walton**  
Leader, SE Virginia Multiple Myeloma Support Group



Tom Glass and Jerry Walton

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



**Marya Kazakova** – Editor-in-Chief, Publications  
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mkazakova@myeloma.org

## Share your thoughts

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

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

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

## The IMF has a social community

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

Find us on [facebook](https://www.facebook.com/myeloma) at [www.facebook.com/myeloma](http://www.facebook.com/myeloma)

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

## Share your stories – we want to help!

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

## The Healthcare Landscape in the Aftermath of the 2012 Elections

With the end of the election season, the IMF is moving forward with its work to ensure that key provisions of health reform that provide high quality of care for cancer patients are maintained. We will continue to educate legislators at the state and federal level about the needs of cancer patients, and, working with our coalition of cancer organizations, we will continue to provide input in Washington as they determine policies and regulations.

Under the Affordable Care Act (ACA), myeloma patients can currently benefit from these important provisions, which:

- Prevent insurers from denying coverage for patients with pre-existing conditions
- Establish a temporary high-risk pool to serve people who have lacked coverage for a six-month period or longer
- Provide grants to states to assist consumers with health insurance complaints, appeals and inquiries
- Help employers maintain plans for early retirees
- Provide tax credits for small businesses with up to 25 full-time employees to help pay premiums
- Allow parents to keep dependent children on health insurance plan up to age 26
- Prevent health plans from imposing annual and lifetime spending caps on coverage
- Eliminate cost sharing for long list of preventive services

Additionally, the insurance exchanges will continue to be implemented over the next one-to-two years. The IMF Advocacy Team has and will continue to work hard to ensure that the needs of all cancer patients are considered by the state lawmakers who are responsible for the health exchanges and that the plan design does not lean too heavily on maximizing flexibility at the expense of ensuring access to comprehensive and quality cancer care. If you have any questions, please contact Meghan Buzby, Director of U.S. Advocacy at [mbuzby@myeloma.org](mailto:mbuzby@myeloma.org).



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## 2013 IMF Calendar of Events

- |             |  |            |  |
|-------------|--|------------|--|
| Feb 15-16   | New Trends in Hematology Annual Conference – Istanbul, TURKEY              | June 11    | Robert A. Kyle Lifetime Achievement Award Presentation – Stockholm, SWEDEN |
| Feb 16      | IMF Regional Community Workshop (RCW) – East Texas, TX                     | June 13-16 | European Hematology Association (EHA) Annual Congress – Stockholm, SWEDEN  |
| March 1-2   | IMF Patient & Family Seminar (PFS) – Boca Raton, FL                        | June 15    | IMF Regional Community Workshop (RCW) – Minneapolis, MN                    |
| March 23    | Myeloma Center Workshop (MCW) at Mayo Jacksonville – Jacksonville, FL      | June 22    | IMF Regional Community Workshop (RCW) – Cincinnati, OH                     |
| April 3-7   | International Myeloma Workshop (IMW) – Kyoto, JAPAN                        | July 13    | IMF Regional Community Workshop (RCW) – Spokane, WA                        |
| April 13    | Myeloma Center Workshop (MCW) at Vanderbilt University – Nashville, TN     | July 26-27 | IMF Support Group Leaders Summit – Dallas, TX                              |
| April 20    | IMF Regional Community Workshop (RCW) – Milwaukee, WI                      | Aug 9-10   | IMF Patient & Family Seminar (PFS) – Chicago, IL                           |
| April 25-27 | Oncology Nursing Society (ONS) Annual Congress – Washington, DC            | Aug 23-24  | IMF Patient & Family Seminar (PFS) – Philadelphia, PA                      |
| May 15-16   | IMF Patient & Family Seminar (PFS) – San Francisco Bay Area, CA            | Oct 5      | IMF Regional Community Workshop (RCW) – St. Louis, MO                      |
| May 18      | IMF Regional Community Workshop (RCW) – Grand Rapids, MI                   | Nov 8      | Myeloma Center Workshop (MCW) at Duke/UNC – Chapel Hill, NC                |
| June 1-3    | American Society of Clinical Oncology (ASCO) Annual Meeting – Chicago, IL  | Nov 23     | Myeloma Center Workshop (MCW) at Mayo Scottsdale – Phoenix, AZ             |
| June 10-12  | 2013 International Myeloma Working Group (IMWG) Summit – Stockholm, SWEDEN | Dec 6-9    | American Society of Hematology (ASH) Annual Meeting – New Orleans, LA      |

*The IMF is proud to work with our global partners.*

*For more information about upcoming events, please visit [myeloma.org](http://myeloma.org) or call 800-452-CURE (2873).*

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

*Latin America [mielomabrasil.org](http://mielomabrasil.org) • Japan [myeloma.gr.jp](http://myeloma.gr.jp) • Israel [amen.org.il](http://amen.org.il)*