2012 ANNUAL REPORT



MYELOMA

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INTERNATIONAL MYELOMA FOUNDATION



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



2012 ANNUAL REPORT

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Dear Supporters of the International Myeloma Foundation,

This year the International Myeloma Foundation celebrated its 22nd anniversary – and to date has reached more than 240,000 members in 120 countries worldwide. We continually strive to improve the quality of life for myeloma patients and their families through research in effective diagnostics and treatments, advocacy in equality of patient access to treatment, education for patients and caregivers, and support to patients and families. This year, our commitment to the mission proved as fruitful as ever and has significantly strengthened patient care and treatment.

In June 2012, the IMF held its annual International Myeloma Working Group Summit in Amsterdam. This summit was yet another opportunity to bring together leading researchers in the field of myeloma from around the globe, to discuss innovations, develop recommendations for management of the disease and guide the direction of future research. You will find in this report further details on the incredible research-driven publications produced throughout 2012 by the IMWG; publications which inform patients and caregivers of therapeutic advances and treatment management.

Shortly after its annual meeting, in the summer of 2012, the IMWG launched the Master Class series. The Master Class is a two-week learning experience, where medical practitioners working in the field of myeloma share experiences in their work and listen to experts in myeloma research. The objective of the Master Class is to encourage knowledge of innovations in myeloma diagnostics, treatment, and management among health care providers. This educational program will be an expanding initiative with multiple programs globally to support providers in the testing and treatment of multiple myeloma.

Also this year, the IMF launched yet another multi-national consortium of leading myeloma experts; the Black Swan Research Initiative[™] – a unique project to develop the first definitive cure for myeloma. Through this initiative, the IMF will support development of sensitive diagnostic technologies to accurately measure minimal residual disease (MRD), new trials to enable us to select the most effective anti-MRD drug combinations, and new methods to perfectly time treatment in order to increase its effectiveness. The Black Swan Research Initiative takes its name from the discovery of black swans in 1697, before which it was assumed all swans were white. Similarly, we have created a paradigm shift by taking an entirely new approach to monitoring treatment efficacy to achieve a cure. An initial meeting of the Black Swan Research Initiative team was held in the summer of 2012.

We are in the midst of an important era in myeloma research and treatment; we are seeing more and more patient outcome improvements with novel drug agents and increased access to care and support. We are finding ourselves closer and closer to a cure, as our work progresses each year. Thanks to all of you who have helped the IMF. It is the support from all of you which makes possible our mission to support patients and families and to drive us closer to curing myeloma.

Yours sincerely,

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

Susie Novis, President International Myeloma Foundation

Dear Friends, Supporters, and Members,

For the first time since the creation of the International Myeloma Foundation, more than 20 years ago, I am able to say that a cure for multiple myeloma is within reach. Last year, IMF Chairman Dr. Brian Durie and I sketched out an idea on a cocktail napkin at dinner one evening for what has now been announced as the Black Swan Research Initiative[™].

I cannot begin to describe the emotional impact of being able to say those words aloud. I am so proud of the accomplishments of this organization, which continues to do so much to support the needs of the myeloma community. Reading through these pages, I think you will find that IMF's 2011-12 fiscal year was one of innovation and excellence. We improved many of our programs based on your feedback, and launched several new programs, most importantly, the Black Swan Research Initiative.

During the twelve-month period of October 1, 2011 to September 30, 2012, we expanded our global reach significantly. The IMF developed the Myeloma Master Class, an intensive course for young clinicians, designed by Dr. Durie and following the 10 Steps for Better Care[®]. The Master Class welcomed seven bright and enthusiastic doctors from seven of the most prestigious hospitals in China to learn from the experts, and who better to learn from than members of the IMF's International Myeloma Working Group!

One of my fondest memories from this past year is from the annual Support Group Leaders Summit. We had just put the final touches on the *Myeloma Post* (the IMF's first iPad® app) and had been telling the support group leaders about it. We were thrilled to surprise them all when we unveiled a table piled high with iPads. Each support group in attendance was given their very own iPad so they could have access the *Myeloma Post* and utilize its other features during their meetings back home! This program has proven to be very successful, and I still get emails from support group leaders letting me know how the iPads have helped improve their meetings and communication.

Last fiscal year was also amazing in terms of IMF Advocacy. We launched the *Postcards for Parity* program, and solidified our standing as the leader in promoting oral parity legislation through coalitions on the state and federal levels. The level of engagement from our members is at an all-time high, and continues to climb as patients and caregivers become active advocates by contacting their elected officials and taking a stand on the critical issues affecting their lives.

But by far the most exciting thing to happen last year was the development of the Black Swan Research Initiative. We announced it in 2013, but the first meeting of the BSRI™ team took place last June, and from that moment on, we knew that it was the path to a CURE!

With your support, 2011-2012 was the best year ever, touching all the cornerstone and innovative programs of the IMF, education, research, support, and advocacy! Thank you for helping us finally open the door to the cure – and we welcome you on the journey ahead.

Warmly,

Susie Novis

Susie Novis President



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Rafat Abonour, MD Indiana University Melvin and Bren Simon Cancer Center Indianapolis, IN

Rafat Abonour, MD, has been in the field of hematology for over 20 years. He first heard of the International Myeloma Foundation while still a fellow, when he attended an IMF-hosted seminar at the American Society of Hematology (ASH). He recalls hearing Dr. Brian Durie speak and thinking of Dr. Durie as a role model and that he hoped to become a compassionate and knowledgeable doctor as well. Dr. Abonour has since become a seasoned hematologist and distinguished researcher. He focuses his research on translational research conducting trials in both newly and relapsed/refractory patients. His goal is to find the most effective myeloma treatment combinations with the least toxicity; a combination that can lead to elimination of myeloma.

Dr. Abonour has been a part of the International Myeloma Working Group (IMWG) for six years and is a member of two committees: the Myeloma Management Group and Refractory Disease Group. As a result of his work, he has been a co-author on many IMWG papers and consensus statements. Dr. Abonour feels that his membership in the IMWG has given him the ability to exchange ideas with the most talented researchers in his field and he credits his membership in this elite group with enabling him to improve health outcomes among his patients.

"Myeloma is a complex and relatively rare disease, but I strongly believe a cure is possible. To obtain it, we will need, as myeloma experts and clinicians, to work together exploring the biology and treatment of the disease. We owe it to our patients to be united in order to realize a cure. The IMWG is a great vehicle to achieve that goal."

RESEARCH

Research is a top priority for the International Myeloma Foundation. In 2012 the IMF continued to bring young investigators into the field through our Junior Research Grants program as well as enhancing funding for more senior investigators. In addition, the Black Swan Research Initiative[™] (BSRI[™]), a key new program, was launched. This exciting new initiative for the first time charts the course to finding a cure for myeloma. Through the continued strong collaboration of the International Myeloma Working Group (IMWG), this year, the IMF developed an important educational tool to provide research updates important to caregivers and patients. The framework for this educational program is the **10 Steps to Better Care[®]**:

- 1. Know what you're dealing with: Get the correct diagnosis
- 2. Tests you really need
- 3. Initial treatment options
- 4. Supportive care and how to get it
- 5. Transplant: Do you need one?
- 6. Response assessment: Is treatment working?
- 7. Consolidation and/or maintenance
- 8. Keeping track of the myeloma: Monitoring without mystery
- 9. Relapse: Do you need a change in treatment?
- 10. New Trials: How to find them

Within this framework, all new information is added as it becomes available. For more information on this guide and important published research organized within, please visit: 10steps.myeloma.org.

Research Groups

Black Swan Research Initiative[™]

In Spring 2012, the IMF formed the Black Swan Research Initiative (BSRI) as a new research platform designed to find a cure for myeloma. It is based on:

- the latest scientific understanding of how myeloma develops in the body
- the most technologically advanced methods to measure and quantify disease development in the body
- the ability to measure and quantify the response to treatments

BSRI held their first in-person meeting in June 2012 in Amsterdam, The Netherlands just prior to the IMWG Summit *(see below)*.

International Myeloma Working Group

The IMF founded the International Myeloma Working Group (IMWG) to globally and collaboratively conduct basic, clinical, and translational research to improve health outcomes for those living with myeloma. The IMWG is



comprised of 161 leading myeloma researchers from 31 different countries who share a goal to improve diagnostic systems, treatment options, and maintenance of multiple myeloma. 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. Since its founding in 2001, the IMWG's achievements have changed the landscape of myeloma research and care. This collaboration has made a profound difference in bringing forward breakthroughs in treatment options and diagnostic systems to prolong lives.



In June 2012, the third annual IMF IMWG Summit was held in Amsterdam, The Netherlands. This Summit brought together 76 myeloma experts from 27 countries, representing 58 institutions. This year's summit focused discussions around key aspects of treating myeloma on a global

scale, given various degrees of access to drugs and costs, essential tests and supportive

care recommendations for bone disease, anemia, infections, pain, and peripheral neuropathy in treating the myeloma patient. Outcomes from the 2012 IMWG Summit included increased focus on which trials were most important to establish globally and how clinicians can include quality of life indicators as an end point in clinical trials. This



year's meeting, furthered collaboration efforts of the IMWG and helped to establish priorities in research and care of multiple myeloma.

IMWG Publications

Long-term IMWG research collaboration led to five publications during the October 2011–November 2012 reporting period:

Plasma cell leukemia: consensus statement on diagnostic requirements, response criteria and treatment recommendations by The International Myeloma Working Group.

Fernández de Larrea C, Kyle RA, Durie BGM, et al. *Leukemia*, November 2012; doi: 10.1038/leu.2012.336. Epub ahead of print.

Combining fluorescent in situ hybridization data with ISS staging improves Risk assessment in myeloma: an International Myeloma Working Group collaborative project.

Avet-Loiseau H, Durie BGM, Cavo M, et al. *Leukemia*. October 2012; doi: 10.1038/leu.2012.282. Epub ahead of print.

Management of treatment-emergent peripheral neuropathy in multiple myeloma.

Richardson PG, Delforge M, Beksac M, et al. Leukemia, April 2012; 26(4):595-608.

IMWG consensus on maintenance therapy in multiple myeloma. Ludwig H, Durie BGM, McCarthy P, et al. *Blood*. March 2012; 119 (13): 3003-3015.

Risk of progression and survival in multiple myeloma relapsing after therapy with IMiDs and bortezomib: a MultiCenter International Myeloma working group study.

Kumar SK, Lee JH, Lahuerta JJ, et al. *Leukemia*. January 2012; 26 (1):149-157.

Full text versions of IMWG publications and presentations may be accessed here: imwg.myeloma.org.



Benjamin Van Camp, MD, PhD Vrije Universiteit Brussel Brussels, Belgium

Dr. Benjamin Van Camp first began his work in myeloma in 1970. He is now the Head of the Division of Hematology at the University Hospital of the Vrije Universiteit Brussel, Belgium. For over 25 years his research was focused on the origin of myeloma cells along the B cell maturation pathway and the homing of myeloma cells to, and interaction with, the bone marrow environment.

Between 1986-90, Benjamin Van Camp organized and participated in workshops on monoclonal gammopathies, where he was introduced to Dr. Brian Durie. Drs. Durie and Van Camp collaborated in the years that followed on the biology of B cells/plasma cells and the clinical behavior of myeloma cells. Dr. Durie invited Dr. Van Camp to join the IMF's Scientific Advisory Board. "Ever since, I have enjoyed the remarkable achievements of the IMF, the worldwide support of patient advocacy and awareness, its contributions to research, and the successful series of International Myeloma Workshops."

Dr. Van Camp is now also member of the International Myeloma Working Group. He has participated in many annual meetings, published consensus statements and guidelines for the management of myeloma, and worked on translational research, particularly in the area of new drugs and early clinical trials based on agents blocking the growth and interaction of myeloma cells with the bone marrow environmental cells.

"It seems clear that the IMF has played a central role in not only educating patients, but also inspiring doctors to confront the disease. My work in myeloma has greatly profited from the existence of the IMF and the IMWG. Through our collaboration, we will continue to streamline the clinical 'path' in treatment and incorporate new findings. The IMWG may also play an important role in the development of central databanks of patient information and clinical trial updates. I am delighted to be able to contribute to the further development of the IMWG."



Global Clinical Trials Forum

Kenneth C. Anderson, MD Dana-Farber Cancer Institute Boston, MA, USA

Michel Attal, MD Service d'Hematologie, Hospital Purpan Toulouse, France

Hervé Avet-Loiseau, MD Institutes of Biologie Nantes, France

Bart Barlogie, MD Myeloma Institute for Research Therapy Little Rock, AR, USA

William Bensinger, MD Fred Hutchinson Cancer Research Center Seattle, WA, USA

Joan Bladé, MD Hospital Clinica Barcelona, Spain

Mario Boccadoro, MD University of Torino Torino. Italy

Ivan Borrello, MD Johns Hopkins University Baltimore, MD, USA

Wee Joo Chng, MD National University of Singapore Singapore

John Crowley, PhD Cancer Research and Biostatistics Seattle. WA, USA

Angela Dispenzieri, MD Mayo Clinic Rochester, MN, USA

Brian G.M. Durie, MD Cedars-Sinai Samuel Oschin Cancer Center Los Angeles, CA, USA

Morie A. Gertz, MD Mayo Clinic Rochester, MN, USA

Sergio Giralt, MD Memorial Sloan-Kettering Cancer Center New York, NY, USA

Roman Hajek, MD University Hospital Brno Brno, Czech Republic

Vania Hungria, MD Clinica São Germano São Paulo, Brazil

Sundar Jagannath, MD The Mount Sinai Cancer Instittue New York, NY, USA

Shaji Kumar, MD Mayo Clinic Rochester, MN, USA

Robert A. Kyle, MD Mayo Clinic Rochester, MN, USA Ola Landgren, MD, PhD National Cancer Institute, National Institutes of Health Bethesda, MD, USA

Jae-Hoon Lee, MD Gachon University Gil Hospital Incheon, Republic of Korea

Richard F. Little, MD National Cancer Institute Bethesda, MD USA

Sagar Lonial, MD Winship Cancer Institute Atlanta, GA, USA

Heinz Ludwig, MD Wilhelminenspital der Stadt Wien Vienna, Austria

Gareth Morgan, MD, PhD Royal Marsden Hospital Sutton, UK

Nikhil Munshi, MD Dana-Farber Cancer Institute Boston, MA, USA

Antonio Palumbo, MD University of Torino Torino, Italy

S. Vincent Rajkumar, MD Mayo Clinic Rochester, MN, USA

Donna Reece, MD Princess Margaret Hospital Toronto, ON, Canada

Jesús F. San-Miguel, MD University of Salamanca Salamanca, Spain

Kazayuki Shimizu, MD University of Keio for Advanced Biosciences Tsuruoka, Japan

Seema Singhal, MD Northwestern University Medical School Chicago, IL, USA

Pieter Sonneveld, MD, PhD Erasmus Medical Center Rotterdam, The Netherlands

Edward Stadtmauer, MD University of Pennsylvania Philadelphia, PA, USA

A. Keith Stewart, MD Mayo Clinic Scottsdale, AZ, USA

Howard Streicher, MD National Cancer Institute Rockville, MD, USA

Robert Vescio, MD Cedars-Sinai Samuel Oschin Cancer Center Los Angeles, CA, USA

Global Clinical Trials Forum

The IMF created the Global Clinical Trials Forum (GCTF) to enhance the collaboration and cooperation between national and international myeloma research groups and to improve clinical trial design and data accrual. The GCTF provides critical input for pharmaceutical trial design. The objective of this forum is to provide a collaborative work environment and reduce duplication of key stakeholders' efforts to provide input on research on immediate clinical trial priorities.

This forum is held annually and meetings often result in consensus statements and recommendations on immediate clinical trial priorities. In these meetings, the forum takes a closer look at big questions affecting patient care and treatment, such as how best to integrate novel therapies, the best sequence for drugs during the disease course, and autosomal transplant recommendations for patients particularly sensitive to alkylating agents. Taking a fresh look at all treatment options creates better long-term decisions for patients. This year's meeting focused on the integration of translational research projects, and target translation testing. Previously discussed trials were followed up, and updates on U.S., Asian and European trials, and recent drug approvals were given.

Asian Myeloma Network

IMF's Asian Myeloma Network (AMN), comprised of members from China, Hong Kong, Japan, Korea, Singapore, Taiwan, and Thailand, serves to advise the IMF on its Asian programs and to implement regional projects and research activities. At the 2011



American Hematology Society (ASH) meeting in San Diego, the AMN met to discuss the first AMN regional activity, the Asian Myeloma Database. Data on some 4,000



patients from the seven participating countries and territories has been collected and analyzed. The group also discussed priorities for further action, including launching pan-Asian clinical trials.

At the May 2012 AMN annual meeting in Shanghai, China, there was discussion around a comparison of

Asian with US and European myeloma datasets. This meeting covered an update on the Asian Myeloma Database, including an initial analysis of the data, where differences between Asian and western patients have been observed. This annual meeting also provided a forum to reach consensus on pursuit of future AMN multicountry clinical trials, including a randomized study of subcutaneous weekly Velcade versus standard intravenous use for newly diagnosed patients and a randomized phase II study of different doses of Carfilzomib combined with Cyclo-Dex in relapse/ refractory multiple myeloma with prior exposure to Velcade. Other topics of discussion included the growth in hematology training in Asia and updates on the International Myeloma Workshop Kyoto, Japan 2013.

AMN Publications

Clinical profile of multiple myeloma in Asia: An Asian Myeloma Network (AMN) study.

Hoon Lee J, Kim K, Seok Kim J, et al. Presented at the American Society of Clinical Oncology in Chicago, IL on June 3, 2012.

RESEARCH

Research Grants Program

For nearly 20 years, the IMF Research program has funded promising clinical investigators from around the world in an effort to improve outcomes for patients with multiple myeloma. IMF-funded research has made contributions to understanding the biology of myeloma and supporting the development of a cure. The grantees of the 2012 awards will continue to contribute significantly to the field of myeloma.

The IMF grants are funded by donations from private individuals. The presentation ceremony for the 2012 IMF Research Grant awards took place during the American Society of Hematology (ASH) meeting held in San Diego, California in December 2011.

Brian D. Novis Research Grants 2012

In memory of the its 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.



Brian D. Novis Senior Research Grants 2012

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

Nancy L Krett, PhD

Northwestern University – Chicago, IL, USA Identification of gene networks regulated by glucocorticoids in multiple myeloma for the development of targeted therapies for patients with glucocorticoid resistance.

Suzanne Lentzsch, PhD

Columbia College of Physicians and Surgeons – New York, NY, USA *Identification of C/EBP-β as a critical factor regulating growth of MM cells.*

David Smith, PhD

West Virginia University – Morgantown, WV, USA. Specific inhibitors of ubiquitin-dependent proteasomal degradation.

Brian D. Novis Junior Research Grants 2012

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

Antonia Cagnetta, MD

Dana-Farber Cancer Institute – Boston, MA The role of Nicotinamide adenine dinucleotide and Nicotinamide adenine dinucleotide-dependent enzymes in MM.

Ulf Krauss, MD

Texas A&M University – Temple, Texas The effect of glycogen-synthetase-kinase3β (GSK3β) inhibition and its role in MM-induced bone disease.

Charitha Madiraju, PhD

Sanford-Burnham Medical Research Institute – La Jolla, CA *Identification of new inhibitors of the ubiquitin-conjugating enzyme (UBC13).*

Eyal Zcharia, PhD

Bruce Rappaport Faculty of Medicine, Technion University – Haifa, Israel *Heparinase and its role in treatment of MM.*



Charitha Madiraju, MD Sandford-Burnham Medical Research Institute, La Jolla, CA

Charitha Madiraju began her career in medicine in the field of pharmacology. She transitioned to working in the field of myeloma in 2009 through her study on the ubiquitin regulatory pathway as a promising therapeutic target for myeloma treatment. Dr. Madiraju heard about the International Myeloma Foundation through an ASH meeting in 2009 and was awarded a Brian Novis Junior Grant in 2012.

Her research under this award, which will take place under the mentorship of Dr. John C. Reed at Sanford-Burnham Medical Research Institute, La Jolla, CA, is aimed at finding novel therapeutics for treatment of multiple myeloma. She and co-investigators are working on identification of chemical inhibitors of the ubiquitin conjugating enzyme complex UBC13-UEV1A. Financial support from the IMF has been helpful in the discovery, characterization, and testing of inhibitors in preclinical models of myeloma.

"We hope UBC13-UEV1A inhibitors will have a synergistic action with FDA-approved drugs such as Velcade, thus providing new weapons for treatment. I am ever grateful to the IMF - for Susie Novis, Dr. Robert Kyle, Dr. Brian Durie, and the IMF Scientific Advisory Board - for considering our junior grant proposal and for creating such a positive working relationship, which has been invaluably supportive."

Dr. Madiraju says she appreciates that, through the IMF, she has been able to connect more with patients and caregivers and that this opportunity has given her work in myeloma treatment research further meaning and motivation.

IMF Japan Research Grants

The annual multiple myeloma research awards were instituted in 2002 by IMF-Japan, in memory of its founder, Aki Horinouchi. These awards have funded 14 important research projects. The following awards were presented at ASH 2011 by IMF-Japan.

The Aki Horinouchi Award

Hiroyuki Tagawa, PhD Akita University Graduate School of Medicine Akita City, Akita, Japan Identification of Genes for Molecular Targeting Therapy Against Side Population Cells of Multiple Myeloma.

The Special Award in Sugi's Memory

Ai Kotani, PhD

Medical Science Division Tokai University Institute of Innovative Science and Technology Hiratsuka City, Kanagawa, Japan **The Research for Prevention of Symptomatic Multiple Myeloma.**

The Award of IMF-Japan

Miyuki Takasu, PhD Graduate School of Biomedical Sciences, Hiroshima University Higashi-Hiroshima City, Hiroshima, Japan Fat Fraction Analysis of Multiple Myeloma Using 3T–MRI.

Research Events of 2012

There are several annual conferences that bring together myeloma researchers from around the world. The IMF participates in each, to present, to increase dialogue around this disease, and to stay abreast of important findings on multiple myeloma research from around the world. ASH 2011 and the American Society of Clinical Oncology (ASCO) brought to light some critical new successes and innovations in myeloma diagnostics, treatment, and maintenance.

IMF at ASH

The 53rd American Society of Hematology (ASH) conference took place December 10–13, 2011, in San Diego, California. ASH 2011 published 712 abstracts on multiple myeloma, the largest publication of myeloma-related abstracts ever presented in this meeting's history.



These abstracts offer evidence of a year of significant steps forward in understanding, diagnosing, treating, and monitoring myeloma. The IMF was in attendance to report on this impressive collection of research activities in the field of MM. IMF staff interviewed key ASH 2011 myeloma presenters to discuss the implications of their findings; these interviews and all related abstracts were posted to the IMF website to inform patients, families, and caregivers.

IMF at ASCO

The American Society of Clinical Oncology (ASCO) 2012

conference brought together over 25,000 experts and professionals in the field of oncology. At this event, nearly 66 myeloma-related abstracts about characteristics, risks, diagnostics, and treatment of multiple myeloma were published. The conference brought to light important work on efficacy and acceptability of new combination therapies, use of novel agents, and oral treatment options. This year's presentations and discussions particularly focused on therapy options for those with refractory and/or relapsed multiple myeloma and encouraging data on antibodies and proteasome inhibitors.

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.





TENTH ANNUAL INTERNATIONAL MYELOMA FOUNDATION ROBERT A. KYLE LIFETIME ACHIEVEMENT AWARD



Prof. Jesús F. San-Miguel

Robert A. Kyle Lifetime Achievement Award

The Robert A. Kyle Lifetime Achievement Award, named for its first recipient, 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.

In June 2012, in Amsterdam, The Netherlands, Prof. Jesús San-Miguel, head of the Hematology Department at the University Hospital of Salamanca, and Director of the Biomedical Research Institute of Salamanca, Spain was awarded the Robert A. Kyle Lifetime Achievement Award. Prof. San-Miguel is a veteran in the field of myeloma; he has published over 500 original papers in international, peer-reviewed journals and is the winner of numerous prizes, including the Waldenström Award (2007) in both oncology and translational research.

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Giampaolo Merlini, MD University of Pavia Biotechnology Research Laboratories

Pavia, Italy Angelina Rodriguez Morales, MD

Hemato-Oncology Clinica Caracas, Venezuela

Gareth Morgan, MD, PhD Roval Marsden Hospital Sutton, UK

Nikhil Munshi, MD Dana-Farber Cancer Institute Boston, MA, USA

Amara Nouel, MD Hospital Rutz y Paez Bolivar, Venezuela

Antonio Palumbo, MD University of Torino Torino, Italy

Linda Pilarski, MD University of Alberta Edmonton, AB, Canada

Raymond Powles, MD Parkside Oncology Clinic London, UK

S. Vincent Rajkumar, MD Mayo Clinic Rochester, MN, USA

Donna E. Reece, MD Princess Margaret Hospital Toronto, Canada

Paul G. Richardson, MD Dana-Farber Cancer Institute Boston, MA, USA

David Roodman, MD Indiana University School of Medicine Indianapolis, IN, ÚSA

Jesús F. San-Miguel, MD University of Salamanca Salamanca, Spain

Orhan Sezer, MD University of Hamburg Hamburg, Germany

Kazayuki Shimizu, MD University of Keio for Advanced Biosciences Tsuruoka, Japan

Chaim Shustik, MD McGill University Montreal OC Canada

David Siegel, MD Hackensack University Medical Center Hackensack, NJ, USA

Seema Singhal, MD Northwestern University Medical Center Chicago, IL, USA

Alan Solomon, MD University of Tennessee Medical Center Knoxville, TN, USA

Pieter Sonneveld, MD, PhD Erasmus Medical Center Rotterdam, The Netherlands

Andrew Spencer, MD The Alfred Hospital Melbourne, Australia

A. Keith Stewart, MD Mavo Clinic Scottsdale, AZ, USA

Guido Tricot, MD University of Utah Huntsman Cancer Institute Salt Lake City, UT, USA

Benjamin Van Camp, MD, PhD Vrije Universiteit Brussel Brussels, Belgium

Brian G. Van Ness, MD, PhD University of Minnesota Minneapolis, MN, USA

David H. Vesole, MD John Theurer Cancer Center at Hackensack University Medical Center Hackensack, NJ, USA

Jan Westin, MD Sahlgrenska University Hospital Göteborg, Sweden

Emeriti Raymond Alexanian, MD USĂ

Y.C. Chen, MD Republic of China

lan Franklin, MD Scotland, UK

Tadamitsu Kishimoto, MD Japan

Ian MacLennan, MD England, UK

James S. Malpas, MD England, UK

Martin M. Oken, MD USA

RESEARCH



Prudy and David Brown Cupertino, CA

Dave Brown was diagnosed with multiple myeloma in June of 1978 and was first treated with an excision and radiation therapy. After that, Dave was myeloma-free for nearly 16 years. In 1994, his myeloma returned and over the years he has undergone more excisions, radiation, a stem cell harvest, and a variety of drug therapies.

He initially heard about the International Myeloma Foundation through an oncologist he worked with in Tucson, AZ and then learned about the IMF's Patient & Family Seminars through the IMF website. He decided to attend his first in 2003. After that first seminar, Dave felt scared and overwhelmed, but wanted to know more about myeloma and treatment options. He now attends a seminar every time they occur in the San Francisco and Los Angeles areas. He has kept his "need to know" attitude and enjoys meeting medical professionals in the field of myeloma, as well as sharing experiences with other patients. He knows that his presence, as a 30+ year myeloma survivor, brings hope to other patients.

"There is a spectrum from 'I'll just let the doctor handle it' to learning as much as you can. For 16 years, 'let them handle it' worked. As myeloma came to have a deeper effect on my health, I bit the bullet and have tried to learn something about myeloma and its treatments. This wasn't easy for me; but sympathetic health librarians and a nearby Häagen-Dazs got me through the early rough spots. Now I rely on IMF Patient & Family Seminars and IMF publications. I like being able to understand what the doctors are saying, I like being able to ask about something new when the old isn't working, and I like being able to recognize trouble and bring it to my doctor's attention."

Dave now lives a healthy and active life. He walks two miles every day, plays tennis and bridge, and sings in a chorus. He takes no pain medications. He and his wife, Prudy, travel extensively. Dave stays informed through the IMF and shares his stories and education with other multiple myeloma patients.

EDUCATION

Although it is the second most common blood cancer, multiple myeloma is still a relatively unknown disease. For many patients and their caregivers, it is at diagnosis when they first hear the word "myeloma." The International Myeloma Foundation recognizes the need for comprehensive education programs for both the patient and the physician – to ensure that patients are diagnosed correctly and treated effectively.

IMF co-founder Brian Novis often said, "Knowledge is power." His diagnosis and subsequent journey to fully understand the little-known disease ravaging his body led to the founding of the IMF in 1990. Since then, the IMF has remained fully committed to empowering patients through education, while ensuring that their doctors and nurses receive the most current information to diagnose and treat them.

IMF Patient & Family Seminars



Patient education programs provide patients and their caregivers their most powerful weapon in the fight against myeloma: knowledge. In 1993, the IMF became the first

organization to offer Patient & Family Seminars, granting patients and their caregivers access to top doctors working in the field of myeloma.

IMF Patient and Family Seminars have reached tens of thousands of people around the world. In 2012, over 1,100 people attended US-based seminars held in Boca Raton, FL; Seattle, WA; Boston, MA; and Los Angeles, CA. Outside of the US, nearly 2,000 people



attended seminars held in Lednice and Lazne Belohard, Czech Republic; Nyborg, Denmark; Heidelberg, Wurzburg, and Munich, Germany; Paris, France; Vienna, Austria; Trondheim, Norway; Turin and Catania Italy; and Liptovsky Jan, Slovakia

Regional Community Workshops



To address the need for similar events in smaller communities, the IMF now hosts frequent Regional Community Workshops and Myeloma Center Workshops as well. These half-day workshops offer families a condensed version of the full seminar at no charge.

From October 2011 to September 2012, almost 900 people attended US workshops held in Chapel Hill, NC; Atlanta, GA; Houston, TX; Indianapolis, IN; Little Rock, AR;

Overland Park, KS; San Antonio, TX; and Milwaukee, WI. Additionally, nearly 900 people attended international workshops held in Berlin, Ulm, Leipzig, Munster, and Koblenz, Germany; Florence, Italy; and Brno, Czech Republic.



Publications

The IMF produces a growing number of publications, which are regularly updated and offered free of charge both



in print as well as digitally on the IMF website. The IMF library of publications provides up-to-date information on all issues affecting the myeloma community, including innovations in treatment, information on clinical trials, updates on policy issues, and more. Popular titles include the *Patient Handbook*, the *Understanding* series, the IMF's quarterly newsletter *Myeloma Today*, and weekly e-newsletter *Myeloma Minute*. Many



of the IMF's publications are translated into 16 languages, including Spanish, German, Italian, French, and Turkish.

The InfoPack is made up

of a selection of the IMF's publications and is designed to provide newly diagnosed patients and their families with a complete understanding of the disease and care. During the 2012 Fiscal Year, over 2,350 InfoPacks were disseminated to patients, healthcare providers, and support groups around the world.

From October 2011 through September 2012, the IMF published sixteen new publications. An additional seven titles were updated during this period. In this period, IMF periodicals *Myeloma Today* and *Myeloma Minute* both saw an increase in subscriber rates. The quarterly *Myeloma Today* had a print subscriber base of over 15,000, as well as a web-view and pass-along rate independently estimated at 75,000. The weekly *Myeloma Minute* subscriber base reached 28,500 readers.

Teleconferences

IMF teleconferences are a way for members of the myeloma patient and caregiver community to receive top-level, up-todate information on topics relevant to their issues. In addition to the *Living Well with Myeloma* series, the IMF held six teleconferences for patients and caregivers during the 2011-12 fiscal year. One of the most popular teleconferences was Dr. Brian Durie's 10 Steps to Better Nutrition, which



covered some of the latest research concerning chemicals in some food and beverages that have been linked to myeloma and other diseases. Recordings of all the IMF

teleconferences are made available on the IMF website.



IMF 2012 List of Publications

ASCO 2012 Highlights* ASH 2011 Highlights* Citings – pre-ASH 2011 Freelite®/Hevylite® Highlights* Citings – pre-ASH 2011 Novel Therapies Highlights* Clinical Trial Fact Sheet: Zolinza® (vorinostat)* Clinical Trial Fact Sheet: Eloquent 1* Clinical Trial Fact Sheet: Eloquent 2* **Concise Review** Early Screening for MGUS Flowchart* Hotline Bookmark Making Miracles* Monitoring Patients with M-Proteins Flowchart* Myeloma Matrix: Clinical Trials** Myeloma Minute* (weekly e-newsletter) Myeloma Today* (quarterly newsletter) Myeloma Today Gala Supplement* (annual supplement) Patient Handbook** Tip Card – Freelite® Tip Card – International Staging System Tip Card – Kyprolis[®] (carfilzomib)* Tip Card – Mozobil[®] (plerixafor) Tip Card – Pomalyst® (pomalidomide) Tip Card – SQ Velcade[®] (bortezomib)* Tip Card - What is the IMF?** **Understanding Anemia & Fatigue Understanding Balloon Kyphoplasty** Understanding Bisphosphonate Therapy** **Understanding Clinical Trials*** Understanding Dexamethasone Understanding High-Dose Therapy with Stem Cell Rescue** Understanding Kyprolis® (carfilzomib)* Understanding Mozobil® (plerixafor)* Understanding Pomalyst® (pomalidomide) Understanding Protein Electrophoresis* Understanding Revlimid® (lenalidomide)** Understanding Serum Free Light Chain Assays Understanding Thalidomide Understanding Velcade® (bortezomib)** Understanding Your Test Results *New (between 10/1/11 and 9/30/12

EDUCATION

**Updated (between 10/1/11 and 9/30/12)

IMWG Conference Series



Another new medical education program created by the IMF during the 2011-12 fiscal year was the International Myeloma Working Group Conference Series. This debate between four prominent members of the IMWG – Dr. Brian Durie, Dr. Paul Richardson, Dr. Jesús San-Miguel, and Dr. Antonio Palumbo – was held in Amsterdam and live-streamed via the internet. The topic of debate was "Making Sense of Treatment," and 7,200 people around the world tuned in to watch the live and the recorded debate. The debate can be viewed on the IMF website at replay.myeloma.org.

Medical Professional Education

Another staple of the IMF's education platform are the programs offered in continuing education for physicians



and nurses who treat myeloma patients. In 1999, IMF began sponsoring annual CMEaccredited medical education programs in conjunction with the American Society of Hematology (ASH) conferences. In 2006, the IMF formed the Nurse Leadership Board (NLB), consisting of 20 specialty oncology nurses from major medical centers across the United States.

Myeloma Master Class

The most recent medical education program developed by the IMF is the Myeloma Master Class, an intensive educational course designed for clinicians who specialize in myeloma. The inaugural Master Class, held in 2012, welcomed seven young doctors from seven of





the top medical centers in China. The curriculum, designed by IMF Chairman Dr. Brian Durie and taught by fellow members

of the International Myeloma Working Group, was structured around the format of the 10 Steps to Better Care[®], and culminated in a final exam and diplomas for the participants.



Nurse Leadership Board

Nurse Leadership Board (NLB) members work each year to present relevant information to patients and providers by presenting at key conferences, participating in Patient & Family Seminars, and at Regional Community and Myeloma Center Workshops. They also conduct webinars



and other educational teleconferences, engage in outreach through blogs and make contributions to IMF website content, and publish materials and guidelines on myeloma management. This board of experienced multiple myeloma nurses has accomplished much in this field in a relatively short time since the first NLB gathering seven years ago.

In 2012, the NLB worked harder than ever to engage in various social media/web outreach activities, held teleconferences for patients, participated in seminars, workshops and Support Groups – all to support access to information and patient needs. Additionally, the NLB hosted a Satellite Symposium entitled *Multiple Myeloma: The Patient Journey Through Survivorship*, attended by over 600 participants at the 2012 Oncology Nursing Society Meeting.

The IMF NLB held two meetings during the 2011-12 fiscal year. During their meeting on September 24-25, 2011 in Las Vegas, NV, the NLB held four webcasts, reviewed presentations, discussed the Consensus Statements on Survivorship Care Guidelines for Patients Living With Multiple Myeloma, and participated in discussions on future clinical research, manuscript development, drafting guidelines, and development of the survivorship care plan online tool.

During their meeting on June 30 and July 1, 2012 in New York City, NY, the NLB reviewed the execution of completed projects, works-in-progress status, and future activities planning. Particular topics of discussion included nurse-led clinical research in myeloma, transplant guidelines, updates on the Survivorship Care Plan Online Resource Tool, and participation in teleconferences, seminars, and workshops in the coming year.



IMF Nurse Leadership Board Members

Page Bertolotti, RN, BSN, OCN Cedars-Sinai Outpatient Cancer Center Samuel Oschin Comprehensive Cancer Institute Los Angeles, CA

Elizabeth Bilotti, RN, MSN, APRN, BC, OCN The John Theurer Cancer Center at HUMC Multiple Myeloma Division Hackensack, NJ

Kathleen Colson, RN, BSN, BS Dana-Farber Cancer Institute Boston, MA

Deborah Doss, RN, OCN Dana-Farber Cancer Institute Boston, MA

Beth Faiman, MSN, APRN-BC, AOCN Cleveland Clinic Taussig Cancer Institute Multiple Myeloma Program Cleveland, OH

Charise Gleason, MSN, NP-BC, AOCNP Emory University Winship Cancer Institute Atlanta, GA

Kathy Lilleby, RN Fred Hutchinson Cancer Research Center Seattle, WA Patricia A. Mangan, APRN, BC Abramson Cancer Center University of Pennsylvania Philadelphia, PA

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

Kena C. Miller, RN, MSN, FNP Mayo Clinic Jacksonville Jacksonville, Florida

Tiffany Richards, MS, ANP, AOCNP MD Anderson Cancer Center Houston, TX

Sandra Rome, RN, MN, AOCN Cedars-Sinai Medical Center Los Angeles, CA

Jacy Spong, RN, BSN, OCN Mayo Clinic Arizona

Scottsdale, AZ Joseph D. Tariman, PhD, APRN, BC Northwestern University Myeloma Program Chicago, IL



Sandra Rome, RN, MN, AOCN Cedars-Sinai Medical Center Los Angeles, CA

Sandra Rome became an oncology nurse in 1984 and a Clinical Nurse Specialist in Oncology in 1988. In the first years of her career in this field, Sandra did not come in contact with many myeloma patients, but with increased availability and access to effective therapies, and subsequently, increased survivorship, Sandra has been able to work with a growing population of patients living with myeloma.

Sandra first heard of the International Myeloma Foundation ten years ago through a number of myeloma patients who had remarked on the level of patient education and support services offered by the IMF. Sandra requested to be a member of the IMF's Nurse Leadership Board (NLB) at its inception in September 2007, so that she could have the opportunity to collaborate with others in the field and to further support patients, caregivers, and families affected by myeloma.

"The NLB has been a phenomenal experience. It is so gratifying and inspiring to work with these exceptional nurses from all over the country. Sharing our diverse professional experiences has strengthened our ability to care for those living with or affected by myeloma and it has enriched my daily practice, as I interact with patients and nursing staff. I am more in tune with current evidence-based practice because of the NLB. I feel proud to be a part of this."

RECOGNITION OF NLB MEMBERS IN 2012

- Beth Faiman received the 2012 Excellence in Medical Oncology Award from the ONS.
- Sandra Rome received the 2012 Distinguished Alumni Award from the UCLA School of Nursing.
- Kathy Colson was a contributing author published in the Oncology Nurse May/June 2012 issue.
- Beth Faiman published 11 manuscripts in 2011–2012.
- Sandra Rome published 5 articles in peer journals.
- Sandy Kurtin published 14 peer-reviewed journal articles and 9 oncology chapters.

NLB Associate Members

Elizabeth Finley-Oliver, RN

H. Lee Moffitt Cancer Center

and Research Institute

Bonnie Jenkins, RN

Arizona Cancer Center

Ann McNeill, RN, MSN, APN

Multiple Myeloma Division

Dana-Farber Cancer Institute

Little Rock, AR

Tucson, AZ

Hackensack, NJ

Boston, MA

Little Rock, AR

Tampa, FL

B. Nadine Baxter-Hale, MNSc, APN-BC, AOCNP

University of Arkansas for Medical Sciences

Myeloma Institute of Research and Therapy

University of Arkansas Medical School

Sandra Kurtin, RN, MS, AOCN, ANP-C

The John Theurer Cancer Center at HUMC

Kimberly Noonan, RN, ANP, AOCN



Stephanie and John Stambolitis Charlotte, NC

When Stephanie Stambolitis' husband, John, was diagnosed with multiple myeloma in March 2001, she was in complete disbelief. This moment of shock was compounded by them never having heard of the cancer prior to that moment. Their daughter found the International Myeloma Foundation in her first days of research about the disease and informed them of its educational and support resources. The pair requested information from the IMF and received an InfoPack. Ever since, they regularly reach out to the IMF for support through various mechanisms, in particular through the Hotline.

"I do not know what I would do without the IMF Hotline. Debbie, Missy, Judy and Paul are amazing and I feel like I can call them with anything and they are always there to listen. With the care and support they offer, I feel like they are a part of my family...I feel like I have known them all my life."

Stephanie's husband has been stable on treatment these last twelve years. He and Stephanie stay informed and are supported by the IMF. The Hotline continues and will continue to support them through care, treatment, and life.

SUPPORT

The International Myeloma Foundation remains dedicated to ensuring the support of those living with multiple myeloma. The IMF is a leader in myeloma patient support; support 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 to patients and caregivers through its website, listserv, a toll-free Hotline, its social media outreach, and through its wide-ranging network of community support groups.

myeloma.org

The IMF offers patients and caregivers multi-lingual access to all current myeloma research (IMF-funded research and otherwise), the latest community developments, and linkage to support services and advocacy forums. Myeloma.org receives nearly 70 million hits per year. From October 2011 through September 2012, 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. The IMF website is a leading mechanism in myeloma-related content and the most common source of answers to the many questions of those newly diagnosed.



This year, the IMF, with guidance from Dr. Brian G.M. Durie, adopted a

new organizing principle for its website. The *10 Steps to Better Care*® is a unique tool for diagnostic and treatment information and is designed to help both patients and physicians better navigate the course of myeloma, from diagnosis through long-term survival.

Social Media



The IMF has worked in recent years, and especially in 2012, to expand its support to those living with or affected by multiple myeloma through social media. The IMF now has a growing presence of support on both Facebook and Twitter, with over 3,000 and 1,000 followers, respectively. The IMF is using media tools to increase visibility and awareness of myeloma and to support those living with or affected by myeloma.

Toll-Free Hotline

The IMF's toll-free Hotline provides life-saving myeloma treatment and management support from highly trained specialists. This year, as new treatment options are gaining attention and use in multiple myeloma, answering questions about myeloma, its treatment, drug side effects, other health concerns, and where to find local support, is more important than ever.



The toll-free Hotline has been an incredible resource to patients, families, and caregivers in 2012. From October 2011 through September 2012, hotline responders supported 4,300 callers and answered 3,600 emails.

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 over 150 support groups worldwide. The IMF's team of Support Group Directors made in-person visits to 87 support groups in the US, 48 of them more than once for a total of 135 visits during the fiscal year. From October 2011 through September 2012, a total of seven new support groups were formed in Polk County, Sebring, and Boca Raton, FL; Easton, MD; Toledo, OH; Lubbock, TX; and San Fernando Valley, CA.

The annual IMF's Support Group Leaders' Summit took place in July 2012 in Dallas, TX. A total of 75 support group leaders, representing 50 groups, attended the summit and for 19 leaders, this was their first Summit. Participants were updated on the latest



innovations in diagnostics, treatment and maintenance research, news in treatmentaccess advocacy (Oral Parity Act legislation), the latest IMF tools and publications, and were given advice on leading effective support groups. At this year's summit, Dr. Brian Durie held a Q&A session during which he attended to each participant's questions on current myeloma research and treatment.



Another special moment at this year's event included dissemination of iPads to each support group leader. The program, funded by Celgene, Millennium, Onyx, and Sanofi, provided iPads for the leaders that were loaded with educational tools, resources, and the new IMF myeloma application, *Myeloma Post*[®]. These iPads will support the

hard work of the IMF support group leaders into the next year.

Myeloma Post®

In 2012, the IMF released its first ever iPad application, Myeloma Post. This app is a comprehensive multiple myeloma resource application available for use by patients, caregivers, and healthcare providers. It was developed by the IMF to serve as a mobile gateway to



educational, research, support, and advocacy programs and information found on myeloma.org.

"The Myeloma Post gives me fast and easy access to IMF's website so I can stay informed of all medical news and other developments. It's a great addition to the array of educational tools made available by the IMF," says myeloma patient Michael Tuohy.

Myeloma Manager[™]

Designed and developed by the IMF specifically to help patients and caregivers, the Myeloma Manager is a tool to capture laboratory results and display and print tables and charts to show how those results change over time. It is an incredible tool to support patients and caregivers in the management of myeloma. In 2012, the IMF launched new Myeloma Manager software v4.0.2, making it as useful and userfriendly as ever.



Gail and Ray Fargason Lubbock, TX

Ray Fargason was diagnosed with multiple myeloma several years ago. He and his wife, Gail, sought information on the disease and treatment options immediately and found the International Myeloma Foundation.

Gail and Ray quickly realized a need for a multiple myeloma support group in their area of Lubbock, TX. There are quite a few patients treated at the major cancer centers in this area, and yet, there had never been a support network for these patients. Gail and Ray contacted the IMF about starting a support group and were invited to join the Support Group Leaders' Summit in Dallas, TX in July 2012. After attending, they began work preparing for their first meeting which was held a few months later. They were overwhelmed by the response; they had a large number of attendees and average 20–25 patients and caregivers at each monthly meeting.

Meetings include planned speakers who inform and update attendees on topics related to treatment and management of multiple myeloma. Gail and Ray usually invite nurses, clinicians, or counselors to give these providers an opportunity to further bond with their patients and caregivers outside treatment room settings and to provide helpful information to attendees. At the end of each meeting they discuss their own personal experiences. "We try to provide our members an opportunity to share their personal stories and provide emotional support for each other."

Gail and Ray have found the IMF to be very helpful; they underscore the usefulness of the IMF website and iPad application at the meeting each month and encourage members to make use of the vast amount of information the IMF has to offer. Gail and Ray carefully run this support group with an implicit level of thoughtfulness and they actively engage with patients, caregivers, and all affected by multiple myeloma in their community.

"We remember a newly diagnosed patient who came with his wife and son and were delighted to meet other patients who had survived several years, some of whom were in remission. For the first time since his diagnosis he felt hope for the future. Those times are priceless and make this effort worthwhile. At our meetings we laugh a lot, we cry some, we learn new insights, and we make wonderful new friends."



Kelley Campbell Clayton, DE

For 22 years Kelley Campbell owned a child-care business, which she referred to as her "calling in life." When she was diagnosed with multiple myeloma, her spine was broken in several places but she continued to work her usual long hours, with all of the lifting and activity, until the day before her stem cell transplant. Multiple myeloma has affected her life in many ways. She had to leave her business, she has trouble picking up her grandchildren, and her hobby, dancing, has become harder. Kelley got in touch with the International Myeloma Foundation almost immediately after her diagnosis (she found the IMF through an internet search).

Kelley's insurance wouldn't cover her treatment prescription. After three scary weeks, a biopharmaceutical company agreed to cover the cost of her treatment. Soon after, Kelley read an IMF tweet asking if anyone had coverage trouble with the treatment she was on at the time, and if those who did could speak to their local and state representatives. She realized she could help, and the next thing she knew, she was calling representatives and senators and asking friends to send emails. She found herself speaking in front of a committee of legislators and realized that even one person can make a meaningful change. Kelley got her confidence back, something that seemed to have left her upon diagnosis.

"Working on this campaign has made me feel alive and strong again. I hope patients' access to care will become so easy, that they never have to face mortality just because they can't afford treatment. I hope that the stress of trying to figure out a way to afford and obtain treatment will be a thing of the past. Fighting cancer is hard enough, but that fight should be our focus, not the fight to afford medication we deserve."

ADVOCACY

The International Myeloma Foundation advocates on behalf of those affected by multiple myeloma, for the need to increase accessibility of high-guality diagnostics and treatments, for funding for myeloma-related research, and for an end to insurance and treatment disparities. 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. In 2012, the IMF made headway on legislation to increase myeloma patients' accessibility to oral chemotherapy (through both federal- and state-level legislation), increased Congressional awareness of myeloma, and furthered the national dialogue of myeloma.

Public Policy

IMF advocacy efforts have focused on calling on the US Congress to strengthen preventative care, improve patient access to treatment, and maintain key provisions of health reform essential to the care for all cancer patients. Legislation for the coverage of cancer treatment costs has been introduced at the federal level and in various states. The IMF has been ever-present and supportive in these discussions to ensure fair access to treatment among all myeloma patients.

Advocacy Efforts at the Federal Level

On October 25, 2011, in Washington, DC, the IMF Advocacy team held a Congressional briefing, Why Investment in Biomedical Research is Necessary: a Case Study on Myeloma. This event was held to raise awareness of MM and diagnostic and treatment research among 50 leaders on Capitol Hill. It opened with remarks from Congresswoman Jackie Speier (D-CA) and included a presentation by Dr. Ola Landgren, Chief of the Multiple Myeloma Section at the National Cancer Institute (NCI), and a panel discussion, led by Dr. Barbara Klencke of Onyx Pharmaceuticals and Michael Katz, a patient advocate,



21-year myeloma survivor, and member of the IMF Board of Directors.



The Patients Equal Access Coalition (PEAC), founded by the IMF in 2010, is a partnership of organizations representing patients, health care professionals, care ACCESS COALITION centers, and industry dedicated to the rights and care of cancer patients. In 2012, this collaboration, which

aims to ensure equal access to approved anticancer regimens nationally, further increased support around the Cancer Drug Coverage Parity Act (HR2746). Many patients have unmanageable out-of-pocket expenses for prescribed oral medication; HR2746 will ensure patients have equal and appropriate access to all cancer treatments (both oral or intravenous), by equalizing the patient's out-of-pocket cost. On June 26th, 2012, PEAC held its first ever lobby day in DC. The IMF and volunteers from seven other PEAC member organizations held nearly 30 meetings with representatives and senators to encourage support of our efforts in improving insurance coverage for oral chemotherapy. More than 100 activists from across the country participated, contacting nearly 100 different legislators by phone or email.

This legislation is a high priority for the IMF. Through PEAC, Congressional co-sponsors of the legislation grew from 5 to 54 in 2012.

The IMF created a PEAC Steering Committee leading to increased participation and buy-in of several members and a more structured, formal coalition. Several members were added to the Coalition, which now numbers 27 groups representing patients, providers, and industry.

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 by sharing stories of how disparities in treatment access affected their lives. The IMF's advocacy in this area is more determined than ever, and two important successes were noted in 2012.

Paula Van Riper, leader of the central New Jersey MM Support Group, gave oral testimony before New Jersey's Assembly Health Committee in June 2011, in support of the state's proposed oral chemotherapy access bill. Elizabeth Bilotti, RN, MSN, APRN, BC, of the Cancer Center of Hackensack and IMF Nurse Leadership Board Member, testified in support of the same state legislation before the Senate Budget and Appropriations Committee in October 2011. New Jersey's Oral Chemotherapy Access Bill was signed into law by Governor Chris Christie in January 2012, making New Jersey the 15th state to pass the legislation into law.

On January 25, 2012, Delaware Congressional Representative Deborah Hudson and her colleagues – Representatives Ruth Briggs-King and Bryon Short, and Senators Patricia Blevins and Liane Sorenson introduced the Delaware Cancer Treatment Access Act. At a press conference held to announce this legislation,



Kelly Campbell, Rep. Deborah Hudson, Aimee Martin, Governor Jack Markell, and Josephine Diagonale at the signing of the Delaware Cancer Treatment Access Act

the IMF's Meghan Buzby and Delaware multiple myeloma support group leader Josephine Diagonale informed participants, including legislators and supporters, of the importance of passing this bill. IMF advocates flooded the Delaware House of Representatives and Senate offices with letters of support via the IMF Action Center. On May 1, 2012, the Delaware Cancer Treatment Access Act was signed into law by Governor Jack Markell.

Advocacy Partnerships

In July 2012, the IMF formed the State Patients Equal Access Coalition (SPEAC), which is a patientfocused coalition representing patients, health care



professionals, and cancer care centers, working collaboratively at the state level to ensure that cancer patients have appropriate access to a broad range of approved and medically-accepted anticancer regimens. Driven by the strategic plan of the national Patients Equal Access Coalition, SPEAC seeks to influence the development of insurance health exchanges in each state that will ensure an equal payment system and cost-sharing requirements for patients receiving intravenous, injectable, and/or orally-administered oncolytic therapies.

IMF Myeloma Awareness Month



The IMF observed Myeloma Awareness Month (March) of 2012, by increasing awareness of this disease. On March 1, 2012, the IMF launched the *Tell One Person* campaign, where patients, caregivers, friends, and family members pledged to tell one person, unaware of the disease, about myeloma.



The IMF relied heavily on social media tools to encourage the spread of awareness, posting daily myeloma facts on Twitter and Facebook. The IMF's Facebook page-views grew by a factor of 90 in March, as friends and followers further spread this important information.





ADVOCACY

IMF Advocacy Action Center

The IMF's Advocacy Action Center is an online, centralized hub that shares government activity affecting the myeloma community and provides tools and training for myeloma patients, families, caregivers, and medical professionals to become a part of the process.



From October 2011 through December 2012, 2,336 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 nearly 1,500 emails to their state and federal legislators during this reporting period.

In addition, the IMF kicked off its Postcards for Parity Program in 2012. Ninety participants



across the country worked hard to collect over 3,100 postcards in support of oral chemotherapy access.



Member organizations of SPEAC include the American Cancer Society Cancer Action Network (ACS-CAN), Association of Community Cancer Centers (ACCC), National Brain Tumor Society, Susan G. Komen for the Cure Advocacy Alliance, the Leukemia & Lymphoma Society (LLS), and the Lymphoma Research Foundation (LRF).



The IMF advocacy team is laying the foundation to launch campaigns through SPEAC in New Jersey, Nevada, and Illinois. Efforts will focus on bringing together the cancer community in those states to work collaboratively and to ensure that implementation of the Affordable Care Act (ACA) includes affordable access to all health care services needed by cancer patients.



One Voice against Cancer (OVAC) is a collaboration of 40 national nonprofit organizations representing millions of Americans with cancer. It is one of the leading cancer coalitions in the nation's capital and delivers a unified message to Congress on the need for increased cancer-related appropriations. The IMF has been a member since 2001.

At the annual OVAC lobby day in July 2012 in Washington, DC,

close to 100 advocates, including many through the IMF, met with hundreds of US senators and representatives to request increased funding for cancer research and prevention.





Anthony Sibert and Geri Smith-Benjamin at the OVAC Lobby Day 2012 in Washington, DC



DEVELOPMENT

Support for the International Myeloma Foundation comes from many sources, including large corporations, pharmaceutical sponsors, private donors, bequests, and fundraising events. Whether the gift is \$5 or \$5,000 – each contribution makes it possible for the IMF to continue offering and improving upon existing programs, while exploring new ways to service the myeloma community with top-rate information and support.

This is evident in the number of new programs the IMF added to our repertoire during the last fiscal year. From the Myeloma Master Class (page 12), to the IMWG Conference series (page 12) – the IMF's expanded reach in the medical community is made possible through the generosity of its donor base.

During the 2011-12 fiscal year, the IMF received \$9.3 million in support of vital programs and services.

Major Gifts & Planned Giving

Major gifts of \$5,000 and above make a powerful impact on the IMF's fiscal stability. During the 2011-12 fiscal year, the IMF received 47 gifts totaling \$824,912. Major donors are a small but dedicated group of supporters whose contributions help sustain the quality and longevity of critical programs and research.

Planned Giving

The IMF continues to support programs that help extend lives of myeloma patients, but respects that for many of our members estate planning is a rite of passage that must be acknowledged.

Members who support the IMF through the

Brian D. Novis Legacy Society, the IMF's planned giving

program, 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. All that is required to be recognized as a member of the Legacy Society is written confirmation of a planned gift. There is no minimum commitment necessary.

Sustained Giving

Members of the IMF's sustained giving program, The Hope Society, commit to a monthly or quarterly gift in support of the IMF's programs and services. With recurring contributions ranging



from \$5 to \$500, 138 Hope Society members contributed a total of \$31,056 during the 2011-12 fiscal year, a 20% increase over the previous year.

The IMF thanks members of The Hope Society for their continued commitment to sustaining the needs of the myeloma community.



Paul and Carol Ann Rothman Denver, CO

In October 2006, Paul Rothman was a healthy, active 66-year-old man. At his annual physical, he was blindsided by a diagnosis of multiple myeloma. He and his wife, Carol Ann, had never heard of the disease and were in a state of shock. It seemed unreal to them, like a bad dream.

Paul's doctors provided him and Carol Ann with information about myeloma and referred them to the International Myeloma Foundation support group in Denver. They attended a support group meeting and later participated in a two-day IMF Patient & Family Seminar in Portland, OR. They met others with multiple myeloma and shared experiences and resources. "The IMF made all of this information available to us."

Carol Ann and Paul are major donors to the IMF because they found that information provided to them in their time of need was invaluable and because they want to help fund myeloma research. They hope for progress toward better treatment options and a cure. Multiple myeloma has had a major impact on the Rothmans' lives. They went through the hardships and now, six and a half years in, feel things are better than they had originally anticipated. They feel the IMF has played an important role in their growth.

"Before I had bone issues, I had taught my three Colorado grandchildren to ski. I loved to ski with them. It saddens me that I no longer can, but if I could, I couldn't keep up with them. I think of Pete Seeger and Turn! Turn! Turn!: 'To everything there is a season and a time for every purpose under heaven.'" Paul says, "My ski season has ended, but thanks to support from my wife, family, friends, doctors, and the IMF, many wonderful seasons have not ended."



Daniel Ellis Laguna Niguel, CA

During a routine physical in 1996, Stephanie Ellis' doctor found abnormal protein in her blood. He referred her to an oncologist who diagnosed her with smoldering myeloma. She had her blood checked annually and lived a healthy life for 12 years, raising her children, aged four, seven, and eight at the time of her diagnosis. Upon her diagnosis, a doctor told her and her husband, Danny, about the IMF. She and Danny were eager to understand as much as they could about the disease and began attending Patient & Family Seminars and support group meetings.

They went on living their lives while worries about smoldering myeloma took a backseat to spending time with their growing kids, helping with homework, attending school activities, growing together spiritually, enjoying trips. In June of 2008, however, Stephanie was diagnosed with active myeloma. She underwent a chemotherapy regimen and an autologous stem cell transplant at Cedars Sinai Cancer Center, Los Angeles in 2009. In 2010, one short year later, she lost her battle with multiple myeloma.

After Stephanie's death, Danny decided to support the IMF and become a Hope Society member. "In 2008 when her myeloma became active and our lives became an emotional rollercoaster, we again turned to the IMF – its website, hotline, seminars, and materials – to help us understand the disease and make decisions about her treatment. Whenever we needed to understand an aspect of myeloma, we turned to the IMF. After Stephanie's death I was determined to help the organization that helped Stephanie and me during the worst time of our lives."

He hopes his support will allow the IMF to continue its education and support programs, as he believes these programs bring knowledge and comfort to patients and caregivers. He also hopes that his support will bring the world closer to a cure for myeloma.

"During our fight with myeloma there were four contributing factors to Stephanie's and my hope; our faith in God, our family, our friends, and the IMF. I cannot imagine fighting myeloma without the IMF. The IMF is the patient's advocate. I know that one day there will be a cure discovered and I think a major catalyst for that cure is the IMF. Thank you to Susie Novis and Dr. Durie – the IMF is doing wonders."

The Hope Society Honor Roll

Jeff Allyn Cathie Alonzo Bonnie J. Anderson Deborah and John Anderson Scott and Pam Andrews **Funice Becker Elizabeth Beckley David Bennett** Marcy Bernstein Rita and Ivan Billson Anne and John Boehle Jan and Alan Boggs Marie Bovarnick Frances and James Bowles Julia Brock David and Prudy Brown Patricia Vigilante and Robert Candela Holly Carson Annette and Patrick Cavanagh **Charlotte Chaffin** John and Cynthia Chmielewski Cynthia D. Clark Susie Cobb Carol and Phillip Collins David Cook Karen Countryman Marureen Cronin Carolyn and Monte Cunningham Franci M. Dale Myla De La Cruz Lind and Charles DeLong **Brian Denyer** Niall S. Doherty Rene Dvalery and James Baker Linda and Mark Edwards Joseph Daniel Ellis Kate and Douglas Farrell Virginia Field Kyoko Kashiwagi and Ronald C. Fischer Donna and Richard Font Rosalyn L. Gaffney Clara and Charles Gallagher Dean Gallea Susan and Daniel Gannon Irene and Laurence Gauthier Roseann and Philip Geiger Carl Gilliam

Carla Goode Gail Bernstein Roberta and Arnold* Greenberg **Roslyn and Harold Grueskin Carol Hornreich** Nicci Hubert **Timothy John Huss** Kathleen and David Johnson Shirley S. Johnson Steven M. Johnson Debbie and Jerry Jordan Jane Kamstra **Eileen and Frank Kealty** Rita and Robert Keating Anita Marie and Walter Kemper Elise and Kenneth Ketner Roberta and Raymond Klein Judy and Henry Koepfle Leny and Ben Kolsteren Ann Nora Kruger Rose and George Leek Jean Novak and Mike LeTarte Kathleen and Charles Lewis Nancy and Don Lorenzen Mary Jane Lundy Helene and Alan Marks Mary Anne and Chuck Martz Marian and Ed Mayo Vicki and Dwight Mays Jodi M. McClure Laura McClothlin Joseph Mekler Paula Merrigan Alanna Morgan Imad S. Mufarrij Karen and Edward Necela Paul O'Dea Patricia and Jim Omel Marcelo Pakman **Phyllis and Tom Parker** Azella Perryman Marlys and Ralph Peterson Hal Piel Gail Pollard Agatha M. Plowy **Ellen Whitworth Powell** Dan Quattrochi Lauren Regan

Tina and Michael Rettig Linda and Jerry Reynolds Mary Alex Rohleder Cesar Romero Heidi Rubinstein and Brian Kuchynskas Marti and Robert* Santos Sally Anne and Richard* Scherr Cynthia Schulze Joland and Elwood Schut Barbara K. Scott Marguerite and Daniel Scott Diane Seccombe **Fay Shaprio** Ed Sharp Nancy Shealy Julie* and Robert Singdahlsen Dick Skalitzky Rachel and Michael Small Marilyn C. Smith Nikki and Allan Smith Randall Smith Jessica Sobat Jardee Stanley Sandra M. Stokes* Elizabeth and Frank Streff Nancy and Jay Style Henry B. Thomas Doris and James Thurau Nancy and William Tidwell **Douglas P. Valente** Kathleen and Paul* Vergamini Marianne Viviano Patricia and James Wangner Linda M. Wakefield Marcia and Peter Webber Jill and Mike Weiland Charlotte and Joseph Werkmeister Theresa and Phillip Westine Becky and Charles Whitehead Bernadette and Dave Wolf Beth and Woodring Wright Sandy Kay Wytroval Natalie Young

Annual Comedy Celebration

On Saturday, November 5, 2011, nearly 1,200 guests gathered at the Wilshire Ebell Theatre in Los Angeles for the IMF's 5th Annual Comedy Celebration benefiting the Peter Boyle Memorial Fund, which supports the IMF's innovative research program and patient services. Since its inception, the annual event has been the largest annual fundraiser in IMF history.





The first Annual Comedy Celebration was held in 2007, after Loraine Boyle, IMF Board member and wife of the late actor Peter Boyle, approached the IMF with her desire to make a difference in the lives of people coping with multiple myeloma. During the 2011-12 fiscal year, the 5th Annual Comedy Celebration raised \$585,000, bringing the total funds raised for the Peter Boyle Memorial Fund to over \$3 million.

Joined by vice chairs Donna & Steve Feig, Loraine 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. In addition,

the event benefited from the talents of Tom Arnold, Darrell Hammond, Dom Irrera, Colin Quinn, and a special musical performance by Peter Gallagher.

Member Fundraisers

Myeloma patients and family members often contact the IMF wishing for opportunities to get involved in supporting myeloma research and education programs. People who have hosted member fundraisers in their communities have said they derive strength and empowerment from participating in the fight against myeloma.

During the last fiscal year IMF members held 40 events, raising a total of \$250,000. Many of the recurring events will go on to fund Brian D. Novis Research Grants in the coming year – a testament to the efforts of a regular group of people who make an extraordinary impact on the future of myeloma research.

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



Vicki Hamby Bluffton, SC

When Wayne Hamby was diagnosed with multiple myeloma, his friends held a party in a show of support for him and his wife, Vicki. All in attendance were wearing the IMF myeloma awareness bracelets. Vicki and Wayne, from that moment on, became friends of the IMF and relied on the organization for education and support.

Wayne passed away in 2010. That year, his friends from Pinecrest Golf Club in Bluffton, SC held a golf tournament, raising awareness in Wayne's name and memory to fight multiple myeloma. The Wayne Hamby Memorial Golf Tournament has occurred annually since then.

In 2012, Vicki, along with close friends Gail and Andy Bertram, created a volunteer force of over 25 Pinecrest Golf Club members and staff. Their efforts, along with the overwhelming support from friends and local community businesses, allowed for inclusion of a raffle, a silent auction, and various on-course fundraising activities. Through this collective effort, Vicki and her wonderful circle of family and friends donated \$7,500 to the IMF.

In addition to their IMF contribution, a memorial area was established at the Pinecrest Golf Club and a memorial bench for Wayne Hamby looks out onto the



18th green. In 2012, Tom Dardaris, a club member, donated time and materials to add a patio area where currently four engraved bricks have been installed in memory of other members who have passed away, two of whom from multiple myeloma.

"Wayne loved being with his friends and family and I truly believe he would be honored to see them gather each year for a tournament that bears his name and contributes to such a worthy cause. It is our hope that the 2013 tournament will be even more successful, as we strive to assist the IMF in improving the lives of others affected by multiple myeloma and ultimately find a cure."



A Tribute to Dominik Zuchowicz

Dear International Myeloma Eurodation,

you and I hope you find

Sincerely, Naelle Elizabeth Rustica

collected money for your charity from may birth

e deale money instead of buying me to help people with this divease

William Harold Hodges, w

Fall Bocce Classic



Be Bold Be Bald



Walk to Cure



Bicyclist Riding in Search of a Cure



Jack Aiello's Poker Bash



The Meier/Grammel Family Run



Member Fundraisers October 1, 2011 – September 30, 2012

BENEFACTORS CIRCLE \$25,000 AND UP

Miles for Myeloma 5k Philadelphia Multiple Myeloma Networking Group, New Jersey Support Group, Northeastern New Jersey Support Group Philadelphia, PA

Carolyn Czerkies Charity Golf Outing **Czerkies Family** Naperville, IL

FOUNDERS CIRCLE

\$10,000 - \$24,999

Jeans & Jewels Gala Lisa Mehalick Gibsonia, PA

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

Coach Rob's Benefit Bash Rob Bradford Apopka, FL

PARTNERS CIRCLE \$5,000 - \$9,999

Music Against Myeloma

Slava Rubin New York, NY

Bridge Blasts Myeloma Ann Girod Potomac, MD

Matthew Jacobs Letter Campaign Matthew Jacobs Frisco, TX

Misbehaving for Multiple Myeloma Alexander Zousmer and Joanna Share Chicago, IL

Tracy's Run Tracy Finegan Swedesboro, NJ

Trooper Benson Klein Research Fund Benson Klein Bethesda, MD

Pipo's Fund for a Miracle Cecelia Izquierdo Miami, FL

ASSOCIATES CIRCLE \$1,000 - \$4,999

Dr. Manuel Rivero **One-Year Memorial Event** Penny Rivero Mesquite, TX

Jack's 7th Annual Texas Hold 'em Benefit Bash Jack Aiello San Jose, CA

Meredith Fiacco Memorial Golf Tournament Meredith Nicols and Suzanne Fiacco Potsdam, NY

Dennis Werra Fundraiser Javson Werra New Berlin, WI

A Walk To Cure Jeff Kearney Orlando, FL

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

Glenda Hinson Memorial Fund Benson Rabitsch Suwanee, GA

Bruce Morton Wright Fundraiser Susan Spafford Harrison, NJ

Flying Pig Marathon Grammel Family Fairfield, CT

Nowacki Fundraiser Craig Nowacki Malvern, PA

Delmarva Monster Mile Fundraiser Delmarva Myeloma Support Group Dover, DE

Jerry Walton's **Veterans Against Myeloma** Campaign Jerry Walton Virginia Beach, VA

Matney Walk Charlotte Matney West Portsmouth, OH

Lynn Wolfe **Casual Jeans Day** Rumberger Kirk & Caldwell Orlando, FL

Southeastern Virginia Raffle

Southeastern Virginia Multiple Myeloma Support Group Virginia Beach, VA

Steve's Run Steve Schecter Clarksburg, MD

McNab Tee Shirt Fundraiser Robert McNab Minneapolis, MN

Bon-Ton Fundraiser Melanie Nicols and Suzanne Fiacco Potsdam, NY

Honoring **Dominik Zuchowicz** Nancy Ellis Magnolia, TX

Super Shag Fundraiser Super Shag Productions Waltham, MA

Art Institute International Fundraiser Darlene Ritz San Diego, CA

FRIENDS CIRCLE \$500-\$999

Ben Venue Jeans Day Ben Venue Laboratories Bedford, OH

Snook Casual Day Su Snook Long Beach, CA

Bicycle Mojave and Beyond Andrew Sninsky Newport Beach, CA

Multiple Colors for Multiple Myeloma Pam Larsen Honolulu, HI

Joyce Dean **Birthday Fundraiser** Joyce Dean Cape Coral, FL

Wine Tasting Fundraiser Holly Carson Lancaster, CA

Rachel Cavenaugh's Wedding Rachel Cavenaugh Kingwood, TX

DEVELOPMENT

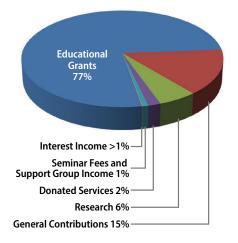
SUMMARY FINANCIAL INFORMATION

INTERNATIONAL MYELOMA FOUNDATION Statement of Financial Position September 30, 2012

Total Net Assets	\$1,042,353
Temporarily restricted	
NET ASSETS Unrestricted	1,042,353
Total Current Liabilities	\$3,294,239
CURRENT LIABILITIES Accounts payable and accrued expenses Deferred and unrestricted educational grants	\$ 679,521 2,614,718
Liabilities and Net Assets	
TOTAL ASSETS	\$4,336,592
Total Other Assets	\$ 596,606
Property and equipment, net Intangible assets, net	587,944 8,662
OTHER ASSETS	
Total Current Assets	\$3,739,986
Prepaid expenses	523,894
Cash and cash equivalents Contributions and other receivables	\$ 1,663,974 1,552,118
CURRENT ASSETS	
Assets	

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

Revenue Breakdown



INTERNATIONAL MYELOMA FOUNDATION Statement of Activities for the Year Ended September 30, 2012

Change in Unrestricted Net Assets REVENUES Educational grants \$6,779,379 General contributions 1,333,995 Donated services 161,026 Seminar fees and support group income 68,646 Interest income 6,257 **Total Revenues** \$8,349,303 **Net Assets Released From Restrictions** Satisfaction of program restrictions \$499,205 **Total Unrestricted Revenue and Other Support** \$8,848,508 **Expenses** Program expenses 7,765,565 General supporting expenses 511,212 Fundraising expenses 441,976 **Total Expenses** \$8,718,753 **INCREASE IN UNRESTRICTED NET ASSETS** \$129,755 **Changes in Temporarily Restricted Net Assets** Contributions 250,629 Fundraising event, net of direct benefit to donors of \$325,242 248,576 Net assets released from restrictions (499,205) **Increase in Temporarily Restricted Net Assets** _ **Increase in Net Assets** 129,755

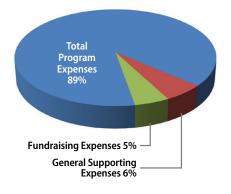
NET ASSETS, September 30, 2012 \$1,042,353

912,598

NET ASSETS, September 30, 2011

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

Expense Breakdown



INTERNATIONAL MYELOMA FOUNDATION Statement of Functional Expenses for the Year Ended September 30, 2012

Program expenses	\$ 7,765,565
General supporting expenses	511,212
Fundraising expenses	441,976
Total Expenses	\$8,718,753
Breakdown of Expenses by Program	
PROGRAM	TOTAL EXPENSES
Research	\$ 1,587,627
Patient & Family Seminars	958,313
Education & Awareness	918,628
International	826,773
Nurse	581,943
Support Groups	629,836
Clinical Meetings	529,590
Advocacy	495,340
Myeloma Today	305,590
Hotline	300,744
Website	268,755
Public Relations	171,518
Information Mailings	151,975
Myeloma Manager	22,250
Myeloma Advisor	16,683
Total Program Expenses	\$7,765,565

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

HONOR ROLL

The International Myeloma Foundation gratefully acknowledges the many people and organizations whose contributions have made it possible to provide the excellent, high-quality programs and services upon which our members have come to rely. Their generosity allows the IMF to:

- Conduct and support innovative research programs that are bridging the gap from long-term remission to cure, while simultaneously advancing the next generation of researchers in the field;
- Empower patients, family members, physicians, and nurses to participate in advocating on behalf of cancer patients by urging federal and state legislators to stand behind critical healthcare policies that will improve the lives of cancer patients;
- Maintain a vast and comprehensive website that provides 24-hour access to the latest updates about myeloma, from clinical trials to the 10 Steps to Better Care®;
- 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 and Myeloma Center 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 thanks our donors for allowing us the opportunity to serve you.

Chairmans Circle

\$100,000 and above AMGEN Oncology The Binding Site, Ltd. Bristol-Myers Squibb Company Celgene Corporation GlaxcoSmithKline Merck & Co. Millennium: The Takeda Oncology Company Novartis Pharmaceuticals Onyx Pharmaceuticals, Inc. The V & L Marx Foundation / Jennifer and Bud Gruenberg

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\$50,000 - \$99,999 Lynne H. Laughlin Estate Medtronic, Inc. Metzger Law Group Dorothy and John O'Dwyer Sharon E. Comp Trust

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\$25,000 - \$49,999 Astellas Pharma US INC CBS Corporation Daiichi Sankyo, Inc. Diplomat Specialty Pharmacy Donna and Steve Feig / Foreign Parts Distributors, Inc. Genentech Inc General Atlantic Corporation / Michael Windsor* Susie Novis and Dr. Brian Durie Philadelphia Multiple Myeloma Networking Group The Estate of Augustine P. Pisto Raymond James & Assoc. / Robert Ebersole Richard and Judith Voltmer Foundation Monica and Philip Rosenthal Sebia, Inc.

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\$10,000 - \$24,999 Heidi and Craig Albert Walsh Street Foundation / Henry Belber Loraine Boyle Cancer Cure of America Nilene and Arnold Chase Coach Rob's Benefit Bash, Inc. / Kimberly and Robert Bradford Dina and Clint Eastwood Mark and Eileen Eisenberg HBO Inc. Spencer Howard Indianapolis Colts, Inc. J.C. Invitational Golf Tournament / Beverly Lundorff Janssen Pharmaceutica John J. McDonnell & Margaret T. O'Brien Foundation

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\$5,000 - \$9,999 Amazon.com, Inc. Susan and Frank Armo Clifford and LaVonne Graese Foundation Gail-Ann and loe Colaruotolo David Geffen Foundation Joele Frank and Larry Klurfeld Barbara and Buddy* Freitag Genzyme Corporation Cindy and James Gilbert George Hayum and Dianna Wong Herbrandson Engines, Inc. / Charlotte and Dale Herbrandson Adriana and Albert Hernandez JVK Foundation Susan and Michael Katz Carol and Benson Klein Laurie and Andrew Kuzneski Sharon and Chuck Newman Linda and Jeff Peotter Rose and Sherle Wagner Foundation / Amy Wagner Carol Ann and Paul Rothman Louise L Takata Teva Pharmaceuticals Dorothy Tinsler Henry, Rita, and Martin Wells Michael Winkler Michele and Arnold* Zousmer

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\$1,000 - \$4,999 12650 Riverside Drive Office Building / Steve Weiss Kevin and James Abernathy Nelleke and Jack Aiello Peggy Aiello Mark Alles Jeff Allyn Sandra and H.P. (Andy) Andrews Ondine Anargola Art Institute International Jennet Walker and John Auerbacher Ellen and Marty Barrett John Bartle Malea and Michael Bell Michel Berg Celia and Leon Birbagher

Bloom Hergott Diemer / Ruth and Jake Bloom Heather and Tobin Bogard Richard Boisture Noeline and Dr. Henri Boshoff Joanne G. Boyle Norman Braman Wendy Breslow Jean T. Brewer Briscoe Family Foundation The Brunetti Foundation Nancy Bruno Mari and Ward Bukofsky Meghan and Christopher Buzby Capital Group Charitable Foundation / Leigh A. Morris Denise Carmody Janice and John Cartwright Charlotte and William Hinson Charitable Foundation Ian Wallach and Cindy Chupack Citrin Cooperman & Company, LLP Madeline and Roger Cole Constellation Energy Group Employee Fund Judy and Ric Corts Janice Corwin Marilyn and Lee Cox Barbara and James Coy Jon Cross Tim Crudo Craig Czerkies Frances and Donal Daley David Buntzman Foundation Betsy and Paul Dawes Design Printing Donna and Mark Di Cicilia Gordon Doble Dana Dubrovsky Alice Duffy Debbie and John Dyer Jim Edwards Judith Eiting Vince and Mary Jo Elhilow Joseph Daniel Ellis Frances Fahsel Gail and Ray Fargason Kate and Douglas Farrell Noreen Feig Stephanie Hope Feld Lana and Paul Franklin Laurie K. Frankoff Carolyn and Joel Fromer Judith and Martin Gang Susan and Daniel Gannon Carol Gay The Greater Kansas City Community Foundation Barbara and Jack Geiger JoAnn Gilbert

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Laura Schneider

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Stacey Annen

Carolyn Armington

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