



MYELOMA TODAY

FALL 2005

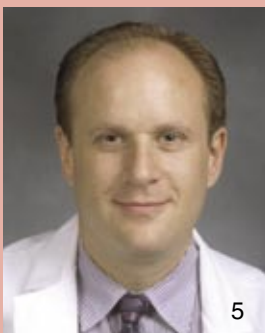
VOLUME 6 NUMBER 6

A PUBLICATION OF THE INTERNATIONAL MYELOMA FOUNDATION

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

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Robert A. Kyle presents Kenneth C. Anderson with the Third Annual Lifetime Achievement Award.

PATHOGENESIS AND MAINTENANCE OF MULTIPLE MYELOMA

By Diane F. Jelinek, PhD

Multiple myeloma is a disease characterized by the significant accumulation of malignant plasma cells in the bone marrow. There is a clear need to achieve a better understanding of the mechanisms underlying myeloma cell growth and survival control. It is important to note that the overall proliferative index of this tumor is quite low by comparison with other malignancies. Thus, an equally important clinically relevant aspect of myeloma cell biology is the mechanisms that underlie malignant plasma cell resistance to apoptosis leading to prolonged survival and tumor cell accumulation. Our current lack of knowledge concerning this process in myeloma is paralleled and amplified by our current lack of insight into signals that regulate survival of normal bone marrow resident, long-lived plasma cells. Therefore, it



Diane F. Jelinek, PhD – Professor of Immunology
Mayo Clinic College of Medicine, Rochester, MN

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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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MAKING CLINICAL TRIALS MORE PATIENT-FRIENDLY

A Special Report by The Unknown Patient

All new cancer drugs must be proven safe and effective in clinical trials before they can be made available to patients. At the 2005 IMF Support Group Leader Retreat, IMFer and leader of the Manhattan and White Plains (New York) myeloma support groups, Mike Katz, facilitated a focus group on patient concerns and preferences relative to clinical trials. Many issues previously Unknown to your reclusive author were discussed at this session and I thought it would be helpful to put some of them on paper.

Clinical trials are very important to patients. Without clinical trials, there could be no new drugs approved for the treatment of myeloma. When a promising new drug comes out of the laboratory, it must be tested in people via clinical trials. Clinical trials are conducted under very strict ethical standards, with many layers of scientific and regulatory review. As a result, they are very expensive and time-consuming to conduct. In recent years, patients have been brought more and more into the design process, which is very good news.

IMFer Mike Katz is co-chair of the Patient Representative Committee at the Eastern Cooperative Oncology Group (ECOG) and the liaison to ECOG's Myeloma Committee. This committee is co-chaired by Dr. Phillip Greipp (Mayo Clinic) and Dr. David Vesole (St. Vincent's Comprehensive Cancer Center).

ECOG has conducted many important cancer clinical trials. It is a cooperative group, funded by the National Cancer Institute (NCI), and its trials are available to patients via hundreds of participating treatment centers. ECOG's Myeloma Committee recently concluded a trial proving the safety and superiority of thalidomide and dexamethasone versus dexamethasone alone. This trial was cited in the "Approvable Letter" issued by the FDA in response to Celgene's submission of thalidomide. The FDA said that it expected to approve thalidomide after the results of this trial are submitted. The trial has already had a profound impact on patient care, with the thalidomide/dexamethasone combination all but replacing VAD (vincristine, Adriamycin, dexamethasone) as the standard front-line treatment for patients planning a stem cell transplant.

ECOG is currently conducting a trial testing the new agent Revlimid®. However, the Myeloma Committee designed this trial to go beyond the question of whether Revlimid is a safe and effective front-line treatment for myeloma. (Further information about this trial can be found at <http://e4a03.myeloma.org>.) The trial is asking two questions that are very important to patients:

- If Revlimid does not work, will thalidomide work?
- When given with Revlimid or thalidomide, will a lower dose of dexamethasone (40mg, given 1 day on, 7 days off) be as effective as the standard dose (40 mg, given 4 days on, 4 days off)?

This trial design received rave reviews at the 2004 IMF Support Group Leader Retreat. It was approved by the NCI in record time and is enrolling patients faster than original projections. It is an example of a "patient-friendly" trial in that it asks questions important to patients and is actually testing the efficacy of potentially less toxic treatments (Revlimid versus thalidomide, lower-dose versus standard-dose dexamethasone.) Traditionally, trials used "maximum tolerated doses" to maximize the possibility of a positive result for the treatment being tested, often in support of drug approval applications.

Having Mike Katz on the Myeloma Committee and having the Myeloma Committee participate in a focus group with the IMF Support Group Leaders clearly played a part in making this trial design more "patient-friendly." ECOG has been a pioneer in this area. Mike and his co-chair, Mary Lou Smith, sit on the ECOG Executive Committee, which reviews and approves all trial concepts.

At this year's IMF Support Group Leader Retreat, the Myeloma Committee once again participated in a focus group discussion with the attendees. The discussion first covered general issues that the support group leaders had with myeloma treatment and clinical trials, including:

- Whether to have a stem cell transplant and the appropriate timing
- If and when stem cells should be harvested if not having a transplant

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IMF Calendar

2005

December 10-13 ASH – Atlanta, GA

2006

January 26-29 IMF Board Retreat – Ojai Valley Inn, Ojai, CA

February 10-11 P&F Seminar – Sir Francis Drake Hotel,
San Francisco, CA

February 16-20 Annual Bone Marrow Transplant Mtg, Honolulu, HI

March 14-15 Advocacy Days – Washington, DC

March 24-25 Bart Barlogie Clinical Conference – South Beach, FL

March 31-April 1 Ft. Lauderdale P&F Seminar – Wyndham Hotel

April 1-5 AACR Meeting – Washington, DC

April 8 Japan/SWOG USA Clinical Summit Meeting

April 19-23 SWOG – The Grand American Hotel, Salt Lake City, UT

April 27-30 Scientific Advisory Board Retreat

May 4-7 ONS – New Orleans, LA

May 18-21 Support Group Leaders Retreat

June 2-6 ASCO – Atlanta, GA

June 15-18 EHA Meeting – Amsterdam

June 23-25 ECOC – Washington, DC

October 4-8 SWOG – Sheraton Seattle Hotel & Towers, Seattle, WA

October 14 Ribbon of Hope Gala – Los Angeles, CA

December 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(Japan) and IMF(UK) events are not included above.

MOZOBIL™, A POTENTIAL NEW AGENT FOR STEM CELL HARVESTING

An interview with Neal Flomenberg, MD

What is the idea behind stem cell transplantation for multiple myeloma?

A peripheral blood stem cell (PBSC) transplant is commonly employed in the treatment of myeloma. It is a procedure used to restore the immune system of myeloma patients who have had high-dose chemotherapy treatments that previously destroyed their immune cells. The idea behind transplant is that it allows one to treat more intensively than one could in the absence of a transplant. Many chemotherapy drugs suppress some of the faster-growing cells in the body, of which the bone marrow is one. When the bone marrow is suppressed, you cannot make certain blood components because the marrow is the “blood factory.” A low white count puts you at risk for infection; a low platelet count puts you at risk for bleeding. Most people can tolerate low blood counts for short period of time, but the longer such conditions last, the more vulnerable one becomes to these side effects. So, after high doses of chemotherapy completely destroy the marrow and, hopefully, the myeloma cells as well, the re-infusion of these “baby cells” restarts the



Neal Flomenberg, MD
Director, Bone Marrow Transplant Program
Thomas Jefferson University
Philadelphia, Pennsylvania

marrow growth and function. In order to perform a PBSC transplant, one must collect stem cells that will be used to restart the marrow after the transplant. The more stem cells you transplant, the faster you restart the marrow, and the shorter the period of vulnerability.

How would you compare the colony-stimulating factors that are currently used and MOZOBIL™ (AMD3100)?

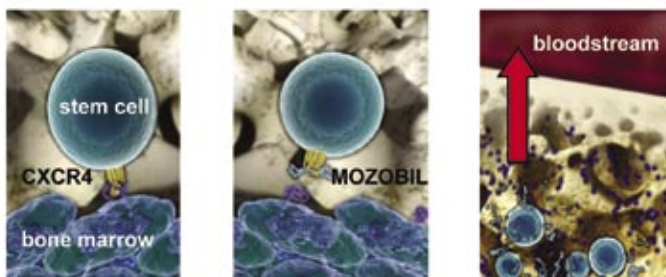
Colony-stimulating factors such as G-CSF (filgrastim) induce the marrow to grow, while MOZOBIL is a new agent that aids in releasing stem cells into circulating blood where they can be collected by a process called apheresis.

What is MOZOBIL's mechanism of action?

MOZOBIL inhibits the chemokine receptors that act as “anchors” holding these baby cells to the marrow. Alternatively, you can think of this “anchoring” as two sides of a piece of Velcro, or a lock and key. MOZOBIL disrupts this action, and it does so directly, as opposed to the indirect effects of G-CSF. The effects of G-CSF are not seen for 4 or 5 days. The effects of MOZOBIL are seen much more quickly, in 4 to 6 hours, reflecting the fact that the cells aren't just growing, but also being released. It may be that these complementary effects are why the combination seems to be more effective than either of the drugs alone.

Has MOZOBIL been studied as a single agent?

It is currently being studied as a single agent in a Phase II clinical trial. Also, it is being used in addition to one of the current standards of care. In Europe, Phase II trials are ongoing to evaluate MOZOBIL in combination with



MOZOBIL Mechanism of Action

By blocking CXCR4, a specific cellular receptor, MOZOBIL triggers the rapid movement of stem cells out of the bone marrow and into circulating blood. Once in the circulating blood, the stem cells can be collected for use in stem cell transplant. Stem cell transplant is a procedure used to restore the immune system of cancer patients who have had treatments that previously destroyed their immune cells.

PLEASE SEE MOZOBIL PAGE NEXT PAGE

MOZOBIL — continued

different stem cell mobilizing regimens, including chemotherapy.

Can you tell us about MOZOBIL's clinical development?

In Phase I clinical trials, researchers test a new drug or treatment in a small group of people for the first time to evaluate its safety, determine a safe dosage range, and identify side effects. In Phase II clinical trials, the study drug or treatment is given to a larger group of people to see if it is effective and to further evaluate its safety. In Phase III clinical trials, the study drug or treatment is given to large groups of people to confirm its effectiveness, monitor side effects, compare it to commonly used treatments, and collect information that will allow the drug or treatment to be used safely. MOZOBIL's clinical program is designed to evaluate its ability to improve overall transplantation procedure by increasing stem cells available for transplant.

Can you describe the study design and how each patient was able to be his or her own control?

Each patient got mobilized twice, first either with G-CSF alone followed by G-CSF and MOZOBIL combined, or vice versa. There were approximately 2 weeks of rest between the two mobilizing approaches. Who got mobilized with which approach first was decided by a "computer coin toss." That way, the results were not biased in favor of either approach. Scientifically, we thought that this was a more precise way to do the study. Controlled trials are more convincing than studies that do not use a control, and allow investigators to get a better handle on the effectiveness of the drug when studying a smaller group of patients. While a Phase II trial is not as definitive as a randomized Phase III trial with hundreds of patients, I do think that it gave us far more information than we would have had if we only mobilized with a combination and not studied how these same patients did with G-CSF alone.

What did the data from your Phase II trial show?

A combination of MOZOBIL and G-CSF is better than G-CSF alone to mobilize and collect the optimal number of stem cells for autologous transplantation. The

combination has shown potential to help more patients collect more cells and improve the transplant procedure. The use of MOZOBIL increased the number of stem cells in peripheral blood and also reduced the number of apheresis sessions required for patients to reach the target number of stem cells collected.

Five of the patients who received G-CSF alone and failed to collect, were then successfully able to mobilize enough stem cells with a combination of G-CSF and MOZOBIL. Four of the patients who were successfully given a combination of G-CSF and MOZOBIL initially, afterwards failed to collect with G-CSF alone.

Up to 65% of transplant patients have poor or sub-optimal mobilization using G-CSF alone, and there are no medical guidelines to predict which patients will respond poorly to G-CSF mobilization. These patients may require additional mobilization sessions to achieve a sufficient collection for transplantation. Patients transplanted with a sub-optimal number of cells can experience a delayed recovery of their immune system, and are at greater risk for infection and may require additional days of antibiotics, blood transfusions, and extended hospitalization. MOZOBIL possibly allows for a more rapid collection of a larger number of stem cells from the peripheral blood. Larger stem cell doses for transplantation are correlated to faster recovery times.

At this time, I am very upbeat that MOZOBIL has the potential to become part of the standard of care for myeloma. Of the 25 patients treated, 9 could not have been transplanted with G-CSF mobilization alone. Other patients in the study were able to save one or more days of apheresis due to the use of the G-CSF and MOZOBIL combination. Approximately 84% of patients treated derived benefit from the combination, and that's a very substantial improvement.

Blood published Phase II data in September 2005, and we will report new Phase II data at the American Society of Hematology (ASH) conference in December 2005. Based on Phase II results, as well as historical data from standard stem cell mobilization regimens using G-CSF alone, a Phase III clinical trial initiated patient enrollment in January 2005.

What about side effects?

The side effects profile is very good. There have been very few serious side effects, and none of them could be related to MOZOBIL – they occurred during or after transplant, well after MOZOBIL was administered, or they occurred during mobilization with G-CSF alone, before MOZOBIL was ever administered. The fairly mild and brief side effects we've seen include discomfort at the site of the injection, pins and needles in the fingers and toes, and GI upset.

What can you tell us about the Phase III trial?

This study is intended to determine whether the combination of MOZOBIL plus G-CSF is better than placebo plus G-CSF. One of the Phase III studies being conducted is exclusively enrolling several hundred myeloma patients (see list of U.S. centers below). This study is randomized, double-blind, placebo controlled, comparative. To be as scientifically rigorous as possible, and to avoid any bias, the Phase III study is only enrolling patients undergoing the stem cell collection process for a transplant for the first time.

What about patients who have previously failed to collect enough stem cells for a transplant?

AnorMED, the pharmaceutical company developing MOZOBIL, has a compassionate use program that might be available to patients who have already attempted mobilization and were not successful.

What are your thoughts about PBSC transplant for myeloma as opposed to standard therapy?

There have been some randomized studies, which have suggested that there are more patients disease-free at later time points in their illness with PBSC transplant than with non-transplant therapies. But this is a moving target because new agents continue to become available for treatment within and outside the transplant setting. Fortunately, there is much progress being made in the field of myeloma. **MT**

Editor's Note: For additional MOZOBIL Phase III study information, please visit www.ClinicalTrials.gov and use identifier NCT00103662.

Phase III study sites in the U.S.

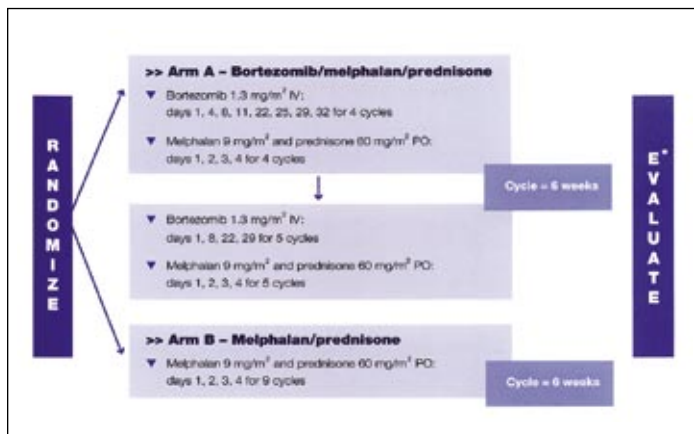
- City of Hope, Phoenix, Arizona
- Myeloma Institute for Research and Therapy, Little Rock, Arkansas
- Rocky Mountain Cancer Center, Denver, Colorado
- Yale University School of Medicine, New Haven, Connecticut
- H. Lee Moffitt Cancer Center and Research Institute, Tampa, Florida
- Loyola University Medical Center, Maywood, Illinois
- Indiana Blood and Marrow Transplantation Center, Beech Grove, Indiana
- University of Iowa, Iowa City, Iowa
- Fairview-University Medical Center, University of Minnesota, Minneapolis, Minnesota
- Mayo Clinic, Rochester, Minnesota
- Washington University School of Medicine, Saint Louis, Missouri
- Kansas City Cancer Center, Kansas City, Missouri
- The Cancer Center at Hackensack University Medical Center, Hackensack, New Jersey
- University of Rochester Medical Center, Rochester, New York
- Roswell Park Cancer Institute, Buffalo, New York
- Duke University Medical Center, Durham, North Carolina
- Cleveland Clinic Foundation, Cleveland, Ohio
- Oregon Health & Science University, Portland, Oregon
- Hospital of the University of Pennsylvania, Philadelphia, Pennsylvania
- University of Texas Health Science Center, San Antonio, Texas
- Texas Transplant Institute, San Antonio, Texas
- Utah Blood and Marrow Transplant Program, Salt Lake City, Utah
- Virginia Commonwealth University, Richmond, Virginia
- Fred Hutchinson Cancer Research Center, Seattle, Washington
- Thomas Jefferson University, Philadelphia, Pennsylvania

VELCADE® PHASE III TRIALS

VELCADE® (bortezomib) for Injection

VELCADE® (bortezomib) for Injection is currently approved in the United States and more than 50 countries worldwide for the treatment of patients with relapsed and refractory multiple myeloma. The timetable for clinical development and approval of VELCADE was unusually rapid; the FDA granted approval for U.S. marketing just over four and a half years after the first patient received VELCADE in a clinical trial. VELCADE is the first treatment in more than a decade to be approved for patients with myeloma.

VELCADE is proteasome inhibitor. The proteasome is an enzyme complex found within all cells. Many of the processes that rely on proteasome function can contribute to the growth and survival of cancer cells. VELCADE appears to induce myeloma cell death and to inhibit myeloma cell growth and survival by acting on the bone microenvironment. Due to the reversibility of proteasome inhibition with VELCADE, normal cells can recover from its effects, whereas cancer cells are more likely to undergo cell death.



APEX Trial

The results of the phase III APEX clinical trial demonstrated a statistically significant survival advantage of VELCADE versus a standard therapy (high-dose dexamethasone). Early closure was recommended by an independent data monitoring committee at interim

analysis of time to progression (50% of progressive disease events). At termination, a final statistical analysis was performed. Survival advantage maintained despite at least 44% of dexamethasone patients crossing over to VELCADE prior to early study closure.

Of 333 patients on the VELCADE arm, 315 were evaluable for response. Of 336 patients on the dexamethasone arm, 312 were evaluable for response. Complete response (CR) required 100% disappearance of the original myeloma protein from blood and urine on at least 2 determinations 6 weeks apart by immunofixation, less than 5% plasma cells in the bone marrow, stable bone disease, and normal calcium. Near complete response (nCR) required that all CR criteria be met except that immunofixation was positive. Partial response (PR) required greater than or equal to 50% reduction in serum myeloma protein and greater than or equal to 90% reduction in urine myeloma protein on at least 2 determinations 6 weeks apart, stable bone disease, and normal calcium.

VISTA Trial

Several Phase III clinical trials of VELCADE are currently underway. In January 2005, Millennium Pharmaceuticals, Inc. announced the initiation of VISTA (VELCADE as Initial Standard Therapy in multiple myeloma: Assessment with melphalan and prednisone), an open-label, randomized, multicenter, international clinical trial of VELCADE in combination with melphalan and prednisone versus melphalan and prednisone in patients with newly diagnosed multiple myeloma who are not transplant candidates.

The VISTA study is designed to assess efficacy, overall safety, and tolerability of the combination regimen compared with melphalan and prednisone alone. “The frontline data seen to date have been very promising, and we are eager to explore the potential of VELCADE in combination with other therapies so that we may be able to offer new options for patients in need,” said

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INSIGHTS INTO NEW MULTIPLE MYELOMA TREATMENT

Revlimid study tops list of investigations that may benefit patients

By Ruben Niesvizky, MD

Introduction

The Multiple Myeloma Program at NewYork-Presbyterian Hospital/Weill Cornell Medical Center, one of the largest myeloma programs in the United States, is forging ahead with a number of clinical and basic science investigations that may yield promising new treatments for patients. The Multiple Myeloma Program includes a clinical trial of a unique combination regimen including Revlimid® (lenalidomide), a new thalidomide analogue that has already shown promising activity in a variety of hematologic malignancies.



Ruben Niesvizky, MD
 Director, Multiple Myeloma Program
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 New York, NY

development of new therapeutic regimens for multiple myeloma.

While dexamethasone alone has a response rate of approximately 50%, a protocol called BLTD (Biaxin, low-dose thalidomide, and dexamethasone) has yielded a response rate of 93% and a complete remission rate of 13% in recent clinical studies. The BLTD protocol was pioneered by Dr. Morton Coleman.

Promising New Treatments

Recently, the Multiple Myeloma Program has generated a considerable amount of excitement by launching a study evaluating a combination regimen, known as BiRD, that includes the antibiotic Biaxin® (clarithromycin), Revlimid, and dexamethasone. The BiRD regimen represents an important next step in the

These studies, presented at the ASH and ASCO meetings, confirmed the initial observation by Dr. Brian Durie and others that Biaxin contributes to tumor mass reduction in patients with myeloma and Waldenström's macroglobulinemia.

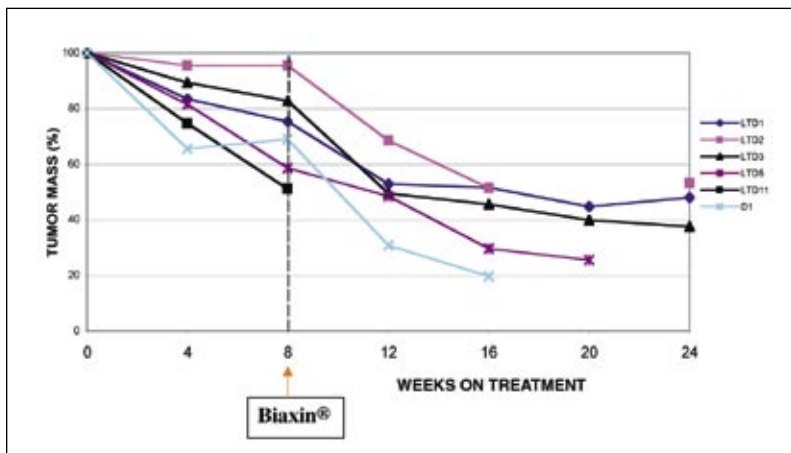


Figure: Biaxin contributes to tumor mass reduction in patients receiving Dexamethasone

In order to further our understanding of these findings, we recently randomized patients to receive either low-dose thalidomide plus dexamethasone or dexamethasone alone. Patients without a satisfactory response (<50% drop in tumor mass) were started on Biaxin. Figure 1 illustrates several patients resistant to either T or LTD and how tumor mass significantly declines immediately after the initiation of Biaxin. The addition of Biaxin to this regimen seems to dramatically improve both response rate and time to response, even in patients who were previously unresponsive to D or LTD. Whether this effect is solely a pharmacokinetic effect, or involves other cellular targets, remains to be determined.

While acknowledged to be much more potent than its parent drug, thalidomide, Revlimid

CONTINUES ON NEXT PAGE

INSIGHTS INTO NEW TREATMENTS — continued

avoids many of thalidomide's side effects. We hope that the BiRD combination, by replacing thalidomide with Revlimid, will improve patient safety while maintaining the favorable patient outcomes seen with BLTD. We fully anticipate that Revlimid will achieve an impressive complete remission rate, therefore allowing patients to achieve long-term survival. We have recognized the challenges of the use of this drug alone or in combination and we have observed the benefits of aspirin in preventing serious thrombotic events. We have submitted our data to the upcoming ASH meeting and we will be presenting in a dedicated session.

Multidisciplinary Research Effort

The BiRD study is just one of several ongoing clinical trials in which Multiple Myeloma Program investigators are playing a major role. In particular, our investigators have already initiated a clinical trial of consolidation therapy or second-line treatment for myeloma with dexamethasone plus VELCADE® (bortezomib) for Injection, as preamble for an autologous stem cell transplant. The program at Cornell is one of the first

to launch the expanded access protocol for Revlimid in the relapsed setting. Investigators are also evaluating SGN-40, a humanized anti-CD40 monoclonal antibody, and are evaluating a new class of drugs called histone deacetylase inhibitors in three separate protocols. Together, these six protocols cover a wide range of patients.

Our goal is to expand our understanding of myeloma, to improve treatment and, ultimately, to find a cure. In order to do that, we must translate research from the bench to the bedside, and likewise, from the bedside to the bench. We need to investigate treatments for myeloma patients in every stage of the disease. My colleagues include Dr. Selina Chen-Kiang, an immunology and cell cycle expert who is currently focused on elucidating the molecular basis of myeloma, Dr. Roger N. Pearse, expert in the field of cell biology, Dr. Hearn J. Cho, an immunology expert, and Dr. Scott Ely, an expert in pathology. We collaborate with a full team of expert scientists and physicians who meet regularly to share new ideas and communicate findings in multiple myeloma. **MT**

VELCADE TRIALS — continued

David Schenkein, MD, vice president, clinical oncology development, Millennium.

The primary study objective is to determine whether the addition of VELCADE to standard melphalan and prednisone therapy improves the time to disease progression in patients with previously untreated myeloma. The secondary study objectives are to determine overall survival, progression-free survival, time to response, CR rate and overall response rate, duration of response, and safety. Approximately 680 patients will be enrolled in 21 countries.

EVEREST Trial

Millennium is also conducting a multicenter Phase IV clinical trial known as EVEREST (Evaluation of VELCADE Employed as Retreatment for Efficacy, Safety, and Tolerability). This study is designed to assess M-protein response in patients who have previously responded to VELCADE and relapsed following a treatment-free remission. Because there is no known mechanism of resistance to VELCADE and no new cumulative toxicity with extended therapy, it is hoped that retreatment with VELCADE will be beneficial.

NOTE: For more information about VELCADE® (bortezomib) for Injection clinical trials, patients and physicians can visit www.millennium.com or call the Millennium Medical Product Information Department at 866-VELCADE.

CLINICAL TRIALS — continued

- Whether there are better therapies than stem cell transplants that patients would be forgoing by tracking into a front-line transplant program
- What the alternatives to a stem cell transplant are
- How to sort through all of the available combination therapies available today, both in terms of effectiveness of treatment as well as side effects/risks
- General frustration with continued role of high-dose dexamethasone in so many treatment regimens and trials, given the side effects
- Concerns about wasting time with drugs/treatments that don't work
- Concerns that patients are being steered into clinical trials without being told what the alternative standard treatments would be
- Feeling that the informed consent forms for clinical trials are too long and too hard to understand
- Insurance coverage issues often influencing choice to enter clinical trial based on availability of free drug, leading more people with insurance issues to enroll
- The need for more information on alternative/complimentary therapies, such as curcumin, particularly for MGUS and smoldering patient who have no imperative for standard treatment options but are looking to do something
- The need for better pain management services

The next part of the discussion focused on clinical trials designs being considered by ECOG for the future. While confidentiality issues prevent discussion of the details of those designs, there were some general conclusions worth sharing:

- In discussing potential trials for patients with Smoldering Myeloma, the group saw the following pros/cons but felt it was worth having trials available for patients who were anxious to do something beyond “watchful waiting”:
 - Pros: Opportunity for a patient who feels like there's a “time bomb” in his/her body to participate in a trial that would allow one to do something to stop it from “exploding”
 - Cons:
 - Why should patients take a drug with possible side effects and risks when they are symptom free and feeling well?
 - Why should a patient risk developing a resistance

to a medication that might be needed more urgently later on in the disease progression?

- A number of concepts for front-line trials were discussed. The group strongly encouraged the Committee to consider designs that used newer, less toxic agents than thalidomide, the feeling being that patients need not be subjected to thalidomide's side-effects and risks if there were better alternatives available
- A concept for a consolidation therapy trial was discussed:
 - Consolidation therapy is given after the myeloma has been driven into remission by another therapy. For example, transplant is a consolidation therapy, as it is given after another therapy has driven the myeloma into remission.
 - The group was receptive to the trial concept, as they had been when an earlier version was discussed with them at the 2004 retreat. It was felt to be a good alternative for people who did not want to pursue transplant immediately after front-line therapy. People also liked the idea of having their stem cells harvested early in the process, as this was part of the trial design.
 - There was concern about the specification of double transplant as the salvage regimen (to be used if the patient relapsed after consolidation therapy). However, the Myeloma Committee representatives explained that the salvage regimen was not part of the trial protocol and did not necessarily have to be a tandem transplant or even an auto transplant.

The attendees felt empowered to be able to engage directly in the design process and the Myeloma Committee was grateful for their input. It does no one any good to go through the time and expense of opening clinical trials that are not attractive to patients.

The success of the Myeloma Committee Focus Group paved the way for a recommendation that annual patient focus groups be incorporated into the NCI's Blueprint for a Redesigned National Clinical Trials system. This recommendation was presented to the National Cancer Advisory Board and accepted for implementation. So, the myeloma community has once again led the way, setting an example for how to get things right in cancer treatment and research. **MT**

IMF HOTLINE COORDINATORS ANSWER 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.

Question: I have been diagnosed with a solitary plasmacytoma of the bone. What is it? And what is the likelihood that I will develop multiple myeloma?

Answer: A solitary plasmacytoma of the bone (SPB) is defined as a collection of malignant plasma cells found in a single location in the bone without evidence of disease elsewhere. If, in fact, you have a true SPB, your chances of cure with radiation (3500 cGy) therapy are quite good. When a patient is treated with attempted curative radiotherapy for a SPB and then goes on within a few years to develop multiple myeloma (MM), the major reason for this failure is that the patient had underlying MM all along and did not have a true SPB. Thus the failure was not that of the radiation therapy, but that the patient was not accurately diagnosed.

Diagnosis of SPB

In the past, it has been difficult to assess whether a patient who presents with what appears to be a SPB actually has some small or hidden amount of systemic myeloma. Blood work can determine the amount, if any, of the myeloma protein. A high amount of such protein would point towards the presence of MM. The term MM is used if there is, in addition to a plasmacytoma, an increase in plasma cells in the routine bone marrow. The patient should be checked for other relevant indicators of MM, such as low hemoglobin, elevated serum calcium, and elevated serum creatinine. Another important diagnostic factor is the presence or absence of other bone lesions. In the past, a skeletal survey was used to make this determination. However, negative skeletal surveys alone cannot rule out other bone lesions because such surveys are not sufficiently accurate. With MRI and/or FDG PET scanning, doctors can better determine if the patient has more wide-spread marrow involvement. The absence of such involvement after these more sensitive tests would give the doctor (and patient!) more confidence that there is no occult MM.

Adjuvant Therapy

Adjuvant therapy is a term used to describe additional therapy such as chemotherapy, steroids, thalidomide, or alpha-interferon after radiation. Studies done in the 1980s and 1990s evaluating the benefit of post-radiation therapy with various chemotherapies in an effort to reduce the chance of, or time to, new disease were inconclusive. The prevailing view at this time is that adjuvant chemotherapy should not be given for patients with SPB. However, bisphosphonate therapy can be considered to help heal the bone that was damaged by the plasmacytoma.

Follow-up

Even in the absence of adjuvant therapy for SPB, patients should be monitored regularly. It may take up to a year (or occasionally even longer) for the effects of the radiation therapy to be fully demonstrated in dropping monoclonal protein levels. During that time, you and your doctor should determine a schedule of visits every 2 or 3 months to evaluate your status. As time goes on, if you remain disease-free, this schedule can be lengthened to, for example, 4-6 month intervals. Such close monitoring will allow the doctor to find any sign of a recurrence or development of MM at an earlier point when treatment options are greater.

Likelihood of Curing SPB

As stated above, the important issue is accurate diagnosis. Local control of an SPB has been achieved in about 90% of cases. Disease-free survival of 10 years has been reported to be from 16% to 46%, depending on the study. This discrepancy is most likely a result of the fact that not all of the patients in each study had true SPBs, but rather had underlying MM. There have also been studies looking at what prognostic factors can be identified that will predict which patients will be cured and which patients will ultimately relapse and develop MM. The following factors have been identified in at least one study as increasing the likelihood of relapse: osteopenia



Paul Hewitt

PLEASE SEE HOTLINE PAGE NEXT PAGE

THE MULTIPLE MYELOMA LISTSERVE

by Nancy Baxter

Many patients and caregivers do not live close to a myeloma support group. Those who might have a support group conveniently nearby may find that the group meets at a time when they are working, busy with family obligations, or when they are just too tired to get in the car and drive. Others just don't like talking face to face. Whatever the reason, the IMF has, for many years, provided an alternative source of information and support to myeloma patients, caregivers, friends, and family.

The Multiple Myeloma ListServ – affectionately called “The List” by its 1500 members – was founded by Michael Katz, an IMF Director, and June Brazil, a myeloma patient. At a time when the number of in-person myeloma support groups was nowhere near the over 140 groups that exist today, Mike and June sought to link myeloma patients via an e-mail discussion forum.

The List has created a true “cyber family” that includes doctors and lawyers, construction workers and homemakers, teachers and salesmen, retired people, musicians, writers, and others. Members of this diverse group share their experiences, accumulated knowledge, and moral support. They discuss everything from treatments and side effects to family issues and useful tips about dealing with health insurance and improving relationships with healthcare providers. The List has created countless friendships, often between people who have never met.

Recently, List members have even participated in an IMF-led online study that looked at the possible link between bisphosphonate use and a serious condition

called osteonecrosis of the jaw. In July 2005, the results of this study were reported in the *New England Journal of medicine*. The remarkable group thus not only helps each other directly, but has also added to the body of knowledge of an important issue facing many myeloma patients today.



Nancy Baxter

Joining this group couldn't be easier. Here's how:

- 1) Log on to the IMF website at www.myeloma.org
- 2) Click on “Finding Support”
- 3) Click on “Online Group”

This will lead you to a web page where you can sign up to join the list.

List members are welcome to participate in discussions or to simply avail themselves of the information being shared by others. If you are interested in researching a particular topic, a searchable archive is also available, dating back to June of 1998. When posting an inquiry to the List, you will find that the responses you receive are almost always compassionate, knowledgeable, and relevant. The List will probably be the best group you never wanted to join! **MT**

HOTLINE — continued

(reduced bone density, perhaps indicating early evidence of MM), low levels of uninvolved immunoglobulins (again, this probably means the patient actually had occult MM at diagnosis), age over 60, and/or SPB on axial (head and trunk) skeleton region. In patients whose monoclonal protein persists after radiation therapy, the likelihood of relapse is greater; conversely, those whose monoclonal protein disappears after local radiotherapy are less likely to relapse.

Overall Outlook

As our understanding of how plasma cell cancers develop increases, and as our ability to accurately diagnosis and stage plasmacytomas and MM improves, doctors are better able to guide patients in making treatment decisions. **MT**

PROFILE OF ROBIN TUOHY

My family's journey through cancer began in September of 2000. My husband, Michael, and I were enjoying a family vacation with our children, Allison and Mikey, then ages 7 and 2. On one of the "kiddie" rides at Santa's Village, Michael experienced extreme back pain. After numerous medical tests, we first heard the words "multiple myeloma." Michael was 36 years old.

After the diagnosis, we were shocked, scared, and anxious. Fortunately, we found the IMF and were impressed with the extensive information and support provided by this organization. In 2001, with the help of the IMF, Michael and I started the first myeloma support group in Connecticut. After attending the blood cancer hearings in which Geraldine Ferraro announced that she had multiple myeloma, we were further inspired to become advocates for the myeloma community. Through our involvement with the IMF and with our support group, we strive to reach out to myeloma patients and their caregivers to help them better understand this disease.



Robin Tuohy and her family

Earlier this year, Susie Novis invited me to work for the IMF as an assistant to Andrew Lebkuecher, Director of Support Groups. I have truly enjoyed working at the IMF and building relationships with other myeloma support group leaders, as well as patients and caregivers. This job is more like an act of love.

It has been my pleasure to visit myeloma support groups in Rhode Island, Pennsylvania, and New Jersey; and I look forward to my upcoming visits to groups in New York, Vermont, and Ohio. If you are interested in having me visit with your group, please contact me at Tuohey@snet.net or 203-206-3536. I am genuinely thankful to have the opportunity to help you, your family, your support group, and the extended myeloma community.

Statistically, cancer patients who attend support groups do better! If you do not yet belong to a support group, let us help you find one in your area. Just contact me, or visit www.myeloma.org and click on the "People Helping People" link.

I am sorry that your lives have been touched by myeloma. But, along with the rest of the IMF staff, I take heart in doing my best to assist you in any way I can. Let's work together to find a cure, while helping each other along the way on our journey through cancer.

SIXTH ANNUAL SUPPORT GROUP LEADER RETREAT

By Robin Tuohy

The word “Retreat” is defined in various ways: (1) an act or process of withdrawing especially from what is difficult or dangerous, and also (2) a period of group withdrawal for meditation, study, and instruction under a director. Well, I would have to say that the IMF’s retreat is a combination of both. Under the direction of our Untiring Leaders, Dr. Brian Durie and Susie Novis, we were well fed, thoroughly educated, and delightfully entertained (not to mention exhausted by Sunday)!

For those of you who have not yet had the pleasure of attending the Retreat, I can tell you that it is like a family reunion. As in our own families, our “myeloma family” is one that we did not choose – but we care and want to help each other in our journey. To those with whom we have become close, we give hugs and catch up; to those we’ve just met, we give hugs and learn about each other. We are all together in this with a common bond: multiple myeloma and how to fight the beast.

The weekend began on Friday afternoon with Dr. Durie conducting an informative question and answer session with the leaders and detailing important support issues in 2005. We learned what the IMF has to offer to support groups, and then launched into standard and new diagnostic tests, updates on Revlimid®, VELCADE®, and AnorMed’s new stem cell mobilizer, AMD-3100. It was a total “A to Z” on myeloma from staging and initial diagnosis to relapsed disease and what choices we now have. We then enjoyed cocktails, dinner, and a movie—“The IMF Research Initiatives” DVD—which focuses on Bank on a Cure®, Circulating DNA, and Proteomics. Greg Brozeit spoke with us regarding advocacy issues and how we can participate effectively. His main message is that all cancer groups need to work together to get things accomplished in Washington.

Saturday was jam packed with presentations. We were told later in the day that there are only 1440 minutes in a day (and we used each one of them)! Susie began the day with introductions and a heartfelt welcome.



Another successful retreat for the Support Group leaders from the U.S. and Canada and IMF staff

Our first presenter was Vicki Anderson-Ferraro, leader of the Miami Multiple Myeloma Networking Group. Vicki spoke on “Starting and Maintaining a Support Group.” There are many recipes for success and each leader needs to evaluate his or her own situation and assess the many ideas shared to determine which ones would work best. Vicki discussed the importance of determining and meeting the needs of the members, identifying co-leaders, and developing partnerships with various organizations. Vicki left us with this question: If you don’t know what you want to accomplish, how will you monitor and measure your progress?

Marcia and Jerry Sawyer, co-leaders with the North Texas Myeloma Support Group, gave a presentation on “Communications: Newsletters and Websites.” Their group uses a combination of a detailed website, newcomer packets, and newsletters. Additionally they now have a “patient voice mail” telephone number to enable information seekers to contact them (972) 504-6307. Check out their website at www.northtexas.myeloma.org/newsletters.html.

Chuck Koval, leader of the Madison, Wisconsin Support Group collaborated with the Racine and Milwaukee support groups in a “Collective Group Seminar.” This was the first of its kind: a statewide education day for multiple myeloma! The Madison, Racine, and Milwaukee support groups were all involved in this project and

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SIXTH ANNUAL — continued

worked with various organizations to make it a success. They are already planning next year's event for November 5, so if you are in the area please stop by to see what it's all about!

Mike Katz, co-leader of groups in Manhattan and White Plains, conducted a clinical trial discussion conference call with ECOG Myeloma Committee Investigators (Drs. Phil Greipp, David Vesole, Morie Gertz, Rafael Fonseca, Vincent Rajkumar, Angela Dispenzieri, and co-chair Mary Lou Smith). Currently, ECOG has more than 90 active clinical trials in all types of adult malignancies. The objectives of this session were to provide patient perspectives on the most important questions that need to be answered with clinical trials and to comment upon concepts for a potential trial currently under discussion. We learned that it takes a long time to get a trial designed, approved, completed, and analyzed – so we want to get it right! This was the second year that the group participated in a clinical trial teleconference.

Dr. Dixie Esseltine from Millennium Pharmaceuticals updated us on the latest multi-center clinical trial with VELCADE, which resulted in expanded FDA approval for Velcade as second-line therapy. She discussed the management of VELCADE-induced peripheral neuropathy and reviewed the research demonstrating VELCADE's efficacy when it is combined with other drugs, particularly chemotherapy agents and dexamethasone. Of particular note was the information that VELCADE is effective even for patients who have chromosome 13 deletion.

Back for a second time was our friend Maureen Carling, RN. Maureen commanded our attention right from the start. She spoke on a subject that most of us deal with on a daily basis – pain management. Pain in malignant disease is common, yet in most patients pain can be effectively controlled. For effective pain management there are three basic things which must be done: assessment, titration, and regular and frequent monitoring. She informed us that there are neurological receptors for eight different types of pain, most myeloma patients are experiencing at least four kinds of pain at once, and yet the most commonly given type of medication, opioid therapies, affect only two types of receptors. Maureen ended with this: Pain CAN and SHOULD be controlled. You have nothing to fear but fear itself!

To close the afternoon, we took a deep breath, and listened and interacted with Greg Pacini, a licensed professional counselor. It is always a powerful thing when a group trusts its members enough to communicate somehow what is needed in the moment. Greg started out his agenda with an educational discussion on "Travel Tips for Couples on The Journey Beyond Diagnosis." That discussion led us to a cleansing of emotions; the perfect ending to a long but inspirational day.

After a fabulous dinner we were treated to the uplifting words of Tom Bay. Having amassed 20-plus years of interviews with individuals from all walks of life, Tom has distilled a list of 13 traits that winners all share. Tom feels that the IMF staff, patients, and caregivers are the personification of these traits. He tells us that we are the "Eagles" that soar above the problems that the "Ducks" quack about...! Here are Tom's 13 Qualities Winners All Share: Discipline, Self-Confidence, Progressive, Decisive, Focused, Visionary, Lucky, Excels, Enthusiastic, Purposeful, Empower, and Spiritual. Tom made us all feel like "Eagles" (a bit tired, but still Eagles)! The evening ended with my husband, Michael Tuohy, playing a song that he wrote for our children and donated to the IMF entitled "I'm Not Leavin'."

On Sunday we wrapped up the weekend with Dr. Durie and Mike Katz providing us with an overview of osteonecrosis of the jaws in myeloma. This is increasingly recognized as a complication of bisphosphonate therapy. Based upon the responses to their web-based survey it was concluded:

- Duration of bisphosphonate use in myeloma and breast cancer is associated with increased risk of osteonecrosis (ONJ);
- 36-month estimates of ONJ are higher for Zometa versus Aredia;
- None of the other therapies analyzed were associated with increased risk of ONJ;
- Patients with prior dental problems have a higher risk of ONJ.

Please inform your dentist/oral surgeon if you are on bisphosphonates. For more information please go to the IMF website at www.myeloma.org.

David Smith, Vice President, Operations, ended the morning with updates on Bank on a Cure[®] and a preven-

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IMF AROUND THE GLOBE: ISRAELI ASSOCIATION OF MYELOMA PATIENTS

By Paula Azulai

The Israeli Association of Myeloma Patients, also known as AMEN, was founded to benefit the welfare of myeloma patients in Israel. AMEN's mission is to improve the quality of life of myeloma patients by being a centralized source of information about the disease, treatment options, and ongoing scientific research, as well as offering support in dealing with Bituah Leumi (Israeli Social Security), health insurance companies, and patients' rights. AMEN is dedicated to helping myeloma patients and family members cope with the impact of diagnosis and the ensuing issues. AMEN's Hebrew language website will offer educational content, including translations of IMF materials and publications.

On July 29, 2005, AMEN held the first meeting of the Israeli Myeloma Working Group, which was sponsored by Roche Pharmaceuticals. AMEN initiated the creation of the working group as a joint venture with the Israeli Society of Hematologists. Chairing the meeting were AMEN's Medical Advisor, Professor Aaron Polliack, and the head of the Israeli Society of Hematologists and Blood Bank, Professor Gil Lugassy. Invitations were sent to all the medical institutions in Israel that treat myeloma patients.

The Israeli medical community responded favorably – 29 representatives from the most important medical and research centers attended the meeting. Never before has there been a forum of this size addressing the issue of myeloma in Israel! Without a doubt, this can be seen as a breakthrough in the history of myeloma in Israel.

At the meeting, the participants addressed the following four topics:

1. Establishment of a registry
2. Establishment of a computerized database accessible by all medical institutions
3. Basic research
4. Clinical research

The registry and database topics were presented by Dr. Marilius (Zamenhoff Clinic) and Mr. Edelist (AMEN). The clinical study program was presented by Dr. Hardan



(left to right) Prof. Gil Lugassy, Mrs. Paula Azulai, and Prof. Aaron Polliack

(Tel Hashomer). The research program was presented by Dr. Cohen (Meir Center), Mrs. Neuman (University of Tel-Aviv), Dr. Gesundheit (Hadassah en Karem), Dr. Bullvick (Laniado Hospital), and Prof. Berrebi (Kaplan Medical Center).

Prof. Ben-Yehuda (Hadassa en Karem) was elected chairman of the Israeli Myeloma Study Group, Dr. Hardan was elected secretary of the group, and Dr. Marilius has been named its clinical research coordinator. The research group will be headed by Mr. Zion Katz (Ichilov Medical Center) who will organize scientists from the Weizman Institute, local universities, and medical research centers dealing with myeloma. Many other physicians registered to take part in the group's activities.

This forum has the power to create a new and better future for the myeloma community in Israel, and AMEN has made it a priority to raise the necessary funds to support the group as part of its mission to find a cure for myeloma. **MT**

EDITOR'S NOTE: AMEN was founded by Paula Azulai, a myeloma patient, who is now the chairperson of the organization. For more information, please contact Paula at appaul@attglobal.net or 0544-906635.

SOUTH FLORIDA'S DYNAMIC DUO: CINDY FELTZIN AND VICKI ANDERSON FERRARO

By Cindy Feltzin

I met Vicki in 2001 at a Wellness Community luncheon. Immediately, we had something in common... multiple myeloma. As a caregiver for my husband, Bob, I was taking a crash course in myeloma as Bob began his chemo (VAD) and radiation treatments.

It seems that every day I would have a new concern or question, or even a tearful moment, and I would find myself reaching out to the IMF Hotline. A cheerful voice would always welcome my call and respond to my needs. I didn't know it at the time, but I was already in training to become head cheerleader of the Miami Multiple Myeloma Support Group. The IMF had put me in touch with Ed Blumenthal. A caregiver, Ed organized a Miami support group and ran it until his wife passed away. But Ed still maintained a list of the group's past members. Together, he and I culled the list, made the phone calls, and welcomed the past members into a reorganized group, which Bob and I would run.

When Vicki retired from her position in the Federal Reserve, she had more time to help Bob and me with the Miami support group. In 2003, when Bob and I moved to West Palm Beach, Vicki took over the responsibility of running the Miami group. Vicki's professional expertise and leadership skills have helped this group to reach a new level of excellence. She writes a very detailed monthly newsletter and stays in touch with her members by phone and email. And she always has a hug to welcome each person at her meetings. I am thrilled that the Miami group is in such capable hands.

As Bob and I settled into our new home, our passion for MM education continued. Committed to starting a myeloma support group near our new home, we began to collect names of South Florida patients. On May 6, 2005, with the invaluable assistance of Millennium Pharmaceuticals representative, Rick Sulak, we put the group on the map!

Rick helped secure our first speaker, Joe Tarriman, RN, and we had 30 people gather for our group's first meeting! When Vicki secured Maureen Carling, RN, to speak to the Miami group, Bob and I offered to provide Maureen with transportation and lodging if she would



agree to expand her visit to cover both support groups.

Our group's focus is to empower myeloma patients and caregivers with as much support, information, and education as possible. I am happy to offer encouragement and Bob is very good at handling calls and emails that are too technical for me. We have formed relationships with a number of people strictly via phone and email, and we consider them to be full-fledged members of the group. As winter approached, we have welcomed a number of "snowbirds"* from other parts of the country to our group, and I encourage all members of the myeloma community to join us when they come to South Florida.

NOTE: Cindy and Bob Feltzin can be reached at felcinbob@aol.com or 561-624-8888.

By Vicki Anderson Ferraro

My entire working career was with the Federal Reserve Bank. From the mid-1990s until I retired in 2003 I served as an official in the Retail Payments Office of the Federal Reserve System, with responsibility for the Automated Clearinghouse (ACH) product development function. It was an exciting, one-of-a-kind job that required extensive domestic and international travel and there was intense pressure and lots of long hours.

In 1999, after being anemic for a long time, my primary care physician referred me to a hematologist. I was told that I had MGUS. Although the doctor said that he wanted me to have a bone marrow biopsy, I just never got around to doing it because I was traveling so much. Several months later, I became very ill while out of the country on business. When I returned to the US, I went to the emergency room, with extreme fatigue

Education, Advocacy, and Awareness

and back pain my primary complaints. I was diagnosed with Stage 3 multiple myeloma. After a few days in the intensive care unit and several more days in the hospital, I returned home to recuperate.

I took a two-month leave but, being a workaholic, I couldn't wait to get back to the office. I wasn't going to be a "sick person" or let myeloma interfere with my life. In retrospect, getting back to work helped me cope with the diagnosis and prognosis of an incurable cancer. (Of course, now I have outlived all the statistics that I was quoted at the outset!) During this time, a friend had encouraged me to contact the IMF. I found the IMF staff very caring and helpful and the information and assistance that the IMF provided was invaluable.

Facing a range of treatment options, I decided against having a transplant. From my research, I learned that thalidomide was being used with some success on refractory patients that had failed all other treatments. I convinced my doctors to let me try thalidomide as frontline therapy



and it worked very well for me for several years. In late 2002, my myeloma began to slowly progress and I realized that

although I loved my work, the stress of long hours and constant travel were having an adverse effect on my health. It was a very difficult decision but in February of 2003 I began an extended leave of absence, which eventually led to retirement.

When I was first diagnosed, the IMF helped me locate a myeloma support group, but it met in the afternoons so I was unable to attend meetings due to my work schedule. The support group leader, Ed Blumenthal, kept in touch with me via telephone and mailed me a wealth of information. The group eventually became defunct but, in mid-2002, I received a flyer from the IMF announcing a new myeloma support group that was forming at the local Wellness Community.

I first met Cindy Feltzin at an educational event sponsored by the Wellness Community. Cindy sought me out to tell me about her efforts to start a myeloma group in cooperation with Ed and the Wellness Community. She

was so dynamic and passionate about obtaining knowledge related to myeloma, which included traveling to many seminars and speaking to experts about the disease. I liked Cindy immediately and wanted to provide any assistance I could. When Cindy and Bob moved to West Palm Beach in April 2003, I assumed responsibility for leading the Miami support group.

The mission of our group is to provide education, hope, and support in a caring environment to myeloma patients, family members, and friends. My initial goal for the group was to have at least 10 people attend each meeting. By the end of 2003, we far exceeded that goal and were averaging 20 people per meeting. There was a core group of regular participants and friendships began to develop. Everyone had a different story with myeloma but we were able to share experiences and offer support to one another, both in person and on the phone.

Every support group has a personality. Our group is a family. I want everyone who joins us to feel welcome, to feel safe, and to feel very hopeful. The Wellness Community has provided us with a wonderful meeting environment and an outstanding facilitator, Mae Greenberg. The local Millennium Pharmaceuticals representative, Norma Ortega, has been extremely supportive and has significantly contributed to the success of our group. She is personally engaged in my annual planning process. Based on feedback received from our members, we develop a draft agenda for the year that is reviewed and approved by the members. Norma and Millennium have generously assisted our group by bringing in excellent speakers and sponsoring refreshments for the meetings, which take place the 4th Wednesday of every month from 6 to 8 PM.

I am very grateful for the many wonderful relationships that have formed as a result of the Miami support group. Sadly, last



year we experienced our first losses and we still feel the void left by several long-time members. I am delighted that their spouses still attend meetings on occasion. I keep in touch with them and assure them that they will

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IMF AROUND THE GLOBE: THE GREATER MONTREAL MULTIPLE MYELOMA SUPPORT GROUP

By Aldo DelCol

As The Greater Montreal Multiple Myeloma Support Group approaches its first anniversary, it is encouraging to review the progress that the group has made since our first meeting in November 2004.

Over three years ago, when I was diagnosed with multiple myeloma, I felt frightened and all alone. One of the first things I did was to look for a local support group. Having many questions and a thirst for knowledge, I desperately wanted to learn from other patients' experiences. Alas, no myeloma support group existed in Montreal at that time. Thankfully, the Internet led me to the International Myeloma Foundation. The IMF was the inspiration and motivation for the founding of the Greater Montreal Multiple Myeloma Support Group.

In the Fall of 2004, when I decided to take the initiative to form a myeloma support group in Montreal, serendipity stepped in to provide the necessary momentum. I knew that I needed to work with a team that possessed specific skills: communication, public relations, legal knowledge, accounting, web design and, of course, translation – remember that Montreal is a bilingual city! Through a unique set of circumstances, all these resources came together and the group quickly took shape. Our website was created thanks to the financial assistance of Ortho Biotech. The support group was incorporated as Myeloma Canada, a federal non-profit organization. We created a flyer and began to spread the word to hospitals and clinics.

The first meeting of the Greater Montreal Multiple Myeloma Support Group took place on November 2, 2004. The gathering drew fifty participants, including patients, caregivers, and healthcare professionals. Given the success of the inaugural meeting, we decided to organize a Patient & Family seminar, with the encouragement and support of the IMF. This was no small

task. We had to find a venue, secure top-notch speakers, arrange for simultaneous translation, build an on-line registration site, and find a camera crew. Of course, the most challenging task was to get the members of the local myeloma community to come out in great numbers to this educational event.



When I was told that an audience of 80 people would be considered a good turnout for such a seminar, I thought this a daunting objective. But the support group members worked

hard in promoting the event and, once again, serendipity came to our rescue. I received a phone call from one of Montreal's leading myeloma specialists, the head of a stem cell transplant unit, enquiring about the group and offering his assistance. He assisted us in promoting the seminar not only to the patients but also to the nursing staff and social workers at his hospital. An article in the Montreal Gazette about our support group prompted even more interest and we quickly reached the maximum occupancy of the meeting room: 150 people.

The seminar attracted people from as far as six hours away by car. The speakers covered subjects such as the basics of myeloma, coping with fatigue and depression, stem cell transplantation, and novel therapies. The faculty consisted of myeloma specialists, researchers, a symptoms management nurse, and a psychologist specializing in psychosocial oncology. Each of the speakers was associated with a university and practiced in a teaching hospital. We were also very fortunate to have Susie Novis and Dr. Brian Durie lend additional "star quality" to the seminar.

Besides the educational presentations, the seminar also offered information on the Bank On A Cure research initiative. Thanks to IMF's David Smith, plenty of "swish and rinse" kits were available and we managed to collect more than 40 samples from Canadian myeloma patients.

CONTINUES ON NEXT PAGE

Education, Advocacy, and Awareness

I am very proud of what the Greater Montreal Multiple Myeloma Support Group has been able to accomplish since its inception. Although we are still faced with the challenges of expanding the group in Montreal and across the province, as well as locating a permanent home for our meetings, we are moving forward with an ambitious plan for our second year. In addition to finalizing the speakers and topics for our group's regular meetings, we are also planning the second Montreal Patient & Family Seminar for 2006. Another objective is to mobilize the 13 support groups across Canada to come together to create a fully functional national organization to serve the particular needs of the Canadian myeloma commu-

nity. Already, an agreement in principle has been reached on the structure and regional representation, and we are preparing to elect the Board of Directors and begin the task of developing a business plan.

In closing, I would like to thank the Montreal Executive Committee, whose talents and dedication were instrumental in helping make this dream a reality, as well as the entire team at the IMF whose insight and encouragement continue to sustain the dream. **MT**

Editor's Note: For more information, please visit the website www.myelomacanada.ca or you can email Aldo DelCol at adc@videotron.ca.

SIXTH ANNUAL — continued

tion grant from the Centers for Disease Control. Bank On A Cure is the first international cooperative DNA bank for genetic analysis – to allow physicians to better understand patient treatment response and to find a cure. Bank On A Cure now has thousands of samples “in the bank” and the IMF held a formal launch in NYC on May 9th with Geraldine Ferraro. If you are interested in participating in Bank On A Cure, please contact David at dsmith@myeloma.org or 800-452-CURE (2873). As for the Centers for Disease Control prevention grant, it is a three-year initiative to fund educational outreach that targets specific underserved populations who are at high risk for hematologic cancers. It is up to each of us to help spread the word! We can do so by reaching out to African-Americans, the elderly, the uninsured,

and the under-insured. The IMF has made available on our website a video, brochures, and information. Again, please contact David if you are interested in this outreach program.

As the weekend came to a close, we were invigorated, inspired, and ready to go back to our groups and share our experiences. I wholeheartedly encourage each and every group leader, whether you are facilitating a new group or an established group, to attend next year's Retreat. I guarantee you will not only learn more about this disease but the friendships that you will form will be invaluable. Please keep an eye out for next year's invitation to the Retreat and sign up early to attend. Remember, Knowledge is Power! **MT**

SOUTH FLORIDA SG — continued

always be a part of our group. We continue to welcome new members and I am encouraged that we have had at least one new attendee at each meeting for the past few months.

My husband Dennis and I have become good friends with Cindy and Bob Feltzin. Last year, the four of us traveled to Los Angeles together to attend the IMF Gala and take in some sights. Cindy planned a whirlwind of activities while we were there and we had a fabulous time. Cindy and I also work together to support and promote each other's groups. One successful strategy that we pursue is to share speakers when possible. The

Miami group meets Wednesday in the evening and the Palm Beach group meets on Thursday afternoon, which has allowed us to invite speakers to address both support groups on consecutive days. Cindy and Bob are very gracious hosts, and they have even provided transportation from Miami and opened their home to speakers. Like Cindy, we welcome visitors and encourage all myeloma patients, family members and friends to attend our meetings if they are in town.

NOTE: Vicki Anderson and Dennis Ferraro can be reached at vickiaferraro@bellsouth.net or 305-665-8284.

2005 Robert A. Kyle Lifetime Achievement Award

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2005 Robert A. Kyle Lifetime Achievement Award

IMF HONORS KENNETH C. ANDERSON, MD

By Candace McDonald

The International Myeloma Foundation (IMF) honored Kenneth Anderson, MD, with the Robert A. Kyle Lifetime Achievement Award on Sept. 27, 2005 at the Harvard Club in Boston, MA. Anderson is the director of the Dana-Faber Cancer Institute's (DFCI) Jerome Lipper Multiple Myeloma Center and the Kraft Family Professor of Medicine at Harvard Medical School. Dr. Anderson was selected for pioneering critical advances against multiple myeloma, leading not only to improved treatments but also to a deeper understanding of how myeloma occurs at the basic level of cells and genes.

Featured speakers at the event included Edward Benz, M.D., president of the DFCI; Robert Kraft, owner of the NFL's New England Patriots; and the Honorable Geraldine Ferraro, myeloma patient and advocate; among others. The Master of Ceremonies was Steve Burton, a local Boston sports newscaster.

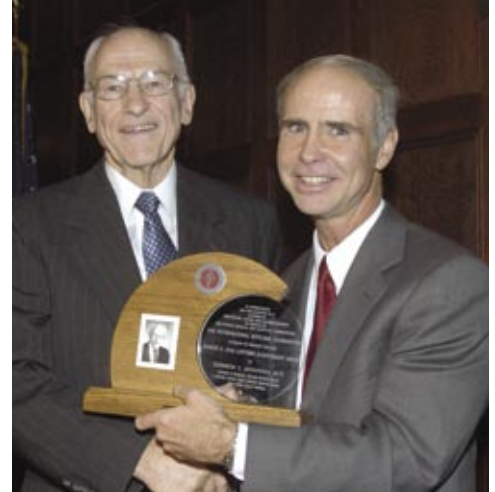


Speaker Honorable Geraldine Ferraro



Robert A. Kyle, MD, IMF Chairman of Scientific Advisory Board, Susie Novis, IMF President, Brian G.M. Durie, MD, IMF Chairman of the Board

“Ken’s work in the field of myeloma has helped raise awareness of this disease,” said Susie Novis, IMF president. “His lab is one of the leading institutions moving myeloma research forward and, for that, we are proud to present him with this award.”



Robert A. Kyle presents Kenneth C. Anderson with the Third Annual Lifetime Achievement Award.

The IMF established the Robert A. Kyle Award to honor an individual whose lifetime body of work furthers the ultimate goal of finding a cure for myeloma, and is named after noted physician and founder of the Myeloma and Related Diseases Research Group at the Mayo Clinic in Rochester, Minn.

“It is a great honor for me to follow in the footsteps of Bob Kyle, a giant in myeloma research, role model, and dear personal friend,” said Anderson in accepting the award. “It was a wonderful and



Kenneth C. Anderson, MD and the Honorable Geraldine Ferraro

loving celebration of researchers, clinicians, supporters, companies, and most importantly patients and their families, all working together to give hope and health to myeloma patients everywhere.” **MT**

ROCKING IN RHODE ISLAND

By Jason and Matthew Rossi

Our mother, Carol Murray-Rossi, was diagnosed with multiple myeloma in 2003. But her personal struggle with this disease did not stop her from looking for ways to reach out and help others fighting myeloma. In April of 2005, she started the first myeloma support group in the state of Rhode Island.

It was time for us to step up and do our part. With the help of friends and family, we worked for months to prepare for the Rocking in Rhode Island party to honor our mom and to raise funds to benefit the International Myeloma Foundation. Our efforts paid off – August 27th was a night to remember!

Local businesses donated many raffle prizes, including salon and spa treatments, surfing lessons, restaurant dinners, theatre passes, and liquor store and grocery gift cards. Our friends helped prepare food for the event and make a huge piñata. A tree-lined yard was transformed into a great party environment, with outdoor “rooms” full of furniture set up on the grass and dining tables decorated with beautiful flowers. Large projection screens

showcased photos and film clips. Guests purchased tickets for drinks, raffle prizes, and fun contests – a dunk tank was rented for the evening! An outdoor bar was built, and a life-sized cardboard cutout of Austin Powers was set up to help tend bar. Our “bartender” was even equipped with recorded messages to greet the guests. Groovy, baby!



Jason Rossi, Austin Powers,
Carol Murray-Rossi

This most dreadful disease managed to bring out the best in everyone who attended. As we celebrated our bonds of love and friendship, and our common commitment and determination

to win the fight against myeloma, the Rocking in Rhode Island event succeeded in raising \$1,587 to benefit IMF programs and services while it also served to raise awareness of this disease.

The event was a group effort and we greatly appreciate the assistance we received from so many supporters. Special thanks go to Andy Unger and Jeremy Furtado for their hard work and dedication, and to the IMF for all they do for the myeloma community! **MT**

KATIE'S BIRTHDAY CHARITY BASH

By Julie Smith

My mother, Frankie Reinhardt, was diagnosed with osteoporosis in August of 2004. She was 55 years old. Mom had always taken good care of her health, lifting weights at the gym three days a week and playing tennis. As her back pain progressed over the next two months, the doctor ran more tests and the diagnosis was changed from osteoporosis to multiple myeloma.

I did my best trying to explain the diagnosis to my children. At 11, 4, 3, and 2 years old, all four were extremely close to their grandmother, enjoying regular playtimes and overnight visits with their “Nana.” I told them that Nana had a disease in her body, and that the doctor advised that she would no longer be able to lift them up.

My eldest daughter, Katie, had a particularly close relationship with Nana. For six years, she had been my mom’s only grandchild and the two of them were the best of friends. As

Katie’s birthday approached, she came to me with an idea of how she wanted to celebrate. In lieu of birthday gifts, Katie asked her friends to honor her grandmother by donating money to help cancer patients. Katie’s birthday was turned into a surprise party for Nana, as well as a fundraiser for the IMF’s myeloma research program. At “Katie’s Birthday Charity Bash,” Katie and her friends were able to raise \$1,400 – a big feat in a small town!



Julie Smith, Frankie Reinhardt,
Katie Smith

I am very proud of my daughter and her friends, and grateful that Nana lived long enough to participate in this joyful celebration.” **MT**

NUMBERS DON'T LIE, OR DO THEY?

By Robert J. Heller

In the business world we're often told that Figures Don't Lie, but that Liars Can Figure. While that may be true in some scandalous incidents of corporate wrongdoing, we who are cancer advocates also know that while medical statistics don't lie, that they don't always portray the picture in a way that is most meaningful to the average patient.

My wife, Phyllis, was diagnosed with advanced (Stage IIIB) multiple myeloma in May 2003. The attending oncologist told her at the very first meeting that the 2-year overall survival (OS) rate was 40% and the 5-year survival rate was only 20%. To have the prognostic stats presented in such a manner was devastating. I was fairly good in math when I was in high school and although I can't remember a cosine from a tangent, I can rationalize what 40% means as a part of a whole.

So I tried to explain to Phyllis that what she was being told was a simplification of the survival statistics that amounted to an arithmetic mean average. She was distressed, assuming that 4 out of 5 myeloma patients would die within five years and that her chance of surviving more than 5 years was but 20%. It was then that I explained that these numbers took in all patients who ranged from very ill when diagnosed, to those who were only slightly ill. It included patients of differing age, physical status prior to diagnosis, and additional complications and prior conditions.

When you look at the raw data you see a continuum from those dangerously ill and previously undiagnosed patients who may expire within a matter of months, to those who have been diagnosed, treated, and have survived 10 or more years. In the case of my wife, she had been a gym rat five days a week for more than 10 years prior to diagnosis. She was in excellent condition -- other than the myeloma -- and had no other complications that we knew of. So, I tried to explain that she had a lot going FOR her. She had a hard fight ahead, but she COULD win and WOULD win.

As I learned more about myeloma, I did become aware that some prognostic indicators may augur well or not so well. A chromosome-13 deletion or Bence-Jones protein prominence may be unwelcome. The blood panels and chemistries may point to strengths or weaknesses. The Kappa/Lambda light chain ratios may portend trouble, although these are undoubtedly the most difficult of all factors for us mere mortals to understand.

What we in the myeloma community need to do is keep our minds concentrated on the fight. We can know one thing intellectually yet work on another model subjectively. For most of us, fighting myeloma is like getting into the ring with a professional heavy-weight boxer. We ask ourselves:

How long will the fight last? How badly beaten up will we get?

But, while that intellectual model may seem depressing, we need to remember that the professional fighter is just using his same old tricks and that WE have an army of trainers and supporters working to help us beat the odds. That's what clinicians, researchers, and organizations like the IMF are working so hard for. And we in the myeloma community owe it to ourselves and to each other to keep on fighting. Don't get freaked by grand scale statistics. They don't apply to everybody. As a matter of fact, no statistic applies to an INDIVIDUAL patient.

We didn't ask for the fight. But we're in the ring, so we are going to give it our best shot. Phyllis has beaten the 2-year OS. In August, we celebrated our 50th Anniversary. Now, we are thinking about what we want to do for our 55th. We remember the words of Dylan Thomas: "Do not go gentle into that good night./ Rage, rage against the dying of the light." **MT**

EDITOR'S NOTE: After a year of helping his wife fight myeloma, and compiling extensive notes on the disease, Robert Heller wrote *Multiple Myeloma: The plain English Handbook for Patients and Care Givers*, in the hopes that it may be of help to others on their journey through myeloma. Bob can be reached via email at morewords@comcast.net.



ONE DAY AT A TIME... FOR 18 YEARS

By Carole Levis

I was born in Pennsylvania, and I have lived here all my life. I raised my daughter, Deborah, and son, Kelly, as a single parent. To support the family, I worked two jobs. During the day, I worked in an office. I would come home to have supper with my children, then head off to my second job as a banquet waitress. When I turned 38, I decided to go to cosmetology school and, when I completed the course of study, I got a part-time job doing that. Back then, things were really tough, but we managed to make it through.



In 1987, when I was 43 years old, I started experiencing severe pain in my shoulder blade. The pain was attributed to muscle spasms. But when I started having trouble turning my neck, and losing control over my arms and hands, I traveled to a neurosurgeon in Pittsburgh for an evaluation. On December 3, 1987, I was told that I had a plasmacytoma wrapped around my spinal cord at the C7 vertebra of the neck. I was given 5 years to live, a common statistic. That's when I said, "I don't live by statistics. I live by the hand of God."

I had never heard of multiple myeloma. There were no support groups in the small rural area where I lived. I felt very isolated, and had to gather information wherever I found it. But I never asked why – I only asked for the strength to carry me through the challenges I was facing. The night before the surgery to remove my tumor, the doctor warned me that I might be paralyzed after the procedure. But I was lucky and, after most of the tumor was successfully removed, I only needed to wear a neck brace for six weeks while undergoing radiation. I was able to achieve remission. That was a blessing.

In 1989, after about two years of remission, my oncologist recommended a procedure that he called my "insurance policy" in case the disease came back. I was definitely interested, but my insurance company would not cover bone marrow harvesting. My second husband and I fought and eventually prevailed in having the procedure covered by insurance. I had 50 holes drilled in each hip for a total of 100 aspirations.

In May of 1992, my second husband died in my arms of a heart attack. He was 55 years old. We had no idea that there was a problem with his heart. I brought him back once with CPR but then lost him again. In the ambulance, he came back once more but, by the time we arrived at the hospital, he had passed. It was a very traumatic time. Shortly thereafter, I started experiencing bone pain again, but the tests did not show any active disease. About two years later, in 1994, I bent over a bathtub and my pelvis fractured. After a total of 8 years in remission, I was facing aggressive myeloma. It was time to use my "insurance policy."

However, by this time, my bone marrow had been frozen for over 6 years – and frozen marrow was only known to last for 3 or 4 years! – so we were not certain if the marrow that would be transplanted could still do its job. After the transplant, I was in isolation for 25 days, facing a difficult recovery and an uncertain future. To make the most of my time during my hospitalization, I put my cosmetology skills to use, working on wigs for cancer patients. I also hosted a Superbowl party for the doctors and nurses at the hospital. I was too busy being sick to eat the pizza and chicken wings that I had brought in, but I was happy to see the staff enjoy themselves! It was a difficult time but I tried to make the best of it.

In January 1995, when it came time to have the second transplant, they had to drag me back kicking and screaming. I still hadn't yet recovered from the first transplant! But I was told that two transplants would be more beneficial and, eventually, I consented. The second transplant was much harder on me than the first. After 21 days in isolation, I came home from the cancer center only to find myself back at the local hospital, packed in ice to bring down a high fever. I vowed that if I would just be given the strength to make it through, I would give back of myself in any way I could. Within an hour, my fever broke, and I was home shortly thereafter.

Since then, I have been working on wigs for cancer patients. Helping women look good while battling cancer helps them feel more comfortable and less isolated. Every time I help someone with her hair and makeup, and I see a smile... that's a blessing to me. I also try to offer support on the phone and via email. Occasionally, I get requests from the cancer center to come in and talk with a patient who's having a hard time, and I am more than happy to help. Perhaps because I felt so alone when I was first diagnosed, I am absolutely obsessed with helping others.

Every day of my life consists of something that has to do with cancer. It's become a way of life. But the key word in that sentence is "LIFE." I look at my disease as an inconvenience. But that's not the way it's always been for me. I remember coming home one day, ripping off my wig, and just tossing it! The wig landed on the ceiling fan, and I laughed until tears ran down my cheeks. Another time, while I was on a date on a golf course, the wind grabbed my wig. I started chasing the wig as it flew and bounced all around the course. (In the meantime, my date was such a gentleman that he just kept hitting those balls like nothing happened.) After I finally caught the wig, I called the beauty shop to tell them the story. I started laughing, and everyone at the salon started howling with laughter. Sometimes you just have to find the humor in these things!

My second remission lasted for about 8 years, just like the first, but the myeloma relapsed once again in January of 2005. In May, I started four cycles of Doxil and VELCADE. I am now pain-free and my energy is slowly coming back. I have been fortunate to work with a team of wonderful doctors and nurses. But, from my experience, I would say that the most powerful tool in a cancer patient's arsenal is the mind – when your body is beaten down physically, you can push your mind to keep you strong mentally while you face the challenges life has given you.

Over the past 18 (almost 19!) years, I've been sliced, diced, hacked, whacked, chemo'd, and radiated so as to glow in the dark, yet I feel lucky and blessed in so many ways. When I was first diagnosed, my grandson was 4 years old, and my goal was to live long enough to see him graduate from high school. He is now in law school. When I was diagnosed, my granddaughter had not yet been born. She is now 10 years old, and my goal is to be around to see the woman she becomes!

When I found the IMF, I really wanted to attend one of its Patient & Family seminars, but there was never one close enough to me. So I became involved with the myeloma ListServ and joined the online chat group. This year, when a friend volunteered to drive me to the IMF meeting in Baltimore, I found myself in a room with over 200 others whose lives have been touched by myeloma. I am just a regular person, taking life one day at a time, so I was very honored to be asked to join the seminar's Patient Panel, and grateful for the opportunity to offer encouragement to so many patients who are trying to cope with grim statistics. In turn, the many wonderful people I met, both patients and seminar faculty, gave me great hope for a brighter future. There are so many strides being made in the field of myeloma that I look forward to the day when I can say, "I used to have a cancer called multiple myeloma." **MT**

Editor's Note: If you wish to contact Carole, she can be reached at 814-372-2428 or via email at meemmaw@webtv.net.

4TH ANNUAL MMAMM BENEFIT KEEPS LEE GRAYSON'S MEMORY ALIVE

By Jenna Kern-Rugile

Sitting above a set of French doors inside Tupelo Honey, a landmark restaurant in the funky little town of Sea Cliff, Long Island, is a charming mosaic depicting a guitar-playing frog. The scene evokes smiles for the legions of fans who spent many Monday evenings listening to the music of Lee Grayson, the inspiration for the colorful mosaic. Lee had a true passion for the Muppets, and had adopted Kermit as his virtual alter ego. That's largely because he admired in the Muppet character the same things that others loved so much in Lee: his gentleness, quirky humor, and great sense of curiosity about the world.

After a nine-year battle, Lee succumbed to multiple myeloma in the fall of 2002, at only 55 years old. His signature song, the Muppets' "Rainbow Connection," was sung by all who attended his memorial. It was a bittersweet moment, as friends bid good-bye to a loving, talented man who is still sorely missed today.

Grayson's song, however, rang out loud and clear on July 17, 2005, a sultry New York day, as Tupelo Honey once again hosted "A Lee Grayson Production: Multiple Musicians Against Multiple Myeloma (MMAMM)." This year marked the fourth annual MMAMM concert, which benefits the International Myeloma



Foundation by raising not just money, but also hope, support, and awareness.

The tradition began on another steamy July day in 2002, when Lee gathered his large group of friends from Long Island's musician community to perform at the first MMAMM benefit. It was an enormous effort for a man struggling in the latter stages of myeloma, making its success even more remarkable. Every year since, Tupelo Honey has served as host of the MMAMM benefit, where musicians lend their talents in celebration of their friend Lee, and in an effort to help eradicate the disease that took his life. The event serves as a fitting legacy for Lee, who spent many hours visiting (in person or by phone) with other myeloma patients, lending a loving ear and helping hand.

"In the first year of the benefit, everyone came to support Lee, rallying around someone they loved so dearly," recalls Naomi Margolin, Lee's girlfriend and the driving force behind the last three benefits. "Now, people who never heard of him travel many hours to come to the benefit, because there are so few events like this."



Lee, who never had children, or a hit song, or huge record deal, worried that his life would leave no mark on the planet. But those who knew him, and

Member Events

even those who never had the blessing of knowing him, feel his presence each year at MMAMM. “Ask anyone who’s come to any of the benefits, and they all tell the same story,” says Naomi. “People can’t get over the healing energy, the support, the love that’s in the air. That’s what Lee left behind. That was Lee.”

The musicians, restaurant staff, and all the other volunteers – close to 100 people altogether – freely give their time to honor their friend and help raise funds for the IMF. Tupelo Honey and its manager, Willie Stephens, donate all the proceeds from the event to the IMF, while the Village of Sea Cliff lends a hand by closing down the street for the day, making the benefit not only a concert but a street fair, with face painting, drumming circles, and auctions. Profits from MMAMM have grown each year, with this year’s total at more than \$18,000, but its real benefits extend far beyond the financial ones.

“Part of what I love so much about this event is that, while most fundraisers are about making money, this one is about raising awareness,” says Naomi. While expensive dinners or golf outings are the norm for many benefits, MMAMM costs \$20 (a suggested donation) for an entire day of music, conversation, information, and connections.

“I spend more than half the day introducing patients and their families to each other,” notes Naomi, who hopes to have a special tent set up at next year’s benefit for patients to network and possibly meet with an IMF representative.

This year, those people included the Tuohy family, who drove several hours from Connecticut not only to attend the event but to lend their talents. Michael Tuohy, a



myeloma patient and musician, played his song, “I’m Not Leavin’,” which he wrote after his stem cell transplant in 2002. “It was our first year at the Multiple Musicians Against Multiple Myeloma event, and we were amazed at the amount of people and activities,” says Michael’s wife Robin, who heads up a local support group. “Everyone was there for a cause, but it was more than that: It was fun and contagious and inspiring. What a beautiful and lasting tribute to Lee!”



Manhattan resident, and myeloma patient, Myrna Shinnbaum was particularly moved by Michael Tuohy’s performance, and spoke to the father of three after he sang. “He said that nothing would stop him from enjoying his life, and that he is a fighter,” says Myrna. “He went through all the treatments and is still here to tell about it through his music and his songwriting.” Myrna was introduced to many other myeloma patients, and met with an IMF representative who told her about the foundation and its programs, such as patient seminars and myeloma support groups. “I had the greatest time,” says Myrna. “The music was incredible. You could not stop moving

PLEASE SEE MMAMM BENEFIT NEXT PAGE

Member Events

MMAMM Benefit — continued

your feet, clapping your hands, and wanting to dance in the aisles. It was like being at the best open air concert.”

Bob Romanoff, a Long Island resident who was diagnosed with myeloma about four years ago, found out about the benefit through an ad in the local *Pennysaver*. He'd never heard of the IMF before, or of MMAMM, which, ironically, had been held for years just minutes from his home. Now, he has the full support of the IMF and its many resources, plus the friendship and support of other patients he met that day.

This year, one regular MMAMM attendee was sorely missed. Sol Finkelstein, father of musicians Steve and Lee, attended the first two benefits in 2002 and 2003, but was too ill to make it the next year. “I held up the phone so everyone could yell, ‘Get Well Sol’ to my Dad, who was in the hospital at the time,” says Steve, one of Lee’s closest friends. Sol passed away several months before this year’s benefit took place. “Lee helped so much when my Dad was first diagnosed with myeloma five years ago,” says Steve. That’s one reason Steve was so moved by an addition to this year’s event: “Naomi hung a sign behind all the musicians that read ‘Sol Finkelstein Memorial Stage,’” says Steve. “It brought tears to my eyes and joy to my heart.”

Steve’s eight-year-old daughter, along with her cousins and friends, got into the act this year, selling candy and carrot sticks (the candy sold better). “They raised more than \$100!” says Steve. “It was just another amazing part of the day, which is such a positive celebration of life. It’s a great way to gather people and increase their awareness about this horrible yet little-known disease.”

Indeed, many people who attended the event and learned about myeloma for the first time ended up there virtually by accident. “People who happened to be driving by stopped out of curiosity to hear the music and see what all the activity is about,” says Naomi. “They got



information about the disease, and the work of the IMF, and then spread the word.”

Spreading the word about myeloma became a passion for Lee Grayson in the years after his diagnosis. At one time, Lee summed up the devastating effects of the disease succinctly, stating, “Myeloma Sucks.” Each year, Naomi makes sure that a bucketful of pins with that expression (and Lee’s attribution, of course) are handed out to MMAMM attendees.

“This year, when the IMF emailed support groups offering the remaining pins, it was inundated with requests from all over the world,” says Naomi. Although people often offered money for them, she was happy to send them for free. “I want this event to be about covering the world with these pins, to help get the message out,” says Naomi. “Raising money is great, but raising awareness is what will foster the research and support to find a cure.”

One day, when a cure does come, Lee Grayson will stand as a warrior who, though he lost his personal battle against myeloma, helped win the war for those who came after. And that’s a mighty powerful legacy. Here’s to you, Lee. **MT**

GARY C. HEUER, JR. MEMORIAL GOLF TOURNAMENT

By Nancy Heuer

The 4th Annual Gary C. Heuer, Jr. Memorial Golf Tournament was held on Saturday, September 10, 2005. The weather cooperated fully – it was a glorious day! The 140 golfers started out the



Tom DeMarco, Vicki Whiteside, Kevin Cappotelli, Steve Cappotelli

day's activities with breakfast at Craigie Brae Golf Course in N. Chili, NY. Following the exciting 18-hole tournament, the event's participants gathered for a chicken barbecue at Freeman Park in

Mumford, NY. The tournament was a great success, raising more than \$5,000 to benefit the International Myeloma

Foundation. Our deepest thanks go to all the sponsors, golfers, friends, family, and members of the business community who contributed to the success of this event. Join us again next year – the 4th Annual Gary C.



Back Row: Kim Strathearn, Dawn McCullough, Missy Osborne
Front Row: Gretchen Bailey, Bobbi Jo Seaman, Tammy Keroack

Heuer, Jr. Memorial Golf Tournament will be held on September 9, 2006. **MT**



Ian Rowland, Jerry O'Donoghue, Matt Loughry, Scott DiLiberto

SHOPPING FOR THE HOLIDAYS AND THE CURE

Yes, it's that time of year, when we're all looking at the calendar and counting up how many more shopping days we have left until Christmas or Hannukah. Here's a way to make your already busy life less hectic. Just visit the IMF website at www.myeloma.org and order the gift you want! Clicking on the "Helping the IMF" tab, then select "Shop For The Cure" on the left side of your screen. Shopping opportunities include retailers such as *Barnes & Noble*, *Amazon.com*, *buy.com*, *FTD.com*, and *1-800-Flowers.com*, *Lands' End*, *Macy's*, *Sharper Image*, and *Walmart*, just to name a few. When you access these retailers through the IMF website, a portion of all monies spent goes to benefit the IMF! Not only will you be saving money on gas by not driving from store to store, you'll be helping to raise money for myeloma. Then click on the "Events" tab and scroll down through the items that are designed by our IMFers, such as Pam Larsen's beautiful personalized key chains and earrings, Multiple Colors For Multiple Myeloma, or Kristi Difford's gorgeous personalized jewelry. You'll also find scenic cards designed by Irma Catlett and wine bottle "vests" for dressing up that holiday gift. And of course, there are the multiple myeloma wrist bands, which you can tie into your package ribbons, and the Ribbon of Hope pin for giving the gift of hope. So start early, avoid the crowds while shopping from the comfort of your laptop, and be the first in your neighborhood to cross all those gift items off your list!



IMF Board Member Interview

INTERVIEW WITH BENSON AND CAROL KLEIN

How did the two of you meet?

Carol: We met in college. We married after I graduated in the Summer of 1968. By that time, Benson had just finished his first year of law school. In 1969, our daughter, Lori, was born. Leanne was born in 1972. Benson finished law school and went into practice. I taught elementary education and got involved with volunteer work. Our youngest daughter, Sarah, was born in 1980.

When did multiple myeloma enter your lives?

Benson: Since the early 1990s, I've had a problem with my lower back. In 1997, I had a fall while playing tennis. The orthopedist took an x-ray, which revealed nothing, and told me that I must have pulled a muscle. In 1998, I met a friend for lunch and he didn't like the fact that I was still in pain. Fred Smith, who happened to be an oncologist, insisted that I see a different orthopedist and have an MRI. Fifteen minutes after I left the radiologist's office, Dr. Smith called and asked me to stop by his office. This was in April of 1998, and we were packing to take Sarah to visit the college that she would later attend. I stopped by to see Dr. Smith on the way to the airport and learned that the MRI had revealed a tumor on my spine. He thought that it was multiple myeloma. We were devastated but needed to stay upbeat for Sarah's sake.

When was the diagnosis confirmed?

Benson: Everything happened on a very fast track. The day we returned home, I had a CT scan, which confirmed Dr. Smith's diagnosis. The next day, I saw a radiation oncologist. The following day, I started radiation on the tumor. We held family meeting, then we informed our friends, and then I shared the news with my office staff. Everyone was very supportive. I put together a team of doctors, and traveled to the Dana-Farber Cancer Center for a consultation. There, I met one of my favorite people, Deborah Doss, RN, OCN. We decided to proceed with the Dana-Farber protocol, under the auspices of Dr. Smith.

How did you educate yourselves about the disease?

Benson: Carol did a lot of research. I did not want to know any of it. That's what doctors are for! As a lawyer,

when I represent a client, I do not expect them to learn how to handle their case. I did try to do some reading about myeloma but when I got to the part that average life expectancy was only 3 years, I stopped reading.



Benson and Carol Klein with their grandchildren

What treatment did you receive for your myeloma?

I received three rounds of VAD, followed by TBI (Total Body Irradiation). In December of 1998, I had the transplant at Dana-Farber. Back then, going through a transplant was rougher than it is these days. One day, two of my doctors flew up to Boston to see me. I thought that was

the greatest house call in the world! Later, I found out that they came because they weren't sure that I was going to make it.

Carol: But Benson never lost his sense of humor. He has always tried to have a very positive outlook. Cancer did not change that.

How did you find the IMF?

Carol: I found the IMF on the Internet right after Benson's diagnosis. I received the IMF InfoPack and ordered the back issues of Myeloma Today.

Benson: Then we called the IMF and asked if we could help raise some money for myeloma research. I was taking dexamethasone and I couldn't sleep, so I would lie awake at night thinking about fundraising. And I had an idea. Since 1983, the comic strip "Crock" would occasionally feature a character named Trooper Benson. I've been friendly with the strip's creators, Bill Rechin and Don Wilder, since 1980. Bill and Don gave their permission for us to use the Trooper Benson character on T-shirts and baseball hats. We distributed the hats and T-shirts, and Carol and I wrote a letter, asking our friends to contribute to the cause that had become so important to us. In 1999, Bill and Don ran another cartoon in the paper, and Carol and I sent out more letters. Over the years, we've written a lot of letters.

Carol: Then, in 2002, we co-chaired the IMF Gala in Washington, DC. And, this year, when Benson turned

CONTINUES ON NEXT PAGE

IMF Board Member Interview

60, we had a big party and asked our guests to make donations to the IMF in lieu of birthday gifts. We raised over \$11,000. So, over the years, through various fund-raising ideas, we've been able to fund several \$40,000 myeloma research grants in Benson's honor. And, in the next few months, we'd like to do another Trooper Benson campaign and fund another research grant.

Benson, how are you feeling these days?

Benson: I take Aredia once a month. I have arthritis in the area where the tumor was located, and in a few other spots. I have no myeloma symptoms. As a matter of fact, when my orthopedist told me that my current back pain is due to arthritis, I was so happy that I kissed him! Now,

I don't think about my myeloma as much as I used to, and I keep myself busy.

Carol: Benson still works full time, and he is on the Boards of four foundations. He has a lot of energy!

Benson: But I have a different outlook. I used to worry about the little things. Now, I only think about the big picture. When I was diagnosed, my first question to Fred Smith was, "Will I be around long enough to see my grandchildren?" Now, we have four grandkids: Lori's daughters Ava and Cecilia, and Leanne's daughters Morgan and Sadie. I just love them! Lori and her family live in town and we see Leanne and her family monthly. And the big picture is just wonderful! **MT**

Letter to the IMF

From Australia

My wife Glenys and I are holidaying with our son and daughter-in-law in Queensland. The climate is perfect and our holiday is so enjoyable. We have completely put thoughts of our common enemy to one side. It is just great. However, our state of relative euphoria is tempered by what we are watching on TV and reading in the local press. The devastation in your country beggars belief.

All Americans must be affected by this natural disaster and wonder just how it has come to pass. I thought I should let you know that the Australian community is also shocked by what is taking place and, for what it is worth, our thoughts at this time are very much with you and your families and colleagues all over.

Robert Moran

PATHOGENESIS & MAINTENANCE — continued

one or more of these receptors are active as evidenced by the ability of exogenous³ BLyS and APRIL to augment myeloma cell growth and enhance cell survival. These observations, taking together with the striking effects of BLyS on normal B cell maintenance and survival support the overall hypothesis that the BLyS/APRIL-TACI/BCMA/BAFF-R ligand-receptor system may be involved in the pathogenesis and maintenance of multiple myeloma. In an effort to test this hypothesis, current work centers on a number of integrated projects. First, we are using a variety of methodologies to elucidate the precise impact of BLyS and APRIL on both normal and malignant plasma cell (myeloma cell) survival and growth. In accompanying studies, we are characterizing the downstream signaling and genetic consequences of BLyS and

APRIL activation in malignant plasma cells. Finally, we are very eager to better understand how myeloma cells acquire the ability to express autocrine BLyS given its ability to support myeloma cell survival. **MT**

TERMS & DEFINITIONS

Autocrine – Denoting a mode of hormone action in which it binds to receptors on and affects the function of the cell type that produced it.

Heterogeneous – Composed of parts having dissimilar characteristics or properties.

Exogenous – Derived or originating externally; produced outside of an organism, a tissue, or a cell.

Editor's Note: This research project is supported in part by an IMF donation to the Robert A. Kyle Fund for Multiple Myeloma Research. As such, this project is subject to detailed peer review.

remains unclear whether tumor cells undergo a specific transformation-associated biological change(s) to acquire this property, or whether they exploit and amplify intrinsic tools, present in normal plasma cells, to ensure their survival.

Recent studies in my laboratory have identified a novel pathway promoting enhanced survival of chronic B cell malignancies. We demonstrated that B lymphocyte stimulator (BLyS), a member of the tumor necrosis factor family, was expressed in an autocrine manner by some leukemic B cells as well as by some myeloma cells. This observation is of great interest because BLyS is critical for maintenance of normal B cell development and homeostasis and shares significant homology with a proliferation-inducing ligand (APRIL). APRIL stimulates tumor cell growth as well as proliferation of primary lymphocytes and is expressed by a variety of human cancers. Three receptors for BLyS and APRIL have been identified: B cell maturation antigen (BCMA), transmembrane activator and CAML interactor (TACI), and BAFF-R. Whereas BLyS binds to all three receptors, APRIL only

binds to TACI and BCMA. Although BAFF-R appears to be the primary receptor underlying BLyS-regulated B cell development and survival, the precise role that each receptor plays in normal B cell and malignant plasma cell biology remains unknown and is therefore the subject of ongoing work in the laboratory.

Work thus far has taken advantage of the well-characterized panel of cytokine-responsive myeloma cell lines established in our laboratory over the past 10 years. Access to primary patient tumor cells has allowed us to make a number of observations. First, we have demonstrated that all of our myeloma cell lines express BLyS mRNA as do the majority of primary myeloma cells tested to date. Moreover, we have been able to detect BLyS at the protein level. Because normal resting B lineage cells do not express BLyS, we believe this is a striking result and has direct clinical implications. Second, we have demonstrated that myeloma cells express a heterogeneous pattern of receptor expression for BLyS/APRIL and that

PLEASE SEE PATHOGENESIS & MAINTENANCE ON PAGE 33

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Dear Reader,

The IMF, along with researchers, physicians, patients, and industry leaders, is extremely excited as we prepare for the annual American Society of Hematology (ASH) meeting, this year being held in Atlanta, Georgia on December 10th through 13th. The ASH meeting is the annual high point of the year in blood cancer research, and myeloma research is fast becoming the bellwether for blood-cancer studies and treatment. The IMF, through our groundbreaking program, Bank On A Cure[®], is at the forefront of it all. This year, five abstracts from Bank On A Cure research have been accepted at ASH, an impressive accomplishment. The IMF will once again be on site at ASH conducting web interviews with leading myeloma clinicians and researchers, capturing their first impressions and responses to the new data being presented. These reports from ASH, bring you breaking news as it happens. You can access this information by logging onto our website, www.myeloma.org.

However, those of you familiar with the work of the IMF should not be surprised by this announcement. Over the years, the IMF has awarded a total of 65 grants by means of the Brian D. Novis Research Grant program, to clinical researchers around the world. These grants are producing amazing results in the area of myeloma treatment as well as our overall understanding of the disease. At the annual ASH meeting, the IMF announces the grant winners for the upcoming year. Please look to future editions of Myeloma Today and to our website www.myeloma.org, for information about our newest awardees.

In all aspects of cancer research, knowledge is power, and the more you know about developments in myeloma research, the better equipped you are to face this devastating disease. To that end, please use all of the tools that the IMF provides. If you do not already subscribe to this publication, please call us at 800-452-CURE (2873) and do so today! If you have internet access, please visit our award-winning website, and subscribe to our weekly e-mail newsletter, the Myeloma Minute. Our thorough catalogue of publications is overseen by our chairman,



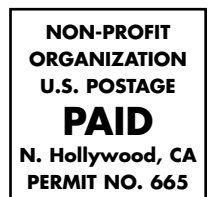
Dr. Brian G.M. Durie, and our materials have proven to be the most informative and helpful resources available. They can be viewed online or ordered directly through our website or by telephone. Lastly, all of those who have called our toll-free hotline and spoken with Debbie, Nancy, and Paul know that we are available to help you better understand myeloma research and treatment with the most up-to-date information possible. Please tell those who may not know about the IMF that we are available to assist anyone touched by this disease.

We are here to help you in any and all ways possible, and look forward to reporting back to you about our accomplishments and the important updates on the advances in myeloma research and treatment that will be presented at this year's ASH conference.

Best wishes,
Susie Novis



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