INTERNATIONAL MYELOMA FOUNDATION

2016
GLOBAL ANNUAL REPORT

MAKING A WORLD OF DIFFERENCE

Improving Lives **Finding the Cure**®

International
Myeloma
Foundation®

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2016

GLOBAL ANNUAL REPORT

FISCAL YEAR OCTOBER 1, 2015 – SEPTEMBER 30, 2016

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International
Myeloma
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A message from the President and the Chairman of the Board

Dear Friends,

It's always a pleasure to be able to share with you all the advances and achievements the IMF has accomplished. Once again, this past year has been very busy and incredibly productive in all of our four key areas: research, education, support and advocacy.

We're most excited to share with you the advances we've made in research! In April of 2016 the IMF's Black Swan Research Initiative® launched its first large-scale screening to identify and treat the precursors of myeloma before the disease develops. The study iStopMM® (Iceland Screens, Treats, or Prevents Multiple Myeloma) is examining blood samples from approximately 120,000 adults over the age of 40 in Iceland for the earliest signs of myeloma.

We traveled to Iceland twice in the past year. Our second trip was very exciting, as CNN's Sanjay Gupta joined us there to interview both Dr. Brian Durie and Dr. Sigurdur Kristinsson, who is the project leader of iStopMM. Dr. Gupta was very interested in this project. It's the first of its kind and could open the door to finally being able to cure early myeloma. CNN aired the segment on "Vital Signs," and we encourage you to view it if you haven't already done so.

In July of 2016 The International Myeloma Working Group (IMWG) published the new response criteria incorporating minimal residual disease (MRD) in *Lancet Oncology*. This was a significant accomplishment – 2 years in the making – achieved by reaching a consensus among more than 200 of the world's top myeloma researchers. No small task!

While we're making all these advances, it's also very important that we continue to bring young investigators into the field of myeloma by nurturing and inspiring them. Since 1994 we've awarded 130 grants to both junior and senior researchers. To date we've awarded more than $7 million dollars. Most of the funding comes from private donations and from Member FUNdraisers!

Knowledge is Power! We said that back in 1993, when we held the first ever Patient & Family Seminar. A lot has changed since then and today seminars are held all across the country and around the world. Empowering both patients and caregivers with information enables them to have meaningful discussions with their doctors about what treatment options are right for them. In the US, the IMF holds four Patient & Family Seminars a year, and this year we also held 9 Regional Community Workshops across the US. Our colleague Nadia Elkebir held seminars in 14 countries all across Europe and Scandinavia.

Many years ago four women met in a coffee shop in San Francisco – they had myeloma and just needed to talk and share with each other their hopes and their fears. And thus, the first myeloma support group was born. Today the IMF assists over 150 Support Groups across the US.

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

Sincerely yours,

Susie Novis Durie

Susie Novis Durie
President

Brian GM Durie

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

IMF Board of Directors

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

RESEARCH

Black Swan Research Initiative

The International Myeloma Foundation's signature research project

The Black Swan Research Initiative® is made up of an exciting team of multinational researchers who have developed a way to monitor the status of myeloma at very low levels, or minimal residual disease (MRD). By developing accurate testing to identify MRD, treatment efforts to rid the body of the disease entirely can be enhanced. During 2016, the Black Swan team developed such a test, known as Next Generation Flow.

With this flow cytometry technique, the bone marrow cells are passed through a specialized machine that is able to detect whether the bone marrow contains myeloma cells or not. Then, a sophisticated software program delivers a computer printout of the test. This printout tells whether the test results indicate MRD-negative, or whether there are some myeloma cells left, known as MRD-positive. This software will even identify the number of cells, for example, if one in one million cells has myeloma.

The next step, now that Next Generation Flow technology has been enhanced, is to set up labs throughout the world to conduct these tests. In the US, there are about a dozen labs where samples can be analyzed, and three reference labs where the samples can be received and tested. Outside of the US, labs are active in Europe, Latin America, and Asia for a total of about 60 centers in 26 different countries.

With the most sensitive and accurate MRD measuring tool in place, the BSRI investigators are now poised to carry out two important "cure" trials. The CESAR trial launched in Spain in the spring of 2016, and the US ASCENT trial will begin in 2017. Finally, iStopMM, the first large-scale screening of its kind (see side-column article) was launched in September of 2016.

International Myeloma Working Group

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

In 2016, the IMF's International Myeloma Working Group® (founded in 2011) published several highly regarded consensus statements and guidelines for the management of multiple myeloma. The group also presented lively teleconferences, debating the merits of newly presented research.

In June 2016, the seventh annual IMF IMWG® Summit was held in Copenhagen, Denmark, from June 7–9, 2016. A key focus of the Summit was to create IMWG guidelines to address the rising cost of myeloma drugs.

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 Thursday, June 9. Other highlights from the summit included the presentation of the IMF's 14th Annual Robert A. Kyle Lifetime Achievement Award to Dr. S. Vincent Rajkumar, the Edward W. and Betty Knight Scripps Professor of Medicine at the Mayo Clinic in Rochester, Minnesota. This award honors an individual whose body of work has made significant contributions to myeloma research and patient care.

In July 2016, the IMWG published new criteria for minimal residual disease assessment in *The Lancet Oncology* (detailed in the side-column on page 7). Achieving a consensus on these criteria from more than 200 top myeloma experts around the world who make up the IMWG took two years and required many rounds of review and input. "This paper is another landmark accomplishment for the IMWG," said Dr. Rajkumar. "These revised response criteria will be used in clinical practice, research, and in regulatory studies that lead to the approval of new drugs by agencies worldwide."

IMF President and Co-Founder Susie Novis Durie said, "This important work brings us closer to fulfilling the IMF's mission—finding a cure for myeloma. We are sincerely grateful to the IMWG members for their tireless contributions to that mission."

Led by Prinicipal Investigator Dr. Sigurdur Kristinsson (center), the iStopMM team poses in their lab in Iceland.

IMF Launches Study to Prevent Myeloma Before It Develops

The IMF launched iStopMM® in September 2016, a study aimed at preventing myeloma before it develops. iStop MM, which stands for Iceland Screens, Treats, or Prevents Multiple Myeloma, examines blood samples from approximately 120,000 adults over age 40 in Iceland for the earliest signs of myeloma.

Because nearly all the citizens of Iceland over age 40 undergo routine blood tests, the country is an ideal setting for such research. After obtaining informed consent in the beginning stages of this study in 2016, principal investigator Dr. Sigurdur Kristinsson of the University of Iceland and his team will screen blood samples from approximately 120,000 individuals for the precursors to myeloma—MGUS (monoclonal gammopathy of undetermined significance) and smoldering myeloma.

Those individuals diagnosed with the precursors will then be invited to participate in a randomized clinical trial to identify the best strategy for treatment and to create a new risk model for disease progression.

"The IMF is excited to fund this study, which will finally shed light on how we can stop myeloma at its earliest stage, before it progresses into full-blown cancer," said IMF President and Co-Founder Susie Novis Durie.

While most MGUS cases are never diagnosed, it is estimated that 4% of people over age 50 have MGUS.

"The impact of early diagnosis in a whole population is a very ambitious and challenging goal," said Dr. Kristinsson. "With more potent therapies available and fewer side effects, it is very likely that treatment of precursor states will be shown to improve survival and quality of life in smoldering and MGUS patients."

IMWG Publications

Chng, W. J., T. H. Chung, Shaji Kumar, Saad Usmani, N. Munshi, Hervé Avet-Loiseau, Harmut Goldschmidt, Brian Durie, and Pieter Sonneveld. "Gene signature combinations improve prognostic stratification of multiple myeloma patients." *Leukemia* 30, no. 5 (2016): 1071–1078.

Dimopoulos, Meletios A., Pieter Sonneveld, Nelson Leung, Giampaolo Merlini, Heinz Ludwig, Efstathios Kastritis, Hartmut Goldschmidt et al. "International Myeloma working group recommendations for the diagnosis and management of myeloma-related renal impairment." *J Clin Oncol.* 2016 May 1; 34(13)1544–57

Kumar, Shaji, Bruno Paiva, Kenneth C. Anderson, Brian Durie, Ola Landgren, Philippe Moreau, Nikhil Munshi et al. "International Myeloma Working Group consensus criteria for response and minimal residual disease assessment in multiple myeloma." *The Lancet Oncology* 17, no. 8 (2016): e328-e346.

Laubach, Jacob, Laurent Garderet, Anuj Mahindra, Gösta Gahrton, Jo Caers, Orhan Sezer, Peter M. Voorhees et al. "Management of relapsed multiple myeloma: recommendations of the International Myeloma Working Group." *Leukemia* 2016 May;30(5):1005–17

Sonneveld, Pieter, Hervé Avet-Loiseau, Sagar Lonial, Saad Usmani, David Siegel, Kenneth C. Anderson, Wee-Joo Chng et al. "Treatment of multiple myeloma with high-risk cytogenics: a consensus of the International Myeloma Working Group." *Blood* 2016 Jun 16; 127(24):2955–62

Asian Myeloma Network

The International Myeloma Foundation's Asian Myeloma Network® (AMN), an advisory body of 38 experts from 7 Asian countries/regions, continued to expand their reach in Fiscal Year 2016, with a focus on clinical trials, physician education, Asian research priorities, and patient support.

AMN's first clinical trial (AMN001) was successfully completed; it followed-up with relapsed myeloma patients who had previous exposure to bortezomib + lenalidomide and were then treated with pomalidomide + dexamethasone. The data demonstrated high response rates and patient tolerance, as well as provided treatment that was otherwise unavailable in Asia.

Two more AMN clinical trials were chosen to launch for 2017.

- AMN002 – This randomized phase II study used different doses of carfilzomib + cyclophosphamide + dexamethasone for relapse/refractory myeloma patients who had prior exposure to bortezomib. The project will involve 50 patients in Asian countries/regions and 50 patients in Australia and New Zealand.
- AMN003 – This randomized phase III study compares the use of pomalidomide + cyclophosphamide + dexamethasone to pomalidomide + dexamethasone-alone in relapse or refractory myeloma patients. The project will involve 120 patients in Asian countries/regions.

In addition to clinical trials, the AMN focused on the following training programs in fiscal year 2016.

- Physician training programs in Beijing, China in May 2016 and Shanghai, China in October 2016
- The fifth annual Myeloma Master Class for Chinese hematologists in Los Angeles in August 2016
- An ad-hoc training session for Chinese doctors during the International Myeloma Working Group conference in Copenhagen in June 2016

AMN was also active in myeloma research.

- AMN assisted with Black Swan Research Initiative® projects launched in China and Japan.
- Minimal residual disease (MRD) training sessions were held for Chinese doctors.
- Patients' country of residence information was added to an existing AMN database.
- AMN published the document, *Asian Treatment Guidelines*.

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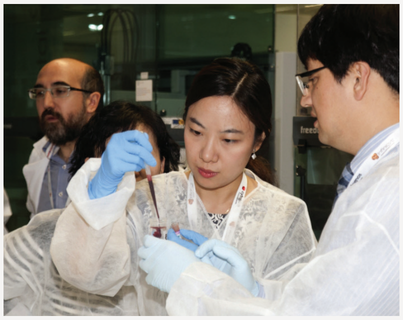


Lab workers at the University of Salamanca in Spain learn how to implement Next-Generation Flow technology

International Myeloma Working Group Publishes Consensus Criteria for Response and Minimal Residual Disease Assessment in Multiple Myeloma

On July 27, 2016, the members of the International Myeloma Working Group® (IMWG) published consensus criteria for response and minimal residual disease assessment in multiple myeloma in *The Lancet Oncology*. To standardize testing in patients who are having an excellent response to treatment in clinical trials, these criteria define the new response category of minimal residual disease (MRD) negativity.

"The treatment landscape for multiple myeloma has been radically transformed during the past decade by the introduction of several new drugs with different mechanisms of action," writes the paper's lead author, Dr. Shaji Kumar of Mayo Clinic in Rochester, Minnesota. High rates of complete response in myeloma patients treated with the new drugs called for new categories to identify responses that are deeper than those conventionally defined as complete response.

According to the new IMWG response criteria, MRD negativity that is sustained for at least one year is a key benchmark toward a cure. IMF Chairman and Co-Founder Dr. Brian Durie said, "For the first time, we've delineated a framework that can be uniformly applied around the world. It is a critical step as we work toward a cure for this serious cancer."

The 2016 response criteria specify MRD measurement using a combination of flow cytometry or gene sequencing, and sensitive imaging techniques, all of which can quantify any remaining myeloma clones as low as one in a million cells.

Achieving agreement on these criteria from more than 200 top myeloma experts around the world who make up the IMWG took two years and required many rounds of review and input.

In June 2016, IMF President and Co-Founder Susie Novis Durie (left) and IMF Chairman Dr. Brian Durie (right) presented Dr. S. Vincent Rajkumar the Robert A. Kyle Lifetime Achievement Award.

Robert A. Kyle Lifetime Achievement Award

The International Myeloma Foundation presented the 14th annual Robert A. Kyle Lifetime Achievement Award to Dr. S. Vincent Rajkumar during a ceremony in Copenhagen, Denmark on Wednesday evening, June 8, 2016. High spirits were accompanied by emotional tributes to Dr. Rajkumar by his closest colleagues, including a moving video from Dr. Robert Kyle, the award's namesake and a man who has served as a mentor to Dr. Rajkumar.

Dr. Rajkumar, who is the Edward W. and Betty Knight Scripps Professor of Medicine at the Mayo Clinic in Rochester, Minnesota, has worked closely with Dr. Kyle for 20 years. "Bob Kyle is an inspiration," said Dr. Rajkumar. "This award is a reflection of Dr. Kyle's leadership, vision, and guidance, more than anything I have done. The people who have won this award in the past are giants in the field, and I am very humbled."

Dr. Rajkumar has led numerous clinical trials investigating the role of new agents in myeloma, including the pivotal trials that led to the approval of thalidomide in myeloma in the US, and has published more than 300 peer-reviewed papers primarily in the field of myeloma and related plasma cell disorders. He also excels at science communications, serving as Associate Editor for the Mayo Clinic Proceedings; Section Editor for the journal *Leukemia*; Associate Editor for the *European Journal of Haematology*; and Editor-in-Chief of *Blood Cancer Journal.*

(Continued from page 7)

Finally, the AMN hosted Patient & Family Seminars throughout Asia in the following regions:

- Beijing, China in May 2016
- Shanghai, China in October 2016
- Seoul, Korea in October 2016
- Hong Kong in April 2016

Research Grants Program

The International Myeloma Foundation presented its 2016 Research Grants awards ceremony held during the 57th annual meeting of the American Society of Hematology (ASH) in December 2015 in Orlando, Florida. For nearly 21 years, the IMF has funded promising international clinical investigators through donations from private individuals and IMF Member FUNdraisers.

Recipients of the Brian D. Novis grants convened at the 57th annual meeting of the American Society of Hematology.

Senior Grant Recipients

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

Blood biomarkers for clonal progression in multiple myeloma
Irene Ghobrial, MD (BSRI) | Dana-Farber Cancer Institute – Boston, MA, USA

Optimization and validation of an automated capillary immunoelectrophoresis technology to quantify the expression of essential proteins in the pathogenesis of multiple myeloma
Norma C. Gutierrez, MD, PhD (BSRI) | Salamanca Institute for Biomedical Research (IBSAL)
University Hospital of Salamanca – Salamanca, Spain

Runx2 regulation of EMT and a bone resident of cell-like phenotype in myeloma cells
Yang Yang, MD, PhD (2nd year funding) | University of Alabama at Birmingham – Birmingham, AL, USA

NEK2 signaling in myeloma osteolytic disease
Fenghuang Zhan, MD, PhD | University of Iowa – Iowa City, IA, USA

Junior Grant Recipients

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

Investigating the Role of Robo1 in Migration and Homing in Multiple Myeloma
Giada Bianchi, MD | Dana-Farber Cancer Institute – Boston, MA, USA

Targeting the inhibitory pathways in the bone marrow microenvironment of multiple myeloma patients
Barbara Castella, PhD | CERMS - AOU Citta della salute e della scienza di Torino – Torino, Italy

Proteasome Deubiquitinase Inhibitors as a new treatment for Multiple Myeloma
Padraig D'Arcy, PhD | Karolinska Institute – Stockholm, Sweden

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

Targeting glutamine addiction in MM cells to inhibit disease progression and enhance myeloma therapeutics
Vijay Ramakrishnan, PhD | Mayo Clinic – Rochester, MN, USA

IMF Japan Grant Recipients

IMF Japan Aki Horinouchi Research Grant:
Regulation of PDPK1 and its clinical significance in multiple myeloma
Yoshiaki Chinen MD, PhD | Kyoto Prefectural University of Medicine
Graduate School of Medical Science – Kyoto, Japan

Identification of novel thalidomide-binding proteins and drug design for teratogenicity-negative IMiDs
Daiju Ichikawa, PhD | Keio University – Tokyo, Japan

Research Events of 2016

Several conferences bring together myeloma researchers from around the world annually. The IMF participates in each in order to present our research, to increase dialogue around this disease, and to stay abreast of important findings on global myeloma research. The 57th American Society of Hematology (ASH) Annual Meeting and the annual meeting of the American Society of Clinical Oncology (ASCO) brought to light some critical new successes in myeloma diagnostics and treatment.

IMF at ASH

The 57th American Society of Hematology Annual Meeting and Exposition took place in early December in Orlando, FL. The IMF team was seemingly everywhere at the meeting, which attracts more than 20,000 hematology professionals. The 798 myeloma-related presentations demonstrated steady progress on the research side in understanding myeloma's complex and evolving biology. Topics were divided among separate sessions on biology and pathophysiology, transplant, treatments other than transplant, new agents, and, for the first time, immune therapy.

Led by Robin Tuohy, IMF's Senior Director of Support Groups, a team of 14 myeloma Support Group Leaders from across the country reported on the news from ASH through social media. IMF's video team interviewed key ASH 2015 myeloma presenters to discuss the implications of their findings. These video interviews are available on the IMF website at https://www.myeloma.org/understanding/imf-tv.

IMF at ASCO

The Annual Meeting of the American Society of Clinical Oncology (ASCO) was held in early June 2016, in Chicago, IL. Far fewer abstracts were presented at ASCO 2016 than ASH 2016, however, there was quite a bit of excitement about the results of the phase III CASTOR study, a randomized trial comparing daratumumab + bortezomib (Velcade [V]) + dexamethasone [d] versus V + d alone. Beyond this study, another interesting aspect of this year's ASCO meeting was the number of abstracts focused on treatment costs, quality of life, and value measures—13 in all!

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

Prof. Jean-Luc Harousseau, MD

Prof. Jean-Luc Harousseau, MD, and Dr. Rafat Abonour Join the IMF

Renowned myeloma researchers Prof. Jean-Luc Harousseau, MD, and Rafat Abonour, MD have joined the International Myeloma Foundation.

Professor Harousseau recently retired from his position as professor of hematology at the University of Nantes, France – a position he held since 1980. He served as Chairman of the French National Authority for Health (HAS) from 2011 through 2015, and as Director of the Cancer Center René Gauducheau in Nantes from 2008 to 2011.

He was a founding member and served as President of the internationally renowned Intergroupe Français du Myélome (IFM), whose clinical trials have contributed significantly to the major improvements in the prognosis of myeloma. He has contributed to more than 500 peer-reviewed publications, including the *New England Journal of Medicine*, *Blood*, and the *Journal of Clinical Oncology*. In his new role, Prof. Harousseau will help increase access to treatment for myeloma patients globally.

Rafat Abonour, MD

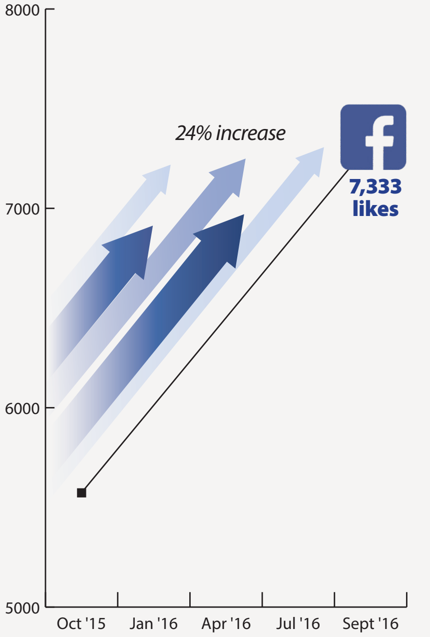
To further accelerate the IMF's mission to affect positive change around the world, Dr. Rafat Abonour was appointed as Medical Liaison. "Helping patients navigate this complex disease through the plethora of new drugs while keeping an eye on the ultimate goal of curing myeloma is challenging and rewarding work," said Dr. Abonour.

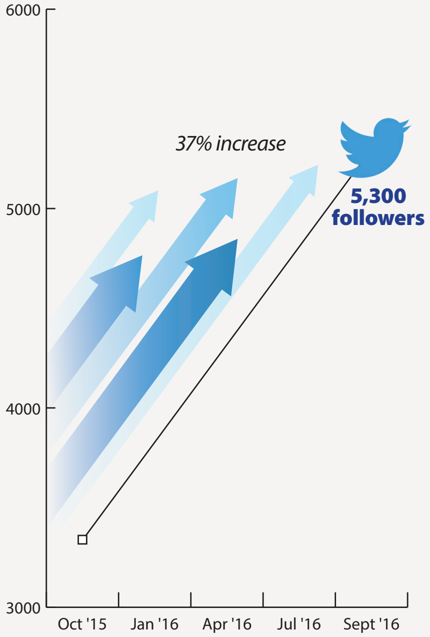
He established and currently directs the multiple myeloma and plasma cell program at Indiana University Simon Cancer Center.

He is principal or co-investigator of several ongoing clinical trials, and his work has been published in key medical journals, including the *New England Journal of Medicine* and *Nature*.

The IMF on Social Media

The IMF now has a growing presence both on Facebook and Twitter, with more than 7,333 "Likes" and 5,300 "Followers," respectively. This represents a 24% increase in Likes on Facebook and a 37% increase of Followers on Twitter in the past year.





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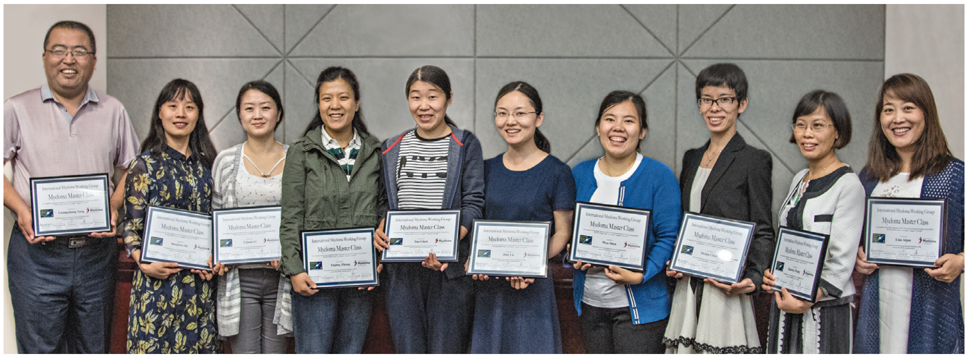
GLOBAL EDUCATIONAL OUTREACH

Asian Outreach



This young class of Chinese doctors proudly display their certificates from the fourth annual Master Class.

The Myeloma Master Class is a medical education program that was developed by the IMF five years ago, and is an intensive educational course designed for clinicians who specialize in myeloma. The fourth annual Master Class, held in August 2016 in Los Angeles, welcomed 10 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 Durie (IMF Chairman and Cedars-Sinai Samuel Oschin Cancer Center). The Master Class featured several days of interactive lectures and discussions on the full range of modern myeloma diagnosis and treatment with leading myeloma specialists Dr. Brian Durie, Dr. S. Vincent Rajkumar (Mayo Clinic, Rochester, MN); Dr. Tom Martin (Helen Diller Family Comprehensive Cancer Center, San Francisco, CA); and Dr. Jean-Luc Harousseau (University of Nantes, Nantes, France). By meeting with world-renowned myeloma experts, the young Chinese doctors allowed these skilled clinicians to refine their knowledge of myeloma and its treatment issues. But perhaps, most importantly, the Master Class provides the chance to see doctor-patient interactions in the US.

European Outreach

In Budapest, participants at IMF Lymphoma/Myeloma Day release balloons in front of St. Stephens Cathedral to honor patients around the world.

The IMF continued to strengthen its international relationships with patients, families, and advocacy groups abroad in 2015 with educational meetings in 10 European countries and 18 cities. By collaborating with doctors in each country and with European support groups, the IMF works to provide the most updated myeloma research and treatment information to patients in their own languages. In the coming year, the IMF will expand its presence to 5 more countries.

Dr. Roman Hájek speaks to a breakout group at the combined IMF, Czech Multiple Myleoma and Slovenská myelómová spoločnosť (Slovak Myeloma Society) in Lazne Belhorad, Czech Republic.

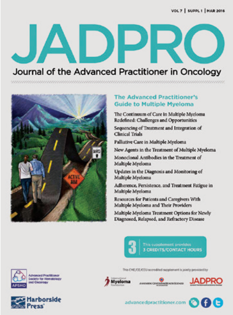
More than 140 people attended an IMF Patient & Family Seminar in Bergen, Norway.

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 primary mission is to improve the nursing care and self-care of patients with myeloma by educating nurses and patients via publications, symposia, multimedia, and research.

The NLB's eleventh annual meeting, held in Los Angeles, CA in October 2015, provided the opportunity to discuss the current state of myeloma care, identify unmet needs for patients and nurses, and plan ways to address those unmet needs. During the meeting, the NLB reviewed the results of their original research into the health maintenance of myeloma patients, and made plans for publishing their research, as well as a myeloma supplement targeted to nurses and advance practice health care providers.

Throughout fiscal year 2016, NLB members led education sessions at IMF Patient & Family Seminars and Regional Community Workshops, accompanied support group leaders to the 2015 Annual Meeting of the American Society of Hematology (ASH), and addressed the IMF's 2016 Support Group Leaders Summit. The NLB contributed to IMF publications and spoke on teleconferences in the IMF's popular "Living Well with Myeloma" series, which is open to the entire myeloma community.



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JADPRO

Journal of the Advanced Practitioner in Oncology

The Advanced Practitioner's Guide to Multiple Myeloma

The Continuum of Care in Multiple Myeloma Redefined: Challenges and Opportunities

Sequencing of Treatment and Integration of Clinical Trials

Palliative Care in Multiple Myeloma

New Agents in the Treatment of Multiple Myeloma

Monoclonal Antibodies in the Treatment of Multiple Myeloma

Updates in the Diagnosis and Monitoring of Multiple Myeloma

Adherence, Persistence, and Treatment Fatigue in Multiple Myeloma

Resources for Patients and Caregivers With Multiple Myeloma and Their Providers

Multiple Myeloma Treatment Options for Newly Diagnosed, Relapsed, and Refractory Disease

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In March of 2016, the *Journal of the Advanced Practitioner in Oncology* (*JADPRO*) published a CME/CE/CEU accredited supplement jointly provided by the IMF, the Annenberg Center for Health Sciences at Eisenhower, and *JADPRO*. NLB members developed this supplement, entitled "The Advanced Practitioner's Guide to Multiple Myeloma," as a continuing education activity for nurse practitioners, physician assistants, clinical nurse specialists, advanced degree nurses, oncology and hematology nurses, pharmacists, and physicians. It aims to provide oncology professionals with state-of-the-science information that they need to effectively manage patients with multiple myeloma.

Then, at the 2016 Oncology Nursing Society annual conference in San Antonio, Texas in April, the NLB hosted a CNE-accredited satellite symposium entitled "Updates in Multiple Myeloma: Case Studies in Collaborative Nursing and Patient Care," which was attended by nearly 1000 health care practitioners. Co-chaired by Beth Faiman, PhD, RN, MSN, APRN-BC, AOCN® (Taussig Cancer Institute-Cleveland Clinic) and Joseph Tariman, PhD, RN, ANP-BC, FAAN (DePaul University-Chicago, IL), the presentation highlighted six myeloma patient case studies on how to effectively practice shared-decision making between patients, caregivers, and healthcare providers in these scenarios.

Health-care practitioners listen attentively to the presentations at the most recent IMF satellite symposium at the Oncology Nursing Symposium.

IMF Nurse Leadership Board Members

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Acute Leukemia Research Program
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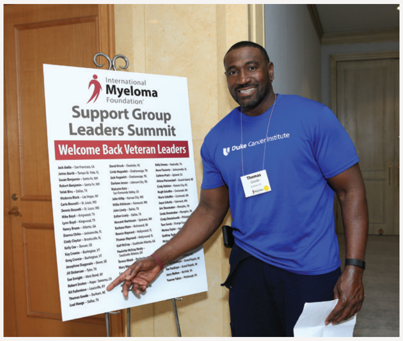
Daniel Verina, BS, BSN, MSN, ACNP-BC
Mount Sinai Medical Center
Hematology, Myeloma Team
New York, NY

International Affiliates

Tracy King, RN, MN
Institute of Hematology
Royal Prince Alfred Hospital
Sydney, Australia

Cindy Manchulenko, RN, BN, MSN
Clinical Trials Project Manager, Clinical & Systems Transformation
Vancouver Coastal Health
Vancouver, BC, Canada



Thomas Goode
Support Group Leader
Raleigh-Durham, North Carolina

Thomas Goode was diagnosed with a plasmacytoma in 2005. In 2006, after treatment with radiation, he then underwent an autologous stem cell transplant. Two months after completion of the transplant, Thomas's brother matched as a candidate for Thomas's allogeneic stem cell transplant. Today, Thomas is on maintenance therapy and continues to run a support group in the Raleigh-Durham area, which he has facilitated for the past three years. Thomas describes the Triangle Area Support Group as "a small group but powerful with knowledge."

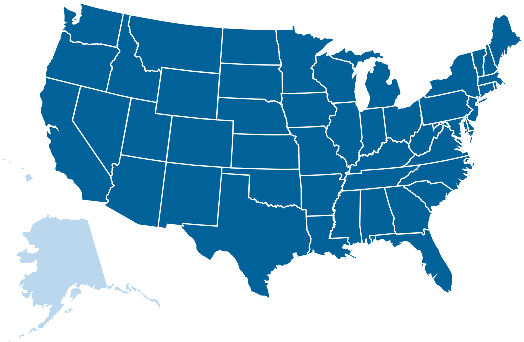
Since diagnosis, Thomas says, "I have a totally different outlook on life; I live my life to the fullest and cherish each day as if it's my last. Not only do I co-lead the Triangle Area Support Group in North Carolina, but I'm also a Reflective Ambassador for Celgene. This role gives me the privilege of visiting other support groups and telling my story about my journey with myeloma and my experience with Revlimid + dexamethasone."

Thomas Goode presents at the annual Support Group Leaders' Summit.

You can learn more about Thomas's involvement with the IMF at http://ash2016blogs.myeloma.org/category/thomas-goode/ or listen to his story at the IMF website at https://www.myeloma.org/videos/thomas-goode.

EMPOWERING PATIENTS

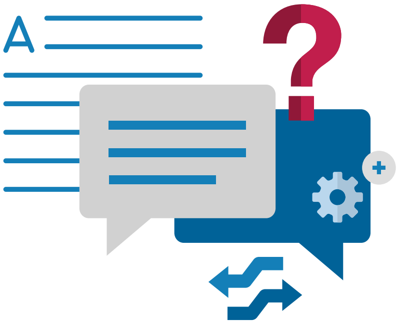
Patient Outreach in Fiscal Year 2016



900 individuals
attended 4 US-based Patient & Family Seminars

1,150 individuals
attended 9 US-based Regional Community Workshops

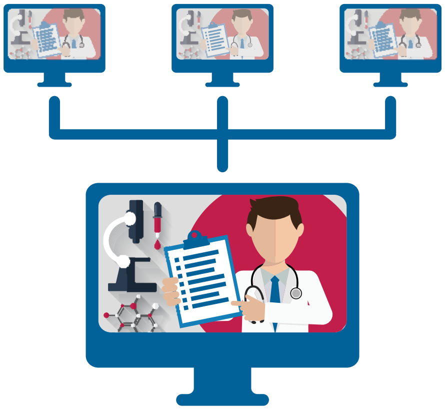
Responded to 2,300 InfoLine calls globally



Responded to more than 1,000 InfoLine emails globally

10,000 listeners tuned in live
for the IMF's popular
"Living Well with Myeloma"
teleconferences

25,000 people
listened to archived versions



10 Patient & Family Seminars
hosted throughout Europe

Patient Education in Fiscal Year 2016

From October 2015 through September 2016:

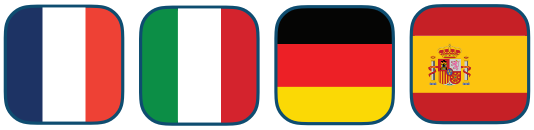
More than 3,000 InfoPacks sent to patients and their families

14 new booklets published and more than 40 publications updated

More than 28,000 people subscribed to the ***Myeloma Minute®* eNewsletter**

20,700 people subscribed to ***Myeloma Today®***

Translated many IMF publications and medical articles on a quarterly basis into **French, Italian, German, and Spanish**



The foreign language articles are **at myeloma.org** and disseminated via the quarterly **eNewsletter Myeloma Messenger**

IMF 2016 List of Publications

*Bookmark***

*Concise Review***

*Guide to Multiple Myeloma Acronyms and Abbreviations***

*Guide to Multiple Myeloma Terms and Definitions***

Mail for the CURE

*Making Miracles**

*Myeloma Matrix***

*Myeloma Matrix 2.0: Smart Patients**

*Myeloma Today**

*Patient Handbook***

*Tip Card - Adherence to Oral Cancer Therapy**

*Tip Card - Darzalex**

*Tip Card - Electronic Medical Records**

*Tip Card - Empliciti (elotuzumab)**

*Tip Card - Farydak (panobinostat) capsules**

*Tip Card – Freelite® and Hevylite® Tests***

*Tip Card - Kyprolis® (carfilzomib)***

*Tip Card – Matrix**

*Tip Card –Myeloma and the Immune System***

*Tip Card - Ninlaro (ixazomib)**

*Tip Card - Pomalyst® (pomalidomide)***

Tip Card - SQ Velcade ® (bortezomib)

Tip Card - Veterans Against Myeloma (VAM)

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

*Understanding - Adherence to Oral Cancer Therapy***

*Understanding - Bisphosphonate Therapy***

*Understanding - Clinical Trials***

*Understanding - Darzalex (daratumumab) injection**

*Understanding - Dexamethasone and Other Steroids***

*Understanding - Empliciti (elotuzumab)**

*Understanding - Farydak (panobinostat) capsules**

*Understanding - Fatigue***

*Understanding – Freelite® and Hevylite® Tests***

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

*Understanding - Kyprolis® (carfilzomib)***

*Understanding - MGUS and Smoldering Multiple Myeloma***

*Understanding - Pomalyst® (pomalidomide) capsules***

*Understanding - Revlimid® (lenalidomide)***

*Understanding - Thalidomide Therapy***

*Understanding – The Immune System in Myeloma***

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

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

*Understanding - Your Test Results ***

*New (between 10/1/15 and 9/30/16)
**Updated (between 10/1/15 and 9/30/16)

Janet Kerrigan
Support Group Leader
Myrtle Beach, South Carolina

Janet Kerrigan recalls that “2011 was going to be great year.” Her youngest daughter was getting married. In October, 126 family members and friends attended her daughter’s wedding at the Kingston Plantation in South Carolina. Shortly after that, Janet’s family rescued a dog from a shelter. Then a couple weeks later, Janet felt a sharp pain in her chest while she was at work. That sharp pain soon led doctors down a trail of breadcrumbs in testing Janet’s health - ultimately ending with a bone marrow biopsy diagnosing her with multiple myeloma on December 1st. After many treatments, Janet finds that she “continues to fight for others” and herself. She says that her “journey is not of sadness, but of new experiences.” This attitude inspired her to start a myeloma support group in Myrtle Beach, South Carolina, which she continues to facilitate today. She is also active in partnering with the IMF to organize Member FUNdraisers.

Janet Kerrigan (far right) with her two daughters and grandchild

You can learn more about Janet’s fundraising efforts at her Facebook page https://www.facebook.com/KixCancersButt/ or listen to her story at the IMF website at https://www.myeloma.org/videos/janet-and-joe-kerrigan. Janet hopes to continue to try and assist others with myeloma that need guidance with their journey.

SUPPORT

Myeloma Action Month

The International Myeloma Foundation harnessed the energy of patient advocates to raise awareness of the disease during the month of March. In 2009, inspired by the organization’s key message “knowledge is power,” the IMF recognized the need to heighten the profile of this as-yet incurable cancer and declared March as Myeloma Awareness Month. In 2016, the IMF renamed the campaign Myeloma ACTION Month to better reflect the dynamic, proactive approach to affect myeloma patients’ lives.

Other outreach components of Myeloma ACTION Month seized on new ways to “actively” spread awareness about myeloma. Some examples of these actions included the following:

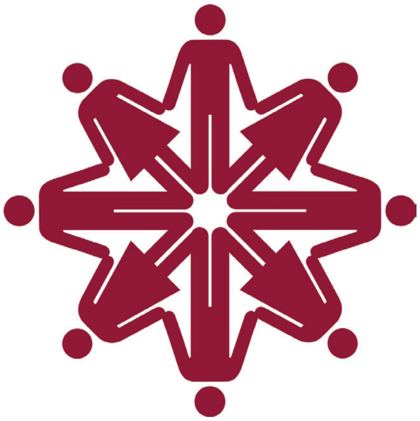
- A one-page letter crafted by IMF Chairman Dr. Brian Durie was aimed at US primary care doctors who may not be familiar with myeloma but may be faced with diagnosing patients with the disease. The letter, posted on the Myeloma ACTION Month website, was available for anyone to download and mail to health care providers.
- Members of the myeloma community were invited to share their stories on the website mam.myeloma.org.
- Nancy Bruno, Southeast Regional Director of Support Groups, attended a meeting of the Concerned Black Clergy in Atlanta to educate community members there about myeloma.

- The IMF partnered with the Boston Celtics and Takeda Oncology in “3 Points for Patients,” for which each three-pointer made by the Celtics triggered a donation to IMF research.
- Takeda also sponsored an effort with the music-sharing platform Spotify; every time anyone followed the “Music 2 Fight Myeloma” Playlist at this site, Takeda donated to the IMF.
- Last, but glaringly not least, was the IMF message flashing from two digital billboards, thanks to a generous donation from Tom and Cathy Ordway, along a well-travelled highway in the Ordways’ home state of Connecticut.

The IMF benefited tremendously from the actions of each individual that impacted the myeloma community as a whole.

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

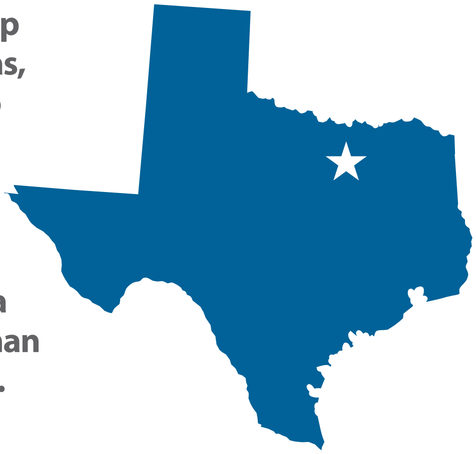
More than 300 myeloma support groups worldwide are affiliated with the IMF.



In the 2016 fiscal year, IMF Support Group Directors made 244 in-person visits to local support group meetings, Patient & Family Seminars, Regional Community Workshops, and other outreach events.

In the 2016 fiscal year, 8 new myeloma support groups were formed across the United States.

The 17th Annual IMF Support Group Leaders Summit took place in Dallas, Texas. A total of 100 support group leaders, representing 68 groups, with 33 first-time attendees, participated in the three-day program. The reach of these 100 leaders back to their local myeloma support groups extends to more than 5,300 patients and their caregivers.



To increase resources to the local myeloma community, the IMF has provided 73 iPads and 28 Technology Kits (projector, speaker, tripod, cables, and carrying case) plus 100 flash drives loaded with updated information, to support group leaders to use at their meetings.

Blogging, Tweeting, and Social Sharing Their Way Through ASH

The IMF provided a unique opportunity for 14 support group leaders to attend the American Society of Hematology (ASH) Annual Meeting in Orlando, Florida in December 2015. They shared their experiences through nearly 50 blogs, thousands of Tweets, and Facebook posts. The IMF ASH Support Group Leaders' Team earned the IMF a perch among the "Most Influential on Twitter," a title bestowed by Symplur, an organization that ranks healthcare activity on social media.

A site dedicated to the IMF at ASH 2015 can be visited at: http://ash2015blogs.myeloma.org. Some standouts on the site include Jack Aiello, ten-year veteran patient attendee to ASH, and Jim Omel, patient and medical doctor, who distilled the most high-level medical news in patient-friendly language. IMF Board Member and twenty-year myeloma survivor, Yelak Biru added gorgeous infographics to his page. John Auerbacher joked that he was attending a vampire convention, telling his daughter, "I'm going to a blood convention." John used a great analogy on what he learned about managing treatment and wrote, "Have you played with those wooden paddles with an elasticized red rubber ball attached? They require skill and attentiveness. So does managing one's treatment. There are times when we feel in control and times when that ball is bouncing all over. You just can't hit it square."

Many patients used the blogs as an opportunity to share how they manage their disease day-to-day. Linda Huguelet wrote, "The results of the ongoing research is part of the reason I'm able to keep moving forward—walking every day, enjoying Tai Chi classes a few times a week, and weekly water aerobics. My goal is to keep my body strong and fit so that I'm ready for the next treatment that I may need. And, more importantly, to keep me strong until a cure is found and life can truly return to normal."

The IMF and our community was so impressed by the stamina and writing chops of our bloggers, that we sponsored more patients to attend ASH in 2016.

ADVOCACY

International Advocacy Efforts

Global Myeloma Action Network

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

The first large-scale GMAN meeting in fiscal year 2015 was at the Annual Meeting of the American Society of Hematology in Orlando, Florida in early December 2015. Susie Novis Durie, President of the IMF, kicked off the meeting with a warm welcome and thanked participants for their willingness to work together to benefit patients. A first at this meeting, GMAN members had a chance to meet with industry physicians from around the world. During this interaction, Christine Battistini, President of IMF Latin America, described her group's success in hosting a myeloma awareness campaign throughout the continent and suggested this strategy may be used in other parts of the world. Following the presentations, members united in declaring that 2016 as the "Year of the Advocate." Ultimately, the group felt that creating a patient charter of basic treatment rights was the best first step for the following new year. The charter would help to establish an underlying set of principles for patients that, in turn, can help govern clinical trial design, help access treatment options, and ensure patients receive a quality standard of care.

global myeloma action network — an advocacy initiative of the IMF

The second GMAN meeting took place in June 2016 at the European Hematology Association meeting in Copenhagen, Denmark. The GMAN summit garnered impressive participation, drawing 40 individuals from 30 organizations and 25 countries. Members from as far as Australia, South Korea, and Brazil joined their counterparts from Europe and North America to discuss issues that affect myeloma patients on a global level. Three issues emerged from summit discussions that require clear next steps: defining global awareness by creating a "Global Myeloma Awareness Day," proposing a cost-benefit formula that uses the same scientific inputs used by all European Union members, and drafting an "International Charter for People with Myeloma" that outlines the rights and expectations of patients, caregivers, health providers, governments, and pharmaceutical companies.

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

US Advocacy Efforts at the Federal Level

Patients Equal Access Coalition

PEAC PATIENTS EQUAL ACCESS COALITION

In fiscal year 2016, the Patients Equal Access Coalition® (PEAC), a collection of 30 patient advocacy organizations, provider groups, and pharmaceutical companies that work collaboratively on treatment access issues for patients at the federal level, hit Capitol Hill and gained momentum with their efforts. As of February 2016, the IMF Advocacy team had met with key lawmakers in Washington, DC, for a total of 20 legislative office meetings. During these meetings, they discussed oral parity and its impact on patients across the nation. As a result of PEAC's efforts, both H.R. 2739 and S.1566 had equal bipartisan support. By July, PEAC added 55 co-sponsors to the bill, bringing the total number to 106. Additionally, they secured the support of House Republican leaders, Representatives Greg Walden and Pete Sessions. In the Senate, they gained an additional 16 cosponsors (bringing the total number to 20).

IMF's Director of Support Groups Makes Wave at the Comparative Effectiveness Public Advisory Council's Public Meeting (CEPAC) on Treatment Options for Relapsed and Refractory Myeloma

In May of 2016, a draft report on myeloma drug cost-effectiveness produced by the Institute of Clinical and Economic Review (ICER) sparked controversy in the myeloma community. ICER held a public discussion of the report's findings on May 26th in St. Louis. Panelists included two IMF Board Members: North Texas Support Group Leader Yelak Biru and Mayo Clinic myeloma researcher and professor Dr. S. Vincent Rajkumar. Most notable though was when IMF Director of Support Groups Robin Tuohy delivered a public comment. Robin testified at the Comparative Effectiveness Public Advisory Council's Public (CEPAC) Meeting on Treatment Options for Relapsed and Refractory Myeloma.

In her compelling testimony, Robin shared how her husband Michael's survival as a myeloma patient may not have been possible without access to a clinical trial, and an oral therapy regimen, which he has been on for the past eleven years. She pointed out, "Today we are able to treat myeloma in sequence and in combination that reflects our individual disease markers, chromosomal abnormalities, and yes, even side-effect management and quality of life choices. I'll say that again: choices!" She urged ICER that while their recent report was "well-intended," when it comes to patient care, "This is a very slippery slope that should not give anyone leverage to limit or deny access to treatment."

A video and transcript of Robin's entire testimony is housed on the IMF website at https://www.myeloma.org/article/robin-tuohys-testimony-cepac-treatment-options-relapsed-and-refractory-myeloma.

US Advocacy Efforts at the State Level

State Patients Equal Access Coalition

The State Patients Equal Access Coalition® (SPEAC), a collection of 25 advocacy organizations that represent the patient, provider, and industry perspective, worked toward securing legislation co-sponsorships as well as introducing legislation at the state level. In particular, in fiscal year 2016 SPEAC's work led to the passing of oral parity laws in Pennsylvania and Alaska, making them the 41st and 42nd states to do so. Some health insurance plans cause patients to be responsible for up to 20% of the cost of anti-myeloma drugs. Without oral parity laws, patients could pay tens of thousands of dollars a year for their prescription(s). In 2017, SPEAC will introduce oral parity bills in Tennessee, Michigan, North Carolina, and possibly Arkansas. In South Carolina and Alabama, SPEAC will educate legislators and citizens about oral parity in preparation for future introduction of this seminal legislation.

Raising Awareness

In 2016, IMF Advocacy led a campaign to acquire proclamations at the local, state, and federal level. The team created a tool kit with a step-by-step guide on how to talk to officials about obtaining proclamations, samples letters, and templates, to use in their respective conversations with legislators. Working with Rep. Brian Higgins office (a long-time friend and ally to the IMF), the advocacy team introduced a federal resolution to designate March as national Myeloma Awareness Month (MAM). Also included in this tool kit was information on how to talk to officials about MAM. In July and September IMF Advocacy presented to Support Group Leaders the importance of the State Health Insurance Programs (SHIP), which was facing defunding. Advocacy created a toolkit that included how to schedule a call or meeting with your representative on this issue. Also included in the toolkit were templates of emails and petitions advocates can use to make their voice heard on this important issue.

City of Los Angeles Proclaims "International Myeloma Foundation Day"

The City of Los Angeles marked Myeloma ACTION Month by honoring the International Myeloma Foundation and IMF President and Co-Founder Susie Novis Durie in a ceremony at City Hall. "March is Myeloma Awareness month, and it is fitting and well-deserved to declare March 30th as International Myeloma Foundation Day in the City of Los Angeles to recognize and support the advancements made towards the cure for myeloma," said L.A. City Councilmember David Ryu.

LA City Councilmember David Ryu, center, presents to IMF President Susie Novis Durie a proclamation declaring March 30, 2016 "International Myeloma Foundation Day." From left, IMF team members: Kelly Cox, Selma Plascencia, Susie Novis Durie, Debra Gendel, IMF Chairman Dr. Brian Durie, Lisa Paik, Rafi Stephan, and Suzanne Battaglia.

Susie Novis Durie thanked members of the Los Angeles City Coucil for honoring the IMF. She said, "The IMF started with 3 people, and today, we have more than 400,000 members in 140 countries worldwide. The most exciting news is, thanks to our Black Swan Research Initiative®, we're on the brink of finding a cure for myeloma."

City Council President Herb Wesson said, "I don't have the words to let you know how much we appreciate all you have done. Thanks for giving us hope."

An Eye on IMF Advocates

In fiscal year 2016, a heated issue that the advocacy team tackled was oral parity laws. Without these laws, patients would be responsible for paying tens of thousands of dollars a year for their prescriptions.

Eric Hansen

In June of 2016, IMF advocate and myeloma patient Eric Hansen delivered a compelling testimony to Alaska's state House and Senate Labor and Commerce committees, explaining how patients in rural parts of the state must travel great distances to receive care at infusion centers. Eric was instrumental in ensuring that oral parity laws were passed in Alaska, and in fact, the House and Senate voted unanimously to do so.

Another issue that advocacy faced was the May 26, 2016 ICER (Institute for Clinical and Economic Review) public meeting, where advocates presented their perspectives on the ICER Report. This report called for the use of Quality-Adjusted Life Years (QALY) in assessing a patient's need for and access to new and innovative drugs. Advocates John Kilip and Tom Hardy helped the IMF lead impactful campaigns, speaking out against QALYs.

Kilip, an active member of the IMF's ACTION Team was enthusiastic about participating in advocacy efforts in Missouri. A nine-year myeloma survivor, John said to Missouri legislators, "Where would I be if they based the value of my treatment to a five-year survival? It is inappropriate that ICER or anyone challenge the value of that treatment to me and to my family."

John Kilip of the IMF ACTION Team

Tom Hardy echoed John's sentiments, "When I was diagnosed with myeloma, I was given five years to live. Now I'm alive and feeling very well six years later." Tom expressed that, like many, getting a diagnosis changed his outlook on life, and he feels that post-cancer, his life is more fulfilling than ever before, urging legislators not to assign arbitrary values to human life.

DEVELOPMENT

Donor Profile: Nancy Sidhu

Nancy Sidhu in downtown Los Angeles

When Victor Sidhu was diagnosed with multiple myeloma in 2011, he and his wife, Nancy, turned to the IMF for help. "He signed up as a member because he was the patient," she says, "but I was the one who read everything carefully." During the three years that Victor struggled with his disease, he and Nancy availed themselves of every service the IMF could provide along their journey.

They'd started by reading all of the materials in the IMF's library of publications. Any additional questions they had were answered by the IMF's toll-free InfoLine. Soon, she and Victor were making regular visits to their local support group meetings. And, finally, in 2012, they attended the Los Angeles Patient & Family Seminar. "It was a revelation," says Nancy, "because it allowed us to meet all kinds of other people who had this disease, and their spouses."

In 2014, Victor passed away after developing amyloidosis. Still, Nancy remains committed to supporting the efforts of the organization every year. "We weren't with the IMF for very long, but while we were, we did almost everything."

When asked why she continues to support the IMF with a significant annual gift, Nancy points to the support the IMF provided to her and Victor in their time of need. "We both benefited from your programs," she said.

But, more importantly, she looks to the future. "I just want to beat this darned disease," she says, acknowledging the incredible advances made in recent years. "We're making real progress, and we're just beginning to make it on amyloidosis, so I think supporting this is important."

Last year, Nancy discovered a new way to help the IMF. "I'm retired," she explained. "Putting on running races is not a thing that I do, so monetary contributions are the best way for me to support the IMF." After consulting with her tax preparer, she discovered that by making her contributions through distributions from her IRA account meant she could give even more.

"Anybody with an IRA that's over 70.5 years old is required to take out an annual minimum distribution. By deducting these contributions from my income taxes, I am able to meet this requirement each year, effectively supporting the IMF without paying additional taxes on the withdrawal."

For Nancy, it's a win-win. "Frankly, the more I can give, the better," she says. "Anybody who's over 70 should talk to their tax person about whether or not this applies to them. But if you have to pull that money out anyway, then you can use it to make a contribution to the IMF."

And, for Nancy, that means knowing she's helping families like hers stay in this fight for years to come.

International Myeloma Foundation

Hope Society

Cultivating the future by planting the seeds to sustain the IMF

During the last fiscal year (October 1, 2015 to September 30, 2016), the following members of the International Myeloma Foundation's monthly donor club - The Hope Society - contributed $67,791 in support of IMF programs and services. The impact made by this passionate group of donors is palpable.

We recognize the following members for their monthly contributions in support of the IMF's programs and services through The Hope Society. To learn more about The Hope Society, visit us online at http://hope.myeloma.org. *(Continued on page 19)*

Carol Ann and Paul Rothman

Donor Profile: The Rothmans

On December 3, 2015, Paul and Carol Ann Rothman donated $80,000 to fund an IMF Brian D. Novis Research Grant. Their generous gift will be used to underwrite a 2016 Black Swan Research Initiative® project led by Norma C. Gutierrez, MD, PhD, of the University Hospital of Salamanca, Spain. The Rothmans said they were inspired to donate to IMF research because they feel that Paul – who was diagnosed with multiple myeloma nine years ago – has been able to live beyond his original prognosis due to the amazing research leaps that have been made in the myeloma field.

Paul said, "If you have benefited from the research that has been done in the past, you can, in a small way, make research possible that will hopefully help multiple myeloma patients in the future."

The IMF is immensely grateful to the Rothmans for supporting Dr. Gutierrez's project, which is entitled, "Optimization and validation of an automated capillary immunoelectrophoresis technology to quantify the expression of essential proteins in the pathogenesis of multiple myeloma." For the project, Dr. Gutierrez will analyze 20 key proteins produced by 100 myeloma patient samples. This protein production reflects the important messaging between myeloma cells and the microenvironment in the bone marrow. Detection of specific proteins can indicate the presence of active myeloma, and therefore, be the basis for the new sensitive testing for MRD, including a new blood test, which would be in lieu of a more expensive and painful bone marrow biopsy.

The IMF and the Black Swan Research Initiative® team share in Carol Ann and Paul Rothman's excitement about what Dr. Gutierrez's research might yield, as we all continue together toward our core mission of "Improving Lives, Finding the Cure®."

The Hope Society Honor Roll

Amy Adams
Pamela Ahlen
Kathy Maeglin and Albert Allen
Mary Ann and Jeffrey Allyn
Cathie Alonzo
Janet Ames
Bonita and James Anderson
Betty Arevalo
Carol and Eric Ashihara
John Backlund
Laura Bates
Suzanne Battaglia
Eunice Becker
Judy and Bill Bennett
David Bennett
Donald Bennett
Marcy R. Bernstein
Anne and John Blair
Norma Jean Bodey Galiher
Anne and John Boehle
Frances and James Bowles
Jeannie Brady
Kathy Brens
Julia Brock
Helen and Darrell Brookstein
Claudia and Philip Brown
Prudy Brown
Teresa Brown
Nancy Bruno
Britney Burgess
Pamela and Mark Burmeister
William Burns
Meghan and Chris Buzby
M. Elena Cabral and David Gonzalez
John C. Campbell
Patricia Vigilante and Robert Candela
Catherine and John Capo
Annette and Patrick Cavanagh
Fred Charles
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Niall Doherty
Andrew Drenick
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Calogera and Carmelo Gallico
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Cheryl Habr
Nancy and William Halliwell
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Sallie and Hadley Hasemeier
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Carol Hornreich
Nicci Hubert
Harriet and Martin Hurlich
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Peter Lundell
Mary Jane Lundy
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Marguerite and Daniel Scott
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Marie and Charles Shanley
Newton Sharp
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Carole Skelly
Rachel Small
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Mari Stassi
Diane Staves
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Mary and Lyndell Worthen, Jr.
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Melissa and Ben Wright
Beth and Woodring Wright
Sandy Wytroval
Sandy Zajdel
Claire Zupancic

**deceased*

Kent Oliver greets event supporters.

Laughs for Life FUNdraiser Raises Nearly $125,000

In the fall of 2015, at the age of 34, with two young girls, Kent Oliver recalls being diagnosed with multiple myeloma: "Hearing the words 'myeloma' and 'incurable' left me feeling stunned." Soon after, Kent underwent a stem cell transplant at Vanderbilt University. It was during his recovery from the transplant that he found himself laughing for the first time since diagnosis. "That's when I realized that laughter had been absent from our lives for months. As we face challenges – of all types – laughter is all too often silenced. My wife Candace and I wanted to change this."

When the Olivers returned to their family in Hattiesburg, Mississippi, they searched for a special way to thank their hometown that had been so supportive. That's when they decided to organize the Laughs 4 Life event on July 28, 2016, in downtown Hattiesburg.

The pre-show VIP dinner at the Bottling Company was headlined by Marshall Ramsey, a two-time Pulitzer Finalist known for his award-winning cartoons and entertaining radio program. After dinner, headlining comedian and virtuoso of impressions Frank Caliendo entertained a near-capacity crowd at the historic Saenger Theater.

Kent and his wife Candace were astounded with the event's success: "In our mission to improve the future outlook for cancer patients, we are filled with gratitude to all the people who joined us for a night of laughter, fun, and philanthropy, and to all who were so generous with their support even if they were unable to attend. Our goal was to raise $100,000 and we raised over $124,000!" The funds were split between the Forrest General Cancer Center and the International Myeloma Foundation.

2016 Member FUNdraisers

Aleta George swam 30 Miles in 30 Days for myeloma.

These runners completed the Mile for Myeloma 5K Run/Walk, presented by the Philadelphia Multiple Myeloma Networking Group.

Theresa Tucker and Shelia Barton spearheaded a Walk in the Park for Myeloma in Flushing Meadows Corona Park in Queens, New York.

Sheree and Ron Pask and Gina Klemm organized Miracles for Myeloma 5K.

Sharon and Scott Kowalcyzk held the ChekFest Golf Outing.

Member Fundraisers

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

During the 2016 fiscal year, IMF members held more than 60 events that raised over $716,000. Many of the recurring events support the IMF's Brian D. Novis Research Grants, a testament to the ability of a regular group of people to make an extraordinary impact on the future of myeloma research.

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

Member Events
October 1, 2015 – September 30, 2016

BENEFACTORS CIRCLE
$25,000 and up

Miracles For Myeloma
Ron and Sheree Pask and Gina Klemm
Clark, NJ

Miracles For Myeloma
Ron and Sheree Pask and Gina Klemm
Clark, NJ

Laughs 4 Life
Kent Oliver
Hattiesburg, MS

Boca 5K
Shawna Wannamacher
Boca Raton, FL

ChekFest Golf Tournament
Sharon and Scott Kowalczyk
Grand Rapids, MI

Miles for Myeloma 5K
Philadelphi Multiple Myeloma Networking Group
Philadelphia, PA

Carolyn Czerkies Charity Golf Outing
Czerkies Family
Naperville, IL

FOUNDERS CIRCLE
$10,000 - $24,999

Bridge Blasts Myeloma
Carol Klein
Bethesda, MD

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

Coach Rob's Benefit Bash
Kim Bradford and Todd Birmingham
Apopka, FL

Strengthen for a Cure
Tara Ginsburg
Long Island, NY

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

Kubik Golf Tournament
Darla Kubik and Dwight Royall
Rockwall, TX

2nd Annual Race to Beat Myeloma
Ava and Cece Fainberg and Betsy Mencher
Chevy Chase, MD

Wiff Out Myeloma
Michael Tuohy
Prospect, CT

Wayne Hamby Memorial Golf Tournament
Gail and Andrew Bertram; Vicki Hamby
Bluffton, SC

North Texas Multiple Myeloma Support Group
NTMSG
Dallas, TX

Paddle to Battle Multiple Myeloma
John Taussig
Santa Cruz, CA

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

2nd Annual March Against Myeloma
Justin McWethy
Hood River, OR

A Mission for Matt
Debbie Beatty
Williston Park, NY

PARTNERS CIRCLE
$5,000 - $9,999

Flying Pig Marathon
Ellen and Brian Grammel
Fairfield, CT

Jack's Annual Benefit Bash
Jack Aiello
San Jose, CA

Movember Against Myeloma
Jonathan Green
Austin, TX

Red House Carnival
Julianne Stafford
Brighton, MA

San Diego Myeloma Olympics
Alex Murer
San Diego, CA

Trooper Benson Klein Research Fund
Benson Klein
Bethesda, MD

SE Virginia Support Group Fundraiser
Jerry Walton
Virginia Beach, VA

ASSOCIATES CIRCLE
$1,000 - $4,999

A Night of Comedy
Laura and Charlie Mooney
Staten Island, NY

Doris Morgan's 75th Birthday Gala
Bridget McKenzie
Atlanta, GA

Grand Tour of Scotland
Gary McAdam
Austin, TX

Rachel's Ride Against Myeloma
Rachel Smith
Raleigh, NC

Improv Comedy Night
Forrest Shaw
Hollywood, CA

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

Support Sheldon Golf Tournament
Maurice Pierre
Yantis, TX

30 Miles in 30 Days
Aleta George
Atlanta, GA

Celebration of Life
Central NJ MM Support Group
Sommerville, NJ

Scales Birthday Celebration
Robert Scales
Los Angeles, CA

Nuveen Cashual Jeans Day
Chicago, IL

Heritage Singers Fundraiser
Heritage Singers of Jacksonville
Jacksonville, FL

FRIENDS CIRCLE
$500 - $999

Running NOLA for Carrie
Julie Christianson
Overland Park, KS

Holly Carson Fundraiser
Holly Carson
Lancaster, CA

SUMMARY FINANCIAL INFORMATION

INTERNATIONAL MYELOMA FOUNDATION

Statement of Financial Position
September 30, 2016

Assets

Cash and cash equivalents	$ 1,389,912
Contributions, program grants, and other receivables	11,773,560
Prepaid expenses	765,178
Investments, at fair value	7,310,962
Property and equipment, net	537,245
Gift annuity investments, restricted cash	8,679
Intangible assets, net	79,744
TOTAL ASSETS	**$ 21,865,280**

Liabilities and Net Assets

Accounts payable and accrued expenses	$ 806,174
Deferred and unrestricted educational grants	12,634,601
Gift annuity obligation	6,028
TOTAL LIABILITIES	$ 13,446,803
NET ASSETS	
Unrestricted	$ 5,827,417
Temporarily restricted	2,591,060
TOTAL NET ASSETS	$ 8,418,477
TOTAL LIABILITIES AND NET ASSETS	**$ 21,865,280**

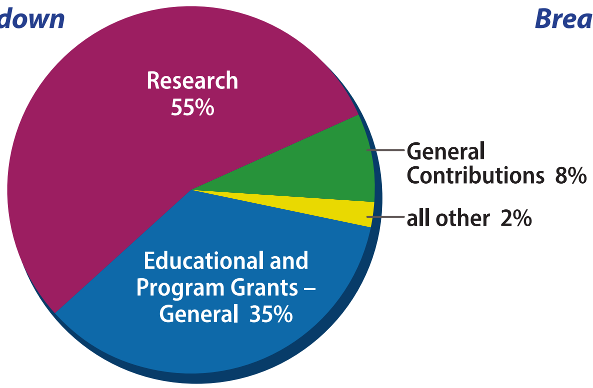
For a copy of our complete audited financial statements, please contact the IMF office.

INTERNATIONAL MYELOMA FOUNDATION

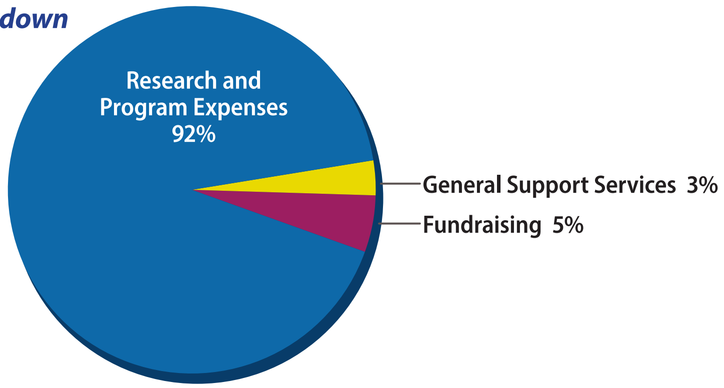
Statement of Activities for the Year Ended September 30, 2016

	UNRESTRICTED	TEMPORARILY RESTRICTED	TOTAL
Revenues and Support			
Educational and program grants	$ 16,518,387	$ 3,037,320	$ 19,555,707
General contributions	833,864	169,609	1,003,473
Fundraising programs	326,146	14,026	340,172
Donated services	600	-	600
Seminar fees and support group income	75,138	-	75,138
Fundraising events, net of direct benefit to donors of $355,371	526,166	468,620	994,786
Realized and unrealized gains, net	200,061	-	200,061
Investment income	198,827	(1,073)	197,754
	18,679,189	3,688,502	22,367,691
Net assets released from restrictions	1,101,165	(1,101,165)	-
Total Revenues and Support	***$ 19,780,354***	***$ 2,587,337***	***$ 22,367,691***
Functional Expenses			
Program services	14,616,782	-	14,616,782
General supporting services	431,497	-	431,497
Fundraising	774,356	-	774,356
Total Functional Expenses	***$ 15,822,635***	***-***	***$ 15,822,635***
Change in Net Assets	3,957,719	2,587,337	6,545,056
NET ASSETS – Beginning of year	1,869,698	3,723	1,873,421
NET ASSETS – End of year	**$ 5,827,417**	**$ 2,591,060**	**$ 8,418,477**

Revenue Breakdown



Expense Breakdown



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

INTERNATIONAL MYELOMA FOUNDATION

Statement of Functional Expenses for the Year Ended September 30, 2016

Breakdown of Expenses by Program

PROGRAM	TOTAL EXPENSES
Research	$ 7,108,307
Education & Awareness	1,476,645
Patient & Family Seminars	1,355,837
International	1,141,388
Support Groups	758,988
Clinical Meetings	697,584
Nurse	474,634
Advocacy	463,306
Myeloma Today	394,163
Website	337,320
InfoLine	299,510
Information Mailings	109,100
Total Program Expenses	***$ 14,616,782***
General supporting expenses	431,497
Fundraising expenses	774,356
Total Expenses	***$ 15,822,635***

CHARITY NAVIGATOR
★★★★
Four Star Charity

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

HONOR ROLL

The International Myeloma Foundation is grateful for the support of the individuals, organizations, and foundations who fund the high-quality programs and services that serve our members. **We are pleased to recognize the following donors for their support during the calendar year, January 1, 2016 – December 31, 2016.**

In addition to those listed here, a combined 4907 people contributed gifts between $1 and $499, totaling $535,300. Unfortunately, space does not allow us to list everyone's names, but every donor is deeply valued.

We regret any omissions or errors. Please contact the IMF's Development department to report any corrections needed at development@myeloma.org or 800-452-CURE.

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

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

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$100,000 and above

AMGEN Oncology
The Binding Site, Ltd.
Bristol-Myers Squibb Company
Celgene Corporation
Janssen Biotech, Inc.
Karyopharm Therapeutics
Novartis Pharmaceuticals
Dorothy and John O'Dwyer
Sanofi
Millennium: The Takeda Oncology Company
Willette Charitable Foundation

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$50,000 – $99,999

Astellas Pharma US INC
Clinical Care Options, LLC
Susie Novis and Dr. Brian Durie
Laughs 4 Life / Kent Oliver
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Jane F. Petitmermet Trust
Pharmacyclics, Inc.
Reliance Trust Company of Delaware / Easterday Foundation
Carol Ann and Paul Rothman

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CBS Corporation
Coach Rob's Benefit Bash, Inc. / Kimberly and Robert Bradford
Diplomat Specialty Pharmacy
Robert C. Ebersole
Stephanie Hope Feld
Noah Mitchell Trust
Philadelphia Multiple Myeloma Networking Group
Runners Edge Foundation Inc / Boca 5k / Shawna Wanamacher
Walsh Street Foundation / Henry Belber

Founders Circle

$10,000 – $24,999

Oncopeptides AB
Sandra and H.P. (Andy) Andrews
Jeanne and Edwin* Bernstein
Bill and Joy McGinnis Fund
Loraine Boyle
Gail-Ann and Joe Colaruotolo
David Geffen Foundation
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Vicki Hamby / Wayne Hamby Memorial Golf Tournament
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HBO Inc.
J.C. Invitational Golf Tournament / Beverly Lundorff
Joele Frank and Laurence Klurfeld Charitable Fund
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Gilbert Memorial Fund / Elizabeth and J. Ronald Gilbert

Partners Circle

$5,000 – $9,999

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Thiel Family Foundation of the Bank of America Charitable Gi
Walsh Family Fund
Rita and Henry Wells / American Food & Vending Enterprises
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$1,000 – $4,999

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Vera Bond
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$500 – $999

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Petra Beucher
Joan Biddison
Anessa Birkemeier
Carol and Jeffrey Blake
Patricia and Frank Blennau
Bliley's
Bloom Hergott Diemer / Ruth and Jake Bloom
Boeing Employee Individual Giving Program
The Boeing Company
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Gilbert Bowman
Craig H. Brashier
Brett Brinker
Brooke Graphics LLC
Helen and Darrell Brookstein
Prudy Brown
Emily Brown
Tonia and Matthew Brown
Claudia and Philip Brown
Catherine Bryson
Siegfried Buschmann
Cindy Camozzi
Catherine and John Capo
Peter Caputo
The Denise Lardner Carmody 1996 Trust
Christopher Chandlee
Beatrice Chaney
Clark Township Board of Education Internal School Account
Jen Cloutier
Debbie S. Cohen
Rita and Joe Cohen
Peter Cole
Jason Coller
Connecticut Multiple Myeloma Fighters
Jim Corradetti
Melissa Corrigan
John Daly
Bill Damaschke
Terrence D'Arcy
Richard Davies
Charisse and Dr. John DeFlice
Marnie L. DeGregorio
Fred Demers
Brigitte Demes
Dennis A. Quinn & Associates
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Dilorenzo Realty Group, LLC
Doyle Family Charitable Fund
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