International Myeloma Foundation

Dedicated to improving
the quality of life of myeloma patients
while working toward prevention and a cure.
2011 ANNUAL REPORT

TABLE OF CONTENTS

Letter from the Chairman 2
Update from the President 3
Research 4
Education 10
Support 13
Advocacy 15
Development 17
Financial Statements 21
Honor Roll 24
Dear Supporters of the International Myeloma Foundation,

We have worked together for 20 years to help myeloma patients, their caregivers, and loved ones around the world. This year, our commitment to this mission proved as fruitful as ever. The work over the 2010-2011 fiscal year has strengthened patient care and treatment, bringing us closer to calling this disease “treatable.”

In March 2011, the IMF launched the Asian Myeloma Network to support physician and patient education throughout Asia. Multiple myeloma is increasing in Asia, with an incidence that is approaching that of western countries, yet with a much larger population base. Launching the network and the China Myeloma Working Group in August 2011 represents a great leap toward increasing a research base and strengthening access of myeloma patient and caregiver support.

In June 2011, the IMF held its annual International Myeloma Working Group Summit in London. This summit was yet another opportunity to bring together leading researchers in the field of myeloma, to establish recommendations for management of the disease, and guide the direction of future research. You will find in this report further detail on the incredible research-driven publications produced throughout 2011 by the IMWG; publications which work to inform patients and caregivers of therapeutic advances and treatment management.

This year, we launched the Search for a Cure program, with the intent to seek and fund promising myeloma research. We funded incredible research through our 2011 grants and we collaborated with key researchers to communicate important findings.

As one of the Foundation’s four main pillars, the Education division created a new tool to inform patients and their families about diagnosis and treatment information entitled “10 Steps to Better Care™.” This is an interactive online, downloadable resource for patients and caregivers.

We are in the midst of an important era for the myeloma community; we are seeing more and more patient outcome improvements with novel drug agents, tailored therapies, and increased access to care and support. The IMF will continue to build upon its platform of research to inform more effective treatment regimens and will continue to support all who are affected by this disease.

I would like to thank all of our supporters and partners for enabling our mission to grow stronger and improving the care and treatment of myeloma.

Sincerely yours,

Brian G.M. Durie, MD
Chairman, IMF Board of Directors
Dear Friends, Supporters, and Members,

The International Myeloma Foundation celebrated its 20th anniversary during the 2010-2011 fiscal year. It turned out to be our biggest year ever with more than $9.2 million received in support of our outstanding programs and services! As I look through the pages of this Annual Report, I am both humbled by and grateful for the opportunity to improve the lives of myeloma patients and family members, and to partner with the medical community. The IMF experienced a year of truly remarkable accomplishments through its Advocacy, Support, Education and Research programs.

In the area of Advocacy, IMF members worked tirelessly to provide oral testimony in state governments, which led to the successful passing of drug parity laws in New York, Mexico, and Texas. Through our partnership with other cancer advocacy organizations, we supported the re-introduction of the Cancer Coverage Parity Act of 2011 on the federal level, which has the potential to impact tens of thousands of lives.

The IMF Support Groups program grew steadily over the year; 150 groups in the United States, Canada, and Europe are now active. The volunteers that serve as support group leaders are the heroes of the IMF, helping people in the community on a daily basis.

Furthering Education, the IMF sponsored four incredibly strong Patient & Family Seminars featuring important discussions around new drug effectiveness, and eleven Regional Community Workshops; four of which had over 100 people in attendance. Last February in Boca Raton, a spontaneous – and highly unusual – wave of generosity initiated by IMF member Bob Feltzin resulted in donations totaling $40,000 to the IMF research fund. I am very proud to have been able to establish a grant in his honor and memory.

In the area of Research, we experienced tremendous successes. We established the Asian Myeloma Network to extend the breadth of international myeloma education and research. We also announced research projects funded through this year’s Brian D. Novis Grants; projects that will bring us closer to more effective care and treatment of myeloma.

As you read through these pages, consider the many different ways the IMF, through generous donor support, touches the lives of myeloma patients and caregivers who come to rely on its programs. The IMF has been in the business of improving lives and finding a cure for 20 years. With your support, we will continue making outstanding progress.

Warmly,

Susie Novis
President
The International Myeloma Foundation is a leader of innovative, globally collaborative myeloma research that aims to improve the quality of life of those living with myeloma. The IMF is at the forefront of research and knowledge around “tailored treatment,” where new and combined myeloma therapies aim to address the precise needs of each myeloma patient. Tailoring myeloma treatment will lead to an era where myeloma will be managed as a chronic disease rather than a terminal diagnosis.

International Myeloma Working Group

The IMF’s International Myeloma Working Group (IMWG) consists of 159 leading myeloma researchers from around the world. They collaborate on a broad range of myeloma research projects. With a goal to improve myeloma treatment options and diagnostic systems, their work focuses on protocols to provide a more durable remission for myeloma patients while improving quality of life, addressing the needs of both myeloma patients and the physicians who treat them.

In June 2011, the second annual IMF IMWG Summit was held in London, England, 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 71 myeloma experts from 25 countries, representing 55 institutions, and led to discussions about the key issues surrounding myeloma, including the diagnosis and management of high-risk smoldering myeloma, induction therapy, maintenance versus consolidation therapy, the role of early transplantation, the integration of new and existing drugs, and risk stratification. Recommendations for publications and research were produced, which will inform future research projects and clinical trials.

IMWG PUBLICATIONS

Long-term IMWG research collaboration led to four publications during the October 2010–September 2011 reporting period:

Risk of progression and survival in multiple myeloma relapsing after therapy with IMiDs and bortezomib: A multicenter international myeloma working group study

International Myeloma Working Group consensus approach to the treatment of multiple myeloma patients who are candidates for autologous stem cell transplantation
Asian Myeloma Network

On March 17, 2011, in Singapore the IMF launched the Asian Myeloma Network (AMN), which is composed of myeloma experts from China, Hong Kong, Taiwan, Japan, Rep. of Korea, Singapore, and Thailand. This network was initiated to spearhead physician education about myeloma and patient care and support throughout Asia. Multiple myeloma is a growing health problem in Asia, with an incidence that is approaching that of Western countries, however with a much larger population base.

One aim of this network is the development of a unified database to assess the incidence of myeloma in Asian countries to formulate the design of a region-specific treatment management plan. The IMF will provide help establishing this database with the creation of a template for data entry. Intended future projects will include the establishment of Asian clinical trials, as well as the development of informational resource materials in local languages, based on previous IMF-produced materials, intended for patients and caregiver use.

Wee Joo Chng, MD, PhD
National University Cancer Institute of Singapore, National University Health System, Singapore

Dr. Chng began his work in myeloma at the Mayo Clinic in Arizona in 2004. His present work in the field is around disease biology and risk assessment of patients in order to identify best possible therapeutic avenues, customized to individual patient needs.

“I was always interested in myeloma because of its complexity, its challenging nature, and because myeloma is at the forefront of the genomic revolution – an exciting area for drug development in hematologic malignancies.”

Dr. Chng was first introduced to the IMF during his fellowship at the Mayo Clinic in 2005. The range of researchers working within the organization and its involvement of patients and families into the realm of cancer research are what drew him to the IMF. He later joined the IMWG, where he worked on the study of the survival among novel agent-treated myeloma patients who relapsed and the consensus statement on the role of risk stratification in myeloma treatment. He has also been working with Dr. Munshi of the Dana Farber Cancer Institute on a gene expressions analysis that promises to strengthen prognostics.

“Being part of the IMWG brought me closer to a community of thought leaders in the field. The frequent interaction and collaboration have greatly informed my practice in the management of myeloma patients in Singapore. My role in the IMWG has allowed me to participate in charting the future course of research and clinical management of myeloma.”

Dr. Chng, with the help of the IMF, has started patient education initiatives in Singapore and recently organized the first patient forum in Singapore. It is his hope that the IMF’s presence in Asia will grow and will strengthen our understanding of epidemiologic variations across ethnic groups in the myeloma community.
IMF Research-focused Presentations/Symposia at 2011 Myeloma Research-related Global Conferences

The International Myeloma Workshop

The International Myeloma Workshop, which took place in May 2011 in Paris, France, focused on the biology, genetics, diagnosis, and treatment of multiple myeloma. The IMF held a seminar on key findings of this conference on May 6, facilitated by Brian Durie, Xavier LeLeu, Jean Fermand, and Thierry Facon.

Topics included:
- New data around long-term continuous lenalidomide maintenance therapy following stem cell transplants (seen to delay disease progression and improve overall survival)
- Pomalidomide and carfilzomib moving closer to FDA approval

The American Society Of Hematology (ASH)

The American Society Of Hematology (ASH), which was held in December 2010 in Orlando, Florida, featured multiple myeloma as a key topic. On December 3, the IMF and the Postgraduate Institute for Medicine sponsored a symposium featuring the most recent reported observations from clinical trials of new drugs in development and combination therapies:

New drugs discussed at the IMF-sponsored symposium
- Carfilzomib, a proteasome inhibitor, shows promising activity among relapsed/refractory myeloma in phase I of a three-phased Multiple Myeloma Consortium study
- Pomalidomide, a promising immunomodulatory drug, is undergoing studies to determine best dosage practices
- Elotuzumab, a humanized monoclonal antibody, shows positive activity in a clinical trial; further research is required to look into effective dosage levels.
- MAbs in development: mapatumumab and lexatumumab

Combined regimens discussed
- Weekly bortezomib in combination with temsirolimus has shown positive activity
- A phase I trial is underway to assess dual targeting of –TORC1 and –TORC2
- An evaluation of lenalidomide and PD-0332991 showed an additive effect on reduction of IRF4, a myeloma survival cell factor.

The symposium concluded with a discussion on how these novel agents and new drug regimens are evolving. The trend of increased survival for patients with myeloma that began in the era of novel agents is continuing. Future regimens are likely to be based on combination therapies with unique mechanisms of action and non-overlapping toxicities. Risk stratification and tailoring of therapy to individual needs is advancing to include patient quality of life.

Robert A. Kyle Lifetime Achievement Award

Named for its first recipient, the Robert A. Kyle Lifetime Achievement Award is presented annually by the IMF to an individual whose body of work in the field of myeloma has made significant advances in research, treatment, and care of myeloma patients.

Douglas Joshua, AM received this year’s award. He is Head of Clinical and Laboratory Haematology at Sydney Cancer Centre, Head of Sydney South Western Area Health Service Haematology, the Alan Ng Professor in Medicine at University of Sydney, and the Director of the Institute of Hematology, Royal Prince Alfred Hospital. Professor Joshua is the ninth Kyle Award winner, and was honored in London on June 8, 2011.
**Brian D. Novis Research Grants**

Through its Brian D. Novis 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 111 grants since the program’s inception in 1994. This IMF-supported work, which has led to more than 250 publications in the world’s top research journals, continues to build knowledge around this disease and its treatment.

**Brian D. Novis Senior Research Grants 2011**

*In memory of the IMF’s co-founder, Brian Novis, the IMF has established annual grants to promote research into better treatments, management, prevention, and a cure. These grants are made possible through donations from private individuals and are awarded annually to doctors and researchers of promising work in the field of myeloma.*

Laurence Catley, VIBBS, FRACP, FRCPA  
Mater Medical Research Institute  
Cancer and Immunology Program  
South Brisbane, Australia

*Metabolic targeting therapy for multiple myeloma*

Hearn J. Cho, MD, PhD  
New York University School of Medicine  
New York University Cancer Institute  
New York, NY, USA

*Rationally designed pralatrexate combination therapies for multiple myeloma*

Brian D. Novis Junior Research Grants 2011

Shirong Li, PhD  
University of Pittsburgh  
Division of Hematology/Oncology  
Pittsburgh, PA, USA

*Targeting the translational machinery in multiple myeloma*

Naoya Mimura, MD, PhD  
Jerome Lipper Multiple Myeloma Center  
Dana-Farber Cancer Institute  
Harvard Medical School  
Boston, MA, USA

*Targeting the IREα-XBPI pathway in multiple myeloma*

Vyacheslav Yurchenko, PhD  
Rockefeller University  
Laboratory of Lymphocyte Signaling  
New York, NY, USA

*MMSET and epigenetic control in t(4;14) myelomas*

**The 9th Annual Aki Horinouchi Research Grant**

Instituted by IMF-Japan in memory of its founder, this annual award has funded nine important research projects from 2002 to 2010 and two myeloma clinical group studies. The 2011 grant was awarded to two projects, for the first time since its inception:

Hiroshi Yasuim, MD, PhD  
Sapporo University School of Medicine  
Sapporo, Japan

*Epigenetics in multiple myeloma and prospects for translational research*

Yusuke Furukawa, MD  
Jichi University School of Medicine  
Tochigi-ken, Japan

*The role of histone deacetylases (HDAC) in drug resistance of multiple myeloma cells*
Dr. Cho was introduced to the field of myeloma research by a teacher and leading clinician in the field, Dr. Josi Michaeli. Through their collaborative work, Dr. Michaeli passed on to Dr. Cho his passion to eliminate this disease.

Dr. Cho has been a friend of the IMF for years and pursued the Brian D. Novis Senior Research Grant to investigate the effectiveness of pralatrexate for use in relapsed T-cell lymphoma. This class of anti-folate drug has not been commonly used in myeloma, but Dr. Cho’s work has shown its effectiveness in lab trials. His work with this novel therapeutic agent and his work on vaccine immunotherapy is greatly contributing to superior treatment strategies and targeted therapeutic approaches.

“The IMF is an organization of dedicated and passionate people, and their efforts are a critical complement to the clinical and translational research side of the myeloma field. We all have the same goal, and we all contribute to that goal. Independent funding agencies such as the IMF play a critical role in biomedical research and the IMF ensures that myeloma researchers will continue to receive funding to advance the search for a cure.”
In this bird’s-eye view, the colored dots represent the locations where IMF research programs take place all around the globe.
Although myeloma is one of the most prevalent forms of blood cancer, prior to diagnosis few patients have heard of the disease. To help address the many questions those newly affected by myeloma have, the IMF works to continuously share information on care, treatment, and support through the workshops and publications mentioned below. The IMF is also dedicated to supporting myeloma health care professionals with up-to-date information on treatment through its Nurse Leadership Board (see page 13).

IMF educational support gives patients an opportunity to join health care providers in decisions around treatment, creating the best possible quality of life for every myeloma patient.

**IMF Patient & Family Seminars**

The IMF’s Patient & Family Seminars present vital information about new treatments and clinical trials, provide time with myeloma specialists in intimate settings, and allow participants to share personal experiences and support. Premier myeloma experts volunteer their time to the seminars, to empower patients and their families to make educated treatment choices tailored to their needs.

Since 1993, the IMF has hosted over 200 Patient & Family Seminars in 16 countries. From October 2010 to September 2011, approximately 1,000 participants attended US-based seminars in San Francisco, CA; Dallas, TX; Boca Raton, FL; and Philadelphia, PA.

Internationally, approximately 1,300 people attended IMF Patient & Family Seminars in Barcelona, Spain; Göteborg, Sweden; Hamburg, Heidelberg, and Würzburg, Germany; Lednice, Czech Republic; Lucca, Italy; Oslo, Norway; Rome, Italy; and Vienna, Austria.

**Regional Community Workshops**

In addition to Patient & Family Seminars, the IMF facilitates Regional Community Workshops, which serve as condensed seminars in smaller cities to expand the reach of IMF programs and up-to-date information on myeloma care, support, and treatment to a wider audience. From October 2010 to September 2011, 12 US-based workshops were held in Shreveport, LA; Denver, CO; Las Vegas, NV; Raleigh, NC; Kansas City, KS; San Diego, CA; Atlanta, GA; Jacksonville, FL; Detroit, Mi; Hartford, TX; Minneapolis, MO; and Norfolk, VA and were attended by approximately 960 participants.

The IMF also facilitated international Community Workshops, which attracted more than 400 participants in Berlin, Koblenz, and Leipzig, Germany; and Prague, Czech Republic.
International Education

Community Workshops and Roundtables for more than 130 clinicians and researchers were held in Bergen, Norway; Berlin and Heidelberg, Germany; Göteborg, Lund, and Stockholm, Sweden; and Trondheim, Norway.

IMF Board Member and Scientific Advisory Board Chair Dr. Robert Kyle participated in meetings in Berlin, Göteborg, Heidelberg, Koblenz, Lund, Sweden, and Oslo. IMF Founder and Chairman Dr. Brian Durie spoke in Rome, Stockholm, and Vienna. IMF Scientific Advisory Board member Dr. Bart Barlogie was featured in Berlin, Heidelberg, Stuttgart, and Würzburg. All three are members of the International Myeloma Working Group (IMWG).

Publications

The IMF is committed to the production of written materials that provide the myeloma community with an extensive knowledge base. The IMF’s catalogue of materials includes a wide-ranging collection of communications materials, such as informational brochures and tip cards for patient and provider use, and journal articles which contribute to the body of knowledge of the latest research in the field of myeloma. This library is also home to the IMF’s quarterly produced newsletter, Myeloma Today, and its email-based newsletter the Myeloma Minute, both of which provide up-to-date information on all issues affecting the myeloma community, including innovations in treatment, information on clinical trials, updates on policy issues, and guidance on where support can be accessed. All of these materials are 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.

From October 2010 through September 2011, the IMF created seventeen new publications. Seventeen additional publications were updated with the latest information. Many of these are bundled into the IMF InfoPack, designed to provide newly diagnosed patients and their families with complete understanding of the disease and patient care. From October 2010 to September 2011, the IMF disseminated approximately 2,200 Info Packs to patients, health care providers, and support groups around the world.

The IMF’s Myeloma Today is one of the few resources in the world which provides regularly updated information on advances in treatment, research, and quality of life. This newsletter has a readership estimated at 75,000 per issue.

The Myeloma Minute provides up-to-the-minute information about research, events, and IMF programs. In September 2011, its subscriber-base was nearly 30,000 readers.

IMF 2011 List of Publications

CITINGS: ASCO 2011 – Novel Therapies – Special Edition*
CITINGS: ASCO 2011 – Freelite®/Hevylite™ – Special Edition*
CITINGS: ASH 2011 – Novel Therapies – Special Edition*
CITINGS: ASH 2011 – Freelite®/Hevylite™ – Special Edition*
CITINGS: Freelite®/Hevylite™**
CITINGS: Novel Therapies**
CITINGS: ASCO 2011 – Novel Therapies – March 2011*
CITINGS: ASCO 2011 – Novel Therapies – May 2011*
Clinical Trial Data Sheets: ASPIRE and FOCUS trials*
Concise Review of the Disease and Treatment Options**
Early Screening for MGUS flowchart*
Freelite® tip card*
ASCO 2011 Highlights for Patients*
ASCO 2011 Highlights for Physicians*
ASH 2010 Highlights for Patients*
ASH 2010 Highlights for Physicians*
I Have Myeloma…What’s Next? (DVD)*
IMF Patient & Family Seminar: Boca Raton 2011 (DVD)*
International Myeloma Workshop: Paris 2011 (set of 4 DVDs)*
International Myeloma Workshop: Paris 2011 – Comprehensive Guide*
IMF Patient Handbook**
International Myeloma Working Group (IMWG) publications (a total of 39 as of 9/30/11)
International Staging System tip card
MM Support Group tip card**
Monitoring Patients with M-Proteins flowchart
Mozobil® tip card
Multiple Myeloma tip card
Myeloma Manager™ tip card
Myeloma Matrix: Clinical Trials**
Myeloma Minute e-newsletter**
Myeloma Today quarterly newsletter**
Nurse Leadership Board Survivorship Care Guidelines*
ONS Symposium 2011 (DVD)**
Understanding Anemia and Fatigue**
Understanding Balloon Kyphoplasty and Myeloma-Induced Vertebral Compression Fractures
Understanding Bisphosphonate Therapy**
Understanding Dexamethasone and other Steroids**
Understanding Protein Electrophoresis*
Understanding Revlimid***
Understanding Serum Free Light Chain Assays**
Understanding Stem Cell Transplant**
Understanding Thalidomide Therapy**
Understanding VELCADE (bortezomib) for Injection Therapy**
Understanding Your Test Results*

*New for 2011
**Updated for 2011
Since 2004, Tiffany Richards has focused her career in nursing on the care and support of patients with myeloma. In an effort to increase education of myeloma and its treatment among patients and caregivers, Tiffany reached out to support groups and began presenting at an IMF-led support group in her community. Through her relationship with this group and with the IMF, Tiffany was introduced to the work of the Nurse Leadership Board (NLB) and has become an invaluable member.

At the sixth annual NLB meeting in November 2010, Tiffany gave a lecture entitled Impact of Myeloma Disease, Treatments, Long-Term Effects, and Patient-Specific Characteristics on Renal Complications, Sexuality, and Sexual Dysfunction. In her words, "Sexual dysfunction is one of the most common and enduring consequences of cancer treatment and one that is not often addressed." She pleaded for increased communication among patients, nurses, and physicians in this area to increase patient quality of life.

Currently, Tiffany sits on the NLB publications committee and is chairing the survivorship tool committee. She feels that the work she accomplishes through the NLB is immensely valuable.

"The NLB works to educate nurses on how to manage patients with myeloma, which is incredibly important. Most nurses are not familiar with the disease, but I see this beginning to change."

**IMF Nurse Leadership Board Members**

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page Bertolotti, RN, BSN, OCN</td>
<td>Cedars-Sinai Outpatient Cancer Center</td>
</tr>
<tr>
<td>Elizabeth Bilotti, RN, MSN, APRN, BC, OCN</td>
<td>The John Theurer Cancer Center at HUMC</td>
</tr>
<tr>
<td>Kathleen Colson, RN, BSN, BS</td>
<td>Dana-Farber Cancer Institute</td>
</tr>
<tr>
<td>Deborah Doss, RN, OCN</td>
<td>Dana-Farber Cancer Institute</td>
</tr>
<tr>
<td>Beth Faiman, MSN, APRN-BC, AOCN</td>
<td>Cleveland Clinic Taussig Cancer Institute</td>
</tr>
<tr>
<td>Charise Gleason, MSN, NP-BC, AOCNP</td>
<td>Emory University Winship Cancer Institute</td>
</tr>
<tr>
<td>Bonnie Jenkins, RN</td>
<td>University of Arkansas Medical School</td>
</tr>
<tr>
<td>Kathy Lilleby, RN</td>
<td>Fred Hutchinson Cancer Research Center</td>
</tr>
<tr>
<td>Patricia A. Mangan, APRN, BC</td>
<td>Abramson Cancer Center University of Pennsylvania</td>
</tr>
<tr>
<td>Ann McNeill, RN, MSN, APN</td>
<td>The John Theurer Cancer Center at HUMC</td>
</tr>
<tr>
<td>Teresa Miceli, RN, BSN, OCN</td>
<td>Mayo Clinic Rochester</td>
</tr>
<tr>
<td>Kathy Lilleby, RN</td>
<td>Fred Hutchinson Cancer Research Center</td>
</tr>
<tr>
<td>Patricia A. Mangan, APRN, BC</td>
<td>Abramson Cancer Center University of Pennsylvania</td>
</tr>
<tr>
<td>Teresa Miceli, RN, BSN, OCN</td>
<td>Mayo Clinic Rochester</td>
</tr>
<tr>
<td>Kafka C. Miller, RN, MSN, FNP</td>
<td>Roswell Park Cancer Institute</td>
</tr>
<tr>
<td>Tiffany Richards, MS, APN, AOCNP</td>
<td>MD Anderson Cancer Center Houston, TX</td>
</tr>
<tr>
<td>Sandra Rome, RN, MN, AOCN</td>
<td>Cedars-Sinai Medical Center Los Angeles, CA</td>
</tr>
</tbody>
</table>

**Nurse Leadership Board**

The IMF Nurse Leadership Board (NLB) is comprised of 20 nurses from major centers treating myeloma patients throughout the US. The NLB provides a forum for addressing the needs of the myeloma nurse and patient communities. NLB members work each year to provide relevant information to patients and providers by presenting at key conferences, participating in IMF Patient and Family Seminars and Regional Workshops, conducting nurse education webinars and other educational teleconferences and through publication of educational materials and guidelines on myeloma management.

In November 2010, the NLB convened its sixth annual meeting in New Jersey, where NLB members discussed their projects including publication and dissemination of the Survivorship Care Plans for Myeloma Patients, development of a web-based survivorship tool, design and implementation of nurse-led research, and developing guidelines for care of the myeloma patient undergoing transplant.

In April 2011, the NLB hosted a symposium at the 36th Annual Congress of the Oncology Nursing Society to present the NLB Long Term Care Survivorship Guidelines for Multiple Myeloma Patients. The symposium focused on promising agents in clinical development, optimal patient treatments, follow-up of treatment outcomes, and how to maintain quality of life through this continuum of cancer and treatment. This conference was attended by 750 nurses.

**IMF Nurse Leadership Board Members**

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page Bertolotti, RN, BSN, OCN</td>
<td>Cedars-Sinai Outpatient Cancer Center</td>
</tr>
<tr>
<td>Elizabeth Bilotti, RN, MSN, APRN, BC, OCN</td>
<td>The John Theurer Cancer Center at HUMC</td>
</tr>
<tr>
<td>Kathleen Colson, RN, BSN, BS</td>
<td>Dana-Farber Cancer Institute</td>
</tr>
<tr>
<td>Deborah Doss, RN, OCN</td>
<td>Dana-Farber Cancer Institute</td>
</tr>
<tr>
<td>Beth Faiman, MSN, APRN-BC, AOCN</td>
<td>Cleveland Clinic Taussig Cancer Institute</td>
</tr>
<tr>
<td>Charise Gleason, MSN, NP-BC, AOCNP</td>
<td>Emory University Winship Cancer Institute</td>
</tr>
<tr>
<td>Bonnie Jenkins, RN</td>
<td>University of Arkansas Medical School</td>
</tr>
<tr>
<td>Kathy Lilleby, RN</td>
<td>Fred Hutchinson Cancer Research Center</td>
</tr>
<tr>
<td>Patricia A. Mangan, APRN, BC</td>
<td>Abramson Cancer Center University of Pennsylvania</td>
</tr>
<tr>
<td>Ann McNeill, RN, MSN, APN</td>
<td>The John Theurer Cancer Center at HUMC</td>
</tr>
<tr>
<td>Teresa Miceli, RN, BSN, OCN</td>
<td>Mayo Clinic Rochester</td>
</tr>
<tr>
<td>Kafka C. Miller, RN, MSN, FNP</td>
<td>Roswell Park Cancer Institute</td>
</tr>
<tr>
<td>Tiffany Richards, MS, APN, AOCNP</td>
<td>MD Anderson Cancer Center Houston, TX</td>
</tr>
<tr>
<td>Sandra Rome, RN, MN, AOCN</td>
<td>Cedars-Sinai Medical Center Los Angeles, CA</td>
</tr>
</tbody>
</table>

**Nurse Leadership Board Members**

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tiffany Richards, MS, ANP, AOCNP</td>
<td>MD Anderson Cancer Center Houston, TX</td>
</tr>
</tbody>
</table>

**Nurse Leadership Board Members**

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tiffany Richards, MS, ANP, AOCNP</td>
<td>MD Anderson Cancer Center Houston, TX</td>
</tr>
</tbody>
</table>
The IMF remains dedicated to ensuring the Support of those living with myeloma. The IMF’s programs and services are designed to provide patients and their loved ones with local and global support networks and easily accessible, up-to-date information. The IMF provides educational and psychosocial support of the myeloma community through its website, listserv, social media efforts, and its toll-free Hotline, as well as its wide-ranging network of community support groups.

myeloma.org

Through its website, the IMF offers patients, caregivers, and health care professionals multi-lingual access to the IMF and externally published literature, research updates, the latest community developments, and linkage to support services and advocacy forums. From October 2010 through September 2011, over 340,000 visitors went to myeloma.org, tallying nearly 1,400,000 page views. Of these visitors, 60% were new to the IMF website. The almost 1,000 IMF-produced videos housed on the web brought nearly 58,000 views. Website visitors viewed and downloaded over 23,000 PDFs of documents created or updated during the year. During this time period, the IMF’s website was also visited over 18,000 times from mobile devices.

Summer of 2011 saw the addition to the website of 10 Steps to Better Care™, an interactive online, downloadable resource. Patients and caregivers can drill down into each step to read articles, watch videos, and gain a better understanding about everything from initial diagnosis, to relapse, tests, and clinical trials.

Toll-Free Hotline

The IMF’s toll-free Hotline provides life-saving and life-changing myeloma treatment and management support from highly trained specialists. From October 2010 through September 2011, Hotline responders supported 2,179 callers and answered nearly 1,500 emails.

Barbara Hammack
Kensington, MD

In 1991, Barbara Hammack was told she “probably” had smoldering myeloma. At the time, Barbara (or Boogie, as she’s often called) was 45, busy, career-focused, and not particularly well-informed by her then-provider. She went through the motions of this seemingly strange diagnosis and treatment. It was not until after multiple rounds of treatment (with the ensuing hair loss), and preparation for stem cell transplantation that Boogie realized she had cancer and that this cancer would greatly impact her life. She had her transplant in 1994. Her transplant and her treatment, although extremely difficult to live through, have been met with success.

Barb retired in 1999 and was looking for something meaningful to make of her time. She found a myeloma support group in her community and started to build relationships with other patients, caregivers, and the IMF. Soon after joining the group, she attended her first Patient & Family Seminar where she connected with an IMF Hotline coordinator. Over the years, Barb has stayed in close communication with the Hotline; it has proved an immense resource for Barb in understanding her disease.

“During my transplant in 1994, I didn’t know about the IMF; I don’t even think we had reliable internet then. I was living in a bit of a vacuum. I now have the opportunity to prevent that knowledge gap. I have referred countless patients to the IMF Hotline, knowing that they will be given the best information from the most caring people.”

Today, Boogie is doing well. Her oncologist started her on an oral chemotherapy with promising outcomes in the first few months. She continues her volunteer work and her outreach and support of myeloma awareness, and her steadfast relationship with the IMF, because in her words “Myeloma may suck, but the IMF rocks.”
In 2003, Jack Pacowta was diagnosed with myeloma. Soon after his diagnosis, Jack and his wife, Anne, learned of the IMF and a local IMF support group in their community of Waterbury, CT. They began to attend support group meetings and took some comfort in educating themselves about this disease and treatment innovations, as well as the personal support received there.

Jack retired in 2006 and he and Anne decided it was best to move down to Ponte Vedra, where they vacationed for years. In their new community, there were no myeloma-specific support groups and Anne and Jack realized the importance of the help provided through those meetings.

They reached out to the IMF and consulted with staff on how, where, and when to build their own support group. In December 2007, they held their first meeting, with twelve people in attendance.

Jack passed away in 2008. Before he died, he expressed his wish for the group to continue. Anne and her co-leaders, Hunter and Diana Chiles, have served Jack’s legacy well; there are now 49 members of the North Florida Multiple Myeloma Support Group.

“Jack’s diagnosis was both a devastation and blessing to our family. No other event in our lives made our priorities so very crystal clear and brought an already close family even closer. It’s been three years that I’ve been carrying on his wish, and at times it becomes painful, but the ability to help someone take charge of their situation and be empowered by education is very gratifying. I made a commitment to continue as long as I can.”

Support Groups

Through a global community of assisted support groups, the IMF seeks to ensure that patients and families have local access to psychosocial support and education. The IMF currently supports more than 150 support groups worldwide. From October 2010 through September 2011, a total of nine new support groups were formed in: Dover, DE; Chico, CA; Grand Rapids, MI; Nature Coast, FL; Texarkana, AR; Kingwood, TX; Indianapolis, IN; Charlotte, NC; and Nashville, TN.

The IMF is dedicated to overseeing the needs of these groups and their leaders. From October 2010 through September 2011, IMF staff visited 95 percent of its US-based groups at least once.

In addition, the IMF’s 12th annual Support Group Leaders’ Summit took place in July 2011 in Dallas, TX. A total of 76 Support Group Leaders representing 50 groups attended the summit, including 33 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 2010 through September 2011, this groundbreaking program was downloaded for new use 1,443 times, with an additional 50 downloads of the amyloidosis-specific version of the program.
The IMF is dedicated to creating an inclusive community that supports the wide-ranging needs of all affected by myeloma. By advocating at state and federal levels, the IMF serves as a voice to heighten quality access to care and end disparities in insurance coverage that affect patient care, protect and increase myeloma research budgets, strengthen clinical trials, and advocate for prompt Food and Drug Administration approval of effective treatments. The IMF includes the entire myeloma community in these efforts and continues to expand its commitment to empowering patients, families, and friends to advocate on behalf of patient rights.

**Public Policy**

At the governmental level, the IMF remains committed to creating effective and prompt solutions, while simultaneously strengthening care strategies, cancer prevention, and treatment innovations. The IMF advocacy efforts have included calling on the US Congress to strengthen preventive care, improve patient access to treatment, and maintain the key provisions of health reform essential for high quality of care for cancer patients.

Despite the difficult economic times our country faced in 2011, the IMF successfully advocated for the funding of important cancer research through government agencies. These efforts resulted in funding for programs at the National Institutes of Health (NIH), the National Cancer Institute (NCI), and the US Centers for Disease Control and Prevention (CDC) in fiscal year 2011.

**Advocacy Efforts at the Federal Level**

This year, the IMF advocacy team focused on collaborating with a variety of cancer-focused patient organizations with a common goal: to increase access to treatment. In July 2011, the IMF formed the Patients Equal Access Coalition (PEAC), as a vehicle to achieve this goal. PEAC is comprised of advocacy groups from across the cancer spectrum, including breast, colorectal, ovarian, pancreatic, brain, myeloma, and other blood cancers.

PEAC supported Representative Brian Higgins (D-NJ) in championing cancer issues in Congress and reintroducing the Cancer Coverage Parity Act of 2011. This important legislation is instrumental in making progress to eliminate the disparity in insurance coverage and reimbursement between oral and intravenous chemotherapy treatment, and to decrease the unmanageable out-of-pocket expenses for patients who have been prescribed an oral medication by their doctors.

---

**Sue Enright**

Jackson, WI

“Nobody should have to max out their credit cards, or lose their home just to afford cancer treatment. Sadly, that is a reality for many cancer patients. They have enough on their plate just trying to regain their health without the added burden of figuring out how to pay for life-saving treatment and going deeply into debt in the process.”

– Sue Enright in support of the oral drug parity bill in Wisconsin

Sue Enright, a caregiver and IMF advocate, has been lending her voice to support patient rights in Wisconsin. She co-founded the West Bend Myeloma Support Group in 2008 and later became a charter member of the Wisconsin Coalition for Cancer Treatment Access (WCCTA).

In January 2011, Sue and her husband Rob, a myeloma patient, along with three other members of their support group met with Wisconsin Representative Pat Strachota. They emphasized the importance of equal access to anticancer treatments for all patients. The group presented an overview of multiple myeloma, its treatments, and side effects.

Shortly after their meeting, Representative Strachota helped to introduce an oral chemotherapy access bill to ensure that insurance plans reimburse oral anticancer medications on the same basis as IV or injected anticancer medications.

In April 2011, Sue was part of a small but powerful group of IMF advocates for a Day at the Capitol, a lobby event hosted by the IMF, WCCTA, and the Leukemia and Lymphoma Society. The group of six met with three State Representatives and one State Senator to encourage the passage of the oral chemotherapy access bill in Wisconsin.

Sue hosted her second support group meeting with a member of the Wisconsin legislature, Senator Glenn Grothmann in August 2011. In all of these meetings, the group illustrated the importance of patient-physician collaboration in designing an effective treatment regimen and how inequity in coverage should not play a factor in those careful and life-saving discussions.

Sue calls her work a privilege. She looks forward to a brighter future for all cancer patients. Sue was recently voted IMF Advocate of the Month twice.
Advocacy Partnerships

In May 2011, 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 medical research at the NIH, NCI, CDC, and the FDA. In addition to its collaboration with OVAC, from October 2010 through September 2011, the IMF continued our partnerships with the Cancer Leadership Council, the Hematological Cancers Coalition, the Lethal Cancer Coalition and the National Coalition for Cancer Research, Alliance for a Stronger FDA and the National Organization for Rare Disorders, and formed a new partnership with the Wisconsin Coalition for Cancer Treatment Access.

Advocacy Efforts at the State Level

Cancer treatment coverage legislation has been introduced in multiple states across the country and many IMF advocates turned out to support state bills and share their stories of how disparity in treatment access has affected their lives.

In March, myeloma survivor and IMF advocate David Cowan from New Mexico shared his story before the House, Health, and Government Affairs Committee in support of SB 385, which requires equal coverage for orally administered and intravenous chemotherapy in New Mexico. The bill passed unanimously and was signed into law in April 2011. In June, Paula Van Riper, an IMF Support Group Leader from New Jersey, provided oral testimony on behalf of her group to support an oral chemotherapy access bill to the New Jersey Assembly Health Committee. In early summer, Kena Miller, RN, MSN, FNP, an IMF Nurse Leadership Board member, met with ten New York legislators in Albany to emphasize the importance of the oral chemotherapy access legislation. The bill was signed into law in New York in September 2011. Support of similar legislation also took place in Wisconsin.

In Texas and Illinois the IMF issued action alerts to in-state network members, where chemotherapy access legislation was passed in May and July 2011 respectively. The IMF also worked with advocates to schedule meetings and encourage letters to state legislators in Pennsylvania, Oklahoma, and California to ensure the passage of this bill.

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 process.

From October 2010 through September 2011, nearly 1,000 new subscribers joined the IMF Myeloma Action Network, an email service that alerts members when a new government representative or legislative issue 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.

On August 11, 2011, the Action Center hosted a training webinar for all advocates that focused on the best ways to connect with Congress. This skills-building session was attended by more than 50 advocates and resulted in more than 10 face-to-face meetings with US Representatives across the country.

IMF Myeloma Awareness Month

The IMF advocates for research and treatment issues affecting the myeloma community by observing Myeloma Awareness Month. The March 2011 event included a four-part teleconference series, free of charge for all listeners. Topics addressed included an update on management of side effects treatments and novel agents, participations in clinical trials, issues of consideration in Medicare, and the psychosocial implications of myeloma.
DEVELOPMENT

“You can either be frustrated your whole life, or try to create some semblance of understanding and do something about it.”

– STEVE FEIG, Miami, FL

The IMF’s mission to improve lives and find a cure began 21 years ago with the belief that no one should ever have to face myeloma alone. The IMF’s core programs in each of the four areas of research, education, support, and advocacy provide patients and their families with the most important tools to fight the disease.

These programs receive support through the IMF’s relationships with individual donors, corporate sponsors, and grants from pharmaceutical partners. The results of the IMF’s fundraising activities provide access to low- and no-cost programs and services to the myeloma community.

The IMF appreciates the support from all donors regardless of how large or small their gift may be. Each dollar received makes it possible to continue offering and improving upon existing programs, while exploring new ways to service the myeloma community.

During the 2010-11 Fiscal Year, the IMF exceeded its fundraising goals through the generous support of our donors. During the twelve-month period from October 1, 2010 to September 30, 2011, the IMF raised a total of $9.2 million in support of vital programs and services.

Major Gifts & Planned Giving

The IMF received major gifts from 43 donors, totaling $742,000 during the 2010-11 Fiscal Year. Major donors are a small but dedicated group of supporters who make a powerful impact on the IMF’s fiscal stability through their generous and substantial gifts.

Brian D. Novis Legacy Society

The IMF recognizes individuals who have made arrangements to include the organization in their long-term estate plans through the Brian D. Novis Legacy Society. Members in the 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 and their families, but also recognizes that this development strategy will yield long-term results to help 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.

In 1991, Donna Feig’s mother, Leta Garvett, was diagnosed with myeloma. Leta, a health-minded and resourceful person, took careful steps in her treatment. She joined an IMF Support Group soon after her diagnosis and initiated one of her own for her community of South Florida. Upon her passing, her husband, Robert, took it over. Robert Garvett not only ran the support group, but also leveraged funds for a research grant and helped coordinate a Patient & Family Seminar.

Donna and Steve Feig have a long and trusted relationship with the IMF and began giving to the IMF after Leta passed away. Their contributions and efforts on behalf of the IMF over the years, in particular their participation in the Annual Comedy Celebration, has had a major impact on the Foundation.

The Feigs hope their contributions will help patients and families the world over to benefit from the IMF-provided education and support from which their family benefitted. Donna is now a member of the IMF Board of Directors where she works to increase doctor- and patient-level education of this disease.

“In some way, both Donna and I have been very fortunate. In others, we’ve been very unfortunate. My child Clayton died at age 18, which is why we have created a Clayton Feig Research Grant. You can either be frustrated your whole life, or try to create some semblance of understanding and do something about it. We did the latter. The IMF stands for what we try to do.”

– Steve Feig
Randy Tammara's father, Steve, was diagnosed with myeloma at the age of 65. He's been battling this cancer, osteopenia, and anemia. He uses oral chemotherapy and supplements and he visits two oncologists on an alternating basis. Despite all of the challenges related to Steve's diagnosis, he shows up for work every day to help Randy run their co-owned pharmacy in Philadelphia, PA.

When it comes to receiving support for multiple myeloma, both Randy and Steve turn to the IMF. They value the up-to-date information provided through the IMF's educational and support resources. They also attend local support group meetings, through which their family has connected with care providers and other patients.

That is why both Randy and Steve support the IMF's mission through monthly giving. Their monthly donations were part of the inspiration behind creating the IMF's recurring giving program, The Hope Society. Their collective monthly support over the last five years has been considerable.

The IMF is grateful for this father and son team's generous dedication to its mission and hopes to continue to support Steve and the Tammara family in the management and care of myeloma.

The Hope Society

The IMF’s sustained giving program allows members to make recurring contributions on a monthly or quarterly basis. Participants in this program make small, regular donations that add up to make a significant impact on the organization’s mission. Hope Society members gave a total of $25,255 during the 2010-11 Fiscal Year, a 69% increase over last year.

The Hope Society Honor Roll

<table>
<thead>
<tr>
<th>Kathy and Charles Albino</th>
<th>Gerda Ann Gassman</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mary Ann and Jeffrey Allyn</td>
<td>Irene and Laurence Gauthier</td>
</tr>
<tr>
<td>Cathie Alonzo</td>
<td>Roseann and Philip Geiger</td>
</tr>
<tr>
<td>Bonnie Anderson</td>
<td>Patricia Giaimo</td>
</tr>
<tr>
<td>Deborah and John Anderson</td>
<td>Carl Gilliam</td>
</tr>
<tr>
<td>Pam and Scott Andrews</td>
<td>Carl Goode</td>
</tr>
<tr>
<td>Mary Authors</td>
<td>Vivian Gould</td>
</tr>
<tr>
<td>Elizabeth Beckley</td>
<td>Roberta and Arnold Greenberg</td>
</tr>
<tr>
<td>David Bennett</td>
<td>Janet and Randy Haghara</td>
</tr>
<tr>
<td>Marcy Bernstein</td>
<td>Carol Horreich</td>
</tr>
<tr>
<td>John Boehle, Jr.</td>
<td>Nicci Hubert</td>
</tr>
<tr>
<td>Frances and James D. Bowles</td>
<td>Caroll Anne and William Hynes</td>
</tr>
<tr>
<td>Connie Brawley</td>
<td>Eileen and John Iammarino</td>
</tr>
<tr>
<td>Julia Brock</td>
<td>Judith Torrez and William Jewell</td>
</tr>
<tr>
<td>David and Prudy Brown</td>
<td>Kathleen and David Johnson</td>
</tr>
<tr>
<td>Patricia Vigilante and Robert Candela</td>
<td>Steven M. Johnson</td>
</tr>
<tr>
<td>Annette and Patrick Cavanagh</td>
<td>Debbie and Jerry Jordan</td>
</tr>
<tr>
<td>Anne Chapman</td>
<td>Sheila Kaplow</td>
</tr>
<tr>
<td>Cynthia Ann and John Chmielewski</td>
<td>Eileen and Frank Kealty</td>
</tr>
<tr>
<td>Cynthia Clark</td>
<td>Rita and Robert Keating</td>
</tr>
<tr>
<td>David Cook</td>
<td>Elise Ketner</td>
</tr>
<tr>
<td>Karen Countryman</td>
<td>Roberta and Raymond Klein</td>
</tr>
<tr>
<td>Maureen Cronin</td>
<td>Leny and Ben Kolsteren</td>
</tr>
<tr>
<td>Carolyn and Monte Cunningham</td>
<td>Ann Nora Kruger</td>
</tr>
<tr>
<td>Franci Dale</td>
<td>Kristin and Scott La Berge</td>
</tr>
<tr>
<td>Myla De La Cruz</td>
<td>Sharon Lackey</td>
</tr>
<tr>
<td>Linda and Charles DeLong</td>
<td>Rose and George Leek</td>
</tr>
<tr>
<td>Brian Denyer</td>
<td>Linda and Joseph Lerner</td>
</tr>
<tr>
<td>Donald Detener</td>
<td>Jean Novak and Mike Lefarte</td>
</tr>
<tr>
<td>Niall Doherty</td>
<td>Kathleen and Charles Lewis</td>
</tr>
<tr>
<td>Joyce and James Donnell</td>
<td>Nancy and Don Lorenzen</td>
</tr>
<tr>
<td>Rene D’Valery and James Baker</td>
<td>Mary Jane Lundy</td>
</tr>
<tr>
<td>Linda and Mark Edwards</td>
<td>Helene and Alan Marks</td>
</tr>
<tr>
<td>Joseph Daniel Ellis</td>
<td>Laura Mclothin</td>
</tr>
<tr>
<td>Kate and Douglas Farrell</td>
<td>Marie Muccioi</td>
</tr>
<tr>
<td>Donna and Lawrence Farrell</td>
<td>Karen and Edward Necela</td>
</tr>
<tr>
<td>Bernadette and Andrew Farrell</td>
<td>Barbara L. Neilion</td>
</tr>
<tr>
<td>Virginia Field</td>
<td>Marcelo Pakman</td>
</tr>
<tr>
<td>Donna Font</td>
<td>Phyllis and Tom Parker</td>
</tr>
<tr>
<td>Clara and Charles Francis Gallagher</td>
<td>Marilyn and Ralph Peterson</td>
</tr>
<tr>
<td>Dean Gallea</td>
<td>Darlene Pickard</td>
</tr>
<tr>
<td>Susan and Daniel Gannon</td>
<td>Joyce and Harold Piel</td>
</tr>
</tbody>
</table>

*deceased*
**4th Annual Comedy Celebration**

On November 13, 2010, almost 1,200 guests packed the Wilshire Ebell Theatre in Los Angeles for the IMF’s 4th Annual Comedy Celebration benefiting the Peter Boyle Memorial Fund, which supports the IMF’s award-winning research program. The fundraiser raised nearly $570,000 this year.

Lorraine Boyle and returning co-chairs Amy and Steve Weiss once again rounded up an exceptional cast of comedians to come out in support of the IMF. As in previous years, the event was hosted by Ray Romano and featured appearances from fellow *Everybody Loves Raymond* castmates Doris Roberts and Fred Willard, as well as Jeff Garlin from *Curb Your Enthusiasm*. In addition, this year’s show benefited from the talents of Dana Carvey, Carlos Mencia, Alex Trebek, Annette O’Toole, and Susie Essman, and a special musical performance by Dr. Ken Jeong and Mike O’Connell.

The IMF welcomed attendees to a pre-show cocktail party and silent auction that made a significant impact on the overall success of the event. Items up for bid in the auction included a guitar signed by Bruce Springsteen, a behind-the-scenes visit to *60 Minutes*, and a fantastic assortment of trips, memorabilia, jewelry, and more 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**

Events held by IMF members around the country empower myeloma patients, their families, and their friends to make a difference on a community level. As the longest-running development program, Member Fundraisers have generated critical funds for the fight against myeloma through community events held nationwide.

IMF members held 63 events during the 2010-11 Fiscal Year, raising a total of $397,400. Six of these events funded Brian D. Novis Research Grants — a testament to the efforts of regular people with an extraordinary dedication to the IMF’s mission.

The IMF is tremendously grateful to this incredibly dedicated and passionate group of members who have a profound effect on IMF programs, services, and research initiatives.

IMF member Chris Hollyer touched the lives of many. In 2005, Chris ran both the Association of Cancer Online Resources and the IMF listserv. His vast knowledge of myeloma and its treatment, his kindness and his energy allowed him to reach thousands of patients throughout the world.

After Chris passed away in 2006, the outpouring of both admiration and grief from members of both online communities was overwhelming. Members wanted to find a way to thank and honor him for his commitment to help patients.

One couple in particular decided to put their words into action. In September 2006, Kim and Rob Bradford began hosting the annual *Coach Rob Charity Golf and Benefit Bash* to support a Brian D. Novis Research Grant in Chris’ honor. At the time of the inaugural event, Rob had just completed two rounds of chemotherapy and a stem cell transplant to treat his multiple myeloma. This two-day event was then, and is now, a labor of love; it is a way for Rob and Kim to return the support that they were given while he was treated for myeloma.

“This event is a way to give back to all of the great people that assisted me in my time of need. It also supports finding a cure.” — Rob Bradford

In December 2011, Kim and Rob Bradford’s efforts resulted in a Brian D. Novis Junior Grant awarded to Dr. Caritha Madiraju. With this funding, in Chris Hollyer’s honor, Dr. Madiraju can continue her work at the Sanford-Burnham Medical Research Institute on targeting UBC13-UEV1A for treatment of multiple myeloma.

Like all of our Brian D. Novis Grant winners, research pursuits will lead to improved quality of life for myeloma patients and families everywhere — including Chris Hollyer’s listserv friends.
Member Fundraisers held between October 1, 2010 – September 30, 2011

**BENEFACTORS’ CIRCLE**

$25,000 AND UP

- **Miles For Myeloma 5K**
  - Philadelphia Multi-Myeloma Networking Group, Central New Jersey Support Group, Northern New Jersey Support Group
  - Philadelphia, PA
- **A Celebration of Life at Kasbah**
  - Allan Weinstien
  - Paradise Valley, AZ
- **Coach Rob’s Benefit Bash**
  - Rob Bradford
  - Apopka, FL
- **Annual Carolyn Czerkies Charity Golf Outing**
  - Czerkies Family
  - Naperville, IL

**FOUNDERS’ CIRCLE**

$10,000 - $24,999

- **RHS Open**
  - Suzanne Salteren and Family
  - Wellington, FL
- **Miszbehave for Myeloma 2**
  - Alexandra Zouminer and Joanna Share
  - Chicago, IL
- **J.C. Golf Tournament**
  - David Johnson
  - St. Cloud, MN
- **Pytlík Walk of Hope**
  - Barb Pytlík
  - Tonawanda, NY
- **A Song for Ireland**
  - Doug and Kate Farrell
  - Philadelphia, PA
- **Honoring Peter Pritchett Fundraiser**
  - Paul Wiesner
  - Montrose, CO
- **Matthew Jacobs Annual Fundraiser**
  - Matthew Jacobs
  - Frisco, TX

**PARTNERS’ CIRCLE**

$5,000 - $9,999

- **Music Against Myeloma**
  - Slava Rubin
  - New York, NY
- **Bonacorsi Car Raffle Fundraiser**
  - Mario Bonacorsi
  - Barre, VT
- **Bald For Bucks**
  - David Chan and Steven Brown
  - Bayside, NY
- **Pipo’s Fund For A Miracle**
  - Cecilia Izquierdo
  - Miami, FL
- **Passport To A Cure**
  - Greg Strouse
  - Brighton, MI
- **Glee Fundraiser**
  - Allison Tushy
  - Prospect, CT
- **Paparella Family Fundraiser**
  - Carl Paparella
  - St. James, NY

**ASSOCIATES’ CIRCLE**

$1,000 - $4,999

- **Fall Bocce Classic for The IMF**
  - Dick Bloom
  - Dayton, OH
- **Bridge Blasts Myeloma**
  - Ann Grod
  - Potomac, MD
- **Meredith Fiacco Memorial Golf Tournament**
  - Melanie Nichols and Suzanne Fiacco
  - Potomac, MD
- **Gary C. Heuer, Jr. Memorial Golf Tournament**
  - Nancy Heuer
  - Guilderland, NY
- **Jack’s 6th Annual Texas Hold’em Benefit Bash**
  - Jack Astello
  - San Jose, CA
- **Dennis Werra Fundraiser**
  - Jayson Werra
  - New Berlin, WI
- **Trooper Benson Klein Research Fund**
  - Benson Klein
  - Bethesda, MD
- **Margaret R. Cole Memorial Fund**
  - Roger Cole
  - Upper Montclair, NJ
- **Concannon Family Fundraiser**
  - Karen Concannon
  - Niantic, CT
- **Central Florida Support Group Spaghetti Dinner**
  - Ken Fabian and Dick Wells
  - Apopka, FL
- **Multiple Colors for Multiple Myeloma**
  - Pam Larsen
  - Honolulu, HI

**FRIENDS’ CIRCLE**

$500 - $999

- **Bicycle Mojave and Beyond**
  - Andrew Smirsky
  - Newport Beach, CA
- **Volvo Cars Jeans Day**
  - Rockleigh, NJ
- **An Autumn Tea**
  - Debra Schultz
  - Temple, CA
- **Alpha Omega Chapter Fundraiser**
  - Pam Kerkendall
  - Temple, CA
- **Morgan’s Mitzvah**
  - Morgan Machado
  - Potomac, MD
- **Balds 4 Bucks**
  - Briggs Family Fundraiser
  - Kathleen Briggs
  - Comstock Park, MI
- **Dinkins Fundraiser**
  - Paula Dinkins
  - Pasadena, CA
- **MMA Fight Fundraiser**
  - Doug Elhendt
  - Arlington, VA
- **Hoeflinger Wedding**
  - Beth Hoeflinger
  - Newton, PA
- **Basque San Francisco 5K**
  - Julianne Basques
  - Groveland, CA
- **Multiple Colors for Multiple Myeloma**
  - Pam Larsen
  - Honolulu, HI
- **Our Friend Dan Fundraiser**
  - Dan Odegard
  - St. Paul, MN
- **Hirschworn 6th Annual**
  - Deborah Hadra
  - Castleton, VT
- **Our Friend Dan Fundraiser**
  - Dan Odegard
  - St. Paul, MN
- **Ida’s Day**
  - Deborah Hadra
  - Castleton, VT
- **Kindness for a Cure**
  - Deborah Hadra
  - Castleton, VT
- **Mary’s Garden Fundraiser**
  - Andrew Sninsky
  - Newport Beach, CA
- **Volvo Cars Jeans Day**
  - Paul Keddell
  - Newport, WA
- **Bon-Ton Fundraiser**
  - Melanie Nicols and Suzanne Fiacco
  - Potsdam, NY
- **Schaap Fundraiser**
  - Susan Schaap
  - Lakeview, CA
- **Marion Saloon Fundraiser**
  - Keri Marioni
  - Newark, DE
- **Jerry Walton’s Veterans Against Myeloma Campaign**
  - Jerry Walton
  - Virginia Beach, VA
# INTERNATIONAL MYELOMA FOUNDATION

## Statement of Financial Position

**September 30, 2011**

### Assets

**CURRENT ASSETS**

- Cash and cash equivalents: $1,473,513
- Contributions and other receivables: 1,148,507
- Prepaid expenses: 330,223

<table>
<thead>
<tr>
<th></th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Current Assets</strong></td>
<td><strong>$2,952,243</strong></td>
</tr>
</tbody>
</table>

**PROPERTY AND EQUIPMENT, at cost**

- Furniture, fixtures and equipment: 38,062
- Computer equipment: 127,671
- Computer software: 928,628

<table>
<thead>
<tr>
<th></th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Net Property And Equipment</strong></td>
<td><strong>$655,709</strong></td>
</tr>
</tbody>
</table>

**TOTAL ASSETS**

$3,607,952

### Liabilities and Net Assets

**CURRENT LIABILITIES**

- Accounts payable and accrued expenses: $622,605
- Deferred and unrestricted educational grants: 2,041,578
- Current obligations under capital leases: 2,668
- Line of credit: 25,000

<table>
<thead>
<tr>
<th></th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Current Liabilities</strong></td>
<td><strong>$2,691,851</strong></td>
</tr>
</tbody>
</table>

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

3,503

**NET ASSETS**

- Unrestricted: 912,598
- Temporarily restricted: -

<table>
<thead>
<tr>
<th></th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Net Assets</strong></td>
<td><strong>$912,598</strong></td>
</tr>
</tbody>
</table>

**TOTAL LIABILITIES AND NET ASSETS**

$3,607,952

---

*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, 2011

Change in Unrestricted Net Assets

REVENUES
Educational grants $6,829,672
General contributions 1,298,889
Donated goods and services 175,651
Seminar fees and support group income 79,446
Interest income 9,620
Total Revenues $8,393,278

Net Assets Released From Restrictions
Satisfaction of program restrictions $440,932
Total Unrestricted Revenue And Other Support $8,834,210

Expenses
Program expenses 7,829,756
General supporting expenses 483,057
Fundraising expenses 551,452
Total Expenses $8,864,265

DECREASE IN UNRESTRICTED NET ASSETS (30,055)

Changes in Temporarily Restricted Net Assets
Contributions 220,150
Fundraising event, net of direct benefit to donors of $365,390 220,782
Net assets released from restrictions (440,932)

Change in Temporarily Restricted Net Assets -

Decrease in Net Assets (30,055)

NET ASSETS, September 30, 2010 942,653

NET ASSETS, September 30, 2011 $912,598

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, 2011

Total Program Expenses $7,829,756
General Supporting Expenses 483,057
Fundraising Expenses 551,452

Total Expenses $8,864,265

Breakdown of Expenses by Program

<table>
<thead>
<tr>
<th>PROGRAM</th>
<th>TOTAL EXPENSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>$1,481,493</td>
</tr>
<tr>
<td>Patient &amp; Family Seminars</td>
<td>924,144</td>
</tr>
<tr>
<td>Education and Awareness</td>
<td>919,708</td>
</tr>
<tr>
<td>International</td>
<td>897,733</td>
</tr>
<tr>
<td>Nurse</td>
<td>856,111</td>
</tr>
<tr>
<td>Support Groups</td>
<td>566,664</td>
</tr>
<tr>
<td>Clinical Meetings</td>
<td>470,986</td>
</tr>
<tr>
<td>Advocacy</td>
<td>416,742</td>
</tr>
<tr>
<td>Myeloma Today</td>
<td>352,967</td>
</tr>
<tr>
<td>Hotline</td>
<td>305,137</td>
</tr>
<tr>
<td>Website</td>
<td>234,678</td>
</tr>
<tr>
<td>Public Relations</td>
<td>188,744</td>
</tr>
<tr>
<td>Information Mailings</td>
<td>172,783</td>
</tr>
<tr>
<td>Myeloma Manager</td>
<td>19,167</td>
</tr>
<tr>
<td>Bank On A Cure®</td>
<td>16,000</td>
</tr>
<tr>
<td>Myeloma Advisor</td>
<td>6,699</td>
</tr>
</tbody>
</table>

Total Program Expenses $7,829,756

For a copy of our complete audited financial statement, please contact the IMF office.
The IMF is here for you.

quality of life of myeloma patients while
The IMF is dedicated to improving the
their generosity allows the IMF to:

- Invest wisely in research programs like the International Myeloma Working Group, that lead to better treatments for patients today while also funding research grants that lead to critical breakthroughs for tomorrow;
- Advocate on behalf of the entire myeloma community to promote legislation to increase the availability and accessibility of all approved drugs;
- Develop and maintain its highly acclaimed website providing daily updates of the most relevant information available and make available 24 hours a day to all those interested in myeloma;
- Support the IMF’s network of over 150 support groups through leadership training, educational materials, and assistance in securing guest speakers and teleconferences with the Hotline;
- 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;
- 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.
The IMF’s 2011 fiscal year ran October 1, 2010 – September 30, 2011. This list includes gifts received during 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. More than 5,100 people contributed gifts between $1 and $499, totaling $538,225 of support for programs, services, and research. Unfortunately, space does not allow for everyone’s name to be listed but every donor is deeply valued.

* deceased