

Improving Lives • Finding the Cure®



INTERNATIONAL MYELOMA FOUNDATION

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2013

Improving Lives • Finding the Cure®

2013



INTERNATIONAL
MYELOMA
FOUNDATION

2013 ANNUAL REPORT

Improving Lives • Finding the Cure®

INTERNATIONAL MYELOMA FOUNDATION



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



RESEARCH



EDUCATION



SUPPORT



ADVOCACY

2013 ANNUAL REPORT

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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 Oschin Comprehensive Cancer Institute

Dear Supporters of the International Myeloma Foundation,

This year the International Myeloma Foundation celebrated its 23rd anniversary – and to date has reached more than 350,000 members in 120 countries worldwide. We continue to improve the quality of life for myeloma patients and their families through research in effective diagnostics and treatments, advocacy in equality of patient access to treatment, education for patients and caregivers, and support to patients and families. This year, our commitment to the mission proved as fruitful as ever.

In June 2013, the IMF held its annual International Myeloma Working Group (IMWG) Summit in Stockholm. This summit was yet another opportunity to bring together leading researchers in the field of myeloma from around the globe, to discuss innovations, develop recommendations for management of the disease, and guide the direction of future research. You will find in this report further detail on the incredible research-driven publications produced throughout 2013 by the IMWG team, which inform patients and caregivers of therapeutic advances and treatment management.

Shortly after its annual meeting, in the summer of 2013, the IMWG reconvened the Master Class program. The Master Class is a one-to-two-week learning experience in which medical practitioners working in the field of myeloma share experiences in their work and listen to experts in myeloma research. The objective of the Master Class is to encourage knowledge of innovations in myeloma diagnostics, treatment, and management among healthcare providers. This educational program is an expanding initiative expected to have multiple programs globally to support providers in the testing and treatment of multiple myeloma.

Also this past year, the IMF completed phase one of the Black Swan Research Initiative® – a unique project to develop the first definitive cure for myeloma. Through this initiative, the IMF is developing sensitive diagnostic technologies to accurately measure minimal residual disease (MRD), new trials to enable us to select the most effective anti-MRD drug combinations, and new methods to perfectly time treatment in order to increase its effectiveness. The Black Swan Research Initiative takes its name from the discovery of black swans in 1697, before which it was assumed all swans were white. Similarly, we have created a paradigm shift by taking an entirely new approach to monitoring treatment efficacy to achieve a cure. Meetings of the Black Swan Research Initiative team occurred throughout 2013.

We are in the midst of an important era in myeloma research and treatment. We are seeing more and more patient-outcome improvements with novel drug agents, and increased access to care and support. We are finding ourselves closer and closer to a cure as our work progresses each year. Thanks to all of you who have helped the IMF. It is the support from all of you that makes possible our mission to support patients and families, and to drive us closer to curing myeloma.

Sincerely yours,

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

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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 23 years ago, I am able to say that a cure for multiple myeloma is within reach. In just two years, the Black Swan Research Initiative® has made tremendous strides in both developing a new, highly sensitive test to determine minimal residual disease and establishing trials that 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.

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 funding 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, 2012 to September 30, 2013, we continued to have a significant global reach. Thanks to continued funding support from our pharmaceutical partners, the IMF held the 2nd 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 14th annual Support Group Leaders Summit. More than 75 people attended, representing groups from across the US, along with two representatives from Canada and one from Australia! The weekend was spent learning about the latest advances in myeloma treatment and management, as well as learning from each other. There was even a session called "Tech Time" led by our IT department to help the leaders maximize the use of their iPads to enhance their reach to members.

Thanks to the efforts of our Advocacy team, oral anticancer drug parity bills have been passed in 29 states plus D.C. and 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). PEAC and SPEAC expanded to now include 30 and 26 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 organizations from 13 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, 2012-2013 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. We've opened the door to the cure – let's walk through it together!

Warm regards,

Susie Novis
President

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Judy Webb
Hotline Coordinator



Ola Landgren, MD, PhD
The National Cancer Institute
Bethesda, Maryland

Dr. Ola Landgren began his career as an attending physician and clinical researcher specializing in lymphoproliferative malignancies and related precursors at the Karolinska Institute in Stockholm, Sweden. While there, he first became aware of the work of the International Myeloma Foundation (IMF).

Then, in 2004, while working at the National Cancer Institute (NCI) as a visiting scientist, Dr. Landgren met IMF Chairman and Co-Founder Dr. Brian Durie. After attending the annual meeting of the International Myeloma Working Group (IMWG), Dr. Landgren became a member.

A clinician and Senior Investigator at the NCI Lymphoid Malignancies Branch, Dr. Landgren's research focuses on the treatment, causation, diagnostics, and prognostics, and natural history of multiple myeloma and its precursor, monoclonal gammopathy of undetermined significance (MGUS); and treatment-, host-, disease-, and immune-related factors in the pathway from precursor to full-blown malignancy, and their relation to outcome.

"The International Myeloma Working Group provides a network for collaboration, development of new ideas, and the opportunity to move larger questions forward," said Dr. Landgren.

Dr. Landgren, who serves as a member of the IMF's Black Swan Research Initiative® team, said he also appreciates the opportunities the IMF offers physicians to interact with patients through the organization's patient seminars.

"The International Myeloma Working Group provides an opportunity to develop the clinical field and to help patients by clarifying important details and by removing unnecessary obstacles in the literature, clinical, and regulatory arenas."

RESEARCH

Research is a top priority for the International Myeloma Foundation. In fiscal year 2013 the IMF announced the launch of the Black Swan Research Initiative®, an innovative and collaborative approach to finding a pathway to a cure for myeloma. In fiscal year 2013 the IMF continued to bring young investigators into the field through the Junior Research Grants program, and enhanced funding for more senior investigators as well. 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 the 2013 fiscal year, the Black Swan Research investigative team completed work on how to define and identify minimal residual disease (MRD) clinically, laying the groundwork for the standardization of MRD testing. The team focused on previous studies to glean new information about MRD and to examine responses to treatment that may point toward a cure. In addition, the team reviewed new myeloma drugs already in clinical trials, which could play important roles in achieving a cure.

In the last months of 2013, the Black Swan Research Initiative team planned two in-person meetings of its international members to review the status of next-generation myeloma tests that will enable researchers to more accurately assess MRD in patients. This new technology will be incorporated in multiple clinical trials moving forward in order to standardize and validate the approach, and may soon identify patients who have already been cured. This would pave the way for successfully replicating their particular portfolio of treatments.

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 170 of the world's leading myeloma researchers from 32 countries, the group publishes highly regarded consensus statements and guidelines for the management of myeloma.



In June 2013, the fourth annual IMF IMWG Summit was held in Stockholm, Sweden. There, 75 of the world's leading myeloma experts from 28 countries representing 51 institutions grappled with subjects of vital concern to the myeloma community:



frontline therapy, maintenance therapy, transplant, and complete remission (CR) assessment and minimal residual disease (MRD). (Also, see the sidebar on page 8)



Myeloma researchers and patients around the world were able to sample some of the findings and excitement generated at the IMWG



Summit through the magic of modern technology. Dr. Durie moderated the third in the IMWG Conference Series "Making Sense of Treatment," a live-streamed panel discussion that included Drs. Antonio Palumbo, Ola Landgren, and Joseph Mikhael. The topics covered on the webcast



(archived at <http://tinyurl.com/IMWG2013webcast>) ranged from frontline treatment options to maintenance, second primary malignancies to 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 three publications during the October 2012 – November 2013 reporting period:

Combining Fluorescent In Situ Hybridization (iFISH) data with ISS staging improves risk assessment in myeloma: an International Myeloma Working Group (IMWG) collaborative project.

Avet-Loiseau H, Morgan, G, et al. *Leukemia*. 2013 March; 27(3):711-7.

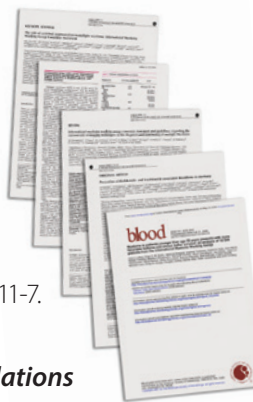
Plasma cell leukemia: consensus statement on diagnostic requirements, response criteria and treatment recommendations by the International Myeloma Working Group.

Fernández de Larrea, Carlos, Jatin Shah, Robert Orlowski, J. Blade et al. *Leukemia*. 2013 April; 27(4):780-91.

International Myeloma Working Group recommendations for the treatment of multiple myeloma-related bone disease.

Terpos E, Roodman GD, et al. *J Clin Oncol*. 2013 June 20;31(18):2347-57.

Full text versions of IMWG publications and presentations may be accessed here: imwg.myeloma.org.



Prof. Alberto Orfao, MD, PhD
University of Salamanca
Department of Medicine
Salamanca, Spain

Dr. Alberto Orfao, professor of medicine at the University of Salamanca, began his work in myeloma after receiving his PhD in 1988. His first research project was focused on the understanding of the biology of the tumor plasma cell and its clinical impact, and the status of the immune system in myeloma and MGUS patients.

Since then, Dr. Orfao's research efforts, in close collaboration with Dr. Jesús San Miguel and his colleagues, have focused on the biology of the myeloma plasma cell and the myeloma plasma cell microenvironment, particularly the immune system. This has led to more than 50 publications in indexed journals. "Our results were always focused on having a direct translation into clinical practice, from minimal residual disease (MRD) monitoring to diagnostics." Key areas of focus currently for Dr. Orfao are intra-patient myeloma plasma cell heterogeneity; the ontogeny of myeloma tumor cells; the role of the immune system in long-term disease control; standardization of immunophenotypic diagnosis; and monitoring (MRD) of therapy.

Dr. Orfao was a young medical fellow when he met Dr. Durie for the first time in the 1980s. "It was an honor to meet a clinical scientist who had made a major contribution to the classification of myeloma, among other relevant contributions." Now Dr. Orfao is a member of the International Myeloma Working Group, as well as a key member of the Black Swan Research Initiative investigators team, where the two researchers are enjoying a fruitful collaboration.

"Support through the Black Swan Research Initiative has had an undisputable and key impact on the development and success of the MRD work done so far, which has been really impressive. Our group was prepared to do the work, but really needed the support provided to speed up the translation of concepts into real development. I really hope this will be a longstanding collaboration that will only end once myeloma is cured."

Top Myeloma Experts Gather in Stockholm for 2013 IMWG Summit

More than 70 leading myeloma experts from 28 countries gathered in Stockholm, Sweden in June 2013 for the IMF's International Myeloma Working Group Summit. The Summit provides researchers from around the world an opportunity to share ideas, collaborate on projects, and learn from their peers from around the globe in order to improve the lives of myeloma patients everywhere.



In Stockholm, Dr. Douglas Joshua confers with colleague Dr. Joy Ho, both of Royal Prince Alfred Hospital, Sydney, Australia.



Robert A. Kyle Awardee Dr. Joan Bladé and Carlos Fernández de Larrea, both of the Hospital Clinic, Barcelona, Spain, participate in an IMWG breakout session.



Dr. Karen Van Hoeven (Binding Site, San Diego, CA) and Dr. Suzanne Lentzsch (New York Presbyterian Hospital/Columbia University Medical Center, New York, NY) compare notes.

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 2013 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 2013 IMF Research Grant awards took place during the American Society of Hematology (ASH) annual meeting held in Atlanta, Georgia in December 2012.



Brian D. Novis Research Grants 2013

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 2013

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

Manoj Pandey, PhD

Pennsylvania State University – Hershey, Pennsylvania, USA

Gamgobic Acid: A potential therapeutic agent for multiple myeloma and associated bone loss.

Jetze J. Tepe, PhD

Michigan State University – East Lansing, Michigan, USA

Validation of non-competitive proteasome modulation for multiple myeloma.

Brian D. Novis Junior Research Grants 2013

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

Antonia Cagnetta, MD

Dana-Farber Cancer Institute – Boston, Massachusetts, USA

Potent in vitro and in vivo synergistic anti-MM activity of Nampt inhibitor and Bortezomib by augmented intracellular ER stress.

Brenda De Keersmaecker, PhD

Medical School of the Vrije Universiteit Brussel – Brussels, Belgium

Evaluation of the potency of immunomodulatory drugs to enhance the effectiveness of dendritic cell based immunotherapy for multiple myeloma.

Thang Van Nguyen, PhD

California Institute of Technology – Pasadena, California, USA

Identification of specific substrates for the Cereblon E3 ubiquitin ligase.

Els Van Valckenborgh, PhD

Vrije Universiteit Brussel – Brussels, Belgium

Myeloid-derived suppressor cell generation and activation regulated by multiple myeloma cells.

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 16 important research projects. The following awards were presented at ASH 2012 by IMF-Japan.

The Aki Horinouchi Award

Tetsuro Sasada, MD, PhD

Kurume University School of Medicine

Department of Immunology and Immunotherapy – Kurume, Japan

Development of Novel Immunotherapy Against Multiple Myeloma.

The IMF Japan Special Research Grant

Masaki Ri, MD, PhD

Nagoya City University Graduate School of Medical Sciences

Department of Medical Oncology and Immunology – Nagoya, Japan

Pursuit of Mechanisms Responsible for the Resistance Against Bortezomib Treatment and the Way to Conquer It in Multiple Myeloma.

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.

AMN's first project, the Asian Myeloma Data Base, led by Dr. JH Lee of Korea and with entries for some 4,000 patients, has provided a wealth of data about myeloma incidence and treatment in the region. It led to the 2013 publication of AMN treatment guidelines for Asia and has provided the impetus for the creation of an AMN clinical trials network.

The 2013 AMN annual meeting was held during the International Myeloma Workshop (IMW) in Kyoto, Japan, the first occasion for that global event to be held in Asia. AMN members participated extensively in the IMW, including the



Manoj Pandey, PhD

Research Associate

Department of Pharmacology

Pennsylvania State University

College of Medicine

Hershey, Pennsylvania

Manoj Pandey began his career in medicine in 2000 as a toxicology researcher. In 2006, he earned a PhD in biochemistry from Lucknow University in India, and in 2005, began working as a post-doctoral fellow at the University of Texas MD Anderson Cancer Center, working on hematological malignancies, including multiple myeloma. Dr. Pandey learned about the International Myeloma Foundation in India in 2004, and at the American Society of Hematology Annual Meeting in December, 2012, he was awarded a Brian D. Novis Junior Grant.

Dr. Pandey's research study, *Gambogic Acid: A potential therapeutic agent for multiple myeloma and associated bone loss*, conducted at the Department of Pharmacology at Pennsylvania State University College of Medicine, Hershey, Pennsylvania, is aimed at finding novel therapeutics for the treatment of multiple myeloma. He is investigating whether gambogic acid – a compound derived from natural sources and an inhibitor of nuclear factor kappa B (NF- κ B), which plays a critical role in the pathogenesis of myeloma – could be an effective treatment for multiple myeloma and associated bone loss.

Financial support from the IMF has been helpful in the discovery, characterization, and testing of gambogic acid in preclinical models of myeloma. Under the Novis grant, Dr. Pandey and colleagues are also working with clinicians at the Pennsylvania State University College of Medicine to begin a clinical trial.

"Early in my research career, myeloma caught my attention because despite the overall improvement in treatment of myeloma, osteoclastogenesis and drug resistance are still areas of intense investigation, and novel therapies are urgently required. The IMF is a leader in supporting research in the area of hematological malignancies, and is highly regarded by myeloma researchers around the world. This Brian D. Novis Senior Grant has helped my research tremendously, and I thank the IMF for its support."

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, treatment, and care of myeloma patients.



Prof. Gösta Gahrton

ELEVENTH ANNUAL INTERNATIONAL MYELOMA FOUNDATION
ROBERT A. KYLE
LIFETIME ACHIEVEMENT AWARD

In June 2013, in Stockholm, Sweden, Prof. Gösta Gahrton was awarded the 11th annual Robert A. Kyle Lifetime Achievement Award. Prof. Gahrton, a veteran in the field of hematology, has published more than 400 articles in international scientific journals, is the recipient of numerous honors, and has been a member and chairman of the Nobel Committee of the Karolinska Institute.

organization of a plenary session on myeloma in Asia. Also in 2013, the AMN met in Shanghai in conjunction with an IMF-Janssen Asian Myeloma Summit.

A major focus in 2013 has been the development of the AMN Clinical Trials network. Led by Dr. WJ Chng of Singapore, a first initiative was launched for a pomalidomide patient study. This will be an access program for some 100 patients in the various AMN countries and regions. A second project, a clinical trial in cooperation with Onyx, is being designed to examine carfilzomib, thalidomide, and dexamethasone in relapsed and refractory myeloma. Further trials are under consideration in cooperation with Janssen and with Millennium.

Research Events of 2013

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 54th 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, treatment, and maintenance.

IMF at ASH

The 54th American Society of Hematology Annual Meeting and Exposition took place December 8-11, 2012, in Atlanta, Georgia. The meeting, the premier hematology conclave in the world, drew approximately 18,000 hematologists and health-care professionals. More than 700 abstracts on myeloma were presented. They fell into four major groups: new drug trials; frontline options; biology and molecular genetics; and myelodysplastic syndrome (MDS) prior to the onset of myeloma and myeloma treatment.



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 2012 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 31-June 4, 2013 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 – a record number submitted, according to the organization. The IMF spotlighted the most significant news for myeloma patients from those abstracts and interviewed top myeloma researchers on topics such as new myeloma drugs, transplant, and promising clinical trials.



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Seema Singhal, MD

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Pieter Sonneveld, MD, PhD

Erasmus Medical Center
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Andrew Spencer, MD

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Guido Tricot, MD

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Brian G. Van Ness, MD, PhD

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David H. Vesole, MD

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Hackensack, NJ, USA

Jan Westin, MD

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Emeriti

Raymond Alexanian, MD

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Y.C. Chen, MD

Republic of China

Ian Franklin, MD

Scotland, UK

Tadamitsu Kishimoto, MD

Japan

Ian MacLennan, MD

England, UK

James S. Malpas, MD

England, UK

Martin M. Oken, MD

USA



Shirley & Rod Jonas
Bismarck, ND

Knowledge is a powerful weapon following a diagnosis of multiple myeloma. Just ask Shirley Jonas. The Bismarck, North Dakota resident traveled 2,000 miles for the latest information.

When her doctor diagnosed her with the disease in 2009, her first reaction was "I have no idea what I am going to tell my husband." And when Rod, her husband of 36 years, took to the internet for answers, what he found was not encouraging. "We went on the internet, looked at statistics, and he told me 'Don't look.'"

But she got a crash course over the next few years, undergoing a stem cell transplant at the Mayo Clinic in Rochester, Minnesota, followed by Revlimid® maintenance, which she continues today. Fortunately for the Jonases, a co-worker of Rod's put them almost immediately in touch with the International Myeloma Foundation (IMF). "I know they're always just an email or phone call away," said Shirley. "They've been awesome."

But emails and phone calls are no substitute for connecting face-to-face, and the nearest IMF support group was a state away, in Minnesota. So early in 2013, Shirley and Rod traveled to Boca Raton, Florida, for one of IMF's Patient & Family Seminars.

"It was wonderful," said Shirley. "We made friends, we networked, we met Dr. Brian Durie and other experts."

And they saw IMF's map of support groups around the country, with a big gap in North Dakota. For Shirley, who had long wanted to give back to others with myeloma, it was an "aha!" moment. "And I said, 'oh my goodness.' They've got all this great information here and I don't have to reinvent the wheel!"

When they returned to Bismarck, she started the area's first support group. The first meeting attracted about 20 people, and a year later, Shirley says they're still coming back. "Nobody knew what to expect, but I guess I haven't scared anyone away!"

She thanks the Patient & Family Seminar for the group's success. "It gave me the confidence I needed to take on starting a support group in Bismarck. I'm excited to learn in this process and I hope it will help others in their journey with myeloma."

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 co-founder Brian Novis often said, "Knowledge is power." His diagnosis and 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 offer Patient & Family Seminars, granting 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 2012 to September 2013, more than 2,000 people attended US-based seminars held in Boca Raton, FL; Chicago, IL; Philadelphia, PA; and San Francisco, CA.

Outside of the US, nearly 1,300 people attended seminars held in Paris and Nantes, France; Mikulov, Czech Republic; Ancona and Rome, Italy; Oslo, Norway; Middelfart, Denmark; and Istanbul, Adana, and Ankara, Turkey.



Regional Community Workshops

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

From October 2012 to September 2013, more than 900 people attended US workshops held in Chapel Hill, NC; Cincinnati, OH; East Texas, TX; Grand Rapids, MI; Jacksonville, FL; Milwaukee, WI; Minneapolis, MN; Nashville, TN; Sacramento, CA; Scottsdale, AZ; and Spokane, WA.

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 2013, nearly 90 physicians attended workshops held in Oslo, Norway; Odense, Denmark; and Istanbul, Ankara, Izmir, and Adana, Turkey.

Publications

The IMF produces a growing number 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 titles 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 16 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 2013 fiscal year, more than 2,500 Info Packs were disseminated to patients, healthcare providers, and support groups around the world.

From October 2012 through September 2013, the IMF produced ten new publications. An additional six titles were updated during this period. The quarterly *Myeloma Today* newsletter had a print subscriber base of more than 15,000, as well as a web-view and pass-along rate independently estimated at 75,000. The weekly *Myeloma Minute* subscriber base includes more than 32,000 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 topics relevant to their issues. The IMF held six teleconferences for patients and caregivers during the 2013 fiscal year, including three calls under the IMF's popular *Living Well with Myeloma Series*. Calls covered nutrition, infection prevention, and important myeloma updates from medical meetings. Recordings of all IMF teleconferences are made available on the IMF website.



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

IMF 2013 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

Hotline Bookmark

*Making Miracles**

Monitoring Patients with M-Proteins Flowchart

*Myeloma Matrix: Clinical Trials***

*Myeloma Minute** (weekly e-newsletter)

*Myeloma Today** (quarterly newsletter)

*Myeloma Today Gala Supplement** (annual supplement)

*Patient Handbook***

Tip Card – Freelite®

Tip Card – International Staging System

Tip Card – Kyprolis® (carfilzomib)**

Tip Card – Mozobil® (plerixafor)

Tip Card – Pomalyst® (pomalidomide)**

Tip Card – SQ Velcade® (bortezomib)

Tip Card – What is the IMF?*

*Understanding Adherence to Oral Cancer Therapy**

Understanding Balloon Kyphoplasty

Understanding Bisphosphonate Therapy

Understanding Clinical Trials

Understanding Dexamethasone

*Understanding Fatigue**

Understanding High-Dose Therapy with Stem Cell Rescue

*Understanding Kyprolis® (carfilzomib)***

Understanding Pomalyst® (pomalidomide)

Understanding Protein Electrophoresis

Understanding Revlimid® (lenalidomide)

Understanding Serum Free Light Chain Assays

Understanding Thalidomide

Understanding Velcade® (bortezomib)

Understanding Your Test Results

*New (between 10/1/12 and 9/30/13)

**Updated (between 10/1/12 and 9/30/13)

IMWG Conference Series



The International Myeloma Working Group (IMWG) Conference Series 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 second 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 on the IMF website.

A December 2012 debate among Dr. Brian Durie, Dr. Philippe Moreau, Dr. Antonio Palumbo, and Dr. Paul Richardson was held in Atlanta, Georgia following the American Society of Hematology (ASH) annual meeting.

A June 2013 debate held in Stockholm, Sweden before the start of the European Hematology Association (EHA) annual congress featured panelists Dr. Brian Durie, Dr. Ola Landgren, Dr. Joseph Mikhael, and Dr. Antonio Palumbo.

The IMWG Conference Series debates provide an innovative and exciting format for discussion on trends and new information, including: options for frontline myeloma therapy; recommendations for maintenance therapy; new options for management of relapsing disease; recommendations to reduce the occurrence of second primary malignancies; and what's new on the horizon.

conjunction with the American Society of Hematology (ASH) annual meeting. 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 spring 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 second annual Master Class, held in 2013, welcomed seven doctors from top medical centers in China. The intensive myeloma course, which was created and led by Dr. Brian Durie, was compressed into an accelerated three-day version this year. Featured speakers were Dr. Durie, Dr. Sagar Lonial of Emory University in Atlanta, and Dr. Joseph Mikhael of the Mayo Clinic in Scottsdale, Arizona. The participants also attended an IMF



Patient & Family Seminar in San Francisco, where they audited patient chart reviews with myeloma doctors.

Nurse Leadership Board

The International Myeloma Foundation (IMF) Nurse Leadership Board (NLB) is comprised of nurse leaders from leading myeloma centers across the country who care for patients with myeloma. 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 in an effort to optimize outcomes for patients with myeloma.



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 webinars and other educational teleconferences, make contributions to IMF website content, and publish materials 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.

In 2013, NLB members led education sessions at IMF Patient & Family Seminars, Myeloma Center Workshops and Regional Community Workshops; addressed the 2013 Support Group Leaders Summit; and accompanied support group leaders to ASH 2012. NLB members contributed to IMF publications, including *Understanding Clinical Trials*, *Understanding Adherence*, and *Myeloma Today*. Additionally, NLB nurses spoke on monthly teleconferences with support group leaders and led a *Living Well with Myeloma* teleconference, open to the entire myeloma community.



In 2013, 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* reviewing the use of novel agents in myeloma treatment.

Additionally, some NLB members worked in 2013 with the IMF's Advocacy team to address policy and access issues affecting myeloma patients.

At the 2013 Oncology Nursing Society Annual Congress in Washington, DC, the NLB hosted a satellite symposium entitled "New Paradigms in Multiple Myeloma Management: Nurse-Centric Case Studies in Patient Survivorship," which was attended by over 700 nursing professionals.



During the NLB's ninth annual meeting, held in New Jersey in fall 2013, the NLB reviewed the execution of completed projects, discussed the status of works-in-progress, and planned future activities. Current projects

discussed included a research project on health maintenance practices of myeloma patients, development of an electronic survivorship care plan tool, and a continuum of care project. NLB members also planned participation in teleconferences, seminars, and workshops for the coming year, which looks to be just as productive for the NLB as 2013 was.



IMF Nurse Leadership Board Members

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Samuel Oschin Cancer Center
at Cedars-Sinai Medical Center
Los Angeles, CA

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

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

Beth Faيمان, PhD, MSN, APRN-BC, AOCN
Cleveland Clinic Taussig Cancer Institute
Multiple Myeloma Program
Cleveland, OH

Elizabeth Finley-Oliver, RN
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Philadelphia, PA

Ann McNeill, RN, MSN, APN
John Theurer Cancer Center at HUMC
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Sandra Rome, RN, MN, AOCN
Cedars-Sinai Medical Center
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Joseph D. Tariman, PhD, ANP-BC
Assistant Professor
School of Nursing/
College of Science and Health
De Paul University
Chicago, IL



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

Charise Gleason, who became a nurse practitioner and began working in the myeloma clinic at the Winship Cancer Institute of Emory University in 2003, joined the Nurse Leadership Board (NLB) of the International Myeloma Foundation (IMF) shortly after it was founded. She joined the NLB to collaborate with other expert myeloma nurses who share their knowledge and passion to improve the self-care and nursing care of myeloma patients.

Charise is currently co-leading the NLB's research project on myeloma patients' health maintenance practices. The project consists of a comprehensive questionnaire about patients' general health maintenance practices--such as whether they see a general practitioner--in addition to their myeloma treatment.

The NLB has given Charise opportunities to connect with myeloma patients and healthcare providers throughout the world. In 2013, she spoke to patients and local healthcare providers at several Patient & Family Seminars throughout the US, and presented at the Annual Congress of the Oncology Nursing Society in Washington, DC and the 14th Annual International Myeloma Workshop meeting in Kyoto, Japan. Charise noted, "I appreciate the opportunity the NLB has given me to reach out to patients and community physicians who may not otherwise have known about the latest myeloma developments."

Charise was recently promoted to Chief Nurse Practitioner of the Department of Hematology and Medical Oncology at the Winship Cancer Institute. She is also currently pursuing a Doctor of Nursing Practice degree and works with the Emory myeloma clinic team to conduct and publish on clinical trials.

"I love working with myeloma patients, and it is a pleasure to be a member of the NLB," said Charise. "It is inspiring to collaborate with such accomplished leaders in myeloma nursing, and sharing our best practices enriches our interactions with our own patients."



Malcolm Katz
Encino, CA

When 72-year-old Malcolm Katz founded a myeloma support group in L.A.'s San Fernando Valley, he discovered he had an important resource in his own backyard: International Myeloma Foundation (IMF) Hotline Coordinator Debbie Birns.

"We've had visits from the Hotline folks at our meetings several times," said Malcolm. "Debbie came to talk about making sense of blood work – we're lucky she lives here in the Valley, she's very knowledgeable."

Malcolm was diagnosed in 2009, when the then-avid cyclist noticed that the sore back he often suffered for a day or two following a ride wasn't going away. An MRI showed a cloud on his lower vertebrae; an oncologist confirmed it was myeloma.

"I had never heard of it," said Malcolm. "You read about it, and even then, some of the literature says three to five years life expectancy."

Thanks to the IMF, Malcolm learned that was no longer the case. His myeloma is under control. He's back on his bike and at the gym, and he wants to make sure anyone diagnosed with the disease knows the options available.

"By and large, people are coping with this," he said. "The fact that we have cancer is something we have to adjust to, but it shouldn't become our life. We are not our disease."

And thanks to the Hotline, patients around the world can tap into the same resource available to Malcolm and his San Fernando Valley support group. IMF Hotline coordinators are available to answer questions about myeloma and related health concerns, the latest treatments, local support options for patients and family, and more.

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, Listserv, a toll-free Hotline, 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. Myeloma.org receives nearly 70 million hits per year. From October 2012 through September 2013, 432,000 visitors went to myeloma.org, tallying nearly 1,400,000 page views. IMF-produced videos and presentations received 79,000 views. During this time period, the IMF's website also received 97,000 views from mobile devices. The IMF website is a leading resource for myeloma-related content and the most common source of answers to the many questions of those newly diagnosed.



Social Media



The IMF has worked in recent years, and especially in 2013, 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 over 4,300 "likes" and 2,000 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 Hotline

The IMF's toll-free Hotline 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, other health concerns, and where to find local support, is more important than ever.



The toll-free Hotline has been an incredible resource to patients, families, and caregivers in 2013. From October 2012 through September 2013, Hotline responders supported 4,800 callers and answered 2,900 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 over 245 support groups worldwide. The IMF's team of Support Group Directors made 166 in-person visits to support groups during the fiscal year, visiting 135 support groups in the US; 31 of them more than once. The team of Support Group Directors also made in-person visits to Patient & Family

Seminars and other workshops; in all, they made 200 visits in 2013.

From October 2012 through September 2013, a total of 21 new support groups were formed.

During the 2013 fiscal year, the IMF held seven teleconferences for support group leaders and 10 calls for Nurse Leadership Board (NLB) members to speak to support groups.

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 27 local websites.

The IMF provided a unique opportunity for some support group leaders to attend the American Society of Hematology (ASH) annual meeting in Atlanta, Georgia in December 2012. During the meeting, 12 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 blog, Twitter, and Facebook posts, and with their local communities.

Through the IMF Ambassador Program, support group members attended the 2013 Patient & Family Seminars, creating a welcoming atmosphere and raising awareness for the local support groups.

The 14th annual IMF Support Group Leaders Summit took place in July 2013 in Dallas, Texas. A total of 80 support group leaders, representing



57 groups, attended the Summit, and for 28 leaders, this was their first Summit. The Summit focused on providing advice and support to help the participants lead effective support groups. Participants heard updates on medical news and advocacy issues, worked in groups to discuss the "Top Ten Topics" important to leaders, and learned from the panel "Support for Support Group Leaders."

A major theme of the 2013 Summit was technology. At the 2012 Summit, leaders received iPads (funded by Celgene, Millennium, Onyx, and Sanofi) for their groups and were introduced to the Myeloma Post® app, available to everyone. This year, the IMF unveiled a new app just for support group leaders – the Support Group Leaders Toolkit. The Toolkit app places information at support group leaders' fingertips during meetings and meeting prep.

Myeloma Post®

In 2013, the IMF enhanced its Myeloma Post app, and made it available for smartphones. Introduced in 2012 for the iPad, this app is a comprehensive myeloma resource application available for use by patients, caregivers, and healthcare providers. It was developed by the IMF to serve as a mobile gateway to educational, research, support, and advocacy programs and information found on myeloma.org.

Support Group Leaders Toolkit

In 2013, the IMF developed this app specifically for support group leaders. It offers sample meeting agendas and group surveys, as well as videos, blogs, webcasts, and slide presentations that can be used during meetings.



Laura and Charlie Mooney
Staten Island, NY

For some people, forming a community comes easily. When her husband, Charlie, 66, was diagnosed with multiple myeloma in 2010, Laura Mooney went to work.

A doctor discovered irregularities in Charlie's blood protein profile during a routine cholesterol screening. "We got the diagnosis and freaked," said Laura. Like so many of the newly diagnosed, they had never heard of the disease. Laura, 62, grew up on Staten Island, and used her many connections to make more, leading to a meeting with another couple impacted by multiple myeloma. She eventually contacted the International Myeloma Foundation (IMF) and the two began attending meetings in New Jersey. "We said 'there have got to be other people on the Island with this disease.'"

It turns out there were. But the local hospital had no myeloma specialist on staff, and the narrow waterways that separate Staten Island from Manhattan and New Jersey form a psychological barrier to many residents; many were unwilling to travel for information or treatment. Still, Laura was determined to start a support group in Staten Island.

With the help of the IMF, Laura and Charlie formed a group, and, using Laura's lifetime of connections, publicized it. To her surprise, the first meeting, at Laura's office conference room, attracted 35 people. Subsequent meetings, the second Wednesday of every month, attract around 20 people. "The group has really gelled, really bonded," said Laura. The group features speakers up to six times a year. The speaker for March was New York City Councilwoman Debbie Rose, who signed a city proclamation recognizing Multiple Myeloma Awareness Month. IMF helped Laura and Charlie establish a website that has provided Island residents with a link to vital information. "Some people call and I never meet them, but the important thing is to talk, give them info and connect them with the IMF. That's where the information lies."

Charlie has been in remission since a stem cell transplant in 2011, but if anything, that's only strengthened Laura's commitment. "'You're an inspiration,' I told him. If we help one person, that one person matters. It's like 'pay it forward,' you know?"



Tom Chelius
West Bend, WI

A funny thing about inspiration – it often strikes where you least expect it.

For International Myeloma Foundation (IMF) Advocate Liaison Tom Chelius, it struck in the middle of an MRI tube, groggy from Ativan he'd been given to ward off claustrophobia. It was April of 2007, a month after his 38th birthday, and he was undergoing tests for what turned out to be multiple myeloma. "I wanted to write a book about my experiences," he said. "And I wanted to make sure something good came out of this."

Something did. Tom got involved with his local IMF support group in West Bend, Wisconsin, which led him to participate in a patient lobbying day at the Wisconsin Capitol. "We were meeting with state lawmakers, including the sponsor of the oral chemo parity bill," he said. "I showed up with photos of the tumor on my brain and droopy eyelid. I caught the lobbying bug."

He has since testified in front of committees and even had one state senator say that he was her hero. It's something that flows naturally from his passion for the issue. "This is something the insurance companies should be doing anyway," said Tom. "It would save them money over IV [intravenous] medications." Tom considers himself lucky that he has good insurance coverage, but knows others aren't as lucky. "I want to make sure everyone has the same opportunities I do."

The Wisconsin Cancer Treatment Fairness Act would prohibit insurance companies from charging higher co-payments or deductibles for oral medications than they do for IV treatments, and is currently making its way through the Wisconsin State Legislature. Tom has pushed for its passage from the beginning.

"I think anyone can do this," he said. "All they have to do is tell their story. It's something they know well."

ADVOCACY

The International Myeloma Foundation (IMF) advocates on behalf of those affected by multiple myeloma for an increase in accessibility of high-quality diagnostics and treatments, for funding of myeloma-related research, and for an end to insurance coverage disparities for treatment. The IMF includes the entire myeloma community in these efforts and continues to expand its commitment to empowering patients, families, and friends to advocate on behalf of patient rights. In 2013, the IMF established 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 (through both federal- and state-level legislation), increased legislators' awareness of myeloma, and furthered the national dialogue on myeloma.

International Advocacy Efforts

Global Myeloma Alliance

In June 2013, the IMF formed the first global myeloma advocacy coalition, the Global Myeloma Alliance (GMA).



The GMA was formed in Stockholm, Sweden during the inaugural Global Leaders Summit (GLS), led by Arin Assero, IMF Vice President, Global Advocacy. The GMA brings together advocacy



leaders in myeloma and blood cancer from Asia, Europe, the Middle East, North America, and South America. The GMA's goals include increasing access to approved treatments for patients, improving patient outcomes through earlier diagnosis, raising global awareness of multiple myeloma, and supporting continued innovation in blood cancer.

Advocacy in South Korea

In October 2012, Arin Assero and Lisa Paik, IMF Senior Vice President, Clinical Education & Research Initiatives, 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. Both Arin and Lisa were featured as guest speakers for the audience of more than 200 patients and family members. They spoke about the IMF's 22-year history, our mission, and our wide range of programs in the areas of research, education, support, and advocacy. Arin provided examples of the many ways patients could make a difference through advocacy, especially as it relates to access to

the newest approved treatments for myeloma. This message resonated with those in attendance and prompted an additional conversation with patient leaders of the Korean Federation of Multiple Myeloma Patients (KFMMPP), a patient organization

that has online advocacy activities already underway. The IMF is moving forward on collaborations with KBCA and KFMMF to improve the circumstances for patients in Korea.

Raising Awareness in Turkey

During an IMF visit to Istanbul, Turkey, Arin Assero was interviewed on Turkish television with Dr. Mustafa Centiner of the American Hospital in Istanbul. The topic was myeloma patient advocacy, which, in Turkey, centers around patient education, access to physicians and treatment, and encouraging patients to be a more proactive part of treatment decisions. Arin explained the IMF's role in patient support in English, which was then translated into Turkish by Dr. Centiner. This effort was arranged by our partners at MiyelomlaYaşam.com, an online resource for patient education and support in Turkey and a member of the Global Myeloma Alliance



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 30 organizations representing patients, healthcare professionals, care centers, and industry, dedicated to the rights and care of cancer patients. In 2013, this collaboration, which aims to ensure equal access to approved anticancer regimens nationally, increased support around the Cancer Drug Coverage Parity Act (H.R. 1801). Many patients have unmanageable out-of-pocket expenses for prescribed oral anticancer medication; 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 spoke at the press conference introducing H.R. 1801 and secured 66 bipartisan cosponsors for the bill.



PEAC held two lobby days in 2013. The IMF and volunteers from 17 other PEAC member organizations held 30 meetings with representatives and senators to encourage support of our efforts in improving insurance coverage for oral anticancer medication. Additionally, PEAC identified two Senate sponsors, Senator Al Franken (MN) and Senator Mark Kirk (IL), to introduce companion bill S. 1879, the Cancer Treatment Parity Act. During the 2013 fiscal year, 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. S. 1879 was introduced in the Senate in December 2013.

Capitol Hill Briefing

On April 11, 2013, the IMF held a briefing to discuss health disparities in cancer on Capitol Hill. Disparities persist in multiple myeloma, which affects African Americans approximately twice as often as Caucasians and Hispanics. Even when controlling for factors such as distance from treatment centers, African Americans are statistically more likely to die from myeloma. In



IMF Myeloma Awareness Month



The IMF observed Myeloma Awareness Month (March) of 2013 with many activities and initiatives that increased awareness of this disease. The IMF's work with local support groups and IMF members resulted in 60 towns and cities and four states issuing proclamations that March was Myeloma Awareness Month.

During the month, the IMF held two teleconferences reaching over 660 live listeners, issued press releases, authored guest blog posts on the website of popular cancer magazine *CURE*, and used its own social media tools to encourage the spread of awareness, posting daily myeloma facts on Twitter and Facebook.

facebook

twitter



Affordable Care Act Education

In 2013, the IMF reached more than 450 patients, caregivers, and family members with its patient education series, “Health Care Reform and You: Navigating the Changing Health Insurance System.” Three online seminars and three in-person forums in California, New Jersey, and Illinois explained what the Affordable Care Act (ACA) is and how the law can benefit patients. Attendees heard from experts from the regional offices of the American Cancer Society Cancer Action Network, Centers of Medicare and Medicaid, and state health insurance marketplaces. Topics reviewed included the ACA’s new patient protections, changes to Medicare, and the new health insurance marketplaces/exchanges. Terms such as “Essential Health Benefits,” “Qualified Health Plans,” and “Out-of-Pocket Limits” were defined and explained, and many questions and concerns were answered.

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 2013, 7,126 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 over 8,860 emails to their state and federal legislators during this reporting period. In addition, the IMF’s Postcards for Parity Program has resulted in 7,131 postcards sent to representatives in support of oral anticancer treatment access since the program’s inception in 2012. Join our efforts at advocacy.myeloma.org.

a packed room of Congressional staff and colleagues from other cancer organizations, participants heard from expert speakers on the challenges of reducing and eliminating cancer health disparities for patients with myeloma. Meghan Buzby, IMF Director of US Advocacy, spoke to the attendees along with myeloma patients and expert physicians and researchers. Participants left the briefing with a picture of the obstacles faced by patients and ideas for strategies to address these health disparities.



US Advocacy Efforts at the State Level

State Patients Equal Access Coalition



SPEAC
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. In 2013, SPEAC expanded to include 26 organizations representing patients, healthcare professionals, and cancer care centers. SPEAC has worked to ensure that oral parity is included in state health exchanges under the Affordable Care Act. In 2013, SPEAC was successful in ensuring that oral parity applied to health plans offered in New Jersey and Illinois. Additionally, Nevada passed an oral parity law in 2013, which included language requiring that it apply to plans offered in the marketplace.

State Legislation

Anticancer treatment access legislation has been introduced in many states, and IMF advocates turned out to support state bills by sharing stories of how disparities in treatment access affected their lives. In 2013, seven states passed laws ensuring equal access to approved anticancer regimens. These states include Oklahoma, Florida, Rhode Island, California, Louisiana, Massachusetts, and Nevada. The IMF played a key role in gaining support for the Nevada bill, working with Senator Mo Denis to introduce the bill, leading a state-based coalition, and generating grassroots support for bill passage. These efforts resulted in local media coverage and additional awareness of the bill. Additionally, IMF advocate Christy Joyce testified in support of SB 266 to the Nevada Assembly Commerce & Labor Committee. These efforts culminated in the Nevada bill being signed into law by Governor Brian Sandoval in June 2013.

Myeloma ACTION Team

In 2013, the IMF formed the Myeloma ACTION Team to unite all of our advocates to build a community that will foster education, action, and empowerment. 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 collects Postcards for Parity in support of anticancer treatment access legislation, 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, which speaks to the IMF on monthly teleconferences, consists of 37 advocates who made 12 in-district visits and sent 415 messages to legislators in fiscal year 2013.

DEVELOPMENT

Support for the International Myeloma Foundation comes from many sources, including large corporations, pharmaceutical sponsors, private donors, bequests, and fundraising events. Whether the gift is \$5 or \$5,000 – each contribution makes it possible for the IMF to continue offering and improving upon existing programs, while exploring new ways to service the myeloma community with top-rate information and support.

This is evident in the number of new programs the IMF added to our repertoire during the last fiscal year. From the Myeloma Master Class (page 14) to the IMWG Conference Series (page 14), the IMF's expanded reach in the medical community is made possible through the generosity of its donor base.

During the 2012-13 fiscal year, the IMF received \$9.4 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 2012-13 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

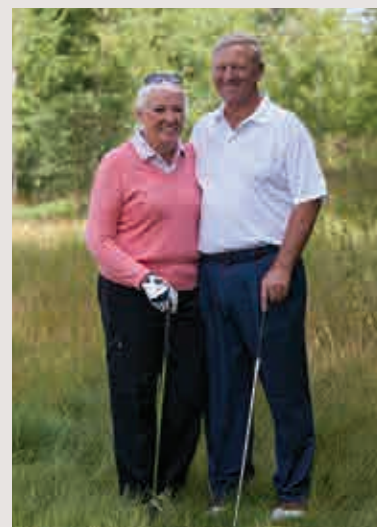
The IMF continues to support programs that help extend lives of myeloma patients, but respects that for many of our members estate planning is a rite of passage that must be acknowledged.

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, 169 Hope Society members contributed a total of \$39,325 during the 2012-13 fiscal year.

The IMF thanks members of The Hope Society for their continued commitment to sustaining the needs of the myeloma community.



John and Dorothy O'Dwyer
Plano, TX

In June 2007, while John O'Dwyer was living and working in Shanghai, China with his wife, Dorothy, he was diagnosed with cancer. The following day the couple flew back home to Texas, where John was diagnosed with multiple myeloma.

Immediately, Dorothy and John began doing their homework and came across the International Myeloma Foundation (IMF). "We considered it a large, credible organization that could give us unique access to education and experts in the field of myeloma...but what I really wanted—and what I wanted to fund—was research toward a cure." Since becoming a member of the IMF Board of Directors in 2009, John's entire focus has been on a cure for myeloma. He has now stepped in as chair of the Black Swan Research Initiative® campaign. "My hope for this initiative is to bring us to a cure for myeloma. I'm six years in and I enjoy my life. I have a loving family; a wife, four children, eight grandchildren. I do not want to lose my life to this disease."

In March 2013, John and Dorothy made a commitment of \$500,000 to the IMF for the Black Swan Initiative. "For years, the IMF and other organizations have been adding to a body of knowledge on myeloma through various research projects. All of this research has been important. I feel, however, most excited about the Black Swan Research Initiative in particular because this is the best chance that I have seen so far to ensure a longer life for myeloma patients."

"With myeloma, you realize that the disease doesn't just affect you as a patient. It can be something that your loved ones and future generations have to go through, too. Everyone should be a part of a movement toward a cure, but those who are touched by the disease in any way can play an important and meaningful role in the Black Swan Research Initiative."



In memoriam

Kenneth B. Kochmann, MD **Baltimore, MD**

Kenneth B. Kochmann, MD, left a generous bequest to the International Myeloma Foundation (IMF) when he lost his battle with myeloma in March 2013. He had believed a cure was just around the corner and if he could just hold on, he would meet that cure. But it was not to be.

Instead, Dr. Kochmann's \$50,000 donation will have a lasting impact on others who are still fighting the disease. With his support of the IMF, he will always be remembered as a man whose deep compassion for others extended to his fellow myeloma patients.

Diagnosed in 2003, Dr. Kochmann completed several rounds of chemotherapy and had two stem cell transplants, yet, according to his family, he remained positive, maintained his keen sense of humor, and continued to see patients as a family practice physician until three weeks before his death.

Dr. Kochmann believed that you care for your patients by caring about your patients. After his death, his sisters, Carol Kochmann and Jill Blumkin, found hundreds of letters from his patients thanking him for being the best listener and the best doctor they had ever had.

While Dr. Kochmann chose clinical practice over the genetics lab, he strongly believed in the power of research. He did his research on the latest myeloma developments and became an active participant in his treatment decisions. Dr. Kochmann hoped for a cure, but it wasn't coming soon enough.

As he and his sisters filled out the Five Wishes form in the last weeks of his life, they laughed together over the questions and his answers to them. But when they got to *Wish Five: My Wish for What I Want My Loved Ones to Know*, he teasingly answered the question: "If anyone asks how I want to be remembered, please say the following about me" with "I want to be remembered as the man who cured multiple myeloma."

Funny to the end, with his generous bequest to the IMF, Dr. Kochmann's wish may be closer to the truth than he could know.

Dr. Kochmann's sister Carol said in an obituary in The Baltimore Sun, "He never complained, and to the very end, always maintained his puckish sense of humor, affable sunny demeanor, and was determined to beat the disease."

The Hope Society Honor Roll

| | | |
|---------------------------------------|---------------------------------|---------------------------------------|
| Amy Adams | Roberta and Arnold* Greenberg | Elida and Jorge Peragallo |
| Jeff Allyn | Paul Griffin | Hal Piel |
| Cathie Alonzo | Diane Grosso | Selma Plascencia |
| Janet Aimes | Roslyn and Harold Grueskin | Gail Pollard |
| Bonnie Anderson | Lorraine Hardy | Agatha Polowy |
| Carol and Eric Ashihara | Florence Hooker | Ellen Powell |
| Laura Bates | Carol Hornreich | Joanne and William Powell |
| Eunice Becker | Nicci Hubert | Dan Quattrochi |
| David Bennett | Timothy John Huss | Lauren Regan |
| Donald Bennett | Ros and Larry Isakowitz | Tina and Michael Rettig |
| Marcy Berstein | Nancy and Richard Jackson | Dawn Rochester |
| Rita and Ivan Billson | Sally and Reggie Jardon | Mary Rohleder |
| Dennis Bloom | Larry Jeffries | Cesar Romero |
| Anne and John Boehle | Kathleen and David Johnson | Gregory Rosasco |
| Jan and Alan Boggs | Shirley Johnson | Sara and Richard Rosene |
| Marie Bovarnick | Debbie and Jerry Jordan | Charlie Roundtree |
| Frances and James Bowles | Jane Kamstra | Heidi Rubinstein and Brian Kuchynskas |
| Jeannie Brady and William* Fennessy | Jacqueline and Michael Katz | Marti and Robert* Santos |
| Kathy Brens | Eileen and Frank Kealty | Cynthia Schulze |
| Julia Brock | Anita Marie and Walter Kemper | Barbara Scott |
| Claudia and Philip Brown | Julia Kennedy | Marguerite and Daniel Scott |
| Prudy and David Brown | Elise Ketner | Diane Seccombe |
| Patricia Vigilante and Robert Candela | Abdul Khatri | Janice Sejut |
| Catherine and John Capo | Roberta and Raymond Klein | Ed Sharp |
| Carleton Carroll | Judy and Henry Koepfle | Nancy Shealy |
| Annette and Patrick Cavana | Leny and Ben Kolsteren | Robert Singdahlsen |
| Cynthia and John Chmielewski | Ann Nora Kruger | Richard Skalitzy |
| Cynthia Clark | Rachel and Duan Lashbrook | David Skelly |
| Susie Cobb | John Law | Rachel Small |
| Anonymous | Rose Mary and George Leek | Jack Smith |
| Carol and Phillip Collins | Linda and Joseph Lerner | Nikki and Allen Smith |
| David Cook | Jean and Mike LeTarte | Randall Smith |
| Volindah Costabell and Ron Stout | Nancy and Don Lorenzen | Iwona Srienc |
| Thomas Coyne | Peter Lundell | Diane Staves |
| Maureen Cronin | Mary Jane Lundy | Elizabeth and Frank Streff |
| Stephanie Davis | Elizabeth Manczak | James Stuart |
| Myla and Jamie De La Cruz | Helene and Alan Marks | Janet Studnicki* |
| Linda and Charles De Long | Stephen Marsh | Nancy and Jay Style |
| Brian Denyer | Vicki and Dwight Mays | Henry Thomas |
| Niall Doherty | Jodi McClure | Paula Thompson and Hani Al-Nakib |
| Rene Dvalery and James Baker | Laura McGlothlin | Doris and James Thureau |
| Linda and Mark Edwards | Joseph Mekler | Nancy and William Tidwell |
| Joseph Ellis | Evalyn and Richard Merrick | Ray Vines |
| Kate and Douglas Farrell | Paula Merrigan | Patricia and James Wagner |
| Virginia Field | Barbara Montalbano | Linda Wakefield |
| Kyoko Kashiwagi and Ronald C. Fischer | Laura and Charles Mooney | Marcia and Peter Webber |
| Kim and Doug Foreman | Allana Morgan | Charlotte and Joseph Werkmeister |
| Norma Jean Galiher | Imad Mufarrij | Becky and Charles Whitehead |
| Dean Gallea | Karen and Edward Necela | Maryellen Wilkinson |
| Susan and Daniel Gannon | Susie Novis and Dr. Brian Durie | Carol Wock |
| Irene and Laurence Gauthier | Paul O'Dea | Bernadette and Dave Wolf |
| Carl Gilliam | Patricia and Jim Omel | Beth and Woodring Wright |
| Anil Godbole | Marcelo Pakman | Sandy Wytroval |
| Carla Goode | Phyllis and Tom Parker | Natalie Young |
| Gail B. Goodwin | Tom Parker | Randy Zittel |
| Donna Wyatt and Daryl G. Graham | Jack Pascale | |

*deceased

6th Annual Comedy Celebration Benefiting the Peter Boyle Research Fund

The International Myeloma Foundation's 6th Annual Comedy Celebration benefiting the Peter Boyle Research Fund drew nearly 1,200 guests to the Wilshire Ebell Theatre Saturday, October 27th, 2012. The late actor, who died in 2006 after a four-year battle with myeloma, was remembered with poignant anecdotes, which were followed by an evening of stellar comedic performances.



The Annual Comedy Celebration began in 2007, when event Chair Loraine Boyle, IMF Board member and wife of the late actor Peter Boyle, reached out to IMF co-founders Susie Novis and Dr. Brian Durie with a profound desire to make a difference in the lives of people coping with multiple myeloma. 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 2012-2013 fiscal year, the 6th Annual Comedy Celebration raised \$590,000, bringing the total funds raised for the Peter Boyle Memorial fund to \$4 million.

Ray Romano, whose support over the years has played an integral part in the success of the event, opened the show with his *Everybody Loves Raymond* co-star, Doris Roberts. The TV mother and son reminisced about their favorite moments on the show and fondest memories of Peter. Also appearing on stage that night were fellow comedians Jeff Garlin, Judy Gold, Gilbert Gottfried, Dom Irrera, and Fred Willard – all of whom had the audience laughing for 90 minutes straight. The show-stopping finale was a high-energy musical performance by Joe Walsh and his band.



Doug Farrell Philadelphia, PA

You can't force fun, according to Doug Farrell. If it's fun, it just happens.

Maybe that's why he refused to let his 2006 multiple myeloma diagnosis derail his biennial St. Patrick's Day party, held for about 200 of his friends and family. Instead, Doug turned the wildly successful extravaganza – complete with food, drink, and an Irish band with himself as lead vocalist – into the wildly successful "Song for Ireland" fundraiser. Last year, the fifth annual event raised nearly \$12,000 for the International Myeloma Foundation (IMF).

"Fundraising events should be fun," said Farrell. "If you make it fun, they will come."

Not that receiving his diagnosis was easy. The Philadelphia podiatrist knew only a few basic facts about myeloma: that it can affect the skeletal system, and that it's incurable. "The hardest thing was sitting the kids down to tell them I'd been diagnosed with incurable cancer," he said.

His wife, Kate, a registered nurse, scoured the internet and quickly found out about the IMF. Doug underwent a stem cell transplant and was included in clinical trials for Revlimid®, a treatment he continues today. Doug says the IMF proved invaluable. "Suddenly we didn't feel like we were alone anymore... you're on a great team to help you deal with this disease."

"Song for Ireland" was a way Doug and Kate could give back. Last year, they began another fundraiser in Longport, New Jersey, the town where their family has summered for 32 years. Town lifeguards had run the annual "Captain Jim Turner Memorial Ocean Swim" every summer for 15 years. When Doug, who had spent so much time on the beach over the past four decades they named him an honorary lifeguard, approached them about having proceeds benefit the IMF, they were thrilled. "It brings the community in, not just swimmers, because it has something for everyone," said Doug.

But Doug says that the events he's organized serve an even more important purpose than raising funds. "Of course, the main thing is awareness – people need to know about new therapies and the wonderful explosion of research. That's what saves lives."



Miracles for Myeloma



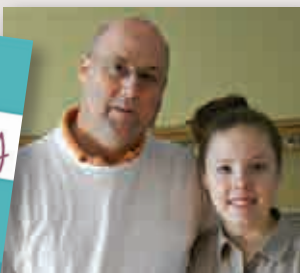
Burkard Birthday Celebration



A Visit to
Virginia's
Wine Country



Dairy Queen Fundraiser



Abby's Book

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 63 events, raising nearly \$300,000. 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, 2012– September 30, 2013

BENEFACTORS CIRCLE \$25,000 AND UP

Miles for Myeloma 5K
Philadelphia Multiple Myeloma Networking Group, New Jersey Support Group, Northeastern New Jersey Support Group Philadelphia, PA

Miracles for Myeloma
Ron & Sheree Pask and Gina Klemm Clark, NJ

Coach Rob's Benefit Bash
Rob Bradford Apopka, FL

Carolyn Czerkies Charity Golf Outing
Czerkies Family Naperville, IL

FOUNDERS CIRCLE \$10,000 - \$24,999

RHS Open Fundraiser
Saletan Family Wellington, FL

J.C. Golf Tournament
David Johnson, Bob Zins St. Cloud, MN

Bridge Blasts Myeloma
Ann Girod and Carol Klein Potomac, MD

A Song for Ireland
Doug & Kate Farrell Philadelphia, PA

Wayne Hamby Memorial Golf Tournament
Gail & Andrew Bertram Bluffton, SC

Music against Myeloma
Slava Rubin New York, NY

PARTNERS CIRCLE \$5,000 - \$9,999

A Visit to Virginia's Wine Country
Nancy Raible Richmond, VA

Cynthia's "Pack" 5K Fun Walk
Lin Bostian Greensboro, NC

Modern Art against Myeloma
John Bianco Philadelphia, PA

Meredith Fiacco Memorial Golf Tournament
Meredith Nicols and Suzanne Fiacco Potsdam, NY

ASSOCIATES CIRCLE \$1,000 - \$4,999

Margaret R. Cole Memorial Fund
Roger Cole Upper Montclair, NJ

Flying Pig Marathon
Ellen & Brian Grammel Fairfield, CT

Dairy Queen Fundraiser
Ruth Schimmel Allendale, MI

Jack's Annual Texas Hold 'em Benefit Bash
Jack Aiello San Jose, CA

Rock for a Cure
Adam Baczkowski Asbury Park, NJ

Raven's Roost Bull & Shrimp Feast
Bonnie & Jim Schleicher Edgewood, MD

Wins for a Cause
Brian Cohen Cleveland, TN

A Day at the Races
Janine Granit Point Pleasant, NJ

Marioni Salon Fundraiser
Kerri Marioni, Salon 926 Newark, DE

Zachary Stoloff Bar Mitzvah Fundraiser
Palm Beach Gardens, FL

Celebrating Mom Tea
Lisa Bence Durham, NC

Burkard Birthday Celebration
Mary Burkard Amherst, NY

FRIENDS CIRCLE \$500 - \$999

Abby's Book
Abby and Stephen McLaughlin Fall River, MA

Nuveen Casual Jeans Day
Chicago, IL

Jerry Walton's Veterans Against Myeloma Campaign
Jerry Walton Virginia Beach, VA

Honeybeaders Bracelets
Lu Woodward Akron, NY

99 Restaurant Fundraiser
Carol Rossi Warwick, RI

Capt. Turner Ocean Swim
Doug & Kate Farrell Longport, NJ

SUMMARY FINANCIAL INFORMATION

INTERNATIONAL MYELOMA FOUNDATION Statement of Financial Position September 30, 2013

Assets

CURRENT ASSETS

| | |
|-------------------------------------|--------------|
| Cash and cash equivalents | \$ 1,716,305 |
| Contributions and other receivables | 2,015,764 |
| Prepaid expenses | 428,379 |

| | |
|-----------------------------|--------------------|
| Total Current Assets | \$4,160,448 |
|-----------------------------|--------------------|

OTHER ASSETS

| | |
|---|---------|
| Property and equipment, net | 516,335 |
| Gift annuity investments, restricted cash | 9,935 |
| Intangible assets, net | 20,166 |

| | |
|---------------------------|-------------------|
| Total Other Assets | \$ 546,436 |
|---------------------------|-------------------|

| | |
|---------------------|--------------------|
| TOTAL ASSETS | \$4,706,884 |
|---------------------|--------------------|

Liabilities and Net Assets

CURRENT LIABILITIES

| | |
|--|------------|
| Accounts payable and accrued expenses | \$ 495,022 |
| Deferred and unrestricted educational grants | 3,054,465 |

| | |
|----------------------------------|------------------|
| Total Current Liabilities | 3,549,487 |
|----------------------------------|------------------|

| | |
|--------------------------------|--------------|
| GIFT ANNUITY OBLIGATION | 6,339 |
|--------------------------------|--------------|

| | |
|--------------------------|------------------|
| Total Liabilities | 3,555,826 |
|--------------------------|------------------|

NET ASSETS

| | |
|------------------------|-----------|
| Unrestricted | 1,147,462 |
| Temporarily restricted | 3,596 |

| | |
|-------------------------|--------------------|
| Total Net Assets | \$1,151,058 |
|-------------------------|--------------------|

| | |
|---|--------------------|
| TOTAL LIABILITIES AND NET ASSETS | \$4,706,884 |
|---|--------------------|

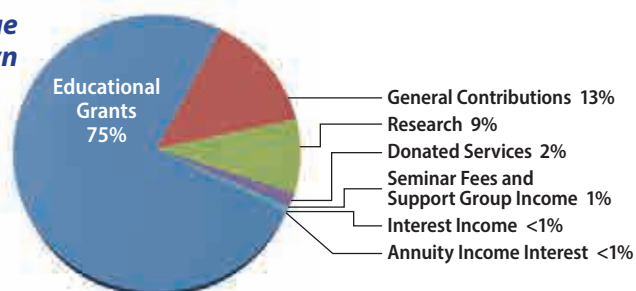
For a copy of our complete audited financial statements, please contact the IMF office

INTERNATIONAL MYELOMA FOUNDATION

Statement of Activities for the Year Ended September 30, 2013

| | UNRESTRICTED | TEMPORARILY RESTRICTED | TOTAL |
|---|---------------------|---------------------------|---------------------|
| Revenues and Support | | | |
| Educational grants | \$ 7,033,130 | \$ - | \$ 7,033,130 |
| General contributions | 890,535 | 364,710 | 1,255,245 |
| Fundraising programs | 285,693 | 2,664 | 288,357 |
| Donated services | 147,757 | - | 147,757 |
| Seminar fees and support group income | 57,152 | - | 57,152 |
| Fundraising event, net of direct benefit to donors of \$318,327 | 122,629 | 447,615 | 570,244 |
| Change in split-interest obligation | - | 3,596 | 3,596 |
| Interest income | 5,075 | - | 5,075 |
| | 8,541,971 | 818,585 | 9,360,556 |
| Released from restriction | 814,989 | (814,989) | - |
| Total Revenue and Support | 9,356,960 | 3,596 | 9,360,556 |
| Expenses | | | |
| Program services | 8,199,686 | - | 8,199,686 |
| General supporting services | 507,783 | - | 507,783 |
| Fundraising | 544,382 | - | 544,382 |
| Total Expenses | 9,251,851 | - | 9,251,851 |
| Change in Net Assets | 105,109 | 3,596 | 108,705 |
| NET ASSETS – Beginning of year | 1,042,353 | - | 1,042,353 |
| NET ASSETS – End of year | \$ 1,147,462 | \$ 3,596 | \$ 1,151,058 |

**Revenue
Breakdown**



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

INTERNATIONAL MYELOMA FOUNDATION

Statement of Functional Expenses

for the Year Ended

September 30, 2013

Breakdown of Expenses by Program

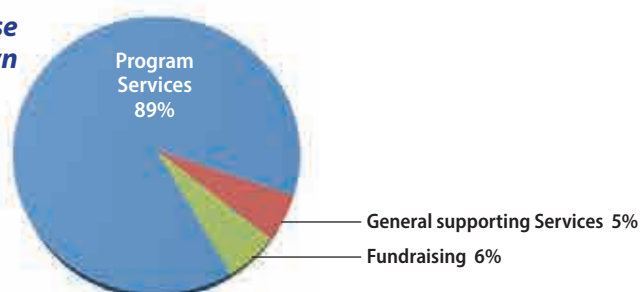
| PROGRAM | TOTAL EXPENSES |
|---------------------------|----------------|
| Research | \$1,848,810 |
| Education & Awareness | 1,196,358 |
| International | 970,333 |
| Patient & Family Seminars | 924,738 |
| Clinical Meetings | 617,058 |
| Support Groups | 608,619 |
| Advocacy | 548,298 |
| Nurse | 405,866 |
| Hotline | 321,072 |
| Website | 317,641 |
| Myeloma Today | 259,703 |
| Information Mailings | 142,818 |
| Myeloma Manager | 38,372 |

| | |
|-------------------------------|--------------------|
| Total Program Expenses | \$8,199,686 |
|-------------------------------|--------------------|

| | |
|-----------------------------|---------|
| General supporting expenses | 507,783 |
| Fundraising expenses | 544,382 |

| | |
|-----------------------|--------------------|
| Total Expenses | \$9,251,851 |
|-----------------------|--------------------|

Expense Breakdown



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

HONOR ROLL

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 24-hour access to the latest updates about myeloma, from clinical trials to the 10 Steps to Better Care®;
- Support the IMF's network of over 150 support groups through leadership training, educational materials, and assistance in securing guest speakers and teleconferences with the Hotline;
- Maintain the Hotline and ensure that its coordinators are up to date on the latest research and treatment options so that patients, family, and friends always have a place to turn;
- Expand successful programs such as the Regional Community Workshops and Myeloma Center Workshops to reach even more patients and families, while maintaining unwavering support of established and relied-upon programs like the Patient & Family Seminars;
- Continue to produce and regularly update the more than 100 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.

Chairmans Circle \$100,000 and above

Bristol-Myers Squibb Company
Celgene Corporation
Janssen Pharmaceutica
Merck & Co.
Millennium: The Takeda Oncology Company
Novartis Pharmaceuticals
Dorothy and John O'Dwyer
Onyx Pharmaceuticals, Inc.
Sanofi
The Binding Site, Ltd.

Presidents Circle \$50,000 - \$99,999

Susie Novis and Dr. Brian Durie
Jill Blumkin and
Estate of Kenneth Burton Kochmann
Genentech, Inc.
GlaxoSmithKline
Parexel International
The V & L Marx Foundation /
Jennifer and Bud Gruenberg

Benefactors Circle \$25,000 - \$49,999

Amgen Oncology
Sandra and H.P. (Andy) Andrews
Coach Rob's Benefit Bash, Inc. /
Kimberly and Robert Bradford
Diplomat Specialty Pharmacy
Donna and Steve Feig /
Foreign Parts Distributors
Philadelphia Multiple Myeloma
Networking Group
Raymond James & Assoc. / Robert Ebersole

Founders Circle \$10,000 - \$24,999

Loraine Boyle
David Geffen Foundation
Estate of Jack Ozard
Harold and Isabel Feld Philanthropic Fund
Susan Flagg
Foreign Parts Distributors Inc.
Joele Frank and Larry Klurfeld
HBO Inc.
Bruce Hoitt
Independent Charities of America
J.C. Invitational Golf Tournament /
Beverly Lunderoff
John J. McDonnell &
Margaret T. O'Brien Foundation
Richard King
Carol and Benson Klein
Robert Max

Joy and Bill McGinnis
Abigail and Jim Rich
Monica and Philip Rosenthal
Carol Ann and Paul Rothman
Dorothy Tinsler
Walsh Street Foundation / Henry Belber
Worldwide Pants, Inc.

Partners Circle \$5,000 - \$9,999

Amazon.com, Inc.
Susan and Frank Armo
Jennet Walker and John Auerbacher
Gail and Andrew Bertram
Cancer Cure of America
Clifford and LaVonne Graese Foundation
Gail-Ann and Joe Colaruotolo
Bonnie and Craig Czerkies
Edward Czerkies
Mary Jo and Vincent Eihilow
Envision Communications
Estate of Janet Snow
Estate of Robert Allen Foster Living Trust
Allison and Brian Feltzin
Irving Finkelstein
Cindy and James Gilbert
Judith Goldman
Vicky Hamby
Patricia Heaton and David Hunt
Emil and Ann Herkert
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