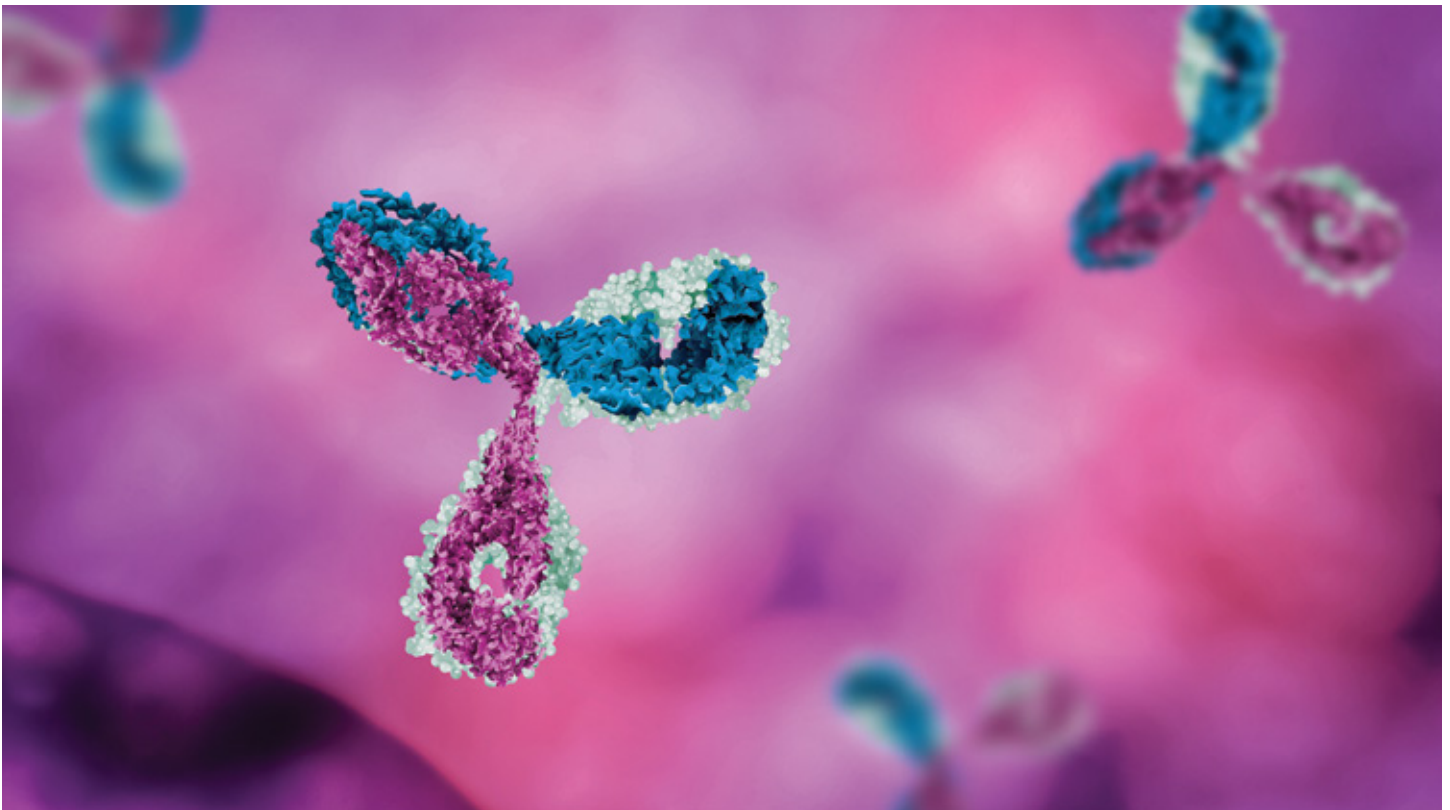




# Myeloma Today

A publication of the International Myeloma Foundation

## Immunotherapy in Myeloma: Monoclonal Antibodies



*Dr. Thomas Martin discusses antibody therapies in myeloma, ADCs that deliver toxins directly to BCMA-positive myeloma cells, multi-targeted BiTEs<sup>®</sup> antibodies, and the promising future of next-generation therapeutics that may be more effective than any other class of drugs tested so far in myeloma. PAGE 4*

### Other top stories

► **Expanded Approval for Xgeva<sup>®</sup> (denosumab)**

The FDA has expanded the approval of denosumab to include prevention of skeletal-related events in myeloma.

PAGE 5

► **Updates on Drug Therapies in Multiple Myeloma**

News on the use of Darzalex<sup>®</sup> (daratumumab), Kyprolis<sup>®</sup> (carfilzomib), Pomalyst<sup>®</sup> (pomalidomide), and selinexor in myeloma.

PAGE 6

► **Outreach Initiative for Community Physicians**

The IMF launches an initiative to provide recommendations for myeloma management to community healthcare practitioners

PAGE 7

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## IMF Executive Team

**Chief Financial Officer & Chief Operating Officer**  
Jennifer Scarne  
[jscarne@myeloma.org](mailto:jscarne@myeloma.org)

**Senior Vice President, Strategic Planning**  
Diane Moran  
[dmoran@myeloma.org](mailto:dmoran@myeloma.org)

**Senior Vice President, Clinical Education & Research Initiatives**  
Lisa Paik  
[lpaik@myeloma.org](mailto:lpaik@myeloma.org)

**Senior Vice President, Global Affairs**  
Daniel Navid  
[dnavid@myeloma.org](mailto:dnavid@myeloma.org)

**Chief Medical Officer**  
Dr. Joseph Mikhael  
[jmikhael@myeloma.org](mailto:jmikhael@myeloma.org)

## IMF Staff

**Database Manager**  
Sevag Abajian  
[sabajian@myeloma.org](mailto:sabajian@myeloma.org)

**Senior Director, Marketing**  
Peter Anton  
[panton@myeloma.org](mailto:panton@myeloma.org)

**Inventory Control Manager**  
Betty Arevalo  
[marevalo@myeloma.org](mailto:marevalo@myeloma.org)

**Senior Director, Member Events**  
Suzanne Battaglia  
[sbattaglia@myeloma.org](mailto:sbattaglia@myeloma.org)

**Medical Editor**  
Debbie Birns  
[dbirns@myeloma.org](mailto:dbirns@myeloma.org)

**Southeast Regional Director, Support Groups**  
Nancy Bruno  
[nbruno@myeloma.org](mailto:nbruno@myeloma.org)

**Director, Support Groups & Regional Community Workshops**  
Kelly Cox  
[kcox@myeloma.org](mailto:kcox@myeloma.org)

**Administrative Assistant, Strategic Planning**  
Elaine DeLasho  
[edelasho@myeloma.org](mailto:edelasho@myeloma.org)

**Director, Public Policy & Advocacy**  
Danielle Doherty  
[ddoherty@myeloma.org](mailto:ddoherty@myeloma.org)

**Senior Global Director of Advocacy, Europe & Middle East and GMAN Executive Director**  
Nadia Elkebir  
[nelkebir@myeloma.org](mailto:nelkebir@myeloma.org)

**Donor Relations**  
Heather Fishman  
[hfishman@myeloma.org](mailto:hfishman@myeloma.org)

**Support Group Coordinator**  
Jon Fitzpatrick  
[jfitzpatrick@myeloma.org](mailto:jfitzpatrick@myeloma.org)

**Patient Meetings Coordinator, US**  
Carmen Greene  
[cgreene@myeloma.org](mailto:cgreene@myeloma.org)

**Meeting Registration & Guest Relations**  
Abigail Guzman  
[aguzman@myeloma.org](mailto:aguzman@myeloma.org)

**InfoLine Coordinator**  
Paul Hewitt  
[phewitt@myeloma.org](mailto:phewitt@myeloma.org)

**Web Specialist**  
Kevin Huynh  
[khuyh@myeloma.org](mailto:khuyh@myeloma.org)

**Editor-in-Chief, Publications**  
Marya Kazakova  
[mkazakova@myeloma.org](mailto:mkazakova@myeloma.org)

**Assistant Director, Member Events**  
Ilana Kenville  
[ikenville@myeloma.org](mailto:ikenville@myeloma.org)

**InfoLine Coordinator**  
Missy Klepetar  
[mklepetar@myeloma.org](mailto:mklepetar@myeloma.org)

**Communications Associate**  
Sapna Kumar  
[skumar@myeloma.org](mailto:skumar@myeloma.org)

**Medical Affairs Assistant**  
Xuan Lam  
[xlam@myeloma.org](mailto:xlam@myeloma.org)

**Accountant**  
Phil Lange  
[plange@myeloma.org](mailto:plange@myeloma.org)

**Senior Director, Public Policy & Advocacy**  
Robin Levy  
[rlevy@myeloma.org](mailto:rlevy@myeloma.org)

**Research Project Coordinator**  
Amirah Limayo  
[alimayo@myeloma.org](mailto:alimayo@myeloma.org)

**Vice President, Development**  
Randi Lovett  
[rlovett@myeloma.org](mailto:rlovett@myeloma.org)

**Publication Design**  
Jim Needham  
[jneedham@myeloma.org](mailto:jneedham@myeloma.org)

**Florida Regional Director, Support Groups**  
Anne Pacowta  
[apacowta@myeloma.org](mailto:apacowta@myeloma.org)

**Director, Operations**  
Selma Plascencia  
[splascencia@myeloma.org](mailto:splascencia@myeloma.org)

**Director, Meetings & Events**  
Annabel Reardon  
[areardon@myeloma.org](mailto:areardon@myeloma.org)

**Development Associate**  
Joy Riznikove  
[jriznikove@myeloma.org](mailto:jriznikove@myeloma.org)

**Web Producer**  
Miko Santos  
[msantos@myeloma.org](mailto:msantos@myeloma.org)

**Director, Public Policy & Advocacy**  
Kelley Sidorowicz  
[kjones@myeloma.org](mailto:kjones@myeloma.org)

**Accounting & Distribution**  
Brando Sordoni  
[bsordoni@myeloma.org](mailto:bsordoni@myeloma.org)

**Assistant to the President**  
Rafi Stephan  
[rstephan@myeloma.org](mailto:rstephan@myeloma.org)

**Accounting Manager**  
Arthur Tan  
[atan@myeloma.org](mailto:atan@myeloma.org)

**Senior Director, Support Groups**  
Robin Tuohy  
[rtuohy@myeloma.org](mailto:rtuohy@myeloma.org)

**InfoLine Coordinator**  
Judy Webb  
[jwebb@myeloma.org](mailto:jwebb@myeloma.org)

**Outreach**  
Jonathan Weitz  
[jweitz@myeloma.org](mailto:jweitz@myeloma.org)

**Director, Public Policy & Advocacy**  
Raymond L. Wezik, JD  
[rwezik@myeloma.org](mailto:rwezik@myeloma.org)

## Also in this issue

### Shared Decision Making and Myeloma

The IMF's Nurse Leadership Board helps myeloma patients and caregivers to serve as their own best advocates in making key treatment choices. **PAGE 8**

### New Advocacy Coalition is Launched

The Patients Equal Access Coalition relaunches as the Coalition to Improve Access to Cancer Care to enhance the ability to pass meaningful legislation. **PAGE 9**

### 2018 Myeloma ACTION Month

The 2018 MAM global campaign honored Myeloma Warriors – individuals surviving with the disease, supporting loved ones, or helping to find the cure. **PAGE 10**

This free issue of *Myeloma Today*® (Volume 18, Number 2) is dated April 15, 2018. *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

## A Message from the IMF President

### Dear Reader,

Spring is finally here! Many of you encountered a winter that seemed endless and I'm sure it must have felt like Spring would never arrive. But it's here and let's make the most of it.

It's that time of year when anything seems possible, and at the IMF we definitely feel that way. For 28 years we've been making change happen, and we never stop. We keep expanding our global reach keeping patients, their families, doctors and nurses updated on the latest advances in myeloma treatment and management.

The IMF is the world's oldest and largest myeloma foundation and we never lose sight of our mission "to improve the quality of life for myeloma patients while working toward prevention and a cure." We have a cornucopia of new drugs in the pipeline and a host of drugs that have been approved – surely that once elusive cure is right around the corner.

I've always felt that we are a family and I would like to challenge each and every "family member" to get involved with the IMF. We need your help. Be a part of making myeloma history!

- ✓ Start a support in your area or join one.
- ✓ Attend or create a "member fundraiser event" – our team will help you every step of the way.
- ✓ Become empowered! Attend a Patient & Family Seminar or a Regional Community Workshop
- ✓ Become a grassroots advocate – our advocacy team is here to help you.
- ✓ Support myeloma research or any one of our many other programs – no donation is too small or too large!

In June the IMF will once again hold the annual International Myeloma Working Group (IMWG) meeting. This year's meeting will take place in Copenhagen, Denmark, just prior to the annual meeting of the European Hematology Association (EHA). Doctors from

around the world will convene and form workgroups in their areas of expertise. Why is this so important, you might ask. It's important because when these myeloma experts get together they share information, they report on clinical trials that are underway, they discuss the key topics for 2018 including the potential role for mass spectrometry testing – a new very sensitive tool to measure myeloma protein levels and the role of CAR-T cell for immune therapy treatment.



We'll also be bringing together the members of GMAN (Global Myeloma Action Network) which is comprised of Myeloma Association leaders around the world. They come from as far away as Australia, S. Korea, Latin America, all across Europe, and of course the US and Canada! This annual meeting is so important and empowering, and I'm very grateful to our pharmaceutical partners who help support this outstanding meeting.

So much has happened and we didn't do it alone. By bringing the myeloma community together we have moved myeloma research forward and today I can honestly say we are on the cusp of being able to "cure" a subset of myeloma patients. Once we kick the door to a cure open - let's get everyone through that door!

Best regards,

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

Susie Durie, President & CEO

## SAVE THE DATE

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# Immunotherapy in Myeloma: Monoclonal Antibodies

*Myeloma Today* in conversation with Thomas Martin, MD

**Dr. Martin, you are investigating the use of antibody therapies in myeloma. Please give us a brief primer on BCMA as a target.**

BCMA (B-cell maturation antigen), also called TNFRSF17 (tumor necrosis factor receptor superfamily 17), is a protein expressed on the surface of both normal and malignant B cells. There are two proteins that bind to BCMA. One is called APRIL (A proliferation inducing ligand) and the other is BAFF (B cell activating factor), and they probably cause some signaling through BCMA that cause B cells to grow or to survive. BCMA is a potential target for therapeutic intervention in myeloma because it is a unique marker – BCMA is primarily in the B-cell lineage and myeloma plasma cells are B cells, so BCMA selectively kills off mostly myeloma cells. There are no BCMA receptors on kidneys, heart, liver, or lungs, and that’s what makes BCMA more tumor-specific.

**Tell us about the investigations in myeloma targeting BCMA.**

Seattle Genetics Inc. has a “naked” monoclonal antibody that specifically binds to BCMA. It waves the tail of the antibody like a flag to tell the immune system to kill that cell. This monoclonal antibody works in a similar way to daratumumab (Darzalex®) and isatuximab. In early studies, the results are not as good as responses to the CD38 antibodies, and perhaps this is because the level of BCMA on the myeloma cell surface is not as high as the level of CD38.

Several other companies are trying to improve on antibody-based therapies by attaching a poison to the antibody. For example, GlaxoSmithKline has GSK2857916, an ADC (antibody-drug conjugate) that binds to BCMA. When this ADC is metabolized by the myeloma cell, the poison is activated. The goal is to deliver these potent toxins directly to the BCMA-positive myeloma cells. The phase I study of GSK2857916 showed this ADC to be safe, but there are some toxicities from the poison.

**What were the side effects of GSK2857916 in phase I?**

The antibody itself has minimal toxicity, with fewer than a quarter of the study patients having a mild infusion reaction with the first infusion. But once the toxin is released in the tumor cell, it sometimes can get into the circulation. This can cause some fatigue, mild nausea, low blood counts, and it can affect the eyes. Some patients receiving GSK2857916 developed photophobia or inflammation of the surface of the eye. A strong microscope can pick up small ulcers on the surface of the eye, but these heal readily and can be ameliorated by steroid drops.

**Tell us about the GSK2857916 trial data.**

The investigators were able to see some very encouraging activity. Please remember that this ADC is given as a single agent, without premedication or steroids or any other anti-myeloma therapies, once every three weeks. Based on phase I data presented at the 2017 annual meeting of the American Society of Hematology (ASH) from 35 relapsed/refractory patients treated in the second part of the ongoing phase I study, GSK2857916 was granted “breakthrough therapy” designation by the FDA. The overall response rate (ORR) to single-agent GSK2857916 was a robust 60% of patients with at least a very good partial response (VGPR, more than a 90% reduction in the myeloma burden), and some

achieved a complete response (CR), with a median progression-free survival (PFS) of 7.9 months. It is important to note that 90% of the patients in this study were double-refractory to proteasome inhibitors and to immunomodulatory drugs, plus a third of the patients were also refractory to daratumumab.

GSK2857916 is now moving forward to a phase II study with a larger number of patients, probably 70 to 100, being enrolled in the US and Europe. If the phase II also shows a 60% response rate, I suspect this agent will be on track for accelerated approval in myeloma.

So that’s one way we are trying to enhance the activity of the BCMA-directed antibody therapeutic. The other way that drug companies are trying to target BCMA is through a multi-targeted antibody principle.

**How do multi-targeted antibodies work?**

An antibody can bind two, three, five things at the same time. We are now looking at multi-targeted antibodies called BiTEs® (bispecific T-cell engagers). One arm of this antibody binds to BCMA while the other arm binds directly to an immune cell like a T cell, then it puts the two cells together. This activates the T cell to kill the myeloma cell. In the lab and in animal models, this has been a highly effective strategy to eradicate myeloma cells. Multiple phase I studies are either planned or ongoing, with several drug companies moving forward with BCMA-targeted therapeutics. Within the next 6-12 months, we should know if the promising results seen in pre-clinical studies translate into the clinical setting.

One center compared a BiTE therapeutic vs. an anti-BCMA CAR T-cell therapeutic vs. an anti-BCMA antibody in an animal model, and all worked well, with no benefit seen in one over the other. However, CAR T-cells must be made from an individual patient’s own blood cells, whereas a drug company can produce a large amount of a BiTE antibody to be readily available for patients “off the shelf” as needed, plus they are easier to use than CAR T-cell therapeutics.

**Can you address the issue of cost?**

The off-the-shelf drugs do cost much less than CAR therapy, but one CAR treatment may last a patient for two or three years without any additional therapy, while an ADC or BiTE therapeutic may have to be purchased on a month-to-month basis. It’s too soon to tell how the total cost may compare in the end.

**Is there a down-side to how BiTEs work?**

BiTE therapeutics activate T cells, so there is a risk of a “cytokine storm” or an overproduction of immune cells and their cytokines, but typically this is the case only with the first infusion, because thereafter the tumor is responding and there is less cytokine release.



Thomas Martin, MD  
Co-Director, Myeloma Program  
UCSF Medical Center, San Francisco

*(continues on next page)*

# FDA Expands Approval of Xgeva in Patients with Myeloma

On January 5, 2018, Amgen announced that the US Food and Drug Administration (FDA) had expanded the approval of Xgeva® (denosumab) to include the prevention of skeletal-related events (SREs) in patients with myeloma. The expanded approval was based on randomized phase III clinical trial data that indicated equivalency with regard to reduction in SREs and lesser renal (kidney) toxicities with denosumab as compared to zoledronic acid (Zometa®). “A total of 1,718 patients (859 on each arm) were randomized to receive either subcutaneous Xgeva 120mg and intravenous placebo every four weeks, or intravenous zoledronic acid 4mg (adjusted for renal function) and subcutaneous placebo every four weeks,” according to Amgen, the biopharmaceutical company that makes Xgeva.

“The data we presented and published in February 2018 indicates that when zoledronic acid was compared to denosumab, we had more renal toxicity in the zoledronic acid arm and did not see that in folks who were getting denosumab,” said Dr. Noopur S. Raje, the study’s principal investigator. A major complicating factor of myeloma is the associated bone disease. “It happens in the majority of patients,” Dr. Raje said. “It starts out with 60% to 70% of people, but over their lifetime with myeloma, it impacts pretty much 100% of patients.”

As a result, the need for supportive care strategies for bone disease is critical, Dr. Raje noted. “If left untreated, you are going to end up with end-organ issues such as fractures, high calcium levels, need for radiation, need for pain medications, and the need for procedures such as kyphoplasty and vertebroplasty.” In addition to bone disease, Dr. Raje said many myeloma patients also face kidney dysfunction. “When myeloma patients first present, it happens in about 20% to 30% of people, but over time, more than 50% to 60% of people will have renal dysfunction,” Dr. Raje said. “This is critically important because a lot of the treatments we use for myeloma are regulated by how your kidneys are functioning, and if your kidneys are not functioning to a completely normal extent, it is going to impact the choice of therapy we use and the dosages of treatments we use.”

Up until recently, Dr. Raje explained, myeloma patients with bone disease had limited options. “We only had one approved drug class for the treatment of bone-related disease in myeloma and that was the class of drugs known as bisphosphonates, which includes zoledronic acid

and pamidronate. These are very effective bone-targeted agents, but the way they metabolize is through the kidneys.”

The phase III clinical trial led by Dr. Raje demonstrated that denosumab treats bone disease but doesn’t have an impact on kidney function like zoledronic acid. “Because denosumab is a monoclonal antibody, it’s not renally excreted,” Dr. Raje said. “Most patients with myeloma tolerate monoclonal antibodies perfectly well.”

Dr. Raje also pointed out that denosumab has its advantages in terms of delivery: “The other nice thing about denosumab is that it’s a subcutaneous shot as opposed to getting an intravenous treatment with a bisphosphonate.” Progression-free survival (PFS) statistics from the clinical trial also stood out for Dr. Raje. “From the bone protection standpoint, both the bisphosphonate, which was zoledronic acid, or denosumab worked just as well, but when it came to control of the myeloma – the PFS from the myeloma – it significantly had a benefit for denosumab such that the PFS was increased by 10.8 months.”

Dr. Raje expects the FDA’s approval of denosumab to make an impact on the choice of treatments for patients with myeloma. “I think it gives us an alternative that we’ve not had for years. My suspicion would be that most of us would prefer to use this compared to the bisphosphonates.” Although Xgeva is significantly more expensive, as highlighted in the *Journal of Clinical Oncology* guideline update, thus far, it appears that reimbursement will allow patients to select the more expensive agent for their therapy if preferred. **MT**

“Role of Bone-Modifying Agents in Multiple Myeloma: American Society of Clinical Oncology Clinical Practice Guideline Update” was published in the *Journal of Clinical Oncology* on February 6, 2018.



Noopur S. Raje, MD  
Director, Multiple Myeloma Center  
Massachusetts General Hospital

## MONOCLONAL ANTIBODIES – CONTINUED FROM PREVIOUS PAGE

### What is your overall outlook on the use of ADCs and BiTEs and other forthcoming innovations in myeloma?

I believe it is possible that we will see a better response to these single-agent therapeutics than to any other class of drugs that has been tested so far in myeloma. Just consider these numbers: single-agent activity of daratumumab and isatuximab is around 25% or 30%, while the single-agent activity of an anti-BCMA ADC is 60%. There is a lot of excitement about what can turn out to be our next generation of anti-myeloma therapeutics that are more effective than anything else we have available today.

We will certainly see more investigations of multi-targeted antibodies. Some may target a different cell surface protein, like CD38

or SLAM F7. We may also see the development of multi-targeted antibodies that target cytokines or the stromal cells in the bone marrow. We may see therapies that do not target myeloma at all, but instead target cells that support myeloma, thereby augmenting the ability of myeloma cells to attack.

There are several interesting ongoing clinical trials. Our initial studies using immune checkpoint blockade in myeloma, called PD-1/PD-L1 inhibitors, have shown impressive responses but also some toxicities when used in combination with immunomodulatory drugs, but perhaps we can use these agents with ADC or BCMA-targeted antibodies, making the therapy more potent than anything we have at the present time. **MT**

# Updates on Drug Therapies for Multiple Myeloma

By Debbie Birns  
IMF Medical Editor

The early months of 2018 have brought good news to myeloma patients, notably a number of updates on several approved therapies and one therapy that is available in two expanded clinical trials.

## Darzalex® (daratumumab)

On January 22, the US Food and Drug Administration (FDA) granted a priority review designation to Darzalex in combination with Velcade® (bortezomib) + melphalan + prednisone (VMP) for the treatment of patients with newly diagnosed myeloma who are ineligible for autologous stem cell transplant (ASCT). The designation was based on findings from the European phase III ALCYONE clinical trial, which were presented in December 2017 at the 59th Annual Meeting & Exposition of the American Society of Hematology (ASH) by Dr. María-Victoria Mateos and were subsequently published in the *New England Journal of Medicine*. Data from the ALCYONE study of Darzalex + VMP (D-VMP) vs. VMP in newly diagnosed myeloma patients demonstrated that D-VMP elicited an 18-month progression-free survival (PFS) rate of 71.6% compared with 50.2% for VMP alone, a 50% reduction in the risk of progression or death. The overall survival (OS) analysis is ongoing. The FDA will decide on this new designation by May 21, 2018. If approved, this will be the first approved use of Darzalex in the newly diagnosed setting.

On January 26, the FDA approved a new assay for evaluating monoclonal protein in serum by immunofixation electrophoresis (IFE) for myeloma patients treated with Darzalex. Previously, the monoclonal antibody itself (that is, the Darzalex) was being detected as part of the monoclonal protein, making it difficult to evaluate complete response.

## Kyprolis® (carfilzomib)

On January 17, the FDA approved a supplemental new drug application that adds overall survival data from the phase III ENDEAVOR trial to the label for Kyprolis for use in patients with relapsed or refractory myeloma. Three-year follow-up data from the ENDEAVOR clinical trial showed that Kyprolis + dexamethasone (Kd) reduced the risk of death by 24% compared to Velcade + dexamethasone (Vd), with a 9-month longer median overall survival benefit than Vd.

On January 30, the Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency (EMA) adopted a positive opinion for recommending a label variation for Kyprolis. As in the US, the new label will include updated overall survival data from the phase III ENDEAVOR trial.

On February 5, the Ministry of Health and Welfare in Korea granted insurance coverage for use of Kyprolis in the treatment of myeloma patients. The decision to cover Kyprolis for myeloma as well as two

immunotherapies for melanoma reflects Korea's determination to help patients benefit from increased access to drugs with lower financial burden.

## Pomalyst® (pomalidomide)

On February 6, a press release from Celgene revealed "a statistically significant and clinically meaningful improvement in progression-free survival" for the phase III OPTIMISMM clinical trial. This study compared the combination of Pomalyst + Velcade + dexamethasone (PVd) vs. Vd in patients with relapsed and/or refractory myeloma previously treated with at least one but not more than three prior regimens, including a regimen containing Revlimid® (lenalidomide). The reported data were kept to a minimum. Full data will be presented at an upcoming medical meeting, likely the American Society of Clinical Oncology (ASCO) annual meeting in June 2018.

Also in February, the *Journal of Clinical Oncology* featured results from a European phase II clinical trial of Pomalyst + dexamethasone (Pd) in patients with relapsed/refractory myeloma and renal (kidney) impairment. Dr. Meletios Dimopoulos, member of the International Myeloma Working Group (IMWG), was the lead author and lead investigator on this trial, which divided patients into three study arms according to their degree of renal impairment. Pomalyst, which is metabolized primarily in the liver (not the kidneys), was, not surprisingly, most effective and best tolerated in the group of patients with the least renal impairment. 100% of the patients in that arm of the study achieved disease control, and their median overall survival was 16.4 months. Of those with the poorest kidney function, 78.6% had disease control, and overall survival was 5.2 months.

## Selinexor

Karyopharm Pharmaceuticals, manufacturer of selinexor, an experimental agent that prevents cells from exporting tumor suppressor genes from their nuclei, has opened many new sites in its BOSTON clinical trial in the US and abroad. BOSTON is a phase III study comparing selinexor + Velcade + dexamethasone (SVd) to Velcade + dexamethasone (Vd) for patients with relapsed/refractory myeloma following one to three prior regimens (induction therapy followed by ASCT is considered one therapy). Both selinexor and Velcade are given once weekly, and patients on the Vd arm of the study are allowed to cross over to the SVd arm if their disease progresses. There are 164 sites currently open in the US, Australia, Austria, Belgium, Bulgaria, Canada, Czechia, France, Germany, Greece, Hungary, India, Israel, Italy, Poland, Romania, Russian Federation, Serbia, Spain, Ukraine, and the United Kingdom. **MT**

*For more information, please visit the IMF website [myeloma.org](http://myeloma.org) or call our InfoLine at 800-452-CURE (2872) or 818-487-7455.*



# IMF Reaches Out to Community Healthcare Providers

By Debbie Birns  
IMF Medical Editor

The IMF InfoLine staff speaks to and exchanges emails with patients all over the world, and knows that most myeloma patients are cared for by doctors who are not hematologist/oncologists specializing in myeloma. Myeloma specialists tend to work in large cities with teaching hospitals where hematology/oncology fellows are trained. And, as many of you know, even many large cities with excellent hospitals lack myeloma specialists. While we encourage patients who are able to travel and who do not have local access to a myeloma specialist to travel to see one, most patients receive their ongoing care from general hematologist/oncologists in their local communities. These community hematology/oncology practices reflect overall cancer demographics: there is a high percentage of patients with lung, breast, prostate, or colon cancer, and few (if any) with myeloma or other less common cancers. Patients in some areas may not even have access to a general hematologist, and must rely on a family medicine doctor or a primary care physician whose specialty training is not in hematology. These doctors must not only treat every type of medical problem that walks in the door, but every type of cancer as well. That is a tall order, indeed.

To address the needs of these hard-working community healthcare practitioners, the IMF launched a new education initiative to provide current recommendations for myeloma management to community physicians, pharmacists, and nurses who are on the frontlines of providing patient care. Community healthcare providers need, and value, expert recommendations delivered via a variety of platforms – video, online, in print, and in person.

The IMF’s education initiative currently includes three programs. The first part of the education initiative includes six videos on the Medscape website that use the “Ask Dr. Durie” format, but are designed to earn continuing medical education credits for doctors. These videos, in which Dr. Durie interviews leading myeloma specialists from around the US, are also available to patients and caregivers on the IMF website.

A second aspect of the education program will be virtual and in-person “Grand Rounds” seminars for community hematologist/oncologists across the US. In March 2018, myeloma specialists from around the country gathered in Los Angeles to prepare slides and other educational materials for these seminars.

IMF InfoLine team member Paul Hewitt is spearheading the third aspect of this effort by gathering the names and contact information for every community doctor we can possibly reach. Paul is sending forms to each US support group, requesting that members provide the names, addresses, phone numbers, and email addresses of their primary care physicians and their hematologist/oncologists. He has



already collected hundreds of names, but we would like to be as inclusive as possible in our effort to make sure that every myeloma patient in America can receive the best possible care. If you haven’t done so already, please help with this project by emailing, calling, faxing, or mailing us the contact information for your primary care physician and hematologist/oncologist. The IMF will send them the most important myeloma disease-management guidelines, each with a brief introductory “top-line” statement from Dr. Durie. Together we’ll ensure that the best information possible is available to every doctor who treats myeloma patients.



How to contact Paul:

**EMAIL** [phewitt@myeloma.org](mailto:phewitt@myeloma.org)

**PHONE** 818-487-7455, extension 226

**FAX** 818-487-7454

**MAIL** International Myeloma Foundation  
c/o Paul Hewitt  
12650 Riverside Drive, suite 206  
North Hollywood, CA 91607

*The IMF and our InfoLine Coordinators are here to help with your myeloma-related questions and concerns. The IMF InfoLine consistently provides callers with up-to-date information about myeloma in a caring and compassionate manner. InfoLine specialists Paul Hewitt, Missy Klepetar, and Judy Webb 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 query electronically, please email [InfoLine@myeloma.org](mailto:InfoLine@myeloma.org). **MT***



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

**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**  
Dana-Farber Cancer Institute  
Boston, MA

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

**Elizabeth Finley-Oliver,  
MSN, ARNP, AGNP-BC**  
H. Lee Moffitt Cancer Center  
and Research Institute  
Tampa, FL

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

**Patricia A. Mangan, RN, MSN, 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, PhD, ANP-BC**  
MD Anderson Cancer Center  
Houston, TX

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

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

**Daniel Verina, RN, 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**  
Clinical & Systems Transformation  
Vancouver Coastal Health  
Vancouver, Canada

# Shared Decision Making for Myeloma Patients and Caregivers

By Diane Moran  
IMF Senior Vice President, Strategic Planning



Dr. Beth Faiman



Charise Gleason

One of the key tenets of the International Myeloma Foundation (IMF) and its Nurse Leadership Board (NLB) is to inform and empower myeloma patients and caregivers as they navigate their journey with myeloma. Much has changed in the myeloma world since 1990 when the IMF was founded. In the past, it was not unusual for healthcare providers to dominate the decision-making process for patients. Today, there is a much greater emphasis on patient involvement in making key treatment choices. This is referred to as Shared Decision Making.

## Shared Decision Making and myeloma

On November 9, 2017, the IMF presented “How To Talk With Your Healthcare Team About What’s Best for You,” a webinar and teleconference led by NLB’s Dr. Beth Faiman and Charise Gleason. This 60-minute program was designed to address how myeloma patients and caregivers can serve as their own best advocates. The following is a brief summary of the presentation.

Shared Decision Making has four essential principles. First and foremost, healthcare providers and patients/caregivers are both involved in making decisions. Second, through this joint process, they share information. Third, they take steps together to build consensus about preferred treatment. Lastly, they reach a mutual agreement regarding selecting the treatment approach.

Wonderfully, there are now many FDA-approved treatment options for myeloma, with even more potential therapies in the clinical trial pipeline. But with options come important choices, and such decisions may be influenced by a patient’s and caregiver’s goals, preferences, and values. The goals for Shared Decision Making for myeloma treatment are to control disease and symptoms, to extend life expectancy, and to promote quality of life.

Myeloma patients are now living longer, so it’s also important to recognize that goals, preferences, and values may change over time. And, given the

relapsing nature of myeloma, there may be multiple decision-making points along the way.

## The benefits of Shared Decision Making

It is natural for patients and their caregivers to sometimes worry that voicing their opinions may get in the way or slow down the process of making headway with treatment. But research clearly shows that healthcare providers want to hear and understand their patients’ preferences. Research also shows that when patients express their opinions, their increased confidence and satisfaction with treatment decisions results in fewer regrets and a lower level of stress and anxiety. Longer-term, when patients take an active role in making a decision, it leads to stronger adherence to the treatment regimen, a better quality of life, and improved treatment outcomes – including disease remission.

Myeloma is a complex disease that comes with an enormous learning curve. The IMF, including the nurses who comprise our NLB, is here to support patients and caregivers in that process. In the spirit of Shared Decision Making, we suggest that patients prepare for doctor visits by making lists of their priorities and their questions in advance. At appointments, we encourage patients to state their desire to participate in decision-making and to communicate their goals, preferences, and values in order to enhance that dialogue. Ultimately, the goal is to arrive at a treatment decision together.

## Shared Decision Making for your own treatment

There is a lot to consider with myeloma. Making decisions around treatment and its timing has an impact on many aspects of daily life. Shared Decision Making creates an ongoing forum for patients to voice their concerns and challenges, and for the healthcare team to answer questions from patients and caregivers and to accommodate their needs as best as possible. Since no healthcare provider knows all of the approaches and programs that potentially could be valuable to any given patient, Shared Decision Making also encourages patients to seek second opinions. With all of today’s treatment options, it is more important than ever to have open discussions. **MT**

“How To Talk With Your Healthcare Team About What’s Best for You” is archived on the IMF website at [myeloma.org/understanding/imf-tv/living-well-myeloma-along-with-accompanying-slides](http://myeloma.org/understanding/imf-tv/living-well-myeloma-along-with-accompanying-slides).



# New Advocacy Coalition is Launched to Fix Outdated Insurance Benefit Design

By Raymond L. Wezik, Esq.  
IMF Director, Public Policy & Advocacy

On March 6, 2018, the Patients Equal Access Coalition (PEAC), which is run by the IMF advocacy department, held an event in Washington, D.C., to relaunch the coalition as the Coalition to Improve Access to Cancer Care (CIACC). The relaunch effort is part of a larger process to enhance our ability to pass meaningful legislation. CIACC is unique in the diversity of its membership, including patient advocates, hospitals, biopharmaceutical companies, pharmacists and some of the country's premier research institutions. The primary mission of the coalition is improving the quality of care and access for cancer patients.

The event included a presentation on the new name, logo, website, and polling information conducted on behalf of the coalition. Seventy percent of those polled support legislation that would modernize insurance coverage to keep pace with medical innovations. H.R. 1409, the *Cancer Drug Parity Act of 2017*, would prevent insurance companies from applying different co-pays to oral cancer medicine than they do to intravenous chemotherapy or other injected treatments. In the 43 states and the District of Columbia, where comparable state laws are in place, 74% of cancer patients paid no co-pay for their treatments, regardless of form. Insurers also faced no cost increases. Unfortunately, those laws only impact patients under state-regulated plans, about 40% of the market. H.R. 1409 is needed to cover the other 60% on federally regulated plans under the Employee Retirement Income Security Act of 1974, better known as ERISA.



Paul O'Hara and former Rep. Phil Gingrey (R-GA)

During the event, CIACC members and guests heard from Paul O'Hara, a CML (chronic myeloid leukemia) patient in Pennsylvania who, before his state adopted legislation like H.R. 1409, paid several thousand dollars out of pocket every month for a daily pill that allows him to live a normal life. Paul described the choices he had to make between

affording his medication and paying his other bills; about not being able to take his family on vacation, skipping doses to make the medication last longer and worrying about affording college for his daughters. In January 2018, when Paul called his insurer to find out what his co-pay would be he was told that it was a new insurance year and he had not yet hit his deductible limit. Paul's insurer told him his first round of oral pills would cost him \$10,000. Luckily, Paul knew about the state law and made his insurance company aware as well. His new monthly bill is \$50.



The IMF's Advocacy Team on Capitol Hill: Raymond Wezik, Danielle Doheny, Kelley Sidorowicz, and Robin Levy

There are many more patients like Paul in Pennsylvania who work for large multi-state employers and who are not protected by these laws, even if their state has one. That is why on March 7 the CIACC stormed Capitol Hill to garner support for H.R. 1409. Five groups of CIACC members met with 37 House and Senate offices to spread awareness on the issue and ask for support.



Kelley Sidorowicz of the IMF's Advocacy Team, Elridge Proctor of Lung Cancer Alliance, and Jeremy Scott with DPG on a Hill Visit

At the time of this writing, the *Cancer Drug Parity Act of 2017* has 140 cosponsors and is gaining momentum, but we still need your help to cross the finish line. Contact us at [advocacy@myeloma.org](mailto:advocacy@myeloma.org) to check if your Representative has become a sponsor. You can also visit our new website, [access2cancercare.com](http://access2cancercare.com), to see how you can take action or follow us on Twitter @CancerCare4All to keep up to date on the Coalition and chances to get involved. **MT**

# 2018 Myeloma Action Month!

By Robin Tuohy  
IMF Senior Director, Support Groups

In 2009, the IMF was the first organization to declare March as Myeloma Awareness Month. Since that time, we have elevated our program to Myeloma ACTION Month (MAM). The 2018 MAM campaign focused on Myeloma Warriors – individuals surviving with the disease, supporting loved ones, or helping to find the cure.

As part of this year’s worldwide MAM campaign, Myeloma Warriors used technology so their voices could be heard across the globe. Many created video blogs, changed their Facebook profile pictures to include a Myeloma Warrior frame, tweeted with the hashtag #myelomawarrior which allowed their tweets to be streamed to the MAM website’s homepage and, overall, raised the visibility of the myeloma community by sharing their stories online. IMF President & CEO Susie Durie said, “We are creating a timeless and worldwide forum for myeloma awareness.”

## Sharing stories and actions

Myeloma Warriors who shared their deeply moving stories, life lessons, and advice on the MAM website [mam.myeloma.org](http://mam.myeloma.org) inspired patients and caregivers across the country and around the world. Their stories may also encourage individuals to see their doctor to get their symptoms checked.

Several patients, caregivers, and healthcare professionals who were asked “What does it mean to you to be a Myeloma Warrior?” responded with video blogs and a mash-up of their responses can be viewed at [mam.myeloma.org/be-a-warrior](http://mam.myeloma.org/be-a-warrior). Watch to hear myeloma patient Linda Huguélet give this advice to patients: “Don’t let it consume your life. Cherish every day!” Another patient, Lawrence Ward, tells how the IMF provided him with the “one commodity you can get nowhere else – and that is, HOPE!” His daughter Alie Ward says that being a Myeloma Warrior means to “really be an advocate for your own health. And that is one thing that has inspired me with my dad. My dad has faced it [myeloma] head on.”

We are also grateful for all the Myeloma Warriors who took to Twitter and Facebook. Many chose to display social media badges with slogans such as “I am a #myelomawarrior caregiver; I am a #myelomawarrior nurse; I am a #myelomawarrior supporter.”

IMF’s affiliate partner in Latin America inspired Myeloma Warriors throughout the continent to share their stories of hope and strength,

as well as to engage in a variety of activities. Myeloma patients, caregivers, and supporters in Brazil, Colombia, Ecuador, Mexico, Peru, Uruguay, and Venezuela took part. In addition, the reach of IMF Latin America extended as far as Spain and Portugal in Europe.

The IMF felt the impact on social media. On the IMF’s Facebook page and across all social media channels, including Twitter and Instagram, we were so excited to see that the reach of 2018 MAM engagement increased by more than 250% when compared to 2017 MAM activity. The #myelomawarrior hashtag reached more than a million individuals.

## Educating the public

As has been the MAM tradition since the inception of the program, the IMF assembled countless myeloma outreach kits containing information and educational materials. In the US, these kits were distributed by members of approximately 150 myeloma support groups, delivering important resources far and wide.



Connecticut Multiple Myeloma Fighters Information Group

Some support groups added fundraising activities to their educational outreach efforts. Members of the Southeastern Virginia (SEVA) Myeloma Networking Group organized the “Ten to Win” challenge to benefit IMF programs and services. Their concept was, “If 10 people donate just \$10 and challenge their family and friends to do the same, there’s no limit to how much can be raised!”

The Jamaica Multiple Myeloma Support Group kicked off MAM with a biennial symposium spearheaded by myeloma patient, Dr. Monica Taylor, and attended by more than 200 people. And on March 29 – International Multiple Myeloma Awareness Day – they held a virtual tea party.

MAM was also celebrated in Europe by the Nordic Myeloma Patient Alliance (a Facebook communication platform of Nordic doctors and



IMF friends and supporters from across the globe proudly displayed MAM badges on social media



patient groups), the two official myeloma support groups in Czechia (CMG and KPPM), Myeloma Euronet Romania, and the Armenian myeloma group (which celebrated the fifth autologous transplant performed in the Yerevan Hospital on March 1, and used this success to drive awareness about myeloma).



Doctors at the Yerevan Hospital in Armenia

IMF's affiliate partner in South Korea, the Korean Blood Cancer Association (KBCA), organized a highly effective campaign, as did Myeloma Canada, IMF's affiliate partner in North America. A cancer support group in India named Yoddhas (which means "Warrior") was a welcome addition to the global education campaign.

### Advocating for change

To promote the interests of the myeloma community, Myeloma Warriors reached out to their city and state legislators, as well as to healthcare professionals in their area and local media outlets. Rosemarie Kibitlewski, a caregiver to her adult son who has myeloma and a member of the Tampa/St. Petersburg Support Group, was successful in having March declared as Myeloma Awareness Month by Tampa's Mayor, Bob Buckhorn. Rosemarie presented the MAM proclamation from the city of Tampa to IMF President & CEO Susie Durie at the IMF Patient & Family Seminar in Boca Raton, Florida. Debbie Morelli and the Central New Jersey Multiple Myeloma Support Group were successful in having MAM covered in three local newspapers. Thanks to members of the Orange County (NY) Multiple Myeloma Support Group group and its leader, Adina Epstein, the County legislature issued a proclamation declaring March as Myeloma Action Month, and the group hosted a visit by Paul Ruskiewicz (county legislator), Carlos Valle (representative of Assemblyman James Skoufis), and Robin Levy (IMF Senior Director, Public Policy & Advocacy).



Susie Durie with Rosemarie Kibitlewski



Paul Ruskiewicz, Adina Epstein, Carlos Valle, Robin Levy, and members of the Orange County Multiple Myeloma Support Group

I was proud to represent the IMF during the Amgen-supported MAM Satellite Media Tour in New York City. The tour, which stretched over a number of days in order to accommodate interviews by 19 television and radio stations from across the US, also featured IMF Chief Medical Officer, Dr. Joseph Mikhael, and my husband and 18-year myeloma survivor, Michael Tuohy.



Dr. Joseph Mikhael with Robin Tuohy and Michael Tuohy

### Lifting our spirits

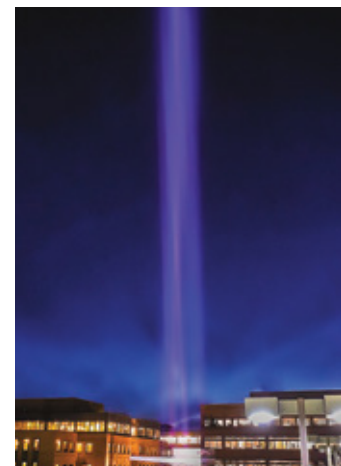
Our generous sponsors launched several programs to support MAM:

- Takeda sponsored Music 2 Fight Myeloma on Spotify. For every person who followed the inspirational playlist curated by members of the myeloma community, Takeda made a donation to the IMF. Takeda also donated to the IMF for each tweet that used the hashtag #Music2FightMyeloma.
- Johnson & Johnson gave \$1 to the IMF for myeloma research for each photo uploaded via the Donate a Photo mobile app. For every 25 photos donated, 100 blood samples were able to be collected for myeloma research.
- Amgen hosted the MAM Satellite Media Tour noted above, as well as beaming the "Spotlight on Myeloma" over their headquarters for the entire month of March while also tweeting myeloma facts with the #SpotlightMyeloma hashtag.



MAM supporters gather at Amgen headquarters for the lighting of the #SpotlightMyeloma beacon

Vlogging, photo-sharing, fundraising, letter-writing, storytelling, and political advocacy were some of the many ways that the spirited Myeloma Warriors took action this Myeloma Action Month. The IMF is grateful to all those who joined us to raise myeloma awareness and funds. March may be behind us, but you can still take Action at the IMF website [mam.myeloma.org](http://mam.myeloma.org). **MT**







# A 5K Walk to Support the Work That Wins the Battle

By Ilana Kenville  
IMF Member Events Associate

Before she was diagnosed with myeloma in May 2012, Helene Watts had been “living the somewhat normal, hectic life of a working mother,” she recalls. She had never heard of myeloma, but her learning curve was quick.



Five years later, her daughter Brooke celebrated her Sweet 16, and Helene and her husband, Lloyd, celebrated their 25<sup>th</sup> Wedding Anniversary. Also, Helene’s myeloma returned. Lloyd suggested that they throw a fundraiser, so that Helene’s time could be occupied by positive plan-making.

Helene felt inspired by her husband’s suggestion. She decided to create a 5K Walk/Run event because she felt it was something she could put together quickly. North Carolina’s Mecklenburg County Park and Recreation Department helped Helene identify available places – and she was off and running.

Helene decided to call the event Walk-Work-Win. “We wanted something catchy and memorable,” Helene says. She developed a dedicated event page through the IMF’s website. “It was the centerpiece for all of our fundraising, and the only place to register for the 5K.”

To promote Walk-Work-Win, Helene and her family heavily relied on social media. Helene, Lloyd, and Brooke all created “teaser posts” on Facebook, which led up to a Facebook Live video that officially launched their fundraising campaign. For that Facebook Live feed, Helene told her story and asked people to participate in the 5K, or to still consider donating if they couldn’t join.

“Soon after the Facebook Live feed was over, the funds started coming in,” Helene says. She asked people to share her video, and every time she created new posts about their fundraising progress, she also asked people to keep sharing her story through social media.

On October 28, 2017, Helene’s family, friends, neighbors, and colleagues joined her at Reedy Creek Park in Charlotte. “My husband arranged for people to say a few words about their relationship with me,” Helene says. “I was honored that they took the time to say such nice things.” There was also a raffle for dance classes, tickets to an amusement park, and custom-made home goods. Some adults even joined with the kids to paint their faces before they set off on their 5K adventures.

Everyone who signed up also received an event t-shirt that on the back said “Luvume,” which Helene explains “has been my personal tag line for years.” Her nephew designed the special logo.



Importantly for Helene, Walk-Work-Win also included a promotion for the Be The Match Registry. “Not every patient needs a bone marrow donor, but for those who do, finding a match is critical,” Helene explains. “I feel it’s especially important in the African American community to continually feed the pipeline whenever we have the chance, since it’s even more difficult to find a match in our community.” At Helene’s event, people were encouraged to sign up for the Registry. There was also a rock-painting activity, with Be The Match information on the other side of each rock. Later, they hid the rocks throughout the city for other Charlotte residents to find.

For Helene, the whole experience was wonderful and affirming. “It was amazing to see so many people choose to share their weekend with us,” she says. “I felt grateful, happy, and loved.” **MT**



1. Family is everything! Helene’s extended family gathered to support the cause.
2. Ritta Armstead and Renata Turner enjoy their walk together.
3. Wanda J. Burnette-Walker demonstrates that face-painting isn’t just for the kids.
4. Katrina Boxley, Helene’s sister, delivered a speech that was a truly moving tribute.
5. Painted rocks were hidden throughout Charlotte, each carrying a message to encourage its finder to consider becoming a bone marrow donor.

# There Is No Such Thing As a Drop in the Bucket – Everything Counts!

By Randi Lovett  
IMF Vice President, Development



After losing his mother Carole Newman to multiple myeloma, Jeffrey Newman was compelled to take action. Carole's battle with the disease lasted five years. Carole lived independently in New York City during most of her life, and Jeffrey's sister Cynthia along with his brother Bill provided the care his mother needed during her illness. During the final four months of life, the family moved Carole closer to Jeffrey's brother's home in Massachusetts.

Jeffrey commented that, surrounded by family, his mother maintained her remarkable poise until the very end.

Not only affected by the loss of his mother, Jeffrey also has a close friend who has been living with myeloma for several years. Jeffrey felt a strong drive to "fight back" and decided to take action. His friend then introduced him to the International Myeloma Foundation (IMF).

The IMF's signature research program, the Black Swan Research Initiative® (BSRI), which aims to develop a definitive cure for myeloma, piqued Jeffrey's interest. Led by a team of global myeloma experts, the BSRI coordinates and supports more than 40 research projects around the world.

Jeffrey was especially excited to hear about how the BSRI team has overcome the first obstacle to finding a cure for myeloma by developing a very sensitive, reliable, standardized, and affordable test to detect minimal residual disease (MRD). The BSRI's Next Generation Flow (NGF) flow cytometry technique, paired with a specialized software package, can quantify and characterize even one single myeloma cell that may remain after a patient is in complete response (CR).

Jeffrey was drawn to this aspect of BSRI research because it makes a tangible contribution to the field of myeloma in very specific way. The family's fund – the Jerome A. and Estelle R. Newman Assistance Fund – as well as Jeffrey individually – contribute to BSRI research.

The hope is that this simple blood test is truly the next step in detecting and preventing the progression of disease in patients with myeloma. "It gives me great satisfaction to know that there is real light in the battle against this insidious disease and that our contributions will have a real impact. I encourage others – if they have the means – to get involved in any way they can," said Jeffrey. "Some people feel that fighting a disease is such an enormous task, and ask themselves, 'What can I do? I mean, anything I can give is only like a drop in the bucket.' But everything counts, especially when it comes to research."



Jeffrey hopes that you, too, will connect with the IMF to learn how to give in a targeted way that speaks to you. And most of all, he honors the memory of his mother Carole whom he will always value as "a respectful, decent, loving person who endowed me with an appreciation for sports and art and culture. She lived her life in an unpretentious way and would most appreciate what we are doing in her honor."

The entire IMF team is grateful to Jeffrey and the Newman family for all they do. **MT**

*If you wish to discuss supporting the IMF in a way that works best for you, please contact Randi Lovett at [rl Lovett@myeloma.org](mailto:rl Lovett@myeloma.org) or 818-487-7455.*

## Give a Gift to the IMF at No Added Cost to You!

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**[amazon.myeloma.org](https://www.amazon.com/myeloma.org)**

You can also generate donations by making purchases through the IMF Shopping Mall at [shop.myeloma.org](https://shop.myeloma.org) from vendors such as Macy's, 1-800-Flowers, the Mac Game Store, Drugstore.com, Dollar Rent-a-Car, Avon, Omaha Steaks, Champion, Beauty.com, David's Cookies, and Paul Fredrick. Donating to the IMF is as easy as a point-and-click, all at no added cost to you!



# IMF Holds Another Successful Patient & Family Seminar in Italy

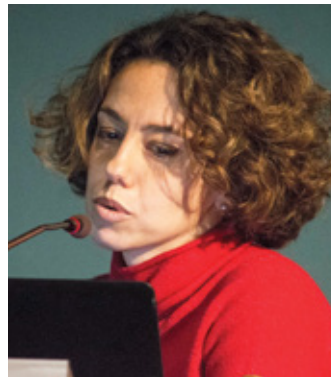
By **Nadia Elkebir**  
IMF Senior Global Director of Advocacy, Europe & Middle East

On February 16, the IMF kicked off its 2018 program of international Patient & Family Seminars. First stop: Torino, Italy. The meeting was held in the auditorium of Hospital Molinette, and an incredible variety of myeloma experts from all over Italy gathered as faculty for the meeting.

Dr. Mario Boccardo (Torino) presented a total of 11 speakers, including members of the International Myeloma Working Group (IMWG) Drs. Francesca Gay (Torino), Elena Zamagni (Bologna), and Sara Bringham (Torino). The rich program included many topics:

- “The importance of clinical studies”  
by Dr. Alessandro Corso (Pavia)
- “The role of psycho-oncology in hematological malignancies”  
by Dr. Ricardo Torta (Torino)
- “Focus on therapy with and without transplant”  
by Dr. Francesca Gay and Dr. Vittorio Montefusco (Milano)
- “Evolution of therapy and new drugs”  
Dr. Maria Teresa Petrucci (Roma) with Dr. Sara Bringham

Each session was followed by questions from the audience, which numbered approximately 170 participants. This successful meeting was recorded for the benefit of those who could not participate in person, and the recording has been archived at [www.ail.it](http://www.ail.it) **MT**



1. Dr. Mario Boccardo (Torino)  
2. Dr. Alessandro Corso (Pavia)  
3. Dr. Francesca Gay (Milano)  
4. An audience member at the Torino seminar poses a question to the faculty

## Upcoming IMF Patient & Family Seminars in Europe

We invite you to attend an IMF Patient & Family Seminar in Europe.  
For more information, please contact Nadia Elkebir at [nelkebir@myeloma.org](mailto:nelkebir@myeloma.org)

Belgium (La Hulpe)	May 5	Dolce Hotel	Iceland (Reykjavik)	Nov 16	Hilton Nordica Reykjavik
Bosnia + Herzegovina (Sarajevo)	May 26	TBC	Italy (Pisa)	Sept 7	TBC
Croatia (Zagreb)	Oct 16	TBC	Italy (Cagliari)	TBC	TBC
Czechia (Ustupky)	Oct 19-20	Congress Hotel Jezerka	Norway (Oslo)	Oct 31	Scandic Hotel
Denmark (Nyborg)	Oct 4	Nyborg Hotel	Norway (Trondheim)	Nov 2	Scandic Hotel
Finland (Helsinki)	Sept 28-29	Scandic Center Hotel	Norway (Bergen)	Nov 5	Scandic Hotel
France (Paris)	June 9	La Maison De L’Amerique Latine	Poland (Krakow)	Sept 1	International Cultural Center
Germany (Heidelberg)	Sept 22-23	Heidelberg University	Slovakia (Liptovsky Jan)	Sept 7-8	Morea Jan Hotel
Hungary (Budapest)	June 2	Moha House	Spain (Madrid)	Sept 13	Hotel Tryp Atocha
			Sweden (Stockholm)	April 21	Sheraton Stockholm





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Learn more about our global commitment to oncology. Visit us online at [takedaoncology.com](http://takedaoncology.com).

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

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## 2018 IMF Calendar of Events

- |            |   |            |   |
|------------|---|------------|---|
| April 21   | IMF Regional Community Workshop – Nashville, TN   | June 17-19 | Global Myeloma Action Network (GMAN) Annual Summit – Stockholm, Sweden                              |
| May 12     | IMF Regional Community Workshop – Seattle, WA   | June 30    | IMF Regional Community Workshop – Ann Arbor, MI   |
| May 17-20  | 43 <sup>rd</sup> Annual Congress of the Oncology Nursing Society (ONS) – Washington, DC             | July 21    | IMF Regional Community Workshop – Minneapolis, MN   |
| June 1-5   | 53 <sup>rd</sup> Annual Meeting of the American Society of Clinical Oncology (ASCO) – Chicago, IL   | Aug 24-25  | IMF Patient & Family Seminar – Los Angeles, CA  |
| June 9     | IMF Regional Community Workshop – Indianapolis, IN  | Oct 12-13  | IMF Patient & Family Seminar – Philadelphia, PA   |
| June 11-13 | 9 <sup>th</sup> Annual Summit of the International Myeloma Working Group (IMWG) – Stockholm, Sweden | Oct 19-21  | Asian Myeloma Network (AMN) Summit – Beijing, China   |
| June 14-17 | 23 <sup>rd</sup> Congress of the European Hematology Association (EHA) – Stockholm, Sweden          | Nov 3      | 12 <sup>th</sup> Annual Comedy Celebration – Los Angeles, CA  |
|            |   | Dec 1-4    | 60 <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 [myeloma.org/events/all](http://myeloma.org/events/all) or call 800-452-CURE (2873).*

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

**Australia** [myeloma.org.au](http://myeloma.org.au) • **Canada** [myelomacanada.ca](http://myelomacanada.ca) • **Israel** [amen.org.il](http://amen.org.il) • **Japan** [myeloma.gr.jp](http://myeloma.gr.jp) • **Latin America** [mielomabrasil.org](http://mielomabrasil.org)