



Improving Lives • Finding the Cure®

# MYELOMA TODAY

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VOLUME 9 NUMBER 10

A Publication of the International Myeloma Foundation

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

## Scientific & Clinical News



**IMF Black Swan Research Initiative® (BSRI®)** moved into high gear in March with the IMF-EuroFlow Workshop in Salamanca, where 70 experts from myeloma centers around the world were trained in an automated and highly sensitive flow cytometry technique for standardized detection of MRD. Immediately after the Salamanca workshop, Dr. Brian Durie and key BSRI investigator Dr. Bruno Paiva flew to Silver Spring, MD, to participate in an FDA Roundtable, "Symposium on Flow Cytometry Based on the Detection of Minimal Residual Disease in Multiple Myeloma." **PAGE 5**



**Dr. Thomas Martin** of UCSF Medical Center shares his experience with SAR650984, an anti-CD 38 monoclonal antibody that belongs to a new "blockbuster" class of drugs to fight myeloma. Dr. Martin explains how SAR650984 works, and he reviews the findings of phase I trials with SAR650984 alone and in combination with Revlimid and dexamethasone. **PAGE 4**



Meet the recipients of the IMF's 2014 Brian D. Novis Senior Research Grants, **Dr. Roman Hájek** of the University Hospital Ostrava, Czech Republic, and **Dr. Manoj Pandey** of Pennsylvania State University College of Medicine. Drs. Hájek and Pandey discuss their research interests and their history of involvement with the IMF. **PAGE 6**



## Supportive Care

The IMF Hotline Coordinators discuss the newly FDA-approved serum heavy/light chain assay, or Hevylite® immunoglobulin assay, which will play an important role in monitoring myeloma. They

explain this highly sensitive and specific assay and its benefits to the myeloma patient community in quantifying IgA myeloma, detecting early relapse, and accurately determining complete response. **PAGE 9**



The IMF's Nurse Leadership Board's new manuscript on stem cell transplantation has been published by the Oncology Nursing Society (ONS) in the *Clinical Journal of Oncology Nursing*, or CJON. This CJON supplement was written to support oncology nurses and to positively affect outcomes throughout the continuum of care, including quality of life of patients with myeloma and their caregivers. **PAGE 7**

## Education & Awareness

The IMF Advocacy Team has been working on the federal and state levels to advance the cause



of myeloma patients. At the federal level, our advocacy team has endorsed several pieces of legislation to address healthcare challenges other than oral parity: The Part D Beneficiary Appeals Fairness Act, The Blue Water Navy Vietnam Veterans Act of 2013 and The Blue Water Navy Ship Accountability Act, and The Planning Actively for Cancer Treatment Act of 2013. Our state advocacy team has been furthering the cause of oral cancer treatment access legislation in another 10 states. **PAGE 10**

## Member Events

IMF members **Matthew Stolper** and **Frank Tramontano** found creative and fun ways to raise funds in support of essential multiple myeloma research while also raising



awareness. The Stolpers raised \$500 by creating and selling "I Am Stolper Strong" T-shirts after Matthew returned home from his stem cell transplant, while Frank Tramontano organized a "Dance For A Cure" evening in memory of Evelyn Siegfried. **PAGE 12**

## Patient Experience

**Kenton Hofmeister** was diagnosed with myeloma in December 2010 after suffering debilitating vertebral compression fractures. With the support and love of his family and the game-changing experience of an



IMF seminar in Boca Raton, Kenton was able to say, "I can do this." **PAGE 14**

## Also in this issue...

**Dear Reader**  
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**IMF Staff Updates** . . . . . **PAGE 13**  
**IMF Calendar of Events** . . . . . **BACK COVER**

### In the next edition of *Myeloma Today*...

Updates from the meetings of the:  
• American Society of Clinical Oncology (ASCO)  
• European Hematology Association (EHA)  
• International Myeloma Working Group (IMWG) Summit

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# A Message from the President



## Dear Reader,

For the first time since the International Myeloma Foundation (IMF) was founded, more than 23 years ago, I am able to say that a cure for multiple myeloma is within reach. In just two years, the Black Swan Research Initiative® (BSRI) has made tremendous strides in developing both a new, highly sensitive test to determine minimal residual disease and establishing trials that can lead to a cure for a subset of myeloma patients. Our goal is to find a cure for all patients, and this is a big step in the right direction.

The IMF also focuses on funding Junior and Senior Research Grants for doctors working in institutions around the world. These grants are incredibly important, as they provide much-needed funding support for research projects being conducted by the best and the brightest in our field. Funding grants since 1994, the IMF is now the premier funder of myeloma research grants, having awarded over 115 grants that have opened the doors to new ideas and major advancements in treatments.

The IMF continues to have a significant global reach. Thanks to funding support from our pharmaceutical partners, in 2013 the IMF held the 2<sup>nd</sup> Annual Myeloma Master Class, an intensive course for young clinicians, designed by Dr. Brian G.M. Durie and following the 10 Steps for Better Care®. The Master Class once again welcomed seven bright and enthusiastic doctors from seven of the most prestigious hospitals in China to learn from the experts who are members of the IMF's International Myeloma Working Group (IMWG).

The IMF held our 14<sup>th</sup> annual Support Group Leaders Summit in the summer of 2013. More than 75 people attended, representing groups from across the US, along with two representatives from Canada and one from Australia! The weekend was spent learning about the latest advances

in myeloma treatment and management, as well as learning from each other. There was even a session called "Tech Time" led by our IT department to help the leaders maximize the use of their iPads to enhance their reach to members. The 15<sup>th</sup> annual Support Group Leaders Summit will take place in July 2014.

Thanks to the efforts of our Advocacy team, oral anticancer drug parity bills have been passed in 31 states plus D.C. and introduced in both the US House and Senate with help from IMF-led coalitions, PEAC (Patients Equal Access Coalition) and SPEAC (State Patients Equal Access Coalition). Both *PEAC* and *SPEAC* expanded to include 30 and 26 member organizations respectively. We also expanded our global advocacy efforts with the launch of the Global Myeloma Alliance (GMA), the first and only international coalition of patient organizations working in the field of myeloma. The GMA members joined together to ensure that patients have access to the newest approved treatments and to support continued innovation in blood cancer. The GMA now includes organizations from 13 countries around the world, and is poised to grow beyond that number.

But by far the most exciting thing to happen last year was the amazing progress the Black Swan Research Initiative is making and how much we've already accomplished. What began with a small team is now a global entity working together to ensure that the dream of finding a cure quickly becomes a reality.

With your support, 2013 was the best year ever, touching all the cornerstone and innovative programs of the IMF, education, research, support, and advocacy! Thank you for support. We've opened the door to the cure – let's walk through it together!

Warm regards,

Susie Novis, President

## IMF WELCOMES ALDO DEL COL TO THE BOARD OF DIRECTORS

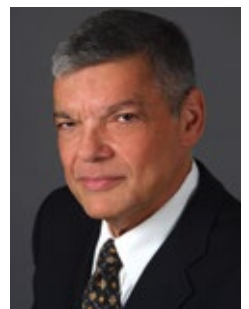
The IMF is pleased to announce the appointment of Aldo Del Col to its Board of Directors. Mr. Del Col holds a Bachelor of Science in Pharmacy degree from the University of Toronto and a Master in Business Administration from the York University Schulich School of Business.

Since being diagnosed with myeloma in 2002, Mr. Del Col has helped build an effective national platform to address the needs of the Canadian myeloma community. Co-founded by Mr. Del Col in 2004, Myeloma Canada is the only national non-profit organization uniquely focused on the needs of the Canadian myeloma community. As a patient-driven, grassroots organization, Myeloma Canada's mission is to provide educational resources to patients and caregivers, raise awareness of the disease, advocate for improved access to new therapies and accelerate patient-focused myeloma research.

Mr. Del Col has worked steadily to build a strong foundation and firmly establish Myeloma Canada as an effective national platform for the Canadian myeloma community, first as a volunteer and Vice President of the Board of Directors and, since 2010, as Executive Director. In this capacity, Mr. Del Col's leadership responsibilities included the implementation of board policy, development of programs and services, advancement of community

relations with a broad range of stakeholders, and oversight of the financial management of the organization. With the hiring of a new Executive Director in April 2013, Mr. Del Col has focused his attention on advancing myeloma research. In his new role as Chief Scientific Advisor, Mr. Del Col draws upon his scientific and pharmaceutical background to work closely with the Scientific Advisory Board and Canada's leading myeloma scientists and clinicians to drive research focused on optimizing patient outcomes.

In addition, Mr. Del Col works part-time as a Community Pharmacist, co-leads the Myeloma Montreal Support Network, which he founded in 2004, and serves as the patient representative for hematology in the National Cancer Institute of Canada (NCIC) Clinical Trials Group. Mr. Del Col is a member of the Global Myeloma Alliance Steering Committee, is involved with the Canadian Organization for Rare Disorders (CORD), and volunteers for Hope and Cope, a cancer patient support organization. In his spare time, Aldo indulges his passion for travel and has visited almost 50 countries. **MT**



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## SAR650984: A NEW “BLOCKBUSTER” DRUG FOR MYELOMA

*Myeloma Today* in conversation with Dr. Thomas Martin



*Dr. Thomas Martin, a member of the International Myeloma Working Group (IMWG), is associate director of the myeloma program at University of California San Francisco (UCSF) Medical Center. More patients have been treated with Sanofi's new anti-CD38 monoclonal antibody, SAR650984, in Dr. Martin's clinical trials at UCSF than at any other institution in the world.*

### Please give us some context for the use of SAR650984 in myeloma.

In the last 5 to 10 years, treatment of multiple myeloma has revolved around two types of drugs, proteasome inhibitors Velcade® (bortezomib) and Kyprolis® (carfilzomib) and immunomodulatory drugs (a.k.a. IMiDs®) such as Thalomid® (thalidomide), Revlimid® (lenalidomide), and Pomalyst® (pomalidomide). I call these drugs “blockbusters” because we know they have significant single-agent activity in myeloma, meaning that they produce good responses when used alone, without the addition of other anti-myeloma therapies. In my opinion, the monoclonal antibodies including SAR650984 (an anti-CD38 monoclonal antibody) also have the potential to be “blockbuster” drugs because, in early phase trials, we have seen significant responses (specifically with anti-CD38 antibodies like SAR650984) in heavily pretreated myeloma patients whose myeloma has failed to respond to other therapies.

Monoclonal antibodies are a new class of immunotherapy drugs that have been widely tested and selectively approved in other cancers. Elotuzumab, an anti-CS1 monoclonal antibody, was the first MAb successfully tested in myeloma, and it is now in phase III trials in combination with Revlimid plus dexamethasone for both newly diagnosed and relapsed/refractory myeloma. While it has been very effective in combination with Revlimid/dexamethasone, elotuzumab did not demonstrate single-agent activity. The anti-CD38 monoclonal antibodies, including daratumumab and SAR650984, however, have been particularly impressive in early trials for myeloma patients, demonstrating their ability to effectively kill myeloma cells without the aid of steroids or other anti-myeloma agents.

### How does SAR650984 work?

SAR650984 is a “naked” MAb, meaning that there is no toxin or other drug chemically bound to it. It presumably works by attaching to an antigen, or receptor protein, on the cell surface of plasma cells or myeloma cells (which are malignant plasma cells). The CD (Cluster of Differentiation) 38 cell surface antigen is highly expressed in all myeloma patients, so it is an excellent target in myeloma, and may work in other blood cancers as well.

There are three ways in which I believe SAR (as it is called for short) may cause myeloma cell death:

1. SAR binds to the CD38 on the surface of a myeloma cell, holds up a flag to the immune system, and says, “Come here and get this cell and kill it!” Macrophages and NK (natural killer) cells from the immune system's arsenal then recognize the MAb attached to the myeloma cell, and engulf and kill the myeloma cell.

2. Complement proteins (which circulate in our blood to boost the killing power of antibodies) bind to SAR after it binds to CD 38 on the myeloma cell surface, and help kill the myeloma cells by “punching holes” in them.
3. CD38 is a receptor protein that also serves the enzymatic function of regulating calcium metabolism in the cell. When SAR binds to CD38 on the myeloma cell surface, it blocks CD38's ability to preserve normal calcium flux in the myeloma cell. It is possible that blocking calcium flux may initiate a signal for apoptosis, or programmed cell suicide.

### What has been learned in phase I trials of SAR?

More than 30 heavily pretreated patients have been treated in a first-in-man dose-escalation trial of single-agent SAR. In patients who received a dose greater than 10 milligrams per kilogram of body weight (mg/kg) administered by intravenous (IV) infusion every other week, the partial response (PR) rate, defined as a 50% drop in monoclonal protein or better (PR or better), was 31%. There were two complete responses (CRs). Responses appear to be durable, with a median time to progression (TTP) not yet reached at six months of follow-up.

If minimal response (MR), defined as a 25% or greater reduction in monoclonal protein, is taken into account, then the response rate is approximately 40%, a most impressive rate for a single agent. Many of the patients in the trial had received prior Kyprolis and/or Pomalyst, and almost all of them had had both Velcade and Revlimid. Such a high and durable response rate in a population of heavily pretreated myeloma patients is significant.

We also enrolled patients with relapsed/refractory myeloma in a phase I clinical trial of SAR650984 in combination with Revlimid and dexamethasone. All the patients in the dose-escalation part of the trial and the expansion cohort have now been treated, and responses are being assessed by the data monitoring committee. Without being able to discuss response rates at the point in time of this conversation, I can report that the regimen was very well tolerated. SAR causes few side effects other than mild reactions to the first infusion. I will present data from this trial at the upcoming American Society of Clinical Oncology (ASCO) annual meeting in May 2014. I am looking forward to showing whether or not the response rate is even higher with SAR in combination with Revlimid/dexamethasone than it was with SAR alone. This combination study also involved patients who were heavily pretreated and often refractory to current therapies.

### What are the next steps in the development of SAR?

Sanofi-Aventis Inc. will be initiating additional studies soon. This likely will include combination studies with other active anti-myeloma agents.

### What has been your experience as an investigator of this MAb?

For two years, I have been studying SAR in patients with relapse and refractory myeloma. At UCSF, we have been lucky enough to be the

CONTINUES ON PAGE 8

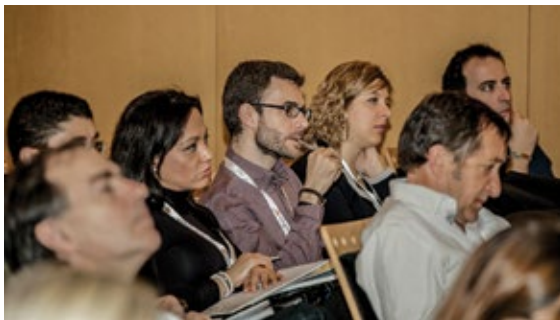
## BLACK SWAN, SALAMANCA, AND THE FDA: DEBUT OF A HIGHLY SENSITIVE NEW MRD TEST



by Brian G.M. Durie, MD  
IMF Chairman

A significant event in the evolution of the IMF's Black Swan Research Initiative® (BSRI) occurred recently in Salamanca, Spain. On March 21-22, the IMF-EuroFlow Workshop – co-organized by Lisa Paik (Senior Vice President of Clinical Education and Research Initiatives at the IMF) and the Salamanca-based flow cytometry team – focused on a breakthrough in the standardized detection of minimal residual disease (MRD) in multiple myeloma.

This new technique is an automated and highly sensitive flow cytometry for the standardized detection of MRD in myeloma. It simplifies and optimizes the test using standardized algorithms, and also increases the sensitivity of the test, which means an ability to detect as little as one myeloma cell in a million cells.



This new technology will lead to more effective myeloma diagnosis. And measuring the myeloma cells that remain after treatment will provide a much clearer framework

for a cure, allowing us to select the most effective anti-MRD drug combinations for patient subgroups. It will also help guide the timing of myeloma treatment, determining whether early intervention, at onset, or relapse, eradicates the most residual disease.

Excited to learn about the latest advance in this method, approximately 70 participants from 13 different countries attended the two-day workshop at the Cancer Research Center at the University of Salamanca. There, they attended presentations by top myeloma researchers and learned in a “hands-on” fashion the full details of the sophisticated new myeloma detection antibody panel and the computer software, which provides results in a standardized automated fashion: identifying each single cell (myeloma or not) in the bone marrow and/or blood samples.



Professor Jacques van Dongen from the EuroFlow team at Erasmus in Amsterdam

I am thrilled to report that the workshop was a success! Attendees left ready and enthusiastic to introduce the new methods in their home laboratories. Professor Alberto Orfao (Head of the Flow Team in Salamanca) and Professor Jacques van Dongen (his colleague from the EuroFlow team at Erasmus in Amsterdam) did a fantastic job in constructing and implementing an intense and detailed program that more than fulfilled the educational needs of the attendees.



A software training session



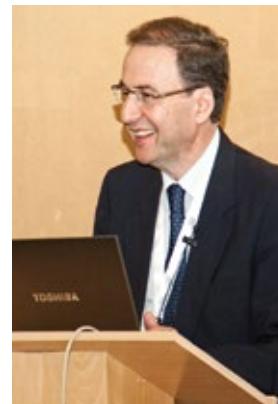
Dr. Bruno Paiva,  
a key BSRI investigator  
from Pamplona, Spain

From there, Dr. Bruno Paiva (a key BSRI investigator from Pamplona in Spain and expert at analyzing patient outcomes) and I traveled directly to the FDA in Silver Spring, Maryland to participate in the FDA-NCI Roundtable: “Symposium on Flow Cytometry Based on the Detection of Minimal Residual Disease in Multiple Myeloma.” The bottom line for this roundtable was also tremendously helpful and important for the BSRI. There is a strong consensus evolving that MRD assessment is both required

and recommended for response assessment in clinical trials, and that the new flow methodology is the most promising current approach.

Thus, MRD testing is becoming mainstream and flow is the method of choice. So the Black Swan Research Initiative is definitely “going with flow” right now and we have high expectations that new trials including MRD assessment will lead to better outcomes for all myeloma patients. **MT**

**Editor's Note:** The EuroFlow consortium consists of 17 diagnostic research groups and two associated SME's, which are regarded as experts in the fields of flow cytometric and molecular diagnostics. Together, the 19 participants have sufficient complementarity and congruence to cover all aspects of development, standardization, and validation of highly sensitive tests for diagnosis and follow-up. EuroFlow is a division of the European Scientific foundation for Laboratory HematoOncology (ESLHO).



Professor Alberto Orfao, head of  
the Flow Team in Salamanca

## MEET THE RESEARCHERS

*Myeloma Today* in conversation with Drs. Roman Hájek and Manoj Pandey

*Since 1994, the International Myeloma Foundation has funded promising clinical investigators in the field of myeloma from around the world through donations from private individuals and IMF member fundraisers. In this issue of Myeloma Today, we introduce you to two recipients of the 2014 Brian D. Novis Senior Research Grant, Roman Hájek and Manoj Pandey.*



### **Roman Hájek, MD, PhD**

Head of the Department of Haemato-oncology  
University Hospital Ostrava and  
the Faculty of Medicine  
University of Ostrava  
Czech Republic

#### **Please tell us about your interest in myeloma.**

I began my work in myeloma in 1995 while researching for a short time at Georgetown University Medical Center in Washington, DC. At the time, autologous stem cell transplantation (ASCT) was the newest treatment option, with very impressive data, and my first research project focused on myeloablative therapy in conjunction with transplants in myeloma patients. From 1996 to 2002, my research focused on dendritic cells and immunotherapy in myeloma.

In 1996, I co-founded the Czech Myeloma Group (CMG), a group of myeloma clinicians with the goals of coordinating clinical trials and making ASCT available to all patients in the Czech Republic. Over the years, the scope of CMG's focus has expanded as myeloma treatment has evolved. One important issue the group has addressed was clinician outreach to myeloma patients. In 2002, we established the Czech Myeloma Foundation after gathering information about patient outreach. That was the year I finally had the great pleasure of meeting Dr. Brian Durie in person. The International Myeloma Foundation (IMF) was, of course, the most important resource of information and experience, and was the key facilitator of our patient-related activities from the beginning. In 2006, I was pleased to welcome IMF Chairman Dr. Durie and IMF President Susie Novis to the Czech Myeloma Foundation's annual patients' seminar.

The IMF has always been an extraordinary resource for all members of the myeloma community, including patients and their families, as well as clinicians and researchers. And the reach of the IMF's programs and services is truly international. It offers support to patients around the world and it seeks out the most promising myeloma research, regardless of where it is being done. I am proud to be a recipient of the IMF's 2014 Brian D. Novis Grant for my study of the dynamics of microRNA and cell-free DNA profiles during myeloma progression, and I look forward to sharing the data this study produces.

#### **When did you become a member of the IMF's Scientific Advisory Board and the International Myeloma Working Group?**

I became a member of the IMF's Scientific Advisory Board in 2007 and the International Myeloma Working Group (IMWG) in 2008. Although I am very busy with my clinical and scientific endeavors, I believe that it is a privilege to attend the IMWG annual meeting, and I have never missed one.

I can talk for several hours, citing many examples of how belonging to the IMWG has enhanced my myeloma research. A key benefit, which is also the key mission of the IMWG, is that my membership allows me and CMG to collaborate with international colleagues and to be involved in international efforts to address the key issues of myeloma research and clinics today. It is very important for the scientific activity of the Czech Myeloma Group to be involved in such a prestigious group of experts as the IMWG. I am very pleased that we are able to be involved in the process.



### **Manoj Pandey, PhD**

Research Associate, Department of Pharmacology  
Pennsylvania State University College of Medicine  
Hershey, Pennsylvania

#### **Please tell us about your interest in myeloma.**

I began my career in medicine in 2000 as a toxicology researcher. In 2005, I came to the University of Texas MD Anderson Cancer Center as a post-doctoral fellow working on hematological malignancies. That was the beginning of my work in myeloma. In 2006, I earned a PhD in biochemistry from Lucknow University in India. I am now a research associate at the Pennsylvania State University College of Medicine, where I continue to pursue my interest in myeloma.

At MD Anderson Cancer Center, I was involved in identifying anti-inflammatory or anti-carcinogenic agents derived from natural agents. Myeloma caught my attention because despite the overall improvement in the treatment of this disease, osteoclastogenesis and drug resistance are still areas of intense investigation, and novel therapies are urgently required.

Several factors play important roles in the development of myeloma. For example, nuclear factor kappa B (NF-κB) plays a critical role in pathogenesis, progression, and prognosis of myeloma. We hypothesized that blockade of NF-κB signaling represents a novel therapeutic strategy in myeloma, and provide a rationale for the development of NF-κB inhibitor for the treatment of myeloma. Since natural agents are non-toxic, safe, efficacious and multi-target, I started investigating whether NF-κB inhibitor derived from natural sources are effective agents for myeloma treatment.

#### **What has been your experience working with the IMF?**

I learned about the International Myeloma Foundation in India in 2004. The IMF is a leader for supporting research in the area of hematological malignancies. I was awarded a 2013 Brian D. Novis Junior Grant for the research study, *Gambogic Acid: A potential therapeutic agent for multiple myeloma and associated bone loss*, conducted at the Department of Pharmacology at Pennsylvania State University College of Medicine.

The 2013 grant from IMF helped my research tremendously, and I thank the IMF for its support. After this funding, my colleagues and I generated a lot of data, learning that gambogic acid inhibits survival of myeloma as well osteoclastogenesis induced by myeloma, making gambogic acid a potent agent for the treatment of this disease. As a result of our success, I was awarded a 2014 Brian D. Novis Senior Grant so we could continue my work. We are investigating whether gambogic acid – a compound derived from natural sources and an inhibitor of NF-κB – could be an effective treatment for myeloma and associated bone loss.

Financial support from the IMF has been immensely helpful in the discovery, characterization, and testing of gambogic acid in preclinical models of myeloma. Under the Novis grant, my colleagues and I are also working with clinicians at the Pennsylvania State University College of Medicine to begin a clinical trial. **MT**





# Nurse Leadership Board

## HEMATOPOIETIC STEM CELL TRANSPLANTATION AND MULTIPLE MYELOMA

IMF Nurse Leadership Board manuscript published by ONS

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The IMF Nurse Leadership Board is a professional nursing partnership representing leading cancer centers and community practices in the United States with the primary mission of understanding and developing strategies to address the unmet needs of multiple myeloma (MM) nurses, their patients, and caregivers. One of the NLB's current priorities is addressing the specialty needs of patients undergoing autologous stem cell transplantation (ASCT). As a part of this goal, the *Clinical Journal of Oncology Nursing*® (CJON), an official journal of the Oncology Nursing Society (ONS), published a supplement in December 2013 (Vol. 17, No. 6) – Hematopoietic Stem Cell Transplantation and Multiple Myeloma – to support oncology nurses, and positively affect outcomes, including quality of life of patients with myeloma and their caregivers throughout the continuum of care. In this issue of *Myeloma Today*, we bring you a synopsis of the NLB manuscript and invite you to visit the IMF website [myeloma.org](http://myeloma.org) to access the full CJON supplement.

### The changing treatment landscape overview

The scientific advances in the field of MM relative to the pathobiology of the disease, identification of potential new targets for therapy, mechanisms of resistance, and integration of new agents into the existing treatment paradigm are ongoing. Integrating these changes into clinical practice and anticipating continued developments is a challenge for the oncology professional. Hematopoietic stem cell transplantation (HSCT), in particular autologous HSCT (AHSCT), remains an important component in the overall treatment paradigm for MM. Familiarity with eligibility criteria, pre-transplantation evaluation, the actual transplantation process, and supportive care for the patient throughout the treatment continuum will improve the care of patients with MM undergoing HSCT.

### AHSCT Overview

AHSCT is approved for the treatment of select solid tumors, autoimmune disorders, and most hematologic malignancies. MM is the most com-

mon indication for AHSCT. Despite improvement in response and survival rates in the era of novel agents, AHSCT remains an important treatment option for patients with MM who are eligible. Clinical management of patients with MM requires an interprofessional approach that incorporates healthcare professionals in a number of clinical settings, as well as caregivers and patients. Those about to undergo AHSCT are generally referred to tertiary care centers that specialize in ASCT. Pre- and post-transplantation treatments and long-term follow-up often are managed by a community-based referring oncologist in collaboration with the transplantation team.

Oncology nurses play an integral role in the care of patients with MM in each clinical setting. Care of the patient following AHSCT is complex. This paper discusses autologous versus allogeneic HSCT, treatment from induction to post-transplantation recovery, as well as symptom management, infection risk and prevention, post-transplantation immunizations, medication considerations, and disease management post-AHSCT.

Patient care must be individualized based on pre-transplantation patient status, transplant-related side effects, and recovery. Post-transplantation guidelines are not standardized, and recommendations for post-transplantation care vary between transplantation centers. These factors add to the challenge of caring for the transplantation patient in a community-based setting. Maintaining a collaborative management approach with consistent communication between the transplantation center and community healthcare provider team will improve overall outcomes for patients undergoing transplantation.

### Caregivers of myeloma survivors

Patients living with MM face complex decisions throughout their journey relative to their diagnosis, options for treatment, and how their disease and treatment choices may affect them physically, emotionally, financially, and spiritually. Patients considering HSCT face



Sandra Kurtin



Beth Faiman



Teresa Miceli



Kathryn Lilleby,



Kimberly Noonan



Patricia A. Mangan



Jacy Spong



Charise F. Gleason

CONTINUES ON PAGE 8

specific self-management challenges. The availability of a reliable caregiver is a prerequisite to transplantation eligibility. Currently, the majority of clinical management is episodic and provided in the outpatient setting. Therefore, the bulk of care for patients living with MM is provided by the patient together with his or her caregivers, who face similar challenges to those faced by the patient living with MM. Caregivers are required to take in complex information, perform often complicated or technical procedures such as line care or injections, assist the patient with activities of daily living, and attend the myriad of appointments required.

Understanding the dynamics of the patient-caregiver relationship, the strengths and weaknesses unique to that relationship, common elements of caregiver stress or strain, and available tools and strategies to promote a sense of control and enhance self-management skills may improve the health-related quality of life for both the patient with MM and his or her caregiver. The CJON supplement discusses preparing the patient and caregiver for self-management, the impact of patient quality of life on the caregiver, as well as several key concepts to help manage the role of caregiver for the patient with MM during the HSCT process.

## Clinical updates in blood and marrow transplantation

HSCT remains an important treatment option for patients with MM. Since the 1980s, survival advances have been made with the use of newer agents by recognizing the role of transplantation, identifying the anticipated side effects at each phase, and improving supportive care strategies. Data support transplantation as part of the treatment strategy, but the optimal induction regimen and timing of transplantation have yet to be defined. The general consensus is that eligible patients should undergo autologous HSCT at some point in the treatment spectrum. Allogeneic transplantation is only recommended in the context of a clinical trial and in patients with high-risk disease characteristics.

The goal of transplantation is to reinforce the response achieved by induction therapy and improve progression-free survival and overall survival. The transplantation process can be challenging for patients and caregivers. This section of the NLB manuscript is intended to expand discussion on the role of nurses in assisting patients and families undergoing transplantation to include an overview of the acute care phase of the transplantation process. It encompasses discussions from induction

or initial treatment all the way through life post-transplantation, including risk for developing late complications secondary to pre-, peri-, and post-transplantation exposures. An understanding of each phase of transplantation will help patients and caregivers through this process, improve outcomes, and enhance quality of life.

## Autologous transplantation FAQ

As a complement to the other articles in the *Hematopoietic Stem Cell Transplantation and Multiple Myeloma* supplement, in the closing section the authors address eight frequently asked questions about common decision points in the process of AHSCT as a treatment for patients with MM.

1. Who are the best candidates for transplantation?
2. What is the optimal timing for transplantation?
3. What is the role of tandem transplantation?
4. What is the role of salvage transplantation?
5. What is the role of consolidation therapy after stem cell transplantation?
6. What is the role of maintenance therapy after AHSCT?
7. Is there a role for transplantation in the era of novel therapies?
8. What needs to be considered when choosing a transplantation center?

## Summary

Since 1998, high-dose melphalan and AHSCT have been a standard of care for patients with MM. The willingness of patients to participate in randomized comparative trials has been essential to the development of successful treatment approaches, resulting in unprecedented survival for this disease. Ongoing clinical trials of innovative approaches hold great promise that more questions will be answered soon. The ultimate result will be improved survival and quality of life for patients with myeloma. **MT**

**Editor's Note:** We invite you to visit the IMF website [myeloma.org](http://myeloma.org) to access the full text of the *Hematopoietic Stem Cell Transplantation and Multiple Myeloma* CJON supplement. In addition, *Understanding High-Dose Therapy with Stem Cell Rescue*, a separate IMF publication, can be read or downloaded from the IMF website or ordered by calling 800-452-CURE (2873).

## SAR650984: A NEW "BLOCKBUSTER" DRUG FOR MYELOMA — continued from page 4

lead center on two SAR phase I clinical trials. I have seen patients who, after failing to respond to some of our newest approved agents, have responded to antibody therapy. In general, these patients were without therapeutic options other than clinical trials. Several of these patients have now been receiving single-agent SAR for more than 6 months, and have maintained stable partial responses. They will continue to receive SAR.

The anti-CD38 class of antibodies like SAR have been the first monoclonal antibodies in myeloma to show such dramatic response rates. Moreover,

patients will be very happy to know that these agents, like SAR, appear to have the lowest rate of side effects of any therapy currently approved for use in myeloma. This is win-win news, and I am delighted to share it with the myeloma community. **MT**

**Editor's Note:** Please stay tuned to the IMF's report from ASCO 2014. We look forward to hearing Dr. Martin's presentation and sharing with our readers the data from the SAR/Rev/dex trial.



## MULTIPLE MYELOMA AND THE HEVYLITE® ASSAYS

### IMF Hotline Coordinators Answer Your Questions

**I have heard about the recent approval of the Hevylite® test for myeloma, but I don't understand why it is important or how it differs from tests that are already available to track my disease. Can you explain?**

The U.S. Food and Drug Administration (FDA) Medical Devices Section recently approved a new test from The Binding Site, makers of the serum free light chain assay (the Freelite® test). The new test is called the Hevylite® immunoglobulin assay, or serum heavy/light chain pair assay, and it will play an important role as an additional tool for monitoring multiple myeloma.

According to the FDA approval, the Hevylite test is intended for the in vitro quantification of IgA kappa/lambda and IgG kappa/lambda concentration in human serum. (A test kit for IgM kappa/lambda was also approved, but only for Waldenström's Macroglobulinemia.) The results of the Hevylite assay are to be used with previously diagnosed IgA or IgG multiple myeloma, in conjunction with other clinical and laboratory findings.

Myeloma is a disease that is characterized by the presence of plasma cells that over-produce a single antibody type referred to as "monoclonal protein," or M-protein. Because monoclonal protein is an indirect measurement of the activity of the cancer cells, quantifying it has been a very useful way to gauge the activity of myeloma cells without having to do an invasive (and painful) bone marrow biopsy. Measurement of circulating monoclonal protein has been the mainstay of diagnosis, prognosis, and management of myeloma, since it represents a marker of myeloma cell production.

M-protein can be made up of just an immunoglobulin heavy chain (IgG, IgA, IgM, IgD, or IgE), just a free light chain (free kappa or lambda), or, in the majority of cases, a heavy chain with an associated free light chain (IgG kappa, IgG lambda; IgA kappa, IgA lambda; etc.). While the Freelite test quantifies free light chains, and has been most helpful for patients with light chain disease, low-secreting disease, and amyloidosis, the Hevylite test quantifies both the heavy and light chains involved in the patient's myeloma (IgG kappa or IgA lambda, for example).

The serum Hevylite test has both high specificity and high sensitivity (that is, it is a reliable test that reports very few false negative or false positive results). Hevylite is a fully automated test that recognizes when a specific monoclonal heavy chain pairs with a specific monoclonal light chain. Thus it can distinguish between the "involved" proteins – the heavy and light chain involved in the myeloma – and their "uninvolved" (i.e., normal or polyclonal, not monoclonal) counterparts. An example would be that of a patient with IgG lambda monoclonal protein (the "involved" heavy and light chain) and the patient's normal or "uninvolved" antibody pair, IgG kappa. Similarly, a patient with IgA lambda myeloma would have the uninvolved pair IgA kappa. Not only does the Hevylite test calculate the involved and uninvolved protein pairs, but like the Freelite test, it calculates the ratio between the involved and uninvolved proteins, and then compares them to normal ranges for these blood proteins.



Judy Webb, Missy Klepetar, and Paul Hewitt

These values are very important in assessing myeloma activity because they reveal not only the amount of monoclonal protein, but the amount of polyclonal "paired" immunoglobulin protein as well. When the normal polyclonal paired immunoglobulin is lower than normal, it demonstrates the extent to which normal immunoglobulin production has been suppressed by the myeloma.

The standard test for quantifying myeloma protein, serum protein electrophoresis

(SPEP), is performed by placing a patient's serum in a gel and applying an electrical charge. The blood-born proteins are separated according to their electric charge, and then stained using a specific dye which reveals proteins as bands that can be scanned and quantified. Since each type of blood protein has a different electrical charge, the proteins plot out in different regions, or zones, when the test is analyzed. However, IgA protein often fails to show up in the gamma zone on electrophoresis, where antibody proteins normally migrate. Instead, it tends to plot out in the beta region, where it cannot be quantified. Thus for patients with IgA kappa or IgA lambda myeloma, standard SPEP is not a particularly reliable test. The Hevylite assay is a viable alternative for quantifying the M-protein of these IgA patients.

A further benefit of the Hevylite test is that it can detect relapses earlier than any other method currently available. If a patient's HLC (Hevylite Chain) test does not produce a normal HLC ratio, then we know that the myeloma cells are again producing monoclonal protein that is as yet undetectable by other means. The current International Myeloma Working Group (IMWG) Uniform Response Criteria for Multiple Myeloma state that the standard for determining complete response (CR) is immunofixation-negative blood and urine. Now, however, with the approval of the serum Hevylite test, we have a much more sensitive marker for CR.

Stay tuned in the coming months as the IMWG re-evaluates response criteria, standards for monitoring relapse, and measures of prognosis in light of this new test.

In the next edition of *Myeloma Today*, Dr. Heinz Ludwig, who has done much of the initial research with the Hevylite test, will be interviewed about its meaning and potential for myeloma patients. In addition, watch out for a forthcoming new IMF publication: *Understanding the Serum Free Light Chain and Serum Heavy/Light Chain Assays*.

As always, we encourage you to speak with your physician about your myeloma treatment and monitoring plan, and to discuss this new test. **MT**

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

## SPOTLIGHT ON ADVOCACY



### Federal policy update

Johanna Gray  
Federal Government Affairs Consultant

For several years, the IMF has focused on the enactment of the Cancer Drug Coverage Parity Act to increase access to oral and other forms of patient-administered cancer treatments. In recent months, the IMF has endorsed several additional pieces of legislation to address other healthcare challenges to benefit the myeloma community, including:

#### HR 2827/S.1365 – The Part D Beneficiary Appeals Fairness Act

This bill would create an appeals process in Medicare Part D for people to access drugs that are placed on specialty tiers. Currently, Medicare beneficiaries can appeal to their Part D plan for a “tiering exception” to access a drug with lower cost-sharing, but only if their physician determines that no drug offered in a lower tier can be used to effectively treat the patient’s illness. This appeals process is not allowed for any drugs placed on a specialty tier. This poses a barrier to accessing treatment since specialty tiers require patients to pay a percentage of the cost of the drug (frequently as high as 25% or 33%). The bill would allow this “exception” process to apply to drugs on the specialty tier as well, which will improve patient access to these life-saving drugs.

#### HR 543 – The Blue Water Navy Vietnam Veterans Act of 2013 and HR 1491 – The Blue Water Navy Ship Accountability Act

HR 1491 directs the Secretary of the Navy to review and publish a list of all Navy ships that operated in certain areas near Vietnam during the Vietnam War. HR 543 extends health coverage to sailors who were on those ships during the Vietnam War who were exposed to Agent Orange. The idea behind the bills is to extend to sailors the healthcare coverage that soldiers in Vietnam can access as a result of exposure to Agent Orange. Since exposure to Agent Orange is associated with a higher incidence of myeloma, the IMF believes that all veterans who may have been exposed should have this additional access to the healthcare coverage they need to treat myeloma.

#### HR 2477 – The Planning Actively for Cancer Treatment (PACT) Act of 2013

HR 2477 provides coverage for cancer care planning and coordination services for Medicare beneficiaries. The bill essentially creates a new service to enable care providers to bill Medicare for work done with patients in developing a written cancer care treatment plan. This will improve patients’ understanding of their treatment plan.



### As the Bill Turns – state policy update

Meghan Buzby  
Director, US Advocacy

The IMF advocacy team members have been on their toes, actively working to pass oral anticancer treatment access legislation in 10 states. We are happy to announce that at the time of publication, two states have new laws in place and many more are almost there. Thank you to everyone who contacted your legislators and headed to your state capitol building to show support (or opposition) for these bills. To catch you up, we have put together a special edition of As the Bill Turns, our rundown of what is happening around the country.

### Maine

On February 26, Maine became the first state this year to pass an oral anticancer treatment access bill! Not only did Maine bring us to 28 states with such laws, but it also showed the rest of the country that it is possible to pass a pure parity bill without caps.

### Missouri

On March 19, Governor Jay Nixon of Missouri signed SB 668, the Cancer Treatment Fairness Act, into law, making it the 29th state to pass oral anticancer treatment legislation. This law puts in place a cap of \$75 per prescription per month for oral anticancer medications under private insurance plans. Thanks to the great work of our Missouri ACTION team, who delivered over 375 postcards to Governor Nixon requesting his signature on the bill, many more cancer patients in Missouri will have affordable access to all anticancer treatments. ACTION team member John Killip attended the signing and thanked the Governor on behalf of Missouri myeloma patients.



Governor Jay Nixon of Missouri signs SB 668, the Cancer Treatment Fairness Act into law

### Kentucky

On February 19, the IMF hosted an amazing Lobby Day in Frankfort, Kentucky. Our intent was to educate and inform legislators about the need for an oral anticancer treatment access bill in Kentucky. By the end of the day, we had a bill introduced! In a meeting with his constituents, Senator Tom Buford committed to introducing the Cancer Treatment Modernization Act. At the time of publication, SB 148 had passed the full Senate and awaits action in the House. Thank you to everyone who helped move this legislation forward, especially advocate Toni O’Neil who spoke of her son who was diagnosed with myeloma at age 27.



The IMF Lobby Day in Kentucky successfully secured a bill champion

### Georgia

At the start of this legislative session, we were excited to work on passing a law to help Georgians gain access to oral anticancer treatments, but were quickly disappointed. HB 493, the Georgia Cancer Treatment Fairness Act, took a turn for the worse when the bill adopted language that would allow insurance companies to cap the cost of oral anticancer treatments at \$200 per prescription per month. Studies have shown that an out-of-pocket cost exceeding \$100 will cause patients to walk away from treatment. The IMF and other patient groups worked hard to amend the bill in the Senate Insurance and Labor Committee, but were unsuccessful. Thank you to our advocates who did an amazing job conveying their disappointment in HB 943. Unfortunately, the bill is expected to become law. But we haven’t given up, and plan to work with coalition partners over the next year to educate legislators and strengthen support to lower the cap.

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## Maryland

In mid-March, SB 641, the Kathleen A. Mathias Oral Chemotherapy Improvement Act of 2014, passed both chambers and awaits the Governor's signature. This bill will fix an exemption included in the legislation approved in 2012 that excluded plans subject to the essential health benefits as part of the Affordable Care Act. We are very excited that more cancer patients in Maryland will not have to wait another year for equal coverage as this bill goes into effect January 1, 2015.

For more information, please visit the Advocacy homepage on [myeloma.org](http://myeloma.org).



## Advocates secure legislator support

**Aimee Martin**  
Grassroots Liaison

On February 17, Mary Ming-Mosley, Russel Wood, and Pat Hardy met with Congresswoman Gloria Negrete McLeod in Montclair, California, to request her support of HR 1801, the Cancer Drug Coverage Parity Act. One week later, she was added as a co-sponsor. How, you ask, did this happen? I recently sat down with Mary and Russel to find out.

First, Mary participated in our "10 Steps to Meeting Your Legislator" webinar, which covered the details of HR 1801 and best practices of in-district legislator meetings. Then, an ACTION Team In-District Meeting mentor called Mary to answer questions and give her support throughout the process. "It was great to have an advocate who had done this before as a resource," says Mary.

Setting up the meeting was easier than Mary imagined. "I was scared because I thought it was going to be hard," she recalls. "I called and spoke with Marty, the office manager. She was more than willing to make an appointment for me with the Congresswoman. Marty asked me what we wanted to meet about, how many people were coming, and their names and addresses. She wanted to make sure we lived in the district. Then a few days later Marty called back to say we had a meeting scheduled for February 17."

Like Mary discovered, the best way to get a meeting is to call the office and ask for one. The manager may ask you to email or fax a follow up request, but the initial contact should be over the phone to create a relationship and show that you are serious about the meeting.

Once the meeting was scheduled, I mailed Mary a folder with information on the legislation and post-cards the group had collected to leave with the Congresswoman. Additionally, the group researched the legislation and the Congresswoman. "One of the most important things we did ahead of time was visit the Congresswoman's website to learn what was important to her," says Russel. "I found out that she is very interested in veterans' rights. I served 36 years in the Air Force, so the first thing I did after introducing myself was to thank her for being an advocate for veterans in Washington. We then talked for a few minutes about this topic and I could tell she was pleased that we had done our research on her. I recommend that everyone do this before they meet with a legislator."

Because this was their first time, the group was unsure what the Congresswoman would expect from them. Russel says, "We went in there with a plan

to ask her for something and were nervous about that, but during the meeting it was clear that she was asking us what she could do for us. She was very eager to support what was important to us, which made it a very comfortable conversation." The advocates felt like they were speaking with an old friend, not an elected official. "The Congresswoman was very easy to talk with," recalls Mary. "She treated us as if she had known us for years, and did not rush us even though she had another appointment after ours. She was attentive, engaged, and really listened to us. It made me want to campaign for her."

The group then explained multiple myeloma and the Cancer Drug Coverage Parity Act. "At the beginning of the meeting, she said she had heard a little about the cost disparity between oral and IV cancer treatments, but did not understand the issue fully. Russel did a great job explaining the bill and then I spoke of a support group member who had to pay \$7,000 a month for his oral treatments. Luckily, that member could afford it, but if it was me, I would have to go without treatment. With myeloma, we have to be able to access every treatment because there is no cure and the disease becomes resistant. The Congresswoman had never heard of myeloma and was struck with the realities of what the disparity can do to a person," recalled Mary.

Forty-five minutes later, the group left with a newfound relationship with Congresswoman McLeod and a new co-sponsor for HR 1801. In-district meetings make a huge difference in moving the Cancer Drug Coverage Parity Act forward. When you take the time to meet with your legislators it forces them to pay attention to the bill and puts a face to the issue. With roughly 5,000 bills introduced each session, the personal outreach from a constituent is what makes a difference.

Based on their experience, Mary and Russel compiled their Top 5 Tips:

- Be clear on the issue that is important to you and what you are asking for.
- Take 10 minutes to research what is important to the legislator.
- Don't be afraid to talk to elected officials because they are people just like you.
- Legislators work for you.
- Be polite, no matter what.

Thank you Mary, Russel, and Pat for your hard work and making this meeting happen! **MT**



Russel Wood, Pat Hardy, and Mary Ming-Mosley pose with Congresswoman Gloria Negrete McLeod during their in-district meeting

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

Want to make a difference like Mary, Russel, and Pat? An in-district meeting is focused, effective, and most importantly it's easy! We have everything to get you started. Email Aimee Martin, Grassroots Liaison at [amartin@myeloma.org](mailto:amartin@myeloma.org) or call her at 617-870-4870.

## How to contact the IMF Advocacy Team



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### IMFers RAISE FUNDS TO SUPPORT RESEARCH



By Suzanne Battaglia

*International Myeloma Foundation (IMF) members are raising funds to support essential multiple 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 incredibly empowering. The IMF’s FUNdraising program is fun and easy, and brings with it the satisfaction of knowing that YOU are making a difference in many lives.*

*The two articles that follow demonstrate the flexibility you have in choosing an event that will be both fun and valuable in fundraising and raising public awareness in your community. 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 smaller-scale event, consider putting a twist on something you normally might do, such as a bake sale, garage sale, holiday party or, like one member, 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.*

*Here are some examples of recent events...*

#### Stolper Strong

Matthew Stolper’s myeloma diagnosis in May of 2012 came as a shock to him and to his wife Ellen. Matthew was in his mid-50s and generally healthy, except for degenerative disc disease. The changes in his discs



Matthew Stolper at home,  
one year post-transplant

resulted in pain that necessitated spinal fusion and Matthew was having difficulty recovering from the surgery. But the cancer diagnosis felt like a bolt out of the blue.

The Stolpers shared the news with their children: Gary (29), Mara (25), and Julie (20). “Being a very close family, all five of us coped with the devastating news as a family unit,” says Gary. “Characteristically, our first question was... What can we DO?” The entire family set out to learn as much as possible about myeloma and its treatment options, and reached out to the IMF for assistance.

Eventually, Matthew chose to undergo high-dose therapy and an autologous stem cell transplant. While he was recovering in the hospital, the Stolper Family focused on keeping his spirits high. One day, they showed up at the hospital wearing t-shirts emblazoned with the words “Stolper Strong” in Matthew’s honor. Someone took a photo, which made its way via text and email to more than 40 family members and friends who similarly wanted to show their support.

“As people started to inquire about the shirts, we decided to make more of them to raise funds to help the IMF help other myeloma patients,” explains Gary. “We really appreciated the support we received from the

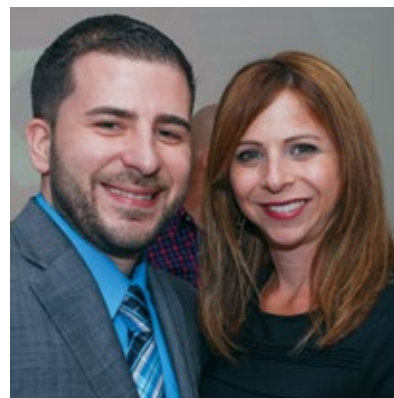


Matthew Stolper with Family at the time of his 2013 hospitalization

Foundation, so the backs of the shirts feature the IMF’s name, tag line, and web address. We raised \$500 plus a lot of awareness, and we are very happy with the results of our campaign. In fact, all of us look forward to future charity events. This has been a wonderful experience and a terrific way to honor Dad while putting a smile on his face!”

#### Dance For A Cure

When the General Manager of the Long Beach Hotel in New York, Frank Tramontano, learned the sad news that Evelyne Siegfried lost her battle with myeloma, he knew he wanted to do something special to comfort her grieving family. He approached David Kadosh, owner of the Long Beach Hotel and Evelyne’s brother, who said that one way to honor his sister’s memory would be to help others battling this disease. Together, Frank and David wasted



Event organizer Frank Tramontano  
with IMF’s Ilana Kenville

## Member Events



Dance For A Cure supporters and guests

no time in organizing a fundraiser. "I have always been an advocate for cancer research and I learned a lot about myeloma over the years," says Frank. "In their time of grief, choosing to contribute to the search for a cure for this horrible disease is a true reflection of the Kadosh Family."

Frank has been actively helping US troops returning home from active tours of duty, but Dance For A Cure was his first experience with raising funds for myeloma research. "We decided to organize a dance because the concept has a positive and uplifting message. We set the date for February 22 and started selling tickets for \$50 a person. More than 60 people gathered to celebrate Evelyne and to support myeloma research. I was truly touched to see the turnout, which included other myeloma patients and their families, and representatives of a local support group."

Among guest speakers at the event were myeloma support group leaders from Staten Island, Laura and Charlie Mooney, as well as the IMF's Ilana Kenville. "We had excellent invited speakers who were able to educate

our guests about the challenges of living with myeloma and the need to find a cure," recalls Frank. "We also had great music, food and drinks, lots of raffle prizes, and a silent auction of sports memorabilia. And the venue looked absolutely spectacular!" Fittingly, the event's grand prize was awarded to a guest who was a newly diagnosed myeloma patient.

Sharing the experience of honoring Evelyne has further solidified the relationship between Frank Tramontano and the Kadosh Family, as well as their commitment to support myeloma research. "Dance for a Cure

was such a good and rewarding experience that I am humbled to have been a part of it. My heart goes out to everyone fighting myeloma, as well as to their loved ones, and I will continue to do whatever I can to be of help." **MT**



(l to r) Long Beach Hotel owner David Kadosh with Staten Island myeloma support group leaders Laura and Charlie Mooney

## IMF Staff Updates



### **Elise Segar** Director of Major Gifts

Elise has been an active supporter of the IMF and its mission for many years, and has previously raised funds to support our search for a cure.

We are thrilled to welcome her to our team as the Director of Major Gifts.

Elise earned a Bachelor's degree from the University of Connecticut and comes to the IMF with 10 years of experience as a senior executive and team leader in enterprise technology, management, marketing, and lead business development. Elise can be reached at [esegar@myeloma.org](mailto:esegar@myeloma.org).



### **Ilana Kenville** Development Associate

Ilana Kenville became one of the IMF's first volunteers when her uncle, Brian Novis, co-founded the IMF with Susie Novis and Dr. Brian

G.M. Durie in 1990. When the IMF supported the establishment of Myeloma UK, Ilana traveled to Scotland to work with Eric Low on launching that new organization.

Ilana holds a degree in Liberal Studies from National University, San Diego, California. Building on her experience of founding and managing a club for World War II veterans in Arizona, Ilana will assist Suzanne Battaglia, IMF's Director of Member Events, with the IMF's Veterans Against Myeloma initiative. Ilana can be reached at [ikenville@myeloma.org](mailto:ikenville@myeloma.org).



### **Christine Legaspi Berlingis** Assistant Meeting Coordinator

Christine earned her Bachelor's degree in Hotel & Restaurant Management from the

California Polytechnic Institute in 2005. In the course of her professional career, she has used her exceptional skills to successfully negotiate and supervise a broad range of meetings, conventions, and trade shows.

Christine has now joined the IMF team, working directly with Annabel Reardon to assist with the IMF's 2014 meetings and events program. Christine can be reached at [clberlingis@myeloma.org](mailto:clberlingis@myeloma.org).



### **LIFE IS GOOD AND MISERY IS OPTIONAL!**

*Myeloma Today* in conversation with Kenton Hofmeister

#### **When and how were you diagnosed with myeloma?**

In December 2010, I was in considerable pain and my internist ordered X-rays which identified cracked ribs and a fractured sternum. The M-spike was identified as a result of a 24-hour urine collection. Shortly thereafter, I developed five vertebral compression fractures (VCFs). These were confirmed by MRI and CT scans. We live in Florida, so we went to the H. Lee Moffitt Cancer Center where the diagnosis of myeloma was confirmed with a bone marrow biopsy.

#### **How did you handle the diagnosis and tackle the disease?**

My family consists of my wife Ann, and our three kids and six grandkids. When I was diagnosed, all the kids flew into town and each gave me some very specific help in addition to their love and support. My son helped me see that the myeloma statistics have outliers and, with the right steps and a positive attitude, I could be such an outlier. One daughter helped find a special chair I could sit in comfortably with fractured vertebrae. And my other daughter was an example of the empathy and love that I find in our family – I couldn't even get out of bed on my own. Things looked pretty grim back then.



I was 74 years old. After learning about myeloma statistics and treatment options available to a man my age, I chose to enter a clinical trial of single-agent Revlimid® (lenalidomide). I responded to the therapy, and it continued to work well for me for two and a half years before we had to add dexamethasone. From the beginning, I knew that my myeloma picture would continue to evolve, so being educated about my disease has always been a high priority.

The IMF was the first place I found solid information that helped me understand what I was dealing with. I attended my first IMF Patient & Family Seminar at Boca Raton in 2011, two months after diagnosis. That experience was a game changer. I found hope, help, tips, and decision-making data. You have no idea how powerful it is to listen to presenters discuss the latest in research and treatment, while being in a room full of vibrant people who are living with this disease. That was when I said to myself, "I can do this."



At the 2011 seminar, after talking with other patients, I decided to go ahead with kyphoplasty to address the fractured vertebrae. The procedure, which repaired four of the five VCFs, gave me immediate relief and I've never looked back. I lead an active life, riding a bike 10 to 12 miles at a time and fishing almost every day.

I have not missed a single IMF seminar since 2011, and they continue to be a source of inspiration for me. I always glean new information and keep an eye on the big picture. In February 2014, I was back at the IMF's Patient

& Family Seminar in Boca. Now I find that sharing my experience with others helps them cope with those dark early days of myeloma. I have seen hope begin to emerge on the faces of newly diagnosed patients I have met. You can't keep a positive spirit unless you give it away.

#### **What have been the lessons of your myeloma experience?**

It was Christmas morning 2010 when I faced my fear of the unknown. I had to claim that fear, name it, and turn it over to a higher power. Acceptance was key in coping with my situation. But let me be clear... I had to accept the diagnosis; I did not accept the prognosis. I identified my own support team of doctors, family members, and friends who share the same spiritual principles, and every single one of them has come through for me, and countless more have joined the team over the years. My wife turned into Florence Nightingale -- she didn't overdo it by giving me anything that I didn't want, need, or couldn't use, but she has given me all the support I've needed. I feel so fortunate.

The IMF is here for us with an unbelievable quantity and quality of knowledge. It is hard to fathom that this much good information is

there for the taking, but the IMF makes it so! I know that the IMF will help me make an informed decision next time I need to review my treatment options. And I know that talented clinicians and researchers are working hard on solving the riddle of this disease. With their help, I am determined to die of something besides multiple myeloma. Certainly, the Black Swan Research Initiative® is very encouraging.

I don't think of myself as a cancer patient; I focus on living my life to the fullest. Myeloma does not define me. I can do anything one day at a time or one hour at a time. I learned that if I focus on a problem, the problem gets bigger; but if I focus on a solution, the solution gets bigger. I have let go of self-pity and entitlement, and replaced them with joy and gratitude. I think about what I can do for others. I know that life is good and misery is optional. **MT**







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

## 2014 IMF Calendar of Events

April 26	IMF Regional Community Workshop (RCW) – Virginia Beach, VA	June 12	IMF Global Myeloma Alliance Summit – Milan, Italy
May 1-4	39th Annual Congress of Oncology Nursing Society (ONS) – Anaheim, CA	June 14	IMF Myeloma Center Workshop (MCW) – Minneapolis, MN
May 1	IMF Satellite Symposia “Case Studies in Multiple Myeloma Treatment Best Practices for Nurses” at ONS– Anaheim, CA	July 19	IMF Regional Community Workshop (RCW) – Salt Lake City, UT
May 8	IMF Living Well with Myeloma Teleconference Series – <i>Benefits of Exercise and Relaxation*</i>	July 25-27	IMF Support Group Leader Summit – Dallas, TX
May 16-17	IMF Patient & Family Seminar (PFS) – Atlanta, GA	Aug 22-23	IMF Patient & Family Seminar (PFS) – Los Angeles, CA
May 30-June 3	50th Annual Meeting American Society of Clinical Oncology – Chicago, IL	Aug 28	IMF Living Well with Myeloma Teleconference Series – <i>Understanding the Immune System and Lab Values in Myeloma*</i>
June 9-11	IMF 2014 International Myeloma Working Group (IMWG) Summit – Milan, Italy	Sept 25	IMF Living Well with Myeloma Teleconference Series – <i>Management of Bone Disease*</i>
June 10	IMF Robert A. Kyle Lifetime Achievement Award Presentation – Milan, Italy	Oct 10-11	IMF Patient & Family Seminar (PFS) – Short Hills, NJ
June 11	IMF International Myeloma Working Group Conference Series <i>Making Sense of Treatment</i> – Milan, Italy	Oct 25	IMF Regional Community Workshop (RCW) – Nashville, TN
June 12-15	19th Congress of European Hematology Association – Milan, Italy	Dec 5-8	56th Annual Meeting & Exposition of the American Society of Hematology (ASH) – San Francisco, CA
		Dec 5	IMF Satellite Symposium at ASH – San Francisco, 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](http://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](http://myeloma.org.au) • Canada [myelomacanada.ca](http://myelomacanada.ca) • Israel [amen.org.il](http://amen.org.il) • Japan [myeloma.gr.jp](http://myeloma.gr.jp) • Latin America [mielomabrasil.org](http://mielomabrasil.org)*

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