Until there is a cure…

INTERNATIONAL MYELOMA FOUNDATION

2010 ANNUAL REPORT
…There is the IMF

INTERNATIONAL MYELOMA FOUNDATION

Dedicated to improving
the quality of life of myeloma patients
while working toward prevention and a cure.
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Dear Supporters of the International Myeloma Foundation,

It has now been 20 years since the International Myeloma Foundation forged its commitment to helping myeloma patients and their families all around the world.

The IMF is now 195,000 members strong and active in 113 countries. It is an honor to be part of such a passionate community. I believe the work done by the IMF over the past 20 years has helped in the ongoing transition of myeloma from “deadly” to “treatable.” I also firmly believe that the IMF will play an equally important role in transitioning the disease from “treatable” to “preventable.” Although it hasn’t happened yet, prevention will happen as we continue to build upon the successes described in these pages – the IMF’s work from October 2009 through September 2010.

In June 2010, the IMF held the Inaugural International Myeloma Working Group Summit. This summit was a true workshop, bringing together the world’s foremost myeloma leaders to think through and discuss all the issues on the research horizon. While together in June, we established unprecedented consensus agreements and began shaping the direction of future research collaborations, all in order to achieve the most promising results for myeloma patients in the shortest period of time possible.

The IMF also remains dedicated to effective and directed research through Bank On A Cure®, which continues to reach exciting milestones through our significant data analysis in partnership with other important research entities, including the National Cancer Institute. This analysis provides us with important building blocks that will lead us to the day where myeloma will truly be treatable as a chronic disease.

Just as importantly, the IMF remains dedicated to sharing scientific progress directly with patients, families, friends, caregivers, and healthcare professionals all around the world. New technology empowers us, and the IMF embraces all of the information portals at our disposal. We will continue to use every platform available to inform patients and doctors about effective treatment choices, to support our families, and to advocate on behalf of the global myeloma community.

Twenty years is the mark of a long journey. Yes, it has sometimes been frustrating, but far more often it has been incredibly successful and profoundly gratifying. This is because of you – our supporters, our partners, and our collaborators. Here’s to many more successful and gratifying achievements as we continue forward.

Sincerely yours,

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

As I sat in front of the blank screen of my laptop to write this update, I found myself hard pressed to know what to say. So much is being accomplished by so many people every single day.

Then I said to myself, “Let’s just make a list and see what happens.” Here it is:

• Despite the continuing recession, the IMF again received high levels of support from individual donors, events organized by our members, corporate donors, and one specific miracle.

• Michael McKeon, playing in memory of his friend Lee Grayson, won the nationally televised 2010 Jeopardy! Million Dollar Celebrity Invitational. The $1,000,000 payout was the largest single gift the IMF has received to date and established the McKeon/Grayson Research and Education Fund.

• At the Inaugural Summit of the International Myeloma Working Group in Barcelona, Spain, nearly 70 of the world’s leading experts came together to chart the future of myeloma treatment and care.

• IMF advocacy helped to ensure passage of legislation in Connecticut mandating coverage of oral anti-cancer drugs at comparable rates to that of intravenous infusions and other procedures.

• We began to make high-quality information and care available for myeloma patients in the world’s most populous nation through the launch of a partnership between the IMF and a cooperative agreement with the Chinese Health Promotion Foundation.

• The annual meeting of the American Society of Hematology in December was awash with exciting and important new data about the use of approved and investigational treatments for every stage of myeloma.

• Our Annual Comedy Celebration in Los Angeles – hosted again by Ray Romano – packed 1,200 people into the Wilshire Ebell Theatre for a stellar evening of entertainment.

There are so many people to thank for their roles in everything we accomplished together in the fiscal year reported here. Time and space won’t allow me to list them all. I must, however, thank Michael McKeon for his astonishing gift – and his graciousness in the face of all the publicity. I need to thank two IMF Board members, Loraine Boyle and Amy Weiss, for making the Annual Comedy Celebration such an outstanding success. And I really must try to thank everyone else: all our corporate and pharmaceutical partners; the IMF’s astonishing and indefatigable staff; every member of the IMF from around the world who found a way to continue supporting us; all the physicians, scientists, and other healthcare professionals who work with us because of their passion to improve opportunities for myeloma patients; and lastly Michael Katz – another member of the IMF Board – for his determination to make the IMF’s website the best source of myeloma information absolutely anywhere.

Without all these people and so many more, none of the accomplishments listed in these pages would have been possible. We are so grateful to you all for your continued support.

With gratitude,

Susie Novis
IMF President
Myeloma is one of the most prevalent forms of blood cancer, affecting more than 750,000 patients worldwide. Prior to diagnosis, most patients and their families have never heard of myeloma. But knowledge is power, and the IMF is committed to gathering a comprehensive array of information and sharing it with myeloma patients, families, caregivers, and healthcare professionals throughout the world.

The IMF is a primary resource for up-to-date disease and treatment information for new patients and families, as well as for long-term patients and families. The IMF also remains dedicated to serving as a valued educational asset for myeloma healthcare professionals. The knowledge provided means that patients and their caregivers can join healthcare providers in a decision-making partnership, creating the best possible quality of life for every myeloma patient.

**IMF Patient & Family Seminars**

"You will learn so much, it will help you get a perspective of the disease, and you will meet many others in your shoes. You will leave feeling much less afraid, much less alone, and empowered to go forward with confidence."

– SUE GOFF ENRIGHT, Jackson, WI

The IMF’s flagship Patient & Family Seminars present vital information about new treatments, provide one-on-one time with myeloma specialists, and allow participants to share their experiences and gain strength from hearing other people's stories. Premier myeloma experts volunteer their time to the IMF’s Patient & Family Seminars because the knowledge gained is vital, and empowers patients and their families to make intelligent treatment choices that are specifically right for them.

Since 1993, the IMF has hosted 145 Patient & Family Seminars in 14 countries all around the world. From October 2009 to September 2010, more than 900 participants attended U.S.-based seminars in Cincinnati, OH; Los Angeles, CA; Philadelphia, PA; and Portland, OR. Internationally, 2,050 participants attended international seminars in Heidelberg, Germany; Madrid, Spain; Niigata City, Japan; Paris, France; Podebrady, Czech Republic; Rehovot, Israel; São Paulo, Brazil; and Turin, Italy.
IMF Regional Community Workshops

The IMF is dedicated to connecting with as many patients as possible through live and engaging opportunities. Therefore, in addition to its flagship Patient & Family Seminars, from October 2009 to September 2010, the IMF facilitated Regional Community Workshops in Cincinnati, OH; Denver, CO; Honolulu, HI; Las Vegas, NV; Longview, TX; Milwaukee, WI; Overland Park, KS; Salt Lake City, UT; Shreveport, LA; and Spokane, WA, attended by a total of 384 participants. The IMF also facilitated international Community Workshops in Berlin, Koblenz and Leipzig, Germany, and Florence, Italy, attended by a total of 360 participants.

Publications

“It is so helpful to know the results of current research and the general consensus of the Scientific Advisory Board of the IMF. It would take me forever to find all the information on my own.”

– KRIS GRANDINETTI, Peoria, AZ

The IMF produces comprehensive but “user-friendly” information for the entire myeloma community. The IMF’s publications library includes an extensive catalog of booklets, tip cards, articles, and DVDs, all written, created, and produced by the IMF with oversight by its Scientific Advisory Board. The IMF library’s broad scope includes information about myeloma treatment options, clinical trials, and quality of life considerations for patients and physicians. IMF publications are provided free of charge, in 16 languages.

The IMF remains at the forefront of assessing the latest and newest information and promptly and effectively disseminating it to the myeloma community. From October 2009 through September 2010, the IMF created nine new publications. Fifteen additional publications were updated with the latest information.

Many of these publications are bundled into the IMF InfoPack, designed to provide newly diagnosed patients and their families with a well-rounded understanding of the disease and patient care. From October 2009 to September 2010, the IMF provided approximately 25,000 InfoPacks to patients, healthcare providers, and support groups around the world.

The IMF’s quarterly newsletter Myeloma Today is the go-to resource for learning about the latest advances in myeloma treatment, research, and quality of life issues. A print subscriber base of nearly 13,724 (a three percent increase over the previous year), in addition to pass-along rates and web-views, meant an estimated additional Myeloma Today readership of more than 100,000 per issue from October 2009 through September 2010.

The Myeloma Minute is the IMF’s email newsletter, providing up-to-the-minute information about myeloma research, events, and IMF programs. In September 2010, its subscriber-base was 26,500 readers. Myelom Merkur, the newsletter’s German edition, increased its readership to 2,000. The French, Italian, and Spanish editions (Le Messager de Myélome, Il Messaggero di Mieloma and Mensajero del Mieloma) brought an additional 800 subscribers as of September 2010.
Teresa Miceli is proud that she has spent her entire career, since 1991, at the Mayo Clinic Rochester, working in the area of blood and marrow transplantation. Surrounded by leading myeloma physicians, she had always been familiar with the IMF. But she wasn’t aware of the IMF’s scope of programs and services until she joined its Nurse Leadership Board (NLB) as a founding member in 2006.

Now, as a regular presenter at Patient & Family Seminars and Regional Community Workshops, Teresa views these IMF programs as a true highlight of her work. “Meeting myeloma survivors from across the country is such an inspiration,” she says. “I am so grateful for these opportunities to provide education to patients and caregivers regarding possible side effects and management of the therapies they are receiving.”

Teresa’s commitment to addressing myeloma’s side effects includes leading the Bone Health & Bone Disease section of the NLB’s ongoing Survivorship Care Plan. “The need to manage bone disease, pain, and related mobility issues is paramount in promoting quality of life,” Teresa says. “We must recognize how bone disease impacts day-to-day living – for the long term.”

Teresa has also served as chair of the myeloma-suppression task force, part of the NLB’s Consensus Guidelines, published in 2008, an experience that solidified her views of myeloma nursing. “Nurses play a key role in the education of patients and other healthcare providers,” she says. It is this knowledge, she believes, that provides patients with hope.

“When I agreed to participate in the first NLB meeting, I had no idea what the vision was going to be,” Teresa reflects. “Once we came together, the energy and synergy were amazing, and the rest is history – and the future!”

The IMF Nurse Leadership Board (NLB) consists of 20 myeloma nurse experts from major treatment centers throughout the U.S. The NLB provides a forum for addressing the needs of the myeloma nursing and patient communities.

In October 2009, the NLB convened its fifth organization-wide meeting, in New York City, with a focus on advancing a series of publications for their Long Term Survivorship Care Plan for myeloma patients. At this meeting they presented the rationale, content, and a top line overview of the manuscripts in development: renal complications, functional mobility and safety, bone health and bone disease, sexuality and sexual dysfunction, and health maintenance. The NLB also identified future projects, including Consensus Guidelines in Transplantation (to include education, the decision-making process, timing, drugs, and stem-cell collection issues) and developing a health maintenance online interactive tool that can be integrated with the IMF’s Myeloma Manager™.

In May 2010, the NLB presented a summary of the five core elements of their Long Term Survivorship Care Plan at the Oncology Nursing Society annual meeting. The NLB presented to a full-capacity room of 625 nurses.

From October 2009 through September 2010, NLB members also spoke at IMF Patient & Family Seminars and Regional Community Workshops, facilitated informational conference calls with IMF support groups, and continued its NLB Speaker Programs – educating community nurses about myeloma treatment side effects.

Teresa Miceli, RN, BSN
Mayo Clinic Rochester
Rochester, MN

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**Nurse Leadership Board**

“Our membership has become a very close network that represents the best nurses in the field of myeloma.”

– JOSEPH D. TARIMAN, RN, MN, PHD(C), ARNP-BC, OCN
Northwestern Myeloma Program, Chicago, IL

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**IMF Nurse Leadership Board Members**

- Page Bertolotti, RN, BSN, OCN
  Cedars-Sinai Outpatient Cancer Center at the Samuel Oschin Comprehensive Cancer Institute
  Los Angeles, CA
- Elizabeth Bilotti, RN, MSN, APRN, BC
  The John Theurer Cancer Center at HUMC
  Hackensack, NJ
- Kathleen Colson, RN, BSN, BS
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- Deborah Doss, RN, OCN
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- Beth Faiman, MSN, APRN-BC, AOCN
  Cleveland Clinic Taussig Cancer Institute
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- Sandra Rome, RN, MN, AOCN
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- Jacy Spong, RN, BSN, OCN
  Mayo Clinic – Arizona
  Scottsdale, AZ
- Joseph Tariman, PhN, RN, APRN, BC
  Northwestern University
  Chicago, IL

**NLB Associate Members**

- B. Nadine Baxter-Hale, MNSc, APN-BC, AOCNP
  University of Arkansas for Medical Sciences
  Myeloma Institute of Research and Therapy
  Little Rock, AR
- Elizabeth Finley-Oliver, RN
  H. Lee Moffitt Cancer Center & Research Institute
  Tampa, FL
- Sandra Kurtin, RN, MS, AOCN, ANP-C
  Arizona Cancer Center
  Tucson, AZ
- Kimberly Noonan, RN, ANP, AOCN
  Dana-Farber Cancer Institute
  Boston, MA

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The IMF is a leader of innovative, globally collaborative myeloma research as a means of improving quality of life while working toward prevention and a cure. The IMF is at the forefront as the myeloma community enters the era of “tailored treatment” – with new therapies and approaches aimed at customizing each patient’s specific needs. This will lead to an era where myeloma will be managed as a chronic disease rather than a terminal diagnosis.

The IMF’s International Myeloma Working Group (IMWG) consists of 144 leading myeloma researchers from around the world. They collaborate on a broad range of treatment issues in order to create new myeloma management guidelines that provide patients with more durable remissions and improved quality of life. The IMWG focuses on treatment protocols and diagnostic systems, addressing the needs of both myeloma patients and the physicians who treat them. This group is also dedicated to assuring that their research results are made readily accessible to all patients, caregivers, and medical professionals, regardless of where they live or practice.

In June 2010 in Barcelona, Spain, the IMF held the inaugural Myeloma Summit, a first-of-its-kind meeting of the IMWG, with a mission to identify, support, and implement the most promising research to prevent onset of active disease, improve treatment, and find a cure for myeloma. This summit brought together 69 myeloma experts from 23 countries, representing 58 institutions, and led to recommendations addressing:

- Early high-risk smoldering myeloma;
- Sequential versus curative strategies;
- Role of autologous stem cell transplant and consolidation;
- Maintenance therapy;
- New drugs.

In addition to these broad recommendations, Myeloma Summit attendees discussed ongoing and recently conceived IMWG consensus and database projects. The group enthusiastically agreed that continued collaboration would lay the groundwork to move beyond long-term remissions and begin charting a roadmap for a cure.

The International Myeloma Working Group plays a big role in the delivery of high-quality, up-to-date treatment for myeloma patients worldwide by developing and publishing important practice guidelines and carrying out key research projects that have a direct impact on the diagnosis, prognosis, and treatment of myeloma.

- S. VINCENT RAJKUMAR, MD
  Mayo Clinic, Rochester, MN

Dr. Hervé Avet-Loiseau’s research is dedicated to the prognostication of patients with myeloma. “My interest in myeloma is focused on the genetic abnormalities that occur in the malignant plasma cells,” he explains. “I believe that these chromosomal and molecular abnormalities are the basis for patient outcome.”

Dr. Avet-Loiseau was the principal investigator for the International Myeloma Working Group’s recent project selected for oral presentation at ASH 2009, which addressed follow-up of the group’s renown International Staging System. He also co-authored one of the group’s recent papers published in *Leukemia*. Dr. Avet-Loiseau also served as a collaborator on two Bank On A Cure poster presentations also selected for ASH 2009.

He is honored that as his career has grown, so has his collaboration with the IMF. “The IMF does a great job running consensus meetings for diagnostic assessment, prognostic evaluation, and patient management,” he says. “The IMF also enables researchers to meet and discuss.” He also looks forward to a promising future – and sees it drawing near. “My hope is that soon patients will be treated on a risk-adapted strategy. I am convinced that it we will be able to identify the best treatment strategies and targeted therapies for each patient as soon as they are diagnosed.”
Dr. Shaji Kumar's involvement in myeloma research began while receiving his hematology/oncology training at the Mayo Clinic. “All the myeloma physicians at Mayo have been closely involved with the IMF,” Dr. Kumar says. “As a result, I was exposed to the IMF’s work early in my career. Since then I’ve considered the IMF a key partner in improving the care of myeloma patients.”

Dr. Kumar’s research focuses on disease evolution and the mechanisms underlying disease progression, with a specific interest in the marrow microenvironment. “In the laboratory, we study how new drugs work and focus on developing new drug combinations,” he explains. “The goal is to develop treatment strategies based on a better understanding of disease biology.”

As a member of the IMF’s International Myeloma Working Group, Dr. Kumar was the principal investigator for one of the group’s recent projects for presentation at its December 2009 conference in New Orleans, LA:

The International Myeloma Working Group (IMWG) consensus statement and guidelines regarding the current status of stem cell collection and high-dose therapy for multiple myeloma and the role of plerixafor (AMD 3100)


International Myeloma Working Group guidelines for the management of multiple myeloma patients ineligible for standard high-dose chemotherapy with autologous stem cell transplantation


International Myeloma Working Group molecular classification of multiple myeloma: spotlight review.


The American Society of Hematology (ASH) selected two IMWG research projects for presentation at its December 2009 conference in New Orleans, LA:

Oral presentation:

Impact of FISH and Cytogenetics On Overall and Event Free Survival in Myeloma: An IMWG Analysis of 9,897 Patients


Poster presentation:

Natural History of Multiple Myeloma Relapsing After Therapy with IMiDs and Bortezomib: A Multicenter International Myeloma Working Group Study

S Kumar, J Bladé, J Crowley, H Goldschmidt, A Hoering, S Jagannath, JJ Lahuerta, J Laubach, P Moreau, G Morgan, RZ Orlowski, A Palumbo, P Richardson, JF San Miguel, O Sezer, D Siegel, P Sonneveld, J Szymonifka, SV Rajkumar, and BG Durie

The American Society of Clinical Oncology conference selected an additional IMWG study for poster presentation at its June 2010 conference:

Treatment patterns and outcome among patients with multiple myeloma relapsing and or refractory to bortezomib and immunomodulatory drugs: A multicenter International Myeloma Working Group study.

S Kumar, J Crowley, SK Klein, JJ Lahuerta, J Lee, P Moreau, G Morgan, PG Richardson, D Siegel, BG Durie, on behalf of the IMWG
Bank On A Cure®

Bank On A Cure (BOAC) is the world’s first global, myeloma-specific DNA bank and research initiative. Using the IMF’s own custom-designed gene-testing chip, BOAC scientists are poring over vast amounts of genetic information the IMF has gathered from myeloma patients worldwide in order to determine common genetic factors. Through finding and studying these commonalities, researchers will be able to develop and tailor more effective treatment options and minimize treatment side effects. Discovering these genetic patterns will also unlock the mysteries of what causes myeloma – and ultimately lead to its cure.

The December 2009 ASH conference selected four BOAC research projects for presentation:

**Oral Presentation:**

*Genetic Variations Associated with Overall and Progression-Free Survival in Multiple Myeloma Patients Treated with Thalidomide Combinations*

DC Johnson, WM Gregory, N Dickens, B Walker, A Szubert, F Davies, BG Durie, BG Van Ness, and GJ Morgan

**Poster Presentations:**

*Developing a SNP Classifier for Predicting Peripheral Neuropathy by Bortezomib in Multiple Myeloma Patients*

R Kuiper, SL Corthals, P Hanifi-Moghaddam, Y de Knecht, H Lokhorst, H Goldschmidt, BG Durie, BG Van Ness, GJ Morgan, M van Duin, H Avet-Loiseau, and P Sonneveld

*Genetic Associations with Bortezomib Mediated Neuropathy in Multiple Myeloma*

SL Corthals, DC Johnson, Y de Knecht, H Goldschmidt, H Lokhorst, S Minivielle, F Magrangeas, J Harousseau, BG Durie, BG Van Ness, GJ Morgan, P Sonneveld, and H Avet-Loiseau

*Genetic Associations with Therapy Response in the HOVON-65/GMMG-HD4 Trial in Patients with Multiple Myeloma*

SL Corthals, H Goldschmidt, DC Johnson, H Lokhorst, Y de Knecht, S Zweegman, B van der Holt, D Hose, MJ Kersten, E Vellenga, BG Duire, GJ Morgan, and P Sonneveld

From October 2009 through September 2010, BOAC researchers also continued its epidemiology plan and pursued SNP testing addressing peripheral neuropathy, research leading to publication in late 2010 (to be discussed further in next year’s annual report).

**Robert A. Kyle Lifetime Achievement Award**

On June 9, 2010 in Barcelona, Spain, the Robert A. Kyle Lifetime Achievement Award was presented to Joan Bladé, Senior Consultant and Director of Myeloma Programs at the Hospital Clinic de Barcelona. The IMF joined with 50 international myeloma clinicians and researchers for a dinner ceremony in Dr. Bladé’s honor, raising $50,000 for IMF research.

**Bank on A Cure® Research Team**

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<tr>
<th>Name</th>
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<tr>
<td>Gareth Morgan, MD, Co-Chair</td>
<td>Royal Marsden Hospital</td>
<td>Sutton, UK</td>
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<tr>
<td>Brian Van Ness, MD, PhD, Co-Chair</td>
<td>University of Minnesota</td>
<td>Minneapolis, MN, USA</td>
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<tr>
<td>Herve Avet-Loiseau, MD</td>
<td>Institute de Biologie</td>
<td>Nantes, France</td>
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<td>Dalsu Baris, MD, PhD</td>
<td>National Cancer Institute</td>
<td>Rockville, Maryland, USA</td>
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<td>John Crowley, PhD</td>
<td>Cancer Research and Biostatistics</td>
<td>Seattle, WA, USA</td>
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<td>Brian G.M. Durie, MD</td>
<td>Cedars-Sinai Outpatient Cancer Center</td>
<td>Los Angeles, CA, USA</td>
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<td>University of Heidelberg</td>
<td>Heidelberg, Germany</td>
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<td>Roman Hájek, MD</td>
<td>University Hospital Brno</td>
<td>Brno, Czech Republic</td>
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<td>S. Vincent Rajkumar, MD</td>
<td>Mayo Clinic</td>
<td>Rochester, MN, USA</td>
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<td>Jesus San Miguel, MD</td>
<td>Hospital Clinico Universitari</td>
<td>Salamanca, Spain</td>
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<td>John Shaughnessy, PhD</td>
<td>Myeloma Institute for Research and Therapy</td>
<td>University of Arkansas for Medical Sciences Little Rock, AR, USA</td>
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<tr>
<td>Pieter Sonneveld, MD, PhD</td>
<td>Erasmus Medical Center</td>
<td>Rotterdam, The Netherlands</td>
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Research Grants Program

Through its Research Grants Program, the IMF remains at the forefront of identifying, supporting, and developing the world’s most promising myeloma research. The IMF backs both junior and senior researchers, funding 104 grants since the program’s inception in 1994. This IMF-supported work continues to lead to further funding from other highly regarded institutions and more than 250 publications in the world’s top research journals.

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<th>Research Grant Recipients</th>
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<tr>
<td>Chilgrove, UK</td>
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<td>Barn House</td>
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<td>CLINICAL RESEARCH INSTITUTE, TAMPA, FL</td>
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<td>H. Lee Moffitt Cancer and Research Institute, Tampa, FL</td>
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The Brian D. Novis Research Grant was the first grant I was awarded. Thanks to the IMF, I was able to focus one entire year on myeloma research, and my work allowed me to successfully apply for a faculty position where I will continue my career as an independent researcher focused on myeloma.

– ARIOSTO SILVA, PhD

IMF Scientific Advisory Board

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<th>Name</th>
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<td>Raymond Alexander, MD</td>
<td>MD Anderson Cancer Center</td>
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<td>Dana-Farber Cancer Institute</td>
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<td>Régis Bataire, MD</td>
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<td>Ankara University</td>
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<td>William Bensinger, MD</td>
<td>Fred Hutchinson Cancer Research Center</td>
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<td>James R. Berenson, MD</td>
<td>Institute for Myeloma &amp; Bone Cancer Research</td>
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<td>P. Leif Bergsagel, MD</td>
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<td>Joan Bladé, MD</td>
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<td>Mario Boccaduro, MD</td>
<td>Cattedo Di Ematologia, Torino, Italy</td>
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<td>J. Anthony Child, MD</td>
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<td>Raymond L. Comenzo, MD</td>
<td>Memorial Sloan Kettering Cancer Research Center</td>
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<td>Franco Dammarco, MD</td>
<td>University of Bari Medical School, Italy</td>
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<td>Faith Davies, MD</td>
<td>Royal Marsden NHS Foundation Trust, Sutton, UK</td>
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<td>Meletios Dimopoulos, MD</td>
<td>University of Athens School of Medicine</td>
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<td>Johannes Drach, MD</td>
<td>University of Vienna</td>
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<td>Brian G.M. Durie, MD</td>
<td>Medical University of Vienna</td>
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<td>University Clinic of Wurzburg, Wurzburg, Germany</td>
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<td>Herman Einsele, MD</td>
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<td>Henk M. Lokhorst, MD</td>
<td>University Hospital Utrecht, Utrecht, Netherlands</td>
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<td>Sagar Lonial, MD</td>
<td>Emory Winship Cancer Institute</td>
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<td>Heinz Ludwig, MD</td>
<td>Wilhelminenspital der Stadt Wien, Vienna, Austria</td>
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<td>Marie A. Gertz, MD</td>
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<td>Möreken Melstedt, MD</td>
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<td>Häkan Merklein, MD</td>
<td>Hammarby Sjukhuset, Stockholm, Sweden</td>
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<td>Hartmut Goldschmidt, MD</td>
<td>Medical Klinik and Poliklinik V, University of Heidelberg, Germany</td>
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<td>Roman Härek, MD</td>
<td>University Hospital Brno</td>
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<td>Joy Ho, MD</td>
<td>Royal Prince Alfred Hospitals and Concord Hospitals</td>
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<td>Vania Hungria, MD</td>
<td>Clinica São Paulo, Brasilia</td>
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<td>Sundar Jagannath, MD</td>
<td>St. Vincent’s Comprehensive Cancer Center</td>
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<td>Michio M. Kawano, MD</td>
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<td>Henrik M. Lokhorst, MD</td>
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<td>Paul G. Richardson, MD</td>
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<td>Paul L. Zeman, MD</td>
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<td>Jesús Santonja, MD</td>
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<td>Ramon H. Lurie Comprehensive Center, Chicago, IL, USA</td>
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<td>Mario Boccadoro, MD</td>
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<td>Giampaolo Merlini, MD</td>
<td>Amyloidosis Centre, University of Pavia, Italy</td>
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<td>Sven Olsson, MD</td>
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<td>Nikhil Munshi, MD</td>
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<td>Amara Nouel, MD</td>
<td>Hospital Rut y Paez, Bolivar, Venezuela</td>
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<td>Martin Oken, MD</td>
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<td>Antonio Palumbo, MD</td>
<td>Ospedale Mollinette, Torino, Italy</td>
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<td>S. Vincent Rajkumar, MD</td>
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<td>Donna E. Reece, MD</td>
<td>Princess Margaret Hospital, Toronto, Canada</td>
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<td>David Roodman, MD</td>
<td>VA Medical Hospital</td>
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<td>Jesús San Miguel, MD</td>
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<td>Chaim Shustik, MD</td>
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<td>David Siegel, MD</td>
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<td>Seema Singhal, MD</td>
<td>Robert H. Lurie Comprehensive Cancer Center, Northwestern University, Chicago, IL, USA</td>
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<td>Alan Solomon, MD</td>
<td>University of Tennessee</td>
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<td>Andrew Spencer, MD</td>
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<td>A. Keith Stewart, MD</td>
<td>Scottsdaile, AZ, USA</td>
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<td>Guido Tricot, MD</td>
<td>Huntman Cancer Institute</td>
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<td>Benjamin Van Camp, MD</td>
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<td>Brian Van Ness, MD</td>
<td>University of Minnesota</td>
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<td>David Vesole, MD</td>
<td>Hackensak University</td>
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<td>Jan Westin, MD</td>
<td>Salzburg General Hospital, Salzburg, Austria</td>
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RESEARCH
In December 2009, the IMF announced its six 2010 research grant recipients, supporting them with a total of $355,000:

**Brian D. Novis Senior Research Grants 2010**
- Aaron Schimmer, MD, PhD, FRCPC
  Princess Margaret Hospital, Ontario Cancer Institute
  Toronto, Canada
  *Development of the antihelmintic flubendazole as a novel therapeutic agent for the treatment of multiple myeloma*

**Brian D. Novis Junior Research Grants 2010**
- Xin Li, PhD
  Myeloma Institute for Research and Therapy
  Winthrop P. Rockefeller Cancer Institute
  University of Arkansas for Medical Sciences
  Little Rock, AR, USA
  *Mesenchymal cell cytotherapy for multiple myeloma*
- Eline Menu, PhD
  Vrije Universiteit Brussel
  Brussels, Belgium
  *Characterization and preclinical evaluation of NKT cells in multiple myeloma*
- Steffan Nawrocki, PhD
  The University of Texas Health Sciences Center
  San Antonio, TX, USA
  *Reolysin: a novel reovirus-based therapy for multiple myeloma*
- Ariosto Silva, PhD
  H. Lee Moffitt Cancer and Research Institute
  Tampa, FL, USA
  *Bone marrow microenvironment and multiple myeloma chemotherapy optimization*
- Vyacheslav Yurchenko, PhD
  Laboratory of Lymphocyte Signaling
  Rockefeller University
  New York, NY, USA
  *MMSET and epigenetic control in t(4;14) myelomas*

**IMF Japan Aki Award 2010**
- Junya Kuroda, MD, PhD
  Division of Hematology and Oncology
  Kyoto Prefectural University
  Kyoto, Japan
  *Novel anti-myeloma therapy by targeting molecular signaling regulated by galectin family proteins*
Global Clinical Trials Forum

The IMF’s Global Clinical Trials Forum was created to enhance the collaboration and cooperation between national and international myeloma research groups in order to improve clinical trial design and data accrual. In 2010, the efforts of this 32-member group led to the establishment of a myeloma-specific Cancer Therapy Evaluation Program at the National Cancer Institute, a goal set forth in last year’s agenda.

This year, the Global Clinical Trials Forum convened at the ASH conference in December 2009, setting an agenda to work with the Food and Drug Administration in order to accelerate new drug approvals and reach agreement on required comparator studies.

Our collaborative research extends worldwide.

In this bird’s-eye view, the colored dots represent the locations where IMF research programs take place all around the globe.
**SUPPORT**

”Whether we are newly diagnosed or long-term survivors, it always helps to know that we are not alone on our journey.”

— PAT LAAS, Bettendorf, IA

The IMF remains dedicated to ensuring that no one feels isolated by a myeloma diagnosis. The IMF’s programs and services are designed to provide patients and their loved ones with a strong network of local and global support and easy access to up-to-date information.

**myeloma.org**

”With so much misinformation flying over the Internet, it is so nice to have a ‘place of reason’ to get accurate, timely knowledge.”

— NANCY RHYME, San Clemente, CA

The IMF website is a hub for everything the IMF has to offer.* With 24-hour access to the IMF’s comprehensive publications, videos, blogs, research updates, and the latest community developments, it is a crucial resource for patients, families, caregivers, and health care professionals throughout the world.

From October 2009 through September 2010, nearly 353,000 visitors went to myeloma.org, tallying nearly 1,400,000 page views. IMF-produced videos brought 53,500 views of 200 unique interviews and presentations. Website visitors viewed and downloaded almost 48,000 documents. During this time period, the IMF’s website was also visited via nearly 6,200 mobile devices.

**Toll-Free Hotline**

”The counsel I have gotten from the IMF Hotline has been outstanding – everything from handholding and encouragement to medical pointers and answers to very specific technical questions.”

— CHARTY BASSETT, Escondido, CA

The IMF’s Toll-Free Hotline provides life-saving and life-changing myeloma treatment and management support from compassionate, highly trained specialists. With a commitment in making hotline specialists as available to the community as possible, in April 2010, the IMF added a new feature where clicking on telephone icon on the IMF website triggers a timely “return” phone call from the Hotline to the number provided. From October 2009 through September 2010, the hotline supported 2,457 callers and responded to 2,000 emails.

* IMF website is a hub for everything the IMF has to offer.

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**David Miller**
Northfield, MA

In October 2003, David Miller went for a routine annual physical. But his internist noted something far from routine – unusual protein readings in Dave’s blood work led to a prompt diagnosis of myeloma. “I later learned that many internists would have ignored the anomalies,” Dave says. “I am very grateful that my myeloma was found quite early, when the disease had not had time to do much pre-treatment damage.”

For more than five years Dave was successfully treated by a general oncologist in Washington, DC, but in 2009 he was looking to make a change. He wanted to keep his appointments much closer to home and, more importantly, “I felt I had reached a point where some new and different treatment seemed advisable,” he says.

Dave found the IMF website (myeloma.org) while seeking information about myeloma specialists in his area and took the opportunity to contact the IMF’s Hotline (800-452-CURE). “I had contacted two or three other organizations by phone and got only a limited response,” Dave recalls. “But with the IMF I got a pro-active response. The Hotline was completely engaged in my case, asked a series of focused and relevant questions, and strongly endorsed my plan to seek a myeloma expert.”

The IMF Hotline provided Dave with several referrals. After meeting with his options, he called the Hotline once again. “They could not have been more helpful to my ‘sorting out’ process, and providing sound counsel on all my issues at the time,” he says.

The new specialist Dave selected was the one the Hotline felt was the strongest choice for him from the start. “She has treated me with clinical and human excellence since August 2009,” Dave reports. “I could not be more satisfied with the IMF response and ultimate recommendation.”

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**Support**

14
Support Groups

“We are just so comforted and grateful, knowing that expert advice from the compassionate members of the IMF team is guiding us through the myeloma journey.”

– CAROL MURRAY-ROSSI, Support Group Leader, Warwick, RI

Through a global community of IMF-assisted support groups, the IMF seeks to ensure that patients and families have local access to support, information, and a strong sense of collective identity. The IMF currently supports 114 groups in the United States. From October 2009 through September 2010, the IMF facilitated the formation of the first Spanish language group, based in Los Angeles, CA. In total, 14 new U.S.-based groups were formed in: Boca Raton, FL; Columbia, SC; Dayton, OH; Eau Claire, WI; Fayetteville, NC; Jackson, MS; Los Angeles, CA; Montgomery, AL; Naples, FL; Richmond, KY; Richmond, VA; Shreveport/Bossier City, LA; South Bend, IN; Springfield, MO.

The IMF is dedicated to overseeing the needs of these groups and their leaders. From October 2009 through September 2010, IMF staff visited 95 percent of its U.S.-based groups at least once, and 50 percent of these groups at least twice.

In addition, the IMF’s 11th annual Support Group Leaders’ Summit took place in July 2010 in Irving, TX. A total of 67 Support Group Leaders representing 52 groups attended the summit, including 16 leaders who attended for the first time. Participants were updated on the latest information about myeloma treatment and care, and provided with new leadership tools and approaches – all to further enhance the experience for their support groups back home.

Myeloma Manager™

The IMF’s Myeloma Manager™ Personal Care Assistant™ is a computer program that tracks a patient’s individual laboratory results and also displays and prints charts to show how these results change over time. This is an unprecedented way for patients to fully understand their own personal trends and assess progress over an extended period, helping them and their caregivers maximize the growing wealth of information and constantly increasing complexity of myeloma treatment programs.

The Myeloma Manager is available for download, free of charge, through the IMF website. From October 2009 through September 2010, this groundbreaking program was downloaded for new use 1,765 times, with an additional 75 downloads of the amyloidosis-specific version of the program.

* The IMF changed its website tracking systems at the beginning of the fiscal year.

Elliot Recht
San Diego, CA

In 1998, at age 45, Elliot Recht felt that he was in the best shape of his life. Then he received the shock of a lifetime: He was diagnosed with myeloma.

Like many others, Elliot had never heard of myeloma before his diagnosis. He felt compelled to learn, and learn fast. He was diagnosed on a Wednesday; he found the IMF on Thursday; he called the IMF’s Hotline on Friday and was provided with information about a support group in San Diego. The group’s monthly meeting was scheduled for that upcoming Monday night. Less than a week after his diagnosis, Elliot attended his first meeting. He was grateful to so quickly find a local community of support.

More than 12 years later, it is a community that remains integral to his life. Elliot now serves as the group’s leader, succeeding founders Fred and Virginia Gloor. He relishes the “thank you” emails after successful meetings, and he is happy to be able to help new, overwhelmed members – like he once was – become more comfortable.

In both 2008 and 2009, the San Diego Multiple Myeloma Cancer Support Group was a finalist for the San Diego Business Journal’s Health Care Champion Award. “It’s a tremendous honor, because we’re competing with prestigious and established health care organizations throughout the city,” Elliot says.

Elliot credits the IMF with helping build the group’s success. He relies on the IMF’s website (myeloma.org) for up-to-date information and participates in the IMF’s webinars for more in-depth discussions. He attends Patient & Family Seminars and calls the Hotline (800-452-CURE) for resource referrals.

Elliot has also attended four Support Group Leaders’ Summits. “The IMF takes that time to show appreciation for the leaders,” he says. “The IMF also provides great information for running a successful group – which benefits patients and caregivers everywhere.”
Because of the preparation and encouragement of the IMF, I have become a believer of the power of advocacy.

– MARTI HILL, Indian Rock Beach, FL

The IMF is dedicated to creating an inclusive community that supports the wide-ranging needs of all myeloma patients, their families, their caregivers, and researchers working to combat the disease. By advocating at state and federal levels, the IMF continues to build relationships and foster change in strategic and systemic ways.

The IMF believes in including the entire myeloma community in these efforts and continues to expand its commitment to empowering patients, families and friends to advocate on their own behalf. In August 2010, the IMF created the position of Grassroots Liaison to help promote advocacy outreach and coordinate grassroots campaigns.

Madam Speaker, I come to the floor today to help raise awareness about myeloma. . . I ask my distinguished colleagues to join me in recognizing the exemplary work being done by the IMF to improve the quality of life of myeloma patients and their families and their efforts to find a cure in the fight against cancer.

– HON. BRIAN HIGGINS, United States House of Representatives from the Congressional Record, May 25, 2010

At the governmental level, the IMF remains committed to creating effective, immediate solutions while simultaneously building and strengthening relationships for the future. This strategy continues to bring success. IMF-supported programs received increased support during the 2010 fiscal year, including cancer research funding attached to the congressional economic stimulus package, as well as funding for programs overseen by the National Institutes of Health and the National Cancer Institute.

In August and September 2010, the U.S. Senate and House of Representatives passed the Improving Access to Clinical Trials Act, strongly advocated by the IMF and its members. This act changes current Supplemental Security Income (SSI) so that research compensation (up to $2,000) for participation in a clinical drug study for a rare disease or condition is no longer considered income for determining SSI eligibility. (The act was formally signed into law in October 2010.) Access to trials and treatment options remains a vital issue for the myeloma community and the IMF’s advocacy in this arena is more determined than ever.

IMF action was also an important component in the U.S. House of Representatives resolution declaring September 2010 as Blood Cancer Awareness Month, highlighting the impact blood cancers have in the United States and encouraging greater support for blood cancer research and education.

In April 2010, the IMF was invited to submit congressional testimony regarding fiscal year 2011 appropriations for myeloma cancer programs. From October 2009 through September 2010, the IMF also authored and co-authored 12 letters on funding and appropriations, health care reform, insurance coverage, and access to clinical trials to the Centers for Medicare & Medicaid Services, the Department of

Jerry Walton
Virginia Beach, VA

“I decided to contact our congressman in the House of Representatives because I wanted him to know about the concerns of myeloma patients in his district,” says Jerry Walton, a myeloma patient diagnosed in 2006. “I also wanted to enlist his support on specific legislation that would immensely benefit myeloma and other cancer patients.”

Jerry’s meeting with Congressman Glenn Nye was arranged through the IMF’s Advocacy Team. They augmented his idea by also scheduling meetings with both of Jerry’s senators: Mark Warner and Jim Webb. “Piece of cake, to my surprise!” Jerry notes.

Jerry and the IMF Advocacy Team met with Congressman Nye himself and staff members for Senator Warner and Senator Webb in Washington, DC on March 11, 2010. After briefly discussing the nature of myeloma, the conversations shifted to legislation on the congressional docket: the Cancer Drug Coverage Parity Act (HR.2366), the Access to Clinical Trials Act (S.488 and HR.716) and the 21st Century Cancer ALERT Act (S.717). Jerry seized the opportunity to personalize the issues, using himself as an example and also sharing stories of members of the southeastern Virginia support group, which he founded in 2007 with the help of the IMF.

Great results have already been achieved thanks to the efforts of Jerry and other IMF advocates. The Access to Cancer Clinical Trials Act was ultimately included in the Patient Protection and Affordable Care Act, signed into law on March 23, 2010.

“In this wired and wireless society, the importance of communication with our legislators has never been more important,” he says. “The IMF’s advocacy efforts have and will continue to help us become an effective chorus with a positive influence on our leaders’ healthcare decisions.”
IMF Advocacy
Action Center

The IMF’s Advocacy Action Center is an online, centralized hub that shares governmental activity affecting the myeloma community and provides the tools for myeloma patients, families, caregivers, and medical professionals to become part of the advocacy process. When the Action Center was originally established in early 2009, this activity focused on a federal level; from October 2009 through September 2010, the IMF added state programming, which allows advocates to communicate with legislators on state-level issues.

In February 2010, the Action Center hosted two webinars, Advocacy 101 and Building Relationships with Your Members of Congress. These sessions covered building relationships with legislators, congressional visits in Washington, DC, maximizing legislative meetings, effective use of the IMF’s Advocacy Action Center, and the IMF’s 2010 public policy agenda.

From October 2009 through September 2010, nearly 1,000 new subscribers joined the IMF Advocacy Action Center’s Myeloma Action Network, an email service that alerts members when a new government representative or cause needs to be addressed by the myeloma community. Members of the Myeloma Action Network sent more than 3,000 emails to their state and federal legislators during this reporting period.

Advocacy Partners

- Alliance for a Stronger FDA
- Cancer Leadership Council
- Hematological Cancers Group
- Lethal Cancer Coalition
- National Coalition for Cancer Research
- National Organization for Rare Disorders
- One Voice Against Cancer
- Patient Equal Access Coalition

IMF Myeloma Awareness Month

The IMF advocates for research and treatment issues affecting the myeloma community by observing Myeloma Awareness Month. The March 2010 event included a four-part teleconference, free of charge for all listeners. Topics addressed the pillars of the IMF: Education, Research, Support and Advocacy.

Advocacy Partnerships

“On behalf of my grandfather, I was an advocate for the IMF at this year’s One Voice Against Cancer Lobby Day. People from all over the United States gathered to tell their stories to members of Congress. I will never forget the stories that were told. They made me think a little more about life itself.”

– WILLIAM CARROLL GUNThER, IV, Aberdeen, MD

The IMF firmly believes that partnership is the strongest approach for reaching goals, and therefore proudly joins forces with other cancer organizations in order to most effectively advocate for the cancer community’s many common needs. Building these mutually beneficial relationships also ensures that myeloma patients and their families are always represented when key governmental agencies create and reflect upon their agendas.

In June 2010, the IMF once again participated in the One Voice Against Cancer (OVAC) Lobby Day in Washington, DC, organized to urge the federal government to increase funding for cancer research and prevention programs. In addition to its collaboration with OVAC, from October 2009 through September 2010, the IMF continued rewarding partnerships with the Cancer Leadership Council, the Hematological Cancers Group, the Lethal Cancer Coalition, and the National Coalition for Cancer Research, and formed new partnerships with the Alliance for a Stronger FDA and the National Organization for Rare Disorders.

The IMF Advocacy team also led an effort to form a new coalition, called the Patient Equal Access Coalition (PEAC). Comprised of advocacy groups from across the cancer spectrum – including breast, colorectal, ovarian, myeloma, and other blood cancers – the IMF and PEAC believe that every cancer patient should have access to the anticancer regimens recommended by their physicians and should not suffer from cost discrimination based on the type of therapy provided or the mechanism of delivery. PEAC is therefore dedicated to ensuring that all cancer patients have equality of access and equality of insurance coverage for all approved anticancer regimens.

IMF Advocacy Partners

- Alliance for a Stronger FDA
- Cancer Leadership Council
- Hematological Cancers Group
- Lethal Cancer Coalition
- National Coalition for Cancer Research
- National Organization for Rare Disorders
- One Voice Against Cancer
- Patient Equal Access Coalition

The IMF also empowers its individual members to claim their own voices and partners with them in bringing their stories and concerns directly to their governmental representatives. From October 2009 through September 2010, the IMF joined some of its members in meeting with Representative Glenn Nye and the staffs of Senator Barbara Boxer, Senator Mark Warner, Senator Jim Webb, and Representative Bill Young. IMF members also testified in state hearings in California, Connecticut, Maryland, Massachusetts, and New Hampshire regarding legislation for equal coverage of oral chemotherapy treatments.

Internationally, on September 9, 2010, the IMF signed an unprecedented agreement with the Chinese Health Promotion Foundation, an agency that operates under the Chinese Ministry of Health. This agreement promotes awareness of myeloma in China and encourages measures to prevent and combat the disease, substantially expanding the IMF’s presence in Asia.

Health and Human Services, the Employee Benefits Security Administration, and the Internal Revenue Service, as well as to nine different U.S. Senators and two members of the House of Representatives.

In February 2010, the IMF Advocacy team also led an effort to form a new coalition, called the Patient Equal Access Coalition (PEAC). Comprised of advocacy groups from across the cancer spectrum – including breast, colorectal, ovarian, myeloma, and other blood cancers – the IMF and PEAC believe that every cancer patient should have access to the anticancer regimens recommended by their physicians and should not suffer from cost discrimination based on the type of therapy provided or the mechanism of delivery. PEAC is therefore dedicated to ensuring that all cancer patients have equality of access and equality of insurance coverage for all approved anticancer regimens.
There is a direct connection between my disease and my support for the organization that does so much for so many people in the myeloma community.

– ALLAN WEINSTEIN, Paradise Valley, AZ

Since the IMF’s inception 20 years ago, its mission has been to improve the quality of life for myeloma patients while working toward prevention and a cure. With that in mind, the importance of improving and expanding the IMF’s core programs and services is intrinsically tied to the support received through the IMF’s ongoing relationships with individual donors, corporate sponsors, and grants from pharmaceutical partners.

The results of the IMF’s extensive fundraising activities provide opportunities for the myeloma community to participate in programs that offer comprehensive education, results-driven research, compassionate support services, and passionate advocates in our nation’s capital for issues affecting myeloma patients and the medical professionals treating them.

All gifts, regardless of size, help fund these programs, and for this the IMF remains deeply grateful to all its donors. The support received from IMF donors makes it possible to continue all programs without any adverse effects caused by the economic recession, and the IMF continues to take pride in maintaining sure footing during a time of great economic uncertainty.

Generous donor support made it possible for the IMF to achieve all of its financial goals for the Fiscal Year. During the twelve-month period covering October 1, 2009 through September 30, 2010, the IMF raised a total of $8.2 million in support of its programs and services. The IMF additionally received an unprecedented $1 million through Michael McKean’s win on the Jeopardy! Million Dollar Celebrity Invitational.

Major Gifts & Planned Giving

The IMF received 47 major gifts totaling almost $700,000 during the 2009-10 Fiscal Year. This small group of staunch supporters makes an incredible impact on the fiscal stability of the organization through substantial and personally meaningful gifts.

Founders’ Circle Summit

The IMF hosted its 3rd Annual Founders’ Circle Summit on June 30, 2010. Members of the Founders’ Circle, who contribute a minimum of $10,000 annually to the IMF, were treated to in-depth briefings from IMF Chairman Dr. Brian Durie, International Myeloma Working Group Co-Leader Dr. S. Vincent Rajkumar, and Lead Principal Investigator, IMF Historical Controls Project Dr. Shaji Kumar.

Leon H. Rittenberg, Jr.
New Orleans, LA

When Leon Rittenberg Jr. was diagnosed with myeloma ten years ago, he first believed that his life expectancy would be two years, the typical statistic a newly diagnosed patient might hear. That assumption did not account for the fact that Leon was diagnosed with smoldering myeloma, nor the increasingly successful treatment options made available to all myeloma patients.

Thankfully, Leon had a knowledgeable resource at home. His wife, Cindy, spent her career as an oncology nurse, culminating as the executive director of a multi-national association for supportive care in cancer. When Cindy met the IMF at a myeloma conference, she knew it would be an important organization for her, both professionally and personally.

The Rittenbergs subsequently familiarized themselves with the IMF website and IMF-authored literature. “IMF communications are most helpful, since understanding a problem helps to give you the tools to solve it,” Leon observes. “I’m a firm believer that one needs to help him or herself.”

One important aspect of helping himself is through financial support of the IMF. By participating in the Founders’ Circle Summit, the Rittenbergs feel they have learned a great deal more about myeloma, and feel privileged that they have had the opportunity to communicate with leading professionals in the field.

“The IMF can open doors for you,” Leon says. “They do a wonderful job educating their constituency, promoting research, and financing projects.

“My family has made a significant commitment to the IMF,” he continues. “Why? Really, it’s to help me. But because of the IMF’s educational programs and research initiatives, a valuable side effect is that our support also benefits many others.”
Once again, the Founders’ Circle Summit was conducted virtually, with presentations and interactive question-and-answer sessions with all of the experts streamed live over the Internet. By eliminating the need to travel and allowing participants to take part in this exclusive meeting from the comfort of their own homes, the event became accessible to more of the dedicated donors of the Founders’ Circle.

This 3rd Annual Founders’ Circle Summit raised over $100,000 in support of the IMF research programs, including the International Myeloma Working Group.

**Brian D. Novis Legacy Society**

Now in its third year, the Brian D. Novis Legacy Society recognizes individuals who inform the IMF that they have made plans to include the organization in their long-term estate plans. Members of this society make bequest provisions in their will or revocable trust, or name the IMF as a beneficiary of qualified retirement plan assets (IRA or 401(K)) or life insurance policy.

The IMF sincerely wishes long, happy, and healthy lives for all myeloma patients, but also recognizes that this development strategy will yield long-term results to help to ensure the future of the IMF’s life-saving programs and services. To become a member of the Legacy Society, the IMF requests that individuals simply confirm their planned gift in writing. No minimum commitment is necessary.

**The Hope Society**

The IMF’s sustained giving program, The Hope Society, allows members to make recurring contributions on a monthly or quarterly basis. Hope Society participants make a large impact on the IMF’s mission by making small, regular donations to the organization. Most Hope Society members ultimately donate more over the course of a year through this program than they would in a single lump-sum donation, for which the IMF is truly grateful. Since being launched in August 2009, The Hope Society has grown significantly to include 138 participants who donated $17,500 during the 2009-10 Fiscal Year.

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**Steven Hirschorn**

Overland Park, KS

When Steven Hirschorn was diagnosed with myeloma in August 2007, he was already aware of myeloma. He had first heard the word a mere two weeks before, when his friend was diagnosed.

Yes, he had heard of the word, but as Steve reflects, “I was totally unaware of what myeloma was.” That friend recommended the IMF Hotline in order to get an understanding of the disease. “The Hotline was phenomenal in answering my questions,” Steve says.

He continues to use the IMF to educate not only himself, but also to educate others – and to raise awareness about myeloma. To his family, friends, and neighbors, he passes along IMF-authored information booklets addressing myeloma disease and treatment. He has also distributed more than 200 of the IMF’s myeloma awareness wristbands. As Steve sees it, education and awareness are two of the most powerful tools for advocacy.

Funding for myeloma research is the other tool Steve sees as vital to the cause. When he learned about the IMF’s Brian D. Novis Legacy Society, Steve immediately knew that it was a simple and powerful way that he could make even more of a difference. By specifying now that he will be leaving a part of his estate to the IMF, Steve has the immediate satisfaction of knowing he’s contributing to myeloma’s future research and development.

“Myeloma is such a rare disease and does not get the funding for research that other cancers do,” Steve says. “I want to make sure that I do what I feel is necessary to help others and be part of the cure.

“The IMF has been so good to my family and me. That’s why I wanted to specify that my partnership in the cure be linked with the IMF and everything that they do.”
On May 7, 2010, the world saw the IMF receive $1,000,000 when Michael McKean won the *Jeopardy!* Million Dollar Celebrity Invitational. It is the single largest gift in the IMF’s 20-year history, and is being used to establish the McKean-Grayson Education and Research Fund, in honor of Michael and in memory of his friend, Lee Grayson.

A Grammy Award winner, an Academy Award nominee, and a multi-talented actor, singer, writer, and director, Michael had never heard of myeloma when Lee was diagnosed. “But throughout it all, Lee was working, he was staying vital,” Michael recalls.

Michael’s introduction to the IMF came from *Multiple Musicians Against Multiple Myeloma*, a fundraiser that Lee first produced with Naomi Margolin in 2002, several months before he passed away. Michael’s appreciation of the IMF further solidified when Peter Boyle also passed away from myeloma; if the IMF was important to Lee and Peter, it was important to him. In 2007, Michael raised over $45,000 for the IMF by headlining *Concert For A Cause*.

As for *Celebrity Jeopardy!*: “David Letterman once called me smart on air,” Michael says, as the explanation for his initial selection in 1999, as a standby. He subsequently made the show, and had already won $25,000 for the IMF in 2006.

“Because of the money at stake, the material for this year’s Celebrity Invitational was more difficult than our normal celebrity fare,” says host Alex Trebek of the 2010 event. Michael won his quarterfinal round, then his semi-final round, then – eventually – found himself on the final day of the Finals.

During Final Jeopardy!, there was a technical glitch. Taping paused for five minutes before he could reveal his answer, and his wager. “It was this crazy time bubble,” Michael says – because he did the math, and realized he’d won. For five whole minutes he had to keep it to himself.

Once the news was out, the IMF was flooded with messages from grateful patients all over the world. The IMF forwarded these thoughts to Michael, who sent this letter in response:

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To All,

I just got back from New York City, where I had spent an unanticipated month playing the role of The Stage Manager in Thornton Wilder’s *Our Town*. I had long admired this brilliant production now residing at the Barrow Street Theatre, and to wind up playing this great role for the month of June was breathtaking.

Do you know the play? It’s only about everything in the world: all the mysteries of the universe reflected in this little dewdrop of a town, Grover’s Corners. Performing the role put me at the center of that universe and I will miss the symmetry and beauty of Wilder’s world.

Upon returning to Los Angeles, I opened a bulging envelope to discover a huge stack of printed emails, cards, and other communications from you: the diagnosed, the survivors, the brave ones, and your brave families. It took a while to read them all; I had to stop often to breathe, count my blessings, hug the kids… you know what I’m talking about here.

I’m a little overwhelmed by your gratitude. I took a little (mostly trivial) knowledge into a TV game show, did my best against some worthy opponents and emerged with a chunk of cash with IMF’s address on it. Your thanks are much appreciated; your stories, shared via email, etc., are appreciated even more. I will treasure them always.

We all live in hope: here in California, in New York, in Grover’s Corners, and wherever you may be, we’re all hoping for a cure, a breakthrough, a miracle to offset the terror of this disease. Hope begets hope, and any move toward the realization of these hopes and prayers is a good move. I’m proud to have been of some help in this, and prouder still to be associated with all of you, with this great organization, and with this hopeful step into the future.

Yours,

Michael McKean
On November 7, 2009, nearly 1,200 people packed the Wilshire Ebell Theatre in Los Angeles, CA for the IMF’s 3rd Annual Comedy Celebration benefiting the Peter Boyle Memorial Fund. This annual event once again broke IMF fundraising records by bringing in $650,000 for the organization’s award-winning research program.

This year, Amy and Steve Weiss joined Loraine Boyle as event co-chairs. Together, they put on a show featuring a fantastic cast of celebrity comedians who agreed to come out in support of the IMF. The event, hosted by Ray Romano with the help of Jimmy Kimmel, featured appearances from Jason Alexander, Brad Garrett, Doris Roberts, Bob Saget, Fred Willard, and a special musical performance by Tenacious D with Jack Black and Kyle Gass.

The IMF also welcomed VIP attendees to enjoy a pre-show cocktail party and silent auction, which made a significant impact on the overall success of the event. Items up for bid in the auction included guitars signed by Sting and Meat Loaf, boxing gloves from Muhammad Ali and Sugar Ray Leonard, and a fantastic assortment of trips, memorabilia, and jewelry that were graciously donated for the cause. VIP guests were also treated to a post-show champagne and dessert reception that lasted well into the night.

Member Fundraisers

“I promised my husband we would turn the pain we experienced into something positive and meaningful. The IMF offered much encouragement and support as I organized my first fundraiser.”

– JOANNE GUNThER, Aberdeen, MD

One of the IMF’s longest running development programs, Member Fundraisers empower myeloma patients, their families, and their friends to generate support on a grassroots level, holding events in and around their communities to raise funds and awareness in support of the IMF. These member fundraisers generate critical funds for the fight against myeloma, increase awareness of the disease, and inspire patients, their families, and their friends to keep fighting. Some of the larger fundraisers are able to fund a Brian D. Novis Research Grant – a testament to the efforts of regular people with an extraordinary dedication to the IMF’s mission.

From October 2009 through September 2010, IMF members held 55 events and raised over $350,000. The IMF is tremendously grateful to this passionate and devoted group of members. Together, they make a profound impact on IMF programs, services, and research initiatives.
# Member Fundraisers held between October 1, 2009 – September 30, 2010

### Benefactors’ Circle
**$25,000 and up**
- **Miles For Myeloma 5K Walk/Run**
  - Philadelphia Multiple Myeloma Networking Group
  - Central New Jersey Support Group
  - Northern New Jersey Support Group
  - Philadelphia, PA

### Founders’ Circle
**$10,000 - $24,000**
- Carolyn Czerkies
  - Charity Golf Outing
  - Czerkies Family
  - Naperville, IL
- Coach Rob’s Benefit Bash
  - Rob Bradford
  - Apopka, FL
- J.C. Golf Tournament
  - David Johnson
  - St. Cloud, MN
- Music Against Myeloma
  - Slava Rubin
  - New York, NY
- WAMP Swim-A-Thon
  - Stafford Family
  - West Hartford, CT
- Jeans & Jewels Gala
  - Lisa Mihalick
  - Goshen, PA
- Fishing For A Cure
  - JoAnne Gunther
  - Aberdeen, MD
- RHS Open
  - Steven Saletan
  - Mt. Pleasant, SC

### Partners’ Circle
**$5,000 - $9,999**
- Heuer Memorial Golf Tournament
  - Nancy Heuer
  - Caledonia, NY
- Pytluk Walk of Hope
  - Barb Pytluk
  - Tonawanda, NY
- Trooper Benson Klein Research Fund
  - Benson Klein
  - Bethesda, MD
- Dennis Werra Fundraiser
  - Jayson Werra
  - New Berlin, WI
- Divesto Norton Golf Tournament
  - Calgary, Alberta, Canada
- Paparella Family Fundraiser
  - Carl Paparella
  - St. James, NY

### Associates’ Circle
**$1,000 - $4,999**
- Matthew Jacobs Annual Fundraiser
  - Matthew Jacobs
  - Frisco, TX
- Bridge Blasts Myeloma
  - Ann Gind
  - Potomac, MD
- Meredith Fiacco
  - Memorial Golf Tournament
  - Melanie Nichols and Suzanne Fiacco
  - Potomac, MD
- On The Fritz Fundraiser
  - Fritz Coleman
  - Studio City, CA
- Multiple Musicians Against Multiple Myeloma
  - Naomi Marpolin
  - Great Neck, NY
- Multiple Colors for Multiple Myeloma
  - Pam Larsen
  - Honolulu, HI
- Cabaret For A Cure
  - Courtney Charatsaris
  - Totowa, NJ
- Margaret R. Cole Memorial Fund
  - Roger Cole
  - Upper Montclair, NJ
- Timberwolves 5K
  - Julienne Basques
  - Groveland, CA
- Twin Cities Fundraiser
  - Pat Harwood
  - St. Louis Park, MN
- Jack’s 6th Annual Texas Hold’em Benefit Bash
  - Jack Aiello
  - San Jose, CA
- Lucier Birthday Fundraiser
  - Lynn Lucier
  - San Juan Capistrano, CA
- Who’s Your Daddy? Rally
  - Lisa Cash
  - Paducah, KY
- Jerry Walton’s Veterans Against Myeloma Campaign
  - Jerry Walton
  - Virginia Beach, VA
- Marioni Salon Fundraiser
  - Keri Marioni
  - Newark, DE
- Our Friend Dan Fundraiser
  - Dan Odegard
  - St. Paul, MN
- Central Florida Support Group Car Wash & Bake Sale
  - Ken Fabian
  - Apopka, FL
- TriBeCans Against Myeloma
  - Donna Hanita
  - New York, NY
- Chinatown Optical Fundraiser
  - Kaleena Ma
  - New York, NY
- Alexander MM Fashion Show
  - Nina Alexander
  - Louisville, TN
- Cirque De La Mode
  - Ashley Jeter
  - Temecula, CA
- Passport To A Cure
  - Greg Strouse & Kim Simecek
  - Brighton, MD

### Friends’ Circle
**$500 - $999**
- Bon-Ton Fundraiser
  - Suzanne Fiacco and Melanie Nichols
  - Potomac, MD
- Pilfer’s Car Show Fundraiser
  - Randy Cheney
  - Golden, CO
- Ida’s Day
  - Debbie Hadeka
  - Castleton, VT
- Christine Phillips Fashion Show “The Bloom”
  - Christine Phillips
  - Voorhees, NJ
- Paul Keddeli’s Veterans Against Myeloma
  - Paul Keddeli
  - Poquoson, VA
- Craft Fair Fundraiser
  - Carmen Sicelotta
  - Port Washington, NY
- Kindness For A Cure
  - Denise Bencel
  - Quakertown, PA

### Under $500
- Aslantrends Knitting Challenge
  - Angelo Fernandez
  - Port Washington, NY
- Walk for Myeloma
  - Denise Vidot
  - Miami, FL
- Burr Walk
  - Kelley Burr
  - San Diego, CA
- Bob Brunner’s Veterans Against Myeloma Campaign
  - Bob Brunner
  - Virginia Beach, VA
- Hirschorn For Myeloma
  - Steve Hirschorn
  - Overland Park, KS
- Stokes Art Fundraiser
  - Bill Stokes
  - Roanoke, VA
- The Cosmopolitans Fundraiser
  - Arlington, VA
- Hanson Cards
  - Jeffrey O. Hanson
  - Overland Park, KS
- Help from Heaven
  - Meghan Lowell
  - Rollingstone, MN

### Additional Events
- Celebration of Life Singers’ Fundraiser
  - Garden Grove, CA
- MMORE Foundation
  - Nancy Kaufmann
  - Columbus, OH
**INTERNATIONAL MYELOMA FOUNDATION**

*Statement of Financial Position*

*September 30, 2010*

### Assets

**CURRENT ASSETS**

- Cash and cash equivalents $1,694,124
- Contributions and other receivables 738,270
- Prepaid expenses 384,919

**Total Current Assets** $2,817,313

**PROPERTY AND EQUIPMENT, at cost**

- Furniture, fixtures and equipment 58,354
- Computer equipment 175,478
- Computer software 667,688
- Laboratory research equipment 449,200

Less accumulated appreciation (825,566)

**Net Property And Equipment** $525,154

**TOTAL ASSETS** $3,342,467

### Liabilities & Net Assets

**CURRENT LIABILITIES**

- Accounts payable and accrued expenses $379,746
- Deferred and unrestricted educational grants 1,987,279
- Current obligations under capital leases 1,619
- Line of credit 25,000

**Total Current Liabilities** $2,393,644

**OBLIGATIONS UNDER CAPITAL LEASES, less current portion** 6,170

**NET ASSETS**

- Unrestricted 942,653
- Temporarily restricted -

**Total Net Assets** $942,653

**TOTAL LIABILITIES AND NET ASSETS** $3,342,467

*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, 2010  

Change in Unrestricted Net Assets  

REVENUES  
Educational grants $5,689,636  
General contributions 2,263,175  
Fundraising event income 56,568  
Seminar fees and support group income 61,847  
Donated services 182,150  
Interest income 8,315  
Total Revenues $8,261,691  

Net assets Released From Restrictions  
Satisfaction of program restrictions $442,095  

Total Unrestricted Revenue And Other Support $8,703,786  

Expenses  
Program expenses 6,734,128  
General supporting expenses 496,349  
Fundraising expenses 512,943  
Total Expenses $7,743,420  

INCREASE in UNRESTRICTED NET ASSETS 960,366  

Changes in Temporarily Restricted Net Assets  
Contributions 145,990  
Fundraising event, net of direct benefit to donors of $367,946 296,105  
Net assets released from restrictions (442,095)  
Increase in Temporarily Restricted Net Assets -  
Increase in Net Assets 960,366  
NET ASSETS (DEFICIT), September 30, 2009 (17,713)  
NET ASSETS, September 30, 2010 $942,653  

For a copy of our complete audited financial statement, please contact the IMF office.
INTERNATIONAL MYELOMA FOUNDATION

Statement of Functional Expenses

For the Year Ended

September 30, 2010

Total Program Expenses  6,734,128
General Supporting Expenses  496,349
Fundraising Expenses  512,943

Total Expenses  $7,743,420

Breakdown of Expenses by Program

<table>
<thead>
<tr>
<th>PROGRAM</th>
<th>TOTAL EXPENSES</th>
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<tbody>
<tr>
<td>Patient &amp; Family Seminars</td>
<td>1,123,439</td>
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<tr>
<td>Research</td>
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<tr>
<td>Education &amp; Awareness</td>
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<td>Support Groups</td>
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<td>Bank On A Cure®</td>
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<td>Myeloma Today</td>
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<td>Information Mailings</td>
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<tr>
<td>Myeloma Manager</td>
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</table>

Total Program Expenses  $6,734,128

For a copy of our complete audited financial statement, please contact the IMF office.
The International Myeloma Foundation gratefully acknowledges the many people and organizations which have made contributions to our various programs and projects during the past year. Without them, the IMF would not be able to continue providing the excellent, high-quality programs and services upon which our members have come to rely. Their generosity allows the IMF to:

- Convene the Inaugural International Myeloma Working Group Summit bringing together the world’s foremost experts to collaborate on the future of myeloma research world-wide;
- Develop and maintain its highly-acclaimed website performing daily updates of the most relevant information available and made available 24 hours a day to all those interested in myeloma;
- Advocate on behalf of the entire myeloma community to ensure that myeloma research and patient care issues are ever-present in our lawmakers’ thoughts;
- Invest wisely in research programs like the International Myeloma Working Group and Bank On A Cure* that lead to better treatments for patients today while also funding research grants that lead to critical breakthroughs for tomorrow;
- Maintain the Hotline and ensure that its coordinators are up-to-date on the latest research and treatment options so that patients, family, and friends always have a place to turn;
- Expand successful programs such as the Regional Community Workshops to reach even more patients and families, while maintaining unwavering support of established and relied upon programs like the Patient & Family Seminars; the Patient & Family Seminars; and the Regional Community Workshops to reach even more patients and families, while maintaining unwavering support of established and relied upon programs like the Patient & Family Seminars; and
- Continue to produce and regularly update the more than 100 publications that support patients, doctors, and nurses in making informed treatment choices.

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

The IMF is here for you.

Chairman’s Circle
$100,000 and above
AMGEN Oncology
The Binding Site, Ltd.
Celgene Corporation
Medtronic, Inc.
Merck & Co.
Millennium: The Takeda Oncology Company
Onyx Pharmaceuticals, Inc.
Quadra Productions / Jeopardy!

President’s Circle
$50,000 - $99,999
The Virginia and Leonard Marx Foundation / Jennifer and Bud Gruenberg
Novartis Pharmaceuticals
Dorothy and John O’Dwyer
Philadelphia Multiple Myeloma Networking Group
Alice and Louis Weiss
Michael Windsor

Benefactor’s Circle
$25,000 - $49,999
Patricia and Bruce Bartlett
CBS Corporation
Susie Novis and Dr. Brian Durren
Robert C. Ebensole
Genzyme Corporation
John A. McConnell & Margaret T. O’Brien Foundation
Jae-Hoon Lee, MD
Ortho-McNeil Pharmaceutical/Johnson & Johnson

Founders’ Circle
$10,000 - $24,999
Henry Belber
Cancer Cure of America
Coach Rob’s Benefit Bash, Inc. / Kimberly and Robert Bradford
David Geffen Foundation
Donna and Steve Feig
GR Research Matters AG
Cindy and James Gilbert
Dianne M. Glick
HBO Inc.
J.C. Invitational Golf Tournament / Beverly Lundorf
Joy and Bill McGinnis
Estate of Caroline McWilliams
Alex Meneses and John Simpson
Paramount Network Television
Monica and Philip Rosenthal
Sebia, Inc.
Louise Takata
The Estate of Janet Kreh
The Hazel R. Osborn Charitable Remainder Unitrust
Dorothea *and Halis Tinsler
Twentieth Century-Fox
Phyllis and Allan Weinstein
Worldwide Pants, Inc.

Partner’s Circle
$5,000 - $9,999
Stacey Annen
Aptium Oncology, Inc.
Susan and Frank Armo
Loraine Boyle
Brillstein Entertainment Partners
Bristol-Myers Squibb Company
Cephalon, Inc.
Clifford and LaVonne Greene Foundation
Creative Artists Agency
Diplomat Specialty Pharmacy
Disney/ABC
Diverseco Inc.
Estate of Susan O. Pinals
Joel Frank and Larry Kurlfied
Genetech, Inc.
David Girard
Giving Generations Foundation
Helene S. Whitman Memorial Cancer Fund / Joel Whitman
Charlotte and Dale Herbrandson
InSightec
Janssen-Cilag
Jenya and Mark Borovitz
Lindsay Luke

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Helene S. Whitman Memorial Cancer Fund / Joel Whitman
Charlotte and Dale Herbrandson
InSightec
Janssen-Cilag
Jenya and Mark Borovitz
Lindsay Luke

Associate’s Circle
$1,000 - $4,999
Nora Alexander
Mark Allen
Altitude Aviation Inc
Jennifer and Bryan Anderson
Monica and Kristofer Anderson
Linn Anderson
Sandra Andrews
Jennet Walker and John Auerbacher
Mart Barreto
Bill Barretta
Beatrice Bass
Suzanne Battaglia
Barbara Baumanstein
Gary Benanav
Lisa Bernstein
Mr. and Mrs. Jake Bloom
Richard Boitue
Louis Borick
Harriet Rosetto and
Rabbi Mark Borovitz
Noeline and Dr. Henri Boshoff
Paula Bourlee
Sandra Powers and Bradford Porter
Mitzi and Gerald Bozarth
Warren Brealow
Wendy Brealow
L.J. Brewer
Carrie Brillstein
Henry Brock
Prudy and David Brown
Mani and Ward Bukofsky
Alan Bundy
Jenya and Mark Buntzman
Robin Green and Mitchell Burgess
Colleen and John Busch
Carter Foundation, Inc
Jack Carter
Tom Carver
Celebration of Life Singers
Celgene Germany
Celgene International
Manish Chablani
Charlotte and William Hinson
Chalmers Foundation
Roxie Chen
Chinatown Optical Inc.
Karen Chopra
Louise and Frank Chut
Citigroup Asset Management
…There is the IMF

INTERNATIONAL MYELOMA FOUNDATION
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800-452-CURE
ThelMF@myeloma.org
myeloma.org
The IMF’s 2010 fiscal year ran October 1, 2009 – September 30, 2010. This list includes gifts received between those dates. We apologize for any omissions or errors. Please call the IMF office to report any corrections needed.

Every gift is appreciated by the IMF. Every dollar counts. Nearly 5,000 people contributed gifts between $1 and $499, totaling $506,940 of support from programs, services and research. Unfortunately, space does not allow for everyone’s name to be listed but every donor is deeply valued.

* deceased
Until there is a cure… There is the IMF.

INTERNATIONAL MYELOMA FOUNDATION

myeloma.org