“Until There is a Cure… There is the IMF.”

MYELOMA TODAY

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

Highlights

Report from ASCO 2006

2006 Robert A. Kyle
Lifetime Achievement Award

Maddie Hunter
at 2006 SGLR in Arizona

2006 IMF SCIENTIFIC ADVISORY BOARD RETREAT

REPORT FROM THE SAB ANNUAL MEETING FARO, PORTUGAL • APRIL 2006

By Douglas E. Joshua, BSc MBBS DPhil FRACP FRCPA

I attended the first IMF Scientific Advisory Board Retreat, which was held in 2000 on the island of St. John in the U.S. Virgin Islands. The retreats continued to take place on a biannual basis, with groups of IMF Scientific Advisors gathering in an informal setting. The focus of these meetings is to enable free-flowing discussion among members of the Board. The topics of the discussions are agreed upon in advance but the format is quite flexible.

The main aim of discussion for the 2006 IMF Scientific Advisory Board Retreat – which took place in April near Faro, Portugal – was to move toward a consensus for Management Guidelines in Myeloma in 2006. Twenty-two participants gathered to consider questions relating to diagnostic testing, frontline therapy, transplantation, maintenance, supportive care, and other ancillary topics. We also discussed the IMF's support of major myeloma research initiatives, such as Bank On A Cure®.

Prof. Douglas E. Joshua
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The meeting was chaired by Dr. Brian Durie. Specific questions on various topics were circulated to the participants. We replied via an electronic interactive device, which immediately displayed our answers. I found it very interesting to learn my colleagues' anonymous opinions.

For example, the first question posed to us dealt with whether or not every patient should get an MRI at diagnosis. Our answers clearly indicated that there were several opinions

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REPORT FROM 2006 ANNUAL MEETING OF THE AMERICAN SOCIETY OF CLINICAL ONCOLOGY

By Lynne Lederman, PhD

Encouraging News

The 2006 meeting of the American Society for Clinical Oncology (ASCO), which took place June 2nd through 6th in Atlanta, Georgia, provided encouraging news about the use of novel therapeutics as single agents and in combination therapy in patients with newly diagnosed or relapsed myeloma. In addition, studies on the use of agents affecting bones are continuing. New agents are being investigated. Because some of the newer agents affect different pathways in myeloma cells, the use of these agents in combination may result in even higher response rates than the current standards of care.

Novel Agents in Patients with Newly Diagnosed Myeloma

For the first time at ASCO, myeloma was featured in the plenary session. Thierry Facon of the University of Lille (Lille, France) presented the results of the Intergroupe Francophone du Myelome (IFM) study comparing melphalan and prednisone plus thalidomide (MPT) with standard MP therapy or with high-dose melphalan followed by stem cell transplantation (SCT) in patients with newly diagnosed myeloma. The study included patients 65 to 75 years of age. Patients receiving the MPT treatment had a higher response rate than patients receiving standard MP, increased time to disease progression, and increased overall survival. In a discussion of this presentation, Kenneth Anderson of the Dana-Farber Cancer Institute (Boston, Massachusetts) called the results “a wonderful example of progress in our disease,” and noted that MPT should be considered as an option for a standard comparator to use in future trials of novel therapies for the treatment of elderly, newly diagnosed patients with myeloma. However, since patients receiving MPT experienced more side effects than those receiving MP, including a higher rate of blood clots (thrombosis) and neuropathy associated with thalidomide, other investigators feel that dose reductions may be required. Further studies are required to establish the role of MPT for elderly patients. Follow-up studies are needed to evaluate better-tolerated regimens with prophylaxis for thrombosis and infectious complications. In the meantime, MP will remain the comparator of choice, for example, in an upcoming trial of MP versus Revlimid®-MP (see Palumbo below). In addition, further studies are required to evaluate double stem cell transplant with reduced dose melphalan (100 mg/m2) versus MPT in eligible patients, including patients less than age 65 years. However, MPT may represent a good option for patients ineligible for SCT.

Vincent Rajkumar of Mayo Clinic (Rochester, Minnesota) presented another late-phase study in patients with newly diagnosed myeloma. He noted that although the response rates were higher in patients treated with thalidomide plus dexamethasone (thal-dex) than with dexamethasone alone, the time to disease progression has not yet been reached, and the differences in overall survival between treatments at about 2 years of follow-up are not significant. Potentially fatal blood clots occurred at a much higher rate in patients receiving thalidomide, leading to the use of aspirin as a preventative blood thinner. Decreased numbers of white blood cells was another side effect associated with thalidomide.

Antonio Palumbo of the University of Torino (Torino, Italy) presented an earlier phase study of lenalidomide (Revlimid) plus MP (R-MP) in patients with newly diagnosed myeloma. In this study, which was designed to determine the best dose of the agents used, response rates were promising, although further studies are needed.

Bortezomib was also studied in the frontline setting as a single agent. Paul Richardson of the Dana-Farber Cancer Institute reported on the study, which included an analysis of neuropathy in patients before, during, and after treatment. The study also evaluated ways to treat neuropathy

PLEASE SEE ASCO 2006 ON PAGE 5

The IMF Applauds the Food and Drug Administration’s Approval of Thalidomide for Multiple Myeloma Patients

The IMF applauds the FDA’s formal approval of thalidomide, marketed under the brand name THALOMID® by the Celgene Corporation, for the treatment of myeloma. Thalidomide was associated with an epidemic of birth defects in the 1950s-1960s when it was prescribed as a sedative for pregnant women across Europe, but the drug was later discovered to have powerful anti-cancer properties and has been transformed into the most widely prescribed treatment for myeloma today.

The use of thalidomide in multiple myeloma has evolved into a “Standard of Care” that extends and improves the quality of life of myeloma patients.

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IMF Calendar 2006

July	7-8	Portland P&F Seminar
Aug	4-5	Philadelphia P&F Seminar
Sept	2	P&F Seminar – CZECH REPUBLIC
	8	P&F Seminar – Paris, FRANCE
	23	P&F Seminar – Pamplona, SPAIN
	29	P&F Seminar – Bologna, ITALY
Oct	4-8	SWOG – Seattle, WA
	21	IMF 16th Anniversary Gala Celebration – Regent Beverly Wilshire Hotel, Los Angeles, CA
	19-21	Lymphoma/Myeloma Conference
	22-28	Myeloma Awareness Week
Nov	4-6	ECOG – Ft. Lauderdale, FL
	4	Second Annual Southwest Symposium – Tempe, AZ
Dec	8-12	ASH – Orlando, FL

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.

ASCO 2006 — continued

if it occurred. In this study, at least half of the patients had neuropathy at enrollment, although in the scientific literature only 10% of patients with myeloma were thought to have clinical neuropathy at diagnosis. Neuropathy that arose during bortezomib treatment was manageable and mostly reversible. The overall response rate with bortezomib as a single agent was 40%, with 10% complete response (CR), making bortezomib the most active single agent in myeloma. Richardson acknowledged that bortezomib will probably be used primarily in combination therapy, although it does offer a steroid-sparing option, and was not associated with clotting. Sundar Jagannath of St. Vincent's Cancer Center (New York, New York), in discussing Richardson's data, indicated that it confirmed prior published data and that current studies with bortezomib in combination with dexamethasone and/or other agents are necessary to offer response rates higher than 40% for frontline patients. Several combinations have produced responses in >90% of patients in the frontline setting.

Bart Barlogie of the Myeloma Institute for Research and Therapy at the University of Arkansas for Medical Sciences (Little Rock, Arkansas) presented early results of a trial investigating the incorporation of bortezomib into total therapy 3 (TT3) in patients with newly diagnosed myeloma. TT3 has been developed to improve on the results of TT2, and consists of a shortened course of induction therapy with DTPACE (dexamethasone, thalidomide, cisplatin, Adriamycin, cyclophosphamide, and etoposide) plus bortezomib followed by stem cell collection and tandem SCT. Patients also received thal-dex before and after the high-dose melphalan used before SCT, as well as bortezomib plus DTPACE until the end of the first year of treatment. During the second year of treatment, patients received monthly bortezomib plus thal-dex, then thal-dex alone during years three and four of therapy. So far, response rates for TT3 are higher than for TT2, and responses occur earlier in the course of therapy. Patients who are over age 65, have higher lactate dehydrogenase (LDH) levels, abnormal cytogenetics, or more advanced disease, are more likely not to respond to TT3. LDH appears to be the key factor, and is a marker for high-risk myeloma. Side effects with TT3 appear to be lower than with TT2, including the risk of blood clots, although the rate for TT3 was 27%, and all patients received low molecular weight heparin as a preventative.

Ruben Niesvizky of Weill Medical College of Cornell University (New York, New York) presented results of a Phase II trial of lenalidomide plus dexamethasone (len-dex) in combination with clarithromycin in patients with newly diagnosed myeloma. This combination appears to safe and well tolerated at approximately one year of follow-up, allowing eventual SCT in some patients, although 15% of patients had clots. The initial CR rate is equal to or better than reported with len-dex alone (without clarithromycin). The study group suggests that this combination be investigated further.

Novel Agents in Patients with Relapsed Myeloma

More results of the North American study (MM-009) of len-dex compared with dexamethasone alone in patients with relapsed myeloma were presented by Donna Weber of the M.D. Anderson Cancer Center (Houston, Texas). This is a companion study to one conducted in Europe (MM-010), for which results were presented at the 2005 American Society of Hematology (ASH) conference. As in the companion study, this study showed that patients treated with len-dex had significantly higher response rates, longer time to progression, and increased overall survival. Weber noted that not all of the analyses are complete. Although some side effects, such as neuropathy, constipation, and fatigue, are less frequent with lenalidomide than with thalidomide, lenalidomide is associated with increased effects on blood-forming cells, resulting in anemia and decreased white blood cells and platelets. Lenalidomide also causes blood clots at about the same rate as thalidomide, which will probably require some preventative therapy. The rates of clotting were different in the North American and European studies, and the reasons for are not known. Ruben Niesvizky gave an analysis of both studies that showed that there was an increased risk of blood clots in patients receiving lenalidomide in combination with dexamethasone and erythropoietin. Increased patient age, higher numbers of plasma cells, and a decreased performance status (a measure of patients overall health), were also associated with an increased rate of clotting. Although aspirin use appeared to protect against blood clots, Niesvizky said a prospective, randomized, clinical trial was needed to study the effects of aspirin and other preventative agents, and that the use of erythropoietin should be minimized for patients receiving len-dex.

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ASCO 2006 — continued

M. Wang discussed a companion analysis of the MM-009 and MM-010 studies, which attempted to determine if prior treatment with thalidomide had an effect on the response to len-dex. Because the groups receiving and not receiving thalidomide did not have comparable histories of prior therapy and course of disease, it was not possible to answer this question. Another analysis of these two studies, presented by Edward A. Stadtmauer of the Abramson Cancer Center at the University of Pennsylvania (Philadelphia, Pennsylvania) concluded that the time to progression was longer for patients who received len-dex earlier at first relapse, rather than later as salvage therapy.

Ibrahim Yacoub-Agha (Lille, France) presented a final analysis of the IFM 01-02 study of low vs. high doses of thalidomide plus dexamethasone (at 3 months if disease was stable or at progression) and pamidronate. Patients receiving the lower dose of thalidomide required dexamethasone more frequently, and there was no difference in the two treatment groups for overall survival at one year, although it was better tolerated. There was a discussion of the best starting dose of thalidomide, with no consensus reached.

Additional data analyses were reported for the APEX Phase III clinical trial of bortezomib vs. dexamethasone in patients with relapsed/refractory myeloma. Dan Vogl of the University of Pennsylvania Cancer Center (Philadelphia, Pennsylvania) presented an evaluation of the impact of prior autologous SCT. The analysis showed that patients receiving bortezomib had significantly higher overall rates of response, significantly higher CR rates, and longer times to disease progression than patients receiving dexamethasone whether or not they had received prior SCT, and regardless of whether the SCT was part of their only line of prior therapy.

Results of weekly treatment with bortezomib in patients with previously treated myeloma who had received 1 or 2 prior treatment regimens was reported by T. Anthony Greco for the Minnie Pearl Caner Research Network. In this Phase II trial, the overall response rate and median progression free survival was similar to patients receiving twice-weekly bortezomib. The weekly dosing was well-tolerated and active, although the number of patients in this study was small. Another study looked at bone markers in patients receiving weekly bortezomib, and this study is summarized below.

Results of a small preliminary study evaluating bortezomib in patients with cancer and impaired kidney function were reported by D. Mulkerin for the National Cancer Institute (NCI) Organ Dysfunction Working Group. The study included 13 patients with myeloma and showed that bortezomib at the approved dose and schedule was well tolerated in patients with varying degrees of impaired kidney function, including patients on dialysis.

Agents Affecting Bone Metabolism

James Berenson of the Institute for Myeloma and Bone Cancer Research (West Hollywood, California) presented results of a Phase I trial of a radioactive, bone-seeking compound, samarium (Sm153) lexidronam (Sam) in combination with bortezomib in patients with relapsed/refractory myeloma. Bortezomib is given in 8-week cycles in order to reduce the potential side effects of the combination therapy. Sam targets remodeling bone, which may be sites of myeloma cell activity. Myeloma cells are sensitive to radiation, and Berenson feels that bortezomib increases this radiosensitivity. So far the combination of bortezomib and Sam appears to be well-tolerated and Berenson expects the non-overlapping side effect profiles of the two drugs to contribute to patient quality of life. Additional patients are being enrolled in this study.

Berenson also presented the results of a study looking at the survival of patients with myeloma who received zolendronic acid, a bisphosphonate that is indicated for treatment of bone metastases. Survival of patients receiving zolendronic acid was compared to that of patients receiving another bisphosphonate, pamidronate. The researchers also looked at the levels of bone alkaline phosphatase (BALP), a marker of bone metabolism, at baseline. At 25 months, the survival was significantly higher for patients receiving zolendronic acid compared with pamidronate. For patients with low baseline BALP levels, survival was similar in both treatment groups. However, for patients with high baseline BALP, which may be a marker of more aggressive bone disease, survival was significantly higher for those who received zolendronic acid. Another risk factor in addition to high baseline BALP is a history of skeletal related events, such as bone fractures. Comments from the audience indicated the need for a prospective randomized trial incorporating testing of established bone activity markers such as NTX are required to draw any conclusions.

Shachar Peles presented the results of a prospective study on the effects of weekly bortezomib on bone markers in patients with myeloma. Patients received bortezomib pre-SCT after induction, and as consolidation following

SCT. Patients did not receive bisphosphonates for 42 days before SCT and for the first 3 cycles of consolidation therapy. Bortezomib inhibited bone resorption by osteoclasts, the cells that break down bone, even in patients whose myeloma cells did not respond to bortezomib. It was suggested that bortezomib may provide an alternative and/or adjunct to bisphosphonates, which have been associated with long term side effects in patients with myeloma, including kidney toxicity and erosion of the jawbones.

Early Clinical Trials

A Phase I trial, reported by Asher Chanan-Khan of the Roswell Park Cancer Institute (Buffalo, New York) evaluated the combination of KOS-953 (17-AAG in Cremophor) plus bortezomib in patients with relapsed refractory myeloma. KOS-953 inhibits heat shock protein 90 (HSP90), which is required for the function of certain cancer-related proteins. As a single agent, KOS-953 is not very active; in combination with bortezomib, better responses were seen whether patients had received prior bortezomib or not, and whether or not they had responded to bortezomib without KOS-953. The study is continuing to enroll patients.

Martha Lacy of Mayo Clinic (Rochester, Minnesota) described a Phase I trial of a monoclonal antibody (CP-751, 871), which reacts with the insulin-like growth factor 1 receptor (IGF-1R), in relapsed or refractory myeloma. The antibody was safe and well tolerated as a single agent and in combination with dexamethasone, and the combination showed potential anti-myeloma activity.

S.E. Biehn of the University of North Carolina at Chapel Hill School of Medicine (Chapel Hill, North Carolina) presented follow-up data for a Phase I trial of bortezomib and pegylated liposomal doxorubicin in patients with myeloma. This combination significantly increased both time to progression and time to re-treatment compared with patients' previous treatment. The patients' red blood cell and platelet counts, performance status, and level of response, were associated with outcome and might be predictive, although a larger study is needed to confirm this.

Other early-phase trials that reported encouraging preliminary responses and/or tolerability results in patients with relapsed or refractory myeloma include studies of the combination of arsenic trioxide, bortezomib, and ascorbic acid (vitamin C), presented by James Berenson; combination bendamustine in combination with thalidomide and prenisolone presented by W. Poenisch of the University of Leipzig (Leipzig, Germany); and temsirolimus (CCI-779) as a single agent, which warrants further study alone and in combination, presented by S.S. Farag of the Ohio State University (Columbus, Ohio). For all of theses therapies, additional trials have been suggested.

Unanswered Questions and Future Directions

Although the problem of blood clots associated with both thalidomide and lenalidomide was discussed, there was no consensus on the best way to prevent them. Preventative therapy may include the use of aspirin or other clot-preventing drugs, such as Coumadin® or low molecular weight heparin, depending upon a particular patient's risk factors. Factors that increase the risk of blood clots include the use of certain chemotherapy agents, for example, doxorubicin and melphalan, and the use of erythropoietin. Whereas patients taking high doses of corticosteroids, such as dexamethasone, appear to have a lower risk of blood clots if it is not given in combination with lenalidomide or thalidomide.

Given the encouraging results with bortezomib, lenalidomide, and thalidomide, additional clinical trials combining these drugs with each other and with some of the more traditional agents are expected. The best combinations and courses of therapy still need to be determined. Richardson suggested that physicians should "be thoughtful in the selection of combinations, so that efficacy won't be lost to toxicity." It is still not known what treatments to use as maintenance therapy for patients whose myeloma is in remission, and this question, too, will need to be answered using clinical trials. The best measure of response was also an issue for some investigators. Barlogie believes that CR is an important surrogate for improved survival, whereas Berenson believes that paraprotein production, used as a marker for CR, is probably not produced by the population of cells responsible for fatal disease. However, at this time, there isn't a better marker for those cells.

Several new anti-myeloma agents are in early stages of development, as well as in early clinical trials. As new agents are developed that act against myeloma in different ways, combinations of new and established therapies should continue to results in increased numbers of patients with complete responses that are maintained for longer periods of time. **MT**

NOTE: Lynne Lederman, PhD, is a medical writer based in Mamaroneck, New York.

SAB MEETING — continued

on the matter. While an MRI is valuable in a clinical trial setting, this test is certainly not routine. Most participants felt that, at present, an MRI should only be performed if symptoms indicated the necessity for this test. Of course, if the costs of performing an MRI were to decrease, the consensus might shift in a different direction. In the meantime, an MRI should always be performed in patients who appear to have a solitary plasmacytoma but might actually be demonstrating an apparently single manifestation of multiple myeloma.

The next question we addressed related to the use of the FREELITE® test, which measures free lambda and kappa light chains in the blood. This diagnostic test enables subsequent monitoring of myeloma patients who do not have an identifiable immunoglobulin heavy chain. There was an overwhelming consensus that this is a very valuable test. Our responses indicated that while some of us use this test routinely, others use it only in the presence of light chain disease.

Next, we addressed baseline cytogenetics and the FISH (fluorescent in situ hybridization) technique. Cytogenetics is a way to look at chromosome abnormalities in dividing cells. FISH provides researchers with a way to visualize and map an individual's genetic material, which is important for understanding a variety of chromosomal abnormalities and other genetic mutations. There was an almost unanimous agreement that baseline cytogenetics and FISH should be done at diagnosis.

We then discussed how we should best treat patients who are suitable for transplantation, before they undergo that procedure. Our survey made it clear that the use of VAD as induction therapy has decreased dramatically. The participants have had different experiences with frontline therapy prior to transplantation. In part, this was due to cost and reimbursement issues in the countries where the Scientific Advisors practice. For example, while thalidomide is used as part of induction in some countries, in Australia it is NOT currently covered by insurance when used in a frontline setting. These differences in financial scenarios alter treatment options because most patients who are not enrolled in clinical trials must rely on insurance to help with the cost of their cancer therapy.

There was a consensus reached that, after transplantation, patients should be re-vaccinated with the standard childhood vaccines.

When no harvest or transplant is planned for a myeloma patient, many types of drug combinations are currently available for frontline therapy. Certainly it can be said that we have better treatment tools at our disposal now than ever before, but there is not one single recommendation that can be made at this time. We now see some myeloma patients achieve complete remission without transplant, but it is still unclear if these remissions are as stable and durable as with transplantation. Based on the Italian study, the optimal treatment for elderly newly diagnosed patients seems to be a combination of melphalan, prednisone, and thalidomide (MPT).

Treatment after relapse often depends on what's available – not everyone has access to all the novel therapies. Patient preference must also be taken into account – some patients are not able to visit a hospital several times a week to receive treatment and, therefore, opt for treatments available orally. Patient toxicity is another important aspect of selecting treatment. If a laboratory or biochemical relapse occurs without any clinical problems, most Scientific Advisors felt that observing a patient was preferable to initiating another course of treatment before the patient develops symptoms or laboratory changes (e.g. anemia).

Regarding bisphosphonate usage, some participants recommended bisphosphonates for all patients with active myeloma, while others thought that use should be restricted to patients with documented bone disease. There was a consensus that careful dental baseline evaluation is mandatory prior to starting bisphosphonates, and that bisphosphonates should be stopped if patients develop osteonecrosis of the jaw (ONJ). There was some disagreement whether patients without complications and in clinical remission should continue or stop bisphosphonate therapy. However, a consensus view evolved to suggest that patients' use of bisphosphonates should be re-evaluated after two years.

ADVANCING ACCESS TO MULTIPLE MYELOMA TREATMENT

IMF Sponsors Symposium at ONS Annual Congress

Nurses are on the front line in the battle against myeloma. A nurse can be your biggest advocate and a great source of information and empathy. With that in mind, The IMF annually attends the Congress of the Oncology Nursing Society (ONS), the better to meet, educate, and share information with the nursing community.

This year, the annual congress was held in Boston, and the IMF Hotline closed for a week so that the hotline staff could attend. We decided to embrace the revolutionary spirit of that fine city and "revolutionize" our presence and participation at the conference. The IMF thus held our first breakfast meeting – Advancing Access to Multiple Myeloma Treatment – a two-hour presentation designed to provide continuing education units (CEUs) for the nurses.

Three esteemed oncology nurses, Patricia Mangan from University of Pennsylvania Hospital, and Kathleen A. Colson and Deborah S. Doss from the Dana-Farber Cancer Institute, gave presentations designed to shed light on advancements in the treatment of myeloma. The room was packed! Over 350 nurses attended the Advancing Access to Multiple Myeloma Treatment meeting, which ran from 6:30 to 8:30 A.M. on Thursday, May 4th.

Advancing Access to Multiple Myeloma Treatment

EDUCATIONAL OBJECTIVES

- Describe novel therapies of the treatment of MM and identify patients who will benefit most from these novel therapies;
- Manage new and relapsing patients who are prescribed novel therapies for the treatment of myeloma;
- Locate clinical trials and expanded access programs where patients can receive novel therapies for treatment of myeloma; and
- Understand the potential use of novel therapies for special populations.

Throughout the rest of the week, in the IMF booth at the conference center, many nurses stopped by to pick up our free educational materials and to chat. They were delighted to learn that we had an almost instant DVD of the breakfast meeting, available the next morning. Many who attended the meeting were eager to pick up the DVD in order to have the information at hand as a resource for themselves and their colleagues. Others – those who didn't wake up early enough to get to the meeting or were attending another breakfast meeting – were delighted to be able to attend "virtually." We heard from many attendees that our meeting was the best source of information about myeloma care and treatment that they had ever received.

It is evident from the post symposium reactions that the IMF filled a void in further educating the ONS community. The Foundation takes very seriously our responsibility to be the world's best source of information on myeloma – for patients and the medical community alike. The nurses' appreciation galvanized our decision to make this event a yearly offering.

NOTE: To learn more about the presentation made by Deborah S. Doss from the Dana-Farber Cancer Institute, please see page 20.

SAB MEETING — continued

Another area that the Scientific Advisors discussed was which research is likely to provide the best leads to improve therapy. There were many opinions on this subject, and this discussion will continue at the level of the IMF Board.

In conclusion, I'd like to say that the IMF Scientific Advisory Board Retreat program is a very valuable venue for myeloma specialists to share their experience, as well as gain knowledge about clinical research data that is yet to be published. **MT**

NOTE: Responses to questionnaires distributed to IMF Scientific Advisors not in attendance at the Retreat in Portugal have begun to come in, with the majority reinforcing the responses collected in Faro. The final consensus results will be written up and presented as 2006 Management Guidelines in Myeloma, and will reflect current evidence, plus areas of ongoing research and potential controversy.

2006 BRIAN D. NOVIS JUNIOR RESEARCH GRANT PROJECT PROFILE

Role of WNT and RUNX2 Pathways in the Inhibitions of Osteoblasts in Myeloma Patients

Introduction

At the IMF Scientific Advisors Meeting held in December of 2005 in Atlanta, Georgia, the IMF announce the recipients of its 2006 Brian D. Novis Research Grants. One of the Junior Research Grants worth $40,000 was awarded to Dr. Nicola Giuliani for his project investigating the role of WNT and RUNX2 pathways in the inhibitions of osteoblasts in Myeloma patients. Myeloma Today is pleased to present Dr. Guiliani's research profile.

Research Profile

Multiple myeloma is characterized by its high capacity to induce osteolytic bone lesions. Bone lesions have a critical impact on patient quality of life. Growing evidence has suggested that the bone marrow microenvironment plays a pivotal role in the regulation of myeloma cell growth and in the development of bone lesions.

Nicola Giuliani, MD, PhD
University of Parma
Parma, Italy

The study of the interactions between myeloma cells and the bone microenviroment may lead to the identification of new therapeutic targets in myeloma. In particular, histomorphometric studies have demonstrated that myeloma patients with high plasma cell infiltration are characterized by a lower number of osteoblasts and decreased bone formation, suggesting that the inhibitory effect of myeloma cells on osteoblast formation is a critical point in the development of lytic bone lesions.

The biological mechanisms by which human myeloma cells inhibit bone formation have not been completely understood. Dr. Guiliani's research project is focused on the study of the biological mechanisms involved in the interaction between myeloma cells and osteoblasts. Osteoblast formation and differentiation is critically regulated by the transcription factor Runx2; Dr. Guiliani and his colleagues have demonstrated that myeloma cells are able to suppress the activity of Runx2 in human bone marrow (BM) osteoprogenitor cells, thus inhibiting osteoblastogenesis. Wnt signaling is also involved in the regulation of osteoblast formation. There is a relationship between Wnt signaling inhibitor DKK1 and the presence of bone lesions in myeloma patients. The effect of myeloma cells on the Wnt signaling pathway in human osteoblastic and BM osteoprogenitor cells, however, has never been investigated. Moreover, the potential alterations of Wnt signaling, Runx2, and other pathways that regulate osteoblastogenesis, as well as their relationship in osteoblastic and osteoprogenitor cells in myeloma patients, are not known. Dr. Guiliani is investigating which pathways are involved in the inhibition of osteoblast function in myeloma patients in order to identify new therapeutic targets. Dr. Guiliani is also analyzing the potential role of osteoblast inhibition in the transition from monoclonal gammopathy of unknown significance (MGUS) to myeloma.

Dr. Giuliani will create an in vitro co-culture system between myeloma cells obtained from both osteolytic and non-osteolytic patients and human osteoblastic cells or osteoprogenitor cells. After the culture period, Wnt signaling and Runx2 pathways will be analyzed in osteoblasts by microarray and further evaluated by real time PCR and western-blot analysis on selected molecules. Both canonical and non-canonical Wnt pathways will be checked, evaluating either nuclear/cytosolic active and non-active beta-catenin or JNK expression. In addition, the activity of the transcription factor LEF-1 and the TCF family, along with Runx2, its co-factors Hey-1 and ATF-4, and the transcription factors AP-1 and FRA-1, will be analyzed by EMSA and ELISA-based methods.

Results obtained will be correlated with the expression of osteoblastic markers and with osteoblast formation in vitro. The effect of the selected activation of Wnt and Runx2 on myeloma – induced inhibition of osteoblast formation and differentiation will be investigated using an in vitro system. To investigate the mechanism by which myeloma cells could affect Wnt and Runx2 signaling in osteoblasts, Dr. Giuliani will screen for the myeloma cells' production of inhibitors of both pathways, and determine the potential involvement of cell contact and integrin systems using specific blocking

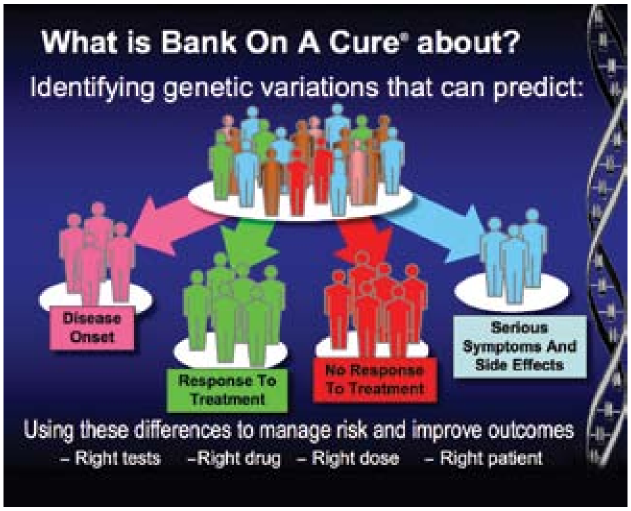
PLEASE SEE JUNIOR RESEARCH GRANT ON NEXT PAGE

PROGRESS REPORT: BANK ON A CURE® RESEARCH INITIATIVE

We don't just believe in a cure, we're banking on one!

Our Project

Bank On A Cure® is the International Myeloma Foundation's groundbreaking myeloma research project. With the understanding that each patient's response to therapy is unique and influenced by his or her own DNA patterns, the IMF has developed this first-ever comprehensive databank of myeloma patient DNA and information. Bank On A Cure brings together the global myeloma community – researchers, patients, families, and caregivers.



What is Bank On A Cure® about?

Identifying genetic variations that can predict:

Using these differences to manage risk and improve outcomes

– Right tests –Right drug – Right dose – Right patient

Our Goal

The goal of Bank On A Cure is to collect DNA samples from at least 10,000 participants. Processing and analyzing this data will yield important clues about each individual person's response to treatment and susceptibility to toxic side effects. This will help researchers gain a greater understanding of how myeloma drugs work, and how they can be improved.

Bank On A Cure data will also provide vital insights into the causes of myeloma, and, ultimately, will lead to its prevention and a cure.

Our Progress So Far

The IMF has acquired many DNA samples and correlative data from myeloma patients who have submitted kits individually or participated in "Swish and Rinse" group events. In addition, investigators from various institutions and major clinical trials groups have transferred samples gathered from patients enrolled in their current clinical trials.

The IMF has acquired two Affymetrix MegaAllele systems, completed the design of the custom myeloma SNP (single nucleotide polymorphism) testing chip, taken delivery on the first batch of chips, and run control samples. The IMF Scientific Advisors involved with the Bank On A Cure project have established the near-term priorities for analysis.

Using our Bank On A Cure data, the IMF is conducting comprehensive research with the National Cancer Institute (NCI) in order to identify genes linked to the causes of myeloma.

So far, we have processed over 3,500 DNA samples.

Our custom-designed DNA testing chip has helped us identify variations in genes that may explain why some people experience toxic side effects, and is helping us target more effective myeloma treatments.

In the near term, we plan to focus our efforts on investigating pharmacogenomics of thalidomide, Revlimid®, and VELCADE®, as well as on performing epidemiological studies.

The IMF will continue to update its members on the Bank On A Cure project as further progress is made. We thank all the friends of the IMF for the generous support that has made this innovative myeloma research project possible! **MT**

BANK on a CURE®

JUNIOR RESEARCH GRANT — continued

antibodies in the co-cultures. Further bone biopsies will be obtained from a large cohort of myeloma and MGUS patients with or without bone lesions. By immunohistochemistry, the expression of beta-catenin and Runx2 will be evaluated in stromal/osteobtastic cells of the different groups of patients, and will be correlated with the presence of bone lesions. Fresh isolated osteoblasts will be obtained from bone biopsies using a modified previously published method. The expression of the different molecules of Wnt signaling and the Runx2 system, as well as the activity of the main transcription factors involved in osteoblastogenesis, will be analyzed.

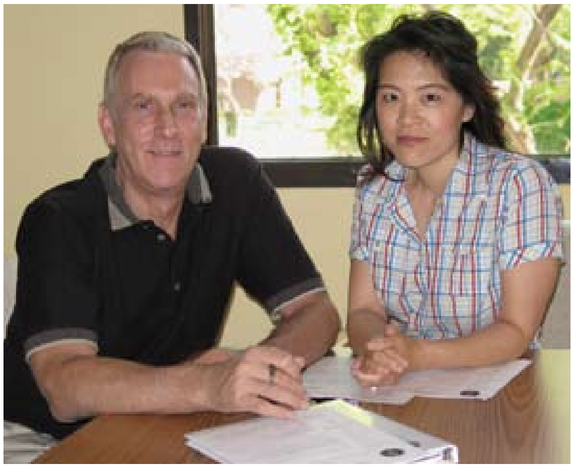
Dr. Guiliani's analyses will better enable us to understand the mechanisms by which osteoblast formation and differentiation are impaired in myeloma patients. **MT**

IMF PATIENT & FAMILY SEMINAR PROGRAM

A Conversation with Lisa Paik and Spencer Howard

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

Lisa Paik: I started working with the IMF in June of 2001. The first IMF Patient & Family Seminar that I worked on was in October of that same year in Stamford, CT. That experience afforded me my first interaction with a large group of myeloma patients and caregivers. I was so impressed! The local myeloma community welcomed the IMF warmly and enthusiastically and, in turn, it was evident just how much the Foundation cared for its members.


Spencer Howard (Meeting & Event Services) and Lisa Paik (Director, Medical Meetings & CME Programs)

Spencer Howard: I also came onboard with the IMF in 2001, just before the Foundation's 11th Anniversary Gala Celebration. My background is in event planning, and I was involved in organizing that evening. In early 2002, I worked on my first IMF Patient & Family Seminar.

Myeloma Today: Please describe your involvement with the seminar program.

Spencer Howard: Lisa and I meet with Susie Novis and Dr. Brian Durie. Sometimes, other IMF staffers join us. We identify potential locations for upcoming seminars, along with possible dates. Then I work with visitor and convention bureaus in the locations we are considering to find venues that would be appropriate for us. I narrow it down to three or four possible venues in each city, then conduct site visits to identify the facilities that best meet our requirements. Once the venue and meeting dates are set, I proceed with organizing various logistical aspects of the seminar, keeping in mind the special needs of our attendees.

Lisa Paik: I handle the faculty coordination. Dr. Durie and I identify faculty candidates for each meeting. Every doctor has a special area of interest, so we work on selecting a very balanced panel of experts.

Myeloma Today: What are the basic components of an IMF Patient & Family Seminar?

Lisa Paik: On Friday, an invited Quality of Life speaker addresses a specific topic of interest to the myeloma community. On Saturday, the general session is divided into five basic sections: Myeloma 101 is a great introductory overview of various aspects of the disease. Standard (a.k.a. Frontline) Therapy is a presentation of treatment options. Transplantation options are always addressed. Supportive Care, Bone Disease, and Post-Transplant Maintenance regimens are discussed. The last section tackles either Novel Agents or treatment options after relapse. Each session is comprised of an uninterrupted lecture by a faculty member, followed by a question and answer period, and an interactive multiple-choice electronic survey. After the general assembly portion of the seminar, we hold several smaller breakout sessions; each presided over by a member of the faculty. In addition, Susie Novis, President of the IMF, conducts a breakout session for caregivers. Attendees can choose to attend all or just some of these breakouts.

Myeloma Today: What comprises the interactive component of the seminar?

Lisa Paik: The interactive part of our seminar program was initiated in 2003. It involves an electronic keypad that allows audience members to communicate information to the presenters of each session quickly and efficiently. Interactive participation has long been a standard part of conferences for medical professionals. Since this was a format that was clearly beneficial to doctors, it made sense to make it available to the patient community as well. It's been a great addition to our program, and an abstract resulting from our interactive component was recently presented at the 2004 meeting of the American Society of Hematology (ASH).

Myeloma Today: What about patients who are unable to attend a seminar? How do you serve them?

Spencer Howard: The IMF videotapes one seminar per year and makes the videos available through our lending library. The next seminar to be filmed will take place on July 7 and 8 in Portland, OR. Arranging the audio/visual and interactive aspects of each seminar falls under my responsibility.

Myeloma Today: Do you attend the seminars you organize?

Spencer Howard: Yes, of course, Lisa and I are always there, overseeing our areas of responsibility. We are also joined by IMF staffers representing all of our departments. Usually, at least one member of the IMF Board of Directors attends as well.

Myeloma Today: What is your personal impression of the IMF Patient & Family Seminar program?

Spencer Howard: It's a great opportunity for us to interact with our members, and for them to better know us. So many people who come to our seminars thank us for the experience, and its very gratifying to hear that they feel we've taken such good care of them.

Lisa Paik: I've learned a lot from Susie Novis and Dr. Brian Durie. And I feel that I've personally grown a lot as the IMF meetings program has expanded and developed. It's hard to describe what it's like to spend a weekend attending an IMF Patient & Family Seminar. Beyond the invaluable information being presented and the camaraderie of other patients and caregivers, attendees have unparalleled access to renowned myeloma specialists. Now that's something you really have to experience for yourself! **MT**

Portland IMF Patient & Family Seminar

Friday & Saturday, July 7–8, 2006

SATURDAY GENERAL SESSION FACULTY:

Dr. Ken Anderson, Dana-Farber Cancer Center, Boston, MA

Dr. Brian Durie, Cedars-Sinai Comprehensive Cancer Center, Los Angeles, CA

Dr. Robert Kyle, Mayo Clinic, Rochester, MN

Dr. Nikhil Munshi, Dana-Farber Cancer Center, Boston, MA

Dr. Robert Vescio, Cedars-Sinai Comprehensive Cancer Center, Los Angeles, CA

FRIDAY QUALITY OF LIFE SPEAKERS:

Dr. Loch Chandler, Nutrition and Lifestyle Influences on Myeloma

Dr. Eren Erdem, Balloon Kyphoplasty in Myeloma

Tina Kuus-Reichel, Ph.D. Freelite Testing in Myeloma

Philadelphia IMF Patient & Family Seminar

Friday & Saturday, August 4–5, 2006

FACULTY:

Dr. Brian Durie, Cedars-Sinai Comprehensive Cancer Center, Los Angeles, CA
Dr. Robert Kyle, Mayo Clinic, Rochester, MN
Dr. Sundar Jagannath, St. Vincent's Comprehensive Cancer Center, NY, NY
Dr. Greg Mundy, Vanderbilt University, Nashville, TN
Dr. Edward Stadtmauer, University of Pennsylvania, PA

FRIDAY QUALITY OF LIFE SPEAKERS:

Quality of Life discussion reserved for CEPHALON ONCOLOGY

Quality of Life Session discussion on Freelite Testing led by Technical Director Dr. Karen van Hoeven, Ph.D., The Binding Site

Quality of Life presentation reserved for Millennium Pharmaceuticals

Registration information for all seminars:

Package "A" – $85
includes Friday Welcome Dinner and
Saturday All-Day Seminar

Package "B" – $50
includes Saturday All-Day Seminar only,
no Friday Welcome Dinner

NOTE: For more information, please visit www.myeloma.org or call 800-452-CURE (2873).

Don't delay! Register for our seminars TODAY!

CDC GRANT UPDATE

By David Smith

The IMF has a history of grass-roots efforts and, with the IMF's Centers for Disease Control and Prevention (CDC) government grant renewed for second year funding, the IMF has continued to reach out to additional communities while strengthening our existing relationships. Our overall mission is to inform, educate, and support those affected by myeloma by raising awareness about the disease and its treatment, as well as about the programs of the IMF and ongoing research in the field.

An important component of the IMF's CDC grant is the creation of partnerships that foster the successful implementation of the objectives for which the grant was awarded. To that end, the IMF has partnered with the Urban Latino African-American Cancer Project (ULAAC) to offer an informative seminar on multiple myeloma. The incidence rate among African-American men is twice that of Caucasian men. In addition, the disease is often more advanced at the time of diagnosis. Clearly, there is a special need for information regarding myeloma at clinics, hospitals, senior centers, and churches in the African-American community.

On June 29, 2006, the IMF and ULAAC jointly sponsored a seminar on myeloma treatment and care. The seminar was held at the Memorial Campus of the Centinela Freeman Regional Medical Center in Inglewood, California. Specifically designed for members of the inner-city African-American myeloma community, the seminar brought together many Los Angeles Area myeloma patients and caregivers. Following a presentation by Dr. Brian Durie, time was set aside to respond to questions from the audience. Also, our CDC-funded video "I have myeloma…what's next?" was shown. This video is available free of charge and has been distributed across the U.S., as we reported in the Winter 2005/2006 edition of Myeloma Today.

As a result of the IMF outreach into the African-American community, interest in several inner-city areas has begun to develop, and we hope that awareness of myeloma in these communities continues to grow as a result of such partnerships. For more information regarding this program, please contact me at dsmith@myeloma.org or 800-452-CURE (2873). **MT**

Putting Your Donations To Work

At the IMF, we are proud of our record of keeping the cost of supporting services low. In 2005, the IMF devoted only 14 percent of revenue to administration and fundraising expenses. In other words, 86 cents of every dollar was put to work in IMF's programs and services. We are dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure as efficiently as possible. Thank you for your continued support! **MT**

INTERNATIONAL MYELOMA FOUNDATION
EDUCATION • RESEARCH • SUPPORT • ADVOCACY

We are proud to announce

The Second
SOUTHWEST SYMPOSIUM on MULTIPLE MYELOMA

at Arizona State University College of Law
Tempe, Arizona

Saturday, November 4, 2006

Featuring world-renowned myeloma specialists

SAVE THE DATE – REGISTER NOW

This informative and empowering symposium is ***FREE*** *to all, including healthcare professionals, patients, caregivers, and family members.*
However, you must register prior to the event.
For seminar registration and information, please contact Kelly Cox at 800 452-CURE (2873) ext 233 or email kcox@myeloma.org

Today there is much information available about myeloma, and that's good…but how do you make sense of it all? How do you know what's right for you or your patients? This symposium is designed to answer those questions.

Special room rates available for symposium participants.
The Courtyard Marriott
601 South Ash Avenue
Tempe, AZ 85281
480 966-2800

"Until There is a Cure... There is the IMF"

International Myeloma Foundation
12650 Riverside Drive, Suite 206
North Hollywood, CA 91607
800 452-CURE (2873)
www.myeloma.org

IMF'S 16TH ANNIVERSARY GALA CELEBRATION

Join us for a very special evening!

On Saturday, October 21, 2006, the International Myeloma Foundation will celebrate its 16th Anniversary. Our annual gala event will once again will be hosted by Robin Leach of "Lifestyles of the Rich and Famous," a friend of the IMF and the myeloma community. Set at the magnificent Regent Beverly Wilshire Hotel in Beverly Hills, the evening will feature live and silent auctions and an elegant dinner with dancing.

Master of Ceremonies
Robin Leach

Elegant Regent Beverly Wilshire Hotel

Last year, more than 350 people attended the IMF anniversary celebration, which raised over $300,000 to support the IMF's life-saving programs and services.

As you know, the IMF is the lifeline for myeloma education, research, support, and advocacy to over 135,000 patients, family members, caregivers, medical professionals, and researchers throughout the world. Our goal is to fund the best research, provide the highest quality education, offer the most thoughtful and comprehensive support, and serve as fervent advocates for the myeloma community.

The IMF is nothing without its most valuable members. 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 cmcdomald@myeloma.org or call at 800-452-CURE (2873). **MT**

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
United Kingdom

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

2006 ROBERT A. KYLE LIFETIME ACHIEVEMENT AWARD

Report from the Dinner Chairs

By Carol & Benson Klein

The IMF's Robert A. Kyle Lifetime Achievement Award was established in 2003 to honor physicians whose lifetime body of work most exemplifies a singular dedication to and compassion for myeloma patients and treatment of their disease, and furthers the ultimate goal of finding a cure. Dr. Kyle was the first recipient of the award named in his honor. In his more than 40 years at Mayo Clinic, Dr. Kyle has never wavered from his commitment to the needs of patients with myeloma. He has devoted his life's work to them, gaining recognition the world over as a pioneer and respected leader in the advancement of research, clinical treatment, and education about myeloma. Dr. Kyle is a founding member of the IMF Board of Directors and chairman of the IMF Scientific Advisory Board, a position he has held for the past 15 years. His humility, dedication, sense of humor, and compassionate nature are among the many reasons why the IMF named this award in his honor.


Benson and Carol Klein

The Fourth Annual Robert A. Kyle Lifetime Achievement Award was presented to Dr. Brian G.M. Durie, an absolutely terrific human being, dedicated physician, and friend. Dr. Durie is National Director for Hematologic Malignancies for Aptium Oncology in Los Angeles, California, where he is also Specialist in Multiple Myeloma and Related Disorders for Cedars-Sinai Outpatient Cancer Center. He is the Chairman of the Board of the IMF, and also serves as one of its Scientific Advisors. Among his many impressive appointments, publications, and research accomplishments, Dr. Durie co-created the Durie/Salmon Myeloma Staging System, which is the vital building block for the International Staging System that was co-developed by Dr. Durie with the International Working Group. Dr. Durie has written over 400 research papers, sixteen book chapters, and five books, work which has impacted myeloma treatment around the world.

We were honored to be asked to serve as dinner chairs for the 2006 Robert A. Kyle Lifetime Achievement Award. We have the highest respect for both Dr. Kyle and Dr. Durie, and we enjoy working on behalf of a community and a foundation that's given us so much. In advance of the event, we sent letters inviting our friends and family to join us for this very worthwhile cause that is so near and dear to our hearts. We enclosed two recent Myeloma Today articles. The first focused on the IMF's Kyle Awards. The second article featured our journey with myeloma and explained why we've become so involved in volunteering for the IMF. The response was terrific!

The award dinner took place on May 16, 2006, at the National Press Club in Washington, DC. We have been a part of the IMF and have known Dr. Durie since 1999, and the location of this year's award ceremony enabled many of our friends and family members to join us at the event and see firsthand why this Foundation is so near and dear to our hearts.


Dr. Robert Kyle presents award to Dr. Brian Durie

The award evening at the National Press Club started with a cocktail reception featuring fabulous wines from the Calistoga Estate in Napa Valley, California. Our friends Bill Redkin and Don Wilder drew an original comic and presented it to Dr. Durie. Since 1983, their comic strip "Crock" has occasionally featured a character named "Trooper Benson" and, with Bill and Don's permission, we have used the character on T-shirts and baseball hats as part of our fundraising campaigns to benefit the IMF.

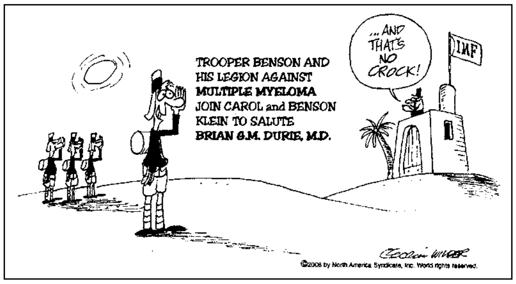
Guests spent a very friendly and enjoyable cocktail hour before proceeding into the main dining room. Mr. Michael Katz (Senior Vice President, Booz Allen Hamilton) served as the evening's Master of Ceremonies. Michael has been a member of the IMF Board of Directors for over ten years and has been a myeloma survivor since 1990. He introduced Susie Novis, who extended a warm welcome to the crowd.

Then it was Benson's turn to address the crowd. It was truly an honor to speak in the presence of so many remarkable physicians. It was an even greater honor to be a part of a tribute to such a respected, brilliant, dedicated, and truly beloved person as Dr. Brian Durie. Over the years, we have had the opportunity to learn of Brian's extensive education, experience, and commitment to the myeloma community. Benson's remarks were intended as a "Roast to Brian," and the dinner guests were happy to share a moment of levity while honoring this superb human being and physician. As far as we are concerned, there is no one more deserving of the prestigious Robert A. Kyle Lifetime Achievement Award.

The impressive roster of speakers that followed included Julian Adams (Chief Scientific Officer, Infinity Pharmaceuticals), Dalsu Baris (Staff Scientist, Cancer Epidemiology, National Cancer Institute), Stephanie Gallagher (President, World City America & World City Foundation), Gregory Mundy (Professor of Medicine, University of Texas Health Science Center), and Richard Saletan (Founder, Chairman, and CEO, Weston Group). Howard Urnovitz (Chief Executive Officer, Chronix Biomedical) was unable to attend but his words were read on his behalf.

(left to right) Dr. Gregory Mundy, Benson Klein, Susie Novis, Michael Katz, Dr. Brian Durie, Dr. Julian Adams, Stephanie Gallagher, Dr. Robert Kyle, Dr. Dalsu Baris, and Richard Saletan

Dr. Kyle, who has known Dr. Durie for more than 30 years, spoke of Dr. Durie's many professional accomplishments and his dedication to putting patients first. He then presented the award to Dr. Durie. The acceptance speech was wonderful, and allowed the guests to glimpse Dr. Durie's warm and jovial personality. Dr. Durie shared with all of us what the IMF and myeloma researchers and clinicians are all about. His speech was delightful, educational, and very meaningful, and ended the evening on a high note. **MT**



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NOTE: Benson Klein was diagnosed with multiple myeloma in 1998. For the past four years, he has served on the IMF Board of Directors. Benson and Carol Klein have chaired two IMF Galas. Thanks to the generosity of the Kleins, and their friends and family, the "Trooper" Benson Campaigns have raised over $250,000 for the IMF's research grant program.

IMF & MYELOMA CANADA

By David Smith

As Maddie Hunter reports so eloquently in this issue of Myeloma Today, the 7th annual IMF Support Group Leaders' Retreat had a clear recipe for success with an informative end result. This year's retreat also featured a Canadian Support Group Leaders Breakout Session. This breakout was organized by Aldo Del Col of the Greater Montreal support group and myself. The leaders of nine Canadian myeloma support groups were in attendance.

The need for a Canadian Support Group Leaders Breakout Session was articulated during last year's IMF Support Group Leaders' Retreat when a support group leader — Francesca Plaster of the Greater Vancouver group — suggested that the 2006 retreat contain some Canadian-oriented content. It was no surprise at this year's event that Francesca gave an excellent presentation about the growth of her group.

Since the IMF was founded, we have promoted a relationship with our "neighbours" to the north and with others around the world. Together with all the members of the global myeloma community, we look forward to the day when we can move myeloma to the list of curable diseases. The IMF hotline, website, publications, and seminars and conferences have helped us share information about myeloma treatments and promote awareness, education, and research. There is much to unite us, and our relationships continue to grow and develop.

In Canada, access to medications and to clinical trials is not controlled federally as in the U.S., but decided on the provincial level. In addition, in many parts of Canada, access to information and support can be problematic. In order to better inform Canadians affected by myeloma, Aldo and I proposed a partnership between our two organizations that would bring us closer together. Dr. Brian Durie spoke about the IMF's support of this relationship and the need for international collaboration that ultimately benefits the patient. I am very happy to report that this proposal was met with approval and enthusiasm.

In the coming editions of Myeloma Today, I will update you on the progress made in reaching a consensus towards this new step forward for both organizations. **MT**

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.

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:

I have been recently diagnosed with myeloma. Other than some general fatigue and some pain in my ribs, I feel pretty well. I am beginning a course of thalidomide and dexamethasone. I have always been fairly active (I am in my early 60's and have always played tennis and jogged regularly). What type of exercise do you recommend that I do to stay as strong as possible?

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

Answer:

The question of exercise for a myeloma patient is an important one. Dana-Farber Cancer Institute nurses with long experience have discovered that patients who experience weakness and fatigue improve more quickly and feel much stronger when they are well hydrated and get some exercise.

First and foremost, you must discuss any exercise plans with the doctor treating your myeloma and get clearance for anything you plan to do. Because bone involvement is quite common with myeloma; you must take into account the location of involved bones and what type of exercise, if any, is safe. In general, exercise is important for a myeloma patient; it will keep you feeling better physically and psychologically.

Since you are newly diagnosed, you should consider putting any form of strenuous exercise on hold for the first two or three months, or at least until your myeloma is well controlled. Until then, you are at a higher risk for progressive bone disease, infection, and deep vein thrombosis. It is nevertheless important to keep moving. Two of the safest and easiest forms of exercise are walking and swimming. (If you have a catheter in place for chemotherapy, however, you may not be able to swim.)

After about three months of treatment, your doctor will be able to re-evaluate your situation and let you know if the myeloma is sufficiently stabilized to permit more vigorous exercise. A CT or MRI scan might be required to assess your status. The doctor will provide guidelines according to your particular situation and possible limitations.

Any exercise program you undertake at this point should aim to achieve three goals: strength, flexibility, and endurance. Most exercises that increase strength are quite safe, in moderation (e.g. 2- to 5-pound weights). Flexibility exercises are best performed when the muscles are warm, so you should do them at the end of exercising or in warm water (aqua therapy). A personalized yoga program could also be of benefit. Endurance can be achieved with a 15 to 20-minute daily brisk walk. Some patients have been able to work with highly experienced physical therapists to increase and maintain strength and mobility. Such physical therapy should be discussed with your oncologist, who will determine if it is appropriate, write a prescription for it, and recommend a therapist who has experience with myeloma patients, if possible.

As for your tennis and jogging, you may probably resume the tennis, with your doctor's permission. Most doctors feel that jogging is too jarring to the bones, and should be avoided by myeloma patients. Other sports that should be avoided are contact sports (football, basketball, rugby, etc.), biking (mountain or road as opposed to stationary, which is fine), ice-related sports (skiing, ice skating, hockey), water-skiing and ski jumping, and driving in off-road vehicles.

Keep in mind that every patient's situation is different with regard to pre-myeloma fitness, overall health, and how myeloma affects the body. The key to any safe and effective exercise program is careful and regular consultation with your doctor. **MT**

MYELOMA PATIENTS & NOVEL THERAPIES: MANAGEMENT OF SIDE EFFECTS

By Deborah S. Doss, RN

The Oncology Nursing Society (ONS) is a professional organization of registered nurses and other healthcare providers that promotes excellence in oncology nursing and quality cancer care. The 31st Annual Congress of the ONS featured an educational symposium, Advancing Access to Multiple Myeloma Treatment, which was sponsored by the IMF and the Institute for Continuing Healthcare Education (ICHE). Designed to meet the needs of oncology nurses who manage the treatment of myeloma patients, the symposium addressed the development of and access to emerging treatments.


Deborah S. Doss, RN
Multiple Myeloma Clinical Research Nurse
Dana-Farber Cancer Institute
Boston, Massachusetts

My presentation at the IMF symposium focused on the management of patients who are prescribed novel therapies for the treatment of multiple myeloma. New drugs can produce new problems, and nurses are on the front lines of intervention, symptom management, and education. Total or holistic care of patients involves being familiar with a patient's medical status, unique disease, and personal history. Educating patients as to what side effects they may expect, and continually assessing them for symptoms, is an integral part of the nurse-patient relationship. For example, it may be a nurse who first recognizes a patient's vague remarks as symptoms of peripheral neuropathy.

Peripheral neuropathy is not an uncommon side effect of thalidomide and VELCADE®. All over the world, there are studies going on trying to find ways to combat peripheral neuropathy produced by drug therapy and also in diabetes. At the cancer institute where I work, we do a lot of reading on this topic while researching new treatments. In the literature there is now a great deal of anecdotal evidence that suggests that a regimen of high-dose vitamin B complex, along with folic acid and two amino acids, helps with peripheral neuropathy. Many of our patients have reported back to us that they do find this combination of vitamins and minerals helpful in decreasing the discomfort of their neuropathies. There are also new prescription drugs on the market that we are using for patients who have more severe peripheral neuropathy. Recently approved by the FDA for treatment of peripheral neuropathy are Duloxetine® and Lyrica®. Gabapentin is also frequently used to treat neuropathic pain.

At the Dana-Farber Cancer Institute, we have been tracking side effects of Revlimid® for the past five years. Three patients from the first Phase I protocol of five years ago are still on the drug, and they still have stable disease. Fifteen to twenty patients from the Phase II protocol of four years ago also continue to have very stable disease. We have seen mild gastrointestinal (GI) side effects, rashes, and lowering of blood counts. So far, there seem to be fewer side effects associated with Revlimid than with thalidomide.

VELCADE is another novel therapy currently being used in the treatment of multiple myeloma. One common GI complaint is constipation and loose stools. Because each patient is unique, we try to devise a bowel regimen tailored for each person's needs. Often, patients will have to experiment for a week or two until, together, we find the best solution for each individual. It is important that the patient or caregiver understands that whichever regimen is used must be taken on a daily basis. Sometimes we recommend Benefiber®, which provides a natural source of soluble fiber that gently helps to maintain regularity. Another product we've found useful to maintaining a healthy intestinal tract is Culturelle®, a natural probiotic dietary supplement containing Lactobacillus GG. When it comes to treating severe diarrhea, adding glutamine supplements to the fiber and probiotic regimen can be helpful.

Please see MANAGEMENT OF SIDE EFFECTS on page 22

2006 IMF SUPPORT GROUP LEADERS' RETREAT

Cooking Up Great Ideas in Arizona!

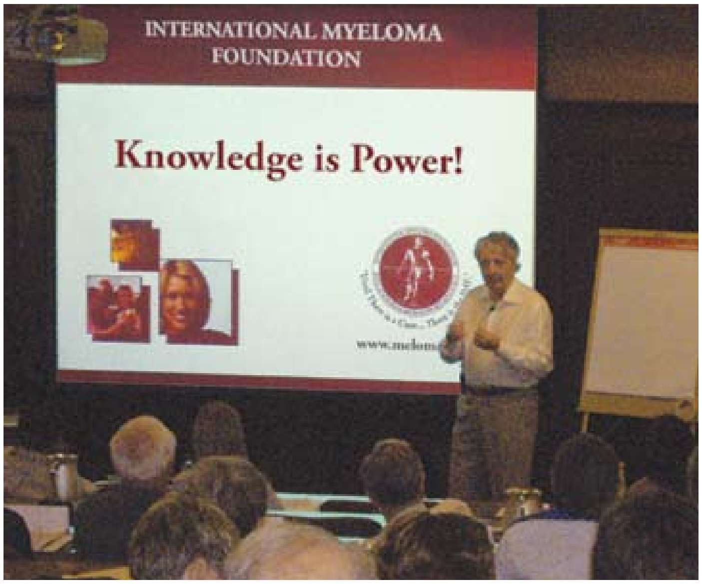
By Maddie Hunter

Take red wine, dark chocolate, donuts, and custom chips. Mix in people from 4 European countries, 5 Canadian provinces, and 18 US states, along with stellar IMF staff and Board members, plus 1 psychotherapist. Cook at about 100F degrees in an Arizona resort and you have the 7th annual IMF Support Group Leaders' Retreat. What a recipe for success!


Maddie Hunter of the Philadelphia Multiple Myeloma Networking Group

During the weekend of May 19 – 21, 2006, representatives of over 55 support groups came together at the Scottsdale Plaza Resort to learn, share, express, and inquire. We came to hear the latest news from the myeloma treatment front, to share tips for making our groups more effective, and to explore the emotional challenges of staying hopeful. Susie Novis and Dr. Brian Durie were our grand chefs, welcoming us as a global group and urging us to see the retreat as an opportunity to learn from one another. We did just that. During the retreat sessions, over dinner or during the breaks, we mixed and laughed! New friendships were made and old ones renewed.

During our first afternoon together, sous chef Robin Tuouy, Regional Director Support Groups – Northeast US, used her characteristic flare to remind us of all the ways that the IMF lives the belief that "Knowledge is Power." Robin reviewed the 42 free IMF publications available to keep the patient community informed. Over 125,000 people benefit from the IMF's outreach in 85 domestic and 73 international support groups!



Dr. Brian Durie giving his presentation at the SGLR

The next course in our Friday afternoon featured the duo of Drs. Brian Durie and Jim Omel. The topic was "Osteonecrosis of the Jaw" (ONJ). We were offered a sneak preview of a soon-to-be-released precautionary video on ONJ jointly created by Novartis and IMF. Dr. Jim Omel told his compelling story of ONJ. Although Jim has come to see his jaw damage as linked to Zometa® treatments, he cautioned us to keep the use of bisphosphonates in perspective. Both doctors advocated for clearer guidelines to be developed for safer bisphosphonate use. Information on ONJ is changing quickly so we were urged to watch for more specific information in the near future.

A picture of a sun rising over mountains introduced our last course for the afternoon – The Greater Vancouver Multiple Myeloma Support Group. Francesca Plaster, the group leader, came accompanied by her group via a touching DVD photo gallery. She treated us to the story of how her support group grew since 2005 through their

PLEASE SEE SGLR ON PAGE 22

MANAGEMENT OF SIDE EFFECTS — continued

Fatigue is another common complaint. It may be alleviated in part by adjusting the dose or schedule of other drugs that a patient is taking. For instance changing the time of day an anti-depressant is taken might help reduce fatigue during the day. Hydration and exercise are now thought to reduce weakness that patients experience on chemotherapy and other novel therapies. But each case is idiosyncratic and a solution must be sought on an individual basis.

Every myeloma patient should drink at least two quarts of fluid per day because this helps keep the kidneys flushed out. In fact, intravenous hydration is recommended for some patients. An otherwise healthy younger patient can be hydrated with one liter over two hours. If the patient is elderly or frail, or has cardiac problems, it may be prudent to hydrate with only 250CC-500CC of normal saline. Possibly the reason we've seen very little nausea associated with VELCADE at our institute is because we initially intravenously hydrate all patients who have myeloma.

Bisphosphonates and their potential side effects have been the focus of much discussion lately. I must give credit to the IMF for being on the frontlines of disseminating information about bisphosphonates and ONJ (osteonecrosis of the jaw), as well as kidney function. Bisphosphonates can be very helpful to myeloma patients, and the medical community is making progress toward arriving at a consensus regarding long-term use of these drugs.

At this time, there are 10 to 15 new drugs being studied in clinical trials at our facility, and each of them presents us with different challenges. Heat Shock Protein (HSP) inhibitors are some of the newcomers being studies in Phase I clinical trials that we may be hearing a lot about in the future. When the cancer cells are under stress, Heat Shock Proteins protect myeloma cells from the chemotherapy being administered. HSP inhibitors in initial trials seem to be effective, while causing few adverse reactions.

As novel therapies continue to be introduced into the myeloma field, they are likely to be associated with new side effects. And we will continue to strive to deal with these problems as they arise. **MT**

NOTE: Ms. Doss is a multiple myeloma clinical research nurse at the Dana-Farber Cancer Institute. She is a past recipient of the IMF Quality of Care Award for the outstanding service and care she provides to myeloma patients and caregivers.

SGLR — continued

slogan "Impossible is nothing." Guided by the desire to create meetings that were as warm and inviting as being in her home for dinner, Francesca and her group have developed a mentor program for patients, along with a visitation program for both inpatient and outpatient units. Their 2006-2007 plan includes enhancing the group's website, www.myelomavancover.ca, developing a patient lending library, and expanding the mentor program.

First on the menu for Saturday was Dr. Durie's update from the IMF Scientific Advisors's retreat. We savored every word of hope that Dr. Durie offered. The sweet finale of Dr. Durie's comments came with his suggestion that red wine, dark chocolate and stress management may be beneficial to those with myeloma!!!! We were ready to respond to this news immediately, but held off for the lovely cocktail hour and dinner awaiting us later in the day!

Two concurrent breakout sessions were served up next: Medicare Part D update and Canadian support Groups. Lisa Crist (Reimbursement Director, Ortho Biotech) described the history of Medicare Part D and shared her perspective about the challenges of this program for physicians and patients. Pertaining to the infamous "donut" or "bagel" gap in Medicare coverage, Lisa made some suggestions including working with our physicians to get some of the more expensive medications treated as a medical expense versus a pharmaceutical Part D expense. Many more details were given and, for this author, another serving is needed to have this complex topic become more clear.

Please see SGLR on next page

SGLR — continued

Dished up next was Stephen Gendel, IMF's Public Relations Executive. With his deep expertise in the news business, Stephen shared his intent to help us to focus more media attention on myeloma. In Stephen's recipe for success, his main ingredient is the "hook" – the message that is new, important, relevant, and can carry impact beyond the myeloma community. He encouraged us to branch out with our local media sources. He urged us to create a personal face for each story and offered ideas for materials and contacts to use. Stephen is a great new resource for us to leverage!

During the afternoon breakout sessions, Susie Novis gathered caregivers for a private dialogue, and Mike Katz (NY and White Plains Support Group Leader) led a focus group on future clinical trials. At the clinical trial discussion, physicians from the Eastern Cooperative Oncology Group (ECOG) called in to hear our comments about proposed trials. Suggestions included questions of proper administration of bisphosphonates, how to apply genetic understanding to treatment options, and advantages of treatment with novel therapies versus high-dose therapy and transplant. Additionally, seven ECOG trial concepts were offered for our reaction. We were asked whether we thought the trial addressed something important, who would want to enroll, why someone would not want to enroll, and what would make the trial more attractive. It was exciting to hear how the results of last year's feedback to ECOG shaped this year's trials.

Next to take the job of stirring us was psychotherapist and author Greg Pacini, whose focus is on issues beyond diagnosis for cancer survivors and their caregivers. He addresses the emotional aspects of being a member of the myeloma community. He engaged us in a discussion of the ups and downs of being a support group leader. We spoke of challenges around facilitating discussions when members have different needs, advocate for specific solutions, or have strong emotional reactions in the moment. Greg encouraged us to be clear about the type of group we want to create.

Dinnertime on Saturday brought us the inspiration and encouragement of IMF board member and myeloma patient Tom Bay. He reminded us of the choice we have to soar like an eagle as we walk the myeloma path and generously offered us insights from his life. The flavor Tom added to our evening brought zest to the end of our day.

Mike Katz at the podium for his BOAC presentation

Sunday, our last day together, began with Mike Katz updating us on the Bank On A Cure® program. The UK and US labs, supported by the arrival of a new custom computer chip, are ready to begin the complex analyses of donated tissue. Through the added cooperation of ECOG, the IMF has been given access to a large number of additional clinical trial databases that will offer many more samples for analyses. Additional funding is being sought to support this project.

Tom Courbat, leader from California, encouraged all groups to become more aware of the benefits available to patients. Susie reminded us that the transportation grants for the leaders' retreat were made possible by the Marx Family, and we all acknowledged thanks to Jennifer Gruenberg and her family for their generosity.

By mid morning, the retreat was coming to an end and the consensus was that it had definitely reached "well done"! The retreat recipe this year strengthened our community and enabled us to cook up more ideas together. Thanks to the IMF and to all of us who continue to hold together "until there is a cure." **MT**

There is a worldwide network of more than 100 myeloma support groups that hold regular meetings for members of the myeloma community. The IMF applauds their efforts and encourages you to seek them out. Please call 800-452-CURE (2873) or visit www.myeloma.org to locate a group in your area.

SPOTLIGHT ON TWIN CITIES AREA, MINNESOTA

By Pat Harwood

The Minneapolis/St. Paul Twin Cities Area Multiple Myeloma Support Group was founded in 1996 when I was diagnosed with Stage III myeloma. I wanted to live long enough to see my son graduate from high school, but my future seemed so uncertain. I was in severe back pain. The day after my diagnosis, I was in the hospital undergoing chemotherapy. I remember being in my room, crying, when I got an unexpected visit from one of the hospital volunteers. Helen Berg introduced herself as a myeloma patient. She had been diagnosed in 1994, with a tumor on her spine. Helen knew a couple of other myeloma patients, and invited me to attend an informal gathering.

> *"I was diagnosed with myeloma in February of 2005, at a time when I did not even know that the disease existed. Learning that one has an incurable disease of this seriousness came as a severe blow. Through the Minneapolis support group, I have met long-term survivors, whose very existence gives rise to hope. Group meetings are beneficial in other ways too. There is just no substitute for communicating with people of like circumstance."*
>
> **— Peter T. Harstad**

There were five of us back then: Helen, Connie, Ruth, Bonnie, and me. Connie was in a wheelchair so the meeting took place at her home. A month later, in September, Connie passed away. By Christmas, Bonnie had died. During this time, in October of 1996, I had an allogeneic transplant, with my sister as my donor. Nine days after my transplant, my husband was killed in a car accident. It was a sad and scary time.

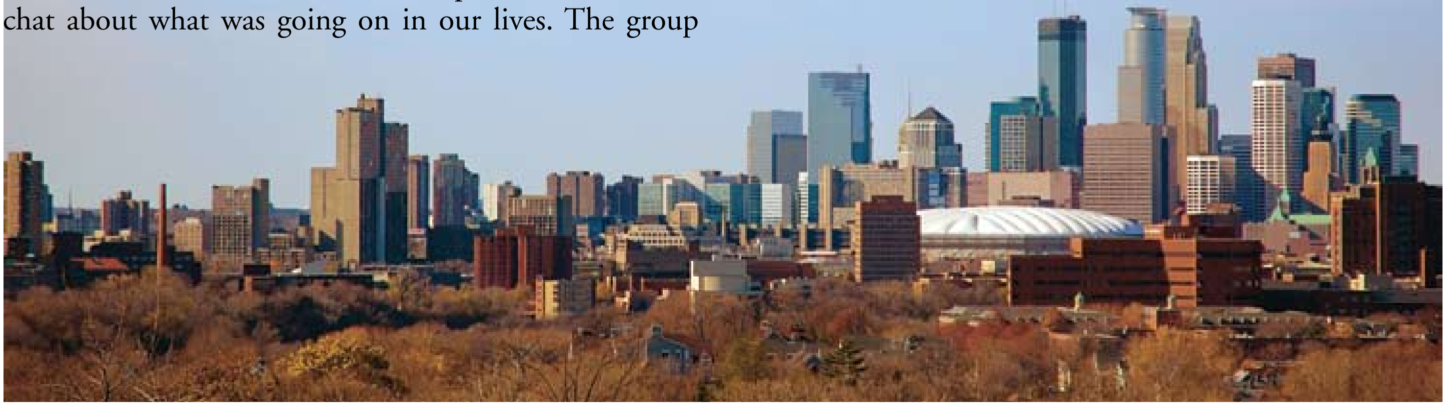
All of a sudden, our group started to attract new members. We started meeting monthly, on Sunday afternoons, at a small local restaurant. We'd have pie and coffee, and chat about what was going on in our lives. The group membership rose to 18 people, then 25. By 1999, as more people learned that we existed, our membership ranks had exploded.

Today, 95 patients participate in our group, and word continues to spread. Our group is very focused on the needs of the patient. We share hope and up-to-date information. Many of our members have formed close personal relationships, and the support we give each other is invaluable.

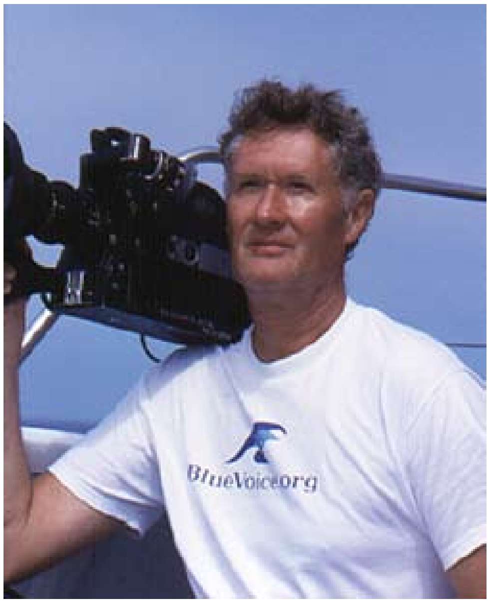
Two years ago, we were thrilled to have the IMF visit our area with the Patient & Family Seminar program. Everyone in our group just loved the seminar! It gave us an opportunity to further our myeloma education, to better know the Foundation, and to connect with the larger myeloma community.

I have seen my son graduate not only from high school but also from college. Thanks to talented doctors, courageous nurses, groundbreaking research, and the support and inspiration I receive from the Twin Cities Area Multiple Myeloma Support Group, I have been winning my fight with multiple myeloma for nine years. **MT**

NOTE: For more information about the Twin Cities Area Multiple Myeloma Support Group, please contact Pat Harwood at Mplsmyeloma@hotmail.com or 952-473-1782.



IMFER PROFILE: HARDY JONES



Myeloma Today: Please tell us a little about yourself.

Hardy Jones: I am a former journalist with CBS News and UPI. For more than 25 years, I have been making television documentaries about the oceans and marine mammals in particular. I have produced films for the Discovery Channel, National Geographic, and PBS, among others. Initially, my films focused on the beauty of these animals and their environment. Now, my goal is both to continue to inform the world about the marvel of these animals and to end the threats to their lives. Currently, I am Executive Director of BlueVoice (www.bluevoice.org), which I co-founded with actor Ted Danson. BlueVoice is an oceanic conservation group that goes to the scene of urgent ocean environmental issues.

Myeloma Today: What can you tell us about these marine mammals and the threats that they are facing?

Hardy Jones: I have spent many days at sea with dolphins and whales, filming and swimming eye-to-eye with these magnificent animals. Ample evidence exists to show that dolphins are highly intelligent, social, and sentient animals with brains and minds of equal magnitude to those of humans. Yet, despite international outrage, dolphins and whales are being killed and hunted. In addition to threats from humans, dolphins and whales are beings imperiled by ocean contaminants. The ocean environment now contains high concentrations of PCBs, mercury, and other chemical contaminants that may be produced as far as thousands of miles away. A National Academy of Sciences committee stated that PCBs pose the largest potential carcinogenic risk of any environmental contaminant for which measurements exist. And new contaminants are continually entering our marine ecosystem. Of course, the contamination of our oceans is a threat to human beings as well.

Myeloma Today: When and how were you diagnosed with myeloma?

Hardy Jones: I started experiencing fatigue, and pain in the back and shoulders, in the Fall of 2002. I thought that all my aches and pains were attributable to getting older. Finally, the symptoms caused me to see a doctor. Tests revealed a low red blood cell count and an elevated serum creatinine level. Even before the results came back, my doctor suspected multiple myeloma. The diagnosis was confirmed In May of 2003. I was shocked to learn that I had a potentially fatal disease that I didn't even know existed.

Myeloma Today: Which treatment regimen did you follow?

Hardy Jones: My doctor told me about thalidomide and dexamethasone, and I started treatment immediately. I feel extremely fortunate that my doctor put me on a therapy that quickly produced a 97% reduction in my myeloma tumor burden. I did have a side effect – double DVTs (deep vein thromboses) – which landed me in the hospital for five days, but I am now on Coumadin® and doing well. I have remained in partial remission – my numbers are low and stable – and all of my pains have gone away. I have switched from dexamethasone to Medrol® (methylprednisolone), which seems to work better for me. Since mid-2004, I've been receiving infusions of Zometa® every three months or so.

Myeloma Today: How has your life been impacted by myeloma?

Hardy Jones: Myeloma is never off my mind. I know that I am fortunate to have found an effective drug regimen for my disease, and I am grateful to have found it so quickly. Despite having myeloma, I have been able to continue my work as a wildlife filmmaker and to actively continue working to protect wild dolphins. Thalidomide has made that possible. Since my diagnosis, I have filmed above the Arctic Circle in Norway, in French Polynesia,

PLEASE SEE HARDY JONES ON PAGE 26

VELDHUIZEN WEDDING RAISES FUNDS FOR MYELOMA


Diane Tanenbaum and Ap Veldhuizen

After six years together, Diane Tanenbaum and Ap Veldhuizen decided to get married in April of 2006. Neither of them likes clutter and their spacious apartment was already overcrowded with the accumulation of combined households. They wanted to find an alternative to receiving superfluous wedding gifts and they didn't have to look far. Ap's brother had been living with multiple myeloma for several years and, as his disease progressed, more intensive treatments were becoming necessary. The family recognized the importance of supporting myeloma research to find improved treatments and, eventually, a cure. Asking family and friends to donate to the IMF in lieu of wedding gifts seemed the perfect solution. Everyone was happy to give generously and the wedding was all the more special because of it. The lovely, intimate ceremony was held in Belgium at the Waterloo Town Hall. The reception was held at an old manor overlooking a lake. Now the newlyweds are settling into married life and looking forward to their honeymoon in June on a cruise up the Norwegian fjords! **MT**

HARDY JONES — continued

Hong Kong, and the Bahamas. I continue to travel a lot, and spend a lot of time underwater. And I recognize that being able to continue my work – and to continue to earn a living – has softened the psychological impact of my myeloma diagnosis.

Myeloma Today: What can you tell us about your new research project?

Hardy Jones: There are many places in the US and around the world that have dangerous levels of chemicals and heavy metals. I am starting to correlate the areas where marine mammals are being exposed to high levels of persistent organic pollutants with the areas that are known as "hot spots" of myeloma incidence in human beings. The early results are quite intriguing.

Myeloma Today: What advice can you share with other myeloma patients?

Hardy Jones: I feel that, given the intricacies of this disease, it's absolutely essential to get a second opinion from a myeloma expert. I am glad that I opted out of having a stem cell transplant because, in hindsight, I would not have been a good candidate for the procedure. In addition, having a transplant would have prevented me from making two films that were very important for me to make, and very important for people to see.

Myeloma Today: What can you tell us about your personal life?

Hardy Jones: I live in Sonoma, California, right between the vineyards and the sea. I go surfing whenever the weather and waves permit (which isn't often these days). I love wine. My wife, Deborah, and I travel together, Paris being a favorite destination. We have a dog, Lady, who gets two walks a day, which keeps me from settling too long into a couch, and we have a cat, Lucky, whom we rescued nine years ago. **MT**

NOTE: Hardy Jones has studied and filmed dolphins since 1978. His films have won many awards and he was recently named Filmmaker of the Year at the 2005 Wildlife Film Festival.

AUGUSTO MARIO SCHIRINZI MEMORIAL GOLF TOURNAMENT

By Vittorio Schirinzi

When my uncle, Augusto Mario Schirinzi, was diagnosed with myeloma, the IMF was very helpful in educating my family about the disease and treatment options, as well as in making referrals to healthcare facilities here in Italy that specialize in myeloma.

My uncle lost his battle with multiple myeloma, but I have remained committed to doing what I can to improve the outlook for other members of the myeloma community. So, when my golf club, Poggio dei Medici, offered to me a chance to sponsor an event of my choice using their facilities, I naturally thought of dedicating my efforts to celebrating the memory of my uncle and benefiting the IMF.

When I first discussed my plans with Susie Novis, President of the IMF, I learned that one of the foundation's myeloma research grants for 2006 was being awarded to Dr. Nicola Giuliani of Parma, Italy. Dr. Giuliani's research project aims to identify new potential therapeutic targets by clarifying the mechanisms of interaction between myeloma cells and osteoblasts in the bone marrow microenvironment. This project presented me with an opportunity to focus my fundraising efforts on helping advance promising myeloma research right here in Italy.

Vittorio Schirinzi takes a swing against myeloma

Vittorio Schirinzi with Susie Novis and Dr. Brian Durie

The Augusto Mario Schirinzi Memorial Golf Tournament took place in Florence on April 22, 2006. About 35 players took part in the golf tournament, and participants who were unable to attend in person lent their support and encouragement from afar. I was very touched by all the positive response I received as a result of this event. It was a very satisfying and rewarding experience for me.

Now, with the experience of organizing one charity golf tournament under my belt, I am planning to expand and bring back this event on an annual basis. I hope to be able to build this tournament into an event that will continue to contribute to helping and encouraging the brilliant minds here in Italy, and in the larger European Community, to pursue their much-needed research in the field of myeloma. **MT**

RALPH FERRIZZI MEMORIAL GOLF TOURNAMENT

By Suzanne Battaglia

The Ferrizzi family with IMF's Suzanne Battaglia: (l-r) Angela Henry, Samantha Ferrizzi, Emily Henry, Midge Ferrizzi, Suzanne Battaglia, Kathy Ferrizzi, Ralph Ferrizzi, Mark Ferrizzi, and Raymond Henry

Working at the IMF, you get to meet a lot of people and, over the ten years that I've been with the Foundation, I've met quite a few. Most of the relationships with our members are formed and maintained via telephone or through email. I enjoy getting to know IMFers who have an interest in doing something proactive in their communities to help raise money for myeloma research and education, and helping them plan and organize their events.

The Ferrizzi Family – Midge, son Ralph Jr. and wife Vanessa, daughter Angela and her husband Ray, and son Mark and his wife Kathy, along with cousins, grandchildren and lots of friends – organized the 3rd Ralph Ferrizzi Memorial Golf Tournament. Midge's husband, Ralph, went misdiagnosed for over a year before being diagnosed with myeloma in 2001. Midge and her family decided to hold a golf tournament, in honor of her husband's love of the game, and everyone rallied around.

Stacey Mondschein, Gail Minar, Midge Ferrizzi, Ruth Ferrizzi

First place winners of the tournament were Brian Mondschein, Steve Gensemer, Dave Rader, and Walt Lucki

I have been working with Midge over the past three years, but we had never met. This year I was able to attend the tournament, held in Bethlehem, PA on May 20th. I summoned all my courage to get on a small shuttle from Washington, DC, where I had just attended the Robert A. Kyle Lifetime Achievement Award dinner, to fly into the Lehigh International Airport (yes, I said International!) in Allentown, PA. I was picked up by Midge and Ralph Jr., and I can't tell you what a joy it was for me to finally meet this wonderful family! Midge put out a delicious buffet and as more and more people arrived, we began stuffing bags and organizing the raffle.

This year's tournament was held at the Green Pond Country Club in Bethlehem, PA. Golfers arrived around 1:00 pm for a 1:30 pm tee-off, and the organizing committee busied themselves setting up for the raffle and dinner. Everyone helped with enthusiasm, including 7-year-old Emily and 14-year-old Samantha. After dinner, winners were drawn for the raffle prizes, which included a TV with DVD, an iPOD, various golf clubs, and other prizes. There were a total of 75 prizes to be handed out! First place winners were Brian Mondschein, Steve Gensemer, Dave Rader and Walt Lucki.

When I presented Midge Ferrizzi with the IMF's Certificate of Recognition, she claimed that she'd won the biggest prize of the whole day! Well, I think I won the biggest prize – a chance to spend some time with a wonderful community of people. **MT**

If you are interested in planning a fundraising activity in your community, please contact Suzanne at SBattaglia@myeloma.org or 800-452-CURE (2873).

GOLFING FOR A CURE

Third Annual Leona Cravotta Memorial Golf Tournament

By Katelyn Marie Martin

On May 20, 2006, my family and I held the Third Annual Leona Cravotta Memorial Golf Tournament. The event was founded in 2004 in honor of my grandmother, Leona Cravotta.


Katelyn Martin with her grandfather Charlie, mother Lynda, and sister Liesel

This year's 4-person Captain's Choice (Shotgun Format) tournament took place at the Tanyard Country Club in Louisa, VA. The golfers started play at 9:30 a.m. on an absolutely gorgeous day. The sun was out, the sky was blue, and the water sparkled in the sunshine.


Golf tournament winning team

Eight 4-person teams, 19 hole sponsors, and 2 tournament sponsors participated in the event. We were happy to see many returning players and to welcome several new participants. After the golf, everyone gathered for a nice cookout and beverages. Prizes were awarded to the top five teams, and two players received Closest to the Pin and Long Drive awards. Fun was had by all, and the fundraising efforts were a success for yet another year!

We were proud to be able to raise a lot of money for the IMF while raising myeloma awareness among members of our local community. This annual tournament program has been a great way for me and my family to help the myeloma community while honoring the memory of my grandmother. I know that she would have approved of our efforts.

My family and I would like to extend our gratitude to the event's individual and corporate sponsors, tournament players and volunteers, and Tanyard's Head Golf Professional, Kevin Daughtrey, for their participation and support. We look forward to seeing all of you again next year! **MT**


Event volunteers Liesel, Brittany, and Ande

MY JOURNEY THROUGH MYELOMA

By Julie Bice

October 17, 1994, was my birthday – I turned 49 years old. It was also the day my doctor told me I had multiple myeloma.

My daughter, Melissa, searched the Internet for information about this little-known disease. That is when she found the International Myeloma Foundation and ordered the IMF InfoPack. Shortly thereafter, our family attended an IMF Patient & Family Seminar. We found ourselves on a steep learning curve and needed to do all we could to enhance our level of education about this disease. The information provided by the IMF was invaluable.

At that time, melphalan and prednisone was considered to be the "Gold Standard" of myeloma treatment. After eighteen months on this chemotherapy regimen, plus six more months of self-administered shots of Interferon, I was told that the indicators for myeloma were so low that I was "almost in remission."

Throughout my treatment, I continued to teach for the local school system. In addition, I returned to college and obtained a Masters Degree in 1997. In 1998, blood work indicated that the myeloma was staging a comeback. I was put back on melphalan and prednisone for another six months of treatment. In July of 1999, with myeloma on the rise once more, I headed to the University of Arkansas for Medical Sciences (UAMS), together with my husband, Gilbert, and daughter, Jennifer.

Doctors at UAMS first recommended a stem cell transplant but, when I resisted, proposed that I become part of a study involving thalidomide, an old drug that was new to myeloma therapy. I elected to join the study. I also received monthly infusions of Aredia (pamidronate), a bisphosphonate to strengthen my bones. Thankfully, I responded to my new treatment regimen.

I continued in the study until March of 2004 when, while on a trip back to UAMS, I fell and fractured my left femur. During a two-week hospitalization, a rod was inserted, followed by another two weeks in a rehabilitation hospital back home in Alabama. A year later, my non-union fracture finally healed but left me with a severe limp. My final year as a teacher was completed mostly from a wheelchair. I retired at the end of the 2005 school year.

By this time, VELCADE® was one of a new crop of drugs being used in the fight against myeloma, and my doctor recommended that I give it a try. In addition, in January of 2005, I was switched from Aredia to Zometa®. Sadly, within just a few months, I was one of the patients to develop osteonecrosis of the jaw (ONJ). Zometa was discontinued and, luckily, the lesion has since healed. The VELCADE continues to work well for me .

Throughout my journey with myeloma, the IMF has been a source of information and encouragement for me and my family. We wanted to do something to express our gratitude. On the weekend of April 21, 2006, the 8th Annual Heart of Dixie American Bulldog Specialty was held at Horse Pens 40, a historic outdoor nature park located near our family home. We set up a booth at the dog show, and handed out IMF printed materials and sold the burgundy IMF bracelets. Thanks to the cooperation of the event organizers, IMF donation envelopes were included with the participant registration packets. My family is so pleased to have been able to contribute our efforts to help the foundation that has helped me so much.

In closing, I'd like to share that on October 17, 2006, I will be celebrating my 60th birthday. The date will also mark my 12th anniversary as a myeloma survivor. MT

2006 "JC" GOLF TOURNAMENT UPDATE

Held in memory of Janet "JC" Johnson, the 7th annual "JC" Golf Tournament took place on May 20 at Wapicada Golf Club in St. Cloud, Minnesota. Tickets for the event sold out in record time, with almost 200 golfers and 240 diners registered. And the registrations kept coming in even after the tournament reached capacity. Some golfing fivesomes generously made room for additional players by deciding to alternate shots, giving new meaning to the saying, "The more the merrier!"

New participants and sponsors made the 2006 event the biggest and best tournament yet. As in the past, the tournament featured a putting contest, a "hole in one" contest to win a new car, numerous other golf contests, and a silent auction and raffle. A new "Gallery Pledge" program allowed non-golfers to participate in the golf tournament. After the golf tournament, all the event participants gathered for a dinner celebration. An awards ceremony followed dinner, and the band "Canoise" entertained everyone late into the evening.

Our heartfelt thanks to the event organizers, sponsors, and participants for making the annual "JC" Golf Tournament such a stellar success. To date, the tournament has raised over $111,000 to benefit IMF programs and services. In December of 2006, an IMF research grant will be awarded in the name of Janet "JC" Johnson. **MT**

2006 "JC" Golf Tournament Sponsors

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Wapicada Golf Club

OLDIES NIGHT: BEEF & BEER & CHINESE AUCTION

By Pat Cinelli

On May 6, 2006, the Ronald J. Cinelli Multiple Myeloma Foundation hosted an "Oldies Night: Beef & Beer & Chinese Auction" at Saint Pius X Recreation Center in Cherry Hill, New Jersey.

Delicious roast beef sandwiches were served with all the trimmings, along with cold beer and soda. All food and drinks were generously donated by event sponsors.

The Chinese auction, a combination auction and raffle in which bidders buy tickets for a chance to win items, featured four tickets to the Stadium Club at a Yankees baseball game in New York, gift baskets and gift certificates, live plants, a golf bag, sports memorabilia, framed artwork, hand-painted martini glasses, a ladies' watch, children's games, and a parakeet!

A disc jockey had event guests out on the dance floor for the entire evening. Approximately 100 people attended, and several who were unable to be there in person sent contributions to help with myeloma research. Proceeds from the event benefit the IMF. And donations are still coming in!

My thanks go to the event's committee members who helped make this evening a success: my daughter, Marny Matricardi, and long-time friends, Peggy & Corky Cantera and Jim & Carol Maccaroni. My family and I really appreciate the work of the IMF on behalf of myeloma patients, as well as the kindness, support, and assistance provided to us by the IMF staff. We are so pleased to be able to make a contribution toward the research for a cure and plan to continue to do so with future events. **MT**

BOOK CLUBS HELP FIGHT MYELOMA

Members of book clubs around the country have been supporting IMF programs while making their online book selection purchases. Any online purchase made through http://amazon.myeloma.org or http://barnesandnoble.myeloma.org generates a referral commission to the IMF. So please remember the IMF when buying your next book and make your purchase count! **MT**

WALKING OR RUNNING FOR THE IMF?

Are you thinking of running in a marathon, 5K or 10K, or doing a walk-a-thon? If so, there is no easier way to help raise money and public awareness for myeloma programs and research, than to walk or run for the IMF! We will provide you with IMF T-shirt and cap, and sponsorship forms and a letter template. Then, all you have to do is a mailing to your friends, family, and associates, and include the sponsorship form or donation envelope. Then, as easy as 1-2-3, you'll be fundraising while doing something you were going to do anyway! And, you can be sure that 100% of the money you raise will go to myeloma programs and research. We can also provide you with printed materials about myeloma and the IMF to include in your mailing. You can run or walk in honor of someone, or just do it for yourself. Please contact IMF's Suzanne Battaglia at SBattaglia@myeloma.org or 800-452-CURE (2873). She will work with you to set the wheels in motion, and you'll be surprised to learn how easy it is! **MT**

MEMORIAL GOLF OUTING

On May 8, 2006, a Memorial Golf Outing was held at the Gull Haven Golf course in Central Islip on Long Island, New York. The event was held in honor of John Horan. The outing, and the luncheon that followed, were a great success. Event trophies were awarded to Art Wiengartner (First Place), Jack Bradley (Second Place), and Leo Doerch (Third Place). A good time was had by all, and the organizers hope to hold the event again next year. **MT**

Art Wiengartner, Jack Bradley, and Leo Doerch

2006 MEMBER EVENTS CALENDAR

July 9, 2006 –
Multiple Musicians Against Multiple Myeloma
Naomi Margolin, (516) 487-6712, NMargolin@aol.com
Tupelo Honey, Sea Cliff, Long Island

July 22, 2006 – Wamp Swim-a-Thon 2006 – Wampanoag Country Club, 60 Wampanoag Dr., West Hartford, CT,
Contact: Liz Stafford, (860) 778-3766

August 13, 2006 – Theresa's Run for Myeloma
Chicago Distance Classic Half Marathon and 5K Race
Contact: Theresa Burkhart, 312-492-9538,
Theresa_M_Burkhart@rush.edu
To run in this event, go to www.chicagodistanceclassic.com

August 28, 2006 – Corporate Cup Challenge
Brad Springer, 630-848-1335 – brad@hhpmail.com,
Cross Creek Country Club, Naperville, IL

October 14, 2006 – Second Annual Myeloma Walk
Lake Oseola, University of Miami, Miami, FL –
Contact: Denise Vidot peaches2822@aol.com

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.*

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.

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.

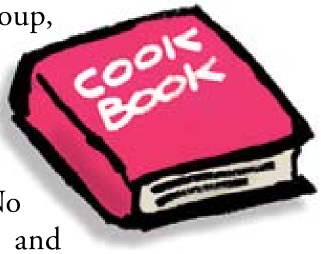
Cell Phones 4 A Cure

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).

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.

Board Member Profile

ISABELLE LOUSADA

Myeloma Today: Ms. Lousada, please tell us a little about your life before your AL Amyloidosis diagnosis.

Isabelle Lousada with Joey and Iris

Isabelle Lousada: In 1995, I had just graduated from architecture school in the United Kingdom. My fiancé Adam and I were planning to get married. For the preceding 10 years, I had lived with a diagnosis of Chronic Fatigue Syndrome (CFS), so having a very low energy level was nothing new to me. A variety of physical symptoms began accumulating, however, all of which were chalked up to stress at the time. The day after the wedding, we flew to America to see Adam's family. His brother is a doctor and, when I started to experience severe stomach pains, he rushed me to the emergency room. The pain turned out to be related to a problem with my liver. Adam and I returned to England where, over the next few months, my health continued to get worse. Finally, a diagnosis of AL Amyloidosis was established. Amyloidosis is closely related to multiple myeloma. The amyloid fibrils consist of monoclonal light chains of amino acids that deposit as fibrils in tissues of the body. These fibrils damage the normal cells, and patients present with involvement of one or more organs, frequently the kidneys and/or heart. Amyloidosis is even more rare than myeloma.

MT: What was the prognosis at the time?

Isabelle Lousada: I was told that, without treatment, I had three to six months to live. With treatment approaches available in England at the time, I might have been able to lengthen my life expectancy to a year or two. I was given the first of six planned courses of VAD chemotherapy, but the side effects of the treatment were so severe that it was stopped. There seemed little hope. Then we learned that Dr. Raymond Comenzo, who was working at the Boston University Medical Center at the time, was experimenting with transplants for amyloidosis. So, in February of 1996, I had the procedure. The experience was hellish, and was followed by five months of hospitalization. I was in very bad shape, with all of my organs having difficulty accepting the treatment. Then, I slowly began to recover. It took a couple of years but, bit by bit, I learned to walk again and do all the little things I used to do. In fact, in 1998, I started to feel better than I had since the CFS diagnosis. I have remained in complete remission.

MT: How was your outlook on life changed by the experience?

Isabelle Lousada: It changed my outlook and my ambitions. I used to be very career driven. Now, I realize that the most important thing in my life is family. Adam and I adopted two children. Joey is now seven, and Iris is five. I continue to have semi-annual visits with my doctor but, other than that, my life has been quite normal. A year ago, our family relocated to America.

MT: How and why did you become involved with the IMF?

Isabelle Lousada: When I was first diagnosed, there was very little available information about my disease. Dr. Comenzo put me in touch with the IMF. I became quite involved with the Foundation, and served on the Board of IMF(UK). Just as my service term on the IMF(UK) Board was coming to an end, we moved to the US and I joined the IMF Board here. In my opinion, it is essential for an organization to be responsive both to the need for patient education and the need for research, and the IMF does both. One of the most important things that a patient can do is to become empowered through education, and the IMF does a great job of giving patients the tools to better cope with their diagnosis and their disease. And the research being funded by the Foundation is making a significant contribution to the fight. On behalf of the IMF, I speak at patient seminars and nursing conferences in order to help educate both the patient community and the medical professionals about the disease from a patient's point of view. There is no question that we've come a long way, but there is still a journey ahead. **MT**

HARTMUT GOLDSCHMIDT, MD, PHD

Myeloma Today: You were born and raised in the former East Germany. How did you secure a position at the University of Heidelberg, arguably one of the leading medical institutions of Europe?

Prof. Dr. Goldschmidt: After the fall of the Berlin Wall, a rapid exchange took place between colleagues from East and West Germany. My friends from Heidelberg invited me to present our work, which was hitherto virtually unknown. To learn more about this leading medical school in Germany, I asked for a 3-month fellowship. On my second day in Heidelberg, Professor Hunstein asked me to join his clinic. I started work there in September 1991. After six months, Professor Haas asked me to establish a separate myeloma program. In those days, no myeloma support groups existed. But I found the IMF and initiated contact with the Foundation at a CME workshop in Singapore in 1993. There, I met Susie Novis and Drs. Brian Durie and Ken Anderson. Then I gave a talk on leukapheresis in Houston, Texas, and at the European Bone Marrow Transplant Group meeting in Hamburg, Germany. That trip around the world took place for scientific reasons, but just four years earlier it could only have been a dream!

Hartmut Goldschmidt, MD, PhD
Heidelberg University Medical Clinic
University of Heidelberg and
National Center of Tumor Diseases
Heidelberg, Germany

MT: How did you come to work in the field of myeloma?

Prof. Dr. Goldschmidt: During my early clinical work at the Charité Medical Center in former East Berlin, I was responsible for multiple myeloma studies. After the fall of the Berlin Wall, I had the opportunity to continue my myeloma research efforts under the guidance of Professor Haas and Professor Hunstein. I was highly motivated by the relative success of high-dose therapy, and I wanted to help patients with a fatal prognosis. In Heidelberg we studied thalidomide in one of the first worldwide clinical trials, and we were able to show that patients improved considerably. It was particularly difficult to reintroduce thalidomide after its painful history here in Germany but, eventually, patients came to have faith in this drug's benefits.

MT: The University of Heidelberg recently made a commitment to expand its work in multiple myeloma. What is the significance of this new venture?

Prof. Dr. Goldschmidt: In July 2005, the Heidelberg University Medical Clinic established the Multiple Myeloma Section in collaboration with the National Center for Tumor Diseases. The aim of this clinical experimental unit is to optimize diagnosis and treatment of plasma cell diseases. With comprehensive technologies available on site, we diagnose and treat approximately 250 new patients each year. In addition, our integration into the National Center for Tumor Diseases enhances our interdisciplinary networking. We have presented data resulting from our comprehensive therapeutic strategies in multidisciplinary conferences with radiologists, radiotherapists, orthopedists, emergency surgeons, and endocrinologists.

MT: What is the focus of your research work in myeloma?

Prof. Dr. Goldschmidt: My main focus is on clinical trials. At our center in Heidelberg, we aim to initiate and coordinate local, national, and international studies. Our German Speaking Multiple Myeloma Multicenter Group has treated 1,500 patients so far. Our cooperation with the HOVON study group in the Netherlands has enabled us to participate in new Phase III studies. For years, we have been analyzing molecular genetic changes in myeloma cells. Newly diagnosed patients, as well as those at the start of a new therapy, are subject to gene expression analysis. We are convinced of the existence of a number of genetically determined myeloma diseases. The aim of our research efforts in this field is to create individual prognosis patterns and assign new therapies to these genetic subgroups. I sincerely hope that myeloma researchers worldwide will continue to increasingly coordinate their studies, and I am glad that IMF is furthering this cause.

MT: The German Cancer Research Center (DKFZ) in located on the campus of Heidelberg University

PLEASE SEE HARTMUT GOLDSCHMIDT ON PAGE 36

HARTMUT GOLDSCHMIDT — continued

Medical Clinic. Does such proximity benefit your work in myeloma?

Prof. Dr. Goldschmidt: The DKFZ is a foundation financed by the Federal German Government and the State of Baden-Wuerttemberg. In addition, the Center is part of the cooperative association of the Tumor Center Heidelberg/Mannheim. The goal of DKFZ is to investigate the mechanisms of cancer development and to identify cancer risk factors. The results of this basic research are expected to be developed into new approaches in the prevention, diagnosis, and treatment of cancer. DKFZ is an excellent partner for non-routine diagnostics, experimental therapy, and complicated statistical aspects of our studies. Our advanced imaging techniques are an example of our collaboration. For years, we have been analyzing the blood circulation in bone marrow and myeloma sites. We can now diagnose myeloma sites in the bone marrow at an early stage and make a determination about their prognostic significance. In some of our other projects, we are looking for new treatment targets in myeloma cells. We are also working to improve immunotherapy.

MT: Do you have any public events scheduled to raise awareness about your work?

Prof. Dr. Goldschmidt: The Heidelberg Multiple Myeloma Days will take place September 20-23, 2006. We are expecting 300 patients, 150 researchers, and 150 clinicians to participate in the event. The Heidelberg Multiple Myeloma Days, which will feature presentations of the latest research results, as well as discussions and the exchange of ideas for new studies, will offer CME units to physicians. This is the third symposium of its kind in Heidelberg since 2001.

3rd Heidelberg Multiple Myeloma Days

Wednesday, September 20, 2006:

6th Heidelberg Grand Rounds – Multiple Myeloma

- History and epidemiology of myeloma
- Biological significance of gene expression
- Case presentation
- New diagnostic approaches in radiology
- New treatment options

Friday, September 22, 2006:

Meeting of the GMMG Study Group

- New diagnostic and treatment approaches
- Collaboration between practice and clinic

Saturday, September 23, 2006:

Breakfast Symposium
Novel Therapies
Patients' Seminar

- Diagnosis and prognostic factors
- Conventional treatment
- Supportive care
- High-dose therapy
- New drugs

MT: Your myeloma center is among the leading institutions participating in IMF's Bank On A Cure® initiative. Please describe your collaboration and tell us what you believe the benefits of this research will be for myeloma patients.

Prof. Dr. Goldschmidt: Bank On A Cure is giving researchers an opportunity to define new prognostic factors. In this project, major myeloma centers and study groups are working together on a worldwide basis. We are certain to be able to correlate genetic characteristics of patients with their possible prognosis and side effects of therapy. We will be able to determine the efficacy of new drugs. Consistent data collections, and an excellent cell bank of both diseased and healthy cells of our patients in Heidelberg, will enable us to further our efforts. Of course, all results will be shared with other groups in an anonymous fashion in order to protect patient privacy.

MT: Does your service on the IMF's Scientific Advisory Board benefit you and your patients? Has the Foundation been helpful to the myeloma community in Germany?

Prof. Dr. Goldschmidt: As an IMF Scientific Advisor, I am able to engage in a comprehensive exchange of information with myeloma experts from all over the world. This facilitates a very fast translation of results into clinical reality. Also, the IMF has supported several patient seminars in Germany, including three seminars in Heidelberg. I think that having 300 patients attend each seminar is telling of their importance and success.

MT: Please tell us about your personal life. What are your interests outside of myeloma?

Prof. Dr. Goldschmidt: My family is my foundation. My wife has always been supportive of my medical work, and she has taken wonderful care of our family. Both our sons are grown and are successful in their respective fields. But we spend lots of time together, especially now

PLEASE SEE HARTMUT GOLDSCHMIDT ON NEXT PAGE

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.

New IMF Website for Global Spanish-Speaking Community

Spanish is spoken by nearly 400 million people in Spain, Central and South America, and the Canary Islands, Morocco, the Philippines, and the United States. The IMF has launched a Spanish language website to provide complete and up-to-date information about multiple myeloma to the Spanish-speaking population worldwide. The new "Website en español" will provide the same comprehensive level of contacts, support, and medical and pharmaceutical information that has been available in English. The website is available at www.mielomala.org.

One Voice Against Cancer Lobby Day


Senator Orrin Hatch (R-UT) meets with Rula and Joe Greenwood at the 2006 OVAC Lobby Day

The One Voice Against Cancer (OVAC) Lobby Day took place in Washington, DC on April 26, 2006. OVAC is a coalition of more than 40 cancer advocacy organizations. Working together is the best way to achieve more funding for cancer research. On the heels of approving the first cuts to the National Institutes of Health (NIH) and the National Cancer Institute (NCI) since 1970 in FY (Federal Year) 2006, President Bush has proposed even deeper cuts to the NCI in FY 2007. As a result, the number of NIH-funded research project grants would drop below last year's level. The President's budget would cut funding for 18 of the 19 institutes—all, except the National Institute of Allergy and Infectious Diseases. Funding for the NCI would be cut by $40 million. In addition to these cuts in medical research, the President's budget also proposes deep reductions at the CDC (Centers for Disease Control and Prevention). The President himself has said, "in order to win the war against cancer we must fund the war against cancer," but the budget he has proposed is far from adequate to fulfill this pledge for "aggressive funding." IMF's active involvement with the advocacy event ensures that the myeloma community is represented during this crucial congressional process of reviewing and voting upon the federal legislative agenda.

FDA Advances Federal E-Health Effort

The U.S. Food and Drug Administration (FDA) has advanced the federal effort to create electronic health records for Americans within the next decade by making it easier to share drug information electronically. FDA is

Please see NEWS & NOTES on page 38

HARTMUT GOLDSCHMIDT — continued

that we have two grandsons. My great hobby, chess, has suffered clearly from my clinical and research work, but I cherish the rare opportunities when I am able to prepare my brother for an important match in his chess club. I am very thankful for the short periods of relaxation in a busy researcher's life. **MT**

NOTE: Dr. Goldschmidt is a specialist in Hematology and Oncology. From 1999 to 2005, he headed the Autologous Bone Marrow Transplantation Program at the University of Heidelberg Hospital, where each year approximately 150 myeloma patients are treated with high-dose therapy and autografting.

NEWS & NOTES — continued

moving the effort forward by adopting the Systematized Nomenclature of Medicine (SNOMED) as the standard computerized medical vocabulary system to be used to electronically code important terms in the Highlights section of prescription drug labeling. This will allow healthcare professionals to access and share critical health and treatment information more easily and efficiently.

The FDA is adopting the "Problem List Subset" of SNOMED for use in this electronic labeling initiative for prescription drug products. This format will be required beginning June 30, 2006, for newly approved drug products, as well as drugs approved within the last 5 years.

The new labeling format will be integrated into FDA's other e-Health efforts through a variety of ongoing initiatives. As prescription information is updated in this new format it will be used to provide medication information for DailyMed – an interagency online health information clearinghouse, sponsored by the National Library of Medicine, which is maintaining the most up-to-date medication information free to consumers, healthcare professionals, and healthcare information providers. The DailyMed information about FDA-regulated products is available at http://dailymed.nlm.nih.gov.

National Oncologic PET Registry Ensures Access to Medicare

The National Oncologic PET Registry (NOPR) started accepting patient entries on May 8, 2006. NOPR aims to ensure access to Medicare reimbursement for certain types of positron emission tomography (PET) scans. PET scanning is an important tool for diagnostic evaluation, staging, and monitoring of myeloma. The National Oncologic PET Registry (NOPR) is a collaboration of the American College of Radiology Imaging Network (ACRIN), the American College of Radiology (ACR), and the Academy of Molecular Imaging (AMI). Additional information is available at the website www.cancerpetregistry.org. **MT**

Letters to the IMF

Thank you so much! The IMF materials arrived just before my Dad's first oncology consultation. Although I am an RN and have worked with many cancer patients, there was much I needed to learn about a multiple myeloma diagnosis. Your info helped me to do that, and gave me much to share with the rest of my family, including the bracelets that I ordered for them! We wholeheartedly support your cause, and "Imagine Moving Forward" to help my Dad fight this disease. Thank you, and keep up the good work!

Lisa Jurek, RN

Thank you SO MUCH! The IMF reading material helped to explain the diagnosis in terms that are easily understood, even during this time of tremendous stress and confusion. It was wonderful reading the articles written by the brave long-term survivors of this awful disease, and they gave us renewed hope that maybe the picture is not quite as bleak and hopeless as we first thought. Your website is a blessing, and I will be visiting it often. Thank you for your kindness, your caring, and your determination to educate the victims and their families as to the latest and most effective treatments currently available.

Helene Friedlander

I attended the recent IMF Patient & Family Seminar in Fort Lauderdale and was blown away by the IMF's publications. The booklet on dexamethasone and other steroids was particularly useful to me. Of all the info I have read in the last year and a half, I have learned more about steroids from that booklet than any other, and in a user-friendly manner that I could understand. Every myeloma patient should have your information available to them! I have even approached my doctor's office about compiling IMF educational materials for distribution to their newly diagnosed myeloma patients.

Carole Demopoulos

Thank you very much for the InfoPack. It is very good, with thorough information on myeloma. The information has been very useful to me and my patients here in Western India. This is a great service, as you mention rightly that the weapon against cancer is INFORMATION.

Dr. Sonia Parikh

To share your personal stories of how you and your loved ones are coping with myeloma, or how the IMF or a support group has had an impact on your life, please email your letters to IMF Publications Editor, Marya Kazakova, at mkazakova@myeloma.org. **MT**

This quarterly publication is available free of charge.
To subscribe, fill out the form below, visit www.myeloma.org, or call 800-452-CURE (2873).

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ORDER FORM

Dear Reader,

To quote Bob Dylan “the times they are a changin’.” Thalidomide was just approved for use in the treatment of myeloma! A once reviled drug that caused birth defects in babies is today prolonging survival in myeloma patients longer than we have seen with earlier myeloma therapies. In reflecting on thalidomide’s past history, I recently heard someone say that thalidomide was a good drug used badly. Today it’s obvious that that is no longer true.

What’s happening today in myeloma, “an orphan disease,” is unprecedented. In the short span of a couple of years we’ve had two drugs approved for use in myeloma. VELCADE®, which was approved in 2003, was the first drug to be specifically approved for anti-myeloma therapy in 30 years, and now we have thalidomide. And, there is a strong likelihood that by the time Myeloma Today reaches your home, we’ll add a third – Revlimid®. These are indeed exciting and changing times.

What these drugs bring to us is not a single magic bullet that will be the cure for myeloma, but amazing and very powerful tools that we now have in our toolbox. And approval means that they will be accessible for patients.

There are a host of clinical trials going on right now that are using these drugs in a variety of combinations; keeping track of them all is a challenging effort.

We hear about MPT – melphalan, prednisone and thalidomide in combination – with improved remission time and survival versus melphalan/prednisone alone. Now researchers are evaluating VELCADE/melphalan prednisone (VMP) versus MP, and Revlmid/melphalan prednisone (RMP) versus MP.

I recently attended the annual meeting of the European Society of Hematology, and there was a lot of buzz about a study that IMF Scientific Advisor Prof. Mario Boccadoro presented. He showed that Revlimid in combination with MP showed 100% remissions. This is an early study, but a very exciting one, and perhaps it shows a glimpse of what’s to come.

At the recent meeting of ASCO (American Society of Hematology) I had a meeting with a very well known researcher and I actually heard him say that he thinks we could see a cure in the next five years – yes, he used the “C” word!

“The times they are a changin’” indeed.

Warm regards,

Susie Novis

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