

Myeloma Today

A publication of the International Myeloma Foundation

Research



The IMF previews a key element of the Black Swan Research Initiative® to more than 160 researchers in Japan. **PAGE 5**

Advocacy



The IMF raises myeloma awareness and fights barriers to treatment access. **PAGE 10**

Education



Profiles in patient courage pour in from around the globe. **PAGE 8**

Support



At the recent IMF Patient & Family Seminar in Boca Raton, FL, patient Elverta Mock (with her husband, Harold Harris), above, were among the volunteers who shared advice for others via the IMF's new Oral History Project. **PAGE 7**. Also, in Boca Raton, the InfoLine Team investigated the needs of US military veterans and reports on how the IMF can help. **PAGE 11**

One Myeloma Nation

The IMF brings people together around the world

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A Message from the President

Dear Reader,

This is a big year for the IMF, as it's our 25th anniversary year! It's hard to believe how fast the time has gone by. 2015 is definitely a year of reflection – we've done so much, and we've been deeply touched by the people we've met over the years. We're proud of what we've accomplished and what we're able to do by working together globally. The word "international" in our name reflects our strong belief that we are "One Myeloma Nation."

Today, the IMF reaches people in more than 140 countries around the world, and this edition of *Myeloma Today* offers a glimpse of that activity.

The IMF's medical education team just returned from Japan, where we chaired an exciting workshop in Tokyo as part of the Black Swan Research Initiative* (BSRI*) to introduce a new super-sensitive, automated myeloma-measuring method to more than 160 researchers. Next Generation Flow (NGF) cytometry was developed with the support of BSRI and, as IMF Chairman Dr. Brian Durie explains (page 5), it is an important element in our *pathway to a cure*. I was thrilled to listen as researchers from Japan, China, Hong Kong, Korea, Singapore, Taiwan, and Thailand discussed the role this incredibly precise method of measuring myeloma cells can have in their work going forward.

On page 12, you can read about the work done by the IMF and the Asian Myeloma Network (AMN) to ensure that the new myeloma drug pomalidomide becomes available to myeloma patients. Pomalyst® is not available for relapsing patients in Asia, but through negotiations by the IMF and the AMN with Celgene Corporation, patients in Korea are now being treated in a clinical trial. Patients are now also enrolling in Singapore, to be followed by Thailand, Hong Kong, and Taiwan. That's progress!

In February, the IMF traveled to Turkey, where news about myeloma was the lead topic at a press conference, followed by an interview by CNN Turkey with Dr. Durie. The Turkish myeloma community continues to grow and is eager for information. We are proud to work with the online myeloma support group Miyelomla Yaşam, whose founders are members of the IMF's Global Myeloma Action Network, as they bring the most up-to-date information to patients across Turkey.

Our successful celebration of March as Myeloma Awareness Month – launched by the IMF in 2009 – has become global as well, and now includes participation by patients around the world. On page 8, you can read just a few of the first-person accounts that myeloma patients have submitted to our "Share Your Stories" web page, which includes stories from patients in Austria and Denmark, as well as in the US. Some examples:



- Elfi, from Vienna, Austria, vice-president of the Austrian Multiple Myeloma Association, wrote that her motto is, *I am healthy as a principle... I believe in the power of a smile and positive thinking.*
- Tammi, from The Netherlands, has been busy since her year of treatment. As she wrote on our Myeloma Awareness Month website, she has traveled *to Seoul for work, to Botswana on safari, walked 112 kilometers of the Camino de Santiago in Spain, hiked high in the Swiss Alps, and last week was skiing in the Austrian Alps... This beast CAN be tamed, or at least lived with.*

We are *One Myeloma Nation* and the IMF ensures that patients have access to the most up-to-date myeloma educational materials. We are translating the latest editions of the *Patient Handbook* and the *Concise Review of the Disease and Treatment Options* into Chinese, Czech, French, German, Italian, Norwegian, Polish, Spanish, and Turkish (page 12).

The IMF was founded by a South African – Brian Novis, a Scot – Dr. Brian Durie, and me – an American. From the very beginning we were "international" and we'll continue to reach out and help people no matter where they live. It's our mission and our passion.

Warm regards,

Susie Novis

Susie Novis, President



Hosted by
Ray Romano
(additional performances to be announced)

SAVE THE DATE

INTERNATIONAL MYELOMA FOUNDATION

9th Annual Comedy Celebration

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

Saturday, October 10, 2015

The Wilshire Ebell Theatre & Club in Los Angeles, California



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Myeloma Treatment Progress Accelerates in US and Europe

Regulatory agencies issue spate of new rulings

United States

Selinexor receives orphan drug designation from the FDA

The US Food and Drug Administration (FDA) granted orphan drug designation to selinexor for the treatment of myeloma. Selinexor is an oral drug from Karyopharm Therapeutics that is currently being evaluated in clinical trials. The FDA grants orphan drug designation to encourage companies to develop drugs that have the potential to treat conditions affecting 200,000 or fewer US patients annually. Advantages include an accelerated FDA review process. You can learn more about selinexor from IMF Chairman Dr. Brian Durie by going to askdrdurie.myeloma.org and searching for “selinexor” in the archived episodes of the IMF’s video web series *Ask Dr. Durie*.

FDA approves Revlimid® for newly diagnosed myeloma

The FDA approved Revlimid in combination with dexamethasone for newly diagnosed myeloma patients. This approval consolidates what has been widespread off-label use of Revlimid in the frontline setting in the US for several years. The FDA has also added much more detailed guidance than in the past, recommending stem-cell harvesting after the first four cycles of therapy, if possible, and much closer blood-count monitoring.

FDA approves Farydak® (panobinostat) for myeloma

The FDA approved panobinostat for the treatment of myeloma. Marketed by Novartis under the name Farydak, panobinostat is an HDAC inhibitor intended for patients who have received at least two prior therapies. The safety and efficacy of panobinostat, which is used in combination with bortezomib and dexamethasone, was demonstrated in 193 clinical trial participants.

“It appears that the FDA circumvented the prior controversy regarding less-than-impressive efficacy and some serious toxicities by focusing on a pre-specified subset analysis of patients treated previously with bortezomib and an iMiD (thalidomide and/or Revlimid),” noted Dr. Durie. For these 193 patients, the median progression-free survival (PFS) was 10.6 months for the panobinostat combination versus 5.8 months with placebo: a 4.8 month advantage. This trumped the prior numbers which ranged from 1.7 to 3.9 months of PFS benefit. The overall response rate was also higher: 59 percent versus 41 percent.” The FDA addressed the serious toxicity issues by using a “Boxed Warning” approach with a specified Risk Evaluation and Mitigation (REMS) plan for severe diarrhea and potential severe and fatal cardiac events, arrhythmias and ECG changes.



Researchers at Onyx Pharmaceuticals’ lab in San Francisco.

Interim trial results show benefit of carfilzomib (Kyprolis®) in relapsed myeloma

Analysis of interim results released by Amgen/Onyx from the ENDEAVOR trial, a head-to-head comparison of “real world” schedules of Kyprolis versus Velcade, showed an impressive benefit of carfilzomib over bortezomib in relapsed myeloma. The 929-patient phase III trial showed a progression-free survival (PFS) of 18.7 months for Kyprolis versus 9.4 months for Velcade – a doubling of PFS or remission duration.

In the trial, Kyprolis was given in the usual schedule of two IV infusions per week for three out of four weeks, with dose escalation to 56mg/m². Velcade was also given according to the standard schedule, with subcutaneous (versus IV) administration allowed at the discretion of the investigator. (Sub-Q administration occurred more than 75 percent of the time.) Full data from the ENDEAVOR trial will be submitted for presentation at the 2015 American Society of Clinical Oncology (ASCO) Annual Meeting in Chicago.

Europe

European Commission approves Revlimid for newly diagnosed myeloma

The approval of Revlimid for newly diagnosed myeloma patients by the European Commission (EC) followed within days of the FDA’s approval in the US. “This near simultaneous approval by both organizations reflects the value and safety of Revlimid/dexamethasone, especially for unfit or frail patients for whom transplant is never an option,” said Dr. Durie.

European Medicines Agency grants accelerated assessment to Kyprolis®

The European Medicines Agency (EMA) has accepted the Marketing Authorization Application (MAA) of Kyprolis® (carfilzomib) for Injection for the treatment of patients with relapsed multiple myeloma who have received at least one prior therapy. The MAA, which has been granted accelerated assessment by the EMA, includes data from the phase III ASPIRE trial as well as other relevant data. **MT**

IMF Chairs Tokyo Flow Workshop

Next generation flow now faster and even more precise



By Brian G.M. Durie, MD

The International Myeloma Foundation was honored to chair a workshop in Tokyo, Japan, March 7-8, which introduced Next Generation Flow Cytometry to more than 160 researchers and technicians eager to learn about this new super-sensitive, automated myeloma-measuring method.

Next Generation Flow (NGF) cytometry was developed with the support of

the IMF's signature Black Swan Research Initiative® and is a crucial step in our ability to chart a pathway to a cure.

Susie Novis, IMF president, welcomed workshop attendees on behalf of the organization, and was followed by Hirokazu Murakami (current President of the Japanese Society of Myeloma) and Kenshi Suzuki (Deputy Director of the Red Cross Medical Center), who greeted the audience and thanked the IMF for organizing the workshop. The opening session was co-chaired by myself and Dr. Kazuyuki Shimizu. Dr. Hiroyuki Takamatsu of Kanazawa University set the stage for the presentations to come by describing the perspective of minimal residual disease (MRD) testing in Japan.

Up to now, the key effort in Japan has been to assess NGS (Next Generation Sequencing), which measures MRD using molecular data. As such, Dr. Takamatsu presented a recap of his NGS presentation at the ASH 2014 meeting in December in San Francisco. However, Japanese investigators at the workshop were very keen to hear about Next Generation Flow testing, which can be equally sensitive and much more practical for broad use in Japan.

A vast improvement in disease detection

Throughout the day, Dr. Alberto Orfao of the University of Salamanca in Spain and Dr. Jacques van Dongen of Erasmus University Medical Center in The Netherlands examined the current conventional flow methods of detecting MRD in myeloma as a backdrop to their presentations on the Next Generation Flow technology details, which included panel design, data analysis and interpretation, and cross-platform applicability. The day's closing remarks (by myself, Dr. Orfao and Dr. van Dongen) concentrated on the vast improvement in disease detection NGF represents.

It was really heartwarming – and very much appreciated – to hear Dr. Takamatsu, who started the day talking about NGS, tell Dr. Orfao: “I am convinced about the sensitivity and practicality of the NGF method, and look forward to implementing NGF at my center as soon as possible!”

In addition, Dr. Suzuki indicated similar enthusiasm and a desire to adopt the NGF broadly for Japanese Society of Myeloma investigators.

The Japanese were actually the first to hear that based upon the most recent testing, the new NGF method is even more sensitive than originally anticipated: able to detect one myeloma cell in a million or even one in 10 million! In addition, as Dr. Orfao explained, the computer software program for automatic data analysis has been improved since our last workshop was presented in New York at Memorial Sloan Kettering Cancer Center, with a data analysis time of now only 12 minutes – reduced from several hours! This means that samples can easily be analyzed with same-day results, which is a huge advantage.

Hands-on training aided by a detailed video

On the second day of the workshop, participants attended “hands-on” training, courtesy of Juan Flores-Montero of the University of Salamanca. Dr. Suzuki had done a fantastic job in facilitating the “hands-on” session, which went very smoothly and generated tremendous interest from the participants. Especially helpful was a practical, step-by-step video, subtitled in Japanese, which had been prepared in advance by the Salamanca team to demonstrate sample preparation.

Members of IMF's Asian Myeloma Network (AMN) from Japan, China, Hong Kong, Korea, Singapore, Taiwan, and Thailand engaged in a spirited discussion of the role NGF might play in their respective myeloma treatment practice and research.

Speaking on behalf of the AMN team, Dr. Wee Joo Chng said that the new NGF method represents a major step forward for the myeloma community and provides a reliable, accessible method for routine MRD testing throughout Asia. According to Dr. Chng, who chairs the AMN Clinical Trials Group, the plan is to integrate NGF into upcoming trials.

The IMF's Tokyo Next Gen Flow Workshop ended on a very positive note, with plans to move forward in the near future. The concrete plans at the end of the workshop were many, ranging from multiple individual contacts with the visiting NGF team, as well as broad commitments for collaborations with the JSM.

Dr. Kazuyuki Shimizu, past President of the Japanese Society of Myeloma and Chairman for the IMW Congress held in Kyoto in 2013, noted: “Now I believe most Japanese doctors can understand the importance of JSM... I believe that the landscape of the [use of] flow testing in Japan will be changed.” So stay tuned for further developments! **MT**

Read more about the IMF's Black Swan Research Initiative:
bsri.myeloma.org

Watch IMF's video about the groundbreaking new flow technology:
bsri.myeloma.org/imf-salamanca-flow-cytometry-workshop

Read more details about Next Generation Flow in Dr. Durie's blogs:
brianduriemd.myeloma.org

Spotlight on NLB Nurse Leaders Bringing dedication, compassion, and up-to-the-minute research to myeloma patients

In this issue of MT, we launch a series of profiles of the nurses who make up the International Myeloma Foundation (IMF) Nurse Leadership Board (NLB). These dedicated nurses are from the leading centers treating myeloma patients across the US. Their mission is to develop broad recommendations for nursing

care for myeloma patients, which they present at key conferences, IMF Patient & Family Seminars, Regional Community and Myeloma Center Workshops, and via educational webinars. On behalf of myeloma patients everywhere, the IMF is grateful to the NLB for its dedication, compassion, and commitment to care.

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**Beth Faiman,
PhD, MSN,
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Beth Faiman, PhD, MSN, APRN-BC, AOCN®, who has also recently acquired her doctorate, takes the

word “leadership” in the Nurse Leadership Board (NLB) title as seriously as she does all her work in the fields of hematology and oncology. Beth is a nurse practitioner at the Cleveland Clinic in Ohio. Thousands of myeloma patients and researchers are more knowledgeable about the disease thanks to Beth’s role as author, presenter, and educator on the topics of myeloma, plasma cell dyscrasias, and general cancer diagnosis and treatment.

Beth received her Bachelor of Science degree from Ursuline College in Pepper Pike, Ohio; a master of science from Kent State University; and her PhD in Nursing and Clinical Research from Case Western Reserve University in Cleveland.

She is editor-in-chief of The Oncology Nurse APN/PA and serves on the editorial boards of ASH Clinical News and other publications. She has edited several books including “Multiple Myeloma: A Textbook for Nurses,” and authored several chapters relating to diagnosis and management of multiple myeloma.

Today, the NLB continues to bring Beth and her stirring talks about staying healthy to myeloma patients on a regular basis. In the past 18 months she has participated in such events as NLB teleconferences originating from Ann Arbor, Michigan; Patient & Family Seminars in Boca Raton, Florida; and has been faculty for numerous IMF nurse advisory boards and Co-Chair of the IMF Satellite Symposium at Oncology Nursing Society.



**Sandra Kurtin,
RN, MS, AOCN®,
ANP-C**
The University of
Arizona Cancer
Center – Tucson, AZ

As a nurse practitioner for 20 years and a member of the oncology nursing community for 30, Sandra Kurtin, RN, MS, AOCN®, ANP-C, who is also currently working on her doctorate, more than understands the value of keeping patients “well and alive so they have the best opportunity to benefit from all of the amazing science” advancing myeloma treatment today. She also sees great value in educating not only healthcare providers, but also patients and caregivers as partners who translate that science into better patient care.

Sandra became involved in the myeloma field while working with acclaimed myeloma physicians IMF Chairman Dr. Brian Durie and Dr. Sydney Salmon, who together developed the Durie-Salmon myeloma staging system. She joined the International Myeloma Foundation (IMF) Nurse Leadership Board (NLB) in 2009.

“The IMF is one of the best-run organizations I’ve been involved with, and I do a lot of different things, with many hats,” Sandra said. “I love the collegiality of the group among the physicians, nurses, and everyone involved. There has been, thankfully, a great deal of discovery in multiple myeloma. It’s important to make the best of that – not every disease has been that fortunate.”

Through her participation in the NLB, Sandra has become a key educator in a number of IMF programs and events, including Regional Community Workshops, Living Well with Myeloma teleconferences, and the Oncology Nursing Society IMF Nursing Symposia.

This year, Sandra led a Living Well with Myeloma teleconference called “Complementary & Alternative Medicine: What Myeloma Patients and Caregivers Need to Know.” More than 1,000 people have listened to this teleconference

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IMF Launches Oral History Project

Myeloma patients go on the record in Boca Raton

“Make sure you have doctors that you love – not just like! . . . and find those people who are going where you’re going, who can see that vision even if you can’t.”

— **Elverta Mock**, IMF Oral History Project interviewee, on advice for fellow myeloma patients

The International Myeloma Foundation (IMF) hosted the organization’s annual Boca Raton Patient & Family Seminar February 13–14, featuring a panel of top cancer specialists. As a new focus of this year’s seminar, the IMF teamed up with oral historian Ryan White, who interviewed almost a dozen patients about the day they received their diagnosis of myeloma.



Oral historian Ryan White prepares to interview Kathleen and Terry Nairn of Hobe Sound, FL.

Patient stories about living with myeloma provide valuable insight into the disease’s impact in a way medical information alone cannot, White said.

“I was struck by the grace, humility and strength of character displayed in all the interviewees’ stories,” White added.

“They’ve all had their share of difficult times, balanced by acts of generosity and caring, and humor.”

The Boca Raton Patient & Family Seminar was led by IMF Chairman and Co-Founder Dr. Brian Durie. The panelists included Dr. Ola Landgren from Memorial Sloan Kettering Cancer Center in New York City; Dr. Kenneth Anderson from Dana-Farber Cancer Institution in Boston; Dr. Sagar Lonial from the Winship Cancer Institute in Atlanta;



Harold Harris and Elverta Mock of Hollywood, Florida.

Dr. Rafat Abonour from Indiana University’s Melvin and Bren Simon Cancer Center; and Dr. Hoffman from University of Miami’s Sylvester Comprehensive Cancer Center.

IMF President and Co-Founder Susie Novis corroborated the sentiments of oral historian White when she said, “informed patients are equipped to make the best decisions about their own care.” Toward that end, the cancer experts on the panel took part in interactive seminars covering key topics in the myeloma community, including management of side effects, best therapies for elderly patients, the psychosocial issues of myeloma, clinical trials, new drugs, and more.

The patient interviews – which chronicle how individuals have navigated the challenge of having a life-threatening cancer – are yet another creative and powerful way the IMF makes sure patients are informed. The interviews will be archived and shared with patients around the world on the IMF website, myeloma.org. **MT**

NLB – BETH FAIMAN — continued from page 6

Many of the keys to ongoing health are enumerated in the title of her talk at last year’s “Living Well with Myeloma” teleconference: “Stopping to breathe while moving forward: the benefits of rest, relaxation, exercise and nutrition for long-term management of myeloma.” Those holistic health-management efforts are more important than ever for myeloma patients, Beth noted at the talk, since they are “living longer than ever. I can’t tell you how many patients I have that have had multiple myeloma over 10, 15, 20 years and are living healthy robust lifestyles.”

“Multiple myeloma is like a puzzle,” Beth added. “The diagnosis and management requires a lot of different pieces. Caregivers, patients with myeloma – you’re all critical parts of the puzzle.” **MT**

NLB – SANDRA KURTIN — continued from page 6

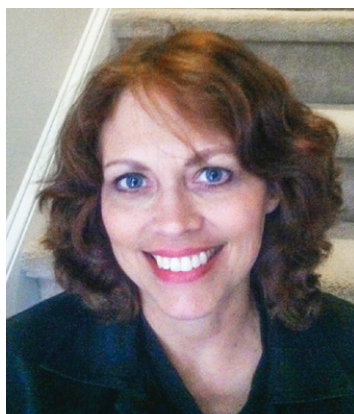
In her role with the NLB and as a nurse practitioner, Sandra encourages patient and caregiver education.

“I try to give patients and their caregivers the tools to take ownership of their care: how to stay well, how to track progress, how to ask questions, and where to find answers that will provide them the best options and outcomes,” Sandra said. “I encourage people to join their local support group and to take part in the national programs and meetings such as the ones offered by the IMF. There’s so much good work being done through clinical trials and laboratory research that we have every reason to be optimistic about the future.” **MT**

Inspirational Stories Raise Myeloma

Myeloma Awareness Month (MAM) was created by the IMF, which declared March to be MAM in 2009. Since then, MAM has united people across the country and around the world. During this year's MAM, individuals whose lives have been touched by myeloma are sharing their stories to provide hope to those who may be going through a difficult

time and to encourage others to have any symptoms evaluated by a physician. Please visit mam.myeloma.org/share/ to read more stories like those below or to contribute your own inspirational experience, lesson, or piece of advice. We all have stories to tell – yours can truly make a difference in someone's life.



Susan Mandel
Columbia, SC

Suffering from back problems for years, I never dreamed that at the age of 42 I would be diagnosed with cancer. I was pretty healthy, though had become used to the fatigue that accompanies anemia. My back problems were not muscular but a vertebra that was fractured and collapsing. I figured that if I didn't present with leukemia symptoms like my father, who passed away at the age

of 45, I was in the clear after having been exposed to radiation in a small town in Colorado at the age of 4.

Nope! My cells took on a different mutation and I had probably been living with myeloma for years while the tumors were eating away at my spine and other areas. With a grateful heart for a family member who is a doctor and who found a recommendation for a wonderful oncologist, I was started on an induction therapy of Velcade, thalidomide, and dexamethasone (VTD). I also went through two vertebral kyphoplasty surgeries to halfway repair what was left of one vertebra and repair one I broke two weeks after my first surgery.

After four rounds of VTD, my numbers were awesome, and I have remained in that state and on a maintenance drug of Revlimid ever since (almost seven years!). I am tested every three months to monitor and make sure I do not relapse. I don't know what the future holds, but I am very thankful for my response thus far!

Carole Levis
Dubois, PA

Twenty-eight years ago I was told I had myeloma. I could not imagine what it was. I had never heard of it. In fact, the doctors were not sure about it either. I had a tumor eat through the seventh vertebrae in my neck. Again, how could this happen? I never asked why, I just said let's fix this.

Now, 28 years later I can tell you that if you are a new myeloma patient, you are so lucky to have the many options I didn't have. I have pioneered through all the chemotherapies, radiation, and three transplants. It wasn't always easy, but in 28 years I have been able to watch science evolve...



What I can tell you is to be patient, have a doctor who is knowledgeable in myeloma, and never give up. If I can make it through 28 years, you can, too.

God bless each and every one, and give us strength.

Elfi Jirsa
Vienna, Austria

In 1989, I wanted to know my cholesterol level. At that time I worked as a food journalist and our recipes were full of butter, cream, yolks – pure cholesterol. I told my boss that we should take into account the sedentary lifestyle nowadays and should reduce these ingredients. The outcome of the argument was that – not knowing my own cholesterol-level – I went to my doctor and had a blood sample taken.

He included an electrophoresis in his laboratory description. This was how I found out that I was a potential myeloma patient.

For 14 years I more or less faithfully went in for the routine exams. In 2000, I was admitted to the hematological ward for treatment, but they considered my situation did not require immediate action right away and I went home again. In 2003, the values required therapy. I changed hospitals during the first part of my treatment since I was not happy with the way I was addressed as a patient. I moved and have stayed with the institution where I was administered the standard treatment with a tandem autologous stem-cell transplant.

I never had any doubt I would reach a complete remission. This was the case for eight consecutive years. I was able to continue working as a food journalist, I became a grandmother, and finally retired. During these years I became more and more involved with patient advocacy and patient groups and finally became vice-president of the Austrian Multiple Myeloma Association founded by our memorable pioneer Elke Weichenberger.

In 2011, my treating physician, Dr. Heinz Ludwig, suggested a second round of chemotherapy. After nine cycles I had again regained complete remission – which is my present situation. I had to step in as president of our support group in 2011 – which shows that the treatment had been successful. My motto is: I am healthy as a principle. And: I believe in the power of a smile and positive thinking.



Awareness Around the World

Sara Calvert Johns Creek, GA

In October of 2010, I was figure skating and as I entered a spin I felt extreme pain in my lower back. After over-the-counter drugs didn't seem to help, I went to a doctor who x-rayed my back and proclaimed I had a lot



Sara Calvert and her family

of arthritis (due to many falls taken figure skating). He told me no more jumping or impact sports and recommended yoga. He also gave me prescription pain meds. I tried yoga and even sports massage, but the pain never got better, so I scheduled an appointment with an orthopedist. In late December, a few days before the orthopedist appointment, the pain was so severe I couldn't get out of bed. My husband called an ambulance. It took three firefighters and two paramedics to put me on the stretcher to take me to the hospital.

After x-rays and a CT scan, the emergency room doctor told me the pain was caused by a collapsed L2 vertebrae and I had lesions on some of my other vertebrae which were all caused by a cancer called multiple myeloma. They admitted me to the hospital. Here's what went through my mind: Cancer? At age 47? But, I'm in great physical shape, or was! Am I gonna die? Will life ever be normal again? Will I ever walk, skate, or even lead an active life again?

After four days in the hospital and numerous tests, myeloma was confirmed, my pain was under control, I was fitted with a body brace and sent home. A few days later, January 2011, my oncologist told me "we've got this" and eventually, I'd be fine. He did an MRI and skeletal survey and determined that, in addition to the lesions on my spine, I had lesions on my thigh, hip and arm bones. The collapsed vertebrae was repaired with a vertebroplasty. I was treated for four months with Velcade, dexamethasone, and Revlimid and achieved a complete remission.

During that time, I began to do yoga and was able to do a little figure skating. Next, I had an autologous stem cell transplant, which resulted in a stringent complete remission. After the transplant I had monthly infusions of Zometa for two years and took Revlimid for three years. Now, almost four years later, I am happy to say that I am still in stringent complete remission.

Two months after the transplant I returned to figure skating and, six months after the transplant, I returned to teaching figure skating classes. I can jump and spin again and still take some falls. I have passed two

United States Figure Skating tests (one being the adult gold test – the highest adult level) and competed again last year, skating a 2-minute 40-second program.

My recovery has been remarkable and I am stronger and more active than ever. Every day I am thankful for modern medicine and the prayers and positive thoughts of my family and friends. My life is relatively normal – except for the annual testing at the transplant clinic and visits to the oncologist every few months. Also, I have met some truly exceptional people through mentoring myeloma patients.

Tamra F. Rotterdam, The Netherlands:

Receiving a diagnosis of multiple myeloma is daunting, and even more so when you're an expat living abroad. But I was lucky – there's a hospital with one of Europe's leaders in myeloma in my town, and I was able to get into a trial with carfilzomib, dexamethasone, and thalidomide to treat newly diagnosed patients.

After a year of treatment – four months of chemo, autologous stem cell transplant, and four more months of consolidation chemo – I am in stringent complete remission and life has returned to normal.

I finished treatment a year ago and since then, I've traveled to Seoul for work, to Botswana on safari, walked 112 kilometers of the in Spain, hiked high in the Swiss Alps, and last week I was skiing in the Austrian Alps. I was able to work on a reduced schedule all through my year of treatment, with the exception of a month after transplant.

I was lucky in that my myeloma was found relatively early (Stage 2) and responded quickly and well to treatment. I urge anyone with symptoms or fears to be tested – if you have it, the sooner you start treatment, the better.

This beast CAN be tamed, or at least lived with. And if you are diagnosed, get yourself into as good condition as you can – it will help you in your fight against it. Eat a healthy diet rich in fresh fruits and veggies, drink LOTS of water, get eight hours of sleep per night. And – at least while in chemo – forego alcohol (not even a glass of Champagne on New Year's Eve). I had a year of some interruptions, but now my life has returned to normal and I can often forget that I am living with this disease. **MT**



IMF Advocacy Team Tackles Treatment Barriers

A path to 21st century cures

Johanna Gray
IMF Federal Government Affairs Consultant

In April 2014, the House of Representatives Energy & Commerce Committee Chairman Fred Upton (R-MI) and Representative Diana DeGette (D-CO) announced an initiative aimed at accelerating the development of new treatments and medical breakthroughs called “A Path to 21st Century Cures.” Since the announcement, the bipartisan duo, along with other members of the House Energy & Commerce Committee, has held a series of roundtables both in Washington and across the country, welcoming input from various stakeholders. Based on all of the information they collected, in late January 2015, Chairman Upton unveiled draft legislation addressing many of the roadblocks to medical innovation. This almost 400-page draft included provisions of great interest to the IMF, such as increasing patient participation in the US Food and Drug Administration (FDA) regulatory process and improving data sharing in clinical trials. The IMF is actively monitoring this process and has submitted comments through the Patients Equal Access Coalition requesting that the Cancer Drug Coverage Parity Act also be included into any legislation stemming from this initiative. Additionally, as the Senate begins working on its own legislation on “A Path to 21st Century Cures,” the IMF will advocate for the inclusion of provisions that will benefit myeloma patients.

West Virginia moves on oral parity

Ray Wezik
IMF Global Advocacy Executive

The IMF is thrilled to include West Virginia as the 37th state to pass oral parity legislation, which was signed into law March 23rd by Gov. Earl



Delegate John B. McCuskey and Ray Wezik with the IMF's letter for support of HB 2493

Ray Tomblin. West Virginia becomes the third state in March to do so. But when the West Virginia Cancer Treatment Fairness Coalition was launched in September 2014, uncertainty prevailed. At the time, 34 states plus the District of Columbia had already passed oral parity, including West Virginia's neighbors: Kentucky, Ohio, Virginia, and Maryland. The question then was, “How receptive will West

Virginia be to oral parity?” As it turned out, the answer was “very.” West Virginia has one of the highest cancer rates in the country, according

to the North American Association of Central Cancer Registries, and legislators embraced oral parity as a means to address the needs of cancer patients and provide the best possible treatment.¹

One such supportive legislator was Delegate John B. McCuskey (R-35), who was the lead sponsor of House Bill (HB) 2493, West Virginia's oral parity bill. Delegate McCuskey chairs the House Banking and Insurance Committee, which HB 2493 easily cleared at the beginning of the campaign. He was instrumental in rallying bipartisan support for the bill.

While the battle for oral parity is not over, the recent gains in West Virginia, South Dakota, and Wyoming prove that legislators around the country understand the importance of drug access for their constituents. The IMF will continue to fight for all cancer patients in the United States and around the world to ensure their issues are heard.

More information on the IMF state and federal policy initiatives can be found at advocacy.myeloma.org. Please contact advocacy@myeloma.org if you have questions or want to get involved in our efforts.

Advocates Take Action

Laena Shakarian
IMF Advocacy Associate

In 2013, the IMF created the Myeloma ACTION Team, which stands for Advocates Committed to Inspiring Others Nationwide. The group unites advocates across the country to help build a community that fosters education, action, and empowerment. Each month, the ACTION Team meets via teleconference to learn and discuss the IMF's advocacy initiatives at both the state and federal level. The IMF helps guide the team, which in turn helps guide other individuals in taking a stand about critical health issues affecting the myeloma community. The IMF believes in making a difference by taking action. Working together, we help strengthen support for legislation on oral chemotherapy parity, state level grassroots networks, and nationwide myeloma awareness. If you are interested in learning more about the Myeloma ACTION Team and would like to become a member, please email advocacy@myeloma.org. **MT**



A few ACTION Team members at the IMF Support Group Leader Summit: John Killip, Cindy Chmielewski, Kathy Cartwright, and Cindy Ralston

¹ NAACCR, CINA+Online, <http://www.cancer-rates.info/naaccr/> last accessed Feb 20, 2015

Helping Veterans with Myeloma

The IMF InfoLine coordinators answer your questions



by Debbie Birns
IMF Medical Editor

Q. I'm a US military veteran with myeloma. How can the IMF help me?

A. The IMF has long recognized the special needs of US veterans with myeloma and has relied upon Tom Courbat and Jerry Walton, both of whom are vets and present or former support group leaders, to reach out to individual vets with myeloma who have had service-related questions. As the number of veterans diagnosed with myeloma has increased in recent years, the need to do more for these former servicemen and servicewomen has become urgent. The IMF has committed itself to educating veterans with myeloma about their disease and assisting them with veterans' issues. Last year, with Jerry Walton at the helm, the IMF unveiled a new section of our website, Veterans Against Myeloma, veterans.myeloma.org.

The IMF's Veterans Against Myeloma (VAM) web pages were designed not only to bring vets together to share their stories, their problems, and their successes, but to provide information and resources to help vets get the best possible care. They can find information to help identify service-related exposures that may have caused myeloma, file disability compensation claims, navigate the Veterans Affairs (VA) system, buy federal insurance, and find the veterans' service organizations that are most helpful. Once vets have signed up with VAM, they receive regular updates on veterans' issues in the news via email alerts.

In addition, like other patients, vets need the most current and best information available about their disease as well as treatment options. The VAM website therefore links to the "About Myeloma" section of the IMF website, where patients can watch a video called "What Is Myeloma," read through the extensive information in the "10 Steps to Better Care" pages, find a local support group, request or read IMF publications, find contact information for the IMF's InfoLine, register for a Patient & Family Seminar or a Regional Community Workshop, or download a glossary to help demystify the vocabulary of myeloma.

What do veterans with myeloma need?

The type and extent of military service and the medical care, disease status, disability status, and financial status of the veterans varies greatly; veterans with myeloma are a diverse group. The IMF recently conducted a survey among veterans with myeloma to identify common areas of need, and we are taking steps to address them. Our first step was to conduct a focus group for veterans on February 13 at the first Patient &

Family Seminar of 2015 in Boca Raton, Florida, in order to learn from the vets themselves how they would like the IMF to help them. Among the many needs vets identified, those which stood out were:

1. The need to better understand various options for healthcare coverage, including Tricare, Tricare for Life, Tricare Prime, Medicare, Veteran's Choice, military medical centers, and private insurance.
2. The need for help in overcoming obstacles to filing a successful disability claim, whether through private disability insurance, the Social Security Administration, or the VA.
3. The need to better understand the disease – how it's treated, how it's monitored, and what supportive care options are available and appropriate.
4. The need to understand toxic exposures and myeloma – which exposures are most likely related, and which other illnesses or conditions caused by these toxic agents should be taken into consideration during myeloma treatment.

The IMF will be conducting two teleconferences this year, and IMF Chairman Dr. Brian Durie will be filming two episodes of *Ask Dr. Durie* in the coming months, to address these identified needs. Our goal is to help vets with myeloma receive the best care possible.

If you're a veteran with myeloma, please log in to veterans.myeloma.org, sign up for email alerts, and share your story with others. You'll also receive notifications of the upcoming VAM teleconferences and *Ask Dr. Durie* segments.

As always, if you have questions about myeloma, treatment options, supportive care, or clinical trials, call the IMF InfoLine at 800-452-2873, or email us at info@myeloma.org. **MT**

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

Asian Myeloma Network Scores Treatment Access Victory

by Brian G.M. Durie, MD

Access to new drugs outside of the United States is frequently delayed by several years following Food and Drug Administration (FDA) approval in the US. For example, lenalidomide (Revlimid®) received US FDA approval in June 2006, yet is still not fully approved and available globally. This lack of access has a significant negative impact for myeloma patients. At the point of relapse, patients who may have been treated with VTD (Velcade®, Thalomid®, dexamethasone) or CyBORd in the frontline setting, only relatively recently and in some cases have been able to turn to Revlimid.

In the case of pomalidomide (Pomalyst®), the most recently approved IMiD (approved in the US for relapse/refractory disease in February 2013 and in Europe in August 2013), global access is currently very limited. Pomalidomide is not available for relapsing patients in Asia.

The IMF's Asian Myeloma Network (AMN) has therefore negotiated with the Celgene Corporation to establish an individual or "named" patient access program for pomalidomide. Utilizing a treatment protocol very similar to the trials conducted in the US and Europe, eligible relapsing patients can now gain access to pomalidomide through the main Asian treatment centers. After overcoming numerous regulatory and logistic hurdles, the protocol was activated in December 2014 with Dr. Wee Joo Chng as the principal investigator. Dr. Chng, a member of both the AMN and the IMF's research arm, the International Myeloma Working Group (IMWG), is based at the University of Singapore, where the data management and coordination center is housed and funded.

Accruals started rapidly in Korea with Dr. Jae Hoon Lee, who enrolled four myeloma patients in December. He is excited to report that at first



Dr. Jae Hoon Lee of the Asia Myeloma Network worked with the IMF to help patients in Asia gain access to pomalidomide.

follow-up all patients showed evidence of response and excellent tolerance. Patients are now enrolling in Singapore, to be followed by Thailand, Hong Kong, and Taiwan. Unfortunately, it is not yet feasible to open the program in Japan and China, the other two AMN members.

The successful launch of this pomalidomide access program is very exciting for both patients and physicians in Asia. This is a model through which patients can gain early access to new drugs which can be literally lifesaving. It is hoped that it is just the beginning of programs to enhance global access to new FDA approved drugs, which are so desperately needed to improve myeloma patient survival. **MT**

2015 Patient Meetings Planned throughout Europe

by Nadia Elkebir

IMF Director, Europe and the Middle East

After a year of successful seminars throughout Europe and in Jordan in 2014, the IMF continues to strengthen its international relationships with patients and caregivers, advocacy organizations, myeloma researchers, and pharmaceutical partners. Many patient education meetings have been planned for 2015, and more seminars will soon be added to the calendar.

The IMF will host or co-host at least 11 Patient & Family Seminars in Europe in 2015. Some locations have become an annual tradition and others are new to us. Two meetings will take place in Italy, one on April 18th in Udine and another on October 3rd in Rimini. The annual seminar in France will take place on June 6th in Paris. The IMF is pleased to be returning to the Czech Republic for a two-day meeting to be held September 4th and 5th in Mikulov. In Germany, a seminar will take place on September 23rd in Heidelberg. In Slovakia, a meeting is scheduled for October 16th and 17th in Liptovsky Jan.

In Poland, a location is being secured for a seminar to take place during the first half of September. In Norway, meetings will take place in early November in Oslo – Trondheim and Bergen. Also in early November, there will be two seminars in Odense and Middelfart in Denmark. In addition, meetings are being organized in Budapest, Hungary, as well as in the Ankara and/or Black Sea regions in Turkey. Stay tuned for more information!

As we prepare for the seminars in Europe, the IMF will be producing translations of two of our key educational publications: the Patient Handbook and the Concise Review of the Disease and Treatment Options. The 2015 editions of these booklets will be available in Czech, French, German, Italian, Norwegian, Polish, Spanish, and Turkish. Also in progress are translations into Chinese.

For updated information about IMF meetings and publications, please visit myeloma.org. **MT**

What 'Just a Kid' Can Do

Fundraisers are taking place all across the country as friends of the IMF help support essential myeloma research while also raising awareness. Most events start with a call to the IMF and one simple question – “What can I do?” Those who become involved find their efforts to be fulfilling and empowering. No idea is too large or too small! From a large event such as a marathon or golf tournament to a small bake sale, garage sale, or a dance-a-thon with friends at your local gym, the IMF provides you with tools and assistance to make your fundraiser a success. Please contact Suzanne Battaglia at sbattaglia@myeloma.org or 800-452-CURE (2873) to chat about any ideas you might have. Become a part of making miracles happen and join us in working together toward our common goal...a CURE.



Zachary Barten's bar mitzvah was a chance for Zachary to raise money for myeloma research. His father, Andrew, at left, with daughter Jillian, was diagnosed with myeloma 10 years ago.

by **Suzanne Battaglia**
IMF Director, Member Events

Andrew 'Andy' Barten was diagnosed with myeloma approximately 10 years ago, when his son Zachary was just a toddler. At the time, the oncologist told him she had never seen anyone live more than two years with the disease, but the advances in myeloma research and therapies over the past decade have managed Andy's disease. Andy knows that "awareness of this disease is what drives research forward," so when his son Zachary was preparing for his bar mitzvah and tasked with a project designed to help the community or otherwise make a difference, Andy immediately thought of the IMF.

"I contacted Suzanne Battaglia, who put me in touch with Ilana Kenville of the IMF, and I explained that my son would like to do something to help and we only had about eight weeks for this project," Andy said.

Acting on Ilana's idea for a unique fundraiser, Zachary began collecting recyclables, with the goal that the money raised would go to the IMF and myeloma research. Andy and Zachary posted flyers about the project in their local library and supermarket in order to get more of their Plainview, New York community involved. As word spread about Zachary's project, he received many cash contributions, too.

"One donation in particular was quite touching. It was from a lady whose husband has myeloma. The couple lives right around the corner from

us, but we did not know them. This showed us that we are not alone!" Andy said.

Zachary's bar mitzvah was held on February 21, 2015 at the family's temple, Plainview Jewish Center, which also made a donation in Andy's honor. At the service, the Rabbi spoke about Zachary's project in his sermon. He described it as a "wonderful, thoughtful" project and was impressed with how successful it was, as well. The project raised over \$500 for the IMF.

"I was afraid that I would cry and be upset that I have this disease. Instead, I was incredibly proud of not only my son, but also my daughter Jillian, who drives and helped take Zach to do the recyclables," Andy said.

Andy's myeloma is being managed, but his fight with the disease won't be truly over until there is a cure. Similarly, Zachary's bar mitzvah is over, but that doesn't stop the donations and the recyclables from coming in from those who have been touched by this story and want to help the cause as well.

"I think my son was surprised at what 'just a kid' can do to help a charitable cause, but it is inspiring many in our community and hopefully beyond," Andy said. **MT**

A Lasting Legacy

Terry Lynn Miller was considered a bundle of contradictions—frugal in his personal life but generous to a fault with his friends and with the various charities and political causes he supported.

Add the International Myeloma Foundation to that list. Miller, who died of myeloma in 2013, has bequeathed a generous donation to IMF, adding to his earlier significant contributions. His total gift stands at \$337,000, money that he would be pleased to see being spent on research and the pathway to a cure.

Terry himself was grateful for the years he got to enjoy life beyond what doctors first predicted. Originally given two years to live, Terry fought every challenge that came his way, his trademark dry sense of humor always present. He lived 21 years past his initial diagnosis, crediting the strides in myeloma research for his longevity.

“I know he was grateful for the gift of so much time, which would not have been possible without the efforts made by the [International Myeloma] Foundation and others,” says his close friend Beth-Ann Herschaft. “I’m sure that’s why the Foundation played such a big part in his estate gifting plan.”



Terry Lynn Miller was born in Ohio on July 7, 1944 and later moved with his family to Florida, eventually earning an MBA from Florida Atlantic University. He went on to work for several governmental agencies, including the Internal Revenue Service, the Florida Department of Corrections, and the Florida Child Support Enforcement Division, where he was vigilant about contacting absent parents.

He was an avid reader of historical books and spy novels, and loved crossword puzzles and other word games – “any challenge to his thought processes was welcome,” said Beth-Ann. “You really had to concentrate to keep up with him. And when he saw that you got the joke, he engaged in hearty and heartfelt laughter.”

Thanks to Terry Miller’s generous gift, others like him may get to laugh harder and longer. **MT**

If you are interested in helping the IMF through your estate, please contact Stanley Baratta at (818) 487-7455 ext. 248 or sbaratta@myeloma.org.

Staff Update



Rafi Stephan Assistant to the President of the IMF

The IMF is pleased to welcome its newest team member, Rafi Stephan, Assistant to the President of the IMF. Rafi comes to us from the world of entertainment, where he last served as an executive assistant in International Television Distribution at Warner Brothers. He was at Warner Brothers from 2006 to 2014, during which time

he also served as special events director for the business resource group Network for Asian Pacific Americans (NAPA).

Rafi’s film industry experience includes being a producer and production manager for independent films, including Sundance selection *Must Be The Music* and Gus Van Sant’s *Speedway Junky*. He is a graduate of Texas Christian University in Fort Worth with a degree in Film/Television and a minor in History. Rafi is an avid reader, a film buff, and a comic book geek. He also plays on the trivia team We Got Nothing, which placed third in a Los Angeles Tournament of Champions last year.

“I’m very excited to join the dynamic team of the IMF to help carry on the innovative and important work they’ve been doing for the past 25 years,” Rafi said.

Rafi Stephan can be reached at rstephan@myeloma.org. **MT**

Hope Society

Inspire HOPE, and contribute to the fight against myeloma

With small, easy steps, you can make a huge impact on the continuation of the IMF’s mission. Hope Society members make simple, secure, recurring contributions to maintain the level of quality that you expect from our programs and services.

From one of our members to you:

“The IMF gives me the InfoLine, the forums, Dr. Durie’s blog, Patient & Family Seminars, webcasts, videos from scientific meetings, and more. Best of all, the IMF supports research which may **save my life**.

Surely, the least I can do is support them through the Hope Society.”

– Chip Shanley,
monthly donor

Ways to join:

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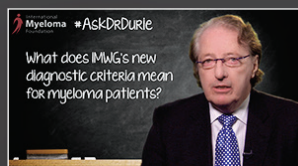
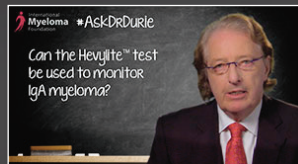
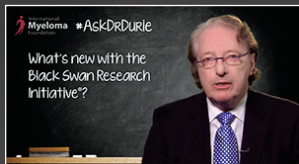
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#AskDrDurie



*A weekly web series from
the International Myeloma
Foundation*



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

2015 IMF Calendar of Events

- | | | | |
|---------------|---|------------|---|
| April 11 | IMF Myeloma Center Workshop (MCW) – Dallas, TX | June 20 | IMF Regional Community Workshop (RCW) – Edina, MN |
| April 23-26 | 40th Annual Congress of the Oncology Nursing Society (ONS) – Orlando, FL | Aug 21-22 | IMF Patient & Family Seminar (PFS) – Los Angeles, CA |
| April 24-25 | 5th Heidelberg Myeloma Workshop – Heidelberg, Germany | Sept 12 | IMF Regional Community Workshop (RCW) – Chicago (North Shore), IL |
| May 15 | IMF Next Generation Flow Workshop – Beijing, China | Sept 19 | IMF Regional Community Workshop (RCW) – Richmond, VA |
| May 16 | IMF Clinical Conference and Chinese Myeloma Working Group (CMWG) meeting – Beijing, China | Sept 24-26 | 15th International Myeloma Workshop (IMW) – Rome, Italy |
| May 29-June 2 | 51st Annual Meeting of the American Society of Clinical Oncology (ASCO) – Chicago, IL | Oct 10 | 9th Annual Comedy Celebration – Los Angeles, CA |
| June 6 | IMF Regional Community Workshop (RCW) – Charlotte, NC | Oct 16-17 | IMF Patient & Family Seminar (PFS) – Stamford, CT |
| June 8-10 | International Myeloma Working Group (IMWG) Summit – Vienna, Austria | Oct 24 | IMF Regional Community Workshop (RCW) – Richmond, VA |
| June 11-14 | 20th Congress of the European Hematology Association (EHA) – Vienna, Austria | Dec 5-8 | 57th American Society of Hematology (ASH) Annual Meeting and Exposition – Orlando, FL |

The IMF is proud to work with our global partners. We thank them for supporting our international meetings.

For more information about upcoming events, please visit calendar.myeloma.org or call 800-452-CURE (2873).

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

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