

MAKING A WORLD OF DIFFERENCE

2019 GLOBAL ANNUAL REPORT



CELEBRATING 30 YEARS

INTERNATIONAL MYELOMA FOUNDATION



RESEARCH | GLOBAL OUTREACH | EMPOWERING PATIENTS | TAKING ACTION

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

2019 GLOBAL ANNUAL REPORT

FISCAL YEAR OCTOBER 1, 2018 – SEPTEMBER 30, 2019

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A MESSAGE FROM
THE PRESIDENT AND THE CHAIRMAN OF THE BOARD



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

Dear Friends,

The International Myeloma Foundation (IMF) is proud of our team and our accomplishments. As I write this, we are celebrating our 30th anniversary. I'm reminded of the words of my late husband, Brian D. Novis, when we started the IMF: "One person can make a difference, but two can make a miracle." With this sentiment in mind, the IMF brings together members of the myeloma community and beyond to focus on the theme of resilience.

During the 20th annual Support Group Leaders Summit held each year in Dallas, Texas, the IMF showcased an art display known as the "Wall of Resilience." Conceived and curated by Susan Dunnett, PhD, a senior lecturer at the University of Edinburgh, this display offered a visual exploration of personal resilience. It featured photographs from 100 IMF-affiliated myeloma support group leaders. Each photograph was paired with stories that explained how these images represented resilience to the leaders. The IMF has expanded this art display to the digital landscape and more IMF events.

Each year, the IMF holds four Patient & Family Seminars in the U.S. In 2019, we held seminars in Boca Raton, FL, Los Angeles, CA, Short Hills, NJ, and Charlotte, NC. In addition, we held Regional Community Workshops in 9 cities across the US, and 15 Patient & Family Seminars throughout Europe and the Middle East.

1995 was an important year for the IMF; we were still a young organization. Yet, we had big ideas, energy, and a passion to make "a world of difference" to people across the globe. We knew research was paramount to finding a cure. That year we awarded our first Brian D. Novis Research Grant, and it was presented to Dr. Atsushi Ogata

from Japan. Since then, we've awarded 142 research grants, totaling more than \$8 million to date.

The IMF has two signature research projects aimed at finding a cure. One is taking place in Iceland and is called "iStopMM" (Iceland Screens Treats or Prevents Multiple Myeloma). We began this project five years ago; and today, we are on the cusp of being able to start to cure a subset of myeloma patients. The second project involves the Cure Trials. These include the CESAR and ASCENT trials. Results of the CESAR trial demonstrate that with three years of follow-up, 62% of patients have sustained MRD negativity which is very promising for potential cure. Early results in the ASCENT trial which adds daratumumab to the KRd treatment regimen are even more promising. We are very proud to be able to support these research trials.

Thank you to our dedicated IMF team for all the hard work, along with our generous donors, who help us to make a difference to myeloma patients and caregivers around the world. Together, we are resilient!

Sincerely yours,

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

IMF Board of Directors

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International Myeloma Foundation
Los Angeles, CA

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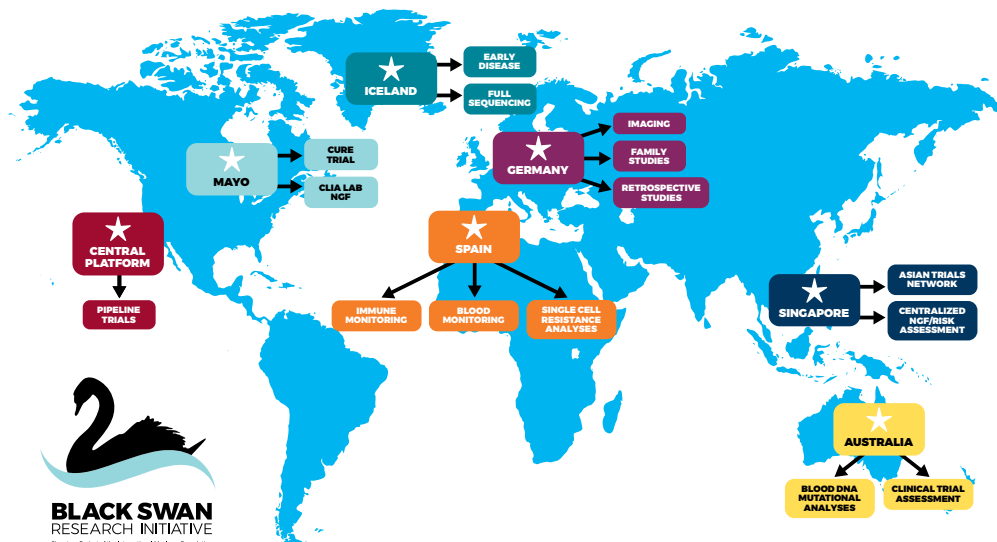
Raymond L. Wezik, JD

Director, Public Policy & Advocacy



The IMF team meets in Los Angeles for an annual retreat to brainstorm and plan for the coming year.

IMF GLOBAL TECHNOLOGY PLATFORM



To accelerate progress to achieve a cure, the IMF (through the Black Swan Research Initiative®) has created the IMF Global Technology Platform to attack myeloma on all fronts. Visit the webpage myeloma.org/cure to learn more about each of the projects displayed on this map.

IMF RESEARCH

BLACK SWAN RESEARCH INITIATIVE

The International Myeloma Foundation’s signature research project The Black Swan Research Initiative®, the IMF’s team of multinational researchers, continues to make strides. Here are some of their pivotal achievements from fiscal year 2019.

FOUR-DRUG COMBINATIONS TESTED TO FIND POTENTIAL CURE

The ASCENT trial (Aggressive Smoldering Curative Approach Evaluating Novel Therapies) continues to evaluate the efficacy and safety of the combination of Darzalex® (daratumumab), Kyprolis® (carfilzomib), Revlimid® (lenalidomide), and dexamethasone in high-risk smoldering multiple myeloma (HRSMM). Its goal: to learn whether starting treatment early substantially improves outcomes, leads to a higher level of undetected minimal residual disease (MRD), sustained remissions, and potential cure.

Dr. Shaji K. Kumar (Mayo Clinic) and IMF Chairman of the Board Dr. Brian G.M. Durie are Principal Investigators for this project. The trial sites include Mayo Clinic (Rochester, Minnesota); Indiana University Simon Cancer Center (Indianapolis); University of Maryland Medical Center (Baltimore) MD Anderson (Houston); Swedish Cancer Institute (Seattle); Emory University (Atlanta); University of Chicago Medical Center (Chicago); Weill Cornell Medicine (New York); University of North Carolina; Medical College of Wisconsin (Milwaukee, Wisconsin); University of Kansas Cancer Center (Westwood, Kansas); and Moffitt Cancer Center (Tampa, Florida).

The CESAR trial is ongoing in Spain with Professor María Victoria Mateos as the Principal Investigator. CESAR uses the combination of Kyprolis, Revlimid, and dexamethasone (KRd) with autologous stem cell transplant in the same setting as ASCENT. With a median follow-up of 28 months, 94 percent of patients are in remission, with 62 percent having undetected MRD at the 10⁻⁶ (zero out of a million cells) level. It is hoped that the addition of daratumumab in the U.S. ASCENT trial will enhance the undetected MRD level among patients to approximately 80 percent (at the 10⁻⁶ level). Because the CESAR trial has been well tolerated, there is great optimism moving forward.

RETROSPECTIVE COHORT STUDIES

Retrospective cohort studies have been conducted. Research groups formed within the International Myeloma Working Group (IMWG) developed these studies. Some examples of the patient populations include, but are not limited to:

- patients with multiple myeloma with t(11;14) identified on FISH studies performed within 6 months of diagnosis
- patients with smoldering multiple myeloma
- patients with relapsed multiple myeloma who have received at least 3 prior lines of therapy, are refractory to both an immunomodulatory drug, a proteasome inhibitor, and have been exposed to an alkylating agent



Iceland's President Gudni Thorlacius Jóhannesson, IMF President and CEO Susie Durie, and IMF Chairman of the Board Dr. Brian G.M. Durie

2019 IN REVIEW

ISTOPMM AIMS TO STOP MYELOMA IN ITS TRACKS

On November 15, 2018, the iStopMM (Iceland Screens Treats or Prevents Multiple Myeloma) team gathered at the deCODE genetics facility in Reykjavik, Iceland, for the 3rd Annual iStopMM Research Review meeting. This marked the end of a successful second year and the launch of the project's third year. The IMF-funded project recruited more than 80,000 Icelandic participants, making it the world's largest myeloma study. It drew the attention of Iceland's president, Gudni Thorlacius Jóhannesson. He was the first to publicly volunteer for the project when it launched in 2016.

Also, in November 2018, President Jóhannesson invited IMF President and CEO Susie Durie, IMF Chairman of the Board Dr. Brian G.M. Durie, iStopMM principal investigator Prof. Sigurdur Kristinsson, Una Jóhannesdóttir, and three Icelandic myeloma patients—Kristín Einarsdóttir, Kjartan Gunnarsson, and Gunnar Rúnar Kristjánsson—along with their spouses, to a luncheon at the president's residence, Bessastadir.

The 17-member iStopMM team so far has been able to:

- Test more than 80,000 of the study participants' blood samples
- Perform detailed testing, including imaging plus blood and bone marrow evaluation in approximately 4,000 patients with newly diagnosed MGUS
- Test more than 100 samples using next-generation flow cytometry
- Proceed to randomization for follow-up of more detailed testing and potential early intervention therapy



IMF Co-Founders Susie Durie and Dr. Brian Durie joyously accept their Honorary Doctorate in Brussels.

IMF CO-FOUNDERS AWARDED A JOINT HONORARY DOCTORATE IN RECOGNITION OF SCIENTIFIC EXCELLENCE

In a ceremony on April 2, 2019, International Myeloma Foundation President, CEO, and Co-Founder Susie Durie, and Chairman of the Board and Co-Founder Brian G.M. Durie, MD, were awarded a joint honorary doctorate for scientific excellence from the Vrije Universiteit Brussel (VUB) at a ceremony in Brussels, Belgium. Jacques Cousteau, Nelson Mandela, and Václav Havel are among past recipients of the award.

"We are tremendously honored that the work of the International Myeloma Foundation has been recognized in this way," said Susie Durie. "It is humbling to be in the company of other such accomplished honorees."

Dr. Durie said, "The global impact of the IMF's education, support, and research programs is a shared achievement with collegial and committed stakeholders in the myeloma community. This award is also for them."



More than 100 myeloma experts gathered for the 2019 International Myeloma Working Group Annual Summit.

IMF RESEARCH

INTERNATIONAL MYELOMA WORKING GROUP'S MILESTONES IN 2019

The 10th 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 10–12, 2019, in Amsterdam, the Netherlands. 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 12. Other highlights from the Summit included the presentation of the IMF's 18th Annual Robert A. Kyle Lifetime Achievement Award to Dr. Meletios A. Dimopoulos. 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, was awarded to Dr. María V. Mateos.

Most notably, the Mayo Clinic and the IMWG released new criteria for high-risk of progression of smoldering multiple myeloma, known as the "2/20/20" model, published in the June 2019 issue of the journal *Blood*.

The 2/20/20 criteria is based on the presence of

- 2 or more grams of monoclonal protein
- 20% or more monoclonal plasma cells in the bone marrow
- A free light chain ratio of involved to uninvolved light chains of 20 or more

The IMWG completed an analysis of more than 2,000 patients to confirm this finding.

IMWG PUBLICATIONS IN FISCAL YEAR 2019

Hillengass J, et al. International myeloma working group consensus recommendations on imaging in monoclonal plasma cell disorders. *Lancet Oncol* 2019; 20: e302–12. doi: 10.1016/S1470-2045(19)30309-2.

Kyriakou C, et al. The Role of Cement Augmentation with Percutaneous Vertebroplasty and Balloon Kyphoplasty for Treatment of Vertebral Compression Fractures in Multiple Myeloma: A Consensus Statement from the International Myeloma Working Group. *Blood Cancer J.* 2019; 9:27. doi: 10.1038/s41408-019-0187-7.

Moulopoulos L, et al. Recommendations for acquisition, interpretation and reporting of Whole Body Low Dose CT in patients with multiple myeloma and other plasma cell disorders: A report of the IMWG Bone Working Group. *Blood Cancer J.* 2018; Oct 4;8(10):95. doi: 10.1038/s41408-018-0124-1.

Usmani SZ, et al. Clinical Predictors of Long-Term Survival in Newly Diagnosed Transplant Eligible Multiple Myeloma – an IMWG Research Project. *Blood Cancer J.* 2018; 8:123. doi: 10.1038/s41408-018-0155-7



Asian Myeloma Network members assemble for their annual summit in Beijing in October 2018.

2019 IN REVIEW

ASIAN MYELOMA NETWORK MEMBERS ASSEMBLE FOR THEIR ANNUAL SUMMIT IN BEIJING, CHINA IN OCTOBER 2018

With over 60% of the planet's population, Asia is home to the greatest number of myeloma patients in the world. Unfortunately, delays in government approval processes and limited insurance and healthcare benefits in many of the Asian countries have resulted in lack of access to the newest myeloma treatments throughout the region. IMF's Asian Myeloma Network serves as a platform for Asian experts to enhance patient support in the Asian region.

The AMN has created working groups. They aim to develop an Asian myeloma database (led by Korea), to prepare clinical trials and treatment guidance (led by Singapore), to foster physician training (led by China), and to enhance understanding of diagnosis and of smoldering multiple myeloma (led by Japan).

In 2019 AMN prepared scientific papers on the Asian myeloma database and on the results of the first AMN clinical trial. The first multi-Asian investigators initiated clinical trials and treatment access programs. These programs generate new data from the Asian region and provide Asian patients with access to novel agents not yet approved for use in most Asian countries.

Most noteworthy was the **2nd Asian Myeloma Network Summit** held from October 19-21, 2018, in Beijing, China. This event brought together 120 of the leading myeloma researchers in Asia to review treatment realities and 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 (pom) and dexamethasone (dex). The data demonstrated high response rates. A publication on the findings will appear in Blood Cancer Journal.
- AMN002 is randomized phase II study that uses different doses of carfilzomib with cyclophosphamide, and dex 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 pom, cyclophosphamide, and dex to the combination of pomalidomide and dexamethasone in relapsed or refractory myeloma patients. The project involves 120 patients in Asia.
- AMN004 is a phase II study examining the use of daratumumab (dara) in combination with thalidomide and dex in patients with relapsed and/or refractory myeloma. This study involves 70 patients in Asia.
- AMN006 is a phase II study that will consider the use of dara in combination with bortezomib and dex in newly diagnosed, transplant-ineligible patients. This study involves 63 patients in Asia.

MORE AMN ACTIVITIES

- A large physician training seminar was held in Beijing, China.
- The 7th IMF Master Class was held in August in Los Angeles.
- The Black Swan Research Initiative® began minimal residual disease projects in China and Japan.
- AMN held member Patient Seminars in China, Hong Kong, Taiwan, Korea, and Singapore.

2019 BRIAN D. NOVIS RESEARCH GRANT AWARDS

The International Myeloma Foundation (IMF) presented its 2019 Research Grant awards at a ceremony held during the 60th annual meeting of the American Society of Hematology (ASH) in December 2018 in San Diego.



Jetze Tepe, PhD



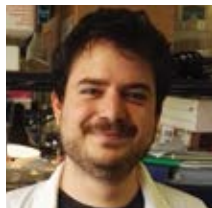
Andrew Zannettino, PhD



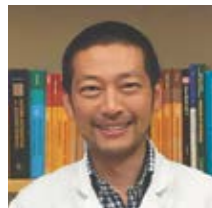
Christian Edward Bryant, BSc(med), MBBS, PhD



Ken Maes, PhD



Enrico Milan, PhD



Ryosuke Shiraski, MD, PhD

Senior Grant Recipients

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

Jetze Tepe, PhD | Michigan State University | United States
Targeting *c-Myc* degradation to treat myeloma
Funded by the 6th Annual Miracles for Myeloma 5K

Andrew Zannettino, PhD | The University of Adelaide | Australia
Single cell sequencing to discover tumor-associated changes in the bone microenvironment of myeloma patients
Funded by Laughs 4 Life

Junior Grant Recipients

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

Christian Edward Bryant, BSc(med), MBBS, PhD | Royal Prince Alfred Hospital | Australia
Dissecting the structural and functional heterogeneity of terminal effector CD8+T cells from MGUS and newly diagnosed myeloma patients in order to identify therapeutic targets and unlock their anti-myeloma potential
Funded by the Capt. Turner Ocean Swim

Ken Maes, PhD | Vrije Universiteit Brussel | Belgium
Unraveling the balance of tolerance and immunogenicity of myeloma cells
Funded by the Miles for Myeloma 5K

Enrico Milan, PhD | Vrije Universiteit Brussel | Belgium
Manipulating endoplasmic reticulum homeostasis and secretory capacity against systemic AL amyloidosis
Funded by the Miles for Myeloma 5K

Ryosuke Shiraski, MD, PhD | Dana-Farber Cancer Institute | United States
Overcoming resistance to pharmacological degraders of myeloma oncoproteins
Funded by the Mission for Matt in Honor of Matt Blennau



During the summer of 2019, the GMAN team assembled for their annual Summit in Amsterdam.



GLOBAL MYELOMA ACTION NETWORK

The Global Myeloma Action Network (GMAN) brings together advocacy leaders in multiple myeloma and blood cancers to improve the lives of patients around the world.

The annual GMAN Summit was held in Amsterdam from June 7–9, 2019. Thirty-five advocates from five continents and twenty-three countries attended. IMF's Director of GMAN, Europe & Middle East Patient Programs Serdar Erdoğan opened with a summary of international advocates' results in the past year.

- Dr. Brian G.M. Durie (IMF Chairman of the Board) updated the attendees about the status of the CESAR trial (in Europe) and the ASCENT trial (in the U.S.). He also highlighted how the IMF's Asian Myeloma Network has increased access to care in the Asian region by bringing clinical trials there.
- Dr. Rafat Abonour (IMF Medical Adviser) covered the results of the FORTE, MAIA, and CASSIOPEIA clinical trials for newly diagnosed patients.
- Robin Tuohy (IMF Vice President, Support Groups) and her husband Michael Tuohy (a 19-year myeloma survivor) shared their story, focusing on such topics as caregiving, talking to your children about cancer, quality of life, and more.
- Dr. Jean-Luc Harousseau (IMF Medical Adviser) and Mimi Choon-Quinones (IMF Senior Vice President, Global Advocacy, Access, Policy & Research) discussed how to expand clinical trials to smaller countries in Europe.

But perhaps, one of the biggest highlights of the Summit was the naming of the recipients of the 2019 Susie Novis Durie Grant. Columbia was awarded for Digital Awareness, South Korea for their Healing Walk, and Sweden for their development of a Toolkit for Patient Preferences.

OUTREACH



Attendees of the IMF Patient & Family Seminar in the Czech Republic celebrate community.

IMF IN EUROPE

The IMF continued to strengthen its international relationships with patients, families, and advocacy groups around the world in Fiscal Year 2019. Featured are some of the key educational meetings in Europe.

Near the end of 2018, the IMF hosted Patient & Family Seminars in Denmark, Croatia, and the Czech Republic. The first in Nyborg, Denmark, garnered an audience of more than 200 participants. It included members of the Danish organization Dansk Myelomatose. Presenters included Dr. Niels Abildgaard, Dr. Thomas Lunch, Dr. Sundar Jagannath, and myeloma patient Thomas Nybo. The seminar also included a talk on the psychological side effects of multiple myeloma, led by Katrina Pitt Winther and Stine Norvuyp.

On October 13, 2018, about 80 people attended the IMF Patient & Family Seminar in Zagreb, Croatia, including brilliant young volunteers from Medicine Faculty of Zagreb. Speakers included Dr. Delfa Radić Kristo, Prof. Jean-Luc Harousseau, and Dr. Aida Dildarevic. The seminar opened with remarks by President of Mijelom CRO, Goran Tudor; and Director of Mijelom CRO, Mira Armor. Also myeloma patient Rudi Konstanjsek shared his experience of seeing 14 different doctors in order to be diagnosed.

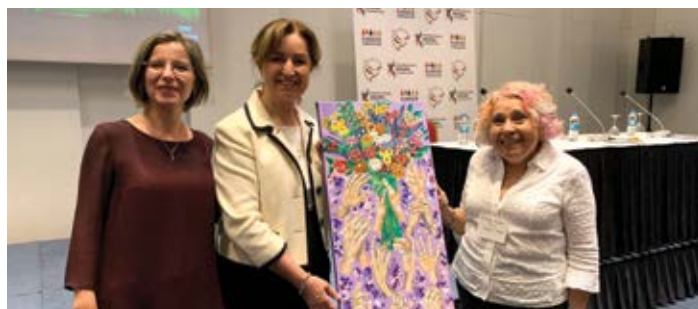
From Oct 19–20, 2018, nearly 120 people gathered at the IMF Patient & Family Seminar in Ústupy, the Czech Republic. Faculty included Drs. Roman Hájek, Jan Straub, Jakub Radocha, Luděk Pour, Jiří Minařík, and Petr Pavlíček. Myeloma patient Petr Hylena shared his experiences. Myeloma experts spoke, and there was a special celebration of long-term survivors.

As of November 2018, approximately 500 patients in Norway attended Patient & Family Seminars in Oslo, Trondheim, and Bergen. Drs. Nina Gulbrandsen and Fredrik Schjesvold (Oslo University Hospital) oversaw the seminar with guest speaker Dr. Jean-Luc Harousseau. Additionally, Drs. Anders Waage from Trondheim and Dr. Fredrik Hellem from Bergen led seminars in their respective cities.

The IMF-led initiative, Myeloma Action Month, held in March 2019 inspired successful patient events during this month. On March



Prof. Harousseau answering questions from attendees in Zagreb.



On the far right: Myeloma patient Aysegul Turcan gives a painting she created to (center) Dr. Meral Beksac at an IMF seminar in Ankara, Turkey. Also pictured is Ayesgul Turcan, the spouse of Serdar Erdoğan, IMF Director, Europe & the Middle East.

23, an IMF Patient & Family Seminar was held in Bari, Italy. It was attended by more than 150 members of the myeloma community and featured more than 20 myeloma experts.

On March 30, 2019, an IMF Patient & Family Seminar took place in Ankara, Turkey. It was attended by more than 90 patients and their family members. Organized by the Cancer Survivors Association, it featured a Facebook Live Event and simultaneous translation. Faculty included Prof. Meral Beksac, Prof. Jean-Luc Harousseau, Prof. İrem Dinçer, Prof. Özden Şener, Dr. Kerem Başarır, Dietician Şeniz Öztürk, Aslı Ortakmaç, and myeloma patient Aysegül Turcan.

EMPOWERING

PATIENT EDUCATION



PRINT PUBLICATIONS

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

PRODUCED
6 NEW
PUBLICATIONS AND
42 UPDATED
PUBLICATIONS



TRANSLATIONS

TRANSLATED MORE THAN
70 TITLES
INTO **14**
LANGUAGES

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



TELECONFERENCES

IMF'S POPULAR BROADCAST
"LIVING WELL WITH MYELOMA"

11,000
LIVE LISTENERS

25,000
ARCHIVED RECORDING
LISTENERS



NEWSLETTER

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

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



NURSE LEADERSHIP BOARD (NLB)

The IMF Nurse Leadership Board® (NLB) is a professional partnership representing nurse experts from leading medical centers caring for myeloma patients.

The NLB's 2019 Oncology Nursing Society (ONS) Satellite Symposium, "Case Studies for Nurses: Evolution in Myeloma Treatment," was led by co-chairs Beth Faiman and Joseph Tariman, and faculty members Sandra Rome and Kim Noonan. They addressed the latest treatment regimens for newly diagnosed and relapsed myeloma, and clinical trials for smoldering myeloma, educating 750 participants. The NLB historically attracts 2,500–5,000



The IMF's Nurse Leadership Board members assemble at their annual meeting in Hoboken, New Jersey.

PATIENTS

PATIENT OUTREACH



SEMINARS & WORKSHOPS



SUPPORT GROUPS

FACILITATED THE LAUNCH OF 11 NEW MYELOMA-FOCUSED SUPPORT GROUPS NATIONWIDE

ASSISTED 252 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

RESPONDED TO 2,500 CALLS GLOBALLY MORE THAN 1,000 EMAILS GLOBALLY



NLB members discuss many agenda items, including the new Myeloma 101 courseware.

on-demand views of this symposium each year on the IMF website. Also at ONS, the NLB presented a research poster showing their 2018 case-based symposium positively changed nurse behavior.

In 2019, NLB members served as faculty at IMF education forums, including 4 Patient & Family Seminars and 11 IMF Regional Community Workshops, reaching 2,000 attendees, and led a Living Well Teleconference on the impact of nutrition on side effect management. The NLB faculty participated at the Support Group Leaders Summit, attended ASH with the Support Group Leaders, and led and conducted 13 collaborative roundtables on the improvement of patient care.

Finally, at their annual meeting in September, the NLB discussed education of myeloma nurses through online modules which will provide a series of short educational videos targeted to nurses. This project can enhance the nursing care provided to myeloma patients and improve myeloma patients' lives.



From Left: IMF Director, Public Policy & Advocacy, Ray Wezik; IMF Director, Public Policy & Advocacy, Danielle Doherty; and IMF Senior Director, Public Policy & Advocacy, Robin Roland Levy

IMF ADVOCACY MAKES STRIDES WITH REGULATORY MATTERS, LEGISLATION, AND RESEARCH FUNDING

The IMF, through individual comments and coalition efforts, sent 34 letters addressing policy proposals that directly affect the myeloma community. These comments to the administration cover the President’s Drug Pricing Request for Information, the administration’s proposed rules on Medicare Part B and D, and the Centers for Medicare & Medicaid Services’ proposals on CAR T-cell therapies.

The Advocacy team called for an out-of-pocket cap for Medicare recipients. In the traditional Medicare program, there is no annual dollar limit to out-of-pocket expenses. If a **Medicare Out-Of-Pocket**

Cap is implemented, Medicare patients would have a yearly limit on their out-of-pocket drug expenses.

In a continued effort to improve patient access to oral chemotherapy drugs, the IMF Advocacy team endorsed **H.R. 1730/S. 741: The Cancer Drug Parity Act of 2019**. This legislation will prevent insurers from imposing higher cost-sharing for orally administered drugs versus intravenous (IV) therapies.

Other legislation endorsed by IMF team includes:

- **H.R. 913: The Clinical Treatment Act:** This bill would improve access to clinical trials for patients with Medicaid.
- **H.R. 1966: The Henrietta Lacks Enhancing Cancer Research Act of 2019:** This bill would require a study to be performed about barriers that exist for patients who are underrepresented in clinical trials.

The IMF, in collaboration with various coalitions of advocates, lobbied to increase funding for the **National Institutes of Health (NIH)**, the **National Cancer Institutes (NCI)**, and the **Food & Drug Administration (FDA)**.

Increased NIH/NCI-funding is essential for cancer researchers and helps advance scientific progress. Increased FDA funding may bring new therapies to patients more quickly.

Finally, the team advocated regarding the Trump administration’s proposals, including those within the President’s Blueprint. IMF Advocacy also successfully worked to stop changes to Medicare’s Six Protected Classes that would result in safeguards being removed. Additionally, the team communicated to the Trump administration the importance of considering access to future therapies, such as CAR T-cell therapies. The Medicare’s Final Decision Memo (released on August 7, 2019) includes some of the team’s suggestions.



2019 FISCAL YEAR REPORT FROM THE IMF’S VETERANS AGAINST MYELOMA

In 2019, the IMF’s Veterans Against Myeloma (VAM) program focused on making sure multiple myeloma remains recognized as a service-connected disease.

VAM ensured myeloma researchers are able to apply for grants through the Peer Reviewed Cancer Research Program (PRCRP) within the Congressionally Directed Medical Research Programs (CDMRP). The PRCRP is a program through the Department of Defense; it allows researchers to apply for grant funding for diseases specified by Congress. Each year, IMF meets with relevant offices on Capitol Hill to guarantee that that blood cancers remain as a topic area for research grants.

In late 2018, VAM successfully recommended two selected consumer reviewers to the myeloma panel under PRCRP. These individuals give patients and caregivers the opportunity to decide which research gets funded.

On January 1, 2020, H.R. 299, the Blue Water Navy Vietnam Veterans Act of 2019, will take effect. The President signed the bill after passage in both chambers last summer. This law restores the presumption of Agent Orange exposure to an estimated 60,000 veterans who served within 12 nautical miles off the coast of Vietnam during the Vietnam War. Myeloma has been directly linked to Agent Orange exposure. Veterans will no longer need to prove personal contact with the chemicals to receive their rightful care and benefits from the Department of Veterans Affairs.

Some other VAM initiatives include revising the Guide to Benefits to include a section on benefits for spouses and updated resources for veterans. Also, VAM focused on burn pit registry legislation, an issue for current and future VAM members.

DONOR SPOTLIGHT



*Irving L. Finkelstein with his colleague James Adams at Taylor's Ridge, Walker County, Georgia, on November 15, 2010, in pursuit of Buck Moths (*Hemileuca maia*)*



BUTTERFLY COLLECTOR LEAVES HIS MARK ON THE MYELOMA COMMUNITY

Often, a person leaves his or her mark on this earth with quiet fortitude. Dr. Irving L. Finkelstein (1936-2015) was one such individual. An Associate Professor Emeritus of Art and Design at Georgia State University, Dr. Finkelstein generously designated more than \$80,000 from his estate to be donated to the International Myeloma Foundation (IMF).

When the IMF received this bequest, our team began to learn more about the fascinating legacy of Dr. Finkelstein. He received his Ph.D. in art history from New York University and joined the faculty of the Department of Art and Design at Georgia State University in 1971. After contributing 25 years of imaginative inspiration to the Art and Design Department, he retired as Associate Professor Emeritus in 1996. Active in art circles in Atlanta and the South, Dr. Finkelstein's achievements were many.

Yet, the most striking quality of Dr. Finkelstein was his passion for Lepidoptera, an order of insects including moths and butterflies. How does one become dedicated to the study of the lives of moths and butterflies? According to Dr. Finkelstein, as he wrote in his acceptance of the 2003 John Abbot Award (a recognition of the Lepidopterists' Society), "Although I discovered and fell in love with lepidoptera at the age of seven, I had a very difficult time fulfilling that love. Growing up in an era and within a milieu in which butterfly collecting was considered a 'sissy' and perverse activity for a boy and adolescent, my life was made even more difficult because my mother was unsympathetic and in fact detested all insects, even butterflies and moths...Pursuing a formal

study and a career in entomology was out of the question, though that was what I wanted most of all. It was decided that I had some artistic talent, and I was sent off to art school, Pratt Institute, to get a degree in advertising design. Afterward, three excruciating years as a graphic designer in New York art studios and ad agencies convinced me I had to get out or go mad!"

Luckily, Dr. Finkelstein followed his heart and began serious study of entomology. In 1972, he joined the Lepidopterists' Society. Soon, he began participating in their collecting trips to Peru, Ecuador, Brazil, French Guiana, Costa Rica, Guatemala, and Belize. Independently, Dr. Finkelstein ventured to Spain, France, Israel, Japan, and more locations to exchange specimens with other collectors.

His life's work is best memorialized at the Irving Finkelstein Collection at the McGuire Center in Gainesville, Florida, viewable at (<https://www.floridamuseum.ufl.edu/index.php/mcguire/collection/irving-finkelstein/about/>).

Unfortunately, Dr. Finkelstein succumbed to multiple myeloma in 2015, but he did not pass without considering those he left behind. The International Myeloma Foundation is humbled by Dr. Finkelstein's gift, and inspired by his capturing of the natural world. Like the butterflies he collected, Dr. Finkelstein gave back to humanity with his value for uniqueness, beauty, and individual expression.

MYELOMA WARRIORS

CELEBRATING MYELOMA WARRIORS OF OUR COMMUNITIES

During the 2019 fiscal year, IMF members held more than 60 events, raising upwards of \$600,000. The IMF is grateful to individuals like you for celebrating the Myeloma Warrior spirit.



15-year myeloma survivor Jameca Barrett created a gathering with her community called Tea & Jeans. It helped her see that "nothing you do to raise funds is too small."



In 2019, Forrest Shaw organized two comedy fundraisers, one at the Hollywood Improv and the other at the New York Comedy Club.



The Philadelphia Multiple Myeloma Networking Group held its 10th Annual Miles for Myeloma 5K Run/Walk.

WAYS TO GIVE



JOIN THE HOPE SOCIETY: OUR MONTHLY GIVING PROGRAM

Members who give \$20 or more per month receive two complimentary registrations to a Patient & Family Seminar per year. New members can select a limited edition Hope Society gift! Contact Jonathan Weitz, IMF Donor Relations, at 1-800-452-2873 ext. 254 or jweitz@myeloma.org to learn more.



DONATE STOCK TO CHARITY

Donor-advised funds allow you to donate to the IMF with gifts of stock, securities, or IRA distributions. These options are the best ways to receive additional tax benefits through your philanthropic giving. Should you or your financial advisor have additional questions, please contact Jennifer Scarne, IMF's CFO/COO, at 1-800-452-2873 ext. 238.



MAJOR/PLANNED GIVING

The IMF welcomes many methods of investment giving, including a legacy gift bequest, a donor-advised fund, or a grant/gift from a private family foundation. These gifts are an excellent way to receive additional tax benefits. Contact Lynn Green, IMF Senior Vice President, Philanthropy, at lgreen@myeloma.org to learn more.



ONE-TIME GIFTS

You can also make a one-time gift at any time. All amounts help—from \$5 to \$500. Visit donate.myeloma.org NOW!

SUMMARY FINANCIAL INFORMATION

INTERNATIONAL MYELOMA FOUNDATION

Statement of Financial Position September 30, 2019

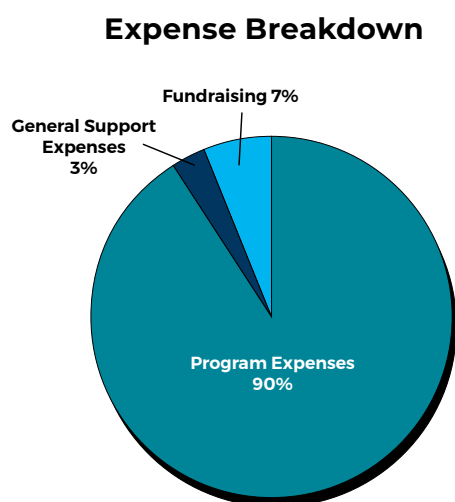
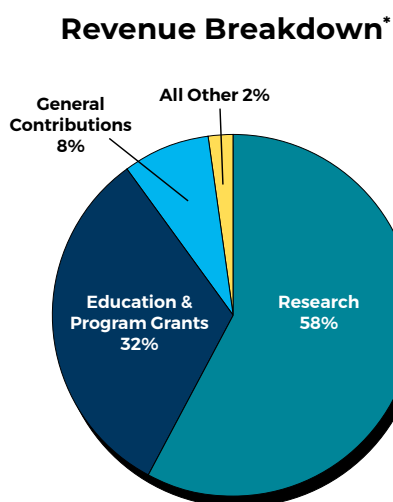
<u>ASSETS</u>	
Cash and cash equivalents	\$ 3,953,520
Restricted cash, gift annuity investment	129,878
Investments, at fair value	6,421,756
Contributions, program grants, and other receivables	5,710,832
Prepaid expenses	1,038,027
Property and equipment, net	624,404
Intangible assets, net	136,202
	<hr/>
TOTAL ASSETS	\$ 18,014,619
	<hr/> <hr/>
<u>LIABILITIES AND NET ASSETS</u>	
LIABILITIES	
Accounts payable and accrued expenses	\$ 2,583,802
Deferred program and educational grants	6,457,610
Gift annuity obligation	78,017
	<hr/>
TOTAL LIABILITIES	9,119,429
	<hr/>
NET ASSETS	
Without donor restrictions	8,708,329
With donor restrictions	186,861
	<hr/>
TOTAL NET ASSETS	8,895,190
	<hr/>
TOTAL LIABILITIES AND NET ASSETS	\$ 18,014,619
	<hr/> <hr/>

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

INTERNATIONAL MYELOMA FOUNDATION

Statement of Activities and Changes in Net Assets for the Year Ended September 30, 2019

	Without Donor Restrictions	With Donor Restrictions	Total
REVENUES AND SUPPORT			
Educational and program grants	\$ 14,545,863	\$ 2,876,535	\$ 17,422,398
General contributions	958,269	263,202	1,221,471
Change in split interest agreements	-	(7,550)	(7,550)
Fundraising programs	340,742	890	341,632
Seminar fees and support group income	72,368	-	72,368
Fundraising events, net of direct benefit to donors of \$376,704	335,479	466,390	801,869
Investment income, net	371,600	-	371,600
	<u>16,624,321</u>	<u>3,599,467</u>	<u>20,223,788</u>
Net assets released from restrictions	<u>5,076,107</u>	<u>(5,076,107)</u>	<u>-</u>
TOTAL REVENUES AND SUPPORT	\$21,700,428	(1,476,640)	20,223,788
FUNCTIONAL EXPENSES			
Program expenses	17,482,863	-	17,482,863
General supporting expenses	605,918	-	605,918
Fundraising	1,242,145	-	1,242,145
TOTAL FUNCTIONAL EXPENSES	\$19,330,926	-	\$19,330,926
CHANGE IN NET ASSETS	2,369,502	(1,476,640)	892,862
NET ASSETS - Beginning of year	<u>6,338,827</u>	<u>1,663,501</u>	<u>8,002,328</u>
NET ASSETS - End of year	<u><u>\$8,708,329</u></u>	<u><u>\$186,861</u></u>	<u><u>\$ 8,895,190</u></u>



* Percentages based upon detailed final trial balance.
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, 2019

Breakdown of Expenses by Program

PROGRAM	TOTAL EXPENSES
Research	\$ 8,988,911
Education and Awareness	1,811,101
Patient and Family Seminars	1,300,135
Support Groups	989,876
International	908,580
Nurse	818,945
Website	635,443
Advocacy	624,236
Clinical Meetings	582,851
InfoLine	384,246
Myeloma Today	326,241
Information Mailings	112,298

Total Program Expenses

\$17,482,863

General Supporting Expenses

605,918

Fundraising Expenses

1,242,145

Total Expenses

\$19,330,926



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



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

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