



MAKING A **WORLD** OF DIFFERENCE

2017 GLOBAL ANNUAL REPORT



INTERNATIONAL
MYELOMA
FOUNDATION

INTERNATIONAL MYELOMA FOUNDATION




Improving Lives **Finding the Cure®**

2017 GLOBAL ANNUAL REPORT

FISCAL YEAR OCTOBER 1, 2016 – SEPTEMBER 30, 2017

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A Message From the President

Dear Friends,

Once again, it's my pleasure to share with you all the advances and achievements the IMF has accomplished! Needless to say, this past year has been very busy and most importantly, very productive in our four key areas: research, education, support, and advocacy.

In November 2016, you may have read that the Black Swan Research Initiative® launched its first large-scale screening to identify and treat the precursors of myeloma before the disease develops. Over the past year, the study iStopMM® (Iceland Screens, Treats or Prevents Multiple Myeloma) has been examining blood samples of patients in Iceland. More than 140,000 adults in Iceland over the age of 40 were invited to be screened to determine if they have the earliest signs of myeloma. Excited about this, 77,777 Icelanders elected to participate in this groundbreaking project!

We've continued to go to Iceland working closely with Dr. Sigurdur Kristinsson and his team. Dr. Kristinsson estimates that 4% of those screened will have MGUS (monoclonal gammopathy of undetermined significance). The accrual is happening quickly and will end up with over 4,000 MGUS patients. This is the largest population-based screening study for myeloma and its earlier disease precursors that has ever been attempted! Needless to say, I'm very proud of Dr. Durie and Dr. Kristinsson for their vision, passion, and tenacity to get this project going; and to all the people in Iceland who are participating in this incredible study! Stay tuned for more updates about iStopMM as we learn which patients will benefit most from early intervention, as well as those identified with high-risk smoldering myeloma.



IMF Chairman of the Board Brian G.M. Durie, MD, and IMF President & CEO Susie Durie

In June we traveled to Madrid, Spain, for the annual meeting of the International Myeloma Working Group (IMWG) meeting. This keystone meeting is held just prior to the annual EHA (European Hematology Association) meeting. About 100 IMWG members attended and the Summit was co-chaired by Drs. Brian Durie, Philippe Moreau, S. Vincent Rajkumar and Jesús F. San Miguel. Important topics included Frontline Therapy for Myeloma, Role of MRD Assessment, Drug Access, and the Costs of Myeloma Care, to name a few. A highlight of the Summit was the Robert A. Kyle Lifetime Achievement Award that was presented to Dr. Paul Richardson of the Dana-Farber Cancer Institute. Another highlight was the annual meeting of GMAN (Global Myeloma Action Network). Thirty-four members gathered from around the world to attend this very active and productive meeting.

The IMF also was very busy on the home front, conducting 4 Patient & Family Seminars and 12 Regional Community Workshops. The Patient & Family Seminars are a half day on Friday and a full day on Saturday, and the Regional Community Workshops are a half day. We're very grateful to the outstanding faculty, who donate their time by participating at these meetings.

Our Support Group Team led by Robin Tuohy along with Nancy Bruno, Kelly Cox, and Ann Pacowta, crisscrosses the country year-round. They visit Support Groups to ensure these groups have what they need and are enabled to overcome any challenges. I'm very proud to note that we have 150 Support Groups nationwide, and we're honored to endorse them!

One of the biggest challenges we face is ensuring that patients have access to the drugs they need, when they need them. I don't have to tell you how expensive myeloma is... No one should have to choose between food or medicine. But in this great country of ours, they do. I'm extremely grateful to our outstanding Advocacy Team, led by Robin Levy, Senior Director of Public Policy & Advocacy. She began her career in the Executive Branch of the federal government working in the White House Counsel's office during the Clinton Administration. She is joined by her amazing team of Ray Wezik, Danielle Doheny, and Kelley Sidorowicz; together, they are working for you to ensure you have access to treatment. Most importantly, though, we are grateful to you – IMF donors and volunteer advocates.

I urge you to get involved in any of these incredible programs: research, education, support, and advocacy. After all, we are One Myeloma Nation!

Sincerely yours,

Susie Durie
President & CEO

IMF Board of Directors

Susie Durie

Founder, President, and CEO
of International Myeloma Foundation
Los Angeles, CA

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Professor of Medicine
Hematologist/Oncologist
Los Angeles, CA

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President of International Myeloma
Foundation Latin America and Instituto
Espaço de Vida
São Paulo, Brazil

Yelak Biru

Director, Business Intelligence and
Advanced Analytics, Walmart
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Professor of Medicine,
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Torino, Italy

Loraine Boyle

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Aldo Del Col

Co-Founder and Chief Scientific
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Laboratory Medicine and Pathology
Mayo Clinic – Rochester, MN

Professor Heinz Ludwig, MD

Director of Department of Medicine
and Medical Oncology
Wilhelmspital der Stadt Wien
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Southeast Regional Director,
Support Groups

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Administrative Assistant,
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Director, Public Policy & Advocacy

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Europe and the Middle East /
GMAN Executive Director

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Meeting Coordinator

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Phil Lange

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Research Project Coordinator

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Communications & Development

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Director, Public Policy & Advocacy



Based in North Hollywood, California, the International Myeloma Foundation gathers yearly for an annual staff retreat.

Asian Myeloma Network's Research and Patient Support Milestones

The International Myeloma Foundation's Asian Myeloma Network (AMN), an advisory body of 38 experts from 7 Asian countries/regions, expanded its reach in fiscal year 2017.

By the spring of 2017, the AMN's first clinical trial led by Dr. Wee Joo Chng was successfully completed. This trial – AMN001 – followed up relapsed myeloma patients who had previous exposure to bortezomib and lenalidomide, and were then treated with pomalidomide and dexamethasone. The data demonstrated high response rates.

Three more AMN clinical trials were launched in 2017:

- AMN002 – A randomized phase II study using different doses of carfilzomib with cyclophosphamide + dexamethasone for relapsed/refractory myeloma patients who had prior exposure to bortezomib. The project involves 50 patients in Asia and 50 patients in Australia and New Zealand.
- AMN003 – A randomized phase III study comparing the use of pomalidomide + cyclophosphamide + dexamethasone to pomalidomide + dexamethasone in relapsed or refractory myeloma patients. The project involves 120 patients in Asia.
- AMN004 – A phase II study examining the use of daratumumab in combination with thalidomide + dexamethasone in patients with relapsed and/or refractory myeloma. This study involves 100 patients in Asia.

In addition, the AMN focused on:

- Physician training programs in Beijing and Shanghai, China, in October 2016
- The sixth annual Myeloma Master Class for Chinese hematologists in Los Angeles
- An ad-hoc training session for Chinese doctors during the International Myeloma Working Group conference in Madrid in June 2017
- Consultations at the International Myeloma Workshop in New Delhi in March 2017
- Hosting Patient & Family seminars in Shanghai, China; Seoul, Korea; Hong Kong; Beijing, China; and Singapore.

RESEARCH



The iStopMM team pauses for a photo in the flow lab in Reykjavik, Iceland.

Black Swan Research Initiative

The International Myeloma Foundation's signature research project

Made up of an exciting team of multinational researchers, the Black Swan Research Initiative® experienced a pivotal year in 2017:

- The IMF celebrated the one-year anniversary of the iStopMM® project, which stands for **Iceland Screens, Treats, or Prevents Multiple Myeloma**. The largest myeloma-related study of its kind under the direction of Dr. Sigurdur Kristinsson (the University of Iceland), the iStopMM project has had an unprecedented response from the Icelandic people. Approximately 140,000 individuals over 40 years of age were asked to participate and be screened for possible monoclonal gammopathy of undetermined significance (MGUS), smoldering multiple myeloma (SMM), or active MM; thus far 77,777 have signed up. These participants have agreed to be tested as well as randomized to be more rigorously tested and/or possibly treated with interventional myeloma therapy.

Because much of the Icelandic population has already undergone genetic coding, iStopMM researchers will be able to use this genetic data to look for linkages to family gene patterns in those with MGUS. In addition, a questionnaire asks participants about family history and exposure history to see what conditions may lead to the disease.

The chances are excellent that answers will be found to help the BSRI team understand the biology of why people develop MGUS and how it can be prevented.

- The U.S.-based ASCENT trial (Aggressive Smoldering Cure Evaluating Novel Therapies) is headed by Dr. Shaji Kumar of the Mayo Clinic (Rochester, MN) and uses a combination of carfilzomib + lenalidomide + dexamethasone + daratumumab in an attempt to cure patients with high-risk smoldering multiple myeloma (HR-SMM). The trial, along with the CESAR and iStopMM clinical trials, is one of three BSRI-funded "Cure" trials.

All enrolled patients will receive a reduced dose of carfilzomib + lenalidomide + daratumumab for one year of maintenance. At this point, a 100 percent level of minimal residual disease (MRD) negativity is highly likely, said Dr. Brian G.M. Durie. MRD testing will be done at diagnosis and during therapy, allowing intensive tracking of the disease in patients. MRD testing can detect even a single myeloma cell surviving among one million bone marrow cells. The number of cycles of therapy will be determined by the individual patient's response.

The ASCENT trial will open for accrual in 2018 at 12 IMF Consortium sites.



- Interim data presented at the 2017 Annual Meeting of the American Society of Hematology from the single-arm, phase II CESAR trial demonstrated a high rate of complete responses (CRs) in patients with high-risk smoldering myeloma. Patients were given induction therapy with carfilzomib + lenalidomide + dexamethasone followed by high-dose therapy and autologous stem cell transplantation (HDT-ASCT), consolidation therapy and then maintenance therapy with lenalidomide + dexamethasone.

The CESAR trial, based in Spain and led by Dr. María-Victoria Mateos of University Hospital of Salamanca (Spain), is, along with the ASCENT and iStopMM clinical trials, one of three BSRI-funded “Cure” trials. Although longer follow-up is required, this curative strategy for high-risk SMM is encouraging.

Results of the CESAR trial were published in the journal *Blood*.

International Myeloma Working Group

The International Myeloma Foundation's collaborative working group of more than 200 myeloma experts

In 2017, the IMF's International Myeloma Working Group (founded in 2001) published “Natural history of relapsed myeloma, refractory to immunomodulatory drugs and proteasome inhibitors: a multicenter IMWG study” by Dr. Shaji Kumar and hosted lively teleconferences, interacting with patient and caregiver communities.



The eighth annual IMF IMWG Summit was held in Madrid from June 19–21, 2017. It included breakout sessions during which participants provided action plans on the following: drug access and the cost of myeloma care, bone scanning and imaging, immunotherapy, studies on smoldering myeloma, and a discussion of how to treat high-risk myeloma.

In addition, patients, caregivers, and doctors from around the world gleaned insights on the latest myeloma research and treatment when they tuned into the livestream broadcast from the Summit on June 21. Other highlights from the Summit included the presentation of the IMF's 14th Annual Robert A. Kyle Lifetime Achievement Award to Dr. Paul G. Richardson on June 20, 2017. This award honors an individual whose body of work has made significant contributions to myeloma research and patient care.

IMWG Publications

Cavo, M. et al. “Role of 18F-FDG PET/CT in the diagnosis and management of multiple myeloma and other plasma cell disorders: a consensus statement by the International Myeloma Working Group.” *The Lancet Oncology* (2017): e206–e217. doi: 10.1016/S1470-2045(17)30189-4

Kumar, SK, Meletios A. Dimopoulos, Efstathios Kastritis, Evangelos Terpos, Hareth Nahi, Hartmut Goldschmidt, Jens Hillengass et al. “Natural history of relapsed myeloma, refractory to immunomodulatory drugs and proteasome inhibitors: a multicenter IMWG study.” *Leukemia* (2017). doi: 10.1038/leu.2017.138

Musto, Pellegrino, K. C. Anderson, M. Attal, P. G. Richardson, A. Badros, J. Hou, R. Comenzo et al. “Second primary malignancies in multiple myeloma: an overview and IMWG consensus.” *Annals of Oncology* 28, no. 2 (2016): 228–245. doi: 10.1093/annonc/mdw606

Hillengass, J et al. Whole-body computed tomography versus conventional skeletal survey in patients with multiple myeloma: a study of the International Myeloma Working Group. *Blood Cancer J.* 2017 Aug 25;7(8):e599. doi: 10.1038/bcj.2017.78.



Brian Strickler inspires the attendees at the 2017 Brian D. Novis Grant Awards reception.

An Evening to Remember: Myeloma Patients and Myeloma Researchers Inspire One Another

The Living Well with Myeloma program and the Brian D. Novis Research Grant award presentation took place at the 58th annual meeting of the American Society of Hematology (ASH) in San Diego on December 3, 2016. This night to remember brought together award-winning myeloma researchers and battle-tested myeloma patients. The following are their stories:

“I’m going to live well. I plan to live well. I want to keep this going in 2017 [and] keep the momentum going: my involvement with the IMF, helping the process move forward, helping to gather resources is just starting.”
– Brian Strickler, myeloma patient

“I never ever imagined that there were so many treatments available in today’s world. It amazes me to see how far we’ve come in the last twenty years. The myeloma patients are truly grateful. I want you to know that you are helping to save lives. Thank you so much: Life is a gift.”
– Patricia Harwood, myeloma patient

“21 years after my diagnosis with myeloma my story is still in the making.”
– Yelak Biru, myeloma patient and IMF Board Member

“I want to really thank the IMF for this magnificent award. We intend to continue our research in myeloma, and to provide new avenues and new ideas for those patients that we have been listening to today.”
– Felipe Prosper, MD (FIMA, Pamplona, Spain)

“It’s been amazing, an awesome experience this year, speaking to some of the patients with myeloma.”
– Geoffrey M. Matthews, PhD
(Dana-Farber Cancer Institute, Boston, MA)

“Thank you all: to the wonderful researchers for all the work that you do, and to all the patients and your families, and just the courage you have to just continue no matter what. And we really can see the cure is on the horizon. It’s not that far away anymore. It used to be a dream somewhere far, far in the distance. But as I look forward now, I can see it. And I hope you can too.”
– IMF President, Founder, & CEO Susie Durie



These Chinese hematologists were presented with their certificates at the close of the Myeloma Master Class.

Myeloma Master Class

The Myeloma Master Class is an intensive educational course the IMF began six years ago to train clinicians who specialize in myeloma. The fifth annual Master Class, held in August 2017 in Los Angeles, welcomed seven young Chinese hematologists from leading myeloma centers throughout China.

In addition to classroom learning, the doctors took part in the IMF Los Angeles Patient & Family Seminar, where they participated in individual patient consultations alongside Dr. Brian G.M. Durie (Hematologist/Oncologist at Samuel Oschin Comprehensive Cancer Institute, Cedars-Sinai, Los Angeles, and IMF Chairman of the Board).

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 G.M. Durie, Dr. S. Vincent Rajkumar (Mayo Clinic, Rochester, MN), Dr. Jonathan Kaufman (Winship Cancer Institute, Emory University, Atlanta), Dr. Thomas G. Martin (Helen Diller Comprehensive Cancer Center, UCSF, San Francisco), Dr. Joseph Mikhael (Mayo Clinic, Scottsdale, AZ), and Dr. Robert Vescio (Samuel Oschin Comprehensive Cancer Institute, Cedars-Sinai, Los Angeles).

The Master Class provided not only a valuable educational opportunity, but a chance for these young Chinese doctors to develop friendships and professional contacts. Master Class alumni are becoming leading figures in the myeloma community in China, which will no doubt lead to improved patient support and care.

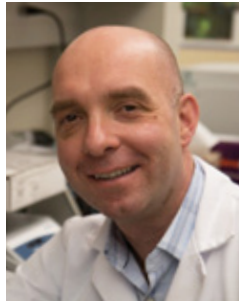
GLOBAL OUTREACH

2017 Brian D. Novis Research Grant Awards

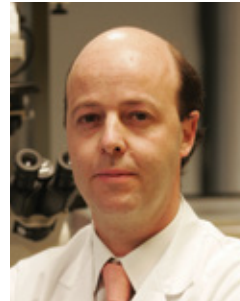
The International Myeloma Foundation (IMF) presented its 2017 Research Grant awards at a ceremony held during the 58th annual meeting of the American Society of Hematology (ASH), December 2016 in San Diego, California.

Senior Grant Recipients

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



Djordje Atanackovic, MD



Felipe Prosper, MD



Karin Vanderkerken, PhD

Djordje Atanackovic, MD | Huntsman Cancer Institute – Salt Lake City, UT
Anti-CD229 chimeric antigen receptor T cells for the treatment of multiple myeloma

Felipe Prosper, MD | Foundation for Applied Medical Research (FIMA) – Pamplona, Navarra, Spain
Deciphering the role of eRNAs in the pathogenesis of multiple myeloma

Karin Vanderkerken, PhD | Vrije Universiteit Brussel – Brussels, Belgium
Targeting residual, dormant cancer cells in myeloma: a new approach

Junior Grant Recipients

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



Neelam Bhardwaj, PhD



Arnold Bolomsky, DI (FH) Dr.



Jesús Delgado-Calle, PhD



Geoffrey M. Matthews, PhD



Alessandra Romano, MD, PhD

Neelam Bhardwaj, PhD | Huntsman Cancer Institute – Salt Lake City, UT
Generation and validation of a monoclonal antibody against VISTA for the immunomodulatory therapy of multiple myeloma

Arnold Bolomsky, DI (FH) Dr. | Wilhelminen Cancer Research Institute – Vienna, Austria
Targeting of BMI-1 as novel treatment option in multiple myeloma: Examination of PTC-028 as putative anti-myeloma drug in vitro and in vivo

Jesús Delgado-Calle, PhD | Indiana University School of Medicine – Indianapolis, IN
Bone/bone marrow-targeted inhibition of Notch signaling in combination with glucocorticoid therapy as a novel approach to treat multiple myeloma

Geoffrey M. Matthews, PhD | Dana-Farber Cancer Institute – Boston, MA
Treating myeloma through inducing degradation of BET bromodomain proteins

Alessandra Romano, MD, PhD | Ospedale San Raffaele – Milano, Italy
Exploiting IDO1-GCN2-p62 axis in MM microenvironment to trigger myeloid-derived suppressor cells in multiple myeloma



GMAN members gather in Madrid, Spain.

Global Myeloma Action Network

GMAN brings together advocacy leaders in myeloma and blood cancers to improve the lives of patients around the world.

Susie Durie – President, Founder, and CEO of the IMF – kicked off the GMAN meeting in fiscal year 2017, at the Annual Meeting of the American Society of Hematology in San Diego in early December 2016. Participants were thanked with a warm welcome for their willingness to work together to benefit patients. At this meeting, GMAN members had a chance to meet with industry physicians from the U.S.



The GMAN Summit, a large-scale meeting, took place in June 2017 at the IMF's International Myeloma Working Group (IMWG) Summit in Madrid, Spain. This GMAN encounter garnered a great level of participation, drawing 35 individuals representing 25 countries around the world. The Summit included presentations and breakout sessions. Dr. Jean-Luc Harousseau (University of Nantes, Nantes, France) presented on "The Cost of New Myeloma Treatments." Dr. Durhane Wong-Rieger (President, Canadian Organization of Rare Disorders), discussed "Real World Advocacy: Advancing Research and Access," and led a training session on "Advancing Public Policies That Support Research, Improve Access to Treatments, and Yield Real Results." Dr. Rafat Abonour (Simon Cancer Center, Indiana University, Bloomington, Indiana) led a breakout session on what to do if access to novel therapies is unavailable, a topic that resonated with many GMAN representatives of countries where myeloma treatment options are limited. The Summit agenda also included a session on navigating clinical trials for access to novel therapies and presentations by several representatives from member organizations in Asia, Europe, Latin America, and North America. GMAN remains a unique global myeloma advocacy initiative, and its annual Summit fosters an environment that supports existing relationships and develops new ones.

Educational Outreach in Europe

The IMF continued to strengthen its international relationships with patients, families, and advocacy groups abroad in 2017 with educational meetings in 15 European countries, which were attended by more than 3,200 people in the international myeloma community. 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.

Patient Meetings Across Europe



The IMF held Patient & Family Seminars (PFS) in many Nordic countries during October 2016.



The IMF's 2017 patient and physician education programs in Europe launched in February with a conference for hematologists/oncologists and a Patient & Family Seminar in Budapest, Hungary.



In March 2017, the IMF and the Blodcancerförbundet (the Swedish Blood Cancer Association) held a joint meeting for patients, families, and caregivers in Stockholm, Sweden.



Pictured is the audience at the IMF Patient & Family Seminar in Heidelberg, Germany.



The IMF's Nurse Leadership Board members assemble at their 12th annual meeting in Los Angeles.

Nurse Leadership Board (NLB)

The International Myeloma Foundation (IMF) Nurse Leadership Board® (NLB) is a professional partnership representing nurse experts from leading medical centers caring for myeloma patients. Throughout fiscal year 2017, NLB members led education sessions at IMF Patient & Family Seminars and Regional Community Workshops, accompanied support group leaders to the 2016 Annual Meeting of the American Society of Hematology (ASH), and addressed the IMF's 2017 Support Group Leaders Summit. The NLB contributed to IMF publications and spoke on teleconferences in the IMF's popular "Living Well with Myeloma" series.

The NLB's 12th annual meeting was held in Los Angeles in August 2017. During this meeting, the NLB heard updates from IMF Chairman Dr. Brian G.M. Durie on the latest Black Swan Research Initiative® studies, reviewed the results of a survey that assessed the unmet needs of myeloma patients, and participated in breakout sessions. Of note, the NLB began testing a Myeloma Nurse app to leverage broader dissemination of NLB resources, manage events, and share information.

In April, at the 2017 Oncology Nursing Society annual conference in Denver, the NLB hosted a CNE-accredited satellite symposium entitled "Case Studies in Multiple Myeloma: Best Practices in Patient Care and Symptom Management." The event was co-chaired by Beth Faiman, PhD, RN, MSN, APRN-BC, AOCN® (Taussig Cancer Institute-Cleveland Clinic, Cleveland, OH) and Joseph Tariman, PhD, RN, ANP-BC, FAAN (DePaul University-Chicago, IL)

In October, the *Clinical Journal of Oncology Nursing* published *Multiple Myeloma*, authored by the International Myeloma Foundation's Nurse Leadership Board. This publication provides downloadable PDFs of research-based articles on myeloma symptoms and complications and their management.

Also, this past fiscal year, the NLB's Dr. Joseph Tariman was inducted as a Fellow to the American Academy of Nursing. The IMF congratulates all of the NLB for their tremendous contributions to myeloma education.

EMPOWERING PATIENT OUTREACH



SEMINARS & WORKSHOPS



SUPPORT GROUPS

**FACILITATED
THE LAUNCH OF
11 NEW**

MYELOMA-FOCUSED
SUPPORT GROUPS
NATIONWIDE

**ASSISTED
310**

IMF-AFFILIATED
MYELOMA
SUPPORT GROUPS
NATIONWIDE



SOCIAL MEDIA

**CONNECTED
WITH MORE THAN**

8,600

FACEBOOK
FOLLOWERS
↑ **18% REACH
INCREASE**

6,600

TWITTER
FOLLOWERS
↑ **24.5% REACH
INCREASE**



INFOLINE



PATIENTS

PATIENT EDUCATION



TELECONFERENCES

IMF'S POPULAR BROADCAST "LIVING WELL WITH MYELOMA"

10,000
LIVE LISTENERS

25,000
ARCHIVED RECORDING
LISTENERS



PRINT PUBLICATIONS

PROVIDED MORE THAN
3,000
INFOPACKS MAILED
TO PATIENTS/FAMILIES

PRODUCED
7 NEW
PUBLICATIONS AND
30 UPDATED
PUBLICATIONS



TRANSLATIONS

TRANSLATED MORE THAN
70 TITLES
INTO 14
LANGUAGES

TRANSLATED MEDICAL
ARTICLES FROM
IMF PERIODICALS INTO
FRENCH, ITALIAN
GERMAN & SPANISH



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IMF Advocacy Navigates Changes in Healthcare

In fiscal year 2017, the IMF Advocacy Team:

- Followed the 21st Century Cures Act, a law passed with bipartisan backing and signed by President Barack Obama. This law authorizes cancer research funding and funds for the U.S. Food and Drug Administration (FDA) to streamline drug and device approval processes. In particular, it authorizes nearly \$5 billion for the National Institutes of Health Innovation Account for more than 10 years with \$300 million allocated to the National Cancer Institute. The IMF Advocacy team informed the public about this Act and bolstered activism related to it.
- Continued to monitor oral parity legislation at both the federal and state level which ensures insurance benefits are meeting up properly with healthcare innovations. At the state level, the IMF Advocacy Team continued to advocate for legislation in North Carolina, Tennessee, and Michigan. In April, oral parity became law in Arkansas. As a result, 43 states and the District of Columbia now have similar laws to increase access to life-saving drugs. At the federal level, the IMF and the Patients Equal Access Coalition (PEAC) thank Congressman Leonard Lance (R-NJ-7th district) and Brian Higgins (D-NY-26th district) for introducing the Cancer Drug Parity Act of 2017.
- Cultivated legislative solutions to reexamine Medicare policies, specifically specialty tiers.
- Advanced helpful measures for U.S. veterans with myeloma, including legislation that would affect Blue Water Veterans who served in the Navy and the Coast Guard off Vietnam's shore during the Vietnam War. The IMF Advocacy team also joined with advocates from other disease groups and researchers nationwide to save the Congressionally Directed Medical Research Program (CDMRP). The CDMRP funds high-impact and risky research that often results in breakthrough treatments and technologies. CDMRP's research efforts to study cancer in service members was under attack by a provision in the National Defense Authorization Act. In part to IMF Advocacy's efforts, the program was saved.

If you have any questions about specific legislation that could affect the myeloma community, contact the IMF Advocacy Team at advocacy@myeloma.org.

Thanks to Members Like You

During the 2017 fiscal year, IMF members held more than 50 events, raising upwards of \$725,000. The IMF is grateful to individuals like you for hosting sporting events, bake sales, dance nights, and comedy shows – all in the name of supporting the myeloma community.



Alex Murer hosted the Myeloma Olympics in honor of his mother who is living with myeloma.



Comedian Forrest Shaw, whose mother has myeloma, organized Comedy for Myeloma at the Hollywood Improv in Los Angeles.



Debbie Beatty, inspired by her brother Matt Blennau's battle with myeloma, held "A Mission for Matt," an evening of dining and dance.



Andy Sninsky – a myeloma patient whose disease is in complete response – supported the IMF by collecting donations and building myeloma awareness on his ride Bicycle Mojave and Beyond.

DEVELOPMENT



Jeffrey Newman relaxes in his hometown of New York City.

There Is No Such Thing As a Drop in the Bucket – Everything Counts!

After losing his mother Carole Newman to multiple myeloma, Jeffrey Newman was compelled to take action. Carole's battle with the disease lasted five years. Carole lived independently in New York City during most of her life, and Jeffrey's sister Cynthia along with his brother Bill provided the care his mother needed

during her illness. During the final four months of life, the family moved Carole closer to Jeffrey's brother's home in Massachusetts. Jeffrey commented that, surrounded by family, his mother maintained her remarkable poise until the very end.

Not only affected by the loss of his mother, Jeffrey also has a close friend who has been living with myeloma for several years. Jeffrey felt a strong drive to "fight back" and decided to take action. His friend then introduced him to the International Myeloma Foundation (IMF).

The IMF's signature research program, the Black Swan Research Initiative® (BSRI), which aims to develop a definitive cure for myeloma, piqued Jeffrey's interest. Led by a team of global myeloma experts, the BSRI coordinates and supports more than 40 research projects around the world.

Jeffrey was especially excited to hear about how the BSRI team has overcome the first obstacle to finding a cure for myeloma by developing a very sensitive, reliable, standardized, and affordable test to detect minimal residual disease (MRD). The BSRI's Next Generation Flow (NGF) flow cytometry technique, paired with a specialized software package, can quantify and characterize even one single myeloma cell that may remain after a patient is in complete response (CR).

Jeffrey was drawn to this aspect of BSRI research because it makes a tangible contribution to the field of myeloma in very specific way. The family's fund, the Jerome A. and Estelle R. Newman Assistance Fund – as well as Jeffrey individually – contribute to BSRI research.

The hope is that this simple blood test is truly the next step in detecting and preventing the progression of disease in patients with myeloma. "It gives me great satisfaction to know that there is real light in the battle against this insidious disease and that our contributions will have a real impact. I encourage others – if they have the means – to get involved in any way they can," said Jeffrey. "Some people feel that fighting a disease is such an enormous task, and ask themselves, 'What can I do? I mean, anything I can give is only like a drop in the bucket.' But everything counts, especially when it comes to research."

Jeffrey hopes that you, too, will connect with the IMF to learn how to give in a targeted way that speaks to you. And most of all, he honors the memory of his mother Carole whom he will always value as "a respectful, decent, loving person who endowed me with an appreciation for sports and art and a classy way of going. She lived her life in an unpretentious way and would most appreciate what we are doing in her honor."

The entire IMF team is grateful to Jeffrey and the Newman family for all they do.

If you wish to discuss supporting the IMF in a way that works best for you, please contact Randi Lovett at rl Lovett@myeloma.org or 818.487.7455.

SUMMARY FINANCIAL INFORMATION

INTERNATIONAL MYELOMA FOUNDATION

Statement of Financial Position September 30, 2017

Assets

Cash and cash equivalents	\$ 1,871,136
Restricted cash, gift annuity investment	8,261
Investments, at fair value	5,315,517
Contributions, program grants, and other receivables	10,184,182
Prepaid expenses	894,936
Property and equipment, net	878,776
Intangible assets, net	100,757

TOTAL ASSETS	\$ 19,253,565
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Liabilities and Net Assets

Accounts payable and accrued expenses	\$ 1,731,656
Deferred program and educational grants	9,434,342
Gift annuity obligation	5,354
TOTAL LIABILITIES	\$ 11,171,352

NET ASSETS

Unrestricted	\$ 7,929,306
Temporarily restricted	152,907
TOTAL NET ASSETS	\$ 8,082,213

TOTAL LIABILITIES AND NET ASSETS	\$ 19,253,565
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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, 2017

	UNRESTRICTED	TEMPORARILY RESTRICTED	TOTAL
Revenues and Support			
Educational and program grants	\$ 7,794,976	\$ 5,144,611	\$ 12,939,587
General contributions	869,654	179,124	1,048,778
Fundraising programs	325,540	3,777	329,317
Seminar fees and support group income	59,198	-	59,198
Fundraising events, net of direct benefit to donors of \$413,826	337,523	627,074	964,597
Realized and unrealized gains, net	177,284	-	177,284
Investment income	169,842	255	170,097
	9,734,017	5,954,841	15,688,858
Net assets released from restrictions	8,392,994	(8,392,994)	-

Total Revenues and Support	\$ 18,127,011	\$ (2,438,153)	\$ 15,688,858
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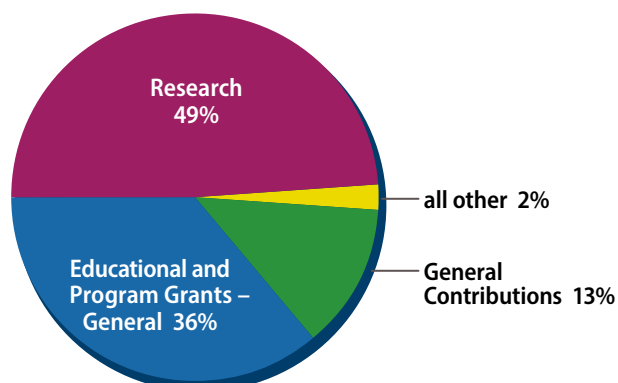
Functional Expenses

Program services	\$ 14,392,302	\$ -	\$ 14,392,302
General supporting services	647,853	-	647,853
Fundraising	984,967	-	984,967

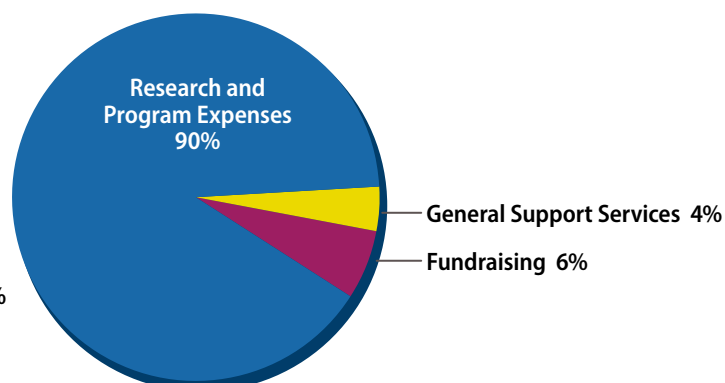
Total Functional Expenses	\$ 16,025,122	-	\$ 16,025,122
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Change in Net Assets	\$ 2,101,889	\$ (2,438,153)	\$ (336,264)
NET ASSETS – Beginning of year	5,827,417	2,591,060	8,418,477
NET ASSETS – End of year	\$ 7,929,306	\$ 152,907	\$ 8,082,213

Revenue Breakdown*



Expense Breakdown



* Percentages based upon detailed final trial balance.

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INTERNATIONAL MYELOMA FOUNDATION

Statement of Functional Expenses for the Year Ended September 30, 2017

Breakdown of Expenses by Program

PROGRAM	TOTAL EXPENSES
Research	\$ 6,993,161
Education & Awareness	1,816,514
Patient & Family Seminars	1,194,623
International	1,045,878
Support Groups	823,684
Nurse	633,083
Advocacy	556,308
Myeloma Today	358,550
InfoLine	344,538
Website	304,974
Clinical Meetings	212,392
Information Mailings	108,597

Total Program Expenses

\$ 14,392,302

General Supporting Expenses

\$ 647,853

Fundraising Expenses

984,967

Total Expenses

\$ 16,025,122



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Improving Lives **Finding the Cure®**

International Myeloma Foundation

12650 Riverside Drive, Suite 206
North Hollywood, CA 91607 USA

800.452.CURE (2873)
toll-free in U.S. and Canada

818.487.7455
worldwide

TheIMF@myeloma.org
myeloma.org



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