



# Myeloma Today

A publication of the International Myeloma Foundation

## IMWG Establishes Updated Guidelines for Disease Assessment

PAGE 4



## *Black Swan Research Initiative®: Achieving a Global Standard for MRD Testing*

*Also in this issue:*

► **Fifth Annual Master Class  
for Leading Chinese  
Hematologists**

PAGE 6

► **New Drug  
Designations and a  
Consensus Update**

PAGE 8

► **Searching for Clinical Trials –  
The IMF InfoLine coordinators  
answer your questions**

PAGE 12

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## A Message from the President

### Dear Reader,

Fall is a very busy time of year at the IMF, as our premier fundraising event will take place on November 5<sup>th</sup> at the historic Wilshire Ebell Theatre and Club in Los Angeles. The 2016 event is very special as it is the 10<sup>th</sup> anniversary of the Annual Comedy Celebration benefiting the Peter Boyle Research Fund and supporting the IMF's Black Swan Research Initiative®.

In the 10 years since the IMF held the first Comedy Celebration, we've raised well over \$5 million thanks to our wonderful sponsors and the thousands of people who have attended. These funds have been used to support cutting edge research, and we are about to start "cure trials" in myeloma. The IMF is truly "out in front" on this, and I'm very proud of everyone who has made it possible.

In celebration of the event's 10th anniversary, the IMF is honoring a very special lady, my dear friend Loraine Alterman Boyle. The Annual Comedy Celebration and its support of the IMF's research programs would not be possible without her extraordinary work as the event chair for the past 10 years.



Loraine began her career as an editor of the *Detroit Free Press*. Back in New York, she freelanced for publications including the *New York Times*, the English rock paper, *Melody Maker*, and served as New York editor of *Rolling Stone*. She is also an accomplished Broadway producer with credits including the Tony Award-winning *Memphis*,

and *Beautiful: The Carole King Musical*. When she married the actor Peter Boyle, John Lennon was best man at their wedding.

She could have stepped out of the world of myeloma – no one would have blamed her if she did – but Loraine is a fighter. She joined the board of the International Myeloma Foundation, and has had a major impact on where we are today. She is passionate about finding a cure, and for 10 years she has been the driving force behind the IMF's Annual Comedy Celebration.

When Loraine calls her friends – she knows just about everybody – who can say no to her? Over the past 10 years, actor and comedian Ray Romano has served as the event's host, and he has been joined by an impressive roster of stellar performers, including Martin Short, Dan Aykroyd & Jim Belushi as The Blues Brothers, Joe Walsh, Jimmy Kimmel, Jason Alexander, Danny DeVito, Rhea Perlman, Rita Wilson, Kevin James, Dana Carvey, and Tom Arnold. The 10th anniversary Annual Comedy Celebration will once again star Ray Romano, as well as Jeff Garlin, JB Smoove, Larry Miller, Bill Burr, Kevin Nealon, Fred Willard, and Dom Irrera.

So thank you, Loraine, for being all that you are, for all that you've done, and for always being there for us. You're a true friend and I hope we give as good as we get.

Warm regards,

Susie Novis Durie, President



Over the past 10 years, our stage has been graced by host Ray Romano and performers (in alphabetical order) Jason Alexander, Tom Arnold, Dan Aykroyd & Jim Belushi as The Blues Brothers, Jack Black & Kyle Gass as Tenacious D, Dana Carvey, Deon Cole, David Crosby, Danny DeVito, Susie Essman, Peter Gallagher, Brad Garrett, Judy Gold, Gilbert Gottfried, Darrell Hammond, Patricia Heaton, Howard Hesseman, Jackie Hoffman, Kevin James, Dr. Ken Jeong, Jay Johnson, Jimmy Kimmel, Andy Kindler, Robert Klein, Richard Lewis, Heather McDonald, Carlos Mencia, Alex Meneses, Laraine Newman, Lesley Nicol, Tig Notaro, Eugene Pack, Rhea Perlman, Colin Quinn, Dayle Reyfel, Doris Roberts, Bob Saget, Paul Shaffer, Martin Short, Bruce Vilanch, Joe Walsh, Fred Willard, Justin Willman, and Rita Wilson.

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# The International Myeloma Working Group Establishes Updated Guidelines for Disease Assessment



By Brian G.M. Durie, MD  
IMF Chairman

On July 27, 2016, the new response criteria from the IMF's International Myeloma Working Group (IMWG) incorporating minimal residual disease (MRD) testing was published in *The Lancet Oncology*. Achieving consensus by more than 200 of the world's top myeloma researchers on these criteria marks a significant accomplishment,

two years in the making, by lead author Dr. Shaji Kumar of Mayo Clinic and his IMWG colleagues. The new response criteria update those set by the group in 2006.

"The treatment landscape for multiple myeloma has been radically transformed during the past decade by the introduction of several new drugs with different mechanisms of action," writes Dr. Kumar. High rates of complete response in myeloma patients treated with the new drugs called for new categories to identify responses that are deeper than those conventionally defined as complete response.



The publication of the new response criteria also represents an important step forward for the IMF's mission to find a cure. As you may know, MRD testing has been a crucial element of our Black Swan Research Initiative® since its inception in 2012. We have been pleased to see that in the four years since then, MRD testing in myeloma has been embraced by the rest of the myeloma research community. But with the publication of the new response criteria, MRD testing has now taken its place as the gold standard of disease measurement – much as we envisioned – and one which now allows us to determine exactly where a patient stands in the course of the disease and how effective treatment has been.



Dr. Shaji Kumar

## What, exactly, is MRD negative, MRD positive?

In the new IMWG MRD response criteria, exact definitions are spelled out for what constitutes a patient considered to be "MRD negative": at what level and with which tests. Either Next-Generation Sequencing (NGS) or Next-Generation Flow (NGF) can be used, with a cutoff which has to be at least less than 1 in 100,000 cells, but hopefully less than 1 in 1,000,000 cells. There are two additional categories in the new response criteria to measure

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*“This important work brings us closer to fulfilling the IMF’s mission – finding a cure for myeloma. We are sincerely grateful to the IMWG members for tireless contribution to our mission.”*

– Susie Novis Durie, IMF President and Co-Founder

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MRD: one in which PET/CT scanning is also negative and a “sustaining MRD negative” category in which the MRD negative testing remains negative after one year – a key endpoint.

Having “sustained MRD negative” as an endpoint in clinical trials provides an important yardstick to point the way to the achievement of cure – which is defined as an MRD negative level sustained at three years and five years. It is wonderful to have this framework for clinical trial design.

### MRD testing in the clinic

But what about MRD testing in the clinic? I very much appreciate and understand the patient perspective that “confirming MRD negative status” would be very reassuring. And I know from talking to patients that they are rightfully anxious to take this next step. However, I have to point out a couple of challenges in the short term:

1. Currently, “routine” MRD testing is not fully set up and standardized. Nor is there an accepted reimbursement plan. The fact that a sample can be sent to one laboratory and get one answer (let’s say “negative”) and another lab with a different answer (let’s say “positive”) is very disturbing. This issue needs to get sorted out before routine testing is recommended.

We hope that standardization and quality controls for NGF will be in place for a significant number of laboratories in the US within six to nine months, and, the Black Swan research team has been working nonstop to make that happen.

2. We need to fully understand the significance of “MRD negative” and “MRD positive” test results. If, for example, a patient is on maintenance therapy, doing well, and is “MRD negative,” is it safe to stop maintenance or maybe continue for a further six months or longer? We don’t know. If such a patient has an “MRD positive” test result, what does that mean? Should maintenance be changed or is everything actually just fine in terms of achieving ongoing benefit with the same maintenance? These are very important questions, which along with many others, need to be answered in top priority clinical trials.

“These revised response criteria will be used in clinical practice, research, and in regulatory studies that lead to the approval of new drugs by agencies worldwide,” explained Dr. S. Vincent Rajkumar of Mayo Clinic, who called the paper “another landmark accomplishment for the IMWG.” **MT**



Dr. S. Vincent Rajkumar

## Achieving a Global Standard for MRD Testing – Over 50 researchers in 22 countries

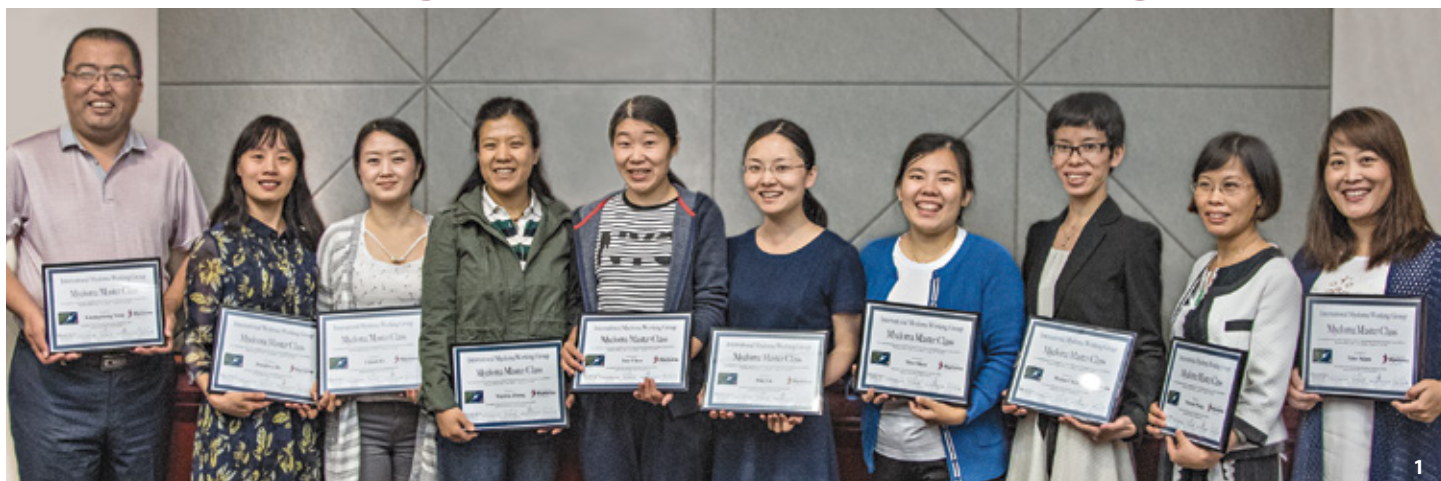
**Africa:** India, South Africa; **Asia-Pacific:** Australia (multiple sites), China (multiple sites), Japan (multiple sites), Singapore, South Korea;  
**Europe:** France, Germany, Iceland, Italy, Netherlands, Spain (multiple sites), Sweden, Turkey; **Latin America:** Argentina, Brazil, Colombia, Mexico, Peru;  
**North America:** Canada (multiple sites), United States (multiple sites).



IMF President Susie Novis Durie with the Black Swan Research Initiative leaders



# Fifth Annual Master Class for Leading Chinese Hematologists



**By Daniel Navid**  
IMF Senior Vice President, Global Affairs

The International Myeloma Foundation held its fifth Master Class from August 15–20, 2016. This prestigious advanced training course is offered annually to leading young Chinese hematologists, selected for participation by the Chinese Myeloma Committee. The course is hosted by the IMF in Los Angeles, California.

The 2016 Master Class participants included 10 young doctors from all corners of China, ranging from Shenyang in the Northeast to Lanzhou in the Northwest, to Nanning and Guangzhou in the South and to Beijing, Hangzhou, and Shanghai in the East.

The Master Class faculty included IMF's Chairman, Dr. Brian Durie, IMF Board Member Dr. S. Vincent Rajkumar, and International Myeloma Working Group (IMWG) experts Dr. Tom Martin and Dr. Jean-Luc Harousseau.

The program included a series of lectures on key myeloma topics, followed by discussion sessions, a visit to the City of Hope cancer transplant center, a tour of the IMF headquarters for discussions on IMF programs, and participation in the IMF's Patient & Family Seminar wherein the young Chinese doctors joined in patient consults with Dr. Durie and IMWG member Dr. Rafat Abonour.

IMF's President Susie Novis Durie opened the Master Class by recalling the origins and history of the program. She expressed the IMF's great satisfaction in being able to participate in the training of Chinese physicians, noting that China is a key country for myeloma patient support. Doctors in China face numerous challenges in treating myeloma due to large numbers of patients and limited access to modern treatment options. The IMF is pleased that the Master Class allows for work in close cooperation with the Chinese Myeloma Committee to enhance understanding about diagnosis and treatment approaches and to promote increased access to the best treatments for Chinese patients.

At the beginning of the session, Chinese doctors were asked to report on the work of their myeloma centers, describing available facilities, the number and type of patients they see, the usual standard of care they provide, and their own work schedules and arrangements. This was important background information for the IMF experts, especially when considering potential guidelines for myeloma treatment in China.

The Master Class program was designed to follow the IMF's 10 Steps for Better Care®. From diagnosis to long-term survival, the 10 Steps paradigm is a guide through the myeloma journey. Dr. Durie presented the 10 Steps, explaining the sequential approach taken in this tool, which covers diagnosis, testing requirements, and various stages of treatment, and concludes with a review of clinical trials and future requirements. Dr. Durie then spoke on frontline therapy recommendations with options first for transplant eligible patients and then for transplant-ineligible patients.

In his sessions, Dr. Rajkumar provided lectures on monoclonal gammopathy of undetermined significance (MGUS) and smoldering multiple myeloma (SMM) as well as a presentation on new diagnostic criteria with implications for the future. Together with Dr. Durie, Dr. Rajkumar also spoke on the IMF's Black Swan Research Initiative® and the integration of minimal residual disease (MRD) testing into clinical trials.

Dr. Martin presented the latest information on approaches to relapse therapy, an overview of new drugs currently being developed and the role of clinical trials for new drug approvals. Challenges in securing clinical trials in China were discussed at length, including regulatory issues as well as commercial considerations.

Dr. Durie also provided lectures on supportive care, with special attention focused on bone health issues.

Dr. Harousseau led the program in the consideration of transplant issues. He spoke about the role of autologous stem cell transplant

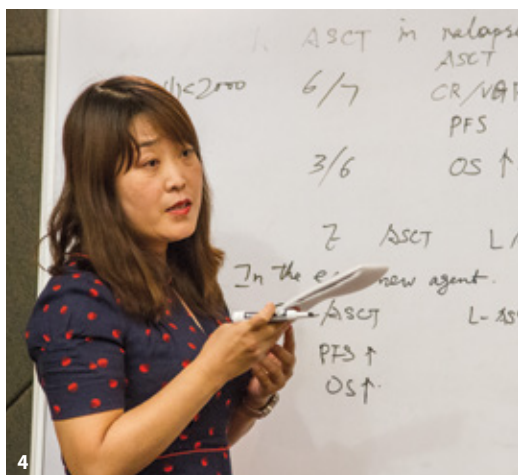
(ASCT) in the frontline setting, the role of allogeneic transplant, and the use of transplant as salvage therapy.

At the close of each session, one of the Chinese doctors was asked in turn to provide a summary of the key points from each lecture and discussion. This was seen to be particularly helpful to ensure that the main points of the day were well conveyed and understood. This also proved to be useful in preparation for the “final examination” given at the end of the course, which all the participants passed with flying colors!

In addition to providing a valuable training opportunity both for the Chinese participants and for the IMF experts and staff, the Master Class provides an invaluable occasion for networking and the

development of friendships and professional contacts. The Master Class alumni in China have become a large and growing group with important linkages to the IMF and our myeloma experts. They are becoming leading figures in the myeloma community in China. No doubt that this will lead to improved patient support in the future.

The IMF thanks our partners at Amgen and Celgene and at the Chinese Myeloma Committee for cooperation with this program. We look forward to continuing to provide the Master Class program well into the future. **MT**



1. Leading young hematologists from China graduate from the 2016 IMF Master Class: (from left to right) Guangzhong Yang, Donghua He, Lijuan Li, Yuping Zhong, Yao Chen, Jing Lu, Man Shen, Meilan Chen, Xiaotao Wang, and Liao Aijun.

2. Master Class in session

3. Dr. Brian G.M. Durie

4. At the conclusion of each lecture by the faculty, Master Class participants took turns presenting a topic summary to the group

5. Dr. Jean-Luc Harousseau

6. Master Class graduates with IMF team





# New Drug Designations and a Consensus Update

## Darzalex (daratumumab) granted “Breakthrough Therapy” designation

Janssen’s Darzalex®, or daratumumab, was granted “Breakthrough Therapy” designation by the US Food and Drug Administration July 26, 2016 for use in combination with Revlimid® (lenalidomide) and dexamethasone, and Velcade® (bortezomib) and dexamethasone, for the treatment of multiple myeloma patients who have received at least one previous therapy. The designation was based on data from the CASTOR and POLLUX trials recently presented at ASCO 2016 and EHA 2016 respectively.



The “Breakthrough Therapy” designation from the FDA provides the potential for accelerated review and approval of the use of Darzalex in combination with standard-of-care regimens in patients who have received at least one prior line of therapy. This is increasingly important as many options are now approved in the early relapse setting, and reimbursement can be critically dependent upon approval of a specific combination. Outside of the US, specific approval is an absolute requirement for patient use.

## Eliminating Darzalex interference in routine blood-transfusion testing

A letter published in the *New England Journal of Medicine* July 21, 2016 pointed out that the presence of Darzalex in the



blood of patients consistently interferes with routine blood-type compatibility testing required for blood transfusion. A method has been discovered that eliminates the interference. A special chemical-based testing method allows blood-matching to be successful even in the presence of the anti-CD 38 antibodies in Darzalex. Increased awareness of this practical solution is urgently required. Not only must patients be aware of this issue, but both physicians who treat myeloma patients and blood bank personnel must be alert for this possible problem if a patient receiving Darzalex requires a blood transfusion.

“As Darzalex becomes more widely available and used more frequently, this practical issue must have a standard procedure set up in hospital and clinic blood banks,” said IMF Chairman Dr. Brian Durie.

## Health Canada approves Ninlaro (ixazomib) for use in relapsed/refractory myeloma

Health Canada approved Ninlaro® (ixazomib) capsules for use in combination with lenalidomide and dexamethasone. The Canadian health ministry made the approval for treatment of patients with

multiple myeloma who have had at least one prior therapy. Approximately 7,500 Canadians are living with multiple myeloma. This approval was mainly based on the results of the phase 3 TOURMALINE-MM1 trial, which demonstrated that this combination therapy can significantly extend progression-free survival in patients with relapsed/refractory myeloma.



## European Commission approves extended indication for Kyprolis for the treatment of relapsed myeloma

The Committee for Medicinal Products for Human Use (CHMP) – a division of the European Medicines Agency – recommended a change to the terms of the marketing authorization for Kyprolis® (carfilzomib) for the treatment of relapsed multiple myeloma. As of July 3, 2016, CHMP approved Kyprolis in combination with dexamethasone alone to treat adult patients who have received at least one prior therapy.



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

The approval is based on results from the phase 3 head-to-head ENDEAVOR study. This new indication for Kyprolis is the second in six months. In July 2015, the FDA approved another expanded indication for Kyprolis in combination with lenalidomide and dexamethasone (KRd) for the treatment of patients with multiple myeloma who have received one to three prior lines of therapy.

## IMF’s International Myeloma Working Group (IMWG) publishes new consensus update

On June 20, 2016, the journal *Blood* published “Treatment of multiple myeloma with high-risk cytogenetics: a consensus of the International Myeloma Working Group.” This consensus updates the definition for high-risk multiple myeloma (HRMM) based on cytogenetics, which is a branch of genetics that analyzes the structure and function of genetic material on chromosomes. The paper states “risk stratification in MM is important to predict survival and to define a treatment strategy.” Furthermore, it concludes that cytogenetic abnormalities detected by FISH (fluorescence in situ hybridization) testing are “clinically relevant prognostic factors in MM.” To access the report, please visit the IMF website. **MT**







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# The IMF's Nurse Leadership Board Celebrates 10 Years of Service



Photo from the first meeting of the Nurse Leadership Board in 2006. Eight of the founding NLB members continue to lead the Board as it enters the second decade of service: Page Bertolotti, Kathleen Colson, Deborah Doss, Beth Faiman, Patricia A. Mangan, Teresa Miceli, Sandra Rome, Joseph Tariman

**By Diane Moran**  
IMF Senior Vice President, Strategic Planning

In 2006, the IMF founded the Nurse Leadership Board® (NLB) as a professional partnership to represent nurse experts caring for multiple myeloma patients at leading medical centers. In the course of the following 10 years, members of the NLB established an exemplary record of improving the nursing care and self-care of patients with myeloma by educating nurses and patients via consensus publications, symposia, multimedia, and research.

In its role as an educational body, the NLB has reached countless medical professionals – including practicing nurses, oncology pharmacists, and physicians' assistants – and patients and caregivers. Below are just a few of the Board's accomplishments.

- Multiple NLB articles have been published as four supplements to major periodicals – *Clinical Journal of Oncology Nursing* (CJON) and *Journal of the Advanced Practitioner in Oncology* (JADPRO) – with a cumulative circulation of more than 150,000. A fifth major NLB manuscript is currently being prepared for publication.
- NLB members have been invited to write or edit textbooks and chapters directed at healthcare professionals. These works have become a part of many nursing curricula.

- At the annual conference of the Oncology Nursing Society (ONS), the NLB hosts a well-attended satellite symposium. This program has grown from 350 attendees in 2006 to a record number of 1,000 nurses taking part in the 2016 symposium.
- The findings of the NLB's research study, "Lack of health maintenance examinations and risk in myeloma patients," was published in *Cancer Medicine* in 2016.
- NLB members have served as patient and caregiver educators at more than 80 IMF Patient & Family Seminars and Regional Community Workshops, 10 Support Group Leaders' Summits, and countless teleconferences and myeloma support groups meetings.

The NLB has expanded to include international affiliates from Australia and Canada. Of the 20 founding NLB members, eight continue to serve on the Board. Seven NLB members have earned their doctoral degrees during their tenure.

All of us at the IMF are so proud to celebrate the NLB's 10th anniversary of service to the myeloma community, and we look forward to all their future accomplishments. **MT**

# 17<sup>th</sup> Annual IMF Support Group Leaders



Robin Tuohy with Leaders from Jamaica, Canada, Vermont, New Jersey, Pittsburgh, Delaware, and Nebraska



Nancy Bruno, IMF Regional Support Group Director with Leaders from the Southeast

*"The 2016 IMF Support Group Leaders Summit brought together 100 Leaders representing 68 myeloma support groups from across the US and beyond, including a record of 33 first-time attendees. Year-round, these remarkable Leaders give their all to the members of their groups. In July, they gathered in Dallas, Texas, for a weekend of receiving support and encouragement. Among the many tools Leaders took home to benefit their groups was an IMF Technology Kit. The Summit agenda included research updates from IMF Chairman Dr. Brian Durie, working groups on top topics, a computer lab, and a special caregivers session with IMF President Susie Novis Durie."*

— Robin Tuohy, IMF Senior Director of Support Groups



Sue Enright, IMF Regional Support Group Director, with Leaders from the Midwest



Kelly Cox, IMF Director Support Groups and Regional Community Workshops, with Leaders from the West



Anne Pacowta, IMF Regional Support Group Director, with Leaders from Florida

"This was the sixth year I've had the privilege to attend the IMF Support Group Leaders Summit. Each year, the Summit leaves me energized and revitalized to continue my work as a support group leader. I am honored to be involved with such a dynamic organization that does so much for the myeloma community."

—Cindy Ralston; Kansas City, MO Support Group Leader

"For the first time since being diagnosed in November 2013, I felt supported. This was my first IMF Summit and the relationships I built were by far the most valuable: I feel that I gained a new myeloma family. This extended family of patients, caregivers, experts, and leaders each contribute and share something different, yet full of impact."

—Tiffany Williams; Charleston, SC Support Group Leader



# Summit: An Overwhelming Success!

“The presentation on ‘compassion fatigue’ gave me important tools to recognize it and help myself through it so I can continue to be of service to other patients. I received an email from a young woman in our group who is on a family vacation. She said that she screamed her head off at the base of a waterfall, just because she was happy to be alive! That is how I feel when I return from the Summit knowing that we have Susie and Dr. Durie ‘as our waterfall.’”

— Yvonne Yaksic; Pittsburgh, PA Support Group Leader

“I was delighted to see several leaders who had attended the December 2015 ASH conference, including Teresa Miceli, RN, who provides technical expertise and a warm heart. I admired the IMF even more for allowing and encouraging diversity and democracy in the support groups. Dr. Durie’s succinct review of new treatments and progress in the Black Swan Research Initiative® was enlightening.”

— John Auerbacher; Westchester, NY Support Group Leader

“At the Summit, I learned how important it is to build positive relationships with other leaders. I now have peers to contact to share information with, and they will share just as much with me. This bond has not only secured a great working relationship with other group leaders, but also created a great friendship.”

— Thomas Goode; Durham, NC Support Group Leader

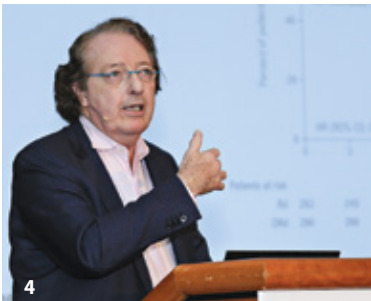
“As a facilitator of the Caregivers Need Care Too panel at the Summit, the one thing I hope caregivers take back home with them is that it’s normal to feel resentful, angry, and sometimes trapped... but voicing your feelings to other caregivers is an important way to justify those feelings and help ease the situation. That’s why it’s essential to meet privately with other caregivers and give them a safe place to air their feelings.”

— Laura Mooney; Staten Island, NY Support Group Leader

“As a first-time Summit participant, I thoroughly enjoyed group sessions and brainstorming ideas. I have made many friendships and hope to continue our connection. A wonderful event!”

— Janet Kerrigan; Myrtle Beach, SC Support Group

The IMF applauds the year-round care and commitment that Support Group Leaders provide to their local myeloma communities. We encourage all patients and caregivers to reach out to an IMF myeloma support group in their area. Visit [myeloma.org/support-groups](http://myeloma.org/support-groups) to locate a nearby group. If you would like to start a group in your area, the IMF can help! For more information, contact Robin Tuohy at [rtuohy@myeloma.org](mailto:rtuohy@myeloma.org) or 203-206-3536. **MT**



1. Myeloma Voices archivist Ryan White at interview with Thomas Goode
2. Kim Alexander and Susie Novis Durie
3. Adrian and Tiffany Williams
4. Dr. Brian G.M. Durie
5. Robin Tuohy, Denise Brunson, and Cindy Ralston
6. Charlie and Laura Mooney
7. John Auerbacher and Susie Novis Durie
8. Janet & Joseph Kerrigan

# Searching for Clinical Trials

## The IMF InfoLine coordinators answer your questions

By Debbie Birns  
IMF Medical Editor

**Q. Should I participate in a clinical trial, and how do I find the one that's best for me?**

A. Clinical trials are a vital part of moving science forward in any disease setting. Without clinical trials, new treatment concepts – whether new drugs or new ways of combining old drugs – could not be tested, validated, and when appropriate, approved. In addition, clinical trials help determine which dosages of drugs are both effective and well tolerated, compare the relative benefits of different therapies, and identify the negative side effects of those therapies. Participation in a clinical trial may offer an opportunity for patients to receive treatment with a promising therapy before it has been approved where they live or afford access to a therapy that would otherwise be too expensive, and provide high-quality care while helping move research forward for the benefit of other patients now and in the future.

Myeloma patients have been blessed with an abundance of clinical trials, four of which brought us new drug approvals in 2015. There are currently 2,120 clinical trials for myeloma listed on the clinicaltrials.gov database of the US National Cancer Institute (NCI). Navigating that enormous repository and finding studies that meet your particular needs or those of a loved one is challenging, even for those familiar with the Boolean search system. For the past 14 years, the IMF has offered the *Myeloma Matrix*, both on our website and in hard copy. This listing of clinical trials is categorized by the phase of a drug's development, from preclinical research through phases I, II, III, and all the way to post-FDA approval. The *Matrix* was designed to keep track of drugs in development for myeloma and to provide links to relevant trial information, but it was never designed to be a clinical trials search tool – something myeloma patients needed and wanted.

With a new IMF website under construction, it was the perfect time to upgrade the function of the *Matrix* into a user-friendly clinical trial search tool. In 2015, the IMF received a grant from Celgene in remembrance of Michael S. Katz, beloved former IMF Board member, patient, and technology guru. Developing the technology to help patients find trials seemed the perfect way to honor Mike, who was a great proponent of, and helped with the design of, clinical studies in myeloma. The IMF decided to support our partner organization, tech-savvy Smart Patients (the organization that hosts, among many others, a myeloma message board, the descendant of the ACOR List Serve that Mike shepherded for many years and helped transition to its new Smart Patients site), in the development of a myeloma clinical trial search tool. We call it the *Myeloma Matrix 2.0 Smart Search: Clinical Trials at Your Fingertips*. Thanks to the wonderful Smart Patients staff, you will find the *Matrix 2.0* on our new website at [myeloma.org/matrix](http://myeloma.org/matrix).

multiple myeloma treatments	6 phase 1	13 phase 2	6 phase 3	0 other*
<b>targeted therapy</b>				
carfilzomib (Kymriah) proteasome	3	3	1	0
ixazomib (Ninlaro) proteasome	0	1	1	0
ONC201 AKT, ERK	1	0	0	0
bortezomib (Velcade) proteasome	2	3	3	0
<b>immunotherapy</b>				

*Myeloma Matrix 2.0 Smart Search* makes it possible to search for a trial in multiple ways: by drug name, drug type, trial phase, or by where you are in the disease process (newly diagnosed, smoldering myeloma, maintenance therapy, or relapsed/refractory). *Smart Search* uses up-to-the minute data from cancer.gov – just made available by the NCI as part of the Cancer Moonshot Summit hosted by Vice President Biden in Washington, DC. Smart Patients was one of the organizations selected by the NCI and the Vice President's office to receive early access to this new data in order to provide feedback and incorporate the data into the Smart Patients online patient community.

One of the most important features of *Myeloma Matrix 2.0 Smart Search* is its ability to create a pathway for conversations among patients and caregivers who are going through a specific trial. Because the database will be updated on a continual basis, patients don't have to worry about missing important trial deadlines or being too late to be considered for a trial. *Myeloma Matrix 2.0* makes the search for a clinical trial as worry-free for patients and caregivers as possible. **MT**

*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. 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).*



# Pennsylvania and Alaska Pass Oral Parity Laws



The IMF Advocacy team worked tirelessly alongside advocates from the myeloma patient community to pass oral parity laws in Pennsylvania

and Alaska, making them the 41st and 42nd states to do so. Some health insurance plans cause patients to be responsible for up to 20% of the cost of oral anti-myeloma drugs. Without oral parity laws, patients could be paying tens of thousands of dollars a year for their prescription.

For seven years, the IMF worked with members of the State Patients Equal Access Coalition (SPEAC) to pass oral parity laws in Pennsylvania. The main opposition came from the insurance companies. After months of negotiations with State Senators and Representatives, SPEAC held a press conference in the rotunda of the Pennsylvania State Capitol, bringing the issue to the forefront of legislation and in the media. Advocates rallied for one final push – sharing their patient and caregiver stories. As of June 28, 2016, Governor Tom Wolf passed the bill into a law. The effort in Pennsylvania demonstrated how organizations can work together to make change happen.

The battle for oral parity in Alaska differed from Pennsylvania in that it faced almost no opposition from insurers and also was supported by politicians on both sides of the aisle. However, one of the most remarkable events in the fight for oral parity in Alaska was the compelling testimony delivered by myeloma patient and IMF advocate Eric Hansen of Juneau. Eric spoke to both the state's House and Senate Labor and Commerce Committees, explaining how patients

in rural parts of the state must travel great distances to receive care at infusion centers. Some rural Alaskan cancer patients have had to take bush planes just to receive their infusions! By sharing his perspective, Eric was key in convincing legislators that cancer patients in Alaska would benefit from home therapy with oral medications. With the facts laid bare in front of them, members of the House and Senate voted unanimously to pass the oral parity bill. By early summer, Governor Bill Walker signed the bill into law.

In 2017, SPEAC will be introducing oral parity bills in Tennessee, Michigan, Arkansas, North Carolina, and possibly Idaho and Montana. In South Carolina and Alabama, SPEAC will educate legislators and citizens about oral parity in preparation for a future introduction of the bill.

As demonstrated by Eric Hansen in Alaska and the patient advocates in Pennsylvania, oral parity bills have succeeded because of the willingness by patients and caregivers to share their stories. If you live in one of the eight remaining states without oral parity, we urge you to join us in this mission. Send emails to your legislators, pay them a visit, or reach out with phone calls. Any level of involvement, large or small, is tremendously helpful to the cause.



Eric Hansen

To get involved, contact the IMF's Advocacy Associate Kelley Jones at [kjones@myeloma.org](mailto:kjones@myeloma.org). To learn about the oral parity legislation in your state, visit [speac.myeloma.org](http://speac.myeloma.org). And, of course, feel free to submit your questions to [advocacy@myeloma.org](mailto:advocacy@myeloma.org). **MT**



IMF Advocacy Associate Kelley Jones (third row, in pink) joins Governor Tom Wolf on Pennsylvania Lobby Day

# Report from the Czech Republic Patient & Family Seminar

By Nadia Elkebir  
IMF Director of Europe and the Middle East

On the evening of September 9, the 2016 Czech Republic Patient & Family Seminar commenced with a welcome dinner at Hotel Tree of Life in the city of Lazne Belhorad. More than 130 patients and the esteemed faculty of Dr. Roman Hájek, Dr. Vladimir Maisnar, and Dr. Peter Hylena enjoyed a lovely meal, socializing, and dancing to the sounds of a live band.



Nadia Elkebir and  
Dr. Vladimir Maisnar

The following morning Dr. Hájek opened the educational portion of the meeting with a warm greeting to the participants. Next, Dr. Maisnar talked about the role of the Czech Myeloma Group in the field of myeloma, followed by Dr. Hylena's report on the 2016

activities of the myeloma patient support group. The Czech Myeloma Group is led by Iveta Mareschova and Miroslav Hrianka helms the Slovak Myeloma Society. Czech Myeloma Group and the Slovak Myeloma Society, which represent patients in neighboring countries, have for many years maintained a very close and collaborative relationship, supporting each other across multiple programs and activities. Miroslav Hrianka gave a talk about the past and future activities of the Slovak Myeloma Society.

Next, I spoke to the attendees about the broad international reach of IMF programs, the significant impact of the IMF's International Myeloma Working Group (IMWG) in the world of science and medicine, and the important advocacy activities of the IMF's Global Myeloma Action Network (GMAN).



Medical faculty Drs. Vladimir Maisnar, Ludek Pour, Jiri Minarik and Roman Hájek at the dais and Iveta Mareschova at the podium



Patients and caregivers attend the open discussion with the faculty

After a break, the expert faculty panel held an open discussion with members of the audience, and many questions flowed from both patients and caregivers.

A very popular talk was Dr. Hájek's presentation on who is a suitable candidate for a clinical trial and why, and physiotherapist Pavla Straubova shared tips and techniques for alleviating backache.

After lunch, participants divided into three breakout groups:

1. Management of neuropathy, by Dr. Ludek Pour and Dr. Jakub Radocha
2. Management of side effects, by Dr. Valdimir Maisnar and Dr. Jan Straub
3. New drugs for myeloma, by Dr. Roman Hájek



New myeloma drug therapies breakout group

The animated interaction between patients and family confirmed how crucial it is to make available programs to help the patient communities far and wide stay up-to-date on the progress in myeloma research while also learning how to better cope with the personal challenges of a myeloma diagnosis and treatment.

I am very proud of both the Czech Myeloma Group and the Slovak Myeloma Society for working so hard to make these meetings as useful as possible to patients and their families. The good spirit and enthusiasm of the members of their groups are truly inspiring, and a beautiful example of what can be accomplished with hard work and dedication. **MT**



# IMF's Community Picnic Day Raises Myeloma Awareness

*"The Community Picnic was organized to not only raise funds for the IMF, but to increase awareness about who we are, what we do, and how our research is moving very quickly toward a cure for multiple myeloma."*

— Sharon Chow, IMF Special Events and Donor Relations Manager

Southern Californians enjoyed a sunny Sunday afternoon in an open clearing in beautiful Griffith Park for the IMF's inaugural Community Picnic Day, held on August 21, 2016. The picnic was free to all thanks to the generous support of Amgen; Takeda Oncology; and the IMF's Kelly Cox, Director of Support Groups and Regional Community Workshops.



Attendees indulged in kale smoothies and took in a healthy cooking demonstration by Robert Russell, owner and head chef at the organic eatery SunCafé.

Children painted pictures, engaged in drama activities, and wrote in journals at the art therapy tent, which was hosted by Mimi Savage of the SoCal Drama Therapy Centre.

But the most popular event of all, with over 25 participants, was the vigorous yoga session led by Mecca Romero, an instructor from the



Heartbeat House – a non-competitive dance/workout/fitness studio located in the Atwater Village neighborhood of Los Angeles.



The afternoon drew to a close with a raffle that included an array of give-aways: backpacks, admission to the 2016 IMF Comedy Celebration, works of art from Harper Fine Art,

an architectural/urban design consultation, Big 5 Sporting Goods gift cards, and bundles of fun Sun-Stashes®, as donated by the IMF's Development and Operations Assistant Joy Riznikove (left) and Director of Development Randi Lovett (right).

The IMF is grateful to all our volunteer picnic vendors. Perhaps the event's biggest success is that more than 50% of the participants had never heard of multiple myeloma before attending. Many donated to the IMF and collected educational materials to inform themselves and families about the disease. **MT**





# Laughter Truly Is the Best Medicine

By Suzanne Battaglia  
IMF Director of Member Events

In the summer of 2015, Kent Oliver and his wife Candace were completing construction of their new home in his native Mississippi. Over the preceding months, Kent's back and rib pain had begun to infringe upon this otherwise joyous time. Given a busy personal and professional life, it was easy to attribute Kent's pain to physical exertion and to actively playing with his two-year-old daughter Annie and newborn Charlotte. But the pain intensified. Kent's family doctor mentioned multiple myeloma early on, but it seemed an unlikely diagnosis for a man in his early thirties.

Kent underwent a series of imaging scans, followed by a bone marrow biopsy. On October 7, 2015, he received his diagnosis. "At 34 years old, with two young girls, I never expected that I would be diagnosed with cancer. Hearing the words 'myeloma' and 'incurable' left me feeling stunned."

Kent's local oncologist immediately called Mayo Clinic to set up an appointment. After months of procedures, chemotherapy and other treatment at Mayo, and locally at the Forrest General Cancer Center, Kent underwent a stem cell transplant at Vanderbilt University. It was during his recovery from the transplant that he found himself laughing for the first time since diagnosis. "That's when I realized that laughter had been absent from our lives for months. As we face challenges – of all types – laughter is all too often silenced. My wife Candace and I wanted to change this."

When the Olivers returned to their family in Hattiesburg, they searched for a special way to thank their hometown and the amazing

community of friends and family that had been so supportive. "As we took a positive step with regards to my personal progress, Candace and I wanted to raise myeloma awareness, as well as funds for research through the IMF. And we wanted to bring greater attention to the Forrest General Hospital Cancer Center. *Laughs 4 Life* was intended to generate smiles and laughter throughout our wonderful Hub City community in a way we've never seen before," said Kent. "It was a way to say Thank You to the friends, family, caregivers, and supporters who have made my personal journey tolerable."

The *Laughs 4 Life* event took place on July 28 in downtown Hattiesburg. "This was our first fundraising experience, and we were thinking BIG! We were very fortunate with our advisory committee, our sponsors, the venue, the auction, the event website, and all the other elements that fell into place. Everyone rallied. About 900 people took part in *Laughs 4 Life*. I am just so proud to call the city of Hattiesburg my home."

The pre-show VIP dinner at the Bottling Company was headlined by Marshall Ramsey, a two-time Pulitzer Finalist known for his award-winning cartoons, entertaining radio program, and engaging short stories. As a malignant melanoma survivor, he has been paying it forward by promoting cancer awareness and education.

After dinner, headlining comedian Frank Caliendo entertained a near-capacity crowd at the historic Saenger Theater. Frank has been a fixture on television for the last decade, and his high-energy act was a blend of observations, impressions, characters, and anecdotal stories that started at a frenetic pace and never let up.

Other performers included opening act George Kanter and Kent's good friend, Hub City Comedy's Jamie Arrington, who helped



1

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Kent's local oncologist immediately called Mayo Clinic to



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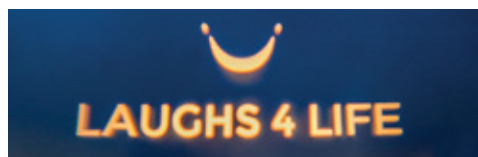
host *Laughs 4 Life*. Brett Favre and his wife Deanna, residents of Hattiesburg, attended *Laughs 4 Life* a week before the former quarterback was inducted into the Pro Football Hall of Fame.

“In our mission to improve the future outlook for cancer patients, we are filled with gratitude to all the people who joined us for a night of laughter, fun, and philanthropy, and to all who were so generous with their support even if they were unable to attend. Our goal was to raise \$100,000 and we raised over \$124,000! The funds are being shared equally between two wonderful organizations: the Forrest General Cancer Center will launch a new patient navigation program to help newly diagnosed patients, and we are very excited to be fully funding a much-needed myeloma research grant through the International

Myeloma Foundation. Candace and I are very hopeful about how these projects might benefit patients. We feel like we accomplished something pretty special, and we’re already looking forward to next year’s event and beyond.”

Laughter truly is the best medicine. **MT**

*Grassroots 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 toward our common goal...a CURE.*



1. Kent and Candace Oliver
2. Annie and Charlotte Oliver
3. Kent onstage, addressing event supporters
4. VIP Dinner
5. Auction included items from award-winning cartoonist Marshall Ramsey
6. Event patrons line up for the show at the historic Saenger Theater
- 7-8. Frank Caliendo entertains the audience
9. Jamie Arrington
10. George Kanter
11. Brett and Deanna Favre backstage
12. IMF's Suzanne Battaglia and Ilana Kenville traveled to Mississippi to represent the IMF at the *Laughs 4 Life* event



# Hope Society

Inspire HOPE, and contribute to the fight against myeloma

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

## From one of our members to you:

"The IMF gives me the InfoLine, the forums, Dr. Durie's blog, Patient & Family Seminars, webcasts, videos from scientific meetings, and more. Best of all, the IMF supports research which may **save my life**. Surely, the least I can do is support them through the Hope Society."

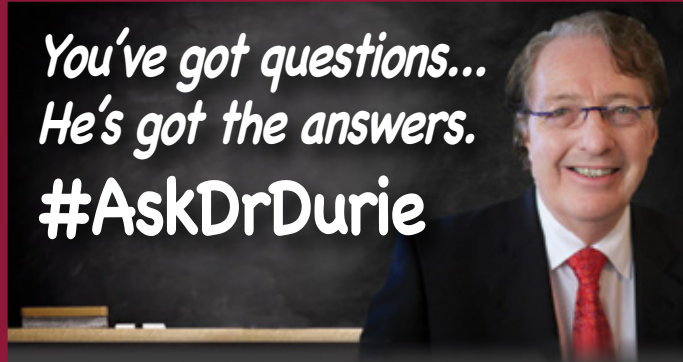
— Chip Shanley,  
monthly donor

## Ways to join:

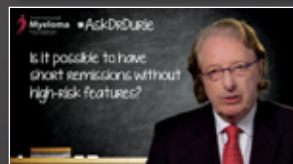
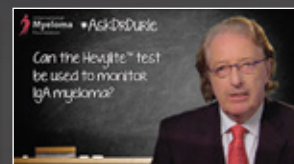
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## Give a Gift to the IMF at No Added Cost to You!

The IMF has a new Amazon link. Whether you shop on Amazon for the holidays or for your daily needs, **please bookmark the brand new [amazon.myeloma.org](http://amazon.myeloma.org) link**, and delete our old Amazon link. At no added cost to you, Amazon will donate to the IMF a percentage of your purchase's total. The percentage that Amazon donates to the IMF will continue to increase – as much as 7% or more – depending on how many orders are placed through the IMF portal.

You can also generate donations by making purchases through the IMF Shopping Mall at [shop.myeloma.org](http://shop.myeloma.org) from vendors such as Macy's, 1-800-Flowers, Drugstore.com, the Mac Game Store, Omaha Steaks, Dollar Rent-a-Car, Avon, Champion, Beauty.com, David's Cookies, and Paul Fredrick.



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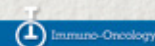
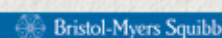
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*Dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure.*

## 2016/2017 IMF Calendar of Events

### 2016

Nov 5 10th 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

### 2017

Feb 4-5 IMF Patient & Family Seminar – Budapest, Hungary  
Feb 25 Regional Community Workshop – Seattle, WA  
Mar 1-4 16th International Myeloma Workshop (IMW) – New Delhi, India  
Mar 11 Regional Community Workshop – La Jolla, CA  
Mar 17-18 IMF Patient & Family Seminar – Boca Raton, FL  
Mar 17-18 IMF Patient & Family Seminar – Stockholm, Sweden  
Apr 1 Regional Community Workshop – Virginia Beach, VA  
Apr 7-8 IMF Patient & Family Seminar – (city TBA), NJ

May 4-7 42nd Annual Congress of the Oncology Nursing Society (ONS) – Denver, CO  
May 6 IMF Patient & Family Seminar – La Hulpe, Belgium  
June 2-6 53rd Annual Meeting of the American Society of Clinical Oncology (ASCO) – Chicago, IL  
June 19-22 8th Annual Summit of the International Myeloma Working Group (IMWG) – Madrid, Spain  
June 22-25 22nd Congress of the European Hematology Association (EHA) – Madrid, Spain  
Aug 18-19 IMF Patient & Family Seminar – Los Angeles, CA  
Nov 4 11th Annual Comedy Celebration – Los Angeles, CA  
Dec 2-4 59th 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)