



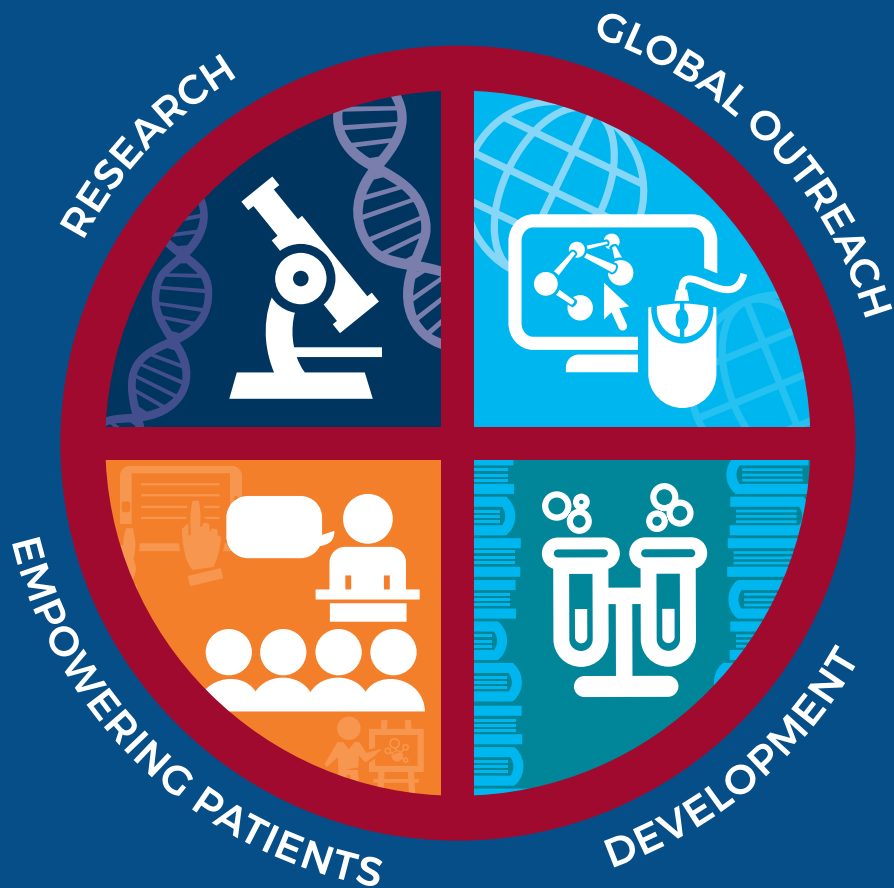
# MAKING A **WORLD** OF DIFFERENCE

2018 GLOBAL ANNUAL REPORT



INTERNATIONAL  
**MYELOMA**  
FOUNDATION

# INTERNATIONAL MYELOMA FOUNDATION



Improving Lives **Finding the Cure®**

# 2018 GLOBAL ANNUAL REPORT

FISCAL YEAR OCTOBER 1, 2017 – SEPTEMBER 30, 2018

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## A MESSAGE FROM THE PRESIDENT AND THE CHAIRMAN OF THE BOARD

Dear Friends,

It's always a pleasure to share with you all of the IMF's advances and achievements. This past year has been busy and productive in our four key areas: research, education, support, and advocacy.

Since 2015, we've been going to Iceland and collaborating with the remarkable team there. Our goal has been to learn more about Icelanders and why their incidence of myeloma cases is lower than much of the world. What's their "secret?" What's the "magic" of Iceland? Is it the food, the climate, the very heterogeneous population? Maybe it's all of the above... so we set out to find answers.

We're very excited to share with you what the iStopMM® (Iceland Screens, Treats, or Prevents Multiple Myeloma) study has done so far. The iStopMM team has screened the population which is approximately 120,000 adults over the age of 40 in Iceland, for the earliest signs of myeloma. This will allow researchers to observe patterns of occurrence, and how best to track disease progression from those early signs. They will also learn which patients will benefit most from early intervention.

In 2017, we took our second trip to Iceland. We were thrilled that CNN's Sanjay Gupta joined us there. He interviewed both Dr. Brian G.M. Durie and Dr. Sigurdur Kristinnsson, who is the Principal Investigator of iStopMM, for the CNN segment "Vital Signs."

We also continue to bring young investigators into the field of myeloma. Since 1994 we've awarded 1,420 grants to both junior and senior researchers worldwide, for a total of \$8 million. We are ONE MYELOMA NATION! We are also MYELOMA WARRIORS.

Who are Myeloma Warriors? They are patients, family members, caregivers, friends – people just like you!

It comes from people like you! People who have a loved one or friend with myeloma or who have lost someone to this disease. We also thank the companies who believe in our mission and donate to the IMF.

Many of you have asked, "Where does our funding come from?"



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

Every contribution counts – large or small. You can bring us closer to a cure by a monetary donation, or by organizing a Member FUNdraiser. My colleague Suzanne Battaglia ([sbattaglia@myeloma.org](mailto:sbattaglia@myeloma.org)) oversees Member FUNdraisers, and she will help you plan your fundraiser every step of the way.

In the U.S., the IMF holds four Patient & Family Seminars a year. We also held 9 Regional Community Workshops across the U.S. Our colleague Serdar Erdogan lives in Turkey. He ensures the IMF hosts seminars throughout Europe. If you'd like to have a seminar in your country, we encourage you to reach out to Serdar at [serdogan@myeloma.org](mailto:serdogan@myeloma.org)

In 1993, at our first-ever Patient & Family Seminar, I said, "Knowledge is Power!" We aim to inform patients with the latest information about best practices in myeloma treatment and supportive care, and remind them to ask questions of their doctors, nurses, and healthcare team. Remember your healthcare professionals work for you.

Many years ago, four women with myeloma met in a coffeeshop in San Francisco. They needed to share their hopes and fears, and thus, the first myeloma support group was born. Today, the IMF assists more than 150 Support Groups in the U.S.

We encourage you to get involved in some way. No task is too small – and you can make a world of difference!

Sincerely yours,

*Susie Durie Brian G.M. Durie*

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

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





Drs. Chen and Du take part in the 2017 Asia Myeloma Network Annual Summit.



## ASIAN MYELOMA NETWORK'S RESEARCH AND PATIENT SUPPORT MILESTONES

The International Myeloma Foundation's Asian Myeloma Network (AMN), an advisory body of 62 experts from 7 Asian countries/regions, expanded its reach in Fiscal Year 2018, with continued focus on clinical trials, physician education, Asian research priorities, and patient support.

This international group of physicians and researchers works collaboratively to advance the science and other clinical aspects of myeloma. Working groups have been created to:

- develop an Asian myeloma database (led by Korea)
- prepare clinical trials and treatment guidance (led by Singapore)
- foster physician training (led by China)
- enhance understanding of diagnosis and of smoldering multiple myeloma (led by Japan)

In 2018 AMN published **Asian treatment guidelines** in *Leukemia and Lymphoma*. Scientific papers were also prepared on the Asian myeloma database. Considerable advances were made with the AMN clinical trials - the first multi-Asian investigator initiated clinical trials and treatment access programs, which serve to generate considerable new data from the Asian region and to provide Asian patients with access to novel agents not yet approved for use in most of the Asian countries.

But the greatest success was the **1st Asian Myeloma Network Summit** held from October 15-17, 2017, in Seoul, Korea.

(continued on page 7)

# RESEARCH



Shaji K. Kumar, MD, (Mayo Clinic) and Brian G.M. Durie, MD (IMF Chairman of the Board) the ASCENT trial Principal Investigators, discuss myeloma research.



## 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® had a banner year in 2018:

- In November 2016, the IMF launched the **iStopMM** project to screen all adults over age 40 in Iceland for monoclonal gammopathy of undetermined significance (MGUS), the precursor to myeloma. In full swing, this project has recruited more than 80,000 participants.
- The **U.S.-based ASCENT trial (Aggressive Smoldering Cure evaluating Evaluating Novel Therapies)** is headed by Dr. Shaji Kumar of the Mayo Clinic (Rochester, MN) and uses a combination of carfilzomib, lenalidomide, dexamethasone, and daratumumab in an attempt to cure patients with high-risk smoldering multiple myeloma (HRSMM). 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 opened for accrual in late 2018 at 12 IMF Consortium sites.

- The Black Swan Research Initiative is now looking toward the future of multiple myeloma clinical trials. The key next step is to establish minimal residual disease testing as an endpoint in these trials. This step requires submitting results from multiple clinical trials that use MRD testing. The goal is to validate MRD testing as a "surrogate endpoint" superior to traditional endpoints, such as complete response (CR) or even stringent complete response (sCR). To achieve this goal, the Black Swan Research Initiative has established I2TEAMM. Led by Dr. Jesús San Miguel, Dr. Brian G.M. Durie, and Dr. Nikhil Munshi, the team will use data from both next-generation flow and next-generation sequencing testing for both frontline and relapse trials to submit to the FDA.

With these ongoing studies, it is hoped that the Black Swan team will be better able to characterize and understand the nature of the disease, its treatments, and patients' responses to various treatments.



Participants take part in Day 2 of the International Myeloma Working Group Annual Summit.



## INTERNATIONAL MYELOMA WORKING GROUP

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

In 2018, the IMF's International Myeloma Working Group (founded in 2001) published "Recommendations for acquisition, interpretation and reporting of whole-body low-dose CT in patients with multiple myeloma and other plasma cell disorders" in *Blood Cancer Journal*. This new report explains the value of whole-body low-dose CT (WBLDCT) for monitoring myeloma patients, thereby justifying reimbursement for its use.

The ninth Annual Summit of the International Myeloma Working Group (IMWG), held just prior to the annual meeting of the European Hematology Association (EHA), took place June 11–13 in Stockholm, Sweden. The Summit convened 100 of the world's top myeloma experts to review works in progress, set the agenda for future myeloma research projects, and learn from those who are exploring new frontiers in the biology and/or treatment of this disease.

In addition, patients, caregivers, and doctors from around the world gleaned insights into the latest myeloma research and treatment when they tuned into the livestream broadcast from the Summit on June 14. Other highlights from the Summit included the presentation of the IMF's 16th Annual Robert A. Kyle Lifetime Achievement Award to Dr. Philippe Moreau. This award honors an individual whose body of work has made significant contributions to myeloma research and patient care. The Brian G.M. Durie Outstanding Achievement Award, recognizing excellence in myeloma research, debuted at the 2018 Summit. Dr. Sigurdur Kristinsson was the award's first recipient.

## IMWG Publications in Fiscal Year 2018

Pessoa de Magalhães Filho RJ, et al. Analysis of Availability and Access of Anti-myeloma Drugs and Impact on the Management of Multiple Myeloma in Latin American Countries. *Clin Lymphoma Myeloma Leuk*. 2018 Aug 29. pii: S2152-2650(18)30361-6.

(continued from page 6)

This event brought together 100 of the leading myeloma researchers in Asia to review treatment realities and to determine research priorities for the Asian region.

### Update on AMN Clinical Trials

- AMN001 is an access program that enrolled 136 patients. It followed relapsed myeloma patients who had previous exposure to bortezomib and lenalidomide, and were later treated with pomalidomide and dexamethasone. The data demonstrated high response rates and is undergoing statistical analysis.
- AMN002 is randomized phase II study that uses different doses of carfilzomib with cyclophosphamide plus dexamethasone for relapsed/refractory myeloma patients who have had prior exposure to bortezomib. The project involves 50 patients in Asia as well as 50 patients in Australia and New Zealand.
- AMN003 is a randomized phase III study that is comparing the combination of pomalidomide, cyclophosphamide, and dexamethasone to the combination of pomalidomide and dexamethasone in relapsed or refractory myeloma patients. The project involves 120 patients in Asia.
- AMN004 – A phase II study is under way, examining the use of daratumumab in combination with thalidomide and dexamethasone in patients with relapsed and/or refractory myeloma. This study involves 100 patients in Asia.

### Update on Other AMN Training and Research Projects

- Physician training seminars were held in Beijing and Guangzhou, China.
- A young doctor training was held prior to ASH in December of 2018.
- The Sixth IMF Master Class was held in August in Los Angeles.
- Black Swan Research Initiative® minimal residual disease projects were implemented in China.
- AMN member Patient Seminars were held in China, Hong Kong, Taiwan, Korea, and Singapore.

## IMF IN EUROPE

The IMF continued to strengthen its international relationships with patients, families, and advocacy groups around the world in Fiscal Year 2018. Featured are some of the key educational meetings in Europe.

Near the end of 2017, the IMF hosted Patient & Family Seminars in Finland, Norway, and Iceland. The first in Helsinki garnered an audience of 200 participants. Dr. Raija Silvennoinen, an International Myeloma Working Group member, led the meeting. Dr. Rafat Abonour (Simon Cancer Center, Indiana University, U.S.) presented on myeloma treatments.



Pictured are Icelandic Patient & Family Seminar participants, including guest speaker Dr. Jean-Luc Harousseau and iStopMM Principal Investigator Dr. Sigurdur Kristinsson.

As of November 2017, more than 500 patients in Norway attended Patient & Family Seminars in Oslo, Trondheim, and Stavanger. Dr. Nina Gulbrandsen (Oslo University Hospital) oversaw the seminar with guest speaker Dr. Sundar Jagannath (Mount Sinai Hospital, New York, NY, U.S.). Additionally, Drs. Anders Waage from Trondheim and Dr. Einar Haukås from Stavanger led seminars in their respective cities.

At the end of 2017, the second Patient & Family Seminar in Reykjavik, Iceland, doubled its attendance from the same event held the previous year. Dr. Jean-Luc Harousseau (University of Nantes, France) was a guest speaker, and Dr. Sigurdur Kristinsson (University of Iceland, Reykjavik) reported on the progress of iStopMM.

In February of 2018, the IMF kicked off its 2018 program of international Patient & Family Seminars. First stop: Torino, Italy. Dr. Mario Boccadoro moderated 11 speakers, including International Myeloma Working Group members: Drs. Francesca Gay, Elena Zamagni, and Sara Brighnen. The session covered topics such as clinical trials, psycho-oncology in hematological malignancies, drug development, and treatment without transplant.

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# GLOBAL OUTREACH

## 2018 BRIAN D. NOVIS RESEARCH GRANT AWARDS

The International Myeloma Foundation (IMF) presented its 2018 Research Grant awards at a ceremony held during the 59th Annual Meeting of the American Society of Hematology (ASH) in December 2017 in Atlanta.

### Senior Grant Recipients

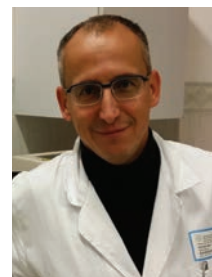
Senior Research Grant projects are funded at \$80,000.



Eline Menu, MD



Sophia Adamia, PhD



Nicola Giuliani, MD, PhD

**Eline Menu, MD** | Hematology and Immunology - Myeloma Center Brussels, Vrije Universiteit Brussel Brussels, Belgium

*Metabolism within the bone marrow microenvironment: targets for MM therapy and drug response*

**Sophia Adamia, PhD** | Medical Oncology, Dana-Farber Cancer Institute and Harvard Medical School – Boston, MA, USA

*Functional role of core splicing factor deregulation in MM pathogenesis*

**Nicola Giuliani, MD, PhD** | Department of Medicine and Surgery, University of Parma – Parma, Italy

*Reprogramming MM cell metabolism to affect bone disease in Multiple Myeloma*

### Junior Grant Recipients

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



Jacqui McGovern, PhD



Simona Segalla, PhD



Elke De Bruyne, PhD

**Jacqui McGovern, PhD** | Institute of Health and Biomedical Innovation, Centre in Regenerative Medicine, Queensland University of Technology – Brisbane, Australia

*Tissue engineering of an orthotopic humanized bone-organ as a preclinical platform for multiple myeloma research*

**Simona Segalla, PhD** | Functional Genomics of Cancer Unit, Division of Experimental Oncology, Ospedale San Raffaele – Milano, Italy

*The ribonuclease DIS3 in the DNA damage response in myeloma: a targetable pathway to protect the genome*

**Elke De Bruyne, PhD** | Hematology and Immunology - Myeloma Center Brussels, Vrije Universiteit Brussel (VUB) – Brussels, Belgium

*Protein arginine methyltransferase 5 (PRMT5) in MM: pivotal role in genomic instability and drug response?*





GMAN members wave hello from their Annual Summit, which was held in Stockholm, Sweden, in June 2018.



## 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 2018, at the Annual Meeting of the American Society of Hematology in Atlanta in early December 2017. Participants were welcomed and thanked 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 2018 at the IMF's International Myeloma Working Group (IMWG) Summit in Stockholm, Sweden. Thirty-five individuals representing twenty-five countries attended the Summit, which featured presentations and breakout sessions. Dr. Jean-Luc Harousseau (University of Nantes, Nantes, France) spoke to attendees about "The Cost of New Myeloma Treatments." Dr. Joseph Mikhael (IMF Chief Medical Officer), discussed myeloma therapies, including CAR T-cell therapy, pomalidomide treatment for early relapse, once-weekly dosing (as opposed to twice-weekly dosing) of Kyprolis (carfilzomib), and the combination of Darzalex (daratumumab) and carfilzomib, as well more drugs in the clinical trial pipeline. Matthew Zachary (Founder and CEO of Stupid Cancer) presented "Patient Advocacy on Your Own Terms," answering the question "How can we guarantee access and choice?" Dr. Arturo Loaiza-Bonilla gave an overview of Global Alliance for Patient Access (GAFPA), a network of physicians and patient advocates that promotes health policy to ensure patient access to appropriate clinical care and approved therapies.

The Summit agenda also hosted a session on navigating clinical trials so patients can access novel therapies as well as presentations by several representatives from member organizations in Asia, Europe, Latin America, Australia, 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.



The Connecticut Multiple Myeloma Fighters Group pose for Myeloma Action Month 2018.



## 2018 MYELOMA ACTION MONTH

The 2018 Myeloma Action Month campaign focused on Myeloma Warriors – individuals surviving with the disease, supporting loved ones, or helping to find the cure.

Myeloma Warriors inspired patients and caregivers across the country and around the world by sharing their deeply moving stories, life lessons, and advice regarding hope and strength on the MAM website [mam.myloma.org](http://mam.myloma.org). Whether they blogged, shared photos or stories, wrote letters, we thank all the spirited Myeloma Warriors who took action in March.

(continued from page 8)

In September 2018, the IMF held Patient & Family Seminars in Slovakia, Spain, and Germany. More than 120 people attended the seminar in Slovakia on September 7-8, which was hosted by 12 physicians. Sessions covered treatment options, myeloma awareness, advocacy, fundraising, and more.



Attendees gathered at the IMF Patient & Family Seminar in Liptoský Ján, Slovakia.

The IMF Patient & Family Seminar in Spain had more than 100 participants on September 13, 2018. These participants were from all parts of Spain, and some even traveled from as far as the Canary Islands. This seminar included a patient meeting and a meeting for doctors. Because the drug reimbursement process is complex in Spain, many myeloma patients must seek the most suitable medical centers for their treatments. For this reason, many Spanish myeloma patients move far from their hometowns to receive appropriate treatment. This scenario was discussed throughout the seminar.



The audience at the IMF Patient & Family Seminar in Heidelberg, Germany listens with rapt attention to the presenters.

In Germany, the Universitätsklinikum Heidelberg hosted a two-day myeloma seminar on September 22-23, known as "Myelomtage 2018." The first day, organized as an educational program for doctors, was attended by nearly 100 doctors. The second day, devoted to the patient community, was attended by more than 200 people. These European meetings were so successful that additional meetings are proposed for the upcoming year – in Berlin and/or Hamburg.



The IMF's Nurse Leadership Board members assemble at their annual meeting in Las Vegas.

## 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. The NLB's mission is to educate nurses, patients, and caregivers to improve patient outcomes.

In October 2017, the NLB authored the supplement Multiple Myeloma published in the Clinical Journal of Oncology Nursing (CJON). The supplement addressed issues for nurses who administer myeloma care, including patient and healthcare provider tip sheets, as well as evidence-based recommendations on the following topics: Myelosuppression, Bone Disease, and Acute Renal Failure; Bone Health, Pain, and Mobility; Heart and Lung Complications; Renal, GI, and Peripheral Nerves; and Distress, Fatigue, and Sexuality.

At the NLB's annual satellite symposium at the Oncology Nursing Society (ONS), 740 participants learned about the latest treatment regimens for newly diagnosed and for relapsed myeloma patients. Topics included symptom management, strategies for encouraging shared decision-making, and survivorship care plans. The NLB also had more than 5,000 online views of their ONS symposium.

In the past year, NLB members served as faculty at 4 Patient & Family Seminars and 10 IMF Regional Community Workshops and Myeloma Center Workshops, reaching about 2,000 attendees. NLB members also led two "Living Well" Teleconferences, and participated at the Support Group Leaders Summit as well as attended ASH with Support Group Leaders.

Finally, at their annual meeting in September, the NLB discussed the education of myeloma nurses through online modules. By the end of the meeting, nurses were ready to engage in the development of innovative approaches for nursing and patient education.

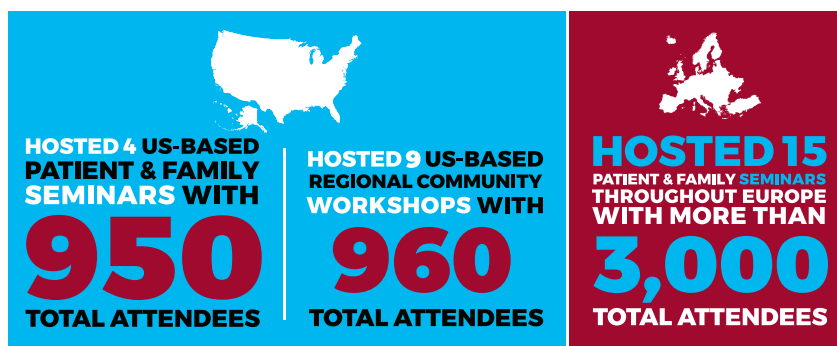
The IMF congratulates the NLB for their contributions to myeloma education.

# EMPOWERING

## PATIENT OUTREACH



### SEMINARS & WORKSHOPS



### SUPPORT GROUPS

**FACILITATED  
THE LAUNCH OF  
14 NEW**  
MYELOMA-FOCUSED  
**SUPPORT GROUPS  
NATIONWIDE**

**ASSISTED  
310**  
IMF-AFFILIATED  
**MYELOMA  
SUPPORT GROUPS  
NATIONWIDE**



### SOCIAL MEDIA

**CONNECTED  
WITH MORE THAN  
12,500**  
**FACEBOOK  
FOLLOWERS**

**↑ 149% REACH  
INCREASE**

**6,800**  
**TWITTER  
FOLLOWERS**

**↑ 30% REACH  
INCREASE**



### INFOLINE



# PATIENTS

## PATIENT EDUCATION



### TELECONFERENCES

#### IMF'S POPULAR BROADCAST "LIVING WELL WITH MYELOMA"

**11,000**  
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**



### NEWSLETTER

MORE THAN  
**30,000**  
SUBSCRIBE TO THE  
**MYELOMA MINUTE®**  
NEWSLETTER

MORE THAN  
**20,000**  
SUBSCRIBE TO THE  
**MYELOMA TODAY®**  
NEWSLETTER



#### IMF'S ADVOCACY TEAM HAS THEIR FINGER ON THE PULSE ON WHAT'S NEW IN HEALTHCARE

In 2018, the Advocacy team endorsed the Blue Water Navy Vietnam Veterans Act. The team created a webinar for patients about the legislation and how to take action on the bill. The webinar was created with the support and input from the offices of Sen. Gillibrand (D-NY) and Rep. Valadao (R-VA).

IMF Advocacy also worked with House and Senate appropriators to ensure blood cancers were included on the list of diseases able to apply for \$80 million in grant funding through the Congressionally Directed Medical Research Program's Peer Reviewed Cancer Research Program for FY2019.

The PEAC Coalition was rebranded as Coalition to Improve Access to Cancer Care (CIACC). The coalition continues to support oral parity legislation. This legislation ensures any health plan providing coverage for cancer treatments will also allow patients taking oral chemotherapy medications to benefit from the same level of cost-sharing as they would have if they were administered as an intravenous medication.

The Advocacy team was thrilled to garner record support for the Cancer Drug Parity Act in the House of Representatives, finishing the Congressional term with 175 bipartisan cosponsors. After the departure of Sen. Franken (D-MN) and Sen. Kirk (R-IL), Sen. Smith (D-MN) and Sen. Moran (R-KS) became new leaders for the Cancer Drug Parity Act.

Most recently, IMF Advocacy produced comment letters on the President's American Patients First Blueprint. Advocacy has also collaborated with other groups by signing 25 letters to federal agencies and lawmakers.

Finally, the IMF Advocacy Team has worked with various coalitions to increase funding for the NIH (\$3 Billion) and NCI (\$275 Million), which both saw budget increases for FY19.

Have questions about legislation that could affect the myeloma community? Contact the IMF's Advocacy Team at [advocacy@myeloma.org](mailto:advocacy@myeloma.org).



## WHAT IS A MYELOMA WARRIOR?

According to IMF Chairman of the Board Dr. Brian G.M. Durie, "Myeloma warriors are patients who become empowered through knowledge, not only for themselves, but by reaching out to help others." Dr. Durie recognizes that many patients may not always be in the right condition – either mentally or physically – to reach out to others. In this case, he suggests that a patient can ask a friend or a loved one, such as a caregiver to be their "Warrior-in-Chief." The IMF celebrates Myeloma Warriors like YOU here: volunteers who have given back to the myeloma community by organizing fundraisers.



[Left] Brenda Riggs, a volunteer fundraiser, made quilts and raffled them to raise funds for the IMF. Here, she is pictured with Darcy McCorristin, winner of the Many Blooms of Life Quilt.



Longtime supporters of the IMF organized another JC Golf Tournament.



Myeloma Warrior Kent Oliver organizes Laughs 4 Life – a yearly large-scale comedy benefit in Hattiesburg, Mississippi.

# DEVELOPMENT



## BRIDGING FUNDRAISING, VOLUNTEERISM, AND SUPPORT: MALCOLM KATZ AND SALLY WEBER

### Community builders

For Malcolm Katz and Sally Weber, building and sustaining community has been a cornerstone of their work as professionals and now as volunteers. When Malcolm was diagnosed with multiple myeloma, the couple both sought a supportive community.

Malcolm and Sally contacted the International Myeloma Foundation (IMF) and discovered there was not a support group close to their home. As Sally described, Malcolm then became like a "man on fire" to begin a support group in their area. Through his efforts, the San Fernando Valley Support Group in Southern California was born.

With the encouragement of the IMF, Malcolm visited doctors, arranged a meeting space at a local temple, and put forth an enormous recruitment effort. The first meeting proved successful, with 15 people in attendance. The couple continues to co-facilitate monthly meetings.

### Volunteering and fundraising

About five years ago, the IMF issued a challenge amongst IMF-affiliated support groups. The support group that raised the most funds for the annual IMF Comedy Celebration would win a visit from Susie Durie, IMF President & Co-Founder, and Dr. Brian G.M. Durie, IMF Chairman of the Board.

Malcolm took up the challenge. He led the San Fernando Valley Support Group and their families and friends to raise \$5K their first year of fundraising. The group won that visit from Susie Durie and Dr. Brian G.M. Durie. To date, the group has delivered more than \$80K in donation dollars to the IMF.

### What inspires these two?

Sally is driven by her personal passions and the joy of engaging in meaningful work. She recommends that people who are considering volunteering find "what they really want to do" and learn "what it takes to make that happen." Then "partner with others to see it through."

Malcolm says volunteering "takes a lot of time but it is rewarding, especially for retired people... Retirement is essentially another career (that) you must define for yourself."

Both Malcolm and Sally will continue to co-facilitate the SFV Support Group, which strives to serve the whole person. As Malcolm explains, "It's important to understand that we are not our disease. At times, the disease can overwhelm us when it flares up. But we are 'whole' people."

The IMF is grateful for the generosity of this pair, and hope that others will follow their stride.



# SUMMARY FINANCIAL INFORMATION

## INTERNATIONAL MYELOMA FOUNDATION

### Statement of Financial Position September 30, 2018

#### ASSETS

Cash and cash equivalents	\$ 2,114,979
Restricted cash, gift annuity investment	128,045
Investments, at fair value	5,018,898
Contributions, program grants, and other receivables	7,041,588
Prepaid expenses	1,287,362
Property and equipment, net	928,345
Intangible assets, net	130,561

<b>TOTAL ASSETS</b>	<b>\$ 16,649,778</b>
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#### LIABILITIES AND NET ASSETS

Accounts payable and accrued expenses	\$ 1,506,735
Deferred program and educational grants	7,062,437
Gift annuity obligation	78,278
<b>TOTAL LIABILITIES</b>	<b>8,647,450</b>

#### **NET ASSETS**

Unrestricted	6,338,827
Temporarily restricted	1,663,501
<b>TOTAL NET ASSETS</b>	<b>8,002,328</b>

<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b>\$ 16,649,778</b>
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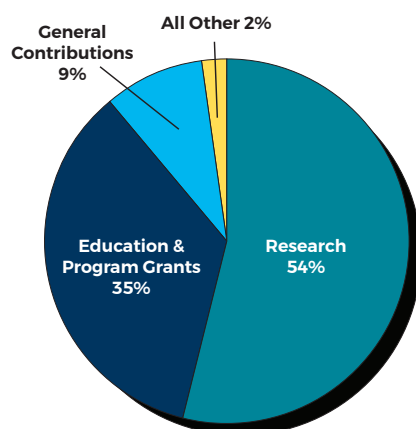
For a copy of our complete audited financial statements, please contact the IMF office.

# INTERNATIONAL MYELOMA FOUNDATION

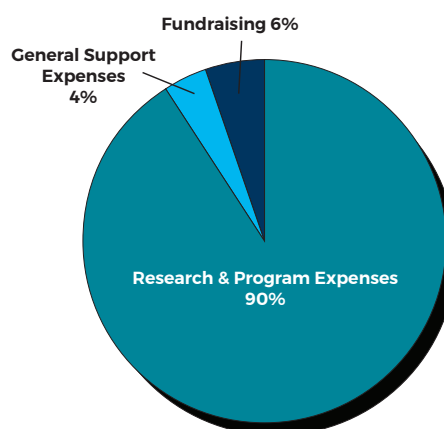
## Statement of Activities for the Year Ended September 30, 2018

	Unrestricted	Temporarily Restricted	Total
<b>REVENUES AND SUPPORT</b>			
Educational and program grants	\$ 11,546,627	\$ 2,689,000	\$ 14,235,627
General contributions	959,440	126,459	1,085,899
Change in split interest agreements	-	46,860	46,860
Fundraising programs	339,123	2,275	341,398
Seminar fees and support group income	59,459	-	59,459
Fundraising events, net of direct benefit to donors of \$402,746	233,186	500,266	733,452
Realized and unrealized gains, net	147,812	-	147,812
Investment income	134,754	-	134,754
	<u>13,420,401</u>	<u>3,364,860</u>	<u>16,785,261</u>
Net assets released from restrictions	<u>1,854,266</u>	<u>(1,854,266)</u>	<u>-</u>
<b>TOTAL REVENUES AND SUPPORT</b>	<b>\$ 15,274,667</b>	<b>\$ 1,510,594</b>	<b>\$ 16,785,261</b>
<b>FUNCTIONAL EXPENSES</b>			
Program expenses	\$ 15,207,222	\$ -	\$ 15,207,222
General supporting expenses	731,734	-	731,734
Fundraising expenses	926,190	-	926,190
	<u></u>	<u></u>	<u></u>
<b>TOTAL FUNCTIONAL EXPENSES</b>	<b>\$ 16,865,146</b>	<b>\$ -</b>	<b>\$ 16,865,146</b>
<b>CHANGE IN NET ASSETS</b>	<b>\$ (1,590,479)</b>	<b>\$ 1,510,594</b>	<b>\$ (79,885)</b>
<b>NET ASSETS</b> – Beginning of year	<u>7,929,306</u>	<u>152,907</u>	<u>8,082,213</u>
<b>NET ASSETS</b> – End of year	<u>\$ 6,338,827</u>	<u>\$ 1,663,501</u>	<u>\$ 8,002,328</u>

**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, 2018

### Breakdown of Expenses by Program

PROGRAM	TOTAL EXPENSES
Research	\$ 6,744,189
Education & Awareness	1,815,666
International	1,313,091
Patient & Family Seminars	1,104,873
Support Groups	975,130
Clinical Meetings	769,253
Nurse	673,083
Advocacy	654,934
InfoLine	370,714
Website	363,616
Myeloma Today	296,892
Information Mailings	125,781

#### Total Program Expenses

**\$ 15,207,222**

General Supporting Expenses	\$ 731,734
Fundraising Expenses	926,190

#### Total Expenses

**\$ 16,865,146**



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Each year, the Philadelphia Multiple Myeloma Networking Group hosts the Miles for Myeloma 5K Walk/Run. They raise funds for the IMF while “racing” toward a cure and working to “knock-out” myeloma.

## Improving Lives **Finding the Cure®**

### **International Myeloma Foundation**

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**INTERNATIONAL  
MYELOMA  
FOUNDATION**