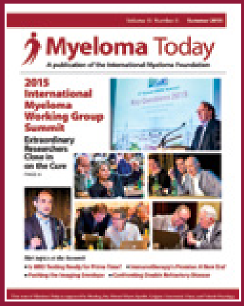
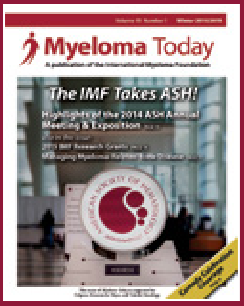
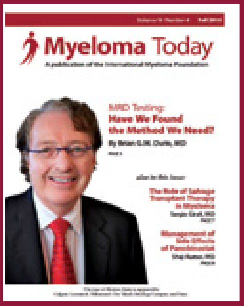
Volume 15 Number 4 **Fall 2015**

Myeloma Today

A publication of the International Myeloma Foundation


Myeloma Today
2015 International Myeloma Working Group Summit
Extraordinary Researchers Close in on the Cure

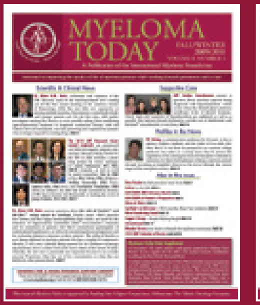

Myeloma Today
The IMF Takes ASH!
Highlights of the 2014 ASH Annual Meeting & Exposition


Myeloma Today
MRD Testing: Have We Found the Method We Need?
By Brian G.M. Durie, MD





Comedy Celebration


IMF Celebrating 25 Years

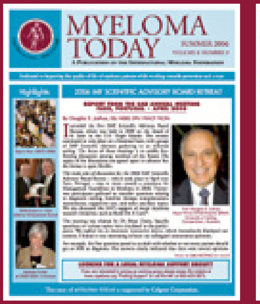
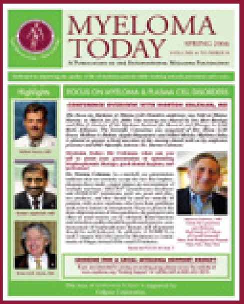
Improving Lives – Finding the Cure

PAGE 12

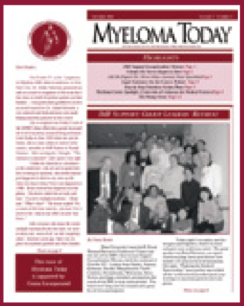










also in this issue: **9th Annual Comedy Celebration** PAGE 18

This issue of *Myeloma Today* is supported by Amgen, Bristol-Myers Squibb, Celgene, Novartis, and Takeda Oncology.

International Myeloma Foundation

Founder
Brian D. Novis

President
Susie Novis Durie

Board of Directors
Chairman Dr. Brian G.M. Durie

Christine Battistini
Yelak Biru
Prof. Dr. Mario Boccadoro
Loraine Boyle
Mark Di Cicilia
Aldo Del Col
Susie Novis Durie
Jason Katz
Benson Klein
Andrew Kuzneski, III
Dr. Robert A. Kyle
Prof. Dr. Heinz Ludwig
Dr. Edith Mitchell
Charles Newman
John O'Dwyer
Dr. S. Vincent Rajkumar
Matthew Robinson
E. Michael D. Scott

Scientific Advisory Board
Chairman Robert A. Kyle, USA

Kenneth C. Anderson, USA
Michel Attal, France
Hervé Avet-Loiseau, France
Dalsu Baris, USA
Bart Barlogie, USA
Régis Bataille, France
Meral Beksaç, Turkey
William Bensinger, USA
P. Leif Bergsagel, USA
Joan Bladé, Spain
Mario Boccadoro, Italy
Michele Cavo, Italy
J. Anthony Child, United Kingdom
Raymond L. Comenzo, USA
John Crowley, USA
Franco Dammacco, Italy
Faith Davies, United Kingdom
Meletios A. Dimopoulos, Greece
Johannes Drach, Austria
Brian G.M. Durie, USA
Hermann Einsele, Germany
Thierry Façon, France
Dorotea Fantl, Argentina
Jean-Paul Fermand, France
Rafael Fonseca, USA
Gösta Gahrton, Sweden
Morie A. Gertz, USA
John Gibson, Australia
Hartmut Goldschmidt, Germany
Roman Hájek, Czech Republic
Joy Ho, Australia
Vania Hungria, Brazil
Sundar Jagannath, USA
Douglas Joshua, Australia
Michio M. Kawano, Japan
Ola Landgren, USA
Jae-Hoon Lee, South Korea
Henk M. Lokhorst, The Netherlands
Sagar Lonial, USA
Heinz Ludwig, Austria
Jayesh Mehta, USA
Håkan Mellstedt, Sweden
Giampaolo Merlini, Italy
Gareth Morgan, United Kingdom
Nikhil Munshi, USA
Amara Nouel, Venezuela
Antonio Palumbo, Italy
Linda Pilarski, Canada
Raymond Powles, United Kingdom
S. Vincent Rajkumar, USA
Donna Reece, Canada
Paul Richardson, USA
Angelina Rodríguez Morales, Venezuela
David Roodman, USA
Jesús F. San Miguel, Spain
Orhan Sezer, Germany
Kazayuki Shimizu, Japan
Chaim Shustik, Canada
David Siegel, USA
Seema Singhal, USA
Alan Solomon, USA
Pieter Sonneveld, The Netherlands
Andrew Spencer, Australia
Keith Stewart, USA
Guido J. Tricot, USA
Benjamin Van Camp, Belgium
Brian Van Ness, USA
David Vesole, USA
Jan Westin, Sweden

Emeriti
Raymond Alexanian, USA
Y.C. Chen, Republic of China
Ian Franklin, Scotland
Tadamitsu Kishimoto, Japan
Ian MacLennan, England
James S. Malpas, England
Martin M. Oken, USA

IMF Executive Team

Chief Financial Officer
Jennifer Scarne
jscarne@myeloma.org

Senior Vice President, Strategic Planning
Diane Moran
dmoran@myeloma.org

Senior Vice President, Clinical Education & Research Initiatives
Lisa Paik
lpaik@myeloma.org

Senior Vice President, Global Affairs
Daniel Navid
dnavid@myeloma.org

IMF Staff

Data Administrator
Sevag Abajian
sabajian@myeloma.org

Database & Inventory Control
Betty Arevalo
marevalo@myeloma.org

Director, Member Events
Suzanne Battaglia
sbattaglia@myeloma.org

Medical Editor
Debbie Birns
dbirns@myeloma.org

Southeast Regional Director, Support Groups
Nancy Bruno
nbruno@myeloma.org

Senior Director of Advocacy
Meghan Buzby, MBA
mbuzby@myeloma.org

Development Associate
Sharon Chow
schow@myeloma.org

Director, Support Groups & Regional Community Workshops
Kelly Cox
kcox@myeloma.org

Director, Europe & the Middle East
Nadia Elkebir
nelkebir@myeloma.org

Midwest Regional Director, Support Groups
Sue Enright
senright@myeloma.org

Assistant Meeting Coordinator
Carmen Greene
cgreene@myeloma.org

InfoLine Coordinator
Paul Hewitt
phewitt@myeloma.org

Web Specialist
Kevin Huynh
khuynh@myeloma.org

Editor-in-Chief, Publications
Marya Kazakova
mkazakova@myeloma.org

Development Associate
Ilana Kenville
ikenville@myeloma.org

InfoLine Coordinator
Missy Klepetar
mklepetar@myeloma.org

Medical Affairs Assistant
Xuan Lam
xlam@myeloma.org

Accountant
Phil Lange
plange@myeloma.org

Research Project Coordinator
Amirah Limayo
alimayo@myeloma.org

Director, Development
Randi Lovett
rlovett@myeloma.org

Publication Design
Jim Needham
jneedham@myeloma.org

Florida Regional Director, Support Groups
Anne Pacowta
apacowta@myeloma.org

Advocacy Associate
Taylor Patton, MSW
tpatton@myeloma.org

Director of Operations
Selma Plascencia
splascencia@myeloma.org

Meeting Coordinator
Annabel Reardon
areardon@myeloma.org

Development & Operations Assistant
Joy Riznikove
jriznikove@myeloma.org

Web Producer
Miko Santos
msantos@myeloma.org

Director of Major Gifts
Elise Segar
esegar@myeloima.org

Distribution
Brando Sordoni
bsordoni@myeloma.org

Assistant to the President
Rafi Stephan
rstephan@myeloma.org

Advocacy Associate
Lindsey Trischler
ltrischler@myeloma.org

Senior Director, Support Groups
Robin Tuohy
rtuohy@myeloma.org

InfoLine Coordinator
Judy Webb
jwebb@myeloma.org

Outreach
Jonathan Weitz
jweitz@myeloma.org

Global Advocacy Executive
Ray Wezik
rwezik@myeloma.org

A Message from the President

Dear Reader,

As the IMF celebrates its 25th anniversary, I'm reminded of the way it all began. In 1989, three people sat in a coffee shop in London talking about what they could do to help make a difference for myeloma patients. Those three people were Brian Novis, Dr. Brian Durie, and me. Little did we realize at the time how that conversation would not only change our own lives but the lives of hundreds of thousands of people around the world.

The idea of starting the International Myeloma Foundation (IMF) became a reality in October 1990 when Brian Novis, working out of a tiny basement office in our home, officially opened the IMF for business.

Hard to believe that was 25 years ago – it passed in the blink of an eye! And yet, over the past quarter of a century – with your help and that of others – the lives of myeloma patients have improved dramatically, far beyond our wildest dreams. Thanks in part to the discovery of an array of novel agents that led to better treatments, myeloma patients can look forward to living far longer than the three to five years that was once the predicted life span. Today, many patients are living 10 years, 15 years and **more** from that initial diagnosis. For the past 25 years, patients and their families have turned to the IMF for a wealth of information and support, knowing the IMF has vast resources of myeloma educational materials – in print, online, and on video.

Knowledge is Power is a phrase we coined long ago and it has been our rallying cry ever since.

As you will see on IMF's 25th Anniversary Timeline (page 12), we've been busy! The IMF's four pillars are Research, Education, Support, and Advocacy. We've brought people together from around the world and all walks of life. Here are a few highlights of what we've accomplished together:

- Since 1995 the IMF has funded 114 research grants, and in 2012 launched the Black Swan Research Initiative®, our groundbreaking, global project to find the cure.
- Since 1994 the IMF has led the world in empowering patients through education, holding the very first Patient & Family Seminar – ever – and proving that Knowledge is indeed Power!
- Since 1994 when the first Support Group was formed, the IMF has fostered and equipped a coalition of myeloma support groups and their leaders across the US and around the world.
- Our dedicated and effective Advocacy team has trained an army of passionate and committed advocates, resulting in significant advances in both State & Federal legislation.

Looking back, we've very proud of what we've accomplished but we're not resting on our laurels. We keep the entire myeloma community – doctors, nurses and healthcare providers, updated on the advances in the treatment and management of myeloma.

What I'm most proud of is that over the past 25 years we've never lost sight of our mission and who we work for. We work for patients and their families; no matter where they live we are going to reach out and help them. It's always about the patient – the patient is at the center of everything we do.

And so, to all the patients and family members I want to convey a special message – this is very, *very* personal for me too, and I'm thrilled to honestly say, hang in there and never give up – a cure really truly is within reach.

Warm regards,

Susie Novis Durie

Susie Novis Durie, President

CELEBRATING
25
YEARS

This free issue of *Myeloma Today*© (Volume 15, Number 4) is dated October 15, 2015. *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

Black Swan Research Initiative Update

> ***"If the patient continues to be MRD-negative for one year, three years, five years off treatment, then this would indicate that the patient is well on the way to being cured."***
>
> **— Brian G.M. Durie, MD**

By Brian G.M. Durie, MD
IMF Chairman

The Black Swan Research Initiative® (BSRI®), the International Myeloma Foundation's innovative approach to finding a cure for myeloma, has entered a very exciting time. The project's first phase – which began with the official launch in 2013 – has been successfully completed. We are now beginning Phase Two of our work to identify treatments that will cure myeloma.

Phase One of the Black Swan Research Initiative: a recap

The goal of Phase One of the BSRI was to establish the best methods for detecting and monitoring Minimal Residual Disease (MRD), which we believe is key to curing myeloma. In recent years, dramatic advances in myeloma treatment made it possible to destroy all but a tiny amount of diseased cells in many patients. Lingering, but hidden cells caused relapse. Only by wiping out all the myeloma could a patient be cured.

The BSRI team realized that existing testing methods were inadequate to measure and identify those cells – a stumbling block for attaining a cure. We had to be able to measure myeloma at a very low level in order to track and treat remaining disease. If we could do so, we could determine a) whether or not any cells remained at all (MRD-negative) or b) which treatment would work best on the cells that remain.

With the support of the BSRI, an extremely sensitive flow cytometry method for MRD detection has been developed by Drs. Alberto Orfao, Bruno Paiva, and team leader Prof. Jesús San Miguel, working at the Universities of Salamanca and Pamplona. This new flow cytometry test is able to detect myeloma cells in the bone marrow at the highly sensitive level of one in a million cells.

Extremely accurate method for measuring myeloma

"Next-Generation Flow" (NGF), as this new method is called, is highly reproducible, with a computer software package that takes just 12 minutes to run. We estimate the total cost of the test will be under $150. The NGF test can be done at centers around the world. In addition, it compares extremely favorably to a molecular or DNA sequencing technique called "Next-Generation Sequencing" (NGS).

Although NGS is also sensitive at a level of approximately one in a million cells, just 88 percent of patients had a bone marrow sample that allowed the DNA sequencing technique to be used, according to our analysis. That left out a sizeable 12 percent of patients. And in myeloma patients who had enough material to perform both NGF and NGS tests, the NGF method was actually positive in a few more cases versus the sequencing method. The NGS method will cost approximately $1,000 per test.

Black Swan Research Initiative: Phase Two

With the most sensitive and accurate MRD measuring tool in place, the BSRI investigators are now poised to begin Phase Two. In the next few months we will be introducing Next-Generation Flow and other types of MRD testing to correlate in what we call "cure" trials. The CESAR trial is launching now in Spain; the US ASCENT trial will begin within a few months at multiple institutions in the US, with Dr. Shaji Kumar of the Mayo Clinic as the principal investigator.

The goal is that these trials will lead to a sustained MRD-negative status for the patient. If we are not able to detect any residual disease at the level of one in a million cells, we feel this is an excellent indicator of sustained MRD-negative. If the patient continues to be MRD-negative for one year, three years, or five years off treatment, then this would indicate that the patient is potentially cured.

Both trials will be conducted in patients who have high-risk smoldering myeloma. We believe if we start early, this is the type of patient who will be amenable to a cure. Starting treatment early means there is less myeloma and fewer mutations or extra or missing chromosomes. Using an aggressive approach to treat these patients as part of the initial therapy, we believe that a significant percentage of these patients will indeed be cured.

What percentage are we predicting? In these trials, we think that as many as 30 to 50 percent of the patients will be cured through an aggressive strategy consisting of carfilzomib, lenalidomide, dexamethasone, autologous stem cell transplant, and – in the US ASCENT trial – the introduction of daratumumab. We believe the anti-CD38 monoclonal antibody will provide that extra bit of treatment that could allow the eradication of many, if not all, resistant clones.

MRD-positive patients

Of course, not every patient will achieve an MRD-negative status. What about the patients who remain MRD-positive? The study of these patients constitutes a huge and very important part of the BSRI. We are now embarking on detailed studies of patients with residual myeloma and asking: What is the nature of the residual clones? What are their molecular characteristics? What are their immune features? What are the drug sensitivity features?

We want to be able to better understand these resistant cells and come up with the best treatment strategies to eradicate the resistant disease – even for the patients who have quite resistant sub-clones. This represents a huge opportunity to introduce new drugs in development and come up with new combinations and new therapies. Those trials will start in 2016.

And so, this is truly an exciting time for the Black Swan Research team. Its membership is rapidly expanding to include representatives from around the world who are contributing through lab-based research and upcoming clinical trials. Stay tuned for many more exciting new details in the coming months.

Black Swan Research Initiative resources

Website
bsri.myeloma.org

Videos

- **BSRI update at the Los Angeles Patient & Family Seminar, August 2015:** http://tinyurl.com/BSRIupdate
- **Ask Dr. Durie, August 2015:** http://tinyurl.com/AskDrDurie

MT

Black Swan Research Initiative

Phase One

- MRD detection methods standardized
- Next-Generation Flow (NGF) can detect one myeloma cell per million
- Flow cytometry has been evaluated in 100s of bone and blood samples to fine-tune this method
- NGF has proven more accurate than Next Generation Sequencing (NGS)

Phase Two

- "Cure" trials will hopefully lead to sustained MRD-negative status for individual patients
- CESAR trials in Spain and ASCENT trials in US begin
- An aggressive approach: novel agents plus autologous stem cell transplant
- Studies of MRD-positive patients to launch
- New drug combinations to eradicate resistant myeloma clone cells

---

Dr. Bruno Paiva Wins Bart Barlogie Young Investigator Award

By Brian G.M. Durie, MD
IMF Chairman

During the "Rising Stars" session held on Saturday, September 26th at the International Myeloma Workshop (IMW) in Rome – co-chaired by IMW organizer Dr. Antonio Palumbo and myself – Dr. Bruno Paiva from the University of Navarra in Pamplona, Spain was awarded the newly established Bart Barlogie Young Investigator Award. This award honors an investigator under 40 years old at the time of the IMW who has made major scientific contributions in terms of publications, funding received, and prior awards or recognition. Bruno has been amazingly prolific at a young age: he is only 31, yet beat out investigators all the way up to age 40!

Bruno's primary research area is the assessment of minimal residual disease (MRD). Among other things, he is the lead investigator for the studies of next-generation flow (NGF) and sequencing as part of the IMF's Black Swan Research Initiative®. Thus, this award acknowledges Bruno individually and the importance of the MRD approach to searching for a cure for myeloma.

Bruno has been a prominent presenter at the annual meeting of the American Society of Hematology (ASH) in recent years, with key presentations on multiple aspects of MRD. One study, for example, focused on the nature of residual subclones after primary induction therapy. Another compared results with NGF versus next-generation sequencing (NGS) in determining the best response at the MRD-negative level.

Dr. Brian Durie with Dr. Bruno Paiva, winner of the Bart Barlogie Young Investigator Award

Bruno gave a very gracious and humble acceptance speech, pointing out the contributions of the other team members and, of course, his primary mentor, Dr. Jesús San Miguel. Dr. San Miguel brought Bruno with him as his lead investigator when he moved from the University of Salamanca in Spain to Pamplona. They are certainly an indomitable duo!

We congratulate Bruno and wish him the greatest of success in the coming years – which will undoubtedly be extraordinary in contributions to the myeloma community. Bruno, a truly stellar individual, so well represents the "Rising Stars" who were honored as the IMW Congress in Rome came to a close.

The "Rising Stars" session also acknowledged four other excellent young researchers, who presented summaries of their research. Prof. Palumbo emphasized the importance of this part of the program in bringing fresh ideas to the table, and contributing to a better understanding of myeloma and approaches to treatment. I am sure we can expect more of this in the future. **MT**

African Americans and Multiple Myeloma

African Americans are more than twice as likely as Caucasians to be diagnosed with multiple myeloma, yet, as a group, respond better to treatment. That is why the IMF is promoting early diagnosis as a key to bringing this group the help it needs to combat the disease.

This past August's annual meeting of the National Medical Association (NMA) in Detroit, Michigan provided an ideal setting for outreach in this area. The key goal of the NMA, which represents more than 30,000 African American physicians and their patients in the US, is to eliminate health disparities. Recent studies have shown that in addition to the disparity in myeloma incidence among African Americans, there are also disparities in treatment and outcomes.


Photo courtesy of the NMA

The goal of the National Medical Association (NMA), which held its annual meeting in August in Detroit, MI, is to eliminate health disparities.

Younger African Americans develop myeloma at a rate three to four times higher than in whites, according to Dr. Vincent Rajkumar, professor of medicine at Mayo Clinic and member of the International Myeloma Foundation (IMF) Board of Directors. Dr. Rajkumar's myeloma presentation at the NMA's 113th annual convention was included in an umbrella session entitled "Disparities and Opportunities in Cancer Care: The Role of Non-Oncologists." The audience members at the well-attended session were largely general practitioners and internists – "primary care physicians…who need to be aware of the increased risk."

A higher risk of MGUS in African Americans, Dr. Rajkumar explained, is one of the hypothesized reasons for their higher risk of myeloma. He cited a 2014 study published in *Leukemia* that showed that there is a significantly higher prevalence of MGUS (monoclonal gammopathy of undetermined significance) among African Americans than among whites.

But studies also show that even though African Americans have a higher risk, they can respond better to treatment than Caucasians.

"If you look at the chromosomal findings of the myeloma in African Americans, they actually have smaller percentages of the high-risk features," said Dr. Brian Durie, IMF chairman. Dr. Rajkumar backed this up when he cited a study from this year that found that African American patients with myeloma have a lower frequency of IgH translocations compared with whites (40 % versus 52 %). The study, which utilized samples from myeloma trials conducted by the Eastern Cooperative Oncology Group (ECOG), "suggests the type of multiple myeloma in African Americans is the good or standard risk and less likely to be high risk," Dr. Rajkumar noted.

Certain types of treatment work better in African Americans with multiple myeloma. In the ECOG trial with lenalidomide, African Americans had almost a two-fold better survival than whites did – "which is something buried in that paper," Dr. Rajkumar noted.

Another treatment that seems to work well for African Americans is stem cell transplantation. But here the racial disparity again rears its head: although the incidence rate of myeloma in African Americans is about twice that of whites, African Americans are 50 % less likely to undergo bone marrow transplantation. This was borne out in a 2010 study published in the journal *Cancer* by researchers at the Medical College of Wisconsin in Milwaukee and the Medical College of Georgia in Augusta. They found that African Americans and whites have identical survival rates after undergoing ASCT, which means that increased use of the therapy would have direct consequences on the African American myeloma population.

"Equal treatment results in equal outcomes," said Parameswaran Hari, MD, assistant professor of medicine at the Medical College of Wisconsin, a member of the IMF International Myeloma Working Group (IMWG), and a co-author of the 2010 study.

"This is a very important concern," Dr. Durie said. "It's tremendously important for the myeloma community to work hard and educate patient communities, doctor communities, experts, to be alert and be ready to provide the best possible care for African Americans."

At the NMA annual meeting, Dr. Rajkumar presented a background discussion of the disease; a review of studies illuminating its manifestation in African American patients; various treatment options; 2015 myeloma survival statistics; and a glimpse of new drugs on the horizon.

Yet, while big medical conventions are an excellent forum for these issues, Dr. Rajkumar believes that outreach efforts "really need to be local." Reaching out via African American churches, social media, and publications are some of his suggestions. "And we need to try to involve African American physicians in academia more."

Dr. Durie agrees. "A comprehensive program," he says, "is required to understand why African American myeloma patients are frequently underserved and to establish new strategies to enhance both earlier diagnosis and optimize treatment protocols."

Drs. Durie and Rajkumar discussed possible new strategies at a special roundtable on the subject launched during IMF's International Myeloma Working Group (IMWG) Summit in Vienna in June. The group will reconvene in December at the 2015 American Society of Hematology Annual Meeting in Orlando, Florida, which MT will report on in the publication's Winter edition. **MT**

Selinexor: A New Mechanism of Action Against Myeloma

Myeloma Today *spoke to Dr. Christine Chen about selinexor, a new oral myeloma drug currently undergoing clinical trials. Dr. Chen, the principal investigator of the STOMP trial, is an assistant professor at the University of Toronto in Canada and hematology faculty at the Princess Margaret Hospital.*

Myeloma Today: Please describe selinexor's unique mechanism of action.

Dr. Christine Chen: Selinexor is a unique inhibitor of a protein called XPO1. XPO1 transports proteins from inside the nucleus of a cancer cell, where the DNA making up the genome is found, to the cytoplasm outside, where some of these important proteins – tumor suppressor proteins – are disabled and cannot function normally. As a result of XPO1 blockade by selinexor, tumor suppressor proteins are retained in the nucleus where they can act on DNA and inhibit growth and survival of the cancer cell, leading to tumor cell death. Unlike cancer cells, normal cells have normal DNA and genomes, so the retention of tumor suppressor proteins in the nucleus does not have much of an effect on them.

Tell us about the data you presented on selinexor at ASH 2014.

CC: At ASH 2014, we presented data on 29 patients with hard-to-treat myeloma who had already received many prior therapies, and were refractory to their last treatment. They were treated with oral selinexor, testing different doses from 3 to 80 mg/m^2, given once to three times weekly. The goal of this phase I trial was to establish not only the safety and side effects of the drug, but also efficacy in this group of patients with advanced myeloma. Of the 29 patients on study, 7 patients (24 %) achieved at least a minor response, with an additional 16 patients (55 %) stabilizing their disease, sometimes for many months. When dexamethasone was added, responses were much greater, with a 60 % overall response rate (6 out of 10 patients with a partial response or better), and a clinical benefit rate of 89 % (8 of 9 patients achieved at least a minor response). One patient achieved a complete remission. We observed very dramatic responses, particularly in patients with light-chain disease, with rapid reductions in the serum light-chain levels even after one dose.

Common side effects of selinexor are related to the gastrointestinal system (nausea, vomiting, loss of appetite, and weight loss). These symptoms can usually be managed with standard anti-nausea medications and tend to lessen after the first months of treatment. Some patients also experienced fatigue. Approximately 20 % of patients may develop low platelets, although bleeding or bruising events are rare. Patients may require platelet transfusions while on therapy. The addition of dexamethasone appears to help with the gastrointestinal side effects and the fatigue.

Has this research led to an FDA approval pathway as fulfilling an unmet need?

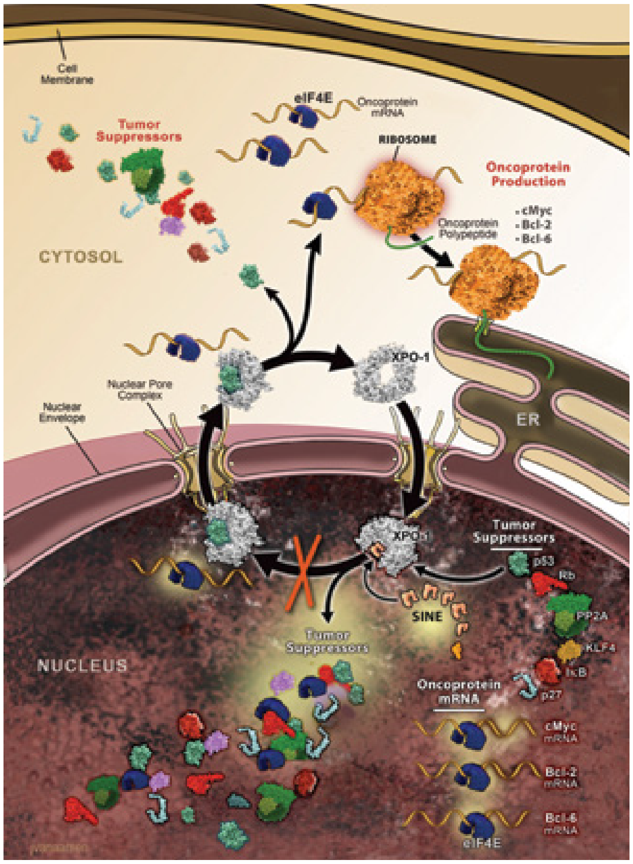
CC: The exciting initial results of the initial phase I study have led to the launch of a number of follow-up studies.

The STORM trial (**S**elinexor **T**reatment of **R**efractory **M**yeloma) is a multi-center, single-arm, phase II study of selinexor in combination with low-dose dexamethasone in patients whose disease was refractory to treatment with bortezomib, lenalidomide, carfilzomib (Kyprolis®), and pomalidomide. The study will evaluate the safety and efficacy of a fixed dose of selinexor (80 mg) plus low-dose dexamethasone (20 mg). Each compound will be given orally twice weekly. The STORM trial is currently enrolling patients across the US and Canada.

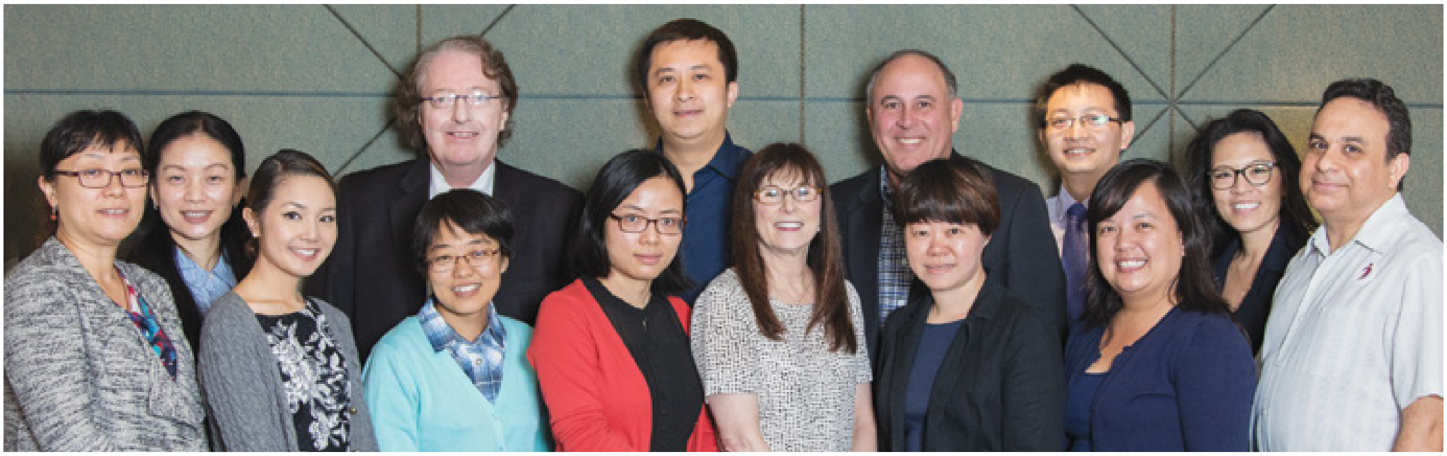
The STOMP trial (**S**elinexor and Backbone **T**reatments of Multiple **M**yeloma **P**atients) is a multicenter study evaluating selinexor in combination with pomalidomide (Pomalyst®), bortezomib (Velcade®), or lenalidomide (Revlimid®). In these combinations, selinexor will be given either once or twice weekly at various doses, with the goal of assessing toxicities of each combination and identifying the optimal dosing schedule. This trial will be opening in sites across Canada and the US later this year. **MT**

Karyopharm, which discovered and is developing selinexor, anticipates that preliminary, top-line data from the STORM trial may be available in mid-2016 and may have discussions with regulatory authorities on the next steps in clinical development and potential paths toward registration.

To learn more about the STORM trial, contact the IMF InfoLine team by telephone at 800-452-CURE (2873) or by email at infoline@myeloma.org.



Fourth Annual Myeloma Master Class Brings Doctors from China to the US



Front row, from left: Yun Leng (Chaoyan Hospital, Beijing); Shenmiao Yang (Peoples Hospital, Beijing); Xuan Lam (IMF); Shuhui Deng (Hospital of Hematology, Tianjin); Lifen Kuang (The First Hospital, Guangzhou); Susie Novis (IMF President); Zhihong Zheng (Union Hospital, Fuzhou); Amirah Limayo (IMF); Lisa Paik (IMF); Rafi Stephan (IMF).
Back row: Dr. Brian Durie (IMF Chairman); Gaofeng Zheng (The First Hospital, Guangzhou); Dan Navid (IMF); Fan Rong (Changzhen Hospital, Shanghai).

By Dan Navid
IMF Senior Vice President, Global Affairs

The International Myeloma Foundation (IMF) held the fourth annual Myeloma Master Class at IMF headquarters in August. This intensive training course for young Chinese hematologists featured lectures, case discussions, and summary presentations in English by the Chinese physicians. In addition to classroom learning, the doctors visited the City of Hope National Medical Center and took part in the IMF Patient & Family Seminar in Los Angeles, where they participated in individual patient consultations. IMF Medical Affairs team members Lisa Paik, Amirah Limayo, and Xuan Lam were instrumental in organizing and supporting this year's course.

Members of this year's Myeloma Master Class included representatives from leading myeloma centers in Beijing, Fuzhou, Guangzhou, Hangzhou, Shanghai, and Tianjin. The Master Class course featured several days of interactive lectures and discussions on the full range of modern myeloma diagnosis and treatment with leading myeloma specialists Dr. Brian Durie (IMF Chairman and Cedars-Sinai Samuel Oschin Cancer Center); Dr. Joseph Mikhael (Mayo Clinic, Scottsdale, AZ); Dr. Tom Martin (Helen Diller Family Comprehensive Cancer Center, San Francisco, CA); Dr. Robert Vescio (Cedars-Sinai Medical Center); and Dr. Amrita Krishnan (City of Hope National Medical Center).

Myeloma incidence in China rising

Evidence compiled by the IMF Asian Myeloma Network indicates that myeloma incidence in Asia is approaching that in the West. Given China's huge population, the number of myeloma patients is substantial. Typically, these patients are diagnosed at a much later stage than is the case in the West. Treatment options are currently limited, with several of the latest treatments either unavailable, or only available at very high cost. Chinese myeloma doctors face challenges to provide the best possible care to their patients and are eager to learn about approaches in other parts of the world. The IMF Master Class was conceived as a practical initiative to expose young Chinese doctors to myeloma treatment methods in the United States. After four years of the Master Class, 28 young doctors are "alumni" and part of the IMF family.

Learning from myeloma experts

The young Chinese doctors participating in the Master Class all have outstanding basic medical education and an understanding of myeloma and its treatment. The Master Class allows them to refine this knowledge and to have a unique opportunity to discuss current treatment issues with world-renowned experts. But perhaps most importantly, the Master Class provides the chance to see doctor-patient interaction in the US.

The Chinese doctors offered kind words of appreciation for the IMF. The IMF is honored to carry out this program and looks forward to its continuation in the future. **MT**

Dr. Robert Vescio of Cedars-Sinai Medical Center in Los Angeles teaches at the IMF's annual Myeloma Master Class, which brings hematologists from China to Los Angeles for a chance to work with world-renowned myeloma experts. The intimate format encourages lively exchanges of ideas.


1


2


3


4


5


6


7


8

1. Dr. Brian Durie explains a slide.
2. Gaofeng Zheng and Yun Leng collaborate.
3. Fan Rong
4. Seven hematologists from China participate in interactive lectures and discussions on the full range of modern myeloma diagnosis and treatment with leading specialists.
5. Shuhui Deng
6. Lifen Kuang
7. Shenmiao Yang
8. Dan Navid, Senior Vice President, Global Affairs, IMF and Shenmiao Yang
9. Zhihong Zheng is interviewed by oral historian Ryan White for IMF's "Myeloma Voices" audio archives.
10. Like students around the world, Master Class students check medical terms and make notes on their smart phones.
11. Graduation: Zhihong Zhen, flanked by Susie Novis, IMF President, and Dr. Brian Durie, IMF Chairman, shows off her Myeloma Master Class certificate of completion.


9


10


11

Medical Updates: Agent Orange,

More evidence links toxic chemical exposure to MGUS and myeloma

For the first time, direct serum measurements of the known human carcinogen 2,3,7,8-tetrachlorodibenzo-p-dioxin (TCDD) in Agent Orange have been linked to the likelihood of developing MGUS (monoclonal gammopathy of undetermined significance) and myeloma. In a study published online Sept. 3 in the journal *JAMA Oncology*, Dr. Ola Landgren and colleagues examined stored serum samples from Vietnam War veterans involved in Operation Ranch Hand, which resulted in significant exposure to TCDD. There was a greater than two-fold increased risk of MGUS associated with higher levels of TCDD versus matched controls. The overall prevalence of MGUS was 7.1 % in Operation Ranch Hand veterans versus 3.1 % in comparison veterans.

The linkage of the occurrence of MGUS with blood levels of TCDD, a chemical known to cause cancer in humans, is important for several reasons. First, this begins to answer the question "What causes MGUS and/or myeloma?" The proof of principle here is that a cancer-causing chemical can be involved. In an editorial accompanying the article in *JAMA*, Dr. Nikhil Munshi explores possible mechanisms of chemical injury, such as p53 loss – a high-risk feature of myeloma. Patients' underlying susceptibility due to impaired immune response increases the likelihood that these toxic chemicals will be activated.

New diagnostic guidelines from the International Myeloma Working Group

The IMF announced the publication of newly revised guidelines for the International Staging System (R-ISS), used to assess progression of myeloma in new patients and determine the proper course of treatment. The update is the result of the collaborative work done by the International Myeloma Working Group (IMWG) and was authored by 32 IMWG myeloma researchers from around the globe, including Dr. Brian Durie, and was led by Dr. Antonio Palumbo, Chief of the Myeloma Unit of the Department of Oncology, Division of Hematology at the University of Torino in Italy. The revisions were published in the peer-reviewed *Journal of Clinical Oncology*, the official journal of the American Society of Clinical Oncology (ASCO).

Daratumumab shows 36 % efficacy rate in treating relapsed and refractory myeloma

A study published in the *New England Journal of Medicine* announced that daratumumab, a monoclonal antibody, has shown favorable treatment results in phase I and phase II trials for patients with relapsed or refractory myeloma. According to the study and a press release issued by daratumumab manufacturers Genmab and Janssen Biotech, the data showed a 36 % response rate in the group treated in phase II of the study and furthermore, 65 % of those patients had not experienced disease progression in the 12 months after the start of treatment.

Expanded Access Program for elotuzumab

An Expanded Access Program (EAP) for elotuzumab with lenalidomide (Revlimid®) and dexamethasone is now open for myeloma patients with relapsed or refractory multiple myeloma. Elotuzumab is the first monoclonal antibody developed to treat multiple myeloma. Clinical trials have provided insights that elotuzumab works more effectively in combination with the immunomodulatory agent Revlimid and the steroid dexamethasone than alone. To learn more about the elotuzumab EAP, read the IMF's Clinical Trial Fact Sheet on the IMF website at elotuzumab.myeloma.org.

Selinexor STORM clinical trials open

Selinexor is an orally administered Selective Inhibitor of Nuclear Export, or SINE™, therapy for the treatment of multiple myeloma. Selinexor inhibits the transport of tumor suppressor proteins from the cell nucleus, where they detect cancerous DNA changes and induce cancer cell death. More than 900 patients have been treated with selinexor in phase I and phase II clinical trials, and in an ongoing phase I clinical trial, selinexor in combination with low-dose dexamethasone demonstrated favorable responses. To find out more about the selinexor STORM clinical trials, please contact the IMF InfoLine at 800-452-CURE (2873) or InfoLine@myeloma.org.

New Drugs, Revised Guidelines

New study investigates carfilzomib, pomalidomide, and dexamethasone in relapsed and/or refractory myeloma

The results of the first clinical trial to investigate carfilzomib (Kyprolis®), pomalidomide (Pomalyst®), and dexamethasone (CPD) in multiple myeloma were published in the journal *BLOOD*. IMF Chairman Dr. Brian Durie, co-author of the study, calls the phase I-II results "remarkably good." According to Dr. Durie, the well-tolerated regimen produces remissions lasting approximately one year, and overall survival of close to two years, in the very-poor-risk setting of double refractory disease in which patients are resistant to both lenalidomide (Revlimid®) and bortezomib (Velcade®).

"As we continue to search for new agents to fulfill the 'unmet need' of rescue therapy – when all else has failed – the CPD regimen is an attractive, available option which can be broadly offered to such patients," he noted.

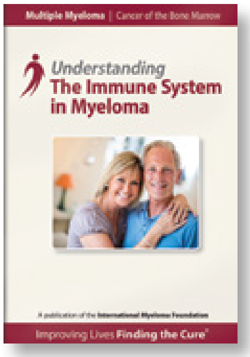
Moving forward, combinations of CPD incorporating monoclonal antibodies or other immune therapies are potential approaches to achieve even longer remissions and survival, he said, adding that "when used in the setting of resistant minimal residual disease, rather than at the point of frank relapse, even better results can be anticipated, which is one of the goals of the Black Swan Research Initiative®."

Clinical trial to assess efficacy of once-weekly dosing for Kyprolis

Onyx/Amgen is conducting the randomized, phase III ARROW clinical trial to potentially provide patients and physicians with a more convenient once-weekly dosing schedule for Kyprolis (carfilzomib). Currently, Kyprolis is administered by IV infusion twice weekly. Patients will randomly be assigned to receive Kyprolis either once or twice a week along with weekly dexamethasone. The ARROW trial is for patients with relapsed and refractory myeloma who have previously been treated with Velcade® and one of the immunomodulatory drugs: Thalomid®, Revlimid®, or Pomalyst®. For more information, read our ARROW Clinical Trial Fact Sheet at tinyurl.com/ARROWtrial or contact the IMF InfoLine at 800-452-CURE (2873).

The newest IMF publication: *Understanding the Immune System in Myeloma*

The latest in the IMF's *Understanding* series of booklets designed to acquaint readers with treatments and supportive care measures for multiple myeloma is *Understanding the Immune System in Myeloma*.



As this booklet explains, the immune system is extremely complex. It is made up of multiple mechanisms that work together to protect and defend the human body from external threats such as bacteria, viruses, and toxins, and from internal threats such as cancer.

The immune system can be likened to a fine Swiss watch, with many tiny moving parts working together seamlessly. A change or malfunction in even one of those tiny parts will affect all the others. Myeloma suppresses immune system responses and compromises its ability to protect the body.

To receive a copy of this informative booklet, contact the IMF at 800-452-CURE (2873) or email theIMF@myeloma.org. **MT**

CELEBRATING 25 YEARS

One Person Can Make a Difference, But Two Can Make a Miracle

1990

The **International Myeloma Foundation** begins operations in the home of Susie and Brian D. Novis. Brian Novis was diagnosed with myeloma at the age of 33, and together with Susie Novis and Dr. Brian Durie, they form the IMF. Their goal is to educate patients about the disease and available treatment options. As Brian Novis tells Susie, “One person can make a difference, but two can make a miracle.”

1992

IMF hosts the first-ever **Clinical Conference** on myeloma in Phoenix, Arizona.

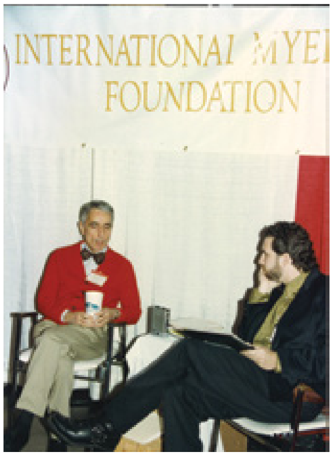
IMF’s first gala to raise funding for myeloma research is held in Los Angeles.

The debut edition of the IMF’s quarterly print newsletter, ***Myeloma Today***, is published, and features medical updates, patient education, and interviews with top myeloma researchers.

MYELOMA TODAY

Features:

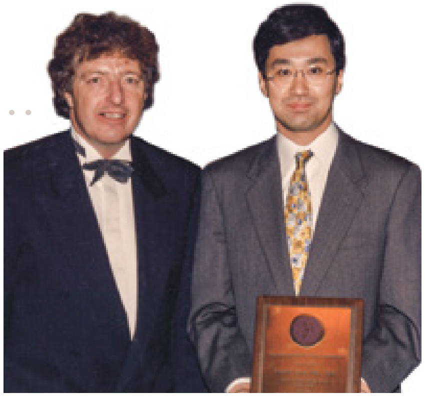
What Is Multiple Myeloma?



1993

IMF attends the **American Society of Hematology** annual meeting for the first time, representing myeloma patients and connecting with researchers working on the latest treatment options.

In Los Angeles, the IMF organizes the inaugural **Patient & Family Seminar**. Attended by just 65 people, the groundbreaking educational meeting quickly evolves into one of the organization’s signature efforts. Today, the IMF’s Patient & Family Seminars are held across the country and around the world, attracting thousands of patients and caregivers.



1994

The first **Brian D. Novis Research Grant** is awarded to Dr. Atsushi Ogata. Named in honor of the IMF's co-founder, the grants are awarded annually to promote research into better treatments, management, prevention, and a cure. Since then, the IMF has funded grants to researchers in more than 40 countries.

Taking the "international" in its name seriously, the IMF organizes and hosts the first international **Myeloma Clinical Conference** in Singapore. This is just the start of the IMF's comprehensive effort to bring myeloma researchers together for collaboration that would go on to benefit patients.

1995

The IMF's first overseas **Patient & Family Seminar** is held in London with IMF UK.

1997

IMF Japan begins operations, led by Akira Horinouchi, a myeloma patient dedicated to improving the quality of life of fellow patients. Other international IMF events include Patient & Family Seminars in Australia and Germany.

1998

IMF launches its advocacy efforts by participating in "**The March**" in Washington, DC. This grassroots cancer event drew more than 100,000 cancer patient advocates, among them were about 400 representing the IMF and the myeloma community.

1999

IMF Board Member **Michael Katz** (1953–2015) is appointed by the National Cancer Institute's newly formed Director's Consumer Liaison Group. Its members are tasked with helping develop programs, set research priorities, and create a forum for exchange between the cancer advocacy and scientific communities. The position is just one of many Mike will shoulder in the myeloma community in the years to come to improve the lives of patients and make sure they have a place at the table.

IMF holds the first **Support Group Leaders Summit**, a well-deserved opportunity for leaders to recharge their batteries, draw strength and encouragement from like-minded people, and learn new skills to take back to their support groups at home. The annual event continues to serve as a vital source of support and peer-to-peer fellowship.

At the 7th Annual International Myeloma Workshop in Stockholm, the IMF initiates a workshop focused on the role of viruses in multiple myeloma. The **Virus Symposium**, hosted by Prof. Haakan Mellestdt and co-chaired by Dr. Brian Durie at the Karolinska Institute, brings together investigators studying viruses that may contribute to the pathogenesis of multiple myeloma.

2000

The IMF organizes the first **Scientific Advisors Retreat** in St. John in the US Virgin Islands. Sessions focus on treatment of newly diagnosed patients, stem cell transplants, new research, supportive care, and the role of maintenance therapy. The event is filled with lively discussions and productive exchanges of ideas.

The IMF hosts Japan's first **Patient & Family Seminar in Tokyo**. Sadly, IMF Japan founder Akira Horinouchi dies just before he sees his dream of having a Patient & Family Seminar in Tokyo become a reality. His wife, Midori, carries on in his place.

2001

The IMF holds its first **Clinical Conference in Russia**. In attendance in St. Petersburg are Susie Novis, Dr. Brian Durie, Prof. Heinz Ludwig, and Dr. Mario Boccadoro. The conference is followed by patient consults.

2002

IMF President Susie Novis testifies before a Senate appropriations subcommittee on Labor and Health and Human Services about the need to fund **cancer research at the National Cancer Institute**. "Some of you may be thinking, 'How can we afford to increase the funding for cancer research?'" she says to the lawmakers. "But I say, how can we afford not to?"

2003

The IMF's first **Robert A. Kyle Lifetime Achievement Award** is given to its namesake, myeloma research pioneer, Dr. Robert Kyle. Friends and family of Dr. Kyle gathered in Rochester, Minnesota – home to Mayo Clinic – to pay tribute to the beloved and respected physician, educator, and leader.

The IMF's first **Scientific Advisors Retreat** in 2000 leads to the publication in 2003 of the first management guidelines for multiple myeloma.

EHA EUROPEAN HEMATOLOGY ASSOCIATION

2004

IMF Latin America is founded in São Paulo, Brazil by Christine Battistini, who serves as the organization's president, and Vania Hungria, MD, a research physician. While serving as her mother's caregiver, Battistini relied on the IMF for information and support. She hopes to help provide that for the myeloma community in Latin America as well.

2006

The first **International Staging System** (ISS) is developed by the IMF's **International Myeloma Working Group** (IMWG) and published in the journal *Leukemia*. Dr. Brian Durie notes the importance of the ISS to the myeloma community, writing, "New uniform response criteria are required to adequately assess clinical outcomes in myeloma."

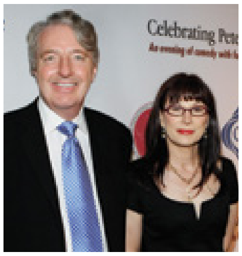
Leukemia

The IMF establishes the **Nurse Leadership Board®** (NLB), comprised of nurses from the leading centers treating myeloma patients in the US. The NLB's mission is to develop broad recommendations for nursing care for myeloma patients. NLB members publish in respected journals, participate in international medical meetings, and reach out to patients through regular IMF-sponsored events.

NURSE LEADERSHIP BOARD

2007

The IMF's **"Celebrating Peter Boyle"** benefit (later renamed the Annual Comedy Celebration) is hosted by Ray Romano, star of the hit series *Everybody Loves Raymond*, and features Peter's co-stars and TV family, Patricia Heaton, Doris Roberts, and Fred Willard, along with friends Jeff Garlin, Richard Lewis, and Martin Short. Peter and his wife, Loraine, were long-time supporters of the IMF. After Peter's passing, Loraine decided to turn her grief into something positive and agrees to chair an event in her late husband's memory.



2009

IMF establishes **Myeloma Awareness Month** to raise the profile of the disease because – although it is the second most common blood cancer – a majority of patients have never heard of it until their diagnosis. Awareness can lead to patients asking whether their doctor has considered myeloma as a possible cause for their symptoms and can lead to earlier diagnosis.

International Myeloma Foundation
MARCH
MYELOMA AWARENESS MONTH

Myeloma Awareness Month is an initiative of the IMF

2010

Actor Michael McKean's million-dollar win on ***Jeopardy!*** results in largest single private gift in IMF history. "The International Myeloma Foundation continues its tireless fight regardless of who's helping foot the bill," says Michael McKean. "I'm glad I was able to kick in my share." McKean began supporting the IMF when his good friend and fellow guitar player Lee Grayson was battling the disease, and continued that support in Lee's memory.

2010 *(continued)*

International Myeloma Working Group

A RESEARCH DIVISION OF THE IMF

The first annual **International Myeloma Working Group (IMWG) Summit** is convened in Barcelona, Spain, drawing nearly 70 of the world's leading experts in myeloma to chart the future of myeloma treatment and care. That number will grow to 200 in the next five years and the IMWG will generate critically important research and consensus guidelines.

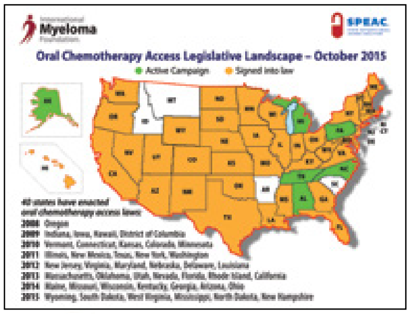
IMF founds **PEAC** (Patients Equal Access Coalition), a patient-focused coalition working to ensure that cancer patients have equal and appropriate access to all cancer treatments.

PEAC
PATIENTS EQUAL
ACCESS COALITION

2011

IMF leads the first state effort on oral anticancer treatment parity to guarantee insurance coverage of all cancer treatments regardless of the drug's delivery method. **SPEAC** grows increasingly important as oral myeloma treatment options expand.

SPEAC®
STATE PATIENTS EQUAL
ACCESS COALITION



40 states have enacted oral chemotherapy access laws
2008 Oregon
2009 Indiana, Iowa, Hawaii, District of Columbia
2010 Vermont, Connecticut, Kansas, Colorado, Minnesota
2011 Illinois, New Mexico, Texas, New York, Washington
2012 New Jersey, Virginia, Maryland, Nebraska, Delaware, Louisiana
2013 Massachusetts, Oklahoma, Utah, Nevada, Florida, Rhode Island, California
2014 Maine, Missouri, Wisconsin, Kentucky, Georgia, Arizona, Ohio
2015 Wyoming, South Dakota, West Virginia, Mississippi, North Dakota, New Hampshire

The IMF establishes the **Asian Myeloma Network** (AMN), comprised of myeloma experts from China, Hong Kong, Taiwan, Japan, Korea, Singapore, and Thailand. Myeloma is a growing health problem in Asia, with an incidence that is approaching that in western countries, but with a much larger population base.

2012

IMF creates the groundbreaking and globally collaborative **Black Swan Research Initiative**® to find a pathway to a cure for myeloma. Since then, the initiative has supported the development of a highly sensitive testing method to detect minute amounts of disease and help determine best treatment plan for eliminating remaining myeloma clones entirely. Clinical trials are now underway in the US and Europe.

BLACK SWAN RESEARCH INITIATIVE®
Signature Project of the International Myeloma Foundation

IMF designs and hosts the first **Myeloma Master Class**. This intensive training course for young hematologists from China features lectures, case studies, and an opportunity to discuss current treatment issues with world-renowned myeloma experts.

2013

IMF launches **IMF-TV**, a website-based channel featuring live-streamed videos from major medical meetings, interviews with top myeloma researchers, and the weekly series, “Ask Dr. Durie,” in which IMF Chairman Dr. Brian Durie answers questions from patients.

2014

The **International Myeloma Working Group** (IMWG) publishes an updated response criteria for the diagnosis of multiple myeloma in the *The Lancet*. This important consensus statement updates the definition of myeloma based on the identification of biomarkers associated with near inevitable development of CRAB features in patients who would otherwise be regarded as having smoldering multiple myeloma.

THE LANCET Oncology

IMF Chairman Dr. Brian Durie is honored by Mayo Clinic with the **Distinguished Alumni Award**, presented to him by Dr. Morie Gertz of Mayo Clinic. Dr. Durie, who completed residencies and fellowships at Mayo Clinic, was honored for his “exceptional contributions” to the field of myeloma.

The IMF unveils the organization’s **new logo**, a clean-lined design that reflects forward movement and hopefulness. “Our original logo served us well for 24 years,” says IMF President Susie Novis. “In our new logo, the image of the man has evolved – as has the IMF. But the constant is that he is moving forward with his arms out, welcoming everyone: patients, families, doctors, nurses, and the entire myeloma community.”

International
Myeloma
Foundation®

2015

IMF President Susie Novis establishes the **Global Myeloma Action Network** (GMAN), whose mission is to improve the lives of myeloma patients around the world. The IMF convenes the first GMAN Summit in Vienna, Austria.

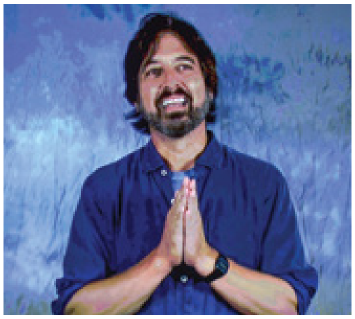
globalmyeloma
action network an advocacy initiative of the IMF

INTERNATIONAL MYELOMA FOUNDATION

9th Annual Comedy Celebration

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

*In memory of **Michael S. Katz***



Actor Ray Romano welcomes the audience with a comic video clip.

The Katz family celebrates the memory of the late Michael Katz: Susan Katz, IMF President Susie Novis, Jeffrey, Jonathan, Jason and his wife, Sharon.

IMF Chairman Dr. Brian Durie and Susie Novis get into the evening's joyful spirit.

Evening's host Fred Willard and Loraine Boyle, who spearheaded IMF's Comedy Celebration.

Fred Willard, Tig Notaro, and Heather McDonald sing back-up on a spirited performance of Paul Shaffer's song "It's Raining Men."

A night of comedy in the name of Peter Boyle raises $600,000 to fight myeloma

By Adam Tschorn
Los Angeles Times

The late, great Peter Boyle may have shuffled off this mortal coil nearly a decade ago, but anyone who was lucky enough to be at the Wilshire Ebell Theatre on Saturday night will tell you his memory – and legacy of laughter – is alive and well.

The occasion was the International Myeloma Foundation's 9th Annual Comedy Celebration to benefit the Peter Boyle Research Fund, named in honor of the Emmy Award-winning actor who passed away in late 2006 after a four-year battle against the bone marrow cancer. The effort, long spearheaded by his widow, **Loraine Boyle**, has raised more than $5 million since 2007.

Peter Boyle wasn't the only person being remembered at this year's event, which was dedicated to the memory of Michael S. Katz, an IMF board member who had battled the disease himself for the last 25 years before passing away in April.

Ray Romano, Boyle's *"Everybody Loves Raymond"* co-star and long-time host of the event, kicked things off via a video announcement from New York City, apologizing for not being able to attend.

"I miss Peter," Romano said, "especially right now with Donald Trump running for president. Peter, you would love this!"

With that, Romano handed the on-site hosting duties to comedian **Fred Willard**, who in his own affably addled way managed to touch on

IMF's annual event brings out the stars

On the red carpet: left, host Fred Willard, IMF President Susie Novis, IMF Chairman Dr. Brian Durie, Loraine Boyle; *above,* cast members of NBC's *Hot & Bothered*; *above right,* Lesley Nicol of *Downton Abbey.*
On the stage: bottom row, left to right, comedians Andy Kindler, Jay Johnson with his sidekick Bob, Tig Notaro, Heather McDonald, Jeff Garlin.

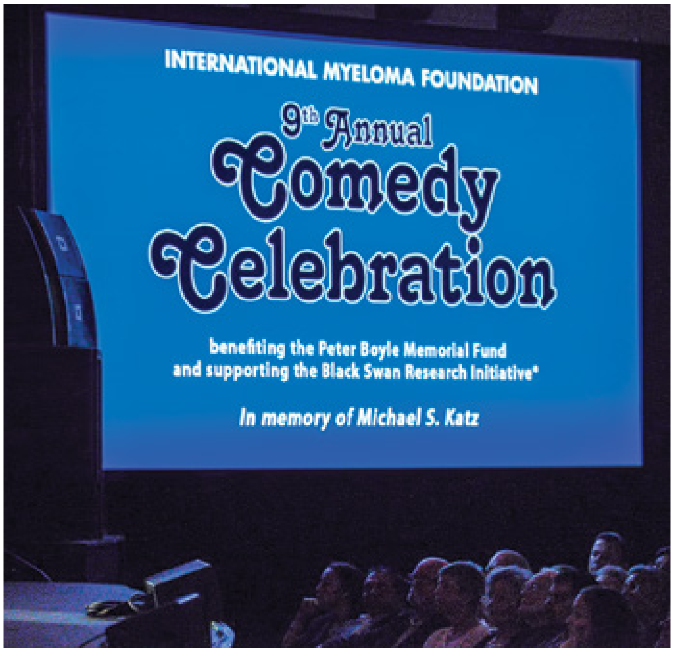
a range of topics including cross-dressing and hotel wake-up calls in his run-up to introducing the evening's slate of comedians.

First out of the gate was **Jeff Garlin** (*The Goldbergs, Curb Your Enthusiasm*), who riffed on Krispy Kreme drive-bys ("five doughnuts is just the right number because you can say you had 'some doughnuts' – if you get six you have to say 'a half dozen'), places he'll never go (Ferris wheels, lotion shops) and gazebo-based sexual shenanigans. He was followed on stage by comedian **Heather McDonald** (*Chelsea Lately*), ventriloquist **Jay Johnson** (and his arm-based sidekick, Bob) and comedian **Andy Kindler** ("Hitler was lactose tolerant," Kindler said. "That was the only thing he was tolerant of ...").

The final comic to take the stage was the brilliant **Tig Notaro**, whose own ability to pull laughs from the jaws of misfortune (she famously turned the one-two punch of her mother's death and her own breast cancer diagnosis into a comedy set) mirrors the comedy fundraiser's efforts to leverage laughter for the greater good. Notaro (who noted that she's getting married in two weeks), made mirthful mountains out of the mundane molehills of relationships from the asking of inane questions ("How do I know what time Yum Yum Donuts opens? You're not dating Google") to being left to drive herself home from a wisdom tooth extraction ("The girl I was dating at the time said she couldn't get time off from work – but the thing was she was self-employed").

The evening came to a close with musical guest **Paul Shaffer** (*The Late Show With David Letterman*) at the piano, performing a short but sweet three-song set that ended with the indelibly hilarious image of Fred Willard, Tig Notaro, and Heather McDonald serving as backup singers to Shaffer on the dance hit "It's Raining Men" (which, you may or may not recall, Shaffer co-wrote in 1979 with Paul Jabara).

Whether or not laughter is truly the best medicine, Saturday night's event proved it can go a long way toward funding the best medicine – as of this writing organizers estimate that ticket sales and two on-site auctions (one silent and one live) have added some $600,000 to the IMF's ongoing battle against myeloma. **MT**



INTERNATIONAL MYELOMA FOUNDATION

9th Annual

Comedy Celebration

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

In memory of Michael S. Katz

A time for laughter

"Tonight is not a time for tears," said IMF President Susie Novis, *above*, with IMF Chairman Dr. Brian Durie, at the 9th Annual Comedy Celebration. Loraine and her daughter Lucy Boyle, *above right*. *Below, from left:* performers Fred Willard and Jeff Garlin; Jay Johnson, Heather McDonald, Tig Notaro, Andy Kindler; and Paul Shaffer, who played "The Impossible Dream" from "Man of La Mancha" as a stirring tribute to Michael Katz.

9th Comedy Celebration Presenting Sponsors

The team from Presenting Sponsor ***Amgen***

The team from Presenting Sponsor ***Celgene***

The team from Presenting Sponsor ***Bristol-Myers Squibb***

The team from Presenting Sponsor ***Takeda***

COMEDY CELEBRATION PRESENTING SPONSORS

AMGEN®

Bristol-Myers Squibb

Celgene

Takeda
ONCOLOGY

DIAMOND

janssen

EMERALD

CBS

NOVARTIS
ONCOLOGY

LORAINE & AMY BOYLE
AND
LUCY BOYLE & JESSE WANN

Susie Novis &
Dr. Brian G.M. Durie

RUBY

Monica & Philip Rosenthal/Rosenthal Family Foundation

SAPPHIRE

Karyopharm
Therapeutics

HBO®

San Fernando Valley
Multiple Myeloma Support Group

Joele Frank &
Larry Klurfeld

TOPAZ

SANOFI

Medtronic

Genentech

Carol & Benson Klein

Joy & Ron Paul

Debra Fine and Marty Schneider

Ben Vanderlinde

SUSAN KATZ

PEARL

kwall

Drinker, Biddle & Reath LLP

11th Annual Nurse Leadership

By Diane Moran
IMF Senior Vice President, Strategic Planning

Founded in 2006, the IMF Nurse Leadership Board® (NLB) is a professional partnership representing nurse experts caring for myeloma patients at leading medical centers. The NLB's primary mission is to improve the nursing care and self-care of patients with myeloma by educating nurses and patients via consensus publications, symposia, multimedia, and research.


Tracy King presents information on the healthcare system and the treatment of myeloma in Australia.

The 11th annual NLB meeting took place in Las Vegas on August 14–15, 2015. The meeting was co-chaired by Beth Faiman of the Cleveland Clinic Taussig Cancer Institute and Sandra Kurtin of the University of Arizona Cancer Center. We were proud to promote all four of our former associate members to full membership based on their proven commitment to the NLB's mission. The newly promoted members are Kevin Brigle, Donna Catamero, Hollie Devine, and Daniel Verina. In addition, the NLB welcomed two new international affiliates, Tracy King of the Royal Prince Alfred Hospital in Australia and Cindy Manchulenko of the Leukemia/Bone Marrow Transplant Program of British Columbia in Canada.

The meeting agenda includes discussing and developing strategies for ongoing and future projects and publications, as well as a review of recent accomplishments. One such achievement is the recently published second edition of the multiple myeloma textbook for nurses. Co-edited by NLB's Joseph Tariman and Beth Faiman, the textbook also features NLB contributing authors Tiffany Richards, Charise Gleason, Kim Noonan, Sandra Rome, Kevin Brigle, Sandra Kurtin, as well as Joseph and Beth. We also recognized the work of NLB members who have directly educated myeloma patients and healthcare providers during the past year. Our members led the NLB Satellite Symposium at the Oncology Nursing Society 40th Annual Congress, as well as conducted sessions at the IMF Support Group Leaders Summit, Patient & Family Seminars, Myeloma Center Workshops, and Regional Community Workshops. Additionally, NLB nurses participated in IMF teleconferences with support group leaders and presented important topics of discussion in the popular "Living Well with Myeloma" teleconference series.

(continues on next page)


The NLB's Collaborative Practice and the Continuum of Care workgroup is led by Sandy Kurtin as Page Bertolotti captures the notes.

Board Meeting

NLB nurses are devoted to supporting the myeloma patient community through IMF programs, and they do so in addition to their full-time nursing and research schedules. We thank them for their commitment and dedication. **MT**

The full library of NLB tools and materials is available at nurses.myeloma.org on the IMF website.


Tracy King and Sandra Kurtin


Page Bertolotti, Lisa Smith, Tiffany Richards, and Sandra Rome

Meet the NLB Members

Joseph D. Tariman, PhD, ANP-BC

Joseph Tariman is Assistant Professor in the School of Nursing/College of Science and Health and a member of the faculty for the Adult-Gerontology Doctor of Nursing Practice (DNP) program at DePaul University in Chicago, Illinois. He has also worked as an Advanced Practice Nurse in the Northwestern University Myeloma Program in Chicago, where one of his primary responsibilities was sub-principal investigator for all phase I and II clinical trials for myeloma.

Dr. Tariman obtained his PhD at the University of Washington in Seattle, where his research fellowship was funded by the National Institute of Health (NIH) and the Achievement Rewards for College Scientists Foundation. He edited a groundbreaking nursing book on myeloma published by the Oncology Nursing Society (ONS) in 2010, and co-edited the second edition of *An Evidence-based and Treatment-focused Approach to Myeloma Nursing Care* in 2015. An author of more than 80 published articles, abstracts, monographs, and five book chapters, Dr. Tariman's research includes cancer treatment decision-making, patient and caregiver education, and quality of life issues and patient reported outcomes, particularly in the older adult cancer patient population.

Dr. Tariman has served as contributing editor for *ONS Connect*, a column writer for *Advance for Nurse Practitioners*, and is a member of the editorial review boards of *CJON* and *The Oncology Nurse*. He has been a member of the NLB since its inception, is Chair of its research committee, and is the recipient of numerous awards, including the 2013 ONS Publishing's Outstanding Achievement for Oncology Nursing Education or Family/Patient Education.

Teresa S. Miceli, RN, BSN, OCN®

Teresa Miceli is an Adult Blood and Marrow Transplant (BMT) Nurse Care Coordinator with the Mayo Clinic in Rochester, Minnesota. In addition to her clinical practice, she works in the areas of staff development and education with a focus on patient education and current practice trends in the transplant setting. A 23-year nurse veteran in the area of BMT, Ms. Miceli earned her Bachelor of Science in Nursing degree from the University of Minnesota in Minneapolis and is an Oncology Certified Nurse.

The author of articles on the subjects of myeloma and side effect management in journals such as *The Oncology Nurse* and *Clinical Journal of Oncology Nursing*, Ms. Miceli is also a national and international speaker in the areas of myeloma, stem cell mobilization, and BMT. She also presents at professional society meetings and patient seminars on the topics of patient care, education, and management of treatment-related side effects.

Ms. Miceli is the facilitator of the Multiple Myeloma Sharing Sessions, a support group for myeloma patients and caregivers. She has been a member of the NLB since its inception. **MT**

What Every (Myeloma) Patient Should Do with His or Her Medical Information

The IMF InfoLine coordinators answer your questions

By Debbie Birns
IMF Medical Editor

Q. What can I do to improve the flow of information among all the doctors involved in my medical care, while also doing my best to remain an informed patient?

A. It may be stating the obvious, but medical care in the US has changed. Large medical enterprises have been buying up doctors' practices and consolidating care, government incentives have made electronic medical records (EMR) commonplace, and many hospitals now have new medical specialists called "hospitalists" who oversee patients' care while they are hospitalized, but otherwise have no relationship with them. While all of these changes can streamline care and reduce costs, they can also pose problems. However, with some preparation, you can safeguard yourself and family members from some of the inherent risks.

When hospitals buy up doctors' practices and consolidate care, it's great if all your doctors are within that system, but not so great if some are and some aren't. EMRs have become mandatory for Medicare providers and are being adopted almost universally in doctor's practices, replacing other more user-friendly methods of communication between doctors. At some medical centers this means that patients have quicker and better access to their medical records, but it also means that doctors who do not practice under the umbrella of the medical center do not have access to the computer system and are out of the communication loop. To further complicate matters, there is not one universal EMR system, but many competing systems, sometimes even within one single institution.

Likely, several doctors are involved in your care – an internist who is your primary care practitioner, a hematologist-oncologist who treats and monitors your myeloma, and perhaps a specialist who takes care of another ongoing medical issue. In "the old days," a simple telephone call from one doctor to another would be sufficient to keep the lines of communication open. One doctor's office would notify another doctor's office of a shared patient's new illness, new treatment, drug reaction, or hospitalization, and the doctor would make a note in the patient's chart and, if necessary, visit the patient in the hospital. If a doctor did not have privileges at that hospital, it was fairly common for the doctor to receive temporary "courtesy privileges" to be able to visit his patient. But times have changed.

Here is a personal example of what can happen when a patient is admitted to the hospital without proper preparation. My father-in-law, Jack, was admitted to a large academic center for surgery on a carcinoid tumor in the abdomen. The surgeon who was to operate on the tumor was at one hospital with its own EMR system, but Jack's internist and other specialists were at another, with a different EMR system. None of the doctors communicated with each other. Despite the fact that Jack entered the hospital for removal of the carcinoid tumor with his blood pressure medicine in hand, the hospitalist supervising his in-patient care was not aware that he was being treated for high blood pressure, and didn't write orders for the nursing staff to administer the medication. As a result, Jack had a debilitating stroke while in the hospital that left him unable to speak, walk, and swallow. He recovered from the carcinoid surgery, but was permanently disabled by the stroke. Tragedy and hindsight are great educators. Here is what I learned and what every patient must do to take responsibility for his or her own care.

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

1. Get copies of all your current medical records from every doctor you see. If you have electronic access through your healthcare system, save digital copies in a folder on your computer. If only paper medical records are available, request copies from your doctor's office. If the office or clinic charges you a copying fee, pay it. Make digital copies by scanning or photographing each page, and save these records in the folder on your computer. If you don't have access to digital technology, then simply keep your medical information in a paper folder or notebook that you carry with you.

2. Create a cover letter for your medical records, which includes:
   - your name
   - your date of birth
   - your insurance information
   - all of your medical conditions
   - the specialty, name, address, and phone number of each of your doctors

3. Compile a comprehensive list of all the medications you are currently taking, with the exact dosage and schedule for each. This

should include not only your prescription drugs, but also all vitamins, supplements, aspirin, antacids, and any other over-the-counter (OTC) medications. Supplements can sometimes interact with medications, and your medical record is not complete without them.

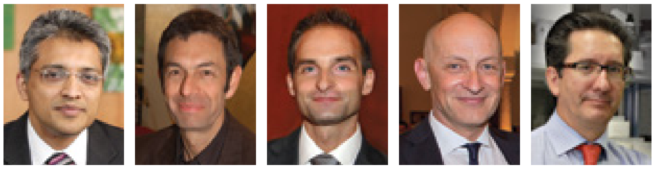
4. Write a summary of your myeloma treatment history, which should include:
   - your diagnosis and the date of diagnosis
   - stage at diagnosis
   - results of any genetic tests
   - which CRAB criteria you had (elevated calcium, renal or kidney dysfunction, anemia, bone disease)
   - all the treatments you've received (with the dosages and the beginning and ending dates you took a particular drug)
5. Keep the above information in the folder on your computer, and make sure the information is up-to-date, comprehensive, and accurate.
6. Make two copies of your medical records folder using USB memory sticks. Keep one stick with you at all times, and give the second to your caregiver or a friend who can be reached in case of a medical emergency. USB memory sticks are available in many forms, including key fobs and bracelets.
7. Each time you see a doctor or are admitted to a hospital, let the doctor know that you have all your medical information with you. If the hospital facility has their USB drives disabled to safeguard their systems, you should be able to provide paper copies of your records (or ask the person with the second flash drive to print them out for you).

Since we can no longer assume that good communication between our healthcare providers is automatic, it is helpful to your doctors and imperative for you to organize and have your medical information available whenever it is needed. Just do it! **MT**

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

Stellar lineup of myeloma experts featured at IMF Satellite Symposium

On Friday, December 4, preceding the 57th Annual Meeting of the American Society of Hematology (ASH) in Orlando, FL, the IMF will present *Global Advances in Myeloma: Providing Best Options for Treatment in 2015.* Led by IMF Chairman and symposium Program Director Dr. Brian Durie, this provocative program includes "point and counterpoint" presentations and interactive case discussions to provide varied perspectives on new data, guideline changes, and expert recommendations in myeloma.



Panelists: **Shaji Kumar, MD**; **Philippe Moreau, MD**; **Bruno Paiva, PhD**; **Antonio Palumbo, MD**; and **Jesús San Miguel, MD**.

For more information and to register to attend, go to the web page: **ashsymposium2015.myeloma.org**

CHARITY
NAVIGATOR
★★★★
Four Star Charity

IMF receives highest 4-star charity rating for 11 years running

The IMF has been awarded Charity Navigator's 4-star, highest rating for 2014! The rating, according to Charity Navigator, indicates that the IMF operates in an ethical and fiscally responsible manner. A 4-star rating is the highest rating a charity can receive from the organization and earning it places the IMF in the "Exceptional" category, meaning the IMF "exceeds industry standards and outperforms most charities in its cause."

Charity Navigator works to promote "a more efficient and responsive philanthropic marketplace in which givers and the charities they support work in tandem to overcome our nation's and the world's most persistent challenges."

We're proud of our 11-year 4-star rating and honored to serve the myeloma community in finding a cure! **MT**

One Voice Making a World of Difference

Advocates from across the United States have answered the call to action. Their efforts are inspired by a variety of causes, each one distinctly different from the other. Whether it is a personal battle or on behalf of a friend or loved one, the reasons are deeply special. Many go above and beyond in their efforts to effect change. Such is the case with Gratia Williams Nakahashi, whose story is featured in this edition of Myeloma Today.

– Taylor Patton, IMF Advocacy Associate

The call to action for advocates is inspired by a variety of causes, each one distinctly different from the other. Whether it is a personal battle or on behalf of a friend or loved one, the reasons are deeply special and inspire many to go above and beyond in their efforts to effect change. Such is the case with IMF supporter, Gratia Williams Nakahashi.


Gratia Williams Nakahashi (right) and her husband Kenji Nakahashi (left)

Gratia's fight began back in March of 2009 when her husband, Kenji Nakahashi, was diagnosed with high-risk myeloma. After a year of standard therapies, he received an autologous stem cell transplant, which provided a complete remission for an entire year. However, he began to relapse, and was placed on a new treatment regimen which kept the disease under control for another year. Unfortunately, this regimen also became ineffective, and he was switched to his current treatment.

Upon hearing from the oncologist that Kenji was on the cusp of another relapse, they began searching for additional treatment options. By coincidence, Gratia happened to be listening to a radio broadcast sponsored through Myeloma Crowd in which Dr. Gunter Koehne of Memorial Sloan Kettering spoke about his T-cell depleted allogeneic transplants that were being pioneered at the institution. The following day, they met with her husband's doctor, who is a transplant specialist at Weill Cornell Myeloma Service (CMS), and he recommended the very same T-cell depleted transplant that Dr. Koehne had mentioned in his broadcast.

A few weeks later, they met with Dr. Koehne to discuss the potential of a T-cell depleted transplant, who warned that they might have issues receiving coverage from Medicare for the treatment. As expected, when Gratia and Kenji met with the Sloan Kettering patient financial services to request the donor search, it was denied. As a result, Gratia began her fight to change the current policy so that Kenji, and other patients like him, could receive these life-saving treatments.

Without truly knowing where to start, Gratia reached out to the National Marrow Donor Program (NMDP) to speak with Stephanie Farnia. "I felt like the blind leading the blind," Gratia said. However, Stephanie was able to provide her with a list of contacts within Medicare and some talking points to guide her conversations with officials. Gratia took over from there and began the process of reaching out to advocates for the addition of T-cell depleted transplants to the list of approved therapies for myeloma.

Initially, progress was slow, and she says she was just "reaching out to whoever would listen." Yet, as she began speaking with more people, they were able to provide her with more specific feedback on who she needed to contact. Concurrently, she raised the issue with the office of Sen. Kirsten Gillibrand (D-NY) to investigate any legislative recourse she may have, and they were very responsive to her requests, providing her with some additional resources.

Gratia then reached back to the NMDP and contacted the IMF to suggest a partnership between the two organizations to advocate further – a suggestion which led our two organizations to begin discussing how we could work together. Additionally, Gratia contacted the Patient Advocate Foundation (PAF) to garner more support, ultimately leading them to search for a solution.

While it has only been a few months, Gratia has already proven to be a hugely successful advocate in that she brought together a senator's office, three national patient advocacy organizations, and officials within CMS to find a remedy to Kenji's transplantation issue. Though she and Kenji are still fighting for the transplant, she has recently heard from both Sean Cavanaugh, the Deputy Administrator and Director of CMS, and Dr. Patrick Conway, the Acting Principal Deputy Administrator and Deputy Administrator for Innovation and Quality & CMS Chief Medical Officer. The latter is the director of the program within CMS that makes coverage determinations on her specific issue. Gratia's fight is far from over, but she is making strides and people are listening.

When asked what she would say to other advocates, the moral is to never give up. "I am working to be the example that becomes the exception. I want to urge others to advocate for themselves." Gratia's passion and dedication are inspiring, and her hard work is paying off. **MT**

Exceptional People, Exceptional Cause

The Global Myeloma Action Network (GMAN) has elected four members to its steering committee, which helps achieve the coalition's goals and fulfill its mission. These exceptional individuals bring to GMAN their unique experience, talent, and professional acumen. Below, they share their stories in their own words. including their unique successes and challenges.

global myeloma action network — an advocacy initiative of the IMF

– Raymond Wezik, JD, IMF Global Advocacy Executive

Aldo Del Col

Since being diagnosed with multiple myeloma in 2002, I have focused my attention on building an effective national platform to address the needs of the Canadian myeloma community. With the support and inspiration of the International Myeloma Foundation, I co-founded Myeloma Canada in 2005. As a patient-driven, grassroots organization, Myeloma Canada's mission is to provide educational resources to patients and caregivers, raise awareness of the disease, advocate for improved access to new therapies, and accelerate patient-focused myeloma research.

An ongoing challenge we face is to ensure access to the right treatment at the right time, both before and after regulatory approval. With five new myeloma therapies scheduled for Canadian regulatory review over the next two years, Myeloma Canada will be increasingly focused on gaining government funding approvals for these new treatment options for our patients on public drug programs.

Our greatest success to date is the formation of the Myeloma Canada Research Network (MCRN). The MCRN is the first and only national academic myeloma research group bringing together Canada's leading myeloma investigators from 17 centers across the country. The MCRN is currently running its first trial (MCRN 001), with two more scheduled to open later in 2015, plus three others in the planning stages for 2016.

Gabriela Simancas

Fundación Unidos contra el Cáncer (FUNCA; United Against Cancer Foundation) is an organization founded in April 2013 and based in Paraguay. Its mission is to advocate so every person with cancer can have a dignified life with access to integral and appropriate treatment. I got involved with FUNCA a few months after my Dad was diagnosed with myeloma.

GMAN has helped FUNCA reach a milestone. FUNCA representatives received training in several subjects, as well as global contacts that can make the difference when we need to share best practices and obtain relevant information on myeloma treatment.

I truly feel that GMAN is part of the FUNCA family, as we feel they support us in the same way our own families would.

Viorica Cursaru

In December 2005, my beloved husband, Mihai Cursaru, was diagnosed with multiple myeloma. It was the turning point in our lives. Before, neither Mihai nor I were aware that happiness can be so easily destroyed by a sneaky disease. In 2006, I joined a group that subsequently established Myeloma Europe, a European organization for patients suffering from myeloma. In 2013, Myeloma Europe merged into Myeloma Patients Europe (MPE).

I currently serve as President of Myeloma Euronet Romania. The biggest challenge in Romania is the negative impact of a low gross domestic product and the funds to spend on health. Lack of access to treatment, lack of modern equipment, and migration of qualified medical staff are just some of our daily challenges. In the last 3 years, 7000 doctors left Romania for a life abroad.

The Romanian myeloma patients are better informed now than ever before. This is due entirely to a very active information campaign by Myeloma Euronet Romania through our website, two publications about multiple myeloma and, equally important, the annual conferences with participation of prestigious Romanian and European hematologists. This, I would define as my greatest success so far.

Dr. Chul Hwan Lee

After being diagnosed with acute myeloid leukemia (AML) in 1995, I established a patient self-help group and then incorporated it into the Korea Blood Cancer Association (KBCA) in 2002 before becoming its executive director in 2003. KBCA learned how to build a coalition of patient support groups through involvement with the IMF, and we are trying to help myeloma patients in Korea, China, Japan, and other Asian countries.

In 2014, I became Vice Chairman of the blood developing committee for the Korean branch of the International Red Cross.

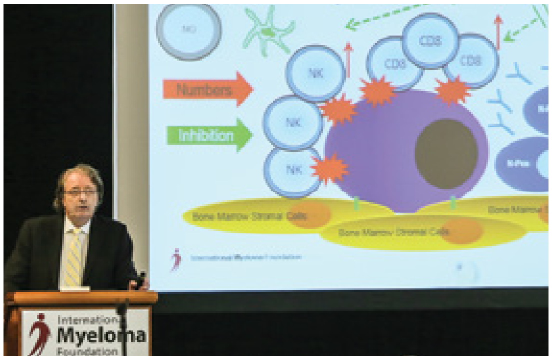
I continue to learn a lot from the IMF, and from other GMAN members. The educational programs for patients are excellent, and I learned greatly from the medical team who opened this year's symposium. I am honored to be a part of the GMAN steering committee. **MT**

16th Annual IMF Support Group Leaders

During a weekend in July, myeloma support group leaders from across the United States and beyond gathered in Dallas, Texas, for the IMF's 16th Annual Support Group Leaders Summit. Year-round, the group leaders give their all to the members of their support groups. But at the IMF's annual Summit, they get a chance to recharge their batteries, share encouragement, learn about the latest advances in the field of myeloma, and acquire skills that will benefit their groups back home. The 2015 Summit brought together more people than ever before, with 100 leaders representing 70 support groups, including 29 first-time attendees.

Below are just a few comments from participating group leaders about their Summit experience

– Robin Tuohy, IMF Senior Director, Support Groups



Dr. Brian G.M. Durie discusses the leaps forward taken by the IMF's Black Swan Research Initiative® since last year's Summit.

Robin Tuohy gives an overview of the available IMF resources, including support group website development and customized toolkits.

Cindy Ralston, a support group leader from Kansas/Missouri networks, with Robin Sully from Ottawa, Canada.

Wow, what a weekend! During the initial introductions, I was struck by how many support group leaders said that they were there in hope of getting rejuvenated. They certainly came to the right place.

Each year, Dr. Durie's medical updates are inspiring; he has such a gift for summing up the recent medical achievements and explaining the pathways forward. In this hard fight against myeloma, we are making rapid progress and it is being knocked back on its heels.

For me, it's hard to beat the combination of the valuable information presented plus the camaraderie shared with old friends and new. If the energy from this weekend is carried back home to all the support groups represented, this weekend will help many people.

– Jack Huguelet, Chattanooga, TN

Susie Novis with Sue Dunnett, PhD (Scotland), the researcher from the University of Edinburgh who studies why so many myeloma patients and caregivers choose to step up to help others.

The 2015 Support Group Leaders Summit left me energized, inspired, and educated. Each year the IMF works diligently to provide the proper tools to help us serve the myeloma patients in our regions. Thanks to the IMF, representatives from 70 support groups were updated on the latest research in myeloma. Topics such as advocacy, technology, leadership skills, marketing, websites, and group administration were presented in a way that left us better equipped to run successful groups. It's an honor to be involved with the IMF and to participate in such a dynamic weekend.

– Cindy Ralston, Kansas City, MO

Bridgette McKenzie (Georgia), Chris Massie (California), Doris Morgan (Georgia), Thomas Goode (North Carolina), and Carlene Pratt (California)

Linda and Jack Huguelet (Tennessee)

Godfrey and Monica Taylor, founding leaders of the myeloma support group in Kingston, Jamaica

Yvonne Yaksic (Pennsylvania), Barbara Marx (Virginia), Susie Novis (IMF President), Carla Bouselli (Missouri/Illinois), and Susan Benjamin (New Mexico)

Summit: "Wow, What a Weekend!"

Although the 2015 Summit was the biggest general assembly to date, topic-driven breakout sessions facilitated interaction and networking among group leaders.

This was my fifth year attending the IMF's Support Group Leaders Summit, and the meetings get better each year. One of my annual favorites is the "Pharmaceutical Round Robin," a chance to hear directly from the companies that develop the medications taken by my support group members and me. Future treatment options continue to grow, and representatives of Amgen, Bristol-Myers Squibb, Celgene, and Takeda Oncology joined us for an enlightening discussion. How exciting to have another company and a new type of medication in the fight against myeloma!

– Linda Huguelet, Chattanooga, TN

Summit participants surprised Dr. Durie and Susie Novis with a giant Thank You card for the IMF's 25th anniversary.

Mike, Robin, Michael, and Allison Tuohy

Maddie Hunter and
Cindy Chmielewski (Pennsylvania)

Michael Tuohy (Connecticut) and
Yelak Biru (Texas)

We thoroughly enjoyed the Summit! There was a wealth of information to address the needs of the caregivers in our group. Unfortunately, caregivers can suffer burn out, depression, and even health issues that result from taking care of those we love. Our group is now committed to planning a session just for caregivers. In addition, the session on medical records was something that we will share again and again. We benefited so much from the Summit, and what we have brought back to our group will without a doubt make a difference to so many. We never cease to be amazed by what the IMF has accomplished over the years, and we are so grateful for the care and education they offer to patients, caregivers, and other members of the myeloma community!

– Laura and Charlie Mooney, Staten Island, NY

There is nothing better than the collaborative learning opportunity the IMF provides support group leaders during the annual Summit. Experienced and new leaders alike were able to share tips to enhance the effectiveness of their groups. The Summit planning team offered us a wide range of sessions and featured numerous leaders sharing their group's successes. I am so grateful for having had this experience. I came away so renewed and inspired.

– Maddie Hunter, Philadelphia, PA

Robin Sully and Aldo del Col
of IMF's affiliate Myeloma Canada

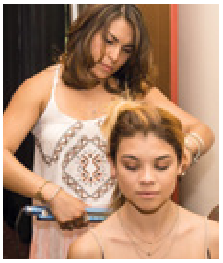
Charlie and Laura Mooney being interviewed for Myeloma Voices, an IMF Audio Archive at myelomavoices.myeloma.org.

Catwalk for Cancer

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

Tristen Douglass has a dream – to work, to create, and to grow as an artist in the world of fashion design. In 2013, Tristen lost her grandfather to myeloma, and she wanted to find a way to honor the memory of this very special man who always encouraged her creativity.

For her year-long "Senior Project" at Warwick Valley High School in New York, Tristen chose to produce an exclusive show featuring the fashions she designed and sewed alongside her teacher and mentor, Erma Wilson-Wyse. All of the proceeds from the Catwalk for Cancer event were donated to the IMF in memory of Alan J. Lustmann, Sr.



"I am proud of my work because I feel my creativity is causing conversation," says Tristen. "It encourages other teens to express themselves through what they wear. A future in fashion design would fuel my passion for style and communication through clothing. My grandfather would be so proud of this endeavor."

So, at age 17, Tristen took on a task that may have intimidated some adults. She organized a fashion show, served as event planner, helped secure sponsors and a venue, designed and sewed a fashion collection for the show, and garnered commitments from more than 100 supporters to attend the evening of fashion, music, food, and fun!

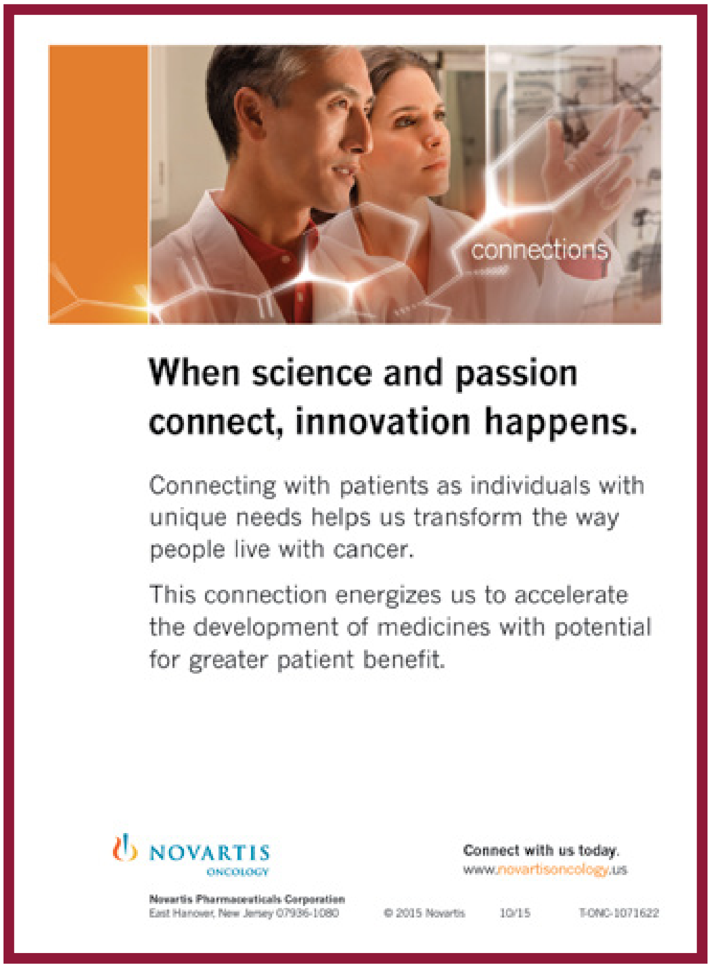
Due to rain, the May 27th event was moved indoors from its original outdoor venue, but the bad weather could not stop the show from going on. Silvio's Italian Villa, the restaurant hosting Catwalk for Cancer, was filled to capacity with over 100 guests. The party was followed by the fashion show, which was followed by a raffle. Since Tristen secured over 80 raffle prize packages from local businesses, hardly anyone left empty-handed, and one young guest was thrilled to win not one but two gift baskets! The restaurant, DJ, photographers, hair stylists, and makeup artists all donated their time and talent.

"Catwalk for Cancer was such a rewarding project," shares Tristen. "By producing this event, I shared my love for fashion while raising money for the IMF, which is very important to me. I am proud of what we accomplished and hope others will be motivated to continue to raise myeloma awareness and strive to make a difference."

"Tristen's Catwalk for Cancer was an amazing experience for everyone involved," adds Lisa Douglass. "As her mother, I am so proud of the hard work and effort she put into organizing every detail of this event. The IMF provided a wonderful support system which only reinforced Tristen's desire to make the evening such a success. It was very heartwarming to see the whole community come together to encourage not only Tristen's passion for fashion, but also to raise money for such an important cause."

Lisa and Tristen Douglass

Since Tristen graduated high school in June, she has been attending the Fashion Institute of Technology (FIT) in New York City. We wish her all the best in making her dreams come true! **MT**


connections

When science and passion connect, innovation happens.

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

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

NOVARTIS
ONCOLOGY

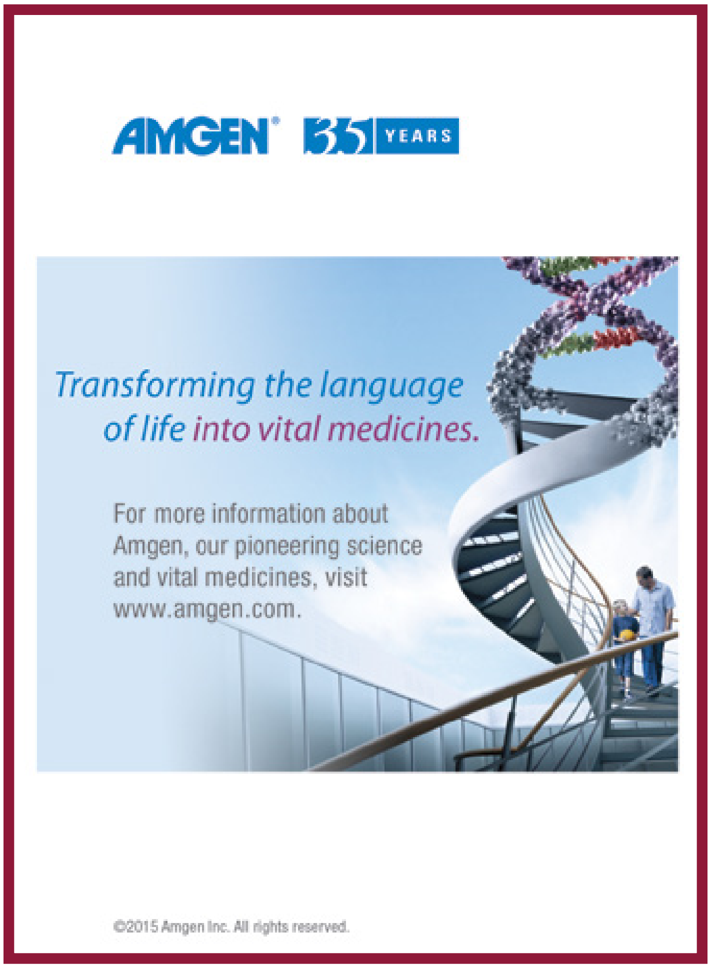
Connect with us today.
www.novartisoncology.us

Novartis Pharmaceuticals Corporation
East Hanover, New Jersey 07936-1080 © 2015 Novartis 10/15 T-ONC-1071622


Celgene

Committed to putting patients first

www.celgene.com


AMGEN® 35 YEARS

Transforming the language of life into vital medicines.

For more information about Amgen, our pioneering science and vital medicines, visit www.amgen.com.

©2015 Amgen Inc. All rights reserved.


Takeda
ONCOLOGY

oncology mission

We Aspire to Cure Cancer

We are excited to announce the launch of **TAKEDA ONCOLOGY**, formerly known as **MILLENNIUM: THE TAKEDA ONCOLOGY COMPANY**. Our mission is unchanged as we endeavor to deliver novel medicines to patients with cancer worldwide through our commitment to science, breakthrough innovation and passion for improving the lives of patients.

Learn more about our global commitment to oncology.

Visit us online at takedaoncology.com

©2015 Millennium Pharmaceuticals, Inc. All rights reserved.

International
Myeloma
Foundation

International Myeloma Foundation
12650 Riverside Drive, Suite 206
North Hollywood, CA 91607-3421 USA

myeloma.org
(800) 452-CURE (2873)

Change Service Requested

Non-Profit Org.
U.S. Postage
PAID
Mercury Mailing
Systems Inc.

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

2015/2016 IMF Calendar of Events

2015

Nov 14	IMF Regional Community Workshop (RCW) – Washington DC
Nov 21	IMF Regional Community Workshop (RCW) – Chicago, IL
Dec 5-8	57th American Society of Hematology (ASH) Annual Meeting and Exposition – Orlando, FL

2016

Feb 26-27	IMF Patient & Family Seminar (PFS) – Boca Raton, FL
Mar 18-19	IMF Patient & Family Seminar (PFS) – Seattle, WA
Apr 28–May 1	41st Annual Congress of the Oncology Nursing Society (ONS) – San Antonio, TX
June 3-7	52nd Annual Meeting of the American Society of Clinical Oncology (ASCO) – Chicago, IL
June 6-8	International Myeloma Working Group (IMWG) Summit – Copenhagen, Denmark
June 9-12	21st Congress of the European Hematology Association (EHA) –Copenhagen, Denmark
Dec 2-5	58th American Society of Hematology (ASH) Annual Meeting and Exposition – San Diego, CA

The IMF is proud to work with our global partners. We thank them for supporting our international meetings.
For more information about upcoming events, please visit **calendar.myeloma.org** *or call* **800-452-CURE** *(2873).*
For information on activities in Australia, Canada, Israel, Japan, or Latin America, please visit:
Australia **myeloma.org.au** • *Canada* **myelomacanada.ca** • *Israel* **amen.org.il** • *Japan* **myeloma.gr.jp** • *Latin America* **mielomabrasil.org**