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MYELOMA TODAY

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VOLUME 9 NUMBER 7

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

Prof. Kazuyuki Shimizu, President of the 14th International Myeloma Workshop (IMW) meeting held in April 2013 in Japan, shares his perspective on the highlights of this important biannual event devoted entirely to myeloma. More than 1700 participants from 64 countries attended the workshop, with presentations covering diverse topics such as treatment strategy and timing, early vs. delayed transplantation, in-depth monitoring of response, and new approaches to detecting, defining, and treating myeloma. ***PAGE 4***

The Black Swan Research Initiative™ (BSRI™) is an exciting new IMF research project. With strong support from the IMF Board of Directors and from the members of the International Myeloma Working Group (IMWG), the Black Swan Research Initiative is already poised to produce important results in the stepwise approach to achieving a cure for myeloma. The IMF will keep you posted every step of the way. ***PAGE 5***

Education & Awareness

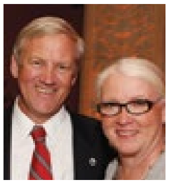
The IMF Nurse Leadership Board presented a Satellite Symposium at the 38th Annual Congress of the Oncology Nursing Society (ONS) in Washington, DC. More than 700 nurses attended the symposium – "New Paradigms in Multiple Myeloma Management: Nurse-Centric Case Studies in Patient Survivorship" – designed to improve management of myeloma patients. Four diverse case studies were discussed: monoclonal gammopathy of undetermined significance (MGUS), newly diagnosed myeloma, first and second relapse, and relapsed/refractory disease. ***PAGE 7***

IMF Hotline Coordinators discuss "clonal evolution," a term that refers to genetic changes that take place within myeloma cells over time, leading both to mutations in the original clone and to the development of new clones. Although myeloma appears to arise from an original monoclone or stem cells of restricted clonal specificity, variant new clones evolve resulting in clonal heterogeneity (or polyclonality). Polyclonality is an important feature at the time of clinical disease and must be included in the conceptual approach to both biological studies and development of new therapies. ***PAGE 8***

Special Event

Myeloma Awareness Month was established by the IMF in 2006 to raise awareness of this often-misdiagnosed disease, and to support myeloma patients and the need for a cure. This special annual effort, which takes place during the month of March, has grown each year and 2013 has been the most successful event to date. Hundreds of dedicated volunteers spread the word about myeloma in their communities, and their outreach touched thousands of people. Four states, as well as more than 60 cities and counties officially declared March to be Myeloma Awareness Month. ***PAGE 10***

Profiles in the News



John and Dorothy O'Dwyer, Founding Donors for the Black Swan Research Initiative™ (BSRI™), have made a substantial investment in the myeloma community and the path to a cure. We hope that the story of how and why they have chosen to commit so significantly to the fight against myeloma will inspire you, as it inspires us. Diagnosed with myeloma in June of 2007, John O'Dwyer's whole focus since becoming a member of the IMF Board of Directors has been on a cure for myeloma. He now serves as Chairman of the BSRI campaign. ***PAGE 15***

The latest MYELOMA RESEARCH that was presented at ASCO 2013 *is now available to YOU with the click of a mouse!*

INTERNATIONAL MYELOMA FOUNDATION
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• webcasts

Overview | Immunomodulatory Agents | Proteasome Inhibitors | Other Novel Agents | Transplant

ASCO 2013: Dr. Anderson - Overview of the 2013 Annual Meeting of the American Society of Clinical Oncology
Ken Anderson, MD
Dana Farber Cancer Institute
Boston, Massachusetts, USA

ASCO 2013: Dr. Jagannath - Data on New Novel Agents
Sundar Jagannath, MD
Mount Sinai Medical Center
New York, New York, USA

ASCO 2013: Dr. Kumar - Emerging Trends for Multiple Myeloma Patient Survival
Shaji Kumar, MD
Mayo Clinic
Rochester, Minnesota, USA

ASCO 2013: Dr. Lonial - Overview of New Novel Agents Presented at ASCO 2013
Sagar Lonial, MD
Emory University School of Medicine
Atlanta, Georgia, USA

The 2013 Annual Meeting of the American Society of Clinical Oncology (ASCO), held May 31 through June 4 in Chicago, brought together more than 25,000 oncology professionals and featured more than 5,000 abstracts. The IMF has sifted through these presentations to spotlight the most significant information for myeloma patients, and has conducted video interviews with top researchers working in the field of myeloma. Please visit asco.myeloma.org to watch the 2013 ASCO interviews.

Also in this issue…

This issue of *Myeloma Today* is supported by Celgene Corporation,
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A Message from the President

Dear Reader,

When I co-founded the International Myeloma Foundation back in 1990, we set out with a simple goal: to create an inclusive community dedicated to supporting the wide-ranging needs of all those affected by multiple myeloma. Twenty-two years later, the IMF has grown to be the global leader in myeloma research and advocacy, serving as a beacon of hope for myeloma patients and their loved ones. Already – though only halfway through 2013 – the IMF has participated in both academic and patient-centric conferences in 10 countries around the world… be it Australia, China, Turkey, or anywhere in-between, the IMF is there – putting patients first, and working to find a cure.

In support of that goal, on June 13th the IMF convened the first-ever Global Leaders Summit in Stockholm, Sweden. Held in advance of the annual congress of the European Hematology Association (EHA), the IMF Global Leaders Summit was developed as a mechanism to more effectively coordinate the communication and collaboration between blood cancer patient organizations at the international level. In attendance at this event were more than a dozen organizations from around the globe, representing a multitude of countries from Asia, Europe, Latin America, the Middle East, and North America.

With the intention of establishing a global advocacy coalition for blood cancer patients, I'm happy to report that the Summit was a resounding success! Without a doubt, the Global Leaders Summit will play an instrumental role in the advancement of myeloma advocacy and awareness on a global scale.

On a personal level, I was touched by the experiences of people who came from far and wide, and were able to take away so much from the Summit. Asli Ortakmac, a journalist and founder of Miyelomla Yasam, a website for patients and their families in Turkey, was one such story. Explaining why she came, she said that "if patients who suffer with myeloma and other blood diseases cannot find any social or psychological support, they fall into despair… Unfortunately, there are almost no patient support groups in Turkey."

Asli is intent on changing that, however. "Meeting with organizations that succeed on these issues… inspires us. We were able to learn shortcuts for setting up successful support groups and creating an effective advocacy or public policy program for patients in our country."

One of the key issues at hand is that more often than not, patients aren't aware of the latest developments that have been made in treatment options, as the availability of new treatments is not uniform worldwide. Although in the past getting the word out on relevant information about new treatments was challenging, today's digital technology makes that task easier than ever.

We hope that the establishment of a Global Leaders Network will strengthen the voices of cancer patients who live in countries that have limited available treatment options. If the global community can come together to raise awareness of an issue, we'll have accomplished the first big step towards meaningful change.

Warmly,

Susie Novis

Susie Novis, President

LIVE FROM STOCKHOLM – BRINGING THE LATEST MYELOMA NEWS TO A GLOBAL AUDIENCE

IMWG Conference Series Debate:

Making Sense of Treatment

SEE THE WEBCAST NOW ON THE IMF WEBSITE

If you missed the live webcast of "Making Sense of Treatment," the International Myeloma Working Group (IMWG) Conference Series Debate broadcast from the 2013 IMWG Summit in Stockholm, Sweden, you can watch an archived version at **imwg2013.myeloma.org**. Myeloma experts Dr. Brian G.M. Durie, Dr. Ola Landgren, Dr. Joseph Mikhael, and Dr. Antonio Palumbo tackle the key questions facing myeloma doctors and their patients, and reveal what, in their opinions, are the hottest topics in the myeloma field today.

Multiple Myeloma Journalists' Workshop

SEE THE WEBCAST NOW ON THE IMF WEBSITE

Did you miss the live webcast of the Multiple Myeloma Journalists' Workshop from the 2013 annual meeting of the European Hematology Association (EHA) in Stockholm, Sweden? This workshop features discussions and analyses of the latest treatments for myeloma by Dr. Brian G.M. Durie, Dr. Xavier Leleu, and Dr. Paul Richardson. Sponsored by the International Myeloma Foundation (IMF), with Myeloma Canada, the archived webcast of this event can be viewed at **journalistworkshop2013.myeloma.org** in English, French, Russian, or Spanish.

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MYELOMA TODAY IN CONVERSATION WITH DR. KAZUYUKI SHIMIZU

Kazuyuki Shimizu, MD
Aichi Gakuin University
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Nagoya, Japan

Please tell us about your medical background.

I have worked in myeloma for 40 years. I developed a method to enumerate immunoglobulin-secreting cells in peripheral blood, with several peer-reviewed papers published in Blood in 1980 and 1982. This was a breakthrough technique because the quantitation of monoclonal immunoglobulin-secreting cells in the peripheral blood is a strong indicator of the prognosis of myeloma, and is now being done using flow cytometry.

I received my medical degree from Nagoya University School of Medicine in 1972 and completed a fellowship in clinical immunology at Memorial Sloan-Kettering Cancer Center in New York City in 1977. Since returning to Japan, I have held many posts. Until 2011, I was the director of the Nagoya City Midori General Hospital. Currently, I am a professor of Multimodal Therapy for Multiple Myeloma at the Aichi Gakuin University School of Dentistry, and a visiting professor at the Fujita Health University School of Medicine. I serve on the Board of Directors for the Japanese Society of Hematology and for the Japanese Society of Clinical Hematology. I am a member of Myeloma Trialists' Collaborative Group of MRC (UK) and the IMF's International Myeloma Working Group (IMWG). Since 2000, I have been a Scientific Advisor for the IMF. I also serve on the scientific advisory boards for IMF-Japan and the European Myeloma Network, and as Scientific Director of the International Myeloma Society. Since 2008, I have been president of the Japanese Society of Myeloma. I was president of the 14th International Myeloma Workshop (IMW).

Please share with our readers some of the highlights of the recent IMW.

The IMW is an important biennial event devoted entirely to myeloma. More than 1700 participants from 64 countries attended the workshop, which was held April 3-7 in Kyoto, Japan. There were 13 scientific programs, more than 130 oral and 448 poster presentations from 30 countries, plus 5 sponsored satellite sessions. We placed blooming cherry trees inside the conference center because our guests had little time to enjoy the blossoms outdoors!

There were so many important topics that I can only touch on a few in brief. The presentations of in-depth monitoring of response were very impressive. Currently, we use serum or urine M-protein to define complete response (CR) but this definition is suboptimal as it can miss the presence of minimal residual disease (MRD). This can lead to missed opportunities to intensify treatment for patients who have residual disease. On the other hand, continuing to treat patients who have *no* MRD is *over*-treatment. Therefore, MRD assessment is very important as it can lead to either intensification or discontinuation of treatment.

The one-size-fits-all vs. risk-adapted treatment strategy debate was very engaging. Myeloma is a heterogeneous disease so a risk-adapted strategy makes sense, especially for high-risk patients who are most challenging to treat. But the one-size-fits-all supporters argue that their approach is best for standard- and low-risk patients, especially as induction treatment. After initial treatment, the risk-adapted strategy comes into play for all patients. High-risk patients usually have cytogenetic disorders. Bortezomib-based regimens are often effective for patients with t(4;14). Standard-risk patients tend to do well on lenalidomide-based combinations. Implementation of consolidation/maintenance therapy should be based on the response of less than VGPR (very good partial response) to the prior therapies.

Another interesting debate focused on early vs. delayed stem cell transplantation. We are awaiting the final conclusion of a major clinical trial currently being conducted in France and the US, which should help answer this question.

Whether or not to treat smoldering myeloma remains a topic without full consensus. Timing of treatment for relapsed disease is also an important issue to resolve. There is a difference between clinical (development of CRAB symptoms) and biochemical relapse (increase of M-protein two-fold during a two-month period). Can we wait to treat a patient until CRAB symptoms appear or until the M-protein doubles?

During discussions of novel agents recently approved for myeloma in the US, such as carfilzomib and pomalidomide, it was sad to acknowledge that these drugs are not available to our patients in Japan. The data are so positive, yet it might take 3-5 years for these agents to be approved in Japan. Here, we refer to this as "drug lag." Thalidomide was finally introduced in Japan in 2008 and lenalidomide was approved in 2010, but both are available only for relapsed disease! The only novel agent we can use for upfront therapy is bortezomib alone. This is a very unfortunate situation for patients with resistant disease, especially when more and more novel agents are showing such promise.

Fascinating scientific topics at IMW included discussions of inhibition of proteasome and aggresome function, histone deacetylase (HDAC) inhibitors, chaperone and co-chaperone inhibitors, and the various pathways used by myeloma cells for survival. When combined, the proteasome inhibitor plus the HDAC inhibitor or heat shock protein (HSP) inhibitor appear to synergistically intensify the efficacy of new drugs. I am very much looking forward to results of the study of bortezomib plus HDAC or HSP inhibitors!

I am very optimistic that inventive approaches to detecting, defining, and treating myeloma will result in more effective targeted therapeutic strategy for patients. The genome and exome research presented at IMW may lead to improved ability to identify and monitor molecular targets of each myeloma patient. We are exploring the possibilities of treatment at every stage in the course of the disease. There is no question that our understanding of myeloma and its intraclonal tumor heterogeneity is improving.

Were there auxiliary meetings in addition to the busy IMW program?

The IMF facilitated meetings of the IMWG and the Asian Myeloma Network (AMN), as well as a Pomalidomide Roundtable and an interactive discussion of how myeloma therapies in Asia compare to those in the U.S. and Europe.

In addition, IMF-Japan held a patient assembly led by Ms. Kyoko Joko and supported by Mrs. Midori Horinouchi, which had approximately 130 patients in attendance. IMF's Susie Novis gave a presentation about the power of information, which was very encouraging and extremely well received by the patients. After the general assembly, patients were divided into groups, and each group was able to observe an IMW session and listen to the discussions among the doctors. I think it was valuable for them to see and hear first-hand about the progress being made in the field of myeloma.

How would you summarize the near-future in the field of myeloma?

I believe that the advances in myeloma research and clinical care will result in highly personalized treatments for patients in the course of the coming decade. Until then, we must make the most of the tools available to us now as well as continue the work already underway towards a near future where myeloma is little more than a chronic and, ultimately, curable disease. **MT**

THE BLACK SWAN RESEARCH INITIATIVE™ (BSRI™): AN EXCITING BREAKTHROUGH IN MYELOMA

by Brian G.M. Durie, MD

The Black Swan Research Initiative (BSRI), which officially launched in March 2013, is the International Myeloma Foundation's innovative approach to finding a cure for myeloma.

It's innovative because until recently the myeloma research community focused its efforts on comparing one treatment to another. Studies were conducted to determine which myeloma treatments or combinations of treatments resulted in comparatively better overall survival. We weren't confident about finding a cure – we were just looking to improve outcomes in myeloma patients by degrees.

But in recent years, with the arrival of the novel myeloma therapies, we realized we were getting closer and closer to eliminating the disease entirely. A few of us began to think: Why not look at myeloma from a new perspective and come up with a plan to cure it?

That question was put before a small group of myeloma researchers at a brainstorming meeting held in Amsterdam in June 2012. There, the seeds of the Black Swan Research Initiative were sown and the strategy mapped out: The team would develop reliable tests for measuring minimal residual disease (MRD) in myeloma patients, and with this testing as our guide, we would enhance myeloma therapy to come up with a cure. This testing would be standardized and validated such that all researchers would use the same approach.

Importantly, the BSRI's international researchers would test multiple treatment approaches simultaneously to see which ones were coming closest to eliminating the disease entirely.

That's the broad overview, now let's delve into the details of the Black Swan Research Initiative.

What is MRD, and why is it important?

MRD is the residual myeloma that remains after we've done our best to achieve remission. Until recently, few patients achieved excellent or complete remissions, so special tests to look in a more sensitive fashion for MRD were not needed. But now, the impact of novel combinations along with autotransplant is striking. Patients are achieving deeper and deeper responses, prompting us to ask: Are some patients cured? And, if there is no MRD in some patients, are they then to be considered to have MRD-Zero™?

The BSRI team recognized that more sensitive tests than have been available previously for myeloma are needed. Such tests can be used to fine-tune treatment in selected patients in order to achieve MRD-Zero – and a possible cure.

What MRD tests are available, and how can they be improved?

The BSRI team will use three techniques for testing MRD in myeloma patients. We anticipate that these tests will be affordable and widely available. They are:

- **Flow Cytometry:** One way to look for myeloma is to sort through bone marrow cells in search of residual myeloma cells using a flow cytometry technique. Bone marrow cells are put in a liquid solution and run through the flow cytometer, which identifies whether or not a cell "flowing" past the counting machine is a myeloma cell or not. The IMF is working with experts in the field to develop a new automated technique able to detect any remaining myeloma cells in either bone marrow or blood.
- **DNA:** Another way to measure MRD is to look for myeloma cells at the DNA level. Again, the IMF is working in a collaborative fashion to enable standardization and validation of testing for very low levels of myeloma DNA in bone marrow, blood, and/or tissue samples.
- **PET/CT scanning:** This is necessary and helpful since small deposits of myeloma can occur outside of the bone marrow even when bone marrow testing is negative.

When flow cytometry, DNA testing, and PET/CT scans all indicate no evidence of myeloma, this is MRD-Zero. The BSRI proposes MRD-Zero as a new definition of response beyond traditional CR (complete response).

However, validation is a critical step. If testing is negative (MRD-Zero), does this really predict long survival free of myeloma and, ultimately, a cure? We anticipate confirming this hypothesis as an early step in the BSRI project.

Why is MRD-Zero an important new response endpoint?

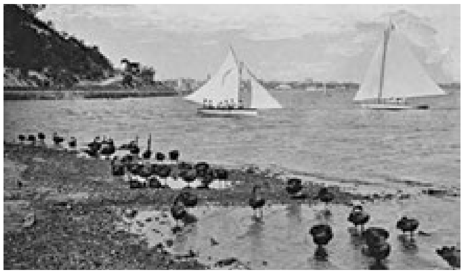
Without MRD-Zero testing, one is really working in the dark. Has the treatment worked well enough? Is there residual disease? Is there possible cure? The ability to test myeloma patients for MRD-Zero is critical in order to develop new and potentially curative therapies.

And this is what the BSRI is all about: developing new curative therapies for myeloma. The BSRI is structured to use MRD-Zero testing in clinical trials designed to achieve cure.

Clearly, the ability to search for a cure in this new precise fashion is a major step forward. In addition, it is hoped that this will lead to a new FDA-accepted endpoint for the assessment of new myeloma therapies. This can lead to much faster and cheaper trial designs.

Instead of having to wait for 5 to 10 years to assess outcomes, imagine knowing after 6 to 12 months if MRD-Zero has been achieved! This is enormously helpful, both in the bigger picture of new drug development and on an individual patient basis. A patient who has achieved MRD-Zero would know that the future is very promising and that further therapy is not required.

Why is it called the "Black Swan" Research Initiative?



There are two reasons for this name. First, after the discovery of black swans in Australia in 1697, explorers realized that the characteristic Northern hemisphere white swan came in an array of shapes, colors, and sizes. A new perspective emerged. This is the essence of the BSRI: Looking at myeloma from a fresh, new perspective to create a plan to cure myeloma.

Second, the 2010 book, *The Black Swan: The Impact of the Highly Improbable*, provides a framework to tackle this ambitious project. Author Nassim Taleb's financial investment theory says that in order to identify rare opportunities, one must cast a wide net to include what are considered "improbable" opportunities or options. In the context of myeloma, this means coming up with a strategy that includes several projects in parallel (simultaneous) with selection of ideas based upon best outcomes – in this case, achieving a cure for myeloma! **MT**

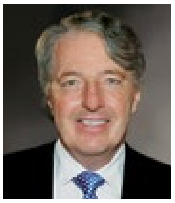
Medical Updates

FDA fast-tracks daratumumab

The U.S. Food and Drug Administration (FDA) has fast-tracked the human CD38 monoclonal antibody daratumumab for myeloma patients who were treated with three previous therapy lines, such as a proteasome inhibitor (PI) and an immunomodulatory drug (IMiD®), or who are double-refractory to a PI and an IMiD. Dr. Torben Plesner of the Vejle Hospital in Denmark discussed data from a Phase I/II study of daratumumab with the IMF in a video interview at the annual meeting of the American Society of Hematology (ASH) in December 2012. To watch this video, please visit myeloma.org.

Dr. Durie featured on BBC radio program

In "Food, Cancer and Well-Being," an in-depth look at the role of diet that aired on BBC Radio on May 19, well-known U.K. food journalist and myeloma patient Sheila Dillon talked to patients, nutritionists, and cancer doctors, including IMF Chairman and Co-Founder, Dr. Brian G.M. Durie. "We need to have good food, an avoidance of bad food, so one can treat the cancer and improve the quality of life," said Dr. Durie. Visit bbc.co.uk to listen to the program and to read Sheila Dillon's accompanying article, "Cancer and diet: Why is nutrition overlooked?"



IMF Responds to Proposed Changes in CMS PET Scan Policy

Advocating for all myeloma patients, Dr. Brian G.M. Durie has submitted a public comment to the Centers for Medicare & Medicaid Services (CMS) regarding a new CMS proposal stating that local Medicare and Medicaid boards would review requests for scans beyond the first covered scan. The IMF played a critical role in establishing the importance of PET scans and securing coverage for myeloma scans in 2009, and continues to advocate for coverage of multiple PET scans as deemed appropriate by a patient's physician.

IMWG member receives ASH grant

Dr. Suzanne Lentzsch, a myeloma researcher at Columbia University Medical Center and member of the IMF's International Myeloma Working Group (IMWG) won a $100,000 research grant from the American Society of Hematology (ASH). After federal budget cuts halted funding for hundreds of research projects, ASH is trying to keep key projects moving forward. A loss of funding would have caused "a big loss in data, knowledge, and potential targets and treatments for myeloma patients," said Dr. Lentzsch, who is studying how certain drugs can stop myeloma growth in mice and later in patients. "Without funding, great research ideas get lost."

New ASCO database

The American Society of Clinical Oncology (ASCO) is creating a new database of information on the treatment of cancer patients typically not studied in clinical trials. The searchable database will include more than 133,000 cases from across the country. Dr. Clifford A. Hudis, ASCO President-Elect, predicts that the ability of ASCO's CancerLinQ™ initiative to collect data and provide feedback will enable the delivery of cutting-edge, state-of-the-art care to patients everywhere. "We're very supportive of this," said IMF Chairman and Co-founder Dr. Brian G.M. Durie. "It's similar to what the International Myeloma Working Group (IMWG) has been doing for over a decade, collecting data from around the world." The IMWG data has resulted in significant myeloma studies published in recent years. **MT**

Staff Updates

Kelly S. Quiggle

Web Master

Kelly S. Quiggle comes to the IMF with more than 10 years of experience in the tech sector. Kelly was the Chief Technologist for a Los Angeles-based web services company specializing in website/social media management, eCommerce solutions, and online business development. Previously, Kelly was a Technical Training Consultant for Apple Computer.

At the IMF, Kelly manages the day-to-day operations of our website, supervises digital media and related content in support of IMF objectives, and administers the sites of more than 100 IMF-affiliated support groups.

Before entering the tech field, Kelly attended undergraduate and graduate school for International Relations at California State University, Northridge, studied International Business and Mandarin Chinese at Tsinghua University in Beijing, and served in the U.S. Army. Kelly has served on the board of directors for the San Fernando Valley Jaycees, LAPD West Valley PALS, and the Mid-Valley YMCA.

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Miko Santos

Web Producer

Miko Santos has more than 15 years' experience working in mass media and news organizations. He started out as a photojournalist for Manila Times and Sun Star covering everything from community events to coups d'état and eventually becoming the New Media Editor for Asian Journal, one of the largest Filipino-American publications in the US. He has also worked as a stringer for Philippine based broadcast networks ABS-CBN and GMA-7.

At the IMF, Miko handles the content creation and maintenance of the IMF and Support Groups website. He is also involved in multimedia production and digital publishing.

A graduate of De La Salle University, he holds a dual degree in Marketing and Behavioral Science and is a candidate for a Masters in Entrepreneurship. Miko is a member of the New America Media (NAM) and the Asian American Journalist Association (AAJA).

No stranger to the cancer cause, he once biked 1,000 miles for three weeks around the Philippines with the Cancer Warriors Foundation to raise awareness and funds for children afflicted with cancer.

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NEW PARADIGMS IN MULTIPLE MYELOMA MANAGEMENT

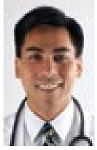
IMF's Nurse Leadership Board presents ONS Satellite Symposium

On April 25, more than 700 nurses attended the IMF's Nurse Leadership Board (NLB) Satellite Symposium at the 38th Annual Congress of the Oncology Nursing Society (ONS) in Washington, DC. The symposium opened with introductory remarks by event chairman Joseph D. Tariman. He introduced the program and shared a brief overview of the learning objectives for the "New Paradigms in Multiple Myeloma Management: Nurse-Centric Case Studies in Patient Survivorship" symposium, a program designed to improve nurse management of multiple myeloma (MM) patients.

Myeloma is a complex disease, and the 2013 NLB Satellite Symposium at ONS focused on the presentation and discussion of four case studies. As a result, participants were prepared to:

- Manage MM patients at different disease stages as illustrated by case studies, latest treatment paradigms, and research;
- Identify patient management and administration considerations for newly approved MM therapies;
- Apply NLB's survivorship care and side effect management tools to build partnerships with MM patients;
- Employ best practices to manage MM patients by educating, inspiring, and empowering nurses to provide optimal care.

Case Study 1: MGUS



Presented by Joseph D. Tariman

The first case study was of a 58-year-old man who had a routine checkup with his primary care physician. Abnormal blood work led to a referral to a hematologist-oncologist. Serum total protein was measured at 9.2 g/dL and M-protein was 1.2 g/dL. Skeletal survey was negative and cytogenetics were normal. Fluorescent in situ hybridization (FISH) assay of genetic markers showed no deletions/translocations.

Joseph Tariman talked about the disease continuum from monoclonal gammopathy of undetermined significance (MGUS) to smoldering multiple myeloma (SMM) to active disease. He also explained the "CRAB" Criteria, a hallmark of active MM. Most patients with MGUS do not progress to MM, with the risk of progression being 1% per year. Screening is recommended every 3 to 6 months during the first year, then at least once every 1 to 2 years. However, not all MGUS is the same. Research is ongoing to define the risk factors that indicate which patients with MGUS are more likely to progress to active MM.

Case Study 2: Newly Diagnosed

Presented by Beth Faiman

The second case study was of a 64-year-old woman. Back and leg pain for several weeks led to self-medicating with NSAIDs, but no improvement. The patient also presented with moderate fatigue. Tests indicated hemoglobin below 9 mg/dL, calcium 13.7 mg/dL, and creatinine 2.1 mg/dL. Beth Faiman talked about the common symptoms at MM diagnosis, some of the risks associated with the disease, and how genetic features of MM indicate risk. Beth also discussed prognostic tools and how risk stratification influences treatment.

Case Study 3: First and Second Relapse

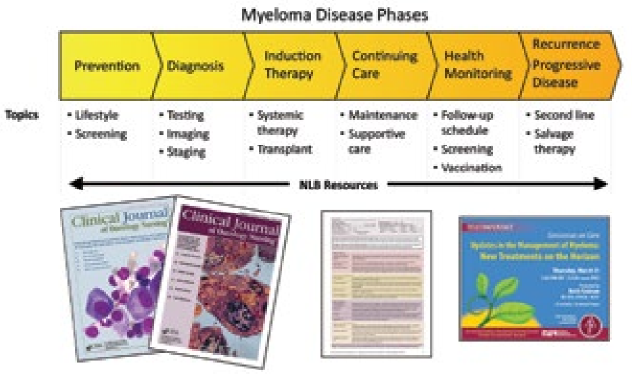
Presented by Sandra Kurtin

Sandy Kurtin talked about the relapsing nature of MM in the context of a case study of a female patient diagnosed seven years ago at age 63 (currently 70) with kappa light chain MM. Skeletal survey at relapse revealed new lytic lesions. Sandy discussed the general goals of MM therapy: rapid and effective control of disease, improving survival and quality of life, and preserving options for future therapy in an era of greatly increased treatment options to manage relapsed disease. Evolving paradigm of combination therapies, maintenance and/or continuous treatment, supportive care, salvage regimens, and secondary malignancies were also addressed.

Case Study 4: Relapsed/Refractory MM

Presented by Charise Gleason

Charise Gleason presented the case of a man diagnosed with active MM at age 37 in 2001. Diagnostic work-up revealed IgG of 6489 mg/dL, extensive bone disease and anemia. The patient has an extensive treatment history. While his disease is currently stable, the discussion included NLB-recommended standard screenings as well as the next treatment option(s) if/when MM progresses. MM is a clonal disease, but clones change over time and after treatment rounds. Effective treatment reduces or eliminates the dominant clone, but other clones can still exist. *(For more on this topic, please see the Hotline column on page 8.)* **MT**



Editor's Note: The NLB is made up of nurses from the leading centers treating myeloma patients in the US. Please visit nlbweb.myeloma.org to view the videos of the case studies presented by the NLB at the 2013 ONS Satellite Symposium, as well as to learn more about other NLB projects, publications, and resources.

WHAT IS “CLONAL EVOLUTION”?

IMF Hotline Coordinators Answer Your Questions

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

What is “clonal evolution”? I have seen this term in the title of many articles and ASH presentations. Can you explain what it is and why it is important in myeloma?

“Clonal evolution” is a term that refers to genetic changes that take place within myeloma cells over time, leading both to mutations in the original clone and to the development of new clones. This topic has been prominent in recent myeloma literature, but is a concept that has actually been around a long time. The first published articles on clonal evolution date to the 1970s and early 1980s, including Dr. Brian Durie’s 1984 editorial in *The British Journal of Hematology* entitled “Is Myeloma Really a Monoclonal Disease?” (BJE, 1984. 57, 357-363) In his editorial, Dr. Durie concludes that “although multiple myeloma appears to arise from an original monoclone or stem cells of restricted clonal specificity, variant new clones evolve resulting in clonal heterogeneity (or polyclonality). Polyclonality is an important feature at the time of clinical disease and must be included in the conceptual approach to both biological studies and development of new therapies.”

Why is clonality an important concept? First, it demonstrates the complexity of the disease and the challenge of treating it. Second, an enhanced understanding of how and why myeloma clones evolve will enable researchers to treat this complex disease more effectively. As the methods for testing myeloma genetics continue to improve, researchers gain a deeper understanding of the biology of this disease and how best to attack it in the clinic.

Cytogenetic and FISH (fluorescent in situ hybridization) studies, whole genome sequencing, and comparative genomic hybridization array have enabled researchers to better characterize the nature of genetic mutations in myeloma clones over time. Hence, the spate of new research on myeloma clonality. In a 2012 *Blood* journal editorial, Dr. Nizar Bahlis of Southern Alberta Cancer Research Institute wrote a lengthy introduction to the three articles in that issue (*Blood* August 2, 2012 vol. 120 no. 5) on the topic of clonal evolution in myeloma:

- Keats *et al.*, Clonal competition with alternating dominance in multiple myeloma;
- Egan *et al.*, Whole-genome sequencing of multiple myeloma from diagnosis to plasma cell leukemia reveals genomic initiating events, evolution, and clonal tides; and
- Walker *et al.*, Intraclonal heterogeneity and distinct molecular mechanisms characterize the development of t(4;14) and t(11;14) myeloma.

Myeloma evolves both spontaneously over time and in response to treatment. For an oncologist treating patients, myeloma is a wily adversary – a moving target. Keats and fellow researchers at the Mayo Clinic (Scottsdale, AZ) used serial genomic analysis to follow 28 patients through their disease course, and analyzed data from one high-risk patient sampled at 7 points. They found that the poor prognosis of high-risk patients is at least partially related to the increased clonal heterogeneity and genomic instability of their myeloma. This careful analysis overturns the older dogma that myeloma cells evolve in a linear fashion. Now we know that their evolution branches and shifts over time. Dr. Bahlis concludes that the presence of clonal heterogeneity at diagnosis argues in favor of “combination rather than single-agent sequential therapies with the goal to eradicate dominant as well as minor clones that often emerge at relapse,” and “in particular, to use this approach for high-risk myeloma where a clonal diversity is found to be more prevalent compared with low-risk disease.”

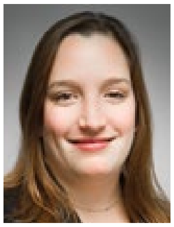
Dr. Bahlis raises other important questions that make us rethink treatment approaches:

- Is it naïve to treat a clonally diverse disease with a highly targeted therapy?
- Do alkylating agents (the class of drugs to which melphalan, cyclophosphamide, and bendamustine belong), which work by damaging DNA, pose a risk particularly to high-risk patients whose myeloma is already prone to clonal divergence?
- If myeloma clones change over time, isn’t it possible and potentially useful to reintroduce therapies to which a patient has become refractory earlier in the disease course?

The answers to these and other questions are now within reach as we more deeply explore and understand the nature of clonal evolution in myeloma. The current studies and concepts of clonal evolution provide the backdrop for the IMF’s new Black Swan Research Initiative™ (BSRI). This initiative is focused upon establishing the presence or absence of residual disease after a particular therapy (minimal residual disease: MRD), then directing therapy based upon the findings to achieve MRD-Zero™ (no residual disease with very sensitive testing), and then validating that this indeed correlates with achieving cure for subsets of patients with myeloma. **MT**

Editor’s Note: We encourage you to visit **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 Debbie Birns, Paul Hewitt, Missy Klepetar, and Judy Webb. The phone lines are open Monday through Friday, 9 a.m. to 4 p.m. (Pacific). To submit your question online, please email hotline@myeloma.org.

SPOTLIGHT ON ADVOCACY



IMF holds Capitol Hill briefing on health disparities in cancer

by Johanna Gray
Federal Government Affairs Consultant

On April 11, 2013, the International Myeloma Foundation (IMF) held a briefing to discuss health disparities in cancer on Capitol Hill. Disparities persist in multiple myeloma (MM), which affects African Americans approximately twice as often as Caucasians and Hispanics. Additionally, African Americans are more likely to die from MM, even when controlling for factors such as distance from treatment centers. In a packed room of Congressional staff and colleagues from other cancer organizations, participants heard from expert speakers on the challenges of reducing and eliminating cancer health disparities for patients with MM.

Meghan Buzby

Meghan Buzby (Director of U.S. Advocacy, IMF) welcomed the participants at the briefing with opening remarks. Then, Dr. Brendan Weiss (Assistant Professor of Medicine, University of Pennsylvania), provided background information on MM and discussed current research into why disparities may exist for patients. He discussed research addressing whether individuals of different races respond differently to stem cell transplants and whether there may be differences in tumor biology. Dr. Weiss emphasized the need for more research to determine why disparities exist and how they can be minimized.

Dr. Brendan Weiss

Dr. Craig Cole

Next, Dr. Craig Cole (Gunderson Lutheran Health System) discussed community-based approaches for treating MM. He emphasized the importance of clinical trials that give patients access to the most cutting edge treatments; he hypothesized that African Americans may be less likely to know about clinical trial opportunities. Dr. Cole discussed the need for programs to educate the African American community about the risks for developing MM and the benefit of clinical trials, and he highlighted several examples of successful education programs.

Dr. Nelson Aguila

Dr. Nelson Aguila (Program Director, Diversity Training Branch, National Cancer Institute Center for Reducing Cancer Health Disparities) focused on current National Institutes of Health (NIH) initiatives related to cancer disparities. The National Cancer Institute (NCI) has several programs related to research, training, and workforce diversity and initiatives to engage communities and researchers. Dr. Aguila cited three researchers in MM whose projects are supported by NCI and seek to discover new insights regarding MM and disparities.

Finally, briefing attendees heard from two patients with MM, Geri Smith-Benjamin and Kateria McCullough Reddick. Each shared an inspiring personal story of being diagnosed with and receiving treatment for MM, and the roadblocks faced along the way. They illustrated the challenges and opportunities discussed by other speakers, including a lengthy time between the onset of symptoms and diagnosis, and the benefits of enrolling in a clinical trial. Their moving accounts provided two critical examples of what it's like to live with MM.

Geri Smith-Benjamin, Meghan Buzby, and Kateria McCullough Reddick

The IMF would like to thank Onyx Pharmaceuticals Inc. for providing us with an educational grant for this important briefing.

The Introduction of the Cancer Drug Coverage Parity Act

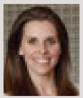
The IMF is very pleased to report that on April 26, 2013, Congressman Brian Higgins (D-NY) introduced H.R.1801, The Cancer Drug Coverage Parity Act. This bipartisan legislation has 15 original co-sponsors thanks to the wonderful advocacy efforts of the members of the Patients Equal Access Coalition (PEAC), which is led by the IMF. The Cancer Drug Coverage Parity Act requires private health insurance plans that provide coverage for chemotherapy to cover patient-administered anticancer medication (such as oral pills) at a cost no less favorable than the cost of physician-administered anticancer medications (such as intravenous medications). This law applies to health plans that already cover chemotherapy and ensures equal access and insurance coverage for all anticancer regimens. The IMF believes that every cancer patient should have access to the treatment recommended by their physician, and should not face cost discrimination based on the way the medication is administered. Through PEAC, the IMF will continue to solicit co-sponsors for H.R.1801 and is working with Senate staff to have companion legislation introduced in the Senate later this year. The introduction of the legislation in the House is the first milestone in this process and we hope that Congress will act quickly. **MT**

The IMF Advocacy Voice:

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

H.R.1801, the Cancer Drug Coverage Parity Act of 2013, already has 30 co-sponsors. Find out if your Congressman is a sponsor. If not, ask him/her to sign on at **advocacy.myeloma.org**!

How to contact the IMF Advocacy Team



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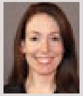

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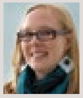

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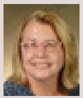

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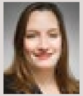

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2013 MYELOMA AWARENESS MONTH MAKES HISTORY

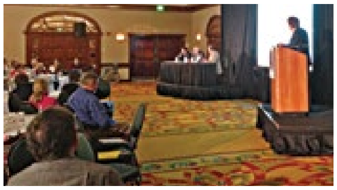
A report from Robin Tuohy (Senior Director, Support Groups) and Aimee Martin (Grassroots Liaison)

Robin Tuohy

Aimee Martin

Multiple myeloma (MM) is the second most common blood cancer in the world, yet there are still many people who hear the word *myeloma* and think, “Isn’t that a skin cancer?” In the US, there are approximately 100,000 patients living with MM, and nearly 20,000 new cases diagnosed each year. MM is increasing in numbers and is becoming more common in younger patients. The majority of patients have never heard of MM before their diagnosis. The need to raise awareness for this often-misdiagnosed disease led the International Myeloma Foundation (IMF) in 2006 to establish March as “Myeloma Awareness Month” (MAM).

In 2013, throughout the month of March, the annual MAM effort was made even more special with the help of hundreds of advocates who spread awareness about MM in their communities. The outreach touched thousands of people, encouraging new advocates to raise their voices, start support groups, and show all MM patients and their loved ones that people care about them. MAM has grown from year to year, thanks to many dedicated volunteers, and 2013 has been our most successful MAM to date.



The kickoff for MAM 2013 took place at the IMF’s Patient & Family Seminar in Boca Raton, Florida. More than 300 people attended in person, plus the live-stream webcast had 400 people joining us from around the world.

During the month of March, the IMF’s *Living Well with Myeloma* teleconference series featured two important topics: “What’s NEW with Novel Therapies” and “How to Prevent Infection in Myeloma Patients.” More than 800 people participated in the live calls, plus hundreds more have listened to the replay online at replay.myeloma.org.

Thanks to outreach by advocates, hundreds of MM patients shared their experiences with the general public, neighbors and friends, on Facebook, with local mayors and county council members, and with reporters from various media outlets.

MAM’s “Tell One Person” campaign, which was initiated in 2011, proved successful once again with countless people who have not been directly touched by MM learning about this disease. This year, IMF supporters wore Myeloma Awareness Month pins to help start conversations about MM. As a result, countless people found out about this disease.

MM patients around the country reached out to their local governments to have March officially declared “Myeloma Awareness Month.” Four states – Delaware, Michigan, Tennessee, and Washington – as well as many cities and counties have cumulatively issued more than 60 “Myeloma Awareness Month” proclamations. Across the country, local officials expressed their support of myeloma patients and the need for a cure.

Josephine Diagonale, leader of the Delmarva MM Support & Networking Group, attends the signing of the MAM 2013 proclamation by Delaware Governor Jack Markell

Bill Bennett and Linda Huguelet at the Hamilton County council meeting

Linda Huguelet, leader for the Chattanooga Tennessee MM Support Group, was featured in three local newspapers and was interviewed about MM on TV and radio. “I appreciate the County Commission’s help in raising awareness of myeloma,” said Linda. “Increased awareness helps patients get diagnosed and treated more quickly. Early diagnosis can lengthen survival and reduce the effects of this disease.”

Hal Anderson accepts the MAM 2013 proclamation at the Michigan State House of Representatives

Hal Anderson’s story was on the front page of the local paper after the Michigan State House of Representatives issued a proclamation based on his request. The following day, Hal received a call from an 85-year-old woman who had never talked to anyone else who had MM. Hal has arranged to bring her to the next support group meeting he attends so she can connect with even more MM patients.

Tanjua Brown and supporters of the “Stomping Out Myeloma!” walk

When Tanjua Brown learned that her town had no plans to mark MAM, she created her own event with support from friends and family. More than 100 people participated in the “Stomping Out Myeloma!” walk in Ocala, Florida. Tanjua invited doctors and nurses to speak about MM at the event and answer questions from the public. She is now organizing a new MM support group for the Ocala area!

Mayor Earnestine D. Pittman with Gail McCray, Alma Robinson, and Doris Morgan

In Georgia, Southside Atlanta Support Group leaders Gail McCray, Doris Morgan, and Alma Robinson attended the East Point City Council meeting where Mayor Earnestine D. Pittman presented them with the MAM proclamation and invited the group to be featured in the annual East Point Health Fair.

Carolyn Higgins with Mayor Mike Davis

In Dunwoody, when Carolyn Higgins asked Mayor Mike Davis to issue a MAM proclamation, she learned that he lost his grandmother to myeloma in 1975 soon after diagnosis. Laura Mooney of Staten Island, New York, had a similar experience when the borough press secretary who issued the MAM proclamation called to share that a close friend had started MM treatment that week.

Bryan Gearry asked Mayor Verne Rupright of Wasilla, Alaska, to proclaim MAM in honor of former Mayor Curt Menard, who passed away from myeloma in 2009, three years into his term as mayor. Curt Menard was diagnosed in 2003 when he was a state senator, but myeloma did not stop him from winning his mayoral seat in 2006.

Bryan Gearry with Linda Menard and Mayor Verne Rupright

Tim Gavallas with Town Manager Chuck Frigon and Town Council Chairman Ray Primini

Newly diagnosed in February 2013, Tim Gavallas of Watertown, Connecticut, contacted a friend on the town council to ask for support. "At the city council meeting," said Tim, "Council chairman Ray Primini, who I have known for 18 years, choked up reading aloud about my battle with myeloma." Tim's story was later published in the *Town Times*.

Mooresville Mayor Pro Tem Mac Herring presents the MAM 2013 proclamation to Van Herring

Brenda Stubbs called upon her son-in-law, Mayor Pro Tem in Mooresville, North Carolina, to issue a proclamation. Brenda's grandson Van Herring accepted it on her behalf at the Mooresville Town Council meeting.

In Wisconsin, Mary Polancih addressed the Madison City Council. "If you have never heard of myeloma before tonight, this proclamation is doing what we intended," she said. A few days later, Mary was approached by a man who recognized her after watching the TV broadcast of the council meeting. "He said that's how he learned about MM. Like stones dropped into a lake, the ripples go out in all directions farther than we can cast."

Members of the Kansas City Metro support group

In Kansas, members of the Kansas City Metro support group, including leaders Cindy Ralston and John Killip, secured seven MAM 2013 proclamations. Jerry Walton, leader of the support group that serves Southeastern Virginia as well as parts of North Carolina, led his team to nine area proclamations and articles in three local papers!

Members of the Southeastern Virginia ("SEVA") MM Support Group with proclamations from nine Hampton Roads cities

All the MAM proclamations, newspaper articles, and TV or radio segments helped raise myeloma awareness. These amazing accomplishments would not have been possible without each and every person who raised a voice of support for the myeloma community. You are our heroes. Together, we know we can go even farther and do even more next year! **MT**

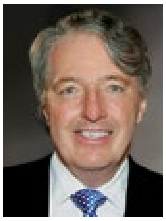
Members of the Connecticut MM Fighters Information Group display MAM 2013 proclamations from Naugatuck, Prospect, and Watertown

Malcolm Katz, leader of the San Fernando Valley MM Support Group, proudly displays the proclamation from the City of Los Angeles

Members of the Charlotte Area MM Support Group celebrate Myeloma Awareness Month

Editor's Note: To participate in the 2014 Myeloma Awareness Month, please contact Robin Tuohy (Senior Director, Support Groups) at rtuohy@myeloma.org or Aimee Martin (Grassroots Liaison) at amartin@myeloma.org.

UPDATES FROM AROUND THE GLOBE



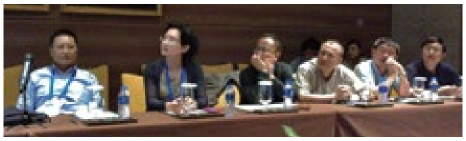
IMF in China

by Brian G.M. Durie, MD
IMF Chairman and Co-Founder

The IMF Asia Team (myself; IMF President and Co-Founder Susie Novis; Lisa Paik, Senior Vice President, Clinical Education & Research Initiatives; and Dan Navid, Vice President, Global Affairs) recently conducted a series of events and meetings to further enhance and extend our educational and research goals in China.

We began in Shanghai as guests at a wonderful dinner hosted by Prof. Jian Hou along with Dr. Juan Du and Dr. Jianling Fan (recent participant of the IMF's Chinese Master Class) – all from the Changzhen Hospital – and the Shanghai Myeloma Center Team, also recipients of a 2012 research grant award. This center was really where myeloma diagnosis, treatment and research began in China with establishment of a laboratory for myeloma-protein testing – the essential first step in diagnosis.

We discussed ongoing projects and the potential for further collaboration. Exhausted, having just arrived in Shanghai, we had an early night before what turned out to be an adventurous trip south to Guangzhou. You may not have heard of Guangzhou, but it is a huge city in southeast China – a bustling manufacturing and financial hub with a population of 13 million. The Pearl River Delta mega-city area, which includes Guangzhou, has a population of approximately 40 million, and encompasses Shenzhen, Dongguan, Foshan, Jiangmen and Zhongshan.

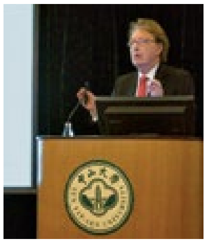


The Guangzhou International Multiple Myeloma Conference meetings were held at a new type of Chinese resort about two hours outside the city—a huge Sheraton Hotel built around a simulated Indian lake that included a floating island in the middle and villas all around. The first IMF meeting was with the Chinese Myeloma Working Group (CMWG), which is part of the International Myeloma Working Group (IMWG) and comprises the top Chinese myeloma experts brought together by the IMF with a focus on the coordination of myeloma care and research in China.

We heard summary presentations of key study results from Shanghai, Beijing, and Guangzhou. It was very impressive to see all the ongoing activities, including analyses of patterns of myeloma in Beijing. Key features included a median patient age of 59 years (younger than in the West), plus more frequent Immunoglobulin D (IgD) myeloma and high-risk disease with 17P- (P53 deletion) findings. Despite that, outcomes are good, with median survivals of four years across the board. Important molecular and clinical trial research is going on in Shanghai. Special analyses of results with upfront versus delayed ASCT were presented from Guangzhou.

The broader focus was on new research and trial collaborations, including AMN trials incorporating both Kyprolis® (carfilzomib) and Pomalyst® (pomalidomide), which would allow the first introduction of these agents into China. The IMF also hopes to begin a trial with SQ Velcade® (bortezomib), which is not yet feasible in China. It is hoped that the Freelite® test will be approved China within the next few months, and there was a lot of excitement among the doctors about the potential to soon have new access to this test for both diagnostic and response assessment. This meeting was followed by a reception during which the IMF was presented with special lucky dragons as a token of appreciation.

The 3rd Annual Chinese National Myeloma Meeting was jointly hosted by the CMWG and IMF. There has been great interest about the IMF's 10 Steps to Better Care®, so I presented an overview to kick off the morning session. This was followed by an overview of Freelite, then two presentations by Dr. Andrew Spencer, an IMWG member from Melbourne, Australia, who presented the whole range of current approaches to myeloma therapy, including detailed case discussions. There was a comprehensive review of myeloma therapy in China from the Chinese experts – predominantly members of the CMWG.



To conduct a Patient Seminar, the IMF joined with the myeloma team at Sun Yat-sen College of Medical Science in Guangzhou. The local host was Prof. Juan Li, along with her colleague Dr. Jingli Gu. Susie Novis presented background details about the IMF and supportive care perspectives, which were greatly appreciated. This was followed by Prof. Wen-Ming Chen from Beijing, who gave an overview about care in China.

Then I presented the approaches to myeloma treatment in the U.S. in 2013. A key element was the basic IMF approach – "Knowledge Is Power" – giving myeloma patients the tools they need to get the best care. I summarized everything from basic testing to recommended treatment options. Then the Sun Yat-sen team presented local approaches and results. This was followed by an extended Q&A session, with patients standing up to present their individual cases and concerns. Dr. Andrew Spencer helped handle the questions, which was much appreciated.

This was especially helpful since there were a whole series of questions about thalidomide maintenance, an area of research for Dr. Spencer.

At a wonderful Chinese lunch that followed, we had a chance to further discuss especially difficult patient problems. Our time in China came to a close with plans to establish further ongoing collaborations. There are great challenges – but there is great potential to improve outcomes for myeloma patients wherever they live!

AMN Meeting in Japan

by Dan Navid
IMF Vice President, Global Affairs

The International Myeloma Foundation (IMF) Asian Myeloma Network (AMN), comprising leading myeloma experts from the Asian region, held its annual meeting on April 3, 2013. This gathering took place in advance of the XIVth International Myeloma Workshop in Kyoto, Japan.

The IMF established the AMN in March 2011 and it remains the only organization of its kind in the region. Composed of myeloma experts from seven territories in Asia – China, Chinese Taipei, Hong Kong, Japan, Korea, Singapore, and Thailand – the initial focus of the network was the development of a unified data base to assess the incidence of myeloma in Asian countries as a key step in the designing of region-specific treatment management tools and strategies.

The AMN discussions in Kyoto were concentrated on three main topics:

- Further steps for the IMF Asian Myeloma Data Study,
- Proposals and procedures for IMF Asian clinical trials, and
- AMN cooperation in the development of Asian treatment guidelines.

The IMF Asian Myeloma Data Base project now includes data from all seven AMN countries and regions. More than 3,600 records have been compiled. AMN poster presentations on the project have been accepted at both the 2013 American Society of Clinical Oncology (ASCO) and 2013 European Hematology Association (EHA) annual conferences.

CONTINUES ON PAGE 19

PEOPLE HELPING PEOPLE

You are never alone in your battle against myeloma

by Robin Tuohy
Senior Director, Support Groups
rtuohy@myeloma.org

The IMF is often asked by patients if we know of support groups in their areas where they can meet others diagnosed with multiple myeloma (MM). There is a worldwide network of more than 200 MM support groups that hold regular meetings for members of the myeloma community, and we encourage you to seek them out.

In the United States, there are more than 140 MM support groups, and more groups are forming every year. Although the IMF does not sponsor these groups, we support their efforts and conduct annual summits for myeloma support group leaders. The members of the IMF's Support Group Team also crisscross the country visiting groups in person.

With so many groups either newly formed or in the process of organizing their first meetings, 2013 has truly become "The Year of the MM Support Groups!" The IMF has a program in place to assist in starting, maintaining, and sustaining MM support groups. If you are looking for a support group in your area, please visit the IMF website myeloma.org. If you wish to start a new group, please contact me at rtuohy@myeloma.org or 203-206-3536.

Since the beginning of this year, 15 newly active MM support groups held their inaugural gatherings, plus seven more groups are in the process of organizing their first meetings. In total, that's 22 new groups in 2013 – a record year!

Alabama

Mayor Gary Ivey presents MAM 2013 proclamation to Eric Huckabee

Birmingham – The Central Alabama MM Support Group meets on the first Saturday of each month from 11 a.m. to 1 p.m. at the Green Valley Baptist Church, 1815 Patton Chapel Road, Hoover, AL 35226. Refreshments are provided. For more information, contact Eric Huckabee at erichuck@bellsouth.net or 205-370-4696. Eric, who was diagnosed with MM in 2008, founded the group in January 2013. In addition to helping the new support group to grow and flourish, Eric was successful in having the mayor of Hoover declare March 2013 as Myeloma Awareness Month.

California

Pasadena – The Pasadena/San Gabriel Valley MM Support Group held its inaugural meeting in April 2013. This group meets on the first Monday of each month from 7 to 8:30 p.m. at Pasadena Public Library, Donald R. Wright Auditorium, 285 E. Walnut Street, Pasadena, CA 91101. For more information, contact Anthony Siebert at 951-233-2394, or Kelly Cox at kcox@myeloma.org or 818 487-7455.

Georgia

Rome – The Coosa Valley MM Support Group, founded in February 2013, meets on the second Tuesday of each month at the Cornerstone Church, Equip Building (South Entrance), 324 Mathis Drive NW, Rome, GA 30165. Free parking is provided in designated areas on the Cornerstone Church Campus. For more information, contact Melba Trapp at melbatrapp@yahoo.com or 706-766-4418, or via the website coosavalley.myeloma.org. Diagnosed with smoldering MM in August 2012, Melba attended the IMF workshop in Atlanta, as well as the Atlanta MM Support Group, and decided to start the Rome group when she discovered that there were other MM patients in her local area.

Florida

Hollywood – The Hollywood MM Support Group, founded in February 2013, meets on the first Tuesday of each month from 6 to 8 p.m. at the office of Dr. Ney Alves, Oncology Hematology Clinic (BB&T Building), 3850 Hollywood Blvd #1B, Hollywood, FL 33021. For more information, contact Tom and Ronnie Maynard at myelomabroward@yahoo.com or 954-971-5549 or Jeanine Mielke at jeanine@adoncology.com or 954-251-8862.

Panama City – The Florida Panhandle MM Support Group, founded in January 2013, meets on the first Saturday of each month at 10 a.m. at the Learning Center of the Diagnostic Building behind the Gulf Coast Medical Hospital, 2024 State Avenue, Panama City, FL 32405. For more information, contact Sarah Davis at scdlight@gmail.com or 850-774-4671. This is the first group in the Florida Panhandle!

Tallahassee – The Tallahassee MM Support group held its inaugural meeting on May 22, 2013. This group meets on the fourth Wednesday of each month from 5:30 to 7:30 p.m. at Westminster Oaks Campus (Pool Clubhouse), 4449 Meandering Way, Tallahassee, FL 32308. For more information, contact Hadley Hasemeier at hadleyhh@comcast.net or 850-668-0691.

Minnesota

Fairmont – The Fairmont Area MM Support Group held its inaugural meeting in April 2013. Meetings are held the fourth Saturday of every other month from 10 a.m. to 12 p.m. at Mayo Clinic Health Systems, 800 Clinic Circle Drive, Fairmont, MN. For more information, contact Joyce Schultz at jsoband@frontiernet.net or 507-230-0207.

New York

Brooklyn – The Brooklyn MM Networking Group held its inaugural meeting in May 2013. This group meets the third Thursday of each month from 6:30 to 8 p.m. at Maimonides Cancer Center, 6300 8th Avenue, Brooklyn, NY 11220. For more information, contact Stanley Wagner at stan@stanwagner.net or 917-804-1050.

Charlie and Laura Mooney

Staten Island – The Staten Island MM Support Group, founded in January 2013, meets on the second Wednesday of each month from 7 to 9 p.m. at the Hampton Inn, 1120 South Avenue, Staten Island, NY 10314. For more information, contact Laura and Charlie Mooney at simyeloma@gmail.com or 718-390-7008 or 718-524-6970. Shortly after Laura initially contacted the IMF about starting a local MM support group, Hurricane Sandy devastated the area. When Laura and Charlie finally hosted the group's first meeting, more than 30 people attended, and the group quickly outgrew its original meeting facility. That same month, the group was successful in receiving a proclamation declaring March as Myeloma Awareness Month.

North Dakota

Bismarck – The Bismarck MM Support Group held its inaugural meeting on June 18, 2013. This group meets the third Tuesday of each month from 6:30 to 8:30 p.m. at the Bismarck Public Library, 515 N. 5th Street, Lower Level Meeting Room C. For more information, contact Shirley Jonas at ndmm@bis.midco.net or 701-258-4690.

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Education & Awareness

SUPPORT GROUPS — continued from page 13

South Carolina

Florence – The Florence MM Support Group, founded in March 2013, meets on the third Tuesday of each month from 6 to 7:30 p.m. in Room 213 of the Frank Lee Nursing Building, Francis Marion University, on Patriot Drive. For more information, contact Jim Byrd at jamescarterbyrd@bellsouth.net or 843-230-9247.

Rock Hill – The Rock Hill MM Support Group, founded in February 2013, meets on the second Saturday of each month at the Catawba Baptist Church 1450 South Anderson Road, Rock Hill SC 29730. For more information, contact Steve Nunn at jsnunn@comporium.net or 803-412-2266.

Tennessee

Memphis – The Memphis MM Support Group had its inaugural meeting on May 21, 2013. This group meets the third Tuesday of each month from 5:30 to 7 p.m. at Shoemaker Financial, 2176 West Street #110, Germantown, TN 38138. For more information, contact Jim Shoemaker at jshoemaker@shoemakerfinancial.com or at 901-757-5757. While Jim's myeloma has been in remission for five years, he feels it is important for all patients to keep up-to-date on the latest MM advances and treatment options.

Vermont

Bennington – The MM Networking Group of SW Vermont Region had its inaugural meeting on June 18, 2013. This group meets the third Tuesday of each month from 6 to 8 p.m. at the First Baptist Church, 601 Main Street, Bennington, VT 05201. For more information, contact Jan Martin Bopp at swvt@imfsupport.org or 802-681-7074. This tri-state area group welcomes participants from Vermont, New York, and Massachusetts.

Virginia

Charlottesville – The Charlottesville MM Support Group, founded in January 2013, meets on the second Tuesday of each month from 5:30 to 7:00 p.m. in conference room 3303 at The Emily Couric Cancer Center, 1240 Lee Street, Charlottesville, VA 22901. Free parking is provided. For more information, contact Annemarie Clemente, LCSW, at ac6f@virginia.edu or 434-924-2717.

New groups

More groups are being formed in California, Florida, and Iowa. If you would like to get involved, please contact the IMF for more information.

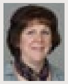
California: Sacramento.
Florida: Ocala, Palm Coast, Tampa, The Villages, and West Palm Beach.
Iowa: Cedar Rapids. **MT**

How to contact the IMF Support Group Team

Robin Tuohy – Senior Director of Support Groups
tel: 203-206-3536 *email:* rtuohy@myeloma.org

Kelly Cox – Director of Support Groups & Community Workshops
tel: 800-452-CURE (2873) *email:* kcox@myeloma.org

Nancy Bruno – SE Regional Director Support Groups
tel: 404-374-9020 *email:* nbruno@myeloma.org



Sue Enright – MW Regional Director Support Groups
tel: 262-903-7911 *email:* senright@myeloma.org

Anne Pacowta – Florida Regional Director Support Groups
tel: 203-233-5813 *email:* apacowta@myeloma.org

Letters to the IMF

To Judy Webb:

Thank you very much, Judy! Thanks to you, we had an excellent talk with Dr. Brian Durie at the recent IMF Patient & Family Seminar in San Francisco. He explained Daniel's status to us very well and made some recommendations that reassured us about the best treatment plan.

We really, really appreciated your assistance. In fact, everybody we met was very nice and supportive, including all the doctors that spoke at the conference, which was amazing.

Thank you very much again, and we will continue to get more information from your website to keep us informed.

– Erika & Daniel Niederer

To Paul Hewitt:

Many thanks for the assistance. You provided just the kind of thing I was looking for. I have used the IMF Hotline several times in the past, and you have all been excellent.

– Larry Molumby

To Aimee Martin:

I attended the recent IMF Regional Community Workshop in Milwaukee and thought the meeting was excellent. I learned a lot and thoroughly appreciated the laughter infused throughout the event.

It was so good to meet you and get to know you better. I admire your energy and enthusiasm for patient advocacy, and I look forward to working with you on lots of projects in the future.

The IMF seems to be filled with positive energy. For this I am very grateful.

– Mary Polancih

To Missy Klepetar:

Thanks again for all the information and recommendations you gave me when I stopped by the IMF office recently. I did attend my first myeloma support group meeting where my husband Paul and I met many wonderful people who have been fighting this disease. Thank you for encouraging me to join a support group and to network with other patients.

– Irene Jeannides

To Debbie Birns:

We cannot thank you enough for your kindness at the IMF Patient & Family Seminar in Boca Raton. You were an inspiration to us. We appreciate all the help you have provided over the years as well.

– Joanne & Fred Lourenso

To Mike Katz:

Thanks very much for all your positive stories shared at the IMF Patient & Family Seminar in Boca Raton. While each of us is handling myeloma in our own way, all patients and caregivers need to know that we are not alone. Your presentation was very moving, enjoyable, and encouraging.

To Suzanne Battaglia:

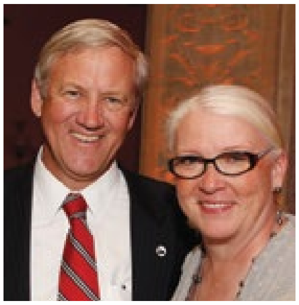
You're so good at making people feel better – you know just what to say and how to say it. Special thanks for all your thoughtfulness at the IMF Patient & Family Seminar in Boca Raton. And your follow-up call checking in on my health was very much appreciated!

– Joyce Dean

Investing in the Future

JOHN & DOROTHY O'DWYER, FOUNDING DONORS FOR THE BLACK SWAN RESEARCH INITIATIVE™

"Investing in the Future" features profiles of IMF members who are making substantial investments in the myeloma community and the path to a cure. We hope that the stories of how and why these individuals have chosen to commit so significantly to the fight against myeloma will inspire you, as they inspire us.



by John O'Dwyer
Member of the IMF Board of Directors and Chairman of the BSRI campaign

Whenever I thought about myeloma research, I always said "give me the best idea you have, and I'll help fund it." The right idea came along in March 2013, and so I made a commitment of $500,000 to the IMF for the Black Swan Research Initiative™ (BSRI™).

I was diagnosed with cancer in June of 2007, while living and working in Shanghai, China, with my wife, Dorothy. Doctors had seen the malignancy throughout my body, had assumed it was advanced, and could offer few treatment options. The day after that diagnosis we left our life and our belongings in Shanghai and came back to Texas. I went directly to a hospital. In fact, an ambulance met me at the airport to take me to the hospital. I was diagnosed with multiple myeloma shortly thereafter. The widespread malignancy seen in Shanghai was the effect the myeloma already had on my bones.

Upon learning the diagnosis, Dorothy and I started doing our homework. We researched myeloma and came across the International Myeloma Foundation (IMF) pretty quickly. I reached out to the IMF, on the phone, and I was invited to attend a few activities: a Patient & Family Seminar and the Founder's Circle Summit. Our relationship with the IMF grew over time; we considered it a large, credible organization that could give us unique access to education and experts in the field of myeloma.

When I was diagnosed, the available data from 2006 indicated that life expectancy of a myeloma patient was around three years. I appreciated education about myeloma from the IMF, but what I *really* wanted, and what I wanted to fund, was research toward a cure. I wanted first and foremost to stay alive. When Bank on a Cure®, an initiative to fund treatment research through the IMF, was launched, I started donating to the IMF. I became a member of the IMF Board of Directors in 2009. My whole focus since becoming a board member has been on a cure for myeloma.

This focus has led us to this moment – to the beginning of the IMF's Black Swan Research Initiative. In late 2012, the IMF asked several key experts in the field of myeloma research to come up with the path toward a cure. This path consists of sensitive and specific diagnostics for myeloma, allowing physicians to identify the disease at a very early stage, coupled with tailored, powerful, early treatment.

The strategy is that early diagnostic information and equally early treatment can be effective in creating a longer life expectancy and higher quality of life – and potentially curing this deadly disease we call myeloma. Through the Black Swan Research Initiative, we can make testing for myeloma a part of routine blood work. We can stop myeloma before it begins to damage bones. The Black Swan Research Initiative team has already started work on creating sensitive and specific diagnostics and hopes to launch a clinical trial as early as before the end of this year.

I stepped in as chair of the Black Swan Research Initiative campaign and have been helping to locate donor support and boost this important area of research. It's been interesting working on this initiative so closely and incredibly gratifying working with seasoned and dedicated experts in the field of myeloma in a grassroots way.

My hope for this initiative is to bring us to a cure for myeloma. The current expectation is that myeloma patients will live on average more than 7.5 years, and that younger patients undergoing autologous transplant will live longer than 12-15 years. I'm six years post-diagnosis and I enjoy my life. I have a loving family; a wife, four children, eight grandchildren. **I do not want to lose my life to this disease.**

For years, the IMF and other organizations have been adding to a body of knowledge about myeloma through various research projects. All of this research has been important – it has educated us and informed treatment practices. I feel, however, most excited about the Black Swan Research Initiative in particular because **this is the best chance that I have seen so far to ensure a longer life for myeloma patients.**

Given the relative small size of the myeloma community, each of us must play a part in seeking a cure. With myeloma, you realize that the disease doesn't just affect you as a patient. It can be something that your loved ones and future generations have to face also. I would ask each of you to consider financially supporting the Black Swan Research Initiative with the goal of finding the cure each one of us hopes for. **MT**

The Hope Society

Cultivating the future
by planting the seeds
to sustain the IMF

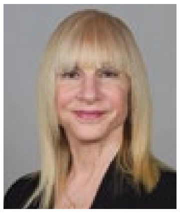
Proof that Every Dollar Counts

Since its launch in 2010, the Hope Society has attracted 102 members who make monthly or quarterly contributions that help fund many of the programs and services provided by the IMF on a daily basis. Currently, Hope Society donors range from those who give $5 per month to those who give $250 four times a year. Collectively, Hope Society donors have given more than $10,000 – proving that even a little bit can go a long way!

For 22 years, the IMF has been the center of education and support for myeloma patients and family members who rely on our services. In a similar way, the IMF depends on its donors to help continue and improve upon those services.

To join The Hope Society simply call the IMF Development department at 800-452-CURE (2873) or email Randi Lovett at rlovett@myeloma.org.

IMFers RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY



By Suzanne Battaglia

*IMF members are raising funds to support essential multiple myeloma research while also raising awareness. Fundraisers as diverse as garage and bake sales, community walks and marathons, parties and entertainment events, sports tournaments, and countless other fundraisers are taking place across the country. Most of these activities start with a call to the IMF and one simple question – "What can **I do**?" Those who became 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.

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

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

Here are some examples of events…

The IMF Plays at Ladies Game Day

Carol & Benson Klein

Myeloma likely entered the lives of Carol and Benson Klein in the early 1990s, but it was not until April of 1998 that Benson was diagnosed. The Kleins have always had a very positive outlook, and cancer did not change that. They quickly found the IMF on the Internet and Benson soon joined the IMF Board of Directors while Carol focused her efforts on finding creative ways to raise funds for myeloma research.

The Kleins' first fundraising project was associated with the comic strip "Crock" by Bill Rechin and Don Wilder, which would occasionally feature a character named Trooper Benson. Many fundraisers followed, including writing campaigns and an annual "Afternoon Tea" that informed and educated hundreds of people about myeloma. In 2002, The Kleins co-chaired the IMF's annual Gala. They celebrated Benson's 60th birthday with a big party and asked guests to make donations to the IMF in lieu of gifts. Over the years, their work on behalf of the IMF has funded several myeloma research grants in Benson's honor.

This year's 4th Annual Ladies Game Day was another example of an outstanding fundraiser. Spearheaded by Carol Klein and Anne Girod, the event was held on May 8th in Rockville, Maryland. The IMF's own Meghan Buzby, Director of U.S. Advocacy, was one of more than 130 women who had the pleasure of playing their hand in support of a good cause. "It was great," Meghan reports. "There were so many people there! The annual Ladies Game Day is an event that just keeps on growing. It was a fun day of bridge, mahjong, canasta, door prizes, tea sandwiches, and drinks and desserts. And the 2013 event raised more than $10,000 to support the IMF's research program!" For more about this popular event, keep an eye out for the upcoming edition of *Making Miracles*, the IMF's fundraising magazine.

Iron Chef Fun-Raiser

Since Aimee Martin joined the IMF's advocacy team as our Grassroots Liaison, she has developed a close bond with many IMFers. "Working with so many amazing grassroots advocates inspires me every day," says Aimee. "They are heroes to me, fighters who won't let myeloma stop them from making a contribution to the lives of others."

Katy Palfrey and Aimee Martin

Aimee formed the IMF's Myeloma ACTION (Advocates Committed To Inspiring Others Nationwide) Team and, as the 2013 Myeloma Awareness Month (MAM) approached, she assisted a number of team members with a variety of advocacy efforts: writing and collecting postcards to support oral drug parity legislation, getting proclamations issued by local and state government officials, and sharing their myeloma stories with others. "My advocates were doing so much that I wanted to do my part, too. It was important for me to make a personal contribution, so I hosted an event to benefit the IMF in honor of my ACTION team members."

A big fan of cooking shows, Aimee organized an event using the basic rules of the Iron Chef competition. "I chose squash as the secret ingredient because it could be made sweet or savory or vegetarian. Each guest made a donation to the IMF in order to participate as a chef or a judge, and a total of 20 people took part."

Everyone had a great time enjoying good food, music, company, and some fun prizes. "I was surprised that this was as easy to plan as any party. Really, the only difference was me giving a brief talk about myeloma and asking folks to donate to a good organization. I will definitely host another event in the future. Next time it might be a game night, a murder mystery party, or something else I haven't even considered yet. The experience was truly rewarding, not just for me but also for my guests... One of my friends commented that she was going to make all her parties fundraisers from now on!"

Dairy Queen for a Day!

When David Schimmel's family learned of his myeloma diagnosis in December 2012, none of them had ever heard of this disease. Their learning curve was quick, as was their instinct to do all they could to support not only David, but the entire myeloma community.

During Myeloma Awareness Month in March, the family focused their efforts on a family business: the Dairy Queen ice cream shop in Allendale, Michigan. Owned by David's niece, Amanda Williams and her husband, the Dairy Queen is where Amanda's mother, Ruth Schimmel, also works. Capitalizing on the word play of "MM" for multiple myeloma, they offered all customers who donated $3 or more to the IMF during the month of March a free mini M&M Blizzard.

Their efforts culminated on March 25th with a Day at Dairy Queen fundraiser. From 4 to 8 p.m., 20% of all of sales were earmarked in support of the IMF. They enticed customers with door prizes and a silent auction, and also sold

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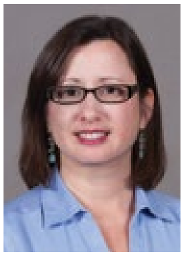
IMF ANNOUNCES NEW DONOR PROGRAM



by Heather Cooper Ortner
Executive Vice President, Development

Sometimes the simplest things have the strongest appeal. Take a charitable gift annuity — through this time-honored arrangement, a donor makes a contribution to a charitable organization in exchange for fixed payments for life. The IMF is excited to announce that we are now offering this opportunity for our donors.

An annuity is "the payment of an annual amount or allowance." A charitable gift is a "gift to a charity." Put them together and you have a charitable gift annuity — the giving technique with something for everyone. It's an ideal plan for those who would like to make a significant gift while continuing to receive income from their assets.

A gift annuity is a simple contract between the donor(s), an individual or couple, and a charitable institution. In exchange for a contribution from the donor(s), the charity promises to make fixed payments for life to one or two annuitants. The amount paid is based on the age of the annuitant(s). The charity invests and manages the contribution, and when the last annuitant has died, uses the remainder of the contribution for its charitable purposes.

One Life Annuity Rates			Two Life Annuity Rates	
Age	*Rate*		*Ages*	*Rate*
60	4.4%		60/60	3.9%
65	4.7%		65/65	4.2%
70	5.1%		70/70	4.6%
75	5.8%		75/75	5.0%
80	6.8%		80/80	5.7%
85	7.8%		85/85	6.7%
90	9.0%		90/90	8.2%

The IMF uses the rates published by the American Council of Gift Annuities. Visit www.acga-web.org for more information.

What are the benefits?

In addition to fixed payments, a charitable gift annuity may provide other benefits, including:

- A portion of the payments is usually tax-free
- Charitable deduction in the year of the gift
- An annuity rate often higher than the interest paid on current fixed investments
- Reduced capital gains tax
- Secure payments backed by the IMF's unencumbered assets
- Often an increase to your cash flow
- Satisfaction of assisting the IMF in its mission.

How does it work?

Most charitable gift annuities are funded with cash or long-term appreciated securities. When you contribute securities, the annuity payments will probably exceed the dividends you were receiving. Married people typically provide for payments to be made over both of their lives. When

CONTINUES ON PAGE 18

THE EPITOME OF A WIN-WIN INVESTMENT

by Abbie Rich

My husband, Jim, and I have made a contribution in exchange for one of the first IMF charitable gift annuities, if not the first. This is a new program for the IMF, and we jumped on it.

Why? Because investing in an IMF charitable gift annuity makes a lot of financial sense. Let me explain how it works: When we made our gift to the IMF, an annuity was triggered to be paid to us. Our payments are fixed, regardless of how the market fluctuates, and we can take an immediate tax deduction on the gift.

It's a conservative annuity. It will earn us about the same rate that we would get if we put the money into a CD. However, the income from our Charitable Gift Annuity may add up to more than the interest we would earn by buying a CD. But that is just considering our benefits.

There is nothing conservative about our desire to benefit the IMF. We are gifting this money to the IMF because doing so is a win-win for the both of us.

We like that we're helping the IMF because we know how much the IMF has done for the entire myeloma community since the organization was founded more than 20 years ago. I've been privileged to see the IMF's contributions first-hand. For almost 12 years I've served as the IMF's web producer. Now, I am retiring. In those 12 years I have seen how much is accomplished by a small but determined staff. How they identify a need, whether it is in research or support or advocacy or education, and they respond to it. How they create programs out of sheer energy and willpower. And I have personally seen how people are touched by their dedication. Honestly, they rock.

Also, I have to tell you that Jim finds this gift infinitely more appealing than the time we attended an IMF gala (before it became the hilarious Comedy Celebration that it is today) and at the live auction I impulsively bid on and spent $6,000 for a weeklong trip to an exclusive resort in Belize. We had a beautiful little house with an infinity pool and two housemen to attend to our every need. Okay, we were sick for six out of the seven days. And we were prohibited from wandering around and speaking to any of the other guests because they were very busy enjoying their "privacy." I'll admit that in our diminished state we couldn't canoe, snorkel, or travel to the interior to see the animals. But I do think my husband exaggerates when he tells people it was the trip from hell.

With the IMF charitable gift annuity, we have no bugs, no intestinal distress, AND we earn money while helping the IMF help others. Really, it's a no-brainer. And the epitome of a win-win investment for us. **MT**

Charitable Gift Annuities

NEW DONOR PROGRAM — continued from page 17

a spouse passes away, the payments continue at the same level to the survivor.

The IMF invests and manages the contribution and at the end of the life of the donor(s) the remainder is available to the IMF to support our research programs and critical educational and support services.

The amount of the annual payments will depend on the amount transferred, the ages of the beneficiaries, and the annuity rate schedule in effect at the time of the gift. Once the annuity is established, the payments will remain fixed, regardless of changes in the economy. This makes the gift annuity especially attractive to donors over 60 who like the security of fixed payments. The IMF is a member of the American Council on Gift Annuities (ACGA), the country's leading organization on charitable gift annuities. The rates published by the ACGA are used by the IMF in the development of all gift annuity contracts *(see inset box for rate examples)*.

What about taxes?

The most notable tax benefit of a gift annuity is the charitable deduction in the year of the gift. The amount of the deduction depends on the rates in effect and on the age(s) of the annuitant(s) at the time the annuity is established. Gift annuities make sense not only for people in their retirement years, but also for those still working. While payments can be deferred until later years, a charitable tax deduction is available to offset current income.

An additional benefit occurs when appreciated securities are contributed. Capital gains tax is avoided on the part of the property that is considered a gift. The rest of the capital gain (assuming the donor is one of the beneficiaries) will be recognized over a period of years, spreading out payment of the capital gains tax. Consider the following examples*:

> *Stuart and Barbara M, who are both 75 years old, contribute $10,000 cash to the IMF for a gift annuity, naming themselves as the beneficiaries. As long as either of them lives, they will receive payments of $500 per year (an annuity rate of 5.0%). For the duration of their life expectancy, $410 of their annual payments will be tax-free. They will also receive a charitable deduction of $3,274.*
>
> *Dorothy P, who is 80 years old, contributes $20,000 of securities (with an original cost of $8,000) to the IMF for a gift annuity. With an annuity rate of 6.8%, she receives fixed payments of $1,360 per year as long as she lives. For the duration of her life expectancy, $454 of her annual payments will be tax-free, and $681 of them will be taxed as capital gain. She also receives a charitable deduction of $9,339.*
>
> ** The above numbers assume a gift made in September 2012, and the calculations are based on the 1.2% Charitable Midterm Federal Rate (CMFR) for July 2012.*

Gift annuities are a popular gift vehicle, allowing people the opportunity to support a charity and at the same time provide for their future financial security. The IMF would be pleased to answer your questions or send you a personal financial illustration. Please contact me at hortner@myeloma.org or 800-452-CURE (2873) to receive personalized information on your charitable gift annuity. **MT**

Editor's Note: The IMF may issue charitable gift annuities in all states WITH THE EXCEPTION OF Alabama, Arkansas, Hawaii, Maryland, New Jersey, New York, North Dakota, Puerto Rico, Tennessee, Washington, and Wisconsin.

MEMBER EVENTS – continued from pg 16

t-shirts for the cause. "So many people came," Ruth reports. "Friends, family, community members, and people from David's myeloma support group. I am glad no fire marshal showed up that night!"

Ruth was equally grateful for the efforts so many people donated to the cause. "Two of David's boys helped behind the counter, as did my son and nephew. My two daughters were dressed up as a big cone and a big Blizzard – that in addition to Amanda sharing her store with us in the first place, and my daughter Stephanie McKinney overseeing much of the event organizing and marketing. And our employees generously donated their time. It was just awesome!" But even as Ruth reflects back, she also looks forward. "I love my brother. I will do whatever it takes to help him in his journey with myeloma." **MT**

Calendar of Upcoming Events

September 14, 2013
Day at the Races! – Ocean Park, NJ
Contact: Janine Grant at janinemariegrant@gmail.com

October 5, 2013
Miracles for Myeloma 5K – Oak Ridge Park, NJ
Contact: Ron & Sheree Pask at rpask@comcast.net or 732-574-9182

October 20-21, 2013
Coach Rob's Benefit Bash & Golf Tournament – Apopka, FL
Contact: Rob Bradford at rbradford@crothall.com

October 26, 2013
Wayne Hamby Memorial Golf Tournament – Bluffton, SC
Contact: Andrew Bertram at abertram@yahoo.com or 843-757-2322

November 2, 2013
Texas Hold 'Em Benefit Bash – San Jose, CA
Contact: Jack Aiello at jackaiello@comcast.net or 408-264-7609

December 27, 2013
F.O.R. Walk – Los Angeles, CA
Contact: Michelle Hass at msgeek703@gmail.com

Shop for the Cure

Shop 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! Visit the merchants using the links at shop.myeloma.org and, if you make a purchase, a percentage goes to support the IMF. Please remember that the IMF receives a donation only if you use the links on the shop.myeloma.org page, so please bookmark this page to ensure that when you are shopping your purchases are properly credited. E-commerce vendors include **Amazon, Macy's, Walmart, iTunes, 1-800-Flowers, Hotwire, The Sharper Image, Omaha Steaks, Dollar** and **Thrifty Car Rental**, and many others. Keep checking back as we regularly add new stores to our mall. Thanks for your support!

INTERNATIONAL — continued from page 12

The main findings of the IMF Asian Myeloma Data Base project were summarized:

1) Myeloma is a significant health problem and is increasing in the Asian region, with an incidence approaching that in Western countries, but with a much larger population base.
2) In general, it can be stated that there are no Asian-specific characteristics of the disease,
3) However, the results show some country-specific characteristics which require further study.

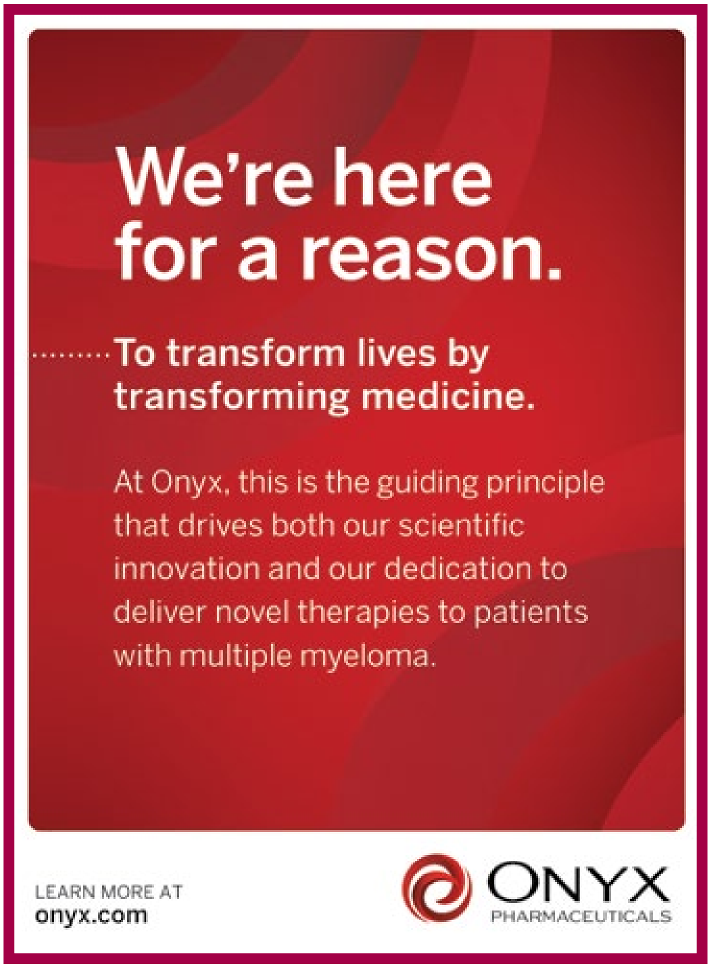
Consequently, manuscripts are in the course of preparation by AMN members to present aspects of the data.

Building upon the success of the Asian Myeloma Data Base project, the AMN is considering possible Asia-wide, multi-national, multi-center clinical trials both for newly diagnosed and for relapsed/refractory myeloma patients.

Recently, consultations have been held between IMF and Celgene Corporation, as well as IMF and Onyx Pharmaceuticals. Discussions include developing a special Pomalyst® (pomalidomide) access program, wherein data would also be analyzed by the AMN, as well planning a Kyprolis® (carfilzomib) clinical trial in various AMN countries/regions. It is hoped that both projects might be implemented in the latter part of 2013.

Finally, the AMN meeting in Kyoto discussed a request for members to join together to submit a manuscript by the end of June 2013 on "Asian treatment guidelines for multiple myeloma" for publication in the *Lancet Oncology* medical journal. The meeting focused on a possible structure for that paper, including AMN data on myeloma incidence in Asia, resource availability, diagnosis in Asia, risk stratification, treatment, supportive care, and relapse treatment. The manuscript would conclude with an AMN consensus statement.

Updates about AMN projects and initiatives will be provided in upcoming issues of *Myeloma Today*. **MT**


We're here for a reason.

To transform lives by transforming medicine.

At Onyx, this is the guiding principle that drives both our scientific innovation and our dedication to deliver novel therapies to patients with multiple myeloma.

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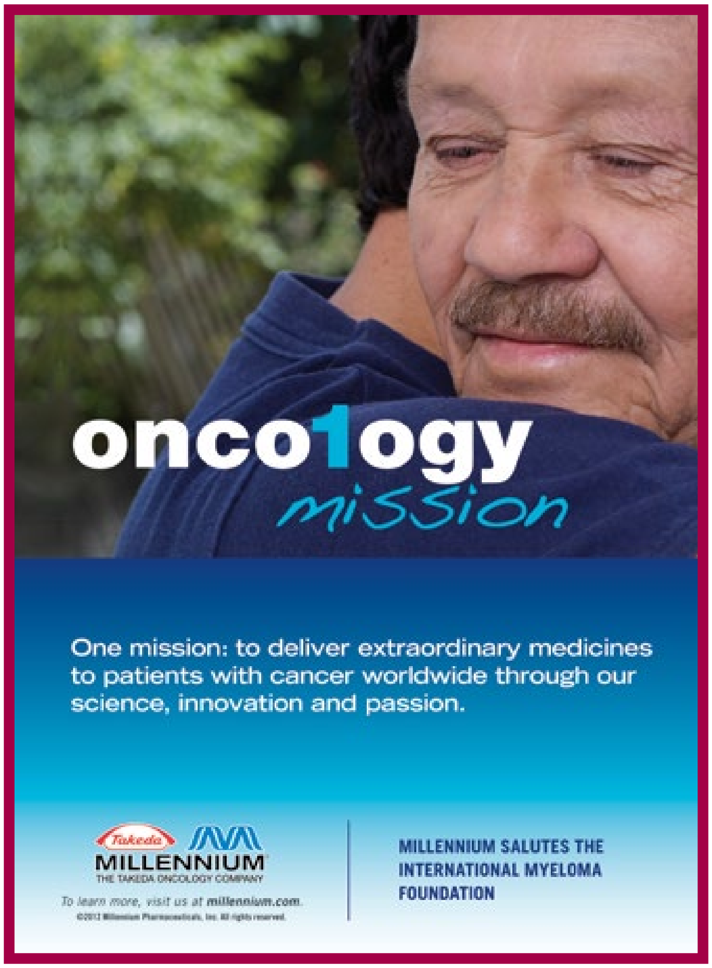

One mission: to deliver extraordinary medicines to patients with cancer worldwide through our science, innovation and passion.

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

2013 IMF Calendar of Events

July 11	Myeloma Updates from 2013 ASCO, EHA, and IMWG meetings – teleconference starts at 4 p.m. (Pacific)*
July 13	IMF Regional Community Workshop (RCW) – Spokane, WA
July 17	Health Reform and You: Navigating the Changing Health Insurance System in NJ – Princeton, NJ
July 26-28	IMF Support Group Leader Summit – Dallas, TX
Aug 9	Health Reform and You: Navigating the Changing Health Insurance System in IL – Northbrook, IL
Aug 9-10	IMF Patient & Family Seminar (PFS) – Chicago, IL
Aug 23-24	IMF Patient & Family Seminar (PFS) – Philadelphia, PA
Oct 12	IMF Regional Community Workshop (RCW) – St. Louis, MO
Nov 9	7th Annual Comedy Celebration – Los Angeles, CA
Nov 22	Myeloma Center Workshop (MCW) – Raleigh-Durham, NC
Dec 6-9	American Society of Hematology (ASH) Annual Meeting – New Orleans, LA

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

* Pre-register for this FREE teleconference at conferencerecap.myeloma.org