



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



Dr. Antonio P. Palumbo, IMF Scientific Advisor, discusses his interests in myeloma research, his work with the IMF and with GIMEMA, the Italian myeloma network. He also shares his thoughts on defibrotide, an anticoagulant currently not approved in the USA but used in a number of other countries. **PAGE 4**



Dr. Robert A. Kyle, Chairman of the IMF Scientific Advisory Board and member of the Board of Directors, talks about the evolution of myeloma diagnosis and treatments, shares his thoughts on what we are likely to see in the future, and summarizes the latest information about MGUS and smoldering myeloma. **PAGE 5**



Prof. Jean-Luc Harousseau, IMF Scientific Advisor and founding member of Intergroupe Français du Myélome and Groupe Ouest-Est Leucémies Aigues et Maladies du Sang, tells the story of the highly successful French myeloma cooperative group and gives a brief overview of its recent and current activities. **PAGE 7**



Brian G.M. Durie, IMF Chairman of the Board and Scientific Advisor, encapsulates the recent recommendations of the International Myeloma Working Group on the prevention of blood clots associated with the use of thalidomide or lenalidomide. **PAGE 9**



Michael S. Katz, IMF Director, provides an update from the recently established US Myeloma Forum, a committee of the world's leading multiple myeloma experts. The Forum has reached agreement on a clinical trial for treatment of newly-diagnosed patients. **PAGE 9**

Supportive Care



Ginger Love, RN, discusses peripheral neuropathy, damage to the peripheral nervous system, which can be caused by any of a variety of factors, including injury, inflammation, and the disease of myeloma itself or several approaches to its treatment. **PAGE 11**

Patient & Caregiver Stories



The Tuohy Family completes the Summer 2007 **Myeloma Mobile** journey to educate and empower patients and their families in local communities across the United States, both in major cancer clinics and smaller support groups. **PAGE 12**



Diana Marquise, a nurse and a 6-year breast cancer survivor, tells the story of her seemingly insurmountable diagnosis with smoldering myeloma and how she has coped during her first year with this disease. **PAGE 16**

Cindy & Bob Feltzin, who are making a profound investment in the myeloma community, talk about why and how they have chosen to commit to the fight against myeloma by funding myeloma research and education initiatives, and leading a local support group. **PAGE 17**



Also in this issue...

- **Dear Reader** by IMF president Susie Novis **PAGE 3**
- **Letters** to the IMF **PAGE 3**
- **Nurse Leadership Board** activities update **PAGE 10**



- **International Affiliates**, AMEN celebrates second anniversary **PAGE 14**
- **Support Groups** from New Jersey and California share their stories **PAGE 15**
- **IMFers raise funds** to benefit the myeloma community **PAGE 18-21**
- **News & Notes** **PAGE 21**
- **Spotlight on Advocacy** **PAGE 22**
- **Calendar of events** **BACK COVER**

Special Events



Read about the recent **Concert For A Cause**, headlined by Spinal Tap to raise funds to benefit the IMF, and the upcoming evening of comedy **Celebrating Peter Boyle**. **PAGE 18-19**



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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HEADQUARTERS

12650 Riverside Drive, Suite 206, North Hollywood, CA 91607-3421 U.S.A.

Tel: 818-487-7455 or 800-452-CURE (2873)

Fax: 818-487-7454 E-mail: TheIMF@myeloma.org Website: www.myeloma.org

IMF STAFF

Executive Director

David Smith (dsmith@myeloma.org)

Senior Vice President, Strategic Planning

Diane Moran (dmoran@myeloma.org)

Vice President, Development

Heather Cooper Ortner (hortner@myeloma.org)

Special Outreach Coordinator

Arin Assero (aassero@myeloma.org)

Hotline Coordinator

Paul Hewitt (phewitt@myeloma.org)

Development Associate

Randi Liberman (rliberman@myeloma.org)

Development Associate

Suzanne Battaglia (sbattaglia@myeloma.org)

Meeting & Event Services

Spencer Howard (showard@myeloma.org)

Data Specialist

Colleen McGonigle (cmcgonigle@myeloma.org)

Hotline Coordinator

Nancy Baxter (nbaxter@myeloma.org)

Publications Editor

Marya Kazakova (mkazakova@myeloma.org)

Publication Design

Jim Needham (jneedham@myeloma.org)

Hotline Coordinator

Debbie Birns (dbirns@myeloma.org)

Executive Assistant

Nancy Kennedy (nkennedy@myeloma.org)

Director, Medical Meetings & CME Programs

Lisa Paik (lpaik@myeloma.org)

Director, IMF Europe

Gregor Brozeit (greg.brozeit@sbcglobal.net)

Development Assistant

Missy Klepetar (mklepetar@myeloma.org)

Webmaster

Abbie Rich (arich@myeloma.org)

Administrative Assistant

Rachael Coffey (rcoffey@myeloma.org)

Regional Director, Support Groups Southeast
Andrew Lebkuecher (imfsupport@charter.net)

Comptroller

Jennifer Scarne (jscarne@myeloma.org)

Director, Support Groups Outreach
Kelly Cox (kcox@myeloma.org)

Specialty Member Services Coordinator
Kemo Lee (klee@myeloma.org)

Regional Director, Support Groups Northeast
Robin Tuohy (tuohy@snet.net)

Database & Inventory Control
Macky Lee (mlee@myeloma.org)

International Myeloma Foundation

Dear Reader,

The Fall edition of *Myeloma Today* is, in a way, a paradox, as Fall usually signifies endings, and this issue is about new beginnings. It's a new beginning because this is the time of year when the IMF awards our research grants, and research as we all know is the path forward – a new start.

Research has provided us with novel therapies that are changing the lives of thousands of patients globally. It is guiding the development of the next generation of drugs that will lead to a cure.

The IMF believes in funding a wide range of research that includes both lab and clinical projects. Our research goal is “to support research that will have the most immediate benefit for patients, while working toward prevention and a cure.” That means we support lab research with our signature project Bank On A Cure® and through our Junior and Senior Research Grant program.

Over the past 12 years, the IMF has awarded 65 research grants to investigators around the world. A goal of our grant program is to not only fund research but to also bring new people into the field of myeloma. The IMF grants provide seed money for innovative projects. Ultimately, these smaller grants are critical because their recipients go on to apply for multi-million dollar government grants. I am happy to note that most of the researchers the IMF has funded have stayed in the field and have gone on to publish over 100 papers in important peer reviewed journals. In addition to such grants, the IMF funds research through two other very important groups:

The International Myeloma Working Group was formed in 2000. Initially, it was a collaboration of about 25 experts. Today, 90 myeloma experts contribute to multiple ongoing projects. They have been very prolific and have published six consensus guideline reports that have



been published in prestigious journals such as *Journal of Clinical Oncology*, *British Journal of Hematology*, *The Mayo Clinic Proceedings*, and *Leukemia*. In addition, their numerous abstracts have been accepted at major medical meetings such as American Society of Hematology (ASH) and the International Myeloma Workshops (IMW). The importance of their work cannot be underestimated, as it has framed the current approach to myeloma treatment and management in the era of novel therapies.

The US Myeloma Forum was recently established to bring together key U.S. opinion leaders to form a coalition whose goal is to work collaboratively to bring focus to projects, and to reduce duplication of efforts and dilution of valuable resources. Like coalitions in Europe, the US Myeloma Forum is working on projects to ensure that drugs make their way through clinical trials and on to FDA approval with speed and efficiency. The Forum's first meeting, held in April of 2007, has already produced results – a collaboration has been formed between Southwest Oncology Group (SWOG), East Coast Oncology Group (ECOG), and Cancer Therapy Evaluation Program (CTEP)!

The IMF has invested wisely, which has allowed modest funds to reap huge benefits. We have been able to move research forward through a variety of innovative projects. Always true to our mission, we put patients first, empowering them through our educational programs and caring for them with equally important supportive programs. We take care of patients today so that they can be here tomorrow to benefit from the newest treatments and, hopefully, the cure.

Warm regards,
Susie Novis

Letters to the IMF

I am an American living abroad. In the past four months, I lost two people in my life to cancer (not multiple myeloma), and now I am dealing with my husband's myeloma diagnosis. My husband chooses not to learn about the disease, so the task of doing research has fallen to me. Thanks to the internet, information about myeloma is more accessible now than ever before, and we are able to communicate, exchange ideas and experiences, and support one another even over great distances.

One *Myeloma Today* article has made a particularly positive impression on me. I found Peter Tischler's Living Successfully with Multiple Myeloma to be a concise but in-depth first-hand account of a disease that I am only now learning about. As a caregiver, I was so grateful to learn so much information. I had so many doubts about the future, and Peter's article

gave me hope. I no longer feel that I must stand on the sidelines watching my husband's struggles. I now feel that there are things I can do to help him fight myeloma.

On our new journey, one of the things that have struck me is how myeloma has touched so many lives. We are not alone. The support, education, and information that the IMF and its members, like Peter Tischler, provide to the patient and caregiver community has empowered me to really take an active part in my husband's treatment and care. I thank your organization and Peter for your positive contribution to our new perspective.

With appreciation,

Deborah Rosenloev

MYELOMA TODAY IN CONVERSATION WITH DR. ANTONIO P. PALUMBO

Please tell us a little about your background and medical training.

I was born in Torino, Italy. I received my medical degree from the Medical School of Torino, and undertook both hematology and clinical oncology specialty training at the Università di Torino. Then I spent five years in the US, where I worked in molecular biology at the Wistar Institute of the University of Pennsylvania. In 1985, I returned to the Università di Torino where I began my work in multiple myeloma. Currently, I am Associate Professor of haematology. Also, since 2000, I have headed the myeloma unit at our department of oncology.

How did you become involved with the IMF, eventually joining its Scientific Advisory Board?

My initial involvement with the IMF was due to my colleague Dr. Mario Boccadoro, who has enjoyed a long-standing friendship with Dr. Brian Durie and has been a member of the IMF and its Scientific Advisory Board for many years. Dr. Boccadoro and I organize IMF seminars and conferences in our country. We are currently working on preparing recommendations on the managements of side effects in myeloma patients being treated with thalidomide or lenalidomide (Revlimid®). These guidelines should be completed and published soon.

What is your personal research focus in myeloma?

My interests in myeloma include the efficacy of high-dose versus conventional chemotherapy, as well as pathogenesis and new therapeutic approaches to treating myeloma. The combination of newer agents such as bortezomib (VELCADE®), Revlimid, and thalidomide with melphalan and prednisone (MP), the standard of care in Europe, is the current focus of our work. These combinations have significantly improved the response rate induced by new drugs. We are also working to improve the safety profile of such regimens.

You are one of the founders of the Italian myeloma network, GIMEMA. Please tell us about it.

GIMEMA (Gruppo Italiano Malattie Ematologiche dell'Adulto) is a joint venture between Italy's two major myeloma groups, one in Torino and the other in Bologna. We joined our efforts to form a unique myeloma group for our country. GIMEMA covers almost 90 hematology centers across Italy. More information about GIMEMA can be found at www.mieloma.it.

What are some of the group's past accomplishments?

Between January 2002 and May 2005, GIMEMA conducted a multi-institutional phase III clinical trial of newly diagnosed myeloma patients who were older than age 64 or not medically able to undergo stem cell transplantation. The patients were randomly assigned to receive either MP alone or in combination with thalidomide (MPT). Data analysis showed that patients whose treatment included thalidomide did significantly better than the comparison group. These results provided the first definitive



Antonio P. Palumbo, MD
Università di Torino
Torino, Italy

evidence of thalidomide's effectiveness in elderly patients. The group is preparing an update of this study, which we hope to finish by the end of the year.

The phase II study of the melphalan, prednisone, and Revlimid combination (MPR) closed about a year ago. We observed a better safety profile with the use of MPR than with the use of MPT. In particular, peripheral neuropathy was not a problem with MPR. And, with the use of aspirin as prophylaxis for deep-vein thrombosis (DVT), the incidence was lowered to approximately 5%. Both response rate and progression-free survival, while not compared in a randomized fashion, demonstrates the improved efficacy of MPR as compared to MPT.

At the 2007 meeting of the American Society of Clinical Oncology (ASCO), GIMEMA members presented an abstract on the factors predictive of outcome in relapsed/refractory myeloma patients treated with VELCADE, melphalan, prednisone, and thalidomide (VMPT). This is the first schedule combining these four drugs at the same time. The peculiarity of this schedule is that thalidomide is lowered to 50mg and the VELCADE dose is lowered to a weekly infusion. From the safety point of view, the incidence of peripheral neuropathy was the same as with MPT, so the findings were very encouraging. From the efficacy point of view, VMPT significantly increased response rate and progression-free survival for patients with relapsed disease.

What are the current activities of GIMEMA?

Members of GIMEMA are currently working on three major trials. One major trial is being led by the Università di Torino, evaluating VELCADE, melphalan, prednisone (VMP) versus MPV plus thalidomide (VMPT).

Another trial, led by Dr. Michele Cavo (Università di Bologna), is comparing the combination of thalidomide plus dexamethasone (thal/dex) to thal/dex plus VELCADE as induction treatment in younger myeloma patients prior to undergoing autologous transplantation.

The third trial is led jointly by centers in Torino and Bologna. This study is comparing three different approaches (aspirin, low fixed-dose warfarin, low-molecular-weight heparin) for the prophylaxis of thrombosis in patients receiving thalidomide as frontline therapy at diagnosis. The study is accruing both younger and older patients. An abstract of this study was presented at the annual meeting of the American Society of Hematology (ASH) in December of 2006.

What has been your experience with defibrotide?

Defibrotide is an anticoagulant currently not approved in the USA but used in a number of other countries. Its mechanism of action seems to disrupt the attachment of plasma cells to stromal cells and to interfere with tumor growth. The hypothesis of using defibrotide in myeloma is based on laboratory studies in mouse models, particularly in cultures containing

CONTINUES ON PAGE 8

MYELOMA TODAY IN CONVERSATION WITH DR. ROBERT A. KYLE

When and how did you become involved in the field of myeloma?

I became involved with myeloma when I was a medical resident, looking at serum protein electrophoretic patterns of our hospitalized patients. I showed what I had observed to the attending consultant, and asked him what the patterns meant. He said he didn't know very much about them because the test was new at the time, and he encouraged me to review the experience of the Mayo Clinic. I reviewed over 6,000 serum protein electrophoretic patterns and found that there were patients who had large spikes in their patterns, and that those patients usually had multiple myeloma, Waldenstrom's macroglobulinemia, or primary amyloidosis. This was before immunoelectrophoresis or immunofixation was available, so I developed a formula using the height and the width of the spike. A narrow spike represented myeloma, macroglobulinemia, or amyloidosis. A broad spike was due to an inflammatory or a reactive process, such as chronic infection or liver disease. A year later, Waldenstrom published his work on monoclonal and polyclonal gammopathies. When immunoelectrophoresis became available in the late 1960s, we developed a laboratory to utilize it to identify the type of monoclonal protein. A decade later, we started using immunofixation.

How has the treatment of myeloma evolved over the years you've worked with this disease?

The first treatment that was proposed for myeloma was a drug called urethane. With this drug, a few patients had a reduction in their monoclonal protein and bone marrow plasma cells. In 1958, a Russian physician named Blokhin discovered what is currently known as melphalan (Alkeran®). This drug has been used to treat myeloma in the US since the early 1960s. In the 1970s and 1980s, there were many treatment combinations of alkylating agents. Since the late 1980s, autologous stem cell transplantation has been used in myeloma, initially utilizing stem cells from the bone marrow. Subsequently it was discovered that a larger collection of stem cells, and better engraftment, was possible by using peripheral blood stem cells. It took a number of years for the kinks to be worked out. In the early days of transplantation for myeloma, the mortality from the procedure itself was as high as 10% to 15%. Now the mortality is about 1%. By the late 1990s, thalidomide became part of available myeloma therapies. Early in the 21st century bortezomib (VELCADE®) was added to the list of myeloma treatments. For the past few years, we have also been using lenalidomide (Revlimid®).

What developments do you anticipate in the available myeloma treatments?

I think that we are likely to see more new drugs with specific actions against various aspects of myeloma cell metabolic pathways. We are also looking forward to more combinations of drugs that will interfere with myeloma cell proliferation. While it is impossible to say if any of the drugs



Robert A. Kyle, MD
Mayo Clinic
Rochester, Minnesota

currently in the development pipeline will come to represent significant advances, there are a dozen or so agents that look promising at this time. I suspect that these new drugs will be utilized in combination with the novel agents being used in myeloma treatment today. At this point, we should not in any way limit the scope of our research. We need to keep our eyes open and be observant, and to take advantage of every new piece of information. It is even conceivable that the information we seek is already out there and we simply need to put the pieces of the puzzle together in order to significantly advance the field of myeloma.

Please tell us about your experience with MGUS.

Monoclonal gammopathy of undetermined significance (MGUS) is a term I coined in 1978. It was the culmination of a long-term follow-up of 241 patients

who had a monoclonal protein in their blood but no evidence of multiple myeloma, Waldenstrom's macroglobulinemia, or primary amyloidosis. All of these patients were completely asymptomatic. MGUS patients have no hypercalcemia, renal insufficiency, anemia, or lytic bone lesions. Their M-spike is less than 3g/dL and their bone marrow contains less than 10% plasma cells.

The progression of MGUS to myeloma was recognized early in our studies. Some of the MGUS patients I followed for a number of years developed symptomatic myeloma or macroglobulinemia. The rate of MGUS progressing to myeloma is 1% per year. This statistic often gets MGUS patients alarmed because their physicians tell them that they have a 25% chance of developing myeloma. This is true if the patient lives for 25 years. Another way to look at it is to tell the patient that there is a 99% percent likelihood of NOT progressing from MGUS to myeloma in the next year. However, a patient remains at that risk, year after year and, over a 25 year period, 25% of the MGUS patients progress to myeloma or a related disease.

One important concept I'd like to get across is that, in general, we are all at risk of developing many disorders and diseases. As we age, the risk increases. The median age of a person diagnosed with MGUS is 72 years, and that patient might have any number of health issues arise in subsequent years. According to our studies, a newly diagnosed 72-year-old MGUS patient has a 25% chance of progressing to myeloma by age 97, if he or she lives that long.

What about smoldering myeloma?

In June, the New England Journal of Medicine published a Mayo Clinic report on the risk of progression from smoldering to symptomatic myeloma. We concluded that the risk of progression from smoldering to active myeloma is related to the proportion of bone marrow plasma cells and the serum monoclonal protein level at the time of diagnosis. By definition, the M-spike of a smoldering myeloma patient is greater than 3g/dL and/or the bone marrow contains more than 10% plasma cells. For the first five years,

CONTINUES ON PAGE 6

DR. ROBERT A. KYLE — continued from page 5

there is a 10% per year chance of developing myeloma. For the next five years, there is a 3% per year chance. After 10 years, the rate of progression is 1.4% per year. Patients who have M-spikes greater than 3g/dL and more than 10% plasma cells in their bone marrow are at greater risk of progressing to active disease than those with only one abnormality (M spike > 3 g/dL or plasma cells > 10%).

Is there anything you can share with us about the genetic aspects of myeloma?

If one were to perform conventional chromosomal studies on patients with myeloma, about one third will have a cytogenetic abnormality, and about 15% will have a chromosome 13q deletion. These patients generally have a poorer prognosis than patients without such abnormalities.

If one were to perform fluorescent in situ hybridization (FISH) on myeloma patients, it is reported that 80% to 90% of patients will have an abnormal result. I think that if one were to use sufficient probes, the number would be very close to 100%. FISH will detect chromosome 13q deletions in 40% to 50% of patients. However, 13q- detected by FISH is not as important a prognostic factor as when it is detected by conventional cytogenetics.

If a patient has a 4;14 or 14;16 translocation, or a deletion of 17p, these would be poor prognostic features. However, translocation of 11;14 does not seem to have an adverse effect on prognosis. The important point is that the genetic abnormalities seen with FISH are seen in patients with MGUS almost as frequently as in patients with myeloma. The only conclusion that one can draw from that fact is that the cytogenetic insult occurs early in the course of monoclonal plasma cell disorders, and it takes multiple “hits” for a person to develop myeloma.

What is the current focus of your work in myeloma?

My major interest in recent years has been MGUS and smoldering myeloma. We are looking at the familial aspects of these disorders. There is a hereditary element in myeloma and related plasma cell diseases. If you were to look at families of myeloma patients, statistically speaking, you would be more likely to find a monoclonal protein in first-degree relatives of those persons than if you were to look at first-degree relatives of people who do not have myeloma. I suspect that there are both genetic and environmental factors at play here. As time goes on, we will surely learn more about this.

But let me be clear that, even if your mother or father has been diagnosed with myeloma, it would still be extremely unlikely for you to develop this disease. When patients ask me if they should have their children tested, I advise against this unless the family is participating in a research study. There is no reason to increase their anxiety. Protein abnormalities are a part of aging, occurring mostly in older people. People diagnosed with myeloma and related disorders are usually between the ages of 65 and 70. Only 2% to 3% of newly diagnosed myeloma patients are under age 40.

Over the years, have you observed an increased incidence of myeloma?

In Olmsted County Minnesota, where Mayo Clinic is located, we have looked at the population over the course of many years. From 1944 to 1967, the incidence of myeloma was 3.1 cases per 100,000 in Olmsted

County, while the national rate was only 0.8 per 100,000 for that same time period. In 1977-1978, we found that the incidence of myeloma had fallen to 2.9 per 100,000. In 1991, the rate rose to 4.2 and we wondered if this represented an increase. But when we did an update a couple of years ago, we found that the incidence remained stable. We have looked back in three-year increments for the past 56 years and there has been no statistically significant difference in the incidence of myeloma in Olmsted County over this period. The reason that the incidence rose slightly and then leveled off is that we have started looking for myeloma using improved and modern diagnostic tools now available. There is also a greater awareness of this disease among physicians.

While I believe that the incidence of myeloma has not changed in many years, the prevalence of myeloma has increased. Besides the reasons already stated, the increased prevalence is due to more people living longer – remember, myeloma is a disease of older people – and improved treatments that have myeloma patients living at least twice as long as they did 50 years ago. That alone doubles the number of patients living with myeloma today.

Let’s talk a bit about your work with the IMF. When Brian Novis and Dr. Brian Durie came up with the dream to start a foundation to help myeloma patients, the first call they made was to you. What do you remember about the early days of the IMF?

I have known Brian Durie since his residency at Mayo Clinic in the late 1960s. When I received a phone call from him and Brian Novis in the Fall of 1990, there were no national or international organizations in existence to serve the myeloma community. The International Myeloma Foundation was formed to fill that void. The IMF was formally incorporated in October 1990. Shortly thereafter, at the annual meeting of the American Society of Hematology (ASH), I met in person with the two Brians to continue our discussions about the mission and activities of the IMF. I was happy to collaborate with them and to become a founding member of the Board of Directors and Chairman of the Scientific Advisory Board.

What are your thoughts about the IMF today?

The goals for the IMF that were laid out back in 1990 are very much what they still are today. Obviously, the IMF has grown markedly over the last 17 years. Its accomplishments are phenomenal. There are more monies being raised for research, and more patients reached with education, awareness, and support. There has also been a surge in the international aspects of the IMF, with the Foundation achieving a broad international scope. I hope that in the future we will continue to increase our funding of myeloma research, expand our patient programs, and make significant strides in battling this challenging disease.

Editor’s Note: Dr. Kyle has received countless awards, titles, and accolades. He is the most frequently requested speaker at IMF Patient & Family Seminars around the world. Since 2003, the IMF has annually bestowed the Robert A. Kyle Lifetime Achievement Award to a physician whose work against myeloma reflects the dedication and compassion inherent in Dr. Mayo’s vow. The IMF chose to name this award for Dr. Kyle, whose life and work give new meaning to these words. **MT**

IFM: THE FRENCH MYELOMA COOPERATIVE GROUP

Myeloma Today in conversation with Prof. Jean-Luc Harousseau

Please tell us about the founding of the French myeloma cooperative group.

In 1989, the principal investigators for the three French cooperative groups working in multiple myeloma at that time began joint cooperation. I was the leader of POF in the West of France, Michel Attal led GEM (South), and Thierry Facon led GERM (North). Other investigators from our three groups also participated. This joint cooperation began the process that resulted in the founding of Intergroupe Français du Myélome (IFM).

What were the objectives of those early cooperative efforts?

Our initial objective was to address questions about myeloma treatment through randomized clinical trials. In 1990, with all three groups participating, we designed three randomized studies. In order not to duplicate efforts, we addressed three different questions about myeloma treatment. One of our studies addressed the role of autologous transplantation, which was a new approach to myeloma at the time. That study, known as IFM-90, was the first randomized clinical trial comparing high-dose therapy (HDT) to conventional chemotherapy. The study looked at 200 previously untreated myeloma patients, all of whom were under the age of 65. IFM-90 was a big success, demonstrating the superiority of high-dose therapy over conventional chemotherapy. The data was presented at many scientific and clinical meetings and was later published.

How did the three cooperative groups evolve into the IFM?

Thanks to the success of IFM-90, our group of researchers was able to continue to work together. We designed the IFM-94 and IFM-95 trials, applying the same philosophy of cooperating by sharing responsibilities and helping each other that had worked so well for us with IFM-90. (By the way, this is how members of IFM continue to work together to this day.) When we formalized our cooperative efforts under French legislation, our association became known as Intergroupe Français du Myélome. The early success of IFM attracted many other investigators and clinical centers to our group. IFM now encompasses almost all cancer centers in France, and includes French-speaking centers in Belgium and Switzerland. This helped expand the scope of our new trials. For example, while IFM-90 included 200 myeloma patients, the participation in our studies grew to 400 patients for IFM-94, and to over 1,000 for IFM-99.

What were the initial goals set for the IFM?

Initially, we focused on designing randomized clinical trials of frontline therapies for myeloma, with the objective of asking specific questions to be answered within a limited period of time. As both IFM's funding and participation increased, we began to look at other aspects of myeloma research, especially the role of cytogenetics and molecular biology. With input from Prof. Hervé Avet-Loiseau, we centralized the bone marrow and



Head of the Department
of Clinical Haematology
Professor of Medicine
Nantes University Hospital
University of Nantes
Nantes, France

blood samples at my center in Nantes. This centralized analysis allowed for good quality data for all our trials, and this became the second reason for our success.

What about IFM's more recent activities?

More recently, we became interested in translational research – the “bench-to-bedside” translation of research into clinical practice. We have also worked with the International Myeloma Foundation on its Patient & Family Seminar program, helping French patients become better informed about their disease and its treatment through interactive discussions. The IMF has done an excellent job with its patient education program, organizing one seminar per year in Paris. The IFM has now taken the IMF's educational initiative beyond Paris, organizing patient seminars throughout the rest of France. We also conduct an annual nationwide doctor education program, which is a video conference via satellite. Thanks to our sponsors, we have now initiated a new program to make the satellite video conferencing technology available to patients. In December

2006, our first video conference for the patient community included the participation of 1,200 people from eight cities. It was a great success.

Please tell us about some of the significant IFM studies.

In one retrospective analysis, we confirmed the benefit of complete remission (CR) on overall survival. Such a study would have been impossible in earlier years because the number of patients achieving CR with conventional chemotherapy was very low compared to HDT followed by autologous transplant. But now we have been able to demonstrate that in myeloma, achieving CR does have an impact on overall survival, as it does in other hematological malignancies. We also looked at patients who did not quite achieve CR and still had a small M-component. We called this VGPR (very good partial response) and demonstrated that CR + VGPR correlated to longer progression-free survival and overall survival. This finding has been confirmed in all of our subsequent trials, as well as by a number of other investigators. The concept holds true not only in the context of HDT, but also with conventional-dose chemotherapy and with the use of novel agents in patients with relapsed disease.

Another IFM randomized study, which started in July 2005 and finished in January 2007, compared vincristine, doxorubicin, and dexamethasone (VAD) to VELCADE® plus dexamethasone (Vel/dex) as induction therapy prior to autologous transplantation. We recruited 480 patients, and we hope to be making a presentation at the upcoming annual meeting of the American Society of Hematology (ASH) in December 2007. The analysis has not been completed at this time, but I can share some information about our interim data on the first 222 patients. The overall response rate (CR + VGPR) is superior with Vel/dex, and the difference is significant. And what is even more important in my opinion is that the higher CR rate

CONTINUES ON PAGE 8

DR. ANTONIO P. PALUMBO — continued from page 4

stromal cells, which seem to show that the drug decreases the proliferation of myeloma cells. This evidence comes from the lab of Dr. Kenneth Anderson, IMF Scientific Advisor from the Dana-Farber Cancer Institute in Boston, MA. Based on this, we initiated a Phase I/II clinical trial of defibrotide in combination with MPT in patients with myeloma. We used a dose-escalating schedule of defibrotide. At present, we can say that this combination is safe and feasible, and that it does not significantly increase toxicity of the MPT regimen. But it is too early to reach a conclusion about the efficacy of the defibrotide plus MPT combination.

What is your outlook for myeloma patients, now and in the near future?

I think that the optimism shared by members of the myeloma scientific and clinical communities is now well known by the patient community. There are many ongoing studies that seem quite promising. After years of using a very limited range of standard treatment approaches for myeloma,

we are now able to tackle this disease with new weapons in our arsenal of armaments. Thalidomide, VELCADE, and Revlimid have changed the scenario of treatment by providing three new lines of myeloma therapies. We are now learning how to use these new drugs more efficiently, and we are already seeing improvement in response rates, progression-free survival, and overall survival. Out there, 30 to 40 new compounds are under investigation in the laboratory setting or in early phase clinical trials, and it is likely that some of these compounds will become new weapons against this disease. These are very exciting days for all members of the myeloma community. **MT**

Editor's Note: In addition to membership in numerous professional organizations, Dr. Palumbo is a journal reviewer. He has authored more than 100 publications in peer-reviewed journals as well as numerous abstracts and several textbook chapters.

PROF. JEAN-LUC HAROUSSEAU — continued from page 7

prior to transplantation translates into a higher CR rate after transplantation. And if, as we believe, survival is related to response rate, then the use of the Vel/dex combination will increase the CR + VGPR rate both before and after transplantation.

Any issues with toxicity?

The Vel/dex regimen is well tolerated overall, but there is a risk of peripheral neuropathy (PN) associated with VELCADE, occurring in approximately one third of the patients. We do not yet know the specific rate of PN in its different grades. We are very vigilant in identifying the early signs of PN and, when necessary, we either adjust the dose of VELCADE or stop the treatment altogether before the onset of severe neuropathy.

How have novel agents impacted the work of IFM investigators?

There are many practical examples of how novel agents -- used in frontline therapies, for relapsed patients, and with transplantation -- are improving survival of myeloma patients. Novel agents have greatly expanded the range of treatment options.

Used sequentially in relapsed patients, novel agents improve survival by approximately two years. In the past, when patients relapsed, we would give them the same cytotoxic agents in different combinations. And we had only two types of active agents, alkylating agents and steroids. Now we have several possibilities at hand at each step of the disease. Because novel agents are active even in heavily pretreated patients, we can achieve good responses in patients where such possibilities did not previously exist.

Of course, the second point of interest in novel agents is their benefit for newly diagnosed patients. There are several proofs of such activity. For elderly patients who are not candidates for HDT and transplantation, melphalan plus prednisone (MP) used to be the only option. At last, we have several combinations utilizing novel agents that are superior to MP not only in impressive response rates but also in progression-free and

overall survival. Such results are almost comparable to what is achieved with HDT in younger patients.

For patients who are candidates for autologous transplantation, we have demonstrated the benefit of using thalidomide as maintenance after HDT. A recent study from Australia has confirmed that thalidomide can improve the results achieved by HDT, and other recent data indicates that the use of novel agents in combination with chemotherapy and HDT plus autologous transplantation improves survival.

Next year, IFM will start a new investigation comparing Revlimid® plus low-dose dexamethasone (Rev/dex) to melphalan, prednisone, and thalidomide (MPT). We also have questions about younger patients who are candidates for HDT.

Is there anything you would like to add in closing?

The IFM seeks to improve treatment strategies and to increase efficacy and reduce toxicity of myeloma therapies. We strive for the highest level of quality in our studies, and good clinical practice according to European legislation is very expensive. We have good ideas and good investigators. Our biggest challenge is to find enough funding to actualize our projects.

The last thing that I would like to stress about the IFM is that we would not have had the success we have experienced without one very important element -- friendship. We are not in competition with one another. We have now worked together as friends for almost 20 years, and we plan to continue in the same spirit. **MT**

Editor's Note: Prof. Harousseau is a founding member of Intergroupe Français du Myélome and Groupe Ouest-Est Leucémies Aigues et Maladies du Sang. He is a member of the European Haematology Association (EHA), the European Group for Blood and Marrow Transplantation (EBMT), the American Society of Hematology (ASH), and the American Society of Clinical Oncology (ASCO).

RECOMMENDATIONS FROM THE IMWG

Prevention of blood clots associated with the use of thalidomide or lenalidomide

By Brian G.M. Durie, MD

Blood clots can occur in patients with myeloma as well as with monoclonal gammopathy of undetermined significance (MGUS). The risk is related to both the underlying disease and the increasing likelihood with increasing age, especially over age 65 years. This background risk is in the range of 3% to 7%, as determined by Prof. Antonio Palumbo, lead author of recommendations from the International Myeloma Working Group (IMWG). Fortunately, most patients have only a localized problem with, for example, phlebitis or inflammation of the veins of the calf of the leg (deep vein thrombosis or DVT). This can be treated with blood thinners. Occasionally, patients do develop blood clots that can travel to the lungs (pulmonary embolism or PE), which can be much more serious.

With the introduction of thalidomide and Revlimid® (lenalidomide) for myeloma treatment, it was quickly noted that more patients were having blood clot problems. This was particularly true during the first few months of treatment for a newly diagnosed patient. The exact risk related to two types of issues.

1. Underlying risk factors for developing blood clots such as:

- Individual risk factors (obesity, prior blood clots, or having a catheter)
- Other diseases (heart or kidney disease, diabetes, or infection)
- Recent surgery, trauma, or “immobilization” (such as on a long air/car trip)
- Other medications, particularly use of “EPO” (e.g. Procrit®, Aranesp®, or Epopgen®)

2. What was the exact drug dosage, schedule, and combination for the thalidomide or Revlimid® treatment? There is increased risk with:

- High-dose dexamethasone
- Doxorubicin combinations using Adriamycin® (such as VAD) or Doxil® (such as thalidomide/Doxil®)
- Multi-agent chemotherapies

For patients taking thalidomide or Revlimid® alone or with low-dose dexamethasone (i.e. using the one day/week schedule), aspirin alone is recommended as a sufficient preventative or blood thinner. For patients who have one of the underlying risk factors and/or who are using one of the increased risk combinations, more potent blood thinner therapy is recommended. The authors recommend a preference for using the blood thinner “low molecular weight heparin” or LMWH (e.g. Lovenox®). This is preferred over the blood thinner Coumadin® (warfarin) because of reduced risk of complications – several drugs and even food items can interfere with warfarin and upset the balance increasing the risk of both clotting and/or bleeding complications.

More studies are required to assess blood clotting risk with different drug combinations. The good news is that most patients can continue with planned treatment with thalidomide and Revlimid® without undue risk. If a blood clotting problem develops, usually blood thinner treatment can be started, and then thalidomide or Revlimid® treatment re-started. All patients are advised to discuss these issues directly with their treating physicians. **MT**

UPDATE FROM THE US MYELOMA FORUM

By Michael S. Katz

Established by the International Myeloma Foundation, the US Myeloma Forum is a committee of the world’s leading multiple myeloma experts. The Forum is a coalition that works collaboratively on key research initiatives and clinical trials. There are many promising therapies emerging from the laboratory. To translate this research “from bench to bedside,” it is crucial that we make the most of the resources available to conduct the most effective clinical trials and get them done as quickly as possible. The US Myeloma Forum is dedicated to accomplishing this goal.

The Forum started as a US enterprise, with the support and participation of the nation’s leading myeloma researchers. Subsequently, a number of key participants from Europe have joined the committee. At the first meeting, held this past April, US cancer clinical trials groups represented included Eastern Cooperative Oncology Group (ECOG), Southwest Oncology Group (SWOG), and Cancer and Leukemia Group B (CALGB). Representatives from the National Cancer Institute’s (NCI) Cancer Therapy Evaluation Program (CTEP), which is a major funder of myeloma clinical trials, also attended. Representatives of myeloma clinical trials groups from Italy, France, Holland, and Spain were also took part in the meeting. In addition, there were myeloma patients and caregivers, and pharmaceu-

tical company leaders involved in myeloma drug development.

The US Myeloma Forum has set a number of goals for integration of new treatments into the standard of care, as well as standardizing measures and methods to accelerate research. It was clear from the discussion that there are substantial issues in reaching consensus on many of the key issues. However, we were able to make progress at the meeting, and the participants agreed to continue to collaborate on working through the open issues.

Perhaps the most encouraging and impressive result of the meeting was agreement on a clinical trial for treatment of newly-diagnosed patients, to be pursued by a consortium of the participating clinical trials groups. The trial, designated S0777, will compare combinations of steroids, Revlimid®, and VELCADE® as frontline treatments for myeloma. Patients treated successfully will continue on the study, collecting stem cells for a potential transplant but initially being placed on maintenance therapy with the hope of prolonging their remissions.

Recently, S077 was approved by NCI’s CTEP and the protocol is expected to be available to patients in the near future. **MT**



NLB ACTIVITIES UPDATE

Myeloma Today in conversation with

Kena Miller, MSN, FNP, and Beth Faiman, RN, MSN CNP, AOCN

How did you become involved with the NLB, and what can you tell us about its activities?

Kena: Most of us were nominated for the Nurse Leadership Board (NLB), either by the myeloma specialists we work with or by our nursing colleagues. The NLB is a unique partnership between the IMF and a group of oncology nurses from leading cancer centers treating multiple myeloma in the United States, as well as from representative community practices. The NLB provides an unprecedented opportunity to improve patient care by sharing myeloma knowledge and experience among our colleagues on the Board, as well as to disseminate our expertise to our colleagues in community-based settings who are also caring for myeloma patients. Healthcare is a team effort – physicians make the decisions, but it is often nurses who implement the treatment and help manage the patients' response to it.

Please bring us up to date with NLB activities.

Kena: At the first NLB retreat in November of 2006, we initiated the drafting of nurse consensus guidelines to clarify specific protocols and procedures that nurses can use to help myeloma patients optimize their treatments, manage side effects, and receive the support they need. In developing the guidelines, NLB members focused on the management of side effect associated with myeloma: myelosuppression, peripheral neuropathy, DVT/PE, GI side effects, and steroids-related side effects. As a result of this initiative, NLB members presented a poster entitled "Nurse Guidelines for Enhanced Patient Care" at the 11th International Myeloma Workshop, which took place in Greece in June 2007.

Tell us about the second NLB retreat.

Beth: The second NLB retreat took place in Santa Monica, CA, in August of 2007. NLB members reviewed and discussed each section of the consensus guidelines. The guidelines are now being prepared

for journal publication, so the NLB is turning its attention to new areas of focus. As myeloma evolves into a chronic disease, there are more and more long-term survivors who are likely to use various myeloma treatment agents repeatedly, often re-combined into new regimens. This is why it is imperative the myeloma nursing community to develop consensus on how to best manage long-term side effects and long-term management of therapy. This applies to standard treatments, novel agents (Thalomid®, Revlimid®, VELCADE®), emerging therapies (low-dose dexamethasone, Doxil® plus VELCADE®), and experimental therapies.

Kena: In general, the management of long-term side effects is not an area that is well-developed in cancer care, and this has been true for the field of myeloma as well. I am currently working with one myeloma patient who is 18 years post-diagnosis, and there are many more patients like that across the country. This is a wonderful new frontier, and we must help our patients maintain their quality of life while managing their disease over the years.

Beth: To address these issues, the NLB formed four task forces focusing on patient education, nursing education, long-term side effects, and publications. All NLB members are involved in working on the long-term side effects task force. In addition to working on our respective teams, Kena and I also served as the retreat's faculty. We worked as a tag-team, facilitating each other's presentations, as well as those by the leaders of the various task forces.

Kena: NLB members also benefited from an educational presentation by Dr. Brian Durie, Chairman of the IMF, who discussed scientific updates on long-term side effects and management approaches, patient-related outcomes, transplant therapies, renal impairment, bone health, and the efficacy of novel, emerging and experimental therapies for myeloma.

CONTINUES ON NEXT PAGE

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

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



Seated, left to right: Diane Moran, Page Bertolotti, Beth Faiman, and Kena Miller.
Standing, left to right: Kathleen Colson, Katie Rogers, Ginger Love, Patricia Mangan, Teresa Jahns Miceli, Bonnie Jenkins, Elizabeth Billoti, Lisa Smith, Joseph Tariman, Sandra Rome, Deborah Doss, Jeanne Westphal, and Kathy Lilleby.

PERIPHERAL NEUROPATHY

Myeloma Today in conversation with Ginger Love, RN

What is peripheral neuropathy, and what is its cause?

Peripheral neuropathy (PN) is damage to the peripheral nervous system. Such damage can be caused by any of a variety of factors, including injury, inflammation, or a number of medical conditions or their treatments. In myeloma, PN is rarely present at diagnosis, although there are such cases. However, several approaches to myeloma treatment, including some novel therapies, are associated with PN as a side effect. With long-term use of Thalomid® (thalidomide), the incidence of PN is between 22% and 54%. With VELCADE® (bortezomib), according to scientific data, the incidence of PN in patients who have had prior therapies is approximately 34%. However, with Revlimid® (lenalidomide), another novel agent used to treat myeloma, the current data indicates that only approximately 2% of patients develop PN.

How and when is PN assessed in myeloma patients?

It is important for all myeloma patients to be assessed for PN at diagnosis in order to establish a baseline. Such assessment should then be repeated whenever it is clinically indicated, especially if the patient is receiving therapy that includes Thalomid or VELCADE. Because PN can be a very challenging side effect, healthcare providers are on the lookout for potential symptoms, but it is also important to educate patients and their caregivers about the symptoms of PN and encourage them to report all possible signs as early as possible. It is easier for doctors and nurses to monitor patients whose therapy is being administered intravenously because we have an opportunity to observe and to question such patients on a more regular basis. Patients who see their healthcare providers less frequently – such as when myeloma therapy is oral and self-administered – must remain vigilant to noting and reporting any potential adverse side effects they may be experiencing. If you are in doubt if what you are experiencing is PN or not, contact your doctor or nurse to report and discuss your symptoms.

What are the signs and symptoms of PN?

In extremely mild cases of PN, it is possible for a patient not to be aware of any symptoms. In such cases, unless a nerve test is performed, it would be difficult to ascertain the presence of PN. However, as the grade of PN increases, common manifestations reported by patients include numbness, tingling, or discomfort in hands or feet. One simple question nurses often ask patients when evaluating them is, “Do you have any trouble buttoning buttons?” Patients can also experience pain, muscle cramps or weakness, trouble walking, sensitivity to touch, cold hands or feet, pricking sensations, or burning pain. Sometimes PN results in hearing problems, or a ringing/buzzing in the ears. Depending on the grade of PN, it can interfere with function or with basic daily activities. PN can have a



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

significant impact on a patient’s quality of life, so it is important to catch, evaluate, and address PN as quickly as possible.

What is the prognosis once it is determined that a patient has PN?

First of all, this depends on whether PN is induced by the myeloma disease itself or if PN is the side effect of treatment. If PN is induced by a specific drug, and if this is caught early, we can often resolve symptoms. In many such cases, we are able to either stop or reverse PN. Otherwise, the patient may end up with irreversible peripheral nerve damage.

How is PN treated or managed?

If a patient is about to start therapy that is associated with a possible side effect of PN, or is exhibiting early signs of PN, we often recommend nutritional

support, supplementation with B-complex vitamins and folic acid, and certain amino acids. There is anecdotal evidence that these approaches work, but this has not been confirmed through scientific studies. If a patient already has a higher grade of PN, we consider treatment with tricyclic antidepressants such as amitriptyline (Elavil®). In cases where there is a more neurotoxicity, we consider using medications such as gabapentin (Neurontin®) or pregabalin (Lyrica®), as well as referring the patient for physical or occupational therapy. If pain is an issue, we may try Lidoderm® patches. Severe pain may require a referral to a neurologist or to a pain management specialist. Dose adjustment, termination, or change of therapy is considered on a case by case basis.

I would like to stress, that patients should not under-report their symptoms for fear that their therapy might be terminated. In many cases, it is possible to address PN with dose adjustments and, even if it is necessary to stop therapy, it can often be possible to restart it at a reduced dose once symptoms are resolved. Because patients who tend to under-report their side effects to their medical teams may also be inclined to withhold their complaints from their caregivers, it is important for family and friends to be on guard for signs of PN.

What are some of the overt signs to watch for?

Patients may be less steady when walking, or be unaware of stubbing their toes. Hand numbness may lead to dropping cups and utensils, and to difficulties with feeling small objects. In general, an informed and educated myeloma patient community, and a heightened awareness of PN, are very effective tools in monitoring or preventing this challenging side effect. **MT**

NLB — continued from previous page

What were your key takeaway messages from this NLB retreat?

Beth: Each NLB member contributes something unique to the group, from experience in direct patient care to expertise in clinical research. Being part of the NLB enhances our education and empowers us to take charge of exciting new projects. In addition to what we have already discussed, the NLB is now addressing how to best disseminate the NLB Consensus Guidelines to the entire nursing community in the US. Besides the upcoming publication of the NLB Consensus Statements, we are

working on coordinating a Speakers Bureau and other new myeloma educational initiatives.

Kena: Our work is an ongoing endeavor. Myeloma is a very intense disease. To work in myeloma, you have to have a particular dedication and a passion and for your patients. These characteristics describe every member of the IMF’s Nurse Leadership Board. It is very gratifying to be a part of such a hard-working group of people. **MT**

THE MYELOMA MOBILE: A FAMILY JOURNEYS ACROSS AMERICA

By Robin Tuohy

My husband Michael was diagnosed with multiple myeloma seven years ago at age 36. Most newly diagnosed patients have never heard of myeloma, unless they already know someone with this disease. This year, 20,000 more people will be diagnosed with myeloma. And we don't ever want anyone to feel as lost or alone as we did seven years ago.



There is limited public awareness of myeloma, and sparse research funding. In collaboration with the IMF, where I work as regional director of support groups for the Northeast, our family wanted to do what we could during the summer of 2007 to change this. Along with our children, 14-year-old Ally and 9-year-old Mikey, we traveled in an RV called the Myeloma Mobile on a cross-country tour. Our plan was to educate and empower patients and their families in local communities across the United States, both in major cancer clinics and smaller support groups

Leaving the East Coast and heading West

We left our Connecticut home on June 16, the last day of school for the kids. The trip got off to a great start when Dr. Mel Goldstein, meteorologist for ABC affiliate WTNH-TV in New Haven, CT, invited us to join him on the noon news. Dr. Mel is an 11-year myeloma survivor and an outspoken patient advocate.



We headed to Boston and Fenway Park, where we set up a table at the gate where thousands of people enter in order to disseminate IMF educational materials. Then we were invited onto the field (where Mikey and I put some Fenway dirt into our pockets). We stood with Wally, the Red Sox

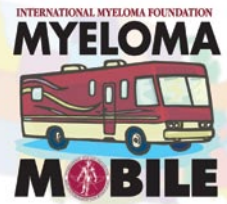
Mascot, and two Red Sox "Socks" Mascots. When the announcer said that Michael was a 7-year cancer survivor, the 36,000+ people in attendance erupted in cheers and applause. It was awesome!

We visited Millennium Pharmaceuticals in Cambridge, MA, for a fun and informal event. Both Michael and I spoke to a crowd of supporters. Then Ally and Mikey played Michael's song, *I'm Not Leavin'*, and the crowd loved it. On our way to the next destination, Michael called in to a live radio show on WDRC and spoke about myeloma, the IMF, and the Myeloma Mobile. After stops in Watkins Glen, NY, and Cleveland, OH, we arrived in Ann Arbor, MI. We were greeted by 24 members of the local myeloma support group! Next day, we visited the University of Michigan Cancer Center, where Dr. Yasser Khaled led an educational program. At many of our stops, the Myeloma Mobile events featured local clinicians who were there to educate the public.



In Wisconsin, we were greeted by three support groups from Madison, Milwaukee, and Racine. We also spent a day filming a two-part story for StoryBridge.tv. The Mayo Clinic in Rochester, MN, was our next stop. IMF's Kelly Cox started off the event with a brief talk, which was followed by a presentation by Dr. Martha Lacey. As we left the building, we were surprised

to see the local Fox/NBC affiliate waiting to meet our entire family – even our dog, Shannon, and cat, Spike, got some media attention! Then we did live radio interviews with KTOE in Rochester and WICC in Connecticut.



In Grand Island, NE, support group leader and long-time friend

Jim Omel hosted a picnic for 30 people – that's a crowd for Nebraska! Mikey especially loved fishing in the lake behind Jim's house. The picnic lasted until 10PM, and we got lots of hugs and encouragement to keep on "keepin' on."

At the Rocky Mountain Cancer Center in Denver, CO, there was a fantastic turnout to the Myeloma Mobile event. IMFers Diane & Jarvis Seccombe and Nancy Thompson decided to start a local support group after they heard us speak. We also received news coverage from CW2.com and KWGN-TV. We celebrated Michael's 43rd birthday in beautiful Colorado!



In Moab, UT, we had our first vacation days of the trip. We escaped the 107-degree heat by rafting down the Colorado River. As we headed for Salt Lake City, UT, we stopped at Arches National Park and Dead Horse State Park, and at the Great Salt Lake. The kids sure got great lessons as we drove across our beautiful country!

After a stop in Nevada, we headed for California. In Lake Tahoe, we were approached by a family from Australia. They were excited to meet us because they had heard about the Myeloma Mobile! We met many people who wanted to donate money, but our tour was strictly about education and awareness, so we just thanked the generous folks and referred them to the IMF.

In Sunnyvale, CA, we had a memorable visit at Kyphon. We toured the facilities, saw how balloon kyphoplasty was developed, and met hundreds of staffers. We were touched by the heartfelt reception we got. At the event, myeloma patients Jeffrey Martinez and Thomas Lujan talked about how kyphoplasty helped with their spinal compressions, and IMF's David Smith and Arin Assero spoke about how innovative tools improve patients' lives. Many thanks to Kyphon's Israel Madera and his family for taking such good care of us.



Education & Awareness

When we rolled into Los Angeles, it was like coming home to our second family, the IMF. Susie Novis and the IMF staff are incredible people who really care. At the Myeloma Mobile event, we also got to see many folks from several Southern California support groups.



Dr. Brian Durie gave a presentation and fielded numerous questions from the audience.

Thanks to IMF's Nancy Baxter, Michael was invited to throw out the first pitch at a San Diego Padres baseball game! He was also interviewed about myeloma by a local TV

station. After the game and a visit with local support group members, we said goodbye to the West Coast.

Heading East via the Southwest & the South

At the Mayo Clinic in Scottsdale, AZ, we were met by our featured speaker, Dr. Rafael Fonseca, as well as many Mayo staffers. The event was attended by both the Phoenix and the Tucson myeloma support groups and several newly diagnosed patients.



In North Texas, we joined 50 support group members at a baseball game between the Frisco Rough Riders and the Corpus Christi Hooks. Michael threw out the first pitch and the announcer

talked about myeloma, the IMF and the Myeloma Mobile. In Dallas, 70 people from several Texas support groups greeted us at the Charles A. Sammons Cancer Center at Baylor University. Drs. Marvin Stone and Robert Berryman led the presentations. Fox 4 KDFW interviewed us, as well as several other patients and caregivers. In Houston, we visited the M.D. Anderson Cancer Center for an event was attended not only by many patients and caregivers, but also by a remarkable number of clinicians! Unfortunately, Michael was under the weather, so it was left to Mikey, Ally, and I to speak to the audience about our Myeloma Mobile journey.



In Louisiana, we were interviewed by Lake Charles NBC affiliate KTLC-TV. In Lafayette, it was Fox15-TV and The Daily Advertiser newspaper.

In Baton Rouge, our segment with WVLA-TV aired twice! After a tour of New Orleans, we continued to Mississippi. We visited the Dexter Avenue Baptist Church, where Martin Luther King organized the Montgomery Bus Boycott in 1955. In Alabama, we stopped at the Rosa Parks Museum and Martin Luther King's church and home.

In Georgia, Andy Lebkuecher, our good friend and IMF's regional director of support groups for the Southeast, joined us for a cookout with the Atlanta Area Myeloma Support Group, one of the largest and oldest groups associated with the IMF. We visited the Winship Cancer Institute of Emory

University for an event featuring Drs. Leonard Heffner and Sagar Lonial.

In the Norfolk area of Virginia, we were honored to be present at the first meeting of a new myeloma support group founded by Jerry Walton, a patient and a recently retired high school teacher who truly understands the meaning of "Knowledge is Power!" Next, our Myeloma Mobile traveled to the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins in Baltimore, MD. The event, which featured Drs. Carol Ann Huff and William Matsui, was standing room only.



At the Abraham Cancer Center of the University of Pennsylvania, we were happy to see Dr. Edward

A. Stadtmauer, a pioneer of non-chemotherapy treatments for myeloma. He fielded lots of questions on everything from immunotherapies to organics. We were happy to see Maddie Hunter and Marilyn Alexander, leaders of the local support group, and Ann McNeill, who leads the support group at New Jersey's Hackensack University Medical Center. The Hackensack center chartered a bus so their patients could to attend the event. Folks from the

Central New Jersey Support Group also came. We met many patients who were not part of any group and we encouraged them to join one!



At the Celgene headquarters in Springfield, NJ, we toured the facility, then participated in a press conference and met with over 750 researchers, developers, and others. The Tuohy family is particularly grateful to Celgene because Revlimid® is the treatment that accounts for Michael's current complete remission. He is my husband, best friend, soul mate, and the absolute best dad to our children. Novel therapies have made it possible for us and for other families to have our lives back, and we are forever grateful.

Ahhh...Homecoming!

During our 63-days journey, we traveled 11,000 miles through 30 states, attended over 20 events, and met thousands of people. And we had one more event left – our homecoming! On August 17, at the Leever Cancer Center in Waterbury, CT, the grand finale of our tour featured Dr. Paul Richardson of the Dana-Farber Cancer Center in Boston, Dr. Kurt Sabbath of the Leever Cancer Center, Mayor Mike Jarjura of Waterbury, Mayor Robert Chatfield of Prospect, and our friend Dr. Mel Goldstein, who arranged for live TV coverage of the event. Michael and I shared the experiences of our journey with patients, family, friends, nurses, and staff who packed the auditorium. We were fortunate to have media coverage from the Waterbury Republican American, The Prospect Pages, WPLR radio, and the Archdiocese of Hartford's television magazine "Crossroads".



Our tour with the Myeloma Mobile may have ended but the friendships we've made will last forever. We thank Susie Novis and the IMF, all of our sponsors, and everyone we have met along the way, for helping make the dream of this crusade a reality. People helping people – that's what it's all about! **MT**

AMEN CELEBRATES SECOND ANNIVERSARY

By Michael S. Katz

AMEN, the Israeli Association of Myeloma Patients, is the IMF's affiliate in Israel. AMEN was founded to help improve the quality of life of myeloma patients through education and support, to centralize information on the disease and its treatments, and to act as a liaison with Bituah Leumi (social security) and health insurance companies.

It has been wonderful to watch the progress that AMEN has made in just two short years, helping the myeloma community in Israel. It has been an honor to be involved even in a small way in this good work. I've had the opportunity to meet with AMEN's Vaad (council), to attend a local support group meeting, and to speak at a program for Israeli oncology nurses.

So, I was thrilled to be invited to be a part of AMEN's recent second anniversary celebration. It was also wonderful to have the opportunity to visit



Michael S. Katz



Dr. Brian Durie with Prof. Dina Ben Yehuda (Hadassah Ein Kerem) and Paula Azulai (AMEN)

AMEN and Israel with my colleagues, Dr. Brian Durie and Susie Novis, the chairman and president of the International Myeloma Foundation. For Susie, it was her first visit. For Brian, it was his first visit since spending a summer on a Kibbutz near Tsfat over 30 years ago.

We arrived a few days

early to tour Jerusalem and the north. Seeing first-hand the incredible historic sites and natural beauty of the country, and visiting diverse communities was a stark contrast to the political caricatures of Israel that we often get from newspapers and television.

On Thursday, we had the opportunity to meet with the Dr. Ben Yehuda and other members of the Department of Hematology at Hadassah Ein Kerem Hospital. Ein Kerem is a beautiful neighborhood in the hills of



southwest Jerusalem. Located in Ein Kerem, Hadassah University Medical Center is a 700-bed facility that deals with virtually every conceivable aspect of modern medicine and serves as a national referral center for the most complex and challenging medical cases.

Dr. Durie was able to share current developments in multiple myeloma and learn about important work in the field being done at Ein Kerem. The doctors took the opportunity to present cases to Dr. Durie to get his perspective. Once we left Ein Kerem for Herzliya, a city on Israel's central coast just north of Tel Aviv, a huge traffic jam (or was it divine intervention?) provided the opportunity for the doctors to continue their discussions and present several more cases.

Once we arrived at Kibbutz Shefayim, we were pleased to meet and speak with many myeloma patients and their families. Many local doctors joined us in our salute to AMEN, an organization that has excelled at providing individual patient support as well as setting up support groups, developing information in four languages, helping to build research collaborations, and pressing the government and drug companies to make the best treatments available to patients in Israel.

Dr. Durie's talk gave the attendees a view of the latest in myeloma treatments and the exciting developments on the horizon. As a patient, it is so encouraging to hear how much progress is being made in treating myeloma. There are new drugs available that are saving lives every day, and more novel therapies are on the way.



On Friday morning, AMEN arranged for Dr. Durie to meet with the Israeli Myeloma Study Group to discuss current clinical trials and potential



research collaborations. In the evening, after a relatively peaceful Shabbat on the Tel Aviv seashore, we had dinner with members of AMEN's Vaad

before hurrying to the airport for the flight back to the US. We thank AMEN for its many accomplishments and for all that it continues to do to support and advance the causes of the myeloma community. **MT**

Editor's Note: Michael S. Katz is a member of the IMF's Board of Directors. For more information about AMEN, please visit www.AMEN.org.il or contact Mati Raviv at mati-r@013.net.il or 052-258-7612, or Zipy Farber at zipyfarb@netvision.net.il or 052-396-1210.

Support Groups

NEW JERSEY: HACKENSACK



Ann McNeill, RN, NP-C,
and Stephen Suppa

In October of 2006, Ann McNeill, an oncology nurse practitioner from the Hackensack University Medical Center (HUMC) in Hackensack, NJ, attended the Lymphoma and Myeloma Conference in New York City. There she met Robifn Tuohy, IMF's Regional Director of Support Groups (Northeast). Robin was interested in revitalizing the myeloma support group at HUMC's Cancer Center. The group had dissipated when it lost its facilitator, and Ann seemed like the perfect candidate to lead the group.

The first meeting of the new HUMC Multiple Myeloma Support Group took place in January of 2007, with 25 people in attendance. In subsequent monthly meetings, the group has bonded well and attendance continues to be good. While some meetings are forums for discussions between facilitators and group members, other meetings have featured guest speakers, including a nutritionist, leaders of other Northeast myeloma support groups, and IMF's Robin Tuohy, who is herself a caregiver. Ann McNeill is always present to answer

questions from group members. She has also led a group presentation on how to understand and interpret test results. The group now has a co-leader, Stephen Suppa, who has become an invaluable asset, working with Ann to help increase the group's outreach.

In August, members of the HUMC Multiple Myeloma Support Group traveled together to Philadelphia to greet Robin Tuohy and her family as they made a stop on their way back home from a cross-country myeloma awareness road trip in the Myeloma Mobile. "We are a very close-knit support group," says Ann. "Attending the Myeloma Mobile awareness event was just one example of the ways that we are always there for one another." **MT**

Editor's Note: The Hackensack University Medical Center Multiple Myeloma Support Group meets on the third Thursday of each month, from 10:30am to noon, on the third floor of the Sanzari Building. This group is open to myeloma patients, family members, caregivers, and friends. For more information, please contact Ann McNeill amcneill@humed.com or 201-996-5983.



CALIFORNIA: INLAND EMPIRE

The Inland Empire multiple myeloma support group held its first meeting in May 2005. The group was organized by Tom Courbat and Jim McCulloch, with the assistance of the IMF. Tom and Jim knew each other through the online myeloma ListServ but they had never met until the IMF suggested they collaborate on starting a support group.

Five people attended the first meeting, but membership has now grown to include 120 patients and caregivers, with 12 to 50 attending most gatherings. The group was founded to serve Riverside and San Bernardino Counties, but has also welcomed participants from as far away as Long Beach, Orange County, and San Diego. Many group members have formed close friendships that go beyond monthly meetings.

"We alternate between hosting guest speakers to holding open discussion forums for members," says Tom, who has been living with myeloma for six years. "We make sure to spend time with new members, making them feel welcome and giving them the opportunity to share their

stories and to ask questions."

Tom's myeloma is related to Agent Orange exposure during the Vietnam War, when he was stationed at Camp Casey, near the demilitarized zone between North Korea and South Korea. Because he has developed extensive experience with getting claims processed through the US Department of Veterans Affairs, the IMF refers myeloma patients to Tom who are in a similar situation and need advice or assistance.

With Jim's passing last year, a new co-leader has joined the group, Valerie Stevenson. Tom and everyone in the group are impressed by and grateful for her dedication and support.

"I found the IMF shortly after my diagnosis, and the Foundation was a big help to me," says Tom, "So I do all I can to help the IMF by sharing my knowledge and providing camaraderie and empathy to other members of the myeloma community." **MT**



Susie Novis & Tom Courbat



Editor's Note: The Inland Empire myeloma support group meets on the third Tuesday of every month from 6:30 to 8:30pm at Riverside Community Hospital Cancer Center in Riverside, CA. For more information, please contact Tom Courbat at Tom68-69Korea@thecourbats.com or call 951-677-6451, or contact Valerie Stevenson at valstevenson2005@yahoo.com or call her at 909-797-7716.

SMOLDERING BATTLES: MY DIAGNOSIS WITH SMOLDERING MYELOMA

By Diana Marquise, RN

Last year on August ninth, at age 50, exactly six years after my diagnosis with breast cancer, I was diagnosed with smoldering multiple myeloma. My diagnosis came unexpectedly via a routine annual blood test.

The day of my appointment, I felt absolutely fine. My family was doing well in their respective lives. I was finishing up some pending writing projects. In terms of my health, there were no indicators that these blood test results would be anything but normal.

Four days after my appointment, my oncologist phoned to report that my blood protein was abnormally elevated. Three days later when I returned for a second blood test, he set aside time to talk with my husband and I. "I'm not sure what's going on," he said, "We won't know until we do further tests."

Not knowing makes me very anxious. I'm a nurse and generally can handle whatever I am told, but I do have a need to know. In spite of my medical background, the condition was rare enough that I'd never even studied it in nursing school, nor read about it in the magazines. I felt more like a patient than a nurse. My husband Simon and I had just moved to California from Florida. My new oncologist hadn't known me long enough to know how I'd respond under the circumstances. "In the best case, your elevated protein can be due to an infection occurring somewhere in your body," he explained. "In the worst case, you could have a type of blood cancer."

I felt the clinical side of me take control. It was as if I'd stepped outside of myself and was speaking about one of my patients. "A blood cancer? Like what?" I feared the worst. My oncologist said that he'd phone with the results as soon as he had them. He seemed to genuinely care about my well-being, but my husband and I left his office dazed, confused and scared.

How could anything be wrong with me again? I'd just passed the critical five-year breast cancer survival mark, and although I dodged chemotherapy and radiation, I was still living with the effects of a mastectomy and reconstruction. For the past six years I've been followed by a holistic internist, eaten organically, swallowed a plethora of herbs and minerals, and exercised on a regular basis. There are people who take less care of themselves who never get sick. I felt doomed.

Two days later my oncologist phoned to say that the second blood test also came back with an elevated IgA, and the only way to make a definitive diagnosis was to do a bone marrow biopsy. "Isn't there any other way to make a definitive diagnosis than such an invasive procedure?" I inquired. My mind flashed back to my oncology internship and all the patients complaining about the discomfort of that intervention.

The next 48 hours before the procedure seemed excruciatingly long. We always fear the worst when it comes to our bodies. I began planning for

my shortened life span and the inability to live out all my dreams. If I wasn't crying I was sleeping.

The morning arrived for my bone marrow biopsy and I requested general anesthesia. The procedure went well and I was discharged home. Four days later we learned about my definitive diagnosis – multiple myeloma. My doctor suspected I had the smoldering type of myeloma. "Chances are you'll die from something else," he said. He told me to go home and make believe that I didn't have the disease. His words were absolutely impossible to execute – how could I live a normal life when one day my bone marrow might get so full of bad blood cells that my bones could fracture?

There were things that people told me during the early days of my diagnosis that I will never forget. My oncologist made a point of saying, "If this condition or experience does not rivet your focus on life, then you've missed the point." Yes, I've had my emotional ups and downs. And, in the early days after my myeloma diagnosis, my family was quite anxious and treated me very tenderly. Now one year later, we've all realized that I am living my usual life, the only difference is that I have frequent blood tests. For now, I've made the decision to only tell my close friends and family about the disease because I don't want sympathy nor do I want people to worry about me prematurely or at all. In addition, I don't want to be treated differently.

I'm also happy to report that, although my protein levels remain high, I feel better than ever. My levels are monitored by my oncologist, and I take all the necessary precautions to remain as healthy as possible. For the most part, I try not to think about myeloma. And my doctors say that it might be a long time, if ever, before my body dictates otherwise. Although I try to be optimistic because my disease is not active, I still must realistically understand that things can change in the years ahead. Naturally, the doctors cannot make me either promises or predictions. To help me through some emotionally difficult moments, I have a therapist who I speak with on a regular basis to help me deal with the present and any eventualities the future might hold.

My life's passion is writing, and this passion has helped me navigate through both the pleasant and the tumultuous times, including difficult pregnancies and breast cancer. Now this passion helps me cope with my new diagnosis, and although at first I thought that multiple myeloma was insurmountable, I have come a long way during this first year. My plan is to survive one more hurdle of surprises my body has sprung on me. My history shows that I am a fighter and I'm determined to fight this battle too! **MT**

*In spite of my medical background,
the condition was rare enough that
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nor read about it in the magazines.
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*My oncologist made a point of saying,
"If this condition or experience does not rivet
your focus on life, then you've missed the point."*

MYELOMA TODAY IN CONVERSATION WITH CINDY & BOB FELTZIN

“Investing in the Future” features profiles of IMF members who are making profound investments in the myeloma community and the path to a cure. We hope that the stories of how and why these individuals have chosen to commit so significantly to the fight against myeloma will inspire you as much as they do us.

Please tell us when and how you were diagnosed with multiple myeloma.

Bob: I was diagnosed with multiple myeloma in 2001, after a year of aches and an infection that just wouldn't go away. The blood tests showed an elevated protein level. My doctor listed a number of potential causes for the blood count abnormality, including something called multiple myeloma. After more tests, I was due to receive my diagnosis on September 11th, but my lab samples were lost at the Ronald Reagan Washington National Airport due to the repercussions of the 9/11 tragedy. My diagnosis was confirmed the next day. I just couldn't feel sorry for myself after thousands of people had just lost their lives in a terrorist attack.

How did you cope with your husband's diagnosis?

Cindy: I fed him. In fact, I fed him so much that his sugar level went into the 400s, a diabetic level! We now know that if steroids are part of a patient's treatment, it is not a good idea to eat a lot of carbohydrates. But, at that time, we knew very little. We were still in shock over the diagnosis. Bob started treatment with a local oncologist. We did not yet realize how important it is to see a myeloma specialist as early as possible in order to be put on the best path of treatment. By the time our son Brian found a myeloma expert in Boston, it was too late for Bob to change his course of treatment.

Tell us how you became involved with the IMF and the myeloma community.

Bob: We attended an IMF Patient & Family Seminar a few months after my diagnosis. That's where we met Susie Novis, the IMF staff, and Drs. Brian Durie, Robert Kyle, Gregory Mundy, and Sundar Jagannath. We learned so much about myeloma! If a myeloma patient, caregiver, or family member wants to be educated about this disease, IMF seminars are “must attend” events. We are now seminar veterans, having attended many meetings in the last six years.

Cindy: My earliest memory of the IMF is calling the Hotline. Whenever I had questions or concerns, the IMF was there to hold my hand. Once we felt comfortable with the disease, we decided to re-start the local myeloma support group at a Wellness Community center in Miami. I reached out to other patients and caregivers via the IMF, local media, and word of mouth. I've always been involved in my community, and now I was part of a new community of people whose lives had been touched by myeloma.

Bob: My wife is a dynamo. After we moved from Miami to West Palm Beach in 2003, she founded a new myeloma support group for Palm Beach, Martin, and St. Lucie Counties. In 2006, Cindy was the recipient of the IMF's Francesca Thompson Outstanding Service Award for her service to the myeloma community. This award was established in 1997 in memory of Dr. Francesca Thompson, a renowned orthopedic surgeon and author of the book *Going for the Cure*.



Cindy and Bob Feltzin

What enables you to lead a support group?

Bob: Cindy's background is in education, and she is a people person. I have a background in biology and chemistry, so I am better suited to analyzing information. When it comes to explaining what's going on in the myeloma world to our support group, that's my job. When it comes to getting 250 people to a meeting – or having Geraldine Ferraro or Drs. Ken Anderson, Bart Barlogie, Mohamad Hussein, or Hermann Einsele speak at sequential meetings – I don't know anyone who can do it better than Cindy.

Why did the two of you choose to invest in the IMF and its research and education programs?

Bob: It's my life. That's how I look at it. So, whenever we are able, we write a check to help support the IMF programs that have been of tremendous help to us over the years. We also donate stocks, which doesn't seem to hurt as much as writing checks, especially if the investment we are donating is worth more now than when we paid for it. We also have an insurance policy in place that benefits our children as part of our estate, and these trusts are set up in such a way that our children can donate money for myeloma research while I am still alive. We are fortunate to be living the 'good life' in south Florida, and we believe that we must do our part.

Cindy: Government funding isn't enough to support the search for the cure. And the research being done by the pharmaceutical companies does not suffice. We feel that we must do our part and contribute economically to help fund myeloma research, as well as important myeloma education programs. We need more action to be taken now. I would like to challenge every member of the myeloma community to get involved in supporting our common cause. I know that families coping with myeloma are under financial strain, but many are still capable of making a donation to support research and education programs. If we don't do it, who will? **MT**

Planned Giving

There are many ways to support the IMF. It is important that you find the approach that best meets your needs and fulfills your wishes. In order to help start the thought process for your gift planning, we suggest the following forms of giving:

- Bequests in your Will or Trust
- Gifts of Securities (Stocks)
- Gifts of Real Estate
- Charitable Lead or Remainder Trusts
- Annuity Trusts
- Unitrusts
- Term-of-year Trusts
- Gifts of Life Insurance

Estate and gift planning requires thoughtful consideration and discussion. To learn more about any of the suggestions listed above, or other forms of giving that might inspire you, please contact Heather Cooper Ortner at 800-452-CURE (2873) or hortner@myeloma.org. We also invite you to visit our website at www.myeloma.org for a more detailed explanation of these giving plans.

Special Events

CONCERT FOR A CAUSE

One amazing night in August, Spinal Tap headlined a concert to raise funds to benefit the IMF

Christopher Guest, Michael McKean and Harry Shearer (also known as Spinal Tap and The Folksmen) invited several of their friends to perform with them at the first ever Concert For A Cause. The event was amazing, with a crowd of over 1000 people packing the historic Avalon Theater in Hollywood. And they were not disappointed with the show they received!

For close to two hours, actor, comedian and singer Michael McKean led an all-star show that entertained and, frankly, cracked up the audience. From lyrical folk songs to soulful jazz to glam rock, these solid performers kept the standing-room-only audience energized and cheering for more!

In the weeks leading up to the event, the IMF and Concert for a Cause generated a great deal of publicity on the radio, in print and on television. By the time doors opened at 7 pm, a line had formed down the street and around the block from the box office. Fans of the performers and IMF supporters came out in droves to support this extraordinary and unique fundraiser.

Thanks to the generosity of our sponsors and a sell-out crowd, the event raised over \$40,000 to support the IMF's programs and services. Concert For A Cause also generated a significant amount of awareness in the larger community about myeloma and its treatment options.

Concert For A Cause grew out of a friendship between Michael McKean and Lee Grayson, a talented musician as well. Michael and Lee had

been friends since high school and Lee's passion for music connected many people, including Michael, to the IMF. Before his death, Lee created a fundraising event called Multiple Musicians Against Multiple Myeloma (MMAMM). Although Lee passed away shortly after



Brian Durie and Susie Novis with Tova Bonem, publisher of *Los Angeles Confidential* magazine



(l-r) C.J. Vanston, Harry Shearer, Michael McKean, Christopher Guest - singing songs from Spinal Tap



Legendary Van Dyke Parks (at keyboards) and friends



(l-r) Actress and wife of Michael McKean, Annette O'Toole, daughter Nell Geisslinger, and actress Jane Lynch



Naomi Margolin joined Michael McKean to sing Rainbow Connection in honor of Lee Grayson

the first concert, his girlfriend, Naomi Margolin, continues to spearhead MMAMM and it is now an annual tradition.

When the IMF first approached Michael about creating a benefit concert, we could not have imagined how amazing he and his wife, Annette O'Toole, and their many, many friends would be. They were incredibly generous with their time and their talents.

Our sincere thanks to our sponsors, Celgene, Millennium, *LA Confidential*

Magazine, 97.1 Free FM, Jimi Hendrix Electric Vodka, DJ Timbo and the Avalon Theater for their generous support of this event. Special thanks also to the amazing performers, Michael McKean, Harry Shearer, Christopher Guest, Annette O'Toole, Judith Owen, Van Dyke Parks, Jane Lynch, Nell Geisslinger and Naomi Margolin. Thanks also go to the fantastic crew of staff and volunteers for making this evening such an enormous success. Not only were we able to generate a significant amount of money for the IMF, we were able to reach out and let people know that "Until there's a cure... There's the IMF!" **MT**



Capacity crowd at the Avalon Hollywood

CELEBRATING PETER BOYLE

Join Us in November for an Evening of Comedy with Family and Friends

Late last year, award-winning actor Peter Boyle lost his battle to myeloma. Peter and his wife, Loraine, were both long-time supporters of the IMF and personal friends of Susie Novis and Dr. Brian Durie. Not long after Peter's passing, Loraine decided to turn her grief into something positive and agreed to chair an event in Peter's memory.

Celebrating Peter Boyle... An Evening of Comedy with Family & Friends is shaping up to be the IMF's biggest and most star-studded event ever. Celebrities and Hollywood insiders have agreed to lend their names and their support to the creation of an event that will truly do honor to Peter's memory and his comedic legacy.

Ray Romano, Peter's long-time friend and colleague from their hit TV show *Everybody Loves Raymond*, will host the show. In addition to Ray, several comedians are generously giving their time to entertain the IMF audience lucky enough to be there that night. The line-up includes Richard Lewis and Jeff Garlin with a special appearance by Martin Short, who starred with Peter in his last movie, *Santa Clause 3*.

The rest of the *Raymond* cast, including Patricia Heaton, Doris Roberts, and Fred Willard, will also be on stage to pay tribute to Peter that night.

At Loraine's request, the IMF has created the Peter Boyle Memorial Fund and all proceeds from the event will go toward this fund. The Peter Boyle Memorial Fund will support the IMF's on-going research projects, including Bank On A Cure®.

Anyone able to be in Los Angeles on Saturday, November 10, 2007, is invited to join us for what is sure to be an extraordinary evening. Individual tickets are available for \$350 and VIP tickets, including access to the post-show Champagne Reception, are available for \$600. Sponsorship opportunities begin at \$5,000. For more information about sponsorships, please call Heather Cooper Ortner, vice president of development, at 800-452-CURE (2873).

We look forward to sharing a fun-filled evening with you! **MT**

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Tova Bonem

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International Myeloma Foundation Celebrating Peter Boyle *An evening of comedy with family & friends*

Saturday, November 10, 2007
THE WILSHIRE EBELL THEATRE & CLUB
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Hosted by

RAY ROMANO

featuring Peter's TV family

PATRICIA HEATON, DORIS ROBERTS

FRED WILLARD

with Peter's friends

JEFF GARLIN, RICHARD LEWIS

and MARTIN SHORT

*All proceeds to benefit
the Peter Boyle Memorial Fund at the IMF*

Reservations required. Please RSVP by October 20, 2007



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List in formation as of September 12, 2007

IMFers RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia

Multiple Musicians Against Multiple Myeloma

On July 15, the sixth annual Multiple Musicians Against Multiple Myeloma, a benefit held to honor the memory of Lee Grayson and raise funds for the IMF and the myeloma community, took place at Tupelo Honey Restaurant in Sea Cliff, NY. Lee was a fixture on the Long Island music scene from the 1970s to the early 2000s, though his career highlights included stints at Carnegie Hall and in Europe. In the summer of 2002,



Lee Grayson



Naomi Margolin

Lee organized a benefit concert for the IMF called “Multiple Musicians Against Multiple Myeloma,” or MMAMM. That November, the much beloved musician succumbed to myeloma at the age of 55. Lee’s girlfriend, Naomi Margolin, has headed up the MMAMM event every July since then. This year, the all-day event featured non-stop performances by some of L.I.’s best-known musicians, including Cadillac Moon, Sean Grace, Cathy Kreger, the Zen Tricksters, and the Jason Crosby Band. The Village of Sea Cliff closed down a street for the day, making the benefit not only a concert but a street fair, with face painting, drumming circles and auctions. Local assemblyman Charles Lavine, who has attended MMAMM each year, said, “Not only is the annual event at

Tupelo Honey one of the best ways to enjoy superb and moving performances by our very best musical artists, but it also a meaningful expression of the unity of our community in the fight against a challenging but treatable form of cancer.” Profits from MMAMM have grown each year, totaling more than \$100,000 to date.

The WAMP Swim for Multiple Myeloma

The Staffords are a busy clan. Despite careers that have taken many of them away from their Connecticut home, Liz Stafford and her siblings continued their family tradition of holding the WAMP Swim again this year at the Wampanoag Country Club in West Hartford, CT. This event honors their father, Jeffrey Stafford, and benefits the IMF.



In 2005, proceeds from the WAMP Swim funded one of the IMF’s Brian D. Novis Research Grants. This year’s event, held on July 21, brought in over \$20,000. Together with other monies raised by the Stafford family and friends, another myeloma research award will be granted at the end of 2007. Our heartfelt thanks to the entire Stafford Family for their continued support of the myeloma community and the search for a cure.

Billy and Devon’s Wedding

On July 28, Billy Jackson and Devon Batson were married at the Ancient Spanish Monastery in North Miami Beach, FL. The couple made a donation to the IMF in honor of their wedding guests, who gathered for the occasion from all over the country. Billy’s dad, Bill, is a myeloma patient and leader of the Cincinnati Area Multiple Myeloma Support Group. “He is the strongest person I know,” says Billy. “Since going through the transplant, he has been living life to the fullest. Devon and I are ecstatic at the funds we raised, together with our friends and family, and hope to generate more support for the IMF in the future.”



Sandy, Billy, Devon, and Bill Jackson

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**

UPCOMING MEMBER EVENTS

October 14, 2007

- Third annual “Walk for Myeloma” – Coral Gables, FL
Contact: Denise Vidot at peaches2822@aol.com

October 27, 2007

- Second annual “Money for Miracles” Dinner~Dancing~Auction~Raffle – Warwick, RI
Contact: Carol Murray Rossi at marcar@gis.com or 401-463-5709

October 28, 2007

- “Linda’s Run for Myeloma” – Washington, DC
Contact: Eric Merkel at ericmerkel@quincypark.net or 703-624-4933

November 2, 2007

- “Evening 4 A Cure” Cocktails~Silent/Live/Chinese Auctions~Dinner~Door Prizes – Fox Valley Club, Lancaster, NY
Contact: Jerra Barit, 716-741-9351, if you’d like to attend

November 11, 2007

- Augusto Mario Schirinzi Memorial Golf Tournament
Le Pavoniere Golf & Country Club – Prato, ITALY
Contact: Vittorio Schirinzi at vschirinzi@tin.it

IMF Issues Prevention and Treatment Guidelines for Firefighters

During the 2007 Fire-Rescue International, a global conference held in Atlanta in August, the IMF released the first guidelines for the prevention and treatment of myeloma for firefighters and rescue personnel. Firefighters are at higher risk for myeloma, and the risk increases with length of service. Most recently, studies linked an increased risk of myeloma to exposures at the World Trade Center site following 9/11. The guidelines grow out of numerous studies. The IMF's Bank on a Cure® gene bank has found possible links between myeloma and genes responsible for the body's processing of dioxins and chemical contaminants produced by combustion. "When firefighters leave a fire they may be covered with toxins that can lead to long-term risks," said Dr. Brian G.M. Durie. "That is why it is essential for them to limit the exposure and seek expert medical help when they need it." The guidelines are issued in cooperation with the Firefighter Cancer Support Network, making firefighters, active and retired, aware of the importance of proper cancer screenings and reducing hazardous exposures to themselves and their immediate family members.

CMS announces NCD for coverage ESAs

A decision summary on national coverage determination (NCD) for coverage of erythropoiesis stimulating agents (ESAs) for non-renal uses in cancer and related neoplastic conditions was issued this summer by the Centers for Medicare and Medicaid Services (CMS). ESAs, available in the US as Epogen®, Aranesp®, and Procrit®, are man-made versions of erythropoietin, a hormone that is produced in the kidney and stimulates the bone marrow to make more red blood cells. CMS stated that emerging safety concerns derived from clinical trials in several populations prompted the review of ESA coverage. An article published on the IMF website earlier this year signaled our concern that the rationale for this decision is not entirely clear.

As this situation continues to develop, the IMF strongly encourages myeloma patients and caregivers to discuss any ongoing or planned use of Aranesp®, Procrit®, and Epogen® directly with the treating physician. It is important to make sure there is access to a needed medication while ensuring that there is not any increased risk with use for each individual

patient. Additional questions for the healthcare provider and the insurer should concern the verification of reimbursement for ESAs. Further information regarding this issue can be found on the IMF website at www.myeloma.org.

Obesity might be a risk factor for myeloma

According to a study published in the July issue of Cancer Epidemiology, Biomarkers & Prevention, a journal of the American Association for Cancer Research, an obese person is more likely than a lean person to develop multiple myeloma. Researchers from Harvard Medical School and Harvard School of Public Health have found that Body Mass Index (BMI) provides an indicator for an individual's risk of developing myeloma. BMI is computed by dividing a person's weight by the square of their height. A BMI between 18.5 and 25 is considered optimal, a BMI of 25-29 is considered overweight, and a BMI of 30 or higher is considered obese. For each person enrolled, researchers also recorded physical activity, diet, medications, smoking habits, and other health behaviors, and have updated that information every two to four years. Of the 136,623 participants who qualified for this study, investigators confirmed 215 cases of myeloma. The association between BMI and myeloma was strongest among men with a BMI of 30 or higher. The increased risk was less pronounced among overweight or obese women. Although the results among women suggested that those who exercise more might have a lower risk, the study findings show that the effect of BMI on risk of myeloma is separate from any possible effect of physical activity.

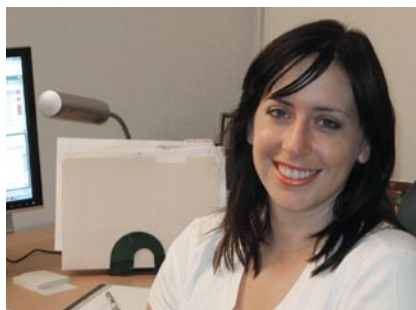
Patient Electronic Access to Medical Records

Medical facilities across the US are beginning to set up specialized websites for patients to conveniently access and review their medical records and test results, communicate electronically with their healthcare providers, and manage appointments and prescription renewals. Kaiser Permanente, for example, is said to have close to two million members who utilize their online portal system. The Dana-Farber Cancer Institute is another medical institution that has made use of this internet technology. All facilities must strictly adhere to HIPA rules about patient privacy. Ask your doctor if the hospital or clinic has a patient portal available for your use. **MT**

Staff Updates

Randi Liberman

joined the IMF in June of 2007 as Development Associate. Previously, Randi served as development coordinator at The Brandeis-Bardin Institute and as special events coordinator at the Motion Picture and Television Fund



Foundation. Her years of experience in data management, will help the Foundation to better communicate with myeloma patients, friends, and family members. Randi will also manage the IMF's direct mail campaign and help with special events and other projects. "I am thrilled to be working with a dedicated team that is deeply focused on continuing the IMF's efforts in myeloma research, education, and patient care," said Randi. To contact Randi, please email rliberman@myeloma.org or call the IMF at 800-452-CURE (2873).

Colleen R. McGonigle

joins the IMF with an extensive background in member services, record keeping, and database management. She moved to Los Angeles in January of 2005 from North Carolina where she managed the data and education reservations for the Museum of Life and Science in Durham. She also worked for organizations such as the Carnegie Science Center in Pennsylvania, and the J. Paul Getty Villa and the Autry National Center in California. As



Data Specialist at the IMF, she is responsible for maintaining accurate data entry and record keeping for IMF patients, friends, and family members. To contact Colleen, please email rmcgonigle@myeloma.org or call the IMF at 800-452-CURE (2873). **MT**

Spotlight on Advocacy

BUSY FALL LEGISLATIVE SESSION FOR CONGRESS

By Christine Murphy, MA

Congress returned to Washington in September with a full slate of legislative business to finalize before the end of the year. With the remaining legislative days numbered, it is unclear if these issues which impact myeloma patients will be resolved this year.

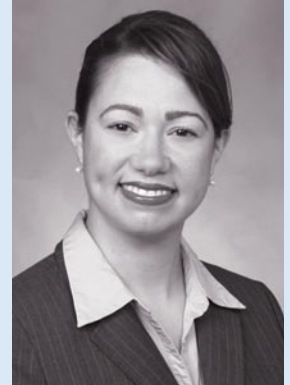
Earlier this summer, both the United States House of Representatives and the Senate increased funding for cancer research at the National Institutes of Health (NIH) and the National Cancer Institute (NCI) for the fiscal year (FY) 2008 Labor-Health and Human Services-Education (LHHS) appropriations bill. While the House allocation has been approved on the House floor, it is unlikely that the FY 2008 LHHS Appropriations bill will be put to a vote on the Senate floor. The House-Senate conference would likely proceed between the Committee-passed Senate bill and the House-passed bill and would be in the context of either a large omnibus bill, or a smaller mini-bus bill. It also looks like the omnibus process will not finish until sometime before Christmas.

Additionally, there are several proposed changes to Medicare that could impact access to critical myeloma care. The House has passed a bill that includes provisions that would prevent the Medicare program from

cutting physician reimbursement fees in both 2008 and 2009. The Senate has no plans to address the scheduled physician payment cuts, and the fate of the House Medicare provisions is unclear.

On the regulatory front, the Centers for Medicare & Medicaid Services (CMS) released policies for erythropoiesis stimulating agents (ESAs) as well as coverage of clinical trials for Medicare beneficiaries. For myeloma, coverage of ESAs will be limited to anemia caused by chemotherapy. The new proposed clinical trials policy will adversely impact myeloma researchers and clinicians, and could limit opportunities for myeloma patients to enter clinical trials.

The IMF continues to monitor these issues to keep you informed. Please visit www.myeloma.org for updates. **MT**



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2007 IMF Calendar of Events

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| <p>Oct 18–20 Lymphoma & Myeloma Conference – New York, NY
 20 IMF Clinical Conference – Beijing, CHINA
 21–27 Multiple Myeloma Awareness Week
 22 IMF Patient & Family Seminar – Barcelona, SPAIN
 26–27 P&F Seminar – Heidelberg, GERMANY</p> <p>Nov 2–3 IMF Patient & Family Seminar – Tampa/St. Petersburg, FL
 9–11 Eastern Cooperative Oncology Group (ECOG) semi-annual meeting – Ft. Lauderdale, FL</p> | <p>10 IMF Annual Gala – Peter Boyle Event – Wilshire Ebell Theatre, Los Angeles, CA
 10 3rd Annual Southwest Symposium – Tempe, AZ
 17 IMF Regional Community Workshop – Bergish-Gladback, GERMANY
 19 IMF Regional Community Workshop – Berlin, GERMANY</p> <p>Dec 8–11 American Society of Hematology (ASH) annual meeting – Atlanta, GA</p> |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

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.

We speak your language

The IMF publishes a comprehensive library of informative myeloma resources. Used by patients, caregivers, healthcare professionals, and anyone needing a reliable source of up-to-date information regarding the disease, these publications are critical to a better understanding of myeloma.



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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).



International Myeloma Foundation
 12650 Riverside Drive, Suite 206
 North Hollywood, CA 91607-3421
 U.S.A.
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