



Myeloma Today

A publication of the International Myeloma Foundation

IMF Takes Charge at ASH 2015



We attract more than 1,000 to our Satellite Symposium.
We present findings from a paradigm-changing study.
We live-stream important myeloma news around the world.
We award research grants that fund groundbreaking work.
We drive global access and awareness, and empower patients.



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A Message from the President

Dear Reader,

On January 5th, the cancer community lost a hero, Ellen Stovall, three-time cancer survivor. William Grimes of *The New York Times*, in his article about Ellen, noted that “She was a prominent advocate for patients dealing with cancer. She was a leader, bringing together people across the cancer spectrum.”

I don't claim to have known her well, but I met her and admired her. A quote in *The Cancer Letter* from Norman Colman, head of the Experimental Therapeutics Section and associate director of the NCI Division of Cancer Treatment and Diagnosis, resonated with me. He said, “Ellen is a rare transformational figure in cancer care, who saw an enormous unfilled need and led the development of the entire concept of cancer survivorship.”



Ellen Stovall, 1956–2016

In 1998, the IMF, along with many other cancer groups, came together in Washington, DC to participate in “The March: Coming Together to Conquer Cancer.” This demonstration drew more than 100,000 people



In 1998, the IMF launched its advocacy efforts in Washington, DC, at “The March: Coming Together to Conquer Cancer.”

and was the first big event that the IMF participated in. We felt the power of what happens when people come together as one to make change happen. Ellen Stovall played a major part in organizing this event. It was very powerful and left a lasting impression on all of us, as did she.

The impact of The March stayed with me and my team at the IMF, and it gave us the impetus to get involved in advocacy and it gave us our voice.

We became organized, we went to Washington, DC and met with congressmen and women, we walked the halls of government, were awed, and we became empowered. On June 4, 2002, I testified before the Senate Appropriations Subcommittee on Labor, Health and Human Services and Education. I was representing *One Voice Against Cancer* and I sat on the panel with Steve Case, Chairman of AOL Time Warner, and three other gentlemen.

Today the IMF has a very powerful and robust Advocacy team, led by Meghan Buzby. They have made change happen across the US. They work with many coalitions and have expanded the IMF's advocacy reach globally with the Global Myeloma Action Network – GMAN, which is now comprised of 36 members in 31 countries around the world (*see Page 17*).

None of this would have happened if I/we hadn't been inspired by Ellen Stovall. She empowered us and helped give us our voice. She leaves a lasting legacy, and will be missed.

Warm regards,

A handwritten signature in blue ink that reads "Susie Novis Durie".

Susie Novis Durie, President



Testifying before a Senate appropriations subcommittee in 2002 about the need to increase the funding for cancer research

This free issue of *Myeloma Today*® (Volume 16, Number 1) is dated January 15, 2016. *Myeloma Today*® is a quarterly (Spring, Summer, Fall, and Winter) publication of the International Myeloma Foundation, located at 12650 Riverside Drive, Suite 206, North Hollywood, CA 91607 USA

Research Highlights of the 2015 Annual Meeting of the American Society of Hematology

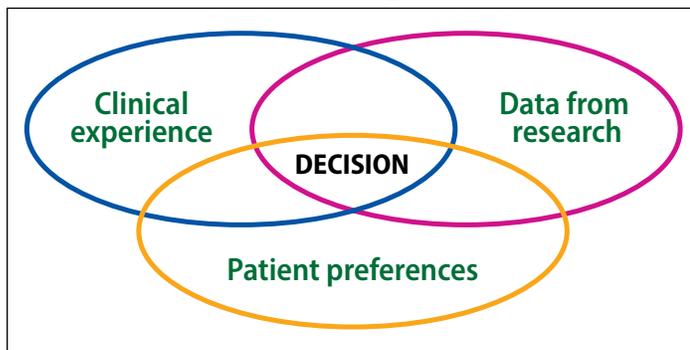
"...patient input was given equal weight with doctor expertise and research data in selecting optimal treatment. This is a huge step forward for myeloma patients."

By Debbie Birns
IMF Medical Editor

The approval of three new myeloma therapies in November 2015 (Darzalex®, Ninlaro®, and Empliciti®) brought high spirits to the grueling annual marathon of satellite, oral, poster, education, and scientific sessions that make up the American Society of Hematology (ASH) meeting, held this year in Orlando, Florida from December 5th–8th. As usual, there were hundreds (798, to be exact) of oral and poster presentations dealing with myeloma. Topics were divided among separate sessions on **biology** and **pathophysiology, transplant, treatments other than transplant, new agents, and, for the first time, immune therapy**. The ASH meeting provides the opportunity for hematologists, oncologists, researchers, and patient advocates from around the globe to share in this massive educational event. We pass along to you the most significant findings, those which will influence clinical practice and improve treatment outcomes.

The IMF sponsored one of the most sought-after sessions of the meeting, a symposium entitled "Global Advances in Myeloma: Providing Best Options for Treatment in 2015." One of ASH's finest moments came during this meeting when Dr. Philippe Moreau of Nantes University in France addressed the question of how to select the best treatment option with a single image: a large Venn diagram composed of three intersecting circles. In one circle were the words "Clinical Experience," referring to the experience and judgment of the doctor. In the next circle was "Data from Research," and in the third was "Patient Preferences." In the center, where all three circles intersected, lay the word "Decision." It was gratifying to see that patient input was given equal weight with doctor expertise and research data in selecting optimal treatment. This in itself is a huge step forward for myeloma patients.

The decision process



MRD dominates biology sessions

MRD (minimal residual disease) testing – the underlying tenet of the IMF's Black Swan Research Initiative® – dominated the biology sessions, with 15 abstracts on that topic alone. Highly sensitive tests for MRD with new methods that can detect one myeloma cell among one million examined cells are being incorporated in clinical trials to assess treatment response and are being used extensively in research to understand the underlying biology of the disease. Presentations on MRD testing at ASH taught us the following:

- The EuroFlow 8-color Next-Generation Flow method developed as part of the IMF's Black Swan Research Initiative® is fast, accurate, and standardized; preliminary results demonstrate that it has higher sensitivity than NGS (Next-Generation Sequencing).
- Results of MRD testing are independent of genetic risk and age, and are predictive of progression-free survival (PFS).
- Some patients who are MRD-positive after therapy have a unique immune signature that confers long survival.
- Only 30%–40% of patients who have complete responses to therapy are MRD-negative and have long survival.
- MRD testing can be done on tumor cells that circulate in the peripheral blood. These cells are detectable in 65% of MGUS patients and in 100% of smoldering multiple myeloma (SMM) and multiple myeloma (MM) patients. Increasing numbers of circulating tumor cells are predictive of poor overall survival (OS).
- The majority of MRD-negative patients also had normalization of their heavy/light chain ratios by HevyLite assay.

Long-awaited transplant news

For many years there has been little or no major news to report from ASH on transplant. We have long been waiting for data to determine the benefit and timing of autologous stem cell transplant (ASCT) in the era of novel therapy. Is it still necessary, given the range of excellent drugs in the armamentarium? This year, at last, the French myeloma group presented their half of the data from the IFM 2009/ Dana-Farber Cancer Institute (DFCI) randomized study evaluating the use of Velcade/Revlimid/Dex (VRD) with upfront transplant vs VRD with no or delayed transplant in newly diagnosed patients. Here are the long-awaited results of the IFM 2009 trial and other studies that corroborated those results:

- Patients who received VRD plus up-front transplant had higher CR rates and longer progression-free survival (PFS) than those



who had VRD without transplant. It was too early to assess OS. A sub-study of the MRD status of all the study patients showed that transplant induced a higher rate of MRD-negative status. When the DFCI data is available, the joint team of researchers in France and the US will be better able to assess whether the addition of ASCT to VRD improves OS.

- An Italian study comparing patients who had Rd induction and then were randomized to receive either ASCT or Cytoxan/Revlimid/prednisone combination therapy followed by maintenance therapy with either Rev/prednisone or Rev alone demonstrated not only that OS and PFS were significantly better in the transplant group, but that prednisone added nothing to Revlimid maintenance therapy and wasn't well tolerated.
- A retrospective study of data amassed between 2000 and 2012 in California, the US's most populous state, demonstrated that the use of ASCT, whether within a year of diagnosis or later in the disease course, is associated with improved OS. More significantly, this effect may be even MORE pronounced in the era of novel agents.

Significant myeloma treatment findings

Our own Dr. Brian Durie, IMF Chairman, gave the very first myeloma oral presentation at this year's ASH. The long-awaited results of a multi-center trial comparing VRD to Revlimid/dexamethasone (Rd) in newly diagnosed patients was designated one of the meeting's highlights by the ASH committee. The results of this study and others from this group of sessions follow:

- PFS and OS were a year longer with VRD than with Rd. These data firmly establish the superiority of triplet frontline therapy and confirm the efficacy of the combination of a proteasome inhibitor and an immunomodulatory agent (IMiD).
- In a sub-group analysis of the ENDEAVOR trial, treatment for relapsed myeloma patients with Kyprolis/dexamethasone (Kd) improved PFS over treatment with Velcade/dexamethasone (Vd) regardless of baseline high-risk genetic mutations, number of prior treatment regimens, or age. In fact, there was a trend for greater improvement in PFS in the eldest age subgroup – those 75 or older.
- Patients with high-risk cytogenetic mutations who received continuous therapy with Rd in the FIRST trial did not benefit from increased OS or PFS.

- Patients treated with Kyprolis/Revlimid/dexamethasone (KRd) who had high-risk cytogenetics had a nine-month improvement in PFS over those who were treated with Rd.
- Adjusting the dose of dexamethasone downward in the Pomalyst/dexamethasone trial for relapsed/refractory myeloma did not compromise response rates. On the contrary, patients had improved OS when their dexamethasone dose was lowered because they could stay on treatment significantly longer.
- A Karolinska Institute study demonstrated that on achieving at least a PR with Rd as second-line therapy, continuing with dexamethasone in addition to Revlimid does not add any benefit.

New agents

Now that elotuzumab (Empliciti), ixazomib (Ninlaro), and daratumumab (Darzalex) are approved, presentations of data from their registration studies (the studies presented to the FDA for evaluation prior to approval) underscored the durability of their efficacy. Highlights with drugs that are still in clinical trials, and with combination therapy studies involving the newly approved agents, include:

- In an interim analysis of the study of the combination of daratumumab/Revlimid/dex for patients with relapsed/refractory myeloma, 26/28 patients remain on the study with excellent responses. It is still too early to assess median PFS since few patients on the study have relapsed at this point.
- The all-oral proteasome inhibitor plus IMiD regimen of ixazomib/Rev/dex (iRd) for relapsed/refractory myeloma was compared to Rd alone in the French "Tourmaline" study. IRd increased median PFS by six months, including in those with high-risk cytogenetics.

Novel combinations in immuno-oncology

Immuno-oncology, the newest field of cancer treatment, is described as the third revolution in therapy after combination chemotherapy and targeted therapy. One of this year's biggest ASH stories is the emergence of the checkpoint inhibitor pembrolizumab (Keytruda®), an anti-PD-1 monoclonal antibody, in the treatment of myeloma. (Keytruda is already FDA-approved for non-small cell lung cancer and melanoma.) Checkpoints are built into the immune system to prevent overwhelming immune responses. PD-1 is attached to the surface of T cells. When bound to its ligand, PDL-1 (L is for ligand), it blocks T cells. Pembrolizumab "releases the brakes" on the T cells,

(continues on next page)

as presenter Jesús San Miguel explained, by blocking the interaction between PD-1 and its ligand, and enabling the T cells to flow to fight the myeloma. Like elotuzumab, pembrolizumab is not effective in myeloma without the synergy provided by an IMiD. In the keynote oral presentation given by Dr. San Miguel on pembro/Rev/dex, and in the pembro/Pom/dex study presented by Dr. Ashraf Badros of the University of Maryland, we learned the following:

- In 17 heavily pre-treated myeloma patients (there was a median of four prior lines of therapy), all of whom had previous treatment with both proteasome inhibitors and IMiDs, at a median follow-up of only 48 days, the overall response rate (meaning responses of at least 50% reduction in the amount of monoclonal protein) to pembrolizumab/Revlimid/dex was 76% (13 of 17 patients).
- In a study of the combination therapy of pembrolizumab/pomalidomide/dex, 42% of the patients had high-risk myeloma, and all had prior exposure to proteasome inhibitors and IMiDs; 90% were refractory to Revlimid. The overall response rate was 55%. Toxicities, however, were widespread and included autoimmune inflammation of lung tissue and infections, requiring the use of prophylactic antibiotics for the remainder of the study.

The last addition to the many myeloma oral presentations was a late-breaking abstract with the early results of a clinical trial of CAR T cells expressing an Anti-B-Cell Maturation Antigen (BCMA) that is ongoing at the medical oncology branch of the National Cancer Institute in Bethesda, Maryland. (NB: All studies done at the NCI's clinical trial center are free.) It is a small study with stunning results:

- In a 3+3 dose-escalation study, two patients treated at the highest dose level, both of whom had extremely aggressive myeloma prior to CAR T-cell therapy, had complete clearance of myeloma plasma cells from their bone marrow. One patient remains in stringent complete response (sCR) two months after treatment, and the other, at four weeks after treatment, is currently in near complete response, as is another patient treated at a lower dose level.

Dr. Durie's "clinical pearls"

In his pre-ASH teleconference, Dr. Durie presented a slide listing abstracts that offered "clinical pearls," bits of new-found wisdom that may help myeloma patients live better and longer. Among them were:

- The use of the antibiotic doxycycline along with combination chemotherapy in AL amyloidosis patients significantly improves OS in advanced cardiac stage III AL disease.
- Although it is an excellent tool for the detection of marrow involvement at diagnosis, MRI is not an effective tool for assessing response to treatment. Normalization of PET/CT after treatment and before maintenance, however, was highly predictive of improved PFS and OS.
- Whole-body diffusion-weighted imaging MRI (WB DWI MRI) has increased ability to detect myeloma infiltration of the bone marrow over PET/CT.
- The decision to use maintenance therapy with Revlimid or Velcade after transplant is more important for PFS and OS than is the choice of which induction therapy to use.

- Myeloma patients previously exposed to Agent Orange have shorter OS than those who were not exposed, perhaps because of higher-risk genetic profiles.
- Baseline characteristics, like calcium and hemoglobin levels, might predict the development of peripheral neuropathy in newly diagnosed patients treated with Velcade-containing regimens.
- Analysis of high-risk smoldering myeloma patients treated in a clinical trial with Rd demonstrated that the combination of these two drugs reactivates the impaired immune system.
- Insurance status, marital status, and income, but not race-ethnicity category or education, have a strong influence on survival in myeloma patients younger than age 65.
- "RVD-lite," with reduced doses of Revlimid, Velcade, and dexamethasone for older patients who would benefit from triplet therapy, may improve both tolerability and clinical benefit.
- More than 1500mg/24 hours of urinary protein loss may represent another "myeloma-defining event" in MGUS and SMM patients who are otherwise asymptomatic. These patients may benefit from early treatment.
- In a long-term study of 15.5 million Taiwanese adults, use of the statin atorvastatin (Lipitor®) was associated with a 20% lower risk of myeloma. Of the six individual types of statins evaluated, atorvastatin was the only drug that was associated with a lower myeloma risk. The protective effect strengthens with increasing cumulative dose.

"New rules"

In all the mass of information gleaned from this year's ASH, perhaps the most important messages – the highlights of the highlights – can be summarized in four sentences:

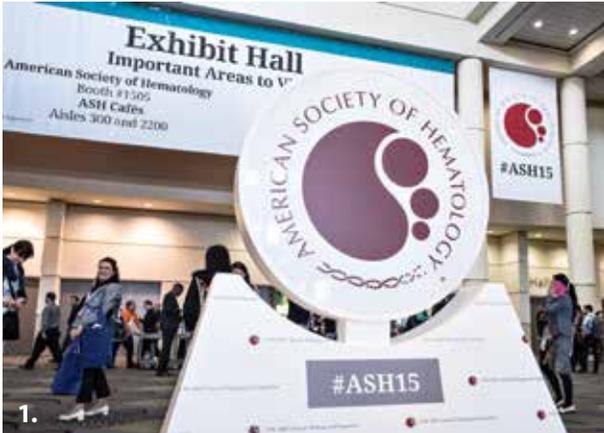
1. Triplet therapy provides improved PFS and OS as compared to doublet combinations. (As one presenter put it, "3>2.")
2. VRD followed by up-front autologous stem cell transplant provides longer PFS, higher rates of MRD negativity, and a trend to longer OS (at 39 months of follow-up, it is still too early to assess OS) than VRD without transplant, and should therefore be the standard of care for transplant-eligible patients.
3. Maintenance (post-transplant) or continuous therapy (for those who do not have a transplant) should be the standard of care.
4. Achieving MRD-negative status is predictive of OS.

The future

With so many therapies now in the myeloma armamentarium (IMiDs Thalomid, Revlimid, and Pomalyst; proteasome inhibitors Velcade, Kyprolis, and Ninlaro; monoclonal antibodies Darzalex and Empliciti; HDAC inhibitor Farydak; the old standards melphalan [oral or high-dose in stem cell rescue] and cyclophosphamide), there is much uncertainty about how best to combine and sequence these many agents, and how to find the best regimens for each patient. As Dr. Ken Anderson of the Dana-Farber Cancer Institute suggested, the myeloma community awaits the guidance of the IMF's International Myeloma Working Group to set the new standards of care and show us the way forward. **MT**

IMF in Action at the 2015 Annual Meeting of the American Society of Hematology

The International Myeloma Foundation (IMF) pushed the myeloma needle ahead once again at the 2015 Annual Meeting of the American Society of Hematology in Orlando, Florida. The IMF team was seemingly everywhere at the meeting – which attracts more than 20,000 hematology professionals – presenting game-changing myeloma treatment research, awarding our highly valued Brian D. Novis research grants, and moving our Black Swan Research Initiative® to the next level.



1. #ASH15 is the official Twitter hashtag for December's Annual ASH Meeting. 2. IMF educational materials are in high demand in ASH exhibit hall. 3. IMF Chairman Dr. Brian Durie leads Black Swan Research Initiative brainstorming session. 4. Bob Zins, an IMF research grant funder, and IMF President Susie Novis Durie. 5. Dr. Bruno Paiva explains Next-Generation Flow. 6. Dr. Michel Attal previews research at IMF's International Myeloma Working Group biannual meeting.

Generous Donations Help Fund 2016

The International Myeloma Foundation (IMF) awarded its 2016 Brian D. Novis Research Grants in a ceremony December 5, 2015 at the 57th annual meeting of the American Society of Hematology (ASH) in Orlando, FL.

For 20 years, the IMF has funded promising clinical investigators in the field of multiple myeloma from around the world through the generous donations of private individuals and IMF Member Fundraisers held across the country. Senior Research Grants are funded at \$80,000. Junior Research Grants are \$50,000.

The awards ceremony was filled with enthusiastic conversations between myeloma patients and the award-winning researchers dedicated to improving the lives of patients around the world.



Kristi Willette announces her \$100,000 donation to the IMF.

Among the generous donors who attended the event was **Kristi Willette**, who leads the Willette Charitable Foundation. She presented the IMF with a check for \$100,000 to support myeloma research.

“We are so grateful for Kristi’s generous and continuing support for research that will surely lead to a cure for myeloma,” said IMF President Susie Novis Durie.



Dr. Brian Durie and Susie Novis Durie celebrate Kristi Willette’s (center) generous donation.

In addition to donations from individuals, organizers of IMF Member Fundraiser events sponsored several of the 2016 Brian D. Novis Research Grants. As she introduced the winners of the Novis research awards at ASH, Susie Novis Durie made it a point to recognize the event organizers whose hard work made specific grants possible. Amidst hugs and tears, it was clear the researchers were thrilled to have a chance to meet and thank their benefactors:

Sharon and Scott Kowalczyk funded their first research grant this year after hosting the ChekFest Multiple Myeloma Golf Fundraiser last year. Their event is funding the research of **Dr. Giada Bianchi** (Dana-Farber Cancer Institute).



(Left to right) Scott and Sharon Kowalczyk and Giada Bianchi, MD, recognized alongside Robert A. Kyle, MD



Ron and Sheree Pask pose alongside Dr. Irene Ghobrial and Dr. Robert A. Kyle.

Ron and Sheree Pask, along with co-organizer **Gina Klemm**, are funding their fourth grant in three years through the Miracles for Myeloma 5K Run/Walk. Their event is funding the research of **Dr. Yang Yang** (University of Alabama at Birmingham).



Bob and Shelley Zins, hosts of the JC Golf Tournament and generous donors to the IMF

Bob and Shelley Zins host the JC Golf Tournament, one of the IMF’s longest-running member fundraisers. This is their fifth research grant, and it is funding the research of **Dr. Geoffrey M. Matthews** (Dana-Farber Cancer Institute).

Craig Czerkies and his family, organizers of the Carolyn Czerkies Memorial Golf Outing in memory of their mother, have funded four research grants. This year their event will fund the research of **Dr. Vijay Ramakrishnan** (Mayo Clinic).

Brian D. Novis Research Grants



(Left to right) Scott Kowalczyk; Yang Yang, PhD; Daiju Ichikawa, PhD; Constantine Mitsiades (on behalf of Geoffrey M. Matthews); Sharon Kowalczyk; Giada Bianchi, MD; Irene Ghobrial, MD; Norma C. Gutierrez, MD, PhD; Barbara Castella, PhD; Fenghuang Zhan, MD, PhD; Bob Zins; Shelley Zins; Vijay Ramakrishnan, PhD; Yoshiaki Chinen, MD, PhD; Sheree Pask; and Ron Pask.

2016 Brian D. Novis Research Grant Recipients

Brian D. Novis Senior Grants

Irene Ghobrial, MD

Dana-Farber Cancer Institute

Blood biomarkers for clonal progression in Multiple Myeloma

Norma C. Gutiérrez, MD, PhD

Salamanca Institute for Biomedical Research (IBSAL),

University Hospital of Salamanca

Optimization and validation of an automated capillary immunoelectrophoresis technology to quantify the expression of essential proteins in the pathogenesis of multiple myeloma

Yang Yang, MD, PhD

University of Alabama at Birmingham

Runx2 regulation of EMT and a bone resident of cell-like phenotype in myeloma cells

Fenghuang Zhan, MD, PhD

University of Iowa

NEK2 signaling in myeloma osteolytic disease

Brian D. Novis Junior Grants

Giada Bianchi, MD

Dana-Farber Cancer Institute

Investigating the Role of Robo1 in Migration and Homing in Multiple Myeloma

Barbara Castella, PhD

CERMS – AOU Città della salute e della scienza di Torino

Targeting the inhibitory pathways in the bone marrow microenvironment of multiple myeloma patients

Pádraig D'Arcy, PhD

Karolinska Institute

Proteasome Deubiquitinase Inhibitors as a new treatment for Multiple Myeloma

Geoffrey M. Matthews, PhD

Dana-Farber Cancer Institute

Treating myeloma through inducing degradation of BET bromodomain proteins

Vijay Ramakrishnan, PhD

Mayo Clinic

Targeting glutamine addiction in MM cells to inhibit disease progression and enhance myeloma therapeutics



IMF-Japan Research Grant recipients Yoshiaki Chinen, MD, PhD (left) and Daiju Ichikawa, PhD (right) with IMF President and Co-Founder Susie Novis Durie

IMF-Japan Aki's Research Grant

Yoshiaki Chinen, MD, PhD

Kyoto Prefectural University of Medicine, Graduate School of Medical Science

Regulation of PDPK1 and its clinical significance in multiple myeloma

IMF-Japan Special Research Grant

Daiju Ichikawa, PhD

Keio University

Identification of novel thalidomide-binding proteins and drug design for teratogenicity-negative IMiDs

MRD Testing in Myeloma Takes Center Stage

By **Brian G.M. Durie, MD**
IMF Chairman

The Fourth Annual ESLHO (European Scientific foundation of Laboratory Hemato Oncology) Symposium in Zurich, Switzerland, November 5–6, 2015 was the first ever dedicated exclusively to examining new developments in minimal residual disease (MRD) diagnostics. Very ably chaired by Prof. Jacques van Dongen, MD (Erasmus University, Rotterdam, The Netherlands), the two-day event provided a comprehensive review of the current status of MRD testing and future options, and included comments from Dr. Gerald Marti (Medical Officer, Center for Devices and Radiological Health, US Food and Drug Administration) on possible FDA approval of both the MRD tests themselves and acceptance of MRD negativity as a new treatment endpoint.



A bit of background

The ESLHO consortia that organize these meetings are scientific working groups of the European Hematology Association (EHA). This is very similar to the IMF's Black Swan Research Initiative® (BSRI), which is an offshoot of the International Myeloma Working Group (IMWG). Both groups are very much focused on MRD, with the BSRI – as you might suspect – fully dedicated to the area of myeloma.

As regular readers may know, a key underpinning of the Black Swan Research Initiative approach to finding a cure for myeloma is the highly sensitive assessment of any remaining disease. Therefore, the ESLHO symposium – with attendees from around the world – was an ideal forum in which to highlight the progress made by our research collaborators.

Prof. Alberto Orfao (University of Salamanca, Spain) provided an overview of new developments in MRD detection in his introduction. He emphasized the importance of the joint collaboration between the EuroFlow Consortium and the IMF's Black Swan Research Initiative in developing the Next Generation Flow (NGF) cytometry for MRD detection in myeloma. This has really spurred the development of MRD detection in myeloma ahead of the other hematologic malignancies, which were also discussed in detail at the meeting.



Prof. Alberto Orfao and IMF Chairman Dr. Brian Durie co-chaired the myeloma panels at the symposium.

'A completely new and innovative approach'

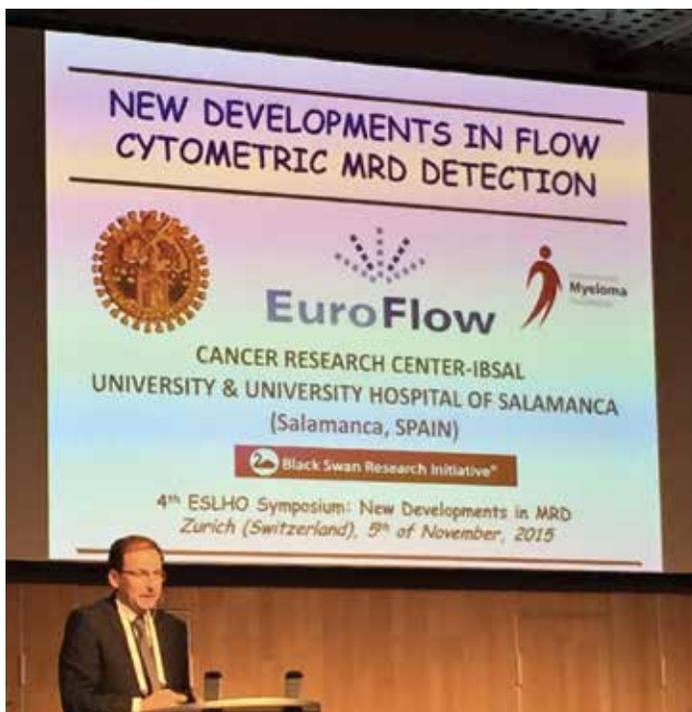
As Prof. Orfao noted, NGF “provides a completely new and innovative approach.” It is obviously disease (myeloma)-specific and provides rapid, accurate, sensitive, and reproducible results. New computer software and database tools give test results in 13 minutes! Greater sensitivity is achieved by several factors, including special sample preparation, routinely analyzing more cells, and using 8 antibodies (to give 8 colors) versus previous 4 or 6 antibody (color) approaches. There is also the potential to expand to 10 or 14 colors if needed.

The fundamental point is that this approach to measuring MRD is standardized and standard operating procedures (SOPs) are available for global use.

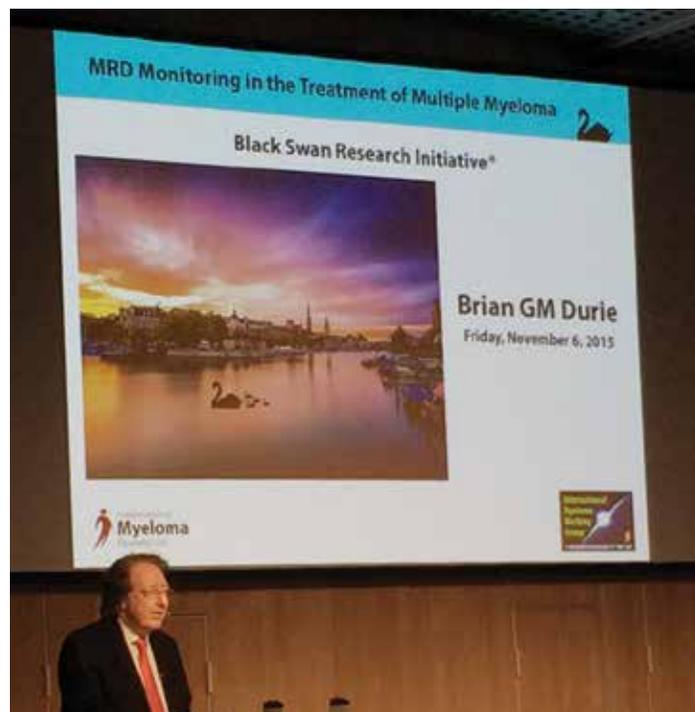
Pros and cons of two MRD testing methods

The myeloma panel discussants in Zurich were Drs. Ola Landgren (Memorial Sloan Kettering Cancer Center, New York); Bruno Paiva (University of Pamplona, Spain), and Philippe Moreau (University Hospital, Nantes, France). Prof. Orfao and I co-chaired. I gave an overview of the IMF's Black Swan Research program and evaluated the significance and importance of the new, sensitive MRD testing achievable using both NGF and Next Generation Sequencing (NGS), the alternate molecular approach. Both methods detect disease at the one-in-a-million level – meaning that if there are a million cells, the presence of just one myeloma cell can be detected.

The pros and cons of both methods were reviewed: NGF needs fresh samples; NGS can use stored samples. NGS does not give answers in 10–15% of cases; NGF gives results in all cases – and is more widely available and cheaper. Traditionally, the flow method has been less reliable. Thus, investigators have preferred NGS, which is tracking the



Prof. Alberto Orfao describes the exciting advances in MRD detection, particularly a method developed in partnership with the IMF.



Dr. Brian Durie's Black Swan Research Initiative® presentation emphasizes role of MRD detection in treating and curing myeloma.

myeloma clone. But now, with the very reliable NGF method, the picture has changed. In addition, we now understand that there are multiple myeloma subclones, and those can be detected and studied using flow (NGF). We are at a transition point during which the evidence demonstrates the clear advantages of using the new NGF method.

Is MRD monitoring feasible today?

Dr. Landgren discussed the feasibility of MRD monitoring at the present time. Obviously, the need for repeated bone marrow samples is a serious negative for patients. He emphasized the need for a blood test that would also avoid potential sampling problems in the bone marrow. (The IMF, through the BSRI project, is well on the way to identifying a blood test. This will really change the landscape for routine MRD monitoring.)



Dr. Papagudi Subramanian and presenter Dr. Ola Landgren, Black Swan Research Initiative team member

Dr. Landgren also raised the question of whether the 1 in a million sensitivity is sensitive enough. I think only time will tell.

Deeper responses, longer remissions

Dr. Bruno Paiva reviewed all the data correlating MRD testing with the outcomes of the patients.

These data came mostly from Spanish trials, but also from UK trials and other trials globally. The correlations are impressive! Deeper responses clearly lead to longer remissions.

The lingering question is: "At what point can we declare that a patient has achieved a functional cure – a likely very long or permanent remission?" Much more work is needed to assess this point. As BSRI moves into phase two, the "Cure Trials" will provide the framework to assess if early aggressive treatment can achieve a permanent MRD-negative status. Obviously, we need to be aware of some patients who have a permanent "MGUS status" or "signature": the disease is not gone, but is in a benign state.

In addition, MRD-positive patients will need additional novel therapies. Dr. Moreau discussed the novel therapies potentially available in this MRD-positive setting. The most promising results have been seen in both daratumumab (as well as the SAR compound, both anti-CD38 agents) and elotuzumab (anti-SLAMF7).

By the end of the Zurich symposium, it was clear that more work needs to be done to gain FDA approval of the MRD tests themselves and acceptance of MRD negativity as a new treatment endpoint. But there *was* broad optimism that the future is bright and that MRD testing will be a new standard in myeloma care very soon! **MT**

A Bounty of New Myeloma Drugs Gains FDA Approval

Late in 2015, the myeloma community saw a flurry of new drugs approved by the US Food and Drug Administration (FDA). Within approximately two weeks, the FDA approved three new myeloma drugs: Darzalex (daratumumab), Ninlaro (ixazomib), and Empliciti (elotuzumab).



First monoclonal antibody approved

First out the gate, on November 16, 2015, was the FDA's accelerated approval of Janssen Pharmaceuticals' **Darzalex** to treat patients with multiple myeloma who have received at least three prior treatments.



While the FDA approval of daratumumab came several months before anticipated, IMF Chairman Dr. Brian Durie said he was not entirely surprised. "In clinical trials reported at ASCO (American Society of Clinical Oncology)," he said, "daratumumab showed promising results as a single agent, producing excellent remissions in relapsed and refractory myeloma."

Darzalex (DAR²-zah-lecks) is the first monoclonal antibody approved for treating myeloma. It is given by infusion and works by helping the immune system attack cancer cells. The drug's safety and efficacy were demonstrated in two studies. In one study of 106 participants receiving Darzalex, 29 percent of patients experienced a complete or partial reduction in their tumor burden, which lasted for an average of 7.4 months. In the second study of 42 participants receiving Darzalex, 36 percent had a complete or partial reduction in their tumor burden.

Dr. Durie noted that daratumumab will be used in the upcoming IMF Black Swan Research Initiative[®] "cure trial, ASCENT. "Along with an aggressive strategy consisting of carfilzomib, lenalidomide, dexamethasone, and autologous stem cell transplant, we believe the anti-CD38 monoclonal antibody will provide that extra bit of treatment that could allow the eradication of many, if not all, resistant clones."

An oral proteasome inhibitor

Next, on November 20, 2015, came FDA approval of Takeda Oncology's **Ninlaro**, an oral, once-weekly proteasome inhibitor, for use in combination with lenalidomide and dexamethasone to treat people with multiple myeloma who have received at least one prior therapy.

"Oral treatments like Ninlaro provide myeloma patients new options for treatment," said Susie Novis Durie, President and Co-founder of the International Myeloma Foundation.

"This opens the door for a fully oral proteasome inhibitor-based triplet combination therapy," said Dr. Durie. "Having worked in multiple myeloma for decades, I've seen notable progress, yet significant unmet

needs remain. With today's approval, we now have another attractive and rather well-tolerated option for many patients living with multiple myeloma."

The safety and efficacy of Ninlaro were demonstrated in an international, randomized, double-blind clinical trial of 722 patients whose multiple myeloma came back after, or did not respond to, previous treatment. Study participants received either ixazomib in combination with lenalidomide and dexamethasone or placebo plus lenalidomide and dexamethasone. Those taking ixazomib in combination with lenalidomide and dexamethasone lived longer without their disease worsening (average 20.6 months) compared to participants taking the other regimen (14.7 months).



A monoclonal antibody

Finally, on November 30, 2015, the FDA granted approval of Bristol-Myers Squibb's **Empliciti**, a monoclonal antibody, for use in combination with lenalidomide and dexamethasone to treat multiple myeloma patients who have received at least one prior therapy.



Dr. Durie described elotuzumab as "a new class of agent which recruits the activity of natural killer (NK) cells to attack myeloma." The FDA approval, he said, is "a very important new addition to the myeloma arsenal."

Clinical trials of elotuzumab showed that the drug works more effectively in combination with the immunomodulatory agent Revlimid[®] and the steroid dexamethasone than alone. In a phase III study of 646 patients, Dr. Sagar Lonial of Emory University found that progression-free survival (PFS) increased by nearly 5 months in patients who had received 1-3 prior therapies and who were treated with elotuzumab combined with Revlimid/dexamethasone.

According to the study, the benefit was durable: PFS in the elo/Revlimid/dex-treated arm was 68% at one year and 41% at two years, compared to 57% at one year and 27% at two years in the Revlimid/dex-treated patients. "It was particularly striking that the difference between the elotuzumab and control groups seems to get bigger over time, which really speaks to the power of this immune-based approach," said Dr. Lonial.

For more information please contact the IMF team of InfoLine specialists by calling 800-452-CURE (2873) in the US or by email at InfoLine@myeloma.org. InfoLine phone lines are open Monday through Friday, 9 a.m. to 4 p.m. (Pacific). **MT**



Prof. Jean-Luc Harousseau, MD, Joins IMF as Medical Education and Research Consultant

The International Myeloma Foundation (IMF) is pleased to announce that renowned myeloma researcher Prof. Jean-Luc Harousseau, MD is joining the organization to help accelerate the IMF's global expansion and outreach efforts in Asia and Europe.

"I am thrilled and honored that Prof. Harousseau is joining our global team," said IMF President Susie Novis Durie. "As Medical Education and Research Consultant, Dr. Harousseau's background and expertise will enhance our global programs. We've had the pleasure of working closely with Dr. Harousseau for many many years, and he's been a dear friend – not only to the IMF, but to myeloma patients around the world."

"Jean-Luc Harousseau brings extensive experience in myeloma treatment and research to his new position with the IMF," said IMF Chairman Dr. Brian Durie. "In addition, his experience on the global stage makes him perfectly suited to playing an important role in our growing patient education and outreach efforts around the world."

Recently retired from his position as professor of hematology at the University of Nantes, France – a position he held since 1980 – Prof. Harousseau served as Chairman of the French National

Authority for Health (HAS) from 2011 through 2015. He served as Director of the Cancer Center Rene Gauducheau in Nantes from 2008 to 2011. From 1984 to 2008, Prof. Harousseau was Head of the Department of Hematology at University Hospital.

Prof. Harousseau was a founding member and served as President of the internationally renowned *Intergroupe Français du Myélome* (IFM), whose clinical trials have contributed significantly to the major improvements in the prognosis of myeloma. Recipient of the 2005 Waldenström Award and the 2009 Robert A. Kyle Lifetime Achievement Award for his work in the field of multiple myeloma, he has contributed to more than 500 peer-reviewed publications, including the *New England Journal of Medicine*, *Blood*, and the *Journal of Clinical Oncology*.

In his new role with the IMF, Prof. Harousseau will help increase access to treatment for myeloma patients globally. His vast experience working with policymakers in France gives him the credentials and inside knowledge to make change happen. "France has an independent body in charge of improving quality of care and patient safety," he said. "One of its most important roles is to evaluate the benefit/risk ratio and the efficiency of new drugs in order to make decisions about their reimbursement and pricing."

Prof. Harousseau's depth and breadth of knowledge, and his dedication to myeloma patients around the globe make him a terrific addition to the IMF's dedicated team, and we welcome him aboard. **MT**

IMF Appoints Dr. Rafat Abonour as Medical Liaison for Patient Education and Outreach

The IMF continues to expand its global education and outreach programs. The appointment of myeloma expert Dr. Rafat Abonour as IMF Medical Liaison accelerates the IMF's mission to affect positive change around the world.

"I am so pleased that Dr. Abonour is now part of our global team," said IMF President Susie Novis Durie. "Not only is Dr. Abonour a highly accomplished physician and researcher, he also embraces the IMF's core belief that knowledge is power. We are excited that Dr. Abonour will be sharing that message with patients, caregivers, and health care professionals."

"I really look forward to serving on the IMF team as Medical Liaison," said Dr. Abonour, a professor of medicine, pathology, and laboratory medicine at Indiana University in Indianapolis, IN. "Helping patients navigate this complex disease through the plethora of new drugs while keeping an eye on the ultimate goal of curing myeloma is challenging and rewarding work."

Dr. Abonour established and currently directs the multiple myeloma and plasma cell program at Indiana University Simon Cancer Center.

He is principal or co-investigator of several ongoing clinical trials, and his work has been published in key medical journals, including the *New England Journal of Medicine* and *Nature*.

According to Dr. Abonour, several years of serving as an expert panelist at the IMF's Patient & Family Seminars introduced him to the foundation's unique

method of patient education: "The IMF creates stress-free venues to learn about diagnosis and treatment of multiple myeloma." And at the seminars, he noted, the education goes both ways. "I was able to meet with some of the best doctors in myeloma care around the world and learn from them," he said. **MT**





Spotlight on Nurse Leaders

Page Bertolotti, RN, BSN, OCN
Samuel Oschin Cancer Center at
Cedars-Sinai Medical Center
Los Angeles, CA

Kevin Brigle, PhD, NP
VCUHS Massey Cancer Center
Richmond, VA

Donna D. Catamero, ANP-BC, OCN, CCRC
Mount Sinai Medical Center
New York, NY

Kathleen Colson, RN, BSN, BS
Dana-Farber Cancer Institute
Boston, MA

Hollie Devine, MSN, ANP-BC, AOCNP
James Cancer Hospital at
Ohio State University Medical Center
Columbus, OH

Deborah Doss, RN, OCN
Dana-Farber Cancer Institute
Boston, MA

Beth Faiman, PhD, MSN, APRN-BC, AOCN®
Cleveland Clinic Taussig Cancer Institute
Cleveland, OH

Elizabeth Finley-Oliver, RN
H. Lee Moffitt Cancer Center
and Research Institute
Tampa, FL

Charise Gleason, MSN, NP-BC, AOCNP
Winship Cancer Institute of Emory University
Atlanta, GA

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

Patricia A. Mangan, APRN, BC
Abramson Cancer Center at
The University of Pennsylvania
Philadelphia, PA

Ann McNeill, RN, MSN, APN
John Theurer Cancer Center at
Hackensack University Medical Center
Hackensack, NJ

Teresa Miceli, RN, BSN, OCN
Mayo Clinic - Rochester
Rochester, MN

Kimberly Noonan, RN, ANP, AOCN
Dana-Farber Cancer Institute
Boston, MA

Tiffany Richards, RN, MSN, ANP, AOCNP
MD Anderson Cancer Center
Houston, TX

Sandra Rome, RN, MN, AOCN
Cedars-Sinai Medical Center
Los Angeles, CA

Joseph Tariman, PhD, ANP-BC
School of Nursing/College of Science and Health
De Paul University
Chicago, IL

Daniel Verina, BS, BSN, MSN, ACNP-BC
Mount Sinai Medical Center
New York, NY

International Affiliates

Tracy King, RN, MN
Royal Prince Alfred Hospital
Institute of Haematology
Camperdown, Australia

Cindy Manchulenko, RN, BN, MSN
Leukemia/BMT Program of British Columbia
Hematology Research and Clinical Trials Unit
Vancouver, Canada

The IMF's Nurse Leadership Board

Founded in 2006, the IMF Nurse Leadership Board® (NLB) is a professional partnership representing nurse experts caring for myeloma patients at leading medical centers. The NLB's primary mission is to improve the nursing care and self-care of patients with myeloma by educating nurses and patients via consensus publications, symposia, multimedia, and research. NLB is thrilled to spotlight two of its accomplished nurse practitioner members, Kathleen Colson RN, BSN, BS, and Sandra Rome, RN, MN, AOCN CNS.



Kathleen Colson, RN, BSN, BS

Kathleen Colson is a long-standing champion for the care and well-being of myeloma patients. For the past 15 years, she has worked as a clinical research nurse with the multiple myeloma program in the Jerome Lipper Multiple Myeloma Center at Dana-Farber Cancer Institute (DFCI) in Boston, Massachusetts.

Previously, Kathleen served as a clinical staff nurse in the hematology/oncology outpatient infusion clinic at DFCI. Kathleen has also worked as a staff nurse both in the bone marrow transplant (BMT) unit at Beth Israel Deaconess Medical Center in Boston and in the hematology/oncology department at Memorial Sloan-Kettering Cancer Center in New York City.

Kathleen received both her BS in business management and a BSN in nursing from the University of Massachusetts. She has authored or co-authored numerous publications about myeloma treatments, supportive care, and side effect management. Kathleen has been featured as a speaker on these topics at many symposia and workshops, both nationally and internationally. In 2011, she was a presenter at the 13th International Myeloma Workshop in Paris, France.



Sandra Rome, RN, MN, AOCN CNS

Sandra Rome is passionate about the clinical care of patients with myeloma. As an oncology clinical nurse specialist, she shares her knowledge with colleagues and students, patients and family members, and many others.

Sandra received her BSN from UCLA in 1984 and started as a staff nurse on a medical and surgical oncology floor as well as the bone marrow transplant (BMT) unit. She obtained her masters with an oncology CNS specialty in 1988, also from UCLA, and was recruited to Cedars-Sinai Medical Center to develop their BMT program in 1991.

Sandra has had an impact on nursing on a national level as a speaker and author. She is a hands-on consultant and advocate. She supports her institution's research endeavors by collaborating with physician colleagues in implementing current clinical trials within the oncology patient care areas. In addition, Sandra has mentored and shared her clinical experiences with more than 50 graduate students at UCLA. In 2012, she was honored to receive the UCLA School of Nursing Distinguished Alumnus Award. **MT**

Immunotherapy in Myeloma

The IMF InfoLine coordinators answer your questions

By Debbie Birns
IMF Medical Editor

Q. Immunotherapy is in all the news I read about cancer treatment. What IS immunotherapy, and how will it be used in myeloma?

A. Cancer cells survive and grow because they are able to avoid detection and destruction by the immune system, which is made up of various types of multi-tasking white blood cells. The immune system doesn't always recognize cancer cells as "foreign invaders" because they aren't invaders, like viruses and bacteria, but instead emerge from inside the body as mutated versions of normal cells. Immunotherapy enhances the immune systems' ability to detect and attack cancer cells.

The rapidly growing field of cancer immunotherapy has produced new treatment methods that work in a variety of ways: some stimulate the activities of specific components of the immune system, while others counteract signals produced by cancer cells that help them avoid immune detection or suppress the immune response.

Dr. Vincent DeVita, the former (and longest-serving) head of the National Cancer Institute (NCI) and himself a cancer survivor, calls immunotherapy "a paradigm shift" in cancer treatment, a revolutionary new approach paralleled only by past insights that led to combination chemotherapy and targeted therapy. Now, he believes, immunotherapy can work in a majority of patients, and the war on cancer may finally be won.

The immune system and myeloma

The immune system is immensely complex, and its intricate functioning is still not fully understood. Research into the biology of myeloma and its progression from MGUS to active disease has provided some important insights into the mysteries of the immune system, and has demonstrated that even at the MGUS stage, there are important changes in immune system function. Research in immunology has made it clear that even small changes in one immune system cell can affect the functioning of all the others. We now understand that myeloma dysregulates the entire immune system: not only are many of the functions of immune system cells suppressed in myeloma patients, but immune system cells that are designed to protect us from cancer can instead enhance the growth and survival of myeloma cells.

Older immunotherapy approaches in myeloma

Immunotherapy for myeloma is actually not a new phenomenon, despite the emergence of new approaches and their recent prominence in the news. Because myeloma is a cancer of the immune system cells that are responsible for making antibodies (B-lymphocytes that mature into plasma cells), many immune-based approaches have been used over the years to fight this immune system malignancy. These older immune approaches are by now familiar to us, and include interferon-alpha, corticosteroids (prednisone and dexamethasone), allogeneic stem cell transplant, and immunomodulatory drugs (IMiDs®) Thalomid® (thalidomide), Revlimid® (lenalidomide), and Pomalyst® (pomalidomide). Even proteasome inhibitors Velcade®



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

(bortezomib) and Kyprolis® (carfilzomib), which kill myeloma cells by blocking the recycling of used proteins in the cells' nuclei, also stimulate immune system cells to attack and kill myeloma cells.

New immunotherapy approaches in myeloma

Over the past decade, the US Food and Drug Administration (FDA) has approved more than a dozen immunotherapies to treat different types of cancer, including lymphoma, leukemia, lung cancer, and melanoma. The FDA recently approved the monoclonal antibody Empliciti™ (elotuzumab), developed for the treatment of relapsed myeloma in combination with Revlimid and dexamethasone. It enlists "Natural Killer" or NK cells to attack and kill myeloma cells. In a phase III study of 646 patients, Dr. Sagar Lonial of Emory University found that progression free survival (PFS) increased by nearly 5 months in patients who were treated with Empliciti plus Revlimid and dexamethasone after 1-3 prior therapies.

Many more new immunotherapy approaches are also in clinical trials for myeloma or soon will be, including checkpoint inhibitors such as pembrolizumab, lirilumab, pidilizumab, and urelumab; oncolytic virotherapies such as the engineered measles and vesicular stomatitis viruses; dendritic cell vaccines, and CAR (chimeric antigen receptor) T-cell therapies.

For a more in-depth look at immune system cells and the new therapies being developed to harness their power in stopping myeloma, please read the new IMF publication, *Understanding the Immune System in Myeloma*, available online at myeloma.org or as a free-of-charge printed copy by request via TheIMF@myeloma.org or 800-452-CURE (2873). Order or download your copy today. **MT**

Please visit myeloma.org for up-to-date information about myeloma, and contact the IMF with your myeloma-related questions and concerns. The IMF 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. IMF InfoLine specialists can be reached at 800-452-CURE (2873) in the US and Canada, or 818-487-7455 worldwide. Phone lines are open Monday through Friday, 9 a.m. to 4 p.m. (Pacific). To submit your question electronically, please email InfoLine@myeloma.org.

IMF Urges Congress to Increase Access to Anticancer Medications

By Taylor Patton
IMF Advocacy Associate

Earlier this year, the IMF advocacy team participated in a briefing on Capitol Hill where representatives from the Patients Equal Access Coalition (PEAC), the IMF's federal advocacy coalition, met to discuss the ongoing oral parity initiative in Congress. The briefing was held on September 30, and hosted by Representatives Leonard Lance (NJ) and Brian Higgins (NY) in an effort to educate other



Rep. Leonard Lance (NJ)



Rep. Brian Higgins (NY)

members about the importance of this issue. A panel of stakeholders, each with a different perspective, provided a comprehensive overview of how the passage of the Cancer Drug Coverage Parity Act – H.R.2739 would have a positive impact on patients, caregivers, and providers. Rep. Lance and Rep. Higgins each spoke about their passion and dedication to cancer patients and their work in pushing the bill through the House of Representatives.

The panel was moderated by Meghan Buzby, IMF Senior Director of Advocacy. As one of the leaders of PEAC and the State Patients Equal Access Coalition (SPEAC), Meghan was able to provide the historical context for the parity efforts at the federal and state level, as well as pose questions that are important for patients and their families. When asked about her role in the briefing, Meghan said, "It was a privilege to moderate the oral anticancer treatment access briefing hosted by Representatives Lance and Higgins. All of our speakers did an excellent job and we added eight additional cosponsors due to our efforts!" The panel included Jolie Ditch, a caregiver for her husband who passed away last year from a glioblastoma; Jody Winsivk-Soluri,



(left to right) Leslie Brady, Legislative Assistant to Rep. Higgins; Meghan Buzby, IMF Senior Director of Advocacy; Jolie Ditch, caregiver; Dr. Randall Oyer, oncologist; Jodie Winsivk-Soluri, patient; and Lisa Nelson, Celgene.

a patient currently battling Acute Lymphoblastic Leukemia (ALL); Dr. Randall Oyer, an oncologist in Pennsylvania; and Lisa Nelson, a representative from the Celgene government policy team.

Following the briefing, the panelists and other representatives from the PEAC coalition held a small lobby day where they met with members of congress to urge their support for H.R.2739 and S.1566, the Senate companion bill. The members were very receptive to the plight of patients and caregivers, and were eager to learn more about the bills and how they may be of help moving forward. With their support, the IMF hopes that the bill will continue to pick up traction in the house and senate. As of this writing, there are 36 house sponsors and 6 senate sponsors.



We urge you to write your senators and representatives to ask for their support for S.1566 and H.R.2739. To do so, please visit advocacy.myeloma.org. **MT**

Help Us Reach All 50 States!



By Lindsey Trischler
IMF Advocacy Associate

In 2016, the IMF and its State Patients Equal Access Coalition (SPEAC) will have active campaigns to get oral parity legislation passed in six more states: Alabama, Alaska, Michigan, North Carolina, Pennsylvania, and Tennessee. We will be working closely with other organizations that represent patients, providers, and industry. And we need your help to reach our goal of laws passed in all 50 states. We only have 10 more to go!

These bills will require state-regulated private insurance plans to cover patient-administered anticancer treatments (such as oral pills) at an equally favorable rate to physician-administered anticancer treatments (such as intravenous or injectable drugs). Without parity, many cancer patients are paying high out-of-pocket co-pays and taking on a crippling financial burden, just to receive their life-saving medicines.

If you or someone you know lives in one of the states listed above, and has a story to share or has a passion to make a difference by helping cancer patients, please email us at advocacy@myeloma.org. **MT**

2016 Declared Year of the Advocate

By Ray Wezik
Global Advocacy Executive, IMF

Members of the Global Myeloma Action Network (GMAN) declared 2016 as the “Year of the Advocate” at their meeting held during the 2015 Annual Meeting of the American Society of Hematology (ASH). The group, comprised of patient advocates, industry partners, and physicians, identified multiple global initiatives and planned outcomes for 2016.



Aldo Del Col, Co-Founder of Myeloma Canada with Crucita Machado and Christine Battistini of IMF Latin America

Susie Novis Durie, President of the IMF, kicked off the meeting with a warm welcome and thanked the participants for their willingness to work together for the benefit of the patient. I gave a brief presentation to help guide the discussion, which centered on continued education of patients and doctors, understanding how to engage government entities, and identifying access barriers to treatment.

A multi-stakeholder approach

This was the first time GMAN members had met with industry and physicians around the table, all with an equal voice in the conversation. With this new multi-stakeholder approach, we hope new solutions to global access issues can be created.

Christine Battistini, President of IMF Latin America, described the success of her group’s recent myeloma awareness campaign throughout the continent, and suggested that this strategy might be used to increase awareness of access barriers around the globe.

Following the presentations, the group dove into a lively discussion of desired outcomes for GMAN with the goal of making 2016 the “Year of the Advocate.” Several fantastic ideas, such as a global awareness campaign, a focus on increasing clinical trial engagement, and several methods of engaging governments, were proposed. Ultimately,



Back row, from left: David McMullen (Myeloma Canada), Joel Beetsch (Celgene), Dan Navid (IMF), Ananda Plate (Myeloma Patients Europe), Meghan Buzby (IMF), Steve Roach (Myeloma Foundation of Australia), Jack Aiello (Support Group Leader), Dr. Roman Hájek (Czech Republic), Raymond L. Wezik (IMF), Brian Rosengarten (Myeloma Foundation of Australia). Front row, from left: Yelak Biru (Support Group Leader), Aldo Del Col (Myeloma Canada), Christine Battistini (IMF Latin America), Amber Spierer (Novartis), Hayley King (Myeloma Foundation of Australia), Susie Novis Durie (IMF President), Chad Saward (Celgene).

global myeloma
action network  an advocacy
initiative of the IMF

the group felt that creating a Patient Charter of basic treatment rights was the best first step to take following the New Year.

A Patient Charter

A charter will help the group establish a basic underlying set of principles for patients that, in turn, can help govern clinical trial design, help access treatment options, and insure patients receive the standard of care. Many at the table also agreed that a patient charter would help members engage in government advocacy efforts by presenting a unified set of acceptable standards for cancer care that does not exist in many parts of the world. Prof. Roman Hájek of Masaryk University in the Czech Republic and a member of the International Myeloma Working Group (IMWG) encouraged patient groups to work with the IMWG and its established guidelines to determine the best possible treatments given the drugs available.



Ananda Plate (Myeloma Patients Europe) and Dan Navid (IMF)

What’s next for GMAN? The group will launch smaller, focused work groups to create the Patient Charter and training groups to amplify members’ voices in government; promote global awareness; and continue the work accomplished this year in patient education. The annual GMAN Summit takes place this June in Copenhagen, Denmark. There, members will gauge progress made in these areas. We look forward to the “Year of the Advocate” and to moving access to myeloma treatment forward across the world. **MT**

IMF's Social Media Team Broadcasts

"The story of hope continues."

– Hugh Schaffer, Support Group Leader

The IMF brought 15 multiple myeloma Support Group Leaders (SGLs) to Orlando, FL, for the 57th annual meeting of the American Society of Hematology (ASH), from December 5 to December 8. The IMF was the first organization to bring patients to ASH, and 2015 marks the ninth year of this tradition. Under the helm of IMF Senior Director of Support Groups, Robin Tuohy, these IMF ASH team members used social media to share the latest clinical updates in myeloma research, therapies, and practice strategies via Twitter (#IMFASH15), Facebook, blogs, and videos. In fact, these tireless and passionate myeloma SGLs not only blogged and tweeted the most important myeloma news, they also earned the IMF a perch among the "Most Influential on Twitter," a title bestowed by Symplur, an organization that ranks healthcare activity on social media. A site dedicated to IMF at ASH 2015 can be visited at <http://ash2015blogs.myeloma.org/>. A greater purpose of this outreach by Support Group Leaders was not just to connect via the Internet, but to connect from global to local – or rather, bring information from the meeting at ASH 2015 home to their local support groups.

Pre-ASH Bash: the IMF Satellite Symposium

Upon arriving at ASH, the Support Group Leaders met for an orientation breakfast and discussed which sessions each of them would be attending. Later on December 4th, (which is officially the "day before ASH begins,") all the SGLs gathered in a cavernous auditorium at Orlando's Orange County Convention Center – the ASH venue – for the IMF Satellite Symposium "Global Advances in Myeloma: Providing Best Options for Treatment in 2015." This point-counterpoint session featured the IMF's Dr. Brian G.M. Durie as the moderator, and the panelists included Drs. Shaji Kumar, Philippe Moreau, Bruno Paiva, Antonio Palumbo, and Jesús F. San Miguel.

As SGL Jim Barth commented, watching the doctors in action was like watching "a soccer match." In his blog from this day, Barth continued his soccer analogy, closing it by saying, "All the doctors held their own, with a sense of sport and humor. However, there were very few black or white answers, and lots of shades of gray!" A replay of this year's IMF Satellite Symposium can be viewed at the IMF Website (www.myeloma.org) under IMF TV, Webcasts from Medical Meetings.

Mid-ASH breakout sessions

The second day at ASH began with the education session, "Multiple Advances in Myeloma." Some of the SGLs then attended a session on "Patient-Reported Outcomes," while others attended a working breakfast meeting (during which Teresa Miceli, RN and IMF Nurse Leadership Board member, helped patient advocates understand the information that they had been hearing at sessions.) At a special interest session called "Social Media for the Hematologist," SGL Cindy Chmielewski provided the patients' perspective on this panel. Cindy is an active myeloma educator on Twitter – @MyelomaTeacher – and has more than 3,500 followers.

Awards presentation

On Saturday night, SGLs attended the IMF's Media and Grant Awards Reception. At this reception, the researchers were thrilled to have a chance to meet and thank their benefactors. SGL Carlene Pratt said, "I really liked how the Senior and Junior Grant winners were able to hear patients' stories." She recounts one of the grant award winners, Dr. Vijay Ramakrishnan's humbling comment: "Hearing the patient's stories has given me more determination."

Carlene Pratt was not the only Support Group Leader who was exhilarated by the doctors' work. SGL Tom Swick said his highlight of the evening was "encountering Dr. Robert A. Kyle," a pioneering myeloma expert that Tom describes as the "Myeloma Messiah!"

The IMWG Conference Series

After going the distance, both literally and figuratively as the Orange County Convention Center is a large campus with several buildings, the IMF's social media team came together on the last day of ASH to watch the live-stream telecast of the International Myeloma Working Group (IMWG) Conference Series "Making Sense of Treatment" in Michael and Robin Tuohy's hotel room – an evening made complete with a dinner of pizza and wings. Again, a "soccer match" feel encompassed the audience as they sat on the edge of their seats to listen to Drs. Brian G.M. Durie, Joseph Mikhael, Antonio Palumbo, and Paul Richardson.

As SGL and myeloma nurse Teresa Miceli explained, "Because myeloma is such a complex, heterogeneous disease, there is not going to be a one-size-fits-all approach."

However, the event could not have closed on a more resounding note from IMF Board Director and North Texas Support Group Leader Yelak Biru, who has been living with multiple myeloma for 20 years. Yelak made the final comment at an "Add-on" FDA session, "As we celebrate many successes in the treatment of multiple myeloma, I urge you to get back to work, as the war is not yet over, but most of all, thank you!"

Meet the Leaders

Jack Aiello facilitates the San Francisco Bay Area Myeloma Support Group. He was diagnosed with Stage III multiple myeloma in 1995 when his kids were 16, 14, and 10. Today, Jack is proud to have walked his daughters down the wedding aisle and "bounced three grand-kids" on his lap.

John Auerbacher co-facilitates the Westchester Myeloma Support Group in Westchester, New York. Injured in a horseback riding accident in 2004 that called attention to his underlying condition of multiple myeloma, John met Dr. Brian Durie and Susie Novis Durie shortly thereafter. Since that time, he has been active in the IMF's myeloma community. As he describes, he "was transported into a wonderful world of caring, learning, and support."

Jim Barth facilitates the Tampa Bay Multiple Myeloma Support Group. Diagnosed with myeloma in August 2006, Jim has been able to maintain a pretty active lifestyle, including teaching full-time as a middle school math teacher.

the News from ASH 2015



IMF Support Group Leaders gather in front of holiday display at ASH 2015. *Back row, from left:* Nick Menedis, Jim Barth, John Auerbacher, Jack Aiello, Linda Huguelet, Hugh Schaffer, Carlene Pratt. *Middle row, from left:* Robin Tuohy, Michael Tuohy, Cindy Chmielewski, Teresa Miceli, Ann Pacowta, Jim Omel, Tom Swick. *Front:* Yelak Biru.

Yelak Biru has attended a half-dozen ASH conferences, facilitates the North Texas Myeloma Support Group in Dallas, and recently joined the IMF Board of Directors. Diagnosed at the young age of 25 with stage III multiple myeloma, Yelak lives by the motto “Evolving diagnoses: fear to hope,” and sharing this hope is his personal motivation.

Cynthia Chmielewski is a myeloma survivor and an active educator on social media. With more than 3,500 followers on Twitter, Cindy facilitates doctor-patient connections online on a daily basis and at break-neck speed! This was her fourth time attending ASH with the IMF.

Linda Huguelet and her husband, Jack, co-facilitate the Chattanooga Multiple Myeloma Networking group. Diagnosed with multiple myeloma at the young age of 46, Linda continues to educate herself and others in the myeloma community. This marks her third year of attending ASH with the IMF.

Nick Menedis has been the Columbus Area Myeloma Support Group Leader for nearly six years. He credits his wife, Sandy, with being his caregiver and major support partner for facilitating the group. At 67 years old, Nick is an active golfer and coaches the First Tee golf group of Central Ohio. In addition, he coaches swimming and bowling Special Olympics teams.

Teresa Miceli, BSN, OCN, is a registered nurse at Mayo Clinic in Rochester, Minnesota. She has been an active member of the IMF’s Nurse Leadership Board for more than a decade. In addition, she facilitates the Multiple Myeloma Sharing Sessions in Rochester, Minnesota, a support group for myeloma survivors and caregivers.

Jim Omel, MD, is a member of the National Cancer Institute’s Myeloma Steering Committee, a member of the ASCO CancerLinQ Patient Advocate Committee, a myeloma patient representative for the US Food and Drug Administration, a member of the Patient Advocate Committee and Transplantation Committees of the Alliance Cooperative Group, and the Co-Chair of the Center for Blood and Bone Marrow Transplant Research Consumer Advocacy Committee. Diagnosed with myeloma in 1997, Jim currently facilitates the Central Nebraska Myeloma Support Group.

Anne Pacowta is IMF’s Florida Regional Director, Support Groups. After her husband Jack was diagnosed with myeloma, they joined a support group in Connecticut, but later relocated to an area of Florida where they founded the North Florida Multiple Myeloma Support Group. Jack lost his battle with myeloma in 2008, and Anne continues to keep his legacy alive with her work.

Carlene Pratt was the co-leader of the Inland Valley Multiple Myeloma Support Group for ten years, and then she established the Upland California Myeloma Support Group in 2013. Having lived with myeloma for nineteen years, Carlene was excited to gather information at ASH about “myeloma patients’ response, remission, and survival.”

Hugh Schaffer is the co-facilitator of the Greater Cincinnati Area Myeloma Support Group. Diagnosed with multiple myeloma in April 2007, he commends his wife Marie as “the consummate caregiver. Her attention to details pays huge dividends with my care. I am very blessed.” Hugh has enjoyed a wonderful career in public education as a teacher, librarian, and district media coordinator. He sings, plays guitar and cello, and enjoys storytelling.

Tom Swick is the Chairman and Leader of the Orange County California Myeloma Support Group. In 2007, he was diagnosed with IgA-lambda type myeloma at the age of 54. He worked as a software engineer in the computer and aerospace industries, and lives in San Clemente, California, with his wife Judy and one of three adult daughters.

Michael Tuohy and his wife, Robin, started the first myeloma support group in Connecticut in the spring of 2001 with the help of the IMF. Michael has lived with myeloma for 15 years. At this year’s ASH, he focused on treatments of myeloma patients in the relapsed and refractory setting and learning more about the benefit of maintenance/continuous therapy.

Robin Tuohy is a caregiver to her husband, Michael, who was diagnosed with multiple myeloma in 2000 at the age of 36. She is also the Senior Director of Support Groups for the International Myeloma Foundation. Robin facilitated the group of 15 myeloma patients and support group leaders through the various programs at ASH 2015. **MT**

First Myeloma Patient Meeting in Hong Kong Is a Success

By Dan Navid
IMF Senior Vice President, Global Affairs

The first myeloma patient group meeting held in Hong Kong on October 9, 2015 drew 51 attendees. Dr. James Chim, Clinical Professor of Hematology and Oncology at the University of Hong Kong and a member of the IMF's International Myeloma Working Group (IMWG), spearheaded the effort to form this group. The idea came to him some time ago, and he recently called up a few patients to discuss how to get started. Not only was a myeloma patient group meeting held in October, a subsequent one took place on November 7, 2015. These meetings covered patients' health concerns, information about the Hong Kong Society of Myeloma, and most importantly, the mission and vision of the group itself.

Once participants had registered for the October meeting, Dr. Chim introduced the patients who sat on the meeting's panel. He highlighted the rapid evolution of myeloma therapy and how it has resulted in improved outcome for patients. Also discussed was the Hong Kong Society of Myeloma's role and how the Society will support myeloma patients to establish a territory-wide myeloma patient group.



Patients give feedback at the Hong Kong meeting.

Patients provided feedback and shared their experiences. Across the board, patients saw the need for this forum of information exchange – they wanted to gain knowledge about nutritional support, exercise, and other care guidelines. Moreover, the group discussed the unmet needs of myeloma patients in this region, including psychosocial support for both the patients and caregivers, the lack of access to novel agents, and the necessity for greater financial support for expensive myeloma drugs.

When sharing their stories, one patient explained how her myeloma was not diagnosed right away, and delayed treatment for almost a year. However, this patient also explained that she achieved complete remission after having an autologous stem cell transplant. Despite the success of the procedure, the patient eventually relapsed and after due management, she is now in very good partial response and back to work again. As a result of this patient's story, many others related how they also had experienced a delayed diagnosis.

Overall, the meetings were very well received. Members of this newly formed myeloma patient group recognized their need for continued information exchange. The group plans to have quarterly meetings to focus on patient and caregivers' needs, as well as to gain better access to treatment. They also hope to host organized social activities, including hiking and tea gatherings. **MT**



Dr. James Chim with panelists Margery, Teresa, Tony, and Erby



The Hong Kong Society of Myeloma at Queen Mary Hospital

Fall 2015 Update from Europe

Across the globe, the IMF had a very productive year in 2015. I am proud of our accomplishments in collaboration with our friends and partners in Europe. The IMF's educational programs continue to expand and grow, reaching more people and making a difference to the lives of many who are fighting myeloma. While each seminar distinguished itself in some way, all meetings successfully addressed the questions that were most pressing to the members of the local myeloma community. Some of the most popular topics included the latest news in international research and clinical trials, innovative treatments for newly diagnosed patients and options for relapsed/refractory disease, pain management and physical therapy, self-care and managing life with a serious illness, and how to better communicate with doctors. I am inspired by the people I met in 2015 and I am enthused about our plans for 2016!

– Nadia Elkebir, IMF Director, Europe and the Middle East

CZECH REPUBLIC

On September 4-5, the 11th Patient & Family Seminar hosted in the Czech Republic in cooperation with IMF was held in Mikulov, located in the beautiful region of Moldavia. Czech seminars are always memorable, and this one was no exception. The event started with a welcome reception for the 130 participants and the traditional champagne toast, followed by a buffet and live Czech music that everyone enjoyed dancing to. Many of the participants have formed friendships, both through the support group and by meeting at the annual IMF seminars.



Dr. Roman Hájek and Nadia Elkebir (IMF)

The faculty featured Dr. Roman Hájek, Dr. Vladimír Maisnar, Dr. Jan Straub, and Dr. Jaub Radocha. Other speakers included Petra Bučková (psychologist), Petr Hylena (support group), and Petr Pavlíček. The local patient group, CMG, was represented by Iveta Mareschová, Alice Onderkova, and three nurses.

HUNGARY

On September 15, I represented the IMF in Budapest at the Lymphoma/Myeloma Patient Day. Organized by Ibolya Kéri, president of the Hungarian patient group MOHA (Magyar Onkohematológiai betegekért Alapítvány), which covers all hematologic cancers, the educational



Ibolya Kéri of MOHA leads the Awareness Walk

seminar was attended by 200 people – the full capacity of the meeting room! In addition to doctors, the event featured nurses, psychologists, and physiotherapists. Dr. Mikala Gábor, the leading myeloma expert in Hungary was a key presenter. This was an excellent experience. The IMF will cohost the first joint IMF/MOHA seminar in 2016, with Dr. Gábor as moderator. In preparation for that meeting, the IMF is currently translating our educational booklets into Hungarian.



Event participants gather in front of St. Stephen Cathedral to release balloons in honor of blood cancer patients everywhere

POLAND

On September 12–13, the IMF was welcomed in the city of Olsztyn by 186 participants of the Patient & Family Seminar. Surrounded by 17 lakes, Olsztyn is a beautiful city. It was



Katri-Evelin Kont and Roman Sadzuga

the residence of Nicolaus Copernicus and the place where he made many of his progressive discoveries – a wonderful setting for an educational two-day meeting featuring specialists from different regions of Poland. Faculty included myeloma expert Dr. Artur Jurczynszyn, Dr. Michak Graczyk, Dr. Wojciech Matuszewicz, Dr. Wanda Knopinska, Dr. Kamila Malinowska, Dr. Katarzyna Nokampf, Dr. Marta Banach, Dr. Joanna Roszak, and 14 nurses. The local myeloma support group was represented by president Roman Sadzuga, who has led the group for 11 years. A guest speaker from Estonia, Katri-Evelin Kont, gave an overview of life with myeloma in Estonia. The seminar was filmed and featured by the local television station.



Eduardo Pinto

ITALY

On October 3, the Patient & Family Seminar in Rimini was hosted by AIL (Associazione Italiana contro le leucemie linfomi e mieloma onlus) in collaboration with the IMF. It was the second AIL-IMF joint seminar in 2015. Eduardo Pinto, President of AIL Rimini gave a warm welcome to the audience of 160. The participants were very inquisitive, which led to spirited Q&A sessions after each presentation.

The faculty featured presenters from different regions of Italy: Dr. Patrizia Tosi (Rimini), Dr. Maria Teresa Petrucci (Rome), Dr. Alessandro Corso (Pavia), and Dr. Massimo Modavi (Ancona), Dr. Sonia Ronconi (Meldola), Dr. Claudia Cellini (Ravenna), and several nurses.

Due to the success of the IMF-AIL partnership over the years, our goal is to expand the seminar program to three Italian cities per year.



Dr. Corso, Nadia Elkebir, Marco Gobi, Dr. Petrucci, Dr. Offidani, and Dr. Tossi

NORWAY

On October 5, the IMF co-hosted a Patient & Family Seminar in Trondheim with the Norwegian patient support group, Blodkreft Foreningen. This was the fifth such seminar in Trondheim, and it opened with a warm welcome from Inger Margrethe Landversk on

behalf of Blodkreft. The faculty featured Dr. Anders Waage and guest speaker Dr. Jens Hillengass of Heidelberg University in Germany. More than 140 participants were in attendance.

On October 6, the IMF continued its collaboration with Blodkreft at a joint Patient & Family Seminar in Oslo, a fifth such meeting in this city. More than 200 participants attended. Dr. Waage and Dr. Hillengass were featured speakers in Oslo, and were joined by



Dr. Anders Waage



Dr. Nina Gulbrandsen



Dr. Fredrik Schjesvold

Dr. Nina Gulbrandsen, Dr. Nina Borge, Dr. Fredrik Schjesvold, and Tone Hansen (President of Blodkreft). At the day's end, Tor Schaathun shared his story of living with myeloma and psychologist Elin Fjerstad made suggestions about coping strategies.



Dr. Ahmed and Tone Hansen

On October 27, the first educational Patient & Family Seminar held by the IMF in Bergen was also a first for Blodkreft Foreningen. Tone Hansen expressed appreciation for the IMF's help in making it possible for 140 people from the local myeloma community to interact

with myeloma specialists from near and far. The faculty included Dr. Ayman Bushra Ahmed, Dr. Anders Sundan, Tom Igelkjønn, Miriam Ostevold, psychiatrist Dr. Tor Jacob Moe, and a myeloma expert from the United States, Dr. Rafat Abonour.

The IMF and Blodkreft are collaborating on hosting three meetings per year in Norway, in Oslo and Trondheim plus a third city (Tromsø in 2016 and Stavanger in 2017).

SLOVAKIA

On October 16–17, the IMF returned to Litopvsky Jan for the third annual seminar cohosted with the Slovak Myeloma Society (SMS). I was happy to join the 138 attendees in celebrating the 10th anniversary of SMS, a notable testament to the dedication of the group's



Miroslav and Milada Hrianka

(continues on next page)



Yelak Biru

In 1995, at age 25, Yelak Biru was diagnosed with Stage III myeloma and was told he had three years to live. Since then, Yelak has witnessed a dramatic increase in treatment options, the approvals of several innovative anti-myeloma drugs, and hundreds of clinical trials.

In 2006, Yelak was part of the first group of patients who attended a meeting of the American Society of

Hematology (ASH) courtesy of the IMF, and he has since attended more than half a dozen ASH meetings. In addition, he has partaken in countless myeloma satellite symposiums, International Myeloma Working Group (IMWG) sessions, and myeloma workshops and seminars. He is a member of the IMF Global Myeloma Action Network (GMAN), a patient advisor for pharmaceutical companies, a liaison for the Smart Patients myeloma community, and the leader of the North Texas Myeloma Support Group.

“As a myeloma patient, I welcome the opportunity to serve on the IMF’s Board of Directors to help advance the IMF’s patient-centric paradigm. Joining the Board is a responsibility I look forward to fulfilling. It is my obligation and my honor to pay it forward, to help change fear to hope.”

Yelak brings with him more than 15 years of experience in business intelligence, helping organizations become data and insight-driven. He earned his master’s degree in computer science from the University of North Texas in Denton. **MT**

Jason S. Katz

The IMF is pleased to welcome Jason Katz to the IMF Board of Directors. Jason is Senior Director of CRM and Digital at HookLogic, a technology company that pioneered performance marketing for brands. As a creative executive, he brings with him 15 years of marketing and technology experience in both Fortune 100 and startups.



As a member of the IMF Board of Directors, Jason carries on the tradition of his father, Michael S. Katz, longtime IMF Director, highly accomplished and widely respected myeloma patient advocate, and beloved member of the IMF family.

“My dad fought hard for 25 years so that multiple myeloma would not define his life. He fought to enjoy his family, the arts, food, religion, and ironically one of the most rewarding and meaningful parts of his life became the IMF. Not only did the IMF help him creatively treat his disease but also gave him purpose in helping as many patients as possible to do the same. Like all my dad’s passions, he went all-in. And I’m grateful he did. It would be my great honor to continue the Katz Family relationship with the IMF and do whatever I can to further its mission, with such wonderful people who loved my dad so much.”

Jason earned an MBA in marketing and management from the Columbia Business School, and a BA in economics from Brandeis University. **MT**

INTERNATIONAL AFFILIATES — continued from page 22

leadership. Seminar faculty included Dr. Pavel Koutoucek, Dr. Petr Pavlíček, Dr. Peter Minarik, Dr. Helena Janotova, Dr. Jozef Novotny, and Miroslav Hrianka, President of SMS and husband of myeloma patient Milada Hrianka.

SPAIN

On October 19, I represented the IMF in Barcelona at a meeting featuring speakers Drs. Joan Bladé, Laura Rosiñal, Teresa Cibeira, Albert Oriol, Carlos Fernandez De Larrea, and Raquel Jimenez. I found the 110 participants very vocal and expressive, asking many pointed questions and providing immediate feedback. The patients have a powerful bond with their doctors, and six people spoke of their experiences. Their words of encouragement and hope were much appreciated by the patients and caregivers in the audience.

GERMANY

On October 24, the IMF was an invited participant at a patient meeting in Heidelberg, with Dr. Hartmut Goldschmidt as host and moderator. More than 100 attended. The next Heidelberg meeting will be



Dr. Joan Bladé



Dr. Hartmut Goldschmidt



Kaja Schmidt

cohosted by the IMF and will take place on October 24, 2016.

DENMARK

On October 29, more than 260 patients and caregivers gathered for the Patient & Family Seminar in Middelfart, where they were welcomed by new President of the Danish Myeloma Foundation, Kaja Schmidt. The faculty featured Dr. Bo Ambi and Dr. Niels Abildgaard. The session by Lene Kongsgaard Nielsen of Aarhus Universitetshospital on the quality of life in myeloma was so well-received that many asked to participate in her study, which includes nearly half the myeloma patients in Denmark. Guest speaker Prof. Philippe Moreau gave an excellent talk. Next year, we hope to help bring this educational seminar program to two cities in Denmark. **MT**

The Rothmans' Race with Research

On December 3, 2015, Paul and Carol Ann Rothman donated \$80,000 to fund an IMF Brian D. Novis Research Grant. Their generous gift will be used to underwrite a 2016 Black Swan Research Initiative® project led by Norma C. Gutierrez, MD, PhD, of the University Hospital of Salamanca, Spain. The Rothmans said they were inspired to donate to IMF research because they feel that Paul – who was diagnosed with multiple myeloma nine years ago – has been able to live beyond his original prognosis due to the amazing research leaps that have been made in the myeloma field.

“If you can live on and enjoy life, and if you have the ability to give back,” said Paul, “you have benefited from research that has been done in the past, and you can, in a small way, make research possible that will hopefully help multiple myeloma patients in the future.”

As a caregiver, Carol Ann said she wanted to give back to the IMF for a number of reasons. She recalls when Paul was first diagnosed and

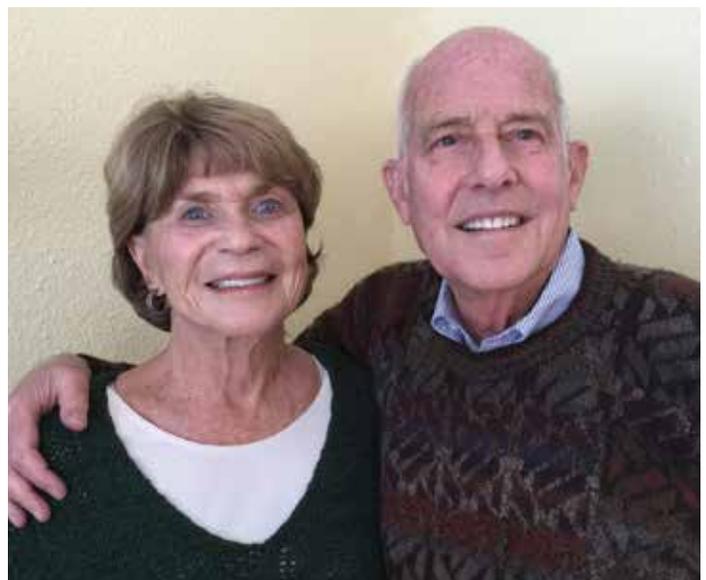


Norma C. Gutierrez, MD, PhD (BSRI), recipient of the Brian D. Novis Research Grant that the Rothmans helped fund

how she found hope and guidance from the IMF. A myeloma diagnosis can be daunting for any patient and caregiver. Carol Ann shared that while being bombarded with so many different opinions at the time of Paul’s diagnosis, she was grateful to the IMF InfoLine team for their ability to “clarify what I had been told, and to help us decide what treatment decisions to make.”

Both the Rothmans credited a personal connection they have developed with IMF InfoLine

Coordinator Paul Hewitt, whom they met two years ago at a Patient & Family Seminar in Short Hills, New Jersey. As Paul Hewitt recalls, “I found that the Rothmans were and are eager to empower themselves with knowledge so that they can effectively partner with Mr. Rothman’s medical team.”



Carol Ann and Paul Rothman, January 2016

The IMF is immensely grateful to the Rothmans for supporting Dr. Gutierrez’s project, which is entitled, “Optimization and validation of an automated capillary immunoelectrophoresis technology to quantify the expression of essential proteins in the pathogenesis of multiple myeloma.” For the project, Dr. Gutierrez will analyze 20 key proteins produced by 100 myeloma patient samples. This protein production reflects the important messaging between myeloma cells and the microenvironment in the bone marrow. Detection of specific proteins can indicate the presence of active myeloma, and therefore, be the basis for the new sensitive testing for MRD, including a new blood test, which would be in lieu of a more expensive and painful bone marrow biopsy. In addition, knowledge of key protein production can lead to the development of new, targeted therapies.

The IMF and the Black Swan Research Initiative® team share in Carol Ann and Paul Rothman’s excitement about what Dr. Gutierrez’s research might yield, as we all continue together on our journey, “Improving Lives, Finding the Cure.” **MT**



Inspire HOPE, and contribute to the fight against myeloma

Hope Society

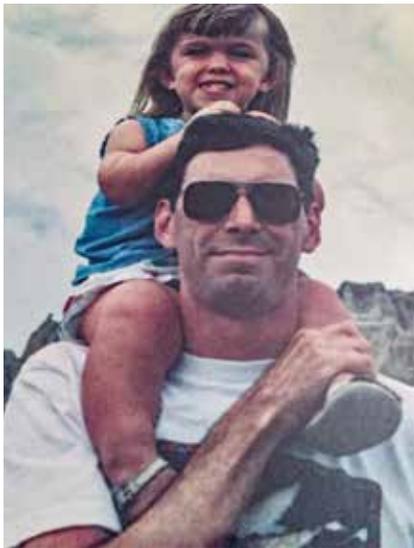
With small, easy steps, you can make a huge impact on the continuation of the IMF’s mission. Hope Society members make simple, secure, recurring contributions to maintain the level of quality that you expect from our programs and services.

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:
 Visit hope.myeloma.org, call 818-487-7455, or email Sharon Chow at schow@myeloma.org.

Ride Against Myeloma

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



Rachel, perched on her father's shoulder at age 4, viewing Mt. Rushmore.

By Rachel Smith

My name is Rachel and I lost my dad to multiple myeloma when I was only 10 years old. I wish that when my dad was diagnosed with this disease there would have been more options for management and treatment, or even a cure. I wish he could have seen me grow up with the qualities of persistence and integrity that he instilled in me.

My dad, Bruce Smith, was diagnosed with myeloma in 1996 at age 44. He graduated from Albion College with a degree in English, then received his master's degree in biology from the University of Michigan. He worked for Reichhold Chemicals for over 20 years, which brought our family to North Carolina. He enjoyed candle-making, running, playing tennis, camping, and going on trips with our family. Even after his myeloma diagnosis, he

would hike with our family. His competitive spirit in playing bridge and other games became an asset in fighting cancer. My dad was a living example of perseverance, and he taught me to always set high standards. He worked every day up until his passing in 1999.

On October 10th, 2015, I rode my bike in the Tour de Femme in honor of my dad and to help those families that are still struggling with myeloma. The Tour de Femme is a 32-mile bike tour for women only. It already raises money for the Livestrong Foundation and for Angels for Hope with REX Hospitals here in Raleigh, NC. My hope was to raise a significant amount of money for these organizations and also for the IMF.

I started training for this tour with my accountability partner Katie in June 2015. It was a beneficial journey as the training process kept me fit as I prepared for the tour. I have to train more



Rachel's mom and brother greet her after the Tour de Femme.



Rachel and her biking partner Katie with their supporters before the 32-mile ride.

than most as I have physical challenges that made it more difficult for me to achieve my goal. I was born with the most common type of dwarfism called Achondroplasia, which means I have an average size torso but my arms and legs are a lot shorter. Due to my dwarfism, I have a smaller bike that fits me, which has smaller wheels. Since I have a smaller bike with smaller wheels, I have to pedal twice as hard and exert twice as much force in order to cover the same distance as an average-sized person. This process helped me learn a lot about myself and I now have an activity that I love which helps me stay active. The Tour de Femme has helped me set several goals, including keeping fit, fundraising, and teaching my students how to set goals as well. As a kindergarten teacher,

(continues on next page)

Member Event

RIDE AGAINST MYELOMA — continued from page 25

I am so excited to share this journey with my students to show them that setting goals, partaking in activities to work towards these goals, and then ultimately achieving these goals is something that is actually attainable!

I was greeted at the start of the Tour de Femme by over 20 coworkers, students, and family members. I have never felt so loved by all the people from different areas of my life. It was the best thing to experience at the start of the Tour, as I had been nervous about getting lost in the crowd among several hundred average height bikers. Plus, it rained for the duration of the Tour! My main goal was to not get off my bike and to finish the race. Within the first 10 miles, there was a huge hill that I successfully defeated. After 16 miles, Katie and I arrived at the one and only rest stop, and were the last in our tour group to get there. By this point, we were soaked to bone but we weren't going to quit. The next 16 miles were a blur but I do remember biking our final mile with the destination in sight. At the finish line, we were greeted by our supporters and I can honestly say that I have never felt such a sense of accomplishment. I had been working towards this goal for months and I finally achieved it! I am proud to say that I successfully completed my first "half-century," the full 32 miles! This would not have been possible if it weren't for my family, friends, coworkers, students, and their families. My school family of 900 students donated over \$3,000 in coins to my cause, and my personal family and friends donated an additional \$1,300. I am so thankful to all who helped me



Rachel celebrates her ride in the bike tour with her trainers Katie and Ed.

with this endeavor, and I look forward to riding the "full century" – 64 miles – next year and attempting to raise \$5,000 for the IMF.

I want to raise money for the IMF so that, hopefully, the Foundation finds a cure. I'm optimistic that one day no one will have to endure what my family went through. There is no donation too small, not even a coin. My family and all the other families out there dealing with this devastating disease truly appreciate any form of support possible. **MT**

*You've got questions...
He's got the answers.*

#AskDrDurie



*A weekly web series from
the International Myeloma
Foundation*



We will change what a cancer diagnosis means. **Together.**

At Janssen, we're not about small steps. We've set our sights on making cancer a preventable and curable disease.

This isn't easy. That's why we partner with the world's top minds, from academic institutions and patient advocates to companies large and small.

Together, we are working toward one goal: changing what a cancer diagnosis means for patients and their loved ones.

We bring to life transformational cancer therapies – with a commitment to help get them to the people who need them.

We are Janssen. We collaborate with the world for the health of everyone in it.

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When science and passion connect, innovation happens.

Connecting with patients as individuals with unique needs helps us transform the way people live with cancer.

This connection energizes us to accelerate the development of medicines with potential for greater patient benefit.



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We Aspire to Cure Cancer.

At Takeda Oncology, we endeavor to deliver novel medicines to patients with cancer worldwide through our commitment to science, breakthrough innovation and passion for improving the lives of patients.

We know that our mission is not a quick or simple one, but we are up for the task: we aspire to cure cancer.

Learn more about our global commitment to oncology. Visit us online at takedaoncology.com.

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2016 IMF Calendar of Events

- February 26–27 IMF Patient & Family Seminar (PFS) – Boca Raton, FL
- March 5 IMF Regional Community Workshop (RCW) – Cleveland, OH
- March 18–19 IMF Patient & Family Seminar (PFS) – Seattle, WA
- April 2 IMF Regional Community Workshop (RCW) – Denver, CO
- April 8–9 IMF Patient & Family Seminar (PFS) – Philadelphia, PA
- April 28–May 1 41st Annual Congress of the Oncology Nursing Society (ONS) – San Antonio, TX
- June 3–7 52nd Annual Meeting of the American Society of Clinical Oncology (ASCO) – Chicago, IL
- June 7–9 7th Annual Summit of the International Myeloma Working Group (IMWG) – Copenhagen, Denmark
- June 9–12 21st Congress of the European Hematology Association (EHA) – Copenhagen, Denmark
- August 19–20 IMF Patient & Family Seminar (PFS) – Los Angeles, CA
- November 5 10th Annual Comedy Celebration – Los Angeles, CA
- Dec 2–5 58th American Society of Hematology (ASH) Annual Meeting and Exposition – San Diego, CA

*The IMF is proud to work with our global partners. We thank them for supporting our international meetings.
For more information about upcoming events, please visit calendar.myeloma.org or call 800-452-CURE (2873).*

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

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