MYELOMA TODAY

SUMMER 2011
VOLUME 8 NUMBER 8

A Publication of the International Myeloma Foundation

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

Scientific & Clinical News

Dr. C. Ola Landgren, Chief of the Multiple Myeloma Section, National Cancer Institute (NCI), National Institutes of Health (NIH), describes the care offered to patients at NCI/NIH. Several clinical studies being conducted by the physicians and scientists at the NCI/NIH aim to improve survival and quality of life for patients diagnosed with plasma cell disorders, and the medical care for study participants is free of charge. Dr. Landgren also discusses his interest in subsequent primary malignancies in patients with myeloma, looking at the biology which puts patients at increased risk of second malignancies (SPMs). ***PAGE 5***

Dr. S. Vincent Rajkumar, Professor of Medicine at Mayo Clinic (Rochester, MN), talks about the current role of serum free light chain (FLC) analysis in myeloma. He explains the four major indications for the FLC assay in the evaluation and management of myeloma and related disorders, as highlighted in the published guidelines of the International Myeloma Working Group (IMWG). Dr. Rajkumar also describes a new disease entity called light chain MGUS, which is present in approximately 1% of the general population over the age of 50 and can be identified with the FLC assay. ***PAGE 7***

Dr. James R. Berenson, Medical and Scientific Director of the Institute for Myeloma and Bone Cancer Research, and **Dr. Frank D. Vrionis**, Director, Spinal and Skull Base Oncology at the H. Lee Moffitt Cancer Center, discuss treating spinal fractures with Balloon Kyphoplasty. They also present the findings of a clinical study that took place across 22 sites in the United States, Europe, Australia, and Canada. Study patients suffering from the effects of painful vertebral compression fractures experienced improved quality of life as measured by both physical and mental component summaries. ***PAGE 8***

Supportive Care

IMF Hotline Coordinators discuss allogeneic (allo) transplantation. The hope has been that, if successful, an allo transplant might be able to cure myeloma patients. In recent years, doctors performing allo transplants have used what is called a "mini-allo" because it is safer than the full allo transplant. In this approach, the patient first receives an autologous transplant to reduce the tumor burden, followed by reduced-intensity chemotherapy. ***PAGE 12***

Profiles in the News

Prof. Michele Cavo, head of the Myeloma Research Unit at the Seragnoli Institute of Hematology (Bologna, Italy) and a member of the International Myeloma Working Group (IMWG) who has recently joined the IMF Scientific Advisory Board, shares some highlights of his work in myeloma from the early 1980s through the present. He was involved in pioneering the use of myeloablative allogeneic stem cell transplantation in myeloma, as well as pivotal clinical studies of autologous stem cell transplantation (ASCT). His latest published study compares two induction therapies before ASCT and consolidation therapy after double-ASCT. Prof. Cavo is the lead author of the IMWG overview of the frontline treatment options in myeloma. ***PAGE 9***

Danny Scott, diagnosed with myeloma five years ago at age 62, has dealt with multiple complications of the disease. But he made a commitment to fight as hard as he could, and to concentrate on living. That resolve helped Danny cope with biopsies, chemotherapy, a stem cell transplant, severe back pain, and a balloon kyphoplasty procedure to decrease the pain and improve the structural integrity of fractured vertebrae, plus a second spinal surgery to help restore his height. It took until December of 2009 for Danny to achieve remission, and he shares his story so others know that there is hope. ***PAGE 19***

Also in this issue...

LOOKING FOR A LOCAL MYELOMA SUPPORT GROUP?

Please visit our website at **myeloma.org** or call the IMF at **800-452-CURE** (2873).

This issue of *Myeloma Today* is supported by Binding Site, Celgene Corporation, Medtronic, Novartis, and Onyx Pharmaceuticals.

A Message from the President

Dear Reader,

Summer is the time of year when things really begin to "bear fruit," and it couldn't be more true this year in myeloma. In 2011, the 13th bi-annual International Myeloma Workshop (IMW) took place in May in Paris, France. The IMW has come a long way from the first workshop, which was held in the late 1980s in London. At that meeting, a handful of myeloma experts gathered to discuss the status of myeloma treatment and research. Over the past two decades, interest in myeloma has exploded from that initial small group of experts to over 2,500 clinicians and scientists attending IMW XIII in Paris.

While there were many impressive presentations at IMW XIII, the size alone no longer allows for detailed discussions. Thankfully, there are other forums where myeloma experts can "roll up their sleeves" and really go to work. I'm very proud to say that one such forum is the IMF's International Myeloma Working Group (IMWG) Annual Summit that took place in June in London, England.

Founded by the IMF, the IMF's IMWG held its first meeting at the 2001 American Society of Hematology (ASH) annual meeting. The idea behind forming IMF's IMWG was to create a forum where myeloma experts from around the world could meet to collaborate on both translational and lab research projects. There was one caveat: they had to produce results.

Over the years, members of the IMF's IMWG have been incredibly productive. As of this writing, 33 papers have been published in peer-reviewed journals and two more are "in press." This body of work has dramatically changed the way myeloma patients are diagnosed, staged, treated, and monitored. The published papers have also focused on managing disease complications. No one else in the world has put together a dream team like the IMF's IMWG, comprised of the most brilliant and accomplished scientists and clinicians whose passion and commitment is evident in their dedication and, most importantly, in their results. No other myeloma forum in the world has been this prolific!

At the second annual IMF IMWG Summit, myeloma experts assembled in London for two days to focus on answering 6 Key Questions:

1. Diagnosis & Management of High-Risk Smoldering Myeloma
2. Induction Therapy – Sequential vs. Curative Strategies: Testing 2- vs. 3- vs. 4-drug combinations
3. Role of Early Transplant
4. Maintenance or Consolidation?
5. Integrating New & Existing Drugs into the Myeloma Treatment Paradigm
6. Risk Stratification in Myeloma

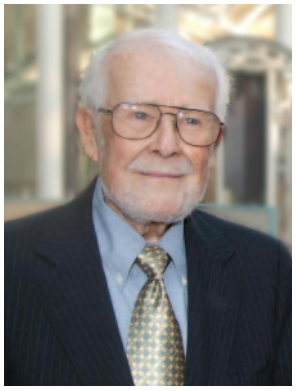
There is no other group in the world like the IMWG. It is truly groundbreaking in its scope, mission, commitment, and output. This group is really moving research forward, achieving results and showing the world that progress can be made when people stay focused and work together in a collaborative way.

In the Summer of 2011, my message to all of you who are living with myeloma, and coping with its many challenges, is… do not lose faith. The IMF and the IMF's IMWG are working very hard, and as fast as we can, to advance research that will improve outcomes and quality of life of myeloma survivors, and we **will** find a cure for this disease.

Susie Novis

Susie Novis

President



In Memoriam

Ty Jurras

1916 – 2011

Ty Jurras, the founding editor of *Myeloma Today*, created the "Dear Reader" column and was its first author. In the early days of the IMF, Ty worked closely with Brian Novis and helped organize the first IMF Clinical Conference for physicians, which was held in June 1992 in Phoenix, AZ. Ty's care, time, and talents have made an impact on the IMF that continues to be felt today.

Letters to the IMF President

Dear Susie,

At the end of your Dear Reader message that appeared in the Summer 2010 issue of *Myeloma Today*, you wrote… "with hope, happiness, and a true sense of family." So I decided to stop procrastinating and write you this letter.

Very belatedly, I want to thank you so much for calling our house when I was admitted to the hospital. When my husband told me that you called on behalf of yourself and Dr. Durie, offering your wishes and prayers of support, I actually cried. I know that you are one super-busy lady and that you took time out of your busy schedule to call touched us both so much. You and the rest of the wonderful folks at the IMF do give me hope, share in my happiness, and offer me a true sense of family. You being there for me and my fellow myeloma warriors and our loved ones means the world to all of us.

Thanks again for EVERYTHING, Susie! Your dedication and support are much appreciated and will never be forgotten.

Valerie Stevenson

Dear Susie,

I had to write this letter to let you know how grateful we were to be invited to the IMF Patient & Family Seminar in Boca Raton, FL. My wife Mary Lou and I have been to other meetings, and this one was the best. I have multiple myeloma, non- Hodgkin's cutaneous T-cell lymphoma (CTCL), and pre-cancer. At the seminar, we were with other people who can understand how we feel and talk the same talk. We met many people during the breaks and at our dinner table, and we could relate so much to them. You have to be in someone's shoes to really understand. We liked the idea of the patient and caregivers meetings Friday morning. We got a lot out of this. Susie, we just wanted to say that you have done a great job running this event. You had us laughing so much, and we all needed a good laugh. You could be an emcee at a Vegas hotel casino, but don't do that, because the IMF needs you.

Gerard (Jerry) L. Lefebvre

IMF Hotline

Hi Paul,

Thank you for all of the information you shared. All of it was EXTREMELY helpful and my whole family remains so grateful for the IMF. We were able to make much more informed decisions about treatment options. I really can't tell you how wonderful it is just to get information that feels clear. The complexity of the disease and treatment definitely compounds the emotional stress of the process. So truly truly, thank you!

Lee Sunday Evans

IMF initiatives in Asia

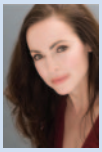
Congratulations regarding your success in building the bridge between the IMF and health ministry officials in the People's Republic of China.

I am a multiple myeloma patient, and am also an adoptive father of two girls, ages 7 and 13, from China. The IMF website was almost a first step for me in gathering information about myeloma when I was diagnosed in November 2008. I have found myself at the site almost daily for the pertinent news and guidance. I have great trust in what you tell me. I can't thank all of you at the IMF enough for your herculean efforts in educating patients and caregivers, and supporting the battle against myeloma. And thank you for promoting hope, courage, and honesty in this struggle.

On a personal note, one of my dreams is to travel back to the Chinese mainland with my family for an extended visit to share, in a meaningful way, my children's cultural heritage with them. To know that myeloma isn't a proverbial 'unknown' condition in China and that there will be an IMF presence there, is comforting. Godspeed with your endeavors in the PRC!

Sean Murray

If you would like to share your thoughts with the IMF or with readers of *Myeloma Today*, or if you wish to suggest or contribute future content for this newsletter, please contact:



Marya Kazakova – Publications Editor
International Myeloma Foundation
12650 Riverside Drive, Suite 206
North Hollywood, CA 91607
mkazakova@myeloma.org

IMF Staff Update

The IMF is pleased to welcome Judy Webb as our new Project Manager. Judy comes to the IMF after practicing for 10 years as a veterinarian, followed by 14 years in the animal healthcare industry working for IDEXX Reference Laboratories. Her role at the IMF is to consolidate and coordinate the project management, logistics, and administration of the many programs and services offered by the foundation. Judy, who is originally from Boston, lives in Los Angeles with her husband, their two cats, and two Golden Retrievers. **MT**

MYELOMA TODAY IN CONVERSATION WITH C. OLA LANDGREN, MD, PHD

In brief, please tell us about your medical background.

By training, I am a medical doctor and a trained clinical hematologist, and I also hold a doctorate from the Karolinska Institute in Stockholm, Sweden. I worked at the Karolinska Institute as an attending physician and conducted clinical research for several years before coming to the US. In 2004, I came to the National Cancer Institute (NCI), National Institutes of Health (NIH), Division of Cancer Epidemiology and Genetics (DCEG), where I worked as an Investigator before joining the Medical Oncology Branch. Scientifically, as reflected by my publications, my major research interests are in the treatment, causation, diagnostics, and prognostics, and natural history of multiple myeloma and its precursor condition, monoclonal gammopathy of undetermined significance (MGUS). My particular interest in the trajectory from precursor to full-blown hematologic malignancies, molecular pathways underlying progression, and the development of targeted strategies aiming to delay, prevent, and cure full-blown disease.

C. Ola Landgren, MD, PhD
Chief, Multiple Myeloma Section
National Cancer Institute (NCI)
National Cancer Institute (NIH)
Bethesda, MD

What is your current professional position?

I am a Senior Investigator and Attending Physician at the Intramural program of the NCI/NIH, and the Chairman of the Scientific Review Committee at the Medical Oncology Branch and Affiliates at NCI. I am Chief of the Multiple Myeloma Section at NCI/NIH in Bethesda, MD.

Please tell us about the work of the NCI/NIH Multiple Myeloma Section.

We provide expert clinical care, treatment, imaging, and follow-up for patients with plasma cell disorders and related diseases. Most of our patients have monoclonal gammopathy of undetermined significance (MGUS), smoldering multiple myeloma (SMM), newly diagnosed or relapsed/refractory multiple myeloma. But we also work with patients who have other plasma cell disorders, such as Waldenström's macroglobulinemia (WM) and amyloidosis, as well as several rare conditions (e.g., heavy chain disease, necrobiotic xantogranuloma, HIV-related plasma cell dyscrasias).

Our research section has several ongoing studies that aim to improve survival and quality of life for patients diagnosed with plasma cell disorders. At present, there is a lot of exciting research taking place in myeloma and related disorders, and we are happy to be able to make a contribution. We have close to 150 patients currently enrolled in our trials, and we are seeing more and more patients coming to us for assessment and treatment. We are very interested in correlative science, genetic changes in tumor cells, biomarkers, and novel imaging modalities. We are developing new "targeted therapies" and new combinations of existing therapies that aim to inflict effective damage on abnormal plasma cells without causing a wide range of toxicities that affect the patient's healthy cells. We are conducting preclinical, clinical, and population-based studies to prevent, cure, or delay plasma cell disease processes, and at the same time, to answer important research questions. All of our clinical studies are developed and conducted by the physicians and scientists at the NCI/NIH. All our studies are based on new drugs and new strategies for clinical management.

Because the NCI/NIH is part of the Department of Health and Human Services (HHS), which is a United States federal government agency, for patients participating in our studies, all costs related to medical care, treatment, and follow-up of that study, are paid for by the NCI/NIH independent of medical health care insurance status. Thus, for patients who participate in a study, all care is free of charge. Patients do not need to have health insurance to be treated here.

We welcome patients to participate in our clinical trials. We also welcome patients for second opinion visits. We try to find the best treatment available for each patient, and our clinical staff provides individualized care to all who are assessed and/or treated here.

Do you mean to say that there are no costs at all incurred by the patients you work with?

This is one way in which our program is different from others. Patients come to us from all 50 states. They are responsible for travel costs associated with their initial screening visits, but the medical care for patients who participate in a clinical study is free of charge. Patients receive a top-of-the-line clinical work-up, with blood-based and bone marrow-based markers, as well as high-quality imaging and very rigorous molecular profiling. We use all types of the latest technologies.

Because the NCI/NIH is part of the Department of Health and Human Services (HHS), which is a United States federal government agency, for patients participating in our studies, all costs related to medical care, treatment, and follow-up of that study, are paid for by the NCI/NIH independent of medical health care insurance status. Thus, for patients who participate in a study, all care is free of charge. Patients do not need to have health insurance to be treated here.

In most cases, once a patient is enrolled in a clinical trial, the NCI pays the transportation costs for all subsequent study-related visits for patients who do not live in the local area. In addition, these patients might receive a small *per diem*

CONTINUES ON PAGE 6

C. OLA LANDGREN, MD, PHD — continued from page 5

to help offset the costs of meals and lodging if they are being treated as outpatients.

Please tell us about some of the research projects at your center.

We are pursuing a very comprehensive range of investigations, all of which are based on solid science, not far-flung experimentation. We have already presented some very interesting data, and we are currently engaged in many ongoing studies. One protocol, which started enrolling in May 2010 and will eventually include a total of 250 patients, will follow patients for 5 years. The molecular profiling from this investigation should yield some robust data for us to communicate next year.

We have been interested in the molecular mechanisms of the anti-myeloma effects which happen in myeloma patients who receive an allogeneic transplant. We now know that, to a large degree, the anti-myeloma effect works through certain immune cells, such as natural killer cells from the donor, which go after the patient's myeloma cells. Consequently, we have developed treatment strategies to mimic the mechanisms that cause this anti-myeloma effect in allogeneic transplant, without giving the transplant. The approach gives the patient repeated anti-KIR monoclonal antibody infusions to trigger an immune response to his or her cancer cells. As part of our ongoing studies, we have started using this strategy to treat patients with SMM. The aim is to delay or prevent the disease from progressing into full-blown myeloma. Results of this first stage of the study should be ready for presentation at the December, 2011, annual meeting of the American Society of Hematology (ASH). The second stage of this study will most likely be initiated in the Fall of 2011.

We are also working on improving imaging. A molecular imaging study, which opened in November of 2010, is using advanced imaging technologies to evaluate and manage patients with various stages of plasma cell diseases. We are conducting PET-CT-based and MRI-based investigations to define disease burden and risk of progression at various clinical disease states. Our aim is to develop more sensitive and more specific imaging tracers. The data from this study should also be ready for presentation at the 2011 ASH meeting.

This year, we are opening a clinical trial of carfilzomib in newly diagnosed myeloma patients. After induction/consolidation therapy, patients will be on extended dosing for a period of one year. We are going to correlate this with minimal residual disease (MRD) to determine how close we can get to actually getting rid of this disease.

In addition, we have two treatment studies for relapsed/refractory patients: one with an oral MEK inhibitor, the other with oral mTOR and HDAC inhibitors. There is a lot going on at our center.

You have had an interest in subsequent primary malignancies in patients with myeloma. Would you share with us some key points of your presentation on this topic at the International Myeloma Workshop XIII in Paris, France?

In collaboration with my colleagues in Scandinavia, we have collected a lot of high-quality population-based data. The Swedish Data Bank covers approximately 10,000,000 people over the period of 20 years (1986-2005), tracking more than 95% of patients with myeloma from this time period. Increased frequency of myeloid malignancies has been noted among myeloma patients since the 1970s, although underlying biological mechanisms are poorly understood. The aims of this study include defining the risk of primary malignancies subsequent to myeloma compared to the general population. For the first time, we aim to assess role of treatment and non-treatment-related factors on the risk of subsequent primary malignancies in patients with multiple myeloma.

The Swedish Data Bank covers approximately 10,000,000 people over the period of 20 years (1986–2005), tracking more than 95% of patients with myeloma from this time period.

We are assessing the risks of developing another malignancy before/after 1995, that is, before and after the introduction of high-dose melphalan plus autologous stem cell transplant (ASCT) as a treatment option for myeloma in Sweden. We are looking not only at the risk of second tumors, but also at the type of second tumors. We are also examining the role of host- and myeloma-related factors. It is very important that we answer these questions. So far, our finding supports a role for non-treatment-related factors, but longer follow-up is needed to better define second tumor risks in the era of novel therapies.

For the first time, we aim to assess role of treatment and non-treatment-related factors on the risk of subsequent primary malignancies in patients with multiple myeloma.

As part of my investigation, I also examined the data of 6,000 MGUS patients that I identified when I worked at the Karolinska Institute. Because MGUS patients do not receive anti-myeloma therapies, this group serves as a negative control. I found a six-fold increase in the risk of acute myeloid leukemia (AML) and myelodysplastic syndrome (MDS) in this untreated population. This suggests that individuals with plasma cell dyscrasias might have an underlying biology that puts them at increased risk of AML/MDS.

Thank you. Any closing comments?

As researchers, we want to know what works and why it works. At NCI/NIH, we are very fortunate to have an excellent staff, which is why our program has been able to grow at such a fast pace. But, ultimately, we are here to serve patients, and we welcome people to come to our clinical center for second opinions and/or to participate in our investigator-initiated protocols. For more information, I would recommend that interested individuals contact our Lead Research Nurse, Mary Ann Yancey, RN, at yanceym@mail.nih.gov or 301-435-9227, or visit our website at multiplemyeloma.cancer.gov. **MT**

Editor's Note: Dr. Landgren is the recipient of the 2010 NCI Bench-to-Bedside Award, as well as numerous other honors and scientific recognitions. He is a member of the Editorial Board of *Haematologica/The Hematology Journal*, and is a popular lecturer and presenter. Dr. Landgren has authored more than 100 peer-reviewed original articles, as well as many peer-reviewed review and editorial articles. He is the lead NCI principal investigator of several clinical trials.

THE CURRENT ROLE OF SERUM FREE LIGHT CHAIN ANALYSIS IN MYELOMA

Myeloma Today in conversation with Dr.S.Vincent Rajkumar

What is serum free light-chain analysis?

The Freelite™ serum immunoglobulin free light chain (FLC) assay measures levels of free kappa (κ) and lambda (λ) immunoglobulin light chains, which are not bound to heavy chains. Measurements of circulating monoclonal immunoglobulins (M-proteins) are the mainstay of diagnosis, prognosis, and management of multiple myeloma and related clonal plasma cell disorders. In the FLC assay we measure both κ and λ free light chains and look at the ratio between the two levels. If the ratio is abnormal (<0.26 or >1.65), the patient is presumed to have an excess of lambda or kappa monoclonal free light chains. The FLC test has proven utility in several settings.

What is the current role of serum free light-chain analysis in myeloma?

As highlighted in the published guidelines of the International Myeloma Working Group (IMWG) by Dr. Angela Dispenzieri and colleagues, there are four major indications for the FLC assay in the evaluation and management of myeloma and related disorders:

S. Vincent Rajkumar, MD
Professor of Medicine
Mayo Clinic
Rochester, MN

In the context of **screening** for the presence of myeloma or related disorders, the serum FLC assay in combination with serum protein electrophoresis (SPEP) and immunofixation (IFE) has high sensitivity, and negates the need for 24-hour urine studies for diagnoses other than when light-chain amyloidosis (AL amyloidosis) is suspected. If a plasma cell disorder is diagnosed, however, 24-hour urine studies are required for all such patients.

Second, the FLC assay is of major **prognostic value** in a variety of plasma cell disorders, including monoclonal gammopathy of undetermined significance (MGUS), smoldering multiple myeloma (SMM), active myeloma, immunoglobulin light-chain amyloidosis, and solitary plasmacytoma. We particularly use the FLC assay for risk stratification of MGUS and SMM.

Third, the FLC assay allows for **quantitative monitoring** of patients with oligosecretory (low secreting) plasma cell disorders, including patients with AL amyloidosis, oligosecretory myeloma, and nearly two-thirds of patients who have previously been deemed to have non-secretory myeloma based on the results of protein electrophoresis. In AL amyloidosis patients, serial FLC measurements outperform protein electrophoresis and immunofixation, and a reduction in FLC levels by >90% is the desired goal of therapy. In patients with oligosecretory myeloma, measurement of FLC is essential. Although this has not been formally validated, it is widely acknowledged in clinical practice that serial FLC measurements reduce the need for frequent bone marrow biopsies in such patients. The FLC assay has not yet replaced the 24-hour urine protein electrophoresis for monitoring myeloma patients with measurable M-proteins by serum or urine PEP.

Fourth, the kappa/lambda FLC ratio (rFLC) is a requirement for documenting **stringent complete response** (sCR) according to the IMWG's Response Criteria. Several myeloma clinical trials in the US and Europe have already reported sCR data, and many ongoing trials are collecting this information.

Is the FLC assay used in risk stratification of myeloma patients?

Not much. There are many tests that can predict prognosis in myeloma. We, for example, risk-stratify patients predominantly using cytogenetics and FISH (fluorescence in situ hibridization). But FLC is one of the valuable prognostic markers we have in our testing arsenal for myeloma. For example, high levels are associated with increased likelihood of renal failure, and we tailor our treatments to keep the FLC levels under control.

Are there any drawbacks to serum FLC testing?

The serum FLC is a valuable assay as I discussed earlier, but there are some technical limitations. These include lot-to-lot variation and assay imprecision. Dr. Jerry Katzmann from our group is studying this carefully, and will soon have results quantifying the variability of the FLC assays, as well as other assays that we currently use to monitor patients.

Have any new uses for the FLC assay been identified since the publication of the IMWG guidelines?

Recently, we described a new disease entity called light chain MGUS, which is present in approximately 1% of the general population over the age of 50.

Light chain MGUS is the likely precursor of approximately 20% of myeloma that are considered "light-chain only" and defined by absence of IgH expression. Light chain MGUS is not a condition we are screening for, nor do we recommend such screening. Rather, it is something that can be identified incidentally when patients are tested with the FLC assay. Like regular IgH MGUS, light chain MGUS has a small chance of progressing to myeloma. In fact, in our study, we found that patients with light chain MGUS had a 0.3% chance per year of progressing to myeloma. This is a lower rate of progression than patients with IgH MGUS. At Mayo Clinic, we recommend that patients with light chain MGUS be monitored for progression every 12 months.

What's next for serum FLC assays?

We need to establish the role of the FLC assay in monitoring response in patients who have measurable M proteins. We also need to define the clinical relevance of early FLC "response" or "relapse" in such patients. We should determine the underlying biologic basis for the ability of the FLC assay to predict risk of progression in MGUS, SMM, etc.

We have heard of another test called the Hevylite™ assay. What can you tell us about this?

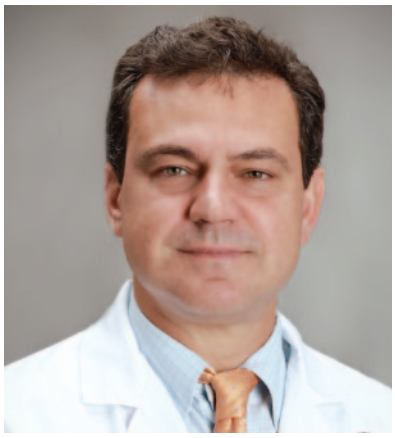
The Hevylite™ assay gives us a quantitative measurement of IgG kappa, IgG lambda, IgM kappa, IgM lambda, IgA kappa and IgA lambda separately. The Hevylite assay appears to be able to precisely measure very low levels of myeloma since the kappa/lambda ratios of the involved immunoglobulins can be measured and tracked. We are likely to see numerical data from clinical studies using the Hevylite test to evaluate patient prognosis and response to treatment in the near future.. **MT**

TREATING SPINAL FRACTURES WITH BALLOON KYPHOPLASTY

Myeloma Today in conversation with Drs. James Berenson and Frank Vrionis

Dr. Berenson, you are the principal investigator of the first randomized, controlled trial comparing Kyphon® Balloon Kyphoplasty with non-surgical care in treating spinal fractures in cancer patients. Please tell us about it.

James R. Berenson, MD
Medical and Scientific Director
Institute for Myeloma and
Bone Cancer Research
West Hollywood, CA



Frank D. Vrionis, MD, MPH, PhD
Director, Spinal and Skull Base Oncology
H. Lee Moffitt Cancer Center
Professor, Neurosurgery & Orthopaedics
Univ of S Florida – College of Medicine
Tampa, FL

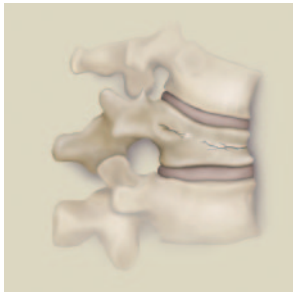
Dr. Berenson: The study, known as CAncer Patient Fracture Evaluation (or CAFE), was published on February 17 in the online edition of The Lancet Oncology. The CAFE study took place across 22 sites in the United States, Europe, Australia, and Canada. We conducted a randomized trial comparing balloon kyphoplasty versus non-surgical fracture management for treatment of painful vertebral body compression fractures in 134 patients with cancer. Patients had 1-3 symptomatic fractures. Participants had various types of cancer, including multiple myeloma.

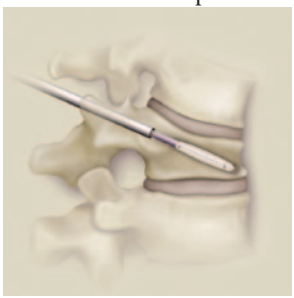
In the CAFE study, 70 patients were randomized to the Kyphon® Balloon Kyphoplasty group and 64 patients were randomized to a non-surgical control group. As medically appropriate, members of both groups were able to receive non-surgical care, such as pain medications, rest, bracing, walking aids, and radiation therapy. Following the primary endpoint after one month of follow up, patients randomized to non-surgical management were allowed to undergo balloon kyphoplasty.

Please tell us more about the procedure from the perspective of a surgeon.

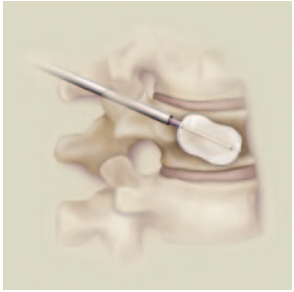
Dr. Vrionis: Approximately 70% of patients with myeloma present with fractures. Most of these fractures are lytic, which means that there is bone loss. Some fractures can be quite serious, with a risk of cord compression and kyphotic deformities (curvatures). Pain can be a substantial issue that has an impact on the patient's quality of life and their ability to undergo the necessary cancer treatment.

Balloon kyphoplasty can be performed under either local or general anesthesia. It is a minimally invasive procedure that is safe and well-tolerated. During the procedure, a hollow needle is inserted into the vertebral body, making a small pathway into the fractured bone. Generally, two such working pathways are used, one on each sides of the vertebral body, to better support the bone and increase the likelihood of deformity correction. An orthopedic balloon is then placed inside the fractured vertebra through each pathway. The balloon is carefully inflated inside the fractured bone, pressing the soft inner bone against the outer wall and raising the collapsed vertebral body in an attempt to return it to its correct position. Inflation of the balloon creates a space (cavity) inside the fractured vertebra, which is then filled with a bone cement. The balloon functions as a "container" for the cement. Once the cement hardens, it restores vertebral body height in the compressed body and stabilizes the fracture, holding the vertebral body in place. Patients usually experience immediate reduction of pain.

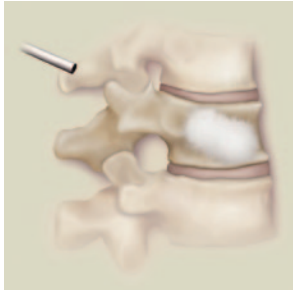




A hollow instrument is used to create a small pathway into the fractured bone. A small, orthopaedic balloon is guided through the instrument into the vertebra. The incision site is approximately 1 cm in length



Next the balloon is carefully inflated in an attempt to raise the collapsed vertebra and restore vertebral body height.



The cavity is filled with bone cement and is designed to form an internal cast to hold the vertebra in place.

How does balloon kyphoplasty differ from other surgical therapies for vertebral compression fractures, such as vertebroplasty?

Dr. Vrionis: Vertebroplasty is designed to stabilize the fracture without correcting vertebral body deformity or providing a controlled fill and distribution of bone cement. Under high pressure in a fixed space, the cement may spread outside the vertebral body, which can cause significant side effects. With balloon kyphoplasty, inflation of the balloons compacts the bone, which may fill fracture lines and restore height in the compressed vertebral body. The presence of the space also allows a more viscous bone cement to be injected under low manual pressure with reduced risk of cement leakage.

There was a roundtable discussion on this subject, held in Paris at the time of the recent International Myeloma Workshop (IMW), which aims to incorporate the analysis of the CAFE study in a consensus statement. What is your opinion on the benefits of balloon kyphoplasty?

Dr. Berenson: One limitation of the CAFE study is that randomization of treatment lasted for only the first month, although this is considered to be a standard timeframe to assess safety and improvements in pain and function. After one month, patients from the control group were allowed to receive balloon kyphoplasty and the majority (38 of 64, or 59%) chose to do so. Another potential limitation of the trial was that we did not perform a sham operation for patients randomized to initial non-surgical management.

There was an article in the recent The New England Journal of Medicine stating that vertebral compression fracture treatment is ineffective because the osteoporosis

CONTINUES ON PAGE 10

SCIENTIFIC ADVISOR PROFILE

Myeloma Today in conversation with Prof. Michele Cavo

Please tell us a bit about your medical background and current position.

I received my medical degree, as well as the post-graduate residency in Hematology, from Bologna University School of Medicine in Bologna, Italy. In 1991, I became Assistant Professor of Hematology. Currently, I am Associate Professor of Hematology at Bologna University School of Medicine and Head of the Myeloma Research Unit at Seràgnoli Institute of Hematology. From January 2000 to June 2005, I was appointed Director of postgraduate residency in Hematology at the University School of Medicine in Bologna. Between 2004 and 2009, I served as Treasurer on the board of the Italian Society of Hematology. Since 2004, I have co-chaired the GIMEMA (**G**ruppo **I**taliano per lo Studio delle **M**alattie **EM**atologiche dell'**A**dulto) Italian Myeloma Network.

Michele Cavo, MD
Seràgnoli Institute of Hematology
Bologna University School of Medicine
Bologna, Italy

How did you come to be interested in multiple myeloma?

My degree thesis was about myeloma therapy, so I have been involved in this field since the very beginning of my work in medicine. I have devoted many years to the biology and the treatment of myeloma.

What were the available treatment options for patients at that time?

Soon after I received my medical degree, efforts to improve clinical outcomes for myeloma patients involved the use of different combinations of cytotoxic drugs given at conventional doses. The early 1980s, when I started my work as hematologist at Seràgnoli Institute, was the era of pilot studies exploring the feasibility and activity of high-dose melphalan followed by autologous hematopoietic stem cell transplantation. Since the mid 1980s, I was directly involved in pioneer studies of myeloablative allogeneic (allo) stem cell transplantation in myeloma. In 1984, the Bologna team performed one of the first allo transplants for myeloma in Europe. The patient was a young female who received the graft from her HLA-identical sister.

What direction did your subsequent work in myeloma take?

My subsequent work was addressed at investigating prognostic factors and alternative treatment strategies for myeloma patients. For example, in 1989, I published in *Blood* one of the first reports on the prognostic relevance of thrombocytopenia and the value of platelet counts in refining the prediction of prognosis established by the Durie/Salmon Staging System. Many subsequent studies have independently confirmed the value of platelet counts as a prognosticator in myeloma. At the same time, I designed and chaired several multicenter Italian studies of chemotherapy both at conventional doses, such as the alternating combination of vincristine, adriamycin, dexamethasone (VAD) and melphalan-prednisone (MP), and at high-doses requiring autologous stem cell transplantation (ASCT). The "Bologna 2002" clinical trial was one of the first studies designed to prospectively compare a single vs. double ASCT as upfront therapy for patients 65 years of age and younger. Final results of this study were published several years ago in the Journal of Cinical Oncology and showed the superiority of double over single ASCT in terms of increased rate of complete response (CR) and extended progression-free survival (PFS). In particular, the major benefits from double ASCT were seen in those patients who failed CR after the first ASCT.

At what point did you begin to study novel agents?

In the late 1990s, the landscape of myeloma therapy was dramatically changed by the report that thalidomide had remarkable activity in relapsed/refractory myeloma. Based on these exciting results obtained in advanced phases of the disease and the lack of toxicity of thalidomide on hematopoietic stem cells. I explored the activity of this novel agent as induction therapy for newly diagnosed patients who were eligible to receive ASCT. The challenge was to use an effective oral regimen incorporating thalidomide plus dexamethasone (TD) instead of the infusional VAD regimen, which at that time was the standard induction therapy in preparation for subsequent ASCT. Results of this pivotal study showed the superiority of TD over VAD in terms of overall response rates (ORR) and were published in *Blood* in 2005. The study was introduced by an *Inside Blood* article titled "Multiple myeloma: the death of VAD as initial therapy." Really, this study changed the treatment paradigm for transplant-eligible myeloma patients since it provided the first demonstration of the benefits offered by incorporation of novel agents into induction therapy before ASCT. More recently, I published in the *Journal of Clinical Oncology* the results of the "Bologna 2005" study showing the superior outcomes for patients receiving TD from the outset until the second ASCT in comparison with patients treated with double ASCT without the incorporation of TD.

What has been the focus of your more recent work?

My latest study, published in *Lancet* in December 2010, was a large phase III clinical trial comparing TD with VTD (TD plus Velcade® [bortezomib]) as induction therapy before and consolidation therapy after double ASCT. The primary endpoint was the rate of CR after TD or VTD induction therapy. Published results showed that after two months of induction therapy the CR rate with VTD was threefold higher than with TD. Importantly, high-dose therapy with ASCT further enhanced the rate of CR in the VTD arm as compared to the TD arm, suggesting that novel agents and ASCT are complementary procedures. An additional important finding was that the VTD regimen retained its superior activity in comparison with TD when used as consolidation therapy after ASCT. The final rate of CR was 62% in the VTD arm as compared to 45% for patients randomized to the TD arm of the study. As a result of the significantly higher rate of CR associated with VTD and double ASCT, the 3-year estimate of PFS was in the 70% range, which is one of the best results reported so far with incorporation of novel agents into ASCT.

What about patients with poor prognostic factors?

The remarkable activity of VTD as induction and consolidation therapy combined with double ASCT was retained in all poor prognosis subgroups of patients, including those with high-risk cytogenetic profiles, such as the presence of t(4;14) with or without del(17p). When we performed a separate analysis of PFS in patients who carried t(4;14), we found that VTD plus double ASCT was able to completely overcome the poor prognosis associated with this cytogenetic abnormality. The PFS curves for patients with and without t(4;14) were almost super-imposable in the VTD arm of the study, while t(4;14) retained its adverse impact on prognosis in the TD arm.

CONTINUES ON PAGE 10

BALLOON KYPHOPLASTY— continued from page 8

patients in randomized blinded trials testing vertebroplasty for vertebral compression fractures showed no significant benefit and, as a result, suggested that insurance companies and Medicare should not cover these procedures. This was rather myopic in its view because our study was in a cancer population using a different procedure and showed a clear consistent benefit. Although our study was not blinded, we believe that it would be unethical, in the setting of cancer, to perform sham surgeries in the patients randomized to non-surgical management. We were NOT willing to insert a needle into a cancer patient, and then simply withdraw it without any procedure being performed to see if there would be a placebo effect. And I do not believe that the endpoint benefits we observed across the board were simply from some spectacular placebo effect. Even subjecting patients to radiation therapy to relieve pain would not likely have had such dramatic benefits.

Now that you mention it, what about radiation as a treatment option?

Dr. Berenson: Radiating the back compromises the patient's bone marrow as well as the local bone and other organs in the vicinity, and the damage is permanent. In the CAFE study, while balloon kyphoplasty patients showed almost an immediate benefit, the non-surgical management group showed no improvement despite the proviso that patients randomized to non-surgical management were allowed to undergo radiation therapy.

Dr. Vrionis: Radiation can be helpful for patients with solid tumors. However, radiation treats the tumor but cannot heal fractures or aid with correcting spinal deformities.

Is balloon kyphoplasty an option for all patients with spinal fractures?

Dr. Vrionis: Any myeloma patient with a vertebral compression fracture should be evaluated by a neurosurgeon or orthopedist. Not all myeloma patients are candidates for balloon kyphoplasty. Patients should discuss the potential benefits and risks of balloon kyphoplasty with their physicians in order to determine whether this procedure is right for them. As with any surgical procedure, there are risks, so patients should talk about the potential adverse events with their doctors. In my opinion, balloon kyphoplasty should be standard of care for patients with myeloma who have compression fractures and are candidates for this procedure.

What are the potential risks of this procedure?

Dr. Berenson: Medical adverse events were similar from baseline to one month between the balloon kyphoplasty group and the control group. The most common adverse events within one month were back pain and symptomatic vertebral fracture.

What were the CAFE study findings?

Dr. Berenson: Balloon kyphoplasty patients experienced improved quality of life compared with the control group as measured by both physical and mental component summaries at one month and these results were generally maintained through 12 months. Multiple outcomes relating to back disability, back pain, use of pain medications, activity levels, quality of life, physical function, and back pain were evaluated in 129 patients (68 kyphoplasty and 61 non-surgical patients). The primary outcome was the change in back-specific function from baseline to one month between the groups as measured by the validated Roland-Morris Disability Questionnaire (RDQ) score, with 0 (best) equal to no disability and 24 (worst) equal to maximum disability. At enrollment, the average score was 17-18. In the group that received kyphoplasty, the score was reduced by half. The group that was randomized to non-surgical management for the first month, showed no improvement in the RDQ score.

Dr. Vrionis: It is documented that patients with several types of cancer can suffer painful vertebral compression fractures: nearly one-fourth (24%) of patients with myeloma, 14% with breast cancer, 8% with lung cancer, and 6% with prostate cancer. Most balloon kyphoplasty patients in the CAFE study experienced significant benefits in early pain reduction, improved mobility, and ability to take part in activities. Seven days after treatment, balloon kyphoplasty patients experienced significant improvement in back pain, compared with no change in the control group. One month after treatment, balloon kyphoplasty was found to provide better back function and more back pain relief, and improve patient quality of life as measured by the RDQ, compared with no statistically significant change in RDQ score in the control group.

Dr. Berenson: With the results of this new randomized study, there is now clinical evidence of a treatment option for spinal fractures in cancer patients that can provide rapid relief of pain and improved quality of life without significant side effects that could potentially delay other therapies required to treat the underlying cancer. Importantly, every endpoint of the study was in favor of the balloon kyphoplasty-treated patients. This is an important study, and our results show that there is a way to help cancer patients suffering from the debilitating effects of painful vertebral compression fractures. **MT**

PROF. MICHELE CAVO — continued from page 9

As the lead author of the recent IMWG paper on the role of ASCT in myeloma, what can you tell us about it?

The International Myeloma Working Group (IMWG) manuscript presents an overview of the most recent studies of novel agents combined with ASCT, and provides important perspectives and guidance on the major issues surrounding the optimal current management of younger, transplant-eligible myeloma patients. As of the time of this conversation, the manuscript has been published as *Blood's* "First Edition Paper" and the final print form will be available soon.

In the era of novel agents, is there still a role for ASCT as upfront therapy for myeloma?

Two ongoing large clinical trials are addressing this issue. One of these trials is being conducted in France and the US. The other trial is headed by the European Myeloma Network; its primary objective is to prospectively compare upfront ASCT, either single or double, with ASCT delayed at the time of relapse after therapy with novel agents. Another important question of this study is to establish the role of consolidation therapy, so there is an additional randomization for patients in both the transplant and the non-transplant arms to receive consolidation therapy or not.

Returning for a moment to the subject of your first allo patient, does she remain disease-free after more than 30 years?

Yes, she is actually cured of myeloma. While there are still a lot of caveats concerning allo transplantation in myeloma, a small fraction of patients benefit from this procedure and are long-term, disease-free survivors. Similarly, approximately one fifth of patients treated with ASCT remain in CR more than 10 years after high-dose therapy, and their number is likely to increase in the future as a result of recent incorporation of novel agents into transplantation.

What is your perspective on future directions in the field?

Advances being made in the field of myeloma are progressively increasing, and the therapeutic armamentarium for this disease is rapidly expanding due to the availability of effective new novel agents, such as second generation proteasome inhibitors and third generation immunomodulatory derivatives. The novel therapeutic paradigm continues to significantly modify the clinical outcome of myeloma patients. These are exciting years. We are looking at a real possibility to transform myeloma into a chronic disease and to offer a cure to an increasing fraction of patients. I think that the future is clearly bright for myeloma patients. **MT**

The IMF at IMW (International Myeloma Workshop) Paris

The International Myeloma Workshop (IMW), an important scientific meeting that is held bi-annually, provides a compelling program highlighting emerging advances in the understanding of the biology, genetics, diagnosis, and treatment of multiple myeloma. IMW XIII, the 13th meeting of the IMW, took place in Paris, running from May 3rd through the 6th, 2011. A written overview of the key presentations from IMW XIII will be published in the Fall 2011 issue of *Myeloma Today*.

Video Library

The video filmed by the IMF at the IMW in Paris is available on the IMF website myeloma.org. The library of available videos features key summary interviews with leading researchers and clinicians, as well as several sessions filmed in their entirety. In total, the IMF's IMW webcasts include more than 100 presentations in 15 scientific sessions and panel discussions. All webcasts are archived at myeloma.org.

Patient Blog

Written by Jack Aiello, an IMF member and a myeloma patient, the blog offers a patient's perspective on the IMW proceedings. To read Jack's blog, "A Patient in Paris," please visit patientinparis.myeloma.org.

Patient & Family Seminar

Immediately following the close of IMW XIII, patients and caregivers in France were able to attend a free seminar to hear an overview of the most important information that was presented at IMW. The faculty included myeloma experts Dr. Brian G.M. Durie, Dr. Xavier LeLeu, Prof. Jean-Paul Fermand, and Prof. Thierry Facon. The seminar was held in Paris on May 6 at the Maison de l'Amerique Latine.

Long-Term Continuous Treatment

Presented at IMW XIII, new data demonstrate that long-term continuous REVLIMID® (lenalidomide) maintenance therapy following stem cell transplant delays time to disease progression and improves overall survival (OS). The figures from the Cancer and Leukemia Group B (CALGB) study sponsored by the U.S. National Cancer Institute (NCI) demonstrated a 90% OS rate in the lenalidomide arm of the trial at more than two years following transplant, compared to 83% survival for patients given a placebo. The CALGB study further showed that lenalidomide maintenance resulted in longer remissions, delaying disease progression by a median of four years. A similar study of lenalidomide following transplant from the French Francophone Myeloma Intergroup (IFM) also demonstrates benefit with progression-free survival, patients living longer without active disease.

Maintenance is being considered as an option with other drugs, including VELCADE® (bortezomib) when administered in a reduced dose or as a subcutaneous injection (instead of the traditional intravenous administration).

Next-Generation Drugs Moving Towards Approval

Pomalidomide, the newest drug in the IMiD® family, and carfilzomib, a next-generation proteasome inhibitor, are both moving closer to approval for patients who have relapsed or do not respond to current drugs. The pomalidomide phase II clinical trial data continues to mature, demonstrating the best overall response rate to date, and accelerated filing strategies in the U.S. are under discussion. Carfilzomib is expected to be filed with the FDA for accelerated approval, also based on phase II data.

DID YOU KNOW? *Exciting news:* The IMF is blogging

We have expanded our website to include blogs by patients, caregivers, nurses, doctors, and others to provide a forum for discussion with the community on matters of importance to everyone battling myeloma. Please visit our blogs and, if you'd like, become part of the discussion by posting your comments and questions. Your input can help others, so please consider adding your thoughts to a blog. You can also subscribe to a blog to receive email notification when a new posting is made. To locate the blogs, visit myeloma.org and click on the "blogs" tab at the top.

Be an active reader: Share your thoughts

In addition, you may also share your thoughts about any article that appears on the IMF website by clicking on the comments tab. We hope you find this new capability helpful.

Join us: The IMF has a social community

We have an active social community, on both twitter and facebook.

Find us on facebook at www.facebook.com/myeloma

Follow us on twitter @IMFmyeloma

We already consider you part of the family… Now, let's be friends!

Help the IMF learn more about myeloma patients

Whether you are a myeloma patient or a caregiver who can provide information on behalf of a patient, you can help the IMF by participating in our latest Myeloma Patient Survey. No personal identifying information is gathered as part of the survey. All responses are anonymous. Please visit at **http://survey.myeloma.org**.

Myeloma Manager™ Personal Care Assistant™ Version 4.0.2

We are pleased to offer you, free of charge, the Myeloma Manager software. Designed and developed by the IMF specifically to help patients and caregivers battling multiple myeloma, the Myeloma Manager provides a tool to capture laboratory results and display and print tables and charts to show how those results change over time. We hope that you will find it useful

IMF HOTLINE COORDINATORS ANSWER YOUR QUESTIONS

The IMF Hotline 800-452-CURE (2873) consistently provides callers with the best information about myeloma in a caring and compassionate manner. The Hotline is staffed by Nancy Baxter, Debbie Birns, Paul Hewitt, and Missy Klepetar. The phone lines are open Monday through Thursday, 9 a.m. to 3 p.m. (Pacific Time), and Friday, 9 a.m. to 2 p.m. To submit your question online, please email TheIMF@myeloma.org.

I have had myeloma for 3 years and am relapsing after a stem cell transplant using my own cells. I am 45 years old and I have a sister who is a bone marrow match for me. My doctor is encouraging me to consider doing what he calls an allogeneic transplant using her cells as a treatment for myeloma, which could cure my myeloma. What is the current thinking on this type of transplant?

(l to r) Paul Hewitt, Missy Klepetar, Nancy Baxter, and Debbie Birns

There has been a big debate in the myeloma community for decades over the role that allogeneic (using stem cells from donor) transplant should play in treatment for patients. The hope has been that, if successful, an allogeneic (allo) transplant might be able to cure myeloma patients. Although the procedure was known to potentially cause severe side effects and even death, doctors (and patients) were willing to take those risks in exchange for a cure. Unfortunately, recent studies have not supported the use of allo transplants outside the setting of a clinical trial.

In recent years, doctors performing allo transplants have used what is called a "mini-allo" transplant because it is safer than the full allo transplant. In this approach, the patient first receives an autologous (using his own stem cells) transplant to reduce the tumor burden. This is followed by reduced-intensity (lower-dose) chemotherapy, which does not destroy the patient's bone marrow but does allow for the donor's blood cells and immune system to grow in the patient after they are infused. Despite the improvement in safety of this approach, there are still enough deaths and severe long-term side effects that doctors have tried to assess if these risks are worth potential benefits of improved survival.

The side effect that creates the biggest problem is graft vs. host disease (GVHD), a result of the donor's stem cells (the graft) thinking that the patient (the host) is alien and must be attacked. GVHD can be acute (occurring within the first 100 days after transplant) or chronic (occurring 60 to 100 days after transplant and possibly lasting years). It can affect the skin (red rash, itching, darkening of skin), the liver (elevated liver tests determined through blood tests, yellowing of the skin and whites of the eyes, abdominal pain) and/or the gastrointestinal tract (watery diarrhea, stomach cramps during bowel movements, and persistent nausea). GVHD is also, however, what can potentially help the patient. The hope is that the graft (the donor's immune system) sees the host (the patient and his myeloma) as foreign, and kills the myeloma. This is the desired "graft vs. myeloma" effect.

In Dr. Keith Stewart's excellent review article ("Reduced-intensity allogeneic transplantation for myeloma: reality bites"), which has been published in *Blood* (2 April 2009, Vol 113, No. 14, pp. 3135-3136), he analyzes three papers that compare mini-allo transplant to autologous stem cell transplant. Dr. Stewart observes that two of the studies show either worse or no improvement in outcome, while the third trial suggests an advantage to the mini-allo transplant. He states that because the results from these randomized trials are conflicting, the myeloma community should wait for the results of a major Bone Marrow Transplant Clinical Trial Network (BMT CTN) study that was underway at that point.

The results of that major trial were reported at the 2010 annual meeting of the American Society of Hemtology (ASH) by Dr. Amrita Krishnan, principal investigator of the trial and head of the multiple myeloma program at the City of Hope Hospital, Duarte, CA. There were 43 participating centers in this large BMT CTN study. The study compared tandem auto transplants with or without maintenance therapy (auto-auto) verses single auto transplant followed by HLA matched sibling non-myeloablative allogeneic transplant (auto-allo) for patients with standard-risk myeloma. There were 710 patients enrolled between December 2003 and March 2007. After analyzing the data, the authors concluded there were no differences in 3-year PFS (progression-free survival) or OS (overall survival) between the two groups. The potential benefits of graft-versus-myeloma to reduce disease progression or relapse were offset by increased TRM (treatment related mortality). This study confirms the conclusion that mini-allo transplants should not be offered as standard therapy (either front-line or at relapse) outside the context of a clinical trial.

As always, we urge you to discuss this and all other medical issues thoroughly with your doctor, and to call the IMF Hotline, 800-452-CURE (2873), for help with your questions. We are also happy to receive your emails at TheIMF@myeloma.org, and we now have a hotline blog accessible via the IMF website myeloma.org. **MT**

LONG-TERM SURVIVORSHIP GUIDELINES FOR MULTIPLE MYELOMA PATIENTS

The Nurse Leadership Board (NLB) is a partnership between the International Myeloma Foundation (IMF) and nurses from the leading centers treating multiple myeloma patients in the US. The NLB's mission is to gain insights into optimal patient care and to address the unmet needs of myeloma nurses and their patients. The IMF's NLB has been very effective in utilizing the clinical and research experience of its membership to develop consensus recommendations for nursing care for myeloma patients.

On April 28, at the 36th Annual Congress of the Oncology Nursing Society (ONS), which took place April 28 – May 1 in Boston, MA, the IMF held an accredited educational satellite symposium to present the NLB Long-Term Survivorship Guidelines for Multiple Myeloma Patients. The symposium was chaired by NLB's Beth Faiman, and the faculty included Elizabeth Bilotti, Kathleen Colson, and Joseph Tariman.

The symposium opened with welcome remarks and an overview of myeloma by Beth Faiman. She discussed the role of the tumor microenvironment in disease progression, the disease continuum from asymptomatic premalignant conditions to active disease, clinical manifestations of myeloma, and the expanded treatment options since the introduction of novel agents to the management of the disease.

Beth presented a detailed update on current therapies used in the management of patients with myeloma. As patients are living longer, the new paradigms in myeloma treatment are focused on maintaining quality of life and patient health. She shared research updates on continuous/maintenance therapy with Revlimid® (lenalidomide), as well as new data on Velcade® (botezomib) maintenance, as well as two key studies of bortezomib administration (once vs. twice weekly and subcutaneous vs. intravenous), bone health, and promising agents in clinical development. New agents being evaluated for efficacy in patients with relapsed/refractory myeloma include carfilzomib, pomalidomide, denosumab, elotuzumab, vorinostat, panobinostat, temsirolimus, and perifosine.

The NLB Long-Term Survivorship Guidelines encompass multiple elements to ensure optimal patient treatment, management, follow-up, quality of life, and survival. The application of the survivorship care plan concepts was demonstrated to symposium participants through several patient case studies: the session that focused on renal health was presented by Joseph Tariman; bone health was presented by Kathleen Colson; health maintenance was presented by Elizabeth Bilotti.

New therapies have improved survival for many patients with myeloma, and there is a clear trend towards risk-stratification and personalized disease treatment. The NLB Long-Term Survivorship Guidelines serve as a practical resource to oncology nurses, addressing the full continuum of cancer survivorship, and enhancing the patient's treatment outcome and quality of life. **MT**

Elizabeth Bilotti, MSN, APRN, BC

Kathleen Colson, RN, BSN, BS

Beth Faiman, MSN, APRN-BC, AOCN

Joseph Tariman, PhD, APRN, BC

Kimberly Noonan, RN, ANP, AOCN

Oncology Nurse Practitioner for Hematological Malignancies
Dana-Farber Cancer Institute – Boston, MA

Kimberly Noonan received her B.S. in Nursing degree from UMASS Boston (Boston State) and earned her Master of Nursing Science degree at Boston College. For the past five years, Kim has been part of the myeloma treatment team at the Dana-Farber Cancer Institute. She works with individuals who have monoclonal gammopathy of undetermined significance (MGUS), smoldering multiple myeloma (SMM), and active disease. She provides care to patients in a variety of settings, including before/after transplant, as well as during their participation in clinical trials.

"The IMF offers so many valuable programs and services that the patients I work with cannot say enough about what a great resource the IMF is to them," said Kim. "I am pleased to have the opportunity to be part of the IMF's Nurse Leadership Board. As oncology nurses, we also play an important role in helping patients manage life with cancer. Our ongoing contact with them gives us a unique perspective to identify a broad range of potential concerns, enhance patient education, and provide valuable feedback to the treating physicians regarding issues that patients might be experiencing. Like the IMF and the NLB, I continually strive to better serve those whose lives have been touched by myeloma. It is gratifying to part of a task force that will be creating the NLB Transplant Management Guidelines, and I look forward to contributing to future NLB projects as well. I've seen such major improvements in the field of myeloma over the last five years, that I think today's patients have more hope than ever before."

SPOTLIGHT ON ADVOCACY

A Day at the Capitol

By Tom Chelius, West Bend Area Myeloma Support Group Member

I am very fortunate to have the insurance coverage that I do. My coverage allowed my oncologist and me to make the most appropriate decisions for a plan of attack against my cancer. I started taking Revlimid® (lenalidomide) the day after I was diagnosed with multiple myeloma. Compared with IV therapies for some patients, I was shocked to learn how much more the out-of-pocket costs were. That was four years ago. When I first heard about the Oral Chemotherapy Parity Bill in Wisconsin, it seemed like common sense to me.

When given the opportunity, I signed up with the Wisconsin Coalition for Cancer Treatment Access's Day at the Capitol. The IMF joined the WCCTA in 2010 along with other patient advocacy organizations to seek legislation that would ensure cancer patients in Wisconsin have access to life-saving oral cancer treatments. For more information, visit www.thewccta.org.

A Day at the Capitol involved meeting with legislators to ask them to co-sponsor the bill, which increases its chance of being taken up and not "lost in committee." I had never done anything like this before, so I was a bit nervous about it. Plus, given the recent political climate in Wisconsin, I wasn't too sure how we would be received.

(left to right) Dick Skalitzky, Shauna Skalitzky, Sue Enright, Tom Chelius, and Christina Vargas

As they say, though, there is strength in numbers. On the morning of April 27th, we gathered at the Madison Concourse Hotel for the orientation meeting. The tables that we were assigned determined the teams that would be meeting with legislators. Here is how our team shook out:

- **Christina Vargas** – Our Team Leader from the IMF. Her positive can-do attitude and background gave us the confidence we needed.
- **Sue Enright** – Caregiver and founder of the West Bend support group. Her knowledge and experience are very extensive and I knew she would be an asset. I first met Sue and her husband, Rob, when Rob and I were having our stem cells collected. We have become good friends since.
- **Dick Skalitzky** – Two-year myeloma survivor from Fond du Lac and a member of the West Bend Support Group. Dick has been on both Velcade (bortezomib) and Revlimid.
- **Shauna Skalitzky** – Dick's daughter who drove up from Chicago and was along for support. She had a vested interest in any future implications that this legislation might have for her father. She proved invaluable helping us navigate around the capitol, and kept notes on each of the discussions.
- **Tom Chelius** (me) – I am a four-year myeloma survivor, diagnosed when I was 38. I have been through both an autologous stem cell transplant and an allogeneic stem cell transplant. I have been on Revlimid for my initial therapy as well as maintenance for a year. I am currently in a complete remission but am dealing with chronic Graft vs. Host Disease for which I briefly used an oral therapy but failed to respond.

For survivors and caregivers, the most important thing was to tell our stories. There is nothing more powerful than putting a face on a problem. So armed with our own experiences and some additional knowledge of the issue from the orientation session, we literally walked up the hill to the Capitol.

Our first scheduled visit was with State Assembly member Evan Wynn. We figured this meeting would be easy since Representative Wynn was already a co-sponsor and spoke at our orientation meeting. When we arrived, Representative Wynn had been called away to another meeting. So the group chatted with his aide and asked him to spread the word about this bill and how important it is to cancer patients.

If our first meeting was simple, the next one definitely upped the ante. On our way to meet with Representative Jeff Stone, we were informed that our meeting was very important because Rep. Stone serves as the chair of the Committee on Health, the committee which would debate the bill prior to it reaching the floor for a vote. Getting Mr. Stone's approval would be significant. This heightened our anxiety…we had to get this one right. Like Mr. Wynn, Representative Stone got called to a meeting. So we met with his aide instead. As Mr. Stone's constituent, I knew I had to speak up. After Christina introduced us, Sue gave a great overview of the issue, then the rest of us chimed in. I had a secret weapon along. I originally brought my iPad to take notes, but decided at the last minute to show MRI images of the rather large plasmacytoma (removed surgically) that was adhered to my skull that required Revlimid to avoid radiation. Everyone explained how the potential cure for myeloma would likely come from a combination of medications, which oral drugs are a part of. The aide felt that Mr. Stone would likely support this legislation and that she would discuss it with him. SUCCESS (sort of)! We were told we did a great job and that we might be needed back at some later time as the bill progressed. This was just the boost in confidence that a bunch of "noobs" needed!

Our third meeting was with State Senator Mary Lazich, again for whom I was the constituent. While Senator Lazich admitted that she hadn't closely studied the draft that was circulated, she did say that it sounded like common sense, which made telling our stories easier. I was able to go a little more into my struggle with chronic Graft vs. Host Disease and how my oncologist and I tried an oral treatment. Ms. Lazich told us she needed to do more homework on the issue before she could commit. This seemed reasonable and given her response to us, it seemed like she would be a promising co-sponsor, or at least a vote.

David's Story

By Meghan Buzby

Meet David Cowan. He is a 51-year-old multiple myeloma survivor from Eunice, NM. David has been through it all – transplants, bone marrow biopsies, radiation, chemo, and numerous other treatments. And, much like you or your loved ones, he had had enough. And decided to stop his treatment.

When the IMF advocacy team found David, it was the beginning of a beautiful friendship. There was a bill being considered in New Mexico that would require insurance plans to cover orally administered chemotherapy at the same rate as intravenous and injected chemotherapy. The bill was scheduled to be heard in the House, Health & Government Affairs Committee and someone was needed to testify. David, who had never even been inside the Capitol building, was up for the challenge.

With guidance from the IMF Advocacy team, David first met with the bill's author, Senator Timothy Z. Jennings. During his visit, he discovered he had an immediate connection with the Senator, whose wife bravely fought breast cancer for four years.

"Sen. Jennings and I sat together in front of eight Representatives and I gave my testimony," David recalled. "It started out fine but as I explained all that I had been through and what this bill meant to me and others, I started having a lot of emotions and I found it hard to talk. Senator Jennings picked up where I left off and told his story about his wife's battle. Our stories complimented each other and the combined effect made for a powerful statement."

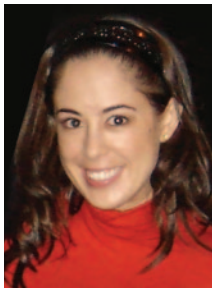
The bill passed the committee unanimously that day and has since been signed into law!

David's experience working with the IMF as a cancer community advocate to enact real change brought him renewed energy and hope. He has since made the choice to resume treatment and continue to fight this battle, for himself, his family, and myeloma patients across the country. **MT**

continued from previous page

Our final meeting was with Representative Richard Spanbauer of whom Dick was a constituent. Mr. Spanbauer was already a co-sponsor, for which we thanked him. We asked if he had any questions, which led to each of us telling our stories. It was an easier way to end the day.

After saying our good-byes, I headed back to Milwaukee. I had never done anything like this before in my life. When I got home, I could only think of how glad I was to have done it…absolutely no regrets. I originally had wondered if I actually would have been of use, since I didn't have insurance coverage issues, but I now look back at the day and think that perhaps I did make a difference, which will hopefully benefit many of my fellow survivors. Like my struggle with myeloma, it took a team effort and we worked wonderfully together. Let's hope and pray that Wisconsin becomes state number 12 to adopt this important legislation. **MT**



IMF Welcomes Christina Vargas

We are pleased to announce that Christina Vargas has joined the IMF Advocacy team. Christina grew up in Peru and witnessed severe poverty, developing a heightened sensitivity to social inequality and the need to expand access to education and health care. This awareness burgeoned into the passion for human rights that formed her educational and professional trajectory.

Christina received her law degree from the UCLA School of Law's Public Interest Law and Policy Program, specializing in Critical Race Studies. She then completed her Master of Education at Harvard University, where she was awarded the Center for Public Leadership's prestigious Zuckerman Fellowship. Throughout her work as a community organizer, community advocate, and as the founder of an educational non-profit, Christina's commitment to social justice has guided her work. She is eager to further IMF's mission. **MT**

How to contact the IMF Advocacy Team

Christine Murphy – *Director, Government Relations*
phone: 703-738-1498
fax: 703-349-5879
email: cmurphy@myeloma.org

Arin Assero – *Director of Advocacy*
phone: 800-452-CURE (2873) ext. 232
fax: 818-487-7454
email: aassero@myeloma.org

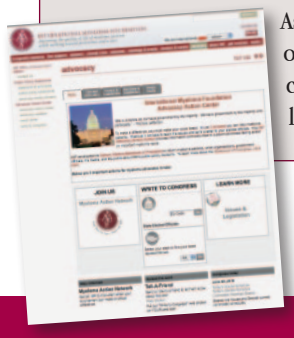
Meghan Buzby – *Grassroots Liaison*
phone: 410-252-3457
email: mbuzby@myeloma.org

Christina Vargas – *State Government Affairs*
phone: 310-592-3201
fax: 909-427-0283
email: cvargas@myeloma.org

The IMF Advocacy Voice

Get Fired Up! Raise Your Voice! Get Out There and Take Action!

Do you want to make positive changes in your life and others' lives? Join David, Tom, and the rest of our advocates – become an IMF Advocate at **advocacy.myeloma.org**.



As an IMF advocate you will be kept informed of critical issues affecting the myeloma community at both the federal and state levels. ***Sign up TODAY!***

advocacy.myeloma.org

UPDATES FROM AROUND THE GLOBE

Asian Myeloma Network

On March 17, the IMF established the Asian Myeloma Network (AMN) at a meeting in Singapore. The inaugural membership of AMN includes myeloma experts from China, Hong Kong, Taiwan, Japan, Rep. of Korea, Singapore, and Thailand. The AMN will take the lead in projects to assist the IMF in providing physician education and patient support throughout Asia.

Myeloma is a growing health problem in Asia, with an incidence that is approaching that of the statistics in Western countries, but with a much larger population base. The initial focus of the AMN will be the development of a unified database to assess the incidence and demographic features (including stage of disease and treatment used) of myeloma in Asian countries as a key step in designing region-specific treatment management tools and strategies. The IMF is funding the AMN to establish this integrated database.

Future projects will include the implementation of Asian clinical trials, as well as the development of informational resource materials in local languages, especially for patients and caregivers. The extensive library of educational materials and publications on the IMF website will be available as a guide.

A formal yearly meeting of the AMN will be held to review progress and plan future projects. The 2012 meeting is scheduled to take place in Shanghai, China.

For more information about the AMN, please contact Dan Navid at dnavid@myeloma.org.

IMF Europe Focuses on Collaboration

Advances in myeloma research and treatment do not happen without collaboration. As anyone who has ever attended an IMF Patient & Family Seminar or kept up with the scientific literature in the field knows, advances are literally happening all over the world. Europe is an extremely active region for myeloma research. Significant advances are occurring in France, Italy, Germany, Spain, and the Nordic nations, as well as in Eastern Europe.

The IMF understands that the term "international" is more than rhetoric; it is reality. People and nations know borders. Diseases do not.

Over the many years that the IMF has been active in Europe, it has been with the understanding that patient education activities needed to reach as many patients and family members as possible. It meant helping to add value to existing institutions, creating new ones where there were none, and developing linkages between best practices and experiences.

In 2011, this philosophy is being realized in a number of ways. The IMF has already co-sponsored patient meetings in Spain (Barcelona) and France (Paris). More patient meetings are scheduled in the Czech Republic (Prague), Germany (Koblenz, Berlin, Leipzig, and Hamburg), Norway (Oslo), Sweden (Gothenburg), and Denmark (city to be announced). Dr. Robert Kyle, who chairs the IMF Scientific Advisory Board, will speak at five of these events.

In addition to bringing American-based myeloma experts to speak at patient meetings in Europe (Drs. Kyle, Barlogie, Durie, Vesole, and Gertz), the IMF is now bringing key European-based leaders in the field to speak at patient meetings in the US. In February, Prof. Mario Boccadoro (Turin, Italy) traveled to Florida to be part of the faculty at the Boca Raton IMF Patient & Family Seminar. In addition to being educated about the scientific and clinical work taking place in other countries, the IMF believes it is important for patients to have the opportunity to see, hear, and meet these leaders as well.

Prof. Mario Boccadoro with his wife, Rosella, at the Boca Raton IMF Patient & Family Seminar

As the IMF sponsors these exchanges, we also schedule formal and informal roundtables for doctors to discuss ideas and nurture the relationships that will create more international linkages for clinical trials and published research.

This summer, at least two doctors' roundtables will be set up in conjunction with patient meetings while Dr. Kyle is in Norway and Sweden. In Norway, Dr. Kyle will be hosted in Trondheim by Dr. Anders Waage (chair of the Norwegian Study Group and past chair of the Nordic Study Group) and in Gothenburg by Drs. Jan Westin and Ulf-Henrik Mellqvist. In Denmark, where Dr. Kyle is scheduled to speak at a patient meeting co-hosted by the DMF, the Danish myeloma patient association, he will also participate in the meeting of the Danish Myeloma Study Group, hosted by chair Dr. Niels Abildgaard.

All of these collaborations build upon and deepen the activities of the IMF's International Myeloma Working Group (IMWG). The major goal of the IMF's programs in Europe is to increase patient education activities, and to nurture patient advocates who will supplement and enhance the important work of researchers and clinicians in their respective nations.

In the future the IMF will also seek more ways to link the efforts of patients, doctors, and nurses on both sides of the Atlantic. Please feel free to contact the IMF if you have ideas on how we can better achieve our goals.

For more information about IMF Europe, please contact Gregor Brozeit at greg.brozeit@sbcglobal.net.

Associazione Schirinzi A. Mario Onlus

The Associazione Schirinzi A. Mario Onlus is the only charity organization in Italy that devotes all its efforts to assisting multiple myeloma patients, caregivers, and family members. The Associazione works towards increasing myeloma awareness in Italy among the general public through sporting events and educational seminars, while raising funds for myeloma programs and services. Several initiatives have been underway in 2011, with more in the pipeline.

Associazione's Vittorio Schirinzi with Gregor Brozeit (IMF Europe), Giancarlo Antognoni (winner of the 1982 FIFA World Cup with the Italian national soccer team), and Niccolò Cateni (communication manager for Conte of Florence sportswear brand)

On April 2, the Associazione Schirinzi A. Mario Onlus kicked off its sixth memorial golf tournament in Pisa, Tuscany, home of one the most important hematology centers in the region. The tournament's next stops were in Florence on May 1 and Pistoia on June 2. The grand finale took place on June 11 in Prato, home of the Associazione's offices. The concluding round of the tournament was followed by a benefit dinner on June 11, with sport and political luminaries in attendance.

CONTINUES ON PAGE 18

PEOPLE HELPING PEOPLE

You are never alone in your battle against myeloma

The IMF takes this opportunity to highlight four myeloma support groups in Virginia. On April 11, an IMF Regional Community Workshop (RCW) will take place in Norfolk, VA. Held in smaller cities to expand the reach of IMF programs to a wider audience, RCWs are half-day meetings designed to provide much of the same information presented at an IMF Patient & Family Seminar, but in a condensed form. RCW faculty consists of local myeloma specialists, a nurse, and a speaker on supportive care issues. The IMF works closely with the local support groups to promote these meetings, and many group members will be in attendance. To view the full schedule of upcoming RCW meetings, as well as information about how to register online, please visit the IMF's website myeloma.org.

Fairfax, VA

Sabine Gnesdiloff, LCSW, OSW-C, has been a social worker and Program Manager with Life with Cancer (part of Inova Health System) since 1989. One of the first long-term patients she met "was a woman who had a disease I'd never heard of – multiple myeloma. She was a medical librarian, and she wanted to meet with and learn from others who had the same disease. She became the driving force behind forming a local myeloma support group." For Sabine, whose first career was also as a librarian, this was the beginning of a 20-year friendship and an ongoing role and interest in myeloma education. In the mid-1990s, Sabine became the facilitator of the recently formed myeloma support group that continues to serve the northern Virginia and Washington DC metro area.

The Faifax group is focused primarily on education, with half its meetings featuring guest speakers and the other half following the open discussion format. The group has almost 125 members on its mailing list, with 25 or more patients and caregivers attending each meeting. The Life with Cancer Family Center, where the myeloma support group meetings take place, offers a broad range of support, wellness, and education services that address the needs of individuals experiencing cancer in their life. In addition to Licensed Clinical Social Workers (oncology counselors), the Center's staff includes Oncology Certified Nurse Educators.

This group meets on the third Tuesday of each month. For more information, please contact Sabine Gnesdiloff at 703.698.2535 or sabine.gnesdiloff@inova.org, or visit the Life with Cancer Family Center's website at lifewithcancer.org.

Richmond, VA

When Barbara Marx was diagnosed with multiple myeloma in 2006, there was no support group in existence near her home. The closest myeloma group was in Virginia Beach, and Barbara traveled to attend their meetings. Later, while at an IMF Patient & Family Seminar, Barbara met three other women living in her area who were also interested in starting a local myeloma group: Mindy Fast, Ronne Jacobs, and Regina Leftwich. In January 2010, after months of planning and scheduling by the four ladies, the Greater Richmond Multiple Myeloma Support Group held its first meeting with 10 patients and caregivers in attendance.

"As a myeloma patient, I know how important it is for us to educate and empower ourselves," said Barbara. "Members of our group support and encourage one another, share experiences, laugh and cry together. We are great listeners, and we are truly there for each other. We are a very friendly and resourceful group, and we have now grown to nearly 30 members. I am very fortunate to be part of this community."

Barbara, along with group co-leaders Mindy Fast and Ronne Jacobs, as well as input from other members, has devised a meeting agenda for 2011 that balances presentations by invited speakers with "sharing" meetings. If you live in or plan to visit the Richmond area, please consider taking part in the group's next gathering.

The Greater Richmond Multiple Myeloma Support Group meets on the third Monday of each month. For more information, please contact Barbara Marx at 804.355.6217 or gobabsgo@aol.com; Mindy Fast at 804.262.1821 or mcfast123@comcast.net; or Ronne Jacobs at 804.310.7722 or ronnej@verizon.net.

Roanoke, VA

The Multiple Myeloma Network of the Blue Ridge is led by Sharon Madagan and Bill Stokes, who co-founded the support group with Deborah Eller (deceased) in January 2003 after meeting through mutual friends. Bill was diagnosed in 2000 at age 47. Sharon was diagnosed in 2001 at age 46, and underwent an autologous stem cell transplant (ASCT) in 2002 at the same facility where Bill had his two transplants.

"Being a dentist, I turned to my medical library for information when I learned my diagnosis," said Bill. "The statistics were bleak, with survival rates hovering at a frightening one to three years. I decided to give up dentistry, a career I loved, to concentrate on getting well." Bill became active in patient advocacy, traveling to Washington to lobby Congress for increased research funding. A veteran of several treatment protocols, including two clinical trials, Bill knew firsthand that only other patients and their caregivers truly understand the rigors and challenges of battling myeloma. "That's why I wanted to be part of starting a myeloma support group in our community. Having a local group is immensely helpful. The Internet can certainly be a source of information, but sometimes that information can be overwhelming and not applicable to one's situation."

Over the past eight years, the group's membership has ranged from 10 to 25 people, with Sharon and Bill almost never missing a meeting. "We also keep in touch with our members via the phone and emails," said Sharon. "We work diligently to make sure the support group is a resource for people with myeloma, as well as for their caregivers. We take extra care to attend to the needs of the entire group, and we all benefit from learning the latest important information, and sharing experiences

CONTINUES ON PAGE 18

PEOPLE HELPING PEOPLE – continued from page 17

and camaraderie. Everyone whose life has been touched by this disease needs to know that much medical progress is being made in the field. As a former teacher, I know knowledge is power, so we are dedicated to empowering patients and caregivers with not only information, but also with our friendship and emotional support."

Sharon and Bill have maintained positive outlooks throughout their years with myeloma, and share the optimism with their fellow group members. "I'm buoyed by the fact that new treatments have enabled me to outlive those dire survival statistics of ten years ago," said Bill. "I know that a brighter future is possible," added Sharon

The Multiple Myeloma Network of the Blue Ridge meets the third Saturday of each month. For more information, please contact Sharon Madagan at 540.206.9000 or kittycentral@cox.net, or Bill Stokes at 540.343.1920 or bstokes47@aol.com.

Virginia Beach, VA

Diagnosed with smoldering multiple myeloma in August 2006, Jerry Walton attended an IMF Patient & Family Seminar in early 2007. At one of the seminar dinners, he found himself sitting with two world-renowned myeloma experts, Drs. Robert Kyle and Bart Barlogie. The seminar faculty also included Dr. Brian Durie and a specialist from a local myeloma center. In addition, Jerry had a chance to network with members of the North Texas MM Support Group. Jerry found the experience of the seminar and the camaraderie of the support group members to be so valuable that he was motivated to start the Southeastern Virginia Multiple Myeloma Support Group a few months later with the help of the IMF. The IMF's Robin Tuohy and family made a special stop in Virginia Beach on their cross-country Myeloma Mobile tour to help kick off the group's very first meeting.

Jerry Walton in Washington, DC

Jerry has a long history of service. He is a 33-year Navy veteran who retired from active duty in 1998. He then taught math in the Virginia public school system until June 2007. Once the school year ended, founding a myeloma-specific support group was a logical step for Jerry. Fifteen patients and caregivers attended the first group meeting in August 2007. Since then, group membership has increased and meeting attendance has on occasion grown to as many as 35 participants when an invited speaker is addressing a popular topic.

"Our group is very focused on education, in line with IMF's Knowledge is Power theme," said Jerry. "We learn both from expert sources and we learn a lot from each other as well. The IMF supplied us with technology for our meetings that allows us to have guest speakers no matter how far removed they are from us geographically. At our group meetings, the voice conferencing system has made it possible for us to learn directly from some of the best doctors and nurses in myeloma, as well as from an IMF Hotline Coordinator. We also benefit enormously from our mutually supportive network – many new friendships and connections have formed between individuals in our group. Personally, I have gained a whole new set of friends who live and understand the experience of myeloma."

As part of the IMF's Advocacy outreach, Jerry has taken a trip to Washington, DC, to talk to his legislators about the issues facing members of his support group and others in the myeloma community. "The IMF Advocacy program helps guide us to meaningful involvement in myeloma-related advocacy issues. While we focus on helping ourselves and members of our group, we can't forget that we are part of a larger myeloma community." Jerry also initiated the idea of an all-service vet effort and was key in developing the IMF's Veterans Against Myeloma website www.vam.myeloma.org.

The Southeastern Virginia Multiple Myeloma Support Group meets on the third Saturday of every month. For more information, please visit the group's website www.seva.myeloma.org or contact Jerry Walton at 757.495.8432 or jerryewalton@cox.net.

NEW support groups invite YOU to join them

California

Chico (Butte County), CA – This group meets on the second Tuesday of each month at 1:30 p.m. at the Enloe Cancer Center Library. For more information, please contact Paul Dragavon at 530.893.2559 or pauldragavon@gmail.com.

Redding (Shasta County), CA – This group meets on the first Saturday of each month at 10:00 a.m. at Yak's Coffee Shop. For more information, please contact Kati Rosten at 530.365.0651 or shastamyelomasupport@gmail.com

Michigan

Grand Rapids, MI – This group's first meeting is taking place on June 20 at Gilda's Club, where the group will continue to meet on the third Monday of each month. Supper is at 5:30 p.m., with meeting starting at 6:00. For more information, please contact Sue and Harold Van Duyn at 616.669.0781 or hsvanduyn2@aol.com. **MT**

UPDATES AROUND THE GLOBE— continued from page 16

Coming up in September 2011, the Associazione Schirinzi A. Mario Onlus is organizing a Regional Community Workshop (RCW), which will take place in Lucca, in the heart of Tuscany. The RCW, which is a joint effort between the IMF and the Associazione, will be held in the center of town on the site of the San Micheletto Foundation. Participants are expected from all over Italy. Discussion topics will span from the basics of multiple myeloma to the newest available treatments.

For more information about Associazione Schirinzi A. Mario Onlus and its activities, please visit http://mielomahelp.blogspot.com or email mielomahelp@gmail.com. **MT**

I CONCENTRATE ON LIVING!

By Danny Scott

My myeloma diagnosis was inadvertent. About five years ago, I complained to my primary care physician about back pain, which led him to order x-rays and diagnose me with arthritis. I was 62 years old at the time, so it sounded logical that I might have arthritis. A couple of months later, when the pain had gotten even worse, I got additional MRI imaging. The MRI showed a lesion on my S2 vertebra. Nuclear testing followed, which confirmed that I had cancer. The news was devastating.

It so happens that my wife works at the H. Lee Moffitt Cancer Center & Research Institute, so I made an appointment there to see the geriatric diagnostician. It was important for us to separate symptoms of age from symptoms of cancer. The doctor ordered a number of additional tests but, as soon as the blood test results came back, we cancelled some of the remaining tests because the diagnosis was crystal clear. I had multiple myeloma. The bone marrow biopsy confirmed the diagnosis. With a prognosis that could be as short as one to two years, I knew that I had a battle on my hands and made a commitment to fight as hard as I could.

In those early days post-diagnosis, the mother of a family member who had cancer advised me to stay away from the Internet until I had a clearer picture of my situation. She was concerned about me being exposed to lots of scary and negative information. So, for the first week after diagnosis, I stayed off the web.

At Moffitt, I was referred to Dr. Melissa Alsina, who leads the myeloma section. Because I am a big advocate of getting a second opinion (whether you need it or not), I took all the information I had and traveled to New York City to see another myeloma specialist. I had a second biopsy because I considered entering a clinical trial, but when it became clear that there was no rush to jump into anything I decided not to enroll. I made the decision not to start therapy until my disease required treatment. That might sound simple and logical now, but it was a pivotal decision.

Let me back up for a moment. Early on I did receive radiation therapy to the bone lesion to stop the tumor growth. The radiation was very precise, targeted solely at the tumor, so that my bone marrow would not be compromised in case I chose to pursue an autologous stem cell transplant (ASCT). But there had been no chemotherapy of any kind.

To prepare for the time when the disease progressed to the point of requiring treatment, I had to make a choice. Where did I want my myeloma treated when the time came to take action? I chose to remain at Moffitt for several reasons, including the center's track record and its geographic convenience.

In October 2006, my test numbers had changed to the degree that it was time to initiate treatment. I started chemotherapy in preparation for an ASCT, which took place in March 2007.

During this entire time, back pain continued to be a problem for me. I got progressively more bent over to alleviate the pain, and my height decreased from 5'7" to 5'2". Eventually, I needed a walker to get around. So I consulted with an orthopedic surgeon about having the Balloon Kyphoplasty procedure while I waited for the transplant.

The kyphoplasty took place before my transplant, and everything went very smoothly. My hope was that the procedure would decrease my pain and improve the structural integrity of my spine. After the procedure, the pain was mostly gone and my height was restored to 5'4-1/2". Not all the back pain was due to myeloma – part of it was due to spinal stenosis, which was also causing pain in my legs. This is different from the pain caused by myeloma.

In July 2007, four months after my transplant, I underwent another surgical procedure on my spine. The vertebrae were pulled off the nerve canal and I received two implants, between L5 and L4, as well as L4 and L3, giving me an additional 2" in height. Since then, I have had no pain.

My test numbers continued to improve after the transplant. On my birthday in December 2009, the doctor informed me that I was in remission. What a great birthday gift! It took a long time to get there, but I remain in remission at this time. The only medical therapy I currently receive is bisphosphonate infusions for my bones, with the frequency of the infusions having been reduced from monthly to once every three months. I also take vitamins prescribed by Dr. Alsina to help alleviate the symptoms of peripheral neuropathy.

There is no question that I've been really lucky, but I've also made a lot of positive changes in my life since the myeloma diagnosis. I take better care of myself. I've started an exercise regimen. I've lost weight. I miss being able to dance – I used to be a very good dancer – because of the neuropathy in my legs, but I have completed a 5K walk-a-thon! I started at the back of the pack with my walker in hand, figuring I'd be the last one to finish, but I finished ahead of more than 30 other participants.

I find a lot of encouragement at various myeloma education meetings and seminars. It is important for me to keep up with the latest information as it becomes available. Sometimes I get a little frightened when I hear the stories of people who have not been as fortunate as I, but that is why I choose to share my experience with others so that they know that there is hope. Personally, I've found a lot of hope in meeting myeloma survivors who've had this disease for 16, 17, 18 years. I am educated about myeloma and I am aware of all the odds, but I choose to concentrate on living and making the most of my life. There is still a lot to look forward to for me. **MT**

IMFers RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia

IMF members are people like you, from across the country and around the globe, and many are raising money for myeloma research and educational programs that have an impact on the lives of patients and family members worldwide.

Being involved is very fulfilling and empowering. Join us in our search for a cure for myeloma. By organizing an event in your community, you are also raising public awareness and helping those whose lives have been touched by this disease. Maybe you want to do something in your community, but deciding on what to do and how to do it can be confusing. That's where we come in! The IMF is here to help you every step of the way. We make it as easy as possible for you to be involved, whether or not you have any previous experience.

*Our FUNdraising program is fun and easy, and brings with it the satisfaction of knowing that YOU have made a difference in many lives. Choose an established event model or create your own – **no idea is too large or too small** – and we provide you with the tools, assistance, and expertise to make your event a success. We are grateful to all who contribute their time, imagination, and hard work to benefit the myeloma community. Join us in working together toward our common goal... a CURE. Please contact me, Suzanne Battaglia, at sbattaglia@myeloma.org or 800-452-CURE (2873) to chat about any ideas you might have. Be part of making miracles happen!*

Here is just a sampling of some past events and a calendar of upcoming ones. .

Central Florida Support Group's Spaghetti Supper

The Central Florida Multiple Myeloma Support Group has a long history of community activities, including raising myeloma awareness and funds for patient programs and services. "Until I was diagnosed, I knew nothing about myeloma," said group leader Ken Fabian. "So I want everyone out there to know about the disease, and that our group and the IMF are here for people who need support and information."

The Spaghetti Supper Planning Team:
Steve & Mary Wolf, Uma Khamare, Kelly Bodiford, Arlene McCutcheon, Ken Fabian, Monica Chill, Pat & Dick Wells, and Bill Mellon.
(*Not pictured:* Victor Alas, Ishwar Khamare, and Roy & Janet Leader.)

To attract the general public to a community awareness and fundraising event, Ken decided to host a $10 Spaghetti dinner at a local community center. "Everyone likes spaghetti! We kept the price reasonable and fed kids free of charge. Felipe Guillen, general manager at the Olive Garden in Winter Park, was enormously generous – he helped us set up, did the cooking (with the assistance of several of our support group members), and provided much of the food free of charge. Our Spaghetti Supper event also featured a belly dancer, a singer, a number of raffles, and a silent auction. It was a fun night, with everyone having a fantastic time and getting an education about myeloma in the process."

Felipe Guillen and Roy Leader

Myeloma survivor Robin Kearney with IMF's Andy Lebkuecher

To promote the Spaghetti Supper, Ken placed notices in the local newspaper, distributed flyers, and did a radio broadcast together with his oncologist. Many support group members got involved to help make the evening a success. Ambassadors from a neighboring myeloma group attended the dinner to show their support, as did IMF's regional director Andy Lebkuecher. The Central Florida Multiple Myeloma Support Group's successful Spaghetti Supper was attended by about 120 diners and raised $2,500 to benefit the IMF.

Concannon Family Fundraiser

When Karen Concannon's daughters, Erin (14) and Claire (11), decided to raise funds for myeloma research, no one anticipated that their idea would quickly grow into an event attended by almost 175 people. The Concannons had been though a lot since Karen's diagnosis in October 2010 and, as she was preparing for her May 2011 stem cell transplant, Erin and Claire wanted to find a way to raise funds for a cure while bringing together friends and family for a fun night of celebration.

The Concannon Family

Jenine Toback and Tracy Wargo

Four of Karen's friends – Tracy Wargo, Jenine Toback, Mary McCarthy, and Suzanne White – offered their assistance with organizing the evening. Another friend, Laurie Schaeffer, who works at Connecticut College, arranged for the school to donate the use of their event facilities. DJ Jammin Johnny (John Wilson) donated his services to the fundraiser. Illiano's Restaurant donated pizzas and pasta dishes

UPCOMING MEMBER EVENTS

July 13, 2011
Music Against Myeloma – New York, NY
Contact: Slava Rubin slavarubin@gmail.com

September 25, 2011
Pytlik Memorial Walk – North Tonawanda, NY
Contact: Barb Pytlik, bpcb3@hotmail.com

October 23–24, 2011
Coach Rob's Benefit Bash & Golf Tournament – Apopka, FL
Contact: Rob Bradford, rbradford@crothall.com

MYELOMA 200 – CLOSER TO A CURE

Teamwork makes everything possible. Start your myeloma 200 Fundraising team and help the IMF reach a goal of $200,000 for our Research, Education, Support, and Advocacy Programs.

Progress in myeloma research and new approaches to treatment are improving patient outcomes, but there is much more to be done. The International Myeloma Foundation is celebrating our 20th year providing myeloma patients, caregivers, physicians, nurses and researchers with the tools they need to fight against this disease.

In honor of this tremendous achievement, we have re-launched one of our most successful fundraisers MYELOMA 200 – CLOSER TO A CURE.

Participating in the MYELOMA 200 Challenge is easy: for every $200 you give or raise, you will be entered in a drawing to win a fabulous vacation getaway for two, for 7 days and 6 nights, at the beautiful Four Seasons Costa Rica at Peninsula Papagayo, including airfare on American Airlines and a $400 gift certificate toward spa treatments. To participate all you have to do is register online at m200.myeloma.org or contact Suzanne Battaglia.

The MYELOMA 200 – CLOSER TO A CURE challenge will continue until April 30, 2012. Anyone can participate, and by helping us reach our goal of $200,000 you help ensure that everyone wins! **MT**

MEMBER EVENTS— continued from page 20

Mary McCarthy, Suzanne White, and Laurie Scheaffer

that could have fed 500, and many of the guests contributed more food and drinks! "So many people wanted to make donations or simply do something to help, and I was very moved by how much they cared," said Karen. "To raise money, we sold IMF merchandise – T-shirts, baseball caps, and pins – and all the items were very popular. And we wanted the event to be a family night, making all the children feel included and welcome; the kids loved the IMF burgundy awareness bracelets they received as party favors. "

Held on March 12, the Concannon Family event also featured a raffle, with $1 tickets and 16 donated gift baskets, each assembled to reflect a specific theme. "The event raised almost $2,400 for myeloma research, and everyone had a lot of fun in the process. My daughters wanted to do a good deed and contribute to finding a cure not only for me but for all the families coping with myeloma. My husband Paul and I are very proud of them and very thankful to everyone who participated."

Birthday Brunch For A Cure

On March 12, Ivy Prosper celebrated her birthday while honoring the memory of her father, Joe Prosper, and raising funds for myeloma research. The 40 guests attending the Sunday brunch in downtown Toronto were asked to make donations to the IMF, and friends and family who were not able to attend the event in person made contributions online through a web page set up by Ivy on the IMF site myeloma.org. In total, almost $1,200 was raised in honor of Ivy and in memory of her father, who passed away in April 2007.

Joe Prosper with 4-yr-old Ivy

Ivy with her father in 2007

To help raise myeloma awareness, Ivy gave a brief talk about the disease and her family's experience with it, and also distributed IMF burgundy wristbands. "I had never heard of myeloma before my father was diagnosed, so I can only imagine how little the general public knows about it," said Ivy. "This was my first experience organizing a fundraiser and trying to raise myeloma awareness, so I didn't know what to expect, but the feedback was so positive that I would definitely consider doing it again. My father has been in my thoughts a lot, and it felt great to be able to honor him at my birthday brunch." **MT**

Ivy with her brother Joe at the Birthday Brunch For A Cure

International Myeloma Foundation
12650 Riverside Drive, Suite 206
North Hollywood, CA 91607-3421
U.S.A.
www.myeloma.org
(800) 452-CURE (2873)
Change Service Requested

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

2011 IMF Calendar of Events

July 15-16	IMF Patient & Family Seminar – Dallas, TX
July 23	IMF Regional Community Workshop – Minneapolis, MN
July 29-31	IMF Support Group Leaders' Summit – Irving, TX
August 13	IMF Regional Community Workshop – San Diego, CA
August 26-27	IMF Patient & Family Seminar – Philadelphia, PA
September 10	IMF Regional Community Workshop – Norfolk, VA
September 17	MM Regional Community Workshop – Lucca (Tuscany), ITALY
September 17	IMF Regional Community Workshop – Honolulu, HI
September 30	IMF Patient & Family Seminar – Rome, ITALY
October 12-15	Southwest Oncology Group (SWOG) – Chicago, IL
October 16	MM Patient & Family Seminar – Heidelberg, GERMANY
October 23	MM Regional Community Workshop – Berlin, GERMANY
October 30	IMF Regional Community Workshop – Raleigh Durham, NC
November 5	IMF 5th Annual Comedy Celebration – Los Angeles, CA
November 12	IMF Regional Community Workshop – Phoenix, AZ
November 19	IMF Regional Community Workshop – Leipzig, GERMANY
December 9-12	American Society of Hematology (ASH) – Orlando, FL

Additional events/meetings will be posted in later editions of *Myeloma Today* as dates are finalized.
For more information, please visit www.myeloma.org or call 800-452-CURE (2873).
IMF–Latin America, IMF–Japan and IMF–Israel events are not included above.