2007 IMF Calendar of Events

Aug	17–19	Nurse Leadership Board (NLB) Retreat – Santa Monica, CA
	27	Concert for a Cause – Avalon, Hollywood, CA
Sept	14	IMF Patient & Family Seminar – Paris, FRANCE
	15	Greater Kansas City Symposium – Kansas City, MO
	21	IMF Patient & Family Seminar – Rome, ITALY
	26	IMF Clinical Conference – St. Petersburg, RUSSIA
Oct	3–7	Southwest Oncology Group (SWOG) semi-annual meeting – Huntington Beach, CA
	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 – Heidleberg, GERMANY
Nov	2–3	IMF Patient & Family Seminar – Tampa/St. Petersburg, FL
	9–11	Eastern Cooperative Oncology Group (ECOG) semi-annual meeting – Ft. Lauderdale, FL
	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
Dec	8–11	American Society of Hematology (ASH) annual meeting – Atlanta, GA

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.

SAVE THE DATE!

The IMF Annual Gala

Celebrating Peter Boyle...
An Evening of Comedy & Music
with his Friends and Family

featuring:

Ray Romano,
Patricia Heaton, Doris Roberts
and Fred Willard as MC

Additional guest performers to be announced soon!
Check the IMF website for updates!

Saturday, November 10, 2007

Wilshire Ebell Theater and Club
Los Angeles, CA

Tickets: $350 per person

Benefitting the Peter Boyle Memorial Fund
at the International Myeloma Foundation

For sponsorship opportunities or more information,
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CONCERT FOR A CAUSE

featuring

A change in the program is in the works!

Greg Grunberg, Bonnie Somerville, Bob Guiney, James Denton, and Hugh Laurie,
with special guest Danny Seraphine, original drummer for *Chicago*

Special Appearance by
Christopher Guest, Michael McKean
and Harry Shearer
(SPINAL TAP, THE FOLKSMEN)

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MONDAY, AUGUST 27, 2007
Doors open at 7:00 pm – Show 8 pm

Please continue to check the IMF website for updates on this event.

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MYELOMA TODAY

SUMMER 2007
VOLUME 7 NUMBER 3

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

Prof. Pieter Sonneveld discusses the founding, and past and present activities of HOVON, the Dutch-Belgian Hemato-Oncology Group. Upcoming projects include continued participation in the Bank On A Cure® research initiative. **PAGE 4**

Dr. Brian G.M. Durie shares the myeloma-relevant news from the recent 12th Congress of the European Hematology Association (EHA), held in early June in Austria, and the 11th International Myeloma Workshop (IMW), held in late June in Greece. **PAGE 5**

Dr. Asher A. Chanan-Khan explains the mechanism of action of mapatumumab, a new cancer therapy currently in development. This novel agent has significant potential for the treatment of a broad range of human malignancies, including myeloma. **PAGE 7**

Michael S. Katz offers an overview of the first meeting of the newly formed U.S. Myeloma Forum, a committee of the nation's leading myeloma experts recently established by the IMF. Mike attended the meeting as a patient representative. **PAGE 8**

Special Announcement

Dr. Robert A. Kyle, IMF Director and Scientific Advisory Board Chair, receives the prestigious 2007 David A. Karnofsky Memorial Award from the American Society of Clinical Oncology (ASCO). This award honors him as a researcher whose work has changed the practice of clinical oncology. **PAGE 22**

Profiles in the News

E. Michael D. Scott, who joined the IMF Board of Directors in 1995 talks about the activities of the IMF and its Board, and shares his thoughts about the patient advocacy community and today's oncology marketplace. **PAGE 9**

Clyde Corales, a myeloma patient and avid cyclist, shares the story of how cycling helped him to fall in love with life all over again after his diagnosis. Clyde participates in bike rides to spread myeloma awareness and education. **PAGE 18**

Carol Klein and Nancy Moses, whose husbands are living with myeloma, teamed up to give back to the myeloma community by spreading myeloma awareness while successfully raising funds for a myeloma research grant. **PAGE 19**

Supportive Care

Deborah Doss RN, OCN, discusses thromboembolic events (TE), a potential side effect for patients with hematologic malignancies, especially myeloma. **PAGE 12**

Meet the **IMF Hotline Coordinators** who answer your questions and emails, and help you address the various aspects of myeloma in a more informed way. **PAGE 13**

Also in this issue…

- **Dear Reader** by IMF president Susie Novis **PAGE 3**
- **Letters** to the IMF **PAGE 3**
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- **IMFers raise funds** to benefit the myeloma community **PAGE 20**
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- **Save the Date!** Join us for two very special events **BACK COVER**

CONCERT FOR A CAUSE

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).

This issue of *Myeloma Today* is supported by Celgene Corporation, Millennium Pharmaceuticals, and Ortho Biotech.

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International Myeloma Foundation

Dear Reader,

Heinz Ludwig with Susie Novis, Robert Kyle, Birgit Ludwig, and Brian Durie

The International Myeloma Foundation was proud to present the 5th Robert A. Kyle Lifetime Achievement Award to Prof. Dr. Heinz Ludwig. This award was established in 2003 and honors the physician whose lifetime body of work best exemplifies compassion for myeloma patients and a singular dedication to the treatment of their disease. Prof. Ludwig was presented with this honor in recognition of his work in medical hematology-oncology and, in particular, multiple myeloma.

The event took place in Vienna, Austria, on June 7, 2007, at the historic and beautiful Vienna Kursalon, famous for providing an exquisite venue for classical concerts, operas, and musicals. Historic Vienna is one of the most beautiful cities in the world, renowned for music, art, architecture, and the famous Lipizzaner horses. It is also where Prof. Ludwig lives and works. He is Director of the Department of Medicine I, Center of Oncology and Hematology at Wilheminenspital, Vienna.

There was some anxiety about our desire to take advantage of the lovely park scenery and hold the event outside, because the skies would darken and it would pour in the evenings preceding the event. So a decision was made to set up inside. However, on the evening of the event, the weatherman made his prediction – it would not rain. As luck would have it, he was right. At the last minute, the tables were moved outside and, by the time the first guests arrived, the setting was perfect.

The evening began with a lovely cocktail hour, sipping drinks and mingling under a clear sky on the fringe of the beautiful park, meeting old friends and making new ones. Everyone was in high spirits, thrilled that Prof. Ludwig was being honored. The atmosphere lent itself to creating a magical evening.

As soon as everyone was seated, the program began with a very heartfelt welcome from Dr. Brian Durie, congratulating Prof. Ludwig and setting the stage for Dr. Kyle's award presentation and a few surprises for the evening.

Since Vienna is known for music, we were not disappointed, as we were treated to a short concert preformed by members of the Vienna Philharmonic Orchestra.

Prof. Ludwig was in for a big surprise as his two children, Claudia and Michael, presented a video they had prepared depicting milestones in their father's life, all set to music. The video was aptly titled "Heinz H to Z," and they had chosen the most perfect photographs showing Heinz in various stages throughout his life – as a young boy, as a sportsman, during his medical career, as a family man, and mostly as a man who truly loves his wife, his family, and life! He was completely surprised and enjoyed every moment of it, as did we all.

Next was the moment we'd all been waiting for, Dr. Kyle's presentation of the award to Dr. Ludwig. Dr. Kyle took the stage and told the audience why Prof. Ludwig was receiving the award, recapping his numerous accomplishments. Then the stage belonged to Prof. Ludwig who, in his very elegant and eloquent manner, thanked everyone and acknowledged several people in the audience.

Once again, music became the night, as two outstanding opera singers took the stage as we sat under the stars, entranced, moved, and thoroughly entertained by the magic and the beauty of their voices.

The evening ended with the most fantastic dessert buffet, lest we forget that Vienna is also known for its pastries. So throwing caution to the wind, we had to sample all that was offered, and thus the evening ended on a very sweet note.

Warm regards,
Susie Novis

Letters to the IMF

IMF Patient & Family Seminars

I have been to probably at least eight IMF Patient & Family Seminars, and they have been absolutely worth it. I recommend both the Friday and Saturday sessions. You get to learn a lot, meet other patients, and talk to myeloma specialist up-close. And Susie Novis and Dr. Brian Durie are very approachable. My oncologist joined me and another myeloma patient at one of these seminars, and he commented that he learned more than at most medical conferences he attends.

Charles Hill

Savings for Patients

I recently learned that both my local electricity and gas utilities companies have a Medical Assistance Program. A compromised immune system is one of the factors that receive approval for a permanent reduction in utility costs. Multiple myeloma folks have extraordinary expenses, and such programs make a difference, especially in the winter and summer months. I would be surprised if most utility companies across the country don't have similar programs, so please pass this information along to other myeloma patients. Thank you for supporting all of us and for the fine job you do.

Eric Vogt

IMF Hotline

You guys are the best! You have given me hope and confidence, and for that you should sit back and take a little credit. I sure do appreciate your business-like approach, your dedication, and your attitude. You and the IMF have become valuable extensions to my own oncology team, and this is very reassuring. Indeed, now that I'm an "old timer" in the world of myeloma, I value your activities even more. My compliments!

Robert Scott

HOVON: THE DUTCH-BELGIAN HEMATO-ONCOLOGY GROUP

Myeloma Today in conversation with Prof. Pieter Sonneveld

Pieter Sonneveld, MD, PhD
University Hospital Rotterdam - Dijkzlgt
Rotterdam, the Nederlands

Please tell us about the origins of HOVON.

HOVON, the Dutch Hemato-Oncology Group, was founded in 1981. Our goal at that time was to set up clinical studies in leukemia. Shortly thereafter, the group expanded its activities to clinical studies in lymphoma and multiple myeloma. When members from Belgium began to join the cooperative, HOVON started being referred to as the Dutch-Belgian Hemato-Oncology Group. Within HOVON, there are three major working groups – leukemia, lymphoma, and myeloma. The Myeloma Working Party consists of hematologists from all the major centers in Holland and Belgium. It is co-chaired by me and Dr. Henk Lokhorst, who also chairs the HOVON group overall.

What have been some of the historically significant HOVON trials in myeloma?

In the early 1990s, there was a Phase II HOVON clinical study on the use of high-dose melphalan therapy in myeloma. From this, we developed the Phase III trial known as HOVON 24, which compared single and double intensive treatments [autologous stem cell transplantation] in previously untreated patients with myeloma. The first analysis was performed in 2002, and the study was published in *Blood* in 2003. Final analysis was performed in 2006, with the update set to be published in 2007 in *Haematologica*, the official journal of the European Hematology Association (EHA). We have also conducted studies in allogeneic transplantation and, in 2003, the *Journal of Clinical Oncology* published the results from a prospective comparison of patients treated in the Phase III HOVON 24 study.

What can you share with our readers about recent and current HOVON activities?

The Myeloma Working Party recently finished the HOVON 50 prospective trial to determine the effect of thalidomide prior to, and as maintenance following, high-dose therapy with autologous transplant for newly diagnosed myeloma patients. We compared induction regimens of VAD (vincristine, doxorubicin, and dexamethasone) with TAD (thalidomide, doxorubicin, and dexamethasone), followed by peripheral blood stem cell (PBSC) collection and transplantation. This Phase III multi-center study was conducted in cooperation with the German-speaking Myeloma Multi-center Group (GMMG) and involved 1150 myeloma patients. It is too early to analyze survival rates, but we have already analyzed response. Engraftment after transplantation showed no difference between TAD and VAD groups, and we concluded that thalidomide as part of induction is associated with better response rates. TAD is far more effective in achieving complete remission (CR) or very good partial response (VGPR).

We recently finished HOVON 49, a prospective Phase III clinical trial in elderly patients comparing frontline therapy of melphalan plus prednisone (MP) with MP plus thalidomide (MPT). The results of that study are being analyzed at this time. Currently, HOVON has a number of ongoing clinical trials, including one with bortezomib (VELCADE®) for induction prior to high-dose melphalan in myeloma patients over age 65, plus another trial (HOVON 65) that compares bortezomib versus thalidomide as maintenance. HOVON 85 will compare MPT to lenalidomide (REVLIMID®) added to standard MP (RMP) in the elderly patient.

What is the current focus of your research?

Primarily, my group is focusing on the use of bortezomib and on defining prognostic subgroups for bortezomib. In terms of the primary endpoints of next generation HOVON clinical trials in myeloma, we will focus on novel drugs added to established treatment; the evaluation of pharmacogenomic, molecular, and epigenetic factors; definitions of disease-related risk profiles and of treatment-related risk profiles; and the development of tailored treatment for prognostic subgroups based on the availability of novel targeted treatments.

How is HOVON involved with the IMF's Bank On A Cure® research initiative?

The first analysis of thrombosis (blood clots) in patients who use thalidomide was performed by Dr. Gareth Morgan (Royal Marsden Hospital, London, UK) on data from HOVON and from the US. In December of 2006, a presentation was made at the annual meeting of the American Society of Hematology (ASH) identifying genetic pathways that may explain why some patients suffer from blood clots when undergoing treatment with thalidomide for myeloma. This may shed new light on individual differences in the response to cancer and its treatment, and may lead to the development of screening techniques and tailored interventions to prevent these side effects. Genes involved with drug metabolism, DNA repair, and inflammation have been identified as predictors of which patients are more likely to experience venous thromboembolism (VTE).

HOVON's next Bank On A Cure project is a comparison of patients responding to bortezomib. This study will be performed at our center in the second half of 2007, in cooperation with Dr. Morgan and the Heidelberg, Germany myeloma group, using data from the HOVON 65 trial. In HOVON 65, we are collecting and purifying stem cells, and using the Bank On A Cure custom single nucleotide polymorphism (SNP) chip for analysis of gene expression signatures identifying response to bortezomib, thalidomide, and high-dose melphalan. The goals of additional biological studies include analysis of the role of genetic polymorphisms (on metabolism, bone disease, thrombosis, polyneuropathy, and myeloma).

Are you presenting at the International Myeloma Workshop in Greece?

Yes. We will be making several presentations, including the results of the HOVON 50 study, data on the risk of thrombosis and neutropenia associated with the use of lenalidomide, recent achievements of the European Myeloma Network, as well as preclinical data from our group on the purification steps that can be used prior to the single nucleotide polymorphism (SNP) analysis. We will also present a paper on gene expression profiling.

What is your overall outlook for the myeloma community?

It is very favorable. At our institution, we are conducting multiple early phase trials of promising agents, like next generation proteasome inhibitors and kinase inhibitors, that should soon find clinical use. As for therapies currently available to patients, there are several novel agents that are producing lots of good responses and, in my opinion, should be part of all induction therapies. And, at relapse, it is now possible to use a combination of novel and conventional agents to achieve good results. There are many positive developments in the field that should give patients hope when facing this disease **MT**

UPDATES FROM RECENT SCIENTIFIC & CLINICAL CONFERENCES

Myeloma Today in conversation with Dr. Brian G.M. Durie

What can you tell us about presentations made at the recent EHA meeting?

There were several important presentations at the 12th Congress of the European Hematology Association (EHA), which was held in early June in Vienna, Austria. The Italian study about mini-allogeneic transplants, which has already been published in *The New England Journal of Medicine*, was presented at the meeting by Mario Boccadoro (University of Medicine, Torino, Italy). This very interesting but controversial study showed that double autologous transplantation was not as effective as one autologous transplant plus one mini-allogeneic transplant. These findings are currently being actively discussed. (*NEJM* June 21, 2007: 356; 2646-2648). The main issues are: Is the mini-allo treatment really better than double auto transplant? Is the graft versus host disease a major deterrent? Will the introduction of novel therapies provide greater benefit than mini-allo with lesser toxicities?

Brian G.M. Durie, MD
Aptium Oncology
Cedars-Sinai Comprehensive Cancer Center
Los Angeles, California

Antonio Palumbo (University of Torino, Italy) presented the updates on MPT (melphalan, prednisone, thalidomide) and MPR (melphalan, prednisone, REVLIMID®) for the non-transplant myeloma patient. The results with MPR were very good, and it appears that the MPR regimen might replace MPT in the same way that REVLIMID plus dexamethasone has replaced thalidomide plus dexamethasone. Dr. Palumbo also showed that MPR overcomes the negative impact of abnormal chromosomes. With MPR, the outcome for patients with chromosome 13 deletion and translocation 4; 14 was the same as for patients without such abnormalities. These excellent MPR results conflict with the "risk-adapted strategy" technique published by the Mayo Clinic team, whereby patients should be treated based on chromosome results. The MPR works well for both good risk and bad risk patients.

Other controversial presentations at EHA were those made by Pieter Sonneveld (University Hospital Rotterdam, Dijkzlgt, the Nederlands) and by Jean-Luc Harousseau (Institute of Biology, Nantes, France). Their work has shown that VELCADE® plus DOXIL® results in a three-month longer response duration than VELCADE alone. A similar US study was sufficient to obtain FDA approval for the combination treatment. However, there is remaining controversy as to the relative clinical value of this modest survival benefit with VELCADE plus DOXIL. Dr. Sonneveld performed a subset analysis looking at whether or not the patients who had previously received thalidomide, and he showed that prior thalidomide does not detract from the outcome, while the survival remains the same. Using the same data, Dr. Harousseau showed that, with longer follow-up, there is a significant but modest survival benefit overall with the combination therapy.

Keith Stewart (Mayo Clinic, Scottsdale, AZ) presented results of the Phase I/II study of the new proteasome inhibitor carfilzomib (PR-171) in myeloma and Waldenström's macroglobulinemia. In his early testing, Dr. Stewart showed that four out of 20 patients responded to the new agent. All of the study patients had very advanced disease. The study dosage was well-tolerated, with no neuropathy side effects.

Joan Bladé (Hospital Clinic, Barcelona, Spain) presented data from the PETHEMA study of high-dose therapy (HDT), including tandem stem cell transplant, in primary refractory myeloma. Dr. Bladé showed that, provided the patient does not have progressive disease, the outcome with different levels of response is the same. Several researchers have evaluated if there is a difference in the outcome for patients with CR (complete response) compared with patients who achieved VGPR (very good partial response) or other response levels. In the Spanish study, there was no difference.

How are the responses being evaluated?

Currently, there is a strong trend to use the published New International Uniform Response Criteria for Myeloma. However, in assessing the above mentioned study, Dr. Bladé used the European Blood and Bone Marrow Transplantation (EBMT) criteria as modified by the new response criteria. In the EBMT criteria, response is documented with two readings six weeks apart, or the response must be listed as "unconfirmed." This means that in the older studies which used the EBMT criteria, approximately 10% of patients could not be evaluated because their protein level could not be re-checked six weeks later. Removing data for 10% of the trial patients from the study can have a major impact on the results. The new criteria simply requires two reading to make sure that a mistake has not been made, but one does not need to wait six weeks to re-check protein levels. This enhances the ability to assess response.

Thank you. What about the presentations made at the International Myeloma Workshop?

There were several interesting presentations made at this bi-annual meeting, which took place is Kos, Greece, June 25–30. In the pathophysiology section, there was an interesting discussion of possible new agents for treating myeloma bone disease. In the genetics section, there was an overview of the molecular classification of myeloma presented by John Shaughnessy (Myeloma Institute for Research and Therapy, Little Rock, AR), prognostic implications of FISH karyotyping was presented by Hervé Avet-Loiseau (Institute of Biology, Nantes, France), and single nucleotide polymorphism (SNP) models in myeloma from the Bank On A Cure® addresses by project co-director Brian Van Ness (University of Minnesota, Minneapolis, MN).

What progress has been made of late with Bank On A Cure?

There are a couple of interesting updates to report. Both Pieter Sonneveld and Hervé Avet-Loiseau now have the equipment in their labs sufficient to do the testing for the Bank On A Cure research project. The IMF is providing the customized chips necessary for them to do their studies.

Continues on Page 6

BRIAN G.M. DURIE — continued from page 5

This means that the Bank On A Cure research being done has expanded from two labs to four labs. Work will now proceed in the US, the UK, the Netherlands, and France.

That's great news. Now let's go back to the Kos presentations.

In the novel treatments section of the International Myeloma Workshop, Paul Richardson (Dana-Farber Cancer Institute, Boston, MA) discussed the impact of VELCADE-based combination treatments on relapsed and refractory myeloma, Donna Weber (M.D. Anderson Cancer Center, Houston, TX) talked about REVLIMID-based combination treatments for relapsed or refractory disease, Dharminder Chauhan (Dana-Farber Cancer Institute) covered the next generation of proteasome inhibitors as therapy in myeloma, and Constantine Mitsiades (Dana-Farber Cancer Institute) presented on the anti-myeloma activity of heat shock protein-90 inhibition.

In the area of frontline treatment of myeloma, there are a number of questions that still need to be answered. Which of the different frontline therapies are best for the approximately 20% of myeloma patients who are planning to proceed to stem cell transplantation? And what is the preferred frontline therapy for the approximately 80% of myeloma patients who do not proceed to transplant? At present, one of the leading candidates in the first category is the combination of REVLIMID plus low-dose dexamethasone. In the second category, we are looking at a number of VELCADE-based regimens, as well as MPT and MPR.

Is there still a place for high-dose therapy?

The medical community is currently re-assessing stem cell transplants. There were a number of presentations made at the International Myeloma Workshop that focused on optimizing stem cell transplantation, single vs. double autologous transplants, allogeneic transplants, analysis of prognostic factor, and post-transplant strategies after allografting. Also on the program was a debate between Bart Barlogie (Myeloma Institute for Research and Therapy, Little Rock, Arkansas) and Jean-Paul Fermand (Hospital Saint-Louis, Paris, France) on whether autologous transplant should be part of the primary treatment in myeloma, with Dr. Barlogie speaking for the affirmative and Dr. Ferman for the negative. Previosly, Dr. Fermand had presented results of his large, randomized trial comparing upfront transplants to delayed transplants at relapse, with the survival benefit being the same for both scenarios.

Did you present at the International Myeloma Workshop?

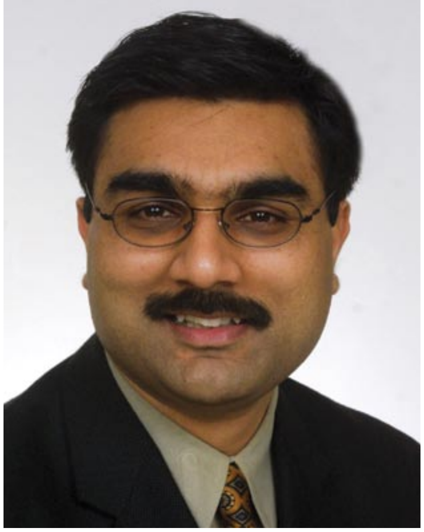
Yes. I presented the Bank On A Cure bone SNP data. Also, in the closing symposium, which focused on current and future perspectives in myeloma, I presented on the importance of the new and evolving uniform response criteria response criteria and how this is changing the way we are structuring all of our protocols for myeloma. As part of the same session, Jesus San Miguel (University Clinic Hospital, Salamanca, Spain) discussed how novel agents are individualizing the treatment of myeloma, Pieter Sonneveld shared plans for European myeloma studies, and Ken Anderson (Dana-Farber Cancer Institute) concluded the symposium with his predictions for the future.

What does the future look like?

This is a very exciting time in the field of myeloma. Never before has so much progress been made in this disease within a relatively short time. There is much work ahead, and there are many clinicians and researchers applying themselves toward a greater understanding of myeloma. In the meantime, the outlook for patients is continuing to improve. I hope that this brief overview will give readers of *Myeloma Today* the sense of just how much is currently going on in the effort to improve the length and quality of life of myeloma patients. Some of the studies I have mentioned warrant follow-up in the future issues of this newsletter, and we will be bringing more comprehensive discussions of those topics to our readers. Please stay tuned. **MT**

MAPATUMUMAB: A NEW CANCER THERAPY IN DEVELOPMENT

Myeloma Today in conversation with Dr. Asher A. Chanan-Khan



Asher A. Chanan-Khan, MD
Roswell Park Cancer Institute
School of Medicine & Biomedical Sciences
University at Buffalo
Buffalo, NY

What is your background in myeloma?

I have worked in the field of multiple myeloma for the past seven years. Currently, I lead the clinical and translational research efforts in myeloma at the Roswell Park Cancer Institute. My research interests include the development of novel therapies to treat this disease. I was involved in the development of bortezomib (VELCADE®) and lenalidomide (Revlimid®) and have worked on numerous myeloma clinical trials.

Please tell us about mapatumumab.

Mapatumumab (also known as HGW-ETR1; TRM-1; and HGS1012) is a new cancer therapy being developed by Human Genome Sciences (HGS). Using genomic techniques, HGS originally identified the TRAIL (tumor necrosis factor apoptosis-inducing ligand) receptor-1 protein as a member of the tumor necrosis factor receptor super-family of proteins. HGS studies, as well as those conducted by others, show that TRAIL receptor-1 plays a key role in directly triggering apoptosis in cancer cells.

Would you explain TRAIL and apoptosis?

Apoptosis is programmed cell death. It is a complex processes that employs many proteins. All cells in general, and cancer cells in particular, require certain proteins to survive. Caspases, a family of cysteine proteases that control and mediate the apoptotic response, are the key enzymes in apoptosis. There are different mechanisms to induce apoptosis in a cancer cell. The "extrinsic" pathway to apoptosis begins outside a cell, when caspases are activated to cut other proteins, and a signal is sent to the cell that it is time for it to die. The "intrinsic" pathway begins within the cell. With the TRAIL mechanism, when the receptor on the surface of a cell is touched by a drug, it causes a signal to be sent into the cell, prompting it to die. Think of a cancer cell as a house with several doors. If you don't have the key to the front door, you might still be able to enter through the back door or the patio door.

How does mapatumumab work?

The results of preclinical and clinical studies to date demonstrate that mapatumumab directly triggers cell death through apoptosis, inhibits tumor growth in a variety of cancer types, and reduces the size of tumors in certain cancers. Mapatumumab triggers apoptosis by mimicking the activity of the natural protein, TRAIL. It attaches itself to the surface of the cell and sends a signal into the cell from the outside, triggering cell death. This is a potentially useful new door into the cancer cell that has not been investigated before. It is very attractive idea, which may provide novel therapeutic options to patients with a wide variety of malignancies. Mapatumumab has significant potential in therapeutic settings either as a single agent or in combination with chemotherapy for the treatment of a broad range of human malignancies.

What did the completed Phase II studies demonstrate?

HGS has completed three Phase II clinical trials of mapatumumab as monotherapy in patients with non-Hodgkin's lymphoma, advanced colorectal cancer, and non-small cell lung cancer. The results of the Phase II clinical trial in non-Hodgkin's lymphoma demonstrated that mapatumumab was well tolerated, could safely be administered intravenously every 21 days at doses up to 10 mg/kg, and was capable of producing clinical responses when administered as monotherapy in patients with advanced non-Hodgkin's lymphoma.

What about the study of mapatumumab in myeloma?

The results of preclinical studies demonstrate that mapatumumab enhances the tumor-killing activity of bortezomib. Bortezomib, which has already been FDA-approved for use in myeloma, has been shown to kill the cancer cells by blocking protein metabolism inside the cell. The combination of mapatumumab and bortezomib attacks the myeloma cell from the inside and from the outside. The science, the hypothesis, and the methodology behind combining these two drugs are solid. We now need to assess how well this idea works in the clinical setting.

HGS has initiated a Phase II trial that is a randomized, multi-center, open-label study to evaluate the efficacy and safety of mapatumumab in combination with bortezomib in patients with relapsed or refractory myeloma. Approximately 100 patients will be enrolled in the United States and Canada and randomized into two treatment groups. The primary objective of this study is to evaluate disease response, with one treatment group receiving the combination of mapatumumab and bortezomib, and the other treatment group receiving bortezomib alone. Secondary objectives are to evaluate safety and tolerability, and to determine plasma concentrations of mapatumumab for use in a population pharmacokinetic analysis.

The patients we have treated at our center have tolerated the mapatumumab very well. And, based on our experience, it does not seem that the addition of mapatumamab is causing more side effects than bortezomib alone. The eligibility criteria for this study, along with a list of institutions currently enrolling patients in the US and Canada, can be found at www.clinicaltrials.gov, or via the IMF hotline at 800-452-CURE (2873).

In closing, what is your opinion about developments in the field of myeloma in the near future?

The new drug and the clinical trial we have just discussed are examples of our approach to myeloma research. We are looking at attacking this disease in new ways, as well as from multiple angles. We are investigating non-chemotherapy drugs, alone and in combination. We are looking at targeting the microenvironment, as well as targeting the myeloma cell and the various processes inside and outside the cell. It is not overly optimistic to state that we are on the way to developing a very effective strategy to attack myeloma from every single angle. **MT**

Editor's Note: Dr. Chanan-Khan is a graduate of Allama Iqbal Medical College, Punjab University, Pakistan. He completed residency training in Internal Medicine at the College of Physicians & Surgeons, Columbia University, Harlem Hospital Center (1997), and fellowships in Clinical Hematology (1998) and Clinical Oncology (1999) at the New York University School of Medicine. Dr. Chanan-Khan serves on the multiple myeloma national guidelines panel of the National Comprehensive Cancer Network (NCCN). He has authored or co-authored several journal publications and abstracts.

U.S. MYELOMA FORUM

Myeloma Today in conversation with Michael S. Katz

Michael S. Katz

What is the U.S. Myeloma Forum?

Established by the International Myeloma Foundation, the U.S. Myeloma Forum is a committee of the nation's leading multiple myeloma experts. The Forum's goal is two-fold: to form a coalition that will work collaboratively on myeloma-related projects, and to avoid duplication of efforts and dilution of valuable resources by various cooperative groups working on myeloma trials in the United States. Multiple clinical trials are required to assess the best impact of new myeloma therapies. These trials need to be organized in a cohesive way to ensure that the final results provide clear comparative data.

How will this work?

Like coalitions in Europe, the U.S. Myeloma Forum will work in an effort to achieve consensus in order to accelerate clinical trial development, approval, activation, and accrual. Historically, while there has been some level of cooperation between the various groups in the US in inter-group clinical trials, these groups have not worked in as open a fashion as their European counterparts. The framework of the U.S. Myeloma Forum will facilitate input from all the major stakeholders in the most productive way. This will include both critical input for pharmaceutical trial design and facilitation of the National Cancer Institute's Cancer Therapy Evaluation Program (CTEP) within the cooperative group setting.

You were in attendance at the Forum's first meeting. What can you tell us about it?

I attended the first meeting of the U.S. Myeloma Forum as a patient representative. The gathering took place on April 17-18 in Santa Monica, CA. The participants were welcomed by Drs. Brian Durie and S. Vincent Rajkumar with introductory remarks. In discussing myeloma clinical trials in the United States, Dr. Rajukumar represented the Eastern Cooperative Oncology Group (ECOG) as its co-chair, Dr. Durie represented the Southwest Oncology Group (SWOG) as its co-chair, and Dr. Sergio Giralt represented the Clinical Trials Network (CTN). Within these groups, hundreds of institutions across America take part in large-scale randomized phase III clinical trials. The European cooperative groups were represented by Dr. Antonio Palumbo of Italy, who is a delegate for the European Hematology Association (EHA). Statistical issues in trial design were addressed by Dr. John Crowley of Cancer Research And Biostatistics (CRAB). The CTEP perspective was presented by Dr. Howard Streicher. Next on the agenda was the establishment of priorities for the U.S. Myeloma Forum.

How was this accomplished?

The participants separated into smaller breakout groups that focused on specific issues. Trial design and statistical issues were tackled by Drs. Crowley and Streicher along with IMF Scientific Advisory Board Chairman, Dr. Robert A. Kyle. Frontline therapy was the issue addressed by Drs. Rajkumar, Durie, and Palumbo. Transplant-related issues were broached by Drs. Giralt, William Bensinger, and Mohamad Hussein. New myeloma drugs and the issue of disease relapse were addressed by Drs. Ken Anderson, Sagar Lonial, Ruben Niesvizky, and Shaji Kumar. Along with Drs. Robert Mundy and Robert Vescio, and IMF president Susie Novis, I was a member of the breakout group that discussed patient issues and supportive care. The breakout sessions were followed by presentations from all subgroups. Next, issues related to transplantation, maintenance therapy, refractory disease, treatments for newly diagnosed myeloma, and how to achieve the best results for a patients in various circumstances were debated by the participants.

Did these debates produce concrete outcomes?

The presentations and debates among participants of the U.S. Myeloma Forum resulted in the formulation of action items and concepts for new clinical trials. And, as the discussion progressed, a consensus began to emerge. Finally, a plan for a joint SWOG-ECOG clinical trial was presented and reviewed by members of the Forum, and the participants signed off on the plan. This was truly an exciting moment.

What happens next?

The next step for the U.S. Myeloma Forum was to submit the plan for a joint SWOG-ECOG clinical trial for review by SWOG and by ECOG. As of this printing, I am happy to report that the plan has been approved by each cooperative group. I look forward to being able to report on further progress in the next issue of Myeloma Today. Please stay tuned.

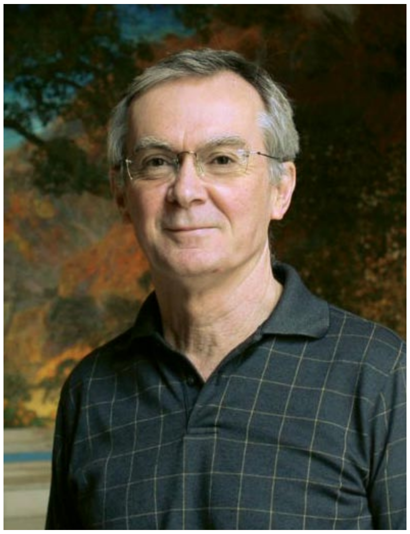
In conclusion, I'd like to add that I think the founding of the U.S. Myeloma Forum by the IMF, and the outcome of its inaugural gathering, are very positive developments for all members of the myeloma community. With this committee acting as an umbrella for the existing myeloma cooperative groups, we patients are more likely to benefit from the accelerated path to more effective treatments for our disease. **MT**

US Myeloma Forum

Inaugural Meeting Participants

Ken Anderson
William Bensinger
Ivan Borrello
John Crowley
Brian Durie
Sergio Giralt
Mohamad Hussein
Shaji Kumar
Robert Kyle
Sagar Lonial
Ruben Niesvizky
Antonio Palumbo
Vincent Rajkumar
Seema Singhal
Howard Streicher
Robert Vescio
Jerome Zeldis (Celgene)
Tom Cavanaugh (Celgene)
Todd Hyde (Celgene)
Dixie Esseltine (Millennium)
Jackie Hilgers (Millennium, SWOG)
Michael Myers (J & J, Millennium)
Craig Tendler (Ortho Biotech)

MYELOMA TODAY IN CONVERSATION WITH E. MICHAEL D. SCOTT


E. Michael D. Scott

Please tell us a little about your background.

I was born in England but my parents moved to work in West Africa when I was a child, so I also spent time in Nigeria and the Cameroons. Initially I went to a small private boarding school in Epsom, in southeastern England. Then I attended Westminster School in London, an institution originally founded in 1179 and reorganized by Queen Elizabeth I in 1560. In 1969, I graduated from the University of Sussex with an honors degree in biochemistry. I have been involved in scientific and medical communications for nearly 40 years. I worked in scientific and medical publishing until 1976, when I formed my own communications services company, providing editorial, communication, and consulting services in the UK. I moved to the US in 1985 and joined a pharmaceutical advertising agency. I have worked for the same company ever since, but in a range of different roles. In communications and health care, my most specific interests include cancer, pharmaceuticals, biotechnology, managed care, marketing and educational communications, publishing, and new information delivery systems.

How did you become interested and involved in the field of cancer?

In 1985, I lost a long-time friend to acute myelogenous leukemia. She was just 32 years old. She had had multiple rounds of chemotherapy and one of the earliest bone marrow transplants for that disorder, carried out by Ray Powles at the Royal Marsden Hospital in England. This led to a continuous interest in patient-related issues in the diagnosis and management of various cancers. From 1989 to 1995, CoMed Communications, the company I was then managing, developed and executed a wide range of informational, educational, and sales training initiatives for Schering Oncology, working on Eulexin® (flutamide), a hormone therapy used to treat prostate cancer, and INTRON® A, an interferon used to treat hematologic malignancies and solid tumors – including myeloma. From 1992 to 2000, I was also president and executive director of the Center for Bioclinical Information, which supported health-care biotechnology educational programs for physicians and other health-care workers. From 1994 to 1997, I was involved in building and maintaining The Prostate Cancer InfoLink, and in 1996, I helped to found the National Prostate Cancer Coalition. Between 1995 and 1997, my colleagues and I developed and executed multiple strategic education, market defining, and informational initiatives for what was then Zeneca Pharmaceuticals (now AstraZeneca). We coordinated and executed various cancer-related educational and informational initiatives, as well as speaker bureaus and CME programming. Also in 1992 we established the Institute for Continuing Healthcare Education and achieved national accreditation as a provider of continuing education for physicians and pharmacists. In 1997, along with other colleagues, I founded Vox Medica Inc., one of the largest independent health-care communications groups in the USA. CoMed Communications became an independent subsidiary of Vox Medica, and I became an executive vice president of Vox Medica. I now serve primarily as a senior consultant for Strategic Solutions, an operating division of Vox Medica. Since last year, I have been helping to develop and execute a range of projects for one of the world's leading biotechnology companies. One of those projects is designed to help expand access to the biopharmaceuticals made and sold by that company in America.

How and when did you become a member of the IMF's Board of Directors?

At the initial recommendation of Schering Oncology, CoMed Communications was hired by the relatively newly formed IMF to coordinate the very first clinical meeting organized by the IMF. A friend had driven IMF founder Brian Novis from Los Angeles to Santa Barbara to meet me at the Four Seasons, where I was organizing a meeting of about 200 urologists. We had a great chat, and Brian sat in at the back of the meeting for a little while. I can only assume that he approved of what he saw because the IMF hired us to run their very first meeting just a few days later. By that time my parents had retired to southern Ireland, and so, since Brian Durie was going to be the chairman of that original IMF meeting, I stopped off to meet with him at the Royal Postgraduate Medical School in London and we were able to talk through the projected structure of the meeting.

That original IMF meeting took place in August 1992 at the Arizona Biltmore in Phoenix, AZ. We were able to get really cheap room rates because of the time of year. (I think the temperature was about 105°F in the shade.) Brian Novis was unfortunately too sick to attend the meeting, and I had to help talk a very nervous Susie into doing the opening address to about 90 physicians and maybe a dozen patients. After Brian's death, we went on helping the IMF in a variety of ways, and Susie would call me occasionally for suggestions and advice. At that time the Board was primarily made up of long-time friends and acquaintances of Brian Novis and Susie, along with Brian Durie and other leading myeloma specialists. I was elected to the IMF Board in 1995.

Please describe some of your Board activities.

It's probably fair to say that I am someone who has, over time, most strongly pushed for global expansion of the IMF, with greater and lesser degrees of success. I was involved in the initial development of the IMF's office in the UK, and have always felt strongly that the IMF would best serve the patient community by operating as internationally as possible. In the early days that was often difficult because of the limits on our funding. However, together with Mike Katz, I persuaded Susie to start a website for the IMF in early 1995. That initial website revolutionized the ability of patients and family members around the world to get information about myeloma. Since 2003, I have served as the IMF's representative on the Cancer Leadership Council (CLC), one of the premier Washington, DC-based cancer patient advocacy organizations. The CLC is now comprised of more than 40 cancer patient organizations, professional societies, and research organizations, including the American Cancer Society, the Leukemia & Lymphoma Foundation, the Lance Armstrong Foundation, and the Susan G. Komen Foundation. The agenda of the CLC is set by the participating organizations, and CLC positions represent the patient-centered consensus of the groups on a wide range of issues related to ensuring patient access to high-quality care. It was through CLC's support that we were, for example, able to ensure that thalidomide was included on the original oral cancer drug demonstration project, even though it was not approved for treatment of myeloma at that time.

In your opinion, what have been the IMF's most significant accomplishments?

The IMF was and remains the first and only global myeloma advocacy initiative. Our mission today is the same as it has always been – to support

Continues on Page 10

E. MICHAEL D. SCOTT – BOD — continued from page 9

patients and their families while seeking a cure for a disease that is no longer just a disorder observed in those of 60 years and older.

There are three things which I believe would never have happened without the initial and continuing efforts of the IMF. In the first place, we have been highly instrumental in helping patients to find the very best physicians with real expertise in the treatment of myeloma. As every patient will know, this is not an easy form of cancer to treat, and when one wants the best possible outcome one should seek out, if at all possible, a physician for whom managing myeloma patients is a major part of his or her daily focus. Second, we were the initial driver behind the increase in funding available for myeloma research. We did not achieve this on our own, but by helping to build global consensus on research priorities and by helping patients to understand how best to participate in important clinical trials, we have truly been a major player in the vast improvements that have taken place in the management of myeloma over the past 15 years. Thirdly, and most importantly, we have been there for everyone who had a question, from the sickest of patients to the child whose father, mother, or grandparent has just been diagnosed and wanted to understand what this meant. The staff who man the IMF Hotlines on a day-to-day basis are at the very heart of what we do.

What are your thoughts about the patient advocacy community in general and the myeloma community in particular?

Healthcare is changing – a lot – on an almost daily basis. My mother was a nurse in England during the Second World War. She left me in no doubt that if people wanted to get the best out of any healthcare system, they needed to become involved in how that system worked. Historically, the average patient had little influence over these systems. Today, that has changed, not just in America, but around the world.

Of course myeloma is only one of hundreds of diseases that we can't cure and that we still can't treat as well as we would like. Any healthcare advocacy organization that thinks solely about its own priorities and interests will become a voice crying in the wilderness, so it is important for the IMF to collaborate with others who have similar interests. So, we belong to various organizations – like the CLC – that advocate for the highest possible levels of cancer research funding. After all, more effective treatments for myeloma aren't necessarily going to come from myeloma-specific research, and we need to optimize the possibility that new myeloma treatments can come from research into any form of cancer.

The costs of healthcare are escalating, rapidly. Deep down, we all know that such cost increases aren't sustainable. In America, managed care companies seek to control the costs of treating the insured, but we have 46 million uninsured. In Europe and Canada, most people have some form of nationalized healthcare coverage, but access to that healthcare is limited in various ways. In Africa and South America, India and China, and other developing countries around the world, only the most affluent have even the hope for treatment with a drug like lenalidomide (Revlimid®) or a bone marrow transplant if they need one.

Advocacy and involvement is essential to ensuring that the most appropriate healthcare is available to the largest possible number of people. We will never find a cure for myeloma without the essential research into the underlying triggers of the disease and its progression. And if the cost of healthcare continues to rise at its present rate, we simply will not be able to afford to provide the highest quality of care for more than a tiny minority of the world's population. People need to find time to support selected advocacy initiatives and make that phone call to their congressman, their member of parliament, even their president or prime minister. If you don't speak out, you won't be heard!

Would you share with us your insights into today's oncology marketplace?

The US and the global oncology marketplaces are coming under increasing pressure for a wide variety of reasons. These include, but are not limited to, the rapidly increasing number of products available to the clinical oncologist, the costs associated with targeted therapy, the improved survival of large numbers of oncology patients, and the projected decline in the number of trained cancer specialists. Currently, there are about 2,000 cancer therapeutics in the biopharmaceutical pipeline, of which about 100 are either awaiting regulatory decisions or in Phase III clinical trials. Some community oncologists are so inundated with so much new information and so many new drugs that it is difficult for them to come to a clear understanding of which patients are good candidates for treatment with a specific agent, how to dose it alone or in combination with other agents, and how to manage side effects of treatment.

Now myeloma is not a disorder that the majority of oncologists expect to have a lot of experience treating. As I said earlier, the IMF has been a driving force in helping patients to get referred to physicians and centers for which myeloma is a major priority. The IMF also helps community physicians to understand the evolving diagnostic and treatment issues, teaches them how to help patients find appropriate clinical trials, and spreads information about the latest advances in care. Often we are able to tell people about the latest advances long before the pharmaceutical industry or the medical device industry is allowed to talk about use of specific products in myeloma. The use of thalidomide was a perfect example. As the number of new products to treat myeloma continues to expand, it will become increasingly important for the IMF to foster the broadest possible understanding of appropriate uses of these agents in the right combinations and in the right patients. As we have seen just this year, Revlimid actually appears to work better with low doses of dexamethasone than with the higher doses used in the past. The IMF has been publicizing this information to try and make sure that patients can be treated in this way.

What are your goals for the future?

My professional goals include continuing management and leadership responsibilities in communications and healthcare. In the cancer community, I'd like to see us take the greatest possible advantage of the vast expansion in knowledge about the human genome. I am an advocate for embryonic and other forms of stem cell research – but I do understand and appreciate the ethical problems that others have with some aspects of such research. And I sincerely hope that within the next 10 years we will find a more rational way to finance and organize healthcare in America.

My goals for the IMF are to go on growing our international presence and availability, to continue to increase the funding that is available for research, and to help to discover one or more simple tests that will allow us to better define patients' risks for progressive disease at the earliest possible stage. The development of our presence in Europe, in South America, and in Israel in the past two years have been particularly important to me. This growth has started to support our activities in other countries such as Japan and Australia where the IMF has had long-term partnerships in place. **MT**

Editor's Note: Mike Scott is a member of the American Society of Clinical Oncology (ASCO), the American Society of Hematology (ASH), the American Urological Association (AUA), the Drug Information Association (DIA), and the Healthcare Marketing and Communications Council (HMC). He was the founding co-chairman of the PILOT Committee, and is a past chairman of the Philadelphia Committee for the Pharmaceutical Advertising Council. Since 2000, Mike Scott has taught courses on health-care communications at the College of Graduate Studies, Thomas Jefferson University.

Nurse Leadership Board

NLB ACTIVITIES UPDATE

By Joseph D. Tariman, RN, MN, ARNP-BC, OCN

The 32nd Annual Congress of the Oncology Nursing Society (ONS) took place April 24-27 in Las Vegas, NV. On April 26, the IMF's Nurse Leadership Board (NLB) sponsored a two-hour satellite breakfast symposium, which was supported by educational grants from Celgene Corporation, Millennium Pharmaceuticals, and the IMF.

Joseph D. Tariman, RN, MN, ARNP-BC, OCN
Achievement Rewards for College Scientists (ARCS) and Biobehavioral Nursing and Health Systems Fellow
School of Nursing
University of Washington
Seattle, WA

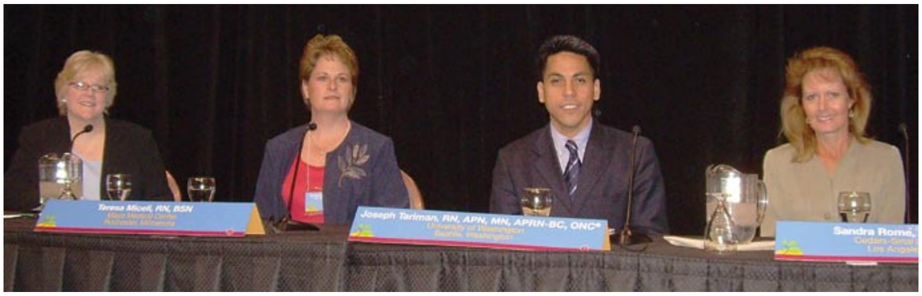
The NLB's purpose and vision is to foster a partnership with multiple myeloma nurses by identifying and addressing their unmet needs, as well as those of their patients. The ONS symposium, Management of Novel Therapeutics' Side Effects: A Nurse Centric Model, was a natural extension of the Board's mission and our opportunity to present NLB's preliminary consensus statement to the oncology nursing community. The program addressed nursing issues along the continuum of side effects management from prevention to palliation. The topic was of great interest to ONS attendees, resulting in the largest symposium pre-registration ever experienced at the congress.

The event was chaired by NLB member Patricia Mangan (Hospital of the University of Pennsylvania, Philadelphia, PA). I served on the faculty along with fellow NLB members Teresa Miceli (Mayo Clinic, Rochester, MN) and Sandra Rome (Cedars-Sinai Medical Center, Los Angeles, CA). Patricia Mangan presented an overview of the NLB and its activities to the audience, and then proceeded with an introduction to multiple myeloma. The faculty presentations focused on the management of the most common side effects associated with novel therapies for myeloma, including peripheral neuropathy, myelosuppression, deep vein thrombosis, and gastrointestinal side effects.

The discussions proved to offer excellent reinforcement of multiple myeloma diagnosis procedures and side effect management and treatment. After the lectures, we disseminated printed information, including the neuro-toxicity assessment tool and slides hand-out. Later, the electronic versions of the faculty presentation slides were emailed to the attendees to enable them to share the information with nursing colleagues at their hospitals.

Next on NLB's agenda is a meeting of its members in August in Santa Monica, CA. At that time, the entire membership will review the consensus statements on the management of the most common side effects submitted by each sub-group of the Board. Besides finalizing information that will be disseminated to healthcare providers, a patient-friendly version of our consensus statement will be prepared for presentation at future IMF Patient & Family Seminars. **MT**

Editor's Note: For four years, Joseph Tariman was part of the multiple myeloma program at Northwestern University in Chicago, IL. There, he worked on the phase II and phase III trials of VELCADE® and REVLIMID®. He is currently completing the second year of a PhD program at the University of Washington in Seattle, WA. Mr. Tariman chairs the peripheral neuropathy group of the NLB.



Patricia Mangan, Teresa Miceli, Joseph D. Tariman, and Sandra Rome

THROMBOEMBOLIC EVENTS

Myeloma Today in conversation with Deborah Doss RN, OCN

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

What are thromboembolic events?

Thromboembolic events (TE) include deep vein thrombosis (DVT), pulmonary embolism (PE), transient ischemic attack (TIA), and stroke. DVT is the formation of a blood clot (thrombus) in a deep vein, most commonly in the legs or the arms. PE is medical emergency where a clot travels to the lungs from another site. TIA is a “warning stroke” or “mini-stroke” that occurs when a blood clot temporarily clogs an artery, and part of the brain doesn’t get the blood it needs, thereby producing stroke-like symptoms but no lasting damage. Recognizing and treating TIAs can reduce the risk of a major stroke, although most strokes aren’t preceded by TIAs.

Who is most at risk of TE?

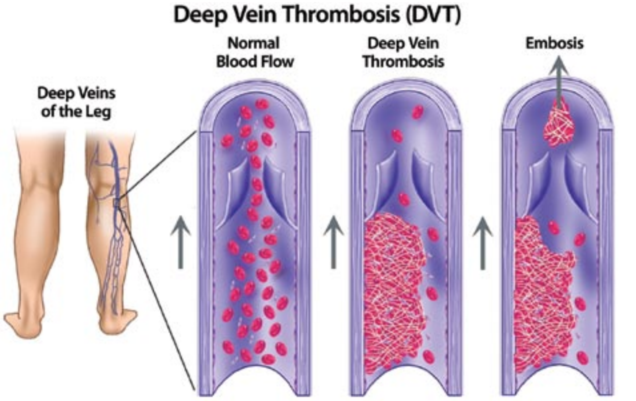
In general, patients with hematologic malignancies have increased risk of TE or bleeding. Patients with multiple myeloma may incur an even higher incidence of TE as a result of protein in the blood, which thickens the blood and increases the chance of coagulation. Other risk factors may include but are not limited to morbid obesity, strong family history, previous occurrences of DVT, immobility, presence of a central venous catheter, recent surgical procedures, and erythropoietin and high-dose dexamethasone, taken either singly or during the same period of time. Some myeloma therapies, such as thalidomide plus dexamethasone or Revlimid® plus dexamethasone, may also increase a patient’s risk of TE.

What are some of the dangers of TE?

TE can affect the lives of both patients and their families by producing life-altering complications, including those affecting breathing, cognition, and overall function. Patient education about identifying symptoms of TE and reporting these to healthcare providers in a timely manner is key to averting these possible dangers. Prompt recognition and diagnostic work-up can help increase positive outcomes.

What signs and symptoms should patients and caregivers look for?

Signs of DVT may include swollen, red, or warm extremities, a fast heartbeat, toes or fingers turning blue, a dull ache or tight feeling over the area, and sudden distension of veins. Signs of PE may include anxiety, sudden shortness of breath or wheezing, chest pain or discomfort on inhalation, and an increased heartbeat. Commonly, signs of TIA are the same as those of stroke, including sudden numbness or weakness of the face, arm, or leg on one side of the body, sudden trouble speaking or understanding, sudden trouble seeing in one or both eyes, sudden trouble walking, dizziness, loss of balance or coordination, sudden severe headache with no known cause. The short duration of these symptoms and lack of permanent brain injury is the main difference between TIA and stroke.

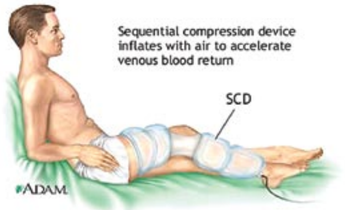


What diagnostic testing may be used to evaluate a patient?

If a patient comes in with a swollen extremity and DVT is suspected, the doctor will most likely order an ultrasound of that extremity. A variety of laboratory tests may be performed as well. If PE is suspected, a V/Q scan of the lungs will be performed.

What prophylactic options might be available to patients?

Some myeloma therapies require prophylaxis to safeguard against TE. The most commonly used regimen prescribed by doctors is therapeutic warfarin (Coumadin®). Low molecular weight heparin (LMWH) is another medication commonly used to thin the blood. Due to the cost associated with LMWH, some doctors are continuing to use injections of heparin. Aspirin may also be recommended by the patient’s healthcare providers. Mechanical prophylaxis prescribed by doctors might include machines (sequential compression devices) or antiembolism stockings (support hose). An exercise regimen might be prescribed by a physical therapist but, due to skeletal issues related to myeloma, a doctor must be consulted prior to embarking on any exercise program.



How do myeloma regimen choices impact the risk of TE?

A decreased incidence of TE has been reported with less aggressive dosing schedules and lower doses of thalidomide and steroids (alone or in combination). Judicious dose reduction by the physician may increase quality of life and adherence to the therapeutic regimen. For example, dose reduction regimens may apply to patients taking thalidomide (50–100 mg daily) and/or dexamethasone (20–40 mg once/week, or 20 mg on days 1–4 of a monthly cycle). It is important to note that prophylaxis must be tailored by the physician in accordance with each individual patient’s risk profile. Many of today’s myeloma patients are quite educated about their disease and I hope that this information will help provide them with talking points to discuss with members of their healthcare team. **MT**

MEET THE IMF HOTLINE COORDINATORS

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

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

How did you become an IMF Hotline Coordinator?

Nancy Baxter: After practicing law for five years, I became a mother and no longer wanted to work full-time. So I trained as a psycho-social cancer counselor at UCLA (University of California Los Angeles), and went to work part-time at UCLA’s Jonsson Comprehensive Cancer Center (JCCC). Two years later, UCLA became one of the National Cancer Institute (NCI) Cancer Information Service centers, and I was asked to supervise a staff of 15 phone counselors. That’s when I recruited Debbie Birns to join our team. All of us received advanced training from the NCI. In 1999, when the NCI consolidated its California call centers and closed the UCLA office, I became a patient services manager at the Leukemia & Lymphoma Society (LLS). In 2001, I met IMF president Susie Novis at an outreach event. She was interviewing candidates for the IMF hotline, and I recommended Debbie for the position.

Debbie Birns: I was an undergraduate major in humanities and English literature. I spent most of my sophomore year in Florence, which is where I learned Italian. I completed two and a half years of a PhD program in comparative literature when I had my first child and became a stay-at-home mom. When the youngest of my three children was a toddler, I went back to UCLA to study professional writing and editing, and became a manuscript editor for the UC Press. During the 1980s, several members of my immediate family were diagnosed with cancer, including my mother-in-law, who had myeloma. Near the end of her illness in 1992, Nancy recruited me for the NCI Cancer Information Service at UCLA. After the program closed, I went to work at UCLA’s Clinical Research Unit under Dr. Dennis Slamon, whose prior work led to the development of the breast cancer drug Herceptin®. I learned a great deal about cancer clinical trials there, but the job entailed only limited aspects of my training and experience. Then Nancy called to tell me about the IMF.

Nancy Baxter: Once Debbie shared with me the impressions of her new job at the IMF, I realized how much I missed working directly with patients and family members. Two months later, I joined the IMF Hotline.

Paul Hewitt: My background is as an actor. After a long run in a Broadway show in New York, I returned to Los Angeles, where Susie Novis and I live on the same street. We would meet while walking our dogs, and we’d chat and catch up. That’s how I originally came to work for the IMF. A couple of years later, when the IMF was ready to add a third coordinator to its Hotline, Nancy and Debbie approached me about joining the department. After six months of intensive training, I was ready to field calls.

What is it like to work on the IMF Hotline?

Paul: Our callers are thirsty for knowledge. Helping them address the various aspects of myeloma in a more informed way is incredibly fulfilling..

Nancy: This is the best job I’ve ever had. I’ve received incredible training from the most extraordinary doctors. I work with wonderful people. I’ve gotten to know many amazing patients and caregivers. I have witnessed myeloma treatments evolve from being primarily transplant-based to a broad range of novel therapies that have improved patients’ survival and quality of life. I have seen first-hand how informed patients are able to make more educated decisions about their treatment options and how the patients’ feedback about various therapies and side effects has impacted doctors’ approaches to dosing and clinical trial design. The IMF Hotline is a unique asset in the dynamic relationship between the patient and medical communities.

Debbie: Working for the IMF has brought together and called upon everything I have ever studied or done professionally, or experienced in my personal life. It is the most fulfilling work I have ever done. I treasure the interaction with patients and caregivers, as well as the intellectual stimulation of having the most accomplished clinicians and researchers as my teachers and mentors.

Each of you has a sub-specialty. What is it?

Debbie: Because of my research background, I track myeloma clinical trials for the Myeloma Matrix. I also work with IMF Board member Mike Katz in conducting video interviews with myeloma specialists at the annual meetings of the American Society of Hematology (ASH) for posting on our website, and I edit the IMF’s educational materials.

Nancy: In between taking Hotline calls and answering emails, I am involved in outreach. I make sure that information about the IMF and myeloma gets out not only to the major cancer centers across the United Stated but also to smaller, community-based doctors.

Paul: My sub-specialty is to coordinate the participant registration aspects of the IMF Patient & Family Seminar program.

What should prospective callers know about the IMF Hotline?

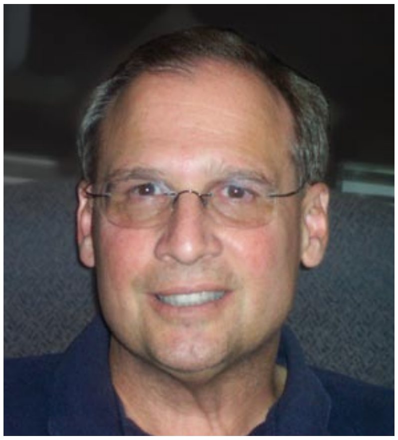
Debbie: Perhaps one of the most surprising and useful aspects of the IMF Hotline is that none of the coordinators are medical professionals. We are not doctors or nurses. We are people who have been trained to translate the most sophisticated science into terms that are accessible to our callers, and to make information about a very complicated cancer and its treatments readily available. Patients and their advocates must have the facts in order to communicate well with the healthcare team. Our take-home message to patients and their loved ones is “KNOWLEDGE IS POWER.”

Paul: We learn the latest developments in the field of myeloma from the specialists who are actively working on putting an end to this disease, and this enables us to better serve our callers. And, if a patient or family member is outside the United States and cannot get in touch with us by phone, I want them to know that we welcome their letters and emails.

Nancy: We understand the issues that myeloma patients and caregivers tackle. We are here to help answer their questions, and to help frame the questions that they need to pose to their healthcare providers in order to have a more productive dialogue. I look forward to going to work in the morning so that I may serve the members of the myeloma community who face each day of their lives with humor, courage, strength, dignity, and hope. **MT**

8TH ANNUAL IMF SUPPORT GROUP LEADERS RETREAT

By Jack Aiello



Jack Aiello

When I was first invited to attend the 8th annual IMF Support Group Leaders Retreat, I was a bit dubious. I knew that some good information would be provided for leaders of relatively new groups, but our patient-led San Francisco Bay Area MM Support Group was founded in 1991, and our monthly meetings are consistently attended by 35 to 60 patients and caregivers. For myself, I was diagnosed with myeloma in April of 1995, went through a tandem auto transplant, then the original thalidomide clinical trial (800mg/day!), and finally a full allogeneic transplant in 1998 before achieving a long-term remission. I stay well informed about myeloma research and treatment progress. So honestly, would I really get much out of this meeting? Would I and our other SF Support Group leaders learn to conduct more effective meetings?

In a word, ABSOLUTELY! The two days of the IMF Support Group Leaders Retreat were packed with informative sessions, and I will now attempt to share with the readers of *Myeloma Today* the "take-aways" that I found most valuable for members of our support group.

Support Group Facilitation: Many good ideas on the subject came from Robin Tuohy, Maddie Hunter, and Lori Curtis. A common problem at meetings is remembering names. Tags offer an easy solution but, when we tried this in our support group, folks stopped wearing them after awhile. One great idea presented was to add a star for every year past diagnosis, making the name tag a "badge of honor" for long-term survivors. This might also offer encouragement to newly diagnosed patients when, for example, they would see a dozen stars on my badge.

Public Profile: It is important to increase the public's awareness about your group's existence. It still surprises me when I learn that someone in my area is unaware of our local support group, especially if the person is not a newly diagnosed patient. But this does happen. One solution is to mail monthly announcements to the Community Calendar sections of local newspapers and TV stations. The IMF can also help build your group's website and do a mailing to your local zip codes to announce meetings. If your group is engaged in a newsworthy event, the IMF's publicist, Stephen Gendel, can help you spread the word. If the IMF's Myeloma Mobile is coming to a city near you this summer, take the opportunity to build a myeloma awareness event around its arrival.

Keeping Members Interested: How do you make meetings interesting so that folks attend regularly? Many groups host guest speakers. Doctors, nurses, nutritionists, and insurance and financial experts can give talks on topics of interest to myeloma patients and caregivers.

Being A Better Patient: IMF's Mike Katz knows a lot about this subject. He was diagnosed in 1991 and has done an incredible amount of patient advocacy on behalf of the myeloma community. In his presentation, Mike reminded us how important it is to be an educated patient. Learning about the markers being used to track your myeloma, and which tests calculate those markers, might give a patient the best chance possible to avoid the "MM sneak attack."

Lifestyle Influences: I did not change my approach to nutrition after I was diagnosed, so I didn't know what to expect from the retreat's presentation about nutritional and lifestyles influences on myeloma. Did you know that the darker the berry or wine, the higher the antioxidant levels and better for you? Or that Vitamin C might interfere with the effectiveness of Velcade? Or how stress created from uncertainty and fear can negatively impact your health?

Pharma Company Updates: Presenters from Celgene (Thalomid, Revlimid) and Millenium (Velcade) addressed issues concerning drug access, reimbursement, Medicare, co-pay assistance, and programs for uninsured or underinsured patients. Check with your support group leader or contact the IMF for more information.

Myeloma Treatment Recap: Dr. Durie reminded us that being educated about available treatments empowers us to make better personal choices. Learn to understand your myeloma activity as measured by CRAB (Calcium, Renal, Anemia, Bone), chromosome information, age, and other medical issues. More effective treatment is now possible, based on chromosome results from tests such as FISH, cytogenetics, GEP (gene expression profiling), SNP (single nucleotide polymorphisms, or changes in small DNA sequences), and DNA/RNA sequencing. For example, I learned that Velcade appears to work independently of chromosome 13 deletion, and that Mayo Clinic doesn't transplant patients who have both chromosome 13 deletion and translocations of genetic information between chromosomes 4 and 14.

Understanding Lab Tests: Mike Katz and Dr. Rodger Tiedeman reviewed the lab tests vital to myeloma patients: SPEP to measure immunoglobulins in the blood, UPEP to measure immunoglobulins in the urine, IFE to measure M-spike, BMB to measure plasma %, and Freelite (FLC) to measure the light chain component of immunoglobulins. It was noted that FLC is a more sensitive test than SPEP, UPEP, or IFE, and that it can detect response to treatment within a few days, as opposed to the month required to detect response in the heavy chain immunoglobulins. FLC is also a sensitive and rapid means of determining relapse.

Clinical Trials: We had a fascinating interactive discussion about clinical trials that evaluate variations of existing treatments. One example of such clinical trials was cited by Dr. Brian Durie, who noted that it has been shown that low-dose dexamethasone (LDD) provides a higher survival rate than standard-dose dex. In fact, Dr. Durie and Mike Katz explained that the LDD clinical trial was the result of an interactive discussion at a previous IMF Support Group Leaders Retreat. At that point, we were joined via conference call by the myeloma experts on the Eastern Cooperative Oncology Group (ECOG) myeloma panel, Drs. David Vesole, Sagar Lonial, Angela Dispenzieri, and Vincent Rajkumar. The participants were polled about other possible clinical trials involving variations in existing treatments, such as aspirin versus warfarin (Coumadin) for prevention of blood clots, the addition of Velcade to Rev plus LDD, and the addition of Oral Cytoxan to Rev plus LDD.

Continues on Next Page

IMF MYELOMA MOBILE

The Tuohy Family: Coming to a City Near You

The IMF is very excited to share with you the schedule for our biggest myeloma awareness project planned for summer 2007. The MYELOMA MOBILE is on the road to educate and empower patients and their families in local communities across the United States. The project is the brainchild of Michael Tuohy of Prospect, CT, who was diagnosed with myeloma at age 36. Michael is traveling with his wife, Robin, and their two children, 14-year-old Ally and 9-year-old Mikey.

The route for the MYELOMA MOBILE has been finalized. Activities will include informative discussions with local myeloma experts and dissemination of educational materials covering a wide range of topics. Please join us in person or via the web. The MYELOMA MOBILE is equipped with a GPS tracking system and you can follow its route on the IMF website www.myeloma.org. For more information, please contact the IMF at myelomamobile@myeloma.org or 800-452-CURE (2873).

June 22 – Ann Arbor, MI – 10AM: Dr. Yasser Khaled
University of Michigan Comprehensive Cancer Center
(Rachel Upjohn Building, East Medical Campus)

June 26 – Rochester, MN – 10AM: Dr. Martha Lacey
Mayo Clinic (Geffen Auditorium, Gonda Building)

July 1 – Denver, CO – 10AM: Dr. Jeffrey Matous
Rocky Mountain Cancer Center (Event in the parking lot outdoors) Parking will be available at the site

July 15 – Los Angeles, CA – 4PM: Dr. Brian Durie
The Samuel Oschin Comprehensive Cancer Institute at Cedars-Sinai Medical Center (Harvey Morse Audi., south tower)

July 23 – Phoenix, AZ – 10AM: Dr. Rafael Fonseca
Mayo Clinic Cancer Center at Mayo Clinic Hospital (Room 1-115)

July 27 – Dallas, TX – 10AM: Dr. Robert Berryman
Charles A. Sammons Cancer Center at Baylor University
(Truett Hospital, Beasley Auditorium)

July 31 – Houston, TX – 10AM: Dr. Sheeba Thomas
The University of Texas M. D. Anderson Cancer Center
(Hickey Auditorium, R11.1400)

August 5 – Atlanta, GA – 10AM: Dr. Sagar Lonial
Winship Cancer Institute of Emory University (First floor lobby)

August 9 – Baltimore, MD – 10AM: Dr. William Matsui
Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins
(David H. Koch Cancer Research Building, Owens auditorium)

August 11 – Philadelphia, PA – 10AM: Dr. Edward Stadtmauer
Abramson Cancer Center of the University of Pennsylvania
(Biomedical Research Building II/III)

SPOTLIGHT ON ADVOCACY

President Bush's 2008 Budget Includes Cuts in Cancer Programs

By Christine Murphy, MA

Along with our friends in the cancer community, the International Myeloma Foundation (IMF) has been working diligently in 2007 to increase funding for myeloma programs at the National Institutes of Health (NIH), the National Cancer Institute (NCI), and the Centers for Disease Control and Prevention (CDC).

On February 5, the President released his budget for fiscal year (FY) 2008. The President's budget included increases for defense and homeland security while at the same time including cuts in domestic programs such as those for cancer research. The President's FY 2008 budget recommended $28.9 billion for NIH and $4.8 billion for NCI. The NCI was one of 5 institutes and centers that received a funding cut at the NIH in the President's FY 2008 budget. Additionally, the Geraldine Ferraro Blood Cancer program was level funded at the FY 2007 level of $4.5 million.

Along with the One Voice Against Cancer (OVAC) coalition, IMF advocates the following allocations for cancer programs in FY 2008:

- $30.869 billion for the NIH,
- $5.114 billion for the NCI, and
- $5.5 billion for the Geraldine Ferraro Blood Cancer Program at the CDC.

In June, the House of Representatives' Labor, Health and Human Services, and Education Appropriations Subcommittee allocated $29.6 billion for the NIH, an increase of approximately $750 million. This increase for NIH includes $201 million targeted for the global HIV/AIDS fund which means that the net increase for NIH is approximately $550 million. The Subcommittee proposed $4.9 billion for NCI, an increase of $72.7 million.

IMF stands ready to work with the House and Senate to secure the highest possible allocations for myeloma programs at NIH, NCI, and CDC in FY 2008; however, it is important that the myeloma community communicate with their Members of Congress on the importance of increased funding for the cancer programs that impact myeloma patients. For updates on funding for these programs and IMF's advocacy efforts, please visit www.myeloma.org. **MT**

SUPPORT GROUP LEADERS RETREAT — continued from previous page

Friends Made, Friends Lost: All the valuable educational information presented at the IMF retreat aside, one wonderful benefit that I took away from this meetings was new friends made and old friendships renewed. Unfortunately, many of us have had to deal with losing friends to this crappy disease. It's important to allow time for grieving and perhaps even to memorialize each passing at a support group meeting. In my group, we lost several folks in 2006, including an active member of 14 years. It was important for many of us to share our grief with each other before trying to move forward.

So that's it. I hope that my "take-aways" are applicable for your support groups as well. If your group leaders attended this year's IMF retreat, I'm sure they will provide you with other useful insights gleaned from this meeting. Perhaps, with your encouragement, group leaders who weren't able to attend this time will do so next year. I certainly plan to. **MT**

UPDATES FROM IMF EUROPE

By Gregor Brozeit

Gregor Brozeit, Christina Anderson (translator), Dr. Morie Gertz, Karin Kleineberg & Rolf Kunstmann (leaders of Myelom Hilfe Würzburg), Wolfgang Zöller, and Dr. Hermann Einsele and Dr. Ralf Bargou (University Clinic of Würzburg)

Sophomore years are always tough, whether you're a baby, a student, or a new program in Europe. But it is a good time to set the stage for future success, whether as an adult, a professional, or a resource for comprehensive patient services.

Dr. Morie Gertz of the Mayo Clinic (Rochester, MN) recently finished up a highly successful trip to Germany. On May 16, he met with 50 members of Myelom Hilfe München, the Munich myeloma support group led by myeloma patient Volker Filipp. Dr. Gertz took more than 38 questions and follow-ups over a period of two and a half hours—none of which could have been achieved without the translation services of Dr. Christian Straka of the Interne Klinik Dr. Argirov (Munich), co-chair of the German study group DSMM.

Three days later, Dr. Gertz participated in a patient meeting attended by more than 120 participants and sponsored by Myelom Hilfe Würzburg (the Würzburg myeloma support group), the IMF, and the University Clinic of Würzburg. This meeting was headed by Dr. Hermann Einsele, who was named to the IMF Scientific Advisory Board in December of 2006. Dr. Gertz presented a variation of his highly effective introduction to myeloma, using the "weeds in the garden" metaphor to provide a clear understanding of the disease.

Dr. Gertz was followed by presentations by Drs. Ralf Bargou, Volker Kunzman, and Einsele, all from the University Clinic in Würzburg. Following the patient meeting, support group leader Karin Kleineberg invited Wolfgang Zöller, a member of the German parliament and patron of the group's events, to speak and kick off an entertainment program.

Some immediate events for the future of IMF Europe include IMF Patient & Family Seminars in Paris, Naples, Barcelona, and Heidelberg. Additional meetings are being planned for Germany, the Czech Republic, France, Spain, and Italy.

The German- and Spanish-language IMF email newsletters, Myeloma Merkur and Mensajero de Mieloma, soon will be supplemented by French and Italian language editions. Release dates and titles will be announced on the IMF website.

As I enter the 19th month of my time with IMF Europe, I reflect on the differences between what I have experienced in Europe and my previous six and half years representing the IMF in American public policy. During that time, I had the honor of representing the IMF in numerous visits with support groups throughout the United States, as well as working within the Washington DC world of cancer politics.

The most startling thing I have found is a striking similarity of fears, hopes, and wishes that myeloma patients experience the world over. As Dr. Kyle put it so directly to me after he spoke last year in Berlin, "Patients are patients." They want to know the same things, regardless of political boundaries. So, I would like to briefly point out what I have discovered over the past 18 months:

1. Boundaries. I have yet to find a disease that knows any man-made boundaries – geographical, political, or historical. Diseases know only genetically-defined boundaries that we have yet to understand.

2. Politics. One similarity I have found on both sides of the Atlantic is that established constituencies sometimes can be blinded by short-term considerations of long-term progress. That is human nature. In my experience at the IMF, I have seen that short-term missteps are always corrected with long-term ideals and organizational integrity. As we continue to bring that philosophy everywhere the IMF goes, we continue to keep the interests of our entire community in the forefront.

3. Policies. Members of the myeloma community, regardless of where they live, must be aware of how they are impacted by public policy from various levels. In the US that means understanding federal, state, and local policies, and how these might affect members of our community, then responding effectively when needed. In Europe that means understanding the European Union, the national governments, the states, and the local medical administrative districts. They all impact research, drug development and approval, and patient issues at all levels.

4. Collaborations. Small disease groups like the myeloma community must work internationally and cooperatively in order to achieve results.

5. Caregivers, friends, and loved ones. If there is one area in which the IMF has been and international leader, it is in the understanding and expression of the idea that caregivers, friends, and loved ones matter. This is one of the most important ideas we have to share worldwide and with each other.

6. Patients. Because parochial interests can sometimes trump positive change, we always have to ask ourselves—no matter what the personal, organizational, or commercial stakes might be—"Does it matter to patients?" Researchers have to go beyond learning about the disease and make sure that their work contributes to longer patient survival. Doctors have to do all they can to treat each case uniquely, and work with the patient in compassionate partnership. And the rest of us in the community have to ask ourselves every day if we are putting patients first.

The IMF continues to strive to find better ways to serve our community – wherever in the world it may be. If you have ideas to contribute to our continued growth and development, please feel free to contact me at greg.brozeit@sbcglobal.net. **MT**

MINNESOTA: TWIN CITIES AREA

In 1996, as Pat Harwood lay in the hospital on the day of her myeloma diagnosis, she received an unexpected visitor. Helen Berg, a hospital volunteer who had been diagnosed with myeloma two years earlier, stopped by to introduce herself and to offer support and encouragement. "She was the angel who took my fear away," said Pat. "That's when we both realized that there was a need for a myeloma support group in our area." The Minneapolis/St. Paul Multiple Myeloma Support Group was founded shortly thereafter, with five patients attending the first gathering. Currently, the group has over 100 regular participants.

Over the years, the group has been active in the local community and has been involved in numerous events and activities. In April of 2007, group members embarked on organizing and hosting the first myeloma community workshop in the Minneapolis/St. Paul area. "I think that it is every patient's responsibility to participate in furthering education, awareness, and research funding for myeloma," said Pat. "And the IMF is our partner in furthering our goals."

Sponsored by the IMF and funded by unrestricted educational grants from Celgene Corporation and Millennium Pharmaceuticals, the Twin Cities Symposium took place on May 18, with an impressive roster of speakers on the faculty. Dr. Brian Van Ness (University of Minnesota) discussed research developments that have resulted from the IMF's Bank On A Cure initiative, Dr. Martha Lacy (Mayo Clinic) presented information about clinical trials and new therapies, oncology nurse and transplant coordinator Teresa Miceli (Mayo Clinic) explained how patients can better prepare for transplantation, and pharmacist Mark Godwin (PharmD BioScrip) talked about various oral therapies, as well as the financial support available to patients with myeloma. In addition, data was presented on nutrition and complementary therapies.

"The sessions were interesting and informative," said Pat Harwood. "Dr. Van Ness gave us all hope when he explained the importance of the recent research breakthroughs in the field of myeloma, as well as the overall progress being made with targeted therapies." Pat, who recently attended the IMF's Support Group Leaders' Retreat *(see page 14)*, also addressed the audience about how to best utilize the resources of a support group. Another feature of the meeting was the presentation of the IMF Courage Award to Mike O'Hara, a myeloma patient with a history of volunteerism that long predates his diagnosis four years ago. While battling a treatment-resistant form of myeloma, Mike has remained a great inspiration and support to his fellow group members, and received a standing ovation as he accepted his award. In addition, Helen Berg was honored as the founder of the support group and for the many years she served as the group's co-leader.

The Twin Cities Symposium was an unqualified hit. Besides providing education and offering camaraderie to members of the Minneapolis/St. Paul, Stillwater, and Rochester support groups, the meeting proved to be an excellent means of raising myeloma awareness, as many of the people in attendance were new to the myeloma community." **MT**

Editor's Note: The Minneapolis/St. Paul support group meets every 4 to 6 weeks. For more information, please email mplsmyeloma@hotmail.com or call 952-473-1782 (Pat Harwood), 952-898-9660 (Donna Costello), or 612-529-8904 (Helen Berg). For information on the Stillwater group, please

CALIFORNIA: INLAND VALLEY

When Mary Ming-Mosley was diagnosed with myeloma in 1994, after years of misdiagnosis and in the face of far-reaching symptoms, she was given two years to live and referred for an allogeneic transplant. Finding no matched donor among her siblings, Mary ended up proceeding to an autologous transplant. After eight years in remission, a second transplant and another remission followed. Throughout her journey with myeloma, Mary would regularly receive phone calls from fellow myeloma patients referred by her local medical center and transplant unit.

While there are a number of myeloma support groups in California, there were none in Mary's area, so she decided to start a new group with the help of two friends and fellow patients. The Inland Valley group held its first meeting in September of 2006, with only its three founders in attendance. With a letter from the IMF, the group quickly secured a regular meeting location at a senior citizens center. Gradually, an outreach effort in the area began to attract new members. Today, the group has several participants who travel from as far as Long Beach to attend meetings. The Inland Valley group also offers support via phone to those who are not able to attend in person. "We are a very caring group," said Mary. "We really do go the extra mile."

Besides offering emotional support and encouragement, the Inland Valley group places particular focus on patient education. Members help each other sort through their healthcare records and laboratory results, document various medications and possible side effects, and prepare questions to be posed during upcoming visits with doctors or nurses. "I have overcome so many obstacles to be here today," said Mary. "And I want to do all I can to encourage, support, and help others through their myeloma journey. Being good patients involves staying informed about our disease and the emerging treatment options available to us. Myeloma survivors must remain proactive about our personal healthcare as well as the well-being of our community." **MT**

Editor's Note: The Inland Valley Multiple Myeloma Support Group meets on the 4th Saturday of each month at 9:00am at the George Gibson Senior Center in Upland, CA. For more information, please contact Mary Ming-Mosley at mingmosley@yahoo.com or 909-622-6616, Pat Hardy at hardyp@netzero.net or 909-463-3127, Carlene Pratt at carvette412@aol.com or 909-875-8871, or Sosthenes Rogers at 909-949-2810.

ONE MILE AT A TIME

By Clyde Corales

I have always been a workaholic. Besides my career at the Internal Revenue Service as an IRS employee service representative, I have traditionally kept at least one other job going at the same time. In 2004, I was also back in college, nearing completion of studies in economics at the University of Texas at Austin. Life was busy to say the least.

While teaching a class to IRS employees, I started experiencing sleep apnea. A visit to the doctor revealed a problem in my sinus area and, within hours, I was getting a head scan. Soon, I was having a biopsy. On October 1, 2004, I was diagnosed with multiple myeloma. My life went into a tailspin of denial and depression.

The plasmacytoma in my nasopharynx had amyloid formations, and therefore it required prompt treatment. After a full course of radiation, the tumor had not shrunk sufficiently, so I had to have additional treatments. Chemotherapy and three surgeries followed, plus a multitude of tests to track my M protein and amyloid deposits.


Clyde Corales

When I was a child, my bicycle was a daily source of fun for me. When I went to college the first time, a bicycle was my primary means of transportation. When I joined the military, I would cycle from the Air Force base all the way to Mexico and back. Riding a bike always helped me to focus my thoughts and to relax, and it brought me closer to the beauty of nature that I love so much. So, on October 1, 2005, I took out a bank loan and bought a bicycle in celebration of the first anniversary of my cancer survival.

When I picked up my new bike from the shop, I could barely ride it around the block. It spent the next six months sitting in my apartment. Then, gradually, I started taking it out. And I found that returning to cycling helped me to fall in love with life all over again. I joined the Leukemia & Lymphoma Society's Team In Training®, the world's largest endurance sports training program, and started participating in group bike rides to raise funds for myeloma.

My first long-distance ride was the 48-mile Pedal Through the Pines in Bastrop, TX. Next came the 70-mile Hill Country Ride in Liberty Hill, TX. My first "century ride" (a name used for bike events that are approximately 100 miles long) took me through 102 miles of the Texas hill country. Then I biked 107 miles in the Armadillo Cross-Country Ride. My next group ride in Blanco, TX, was the last of my training rides prior to embarking on America's Most Beautiful Bike Ride, a 102-mile circle around Lake Tahoe, NV.

In America's Most Beautiful Bike Ride 2006, I was one of more than 3,000 riders united to raise funds for blood cancer causes. As we rode, I was astounded by the beauty of the Sierra Mountains, covered with pine trees and snow, and the intense blue waters of Lake Tahoe. By the time that ride was over, I had cycled over 1,000 miles in a five-month period, both as an individual and as a member of a team. It was the experience of a lifetime.

The next day, a friend approached me and said, "You rode your three centuries. You've made your point." But I kept cycling and, one mile at a time, I had biked a total of 2,500 miles, including 13 century rides, by the end of 2006.

In 2007, I continue to participate in rides, cycling for the benefit of the IMF in hopes of one day reaching a cure. If the IMF's motto is "Until There is a Cure… There is the IMF," then my motto became, "Until there is a cure, I ride for the IMF." To get to the recent IMF Patient & Family Seminar in Houston, I rode 187 miles through some of Texas' most beautiful landscapes. Red poppies, blue bonnets, and all sort of flowers were blooming along the road and throughout fields across the countryside. Cows, donkeys, horses, and other farm animals kept me company. As the Houston skyline appeared on the horizon, I thought of the day when we will all see the cure to our disease, and this filled me with such excitement.

For me, coping with myeloma has been a grueling challenge, both physically and financially. But I wouldn't change a thing. My diagnosis forced me to look at life in a new way. It brought me closer to my family and friends, and has enabled me to see everything from a different perspective. I didn't know what I had until I was in danger of losing it. Myeloma opened my eyes and my heart to helping others. Now I rise every morning with thankfulness for the gift of another day to move closer to achieving my life's goals.

Today, I am 45 years old, and I consider myself lucky to have the life I now live. I have seen my son Christopher (20) go off to study at the Massachusetts Institute of Technology, after successful treatment of a benign condrosarcoma. My son Michael (21) is also in college, and daughter Cristina (12) is doing great in school. For the next step of what I hope will be a long journey of living with cancer, I would like to gather teams of cyclists around the country who will ride to spread the message of hope and to raise awareness of myeloma and the IMF. I am currently training my daughter to cycle, so my rides are not always long-distance, and I hope that some of you might be motivated to join us. If you are interested in riding, please contact me through IMF's Suzanne Battaglia at 800-452-CURE (2873) or sbattaglia@myeloma.org. **MT**

Investing in the Future

MYELOMA TODAY IN CONVERSATION WITH CAROL KLEIN & NANCY MOSES

"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 myeloma entered your lives.

Nancy Moses: In April of 2003, my husband Bill was diagnosed with myeloma. Within hours of his diagnosis, we received a phone call from Carol and Benson. Coincidentally, they called us from the car while on their way to dinner with Susie Novis and Dr. Brian Durie, the president and chairman of the board of the IMF, respectively. From the four of them, we heard what we most needed to hear: that myeloma was not a death sentence, that it is a manageable disease.

Carol Klein, Susie Novis, and Nancy Moses

Were you two friends at the time?

Carol Klein: We knew many people in common, but didn't really know one another. Benson and I learned of Bill's diagnosis from our mutual friends, and immediately reached out to him and Nancy. A couple of days later, we met at our house. Four years later, we are the closest of friends.

Nancy Moses: Benson became my husband's hero in his battle with myeloma, and their relationship has helped Bill through some trying times. And my wonderful friendship with Carol has now evolved into a very successful collaboration.

How did you two come up with the idea of hosting an afternoon tea fundraiser?

Carol Klein: Benson and I chaired the 2006 Robert A. Kyle Lifetime Achievement Award, which honored Dr. Durie and was held at the National Press Club in Washington, DC. Bill and Nancy attended the event. At the end of the evening, Nancy approached me about organizing a fundraiser together.

Nancy Moses: Bill's myeloma was under control by that time, and I felt that it was time for me to give back to the myeloma community. The Kleins had been involved with the IMF for many years, and I knew that Carol had lots of experience with fundraising and event planning. Carol and I met to go over ideas, and we thought that it would be fun to organize a tea for the ladies to spend a Sunday afternoon together. Both of us have many friends who are very philanthropic.

What was it like for you, Nancy, to help plan and execute your first fundraiser?

Nancy Moses: I must say that it was surprisingly easy. The beauty of the idea of hosting a tea was that it did not require sponsorship to get the event off the ground. Also, Carol and I put together an event committee, and those ladies helped us with every task along the way. We are thrilled that we picked such winners!

How did you proceed once the committee was formed?

Carol Klein: Our committee was quite large, about 30 women, and consisted of half Nancy's friends and half mine. We held an organizational meeting to decide when and where to hold the tea, how much to charge for attendance, what the invitations should look like, etc. We also decided to do raffles, which meant we had to secure prizes. IMFers Tim and Donna Eagan contributed a luxurious Napa Valley getaway to the Villagio Inn & Spa, plus we received several donated items and services from vendors in the DC area.

Nancy Moses: We sent out invitations to people all over the country, because we knew that even those who would not be able to attend would choose to support our effort to raise funds for a myeloma research grant. Many people bought raffle tickets, regardless of whether they would be able to join us for the event. And we were thrilled at the turnout for the tea – more than 130 women chose to spend their Sunday with us.

Were the guests at your event members of the myeloma community?

Carol Klein: A few were but most were not. This gave us an opportunity to raise awareness by educating our guests about myeloma. The tea featured a very special guest speaker, Susie Novis of the IMF. Susie is a very accomplished woman, and a compassionate and dedicated friend of the entire myeloma community. She has also been my dear friend for the past eight years. At the tea, Susie shared with us the story of the IMF, from its humble beginnings as a three-person operation in the basement of her home to the international organization that now encompasses a membership exceeding 135,000 individuals in 113 countries. The IMF has raised over forty million dollars to support myeloma research and programs, while keeping overhead to an impressively low 10% for expenditures. All that Susie has accomplished, and the standards of excellence she has set, are a great example of how important women are and what we can achieve.

So what was the outcome of your joint fundraising venture?

Nancy Moses: In total, our afternoon tea raised $40,000 for a myeloma research grant. It was gratifying and empowering to learn what a difference each one of us can make when we commit to a goal. Carol and I both feel so fortunate to have such strong support from so many of our friends and family, and we thank them for their time, energy, and contributions to the fight against myeloma! **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 Susie Novis at 800-452-CURE (2873) or snovis@myeloma.org. We also invite you to visit our website at www.myeloma.org for a more detailed explanation of these giving plans.

IMFers RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia

Richie Hass

On March 31, Safari Sam's club in Hollywood, CA, was alive with music as the F.O.R. (Friends Of Richie) benefit was in full swing. The concert, held in honor of Richie Hass, was the brainchild of Scott Heustis. Richie was diagnosed with myeloma in December of 2006 and, in addition to battling his disease, he had another challenge to overcome. With no medical insurance, getting the proper treatment presented a significant problem. "Richie is a multi-instrumentalist musician who is well known in the California music scene," said Scott. "Everyone just loves the guy, and suddenly we were all involved in organizing a concert to raise money. Sixteen bands signed on before a month had gone by, and we had to turn the rest away." While his friends wanted to raise funds for his upcoming transplant, Richie instead directed the money to the IMF's patient programs so that it would benefit as many people as possible.

Slava Rubin and Suzanne Battaglia

On April 24, Music Against Myeloma, an event founded and organized by Slava Rubin, took place at The Cutting Room in New York City. The evening was a tribute to Slava's father, Mark Rubin, who passed away from myeloma in 1993. More than 160 of the Rubins' family and friends gathered from seven states and three countries. The event featured music by Benji Rogers, Lost In October (led by Matt Ostrower, the event's music director), and Josh Walker. Artisanal Premium Cheese served up gourmet cheeses, Sugar Sweet Sunshine baked scrumptious cupcakes, and Harpoon Brewery sponsored cold beer. Cecilia Rubin provided Pralin socks, which were designed for the event and sold out quickly. Grandstand Sports ran a silent auction, Kendra Shedenhelm created the event's design, and Kezi provided photographic services. Great raffle prizes included an iPod Shuffle. I flew in from Los Angeles to attend the event and to give a talk about the amazing strides that have been made in the field of myeloma treatment. Slava, the perfect host, made everyone feel comfortable and welcome, and created an excellent setting for entertaining guests while raising myeloma awareness and funding much-needed research.

On May 19, the 8th Annual "JC" Golf Tournament returned to Wapicada Golf Course in Saint Cloud, MN. This stellar annual event is held in honor of Janet Carol "JC" Johnson, and is organized by her family and friends with the support of members of the local myeloma community. The fun day-long event started with a putting contest, followed by 18 holes of golf and numerous contests throughout the course, including a hole-in-one contest to win a new car. After golf, the event's major returning sponsors, Green Mill Restaurant and Short Stop Custom Catering, served a delicious meal for over 200 golfers and guests. Dinner was followed by an awards ceremony and dancing to live music by the band "Canoise." There were many opportunities for both golfers and non-golfers to win silent auction and raffle prizes donated by generous local companies and individuals. Our thanks go to all the supporters and volunteers whose participation and contribution has made the JC tournament program one of the most successful local myeloma events ever.

On May 20, the Lewis family – Revina and Norm, and their son Scott – organized a successful benefit to raise myeloma awareness and funds for the IMF's Bank On A Cure initiative. More than 400 guests attended Dr. Scott Lewis's Outrageous Comedy Hypnosis Show, which took place at the Annenberg Center in Rancho Mirage, CA. Dr. Scott has been entertaining audiences with his family-friendly show as a comedy hypnotist at the Riviera Hotel in Las Vegas for the past five years. The Lewis family benefit for the IMF featured Mark Kornhauser as the MC and magician, and a raffle drawing for a wide variety of prizes. The idea for the fundraiser came from Revina Lewis, a myeloma patient currently going through chemotherapy, who was able to leave the hospital just two days prior to attending the event.

Many others dedicated their activities to raising funds and awareness. Twelve-year-old Gabriel Birger made the IMF his bar mitzvah project by writing letters, soliciting autographed sports memorabilia for sale, and organizing a myeloma education booth at the Weston Art Fair in Florida. Isabel Prosper and her sister Ricki honored their father by organizing the Myeloma Research Run/Walk for Joseph Prosper and joining over 50,000 other runners who participated in the Vancouver Sun Run, Canada's largest 10K race. The Meijer Kentucky Derby Festival Marathon welcomed Dan Molnar, who race-walked the 26.2 miles to honor his friend, Jerry Greenlee. "This effort gave me the sense that I am doing something to make a difference," says Dan, "That's a good feeling!" Jim Wilson ran the Bayshore Marathon in Michigan to honor his friends and fellow classmates of the Findlay High School Class of 1974, Edie Posey (Bowman) and Tim Guthrie, both of whom have myeloma. "I wanted to do something to be a part of their fight, just like they did for me when I fought and beat testicular cancer back in 1977," said Jim. Erin Yess, Kirstin Wilson, and Harper Giese held the Help from Heaven 5K Walk at Lake Winona in Minnesota to honor their friend, Brianna Vitek, who was killed in a car accident. "Brianna had supported several myeloma benefits in honor of her aunt Cindy, a patient, so we decided to hold a benefit for the IMF to keep Brianna's spirit alive by helping people who are battling this disease," said Erin.

Ricki Prosper, Peter J. Kletas, and Isabel Prosper

Join Us

For information about upcoming events in your area, please contact me, Suzanne Battaglia, at sbattaglia@myeloma.org or 800-452-CURE (2873). If you are interested in organizing an event, our FUNdraising program provides you with the tools, assistance, and expertise to make your effort a success. No idea is too large or too small. The IMF is grateful to all who contribute their time, imagination, and hard work to benefit the myeloma community. We are committed to working with you to continue to raise awareness and funding for myeloma education and research. Please join us in working together toward our common goal... a CURE. **MT**

News & Notes

VELCADE® plus DOXIL® approved for myeloma

The U.S. Food and Drug Administration has approved a new treatment option for myeloma patients who have relapsed or who have not responded to at least one other course of treatments. The combination of DOXIL® with VELCADE® provides nearly a three-month improvement in time to disease progression as compared to VELCADE® alone, which provides a 43% improvement in response, according to a phase III multinational clinical trial. “This is an important new combination for patients, especially those with resistant myeloma, because of the VELCADE®/DOXIL synergy – VELCADE® increases the sensitivity of cancer cells to DOXIL and DOXIL does the same for VELCADE®,” said Dr. Brian G.M. Durie. “The growing success treating myeloma and extending patients’ lives is due in large part to new drugs that can be used in combination and in sequence, and the approval of the new VELCADE®/DOXIL combination fits perfectly into that strategy.” DOXIL is a specially formulated version of the chemotherapy agent doxorubicin, and is approved for use in other forms of cancer. VELCADE® (bortezomib) is approved for myeloma patients who have relapsed or not responded to a previous course of treatment. VELCADE®/DOXIL may be used with or without steroids, providing patients with a steroid-free alternative.

Reimbursement at Risk for ESAs for Management of Anemia

Recently the Centers for Medicare and Medicaid Services (CMS), the agency that determines government reimbursement policy, proposed changes that, if approved, would impact Medicare coverage for erythropoiesis stimulating agents (ESAs) in the management of patients with myeloma. Many myeloma patients are currently being treated with ESAs such as Procrit, Epogen, or Aranesp, thus reducing or eliminating their need for transfusions. The IMF has weighed in with CMS regarding the myeloma community’s concerns with the proposal. Implications of the CMS proposal include:

- Interfering with the doctor-patient relationship in deciding the best treatment options for myeloma patients.
- Significantly increasing patient out-of-pocket costs for ESA therapy by limiting or denying reimbursement.
- Setting a dangerous precedent for national policy by refusing reimbursement for a treatment before a thorough review of the data and a final determination is made by the Food and Drug Administration.

Because there is always the possibility that private insurance carriers will follow the Medicare policy, many members of the myeloma community submitted their input to CMS before the public comment period for the proposal ended on June 13th. CMS must make a final coverage determination within 60 days after the end of the comment period. The IMF will monitor the outcome of this issue and will keep the myeloma community informed about the final decision.

SWOG trial closed

The Southwest Oncology Group (SWOG) has permanently closed enrollment in a federally-funded, Phase III, randomized, controlled clinical study (S0232) for newly diagnosed myeloma patients comparing dexamethasone with a combined therapy of dexamethasone plus REVLIMID®. SWOG based its decision on the preliminary one-year survival results from the Eastern Cooperative Oncology Group (ECOG) Phase III study (E4A03), which is evaluating the use of low-dose dexamethasone in combination with lenalidomide as compared to the higher, standard dose of dexamethasone used in combination with lenalidomide to treat patients newly diagnosed with multiple myeloma. All patients in S0232 have been given the choice of switching to REVLIMID with dexamethasone, with the option of using low-dose dexamethasone.

Millennium invites Support Group Leader to Kos, Greece

Millennium Pharmaceuticals has invited Maddie Hunter, co-leader of the Philadelphia Multiple Myeloma Networking Group, to attend the XIth International Myeloma Workshop as a Patient Representative. Millennium is underwriting the expenses necessary for Maddie to attend this important conference in Kos, Greece, and to write about presentations and news of interest to myeloma patients and caregivers. “We believe that patients and caregivers will directly benefit from her reporting skills and fresh perspective,” said Ronny Mosston, senior director for patient advocacy and professional relations at Millennium. Please stay tuned to the IMF website for additional information and Maddie’s reports from Greece the last week in June.

Transfusion Expert Urges Use of Filtered Blood

Neil Blumberg, MD, the lead author of a University of Rochester research study, argues that leukoreduced blood is safer for transfusion recipients because removing the white cells from donor blood reduces the chances of a negative reaction by the host immune system. While leukoreduction increases upfront costs, several cost-benefit analyses show that the price of each unit of filtered blood is offset by savings from less use of antibiotics, as well as by reduced overall lengths of stay in the hospital. Dr. Blumberg et al. report that in patients who received leukoreduced blood, post-surgical infection rates dropped from 33% to 23%. In 1998, the University of Rochester’s Strong Memorial Hospital became one of the first hospitals in the country to begin using leukoreduced blood for all cardiac surgery cases. In 2000, the hospital extended this practice to all transfusion patients.

VELCADE Refunds in Britain

The National Health Service (NHS), which provides free healthcare for all British subjects, has to date refused to cover the use of VELCADE® because of its high cost. Now, a division of Johnson & Johnson in Britain is offering to refund the cost of VELCADE® if the patient’s health does not improve as a result of the therapy. This novel approach could enable the NHS to prescribe a wider range of expensive but potentially beneficial drugs. **MT**

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).

Special Announcement

DR. ROBERT A. KYLE RECEIVES DAVID A. KARNOFSKY MEMORIAL AWARD

The 43rd annual meeting of the American Society of Clinical Oncology (ASCO) took place June 1–5 in Chicago, IL. This premier educational and scientific event in the field of oncology was the backdrop for the presentation of the 2007 David A. Karnofsky Memorial Award to IMF Director and Scientific Advisory Board Chair, Dr. Robert A. Kyle. Named for one of the pioneers in the field of oncology, the David A. Karnofsky Memorial Award is bestowed upon researchers whose work has changed the general practice of oncology. The award recognizes Dr. Kyle, who has been honored throughout his career for his groundbreaking work and for pioneering research in multiple myeloma and monoclonal protein abnormalities.

In the 1960s, Dr. Kyle created a special protein laboratory at the Mayo Clinic. He was responsible for establishing Mayo Clinic's dysproteinemia unit for patients with myeloma, macroglobulinemia, primary amyloidosis, and other hematologic disorders. Dr. Kyle's discovery of monoclonal gammopathy of undetermined significance (MGUS) in 1978 and smoldering multiple myeloma in 1980 is considered fundamental to the contemporary understanding of hematology. He initiated numerous programs that have improved patient care and advanced clinical science, and he continues to pursue cutting edge research.

Robert A. Kyle, MD
Mayo Clinic
Rochester, Minnesota

Throughout his distinguished career, Dr. Kyle has been honored with more than 50 awards for his expertise and dedication to both science and patient care. Three prestigious awards given to oncology professionals in various specialties have been named in his honor: the IMF grants the Robert A. Kyle Lifetime Achievement Award to physicians who demonstrate "a singular dedication to and compassion for myeloma patients and treatment of their disease," the Waldenstrom's Macroglobulinemia Foundation presents the Robert A. Kyle Award for important contributions to the therapy of that disease, and Mayo Clinic Arizona presents the Robert A. Kyle Award for Excellence in Clinical Investigation to the physician at that institution who has conducted the most outstanding work in any field of research. Dr. Kyle has over 1,800 published materials to his credit, and has co-editor credit for four editions of Neoplastic Disorders of the Blood and three editions of Myeloma: Biology and Management.

"Dr. Kyle has brought a scientific rigor and integrity to clinical research, which provides a model for everyone. He has the most comprehensive knowledge of published research of anyone working in the field," said IMF Chair, Dr. Brian G. M. Durie. "He brings that breadth of knowledge to the bedside and is able to provide management guidance with skill, elegance, and a great humanity. His carefully measured advice is cherished by all who seek it." **MT**