MYELOMA TODAY

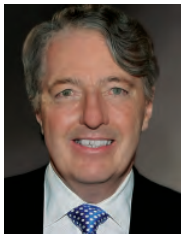
FALL 2010
VOLUME 8 NUMBER 4

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

The International Myeloma Working Group (IMWG) convened its inaugural Myeloma Summit, a first-of-its-kind meeting. Nearly 70 of the world's leading experts in multiple myeloma and related blood cancers, representing more than 20 countries and over 30 institutions, met to identify, support, and implement the most promising research to prevent the onset of active disease, improve treatment, and find a cure for myeloma. As research data builds support for continuous myeloma treatment, the IMWG is laying the groundwork to move beyond long-term remissions and begin charting a roadmap for an actual cure. ***PAGE 5***



Dr. Brian G.M. Durie offers a brief recap of the key presentations made at the 2010 annual meeting of the American Society of Clinical Oncologists (ASCO), which was held June 4–8 in Chicago, IL. Dr. Durie answers questions about new data on the approved novel anti-myeloma agents, new data on the two most promising drugs in development plus agents in early development, as well as advances in combination therapies. Dr. Durie also addresses a general shift of perspective among myeloma clinicians towards continuous treatment of the disease as a way to prevent or delay disease relapse. ***PAGE 6***

Prof. Meletios A. Dimopoulos answers questions about the challenges of treating relapsed and/or refractory multiple myeloma, the currently-available treatment options, and the role of emerging therapies in this setting. For patients with relapsed/refractory disease, there is an urgent need to develop targeted drugs that provide durable disease control and symptomatic relief. Vorinostat, a histone deacetylase (HDAC) inhibitor that has been shown to have activity in myeloma, is being investigated in two major studies. Prof. Dimopoulos offers his assessment of this potential new treatment option for patients with advanced myeloma. ***PAGE 7***

Dr. David S. Siegel shares his experience of working with carfilzomib, a second-generation proteasome inhibitor, and discusses how this new compound differs from bortezomib (VELCADE®), the first proteasome inhibitor approved for use in multiple myeloma. Data from clinical trials of carfilzomib is showing that it is at least as effective against myeloma as bortezomib, has a better toxicity profile, and may be active in patients who have become resistant to bortezomib. The phase I clinical trials of carfilzomib showed that it was well-tolerated and was associated with low rates of peripheral neuropathy (PN). ***PAGE 8***

Supportive Care

Tiffany Richards, member of the IMF Nurse Leadership Board (NLB) and leader of the NLB task force on sexuality and sexual dysfunction, answers questions about the disruption of the sexual response cycle as a result of physical illness or psychological factors. The discussion encompasses the impact of disease and its therapies on sexual activity and function, body image and psychological well-being, treatment of sexual dysfunction, and fertility preservation. ***PAGE 10***

IMF Hotline Coordinators respond to a question about bortezomib (VELCADE®). Effectiveness, dosing, infusion frequency, potential side effects, and current clinical trial data related to this widely-used novel agent are discussed. Specific guidelines for determining bortezomib dose, soon to be published by the International Myeloma Working Group (IMWG), are also summarized. ***PAGE 11***

Special Event

Prof. Joan Bladé is honored with the Robert A. Kyle Lifetime Achievement Award for his body of work in myeloma. Prof. Bladé is Senior Consultant and Director of Myeloma Programs at Hospital Clínic de Barcelona in Spain as well as co-founder of the PETHEMA Foundation, co-founder of the Spanish Myeloma Group, chair of the group that developed the European Group and Marrow Transplantation (EBMT) response criteria, member of the International Myeloma Working Group (IMWG), and author of more than 200 papers on myeloma. ***PAGE 12***

Also in this issue...

LOOKING FOR A LOCAL MYELOMA SUPPORT GROUP?
Please visit our website at **www.myeloma.org** or call the IMF at **800-452-CURE** (2873).

This issue of *Myeloma Today* is supported by
Binding Site, Celgene Corporation, Millennium: The Takeda Oncology Company, Novartis Pharmaceuticals, and Onyx Pharmaceuticals.

International Myeloma Foundation

Headquarters

12650 Riverside Drive, Suite 206, North Hollywood, CA 91607-3421 USA
Tel: 818-487-7455 or 800-452-CURE (2873) Fax: 818-487-7454 Email: TheIMF@myeloma.org Web: www.myeloma.org

A Message from the President

Dear Reader,

After 20 years of reaching out to patients and their families across America and around the world, I am saddened that many people still are not getting the information they so desperately need. Every year, the IMF mails out over 20,000 Info-Packs that contain a wealth of information about myeloma and its treatments. Our award-winning website www.myeloma.org has everything you need to know about this disease, whether you're a patient, caregiver, doctor, nurse, or anyone touched by myeloma. From the IMF's toll-free Hotline 800-452-CURE (2873), Patient & Family Seminars, and Regional Community Workshops, to our conference calls, webinars, and our work with over 100 support groups across the country, we have the most extensive reach in the myeloma community. But we're still not reaching everyone.

Remember how you felt when you first heard the words "multiple myeloma?" I remember how I felt: devastated, depressed, scared, and all alone. But it doesn't have to be that way. I am calling on each and every one of you to help the IMF help others. Together we can help lift people up and empower them. We can tell them about new treatments that can put their myeloma into a very good remission. We can let them know that they are not alone, and that across America and around the world there are people living well with myeloma.

I am asking you to give some of your time to changing someone's life! You have the power to make a positive impact not only on one person, but on an entire family.

No matter how much or how little time you have available, you can make a difference. An hour a week, a day a month, whatever time you can give will go a long way.

I'm asking you to become an IMF volunteer and help us help others.

It can be as simple as placing our free informational materials – especially our bookmarks printed with our toll-free Hotline number – in hospitals, doctors offices, libraries, drug stores, senior centers, schools, or places of worship, just to name a few.

You can tell everyone you meet about the IMF Hotline. When myeloma patients call the Hotline for the first time, you can almost feel them breathing a sigh of relief, because finally they've reached someone who knows about their disease, who can answer their questions and provide guidance, and who really cares about them and their family.

You can help change a patient's outlook from fear and isolation to hope for a brighter future, because *you* took the time to spread the word.

Empower someone today, call the IMF and find out how you can help!

Thank you!

Susie Novis

News & Notes

The content for the News & Notes section of *Myeloma Today* is drawn from a long list of publications based on inquiries received by the IMF Hotline and the interests expressed by our readers. To submit your inquiries or suggestions, please email MKazakova@myeloma.org.

Obesity and risk of MGUS

Obesity has been associated with an increased risk of multiple myeloma among African-Americans, although it is not known whether this increased risk is related to socio-economic status, genetic susceptibility, or both. The association of obesity with monoclonal gammopathy of undetermined significance (MGUS) is unknown. Doctors at the Mayo Clinic investigated a potential association between obesity and race and MGUS by screening 1,000 African-American and 996 Caucasian women between the ages of 40 and 79 years, of similar socio-economic status. A total of 39 (3.9%) African-American women and 21 (2.1%) Caucasian women had MGUS. Obesity, African-American race, and increasing age were independently associated, on multivariate analysis, with an excess risk of MGUS. The findings support the hypothesis that obesity is linked to the development of MGUS. The 2-fold excess of MGUS among African-Americans compared to Caucasians of similar socio-economic status supports the investigators' hypothesis for susceptibility genes in MGUS.

MGUS and risk of skeletal fractures

A group of researchers from Sweden and the United States conducted a study of the risk of skeletal fractures for patients with monoclonal gammopathy of undetermined significance (MGUS). Using population-based data from Sweden, the investigators assessed the risks of fractures in 5,326 MGUS patients diagnosed between 1958 and 2006, and compared these patients to matched controls. It was found that individuals with MGUS had an increased risk of fracture at five and 10 years. The risk was significantly higher for skull, vertebra, pelvis, sternum, and rib fractures when compared to fractures of arms and legs. Risk for fractures did not differ by M-protein concentration at diagnosis. MGUS patients with fractures had no excess risk of progressing to multiple myeloma or Waldenström's macroglobulinemia when compared to individuals in the control group.

Myeloma-associated chromosomal abnormalities

Researchers in the United Kingdom, including IMF Scientific Advisors Gareth Morgan and Faith Davies, are studying myeloma-associated chromosomal copy number abnormalities and their prognostic value. To obtain a comprehensive genomic profile of presenting myeloma cases, the investigators performed high-resolution single nucleotide polymorphism (SNP) mapping array analysis and examined deoxyribonucleic acid (DNA) alterations in order to define the regions in which relevant genes of interest can be found. It was discovered that the most frequent chromosomal deletions relevant to myeloma are located at 1p (30%), 6q (33%), 8p (25%), 12p (15%), 13q (59%), 14q (39%), 16q (35%), 17p (7%), 20 (12%), and 22 (18%). In addition, based on data from fluorescent in situ hybridization (FISH) and other analyses, genes of prognostic importance were found to be located at 1p, 1q, and 17p. The researchers also identified deleted genes that have functions relevant to myeloma biology.

Arterial thrombosis in young myeloma patients

The results of a prospective cohort study by researchers in the Netherlands show a high incidence of arterial thrombosis in young patients treated for myeloma. This study evaluated the risk of arterial thrombosis in 195 newly diagnosed patients, aged 18 to 65 years. All patients were treated with thee cycles of VAD (vincristine, doxorubicin, dexamethasone) or TAD (thalidomide, doxorubicin, dexamethasone) or PAD (bortezomib, doxorubicin, dexamethasone) followed by high-dose melphalan and autologous stem cell transplantation (ASCT). During a total of 522 patient-years, 11 of the 195 patients (5.6%) developed arterial thrombosis. The highest incidence was seen during induction chemotherapy prior to ASCT. Hypertension and smoking were significantly associated with contributing to the risk of arterial thrombosis. The researchers concluded that myeloma patients have an increased risk for arterial thrombotic events during and after induction chemotherapy. **MT**

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**.

WHAT DO YOU GET AT AN IMF PATIENT & FAMILY SEMINAR?

Education • Access to Experts • Camaraderie

Topics Covered

- *What's New in Myeloma?*
- *Ask-the-Expert*
- *Managing Side Effects*
- *How to be a Better Patient*
- *Frontline Therapy*
- *Transplant*
- *Bone Disease*
- *Maintenance Therapy*
- *Relapse*
- *Novel Therapies*

Regional Community Workshops (RCW)

If you cannot get to a P&F Seminar, consider attending a Regional Community Workshop. These half-day meetings provide Education, Access to Experts, and Camaraderie. Registration is free *but you must register*. It's a great way to learn from myeloma experts, as well as share experiences and gain strength from others in the IMF family. Find more details about the next RCW near you at our website.

Go to our website **www.myeloma.org** *and click on the* "meetings & events"*tab for more details, the most up-to-date faculty, hotels and registration information.*

IMWG SUMMIT LAYS THE GROUNDWORK FOR A COURSE TOWARD A CURE

Data builds support for continuous myeloma treatment to extend remissions

The IMF held the inaugural Myeloma Summit, a first-of-its-kind meeting of the International Myeloma Working Group (IMWG). The Myeloma Summit took place on June 7–9 in Barcelona, Spain. The Myeloma Summit convened between two of the year's largest cancer conferences, the American Society of Clinical Oncologists (ASCO) in Chicago and the European Hematology Association (EHA) in Barcelona.

The IMWG consists of 130 myeloma scientific advisors from around the globe, including all the major myeloma research centers and clinical trial groups. The IMWG has been gathering annually at the exposition of the American Society of Hematology (ASH) and for additional roundtable and consensus meetings as necessary. As of now, over 30 publications have been generated from the collaborative efforts of the IMWG members, including numerous myeloma guidelines and consensus statements, as well as genetic publications linked to the IMF's Bank on a Cure® research initiative. This year, it was decided to expand and enhance the IMWG activities by holding a true "working" summit to identify and implement new strategies in the search for better myeloma therapies on the road to finding a cure. The IMWG Myeloma Summit mission is to identify, support, and implement the most promising research to prevent onset of active disease, improve treatment, and find a cure for myeloma.

The IMWG Myeloma Summit mission is to identify, support, and implement the most promising research to prevent onset of active disease, improve treatment, and find a cure for myeloma.

Given the wide range of experience within the IMWG, the Myeloma Summit discussions were intended to lay the groundwork to move beyond long-term remissions and begin charting a roadmap for an actual cure. However, the availability of a growing number of myeloma treatment options raises questions about when to use which treatments for which patients.

The first Myeloma Summit brought together nearly 70 of the world's leading experts in myeloma and related blood cancers charting the future of myeloma treatment and care. The investigators represented more than 20 countries and over 30 institutions. On the evening of June 7, IMF President Susie Novis welcomed the participants to the Myeloma Summit, IMF Chairman and medical director Dr. Brian G.M. Durie summarized the goals and expectations for the meeting, and Dr. S. Vincent Rajkumar provided an overview of the current status of myeloma treatment and highlighted key questions in the search for chronic disease control, as well as potential strategies to ultimately achieve a cure.

June 8 began with concise summaries of translational research (which "translates" scientific discoveries into practical clinical applications). This set the stage for integration of available research into correlative studies for planned clinical trials, as well as enhancing the search for targets for new anti-myeloma drugs. The main part of the meeting then began with overviews of the key myeloma issues for 2010. Each topic presented an opportunity for input from all participants. After general agreement was reached, investigators separated into five smaller discussion groups to devise plans and recommendations to address each key issue. The outcomes were many and diverse. However, it is difficult to summarize all the details. In brief, the main recommendations were:

Group 1: Early high-risk smoldering myeloma

Lead: Dr. Vincent Rajkumar

Recommendations: identify best risk factors; research for new/better factors; use time-to-progression (TTP) as target group; plan and implement new trials, and much more.

Group 2: Sequential versus curative strategies

Lead: Dr. Antonio Palumbo

Recommendations: phase III trials required to provide answers; incorporate risk stratification; use progressive free survival as initial endpoint; develop recommendations to reduce bortezomib (VELCADE®) neuropathy; defer use of gene expression profiling (GEP) for risk classification in the clinic, and much more.

Group 3: Role of autologous stem cell transplant (ASCT) and consolidation

Lead: Dr. Philippe Moreau

Recommendations: further randomized trials required; new conditioning regimens should be explored; age > 65 and renal dysfunction do not exclude ASCT, and much more.

CONTINUES ON PAGE 9

IMWG attendees included: S. Vincent Rajkumar, Niels Abildgaard, Rafat Abonour, Hervé Avet-Loiseau, Michel Attal, Ashraf Badros, Bart Barlogie, Meral Beksaç, Dina Ben-Yehuda, P. Leif Bergsagel, Jenny Bird, Joan Bladé, Mario Boccadoro, Wen-ming Chen, Marta Chesi, James Chim, Wee-Joo Chng, Ray Comenzo, John Crowley, Faith Davies, Cármino De Souza, Matthew Drake, Brian GM Durie, Hermann Einsele, Dorotea Fantl, Gösta Garhton, Christina Gasparetto, Hartmut Goldschmidt, Roman Hájek, Jean-Luc Harousseau, Jian Hou, Vania Hungria, Hans Johnsen, Artur Jurczyszyn, Jonathan Kaufman, Shaji Kumar, Robert Kyle, Ola Landgren, Jae Hoon Lee, Xavier LeLeu, Suzanne Lentzsch, Sagar Lonial, Heinz Ludwig, Angelo Maiolino, María Victoria Mateos, Ulf-Henrik Mellqvist, GiamPaolo Merlini, Philippe Moreau, Amara Nouel, Antonio Palumbo, Angelina Rodríguez Morales, Laura Rosiñol, Jesús San Miguel, Sabina Sevcikova, Orhan Sezer, Jatin Shah, John Shaughnessy, Chaim Shustik, David Siegel, Pieter Sonneveld, Edward Stadtmauer, Keith Stewart, Evangelos Terpos, Ingemar Turesson, Ben Van Camp, Isabelle Vande Broek, David Vesole, and Jan Westin.

2010 ASCO KEY MYELOMA PRESENTATIONS

Myeloma Today in conversation with Dr. Brian G.M. Durie

Please share with our readers a brief recap of the general themes in myeloma and the key presentations at the 2010 ASCO meeting.

The 2010 annual meeting of the American Society of Clinical Oncologists (ASCO) was held June 4–8 in Chicago, IL. ASCO is one of two major annual meetings that take place in the US and involve key topics in myeloma. The second such meeting is held by the American Society of Hematology (ASH) in December of each year. The format of these two meetings is fairly similar. There are educational sessions, overviews from leading experts in the field, oral sessions, and a large number of poster sessions. In addition, there are many abstracts available only in publication form. In recent years, the general discussions in myeloma have followed a pattern:

1. New data on the three approved novel anti-myeloma agents (thalidomide, bortezomib, and lenalidomide) that have made a significant difference in the field in the last 5–10 years.

2. New data on the two most promising drugs in development (carfilzomib and pomalidomide).

3. Drugs in early development (elotuzumab, vorinostat, and others).

4. Advances in combination therapies.

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

What were some of the studies presented this year at ASCO that involved lenalidomide and/or bortezomib?

The role of lenalidomide as maintenance is of much interest for discussion, and two significant randomized trials presented at ASCO garnered a lot of attention. One study is from the IFM, which is the French myeloma study group, and the other study is from the Cancer And Leukemia Group B (CALGB) in the US. Both of these studies looked at the role of lenalidomide (REVLIMID®) in the post-transplant setting. Large numbers of myeloma patients who had gone through induction therapy followed by a single autologous stem cell transplant (ASCT), were randomized 6 to 12 months after transplant into two groups. One group took 10 to 15 mg of lenalidomide as maintenance; the other received a placebo.

The IFM study looked at 614 patients. At three years, 68% of the patients who received lenalidomide were still in remission compared to 35% in the placebo arm. With almost double the number of patients in the placebo arm, the statistical difference is highly significant. Obviously, although it is too early to draw a conclusion, we are hopeful that the patients who achieve prolonged remissions will also have increased overall survival (OS).

The patients in the CALGB study had received a broad variety of induction therapies but were standardized by entering the study after their ASCT. Of the 210 patients randomized to receive lenalidomide maintenance, only 29 patients relapsed. In the placebo arm, 58 of 208 patients relapsed. Both the progression-free survival (PFS) and the time-to-progression (TTP) were better in the lenalidomide arm of the study.

Were there significant studies of bortezomib presented at ASCO?

There were close to 50 abstracts at ASCO that presented data on combination studies with bortezomib (VELCADE®).

One study of particular interest was presented by investigators from Italy. The researchers looked at more than 500 patients on a combination therapy of bortezomib, melphalan, prednisone, and thalidomide followed by maintenance with bortezomib and thalidomide. The four-drug therapy followed by maintenance demonstrated improved responses compared to patients on a three-drug therapy without maintenance. The data had been presented before, but the two significant aspects of the ASCO presentation looked at the possibility of switching to one day a week of bortezomib as induction, with reduced side effects but without reduced efficacy.

Another significant study demonstrating that reduced-dosage bortezomib-based regimens may lessen toxicity without compromising efficacy showed the benefit of low-dose bortezomib administered once every two weeks, combined with low-dose daily thalidomide as maintenance.

There were a number of other promising bortezomib trials, including those that combine bortezomib with lenalidomide.

What other trials did you find to be of most interest?

The two multi-center trials of approximately 600 patients, each of which showed a decreased risk of disease progression in more than half of the patients on a lenalidomide-based maintenance therapy following an ASCT, are very significant. In fact, this development was highlighted by ASCO as one of the most important in 2010.

The Italian study directly comparing a lenalidomide-based regimen to ASCT was interesting. The results of drug therapy were shown to be comparable to ASCT but without the risk, recovery time, and debilitating side effects.

Is there a general shift of perspective among myeloma clinicians?

Continuous therapy is becoming the new paradigm of treatment in myeloma. Traditionally, doctors have treated cancer until a desired response is reached and then treatment stops. The novel anti-myeloma therapies can be tolerated long-term and offer physicians and patients the potential to modulate the immune system to maintain remissions. Myeloma doctors have been leaning toward continuing treatment as a way to prevent or at least delay disease relapse. The ASCO data may tip the balance in favor of that approach.

What about the next generation of anti-myeloma agents?

The two new drugs in development that have emerged as being closest to possible approval for myeloma are pomalidomide (a third-generation immunomodulator in the same class as thalidomide and lenalidomide) and carfilzomib (a second-generation proteasome inhibitor in the same class as bortezomib). At ASCO, the "next generation" data of significance to patients include updates on both of these drugs. Also of importance were presentations on drugs in early development, such as epigenetic drugs that work on the function of genes, as well as drugs that target unique features of myeloma cells.

Any closing comments?

I believe that the clinical and scientific progress being made in myeloma will serve as a roadmap for transforming the treatment of a wide range of

CONTINUES ON PAGE 9

THE ROLE OF VORINOSTAT IN RELAPSED/REFRACTORY MULTIPLE MYELOMA

Myeloma Today in conversation with Prof. Meletios A. Dimopoulos

How do you define "relapsed" and "refractory" multiple myeloma?

I define relapse as the presence of clinically active disease in patients who have received one or more prior therapies. Refractory multiple myeloma can be defined as either progressive disease (PD) or stable disease (SD) while on therapy, or PD within 3 months of the last dose of prior therapy.

What are the challenges of treating relapsed or refractory myeloma?

Patients with relapsed/refractory myeloma can be categorized as following: patients who are refractory to frontline therapies, patients who have relapsed but who are not refractory to treatment, and patients who are both relapsed and refractory. Newly-diagnosed myeloma is usually responsive to initial treatment. However, most patients with this disease eventually relapse or become not readily responsive to currently available anti-myeloma agents. This is due in part to the evolving biology of myeloma and/or the development of drug-resistance within the cancer cells.

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

What are the currently-available treatment options for relapsed/refractory disease?

Currently, three novel agents are approved in most countries for the treatment of myeloma as frontline therapy and/or in the relapsed/refractory setting: thalidomide (THALOMID®), lenalidomide (REVLIMID®), and bortezomib (VELCADE®). These novel agents are used in frontline therapy and can provide clinical benefit in relapsed/refractory disease. But not all relapsed/refractory patients will respond to currently approved drugs, and the responses can be limited in duration. For patients with relapsed myeloma who are refractory to these agents, there is an urgent need to develop targeted agents that provide durable disease control and symptomatic relief.

Please give us a brief overview of the targeted agents that are currently under investigation for myeloma.

The progress being made in the treatment of relapsed/refractory myeloma is encouraging. Several new agents from a range of therapeutic classes and with varied rationales for use in myeloma are showing potential to provide improvements in response and survival in the relapsed/refractory setting. Agents in development for the treatment of bortezomib- or lenalidomide-resistant myeloma include pomalidomide, carfilzomib, perifosine, elotuzumab, and several histone deacetylase (HDAC) inhibitors (e.g., panobinostat, romidepsin, and vorinostat). Completion of the numerous ongoing clinical investigations should determine which, if any, of these newly emerging therapies are viable treatment options for patients with relapsed/refractory myeloma.

You have been involved with studies of vorinostat for relapsed/refractory myeloma. Please tell us about this compound and its development history.

HDAC inhibition may play a critical role in controlling tumor growth and increasing survival. Vorinostat (suberoylanilide hydroxamic acid) is an oral HDAC inhibitor that has been developed for the treatment of several malignancies. In 2006, vorinostat was approved in the United States for the treatment of patients with cutaneous T-cell lymphoma who have progressive, persistent, or recurrent disease on or following two systemic therapies. The safety and tolerability of vorinostat has been well-documented both in patients with hematologic malignancies and those with solid tumors. Preliminary studies of vorinostat in patients with relapsed/refractory myeloma did not show significant single-agent activity, but there was a significant in vitro rationale to combine vorinostat with either bortezomib or lenalidomide.

What was that rationale?

Preclinical data of vorinostat in myeloma showed that it has antiproliferative/proapoptotic activity against human myeloma cells, overcomes the protective effect of bone marrow stromal cells on myeloma cells, and enhances the response of myeloma cells to other anti-myeloma compounds. The data from the preclinical studies provided the "proof of concept" that led to the development of clinical trials to further explore the activity of this compound in myeloma.

VANTAGE 074, a phase I multicenter, open-label study of vorinostat, lenalidomide, and dexamethasone for relapsed/refractory myeloma aimed to determine the maximum tolerated dose (MTD) for that three-drug combination regimen. Most study patients received prior therapy with bortezomib, thalidomide, and/or lenalidomide. Based on April 2010 preliminary data, 26 of 30 patients evaluable for efficacy (86.7%) had clinical benefit: complete response (CR) + partial response (PR) + minimal response (MR) + stable disease (SD) on treatment. In addition, data showed that MTD has not been reached, with no dose-limiting toxicities (DLT) prohibiting dose escalation. This suggests that vorinostat combined with lenalidomide and dexamethasone may be an effective and generally well-tolerated oral regimen for patients with relapsed/relapsed myeloma. Further data collection and review are ongoing, and a phase II study is planned.

Indeed, the phase I and II clinical studies of vorinostat in myeloma showed interesting activity indicating that there was clinical synergy between vorinostat and bortezomib, as well as vorinostat and lenalidomide. Investigation of vorinostat plus lenalidomide has been presented at recent annual meeting of the American Society of Hematology (ASH), the American Society of Clinical Oncology (ASCO), and the European Hematology Association (EHA). Vorinostat was shown to have activity in heavily pretreated myeloma patients and in those who are refractory to bortezomib and lenalidomide.

What are the significant ongoing clinical trials?

At present, there are two major clinical trials of vorinostat. One of these trials – VANTAGE 095 – is a large phase IIb international open-label single-arm study designed to assess efficacy and safety of treatment with vorinostat plus bortezomib in patients who are refractory to bortezomib and ≥1 immunomodulatory drug (IMiD) regimens and are ineligible for other approved regimens. Such patients are known to have very poor outcomes, with a median survival of 6 months or less, so this trial is very

CONTINUES ON PAGE 9

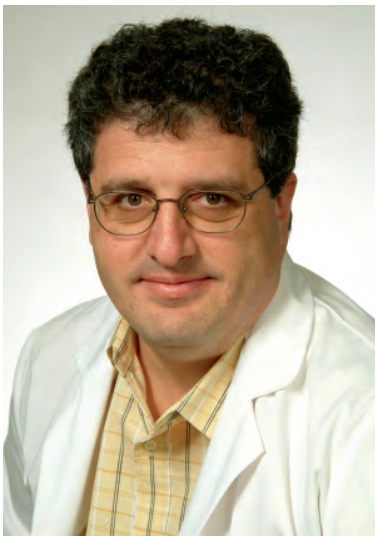
THE ROLE OF CARFILZOMIB IN MYELOMA

Myeloma Today in conversation with Dr. David S. Siegel

You are working with carfilzomib, a second-generation proteasome inhibitor. How does this compound differ from bortezomib?

Proteasome inhibition affects expression of a number of proteins involved in the cell cycle, causing apoptosis in myeloma cells. The first proteasome inhibitor that became commercially available for use in myeloma is bortezomib (VELCADE®), which is a boron salt. Bortezomib is a "competitive" inhibitor of the proteasome. This means that while bortezomib is around, the proteasome is inhibited, but as soon as the levels of bortezomib are reduced, the proteasome resumes its activity.

In contrast to bortezomib, which has an effect on myeloma cells that is reversible, carfilzomib targets the same proteasomes irreversibly. We call carfilzomib a "non-competitive" proteasome inhibitor. Carfilzomib, which is an epoxyketone, binds to and destroys the proteasome permanently. So while both bortezomib and carfilzomib hit the same target, they hit it in very different ways.



David S. Siegel, MD, PhD
Chief, Myeloma Division
John Theuer Cancer Center
Hackensack, NJ

In the myeloma setting, how is the permanent impact of carfilzomib preferable to the temporary action of bortezomib?

Proteasomes are essential to cells, so inhibiting proteasomes is a potentially dangerous thing. While carfilzomib targets the proteasome selectively, we certainly did not know until it was tested that carfilzomib would turn out to be the more effective proteasome inhibitor. But the data gathered from numerous investigations of carfilzomib is showing that it is at least as effective against myeloma as bortezomib, if not more effective, and it has a better toxicity profile.

Part of the rationale for developing a new drug is to improve efficacy and/or tolerability, as well as to address potential drug-resistance to the first-generation drug. In other words, in patients who have become resistant to bortezomib, the use of a new proteasome inhibitor such as carfilzomib might overcome the resistance to bortezomib.

What have the studies shown about carfilzomib?

Carfilzomib has generated very positive data in several early-phase studies. The phase I clinical trials of carfilzomib showed that it was well-tolerated. In addition, the low rates of peripheral neuropathy (PN), a side effect of several myeloma therapies, make carfilzomib very much different from bortezomib and the other boronated proteasome inhibitors.

In a phase I study of 19 patients who had relapsed following or became refractory to previous therapies, treatment with carfilzomib resulted in an overall response rate (ORR) of approximately 17%, indicating that single-agent carfilzomib is active in relapsed/refractory myeloma.

An ongoing phase Ib multicenter, open-label, single-arm, non-randomized dose escalation clinical trial of carfilzomib plus lenalidomide and low-dose dexamethasone in relapsed/refractory myeloma is studying four dose levels in order to evaluate safety and define the maximum tolerated dose (MTD) of this three-drug combination in patients who had failed 1-3 prior therapies, including prior treatment with lenalidomide or bortezomib.

What can you share with us about phase II and III clinical trials of carfilzomib?

The data from phase II trials of carfilzomib in myeloma have been presented at several major meetings, including the American Society of Hematology (ASH), the American Society of Clinical Oncology (ASCO), and the European Hematology Association (EHA). Carfilzomib has been shown to have excellent activity both in heavily pretreated patients and in those who were not. It is active in patients who have been previously treated with bortezomib and, more importantly, carfilzomib has been shown to be active in patients who are bortezomib-resistant.

There are now two ongoing phase II clinical trials investigating the efficacy, safety, and tolerability of carfilzomib as single-agent therapy in myeloma patients with relapsed/refractory disease. One ongoing phase II clinical trial is evaluating relapsed/refractory patients who have received prior treatment with bortezomib, and either thalidomide or lenalidomide, and are refractory to their last treatment. This study is open-label, single-arm, and non-randomized.

The second ongoing phase II clinical trial is an open-label, single-arm, non-randomized study testing the activity and safety of carfilzomib in relapsed/refractory patients who had 1-3 prior therapies and relapsed to the most recently-received therapy. There are two patient populations in this study: patients with relapsed and/or refractory myeloma who had not received prior bortezomib therapy and patients with relapsed and/or refractory disease following treatment with bortezomib.

Phase III clinical trials of carfilzomib will be opening at the end of 2010. One phase III international randomized clinical trial has been initiated to evaluate the safety and efficacy of carfilzomib in combination therapy with lenalidomide and low-dose dexamethasone compared to lenalidomide and low-dose dexamethasone alone in patients with relapsed myeloma.

I'd also like to mention that there are additional ongoing clinical trials with carfilzomib using a different route of administration. It seems that administering carfilzomib via infusion allows for higher doses of the compound to be used and we are hopeful that this will show even better responses in patients.

What are the prospects for this drug to become available to myeloma patients outside the clinical trial setting?

It is anticipated that the clinical trial data will support a new drug application (NDA) filing in the United Stated by the end of 2010, and we are certainly hoping for a fast-track approval by the Food and Drug Administration (FDA).

Is there anything you'd like to add in closing?

The carfilzomib clinical trials are continuing to mature and the data is continuing to be presented at the major hematology meetings. The data from all of the trials seem to confirm the initial presentation that carfilzomib is well-tolerated by patients and that it seems to have a high degree of activity against myeloma. It is also important to add that the patients who respond to carfilzomib achieve responses that are quite durable. Carfilzomib is active in patients who are refractory to bortezomib and it seems to cause little to no PN, which is the main limiting factor in the

CONTINUES ON PAGE 9

IMWG SUMMIT — continued from page 5

Group 4: Maintenance therapy
Lead: Dr. Heinz Ludwig
Recommendations: drug orphans guideline manuscript is planned; further studies required.

Group 5: New drugs
Lead: Dr. Sagar Lonial
Recommendations: new drug development is crucial; testing in relapse/refractory disease *and* other settings; discuss and define ideal from-lab-to-clinic sequence; key current agents identified.

In addition to these broad recommendations, specific projects were discussed in follow up of ongoing or recently planned IMWG consensus and database projects. A few of the newer projects include possible collective analyses of GEP data, updating of both CRAB (C = elevated Calcium, R = Renal failure, A = Anemia, B = Bone lesions) and IMWG response criteria, studies of plasma cell leukemia, extra-medullar disease, and non-secretory myeloma. It was also proposed to record, in a standardized fashion, other diseases and illnesses (so called "co-morbidities") in myeloma patients.

By the end of the Myeloma Summit on June 9, there was great excitement about all that had been presented during the meeting, as well as the plans made for the future. One gratifying sentiment voiced by many Myeloma Summit participants was that this unique meeting had been the best they had ever attended. By popular demand, the timing and location of the next Myeloma Summit is already being explored for 2011. The outlook is very promising for ongoing, active, and collaborative involvement of IMWG members in key projects which will undoubtedly lead to better myeloma disease control and, ultimately, a cure. **MT**

Editor's Note: To read the consensus statements and published papers produced by the IMWG, please visit the IMF website and click on the "research" tab

DURIE / 2010 ASCO — continued from page 6

cancers. We are seeing myeloma treatments work in lymphomas, leukemias, and even solid tumors. In fact, there is much promise in the early data from studies evaluating lenalidomide in prostate cancer, as well as second-generation proteasome inhibitors (carfilzomib and an oral drug from the makers of VELCADE) in several different malignancies.

As for myeloma patients, the presentations made at the 2010 ASCO conference could change the way they are treated. Overall, the data favor fewer stem cell transplants and increased use of maintenance therapy – continuing therapy even in patients who have achieved a complete response (CR). The progress and positive news presented at ASCO and other medical meetings are truly encouraging. While we must continue to work toward a cure, it is clear that many myeloma patients are already living longer, better lives. **MT**

DIMOPOULOS / VORINOSTAT — continued from page 7

important in attempting to address a currently unmet need.

The second major ongoing clinical trial of vorinostat is VANTAGE 088, a phase III multi-center randomized double-blind study of vorinostat or placebo combined with bortezomib in relapsed myeloma. The primary objective of this study is to determine the progression-free survival (PFS) of vorinostat plus bortezomib, compared with placebo plus bortezomib, in myeloma patients who had received between one and three prior treatment regimens. The patients being accepted into this study must not be refractory to bortezomib.

Are you involved with both of the currently ongoing clinical trials?

Yes, I am working on both VANTAGE 088 and VANTAGE 095 as a member of the steering committee. The VANTAGE trial is the largest clinical study for myeloma, enrolling 742 patients at 265 sites in 32 countries throughout the world VANTAGE 088 should conclude the accrual process within the next year. VANTAGE 095 is closer to completion of the patient accrual process, and we should have a formal interim analysis completed by the end of this year.

We do not yet have the final response data from the VANTAGE 095 study, but the preliminary data show that vorinostat has activity in myeloma. This is rather interesting, especially considering that this data comes from a heavily pretreated patient population. Of course, we have to wait until this study is fully accrued. But, hopefully, we will continue to see induced responses in 20-30% of participating patients who have disease which is otherwise refractory to all types of standard treatments. We have submitted an abstract to ASH 2010, and it is now under review.

What is your assessment of vorinostat so far?

I think that vorinostat is a very interesting compound. So far, the safety of the compound is looking reasonable, and we hope that the data will also show positive efficacy. Of course, patients receiving vorinostat require close follow-up, and might require dose adjustment, because it is associated with gastro-intestinal toxicity, a sense of weakness and fatigue. However, the combination of vorinostat with either bortezomib or lenalidomide has been shown to be generally well-tolerated.

Some study patients with resistant myeloma, for whom there are no other available treatment options, are showing some response from vorinostat plus bortezomib. So VANTAGE 088 and VANTAGE 095 are both very important clinical trials. We are looking forward to their completion, as there is a reasonable hope that the results of these trials may lead to a new treatment option being approved for patients with advanced myeloma. **MT**

SIEGEL / CARFILZOMIB — continued from page 8

administration of bortezomib. To be able to achieve a high degree of response that is durable without sacrificing quality of life is very exciting.

I have had wonderful experiences with patients on this drug, both in terms of toxicity and response. I had an experience with one patient, who was in hospice care at another major myeloma institution and came to us for the phase II trial of carfilzomib, who not only responded to treatment but started asking how soon he could return to work!

I have worked with carfilzomib in phase I trials, am now working with it in phase II trials, and will hopefully be involved with the phase III trials of carfilzomib in as well. We have had a tremendous amount of experience with carfilzomib in myeloma and I can tell you that it is a wonderful drug. **MT**

SEXUAL DYSFUNCTION AND ITS IMPACT ON MULTIPLE MYELOMA

Myeloma Today in conversation with Tiffany Richards

Over the past decade, advances in anti-myeloma therapy have led to better overall survival for patients with multiple myeloma. New treatments provide hope for extended disease-free periods and improved outcomes for patients. As more people are living longer with myeloma, members of the IMF Nurse Leadership Board (NLB) are addressing the evolving needs of myeloma survivors. Patient survivorship care planning allows for optimal management of emergent late-term effects and improved quality of life. The NLB Survivorship Care Plan, which is currently being prepared for publication, examines five specific aspects of long-term care for the benefit of patients and the nurses who work with them. The five areas are: Health Maintenance, Sexuality and Sexual Dysfunction, Renal Complications (see Spring 2010 Myeloma Today*), Bone Disease & Bone Health (see Spring 2010 Myeloma Today), and Functional Mobility and Safety (see Summer 2010* Myeloma Today*). Tiffany Richards, the leader of the sexuality and sexual dysfunction task force, spoke with* Myeloma Today *about the work of her team.*

Tiffany Richards, MS, ANP-BC, AOCNP
MD Anderson Cancer Center
Houston, TX

What is the definition of sexual dysfunction?

The World Health Organization defines sexuality as a "central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction." Sexuality is influenced by many interactions of biological, psychological, social, economic, political, cultural, ethical, legal, historical and religious and spiritual factors.

Sexual dysfunction occurs when a disruption of the sexual response cycle occurs as a result of physical illness or psychological factors rather than part of the normal aging process. Sexual dysfunction can be described as one of four main categories: sexual desire disorder (decreased libido), sexual arousal disorder, orgasm disorder, and sexual pain disorders.

What are the causes of sexual dysfunction in illnesses in general and myeloma in particular?

Review of the literature regarding sexual function in cancer patients is limited primarily to patients diagnosed with prostate, breast, or gynecological cancers. There is little research regarding sexual dysfunction in patients with multiple myeloma, so the information related to the assessment and evaluation of sexual dysfunction is gleaned from other malignancies and diseases. My NLB task force is working on promoting dialogue and assessment practices amongst myeloma patients.

Patients undergoing treatment for myeloma may experience an exacerbation of pre-existing disorders or develop new disorders as a consequence of treatment. Physical disorders that may have an impact on sexual functioning include endocrine abnormalities, cardiovascular disease, pelvic disease, cancer, and renal insuffiency. In addition, treatment of these illnesses (medications, chemotherapy, or radiation) or their associated complications, may worsen symptoms. The effects of disease on sexual dysfunction vary in the degree and the type of dysfunction.

In patients with myeloma, treatment may precipitate diseases such as diabetes, hypertension, and anemia. Additionally, myeloma may impact renal function, mobility, and pain due to bone disease or neuropathy. Patients receiving treatment may experience disruptions in sexual response as a result of fatigue, weakness, pain, and alterations in body image. Additionally, patients with compression fractures may experience pain and diminished mobility, inhibiting sexual function. Chronic pain requiring long-term opiate use affects erectile function, hormonal levels, and libido.

Cardiovascular disease (hypertension, atherosclerosis, vascular disease, cerebral vascular events) has systemic effects including sexual dysfunction. Men with erectile dysfunction (ED) have an increased incidence of cardiovascular events. The risk of cardiovascular events among women who have cardiovascular disease is not known. Myeloma patients receiving treatment with steroids are at increased risk of developing hypertension and require close monitoring of blood pressure during treatment.

Radiation to the pelvis may cause delayed arousal and orgasm through damage of the pelvic vascularity and nerves. Women may develop vaginal stenosis and fibrosis leading to dyspareunia and painful pelvic examinations.

The use of thalidomide/lenalidomide in the treatment of women with myeloma may disrupt sexual function due to the requirements of birth control measures. Oral contraceptives may cause decreased libido, and may affect sexual function by decreased testosterone levels.

Body image, depression, concerns about the future, abandonment issues, and history of abuse may have a negative impact on sexual function. A study of cancer patients found that the effects of treatment impaired mental well-being, thus affecting body image. Body image-related side effects were reported as the most severe chemotherapy side effect. In myeloma, treatments produce both temporary and permanent changes, potentially affecting body image and thereby influencing sexuality. Dependency on caregivers may have an impact on psychological well-being, particularly if they require assistance that minimizes their privacy.

What is the impact of myeloma and its treatments on sexual dysfunction?

Disruption of cancer patients' normal sexual functioning and fertility has been documented in those receiving traditional chemotherapy. Additionally, high-dose therapy with melphalan followed by autologous stem cell transplantation precipitates a chemically-induced

CONTINUES ON PAGE 16

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 Friday, 9 a.m. to 4 p.m. (Pacific Time). To submit your question online, please email TheIMF@myeloma.org

I am receiving VELCADE® as part of my treatment regimen. Is there a consensus among myeloma doctors on VELCADE dosing?

Bortezomib (VELCADE®) is an effective and widely used treatment for multiple myeloma. It can be given alone, in combination with dexamethasone, or in a variety of three- and four-drug combinations. Because of bortezomib's effectiveness, it is essential to ensure that patients are able to tolerate it well and not discontinue receiving bortezomib infusions because of side effects.

Peripheral neuropathy (PN) – which causes numbness, tingling, and/or sometimes pain in the hands, arms, feet, and/or legs – is a common problem among myeloma patients. Myeloma itself can cause PN, as can diabetes mellitus. Two of the most common novel therapies for myeloma, thalidomide (Thalomid®) and bortezomib, can also cause PN or worsen pre-existing PN. Because the goal of any treatment for myeloma is to attack the disease while preserving the patient's quality of life, it is important to be aware of this potential problem and to nip it in the bud before it becomes a debilitating and permanent condition.

At a meeting of the International Myeloma Working Group (IMWG) that took place in June 2010 in Barcelona, Spain, the myeloma experts who were gathered from around the world addressed many key questions, including, "How do we minimize the risk of neuropathy?" To answer this question, the experts examined important new clinical trial data that would enable them to draw up a guideline for bortezomib dosing with an eye to reducing the incidence of PN.

Clinical trials are the vehicle through which new drugs and drug combinations are tested, and are often also the means through which new dosing strategies are determined. Results of an Italian study group (GIMEMA) phase III randomized clinical trial, led by the University of Torino's Drs. Antonio Palumbo and Mario Boccadoro, that compared VMPT (VELCADE, melphalan, prednisone, and thalidomide) followed by VT maintenance, versus VMP followed by no maintenance, as first-line therapy in patients ineligible for stem cell transplant were presented at the December 2009 meeting of the American Society of Hematology (ASH) and at the June 2010) meeting of the American Society of Clinical Oncology (ASCO). During this trial, the study was amended to schedule bortezomib weekly (four doses weekly at a dose of 1.3 mg/m^2 followed by one week of rest) instead of the traditional twice weekly schedule, in order to reduce the rates of PN. The study investigators, having analyzed the data from the completed trial, noted, "Compared to twice weekly, the weekly infusion of bortezomib significantly reduced the incidence of PN without affecting outcome."

In a phase III randomized study by the Spanish Myeloma Group (PETHEMA/GEM) that compared VMP versus VTP followed by maintenance with VT or VP as first-line therapy for myeloma, Dr. María Victoria Mateos of the University of Salamanca, Spain, concluded that low rates of PN were observed after a modified bortezomib regimen that consisted of one 6-week cycle administered twice a week, followed by subsequent cycles in which bortezomib was administered in a weekly schedule (four weekly bortezomib doses at 1.3 mg/m^2 followed by one week of rest).

Based on these trial results and the combined clinical experience of the IMWG experts, the IMWG concluded that weekly bortezomib dosing and earlier detection of PN are therapeutic options to minimize the risk of neuropathy. Specific guidelines for determining bortezomib dose, which will soon be published in an IMWG paper, are the following:

- Patients who have no PN can be treated with bortezomib in the traditional twice weekly schedule.
- Patients with low-level neuropathy (defined as "Grade 1" using the National Cancer Institute's common toxicity criteria: numbness, weakness, and/or loss of reflexes, but without any pain or loss of function in performing the activities of daily living) should be carefully evaluated by their physicians for the existence of PN risk factors and managed appropriately. Consideration should be given to administering bortezomib once weekly at a starting dose of 1.3 mg/m^2.
- For patients treated with bortezomib who develop Grade 1 neuropathy who are experiencing pain, or those who have no pain but whose neuropathy limits their ability to perform daily living activities (Grade 2), consideration should be given to change bortezomib to a reduced dose of 1.3 mg/m^2 once per week, as an alternative to the current package insert recommendation of reducing bortezomib dose to 1.0 mg/m^2 twice weekly.
- Patients treated with bortezomib who have Grade 2 neuropathy with pain, or Grade 3, which is defined as severe pain, weakness, sensory alteration or numbness, and/or pain severely interfering with activities of daily living, and needing bracing or assistance to walk, should not be given bortezomib until their side effects improve. When the PN improves, consideration should be given to restarting bortezomib at 1.0 mg/m^2 once per week (the current package insert recommendation includes restarting bortezomib at 0.7 mg/m^2).

As always, we urge you to discuss this information with your hematologist/oncologist, and to report any and all symptoms of PN to your healthcare team AS SOON AS YOU EXPERIENCE THEM. Do not ignore any numbness, weakness, tingling, or pain you feel in your fingers, hands, arms, toes, feet, or legs. By reporting any and all symptoms as soon as possible, you enable your doctor to take prompt action to prevent what could become a debilitating and ongoing problem. **MT**

HONORING PROF. JOAN BLADÉ AND HIS WORK

The Award

In 1910, Dr. William Mayo set the standard for treatment of patients at Mayo Clinic with these words: "The needs of the patient are the only needs to be considered." In 2003, the IMF bestowed the first annual Lifetime Achievement Award to a physician whose work against multiple myeloma reflects the dedication and compassion inherent in Dr. Mayo's vow. The IMF chose to name this award for Dr. Robert Kyle, whose life and work give new meaning to Dr. Mayo's words.

In his more than 40 years at Mayo Clinic, Dr. Kyle has never wavered from his commitment to the needs of patients with myeloma. He has devoted his life's work to them. He has gained recognition the world over as a pioneer and respected leader in the advancement of research, clinical treatment, and education about myeloma.

When Brian Novis sought to learn more about his disease, he was looking for the finest doctor available to help him. When he heard about Dr. Kyle, Brian didn't know at the time that Dr. Kyle was considered to be the "grandfather" of myeloma treatment.

Later, when Brian Novis and Dr. Brian Durie decided to create an international foundation dedicated to helping others with myeloma, Dr. Kyle was the first person they contacted. Dr. Kyle agreed to collaborate with the two Brians, and became a founding member of the International Myeloma Foundation's Board of Directors and chairman of its Scientific Advisory Board, a position he still holds today.

Drs. Brian Durie and Robert Kyle

Dr. Kyle is a sought-after presenter at IMF clinical conferences and workshops, and is the most frequently requested speaker at IMF Patient & Family Seminars. Through IMF programs, Dr. Kyle has made himself accessible to thousands of myeloma patients and their families around the world. His guidance and encouragement are as important to the IMF today as when the IMF first began.

The IMF's Robert A. Kyle Lifetime Achievement Award was established to honor an individual whose lifetime body of work furthers the ultimate goal of finding a cure for myeloma. When Dr. Kyle was first approached about receiving the award, his response to Susie Novis was, "I'm not done yet." His humility, dedication, sense of humor, and caring and compassionate nature are among the many reasons for which the IMF named this award in his honor.

Dr. Kyle himself was the first recipient of the award in 2003. Subsequently, the award has been presented to Dr. Bart Barlogie (2004), Dr. Kenneth C. Anderson (2005), Dr. Brian G.M. Durie (2006), Prof. Heinz Ludwig (2007), Prof. Mario Boccadoro (2008), and Prof. Jean-Luc Harousseau (2009).

The Eighth Annual Robert A. Kyle Lifetime Achievement Award

The Recipient

Prof. Joan Bladé

Senior Consultant and Director of Myeloma Programs
Hospital Clínic de Barcelona – Barcelona, Spain

The IMF is proud to award its prestigious Robert A. Kyle Lifetime Achievement Award for 2010 to Professor Joan Bladé. Prof. Bladé graduated from the Medical School of the University of Barcelona. In 1981, he joined the staff at the Hematology Department of Hospital Clínic de Barcelona, where is now the Senior Consultant and Director of the Myeloma Programs. Prof. Bladé was co-founder of the PETHEMA Foundation, and co-founder of the Spanish Myeloma Group. He chaired the group that developed the European Group and Marrow Transplantation (EBMT) response criteria, known today as the Bladé Criteria. He has published over 200 papers on both myeloma and MGUS, and he is an active member of the International Myeloma Working Group (IMWG).

The Ceremony

Drs. Robert Kyle and Joan Bladé

The eighth annual Robert A. Kyle Lifetime Achievement Award ceremony took place on June 9 in Barcelona, Spain. The setting for the evening was Can Travi Nou, a Catalonian *masia* (typical farmhouse of the region) built in the early part of the 17th century. For 300 years, the farm was dedicated to agriculture and cattle ranching. At the beginning of the 1920s, the *masia* was transformed into an exquisite restaurant that still maintains a sense of Catalonian tradition and history.

It was in this scenic setting that more than 200 friends and colleagues gathered for the ceremony to honor Prof. Bladé and his lifelong dedication and commitment to improving the lives of myeloma patients while working tirelessly to further the ultimate goal of finding a cure for this disease. The rain that had plagued the city all day ended just in time for the arrival of the guests, which allowed the reception to be held in the beautiful gardens of the *masia*.

EIGHTH ANNUAL INTERNATIONAL MYELOMA FOUNDATION
ROBERT A. KYLE
LIFETIME ACHIEVEMENT AWARD

Masia Can Travi Nou - Barcelona, Spain

Maria del Carmen Creixenti, Maite Herrero, Drs. Robert Kyle and Joan Bladé

In attendance were Dr. Bladé's lovely wife Maite, their children Joan and Esther, his mother, his brothers and their wives, and other family members, as well as representatives of the IMF, several past Robert A. Kyle Lifetime Achievement Award honorees, Dr. Bladé's colleagues and staff from the Hospital Clínic de Barcelona, and 50 international myeloma clinicians and researchers.

Lisa Paik, David Girard, and Birgit Ludwig

Peter Radovich and Homa Yaganegi

Birgit and Dr. Heinz Ludwig, Maite Herrero, Dr. Jesús San Miguel and Dr. Laura Rosiñol

Drs. Bart Barlogie (back to camera), Brian Durie, and Michel Attal

Dr. Jesús San Miguel presided over the event as master of ceremonies. The evening's speakers included Susie Novis and Drs. Brian Durie, Robert Kyle, Heinz Ludwig, and Ciril Rozman. Prof. Bladé's colleagues spoke of his career, his dedication, and his meticulousness. His son, Joan Bladé Herrero, spoke of the example he sets for the family. Prof. Bladé gave the last speech of the evening, a heartfelt message to his father, and delivered it in Castilian Spanish, Catalonian, and English. It was a very intimate experience that all in attendance were permitted to share.

Dr. Mario Boccadoro, Tom Cavanaugh, and Dr. Michel Attal

Dr. Brian Durie and Susie Novis

A photo montage, presented with musical accompaniment and prepared by his friend and colleague Dr. Laura Rosiñol, documented the key events in Dr. Bladé's life. It was a humorous and insightful look at Dr. Bladé's childhood, his studies, his career, his hobbies, and his family. (Did you know that Dr. Bladé is also an internationally known and respected breeder of canaries?)

As the very special evening regretfully came to a close, everyone was in agreement that this *una nit molt catalana* (very Catalonian night) was an event to remember fondly for years to come.

Dan Navid, Susie Novis, and Dr. Meral Beksaç

The IMF would like to thank the sponsors for their support of this prestigious event

Presenting Sponsor
Celgene Corporation

Bronze Sponsors
Binding Site
Genentech
Onyx Pharmaceuticals
Medtronic

UPDATES FROM AROUND THE GLOBE

Breakthrough agreement signed with China

Daniel Navid (Senior Global Analyst, IMF) addressing Chinese dignitaries at the signing ceremony in Beijing

On September 9, the International Myeloma Foundation (IMF) signed a cooperative agreement with the Chinese Health Promotion Foundation (CHPF), an agency that operates under the Chinese Ministry of Health, to promote awareness of myeloma in China and to encourage measures to prevent and combat the disease. This groundbreaking agreement substantially expands the IMF's presence in Asia and will support the thousands of patients in China who have multiple myeloma. The agreement was signed at a ceremony in Beijing.

The signing of the cooperative agreement for myeloma awareness and prevention activities in China by Dr. Shuzhong Bai (Chairman of the Board, CHPF) and Daniel Navid

"Chinese health authorities clearly recognize the significance of myeloma in their country, and we are honored and gratified that they acknowledge the role the IMF can play in supporting patients, disseminating information and encouraging research," said Susie Novis, President and Co-Founder of the IMF.

On behalf of the CHPF, Dr. Zhao Yanling, Head of International Relations noted, "The mission of the CHPF is to bring together Chinese medical experts to raise the health standard of the Chinese people, and we can think of no better partner to work with us on behalf of myeloma patients than the IMF."

Initial goals of the agreement include:

- Developing a scientific advisory committee of Chinese myeloma experts;
- Compiling data about the incidence and costs of myeloma in China;
- Developing Chinese-language materials about myeloma for distribution in print and via the Internet.

Longer-range goals of this joint effort include establishing a Myeloma Patient Society in China and hosting a regional clinical conference on myeloma for healthcare experts in Asia.

Daniel Navid with Mr. Yingming Chang (Vice Chairman and Secretary General, CHPF) and Dr. Wenming Chen (member of the IMWG), and other dignitaries attending the signing ceremony

The agreement was signed by Dr. Shuzhong Bai, Chairman of the CHPF, and by Daniel Navid, Senior Global Analyst for the IMF. The ceremony was hosted by Dr. Yingming Chang, Secretary General of the CHPF. Also attending the ceremony were Dr. Xiaojun Huang, Chairman of the Chinese Hematology Association and Hemotology Society of the Chinese Medical Association, and Dr. Wenming Chen, a member of the International Myeloma Working Group (IMWG), an organization of international myeloma experts organized by the IMF.

IMF Asian Program meeting in Singapore

Participants of the IMF Asian Program meeting in Singapore

On July 16, Dr. Wee Joo Chng, member of the IMF's International Myeloma Working Group (IMWG), hosted an ad hoc meeting at the National University of Singapore Hospital to discuss the IMF Asian Program. Leading myeloma experts in Singapore, as well as the regional representatives of IMF partners Celgene and Johnson & Johnson, met with IMF's Senior Global Analyst, Daniel Navid, to consider priority requirements for IMF action in Asia. An IMF Asian program for 2011 through 2013 has subsequently been prepared and is presently under review by additional experts in the region. This program is designed to include regional studies and conferences, intensified work in Japan, the launch of the IMF-China program, and pilot projects for physician and patient support in Hong Kong, Korea, Singapore, and Thailand. **MT**

Editor's Note: For more information, please contact Daniel Navid at dnavid@myeloma.org or +41-21-825-5546

SPOTLIGHT ON ADVOCACY

By Christine Murphy

Cancer Research Receives Boost in House and Senate LHHS Appropriations Bills

The House Labor, Health and Human Services, and Education (LHHS) Appropriations Subcommittee marked up the Fiscal Year (FY) 2011 LHHS Appropriations bill on July 15, 2010. The LHHS Appropriations bill included funding for important myeloma programs at the National Institutes of Health (NIH), the National Cancer Institute (NCI), and the Centers for Disease Control and Prevention (CDC). In the House LHHS bill, the NIH received $32 billion (a $1 billion increase over FY 2010). This is the same amount included in the President's FY 2011 budget. The NCI was allocated $5.265 billion, $162 million more than FY 2010 and the same level in the President's budget.

On July 27, the Senate LHHS Appropriations Subcommittee included the same allocation for the NIH as the House bill and the President's Budget. The Senate allocation for the NCI was $5.257 million. This amount is $153 million above the FY 2010 funding level. For the Geraldine Ferraro Blood Cancer Program at the CDC, the Senate included $5 million for the program in FY 2011 (an increase of $300,000).

The IMF is working with Congress to ensure that these programs receive the highest possible funding allocation in FY 2011. For more information about these programs and IMF's FY 2011 appropriations activities, please visit the advocacy section of the IMF website at www.advocacy.myeloma.org.

Senate Passes Improving Access to Clinical Trials Act

On August 5, 2010 the US Senate passed S 1674, the Improving Access to Clinical Trials Act. Current rules regarding eligibility for Supplemental Security Income (SSI) prevent many people with rare diseases who receive SSI from participating in clinical trials. The inability of SSI beneficiaries to accept research compensation for participation in a clinical trial has been shown to be a significant deterrence to research participation. The Improving Access to Clinical Trials Act (S 1674/HR 2866) changes current SSI eligibility requirements so that research compensation (up to $2,000) for participation in a clinical drug study for a rare disease or condition is no longer considered income for determining SSI eligibility.

Action on this bill turns to the US House of Representatives. In order for this bill to become law, the House must take action before the 111th Congress adjourns later this year. To see if your Members of Congress support the Improving Access to Clinical Trials Act, please visit the advocacy section of the IMF website at www.advocacy.myeloma.org.

Resolution Introduced Recognizing September as Blood Cancer Awareness Month

Representatives Walther Jones (R-NC) and Betsy Markey (D-CO) introduced a resolution (HRes 1433) designating September 2010 as Blood Cancer Awareness Month. HRes 1433 highlights the impact that blood cancers have in the United States each year and encourages greater support for blood cancer research and education. For HRes 1433 to move forward, at least 100 members must commit their support to the resolution before it will be called up for a vote. At press time, this resolution has 59 cosponsors. To find out if your Representative supports Blood Cancer Awareness Month, please visit the advocacy section of the IMF website at www.advocacy.myeloma.org.

CONTINUES ON PAGE 16

The IMF Advocacy Voice

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

This Fall, The IMF is rolling out an even bigger and better advocacy training program and we want YOU to be a part of it. Learn when to act, what to say, who to contact, why it's important, and how to go about making a difference. Our team will provide you with the tools and preparation you need to help fight for issues that affect YOU and the myeloma community.

More details on our program coming soon, including:

- Program features • Course descriptions
- Dates and times • and more!

Take the first step and sign up *NOW* for the MYELOMA ACTION NETWORK to stay informed of critical issues affecting the myeloma community. Visit www.advocacy.myeloma.org.

Based on our "Cancer Patient Statement of Principles," the IMF calls on the US Congress and the White House to:

- **Ensure equality of access for all cancer patients;**
- **Reform and streamline policies and procedures for early approval of new cancer treatments;**
- **Support innovation to develop more effective cancer treatments; and**
- **Support research uncovering the causes of cancer.**

RICHARDS / SEXUAL DYSFUNCTION — continued from page 10

menopause in younger women. Vincristine and cisplatinum temporarily or permanently damage parts of the central nervous system leading to ED and ejaculation difficulties.

There is anecdotal evidence that sexual dysfunction is an occurrence with novel therapies being used in myeloma. Reports of ED and decreased libido in patients receiving bortezomib and lenalidomide are becoming a common experience with practitioners treating myeloma patients. Thalidomide has documented evidence of ED. The restricted use of both thalidomide and lenalidomide may have psychological effects due to the knowledge these drugs may cause birth defects.

In addition, myeloma patients may require a bone survey to determine if there is a current or pending fracture contributing to pain or causing risk during sexual activity.

What are the treatments of male sexual dysfunction?

Oral medications have been shown to improve ED, the most common male sexual problem. However, in patients currently receiving nitrate therapy, the use of of those medications is an absolute contraindication. Other ED interventions include intracavernous or transurethral injections, testosterone replacement, vacuum erection devices, surgical interventions, and/or psychotherapy. It is important to note that the use of intracavernous or transurethral injections is an absolute contraindictation in patients with myeloma and certain other conditions.

What are the treatments of female sexual dysfunction?

Studies have indicated that 30-50% of women have sexual problems resulting in distress and interpersonal difficulty. The most common female sexual disorder is decreased libido. Women have reported improved libido, increased energy and sense of well-being with testosterone replacement. However, there are potential risks and side effects with the use of testosterone and other androgen therapies. Such therapies are not appropriate for postmenopausal women who have a history of breast or uterine cancer or those who have cardiovascular or liver disease.

What about fertility preservation in myeloma?

Chemotherapy and radiation may lead to infertility in 30-75% of male patients. In women, the effects of chemotherapy and radiation may lead to premature menopause thereby leading to a loss of fertility. Currently, the American Society of Clinical Oncology (ASCO) recommends sperm cryopreservation for male patients and embryo cryopreservation for female patients. Other options may be offered at specialty centers. Patients interested in preserving their fertility should discuss this with their healthcare provider.

Any closing comments?

There is a need for improved communication between doctors, nurses, and patients around sexuality issues. Do not be concerned about asking questions or describing changes in your sexual function to your healthcare provider. A referral to a gynecologist or urologist, or clinical psychologist, certified sex therapist, or marriage and family therapist may be appropriate. Sexuality is an important part of overall well-being and open communication with your partner and with your healthcare provider is essential in treating the underlying cause of the problem. **MT**

ADVOCACY — continued from page 15

Congressional Schedule for Remainder of 2010

After the August recess, Congress will return September 13th for a brief pre-election session scheduled to end on October 8th. Congress will spend some of this time passing a Continuing Resolution (CR) to fund the federal government after the federal FY begins on October 1st. Congress will reconvene after the midterm elections for a lame-duck session beginning on November 15th. The session is expected to last one week. After a break for the Thanksgiving holiday, Congress will reconvene again on November 29th. This post-election work period will deal with potential recommendations from the deficit reduction commission set up by President Obama as this commission may deliver a package of budget proposals to Congress in December. Additionally, the FY 2011 Appropriations will also be considered during the lame duck session. A target date for adjournment of the lame duck session has not been set.

Are You a Member of the Myeloma Action Network?

Would you like to stay informed about IMF's advocacy activities and learn more about health care reform and other important advocacy issues that affect the myeloma community? Please visit the advocacy section of the IMF website at www.advocacy.myeloma.org and join the Myeloma Action Network to automatically receive e-mail advocacy alerts from the IMF. **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 – *Advocacy Assistant*
Phone: 410-252-3457
Email: mbuzby@myeloma.org

PEOPLE HELPING PEOPLE

You are never alone in your battle against myeloma

By Jim Barth, Founding Member, Tampa / St. Petersburg Multiple Myeloma Education Group

2010 IMF Annual Support Group Leaders' Summit

This year's IMF Support Group Leaders' Summit commenced at 1 p.m. on July 23rd at the Four Seasons Resort & Club Dallas at Las Colinas, in Irving, TX. In my brief recap, I will attempt to share with you some sense of the events and conversations that took place during the Summit.

The Friday sessions started with a discussion led by Dr. Brian G.M. Durie. He talked about the aspects of myeloma that have become quite common now that patients are living much longer with the disease. He stressed that, beyond having a cancer doctor, it is important for patients to work closely with a general practitioner in order to keep healthy outside of myeloma.

Support Group Leaders and IMF staff at the 2010 SGLS

In a separate session on Friday, Dr. Durie presented an update on the work of the IMF's International Myeloma Working Group (IMWG), which consists of 134 leading myeloma researchers from around the world who collaborate on a broad range of myeloma research projects. Dr. Durie shared information about several exciting consensus projects that IMWG members are currently working on, as well as the work that took place at the recent IMWG gathering in Spain. For more information about the IMWG meeting, please read the story on page 5 of this issue.

The presentation about clinical trials and their outcomes, as well as the related topic of maintenance therapy, were of much interest to the support group leaders at the IMF Summit. Other talking points included the concept of taking a "drug holiday" to eliminate some side effects, the importance of establishing if there are other health issues in the picture besides myeloma (co-morbidities), balancing the tolerability and efficacy of anti-myeloma therapies, and clarifying patient and physician priorities when treating myeloma.

Next, we listened to a presentation from Dr. Richard Kadota of Genzyme, the company working with plerixafor (Mozobil®). Approved at the end of 2008, plerixafor is a relatively new drug. It is used in combination with granulocyte-colony stimulating factor (G-CSF) to mobilize hematopoietic stem cells to the peripheral blood for collection and subsequent use in an autologous stem cell transplant (ASCT) for myeloma. Plerixafor seems to be more effective when more stem cells needed, and it substantially reduces the time needed for apheresis, but it is important to ask your doctor whether you are collecting for one or two procedures. Another issue articulated during the discussion was that the use of either thalidomide (Thalomid®) or lenalidomide (REVLIMID®) reduces a patient's ability to produce stem cells. A guide for patients is available at www.mozobil.com.

After a break, during which I had a chance to talk with Dr. Durie, the Summit program resumed with an overview by Alan Kumamoto of Kumamoto Associates, who served as our meeting facilitator for yet another year. We talked about the tools and information we wished to take back to our local support groups and the successes, opportunities, problems, and challenges that we encounter in the course of working with our groups.

Next, Peter Radovich of Onyx Pharmaceuticals talked about carfilzomib, a new proteasome inhibitor in development for myeloma. (For more information, please read the interview with Dr. David Siegel on page 8 of this issue of *Myeloma Today*.) Phase III clinical trials are enrolling patients, but there is hope that this drug might get approval based on results of the Phase II trials.

To round out the day, the attendees were surveyed to determine what additional services can be offered to the IMF that would be of benefit to support groups. A lot of thought went into this, and the resulting consensus has already led to new web portal services that promise to be very helpful.

On Saturday, IMF's Arin Assero led the discussion of myeloma advocacy efforts, with Greg Chesmore of Celgene Pharmaceuticals making key points about state legislators and effective advocacy for oral cancer drug parity legislation. Of the myeloma drugs currently in development, 25-30% are oral medications and, with many health insurance plans stuck in Dark Ages, patients are subjected to higher out-of-pocket costs for oral meds. The advocacy session addressed how to build relationships with our representatives and how to lobby effectively for the causes that affect the myeloma community. I would encourage everyone to visit http://www.advocacy.myeloma.org and register on the website, and talk to Arin if you need help or guidance.

The Summit agenda continued, including topics such as group management and sustainability, annual planning, fundraising, meeting agendas, burnout, involving members in group leadership and activities, coping with loss of members, reaching new patients, and promoting awareness of myeloma and public awareness of the group's existence.

The next presentation, by Kathy Gram, RN, of Millennium - The Takeda Oncology Company, made us aware of the assistance and resources available from the makers of bortezomib (VELCADE®). This session rounded out a very busy morning and was followed by a break for lunch. The afternoon was very productive, with the attendees dividing into smaller breakout groups for in-depth discussions of the challenges and opportunities we had articulated during the general assembly.

The IMF Support Group Leaders' Summit concluded on Sunday, with the participants looking forward to sharing the many great ideas and plans with their individual groups. **MT**

THE BRIAN D. NOVIS LEGACY SOCIETY

By Heather Cooper Ortner

Everybody knows the Boy Scouts' motto: "Always be prepared." This message holds true in many aspects of life beyond camping in the wilderness and learning to tie knots. Being prepared with end-of-life plans ensures that your wishes for your family and your estate are met swiftly and are as free from complication as possible.

Planned giving also opens up an opportunity to support the International Myeloma Foundation (IMF) in a meaningful and fulfilling way through the Brian D. Novis Legacy Society. Planned or deferred gifts to the IMF are symbolic of the future we are building for myeloma patients. Because such gifts will be realized at a later date, the IMF can make future plans to expand and improve our life-saving programs.

Making a planned gift can be an intensely personal experience as one considers their own legacy. Planned gifts can be arranged through a variety of "vehicles," many of which might entitle you to tax benefits. (Please consult your tax advisor when considering making this type of gift.) The most popular planned gift vehicles include:

Bequests

One of the easiest ways to make a gift to the International Myeloma Foundation is by leaving the IMF a bequest in your Will. You can (1) give a specific amount of money to the IMF; (2) give a specific item of property to the IMF; (3) give a specified percentage of your total estate to the IMF; or (4) give a specified share of the "residue" of your estate to the IMF. (The residue of your estate is that which is left over after all specific charitable or non-charitable gifts have been made to your heirs.)

Life Insurance

Initially, when your life insurance was purchased, you had a need for the benefits. However, you may not need the coverage today. To contribute your life insurance policy, simply name the IMF as its owner and beneficiary. You can also name the IMF as beneficiary only, or partial beneficiary.

Living Trusts

By creating a living trust, you can provide for yourself and your loved ones, both before and after your death. You can arrange a contribution through a living trust by naming the IMF as a beneficiary.

Retirement Plans

Tax-favored retirement plans, such as an IRA or 401(k), have become an increasingly popular way to save money for retirement. If you choose to name the IMF as a beneficiary of your retirement plan, you can avoid a possible double taxation on retirement plan assets left to your heirs.

Real Estate

A charitable contribution of real estate – a personal residence, farm, vacation home, commercial real estate, or vacant land – is a gift with income and capital gains tax advantages. You can contribute a remainder interest in your property to the IMF, ensuring that the IMF will take possession of the property upon your passing, while maintaining lifetime use of your property.

Securities

Making a charitable contribution of appreciated securities, such as stocks or bonds, simultaneously maximizes your deduction, avoids capital gains taxes, and makes a significant gift to the IMF. Simply tell your broker to transfer the desired shares to the IMF, and inform the IMF of your security transfer.

Other options

Giving options also include charitable gift annuities, charitable lead trusts, and charitable remainder trusts.

Every donor who makes arrangements for a planned gift is recognized with membership in the Brian D. Novis Legacy Society, which is named in honor of the IMF's co-founder. By making a gift to the IMF in your Will, you will make a lasting contribution to myeloma patients and their loved ones. **MT**

Editor's Note: We recommend that you speak with your personal legal, financial, and/or tax advisors when considering making any decisions about your planned gifts. If you would like to discuss your personal situation or to advise the IMF of plans you have already made, please contact Heather Cooper Ortner at 800-452-CURE (2873) or hortner@myeloma.org.

Proof that Every Dollar Counts

August 2010 marked the one-year anniversary of the IMF's recurring giving program, the Hope Society. Since its launch, the Hope Society has attracted 102 members who have made a commitment to monthly or quarterly contributions that help to fund many of the programs and services provided by the IMF on a daily basis. Currently, Hope Society donors range from those who give $5 per month to those who give $250 four times a year. Collectively, Hope Society donors have given more than $10,000 over the past year – proving that even a little bit can go a long way!

Becoming a Hope Society member is simple. Donors complete a form that notifies the IMF how much they wish to contribute on a monthly or quarterly basis, as well as their preferred method of payment. The IMF takes care of the rest.

For 20 years, the IMF has been the center of education and support for myeloma patients and family members who rely on our services. In a similar way, the IMF depends on its donors to help continue and improve upon those services. Members of the Hope Society understand this, and together ensure that "Until there is a cure… there is the IMF." **MT**

Editor's Note: To join the Hope Society, call the IMF Development department at 800-452-CURE (2873) or email Randi Lovett at rlovett@myeloma.org.

IMF MEMBERS RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia

In 2010, the IMF is proud to mark its 20-year anniversary of service to the myeloma community. Our membership is a network of people like you, from across the country and around the globe. Many IMF members 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. 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's Fundraising program 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 with such activities.

FUNdraising is fun and easy to do, and brings with it the satisfaction of knowing that YOU have made a difference in many lives. We are grateful to all IMFers who contribute their time, imagination, and hard work to benefit the myeloma community. Our FUNdraising program provides you with the tools, assistance, and expertise to make your event a success. Choose an established event model or create your own – no idea is too large or too small. 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). I am here to chat with you about any ideas you might have. Be part of making miracles happen!

Here is just a sampling of some past and upcoming events…

Carolyn Czerkies Charity Golf Outing

Since 2008, brothers Craig, David, and Scott Czerkies have organized fundraising events as a tribute to their mother to benefit the efforts of the IMF. Carolyn Czerkies passed away in 2000 from complications brought on by multiple myeloma. The goal of the Czerkies brothers, their father Ed, and the rest of the Czerkies family was to reach the $40,000 donation level to fund the IMF's Junior Research Grant to be awarded in the name of Carolyn Czerkies.

Ed, Scott, Dave, and Craig Czerkies

The Czerkies Family organized their 2010 fundraising event – the third annual Carolyn Czerkies Charity Golf Outing – to take place on Jun 5 at the Whitetail Ridge Golf Club in Yorkville, IL. In addition to the funds raised over the past two years with the generous support of participants, sponsors, and volunteers, the outcome from the 2010 golf outing surpassed the Czerkies' original aim of raising a total of $40,000 to fund a myeloma research grant. "It was always a goal of ours to help advance myeloma research until a cure for this disease is in sight," says Craig Czerkies. "Needless to say, it is incredible news that our family will be funding a myeloma research project in honor of our mother!" The family looks forward to learning about the chosen research project and connecting with the grant recipient. The research grant will be awarded at a ceremony during the annual meeting and exposition of the American Society of Hematology (ASH) in December 2010 in Orlando, FL.

The Czerkies Family: (back row) Charlie, Ed, Lanie, Scott, Dave and (front row) Miles, Laura, Louie, Sandra, Cole, Craig, and Bonny

On the Fritz

On August 22, I was delighted to combine business with pleasure when I attended "On The Fritz," a one-man show by Fritz Coleman at the El Portal Theatre in North Hollywood, CA. Fritz is a friend and California's broadcasting icon, appearing on both KNBC-TV in Los Angeles and KNSD-TV in San Diego. He has been named "Best Weathercaster" in nearly every major paper in Southern California, and is the honorary Mayor of Toluca Lake.

Fritz devotes much of his free time to charitable activities and frequently organizes evenings of entertainment for local organizations. As a stand-up comic, he has performed at clubs throughout Southern California, and has written, produced, and starred in several one-man stage plays. Fritz has won a number of awards and honors for his dedication to community service, and has received four Los Angeles area Emmy Awards for his work on the NBC4 comedy specials and series.

As a special event for members of the IMF, Fritz performed his ever-evolving one-man show, offering a witty inside look at LA weather, life-style, and television news. The audience enjoyed his ascerbic comedy, followed by Fritz's candid answers to their questions about the news business, weather, and life under the California sun in the public eye.

"Through my friendship with Suzanne, I became educated about multiple myeloma, a disease I had never heard of before," says Fritz. "Myeloma is a heartbreaking illness and I wanted to do something for those who are coping with it. I don't know how much money I can raise to benefit the IMF, but I can certainly help raise awareness. So we promoted the IMF on

CONTINUES ON PAGE 20

MEMBER EVENTS — continued from page 19

the show's website and IMF staffers handed out literature to theatre-goers at the venue. Since I didn't want the amount of my donation to be predicated on ticket sales in a difficult economy, I decided to make a personal contribution to the IMF on behalf of my family to help support the good works of the IMF." Thank you Fritz for your generous donation to the IMF and for your help with informing and educating the general public about myeloma!

Cabaret for a Cure

Courtney Charatsaris' uncle, Richard Venezia, was diagnosed with multiple myeloma three years ago. "We are very close. He is like an older brother to me, a true role model," says Courtney. "When he was diagnosed, everyone in the family felt devastated. Since I did not qualify as a donor for Richard's stem cell transplant, I wanted to find some other way to help my uncle." Courtney is a theatre major at Montclair State University and a competitor in the Miss New Jersey 2010 pageant, a scholarship organization within the Miss America system. (In June, Courtney was awarded the Miss Congeniality prize and plans to participate in the pageant again in 2011.) "Naturally, I chose myeloma as my platform issue. I wanted to raise funds for myeloma research and for other programs that support myeloma patients and caregivers who are going through the struggles that my own family is experiencing."

Jennifer Wilson, Chris Latini, Kayt Supple, Courtney Charatsaris, Scott Baird, Kaitlin Davis, Natalie Ragazzo, Alaina Dill, Kayla James, and Lindsay Stewart

In the midst of school commitments, theatre work, and a part-time job, Courtney managed to put together her very first fundraising event by producing a cabaret show to benefit the IMF. The show took place on April 18, 2010 at Hamilton Manor in Hamilton, NJ. "We charged $35 for dinner and the show. In addition, we held a drawing for prizes that featured Yankee tickets and various sports memorabilia, as well as gift baskets from local vendors. We received tremendous support from the community, especially from the Spiral Binding Company, our main sponsor. Our thanks also go to The Rech Center for Performing Arts, The New Devils, The New Jersey Nets, The Hamilton Manor, The Miss New Jersey Education Foundation, Red Carpet Pageant and Prom, Pro-Video, MAE Celebrity Services, and Victoria's TV and Appliances. "Producing the cabaret show was a challenge, so it was very gratifying to hear audience members comment on how much fun they had and that they were looking forward to coming to next year's show. My goal now is to make Cabaret for a Cure an annual event for the IMF!"

Performers from The Rech Center for Performing Arts dance studio in Hamilton, NJ

Timberwolves 5K Run/Walk for Research

Julianne Basques first heard the words "multiple myeloma" when her mother, Clara Basques, was diagnosed with the disease in 1988. Although her mother succumbed to the disease in 1996, Julianne's desire to show her support for other patients and caregivers who are coping with myeloma, as well as her understanding of the need to raise myeloma awareness among the general public, led her to initiate the Timberwolves 5K Run/Walk for Research. The event took place on May 22 near Yosemite Park in Groveland, CA. Many members of the Basques Family and their supporters were in attendance. "Julianne did an incredible job of organizing and carrying out this very special event," says her father. "I was very touched by her speech to the run/walk participants as she described how myeloma has affected our family in general and the impact it had on her life in particular. Julianne spent untold hours putting together this 5K for a great cause. I am very proud of her." The IMF would like to second Tony Basques' sentiment and thank Julianne for her time and effort. Julianne's first ever event raised almost $3000 to support IMF programs and services, and we hope that this success will encourage her to do it again in 2011. **MT**

UPCOMING MEMBER EVENTS

October 20, 2010 **Coach Rob's Charity Golf and Benefit Bash**
Rock Springs Ridge Golf Club – Apopka, FL
Contact: Rob Bradford at rbradfdird@crothall.com

October 20, 2010 **A Celebration of Life at Kasbah** Phoenix, AZ
Contact: Allan Weinstein or visit celebrationoflife.myeloma.org

October 30, 2010 **An Autumn Tea** Temecula, CA
Contact: Debra Schuitt at 951-506-0610

November 6, 2010 **Misbehave for Myeloma**
Harry Caray's Italian Steakhouse – Wrigleyville, IL
Contact: Alexandra Zousmer at aezous@gmail.com

November 6, 2010 **Texas Hold 'Em Benefit Bash** San Jose, CA
Contact: Jack Aiello at jackaiello@comcast.net

INTRODUCING OUR NEWEST STAFF MEMBERS

Betty Arevalo

Database & Inventory Control

Betty Arevalo is a Licensed Vocational Nurse (LVN). For three years prior to joining the IMF, she provided patient care at CHA-Presbyterian Medical Center and at a convalescent home for disabled and sub-acute patients in Los Angeles, CA. Betty is working towards her Registered Nursing (RN) degree while continuing her commitment to the IMF. At the IMF, Betty helps maintain the computer database and stock inventory, and prepares materials for all IMF meetings, seminars, and conferences. In addition, she answers Spanish-language IMF Hotline calls, assists Spanish-speaking participants at IMF Patient & Family Seminars, and coordinates Spanish myeloma support group meetings. To contact Betty, please call the IMF or email marevalo@myeloma.org.

Alci Avelar

Inventory Control Associate

Alci Avelar moved to the United States from El Salvador at age 11. In college, he studied drafting and design, but has spent the last six years working in the automobile industry, most recently as a nationwide inventory coordinator in the corporate offices of a major car dealership. At the IMF, Alci assembles and mails out information about myeloma disease and treatment options, as well as IMF merchandise, in response to requests that arrive at the IMF via phone and web. Alci also works with IMF management and staff with their inventory and shipping needs. In addition, being fluent in Spanish, he has become involved with IMF outreach efforts to serve the Spanish-speaking myeloma community. To contact Alci, please call the IMF or email aavelar@myeloma.org.

Phil Lange

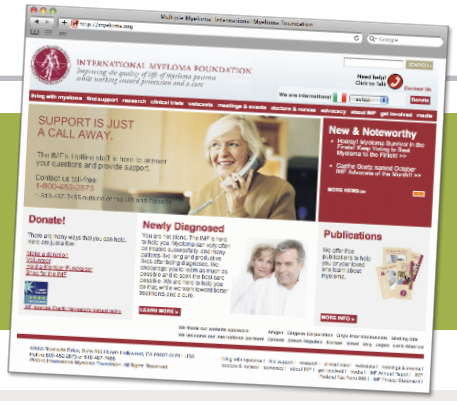
Accounting

Philip Lange brings over 20 years of accounting experience to IMF. He graduated from Loyola Marymont University in 1979. Phil has extensive accounting experience, working for a wide variety of companies in entertainment, commercial real estate development, banking, manufacturing, publishing, non-profit, and healthcare. Phil is excited about working with the incredible team at IMF. Phil and Steve, his life partner of 18 years, were legally married in California on July 24, 2008. This year, they rescued a pair of American Rat Terriers named Jocko and Oreo. To contact Phil, please call the IMF or email plange@myeloma.org.

Do you have a question?

Perhaps you would like to order a publication? Are you thinking about registering for a Patient and Family Seminar or Regional Community Workshop? Would you like to download the Myeloma Manager™? All this and *MORE* is possible on the IMF website.

www.myeloma.org.



Gems for Myeloma

Handcrafted by Marya Kazakova, IMF's Publications Editor, this beautiful jewelry is available for sale to raise funds for the IMF.

The triple toggle design features interlocked 14K gold-filled loops with your choice of cultured freshwater pearls or faceted round gemstone beads. The toggle measures approximately 1.75" long. The earrings dangle from 14K gold-filled French wires (for pierced ears only), and the pendant hangs on a 14K gold-filled 16" ball chain.

Choose white cultured freshwater pearls, blue Amazonite, purple Amethyst, green Aventurine, honey Carnelian, or Garnet in the IMF's signature burgundy color!

To order, call the IMF or visit www.myeloma.org/store/product62.html

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

Don't Miss
Myeloma Patients at the Initial Presentation

Earlier detection saves you and the patient

Advanced disease stage due to late diagnosis constitutes one of the greatest barriers to myeloma patient survival.[1,2]

The International Myeloma Working Group recommends the use of serum free light chains (**Freelite®**) in the initial screening algorithm for suspected multiple myeloma and related disorders.[3]

You can't afford to miss — Use Freelite.

1. Greipp *et al. Journal of Oncology* 2005; 23:3412-3420
2. Kyrtsonis *et al. Seminars in Hematology* 2009; 46:110-117
3. Dispenzieri *et al. Leukemia* 2009; 23:215-224

Binding Site

CHANGING THE WAY CANCER IS TREATED™*

Dedication
to the development of new therapies for cancer patients and their families

Knowledge
and expertise to be on the forefront of novel, innovative medical advances

Passion
for everything we do at Onyx Pharmaceuticals

**Changing the Way Cancer Is Treated is a trademark of Onyx Pharmaceuticals, Inc.*

Onyx Pharmaceuticals

2100 Powell Street, Emeryville, CA 94608 USA

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.

2010 / 2011 IMF Calendar of Events

2010

Oct 15-16	MMHÖ/IMF Patient & Family Seminar – Vienna, AUSTRIA
Oct 16	IMF Regional Community Workshop – Raleigh/Durham, NC
Oct 18	IMF Patient & Family Seminar – Bologna, ITALY
Oct 21-23	Southwest Oncology Group (SWOG) meeting – Chicago, IL
Oct 23	IMF Regional Community Workshop – Overland Park, KS
Oct 23	Myeloma Canada Patient, Family, & Healthcare Professionals Conference – Richmond, BC, CANADA
Nov 5-7	Eastern Cooperative Oncology Group (ECOG) meeting – Ft. Lauderdale, FL
Nov 13	4th Annual Comedy Celebration – Los Angeles, CA
Dec 4-6	American Society of Hematology (ASH) – Orlando, FL
Dec 16	IMF Regional Community Workshop – Stuttgart, GERMANY
Dec 18	IMF Patient and Family Seminar – Würzberg, GERMANY
Dec 21	IMF Regional Community Workshop (Physicians) – Münster, GERMANY

2011

Feb 25-26	IMF Patient & Family Seminar – Boca Raton, FL
March 11-12	IMF Patient & Family Seminar – San Francisco, CA
Aug 26-27	IMF Patient & Family Seminar – Philadelphia, PA

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.

Thank you for your continued support of the IMF.