

 **Myeloma Today**  
A publication of the International Myeloma Foundation

**IMF funds first  
large-scale screening  
to stop myeloma  
in its tracks**

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

**2016 IMF Calendar of Events**

May 19	IMF Patient & Family Seminar – Rome, Italy	Sept 9–10	IMF Patient & Family Seminar – Lázně Bělhorad, Czech Republic
June 3–7	52 <sup>nd</sup> Annual Meeting of the American Society of Clinical Oncology (ASCO) – Chicago, IL	Sept 17–18	IMF Patient & Family Seminar – Olsztyn, Poland
June 4	IMF Patient & Family Seminar – Padova, Italy	Sept 23–25	IMF Patient & Family Seminar – Heidelberg, Germany
June 7–9	7 <sup>th</sup> Annual Summit of the International Myeloma Working Group (IMWG) – Copenhagen, Denmark	Oct 1	IMF Patient & Family Seminar – Napoli, Italy
June 9–12	21 <sup>st</sup> Congress of the European Hematology Association (EHA) – Copenhagen, Denmark	Oct 7–8	IMF Patient & Family Seminar – Liptovský Jan, Slovakia
June 18	IMF Patient & Family Seminar – Paris, France	Oct 17	IMF Patient & Family Seminar – Tromsø, Norway
June 18	IMF Regional Community Workshop (RCW) – Ann Arbor, MI	Oct 18	IMF Patient & Family Seminar – Trondheim, Norway
June 25	IMF Regional Community Workshop (RCW) – Minneapolis, MN	Oct 20	IMF Patient & Family Seminar – Oslo, Norway
June 25	IMF Patient & Family Seminar – Vienna, Austria	Oct 24	IMF Patient & Family Seminar – Reykjavik, Iceland
Aug 19–20	IMF Patient & Family Seminar (PFS) – Los Angeles, CA	Oct 27	IMF Patient & Family Seminar – Sørup Herregaard, Denmark
		Nov 5	10 <sup>th</sup> Annual Comedy Celebration – Los Angeles, CA
		Dec 2–5	58 <sup>th</sup> 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](http://calendar.myeloma.org) or call 800-452-CURE (2873).

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**Dear Reader,**

My dear friend Mike Katz, who passed away on April, 26, 2015, was a passionate advocate for patients. And, as anyone who knew him could tell you, he was a passionate advocate for empowering patients. A dyed-in-the-wool techie, Mike naturally turned to technology to create the tools patients would need.

Mike brought the IMF into the digital age. He was instrumental in creating the IMF website, the Myeloma Manager, and finally, our app, the Myeloma Post. He also spent countless hours counseling and guiding myeloma patients on ACOR (the Association of Cancer Online Resources), a groundbreaking cancer patient online community that offered lifelines to thousands of patients.



At the IMF's annual Comedy Celebration in 2012 with two of my favorite guys – Mike Katz and Dr. Brian Durie.

So when we thought about how we might honor Mike's legacy, clearly it had to be through a project that continued his health-care technology mission – and something that would bring us closer to curing this disease. With that in mind I knew exactly the right guys to make this happen: Dr. Roni Zeiger and Gilles Frydman, founders of the online patient community Smart Patients.

Celgene presented the IMF with a generous grant to honor Mike's memory and his outstanding contribution to the myeloma community. The timing was perfect, as we had been in discussion with Smart Patients about developing a new clinical trials tool. With the support of the Michael S. Katz Legacy Award, Smart Patients has developed an online platform that connects myeloma patients to suitable clinical trials. This new feature will make it easier for patients to locate the best clinical trials for them, based on phase, type of myeloma, type of drug, and geographic location. We're proud to announce that the IMF will soon launch this amazing tool, which we know will be a remarkable resource for the entire myeloma community.

A smarter, faster, and simpler method for patients, caregivers, and even physicians to access trials online is long overdue.

Roni, former Chief Health Strategist at Google and a part-time urgent care doctor, said that it's nearly impossible for physicians to keep up with all the new trials.

"We know if more people are aware of trials and can find options they think might be a good fit for them, they can have more productive conversations with their doctors about which options to pursue," Roni said.

"The IMF is a perfect partner for us because they focus on patients and science, which is our goal as well," Roni said. "We can tap into their expertise to build a myeloma trial resource that's relevant, current, and useful to as many people as possible."

Gilles understands what patients are looking for when they turn to the internet for help – he created the Association of Cancer Online Resources (ACOR) 20 years ago, and worked with Mike, who built and managed the myeloma community on the message board when it was an email-based system.

"Mike led the transition to the Smart Patients web-based platform in early 2014 and worked closely with the Smart Patients team until his passing," Gilles said. Today, Support Group Leader and IMF Board of Directors member Yelak Biru has stepped in to guide conversations on the forum.

"Mike was a constant inspiration with his incredible drive and relentless pursuit of all information about the newest treatments and trials," Gilles said. "Mike always set the bar high, in every project he was interested in. We hope we have built a resource that would make him proud."

The IMF is grateful to Celgene for their generous sponsorship of the Michael S. Katz Legacy Award. "Mike's contribution to engaging the patient community in clinical trials is, and always will be, invaluable to the tremendous progress made in multiple myeloma," said Joel Beetsch, Celgene's Vice President for Advocacy.

We couldn't agree more.

Warm regards,

*Susie Novis Durie*

Susie Novis Durie, President





## IMF Funds First Large-Scale Screening to Identify and Treat Precursor of Blood Cancer before Disease Develops

“The IMF is excited to fund this study, which will finally shed light on how we can stop myeloma at its earliest stage, before it progresses into full-blown cancer.”

– Susie Novis Durie, IMF President and Co-Founder



In April, the International Myeloma Foundation proudly announced that the organization is the major funder of the world's first large-scale screening study aimed at preventing myeloma before it develops.

The study, iStopMM (Iceland Screens Treats or Prevents Multiple Myeloma), will examine

blood samples from approximately 140,000 adults over age 40 in Iceland for the earliest signs of myeloma. A cancer of the blood plasma cells that affects approximately 90,000 people in the US, and more than 200,000 people around the world, myeloma can go undiagnosed until the disease begins to seriously damage health.

“We are incredibly pleased to support the iStopMM project because we strongly believe that early treatment strategies could lead to the cure for myeloma,” IMF Chairman and Co-Founder Dr. Brian Durie said.

Dr. Durie leads the IMF's Black Swan Research Initiative®, a collaborative project to find a pathway to a cure for myeloma that currently supports more than 35 myeloma research efforts around the world, including the Iceland study.

Because nearly all citizens of Iceland over age 40 undergo routine blood tests, the country is an ideal setting for such research. After obtaining informed consent over the next few months of 2016, project leader Dr. Sigurdur Kristinsson of the University of Iceland and his team will screen blood samples from approximately 140,000 individuals for the precursors to myeloma – MGUS (monoclonal gammopathy of undetermined significance) and smoldering myeloma.



Those individuals diagnosed with the precursors will then be invited to participate in a randomized clinical trial to identify the best strategy for treatment and to create a new risk model for disease progression.

“The IMF is excited to fund this study, which will finally shed light on how we can stop myeloma at its earliest stage, before it progresses into full-blown cancer,” said IMF President and Co-Founder Susie Novis Durie.

While most MGUS cases are never diagnosed, it is estimated that 4% of people over the age of 50 have MGUS.

“The impact of early diagnosis in a whole population is a very ambitious and challenging goal,” said Dr. Kristinsson. “With more potent therapies available with fewer side effects, it is very likely that treatment of precursor states will be shown to improve survival and quality of life in smoldering and MGUS patients.”

Binding Site, a UK-based maker of diagnostic assays, will perform the study's initial screening phase, utilizing the Freelite® immunoassays and automated electrophoresis testing equipment, according to Dr. Stephen Harding, the company's R&D Director.

The study's co-principal investigator, Dr. Ola Landgren, Chief of Myeloma Service at Memorial Sloan Kettering Cancer Center in New York City, and his team will perform the molecular characterization of MGUS cases based on DNA sequencing of abnormal plasma cells in the bone marrow. **MT**



Beginning in the fall of 2016, Dr. Sigurdur Kristinsson of the University of Iceland and his team will screen blood samples from approximately 140,000 individuals in Iceland for the precursors to myeloma. Those diagnosed will be invited to participate in a randomized clinical trial to identify the best strategy for treatment and to create a new risk model for disease progression.

## Promising 2016 Clinical Trials



The most promising trials in 2016 involve new drugs, often combined with established ones. At the end of 2015, three new drugs were approved by the US Food and Drug Administration (FDA), so those are available without the need to be in a clinical trial. But which of the drugs in earlier development are the most promising moving forward?

There are really three categories of drugs that I would identify, among the many that are available, which are probably the most promising.

– Brian G.M. Durie, MD, IMF Chairman

### Pembrolizumab

At the 2015 Annual Meeting of the American Society of Hematology (ASH) there was a lot of excitement about one drug (already FDA-approved with the brand name Keytruda® for melanoma and non-small cell lung cancer) that is a new type of monoclonal antibody against a “checkpoint inhibitor” called PD-1. Checkpoint inhibitors are parts of our immune system that read messages on cell surfaces. These messages let them know whether a cell is healthy, unhealthy, or foreign to the body. If the cell is unhealthy or foreign, the checkpoint inhibitor will call out the immune system's troops – T cells – to mount an attack on the unwanted cells. Cancer cells protect themselves from this attack by creating cell surface proteins that say “I'm a healthy cell – don't destroy me!” Pembrolizumab – often referred to as “pembro” – overrides the checkpoint inhibitor, enabling T cells to mount a strong attack on the cancer cells. Like other monoclonal antibodies in the new category of “immuno-oncology” drugs, pembrolizumab may work better against myeloma cells when combined with an immunomodulatory drug (IMiD) such as Revlimid® or Pomalyst®. Used with these IMiDs, pembro has shown early results that are quite promising. There are now seven trials with pembrolizumab that are actively recruiting myeloma patients, and another three that will soon be open to accrual. Pembro is being tested in combination with drugs other than IMiDs – experimental agents in their own right – and across disease settings in myeloma, including for smoldering disease and post-stem cell transplant therapy.

### Clinical trials:

- Phase I pembro+Rd
- Phase III pembro+Rd versus Rd
- Phase III pembro+Pom/dex versus Pom/dex
- Phase I/II pembro+Pom/dex
- Phase I pembro as a single agent in hematologic malignancies
- Phase II pembro+Revlimid post-stem cell transplant
- Phase I/II pembro+ACP-196 in hematologic malignancies
- Phase I pembro+dinaciclib in hematologic malignancies
- Not yet recruiting as of April 15, 2016:
- Pembro for smoldering myeloma
- Phase II pembro in myeloma patients with residual disease

### Selinexor

Selinexor causes tumor suppressor proteins (also known as anti-oncogenes) to remain in the nuclei of myeloma cells, shutting down cancer cells' ability to export proteins that are harmful to them.

Oncogenes turn cancer cells on; anti-oncogenes shut oncogenes down. When anti-oncogenes cannot be exported from cancer cells, they are able to cause cell death.

Selinexor is a completely new type of drug, and is currently being tested in five new clinical trials. In the STORM trial, selinexor is combined with dexamethasone for patients who are “quad refractory” to Velcade, Revlimid, Kyprolis, and Pomalyst. Selinexor is also being tested in other trials with each of these “backbone” drugs individually to see if it is effective for patients who are less heavily pretreated. There are currently five trials with selinexor in myeloma that are ongoing and actively accruing.

### Clinical trials:

- Phase II selinexor+dex for patients who are quad-refractory
- Phase I/II selinexor in combination with backbone treatments
- Phase I selinexor+Kyprolis+dex
- Phase II selinexor+Kyprolis+dex vs placebo+Kyprolis+dex:
- Phase I/II selinexor+Doxil (pegylated liposomal doxorubicin)

### CAR-T cells

The third – and possibly most exciting – category of clinical trials being conducted in 2016 involves what are called CAR (chimeric antigen receptor) -T cells. These are T cells that have been removed from the body, engineered to attack the myeloma, and given back to the patient.

These T cells then target specific antigens on the surface of the myeloma. Results have been achieved in myeloma with T cells engineered to target the CD19 cell surface antigen – anti-CD19 – and were published in *The New England Journal of Medicine* (September 2015). A late-breaking ASH abstract from the annual meeting last December presented data on the use of CAR-T cells targeting the B cell maturation antigen (BCMA). Those results were also very promising, despite severe toxicities.

### Clinical trials:

- Phase I T cells targeting the B cell maturation antigen
- Phase I/II CD138-modified T cells
- Phase I CAR-T cells targeting NKG2D-Ligands
- Phase I CAR-T cells targeting CD19 for lymphoid malignancies

To find locations for these trials or other information about drugs in clinical trials, contact the IMF or visit the IMF's Myeloma Matrix at [matrix.myeloma.org](http://matrix.myeloma.org). **MT**



# Four New Myeloma Drugs – What Now?

## The IMF InfoLine coordinators answer your questions

By Debbie Birns  
IMF Medical Editor

### Q. How are the drugs approved in 2015 used in treatment?

A. In approving Farydak® (panobinostat), Darzalex® (daratumumab), Ninlaro® (ixazomib), and Empliciti® (elotuzumab) in 2015, the US Food and Drug Administration (FDA) broke with precedent and approved three of four new drugs to treat myeloma based not on their improved efficacy over older drugs, but on their novel mechanisms of action. Of the four new therapies, only Darzalex has single-agent activity and was approved based on its superiority to existing treatments for myeloma.

With a new HDAC inhibitor, two monoclonal antibodies, and an oral proteasome inhibitor added to the existing armamentarium of anti-myeloma agents, doctors find themselves with a wealth of anti-myeloma weapons and, as yet, limited approved indications for their deployment. Until further clinical trials better define the optimal use of the new drugs and determine how they fit in with the older drugs, treatment decisions must be based on the new agents' strictly limited FDA-approved indications.

Adding to the drugs' limited indications for use are the hard realities of financial constraints. Although doctors can legally write prescriptions for drugs once they are approved by the FDA, neither Medicare nor most commercial insurers will pay for drugs when they are prescribed "off label," that is, for treatment outside of the indication that is specifically described in the FDA approval language. For example, if a drug is indicated for the treatment of patients who have had one to three prior therapies, insurance will not cover its use in a previously untreated patient. Moreover, in this new era of limits on medical costs, some health plans refuse to authorize single or combination therapies even when prescribed for their approved indications because they are deemed too expensive. And in a new twist on cost-cutting, some healthcare organizations are financially penalizing physicians who prescribe expensive therapies, effectively quashing their use. A well-publicized protest by oncologists and pharmacists at Memorial Sloan-Kettering Cancer Center last year is certain to become more widespread in the coming years as doctors and hospital pharmacists refuse to supply expensive new drugs unless they have been proven better or safer than existing, less expensive agents of the same class.

### Farydak (panobinostat)

Farydak was approved by the FDA in February 2015, and is indicated "in combination with bortezomib (Velcade®) and dexamethasone (dex) for the treatment of adult patients with relapsed and/or refractory myeloma who have received at least two prior regimens including bortezomib and an immunomodulatory



Paul Hewitt, Judy Webb, and Missy Klepetar

drug (IMiD®). Patients in the PANORAMA-1 registration trial (the trial from which data was presented to the FDA to support Farydak's approval) were randomized to Farydak + Velcade + dex (FVD) or to placebo + Velcade + dex, and could not be refractory to Velcade. Patients in the trial could be refractory to an IMiD.

The subset of patients in the PANORAMA-1 study who benefited most from FVD in terms of depth of response and median progression-free survival (PFS) were heavily pretreated and had received both Velcade and an IMiD. Therefore, it was the data only from this subset of patients that was submitted to the FDA for approval of Farydak.

Materials provided to prescribing oncologists from Novartis, the manufacturer of Farydak, indicate that a patient who may be treated with FVD should have had at least a partial response (PR) to prior Velcade treatment with manageable toxicity, and then relapsed after a fixed number of Velcade cycles or after another therapy, such as an IMiD-based therapy. The patient should have had progressive disease on, or be refractory to, an IMiD-based regimen with Revlimid® (lenalidomide), Thalomid® (thalidomide), or Pomalyst® (pomalidomide).

**Advice for patients contemplating FVD:** Patients in the PANORAMA-1 study who received Velcade as a subcutaneous (SQ) injection rather than via an intravenous (IV) infusion tolerated FVD better. Therefore, we encourage patients to ask their doctors about receiving SQ injections of Velcade with this regimen. Side effects must be carefully managed with FVD, and doses of the drugs may be modified to make the regimen safer and improve quality of life.

### Darzalex (daratumumab)

Darzalex is the first monoclonal antibody approved to treat myeloma, and the first of the three new myeloma drugs to be approved last November. Of the four new agents approved last year, only daratumumab was approved as a single agent rather than a part of a combination therapy.



The two registration trials for Darzalex enrolled a total of 148 patients with relapsed/refractory myeloma who had received at least three prior lines of therapy, including an IMiD and a proteasome inhibitor. Nearly 30% of the 106 patients in the larger trial, and 36% of the 42 patients in the smaller trial, had a complete or partial reduction of their disease burden. Based on these data, daratumumab was approved by the FDA "in patients with multiple myeloma who have received at least three prior lines of therapy, including a proteasome inhibitor and an immunomodulatory agent, or who are double-refractory to a proteasome inhibitor and an immunomodulatory agent."

The FDA granted "breakthrough" status for daratumumab when it was in clinical trials and gave it priority review based on clinical evidence suggesting that, if approved, it would offer a "substantial improvement over available therapies." None of the other drugs approved in 2015 received breakthrough status or demonstrated that it was "a substantial improvement over available therapies."

Until clinical trial results broaden the indications for this effective new drug to include additional disease settings and combinations with additional agents, its current use outside of trials is as a single agent for patients who have had at least three prior therapies including an IMiD and a proteasome inhibitor, or who are refractory to both of these drug classes. Prescribing Darzalex in combination with another agent is not an approved indication, and therefore would likely pose a problem with insurance coverage.

**Advice for patients contemplating Darzalex:** Darzalex can cause low blood cell counts, which can be a problem for patients who have been heavily pretreated and already have low levels of white and red blood cells and low platelets. Your doctor should monitor your blood tests carefully and hold or adjust doses accordingly. Darzalex can also interfere with blood typing for transfusions and with some of the tests used to assess response to treatment.

### Ninlaro (ixazomib)

Ninlaro is the first oral proteasome inhibitor – the class of drugs that includes Velcade and Kyprolis® (carfilzomib) – a welcome convenience for patients. Another advantage of Ninlaro is the lower incidence and decreased severity of peripheral neuropathy (PN) in clinical trials with Ninlaro-treated patients as compared to historical data for those treated with Velcade. Despite these advantages, however, the two drugs cannot, at this time, be used interchangeably: Velcade is approved for use throughout the myeloma disease course, while Ninlaro is currently approved only in combination with Revlimid and dexamethasone for the treatment of patients who have received at least one prior therapy.



The registration trial for Ninlaro was the TOURMALINE study, in which patients were randomized to receive either the all-oral triplet regimen Ninlaro (ixazomib) + Revlimid + dex (IRD) or placebo + Revlimid + dex. IRD is a second-line therapy, and may benefit patients who have already had Velcade and/or Revlimid and who may need to boost a waning or suboptimal response to Revlimid + dexamethasone.

**Advice to patients contemplating IRD:** According to the package insert, patients taking IRD should receive preventive treatment with both an anti-viral medication and a blood thinner.

### Empliciti (elotuzumab)

Empliciti, a monoclonal antibody that binds to a myeloma cell surface antigen called SLAMF7, was approved based on the ELOQUENT-2 registration trial in which patients with relapsed/refractory myeloma were randomized to either Empliciti + Rev + dex (ERD) or to placebo + Rev + dex. The addition of Empliciti resulted in a 30% reduction in the risk of disease progression, and an increase in remission duration of 4.5 months. On November 30, Empliciti was approved in combination with Revlimid and dexamethasone for the treatment of patients with myeloma who have received one to three prior therapies.



Nine clinical trials investigating Empliciti's safety and efficacy in combination with other drugs and across disease states are currently recruiting patients, and another trial will begin accrual in the near future; the results of these trials will undoubtedly better define and expand its use. Currently it is often used outside the clinical trial setting for patients who have plateaued with a partial response to Revlimid + dexamethasone in an attempt to deepen their responses.

**Advice to patients contemplating ERD:** Low white blood cell counts are common with ERD, leading to an increased risk of infection. Your blood counts should be monitored carefully on this regimen, and patients who experience any signs of infection – fever, sore throat, mouth sores – should contact their healthcare providers immediately. **MT**

*Please visit [myeloma.org](http://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](mailto:InfoLine@myeloma.org).*



# From Jacksonville to Jamaica: The IMF Spreads the Word about Myeloma

Together with our dedicated army of patient advocates across the country, the IMF went into overdrive in March to raise awareness of multiple myeloma, tackling the project with passion, creativity, social media, and good old-fashioned snail mail. The ultimate goal of Myeloma ACTION Month, according to Robin Tuohy, IMF's Senior Director, Support Groups, is to encourage people to ask their doctors to consider myeloma as a possible cause of the adverse symptoms they are experiencing. Even though myeloma is the second most common blood cancer, it is relatively unknown.

"By harnessing the energy of patient advocates, we can raise awareness of the disease," Robin said. "With more treatment options available than ever, an early diagnosis is vital for achieving the best outcomes for patients."

IMF President Susie Novis Durie was the first to declare March as myeloma awareness month, an action she undertook in 2009. "I am gratified to see how many others in the community are honoring our creation by embracing March as myeloma awareness month," Susie said. "And I'm incredibly proud of the IMF team for the energy they've poured into a very results-oriented Myeloma ACTION Month this year. Each and every one of you has made a difference in fighting this disease."

From March 1st through March 31, Robin and her team hit the road to bring the IMF's myeloma education message – "Knowledge Is Power" – to people in more than 30 communities across the US. In addition to the large-scale IMF Patient & Family Seminar in Boca Raton, Florida, that kicked off the month, the team appeared at dozens of IMF Regional Community workshops, support group meetings, and patient education events at hospitals.

And when they weren't traveling to appearances around the country via planes, trains, or automobiles (often in rain, snow, and sleet), the IMF team took full advantage of every form of modern communication to push out myeloma information. From an old-fashioned letter-writing campaign targeting primary care doctors to a social media partnership with Spotify, IMF's Myeloma ACTION Month efforts were shared on Twitter, Facebook, Skype, and teleconferences. The IMF Myeloma ACTION Month website drew nearly 10,000 visitors, and the special IMF Patient Letter was accessed more than 500 times.

What had previously been called an "awareness" campaign, morphed into a call to "ACTION" in 2016 as the IMF team seized on fresh new ways to spread the word, such as:

- A one-page letter crafted by IMF Chairman Dr. Brian Durie was aimed at US primary care doctors who may not be familiar with myeloma but are on the front lines of a potential diagnosis. It spells

out potential myeloma symptoms and other red flags to look for, and can be downloaded to be sent to one's personal general practitioner. (Available here: [mam.myeloma.org/patient-action-letter](http://mam.myeloma.org/patient-action-letter))

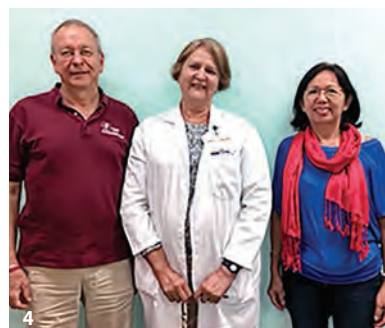
- Nancy Bruno, Southeast Regional Director of Support Groups for the IMF, attended a meeting of the Concerned Black Clergy in Atlanta to talk about myeloma awareness and to reach out to Health Ministers in their congregations for opportunities to provide myeloma education.
- Robin Tuohy appeared at the inaugural Jamaica Myeloma Symposium. Even a trip to Cuba by Tampa Bay support group founder Jim Barth and his wife You (during President Barack Obama's historic March visit) became an opportunity to raise awareness through Jim's sharing of IMF educational materials in Spanish!
- The IMF message flashed out from two digital billboards, thanks to a generous donation from Tom and Cathy Ordway. Throughout March, the IMF myeloma awareness message was broadcast from electronic billboards planted alongside the well-traveled highways in the Ordways' home state of Connecticut. (March is the rare month in which we all hoped for gridlock!)
- More than 500 listeners tuned into a lively "Living Well with Myeloma" teleconference that featured a panel of three top experts – Dr. Durie, Dr. Rafat Abonour and Dr. S. Vincent Rajkumar – and were invited to ask questions about treatment, in particular, the four newly approved myeloma therapies and how they might be used in the relapsed setting.

Funding for research was raised along with myeloma awareness through three separate efforts in March. A generous IMF donor matched donations received in our "\$31 Challenge" campaign, which

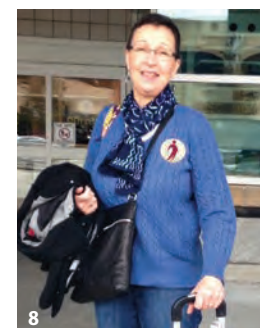
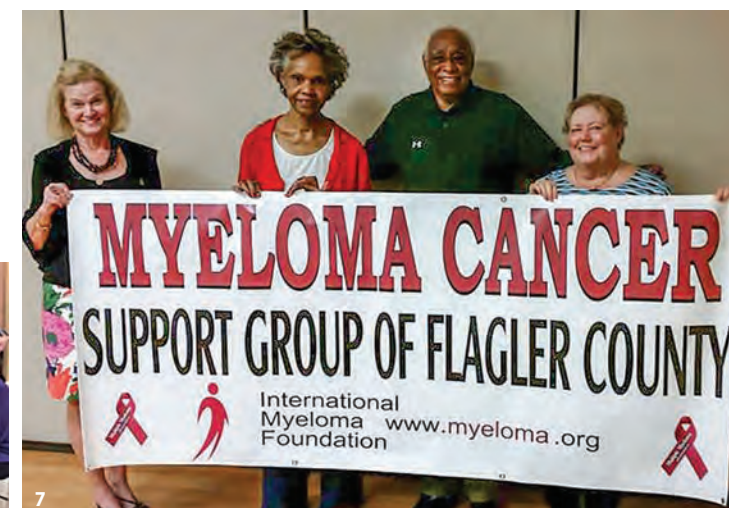
asked for a contribution of a dollar (or more) for each day in March. The IMF partnered with the Boston Celtics and Takeda Oncology in "3 Points for Patients," in which each 3-pointer made by the team triggers a donation to IMF research. The pharmaceutical company also sponsored an effort with Spotify, the music sharing platform, which offered a donation for IMF research each time someone followed the "Music 2 Fight Myeloma" playlist.

March may be behind us, but the IMF's mission to educate never ends. The impact of the IMF's 25-year history of empowering patients through education, can be seen in the simple stories such as the one shared with us on the IMF Myeloma ACTION Month website. Wrote Amy of New Bern, North Carolina:

*"In March of 2006 my husband, 56 years old, and I learned of his multiple myeloma diagnosis after almost year dealing with treatment for what was thought to be a hamstring pull. Although I had researched multiple myeloma on the internet while waiting for the test results, it did not prepare us for what was to follow... the helpful IMF packet that I requested helped me better understand the disease, treatments, and gave some hope that he may have longer to live than the two to five years given to us initially by the oncologist... I am happy to see the increased awareness which is leading to earlier detection and diagnosis so multiple myeloma patients now may be able to forego the handicapping bone damage before beginning treatment."* **MT**



1. Thanks to the Ordways for generously donating billboards to the IMF to raise myeloma awareness in Connecticut.
2. IMF Southeast Regional Director of Support Groups Nancy Bruno meeting with the Concerned Black Clergy in Atlanta, GA
3. Takeda Oncology's logo for the 3 Points for Patients, the initiative that raised \$25,000 for the IMF
4. Tampa Bay Multiple Myeloma Educational members, Jim Barth (left) and his wife, You (right), in Cuba with Dr. Martha Osario of Cuba's National Institute of Oncology
5. During March, Takeda Oncology donated to the IMF for each person who followed the "Music 2 Fight Myeloma" playlist on Spotify.
6. The Kansas City Support Group celebrates Myeloma ACTION Month.
7. The Multiple Myeloma Support Group of Palm Coast, FL, displays a banner that they created to raise awareness.
8. Joanne Gruber, co-leader of the Burlington, VT Multiple Myeloma Support Group, wore her IMF button throughout her cross-country trip.
9. Dr. Brian Durie moderates a panel at the Patient & Family Seminar in Boca Raton, FL.
10. Mike Starvola and Dan List pass out Myeloma ACTION Month flyers at the softball fields in Buffalo, NY.







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

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

Deborah Doss, RN, OCN  
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Beth Faiman, PhD, MSN, APRN-BC, AOCN  
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Charise Gleason, MSN, NP-BC, AOCNP  
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Patricia A. Mangan, RN, MSN, APRN-BC  
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The University of Pennsylvania  
Philadelphia, PA

Ann McNeill, RN, MSN, APN  
John Theurer Cancer Center at  
Hackensack University Medical Center  
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Teresa Miceli, RN, BSN, OCN  
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Kimberly Noonan, RN, ANP, AOCN  
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Tiffany Richards, RN, MS, ANP-BC  
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Cindy Manchulenko, RN, BN, MSN  
Leukemia/BMT Program of British Columbia  
Hematology Research and Clinical Trials Unit  
Vancouver, Canada

# JADPRO Publishes the NLB's Advanced Practitioner's Guide to Multiple Myeloma

## The IMF's Nurse Leadership Board

Founded in 2006, the IMF Nurse Leadership Board® (NLB) is a professional partnership representing nurse experts caring for multiple myeloma (MM) 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.



In March 2016, the *Journal of the Advanced Practitioner in Oncology (JADPRO)* published a CME/CE/CEU accredited supplement jointly provided by the IMF, the Annenberg Center for Health Sciences at Eisenhower, and JADPRO. *The Advanced Practitioner's Guide to Multiple Myeloma* was developed by members of the NLB as a continuing education activity for nurse practitioners, physician assistants, clinical nurse specialists, advanced degree nurses, oncology and hematology nurses, pharmacists, and physicians.

Managing a patient with MM across the continuum of care is challenging given the heterogeneity of the population, the older age of most patients with MM, and the rapidly changing treatment landscape. Many practices in the community or rural settings see relatively few MM patients. *The Advanced Practitioner's Guide to Multiple Myeloma* aims to provide other oncology professionals with state-of-the-science information they need to effectively manage patients with MM.

“Fortunately, great strides have been made in the diagnostic and prognostic processes, which then guide risk-adapted treatment,” said JADPRO guest editor Sandra Kurtin, RN, MSN, AOCN®, ANP-C. “The rapidly shifting treatment paradigm, although a welcomed change, has implications for providers. Assimilating the rapidly evolving scientific advances and effectively integrating these into the care of patients living with MM is necessary to achieve optimal outcomes.”

The JADPRO supplement provides a series of papers (by lead authors acknowledged below on behalf of the NLB) to help guide the advanced practitioner in the clinical management of MM, including:

- The Continuum of Care in MM Redefined: Challenges and Opportunities (by Sandra Kurtin);
- Sequencing of Treatment and Integration of Clinical Trials (by Beth Faiman, Charise Gleason, Kathleen Colson, Ann McNeill, and Donna Catamero);
- Palliative Care in MM (by Tiffany Richards and Kevin Brigle);
- New Agents in the Treatment of MM (by Beth Faiman, Ali McBride, Hollie Devine, Charise Gleason, and Sandra Kurtin);
- Monoclonal Antibodies in the Treatment of MM (by Charise Gleason, Hollie Devine, Beth Faiman, Deborah Doss, and Sandra Kurtin);
- Updates in the Diagnosis and Monitoring of MM (by Sandra Kurtin, Page Bertolotti, Kevin Brigle, and Daniel Verina);
- Adherence, Persistence, and Treatment Fatigue in MM (by Sandra Kurtin, Kathleen Colson, Joseph Tariman, Beth Faiman, and Elizabeth Finley-Oliver);
- Resources for Patients and Caregivers with MM and Their Providers (by Kevin Brigle);
- MM Treatment Options for Newly Diagnosed, Relapsed, and Refractory Disease (compiled by Kimberly Noonan, Teresa S. Miceli, Patricia Mangan, and Sandra Rome).

The IMF salutes the NLB for their commitment to improving the care, outcomes, and quality of life of myeloma patients and their caregivers throughout the continuum of care. **MT**

# 2016 Patient Meetings across Europe

By Nadia Elkebir  
IMF Director of Europe  
and the Middle East

The IMF's 2016 patient education program in Europe had an auspicious start with our first-ever meeting in Budapest. Held on March 19th in partnership with the Hungarian patient group MOHA (Magyar Onkohematológiai betegekért Alapítvány), the seminar was attended by 220 patients and caregivers. The event was moderated by bolya Kéri (MOHA President) and featured presentations by Dr. Mikala Gábor (the leading myeloma expert in Hungary who recently joined the IMWG) and guest speaker Dr. Rafat Abonour of the US. Faculty included Drs. Nagy Zsolt, Bildó Judith, and Riskó Agnes. The IMF has extended our work into new territories with a helping hand for patients and caregivers, and local healthcare providers and advocacy organizations. We look forward to the IMF-MOHA collaboration well into the future. **MT**



Nadia Elkebir, Dr. Abonour, Ibolya Kéri, Dr. Gábor, and a myeloma patient

More seminars to be held by the IMF and our partners in Europe have been confirmed for 2016:

- May 19 – Rome, Italy
- June 4 – Padova, Italy
- June 18 – Paris, France
- June 25 – Vienna, Austria
- September 9–10 – Lázně Bělohod, Czech Republic
- September 17–18 – Olsztyn, Poland
- September 23–25 – Heidelberg, Germany
- October 1 – Napoli, Italy
- October 7–8 – Liptovský Jan, Slovakia
- October 17 – Tromsø, Norway
- October 18 – Trondheim, Norway
- October 20 – Oslo, Norway
- October 24 – Reykjavík, Iceland
- October 27 – Sørup Herregaard, Denmark

# GMAN Members Hold Year-Round Activities

By Raymond Wezik  
IMF Global Advocacy Executive

The Global Myeloma Action Network (GMAN), an advocacy initiative of the IMF, is made up of 37 member organizations working collaboratively to improve the lives of myeloma patients around the world. While we make change globally, our members continue to effect positive change on behalf of patients in their home countries. Here, we highlight some of their great work.

Last fall, the Israeli Association of Myeloma Patients (the acronym for which is the word AMEN) launched a new public awareness campaign focused on the need for more combination therapies. As part of the campaign, a film was created that illustrates the passage of time throughout a life and the desire of myeloma patients to experience their lives to the fullest. The video, in Hebrew, ends with the message, “multiple myeloma patients asking for more time.” AMEN hopes that through public support, approvals for more treatment options will occur that can allow myeloma patients to live longer, healthier lives.

AMEN also recently started a program to provide dental care for myeloma patients who are prescribed drugs from the bisphosphonates class. In Israel, patients who take pamidronate (Aredia®) or zoledronic acid (Zometa®) must follow specific procedures in dental care to prevent damage to the jaw before starting bisphosphonate therapy. The Israeli health system does not cover these procedures and, prior to the launch of the new program by AMEN, some patients were unable to cover the out-of-pocket expense.

Late last year, Leukämiehilfe RHEIN-MAIN (LHRM) and the hematological department from the University of Freiburg in Germany

held a patient and family day featuring lectures by Prof. Dr. Monika Engelhardt and Dr. Andreas Mumm. At the LHRM booth, information about new and existing treatments was distributed via booklets and CDs.

Access to new treatments in Croatia is slowly improving thanks to the awareness campaign of GMAN member organization, Mijelom CRO. They generated media exposure centered around better treatment and access to new drugs for patients, including an article titled “Could it be Multiple Myeloma?” in *Pharmabiz*, a monthly publication circulated to 7,000 healthcare professionals. In addition, Mira Armour (Mijelom CRO Executive Director) was interviewed for a TV news segment about the significance of smart (targeted) drugs that are of much interest to patients and to regulators.

Finally, our Denmark member, Dansk Myelomatose Forening, has several meetings organized for the eleven network groups of the organization, where patients and their family members share all aspects of living with myeloma. On March 12th, a general seminar was held for patients with a special appearance by Søs Egelind, a very famous actress in Denmark, who spoke about how she lives her life with a blood cancer. Additionally, three regional meetings were held on April 2nd, where patients had the opportunity to learn from doctors about the regional protocols for treatment, key specific aspects of myeloma, as well as an overall review of this disease.

These efforts are a great example of the drive, focus, and compassion that all GMAN members demonstrate continually. As we move forward with the agenda for 2016 and beyond, we hope to be able to share more success stories from every member organization of GMAN. **MT**



## IMF and PEAC Hit the Hill



On February 24th, members of the IMF Advocacy team met with several key legislators on the Hill as part of the Patients Equal Access Coalition (PEAC), a collection of patient advocacy organizations, provider groups, and pharmaceutical companies that work collaboratively on treatment access issues for patients at the federal level.

The purpose of these meetings was to urge support of the Cancer Drug Coverage Parity Act in the House and Senate, H.R.2739 and S.1566, respectively, sponsored by representatives Leonard Lance and Brian Higgins in the House and senators Mark Kirk and Al Franken in the Senate.



(left to right) Representative Leonard Lance, Representative Brian Higgins, Senator Mark Kirk, and Senator Al Franken

Several other organizations joined us on the Hill – the Leukemia and Lymphoma Society (LLS), the Ovarian Cancer National Research Fund Alliance (OCNRF), Susan G. Komen®, the Lymphoma Research Foundation (LRF), the American Cancer Society Cancer Action Network (ACS CAN), Astellas Pharma US, and Celgene Corporation were all present.

The targets for the meetings were largely members who sat on the relevant committees in both houses – Energy and Commerce in the House, and Health, Education, Labor, and Pensions in the Senate – as well as members who handle appropriations. All in all, PEAC members met with more than 20 legislative offices to discuss oral parity and the potential impact it can bring to patients on a national scale. Many of the offices were receptive to the plight of the organizations involved and expressed their desire to assist in helping patients.

As a result of the efforts of the various organizations involved in the PEAC Hill Day, both H.R.2739 and S.1566 have equal bipartisan support between Democrats and Republicans. If your representative or senator is not yet a co-sponsor, please visit the IMF Action Center at [advocacy.myeloma.org](http://advocacy.myeloma.org) and follow the easy steps to send them an email. **MT**

## City of Los Angeles Proclaims "International Myeloma Foundation Day"



LA City Councilmember David Ryu, center, presents to IMF President Susie Novis Durie a proclamation declaring March 30, 2016 "International Myeloma Foundation Day." From left, IMF team members: Kelly Cox, Selma Plascencia, Debra Gendel, IMF Chairman Dr. Brian Durie, Lisa Paik, Rafi Stephan, and Suzanne Battaglia.

The City of Los Angeles marked Myeloma ACTION Month by honoring the International Myeloma Foundation and IMF President and Co-Founder Susie Novis Durie in a ceremony at City Hall. "March is Myeloma Awareness month, and it is fitting and well-deserved to declare March 30th as International Myeloma Foundation Day in the City of Los Angeles to recognize and support the advancements made towards the cure for myeloma," said L.A. City Councilmember David Ryu.

Susie thanked the City Council, the IMF team, and "all the myeloma patients" in accepting the honor. "If you have an idea, don't be afraid to move that idea forward," she said. "Don't be afraid



Susie Novis Durie thanks members of the Los Angeles City Council for honoring the IMF.

to let it grow. The IMF started with three people, and today, we have over 400,000 members in 140 countries around the world. The most exciting news is, thanks to our Black Swan Research Initiative, we're on the brink of finding a cure for myeloma."

"Thank you for doing the Lord's work," said City Council President Herb Wesson. "I don't have the words, really, to let you know how much we appreciate all you have done. Thank you for giving us hope." **MT**

## TEAM IMF Races toward a Cure in the Los Angeles Marathon and 5K



By Ilana Kenville  
IMF Member Events Associate

In February 2016, Team IMF participated in the annual Los Angeles Marathon weekend to raise money in support of the important Brian D. Novis Research Grants. On Saturday, February 13, Missy Klepetar (IMF Infoline Coordinator) and Joy Riznikove (IMF Development Associate) ran the LA Big 5K on a course that extended from Elysian Park to Dodger Stadium and back. On Sunday, February 14, Brian Helstien, a myeloma survivor, and Kevin Huynh (IMF Web Specialist) tackled the full Skechers Performance Los Angeles Marathon, the 26.2-mile race that started at Dodger Stadium and ended at the Santa Monica Pier.



Myeloma patient Brian Helstien after he completed the LA Marathon

He said he tackled the LA Marathon "to show other MM patients what is possible."

Kevin Huynh has participated in nine half-marathons and completed one full marathon in 2014. "In 2014, I vowed never to run a



IMF's Kevin Huyhn with his running team

Having been a lifelong athlete, Brian Helstien did not let myeloma stop him from pursuing his passions. Before his myeloma diagnosis in February 2011, he ran marathons and completed the IronMan Triathlon in Hawaii three times. Since being diagnosed, he has continued to run nearly every day, despite a stem cell transplant and ongoing drug therapy. "When the IMF announced it had joined the LA Marathon as a sponsored charity, I announced that I would run for them," said Brian. At 67, despite multiple injuries and a bad cold with fever, he made it across the finish line at 8 hours and 29 minutes.

marathon again because it was so painful. Completing a marathon is very rewarding, but getting to the finish line is a different story. By mile 26, even stretching and the anti-cramp spray no longer worked and I had to hobble to the finish line, crossing it at 5 hours and 47 minutes. My running group, my friends, my IMF coworkers, and total strangers cheered me on. The sense of accomplishment, both personal and on behalf of the IMF, along with the camaraderie and support was an amazing experience that I will never forget."



IMF's Web Specialist Kevin Huyhn with his medal for completing the 2016 LA Marathon

While officially considering herself as a retired runner, Missy Klepetar said she "was happy to put the knee braces back on when presented with the opportunity to support the IMF by running the LA Marathon's 5K. I am one of the InfoLine Coordinators for the IMF, and every



IMF Infoline Coordinator Missy Klepetar and IMF Development & Operations Assistant Joy Riznikove

day I speak with patients and caregivers who are looking for information about myeloma. The IMF provides them with these things, and more, going on 25 years now. It felt great to do some fundraising and promote myeloma awareness away from my desk that Saturday morning, running for Team IMF." Leading up to the day of the race, Joy Riznikove worked hard to bring in donations to support the IMF's research program, and she met and exceeded her goals. "I was honored to run the LA Marathon's 5K on behalf of such a great cause. I saw it as my opportunity to give back to the organization that does so much for so many people. This made my running so much more meaningful. Reaching the finish line together with Missy, we were met by people cheering us on. All the encouragement and the knowledge that I was able to give back to my community truly made the running experience wonderful." **MT**

*Fundraisers are taking place across the country as friends of the IMF help support essential myeloma research and patient programs while also raising awareness. Please contact Suzanne Battaglia, IMF Director of Member Events, at [sbattaglia@myeloma.org](mailto:sbattaglia@myeloma.org) or 800-452-CURE (2873), and join us in working together toward our common goal...a CURE.*



## Staff Updates



**Elaine DeLasho**  
Administrative Assistant  
edelasho@myeloma.org

Elaine DeLasho joined the IMF to assist Diane Moran in our New York location. She has a Bachelor of Science degree in Paralegal Studies and has worked in the legal field as a Contract Specialist. In the non-profit sector, she served as the Program Coordinator for the National Spasmodic Dysphonia Association for four years. Seven years ago, Elaine founded an online support group for moms who have children with life-threatening food allergies, and she continues to organize the group. Elaine has two children; they enjoy spending time together riding on bicycle trails, taking their four-year-old standard poodle to the park, bowling, and exploring the city.



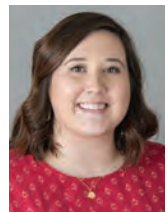
**Sapna Kumar**  
Communications Associate  
skumar@myeloma.org

Sapna Kumar joined the IMF team in October 2015. She provides editorial support for the IMF's digital, print, and video communications; helps expand IMF's media outreach; and copyedits content for the new website. Sapna honed her editorial skills by working in educational publishing at Encyclopaedia Britannica, McGraw-Hill, and Pearson Education. She earned a bachelor's degree in Creative Writing and Theater from Purdue University and has done graduate coursework at DePaul University in Human-Computer Interaction. On the personal side, Sapna first encountered the IMF when her mother was diagnosed with myeloma, and she became her mother's caregiver.



**Xuan Lam**  
Medical Affairs Assistant  
xlam@myeloma.org

Xuan ("Swan") Lam joined the IMF team in June 2015. She reports directly to the Chairman of the Board of Directors, Dr. Brian Durie, and Senior Vice President of Clinical Education & Research Initiative, Lisa Paik. Xuan supports Dr. Durie in clinical, research, and administrative duties. She also acts as a liaison between the IMF and pharmaceutical companies, and acts as program coordinator for Board of Directors meetings, IMF Patient & Family Seminars, and other national and international educational seminars for patients and physicians. Xuan is a graduate of Smith College with a degree in English Literature. She enjoys music, films, and long walks with her puppy.



**Lindsey Trischler**  
Advocacy Associate  
ltrischler@myeloma.org

Lindsey Trischler graduated from the University of Cincinnati in December of 2014 with a degree in Communication and a minor in Public Relations. She joined the IMF in June 2015. Lindsey developed a love for health policy while completing an internship with a lobbying firm focused in health-care. Her favorite part of her job is talking with advocates and educating patients about the IMF's advocacy initiatives. Lindsey is a recent transplant to Washington, DC. In her free time, she enjoys exploring the city and socializing with friends. **MT**

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## New and Updated 2016 IMF Publications

The IMF is pleased to announce several 2016 educational publications of interest to patients and caregivers, and healthcare professionals.

The updated edition of the *Concise Review of the Disease and Treatment Options* is an overview of myeloma, with a discussion of the pathophysiology, clinical features, and treatment options.

The booklets that comprise the IMF's *Understanding* series are designed to acquaint readers with treatments and supportive care measures for myeloma. 2016 editions include *Understanding Bisphosphonate Therapy*, *Understanding Dexamethasone and Other Steroids*, *Understanding Empliciti® (elotuzumab)*, *Understanding Freelite® and Hevylite® Tests*, *Understanding High-Dose Therapy with Stem Cell Rescue*, *Understanding Kyprolis® (carfilzomib)*, *Understanding Ninlaro® (ixazomib) capsules*, *Understanding Treatment of Myeloma-Induced Vertebral Compression Fractures*, *Understanding Velcade® (bortezomib) for injection*, and *Understanding Your Test Results*.

IMF publications are available on the website [myeloma.org](http://myeloma.org), where you will find a wealth of other valuable information, or by emailing [TheIMF@myeloma.org](mailto:TheIMF@myeloma.org) or by calling the IMF. We look forward to hearing from you. **MT**

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