



# MYELOMA TODAY

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A PUBLICATION OF THE INTERNATIONAL MYELOMA FOUNDATION

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

## Scientific & Clinical News



**Dr. Brian G.M. Durie** discusses the status of the initial phases of the IMF's innovative Bank On A Cure<sup>®</sup> research initiative, the world's first repository of DNA created to advance

the understanding of myeloma. **PAGE 6**



**Dr. Robert Z. Orlowski**, the overall study chair for two myeloma clinical trials of **VELCADE<sup>®</sup> plus DOXIL<sup>®</sup>**, explains the role of this combination therapy in multiple myeloma, as well as other treatment options available to patients and their healthcare providers. **PAGE 7**



**Dr. S. Vincent Rajkumar** discusses the current role of lenalidomide (**Revlimid<sup>®</sup>**) in multiple myeloma, focusing on Mayo Clinic's study of this novel agent in the frontline setting and future directions for combination therapies. **PAGE 9**

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**Gary Benanav, 26-year survivor**, tells his story of living with multiple myeloma since 1981 and appreciating the gift of each day of life. **PAGE 18**



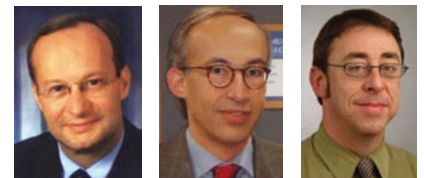
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**David Smith**, who was recently promoted to the newly created position of Executive Director, answers questions about how his professional and personal experiences prepared him for the responsibilities of building upon the successes of the foundation in the core areas of our mission. **PAGE 21**

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## LOOKING FOR A LOCAL MYELOMA SUPPORT GROUP?

If you are interested in joining an existing group please access the website at [www.myeloma.org](http://www.myeloma.org) "Finding Support" or call the IMF at 800-452-CURE (2873).

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## Dear Reader,

Spring is traditionally a time of new beginnings, and a reminder that anything is possible. At the IMF, this is definitely a time when new ideas are blossoming into projects that provide a clear way forward.

The IMF knows that in order to move forward and get results you have to be inclusive, move expeditiously, and involve the key players – patients, physicians, and nurses. And that's exactly what we've been doing, and achieving amazing results!

I'd like to take this opportunity to update you on some of these projects, such as the US Myeloma Forum, Bank On A Cure®, the Nurse Leadership Board (NLB) and, of course, our grassroots outreach to patients.

The US Myeloma Forum's goal is to bring together key opinion leaders from the US to form a coalition whose goal will be to bring focus to projects by working collaboratively and reducing duplication of efforts and dilution of valuable resources. Multiple clinical trials are needed to assess the best impact of the novel therapies for myeloma. In order to ensure success, clinical trials must be organized in a cohesive way to ensure that the final results provide clear comparative data. The US Myeloma Forum will provide both critical input for pharmaceutical trial design and facilitate CTEP review within the Cooperative Group setting. The discussions by US Myeloma Forum participants will result in consensus statements and recommendations to bring clarity to immediate clinical trial priorities, such as how best to integrate novel therapies. Taking a fresh look at all the options will allow for better long-term decisions. The first meeting of the US Myeloma Forum is taking place April 17–18 in Santa Monica, CA.

The most exciting news is that Bank On A Cure is showing amazing results! Findings to date include identifying genes linked to increased risk of deep



Susie Novis  
IMF President

vein thrombosis associated with some of the novel therapies, and identifying genes linked to myeloma bone disease. The Bank On A Cure team is also investigating why some patients respond to novel therapies while others don't. For more detailed information, please see page 6 of this newsletter.

The NLB was established last year. In essence, the NLB is the "link" to optimal care for patients, and that's extremely important. We're very excited that an abstract that the NLB submitted to the XI International Myeloma Workshop has been accepted! Please see page 11 for a more comprehensive update on the Board's current activities.

Our primary focus is always on patients. The IMF reaches out and helps the patient community through a wide variety of innovative programs and services. We work closely with a large network of

myeloma support groups and, in April, the IMF is hosting its 8th annual Support Group Leaders Retreat. With hundreds of support groups around the world representing thousands of patients and caregivers, we're delighted that we'll once again have representatives from groups across the US, Canada, and Europe in attendance at this year's retreat. Working closely with support group leaders ensures that they are better able to meet the many challenges of running and maintaining a group.

To stay informed about the IMF's innovative programs and broad range of activities, please stay tuned to future issues of Myeloma Today, visit the IMF's website regularly, and subscribe to our weekly email letter, the Myeloma Minute.

Warm regards,

Susie Novis

## Letters to the IMF

### The IMF

Thank you so much for all your dedication. I cannot tell you how helpful and comforting it is to know that there is an organization such as the IMF, filled with folks at the service of families dealing with multiple myeloma.

Sophie Leguillette

### Myeloma Today

Just wanted to write to let you know that I thought the article by Peter Tischler – Living Successfully with Multiple Myeloma – was great. It's not real technical and demonstrates a plain common sense way of how to deal with this disease. I have read this article not just once but several times. It's great for newly diagnosed patients!

David Dolinger

### IMF Hotline

I was so pleased with your quick and complete response. I am very thankful to you. You made my day... I am glad that there are people who are experts in the field of multiple myeloma that we can access. It is the great organization of the IMF that makes this possible.

Willem Dieperink, MD

Many thanks for the prompt and detailed response to my question, it was very helpful and reassuring. It is really great to have such easy access to advice and information.

David Reed

## **MYELOMA TODAY IN CONVERSATION WITH MICHAEL KATZ**

### **What were the circumstances surrounding your myeloma diagnosis?**

In 1989, I felt the first symptoms of myeloma. After nine months of diagnostic missteps, doctors found a grapefruit-sized plasmacytoma that had broken through the back of my pelvis. A surgeon removed the tumor and replaced the damaged bone with a graft from a bone bank. After radiation and a year of physical therapy, I was pretty much back to normal.

### **At that point did you think that your troubles were over?**

I was not told and did not understand that I had an incurable disease. In 1991, microfractures appeared above the hip joint, so I had another biopsy, after which I heard the words “multiple myeloma” for the first time. The IMF did not exist then. There was no Internet. It took me six months to find another patient with myeloma. The man was not very helpful but he mentioned a book, *Going for the Cure*, written by Francesca Thompson, a myeloma patient and orthopedic surgeon. I wrote her a letter asking about the bone issues I was having. She called me and we spoke for over an hour.

### **How did you become involved with the International Myeloma Foundation?**

Francesca told me about a doctor in England named Brian Durie, so I used my frequent flyer miles to get myself to London. After we got the medical business out of the way, Dr. Durie told me about the IMF and put me in touch with its co-founder, Brian Novis. In 1993, I flew to Los Angeles to attend the first IMF Patient & Family Seminar. I volunteered to help the IMF, setting up its computer database, building the website, and writing the first Patient Handbook. Fellow patient June Brazil and I founded the Multiple Myeloma ListServ, which provides an online forum for patients and caregivers. As I became more and more involved, I was asked to join the Board of Directors and then the Executive Committee.

### **Please tell us about your decision to keep your diagnosis private.**

I was 37 years old. My sons were 7, 9, and 12. While the diagnosis was devastating, the prognosis was pretty good even all those years ago, and it was not likely I'd die any time soon. My wife and I decided that our best strategy was to try and live as normal a life as possible. We chose not to tell our family, friends, or business associates. We did not tell our children because there was no reason to burden them with thoughts of their parents getting sick and dying. This proved to be a winning strategy for 10 years.

### **Why did your strategy change?**

Over the first 10 years post-diagnosis, we were able to keep the disease under control with a variety of treatments. In the tenth year, I developed a tumor at the base of my skull. I was in horrible pain. It was obvious to my



Michael S. Katz

sons that something was very wrong. By this time, they were 17, 20, and 23. They deserved an explanation, and were old enough to deal with it. The fact that I'd already had myeloma for 10 years helped them put it into perspective. They understood that this was something I would be able to fight.

### **Did you share your diagnosis outside the family?**

After the skull tumor ordeal, my diagnosis became more widely known at work, a global management consulting firm. One morning, I received a call from our chairman. He told me that I was a nominee for a seat on the company's board but, just before the vote was taken, someone spoke of my illness. He was calling to ask if this information was true, and if I would be able to serve if elected. I confirmed that I did have myeloma but felt fine, was carrying a full client load, and was confident that I could serve. I was elected to the board. To his credit, the chairman made the call instead of simply assuming that

a person living with cancer could not handle a responsible position.

### **Please tell us about your involvement with the myeloma community outside the IMF.**

Besides the ListServ, I run two in-person myeloma support groups. I serve as a patient consultant to the FDA. I was a charter member of, and later chaired, the NCI Director's Consumer Liaison Group. I co-chair the Patient Representative Committee at the Eastern Cooperative Oncology Group (ECOG), which conducts large-scale, national clinical trials. I also served on the National Cancer Advisory Board's Clinical Trials Working Group.

### **What is your current outlook?**

Myeloma is a terrible disease but I try to live my life as if I didn't have it. I'm very involved with my family and my children. I love the opera. I'm active in my synagogue and served as its president. I earn a living as a management consultant. I travel frequently, for both business and pleasure. I may ache when I walk, but I power through. It hasn't been easy but I know that taking the easy way out is habit-forming.

The help that I've received from Francesca Thompson, Brian Durie, Susie Novis, Brian Novis, Bob Kyle, and others has enabled me to live the life that I am now living. I feel an obligation to help others, so I devote a lot of time and energy to the IMF and the myeloma community at large.

In the years since my diagnosis, the landscape for myeloma has changed tremendously, and the IMF has played an instrumental role in that. Each year, there are more and better treatment options available to manage myeloma. And the IMF's wide range of services supports the patient community in ways that I could not have imagined when I was diagnosed. I'm so proud to be a part of the International Myeloma Foundation. **MT**

## MYELOMA TODAY IN CONVERSATION WITH PROF. MELETIOS DIMOPOULOS

### Please tell us a little about your background and medical training.

I was born in France but was raised in Greece. I received my medical degree from the University of Athens School of Medicine, did my internship at the V.A. General Hospital in Athens, and completed my residency in Canada at the Royal Victoria Hospital, McGill University. In 1988, I went on to do my fellowship in hematology/oncology at the M.D. Anderson Cancer Center in Texas. There, I worked with a very important figure in the field of myeloma, Dr. Raymond Alexanian. Among his many achievements, in 1968 he was one of the first doctors to describe an effective treatment for myeloma, a combination of melphalan and prednisone. I was inspired by his devotion, so I became involved in clinical research in the field. Currently, I am Professor and Chairman, Department of Clinical Therapeutics, University of Athens School of Medicine.

### How did you become involved with the IMF?

I joined the IMF Scientific Advisory Board in 1992, not long after this innovative foundation was formed. From its inception, besides providing support and education to the myeloma patient community, the IMF has provided physicians with an important opportunity to exchange opinions. Over the years that have followed, under the leadership of Drs. Brian Durie and Robert Kyle, the IMF has had many accomplishments; one such current achievement is the recently published new response criteria that have been actively endorsed by the medical community throughout the world, including at our center in Athens.

### What is the current focus of your myeloma research?

I am actively involved in several clinical trials investigating the best approaches of using novel agents in relapsed/refractory setting. I am also studying the effect of novel agents on bone metabolism. My center is very much involved in autologous transplantation for myeloma, so I am also studying the role of novel agents before and after high-dose therapy. In addition, I am investigating new agents for the treatment of amyloidosis.

### How has the advent of novel agents for myeloma changed the treatment landscape?

Since 1999, when Dr. Barlogie's group reported on the significant activity of thalidomide in patients with relapsed/refractory myeloma, we have seen continuous and important advances in the field. There are now three novel agents that we can use to help our patients and, in the next few years, we expect to add more agents to our existing treatment arsenal. Several exciting early-phase clinical trials are ongoing at major myeloma centers around the world. We in the scientific community share the opinion that the survival of myeloma patients is improving, and we are steadily moving through a process of transforming myeloma from a terminal disease into a chronic condition.

### Have the novel agents changed the role of transplantation in myeloma?

There is a significant and important role for autologous transplantation in myeloma, at least for patients 70 years of age and younger. I believe



Meletios A. Dimopoulos, MD  
University of Athens School of Medicine  
Alexandra Hospital  
Athens, Greece

that transplantation is a very useful modality. The novel agents can help increase the number of patients who achieve an initial response and are then able to proceed to high-dose therapy. Several studies indicate that thalidomide is an important agent after autologous transplantation. Other studies are investigating other novel agents in similar settings. In my opinion, it is premature to think of abandoning high-dose therapy. Instead, we need to continue to explore how best to use novel agents before and after transplantation.

### As Chairman of the organizing committee of the XIth International Myeloma Workshop, what can you tell us about this upcoming meeting?

The XIth International Myeloma Workshop (IMW) will be held in Kos, Greece, from June 25th to 30th, 2007. The IVth International Workshop on Waldenström's Macroglobulinemia will directly follow the myeloma workshop. The

beautiful island of Kos is the home of Hippocrates, the ancient Greek physician called "the father of medicine." This environment seems ideal to host the upcoming workshop, as it will give the attendees an opportunity to participate in the intense scientific program and to exchange ideas, opinions, and data regarding the treatment of myeloma in a pleasant and relaxing atmosphere.

### Given the developments in the field of myeloma since the last IMW in 2005, how will the Kos workshop address those advancements?

Our scientific advisory board, a panel of world-renowned experts in the field, has devised a scientific program that focuses on the latest advances in the genetics, pathophysiology, diagnosis, and management of myeloma. There are 75 invited speakers and 25 planned oral presentations. In addition, the workshop will feature abstracts selected from the more than 500 submitted, the highest number in IMW history.

The latest data on the use of thalidomide, lenalidomide, and bortezomib will be presented, along with the results of several randomized trials that were not yet ready for presentation at ASH in December of 2006. I am very excited about the prospect of significant new knowledge to be presented and I am confident that the Kos workshop will bring us closer to our goal, the cure of both myeloma and Waldenström's macroglobulinemia. **MT**

**Editor's Note:** Dr. Dimopoulos is a member of numerous scientific societies and has authored more than 300 publications in peer-reviewed journals, as well as numerous abstracts and several textbook chapters. He is a journal reviewer for several journals, including *New England Journal of Medicine*, *Blood*, *Journal of Clinical Oncology*, *Haematologica*, *Leukemia*, *Cancer*, *European Journal of Haematology*, and *Leukemia & Lymphoma*. Dr. Dimopoulos is an Associate Editor of the *European Journal of Internal Medicine* and of *Current Hematologic Malignancy Reports*, and is an Editorial Board Member of the *Journal of Clinical Oncology* and of *Haematologica*. Dr. Dimopoulos is a member of the *European Myeloma Network*, and is the recipient of the *Robert A. Kyle Award* for outstanding contributions to Waldenström's macroglobulinemia.

## **BANK ON A CURE® UPDATE**

Myeloma Today in conversation with Dr. Brian Durie

### **What is the status of the initial phases of the IMF's Bank On A Cure® project?**

Bank On A Cure® is the world's first repository of DNA created to advance the understanding of myeloma. The initial phases of this research project, co-chaired by Drs. Gareth Morgan (Institute of Cancer Research, Royal Marsden Hospital, London) and Brian Van Ness (Institute of Human Genetics, University of Minnesota, Minneapolis), have been completed. We have developed a myeloma-specific single nucleotide polymorphism (SNP) chip. Once the custom chip was created, it took several months to get the Affymetrix machines (which run the chip) set up and standardized, both in the US and in the UK, and to get technicians familiarized with the process. Currently, the DNA samples collected from several large clinical trials in the US and in Europe are being analyzed.



Brian G.M. Durie, MD  
Aptium Oncology  
Cedars-Sinai Comprehensive Cancer Center  
Los Angeles, California

### **Can you briefly explain what SNPs are and how the custom chip works?**

Single nucleotide polymorphisms (SNPs) are genetic variations in DNA sequences, which can affect how we develop diseases and respond to pathogens, chemicals, drugs, etc. Our Affymetrix machines are designed to process and analyze SNPs. While it is now possible to screen the human genome for half a million combinations of genes, such a process would be hugely cumbersome, so we have decided that it is much more efficient to target a smaller group of SNPs that is more likely to be relevant in myeloma. To proceed with a more focused and targeted approach, the Bank On A Cure research team helped select the 3,404 SNPs associated with gene functions that we think are most relevant to the regulation of myeloma growth, disease progression, response to treatment, drug metabolism, bone microenvironment, immune responses, DNA repair, and predisposition to side effects like neuropathy, mucositis, or deep vein thrombosis (DVT). Our custom chip includes all the major sequences where a change in the gene can relate to myeloma.

### **Can you give us an example of a discovery made from the data processed so far?**

One of the Bank On A Cure projects sought to identify genetic pathways that may explain why an estimated 15% to 30% of myeloma patients treated with thalidomide suffer venous thromboembolisms (VTEs), or blood clots, as a major complication. We looked at data on 394 myeloma patients produced from three clinical trials, two performed in Europe and one in the US. We identified four gene clusters associated with the VTEs. It was discovered that the risk of developing VTEs while on thalidomide was mostly related to the genes that control inflammation, with IL6 and TNF shown to be the main cytokines to influence inflammation within blood vessels. Other genes related to drug processing and metabolism have also been linked to the risk of VTEs, which might relate to how quickly a patient responds to treatment. If a patient has a dramatic response to thalidomide, the rapid release of all of the products from the breakdown of the dying myeloma cells can promote clotting via inflammation. So, the

more rapid responses to thalidomide are associated with higher risk of VTEs. It is important to note that VTEs were not associated with any of the blood clotting genes, which supports the notion that aspirin can be helpful as a prophylactic treatment for VTEs.

These Bank On A Cure research findings were presented at the annual meeting of the American Society for Hematology (ASH) in December of 2006, and a manuscript is now being finalized for publication, with Gareth Morgan as the senior author. An update will be presented at the International Myeloma Workshop (IMW) in June of 2007. This will be one of two Bank On A Cure oral presentations to take place at the IMW meeting in Greece.

### **What is the focus of the second research project to be presented at the IMW meeting?**

Dr. Van Ness is working on a paper about the development of our custom SNP chip evaluating the relationships to survival and outcome. He is looking for SNPs associated with event-free survival in patients

in two large clinical trials. Early analysis indicates that there may be detectable genetic differences between short- and long-term survivors, and that it may be possible to predict which patients will need more aggressive therapies when they start their treatment. He is also comparing SNPs of people who have myeloma with those who do not.

### **Can you tell us about the Bank On A Cure research projects you recently completed?**

I looked at the impact of genetic variation on bone disease, focusing on SNPs that correlate with the likelihood that a myeloma patient would get bone disease. We analyzed genes related to various end points within the data set from the 256 myeloma patients who were enrolled in Total Therapy II (TT II), a clinical trial by Drs. Bart Barlogie and John Shaughnessy at the Myeloma Institute for Research and Therapy in Little Rock, AR. When it comes to accurately documenting the presence or absence of bone disease, the TT II data set is the strongest anywhere in the world because all 256 patients got whole body x-ray and MRI plus PET imaging studies performed as necessary. In this Bank On A Cure study, we found that there are several SNPs related to bone disease, four of them linked to the production of a peptide that enhances the formation of osteoclasts, MIP1-alpha. The SNP data analysis is now complete, and we have developed a prognostic tool to help evaluate whether a myeloma patient is likely to get bone disease. A paper on the subject is being prepared.

### **What's next for Bank On A Cure?**

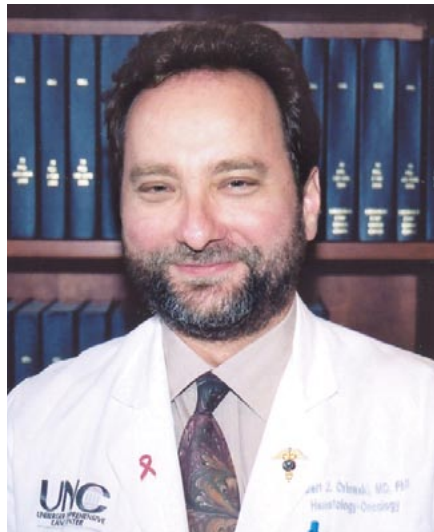
There are many exciting research projects emanating from the Bank On A Cure DNA repository. Readers of Myeloma Today should stay tuned for further developments, which will also be disseminated through the IMF's weekly email updates, Myeloma Minute, as well as the IMF website [www.myeloma.org](http://www.myeloma.org). **MT**

## THE ROLE OF VELCADE® PLUS DOXIL® IN MULTIPLE MYELOMA

Myeloma Today in conversation with Dr. Robert Orlowski

### What is the focus of your research work?

My approach is to understand the molecular pathogenesis of oncologic diseases, and also to dissect the mechanisms of action of chemotherapeutics. The former will identify new cellular targets for therapeutic intervention, and possibly also for disease prevention. The latter promotes the development of rational drug combinations with enhanced efficacy, and may allow targeting of chemotherapy regimens to patients who are most likely to benefit based on the biology of their own disease. Ultimately, the goal is to translate the knowledge garnered from these basic science and preclinical studies into the clinic, and to provide new, effective treatment options for patients afflicted with multiple myeloma. The current line of investigation being pursued by my laboratory and clinical research groups has focused on the proteasome as a target for cancer therapy and in the mechanisms by which inhibitors of this complex induce apoptosis, or programmed cell death.



Robert Z. Orlowski, MD, PhD  
Lineberger Comprehensive Cancer Center  
University of North Carolina at Chapel Hill  
Chapel Hill, NC

### You are the overall study chair for two myeloma clinical trials of VELCADE® plus DOXIL®. What can you tell our readers about these two drugs?

VELCADE (bortezomib for injection) is indicated for the treatment of patients with myeloma who have received at least one prior therapy based on data showing single agent VELCADE extended survival of patients with previously treated myeloma compared with patients treated with standard dexamethasone.

DOXIL (doxorubicin HCl liposome injection) is currently indicated for the treatment of patients with ovarian cancer and Kaposi's sarcoma. Doxorubicin is an established chemotherapeutic that has been used for years. In DOXIL, the drug has been put into small lipid capsules so it stays in the circulation for a longer period of time, and is therefore available to kill cancer cells over a longer period of time. This also makes the drug safer from a cardiac perspective, may allow it to overcome drug resistance compared with plain doxorubicin, and offers better delivery to tumor vasculature.

The reason we've put these two drugs together is because there was data from a number of research groups that VELCADE enhanced the anti-myeloma activity of doxorubicin, and from our group that DOXIL enhanced VELCADE's anti-tumor efficacy.

### What can you tell us about the phase III study you presented at ASH this past December?

We had previously completed a phase I clinical trial which showed that the VELCADE plus DOXIL combination was well tolerated by patients, and there was evidence to suggest that the combination was more effective than VELCADE alone. To more fully test if this was the case, we designed a randomized study. This phase III international multicenter trial randomized 646 relapsed myeloma patients who had received at least one prior therapy. One group received the standard dose and schedule of VELCADE

(1.3 mg/m<sup>2</sup> on days 1, 4, 8, and 11 of every 21-day cycle), and the other received the same dose and schedule of VELCADE plus DOXIL (30 mg/m<sup>2</sup> given on day 4 of each cycle). The two study arms were well balanced; on average patients were diagnosed at least three years prior to enrolling; almost all had been on treatments involving steroids; 90% had received alkylating agents; two thirds had anthracyclines; about 40% had thalidomide or lenalidomide; and over 50% had a prior stem cell transplant.

The primary study endpoint was TTP (time to progression), and an interim analysis was planned, the results of which formed the basis for our report. A highly statistically significant improvement in median TTP to 9.3 months was achieved for patients receiving VELCADE plus DOXIL, as compared with a TTP of 6.5 months for VELCADE alone.

Also, in this interim analysis, a trend was emerging for a better survival on the combination therapy.

That data is not yet mature, but there will be follow-up studies presented in the future.

In the meantime, the main message for patients with relapsed/refractory disease is that the VELCADE plus DOXIL combination may be an excellent treatment option for them that seems to provide a better outcome than VELCADE alone.

### Did some patients benefit more from the combination than others?

We looked at different subsets of patients and we found that just about every patient sub-group benefited more from the combination, compared with VELCADE alone. This included both younger and older patients, those who had a transplant and those who did not, patients with cytogenetic abnormalities other than deletion of chromosome 13, those who had received thalidomide and/or lenalidomide and those who did not, as well as patients who had an elevated beta-2 microglobulin, which is usually a poor prognostic finding.

### Are there benefits to this regimen being free of steroids?

There are many people who are not able to take steroids because of diabetes, or because of their many and often severe side effects. In fact, in my practice, I have seen more patients having problems with high-dose steroids than with many of the other drugs that we use. Also, patients who have been taking dexamethasone with either thalidomide or lenalidomide have shown an increased occurrence of blood clots and pulmonary emboli, and therefore have to take some type of blood thinning agent, which itself increases risks. VELCADE, either alone or with DOXIL, had a very low incidence of this side effect at 1%, and patients do not therefore need prophylactic blood thinning products.

### What about side effects?

Often, when two or more drugs are combined, there is a tendency for an increase in toxicity. We observed some increases in gastrointestinal side effects, such as nausea, diarrhea, and vomiting. There was a slight increase

CONTINUES ON PAGE 8

## VELCADE® PLUS DOXIL® — continued from previous page

in thrombocytopenia and neutropenia (low platelet and white blood counts), bleeding, as well as fatigue and anemia. DOXIL can also cause stomatitis, or mouth sores, and hand/foot syndrome, where redness develops of the palms or the soles and, in more severe cases, cracking and blistering of the skin can occur. About 5% of the study patients experienced this side effect, which was managed by reducing the dose of DOXIL or by stopping it altogether. It is important to note, however, that the combination of VELCADE plus DOXIL does not show an increase in the incidence of neuropathy, and the rate of grade 3 or 4 neuropathy was actually lower with VELCADE plus DOXIL than with VELCADE alone: 4% as opposed to 9%. Also, there was no increased risk of cardiac effects such as congestive heart failure with the combination compared with VELCADE alone.

### What can you tell us about the results thus far from the phase II study of VELCADE plus DOXIL as initial therapy for patients with symptomatic myeloma?

Since patients with relapsed myeloma tend to have disease that is more resistant to therapy, we thought that VELCADE and DOXIL could be especially active as an initial treatment, and again avoid the use of steroid. At the time of the ASH presentation, we had preliminary data on 57 of the 63 patients involved in this phase II study. The toxicity results were predictable, based on what we've seen in both the phase I and III trials, and there were no unusual problems observed. In the 29 patients who had completed their course of treatment, there was a complete response (CR) rate of 28% and an overall response rate (ORR) of 78%. For a two-drug regimen without steroids, this was a very encouraging response rate.

### How does the VELCADE plus DOXIL upfront therapy compare to other VELCADE combinations, and other oral combinations?

VELCADE is being studied in several trials with dexamethasone where it has shown encouraging activity as an upfront therapy. Also, both Thalomid with dexamethasone and Revlimid with dexamethasone are very active induction regimens. Our follow-up with VELCADE plus DOXIL is still too short to make accurate comparisons with these other, more established regimens. However, the response rate is encouraging, and the fact that it does not seem to compromise stem cell collection makes it attractive as an option for newly diagnosed patients who cannot tolerate steroids, or have some contraindications for thalidomide or lenalidomide.

### What about the relapsed/refractory patient?

For the relapsed/refractory patient, the good news is that we now have three phase III studies that show that there are excellent options: lenalidomide plus dexamethasone, VELCADE alone, and VELCADE. Additional analyses of these studies will be needed, as well as some further trials, to see if we can identify certain patient populations who would most benefit from one or another of these options, or if there is an optimal sequence in which these therapies should be used. In practice, most patients will probably get all of these therapies at one point or another, and the good news is that all of them prolong survival.

### Can you speak about the relative convenience of oral vs. intravenous therapies, as well as reimbursement issues?

Sometimes, one advantage of an oral regimen is that a patient can take it at home, so there may be fewer visits to the physician's office than with an intravenous combination. However, one has to also factor into this the need for increased monitoring, and when I first put patients on

lenalidomide plus dexamethasone I have them come once a week to have their blood counts and/or INR (international normalized ratio) checked. Therefore, they still see me several times a month, and there isn't as big difference between that and coming in for VELCADE and DOXIL, which requires four treatment visits per cycle.

Expense is certainly another important feature of cancer therapy. Much of these reimbursement issues depends on the type and extent of insurance coverage that a patient has, and are often different for every individual. Patients who come to an office for VELCADE plus DOXIL may have to make co-pay payments, but the drugs are usually covered by insurance. For patients on lenalidomide plus dexamethasone, they have to deal with the expense of the drugs, and not everyone can afford the treatment, given the Medicare "donut hole" when no insurance for prescription drugs is available.

### Currently, what else are you seeing on the myeloma landscape that warrants attention?

At the most recent meeting of the American Society of Hematology, there was very nice data presented in relapsed/refractory myeloma with two other VELCADE-based combinations that were in early-phase trials. These included VELCADE with Revlimid, and VELCADE with the heat shock protein 90 inhibitor tanespimycin.

A third drug that is very interesting is CNTO 328, a chimeric antibody against interleukin-6, which is an important survival and growth factor for myeloma cells. This drug is a protein molecule with a very favorable toxicity profile, and we have now started a phase II study of this agent in combination with VELCADE because laboratory data shows the combination to be synergistic. Finally, I am very encouraged by our initial phase I data with the novel proteasome inhibitor PR-171, or carfilzomib. PR-171 is a second-generation proteasome inhibitor that, so far, has been tolerated very well by patients without, unlike VELCADE, any significant episodes of neuropathy. We have even seen activity in patients who have been refractory to VELCADE, and phase II studies of this drug have been planned.

### What message would you like to send to the myeloma patient community?

Multiple myeloma continues to be an incurable disease, but the number of options available to patients and their healthcare providers now is greater than it has ever been. With this array of treatment options at hand, people are living longer and with a better quality of life, and that is very encouraging. Also, we understand more about the disease now than we have ever had before, and this has identified many more therapeutic targets to go after, and we have more drugs with which to hit these targets. Finally, our laboratory models for myeloma are improving, which means that we are more likely to be successful with our clinical trials. The trend for new drugs and new combinations of drugs is going to continue and, over time, this will bring us closer to curing this disease. **MT**

*Editor's Note:* Dr. Orlowski is the Lenvel Lee Rothrock Associate Professor of Medicine, Division of Hematology/Oncology, and of Pharmacology, at the University of North Carolina at Chapel Hill. He is the 2006 Leukemia and Lymphoma Society Man of the Year. Dr. Orlowski has authored numerous published book chapters, articles, commentaries, and abstracts.



## UPDATE ON REVLIMID® FOR THE TREATMENT OF MYELOMA

Myeloma Today in conversation with Dr. S. Vincent Rajkumar

### What is the current role of Revlimid® in myeloma?

Lenalidomide (Revlimid®) is currently approved in the US for use in myeloma patients who have received at least one prior therapy. This approval was based on two Phase III clinical trials, one in the US and one in Europe, which compared the combination of lenalidomide plus dexamethasone (dex) to dex plus placebo. These trials showed improved time to progression (TTP) and response rates. As happened with thalidomide earlier, lenalidomide then became an attractive candidate for frontline therapy.

### Can you tell us about the Mayo Clinic study of lenalidomide as frontline therapy?

We studied the combination of lenalidomide plus dex in 34 patients with newly diagnosed myeloma. The initial results, published in *Blood*, showed a response rate of 91%. At the annual meeting of the American Society for Hematology (ASH) in December of 2006, it was showed that these responses were durable. Overall, 56% of patients achieved very good partial response (VGPR) or better. Of the 21 patients who stayed on this therapy without proceeding to transplant, the rate was even higher — 67% achieved VGPR or better. Our study also showed that the average TTP was approximately 30 months. These results are comparable to what has been reported with single autologous transplantation for myeloma, making it important that studies be conducted comparing novel therapies with transplantation.

### What about the risks of side effects?

The Mayo Clinic's lenalidomide plus dex study used the standard high-dose dex (40mg on days 1-4, 9-12, 17-20). Dex is associated with a high risk of side effects, so an Eastern Cooperative Oncology Group (ECOG) trial was mounted to look at whether the dex dose can be reduced in order to reduce toxicity without sacrificing much in the way of efficacy. The ECOG study compared lenalidomide plus standard high-dose dex with a kinder, gentler combination regimen where dex was given once a week (40mg on days 1, 8, 15, 22). The trial results are awaited but, at ASH last year, I was able to present reports on adverse events and early mortality. The data from the low-dose dex arm of the study look very promising, and the incidence of all side effects was lower. Surprisingly, this included significantly lower incidence of deep vein thrombosis (DVT). Early mortality, defined as any death resulting from any cause occurring within the first four months, was low in both arms of the ECOG study: 0.5% in the low-dose arm and 4.7% in the high-dose arm of the study. By the way, early mortality in myeloma is not fully appreciated as a problem. When one considers early mortality, it is important to derive rates from trials that are large enough and that do not restrict trial entry only to transplant candidates (because this is a very select population of myeloma patients). Ideally, early-mortality rates can be studied when the data is derived from Phase III studies that do not restrict trial entry based on transplant-eligibility. When we look at studies like that, we find that early mortality associated with myeloma therapy is about 11% with dex alone, 8% with melphalan and prednisone (MP), 7% with thalidomide plus dex, and 3% with melphalan, prednisone, and thalidomide (MPT).

Recently, our team of 18 Mayo Clinic myeloma experts endorsed an algorithm on what therapy could generally be recommended for newly diagnosed patients. The resulting consensus statement, known as mSMART (Mayo stratification of myeloma and risk-adapted therapy), offers a logical step-by-step procedure for decision-making based on transplant eligibility



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and cytogenetic risk factors such as metaphase deletion 13, hypodiploidy, translocations 4;14 or 14;16, and deletion 17p. Compared with current regimens for newly diagnosed myeloma, lenalidomide plus low-dose dex has shown high activity and low toxicity, and the Mayo group is now recommending this approach as one of our standard frontline regimens. For patients proceeding to transplantation, we feel that lenalidomide plus low-dose dex may be the safest and most effective therapy to get them to the point of transplant.

### Do you follow guidelines for DVT prophylaxis?

We know that there are at least three factors that increase the risk of DVT when patients take lenalidomide plus dex (and likely for thalidomide plus dex as well). The first is the use of chemotherapy drugs, such as doxorubicin or liposomal doxorubicin. The second is how much steroid is being used — it is clear that high-dose dex carries an increased risk of DVT, compared with low-dose dex or no dex. The third is the use of erythropoietin. Because DVT risk can be in the 20% range, if a patient taking lenalidomide plus dex has any of those three risk factors, we recommend anticoagulants such as warfarin or low-molecular-weight heparin. If a patient has none of these risk factors and is taking lenalidomide plus low-dose dex, aspirin should be enough as a prophylaxis. To settle the ongoing debate of which prophylaxis is most effective, there is an active randomized trial currently accruing patients in the US that's comparing aspirin vs. warfarin with lenalidomide plus high-dose dex as frontline therapy.

### What are the future directions for lenalidomide combination therapies?

Dr. Antonio Palumbo's group in Italy has reported the results of their multi-center trial of lenalidomide plus melphalan and prednisone (R-MP) for newly diagnosed myeloma patients 65 years of age and older. A significant response rate was observed, and R-MP was well tolerated with low toxicity. Also, they have found that just one cycle of R-MP is equivalent to six cycles of MP alone in terms of rapidity of response. This regimen has been highly effective for elderly myeloma patients who are not proceeding to transplant. There is an ECOG led Phase III trial scheduled to open soon in the United States comparing R-MP and MPT.

Dr. Paul Richardson of the Dana-Farber Cancer Institute has found that lenalidomide plus bortezomib (VELCADE®) for relapsed/refractory disease produces a high response rate among patient who had failed multiple regimens, including bortezomib alone. There is interest in developing lenalidomide/bortezomib as frontline therapy. There have been some interesting study results already, and more trials are about to open. A Phase III ECOG trial comparing bortezomib, lenalidomide, and dex (VRD) to bortezomib plus dex (VD) is opening soon, with the goal of developing an alternative to transplant. It is possible that we will soon develop a regimen relegating transplantation to second-line therapy.

Of course, the next question is whether we can add alkylating agents to create the ultimate drug cocktail. Several published studies show promising results, and additional trials are planned. In terms of active trials, we are awaiting the efficacy results of the ECOG trial, and anticipating the results of the SWOG trial comparing lenalidomide plus dex to dex alone. **MT**

## IMF WELCOMES NEW SCIENTIFIC ADVISORS

### Hermann Einsele, MD



Hermann Einsele is head of the Clinic of the University of Würzburg, Germany. Dr. Einsele's strong interdisciplinary team of researchers

is focusing on a variety of clinical trials, ranging from the new RAD regimen to innovative in vitro studies. Prior to coming to Würzburg, Dr. Einsele spent years at the University of Tübingen, from medical school through a number of roles culminating in Managing Director of the Medical Clinic. In addition to Tübingen, Dr. Einsele has studied in Manchester and London, England, and conducted research at the Max Planck Institute for Biochemistry in Martinsried, Germany, and the Fred Hutchinson Cancer Center in Seattle, Washington, USA.

### Orhan Sezer, MD



Orhan Sezer is a graduate of the University School of Medicine in Göttingen, Germany, where he later received a doctoral degree in pathophysiology. Dr. Sezer worked at

the Institute of Experimental Pharmacology, Freie Universität Berlin, where he performed research on signal transduction. He is board certified in internal medicine, hematology, and medical oncology. A Professor of Medicine in hematology/oncology at the University Clinic of Berlin, Dr. Sezer is the head of the Multiple Myeloma Group in Berlin. His main research fields are multiple myeloma and malignant lymphomas, with special emphasis on myeloma bone disease, angiogenesis, targeted therapies, and quality of life research.

### Andrew Spencer, MD



Andrew Spencer is Associate Professor and Senior Specialist in the Department of Clinical Haematology and BMT, and Head of the Myeloma Research Group, Alfred Hospital, Australia. He is an Associate Professor of Medicine at Monash University. Active in both translational and clinical research, Dr. Spencer has

a particular interest in drug resistance mechanisms, murine tumor models, and novel therapeutic approaches for myeloma. He serves on the Australasian Leukaemia and Lymphoma Group (ALLG) and is Chairman of the ALLG Myeloma Disease Subcommittee. Dr. Spencer is a member of the Medical Advisory Group for the Australian Myeloma Foundation and the National Medical and Scientific Advisory committee for the Leukaemia Foundation of Australia. He is principal investigator for numerous multi-center clinical trials in both myeloma and non-Hodgkin's lymphoma, and has extensive experience as an advisor to the pharmaceutical industry with a particular emphasis on novel drug development. **MT**

## News & Notes

### IMF Rated #1 Resource for Patients

The IMF is "the number one resource" for individual patients as well as for leaders of regional support groups, according to an independent survey conducted by Target Research Group. The IMF ranked number one in providing a wide range of publications, in-depth educational seminars, information on clinical trials, and helpful resources such as a user-friendly website and a dedicated staff. The survey also found that the IMF excels in areas that matter most to patients: being extremely knowledgeable about issues related to myeloma, having up-to-date information, and putting the needs of patients and caregivers as the first priority. Steve Cook, president and CEO of Target Research noted, "During my 35-plus years in the industry, I don't ever recall seeing positive scores that were so much higher than the other organizations surveyed on virtually all dimensions." As expected for a foundation dedicated to patient support, the IMF ranked second as a research-oriented organization. The survey included more than 600 individuals and 59 people who lead independent myeloma support groups across the US.

### New American Cancer Society Statistics

The American Cancer Society (ACS) tracks cancer occurrence, the number of deaths, new cases, and how long people survive after diagnosis. The 2007 ACS statistics, which include data for the past year, report 19,900 estimated new cases in the United States in 2006. The ACS data has been

age-adjusted to the 2000 U.S. population standard, affecting the comparability of data and results in the rates of cancer incidence and mortality, rates at different ages, magnitude of improvement in cancer, and racial and ethnic differences. To learn more about these statistics, please visit [www.cancer.org/statistics](http://www.cancer.org/statistics). The increase in number of cases of myeloma in 2006 is thought to be because of new methods of data collection; the old method underrepresented the incidence.

### XI<sup>th</sup> International Myeloma Workshop Awaits Record Number of Participants in Greece



From June 25th through June 30th, 2007, myeloma scientists and clinicians from around the world will gather on the beautiful island of Kos, Greece, to attend the XIth International Myeloma Workshop. The IVth International Workshop on Waldenström's Macroglobulinemia will take place as well. An important event in the fields of multiple myeloma and Waldenström's Macroglobulinemia, the workshop will provide a scientific program focusing on the significant advances in the biology and treatment of both diseases. The workshop's Organizing Committee is chaired by IMF Scientific Advisor, Prof. Meletios A.K. Dimopoulos. **MT**

## NLB ACTIVITIES UPDATE

By Diane Moran

The mission of the IMF Nurse Leadership Board (NLB) is to improve the care of multiple myeloma patients at the nursing level. The NLB is comprised of oncology nurses from leading oncology centers treating myeloma in the United States, and focuses on a wide range of nursing care delivery, including patient education, counseling, and treatment management.

The NLB's first mandate is to develop and disseminate consensus guidelines on the nursing management of side effects patients may experience when taking novel therapies to treat their myeloma. Providing management guidelines to nurses who care for myeloma patients will help ensure that patients receive optimal treatment and supportive care related to the management of side effects. Nursing care guidelines are a valuable repository of information that can help nurses who care for myeloma patients in their practice setting, whether they see many myeloma patients weekly or only a handful of myeloma patients per year.

During the inaugural NLB meeting in November of 2006, members worked together to develop the conceptual framework, mission, and charter of the NLB. For purposes of their first undertaking, NLB members formed committees, each focusing on specific side effects related to novel therapies including deep vein thrombosis (DVT) and thromboembolic events, peripheral neuropathy, myelosuppression, and gastro-intestinal and steroid-related side effects. The committees worked for several months to complete development of the guidelines. Currently, those drafted guidelines are under review by the NLB Steering Committee, which includes members of the IMF Scientific Advisory Board. Once the Steering Committee has completed their review and commentary, the guidelines will go back to the entire NLB membership for their approval and sign-off. A Consensus Document will be developed that will contain the final management guidelines, followed by their publication. The NLB



Diane Moran, RN, MA, EdM  
IMF Senior Vice President

will review and update the Consensus Document on an ongoing basis and will expand the topics as progress is made in the field.

Dissemination of the guidelines is an essential part of the strategy of improving the nursing care of myeloma patients and, to that end, the NLB recently finalized a patient education slide kit and is currently finalizing the nurse education slide kit, and building a plan to educate the nursing community nationwide. The launch of this educational endeavor to disseminate the guidelines will take place at the IMF Satellite Symposium held during the Oncology Nurses Society annual meeting in April in Las Vegas, Nevada. In addition, the upcoming XIth International Myeloma Workshop taking place in Greece this summer will feature an abstract from the NLB on the process of how to build a nurse-centric consensus model.

In the future, the NLB plans to expand its membership and activities to include nurses internationally, and to expand its educational compliment of programs. The IMF's goal is to support the nursing community worldwide and to disseminate important information in a nurse-friendly format from leading myeloma academic centers to the grassroots level. It is my privilege to provide general leadership to the NLB during its formation and subsequent development of care-enhancing programs and activities. Providing nurses with targeted programs and tools that enhance their knowledge and ability is an effective and efficient way to ensure that myeloma patients receive optimal care. **MT**

**Editor's Note:** Diane Moran, RN, MA, EdM is an experienced nurse with advanced degrees in education and organizational management. She is a highly accomplished healthcare executive with more than two decades in the pharmaceutical industry, developing programs within governmental, nurse and physician, and patient sectors. She joined the IMF in April of 2006 as the Senior Vice President of Strategic Planning.

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## HOW TO BE A "GOOD" PATIENT

By Michael S. Katz

How to be a "good" myeloma patient is something I've been working on for the past 16 years, but it may take me another 16 to get it right. Here are some of my thoughts on being a "good" patient:

Don't be too good. Mae West said, "When I'm good, I'm very good. But when I'm bad, I'm better." This applies to myeloma patients. Being "too good" can get you killed. Not getting a second opinion because you're afraid of offending the doctor, not asking the nurse hanging that IV what's in there, not speaking up about how bad you're feeling, taking "no" for an answer when you need to hear "yes" (to your requests about insurance approvals, appointments, copies of films, reports, etc.) can have serious consequences. Myeloma is not a time to be nice. And you know what? Sometimes it's fun to be a little evil!

Be good to yourself. And be sensible. This is not the time to suddenly start slogging down mega-doses of vitamins or to become a vegan. It's okay to be scared, but keep a level head and know that there are reasonable things that can be done to control this disease. Try to learn some skills to better manage your stress. Don't abuse your body with alcohol, lack of sleep, and other bad habits. Apply common sense to your daily life.

Keep too busy to be sick. Symptoms and side effects can be awful, so if you're really too sick to "power through," get help and rest up until you feel better. But, don't wave the white flag too soon, because if you act sick, you'll feel sick. If you act healthy, you might fool not only others but even yourself. Don't let myeloma be your life.

Don't let myeloma sneak up on you. There is an incredible range of diagnostic tests available so you can see trouble coming. But, it's a very complicated business, as there are so many things to keep track of. Because people can be very different from one another, it's important to find the best tests for each patient. It's also important to keep a close eye on organs affected by the disease, like the bones and the kidneys. Work with your doctor to figure out exactly which tests you need and why, then get them done and track the results. Tests answer critical questions about disease status and help detect sneak attacks. It's always a good idea to get copies of your test results, including laboratory (blood and urine), radiology (imaging) and pathology (biopsy) reports. You are entitled to them and they are not that hard to read — just look for the summaries and look for anything marked abnormal. Your doctor should be explaining your results to you and discussing anything you should be doing based on the results. You can also bring test results to your support group, visit [www.labtestsonline.org](http://www.labtestsonline.org) for additional info, or call the IMF hotline at 800-452-CURE (2873) for help.

Get organized. Set up file folders with the various reports that you will no doubt accumulate over the years. "Flow sheets" and graphs can be helpful for you and your doctor to track and understand how your disease changes over time. "Flow Sheets"

	A	T	V	W	X	Y	Z	M
1								
2	Old Value	NEW	NEW	NEW	NEW	NEW	NEW	NEW
3	Low	3.5	4.2	13.2	38.8			
4	High	9.1	5.6	17.7	46.4			
5	08/14/95							
6A3	07/25/95	6.5	4.0	11.4	34.1	L		
6A4	08/22/95	5.9	3.9	11.5	32.6	L		
6A5	09/19/95	7.2	4.1	11.5	33.9	L		
6A6	10/17/95	8.2	4.1	11.5	33.7	L		
6A7	11/16/95	9.9	3.7	10.9	32.2	L		
6A8	12/12/95	5.1	4.2	12.5	35.9	L		
6A9	01/09/96	9.2	4.2	12.5	36.9	L		
6B0	02/06/96	4.6	4.2	13.5	36.5	L		
6B1	03/06/96	7.7	4.6	12.8	36.6	L		
6B2	04/03/96	6.6	4.3	12.7	36.7	L		
6B3	05/03/96	4.0	4.4	12.9	36.9	L		
6B4	06/03/96	4.8	4.2	12.9	36.6	L		
6B5	06/26/96	4.1	4.7	13.0	39.7	L		
6B6	08/09/96	4.4	4.2	12.8	35.1	L		
6B7	10/02/96	6.5	4.3	13.2	36.9	L		
6B8	12/15/96	5.9	4.1	12.5	34.2	L		

Flow sheets help you track changes in tests over time

- It's really just a fancy name for a table showing different test results by date
- Many cancer centers can print these out for you from their computer system
- If not, you can also do this on paper. Or, if you're good with the computer, a spreadsheet

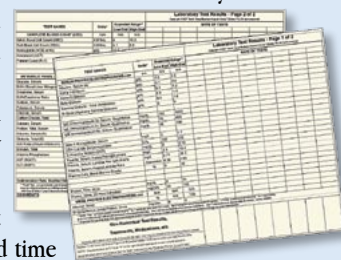
Take good care of yourself – LabTests

are tables that list one or more tests with results tracked over time, one line or one column for each date. Many cancer centers can print out flow sheets for you from their computer system — just ask. Or, set up your own tracking system on paper or a computer spreadsheet.

In closing, I'd like to note that myeloma is hard on the whole family, so be nice to the people who love you. Lastly, if you are lucky enough to be feeling good, it's really important for all of us to remember to be good to our fellow patients. **MT**

### Keeping Tabs on Your Labs

In 2004, IMFer Marcia Sawyer, one of the leaders of the North Texas Myeloma Support Group (NTMSG), found a tool on the American Heart Association website that allows patients to organize their cholesterol, blood pressure, and glucose test results. Marcia contacted fellow group member Dennis McClure, who was already using his own system for charting test results, and suggested that they develop a similar tracking tool for myeloma. Yelak Biru, another NTMSG member, volunteered his computer skills to collaborate on creating a system that would be easy to use, even for people who are not experienced with computers. The resulting NTMSG Testing History Template, which can be easily customized, covers most of the laboratory tests done for myeloma. The computerized worksheets are also programmed to generate Test History Charts, which display data trend lines in different colors to make them easy to visualize for all potential users.



Because many physicians do not have the luxury to spend extended time with each patient, bringing a copy of your tracking tool is a timesaving way to refresh the doctor's memory about details of the case, allowing more of the appointment time to be used for patient evaluation and questions. "I was diagnosed with monoclonal gammopathy of undetermined significance (MGUS) in 1993," said Dennis McClure, "In 2004, when I was told I had moved into the smoldering stage that required treatment, I was able to review the history of my test results, which indicated that I might still be in the MGUS category. Two myeloma specialists I consulted for another opinion both agreed that I shouldn't yet be treated with anything. Monitoring my own lab numbers helped keep my future treatment options open, saved me from unnecessarily developing treatment resistance, and has allowed me an opportunity to develop an optimum treatment strategy in a non-crisis environment."

To download an electronic version of the Testing History Template in Excel format, as well as instructions on how to customize and use it, please visit the North Texas Myeloma Support Group website at [www.northtexas.myeloma.org](http://www.northtexas.myeloma.org). If you do not use (or have) a computer, ask a friend or family member to print out the blank NTMSG forms, which are also available in PDF format, and fill in your lab data manually.

Editor's Note: Questions and suggestions related to the NTMSG tracking tool may be submitted to Dennis McClure at [mmcclure@ix.netcom.com](mailto:mmcclure@ix.netcom.com).

### 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).

**When I was first diagnosed with myeloma, I had a horrible experience with bone marrow biopsy. It was extremely painful and I shudder at the thought that I will have to endure this procedure again. Can you offer any suggestions that would make this procedure less of an ordeal?**

Since a sample is taken directly from bone, it is difficult to avoid some discomfort, but bone marrow biopsy doesn't have to be a horrible experience. With the information and suggestions we list below, the experience can be, if not painless, at least much more tolerable. The best or optimal bone marrow biopsy procedure provides the pathologist with enough intact bone marrow material that an accurate diagnosis can be rendered confidently, while minimizing patient anxiety and discomfort. The technique and patience of the person administering the biopsy are paramount.

A bone marrow biopsy requires several steps. In order to make sure you have the best possible experience, you should discuss these steps with your doctor before you have the procedure.

1. Consider the use of a rapid-acting sedative as general preparation for the procedure. One simple option is to use sublingual (under the tongue) or I.V./I.M. (intravenous or intramuscular) Ativan® (lorazepam) in a small dose to reduce anxiety. Other medications to help reduce pain and anxiety include Demerol®, Vistaril®, and Valium®. Some doctors give their bone marrow biopsy patients an Actiq® (oral transdermal fentanyl) lollipop. Another option is "twilight sedation" with a short-acting general anesthetic such as Propofol®.

2. The doctor or technician will position you on either your stomach or your side, depending on which area of the pelvic bone s/he is going to biopsy.

3. The doctor will clean the skin surrounding the biopsy site and anesthetize a site approximately 1 cm in diameter. You must let the doctor know if you have any allergies to the drug(s) that will be administered. Successful local anesthesia entails two critical points. First, the person performing the biopsy must ensure that not only the skin, but the surface of the bone (periostium) has been anesthetized. Second, it is important to wait for the anesthetic to take full effect. This is where patience comes in. (It can require up to 20-30 minutes for the anesthetic to take effect on the periostium.) An effective anesthetic cocktail recommended by anesthesiologist and myeloma patient Dr. Bill Wheeler (featured in Myeloma Today, Winter 2006) is the combination of xylocaine and marcaine. Patients, nurses, or physicians wishing to learn the details of this "cocktail" can contact Dr. Wheeler at [wheelerjr@sbcglobal.net](mailto:wheelerjr@sbcglobal.net). Local anesthetic can sting because it is acidic; adding sterile sodium bicarbonate solution to the anesthetic can neutralize the acidity and reduce pain.



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

4. The biopsy is performed by inserting the biopsy needle into the bone marrow. While patience and slow going are the order of the day with the local anesthetic, speed and skill are of paramount importance while doing the actual biopsy. The person performing the procedure should attempt to minimize needle manipulations in order to maximize your comfort. There is a general consensus that the pressure applied in going through the bone can be the most uncomfortable part of the biopsy. However, the first part of the sampling, which is to suck some bone marrow (liquid) out for

part of the testing (for example, chromosome testing), can be painful. This pain is caused by the sudden change in pressure caused by the sucking. Thankfully, this is extremely brief, but it is important for the doctor or nurse to warn the patient ahead of time. The dressing placed over the biopsy site should be left intact until the next day. One patient who has had countless bone marrow biopsies says that her best tip is to use an ice pack on the biopsy site after the anesthetic wears off. It helps to reduce pain and inflammation. When removing the dressing the next day, wetting the tape first will make removal easier. If the biopsy site is unusually painful or tender in the next few days, contact your doctor.

In addition to the issues of comfort discussed above, it is also important for the doctor to get a good specimen. A number of guidelines can help your doctor provide the pathologist with a good specimen. Some doctors have established criteria to determine if a bone marrow biopsy specimen is adequate. Dr. Bishop from the Christie Hospital in Britain suggests that a specimen should be at least 1.6 cm in length to be considered adequate (J Clin Pathol 1992). In addition, a specimen should not be significantly disrupted during the biopsy procedure. Achieving these specimen goals requires penetrating sufficiently into the marrow space.

The bone marrow biopsy procedure helps your doctor establish a diagnosis of multiple myeloma. In addition there may be times that it is appropriate to repeat the procedure to help assess the adequacy of your treatments, to estimate the myeloma tumor burden, and to investigate unexpected changes in the blood counts. It is also important to mention that sometimes, if the bone marrow has a high percentage of plasma cells, a bone marrow aspirate (a sample of bone marrow gathered in a syringe) rather than a full biopsy specimen may be sufficient.

Overall, the bone marrow biopsy procedure should not be a source of marked anxiety for the patient and should provide your doctor and pathologist with adequate specimens to help guide your treatment. As always, this often requires good communication between patient and doctor. **MT**

## LOS ANGELES IMF PATIENT & FAMILY SEMINAR

By Robert Green

On February 23 and 24, the IMF hosted a Patient & Family Seminar in Los Angeles, California. The Friday afternoon session started at 1pm with a welcome from president Susie Novis. As the IMF's seminar program is ever-evolving, Susie noted some changes to the upcoming meeting, which were the results of suggestions made by a patient focus group that the Foundation had convened. One unexpected feature of the Los Angeles seminar was that IMF photographer Jim Needham was on hand to offer souvenir photos to any attendees who were feeling particularly photogenic.

Next on Friday's agenda's was the "Ask-the-Expert" session with Dr. Brian G.M. Durie (Cedars-Sinai Comprehensive Cancer Center, Los Angeles, CA). The session was an open forum discussion. Especially of interest to many attendees were outcomes of two large lenalidomide plus dexamethasone studies presented at ASH 2006. Since not all seminar participants chose to attend the Friday sessions, there was more opportunity for the patients and caregivers in attendance to ask questions of Dr. Durie.

After a short coffee break, there was an informative session on managing side effects, presented by oncology nurse Sandra Rome (Cedars-Sinai Comprehensive Cancer Center). As we waited for the next speaker to arrive, Dr. Durie took the floor again to field more questions. This time, one of his topics was the use of antibiotics in myeloma.

The next presenter was Dr. Evan Ross, cancer survivor and practitioner of integrative medicine. He spoke about complementary and supportive therapies, and explained how we get ill and how we heal from the point of view of Chinese medicine. His advice on how to safely incorporate alternative modalities into cancer care and how to properly access practitioner competence seemed quite valuable to those interested in pursuing integrative medicine therapies.

The final speaker of the afternoon was Mike Katz, a myeloma patient and member of the IMF Board of Directors. More on his presentation about how to be a "good" patient can be found on page 12 of this newsletter. The day ended with a reception and dinner hosted by the IMF.

Saturday's activities started with a breakfast buffet. Once Susie Novis convened the meeting, those participants who were new to the IMF seminars were instructed in the use of the Audience Response System, which allows for an instant interactive exchange of information between audience and faculty.



The first presentation featured Dr. Morie Gertz (Mayo Clinic, Rochester, MN). A very effective communicator, Dr. Gertz's comprehensive "Myeloma 101" overview was a good primer for newly diagnosed patients, as well as a good refresher for those of us who have been dealing with myeloma for years.

The second presentation of the morning, Dr. Durie's session on front-line therapies, made it clear that the range of available treatment options continues to increase, with novel agents often being the first approach to treatment. Next, Kristine Kuus-Reichel, PhD, of The Binding Site Inc., discussed the advantages of using the FREELITE assay for the diagnosis and monitoring of myeloma.

After a coffee break, Dr. Robert Vescio (Cedars-Sinai Comprehensive Cancer Center) presented on the progress made in the treatment of myeloma bone disease. His talk covered the use of bisphosphonates, renal issues, Osteonecrosis of the Jaw (ONJ), and the development of new agents to combat myeloma bone disease.

Dr. Gertz's second presentation of the day addressed the changing role of transplant in myeloma. After a lunch break, Dr. Vescio's second presentation focused on treatment of relapsed disease, including an overview of available options and new clinical trials. The update on IMF's Bank On A Cure<sup>®</sup> research initiative was presented by Mike Katz, and you can read more about this project on page 6 of this newsletter. The final general assembly presentation, made by Dr. Durie, focused on what's on the horizon for myeloma patients and included an overview of data from the ASH meeting in December of 2006.

After the afternoon coffee break, each member of the faculty hosted their own Breakout Session, with seminar participants being able to attend one, any, or all of these sessions. The breakouts offer a "cafeteria approach" to multiple topics of interest, as well as an opportunity for more direct interaction with the myeloma experts on the faculty.

In conclusion, for people like me who've attended several IMF Patient & Family Seminars, some of the faculty experts have become old acquaintances and the information presented may no longer be news, but these seminars always have something for all members of the myeloma community, from "newbies" to the long-term patients who are more technically inclined. **MT**

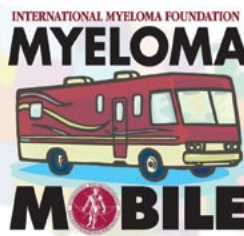
## IMF MYELOMA MOBILE

### The Tuohy Family Will Travel Across the United States

The Tuohy Family of Prospect, CT, plans to travel across the United States this summer in the MYELOMA MOBILE. This national grassroots outreach is the brainchild of Michael Tuohy, who was diagnosed with myeloma when he was just 36 years old. Michael will be traveling with his wife, Robin, and their two children, 14-year-old Ally and 9-year-old Mikey.

Plans for the MYELOMA MOBILE began in 2006 when the Tuohys were vacationing in a region that had no myeloma support resources. "When I was diagnosed I never thought I'd live to celebrate my 40th birthday, but here I am, seven years past diagnosis, in full remission and feeling good," said Michael. "I thought of the MYELOMA MOBILE as a way to reach out to patients and their families who never heard of myeloma before their diagnosis, and to help those who do not have good medical resources to work their way through the many treatment options available today. Facing myeloma can be daunting if you're doing it alone, and we want to be there to help."

The MYELOMA MOBILE is a unique event, providing an opportunity for patients, caregivers, and children of families touched by myeloma to share their experiences with one another. The Tuohy Family will also focus on raising myeloma awareness and on empowerment through education by disseminating the most up-to-date information about the disease, the advancements in myeloma treatment and management, and the benefits of appropriate therapy. "We want to visit communities that have local support groups to add our voice to theirs, and to visit communities that may have limited support and medical resources to bring them literature and



information they need," said Robin, who is also Regional Director of Support Groups for the IMF. The MYELOMA MOBILE will be stocked with over 50 publications covering a wide range of topics in multiple languages.

The Tuohy Family trip will begin in late June when Ally and Mikey are out of school. "When I first found out that my Dad had myeloma, I was in second grade and did not understand what was happening. I now have the opportunity to help others not feel so alone and to realize that there

is lots of hope," said Ally, "I can show kids ways to cope with the stress and sadness, and to appreciate what is most important in life. We've always dealt with my Dad's myeloma as a family, and we have gained strength from each other. I hope that together we will be able to help other families in the same situation." "I know I can help other kids whose family members have myeloma," added Mikey, who was only two years old when his father was diagnosed.

"It helps to talk when you are scared, and learning about myeloma makes it less scary, too. Maybe one of us kids will grow up to be a doctor and find the cure!"

Driving the MYELOMA MOBILE, the Tuohy Family will continue to criss-cross the country through mid-August. The MYELOMA MOBILE will be equipped with a GPS tracking system so you can follow its route on the IMF website [www.myeloma.org](http://www.myeloma.org). If you would like to visit the MYELOMA MOBILE, or for more information, please contact the IMF at [myelomamobile@myeloma.org](mailto:myelomamobile@myeloma.org) or 800-452-CURE (2873). **MT**

## SPOTLIGHT ON ADVOCACY

### Health Care Becomes Key Issue in 110th Congress

By Christine Murphy, MA

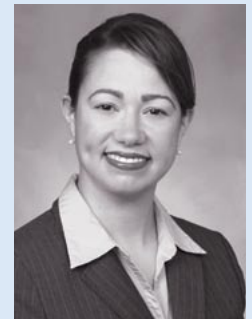
Health care will receive significant time and attention in the 110th Congress as leaders in both the House and Senate have prioritized these issues. Increases in funding are a high priority for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). The Congress will also address thorny issues within the Medicare system such as reimbursement for physicians (Part B) and reducing the "donut hole" in the Medicare prescription drug benefit (Part D).

Other key health care issues that will be addressed in the 110th Congress include:

- Reauthorizing the Prescription Drug User Fee Act at the Food and Drug Administration (FDA);
- Banning employers and health plans from discrimination based on genetic information;
- Expanding federal funding of stem cell research; and
- Addressing the growing number of uninsured Americans.

To ensure that myeloma patients have access to the comprehensive, quality care they need and deserve, IMF advocates ongoing and significant federal funding for cancer research and application. We are happy to report that funding for important myeloma cancer programs will become a higher priority than in years past. The President's budget for fiscal year (FY) 2008 included cuts in cancer programs, but Congressional leaders will largely ignore the President's budget

and have pledged that funding for myeloma cancer programs at the NIH, National Cancer Institute (NCI), and the CDC will be increased in FY 2008. While the ultimate outcome of these issues remains unclear, IMF stands ready to work with policymakers to advance policies and programs that work toward prevention and a cure for myeloma. For updates on these issues and IMF's advocacy efforts, please visit [www.myeloma.org](http://www.myeloma.org). **MT**



## UPDATES FROM EUROPE

### IMF Europe

The IMF has been actively involved with the myeloma community worldwide since its founding – providing services to patients and families, working with clinicians and scientists on projects promoting access to care, new drugs, clinical trials, fostering international collaboration, and funding cutting-edge research.

Integral to its mission to serve the international myeloma community, IMF offices have opened in the UK, Japan, and Latin America. These offices function under the leadership of directors native to those regions and through the efforts of dedicated volunteers. Funding support of these offices is made possible by donations and grants collected within the nations. In early 2006, the IMF made a commitment to increase its activities on the European continent by opening its IMF Europe affiliate, with Gregor Brozeit as Director.

Gregor is working with the European myeloma communities to help provide additional

services to benefit more patients. One of Gregor's projects is to organize Regional Community Workshops (RCWs) to broaden the reach of the IMF's cornerstone educational programs, such as the Patient & Family Seminars and clinical conferences. RCWs are structured as two to three-hour events designed to bring together world-recognized myeloma experts with locally based myeloma doctors to provide information and education to local patients and families.

As part of its ongoing efforts to promote a global exchange of information, IMF Europe has a goal of increasing expert exchanges on both sides of the Atlantic. In 2006, Drs. Robert Kyle and David Vesole of the US participated in three RCWs in Germany (Würzburg, Nürnberg, and Berlin) and Dr. Hermann Einsele of Germany visited US myeloma support groups in Miami and West Palm Beach, Florida.

This year, IMF Europe plans to open a new office in Belgium and to expand its efforts in Germany, France, Italy, and Spain. Projects and programs will include continued development of seminars and RCWs, expanded range of translated patient education materials, and creation of new support groups. Additionally, IMF Europe will work with the European Myeloma Platform (see below) to strengthen patient voices in European public policy issues. For more information, please contact Gregor Brozeit at [greg.brozeit@sbcglobal.net](mailto:greg.brozeit@sbcglobal.net).

### Upcoming Myeloma Regional Community Workshops

**May 16 – Munich, Germany**  
Featuring Dr. Morie Gertz  
(Mayo Clinic, Rochester, MN)

**May 19 – Würzburg, Germany**  
Featuring Dr. Gertz and  
Dr. Hermann Einsele  
(University Clinic of Würzburg)

### European Myeloma Platform

“Patients for Patients” is the motto of the European Myeloma Platform (EMP), an umbrella organization of support groups. EMP is the only pan-European myeloma patient organization run by patients and family members. Membership is free, and all myeloma patient groups in Europe are encouraged to join to make the voices of myeloma patients heard in the European health policy debate. EMP focuses on questions concerning:

- accessibility to treatment and medication;
- access to information on new and current trials;
- stimulation and support of research into new methods of treatment and medication; and
- exchange of information between European myeloma patient associations.

EMP is recognized by the European Medicines Agency (EMA, the European counterpart to the FDA) as a representative of European myeloma patients. EMP has represented the interests of myeloma patients to press for approval of Revlimid® in the European Union. In the future, EMP will participate in the evaluation of European Public Assessment Report (EPAR) to represent patient perspectives for future policy initiatives. EMP is the only blood and bone marrow cancer group involved in this activity, initiated by EMA to help patients properly use drugs.

EMP's main activities will concentrate on:

- collaboration with relevant European and international organizations;
- representation in relevant European political and health care organizations;

- organization of symposia, workshops, and other meetings; and
- web-based information dissemination.

EMP was founded in February of 2006 as a result of the initiative of myeloma patients from Austria, Belgium, Denmark, France, the Netherlands, and Switzerland. Later, EMP expanded to include myeloma patient groups from Germany and Scotland. EMP is a member of the European Cancer Patient Coalition (ECPC) and the European Organization for Rare Diseases (EURORDIS). EMP works in cooperation with the IMF, which provided EMP with start-up support. Politically and financially independent, EMP is registered as a non-profit organization under Belgian law. For more information, please visit [www.european-myeloma-platform.org](http://www.european-myeloma-platform.org). **MT**



### European Union Membership

- |                  |           |               |                  |
|------------------|-----------|---------------|------------------|
| • Austria        | • Finland | • Latvia      | • Romania        |
| • Belgium        | • France  | • Lithuania   | • Slovakia       |
| • Bulgaria       | • Germany | • Luxembourg  | • Slovenia       |
| • Cyprus         | • Greece  | • Malta       | • Spain          |
| • Czech Republic | • Hungary | • Netherlands | • Sweden         |
| • Denmark        | • Ireland | • Poland      | • United Kingdom |
| • Estonia        | • Italy   | • Portugal    |                  |





## Support Groups

### **VENTURA COUNTY MULTIPLE MYELOMA SUPPORT GROUP**

Gary Diehl was diagnosed with myeloma in August of 2000. After an intensive period of treatment, his sense of wellbeing returned but he felt alone with his disease. He had never met another myeloma patient. Then Gary's oncologist told him about an IMF Patient & Family Seminar being held in Los Angeles in January of 2003. That's how Gary became a part of the IMF family, and that's when the seeds for a new support group were planted. In July of 2004 Gary and his wife, Roberta, attended an IMF seminar in San Jose, California. During an open forum discussion, Gary announced his desire to start a myeloma support group in his area. Glen and Marion Seavers, a couple who also live in Ventura County, decided to join the effort.



*Back row:* Lisa Ratcliff, Maria & Fred Weiner, Tom Gilbo, Andy & Melba Forman, George Hurley, Arlene Kirman, Bob Diem, Tom Brondos, Zelda Finestone, Kathy Candish, Anthony & Mary Vara, Tess Daduya.

*Middle row:* Joan & Ivan Curtis, Rich Bintliff, Roberta Diehl, Laura Bintliff, Diane Schaefer, Tony Gaitan, Columbia Stenberg.

*Bottom row:* Mary Jane Helton, Ginny Weisman, Gary Diehl, Jan Diem.

With the help of the IMF, and word of mouth, the Diehls and the Seavers sought out other patients and caregivers in their area. In February of 2005 the group held its first meeting over breakfast in a local restaurant, with nine people in attendance. Since then, the group has found a home at a local chapter of The Wellness Community where approximately 20 regular participants meet in a warm and welcoming atmosphere, sharing a catered lunch. As facilitator, Gary makes sure that each member has a chance to share his or her experiences or questions. In addition, the group frequently circulates educational materials and occasionally hosts invited speakers.

"I started the support group because I needed a support group, and it has been a tremendous help to me," says Gary Diehl, "After many years as a high school teacher focusing on the needs of my students, I found that I was not very good at getting. Now, as I think about the support group and how I can best be of service to its members, I am better able to cope with my own disease. Our support group is a forum, an audience, a morale booster, a knowledgeable and sympathetic ear, a source of information, and above all, a companion." **MT**

**Editor's Note:** This group meets on the first Saturday of each month at 11:30AM at The Wellness Community in Westlake Village, California. For more information, please contact Gary Diehl at [grdiehl@sbcglobal.net](mailto:grdiehl@sbcglobal.net) or 805-647-2852.

### **SPACE COAST MULTIPLE MYELOMA SUPPORT GROUP**

In 2004, Rosemary Herring of Titusville, Florida, was working as a nurse at a teaching hospital for the University of Florida College of Medicine. One day, as she bent to pick up her dropped car keys, she felt a sharp pain. The pain persisted for weeks. Finally, Rosemary spoke with one of the doctors in her clinic. An x-ray revealed fluid in the lungs, which was drained, but six weeks later her condition was not improved. More tests followed until a diagnosis was established. At 52 years old, Rosemary had myeloma in 90% of her bone marrow.



*(left to right)* Jake Schaller, Rosemary & Wayne Herring, Wendy & Roger Widman, Ray & Helma Stern, Josephine & Philip Basilice

Rosemary's compromised immune system caused her to retire from a profession she loved. In September of 2004, she had her first autologous stem cell transplant and, in January of 2005, a second transplant followed. Rosemary's next challenge was dealing with bilateral lung nodules brought on by an infection resulting from the second transplant. As she recovered, Rosemary felt the need to talk to others, and she reached out to the IMF. There was no myeloma support group near Rosemary, so Andy Lebkuecher, IMF Regional Director of Support Groups for the Southeast, helped her to establish a new group.

Titusville is located on the banks of the Indian River, across from the impressive Kennedy Space Center. Hence the name "Space Coast Multiple Myeloma Support Group." The inaugural meeting took place in August of 2006. "A small group of myeloma patients and caregivers attended our first meeting, and Andy Lebkuecher came as well. Over the next few meetings, our group's ranks doubled," said Rosemary, whose healthcare background has helped her share educational information with group members. "The IMF patient pamphlets have been very helpful and the first time I received a copy of Myeloma Today, I can't describe how thankful I was to be reading such an informative publication," added Rosemary. "With so many treatments available these days, it's essential for the patient community to be educated about our disease and to understand the options at hand. Knowledge is power!"

Now in complete remission, Rosemary is able to reflect on her journey over the past two and a half years. "My myeloma experience has been something I wouldn't wish on anyone, but I have received so much support from so many people that I wanted to give something back. Starting a myeloma support group was one way to do that. The people who come to our meetings are so wonderful and, no matter how much I try to give to the group, I always find that I get more in return. This group has been my best therapy!" **MT**

**Editor's Note:** The Space Coast Multiple Myeloma Support Group meets on the second Thursday of each month at 5:30PM in Titusville. For more information, please contact Rosemary Herring at [spacecoastmm@cfl.rr.com](mailto:spacecoastmm@cfl.rr.com) or 321-271-4906.

## TWENTY-SIX YEARS AND COUNTING...

By Gary Benanav

In 1981, when I saw my local doctor in Connecticut for an annual physical, tests revealed that my hemoglobin level was below normal. I was referred to a hematologist, who ran a series of tests, culminating in the bone marrow biopsy that established the diagnosis of multiple myeloma. It looked like my life would be of short duration, with an outside life expectancy of two to two and a half years. A second opinion from a doctor at the University of Pennsylvania confirmed both the diagnosis and the prognosis.

I was 35 years old, a married father of three young children aged 5 to 11 years old. My wife and I decided not to share my cancer diagnosis with anyone, and to try and keep our lives as normal as possible. My personal goal was to live long enough to see my son bar mitzvah in two years. It was time to decide how to best maximize my life expectancy. Twenty-six years ago, the list of treatments for myeloma was very short. Given the options, my doctor said that he would prefer that I forgo treatment. To do nothing seemed like a very daring decision, but we agreed simply to observe the disease without treating it. We called this approach “benign neglect with a watchful eye.”

I saw the doctor regularly. My myeloma was progressing and my hemoglobin counts continued to decline, but I remained otherwise asymptomatic. In 1985, two years past my original life expectancy, I decided to consult Dr. Robert Kyle at the Mayo Clinic. His philosophy on myeloma seemed very close to my own. Unlike other experts working in the field at the time, he did not take an aggressive approach to every case. I continued to see Dr. Kyle every six to eight months. In the meantime, I was working crazy hours and traveling extensively for my job as an executive in the insurance industry, running international business units for a major American insurer. By 1993, my hemoglobin numbers were so low that I required regular blood transfusions, but I remained fully active.

In 1995, Dr. Kyle finally said, “If you don’t do something about your myeloma now, it may be too late.” He recommended chemotherapy followed by a stem cell collection but, because my disease had progressed so slowly, he opted not to perform a transplant at that time. Having to go through chemotherapy, which was administered from a fanny pack through a pump, finally required the disclosure of my diagnosis. But I continued to work and didn’t slow down until I had to fly to the Mayo Clinic for the stem cell harvest. I wasn’t thrilled about losing my hair but, all in all, the experience wasn’t too bad.

The remission lasted until 1998. The disease returned aggressively enough that it was time for a transplant, which was done at Mayo Clinic by Drs. Morie Gertz and Martha Lacy. The experience of the transplant in combination with chemotherapy and radiation (which was still part of the transplant regimen in the late 1990s) was horrible! I was on morphine for the pain, which was unspeakable. Generally, I am a very optimistic person but I found myself wondering if I had made the right decision. A week later it was discovered that a mistake by the pharmacy halved the prescribed strength of a morphine renewal, rather than doubling it. Still, I was one of the first patients at Mayo to do the transplant on an outpatient



Gary Benanav

basis. After a month living in a motel in Rochester, MN, I was back home for an additional two weeks of recovery. In another four weeks, I was back to feeling like myself.

I was in full remission, receiving no treatment aside from taking part in Mayo’s dendritic cell vaccine clinical trial, until early 2003. When the disease relapsed, I decided to transfer my care to Dr. Sundar Jagannath at St. Vincent’s Comprehensive Cancer Center in New York City, where I had moved by that time. Twenty-one years after my diagnosis, the diverse range of treatment options included several impressive novel agents. VELCADE<sup>®</sup>, which had just been approved for myeloma, seemed like my best bet. I was still traveling internationally for my work, so I would carry the drug with me and have it injected by local physicians. I had Velcade administered in

places as far away as India, Korea, Hong Kong, Indonesia, and Bali, usually by physicians or nurses who had never heard of the drug and whom I had to instruct on preparation and administration. Once the round of treatment was completed, another stem cell harvest was done as a precaution. A little less than two years later, I relapsed once again and went through a second round of Velcade, this time in combination with DOXIL<sup>®</sup>. Other than some unpleasant neuropathy in my feet, I tolerated the regimen well and was able to achieve another remission.

In the twenty-six years since my myeloma diagnosis, I’ve set many milestones for myself, and I’ve passed them all. Not only have I seen my oldest child bar mitzvah, I’ve seen my daughter married and my three grandchildren born. A year ago, I retired after a long career. I know that I have been very fortunate. For me, it doesn’t pay to ask, “Why?” I am not someone who believes in mind over matter, but holding to a positive attitude has helped me along the way. Living with the “sword of Damocles” hanging over my head has been a curse that all myeloma patients understand. At the same time, it has made me focus on what’s really important in life. I still wake up every morning and think how lucky I am to have the gift of another day of life. I will continue to appreciate those gifts no matter how much or how little time is left — but I’m determined to see many more days with the gift of life. **MT**

**Imagine Moving Forward** is the theme of the IMF’s myeloma bracelet. Wear one in honor, celebration, or in memory of a loved one. When people ask you about it, you’ll have a perfect opportunity to spread the word about multiple myeloma. These bracelets are only \$1 each in sets of 10. Youth bracelets are now available, so everybody in your family who has been touched by myeloma can wear one! Order bracelets online at our website [www.myeloma.org](http://www.myeloma.org), or contact Suzanne Battaglia at [SBattaglia@myeloma.org](mailto:SBattaglia@myeloma.org) or 800-452-CURE (2873).



## MYELOMA TODAY IN CONVERSATION WITH WALTER BENJAMIN REINHOLD

“Investing in the Future” features profiles of IMF members who are making profound investments in the myeloma community and the path to a cure. We hope that the stories of how and why these individuals have chosen to commit so significantly to the fight against myeloma will inspire you as much as they do us.

### Please tell us a little about your professional background.

I worked for a company that designs and manufactures machinery, tools, and equipment used in oil and gas drilling and production.

### Was your occupation in any way connected to your myeloma diagnosis?

When I was first diagnosed, that question was raised more than once. Although I worked in the oil and gas industry, my company simply produced the products used in the industry, so I had no job-related exposure to carcinogens.

### Under what circumstances were you diagnosed?

After traveling on a long non-stop flight, I developed a sharp pain in my ankle. My doctor suspected that I might have developed a blood clot and, sure enough, a blood clot was found. I spent the next three weeks in a hospital. Unexpectedly, blood tests also showed a protein spike. I was diagnosed with monoclonal gammopathy of undetermined significance (MGUS) and told that I may at some point develop either lymphoma or multiple myeloma or, because of my age (I was 70 at the time), the MGUS might just disappear. This was June of 1994. In June of 1998, my diagnosis was changed to myeloma.

### What is the quality of your life with myeloma?

The quality of my life has been impacted because of the myeloma-related peripheral neuropathy in my feet and lower legs, which continues to get worse. My balance is now so poor that I must use a walker to move around. But it's now been almost 9 years since my myeloma diagnosis. In December of 2006, I turned 82. I have developed the attitude that I really want to live. The world today is an extremely exciting and interesting place, and all of us can be involved in watching the great drama of life unfold. I am enjoying life now in a way that I hadn't anticipated years ago. I can no longer go fishing for trout and salmon, and that's too bad, so I've shifted my interests to the things that I am able to do. I love to read, so I read a great deal. The occasional television program is always welcome. I enjoy a good conversation. We live on the North Shore of Oahu in the Hawaiian Islands and, every afternoon, I take my walker out on the bike path for an hour of cardiovascular exercise. I am just not inclined to give up.

### Why have you chosen to support the IMF?

In January of 2003, I attended the IMF Patient & Family Seminar in Los Angeles. I found the IMF to be a wonderful organization with a very positive overall approach. The IMF does a great deal of good for the myeloma community. The IMF doesn't just give comfort to people. Susie Novis and Dr. Brian Durie travel the world disseminating information and education about multiple myeloma and its treatments. The IMF pursues and promotes means and efforts to cure myeloma through programs like Bank



Walter Benjamin Reinhold

On A Cure® and other endeavors. The IMF has had a significant impact on the entire world community of myeloma patients, caregivers, and healthcare professionals. I don't know of another organization that does a better job for a sickness to which it's dedicated. I believe the overall accomplishments of the IMF are among the very best in our medical society. And, speaking from a selfish standpoint, the IMF is a very good organization for me. I support the IMF because it's been very helpful to a patient like me. It seems to me that my life, and the lives of many other patients, has been extended by the advances that have come about in part due to the IMF. It is now possible, by controlling myeloma more effectively, to prolong life and to improve its quality. And the IMF is continuing to move in very interesting directions, and I am very confident that we will develop a cure for this disease.

In conclusion, I would like to make an observation.

In a baseball game, every time a batter goes to the plate, he would like to hit a home run. Unfortunately, nobody hits a home run every time. So it's important to remember that one of the most important statistics in baseball is “runs batted in.” If the batter manages to get a hit, he can reach first or second base, and this is great. The game keeps going and winning remains a possibility. A good team tries to get as many hits as possible and, at the end of the game, this can be more important than one or two home runs. With the help of my doctor, I am now on second base. We are engaged in a long, tough ball game. We are playing for keeps and the stakes are high. In the meantime, I am alive and I am optimistic. Getting to home plate and winning is now a real possibility. **MT**

### Planned Giving

There are many ways to support the IMF. It is important that you find the approach that best meets your needs and fulfills your wishes. In order to help start the thought process for your gift planning, we suggest the following forms of giving:

- Bequests in your Will or Trust
- Gifts of Securities (Stocks)
- Gifts of Real Estate
- Charitable Lead or Remainder Trusts
- Annuity Trusts
- Unitrusts
- Term-of-year Trusts
- Gifts of Life Insurance

Estate and gift planning requires thoughtful consideration and discussion. To learn more about any of the suggestions listed above, or other forms of giving that might inspire you, please contact Susie Novis at 800-452-CURE (2873) or [snovis@myeloma.org](mailto:snovis@myeloma.org). We also invite you to visit our website at [www.myeloma.org](http://www.myeloma.org) for a more detailed explanation of these giving plans.

## IMFers RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia

### Gina Terry Runs Again!

On December 9, 2006, Gina Terry embarked on her second half-marathon. She ran to honor her mother and to support the IMF's Bank On A Cure<sup>®</sup> research initiative. "As the race date approached, every time I didn't feel like training, I would just think of my mother and other myeloma patients who don't have a choice about facing their daily challenges, and that always kept me going," said Gina, who trained for three months to get to the starting line. "And during the race itself, in my pocket I carried a list of names of all the supporters of our cause to remind me why I was running. The entire experience was fantastic, despite the chilly



Gina at the finish line



Gina (left) with Samuel Boyd, sons Chandler & Cameron, husband Chris Terry, and Sullivan, Tara, Savanna, and Jeff Boyd.

25°F temperature! Many people approached me with questions about myeloma, Bank On A Cure, and the IMF, and everyone was so friendly. I received a lot of support – even my college roommate came to support the event and made a donation, and we

### Crowell Yard Sale

On January 27, Tami & Kevin Crowell held a successful yard sale to raise funds for both the IMF and Tami's mother's medical expenses. The event took place in the parking lot of Just for Kids Learning Center in Jacksonville, FL. Several family members helped organize the logistics of the event, and collected donated items for sale. "It was a fantastic day," said Tami, "We had three 20'-long trailers full of stuff that our friends and family donated – people were buying things even before the trailers were unloaded! We also held a bake sale and a raffle, and served sandwiches, chips, and drinks." To help raise even more money, Tami's brother-in-law, Ray Carnicelli, who played Lacrosse in college, conducted a sports clinic for kids. In addition, IMFer David Mann was on hand to offer support, help distribute IMF brochures, and share his myeloma experience with shoppers and visitors.



Tami & Kevin Crowell

### Members Help Fund Myeloma Research

The recipients of the 2007 IMF Research Grants were announced at the 48th Annual Meeting of the American Society of Hematology in December of 2006. The Senior Research Grant was awarded to Dr. William Matsui (Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins University, Baltimore, MD) for his project "Hedgehog Signaling in Myeloma Cancer Stem Cells." This grant was presented in the name of Janet Carol Johnson, and was funded by the "JC" Golf Invitational Tournament, an annual event organized by Janet's family and friends. The Junior Grant was awarded to Dr. Roberto Bellucci (Dana-Farber Cancer Institute, Boston, MA) for his project "Genetic screening for myeloma cell susceptibility to NK cell-mediated lysis using shRNA libraries." This grant was funded by the late Donald R. Woodward.

### Sheridan-Shedenhelm Wedding

On February 3, Kendra Shedenhelm and Shawn Sheridan were married in Tampa, Florida. Kendra's mother has multiple myeloma and, in less than one year, has undergone two stem cell transplants. Kendra has been her caregiver throughout, so she decided to make her wedding to Shawn even more meaningful. In lieu of gifts, the couple decided to honor Kendra's mother by helping to raise funds for the IMF while raising awareness of myeloma.

### Levine Mitzvah Day

On February 11, Harvey Levine participated in a Mitzvah Day project at Temple Beth Emet in Cooper City, FL. A Mitzvah Day is an event where the community helps charities and individuals in need. Harvey, who was diagnosed with myeloma in 2002, was joined in his fundraising project by his wife Joan and their grandchildren, 7-year-old Joshua and 4-year-old Eva. "A Mitzvah is a commandment, and one of the commandments is to perform good deeds and to help others," said Harvey, "We worked for our favorite cause, the IMF's research program. I look forward to doing many more functions to benefit the IMF."



Harvey Levine

### Join Us

We are grateful to all IMFers who contribute their time, imagination, and hard work to benefit the myeloma community. The IMF is committed to working with you to continue to raise awareness and funding for myeloma education and research. Please join us in working together toward our common goal... a CURE. Our FUNdraising program provides you with the tools, assistance, and expertise to make your event a success.

No idea is too large or too small. Please contact me, Suzanne Battaglia, at sbattaglia@myeloma.org or 800-452-CURE (2873). **MT**

### Upcoming Member Events

- May 6, 2007 – Afternoon Tea**  
(Special Guest Speaker – Susie Novis)  
Four Seasons Hotel – Washington, DC  
Contact: Carol Klein, carol60klein@comcast.net
- May 19, 2007 – 7th Annual "JC" Golf Tournament**  
Wapicada Golf Course – Saint Cloud, MN  
Contact: David Johnson, 952-546-6000
- May 27, 2007 – Myeloma Run/Walk**  
Winona, MN  
Contact: Erin Yess, erinyess\_7@hotmail.com

## MEET THE IMF'S EXECUTIVE DIRECTOR

### David Smith Promoted to Newly Created Position

#### How did you come to work for the IMF?

I was working in the medical affairs department of Salick Oncology when I first met Susie Novis, and the rest was kismet... In 2004, I was recruited to assist the IMF with the administration of the Centers for Disease Control and Prevention (CDC) grant and the internal and external operations of the foundation. I was promoted to the newly created position of Executive Director effective January 1, 2007.

#### What is your educational background?

My concentrations were marketing, accounting, Iberian studies, and languages. My MBA degree is from Thunderbird, the American Graduate School of International Management. My BA is from the University of Michigan. During my undergraduate studies, I attended the Universidad Complutense de Madrid. I am fluent in several languages.

#### What is your connection with Spain?

I fell in love with Spain during my senior year of high school when I went on a three-week trip to Castile and Andalusia. All I ever thought about was returning, so, for my junior year of college, I attended the Universidad Complutense de Madrid's foreign student curriculum. I lived with a local family, and traveled through Spain and Portugal. I've tried to return every year since then, and have been very lucky to have met that goal more times than not!

#### What about your work experience?

Mine is eclectic. I've taught English as a second language; was the director of a Luso-Brazilian research center; managed a store; and worked as a computer technician for one of the Big Three, in the same company from which my father had retired. Then I spent more than seven years in Mexico City, where I started what became a hugely successful software company. When I returned to the States, I gave up the "suit and tie" and studied Oriental medicine. My mother was a nurse, so I suppose that it was destiny to somehow end up caring for people. I graduated and became a full-time reflexologist. The majority of my patients suffered from peripheral neuropathy, a horrible problem that most myeloma patients know too well. I was hired by Salick to begin reflexology trials and to work in administration. That connection eventually brought me to the IMF, where I can combine my compassion for people with my skills in business management. I am incredibly grateful to Susie Novis and Brian Durie for allowing me the opportunity to serve the IMF and its members.

#### Please tell us about your experiences at the IMF.

I was hired as an Associate Director and immediately started work administering the grant from the CDC. Part of the implementation of the CDC grant has taken me to cancer centers and support groups around the country. I believe that my own personal experiences with patients and loss prepared me for the emotional impact of myeloma. I encourage everyone



David Smith  
IMF Executive Director

who does not attend a support group to do so. If there is not a group in the area, the IMF is here to help you start one.

Another of my responsibilities was to expand the IMF's extensive publications. With help from our staff, the Scientific Advisors, and especially Dr. Durie, we have more than doubled the publications we offer to over 60. The IMF has worked very hard to make the translated versions of our materials universally relevant.

When I was named Vice President (Operations) in January of 2005, I took on the additional responsibilities of our human resources needs. As the IMF grew, our staff expanded to more than 20 employees. We are very fortunate to have loyal staff members that care about our mission and our members.

Another important responsibility I have taken on is the operations aspect of the Bank On A Cure® program. By the time that we ended Phase II of the sample kit distribution program last year, we had received over 1,500 samples. We are currently involved with the National Cancer Institute in developing a questionnaire that will be distributed to those individuals and will lead us into further epidemiological results. Then we will embark on the next phase of the program, and we are very excited about that!

#### What are your responsibilities in the new position?

As Executive Director, my aim is to build upon the many successes of the foundation in the core areas of our mission — education, research, support, and advocacy — and to assist the IMF's Board of Directors in the fulfillment of our strategic planning goals. And I will continue to take a "hands-on" approach to areas that fall within my immediate expertise.

#### What do you see for the future of the IMF?

I would like to see the day when myeloma and other incurable diseases become manageable and eventually disappear. Until then, I see how other non-profits can learn from the model that the IMF has created: empowering the patient. At the IMF, we believe that education is the key to disease management, and the IMF continues to lead the way with our programs, publications, and educational forums. I look forward to the day when myeloma diagnosis is early and accurate; when each patient and family member is given the tools to manage the disease; and when all patients and caregivers affected by this disease can really know that they are not alone. **MT**

Editor's Note: If you would like to contact David Smith, he can be reached at [dsmith@myeloma.org](mailto:dsmith@myeloma.org) or 800-452-CURE (2873).

## IMF Staff Updates



IMF's **Kelly Cox** has been promoted to Director of Support Groups Outreach. Kelly works closely with the more than 90 support groups around the country, bringing the IMF's mission directly to those affected by myeloma. Kelly brings enthusiasm and energy to myeloma awareness and outreach wherever he travels for personal visits, as well as via phone calls and e-mails. Under his direction, the Southwest Symposium, an outreach project in Arizona, has grown to become a key source of information about myeloma in the region, as well as a unique forum for healthcare professionals, patients, and others.



**Jennifer Scarne**, the IMF's new comptroller, manages the daily financial operations of the Foundation. She is a Certified Public Accountant with over ten years of accounting and finance experience. Previously, Jennifer served as the controller of Morgan Creek Productions and as manager in Ernst and Young's internal audit entertainment practice, representing such entertainment clients as The Walt Disney Company, AOL Time Warner, and USA Networks. Jennifer has also served as line producer on an independent film, and volunteers her time serving as the vice president of finance on the board of The Good Shepherd Center for Homeless Women and Children.



**Heather Cooper Ortner**, who recently joined the IMF as vice president of development, comes to the Foundation from the Brandeis-Bardin Institute where, as director of development, she created a major gifts program and increased proceeds from an annual event by more than 60%. Previously, Heather was director of the Western Area Development Center of Hadassah, where she directed major gift activities in 16 states. She has also worked at the American Israel Public Affairs Committee and the Venice Family Clinic, the largest free clinic in the nation. Heather's 15 years of professional experience, and the innovation she has shown creating programs and opportunities in her previous positions, have prepared her to manage the relationship the IMF has with our generous and dedicated supporters.



**Arin Assero** recently joined the IMF as the special outreach program coordinator. After years as a dedicated caregiver to a family member with cancer, she decided to change her career path to the nonprofit sector. Previously, Arin enjoyed a long and successful career in restaurant and catering management, establishing a reputation as a reliable provider of solutions in the challenging and competitive Los Angeles food service industry.



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# 2007 IMF Calendar of Events

- |             |   |             |   |
|-------------|---|-------------|---|
| <b>May</b>  | 2-6 Southwest Oncology Group (SWOG) semi-annual meeting – Chicago, IL                         | <b>Sept</b> | 14 IMF Patient & Family Seminar – Paris, FRANCE   |
|             | 16 IMF Regional Community Workshop – Munich, GERMANY  |             | 21 IMF Patient & Family Seminar – Rome, ITALY   |
|             | 17 IMF Regional Community Workshop – Bergish-Gladback, GERMANY                                |             | 26 IMF Clinical Conference – St. Petersburg, RUSSIA                                     |
|             | 17-18 AMEN Israeli Association of Myeloma Patients anniversary celebration – Tel Aviv, ISRAEL | <b>Oct</b>  | 3-7 Southwest Oncology Group (SWOG) semi-annual meeting – Huntington Beach, CA          |
|             | 19 IMF Regional Community Workshop – Würzburg GERMANY   |             | 18-20 Lymphoma & Myeloma Conference – New York, NY                                      |
| <b>June</b> | 1-5 American Society of Clinical Oncology (ASCO) annual meeting – Chicago, IL                 |             | 20 IMF Clinical Conference – Beijing, CHINA   |
|             | 7 Kyle Lifetime Achievement Award Dinner – Vienna, AUSTRIA                                    |             | 21-27 Multiple Myeloma Awareness Week   |
|             | 7-10 European Hematology Association (EHA) annual meeting – Vienna, AUSTRIA                   | <b>Nov</b>  | 22 IMF Patient & Family Seminar – Barcelona, SPAIN                                      |
|             | 8-10 Eastern Cooperative Oncology Group (ECOG) semi-annual meeting – Washington, DC           |             | 2-3 IMF Patient & Family Seminar – Tampa, FL  |
|             | 25-30 XIth Int'l Myeloma Workshop – Kos GREECE  |             | 9-11 Eastern Cooperative Oncology Group (ECOG) semi-annual meeting – Ft. Lauderdale, FL |
| <b>July</b> | 27-28 IMF Patient & Family Seminar – Teaneck, NJ  |             | 17 IMF Regional Community Workshop – Bergish-Gladback, GERMANY                          |
| <b>Aug</b>  | 3-4 IMF (Latin America) Patient & Family Seminar – Sao Paulo, BRAZIL                          |             | 19 IMF Regional Community Workshop – Berlin, GERMANY                                    |
|             | 17-19 Nurse Leadership Board (NLB) Retreat – Santa Monica, CA                                 | <b>Dec</b>  | 8-11 American Society of Hematology (ASH) annual meeting – Atlanta, GA                  |

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-Israel events are not included above.

You are invited to attend a very special evening honoring Prof. Dr. Heinz Ludwig with the prestigious Fifth Annual IMF Robert A. Kyle Lifetime Achievement Award



**Heinz Ludwig, MD, PhD**  
1st Department  
of Medicine  
Center for Oncology  
and Hematology  
Wilhelminenspital  
Vienna, Austria

Fifth Annual International Myeloma Foundation  
**ROBERT A. KYLE**  
LIFETIME ACHIEVEMENT AWARD

Thursday, June 7, 2007 – 7:30pm  
at the VIENNA KURSALON – Vienna, Austria

This event is sponsored by  
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For information about participating in this evening, please contact Suzanne Battaglia at [SBattaglia@myeloma.org](mailto:SBattaglia@myeloma.org) or 800-452-CURE (2873)



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