



MYELOMA TODAY

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A PUBLICATION OF THE INTERNATIONAL MYELOMA FOUNDATION

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

Scientific & Clinical News

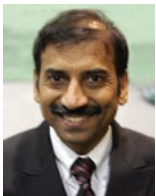


New findings presented at the 49th annual meeting and exposition of the **American Society of Hematology (ASH)** showed that, even without a cure, there are dramatic improvements in treatment and survival for patients with multiple myeloma. Presentations highlighted long-term survival potential for growing numbers of patients, as well as new medical options becoming available for newly diagnosed patients, and powerful new drugs that may delay or replace the need for bone marrow transplants. In addition, key therapies developed for myeloma are showing promise in other blood cancers. **PAGE 5**



The recipients of the **2008 IMF Research Grant awards** are announced. Projects being funded include two promising investigations by senior researcher Dr. William Matsui and junior researcher Dr.

Silvia Ling, both receiving support for the second consecutive year. Three additional junior research awards are funding studies by Drs. Sonia Vallet, Karin Vanderkerken, and Jing Yang. And IMF Japan has bestowed its 2008 Aki Award on researcher Dr. Yutaka Okuno. **PAGE 7**



Dr. Sundar Jagannath, member of the IMF Scientific Advisory Board, discusses **Serum Free Light Chain Testing for Diagnosis and Monitoring (Freelite™)**, a new technology capable of detecting and measuring free light chain in the blood. Freelite is an important advancement in improving the lives of many people living with myeloma and other B-cell dyscrasias, as it has enabled physicians to monitor patients with a monoclonal protein that cannot be measured by conventional electrophoretic methods. **PAGE 9**



Dr. Brian Van Ness, member of the IMF Scientific Advisory Board, updates readers on the **IMF's Bank On A Cure® Research Initiative**, which recently sought and received affiliate membership in the Pharmacogenomics Research Network (PGRN), a nationwide collaboration of scientists working on advancing knowledge of the genetic basis for variable drug responses. As part of the IMF's commitment to develop conglomerate data analysis of genetic variations, the Bank On A Cure panel has so far been run on approximately 1,000 myeloma patient samples and 200 controls. **PAGE 10**

Treatment with **vorinostat (ZOLINZA®)** has demonstrated clinical activity in two investigational Phase I studies of vorinostat in combination with bortezomib (VELCADE®) in patients with advanced multiple myeloma. Vorinostat is believed to decrease the activity of histone deacetylase (HDAC), allowing for the activation of genes that may help to slow or stop the growth of cancer cells. Results demonstrate promising anti-tumor activity in patients with relapsed or refractory myeloma. **PAGE 11**

Special Event



Susie Novis reports on the IMF annual Gala. This year's event, **Celebrating Peter Boyle – An Evening of Comedy with Family & Friends**, was a fitting memorial that raised funds in support of myeloma research while raising myeloma awareness. Ray Romano, Peter's friend and cast mate from *Everybody Loves Raymond*, headlined and hosted the show that also included Patricia Heaton, Doris Roberts, Fred Willard, Jeff Garlin, Richard Lewis, and Martin Short.. **PAGE 12**

Supportive Care



IMF Hotline Coordinators, who answer questions to help you address the various aspects of myeloma in a more informed way, respond to inquiries about smoldering myeloma diagnosis and monitoring, and its potential progress to active disease. **PAGE 16**



Kathy Lilleby, RN, talks to *Myeloma Today* about **myelo-suppression**, a common and expected side effect associated with novel anti-myeloma therapies. These side effects – anemia, neutropenia, and thrombocytopenia – are manageable with appropriate medical interventions, and patient and caregiver education. If not managed effectively, these side effects have the potential to be life-threatening and may interfere with optimal therapy, and can negatively impact quality of life. **PAGE 17**

Also in this issue...



- **Dear Reader** by IMF president Susie Novis **PAGE 3**
- **Letters** to the IMF **PAGE 3**
- **News & Notes** **PAGE 4**
- **Nurse Leadership Board** activities update **PAGE 15**
- **Spotlight on Advocacy**: 2007 myeloma advocacy summary **PAGE 18**
- **International Affiliates**: IMF holds educational meetings throughout Europe **PAGE 19**
- **Member Events**: IMFers raise funds to benefit the myeloma community **PAGE 20**
- **Support Groups**: new group in East Tennessee gets off to a great start **PAGE 21**
- **Calendar of events** **BACK COVER**

LOOKING FOR A LOCAL MYELOMA SUPPORT GROUP?

If you are interested in joining an existing group please access the website at www.myeloma.org "Finding Support" or call the IMF at 800-452-CURE (2873).

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International Myeloma Foundation

Dear Reader,

The IMF has just produced its first Annual Report. The hard work and extraordinary talent of our Board of Directors and the IMF's dedicated staff made the year a resounding success. We are pleased to present the Report with our heartfelt thanks and our appreciation to you – the community that has come together to make our achievements possible.

The year reviewed in this report was a watershed year in the fight against myeloma. In 2006, thalidomide was finally approved in the U.S., as well as in several other countries, as a myeloma treatment. Also in 2006, lenalidomide (Revlimid®) was approved for the treatment of myeloma, and new data demonstrated that the combination of lenalidomide with low-dose dexamethasone could offer a new standard of care for first-line treatment of thousands of patients. VELCADE®, approved as a single agent in 2003, had become a standard of care and was shown to be a backbone of therapy as it was combined with more and more compounds.

New staff joined the IMF in 2006 to take on important new roles, and long-term staff enhanced their roles to take on new opportunities to better meet the needs of patients and their families.

Each year the IMF will publish its Annual Report to keep our members up-to-date on our activities, the progress we're making, and how we utilize the funds we receive from people like you. Your support enables us to move research forward both in the lab and in the clinic, and to improve the quality of life of myeloma patients while working toward prevention and a cure.

As always your comments and suggestions are welcome.

Warmest regards,
Susie Novis
IMF President



Editor's Note: Please visit www.annualreport.myeloma.org to view the annual report online or call 800-452-CURE (2873) to request a copy.

Letters to the IMF

The IMF

As you go through your day, please know how grateful we are to be able to call you friends. You have stood with us and supported us as we fight multiple myeloma. We are humbled to recall the time and resources that you have shared with us over the years, and are still offering. On October 25, 2007, we marked Day T+5000 (the 5000th day after Rhoda's bone marrow transplant). National Cancer Institute statistics indicate that less than 20% of transplant recipients reach day T+2000. There are no statistics for T+5000. Our battle continues, and we are weary, but Rhoda has far exceeded medical expectations and we celebrate the miracle that you have helped to create. Thank you!!!

Rhoda & Gill Lott

The Hotline

Thank you so much for your very helpful answer to my question. Everyone I have communicated with has been so kind, helpful, and informative. The article you cited looks like exactly what I'm looking for. I am thrilled that the IMF is such a great resource for myeloma patients, as I have had some difficulty finding such information on my own. I appreciate so much all the information the IMF has given me. I was diagnosed last year at 38, and I am finding many doctors are unsure of how to treat myeloma in someone my age. It can be very frustrating, as even my transplant doctor seems unsure at times about my course of treatment. I am finding the IMF to be a great resource in my quest for information on myeloma. It will be very helpful in discussing my options with my transplant doctor and oncologist. You are awesome!

Kris Grandinetti

Patient & Family Seminar in St. Petersburg, FL

Congratulations! Our first IMF seminar far exceeded our expectations in every way. We can't remember ever being more satisfied and impressed with any educational seminar that we have attended or participated in, be it business or otherwise. The Durie, Hussein, and Katz team, with supporting

cast, was a perfect choice for us at the time. The program left nothing to be desired. As we search for a meaningful description of this experience, this comes to mind – it was like being with a very high-end support group for a fulfilling one and a half days, with an excellent program, well-chosen to address the interests and needs of the participants. The participants themselves contributed significantly. The words 'meaningful, helpful, quality, first class, organized, and educational' all come to mind. We know how much hard work goes into planning and producing an event of this magnitude. I hope that you will see this note as at least a small recognition of your effort. We're happy to be associated with all of you!

Bob & Lynda Scott

Third Annual Southwest Symposium

I am the president of the Amyloidosis Support Groups (www.amyloidosis-support.com) and I attended the IMF symposium in Arizona on November 10. There were so many terrific people in attendance, and so much hope. If there were a theme for the symposium, it was HOPE. The people of the IMF are amazing – I was impressed both by the Foundations' staff and by the expertise of the faculty. I had a wonderful time, and learned so much!

Muriel Finkel

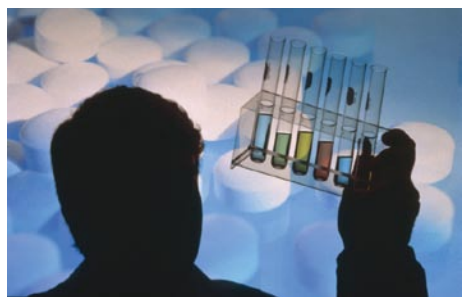
Myeloma Mobile

Thank you for publishing the story about our family's cross-country Myeloma Mobile education and awareness tour in the in the Fall issue of *Myeloma Today*! It was a great experience for the whole Tuohy Family, and we all hope that the patients and caregivers we visited during our "mobile" project found the experience as rewarding as we did. I also wanted to let *Myeloma Today* readers know that *Woman's World* is publishing an article in their January issue, focusing on a wife's perspective of the disease and how our family is coping with Michael's myeloma diagnosis.

Robin Tuohy

New Data Confirms Survival Benefits

Published data provides encouraging news for nearly half the patients newly diagnosed with myeloma, patients who are 65 and older. The results of a multi-center clinical trial show adding thalidomide to the standard treatment, melphalan and prednisone (MP), increased average survival to more than 4 years, a year and a half more than the same treatment without thalidomide. The study comes from the France's Intergroupe Francophone Myélome (IFM), and is published in the medical journal *Lancet*. The IFM study involved patients between 65 and 75 years old who are not eligible for bone marrow transplants. The data verify preliminary findings that first



raised excitement at the international ASCO conference in 2006. They also dovetail with study results in the US where thalidomide is used with the steroid dexamethasone, demonstrating increased survival and a longer

time before the myeloma progresses. "This is an important milestone for all patients because the data are included in Pharmion's application to make Thalidomide Pharmion available for myeloma in Europe," said Susie Novis, president and co-founder of the International Myeloma Foundation (IMF). "The IMF would like all patients to have the same ready and safe access to thalidomide as they do in the United States."

Efficacy Advantages of VMP Combination Therapy Reported

Interim findings from global clinical trial found that adding bortezomib (VELCADE®) to melphalan and prednisone (MP) improved all parameters in newly diagnosed patients including overall survival, complete remission rate and time-to-disease progression, compared to melphalan and prednisone alone. The trial involved 682 newly diagnosed myeloma patients who were ineligible for stem cell transplantation, at 151 clinical trial sites in 22 countries. The data from the trial were reported at the 2007 annual meeting of the American Society of Hematology (ASH). Based on the recommendation of an independent data monitoring committee, the international Phase III VISTA trial (VMP vs. MP) was stopped early, allowing all patients in the trial to have bortezomib added to their therapy at the discretion of their physician. The VMP combination therapy is already approved for use in patients who have received a previous treatment. "Myeloma patients who have failed on previous treatments know the potential of the novel therapies including VELCADE," said Dr. Brian G.M. Durie, chairman and co-founder of the IMF. "These new findings bring VELCADE closer to newly diagnosed patients, and are especially important to patients who are not eligible for stem cell transplants."

New Resource for Exploring Clinical Trial Options

CancerTrialsHelp.org, the website of the Coalition of Cancer Cooperative Groups, offers customized access to information on thousands of cancer clinical trials that are currently open and seeking patients. TrialCheck®, a searchable database, offers trial-searching based on diagnosis and zip code to help users locate trials near their home.



New IMiD Clinical Trial Opens

A Phase II trial for CC4047, a new IMiD under development, has opened. IMiDs are a class of drugs that have been important for myeloma, with thalidomide and lenalidomide (Revlimid®) being prime examples. CC4047 is being studied in myeloma patients with relapsed disease who have received three or fewer previous treatment regimens. This trial is only available at the three Mayo Clinic facilities in Minnesota, Florida and Arizona. For more information call the IMF Hotline at 800-452-2873.

ECOG Randomized Study E1A05

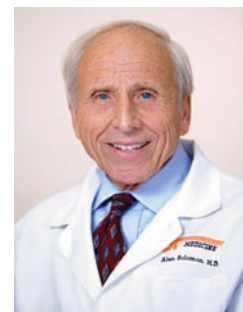
The Eastern Cooperative Oncology Group (ECOG) is accruing myeloma patients for a randomized study of bortezomib in combination with dexamethasone, with and without lenalidomide. Patients must have completed a dexamethasone-based therapy as their first treatment for myeloma. Patients planning to proceed to a stem cell transplant at this time are not eligible. All patients will participate in a Quality of Life Survey both during and after treatment, and will be followed for up to seven years to assess the long-term effects of the study.

Cognitive Function and Transplantation

Some cancer patients who undergo stem cell transplantation exhibit negative changes in cognitive functioning. Researchers at the H. Lee Moffitt Cancer Center and Research Institute in Tampa, FL, first studied 286 patients who were randomized to be tested pre-transplant, and then at 6 and 12 months after. Another group of 124 patients was tested at 6 and 12 months. Eighty-three patients who were tested at 12 months only were not included in the analysis. The majority (63%) of the patients participating in the study had multiple myeloma. Investigators found that, with the exception of attention, there was a significant improvement in cognitive abilities within a year of the transplant. Further research is needed to identify patients who may suffer from deficits for a longer period of time.

IMF Scientific Advisor Sets Grant Longevity Records

Dr. Alan Solomon, IMF Scientific Advisor and University of Tennessee (UT) Graduate School of Medicine researcher, professor of medicine, and director of the Human Immunology and Cancer/Alzheimer's Disease and Amyloid-Related Disorders Research Program, was recently awarded a five-year renewal on a grant from the National Institutes of Health's



(NIH) National Cancer Institute (NCI). This is now one of the longest active grants in NIH history and is the longest running NIH grant in UT history. The grant, originally awarded to Dr. Solomon in 1965, has been renewed continually for the past 42 years and has provided more than \$12 million to fund Dr. Solomon's research. Dr. Solomon has devoted these 42 years to the study, diagnosis, and treatment of cancer. For the past 10 years, his work has focused in part on myeloma-related primary or AL amyloidosis. "I am very appreciative and grateful for the initial and the continuing NIH grant, which will make it possible for us to achieve our ultimate goal, to improve the outcome of patients with these medically devastating amyloid-associated diseases," said Dr. Solomon. "I am thankful to receive this award particularly because so few NIH research grants are being funded at this time due to imposed limitations in governmental support for medical research." **MT**

NEW FINDINGS REPORTED AT ASH



The 49th annual meeting and exposition of the American Society of Hematology (ASH), a global cancer conference, took place in Atlanta, GA, December 8–11, 2007. Findings presented showed that, even without a cure, there are dramatic

improvements in treatment and survival for patients with multiple myeloma.

Presentations highlighted long-term survival potential for growing numbers of patients, as well as new medical options becoming available for newly diagnosed patients, and powerful new drugs that may delay or replace the need for bone marrow transplants. In addition, key therapies developed for myeloma are showing promise in other blood cancers.



Dr. Mario Boccardo and Susie Novis

“We are seeing longer responses with fewer side effects for a growing range of patients,” said Susie Novis, president and co-founder of the IMF. “The findings at this global conference are moving myeloma closer to becoming a chronic disease that can be managed long-term while we continue to search for a cure.”

Among the highlights of the conference are improved response and survival in the important category of patients who are newly diagnosed, combination therapies for newly diagnosed patients in preparation for bone marrow transplant, novel agents enhancing the ability of other drugs such to attack cancer cells, improving survival in elderly myeloma patients, and progress with the IMF’s Bank On A Cure® research initiative.

In addition to helping myeloma patients, the groundbreaking research presented at ASH is paying off with positive results in other blood cancers. Bortezomib (VELCADE®) has been approved for mantle cell lymphoma and other forms of non-Hodgkin’s lymphoma (NHL), and data about lenalidomide (REVLIMID®) was presented in both chronic lymphocytic leukemia (CLL) and in NHL.

“Ultimately which therapies are used when, will depend on how long the benefits last, potential side-effects, patient history and other factors,” said Dr. Brian G.M. Durie, chairman and co-founder of the IMF. “But we are pleased to have choices and potential, where just a few years ago the outlook was guarded and our options were limited.”

IMF Identifies Potential Link Between Genetic Pathways and Environmental Risks for Myeloma

As reported at the 49th annual meeting of ASH, findings from the IMF’s Bank On A Cure® DNA data base identified genetic links to bone disease in multiple myeloma, as well as indications for treatment. These findings also may both support and explain associations that have been observed between environmental toxins such as dioxins and benzene, and an increased risk for myeloma. The findings were made with resources from Bank On A Cure®, the world’s first repository of DNA samples created to advance the understanding of myeloma, and were presented at ASH on December 11th.

The study found that genetic pathways associated with the ability to neutralize environmental toxins are defective in patients with classic myeloma (myeloma with bone involvement). These pathways are identified as specific segments of genes called single nucleotide polymorphisms (SNPs) that are known to be associated with toxin metabolism and DNA repair.

CONTINUES ON PAGE 6



Best of ASH

Dr. Brian Durie’s abstract presentation on results from Bank On A Cure® research singled out as part of 2007’s “Best of ASH” session

“Genetic Polymorphisms Identify the Likelihood of Bone Disease in Myeloma: Correlations with Myeloma Cell DKK1 Expression and High Risk Gene Signatures”, an abstract presented by Dr. Brian G.M. Durie at the 2007 annual meeting of the American Society of Hematology (ASH) has been singled out as part of this year’s “Best of ASH” session. ASH will reprise the “Best of ASH” session for its two ASH Highlights meetings, which are organized by its scientific and education co-chairs. Dr. Durie’s study shows very strong statistical linkage to key single nucleotide polymorphisms (SNPs) associated with bone biology and toxin metabolism. The focus of further studies is likely to include additional data sets, exploring key SNPs in more detail regarding function, and the initiation of studies into targeted biology, predisposition, and/or epidemiology. To explore new hypotheses, Dr. Durie and colleagues will study all SNPs linked to critical bone and/or toxin targets, transition from target SNP to genome-wide screening, and work towards personalized molecular classification for treatment and prevention. The Spring 2008 issue of *Myeloma Today* will feature an interview with Dr. Durie about this important research project.

ASH REPORT — continued from page 5

These findings are in line with observations of patient populations and groups of workers including firefighters that had previously demonstrated a correlation between increased risk for myeloma and exposure to hydrocarbons and related chemicals.

“Identifying these genetic pathways was unexpected,” said Dr. Brian G.M. Durie, lead author of the Bank On A Cure presentation. “We were looking at bone biology and the SNPs associated with toxin metabolism fell into place. Now, working back through the gene pathways, we have a robust model of myeloma bone disease that may explain the epidemiological observations.”

Additionally Bank On A Cure identified multiple SNPs associated with bone biology, the original focus of this research. The findings have identified SNPs that may be predictors for bone disease in patients with myeloma.



Michael Katz

“These findings move us closer to personalized medicine,” said Michael Katz, IMF Director and Bank On A Cure project manager. “If we can use genetic tests to identify those myeloma patients at risk for bone involvement, we can begin treatment earlier with medications to help prevent or slow bone destruction caused by the myeloma.”

The research also turned up some preliminary but intriguing findings that show one

of the cell signaling pathways associated with myeloma is also the natural target of thalidomide, a widely used treatment for myeloma. In a developing fetus thalidomide acting on this target leads to deformed limbs, but in myeloma where the target is defective, the thalidomide appears to block the development of the cancer.

The next steps are to further identify the functions of SNPs involve in all of these findings, study them in-depth and verify the findings with larger studies of patients.

Survival and Longer Term Disease Control Take Precedence over Short Term Response to Treatment

New data reported ASH require a new approach to evaluating cancer treatments. Findings from a multi-center clinical trial sponsored by the National Cancer Institute (NCI) and led by the Eastern Cooperative Oncology Group (ECOG) demonstrated that lowering the dose of the steroid dexamethasone when paired with lenalidomide to treat newly diagnosed myeloma, not only reduces side effects, but also improves long-term survival.



According to the Mayo Clinic Cancer Center, lead institution for the study, the data show a “distinct survival benefit” with lower doses of the dexamethasone combined with lenalidomide. Dr. S. Vincent

Rajkumar, lead investigator of the study at the Mayo Clinic added, “This is a major advance in the treatment of cancer, and also gives researchers



IMF US Support Group Leaders at ASH

a new direction to explore – that more is not necessarily better when it comes to fighting the cancer.” The data showed lenalidomide, an oral medication from Celgene, plus low-dose dexamethasone improves one year survival compared to the standard high-dose dexamethasone, 96% to 88%. Over two years the benefit continues with an 87% survival rate for low-dose dexamethasone compared to a 75% survival rate for high-dose dexamethasone. While lowering the dose of the steroid also lowers some immediate measures of response that is offset by better, long-term disease control.

“Lowering the doses of the steroid dexamethasone with REVLIMID gives us a new paradigm of treatment,” said Dr. Brian G.M. Durie. “When we combine REVLIMID with lower dose dexamethasone, we are seeing reduced side effects so patients stay on the drug longer, and, above all, significant survival benefits. These are the outcomes that patients and physicians find most important, and take precedence over the traditional ways we have used to evaluate new therapies.”

Last April, the independent committee monitoring the trial found the preliminary results so compelling that the trial was stopped and all patients in the trial were moved to lower dose dexamethasone. Because of the overwhelming positive response to lenalidomide plus low-dose dexamethasone in the ECOG study, a trial from the other large cancer



Dr. Brian Durie

cooperative, SWOG, was also stopped prematurely. This trial compared lenalidomide plus high-dose dexamethasone to dexamethasone alone. Because this SWOG trial stopped early, and because nearly half of the patients on the dexamethasone-alone-arm of the study crossed over to the lenalidomide-plus-dexamethasone-arm of the study within the first year, overall impressions regarding survival could be misleading.

According to Dr. Durie: “We do not want patients confused by statistics. In fact, the SWOG trial concluded that REVLIMID with low-dose dexamethasone is among the most active up-front combination regimens against myeloma. These results demonstrate that REVLIMID plus dexamethasone is definitely better than dexamethasone alone, and is an excellent treatment in newly diagnosed multiple myeloma.”

The IMF concludes that overall findings presented at this conference about multiple myeloma in all ages, and across all categories of patients (newly diagnosed, relapsed, patients proceeding to bone marrow transplants and so on) is positive and encouraging and represents major advances in the treatment of blood cancers beginning with myeloma. **MT**

2008 IMF RESEARCH GRANT RECIPIENTS ANNOUNCED

The recipients of the 2008 IMF Research Grant awards were announced at the gathering of the Foundation's Scientific Advisors, held at the 49th annual meeting of the American Society of Hematology.

Since 1995, the IMF's research program has been funding the world's most promising clinical investigators in order to further research into better treatments, management, prevention and, ultimately, a cure



for multiple myeloma. The 2008 IMF grant award presentations took place during the 49th annual meeting and exposition

of the American Society of Hematology (ASH). Susie Novis (president and co-founder of the IMF), Dr. Brian G.M. Durie (chairman and co-founder of the IMF), and Dr. Robert A. Kyle (chairman of the IMF Scientific Advisory Board) were on hand to present the awards.

The IMF grants are funded by donations from private individuals. Junior investigators receive funding in the amount of \$40,000. Senior investigators are funded at \$80,000. While IMF research grants traditionally support one-year projects, two of this year's recipients are receiving continued funding based on the results of the investigators' work in 2007. Over the years, the IMF research grant program has produced significant results that have both increased the overall understanding of the disease and have benefited myeloma patients by improving treatment options. We are certain that the work of the recipients of the 2008 IMF research grants will contribute significantly to the field of myeloma.

2008 Brian D. Novis Senior Research Grant "Hedgehog Signaling in Myeloma Cancer Stem Cells"*



William Matsui, MD
Assistant Professor of Oncology
Division of Hematologic Malignancies
The Sidney Kimmel Comprehensive
Cancer Center at Johns Hopkins
Baltimore, MD

Cancer stem cells are thought to be responsible for the growth and progression of many human tumors including multiple myeloma. Dr. Matsui's laboratory has focused on studying myeloma stem cells and recently found

that the Hedgehog signaling pathway, normally active during embryonic development, regulates the growth and maturation of these cells. With the support of the 2007 IMF Brian D. Novis Senior Research Grant, Dr. Matsui and his laboratory have found that Hedgehog signaling is abnormally activated within cancer stem cells isolated from some, but not all, patients with myeloma. In addition, it appears that myeloma stem cells can be inhibited when Hedgehog signaling is blocked. With the support of the 2008 IMF Brian D. Novis Senior Research Grant, Dr. Matsui and his colleagues will continue these studies and determine whether Hedgehog signaling becomes "turned on" during myeloma relapse and progression, as well as study whether novel agents that block Hedgehog signaling are effective against myeloma cancer stem cells.

2008 Brian D. Novis Junior Research Grants "Role of XBP-1 in Drug Resistance of Multiple Myeloma"



Silvia Ling, MD, MBBS, FRCPA, FRACP
Centenary Institute
of Cancer Medicine
and Cell Biology
Newton, NSW, Australia

Proteasome inhibitors are an effective new approach to treating multiple myeloma. Some 50-60% of myeloma patients respond to bortezomib (VELCADE®), the first drug of this class to be approved for clinical use. It is striking that its relevant mechanism of action in myeloma cells remains unknown. Proteasome inhibitors have numerous biological effects but none of them had been shown to predict response. The causes of bortezomib resistance were also unknown. The first part of the study conducted by Dr. Ling showed that levels of XBP-1, a regulator of the unfolded protein response, predict response to bortezomib in vitro and in a small cohort of patients. Dr. Ling and colleagues have also made myeloma cell lines resistant to bortezomib and showed that they downregulated XBP-1 and other genes of the unfolded protein response. Dr. Ling's goals are now to test the utility of XBP-1 as a marker of response to bortezomib in a larger number of patients, and to characterize the bortezomib-resistant cell lines, in terms of molecular mechanisms and cross-resistance to other drugs. These studies should help clinicians to optimize treatment strategies for myeloma, and aid the development of improved drugs.

"A novel CCR1 Inhibitor for the Treatment of OBD in Multiple Myeloma"*



Sonia Vallet, MD
Massachusetts General Hospital
Boston, MA

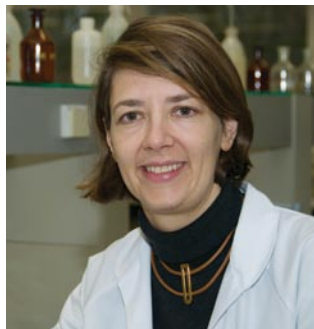
Osteolytic bone disease (OBD) is a frequent complication of multiple myeloma. It is characterized by reduced bone formation and increased bone resorption, resulting in increased risk of fractures. Myeloma cells secrete several cytokines that promote bone resorption by interacting with specific receptors. MLN3897 (Millennium Pharmaceuticals, Cambridge) is a novel, orally available inhibitor of the cytokine receptor CCR1. It has a safe toxicity profile, and its anti-inflammatory properties are under study in rheumatoid arthritis and multiple sclerosis patients. Studies conducted by Dr. Vallet and her colleagues have shown that MLN3897 blocks the formation and activity of osteoclasts cells, resulting in decreased bone resorption. Importantly, they have also shown that MLN3897 reduces myeloma cell growth by inhibiting the growth and

CONTINUES ON PAGE 8

GRANT RECIPIENTS — continued from page 7

survival advantage conferred on them by the bone marrow microenvironment. Therefore, MLN3897 may be an effective treatment for osteolytic bone disease in myeloma patients. Dr. Vallet will study these potential anti-osteolytic and anti-myeloma effects of MLN3897 in an in vivo model. Data generated from these studies will provide the framework for clinical trials in myeloma patients with bone disease.

“Targeting Multiple Myeloma with Nanobodies: study in the 5TMM model”



Karin Vanderkerken, PhD
Vrije Universiteit Brussel
Brussels, Belgium

Dr. Vanderkerken's project investigates using nanobodies in targeting multiple myeloma. Nanobodies are single-domain antigen binding entities, roughly four times smaller than a classical antibody fragment, and very stable. Nanobodies will be generated after immunizing camels with a myeloma-specific antigen, followed by the production of these nanobodies in vitro using different molecular biological techniques. The biodistribution of the nanobodies will be assessed by labeling the nanobodies with ^{99m}Tc, injecting them in myeloma bearing mice, and monitoring in vivo by a combination of gamma tomography and CT imaging. When proven to target the myeloma cells with a high specificity, these nanobodies will be coupled to various molecules and/or compounds to treat the myeloma cells locally, thereby minimizing unwanted toxic side effects.

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“Targeting β 2-Microglobulin for Induction of Tumor Cell Apoptosis in Myeloma”



Jing Yang, PhD
MD Anderson Cancer Center
Department of Lymphoma
and Myeloma
Houston, TX

Multiple myeloma disease relapses despite the most aggressive treatment available today. Successful targeted monoclonal antibodies (mAbs) therapy has had clinical efficacy in lymphomas (anti-CD20 mAbs) and in breast cancer (anti-EGFR mAbs).

Unfortunately, due to the lack of an available therapeutic antibody in clinical trials, no such approach has yet been developed for myeloma. The overall goal of Dr. Yang's research project is to develop more effective therapeutic mAbs to eradicate myeloma cells for clinical study. Dr. Yang and her colleagues recently made a novel and exciting discovery that mAbs specific for human β 2-microglobulin (β 2M) had remarkably strong apoptotic activity both in established myeloma cell lines and in primary myeloma cells from patients. These mAbs selectively targeted and killed myeloma cells in coculture with a large amount of normal hematopoietic

cells without damaging normal cells. Cell death occurred rapidly, without the need for exogenous immunological effectors. Furthermore, the mAbs were also active and therapeutic in vivo in xenograft mouse models of myeloma. In the proposed project, Dr. Yang and colleagues will develop strategies to enhance the antimyeloma efficacy of mAbs. These strategies will include sensitizing myeloma cells to mAb-mediated apoptosis with interferon- α , combining chemotherapy drugs with mAbs to synergize antimyeloma effects, and using immunological effectors to enhance mAb-induced myeloma cell apoptosis. Collectively, these studies will lead to a better understanding of the role of anti- β 2M mAbs in myeloma, and will enable the development of a more potent therapeutic antibody to be translated into clinical application.

2008 IMF Japan Aki Award***

“Establishment of Models for Multiple Myeloma”



Yutaka Okuno, MD, PhD
Department of Hematology
Kumamoto University
Kumamoto, Japan

The transcription factor PU.1 is essential for myeloid and B-cell development. In his recent research study, Dr. Okuno and colleagues found that PU.1 is down-regulated in the majority of human multiple myeloma cell lines and a subset of myeloma patients, in contrast to relatively high expression of PU.1 in normal plasma cells. Conditional expression of PU.1 in myeloma cell lines induced complete growth arrest and apoptosis. Patients in this low PU.1 expression subset may have a poor prognosis. It is possible that down-regulation of PU.1 might induce unregulated plasma cell growth that leads to myeloma. Therefore, Dr. Okuno and colleagues are generating conditional knockout mouse models that lack PU.1 expression only in plasma cells. Those mice would help understanding the role of PU.1 down-regulation in myeloma cells. This may represent a new therapeutic strategy for treatment of myeloma patients.

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* This project has received second-year funding.

** This project has been funded in the name of Jeffrey Stafford (by the WAMP Swim-a-Thon member fundraising event organized by Mr. Stafford's children) and in the name of Mark Rubin (by the Music Against Myeloma member fundraising event organized by son Slava Rubin).

***This annual myeloma research grant was instituted in 2002 by IMF Japan in memory of its founder, Aki Horinouchi.

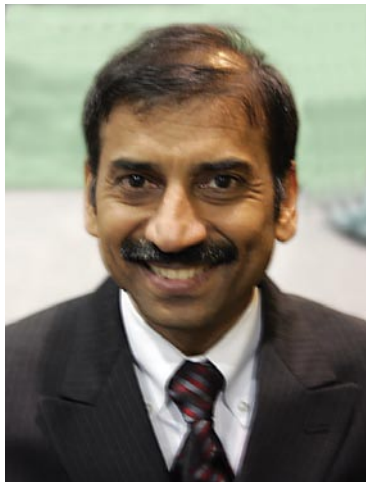
The IMF offers grants to doctors and researchers working in the field of myeloma. To apply for 2009 funding, please download a grant application from the IMF website www.myeloma.org or call 800-452-CURE (2873) to request an application to be mailed to you.

SERUM FREE LIGHT CHAIN TESTING FOR DIAGNOSIS AND MONITORING

Myeloma Today in conversation with Dr. Sundar Jagannath

Please give us a brief overview of myeloma diagnosis and monitoring.

Multiple myeloma is a cancer of the plasma cells. Cancerous plasma cells start from one single cell and multiply over time into a large population of “monoclonal” cells. Plasma cells make antibodies (proteins also known as immunoglobulins) that can be detected and measured in the blood of approximately 80% of myeloma patients. The monoclonal protein made by the malignant plasma cells gives rise to the M-spike in the serum protein electrophoresis (SPEP) test, which has been used for many years to screen for myeloma, MGUS, and AL amyloidosis. The protein also shows up in the urine as Bence Jones protein, named after the doctor who first published his study of this protein in the urine of a myeloma patient in 1848. For many years, we used simple blood and urine tests to diagnose myeloma, and to monitor treatment and disease progression. These tests were surrogate markers that allowed us to reduce the number of bone marrow biopsies and imaging scans that a patient would have to be subjected to.



Sundar Jagannath, MD
St. Vincent's Comprehensive Cancer Center
New York Medical College
New York, NY

Would you please explain the relationship between cancer cells and antibodies?

The antibody is made up of a big protein, which we call “heavy chain,” and a small protein known as “light chain.” Normal plasma cells make complete antibodies, where one big and one small protein are attached to each other, with each antibody having two sets of these paired proteins. The job of the normal plasma cells is to protect us from infection. But cancer cells are only interested in growing and multiplying, not in making antibodies. Some cancer cells do make big and small proteins in equal quantity – such malignant cells are still good antibody producers – and these proteins show up in the blood as the M-spike, and corresponding IgG or IgA will become elevated.

But other cancer cells become what we would term more “de-differentiated” – they are more immature, reproduce more rapidly, and are less efficient at making antibodies. Sometimes such cells make few big proteins but lots of small proteins, which results in an excess of light chains. In the past, we were not able to measure the light chains in the blood because small proteins can be easily filtered out by the kidneys into the urine as Bence Jones protein. In some patients, the kidneys re-absorb quite a bit of the protein that has been filtered, so the amount of Bence Jones protein that can be measured does not accurately correlate with the amount of light chain protein produced by the cancer cell. So there are groups of patients whose myeloma has historically been difficult to monitor. For monitoring the disease in such patients, there was no alternative to performing frequent bone marrow aspirations and imaging scans.

How many myeloma patients fall into these categories?

Light chain myeloma occurs in 10%-20% of patients. These patients don't make the heavy protein at all, so no M-spike abnormality can be measured in blood tests. In such cases the IgG or IgA numbers are actually low. But a 24-hour urine collection will reveal lots of light chain protein in the urine so, in the past, this was our best way to measure myeloma in such patients.

In 2%-3% of myeloma patients, the cancer cells have become so de-differentiated that they have lost all ability to make protein and release it into the blood. This is called “non-secretory” myeloma. In the past, only frequent bone marrow biopsies and imaging scans could effectively help to monitor such patients.

Has this changed with the availability of the Freelite™ technology?

Well into the year 2000, there was no available serum test to identify the light chain in the blood. We could only measure complete proteins in the blood and the light chain in the urine. Then, thanks to doctors in the UK, there was a major breakthrough in the detection and monitoring of myeloma. They created the antibody that would recognize the light chain. Of course, since all normal proteins have equal numbers of light and heavy chains, it was most important to be able to specifically detect excess light chain protein that was free of the heavy chain. With Freelite Serum

Free Light Chain Assays, we finally had a new technology capable of detecting and measuring free light chain in the blood.

This was a huge breakthrough that made several important things possible. Freelite has enabled us to monitor disease in patients with a monoclonal protein that cannot be measured by conventional electrophoretic methods, so we can now monitor all but a very few myeloma patients. Patients who were previously unable to participate in clinical trials can now have access to the same opportunities as patients with secretory myeloma. Freelite has reduced the need for urine studies, especially the 24-hour urine collection, which can be very impractical or inconvenient for patients. Together with the use of SPEP and immunoelectrophoresis, Freelite has improved the diagnosis of monoclonal gammopathies and the risk assessment for progression of MGUS (monoclonal gammopathy of undetermined significance) to myeloma. For patients with primary or AL amyloidosis, we now have a new way to monitor their disease and measure the efficacy of their treatment. If a patient has both light chain and heavy chain myeloma, Freelite allows us to detect the response to treatment much more quickly than previously possible. Also, in patients who make excess light chain, Freelite is a much more sensitive and precise way to confirm if a patient has achieved complete remission.

The Freelite Serum Free Light Chain Assay is not an experimental test – it is FDA-approved and widely available, so patients can ask for it wherever they are receiving their medical care. This is an important new advancement in technology that has improved the lives of many people living with myeloma and other B-cell dyscrasias. **MT**

Editor's Note: Dr. Jagannath is Chief of the Multiple Myeloma Program and Bone Marrow and Stem Cell Transplantation Program at St. Vincent's Comprehensive Cancer Center (SVCCC) and a professor of medicine at New York Medical College. He has received numerous awards for his work related to the study and treatment of myeloma. Dr. Jagannath is an Editor-in-Chief of *Clinical Lymphoma & Myeloma*. He has been published in numerous medical journals, for which he is also a peer reviewer. Dr. Jagannath is an active member of the American College of Physicians, the American Society of Clinical Oncology, and the American Society of Hematology.

UPDATE ON THE IMF'S BANK ON A CURE® RESEARCH INITIATIVE

Myeloma Today in conversation with Dr. Brian Van Ness

What are the most recent developments in the IMF's Bank On A Cure® research initiative?

Bank On A Cure was initiated by the IMF to establish a consortium and centralized approach for DNA banking and genotyping in multiple myeloma. Our mission is to create a DNA bank and develop genetic correlates with myeloma risk, progression, response, and toxicities associated with therapies. Bank On A Cure is an international effort that includes investigators from the US and abroad, and a representative patient advocate.

In October 2007, we sought and received affiliate membership in the Pharmacogenomics Research Network (PGRN), a nationwide collaboration of scientists working on advancing knowledge of the genetic basis for variable drug responses – identifying genetic variations that lead to differences in therapeutic response – which is very much in line with the goals of Bank On A Cure. The PGRN consortium is comprised of 12 independently-funded interactive research groups, with each research group focusing in an identified area of pharmacogenetics. The PGRN is sponsored by the National Institute of General Medical Sciences (NIGMS), which is one of the National Institutes of Health (NIH). NIGMS supports important scientific research that lays the foundation for advances in disease diagnosis, treatment, and prevention.

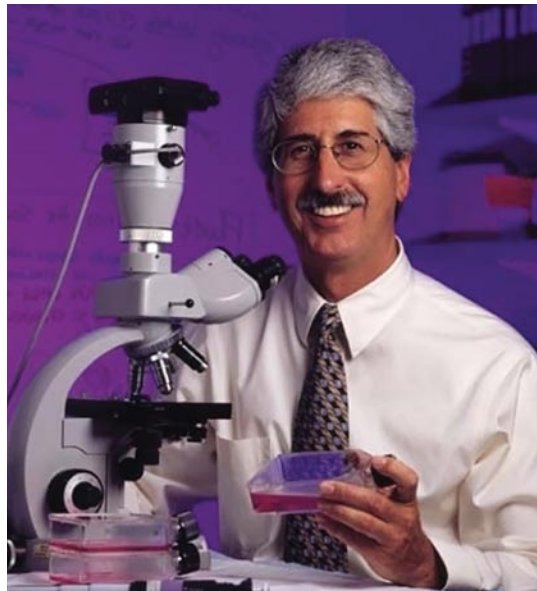
In the US, we have developed Bank On A Cure in conjunction with large national clinical trial groups, such as the Eastern Cooperative Oncology Group (ECOG) and the Southwest Oncology Group (SWOG), as well as with institutional centers of large clinical trials, such as Mayo Clinic and the University of Arkansas for Medical Sciences (UAMS).

In Europe, Bank On A Cure has recruited the British Medical Research Council (MRC) trials, the Dutch HOVAN trial, and are working with the French, German, Spanish, and Italian trial groups. Our goal is to create a bank of 10,000 myeloma patient samples, and we are about half-way to that goal.

What are some of the basic components of Bank On A Cure?

We have done a lot of genetic analysis on samples received from myeloma clinical trials. These trials have a very good set of therapeutic controls, and clinical data and follow-up information on every patient. We have studied data from several large Phase III myeloma clinical trials and have found meaningful information on survival, incidence and severity of bone disease, and the incidence of adverse effects from several specific myeloma drugs.

Gathered from around the world, Bank On A Cure data is assembled in Seattle, WA, at Dr. John Crowley's Cancer Research And Biostatistics (CRAB®), an international leader in designing, managing, and analyzing



Brian Van Ness, PhD
Institute of Human Genetics
University of Minnesota
Minneapolis, MN

therapeutic and prevention cancer clinical trials. CRAB assures accurate trial implementation and reliable data analyses. At CRAB, we are able to combine data sets from clinical trials both in the US and abroad. The IMF is committed to developing conglomerate data analysis of genetic variations, and this follows on the heels of the successful international conglomerate analyses that resulted in the new International Staging System (ISS). The Bank On A Cure platform from SNPs is identical in US and in European laboratories, so the data sets can be easily merged.

Samples have also been collected directly from myeloma patients through the Bank On A Cure “swish and spit” kits, and we are working with the National Cancer Institute (NCI) on looking at genetic risk factors that are associated with environmental exposures in order to develop a risk assessment tool that might provide a prediction of risk for myeloma. We are working with the InterLymph Consortium, the NCI group that is an open scientific forum for epidemiologic research.

What are some of the significant advances that have resulted from Bank On A Cure?

One of the unique contributions made by Bank On A Cure is the creation of a custom single nucleotide polymorphism (SNP) chip, globally targeting a large array of cellular functions and interactions. This custom SNP gene panel was developed in collaboration with Affymetrix to target coding non-synonymous and regulatory SNPs in targeted genes involved in ADME (absorption, distribution, metabolism, and excretion of drugs), DNA repair, cell cycle, inflammatory response, growth factor/cytokine, signaling, etc. that were determined to have potential importance in tumor progression and response.

We have used a wide variety of analytical techniques including pathway analysis, creating cluster and partitioning trees of SNP group effects, vector algorithms that identify group associations, and multi-variate analyses combining SNP profiles with tumor cell gene expression profiles.

To date, the Bank On A Cure SNP panel has been run on approximately 1,000 myeloma patient samples, and 200 controls. There are three current Bank On A Cure studies. I am leading the investigation that focuses on study design and association with survival. Dr. Brian Durie is leading the investigation of bone disease associated with UAMS studies. Dr. Gareth Morgan is leading the investigation of genetic predictors of adverse drug effects, particularly blood clotting. The data will be analyzed in association with specific clinical end-points. Three manuscripts are currently in preparation. Dr. Morgan and Dr. Dalsu Baris (NCI) are working to develop risk assessments by doing case-control studies.

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CLINICAL TRIALS UPDATE: ZOLINZA® (VORINOSTAT)

Treatment Demonstrates Clinical Activity in Phase I Studies of Patients with Advanced Multiple Myeloma

ZOLINZA® (vorinostat) is a histone deacetylase (HDAC) inhibitor. In some cancer cells, excess amounts of the HDAC enzyme prevent the activation of genes that control normal cell activity. Based on *in vitro* studies, vorinostat is believed to decrease the activity of HDAC, allowing for the activation of genes that may help to slow or stop the growth of cancer cells.

Vorinostat (approved in October 2006 for the treatment of cutaneous manifestations in patients with cutaneous T-cell lymphoma (CTCL), a type of non-Hodgkin's lymphoma, who have progressive, persistent, or recurrent disease on or following 2 systemic therapies) is currently being studied in multiple myeloma. Data from two investigational Phase I trials of vorinostat in combination with bortezomib (VELCADE®) were presented at the 49th annual meeting of the American Society of Hematology (ASH). Results demonstrate promising anti-tumor activity in patients with relapsed or refractory myeloma, even for patients who have previously failed treatment with bortezomib therapy.

Data from one study led by Dr. Donna M. Weber of the MD Anderson Cancer Center demonstrated that 48% of patients had a partial or minimal response from the vorinostat and bortezomib combination treatment. Data from a second study, sponsored by the National Cancer Institute (NCI) under a Clinical Trials Agreement with Merck & Co. Inc., and led by Dr. Ashraf Z. Badros of the University of Maryland demonstrated that



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Associate Professor
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Greenebaum Cancer Center
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43% of patients had a partial or greater response from the combination treatment. In addition, 25 patients in the 2 studies, who previously received bortezomib have demonstrated that 48% of the patients had either a VGPR, PR or MR.

These first Phase I myeloma trials of vorinostat in combination with bortezomib evaluated the safety and efficacy of vorinostat as part of a combination regimen in patients with relapsed and/or refractory myeloma. The primary objective of both trials was to determine the maximum tolerated dose (MTD) of vorinostat in combination with bortezomib in these patients; secondary objectives included assessment of activity (using European Group for Blood and Marrow Transplantation criteria for Dr.

Weber's study and International Working Group Criteria for Dr. Badros' study) and safety and tolerability of the combination regimen. Bortezomib is regarded as a standard treatment option against myeloma, while the use of vorinostat in myeloma patients is investigational.

Larger clinical studies are needed to confirm these results, and Merck & Co. Inc. is evaluating plans to accelerate testing of vorinostat in combination with bortezomib in the randomized clinical trial setting to further define the clinical activity in relapsed or refractory myeloma. For more information, please visit www.merck.com or call the IMF Hotline at 800-452-CURE (2873). **MT**

BANK ON A CURE UPDATE — continued from previous page

What are the benefits of Pharmacogenomics Research Network membership?

Our Bank On A Cure consortium is committed to both creating and sharing data bases. In fact, we provide a fully annotated SNP panel via an open access web link, and we are happy to provide more comprehensive data to the PGRN. There are multiple benefits in doing so. Firstly, the PGRN has a process in place by which they discuss and share data analysis, and we hope that the information gleaned from the Bank On A Cure project will be of interest and of use to other investigators. Secondly and significantly, we hope that the input we receive from other investigators will contribute to improving the Bank On A Cure SNP design. All PGRN members benefit from a combined and open source of genetic information, and our Bank On A Cure consortium has sufficient important data and analysis to contribute to the network. We have some very interesting genetic association to share with other investigators.

Given the vast amount of research data, arriving at the key meaningful statistical analysis is a challenge. The PGRN is committed to identifying approaches that provide some of the best answers in understanding the link between genetics and therapeutic outcomes. The PGRN holds three meetings a year for participants to discuss their work and bring new ideas to the table. The next PGRN meeting, which will take place in January, is

devoted specifically to data analysis and new approaches in statistics and genetic data.

But the bottom line is that, with the PGRN, Bank On A Cure has now established its connection with a nationally prominent consortium network. The sharing of information among PGRN participants will benefit both Bank On A Cure and investigators working on other diseases. (Of course, we are committed to data sharing within the limits of HIPPA and protecting patient anonymity.)

How is the information garnered from Bank On A Cure applicable to other diseases?

I would argue that, while myeloma is leading the way as an international consortium, what we are doing is establishing a paradigm for genetic analysis in a number of different diseases. We are looking for genetic associations, and the same genetic variants we see in myeloma can be examined in other diseases. We have established a bank, a genetic panel, and a platform to develop the technologies, and everyone stands to benefit from these efforts. **MT**

Editor's Note: Dr. Van Ness is Co-Director of Bank On A Cure. He is Director of the Division of Medical Genomics in the Institute of Human Genetics, and is Professor and Head of the Department of Genetics, Cell Biology, and Development at the University of Minnesota.

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CELEBRATING PETER BOYLE

An Evening of Comedy with Family and Friends



Lorraine Boyle (center), with daughters Lucy and Amy Boyle, thanks event performers Patricia Heaton, Richard Lewis, Fred Willard, Doris Roberts, Martin Short, and Ray Romano

The IMF held its annual Gala event on November 10, 2007. This year's event was

truly amazing and quite a break from past events – it was *Celebrating Peter Boyle – An Evening of Comedy with Family & Friends*.

The idea for this event was born a year ago, shortly after Peter Boyle passed away. Dr. Brian G.M. Durie

was Peter's doctor and saw him when he would come to L.A. from New York for the shooting of *Everybody Loves Raymond*, or on other movie business. He saw him "under the radar," as Peter didn't want anyone to know that he had been diagnosed with multiple myeloma. In time, Dr. Durie and I became friends with Peter and his wife, Loraine.

Lorraine and I spoke on occasion about Peter and Loraine becoming involved with the IMF; she was

hesitant because they wanted to keep Peter's struggle with myeloma a private matter.



Peter Boyle's wife, Loraine (center), with daughters Lucy and Amy Boyle

After Peter lost his four-year battle with myeloma, his family agreed that a fitting memorial would be to raise funds in support of research into the disease, as well as to raise myeloma awareness. Thus began the year-long road that culminated with a spectacular "Celebration."

Lorraine reached out to Peter's friends and fellow cast mates from *Everybody Loves Raymond*.

Her first call was to Ray Romano, who would headline and host the show. She kept calling, and they all said yes – Patricia Heaton, Doris Roberts, and Fred Willard. Brad Garrett was already committed to be out of town; however he pledged to support the event.



IMF Chairman Dr. Brian Durie and President Susie Novis

Special Event

The all-star comedy line-up took shape including several of Peter's other good friends: Jeff Garlin, Richard Lewis, and Martin Short.

Stu Smiley, Robert Morton, and Ken Shapiro all said yes when the call came from Loraine as to who would help produce and direct the show. She put together an Honorary Committee that reads like "Who's Who in Hollywood!"



Actor Ray Romano hosted the show, keeping the audience laughing between the acts and sharing poignant memories of Peter Boyle from their years together on *Everybody Loves Raymond*

The IMF is grateful to all of our sponsors, led by Presenting Sponsor Celgene, for helping to provide the support to make this event so successful. *Please see the complete list of all our sponsors.*



Comedian Richard Lewis made the audience laugh with his unique view of the world



Actor and comedian Jeff Garlin cracked up the audience with his humorous take on everyday life



Fred Willard performed a campy musical number "Artificial Flowers."

Bringing an event like this to fruition took months of hard work, commitment, and dedication from so many people. It began with Loraine and the outstanding team at the IMF – spearheaded by Heather Cooper Ortner, Spencer Howard, Randi Liberman, and Jim Needham – and included every staff member, family, and friends. The entire cast and crew donated their time and talent.

On Saturday, November 10, 2007, the doors opened, and the show began complete with red carpet arrivals and the media on hand. On the carpet

were Loraine and her daughters, Lucy and Amy. Along with the cast for the show were media mogul Mike Medavoy, actors Billy Baldwin, Michael Keaton, Alfre Woodard, Joe Walsh, John Glover, Peter Gallagher, Teri Garr, and Thomas Ian Nicholas. Dr. Durie and Susie Novis also walked the press line. CNBC News, Access Hollywood, TV Guide Channel, New2Air, WireImage, and the Hollywood Reporter covered the event, which was crucial because raising awareness about myeloma is as important as raising money.



Mike Medavoy, President and CEO of Phoenix Pictures, served as honorary co-chair for the event and provided the opening remarks for the show



Renowned actor and comedian Martin Short brought the house down with his hysterical song "Autumn Makes Me Want to Cheat on My Wife."



Patricia Heaton shared her personal memories of Peter Boyle

Honorary Co-Chairs

Irena & Mike Medavoy • Julie Chen & Leslie Moonves

Chair

Lorraine Boyle

Vice Chair

Tova Bonem

Honorary Committee

Kevin & James Abernathy

Alec Baldwin

Candice Bergen

Halle Berry

Lisa Birnbach

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Carl Gottlieb

Robin Green & Mitchell Burgess

Deborah & Allen Grubman

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Jenny & Robert Morton

Annette O'Toole & Michael McKean

Diane Passage & Ken Starr

Chynna Phillips & William Baldwin

Paula Prentiss & Richard Benjamin

Doris Roberts

Anna & Ray Romano

Jane Rose

Janet & Marvin Rosen

Monica & Philip Rosenthal

Victoria Tennant & Kirk Stambler

Chrisann Verges & Ricky Jay

Mary & Fred Willard

Alfre Woodard & Roderick Spencer



CONTINUES ON NEXT PAGE

Special Event

CELEBRATING PETER BOYLE — continued from page 14

A cocktail hour began the evenings' festivities, and with The Wilshire Ebell's beautiful sprawling setting, more than 500 guests floated from room to room, chatting with one another, enjoying a drink, and delicious hors d'oeuvres.



Ray Romano and Loraine Boyle at the post-show VIP Champagne and Dessert Reception

With the show about to begin, guests made their way into the theatre where they were joined by another 600 people who were there just for the show.

Mike Medavoy, chairman and CEO of Phoenix Pictures opened the show. He introduced a short video about the IMF, which highlighted the foundation's areas of focus and featured

patients' experiences in dealing with myeloma. Dr. Durie and I then came on stage, greeted the guests and spoke about the IMF and myeloma. Dr. Durie talked about the Bank On A Cure[®] DNA initiative, current research, and possible links to what may cause other cancers. Our message was one of collaboration, the importance of working together to end myeloma, and how advances made in myeloma can help other diseases too.

In memory of Peter Boyle, a wonderful retrospective film montage that featured highlights from his extensive body of work was shown. It was funny, poignant, moving, and reminded people of what an incredibly talented and versatile actor Peter was.

A huge applause followed the film and Ray Romano, host of the show took the stage; the audience spent the next hour and a half in raucous laughter. Jeff Garland and Richard Lewis also performed outrageous, bawdy, and hysterically funny comedy routines. Fred Willard performed a



Doris Roberts reminisced about Peter Boyle and then shared a moment on stage with Ray Romano

campy and fun musical number, "Artificial Flowers," accompanied by noted pianist Jeff Babko, Paul Wilson on violin, and five talented backup singers. Patricia Heaton and Doris Roberts both shared funny and touching memories of working

with Peter; it is clear they miss him deeply. Brad Garrett, who couldn't be there in person as he was out of town on location, was there virtually, and he too expressed his deep affection for Peter. The finale of the show was Martin Short being Martin Short; his act culminating in a hysterical musical number called "Autumn Makes Me Want to Cheat on My Wife," which brought the house down.

The stars from the show joined the guests for an after-show champagne and dessert party; they were very gracious and open to having their pictures taken with the fans. People once again enjoyed the surroundings and each other's company while they chatted about the show, sipped champagne, and nibbled on the delicious desserts as the evening came to a close.



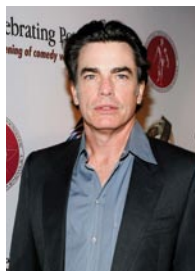
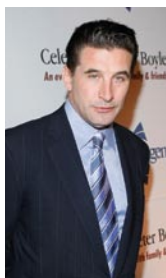
(l to r) Loraine Boyle, Fred Willard, actor Michael Keaton and Peter Boyle's sister, Alice Duffy, at the post-show VIP reception

The IMF raised \$650,000 to support the Peter Boyle Memorial Fund, and we're forever grateful to Loraine, Lucy and Amy Boyle, and their family and friends for making the event possible and a huge success!

We hope you will join us for next year's event! We'll let you know the date soon! **MT**



Guests enjoy champagne and dessert at the post-show VIP reception at the historic Wilshire Ebell



Other celebrity guests in attendance: (l to r) John Glover, William Baldwin, Joe Walsh, Alfre Woodard, Peter Gallagher, Kimberly Alexander, Thomas Ian Nicholas



Nurse Leadership Board

NLB ACTIVITIES UPDATE

Myeloma Today in conversation with Jeanne Westphal and Ginger Love

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

Elizabeth Billoti, ANCP, ONP, AOCN
St. Vincent's Hospital
New York, NY

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

Kathleen Curran, RN, BSN, BS
University of Pittsburgh
Pittsburgh, PA

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

Beth Faiman, RN, MSN CNP, AOCN
Cleveland Clinic
Taussig Cancer Center
Cleveland, OH

Maria Gavino, RN, BSN
M. D. Anderson Cancer Center
Houston, TX

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

Bonnie Jenkins, RN, OCN
University of Arkansas for Medical Sciences
Little Rock, AR

Kathy Lilleby, RN
Fred Hutchinson Cancer Research Center
Seattle, WA

Ginger Love, RN
University Hematology Oncology Care
Cincinnati, OH

Patricia A. Mangan, MSN, CRNP
Hospital of the University of Pennsylvania
Philadelphia, PA

Emily McCullagh, RN, NPC, AOCN
Memorial Sloan-Kettering Cancer Center
New York, NY

Teresa Miceli, RN, BSN
Mayo Clinic
Rochester, MN

Kena Miller, MSN, FNP
Roswell Park Cancer Institute
Lewiston, NY

Katy Rogers, RN
Sidney Kimmel Comprehensive Cancer Center
Johns Hopkins University
Baltimore, MD

Sandra Rome, RN, MN, AOCN
Cedars-Sinai Medical Center
Samuel Oschin Comprehensive Cancer Institute
Los Angeles, CA

Stacey Sandifer, RN, BSN
Cancer Centers of the Carolinas
Greenville, SC

Lisa Smith, MSN, FNP, AOCN
Cancer Centers of the Carolinas
Greenville, SC

Joseph Tariman, RN, MN, ARNP-BC, OCN
Northwestern University
Seattle, WA

Jeanne Westphal, RN
Meeker County Memorial Hospital
Litchfield, MN

Members of the Nurse Leadership Board (NLB) recently divided into new task forces. Please tell us about that.

Jeanne: Once the NLB members completed our first major project of developing nurse guidelines for enhanced patient care, and these consensus guidelines proceeded to journal publication, we turned our attention to addressing Patient Education, Nurse Education, Long-Term Side Effects, and Publications. I am the leader of the Publications task force, which also includes my colleagues Kathy Lilleby, Joseph Tariman, and Tiffany Richards. Our team's mandate is to heighten the profile of myeloma in the press and to make sure that information about the disease and its treatments reaches as many people as possible. In addition, we participate on the Long-Term Side Effects task force, as do all other members of the NLB.

Ginger: This is an exciting time in myeloma care because, with novel therapies, patients are living longer after diagnosis. But side effects of these therapies can greatly impact a patient's ability to live a full life. I am leading the Patient Education task force, which also includes Deb Doss, Bonnie Jenkins, Teresa Miceli, and Jacy Boesiger. We are currently fine-tuning the patient education slide presentations for talks at the IMF Patient & Family Seminars. Because not all patients are able to travel to attend these meetings, we are also working on developing presentations for outreach visits to myeloma support groups. In addition, we are exploring other means of effectively delivering information to patients, and this may include printed publications. It is essential to present patients with comprehensive information, while keeping the information very accessible.

How were NLB members divided into these task forces?

Jeanne: We voted our personal preferences, and it seems that everyone is working in their area of interest. Teaching patients is one of my favorite things to



Jeanne Westphal, RN
Meeker County
Memorial Hospital
Litchfield, MN



Ginger Love, RN
University of Cincinnati
College of Medicine
Cincinnati, OH

do. Patient Education is incredibly helpful for them and very rewarding for me. I recently spoke to about 30 members of the local myeloma support group about side effects and it was one of the best experiences I've had. They've invited me to return in February and I am really looking forward to that!

What other NLB projects are you currently involved in?

Jeanne: While the members of the NLB are divided into teams, we all support one another, both as groups and as individuals. So ultimately everyone participates in all the NLB activities. One new project I'd like to specifically mention was suggested to the NLB by Dr. Brian G.M. Durie, chairman of the IMF. We will be working on defining a process to collect data from myeloma patients, capturing the information by means of a questionnaire. The goal is to examine the long-term effects of myeloma therapies, from conventional chemotherapy to novel agents. We have finally reached the point in the field of myeloma where there is lots of data to collect on the effects of long-term therapies!

How frequently do members of the NLB interact with one another?

Jeanne: We meet several times a year. Most recently, we met at the 49th annual meeting and exposition of the American Society of Hematology (ASH) in Atlanta. The majority of the NLB members were in attendance, which gave us an opportunity to meet multiple times in the course of the ASH meeting. But we also organize and attend our own NLB retreats.

Ginger: The 2008 NLB meetings are in the process of being scheduled. In the meantime, we have a conference call scheduled for January, plus the IMF has set up a web portal to give us easy access to communication and conferencing. Members of the NLB are wonderful individuals, who have a tremendous cumulative depth of knowledge about myeloma, and it's very helpful to be able to tap into so much nursing experience! **MT**

IMF HOTLINE COORDINATORS ANSWER YOUR QUESTIONS

The IMF Hotline 800-452-CURE (2873) is staffed by Debbie Birns, Paul Hewitt, and Nancy Baxter. The phone lines are open Monday through Friday, 8am to 4pm (Pacific Time). To submit your question online, please email TheIMF@myeloma.org.

I have been diagnosed with “smoldering myeloma.” Is that an earlier stage than stage I?

There are several names for smoldering myeloma, and they are used interchangeably. Smoldering myeloma, indolent myeloma, asymptomatic myeloma, and Durie Salmon Stage IA myeloma are synonyms for the same condition, as defined in the International Myeloma Working Group’s Myeloma Management Guidelines (The Hematology Journal, 2003). The basic criteria for smoldering or asymptomatic myeloma set forth in the Management Guidelines are: hemoglobin value of > 10 g/dl, serum calcium < 10.5 mg/dl, bone X-ray normal, M-protein rates of < 5 g/dl for IgG or < 3 g/dl for IgA, and < 4 g of urine light chain M-protein on electrophoresis in a 24-hour period. The requirement for smoldering myeloma is that the patient should have no symptoms or organ damage; that is, no Calcium elevation, kidney (Renal) dysfunction, Anemia, or Bone disease — the so-called CRAB criteria.

Is there anything I can do to prevent smoldering myeloma from progressing to active myeloma?

Because patients with smoldering myeloma are monitored by their doctors without being given treatment, this is an opportune time to concentrate on making life-style adjustments that can have a positive impact on your overall and immune system health: reduce stress, get regular sleep and exercise (nothing risky or high-impact), and eat well (avoid white flour, sugar, and fats, and increase whole grains, fresh fruits and vegetables, and lean protein). Red wine and the skin of red grapes are known to contain resveratrol, an anti-oxidant that is being studied for its anti-myeloma effects. Including these items in your diet, in moderation, may be beneficial as well.

In addition, especially for those who fall into the highest risk group for progression to active myeloma, there are clinical trials studying interventions that may prevent progression. Two that are now enrolling patients are a Phase II trial of celecoxib (Celebrex®), and a Phase III trial of zoledronate (Zometa®) with or without thalidomide (Thalomid®).

What are the risk factors that my smoldering disease will progress to active myeloma?

In the Fall 2007 issue of *Myeloma Today*, Dr. Robert A. Kyle mentioned his article entitled “Clinical Course and Prognosis of Smoldering (Asymptomatic) Myeloma,” which was published this past June in the *New England Journal of Medicine*.

Dr. Kyle and his colleagues, after long-term study of patients at the Mayo Clinic, used their data to create a three-tier chart that ranks the risks of progression from smoldering to active myeloma. The most predictive criteria, of the many studied, turned out to be the percentage of plasma cells in the bone marrow and the amount of monoclonal protein present in the blood. According to the Mayo data:

- Those at highest risk for progression have 10% or more plasma cells in their bone marrow and 3 grams or more of monoclonal protein per deciliter of blood. There is an 87% chance that within 15 years, they will



Hotline staff: Debbie Birns, Paul Hewitt, and Nancy Baxter

progress to active disease. The median time to progression is 2 years.

- In the middle risk group, patients have 10% or more plasma cells in the bone marrow, but less than 3 grams of monoclonal protein. Their risk of progression to myeloma in a 15-year period is 70%. The median time to progression is 8 years.

- In the lowest risk category, patients have less than 10% plasma cells in the bone marrow and less than 3 grams of monoclonal protein. Their risk of progression to active disease is 39% at 15 years. The median time

to progression is 19 years.

Based on the Mayo study, the overall probability of progression to active disease over a 20-year period is 78%.

In addition, an article recently appeared in the online publication *Blood First Edition* (October 17, 2007) by Dispenzieri, Kyle, et al. of the Mayo Clinic that is entitled “Immunoglobulin Free Light Chain Ratio Is an Independent Risk Factor for Progression of Smoldering (Asymptomatic) Multiple Myeloma.” Dr. Dispenzieri’s research enables clinicians to incorporate the results of the Freelite™ Serum Free Light Chain Assays test. (For more information on this test, please see interview with Dr. Sundar Jagannath in this issue of *Myeloma Today*.) Freelite measures the number of kappa and lambda free light chains and then expresses these numbers as a ratio, into the risk model for progression to active myeloma:

- Patients in the highest risk group whose kappa/lambda free light chain (FLC) ratio is < 0.125 (excess lambda light chains) or > 8 (excess kappa light chains) have a 75% risk of progression to active myeloma at 10 years. Those with a FLC ratio greater than or equal to (\geq) 0.125 or less than or equal to (\leq) 8 have a 51% risk of progression to active disease at 10 years.

- Patients in the intermediate risk group with a FLC ratio of < 0.125 or > 8 have 57% risk of progression to active disease at 10 years; those with a FLC ratio ≥ 0.125 or ≤ 8 have a 40% risk of progression at 10 years.

- Patients in the lowest risk group for progression to myeloma who have a FLC ratio of < 0.125 or > 8 have a 25% risk of progression to active myeloma at 10 years; those with a FLC ratio of ≥ 0.125 or ≤ 8 have a 23% risk of progression at 10 years.

An important caveat to remember in assessing risk is that these models are based on statistics and averages; they do not take into account the individual influences on risk that affect any given patient. They are good general guidelines, but are not entirely predictive of what will happen to you as an individual patient.

Why isn’t my doctor treating me now, before the myeloma progresses and I have symptoms? I thought that “early detection is your best protection.”

We realize that not treating myeloma before it causes symptoms seems counterintuitive, but randomized studies have failed to demonstrate any added benefit with immediate systemic therapy in patients with asymptomatic (smoldering) myeloma.

CONTINUES ON NEXT PAGE

MYELOSUPPRESSION

Myeloma Today in conversation with Kathy Lilleby, RN

What is myelosuppression?

Myelosuppression is a common and expected side effect associated with novel anti-myeloma therapies. Novel therapies for multiple myeloma include the immunomodulatory drugs lenalidomide (Revlimid[®]) and thalidomide (Thalomid[®]), and the proteasome inhibitor bortezomib (Velcade[®]). These agents have contributed to increased response rates and increased survival times for myeloma patients. However, they can cause myelosuppression – anemia, neutropenia, and thrombocytopenia. These side effects are manageable with appropriate medical interventions and patient and caregiver education. If not managed effectively, these side effects have the potential to be life-threatening, and to interfere with optimal therapy. In addition to these physiologic effects, myelosuppression may negatively impact a patient's quality of life.

Please define anemia, neutropenia, and thrombocytopenia.

Anemia is defined as abnormally low levels of red blood cells as measured by blood hemoglobin levels. Neutropenia is defined as abnormally low levels of neutrophils (granulocytes), and thrombocytopenia is defined as abnormally low levels of platelets (thrombocytes) in the circulating blood. Anemia can cause fatigue, thrombocytopenia can increase the risk of bleeding, and neutropenia can increase the risk of infection.

How is myelosuppression assessed, monitored, and managed?

All patients receiving novel therapies should have complete blood counts (CBC) monitored carefully. Monitoring of serum creatinine levels is also important because decreased renal function may result in more severe anemia. If prolonged myelosuppression persists after dose modification or withholding therapy, further evaluation is recommended to rule out other possible causes, such as a reaction to other medications or progressive disease.

The severity of anemia, neutropenia, and thrombocytopenia can be assessed using the National Cancer Institute (NCI) Common Terminology Criteria for Adverse Events (CTCAE), which uses grades 1 through 5 to identify treatment-related adverse events. These grades should be used to monitor hematologic toxicities and to determine which management strategies are needed.

Standardized precautions and interventions related to low blood counts vary among institutions. Sometimes blood products are given for anemia



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or thrombocytopenia at the discretion of the patient's physician. It is important to note that blood products should be leukocyte-reduced to reduce the risk of febrile reactions, human leukocyte antigen (HLA) allo-immunization, and cytomegalovirus (CMV) infection. General transfusion guidelines are available through the American Association of Blood Banks, America's Blood Centers, and the American Red Cross.

Management of anemia should take into account that some patients may tolerate a greater degree of anemia than other patients. Generally accepted practices to manage anemia include the use of erythropoiesis-stimulating agents and red blood cell transfusions. Generally accepted practices to manage neutropenia include initiation of institutional standards for neutropenic precautions, antibiotic therapy, and anti-fungal, anti-viral, and anti-pneumococcal prophylaxis. With thrombocytopenia, life-threatening hemorrhage may occur when platelet levels drop below $50 \times 10^9/L$, so management should include initiating institutional standards for thrombocytopenic precautions, mini-

mizing invasive procedures, and transfusing platelets prior to necessary invasive procedures or if there are signs of bleeding or bruising.

What else must patients and caregivers know?

Patients should familiarize themselves with the normal and critical values of blood counts. Patients should discuss any change in prescribed medications (such as increasing or decreasing doses or stopping a medication earlier than prescribed) with medical personnel prior to making any changes. Neutropenic precautions include proper hand washing and good overall personal hygiene to reduce contact exposures, wearing of face mask under certain circumstances to reduce airborne infections, and avoidance of crowds and potential contagion. Thrombocytopenic precautions include avoiding activities that can result in bruising or bleeding, and avoiding using aspirin, ibuprofen, or naproxen unless otherwise instructed (such as when prophylaxis is recommended for thromboembolic events).

It is important for members of the patient community to be educated on the basic concepts of myelosuppression. They should understand that anemia, neutropenia, and thrombocytopenia are manageable with the careful monitoring of blood counts, dose adjustment where indicated, prophylactic treatment and concomitant therapies as necessary, and patient and caregiver education. **MT**

HOTLINE — continued from previous page

In addition, not all patients with smoldering myeloma progress to active myeloma, and in those who do, progression may not occur for years. Not treating such patients spares them the side effects of treatment and prevents the development of myeloma cells that are resistant to treatment. It also means that by the time treatment might be needed, new and better treatment options are likely to be available.

How often, and with what tests, should my doctor be following me?

Depending on where the protein was initially found – urine or blood – the patient should be monitored with that corresponding test – SPEP or UPEP. In addition, baseline Freelite test, CBC, and Chemistry Panel

should be administered, and a set of full skeletal X-rays should be done. Physicians should repeat the lab tests 2 to 3 months after diagnosis to rule out an early active form; if the results prove to be stable, the tests should be repeated every 4 to 6 months. Bone marrow biopsy should be performed at diagnosis, and repeated only if there are signs of progression to active myeloma (i.e. any change in the CRAB criteria or rising lab values on SPEP, UPEP, or Freelite test). **MT**

Editor's Note: For more information, please call the IMF hotline at 800-452-CURE (2873).

SPOTLIGHT ON ADVOCACY

2007 Myeloma Advocacy Summary

By Christine Murphy, MA

Congress returned to Washington with unfinished legislative business in December and it is currently unclear which issues will be delayed until the New Year. Below is a summary of the major legislative issues affecting myeloma patients during 2007.

Cancer Research Funding Threatened

On November 13th, the President vetoed the fiscal year (FY) 2008 Labor, Health and Human Services (LHHS) Appropriations bill. The FY 2008 LHHS Appropriations bill included \$30 billion (\$1.1 billion or 3.8% increase over 2007) for the National Institutes of Health (NIH). The National Cancer Institute (NCI) received \$4.9 billion, an increase of \$128 million. The President's FY 2008 budget proposed a \$278 million cut below the FY 2007 level for the NIH.

The President's veto of the FY 2008 LHHS Appropriations bill was sustained in the House of Representatives on November 15th by a vote of 277-141. A total of 288 votes were needed to override the veto (2/3 of the current membership in the House). It is unclear what the next steps will be for the FY 2008 LHHS Appropriations bill.

Currently, Congress is working with the White House on a deal to cut all spending in the appropriations bills by \$11 billion. House LHHS Appropriations Subcommittee Chairman David Obey (D-Michigan) stated that future LHHS deals could eliminate all Congressional earmarks in an effort to move closer to the President's proposed budget. Based on past history, the FY 2008 LHHS Appropriations bill could be included as part of a larger omnibus appropriations bill in mid-December (after this issue of *Myeloma Today* goes to print).

CMS Nixes Proposed Clinical Trials Policy

Earlier this year, the Centers for Medicare and Medicaid Services (CMS) proposed numerous changes to the coverage policy of clinical trials for Medicare beneficiaries. The proposed onerous and cumbersome changes would have prevented Medicare beneficiaries with cancer from participating in clinical trials. Due to a concentrated effort by the cancer community and Congressional champions, CMS is making no changes to the current policy regarding Medicare coverage for clinical trials.

Additional Compendia Needed for Medicare

Section 1861(t)(2) of the Social Security Act (in conjunction with sections 1832 and 1861(s)(2)) requires Medicare to cover "medically accepted" uses of drugs



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and biologicals used in cancer chemotherapy regimens if the uses are supported by citations that are included, or approved for inclusion, in specified compendia. Three compendia were specified in the statute and unfortunately only one of the three compendia is currently published. The statute did state that CMS "may revise the list of compendia... as is appropriate for identifying medically accepted indications for drugs." Medicare beneficiaries battling cancer rely in significant part on these compendia listings for coverage of their oncology drugs. As a current and up-to-date list of compendia is critical to ensure that myeloma patients have access to the most appropriate treatments, the International Myeloma Foundation has been working to persuade CMS to name additional compendia for the Medicare program.

CMS Issues Final Policy on ESAs

CMS released a final coverage policy for erythropoiesis stimulating agents (ESAs). According to the CMS determination, coverage of ESAs will be limited to anemia caused by myelosuppressive anticancer chemotherapy for solid tumors, multiple myeloma, lymphoma, and lymphocytic leukemia. ESA therapy may be started when the hemoglobin level is below 10 grams per deciliter, is limited to those whose hemoglobin levels remain below 10 grams per deciliter, and may be continued no longer than 8 weeks after the last chemotherapy sessions.

Stem Cell Research Bill Vetoed

The Senate approved the Stem Cell Research Enhancement Act, S. 5, by a vote of 63 to 34 on April 11. All Democrats except Senator Bob Casey (D-Pennsylvania) and Senator Ben Nelson (D-Nebraska) voted for S. 5 and 16 Republicans voted in support of the bill. The House passed (by a vote of 253 to 174) its companion bill, H.R. 3, during its first "100 Hours." President Bush vetoed S. 5 on June 20.

2008 Myeloma Advocacy Goals

With many legislative issues to be finalized, the IMF is already planning advocacy activities for 2008. IMF will continue to advocate for increased funding for cancer research at the NIH and NCI. In addition to campaigning for higher cancer research allocations, IMF will continue to advocate for legislative issues that ensure myeloma patients continue to have access to high quality cancer care. To learn more about IMF's legislative activities, please visit www.myeloma.org. **MT**



IMF HOLDS EDUCATIONAL MEETINGS IN EUROPE AND ASIA

France

On September 14, the fifth annual IMF Patient & Family Seminar was held in Paris. Morgane Yvon assisted the IMF in preparing for this seminar, which returned to the spectacular Maison de l’Amerique Latine venue for another year. Drs. Jean-Luc Harousseau, Philippe Moreau, Jean-Paul Ferman, Thierry Facon, and Bernard Grosbois were joined by the Dr. Brian G.M. Durie, chairman of the IMF, in presenting a well-balanced discussion of themes of special interest to the myeloma community. An interactive session enabled audience members to respond to queries developed by Dr. Durie in conjunction with Dr. Harousseau. An elegant location, fascinating speakers, and a wealth of new information about developments in myeloma treatment and supportive care – all in all, this was a valuable day for everyone attending.

Italy

The IMF partnered with the Associazione Italiana contro le Leucemie-Linfomi e Mieloma (AIL) to present the fifth annual IMF Patient & Family seminar in Italy. This year’s meeting took place on September 21 at the Policlinico Federico II, high above the breathtaking bay of Naples. Prof. Mario Boccadoro was instrumental in bringing the IMF Patient & Family Seminar program to Italy. He held the first seminar in 2003 in Turin, his hometown, and hosted it again the following year. Since then, the IMF has had the pleasure of working with other prominent myeloma doctors in Italy who have hosted seminars throughout the country. In 2005, Dr. Maria Teresa Petrucci organized the event in Rome, and Drs. Patrizia Tosi and Michele Cavo held the program in Bologna the following year.

Approximately 135 attendees gathered at the Naples seminar, listening to presentations and participating in the question and answer sessions with the faculty panel, which included Drs. Durie and Boccadoro, as well as Drs. Antonio Palumbo, Felicetto Ferrara, Lucio Catalano, and Michele Cavo. In true Italian style, a delicious buffet lunch was set out in the lobby of the “aula magna,” or auditorium, providing an excellent setting for patients to mingle with each other, with the doctors, and with the IMF and AIL staffs. Bravo tutti!



Drs. Antonio Palumbo, Mario Boccadoro, and Brian G.M. Durie



Dr. Durie and Prof. Podoltseva (center) during patient consultation

algorithm, planning for treatment with or without transplant, and future perspectives in therapies. Dr. Durie was the featured speaker. “The lectures presented by the IMF are always eagerly anticipated by doctors from Russia,” said Prof. Eleonora I. Podoltseva, who organized the event. “Dr. Durie has been a presenter at every IMF conference held in St. Petersburg, and doctors travel great distances – from Central Russia, Southern Russia, and as far as from Siberia and the Far East – to hear him speak.”

Russia

On September 26, the IMF held its third clinical conference in St. Petersburg. Doctors from across Russia attended the meeting, which aimed to educate local doctors about the modern myeloma treatment

This year, the IMF had available the 2007 editions of the Concise Review and the Patient Handbook, newly translated into Russian, and the publications were distributed among physicians and members of the patient community. In addition, prior to the conference, Dr. Durie spent the day visiting a local hospital and providing case evaluations for 16 ambulatory and hospitalized myeloma patients. “Dr. Durie’s invaluable input helped to resolve several critical cases,” said Prof. Podoltseva. “We are grateful for the continued support and the resources that the IMF has made available both to our patients and to the physicians treating them.”

Spain

On October 20, the fourth annual IMF Patient & Family Seminar in Spain took place in Barcelona. This was the second time that the IMF held a seminar in Barcelona. Once again, the professional and convenient location of the Novartis auditorium was the venue, with Drs. Joan Bladé and Laura Rosiñol of the Hospital Clinic as the co-chairs of the event. They were assisted in presenting a very full agenda by Drs. Ramón Garcia-Sanz, Albert Oriol, Anna Sureda, Juan José Lahuerta, and Maria Teresa Cibeira. Representing the IMF were David Smith, Executive Director, and Gregor Brozeit, Director of IMF Europe. David supplemented his IMF presentation in Spanish with an introduction in Catalan which was quite well-received. The program included eight presentations and a very useful interactive session, which was prepared by Dr. Durie and translated by David Smith. Coffee breaks and a luncheon were provided by Novartis for the more than 100 attendees. Most of the attendees were from Barcelona and the province of Catalonia, but the province of Valencia was also well-represented.

Germany

Fall was a busy time for the IMF in Germany. Dr. Robert Kyle (chairman of the IMF Scientific Advisory Board) participated in five educational meetings for the myeloma patient community and for



Left to right: Ulrich Wolter, Angelika Horstkorte, Heinz Horstkorte, Dr. Robert Kyle, Gregor Brozeit, Dr. Peter Liebisch, and Dr. Rolf Pelzing

local clinicians as he visited Hamburg, Nürnberg, Würzburg, Nordrhein-Westfalen, and Berlin. Also, the IMF sponsored the participation of Dr. David Vesole (St. Vincent’s Hospital, New York City) to speak before two groups of German doctors at the annual University of Heidelberg Multiple Myeloma Days and to participate in the October meeting of the German-speaking Myeloma-Multicenter Cooperative Group.



Drs. Wen-Ming Chen, Sundar Jagganath, Mario Boccadoro, Brian Durie, Xiao-Jun Huang, and Jian Hou

China

The inaugural IMF-China Myeloma Symposium – Advances in Diagnosis and Treatment – was held on October 20 in Beijing. Dr. Durie chaired the

CONTINUES ON PAGE 21

IMFers RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia

On September 15, myeloma patient Richard Davies organized a fundraising hike to Pike's Peak in Colorado. Six hours, 6.8 miles and 3700 feet later, the group arrived at Barr Camp. "My pack weighed 23 pounds – my shoulder blades were killing me and I could hardly walk by the time we arrived at Barr Camp," said Richard, "But the scenery was glorious. There wasn't a cloud in the sky, which was the richest blue that I've never seen anywhere but in Colorado." During the evening, Richard's group grew to nine people, as more friends arrived at the camp to join the hike,



Richard Davies and supporters reach the summit camp to join the hike,

including some supporters from the Rocky Mountain Cancer Center where Richard receives treatment. Setting out early the next morning, all nine hikers reached the summit five hours later. There was a shared sense of accomplishment among the hikers, and the knowledge that their efforts contributed to funding myeloma research only heightened their experience.

On October 7, Ken Fabian organized a plant sale to benefit the IMF and his local myeloma community in Florida. The rainy weather notwithstanding, the event was a big success. "I have been involved in the plant



Ken Fabian and Andy Lebkuecher at the plant sale

business for 35 years, so having this type of fundraiser came easy. Many local nurseries donated plants for the fundraiser,

including Spring Hill Nursery, Peckett's Inc., Bruce Jensen Nurseries, G&T Foliage, Krull and Smith, Foliage Factory Too, Southland Gardens Nursery, and Lake Brantley Plant Corporation. Other businesses gave a hand, too," said Ken. "My thanks also go to IMF's Andy Lebkuecher, who came to the plant sale on Sunday and spoke to our support group on Monday." Ken, who was diagnosed with myeloma in March 2006, is the founder of the myeloma support group in Maitland, FL. "I guess I've officially become an activist for the myeloma community! The experience of making friends with other myeloma patients, sharing our hope and our strength, has changed my life a great deal. I cherish each day and try to live it to the fullest. Life is great!"

On October 27, the second annual "Money for Miracles" event took place in Warwick, RI. The evening of dinner, dancing, auctions, and raffles was thoroughly enjoyed by the more than 250 people who attended the event. The Rhode Island Multiple Myeloma Support Group (RIMMSG) organized the event to benefit the group, the IMF, and the Cathy Lebkuecher Memorial Fund. The elegant event color scheme was

burgundy and white, representing myeloma, the IMF, and the RIMMSG. Banners adorned the walls and balloons floated above the crowd. Dinner and dancing gave way to silent auction bidding and a raffle drawing, with many prizes donated by IMF and RIMMSG supporters. Barbara Morse-Silva, NBC



Barbara Morse-Silva presents award to Carol Murray-Rossi

Channel 10 Anchor and Health Reporter, served as the RIMMSG celebrity hostess for the evening. Her station had donated public awareness spots – which aired 30 times – for a total value of \$18,000! The spots helped increase public awareness of myeloma, the RIMMSG and the IMF, and the "Money for Miracles" fundraiser. On the evening of the event, Barbara Morse-Silva presented the IMF Outstanding Achievement Award to RIMMSG leader Carol Murray-Rossi. Dana Paskalis of the Celgene Corporation was also acknowledged for her support of RIMMSG activities and for making her extensive knowledge of myeloma regularly available to group members. Celgene also supported the "Money for Miracles" fundraiser with a special grant. "In addition to Celgene, the RIMMSG event was generously sponsored by Paul Audette of Helping Hand Associates Inc. and Mr. Dan Lantz of Eloquence Jewelers," said Carol Murray-Rossi. "And the IMF staff worked right along with us, planning and organizing. Thanks to this guidance, we've learned so much about how to raise funds in order to better help our community. The IMF has been our guiding light and beacon of hope. We are here, in part, as a result of the tremendous effort, knowledge and compassion offered to us by the IMF. We also must thank our families and friends, and the local community, for their support of our group and of the myeloma community at large."

On October 28, Eric Merkel ran the Marine Corps Marathon in Washington, DC. Eric dedicated his run to his aunt, Linda Rohrbach, who was diagnosed with aggressive myeloma in April 2006. "She has been through a number of treatments, including a transplant, and several clinical trials. I have seen her be very ill and very brave," said Eric, "So although I quit doing marathons after my eighth run a couple of years ago, I decided to come



Eric Merkel with parents Barbara and John, and sister Becky

out of 'retirement' for my ninth marathon, in honor of my aunt and in hopes of raising funds for the IMF's myeloma research program. Without cutting-edge research and experimental trials, Linda and other myeloma patients like her would not be here today. That's how important research is!" Many of Eric's friends, colleagues, and family members responded to his letters of appeal, and most turned out to see him run the marathon, which he completed in 3 hours and 56 minutes. "This is by far one of the best experiences I've had running a marathon. I was overwhelmed by people's support and generosity. And the knowledge that I was running

CONTINUES ON NEXT PAGE

Support Groups

TENNESSEE: TRI-CITIES

Harvey Jesse was diagnosed with smoldering multiple myeloma in May 2007. His wife, Darlene, immediately took action. She got in touch with the IMF and requested all the printed educational materials that the Foundation provides. "That InfoPack contained the most informative materials we've received. The service that the IMF provides is absolutely wonderful," says Darlene. "And Harvey and I just knew that we had to pass this on to others. We understood how helpful it would be to have a local support network, people to talk to face to face." At that time, the nearest support group was a five-hour drive away.

Harvey and Darlene decided to start a support group in East Tennessee. With the help of IMF's Kelly Cox (Director of Support Groups Outreach) and Andy Lebkuecher (Regional Director, Support Groups, Southeast), Darlene and Harvey began planning for the group's first meeting. They distributed information among the local medical community and posted a notice online on the myeloma list-serve. Darlene also arranged for publicity with local newspapers and a television station. Soon another myeloma patient, Ellen Barrett, joined their effort.



The Tri-Cities Area Multiple Myeloma Support Group held its first meeting in September 2007, with 14 people in attendance. Twenty people participated in the group's October meeting, and the ranks grew to 25 by the following month. In November 2007, the group welcomed IMF's Robin Tuohy (Regional Director, Support Groups, Northeast) as their guest.

"I attended the November meeting to introduce myself and the IMF to the group's members, to answer their questions, and to distribute more of the Foundation's educational materials about myeloma," said Robin. "I was very impressed. Darlene and Harvey are doing a wonderful job, and the group's co-leader Ellen Barrett is working with them on a variety of projects, including newsletters and other technical support of group operations. The group has made such great strides in a very short amount of time because the members truly care about helping each other and the other families in the area who are coping with myeloma. I think this group has tremendous potential!" **MT**

Editor's Note: This group meets the first Saturday of every month from 11am to 1pm. For more information please contact Darlene Jesse at pennywort6@embarqmail.com or 423-538-6923 .

INTERNATIONAL — continued from page 19

meeting, with Drs. Mario Boccadoro and Sundar Jagannath joining him as faculty. Also participating as faculty were Dr. Wen-Ming Chen (Director of the Multiple Myeloma Research Center of Beijing), Dr. Jian Hou (Professor and Director of the Department of Hematology for Changzheng Hospital of Shanghai), and Dr. Xiao-Jun Huang (Chairman of the Chinese Hematological Medical Association, Director of the Hematology Department in Beijing People's Hospital).

The day's presentations covered biology, etiology, epidemiology, diagnosis, prognosis, staging, and treatment of myeloma, as well as genomics and proteomics, biomarkers, and clinical applications for new technologies. Talks took participants from the old myeloma treatment paradigm through to defining the future directions for therapies. The day of intensive sessions ended with a faculty panel discussion about improving therapeutic outcomes for today's patients, as well as the potential for collaborations with Chinese investigators.

"The inaugural China Myeloma Symposium was an auspicious event," noted IMF president Susie Novis. "Since 1993, the IMF has held many international conferences and symposiums to form collaborations with clinicians and researchers, and we will continue to collaborate with doctors throughout the world in helping patients and in working together to find a cure for myeloma. As the IMF concludes another year of its activities around the world, we once again note that the concerns of both the patient and the medical communities center on the same issues: scientific progress, treatment choices, side effects, and quality of life. To continue to answer these questions, the IMF is committed to bringing its seminar and conference programs to as many doctors and patients as possible, regardless of where they might live." **MT**

MEMBER EVENTS — continued from previous page

for a cause so close to my heart, made this one of the most emotional and exhilarating experiences I've ever had."

Join Us

We are grateful to all IMFers who contribute their time, imagination, and hard work to benefit the myeloma community. The IMF is committed to

working with you to continue to raise awareness and funding for myeloma education and research. Join us in working together toward our common goal... a CURE. Our FUNDraising program provides you with the tools, assistance, and expertise to make your event a success. No idea is too large or too small. Please contact me, Suzanne Battaglia, at sbattaglia@myeloma.org or 800-452-CURE (2873). **MT**



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1 Katzmann, J.A., et al. Mayo Clinic Proc. 2006;81(12):1575-78
2 Pratt, G. et al. Leukemia and Lymphoma. 2006;47(1):21-28

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2008 IMF Calendar of Events

- | | | | |
|----------------|---|-----------------|--|
| Jan 12 | IMF Regional Community Workshop – Seattle, WA | May 30 – June 3 | American Society of Clinical Oncology (ASCO) meeting – Chicago, IL |
| Jan 24 – 27 | IMF Board Retreat – Dana Point, CA | June 12 – 15 | European Hematology Association (EHA) meeting – Copenhagen, DENMARK |
| Feb 6 | Robert A. Kyle Lifetime Achievement Award – Torino, ITALY | June 27 – 28 | IMF Patient & Family Seminar – Seattle, WA |
| Feb 10 – 11 | SWOG Retreat – Phoenix, AZ | June 27 – 29 | Eastern Cooperative Oncology Group (ECOG) meeting – Boston, MA |
| Mar 14 – 15 | IMF Patient & Family Seminar – Atlanta, GA | July 25 – 26 | IMF Patient & Family Seminar – Boston, MA |
| Apr 11 – 13 | IMF Support Group Leaders Retreat – Tempe, AZ | Aug 22 – 23 | IMF Patient & Family Seminar – San Diego, CA |
| Apr 17 – 19 | IMF Scientific Advisory Board Retreat – Bermuda, USVI | Oct 29 – Nov 2 | Southwest Oncology Group (SWOG) meeting – Chicago, IL |
| Apr 30 – May 4 | Southwest Oncology Group (SWOG) meeting – Atlanta, GA | Nov 14 – 16 | Eastern Cooperative Oncology Group (ECOG) meeting – Ft. Lauderdale, FL |
| May 15 – 18 | Oncology Nursing Society (ONS) – Philadelphia, PA | Dec 6 – 9 | American Society of Hematology (ASH) meeting – San Francisco, CA |

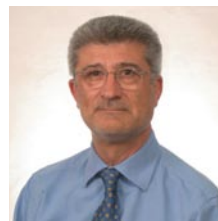
Other events/meetings will be posted in later editions of *Myeloma Today* as dates are finalized.
For more information, please visit www.myeloma.org or call 800-452-CURE (2873).
IMF–Latin America, IMF–Japan and IMF–Israel events are not included above.

Imagine Moving Forward

is the theme of the IMF's myeloma bracelet. Wear one in honor, celebration, or in memory of a loved one. When people ask you about it, you'll have a perfect opportunity to spread the word about multiple myeloma. These bracelets are only \$1 each in sets of 10. Youth bracelets are now available, so everybody in your family who has been touched by myeloma can wear one! Order bracelets online at our website www.myeloma.org, or contact Suzanne Battaglia at SBattaglia@myeloma.org or 800-452-CURE (2873).



Sixth Annual International Myeloma Foundation ROBERT A. KYLE LIFETIME ACHIEVEMENT AWARD



Prof. Mario Boccadoro

PROFESSOR OF MEDICINE, SPECIALIST IN HEMATOLOGY, UNIVERSITY OF TORINO,
DIRECTOR HEMATOLOGY SECTION, UNIVERSITY OF TORINO,
DEPARTMENT OF ONCOLOGY, SAN GIOVANNI HOSPITAL, TORINO

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