INTERNATIONAL MYELOMA FOUNDATION
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"Until There is a Cure… There is the IMF."

MYELOMA TODAY

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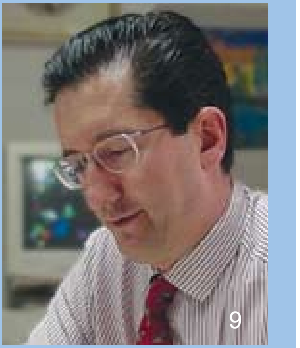
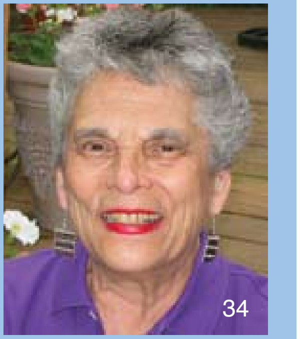
Dedicated to improving the quality of life of myeloma patients while working towards prevention and a cure.

Highlights

Tuna Mutis
IMF 2006 Research Grants



Jesús San Miguel
Spanish V-MP Trial



Rosanne Kalick
Long-term Survivorship

SCIENTIFIC & CLINICAL

AMERICAN SOCIETY OF HEMATOLOGY 47TH ANNUAL MEETING

Brief Overview of Major Myeloma Presentations

The following is a recap from the American Society of Hematology's 47th annual meeting held in Atlanta, Georgia on December 10–14, 2005. We have selected the major myeloma presentations for you to keep informed on the latest myeloma research that was presented.

Dr. Paul Richardson
Dana-Farber Cancer Institute – Boston, MA

Dr. Richardson presented updated, long-term data on the APEX trial to investigate the effects of Velcade in patients with relapsed myeloma who have had at least one prior treatment regimen. Patients in the trial were randomized to receive either Velcade or dexamethasone therapy. Dr. Richardson also presented early data on the Phase I Revlimid + Velcade trial for relapsed and refractory myeloma.

Dr. Rafael Fonseca
Mayo Clinic – Scottsdale, AZ

Dr. Fonseca is currently studying genetic changes in myeloma plasma cells. A precise diagnosis can be made when the doctor can identify different sub-types of myeloma and their unique features. Genetic information is used to estimate prognosis and

PLEASE SEE 2005 ASH REPORT PAGE 3

LOOKING FOR A LOCAL MYELOMA SUPPORT GROUP?

If you are interested in joining an existing group or starting a new group in your area, please contact Andy Lebkuecher, Director of Support Groups at imfsupport@charter.net or call him at 404-353-7127

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to determine the type and sequencing of therapy. Dr. Fonseca's presentation on the genetic abnormalities of patients diagnosed with MGUS or smoldering disease identifies those aberrations that can be seen prior to a myeloma diagnosis. His group is studying these mutations to see if there is a different risk of progression from MGUS or smoldering myeloma to active disease in patients with poor-risk or good-risk mutations.

Dr. Antonio Palumbo

Ospedale San Giovanni Battista – Turin, Italy

Dr. Palumbo began studying the combination of melphalan/prednisone/thalidomide (MPT) more than four years ago in the population of patients who were ineligible for autologous stem cell transplant (those over 65 years if age). His randomized clinical trial comparing MPT with standard MP (melphalan/prednisone) demonstrated a significant increase in the rate of overall response, with an incidence of complete response at approximately 25% in the MPT group. The duration of response was almost twice as long with MPT than with MP. Longer follow-up is needed to determine if there is an overall survival advantage with MPT. Side effects included the significant 25% rate of deep vein thrombosis in the MPT group.

Dr. Sundar Jagannath

St. Vincent's Comprehensive Cancer Center – New York, NY

Dr. Jagannath's presentation concerned a multi-center trial for newly diagnosed myeloma patients receiving frontline therapy with Velcade. Patients received Velcade alone for two cycles, and if they did not demonstrate a response, dexamethasone was added. Ten percent of the patients receiving Velcade alone in the first two cycles achieved complete remission (CR). At the end of six cycles of therapy with Velcade alone or Velcade plus dexamethasone, 90% of the patients had at least a 50% reduction in their M-protein and 19% were in CR. Most of the patients went on to have autologous stem cell transplantation. These patients are being followed for relapse and survival rates.

Dr. Brian Van Ness

University of Minnesota, Institute of Human Genetics – Minneapolis, MN

Dr. Van Ness presented his current work with the IMF Bank On A Cure program's genetic data. His strategy has been to look at genetic variation and its relationship to therapeutic response. Dr. Van Ness is particularly interested in variations in response to drugs and in toxicities from drugs. He has identified 3500 genetic variations (single nucleotide polymorphisms (SNPs) that influence risk and therapeutic response. From a candidate list of some 30,000 genes, he is isolating those that are significant in myeloma patients' responses, finding genes that contribute not only to increased risk (a high-producer IL-6 gene, for example), but to survival (the GST gene that repairs DNA). Thus far work has been done on a number of other SNPs, including those that are responsible for drug metabolism and transport, for levels of tumor necrosis factor alpha (TNF alpha), and for tumor angiogenesis. A computer chip has been customized to examine more globally the 3500 SNPs and their association with myeloma.

Dr. Thierry Facon

Centre Hospitalier Regional Universitaire de Lille – Lille, France

Dr. Facon presented an interim analysis of the ongoing Intergroup Francais du Myelome (IFN) 99-06 clinical trial comparing melphalan–prednisone (MP), melphalan-prednisone-thalidomide (MPT), and stem cell transplant with reduced-dose-chemotherapy (melphalan 100 mg/m2) in 436 newly diagnosed myeloma patients, aged 65-75 years. MPT produced the best progression-free survival and overall survival. There were concerns

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IMF Calendar 2006

March	24-25	Bart Barlogie Clinical Conference – South Beach, FL
	3/31-4/1	P&F Seminar – Wyndham Hotel, Ft. Lauderdale, FL
April	1-5	AACR Meeting – Washington, DC
	6-7	Japan/SWOG USA Clinical Summit Mtg
	8	P&F Seminar – Seoul, KOREA
	19-23	SWOG – The Grand American Hotel, Salt Lake City, Utah
	25-26	OVAC Lobby Days
	27-30	Scientific Advisory Board Retreat
May	4-7	ONS – Boston, MA
	5-6	P&F Seminar – Vienna
	16	Kyle Award Dinner – Nat'l Press Club, Washington, DC
	19-21	Support Group Leaders Retreat
June	2-6	ASCO – Atlanta, GA
	15-18	EHA Meeting – AMSTERDAM
July	7-8	P&F Seminar – Portland, OR
Aug	4-5	P&F Seminar – Philadelphia, PA
Sept	2	P&F Seminar – CZECH REPUBLIC
Oct	21	Ribbon of Hope Gala – Regent Beverly Wilshire Hotel, Los Angeles, CA
	22-28	Multiple Myeloma Awareness Week
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.

2005 ASH REPORT — continued

with toxicity issues that required dose adjustment or discontinuation of therapy, but Dr. Facon concludes that MPT is currently the treatment of choice for the elderly newly diagnosed. He is also encouraged by early studies of MP+Velcade and MP+Revlimid that are also likely to be good combinations for treatment of elderly myeloma patients.

Dr. Pieter Sonneveld
Erasmus University – Rotterdam, The Netherlands

Dr. Sonneveld studied single nucleotide polymorphisms (SNPs) collected from patient tissue samples in a large, multi-center, randomized, single versus double autologous transplant clinical trial that concluded in 1999. Dr. Sonneveld's particular area of investigation is the SNPs of proteins involved in drug metabolism and drug resistance. The ultimate goal of his research, which is being done in conjunction with the IMF's Bank On A Cure DNA study, is to identify groups of patients according to their response to treatment, the treatment-related toxicities they manifest, and their overall survival. He has isolated the MDR (multi-drug resistance) and GCP-1 genes as conferring poor risk, and the C3A5 genetic mutation as one that confers better event-free survival, time to progression, and overall survival. The study is ongoing and will require meta-analysis of the HOVON clinical trials group data.

Dr. Heinz Ludwig
Wilhelminenspital – Vienna, Austria

Dr. Ludwig's major presentations at ASH concerned two studies: the first was of clinical features and outcomes in 259 myeloma patients younger than 40 years versus 8,296 patients older than 40 years; the second was of thalidomide/dexamethasone (thal/dex) versus melphalan/prednisone (MP) as first-line therapy in elderly patients with myeloma. The first study employed the 10,611-patient database used to establish the International Staging System for myeloma. The second presentation was the interim analysis of an ongoing trial of thal/dex versus MP in 205 elderly (median age 72), newly diagnosed patients with myeloma.

Dr. Jamie Cavenagh
St. Bartholomew's Hospital – London, England

Dr. Cavenagh continued to report on his ongoing trial combining Velcade, Adriamycin, and dexamethasone (PAD) in previously untreated myeloma. Among this group of younger (median age 61 years) patients, there was a 95% response rate (≥50% reduction in monoclonal protein) before stem cell transplant, and an 81% very good partial response rate (>50% but ≤90% reduction in monoclonal protein) following transplant with (PAD) as frontline therapy. A second presentation of Dr. Cavenagh's involved combining Velcade with melphalan in patients with relapsed/refractory disease. The Phase I/II multi-center study was done to establish the maximum tolerated dose, safety, and effectiveness of this combination. Velcade appears to be effective in combination with chemotherapy in both the up front and relapse situations.

Dr. Joseph McGuirk
Kansas City Blood and Marrow Transplant Program – Kansas City, MO

Dr. McGuirk reported on the first 70 patients enrolled in the AMD-3100 compassionate use program for poor stem cell mobilizers in need of stem cell harvest prior to autologous stem cell transplantation (SCT). The patients had non-Hodgkins lymphoma, leukemia, myeloma, or solid tumors. They were given a combination of GCSF (granulocyte colony stimulating factor) and AMD-3100 to promote generation of stem cells for harvesting. 60% of the enrolled patients, all of whom had been previously unable to mobilize stem cells, were successfully harvested and moved on to SCT. According to Dr. McGuirk, this is a potentially live-saving combination that produces minimal toxicity.

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Dr. Shaji Kumar
Mayo Clinic – Rochester, MN

Dr. Kumar presented the results of two studies at Mayo. The first was a gene expression study conducted on 50 patients who were randomized to receive either thalidomide and dexamethasone (30 patients) or dexamethasone alone (20 patients). Dr. Kumar's second presentation concerned the use of the free light chain (FLC) assay to assess disease and response to therapy, particularly in oligosecretory and non-secretory patients.

Dr. Jesus San Miguel
University Hospital of Salamanca – Salamanca, Spain

Dr. San Miguel presented interim data on the ongoing PETHEMA study of melphalan, prednisone, and Velcade in elderly, previously untreated myeloma patients. A second presentation by Dr. San Miguel concerned the rate of peripheral neuropathy in the APEX Velcade trial. Dr. San Miguel also presented preliminary data from a Phase I/II study in patients with relapsed/refractory myeloma of the novel therapy Aplidin, which is a marine-derived molecule with a novel mechanism of action.

Dr. Michael Wang
MD Anderson Cancer Center – Houston, TX

Dr. Wang presented data on a Phase I dose escalation multi-center clinical trial with the new drug Atiprimod for patients with relapsed/refractory myeloma. Atiprimod is a small molecule that inhibits angiogenesis (blood vessel formation at the site of the cancer cells) and promotes apoptosis (programmed cell death). Thus far side effects have been tolerable and none have been severe. No maximum tolerated dose has been achieved. Results have been encouraging as researchers continue to define a dose that will be effective in producing significant responses and will be safe and well tolerated.

Dr. Ravi Vij
Washington University Hospital – St. Louis, MO

Dr. Vij presented four posters based on a clinical trial using Velcade as both induction and consolidation therapy before and after transplant (peri-transplant). The first presentation concerned the use of GCSF alone in successful mobilization of stem cells – Dr. Vij and colleagues were the first to document this procedure in patients who went on to successfully harvest stem cells and undergo transplant. The second presentation dealt with markers of immune function and immune modulation after the use of Velcade in the peri-transplant setting. Dr. Vij et al. noted substantial decreases in CD8 cells and in the CD8 to CD4 ration, indicating Velcade's pronounced immunomodulatory activity. His third poster concerned the increased incidence of herpes zoster (shingles) with Velcade in the peri-transplant setting. Dr. Vij's final presentation concerned the effect of Velcade on markers of bone resorption.

Dr. Angela Dispenzieri
Mayo Clinic – Rochester, MN

Dr. Dispenzieri presented data on a pre-clinical mouse study with the combination of Velcade and the radiopharmaceutical Quadramet (153 samarium EDTMP). A previous Mayo study in which Dr. Dispenzieri was involved examined the use of Quadramet along with zoledronic acid to reduce bone pain in myeloma patients. Fourteen months out, the patients continue to have long-term improvement in pain. Even more significantly, of the 8 patients involved in that study, 4 achieved at least a 25% reduction in their M-protein. This led Dr. Dispenzieri to go further with Quadramet by combining it with an effective anti-myeloma agent and assess the results. In vitro studies of Velcade and Quadramet demonstrated synergy between the two drugs. In Dr. Dispenzieri's mouse study, survival more than doubled in the mice who received both drugs. Two new clinical trials have thus been proposed: one with Quadramet alone, to determine both myeloma response and pain response, and one with Quadramet and Velcade in combination. **MT**

NOTE: Webcasts from ASH 2005 are available on the IMF website www.myeloma.org. They include interviews with myeloma researchers, ASH 2005 presentations and posters, and a CME-accredited program, New Agents and New Opportunities for Multiple Myeloma – Today and Tomorrow, which brought together leading experts to discuss changing clinical practice in the context of new agents and new discoveries. We hope you will find this material informative and useful.

2006 IMF BRIAN D. NOVIS RESEARCH GRANT AWARDS

Grant Recipients Honored at IMF Scientific Advisors Meeting

Senior Research Grants worth $80,000

"Impact of human regulatory T-Cells on the graft-versus-myeloma effect"

Tuna Mutis, MD, PhD
University Medical Center Utrecht
Utrecht, The Netherlands

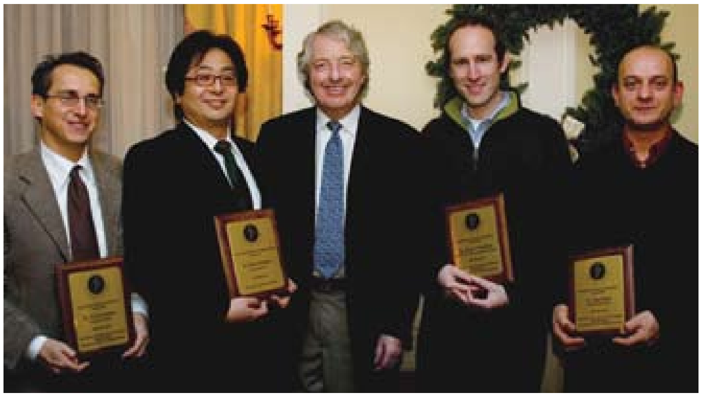
The effectiveness of stem cell transplantation from suitable donors is limited due to the side effect graft-versus-host disease (GvHD). Studies in mice suggest that administration of a specific type of donor blood cells, the "regulatory T-cells", into recipients can prevent GvHD without diminishing the anti-tumor effect. Dr. Mutis and colleagues will explore whether human regulatory T-cells can also separate the anti-myeloma effects of stem cell transplantation from GvHD. These studies will reveal the clinical feasibility and more importantly, the safety of this novel approach to prevent GvHD.

Junior Research Grants worth $40,000

"A novel therapeutic strategy for patients for systemic primary (AL) amyloidosis: Identification of drugs that inhibit light chain fibrillogenesis "

Dr. Brian O'Nuallian
University of Tennessee Medical Center
Knoxville, Tennessee

Currently, there are limited therapeutic options for patients with systemic immunoglobulin light chain (AL) amyloidosis, a disorder that involves the abnormal deposition of antibody light chains, or rarely heavy chains, as discrete insoluble masses (amyloid) within tissues and organs. Thus, the objective of this research is to identify FDA-approved drugs that have promise for 'off-label' use in preventing AL amyloidosis. These drugs will be identified using highly sensitive assays for their capability to prevent amyloid fibril growth. The most promising candidate(s) can then be tested in clinical trials and, if successful, will provide a unique means to prevent amyloid formation.



The IMF awarded the 2006 Brian D. Novis Research Grants at the IMF Scientific Advisors Meeting held in December in Atlanta, Georgia. In this issue of Myeloma Today, we are pleased to present to you summaries of the funded research by Drs. Mutis, O'Nuallian, and Tonon.

"Novel Therapeutic Antibodies for Multiple Myeloma"

Dr. Giovanni Tonon
Dana Farber Cancer Institute
Boston, Massachusetts

The use of antibodies directed against proteins present on the surface of tumor cells and critical for their survival have recently emerged as one of the most powerful tools available to clinicians to treat cancer. However, the genetic alterations and consequently the identity of the proteins driving multiple myeloma (MM) are largely unknown. Dr. Tonon and colleagues have implemented an integrated oncogenomic approach to identify the spectrum of genetic alterations in a large panel of MM cell lines (n=46) and tumors (n=73). Using stringent bioinformatic algorithms, 10 genes were identified that were within genetic lesions, showed high expression level and possessed structural features of membrane proteins. The significance of each of these genes for MM development and their potential

Please see RESEARCH GRANT AWARDS at bottom of page 8

CDC GRANT AWARD UPDATE

IMF Renewed for Second Year Funding

By David Smith

The IMF is pleased to announce that its first Centers for Disease Control and Prevention (CDC) government grant was renewed for second year funding.

David Smith
Vice President, Operations
Bank On A Cure® Administrator
International Myeloma Foundation

In January, I had the honor of representing the IMF at the second meeting of the CDC for grant awardees under Program Announcement 04159 – Hematologic Cancers Initiative. At this meeting, all ten grant recipients, including the IMF, presented their progress in reaching out to varied communities across the country with the overall mission to inform, educate, and support those affected by myeloma, leukemia, and lymphoma.

As I reported last year, the work plan submitted by the IMF involves educating those in major metropolitan areas about the increased risk of myeloma in African American communities, as well as developing outreach that also includes the elderly, the underinsured, and the uninsured. People in these communities affected by myeloma often struggle in their search for information. The video we produced in conjunction with our CDC grant, "I Have Myeloma…What's Next?" is a wonderful means of reaching out to these individuals, and it also educates those who, previous to watching it, were entirely unaware of the disease. Not only is the video a very compelling introduction to myeloma, it also addresses the data surrounding the higher incidence rate of myeloma amongst African Americans.

During 2005 Myeloma Awareness Week we shipped this video and distributed it, with energetic help of our support groups, around the country. The video is also a vital outreach tool in our ongoing efforts to reach underserved clinics, hospitals, community centers and centers of worship.

In all, the IMF shipped more than 500 of these videos during our 2004–2005 program year. For 2005–2006, we will easily triple that figure. If you have not yet seen this video, please contact me for a copy at dsmith@myeloma.org or by calling the IMF at 800-452-2873. It's available in VHS or DVD format.

But don't just watch it yourself – pass it on. The IMF has a rich history of grass-roots efforts in achieving community outreach and education, and for the CDC initiative, this is as important as ever. We must continue to raise the level of awareness about myeloma and the programs of the IMF (our Hotline, Patient and Family Seminars, our publications, and our web site) so we can continue to help those who are diagnosed learn more about support, treatment, and research.

With our CDC grant renewal for 2006, the IMF will reach out to additional communities, as well as strengthen the community relationships we formed in 2005. The IMF includes you. Whether at your local oncology clinic or your community center, please take a moment to let those in need of our services know that the IMF is committed to helping anyone touched by myeloma. **MT**

RESEARCH GRANT AWARDS — continued

as targets will be evaluated both *in vitro* and *in vivo*. The ultimate goal of this research is to provide the scientific and clinical community with a list of thoroughly validated antibody targets, ready to be enlisted into therapeutic antibody development and ultimately translated into drugs capable to impact on patient survival.

Upcoming issues of Myeloma Today will profile research being performed by grant recipients Drs. Agus, Ashihara, Guiliani, and Kisselev. **MT**

COMBINATION THERAPY WITH VELCADE PLUS MELPHALAN & PREDNISONE

By Jesús San Miguel

At the 2005 annual meeting of the American Society of Hematology, Dr. Jesús F. San Miguel presented interim data on the ongoing GEM/PETHEMA study of VELCADE® (bortezomib) plus melphalan and prednisone (V-MP) in elderly, previously untreated myeloma patients. The national, multi-center, open-label study comprises 60 patients, with a median age of 74 years.

Jesús San Miguel, MD
University Hospital
Salmanca, Spain

To date, melphalan and prednisone has remained the gold standard for elderly myeloma patients. Therefore new treatment strategies are needed for these patients. VELCADE, a proteasome inhibitor, has shown significant activity in refractory and relapsed myeloma patients. Moreover, in vitro synergy has been reported when VELCADE is combined with cytotoxic agents such as melphalan.

The goal of the PETHEMA study is to define the appropriate dose of VELCADE in combination with melphalan and prednisone (MP), and to analyze the response and toxicity of the V-MP combination therapy in untreated myeloma patients aged 65 years and older.

The V-MP treatment schedule consists of four 6-week cycles followed by five 5-week cycles. In Phase I, two sequential dose levels of VELCADE (1.0 and 1.3 mg/m^2) were explored, administered on days 1,4,8,11,22,25,29 and 32 in combination with oral melphalan, 9 mg/m^2 and prednisone, 60mg/m^2 once daily on days 1 to 4. No dose limiting toxicity (DLT) was observed in Phase I.

When maximum tolerated dose (MTD) of VELCADE in combination with MP was defined, the cohort of patients at the MTD was expanded to further refine estimates of efficacy and toxicity during Phase II of the PETHEMA study. The recommended dose for Phase II was 1.3 mg/m^2 of VELCADE in combination with MP. Analysis of response after cycle 1 revealed a Response Rate (RR) of 72%. Analysis of best response after a median of 5 cycles revealed a RR of 85%; including 30% Complete Response (CR) by immunofixation, plus 14% by electrophoresis. The toxicity was manageable.

In conclusion, the most significant finding of the PETHEMA V-MP study thus far is the high rate of response to treatment, with more than one third of patients achieving CR – and this was irrespective of chromosomal abnormalities. Longer follow-up is needed to assess the duration of response and the overall survival data, and to determine if V-MP could replace MP as the standard of care for elderly myeloma patients. An international Phase III randomized trial is currently underway. **MT**

Note: IMF Scientific Advisor Dr. San-Miguel is Professor of Hematology at the University of Salamanca, head of the Department of Hematology of the University Hospital of Salamanca, and Principal Investigator of different research projects supported by the Cancer Research Foundation and the Spanish Goverment (FIS & CICYT).

MYELOMA TODAY INTERVIEWS S. VINCENT RAJKUMAR, MD

The role of lenalidomide in multiple myeloma

Myeloma Today: Dr. Rajkumar, please summarize for our readers some of the recent developments in the field of newly diagnosed myeloma.

Dr. S. Vincent Rajkumar: Recently, the combination of thalidomide plus dexamethasone (Thal/Dex) has emerged as an alternative to the use of vincristine, doxorubicin, and dexamethasone (VAD) in newly diagnosed myeloma for patients who are considered candidates for stem cell transplantation. This development was based on three phase 2 clinical trials and a case-control study. Response rates with Thal/Dex range between 64% and 76%, comparable to or better than those obtained with VAD.

S. Vincent Rajkumar, MD
Division of Hematology
Mayo Clinic
Rochester, MN

In a recent randomized trial, conducted by the Eastern Cooperative Oncology Group (ECOG), the response rate with Thal/Dex was significantly higher compared with dexamethasone alone. However, grade III or greater non-hematologic toxicities were significantly higher with Thal/Dex compared with dexamethasone alone indicating the need for better regimens.

MT: How does lenalidomide compare with thalidomide?

SVR: In order to overcome the toxicities of thalidomide, several analogs have been developed.

Lenalidomide (Revlimid®) is an analog of thalidomide. It has demonstrated significantly more potent preclinical activity compared with thalidomide, alone and in combination with dexamethasone.

Two phase 1 studies of lenalidomide showed activity in pretreated patients with relapsed/refractory myeloma. A subsequent phase 2 study in relapsed and refractory myeloma established the activity of this drug. Approximately one third of patients responded to lenalidomide as a single agent. Further, additional responses were observed when dexamethasone was added to the regimen. Recently, two large phase 3 trials compared Rev/Dex to placebo plus dexamethasone in relapsed/refractory myeloma. Both trials showed superior response rates and time to progression in favor of Rev/Dex.

Lenalidomide has fewer non-hematologic side effects compared with thalidomide. Another significant point is that responses to lenalidomide have been observed in patients in whom thalidomide treatment has previously failed.

MT: When did you become involved with lenalidomide clinical trials?

SVR: Mayo Clinic got involved with lenalidomide as soon as the phase 1 trials were done. In general, only a small percentage of phase 1 trials show an active drug. Lenalidomide was one of those exceptions. There was clear evidence of single-agent activity shown by both phase 1 lenalidomide trials in advanced myeloma, where patients had failed all other treatments, including thalidomide. Plus there was a mountain of laboratory data showing that lenalidomide is more potent than thalidomide in all respects.

Mayo Clinic participated in the first phase 2 trial with lenalidomide that was led by Dr. Paul Richardson of the Dana-Farber Cancer Institute – it was a multi-institution trial, with 4 U.S. institutions participating. The results of this trial have not been published yet. We also participated in a subsequent phase 2 confirmatory trial, and in the pivotal phase 3 randomized trial led by Dr. Donna Weber of the MD Anderson Cancer Center.

MT: How does lenalidomide fit into the range of treatment options for newly diagnosed patients?

SVR: The idea that we should go ahead with a trial of lenalidomide in newly diagnosed myeloma occurred to us very early. As soon as the phase 1 trial results became known, it was clear that we should look at this drug in terms of front-line therapy in the near future. Preliminary data from phase 2 trials supported this strategy.

In the phase 2 trial at Mayo Clinic, 34 patients (median age, 64 years; range, 32-78 years) received Rev/Dex as front-line therapy. Lenalidomide was given orally 25 mg daily on days 1-21 of a 28-day cycle, and dexamethasone was given orally 40 mg daily on days 1-4, 9-12, and 17-20 of each cycle. Response was defined as a 50% or greater decrease in serum monoclonal protein level and a 90% or greater decrease (or reduction to a level less than 200 mg/24 hours) in urine M-protein. All response categories were confirmed by 2 consecutive measurements at least 4 weeks apart. Thirty-one patients achieved an objective response to therapy, including 2 who achieved complete response (CR) and 11 very good partial response (VGPR), resulting in an overall objective response rate of 91%. The median time to response was one month.

We concluded that Rev/Dex was highly active in newly diagnosed multiple myeloma, and felt that it may be both a safer and a more effective alternative to Thal/Dex.

MT: Please address the side effects observed with Rev/Dex combination therapy.

SVR: In studies conducted so far, side effects have been manageable. In the Mayo phase 2 trial, approximately 50% of patients experienced grade 3-4 non-hematologic toxicity. This rate of serious adverse effects is similar to that observed with dexamethasone alone in the recent ECOG trial. Unlike thalidomide, peripheral neuropathy, sedation, and constipation do not appear to be frequent. In the Mayo study, we have not encountered any unexpected adverse effects on stem-cell mobilization, indicating that this would be a useful pre-transplantation conditioning regimen.

Based on the efficacy of aspirin in preventing Thal/Dex-associated deep venous thrombosis (DVT), we initiated aspirin prophylaxis routinely for all patients in the Mayo Rev/Dex study. The incidence of DVT was low in this trial (3%), but a higher rate has been observed in the ongoing ECOG trial indicating that more information is needed.

MT: What is the latest information about phase 3 clinical trials with lenalidomide?

SVR: Both cooperative group randomized trials currently ongoing in the U.S. for initial therapy of myeloma are testing Rev/Dex. The Southwest Oncology Group (SWOG) trial compares Rev/Dex with dexamethasone alone as primary therapy, and the ECOG trial compares Rev/Dex as administered in the Mayo phase 2 trial to Rev/low-dose dexamethasone in an attempt to further reduce toxicity while preserving the same response rate. The low-dose dexamethasone arm of the ECOG trial gets dexamethasone only once a week.

The ECOG trial (known as E4A03) has already accrued over 320 of the 412 patients needed. Patients in this trial who do not respond to Rev/Dex will be offered Thal/Dex to determine if thalidomide has activity in myeloma in this setting. This trial is available not only to ECOG institutions but to all the cooperative groups. The IMF website and Hotline has information about all the participating institutions.

In my opinion, pending outcome of these two phase 3 trials, the high effectiveness and low toxicity of this regimen can make this regimen a major contender as standard frontline therapy for myeloma in the near future. **MT**

Revlimid Update: Where Does the IMF Stand?

By Brian G.M. Durie, MD

Revlimid® (lenalidomide) is an important new agent for the treatment of myeloma. It has shown great promise as both a single agent and in combination with dexamethasone and other drugs. With use of Revlimid there is much less risk of nerve toxicity than with thalidomide, which is one of the reasons patients have been eagerly awaiting access to it.

Celgene has opened the unique expanded access protocol (EAP) at over 80 centers across the United States. Through this program, patients with relapsing myeloma can have access to free Revlimid in a protocol that consists of Revlimid plus dexamethasone. To find out if there is an open trial site close to you, call the IMF at 800-452-CURE (2873) or Celgene at 888-423-5436 or visit www.revlimid.com.

For patients with newly diagnosed myeloma, Revlimid is available through two national trials involving ECOG (Eastern Cooperative Oncology Group) and SWOG (Southwest Oncology Group). A number of other trials are being planned and will be available in the coming months in various disease settings. Check the Myeloma Matrix and the Myeloma Minute for announcements as these trials open, or call the IMF hotline at the above number.

At the present time, access to commercially available Revlimid by prescription is more limited. The FDA has approved Revlimid for MDS, (Myelo Dysplastic Syndrome), a type of pre-leukemia. This means that use for myeloma patients is "off-label." For myeloma patients whose oncologists have recommended therapy with Revlimid, this presents problems. First, since Revlimid will probably not be approved specifically for myeloma until later in the year, it will not, generally speaking, be covered by insurance for myeloma patients. Second, and perhaps more importantly, the commercial Revlimid pricing is currently set for the much lower dose schedule used for MDS (5-10mg daily versus 25mg daily for myeloma), thus making the cost disproportionately and prohibitively high for myeloma patients at this time. With specific FDA approval for myeloma, there are indications that the pricing will be geared to the recommended myeloma dosing and schedule. This is a delicate point in that although myeloma patients need and want Revlimid right now, FDA approval is absolutely required to promote use for myeloma. The 25mg capsule that is provided free through EAP is not an appropriate dose for MDS. Thus the 25mg capsule is not currently available commercially! This complex scenario will be worked out in the coming months.

Many drug formularies of insurance companies offering Medicare Part D drug coverage currently do include Revlimid for MDS. Thus if you have not done so already, it is recommended that myeloma patients do some research and sign up for an insurance plan under Medicare Part D prior to the May 15th 2006 deadline in anticipation of reimbursement for Revlimid through this mechanism. Many pharmacies, including Walgreens, will help you determine which insurers in your region include the drugs you need in their coverage formularies.

Stay tuned for future updates.

PAIN MANAGEMENT IN MULTIPLE MYELOMA

Myeloma Today speaks with Daniel R. Kloster, MD

Myeloma Today: What is your specialty, Dr. Kloster?

Daniel R. Kloster, MD: I am a pain management specialist. I treat cancer and chronic pain.

Daniel R. Kloster, MD
Rockhill Pain Specialists
St. Joseph Health Center
Kansas City, MO

MT: What is the most common complaint that you hear from myeloma patients?

DRK: Bone pain is a big problem for many myeloma patients. When the bone tissue of the vertebral body is involved, the patient can experience severe pain. Such pain is often worse with movement or weight-bearing.

MT: How do you treat such cases?

DRK: Myeloma-related pain can be tough to treat. For some such patients, an implantable morphine pump may be the answer. Morphine still has a bit of a social stigma but it is a very good medicine for combating pain.

MT: What is a morphine pump and how is it implanted?

DRK: Implanting the device involves two incisions, one in the back and one in the belly. The unit delivers approximately a raindrop of morphine per day. Morphine works in the spinal cord, regardless of whether it is taken orally, intravenously, or via a patch. When morphine is taken orally, the dosage required to achieve pain relief often causes sedation. The pump delivers the morphine directly where it needs to go, and provides excellent pain relief at a lower dosage without undesirable side effects. The rule-of-thumb calculation is that a 300 mg morphine pill provides pain relief equivalent to only 1 mg of morphine delivered via a pump.

MT: What are the risks associated with this device?

DRK: When you first put in the pump, there is a 2% to 5% risk of infection. If an infection develops, the pump must come out and the patient must wait 3 months before attempting the procedure again. That is the most common problem I've seen. I have never had a pump malfunction or seen any mishaps but, because we're dealing with morphine, I always have a very serious discussion with all my patients so that they understand all the potential consequences.

MT: How is the morphine dosage controlled?

The dosage and rate of delivery are programmed by the doctor through a computer. For some patients, it is best to receive a steady dose throughout the day. However, if a patient complains of experiencing increased pain at certain times of the day, the pump can be programmed accordingly. For example, if a patient complains of severe pain while getting up in the mornings, the pump can be set to deliver a slug of medicine 30 minutes before the alarm clock goes off.

MT: How closely do you monitor your patients?

DRK: Once they are on a steady regimen, I see them when the pump needs to be refilled, usually every 2 to 4 months. But until I've ascertained the most favorable pump settings, I see patients as often as necessary.

MT: Besides bone pain, what is another pain issue that myeloma patients encounter?

DRK: Herpes zoster (shingles) and resulting post-herpetic neuralgia (PHN). Once a person has had the chicken pox, the virus remains dormant in the spinal cord where it is held in check by the immune system. If the immune system is compromised for any reason, it may no longer be able to suppress the virus. Once a shingles outbreak occurs, the nerve is damaged by the viral infection and the patient can experience miserable pain and burning sensation. Quite frankly, PHN is the toughest thing I've had to treat.

MT: What recommendation can you make to a patient experiencing shingles or PHN?

DRK: It is essential to start taking antiviral medication at the earliest sign of shingles and to continue taking it for the entire duration of an outbreak. Taking a low-dose tricyclic antidepressant (TCA) in combination with the antiviral medication dramatically reduces the risk of developing PHN. And even if PHN does occur, it is likely to be much milder. The success rate is highest when TCA treatment is started immediately upon the onset of shingles. Nortriptyline is the TCA that I prescribe most frequently. TCAs work in the brain and spinal cord where messages of pain are received from the nerves.

MT: What other medications reduce the pain of shingles or PHN?

DRK: Anticonvulsant medications change how the body interprets pain. They help to quiet overactive nerves. Gabapentin (Neurontin) is the anticonvulsant that I prescribe most frequently, followed by topiramate (Topamax).

Continues on page 14

TRANSPLANT NUTRITION

Myeloma Today speaks with Heather-Ann Younker, RD, CNSD

Myeloma Today: Please tell us about your work with myeloma patients.

Heather-Ann Younker, RD, CNSD: I am a transplant nutritionist working specifically with the transplant program at Hackensack University Medical Center (HUMC) in New Jersey. It is mandatory for each patient who enters the HUMC transplant program to attend one of our weekly Nutrition and Food Management Program educational sessions. There are separate sessions for patients undergoing autologous and allogeneic transplants, but each includes a class on nutrition. In addition, their nurse clinician or physician will often refer them to me for individualized counseling to help maintain a sound nutritional plan and reduce treatment side effects.


Heather-Ann Younker RD, CNSD
Outpatient Transplant Dietitian
Hackensack University
Medical Center
Hackensack, New Jersey

MT: What does your first meeting with a myeloma patient encompass?

HY: Basically, it is a screening process. I go through a series of detailed questions designed to assess the patient's nutritional status. For example, I need to know about any weight loss or dietary changes that patients may have experience since the onset of their disease. With myeloma, patients who are on a chemotherapy regimen in preparation for their transplant are likely to be experiencing gastrointestinal distress (such as nausea, vomiting, diarrhea, constipation), as well as poor appetite and weight loss.

MT: How are you able to help such patients?

HY: A common approach is to experiment with different foods and to structure a diet with smaller but more frequent meals. The dietary programs I design are tailored to each individual patient. This could be as simple as adding nutritionally balanced milkshakes to the patient's existing dietary practices. But, of course, some cases are more challenging.

MT: How do you approach a challenging case?

HY: Patients who have renal difficulties or are on dialysis present a number of challenges. There are foods that such patients are not allowed to have. This may be a big adjustment for a patient who previously never had to limit his or her dietary intake in any way. Now, all of a sudden, the patient must adhere to a strict high-protein, low-potassium, low-phosphorus, low-sodium diet. The renal diet has many restrictions, which must be taught to both the patient and the caregiver or other family members.

MT: What is your most frequent dietary recommendation?

HY: If there are no renal problems, then I would say that a high-protein diet would benefit many patients, whether or not they are planning to undergo a transplant. Cancer patients often experience loss of muscle mass, and increasing their intake of protein helps curtail this. Conversely, patients I work with who have renal issues but are not on dialysis must be carefully supervised when it comes to protein intake. To maintain good nutrition, small meals and regular snacks are a good rule of thumb. Drinking plenty of water is important.

MT: Are there any restrictions that would apply to all transplant patients, whether or not they have renal issues?

HY: Yes. Before the transplant takes place, and for several months after, I strongly recommend that patients adhere to the Low Microbial Dietary Guidelines. This is due to the suppression of the immune system. The low-microbial diet reduces a patient's exposure to bacteria and prevents foodborne illness. It is important to avoid foods that are likely to have a high bacterial count, such as unwashed fruits or vegetables, and rare meats or raw fish. If food is prepared in advance, it must be immediately frozen (and thawed only when you are ready to eat). All leftovers should be discarded after 24 hours. Dining out is problematic because you can't control food preparation. Adhering to these restrictions is very important, and I recommend that a transplant patient follow these dietary guidelines for a minimum of three months.

MT: How often do you see a newly referred patient?

HY: Teaching patients a new way of eating usually requires several sessions. There's just too much information to be taken in at once. And when it comes to patients who are on dialysis, I try to see them even more frequently until their nutritional status has stabilized.

MT: Do you follow patients after they have had their transplants?

HY: Yes, of course. Either their nurse clinician or physician refers them back to me, or the patients will call me on their own when questions or issues arise. One common issue is that, after a transplant, patients often develop aversions to food they previously liked. So, once again, I must help them learn a new way of eating. Each patient's journey is unique, and I am here to assist in whatever way I can before, during, and after a transplant. And I love my job. Recently I saw a patient who was referred to me in preparation for a transplant. I met him when he was in a wheelchair and on a feeding tube. We continued to work together for six months following his transplant. When I saw him last, he was walking down the hospital corridor, looking as healthy as anyone. That's what it's all about for me. **MT**

IMF HOTLINE COORDINATORS ANWSER YOUR QUESTIONS

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

Q: *My brother was just told he has a very rare form of myeloma called IgM. I can't find anything on it and keep coming across discussions of something called "Waldenstrom's macroglobulinemia." Can you help?*

A: You have raised a very interesting and complicated question. There is a specific disease called Waldenstrom's macroglobulinemia that is different from myeloma. What causes the confusion with myeloma is that Waldenstrom's macroglobulinemia also involves abnormal plasma cells and is characterized by excess monoclonal IgM proteins in the blood.

In Waldenstrom's macroglobulinemia, the abnormal plasma cells invade the bone marrow, lymph nodes, and spleen, and produce excessive amounts of IgM protein. The excess IgM in the blood causes hyperviscosity (thickening) of the blood. Waldenstrom's macroglobulinemia is actually considered to be a form of indolent lymphoma and not a form of myeloma.

We have listed the seven types of myeloma and the percent of cases they represent to give you an idea of how rare IgM myeloma is: IgG – 59%; IgA – 24%; Bence-Jones – 13%; non-secretory myeloma – 2%; IgD – 2%; IgM – less than 0.1%; IgE – less than 0.01%.

The Table should help you distinguish between the two diseases. These distinctions are general and, in fact, no one has completely agreed upon the precise criteria for the differences between IgM myeloma and Waldenstrom's macroglobulinemia.

What is most important to keep in mind is that usually the treatment and outcome for the extremely rare cases of IgM myeloma is essentially the same as that for the typical myeloma. However, in the unusual case where there are features of the IgM myeloma that are more like those of Waldenstrom's macroglobulinemia, then there may be additional treatment options available to those patients. For example, if the IgM patient happens to be CD20 positive, then Rituxan (rituximab) is an option. If there are other indicators of Waldenstrom's macroglobulinemia (see table above), then Fludara (fludaribine), and Cladrabine (2CdA) – which are normally not used in myeloma therapy – may be helpful to these patients.

	Ig M myeloma	**Waldenstrom's macroglobulinemia**
Clinical criteria	Bone lesions	Enlarged lymph nodes, liver, and spleen
Marrow morphology	Plasma cells	Mixture of plasma cells and lymphocytes
Special testing	CD 20 negative Chromosome [11:14 translocation]	CD 20 positive No myeloma-type translocations

For information on Waldenstrom's macroglobulinemia you can contact the International Waldenstrom's Macroglobulinemia Foundation (IWMF) at www.imf.com or by telephone at 941-927-4963. For information on myeloma, our educational materials (Patient Handbook 2002/2003 Edition and the Concise Review of the Disease and Treatment Options) will be applicable to IgM myeloma.

In addition, if your brother calls us here at the Hotline, we can put him in touch with several patients who have also been diagnosed with IgM myeloma. **MT**

PAIN MANAGEMENT — continued

Opioid medications target the same locations in the body as do the body's own endorphins, so they can reduce the level of pain very quickly. Unfortunately, patients with PHN often have a suboptimal response to opioids. However, they are still worth trying.

Local anesthetics impede the pain messages sent to the brain and can be used to treat damaged nerves. For example, a lidocaine patch applied to a painful area can quiet the activity in the nerve cells damaged by shingles. Ointments and gels can be useful as well.

MT: Thank you, Dr. Kloster. Any there any closing thoughts that you would like to share with our readers?

DRK: Creating a pain-management plan is a very individualized process, which often involves trial and error. The doctor and patient must work together to find the best solution for pain relief with the least side effects possible. **MT**

THE IMF RETURNS TO ST. PETERSBURG, RUSSIA

International Clinical Conference Promotes Myeloma Education

By Vitaly Krylov

Conference chair, Dr. Podoltseva, her team, Drs. Durie and Kyle, Susie Novis, and Marya Kazakova

In any scientific arena, progress is dependent upon the speed with which information about the latest developments is disseminated. This is particularly true in the field of medicine, where every step forward can represent many lives saved. It is in this spirit that I view the IMF's contribution to the field of myeloma in Russia.

The first IMF Clinical Conference in Russia took place in 2001. It was organized by Susie Novis of the IMF and Prof. Eleonora Podoltseva of St. Petersburg Hospital #31. The meeting featured an expert faculty: Dr. Brian Durie, Prof. Heinz Ludwig, and Dr. Mario Boccadoro. In addition to scientific presentations, the IMF visit included a review of patients in the transplant ward of Hospital #31. At that time, I was one of the myeloma patients hospitalized in that ward. After a consultation with Dr. Durie, I followed his invaluable recommendations and achieved a lengthy plateau.

Three years later, when my myeloma worsened, I once again consulted with Dr. Durie, this time at the Cedars-Sinai Cancer Center in Los Angeles, California. He recommended a therapy that was not being used in Russia – a combination of dexamethasone and thalidomide. I quickly responded to this treatment and my health improved.

Last summer, as I eagerly anticipated Dr. Durie's return to Russia for the second St. Petersburg IMF Clinical Conference, my lab tests once again showed an increase in the M-protein. I looked forward to consulting with Dr. Durie about my situation, as well as expanding my understanding of novel therapy options by participating in the conference.

The second St. Petersburg IMF Clinical Conference took place in September of 2005. The faculty featured Dr. Durie and his mentor, Dr. Robert Kyle of the Mayo Clinic. The day before the conference, both doctors made rounds at Hospital #31 transplant ward, and participated in patient consultations. Once again, I was one of the patients whose case was reviewed by the visiting experts and, as a result, I have high hopes for improved health and outlook.

The IMF Clinical Conference proved to be essential not only for the participating local doctors, but also for patients such as myself. I would like to commend Prof. Eleonora Podoltseva for doing such an excellent job coordinating the St. Petersburg conference, and extend special thanks to Drs. Durie and Kyle for their generosity of time and effort in educating Russian myeloma physicians.

I hope that the IMF will become a regular visitor to my country, because sharing experience and education helps our doctors improve their ability to diagnose and treat patients, and helps patients better understand their disease and to be empowered by this newly acquired knowledge. **MT**

ARIZONA MYELOMA NETWORK HOSTS TWO SUCCESSFUL EVENTS

By Barbara Baroff Kavanagh, MSW

My husband, Jack, was diagnosed with multiple myeloma just before we got married in 1991. We lived in Boston, so we were fortunate to be near the Dana-Farber Cancer Institute. Shortly thereafter, we moved to Europe for Jack's work – he is an international construction executive. Luckily, we were referred to Dr. Pieter Sonneveld, a myeloma specialist in the Netherlands. He was Jack's doctor for the two years we lived in Holland. It was Dr. Sonneveld who referred us to the IMF.

Over the years, the IMF has been a big part of our life. I got to know Susie Novis in the early days of the IMF, during my visits from Europe to see my two daughters, who lived in Los Angeles. As Jack and I moved from Holland to Germany, Turkey, England, and Ireland, Susie always helped us find excellent medical resources wherever we were. And Dr. Brian Durie has always been a wonderful help.

When Jack retired, we came back to the US and settled in Arizona. In 2004, shortly after we returned from overseas, I became very motivated to get involved with the Phoenix myeloma support group. This was my first opportunity to join a local myeloma community. But Jack just wasn't interested in attending any meetings. That was fine, because I understood that everyone has his or her own way of dealing with this disease. Jack's coping mechanism is to do a lot of reading and to talk to his doctor. I am the one who takes notes and seeks out community support. But Jack and I are a team, and we complement each other very well!

Happily, Jack is doing very well, but I understand the importance of helping others who might need support and encouragement through their struggles with myeloma. I became active in the Phoenix support group, and suggested that the group hold a fundraising event to benefit the IMF's myeloma research program. Brenda Gregory and Minita Levenson, the group's leaders, were very excited about the idea but had never done such a thing before. However, I am a social worker by profession, with many years of volunteering experience, so I organized an event called the Spring Fling. Several group and community members got involved and the fundraiser was a big success.


Barbara Kavanagh and Anne Winter at the Southwest Symposium AzMN

Dr. Raphael Fonseca of the Mayo Clinic in Scottsdale was one of the guests at the Spring Fling. He had a great time and was enjoyed mingling with myeloma patients outside the hospital setting. He asked me if I would be interested in organizing a local symposium where he would address myeloma patients and their healthcare providers.

I formed a broad-based committee, which came to be known as the Arizona Myeloma Network (AzMN), to organize the symposium. Members of both the Phoenix and the Tucson support groups participated. Millennium Pharmaceuticals was also extremely helpful, as were Celgene, Novartis, Kyphon, and Ortho Biotech. With a commitment from Mayo and collaboration with the IMF, we ended up with a wonderful consortium. We broadened the symposium to include not just Arizona but the entire Southwest and, rather quickly, had over 200 people registered to participate. We even had registrants from Colorado. And several members of the California myeloma community, including Margaret and Tony Goeffredo, made the long drive to join us in Arizona!

I had written to our Governor and invited her to attend the Southwest Symposium. The Governor sent us a letter of support and, about three weeks before the event, I also received an email from Anne Winter, the Arizona

Governor's Policy Advisor for Health. Ms. Winter, whose father had myeloma twenty years ago, became the symposium's keynote speaker. She gave the most moving speech about her family's experience with myeloma at a time when there were few resources available to patients and their families.

> *"Barbara truly embodies the spirit of volunteerism, and her passion for helping others is inspiring. Her positive attitude is the driving force behind her successful work and her contribution to volunteering is a model for others. And, her support for the IMF and the myeloma community has meant a lot to all of us."*
>
> **– Susie Novis**

The Southwest Symposium included presentations by Dr. Fonseca, Dr. Keith Stewart (Mayo Clinic), and Dr. Jeffrey M. Trent (Translational Genomics Research Institute), who all spoke eloquently about new therapies, clinical trials, living with myeloma, and other topics. The Southwest Symposium ended up being a very educational, diverse, and successful event.

In 2005, I also made a commitment to organize a charity golf tournament to benefit the IMF's myeloma research program. I spoke with Ron Baker, whom I knew through our country club, because he has a lot of experience with planning golf charity events. Ron's life has also been touched by cancer, so he volunteered his services to the cause. My husband became very involved with the golf committee, and many of our friends offered to help with the event. My friend Nikki Stolee worked on both the symposium and the fundraiser, and helped coordinate our volunteers. All in all, we had over 120 people attend the fundraiser, with 64 golfers taking part in the tournament. We even had four myeloma specialists from Mayo participate in the event!

My objective was to hold two educational and enjoyable events and, when we started receiving calls and letters from participants telling me what a great time they had, I knew that we had gotten our key message out successfully. People who are coping with myeloma are getting the support and the information they need, and people who have never heard of the disease are being educated. I want people to feel empowered. Everyone can find a way to participate in the myeloma community. It's not just about raising money for research. It's also about raising awareness and raising people's spirits. We are part of our own destiny. **MT**

NOTE: Barbara Baroff Kavanagh is Founder and Chairperson of AzMN. She has her Masters Degree in Social Work from Boston University. Over the past 25 years, she has conducted successful team building, volunteer management, and time and stress management programs. Barbara Kavanagh has been on the faculties of Boston University, Boston College, Rhode Island College, and Arizona State University. Barbara is listed in "Who's Who of American Women," "Who's Who of Outstanding Americans," and "Who's Who of International Women." She is the author of numerous articles and co-author of The New Volunteerism: A Community Connection. You may contact Barbara at bjkavan@aolo.com.

Jack & Barbara Kavanagh with Margaret & Anthony Goeffredo at the Golf Tournament

2005 SUPPORT GROUP RECAP

Introduction by Andrew G. Lebkuecher, IMF Director of Support Groups

As the IMF embarks on a new year, it serves well to look back at the accomplishments of 2005. It was an exciting year. Robin Tuohy, Kelly Cox, and I made visits to about a third of the myeloma support groups around the country. This was a very rewarding experience for us, and the response to our visits has been overwhelmingly positive. We traveled to several groups to assist them with Bank On A Cure "Swish & Rinse" DNA parties.

The IMF welcomed several new support groups in 2005, and we are working with more that are about to make their mark in their local myeloma communities. It is very exciting that most of the new groups are in areas of the country that previously did not have myeloma support groups!

In 2005, many support groups organized and held successful events, including the first Southwest Symposium, the first Connecticut Myeloma Week Kick-Off Info Day, and several fundraisers. As we look ahead to the many exciting events slated for 2006, we look forward to seeing more of our friends, old and new, at group meetings, fundraisers, and seminars.

Arizona

In 2005, the Phoenix myeloma support group celebrated its 7th anniversary. It was a very exciting year. The Mayo Clinic in Scottsdale expanded their myeloma department to three specialists, which has helped members of the group to have better access to clinical trials and other progressive treatments for myeloma. The group also entered a partnership with the Tucson support group and the Arizona Myeloma Network, which facilitated the first meeting of the Southwest Symposium for Myeloma. The symposium was held in Phoenix, and it was a great success.

Arkansas

The Arkansas support group serves patients, caregivers, family members, and friends who are dealing with blood-related illnesses, although most of its members are coping with myeloma. The group is facilitated by two social workers from the Myeloma Institute for Research Therapy at the University of Arkansas for Medical Sciences: Harriet Farley, LCSW, and Lenore Arent, LCSW. The Arkansas group was created primarily to offer patients and caregivers a community of trust and caring in which they can explore the emotional impacts of coping with their disease.

California

The San Diego myeloma support group was founded in 1997 with 6 members. The group's membership now includes over 60 patients, and is continuing to grow. With Captain Fred Gloor at its helm, the San Diego support group has celebrated 8 years as a proactive member of the myeloma community.

Connecticut

The Connecticut Multiple Myeloma Fighters held their inaugural meeting in the Spring of 2001 at the Prospect Library.

The Phoenix Myeloma Support Group

In 2005, the support group held an "Information Day," which served as a kick-off event to the IMF's Myeloma Awareness Week. The event featured presentations by Dr. Ruben Niesvizky (Director of the Multiple Myeloma Program at New York Presbyterian Hospital), Dr. Sundar Jagannath (Chief of the Multiple Myeloma Program at St. Vincent's Comprehensive Cancer Center), and Susan Wall, a stress management consultant and yoga therapist. The event was profiled in several newspapers and on broadcast radio. Local businesses contributed great raffle items, with all proceeds benefiting the IMF. The Leever Cancer Center in Waterbury was so impressed with the support group's efforts that it offered them a new "home" for its meetings!

Florida

The Multiple Myeloma Group of Palm Beach, Martin, and St. Lucie Counties was started in May of 2005. The group now has a roster of 70 patients, with an average of 40 attending each meeting. The Multiple Myeloma Group of Palm Beach, Martin, and St. Lucie Counties enjoys a productive partnership with the Miami myeloma support group. The two support groups frequently share speakers and other resources. On December 15, the group's luncheon meeting featured guest speaker Patty Rhee, an oncology pharmacist at the VA Medical Center in West Palm Beach.

Minnesota

The Minneapolis/St. Paul Myeloma Support Group originated in 1996 with five members who gathered at the home of one patient. They offered their personal experiences as support to one another and took comfort in the information provided by others coping with the same disease. Today, the group has over 90 regular participants. Meetings are held monthly and are facilitated by Helen Berg and Pat Harwood.

The Stillwater support group is new to the myeloma community. At present, the group consists of 15 members from both Minnesota and Wisconsin. A recent meeting featured a guest speaker from the local hospital who addressed the topic of diet and nutrition for cancer patients. The group's next meeting is scheduled for March of 2006.

Missouri

The membership of the Kansas City support group has grown in the past year. It now includes about 20 regular monthly attendees. In September, Dr. Daniel R. Kloster visited the group to make a presentation on the topic of post-shingles neuralgia. In November, IMF's Greg Brozeit visited the group to present an update on advocacy. In December, the group celebrated the holidays with a dinner party at a favorite Italian restaurant. And, all three of the group's recent transplant patients continue to do well!

The new multiple myeloma support group in St. Charles is off to a great start. The group held its first meeting in September with just 4 participants. To date, the group has already grown to include 11 patients and caregivers, and the feedback from the attendees has been very positive.

New Jersey

The Central Jersey MM Support Group held its first meeting in July of 2005. The gathering took place at the dining room table of one of the group's members, with only 4 others in attendance. In October, the group moved to its new meeting place at the Bridgewater Township Library. At almost every meeting, the group has welcomed new members, and has now grown to include 18 patients and caregivers.

Philadelphia

Since 1995, the Philadelphia support group mailing list has grown to over 300 and continues to add new members. They have had to move to new larger facilities twice and have instituted more structure to the group, with Maddie Hunter as group leader and Lori Curtis as facilitator and social worker. They have a steering committee of over 15 people who offer their time to keep them organized. They created the positions of treasurer, advocacy lead, fundraising lead, newsletter editor, and more. Because of their strong steering committee, they are able to make transitions in the group's leadership.

PLEASE SEE SUPPORT GROUPS RECAP ON PAGE 20

SUPPORT GROUPS RECAP — continued

The Philadelphia Myeloma Support Group

Most recently, they celebrated Debbie Exner's move to Arizona and welcomed Maddie Hunter. By keeping a yearly schedule of events for each meeting, including speakers, a patient/caregiver split, or just a round table among themselves, they keep the meetings timely and interesting for all. In 2005 they hosted speakers on pain management, caregiving in MM, and the law and MM. Through it all, they feel it is all well worthwhile.

Rhode Island

The Rhode Island multiple myeloma support group held its first meeting in April of 2005 with 5 members in attendance. As of January 2006, the group has grown to include a total of 18 members. In addition, the group has several regular email and telephone participants. Being the only myeloma support group in Rhode Island, the group has entered active contact with patients, caregivers, and medical professionals, and is making great strides in raising statewide awareness about myeloma. The group has been very successful in recruiting professional speakers, distributing IMF educational materials, and reaching out to hospitalized and homebound patients with phone calls and personal visits.

Tennessee

The Chattanooga myeloma support group was started by Tommy Tonkin in 2002. Tommy lost his battle with myeloma in September of 2005, but his wife has continued her involvement with the group in Tommy's honor. Carroll Tonkin and Kim Shank, an oncology nurse at the Cancer Resource Center at Memorial Hospital, now run the support group. In 2005, the group hosted meetings featuring topics such as "Strength for Caregivers," pain management, nutrition, and stress-reduction techniques. Many of the group's members participated in the IMF's Bank On A Cure® program and some attended the IMF Patient & Family Seminar in Atlanta.

Texas

The Houston Area Multiple Myeloma Support Group was started by Norma Jones in January 1998. The first meeting was in Norma's home with about 15 members attending. The group now meets in the American

The North Texas Myeloma Support Group raises awareness for myeloma at the Light the Night Walk

SUPPORT GROUPS RECAP — continued

Cancer Society offices and membership has grown to approximately 150! About 30 to 70 members attended each meeting in 2005. The group hosted talks given by Dr. Brian Durie, IMF's Susie Novis, and Dr. Michael Wang (a myeloma specialist with the M. D. Anderson Cancer Center). In 2004, during Norma Jones' illness and recuperation, the group elected to rename the organization The Norma H. Jones Multiple Myeloma Support Group.

From its inception, the North Texas Myeloma Support Group has been dedicated to serving the local myeloma community with support, comfort, information, and friendship. In 2005, the group hosted a number of guest speakers. Maureen Carling, RN, gave a presentation entitled "Pain CAN and SHOULD be Controlled," which was very enlightening. Dr. Douglas Won, a spine surgery specialist at UT Southwestern, gave a presentation entitled "Metastatic Bone Disease and Multiple Myeloma," which focused on kyphoplasty. These presentations can be viewed at the group's website http://northtexas.myeloma.org. Additionally, the North Texas Myeloma Support Group hosted a Bank On A Cure® event and gathered approximately 30 samples for the IMF research program.

Vermont

The Burlington group held its first meeting in May of 2005, with 7 myeloma patients plus family and friends in attendance. At present the group membership has doubled to include 14 myeloma patients. The group's first invited guest speaker was IMF's Robin Tuohy. Everyone enjoyed listening to her very much and they are still talking about it!

Virginia

The Multiple Myeloma Network for the Blue Ridge has been meeting for over three years. The support group is active in myeloma education and advocacy, and distributes a monthly newsletter. The group was recently profiled in the Roanoke Times for its work in the Virginia myeloma community. In December, the Multiple Myeloma Network for the Blue Ridge celebrated Christmas together at their regular meeting at Our Lady of Nazareth Catholic Church in Roanoke County.

Washington

The Northwest MM FIGHTERS! support group's motto is "FIGHT ON!" The group includes patients, caregivers, and families from Washington, Alaska, and British Columbia. Founded in 1997 with 5 members, the MM FIGHTERS! now serve 150 member families. The main emphasis of the group is to disseminate information. The Northwest MM FIGHTERS! maintains an active email list, and sends out monthly updates on myeloma treatments and group activities. The group's monthly meetings frequently feature speakers and video presentations. Special events in 2005 included a summer potluck picnic and a holiday open house.

Wisconsin

The biggest achievement of the three Wisconsin support groups is hosting the statewide patient and family educational seminar. In 2005, this event took place for the third time! Over 200 attendees gathered in Milwaukee in November. Dr. David Vesole, who had relocated to St. Vincent's Cancer Center in New York, returned to Wisconsin to participate in the seminar as a presenter and to visit with many of his former patients. The full program included two other physicians, a nurse, and a patient panel. IMF Director of Support Groups, Andy Lebkuecher, also attended.

Members of the Racine myeloma support group have continued their very successful cell phone collection drive, and have now shipped out a total of over 2,000 phones! Half of the proceeds from the drive go to support IMF programs, the other half of the proceeds supports various group efforts, including the statewide patient and family educational seminar. **MT**

Note: The 2006 IMF Support Group Leaders Retreat will take place May 19th through May 21st in Scottsdale, AZ. If you have any questions about the retreat, or wish to find or start a myeloma support group in your area, please contact Andrew G. Lebkuecher, IMF Director of Support Groups, at imfsupport@charter.net.

CENTRAL NEBRASKA MYELOMA SUPPORT GROUP

By Jim Omel, MD

The Central Nebraska Multiple Myeloma Support Group was founded by Mary Lou Russell, a myeloma patient, about seven years ago. Mary Lou has the sparkle and energy of Susie Novis. I serve as the group's facilitator. We meet in a beautiful community room graciously donated by Home Federal, a local bank, on the third Wednesday of every month. The group has become our source of information and support, and I challenge other patients and caregivers to start myeloma groups in their local communities. It only takes one committed person and the help of the IMF. The rewards are enormous!


Jim Omel, Mary Lou Russell, Greg Brozeit

Our support group had a special treat in September of 2005 when Greg Brozeit, IMF Advocacy Consultant, spoke to our monthly gathering. Greg was to be the first outside speaker to make a presentation at our meetings. Prior to his arrival, Donna Wernke called each member of our group to remind them of the upcoming meeting. Donna faithfully calls our members every month as the meeting day approaches. In September, in addition to Donna's calls, we had promoted Greg's visit at local medical facilities. As a result, our usual attendance of no more than 10 swelled to over 20!

During his presentation, Greg explained how genomics and proteomics are exposing cancer's dark and dirty secrets. All types of this disease are being shown to have similar characteristics. Greg emphasized the commonality of all cancer patients and shared his conviction that the most effective advocacy must take into consideration the needs of the entire cancer community instead of focusing on individual diseases such as breast, prostate, lung cancer, etc. He also pointed out the political realities in Washington, DC, and the unique independent voting patterns of Senator Nelson and Senator Hagel. Greg energized and challenged our group to become more politically active and advocate for cancer research.

We mused over Greg's observation that all of us enjoy the friendships within our group, but if we had our choice we would all prefer to have never been a part of it! But, even though myeloma is the pits, we've turned it into a source of new friends. Through the IMF, that circle has expanded to include Greg, Andy, Robin, Susie, Nancy, Debbie, and many others. Greg's presentation lived up to our advance billing and everyone left the two-hour meeting inspired.

Greg's sojurn to Nebraska had its origin in July as we became re-acquainted during the 2005 IMF Support Group Leader Retreat held at the R. David Thomas Conference Center at Duke University. I asked Greg why he would find Nebraska a worthwhile trip and reminded him that our membership numbers don't come anywhere close to those of the myeloma support groups in Georgia or Texas. His kind answer emphasized quality over quantity and the fact that the IMF is committed to supporting each and every myeloma group regardless of size. MT

SUPPORT FOR CANCER PRIORITIES SHORT-CHANGED IN PRESIDENT'S BUDGET

By Greg Brozeit

President Bush's recent state-of-the-union speech set the stage for an annual federal spending proposal that threatens to further erode our nation's long-standing commitment to advance the pace of medical research and drug access.

Despite a theme of "When America leads, Americans Win," the President's budget proposal continued a three-year trend of decreasing resources for medical research. Funding for federal medical research will remain well below the rate of inflation, which is estimated to be at least 3.5% annually. The current budget proposal recommends the same level of funding for the National Institutes of Health (NIH) as last year, $28.331 billion.

Within that amount, the National Cancer Institute (NCI) would get a cut of $40 million, or 0.8%. Part of that cut would be shifted to supplement a proposed $140 million increase, or 26.5%, to the Office of the NIH Director to fund institute-wide reform initiatives.

Under the President's budget proposal for fiscal year 2007, cancer programs funded by the Centers for Disease Control and Prevention are slated to be cut by $20 million, or 2.4%, to a total of $819 million. These programs include the Ferraro hematological malignancies education program and other early detection and registry programs.

Another important issue to the cancer community, funding for nurse training and education, would also remain flat funded at $150 million.

Also included in the budget were projections that would trim Medicare costs by up to $36 billion. It remains to be seen if Congress will take up these proposals and what form and shape they will take. However, the newly implemented Medicare Part D prescription is already, by most educated estimates, over-promising benefits that have been committed to the American people. Any further cuts will make an untenable situation even more precarious.

Since many of the past projected savings in Medicare have been and are being borne by the cancer community, time will tell if the new proposed cuts will translate into further reductions in the provision of oncology services.

This news comes on top of the recently released figures breaking down the final appropriations funding figures for fiscal year 2006.

For the first time in our nation's history, Congress passed and the President signed into law a bill that reduced funding of NIH by more than $33 million, or 0.12%. Looking more closely at the numbers, NCI took one of the hardest hits of all the institutes. NCI was reduced by $31.9 million, or 0.66%. CDC cancer programs were reduced by $1.3 million and nursing education and training was reduced by almost $1 million.

These are cuts, and not increases well below the rate of medical inflation. Both translate into reductions in research activity, but the cuts reduce the pace of research more quickly and more painfully than do insufficient increases.

The President's renewed call for extending and making permanent the tax cuts will, if realized, continue to put pressure on Congress to find real cuts all across the board of domestic spending.

Advocates should talk about this situation with their friends, families, neighbors, and communities throughout the year. Current trends indicate that medical research and drug access issues will be swept aside from the national political agenda unless there is a grassroots, person-to-person understanding of the potential crisis the cancer and other disease communities will face in the years to come. **MT**

LIGHTS, CAMERA, CURE!

The IMF's 15th Anniversary Gala a Winner

On November 12, 2005, the International Myeloma Foundation celebrated its 15 years of service to the myeloma community. The IMF's annual gala has been an important and successful fund-raising event for the Foundation, generating funds for myeloma research and other essential programs. The Hollywood-style celebration took place at the Beverly Hilton Hotel, home of the Golden Globes.


Dr. Brian G.M. Durie & Susie Novis

The IMF Galas are fun affairs and this year was no exception. The evening started with a cocktail reception and silent auction, situated in a suite above the flickering lights of Beverly Hills. It was a thrill to mingle with friends, see old acquaintances renew their friendships, and to observe new friendships being formed. However, the socializing did not impede the competitive bidding for the many attractive silent auction items!


Master of Ceremonies
Robin Leach

The evening continued as guests filed into the gorgeous ballroom, elegantly decorated for the occasion. The sounds of the Melanie Taylor Group provided a cheerful musical background that beautifully enhanced the atmosphere and spirit of the evening. It is a testament to the IMF that it can fill the cavernous ballroom of the Beverly Hilton with enough people to lend an air of intimacy, as you bump into friends left and right. Three hundred and fifty guests—clinicians, researchers, myeloma patients, caregivers, family, and friends—gathered to celebrate the IMF and its honorees, and to support the fight against myeloma.

Once again, Robin Leach returned as the IMF Master of Ceremonies. This was Mr. Leach's fifth appearance at the IMF annual gala! Mr. Leach is a true friend of the IMF, continuing his work on behalf of the myeloma community in memory of his dear friend Brian Troop.

When Susie Novis took the podium to extend a warm welcome to the guests, she reflected on the endeavors of the IMF over the past year and updated the audience on the goals that lie ahead. For 15 years, the IMF has been the premier resource for information about myeloma, and has brought empowerment, support, and kinship to members of the global myeloma community.

Next, Drs. Brian Van Ness and Brian Durie spoke of the promise of the IMF's Bank On A Cure® initiative, the first myeloma-specific DNA bank in history. Created by the IMF, Bank On A Cure is an endeavor of truly collaborative research. It is a repository of DNA collected worldwide through large clinical trial groups, clinical centers, hospitals and individual patients. A series of genetic tests are performed on the samples collected in the strictest confidentiality, and the Bank On A Cure technology identifies genetic variations in the DNA that provide the basis for studies identifying factors related to disease onset, symptoms, morbidities, clinical response and toxicities. The goal of Bank On A Cure is to find effective treatment strategies and, ultimately, a cure for multiple myeloma.

The evening progressed to the award presentations. The IMF honored Dr. David Agus, a nationally prominent researcher at Cedars-Sinai Medical Center in Los Angeles, for his cutting edge research to help determine which patients respond best to treatments for cancer. Dr. Agus was introduced, via video, by Desperate Housewives'

Teri Hatcher. Ms. Hatcher related a few humorous anecdotes of her friendship with Dr. Agus and his wife, Amy, which allowed the audience a better understanding of the man inside the lab coat. She also shared her first-hand knowledge of Dr. Agus' compassion and commitment to helping his patients live longer and better lives.

Dr. Agus was honored with the Quality of Life Award for his research focused on understanding the biology of cancer and the development of new drugs and treatments for prostate cancer. He is also using new technologies, such as gene chips and proteomics, which will reveal valuable information and ultimately a more complete understanding of the various factors that influence cancer development, progression and response to treatment. By using some of the world's most powerful superconducting magnets to separate the proteins in a drop of blood, Dr. Agus is engaged in a breakthrough study to help determine which myeloma patients are best able to benefit from bone marrow transplants, a mainstay of myeloma treatment. The data Dr. Agus is able to retrieve from a single droplet of blood is so vast that a bank of super computers is employed to help analyze the results. "Others look at cancer and ask why, but I look at my patients and ask who -- who will benefit, whom can we help," said Dr. Agus.

Carol & Benson Klein and Honoree Dr. & Mrs. David Agus

Robert J. Lipshutz, Affymetix Corporation and Brian Van Ness, PhD

The IMF Science & Technology Award was presented to the Affymetrix Corporation, which was honored for developing "gene chips" that aid in studying the role of genes and their components by holding vast amounts of biological data on a small glass slide.

Affymetrix is a pioneer in creating breakthrough tools for genomic research, and its technology has become the industry standard in molecular biology research. By applying the principles of semiconductor technology to the life sciences, Affymetrix developed and commercialized systems that enable scientists to improve quality of life. These machines produced by Affymetrix are the cornerstone of the IMF's Bank On A Cure program, providing the tools to process myeloma patients' DNA. Thank you, Affymetrix, for helping move our understanding of myeloma forward!

Another highlight of the evening was the much-anticipated live auction conducted by Robin Leach and Viveca Paulin. Mr. Leach encouraged guests to bid on everything from exotic getaways to adorable puppies. The highest selling items generated some friendly rivalries among the bidders.

Robert Klein

The IMF Gala also featured special guest entertainer Robert Klein – actor, comedian, director, composer, author, and Tony-nominated musical theater performer – who quickly had the crowd in stitches with his opening number,

PLEASE SEE 2005 GALA ON PAGE 27

IMFers MAKE A DIFFERENCE!

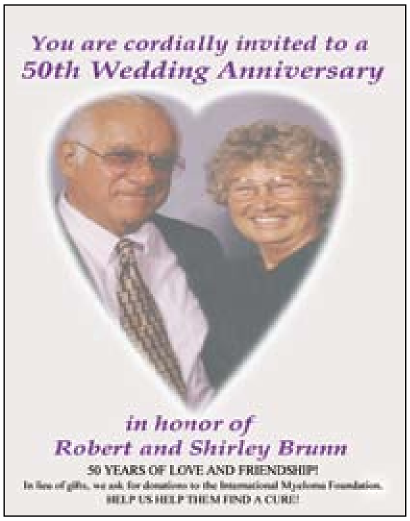
2005 Member Fundraisers in Review

By Suzanne Battaglia

When the IMF started its member fundraising program several years ago, we had no idea how our members would respond. Would they be intimidated? After all, "fundraising" is a daunting word to some of us. Or would the opportunity of being proactive on behalf of themselves and the myeloma community give them a sense of empowerment? For those of you who have not worked with us yet, I want to take this opportunity to inspire you by sharing stories of how some IMFers went about making fundraising FUN! We hope that you will see that no idea is too small and that you'll join the growing number of IMFers who work with us each year.

I am proud to report that 2005 turned out to be a banner year for IMF member fundraisers around the country! IMFers have organized everything from letter-writing campaigns and garage sales to marathons, neighborhood walks, golf tournaments, parties, and entertainment events. I'd like to acknowledge and thank them all for their enthusiasm and dedication to helping the IMF continue its mission of working toward prevention and a cure.

Some of you wanted to celebrate special occasions with donations to the IMF in lieu of gifts. Our thanks go to Mort and Dorothy Abelson who celebrated their anniversary with donations to the IMF. Our thanks also go to the Bren Family, Shirley and Robert Brunn, Susan and Frank Emanuele, and Edith and Richard Scanlan. Ann and Joseph Peters requested IMF donations in lieu of wedding gifts! Katie Smith celebrated her 11th birthday in honor of her Nana and donated money raised for raffle items to the IMF. We thank them all for thinking of the myeloma family while celebrating their own festive family occasions.


You are cordially invited to a
50th Wedding Anniversary

in honor of
Robert and Shirley Brunn

50 YEARS OF LOVE AND FRIENDSHIP!
In lieu of gifts, we ask for donations to the International Myeloma Foundation.
HELP US HELP THEM FIND A CURE!

Letter campaigns requesting donations have been extremely popular this year. Laura Lea Frank wrote letters in honor of her brother Brian. Trooper Benson Klein's letters asked for donations in lieu of gifts to celebrate a milestone birthday (see Fall issue). Other IMFers participated in this year's Mail For The Cure campaign and raised over $7,000 in just a few months!

Some of our artistic friends shared their talents via the IMF website www.myeloma.org. Kristi Difford's myeloma awareness jewelry was a big hit again this year, and we welcomed Pam Larsen and her beautiful crystal awareness keychains (Multiple Colors for Multiple Myeloma). Irma Catlett's scenic cards continue to be a hit for the IMF. Kathleen Tezla's letter-pressed Christmas cards, each featuring an historical background about a familiar Christmas symbol, were very popular during the holiday season. Sharon Newman's lovely Purim baskets were distributed throughout her community.

Our sports enthusiasts came together for the 6th Annual JC Golf Tournament, the Heuer Memorial Golf Tournament, the Leona Cravotta Memorial Golf Tournament, the Danielle Mosher Memorial Soccer Tournament, the Run for Mike, and the Walk For Bob. And "Team Milers" Tony and Kendra Goffredo ran the Rock & Roll Marathon for the IMF. (All of these events have been covered in prior issues of Myeloma Today).


You are cordially invited to a
25th Wedding Anniversary

in honor of
Frank and Susan Emanuele

25 YEARS OF LOVE AND FRIENDSHIP!
In lieu of gifts, we ask for donations to the International Myeloma Foundation.
HELP US HELP THEM FIND A CURE!

Young Anthony and Kayla Tenboer enlisted their family and

CONTINUES ON NEXT PAGE

2005 GALA — continued

a song entitled "My Colonoscopy." By the end of the song, many audience members had joined in singing the chorus, and there were even a few lighters held high in the air. And that was just the beginning! Renowned for his unique brand of observational humor, Mr. Klein kept the crowd entertained by his musings and musical numbers.

IMF Board Members, President, staff and friends

Allen & Phyllis Weinstein,
Bronze Sponsors

Our heartfelt thanks to the many generous event sponsors and auction donors who have made this memorable evening possible, to the members of the dinner committee for their time and dedication, and to our extended myeloma family for making the IMF's 15th Anniversary Gala such a stellar success. **MT**

IMFers MAKE A DIFFERENCE — continued

friends to raise money by collecting cans and bottles in their community in honor of their grandfather, Wayne "Whitey" Tenboer. Celeste Montalvo-Jackson organized the Ride for the Cure in honor of her dear friend, Darrell. Marjorie Morgenroth set up a table with the IMF banner in front of her local Stop & Shop to raise money and pass out awareness materials. Gabriela Spear, who had previously raised money for the IMF by having a "Locks of Love" party, organized this year's Family Fun Day. Robin and Michael Tuohy's children, Allison and Michael, showed their initiative by setting up a lemonade stand in honor of their Dad. Ron Charlton donated a car to "Cars For Causes", which resulted in a very nice contribution to the IMF. Once again, the wonderful Naomi Margolin organized the successful annual Multiple Musicians Against Multiple Myeloma event in memory of Lee Grayson. And Carol Rossi not only started a new support group in Rhode Island, but she and her family put together "Rocking in Rhode Island" to honor her mother and raise money for the IMF.

We are very grateful to all our IMFers who contributed their time, imagination, and hard work to benefit the entire myeloma community each year. The IMF is committed to working with you to continue to raise community awareness and funding for educational and research programs in the field of myeloma.

I look forward to hearing from those of you who would like to join the growing IMF family, and to work together toward our common goal… a cure for myeloma. To do this, simply contact me, Suzanne Battaglia, at SBattaglia@myeloma.org or 800-452-CURE (2873) to request a FUNdraising Guide. I am here to answer any questions you may have and to discuss your ideas about this worthwhile program. **MT**

THE STAFFORD FAMILY FUNDS MYELOMA RESEARCH GRANT

WAMP swim-a-thons raise over $40,000

By Elizabeth Stafford

February of 2001, my dad, Jeffrey Stafford, had surgery for a compression fracture in his upper spine. The surgery revealed a tumor. After further testing, he was diagnosed with multiple myeloma. He was 45 years old.

I am the eldest of four siblings: I am now 23, Julianne is 20, Christopher is 17, and Courtney is 16. At the time of my dad's diagnosis, I was away at college. It was hard, as it would be for anybody, to find out that your dad has a rare form of cancer. But, just as every step throughout the last five years, our family tried to take things in stride. My dad started treatment for his myeloma, and his doctor referred our family to the IMF.

We went online and learned a lot about myeloma and the IMF. We were really impressed by all that the Foundation does – its programs in education and outreach are excellent! And, because of my strong interest in government and politics, the One Voice Against Cancer advocacy event in Washington, DC, was a natural way for me to get involved with the IMF. But it's fair to say that for our family, the scientific search for a cure is most crucial.

We are an active family, very involved in our community of West Hartford, CT, and we knew that we had to take some action. It's just not like us to sit around doing nothing. By the time June approached, we had decided to hold a swim-a-thon, hosted at the WAMP country club where my family has had a membership since the 1960s, and where I was volunteering as a swim coach.

We reached out to the pool director and club manager, and also contacted family and friends to ask them to help sponsor the event. Several local vendors stepped forward to donate food for the event and prizes for the raffle. The country club was very generous by giving us a "free guest" day, so many of the participants brought along their friends and relatives. In total, about 80 swimmers participating in our first all-day event!

At the time, we weren't looking ahead but three more WAMP swim-a-thons followed. Being away at school, I was more of a ringleader when it came to organizing the events. My three siblings did a lot of the legwork and, as they got older, they took on more responsibility in representing the IMF and our family within our community. Also, with each event, we gained experience and expanded our local support base. More people were more willing to contribute and participate.

The WAMP swim-a-thon is a community event. Our local bagel shop has donated bagels for all four fundraisers. Most of the other vendors who contribute are from Connecticut. Many of our supporters know my dad. But the circle of support keeps getting bigger. A couple of years ago, when I was on Cape Cod, a saw a beach stroller wearing our fundraiser T-shirt!

To date, the four WAMP swim-a-thon events have raised more than $40,000 — enough to fund a grant in my dad's honor through the IMF research program. [SEE SIDEBAR] Our family plans to continue our efforts to help fund myeloma research in hopes for a cure for my dad and many others like him. As we continue to face this difficult battle, we are so impressed, bolstered, and humbled by the continued support we receive from our community, both locally and through the IMF. MT

IMF Research Grant Awarded in Honor of Jeffrey Stafford

"Targeting different active sites of proteasomes in multiple myeloma cells"

Dr. Alexei F. Kisselev
Norris Cotton Cancer Center
Dartmouth College
Hanover, New Hampshire

The goal of this project is to determine whether inhibition of the chymotrypsin-like sites alone is sufficient to induce the death of multiple myeloma tumor cells, and to develop specific cell-permeable inhibitors of the trypsin-like sites.

WALKING FOR MYELOMA

By Eve Friedli

In February of 2003, I noticed that my blood pressure was elevated and that I was constantly fatigued. But I am a mom who works full time – I get up too early, I stay up too late – so I didn't think much of the symptoms I was experiencing. It didn't occur to me that disease might be involved. But a blood test revealed an M-spike, and the diagnosis was multiple myeloma.

I started treatment right away, taking dexamethasone for 4 months. In August of 2003, I had an autologous transplant. The good news was that I was able to return to work part-time after only 4 weeks, and resumed a full-time schedule 2 weeks later. However, my doctor was not happy with the results of the transplant and, in April of 2004, I underwent another procedure. This time the transplant was allogeneic, with my brother as donor. I am now at a plateau and I feel better that I have in a long time.

My husband and I have always looked at my cancer as a call to action. We have tried to discover the ***opportunities*** that myeloma has brought into our lives. We asked ourselves, "What are we supposed to learn from this journey?" Our conclusion was that, besides being so focused on the raising of our two children, we needed to get involved in making a contribution to a larger community.

I found the IMF shortly after my diagnosis, and we started fundraising for the Foundation before my second transplant. At first, the idea of fundraising was overwhelming, but Suzanne Battaglia from the IMF's Development Department has been an absolutely fantastic ally – she has been there for us every step of the way! We decide to host a walk because there is little cost involved in holding such an event, and practically everyone can participate.

Walk for the Cure took place on September 24, 2005, at East Silver Lake Park in Rochester, MN. The event included a 2-mile walk, picnic, and prizes. Amy Kuns, anchor for FOX 47 News at 9 and KTTC News at 5, was our celebrity MC. We had an excellent turnout with 97 registered participants! It was such a successful fundraising experience that we already have plans for hosting another walk on September 9, 2006. Our local TV station has already made a commitment to sponsor the event. For more information on the event, please contact Suzanne Battaglia at sbattaglia@myeloma.org or 800-452-CURE (2873). **MT**

UNIVERSITY OF MIAMI HOSTS MYELOMA WALK-A-THON

By Denise Vidot

When my father was diagnosed with multiple myeloma in 2004, I became determined to get involved with raising myeloma awareness and raising funds for myeloma research. To that end, I organized a Myeloma Awareness Week at Florida Atlantic University, Florida International University, Nova Southeastern University, and the University of Miami (where I was a Sophomore on the Pre-Med track). With help from my sorority, Lambda Theta Alpha Latin Sorority Inc., as well as Suzanne Battaglia of the IMF, the event was a success. But I had bigger plans for the future.

I wasn't aware of any myeloma walk-a-thons being held in the Miami area, so I decided to organize one. It seemed like a fun and effective way to raise money for the myeloma community. Through the two local myeloma support groups, I got to know many patients and family members, and I knew that I could count on them to participate. Vicki Anderson-Ferraro, who heads the Miami support group, does such a wonderful job, and group member Marty Rubin has been a great friend to me through very trying times. And IMF's Suzanne Battaglia has been there for me every step of the way. I also knew that I could count on my school, my sorority sisters, and our friends for support.

The Walk for Myeloma took place at the University of Miami on October 15, 2005, almost a year after the initial idea entered my mind. Over 100 people had registered for the event and, even though the day was gray and rainy, most turned out to take part. Norma Ortega of Millennium Pharmaceuticals, who generously sponsors our local support group, volunteered to donate the food for the Walk. Several campus organizations, including my sorority, also pitched in with food and drinks for the event.

At the start of the Walk, I tried to give a little speech welcoming everyone to the event, but the moment was too emotional for me to get too many words out. I was so overwhelmed by the sight of all the people who turned out to support my dad and patients like him. And it was so empowering to know that my actions would impact other. I know that the event meant a lot to my dad, too. He doesn't really like to show his emotions but he had tears in his eyes. The entire family was there for him, including my mom and all my six younger siblings!

The Walk circled the lake at the University of Miami, with each participant holding one white and one burgundy balloon to represent the IMF colors. At the end of the walk, we congregated to release the balloons in honor and memory of our loved ones, and in hope of a cure for myeloma. It was a very moving moment. The rainy day notwithstanding, everyone enjoyed the experience while raising over $3,000 for myeloma research!

I am currently organizing another Myeloma Awareness Week to take place during the month of April, and planning the next Walk for Myeloma to take place in October. I would like to take this opportunity to invite other members of the IMF family to get involved with these events through participation, sponsorship, or donation of raffle items. Please feel free to contact me at peaches2822@aol.com, or get in touch with Suzanne Battaglia of the IMF at sbattaglia@myeloma.org or 800-452-CURE (2873). **MT**

DONATE FOR DREW DAY

Myeloma Today Speaks With Drew & Patrice Spaeth

Drew Spaeth: I felt the first symptoms of what would turn out to be multiple myeloma in July of 2004, at the age of 48. A pain in my midsection and flu-like symptoms (without the actual flu!) caused me to visit our family doctor. After some initial blood tests, I was referred to a specialist. On September 22, I was diagnosed with Stage I myeloma.


Drew Spaeth

I am happily married to my wife, Patrice, and have two sons, Drew Jr. and Ian. My faith is a big part of my life, and it helped me cope with the diagnosis. Also, I had the best support system, comprised of my wife and my family. And I was fortunate to be diagnosed at an early stage of the disease.

Bone surveys did not show any skeletal involvement but there was serious renal involvement. Because I was fairly young and healthy, and because of my kidney condition, my doctors felt that autologous transplantation would be my best bet. After six months on combination therapy of thalidomide and dexamethasone, I underwent the transplant.

Since the transplant, I have been able to regain a lot of my strength, and life has been good. There have been few adverse side effects — mostly some neuropathy in my feet that seems to be getting better. I was back to work less than three months after the transplant.

Patrice Spaeth: Drew and I attend the San Diego myeloma support, headed by Fred Gloor. We are also active in our chuch, and participate in a support group it hosts. A friend of ours from the church was interested in organizing a community blood drive for a national bone marrow registry, and we wanted to raise awareness of myeloma and to raise funds for myeloma research.

I became a member of the six-person "Donate for Drew Day" organizing committee. It was a grass-roots effort. The IMF provided us with valuable assistance and guidance over the phone and via email and, eventually, we had a scheduled meeting with the Candace McDonald and Suzanne Battaglia from the IMF's Development department.

As the event planning progressed, it became clear that there would be more event participants than any private residence could comfortably host, so we needed to secure a venue. The North Coast Presbyterian Church in Encinitas became our home for the event. Drew is a service representative for a custom-home builder and is active in our local community so many people know him, but we were still surprised to learn how many people cared about our family. We had a thousand participants!

The IMF had a booth at the "Donate for Drew Day" and a representative of the Foundation spoke at the event. Myeloma-related educational materials were disseminated throughout the day. In addition, over $50,000 was raised at the event!

Drew Spaeth: The myeloma diagnosis has changed our lives. It has put everything into an entirely different perspective. This is something that's hard to explain to someone who hasn't already traveled down a similar road. But what I'd like to communicate to any newly diagnosed patients out there is that, when it comes to myeloma, many of us are thrivers, not just survivors.

Patrice Spaeth: And we are very thankful to the IMF. The Foundation has been there for us. They are phenomenal people, and I don't believe that we would have come as far in the field of myeloma research without them.

Drew Spaeth: Each and every day, we are inching closer to a cure. We believe that someday soon myeloma will become a chronic disease, not a deadly disease. I am very optimistic about the medical developments in the field of myeloma. In the meantime, we take life day by day, and continue to strive for a quality life. **MT**

HEART AND MUSIC: A CABARET FOR A CURE

By Marlene Urso

I was diagnosed with smoldering multiple myeloma in May of 2004, at the age of 55. My diagnosis was not the first time that myeloma had touched my family. My mother's brother, as well as her cousin, both had myeloma.

Marlene Urso (right) with twin Lorraine Kollar

Although the diagnosis was devastating, I became more hopeful after learning about the many new treatments available for the disease. While searching out myeloma information online, I found the International Myeloma Foundation. Shirley Pogue, our local Pittsburgh support group facilitator replied to my e-mail immediately and put me in touch with Rita and Mart Randall. They were very generous in sharing their personal experiences with me. Obviously, not everyone faces the same challenges but hearing about how others cope with their struggles helped me attain a hopeful attitude about my own future.

My husband, Jack, and I attended our first myeloma support group meeting, where we met others who were diagnosed early and had been doing well for many years. The group members also shared information about treatment options and empowered me to take a proactive role in my own treatment.

My son, Mark, and I attended our first IMF Patient & Family Seminar in Baltimore this past summer. We were both impressed by the faculty and learned a lot from their presentations. The seminar also motivated me to do something to raise myeloma awareness. Having a background in journalism, I distributed press releases to local newspapers about the IMF's Bank On A Cure® program. The resulting article helped promote the "swish and rinse" DNA collection event hosted by our myeloma support group during Myeloma Awareness Week.

(left to right) Cabaret performers Jenn Smith, Jackie Comisar, and Lisa Marinacci

My family and I also began talking about fundraising ideas. My daughter, Jackie Comisar, is a New York musical theatre performer, so the idea of staging a cabaret show seemed natural to us. Jackie coordinated the talent for the show. She and her husband, Jason, designed postcards, programs, and a website for the event. They also secured a facility for the show. Jack and I took care of the mailings. My twin sister, Lorraine Kollar, and I handled the event publicity. My other daughter, Gina Masciola, coordinated a Chinese auction. Gina's husband, Palmer, as well as my son and daughter-in-law, Annie, also helped with auction donations and other aspects of the event. We had the full support of IMF's Suzanne Battaglia as well as that of our local support group every step of the way. We were also honored that Robin Tuohy traveled to Pittsburgh as the IMF's representative and lent a helping hand at the event. The cabaret show was definitely a team effort!

Heart and Music: A Cabaret For A Cure took place on November 5, 2005. The 250-seat theatre was "standing room only!" Twenty-three cabaret acts from New York and Pittsburgh contributed their time and talent to an evening that raised myeloma awareness, funds for research to find a cure, and hope for those who face this disease on a daily basis. I want to extend my heartfelt thanks to my family and all the wonderful performers who donated their time and talent, including The Plaids, Class Act, Stars of Stage 62, Jason Coll, Heather Ferri, Chris Laitta, Lisa Marinacci, Justin Morris, Deana Muro, Jenn Smith, and Laura Solito.

We are grateful to all who participated and contributed to one of the most uplifting experiences I've ever had. We raised $3100, which was divided between the IMF's myeloma research program and our local myeloma support group. Everyone involved was so pleased with the event and its outcme that we now want to make this an annual event!

FLAVIA HIATT SHARES HER STORY

In 1998, Flavia Hiatt's 37-year-old husband, Kerry Roy Hiatt, was diagnosed with Stage III multiple myeloma. He started chemotherapy the next day then progressed to a double autologous transplant, which helped him achieve remission. But the cancer came back in 2003, and it was very aggressive. He lost his battle with myeloma in April of 2005. Shortly after his death, Flavia found out that she was expecting the couple's first child.

Flavia is a native of Italy, and her life in California took her far away from the support of her immediate family. But with many good friends closing ranks around her, she bravely faced the new chapter in her life. Flavia's thoughts were not only of herself and her child – she was committed to helping find a cure for myeloma so that other families would not have to suffer the hearbreak she endured.

The Shop For A Cure fundraising event involved a lot of hard work and preparation but on August 13, 2005, Flavia and her friends transformed the boardroom and mezzanine of Luxe Hotel Rodeo Drive in Beverly Hills into a fabulous fashion trunk show to benefit the IMF's myeloma research program. Shop For A Cure featured Flavia's own clothing line, Bellablu, as well as ten other designers from the Los Angeles area. Many motivated shoppers, including members of the local myeloma support groups, attended the event to purchase handbags, jewelry, and clothing. All of the participants had come to Shop For A Cure to support Flavia and help fund myeloma research through the IMF.

The IMF family would like to extend our heartfelt gratitude to Flavia Hiatt and all others who take part in the fight against myeloma. Thank you for making Shop For A Cure such a success, and for contributing to a brighter future for the entire myeloma community! **MT**

HEART AND MUSIC — continued

I am blessed with all the support that I continue to receive in dealing with my disease from my husband, our three children and their spouses, our family, friends, and the myeloma community. And I am committed to giving back of myself. Yes, I still have worries and fears, but I am also very hopeful that with God's grace there will be a brighter future for myself and for others fighting multiple myeloma. **MT**

2006 MEMBER EVENTS CALENDAR

April 5, 2006 – Music Against Myeloma – Slava Rubin, 312-804-3076, SlavaRubin@gmail.com, Serena Bar, Manhattan, NY, music, food, dancing

April 6, 2006 – Schwartz Bar Mitzvah (Private Event)

April 8, 2006 – Veldhuizen Wedding Fundraiser – Ap Veldhuisen and Diane Tanenbaum (Private Event)

April 20, 2006 – Schirinzi Golf Tournament – Vittorio Schirinzi, Golf Club Poggio Dei Medici, Florence, Italy

May 20, 2006 – Ralph Ferrizzi Memorial Golf Tournament – Ralph Ferrizzi, Jr., 610-438-1619, Ferrizzi@rcn.com, Green Pond Country Club, Bethlehem, PA

May 20, 2006 – JC Invitational Golf Tournament – David Johnson, 952-546-6000, DJohnson@borkonlaw.com, Wapicada Golf Course, Sauk Rapids, MN

May 20, 2006 – Leona Cravotta Memorial Golf Tournament – Katelyn Martin, 540-894-5861, kmm9v@cms.mail.virginia.edu, Tanyard Country Club, Louisa, VA

June 10, 2006 – Terry DuBois' Birthday Bash for Myeloma – Diane DuBois – 715-425-2817, Ellsworth, WI

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

Sept 9, 2006 – Walk For The Cure – Eve Friedli, 507-280-5992, EFriedli@HartlandFuels.com, Rochester, MN

A new list will be circulated as events are scheduled.

You can also refer to the IMF's web site – **www.myeloma.org** – and click the '**Events**" tab

THE YIN AND YANG OF LONG-TERM SURVIVORSHIP

By Rosanne Kalick

Philosophers in the Han dynasty (207 BCE to 9 AD) developed the concept of Yin and Yang, the idea that everything in the universe has its opposite. These opposites are interdependent – we cannot have day without night, winter without summer. If this is so, where does cancer fit into this ancient method of understanding life? Can the concept of Yin and Yang help us deal with the complexities of life with multiple myeloma?

In the fall of 1993, I went for a routine physical. Initial blood work indicated anemia. I had run five miles just before the test, and I wondered whether that run could have affected the result. However, retesting confirmed the anemia. A 24-hour urine test indicated excess protein, and a bone marrow biopsy verified the diagnosis – multiple myeloma.

The 11th edition of Merriam-Webster's Collegiate Dictionary defines a whammy as a supernatural power bringing bad luck. What an accurate description of multiple myeloma! Myeloma was my first whammy.

Two stem cell transplants, four and a half years of Interferon, and years of Aredia followed. At the end of treatment, I was in "excellent partial remission," not complete remission because I still had an M spike of 0.5.

Seven years after the myeloma diagnosis, I went for a routine mammography. That mammography revealed malignancies in both breasts – my double whammy. Thanks to the miracles of science, I had lived long enough to develop a second primary cancer.

Dr. Sundar Jagannath, my oncologist at St. Vincent's in New York City, was extraordinarily supportive and set up consultations with breast cancer specialists. Because of all the chemo I had previously, a tumor committee met to consider my treatment options. I had a double mastectomy followed by more chemotherapy.

Then, three years ago, I was at the theater, watching a one-woman show. For a brief period, the actress had two heads. I had two more incidents of double vision during the next few weeks. When, on a routine visit to my ophthalmologist, I mentioned the episodes, he paused and said, "You either have a brain tumor or you've had a stroke." Tests did show I had had a small stroke. Was there a connection between the transplants and the stroke? Was I more prone to a stroke than someone who had never had cancer? Was it a disparate event? Whatever the cause, it was my triple whammy.

I needed a metaphor to help me deal with these health issues. The concept of Yin and Yang has been useful for me. I'm not saying it will work for everyone, but I think we need a construct to help us deal with the myriad cancer issues we face, especially now that long-term survivorship is more and more a reality. For many, religious faith is their working framework, and I am not suggesting that Yin and Yang is a substitute for religion. If anything, it may complement one's faith.

If, for example, Yin is myeloma, then what is Yang? While I cannot deny my cancers, I think of Yang as my non-cancer life. If Yin is the fact that I am afraid I'll have another stroke, that the myeloma will reemerge, that the breast cancer will metastasize, then Yang is that I've lived to see five grandchildren born, that I'm enjoying my retirement, that I co-chair a multiple myeloma support group, that I volunteer on two cancer hotlines – that my life is full.

If Yin is a "Why me?" approach to myeloma, then Yang may be a "Why not me?" response. "Why me" wastes energy and is non-productive. We can turn that energy outward. When I meet newly diagnosed patients, I try to encourage them to become their own advocates. At a support group meeting, my sense is that when we learn together, when we share experiences, when we discuss options, we all gain strength. We cannot say, "You will go into remission." We can say, "You are not alone." If Yin is our disconnect from what had been our pre-myeloma life, Yang is our connection to those who become part of our myeloma family.

If Yin is the reality that I have permanent neuropathy in my toes, then Yang is that, in spite of that fact, I can still walk three miles several times a week. If Yin is the fact that I've gained 15 pounds in five years because of the breast cancer medication I take, then Yang is that I've just passed my five-year survival period for that cancer. If Yin is the reality that multiple myeloma is a "monster," Yang may be the support we get from IMF seminars and from the interactions we have with other cancer survivors.

Even being positive about cancer can contain a Yin and Yang. I can only speak for myself, but I cannot be positive all the time. Dr. Jimmie Holland, a psychiatrist specializing in psycho-oncology at Memorial Sloan-Kettering Cancer Center, in her book, The Human Side of Cancer, writes of "the tyranny of positive thinking." She encourages patients to accept their feelings about cancer. There are times we are positive, yet we must acknowledge those times when the cancer life is overwhelming.

There are times when I get discouraged. Emotional cancer fatigue is as real as the fatigue from chemotherapy. I'm angry that so many I know have lost their cancer battle. Whether it's healthy or not, I think of cancer every day. However, I also know that researchers are making great strides in terms of new treatments. I know that we have doctors who treat us as individuals and who celebrate our small victories. I know many who are living a full life in spite of multiple myeloma.

As someone who has lived with cancer for twelve years, I'm still learning and still struggling. I believe we must celebrate life. I believe we must tell the people we love that we love them. I believe we must give back, however we define that – by contributions of money, of time, of our presence when others are diagnosed with cancer. Above all, I believe we must never deny hope.

Clearly, cancer transforms one's life. We cannot make up for our lost dreams, our disabilities, or the frustrations, fears, and angst that is routine in our myeloma life. However, we can create new dreams, perhaps more realistic ones. We can laugh, and many of us can still work. I'm learning to do now what I had planned to do "later on." Later on is NOW for us. In our pre-cancer lives, many of us thought we had more control of our lives than we really did. Cancer reminds us of how fragile life is.

But if Yin is what we cannot do; Yang must be what we can still do. We must not allow the disease define who we are. One of the challenges I face every day is to remember that I AM NOT MY CANCER. I am a mother, a grandmother, a friend, a member of two book clubs, and someone who loves the movies, and the theater, and ice cream. Since my first diagnosis, I've traveled to Morocco, Mexico, Italy, Israel, Maine, and Charleston. There is life before cancer; there is life during cancer; there is life after cancer.

As cancer research and treatment progresses, more and more of us will become "long-term survivors." Perhaps the metaphor of Yin and Yang can help others to achieve a cancer balance. We must find ways to celebrate life in spite of our cancer. If we don't, then myeloma wins, no matter what our lab reports say. We have multiple myeloma; multiple myeloma should not have us. **MT**

Note: Rosanne Kalick is the author of "Cancer Etiquette: What to Say, What to Do When Someone You Know or Love Has Cancer". ©2005. If you buy the book online at http://amazon.myeloma.org, a percentage of your purchase will go to support IMF programs and services. Direct inquiries can be emailed to Rosanne Kalick at rklibrary@optonline.net.

MY LIFE WITH MYELOMA

By Robert Silman

In April of 1984, at age 49, I had a routine annual physical that showed an elevated protein level in the blood. I felt great and had no symptoms whatsoever. However, my family physician was able to detect a tumor in the lymph system in my right axilla, the pyramidal space between the upper lateral part of the chest and the medial side of the arm. My childhood best friend was a doctor at Memorial Sloan-Kettering Cancer Center so, of course, I called him right away. He arranged for an appointment with a surgeon, and I was scheduled for a biopsy.

> "It's important to know that you can lead a good life – and a long one – even with myeloma."

The biopsy revealed that the mass was a plasmacytoma in the family of multiple myeloma. The recommendation was to shrink the tumor with radiation, then remove it surgically. After six weeks of radiation, a CT scan revealed that the tumor size had not diminished. In August of 1984, I was scheduled for surgery. All the nodes in the axilla were found to be involved but there was a distinct single tumor that was quite large, about the size of a golf ball. The surgeon removed 40 to 50 nodes but said to me, "I didn't get them all." We realized that, although the presentation was at a single location, the disease was systemic.

My doctor informed me that a case such as mine had never before been seen at Memorial Sloan-Kettering Cancer Center and he recommended that I go to Mayo Clinic to see Dr. Robert A. Kyle, who was known to follow these kind of tumors. A month after my surgery, I traveled to Minnesota to see the wonderful Dr. Kyle. He looked at me and said, "You have monoclonal gammopathy of undetermined significance (MGUS). You've never had a symptom. You've had radiation, which I would have recommended as well because it normally works. Now, there's nothing to treat so I wouldn't do anything." I asked, "You mean that I should just live with this?" "Absolutely," he said, "Go home!" So, that's exactly what I did.

But I am just not the kind of person to go home and do nothing. I didn't know why I got cancer but I knew that there must be something I could do to improve my health. One obvious change I could make was to improve my diet. So I became a macrobiotic eater, eliminating all animal products, caffeine, refined sugars, and alcohol. From that point on, my diet has consisted primarily of grains, vegetables, and fruit.

Between 1984 and 1992, I saw Dr. Kyle at Mayo every 18 months and, in between visits, I would mail him a serum sample every 6 months. Over the years, my IgG levels continued to creep up but I still had no symptoms. In 1992, a CT scan revealed another soft tissue tumor adjacent to the right axilla in the super-clavicular area. My IgG levels had reached 3200 and Dr. Kyle decided that it was time for chemotherapy. I was very reluctant to start treatment but Dr. Kyle said, "If you were my brother, this is what I would recommend."

Dr. Kyle put me on 7-day cycles of melphalan and prednisone, followed by 6 weeks off treatment. The chemotherapy worked brilliantly! The protein numbers went down to 1500 and the tumor size shrank a bit. I had no side effects other than losing some sleep due to the prednisone. Actually, I felt even better during the chemo because the steroid made me feel quite pumped!

After the eighth treatment, my blood counts were no longer rebuilding fast enough for Dr. Kyle's liking, so he started me on another round of… doing nothing. Once again, with the passing years, my blood counts gradually climbed higher and my tumor increased in size. Other tumors appeared and, in 2000, one of the newer tumors began to grow at a rapid rate. Once again, I traveled to

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CHALLENGING CANCER WITH THE POWER OF PAINTING

By Mary Ellen Stokes

June 6th, 2000, arrived cloudy and cool in Roanoke, Virginia. The threatening weather would mirror the mood of this day for the Stokes family. For it was on this day that my husband, Bill, began his journey of co-existence with one of the most insidious and clever cancers of all, multiple myeloma. Official diagnosis would arrive early afternoon; by nightfall, a game plan would be initiated

For the next twelve months, our cancer odyssey took us to the Fred Hutchinson Cancer Research Center in Seattle, Washington. There, Bill received a "mini tandem transplant," autologous and allogeneic. This is also where Bill began to pursue a hobby he never had time to enjoy. The stress and demands of a busy dental practice left him little time to paint. All of sudden, time was on his side, and lots of it. So, Bill began to sketch and paint, and with this creative, therapeutic process, found that he could challenge cancer with the simple strokes of pencil and brush.

Ever since his first art show in 2001, Bill has donated the proceeds of all art revenues for myeloma research and education. "This is one positive and productive way that I can give back," Bill reflects. He enjoys painting, and it has given him a very tangible way of challenging a faceless monster.

Bill likes to paint landscapes, and many are inspired by the beautiful Blue Ridge Mountains and by the time spent in the great Pacific Northwest where our family lived while Bill was in treatment. Some paintings reflect the cancer process itself. Currently, Bill is working on a series of bright, colorful, gyrating figures he calls "Stemmies."

Every art show provides an opportunity to make a difference in the world of multiple myeloma. At one recent show, an interior decorator snatched up three watercolors for an installation in a new retirement center. "Residents love the soothing colors in Bill's paintings," she observed, "and my employer has multiple myeloma so this is one way I can be supportive while adding beauty and pleasure to others' lives." One can't argue with that!

The Stokes family actively supports research with many other venues of expression. We regularly participate in an event to benefit the Fred Hutchinson Center – Bill walks the 5K while I run the 10K. Together, we generate a monthly newsletter for the Multiple Myeloma Network of the Blue Ridge, the support group Bill co-founded in 2003. And, every June, we lobby in Washington, DC, for more blood cancer funding. All in all, our creative efforts have generated more than $50,000 for the myeloma cause to date. And we're not done yet!

It might be a cliché, but the saying is very true for us: When one door closes, another one opens. Bill and I are fortunate that so many doors have opened for us in our journey with myeloma. In late 2004, Bill relapsed and we headed back to "The Hutch" where Bill received a DLI (donor lymphocyte infusion) from his brother, Clay. The procedure was a success and left him feeling better than any other period since diagnosis.

We adhere to the one-day-at-a-time philosophy. But this mentality doesn't prohibit us from looking to the future and having a vision. We've taken a very negative experience and made it as positive as possible. Frankly, there are no other options for us. **MT**

NOTE: To contact the Stokes, email bstokes47@aol.com or mesaab13@aol.com.

Mount Kilimanjaro Climb

Dear friends,

I had an opportunity in September to visit East Africa and in going to East Africa, the country of Tanzania, I had as one of my goals climbing Mt. Kilimanjaro. My interest in doing this was two-fold. I wanted, as someone who has never climbed in his life, to do this at the beginning of my retirement as a symbol of a new beginning on my life's journey. I also wanted to do it as a way to raise some awareness for our cancer, multiple myeloma, and also in the process to raise some funds for myeloma research.

I set out with my niece and 7 other people that I had not known previously. The trek up the mountain involved seven days of going up and 2 days of descending. I found it to be a very powerful experience, the scenery was spectacular, the challenge of making the climb was monumental and the group that we were with were so positive and supportive. I didn't make it to the top but went beyond anything I had ever done before. My niece with great gusto reached the summit and placed the IMF bracelet upon the peak.

The summit is called UHURU, which is a Swahili word meaning FREEDOM. I found it a very nice coincidence that the symbol of dedication to myeloma research would be placed at a point called "freedom," because I think through research one day we will be free from this form of cancer and so many others.

The saying at Mt. Kilimanjaro is that this is the place where ordinary people come to do something extraordinary. I think that is what the story of overcoming cancer is all about. It's about ordinary people doing something extraordinary, giving to research to help combat cancer in all its many forms. The letters IMF stand for "imagine moving forward." They could just as easily speak for all of us who have fought and continue to fight this form of cancer in saying, "inching my way forward." That's how we got up the mountain. I am grateful to the many who supported me on my journey up the mountain with their gifts to myeloma research. Thank you.

Blessings and best wishes,
Father Phil Wallace

Myeloma Today

Yesterday I uncovered a copy of Myeloma Today (Fall, 2005!) and read it cover to cover. I've seen a huge number of "in-house" publications during my short time-span on the planet, but I must say that this is one of the best. You deserve great credit for doing such a fine professional job. I didn't want time to go by without sending out plaudits for fine work, and your staff are high on my list.

Paul J. Hoffman

I just read about Carole Levis' experience with multiple myeloma in the Fall Issue of Myeloma Today and found it very inspiring. She is very brave to have been through so much. I was diagnosed with multiple myeloma two years ago, and have been on and off treatment for over a year. The difficult part for me is that I am a widow – and I just want my husband here to hold my hand. Reading about Carole's experience has encouraged me to seek out a local support group. I really want to thank Carole and Myeloma Today for sharing a story of such optimism. It has helped me a lot.

Barbara Jackson

Continues on next page

Letters — continued

I read Myeloma Today and am always encouraged by the success stories of other patients. In late 2004, I broke a rib playing basketball, which I have done before, but this time it didn't heal. In fact, it got to the point that I was breaking ribs by doing things like hugging my son or getting into a car. Our family doctor sent me to a number of specialists and, after several tests, in February of 2005, I was informed that I had multiple myeloma. The cancer load in my bone marrow was 76% and all my bones had lytic lesions. After four months of treatment, I ended up in ICU with acute renal and respiratory failure, septic shock, and some other unpleasant conditions. Once I regained my strength, I began preparation for a stem cell transplant but encountered another hurdle when our insurance company decided that they were not going to pay for any myeloma treatments – past, present or future. Good friends came to our aid and guided us on how to fight the insurance company and, within 5 days, our coverage was approved. It has now been about 5 months since my transplant and I am in complete remission. My family and I have learned a lot during our journey through myeloma, and I have finally arrived at an understanding of Lou Gehrig's famous words where he claimed to be the luckiest man on Earth even though he had an incurable illness.

Bill Souvall

Baltimore IMF Patient & Family Seminar

The conference in Baltimore was my third IMF Patient & Family Seminar, and I continue to be impressed by the wonderful job the IMF does. I sat with newly diagnosed patients and their caregivers who came filled with fear and left with hope in their hearts. Folks who had never met another person with myeloma finally didn't feel alone anymore. The presentations by all the speakers were excellent, and the energy of the faculty and staff was contagious. Kudos to everyone!

Barb Hammack

My Life with Myeloma — continued

Mayo Clinic to see Dr. Kyle, and I was scheduled for surgery. The tumor removed at six in the morning, and I was out walking along the street of Rochester by noon.

Although Dr. Kyle has since retired from clinical practice, I continue to see him in the lab, and Dr. Philip Greipp has taken over my care. I've developed another tumor at the base of my neck that's quite large but it doesn't impair me, although it is beginning to interfere with my neck movements, such as when I drive and need to look over my shoulder. My M-spike is at 4.2 and my IgG is up to 4000.

Dr. Greipp noted that my numbers would normally indicate treatment but because I am such a healthy patient, and the Mayo approach is to treat each patient individually, he has opted to repeat the protocol of melphalan and prednisone that had worked so well for me in 1992.

It has been almost 22 years after my initial diagnosis. I am now 70 years old and I lead a normal, active life. I work every day as a structural engineer in a business I started 40 years ago. I exercise. I do a lot of cooking and food preparation for the family. Before the diagnosis, my idea of lunch was a slice of pizza in a phone booth at 3 o'clock in the afternoon while making business calls. Now, when I prepare food, I consciously think that I am doing something good for my health. My wife has made some adjustments to my new way of eating but she still enjoys a cup of coffee or a glass of wine. We have now been married for 50 years. We have 3 children and 5 grandchildren.

I give tremendous credit to Mayo Clinic for the excellent care I have received and for their approach to each patient as an individual, not a statistic. I am fortunate to have found Dr. Kyle and Dr. Greipp. And it was through Dr. Kyle that I found the IMF, which has been a wonderful educational resource. I know that I am very lucky to not have a typical presentation of myeloma. I also know that there are more and more long-term myeloma survivors out there. It's important to know that you can lead a good life – and a long one – even with myeloma. **MT**

News & Notes

IMF outreach to European patients, families, and physicians will be coordinated through a new office in Europe. The IMF also maintains regional headquarters in Brazil, Japan, Israel, and has affiliates in Australia and Canada. The global headquarters remain in North Hollywood, California, USA, where the organization was founded. The IMF has been increasingly active in Europe. Within the last five years, Patient & Family Seminars, Scientific Myeloma Symposia, and Myeloma Conferences have been held in Paris, Madrid, Barcelona, Zurich, Istanbul, St. Petersburg, Rome, Vienna, Heidelberg, and Turin. In 2006, IMF activities are already slated for cities in Austria, France, Germany, Spain, Italy, and the Czech Republic. A native of Germany, Greg Brozeit, who currently is the Director of Public Advocacy for the IMF, will direct the European operations. This restructuring will enable the IMF to better serve the growing number of patients on the Continent and to interact directly with the dozens of local myeloma organizations being established across Europe as awareness of the disease increases.

Mail For The Cure

Many IMFers requested envelopes to participate in our Mail For The Cure campaign but were unable to send them out by the end of 2005. So we have decided to extend the program for another six months. Mail For The Cure is a simple but very powerful concept by which you can make a big difference. All over the country, people just like you have mailed letters to their friends and relatives asking for their support of myeloma research and other important IMF programs that benefit the myeloma community. A specially-coded IMF donation envelope is included with each letter to help us to track how much was raised as a result of your efforts. If you have any questions or would like receive envelopes and a letter template, please contact Suzanne Battaglia at sbattaglia@myeloma.org or at 800-452-CURE (2873). Please join us today in this exciting campaign!

Key IMF Publications Updated

With the help, guidance, and direction of IMF Scientific Advisors and the efforts of our team of specialists on the IMF hotline, the IMF is proud to present updated patient information materials prepared under the supervision of Dr. Brian G.M. Durie. The Concise Review, the Patient Handbook, and important treatment volumes from the Understanding Series have been updated in English, Italian, French, German, Spanish, and Portuguese. An updated version of the Patient Handbook in Chinese is also available. Please visit www.myeloma.org to download a PDF file or call 800-452-CURE (2873) to request a printed copy.

New Understanding Revlimid® Publication

As the world of myeloma treatment is changing every second, the IMF wants to make sure that the information we provide is the most up-to-date. Understanding Revlimid®, a new IMF publication, is now available as a PDF download from www.myeloma.com and as a printed copy by request from the Foundation. Revlimid is an immunomodulatory agent that can regulate the functioning of the immune system, enhance the activity of immune cells, and inhibit inflammation. Immunomodulatory agents enhance the activation of specialized white blood cells of the immune system that help kill cancer cells. Revlimid, a vascular endothelial growth factor inhibitor, belongs to a group of immunomodulatory agents with the ability to inhibit new blood vessel development on which cancer cells depend. Revlimid is structurally related to thalidomide but has been modified by researchers to take advantage of the anticancer properties, but to substantially reduce the likelihood of side effects.

Understanding Serum Free Light Chain Assays

The new IMF publication, Understanding Serum Free Light Chain Assays, explains how the laboratory test, also known as the Freelite™ test, helps with diagnosis and treatment of myeloma.

You can download a PDF of this document from www.myeloma.com or request a printed copy from the Foundation.

Free Presciption Drugs

Most pharmaceutical companies have programs for low-income and underinsured individuals, whereby they ship free prescription drugs either right to your door or to your doctor's office. To qualify, most require a maximum income of $16,000 to $18,000 for single households, and $24,000 for multiple-person households. Simply ask your doctor or pharmacist for the name of the manufacturer for your prescription medications. Then call the toll-free number for that company and ask for

Continues on page 41

BOARD OF DIRECTORS PROFILE

Myeloma Today Interviews Matthew Robinson

Myeloma Today: What is your professional background?

Matthew Robinson: After receiving my B.A. cum laude in Economics at Harvard University, I completed my MBA at London Business School. I then started my career as an investment banker in New York and London. Then I went to work for one of my clients, the Walt Disney Company, and stayed with them for five years. Ten years ago, I moved to Los Angeles to take a job with Warner Brothers, which is where I've worked ever since.

Matthew Robinson

MT: How did you first learn about the International Myeloma Foundation?

MR: I met Susie Novis about three years ago. She is very passionate about the IMF mission of improving the quality of life of myeloma patients while working toward prevention and a cure. It was from her that first I learned about both the achievements and challenges of the myeloma community.

MT: When did you join the IMF Board of Directors?

MR: Susie approached me in the latter part of 2004. She was looking to diversify the Board by bringing on new Directors, and my international business experience was a logical fit with the Foundations continued global expansion. I am very pleased to be able to contribute my experience to the IMF Board of Directors, and to serve on the Board's Finance Committee and the ad hoc International Committee.

MT: How do you see the Foundations' priorities?

MR: We need to be where the need is. The IMF is committed to providing a broad range of patient and family services. We are here to help address the tangible needs of the myeloma community today, while striving toward the ultimate goal of a cure for this disease. The IMF's fundraising efforts support its myeloma research program, as well as the innovative Bank On A Cure® initiative. Clearly, the IMF's priorities are in the right place.

MT: What is your outlook for the IMF?

MR: It is very positive. With the continued expansion of the Foundation, we are striving to bring the IMF's programs and services to as many members of the myeloma community as possible. This is a very exciting growth period for the Foundation. And it's enormously rewarding for me to apply my business experience of the last 20 years to helping the IMF accomplish its goals and objectives. **MT**

NEWS & NOTES — continued

the patient assistance program. Usually, you'll get right through to a recorded message that explains the basic requirements for the assistance program. Sometimes, you will be given an option of talking with a live representative who will tell you how to apply for the program.

Thalidomide in Australia

In Australia, thalidomide is now eligible for a taxpayer subsidy. As of February1, 2006, the drug is included on the federal Government's Pharmaceutical Benefits Scheme. This means that each myeloma patients who is currently taking thalidomide will now have access to the drug at a fraction of its $5,000 to $15,000 annual cost.

2006 Kyle Lifetime Achievement Award

The International Myeloma Foundation is pleased to announce Brian G.M. Durie, M.D. as the 2006 recipient of the Robert A. Kyle Lifetime Achievement Award, which honors the physician who most exemplifies a singular dedication to and compassion for myeloma patients and treatment of their disease.

Dr. Durie serves as 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

PLEASE SEE NEWS & NOTES ON PAGE 42

NEWS & NOTES — continued

Outpatient Cancer Center. Dr. Durie is the Chairman of the Board of the International Myeloma Foundation.

After graduating from the University of Edinburgh Medical School, Dr. Durie completed his residencies and his fellowships at the Mayo Clinic and the University of Minnesota. Among his many other impressive appointments, publications, and research accomplishments, while working in the Department of Hematology/Oncology at the University of Arizona, Dr. Durie co-created the Durie/Salmon Myeloma Staging System, the first system ever developed to classify myeloma in a standard, universal fashion, and the vital building block for the International Staging System, also co-developed by Dr. Durie with the International Working Group. In total, Dr. Durie has written over 300 research papers, twelve book chapters, and five books, work which has impacted myeloma treatment around the world.

Dr. Durie has received numerous honors and awards; among them he is a Leukemia Society of America Scholar, a U.S. Hematologic Research Foundation Annual Awardee, and a Marquis Member “Who's Who in America" and "The Best Doctors in America.”

Dr. Durie will accept the Robert A. Kyle Lifetime Achievement Award at a dinner in his honor on May 16th, 2006 at The National Press Club in Washington, D.C.

For more information on participating in the evening, please contact Candace McDonald at cmcdonald@myeloma.org or at 800-452-CURE (2873).

2005 IMF Honor Roll News

The 2005 IMF Honor Roll will be presented in our 2005 Annual Report, to be published this May.

To request a copy of the annual report, please contact Candace McDonald at cmcdonald@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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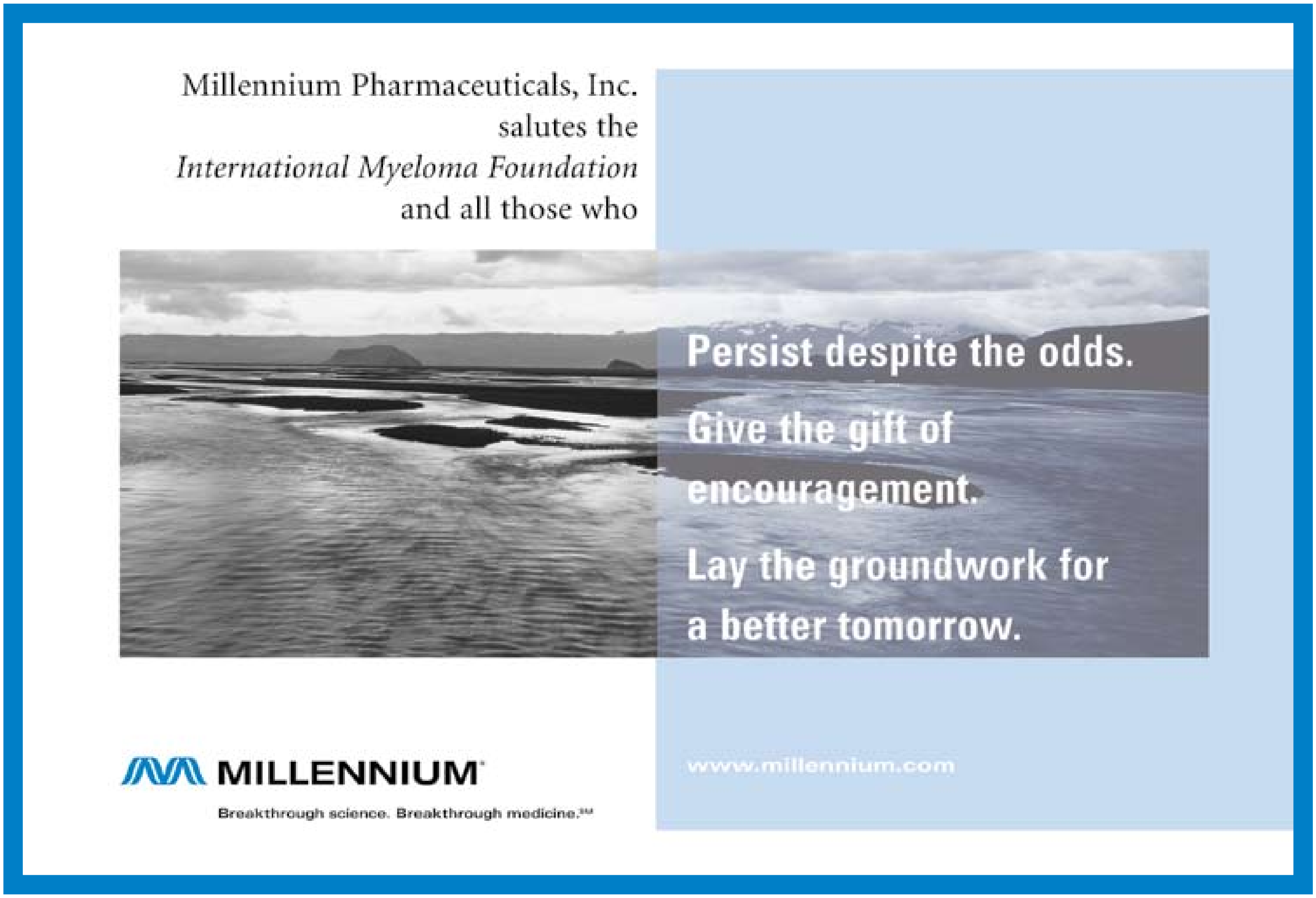

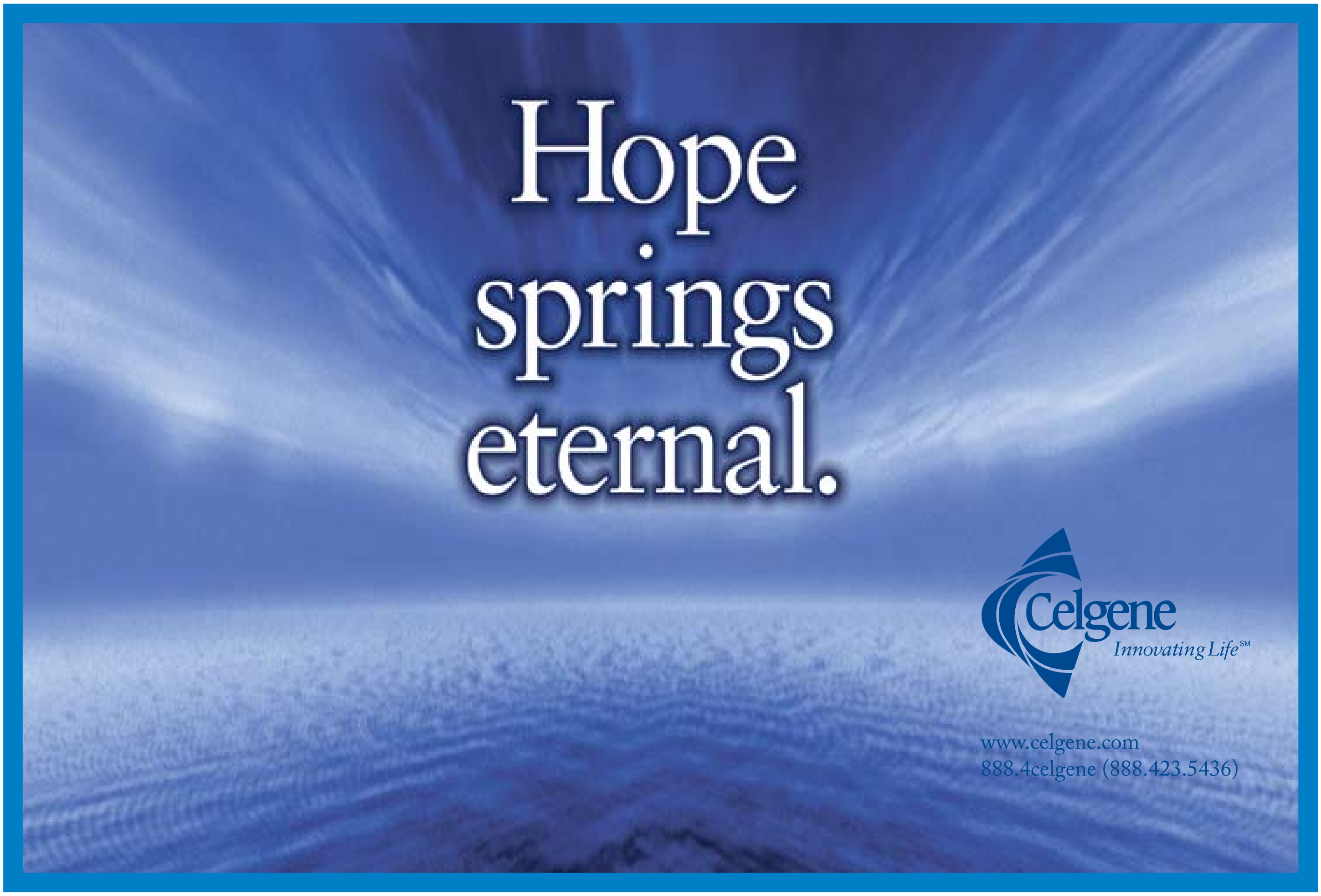

Dear Reader,

2006! Another new year, one filled with new opportunities, new partnerships, and renewed hope. As is customary it's also a time to look back on what we've achieved and this year I'm especially proud of what the IMF has accomplished.

Revenue:

- Raised $5.6 million dollars – a 30% increase over 2004

Education & Support:

- Held 12 Patient & Family Seminars – 5 U.S., 7 international
- Increased our publications from 36 to 42 and updated 19 existing publications.
- Myeloma Today was mailed to 7,500 subscribers with 60,000 web viewers
- Complimentary information packs were sent to 12,000 people
- Produced a DVD – *I have Myeloma… What's Next?*
- IMF Hotline answered 3,900 phone calls and responded to 1,300 emails
- Personal visits to 35 Support Groups
- Held the 6th Annual Support Group Leader Retreat
- Helped start 10 new groups – 9 in underserved areas
- Web site received 35 million hits, reached 25,000 unique visitors, 261,000 were new visitors and increased return rate by 118%

Research:

- Total Research commitment for 2005 was $1.1 million
- Awarded 5 Junior Grants and 2 Senior Grants

The IMF's research goal is to support research that will have the most immediate benefit for patients while working toward prevention and a cure. Toward that end Bank On A Cure® was identified as being the most relevant project to meet that goal.

Bank On A Cure's accomplishments:

Over the past year Bank On A Cure worked with the National Cancer Institute and CRAB (Cancer Research and Biostatistics) to finalize patient/control questionnaires and plan epidemiological studies and formed partnerships with independent investigators including:

French Group
Dutch Group
German Group
Spanish Group
Austrian Group
Czech Group

- Designed first-ever, custom SNP chip for Myeloma with 3,500 SNPs
- Completed the initial studies – current inventory 4,489 samples
- 5 ASH abstracts were accepted – 2 oral presentations
- Bank On A Cure uses healthy tissue samples, which we get from large phase III clinical trials as well as from patient "Swish & Rinse" kits. Laboratory studies are genetic profiling using SNPs. The correlative data will look for clinical outcomes, as well as demographic and environmental data. The hypotheses tested are:
  - ♦ SNPs can predict:
    Myeloma risk
    Response to treatment
    Toxicities
  - ♦ SNPs can identify therapeutic targets

This year Bank On A Cure will expand our partnerships to maximize our ability to rapidly obtain correlations that will show the importance of the DNA information. Vital information that can tailor treatment to avoid toxicities such as deep vein thrombosis (DVT) and improve outcomes increasing the likelihood of long-term survival.

I would like to extend a heartfelt thank you to the thousands of people who helped make 2005 a landmark year for the IMF – we couldn't have done it without you!

Warm regards,

Susie Novis

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

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