



# MYELOMA TODAY

SPRING 2006

VOLUME 6 NUMBER 8

A PUBLICATION OF THE INTERNATIONAL MYELOMA FOUNDATION

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

## Highlights



Robert Vescio, MD



Sundar Jagannath, MD



Brian G.M. Durie, MD

## FOCUS ON MYELOMA & PLASMA CELL DISORDERS

### CONFERENCE OVERVIEW WITH MORTON COLEMAN, MD

*The Focus on Myeloma & Plasma Cell Disorders conference was held in Miami, Florida, on March 24–25, 2006. The meeting was chaired by Drs. Bart Barlogie and Elias J. Anaissie of the Myeloma Institute for Research and Therapy in Little Rock, Arkansas. The Scientific Committee was comprised of Drs. Brian G.M. Durie, William S. Dalton, Angela Dispenzieri, and Nikhil Munshi. Myeloma Today is pleased to present a brief overview of the meeting shared with us by conference presenter and IMF Scientific Advisor, Dr. Morton Coleman.*

#### **Myeloma Today: Dr. Coleman, what can you tell us about your presentation on optimizing bisphosphonate therapy, good dental hygiene, and hydration?**

**Dr. Morton Coleman:** In a nutshell, my presentation indicates that we certainly accept the fact that bisphosphonates have made a major impact in our treatment of multiple myeloma. AREDIA® (pamidronate disodium) and ZOMETA® (zoledronic acid) are good and effective products, and they should be used on virtually all patients with active myeloma who have bone problems such as lytic lesions or osteoporosis. If care is given in the slow administration of these products, the potential side effect of renal toxicity can be obviated. Renal function and urinalysis studies should be performed prior to commencement of bisphosphonate therapy, and all patients should be well hydrated. In addition, if ZOMETA is used, I suggest that it be given for 30 minutes at a minimum, or longer, instead of the usual 15 minutes.

PLEASE SEE FOCUS ON PAGE 3



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### FOCUS — continued

#### **MT: What other potential side effects are associated with bisphosphonate therapy?**

**Dr. Coleman:** All the data that has been generated on bisphosphonates was generated on a 2-year time frame. The major problem we have encountered, osteonecrosis of the jaw (ONJ), is relatively rare and occurs mostly after two years of bisphosphonate therapy. In my mind, ONJ is clearly related to the use of bisphosphonates. So the bisphosphonates can be given quite safely for the first two years, but we should develop a sense of caution when using bisphosphonates beyond that time frame. The incidence of ONJ seems to go up with the duration of therapy, as well as with the potency of the bisphosphonate used – ONJ rates are higher with Zometa than with Aredia.

#### **MT: Are there any measures that can be taken to prevent ONJ?**

**Dr. Coleman:** Yes, there are. All invasive dental work should be done on the patient PRIOR to the commencement of bisphosphonate therapy. And, after two years of therapy, one should be very careful with any procedures that involve exposing the bone.

#### **MT: What are your thoughts about the use of Bondronat (ibandronate) in myeloma?**

**Dr. Coleman:** In his presentation on important adjuncts in myeloma therapy, Dr. James Berenson made mention of this interesting new bisphosphonate. Studies have been performed in Europe, and one such study was recently published abroad. But it is a little early in its development scheme to say exactly what future place this bisphosphonate might have in myeloma therapy.

#### **MT: The expert discussion moderated by Dr. Barlogie – with a panel that included Drs. Mohamad Hussein, Jean-Luc Harousseau, David S. Siegel, and Donna M. Weber – focused on new drugs for myeloma. How good are they, really?**

**Dr. Coleman:** One of the central issues is the role of the new drugs that have been developed. Some of these drugs are already on the market and others' presence on the market is imminent. The three major novel drugs are Thalomid® (thalidomide), Revlimid® (lenalidomide), and VELCADE® (bortezomib). We are now using them in various combinations with chemotherapy and steroids, and some combinations are showing outstanding responses equivalent to what we see with transplantation. The major questions are: How do novel agents fit into the algorithm for treating patients? Are these good responses as durable as the same sort of responses we achieve from

transplantation? Will these responses translate into survival advantage? If we can answer these questions, we can make a major impact on treating myeloma.

#### **MT: What is being done now to answer these questions?**

**Dr. Coleman:** There are studies underway. It is already clear that the incorporation of these new products with old products, such as alkylating agents and steroids, is clearly superior to the old products alone. For many years, Alkeran (melphalan) and prednisone (MP) has been the mainstay for therapy in patients not eligible for a stem cell transplant. Adding thalidomide to MP has been shown to improve the response rate. For example, in a European study of myeloma patients ineligible for transplants, 436 elderly newly diagnosed myeloma patients received half the dose of melphalan, plus prednisone and thalidomide (MPT). MPT was superior to MP alone, producing a longer progression-free survival and overall response rate. Studies of MP+VELCADE and MP+Revlimid are also promising. We still don't know if the novel agents can produce the same durability of high-degree responses.

#### **MT: What other highlights of the Focus on Myeloma & Plasma Cell Disorders conference can you share with our readers?**

**Dr. Coleman:** The myeloma targets and promising agents presentation by John D. Shaughnessy Jr., PhD, and Joshua Epstein, DSc, was very interesting. From using micro-array analysis, Dr. Shaughnessy is able to tease out certain genes that seem to play a role in promulgation of myeloma. Genes are nothing more than packets of DNA. Dr. Shaughnessy looks for the gene pattern that may play a role in multiple myeloma. The next step is to find or develop various medicines that interfere with that specific gene product (e.g., proteins, enzymes).

For the patient and caregiver members of the myeloma community, the most important point to be made about the Focus on Myeloma & Plasma Cell Disorders conference is that the development of novel biologic agents, which are more targeted than the old alkylating agents, can have a significant impact on how we treat this disease. These new agents are here to stay. In combination with old agents, they can produce responses that we only dreamed of before. Not too many years ago we rarely even talked of complete remission (CR) because it was so rare. Today, novel therapies are producing exciting responses. The next step is to determine if these responses are as durable as the responses we are seeing from transplantation. **MT**

## Table of Contents

<b>Scientific &amp; Clinical</b>	Conference Overview with Morton Coleman, MD	1
	Update on the Role of Lenalidomide (Revlimid®) in Myeloma	5
	The Role of Bortezomib in Previously Untreated Myeloma	6
	The Efficacy of Thalidomide in the Treatment of Myeloma	8
	Gene Targeting and Cell Therapy for Refractory Myeloma	9
	Current Imaging of Myeloma	10
<b>Education &amp; Awareness</b>	Two Myeloma Meetings Held in Germany	12
	San Francisco IMF Patient & Family Seminar	13
	Ft. Lauderdale IMF Patient & Family Seminar	14
<b>Special Event</b>	Robert A. Kyle Lifetime Achievement Award 2006	16
<b>International</b>	IMF Latin America	17
<b>Supportive Care</b>	Nutrition & Multiple Myeloma	18
	IMF Hotline Coordinators Answer Your Questions	20
<b>Support Groups</b>	The Atlanta Area Multiple Myeloma Support Group	21
	Preview of IMF Support Group Leaders Retreat	22
<b>Patient &amp; Caregiver Experience</b>	Living Successfully with Multiple Myeloma	23
<b>Member Events</b>	Family & Friends Celebrate the Life of Mario Federis	26
	IMF Honors Member Event Through Research Grant	27
	Music Against Myeloma	28
	2006 Member Events Calendar	28
	Our Guiding Light Shines Bright	29
	Member Events Updates	29
<b>Scientific Advisor Profile</b>	A. Keith Stewart, MB, CHB, MBA	30
<b>Board Member Profile</b>	Igor Sill	31
<b>Letters to the IMF</b>	Fighting with everything you've got, and more	32
<b>News &amp; Notes</b>	Important news bits and late-breaking information	34
<b>Order Form</b>	Request a subscription or place an order for information	35
<b>Dear Reader</b>	Letter from Susie Novis, President	36

## IMF Calendar 2006

<b>May</b>	16	Kyle Award Dinner – National Press Club, Washington, DC	<b>Sept</b>	2	P&F Seminar – CZECH REPUBLIC
	19-21	Support Group Leaders Retreat – Scottsdale, AZ		23	P&F Seminar – Pamplona, SPAIN
<b>June</b>	2-6	ASCO – Atlanta, GA	<b>Oct</b>	4-8	SWOG – Seattle, WA
	15-18	EHA – Amsterdam		21	IMF 16th Anniversary Celebration – Regent Beverly Wilshire Hotel, Los Angeles, CA
	23-25	ECOG – Washington, DC		22-28	Myeloma Awareness Week
<b>July</b>	7-8	Portland P&F Seminar	<b>Nov</b>	4	Second Annual Southwest Symposium – Tempe, AZ
<b>Aug</b>	4-5	Philadelphia P&F Seminar	<b>Dec</b>	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](http://www.myeloma.org) or call 800-452-CURE (2873).  
IMF–Latin America, IMF–Japan and IMF–UK events are not included above.



### UPDATE ON THE ROLE OF LENALIDOMIDE (REVLIMID®) IN MYELOMA

Myeloma Today Interviews Robert Vescio, MD

#### **Myeloma Today: What is lenalidomide?**

**Robert Vescio, MD:** Lenalidomide was developed to be a more potent, at least in the laboratory setting, version of thalidomide.

#### **MT: How does thalidomide work in myeloma?**

**Dr. Vescio:** Thalidomide is known to have activity in multiple myeloma. It has various properties including inhibiting both the production of and response to certain cytokines like tumor necrosis factor (TNF), preventing blood vessel formation, and stimulating the immune system.

#### **MT: How does lenalidomide differ from thalidomide?**

**Dr. Vescio:** Lenalidomide does seem to inhibit TNF as much as 50,000 times as potently as thalidomide. It also seems to be a better stimulator of the immune system. It was also hoped that it would have less of some of the side effects of thalidomide, namely sleepiness and neuropathy. At present, lenalidomide does not seem to have any long-term toxicity, while thalidomide does accumulate in the system.

#### **MT: In what setting has lenalidomide been studied?**

**Dr. Vescio:** While lenalidomide is being studied in clinical trials as part of initial treatment of myeloma, it has been studied most prominently in patients with relapsed disease. It is the drug's success in the relapse setting that is being submitted to the FDA for approval.

#### **MT: Are there subsets of myeloma patients for whom lenalidomide might not be a good idea?**

**Dr. Vescio:** Lenalidomide does suppress the bone marrow and lower the white blood cell count – a feature that thalidomide doesn't really have – so patients that have marginal bone marrow function may have a difficult time tolerating this drug. However, some patients have low blood counts due to the myeloma itself and, if lenalidomide can kill the myeloma cells, then this drug can still be a valid option because eventually the blood counts will get better as the myeloma cells are killed



Robert Vescio, MD  
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off. And, although I have not seen this in my own practice, there is a reported incidence of thrombotic complications, namely blood clots in the legs. This is why aspirin or blood thinners are often given to patients on lenalidomide.

#### **MT: What is the data on remission rates with lenalidomide?**

**Dr. Vescio:** There have been a few studies comparing lenalidomide and dexamethasone to dexamethasone alone. These studies have shown an overall response rate of approximately 60%, with one quarter of the patients achieving a near complete remission (nCR).

#### **MT: Please define complete remission (CR) rates.**

**Dr. Vescio:** The most stringent criteria were developed by Dr. Joan Bladé. In order for someone to be considered to have a complete remission (CR), the bone marrow cannot show more than 5% plasma cells, and there can be no detectable monoclonal protein in the blood or the urine by both electrophoresis and immuno-electrophoresis. The latter is the key because it is most sensitive to detecting monoclonal protein. In nCR, the immuno-fixation test can still be positive for myeloma but there can be no signs of myeloma on the more routine tests. In both conditions, there can be no visible tumors.

#### **MT: What complete remission rates are associated with the use of lenalidomide?**

**Dr. Vescio:** In relapsed patients, the true CR rates were 13% in the North American study and 15% in the European and Australian study. The drug has been used in the frontline setting for newly diagnosed patients and the CR rate in that study is 6% so far. But many of the patients in that study received only 4 months of therapy followed by a stem cell transplant, so it is very possible that if they had more months of therapy, the CR rate would have been higher. In the studies I've just mentioned, lenalidomide was used in combination with dexamethasone.

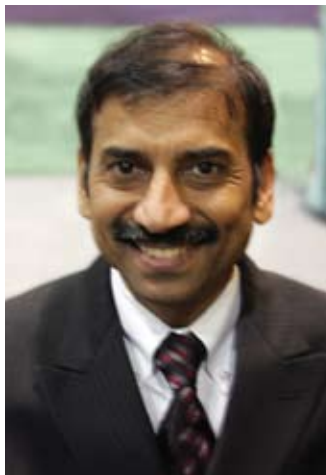
PLEASE SEE UPDATE ON LENALIDOMID ON PAGE 7

### THE ROLE OF BORTEZOMIB IN PREVIOUSLY UNTREATED MYELOMA

Myeloma Today Interviews Sundar Jagannath, MD

#### **Myeloma Today: What is bortezomib (VELCADE®) and how does it work in myeloma?**

**Sundar Jagannath, MD:** Bortezomib is a novel agent. It is a new drug with a new mechanism of action. The bortezomib molecule is a boron-containing dipeptide that works as a proteasome inhibitor. A proteasome is an enzyme in the cell – an important housekeeping enzyme in both the cytoplasm and the nucleus – that is responsible for destroying unwanted proteins. Proteins are very important to cellular function, and to being alive, so this enzyme plays a critical role by breaking down 80% of unwanted proteins in the cell. Bortezomib is the first drug developed to inhibit this particular enzyme. This action is reversible – bortezomib inhibits the enzyme partially for a short period of time, then the enzyme completely recovers. Bortezomib preferentially causes myeloma cells to die as compared to normal cells because the normal cells recover, but the myeloma cells do not. Myeloma cells are plasma cells and their function is to make antibodies (proteins). Plasma cells produce a lot of protein, so once you block the protein, myeloma cells become vulnerable and die. The other reason why the myeloma cell is so sensitive to bortezomib is because it blocks NFκB, a transcription factor responsible for the production of inflammatory cytokines (IL-6, IL-1, TNFα, and VEGF), thereby starving the myeloma cells. Bortezomib also works in the bone marrow microenvironment. In addition, bortezomib down-regulates cell adhesion molecules (sticky substances expressed on the cell surface) which allow myeloma cells to attach to bone marrow stromal cells. The bone marrow stromal cells nourish myeloma cells and protect them from chemotherapeutic agents so that they become resistant to such treatment. If you prevent the myeloma cells from attaching to bone marrow cells, they become even more vulnerable to chemotherapy agents. That is why there is a synergy to using bortezomib in combination with other chemotherapy agents. So there are many different ways that bortezomib targets myeloma cells and kills them.



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#### **MT: What can you tell us about your clinical trial experience with bortezomib in the frontline setting?**

**Dr. Jagannath:** Even before bortezomib was officially approved by the FDA, we had proposed a multi-center clinical trial to pilot bortezomib in newly diagnosed myeloma patients. It was a unique study design because we wanted to use bortezomib alone for the first two 3-week cycles. If the patient did not respond promptly, then we added dexamethasone to the bortezomib. We were able to treat 48 patients and presented the study results at the last meeting of American Society of Hematology (ASH). At the end of the first two cycles, all measurable cancer disappeared in 10% of the patients. Half of

the patients responded with either a complete remission (CR) or partial remission (PR) to the use of bortezomib alone. When the dexamethasone was added, 80% of patients responded by the completion of treatment at six cycles. One out of five patients went into CR or near CR (nCR), so this combination was shown to be very effective. Patients who wanted to go on to having a stem cell transplant were able to do so.

#### **MT: How do these results compare with other investigators' studies?**

**Dr. Jagannath:** Our study was reproduced by Dr. Jean-Luc Harousseau in a multi-institutional trial of 48 patients in France. Instead of six cycles, they did four cycles, and they had 70% of patients respond by the completion of treatment with either CR or nCR. So two investigators, in two separate multi-institutional trials, one in the U.S. and one in France, were able to reproduce each other's data. In addition, in Dr. Harousseau's experience, when patients went on to receive a transplant, about 90% of the patients responded. The results they saw with bortezomib and dexamethasone followed by one transplant were equivalent to what we've seen after two transplants when using VAD as induction.

PLEASE SEE THE ROLE OF BORTEZOMIB ON PAGE 7

### UPDATE ON LENALIDOMIDE — continued

#### **MT: What is the role of dexamethasone when combined with lenalidomide?**

**Dr. Vescio:** There appears to be some synergy, and the two drugs seem to work better together. It has been known for years that thalidomide and steroids are synergistic.

#### **MT: Which lenalidomide clinical trials have you been involved with?**

**Dr. Vescio:** The first trial looked at lenalidomide as a single agent in patients with relapsed myeloma, and I am still following some patients from that trial who have been doing well for years. The current trial I am involved with is still recruiting patients. It is the Phase IV Expanded Access Program (EAP) – a multi-center, single-arm, open-label trial for lenalidomide plus dexamethasone in previously treated subjects with myeloma. The goals are to provide lenalidomide to relapsed patients with a high

likelihood of benefit and to obtain additional safety data. The combination looks very promising, and it is important for patients who need this drug to be able to access it. This study has very few enrollment restrictions and we are expecting a total enrollment of 12,000 patients.

#### **MT: What do you see as the future of lenalidomide as therapy for myeloma?**

**Dr. Vescio:** Lenalidomide very likely will become part of the initial therapy for myeloma but, for the near future, it will be used most frequently for relapsed disease. There are also studies looking at lenalidomide as maintenance treatment following stem cell transplantation. Lenalidomide is an active drug in myeloma and, perhaps in combination with other active agents, it has the promise of becoming a very powerful tool in treating this disease. **MT**

### THE ROLE OF BORTEZOMIB — continued

Another group of investigators in England did a slightly different study, using PAD (VELCADE, Adriamycin, and dexamethasone) as induction. They found that at the end of four cycles almost 90% of the patients responded, and they had an excellent CR rate. Even before transplantation, one third of the patients were in CR or nCR. At the end of transplantation, 57% of patients were in CR or nCR. All patients' blood counts recovered. All patients could get their stem cells collected. All patients recovered promptly. In this study as well, the results with PAD followed by one transplant were equivalent to what we've seen after two transplants with VAD.

In Arkansas, Dr. Bart Barlogie and colleagues are using multi-agent chemotherapy in combination with bortezomib, and they show very good responses. They take patients to two (tandem) transplantations and at the end they can show that about 80% of patients have achieved CR. At MD Anderson, they are using bortezomib, thalidomide, and dexamethasone – so they are putting two novel agents together! – and their results are very exciting. Of 38 patients, 18% have achieved CR and 74% have achieved PR for a total response rate of 92%.

At Dana-Farber Cancer Institute investigators have used bortezomib as a single agent for newly diagnosed

myeloma patients in a multi-institutional trial, with an overall response rate of 40%.

These are milestones! In the 1980s, we never thought that CR could be achieved in myeloma. Now we have been able to achieve CR with the help of bortezomib, which is being used more and more by major centers, and other novel agents as well.

#### **MT: How does bortezomib compare with other novel agents?**

**Dr. Jagannath:** Although thalidomide and lenalidomide are also helping us achieve high response rates, bortezomib is unique because it can be given to patients irrespective of their kidney functions – even patients with renal impairment can get this drug. In addition, we already know from the results of the clinical trials with relapsed disease that bortezomib works in patients with chromosome 13 deletion and t(4;14) translocation. This is a drug that works in people who would have previously been considered to have poor prognosis. Bortezomib alone or in combination with other drugs is an effective therapy in previously untreated patients with myeloma. We are looking at a brand new future. **MT**

### THE EFFICACY OF THALIDOMIDE IN THE TREATMENT OF MYELOMA

By Brian G.M. Durie, MD

Thalidomide has been used since 1997 in the treatment of myeloma. Remarkable efficacy has been observed both alone and in combination with dexamethasone and other drugs. But only recently have comparative trials been completed to show the clear added benefit of thalidomide, and the drug still awaits formal FDA approval for myeloma treatment.

Two recent studies have led to some confusion about thalidomide efficacy. In the first study from the Little Rock team in Arkansas (Barlogie, et al NEJM 354(10); 1021-30, March 9th, 2006) thalidomide was given throughout the treatment course to half the patients undertaking the Total Therapy 2 double transplant protocol. The patients receiving thalidomide throughout the disease course had higher initial complete response rates (62% versus 43%) and a higher percentage of patients in remission at 5 years (56% versus 44%), but the ultimate overall survival was the same as in patients not receiving thalidomide initially. What does this mean?

The problems in interpreting this result are several. Firstly, 83% of the patients not receiving thalidomide initially did receive it as soon as they relapsed. The primary comparison is therefore between early use of thalidomide versus later use of thalidomide. One interpretation is that both are good, in that the overall survival in both patient groups is over 5 years even for patients > 65 years old. Secondly it is truly difficult to sort out the impact of thalidomide in the setting of such a complex multi-drug and multi-procedure protocol. But the use of thalidomide did not appear to be detrimental to the overall outcome, although important side effects such as neuropathy and DVTs (deep vein thrombosis or clotting episodes) are a concern with early continuous use of thalidomide in a multi-drug protocol. This study therefore provides mostly an important caution about study design when a critical endpoint to be evaluated is



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the overall patient survival. Other studies are required to better address the role of thalidomide in this type of complex transplant setting and several ongoing trials are soon to be reported.

Separately, a much simpler study from the Torino group in Italy shows a clear benefit for thalidomide (Palumbo, et al Lancet 367: 825-31, March 11th, 2006). This study evaluates the value of the addition of thalidomide 100 mg daily to the standard melphalan/prednisone (M/P) regimen used for older patients aged 60-85 years. 129 patients received the additional thalidomide and 126 patients received M/P alone. The complete plus partial response rate with MPT was 76%

versus 47.6% for MP alone without added thalidomide. In this case, although there were some increased toxicities, as one might expect (neuropathy, DVTs, infection risk), especially early in treatment, the initial benefit was sustained. In this case, there was an overall trend to both longer remissions ( $p=0.0006$ ) as well as longer survival. Again, the interpretation of survival was complicated by use of thalidomide in MP patients at relapse (21%) as well as the higher up-front risks with the new MPT combination. Recommendations are now made for anticoagulant therapy, preventative antibiotics, and lower doses of thalidomide to reduce toxicities and risks. Overall, there is remarkable benefit with thalidomide in this trial, which has led to several other larger randomized trials that have confirmed the advantages of adding (with due cautions) thalidomide to the standard melphalan/prednisone regimen.

Thus, as they say, the devil is in the details! One has to look closely to assess the results of new trials. The bottom line for now is that thalidomide continues to show remarkable benefit. As with every drug, careful advice is required about the details of thalidomide use, including the dosage, preventative medications such as blood thinners and antibiotics, as well as the most appropriate

PLEASE SEE EFFICACY OF THALIDOMIDE ON PAGE 11



**GENE TARGETING AND CELL THERAPY FOR REFRACTORY MYELOMA**

Dr. Eishi Ashihara Presents Research Project Abstract

*The IMF is proud to announce that Dr. Eishi Ashihara is the recipient of the 2006 Aki Award. This annual myeloma research grant was instituted in 2002 by IMF Japan in memory of its founder, Aki Horinouchi. The 2006 award was presented to Dr. Ashihara at the IMF Scientific Advisors Meeting held in Atlanta, Georgia.*



Eishi Ashihara, MD, PhD  
Kyoto University  
Kyoto, Japan

Agents of molecular targeting therapy inhibit the proliferation of malignant-transformed cells by blocking the signals for cell proliferation. Several targeting agents developed to counteract multiple myeloma (MM) have yielded promising results; however, it is still difficult to achieve a definitive cure for myeloma. Bisphosphonates (BPs), developed primarily to treat bone diseases, may also act as anticancer drugs by inhibiting the

activation of Ras and Ras-related proteins through suppression of both geranylgeranylation and farnesylation. We previously demonstrated that YM529, a third-generation BP, inhibits the proliferation of MM cells. This time, we examined the effects of zoledronate (ZOL), another third-generation BP, on MM cells. ZOL inhibited the proliferation of MM cells in a time- and dose-dependent manner similar to that of YM529 and induced apoptosis by inhibiting the prenylation of Rap1-A, a Ras-related

protein. These effects were observed in l-pam-sensitive cell lines as well as in l-pam-resistant cell lines. It is suggested that ZOL may be useful as a molecular targeting agent in myeloma cells.

In addition to their direct antitumor activities, third-generation BPs expand  $\gamma\delta$ T cells, which exhibit major histocompatibility complex-unrestricted lytic activity. After peripheral blood mononuclear cells were stimulated with ZOL and interleukin-2 for 14 days,  $\gamma\delta$ T cells were expanded by up to about 800-fold. These expanded  $\gamma\delta$ T cells were V $\gamma$ 9V $\delta$ 2 subsets, having cytotoxic activity. We previously observed that pretreatment with ZOL enhanced the cytotoxicity of  $\gamma\delta$ T cells on non-small cell lung cancer cells. Internalization of ZOL by cancer cells rapidly led to the inhibition of farnesyl pyrophosphate (FFP) synthase, resulting in intracellular accumulation of isopentenylpyrophosphate that is situated upstream of FFP synthase in the mevalonate pathway. We investigated the in vitro cytotoxicities of  $\gamma\delta$ T cells on MM cells alone or in combination with

**Aki Award Recipients**

2002

Dr. Masahiro Abe  
Tokushima University

2003

Dr. Takashi Sonoki  
Kumamoto University

2004

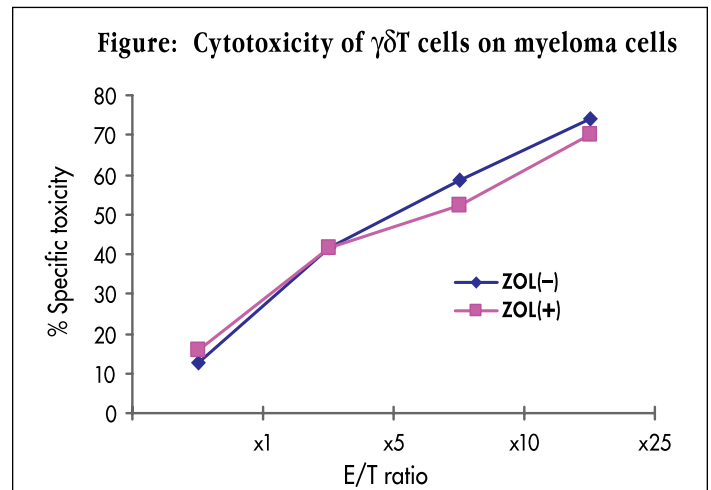
Dr. Hideaki Ishikawa  
Yamaguchi University

2005

Dr. Yutaka Hattori  
Keio University

2006

Dr. Eishi Ashihara  
Kyoto University



PLEASE SEE GENE TARGETING ON PAGE 11

## CURRENT IMAGING OF MYELOMA

By Michael E. Mulligan, MD

There are many different imaging studies available to investigate suspected disease processes, and radiologists are specially trained to perform and interpret these imaging studies. This article will briefly touch on the imaging tools that help in the diagnosis, staging, and follow-up of patients with myeloma.

The current imaging tools available include:

- standard x-rays (radiographs)
- CT (computed tomography)
- MRI (magnetic resonance imaging)
- “bone scanning” (a nuclear medicine study with intravenous injection of a radioactive material)
- PET (positron emission tomography) another nuclear medicine technique

PET scans are often combined with CT scans, and this study is known as PET/CT. PET and PET/CT have been widely available over the last five years, but not all insurance companies cover myeloma patients who have these studies done. Hopefully, this will change soon as more data is published in the medical literature substantiating the benefits of PET/CT.

Once a doctor suspects the diagnosis of myeloma based on a patient’s symptoms and laboratory results, he or she will usually request imaging studies of the skeleton to help confirm the diagnosis. The radiographic “bone survey” may include x-rays of the skull, spine, ribs, pelvis, arms, legs, and/or other specific areas of the skeleton. Newer ways of surveying the entire skeleton include whole-body CT or whole-body MRI. An MR imaging study of the spine may be requested by your doctor even if the regular x-rays are normal because it is known that MR imaging can show abnormality inside the bones of the spine much earlier than regular x-rays, and this could result in a change of the imaging stage.



Michael E. Mulligan, MD  
Associate Professor of Radiology,  
University of Maryland  
Medical System (UMMS)  
Chief, Division of Radiology, Kernan  
Hospital  
Assistant Chief of  
Musculoskeletal Imaging, UMMS  
MSK Fellowship Program Director,  
UMMS  
Baltimore, MD

The latest International Staging System for myeloma is based solely on the laboratory findings of B2 micro-globulin levels and albumin levels. This does not diminish the importance of imaging studies to assess the skeletal changes. Staging of myeloma was based for many years on a number of different tests organized by Drs. Durie and Salmon into the Durie/Salmon staging system, published in the medical literature in 1975. The only imaging study in the original staging system was regular x-rays. In 2003, a new Durie/Salmon PLUS staging system was published. The “plus” of this new staging system was the addition of imaging findings from MR and PET (or PET/CT) to the findings from regular x-rays. Stage 1 by imaging means that there are no more than 4 focal skeletal lesions or there is only mild disease seen in the spine by MR exam. Stage 2 by imaging means that there are between 5 and 20 focal lesions or there is moderate disease in the spine by MR exam. Stage 3 by imaging means that there are more than 20 focal lesions in the skeleton or there is severe disease in the spine by MR exam.

All of the imaging studies mentioned above can be used to follow the course of the disease during and after treatment. However, regular x-rays and CT only show lesions (holes) in the bones. Unless a hole is bigger or there are new holes on the follow-up study, it is impossible to know if there are still active tumor cells in the lesion. MR imaging and PET use properties of active tumor cells to determine if there is still active disease at those sites. In addition, the whole body can be surveyed with just one study. Thus these are becoming the favored techniques for following myeloma patients.

The imaging findings by themselves should never be considered as the sole determinant of disease activity.

PLEASE SEE CURRENT IMAGING ON PAGE 11

### EFFICACY OF THALIDOMIDE — continued

timing and setting to use the drug. The clear benefit of thalidomide plus dexamethasone as frontline therapy in patients proceeding to stem cell harvesting and transplantation is, for example, well established. As always,

myeloma patients need to seek as much information as possible about the appropriate use of drugs in their own personal situation. **MT**

### GENE TARGETING — continued

ZOL-pretreatment. Expanded  $\gamma\delta$ T cells revealed strong anti-myeloma effects either with or without ZOL-pretreatment (Figure). It is suggested that cell therapy using  $\gamma\delta$ T cells could be a powerful strategy for blocking MM. We are now investigating the in vivo effects of  $\gamma\delta$ T cells using a xenograft myeloma mouse model and searching for new antigens on myeloma cells for presentation to  $\gamma\delta$ T cells.

RNA interference is a newly discovered mechanism for silencing genes in a sequence-specific manner at the mRNA level through the introduction of small cognate double-stranded interfering RNA (siRNA) into cells, and has recently been introduced into cancer therapy, primarily in vitro. However, the therapeutic use of siRNA is largely dependent on the development of a drug delivery system that efficiently delivers siRNA into target cells. To deliver siRNA into MM cells, we are creating a CD138 monoclonal antibody (mAb) combined siRNA system.

CD138 (syndecan-1) is highly expressed on MM cells, but not on normal hematopoietic cells. As gene-silencing targets, we selected Polo-like kinase-1 (PLK-1) and  $\beta$ -catenin. PLK-1 is one of the most important regulators of mitotic progression in mammalian cells, and we reported that the expression of PLK-1 in urinary bladder cancer cells correlates with the disease prognosis.  $\beta$ -catenin, a cytoplasmic protein of the Wnt pathway, associates with the TCF/lymphocyte-enhancer factor (TCF/LEF) family.  $\beta$ -catenin-TCF/LEF complexes migrate to the nucleus and activate the transcription of c-myc and cyclin D1, resulting in cell proliferation. Preliminary data show that PLK-1 and  $\beta$ -catenin are overexpressed in myeloma cell lines. We suggest that CD138 mAb combined with PLK-1 siRNA or  $\beta$ -catenin siRNA may have potential as a powerful tool for molecular targeting therapy. A novel therapy based on a combination of gene-targeting therapy and cell therapy for MM is now under investigation in our laboratory. **MT**

### CURRENT IMAGING — continued

The interpretation of the imaging findings can be difficult, and the tests are not 100% accurate. The treating doctor will always take into account all of the information available from other laboratory tests and the patient's current feelings and their symptoms. The radiologists who interpret and report these tests are usually happy to answer patients' general questions about them. Specific questions about imaging results should be directed to the treating physician. **MT**

#### **IMF Research Grant funded by Donate for Drew Day**



#### **“Novel Therapeutic Antibodies for Multiple Myeloma”**

**Dr. Giovanni Tonon**  
Dana Farber Cancer Institute  
Boston, Massachusetts

Dr. Tonon and colleagues have implemented an integrated oncogenomic approach to identify the spectrum of genetic alterations in a large panel of myeloma cell lines and tumors. The ultimate goal of this research is to provide the scientific and clinical community with a list of thoroughly validated antibody targets, ready to be enlisted into therapeutic antibody development and ultimately translated into drugs capable of having as impact upon patient survival.

*In the Winter 2005/2006 issue, we had an article about Donate for Drew Day, a very successful event held in September 2005 that raised over \$50,000. The donation of the proceeds from this event funded a research grant in December, 2005, to Dr. Giovanni Tonon. We are sincerely grateful to Patrice and Drew Spaeth for including the IMF in their celebration.*



### **TWO MYELOMA MEETINGS HELD IN GERMANY**

#### Patient Day and Expert Symposium in Heidelberg

More than 300 myeloma patients attended the third biannual Myeloma Patient Day in Heidelberg, Germany. The event took place on October 22, 2005, at the German Cancer Research Center (Deutsche Krebsforschungszentrum). The meeting was co-sponsored by the Medical Clinic of the University of Heidelberg and the IMF. In conjunction with the Patient Day, an Expert Symposium was held for more than 90 physicians on October 21, 2005.

Dr. Hartmut Goldschmidt, member of the IMF Scientific Advisory Board, chair of the German-speaking Multicenter Myeloma Group (GMMG), one of two major clinical trial cooperative groups in Germany, and professor at the University of Heidelberg, organized both events and led sessions on both days.



Gerlinde Fuhrmann,  
leader of the Jena  
(Germany) Support Group

Dr. Brian Durie, Chairman and cofounder of the IMF, delivered presentations in both sessions. IMF Scientific Advisors Dr. Pieter Sonneveld of Erasmus Medical College University Hospital in Rotterdam, the Netherlands, and Dr. Heinz Ludwig of the Wilhelminenspital in Vienna, Austria, were among the faculty. Other myeloma and bone disease specialists from throughout Germany also participated.

In addition, the IMF organized a meeting with



Rolf Pelzing, board member of the Nordrhein-Westphalen (Germany) Support Group, translates for Dr. Brian Durie

25 support group leaders from Germany, Austria, Switzerland, Belgium, and the Netherlands. The purpose of this meeting was to discuss how IMF programs could better serve the European myeloma patient and medical communities. Interestingly, the leaders expressed many of the same concerns that support group leaders in the U.S. experience – how to maintain consistent group leadership, how to attract new members, and how to better share information.

Two pledges by the IMF were made as a result of the meeting. First, the IMF will create a German language email newsletter, the Myelom Merkur, which will translate articles from Myeloma Today and the Myeloma Minute that are relevant to German-speaking audiences. Additionally, the IMF named Director of Public Advocacy, Gregor Brozeit, to head a new European operations program for continental Europe. He has already met with a number of patient and medical leaders in Europe to develop new projects to serve the European myeloma community and myeloma patients throughout the world. **MT**



### **SAN FRANCISCO IMF PATIENT & FAMILY SEMINAR**

By Paul Hoffman

The IMF hosted a Patient & Family Seminar in San Francisco on February 10-11, 2006. The meeting was attended by about 250 patients and caregivers. It commenced on Friday with an open forum conducted by Drs. Brian Durie and Jeffrey Wolf, followed by presentations on nutrition (Bernadette Festa, MS, RD) and Freelite testing (David Smith, The Binding Site), then an orientation for new IMF members, and cocktail reception and welcome dinner.



Paul & Elaine Hoffman

On Saturday, the general session of the seminar began at 8am, with a welcome from Susie Novis, President of the IMF. Then, an interactive introduction session was followed by Dr. Durie's presentation "Myeloma 101 – what to do when you're first diagnosed." Dr. Wolf addressed "Current options for primary induction & achieving the maximum response pre-transplant." Dr. Bill Bensinger presented on "The role of high-dose therapy and transplant in 2006." Dr. Durie returned to the podium with a presentation on "Achieving best bone health and quality of life." To close out the morning sessions, the IMF Patient Panel shared personal insights about dealing with myeloma, and Greg Brozeit gave us an update on cancer advocacy.

After lunch, Dr. Morton Coleman spoke about "Advancing treatment results with thalidomide and its derivatives," and Dr. Keith Stewart provided an overview of the key data presented at the American Society of Hematology conference in December of 2005. The faculty left a fair amount of time for our questions, as a Q & A session with the panel followed each presentation. The "Break-Out Sessions" commenced after the afternoon coffee break and involved all the faculty and Susie Novis, who held her "Caregivers Need Care Too" session.

The weekend was extraordinary! This was the third IMF Patient & Family Seminar that I've attended, and they've all been a fountainhead of knowledge, plus an

opportunity to talk with the experts and to exchange experiences with other myeloma survivors. But this one was sort of special, in that an atmosphere of great friendship permeated among the attendees, as we exchanged information about chemo, transplants, adverse reactions, up-and-down counts, etc.

I attended my first two IMF seminars with my wife, Elaine, who died of multiple myeloma in December, after a 7-year battle with the disease. Even

with Elaine now gone, I wanted to maintain my association with the IMF, and to continue to be of help, because I think it's such a good organization. Several years ago, I was contacted by IMF's Greg Brozeit as a result of something I had written about the need for the NIH to get more involved with myeloma research. I am a psychologist and a statistician and, in 1977, I had organized the Oregon Research Institute. Because of my prior interaction with the NIH, I knew how they dealt with research issues and proposals, and I was able to help Greg frame questions for the NCI so that they actually had to admit that there wasn't one single research grant at the time that was specifically concerned with myeloma. That's how I became involved with the IMF.

When Elaine was diagnosed with myeloma, she changed from an outgoing person to someone very introverted. She no longer wanted to interact with people, so when I first suggested that we attend an IMF seminar, she didn't want to go. But I was able to persuade her, and the experience was so refreshing that it took some of the burden of fear off her. It made us want to make the most out of the years we had to live.

We met other people who were dealing with myeloma with a positive attitude, and this was very reassuring psychologically. Encountering other members of the myeloma community took us from a condition of isolation and denial to being able to express and share our experience.

PLEASE SEE SAN FRANCISCO P&F SEMINAR ON PAGE 15

### **FT. LAUDERDALE IMF PATIENT & FAMILY SEMINAR**

By Bob Feltzin

It was another beautiful day in South Florida. No golf today... the IMF is in town. As a five-year veteran of IMF seminars, I'm happy to see many old friends who've gathered to attend the meeting. On March 31, during the Q & A session with Drs. Brian Durie and Morton Coleman, eight South Florida support groups were represented, with members asking a million questions. This has to be the best way to kick off a seminar!



Cindy & Bob Feltzin with Nancy Baxter

It's always interesting to see how first-time attendees react to meeting so many other myeloma patients and family members – they are so relieved to find they are not alone. And the amount of information that is presented shows just how much is being done to secure their future.

David Smith's presentation focused on the Freelite test, and it sounded like a very useful tool. Susie conducted her Caregiver Session – where does she get all that energy? – which is always popular with family members. It was great to learn that we can call the IMF Hotline even to discuss “sex, drugs, and money” – those were Susie's words!

On the morning of April 1, over 150 patients and caregivers filled the Ballroom at the Ft. Lauderdale Wyndham Hotel. Mike Katz presented on the progress of IMF's



Ft. Lauderdale seminar faculty members Drs. Vesole and Niesvizky

Bank On A Cure® research initiative. He also introduced an interactive session where patients and caregivers were able to participate in several video question sessions as the day progressed. It is both an interesting way to get audience participation and a fun thing to do. The results of these question sessions demonstrated that myeloma patients everywhere face very similar challenges and outcomes.

Dr. Morie Gertz's presentation “Myeloma 101” was so clear that even a child could easily come to understand the basics of multiple myeloma. It was very well done. Those in the audience who had experienced difficulties understanding this disease gained a much clearer view of the disease.

For the rest of the morning, we learned about treatment options, response to treatments, transplants, bone health, and quality of life. Each presentation was followed by a Q & A session with a panel of experts: Drs. Durie, Gertz, Vesole, Shippman, and Niesvizky. By the way, did you know that bisphosphonates were originally used in the 1950s to de-sludge pipes?!

The Patient and Caregiver Panel members spoke about their experiences, outlooks, and emotions. Some of the discussion centered on whether or not we should be transplanted (the panel chose to wait).

IMF Board member Michael Katz presented the Francesca Thompson Outstanding Service Award to Cindy Feltzin (my wife, the dynamo who started and runs the Palm Beach, Martin, and St. Lucie Counties Multiple Myeloma Support Group) for her service to the myeloma community.

The evening festivities included a dinner where people had a chance to mingle with friends, new and old. Susie greeted everyone and showed a video on myeloma hosted by James Brown. After dinner, I spent a half hour talking to new friends from Naples, Florida and Virginia. All of us were

PLEASE SEE FT. LAUDERDALE P&F SEMINAR ON PAGE 15

## Education & Awareness

### SAN FRANCISCO P&F SEMINAR — continued

We also realized that there are a lot of very smart researchers and clinicians who are doing the best they can to find the answers that will eventually lead to a cure.

While some of the science presented at the IMF Patient

& Family Seminars is a few yards beyond those of us with humble educational backgrounds, I think most of the attendees come away with a better grasp of what multiple myeloma is, where they are, and what opportunities for treatment are available to them. **MT**

### FT. LAUDERDALE P&F SEMINAR — continued

long-term (5 to 10 years) myeloma survivors. The new developments in research have us very excited about our futures.

The next day, at lunch, I had a chance to make more new friends. While this seminar took place in South Florida, I met people from Arizona, West Virginia, Virginia, New York, New Jersey, Massachusetts, Georgia, Louisiana, California, Ohio, Wisconsin, and other states.

In the afternoon, Dr. Niesvizky spoke about thalidomide and derivative treatments. Since most of us have used thalidomide, we were all very interested. Breakout sessions followed with each doctor taking a smaller group to have give-and-take on specific subjects. I chose to attend sessions with Drs. Shipman and Durie.

Susie closed the session by thanking everyone for coming and reminding us to contact our Congressmen to urge them to vote to restore the seven billion dollars for medical research cut from the Federal budget. With all these budget cuts, that leaves us only praying for a cure. And although there is nothing wrong with praying, a few bucks for research can't hurt.

If I got anything out of the meeting, it was that if a myeloma patient or family member wants to be educated about myeloma, these IMF seminars are must-attend events. Thanks to the IMF staff for a terrific weekend and for the care and passion they bring with them. **MT**



### **IMF Honors Cindy Feltzin with the Francesca Thompson Outstanding Service Award – Ft. Lauderdale, Florida**

The IMF was proud to present the Francesca Thompson Outstanding Service award to Cindy Feltzin. This prestigious award was established in 1997 and was named in honor and in memory of Dr. Francesca Thompson. Dr. Thompson was a world-renowned orthopedic surgeon who practiced in New York City. She was also a myeloma patient and author of the book *Going For the Cure*. Dr. Thompson was a founding member of the IMF Board of Directors, and one of her first projects was to personally fund the IMF's hotline. The award was established posthumously in her memory to honor her spirit, her unflagging selflessness, and her devotion to reach out and help others.

Since 1997 the IMF has awarded The Francesca Thompson Outstanding Service Award to eight very deserving individuals, and it was with great pleasure that once again the IMF was able to recognize another very deserving individual by presenting it to Cindy Feltzin.

Cindy and her husband Bob, who is a myeloma patient, live in Palm Beach Gardens, Florida, where Cindy started her second myeloma support group. Her first was when she took the reins of a group in Miami that had been leaderless for some time and was in need of help. Two years later she and Bob moved to Palm Beach Gardens, and it was there that Cindy established the Palm Beach, Martin and St. Lucie Counties MM Support Group.

Today the group has approximately 140 members who meet once a month, and each month Cindy makes sure that they have an informative speaker, great food, and a good time. Cindy formed a wonderful friendship with Rick Sulak from Millennium Pharmaceuticals, and Rick has been a big help to Cindy, providing lunch for the group and offering his assistance in a variety of helpful ways.

Cindy is a tireless worker with a real "can do" attitude, and in addition to devoting endless hours to ensure that the needs of her group are met, she also cares for her husband, her parents, and her extended family.

The IMF congratulates Cindy on being a recipient of the Francesca Thompson Outstanding Service Award. She is a most deserving recipient – and in the spirit of Francesca, she continues to go "above and beyond the call of duty to help others"!



## BE PART OF THE CELEBRATION

*The IMF is pleased to announce that  
Dr. Brian G.M. Durie  
has been selected to receive  
the Fourth Annual Robert A. Kyle  
Lifetime Achievement Award.*



Dr. Robert Kyle and Dr. Brian G.M. Durie

The Robert A. Kyle Lifetime Achievement Award honors a physician who most exemplifies a singular dedication to and compassion for myeloma patients and treatment of their disease. By extension, it also honors everyone in the myeloma community who supports physicians, researchers, and their patients, which is why the IMF invites every one of its members to attend this special event.

Set at the famous National Press Club, the evening will begin with a 6PM cocktail hour followed by a 7PM dinner and program, during which many accomplished, noted members of the myeloma community will speak to the advances being made. The occasion will provide a unique opportunity to visit with physicians and researchers, as well as with patients and their families.

Dr. Kyle, for whom the award is named (and its first recipient), can think of no better person to receive this year's honor than Dr. Durie. "He's the best and brightest," Dr. Kyle says, "and thoroughly dedicated."

Benson Klein, IMF Board Member, who is chairing the dinner with his wife Carol, thoroughly agrees. "Dr. Durie is a wonderful, dedicated human being," he says. "And he is reassuring, forthcoming, and knowledgeable," Carol adds.

To purchase tickets or become a sponsor, please contact Suzanne Battaglia at 800-452-CURE (2873) or visit our web site, [www.myeloma.org](http://www.myeloma.org).

We look forward to seeing you on May 16th. **MT**

Fourth Annual International Myeloma Foundation

## ROBERT A. KYLE LIFETIME ACHIEVEMENT AWARD

May 16, 2006  
National Press Club  
Washington, D.C.

### EVENING SPEAKERS

**Dr. Julian Adams**  
Chief Scientific Officer,  
Infinity Pharmaceuticals

**Dr. Dalsu Baris**  
National Cancer Institute (NCI)  
IMF Scientific Advisory Board

**Dr. Bart Barlogie**  
Professor of Medicine & Pathology,  
University of Arkansas for Medical Sciences  
Director, Myeloma Institute of Research and Therapy  
IMF Scientific Advisory Board

**Ms. Stephanie Gallagher**  
President, World City America, Inc.

**Mr. Michael Katz – Master of Ceremonies**  
Senior Vice President, Booz-Allen & Hamilton, Inc.  
IMF Board of Directors

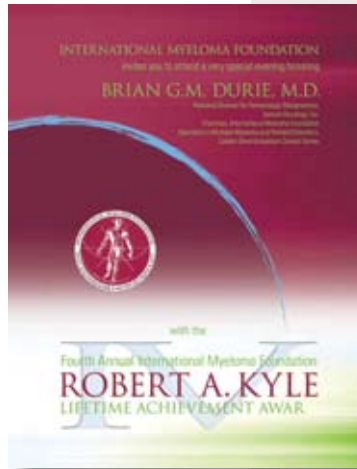
**Mr. Benson Klein**  
Principal, Ward & Klein  
IMF Board of Directors

**Dr. Robert A. Kyle**  
Professor of Medicine and Laboratory Medicine,  
Mayo Medical School  
IMF Board of Directors  
Chairman, IMF Scientific Advisory Board

**Dr. Gregory Mundy**  
Professor of Cellular & Structural Biology  
Assistant Dean for Clinical Research  
University of Texas Health Science Center  
at San Antonio  
IMF Board of Directors  
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**Mr. Richard Saletan**  
Founder, Weston Group  
IMF Board of Directors

**Dr. Howard Urnovitz**  
Chief Executive Officer, Chronix Biomedical, Inc.





## IMF LATIN AMERICA

By Christine J. T. Battistini

**I**MFLA Latin America (IMFLA) has been working very hard on reaching out to all of the Latin American myeloma patient population. When we first opened our office in Brazil, we literally had to start from scratch. Currently, we send out 800 InfoPacks every month within Brazil alone, and our Portuguese-language website gets approximately 200,000 to 300,000 hits per month!

Our accomplishments in Brazil became our calling card for the other Latin American countries. But it was difficult for IMFLA to reach all of the Latin American myeloma community without a website. I am pleased to report that on April 20, 2006, we launched a Spanish-language website to serve the residents of the Spanish-speaking countries that we cover. This was a huge undertaking and a great accomplishment for us.



Attendees at launch of Portugal's website, [www.myelomapt.org](http://www.myelomapt.org)

In 2006, IMF Latin America is proud to present five Patient & Family Seminars:

- Santos, Brazil – May 6, 2006
- Rio de Janeiro, Brazil – June 24, 2006
- São Paulo, Brazil – July 31, 2006
- Caracas, Venezuela – September 30, 2006
- Mexico City, México – October 7, 2006

Prior to each meeting, we visit local hospitals, interact with patients and physicians, distribute educational materials, and then proceed with the Patient & Family Seminar activities. By the time we leave, the local myeloma community knows that we are really there for them – we are not just a website and an InfoPack.

Next year, in co-operation with the IMF, IMFLA is planning the first Patient & Family Seminar in Portugal, which will be part of IMF's European meetings calendar.



President of IMFLA Christine J. T. Battistini (center) with Rita de Cassia Nascimento and Abilio Gunutzman

There are approximately 1,200 myeloma patients currently undergoing active cancer treatment in Portugal, with an average of 300 newly diagnosed cases each year. There are cancer centers specializing in myeloma in Lisbon, Porto, and Coimbra. The 2007 IMF Patient & Family Seminar in Portugal will take place in Lisbon.



IMFLA celebrates launch of Portugal's website

A staff of three including my assistant, Rita de Cassia Nascimento, and Administrative & Financial Director, Abilio Gunutzman, runs the IMFLA office. Together with Dr. Brian Durie, we were able to gather all of the Scientific Advisors of IMF Latin America for a meeting that took place during ASH in December of 2005. We plan to reconvene annually during the ASH conference. **MT**

**NOTE:** To contact IMF Latin America or to view information in Spanish, please visit [www.myelomaLA.org](http://www.myelomaLA.org). To access the Portuguese-language website, please go to [www.myeloma.org.br](http://www.myeloma.org.br). To visit the Portugal website, please go to [www.myelomapt.org](http://www.myelomapt.org).

## NUTRITION & MULTIPLE MYELOMA

By Bernadette Festa, MS, RD

**G**ood eating habits are important to all of us. To a cancer patient, however, good nutrition is a powerful tool that can decrease undesirable side effects of both the disease and its treatment, maintain healthy body weight, enhance energy level and quality of life, and increase potential for favorable response. Here are some simple guidelines to improving your nutrition status:

### Fluid intake

It is essential to have an adequate fluid intake. Fluids help your body detox from the drugs in your body. There is a simple formula to determine if you are getting enough fluids. Divide your body weight by 2 to arrive at the number of fluid ounces you should consume on a daily basis. For example, if you weigh 128 pounds, you should drink 64 ounces of fluids per day ( $128 \div 2 = 64$ ). But fluid intake does not simply mean water intake. For optimal health, you want to consume a balance of different fluids. Please see Figure 1 for suggested proportions of your fluid intake.

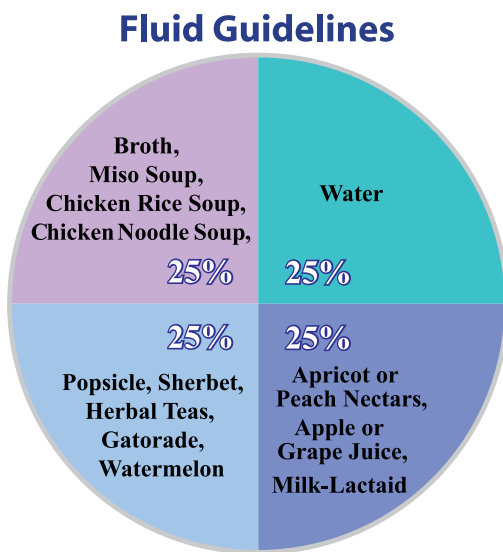


Figure 1. Suggested proportions of fluid intake

### Constipation management

Be sure to drink plenty of liquids to meet your personal fluid goal. Keep a jar of the Anti-Constipation Fruit Paste on hand in your freezer (see recipe). This fruit paste can be consumed by the spoonful, spread on bread, or you can find your own way of incorporating it into your diet. Supplemental magnesium may also be helpful but get approval from your treating physician before taking any supplements.

### Sugar intake

Sugar intake has a significant effect on white blood cell (WBC) count. One hour after ingesting 100 grams of sugar, your body will experience a 37.5% decrease in neutrophil phagocytic activity. This activity ingests foreign or dead cells and helps the body get rid of foreign invaders that we don't want to be there. Two hours after ingesting 100 grams of sugar, your body will experience a 43.7% decrease in neutrophil phagocytic activity. Five long hours after ingesting that sugar, your body will still register an 18.7% decrease in neutrophil phagocytic activity. Neutrophils are the most abundant type of WBCs. They are the body's primary defense against infection, physiologic stress, and foreign invaders. If the number of neutrophils in your body is low, it may be unable to successfully defend itself. Phagocytosis is involved in controlling inflammation and immune tolerance, and plays a part in the body's defense capacity. It is important to remember that while products such as honey and maple syrup may have some trace nutrients that refined sugar does not have, they have the same effect on your body.

### Steroid use

Steroids raise blood glucose levels and body weight, while eventually causing loss of energy. If steroids are a part of your treatment regimen, it is important for you to manage your sugar intake.

### Blood sugar management

One teaspoon contains 4 grams of sugar. The sugar recommendation from the World Health Organization for the average person is 12 teaspoons (48 grams) daily per 2,000 calorie diet. This may appear easy to do but in our culture, it is not. Once you factor in the sugar contained in the foods you eat, you may be eating even more than the recommended amount. Read food labels! You will be shocked to learn how much sugar is contained in



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## Supportive Care

many prepared foods. If you must have something sweet, have it with a well-balanced meal.

### Sugar and Insulin

If you consume sugar, you need a lot of insulin. Reduced insulin sensitivity is associated with reduced glucose tolerance, obesity, and hypertension. Sugar ingestion leads to insulin release. The more sugar eaten, the higher the levels of insulin in the body. Insulin growth factors are associated with many types of cancer.

### Essential Fatty Acids

The average American diet has a high ratio of 25:1 of Omega-6 vs. Omega-3 fatty acids. This leads to an increased tendency toward inflammation, more rigid cell membranes, impaired cell function, and hormone and insulin dysregulation. On a molecular and biochemical level, there is solid evidence to suggest that it worsens the body's ability to fight cancer. In 1999, a NIH Workshop on *"the essentiality of and recommended dietary intakes for Omega-6 and Omega-3 fatty acids"* recommended that 4 to 6 grams of Omega-6 and 2 to 3 grams of Omega-3 be ingested daily. Omega-3 fatty acids are present in cold-water fish, flaxseed, and nuts such as walnuts and almonds. Omega-6 fatty acids are present in safflower, sunflower, cottonseed, and corn oils.

### Trans Fatty Acids

Hydrogenated fats are potentially cancer causing and should be eliminated from your diet as much as possible. These fats are prevalent in prepared foods, especially store-bought baked goods, crackers, and other starchy foods. Be sure to read food labels and control your Trans Fatty Acid intake.

### Probiotics

Probiotics are a group of food products containing live microorganisms that can aid in the maintenance of health and the prevention of disease. Probiotics promote good bacteria, which may play an important role in helping the body protect itself from infection, especially along the mucosal surfaces. Some believe that having a

### 12 MOST pesticide-contaminated fruits & vegetables

- |                   |                   |           |                |
|-------------------|-------------------|-----------|----------------|
| ■ Apples          | ■ Peppers         | ■ Celery  | ■ Cherries     |
| ■ Imported grapes | ■ Nectarines      | ■ Peaches | ■ Pears        |
| ■ Potatoes        | ■ Red raspberries | ■ Spinach | ■ Strawberries |

### 12 LEAST pesticide-contaminated fruits & vegetables

- |               |              |           |            |
|---------------|--------------|-----------|------------|
| ■ Asparagus   | ■ Avocados   | ■ Bananas | ■ Broccoli |
| ■ Cauliflower | ■ Corn       | ■ Onions  | ■ Papayas  |
| ■ Pineapples  | ■ Sweet peas | ■ Mangoes | ■ Kiwi     |

Based on Dept. of Agriculture & FDA data from 100,000 lab tests 1992-2001

healthy immune system is tied in with having a healthy intestinal environment. The intestine is where we absorb a lot of our nutrients and get rid of the wastes in our bodies. Probiotics can be obtained from foods such as plain yogurt or from supplements.

These basic guidelines for good nutrition while coping with cancer give you the ability to improve your quality of life NOW. If you wish to work with a nutritionist on designing a tailor-made dietary program just for you, please make sure that the person you are working with has the expertise necessary to help guide you. Your best bet is to contact a local cancer center and get a referral to a staff nutritionist specializing in working with cancer patients; she/he will have the distinction of being an RD (Registered Dietitian). **MT**

### Anti-Constipation Fruit Paste

- 3–4 oz. Senna tea leaves
- 1 lb. pitted prunes
- 1 lb. raisins
- 1 lb. figs
- 1/2 cup brown sugar
- 1 cup lemon juice

Steep Senna tea leaves in 2-1/2 cups boiled water. Strain tea into a soup pan. Add fruit to tea, and boil for 10 minutes. Add sugar and lemon juice. Remove from heat and set aside until completely cool. Transfer to a food processor, and process until a smooth paste is formed. Store paste in a glass jar in the freezer. Use 1–2 tablespoons daily, as needed.



### IMF HOTLINE COORDINATORS ANSWER YOUR QUESTIONS

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

#### Question:

*I suffer from peripheral neuropathy as a result of my treatments for myeloma. Can you suggest some ways to cope with this debilitating problem? Is it permanent or reversible?*

#### Answer:

Peripheral neuropathy manifests itself as numbness, weakness, tingling, cramping, or burning pain in the extremities (usually the hands and feet). Deposition of monoclonal protein on nerve tissue with resultant neuropathy can occur with myeloma or MGUS (a non-cancerous condition called monoclonal gammopathy of undetermined significance). Peripheral neuropathy can also result from myeloma treatment with vincristine and/or thalidomide. Renal failure and amyloid deposition, potential complications of myeloma, can further exacerbate the neuropathy problem. Patients who have shingles also complain of neuropathic pain that is severe and debilitating (post-herpetic neuralgia or PHN). Although the shingles can be treated with Acyclovir, the neuropathy can persist after treatment.

Although there is no cure for peripheral neuropathy, doctors have offered neuropathy patients a list of vitamins and medications that help them cope with the problem and lessen the symptoms. Some patients' symptoms improve when they have removed the source of the problem. For example, patients whose neuropathy is caused by monoclonal protein deposition may improve when treatment for myeloma reduces the amount of monoclonal protein. Other patients improve when they discontinue therapy with the drug that has caused the problem, usually vincristine, thalidomide, or VELCADE®. Unfortunately, some patients recover only partially or not at all. Keep in mind that what works for one patient may not work for another. Keep in mind, as well, that as the authors of a *New England Journal of Medicine* article (March 27, 2003) entitled "Painful Sensory Neuropathy" conclude, "Treatment of painful sensory neuropathy presents



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

enormous challenges and is currently inadequate." *It is imperative that you consult your oncologist before taking supplements of any kind.*

- On almost everyone's list of remedies for peripheral neuropathy are the B vitamins. Many doctors recommend up to 100 mg per day of vitamin B6. Higher doses of B6 can further damage the nerves. You can also take a vitamin B complex incorporating 100 mg of vitamin B6.

Other doctors recommend 400 IU daily of Vitamin E.

- For leg cramping: tonic water (which has quinine in it) – one glass in the evening and any other time that cramping occurs. Also helpful for leg cramping are potassium (2 teaspoons of apple cider vinegar or bananas and oranges) and magnesium (250 mg twice a day). Be careful with magnesium in larger doses as it can cause diarrhea.
- Amino acids Acetyl L-Carnitine and Alpha lipoic acid have been on the Dana-Farber Cancer Institute's (DFCI) neuropathy regimen since the early days of Velcade clinical trials. These can be obtained at health food stores or some supermarkets. Recommended doses are: Acetyl L-Carnitine 500mg twice a day with food (up to 2000 mg a day can be taken) and Alpha lipoic acid 200mg to 1000mg a day with food. There is also a combination pill of Alpha lipoic acid-200mg and Acetyl-L-Carnitine-500mg which can be taken twice a day.
- Oral tricyclic antidepressants, such as Elavil (amitriptyline), have been widely reported to relieve painful peripheral neuropathy. These versatile drugs have numerous uses other than the treatment of depression. Since these medicines may themselves cause side effects, careful monitoring by a doctor is important. Wellbutrin, an antidepressant with fewer side effects than the tricyclics, has recently been shown to have promise in relieving the pain of peripheral neuropathy.

PLEASE SEE IMF HOTLINE ON PAGE 22



## Support Groups

### THE ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP

By Cathy Lebkuecher

After attending several IMF Patient & Family Seminars and hearing Susie Novis ask the participants if there was a support group in their area, I began to feel a bit guilty. I was diagnosed with myeloma in 1993 and had a bone marrow transplant in 1994, but here I was in 1997 – not receiving any treatment and feeling pretty darned good – and it seemed like I had no excuse not to get involved.

This thought process lasted several months and focused on where we could meet if I started a myeloma support group. My hometown of Sugar Hill was too far from the mainstream; we needed a place closer to Atlanta. In May of 1997, as I was coming home from an ACS Relay for Life, I saw a small church. The location was ideal. I called the church and spoke to the pastor. He was delighted to give us a room at no charge as part of an outreach ministry of the church.

The next step was publicity. It was decided that the first meeting would be in August. Saturday morning was selected to avoid Atlanta traffic and allow those who were working to attend. A flyer was designed and printed and, with the help of two other myeloma patients, it was distributed to local oncologists and clinics. Also, I mailed flyers along with a note explaining who I was through my oncologist's office to their other myeloma patients.

The Atlanta Area Multiple Myeloma Support Group (AAMMSG) had ten people at our first meeting (we were expecting maybe five or six). Everyone was very enthusiastic about the opportunity to speak and learn from other patients. Each month, we had new attendees as word spread. We quickly outgrew our initial meeting room and were able to secure the use of a larger classroom, finally ending up in the very large fellowship hall (still no charge). At one of our very early meetings, the local Novartis representative came to make a presentation about Aredia. He was so impressed with the knowledge and commitment of the group that he offered to sponsor a website for us. Novartis continued to sponsor this website for the next seven years!

I registered AAMMSG with the State of Georgia as a non-profit. My reasoning was that incorporation would give the group better stature with physicians. Unfortunately,



Cathy Lebkuecher at an IMF Support Group Leaders' Retreat

this led to declaring our non-profit status with the Internal Revenue Service. I had not been aware that this had to be done within 18 months, or it could never be done! With the aid of an accountant friend, AAMMSG received our 501(c)(3) status – but this is not something I would recommend to other support groups.

In 1998, support group member Charles Briscoe began meeting with officials from Emory Clinic and the new Winship Cancer Center. Charles felt strongly that myeloma patients should not have to travel many miles to receive quality care. Through a family foundation, Charles pledged \$250,000 to Emory if this pledge was matched by other myeloma patients

and their families. AAMMSG members were spurred on by the possibility of excellent treatment in Atlanta and began a mail campaign to family and friends. The dedication and determination of Charles Briscoe in pursuing this goal has resulted in Emory Winship Cancer Center being “on the map” as a quality treatment center for multiple myeloma.

Since its inception, the AMMSG has been focused on education and the sharing of information. We keep a supply of IMF educational materials on hand, publicize any new information as it becomes available, and seek out speakers whose presentations might benefit our membership. In addition to co-hosting three Patient & Family Seminars with the IMF, we have hosted different guest speakers at special meetings. Among these have been Susie Novis (IMF President), Dr. Brian G.M. Durie (IMF Board Chairman & Scientific Advisor), Dr. Bart Barlogie (Head of the U. of Arkansas Myeloma Institute for Research & Therapy), Dr. James Berenson (President, Institute for Myeloma & Bone Cancer Research), and Dr. Jonathan Simons (Head of the Winship Cancer Center at Emory Clinic).

In our nine years, we have grown to where we average 30-40 people in attendance each month. The complexion of the group constantly changes. Some newly diagnosed patients come to meetings a few times, get the information they need, and never come again. Others form the core of the group and stay to help those who will follow.

PLEASE SEE ATLANTA SUPPORT GROUP ON PAGE 22

## Support Groups

### PREVIEW OF IMF SUPPORT GROUP LEADERS RETREAT

By Maddie Hunter



I was diagnosed with multiple myeloma in 2001. Although I live in New Jersey, I became involved with the myeloma support group in Pennsylvania, The Philadelphia Multiple Myeloma Networking Group. At that time, Debbie Exner was one of the group's leaders and it quickly became apparent to both of us

that I had the energy and the desire to play a stronger role in the group. So, for one year prior to Debbie moving out of state and leaving the group, we partnered in my transition to group co-leader.

We have a lovely structure in our group. One of the founders of the group, Marilyn Alexander, is the group's other co-leader. Our facilitator, Lori Curtis, is a social worker who's been with the group since it was founded. We have a steering committee of 15 to 20 people who are our decision makers. Newcomers to the group are welcomed by greeters and encouraged to spend time

with group "veterans" before our monthly meetings. We have a large group of approximately 300 members, with 30 to 50 people attending each meeting.

I attended last year's IMF Support Group Leaders Retreat in North Carolina, along with my partner and caregiver, Ames Nelson, and Marilyn Alexander and her twin sister, Sharon Klein. The retreat was chockfull of very useful information. The presentations were cutting edge. The networking with other support groups was phenomenal. Meeting other people in leadership positions was very informative. The retreat's guest speaker and counselor, Greg Pacini, got the participants to talk about the more emotional aspects of coping with myeloma. The meeting also allowed us an opportunity to better know the IMF and its leadership, and to build a stronger relationship with the Foundation.

I would advocate that every myeloma support group member take advantage of the wonderful opportunity that the Support Group Leaders Retreat presents. It is a chance to be able to immerse yourself in the most current knowledge that you can bring back home to your group, while relaxing in a supportive and nurturing environment. **MT**

NOTE: To learn more about The Philadelphia Multiple Myeloma Networking Group, please visit the group's website at [www.philadelphia.myeloma.org](http://www.philadelphia.myeloma.org).

### IMF HOTLINE — continued

- Other medications that can be helpful for painful peripheral neuropathy and that require a prescription are: Cymbalta (duloxetine), Celebrex, Lyrica (pregabalin) and/or a Lidoderm Patch. Again, these drugs must be prescribed and monitored by your physician.
- You may want to contact the Neuropathy Association at 800-247-6968, or via the Internet at [www.neuropathy.org](http://www.neuropathy.org).

Like the IMF, the Neuropathy Association is patient-based and non-profit, and provides patient support and education. **MT**

NOTE: Our special thanks to Deborah Doss, oncology nurse extraordinaire at the Dana-Farber Cancer Institute, for sharing their neuropathy information.

### ATLANTA SUPPORT GROUP — continued

We have a board of directors and, over the past fifteen months, have established committees for Greeters, Outreach, and Programs.

As we continue to reach more myeloma patients and family members, we will focus on maintaining continu-

ity as well as adding to our base of support programs. The strength of the group is patients helping patients help each other, a model instituted by the IMF. Together, we can make each other's myeloma journey less frightening and unknown. **MT**

## LIVING SUCCESSFULLY WITH MULTIPLE MYELOMA



By Peter Tischler

*I'm not the smartest guy around and, to be honest, I'd guess that many people in our group are smarter than me. But I'm very good at one thing: I can absorb an enormous amount of data, condense it into a summary, and communicate the results of that data to other people in such a way that they will understand it. That's what I did in business and that's what I've been doing with information about myeloma. Mostly, I do this one-on-one when people ask for help. This editorial is an attempt to reach a larger audience of people with our disease.*

When I was diagnosed with multiple myeloma (MM) and was led to believe that I would only be around for a few years, I thought about what I wanted from medical science. I decided that I wanted quality of life and a chance to survive until a cure was found, with a reasonable quality of life during that survival. I also wanted to avoid undue pain and suffering – I'm a bit of a wimp! As I learned about our disease and how to survive with it, I was often distressed that so many people with MM had not availed themselves of their best chances of survival and quality of life. In some cases, it was not their fault. They hadn't yet had time to learn how to optimize their chances. But in other cases, both the patient and caregiver had abdicated their care to someone who is overworked and cannot possibly devote enough time and resources to them – their doctor. As good as your doctor might be, he (or she) doesn't have the time to do everything for you.

So who's going to take care of you? Who will take that responsibility? It had better be either you or someone who loves you, because nobody else will have the time, energy, resources, and desire to take on the job. The following is a list of things that you (patient, caregiver, family) must know and do in order to best ensure that you will survive with the quality of life you want.

### 1. Take care of your kidneys

- Drink at least three liters of non-carbonated, non-caffeinated, non-alcoholic liquid each day in order to flush your kidneys.
- Avoid ionized contrasts that are typically used for CT scans. Ask for alternative contrast or don't let them use

contrast. Failing to do this could cause your kidneys to shut down and the only solution would be dialysis. Injections for MRI and PET/CT scans are okay.

- Read labels on medications and over-the-counter products. Especially avoid non-steroidal anti-inflammatory drugs (e.g. ibuprofen).

### 2. Avoid infections

- Limit exposure to people who have colds. Be mindful around children, especially during the cold/flu season. In public places (restaurants, church, etc.) stay away from children and anyone else who is coughing and/or sneezing; ask to be seated elsewhere. When flying, consider wearing a mask, and don't be so vain as to think it's not ok. Your life depends on being careful.
- Develop a habit of washing your hands frequently. Always carry anti-bacterial cleaner (e.g. Purell) and anti-bacterial wipes.
- Make sure your family members get a flu shot every year. The flu shot may not work for you, but it will definitely work for your family and, thereby, protect you.
- Be proactive if you do get an infection. A "simple" bronchial infection can easily become a life-threatening pneumonia with your depressed immune system.
- Wound infections easily turn into a septic crisis in you. If a wound is not healing properly, seek medical attention quickly.
- With your immune system, any temperature over 101 (some say 100) is cause for medical attention.

CONTINUES ON PAGE 24



## LIVING SUCCESSFULLY — continued

### 3. Form a survival team

■ You (patient, caregiver, family member) have to be the head of the team. Nobody cares as much about the issues as you do. Make sure that your caregiver has as much knowledge about your condition as you do. At times of treatment with steroids and other chemo drugs you may become overwhelmed with all the information you need to keep straight. Your caregiver is your link with sanity and good judgment.

■ We usually get a local oncologist by circumstance. If that oncologist doesn't meet your needs, change oncologists. Make sure it's somebody you can count on in a crisis (there usually will be a crisis, at some point).

■ Find a myeloma specialist who can direct your treatment. That's somebody who researches and treats only myeloma. There aren't many, so don't be fooled into thinking that someone who has treated a few MM cases is a specialist.

■ Have a good internal medicine physician. Hopefully, you will be in this for the long haul. You need to keep up your general health.

■ If you have kidney problems, add a nephrologist to your team.

■ Add any other specialists for any other chronic conditions you might have.

■ Don't forget nurses – they know much more about symptom control than doctors.

■ Make sure that they all get copies of reports from each other. This is your team – make sure they can work together, and remember that you're the team leader.

### 4. Don't be a "good" patient

■ Make it clear, to each physician, what you (patient and caregiver) want and expect from your medical team members. They are often not all that concerned with issues (e.g. quality of life) that are important to you. You must make sure those other issues are considered by everyone.

■ Get copies of your file records from all your doctors. By law, they cannot be withheld from you, and you need them in order to be team leader.

■ Do not let your physicians "snow" you with medical jargon or condescend to you with overly simplistic explanations. Keep asking questions until they are answered to your satisfaction.

■ Acquire a small cassette recorder and, with the physician's permission, record all appointments. Explain that it's because you don't want to forget anything that is said. Also, take notes during the appointment.

■ It's okay to say, "Let me think about that" when your oncologist tells you that "we're going to start treatment immediately," unless he means that he's going to take the drugs also. This is a very slow-growing cancer and you need to think, research, talk with others, and even get a second opinion.

■ Ask for treatment options (that's plural) and the pros and cons of each one. Ask why he/she favors the one being recommended.

■ When something is wrong, complain – loudly. When something hurts, complain – loudly.

■ Question anything that you're not satisfied is correct, especially with technicians and office staff. But don't become a general pain in the butt. You have to pick your battles – fight and win the important ones.

### 5. Educate yourself

**(This may be you, your spouse, or a family member)**

■ Attend at least one IMF Patient & Family Seminar and participate in it. Go to the breakout sessions and ask questions. Spend time with other MMers there and learn how they're surviving.

■ Attend a local support group as regularly as you can. There are things to learn and you need to feel "part of" a group of survivors. Even physicians can't give you what other survivors can – their experience.

■ Read the "Myeloma 101" written by Peter Tischler and provided by the North Texas Myeloma Support Group. It will explain your disease in lay terms.

■ You'll need a computer and connection to the Internet. The IMF website has an incredible amount of up-to-date information that is essential to the family with myeloma.

CONTINUES ON NEXT PAGE

■ Subscribe to the IMF's online support group of over 1,400 myeloma members worldwide. The daily experiential information is essential for anyone who wants to be proactive in his/her quest for quality survival. You might not understand much at first, but you will quickly become knowledgeable.

### 6. Maintain your immune system

■ Your immune system is defective, but it isn't dead. Optimize it with healthy habits:

- Reduce stress. This is important, as stress can further depress the immune system. Find ways to chill out and relax (in spite of it all).
- Exercise. Also important both physically and emotionally. Find ways to exercise within your limitations. Low impact is best.
- Good diet. Don't go crazy, but try to avoid stressing your systems with "bad" food choices.
- Use multi-vitamins to ensure that your systems are not deprived of any essential nutrients. You might consider a nutritionist or dietician. Those taking steroids must be especially careful.
- In some cases, an endocrinologist might be added to your team in order to ensure that you're staying in balance.

### 7. Keep medical records

■ Trends are important. As you collect your test results, track the important markers (good and bad) so that you will see any trends developing. Learn which markers are significant and use a spreadsheet to visualize trends.

■ Keep all your records in chronological sequence in one or more binders so that you can easily access them when needed.

■ Keep shorthand medical notes in your purse or wallet: e.g. up-to-date medicine list with dosages, physicians with their phone numbers, testing schedule (even doctors will forget or get them wrong, sometimes).

■ Fill out important forms for possible crisis times: Living Will, Medical Power of Attorney, and Do Not Resuscitate (DNR). It's good to have them even if you don't choose to use them.

### 8. Know your doctors' limitations

■ Doctors and nurses are, in most cases, overworked and understaffed. That's the managed care system and you have to learn how to best work with it and get what you need.

■ Doctors make mistakes; so do nurses, technicians, and office staff. That's a fact of 21st century life and your job is to catch the mistakes. Mistakes that have happened to me include:

- Not ordering tests that should be ordered (that's why you have to keep those records)
- Wrong or inadequate instructions for imaging studies
- Not recognizing a trend (those records again)
- Miscommunication between doctor and staff
- Over-medicating and under-medicating

■ Oncologists have a "treatment philosophy" they've adopted through success and failure with other patients. You may not even hear about a treatment from an oncologist because of that physician's experience with it. You may, on the other hand, be urged to take a drug or dosage that's no longer considered cutting edge or even out of common use because of that physician's past experience. You must work through that with your oncologist.

■ Oncologists may be either too aggressive or too conservative to suit your needs. You must deal with that or get another oncologist.

■ Some oncologists are unwilling to communicate with or take direction from other oncologists, especially myeloma specialists. Deal with that or change oncologists.

■ Some oncologists are unwilling to listen to or accede to the wishes of the patient and family. Deal with that or change oncologists.

■ Some oncologists are unwilling to be educated with information from you or the IMF or published studies. Definitely change oncologists.

■ Know your doctors' strengths and weaknesses. Nobody, your doctors included, knows everything.

CONTINUES ON PAGE 26

### **FAMILY & FRIENDS CELEBRATE THE LIFE OF MARIO FEDERIS**

By Marnette Federis

**O**n February 25, 2005, my family celebrated the anniversary of the day, only one year ago, that our beloved Mario Federis lost his battle with multiple myeloma. We wanted to do something special to remember his life and to help educate people about the disease that has had such a profound effect on our family. Our special day of remembrance started with a memorial attended by family and friends. Later, we held a luncheon where we took the opportunity to educate our guests about myeloma and the International Myeloma Foundation. After a brief slideshow, our guests watched a video provided by the IMF about the work that they do to help myeloma patients and their families. Mario understood the power of knowledge. By utilizing various IMF resources to learn more about his disease, its effects, and available treatments, he was able to better



manage his healthcare. Our luncheon ended with hugs and much laughter as we shared memories of Mario with one another. The luncheon was a great way to raise funds for IMF programs, distribute educational information about myeloma, and to just be with our family and friends as we continue to remember the life of a man we all love so much. **MT**



Family & Friends of Mario Federis

### **LIVING SUCCESSFULLY — continued**

#### **9. Early Warning System – Avoiding Crises**

■ Testing is used to track the disease and for tracking the success (or failure) of treatments. It's also important to test when you're in plateau phase so that you will get an early warning when the disease reappears.

- The most important early-warning test is the Freelite Test. This test will show disease progression before any damage occurs.
- Some tests should be run early in your journey with myeloma, even though they're not yet needed for tracking, in order to establish baseline results for tests that will be needed later in your journey. Whole-body MRI, quantitative immunoglobulins, and a bone density test could be run in addition to the usual skeletal survey with x-rays.

■ Consider having prophylactic medications available, especially if you are going to travel. Consider a good

antibiotic (I have Levaquin), an antiviral (I have acyclovir) and something to use for flu (I have Tamiflu).

■ Avoid unnecessary surgery, as the trauma of surgery might trigger an MM "flare." If surgery is necessary, have your oncologist keep close tabs on your markers after the surgery.

■ Above all, react immediately when something is not right. The caregiver must make sure that the person with MM does not "tough it out." Once in a crisis, it could be too late to stop a cascade of system failures in an immune compromised person. "Toughing it out" when it comes to pain is ridiculous. Your oncologist should prescribe a pain medication that will keep you comfortable. **MT**

NOTE: Peter and Lucy Tischler, and Jerry and Marcia Sawyer, are co-leaders of the North Texas Myeloma Support Group. This article first appeared in the support group's January newsletter. More information can be obtained through the group's website at <http://northtexas.myeloma.org>. Peter Tischler has been living with myeloma since 1994.



## Member Events

### IMF HONORS MEMBER EVENT THROUGH RESEARCH GRANT

#### "J.C." Johnson's Family and Friends Raise \$90,000 to Fight Myeloma

Residents of Saint Cloud, Minnesota, are mobilizing friends and neighbors throughout the Minneapolis metropolitan area to support the upcoming 7th annual "J.C." Golf Tournament to benefit the International Myeloma Foundation.



Shelley Zins, Betty Zins, John Spanier, and Mari Johnson at the 2nd annual "J.C." Golf Tournament

Janet Carol "J.C." Johnson lost her four-year battle with multiple myeloma in July of 1999. About two months later, a group of family and friends gathered for a round of golf. While sharing memories of J.C., someone remarked that it had always been her wish that her family and friends continue the fight against cancer by supporting cancer research whenever possible. Suddenly, it was as if everyone had the same idea at the same time! The organizing committee for the first annual "J.C." Golf Tournament was formed on the spot, with Mari Johnson, Shelley Zins, and Betty Zins taking on the brunt of the work.

The first "J.C." Golf Tournament took place in May of 2000, and brought together 75 friends who collectively raised more than \$8,000. Last year, the 6th annual golf tournament brought together 180 golfers plus 50 guests and volunteers to celebrate the life of "J.C." and the spirit of camaraderie, while supporting the myeloma community. Since its inception, the J.C. Golf Tournament has raised \$90,000 for myeloma research.

With the continued support of family, friends, and the myeloma community, this year's tournament will be bigger and better than ever. "We are extremely proud of the people who support this tournament each year through their participation and contributions," said David Johnson, current chair of the tournament commit-

tee. "The event has become a favorite for so many – it is often a sell-out – and we think it is because people truly enjoy having a great time while making a difference in the lives of so many."

To mark the outstanding contribution of the J.C. Golf Tournament, Janet Carol "J.C." Johnson will be named on the 2006 Brian D. Novis Research Grant that the IMF will award to an outstanding researcher in the field of multiple myeloma later this year. This honor recognizes the tournament committee's dedication and commitment to funding research to find a cure for multiple myeloma.



Bob Zins (third from left), David Johnson (second from right), and friends at the 6th annual "J.C." Golf Tournament

"We are so grateful for the Johnsons' fundraising efforts, and the dedication of their friends and family who support the J.C. Golf Tournament every year," said Susie Novis, IMF President. "Events such as these raise significant dollars for myeloma research and patient programs every year. Their determination and hard work inspire us and provide much-needed support for patients and family members everywhere."

**This year's tournament will take place on May 20th at the Wapicada Golf Course in Saint Cloud.** The event will feature 18 holes of golf, and putting and hole-in-one contests followed by dinner, a silent auction, and entertainment. Registration begins at 11 AM and the shotgun start will take place at 12:30 PM The community is invited to attend this event and/or to show their support by making a donation at <http://tinyurl.com/kj6ml>. For more information about the event, please contact David Johnson at 952-546-6000 or Bob Zins at 320-253-4449. **MT**

## Member Events

### **MUSIC AGAINST MYELOMA**

By Slava Rubin

**M**usic, cheese, cupcakes, and an intimate venue in the heart of Manhattan! These were the key ingredients for “Music Against Myeloma,” a charity event to raise awareness and funds for multiple myeloma research in tribute to my father, Mark Rubin, who passed away from this disease in 1993. On April 5, 2006, nearly one hundred Rubin family members and friends gathered at Serena Bar in Chelsea. Together, we were able to raise nearly \$10,000 for the International Myeloma Foundation.



Slava and friends at the Music Against Myeloma event

The event was made successful through the help of many supporters, and included music by Lost in October (led by Matt Ostrower) and Josh Walker accompanied by Samantha

Leigh. Cheese from Artisanal Premium Cheese Center and cupcakes from Sugar Sweet Sunshine highlighted the epicurean delights for the evening. “I am not sure why I don’t have cupcakes and beer more often!” said one anonymous patron. Specially designed socks with a “Cancer Sucks” slogan were made available for the care of Cecilia Rubin.



Slava with his mother, Dr. Emma Rubin

In between the performers’ sets, the crowd heard from Michael Katz, member of the IMF’s Board of Directors, who spoke about the importance of grass roots fundraising efforts and the amazing strides that myeloma research has made since 1993. My mother, Dr. Emma Rubin, and I would like to extend our heartfelt gratitude to everyone who participated in this unforgettable evening and stepped forward to make a difference. **MT**

### **2006 MEMBER EVENTS CALENDAR**

**May 20, 2006 – JC Invitational Golf Tournament –**

David Johnson, 952-546-6000, DJohnson@borkonlaw.com, Wapicada Golf Course, Sauk Rapids, MN

**May 20, 2006 – Leona Cravotta Memorial Golf Tournament –**

Katelyn Martin, 540-894-5861, kmm9v@cms.mail.virginia.edu, Tanyard Country Club, Louisa, VA

**May 20, 2006 – Ralph Ferrizzi Memorial Golf Tournament –**

Ralph Ferrizzi, Jr., 610-438-1619, Ferrizzi@rcn.com, Green Pond Country Club, Bethlehem, PA

**June 10, 2006 – Terry DuBois’ Birthday Bash for Myeloma –**

Diane DuBois – 715-425-2817, Ellsworth, WI

**July 9, 2006 – Multiple Musicians Against Multiple Myeloma–**

Naomi Margolin, 516-487-6712, NMargolin@aol.com, Tupelo Honey, Sea Cliff, Long Island

**July 22, 2006 – WAMP SWIM-A-THON 2006 –** Wampanoag

Country Club, 60 Wampanoag Dr., West Hartford, CT, Contact: Liz Stafford, (860) 778-3766

**August 28, 2006 – Corporate Cup Challenge –**

Brad Springer, 630-848-1335 – brad@hhpmail.com, Cross Creek Country Club, Naperville, IL

**September 9, 2006 – Walk For The Cure –** Eve Friedli,

507-280-5992, EFriedli@HartlandFuels.com, Rochester, MN

**October 14, 2006 – Second Annual Myeloma Walk –**

Lake Oseola, University of Miami, Miami, FL – Contact: Denise Vidot peaches2822@aol.com

**November 3, 2006 – Arizona Fundraiser** (details to follow)

*For up-to-the-minute information on IMF Member Events, please refer to the IMF’s web site – [www.myeloma.org](http://www.myeloma.org) – and click the “Events” tab.*



## Member Events



Lisa Mehalick (right) with her mother, Yvonne Yaksic, and son, David

### OUR GUIDING LIGHT SHINES BRIGHT By Lisa Mehalick

One of my mother's greatest attributes is her ability to teach through example and, when she was diagnosed with myeloma in February of 2005, she continued to acknowledge the many blessings in her life. Throughout her battle with myeloma, she has shown her children and grandchildren how this journey can be one of great healing, physically and spiritually. She has found the silver lining in the dark cloud of myeloma by starting our family on a path of fundraising to help the myeloma community. Our children's birthdays, Christmas celebrations, etc. became an opportunity to seek donations for the IMF in lieu of gifts. This has been met with the great generosity of our friends and family, and made them feel like they're helping an important cause. We have been able to spread the word about myeloma and raise funds to find a cure. Now that is a true celebration! **MT**

## Member Events Updates

### Ribbon of Hope Ornament

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



### Recipes for Research

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

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



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

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

### Mail for the Cure



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

### Cell Phones 4 A Cure

To paraphrase Brian Novis, "One can make a difference, two can make a miracle." Being part of the miracle can be as easy as donating your old cellular phone. Or you can take up a collection of old cell phones from family, friends, and/or business associates. Please mail your phones to the IMF at: 12650 Riverside Dr. #206, North Hollywood, CA 91607. To learn more about this wonderful fundraising program, please call Kemo Lee at 800-452-CURE (2873).





## Scientific Advisor Profile

### **A. KEITH STEWART, MB, CHB, MBA**

#### **Myeloma Today: Dr. Stewart, please tell us a little about your medical training and experience.**

**Dr. A. Keith Stewart:** I graduated from Medical School at the University of Aberdeen in Scotland, and did my internship at Glasgow Royal Infirmary. I trained in Internal Medicine at Queen's University in Kingston, Ontario, Canada. I specialized in Hematology and Oncology at the University of Toronto and was a Medical Research Council Fellow at the New England Medical Centre in Boston. From 1992 to 2005, I was a consultant at the Toronto General and Princess Margaret Hospitals, University of Toronto, where I held the Scott-Whitmore Chair in Hematology. In 2002, I was appointed the inaugural director of the McLaughlin Centre for Molecular Medicine at the University of Toronto. Last year, I joined Mayo Clinic in Scottsdale, Arizona.



Dr. A. Keith Stewart  
Senior Associate Consultant –  
Division of Hematology/Oncology  
Professor of Medicine –  
Mayo Clinic College of Medicine  
Mayo Clinic  
Scottsdale, Arizona

#### **MT: How did you first become interested in multiple myeloma?**

**Dr. Stewart:** My basic research was in B lymphocyte biology. In 1992, transplant for myeloma was the state-of-the-art approach to myeloma treatment. I was trained in stem cell transplant, so I married my two interests together: basic research into this type of cancer and clinical practice with stem cell transplant as the focus.

#### **MT: When did you become involved with the IMF?**

**Dr. Stewart:** Since 1992, I have been heavily invested in the field of myeloma. I became aware of the IMF in 1993 when I attended the International Multiple Myeloma Workshop at Mayo Clinic. A few years later I joined the IMF Patient & Family Seminar program as a faculty member. In 2004, I was invited to join the IMF Scientific Advisory Board and participated in my first Advisors' Retreat, which focused on molecular testing and its clinical applications. The IMF does an excellent job in the area of patient education, and I want to contribute to that cause in whatever way I can. I am interested in what's best for myeloma patients, particularly in the area of improving available treatments.

#### **MT: What has been your experience at Mayo Clinic in Scottsdale?**

**Dr. Stewart:** The myeloma team here was formed just last year, and includes Drs. Rafael Fonseca and Leif Bergsagel. After years of working together while thousands of miles apart, we are all pleased to finally be working at the same center. This has been a very exciting start-up period. We share a lab, we have shared clinical meetings, and we have made some exciting discoveries. The three of us are a good team, and I think it will help myeloma patients to have us working together.

#### **MT: What is the focus of your current activities in myeloma?**

**Dr. Stewart:** We are most interested in defining the genetic basis of myeloma, and developing therapies that target that genetic disruption. My colleagues are most interested in finding the genes that are going awry, and my lab and clinical practice is focused on finding drugs that are most helpful in treating myeloma. We have four Phase I clinical trials currently ongoing, and we are developing or running a number of large Phase III clinical trials. We are particularly excited about exploring inhibitors of fibroblast growth factor receptor 3 (FGFR3), which affects 15% of myeloma patients. We are also investigating a promising new proteasome inhibitor that has a different spectrum of activity than bortezomib, although we do not yet know if it will be better than the existing drug.

#### **MT: Based on your clinical experience in both Canada and the US, how would you compare the two health systems?**

**Dr. Stewart:** Both systems have their own unique advantages and frustrations. In Canada, some of the newer myeloma drugs are either not available or difficult to access. The government there has not been responsive to the needs of the myeloma community – they have refused to pay for certain drugs, making it difficult for clinicians to offer the optimal care to their patients. But, in Canada, doctors can care for their patients without

PLEASE SEE A. KEITH STEWART ON PAGE 31

## Board of Directors Profile

### **IGOR SILL**

#### **Myeloma Today: Mr. Sill, please tell us a little about your educational and professional background.**

**Igor Sill:** I received my MBA from Oxford University, Said Business School, and attended the University of California, Berkeley, as well as Stanford University's Graduate School of Business SEP program, Advanced Management College, and Strategic Marketing Management. I also attended Harvard University's GSB Venture Capital Program, and Stanford University School of Law's Directorship College Program. Currently, I am the Managing Partner of Hambrecht Geneva Ventures, Managing Director and co-founder of Geneva Venture Partners I & II, and the Founder and Chairman of GenevaGroup International, Inc. Prior to forming GenevaGroup, I served as Vice President for Visual Engineering, founding management team member of INGRES, and Director of Sales and Support for MicroPro International (renamed WordStar) during its high-growth pre-IPO period. Prior to entering the software industry, I served as General Manager, EIS, and managed the internal merger and integration of EXXON Corporation's three high technology divisions: Qwip, QYX, and VYDEC.

#### **MT: What about your family life?**

**Mr. Sill:** My wife, Cindy, and I enjoy the wine country of Northern California, and are starting to put in a vineyard at our St Helena home. My daughter, Jessica, works in the business at Geneva Venture Partners. My son, Weston, recently joined the Army National Guard but he is in college so he won't be starting his service

until he finishes college. My other son, Kevin, is a patent attorney in New York City.



#### **MT: Has your life been touched by multiple myeloma?**

**Mr. Sill:** My wife was diagnosed in November of 2005, with 90% myeloma cells. She has already had one stem cell transplant with Dr. Bart Barlogie in Little Rock, Arkansas. Her second transplant is scheduled for the end of May. This is a highly individualized disease, and patients have to make their own individual decision about treatment. Given the range of options, Cindy opted to dive in completely,

rather than just stick her toe in the water. I've taken some time off to be her caregiver. She has had numerous lesions and broken bones, with one remaining, but there is no evidence of myeloma in it. Although we are very early in our myeloma journey, her outlook is good.

#### **MT: How did you become involved with the IMF?**

**Mr. Sill:** My wife and I were hit by the diagnosis pretty hard. The very next day, we met a myeloma patient who lives just a few miles from us, and she referred us to the IMF website. That night, I visited the site and was very impressed with the educational content. Now I want to do whatever I can to provide the resources for the physicians and researchers to combat and eradicate myeloma as quickly as humanly possible. At the end of the day, nothing happens without capitalization of these efforts, and I believe that the best vehicle to do this is the IMF. I see Susie Novis as the propelling entrepreneur behind the IMF, and I want to do whatever I can to support her efforts. **MT**

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### **A. KEITH STEWART — continued**

being hindered by the patients' lack of finances or insurance. My experience in the US has been quite depressing at times. There are patients here who I feel can be looked after but their insurance won't allow them to be treated. So, under Universal Health Coverage in Canada everyone gets good patient care but has to cope with the government's unwillingness to pay for costly new drugs, while in the US everyone can access the drugs but may

be unable to pay for them either on their own or via inadequate insurance coverage.

#### **MT: Please tell us a little about your life outside of myeloma.**

**Dr. Stewart:** My wife, Bridget, is a veterinarian. We have three kids, ages 10, 8, and 5, who are involved in every sport conceivable. And when I am not looking after them, I am an enthusiastic but atrocious golfer! **MT**

### Fighting with everything you've got

**W**hen I was diagnosed with myeloma, I believed no one understood how bad I felt, how much I hurt, how tired I was, how afraid, etc. The problem is that no one can do anything about it EXCEPT US! We are our own best friends on this rocky road. Here are a few things I did:

1. Psychology: Had about four visits with a psychologist and finally accepted my problem instead of denying it. She also taught me to do a process diary where my daily task was to write down ten positive things that made each day a little better. My first entry was a bit-ter and bald, "Got a normal bowel movement!"
2. Antidepressants: Took a tricyclic antidepressant (amitriptyline) which helped with neuropathy, but particularly with those middle of the night waking nightmares where you wonder what is coming next, how long have you got, etc.
3. Prayer and/or meditation: If you are religious, pray. If not, take up some kind of meditation.
4. Support: A cancer support group is likely to have truly inspirational folks as members. Some are enduring much more than you'll ever suspect and from them you will truly learn to cope.
5. Hobbies: A sedentary hobby gives your mind something to enjoy. At our local Gilda's Club I took up a watercolor class. I found out how very untalented I am but the two-hour class was amazingly relaxing. I felt awful because of the chemo in my system but painting took my mind away from the cancer obsession.
6. Don't feel guilty about taking time out for yourself: I went to a program called Healing Touch where nurses at a cancer support center realign your energy centers (called "shakras"). It felt wonderful whatever it was! There may be several of these alternative programs in your area, but make sure that the program will not jeopardize your health. The American Cancer Society has a marvelous program called "Look Good, Feel Better" which provides you with a free wig and cosmetics reputedly worth \$100. A cosmetologist shows you how to use the makeup and will also style the wig if there is enough time.
7. Exercise: There are gentle exercises you can do, even while sitting down, which will help dispel that exhausted flu-like feeling in your arms and legs from

the chemo. Ask a physical therapist to show you appropriate movements. Yoga may NOT be a good idea if you have bone damage.

8. Thankfulness: Be very thankful to all your caregivers who have the most difficult and stressful job of all. There will be times when you won't feel thankful at all but, believe me, they hurt a lot, too.
9. Education: Take advantage of attending seminars in which you will learn more about myeloma and the latest treatments. Knowledge is power. Take charge of your life. You'll be glad you did and happier when you see that helpless look disappear from your family members' faces.

With love and hugs,  
**Ann Collins Hill**

### The IMF

The International Myeloma Foundation is a group of very caring, friendly, and knowledgeable folks who have a great desire to do all in their power to assist every myeloma patient possible in their battle with myeloma.

We have experienced first-hand the IMF Patient & Family Seminars that are extremely informative and provide education about myeloma and provide hope to us that someday this disease will either have a cure or become a chronic disease with an acceptable quality of life.

It gives us great comfort to know that if there are any questions that come up in Jerry's treatment, the IMF hotline is there to assist. The Hotline monitors are ready with up-to-date answers, and if they do not know the



Susie Novis with Marcia and Jerry Sawyer



## Letters to the IMF

### Letters — continued

answer, they have top-notch myeloma specialists to go to for help.

The materials that are available through the IMF are extremely informative. The Patient Handbook was easy to understand and very helpful when Jerry was diagnosed and we were trying to figure out what we were up against.

We are co-leaders of a large support group in the Dallas area. The IMF has been extremely helpful by providing us with materials and information that are invaluable to run a successful group.

**Jerry and Marcia Sawyer**

A group of us are caretakers for a friend and colleague with myeloma. We have received the order I placed for various IMF materials. Your InfoPack is very good, clear, reader-friendly, and attractive. The pins and bracelets have arrived, too. Your materials have increased our understanding of our friend's condition and have helped us to raise myeloma awareness. Thanks for an excellent resource.

**Cay Jurgensen**

I received your materials and have talked with the Hotline's Nancy Baxter, and have received several e-mails from her. Thank you all very much. You have helped me enormously after the shock, fear, and anxiety of learning that I was a potential victim of multiple myeloma. Hope to go to Philadelphia in August for the IMF Patient & Family Seminar with my son who will be my primary care helper.

**Paul Alexander**

#### MT

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

### The IMF has new publications!

In the *Understanding* series: *Dexamethasone and Other Steroids*, *Serum Free Light Chain Assays*, and *Revlimid®*, are available. Please log on to our website at [www.myeloma.org](http://www.myeloma.org) or call us at 800-452-CURE (2873) and we will be happy to send you a copy.



Here are just some highlights of what we will be bringing you in the next issue of Myeloma Today.

### Coming This Summer...

- A report on the meeting of the IMF Scientific Advisory Board in Portugal
- An overview of the outcomes from the annual meeting of the European Hematology Association
- A report from the annual meeting of the Oncology Nursing Society
- A sneak preview of the upcoming American Society of Clinical Oncology meeting
- An update on the IMF's Bank On A Cure® myeloma research initiative
- A report from IMF Research Grants recipient Dr. Nicola Guiliani
- A profile of the IMF Patient & Family Seminar program
- A report on our Myeloma Canada affiliate
- Important supportive care information on oral care and Osteonecrosis of the Jaw
- A report from the IMF Support Group Leaders Retreat

If you or someone you know wants to be kept up-to-date regarding all the significant developments in the field of myeloma, as well as news about the IMF and other topics of interest to the members of the myeloma community, please contact the IMF to subscribe to this free-of-charge quarterly publication.



### **National Physician of the Year: Bart Barlogie, MD, PhD**

Dr. Barlogie is National Physician of the Year in the first awards given by the organization responsible for the annual America's Top Doctors publication. Dr. Barlogie and two other physicians received the award for clinical excellence from Castle Connolly Medical Ltd. during a ceremony March 15 at the Metropolitan Club in New York City. Dr. Barlogie is one of the world's leading experts in the diagnosis and treatment of multiple myeloma. "I am thrilled by this recognition by my fellow physicians and Castle Connolly for our continuing work at the Myeloma Institute to find a cure for multiple myeloma," said Barlogie, who in 2004 received the IMF's Robert A. Kyle Lifetime Achievement Award in recognition of his 20-year career in the treatment of multiple myeloma.

### **IMF Sponsors Symposium for Oncology Nurses**

Newly released information on treatment for myeloma is critical to improving patient care. The IMF is pleased to announce a special education symposium, Advancing Access to Myeloma Treatment: Administration, Side Effects, and Implications for Survival, to be held prior to the ONS 31st Annual Congress. The event will take place on May 4, 2006, at the Boston Convention and Exposition Center. The meeting is designed to meet the needs of oncology nurses who manage the treatment of myeloma patients. This activity is sponsored by the International Myeloma Foundation and the Institute for Continuing Healthcare Education and supported by educational grants from Celgene Corporation and Millennium Pharmaceuticals.

### **Temple University Study Published**

According to a new Temple University study published in the March 2006 issue of the Journal of Health Communication, newly diagnosed cancer patients who use the Internet to gather information about their disease have a more positive outlook and are more active participants in their treatment. For this study, the researchers recruited 442 patients who called a toll-free NCI-funded number, where trained specialists answered questions about the disease and directed callers to resources in their area. During the survey, a strong parallel emerged between Internet use and the patients' feelings about their decision-making ability. Those who used the Internet or received Internet information from family or

friends were more likely to view their relationship with their doctors as a partnership, and were more comfortable asking questions about treatment alternatives.

### **The IMF Publishes German Language Myeloma Newsletter**

The Myelom Merkur, the IMF's first German language newsletter, was inaugurated in April 2006. The idea for this new service came out of a meeting convened by the IMF in October, 2005, of German-speaking support group leaders in Heidelberg, Germany. The Myelom Merkur will feature translations of medical and scientific articles from Myeloma Today and the Myeloma Minute. If you or someone you know might want to receive the Myelom Merkur, please contact Gregor Brozeit at merkur@myeloma.org to register for this free service. A distribution system is also being set up for those without Internet access.



Danish Multiple Myeloma Assembly Leaders Jørgen Gislinge, Peter Randløv, and Ole Dallris meet with newly appointed Director of IMF Europe, Gregor Brozeit (second from right)]

### **National Cancer Survivors Day®**

National Cancer Survivors Day® (NCS D) is an annual, worldwide Celebration of Life that is held in hundreds of communities throughout the United States, Canada, and other participating countries. Participants unite in a symbolic event to show the world that life after a cancer diagnosis can be a reality. In the beginning, cancer survivor Richard Bloch (co-founder of H&R Block) and his wife, Annette, held their first Cancer Survivor Rally in Kansas City, Missouri, to demonstrate that a diagnosis of cancer was not an automatic death sentence. The idea soon caught on in other communities. NCS D is celebrating its 19th year in 2006, and is now the world's largest and fastest-growing annual cancer survivor event. NCS D defines a "survivor" as anyone living with a history of cancer – from the moment of diagnosis through the remainder of life. To attend an official NCS D 2006 event in your area on June 4th, e-mail info@ncsd.org or call 615-794-3006. **MT**

# Hope springs eternal.



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

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**ORDER FORM**



Dear Reader,

It's spring: a time of new beginnings. Winter is over, anything is possible, and a renewed sense of hope is in the air.

There is much activity and momentum in the world of myeloma, giving us good reason for renewed hope. Two important drugs for the treatment of myeloma, thalidomide and Revlimid, should receive FDA approval in the next few months; another milestone for myeloma patients. These drugs would join VELCADE as the first new therapies approved for the treatment of myeloma in over 20 years.

Dr. Julian Adams, who was responsible for the development of VELCADE, is now with Infinity Pharmaceuticals, and he is a driving force in the development of innovative new drugs. He's now spearheading the development of HSP90 inhibitor, IPI-504. This compound in combination with other drugs holds great promise, and we anxiously await the early trial results.

Amgen has developed a new antibody RANK-L inhibitor, AMG 162, which currently is completing clinical trials for its use in the treatment of osteoporosis. Myeloma trials using this new antibody are just getting underway.

There is also a lot of excitement about using the novel agents such as thalidomide, Revlimid and VELCADE in new combinations, along with prior chemo agents. Multiple trials combining these drugs are taking place around the world.

All this activity means that something big is going to happen soon!



In addition, the IMF and the International Working Group have moved us forward by publishing three crucial papers that will ensure better treatment and outcomes for myeloma patients. The Myeloma Management Guidelines ensure that patients today get the best care possible. An updated 2006 version will be available this summer.

The International Staging System provides doctors with the information they need to properly stage and treat their patients. The Diagnostic Criteria establish the baseline criteria for defining and treating active (symptomatic) myeloma.

The International Working Group's most recent project has been the development of the International Response Criteria, which was recently submitted for publication. The Response Criteria simplify and codify the way oncologists define response to treatment. This will allow groups throughout the world to more precisely compare results of various treatments.

These important projects from the International Working Group have changed the landscape for myeloma treatment and provide greater hope with each passing year.

I'm proud of what the IMF has been able to achieve, through its collaboration with doctors and researchers from institutions around the world. I would like to take this opportunity to extend to them a very heartfelt thank you – we couldn't have done it without you!

Warm regards,  
Susie Novis



**International Myeloma Foundation**  
12650 Riverside Drive, Suite 206  
North Hollywood, CA 91607-3421  
U.S.A.  
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