

Improving Lives **Finding the Cure®**

2014



INTERNATIONAL  
MYELOMA  
FOUNDATION

**2014** ANNUAL REPORT

Improving Lives **Finding the Cure®**

# INTERNATIONAL MYELOMA FOUNDATION



**RESEARCH**



**EDUCATION**



**SUPPORT**



**ADVOCACY**

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

# 2014 ANNUAL REPORT

FISCAL YEAR OCTOBER 1, 2013 – SEPTEMBER 30, 2014

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

Medical Director, AMyC Myeloma Consortium  
Specialist in Multiple Myeloma and Related Disorders  
Cedars-Sinai Outpatient Cancer Center  
at the Samuel Oschin Comprehensive Cancer Institute

Dear Supporters of the International Myeloma Foundation,

I am pleased to be able to report that the International Myeloma Foundation (IMF) made important strides to help myeloma patients around the globe in 2014. The IMF was especially successful in the areas of education for both patients and doctors, as well as in several aspects of research.

Patient education is a cornerstone program of the IMF. "Knowledge is power" is the mantra which embodies our outreach to patients everywhere. The menu of opportunities for learning – finding out the best and latest information – has expanded and been enhanced. There are now more than 240 support groups worldwide. We now hold four annual two-day patient seminars in the US and 12 to 15 one-day community workshops annually across the country. The community workshop program has substantially extended the IMF's reach into smaller communities. In addition, there are numerous ways to access information via publications, online resources, and teleconferences. There is *Myeloma Today*, the weekly *Myeloma Minute* e-newsletter and regular *Living Well with Myeloma* teleconferences. Other resources include the weekly "Ask Dr. Durie" YouTube video series, the periodic International Myeloma Working Group (IMWG) Conference Series: *Making Sense of Treatment* online expert debate series, as well as the *10 Steps to Better Care* breakdown of key information, literally in a "step-by-step" fashion.

For physicians, the menu of IMF-generated educational opportunities is also expanding. The American Society of Hematology (ASH) CME-accredited physician symposium "Critical Issues Need Answers" has been an annual mainstay for more than a decade. In December 2013, more than 1,000 physicians attended (with a similar number in December 2014). Other important meetings include physician meetings held globally in sync with patient seminars, the Myeloma Master Class, an in-depth training program for Chinese physicians, plus a whole range of work group and roundtable meetings held globally to focus on specific topics of interest for guideline development or new research projects.

Turning to research, this has been a major area of excitement and growth. Not only have the IMF's annual Brian D. Novis Senior and Junior Research Grants continued (over \$6 million in awards so far), but many new research programs have also emerged. The groundbreaking Black Swan Research Initiative® is truly moving toward achieving a cure for myeloma. Focused on early diagnosis, monitoring disease at the very lowest levels (using new MRD [minimal residual disease] testing), and developing novel therapy combinations to eradicate residual disease, this project has galvanized interest, expectation, and enthusiasm among myeloma researchers and patients everywhere. It has also attracted enthusiasm and support from corporate and private donors. Fiscal year 2014 saw the development of the Next Generation Flow (NGF) technique, a precise new tool to monitor myeloma as cure is being achieved. We have great optimism that over the next one to two years, we will be able to confirm that cure is being achieved.

So, for education and research, 2014 was a stellar year and we look forward to even greater progress in 2015 and beyond.

A deeply felt thank-you to all who have contributed to make so many great things become a reality.

Sincerely yours,

Brian G.M. Durie, MD  
Chairman, IMF Board of Directors

**IMF Board of Directors**

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Proprietor & Executive Vice President, Vox Media  
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**Susie Novis, President**  
International Myeloma Foundation

Dear Friends,

For the first time since the International Myeloma Foundation was founded, more than 24 years ago, I am able to say that a cure for multiple myeloma is within reach. In just three years, the Black Swan Research Initiative® has made tremendous strides in developing both a new, highly sensitive test to determine minimal residual disease and establishing trials that initially can lead to a cure for a subset of myeloma patients. Our goal is to find a cure for all patients, and this is a big step in the right direction.

Research to find a cure is paramount to our mission, and the IMF focuses both on lab and clinical research to achieve our goal. The IMF also focuses on funding Junior and Senior Research Grants for doctors working in institutions around the world. These grants are incredibly important, as they provide much-needed monetary support for research projects being conducted by the best and the brightest in our field. Funding grants since 1994, the IMF is now the premier funder of myeloma research grants, having awarded over 115 grants that have opened the doors to new ideas and major advancements in treatments.

During the twelve-month period of October 1, 2013 to September 30, 2014, we continued to have a significant global reach. Thanks to continued support from our pharmaceutical partners, the IMF held the 3rd Annual Myeloma Master Class, an intensive course for young clinicians, designed by Dr. Durie and following the 10 Steps for Better Care®. The Master Class once again welcomed seven bright and enthusiastic doctors from seven of the most prestigious hospitals in China to learn from the experts, who are members of the IMF's International Myeloma Working Group.

The IMF held our 15th annual Support Group Leaders Summit. More than 85 people attended, representing more than 60 groups from across the US. The weekend was spent learning about the latest advances in myeloma treatment and management, as well as learning from each other. A highlight for the attendees was the Black Swan Research Initiative Update from Dr. Durie, and the "Pharma Round Robin" where they learned about advances in therapies from Celgene, Millennium, and Onyx.

Thanks to the efforts of our Advocacy team, oral anticancer drug parity bills have been passed in 34 states, plus Washington D.C., and have been introduced in both the US House and Senate with help from IMF-led coalitions, PEAC (Patients Equal Access Coalition) and SPEAC (State Patients Equal Access Coalition). Both PEAC and SPEAC continue to have a powerful impact on access issues most important to patients, and the coalition includes 25 and 30 member organizations respectively.

We also expanded our global advocacy efforts with the launch of the Global Myeloma Alliance (GMA), the first and only international coalition of patient organizations working in the field of myeloma. The GMA members joined together to ensure that patients have access to the newest approved treatments and to support continued innovation in blood cancer. The Alliance now includes 29 organizations representing 25 countries around the world, and is poised to grow beyond that number.

But by far the most exciting thing to happen last year was the amazing progress the Black Swan Research Initiative is making and how much we've already accomplished. What began with a small team is now a global entity working together to ensure that the dream of finding a cure quickly becomes a reality.

With your support, 2013-2014 was the best year ever, touching all the cornerstone and innovative programs of the IMF – education, research, support, and advocacy! Thank you for your support. The door to the cure is open – let's walk through it together!

Warm regards,

Susie Novis  
President



### IMF Executive Team

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**Jennifer Scarne**  
Chief Financial Officer  
**Diane Moran**  
Senior Vice President, Strategic Planning  
**Lisa Paik**  
Senior Vice President,  
Clinical Education & Research Initiatives  
**Daniel Navid**  
Vice President, Global Affairs

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Outreach  
**Ray Wezik**  
Global Advocacy Executive



**Bruno Paiva, PhD**  
University of Navarra  
Pamplona, Spain

Dr. Bruno Paiva began his career in the immunopathology laboratory while enrolled in a PhD program under the supervision of noted myeloma specialist Prof. Jesús San Miguel at the University Hospital of Salamanca in Spain. From the start, Dr. Paiva's career has had a laser-like focus on characterizing myeloma cells. In his PhD program, he assessed the clinical value of multiparameter flow cytometry immunophenotyping of plasma cells in multiple myeloma patients.

At the beginning of his career, Dr. Paiva found the International Myeloma Foundation (IMF) when searching for reliable coverage of myeloma developments from medical meetings. Now a major contributor at these meetings, Dr. Paiva was awarded an IMF Brian D. Novis Junior Research Grant at the American Society of Hematology Annual Meeting in December 2013.

Dr. Paiva's research study, "Phenotypic and molecular characterization of circulating tumor cells and minimal residual disease myeloma cells: understanding disease dissemination and chemoresistance," is aimed at understanding the biology of two types of myeloma cells using flow cytometry and other methods. This understanding of myeloma subclones remaining in the body as the disease progresses is a key to the IMF's Black Swan Research Initiative® to find a cure for myeloma. Dr. Paiva is a member of the Black Swan Research Initiative team and has contributed to the development of a fully automated, ultra-sensitive flow cytometry technique for minimal residual disease (MRD) testing in myeloma – a crucial first step in the Black Swan Research Initiative's work.

*"This Brian D. Novis Junior Research Grant presents an exciting opportunity for our team to study the biology of myeloma cells. We hope that with the support of the IMF, we can get some of the answers to shed light in key areas, including disease dissemination and therapy resistance, and improve patients' lives."*

# RESEARCH

Research is a top priority for the International Myeloma Foundation. In fiscal year 2014 the IMF advanced its signature Black Swan Research Initiative®, continued to bring young investigators into the field through the Junior Research Grants program, and enhanced funding for more senior investigators. The IMF International Myeloma Working Group (IMWG) members collaborated on important myeloma projects that led to several publications during the year.

## Research Groups

### Black Swan Research Initiative



Led by IMF Co-Founder and Chairman Dr. Brian Durie, the Black Swan Research Initiative is a multinational consortium of leading myeloma experts who are harnessing new technologies and the latest myeloma treatments to find a pathway to a cure. The Black Swan Research strategy capitalizes on the availability of potent novel therapies and the advent of ultra-sensitive tests to measure exactly when and how those therapies are working in patients.

In fiscal year 2014, the Black Swan Research investigative team pushed forward on several important fronts – collaboration, education, and fundraising. The team convened two meetings designed to achieve consensus on a key element of the Black Swan Research Initiative's pathway to achieving a cure – a new, fully automated, highly sensitive technique for assessing minimal residual disease (MRD). In October 2013, Dr. Alberto Orfao and Dr. Bruno Paiva presented results of this exciting new flow cytometry method. An equally successful follow-up meeting was held in December 2013 in advance of the American Society of Hematology (ASH) meeting in New Orleans. The result was consensus that this test offers an unequaled potential for the most sensitive and accurate response assessment in myeloma clinical trials.

In March 2014, Black Swan Research team members Dr. Brian Durie and Dr. Bruno Paiva participated in the US Food and Drug Administration (FDA)-National Cancer Institute (NCI) Roundtable: "Symposium on Flow Cytometry Based on the Detection of Minimal Residual Disease in Multiple Myeloma."

In the same month, the IMF co-hosted with EuroFlow a well-attended educational workshop at the University of Salamanca in Spain. Nearly 70 participants from 13 different countries learned in a hands-on manner the full details of the new myeloma detection antibody panel and computer software, which provide results in a first-time ever standardized automated fashion. July 2014 saw the IMF co-hosting, with Memorial Sloan Kettering Cancer Center, the US Myeloma Flow Workshop in New York City. Representatives from 24 medical centers across the country, the NCI, and the FDA attended this intensive educational event.

The Black Swan Research Initiative has drawn enthusiastic support from private donors (see IMF Development report, page 21) and industry. In December 2013, the IMF announced the launch of a multiyear partnership with Onyx Pharmaceuticals, Inc., an Amgen subsidiary, and in July 2014, The Binding Site, a UK-based in-vitro clinical diagnostic company, began a partnership in support of the research initiative.

Using new drugs in novel ways, determining the right combination for the right patient at the right time, and measuring the results with the most sophisticated tests to ensure that we've reached a cure are the goals of the Black Swan Research Initiative heading into the future.



## International Myeloma Working Group

The IMF founded the International Working Group in 2001 to globally and collaboratively conduct basic, clinical, and translational research to improve health outcomes for those living with myeloma. Comprised of 185 of the world's leading myeloma researchers from 33 countries, the group publishes highly regarded consensus statements and guidelines for the management of myeloma.



In June 2014, the fifth annual IMF IMWG Summit was held in Milan, Italy. There, 75 of the world's leading myeloma experts from 28 countries representing 55 institutions grappled with subjects of vital concern to the myeloma community: new therapies in development, continuous therapy, treatments for transplant eligible and transplant ineligible patients, and assessment of minimal residual disease (MRD).

Myeloma researchers and patients around the world were able to see some of the findings and excitement generated at the IMWG Summit through the magic of modern technology. Dr. Durie moderated the fifth event in the IMWG Conference Series: "Making Sense of Treatment," a live-streamed panel discussion that included Drs. Ola Landgren, Joseph Mikhael, Antonio Palumbo, and Stephen Russell. The topics covered in the webcast (archived at <http://bit.ly/1m5tbMU>) included a new flow cytometry method to monitor MRD developed in conjunction with the IMF's Black Swan Research Initiative, new therapies in development, best treatment choices for transplant eligible patients and transplant ineligible patients, the role of continuous therapy, measles virotherapy, and everyone's perspective on new ideas for the future. Viewers tuned in from around the world.

### IMWG Publications

Long-term IMWG research collaboration led to two publications during the October 2013 – November 2014 reporting period:

#### ***New Drugs and Novel Mechanisms of Action in Multiple Myeloma in 2013: A report from the International Myeloma Working Group.***

Ocio E, San Miguel J, et al. *Leukemia*. 2013 Nov 20. doi: 10.1038/leu.2013.350.

#### ***International Myeloma Working Group Consensus Statement for the Management, Treatment, and Supportive Care of Patients With Myeloma Not Eligible for Standard Autologous Stem-Cell Transplantation.***

Palumbo A, Orłowski R, et al. *J Clin Oncol*. 2014 Jan 13. doi: 10.1200/JCO.2013.48.7934.

Full text versions of IMWG publications and presentations may be accessed at: [imwg.myeloma.org](http://imwg.myeloma.org).

## Asian Myeloma Network

The IMF's Asian Myeloma Network (AMN), comprised of leading hematologists from China, Hong Kong, Taiwan, Japan, Korea, Singapore, and Thailand, serves to advise the IMF on its Asian programs and to implement regional research projects and research activities. Since its inception in 2010, the AMN has become a recognized source of expertise for myeloma in the Asian region. 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. During 2014, the AMN made considerable progress on several programs in Asia.

In the area of epidemiology, the AMN's Asian Myeloma Data Base was expanded to include information on myeloma incidence and treatment practices for well over 4,000 patients in Asia. Details about this AMN project were published in July 2014 in the peer-



**S. Vincent Rajkumar, MD**  
Mayo Clinic  
Rochester, Minnesota

Dr. S. Vincent Rajkumar is Edward W. and Betty Knight Scripps Professor of Medicine at the Mayo Clinic in Rochester, Minnesota, where he is also Chair of the Myeloma Amyloidosis Dysproteinemia Group. His research focuses on clinical, epidemiological, and laboratory research for myeloma and related disorders.

He first came into contact with the International Myeloma Foundation (IMF) in 1996, when he presented his first abstract at the American Society of Hematology (ASH) Annual Meeting & Exposition. Over the next few years, he learned about the IMF and the role the organization plays in advancing myeloma education and research.

"It is remarkable how time flies, and soon one day you realize, 'Well, I am now part of the IMF,'" said Dr. Rajkumar.

He joined the International Myeloma Working Group (IMWG), the IMF's research division, in 2004, after reading the organization's first three papers and finding himself with "an intense desire to be part of this group, and to contribute." The fourth paper published by the IMWG was co-written by Dr. Rajkumar and IMF Chairman Dr. Brian G.M. Durie. The topic was uniform response criteria for myeloma and it has become one of the most cited papers in myeloma.

Membership in the IMWG has been "very rewarding" for Dr. Rajkumar, not least for its collaborative nature. He has been part of many research projects with the IMWG that "would not have been possible without the cooperation of numerous investigators."

***"The disease is extraordinarily complex, and no one person can have a full understanding of the ever-growing body of knowledge. By pooling resources, databases, and samples we can achieve far more than we can do alone."***

## Asian Myeloma Network Meeting 2014



**Dan David**  
IMF Vice President,  
Global Affairs



**Dr. Shaji Kumar – Mayo Clinic**



reviewed American Journal of Hematology. In 2014, the AMN also made plans to launch a cooperative data base project with IMF colleagues in Latin America.

AMN's work in the treatment field continues to center on the AMN Clinical Trials network. In 2014, the AMN worked with corporate partners to establish clinical trials and special access programs to launch in 2015. This included a partnership with Celgene to establish a pomalidomide patient access program for patients in AMN regions where pomalidomide does not yet have regulatory approval. AMN also laid the groundwork in 2014 for a clinical trial in cooperation with Onyx Pharmaceuticals, an Amgen subsidiary, and the Australian Lymphoma and Leukemia Group to evaluate carfilzomib, thalidomide, and dexamethasone in relapsed and refractory myeloma.

The IMF made great strides in 2014 in expanding Asian physician training, specifically in China. The IMF held five training programs in China, supported by Janssen, as well as the third annual Myeloma Master Class for young Chinese doctors at the IMF's US headquarters, supported by Celgene and Onyx.

## Research Grants Program

For nearly 20 years, the IMF Research program has funded promising clinical investigators from around the world in an effort to improve outcomes for patients with multiple myeloma. IMF-funded research has made contributions to understanding the biology of myeloma and supporting the development of a cure. The grantees of the 2014 awards will continue to contribute significantly to the field of myeloma.

The IMF grants are funded by donations from private individuals. The presentation ceremony for the 2014 IMF Research Grant awards took place during the American Society of Hematology (ASH) annual meeting held in New Orleans, Louisiana in December 2013.

## Brian D. Novis Research Grants 2014

*In memory of its co-founder, Brian D. Novis, the IMF has established annual grants to promote research into all areas of myeloma – better treatments, management, prevention, and a cure. These grants are awarded annually to doctors and researchers conducting promising work in the field of myeloma.*



## Brian D. Novis Senior Research Grants 2014

*Senior Research Grant projects are funded at \$80,000.*

### Fotis Asimakopoulos, PhD

University of Wisconsin, Department of Medicine, Hematology and Oncology – Madison, Wisconsin

***TPL kinase regulates macrophage-tumor cell interactions in the myeloma niche: biological and clinical implications.***

### Roman Hájek, MD

University of Ostrava, Department of Internal Medicine – Ostrava, Czech Republic  
***Dynamics of microRNA and cell free DNA profiles during multiple myeloma progression.***



**Manoj Pandey, PhD**

Pennsylvania State University, College of Medicine – Hershey, Pennsylvania

***Gambogic acid: a potential therapeutic agent for multiple myeloma and associated bone loss.***

**Brian D. Novis Junior Research Grants 2014**

*Junior Research Grant projects are funded at \$50,000.*

**Elke De Bruyne, PhD**

Vrije Universiteit Brussel, Hematology and Immunology – Jette, Belgium

***Study of the epigenetic regulation of multiple myeloma cells within the bone marrow microenvironment.***

**Sham Mailankody, MD**

National Cancer Institute, National Institutes of Health – Bethesda, Maryland

***High throughput sequencing of multiple myeloma and its precursor state, smoldering myeloma.***

**Laura Oliva, PhD**

Fondazione Centro San Raffaele – Milano, Italy

***Exploiting the stress of amyloidogenic light chain production as a therapeutic target.***

**Bruno Paiva, PhD**

Fundación para la Investigación Médica Aplicada Clínica – Pamplona, Navarra, Spain

***Phenotypic and molecular characterization of circulating tumor cells and minimal residual disease myeloma cells: understanding disease dissemination and chemoresistance.***

**Jinsheng Weng, MD , PhD**

MD Anderson Cancer Center – Houston, Texas

***Development of human tumor antigen specific T cells against multiple myeloma.***

**Brian White, PhD**

Washington University in St. Louis – St. Louis, Missouri

***Mechanisms of clonal progression in multiple myeloma.***

**IMF Japan Research Grants**

The annual multiple myeloma research awards were instituted in 2002 by IMF-Japan in memory of its founder, Aki Horinouchi. These awards have funded 19 important research projects. The following awards were presented at ASH 2013 by IMF-Japan.

**The Aki Horinouchi Award****Masahiro Hiasa DDS, PhD**

University of Tokushima Graduate School – Tokushima, Japan

***Development of novel anti-myeloma agents with anabolic actions.***

**The IMF Japan Special Research Grants****Yoichi Imai, MD, PhD**

Tokyo Women's Medical University – Tokyo, Japan

***Elucidation of calcineurin as a novel oncogene in multiple myeloma and development of calcineurin-targeted therapy for multiple myeloma.***

**Ajay Nooka, MD**

Emory University School of Medicine – Atlanta, Georgia

***HevyLite and FreeLite in Diagnostic & Monitoring of Monoclonal Gammopathies***

**Brian D. Novis Research Grants  
2014 Winners**

## Robert A. Kyle Lifetime Achievement Award

The Robert A. Kyle Lifetime Achievement Award, named for its first recipient, is presented annually by the International Myeloma Foundation to an individual whose body of work in the field of myeloma has made significant advances in research and the treatment and care of myeloma patients.



**Prof. Antonio Palumbo**

TWELFTH ANNUAL INTERNATIONAL MYELOMA FOUNDATION  
**ROBERT A. KYLE**  
LIFETIME ACHIEVEMENT AWARD

In June 2014 in Milan, Italy, Professor Antonio Palumbo was awarded the 12th annual Robert A. Kyle Lifetime Achievement Award. Prof. Palumbo serves as Chief of the Myeloma Unit of the Department of Oncology in the Division of Hematology at the University of Torino in Torino, Italy. Prof. Palumbo's work has helped to prolong the survival of patients and improve their quality of life. He currently leads several multidisciplinary projects on the molecular biology and the pathogenesis of multiple myeloma, and on the development of biological markers to predict clinical outcomes. He also serves as principal investigator of many clinical trials investigating the role of new drugs and second-generation novel agents for the treatment of young and elderly patients with multiple myeloma, both at diagnosis and at relapse.



## Research Events of 2014

There are several annual conferences that bring together myeloma researchers from around the world. The IMF participates in each, to present, to increase dialogue around this disease, and to stay abreast of important findings on multiple myeloma research from around the world. The 55th American Society of Hematology (ASH) Annual Meeting and the annual meeting of the American Society of Clinical Oncology (ASCO) brought to light some critical new successes and innovations in myeloma diagnostics and treatment.

### IMF at ASH

The 55th American Society of Hematology Annual Meeting and Exposition took place December 7-10, 2013, in New Orleans, Louisiana. The meeting, the premier hematology conclave in the world, drew more than 18,000 hematologists and healthcare professionals. More than 800 abstracts on myeloma were presented. The myeloma studies



fell into the following major categories: continuous treatment, cumulative dosing, newly approved therapeutics, and pipeline drugs.

The IMF team was in attendance to report on this impressive collection of research activities in the field of myeloma. IMF staff interviewed key ASH 2013 myeloma presenters to discuss the implications of their findings, which were posted to the IMF website to inform physicians, patients, families, and caregivers.

### IMF at ASCO

The Annual Meeting of the American Society of Clinical Oncology (ASCO) was held May 30-June 3, 2014 in Chicago, Illinois. The meeting brought together more than 25,000 oncology professionals from a broad range of specialties and featured more than 5,000 abstracts. The IMF spotlighted the most significant news for myeloma patients from those abstracts and interviewed top myeloma researchers on topics such as continuous therapy, new myeloma drugs, and new dosing regimens and combinations for approved myeloma therapeutics.

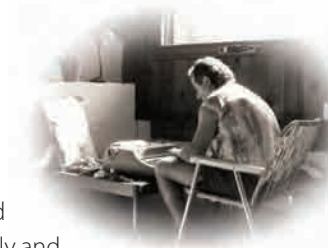


During the ASCO annual meeting, the American Society of Hematology recognized IMF Executive Board member Michael S. Katz with the 2014 Partners in Progress Award, which honors an individual who has made valuable contributions in cancer awareness and public advocacy. ASCO chose Mike as the 2014 recipient because of his efforts to raise myeloma awareness, in addition to his participation in the development of clinical trials to improve treatment of the disease. Since he began volunteering with the IMF in 1990, the year he was diagnosed

with myeloma, Mike has made countless contributions to the field of myeloma. His contributions include: designing disease management tools available to patients through the IMF; speaking at IMF Patient & Family Seminars to educate others; conducting video interviews with researchers at major medical conferences to bring scientific developments directly to patients and physicians; and working to design clinical trials that have had major impacts on myeloma treatment. Mike has worked as a patient advocate across a broad spectrum of cancers, serving as Chair of the Patient Representatives Committee at the Eastern Cooperative Oncology Group (ECOG), Chair of the National Cancer Institute (NCI) Director's Consumer Liaison Group, a Patient Consultant for the US Food and Drug Administration (FDA), and on the Association of Cancer Online Resources (ACOR).

# EDUCATION

Although it is the second most common blood cancer, multiple myeloma is still a relatively unknown disease. For many patients and their caregivers, it is at diagnosis when they first hear the word “myeloma.” The International Myeloma Foundation (IMF) recognizes the need for comprehensive education programs for both the patient and the physician – to ensure that patients are diagnosed correctly and treated effectively. IMF President Susie Novis coined the phrase, “Knowledge is power” after her husband Brian Novis was diagnosed. His subsequent journey to fully understand myeloma led to the founding of the IMF in 1990. Since then, the IMF has remained fully committed to empowering patients through education and ensuring that their doctors and nurses receive the most current information to diagnose and treat them.



## IMF Patient & Family Seminars

Patient education programs provide patients and their caregivers their most powerful weapon in the fight against myeloma: knowledge. In 1993, the IMF became the first organization to conduct Patient & Family Seminars, providing patients and their caregivers access to top doctors working in the field of myeloma.



IMF Patient & Family Seminars have reached tens of thousands of people around the world. From October 2013 to September 2014, more than 700 people attended US-based seminars held in Boca Raton, Florida; Atlanta, Georgia; and Los Angeles, California. Outside of the US, nearly 1,300 people attended seminars held in Paris and Nantes, France; Lázně Bělohrad, Czech Republic; Bari and Milan, Italy; Oslo and Trondheim, Norway; Middelfart, Denmark; Vienna, Austria; Liptovský Ján, Slovakia; and Heidelberg, Germany.



## Regional Community Workshops

To address the need in smaller communities, for events like the Patient & Family Seminars, the IMF now hosts frequent Regional Community Workshops and Myeloma Center Workshops. These half-day workshops offer families a condensed version of the full seminar at no charge.

From October 2013 to September 2014, more than 500 people attended US workshops held in St. Louis, Missouri; Raleigh, North Carolina; Fort Myers, Florida; Portland, Oregon; Minneapolis, Minnesota; Wheeling, Illinois; and Houston, Texas.

## Physician Community Workshops

The IMF also hosts Physician Community Workshops throughout Europe to ensure physicians receive the most current information to diagnose and treat myeloma patients. In 2014, nearly 100 physicians attended workshops held in Odense, Denmark and Oslo and Trondheim, Norway.



**Niel Gnesin**  
Toronto, Ontario

As a text and audio/video blogger, radio host, graphic designer, and content creator, Niel Gnesin is well versed in all things internet. So when he was diagnosed with myeloma nine years ago, that was exactly where he turned.

“I suppose it’s my quest for knowledge that first brought me to the IMF and the Patient & Family Seminars,” Niel said. “I wanted to know everything I possibly could from different sources, and I found a number of organizations online. There were so many, it became overwhelming, so I picked what I considered to be the ‘cream.’”

Niel began attending International Myeloma Foundation (IMF) Patient & Family Seminars in Chicago in 2005. He has now attended more than half a dozen seminars. Niel said he “quickly became addicted to them” because of the different views they brought to the table. Though he has had ups and downs with the disease over the years, Niel’s will to stay informed and involved has never waned.

For Niel, the IMF’s Patient & Family Seminars also fill a hole in his myeloma education.

“At Patient & Family Seminars, my questions are usually answered prior to me asking them. I have found there are so many important aspects to the disease beyond just the medical definition. There is so much knowledge to be gained at these seminars,” Niel said.

In addition to the medical knowledge he gains at Patient & Family Seminars, Niel appreciates the welcoming, collaborative atmosphere – and the fun – he has found at each meeting.

***“The real world can be very scary for cancer patients. Folks have no idea how to talk to people with cancer, but the IMF and those who attend their Patient & Family Seminars do. Just don’t forget to bring your sense of humor!”***



## IMF 2014 List of Publications

*Clinical Trial Fact Sheet: Denosumab*

*Clinical Trial Fact Sheet: DFCI Randomized Phase III Study Comparing Conventional-Dose RVD to High-Dose Treatment with Stem Cell Transplant*

*Concise Review*

*Early Screening for MGUS Flowchart*

*InfoLine Bookmark\*\**

*Making Miracles\**

*Monitoring Patients with M-Proteins Flowchart*

*Myeloma Matrix: Clinical Trials\*\**

*Myeloma Minute\** (weekly e-newsletter)

*Myeloma Today\** (quarterly newsletter)

*Patient Handbook\*\**

*Tip Card – Freelite® and Hevlyte®*

*Tip Card – Kyprolis® (carfilzomib)\*\**

*Tip Card – Pomalyst® (pomalidomide)\*\**

*Tip Card – SQ Velcade® (bortezomib)\*\**

*Tip Card – What is the IMF?\**

*Understanding Adherence to Oral Cancer Therapy*

*Understanding Bisphosphonate Therapy*

*Understanding Clinical Trials*

*Understanding Dexamethasone and Other Steroids*

*Understanding Fatigue\*\**

*Understanding High-Dose Therapy with Stem Cell Rescue\*\**

*Understanding Kyprolis® (carfilzomib)\*\**

*Understanding Pomalyst® (pomalidomide)*

*Understanding Revlimid® (lenalidomide)\*\**

*Understanding Serum Free Light Chain and Serum Heavy/Free Light Chain Assays\**

*Understanding Thalidomide*

*Understanding Treatment of Myeloma-Induced Vertebral Compression Fractures: The Role of Vertebroplasty and Kyphoplasty\**

*Understanding Velcade® (bortezomib)\*\**

*Understanding Your Test Results*

\*New (between 10/1/13 and 9/30/14)

\*\*Updated (between 10/1/13 and 9/30/14)

## Publications

The IMF produces an extensive library of educational materials, which are offered free of charge both in print and on the IMF website. The IMF library of publications provides up-to-date information on all issues affecting the myeloma community, including innovations in treatment, information on clinical trials, updates on policy issues, and more. Frequently requested publications include the *Patient Handbook*, the *Understanding* series, the IMF's quarterly newsletter *Myeloma Today*, and weekly e-newsletter *Myeloma Minute*. Many of the IMF's booklets and medical articles are translated into 20 languages, including Spanish, German, Italian, and French.



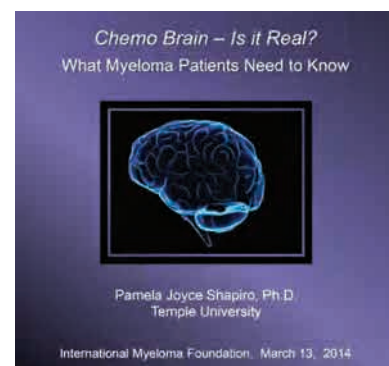
The IMF Info Pack, assembled with a selection of key IMF publications, is designed to provide newly diagnosed patients and their families with a complete understanding of the disease and care. During the 2014 fiscal year, more than 3,000 Info Packs were disseminated to patients, healthcare providers, and support groups around the world.

From October 2013 through September 2014, the IMF produced seven new publications. An additional thirteen titles were updated during this period. Many of the new or updated English-language publications were translated into multiple languages. The quarterly *Myeloma Today* newsletter has a print subscriber base of nearly 16,000, as well as a web-view and pass-along rate independently estimated at 75,000. Key articles from each English-language edition of *Myeloma Today* are translated into French, German, Italian, and Spanish. The weekly *Myeloma Minute* subscriber base includes more than 28,000 readers.

## Teleconferences

IMF teleconferences are a way for members of the myeloma patient and caregiver community to receive top-level, up-to-date information on relevant issues. The IMF held six teleconferences for patients and caregivers during the 2014 fiscal year, including four calls in the IMF's popular Living Well with Myeloma series. Topics of the calls included alternative medicine, "chemo brain," and important myeloma updates from medical meetings.

Recordings of all IMF teleconferences are available on the IMF website. More than 14,000 people have listened to live and archived recordings of the 2014 teleconferences.



## Medical Professional Education

The IMF offers healthcare professionals who treat myeloma patients essential educational courses. In 1999, the IMF began sponsoring CME-certified satellite symposia held in conjunction with the American Society of Hematology (ASH) annual meeting. This symposium has an audience of 900+ attendees from countries around the world. In 2006, the IMF formed the Nurse Leadership Board (NLB), consisting of specialty oncology nurses from major medical centers across the United States, and also embarked on CME-accredited symposia at the Oncology Nursing Society (ONS) annual meeting in 2007.

## Myeloma Master Class

The most recent medical education program developed by the IMF is the Myeloma Master Class, an intensive educational course designed for clinicians who specialize in myeloma. The third annual Master Class, held in August 2014, welcomed seven doctors from top medical centers in China. The comprehensive educational forum, created and led by Dr. Brian Durie and structured around the IMF's 10 Steps to Better Care, is designed to update physicians on the latest advances in myeloma diagnosis and treatment. Featured speakers were Dr. Durie, Dr. Bill Bensinger of the University of Washington Medical Center in Seattle, Dr. S. Vincent Rajkumar of Mayo Clinic in Rochester, Minnesota, Dr. Joseph Mikhael of Mayo Clinic in Scottsdale, Arizona, and Dr. Robert Vescio of Cedars-Sinai Medical Center in Los Angeles. The participants capped off their experience by attending an IMF Patient & Family Seminar in Los Angeles, California.



## Educational Outreach in Europe

The IMF continued to strengthen its international relationships with patients, families, and advocacy groups abroad in 2014 with educational meetings in 11 European countries. By collaborating with doctors in each country, the IMF works to provide the most updated myeloma research and treatment information to patients in their own languages. In the coming year, the IMF will expand its presence to nine additional countries.



## Nurse Leadership Board

The International Myeloma Foundation (IMF) Nurse Leadership Board (NLB) is a professional nursing partnership representing national experts in both academic and community practices treating myeloma. The group's primary mission is understanding and developing strategies to address the unmet needs of myeloma nurses, their patients, and patients' caregivers. Founded in November 2006, the NLB has proven to be invaluable to the myeloma community as a platform that bolsters nursing education, clinical care experience exchange, and patient knowledge and empowerment.

## IMWG Conference Series



The International Myeloma Working Group (IMWG) Conference Series: Making Sense of Treatment is a medical education program created by the International Myeloma Foundation (IMF) to bring lively expert discussion of important myeloma treatment issues into the homes and offices of viewers around the world via live webcast.

Panels are comprised of world-renowned myeloma experts who are members of the IMWG. In its third year, the IMWG Conference Series offered two debates revolving around data, new ideas, and controversies presented at major medical meetings.

More than 16,000 viewers around the world tuned in to watch the live streams or recordings of these debates. They can be viewed at [imwgconferenceseries.myeloma.org](http://imwgconferenceseries.myeloma.org) on the IMF website.

A December 2013 debate among Dr. Brian Durie, Dr. Ola Landgren, Dr. Joseph Mikhael, and Dr. Antonio Palumbo was held in New Orleans, Louisiana following the American Society of Hematology (ASH) annual meeting.

A June 2014 debate held in Milan, Italy during the fifth annual IMWG Summit and before the start of the European Hematology Association (EHA) annual congress featured panelists Dr. Brian Durie, Dr. Ola Landgren, Dr. Joseph Mikhael, Dr. Antonio Palumbo, and Dr. Stephen Russell.

The IMWG Conference Series debates provide an innovative and exciting format for discussion of trends and new information, including: new therapies in development; continuous therapy; best treatment options for various stages of the disease; and assessment of minimal residual disease (MRD).





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

As a nurse practitioner for 20 years and a member of the oncology nursing community for 30, Sandra Kurtin, RN, MS, AOCN®, ANP-C, who is also currently working on her doctorate, understands the value of keeping patients “well and alive so they have the best opportunity to benefit from all of the amazing science advancing myeloma treatment today.” She sees great value in educating not only healthcare providers, but also patients and caregivers as partners who translate that science into better patient care.

Sandra became involved in the myeloma field while working with acclaimed myeloma physicians IMF Chairman Dr. Brian Durie and Dr. Sydney Salmon, who together developed the Durie-Salmon myeloma staging system. She joined the IMF Nurse Leadership Board (NLB) in 2009.

“There has been, thankfully, a great deal of discovery in multiple myeloma. It’s important to make the best of that – not every disease has been that fortunate.”

Sandra has been instrumental in IMF programs and events, including Regional Community Workshops, the Oncology Nursing Society IMF Nursing Symposia, and the Living Well with Myeloma teleconferences, the most recent of which – “Complementary & Alternative Medicine: What Myeloma Patients and Caregivers Need to Know” – has drawn more than 1,000 listeners.

*“I try to give patients and their caregivers the tools to take ownership of their care. I encourage people to join their local support group and to take part in the national programs and meetings such as the ones offered by the IMF. There’s so much good work being done through clinical trials and laboratory research that we have every reason to be optimistic about the future.”*

NLB members work each year to bring relevant information to patients and healthcare providers by presenting at key conferences, seminars, and workshops. They also conduct educational teleconferences, make contributions to IMF website content and publications, and publish research on myeloma management. This board of experienced myeloma nurses has made great strides in improving the nursing care and self-care of myeloma patients since its inception.

The NLB’s ninth annual meeting, held in New Jersey in October 2013, provided an opportunity for the nurse leaders to plan and begin projects to kick off the 2014 fiscal year. During the meeting, the NLB reviewed completed projects, discussed the status of works-in-progress, and planned future activities.

Throughout the year, NLB members led education sessions at IMF Patient & Family Seminars, Myeloma Center Workshops, and Regional Community Workshops; accompanied support group leaders to the 2013 Annual Meeting of the American Society of Hematology (ASH); and addressed the IMF’s 2014 Support Group Leaders Summit. NLB members contributed to IMF publications and spoke on monthly teleconferences with support groups. Additionally, NLB members led three teleconferences in the IMF’s popular Living Well with Myeloma series, which is open to the entire myeloma community.

During the 2014 fiscal year, the NLB published a series of articles on the care of myeloma transplant patients in a supplement to the prestigious *Clinical Journal of Oncology Nursing*, entitled “Hematopoietic Stem Cell Transplantation: A Clinical Guide to Care of the Multiple Myeloma Patient.” NLB members also published an article in the Journal of the Advanced Practitioner in Oncology, “Innovative Agents in Multiple Myeloma,” which provides an overview of new targeted myeloma therapies that have shown activity in patients with relapsed and/or refractory myeloma.

At the 2014 Oncology Nursing Society Annual Congress in Anaheim, California, the NLB hosted a satellite symposium during which NLB members discussed best practices, cutting-edge research, and their own personal experiences with myeloma patients in an exciting and informative presentation. This event, which was attended by more than 625 nursing professionals, exemplified the NLB’s exceptional work to bring expert myeloma advice to nurses in all communities.

### IMF Nurse Leadership Board Members

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

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

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

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

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

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

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

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

**Teresa Miceli, RN, BSN, OCN**  
Mayo Clinic – Rochester  
Rochester, MN

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

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

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

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

#### Associate NLB Members

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

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

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

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

# SUPPORT

The International Myeloma Foundation (IMF) remains dedicated to ensuring the support of those living with multiple myeloma. The IMF is a leader in myeloma patient support, offering services designed to provide patients and their loved ones with local and global support networks and easily accessible, up-to-date information. The IMF provides support to patients and caregivers through its website, a toll-free InfoLine, its social media outreach, and through its wide-ranging network of community support groups.

## myeloma.org

The IMF offers patients and caregivers multilingual access to all current myeloma research (IMF-funded research and otherwise), the latest community developments, and linkage to support services and advocacy forums. From October 2013 through September 2014, 465,000 visitors went to myeloma.org, tallying nearly 1.5 million page views. IMF-produced videos and presentations received 105,000 views. During this time period, the IMF's website also received 150,000 views from mobile devices. The IMF website is a leading resource for myeloma-related content and the most complete source of answers to the many questions asked by those newly diagnosed.

## Social Media



The IMF has worked in recent years, and especially in 2014, to expand its support to those living with or affected by multiple myeloma through social media. The IMF now has a growing presence on both Facebook and Twitter, with more than 5,300 "likes" and 3,100 followers, respectively. The IMF is using social media tools to increase visibility and awareness of myeloma and to support those living with or affected by myeloma.

## Toll-Free InfoLine

The IMF's toll-free InfoLine provides life-saving myeloma treatment and management support from highly trained specialists. As new treatment options are gaining attention and use in multiple myeloma, answering questions about myeloma, its treatment, drug side effects, clinical trials might be an option, and other health concerns. The specialists also assist on and where to find local support, is more important than ever. The toll-free InfoLine has been an incredible resource to patients, families, and caregivers in 2014. From October 2013 through September 2014, InfoLine responders supported 4,800 callers and answered more than 3,200 emails.



## Support Groups

Through a global community of assisted support groups, the IMF seeks to ensure that patients and families have local access to support and education.

The IMF currently supports more than 245 support groups worldwide. In the 2014 fiscal year, the IMF's team of support group directors made 184 in-person visits to local support group meetings, IMF Patient & Family Seminars, and Regional Community Workshops. Support group directors visited several groups many times throughout the year to foster sustainability and support new leadership.

From October 2013 through September 2014, 12 new support groups were formed.



**Jeff and Carolyn Gale**  
Woodland, California

Myeloma patient Richard Pleau used to have phone sessions with the International Myeloma Foundation (IMF) to help him better understand his myeloma diagnosis and what treatments were available to him. He understood the importance of getting as much information as possible. So seven years ago, when his childhood friend Jeff Gale was also diagnosed with myeloma, he passed on his wisdom and the IMF's information to Jeff and his wife, Carolyn.

"We didn't really know too much about myeloma," Carolyn said. "We called the IMF, and they sent a packet of information."

Jeff and Carolyn work with two great myeloma doctors, but over the years have come to rely on the IMF's InfoLine as a source of detailed information and support.

"They're so positive and encouraging when you're low," Carolyn said. "They know what they're talking about! They're up on everything, and this way of communicating is personal, so you feel more connected. You feel like somebody is really listening."

Jeff has "gone through the gamut of available agents" for his myeloma; he has had a stem cell transplant and attempted a clinical trial. He has never been in complete remission or off treatment, and this has kept him and Carolyn coming back to the InfoLine often.

Carolyn and Jeff credit IMF Medical Editor and InfoLine Specialist Debbie Birns and the InfoLine for "always going the extra mile" to answer questions that range from specifics about treatment options, to getting layman's explanations for the scientific sides of myeloma.

***"It's important to have all of the information available to you. It's great to have a place to go to just find out more about the disease. It gives you more hope, and we just appreciate that so much."***

— Carolyn Gale



**Yelak Biru**  
Dallas, Texas

Receiving an unexpected myeloma diagnosis at the age of 25, Yelak Biru, a graduate student worried about his future in school, became a patient worried about his future in general. That was 1995, when a myeloma diagnosis and its survival rates looked far different than they do today.

Thanks to his sister-in-law, Biru found the IMF and the North Texas Myeloma Support Group. He walked into his first meeting in 1996 and never looked back. Biru went from an attendee, to a member in a supportive role, to the leader of the group in 2010.

"I felt like I belonged. I became addicted to support group meetings," he said.

Thanks to Yelak, the North Texas Myeloma Support Group recently celebrated its 18th year and boasts more than 250 members.

He is grateful for the IMF's support along the way. The annual IMF Support Group Leaders Summit has provided him with encouragement, inspiration, and practical tips for running the North Texas Myeloma Support Group.

"The IMF has taught me to know my options—to be on the Board of Directors of my treatment team. It gave me the informational, technical, and human resources to continually hone my myeloma knowledge," Yelak said.

Yelak has also traveled with the IMF to medical meetings, such as the American Society of Hematology (ASH) annual meeting, having become a valuable member of the IMF's patient blogger team.

*"My focus is on helping patients integrate the myeloma into their lives – living with myeloma. I want to make sure I can provide hope for people who still want to work and have a life with myeloma, like I have been able to do."*

During the 2014 fiscal year, the IMF held quarterly teleconferences specifically for support group leaders and 10 calls for Nurse Leadership Board (NLB) members to speak to support groups. More than 350 support group members participated in the calls with NLB members.

The IMF offers unequalled website creation and hosting for local support groups. The IMF has created or updated 23 local support group websites and supports an additional 28 local websites.

The IMF provided a unique opportunity for 12 support group leaders to attend the American Society of Hematology (ASH) annual meeting in New Orleans, Louisiana in December 2013. During the meeting, the support group leaders from across the US attended presentations on myeloma research, the IMF's educational events, and more. They shared their ASH experiences through blogs, Twitter, and Facebook, and with their local communities. IMF support group leaders were among the top social media influencers at ASH 2013 in rankings compiled by a social media metrics company.

Through the IMF Ambassador Program, support group members attended the 2014 Patient & Family Seminars, creating a welcoming atmosphere and raising awareness for the local support groups.

The 15th annual IMF Support Group Leaders Summit took place in July 2014 in Dallas, Texas. A total of 89 support group leaders, representing 61 groups, attended the Summit. This was the first Summit for 27 of the leaders. The 61 groups represented at the Summit serve more than 3,800 support group members, extending the Summit's reach to thousands of myeloma patients and family members.

The 2014 Summit was packed with sessions offering the latest news about myeloma treatments, a panel discussion on clinical trials, a workshop exploring the best practices for running a support group, and updates from IMF President Susie Novis and IMF Chairman Dr. Brian Durie on the exciting progress of the IMF's Black Swan Research Initiative®. The 15th annual Summit also featured a new tai chi exercise program. Leaders were excited to share with their support groups this ancient Chinese tradition thought to reduce stress and improve overall wellbeing. The Summit also included a popular technology session that covered IMF-developed mobile apps the Myeloma Post®, which serves as a mobile gateway to educational, research, support, and advocacy programs and information found on myeloma.org, and the Support Group Leaders Toolkit app, which was developed specifically for support group leaders and offers sample meeting agendas, videos, and slide presentations that can be used during meetings.





# ADVOCACY

The International Myeloma Foundation (IMF) advocates on behalf of patients affected by multiple myeloma. We advocate to insure an increase in accessibility to high-quality diagnostics and treatments, for funding of myeloma-related research and to end insurance coverage disparities for treatment. The IMF works with the entire myeloma community in these efforts and continues to expand its commitment to empower patients, families, and friends. In 2014, the IMF strengthened a network of international advocates to address global advocacy issues; and in the US made headway on legislation to increase myeloma patients' accessibility to oral anticancer medication. This was accomplished through both federal- and state-level legislation, and increased legislators' awareness of myeloma, while furthering the national dialogue on myeloma.

## International Advocacy Efforts

### Global Myeloma Alliance

In 2014, the Global Myeloma Alliance (GMA), hosted two summits for this first global myeloma advocacy coalition formed by the IMF in 2013. The GMA brings together advocacy leaders in myeloma and blood cancer to mobilize the myeloma community to improve the lives of patients around the world. GMA is a patient-driven collaboration of organizations and individuals active in the field of myeloma. GMA members come together to share best practices, elevate global awareness of myeloma, and improve patient outcomes through earlier diagnosis. In addition GMA focuses on better access to treatment, and advance innovation in blood cancer through clinical trial engagement. The first GMA Summit of the fiscal year was held in New Orleans, Louisiana in December 2013 and welcomed advocates representing organizations from 10 countries.



The second GMA Summit took place in June 2014 in Milan, Italy. In attendance were 30 advocates from 17 regions: Asia Pacific, Austria, Canada, Croatia, Czech Republic, Denmark, France, Hungary, Italy, Korea, Portugal, Romania, Slovakia, Sweden, Turkey, and the US, as well as Myeloma Patients Europe (MPE). Participants shared best practices and the GMA Director presented a three-year strategic plan. The attendees reviewed and revised the common mission and goals, and identified GMA's activities for the next year, which included capacity building and sharing best practices.

### Advocacy in South Korea

In October 2013, IMF representatives attended the annual multiple myeloma seminar in Seoul, South Korea hosted by the Korean Blood Cancer Association (KBCA) and the Korean Multiple Myeloma Working Party, a division of the Korean Society of Hematology. IMF speakers shared with an audience of more than 250 myeloma patients and family members, the IMF's history, mission, and wide range of programs in the areas of research, education, support, and advocacy. The importance of advocacy resonated with the attendees, who left inspired to advocate and educate others about myeloma, raise myeloma awareness, and tell their stories as patients to policymakers.

## US Advocacy Efforts at the Federal Level

### Patients Equal Access Coalition

The Patients Equal Access Coalition (PEAC), founded by the IMF in 2010, is a partnership that has grown to 29 organizations representing patients, healthcare professionals, care centers,



**Jenny and Bill Hack**  
Palm Coast, Florida

Jenny Hack has always had a special relationship with "MM." For years she collected M&M's memorabilia for fun, but in 2011 it became a lot more serious, as her life became about a different kind of MM: multiple myeloma.

When she was diagnosed, Jenny was told she had only a year to live. When she learned the pill treatment regimen her doctor prescribed would cost her almost \$9,000 a month, she was devastated.

"I didn't cry at the diagnosis," Jenny said. "But the day I talked to my insurance company, my husband came home and found me hysterical because we couldn't afford it."

Jenny got her insurance policy to cover most of her treatment cost, but the experience had already changed her. Jenny's research led her to the IMF's work on anticancer treatment access legislation.

"Through the IMF I found my voice," Jenny said.

Jenny began spreading the word about anticancer treatment access legislation at her local Jacksonville, Florida myeloma support group and other cancer support groups in her area.

She wrote letters to her Congressman, Ron DeSantis, asking for his support of the Cancer Drug Coverage Parity Act, a bill introduced in the House of Representatives that would require that insurance companies cover oral anticancer treatments on an equal basis with intravenous or injected anticancer treatments. Her efforts led to an in-person meeting with Rep. DeSantis and interviews with local radio stations to further spread awareness.

*"There are millions of people who have cancer, and it's not just myeloma patients who would benefit from this legislation. It's just a little thing that I can do, but maybe I can help others realize there is help out there."*

— Jenny Hack

# IMF Advocacy Action Center



The IMF's Advocacy Action Center is an online, centralized hub that shares government activity affecting the myeloma community and provides tools and training for myeloma patients, families, caregivers, and medical professionals to become a part of the process. In 2014, more than 10,000 advocates were subscribed to the IMF Myeloma Action Network, an email service that alerts members when a new government representative or legislative issue needs to be addressed by the myeloma community. Members of the Myeloma Action Network sent more than 2,040 emails to their state and federal legislators during this reporting period. [advocacy.myeloma.org](http://advocacy.myeloma.org)

## Patient Education and Resources

In 2014, the IMF hosted a Medicare 101 webinar, reaching more than 100 patients, caregivers, and family members. The webinar, featuring Dr. Gretchen Jacobson with the Kaiser Family Foundation, covered a range of topics including enrollment, the different parts of Medicare, and coverage options. Following the webinar, the IMF created a new Medicare Frequently Asked Questions resource for patients.

Following the Capitol Hill briefing on the link between myeloma and environmental toxins, the IMF created two guides to assist those who were exposed to the hazards at Ground Zero in the wake of the 9/11 terrorist attacks. The guides include information on filing claims with the World Trade Center Health Program and the September 11th Victim Compensation Fund

and industry, dedicated to the rights and care of cancer patients. During the 2014 fiscal year, this collaboration, which aims to ensure equal access to approved anticancer regimens nationally, supported introduction of the Cancer Treatment Parity Act (S. 1879) in the Senate. Many patients have unmanageable out-of-pocket expenses for prescribed oral anticancer medication; S. 1879 and companion House bill H.R. 1801 will ensure patients have equal and appropriate access to all cancer treatments (both oral and intravenous), by equalizing the patient's out-of-pocket cost. PEAC identified two Senate sponsors, Senator Al Franken (MN) and Senator Mark Kirk (IL), who introduced S. 1879. Prior to its introduction, the IMF led an effort to analyze the Senate bill, researched and drafted several substantive changes, and facilitated a process to reach consensus on each proposed change among PEAC coalition members. In 2014, PEAC also increased support around the Cancer Drug Coverage Parity Act (H.R. 1801) in the House, securing 29 new bipartisan cosponsors for a total of 90 cosponsors for the bill. PEAC held a government relations lobby day in 2014. The IMF and volunteers from seven other PEAC member organizations held 17 meetings with representatives and senators to encourage support of our efforts in improving insurance coverage for oral anticancer medication.

## Capitol Hill Briefing

On September 10, 2014, the IMF held a briefing on Capitol Hill to discuss research on links between exposure to environmental hazards and multiple myeloma. Research indicated that myeloma is developed at higher rates in certain populations, including first responders at the World Trade Center site, farmers, and others with jobs that expose them to certain chemicals. Meghan Buzby, IMF Senior Director of Advocacy, along with myeloma patients, spoke to the attendees, expert physicians, and researchers. The audience of Congressional representatives and their staff members left the briefing with an understanding of multiple myeloma, opportunities for further research, potential environmental risk factors for myeloma, and efforts among patient advocates, industry, researchers, and policy makers to reduce exposure to environmental toxins associated with myeloma.

## US Advocacy Efforts at the State Level

### State Patients Equal Access Coalition

The IMF formed the State Patients Equal Access Coalition (SPEAC) in 2012 to work collaboratively at the state level to ensure that cancer patients have appropriate access to a broad range of approved and medically accepted anticancer regimens. SPEAC includes 25 organizations representing patients, healthcare professionals, and cancer care centers. SPEAC has worked to ensure the passage of oral anticancer treatment legislation at the state level. As of 2014, 34 states plus the District of Columbia have passed laws providing access to all forms of treatment for patients across the US.



### State Legislation

Access to anticancer treatment legislation has been introduced in many states. IMF advocates turned out to support state bills by sharing stories of how disparities in treatment access affected their lives. In 2014, seven states passed laws ensuring equal access to approved anticancer regimens. These states include Maine, Missouri, Wisconsin, Kentucky, Georgia, Arizona, and Ohio. The IMF played a key role in gaining support for the Kentucky bill, working with Senator Tom Buford to introduce the bill, leading a state-based coalition, hosting a patient lobby day, and generating grassroots support for bill passage. Additionally, IMF advocate Toni O'Neil testified in support of the bill to the Kentucky Senate Banking and Insurance Committee. These efforts culminated in the Kentucky bill being signed into law by Governor Steve Beshear in March 2014.



## Myeloma Awareness Month

The IMF observed Myeloma Awareness Month in March 2014 with many activities and initiatives that increased awareness of the disease. The IMF's work with local support groups and IMF members resulted in 72 towns and cities and 11 states issuing proclamations that March was Myeloma Awareness Month. The IMF launched March as Myeloma Awareness Month in 2009.

For the first time ever, the IMF secured a Congressional Resolution introduced by Congressman Spencer Bachus (AL-6) and Congressman Charles Rangel (NY-13) designating March 2014 as National Multiple Myeloma Awareness Month. The resolution, H. Res. 528, was sponsored by Representatives Brian Higgins (NY-26), Mike Honda (CA-17), Hank Johnson (GA-4), Shelley Moore Capito (WV-2), Eleanor Holmes Norton (DC-At Large), Tom Rice (SC-7), Alcee Hastings (FL-20), Danny Davis (IL-7), and Bradley Byrne (AL-1).

The IMF kicked off Myeloma Awareness Month with a Patient & Family Seminar held in Boca Raton, Florida at the beginning of March and hosted two Regional Community Workshops during the month. The IMF also held a Living Well with Myeloma teleconference, which reached more than 2,300 listeners, issued press releases, and used its social media tools to encourage the spread of awareness, posting daily myeloma facts on Twitter and Facebook.

New in 2014, the IMF established a dedicated Myeloma Awareness Month website, [mam.myloma.org](http://mam.myloma.org). On the Myeloma Awareness Month website, more than 80 patients and family members responded to the IMF's "Share Your Story" campaign by submitting inspiring stories of their own myeloma journeys.

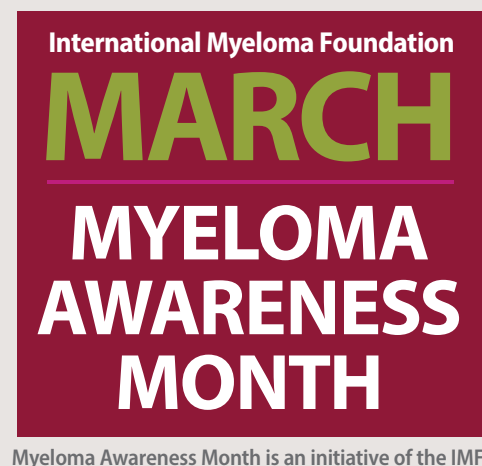
The IMF provided support group members with the tools to reach out to their local news media, resulting in more than 50 reports in newspapers, on the radio, and on television from Vermont to California to Jamaica. Local support groups also spread myeloma awareness by distributing flyers, buttons, and information cards in their communities.

## Myeloma ACTION Team

In 2013, the IMF formed the Myeloma ACTION Team to unite all of our advocates to build a community to foster education, action, and empowerment. In 2014, the ACTION Team continued to grow. This team works together to strengthen the support for federal legislation on anticancer treatment access, build strong grassroots networks in every state, and raise awareness of myeloma across the country. The ACTION Team organizes in-district meetings with federal and state legislators and raises the visibility of issues faced by multiple myeloma patients in the US. The ACTION Team speaks to the IMF on monthly teleconferences, consists of 47 advocates who made seven in-district visits and sent 178 messages to legislators in fiscal year 2014.

## Veterans Against Myeloma

The IMF has long been a resource for information about myeloma for veterans. In November 2013, the IMF went a step further and launched its Veterans Against Myeloma (VAM) website. To launch this initiative, the IMF partnered with Jerry Walton, a 33-year Navy veteran and myeloma patient who founded the Southeastern Virginia Multiple Myeloma Support Group. The VAM website provides relevant information about myeloma and causes that may be specific to veterans, and sends email alerts to notify VAM readers about breaking news and articles of interest. The VAM site also directs veterans to resources from the Veterans Administration and other service organizations. Importantly, the VAM website provides veterans with information and resources to become advocates for legislation that would support veterans with myeloma.





**Kristi Willette**  
Irvine, California

When veteran Chick Willette was diagnosed with myeloma in November 1999, he and his wife Kristi consulted with Dr. Louis Vandermolen of Hoag Hospital in Newport Beach, who recommended they also meet with International Myeloma Foundation (IMF) Chairman Dr. Brian Durie for a deeper assessment of his disease. The two doctors worked together to develop a treatment plan for Chick that allowed him to live for 13 years, but the relationship between the Willettes and the IMF has expanded beyond myeloma treatment and care.

"We believed we had found the very best and most sophisticated treatment team anywhere, and we turned out to be right," Kristi said of the IMF and Dr. Durie.

Chick passed away in August 2012, providing for a foundation in his trust. Inspired by his dignity, grace, and great fight—as well as the "genius and talent" of the medical professionals they had gotten to know over the years—the Willette Charitable Foundation was born. Established in August 2013, one year after Chick passed away, the Willette Charitable Foundation's first donation to the IMF was in December 2013.

"Our mission statement is to promote and support cancer research, treatment, care, and financial assistance," said Kristi.

Because of the "incredible partnership" she developed with Dr. Durie and the IMF during Chick's treatment, Kristi keeps the Willette Foundation focused on supporting the endeavors of the IMF and specifically, the Black Swan Research Initiative®.

*"If we can help find a cure for myeloma, we will help many other heroes, like Chick, who served their country with distinction. I hope our dedication to this cause will inspire others who might be looking for a way to give back to the many who give so much."*

# DEVELOPMENT

Support for the International Myeloma Foundation comes from many sources, including large corporations, pharmaceutical partners, private donors, bequests, and fundraising events. However large or small the gift, each contribution makes it possible for the IMF to continue offering and improving upon existing programs, while exploring new ways to serve the myeloma community with unequaled information and support.

The IMF expanded its reach during the last fiscal year with new programs made possible through the generosity of its donor base.

During the 2014 fiscal year, the IMF received \$13.8 million in support of vital programs and services.

## Major Gifts & Planned Giving

Major gifts of \$5,000 and above make a powerful impact on the IMF's fiscal stability. During the 2014 fiscal year, the IMF received 53 gifts totaling \$868,613. Major donors are a small but dedicated group of supporters whose contributions help sustain the quality and longevity of critical programs and research.

### Planned Giving

The IMF continues to support programs that help extend lives of myeloma patients, but respects that for many of our members estate planning is a rite of passage that must be acknowledged.

Members who support the IMF through the **Brian D. Novis Legacy Society**, the IMF's planned giving program, make bequest provisions in their will or revocable trust, or name the IMF as a beneficiary of qualified retirement plan assets (IRA or 401(k)) or life insurance policy. All that is required to be recognized as a member of the Legacy Society is written confirmation of a planned gift. There is no minimum commitment necessary.

### Sustained Giving

Members of the IMF's sustained giving program, The Hope Society, commit to a monthly or quarterly gift in support of the IMF's programs and services. With recurring contributions ranging from \$5 to \$500, 150 Hope Society members contributed a total of \$47,858 during the 2014 fiscal year. The IMF thanks members of The Hope Society for their continued commitment to sustaining the needs of the myeloma community.

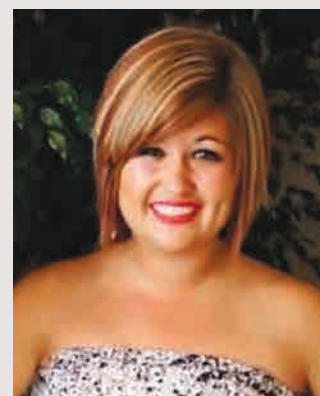


Cultivating the future by planting the seeds to sustain the IMF

## The Hope Society Honor Roll

Amy Adams	Carla Goode	Joyce and Hal Piel
Mary Ann and Jeffrey Allyn	Gail Goodwin	Selma Plascencia
Cathie Alonzo	Donna Wyatt and Daryl Graham	Gail Pollard
Janet Ames	Roberta Greenberg	Agatha Polowy
Bonita and James Anderson	Linda Lamb and Paul Griffin	Ellen Powell
Carol and Eric Ashihara	Diane and Robert Grosso	Joanne and William Powell
Laura Bates	Roslyn and Harold Grueskin	Dan Quattrochi
Eunice Becker	Carol Hornreich	Tina and Michael Rettig
David Bennett	Nicci Hubert	Dawn Rochester
Donald Bennett	Timothy Huss	Mary Rohleder
Marcy Bernstein	Roslyn and Larry Isakowitz	Cesar Romero
Dennis Bloom	Sally and Reggie Jardon	Gregory Rosasco
Anne and John Boehle	Larry Jeffries	Sara and Richard Rosene
Frances and James Bowles	Kathleen and David* Johnson	Charlie Roundtree
Jeannie Brady	Shirley Johnson	Heidi Rubinstein and Brian Kuchynskas
Kathy Brens	Debbie and Jerry Jordan	Doloures Ryan
Julia Brock	Jacqueline and Michael Katz	Susan and Ira Saltzman
Claudia and Philip Brown	Anita and Walter Kemper	Cynthia Schulze
Prudy and David Brown	Julia Kennedy	Barbara Scott
Teresa Brown	Elise Ketner	Marguerite and Daniel Scott
Patricia Vigilante and Robert Candela	Abdul Khatri	Janice Sejut
Catherine and John Capo	Roberta and Raymond Klein	Marie and Charles Shanley
Carleton Carroll	Judy and Henry Koepfle	Ed Sharp
Annette and Patrick Cavanagh	Leny and Ben Kolsteren	Nancy Shealy
Fred Charles	Ann Nora Kruger	Robert Singdahlsen
Cynthia and John Chmielewski	Rachel and Duane Lashbrook	Richard Skalitzy
Cynthia Clark	John Law*	Carole and David* Skelly
Anonymous	RoseMary and George Leek	Rachel Small
Carol and Phillip Collins	Jean and Mike LeTarte	Randall Smith
Volindah Costabell and Ron Stout	Kathleen and Charles Lewis	Diane Staves
Karen Countryman	Nancy and Don Lorenzen	Elizabeth and Frank Streff
Thomas Coyne	Peter Lundell	James Stuart
Maureen Cronin	Mary Jane Lundy	Nancy and Jay Style
Stephanie Davis	Elizabeth Manczak	Henry Thomas
Linda and Charles De Long	Helene and Alan Marks	Paula Thompson
Brian Denyer	Stephen Marsh	Doris and James Thurau
Margaret Diener	Mary Anne and Chuck Martz	Nancy and William Tidwell
Niall Doherty	Vicki and Dwight Mays	Ray Vines
Rene Dvalery and James Baker	Jodi McClure	Karen Waddell
Linda and Mark Edwards	Paula Merrigan	Patricia and James Wagner
Joseph Ellis	Barbara Montalbano	Linda Wakefield
Kathleen and Douglas Farrell	Laura and Charles Mooney	Marcia and Peter Webber
Virginia Field	Alanna Morgan	Charlotte and Joseph Werkmeister
Kyoko Kashiwagi and Ronald Fischer	Karen and Edward Necela	Becky and Charles Whitehead
Kim and Doug Foreman	Edward Novack	Maryellen Wilkinson
Norma Jean Galiher	Susie Novis and Dr. Brian Durie	Bernadette and Dave Wolf
Dean Gallea	Paul O'Dea	Beth and Woodring Wright
Susan and Daniel Gannon	Patricia and Jim Omel	Sandy Wytroval
Irene and Laurence Gauthier	Elizabeth and James Osterburg	Natalie Young
Marie and Carl Gilliam	Peggy Pankey	Sandy Zajdel
Anil Godbole	Jack Pascale	Claire Zupancic

\*deceased



**Janine Granit**  
Toms River, New Jersey

For Janine Granit, the woman behind the annual member fundraiser "A Day at the Races," philanthropy has always been important, but becoming a part of the IMF community and raising money for myeloma research holds a unique place in her heart.

"My relationship with myeloma all comes back to a special man, Jeffrey 'Jeff-O' Stafford," Janine said.

"I forged a deep friendship with Jeff-O's youngest daughter, Courtney, in college, and her family has become my family. When Jeff-O lost his long battle with myeloma in early 2013, I could think of no better way to support a family that had become so much to me than to support the IMF in Jeff-O's honor."

"A Day at the Races" was launched in 2013. In 2014 the event, held at Monmouth Park in Oceanport, New Jersey, raised approximately \$17,000 and included a new partnership with Monmouth Cardiology, an opportunity made possible after the IMF connected Janine with Dr. Mark Rosenbloom and office manager Caroline Brown.

***"Our August 2014 event exceeded any predictions I could have made about its success – most importantly, in funds and awareness raised for myeloma."***

Proceeds from "A Day at the Races" are building toward funding an IMF Brian D. Novis Research Grant. Proceeds from member events held over several years can be combined to fund these grants that the IMF awards annually to doctors and researchers conducting promising work in myeloma. IMF member fundraisers have the ability to directly impact major advances in myeloma.

***"It's important to me to make the community aware of myeloma and give the disease the attention and research funding it deserves. Supporting research is important, and vital to the road for a cure!"***



## IMF's 7th Annual Comedy Celebration: A Night of Stars, Laughter, and Compassion

The International Myeloma Foundation's 7th Annual Comedy Celebration benefiting the Peter Boyle Research Fund and supporting the Black Swan Research Initiative® drew nearly 1,100 guests to the Wilshire Ebell Theatre in Los Angeles, California on Saturday, November 9, 2013.

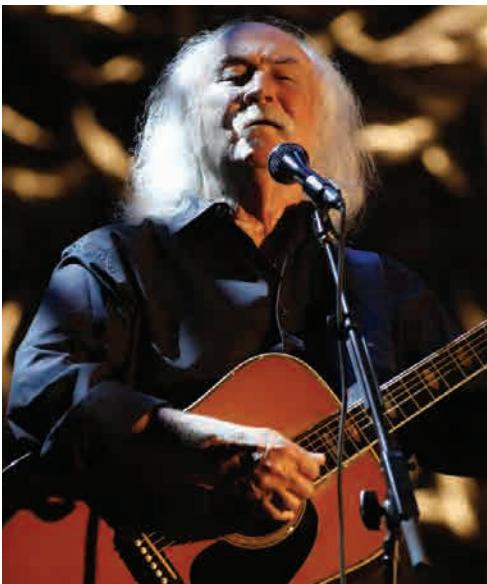
The first Annual Comedy Celebration was held in 2007, thanks to fellow Board member and event Chair Loraine Boyle, wife of the late actor Peter Boyle. Loraine had a wonderful idea, and she reached out to IMF co-founders Susie Novis and Dr. Brian Durie. She expressed a desire to make a difference in the lives of people with multiple myeloma and find a cure. What better way to raise money for research than through laughter!

Loraine established the Peter Boyle Research Fund, calling upon her and Peter's friends to join her in raising awareness and money to find a cure.

During the 2014 fiscal year, the 7th Annual Comedy Celebration raised \$539,639; bringing the total funds raised for the Peter Boyle Research Fund to \$4.6 million.

Peter Boyle, who passed away in 2006 after a four-year battle with myeloma, was remembered with poignant anecdotes, which were followed by an evening of stellar comedic performances. Host Ray Romano, whose support over the years has played an integral part in the success of the event, opened the show and was joined onstage by his *Everybody Loves Raymond* costars, Patricia Heaton, Monica Horan, and the show's creator Phil Rosenthal, who reminisced about working with Peter Boyle.

Also appearing onstage that night were comedians Deon Cole, Jackie Hoffman, Andy Kindler, Larry Miller, Bruce Vilanch, and Justin Willman, who had guests laughing for two hours straight. Rock icon David Crosby closed the show with a heartfelt performance.



### 7<sup>th</sup> Annual Comedy Celebration

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



## Member Fundraisers

Myeloma patients and family members often contact the IMF wishing for opportunities to get involved in supporting myeloma research and education programs. People who have hosted member fundraisers in their communities have said they derive strength and empowerment from participating in the fight against myeloma.

During the last fiscal year, IMF members held 43 events, raising more than \$500,000. Many of the recurring events will go on to fund Brian D. Novis Research Grants in the coming year – a testament to the efforts of a regular group of people who make an extraordinary impact on the future of myeloma research.

The IMF is grateful to members who have held sporting events, bake sales, craft sales, dinner parties, and more – all in the name of supporting IMF programs, services, and research initiatives.

## Member Events

**October 1, 2013 – September 30, 2014**

### BENEFACTORS CIRCLE

**\$25,000 and up**

#### Miracles for Myeloma

Ron and Sheree Pask and Gina Klemm  
Clark, NJ

#### Miles for Myeloma 5K

Philadelphia Multiple Myeloma  
Networking Group  
Philadelphia, PA

#### Coach Rob's Benefit Bash

Rob Bradford  
Apopka, FL

#### Carolyn Czerkies

Charity Golf Outing  
Czerkies Family  
Naperville, IL

#### ChekFest Golf Tournament

Scott Kowalczyk  
Grand Rapids, MI

### FOUNDERS CIRCLE

**\$10,000 – \$24,999**

#### A Day at the Races

Janine Granit  
Oceanport, NJ

#### J.C. Golf Tournament

David Johnson and Bob Zins  
St. Cloud, MN

#### Music Against Myeloma

Slava Rubin  
New York, NY

#### Capt. Turner Ocean Swim

Doug and Kate Farrell  
Longport, NJ

#### Wayne Hamby Memorial Golf Tournament

Gail and Andrew Bertram  
Bluffton, SC

#### Bridge Blasts Myeloma

Ann Girod and Carol Klein  
Potomac, MD

### PARTNERS CIRCLE

**\$5,000 – \$9,999**

#### Modern Art Against Myeloma

Jon Bianco  
Philadelphia, PA

#### Denise & Tom's

#### Wedding Fundraiser

Denise Renee Arevalo and Thomas A. Tormey  
Los Angeles, CA

#### A Visit to Virginia's

#### Wine Country

Nancy Raible  
Richmond, VA

### ASSOCIATES CIRCLE

**\$1,000 – \$4,999**

#### Red House Carnival

Julianne Stafford  
Somerville, MA

#### Scare Away Cancer

Jim Miller and Amanda Miller  
Rancho Mirage, CA

#### Jack's Annual Texas Hold 'em

Jack Aiello  
San Jose, CA

#### Bodiford Fundraisers

Kelly Bodiford  
Winter Springs, FL

#### Trooper Benson Klein

Research Fund  
Benson Klein  
Bethesda, MD

#### Kincaid Bike Ride

Doug Kincaid  
Red Rock Canyon, NV

#### Meredeth Fiacco

Memorial Golf Tournament  
Melanie Nichols and Suzanne Fiacco  
Potsdam, NY

#### Flying Pig Marathon

Ellen and Brian Grammel  
Fairfield, CT

### Heritage Singers Fundraiser

Charlie Eddins  
Jacksonville, FL

#### Dance for a Cure

Frank Tramontano  
Long Beach, NY

#### Margaret R. Cole

#### Memorial Fund

Roger Cole  
Upper Montclair, NJ

#### Gayla's Celebration

Gayla Elsner  
Traverse City, MI

#### Andrew Sninsky's Bicycle

#### Mojave and Beyond

Andy Sninsky  
All over the United States

#### Dairy Queen Fundraiser

Ruth Schimmel  
Granville, MI

#### BusyBody Exercise /

#### Dance-A-Thon

Meryl Coughlin  
Boca Raton, FL

#### Haynes Marathon

Jack Haynes  
Santa Rosa, CA

### FRIENDS CIRCLE

**\$500 – \$999**

#### Wine Tasting

#### For Multiple Myeloma

Ilana Kenville  
Phoenix, AZ

#### Colon Kiwanis Key Club

#### Fundraiser

Diann Colon  
Tracy, CA

#### Stolper Family

#### Tee Shirt Fundraiser

Matt Stolper and Gary Stolper  
Briarcliff Manor, NY



A Visit to Virginia's  
Wine Country



Denise & Tom's  
Wedding Fundraiser



Red Rock Canyon Bike Ride Fundraiser



Dance-a-thon Fundraiser



"I am Stolperstrong" T-Shirt Fundraiser



Miles for Myeloma 5K Run/Walk



Gayla's Celebration – A Five-Year Celebration



# SUMMARY FINANCIAL INFORMATION

## INTERNATIONAL MYELOMA FOUNDATION Statement of Financial Position September 30, 2014

### Assets

#### CURRENT ASSETS

Cash and cash equivalents	\$ 2,328,528
Contributions and other receivables	8,259,372
Investments, at fair value	2,478,665
Prepaid expenses	671,203

<b>Total Current Assets</b>	<b>\$ 13,737,768</b>
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#### OTHER ASSETS

Property and equipment, net	404,657
Gift annuity investments, restricted cash	9,517
Intangible assets, net	22,385

<b>Total Other Assets</b>	<b>\$ 436,559</b>
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<b>TOTAL ASSETS</b>	<b>\$ 14,174,327</b>
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### Liabilities and Net Assets

#### CURRENT LIABILITIES

Accounts payable and accrued expenses	\$ 472,458
Deferred and unrestricted educational grants	12,025,110

<b>Total Current Liabilities</b>	<b>\$ 12,497,568</b>
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GIFT ANNUITY OBLIGATION	5,795
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<b>Total Liabilities</b>	<b>\$ 12,503,363</b>
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#### NET ASSETS

Unrestricted	1,667,242
Temporarily restricted	3,722

<b>Total Net Assets</b>	<b>\$ 1,670,964</b>
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<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b>\$ 14,174,327</b>
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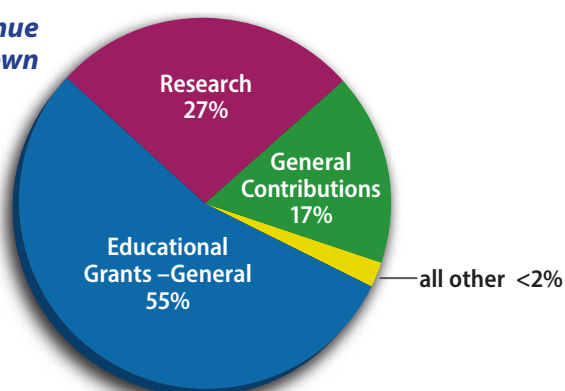
For a copy of our complete audited financial statements, please contact the IMF office.

# INTERNATIONAL MYELOMA FOUNDATION

## Statement of Activities for the Year Ended September 30, 2014

	UNRESTRICTED	TEMPORARILY RESTRICTED	TOTAL
<b>Revenues and Support</b>			
Educational grants	\$ 6,056,247	\$ 2,453,746	\$ 8,509,993
General contributions	1,212,479	251,711	1,464,190
Fundraising programs	289,546	15,745	305,291
Donated services	2,870	-	2,870
Seminar fees and support group income	99,841	-	99,841
Fundraising events, net of direct benefit to donors of \$321,605	331,875	293,691	625,566
Change in split-interest obligation	-	123	123
Investment income	26,921	2	26,923
	8,019,779	3,015,018	11,034,797
Released from restriction	3,014,892	(3,014,892)	-
<b>Total Revenue and Support</b>	<b>\$ 11,034,671</b>	<b>\$ 126</b>	<b>\$ 11,034,797</b>
<b>Expenses</b>			
Program services	9,540,147	-	9,540,147
General supporting services	337,469	-	337,469
Fundraising	637,275	-	637,275
<b>Total Expenses</b>	<b>\$ 10,514,891</b>	<b>-</b>	<b>\$ 10,514,891</b>
<b>Change in Net Assets</b>	<b>519,780</b>	<b>126</b>	<b>519,906</b>
<b>NET ASSETS – Beginning of year</b>	<b>1,147,462</b>	<b>3,596</b>	<b>1,151,058</b>
<b>NET ASSETS – End of year</b>	<b>\$ 1,667,242</b>	<b>\$ 3,722</b>	<b>\$ 1,670,964</b>

**Revenue  
Breakdown**



For a copy of our complete audited financial statements, please contact the IMF office.

# INTERNATIONAL MYELOMA FOUNDATION

## Statement of Functional Expenses

### for the Year Ended

### September 30, 2014

#### Breakdown of Expenses by Program

PROGRAM	TOTAL EXPENSES
Research	\$ 3,432,780
Education & Awareness	1,243,119
International	761,120
Patient & Family Seminars	709,988
Support Groups	672,295
Clinical Meetings	569,067
Nurse	514,389
Advocacy	504,010
InfoLine	332,516
Website	327,938
Myeloma Today	314,186
Information Mailings	158,739

#### Total Program Expenses

\$ 9,540,147

General supporting expenses

337,469

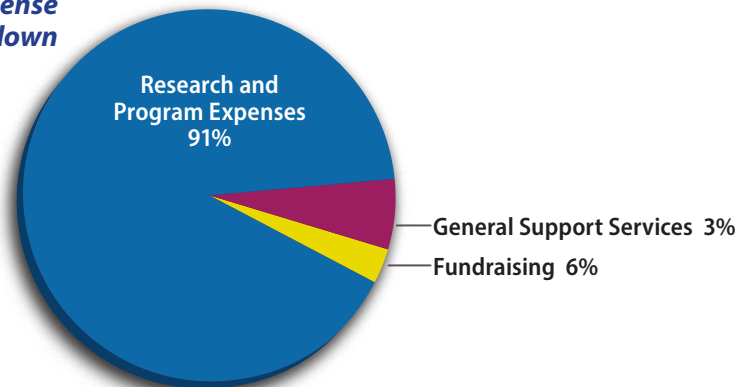
Fundraising expenses

637,275

#### Total Expenses

\$ 10,514,891

#### Expense Breakdown



For a copy of our complete audited financial statements, please contact the IMF office.

# HONOR ROLL

## Chairmans Circle

\$100,000 and above

The Binding Site, Ltd.  
Bristol-Myers Squibb Company  
Celgene Corporation  
Clare Rose Foundation, Inc.  
Eisenhower Medical Center  
Genentech, Inc.  
Janssen Pharmaceutica  
Estate of Terry L. Miller\*  
Novartis Pharmaceuticals  
Dorothy and John O'Dwyer  
Onyx Pharmaceuticals, Inc.  
Sanofi  
Millennium: The Takeda Oncology Company

## Presidents Circle

\$50,000 – \$99,999

Astellas Pharma US INC  
Raymond Uzanus  
The V & L Marx Foundation /  
Jennifer and Bud Gruenberg

## Benefactors Circle

\$25,000 - \$49,999

Amgen  
Array Biopharma  
CBS Corporation  
Coach Rob's Benefit Bash, Inc. /  
Kimberly and Robert Bradford  
Daiichi Sankyo, Inc.  
Diplomat Specialty Pharmacy  
GlaxoSmithKline  
Jane Godin\*  
Estate of Peter J. Holloway  
Philadelphia Support Group  
Raymond James & Assoc. / Robert Ebersole  
Estate of Carol Rosen

## Founders Circle

\$10,000 – \$24,999

Amazon.com, Inc.  
Loraine Boyle  
Susie Novis and Dr. Brian Durie  
Fay J. Lindner Foundation  
Susan Flagg and Carlo Rocca Fund  
FirstGiving  
HBO Inc.

J.C. Invitational Golf Tournament /  
Beverly Lundorff  
Karyopharm Therapeutics  
Local Independent Charities of America (LICA)  
Alex Meneses  
Metzger Law Group  
Larry Miller  
NJ Multiple Myeloma Benefit LLC  
Oncopeptides AB  
Pharmacyclics, Inc.  
Rosenthal Family Foundation  
Carol and Paul Rothman  
The Elsie A. Doerrie Trust  
The John J. McDonnell  
Margaret T. O'Brien Foundation  
Walsh Street Foundation / Henry Belber  
Willette Charitable Foundation  
Worldwide Pants, Inc.  
Wyane Hamby Memorial Golf Tournament /  
Gail & Andrew Bertram and Vicky Hamby

## Partners Circle

\$5,000 – \$9,999

Susan and Frank Armo  
Jennet Walker and John Auerbacher  
Noeline and Henri Boshoff  
Breslow Foundation  
Nancy Bruno  
Charles Schwab  
Chek Fest  
Clifford and LaVonne Graese Foundation  
Gail-Ann and Joe Colaruotolo  
Allison and Brian Feltzin  
Joele Frank and Larry Klurfeld  
Cindy and James Gilbert  
Giving Generations Foundation  
Anne Hearst and Jay McInerney  
Walter Johansen  
Susan and Michael Katz  
Carol and Benson Klein  
The Lifeboat Foundation / Jeremy Hobbs  
Sherie and Leonard Marek  
Medtronic, Inc.  
Merrill Lynch  
Joy and Ronald Paul  
Jane Petitmermet  
Cindy and Leon Rittenberg, Jr.

The International Myeloma Foundation gratefully acknowledges the many people and organizations whose contributions have made it possible to provide the excellent, high-quality programs and services upon which our members have come to rely. Their generosity allows the IMF to:

- Conduct and support the innovative research that is the basis for the IMF's signature Black Swan Research Initiative®, which is bridging the gap from long-term remission to cure, while simultaneously advancing the next generation of researchers in the field.
- Empower patients, family members, physicians, and nurses to participate in advocating on behalf of cancer patients by urging federal and state legislators to stand behind critical healthcare policies that will improve the lives of cancer patients.
- Maintain a vast and comprehensive website that provides the latest updates about myeloma, through the 10 Steps to Better Care®, including initial treatment options, testing and clinical trials.
- Support the IMF's network of over 245 support groups through leadership training, educational materials, and assistance in securing guest speakers.
- Maintain the InfoLine to ensure that its coordinators have the tools they need to help patients, families, and friends make informed treatment options as to what's right for them.
- Expand successful educational programs to reach a wider audience; including the Regional Community Workshops, Myeloma Center Workshops and the 2-day Patient & Family Seminars.
- Continue to produce and regularly update our library of over 100 IMF publications that support patients, doctors, and nurses in making informed treatment choices.

*The IMF is dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure.*

**The IMF thanks our donors for allowing us the opportunity to serve you.**

### ***Honor Roll (continued)***

Nancy and Robert Schulman  
Louise J. Takata  
Estate of Janet M. Snow  
The Omer Foundation  
Judith and Gerald Webb  
Gennifer and Dr. David Yoshimaru

### **Associates Circle**

**\$1,000 – \$4,999**

The John A. Hartford Foundation  
Kevin and James Abernathy  
Rafat Abonour MD  
Fredric Adler  
Naz Afshar  
Nelleke and Jack Aiello  
Marry Ann and Jeffrey Allyn  
Alumnae Assoc. of the Hartford Hospital  
School of Nursing  
American Association of Oral and  
Maxillofacial Surgeons  
Pamela and Wayne Anderson  
Rene Auberjonois  
Martin Barrett  
Baumgardner Construction Co., Inc.  
Benanav Family Foundation  
Jeanne and Edwin Bernstein  
Gregg Bernstein  
John Bianco  
Biotechnology Industry Organization  
Dennis Bloom  
Richard Boisture  
Joanie Borbely  
Mitzi and Gerald Bozarth  
Kelly and Brett Braciak  
Marsha and John Brand  
Jean T. Brewer  
Nina and Marshall Brickman  
Tanya Bryja  
Mari and Ward Bukofsky  
Elizabeth and Monte Burgett  
Craig L. Carver  
Cascade Health Servies, LLC  
Charlotte and William Hinson  
Charitable Foundation /  
Carol and Craig Driver  
Nilene and Arnold Chase  
Dianna and John\* Chiles  
Cibolo Creek  
Cimarron Place Health and  
Rehabilitation Center  
Gary Clucas

CM3 Building Solutions, Inc.  
Elaine Cofell  
Judy and Neil Collier  
Community Foundation of New Jersey  
Pamela Calaoms Congdon  
Janice Corwin  
Barbara and James Coy  
Jon Cross  
Bonnie and Craig Czerkies  
Frances Daley  
James A. Darling  
Betsy and Paul Dawes  
Daniel Diaz  
DMS Production Services, Inc.  
Gordon Doble  
Francisco Doll  
Jane Drexler  
Debbie and John Dyer  
Marcia and Gary Eddy  
Douglas Edelen  
Edward H. Kaplan Revocable Trust  
Eric Edwards  
Jennifer and Ron Edwards  
Joseph Daniel Ellis  
Nilene Evans and Arnold Chase  
Pearl Fang-Sniegowski  
Kathleen and Douglas Farrell  
Cynthia G. Feltzin  
Fidelity Brokerage Services LLC  
Leslie K. Fields  
Kyoko Kashiwagi and Ronald C. Fischer  
Kim and Doug Foreman  
Barbara and Buddy Freitag  
Barbara Frenkel  
Susan C. Frunzi  
John Geiger  
Stephen Gendel  
General Electric Foundation /  
Amy and John Bartle  
Pamela Gibson  
Jeremy Gilbert  
Jo-Ann and Gary Gilbert  
Michele and Michael Ginsburg  
Give With Liberty  
Glenview State Bank  
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