

INTERNATIONAL MYELOMA FOUNDATION
2015
GLOBAL ANNUAL REPORT

MAKING
A WORLD
OF DIFFERENCE



Improving Lives **Finding the Cure**[®]

Celebrating 25 Years



INTERNATIONAL MYELOMA FOUNDATION



Improving Lives **Finding the Cure®**

2015

GLOBAL ANNUAL REPORT

FISCAL YEAR OCTOBER 1, 2014 – SEPTEMBER 30, 2015

TABLE OF CONTENTS

<i>Letter from the Chairman</i>	4
<i>Update from the President</i>	5
<i>Research</i>	6
<i>Education</i>	11
<i>Support</i>	15
<i>Advocacy</i>	17
<i>Development</i>	20
<i>Summary Financial Information</i>	24
<i>Honor Roll</i>	27





Brian G.M. Durie, MD, Chairman

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

Dear Supporters of the International Myeloma Foundation,

I am pleased to be able to report that the International Myeloma Foundation (IMF) continued to make amazingly positive strides to help myeloma patients around the globe in 2015. The IMF was successful in all four areas of focus: education, support, advocacy, and research.

Patient education is the cornerstone program for the IMF. "Knowledge is power" embodies our outreach to patients everywhere. The menu of opportunities for learning – finding out the best and latest information – continues to be expanded and enhanced. There are more than 150 support groups in the US alone. In 2015, we held four two-day patient seminars in the US and 15 one-day community workshops. The community workshop program has substantially extended the IMF's reach into smaller communities. In addition, there are numerous ways to access information via publications, online resources, and teleconferences. These include *Myeloma Today*®, the weekly *Myeloma Minute*® e-newsletter, and regular "Living Well with Myeloma" teleconferences. Other resources are the weekly "Ask Dr. Durie" YouTube video series; the twice-yearly International Myeloma Working Group® (IMWG®) Conference Series: Making Sense of Treatment online expert debate series; and the 10 Steps to Better Care® breakdown of key information, in a "step-by-step" fashion.

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

Turning to research, this has been a major area of excitement and growth. The groundbreaking Black Swan Research Initiative® is truly moving toward achieving a cure for myeloma. Focused on early diagnosis, monitoring disease at the very lowest levels (using new MRD [Minimal Residual Disease] testing) and developing novel therapy combinations to eradicate residual disease, this project has galvanized interest, expectation, and enthusiasm among myeloma researchers and patients everywhere. The project is now moving into Phase 2 which includes trials for patients with residual resistant disease. This will be especially important to attempt to achieve cure for all patients. Fiscal year 2015 saw the final development of the Next-Generation Flow (NGF) technique, a precise new tool to monitor myeloma as cure is being achieved. We have great optimism that in the next one to two years, we will be able to confirm that cure is being achieved.

So, 2015 was a stellar year and we look forward to even greater progress in 2016 and beyond.

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

Sincerely yours,

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

IMF Board of Directors

Brian G.M. Durie, MD
Chairman of the Board
Los Angeles, CA

Susie Novis Durie
President, International Myeloma Foundation
Los Angeles, CA

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IMF-Latin America
São Paulo, Brazil

Yelak Biru
Global Director of Advanced Analytics and
Business Intelligence Architecture, PepsiCo
Plano, TX

Professor Mario Boccadoro, MD
Professor, University of Torino
Torino, Italy

Aldo Del Col
Myeloma Canada
Québec, Canada

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Director of Sales, Agile Los Angeles
Reno, NV

Jason Katz
Senior Director of CRM and Digital, HookLogic
New York, NY

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Principle Member, Ward & Klein
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President, Greyhawk Capital
Indiana, PA

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Medicine and Pathology
Mayo Clinic
Rochester, MN

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Medical Oncology
Wilhelminenspital der Stadt Wien
Vienna, Austria

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Thomas Jefferson University
Brigadier General, National Guard
Philadelphia, PA

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Founder, CEO & President, ReCellular, Inc.
Principal, Newman Computer Group
Ann Arbor, MI

John O'Dwyer
Retired Businessman
Plano, TX

S. Vincent Rajkumar, MD
Professor of Medicine
Mayo Clinic
Rochester, MN

Matthew Robinson, MBA
Senior Vice President of International Television
20th Century Fox Film
Los Angeles, CA

E. Michael D. Scott, CPA, JD
Healthcare strategists/executive rebel, Calcium
Philadelphia, PA

Susie Novis Durie, President
International Myeloma Foundation



Dear Friends,

As the IMF celebrates our 25th anniversary, what could be a better “present” than to know that we are about to launch “Cure Trials” through the IMF’s Black Swan Research Initiative®! This is a huge milestone, not just for the IMF, but for the entire Global Myeloma Community. This comes as the result of dedicated researchers and scientists working together in labs and institutions around the world.

The IMF has brought the Global Myeloma Community together in a profound way that has enabled us to make advances in research we only dreamed about before. To succeed, people have to trust one another, have really good ideas, and most importantly they have to agree to collaborate. The International Myeloma Working Group®, the research arm of the IMF, does just that.

Research to find a cure is paramount to our mission, and the IMF focuses both on lab and clinical research to achieve our goal. The IMF also focuses on funding Junior and Senior Research Grants for doctors working in institutions around the world. The IMF is now the premier funder of myeloma research grants, having awarded more than 100 grants since 1994 that have opened the doors to new ideas and major advancements in treatments.

During the twelve-month period of October 1, 2014 to September 30, 2015, we significantly expanded our global reach. Thanks to continued support from our pharmaceutical partners, the IMF held the 4th Annual Myeloma Master Class, an intensive course for young clinicians, designed by IMF Chairman Dr. Durie and following the 10 Steps for Better Care®. The Master Class once again welcomed 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 16th annual Support Group Leaders Summit. One hundred leaders attended, representing more 70 groups from across the US, and 29 leaders were attending for the first time! The weekend was spent learning about the latest advances in myeloma treatment and management, as well as learning from each other. Once again, a highlight for the attendees was Dr. Durie’s update on the Black Swan Research Initiative® and the “Pharma Round Robin,” where they learned about advances in therapies from Celgene, BMS, Onyx, and Takeda.

Thanks to the efforts of our Advocacy team, oral anticancer drug parity bills have been passed in 40 states plus the District of Columbia, 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®).

We also continued our efforts in global advocacy with the rebranding of the Global Myeloma Alliance (GMA) to the Global Myeloma Action Network® (GMAN®). The name change represents our commitment to action, and the mission remains the same – *to improve the lives of patients around the world*. GMAN members joined together with a common goal, to ensure patients have access to the newest approved treatments and educational materials, and to support continued innovation in blood cancer. GMAN now includes 37 organizations representing 33 countries around the world, with plans for strategic growth in the future.

The year was incredibly busy and very productive. But by far the most exciting of all our accomplishments this past year was the amazing progress the Black Swan Research Initiative is making. We truly are on the cusp of finding a cure.

Thanks to your support, 2014–2015 was a remarkable year, touching both cornerstone and innovative programs of the IMF, education, research, support, and advocacy! Thank you for your support. The door to the cure is open – let’s walk through it together!

Warm regards,

Susie Novis Durie
President

IMF Executive Team

Susie Novis Durie
President

Jennifer Scarne
Chief Financial Officer

Lisa Paik
Senior Vice President,
Clinical Education & Research Initiatives

Diane Moran
Senior Vice President,
Strategic Planning

Daniel Navid
Senior Vice President, Global Affairs

Pierre Sayad
Senior Vice President,
Global Medical Affairs & Strategic Partnerships

IMF Staff

Sevag Abajian, Database Manager

Betty Arevalo, Database & Inventory Control

Suzanne Battaglia, Director, Member Events

Debbie Birns, Medical Editor

Nancy Bruno, Southeast Regional Director,
Support Groups

Meghan Buzby, MBA, Senior Director of Advocacy

Sharon Chow, Special Events and
Donor Relations Manager

Kelly Cox, Director, Support Groups
& Regional Community Workshops

Elaine DeLasho, Administrative Assistant

Nadia Elkebir, Director, Europe & the Middle East

Sue Enright, Midwest Regional Director,
Support Groups

Carmen Greene, Meeting Coordinator

Paul Hewitt, InfoLine Coordinator

Kevin Huynh, Web Specialist

Marya Kazakova, Editor-in-Chief, Publications

Iana Kenville, Member Events Associate

Missy Klepetar, InfoLine Coordinator

Sapna Kumar, Communications Associate

Xuan Lam, Medical Affairs Assistant

Phil Lange, Accountant

Amirah Limayo, Research Project Coordinator

Randi Lovett, Director, Development

Jim Needham, Publication Design

Anne Pacowta, Florida Regional Director,
Support Groups

Selma Plascencia, Director of Operations

Annabel Reardon, Meeting Coordinator

Joy Riznikove, Development & Operations Assistant

Miko Santos, Web Producer

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Rafi Stephan, Assistant to the President

Lindsey Trischler, Advocacy Associate

Robin Tuohy, Senior Director, Support Groups

Judy Webb, InfoLine Coordinator

Jonathan Weitz, Outreach

Ray Wezik, Global Advocacy Executive



Prof. Dr. Jens Hillengass
Deputy Head, Multiple Myeloma Section
Department of Hematology, Oncology,
and Rheumatology
University of Heidelberg, Germany

Prof. Dr. Jens Hillengass studied at the University of Heidelberg medical school and began his research career in 1999 as a medical student in the lab for angiogenesis research of Thomas Moehler. Since 2002, Dr. Hillengass has worked in the Department of Hematology, Oncology, and Rheumatology at the University of Heidelberg, first as a resident, and currently as an attending physician in the Myeloma and Autologous Transplant Outpatient Department, where, he said, “We have a little bit more than 7,000 patient contacts per year and have performed autologous transplants in 250 patients in 2015.”

Dr. Hillengass came to the US in 2012 as a visiting researcher at the National Cancer Institute (NCI). He became a postdoctoral lecturer in 2013, and in 2016 earned an assistant professorship. He specializes in internal medicine, and hematology and oncology, and also teaches at the medical school of the University of Heidelberg.

He has been published in *JCO*, *Leukemia*, and *Clinical Cancer Research*, in studies on the prognostic and pathophysiologic impact of imaging findings in monoclonal plasma cell disorders.

“I learned about the IMF very early in my career working with myeloma patients, but in 2012 Dr. Ola Landgren introduced me to Dr. Brian Durie at the International Myeloma Working Group® (IMWG®) Summit in Amsterdam. Since 2013, I have worked with the Black Swan Research Initiative® (BSRI®), focusing on disease heterogeneity and advanced bone imaging.”

Dr. Hillengass continued, “The BSRI and IMWG meetings inspire me – I hear about new ideas, can discuss with more experienced researchers, and can present my own work and let it be reflected by other experts. I love to treat and educate patients and, together with Nadia Elkebir, [IMF Director of Europe & the Middle East] I have had the opportunity to do so in and outside Germany.”

RESEARCH

Research is a top priority for the International Myeloma Foundation. In fiscal year 2015 the IMF advanced its signature Black Swan Research Initiative®, continued to bring young investigators into the field through the Junior Research Grants program, and enhanced funding for more senior investigators. The IMF’s International Myeloma Working Group® (IMWG®) members collaborated on important myeloma projects that led to significant 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 (BSRI®) 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 new therapies and the advent of ultra-sensitive tests to measure exactly when and how those therapies are working in patients.



Phase One of the Black Swan Research Initiative was successfully completed during fiscal year 2015. An extremely sensitive flow cytometry method for MRD detection, Next-Generation Flow (NGF), was developed with IMF support, and is able to detect myeloma cells in the bone marrow at the highly sensitive level of one in a million cells.

Phase Two, launched at the end of fiscal year 2015, introduces NGF and other types of MRD testing to correlate in “cure” trials. The CESAR trial was launched in Spain, and the US ASCENT trial is set to launch in the first half of fiscal year 2016 at multiple institutions in the US, with Dr. Shaji Kumar of the Mayo Clinic as the principal investigator.

The Black Swan investigative team convened twice in fiscal year 2015 – at the International Myeloma Working Group (IMWG®) Summit in June 2015 in Vienna, Austria, and on the eve of the Annual Meeting of the American Society of Hematology (ASH) in December 2014 in San Francisco – to push ahead on several simultaneous projects designed to move us closer to finding a cure.

International Myeloma Working Group

The IMF founded the International Myeloma 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 more than 200 of the world’s leading myeloma researchers from 35 countries, the group publishes highly regarded consensus statements and guidelines for the management of myeloma.

In June 2015, the sixth annual IMF IMWG® Summit was held in Vienna, Austria. There, 75 of the world’s leading myeloma experts from 28 countries representing 55 institutions grappled with vital subjects to the myeloma community: the challenge of double refractory disease; the optimal use of stem cell transplantation in relapsed myeloma; genome sequencing; the identification of new actionable targets for myeloma therapy; new drug approvals; and the optimization of myeloma therapy.

Through the magic of modern technology, the myeloma community throughout the world was able to see some of the findings at the IMWG Summit. Dr. Durie moderated the IMWG Conference Series: “Making Sense of Treatment,” a live-streamed panel

discussion that included Drs. Ola Landgren, Joseph Mikhael, and Paul Richardson. The topics covered in the webcast (archived at <http://bit.ly/1HKsVuP>) included diagnostic criteria; revised ISS staging and personalized medicine; MRD testing/response criteria; the challenge of double refractory disease; and drug costs and access: 2015 and beyond.

In October 2014, the IMWG published new diagnostic guidelines in *Lancet Oncology*. These guidelines represent “a paradigm shift in myeloma,” according to Dr. Vincent Rajkumar, Edward W. and Betty Knight Scripps Professor of Medicine, Mayo Clinic, and lead author. “We are now willing to treat myeloma before symptoms happen.”



These diagnostic guidelines are a result of several years of study and collaboration by the IMWG's myeloma researchers worldwide. “The guidelines allow for the diagnosis of myeloma to be made in patients without symptoms and before organ damage occurs, using validated biomarkers associated with the near inevitable development of clinical symptoms.”

“This step forward has many important implications,” said IMF Chairman Dr. Brian Durie, “not the least of which is the expectation that earlier treatment will lead to better outcomes.” This, he noted, is the central idea of the IMF's signature Black Swan Research Initiative, in which early treatment is coupled with close assessment of residual disease to determine which therapeutic approach will ultimately achieve cure.

IMWG Publications

Long-term IMWG® research collaboration led to four publications during the October 2014 – November 2015 reporting period:

Revised International Staging System for Multiple Myeloma: A Report from International Myeloma Working Group.

Palumbo A, Avet-Loiseau H, et al. *J Clin Oncol*. 2015 Aug 3. doi: 10.1200/JCO.2015.61.2267

Geriatric Assessment Predicts Survival and Toxicities in Elderly Myeloma: An International Myeloma Working Group Report.

Palumbo A, Bringhen S, et al. *Blood*. 2015 Jan 27. doi: 10.1182/blood-2014-12-615187

Role of Magnetic Resonance Imaging in the Management of Patients with Multiple Myeloma: A Consensus Statement.

Dimopoulos MA, Hillengass J, et al. *J Clin Oncol*. 2015 Jan 22 doi: 10.1200/JCO.2014.57.9961

International Myeloma Working Group Updated Criteria for the Diagnosis of Multiple Myeloma.

Rajkumar Vincent S, Dimopoulos MA, et al. *Lancet Oncology*. 2014 Oct 27 doi: 10.1016/S1470-2045(14)70442-5

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

Asian Myeloma Network

A recognized source of expertise for myeloma in the Asian region, the IMF's Asian Myeloma Network® (AMN®), created in 2010, is comprised of leading hematologists from China, Hong Kong, Taiwan, Japan, Korea, Singapore, and Thailand. The AMN advises the IMF on its Asian programs and implements regional research projects and research activities.

During 2015, the network made considerable progress in several program areas. In the area of epidemiology, the AMN's Asian Myeloma Database was refined and expanded to



Dr. María-Victoria Mateos, MD, PhD
University Hospital of Salamanca
Hematology Department

Dr. María-Victoria Mateos, MD, PhD, is a Consultant Physician in the Haematology Department and Associate Professor of Medicine at the University of Salamanca, Spain. She is the director of the Myeloma Program and coordinates the Clinical Trials Unit in Salamanca's University Hospital Haematology Department. Also, Dr. Mateos serves as coordinator of Grupo Español de Mieloma (GEM, the Spanish myeloma group), with direct involvement in the design and development of clinical trials. She is a member of the International Myeloma Working Group (IMWG), International Myeloma Society (IMS), the European Hematology Association (EHA), and the American Society of Hematology (ASH). She has published more than 130 papers in peer-reviewed international journals. In 2015, she was named a Councilor on the EHA Board, a four-year mandate, is a member of the Steering Committee for the Society of Hematologic Oncology (SOHO), a member of the IMS board, and a member of the European School of Haematology (ESH) Scientific committee.

Dr. Mateos met the IMF and IMF Chairman, Dr. Brian Durie, in 2008, when she was invited to become a member of the International Myeloma Working Group (IMWG). “Since that moment, I am proud of have been involved in many activities supported by the IMF/IMWG, to be the author of some relevant IMWG guidelines, and to actively participate in its annual Summit meeting. I have also been involved in activities organized by the IMF with myeloma groups in Asia, and I serve as scientific advisor for IMF Latin America. I have also participated in the translation of the IMF *Patient Handbook*.”

“Finally, and this represents a key support, the Intergroupe Francophone du Myélome (IFM) is closely working with our group, through the Black Swan Research Initiative®, to standardize one highly-sensitive flow cytometry method for the detection of minimal residual disease (MRD) in myeloma. We are testing MRD detection as primary objective in a trial for asymptomatic myeloma patients at high risk of progression and it will help us to find the cure of some myeloma patients.”

Asian Myeloma Network Meeting 2014



Dr. Jae-Hoon Lee (Gachon University Medical School – Republic of Korea and IMWG member) speaks.



Dr. Bruno Paiva discusses Next-Generation Flow testing.



Prof. Wemming Chen joins Dr. Brian Durie at the lectern during Dr. Durie's keynote address.



Dr. Shaji Kumar speaks about MGUS and myeloma.



Prof. X.J. Huang, Chairman of the Chinese Myeloma Working Group, speaks at the anniversary of the Chinese Multiple Myeloma Research Center.

include information on myeloma incidence and treatment practices for more than 4,500 patients in Asia. A joint database reference was also developed by combining the work of IMF colleagues in Latin America.

In the treatment field, the AMN continued to work towards implementing an AMN Clinical Trials network. During 2015, a partnership was launched with Celgene to establish a pomalidomide patient-access program for some 140 patients in the AMN region where pomalidomide does not yet have regulatory approval (AMN001). A follow-up study (AMN003) is set for implementation in 2016 (randomized phase III study of pomalidomide-cyclophosphamide-dexamethasone [PCD] versus pomalidomide-dexamethasone [PD] in relapsed or refractory myeloma).

During 2015, the clinical trial AMN002, which studies the use of carfilzomib, thalidomide, and dexamethasone in relapsed or refractory myeloma, was arranged in cooperation with Amgen and the Australian Lymphoma and Leukemia Group.

A further project (AMN004) is set with Amgen and the National University of Singapore to extend, under AMN auspices, an existing Kypolis® (carfilzomib) trial in Singapore to patients in Korea. Finally, during 2015, discussions were initiated with Janssen for a Darzalex® (daratumumab) trial, possibly in cooperation with centers in Latin America.

The IMF expanded its Asian physician training during 2015, especially for young Chinese physicians. The IMF held two training programs in China, and two further programs for Chinese hematologists in conjunction with international conferences supported by Janssen, as well as the fourth annual Myeloma Master Class for young Chinese doctors at IMF's headquarters, supported by Celgene and Onyx/Amgen.

In the area of research, the AMN was an active participant in the IMF's Black Swan Research Initiative®, with expert and training sessions held in Japan and China, and a view to apply Next-Generation Flow in Asian laboratories. In addition, a 2015 Asian smoldering multiple myeloma study was initiated.

Finally, the AMN members supported patient education seminars in 2015 in China, Hong Kong, Japan, Korea, and Singapore.

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 2015 awards will continue to contribute significantly to the field of myeloma.



2015 Brian D. Novis Research Grant recipients

The IMF grants are funded by donations from private individuals. The presentation ceremony for the 2015 IMF Research Grant awards took place during the American Society of Hematology (ASH) annual meeting held in San Francisco, California in December 2014.

Brian D. Novis Research Grants 2015

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 2015

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

Claire M. Edwards, PhD

University of Oxford – United Kingdom

Caloric restrictions and bone marrow adiposity in myeloma

Yang Yang, MD, PhD

University of Alabama at Birmingham

The role of myeloma cell-derived Runx2 in myeloma metastasis: focus on bone microenvironment

Brian D. Novis Junior Research Grants 2015

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

Francesca Cottini, MD

Dana-Farber Cancer Institute – Boston, Massachusetts

Targeting the kinase STK4 to treat myeloma

Tarun K. Grag, PhD

University of Arkansas for Medical Science – Little Rock, Arkansas

Myeloma cells modulate ICAM3 to evade natural killer cell-mediated lysis

Patricia Maiso, PhD

Clinical University of Navarra, Spain

Role of hypoxia in myeloma: new therapeutic approaches targeting minimal residual disease and drug resistance

Amit Kumar Mitra, PhD

University of Minnesota at Minneapolis

Identifying tumor response heterogeneity using single-cell transcriptomics

IMF Japan Research Grants

The annual multiple myeloma research awards were instituted in 2002 by IMF-Japan in memory of its founder, Aki Horinouchi. The following awards were presented at ASH 2014 by IMF-Japan.

Hideto Tamura MD, PhD

Nippon Medical School – Tokyo, Japan

The role of SLAM family molecules and immunotherapy with SLAM-directed chimeric antigen receptor (CAR)-engineered T cells in myeloma.

Hirofumi Tachibana, MD, PhD

Kyushu University – Fukuoka, Japan

Elucidation of the molecular mechanism on a novel apoptotic cell death-inducing pathway in myeloma cells

Hiroyuki Tamamatsu, MD, PhD

Kanazawa University Graduate School of Medical Sciences – Kanazawa, Japan

Minimal residual disease monitoring in myeloma using next-generation sequencing

2015 Brian D. Novis and Japan Research Grant Award Winners



Yang Yang, MD, PhD



Claire M. Edwards, PhD



Francesca Cottini, MD



Tarun K. Grag, PhD



Patricia Maiso, PhD



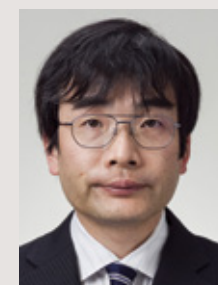
Amit Kumar Mitra, PhD



Hideto Tamura, MD, PhD



Hirofumi Tachibana, MD, PhD



Hiroyuki Tamamatsu, MD, PhD

Robert A. Kyle Lifetime Achievement Award

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



Pieter Sonneveld, MD, PhD
receives the Robert A. Kyle Lifetime
Achievement Award from Dr. Kyle.

In June 2015 in Vienna, Austria, Pieter Sonneveld, MD, PhD, was awarded the 13th annual Robert A. Kyle Lifetime Achievement Award. Dr. Sonneveld earned his doctorate degree with a thesis on the pharmacology of Adriamycin® (doxorubicin) in acute leukemia. Soon after, he performed his first transplant. Through the years, Dr. Sonneveld has attained leadership in numerous professional organizations.

Currently, he is the Chairman of the Dutch HOVON Myeloma Cooperative Group, and he coordinates clinical trials for lymphoma, leukemia, and multiple myeloma in The Netherlands. He serves on the executive board of the European Hematology Association (EHA). He is also on the Scientific Advisory Boards of more than eight major hematology publications, and is the Associate Editor of *Haematologica*. In addition, Dr. Sonneveld is Chairman of the European Myeloma Network.

Dr. Sonneveld accepted the honor with his characteristic modesty. "I feel honored to receive the 2015 Robert A. Kyle Lifetime Achievement Award, and I share it with the people who participated in our trials and research during many years," he told the audience of nearly 200 people.

"I am," he added, "very privileged to work with many gifted and dedicated people from all over the world to find a cure for multiple myeloma and to improve the lives of our patients."

Research Events of 2015

Several conferences bring together myeloma researchers from around the world annually. The IMF participates in each in order to present our research, to increase dialogue around this disease, and to stay abreast of important findings on multiple myeloma research from around the world. The 56th 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 in myeloma diagnostics and treatment.

IMF at ASH

The 56th American Society of Hematology Annual Meeting and Exposition took place December 6–9, 2014 in San Francisco, California, at the Moscone Center. More than 35,000 hematologists/oncologists from around the globe attended the meeting. The myeloma studies fell into two major categories: combination studies with approved agents and studies with experimental agents.



The 855 myeloma-related presentations demonstrated steady progress on the research side in understanding myeloma's complex and evolving biology. On the clinical side, presentations at ASH demonstrated the ever-expanding arsenal of tools available to effectively diagnose, treat, and monitor patients.

Led by Robin Tuohy, IMF's Senior Director of Support Groups, a team of myeloma Support Group Leaders from across the country reported on the news from ASH through social media. The IMF's video team interviewed key ASH 2014 myeloma presenters to discuss the implications of their findings. These video interviews were posted to the IMF website to inform healthcare professionals, patients, families, and caregivers.

IMF at ASCO

The Annual Meeting of the American Society of Clinical Oncology (ASCO) was held May 29–June 2, 2015, in Chicago, IL. The meeting brought together more than 25,000



oncology professionals from a broad range of specialties and featured more than 5,000 abstracts, with nearly 100 that focused on myeloma. The most highly anticipated myeloma presentations in 2015 included trial results for experimental agents which had not yet been FDA-approved at the time (Darzalex® and Empliciti®). Discussion focused on how the arrival of these drugs on the scene signaled a

new era in cancer treatment: the era of immunotherapeutic monoclonal antibodies, which target receptor sites on the cancer cell surface and enlist immune system cells to dispatch the cancer.

The IMF team provided myeloma educational materials to the thousands of ASCO attendees and conducted video interviews with key presenters at the IMF booth in Chicago.

EDUCATION

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

In 1993, the IMF became the first organization to conduct Patient & Family Seminars, which provide 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 2014 to September 2015, more than 990 people attended US-based seminars held in Los Angeles, California; Redwood City, California; Boca Raton, Florida; Short Hills, New Jersey; and Philadelphia, Pennsylvania. Outside of the US, nearly 2,275 people attended seminars held in Italy, France, Austria, Germany, the Czech Republic, Slovakia, Norway, Denmark, Spain, and Poland.



Patients dance and enjoy the deejay at an IMF Patient and Family Seminar.

Regional Community Workshops

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

From October 2014 to September 2015, more than 1,250 people attended US workshops in Ann Arbor, Michigan; Charlotte, North Carolina; Chicago, Illinois; Dallas, Texas; Denver, Colorado; Minneapolis, Minnesota; Richmond, Virginia; San Diego, California; Seattle, Washington; and Washington, DC.

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 2015, 300 physicians attended workshops held in Oslo, Norway; Odense, Denmark; and Heidelberg, Germany.

Publications

The IMF produces an extensive library of educational materials, which are offered free of charge both in print and on the IMF website. The IMF library of publications provides



Tom Swick
Support Group Leader
San Clemente, California

Tom Swick is Chairman and Leader of the Orange County California Myeloma Support Group. In 2007, he was diagnosed with IgA-lambda type myeloma at the age of 54. He feels very fortunate to have maintained a stable remission since initial treatment.

While attending the 2014 American Society of Hematology Annual Meeting in San Francisco, California with the IMF, Tom participated in breakout sessions with a number of myeloma experts, including Drs. Shaji Kumar, Thomas G. Martin III, Torben Plesner, Bart Barlogie, Paul G. Richardson, Rachid Baz, and Martha Q. Lacy, among others. Reporting quietly from the audience in the panel, Tom wrote detailed accounts of these doctors' various studies, which were posted on the IMF ASH 2014 website. In one of these blogs, Tom joked, “I’ve been up for 19 hours now. Thank God For Dex (TGFD).”

Tom wrapped up ASH 2014 with the meeting of the International Working Group® (IMWG®), where the IMWG myeloma experts discussed the status of research papers in progress, changes in IMWG processes, and suggestions for new projects. Tom was grateful that the IMF, particularly Senior Director of Support Groups, Robin Tuohy, and Director of Support Groups & Regional Community Workshops, Kelly Cox, and his fellow Support Group Leaders, helped him to have such a terrific time at ASH 2014.

Tom also participated in the Support Group Leaders Summit in July, and attended the Los Angeles Patient and Family Seminar in August. He has worked as a software engineer in the computer and aerospace industries, and lives in San Clemente, California, with his wife Judy. They have three daughters, a dog, and a bird.

IMF 2015 List of Publications

*Bookmark***

*Concise Review***

*Guide to Multiple Myeloma Acronyms and Abbreviations***

*Guide to Multiple Myeloma Terms and Definitions***

Mail for the CURE

Making Miracles

*Myeloma Matrix***

Myeloma Today

*Patient Handbook***

*Tip Card Freelite® and Hevylite®***

*Tip Card Immune System**

*Tip Card Kyprolis® (carfilzomib)***

*Tip Card Pomalyst® (pomalidomide)***

*Tip Card SQ Velcade® (bortezomib)***

*Tip Card Veterans Against Myeloma (VAM)**

*Tip Card - What is Multiple Myeloma? What is the IMF?**

*Understanding Adherence to Oral Cancer Therapy***

*Understanding Bisphosphonate Therapy***

*Understanding Clinical Trials***

*Understanding Dexamethasone and Other Steroids***

*Understanding Fatigue***

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

*Understanding the Immune System in Myeloma**

*Understanding Kyprolis® (carfilzomib)***

*Understanding MGUS and Smoldering Multiple Myeloma**

*Understanding Pomalyst® (pomalidomide) capsules***

*Understanding Revlimid® (lenalidomide)***

*Understanding Freelite® and Hevylite® Tests***

*Understanding Thalidomide Therapy***

*Understanding Treatment of Myeloma-Induced Vertebral Compression Fractures**

*Understanding Velcade® (bortezomib) for injection***

*Understanding Your Test Results***

*New (between 10/1/14 and 9/30/15)

**Updated (between 10/1/14 and 9/30/15)

up-to-date information on all issues affecting the myeloma community, including innovations in treatment, information on clinical trials, updates on policy issues, and



more. Frequently requested publications include the *IMF Patient Handbook*, *Concise Review*, the *Understanding* series booklets, and the quarterly magazine *Myeloma Today*®. Many IMF publications are translated into multiple languages. In addition, medical articles are translated on a quarterly basis into French, Italian, German, and Spanish – and these are available on the IMF site and via quarterly e-newsletter *Myeloma Messenger*.

The IMF InfoPack, 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 2015 fiscal year, more than 3,000 InfoPacks were disseminated to patients, healthcare providers, and support groups around the world.

From October 2014 through September 2015, the IMF produced 7 new publications and updated more than 30 publications. A selection of the new or updated English-language publications were translated into multiple languages. The quarterly *Myeloma Today* magazine had a print subscriber base of 16,000 as well as a web-view and pass-along rate independently estimated at 75,000. The weekly *Myeloma Minute* subscriber base has more than 28,000 readers.

Teleconferences

IMF teleconferences are a way for the myeloma community to connect with myeloma experts. The IMF held six teleconferences for patients and caregivers during the 2015 fiscal year, including nearly 9,500 calls in the IMF's popular "Living Well with Myeloma" series. Topics of the calls included "Understanding the Immune System," "Sustainable Wellness," "Nurse Leadership Board (NLB) Members Address Patients & Caregivers," and "Myeloma 101 Updates on Treatment and Pain Management." In addition, 2015 teleconferences provided myeloma news immediately following the annual meetings of the American Society of Hematology (ASH) and the American Society of Clinical Oncology (ASCO). Recordings of all IMF teleconferences are available on the IMF website. More than 23,000 people have listened to live and archived recordings of 2015 teleconferences.

Living Well with Myeloma Teleconference Series

Sustainable Wellness – An Integrative Approach to Transform Your Mind, Body, and Spirit



Date: Thursday, May 7, 2015
Time: 4:00 pm PT / 5:00 pm MT / 6:00 pm CT / 7:00 pm ET
Duration: 60 minutes (including Q&A)
Speaker: Matt Mumber, MD
 Radiation Oncologist
 Georgia Research Alliance
 Distinguished Scientist

www.mindbodyspirit.myeloma.org

Medical Professional Education

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

Myeloma Master Class

The Myeloma Master Class is a medical education program developed by the IMF four years ago, and is an intensive educational course designed for clinicians who specialize in myeloma. The fourth annual Master Class, held in August 2015 in Los Angeles,



The 2015 Myeloma Master Class with IMF team

welcomed young Chinese hematologists from leading myeloma centers in Beijing, Fuzhou, Guangzhou, Hangzhou, Shanghai, and Tianjin, China. In addition to classroom learning, the doctors visited the City of Hope National Medical Center and took part in the IMF Los Angeles Patient & Family Seminar, where they participated in individual patient consultations. The Master Class featured several days of interactive lectures and discussions on the full range of modern myeloma diagnosis and treatment with leading myeloma specialists Dr. Brian Durie (IMF Chairman and Cedars-Sinai Samuel Oschin Cancer Center); Dr. Joseph Mikhael (Mayo Clinic, Scottsdale, Arizona); Dr. Tom Martin (Helen Diller Family Comprehensive Cancer Center, San Francisco, California); Dr. Robert Vescio (Cedars-Sinai Medical Center); and Dr. Amrita Krishnan (City of Hope National Medical Center). The young Chinese doctors allowed these skilled clinicians to refine their knowledge of myeloma and its treatment issues by meeting with world-renowned myeloma experts. But perhaps, most importantly, the Master Class provides the chance to see doctor-patient interactions in the US.

Educational Outreach in Europe

The IMF continued to strengthen its international relationships with patients, families, and advocacy groups abroad in 2015 with educational meetings in 10 European countries. By collaborating with doctors in each country, the IMF works to provide the most updated myeloma research and treatment information to patients in their own languages. In the coming year, the IMF will expand its presence to 5 more countries.



Nadia Elkebir, IMF Director of Europe and the Middle East, at the Patient & Family Seminar in the Czech Republic

Nurse Leadership Board

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

NLB members work each year to bring relevant information to patients and healthcare providers by presenting at key conferences, seminars, and workshops. They also conduct educational teleconferences, make contributions to IMF website content and publications, and publish research on myeloma management.



IMWG Conference Series: "Making Sense of Treatment"

The International Myeloma Working Group® (IMWG®) Conference Series: "Making Sense of Treatment" is an IMF medical education program designed to bring experts together to discuss the most pressing myeloma treatment issues. "Making Sense of Treatment" is available to be viewed live online in homes and offices around the world. In fiscal year 2015, the IMWG hosted two 90-minute conferences that garnered more than 4,000 viewers worldwide (combined live stream and recorded replay views). These meetings can be viewed at imwgonferenceseries.myeloma.org on the IMF website.

The first conference of fiscal year 2015 took place on Dec. 8, 2014 at the American Society of Hematology (ASH) annual meeting in San Francisco, California. Its panel included Drs. Brian Durie, Ola Landgren, Joseph Mikhael, and Antonio Palumbo. These doctors provided differing opinions on appropriate therapies for high-risk smoldering multiple myeloma (MM), the timing of beginning frontline therapy, and the role of minimum residual disease (MRD) testing.

The second program of the fiscal year, broadcast on June 10, 2015, featured Drs. Brian Durie, Joseph Mikhael, Ola Landgren, and Paul Richardson. It focused on data presented at the 2015 American Society of Clinical Oncology (ASCO) annual meeting and the 2015 European Hematology Association (EHA) meeting. Topics included the new diagnostic criteria for multiple myeloma (which were published near the end of 2014); the revisions to the International Staging System (ISS) as a baseline for evaluating patients at diagnosis; MRD-testing and how it impacts response criteria; the challenge of double-refractory disease; drug cost escalation; and global access to novel treatments.



**Beth Faiman, PhD, RN, MSN,
APRN-BC, AOCN®**

**Cleveland Clinic Taussig Cancer Institute
Cleveland, Ohio**

Beth Faiman, PhD, received a bachelor of science in nursing and registered nurse certification at Ursuline College in Pepper Pike, Ohio in 1996. She earned a master of science in nursing and certification as an adult nurse practitioner at Kent State University in Kent, Ohio in 2002, and a PhD from Case Western Reserve University in 2014. She holds an advanced oncology nurse certification through the Oncology Nursing Certification Corporation (ONCC). She is an Adult Nurse Practitioner in the department of Hematologic Oncology and Blood Disorders at the Cleveland Clinic in Cleveland, Ohio, and is adjunct faculty at Ursuline College, Case Western Reserve University, and Kent State University.

In 2012, she received an Excellence in Medical Oncology award, and in 2013, was awarded the Commendation for Patient and Nursing Education Award sponsored by The Oncology Nursing Society. In 2015, Beth Faiman earned the Dean's Legacy Award for PhD Studies from Case Western Reserve University.

An active author, presenter, and educator on the topic of blood cancers, Beth Faiman is an appointed delegate on the International Myeloma Foundation Nurse Leadership Board. She is currently Editor-in-Chief of The Oncology Nurse APN/PA and on the editorial board of ASH Clinical News. She has edited several books and authored many works relating to diagnosis and management of multiple myeloma, blood disorders, bone marrow transplant, and cancer symptom management.

Beth began caring for patients with blood disorders and their families at the Cleveland Clinic in 1994. "Until there is a cure for blood cancers, I am passionate to find ways to add to one's quantity of life, preserve their quality of life and manage their side effects. We are in this fight together. Patients and caregivers can count on me for help in the best way that I can provide."

The NLB's tenth annual meeting, held in Los Angeles, California in October 2014, provided the opportunity to discuss the current state of myeloma care, identify unmet needs for patients and nurses, and plan ways to address those unmet needs. During the meeting, the NLB reviewed the results of their original research into the health maintenance of myeloma patients, and made plans for publishing their research.

Throughout fiscal year 2015, NLB members led education sessions at IMF Patient & Family Seminars, Myeloma Center Workshops, and Regional Community Workshops; accompanied support group leaders to the 2014 Annual Meeting of the American Society of Hematology (ASH); and addressed the IMF's 2015 Support Group Leaders Summit. The NLB contributed to IMF publications and spoke on monthly teleconferences in the IMF's popular "Living Well with Myeloma" series, which is open to the entire myeloma community.

With contributions by NLB members, including Beth Faiman PhD, RN, MSN, APRN-BC, AORN®, and Joseph Tariman, PhD, ANP-BC serving as co-authors and editors, the Oncology Nursing Society published the Second Edition of the *Multiple Myeloma Textbook for Nurses* in fiscal year 2015. Also during this time, several NLB members contributed to a series of papers to help guide the advanced practitioner in the clinical management of multiple myeloma. These papers will be published by the journal JADPRO in 2016 as a supplement entitled *The Advanced Practitioners Guide to Multiple Myeloma*.

At the 2015 Oncology Nursing Society Annual Congress in Orlando, Florida, the NLB hosted a CNE-accredited satellite symposium that was attended by more than 600 nursing professionals and served as an example of the NLB's exceptional work to bring expert myeloma advice to nurses in all communities.

IMF Nurse Leadership Board Members

Page Bertolotti, RN, BSN, OCN®

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

Kevin Brigle, PhD, NP

VCUHS Massey Cancer Center
Richmond, VA

Donna D. Catamero, ANP-BC, OCN, CCRC

Mount Sinai Medical Center
Multiple Myeloma Program
New York, NY

Kathleen Colson, RN, BSN, BS

Dana-Farber Cancer Institute
Boston, MA

Hollie Devine, MSN, ANP-BC

The Ohio State University Medical Center
James Cancer Hospital
Multiple Myeloma Program
Columbus, OH

Deborah Doss, RN, OCN

Dana-Farber Cancer Institute
Boston, MA

Beth Faiman, PhD, RN, MSN, APRN-BC, AOCN

Cleveland Clinic Taussig Cancer Institute
Multiple Myeloma Program
Cleveland, OH

Elizabeth Finley-Oliver, RN, BSN, OCN

H. Lee Moffitt Cancer Center & Research Institute
Tampa, FL

Charise Gleason, MSN, NP-BC, AOCNP

Winship Cancer Institute of Emory University
Atlanta, GA

Sandra Kurtin, RN, MS, AOCN, ANP-C

The University of Arizona Cancer Center
Tucson, AZ

Patricia A. Mangan, RN MSN, APRN-BC

Abramson Cancer Center at the University of Pennsylvania
Philadelphia, PA

Ann McNeill, RN, MSN, APN

John Theurer Cancer Center at HUMC
Hackensack, NJ

Teresa Miceli, RN, BSN, OCN

Mayo Clinic - Rochester
Rochester, MN

Kimberly Noonan, MS, RN, ANP, AOCN

Dana-Farber Cancer Institute
Boston, MA

Tiffany Richards, RN, MSN, ANP, AOCNP

MD Anderson Cancer Center
Houston, TX

Sandra Rome, RN, MN, AOCN, CNS

Cedars-Sinai Medical Center
Los Angeles, CA

Joseph Tariman, PhD, ANP-BC

School of Nursing/College of Science & Health De Paul University
Chicago, IL

Daniel Verina, BS, BSN, MSN, ACNP-BC

Mount Sinai Medical Center
Hematology, Myeloma Team
New York, NY

International Affiliates

Tracy King, RN, MN

Institute of Hematology
Royal Prince Alfred Hospital
Sydney, Australia

Cindy Manchulenko, RN, BN, MSN

Clinical Research Nurse
Leukemia/BMT Program of BC
Hematology Research and Clinical Trials Unit
Vancouver, BC

SUPPORT

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

myeloma.org

The IMF offers patients and caregivers multilingual access to all current myeloma research (IMF-funded research and otherwise), the latest community developments, and linkage to support services and advocacy forums. From October 2014 to September 2015, more than 400,000 visitors went to myeloma.org, tallying nearly 1,110,000 page views. IMF-produced videos and presentations received close to 25,000 views. During this time period, the IMF's website also received more than 150,000 views from mobile devices. The IMF website is a leading resource for myeloma-related content and the most complete source of answers to the many questions asked by those who are newly diagnosed.

Social Media



The IMF has worked in recent years, and especially in 2015, to expand its support to those living with or affected by multiple myeloma through social media. To increase visibility and awareness of myeloma and to support those living with or affected by myeloma, the IMF now has a growing presence both on Facebook and Twitter, with more than 6,200 "Likes" and 4,200 "Followers," respectively. This represents a 17% increase in Likes on Facebook and a 31% increase of Followers on Twitter in the past year.

Toll-Free InfoLine

The IMF's toll-free InfoLine provides life-saving myeloma treatment and management support from highly trained specialists. As new treatment options are gaining attention and use in multiple myeloma, the team answers increasingly more questions about myeloma, its treatment, drug side effects, options for possible clinical trials, and other health concerns. The specialists also assist callers in finding local support, which is more important than ever. The toll-free InfoLine has been a valuable resource to patients, families, and caregivers in 2015. From October 2014 to September 2015, InfoLine responders supported 2,481 callers and answered more than 1,000 emails.



InfoLine coordinators Paul Hewitt, Judy Webb, and Missy Klepatar

Support Groups

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

The IMF currently supports more than 300 support groups worldwide. In the 2015 fiscal year, the IMF's team of support group directors made 219 in-person visits to local support group meetings, IMF Patient & Family Seminars, and Regional Community Workshops. Support group directors visited several groups many times throughout the year to foster sustainability and support new leadership.

From October 2014 through September 2015, six new support groups were formed.



Cindy Ralston
Support Group Leader
Kansas City, Missouri

Cindy Ralston, Myeloma ACTION Team member and Kansas City Support Group Leader, successfully passed a proclamation in her town declaring March 2015 to be Myeloma Awareness Month. She then drafted an email for the members in her support group that could be customized to each person's city or town, which was used as a template for everyone requesting a proclamation be passed. Cindy also made herself available to those who had questions about the process.

Overall, Cindy and her support group enabled six towns in the area to declare March as Myeloma Awareness Month. The group also has done amazing work by collecting postcards to make legislators aware of the anticancer drug oral parity issue.

When asked about her involvement in advocacy and support, Cindy began with a quote by Adlai E. Stevenson, who once said, "Some people come into our lives and quickly go. Some stay for a while, leave footprints on our hearts, and we are never ever the same." "This is true of myeloma and what it has brought into my life," said Cindy. "Since being involved in a support group since 1996, I have come to realize the physical and mental challenges that myeloma brings to each one of our members and their supporters. I refer to my group as my 'Myeloma Family.' ... From our support group members to the IMF Staff and other support group leaders across the country who share and help each other to support, educate, and enhance the lives of the myeloma community. They are truly the strength behind the battle to fight myeloma until there is a cure."

Cindy's initiative to get more group members involved played an intricate role in the IMF's Myeloma Awareness efforts, and we cannot thank her enough for her leadership.



John Auerbacher
Support Group Leader
White Plains, New York

In April of 2015, the IMF suffered a great loss – founding member Mike S. Katz lost his twenty-five-year battle with multiple myeloma. Mike's accomplishments were immeasurable. Nevertheless, myeloma patient John Auerbacher did not hesitate to step up to the plate to continue Mike's compassionate work.

Since Mike's passing, John has co-led the Westchester Myeloma Support Group (NY), along with Jeff O'Donnell. He has participated in the IMF's "Living Well with Myeloma" teleconferences, quarterly support group leaders' calls, and attended the 2015 American Society of Hematology annual conference.

In August 2004, before learning of his multiple myeloma diagnosis, John was vacationing with his wife, his eight-year-old son, and his five-year-old daughter at a Montana dude ranch. John was injured during a horseback ride, but he continued his vacation so his children could enjoy Yellowstone and Old Faithful. Unfortunately, the pathological nature of John's L5 spinal fracture was not recognized. Upon returning to New York, an orthopedist realized that John had multiple myeloma.

Shortly after this trip, John met IMF Chairman Dr. Brian Durie and IMF President Susie Novis Durie at an IMF Patient & Family Seminar.

In an IMF ASH blog post, John provided insight into patient care. He wrote, "I have been thinking about second opinions. Maybe 'second relationship' should be the next-generation moniker. A second opinion is a one-time occurrence. A second relationship is what patients need, whether the first relationship is with a myeloma specialist or a general hematologist/oncologist. A second relationship with a myeloma specialist affords comparison as to the efficiency, hospitality, and competency of your first relationship [on a continuing basis]." The IMF is proud to have John Auerbacher as part of our patient support team. We are sure Mike Katz would be proud as well!

During the 2015 fiscal year, the IMF conducted 20 teleconferences for patients, caregivers, medical professionals, and researchers; these teleconferences also included 10 calls with Nurse Leadership Board (NLB) members to speak to support groups. Three-hundred support group members participated in the calls with NLB members. Quarterly support group leader conference calls had an average of 50 participants per call.

The IMF offers unequalled website creation and hosting for local support groups. The IMF has created or updated 130 local support group websites and supports an additional 12 local group websites.

The IMF provided a unique opportunity for 12 support group leaders to attend the American Society of Hematology (ASH) annual meeting in San Francisco, California in December 2014. During the meeting, the support group leaders from across the US attended presentations on myeloma research, the IMF's educational events, and more. They shared their experiences through nearly 50 blogs, Twitter, and Facebook, and with their local support communities. In fact, these tireless and passionate myeloma SGLs not only blogged and tweeted the most important myeloma news, they also earned the IMF a perch among the "Most Influential on Twitter," a title bestowed by Symplur, an organization that ranks healthcare activity on social media. A site dedicated to IMF at ASH 2014 can be visited at <http://ash2014blogs.myeloma.org/>.

Through the IMF Ambassador Program, support group members attended 2014 Patient & Family Seminars, creating a welcoming atmosphere and introducing them to other myeloma patients. In addition, the Ambassador Program brought greater awareness to local support groups and increased membership.

The 16th annual IMF Support Group Leaders Summit took place in Dallas, Texas. A total of 100 Support Group Leaders (SGLs), representing 70 groups, attended the Summit. This was the first summit for 29 of the SGLs. The 70 groups represented at the Summit serve more than 4,000 support group members, extending the Summit's reach to thousands of myeloma patients and family members.

The 2015 Summit was packed with sessions offering the latest news about myeloma treatments, medical updates from Dr. Brian Durie, and topics such as advocacy, technology, leadership skills, marketing, websites, and group administration were presented to equip SGLs to run successful groups. In addition, the needs of caregivers were addressed. Some groups left the Summit with intentions of planning special sessions just for the caregivers who attend their local support communities!

Finally, technology was also emphasized for SGLs. Through the IMF Support Group Leader Toolkit/Technology Grant, 70 SGLs received iPads and jump drives with updated information on myeloma support.



Support Group Leaders with IMF team members at the 2015 Annual Support Group Leaders Summit

ADVOCACY

The International Myeloma Foundation (IMF) advocates on behalf of patients affected by multiple myeloma to insure an increase in accessibility to high-quality diagnostics and treatments, for funding of myeloma-related research, and to end insurance coverage disparities for treatment. The IMF works with the entire myeloma community in these efforts. In 2015, the IMF strengthened a network of international advocates to address global advocacy issues; and in the US made headway on legislation to increase myeloma patients' accessibility to oral anticancer medication. The IMF accomplished this by lobbying for state and federal legislation, increasing legislators' awareness of myeloma, and furthering the national dialogue on myeloma.

International Advocacy Efforts

Global Myeloma Action Network

The Global Myeloma Action Network® brings together advocacy leaders in myeloma and blood cancer to mobilize the myeloma community to improve the lives of patients around the world.

The first large-scale GMAN® meeting in fiscal year 2015 was at the Annual Meeting of the American Society

of Hematology in San Francisco on December 7, 2014. The meeting was attended by IMF President & Co-Founder Susie Novis Durie; IMF Global Advocacy Executive Ray Wezik; patient advocates Eric Low (Myeloma UK); Steve Roach, Brian Rosengarten, and Haley King (Myeloma Australia); Aldo Del Col and Francine Gendron (Myeloma Canada); and Christine Battistini and Crucita Machado (IMF Latin America). Increasing patient access to clinical trials, working with key stakeholders to expedite this access, and helping to improve trial design were among the important goals decided upon by the group.

The second GMAN meeting took place in June 2015 at the IMF's International Myeloma Working Group® (IMWG®) Summit in Vienna, Austria. Twenty-five groups represented the 23 countries that attended. These countries included Australia, Austria, Belgium, Brazil, Canada, Croatia, Denmark, Estonia, France, Germany, Hungary, Israel, Italy, Paraguay, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, South Korea, the United Kingdom, and the United States. Dr. Paul Richardson of Dana Farber Cancer Institute in Boston, MA, was guest speaker.

A survey of GMAN members unearthed common challenges faced by many myeloma patients world round. Then, Summit participants shared the challenges their groups face in educating patients and ensuring physicians have access to the latest myeloma information.

IMF Medical Editor Debbie Birns walked the group through the organization's 10 Steps to Better Care®, which is IMF Chairman Dr. Brian Durie's myeloma treatment framework. And IMF Member Events Director Suzanne Battaglia encouraged member nations to initiate fundraising efforts at a local level. She commented that organizing a fundraising event in a person's honor helps the family's healing process, providing an unexpected benefit.

Finally, Susie Novis Durie offered a well-received overview of best practices in applying for education grants from industry partners. "Meet with them," she advised. "See what their needs are. Then, go back to your team and brainstorm to come up with a program that will address their challenge."



Gratia Williams Nakahashi
New York, NY

IMF supporter Gratia Williams Nakahashi is an advocate who has gone above and beyond in her efforts to affect change in myeloma legislation. In March of 2009, her husband Kenji Nakahashi was diagnosed with high-risk multiple myeloma. After two treatment regimens and one successful remission, Kenji was on the cusp of another relapse. The couple began searching for additional treatment options. Kenji's doctor, a transplant specialist at Weill Cornell Medicine's Multiple Myeloma Center, recommended a T-cell depleted allogeneic transplant that had been pioneered at Memorial Sloan Kettering Cancer Center by Dr. Gunter Koehne.

A few weeks later, the couple met Dr. Koehne, who warned that they might have issues receiving coverage from Medicare for the T-cell depleted transplant. As a result, Gratia embarked on her fight to change Medicare policy so Kenji, and other patients like him, could receive life-saving treatments.

She began speaking with the National Marrow Donor Program (NMDP). At the same time, she raised the issue with the office of Senator Kirsten Gillibrand (D-NY) to investigate any legislative recourse she may have. Finally, Gratia re-contacted the NMDP and also connected with the IMF to suggest a partnership between the two organizations. She also garnered more support from the Patient Advocate Foundation.

Within only a few months, Gratia has proved to be an inspiring advocate. She has recently heard from Sean Cavanaugh and Dr. Patrick Conway, both acting members of the CMS's administration team. The latter is the director of the program within CMS that makes coverage determinations on the Nakahashis' treatment issues. Gratia and her husband made strides in their fight, and by 2016, CMS policies on allogeneic transplants finally changed.



Kelly Fields Owens
Support Group Leader
Nashville, Tennessee

Kelly Fields Owens is the Nashville Multiple Myeloma Support Group leader and also works as a social worker at Vanderbilt University Ingram Cancer Center. Her primary job function at the cancer center is patient support – that support can be to help procure financial resources for families or to provide the extra emotional support they need. Often, it's both. Because Kelly knows how expensive many chemotherapy regimens may be, she often refers patients to foundations that can provide grants to offset the cost of drugs and/or out-of-pocket medical expenses.

Over the course of the IMF Advocacy's oral parity campaign, Kelly has excelled in recruiting advocates, finding patient stories, and mobilizing members of her support group to call their legislators. She has participated in stakeholder meetings and testified before the Tennessee State Senate Commerce and Labor Committee, where she represented the patient's perspective and gave insight on what it is like for those who cannot afford their medications. As Kelly told the committee, "I see patients at the worst times of their lives. I see the fears. I see the tears. I hear the agony and anxiousness in their voice when they have to choose either to pay a bill, buy food, or buy their medications. Just this week, I had a patient call crying because she had been without her medicines for one week. These are citizens who work and have insurance."

Kelly has not lost steam in the fight for oral parity legislation. She currently emails with members of her support group to encourage them to reach out to Tennessee representatives in favor of getting an oral parity bill passed. Even though Kelly realizes she cannot take away someone's cancer diagnosis, she says, "I can make a difference in their journey with their cancer treatment by being an advocate. Being an advocate is social work 101. It's where the patient is. I'm inspired by the work I do because I know I can make a difference." The IMF could not be more grateful for Kelly's passionate work.

The third GMAN meeting occurred at the International Myeloma Workshop (IMW) in September 2015. The GMAN meeting focused on sustainability of organizations. A total of 15 groups representing 14 countries were present, plus 19 non-IMF, non-industry individuals. Speakers included Dr. Jean-Luc Harousseau and Sofia Cardoso of the Portuguese Patient Association Against Leukemia.

US Advocacy Efforts at the Federal Level

Patients Equal Access Coalition

In fiscal year 2015, the Patients' Equal Access Coalition® (PEAC®), a collection of 30 different advocacy organizations that represent the patient, provider, and industry perspective on the rights and care of cancer patients.

For example, on June 11, 2015, the Cancer Drug Coverage Parity Acts were introduced with bipartisan and bicameral support. PEAC secured 45 co-sponsors for the House bill (H.R. 2739) and seven co-sponsors for the Senate bill (S. 1566).



In addition, on September 30, 2015, PEAC held its first Congressional briefing on oral parity. Senior Director of Advocacy, Meghan Buzby, moderated the event, during which members of Congress and their staff members heard from advocates representing the patient, provider, caregiver, and industry perspectives. As a result, PEAC was able to secure eight additional co-sponsors.

US Advocacy Efforts at the State Level

State Patients Equal Access Coalition

The State Patients Equal Access Coalition® (SPEAC®), a collection of 25 advocacy organizations that represent the patient, provider, and industry perspective on the rights and care of cancer patients. In particular, in fiscal year 2015, SPEAC's work

led to the passing of oral parity legislation in six states: Wyoming, South Dakota, West Virginia, Mississippi, North Dakota, and New Hampshire. To date, SPEAC has been responsible for aiding the passage of oral parity laws in 40 states as well as in the District of Columbia. In addition to oral parity, the IMF followed specialty tier legislation that would protect patients from high-cost sharing for specialty medicines. So far, bills have been enacted in Delaware, Maine, Louisiana, Maryland, New York, Pennsylvania, and Vermont. Bills have been introduced in Arkansas, California, Connecticut, Illinois, Kentucky, Massachusetts, Mississippi, Virginia, and the District of Columbia.



Raising Awareness

In 2015, IMF Advocacy led a campaign to acquire proclamations at the local, state, and federal level. The team created a tool kit with a step-by-step guide on how to talk to officials about obtaining proclamations, as well as sample letters and templates to use in their respective conversations with legislators. Working with Rep. Brian Higgins' office (a long-time friend and ally to the IMF), the advocacy team introduced a federal resolution to designate March as national Myeloma Awareness Month (MAM). Currently, that resolution has six co-sponsors, and IMF Advocacy will continue to seek more in 2016.

Myeloma Awareness Month

The IMF observed Myeloma Awareness Month in March 2015 with many activities and initiatives that increased awareness of the disease. A national resolution (H. Res 174) was introduced to designate March as “National Myeloma Awareness Month.” The resolution added to the immense successes of patient advocates across the country who received proclamations for individual states, counties, and cities.

Myeloma Awareness Month kicked off with two Patient & Family Seminars – one in Boca Raton, Florida, and the other in Redwood City, California. Regional Community Workshops were held in Denver, Colorado, and in San Diego, California. The IMF also held a “Living Well with Myeloma” teleconference, which reached more than 2,600 listeners. In addition, press releases and social media spread awareness, with myeloma facts issued daily on Twitter and Facebook, using the hashtag #DiscoverMyeloma.

Other outreach components of Myeloma Awareness Month included Mambo for Myeloma – an initiative that asked patients, caregivers, doctors, friends, family members and groups to film themselves dancing and share a donation link for the cause. The “Share Your Story” campaign allowed myeloma patients to post their inspiring stories to the IMF website.

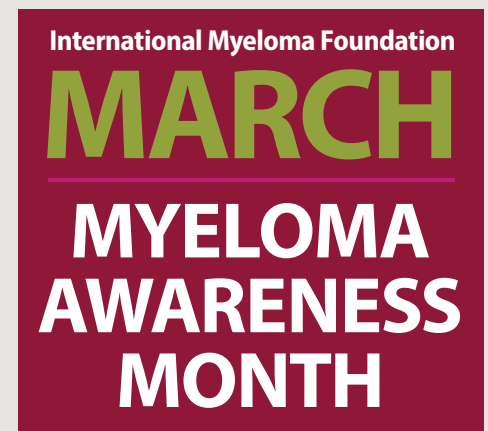
Furthermore, the IMF provided support group members with the tools to reach out to their local news media, resulting in more than 50 reports in newspapers, on the radio, and on television from Vermont to California to Jamaica. Local support groups also spread myeloma awareness by distributing flyers,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

Myeloma ACTION Team

The Myeloma ACTION Team, formed in 2013, continued to grow. Forty-eight advocates made in-district visits and sent more than 180 messages to legislators in fiscal year 2015. This team builds community by fostering education, action, and empowerment. The team works together to strengthen the support for federal legislation on anticancer treatment access, to build strong grassroots networks in every state, and to raise awareness of myeloma across the country. In addition, the team speaks to the IMF on monthly teleconferences, and organizes in-district meetings with federal and state legislators to raise the visibility of issues that myeloma patients face.

Veterans Against Myeloma

The IMF has long been a resource for veterans for information about myeloma. In 2015, Veterans Against Myeloma (VAM) grew from 179 members to 311 members. In addition, a focus group was conducted with 49 participants. The purpose of this focus group was to determine what further needs VAM could fulfill for its members. VAM also led two teleconferences – “The Military Veteran’s Perspective on Living with Multiple Myeloma” and “Multiple Myeloma and VA Benefits,” with 71 and 52 participants respectively. Created in 2013, the VAM website continues to provide relevant information about myeloma and causes that may be specific to veterans, with a total of 160 alerts sent to members in the past fiscal year. The website (<http://veterans.myeloma.org/>) also disseminates information and resources to members so they may become advocates for legislation that could support veterans with myeloma.



An initiative of the IMF since 2009





Terry Miller

Terry Lynn Miller was considered a man of contradictions – frugal in his personal life but generous with his friends and with the various charities and political causes he supported.

Add the International Myeloma Foundation to that list. Miller, who passed away from myeloma in 2013, bequeathed a generous donation to the IMF, adding to his earlier significant contributions. His total gift stands at \$337,000, money that he would be pleased to see being spent on research to find a cure.

Terry himself was grateful for the years he got to enjoy life beyond what doctors first predicted. Originally given two years to live, Terry fought every challenge that came his way, his trademark dry sense of humor always present. He lived 21 years past his initial diagnosis, crediting the strides in myeloma research for his longevity.

"I know he was grateful for the gift of so much time, which would not have been possible without the efforts made by the [International Myeloma] Foundation and others," says his close friend Beth-Ann Herschaft, "I'm sure that's why the Foundation played such a big part in his estate giving plan."

Terry Lynn Miller, was born in Ohio on July 7, 1944, and later moved with his family to Florida, eventually earning an MBA from Florida Atlantic University. He went on to work for several governmental agencies, including the Internal Revenue Service, the Florida Department of Corrections, and the Florida Child Support Enforcement Division, where he was vigilant about contacting absent parents. Terry was also an avid reader of historical books and spy novels, and loved crossword puzzles and other word games.

Thanks to Terry Miller's generous gift, others like him may get to laugh harder and longer.

DEVELOPMENT

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

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

During the 2015 fiscal year, the IMF received nearly \$17 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 2015 fiscal year, the IMF received 46 gifts totaling \$890,591. 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 401k) or life insurance policies. All that is required to be recognized as a member of 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, 155 Hope Society members contributed a total of \$51,654 during the 2015 fiscal year. The IMF thanks members of the Hope Society for their continued commitment to sustaining the needs of the myeloma community.



Cultivating the future by planting the seeds to sustain the IMF

The Hope Society Honor Roll

Amy Adams	Dean Gallea	Karen and Edward Necela
Mary Ann and Jeffrey Allyn	Calogera and Carmelo Gallico	Edward Novack
Cathie Alonzo	Irene and Laurence Gauthier	Paul R. O'Dea
Janet Ames	Marie and Carl Gilliam	Patricia and Jim Omel
Bonita and James Anderson	Anil Godbole	Elizabeth and James* Osterburg
Anonymous	Carla Goode	Peggy Pankey
Betty Arevalo	Gail Goodwin	Jack Pascale
Carol and Eric Ashihara	Donna Wyatt and Daryl Graham	Ellen Powell
Rene Dvalery and James Baker	Mary Granger	Joanne and William Powell
Laura Bates	Roberta Greenberg	Dan Quattrochi
Eunice Becker	Linda Lamb and Paul Griffin	Tina and Michael Rettig
David Bennett	Diane and Robert Grosso	Dawn Rochester
Donald Bennett	Roslyn and Harold Grueskin	Mary Rohleder
Marcy R. Bernstein	Rebecca and Michael Heinold	Melissa Klepetar and Ben Rolling
Anne and John Boehle	Carol Hornreich	Gregory Rosasco
Frances and James Bowles	Nicci Hubert	Sara and Richard Rosene
Jeannie Brady	Harriet and Martin Hurlich	Doloures Ryan
Kathy Brens	Timothy Huss	Susan and Ira Saltzman
Julia Brock	Roslyn and Larry Isakowitz	Charl L. Sauer
Claudia and Philip Brown	Sally and Reggie Jardon	Jennifer and Tim Scarne
Prudy and David* Brown	Larry Jeffries	Cynthia Schulze
Teresa Brown	Shirley Johnson*	Marguerite and Daniel Scott
Nancy Bruno	Debbie and Jerry Jordan	Janice Sejut
Britney Burgess	Mary and Bill Joswig	Newton Sharp
Meghan and Chris Buzby	Jacqueline and Michael Katz*	Nancy Shealy
Patricia Vigilante and Robert Candela	Anita and Walter Kemper	Susan and Barry Shulstein
Catherine and John Capo	Julia Kennedy	Robert Singdahlsen
Carleton Carroll	Elise Ketner	Richard Skalitzy
Annette and Patrick Cavanagh	Roberta and Raymond Klein	Carole and David* Skelly
Fred Charles	Leny and Ben Kolsteren	Rachel Small
Cynthia and John Chmielewski	Ann Nora Kruger	Randall Smith
Donna and Mark Di Cicilia	Heidi Rubinstein and Brian Kuchynskas	Diane Staves
Cynthia Clark	Phil Lange	Volindah Costabell and Ron Stout
Carol and Phillip Collins	Rachel and Duane Lashbrook	James Stuart
Mary Turner and Kelly Cox	Rose Mary and George Leek	Nancy and Jay Style
Maureen Cronin	Jean and Mike LeTarte	Henry Thomas
Catherine and Willard Cullum	Kathleen and Charles Lewis	Paula Thompson
Laurie Dahle	Nancy and Don Lorenzen	Doris and James Thureau
Stephanie Davis	Peter Lundell	Nancy and William Tidwell
Brian L. Denyer	Elizabeth Manczak	Ray Vines
Niall Doherty	Helene and Alan Marks	Patricia and James Wagner
Susie Novis Durie	Stephen Marsh	Jonathan Weitz
Linda and Mark Edwards	Mary Anne and Chuck Martz	Charlotte and Joseph Werkmeister
Joseph Ellis	Vicki and Dwight Mays	Michael D. Wood
Kate and Douglas Farrell	Kathleen McHugh	Beth and Woodring Wright
Kyoko Kashiwagi and Ronald Fischer	Paula Merrigan	Sandy Wytroval
Kim and Doug Foreman	Laura and Charles Mooney	Sandy Zajdel
Norma Jean Brodey Galiher	Alanna Morgan	Claire Zupancic

*deceased



IMF's Paul Hewitt with Steering Committee Vicki Hamby, Gail Bertram, and Andy Bertram Wayne Hamby Golf Tournament

The Wayne Hamby Memorial Golf Tournament began in 2010 when Wayne Hamby passed away from multiple myeloma, and his Pinecrest Golf Club friends held a golf tournament in his memory. In 2012, the tournament became a charity event to benefit the International Myeloma Foundation and raised \$7,500 for the organization. Each year since 2012 the donations have increased.

The Steering Committee of the Wayne Hamby Golf Tournament includes the team of Vicki Hamby, Gail Bertram, and Andy Bertram. All three of their lives have been touched by cancer in one way or another. The International Myeloma Foundation's focus on increasing rates of survival of myeloma patients and supporting patients and families are the reasons this team organizes fundraisers. Simply, they want donations to the IMF to count. In the last two years, their efforts resulted in a research grant in Wayne Hamby's name – which motivated not only the Steering Committee but also their many loyal volunteers.

The greatest challenge that Vicki, Gail, and Andy face yearly is obtaining donations for the event (prizes, silent auction items, raffles, and so forth). Although the Bluffton, South Carolina community and surrounding areas have always been extremely generous, an increased demand by many worthy charities can be difficult for many of the businesses.

The team discovered that undertaking an IMF fundraiser gave them access to "tremendous resources and encouragement from the IMF's staff." To provide yearlong exposure to this event and an avenue for donations from those unable to attend the Wayne Hamby Memorial Golf Tournament, the Steering Committee and the IMF developed a website (www.hamby4imf.org). The IMF is incredibly thankful to Vicki Hamby, Gail Bertram, Andy Bertram, and all the volunteers they rally to raise funds to fight myeloma.

IMF's 8th Annual Comedy Celebration

The International Myeloma Foundation's 8th Annual Comedy Celebration benefiting the Peter Boyle Research Fund and supporting the Black Swan Research Initiative® drew more than 1,100 guests to the Wilshire Ebell Theatre in Los Angeles, California on Saturday, November 8, 2014.

The first Annual Comedy Celebration was held in 2007, thanks to fellow Board member and event chair Loraine Boyle, IMF Board Member and wife of the late actor Peter Boyle. Loraine Boyle reached out to IMF Co-Founders Susie Novis Durie and Dr. Brian Durie with a profound desire to make a difference in the lives of people coping with myeloma. Loraine established the Peter Boyle Research Fund, calling upon her and Peter's friends to join her in raising awareness and finding a cure for myeloma. Boyle's friends, an assortment of actors and comedians, answered her call without hesitation, and they have been donating their time and talents to our cause ever since.

During the 2015 fiscal year, the 8th Annual Comedy Celebration raised \$565,000, bringing the total funds raised for the Peter Boyle Research Fund to \$5 million.

Peter Boyle, who passed away in 2006 after a four-year battle with myeloma, was remembered with poignant anecdotes, which were followed by an evening of stellar comedic performances. Host Ray Romano, whose support over the years has played an integral part in the success in the event, opened the show. Throughout the evening, we welcomed familiar faces from *"Everybody Loves Raymond"* and some new faces too. Appearances were made by Rita Wilson, Alex Meneses, Gene Pack, Dayle Reyfel, Howard Hesseman, Rhea Perlman, Laraine Newman, Danny DeVito, Lucy DeVito, Doris Roberts, Lesley Nicol, and Patricia Heaton.

In addition, more than 400 VIP guests gathered before and after the show to peruse the evening's silent auction offerings and enjoy the atmosphere with friends.

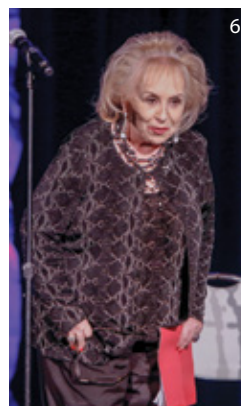


Comedian Ray Romano hosts the IMF's 8th Annual Comedy Celebration.



8th Annual Comedy Celebration

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



- 1) Dr. Brian Durie, Loraine Boyle, and Ray Romano, 2) Gene Pack, Dayle Reyfel, Howard Hesseman, Rhea Perlman, and Laraine Newman,
- 3) Lesley Nicol and Carol Klein, 4) Guests enjoying the event's silent auction and post-show VIP reception,
- 5) Matthew Robinson, Susie Novis Durie, and Dr. Brian Durie, 6) the late Doris Roberts,
- 7) Dr. Brian Durie and IMF President and Co-Founder Susie Novis Durie

Member Fundraisers

Myeloma patients and family members often ask the IMF about opportunities to help support myeloma research and education programs. People who have hosted member fundraisers in their communities have said they derive strength and empowerment in the fight against myeloma.

During the 2015 fiscal year, IMF members held 78 events that raised nearly \$620,000. Many of the recurring events support the IMF's Brian D. Novis Research Grants, a testament to the ability of a regular group of people to make an extraordinary impact on the future of myeloma research.

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

Member Events

October 1, 2014 – September 30, 2015

BENEFACTORS CIRCLE

\$25,000 and up

Miracles For Myeloma

Ron and Sheree Pask and Gina Klemm
Clark, NJ

ChekFest Golf Tournament

Sharon and Scott Kowalczyk
Grand Rapids, MI

Coach Rob's Benefit Bash

Kim Bradford and Todd Birmingham
Apopka, FL

Miles for Myeloma 5K

Philadelphia Multiple Myeloma
Networking Group
Philadelphia, PA

Carolyn Czerkies Charity Golf Outing

Czerkies Family
Naperville, IL

FOUNDERS CIRCLE

\$10,000 – \$24,999

Capt. Turner Ocean Swim

Doug and Kate Farrell
Longport, NJ

A Day At the Races

Janine Granit
Monmouth, NJ

J.C. Golf Tournament

David Johnson and Bob Zins
St. Cloud, MN

Ava & Cece's Race to Beat Myeloma

Ava and Cece Fainberg
Chevy Chase, MD

McWethy March Against Myeloma

Justin McWethy
Yosemite, CA

Team Synergy – Strengthen for a Cure

Tara Ginsburg
Long Island, NY

Wayne Hamby Memorial Golf Tournament

Gail and Andrew Bertram
Bluffton, SC

Bridge Blasts Myeloma

Carol Klein
Bethesda, MD

PARTNERS CIRCLE

\$5,000 – \$9,999

Trooper Benson Klein Research Fund

Benson Klein
Bethesda, MD

Red House Carnival

Julianne Stafford
Brighton, MA

Slava Rubin's Wedding

Slava and Alana Rubin
New York, NY

Kubik Multiple Myeloma Benefit

Darla Kubik and Dwight Royall
Rockwall, TX

Art on the Gogh

Frank and Beth Harman
Virginia Beach, VA

ASSOCIATES CIRCLE

\$1,000 – \$4,999

Jack's Annual Benefit Bash

Jack Aiello
San Jose, CA

Margaret R. Cole Memorial Fund

Roger O. Cole
Upper Montclair, NJ

Flying Pig Marathon

Ellen and Brian Grammel
Fairfield, CT

Night of Epic Awareness

Nicole Czipulis
Coral Springs, FL

Doris Morgan's 75th Birthday Gala

Bridget McKenzie
Atlanta, GA

Many Blooms of Life Quilt

Brenda Riggs
Virginia Beach, VA

Dairy Queen Fundraiser

Ruth Schimmel
Granville, MI

Catwalk for Cancer

Tristen Douglas
Warwick, NY

Zumbathon for Multiple Myeloma

Sandi Hunsuckle
St. Augustine, FL

Yoga for Myeloma

Vicki Johnson
Long Beach, CA

Heritage Singers Fundraiser

Heritage Singers of Jacksonville
Jacksonville, FL

Laura Bates Bottle Fundraiser

Laura Bates
Penfield, NY

FRIENDS CIRCLE

\$500 – \$999

A Visit to Virginia's Wine Country

Nancy Raible
Richmond, VA

Caputo 50th Anniversary

Mike and Rose Mary Caputo
Somerset, NJ

Zach Barten's Bar Mitzvah Project

Zachary Barten
Plainview, NY

Christopher Stafford Wedding

Christopher Stafford and Tyler Hornyak
Norwalk, CT

Brady Mudders Day Fun Run

Niall Brady
Hamilton, NJ

Colon Kiwanis Key Club Fundraiser

Diane Colon
Tracy, CA

William Koch's Confirmation

William Koch
Haworth, NJ

Denise and Tom's Wedding

Denise Arevalo and Thomas A. Tormey
Los Angeles, CA

Bicycle Mojave and Beyond

Andrew Sninsky
Newport Beach, CA

Robert Scales' Birthday Celebration

Robert Scales
Los Angeles, CA

Great Turtle Half Marathon

Linda Davis
Mackinac Island, MI

Ted & Cabrey Go Maroon for Myeloma

Ted Lamparski
Lansdale, PA



Jack Aiello hosts the Texas Hold 'Em Benefit Bash in San Jose, CA.



Frank and Beth Harman host an IMF Fundraiser at Art-On-The-Gogh.



In lieu of gifts at Zachary Barten's Bar Mitzvah, guests donated to the IMF.



Denise Arevalo and Thomas Tormey cut the cake at their wedding, for which they requested donations to the IMF in lieu of wedding gifts.



A Catwalk from Cancer was organized by 17-year-old Tristen Douglas, who lost her grandfather to myeloma.



Sandi Hunsuckle and her Zumba class held a Zumbathon Fundraiser for the IMF.



Bicyclists gather for Doug Kinkade's Red Rock Canyon Ride.

SUMMARY FINANCIAL INFORMATION

INTERNATIONAL MYELOMA FOUNDATION Statement of Financial Position September 30, 2015

Assets

CURRENT ASSETS

Cash and cash equivalents	\$ 2,696,368
Contributions and other receivables	5,712,432
Prepaid expenses	661,840

Total Current Assets	\$ 9,070,640
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OTHER ASSETS

Investments, at fair value	\$ 6,298,901
Property and equipment, net	230,734
Gift annuity investments, restricted cash	9,098
Intangible assets, net	58,430

Total Other Assets	\$ 6,597,163
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TOTAL ASSETS	\$ 15,667,803
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Liabilities and Net Assets

CURRENT LIABILITIES

Accounts payable and accrued expenses	\$ 727,079
Deferred and unrestricted educational grants	13,061,928

Total Current Liabilities	\$ 13,789,007
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GIFT ANNUITY OBLIGATION	5,375
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Total Liabilities	\$ 13,794,382
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NET ASSETS

Unrestricted	1,869,698
Temporarily restricted	3,723

Total Net Assets	\$ 1,873,421
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TOTAL LIABILITIES AND NET ASSETS	\$ 15,667,803
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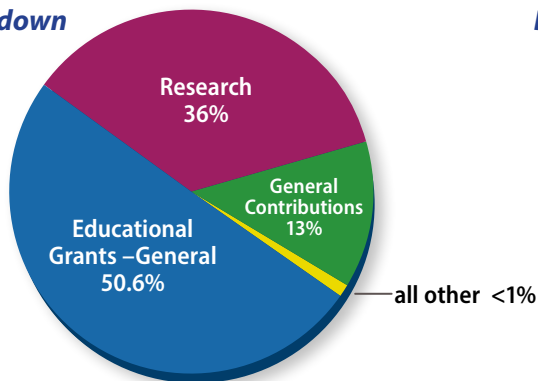
For a copy of our complete audited financial statements, please contact the IMF office.

INTERNATIONAL MYELOMA FOUNDATION

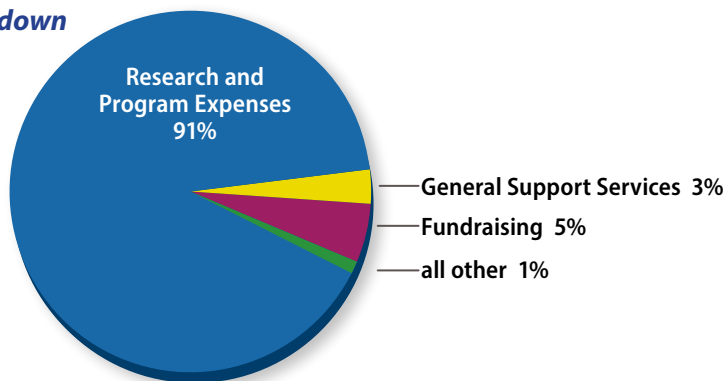
Statement of Activities for the Year Ended September 30, 2015

	UNRESTRICTED	TEMPORARILY RESTRICTED	TOTAL
Revenues and Support			
Educational grants	\$ 6,505,559	\$ 4,098,115	\$ 10,603,674
General contributions	801,040	214,332	1,015,372
Fundraising programs	313,119	3,413	316,532
Donated services	288	-	288
Seminar fees and support group income	89,256	-	89,256
Fundraising events, net of direct benefit to donors of \$344,083	520,656	313,204	833,860
Realized and unrealized losses	(142,245)	-	(142,245)
Investment income	128,517	1	128,518
	8,216,190	4,629,065	12,845,255
Released from restriction	4,629,064	(4,629,064)	-
Total Revenue and Support	\$ 12,845,254	\$ 1	\$ 12,845,255
Expenses			
Program services	11,562,860	-	11,562,860
General supporting services	424,563	-	424,563
Fundraising	655,376	-	655,376
Total Expenses	\$ 12,642,799	-	\$ 12,642,799
Change in Net Assets	202,455	1	202,456
NET ASSETS – Beginning of year	1,667,243	3,722	1,670,965
NET ASSETS – End of year	\$ 1,869,698	\$ 3,723	\$ 1,873,421

**Revenue
Breakdown**



**Expense
Breakdown**



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

INTERNATIONAL MYELOMA FOUNDATION

Statement of Functional Expenses

for the Year Ended

September 30, 2015

Breakdown of Expenses by Program

PROGRAM	TOTAL EXPENSES
Research	\$ 4,263,356
Education & Awareness	1,474,146
Patient & Family Seminars	1,105,336
International	858,938
Nurse	808,872
Support Groups	801,975
Clinical Meetings	701,983
Advocacy	444,890
Website	372,161
Myeloma Today	332,561
InfoLine	270,024
Information Mailings	128,617

Total Program Expenses

\$ 11,562,860

General supporting expenses

424,563

Fundraising expenses

655,376

Total Expenses

\$ 12,642,799



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

HONOR ROLL

Chairmans Circle

\$100,000 and above

Amgen Oncology
The Binding Site, Ltd.
Bristol-Myers Squibb Company
Celgene Corporation
Eisenhower Medical Center
Janssen Biotech, Inc.
Novartis Pharmaceuticals
Dorothy and John O'Dwyer
Carol Rosen Estate
Sanofi
Millennium: The Takeda Oncology Company
The V & L Marx Foundation

Presidents Circle

\$50,000 – \$99,999

Astellas Pharma US, Inc.
CBS Corporation
Estate of Peter J. Holloway
Karyopharm Therapeutics
Joele Frank and Larry Klurfeld
Willette Charitable Foundation

Benefactors Circle

\$25,000 – \$49,999

Coach Rob's Benefit Bash, Inc. /
Kimberly and Robert Bradford
Diplomat Specialty Pharmacy
Robert C. Ebersole
J. Claude Gaulin & Marie Lise May Gaulin
Charitable Trust
Pharmacyclics, Inc.
Philadelphia Multiple Myeloma Networking Group
Debra Fine-Schneider and Martin Schneider
Consuelo P. Sherron Irrevocable Trust
Sundquist Family Trust

Founders Circle

\$10,000 – \$24,999

Amazon.com, Inc.
Sandra and H.P. (Andy) Andrews
Loraine Boyle
Cascade Health Servies, LLC
Gail-Ann and Joe Colaruotolo
David Geffen Foundation
Susie Novis Durie and Dr. Brian Durie
HBO, Inc.

Leigh Hinkamp
Hoffman Trust
Ike and Ellen Kier Philanthropic Fund
J.C. Invitational Golf Tournament /
Beverly Lunderoff
John J. McDonnell & Margaret T. O'Brien
Foundation
Joy and Bill McGinnis
Oncopeptides AB
Joy and Ronald Paul
Rittenberg Family Foundation /
Cindy and Leon Rittenberg, Jr.
Rosenthal Family Foundation
TR & A, Inc.
Trevie, Inc.
Walsh Street Foundation / Henry Belber
Wayne Hamby Memorial Golf Tournament
Worldwide Pants, Inc.

Partners Circle

\$5,000 – \$9,999

Jennet Walker and John Auerbacher
Benvenue Medical, Inc.
Jeanne and Edwin Bernstein
Biotechnology Industry Organization
Carol and Willard Thompson Fund
Chek Fest
Clare Rose Foundation, Inc.
Clifford and LaVonne Graese Foundation
Vince and Mary Jo Elhilow
Frank and Susan Armo Fund
Genentech, Inc.
Dianna Wong and George T. Hayum
Indiegogo, Inc.
Sara and Rafael* Kapustin
Susie and Michael* Katz
Carol and Benson Klein
Donna Lichtman
Local Independent Charities of America
Anne McCauslin
Medtronic, Inc.
The North Texas Myeloma Support Group
C.W. Reed*
Iris and Michael Smith
Joseph R. Suffoletta
Louise Takata
The Omer Foundation

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 that serve our members. Their generosity allows the IMF to do the following:

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

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

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

Honor Roll (continued)

Karen and John Thiel
Rositsa Tsanova and William Rowell
Twentieth Century Fox
Ben Vanderlinde
Judith and Gerald Webb
Rita and Henry Wells and Martin Wells

Associates Circle

\$1,000 – \$4,999

Kevin and James Abernathy
Acompuco
Airefco, Inc.
Mary Jo and David Albee
Allendale Dairy Queen – Orange Julius
Mary Ann and Jeffrey Allyn
Pam and Wayne Anderson
Anonymous
Heather and Felix Baker
The Barra Foundation
Martin Barrett
Laura Bates
Baumgardner Construction Co., Inc.
Leigh Beck
Benjamin Begley
Malea and Michael Bell
Benanav Family Foundation
Natalie and Gregg Bernstein
Jerome Bess
Best Western Kodiak Inn
Susan and John Bianco
Loul Haugs and Yelak Biru
Richard Boisture
Vera Bond
Janet and Terrance* Borchard
Thomas and Marcia Borger
Mitzi and Gerald Bozarth
Kelly and Brett Braciak
Marsha and John Brand
Judith and Bernard Briskin
Bette Brockman
Mel Brooks
Nancy Bruno
Mari and Ward Bukofsky
Robin Green and Mitchell Burgess
Monte and Elizabeth Burgett
Steve Burns
Colleen and John Busch
John Callahan
Donald Cann

Janice and William Cassese
Dianna and Chiles
Chopra Family Foundation
Chubb & Son
Dolly Cincotta
Alice B. Clark
Deborah L. Clausen
Gary Clucas
CM3 Building Solutions, Inc.
Gail-Ann and Joe Colaruotolo
Judy and Neil Collier
Community Foundation of New Jersey
Brad and Jeanne Cook Charitable Foundation
Janice Corwin
Mary Turner and Kelly Cox
Creative Artists Agency
Jon Cross
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