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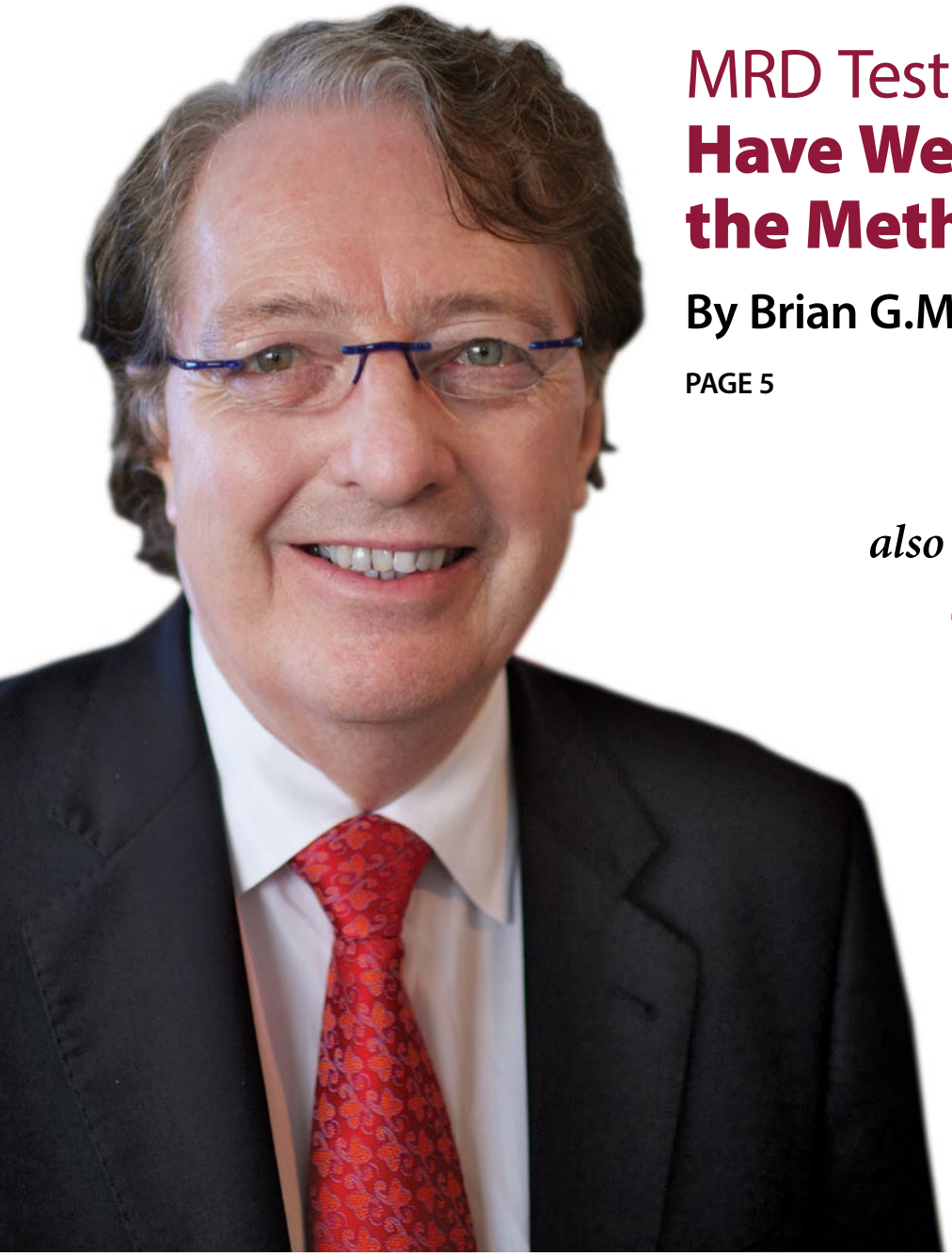

MRD Testing: **Have We Found the Method We Need?**

By Brian G.M. Durie, MD

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International Myeloma Foundation

A Message from the President

Dear Reader,

The myeloma community is truly global. No matter where you live, we are One Myeloma Nation. We are all connected, and when we work together as one entity, we have significant power. Together, we can make significant changes.

Over the years, the International Myeloma Foundation established and continued a collaborative relationship with clinicians and researchers who are experts in the field of myeloma. This collaborative group, under the auspices of the IMF, became the world renowned International Myeloma Working Group (IMWG)! Members of the Working Group represent more than 30 countries, and working together they prove that we are One Myeloma Nation.

One Myeloma Nation is made up of patients, their families, friends, and colleagues, who face different challenges but who share a belief that a cure is within reach and it will happen in their lifetime.

The IMF and the IMWG are the catalysts for uniting people from all walks of life, who speak different languages and have much in common. They are doctors, researchers, nurses, patients, caregivers, family members, friends, colleagues, and industry. We are One Myeloma Nation – and we make things happen. We collaborate! We share information, become empowered, become advocates, start support groups, share experiences, and we raise money to help fight this disease.

Knowledge is power! The IMF has conducted more than 250 educational seminars worldwide. We serve 350,000 people in 140 countries, and we empower them to take an active role working with their healthcare team to make informed treatment decisions. An empowered patient gains another significant benefit… *HOPE*.

We've been incredibly lucky in myeloma. Major advances have been made. We have a wealth of novel therapies and an incredibly robust pipeline. Today, there are myeloma therapies that enable patients to achieve long durable remissions and a good quality of life.

Over the span of 24 years, the IMF has built One Myeloma Nation. Working together and through the Black Swan Research Initiative® we will, as a "nation," put an end to this terrible disease.

Warm regards,

Susie Novis

Susie Novis, President

Letters to the IMF

Dear IMF staff,

I am writing you from Iran. Two weeks ago, I requested information on multiple myeloma and yesterday received a full package handed at my home door in Iran. My family and I deeply appreciate it. All brochures are very informative and more than that gave hope and the sense of not being alone fighting myeloma. Since there is no organization like yours in Iran, your very kind attempt sending all these brochures was extremely helpful expanding our knowledge on this disease and elevated our morale condition. Thanks to United States existing in this world and to the IMF for all that you have done for the humanity worldwide.

– Lots of love from Iran

Just want to take a minute to say "kudoo's!" with regard to the IMF's Regional Community Workshop I attended. The agenda was so very informative... and so timely and the presenters were excellent. The IMF staff… I can't say enough about. Also, I should mention… another of the attendees commented that this was the best workshop she had attended to date. I feel it's important to recognize those who do wonderful things and to thank those who make this type of workshop possible. So –

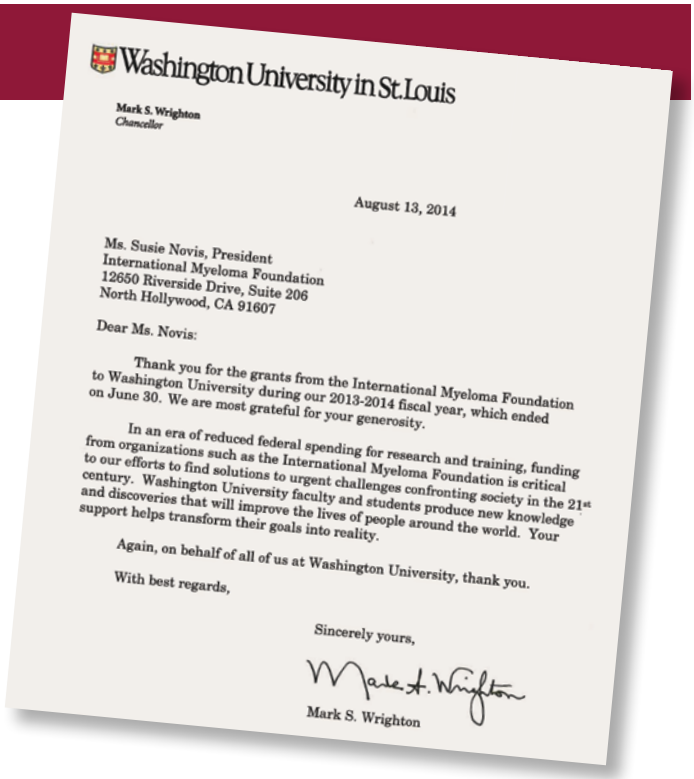
My thanks,

– Melba Trapp

This is just a quick note to say thank you for your support and assistance. My wife, Liz, had her first stem cell transplant last month. Here we are less than a month after discharge, and life is back to normal. We are pleasantly surprised at Liz's speedy recovery.

From diagnosis through transplant, the IMF's InfoLine team assisted us on several occasions. We greatly appreciate all that you have done for us.

– Sergio Murer



Washington University in St.Louis

Mark S. Wrighton
Chancellor

August 13, 2014

Ms. Susie Novis, President
International Myeloma Foundation
12650 Riverside Drive, Suite 206
North Hollywood, CA 91607

Dear Ms. Novis:

Thank you for the grants from the International Myeloma Foundation to Washington University during our 2013-2014 fiscal year, which ended on June 30. We are most grateful for your generosity.

In an era of reduced federal spending for research and training, funding from organizations such as the International Myeloma Foundation is critical to our efforts to find solutions to urgent challenges confronting society in the 21st century. Washington University faculty and students produce new knowledge and discoveries that will improve the lives of people around the world. Your support helps transform their goals into reality.

Again, on behalf of all of us at Washington University, thank you.

With best regards,

Sincerely yours,

Mark S. Wrighton

Mark S. Wrighton

Thank you for helping me on the InfoLine with the Medicare information. I called the number you gave me and Medicare will pay all! Thanks to Judy Webb and to all of you for your help. I have always received assistance from the IMF. What a great Team!

May God Bless All of You,

– Virginia Heard

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MRD Testing: Have We Found the Method We Need?

By Brian G.M. Durie, MD

(left to right) Drs. Ola Landgren, Bruno Paiva, Alberto Orfao, Brian G.M. Durie

After more than 10 years of progress in myeloma treatment due to the introduction of the novel therapies, researchers now need to know how to eliminate the myeloma cells that remain after current therapies. Today, we are on the brink of having a test that will help us have a clear plan to eradicate residual disease.

The new highly sensitive and extremely accurate flow cytometry test developed with the support of the IMF's Black Swan Research Initiative® by Spanish researchers is that test. It is proving itself to be the most affordable, most sensitive, most easily accessible minimal residual disease (MRD) test yet, and earned near-unanimous acclaim from researchers at a flow workshop co-hosted by the IMF at the Zuckerman Research Center at Memorial Sloan Kettering Cancer Center (MSKCC) in New York City on July 18-19, 2014.

Flow workshop in New York

At the workshop, there were 24 participating medical centers from across the United States, plus representatives from the National Cancer Institute (NCI) and the US Food and Drug Administration (FDA). Attendees included key myeloma experts from the centers as well as technical staff responsible for the running of flow cytometry laboratories. US myeloma experts present included Drs. Vincent Rajkumar, Shaji Kumar, Ola Landgren, Ken Anderson, Saad Usmani, Suzanne Lentzsch, Jonathan Kaufman, Phillip McCarthy, and Andrzej Jakubowiak. This educational workshop was structured to inform participants about the role of testing for MRD and currently available testing procedures. The main focus was the new automated, highly sensitive flow cytometry method developed by the Spanish team for standardized detection of MRD in myeloma.

The establishment of a reliable MRD test is a key first step for the Black Swan Research Initiative. This approach focuses on the use of the best MRD testing to track myeloma at the lowest levels as a basis for treatment decisions to achieve cure. It was therefore very exciting to have the top experts in flow cytometry in the room to assess the value of the new flow test for MRD.

During the workshop, Dr. Bruno Paiva (University of Navarra, Pamplona, Spain) summarized the importance of MRD testing in assessing treatment outcomes – much as he had done in March 2014 before an audience of 70 global experts at the Flow Workshop in Salamanca, Spain. After the Spain meeting, the flow cytometrists set up the new method in labs from Germany to Australia. Would it be the same in the US?

The next presenter at the New York workshop was Dr. Alberto Orfao (University of Salamanca, Salamanca, Spain), the Flow MRD test

developer. He explained the details of the new flow cytometry method he and his team had worked for years to develop, a project that has received IMF support as a key element of the Black Swan Research Initiative.

As workshop presenter Dr. Brent Wood (University of Washington, Seattle, Washington) would later ask, "What is more important for us? To do our own thing? Or to come together and standardize in a way that is good for our patients?" The consensus among workshop participants was "Yes, we want to standardize. But how?" Among the practical questions and concerns voiced were the following:

- Do samples need to be processed in 24 hours?
- When is the best time to get samples for response assessment?
- How can we find the time to set up a new method in a very busy laboratory?
- What about the costs?
- We have contracts for the old antibodies – how about the new antibodies?
- What about the new software which standardizes the analysis and results?

The software for this cutting-edge test is a very important aspect because the cytometer uses eight colors and the results consist of clusters displayed in eight dimensions! If this sounds mind-bending, it really is. Sophisticated software is required to accurately sort or "gate" the cells and determine which are myeloma cells and which are not. This is the fundamental question the new flow method can answer: Are there any myeloma cells left or not – and *ARE WE REALLY SURE*?

Everyone who attended the flow workshop was eager to have the means to answer this question. That left the matter of whether or not the practical laboratory implementation issues can be resolved in order to begin using the new flow method. The workshop participants asked the IMF team to help. There was immediate agreement that every effort will be made to assist labs that are anxious to start the new method, but which face challenges doing so.

Workshop participants left well informed and highly motivated to implement a new highly sensitive flow MRD method. There is a strong sense of optimism that a reliable MRD test will be available very soon for US patients.

Exciting new data from France

A recent study illustrates just how useful MRD testing by flow cytometry is to predict excellent outcomes with new highly active combination therapies. A phase II study from the Intergroupe Francophone du Myelome (IFM) served as a pilot protocol for the ongoing IFM/Dana-Farber Cancer Institute 2009 phase II study assessing lenalidomide (Revlimid®), bortezomib (Velcade®), and dexamethasone frontline therapy with or without autologous stem cell transplantation (ASCT). As reported in the *Journal of Clinical Oncology*, 31 patients with newly diagnosed symptomatic myeloma all received RVD followed by ASCT plus RVD consolidation and one year of Revlimid maintenance.

The results with this protocol were extremely good. Very good partial response (VGPR) or better was achieved in 58%, 70%, and 87% of patients after RVD induction, ASCT, and RVD consolidation, respectively. What was especially exciting is that 68% of patients achieved MRD-negative status as measured by flow cytometry. MRD negative by flow is an extremely helpful category as a one-time test measured at the point of maximum response. When MRD negativity is confirmed by subsequent serial testing (i.e., sustained MRD-negativity) and supported by additional testing, such as a negative pet/CT scan and normal Hevylite® test, one can use MRD-Zero as a new category indicative of potential cure status.

With a median follow-up of more than 3 years (39 months), patients achieving MRD-flow negative status are still in remission. The overall survival (OS) is obviously 100% at over 3 years. Thus, as we await the results of the phase III comparison study, the impact of induction, ASCT, consolidation, and maintenance is quite impressive, especially with regard to the MRD-negative status and stable remission status of the patients.

These findings strongly validate the key principle of the Black Swan Research Initiative. Monitoring with sensitive MRD testing at very low levels of disease both predicts exceptionally good outcomes and can be the basis for additional treatment decisions to achieve the sustained deep responses noted above, which can translate into cure.

It is important to emphasize that these new data support considerable prior data. The clinical benefit of achieving MRD-negative status documented using the Spanish flow methodology has been recognized for more than 10 years. Two sequential studies by the Spanish team in 2008 and 2012, and one from the UK team have shown that patients achieving MRD-negative status by flow have longer remissions and OS. What is remarkable about the new data is the sustained value of the deep responses in the IFM trial: no relapses after more than 3 years.

Thus, with the even more sensitive and standardized new flow method now available and use of increasingly effective novel combinations of therapy, it seems very likely that it will be easily feasible to reliably predict unusually good outcomes and define a patient population potentially curable with comprehensive frontline treatment. This new IFM study points the way to incorporation of MRD testing by flow cytometry into tailored approaches to achieve the very best results with therapy throughout the course of disease.

Have we found the method we need?

At the July flow workshop at MSKCC, an audience member asked, "Can one of the fluorescent dyes (fluorochromes) used in the Flow MRD test be changed or improved?"

Dr. Alberto Orfao said, "Of course – possibly yes!" But these types of tweaks can be never ending, he added. "Do we have a test right now which is working very well? The answer is: YES," said Dr. Orfao. "It is standardized, reliable, and sensitive enough at the 10^{-5} level. Nothing more is needed. It is time to stop tweaking and move forward with full validation in patient trials!"

Some in the myeloma community argue that we need a DNA sequencing [molecular] test for MRD in the bone marrow. The main potential advantage of the molecular test, they contend, is greater sensitivity versus flow. However, the new flow method is now equally sensitive and provides excellent prediction of very good patient outcomes. I would add that a more sensitive test might encourage overly aggressive, unnecessary treatment, causing more harm than good!

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BRIAN G.M DURIE, MD — continued from page 5

To be sure, careful comparisons of molecular and flow testing are essential. But after careful consideration of all the pros and cons of each method, the Black Swan Research Initiative team has chosen Flow MRD as the primary MRD detection method – as the benchmark for comparison with other methods.

An important benefit of the new flow method is that it utilizes a stored computer database of all possible myeloma clones or subclones for instant comparison and classification. All myeloma clones or subclones can be identified by flow methodology at any point during the course of the disease. Conversely, the DNA "dominant clone" approach risks missing minor subclones, which take over later in the disease. If residual subclones are identified, these can be characterized and sorted one by one with the flow method for detailed studies, including full sequencing of the DNA. Applying DNA technology in this combined flow/molecular fashion is simple and very informative.

The new flow method allows careful measurement of myeloma at the very low levels of disease needed to predict excellent outcomes and enhance treatment for some patients to achieve an MRD-Negative status.

Since the flow test is standardized, widely available and cheap, there is no longer a need for another method such as the molecular method, which has a number of disadvantages. One limitation of the molecular method is that the bone marrow from the time of diagnosis (or a new relapse) is needed to identify the "dominant or main clone" for future monitoring. In my opinion, the molecular method has other disadvantages. It is more expensive – estimates range between $750 and $1,000 (compared to between $100 and $150 for the new flow test) – and cannot be performed at the local center. To those who would argue for using both the molecular and flow tests, a practical point to keep in mind is that "splitting" bone marrow samples into two parts, one for flow and one for molecular, is not ideal. For the best results, the flow test needs the maximum number of myeloma cells from the "first pull" from the bone marrow aspiration sample to give the most accurate results.

Thus, although it is important to compare the flow and molecular methods in some trials, it seems likely that flow is all that we need! Moving forward, there can be some "fine-tuning," with the addition of the Hevylite ratio test as a quantitative replacement for immunofixation (IFE) and whole body PET/CT to directly evaluate myeloma disease outside the bone marrow.

So stay tuned as the Black Swan Research Initiative moves rapidly forward to achieving chronic disease control and a cure! **MT**

Medical Updates

Should MM patients get a flu shot?

The beginning of Fall also signals the beginning of flu season, so now is the time to get your flu vaccine. The flu vaccine is safe for myeloma patients and the IMF recommends that all myeloma patients receive a flu shot annually. The National Institutes of Health's 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.

Measles virotherapy for MM

Earlier this year, the Mayo Clinic shared exciting results from a clinical trial conducted by Dr. Stephen Russell and his team to test engineered measles virus in myeloma patients. Dr. Russell discussed the approach during the IMF's International Myeloma Working Group (IMWG) Conference Series Debate in June 2014. The Mayo Clinic is now enrolling patients in a second clinical trial. For more information, please visit mayo.edu and click on the "research" tab.

Recently, the popular radio show Science Friday broadcast on National Public Radio (NPR) explored the exciting science around cancer virotherapy, with Dr. Russell sharing his experience treating myeloma patients with massive doses of the measles virus. Visit sciencefriday.com to listen to a recording or go to myeloma.org to read Dr. Durie's thoughts on the subject.

FDA approves use of Velcade for retreatment

The US Food and Drug Administration (FDA) has approved the use of Velcade® (bortezomib) for retreatment of myeloma patients who have previously responded to Velcade and have relapsed at least six months after their prior treatment. The expanded approval was granted based on data from a phase II clinical trial. This approval includes intravenous (IV) and subcutaneous (SQ) administration of Velcade, and was also accompanied by updates of the dosing guidelines, efficacy, and safety.

New approach to detect bone loss in MM

Researchers from Arizona State University and the Mayo Clinic recently published a study in the journal *Leukemia* on a blood test for calcium atoms that could be used in the future to monitor bone loss associated with myeloma. The method is commonly used in earth science and detects calcium atoms with different masses. Study author and Arizona State University professor Ariel Anbar, PhD, explained, "If the method proves to be robust after more careful validation, it could provide earlier detection of bone involvement than presently possible." **MT**

The Role of Salvage Transplant Therapy in Myeloma

Myeloma Today in conversation with Sergio Giralt, MD

Dr. Sergio Giralt is Chief of the Adult Bone Marrow Transplantation Service and holds the Melvin Berlin Family Chair in Multiple Myeloma at Memorial Sloan Kettering Cancer Center in New York City. He will be taking a leading role at the IMF / BMT CTN International Workshop on Salvage Stem Cell Transplantation for Multiple Myeloma, which will be held on October 28 in Minneapolis, Minnesota. Participants include representatives from four major organizations: the Blood and Marrow Transplant Clinical Trials Network (BMT CTN), the International Myeloma Foundation (IMF), the American Society of Blood and Marrow Transplant (ASBMT), and Be The Match.

What can you tell us about the aims of the upcoming IMF / BMT CTN workshop?

There have been multiple retrospective studies (people looking back at their own data) suggesting that salvage transplant using autologous cells plays a definitive role in inducing long remissions in people who have relapsed after initial remission.

The meeting we are going to have in Minneapolis will bring together both national and international investigators looking at the role of salvage transplants in myeloma, not only with autologous stem cell transplants (ASCT), but also with allogeneic (allo) transplants. We aim to develop a consensus on the role of salvage transplant in myeloma, and to publish the resulting consensus guidelines.

At the workshop, we will review retrospective studies of second ASCTs as well as second allo SCTs, examining both the American and the European landscape for salvage auto and allo transplants. We will also discuss ongoing and proposed clinical trials. In conjunction with the cooperative groups and the Blood and Marrow Transplant Clinical Trials Network, we are already in the process of planning and developing a national prospective ASCT trial for myeloma patients.

In part, arriving at the consensus among myeloma experts will help to inform third-party payers such as Medicare and Medicaid when these procedures are considered valid and should be covered benefits.

What is the role of salvage transplant therapy in myeloma?

Salvage therapy is treatment to induce remission in patients who have failed to respond to, or lost the response to, initial treatment. The two sides of the coin are: On the one hand, we would like to have multiple treatments to offer people if they relapse multiple times. On the other hand, we are trying to treat this disease the least amount of times possible, and we would like to have treatments that offer long remissions.

It has been customary in many parts of the US to collect enough stem cells for 2 transplants, and since common knowledge has been that if you have a remission that lasts 2 or 3 years after first transplant, it is reasonable to try this strategy again to achieve a similar long remission, we believe that the number of salvage transplants that are performed should be increased.

There are now many more active treatments for myeloma, and we have many studies that have examined the question "What is the optimal treatment for patients who have relapsed after primary therapy?" I think we have to ask the same question about high-dose melphalan consolidation. "If there is a benefit for high-dose melphalan up-front, may there also be a benefit for high-dose consolidation therapy at relapse?" This question needs to be more fully explored.

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Management of Side Effects of Panobinostat

Myeloma Today in conversation with Shaji Kumar, MD

Dr. Shaji Kumar is a Professor of Medicine at Mayo Clinic in Rochester, Minnesota, whose laboratory focuses on the development of novel drugs for the treatment of myeloma and on unraveling the mysteries of myeloma's biology. He has published more than 275 medical articles, and is currently working on updating the International Myeloma Working Group (IMWG) response criteria. Dr. Kumar is the principal investigator of many early-phase trials with new anti-myeloma agents, including panobinostat, which will soon be considered for approval by the US Food and Drug Administration (FDA).

Please give us some background on the development of panobinostat.

Histone deacetylases (HDACs) have been under investigation for many years. We knew from preclinical research that several HDAC inhibitors worked really well with proteasome inhibitors. Clinical trials published two years ago with another HDAC inhibitor, vorinostat, were disappointing. Progression-free survival (PFS) improved only slightly, and overall survival (OS) was not improved. Panobinostat, however, is a different HDAC from vorinostat.

As patients live longer and longer, and become refractory to existing drug groups such as proteasome inhibitors, immunomodulatory drugs (IMiDs®), and alkylating agents, it is critical that we explore agents with new mechanisms of action. The development of panobinostat opens up a new class of drugs – the histone deacetylase inhibitors, or HDACS – for the treatment of myeloma.

What do you see as the role of panobinostat in the treatment of myeloma?

In an early trial in which panobinostat was combined with bortezomib (Velcade®), several patients did very well even though they had previously been refractory to bortezomib. This study was published in *The Lancet*, and provided some evidence that panobinostat could make some bortezomib-refractory patients sensitive to bortezomib again.

Current clinical trial data indicates that panobinostat plus bortezomib improves PFS over bortezomib alone by about four months. There is not enough data yet to evaluate OS benefit, but whether there is OS benefit or not, panobinostat still may have a role to play in helping patients. It improves response to bortezomib and has activity against myeloma. For patients who have been heavily pretreated, like the patients in clinical trials, and especially for those who are double refractory (to both existing approved drug classes, IMiDs and proteasome inhibitors), panobinostat offers another option.

We must ask the question, "Where do we place this agent among all our other drugs, including the monoclonal antibodies coming along?" Panobinostat could be used for a patient who is receiving but not responding well to bortezomib, to boost response, or it could be used in a situation where someone previously responded to bortezomib and then became refractory. Panobinostat may also be considered for patients who are no longer responding to IMiDs. Its use must be placed in the context of side effects a patient has experienced as well as drugs to which the patient is refractory.

What are the most common side effects of panobinostat?

There are three main side effects of panobinostat: low platelet counts, or thrombocytopenia, which affects 2/3 of patients, diarrhea, which affects

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SHAJI KUMAR, MD — continued from page 8

about a quarter of patients, and fatigue, which also affects about 1/4 of patients. Fatigue has an impact, especially on patients' quality of life.

How are these side effects best managed?

Panobinostat is an oral agent that comes in different doses. We don't yet know – if it is approved by the FDA – what the approved dose and various pill or capsule dose options will be. In the early trials in which I was involved, panobinostat was given three times a week, so it may be possible to give it less frequently. We know that fatigue responded well to dose reductions in the clinical trials, but until we know what the approved dose and schedule will be, I can't offer specifics on dose reductions.

For patients with peripheral neuropathy (PN), we know that this is related to the bortezomib. These patients should receive bortezomib by subcutaneous (SQ) administration [by injection, or shot] once weekly instead of twice. Thrombocytopenia is caused by both panobinostat and bortezomib. The best approach is to reduce the dose of each drug in an alternating fashion to see which is drug is more responsible for the problem. When the responsible drug is found, the dose should be reduced. For diarrhea, Lomotil (a prescription drug for the treatment of diarrhea) and Imodium (an over-the-counter drug for treating diarrhea) can both be helpful. Dose reductions of one drug at a time – either panobinostat or bortezomib – should only be made if these anti-diarrheal medications don't work. Nausea should also be managed with medications first. Only if the nausea is not resolved should dose reductions be made. In the clinical trials, dose reductions in panobinostat, bortezomib, and dexamethasone were made as needed.

What is your personal experience with managing panobinostat side effects in the patients you treated?

With the combination of panobinostat and other drugs, I learned that management of side effects had to be individualized for each patient.

What is your vision for panobinostat going forward?

Panobinostat is one more potential agent in our armamentarium, a new drug class to try with bortezomib. If it works, it buys a patient time until he or she must move on to the next available therapy. HDACs will have a role to play in treatment. We may be able to identify the sub-group of patients who respond to them better than others. We may be able to use them selectively without compromising quality of life.

There are ongoing early-phase trials combining panobinostat with proteasome inhibitors other than bortezomib. These trials will help us answer the question, "Does panobinostat have to be combined with bortezomib to be effective in myeloma?"

What is your perspective on the outlook for myeloma treatment in general?

The landscape is both promising and exciting. Many new types of drug classes will be approved in the next two to three years and added to the IMiDs, proteasome inhibitors, and HDAC inhibitors. There will be a dramatic shift in treatment over the next decade: I expect that there will be six to ten classes of drugs available to treat myeloma. **MT**

SERGIO GIRALT, MD — continued from page 7

What about allogeneic transplant?

In the donor setting, we do know that allogeneic transplant can cure a fraction of patients – even those with relapsed myeloma. Many of us believe it is the only curative approach for patients who have relapsed disease. I think it is valid to start exploring the role of allogeneic transplant in the up-front setting for patients with high-risk myeloma, and in the relapse setting as well, particularly in the context of new potential maintenance strategies. This will also be a focus of the discussion in Minneapolis.

Can you comment on the status of transplant coupled with adoptive immunotherapy?

On a local note, Dr. Guenther Koehne of the Memorial Sloan Kettering cytotherapy laboratory is pioneering a new type of stem cell transplantation using CD34-selected allogeneic stem cells followed by cellular therapies. Initially these were simple donor lymphocyte infusions, but the latest version of his protocol uses donor lymphocytes that have been skewed to react primarily against the WT-1 antigen, which is expressed on the surface of myeloma cells. This is a form of targeted immunotherapy against myeloma.

Are there any closing comments that you would like to share with our readers?

Although we routinely say that myeloma is incurable with modern therapy, we must recognize that for a fraction of patients, the combination of induction therapy, autologous transplant, and maintenance therapy provided a 10- to15-year remission without disease relapse even before the advent of IMiDs (such as thalidomide, lenalidomide, and pomalidomide) and proteasome inhibitors (such as bortezomib and carfilzomib). That fraction of patients was very small, perhaps only one third of the patients who achieved a complete remission (CR) after treatment.

For many years we have recognized that CR, meaning inability to find signs or symptoms of disease using standard techniques, was a surrogate marker for long-term disease control. With modern treatments, there is now a substantial increase in the number of patients who achieve CR, and one third of patients who achieve CR can remain in CR for 10 or more years. Our expectation is that the number of patients who will live for many years without having to deal with their disease will significantly increase. These are very exciting times. **MT**

Editor's Note: Please stay tuned to future editions of *Myeloma Today*, visit the IMF website myeloma.org, and subscribe to the Myeloma Minute e-newsletter for more information about the IMF / BMT CTN International Workshop on Salvage Stem Cell Transplantation for Multiple Myeloma and the upcoming consensus guidelines.

Case Studies in Multiple Myeloma Treatment
Best Practices for Nurses

Presented at 2014 Oncology Nursing Society (ONS) Satellite Symposium

Co-Chairs

Joseph D. Tariman

Beth Faiman

Faculty

Page A. Bertolotti

Sandra Kurtin

The IMF Nurse Leadership Board (NLB) is a professional nursing partnership representing national experts in both academic and community practices treating myeloma, with the primary mission of understanding and developing strategies to address the unmet needs of myeloma nurses, and their patients and caregivers.

In this edition of *Myeloma Today*, NLB members and co-chairs of a 2014 Oncology Nursing Society (ONS) Satellite Symposium, Joseph D. Tariman and Beth Faiman, summarize the IMF's "Case Studies in Multiple Myeloma Treatment Best Practices for Nurses" program, which was designed to meet the educational needs of oncology nurses in community or academic settings who are involved in the care of patients with myeloma. At the completion of this activity, oncology nurses are to be able to review myeloma disease state and disease stages, discuss new therapies and combination regimens in myeloma, identify best practices for long-term management and care of myeloma patients, and define strategies to empower nurses in their care of patients. Detailed slides and full-length videos of the case studies are available on the IMF website myeloma.org. All case studies presented are HIPAA compliant to protect patient privacy.

Patient #1:
Asymptomatic smoldering multiple myeloma

The first patient discussed was a 59-year-old man whose abnormal blood work was noted after a routine checkup with primary a care physician. He was referred to a hematologist-oncologist, and a diagnosis of high-risk smoldering multiple myeloma (SMM) was established. Patient health status is otherwise excellent; no comorbid conditions.

The NLB presentation recommended clinical trials for high-risk SMM patients, and study design and results of an open-label phase III trial of high-risk SMM were discussed. The patient in question entered a clinical trial and is doing well six months later, responding to therapy and following a monthly myeloma lab monitoring schedule as ordered by the physician.

Nursing implications for SMM patients include education and advocacy. As noted, survivorship begins at diagnosis, so it is important to protect bone and renal health, and to maintain a healthy lifestyle and to minimize risk factors.

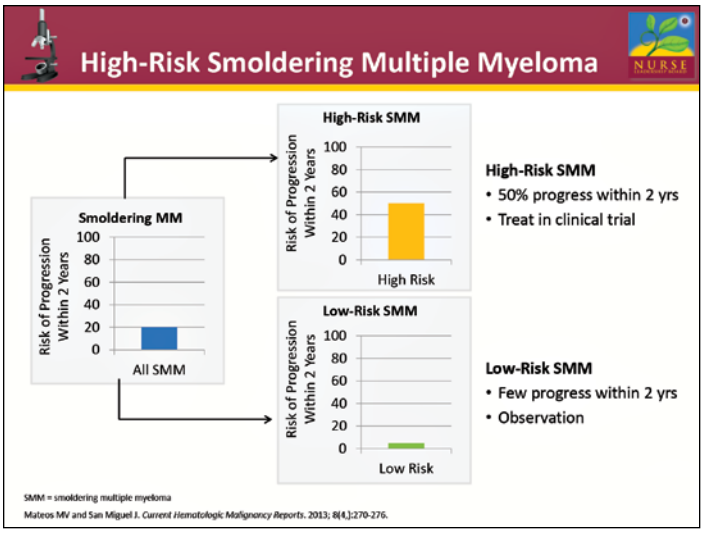
Patients #2 & #3:
Newly diagnosed myeloma

The second patient presented is a 48-year-old woman who self-medicated with NSAIDs for back pain, but without improvement. Initial testing revealed abnormal blood work, and a vertebral compression fracture and lytic lesions. Case discussion included common myeloma symptoms, imaging techniques for assessing myeloma bone disease, and disease staging. The ensuing discussion of expectations and goals of the greatly expanded treatment options included rapid control of disease and its symptoms, optimal treatment outcomes, maintaining quality of life while on therapy, and utilizing available support and education resources.

The third patient is a 79-year-old male with Type 2 diabetes, peripheral neuropathy (PN), and pulmonary hypertension. An emergency room visit following a fall revealed rib fractures and lytic lesions. Referral to oncologist resulted in diagnosis of ISS stage II myeloma. For older, frail, transplant-ineligible patients, "less can be more" when it comes to anti-myeloma therapies. Clinical trial options were reviewed. This patient's treatment plan included continuous therapy, which has been shown to improve outcomes. Nursing considerations included blood sugar monitoring, antiviral prophylaxis (if shingles history), DVT prophylaxis, and patient and caregiver education on renal function, bone health, dental and oral care, steroid side effects, and safety and mobility recommendations.

Transplant eligibility continues to be a major factor when deciding among available myeloma therapies.

We are excited about new testing methods to detect minimal residual disease (MRD) that are predictive of survival outcomes.



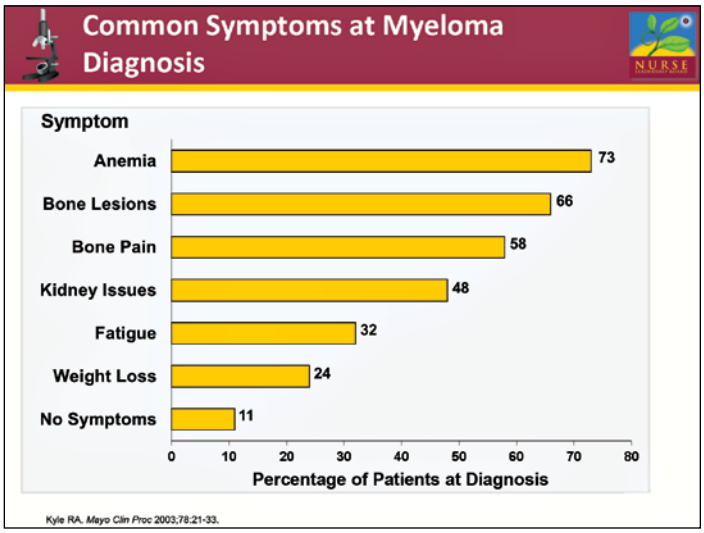
Patients #4 & #5:
Relapsed myeloma

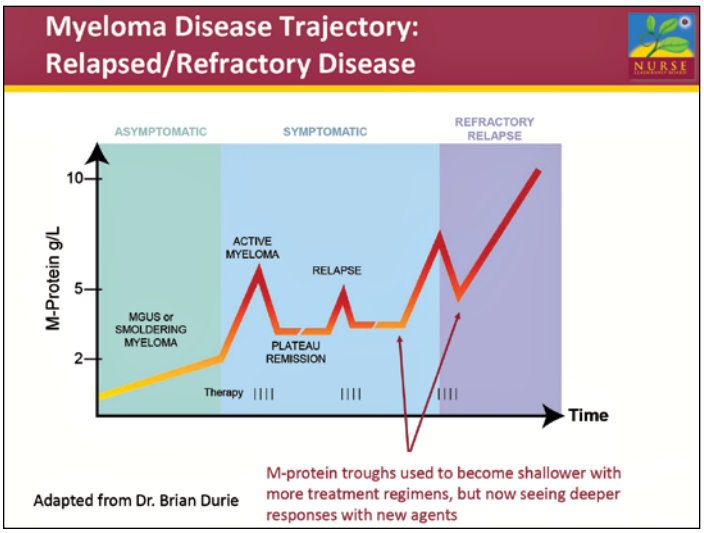
Relapse or progression is likely for the majority of myeloma patients. In recent years, new treatment options have become available for relapsed/refractory myeloma patients, including Kyprolis® (carfilzomib) and Pomalyst® (pomalidomide). Both drugs are indicated for patients who have previously received a proteasome inhibitor and an immunomodulatory drug (IMiD). Many more new agents in development may be available in coming years.

The fourth patient history presented was of a woman diagnosed with IgG kappa myeloma six years ago at age 61. Treated with bortezomib plus dexamethasone, followed by an autologous transplant and a six-year remission. At age 67, diagnosed with relapsed myeloma with clonal evolution and new lytic lesions. Myeloma clones change over time, especially after treatment rounds. Effective myeloma treatment reduces or eliminates the dominant clone; however, other clones can still exist. Relapse can occur when another clone no longer has to compete for space with the formerly dominant clone or acquires additional mutation(s), providing a growth and/or survival advantage. Optimal treatment selection for a relapsed patient is evolving and depends on many factors. The patient in question declined a second transplant in favor of combination therapy; complete remission (CR) was achieved followed by 14 months of maintenance therapy as of the time of the ONS symposium.

The fifth case study was of a patient diagnosed with myeloma 3 years ago at age 66, treated with CyBorD, followed by an autologous transplant. Six months post-transplant he had rising serum free light-chains (sFLC). Relapse work-up revealed new lytic lesions, 20% plasma cells, and renal compromise. Carfilzomib continuous therapy and supportive care were initiated. **MT**

We invite you to visit nurses.myeloma.org to access the library of NLB materials, including slides and videos from the NLB's 2014 ONS Satellite Symposium. Nurses are increasingly crucial in patient care, as well as the education of patients and caregivers and, as always, the IMF is here to help. Please contact us for further information and resources.





Risk of Progression from MGUS to Myeloma

IMF InfoLine coordinators answer your questions

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

by Debbie Birns
IMF Medical Editor

I was recently diagnosed with MGUS. Is there a way to know what my risk of progressing to myeloma is? What kind of follow-up care should I receive?

MGUS is the acronym for Monoclonal Gammopathy of Undetermined Significance, a condition that requires no treatment. MGUS is typically diagnosed when a low level of monoclonal protein is detected in the blood. It occurs in 3-4% of the population over 50 years of age, but most people never know they have it. In the first place, MGUS causes no symptoms or any of the CRAB features found in patients with active myeloma: i.e. elevated calcium (C); renal (kidney) dysfunction, (R); anemia (A); or bone lesions (B). Secondly, there is only a 1% per year chance that MGUS will progress to myeloma. That means that each year, once a diagnosis is established, there is a 99% chance the MGUS will remain stable! Given the age of most MGUS patients, it is far more likely that some other medical problem will emerge and take precedence during the years following diagnosis than that the MGUS will progress to myeloma. The key question is, can we identify or predict the 1% each year, or the 10% over 10 years, who will progress?

The Bottom Line: MGUS

- Benign condition
- Risk of active myeloma is low
- Baseline testing and serial monitoring plans are key

Establish MGUS diagnosis

To establish a diagnosis of MGUS, a patient must remain stable for a minimum of 6 months to 1 year. During that period, the doctor will be assessing for any signs of disease progression, including any CRAB criteria or an increase in monoclonal protein. The hematologist/oncologist who is monitoring a suspected MGUS patient will also be checking for underlying causes of a spike in monoclonal protein, such as AL amyloidosis, autoimmune disease, acute or chronic infection, or other malignancy. Treating an underlying medical problem such as an infection or, for example, surgically removing a tumor (kidney, lung, or ovarian) can sometimes eliminate the monoclonal protein. It is important to note that many other illnesses and medical conditions can mimic CRAB features and suggest myeloma when there is another unrelated cause for the problem. Careful studies must be done to rule out hyperparathyroidism, which can cause increased serum calcium; diabetes, hypertension, or nephritis, all of which can cause kidney dysfunction; iron and/or vitamin deficiency or thalassemia, which can cause anemia; and osteoporosis, complex arthritis, Paget's disease, and other conditions that can cause bone abnormalities.

As with all things having to do with myeloma, knowledge is power. Being armed with the facts provides realistic parameters for maintaining physical and mental health. Those more likely to progress to MGUS need to be monitored more frequently. Examinations and serial testing indicate if there is stability or if there is a need for more frequent and/or additional testing; a patient can progress from a lower- to a higher-risk MGUS category. A key step is to more aggressively evaluate patients in whom two serial readings show increasing monoclonal protein levels, especially in a span of 3-6 months. These assessments empower patients to anticipate the future and act appropriately.

According to the IMF's International Myeloma Working Group (IMWG), the type and amount of an MGUS patient's monoclonal protein, the number of bone marrow plasma cells, and the free light chain ratio determine risk of progression to myeloma. Knowing the type of monoclonal heavy and light chains that make up your MGUS (e.g., IgG kappa or IgG lambda) is job one. To understand what heavy and light chains are, begin by reading the IMF's *Patient Handbook*. When you understand what you're asking for, you should request copies of your lab reports and discuss the results with your doctor. If you're having difficulty sorting out the various tests, the IMF InfoLine staff can help you find the numbers you're looking for on the lab report.

MGUS risk categories

The IMWG's 2010 publication, *Monoclonal Gammopathy of Undetermined Significance (MGUS) and Smoldering (Asymptomatic) Multiple Myeloma: IMWG Consensus Perspectives – Risk Factors for Progression and Guidelines for Monitoring and Management*, establishes criteria for MGUS that is at low, intermediate, and higher risk of progression to myeloma.

Low-risk MGUS (0.25% chance of progressing to myeloma each year)

The three criteria for low-risk MGUS are:

- monoclonal protein (M-protein) less than 1.5 g/dL (or 15 g/L),
- IgG-type monoclonal protein,
- normal free light chain (FLC) ratio as assessed by the Freelite® test (the ratio is the number of kappa chains divided by the number of lambda chains; the result should be close to 1.65).

Intermediate-risk MGUS (1% chance of progressing to myeloma each year) is defined as having **one** of the risk factors:

- a type of M-protein other than IgG,
- ≥ 1.5 g/dL of monoclonal protein,
- an abnormal FLC ratio.

Higher-risk MGUS (2% chance of progressing to myeloma each year) is defined as having **two or three** of the risk factors:

- a type of M-protein other than IgG,
- ≥ 1.5 g/dL of monoclonal protein,
- an abnormal FLC ratio.

Risk of progression

Patients with 3 risk factors have a rate of progression to myeloma of 58% within 20 years; patients with 2 risk factors have a 37% risk of progression within 20 years; patients with 1 risk factor have a 21% risk of progression within 20 years, and patients with no risk factors have only a 5% risk of progression to myeloma within 20 years. If broken down into annual risk, this would mean that low-risk patients have a 99.75% chance of NOT progressing to myeloma each year; intermediate-risk patients have a 99% chance of not progressing; and higher-risk patients have about a 98% annual chance of not progressing to active disease.

Researchers have developed some understanding of the biologic events that take place when MGUS develops into myeloma, but they do not yet know what triggers the progression in certain patients and not in others, or how to prevent it. Intensive study is underway in these areas, and is a particular focus of research at several institutions. It has been well established that although only one fifth of patients with MGUS will develop myeloma or another malignancy, all cases of myeloma are preceded by MGUS. That is, if we could trace back through the biology of each case of active myeloma, we would find that there was a pre-existing MGUS state.

Approximately half of the cases of MGUS will develop rapidly, with a sudden change from MGUS to active disease, while the other half will develop gradually, and become asymptomatic or "smoldering multiple myeloma" (SMM) before they eventually progress to active disease. Based on heightened understanding of evolving smoldering disease, the IMWG has recently published new guidelines for the diagnosis of myeloma. These new guidelines stipulate that myeloma can be treated at a very early stage formerly called "ultra-high-risk" SMM, but now redefined as early active myeloma. The good news for patients whose SMM is progressing is that for the first time, we now have treatments for myeloma that may be able to cure this early active disease.

The other half of MGUS cases that evolve more rapidly to active disease, bypassing the smoldering stage altogether, are less predictable, and therefore riskier. Current research is, however, providing insights into the genetic changes that take place at different steps of the transformation process from MGUS to active disease. Tracking these changes may, in the not-too-distant future, provide doctors with the necessary clues they need to start treatment before damage to bones, kidneys, or the bone marrow occurs.

Key tests for diagnosis and monitoring

While all MGUS patients should be assessed with a skeletal survey (x-rays of the full skeleton), a hematologist/oncologist following an MGUS patient may also consider ordering more sensitive studies, such as a CT scan or a whole-body PET/CT scan, in search of myeloma or other serious disease. It is also not uncommon for an MGUS patient to undergo a bone density scan to determine if there are early signs of bone loss. In the not-distant future, it's likely that whole-body low-dose CT scanning will be done routinely to assess for early bone disease, since it is a more accurate study than the skeletal survey. Some myeloma specialty centers routinely biopsy the bone marrow of MGUS patients in order to quantify and characterize the plasma cells and also to perform genetic risk assessment studies on those plasma cells (cytogenetics, FISH, and/or Gene Expression Profiling). Genetic risk assessment is different from assessment of risk of progression to myeloma, and is used to better understand the nature of the myeloma that may develop over time. In the realm of research, genetic tests of MGUS patients are being studied to try to identify the specific DNA "driver" mutations that initiate many other mutations and lead to the evolution of myeloma.

While only 20% of MGUS cases will develop into myeloma over the course of 20 years, all cases of myeloma will arise from that 20%. While it is understandable that many patients – and doctors – become complacent about following up on long-term MGUS, continued regular monitoring is crucial. An added incentive to have ongoing monitoring is the possibility of cure: clinical trials are now underway to determine if early intervention can be curative. If you and your doctor remain vigilant and your MGUS progresses to early active disease, it may be possible to cure you before the myeloma becomes destructive.

For further reading on MGUS and SMM, please see the new IMF publication *Understanding MGUS and Smoldering Myeloma*. **MT**

Editor's Note: We encourage you to visit myeloma.org for up-to-date information about myeloma, and to contact the IMF with your myeloma-related questions and concerns. The IMF InfoLine specialists can be reached at 800-452-CURE (2873) in the US and Canada, or 818-487-7455 from abroad. The InfoLine consistently provides callers with the best information about myeloma in a caring and compassionate manner. The InfoLine is staffed by Paul Hewitt, Missy Klepetar, and Judy Webb. Phone lines are open Monday through Thursday, 9 a.m. to 4 p.m. (Pacific), and until 2 p.m. on Friday. To submit your question electronically, please email infoline@myeloma.org.

NCI Clinical Trial Enrolling Patients with Asymptomatic High-Risk SMM

The National Cancer Institute (NCI) is enrolling patients into phase II/III clinical studies comparing treatment with Revlimid® (lenalidomide) to observation in patients with asymptomatic high-risk smoldering multiple myeloma (SMM). Biological therapies such as lenalidomide may stimulate the immune system and stop cancer cells from growing; in other cases, the cancer may not need treatment until it progresses and observation may be sufficient. To participate, patients must be diagnosed with asymptomatic high-risk SMM within the past 60 months. Details, including trial site information, can be found at cancer.gov or directly at **http://tinyurl.com/NCIclintrial**.

Spotlight on Advocacy

US federal policy update

(left to right) Ray Wezik, Meghan Buzby, Dr. Ola Landgren, Patricia Workman, Dr. Laura Crowley, and Taylor Patton

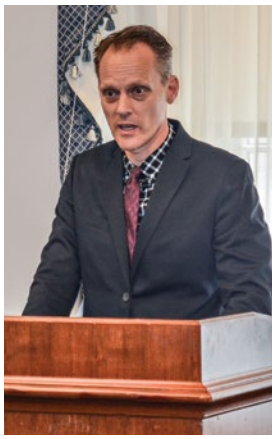
IMF hosts Congressional briefing on environmental agents and their effect on myeloma

by Taylor Patton
IMF Advocacy Associate

On September 10, 2014, the IMF held a congressional briefing, "Understanding Environmental Exposures and Cancer: The Case of Multiple Myeloma," to discuss the effect that certain environmental agents have on the development and progression of multiple myeloma (MM), particularly the chemicals found in the debris in the aftermath of the attacks on 9/11. Guest speakers included Dr. Ola Landgren (Chief of the Myeloma Service, Memorial Sloan Kettering Cancer Center) Dr. Laura Crowley (Assistant Clinical Professor for Preventive Medicine at Mount Sinai School of Medicine and Senior Physician in the World Trade Center Health Program), and Ms. Pat Workman (World Trade Center site volunteer and MM patient).

Meghan Buzby at the podium

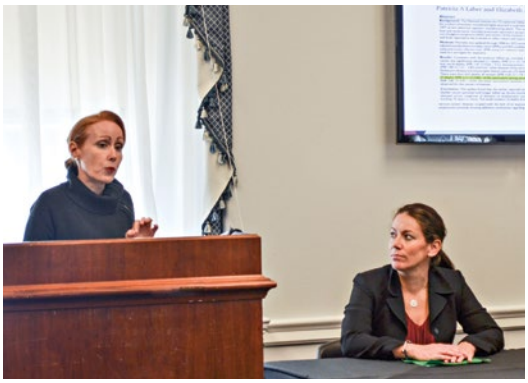
Meghan Buzby (IMF Senior Director of Advocacy) began the briefing by discussing the James Zadroga 9/11 Health and Compensation Act. This legislation provides funding to support the medical treatment for the 30,000 first-responders, medical personnel, and volunteers who were exposed to the toxins at the 9/11 terrorist attack sites. Currently, it is set to expire in October of 2016; however, recent legislation was introduced to reauthorize the act for an additional 25 years. *(See related article on page 15.)*



Dr. Ola Landgren

Dr. Landgren focused his presentation on pesticide use and the onset of MM. He described the disease as well as made the case for the correlation between the precursor state of monoclonal gammopathy of undermined significance (MGUS) and developing MM. One study found that pesticide applicators were six times more likely to develop MM than individuals that were not exposed. In his work with 9/11 responders, Dr. Landgren observed that onset was as early as 30 years of age, while it is typically 70 in other populations. Other risk factors he identified were: older age, male gender, family history of myeloma, African-American descent, and obesity.

Dr. Crowley presented the empirical data collected by healthcare facilities following the attacks on 9/11, detailing the treatment of responders, volunteers, and bystanders. These individuals were found to have been exposed to heavily concentrated amounts of various carcinogens, including asbestos, benzenes,



Dr. Laura Crowley making her presentation

polychlorinated biphenyls (PCBs), and polyaromatic hydrocarbons (PAHs). In her research, Dr. Crowley found higher rates of MM in these individuals. For example, 8 participants developed MM, when only 6.8 were expected. Further, 4 out of the 8 developed MM before age 45, where it is typically expected to be 1.2 persons. Dr. Crowley called for investment in more research to quantify the effects of exposure to the toxins on 9/11 responders.

Ms. Workman shared her personal experiences as a volunteer at Ground Zero after 9/11. From October 2001 to May 2002, she and her sister worked at Ground Zero 3 to 4 times per week. They were exposed to immeasurable amounts of debris brought into the volunteer sites from

Myeloma patient Patricia Workman

the various first responders in addition to the airborne carcinogens that we now know were present. In 2007, her bones began to fracture, and she was eventually diagnosed with MM, which she attributes to her exposure. In 2009, she underwent a stem cell transplant and was told that the MM was gone; however, she relapsed in 2013. Despite all that has happened, Ms. Workman remains adamant that her volunteer work was both invaluable and necessary. She now serves as an advocate, raising public awareness and fighting on behalf of her fellow MM patients.

Reintroduction of the Zadroga Act

by Johanna Gray
IMF Federal Government Affairs Consultant

This September, more than 50 legislators from both political parties and both branches of Congress introduced the James Zadroga 9/11 Health and Compensation Reauthorization Act.

This legislation would reauthorize two critical programs providing medical treatment and compensation for individuals who suffered health injuries as a consequence of the attacks on September 11, 2001 – the World Trade Center Health Program (WTCHP) and the September 11

CONTINUES ON PAGE 16

Saving the Planet – and Preventing Myeloma

by Brian G.M. Durie, MD

In recent weeks, you may have seen full-page newspaper ads signed by 160 award-winning scientists from around the world pleading for funding to help save the planet in the face of climate change. The United Nations convened what the *New York Times* called "the largest gathering of world leaders ever devoted to climate change." The need is clear, but momentum to take action has been strangely lacking.

Toxic chemicals not only affect our planet, they affect the humans who inhabit it. On September 10, the IMF held a congressional briefing in Washington, DC that presented information about the link between chemicals at the 9/11 sites and cancer. There are clear links between exposure to certain environmental toxins and myeloma, but the cause of myeloma has typically been listed as unknown. There is no momentum to investigate further or try to prevent myeloma.

We have knowledge about environmental toxins that could help make myeloma a preventable disease; there is a long list of chemicals that cause cancer, and there are thousands more – equally or more toxic – in widespread use that have never been tested to see if they cause cancer.

Where is the motivation to use energy and chemicals wisely, and to begin decontaminating our planet and its people?

Ever so slowly, the tide is beginning to turn. The Rockefeller Brothers Fund announced it will sell assets in fossil fuel companies and invest in cleaner alternatives. Germany is building massive wind farms offshore to make a meaningful contribution to cleaner energy generation. The European Commission now requires toxicology testing for all new chemicals, and older chemicals are under much tighter review. Reduced use of chemicals is now on the agenda. And innovative, environmentally sensitive companies such as Pylantis are working to replace petrochemical plastics with non-toxic, recyclable, and compost-ready alternatives. Even China has announced a multi-billion-yuan program to reduce and shift away from pollution.

A study published recently in the journal *Nature* illustrates the need to eliminate toxic chemicals, not just in the environment, but in our diets as well. According to NPR, the study suggests that for some people, diet sodas may alter "gut microbes in a way that increases the risk of metabolic diseases such as Type 2 diabetes." The change in gastrointestinal microbes leading to diabetes and obesity is also linked to myeloma and other cancers (breast cancer and certain pediatric cancers), again demonstrating that there is a multi-system, multi-step disease causation process. In the case of diet soda, it is potentially a reversible process.

Reversing our exposure to toxic chemicals requires recognition of their effects: agricultural run-off leaks into rivers, lakes, and oceans, and then into fish and into food, causing DNA damage and reducing the strength of the immune system. Inflammation triggers the growth of damaged plasma cells in the case of myeloma, or of other cells, causing other types of cancer.

Cancer prevention requires a multifaceted approach that focuses on eliminating ALL toxic chemicals. Safe chemicals, real food, clean water, and clean energy are critical elements for insuring our good health.

Is it too late? Let's hope not! We really need our planet – one on which myeloma is decreasing, not increasing.

I invite members of the myeloma community who have an interest in raising awareness about pollution and toxic chemicals to think about what might be done to change the momentum and get rid of the lethargy! MT

US FEDERAL ADVOCACY — continued from page 15

Victim Compensation Fund (VCF). The WTCHP and VCF are set to expire in October 2015 and October 2016 respectively; however, the present legislation would continue these programs through 2041.

The VCF was created to provide financial compensation for any individual (or a personal representative of a deceased individual) who suffered physical harm or was killed as a result of the terrorist-related aircraft crashes of September 11, 2001 or the debris removal efforts that took place in the immediate aftermath of those crashes. Individuals are eligible to receive money from VCF if they were present at a 9/11 crash site, defined as the World Trade Center site, the Pentagon site, and the Shanksville, Pennsylvania site, at the time of or in the immediate aftermath of the terrorist-related aircraft crashes (9/11/2001–5/30/2002) and if they suffered physical harm as a direct result of the crashes or debris removal.

The IMF created patient guides for both WTCHP and VCF to assist those eligible for enrollment. They are available for download at advocacy.myeloma.org.

Advocates in the spotlight

by Ray Wezik
IMF Advocacy Associate

HR 1801, the Cancer Drug Coverage Parity Act of 2013, stands (at the time this article was written) at 90 co-sponsors and within striking distance of 100; a goal set at the beginning of the year when co-sponsors numbered only 66. That is 24 co-sponsors in one year's time! This feat is especially exceptional given that this is an election year. Who made this achievement possible? YOU! – our patient advocates who made the commitment to see this legislation signed into law.

Pam Anderson in the Linnaeus flower garden in Stockholm, Sweden

On August 26, patient advocate Pam Anderson met with Rep. John Yarmuth in Kentucky. Pam took the time to become informed on the issue in order to convey the need for the bill both from a personal perspective and also on behalf of the larger cancer community. Pam reached out to a group of professionals and advocates for help, including the IMF Advocacy team. The IMF helped Pam prepare for her meeting and provided her with materials to leave with the Congressman and his staff. As a result, Pam shared her story in a most effective way during the meeting and continued to push for sponsorship after the meeting. Less than one month later, Rep. Yarmuth signed onto the bill.

Bill and Jenny Hack with a Myeloma Awareness Month proclamation from Palm Coast, Florida

On August 11, patient advocate Jenny Hack met with Rep. Ron DeSantis in Florida. Like Pam, Jenny reached out to her circle of friends for support, as well as to the IMF for preparation. During Jenny's meeting, Congressman DeSantis seemed inclined to co-sponsor the bill, but he has not yet signed on. Most members of Congress take time to research an issue before they agree to support a bill, which is why follow-up is so critically important after any meeting. Jenny continues to work on making her Congressman co-sponsor number 91!

The goal of 100 co-sponsors by 2015 is within reach. All it takes is dedicated advocates. We ask you to commit to making a phone call to set a meeting with your Representative. The IMF can help in many ways, including providing contact information, coaching you on how best to approach the meeting, and much more. Please email advocacy@myeloma.org or visit our website at advocacy.myeloma.org – we look forward to working with you! **MT**

The IMF Advocacy Voice: Home Stretch!
Help Us Get to 100 Co-Sponsors by 2015!

HR 1801, the Cancer Drug Coverage Parity Act of 2013 currently stands 10 co-sponsors away from our goal of 100. Help us cross the finish line and take action today at advocacy.myeloma.org. Take 5 minutes to send an email to your US Representative urging support of HR 1801. Remember, **YOU** are the most powerful voice to your legislator.

Sign up to become an IMF advocate and you will be kept informed of critical issues affecting the myeloma community, and legislation at both federal and state levels to help resolve them. Visit advocacy.myeloma.org **TODAY!**

Dr. Durie Receives Mayo Clinic's Distinguished Alumni Award

IMF Chairman and co-founder Dr. Brian G.M. Durie has been selected as one of this year's Distinguished Alumni by the Mayo Clinic. Each year since 1981, the Mayo Clinic Board of Trustees has given Distinguished Alumni Awards to four individuals who have been recognized nationally, and often internationally, in their fields of medicine. Dr. Durie, who completed residencies and fellowships at the Mayo Clinic, is honored for his "exceptional contributions" in myeloma research. Dr. Durie is only the second person to be honored for work in blood cancer, following myeloma pioneer Dr. Robert A. Kyle. Congratulations, Dr. Durie!

MM Support Group Wins UNESCO Award

Yoddhas, the first myeloma support group in India, founded by 29-year-old myeloma patient Rahul Yadav, won the People's Choice Award for best project in the global Youth Citizenship Entrepreneurship Competition. The competition was sponsored by UNESCO, the United Nations Organization for Education, Science and Culture. Congratulations Rahul and Yoddhas! Visit yoddhas.com to learn more about Yoddhas, which means "warrior" in Hindi.

IMF Master Class Welcomes MM Doctors from China

In August, the IMF brought to the US a group of physicians from China's top medical institutions to the organization's 3rd Annual Myeloma Master Class. The comprehensive educational forum, created and led by Dr. Brian G.M. Durie and structured around the IMF's 10 Steps to Better Care®, is designed to help physicians learn about the latest thinking in myeloma diagnosis and treatment. "They will have the opportunity to see first-hand how myeloma patients are diagnosed and treated in the US," said Dr. Durie, who has been visiting China since 1990. Additional Master Class faculty included Drs. Bill Bensinger, Vincent Rajkumar, Joseph Mikhael, and Robert Vescio. The Chinese doctors capped off their visit by attending the Los Angeles IMF Patient & Family Seminar.

Dr. Robert A. Kyle: Myeloma Pioneer

The medical publication *OncLive* has profiled Dr. Robert A. Kyle, a myeloma pioneer who has improved outcomes for countless myeloma patients, and inspired and trained many myeloma researchers and physicians. Dr. Kyle is a founding member of the IMF Board of Directors and is Chairman of the IMF Scientific Advisory Board. Since 2003, the IMF has honored an outstanding physician each year with the Robert A. Kyle Lifetime Achievement Award.

ASCO Post Features Profile of Michael Katz

IMF Board member Michael S. Katz is profiled in the latest issue of the *ASCO Post*, a publication of the American Society of Clinical Oncology (ASCO). Mike talks about his advocacy for myeloma patients and how he has helped to alter the standard of care. "I've always chosen to live my life as if I didn't have cancer," he says. "I just face forward and try to do everything I want to do, working around symptoms and treatment side effects."

MM Support Group Leaders Honor IMF Leaders

As part of the program at the 15th Annual Support Group Leaders Summit, the IMF honored group leaders for their commitment to local myeloma communities. As the IMF thanked the local groups, the leaders had a surprise in store for IMF's Susie Novis and Dr. Brian G.M. Durie. They organized a heartfelt tribute to acknowledge the daily dedication and care that Susie and Dr. Durie have been providing to the entire myeloma community for so many years.

"We have benefited greatly from our partnership with the IMF, and we wanted to recognize the people who made it possible: Susie and Dr. Durie," said support group leader Dr. Jim Omel. "For 24 years since founding the IMF, they have made an immeasurable contribution to the progress in the field of myeloma. And Dr. Durie has been doing myeloma research for more than 40 years! In the pre-IMF world, there were no patient programs, publications, websites… no education, support, advocacy … and there was very little RESEARCH. Susie and Dr. Durie changed this. Much progress has been made thanks to Susie, Dr. Durie, and the IMF. They started the 'enlightenment period' in myeloma."

Adds Jim, "Susie is a giver of compliments and awards. She is not used to being the recipient of effusive praise. It was a pleasure to see HER be the one being thanked. Susie, Dr. Durie, and the IMF have been there for all of us for 24 years. There was not a dry eye in the house when Susie and Dr. Durie walked to the podium to accept their award. From the bottom of our hearts…….*THANK YOU!*"

Updates from Around the Globe

Participants gather for the Patient & Family Seminar in Lazne Belhorad, Czech Republic

Update from Europe

by Nadia Elkebir
IMF Director, Europe and the Middle East

The IMF continued to strengthen its international relationships with patients, advocacy groups, and biopharmaceutical companies focusing on myeloma research.

On September 5 and 6, I attended the Patient & Family Seminar in Lazne Belhorad, Czech Republic, and shared information with the more than 110 patients, family members, and physicians about the resources and support the IMF provides worldwide. This meeting was organized by the Czech Myeloma Group Foundation in cooperation with KPMM (Klub Pacientu Mnohocetny Myelom) and the IMF.

The meeting marked a special occasion for KPMM – the organization's 10-year anniversary. The two-day seminar opened with a well-received video from IMF President Susie Novis congratulating the Czech Myeloma Group (CMG) on its success. The seminar was educational, lively, and enjoyable, thanks to the hard work and professionalism of Iveta Mareshova and Alice Onderkova of CMG. From the medical presentations and patient interactions to the beautiful location of the Tree of Life Resort, the meeting was a huge success.

Nadia Elkebir of the IMF

The first evening of the seminar also hosted local entertainers: a magician and ballroom dancers. The welcoming atmosphere put patients at ease and encouraged them to socialize with one another.

The educational program began during the second day of the seminar. Dr. Roman Hájek presented news about myeloma research and treatments, while Dr. Petr Hylena described the accomplishments and activities of GMG over the past year.

Dr. Miroslav Hrianka, president of the Slovak Myeloma Society, spoke about his group's activities and the treatment landscape for patients in Slovakia. The myeloma communities from the Czech Republic and Slovakia have a close relationship, supporting each other and working together.

Dr. Roman Hájek leads a patient education session

INTERNATIONAL — continued from page 18

Patients living with myeloma told stories about their lives and experiencing new things no matter the heaviness of the disease. We heard about and saw pictures of the exciting life of a patient who decided with his wife not to allow his myeloma to run his life. He and his family travel the world to hike, walk, swim, and enjoy other physical activities. It was very touching and definitely inspiring.

The rest of the day included a presentation by Lea Janku on changes in social security in the Czech Republic, a panel discussion that included questions from the audience, and breakout sessions for more concentrated discussions. With beautiful weather, the afternoon Q&A sessions were conducted outdoors by the lake. Dr. Hajek led a session on clinical trials, Dr. Vladimir Maisnar led a session on the management of side effects, and Dr. Pavlicek led a session on alternative treatment approaches.

This very successful meeting was a wonderful way to celebrate CMG's anniversary.

I also visited Switzerland to meet with myeloma researchers at Europe's headquarters of Celgene, a developer of important myeloma therapies. The company's therapies include Thalomid® (thalidomide), Revlimid® (lenalidomide), and Pomalyst®/Imnovid® (pomalidomide). Celgene scientists continue their commitment to myeloma with research on additional therapies.

I met with 15 researchers and many Celgene Europe employees – and many more via video – to share the important work the IMF is doing with myeloma patients around the world. In addition to learning about the IMF's education, support, and advocacy efforts, the audience was very interested to hear about IMF-led research projects, including the Black Swan Research Initiative®.

I look forward to continuing to expand the IMF's relationships with researchers and patient organizations that share the common goal of supporting and improving the lives of myeloma patients. **MT**

Patients and caregivers celebrate the spirit of survivorship at the evening dance

New IMF Publications

The IMF is committed to making educational information easy to read and understand. These new IMF publications are available for viewing or downloading in PDF format online at myeloma.org or order printed copies by emailing TheIMF@myeloma.org or calling 800-452-CURE (2873).

Understanding Serum Free Light Chain and Serum Heavy/Light Chain Assays

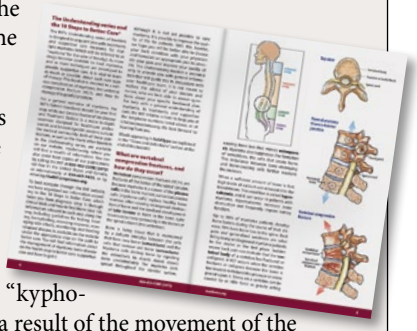
This new IMF booklet is devoted to two tests used in the diagnosis and monitoring of myeloma, the serum free light chain assay (Freelite®) and the serum heavy/light chain assay (Hevylite®). Since Freelite and Hevylite are independent biomarkers of disease activity, it is important to monitor patients with both tests.

Changes in Freelite levels are useful for tracking the disease status in almost all people with myeloma, not just those with light chain (Bence Jones) myeloma or nonsecretory disease. The Freelite test can help in the detection and monitoring of myeloma by quantifying monoclonal protein in multiple disease settings. While the Freelite test quantifies free light chains, the Hevylite test quantifies the intact (or whole) heavy and light chain pairs involved in a patient's myeloma. Given the heterogeneity of clones in an individual patient's myeloma, these two assays, when used together, are complementary.

This publication has been translated into French, German, Italian, and Spanish

Understanding Treatment of Myeloma-Induced Vertebral Compression Fractures

As treatment for myeloma improves and patients live longer, it is important to reduce the disability that can result from the painful problem of vertebral compression fractures (VCFs), which occur when the vertebra collapses or fractures because the bone is too weak to withstand the pressure or stress placed upon it.



Up to 90% of myeloma patients develop bone lesions during the course of their disease; 70% have bone loss in the spine. With multiple fractures, the spine shortens and becomes misaligned, causing a curvature of the spine known as "kyphosis." Pain occurs both suddenly, as a result of the movement of the fracture fragments, and often secondarily, as a result of the deformity, causing a chronic dull ache in the facet joint of the vertebra. This IMF booklet describes how to manage myeloma-induced VCFs. **MT**

15th Annual IMF Support Group Leaders Summit

by Robin Tuohy
IMF Senior Director, Support Groups

Nearly 100 myeloma support group leaders gathered in Dallas, Texas, over a weekend in July for the International Myeloma Foundation's 15th Annual Support Group Leaders Summit. At this annual Summit, people with the compassionate spirit characteristic of patient support group leaders get a chance to recharge their batteries as they draw strength and encouragement from like-minded souls, and learn new skills to take back home.

During the rest of the year, these leaders give their all to their myeloma support groups, but at the Summit, they're on the receiving end. Participants ranged from group leaders with more than 20 years of experience to those with as little as few months' experience.

The IMF team plans the agenda for each Summit months in advance, focusing on the needs of support group leaders from around the country and, this year, from around the world. The 2014 event was jam-packed with sessions offering the latest news about myeloma treatments, a panel discussion of clinical trials, a workshop exploring the best practices for running a support group, a popular computer tutorial, and updates from IMF President Susie Novis and IMF Chairman Dr. Brian G.M. Durie. As expected, the presentation about the progress of the IMF's Black Swan Research Initiative® drew a high degree of interest and excitement.

"This was my first Summit, and it was terrific. As a 'newbie' I felt welcomed and nurtured by everyone there," said Susan Benjamin, a support group leader from Los Alamos, New Mexico. The Summit sessions, she added, will greatly enhance her skills as a support group leader.

During the weekend, Summit attendees like Susan were divided into working groups with topics such as Caregivers, Outreach, Technology, Agenda/Meeting Planning, and Sustainability of Group. The curriculum was tailored to the specific needs of a support group – whether that group is in a rural or urban setting, is well-established or just getting off the ground, has just a few members or attracts a standing-room-only crowd.

Each group has different needs. For example, the IMF offers a Virtual Speaker Bank resource, which is really valuable for groups located in remote areas too far from major medical centers or myeloma experts. The Speaker Bank consists of two DVDs filled with IMF's important myeloma video content, from #AskDrDurie episodes to the latest International Myeloma Working Group (IMWG) Conference Series "Making Sense of Treatment" panel discussion, recorded live at the IMWG meetings. The Virtual Speaker Bank is also available on the IMF Support Group Leader Toolkit App, accessed by leaders via iPads donated to them by the IMF two years ago. The app is continuously updated with information specific to leaders to support their local groups.

At the Summit, representatives from pharmaceutical companies Celgene, Millennium, and Onyx, shared information about myeloma clinical trials and patient support programs, which the leaders can bring back to their own local communities so their members can have access to these resources. Three myeloma patients – Jack Aiello, Mike Katz and Dr. Jim Omel – spoke about their experiences participating in clinical trials. The goal of their talk, they said, was to clear up the myths surrounding clinical trials and explain why it's important to participate. A robust Q&A followed.

Researcher Susan Dunnett from the United Kingdom conducts a very different kind of research. She gave a presentation about her study of patient-caregiver-led support groups, which was supported by a research grant from the University of Edinburgh. Such models, she pointed out, are unique in the support group arena, as most patient support groups are led by social workers, healthcare workers, or hospitals. The patient-caregiver-led support group is a model for the world, she said, a statement with which the attendees heartily agreed.

It wasn't all research and science at the IMF Support Group Leader Summit, though. Support group leaders were invited to partake in tai chi lessons, an innovative way myeloma patients might combat the stress that accompanies serious illness. Response to the lessons was overwhelmingly

CONTINUES ON PAGE 22

Summit gets high marks from Group Leaders

Thanks for all you did to make the Summit such a success! I was talking to another leader who said it's so hard to explain to others when she gets home what happens at the Summit, but she feels sorry for whoever sits next to her on the plane ride home. Funny but so true – it's a kind of magic that happens in Dallas that can't be explained. We had to leave a little early this year and I'll never do that again – I don't want to miss a minute of the magic!

Sue VanDuyn, Grand Rapids, MI

I am so thankful to have been given this weekend of the Summit! I have been equipped to take back to my support group so many positive updates, information, connections, and so much more. The Summit has fed my Soul! I now understand the Black Swan Research Initiative® – Dr. Durie has always given me clarity and I and truly appreciated his presentation.

Carlene Pratt, Upland, CA

Thank you IMF for a helpful Summit. I feel confident that I can be a better co-leader now. God Bless all of the participants. Thank you IMF for the tools we need to do our job as support group facilitators.

Jennie Handy, Los Angeles, CA

We cram so much important information into a weekend! We love it & we learn a lot! I am glad you include fellow patients to share information as well as lectures. It shows how active, creative and smart these leaders are. They are examples to all of us, especially to the new folks. Love you all – Thanks with all our Heart!

Jeff & Kathy Cartwright, Missouri/Illinois

Based on the premises that knowledge is power, and how to go from fear to hope, IMF provides a set of tools for positive outcomes for survivors of myeloma, their families, and communities. I appreciate the inclusion of young people invited to become part of the Myeloma Movement who can provide valuable perspective and energy in areas such as media, legislative action, and worldwide advocacy.

Linda Borgeson, Sacramento, CA

The Summit was absolutely fabulous, filled with tremendous information! But the biggest take-away for me was being inspired by the level of caring, dedication, and passion of so many of the group leaders in attendance, as well as by the IMF and its staff.

David McMullen, Toronto, ON, Canada

We always enjoy the Summit, and we're so impressed by how well it is planned and executed. The opportunity to network with others is so important to us. The IMF staff is amazing! You all do a fantastic job making our work back home so much easier and more effective. Thanks so much.

Jack & Linda Huguelet, Chattanooga, TN

I can't begin to thank the IMF for this wonderful opportunity. Each year, the summit gets better and better. I am always amazed at how you improve upon perfection. Thank you for all your hard work and being there for us. We are not alone! I always tell my group, IMF is one of the best things we have going for us while fighting myeloma.

Cindy Ralston, Kansas City, KS

SUPPORT GROUPS — continued from page 21

positive. Maybe they'll go home and add tai chi as a component in their support groups. We have to think outside the box!

Perhaps the most heartfelt element of the IMF Support Group Leader Summit this year – and every year – is the forging of lifelong bonds with fellow leaders.

People call it the best family reunion they ever attended. Best of all, when they go back home, they can call their new best friends and connect with someone who can offer them support. **MT**

Myeloma Support Groups Mark Significant Milestones

Across the United States, myeloma support groups are celebrating significant milestones and anniversaries in 2014. In addition, the IMF's international affiliate, Myeloma Canada, is celebrating 10 years of service in November. The IMF is very proud of all that each of these groups has accomplished, and we look forward to a continued partnership of providing support and education to the myeloma community.

Support groups celebrating major milestones:

- 15 years: Grand Island, NE
- 15 years: Madison, WI
- 10 years: Stillwater, MN
- 5 years: Shasta County, CA
- 5 years: Albany, GA
- 5 years: Flint, MI
- 5 years: Columbus, OH
- 5 years: Nashville, TN
- 5 years: Eau Claire, WI

Support groups marking 1-year anniversaries:

- Jonesboro, AR
- Sacramento, CA
- Palm Beach Gardens, FL
- Cedar Rapids, IA
- Santa Fe, NM

Members of the Flint Multiple Myeloma Support Group, founded in Michigan in February 2009, celebrate their group's 5-year anniversary.

Congratulations to the Cedar Rapids Multiple Myeloma Support Group, founded in Iowa in September 2013, on marking the group's first anniversary

First meeting scheduled for first NH support group

Exciting news for New Hampshire myeloma patients and family members! The first NH myeloma support group, the Manchester Multiple Myeloma Information Group, is holding its first meeting on October 16. This group joins a family of more than 245 local groups that the IMF supports worldwide. For more information, please contact Susan Gimilaro at ManchesterNH@IMFsupport.org or 603-426-2035. **MT**

IMF Staff Updates

Meghan Buzby, MBA

Senior Director of Advocacy
mbuzby@myeloma.org

The IMF is pleased to announce the promotion of Meghan Buzby to Senior Director of Advocacy. Meghan joined the IMF in 2010 with more than eight years of marketing and communications experience. Within one year, she expanded the IMF grassroots network to more than double the number of advocates from the year previous.

As Senior Director of Advocacy, Meghan is now tasked with leading the IMF's advocacy department. "I am excited to continue the important advocacy work of the IMF and look forward to broadening our reach here in the US and globally." In her new role, Meghan oversees all advocacy initiatives, including US federal and state policy issues, efforts focused on prevention, innovation, access, and approval of treatments. She leads both the Patients Equal Access Coalition (PEAC) and the State Patients Equal Access Coalition (SPEAC) under the IMF. Meghan earned her Bachelor's degree from Towson University, and holds an MBA from Loyola University Maryland.

Amirah Limayo

Research Project Coordinator
alimayo@myeloma.org

Amirah Limayo has joined the IMF team as Research Project Coordinator. As a member of the IMF's Medical Education Department, Amirah's responsibilities include coordination for the Brian D. Novis Research Grant program, International Myeloma Working Group (IMWG) and Black Swan Research Initiative® data collection projects, ASH Satellite Symposia Registrations, and trademark and copyright protections.

Amirah has worked in the nonprofit sector for more than 10 years, providing program support to a wide range of health, education, and civic projects for limited-English-proficient and low-income communities. In her recent work at the Los Angeles Biomedical Research Institute, she coordinated cardiac computed tomography angiography (CCTA) trainings and symposiums with Harbor-UCLA Medical Center medical professionals. She also worked with the Research Study staff on monitoring cardiology clinical trials.

Amirah earned her Master's degree in Public Administration with a Graduate Certificate in Nonprofit Sector Management in 2014. She is passionate about mission-driven work and being of service to others.

Taylor Patton, MSW

Advocacy Associate
tpatton@myeloma.org, 205-602-9539

Taylor Patton has joined the IMF Advocacy team to help expand the IMF's US advocacy program and grassroots network, focusing specifically on prevention, equality of access, continuing innovation, and expanded access to unapproved therapies and treatments for people living with myeloma.

Before joining the IMF, Taylor worked for Grant Associates, counseling low-income District of Columbia residents in all aspects of job readiness, empowering them to engage in successful careers. He also collaborated with several child welfare agencies to lobby the DC City Council for increased funding of programs serving homeless youth.

Taylor earned his Bachelor's degree in Psychology and History in 2010 from the University of Alabama at Birmingham (UAB) and a Master of Social Work in 2013 from the University of Alabama. While at the University of Alabama, Taylor was chosen to participate in the prestigious Washington Interns program, which launched his career in advocacy. He lives and works in Washington, DC.

Diana Wang

Medical Affairs Assistant
dwang@myeloma.org

In her new role at the IMF, Diana Wang supports Dr. Brian G.M. Durie (IMF Chairman and co-founder) and Lisa Paik (Vice President, Clinical Education & Research Initiatives) in the development of patient education programs and research initiatives.

Diana is a recent graduate of University of California, Los Angeles (UCLA) with a Bachelor of Science degree in Psychobiology. Diana worked as a clinical and research assistant at UCLA's Jules Stein Eye Institute for four years. She was also involved in a variety of research studies throughout college and recently published a paper in the Archives of Plastic Surgery investigating risk factors for post-mastectomy infection in breast cancer patients.

Diana is excited to contribute to the IMF's strong commitment to the myeloma community.

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The IMF welcomes Acompuco LLC as advanced service provider for managing Information Technology Systems. Since 2002, Acompuco has helped more than 500 companies optimize system functionality and improve operation efficiency by upgrading and maintaining technology infrastructures. "Acompuco is excited to work with the IMF on strategic IT planning and to provide uniform service for IMF users across the globe," says Laith Pahlawan, Acompuco's Solution Architect.

First Annual Chek Fest Golf Tournament

IMFers raise funds to benefit myeloma community

by Suzanne Battaglia
IMF Director, Member Events

Friends of the IMF are raising funds to support essential myeloma research while also raising awareness. Fundraisers are taking place all across the country! Most of these activities start with a call to the IMF and one simple question – "What can I do?" Those who become involved find their efforts to be not only fulfilling but also 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.

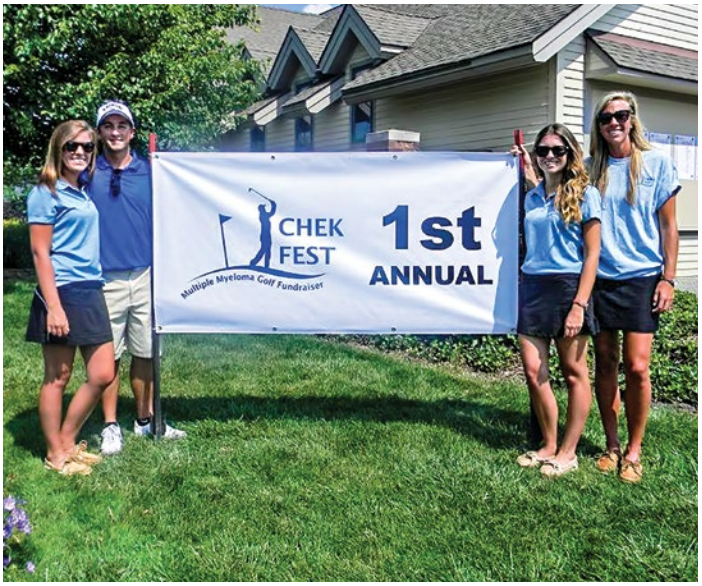
The story that follows demonstrates the flexibility you have in choosing an event. If you have resources for a large community outreach effort and lots of help, you can plan a marathon, walk, golf tournament, or carnival. To plan a small event, consider putting a twist on something you normally might do, such as a bake sale, garage sale, holiday party, or a dance-a-thon with friends at your local gym.

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 web and social media outlets. Please contact me at sbattaglia@myeloma.org or 800-452-CURE (2873) to chat about any ideas you might have. Become a part of making miracles happen! Join us in working together toward our common goal... a CURE.

Scott Kowalczyk has always been athletic. He played basketball in college and he has always enjoyed the game of golf. In October 2012, Scott was taking part in a golfing event when he felt like he pulled a muscle on his left side. "The soreness just wouldn't go away, but my routine physical was coming up soon so I waited to mention it to my doctor," recalls Scott. "I was 53 years old and my doctor commented that my body was simply taking longer to recover from an injury." Shortly thereafter, Scott felt the same sensation on his right side, then his leg started to expand and his back was hurting. When the blood test results came back from the lab, it was clear something was wrong.

After more tests, Scott and his wife Sharon were told to go to the emergency room. There, scans revealed lesions and broken ribs, and Scott was admitted to the hospital. The next day, a bone marrow biopsy confirmed the diagnosis of multiple myeloma. "That was on December 20 and I stayed in the hospital until Christmas Eve day," recalls Scott. "I started chemotherapy on January 1; everything moved very quickly. My wife and I also started attending Gilda's Club in Grand Rapids which has a large multiple myeloma support group."

In the Fall of 2013, as Scott was recovering from a transplant, he and Sharon started to talk about doing something to support all the positive advances that have been taking place



in the field of myeloma. "Sharon and I were talking about the event as a celebration of life, as a festival. And Chek has been my nickname since college because my last name is hard for some people to pronounce. That's how the name of the event – Chek Fest – came about. Once we made the commitment to go forward and decided that we would host a golf tournament, organizing it moved along pretty quickly. We had more than 20 volunteers!"

The tournament was held at The Meadows golf course in Allendale, Michigan. A total of 132 golfers came out to play and to support Scott and the work of the IMF. In the evening, over 70 non-golfers joined Chek Fest for a grand total of more than 200 participants!

"Chek Fest was held on Monday, July 21, and took place instead of our support group's annual picnic. Group members came out in force to represent the patient and caregiver community. And our wonderful friends came out to support the cause, and they were so generous. For us, it was truly moving to witness our friends and family mingling with our myeloma family, and to have our fellow patients and caregivers acknowledged. It was a very special day and we raised more than $25,000 to benefit the International Myeloma Foundation." **MT**

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Shop through shop.myeloma.org with the leading merchants on the internet, receive the same price as anyone else visiting their sites, and support the IMF at the same time. The IMF receives a donation only if you use the links at myelmoa.org, so use this page to ensure that when you are shopping your purchases are properly credited. Keep checking back as we regularly add new e-commerce vendors to our mall. Thanks for your support!

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Mambo for Myeloma

IMFers are trying to come up with the next big fundraising and awareness challenge for multiple myeloma. One cool idea we've seen from our members is **Mambo for Multiple Myeloma**. Here's how it works:

YouTube facebook Take videos of yourself, friends, or family members dancing in honor of myeloma research – any solo or group dance moves work! Mention that it is for **multiple myeloma** (we don't want it confused with melanoma). Upload your video to YouTube and tag it as Mambo for Multiple Myeloma, then share it on the Mambo for Multiple Myeloma Facebook page. Challenge others to do the same.

Can't do a video? No problem! Just take a dance move photo and post it to the Mambo for Multiple Myeloma Facebook page. Want to help spread the word? Help raise myeloma awareness by "liking" the page and sharing it. (Or, if you just want to support the campaign, simply visit mambo.myeloma.org and make a donation.)

Do your dance today and help spread awareness, and let us know if you've started your own "challenge" idea in your community!

INTERNATIONAL MYELOMA FOUNDATION

8th Annual

Comedy Celebration

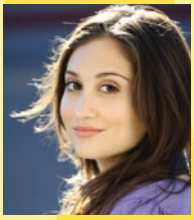
benefiting the Peter Boyle Research Fund
and supporting the Black Swan Research Initiative®

Saturday, November 8, 2014

The Wilshire Ebell Theatre & Club in Los Angeles, California

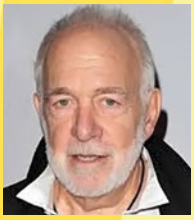
featuring a Special Live Performance...


Danny DeVito


Lucy DeVito


Will Forte


Patricia Heaton


Howard Hesseman


Alex Meneses


Laraine Newman


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

IMF Calendar of Events

2014

Oct 25	IMF Regional Community Workshop (RCW) – Nashville, TN
Nov 3	IMF Patient & Family Seminar (PFS) – Oslo, Norway
Nov 5	IMF Physician Meeting – Throndheim, Norway
Nov 6	IMF Physician Meeting – Odense, Denmark
Nov 7	IMF Patient & Family Seminar (PFS) – Middlefart, Denmark
Nov 8	8th Annual IMF Comedy Celebration benefiting the Peter Boyle Research Fund – Los Angeles, CA
Nov 13	IMF Living Well with Myeloma Teleconference Series – Management of Bone Disease in Myeloma*
Nov 22	IMF Regional Community Workshop (RCW) – Chapel Hill, NC
Dec 5	IMF Satellite Symposium at ASH – San Francisco, CA
Dec 5-8	56th Annual Meeting & Exposition of the American Society of Hematology (ASH) – San Francisco, CA

2015

Feb 13-14	IMF Patient & Family Seminar (PFS) – Boca Raton, FL
March 27-28	IMF Patient & Family Seminar (PFS) – San Francisco area (Redwood City), CA
April 23-26	40th Annual Congress of the Oncology Nursing Society (ONS) – Orlando, FL
May 29-June 2	51st Annual Meeting of the American Society of Clinical Oncology (ASCO) – Chicago, IL
June 8-10	2015 International Myeloma Working Group (IMWG) Summit – Vienna, Austria
June 11–14	20th Congress of the European Hematology Association (EHA) – Vienna, Austria
Aug 21-22	IMF Patient & Family Seminar (PFS) – Los Angeles, CA

The IMF is proud to work with our global partners. We thank them for supporting our international meetings.
For more information about upcoming events, please visit* calendar.myeloma.org *or call* 800-452-CURE *(2873).
For information on activities in Australia, Canada, Israel, Japan, or Latin America, please visit:
***Australia* myeloma.org.au • *Canada* myelomacanada.ca • *Israel* amen.org.il • *Japan* myeloma.gr.jp • *Latin America* mielomabrasil.org**

* Pre-register for these FREE teleconferences on the IMF website: **myeloma.org**. Each 60-minute *Living Well* teleconference starts at 4 p.m. Pacific/7:00 p.m. Eastern.