



MYELOMA TODAY

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A PUBLICATION OF THE INTERNATIONAL MYELOMA FOUNDATION

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

Highlights



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Manuel L. Penichet, MD, PhD



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REVLIMID® APPROVED FOR MYELOMA

TARGETED THERAPIES CAN BE LIFE-CHANGING FOR CANCER PATIENTS

The U.S. Food and Drug Administration (FDA) has granted approval for its Supplemental New Drug Application (sNDA) to the drug Revlimid® (lenalidomide) for use in combination with Decadron® (dexamethasone) as a treatment for patients with multiple myeloma who have received at least one prior therapy.

The FDA approval of Revlimid is a major new addition to the group of myeloma treatments that together have the potential to significantly extend patients' lives. Revlimid was approved by the FDA in December of 2005 to treat certain patients with a malignant blood condition called myelodysplastic syndrome (MDS). The supplementary approval of Revlimid for myeloma patients who have relapsed after at least one prior therapy provides them with a targeted, oral treatment that can be used in combination regimens and in sequence with other treatments to help keep many patients alive, active, productive, and feeling well.

"REVLIMID® is an important addition to the drugs we use for myeloma and gives us an important new option when patients come out of remission. By using drug regimens in sequence, we have kept some of our patients alive and feeling well for 10, 12, and in some cases more than 15 years. These new options are truly changing the way we think about myeloma, about blood cancers, and perhaps about other cancers in the foreseeable future."

— **Brian G.M. Durie, MD**

Revlimid is an oral medication taken as a pill at home. It is called a targeted therapy because it affects cancer cells rather than all rapidly dividing cells, thus attacking the cancer without causing the ravages usually associated with chemotherapy. Revlimid belongs to a new class of drugs called IMiDs, immunomodulatory drugs, developed by Celgene Corporation based on the company's

PLEASE SEE REVLIMID ON PAGE 5

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 800-452-2873.

This issue of Myeloma Today is supported by Celgene Corporation and Millennium Pharmaceuticals.

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NEW INTERNATIONAL UNIFORM RESPONSE CRITERIA FOR MYELOMA

By S. Vincent Rajkumar, MD

Introduction

Several response criteria are currently in use in myeloma, and the lack of uniformity is problematic. The US cooperative clinical trials groups (e.g., ECOG and SWOG) have differing systems, as do European groups such as the MRC (UK) and the IFM (France). The European Group for Blood and Bone Marrow Transplant/International Bone Marrow Transplant Registry/American Bone Marrow Transplant Registry (EBMT/IBMTR/ABMTR, commonly referred to as EBMT) developed widely used criteria for myeloma, but the EBMT criteria have some inconsistencies and lack precision in some definitions. In addition, the EBMT criteria do not include some important response categories.

Uniform response criteria are required to adequately assess clinical outcomes. The new criteria expand, clarify, and update EBMT criteria to provide a comprehensive evaluation system that aims to:

- Facilitate precise comparisons of efficacy between new treatment strategies in clinical trials;
- Include assessment of patients with oligo-secretory and non-secretory disease (patients without sufficient M-component in serum and/or urine to monitor response) using the sensitive serum free light-chain assay (Freelite™) in order to help patients enter clinical trials;
- Establish stricter definitions for complete response (CR);
- Provide clarifications, improve detail, and correct inconsistencies in prior response criteria.

Development of new response criteria

The International Myeloma Working Group has already developed new standard diagnostic criteria and a new International Staging System (ISS) for myeloma, which



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are being widely accepted as the current standards for diagnosis and staging. The development of the new response criteria started with a meeting of the International Myeloma Working Group during the Xth International Myeloma Workshop in April of 2005 in Sydney, Australia. Over 70 myeloma specialists participated and gave their input, and the final approval of the proposed new criteria. The important changes in the new criteria compared to the EBMT criteria are as follows:

- Clarification and revision of important practical details of response evaluation
- Elimination of mandatory 6-week wait time to confirm achievement of response
- Introduction of a similar non-time-dependent confirmation for progression
- Requirement of partial response (PR) as response requirement for new drug trials
- Introduction of new response categories
 - Addition of a new category of stringent CR (sCR)
 - Formal addition of a category of very good partial response (VGPR)
- Elimination of the minor response category
- Addition of response criteria for interpreting the free light chain assay, which will enable numerous patients hitherto excluded from clinical trials for lack of measurable disease to enter and be evaluated in clinical trials
- Clarification that criteria for progressive disease (PD) are to be used for calculation of time to progression and progression-free survival in patients who are in CR. Criteria for relapse from CR are to be used only if disease-free survival (DFS) is calculated and reported

Of note, for patients with measurable M-protein levels in the serum and urine, the definitions of complete and

PLEASE SEE RESPONSE CRITERIA ON PAGE 5

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IMF Calendar 2006

Oct	4-8	SWOG – Seattle, WA	Nov	4-6	ECOG – Ft. Lauderdale, FL
	7	P&F Seminar – Mexico City, MEXICO		4	P&F Seminar – Pamplona, SPAIN
	21	IMF 16th Anniversary Gala Celebration – Regent Beverly Wilshire Hotel, Los Angeles, CA		4	Second Annual Southwest Symposium – Tempe, AZ
	19-21	Lymphoma/Myeloma Conference	Dec	8-12	ASH – Orlando, FL
	22-28	Myeloma Awareness Week	Feb 07	23-24	Los Angeles P&F Seminar – Los Angeles, CA
	28	Patient, Family & Healthcare Professionals Seminar – Montreal, CANADA	Mar 07	23-24	Houston P&F Seminar – Houston, TX

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-UK events are not included above.

REVLIMID — continued

work with thalidomide. It is covered by most Medicare Part D plans.

Revlimid is a derivative of Thalomid® (thalidomide), which was used off-label until the drug was approved to treat newly diagnosed multiple myeloma in May 2006. Although Revlimid belongs to the same class of drugs as thalidomide, it produces fewer and less severe side effects. Revlimid, along with thalidomide, is the second FDA-approved therapy this year from the Celgene Corporation that is specifically indicated for the treatment of myeloma. The use of these therapies in combination regimens shows promise and innovation in dramatically changing the outlook for myeloma patients.

Michael Tuohy, father of two young children in Connecticut, was just 36 years old when he was diagnosed six years ago: “Treatments worked at first, but myeloma inevitably comes back. My doctor told me that Revlimid was my best option for treatment that would also allow me to maintain a good quality of life, and he got me on Revlimid in a clinical trial last November. Today, I’m in complete remission. I have just celebrated my 42nd birthday with my wife and children, a milestone I was afraid I’d never see.”

At the annual meeting of the American Society of Clinical Oncology (ASCO) in June of 2006, researchers said that newly diagnosed myeloma patients treated with Revlimid plus dexamethasone showed no disease progression during the course of the study, and even patients who had stopped responding to previous treatments showed improved survival with this regimen. Multiple myeloma treated with the combination therapy, on

RESPONSE CRITERIA — continued

partial response as well as disease progression match those used in the EBMT criteria. Therefore, in trials that include only patients with measurable disease response rates and progression, estimates reported using the using the new criteria will be comparable to those using the EBMT criteria. This will allow easy comparison of rates reported in trials using the EBMT criteria with those using the new criteria.

Conclusions

It is significant that so many myeloma specialists around the world have reached consensus on the outlined new

IMF Addresses the High Cost of Cancer Therapies

The IMF is concerned about the high cost of cancer therapies, including Revlimid, in the current reimbursement environment. Our Hotline receives frequent calls from patients who are forced to choose medical alternatives when costs are too high and reimbursement too low. Our Hotline Coordinators are here to help patients through the system of reimbursement and coverage under the various Medicare plans. As patient advocates, we will work with Revlimid’s maker, Celgene Corporation, as well as with other pharmaceutical companies and with the government, to help ensure that therapies are available to all who need them and are not out of reach because of price or reimbursement. For more information, please see page 23.

average, did not progress for 11 months compared with 4.7 months with dexamethasone alone. Revlimid’s overall response against myeloma was more than double that of dexamethasone (59% compared with 21%), and the complete response rate was higher (13% versus 0.6%).

“Revlimid is an important addition to the drugs we use for myeloma and gives us an important new option when patients come out of remission,” says IMF’s chairman Brian G.M. Durie, MD. “By using drug regimens in sequence, we have kept some of our patients alive and feeling well for 10, 12, and in some cases more than 15 years. These new options are truly changing the way we think about myeloma, about blood cancers, and perhaps about other cancers in the foreseeable future.” **MT**

Note: For more information on Revlimid®, please visit the site www.revlimid.com.

response criteria, which has been widely disseminated and is expected to be used both in future myeloma clinical trials and by treating physicians. SWOG and ECOG have already incorporated the new criteria into their protocols. The new criteria is backwards-compatible with the old EBMT criteria. **MT**

Editor’s Note: To read the published text of the proposed new response criteria for multiple myeloma in its entirety, visit the IMF website at www.myeloma.org for a link to the lead article published online on July 20, 2006: *Leukemia* (2006) 20, 1467–1473. doi: 10.1038/sj.leu.2404284

PROGRESS REPORT FROM IMF'S SENIOR RESEARCH GRANT RECIPIENT

Antibody-avidin Fusion Proteins Targeting the Transferrin Receptor: Potential Therapeutics for the Treatment of Multiple Myeloma

By Manuel L. Penichet, MD, PhD

Introduction

We have developed a new antibody named “anti-human TfR IgG3-Av” that acts as a “magic bullet” targeting myeloma cancer cells and causing their death by depriving them of important nutrients that the cancer cells need for their survival. In addition, we have demonstrated that the anti-hTfR IgG3-Av antibody can be loaded with other anti-cancer drugs which would act as “war heads” to increase the antibody’s anti-cancer activity and eventually cure the disease. The anti-hTfR IgG3-Av is expected to be a novel therapeutic capable of a two-pronged attack against myeloma cells through their direct destruction and through the delivery of other anti-cancer drugs.

Research

This research project was based on a novel antibody-avidin fusion protein targeting the human transferrin receptor, which is overexpressed on hematopoietic malignant cells such as multiple myeloma cells. We have developed an antibody fusion protein composed of avidin fused to a mouse/human chimeric IgG3 specific for the human transferrin receptor (TfR). Our initial goal was to use the anti-hTfR IgG3-Av molecule as a universal vector to deliver biotinylated agents into cancer cells. We found that anti-hTfR IgG3-Av effectively delivers biotinylated molecules into cancer cells by receptor-mediated endocytosis while they remain active after their internalization. Furthermore, we have unexpectedly discovered that anti-hTfR IgG3-Av, but not the original monoclonal antibody 128.1 or a non-specific IgG3-Av, possesses strong intrinsic antiproliferative/pro-apoptotic activity against hematopoietic malignant cell lines. Therefore, anti-hTfR IgG3-Av is potentially capable of a two-pronged attack on malignant hematopoietic cells through both toxin delivery and direct induction of apoptosis, which makes anti-hTfR IgG3-Av a unique drug for the treatment of



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hematopoietic malignancies including multiple myeloma. We would like to stress that our project has both a translational and a basic science potential. In fact, it is expected that the elucidation of the mechanism responsible for the induction of apoptosis elicited by anti-hTfR IgG3-Av and the identification of potential mechanism of resistance would contribute to a better understanding of the function of the overexpressed TfR in hematopoietic cancer cells, an issue that is still unclear.

Prior to being awarded IMF funding, we tested the intrinsic anti-proliferative activity of anti-human IgG3-Av against a broad spectrum of human malignant plasma cell lines such as 8226/S and 8226/DOX40 (doxorubicin-resistant and also multidrug resistant), ARH-77, U266B1, MM.1S, OCI-My5, S6B45 and IM-

9. We found that anti-human IgG3-Av binds to the TfR expressed on the surface of all these human malignant plasma cell lines and inhibits their growth in a dose-dependent manner. In all cases, the inhibition of proliferation is associated with the induction of apoptosis. It is important to stress that this anti-proliferative/pro-apoptotic activity was obtained without the use of biotinylated anti-cancer drugs. The following is a list of our research accomplishments obtained thanks to the support of the IMF’s 2004 Brian D. Novis Senior Research Grant.

Results, publications, and presentations

1. We developed better producers of anti-hTfR IgG3-Av and established the methods to scale-up the production of the protein. This would allow us to conduct multiple in vitro and in vivo experiments. In fact, we prepared significant batches of antibody fusion protein to be used in animal experiments that are schedule to start soon. We have also constructed and expressed an anti-hTfR IgG3

CONTINUES ON NEXT PAGE

(mouse/human chimeric) to be used as a more meaningful control compared to the original anti-human TfR murine monoclonal antibody 128.1.

2. We made significant progress in understanding the mechanism responsible for the anti-proliferative/pro-apoptotic activity exhibited by anti-hTfR IgG3-Av in malignant plasma cells. These studies are critical since an understanding of the anti-tumor activity exhibited by the anti-TfR antibody-avidin fusion protein would result in a more rational design of combined therapeutic approaches directed against multiple myeloma and other hematopoietic tumors.

- These results and their potential implications are shown in the article, Molecular events contributing to cell death in malignant human hematopoietic cells elicited by an IgG3-avidin fusion protein targeting the transferrin receptor, to be published in *Blood*, the journal of the American Society of Hematology (ASH).
- At the 2004 annual meeting of the American Association for Cancer Research (AACR), the following study was presented. Anti-human TfR-IgG3-avidin: A molecule capable of a two-pronged attack on malignant plasma cells through toxin delivery and direct induction of apoptosis. Proceedings of the American Association for Cancer Research 95th Annual Meeting (v. 45, p. 678).
- At the 2005 AACR annual meeting, the following study was presented: Mechanism of apoptosis induced by an IgG3-avidin fusion protein specific for the human transferrin receptor. Proceedings of the American Association for Cancer Research 96th Annual Meeting (v. 46, pp. 166-167).

3. We found that the anti-hTfR IgG3-Av fusion protein is able to bind to the human TfR not only expressed on

“Dr. Penichet and his colleagues have developed an antibody named anti-hTfR IgG3V-AV. This antibody-avidin fusion protein reacts with the human transferrin receptor that is expressed on human myeloma cells. This antibody slows the growth of tumor cells and promotes their death (apoptosis). In addition, this antibody is able to deliver biotinylated drugs into cancer cells, which is another approach to the destruction of myeloma cells.

Dr. Penichet and his colleagues have prepared larger amounts of the antibody fusion protein, so that they can conduct experiments in animals. If the antibody is effective and relatively non-toxic, the next step will be phase I studies in humans to determine the toxicity of the antibody, followed by phase II studies to determine whether the monoclonal antibody has sufficient anti-tumor effect. Even though this is a promising approach, much more work needs to be done.

We congratulate Dr. Penichet on his work and look forward to future developments.”

— Robert A. Kyle, MD

the surface of cancer cells but also in solution (the soluble TfR, also known as sTfR) and attached to a solid surface. Moreover, we found that anti-hTfR IgG3-Av does not cross-react with TfR2 and that the natural ligands of TfR (Tf and HFE) do not compete with the antibody fusion protein. These results were presented at the following meetings:

- At the 2005 SACNAS National Conference, the following poster was presented: Anti-human transferrin receptor IgG3-avidin fusion protein: interactions with solid surface bound and soluble transferrin receptor. Proceedings of the 2005 SACNAS National Conference (v. 2, p. 73).
 - At the 2006 AACR annual meeting, the following poster was presented: Binding properties of a mouse/human chimeric IgG3-Avidin fusion protein specific for the human transferrin receptor. Proceedings of the American Association for Cancer Research 97th Annual Meeting (v. 46, p. 1091).
 - A manuscript about the binding properties of the anti-TfR IgG3-Av, which would also include real-time studies of the affinity for TfR and biotin, is currently in preparation.
4. We found that the anti-hTfR IgG3-Av fusion protein is able to sensitize CDDP-resistant multiple myeloma cell lines. These results were presented (poster) at the 2005 ASH annual meeting: Chemosensitization of CDDP-resistant multiple myeloma cell lines following treatment with anti-TfR IgG3-Av. The American Society of Hematology 47th Annual Meeting and Exposition. *Blood*, v. 106, n.11, SUPPL 1, PART 2. (Nov. 16, p. 363b).
5. After testing the potential enhancement of cytotoxicity triggered by a variety of biotinylated toxins bound (and delivered by) anti-TfR IgG3-Av, we found that the

PLEASE SEE PENICHER PROGRESS REPORT ON PAGE 9

VEL-CTD IN PREVIOUSLY UNTREATED MULTIPLE MYELOMA

A Conversation with William I. Bensinger, MD

Myeloma Today: What is the VEL-CTD study?

Dr. William Bensinger: VEL-CTD is a combination therapy of VELCADE® (bortezomib), Cytoxan® (cyclophosphamide), Thalomid® (thalidomide), and Decadron® (dexamethasone). I am the principal investigator at the Fred Hutchinson Cancer Research Center of a Phase II trial with VEL-CTD in previously untreated multiple myeloma patients. This is a national, multi-center, open-label, single arm clinical trial sponsored by the Aptium Oncology Research Network. Drs. Brian Durie (Cedars-Sinai Outpatient Cancer Center), Sundar Jagannath (St. Vincent's Comprehensive Cancer Center), and Jeffrey Wolf (Alta Bates Comprehensive Cancer Center) are also conducting this study at their respective centers.

Myeloma Today: What can you tell us about this clinical trial?

Dr. Bensinger: The primary objective is to assess the response rate to VEL-CTD in newly diagnosed myeloma patients. The secondary objective is to determine the safety and tolerability of VEL-CTD in newly diagnosed myeloma patients. The treatment schedule will consist of six 21-day cycles. The first three cycles will consist of VELCADE, cyclophosphamide, and dexamethasone. The next three cycles will consist of VELCADE, dexamethasone, and thalidomide. The response rate will be evaluated after six cycles of therapy. At the end of the six cycles of treatment, patients will have follow-up every three months, will have the option of proceeding to a stem cell transplant, or no treatment until new chemotherapy treatment is started.

Myeloma Today: What are the eligibility criteria, and how many patients will be enrolled?

Dr. Bensinger: VEL-CTD is a frontline therapy. Patients must have newly diagnosed symptomatic disease requiring treatment. In secretory disease, there must be measurable paraprotein in serum and/or urine. In non-secretory disease, there must have measurable protein by FREELITE™ Serum Free Light Chain Assays, measur-



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able disease such as untreated soft tissue plasmacytoma, or evaluable disease in the bone marrow. The multi-center will enroll 43 patients who will be studied for the duration of one year.

Myeloma Today: What is the benefit of using cyclophosphamide as the alkylating agent in VEL-CTD?

Dr. Bensinger: Cyclophosphamide is an alkylating agent in the same class as melphalan but, unlike melphalan, cyclophosphamide does not damage the bone marrow. Melphalan compromises a patient's ability to proceed to a stem cell transplant. Because a significant number of newly diagnosed myeloma patients choose go on to transplantation, it is important to preserve stem cell function in these patients.

Myeloma Today: Many myeloma patients are now achieving complete remission (CR) with frontline therapy. Has the role of transplantation changed since the introduction of novel agents?

Dr. Bensinger: Because CR is associated with a survival benefit, it is certainly an important goal for a patient with myeloma. But we do not yet know if the CR achieved with conventional therapy using novel agents confers the same survival advantage as CR with high-dose therapy followed by transplant. Until recently, we were not able to produce CR with conventional therapy except in a small fraction of patients. While new drug combinations have enabled a larger percentage of patients to achieve CR, we do not yet know how durable these responses will be.

Myeloma Today: So will you be using VEL-CTD as induction therapy?

Dr. Bensinger: Yes, there will be patients participating in the VEL-CTD study who will choose to proceed to a transplant. But we will also be treating patients in the VEL-CTD study who are simply not eligible for transplantation. At our center we generally recommend a transplant to patients up to age 70, although we take both biologic and chronologic age into account. I've seen

PLEASE SEE VEL-CTD ON NEXT PAGE

PENICHERET PROGRESS REPORT — continued

biotinylated plan toxin saporin (b-saporin) shows the most impressive enhancement of the cytotoxicity triggered by anti-TfR IgG3-Av.

- These results were presented (poster) at the 2006 AACR annual meeting: Conjugation of an anti-TfR IgG3-avidin fusion protein with biotinylated saporin results in significant enhancement of its cytotoxicity against malignant hematopoietic cells. Proceedings of the American Association for Cancer Research 97th Annual Meeting (v. 47, pg. 1283).
- A manuscript about the delivery of saporin by anti-TfR IgG3-Av is currently in preparation.

Book Chapter

Helguera G. and Penichet M.L. “Antibody-cytokine fusion proteins for the therapy of cancer”. In *Adoptive Immunotherapy: Methods and Protocols* (Methods in Molecular Medicine series). Burkhard Ludewig and Matthias W. Hoffmann eds. The Humana Press Inc, Totowa, New Jersey. 2005, pp. 347-373.

The above is the first Methods and Protocols book chapter about antibody fusion proteins for the treatment of cancer. We hope that this chapter will become a standard

VEL-CTD — continued

patients who are 75 but look like they are in their 50s, and I’ve seen patients in their 50s who look considerably older and may have other conditions that must be taken into account.

Myeloma Today: How does VEL-CTD combination therapy compare with other treatments currently being studied for myeloma?

Dr. Bensinger: There are a lot of initial therapies being studied for myeloma. At this point, nobody knows which will be shown to be the best regimen. The VEL-CTD regimen combines four of the most active agents in the treatment of multiple myeloma. Our goal is to develop a regimen for myeloma that is comparable to the CHOP regimen for lymphoma. CHOP combines four drugs that, as initial therapy, have been proven to be highly effective for lymphoma. There are several myeloma studies that suggest VELCADE or thalidomide combined with other active agents improves the proportion of patients who respond to the therapy. VEL-CTD builds on that idea, combining a total of four drugs that are known to be highly effective for myeloma.

in the field. The chapter describes the technology that we used to develop antibody fusion proteins such as anti-TfR IgG3-Av, our experimental drug for the treatment of myeloma.

Literature Reviews

Daniels T.R., Delgado T., Rodriguez J.A., Helguera G., and Penichet M.L. “The transferrin receptor part I: Biology and targeting with cytotoxic antibodies for the treatment of cancer.” *Clinical Immunology*. In press.

Daniels T.R., Delgado T., Helguera G., and Penichet M.L. “The transferrin receptor part II: Targeted delivery of therapeutic agents into cancer cells.” *Clinical Immunology*. In press.

Conclusions

The above information represents the scientific progress in our multiple myeloma research projects funded by the IMF. In addition, we have started working on gene profiling (micro-array) studies. Soon, we will expand our studies using more primary cells from patients and using animal models. **MT**

In the VEL-CTD study, both VELCADE and dexamethasone will be used for all six cycles of treatment. VELCADE has been an important new drug for the management of patients with myeloma. It is a very active drug that results in good response rates. In second- and third-line therapy, it has been used successfully in patients who have failed other therapies. There is promising new data from several research groups combining VELCADE with other drugs as frontline therapy, and the response rates that have been achieved are higher than what we have previously observed with other drug combinations. Several research groups have reported on the combination of VELCADE and dexamethasone as induction therapy, and there are suggestions that this combination is effective. In VEL-CTD, we are adding cyclophosphamide and thalidomide to VELCADE and dexamethasone, and I am excited about the possibility that this new drug combination can improve the outcome for patients. **MT**

PATIENT & FAMILY SEMINAR: PORTLAND, OREGON

By Tom Blakney, Facilitator
Northwest MMFIGHTERS!

The Portland IMF Patient & Family Seminar got underway with over 200 participants in attendance. The first session was an open forum with Dr. Robert Kyle and Dr. Brian Durie. There were lots of good questions asked by the attendees, with articulate and informative answers given by both doctors. Osteonecrosis of the jaw (ONJ) was just one of the subjects that seemed to draw a lot of attention.

Another hot topic of discussion was Revlimid®. There was a question raised regarding oral vs. intravenous myeloma treatment. It still seems unclear which is more effective but oral drugs seem to be preferred by some because of ease of administration. One patient asked about the pros and cons of a stem cell transplant if you are already responding well to the combination of Revlimid and dexamethasone. Dr. Durie's advice was not to change something that is working. If, at a later time, the combination no longer works quite as well, then other options should be considered.



IMFers signing up for the Saturday afternoon break-out sessions

Dr. Tina Kuus-Reichel of The Binding Site spoke about The FREELITE™ Serum Free Light Chain Assay. This blood test measures free lambda and free kappa immunoglobulin light chains, and is a great tool for the detection and monitoring of myeloma. There is now significant clinical evidence indicating the benefit of these assays in initial screening for monoclonal gammopathies and non-secretory myeloma, as well as rapid evaluation of treatment efficacy.



Tom Blakney

After the Open Forum ended, Dr. Loch Chandler of the Providence Health System in Portland made a very effective Quality of Life presentation about nutritional and lifestyle influences on myeloma. Dr. Chandler is a naturopathic doctor, and he emphasized the benefit of the Mediterranean Diet in reducing the risk of obesity and heart disease, as well as a 60%-70% reduction of cancer risk. He also talked about the importance of fruits, vegetables, whole grains, legumes, and the right fats in our diets. He also recommended drinking green tea because of its anti-angiogenic properties.

Dr. Chandler also presented information about dexamethasone and diabetes, and suggested ways to reduce the impact of steroid use on the body. In the lifestyle section of the presentation, Dr. Chandler stressed the importance of exercise for both cancer patients and caregivers. He also discussed several ways to reduce the effects of peripheral neuropathy.

The final event on Friday was the IMF Welcome Dinner & Cocktail Reception. It was a great opportunity to chat with the seminar's faculty members and to network with other guests. As the evening progressed, it was noted that the food being served was not exactly in line with Dr. Chandler's earlier recommendations for good nutrition. Nevertheless, the snack line was long and the food was delicious!

Next, Susie Novis made some introductory remarks in her normal super-



Robert & Ellie Moyer with Dr. Robert Kyle

enthusiastic way. It was good to hear about the IMF's recent successes. There were updates on the US and

"The Portland Patient & Family Seminar continued the great tradition of the IMF in providing the latest information on the treatment of this disease. To have the opportunity to have your questions answered by the top doctors in the field is an amazing benefit to patients trying to negotiate their treatment options."

— Dian Alyea

Canada, as well as the rest of the myeloma world. It sounds like real progress is being made and we are moving toward beating this disease!

The Keynote Speaker of the evening was Dr. John Crowley of CRAB (Cancer Research and Biostatistics, Seattle). Dr. Crowley is a statistician working with clinical trials. He gave the audience an inkling of some of the challenges encountered in setting up the response goals of a trial, the number of patients needed in the different clinical phases, and the analysis of the resulting data. Dr. Crowley made it clear to



Susie Novis and guests
at the IMF cocktail reception

us that progress almost always results from clinical trials and that more patient participation is essential to further progress. It should be noted that Dr. Crowley has quite a keen sense of humor — one of his slides featured a chart for a large-dose, a medium-dose, and a small-dose placebo.

The first session on Saturday morning, Myeloma 101: What to Do When You're First Diagnosed, featured Dr. Robert Kyle. He gave an excellent presentation about the terminologies used in myeloma. He also shared information on complications, response rates, and some of the frequently used myeloma treatments. After Dr. Kyle's presentation, many questions were asked of the expert panel that, in addition to Dr. Kyle, featured Drs. Brian Durie and Robert Vescio, both of the Cedars-Sinai Medical Center in Los Angeles.

The second session featured Dr. Durie's talk about Current Options for Frontline Therapy & Transplantation. Dr. Durie offered up-to-date information on current treatment strategies, including VELCADE® and Revlimid. He also discussed the role of transplantation and offered advice on how to determine whether or not a transplant should be considered.



Dr. Brian Durie chats
with seminar participants

The third session of the morning, Achieving Best Bone Health and Quality of Life, featured a talk by Dr. Vescio. He explained the effects of myeloma on the bones, and presented results from relevant clinical studies. Dr. Vescio also discussed the latest available information on ONJ. Apparently, up to 11% of myeloma patients using bisphosphonates have either a firm diagnosis of ONJ or early suspicious findings. The observed risk increases significantly if the bisphosphonate treatments continue for longer than 5 years. However, Dr. Vescio believes that the risk-benefit ratio is very high and that prevention through bone mineral density evaluation is needed. Dentists are becoming progressively more educated to the possibility of ONJ among patients undergoing bisphosphonate therapy.

The fourth presentation was made by Dr. Nikhil Munshi. His topic, What is the Approach for the Relapsing Patient and the Recommendations in Relapse Therapy?, provided



Surendra & Tarulata Barot

participants with an opportunity to better understand the many available myeloma therapies and to learn about the therapies currently in Phase II and Phase III clinical trials, which may further expand a patient's range of treatment options. **MT**

Editor's Note: Many of the presentations made at the Portland IMF Patient & Family Seminar are available in PowerPoint format at www.myeloma.org.

PATIENT & FAMILY SEMINAR: PHILADELPHIA, PENNSYLVANIA

By Maddie Hunter

The Doubletree Hotel in Philadelphia was overflowing with IMF Patient & Family Seminar participants on August 4th and 5th. Friday's Open Forum with Drs. Brian Durie and Morton Coleman was a great way to begin the meeting, with both doctors fielding questions on a wide range of topics. At the conclusion of the scheduled session, lines formed in front of each doctor so patients could ask questions that hadn't gotten airtime. These doctors are sure generous with their time!

The "Pain Management" discussion by Erin McMenam, an oncology nurse, provided us with a thorough overview of this important issue. Erin differentiated between boney pain from lytic lesions and nerve pain that often comes from the treatments we receive. In addition to typical relief options, we heard about what's new in pain management. Erin showed us a new lozenge that works as it melts against the cheek. An effervescent version is another alternative. In response to voiced concerns about addiction, Erin assured us that this usually occurs when people are using pain meds for non-medicinal purposes. She suggested rotating pain meds to avoid the build-up of tolerance to a single medication, and discussed a few specific medications and the situations that call for them.

The Freelite Testing discussion led by Dr. Karen van Hoeven finally made it clear to me why this test is such a valuable tool in diagnosis and tracking of myeloma. Since free light chains circulate in the blood at abnormally high levels in most myeloma patients, having a blood test that can measure and track them is very useful. This test is so sensitive that it can even be used in monitoring non-secretory disease, and it also offers a rapid indication of a patient's response to treatment.

The Quality of Life presentation was the last afternoon session on Friday before the IMF's cocktail reception and dinner. Patricia Mangan, nurse practitioner associated with Dr. Stadtmauer here in Philly, spoke about



Maddie Hunter busy blogging the seminar for all to read on the IMF website

the strategies available to assist us with our treatment protocols, as well as the toxicities from treatments that can be a challenge to manage. Neuropathy can be addressed with dose reductions, vitamin and amino-acid supplements, topical creams, and tonic water. Dose reductions and transfusions are commonly considered when platelet or white blood cell counts drop. Dietary and over-the-counter remedies can help with gastrointestinal side effects. Antihistamines seem to be helpful with the occurrence of a skin rash. Blood thinners can be used if there is an incidence of blood clots. There was much more to say when we ran out of time, so many IMFers gathered around Trish as the session ended.

On the morning of Saturday, August 5, Susie Novis welcomed the attendees and opened the seminar with a review of the IMF's research program. Last year the IMF funded \$1.2 million in carefully defined research projects. In total, 72 grants have been awarded since 1994. The approach is to fund what will offer the best outcome, and the IMF's Scientific Advisory Board assesses which projects put our donation dollars to work optimally. Susie further announced that the Bank on a Cure® project has widened its reach into Europe.

The first general session, "Myeloma 101; What to Do When You are First Diagnosed," was presented by



Dr. Robert Kyle. He discussed the incidence of myeloma, typical symptoms at diagnosis, how diagnosis is made, and how to differentiate between active and smoldering disease. While asymptomatic myeloma needs to be recognized, it doesn't have to be treated, and can remain stable for up to 20 years. Dr. Kyle went on to talk about the indications for treatment, as well as possible complications resulting from the disease and its treatments. An open opportunity for questions from the audience yielded many inquiries about bisphosphonates, side effects, and vaccinations against flu and pneumonia.

“Current Options for Frontline Therapy” were discussed in Dr. Brian Durie's presentation.

He talked about the variables that go into making treatment choices, outlined his approach to treatment, and told us that most people's myeloma can be controlled within 2-3 months (>90%) after treatment has begun. He added that length of remission is highly variable but long-term survival is possible, with one study showing that 30% of patients <50 years of age are living beyond 10 years! He then talked about response rates of each frontline option he identified. Many treatment options work well and, with the aim of sustaining remissions as long as possible, he recommended that we consider the use of treatments sequentially, keeping our options open and avoiding unnecessary toxicity. Dr. Durie's final recommendation was to care for ourselves. Relaxing, reducing stress, and helping others are all good healing strategies!

After the morning coffee break, Dr. Greg Mundy spoke about “Achieving Best Bone Health and Quality of Life.” We learned that about 90% of MM patients have bone lesions as first sign of the disease. We saw pictures of lesions in the skull, spine, and long bones. It is critical to identify where the lesions are so that you can modify your activity accordingly. Treatment options include chemo, radiation, and bisphosphonates, which limit bone breakdown, provide pain relief, and reduce hypercalcemia. Diet and avoidance of fractures are also important. The use of bisphosphonates dates back about 100 years but had a rebirth in the 1950s as a mechanism to

de-sludge plumbing pipes. Then Crest toothpaste took hold of bisphosphonates as plaque removers. It was by accident that bisphosphonates were discovered to inhibit bone breakdown, but now this is a \$2 billion business! Adverse effects may include transient flu-like symptoms, impaired renal function, and osteonecrosis of the jaw (ONJ)). Dr. Mundy stated that there are effective new bone health products in the works that will possibly be available by 2009.



IMFer poses a question to the faculty

The IMF Patient Panel, “Personal Insights in Dealing with Myeloma,” featured Marilyn Alexander, Michael Tuohy, and Laura Williams. Paul Hewitt from the IMF moderated. All three panelists are currently Revlimid users, and they openly shared their diverse experiences. They have different types of myeloma, and are tracking their disease differently. Marilyn Alexander told us of her 13-year journey with myeloma, including a transplant from her twin sister. Michael Tuohy reported his participation in the EAP trial. Laura Williams spoke of her neuropathy

and the adjustments she is making as a result. Thanks to Marilyn, Mike, and Laura, we got an interesting insight into the real experiences of people with one of our newest treatment options.

Next, Dr. Durie updated us on the IMF's Bank On A Cure[®] program. A custom chip has enabled us to look at genetic features of the key 3400 genes that are relevant to myeloma. Analysis of these genes will tell us, among other things, how we might respond to treatment. Tissue samples are still being gathered from individuals as well as “wholesale” channels such as ECOG trials. Over the past year, we have established the process in both the US and UK, with more agreements being struck with investigators from various institutions. Collaboration is the name of the game!

After a lunch break, Dr. Edward Stadtmauer discussed “Transplantation in Myeloma.” Dr. Stadtmauer believes that high-dose induction therapy followed by a stem cell transplant improves survival over standard therapies. He reviewed the autologous transplant procedure

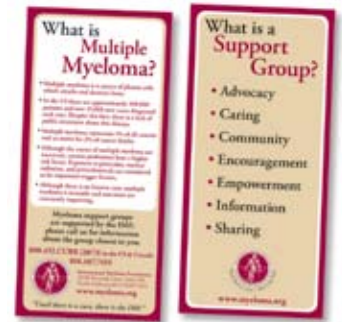
PLEASE SEE PHILLY P&F ON PAGE 14

MYELOMA AWARENESS WEEK 2006

October 22–28, 2006



The focus of this year's campaign is to increase awareness about myeloma support groups and the benefits they offer to patients. Posters that can be posted in clinics and hospitals where myeloma patients are treated as well as informational “tip-cards” that explain the many benefits of a local myeloma support group have been distributed to leaders across the United States and Canada to assist in this effort.



If you would like to receive these materials to distribute, please call the IMF at 1-800-452-CURE (2873) or e-mail us at TheIMF@myeloma.org. Remember, Knowledge is Power!

It is the hope of the IMF that these posters and cards will be used to bring new members to support groups (including the newly-diagnosed, who often need special care) as well as return those who may have stopped attending meetings. The IMF often receives calls and e-mails from patients who did not know that a local group was available to help them. **MT**

PHILLY P&F — continued

from mobilization and collection of stem cells, freezing of the collected cells, administration of chemotherapy, thawing out and re-infusing the cells. This is usually a 3-day process but Dr. Stadtmauer has frozen and used cells 12 years after collection! Dr. Stadtmauer explained the response rate achieved with transplants. Success has been reported with people into their mid-70s but MPT chemotherapy may be a better option for patients who are older than that. Dr. Stadtmauer's rule of thumb is to collect lots of stem cells early, before the myeloma cells can become resistant.

The “Novel Therapies in Myeloma” presentation was made by Dr. Sundar Jagannath. He introduced his talk by emphatically saying that each one of the new drugs we have been hearing about all day has made a dramatic impact on the lives of myeloma patients, both in terms of quality and longevity. He declared that he was going to prove it to us and that he did! He gave us some background on how clinical trials are set up, and discussed improved survival as a result of recent advances. He described a study where VELCADE® was compared to high-dose dexamethsone in 93 centers throughout Europe and the US. The result showed 43% responded to VELCADE and the control of the cancer was bet-

ter over a longer period of time. He also described a study that demonstrated that Revlimid® plus dexamethsone was more effective than dexamethsone alone. Dr. Jagannath reported on a variety of studies using novel agents paired with dexamethsone, all showing dramatic increases in the percentages of patients who responded. Even conventional therapies like melphalan and prednisone are now being paired with novel agents and the results show advantages; using novel agents in induction therapies prior to transplant is providing better results. Dr. Jagannath shared information about the development of new drugs and drug regimens that are currently in Phase I studies. This was a presentation that generated a lot of optimism.

Dr. Jagannath's presentation concluded the general sessions and, after a short break, attendees proceeded to the breakout sessions where each faculty member facilitated small group discussions. In addition, Susie Novis facilitated a “Caregivers Need Care Too!” gathering. All of the breakout sessions offered the participants yet another opportunity to listen and learn. In the end, the Philadelphia seminar left me with renewed hope and connection with our wonderful myeloma community! **MT**

IMF'S FISCAL YEAR 2007 FUNDING PRIORITIES AND CALL TO ACTION

By Christine Murphy

Earlier this year, the IMF retained Gardner Carton & Douglas (GCD) to represent the myeloma community in cancer community coalitions, Capitol Hill, and federal regulatory agencies. The IMF will work closely with GCD to continue its dialogue with members of Congress, policy makers, and the cancer community to improve the quality of life of myeloma patients while working toward prevention and a cure.

Status of IMF FY 2007 Funding Priorities

Significant gains in the War Against Cancer have been made through our nation's investment in research and application. Research holds the key to improved cancer prevention, early detection, diagnosis, and treatment, but such breakthroughs are meaningless unless we can deliver them to all Americans in need. The IMF, along with our partners in

"Significant gains in the War Against Cancer have been made through our nation's investment in research and application. Research holds the key to improved cancer prevention, early detection, diagnosis, and treatment, but such breakthroughs are meaningless unless we can deliver them to all Americans in need."

the cancer community, including the One Voice Against Cancer (OVAC) coalition, the National Coalition for Cancer Research (NCCR), the Cancer Leadership Council (CLC) and C-Change will call upon Congress to provide increased funding for cancer-related efforts at the National Institutes of Health (NIH), the National Cancer Institute (NCI), and the cancer programs of the Centers for Disease Control and Prevention (CDC) in Fiscal Year (FY) 2007.



Christine K. Murphy, MA
Government Relations Director
Gardner Carton & Douglas LLP
Washington, DC

In FY 2007, IMF urges Congress to provide:

- \$29.7 billion for the NIH;
- \$5.034 billion to the NCI; and,
- \$5 million for the Geraldine Ferraro Blood Cancer Program at the CDC.

Each year the budget and appropriations process is kicked off by the release of the President's budget. The President's fiscal year (FY) 2007 budget was released on February 6, 2006 and included decreases for the NIH, NCI, and the CDC Blood Cancer Program. On June 7, the House Labor, Health and Human Services, and Education (LHHS) Appropriations Subcommittee allocated \$28.258 billion for the NIH (a decrease of \$306 million below FY 2006), \$4.754 bil-

lion for the NCI (a decrease of \$39.7 million), and \$4.539 million (a decrease of \$2,000 below FY 2006) to the CDC Blood Cancer Program. All of the House LHHS allocations for the NIH and CDC in FY 2007 are identical to the FY 2007 funding requests contained in the President's budget proposal.

When the Senate LHHS Appropriations Subcommittee passed its funding bill on July 18, it included small increases for NIH and NCI while maintaining last year's funding level for the CDC Blood Cancer Program. Specifically, NIH received \$28.5 billion (an increase of \$241 million over FY 2006), NCI received \$4.8 billion (an increase of \$9 million), and the Blood Cancer Program received \$5.41 million.

Despite the fact that FY 2007 begins on October 1, currently Congress is only approximately halfway through the appropriations process. While both the House and Senate Appropriations Committees have finished their

PLEASE SEE 2007 FUNDING PRIORITIES ON PAGE 16

2007 FUNDING PRIORITIES — continued

work on their respective LHHS appropriations bills, neither the full House nor the full Senate has considered its version of the LHHS measure. This is due to a truncated timeline in the run-up to the November elections and a number of other political factors. It is anticipated that the House and Senate will complete this process sometime after the November elections.

While the small funding increase for the NIH and NCI in the Senate proposal is not very good news, realistically, these funding levels are the highest possible levels that the myeloma community can expect for these programs in FY 2007. Because the House has followed the President's lower recommendations, the funding for the NIH and NCI will likely be lower as these issues finalize after the elections. It is unclear whether the Blood Cancer Program at the CDC will get the same amount of funds as last year or will receive a small decrease.

Due in large part to the NIH doubling effort a few years ago, the nation is on the cusp of making fundamental progress in many areas including cancer. Unfortunately, the proposed congressional funding levels for NIH, NCI, and CDC are a direct retreat from medical research progress. This comes at a time when the nation needs to continue marching forward in our progress against cancer.

Since the process is not yet complete, Congress must hear from the entire cancer community that the funding levels at NIH, NCI, and CDC proposed in the House and Senate are detrimental to improving the quality of life of patients with myeloma and every other type of cancer. Congressional and administration neglect of these priorities is slowing progress on the important work being done to prevent and cure myeloma and all cancers.

“Due in large part to the NIH doubling effort a few years ago, the nation is on the cusp of making fundamental progress in many areas including cancer. Unfortunately, the proposed congressional funding levels for NIH, NCI, and CDC are a direct retreat from medical research progress. This comes at a time when the nation needs to continue marching forward in our progress against cancer.”

IMF Call to Action

IMF and GCD will continue to monitor the FY 2007 appropriations process and regularly update the myeloma community as the appropriations process unfolds. Although Congress is delaying final funding decisions for priority IMF programs, their inaction allows myeloma advocates time to express their concerns.

Advocates should contact their members of Congress between now and Thanksgiving to work to have an impact on the final FY 2007 funding figures. Members of Congress and their staff must continue to hear from myeloma and other cancer advocates about the

importance of these programs to ensure that the nation continues to provide quality cancer care that myeloma patients need and deserve.

Regular communication with elected officials and their staff is necessary to ensure a constant drumbeat of support and remind them that there are thousands of individuals, families, and health care providers across the country who are counting on them to make a difference in the lives of myeloma patients.

To voice your concerns over the funding levels proposed for myeloma – and all cancer – research and education programs and to send a note to your elected officials on these important programs, please visit www.house.gov or www.senate.gov to find out how to contact your House and Senate Members. Take action today – it does make a difference! **MT**

Editor's Note: Christine Murphy, Government Relations Director at GCD, has nine years of experience working in the cancer community with the American Cancer Society, as well as a consultant with the Oncology Nursing Society and the Ovarian Cancer National Alliance.

LAST CHANCE TO JOIN US FOR THE IMF'S 16th ANNIVERSARY GALA!

Please join the IMF on Saturday, October 21st, as we celebrate our 16th anniversary, honor the Bank On A Cure[®] research program team, and raise much-needed funds to support the Foundation's life-saving programs and services. It is the IMF's goal to sponsor the best research, provide the highest quality education, offer the most thoughtful and comprehensive support, and serve as fervent advocates for the myeloma community.

This year's event will be held at the Regent Beverly Wilshire Hotel in Beverly Hills. The evening will feature live and silent auctions, and an elegant dinner with dancing. Please join us as we celebrate the advances that have been made in the fight against myeloma, and as we band together to continue moving forward. For further information, please contact Candace McDonald at 800-452-CURE(2873) or cmcdonald@myeloma.org. **MT**

WIN A TRIP FOR TWO TO SPAIN!

You could support the IMF's myeloma research and win a trip to Barcelona, Spain.



Fly American Airlines and stay at the Hotel Arts Ritz-Carlton in Barcelona for 7 days and 6 nights, including daily breakfast for two. The Hotel Arts Barcelona is a striking contemporary hotel with a graceful silhouette, located on the shores of the Mediterranean overlooking Port Olimpic. It offers guests spectacular views over Barcelona and the sea.

Make the most of its spectacular beachfront location near the city's finest shops and restaurants, and world famous Gaudi architecture. Spend time in the terraced gardens and the outdoor swimming pool. Enjoy restaurants and bars with outdoor terraces. Relax and unwind at The Spa by Six Senses, located on the hotel's 43rd floor, with a pampering body or facial treatment.

Only 350 tickets remaining! All proceeds benefit the IMF's Bank On A Cure[®] research program.

Drawing will take place at the IMF's 16th Anniversary Gala on Saturday, October 21, 2006. Winner need not be present.

Some restrictions apply. To purchase your Gala Opportunity Drawing Tickets or for more information, please contact Candace McDonald at 818-487-7455 or cmcdonald@myeloma.org. Tickets are \$50 each and can also be purchased online at www.myeloma.org or via a faxable form that can be downloaded from the IMF website.

International Myeloma Foundation **16th Anniversary Gala**

October 21, 2006

Regent Beverly Wilshire
Beverly Hills, CA

Honoring the **Bank On A Cure[®] Team**

Dr. Herve Avet-Loiseau

Laboratory of Hematology,
University Hospital, Nantes, France

Dr. Dalsu Baris

Staff Scientist, Division of Cancer Epidemiology,
National Cancer Institute (NCI), USA

Cancer Research And Biostatistics (CRAB), USA

Dr. Hartmut Goldschmidt

Autologous Bone Marrow Transplantation Program,
University of Heidelberg, Germany

Dr. Gareth Morgan

Professor of Haematology, The Royal Marsden Hospital, UK

Dr. Jesus San Miguel

Head, Department of Hematology,
Hospital Universitario de Salamanca, Spain

Dr. John Shaughnessy

Associate Professor of Medicine,
University of Arkansas for Medical Sciences
Director, Lambert Laboratory of Myeloma Genetics, USA

Dr. Pieter Sonneveld

Senior Staff Hematologist,
University Hospital Rotterdam/Dijkzigt
Professor of Hematology, Erasmus University, Rotterdam
The Netherlands

Dr. Brian Van Ness

Professor & Department Head,
Genetics, Cell Biology and Development
University of Minnesota, USA

THE VISIONARY AWARD

This honor is given to an individual whose personal mission mirrors that of the IMF to improve the quality of life of myeloma patients while working toward prevention and a cure.

Jerome B. Zeldis, MD, PhD

Chief Medical Officer
Celgene Corporation

EUROPEANS ATTEND IMF SUPPORT GROUP LEADERS RETREAT

By Lia van Ginneken-Noordman

Contactgroep Kahler en Waldenström Patiënten (CKP), The Netherlands

SEI had the honour and pleasure to be invited to the 2006 IMF Support Group Leaders' Retreat in Scottsdale, Arizona. I was joined by European patient advocates Ilse Hein from Austria and Rolf Pelzing from Germany. All three of us are board members of the newly established European Myeloma Platform (EMP), a patient-for-patient advocacy network that represents the myeloma community before European governmental and regulatory agencies. Most of the other participants of the retreat were from the United States and Canada.



The workshop program was extensive. Excellent presenters and in-depth panel discussions made it a very educational retreat. Topics ranged from medical issues to sessions for caregivers, and included medical updates, support group organizational issues, psycho-social support for group leaders and patients, group facilitation techniques, public relations, clinical trials, and updates on the IMF's Bank On A Cure® research initiative. Our European contingent enjoyed many opportunities to learn from invited speakers, to meet one another, and to discuss the many issues that are encountered by support group leaders. The atmosphere was open, friendly, and easy-going, which made networking very easy.

It was very interesting for me to compare and contrast the differences between the American and Canadian groups, with my group in the Netherlands. In the Netherlands, the myeloma support groups are organized on a national level by our national myeloma organization, Contactgroep Kahler en Waldenström Patiënten (CKP, Multiple Myeloma & Waldenström's Macroglobulinemia Patient Association). We have 17 myeloma support groups dispersed throughout our entire nation. All support group leaders in the Netherlands – 26 persons at the moment – are members of CKP. In principle, only members of CKP are invited to attend the support group

meetings. Financial support, educational materials, public relations, etc. are provided by CKP on a national level. The regional CKP groups organize the regional meetings.

All CPK support group leaders receive compulsory training. These training sessions are organized by our national cancer patient association, an umbrella organization of all cancer patient organizations in the Netherlands. Support group leaders representing all of the different cancer

communities are trained on issues related to the leadership of a support group.

In addition to this, on a national level, CKP organizes a semi-annual myeloma support group leaders' day. During this day, the most relevant issues are discussed between the board of CKP and the group leaders. A short training session is included as well.

During CKP's Annual General Meeting, extensive medical updates on myeloma are presented for all members and the leaders. We also update our members via a newsletter and other publications, as well as occasional workshops and symposia.

Striking features in North American Support Groups

In my opinion, the most remarkable differences I noted between the North American myeloma support groups as compared to the Netherlands were:

1. The initiative of starting up and conducting a myeloma support group is taken on by the patient advocates themselves. They can make the most of all the support that the IMF has to offer, but the responsibility for organization, finding facilities, public relations, and financial support belongs to the groups.
2. Since the IMF does not have formal membership rules

PLEASE SEE EUROPEANS ATTEND RETREAT ON PAGE 20

UPDATE FROM THE ISRAELI ASSOCIATION OF MYELOMA PATIENTS (AMEN)

By Paula Azulai

On May 25, AMEN celebrated its first anniversary of serving the Israeli myeloma community! Our celebration took place in Shefayim, a wonderful place near the sea. More than 300 people were in attendance, with many people traveling from across the country to join us. Arriving guests were greeted with birthday balloons, plus each received a small present to commemorate the occasion.

Next, the guests were welcomed into two reception halls where they mingled until it was time to proceed to the auditorium. After I welcomed the guests, I introduced Dr. Antonio Palumbo, who traveled to our celebration from Torino, Italy. Dr. Palumbo's introduction was followed by several esteemed guests taking the podium: Mati Raviv (National Affairs, AMEN), Prof. Gil Lugassy (Head, Israeli Society of Hematology), and Prof. Dina Ben-Yehuda (Chair, Israeli Myeloma Study Group). Finally, attendees put on their earphones to follow Dr. Palumbo's lecture, "New Treatment Strategies in Multiple Myeloma," with the aid of simultaneous translation.

After a brief intermission featuring drinks and dessert, the famous humorist, Mr. Yoram Tehar Lev, entertained



Antonio Palumbo, MD, PhD, with AMEN's Medical Advisor, Prof. Polliack

guests. The audience even joined in some group singing! The atmosphere of the entire event was quite extraordinary and the last guests lingered long past the scheduled end of the celebration. AMEN's medical advisor, Prof. A. Polliack, acted as the master of ceremonies throughout the evening, and I would like to thank him for doing such a wonderful job

The next day, AMEN hosted a meeting of the Israeli Myeloma Study Group (IMSG). The session was headed by IMSG's Chair, Prof. Dina Ben-Yehuda. Once again, our special guest was Dr. Palumbo. About 20 physicians participated, including myeloma specialists from all of Israel's major medical institutions. Many members of AMEN were in attendance as well.

On June 7, AMEN organized a multiple myeloma seminar for hematology residents. The event took place in Herzeliya and was sponsored by Janssen-Cilag. The aim of this seminar was to spread myeloma awareness and to update future hematology professionals on the wide range of available myeloma treatments.

The seminar opened with a presentation by Dr. Ben Zion Katz, who heads the Israeli Myeloma Basic Science Group. His presentation on microenvironmental interactions in multiple myeloma was very informative. Next, Prof. Dina Ben-Yehuda discussed molecular and cytogenetic changes in multiple myeloma. Following these presentations was a Q&A session with the expert panel. Mr. Yigal Chetritt and Mrs. Malka Arbel of AMEN's support group led the discussion. Next, Dr. Izhar Hardan presented a talk on myeloma treatment strategies. Following a lunch break, Dr. Hila Magen discussed "total therapy I, II, III." Then, Dr. Avihai Shimony educated the participants about the risks and



left-right: Mati Raviv, Zipy Farber (Finance, AMEN), Prof. Gil Lugassy, Paula Azulai (Chair, AMEN), and Yigal Chetritt

PLEASE SEE UPDATE FROM ISRAEL ON PAGE 20

ONTARIO COVERS MYELOMA DRUG

VELCADE® is one of four expensive cancer drugs that have finally been approved for coverage by the Ontario province in Canada. Myeloma patients in Ontario have been lobbying their politicians for over two years for this successful outcome. VELCADE, a last-resort drug for many myeloma patients, was a covered medical expense in other Canadian provinces, but not in Ontario. That left some Ontario patients burdened with bills of up to \$60,000 until the decision was reversed at the urging of Ontario's Drug Quality and Therapeutics Committee after the drug manufacturer provided new information. **MT**

IMF LATIN AMERICA HOSTS FIVE PATIENT & FAMILY SEMINARS IN 2006

Congratulations to Christine J. T. Battistini, President of IMF Latin America for organizing five Patient & Family Seminars in 2006:

- Santos, Brazil — May 6
- Rio de Janeiro, Brazil — June 24
- São Paulo, Brazil — July 31
- Caracas, Venezuela — September 30
- Mexico City, México — October 7

Prior to each meeting, IMF LA visits local hospitals to interact with patients and physicians, and distribute educational materials. To contact IMF LA or to access myeloma information in Spanish, please visit www.myelomaLA.org. To access the Portuguese-language website, please go to www.myeloma.org.br. **MT**

UPDATE FROM ISRAEL — continued

potential benefits of allogeneic transplantation for myeloma. All in all, it was a very educational seminar, covering many important topics.

AMEN's mission is to benefit the welfare of myeloma patients in Israel, and our growing membership is working hard to stay true to our commitment to improve the quality of life of patients in Israel. So, if you live in Israel, or are looking for information and support in Hebrew, please contact me at appaul@attglobal.net or 0544-906635. AMEN is here to help you! **MT**



AMEN welcomes guests to its celebration

EUROPEANS ATTEND RETREAT — continued

or guidelines, the North American myeloma support group meetings are open to everyone: patients, caregivers, family members, and other interested persons.

3. Apart from receiving a lot of information thanks to the IMF during the retreat, the support group leaders were an important source of information for the IMF as well.

The most striking example I found was the session about clinical trials. In this session, a number of ongoing clinical trials were presented and explained by Michael Katz, an IMF Board member. Mr. Katz was supported by three principle investigators who presented additional information about clinical trials to the gathering via a telephone conference. These myeloma researchers even asked retreat participants for information that would help them design better trials, as well as to better explain

the trials to the enrolled participants. What an excellent way to engage patients in the clinical trial process! The following questions are an example of the exchange that occurred:

- Does this clinical trial ask or answer a question that is important to you?
- Why would a patient wish to enrol in this trial?
- Why wouldn't they want to enroll?
- What would make this trial more attractive to prospective participants?

Altogether, this IMF retreat was an educational and enjoyable experience that helped strengthen the bonds between the myeloma communities in the United States, Canada, and Europe. **MT**

OSTEONECROSIS OF THE JAW AND ORAL CARE

A Conversation with Dr. Robert E. Marx

Myeloma Today: What is Osteonecrosis of the Jaw?

Dr. Robert Marx: Osteonecrosis of the jaw (ONJ), death of areas of bone in the jaw, is a serious but manageable complication that has been observed in a percentage of myeloma patients taking Aredia® or Zometa®. There may be no symptoms initially, or the patient may experience pain, swelling, numbness, a “heavy jaw” feeling, loosening of a tooth, breaking loose of small bone spicules, and/or sharp edges of exposed bone. The exposed bone itself is not painful and is not at great risk for a pathologic fracture, but the condition becomes painful when the exposed bone becomes secondarily infected and may even fistulate externally.

Myeloma Today: What is the connection between the use of bisphosphonates and ONJ?

Dr. Marx: The mechanism of ONJ is now certain. It is due to the toxic effects of bisphosphonates on osteoclasts, which induces their apoptosis and in turn results in bone necrosis by prevention of cellular renewal in the resorption-remodeling cycle of bone. It is important to remember that even after patients stop taking bisphosphonates, the drugs remain in bone for more than ten years.

Myeloma Today: How was this problem first recognized?

Dr. Marx: In September 2003, the Journal of Oral and Maxillofacial Surgery published a Medical Alert based on my Letter To The Editor about the growing epidemic of ONJ. I reported on 36 cancer patients, including 18 with myeloma, who had received intravenous bisphosphonates. All of these patients had painful bone exposure and were unresponsive to surgical or medical treatments. In 2004, Dr. Salvatore Ruggiero of Long Island Jewish Hospital published a report on 63 patients, 56 with cancer and 7 with osteoporosis. More studies have followed.



Robert E. Marx, DDS
Professor of Surgery and Chief
Division of Oral/Maxillofacial Surgery
Miller School of Medicine
University of Miami
Miami, FL

Myeloma Today: What advice would you offer to myeloma patients?

Dr. Marx: Myeloma patients value bisphosphonates for their efficacy in inhibiting bone resorption and thereby reducing secondary fractures, pain, and disability. There is every reason to hope that with appropriate awareness and early management, serious problems from ONJ can be avoided, although my 2005 study showed that complete prevention of this complication is not currently possible.

Myeloma Today: Is there anything that can be done?

Dr. Marx: Pre-therapy dental care reduces ONJ incidence and non-surgical dental procedures can prevent new cases, so oncologists should refer patients for dental evaluations prior to starting bisphosphonates. I recommend that individuals maintain excellent mouth hygiene, reduce the risk of infections or injuries, and treat any infections promptly. It is recommended that the dental team provide a cleaning, caries and periodontal disease prevention counseling, fluoride treatments, caries controls, as well as definitive root-canal treatments and tooth removals of diseased teeth so as to prevent abscesses and the need for tooth removals once patients have begun therapy. This parallels the standard of care for patients prior to radiotherapy to the jaws, which has been very effective.

Myeloma Today: What can be done upon onset of ONJ?

Dr. Marx: Patients who are experiencing problems, such as an infection or pain that indicates the need for an extraction, should be referred to an oral/maxillofacial surgeon who can make the difficult clinical decisions and weigh the options appropriately. For those who present

PLEASE SEE ONJ ON PAGE 22

ONJ — continued

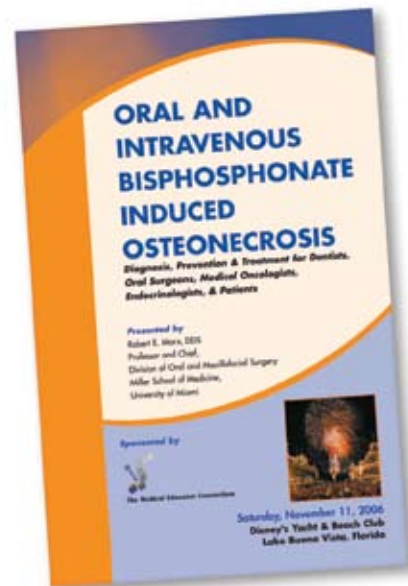
with painful exposed bone, effective control to a pain-free state but without resolution of the exposed bone is 90.1% effective using a regimen of antibiotics along with 0.12% chlorohexidine antiseptic mouthwash. The goals in treatment are to have the patient live with and function with the exposed bone and to prevent secondary infections. In cases of acute exacerbations and cellulitis, it may be necessary to institute intravenous antibiotic therapy, but we do not recommend surgery beyond reducing sharp bone edges unless the exposed bone remains painful and is refractory to antibiotic care.

Myeloma Today: So what is the current state of ONJ? Any specific prevention guidelines and patient management recommendations?

Dr. Marx: We are finally achieving recognition for ONJ, and communication between doctors who diagnose and treat ONJ and medical oncologists who prescribe bisphosphonates is improving. The treatment protocols that we outlined in the November 2005 issue of the *Journal of Oral and Maxillofacial Surgery* (Volume 63: pages 1567–1575) are being followed. Doctors at Mayo Clinic recently successfully performed two major resections, but that is something that I would not like to see become common treatment – if at all possible, I'd like to save the jaw and not cut it out. Unfortunately, with ONJ there is nothing in between avoiding surgery altogether and doing major surgery. In my clinical experience, we have partially removed the jaws of six patients. The procedure has served them well, but it is not ideal and

not without its own risks; it's better not to put patients through that if it can be avoided. In my opinion, the most useful organization's position paper on ONJ has been issued by the American Association of Oral and Maxillofacial Surgeons (AAOMS) because it is the specialty that ends up treating the patients with ONJ. **MT**

Editor's Note: To read the Mayo Clinic Consensus Statement for the Use of Bisphosphonates in Multiple Myeloma, please visit the IMF website at www.myeloma.org. The AAOMS position paper is anticipated to be presented at the Association's annual meeting in October.



For more information on Dr. Marx's presentation, please contact:
Meetings Events & Conference Coordinators, Inc
(MECC)

(305) 663-1628

www.meccinc.com

Mayo Clinic Consensus Statement for the Use of Bisphosphonates in Multiple Myeloma

Bisphosphonates are effective in the prevention and treatment of bone disease in multiple myeloma (MM). Osteonecrosis of the jaw (ONJ) is increasingly recognized as a serious complication of long-term bisphosphonate therapy. Issues such as the choice of bisphosphonate and duration of therapy have become the subject of intense debate given patient safety concerns. We reviewed available data concerning the use of bisphosphonates in MM. Guidelines for the use of bisphosphonates in MM were developed by a multidisciplinary panel consisting of hematologists, dental specialists, and nurses specializing in the treatment of MM. We conclude that intravenous pamidronate and intravenous

zoledronic acid are equally effective and superior to placebo in reducing skeletal complications. Pamidronate is favored over zoledronic acid until more data are available on the risk of complications. We recommend discontinuing bisphosphonates after 2 years of therapy for patients who achieve complete response and/or plateau phase. For patients whose disease is active, who have not achieved a response, or who have threatening bone disease beyond 2 years, therapy can be decreased to every 3 months. These guidelines were developed in the interest of patient safety and will be reexamined as new data emerge regarding risks and benefits.

Mayo Clin Proc. 2006;81(8):1047-1053

IMF HOTLINE COORDINATORS ANSWER YOUR QUESTIONS

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

Question:

Do you have any tips for drug access and reimbursement, especially for Revlimid®?

Answer:

With the advent of approval for the indication of patients with multiple myeloma who have received one prior therapy, the IMF Hotline has received many calls regarding the availability of, and reimbursement for, Revlimid. This year's changes in Medicare prescription drug coverage coupled with the FDA approval have highlighted patients' financial concerns in recent months. The Medicare Part D benefit provides greater access to medications for Medicare patients. Since this is the first year for this new Medicare Part D benefit, it is important to understand that improving access to medication is a process that is evolving and not all managed care organizations, co-pay assistance foundations, and/or patient assistance programs are the same. While some patients may have insurance plans that completely cover drug costs, others are either without insurance or find themselves in a coverage gap that they may not be able to afford, with access to life-saving drugs threatened or denied altogether.

Uninsured Patients

Patients who have no insurance coverage may be eligible for Medicaid. To check for eligibility requirements for Medicaid, consult the social worker at the hospital or clinic where you are being treated, or check the Medicaid website at www.cms.hhs.gov/MedicaidEligibility/downloads/MedGlance05.pdf. Medicaid pays Medicare premiums for eligible uninsured patients who are over 65 years of age.

Patients who are not covered by Medicare or Medicaid and have no insurance and few financial resources may be eligible for therapy assistance programs established by the drug manufacturers. If you are uninsured altogether, or have no prescription drug coverage, and wish to



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

contact a therapy assistance program to cover a medication your doctor has prescribed, please call the IMF Hotline at 800-452-CURE (2873) for further information. We will explain the application process and give you contact information for the program you need. For those patients who were enrolled in the EAP

(MM-016) Trial, the Celgene Patient Support Solutions (see below) will assist them with the transition from the EAP to commercial drug.

Medicare Patients

The complexities of the current changes in Medicare coverage have been daunting to many patients. If you are a Medicare patient receiving intravenous (IV) drug therapy at the doctor's office, at a hospital, or at a clinic, then you should be covered by Medicare Part B. Patients who have Medicare Part B coverage pay an average annual premium of \$600. After your deductible, Part B provides 80% coverage of "usual and customary" charges for in office and hospital care including IV drug therapy. Some patients have secondary insurance policy that picks up the 20% that Medicare Part B does not cover, but if you do not have a secondary insurance policy then you are financially responsible for that 20% and will likely be billed.

If you are receiving an oral therapy (such as Thalomid® or Revlimid) and have prescription drug coverage through a Medicare Part D insurer, the details of your coverage will vary according to the plan. Each Medicare Part D insurer has its own co-pay structure and its own formulary (list of drugs they pay for) and not every Part D insurer covers every drug. You must check with your Medicare Part D insurer to make sure that the drugs you need are on their formulary.* If you have already signed up for

PLEASE SEE HOTLINE ON NEXT PAGE

a Part D plan that does not cover the drugs you need, you may be able to enlist your doctor's help in appealing to have the drug covered. Additionally there is a once a year opportunity, between November 15 and December 31, to elect a new Medicare Part D insurer for the following calendar year. For more information, call 800-MEDICARE (be prepared to hold for assistance) or visit internet resources such as www.medicare.gov and www.medicare.gov/medicarerereform/drugbenefit.asp.

If the drug is covered by your Medicare Part D insurer, the amount of money you pay may vary, depending upon the policy you have selected and the pharmacy from which you or your insurer purchase the drug. Medicare Part D patients are by now familiar with the terms “deductible” (the amount of money some policies require that you pay up front before insurance coverage begins) and “doughnut hole” (the amount of money a patient must pay out of pocket before Medicare begins to pay 95% of their combined drug costs).

There are numerous Medicare Part D plans, and they are all different in their co-pay structures and formulary of approved drugs. For patients who are in a standard Part-D plan (benefits level 1) without co-insurance Medicare Part D plans require that you pay the first \$250 in drug costs (your deductible) and then 25% of all your combined drug ‘costs’ up to \$2250 out of pocket. Under this scenario, once your total drug cost reaches \$2250, you would need to pay 100% of costs between \$2250 and \$5100. This gap between \$2250 and \$5100 has come to be known as the “doughnut hole.” After your total drug costs reach \$5100 then Medicare Part D would pay for 95% of your drug costs for the remainder of that calendar year. Thus, under this scenario, patients would pay:

- \$250 deductible
- + • 25% of the next \$2250 (= \$562.50)
- + • 100% cost (“doughnut hole”) between \$2250 and \$5100 (= \$2850)
- + • 5% drug costs for remainder of the calendar year

Total out of pocket cost would be \$3662.50 plus the 5% of all formulary approved drug costs for the remainder of the calendar year.

Keep in mind that this is only a guideline of how many plans work. Since plans vary, you must check with the Medicare Part D insurers for conditions under the specific plan in which you are enrolled.

Underinsured Patients

For many insured patients, whether under Medicare coverage or non-Medicare private insurance, the amount of money they must pay out of pocket for their prescription drugs may be beyond their available means. If patients are unable to pay for Thalomid or Revlimid, both made by Celgene, they can contact Patient Support Solutions at 888-423-5436. Specialists there will help evaluate your benefits and identify other support to see if they can help you with any out of pocket costs.

As of today, there are 3 foundations that offer co-pay assistance for myeloma patients. They are The Chronic Disease Fund, Patient Access Network Foundation, and the Healthwell Foundation. The Chronic Disease Fund is the only foundation for qualified underinsured patients which is currently offering co-pay assistance for myeloma therapy. To check if you qualify for help and to file an application, call 877-968-7233 or visit www.cdfund.org.

Two funds that were originally set up to cover the myeloma underinsured, the HealthWell Foundation and the Patient Access Network Foundation, have depleted their funding for myeloma patients and cannot help them at this time. Neither foundation is sure when or if they will be able to do so in the future.

Conclusion

Remember to use all your resources when making decisions on coverage. In addition to the resources discussed above, be sure to consult your physician and pharmacist. When deciding on a plan, have the list of all your drugs available and select a plan with a formulary that covers your greatest expenses.

Reimbursement for drug costs continues to be huge area of concern for patients and advocates alike. The IMF is in direct contact with all parties on an ongoing basis – including the pharmaceutical companies – to find solutions to the problem.

Many of the Medicare programs that do cover Revlimid are behind in updating their documentation. Just because Revlimid does not yet appear on their formulary does not mean it will not be covered. If it is not currently on the formulary of the insurance carrier that you use, please consult with your health-care provider on the prior authorization process.

MT

SPOTLIGHT ON PORTLAND, OREGON

By Sue Sumpter, RN

My background is in nursing administration and intensive care. Ten years ago, my mother and my 4-year-old son were both diagnosed with hematological cancers at the same time, my mother with non-Hodgkin's lymphoma and Andrew with leukemia. It was my crash course in blood cancers. As a result of those personal experiences, I made a decision to change my career path. That's how I came to be a Patient Services Manager at the Leukemia and Lymphoma Society (LLS). Because I now had an understanding of how a hematological malignancy can impact the entire family, helping patients and their loved ones became my passion.



The decision to form our myeloma support group came because I had been getting so many inquiries from local patients who had been diagnosed with myeloma. I know how important it is to be able to interact with people affected by the same cancer that has touched your life. It was clear that there was a real need for myeloma services and education here in Portland, as well as in neighboring areas of SW Washington State. In February of 2002, I disseminated a notice that a doctor would be giving a myeloma talk at LLS, and over 50 people showed up to hear it. The myeloma support group was founded out of that meeting.

I started the group with my colleague, Toni Lonning, MSW, LCSW, who is a cancer counselor and social worker at St Vincent's Medical Center in Portland. With our separate but complementary specialties, Toni and I are able to meet a wide range of psychosocial needs that our members might have. The group as a whole is very focused on myeloma education. Our members tend to be well informed and active in the myeloma community. We regularly organize presentations by invited speakers, from local pharmacists to world-renowned myeloma experts, on a broad scope of topics. Although our regular monthly meetings are held in the morning, we also organize occasional evening education programs. In addition

to the meetings, we maintain an email list and disseminate information and updates on a regular basis.

We have a program, First Connection, where group members who are trained by LLS interact with newly diagnosed patients and offer one-on-one support. I run the First Connection training program, along with a couple of my colleagues. Our support group is known by medical professionals in the area, so newly diagnosed myeloma patients are often referred to us. Toni and I are

here and available to talk with them. We supply them with a packet of educational materials, as well as a list of various myeloma resources. Our group also disseminates many of the IMF's helpful publications. The IMF is a wonderful organization, and a great asset to the myeloma community. The Foundation has been very helpful to me and to our patients.

Our group is a thriving community, with members who are committed to supporting one another. The active exchange of information and education is one very important aspect of our support group. We take the time to check in and to share with one another, as well as to assess the group's needs. I can honestly say that I am in awe of the people who are part of our group. They are the most dynamic and positive people I have ever met. They are living with myeloma. They are taking steps to increase their understanding of their disease. They are educating themselves about their treatment options, and are actively involved in trying to increase the length and quality of their lives. They are not taking their diagnosis lying down. They are working hard for a brighter future. **MT**

Editor's Note: The myeloma support group of the Oregon and SW Washington chapter of the Leukemia & Lymphoma Society meets on the second Wednesday of each month at St. Vincent's Medical Center in Portland. For more information, please contact Sue Sumpter, RN, at 503-245-9866 Ext 14 or sue.sumpter@lls.org; or Toni Lonning, MSW, at toni.lonning@providence.org

Support Groups

THE PHILADELPHIA STORY!

By Maddie C. Hunter

Like many other support groups, our group began with six people seeking and finding each other through the Wellness Community in Philadelphia. It was 1995. One of the myeloma patients was Marilyn Alexander. Along with her twin sister, Sharon Klein, and two other couples, Marilyn was a founder of the Philadelphia MM Networking Group. Through coaching from the IMF, Marilyn learned to reach out to local community organizations to locate a meeting space, but met with obstacles every way she turned because not one of the group's members was a trained facilitator. So, not being easily discouraged, the group decided to meet in the home of one of the founding members.

The group flourished immediately and, as a collective, we gradually established ourselves as a unique resource



for those touched by myeloma in the Philadelphia area. In the past decade, we have grown to over 300 members who participate in our mailing list, and our meetings are lively and well-attended. Through a strong and involved Steering Committee, we have created numerous roles to help share the leadership of the group. We have found a balance of circle discussions, support, and education in our programs. Our members enjoy speakers, so we have sponsored myriad talks and workshops covering medical issues and quality of life topics. The 2005/2006 program line-up of the Philadelphia MM Networking Group featured presentations on the proceedings from clinical and scientific meetings, the legal issues involved in having myeloma, pain management, the challenges of being a caregiver, the psychological and

CONTINUES ON NEXT PAGE

"I first heard the words MULTIPLE MYELOMA when I was diagnosed in 1993. I was too numb with fright to do anything. It was my twin sister, Sharon, who searched for all available information about myeloma. It was Sharon who found the IMF. They provided us with an InfoPack, a newsletter, a hotline, moral support and, most of all, HOPE. My sister and her husband, Art, attended the IMF's Patient & Family Seminar while I recuperated from a transplant (with my twin as my donor). When they returned, they were in a state of total euphoria, having been armed with so much information. They were so excited to be able to let me know that I was not alone.

The Philadelphia MM Networking Group was established in 1995, with the support of the IMF. Our membership is now 300+ strong, with Maddie Hunter, Lori Curtis, and myself co-leading the group. But if it had not been for the support of the wonderful IMF staff and the guidance of Susie Novis, we would not be here today providing support, guidance and hope to others.

Susie Novis has given us hope when we thought we had none, education when we didn't know what to do, and compassion when we really needed a helping hand. I would like to take this opportunity to recognize and honor this very special lady. She has devoted her life to helping people face the diagnosis of myeloma."

— Marilyn Alexander

The IMF Welcomes New Myeloma Support Groups

California

The IMF is pleased to announce that the first meeting of the new California multiple myeloma support group took place in Hanford (near Fresno) on September 2, 2006. For more information about this group and its upcoming meetings, please contact Walter & Erlinda Graves at waltergra@comcast.net or 559-589-0758.

Florida

The newly formed Space Coast Multiple Myeloma Support Group held its first meeting in August of 2006. The group will meet on the 2nd Thursday of each month, from 5:30pm to 6:30pm, in Conference Room 6 at Parrish Medical Center in Titusville. For more information, please contact Rosemary Herring at 321-271-4906 or spacecoastmm@cfl.rr.com.

Georgia

The newly formed Southside Multiple Myeloma Support Group meets on the 4th Saturday each month from 10:00am to 12:00pm at the Ben Hill Recreation Center in Southwest Atlanta. For more

information, please contact Doris Morgan at 404-346-1372 or dorismorgana@aol.com, or Montine Wilburn at 404-344-7758, or Ida Creal at 404-228-2288 or icreal@comcast.net.

New York

If you are interested in attending or helping with this Nassau County group, please contact Sheryl Goldberg at 516-379-5221 or SherylIMF@aol.com.

North Carolina

If you are interested in attending or helping with this Fayetteville group, please contact Stephanie Chavis, MFT, at The Blood & Cancer Clinic at 910-483-8586, extension 127.

Washington

The newly formed Spokane Multiple Myeloma Support Group is looking for members. The group meets on the 4th Monday of each month at 5:30pm at the Cancer Care Northwest in Spokane. For more information, please contact Daniel Jones at 509-324-2838 or dojones@comcast.net.

THE PHILADELPHIA STORY! — continued

emotional journey of living with myeloma, dental complications, and various maintenance therapies.

Throughout the 11 years of our group's history, Marilyn Alexander has been an important glue for the group. Her sustained efforts to organize activities, fund-raise, keep strong links with the IMF, and maintain an intimate relationship with our members have given the group a strong center-point. Always modest, Marilyn works without fanfare so she was quite stunned to be presented with the IMF's Francesca Thompson Distinguished Service Award during the August Patient & Family Seminar in Philadelphia. IMF's dynamic president, Susie Novis, took the podium while pictures of Marilyn were projected onto a large screen. Susie acknowledged Marilyn's dedication to the IMF and to the myeloma

community, making special mention of the successful cookbook projects Marilyn initiated to raise funds for myeloma research. Marilyn humbly thanked Susie and then smiled as she took her turn as a surprise maker. Always one to acknowledge the efforts of others, Marilyn reached for a plaque, which she then presented to Susie on behalf of the Philadelphia MM Networking Group. It was an honor for our group to recognize Susie's strong contribution to our community. Marilyn read a beautiful, heartfelt tribute to Susie and all in attendance replied with long applause. These two women standing on that stage together represent the sort of partnership that enables our myeloma community to be so strong. Thanks to Marilyn and Susie for your belief in the power of togetherness! **MT**

RUNNING WITH CANCER

By Paul Nicholls

I came to New York in September 1999 to work for Ogilvy & Mather, an international advertising agency. I was supposed to be here for only three years. Little did I know that within six months I would be married and New York would become my permanent home. “Time to shape up,” I told myself. I was overweight – I entertained far too much and didn’t exercise at all – so I decided to get fit. At 52 years old, I was taking control of my life.



Paul Nicholls and a young friend

In November 2000, after my first visit to the Mid City Gym in Manhattan, I got home from the workout and turned on the television. And there it was: the New York City Marathon! I decided to make running the 2001 marathon my goal, training for it over the next year.

Despite the September 11th attacks on the World Trade Center, the organizers decided to proceed with the Marathon and I joined countless others for what was to be one of the most exhilarating and uplifting experiences of my life. I finished in a little over 4 hours. Not bad for a fat kid from England who only a year earlier weighed in at 245 pounds. I knew when I crossed the finish line that the Marathon was to become a regular event in my life. I felt so much healthier and so much more achieved.

Immediately, I began training for the 2002 event, running 34 New York Runners Club races in the preparation and regularly finishing in the top 5% of my age group. On September 14, 2002, I ran the Race to Freedom, to commemorate 9/11. The next day, I was back at the gym training for the Marathon when a weight I was working with slipped. The pain was unbelievable and my first thought was that I had dislocated my shoulder. An ambulance rushed me to the emergency room.

X-rays showed a clean break on the left upper humerus, but that was not all they revealed. There was a large and suspicious mass at the site of the break. The doctors patched me up with a temporary cast and advised that I consult with my primary care physician. My doctor sent me for an MRI, then to an arm and shoulder specialist who then sent me to St. Luke’s-Roosevelt Hospital.

To help mend the break, a titanium rod was implanted from the

shoulder to the elbow. Then I had a needle biopsy, which failed, followed by an open biopsy two weeks later. The results showed that I had a malignancy, most likely a plasmacytoma. Now I was officially a member of the hematology/oncology club. That’s how I met Dr. Michael Grossbard, Chief of Hematology-Oncology at St. Luke’s-Roosevelt, who would have a great deal of influence over what was to come. He performed a series of tests and the results were conclusive. I had Stage III multiple myeloma. Being a practical person, I asked Dr. Grossbard about the worst-case scenario. He told me that although the worst-case scenario was a life expectancy of two years, there were treatment options available. We chose to proceed with VAD and high-dose chemotherapy, followed by tandem transplants. At that time, St. Luke’s-Roosevelt didn’t have harvesting or transplant facilities so I was referred to the Columbia University Medical Center.

I achieved a complete response after the first transplant, so we made the decision not to proceed with the tandem. As I was recovering, it became even more important for me to resume the daily rhythms of my life before cancer. I trained for and ran in the 2003 New York City

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Patient & Caregiver Experience

Marathon. This time, I ran for a cause. I started Team Continuum, a foundation to help people living with the disease. Being a former ad man, I felt that I could enlist the support of the biotech industry, as well as obtain personal sponsorships to help raise funds for the cancer patient care programs in my local hospitals. Together with 16 other patients, survivors, doctors, and nurses, we ran the Marathon and raised over \$250,000. The marathon and the foundation became indelibly linked. We ran again in 2004, but this time there were 67 of us and we raised \$500,000.

In March 2005, my myeloma relapsed. Extensive disease was discovered in my skull, ribs, thoracic spine, right femur, and tibia. I was back in the system, but my options were now different. New drugs and protocols had become available, promising clinical trials were ongoing, and my stem cells from 2002 were still in storage. Running the 2005 Marathon was my goal as I endured a summer of chemo and radiation, culminating with a second transplant on September 23, 2005. Forty-two days later, I ran the Marathon. It took me 8 hours and 21 minutes, but I did it. And, together with 101 other Team Continuum members, we raised almost \$1,000,000.

I joined the Revlimid® clinical trial and now feel the best I have felt since *before* my original diagnosis in 2002! I am looking forward to running the 2006

Marathon with 300 Team Continuum members, including five IMF athletes. Part of the funds we will raise will go to the IMF.

Of course, everyone's experience is unique, and I don't want to generalize, but for me running with cancer proves that my body is capable of resilience. I run because I love the feeling of being fit. Running energizes and enables me to achieve much more in my daily life. Running grounds, centers, and prepares me for the challenges I face, such as dealing with cancer. And, if I can run the Marathon, there's not much I can't do.

Most runners know about something that happens around Mile 20 of a marathon, called "Hitting the Wall." Your body tightens up and the pain in your legs begins to get unbearable. You start asking yourself why you ever signed up for this and swearing that you'll never do it again, that you want to stop. Those of us who have been through cancer treatment have had similar experiences – pain and discomfort that lead to emotional thoughts like, "Why did this happen to me? When will it be over? What if I just stop my treatment now?" But, through both we persevere.

Team Continuum is comprised of athletes, cancer patients and survivors, oncologists and other health professionals, and friends and family members who run the New York City Marathon. I founded Team Continuum

PLEASE SEE RUNNING ON PAGE 31



SHIFTING FOCUS: MY "NEW" LIFE WITH MULTIPLE MYELOMA

By Sharon Gondek

At 28 years old, I had developed a stubborn case of anemia. For over a year, I had been missing work by taking one sick-day after another. My doctors were puzzled. That is, until I broke my hip by simply slipping on the stairs. The fracture prompted my hematologist (and soon-to-be oncologist) to order a bone marrow biopsy. I was diagnosed with multiple myeloma in September of 2001.

I had no idea what was in store for my future. I was immediately thrown into radiation to reduce the tumor that had eaten a hole in my hipbone. Then I underwent three grueling rounds of chemo. Next came a stem cell transplant, which was one of the hardest things I had yet to go through. It was a lot to handle. Luckily, I had my husband Jason to assist and support me through this difficult time. My younger brother,



Jason & Sharon Gondek

Paul Purvis, also flew to California to help.

When I was finally able to come home from the hospital, I had to focus on my hip recovery. I received physical therapy at home and, eventually, was able to progress from wheelchair to crutches. After a year of slow but steady recovery, I was given the green light for a total hip replacement. The recovery from this surgery

required intensive physical therapy for another year. But I was finally walking with only a cane.

My life had changed. Before all of this, there was nothing particularly remarkable about my life. After graduating from college with a degree in Motion Picture/TV Production, I moved from Texas to California and, eventually, worked my way up to a respectable job as an assistant to a Vice President at Paramount Pictures. That's where I met my husband.

After several months on the job, I began missing work due to colds that I just couldn't shake. Assuming that my problems were stress related, I changed direction and took a less stressful position in the Music Clearance department

of Warner Bros.

But my energy level did not improve. Jason and I decided that it would be best for me to leave the hectic, pressure-filled entertainment industry. I found a position assisting veterinarians at the Cat Doctor. But I continued to feel unwell. Then I slipped on the stairs and broke my hip.



Morning Fog
Award of Excellence, National Photo Awards
Award of Excellence, Photographers Forum Magazine



Springtime in Gorman
Award of Excellence, National Photo Awards
Award of Excellence, Photographer's Forum Magazine
High Score Ribbon, Santa Clarita Valley Photographers Association

CONTINUES ON NEXT PAGE

SHIFTING FOCUS — continued

After two tumultuous years of battling myeloma, I needed a distraction from my “new” life. Sensing that I was searching for a new focus, Jason gave me my first single lens reflex camera. Ever since I was a little kid, I enjoyed using the little point and shoot cameras on family vacations. I was very excited to rediscover photography. I immersed myself in books and magazines. I studied the work of famous photographers, past and present. I found that I was particularly drawn to wildlife and landscape photography, and started taking pictures on our trips to Yosemite, Sequoia, Santa Barbara, Boston, Maine, and Texas.



Owens Valley
Award of Excellence, National Photo Awards

My husband encouraged me to enter some contests and I was soon getting surprising feedback, winning ribbons from the National Photo Awards and Photographers Forum. Because of the awards, I was featured in a large

article in our local newspaper, *The Signal*.

I started to frame my favorite photos and to give them as gifts. Then I sold a couple! Two of my photos were in a movie my husband worked on, which was a great opportunity. Another two are currently being displayed at our local chapter of the American Cancer Society.

After all I have been through, with all of life’s twists and turns, I find it interesting that myeloma was part of my path to this new creative opportunity. Through photography, I found a new way to celebrate life. I still deal with constant pain in my hip and the requisite oncology appointments. I still hope and wait for a cure for myeloma. But I look forward to each day and the new wonders and adventures that await me. **MT**

RUNNING — continued

because I wanted to demonstrate that cancer patients are capable of doing two of the toughest things asked of a person: fighting cancer and completing a marathon. Having cancer and running a marathon are both experiences that challenge and test your physical, mental, and emotional endurance. And both experiences can reveal strengths you may not have thought that you had. Some of our members have even run the New York City Marathon during the course of their cancer treatment.

While I have personally benefited from myeloma research and I support research into finding a cure whole-heartedly, Team Continuum is NOT about research. We are here to care for the immediate needs of people who are living with the disease today, and who are in treatment in New York City’s medical facilities. We raise money to provide immediate assistance, either through by grants to cover patient needs, or through funding and improving hospital patient care programs. Although we are a

local organization, more than 50% of the cancer patients being treated in New York are either from out of state or from overseas.

The successful management of myeloma as a chronic condition is now within our grasp, thanks to organizations like the IMF and the availability of novel agents to combat the disease.

Cancer doesn’t define us, and it need not diminish any of the aspects of our identity. We are many things, and some of us are athletes. And we are redefining the vocabulary of living with cancer. **MT**

Editor’s Note: Paul Nicholls is President and CEO of Team Continuum. On November 5, 2006, he will be on the start line of this year’s New York Marathon. To find out how Team Continuum can help you or to sponsor Paul Nicholls and help raise funds for the IMF and other cancer patient programs, please visit www.teamcontinuum.net.

HOW I CELEBRATED MY 8th BIRTHDAY

By Chandler Terry



Chandler Terry

Hello, my name is Chandler Terry.

One thing I try to remember is to not always RECEIVE, but to GIVE.

Last March, my grandparents came over to my house in Statesville, NC, and my Nana didn't feel good. We thought she just had a hurt back but

after she went back home to Arkansas, we found out she had multiple myeloma.

This made me feel very sorry, sad, and SCARED. I wanted to do something to help! So one day I got the idea that for my 8th birthday I could do something to make Nana feel better. I decided to raise money for the IMF (because they are looking for a cure to make Nana well) and for the Dove House Children's Advocacy Center here in my hometown (because helping abused children is important to her).



Gina & Chris Terry, Carol & Frank Allen, and Chandler and his little brother Cameron

I put a note in my party invitations and asked my friends to give a donation instead of a present. My goal was to raise \$100. My friends in my class gave money. And my friend Katie gave an additional \$1 of her own allowance, and that one dollar put me past my goal. I raised \$101!!!

I sent my donation in to IMF in honor of my Nana, Carol Allen, and her doctor, Dr. Neeraj Bharany. To be honest with you, it was a little weird not to have presents, but we had a really fun time at my party. Everybody got the IMF bracelet in a treat bag. Getting presents is not as important as having a Nana. It felt good to make her happy. **MT**



Chandler with his "Nana," Carol Allen

"We are very proud of Chandler's compassion and spirit. He is no stranger to fundraising and charities; he has been the top fund-raiser at his school the past two years for the American Heart Association through the Jump Rope for Heart program and is regularly involved in fundraising in our church through talent shows, canned food drives, cereal collections, etc.

We hope Chandler's character, and the story of his birthday party, can serve as an example for other children to be inspired and empowered to support charities such as the IMF. Like the boy with only a small number of loaves and fishes, just a little contribution from a humble child can go a long way to help others."

— The Terry Family

13th BIRTHDAY CELEBRATION HONORS MYELOMA SURVIVOR

By Chandler Terry

It was Chandler Terry's birthday fundraiser for the IMF that gave me the idea to celebrate my 13th birthday in a similar fashion. Chandler and I are first cousins, once removed. My aunt, Carol Allen, is his grandmother, and she is fighting multiple myeloma. I was very impressed by Chandler's initiative, and was inspired to try and help the myeloma community as well.

So, for my 13th birthday, I decided to organize my very first fundraising benefit. I have participated in a couple of fundraising events in the past, and I really enjoyed doing something that would benefit others, but this was the first time that I did something like this for a cause that is important to me and my family.

Aunt Carol is my mother's sister, and she is only 63 years old. She was diagnosed with myeloma in April of 2006, when she broke her back by simply driving over a speed bump in her car. Then she got very sick and there were several times when we thought we might lose her. Now, although Aunt Carol is still struggling with pain, she has undergone treatment, she is in good spirits, she is back to walking, and she seems to be on the road to recovery!

The IMF has been very helpful to Aunt Carol, as well as the rest of my family. The Foundation has sent us literature that gave us a better understanding about this cancer and its treatments, and we still receive regular updates on research and progress in the field. And the support they have personally provided to us has been invaluable.



Joanna Fureigh

For my birthday celebration, I set a goal of raising \$100 in lieu of gifts in honor of Aunt Carol. To my surprise, as soon as people heard that I was planning a benefit, I started to receive donations and pledges. I reached my fundraising goal before the party date was even set and the invitations were sent out!

My party was held at the Little Rock Climbing Center on July 21, 2006. My mom and I sent out invitations, and I chose the party decorations. We had about 15 kids participate in a group lesson followed by the climbing. I love rock climbing! The Little Rock Climbing Center gave us two extra hours of time at no charge as a way of making a contribution to our cause. We climbed for two and a

half hours! And there were at least as many adults who came to the party and had a lot of fun even though they didn't climb.

In total, I raised about \$1000, which is ten times my original goal. In addition, several of our friends and family have used the IMF website for their online shopping, which generated even more money to benefit myeloma patients. Personally, I purchased some IMF wristbands to use as party favors.

Surprisingly, I really didn't mind not getting birthday presents. In fact, the experience was so rewarding that I'd like to hold a fundraising benefit for my next birthday party as well. I was extremely excited to have an opportunity to share the hope for so many patients and their families. My family and I would like to thank all who contributed for their thoughtful and loving generosity.

MT

Member Events

TERRY DUBOIS CELEBRATES HIS 65TH BIRTHDAY WITH A BASH!

By Diane DuBois

As my husband Terry's 65th birthday was approaching, I looked at the calendar and realized that June 10th, which was his birthday, fell on a Saturday. I knew that we wanted to celebrate Terry's big day in style. We also wanted to celebrate another important milestone: his myeloma has been stable since his stem cell transplant in December of 2000. A regular reader of Myeloma Today, I was inspired by the various fundraising events that IMF members hold around the country. One particular event, an annual motorcycle ride, stuck in my memory. Motorcycles are a hobby that Terry and I share, so planning a ride in his honor seemed like a natural next step.

I called on a few of our friends for help, and contacted the IMF's Suzanne Battaglia for support. The all-day celebration we planned started with a 100-mile ride. About 30 motorcycles and a few classic cars took part in the morning road rally. The riders got back to the party zone by 3PM, which was when they drew a poker hand for a cash prize.

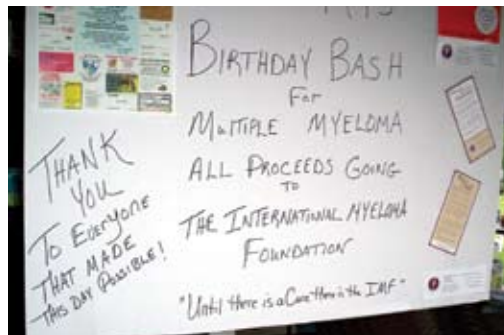
We were fortunate to have the GasLite, a local venue, donate the party facilities and run a bar for our guests. IMF's



IMF's Andy Lebkuecher with Terry & Diane DuBois

Andy Lebkuecher, who was able to travel to Wisconsin to attend Terry's celebration, lent a hand at the BBQ, cooking hotdogs that we served over the lunch hour. It was great to have him join us — everyone who got to spend time with Andy just couldn't say enough nice things about him!

He even presented Terry and me with an IMF certificate and took pictures of the event. We had IMF stuff everywhere, and several people bought T-shirts, bracelets, and other IMF items.



Terry's celebration also included a silent auction, and number boards for a chance to win lots of raffle prizes. A live band played for a couple of hours, followed by a DJ. We served over 200 people catered chicken dinners. All in

all, even in 60-degree weather, Terry's Bash was attended by over 300 people! We can't thank our families, friends, and local businesses enough for all the help and support that made our day such a huge success.



Member Events



Auction items and raffle sign-up

Terry and I met in 1985 as a result of our careers in law enforcement for the Pierce County Sheriff's Department. I am still active in law enforcement but Terry retired in 2000. Little did we know that he would spend the first week of his retirement at Mayo Clinic being diagnosed with myeloma. This was followed by six months of thalidomide and dexamethasone therapy, then a transplant.

Between the two of us, Terry and I have six kids and, thankfully, they live not far from us. Our family members have been very supportive throughout our journey with myeloma. We are also blessed to have wonderful friends and lots of people praying for us. Terry is a member of the Blue Knights Motorcycle Club, which is made up of active and retired law enforcement officers, and several members attended Terry's Bash as a show of support.

Terry's 65th Birthday Bash was a celebration we won't forget. Together, we were able to raise over \$7,000 of much-needed funds for myeloma research and programs while also raising myeloma awareness. We thank everyone at the IMF for all you do for myeloma patients and families by giving support, offering myeloma education,



and working toward a cure by funding research. Terry and I have both learned to live with myeloma as part of our lives and enjoy each day as it comes, and we wish the best to all others who are living with this disease. **MT**



UPCOMING MEMBER EVENTS

September 24, 2006

**THIRD ANNUAL RIDE FOR THE CURE
in honor of Darrell Berthiaume**

Breakfast, Poker Run, BBQ Lunch, Drawing,
and Cellphone Drive – Santee, California

Contact: Celeste Montalvo-Jackson, sasquach@yahoo.com

October 15, 2006

SECOND ANNUAL WALK FOR MYELOMA

Lake Oseola, University of Miami, Florida

Contact: Denise Vidot, peaches2822@aol.com

October 27, 2006

**MONEY FOR MIRACLES: Dinner, Dancing, Raffles,
and Silent Auction**

Rhode Island Myeloma Support Group's first annual
fundraiser

Cranston Country Club, Cranston, Rhode Island

Contact: Carol Murray-Rossi, marcar@gis.net, 401-46305709
or 401-374-1607

*For more information, please visit www.myeloma.org
or contact Suzanne Battaglia at 800-452-CURE (2873)*

***For up-to-the-minute information on IMF Member Events,
please refer to the IMF's web site www.myeloma.org
and click the Events tab.***

5th ANNUAL MULTIPLE MUSICIANS AGAINST MULTIPLE MYELOMA BENEFIT

Making Music, Creating Connections

By Jenna Kern-Rugile

The sun shone down as sweet as “Tupelo Honey” as the Long Island restaurant of the same name once again hosted “A Lee Grayson Production: Multiple Musicians Against Multiple Myeloma,” or MMAMM. For the fifth year in a row, a talented group of musicians entertained folks at Tupelo Honey, a shining star of the Long Island restaurant scene, with amazing music, wonderful food, and a day filled with love and hope. Those who came to the event – including patients and their families, International Myeloma Foundation supporters and staff, and caring souls of all kinds – raised money, awareness, and support for the battle against multiple myeloma.

MMAMM was born on another July day in 2002, when guitarist and singer Lee Grayson brought together his large and loving group of musicians and friends to launch what has become a tradition in the funky Victorian town on the harbor. Lee, who had been diagnosed with multiple myeloma nine years earlier, was one of the IMF’s most dedicated volunteers; he spent countless hours speaking with newly diagnosed patients, sharing his story and useful information, and, most important, inspiration.



Naomi Margolin takes center stage with MMAMM musician

“Lee felt like one of his greatest accomplishments was his work with myeloma patients,” says Naomi Margolin, Lee’s girlfriend who has spearheaded the event since his death in the fall of 2002. “He gave them hope, and for him, that was the most important role he ever played in his life. The amazing thing is that, four years after his death, he’s still doing the work.”

This year’s MMAMM event – held on July 9, what would have been Lee’s 59th birthday – marked the first time IMF Development Associate

Suzanne Battaglia attended in person. She first met Lee when he and his band played at the IMF gala in 2000. “I was overwhelmed by the spirit of Lee that was everywhere at MMAMM,” says Suzanne. “And I was so impressed by the fact that the community comes together every year to carry on his dream.”

Suzanne gives Naomi enormous credit for not only putting together the MMAMM benefit, but for other all the other work she does for the IMF. “She’s a very special lady; like Susie Novis, the IMF’s president, Naomi has taken a very painful situation and turned it into something very positive.”

This year’s benefit raised more than in any previous year, grossing \$22,000 before expenses (the five-year net total is well over \$80,000). The list of people who donate their time, services, and goods is lengthy. “For the fifth year in a row, Willie Stephens [the manager of Tupelo Honey, where Lee played for many years] closed down the restaurant on one of his busiest days of the week and donated all food and beverage proceeds to the IMF,” says Naomi. “Eileen Krieb, the mayor of Sea Cliff, shut down the street for the day. Tons of area businesses donated



Member Events

raffle prizes. Nearly a hundred volunteers pitched in. It's a real team effort."

Kids get in the act, too. For the second year in a row, Aly Finkelstein, daughter of musician and FOL (friend of Lee) Steve Finkelstein, sold "Carrots and Candy for Cancer," raising \$175. "She would've made Poppa so proud," says Steve, referring to his dad Sol, who died from multiple myeloma in 2005. The stage at the benefit is named in Sol's honor.

But Naomi, Suzanne, and Steve all agree that what's most important about MMAMM isn't the money – though, of course, funds are an essential tool for the IMF. Still, what's most significant has more to do with the connections that are made that day.

"MMAMM isn't just about dollars," says Steve. "It's about creating awareness and connectedness among people; it's about creating that network of supportive friends and family."



When people first receive a diagnosis of multiple myeloma, they often have never heard of the disease and don't know anyone who has it, explains Suzanne. "One of the best things about this type of fundraiser is that, aside from money, it raises public awareness," she says. "It gets the message out to communities where people might not know that others are dealing with the same thing they are."

Putting on such a large-scale effort is no easy task. Each year, the organizational aggravation grows larger, and during all the preparations, acknowledges Naomi, she has moments of wondering "why the heck I still do it. But the moment I introduce one patient to another patient,

or put a family member together with an IMF representative, I have my answer. When patients show up, they feel connected. They have a sense of belonging and purpose that they might not have had before."

Naomi saw Lee through many years of ups and downs with multiple myeloma, and that experience has given her deep empathy for both patients and their families. "There's an enormous sense of helplessness you have when you're watching someone you love go through this," she says. "It eats you up from the inside out. But coming to the benefit gives people a way to do something positive and connect with other people who are going through the same thing."

Having the opportunity to meet with IMF representatives at MMAMM was a godsend for Sea Cliff resident Sylvia Wagner, whose sister has been battling multiple myeloma for 16 years. "The music was wonderful and the raffles were fun," says Sylvia, "but the highlight for me was definitely talking to Naomi and Kelly Cox [IMF Vice President Member Services]. My sister has been on Velcade and thalidomide, and her system doesn't tolerate



PLEASE SEE MMAMM ON PAGE 38

Member Events

MMAMM — continued

them. She'd been reading about Revlimid but had trouble finding further information about it. Kelly put me in touch with Paul Hewitt, a hotline coordinator at the IME. When my sister spoke with Paul over the phone, he had the exact information she needed, and she'll be starting Revlimid in the next few weeks. She said he was full of information and a delight to talk to."

"I'm touched by Sylvia's sentiment," says Paul. "It's a privilege to be able to help her and others like her."

Helping those dealing with multiple myeloma is what MMAMM is all about. "This is one of the huge benefits derived from these types of community events," says Kelly. "It gives patients and their family members who attend the feeling that they're not alone."

Like the Wagners, John Kahler and his wife Ann, who was diagnosed with multiple myeloma in 2005, found the day informative and uplifting. "I loved seeing that so many people came out to an event like this, since nobody knows about myeloma," says John. The Kahlers, along with their friends and family, helped out in a big way, sponsoring the event through John's company, North Shore Fire Equipment, and getting raffle prizes from local businesses. "It's a great hometown, grass-roots effort," says John. "I'm looking forward to being involved next year."

One of the biggest joys of the day, he adds, was having the opportunity to thank Ann's physician, Dr. Sundar



Jagannath, and the rest of his medical staff. "Ann went through chemo for nine months, and then did a stem cell transplant this past May," says John. "We just found out it was a success!"

That spirit of joy is a great testament to Lee Grayson, who put on the first benefit at a difficult point in his medical saga. Lee's stem cell transplant, which had taken place in October 2001, wasn't successful, and his nine-year battle with multiple myeloma was nearing an end when he summoned all his energy to organize that first benefit in 2002. Many MMAMM volunteers have been part of the event every year since its inception; it gives them an opportunity to celebrate the life of their cherished friend, a sweet and soulful man who is still sorely missed.

"Lee Grayson was a musical matchmaker, a jester, a troubadour... the center of so many overlapping circles of musicians and their special friends," says Steve. "His whole existence was about making peace through magical musical moments, and this benefit is a complete extension and reflection of that sensibility."

Still, as Naomi explains, MMAMM is not just for Lee anymore, or for the musicians, or for the volunteers. "It's for the patients, the people who need a place to come and feel like something is for them," she says. "Every year, it's about people who are dealing with multiple myeloma. It's more about the future than the past. It has to be." **MT**



5TH ANNUAL WAMP SWIM-A-THON

By Elizabeth Stafford

My father, Jeffrey Stafford, was diagnosed with myeloma in 2001 at the age of 45. Our family has always been active in our local community in Connecticut and, when my dad was diagnosed, we knew that we had to get involved with the myeloma community as well. In June of 2001, we held our first swim-a-thon fundraiser to benefit the IMF's myeloma research program. The event was hosted at the Wampanoag Country Club in West Hartford, where my family has had a membership since the 1960s.

The first four WAMP Swim-a-Thons raised more than \$40,000. With that money, the IMF awarded a myeloma research grant in honor of my father to Dr. Alexei Kisselev of the Norris Cotton Cancer Center in New Hampshire. We also received an award commemorating the funding of this research grant, and it was featured in the trophy case



over 75 swimmers participated in the all-day event. For yet another year, our family and friends, as well as several local vendors, stepped forward to help sponsor the event and to donate food, drinks, and prizes for the raffle. With each successive year, our cumulative experience and the ever-expanding circle of support have helped establish this event as a true community effort.

For the first time since our family started hosting the event, one of my four siblings was not in attendance. My brother, Christopher, was away at the United States Merchant Marine Academy. It was hard to have him away and his presence was sorely missed but my sisters, Julianne and Courtney, and I managed to divvy up the work to get the event organized. We could not have done it without the support of some of the veteran WAMP Swim-a-Thon participants like Hailey Heslin (14), Cathleen Collins (13), and Gena Guliano (12), who helped us spread the word and get people in the pool.

In all, this year we raised over \$11,000, including in-kind contributions. We continue to be very motivated to support myeloma research and are encouraged by the advancements being made in the field. Our family's experience of life with myeloma has only strengthened our commitment to continue to help fund myeloma research in hopes for a cure for my dad and others like him. **MT**



at the Wampanoag Country Club for many months. Our fundraiser is not a Stafford event; it is the WAMP Swim-a-Thon, a true community effort. The research award was the tangible outcome of the efforts of so many people, and it really meant a lot to everyone whose participation and generosity made the grant possible.

The 5th Annual WAMP Swim-a-Thon took place on July 22, 2006. Although the day turned out to be rainy,

Member Events

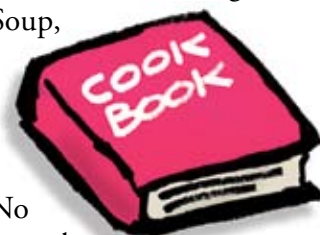
Ribbon of Hope Ornament

Whether you hang it on your holiday tree, your wall, or another creative place, the IMF's 4" Ribbon of Hope ornament will bring a message of hope to anyone you give it to. Fashioned after our popular Ribbon of Hope lapel pin, the enameled ornament comes in a black velvet pouch with a gold ribbon tie. We have a limited number available, so even though it's early, get your order in now! At only \$10 each, they will make wonderful gifts. If you would like to place an order, please contact Rolake Bamgbose at 800-452-CURE (2873) or email to rbamgbose@myeloma.org. You can also order online with a credit card or simply mail a check to the IMF.



Recipes for Research

Extra! Extra! Marilyn Alexander, the Philadelphia Support Group, and the IMF community have come together to create one terrific cookbook and handy kitchen reference. The original cookbook was a huge success, and if you have one, you'll want to add this all-new version to your collection. From Autumn Apple Cake to Veal Stimbarada, there is something here for every taste. Favorite recipes, tried and true: Vegetarian Hot and Sour Soup, Crab Souffle Casserole, Mom's Chicken (who can resist that!), Spaghetti Toss, No Carb Cheesecake and much more! And if you aren't in the mood to cook tonight, there is an entire section with tips on everything from setting the table to stain removal. Did you know that the twist tie on a loaf of bread can tell you what day it was delivered to the store? Move over Heloise! And who can resist Marilyn's Recipe for Friendship:



- 3 Phone Calls a Week
- 2 Cups of Kindness
- 1 Letter a Month
- 4 Saturdays of Shopping

Mix all ingredients carefully. Take turns stirring. Heap with hugs and lace with laughter. Sweeten to taste and sprinkle with smiles. Bake until Memories turn golden.

Act now to order your copies of Recipes for Research. They are only \$15, including shipping and handling, with all proceeds going to support the IMF's research programs. This is a great gift for Mother's Day. If you would like to place an order, please contact Rolake Bamgbose at 800-452-CURE (2873) or rbamgbose@myeloma.org. You can also order online with a credit card or simply mail a check to the IMF.



Mail for the Cure

Many of you requested envelopes to participate in our Mail For The Cure campaign, but were unable to send them out by the end of the year. So we have decided to extend the program for another six months. So far, the campaign has raised over \$8,000 to support the IMF's programs, and we know there will be a lot more coming in judging by your requests for information. If you have any questions about starting or continuing your participation in this program, or would like to request more envelopes and/or a letter template, please contact Rolake Bamgbose at 800-452-CURE (2873) or rbamgbose@myeloma.org.

Cell Phones 4 A Cure

To paraphrase Brian Novis, "One can make a difference, two can make a miracle." Being part of the miracle can be as easy as donating your old cellular phone. Or you can take up a collection of old cell phones from family, friends, and/or business associates. Please mail your phones to the IMF at:

12650 Riverside Dr. #206,
North Hollywood, CA 91607.

To learn more about this wonderful fundraising program, please call Kemo Lee at 800-452-CURE (2873).



LASALLE BANK CHICAGO DISTANCE CLASSIC

By Theresa Burkhart

It was a beautiful morning on August 13, 2006. A week-long heat wave had passed and ten thousand runners and I turned out to run the 13.1 miles of the Chicago Distance Classic Half Marathon. For all of us, this was the culmination of months of training, but for me, it was also a time to honor the courage of a very



Teresa Burkhart and her medal

and strong. She and my father, Gene, have 16 grandchildren and 2 great-grandchildren. My Mom worries more about the kids' or grandkids' health than her own. The diagnosis stunned all of us. Half of us live in cities far away from our small hometown in Ohio, so we started group e-mails to keep everyone posted on Mom's condition. Slowly, we scraped together the critical information that we all wanted to know: What is myeloma? Is there a cure? What is the treatment? What next?

The IMF educational materials were very helpful to us in those first few months. My sister Angela

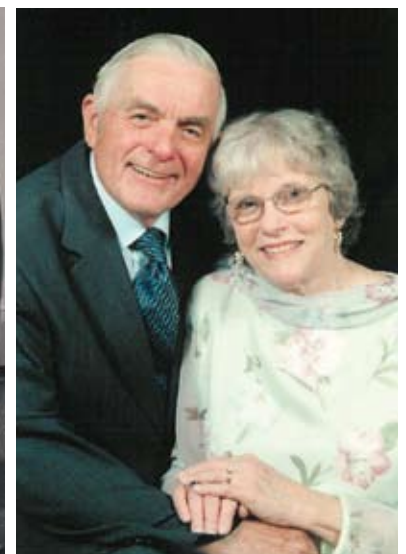
special lady who has faced a lot this year.

My mom was diagnosed with myeloma after falling and breaking her leg on January 4th, two weeks before her 71st birthday and a month before her 50th wedding anniversary. A mother of 12, Mom has been through a lot in life, but she has always been healthy

a "ribbon" for myeloma and she wears hers everywhere and is glad to explain what myeloma is. These resources were a great help as Mom made her way through the first six months of this year: orthopedic surgery and rehabilitation for her leg, chemotherapy and radiation, and finally, an autologous stem cell transplant in June. Everything went "according to plan," as the doctors say. She is home now and getting "back to normal." (I told you she was strong!)

In early June, when Mom was getting ready for her transplant, Myeloma Minute ran a notice inviting

PLEASE SEE LASALLE BANK ON PAGE 42



Gene and Marilyn Burkhart of Barnesville, Ohio, celebrated their Golden Wedding Anniversary on Saturday, February 11, 2006.

MEMBER FUNDRAISER UPDATES & OPPORTUNITIES

Student Organizes Phone Drive to Aid Myeloma Community

Myeloma survivor Victor Giardini, an instructor in the Lerner College of Business and Economics at the University of Delaware, mentioned in class that he was collecting old cellphones for the IMF. In response, Graham Worrall, a student of Giardini's and a member of Circle K, the Kiwanis Club student service organization on campus, organized a phone drive.



Not only did the efforts of Worrall and the other students net more than 50 phones, they raised awareness of multiple myeloma and the IMF. The phones were sent to IMF and the proceeds of the drive were shared with the local myeloma support group, which serves members from Delaware, Pennsylvania, and New Jersey.

Monet for Myeloma?

IMFer Jack Verespy is a multiple myeloma survivor who is in the fine art and fine art reproduction business. His company, Oscar LLC, is working on authenticating two paintings widely believed to be signed original Claude Monet pieces. These paintings were discovered at an estate auction in 2002. Oscar LLC is selling very limited edition giclée on canvas prints and will donate a portion of the proceeds from the sale of these prints to the IMF. In addition, a 20% discount on the prints is available to members of the IMF. For more information, please visit www.oscarllc.com. Until the authentication of the paintings is completed, Oscar LLC is not identifying these prints as reproductions of original Monet works.



Turn Your Vacations Into Donations - Book them at www.myelomatravel.com

Book your personal and business travel on our new travel website www.myelomatravel.com and you will get the same low rates offered by other travel websites while the IMF receives a portion of the travel commissions. Yes, it's that simple to raise funds for the IMF's education and research programs!



LASALLE BANK — continued

IMFers who run races to use them to raise funds for IMF. I had registered for the race earlier in the year (part of my New Year's Resolution to get into shape), and thought this would be a way I could help Mom, even though I am far from her hospital bed. I also hoped to raise awareness of myeloma and help other people who live with this disease. Plus, it is more motivating to run for a cause.

Even on short notice, IMF's Suzanne Battaglia was glad to offer her help. We were able to get IMF set up as an official

charity of the race, which gave IMF visibility on the race website and marketing materials. Suzanne also sent out notices for local IMFers to run or volunteer for the race. (The race organizers make donations to charities that

volunteer to work at the health expo or to do other functions during the race.) Although we didn't get a team to run or volunteer for the race this year, I did raise some funds and every donation was a motivation to put one step in front of the other. And there is always next year! **MT**



A BRAND NEW PROGRAM, JUST FOR YOUNG PEOPLE

The IMF's new program – **KIDS FIGHT BACK!** – enables young people of all ages to fight back against myeloma. We are delighted that so many children have been so creative and proactive in honor of their beloved family members who are battling multiple myeloma. Kids have been recycling bottles and cans, and forging birthday and holiday presents, because it makes

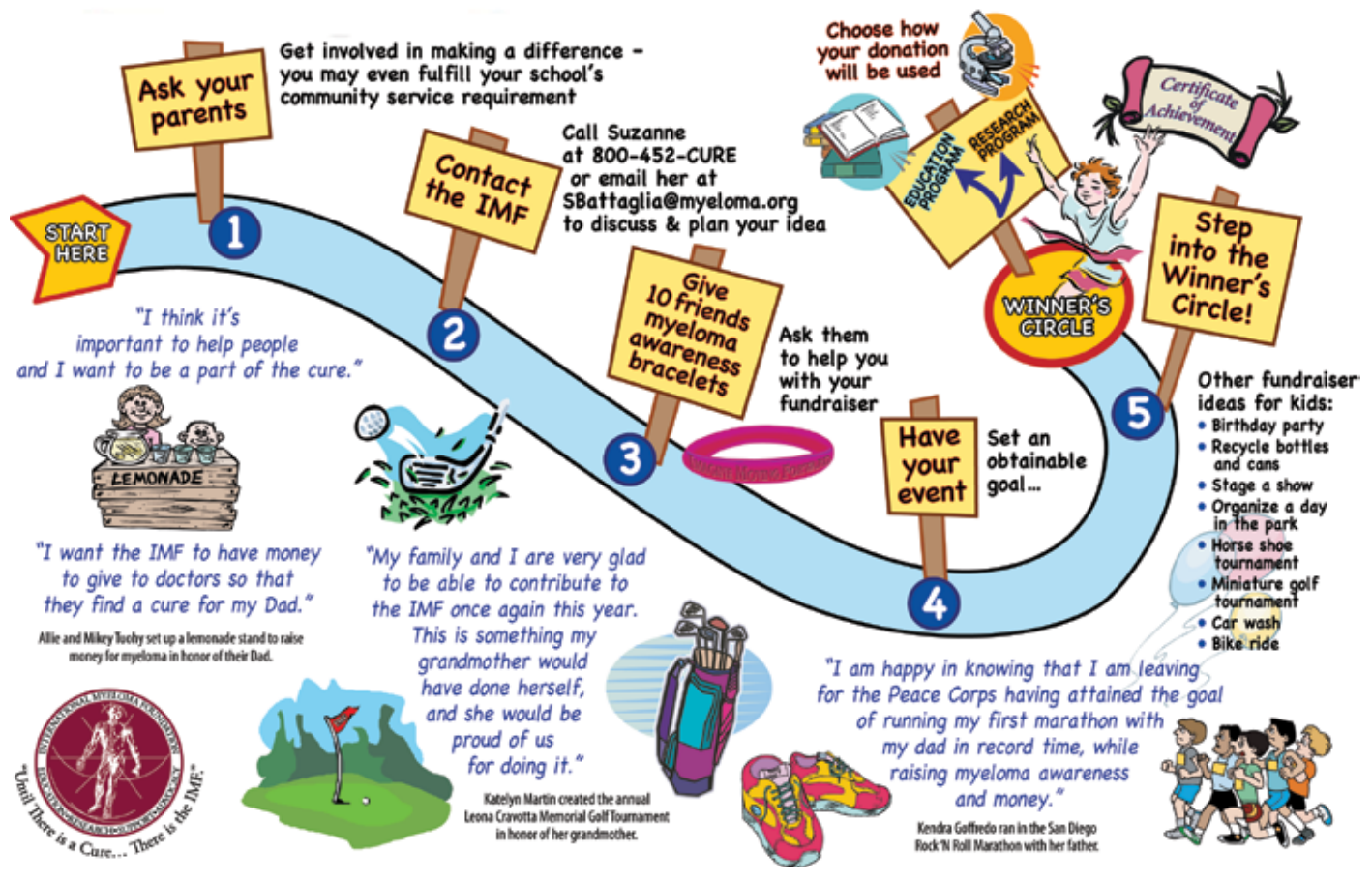
them feel good to know that they are helping others. We are thankful for their contributions to the IMF and the myeloma community, and we are here to help and encourage them to achieve their fundraising goals. For more information, contact Suzanne Battaglia at SBattaglia@myeloma.org or (800) 452-CURE (2873).

MT

A Research & Education Fundraising Program...
especially for Kids

Kids Fight Back!

If you're a kid who's ready to fight back against myeloma, keep reading. We'll help you develop and organize your ideas, and give you the materials and encouragement you need to **FIGHT BACK!** Here's how it works.



MEET THE IMF DEVELOPMENT DEPARTMENT

A Conversation with Candace McDonald and Suzanne Battaglia

Myeloma Today: How did you come to be a part of the IMF Family?

Suzanne Battaglia: Susie Novis and I have known each other for many years. One night in 1996, over dinner, I expressed my desire to change career paths and go back to working full-time. My background is in theatrical and event production but, at the time, I was free-lancing in the financial and real estate industry. Susie suggested that I consider joining the IMF. It has always been important to me to be involved in ventures that in some way help people, so working for a non-profit cancer foundation seemed like a good fit, especially since I had a personal connection to the IMF. I joined the IMF staff in January of 1997. At the time, the entire IMF staff consisted of only four people, crowded into a tiny room in a basement. I read everything I could about myeloma, but I probably learned the most from listening to Susie talk to patients on the Hotline. Eventually, I started fielding Hotline calls as well, which really helped me feel a part of the myeloma community. The IMF now has a trained staff of Hotline Coordinators, but connecting with patients and family members has remained my favorite part of working at the IMF.

Candace McDonald: A friend whose father had myeloma introduced me to Susie Novis and the IMF. By that point, I had been working in fundraising for several years, including time at the Anti-Defamation League and the American Cancer Society. My professional and volunteer background has always been strongly rooted in humanitarian causes. Because I felt a personal connection to the world of myeloma, and had an interest in focusing



Candace McDonald (Associate Director, Development) and Suzanne Battaglia (Development Associate)

my professional fundraising efforts on just one cancer, I joined the staff in August of 2004 with the goal of growing the IMF's Development Department.

Myeloma Today: Suzanne, please tell us about some of the specific IMF programs that you've been involved with.

Suzanne Battaglia: Because of my experience with event planning, I was committed to getting some fundraising programs off the ground that would directly benefit the good works of the IMF. My first idea was to organize a

Myeloma Today subscription drive. I sent out a letter to IMF members, and they responded with \$27,000 in donations! Other fundraising efforts, such as Myeloma 200 and Mail For The Cure followed and, as the Foundation grew, I broached the idea of hosting a large Gala. The IMF's 10th Anniversary Celebration Gala took place in October of 2000, at the historic Waldorf Astoria Hotel in New York. The Gala became the IMF's signature annual celebration program. I also organized the first two Robert A. Kyle Lifetime Achievement Awards. Eventually, I branched out into working on more grassroots member fundraising events.

Myeloma Today: What are your current areas of responsibility within the Development Department?

Candace McDonald: I am responsible for all fundraising efforts, including designing and implementing strategy and ongoing development of funding programs. I also act as the liaison between donors, local businesses, and corporate sponsors for raising funds for the IMF's patient programs. I oversee the two major annual

CONTINUES ON NEXT PAGE

Meet the IMF

IMF events. The Gala is the IMF's way to celebrate the Foundation's anniversary and to recognize key individuals who are making a positive impact on the myeloma community. The Robert A. Kyle Lifetime Achievement Award recognizes a doctor who is making an immediate difference in lives of myeloma patients, and bestows a grant that funds the award recipient's myeloma research. I also head up the IMF's direct mail and marketing campaigns, keep the IMF up to date with our accreditations, and make sure that we follow all applicable non-profit procedures. I also focus on planned gifts such as wills, estates, and trusts for the foundation.

Suzanne Battaglia: I now focus primarily on member fundraising but I still participate in the Gala and the Kyle Lifetime Achievement Award programs. The member fundraising program has allowed me to reconnect with our membership, which is something I have always valued, ever since I worked on the Hotline early in my IMF tenure. And I really enjoy meeting the IMFers I've had the pleasure to get to know and work with. At a recent IMF Patient & Family Seminar in Philadelphia, I was able to meet three IMF members who had organized events in their local areas but with whom I had only communicated over the phone!

Myeloma Today: What are your hopes and plans for your future at the IMF?

Suzanne Battaglia: I have just developed a new program – KIDS FIGHT BACK! – that enables young people of all ages to fight back against myeloma. I wanted to design something especially geared to kids, because so many children have been sending money to the IMF in honor of their beloved family members. Kids have been recycling bottles and cans, and forgoing birthday and holiday presents, because it makes them feel good knowing that they are helping. Fundraising might seem intimidating to someone who's never done it, but I am here to make it as easy as possible. It is my pleasure to help all of our members develop and organize their ideas, as well as to provide any materials or encouragement they may need. No event or idea is too small – every little bit helps the myeloma community! Raising money for myeloma programs and research can be a very positive and empowering experience for patients, caregivers, and their loved ones. In addition, member events are a

very effective way to raise myeloma awareness. I am very optimistic about the continued growth of the member events program, and I am currently working on developing another IMF signature nationwide program. And, on a personal note, I'd like to add in conclusion that my work at the IMF has been very fulfilling to me, both emotionally and creatively.

Candace McDonald: I am planning to expand the development department in order to enhance the IMF's ability to carry out its mission of improving the quality of life of myeloma patients while working toward prevention and a cure. My experience at the IMF continues to be highly rewarding, and my constant interaction with people whose lives have been touched by myeloma reminds me of why I joined the IMF. **MT**

Note: To contact Candace McDonald or Suzanne Battaglia, please call 800-452-CURE (2873) or email cmcdonald@myeloma.org or sbattaglia@myeloma.org.

Gift Planning

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
- Gifts of Life Insurance
- Annuity Trusts
- Unitrusts
- Term-of-year Trusts
- Charitable Lead or Remainder Trusts

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 Candace McDonald at 800-452-CURE (2873) or cmcdonald@myeloma.org. We also invite you to visit www.myeloma.org for a more detailed explanation of these giving plans.

GREGORY R. MUNDY, MD

Myeloma Today: Please tell us a little about your medical background.

Gregory R. Mundy, MD: I was born in Melbourne, Australia. I graduated from the University of Melbourne with my basic medical degree in 1966 and received a post-graduate medical degree from the University of Tasmania in 1973. I moved to the US for my fellowship in clinical pharmacology at the University of Rochester in New York. I was Head of the Division of Endocrinology and Metabolism at the University of Texas Health Science Center in San Antonio from 1980-2001. In July of this year, I was appointed Director of the Vanderbilt University Medical Center (VUMC) Center for Bone Biology. Immediately prior to this, I was Assistant Dean for Clinical Research, Professor of Cellular and Structural Biology, and Interim Director of the San Antonio Cancer Institute at the University of Texas Health Science Center at San Antonio. The training program I directed at the University of Texas has trained 140 postdoctoral fellows in bone and mineral metabolism.

Myeloma Today: When did you become interested in myeloma?

Prof. Mundy: My interest in bone biology goes back to my days as a medical resident at the University of Tasmania, where I cared for many patients with myeloma. Myeloma is the cause of one of the worst bone diseases that I know of. I began studying the basic science of bone biology during my fellowship at the University of Rochester, and continued my research at the University of Connecticut. In the late 1980s, in cooperation with the University of Texas, I founded a company called Osteoscreen with the goal of looking for drugs that stimulate bone growth. The company's success in identifying compounds that may improve fracture healing has led to the founding of two additional biotechnology companies. It has always been important to me that my research be relevant to patients – to real problems that people have.



Gregory R. Mundy, MD
John A. Oates Chair in Translational Medicine
Director, Professor of Medicine, Pharmacology,
Orthopaedics, Cancer Biology
Vanderbilt Center for Bone Biology
Vanderbilt University Medical Center
Nashville, TN

Myeloma Today: How did you become involved with the IMF?

Prof. Mundy: After I moved to the US in the 1970s, I started collaborating with Dr. Syd Salmon on my first papers. At that time, Dr. Brian Durie was Dr. Salmon's post-doctoral fellow in Arizona, and we became friends. Later, Brian and I collaborated on some studies and we kept in touch over the years. When the IMF was formed, I was invited to join the faculty on some of the Patient & Family Seminars, to make presentations on myeloma bone disease. In 1995, I was asked to join the IMF's Scientific Advisory Board.

Myeloma Today: What can you tell us about the IMF's Bank On A Cure® research initiative?

Prof. Mundy: I am involved with Bank On A Cure in my capacity as a Board member, and I am excited about this project. It is the wave of

the future. Personally, I am very interested in having this project provide critical information on why some people with myeloma get bone disease and why some don't.

Myeloma Today: What are the recent advances in the management of myeloma bone disease?

Prof. Mundy: We now know a lot more about the benefits and risks of bisphosphonates we use, and how to best use them to optimize benefits and reduce risks. The guidelines currently being revised should be very helpful to physicians who are treating myeloma patients. AMGEN is developing an important new drug, known as AMG 162 (also called denosomab), which is an antibody that acts in a similar way to bisphosphonates. The current Phase II clinical trial aims to determine the effectiveness of AMG 162 in advanced cancer with bone metastases in subjects being treated with intravenous bisphosphonates. It is possible that this drug will be launched as early as 2009. The other important development is that VELCADE®, a drug known to have an effect on myeloma, might have a beneficial effect on

PLEASE SEE GREGORY R. MUNDY ON PAGE 48

Scientific Advisory Board: Member Profile

JESUS SAN MIGUEL, MD, PHD

Myeloma Today: Please tell us about your medical training and how you entered the field of myeloma.

Jesus San Miguel, MD, PhD: I studied medicine at the University of Navarra and completed my residency in hematology and Internal Medicine at the University Hospital of Salamanca, Spain. I have been interested in multiple myeloma since 1978, when I started work on my PhD thesis in immunoglobulin subclasses in myeloma. Myeloma has been my field ever since. From early on, my areas of interest in myeloma included subclasses of immunoglobulins, acute-phase reactant proteins, and prognostic factors. Later on, I also became involved in immunophenotyping analysis for leukemias and myeloma.

Myeloma Today: What is the focus of your current activities in myeloma?

Prof. San Miguel: Clinical trials within the Spanish Myeloma Group, for which I served as chairman until last year, are one of my main areas of focus. I am a member of the board of the Spanish Myeloma Group, and am deeply involved in the design and follow up of all of its clinical trials. Another area of focus is my work at the University Hospital of Salamanca and the Cancer Center of Salamanca. We are a reference center for biological studies in clinical trials. This includes cytogenetic analysis, molecular analysis, and in-vitro investigation of novel agents. In addition, in close collaboration with Dr. Pandillia, we have set up a lab investigating the efficacy and mechanism of action of novel agents in myeloma. Dr. Pandillia is responsible for the Signal Transduction Lab at our Cancer Research Center. This includes single agents, as well as combinations of novel agents and drugs with proven efficacies in myeloma.

Myeloma Today: You were principal investigator on a recent VMP study. Please tell us about it.



Jesus San Miguel, MD, PhD
Professor of Medicine, Haematology
Head of the Haematology Department
Councillor of the Research Commission
Hospital Clínico Universitario
University of Salamanca
Salamanca, Spain

Prof. San Miguel: Approximately half of all myeloma patients cannot tolerate high-dose chemotherapy followed by a stem cell transplant. The usual drug treatment for these patients is a combination of melphalan and prednisone (MP). This drug combination is easy to take and has few side effects, but MP is only moderately effective in myeloma. VELCADE® (bortezomib) is one of the novel agents that has been shown to be important in treating myeloma after relapse. Our study showed that VELCADE combined with MP, known as VMP, shows promise to be an effective treatment superior to MP alone. In the Spanish VMP study, we treated 60 myeloma patients who were not eligible to have a stem cell transplant. All patients were over age 65 (median age 74 years). One-fourth of our patients were older than 80! Our

study reported improved outcomes, with a higher remission rate and better survival. The most significant finding of this study thus far is the 85% rate of response to treatment, including 30% complete response (CR) and 55% partial response (PR), irrespective of chromosomal abnormalities. To gather further information about the efficacy of VMP, a randomized controlled study comparing VMP with MP alone (the VISTA clinical trial) is now in progress.

Myeloma Today: What is the focus of your work with the IMF's Bank On A Cure® research initiative?

Prof. San Miguel: The identification of genes related to the susceptibility of developing Osteonecrosis of the Jaw (ONJ). We are currently recruiting patients. Data will be forthcoming in the future.

Myeloma Today: When did you become involved with the IMF?

Prof. San Miguel: I've been with the IMF since it was first founded, when Dr. Brian Durie and Susie Novis

PLEASE SEE JESUS SAN MIGUEL ON PAGE 48

Board Member/Scientific Advisor Profile

GREGORY R. MUNDY — continued

bone as well, and this may be why it is so effective in myeloma patients. Definitive studies of the effects of VELCADE on bone are now being planned.

Myeloma Today: What can you tell us about the proposed work of the specialized Center in Bone Biology that you've established at VUMC?

Prof. Mundy: The Vanderbilt Center in Bone Biology will focus on the major diseases of the bone and on identifying new drugs to treat them. I've brought several talented scientists to the center with me and, together, we will create a large and vibrant program in the bone sciences. My vision for this new center is to have a group of people here who are interested in all of the common bone diseases, from the very basic to the clinical aspects, so that Vanderbilt is known internationally as a center for people to be trained in studying bone disease. Research on myeloma bone disease is an important part

of our work, and we have several people in the Center who are devoted entirely to this. However, we think that our other research in bone disease is also providing insights into the cause of myeloma bone disease, and how to treat it. I am very interested in early-stage drug discovery and identifying drugs that will stimulate bone growth or inhibit cancer metastasis to bone. **MT**

Editor's Note: Dr. Mundy has been the recipient of many honors and awards including the Fuller Albright Award in 1982, an NIH Merit Award in 1986, and the William F. Neuman Award in 1999. In 1999, he was also named a University of Texas Health Science Center Presidential Distinguished Scholar. He is the Immediate Past-President of the International Bone and Mineral Society, a Past-President of ASBMR, and a former Chairman of the Research Grants Committee of the National Osteoporosis Foundation. He has published more than 550 articles, reviews, and book chapters, and has published 2 monographs on calcium homeostasis and bone remodeling and its disorders. Dr. Mundy is an inventor on 34 issued patents. **MT**

JESUS SAN MIGUEL — continued

invited me to join its Scientific Advisory Board. So, I have served the Foundation and its membership for many years.

Myeloma Today: What is your assessment of the current state of myeloma?

Prof. San Miguel: We are working on finding a cure for myeloma, but it is hard to estimate when we will be able to achieve that goal. While we pursue a cure, we are focusing on improving the length and the quality of life of today's myeloma patients. Worldwide collaboration between various labs, research institutions, and clinical groups is critically important in order for all of us to best serve the myeloma community. Collaboration is the shortest path and the best way to accelerate progress.

Myeloma Today: Speaking of collaboration, what are your thoughts on the proposed new uniform response criteria for myeloma?

Prof. San Miguel: I was involved, together with Drs. Brian Durie and Phil Greipp, in the development of the new International Staging System (ISS) for myeloma, which has been widely accepted as the current standard for staging myeloma. This staging system was based on >11,000 patients and involved the collaboration of the most relevant groups working in myeloma. The next step has been the development of new uniform response

criteria for myeloma. The new criteria have been the result of a new joint consensus effort of a large group of myeloma leaders and received final approval from its collaborators at the December 2005 annual meeting of the American Society of Hematology (ASH). The new proposal is similar to the EBMT criteria, but it adds critical new information such as a more stringent definition of complete response (CR), the introduction of the term very good partial response (VGPR), and the introduction of new tests in the evaluation of response such as molecular immunophenotypic techniques or the Freelite test which will be most valuable for oligosecretory or non-secretory myeloma.

Myeloma Today: What is your life like outside of the world of myeloma?

Prof. San Miguel: I have a very large family. I am the father of six children, ages 12 to 25, who keep me both very busy and very happy. My family life is my treasure, and my children are my joy. **MT**

Editor's Note: Prof. San Miguel is a board member of the Spanish Hematology and Genome Foundations. He is National Councillor at the International Society of Hematology and Board Councillor of the European Hematology Association, and is a seven-time prize recipient of the Spanish Society of Haematology and Spanish Cancer Association. Prof. San Miguel has published more than 500 articles, 80 book chapters, and 340 abstracts.



George and Judy Goldman
with Dr. Brian Van Ness

IMF Receives Grant from Goldman Philanthropic Foundation

The Goldman Philanthropic Partnerships (GPP) has committed a \$25,000 grant to the IMF for its Bank On A Cure[®] research project. The grant is part of a collaboration between GPP and Partnership for Cures

(PFC), a charity committed to accelerating the discovery of new treatments for life-threatening diseases. PFC was founded by GPP to expand its mission of bringing business rigor to medical research by forming partnerships among motivated donors, researchers, and leading research institutions. “George and Judy Goldman, founders of Goldman Philanthropic Partnerships, have long been supporters of the IMF and donors to innovative multiple myeloma research,” said Dr. Bruce E. Bloom, PFC President and Chief Science Officer. “Judy was diagnosed with multiple myeloma back in 1990 and has dedicated her remission to finding a cure for others. George and Judy are thrilled to be able to support the work that the IMF research team is doing to understand how genetic variations are associated with risk, disease progression, and individual responses to therapies.” Dr. Brian Van Ness accepted the grant on IMF’s behalf on June 24, 2006, at Concert for Cures, a Chicago event hosted by PFC to kick off a campaign to help donors fund groundbreaking research.

The IMF at ASCO 2006

Some very exciting research was presented at the 42nd annual meeting of the American Society of Clinical Oncology (ASCO) in Atlanta, Georgia. The IMF was there. And now you, too, can be a part of the many significant discussions that took place. If you wish to view ASCO webcasts and listen to the presenters as they discuss the future of myeloma research and treatment, please visit www.myeloma.org.

Multiple Myeloma Featured on The Group Room[®]

The Group Room[®] is a nationally syndicated radio call-in talk show about cancer hosted by Selma Schimmel. It is produced by Vital Options[®] in association with

The IMF Joins the Combined Federal Campaign

The IMF is thrilled to announce that it has been selected to join the Combined Federal Campaign (CFC).

Each year, the CFC’s workplace campaigns help raise millions of dollars. Pledges made by Federal civilian, postal, and military donors during the campaign season (September 1st to December 15th) support eligible non-profit organizations that provide health and human service benefits throughout the world – now including the IMF!

If you are a Federal employee, please participate in the CFC campaign, September 1st through December 15th, and designate the IMF as your beneficiary by using our organization code 1178.

For more information on this exciting new giving opportunity, please visit our web site, www.myeloma.org.

Premiere Radio Networks, the largest radio network in the United States. The two-hour program reaches over 500,000 listeners every Sunday in select cities in the U.S. and is also simulcast worldwide via www.vitaloptions.org. Alternatively, The Group Room can be heard live via XM Satellite Radio on TalkRadio Channel 165, as well as at iRadioNow.com. The show also broadcasts periodically in Europe. Vital Options is a not-for-profit cancer communications, support, and advocacy organization whose mission is to facilitate a global cancer dialogue by using communications technology to reach every person touched by cancer.

On July 30, 2006, The Group Room topic was multiple myeloma. Host Schimmel was joined by guests Dr. Paul Richardson (Clinical Director of the Jerome Lipper Multiple Myeloma Center at the Dana-Farber Cancer Institute and Assistant Professor of Medicine at Harvard Medical School, Boston, Massachusetts) and Dr. Brian Durie (Chairman of the IMF and National Director, Multiple Myeloma, Aptium Oncology, Inc. and attending physician at Cedars Sinai Medical Center and the Outpatient Cancer Center at the Samuel Oschin Comprehensive Cancer Institute in Los Angeles, California). Due to the overwhelming response to the program, Dr. Brian Durie and Susie Novis were invited to join Schimmel for another segment — Highlights from the International Myeloma Foundation’s Patient

PLEASE SEE NEWS & NOTES ON PAGE 50

NEWS & NOTES — continued

& Family Seminar Program — on August 27, 2006. If you've missed hearing these programs live, audio archives are available on www.vitaloptions.org free of charge. Audiotapes of The Group Room programs are available from the same website at a cost of \$12.99 per tape.

CAUTION: Hypertension Medication and Multiple Myeloma

Myeloma patients who are being treated for high blood pressure (hypertension) should be aware that ACE (angiotensin-converting enzyme) inhibitors should be used with great caution or avoided altogether. There is medical documentation that ACE inhibitors can cause kidney damage or even kidney failure in patients with underlying light chain deposition of the kidneys. Since the tendency to develop light chain deposition is often not established or well documented, ACE inhibitors must be used with due caution or avoided. There are many other therapy options, including diuretics, that can be used safely to control hypertension in myeloma patients. Please consult with your primary care physician and oncologist before you select a therapy for hypertension or if you are currently receiving treatment with an ACE inhibitor.

RIMMSG Represents Myeloma Community at Relay for Life

The American Cancer Society held their annual Relay For Life overnight event in Warwick, RI, on June 16th & 17th. For the first time at this event, members of the Rhode Island Multiple Myeloma Support Group (RIMMSG) represented the local myeloma community by organizing an information booth. IMF educational



RIMMSG leader Carol Murray-Rossi (in the purple survivor shirt) with support group members Adrienne Southgate, Matt Rossi, Rosemary Murray, Jason Rossi, and Kathi Herron

materials and RIMMSG contact information were disseminated to the multitudes in attendance. The event was a wonderful opportunity for the RIMMSG to network with the larger Rhode Island cancer community, as well as to raise public awareness about myeloma and the IMF.

Free Online Access to The Merck Manuals

In 1899, the American drug manufacturer Merck & Co. Inc. began publishing The Merck Manual of Diagnosis and Therapy, an important reference tool for health-care professionals. Since 1997, The Merck Manual of Medical Information (Home Edition) has been available to people interested in medical care who do not have a medical degree. The Merck Manual, The Merck Manual of Medical Information (Second Home Edition), The Merck Manual of Geriatrics, The Merck Manual of Health & Aging, and The Merck Veterinary Manual are available on Merck's Internet site at www.merck.com. Merck & Co. Inc. provides all of The Merck Manuals on a not-for-profit basis as a service to the community.

AACR Publishes New Advocates Newsletter

The American Association for Cancer Research (AACR) has begun publishing the Survivor and Patient Advocacy e-Newsletter, a new electronic magazine about people and progress in cancer. There is a fee associated with a subscription but if you visit www.CRMagazine.org and click on MAGAZINE in the navigation bar, you will be able to read selections from the newsletter free of charge. IMFer and myeloma support group leader Jim Omel is a contributor to the Summer edition, sharing the personal account of his myeloma diagnosis.

New Online Patient Guide to Side Effects

The Cure Magazine website has added A Patient's Guide to Side Effects to its roster of guides for the newly diagnosed. Please visit www.curetoday.com and click on "Patient Guides" along the right side of your screen. The publication addresses the issues associated with fatigue, hair loss, pain, nausea and vomiting, anemia, neutropenia, depression, oral mucositis, and skin reactions. **MT**



C. Everett Tilson, left, was a pivotal player in the Civil Rights movement of the '50s and '60s. Pictured here with Martin Luther King Jr.

I want to thank the IMF Hotline's Nancy Baxter for all she does. She is an amazing lady. After talking with her, I had a good night's sleep for the first time since my father's myeloma diagnosis. Sadly, my remarkable father passed away from a complication. I felt a need to contact Nancy Baxter and tell her. While I regret having possibly kept her from assisting another caller, I wanted to let her know how valuable her time and advice were to me and my family. When dad died suddenly and unexpectedly, we were able to comfort ourselves that we had obtained reliable information and made intelligent decisions. Nancy's advice may not have lengthened my father's life, but it provided enormous comfort to us. We don't have to torment ourselves about whether we "should have" or "could have" learned more about myeloma or made one more phone call. Nancy knew. Nancy shared. She was generous with both her time and expertise. Thank you IMF for sharing Nancy Baxter with us.

Lee Tilson

Just wanted to let you know that your InfoPack has arrived in the mail. I appreciate the time and effort everyone at the IMF has taken to help our family through a very difficult time. My brother-in-law has been diagnosed with Stage I multiple myeloma. He also has high blood pressure and diabetes. In addition, I am coping with my husband's Marfan Syndrome, a connective tissue disorder. With two rare diseases in the family, it is important for us to educate ourselves so that we can act as our own best advocates.

Kim Natzke

My husband and I recently attended our first IMF Patient & Family Seminar in Portland. To say that we were impressed with the information shared is an understatement! We particularly enjoyed the question and answer sessions. Where else but in this type of setting could you put your question to not just one professional, but in some cases three?! I have lead the Vancouver (British Columbia, Canada) myeloma support group for two years now and have heard all about these seminars and how good they are, but now that I have had first hand experience, I can recommend them even more so. Everyone who has myeloma should attend one session. I for one feel blessed to know that we have Susie and the IMF on our side!



Francesca & Richard Plaster at the IMF Patient & Family Seminar in Portland

Francesca Plaster

Thank you all for the factual information, and for the encouraging helpful spirit in which you deliver it. You enrich thousands of lives with knowledge and hope. The IMF's Hotline Coordinators are the greatest! Your reliable answers to our questions are always appreciated, and we are all grateful for how much you hate myeloma. Also, Andy Lebkuecher's emails to myeloma support group leaders are gems full of scientific information. All of you at the IMF deserve our thanks.

Jim Omel, MD

I have had multiple myeloma for a little over three years. Over the past year, I have been working on spreading the word about myeloma in my local area. In February of 2006, the Faces of Hope campaign poster featured my picture, along with my daughters. Then I participated in a gathering to get the word out about cancer, and the effort seems to be working. On June 10th and 11th, our local team enjoyed a great turnout to celebrate survivorship!

Joyce Bradley

MT

RIMMSG Represents Myeloma Community at the NBC 10 Health Fit Expo

I am a 3-year myeloma survivor, and founder and leader of the Rhode Island Multiple Myeloma Support Group (RIMMSG). On September 9 and 10, RIMMSG operated a myeloma informational outreach booth at the Fifth Annual NBC 10 Health Fit Expo. This healthy lifestyle two-day event was held at the Providence Convention Center in Providence, RI. The expo, which was available to the public free of charge, offered a full range of fitness activities and health related information.

I ran the booth along with my mother, Rosemary Murray, who is an avid supporter and active member of RIMMSG. We were happy to welcome the assistance of our neighbor, Connecticut myeloma support group leader and IMF Regional Director of Support Groups (Northeast), Robin Tuohy. Our myeloma informational outreach booth featured the IMF banner and a large assortment of IMF educational materials and fundraising items.

The massive crowd at the expo offered us an opportunity to spread myeloma awareness to the general public and to make personal connections with many individuals. Several myeloma patients, as well as friends and relatives of patients, stopped by our booth to sign up for support group participation and to join our mailing list.

We also made the most out of the wonderful networking opportunities by establishing connections with healthcare professionals, as well as community and media resources. And several of our new contacts offered volunteer services to our group! The media connections lead to the upcoming television segment on NBC, which will feature a member of the RIMMSG and a local oncologist. The segment will include information about the IMF and the RIMMSG, and will announce the RIMMSG's October 27th fundraiser and November 5th Blood/Marrow Drive.

Participating in the NBC 10 Health Fit Expo was a great experience and I look forward to representing the IMF and the RIMMSG every year at this statewide event. Many thanks to the IMF for your overwhelming support of the RIMMSG efforts to bring public awareness of multiple myeloma to the state of Rhode Island!

Carol Murray-Rossi



RIMMSG members (left to right)
Frank John, Carol Murray-Rossi,
Rosemary Murray, and Earlene John

IMF Patient & Family Seminars

Get one-on-one time with myeloma experts, such as Dr. Brian Durie



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- Learn what to do when you are first diagnosed
- Learn how new findings in novel therapies affect your treatment options
- Learn how to achieve best bone health and quality of life

Camaraderie

Share your experiences and gain strength from hearing other people's stories, as you become part of the IMF family.



"Your doctor cares, but no one cares as much about your survival as you do, and knowledge is power."

— Recent Attendee

Los Angeles Patient & Family Seminar

Friday & Saturday, Feb 23–24, 2007

Registration Cost

Package A – \$85: Includes Friday Half-Day Seminar (1PM–5PM), Welcome Cocktail Reception & Dinner, and Saturday All-Day Seminar (8AM–5PM)

Package B – \$50: Includes Saturday All-Day Seminar only (no Friday Seminar or Dinner)

Registration Discounts

- 20% Discount if you register on or before January 23, 2007.
- Scholarships available, contact IMF.
- If you register for a second seminar in another city in 2007, we will waive that registration fee. *(Note: there will be four P&F Seminars in 2007. Check the website for dates and locations as they become available.)*

Hotel Information

Sheraton Universal Hotel

333 Universal Hollywood Drive, Universal City, CA 91608
(818) 980-1212 reservations & info

Discounted Room Rate: \$149 + tax *(Please ask for our discounted rate; there are only a limited number of rooms at this rate and they are on a first-come basis)*

Houston Patient & Family Seminar

Friday & Saturday, March 23–24, 2007

Registration Cost

Package A – \$85: Includes Friday Half-Day Seminar (1PM–5PM), Welcome Cocktail Reception & Dinner, and Saturday All-Day Seminar (8AM–5PM)

Package B – \$50: Includes Saturday All-Day Seminar only (no Friday Seminar or Dinner)

Registration Discounts

- 20% Discount if you register on or before February 23, 2007.
- Scholarships available, contact IMF.
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Hotel Information

Four Seasons Hotel

1300 Lamar Street Houston, TX 77010

(713) 650-1300 reservations & info, www.FourSeasons.com/Houston
Discounted Room Rate: \$149 + tax *(Please ask for our discounted rate; there are only a limited number of rooms at this rate and they are on a first-come basis)*

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www.myeloma.org



NEW Understanding Series Brochures Available

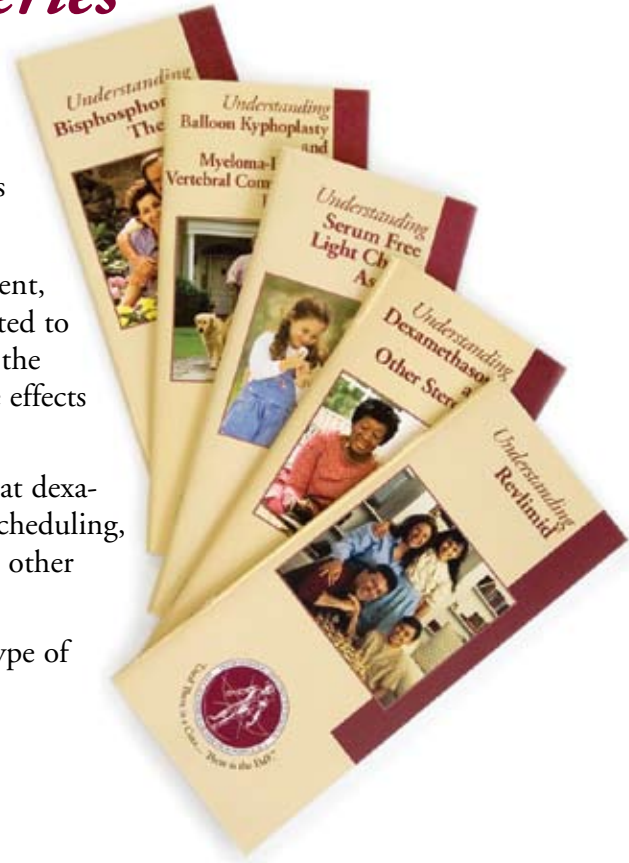
We are pleased to announce new additions to our Understanding Series brochures.

Understanding Revlimid® explains the new immunomodulatory agent, a vascular endothelial growth factor inhibitor, which is structurally related to thalidomide but has been modified by researchers to take advantage of the anticancer properties while substantially reducing the likelihood of side effects such as peripheral neuropathy.

Understanding Dexamethasone and Other Steroids explains what dexamethasone is, how it works, its possible side effects, dosages and dose scheduling, how dexamethasone is given, and drug interactions. Information about other corticosteroids used in the treatment of myeloma is presented as well.

Understanding Serum Free Light Chain Assays explains a new type of laboratory test called the serum Free Light Chain assay (FREELITE®).

Please log on to our website at www.myeloma.org or call us at 800-452-CURE (2873) and we will be happy to send you a copy.



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Dear Reader,

At a time when recent advances with novel therapies are beginning to become incorporated into mainstream treatments for myeloma, the IMF's role as the disseminator of crucial information regarding the use

and access to these drugs has been heightened.

It's a challenge for all constituencies – patients, doctors, nurses, and healthcare providers – to keep current on the new protocols, data from new and ongoing trials, and novel drugs as they move from use in relapsed settings into frontline therapy options.

The role of the IMF has always been to provide the most up-to-date information on the treatment and management for myeloma, so that patients and their families can effectively partner with their doctors and make informed decisions about what's the right treatment choice for them. To meet the ever-increasing demand for accurate and up-to-date information, the IMF has expanded the myriad programs we provide.

We've expanded our highly acclaimed Understanding series of brochures. These brochures provide in-depth information on specific therapies and drugs, and now include:

- Thalidomide
- Revlimid®
- VELCADE®
- Bisphosphonates
- Dexamethasone and other Steroids
- Quadramet®
- Trisenox®
- Kyphoplasty
- Serum Free Light Chain Assays.

Many of the Understanding series brochures are available in several languages besides English, including French, German, Hebrew, Italian, Portuguese, and Spanish. These publications are offered in hard copy, as well as on the web.

The IMF has been conducting teleconferences with Support Group Leaders to inform them about the breaking news on specific therapies, so they can relay that information back to their members. We've also initiated a dialogue with the Leaders and have received their valuable input and feedback on clinical trial design.

The IMF website is rich with interviews conducted with key opinion leaders in the myeloma community. These interviews provide a wonderful opportunity to hear their comments and thoughts on trials they are conducting, as well as emerging data from the studies that could lead to new treatment protocols.

We are all on the cusp of a very exciting future!

Warm regards, Susie Novis



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