MYELOMA TODAY

FALL 2011
VOLUME 8 NUMBER 9

A Publication of the International Myeloma Foundation

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

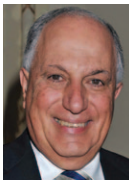
Scientific & Clinical News

Dr. Brian G.M. Durie (Chairman, IMF Board of Directors; Cedars-Sinai Comprehensive Cancer Center, Los Angeles, CA) discussed the 2011 annual IMF International Myeloma Working Group (IMWG) Summit, which took place on June 7–9 in London, United Kingdom. Many important current issues were debated and recommendations were made for consensus or guideline publications, as well as research projects and clinical trials. Dr. Durie summarizes the work of the six Sumit work/discussion groups. ***PAGE 5***

Dr. Brian G.M. Durie addresses the role of protein electrophoresis testing in myeloma. He explains monoclonal proteins (M-proteins) and the significance of these immunoglobulins in myeloma, and how protein electrophoresis testing detects and measures the amount of M-protein in the blood or urine. Dr. Durie also talks about immunofixation, a test that determines the type of M-protein. In conjunction with other data, both tests are used to establish a diagnosis, and monitor the evolution of the disease and its response to treatment. ***PAGE 6***

Dr. Sergio A. Giralt (Memorial Sloan-Kettering Cancer Center, New York, NY), whose practice is devoted to transplantation, shares the history of transplants in myeloma and explains the role of Mozobil® (plerixafor), a novel stem cell mobilization agent. While autologous stem cell transplant (ASCT) remains the treatment associated with the highest CR rate in myeloma, Dr. Giralt recommends that all transplant-eligible newly diagnosed patients discuss stem cell collection with their doctors, even if ASCT is put off until consideration at a later time. ***PAGE 7***

Special Event



Prof. Douglas E. Joshua, this year's recipient of the Robert A. Kyle Lifetime Achievement Award, was honored for 40 years of work in the field of myeloma that has furthered advances in basic and clinical research, and treatment and care of patients. Prof. Joshua is Head of Clinical and Laboratory Hematology at Sydney Cancer Centre, Head of Sydney South Western Area Health Service (SSWAHS), the Alan Ng Professor in Medicine at University of Sydney, and the Director of the Institute of Hematology, Royal Prince Alfred Hospital in Sydney. ***PAGE 11***

LOOKING FOR A LOCAL MYELOMA SUPPORT GROUP?

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

Supportive Care

IMF Hotline Coordinators answer a question about whether calcium supplementation in myeloma patients might help with bone health. Calcium is not only essential for bone formation and bone health, but is also needed for the heart, muscles, and nerves to function properly and for the blood to clot normally. But, in myeloma, there are no simple answers to even the most straightforward questions. Even for the segment of the healthy population that has traditionally been urged to take calcium supplements, there are risks of too much calcium intake. ***PAGE 9***

The IMF's Nurse Leadership Board (NLB) Survivorship Care Plan, which examines five specific aspects of long-term care, has been published by the Clinical Journal of Oncology Nursing (CJON). In this issue of Myeloma Today, we offer a brief summary of NLB recommendations regarding the routine health maintenance in patients living with myeloma. Patients with myeloma are at risk for the illnesses experienced by the general population, as well as at additional risk related to both the disease and its treatment. ***PAGE 13***

Profiles in the News

Harold Dozier was diagnosed with myeloma more than 25 years ago. Since 1986, when the average life expectancy of a myeloma patient was only two to three years, he has experienced numerous treatment protocols and various side effects. In that time, Harold has dealt with health issues besides myeloma, including several surgeries and other setbacks. But there has been much to learn from these experiences, and he is happy to share his lessons with readers of *Myeloma Today*. His cancer diagnosis is only one part of a much larger story. ***PAGE 19***

Also in this issue...

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

International Myeloma Foundation

Founder
Brian D. Novis

President
Susie Novis

Board of Directors
Chairman Dr. Brian G.M. Durie

Loraine Boyle
Mark Di Cicilia
Donna Feig
Michael S. Katz
Benson Klein
Dr. Robert A. Kyle
Dr. Edith Mitchell
Charles Newman
Susie Novis
John O'Dwyer
Dr. S. Vincent Rajkumar
Matthew Robinson
E. Michael D. Scott
Igor Sill
Allan Weinstein
Amy Weiss

Scientific Advisory Board
Chairman Robert A. Kyle, USA

Scientific Advisors

Raymond Alexanian, USA
Kenneth C. Anderson, USA
Michel Attal, France
Hervé Avet-Loiseau, France
Dalsu Baris, USA
Bart Barlogie, USA
Régis Bataille, France
Meral Beksaç, Turkey
William Bensinger, USA
Leif Bergsagel, USA
Joan Bladé, Spain
Mario Boccadoro, Italy
Michele Cavo, Italy
J. Anthony Child, United Kingdom
Raymond L. Comenzo, USA
John Crowley, USA
Franco Dammacco, Italy
Faith Davies, United Kingdom
Meletios A. Dimopoulos, Greece
Johannes Drach, Austria
Brian G.M. Durie, USA
Hermann Einsele, Germany
Thierry Facon, France
Dorotea Fantl, Argentina
Jean-Paul Fermand, France
Rafael Fonseca, USA
Gösta Gahrton, Sweden
Morie A. Gertz, USA
John Gibson, Australia
Hartmut Goldschmidt, Germany
Roman Hájek, Czech Republic
Joy Ho, Australia
Vania Hungria, Brazil
Sundar Jagannath, USA
Douglas Joshua, Australia
Michio M. Kawano, Japan
C. Ola Landgren, USA
Henk M. Lokhorst, The Netherlands
Sagar Lonial, USA
Heinz Ludwig, Austria
Jayesh Mehta, USA
Håkan Mellstedt, Sweden
GiamPaolo Merlini, Italy
Gareth Morgan, United Kingdom
Nikhil Munshi, USA
Amara Nouel, Venezuela
Antonio Palumbo, Italy
Linda Pilarski, Canada
Raymond Powles, United Kingdom
S. Vincent Rajkumar, USA
Donna Reece, Canada
Paul Richardson, USA
Angelina Rodríguez Morales, Venezuela
David Roodman, USA
Jesús San Miguel, Spain
Orhan Sezer, Germany
Kazayuki Shimizu, Japan
Chaim Shustik, Canada
David Siegel, USA
Seema Singhal, USA
Alan Solomon, USA
Pieter Sonneveld, The Netherlands
Andrew Spencer, Australia
A. Keith Stewart, USA
Guido J. Tricot, USA
Benjamin Van Camp, Belgium
Brian Van Ness, USA
David Vesole, USA
Jan Westin, Sweden

IMF Staff

Executive Director
David Girard *(dgirard@myeloma.org)*

Chief Financial Officer
Jennifer Scarne
(jscarne@myeloma.org)

Senior Global Analyst
Dan Navid
(dnavid@myeloma.org)

Senior Vice President, Strategic Planning
Diane Moran
(dmoran@myeloma.org)

Vice President, Development
Heather Cooper Ortner
(hortner@myeloma.org)

Vice President, Clinical Education & Research Initiatives
Lisa Paik
(lpaik@myeloma.org)

Database & Inventory Control
Betty Arevalo
(marevalo@myeloma.org)

Director of Advocacy
Arin Assero
(aassero@myeloma.org)

Director of Member Events
Suzanne Battaglia
(sbattaglia@myeloma.org)

Hotline Coordinator
Debbie Birns
(dbirns@myeloma.org)

Regional Director, Support Groups
Joanie Borbely
(jborbely@myeloma.org)

European Programs
Gregor Brozeit
(greg.brozeit@sbcglobal.net)

Grassroots Liaison
Meghan Buzby
(mbuzby@myeloma.org)

Regional Director, Support Groups
Regional Community Workshops
Kelly Cox
(kcox@myeloma.org)

Hotline Coordinator
Paul Hewitt
(phewitt@myeloma.org)

Meeting & Event Services
Spencer Howard
(SHoward@SignatureEventsLA.com)

Publications Editor
Marya Kazakova
(mkazakova@myeloma.org)

Hotline Coordinator
Missy Klepetar
(mklepetar@myeloma.org)

Accountant
Phil Lange
(plange@myeloma.org)

Regional Director, Support Groups
Andrew Lebkuecher
(alebkuecher@myeloma.org)

Specialty Member Services Coordinator
Kemo Lee
(klee@myeloma.org)

Director of Annual Giving and Social Media
Randi Lovett
(rlovett@myeloma.org)

Assistant to Development & Medical Affairs Depts
Danielle Loi
(dloi@myeloma.org)

Publication Design
Jim Needham
(jneedham@myeloma.org)

Data Specialist, Office Manager
Selma Plascencia
(splascencia@myeloma.org)

Webmaster
Abbie Rich
(arich@myeloma.org)

Major Gifts Officer
James Ross
(jross@myeloma.org)

IT Systems Admin
Thomas Shin
(tshin@myeloma.org)

Regional Director, Support Groups
Robin Tuohy
(tuohy@snet.net)

Hotline Coordinator
Judy Webb
(jwebb@myeloma.org)

A Message from the President

Dear Reader,

In 2006, at a time of great personal loss, Loraine Boyle had the strength and the vision to create the *Peter Boyle Memorial Fund* to support vital myeloma research projects and programs. When she and I first spoke about organizing an evening to honor the memory of her husband, we both knew that any celebration of Peter could not be just another boring sitdown dinner. It had to be an event that Peter would have loved to have taken part in – filled with family, friends, colleagues, music, and laughter. In 2007, the IMF's First Annual *Comedy Celebration*, benefiting the *Peter Boyle Memorial Fund*, was a spectacular star-studded show that rocked the historic Wilshire Ebell Theatre with laughter while raising much-needed funds for myeloma research.

Loraine Boyle flanked by Dr. Brian GM Durie and Susie Novis

In the first four years, the *Comedy Celebration* has raised more than $2,500,000! If not for this event, several key projects would not have received funding to initiate or continue important work. We are proud of all that we've accomplished and of everyone who has contributed to the cause. Over the years, in addition to our returning host Ray Romano, many talented performers have taken the stage at the *Comedy Celebration*: (in alphabetical order) Jason Alexander, Dana Carvey, Susie Essman, Jeff Garlin, Brad Garrett, Patricia Heaton, Kevin James, Jimmy Kimmel, Robert Klein, Richard Lewis, Doris Roberts, Bob Saget, Martin Short, Fred Willard, and musical performers Tenacious D (Jack Black & Kyle Gass) and Dan Aykroyd & Jim Belushi (as The Blues Brothers with The Sacred Hearts).

This year's 5th Annual *Comedy Celebration* promises to be another stellar evening, and I invite you to join us at the Wilshire Ebell Theatre on November 5. Where else will you be able to walk the red carpet in front of paparazzi photographers, bid on extraordinary auction items, watch a hilarious comedy show, then enjoy a celebrity-studded after-show champagne reception? If you cannot attend in person, please consider supporting the event and the IMF in spirit through sponsorship, participation in the Tribute Journal, or donation. We need your assistance to continue moving towards a cure for this devastating disease. Join us in making the dream of a cure a reality. Please contact Heather Cooper Ortner with all your Gala inquiries at hortner@myeloma.org or 800-452-CURE (2873).

Sincerely,

Susie Novis

Susie Novis, President

Hosted by

Ray Romano

Featuring

Tom Arnold
Darrell Hammond
Dom Irrera
Colin Quinn
Doris Roberts
Garry Shandling
Fred Willard

All performers subject to availability.
Additional performers to be announced.

Visit us at comedy.myeloma.org or
follow us at facebook.com/myeloma
or @IMFComedy for program updates.

INTERNATIONAL MYELOMA FOUNDATION

5th Annual Comedy Celebration

benefiting the Peter Boyle Memorial Fund

Saturday, November 5, 2011

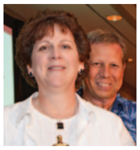
The Wilshire Ebell Theatre & Club in Los Angeles, California

Buy tickets today at comedy.myeloma.org *or by calling* (800) 452-2873

Presented by
Celgene

This free issue of *Myeloma Today*© (Volume 8, Number 9) is dated September 15, 2011. *Myeloma Today*© is a quarterly-published (Spring, Summer, Fall, and Winter) publication of the International Myeloma Foundation, located at 12650 Riverside Drive, Suite 206, North Hollywood, CA 91607 USA.

Letters to the IMF



Wow. THIS is what sets the IMF so far above every other myeloma organization. Nobody can hold a candle to you guys!!! I am impressed and thrilled with the IMF Hotline. Thank you so much, Debbie, for the amount of time you spent researching an answer. I will not only share the information tonight at our support group meeting, but I also plan to share how much above and beyond you went to get the answer! Thanks again for the answer, for getting back to me so quickly, and mostly, for your dedication to myeloma patients and families. You are awesome!

Sue Enright *(shown with Bob Enright)*

Thank you so much for giving the wonderful Dr. Ola Landgren and his work the attention it deserves in the Summer issue of the IMF newsletter Myeloma Today. I am fortunate to be a patient in his MGUS study, and I'm very impressed with the NIH, Dr. Landgren, and his research nurse Mary Ann Yancey, RN. For most us who have MGUS, it is not a minimal condition, psychologically or physically. If this research can help figure out how to stop the myeloma beast before it evolves into a malignant condition, then woo hoo for all of us!

Amy Hans *(shown with Dr. Landgren)*

Since my myeloma diagnosis in August 2005, I have learned a lot. It has opened a whole new world for me and for my husband Vince who so beautifully supports me. I have been a myeloma survivor for 7 years, and I would like to thank the IMF for the helpful education and information, and your dedication to us cancer patients.

Everyone's cancer is different, and it is important to be educated about it so we can work with our oncologists and caregivers. I listen to my body and take rest when needed, but it is just as important for me to stay active. I maintain a positive attitude and a good sense of humor. I feel grateful no matter what, and help others as much as I can. We are all in this together.

Marguerite A. Mueller

My partner and I, along with a family friend, attended the wonderfully informative IMF Regional Community Workshop held in July in Minneapolis, MN. We learned a tremendous amount that will help us navigate our way through the many challenges and choices ahead, and appreciate the hard work you put into it. The presenters were first rate – clear, accessible, intelligent, warm, and practical.

Afterwards, as we compared notes, we found there was one thing that disturbed all three of us: the clapping for survivors. Survival chances are often enhanced by attitude and proactiveness, but luck and timing are huge factors. We each felt that there was a large group that deserved our applause: those who have died, many of whom participated in trials for the drugs that are making the survivor stories possible. Acknowledging them, in a culture that increasing views cancer deaths as being somehow a failure of will, optimism, or effort, seems vitally important.

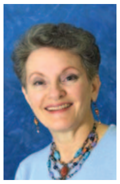
We admire the work of the IMF, and it has been a great resource for us from Day Two. That initial information packet, free of charge and sent immediately, was such a gift. We were happy to repay it in part by including the IMF in the Friends of Dan fundraiser friends organized a year ago.

Keep up the great work!

Tib Shaw and Dan Odegard

All the IMF Support Group Leaders' Summits have been excellent in years past, but the 2011 Summit was the BEST one yet. I learned a lot – we always do – and found it to be much-needed and enjoyable stress reliever for me. Almost hated to come home.

Darlene Jessee



The IMF Hotline has really been a help to me since I was diagnosed with myeloma in April of 2009. When you don't have the answer to one of my questions close at hand, you do some research and quickly get back to me. You even contacted a well-known myeloma expert for an answer to one of my questions. It is reassuring to know that the caring people at the IMF are just a phone call away with so much helpful information.

Dotty Stringfield

Just a short note to thank you on behalf of the members of the San Diego Support Group for scheduling the IMF Regional Community Workshop (RCW) in our area. Many of our members expressed their gratitude to me for being able to participate in such a high quality program. Specifically, members commented about the excellent speakers, the venue, and the educational content provided by the IMF that assists both patients and caregivers to be up-to-date about changes and progress in treating myeloma.

Elliot Recht

Your web site great!!! On it, I found a lot of help while dealing with my mom who is battling this awful cancer. Thank you all for doing what you do… all of you are ANGELS.

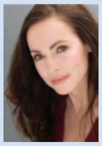
Karen Higgins

I met IMF's Kelly Cox in August at the myeloma support group meeting in Orange County, CA. He did a very good job of giving us all hope through his energy and inspired lecture. Diagnosed with Stage III myeloma in 2008, I'm trying to do my part to support my fellow patients and the IMF by raising funds for research. Having journeyed across the Mojave Desert in April, a distance of 300 miles in just over 5 days, I have a new goal. I will be biking the Great Allegheny Passage and Cumberland Tow Canal Route of "Rails to Trails" in late September 2011. I hope that what I do will help others; I know it helps me. Through riding, I want to bring hope to those who, like me, suffer with this illness. I try to show people that all is not lost even when it certainly seems so. In April of 2009, I came out of the hospital using a walker, but in the last 6 months I have accomplished more than I thought I ever would.

Andy Sninsky

Editor's Note: For more information on Andy bike rides, please visit bicyclemojave.myeloma.org

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



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

IMF'S INTERNATIONAL MYELOMA WORKING GROUP

The Annual IMWG Summit: London June 7–9, 2011

By Brian G.M Durie, MD

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

The 2011 annual IMF's International Myeloma Working Group (IMWG) Summit took place on June 7–9 in London, United Kingdom. It was a very lively and productive meeting. The unique format, with a focus on 6 work/discussion groups, was greatly appreciated by the attendees. Many important current issues were debated and recommendations were made for both consensus or guideline publications and research projects or clinical trials.

In Group 1 (S. Vincent Rajkumar and GiamPaolo Merlini), the crucial question was how to maximize benefits of early treatment for patients with high-risk smoldering myeloma, yet avoid unnecessary treatment and toxicities. Tests are needed to predict ≥90% chance of early disease progression without therapy. The group considered the potential role of imaging. For example, ≥3 lesions on MRI or PET/CT can indicate significant risk of disease activation. However, at this point, definitive data are lacking. The group proposed to gather and analyze imaging data as soon as possible to allow evidence-based recommendations to be developed. It was also proposed that more precise measurement of renal function (eGFR) could indicate an earlier need for intervention, but data are needed and will be collected by the group.

Clearly, the group feels that early intervention has great potential for improved overall survival and quality of life. However, better diagnostic criteria are required and a range of trials will be needed to assess the best options for interventions. The options are for both disease control and attempted curative approaches.

In Group 2 (Antonio Palumbo and Shaji Kumar), several aspects of treatment selection and disease monitoring were reviewed and discussed. The role of Freelite® testing was addressed: use in response assessment in patients with less than measurable disease by SPEP (<1 gm/dL) and UPEP (<200 mg/24 hrs) was affirmed as the primary recommendation.

There was a strong endorsement for the new dose (and schedule/route) modifications for Velcade® (bortezomib) to limit potential neurotoxicity. There are new guidelines that have just been submitted for publication by the IMWG. Antonio Palumbo presented updated recommendations for the identification and management of "frail" patients. The categories, "go-go," "moderate-go," and "slow-go," are helpful and clear. The group spent considerable time reviewing the numbers and types of cycles of therapy required for ideal initial or frontline treatment. Considering response, length of remission, and overall survival, as well as ongoing quality of life, different combinations and sequences can be considered. In general, they favored starting with a more limited combo, such as with two drugs, and adding drugs if needed. They also favored stratification within trials to assess the impact within different risk groups (e.g. good vs. poor risk). Several different trial structures were recommended.

In Group 3 (Philippe Moreau, Gareth Morgan, and Michele Cavo), the current role of high-dose chemotherapy with stem cell transplant (SCT) was reviewed and discussed. The recommendations were rather clear-cut and included:

- SCT still recommended as "standard of care" for eligible patients under age 65 years.
- For patients aged 65–70 years, SCT can be considered and recommended on a patient-by-patient basis.
- SCT is still recommended if complete response has been achieved with induction.
- 4–6 cycles of induction therapy are recommended.
- If ≥VGPR is not achieved, SCT can still be considered. There is no need to persist with longer induction pre-transplant in this setting.
- Double or second transplant can be considered for patients with <VGPR after a first transplant, but is not recommended as a routine procedure.
- Several ideas for new preparative regimens were discussed.

In Group 4 (Heinz Ludwig and Michel Attal), the current role of maintenance was discussed at length. A new guideline manuscript is in the final stages of preparation. The main recommendations included:

Thalidomide

- This is an option for maintenance for patients who have not achieved CR, are not "high-risk", and do not have significant underlying neuropathy.
- A starting dose of 100 mg/daily is recommended for a duration of ≥6–12 months. The ideal duration is currently unknown.

Revlimid® (lenalidomide)

- The recent phase III trial results from IFM and CALGB were noted.
- Although maintenance is considered a valid approach, the group felt that it was not possible to make a definite recommendation at this time. Overall survival is considered the appropriate endpoint to assess benefit.
- Enhanced monitoring and assessment with respect to the potential risk of second primary malignancies (SPMs) was recommended.

Velcade® (bortezomib)

- It was felt that it is too early to make any recommendation with regard to Velcade® maintenance. More data are required.
- The potential for every 2 week IV or SQ regimens with Velcade® was noted.

Needed trials

- Clearly, additional trials are required involving one or more of Thalomid®, Revlimid®, and/or Velcade® as well as potential new agents, such as elotuzumab, HDAC inhibitors, or new oral derivatives.

In Group 5 (Sundar Jagannath, Pieter Sonneveld, Jatin Shah, and Paul Richardson), new drugs were discussed. Assessments were very similar to discussions in Barcelona last year. Carfilzomib and Pomalidomide are the drugs most likely to obtain FDA approval in 2012. There are many

CONTINUES ON PAGE 8

THE ROLE OF PROTEIN ELECTROPHORESIS TESTING IN MYELOMA

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

What is a monoclonal protein and what is its significance in myeloma?

Monoclonal proteins are immunoglobulin ("Ig") molecules or parts of immunoglobulin molecules. Normal plasma cells produce immunoglobulins, which are the antibodies necessary to fight infection, but the abnormal plasma cells present in myeloma patients do not produce antibodies in response to infection. Instead, they produce a monoclonal immunoglobulin molecule that cannot function as an antibody.

Production of a single, monoclonal protein (M-protein) is a characteristic feature of multiple myeloma. This M-protein is manufactured (synthesized) by malignant plasma cells (or myeloma cells). The amount of protein produced and released into the serum (the liquid part of the blood that is left after the blood cells are removed), and sometimes into the urine, reflects the amount of myeloma present in the body at any given time. This protein is called a serum or urine tumor marker.

Only a very few cancers have this type of marker which, in the case of myeloma, makes it possible to assess the amount of disease at the time of initial diagnosis and track the amount of myeloma throughout the course of the disease. One can measure M-protein to assess response to treatment, depth of remission, and, if necessary, the patient's relapse using exact numbers, which is a unique advantage.

For example, we can determine if a response is: Partial (PR) = 50% reduction of M-protein; very good partial (VGPR) = 90% reduction of M-protein; or complete (CR) = no protein detected. We can also identify a ≥ 25% increase in protein level, which we call relapse.

What is protein electrophoresis?

Protein electrophoresis (PEP) is a test used to measure the amount of M-protein in the blood or urine. If the M-protein is present in serum, the electrophoresis test for it is called Serum Protein ElectroPhoresis (SPEP). Likewise, when the M-protein is found in urine, the test for it is called Urine Protein ElectroPhoresis (UPEP).

In myeloma, immunoglobulins can be formed from one of five possible types of heavy chains (IgG, IgA, IgM, IgD and IgE) and two types of light chains (kappa and lambda). Therefore, there are 10 possible combinations of heavy and light chains. Protein electrophoresis testing is able to detect all of them.

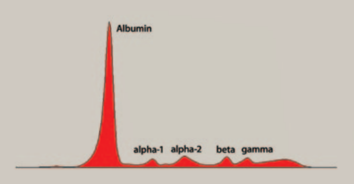


Figure 1. Representation of a normal SPEP result

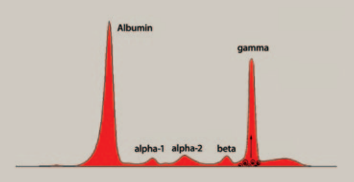


Figure 2. Representation of an abnormal SPEP result, with myeloma cells producing the M-protein, creating an M-spike in the gamma zone.

How is the M-protein measured?

To measure the amount of the M-protein, one needs two pieces of information:

1. What is the total amount of protein in the serum or urine?
2. What percentage of the total is the M-protein?

Serum contains a variety of different proteins that will be separated by electrophoresis into five or six fractions (according to the method used by the laboratory). The diverse, normal immunoglobulins present in serum differ slightly from each other in their structure and electrical charge. For that reason, when they are subjected to electrophoresis, they form a large zone, which is spread out and symmetrical. M-proteins are produced by one clone of plasma cells, and thus all the molecules are identical and have the same electrical charge. That is why on electrophoresis a monoclonal protein will migrate as a narrow spike.

SPEP can be used to search for a monoclonal protein as well as to monitor the amount of M-protein.

The kidney acts as a filter, eliminating only a few molecules and leaving most of the proteins in the bloodstream. Although some small proteins do pass through the kidney filter, they are later resorbed and recycled into amino acids. Thus, normally urine contains only traces of proteins.

When M-protein is present in serum, often the excess of free light chains will be found in the urine as Bence Jones protein. UPEP is used to search for Bence Jones protein and to monitor its concentration. It can also help to assess kidney damage, which is a common complication of myeloma.

By calculating the size of the "spike" that appears with protein electrophoresis, one can measure the area between the top of the spike and the baseline of the graph to assess the percentage of the total protein that represents the M-protein. Both the total protein and the percentage of M-protein can change over time. (For example, with response to treatment, the spike can drop.) This type of serial measurement and assessment to document the speed and level of response is key to all myeloma disease monitoring. This is why SPEP and UPEP tests are so important.

Is immunofixation a part of the PEP testing?

Once a narrow spike of protein is detected by SPEP or UPEP testing, the presence of M-protein is suspected. At this point, it is necessary to confirm its presence and to determine its type by identifying which heavy chains and light chains are involved in its structure. Knowing the type of M-protein is important in establishing a diagnosis and in monitoring the patient.

Immunofixation is an additional test, which is another method of electrophoresis, called IFE (ImmunoFixation Electrophoresis). IFE is used to determine the type of M-protein. This is important at the time of baseline diagnosis and at the point of maximum response with treatment. Immunofixation methods are more sensitive to the presence of faint M-proteins and may detect them even if electrophoresis does not show any visible abnormality. But immunofixation does not determine how much M-protein is present. Therefore, both methods are used together: electrophoresis to detect the M-protein and to quantify it, and immunofixation to identify its type.

How is this information utilized?

This information is used by a doctor, in conjunction with other data, to establish a diagnosis. Later, it will be compared with the values obtained by subsequent electrophoresis results to monitor the evolution of the disease and the response to treatment, as recommended by the IMF's International Myeloma Working

CONTINUES ON PAGE 10

THE ROLE OF MOZOBIL® IN MYELOMA

Myeloma Today in conversation with Dr. Sergio A. Giralt

What is the current role of transplantation in myeloma?

I'd like to start with a brief history of transplantation in multiple myeloma. It does not go back very far – less than 30 years. In the early 1980s, Professor Tim McElwain of the Royal Marsden Hospital in the United Kingdom made a seminal observation that by giving myeloma patients high doses of melphalan, it was possible to overcome the resistance of their disease to standard doses of melphalan. But some patients died of complications from the toxicity affecting the bone marrow, caused by high doses of melphalan.

It was Dr. Bart Barlogie who had the idea of harvesting the patients' marrow from the bones prior to high-dose melphalan therapy, then helping patients recover by re-infusing the marrow. In essence, autologous bone marrow transplantation (BMT) was a support or rescue treatment after administration of high-dose therapy (HDT). Studies confirmed that BMT patients could achieve higher rates of complete remission (CR).

Sergio A. Giralt, MD
Chief, Adult Bone Marrow Transplant Service
Memorial Sloan-Kettering Cancer Center
New York, NY

In the late 1980s, granulocyte-colony stimulating factors (G-CSF) became available to help patients receive chemotherapy with less marrow toxicity. It was discovered that G-CSF helped release stem cells (which give birth to all mature cells) from the bone marrow into the bloodstream. Stem cells (CD34) can be mobilized with or without the use of chemotherapy. They are collected from the peripheral blood through a procedure called apheresis, with the remaining blood components simply being re-introduced back into the patient's bloodstream. The CD34 cells are re-infused after HDT. It is far easier and less invasive to collect CD34 cells from the peripheral blood than to harvest bone marrow. This is why the autologous stem cell transplant (ASCT) replaced BMT.

With the introduction of novel agents – thalidomide, Velcade® (bortezomib), and Revlimid® (lenalidomide) – unprecedented CR rates became possible without the use of ASCT. However, ASCT remains the treatment associated with the highest CR rate in myeloma. Novel agents can form complementary treatment strategies with ASCT: they are being incorporated into induction therapies prior to transplant and can be used as consolidation/maintenance after. As part of myeloma treatment planning, I encourage all transplant-eligible newly diagnosed myeloma patients, especially those with symptomatic disease, to discuss these options with their physicians.

If an ASCT-eligible patient chooses not to move forward with transplant as frontline therapy, what action can be taken?

For eligible patients, ASCT remains an important component of therapy, both frontline and at relapse. But whether ASCT is performed upfront or later in the course of the disease is a decision that can only be made by patients in consultation with their doctors. In my opinion, stem cell collection should be attempted early in the course of therapy by all ASCT-eligible patients, even if the transplant itself is put off until consideration at a later time. Some patients who achieve a good response with an induction regimen choose to reserve the option of an ASCT for first relapse, and such patients can continue their initial therapy after stem cell collection.

What is the optimal number of CD34 cells to be collected for infusion?

Determining the optimal CD34 cell infusion dose for ASCT in myeloma requires prospective clinical investigation, so at present there is no definitive answer to this question. The current minimum dose of CD34 cells for infusion is considered to be 2 million CD34 cells per kilogram (kg) of body weight for the support of a single transplant. Therefore, it is suggested that at least 4 million CD34 cells/kg be collected, which would allow most myeloma patients to undergo at least two ASCT procedures during the course of their disease. The IMF's International Myeloma Working Group (IMWG) suggests that, if feasible, 8-10 million CD34 cells/kg should be collected, although it remains to be seen if higher doses of CD34 cells can improve patient outcomes.

How does Mozobil® fit into the current landscape of stem cell mobilization in myeloma?

Mozobil® (plerixafor) is a novel stem cell mobilization agent, administered as an injection under the skin, which has been approved by the FDA for use in combination with a G-CSF medication in both the myeloma and lymphoma settings. In myeloma, plerixafor in combination with G-CSF has been shown to be more effective as an initial mobilizing regimen than G-CSF alone.

This is a very effective primary regimen for stem cell mobilization – a major advance in ASCT in myeloma – without the downside of added exposure to chemotherapy.

The vast majority of myeloma patients (approximately 90-95%) can be successfully mobilized with enough cells for one or two transplants. Most clinical trials suggest that more cells can be collected after chemomobilization, but this approach is associated with more toxicity while not insuring superior outcome, and the collection failure rate with chemomobilization is similar to the failure rate with G-CSF alone.

Compared to mobilizing with G-CSF alone, the addition of plerixafor increases circulating hematopoietic stem cells in the peripheral blood, resulting in fewer apheresis procedures performed over fewer days to reach the target dose of CD34 cells collected. Myeloma patients in a phase III study collected the target dose of stem cells in a median of 3 fewer days with plerixafor than with G-CSF alone, and collected 3 times as many cells on day 1 than with G-CSF alone.

But besides allowing a more efficient collection of larger numbers of stem cells from good responders, plerixafor has been shown to improve collection yield for patients who otherwise fail to mobilize an adequate quantity of stem cells despite multiple attempts with other modalities. In the past, these patients would never have been able to proceed to ASCT.

Plerixafor also allows for collecting stem cells from patients previously exposed to HDT. For myeloma patients who have already had an ASCT

CONTINUES ON PAGE 10

XIII INTERNATIONAL MYELOMA WORKSHOP

IMF videos provide unprecedented access to latest advances in worldwide myeloma research

The 13th International Myeloma Workshop (IMW) was held May 3–6 at the Carrousel du Louvre in Paris, France. Organized by Professors Jean-Paul Fermand, Thierry Facon, and Philippe Moreau, this clinical conference drew nearly 3,000 myeloma clinicians and researchers from around the world.

The biannual workshop offers a lecture-based scientific program highlighting emerging advances in the understanding of the biology and treatment of myeloma. Clinical and scientific data is presented by myeloma experts, and the medical content of the meeting is not readily accessible to patients and caregivers.

To provide access for the entire myeloma community to this important educational material, the IMF recorded every public presentation and created a series of video summaries of the sessions with interviews of the experts following their presentations. Each day the video summaries were posted to the IMF website, allowing the patient community to feel like they were there in person.

A full library of the videos is archived on the IMF website, and can be accessed at http://imw.myeloma.org. The videos are filed by subject:

- Session Summaries
- Opening Remarks
- Molecular Pathways/Genetics
- Plasma Cell Biology
- Bone Disease and Animal Models
- Newly Diagnosed <65 Years
- High-Risk Entities of Myeloma
- Debate: Should We Treat Stage I MM?
- Management of Myeloma Bone Disease
- MM Cast Nephropathy & AL Amyloidosis
- Newly Diagnosed >65 Years
- New Drugs and Therapeutic Approaches
- Secondary Malignancy in Myeloma
- Plenary Abstract Session I
- Monoclonal Immunoglobulin and the Nerve, Waldenström's Macroglobulinemia
- Plenary Abstract Session II
- Consensus Report
- Novel Agents Updates

You can order a copy of the DVDs by sending an email with your name and mailing address to theIMF@myeloma.org. There is no charge for this service; however, donations are always appreciated.

We invite you to take full advantage of these unprecedented resources. And, as always, we urge you to discuss all medical issues thoroughly with your doctor, as well as to contact the IMF Hotline with your questions at info@myeloma.org or 800-452-CURE (2873).

INTERNATIONAL MYELOMA WORKING GROUP — continued from page 5

ongoing trials to assess these agents, both individually and as a part of new combinations. Although response is crucial as part of initial assessment, ultimately prolonged remission and improved overall survival are essential endpoints.

In Group 6 (Brian Durie, Hervé Avet-Loiseau, and Wee Joo Chng), the key question was how to tailor therapy to accommodate the risk features of all patients. It was noted that we already routinely "risk adapt" therapy based upon age, performance status, kidney function, and other medical issues encountered by individual patients. The question was how best to fine-tune therapy based upon molecular or genetic features of the myeloma. Consensus was reached upon the best definitions for "poor-" and "good-"risk myeloma . This is based upon a recent IMWG analysis submitted for publication by Hervé Avet-Loiseau. For now, it is felt that ISS and FISH results can be used and are available for most patients. Results with GEP can be assessed within ongoing clinical trials. It is very important to note that the Group unanimously recommended that risk groups continue to be assessed *within* large clinical trials that incorporate both "poor-" and "good-" risk groups. These trials require sufficient patients to adequately assess the impact of risk *AND* to provide as much molecular testing as possible (including GEP when feasible) to gather the best correlative data. A manuscript, with recommendations, is in development, and further analyses within the IMWG are planned.

An exciting new feature on the Summit's agenda this year was the "Cure vs. Control" debate (with Jonathan Kaufman [cure] and Rafat Abonour [control]). Although "cure" is clearly an ideal goal, for now, "control" is a more achievable and broadly applicable option. The good news is that with the advent of the novel agents, long-term disease control is a tangible reality. Although complete remissions lasting ≥4 years (sometimes called "functional cures") are achievable, true "cures" (disease-free with no evidence of residual disease for >1–2 decades) are still elusive and largely undocumented. The debate was heated. Those supporting potential curative approaches feel that "functional cures" are an acceptable endpoint for now. Ultimately the question becomes: "In which patients is it reasonable to propose the added toxicities of more aggressive therapy for the chance of achieving cure?" The dilemma is that patients who are "good" risk are the most readily "controlled" long term with simpler approaches to therapy, but nonetheless could potentially achieve cure with more aggressive treatment. The debate will clearly continue. New trials are planned. **MT**

Myeloma Manager™ Personal Care Assistant™

We are pleased to offer you, free of charge, the Myeloma Manager software, v4.0.2. Designed and developed by the IMF specifically to help patients and caregivers battling multiple myeloma, the Myeloma Manager provides a tool to capture laboratory results and display and print tables and charts to show how those results change over time. We hope that you will find it useful.

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.

myeloma.org

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 Debbie Birns, Paul Hewitt, Missy Klepetar, and Judy Webb. The phone lines are open Monday through Friday, 9 a.m. to 4 p.m. To submit your question online, please email TheIMF@myeloma.org.

(l to r) Paul Hewitt, Judy Webb, Debbie Birns, and Missy Klepetar

Should myeloma patients take calcium to help with bone health or not?

As those of you familiar with myeloma already know, there are no simple answers to even the most straightforward questions. Every myeloma-related issue seems to have its own caveats and complications.

Calcium is not only essential for bone formation and bone health, but is also needed for the heart, muscles, and nerves to function properly and for the blood to clot normally. The body carefully regulates the amount of calcium in the blood. Even in healthy individuals, the body loses calcium each day and requires constant replenishment. If you don't consume enough calcium in your food, and you do not take supplements to offset the deficit, the body releases parathyroid hormone to stimulate the bones to release calcium into the blood. If this process goes on over a long period of time, the bones continue to lose density, and osteoporosis results.

But even for the segment of the healthy population that has traditionally been urged to take calcium supplements (adult women), there are risks of too much calcium intake. The large *Women's Health Initiative Calcium/Vitamin D Supplementation Study* linked calcium supplements to an increased risk for cardiovascular events, vascular calcification, and kidney stones. A large prospective study from Sweden recently published in the *British Medical Journal* indicates that even in regard to bone health, more may not be better when it comes to calcium intake. Like women whose calcium intake was too low (less than 750 mg/day), women who had the highest intake of calcium a day actually had a hint of increased risk for hip fracture too. More moderate levels of calcium intake seem to be better for bone health.

For patients with myeloma, the problem of calcium balance in the blood is even more complicated. The presence of myeloma cells in the bone marrow upsets the process of bone formation and bone breakdown that occurs normally each day. Myeloma cells in the bone marrow lead to over-activity of cells that cause bone breakdown (osteoclasts), and inhibition of the cells that form new bone (osteoblasts). Thus myeloma patients may have additional calcium in the blood as a result of too much bone breakdown.

Selected Food Sources of Calcium

Food	Calcium (mg)
Yogurt, plain, low fat, 8 ounces	415
Orange juice, calcium-fortified, 6 ounces	378
Mozzarella, part skim, 1.5 ounces	333
Sardines, canned in oil, with bones, 3 ounces	324
Cheddar cheese, 1.5 ounces	306
Yogurt, fruit, low fat, 8 ounces	313-384
Milk, nonfat, 8 ounces**	296
Milk, reduced-fat (2% milk fat), 8 ounces	296
Milk, buttermilk, 8 ounces	280
Milk, whole (3.25% milk fat), 8 ounces	272
Tofu, firm, made with calcium sulfate, ½ cup***	253
Salmon, pink, canned, solids with bone, 3 ounces	181
Cottage cheese, 1% milk fat, 1 cup unpacked	138
Tofu, soft, made with calcium sulfate, ½ cup***	138
Pudding, chocolate, instant, made with 2% milk, ½ cup	127
Spinach, cooked, ½ cup	123
Ready-to-eat cereal, calcium-fortified, 1 cup	100–1,000
Instant breakfast drink, various flavors and brands, powder prepared with water, 8 ounces	105–250
Frozen yogurt, vanilla, soft serve, ½ cup	103
Turnip greens, boiled, ½ cup	99
Kale, cooked, 1 cup	94
Kale, raw, 1 cup	90
Soy beverage, calcium-fortified, 8 ounces	80–500
Ice cream, vanilla, ½ cup	84
Chinese cabbage, raw, 1 cup	74
Tortilla, corn, ready-to-bake/fry, 1 medium	46
Tortilla, flour, ready-to-bake/fry, one 6" diameter	39
Sour cream, reduced fat, cultured, 2 tablespoons	32
Bread, white, 1 ounce	31
Broccoli, raw, ½ cup	21
Bread, whole-wheat, 1 slice	30
Cheese, cream, regular, 1 tablespoon	14

The National Institutes of Health provides the above information on dietary sources of calcium. Remember that at least half your daily calcium intake should be from food.

The Mayo Clinic's recommended dietary allowance for calcium from dietary sources is 1000 mg a day for men and women between 19 and 50 years of age, and 1200 mg a day for those who are 51 years and older.

No myeloma patient should ever start calcium supplementation simply because "it's good for the bones." All myeloma patients should be having regular blood testing to monitor their disease and/or response to treatment, and part of that testing is the "chemistry panel," which includes the blood calcium level. Your doctor must assess your blood calcium level (and your vitamin D level, which aids calcium absorption) before you take calcium supplements. If your serum calcium level is not elevated, and your doctor thinks you need to supplement your intake, you also need to know approximately how much calcium you take in through food each day (see chart on food sources of calcium) so that your supplement intake is adjusted correctly.

International Myeloma Working Group (IMWG) bone expert and former *Myeloma Today* contributor Matthew Drake, MD, PhD, of the Mayo Clinic, kindly supplied the following advice on calcium supplementation for this column:

- Your total daily dose should not exceed 1200 mg in divided doses of 500 mg or so at most. More at one time will lead to constipation, because the GI tract cannot absorb more than that at once.

CONTINUES ON PAGE 10

---

* DV = Daily Value. DVs were developed by the U.S. Food and Drug Administration to help consumers compare the nutrient contents among products within the context of a total daily diet. The DV for calcium is 1,000 mg for adults and children aged 4 years and older. Foods providing 20% or more of the DV are considered to be high sources of a nutrient, but foods providing lower percentages of the DV also contribute to a healthful diet.

The U.S. Department of Agriculture's Nutrient Database Web site lists the nutrient content of many foods. It also provides a comprehensive list of foods containing calcium.

** Calcium content varies slightly by fat content; the more fat, the less calcium the food contains.

*** Calcium content is for tofu processed with a calcium salt. Tofu processed with other salts does not provide significant amounts of calcium.

PROTEIN ELECTROPHORESIS — continued from page 6

Group (IMWG) in their published Uniform Response Criteria guidelines. This information is also available in the IMF publication Concise Review of the Disease and Treatment Options, which can be requested from the IMF, viewed online at myeloma.org, or downloaded from the website in PDF format.

According to the IMWG guidelines, when a monoclonal protein can be detected and measured by electrophoresis, monitoring should be performed using SPEP and/or UPEP. Disease monitoring in the absence of a spike on SPEP or UPEP can be quite difficult. When the M-protein is undetectable by electrophoresis or is too small to be measured, the free light chain assay can be used to monitor the patient's condition.

Are there other practical recommendations that might be helpful to our readers?

It is important to note that at the time of diagnosis, some patients have a very high M-spike in the serum but not such a high level of myeloma in the bone marrow or bones. And the opposite is also true: some patients can have a low M-spike, but a lot of myeloma cells. Thus, at diagnosis, it is very important to correlate the spike level with the amount of myeloma in an individual patient. If the spike is low, this can be especially important, since small changes can be more significant in terms of response to treatment, as well as potential progression or relapse.

When new myeloma treatment is started, the SPEP and/or UPEP test(s) should be used each month or each cycle of treatment. Regular testing is required to assess the impact of treatment. If the treatment is not working well, this will be evident within 2–3 months: the SPEP/UPEP M-protein levels would drop by <25% or increase by ≥25% (in cases of progressive disease). At this point, a change in treatment may be required. This is an important time to discuss the results and treatment options with the doctor.

If the treatment is working well, frequently there will have been substantial reduction in the M-protein levels on SPEP/UPEP within the first 2–3 months. Achieving the higher levels of response will typically take at least another 2–3 months of treatment (total of 4–6 months at that point). Several additional months of therapy may be required to achieve maximum response. The classification of complete response (CR) requires that no M-protein is detectible using IFE and that a bone marrow test shows no evidence of myeloma.

Once a stable level of response is reached, the frequency of monitoring can be reduced to every 2–3 months, which can continue on an ongoing basis unless new issues emerge. It is most helpful if direct discussions with the treating physician occur about the SPEP/UPEP results as they become available, since further decisions may be required with respect to additional treatment options.

The IMF's Myeloma Manager™ computer program, which enables one to create tables, graphs, and flow charts of test results over time, may facilitate patient-doctor discussions and planning. And, as always, the IMF Hotline Coordinators are available to answer patient questions on this and other subjects via TheIMF@myeloma.org or 800-452-CURE (2873). **MT**

HOTLINE — continued from page 9

- Optimal absorption of calcium occurs when vitamin D levels are good; you should have your vitamin D level checked as well as your blood calcium level. (See the Hotline column in *Myeloma Today*, Winter 2010/2011, on vitamin D.)
- Any supplemental calcium should be taken with meals if possible, as the acid made to digest food aids calcium absorption.
- Proton pump inhibitors ("PPIs" given for gastrointestinal reflux disorder, or GERD) limit acid production, and thus patients on PPIs who are taking supplemental calcium should definitely do so at mealtimes, when they will make a little acid to aid digestion.
- No supplementation is needed if patients are getting adequate dietary calcium. In general, Dr. Drake does not recommend that patients get more than half of their daily calcium from supplements. Food is a more natural option and is more easily absorbed.
- For most patients, Dr. Drake recommends an acidic form of calcium (Citracal), since it is easily absorbed and is less likely to cause constipation. This form has the lowest amount of elemental calcium, however, so more pills are required. The other common form of calcium supplement is calcium carbonate. That form is not absorbed as well since it neutralizes the acid that is necessary for absorption (as in the case of TUMS).
- Maintaining adequate calcium and vitamin D intake is important for the bisphosphonates Aredia® (pamidronate) and Zometa® (zoledronate) to work well. Note that both (and in particular Zometa, since it is more potent) reduce the amount of calcium in the blood, so calcium levels of patients, particularly those who receive Zometa treatments, should be checked periodically.

As always, we urge you to discuss this and all other medical issues thoroughly with your doctor.

We welcome your questions on this or any other myeloma-related issue at the IMF Hotline, via phone at 800-452-CURE (2873) or email at info@myeloma.org. The Hotline blog is accessible via the IMF website myeloma.org. **MT**

DR. SERGIO A. GIRALT / MOZOBIL — continued from page 7

but who were unable to achieve a complete response (CR) or a very good partial response (VGPR), a second transplant may be beneficial. However, patients who have already had one transplant generally collect fewer stem cells than those who have not received a prior transplant. The use of plerixafor may help previously transplanted myeloma patients collect enough stem cells for a second ASCT.

As an additional consideration for patients in the United States, some US insurance carriers do not pay for the 'harvest and hold' treatment strategy, so patients must bear the costs associated with stem cell collection. The use of plerixafor by US patients may help save their resources.

As with all therapies, patients should consult with their treating physicians about their care. But I have seen first-hand the benefits of plerixafor in myeloma, and would recommend that eligible patients include it in discussions with their doctors. **MT**

PROF. DOUGLAS E. JOSHUA

Receives the Robert A. Kyle Lifetime Achievement Award

The Award

In 1910, Dr. William Mayo set the standard for treatment of patients at Mayo Clinic when he said, “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 words. The IMF chose to name this award for Dr. Robert Kyle, whose life and work give new meaning to Dr. Mayo’s statement.

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 myeloma research, clinical treatment, and education.

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 “father” 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.

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 other individuals whose body of work in the field of myeloma has made significant advances in research, treatment, and care of myeloma patients: Dr. Bart Barlogie (2004), Dr. Kenneth C. Anderson (2005), Dr. Brian G.M. Durie (2006), Prof. Heinz Ludwig (2007), Prof. Mario Boccadoro (2008), Prof. Jean-Luc Harousseau (2009), and Prof. Joan Bladé (2010).

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

Amgen
The Binding Site Group, Ltd.
Celgene Corporation
Millennium:
The Takeda Oncology Company
Novartis Pharmaceuticals
Onyx Pharmaceuticals, Inc.

The Recipient

Prof. Douglas E. Joshua, AM
Director, Institute of Hematology
Royal Prince Alfred Hospital
University of Sydney
Sydney, Australia

Prof. Joshua is the ninth recipient of the IMF’s Robert A. Kyle Lifetime Achievement Award. His work in hematology has spanned 40 years, and his expertise in myeloma is recognized world-wide. He is Head of Clinical and Laboratory Hematology at Sydney Cancer Centre, Head of Sydney South Western Area Health Service (SSWAHS), the Alan Ng Professor in Medicine at University of Sydney, and the Director of the Institute of Hematology, Royal Prince Alfred Hospital in Sydney. Prof. Joshua is the chairman of the SSWAHS Blood Transfusion committee and a member of the CEC Blood Watch program. He is chairman of the Blood Clinical and Scientific Advisory Committee (BCSAC) of the NSW Department of Health, as well as Chairman of the National ARCBS Ethics committee.

Prof. Joshua received his BS, BSC, MB, and PhD degrees from the University of Sydney and the University of Oxford. He is a fellow of The Royal Australasian College of Physicians and the Royal College of Pathologists of Australasia. Prof. Joshua is secretary of the International Myeloma Society, and he serves on the editorial board of numerous journals. Prof. Joshua has a long-standing interest in both basic and clinical research in myeloma and has been supported by the IMF, National Health and Medical Research Council, NSW State Cancer Council, Cancer Institute of NSW, the University of Sydney Cancer Research Fund, MMRF, and the Sydney Foundation for Medical Research. He has held sabbatical appointments as a visiting scholar at the University of Birmingham and Harvard.

The award ceremony and reception were held on June 8 at the Millennium Hotel London Mayfair in Grosvenor Square, London, United Kingdom. Many of Prof. Joshua’s friends and colleagues from the IMF’s International Myeloma Working Group (IMWG) were in attendance. **MT**

Doctor, Doctor!

A stimulating blog by Brian G.M. Durie, MD, is now available on the IMF website. Dr. Durie's entries cover topics as diverse as the physics of myeloma, early access to carfilzomib for eligible patients, and how he would spend a hypothetical $100 million in funding to search for a cure. To read the "Doctor, Doctor!" blog, please visit www.myeloma.org and click on the link inside the New & Noteworthy box. Or you can follow along on twitter at @BrianDurieMD.

Be an active reader

With the recent addition of "Doctor, Doctor!" the IMF website is now home to eight blogs by myeloma patients, caregivers, nurses, and others. We invite you to be an active reader. Click on the "blogs" tab in the top navigation bar to locate the entries. Become part of the community discussion on matters of importance to everyone battling myeloma by sharing your thoughts by posting comments and questions. Your input can help others, so please consider adding thoughts to a blog. You can also subscribe to a blog to receive email notification when a new posting is made. To share your thoughts about any article that appears on the IMF website, simply click on the comments tab. We hope you find this new capability helpful.

The IMF has a social community

Join the IMF's active social community, on both twitter and facebook.

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

Follow us on twitter @IMFmyeloma

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

Help the IMF learn more about myeloma patients

Please help the IMF learn more about myeloma patients by completing the latest online Myeloma Patient Survey at http://survey.myeloma.org. You can complete this survey either as a patient or as a caregiver on behalf of a patient. All responses will be anonymous. No personal identifying information will be gathered.

IMF Staff Updates

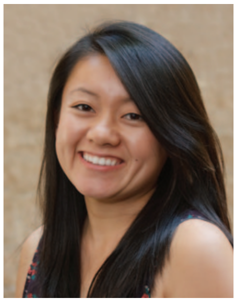
The IMF is pleased to welcome three new members to our team.

James Ross

Major Gifts Officer

With his wealth of experience in non-profit fundraising, we know our members will find James to be an invaluable resource when making important philanthropic decisions. James is a graduate of Bloomsburg University in Pennsylvania and a four-year veteran of the United States Coast Guard. Before joining the IMF, James served as the Executive Director of Gettysburg Hospital Foundation where he managed special gift campaigns that facilitated the construction some of the hospital's newer facilities. He has also served as the Director of Development and Director of Major Gifts at the Massanutten Military Academy and the Appalachian Trail Conservancy, respectively.

One of James's favorite aspects of working for non-profit organizations is the ability to meet people from all over the country. As such, he is enthusiastic to be on the road visiting the IMF's numerous and devoted supporters. Feel free to contact James directly at 717-360-8687 or via e-mail at jross@myeloma.org if you have any questions regarding major gifts, bequests, planned giving opportunities, or if you would just like to chat about your experiences with the IMF.

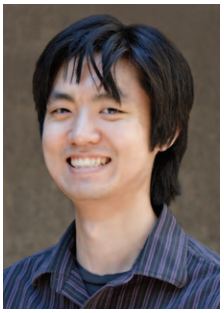


Danielle Loi

Development Assistant/Medical Affairs Assistant

Danielle recently graduated from UCLA with a degree in Architecture. While at UCLA, she worked at the Department of Architecture and Urban Design, participating in a wide variety of projects. Danielle also held an internship with ABC's Extreme Makeover: Home Edition, where her responsibilities included researching products and securing vendor contributions for the families receiving home makeovers. In addition, Danielle has been a long-standing volunteer with Unicamp, a summer program for inner-city youth.

At the IMF, Danielle supports both Heather Cooper Ortner (Vice President, Development) and Lisa Paik (Vice President, Clinical Education & Research Initiatives). Danielle is committed to a professional path that is of service to others and is looking forward to gaining experience in the non-profit sector through her work with the IMF.



Thomas Shin

IT Systems Administrator

Thomas has a varied technical and business-related background, and holds several IT certifications. He also holds a degree in Sociology from CSUN (California State University, Northridge). In addition to a private web-design practice, Thomas was an executive for Yours Truly Accessibility, a private consulting firm. He promoted disability-awareness, assisted businesses with structural and service-related compliance according to various standards and laws (including the Americans with Disabilities Act), and assisted clients with strategies to reduce their litigation exposure and to promote rapport with their local disabled community.

As the systems administrator and technical support specialist for the IMF, he maintains the office network and ensures the smoothness of day-to-day operations. **MT**

SURVIVORSHIP CARE PLAN

Routine health maintenance for patients living with multiple myeloma

To address the evolving needs of myeloma patients and the nurses who work with them, the IMF's Nurse Leadership Board (NLB) has developed a Survivorship Care Plan that examines five specific aspects of long-term care. The full manuscript has been published by the *Clinical Journal of Oncology Nursing* (CJON) in August 2011 as supplement to Volume 15, Number 4. In this issue of *Myeloma Today*, we offer a brief summary of NLB recommendations regarding the routine health maintenance in patients living with myeloma. Future newsletters will cover other sections of the Survivorship Care Plan.

As myeloma patients are living longer due to new therapeutic options, it is imperative to help them maintain a good state of health from the time of diagnosis and throughout therapy to improve survival and quality of life within the context of attendant drug toxicity and patient's pre-existing or therapy-induced co-morbid conditions. The NLB recommendations for health promotion, screening, and disease prevention are designed to meet the particular needs of patients with myeloma and their nurses, and provide an overview rather than an in-depth examination of all possible issues. The following text is a condensed summary of the CJON manuscript chapter prepared by Elizabeth Bilotti, Charise Gleason, Ann McNeill and other members of the IMF's NLB.

Cardiovascular

Essential or primary hypertension has no identifiable cause. Secondary hypertension can develop from a number of diseases and conditions. Undetected or uncontrolled hypertension over a period of time can lead to stroke, heart attack, heart failure, and renal failure. The various therapies used for treatment of myeloma can lead to either hypertension or hypotension; patients may require initiation of medications or dose adjustment of their current regimen.

Over age 20, 15% of Americans have a total cholesterol level >240 mg/dL, which is considered high risk. Testing and intervention are stratified depending on an individual's risk. Current recommendations for the primary prevention of hyperlipidemia may include lifestyle modifications and/or pharmacologic interventions.

Malignancies

Skin cancer is the most common malignancy diagnosed in the US. While the benefits of screening are unproven, people should remain alert for skin lesions with malignant features. Treatments such as chemotherapy, transplantation, radiation, and immunosuppressive agents along with age and sun exposure may place myeloma patients at higher risk for developing skin cancer. Patients should have regular skin examinations, use sunscreens, and limit intense or chronic sun exposure as recommended by their health care team.

Prostate cancer is the most common second malignancy in men with myeloma, and blood test and digital rectal exam should be performed annually in men ≥ 50 (at risk start at 45). Education regarding the screening for prostate cancer is extremely important in the myeloma patient population. Screening for colorectal cancer should begin at age 50 and continuing until age 75. In persons at higher risk, initiating screening at an earlier age is reasonable. Prevention of cervical cancer can be successful with frequent Pap tests and safe sex practices. Women ≥ 40 years should have screening mammography with/without clinical breast exam every 1-2 yrs.

Endocrine

It is estimated that 7% of the US population is living with diabetes, and approximately 90-95% of those cases are type 2 diabetics. Common complications of diabetes include damage to the heart, blood vessels, eyes, kidneys, and nerves. Many of these co-morbidities overlap with the common toxicity profiles of anti-myeloma therapeutics. Prompt recognition and intervention for a pre-existing or new onset diagnosis of diabetes mellitus type 2 is imperative for quality care. The treatment for diabetes mellitus type 2 can vary dramatically from conservative interventions such as lifestyle modifications to pharmacologic intervention with either oral or injectable medications.

Studies have shown that up to 80% of patients on steroids will develop hyperglycemia. Pharmacologic management may be indicated.

Primary hypothyroidism relates to a problem within the thyroid gland itself, rather than a different part of the hypothalamic-pituitary-thyroid axis. The diagnostic workup for primary thyroid dysfunction will often stem from the patient's subjective complaints in combination with their history and a physical examination. Thalidomide or lenalidomide therapy can lead to subclinical hypothyroidism. There are currently no screening recommendations for routine evaluation for thyroid disease in asymptomatic patients. However, the NLB recommend a baseline screening, prior to the initiation of therapy, with regular interval screening every 3 months.

Bone health is so important in myeloma, that it is the subject of a companion NLB manuscript and will be addressed separately in a future issue of Myeloma Today. The related topic of functional mobility and safety is the subject of another companion manuscript, and was addressed in the Summer 2010 issue of Myeloma Today.

Sensory

Comprehensive medical eye examinations should be performed for adults with and without known risk factors. Myeloma patients treated with dexamethasone are at increased risk for blurred vision and cataract formation and should be evaluated as such.

Thirty percent of people over age 65 and 14% of those ages 45-64 years have hearing loss. Adults generally ignore its effects, delay decision to seek audiologic services, and put off recommended treatment (such as a hearing aid). The effects of medication-induced ototoxicity may be reversible and temporary, or irreversible and permanent, and individuals should be aware of potential dangers and may be

CONTINUES ON PAGE 15

SPOTLIGHT ON ADVOCACY

Cancer Coverage Parity Act of 2011 Introduced in the House

By Christine Murphy

Representative Brian Higgins (D-NY) introduced HR 2746, the Cancer Coverage Parity Act of 2011, on August 1. This important piece of legislation requires health insurance coverage of oral anticancer drugs on terms no less favorable than the coverage provided for intravenously (IV) administered anticancer medications.

IV and injected treatments were once the primary methods of cancer treatment. However, oral treatments have become more prevalent and are the standard care for many types of cancer. Unfortunately, the insurance benefit design has not kept pace with this innovation. As it stands now, IV treatments are covered under a health plan's medical benefit where the patient is typically required to pay a co-pay for the office visit. Conversely, oral treatments are being covered under a health plan's prescription benefit and many times, patients are responsible for extremely high and unmanageable copays to fill these prescriptions, which creates a huge barrier to accessing the life saving medications that patients need.

HR 2746 ensures chemotherapy parity for cancer patients by requiring:

- Any health plan that provides coverage for cancer chemotherapy treatment shall provide coverage for prescribed, orally administered anticancer medication that has been approved by the FDA and is used to kill or slow the growth of cancerous cells.
- Orally administered medication shall be provided at a cost to the covered person not to exceed the coinsurance percentage or the copayment amount as is applied to the delivery of an intravenously or port administered or an injected cancer medication prescribed for the same purpose.
- A health plan shall not achieve compliance with legislation by imposing an increase in patient out-of-pocket costs with respect to anticancer medications used to kill or slow the growth of cancerous cells.
- Health plans shall not reclassify such anticancer medications, whether orally-administered, intravenously or port administered or injected, as other than medical benefits to achieve compliance with legislation.

What You Can Do to Help

The IMF needs your help to build support for HR 2746 among Members of Congress. There are two easy things you can do to help.

- Write to your U.S. Representative and ask them to co-sponsor HR 2746. Visit advocacy.myeloma.org and click on Help Eliminate the Disparity in Coverage for Chemotherapy under Issues & Legislation. We have a template letter already set up. Simply fill in your information and click submit. Your message will automatically be delivered to your Representative based on your address information.
- Schedule a district meeting with your Congressional Member to bring HR 2746 to their attention. The IMF has drafted everything you need for a district meeting, including talking points, advocacy tips, and materials to leave with Congressional staff at the meeting. All of these documents can be found on the IMF website at myeloma.org under "Become an Advocate."

The IMF Advocacy Voice

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

Take the first step to help pass HR 2746, the Cancer Coverage Parity Act of 2011 – become an IMF Advocate at **advocacy.myeloma.org**.

As an IMF advocate you will be kept informed of critical issues affecting the myeloma community and legislation at both the federal and state levels to help resolve them. You will also make positive changes in your life and the lives of ALL cancer patients in the US. ***Sign up TODAY!***

advocacy.myeloma.org

Follow this step-by-step guide to schedule a face-to-face meeting with your members of Congress!

Step 1: Visit the Advocacy Action Center. Click on the "Elected Officials" tab on the homepage.

Step 2: Type in your zip code to locate your Representative.

Step 3: Click on your Representative's picture and select the "Contact" tab. Please be sure to locate the local district office and not the DC office.

Step 4: Write down the phone number, fax number, and address of the district office.

Step 5: Click on the Staff tab to locate and write down the name of the Health LA (Legislative Assistant).

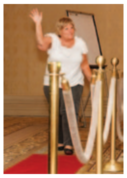
Step 6: Identify yourself as a constituent and request a personal visit with your Representative with the appointment scheduler. If your Senator or Representative cannot meet with you ask to meet with a Legislative Assistant.

Step 7: During your visit share your personal story with myeloma and ask him/her to co-sponsor HR 2746, the Cancer Coverage Parity Act.

Step 8: Continue building relationships with your legislators. Make this the first of many visits. And, have fun!

1st Annual All-Star Advocates Oscars Ceremony

By Meghan Buzby



Lights…Camera…Action! The IMF brought its Hollywood roots to Dallas this summer at the Support Group Leader Summit where the Advocacy team hosted its first annual All-Star Advocates Oscars Ceremony. With the spotlight shining, each winner was announced to drum rolls and music and asked to walk the red carpet to receive their Oscar statue and have their picture taken by the IMF "paparazzi." What better way to honor our advocates who have consistently gone above and beyond for us.

And the winners are…

1. Michael & Robin Tuohy – ***Best Advocate Duo in Connecticut*** for providing oral testimony to the Connecticut Senate Insurance and Real Estate Committee in support of SB 50, the Oral Parity bill in CT. The bill was signed into law in 2010. The dynamic duo is also responsible for sending 115 messages to their federal and state legislators! Michael and Robin are the Waterbury, CT support group leaders.

2. Rob & Sue Enright – ***Best Advocate Duo in Wisconsin*** for their work on oral parity legislation in Wisconsin. Rob and Sue met with State Rep. Pat Strachota to gain her support of the issue and were instrumental in persuading her to co-author and introduce a bill. Sue also participated in the lobby day A Day at the Capitol in Madison to educate other state Representatives and Senators about the bill. Rob and Sue are the support group leaders from West Bend, WI.

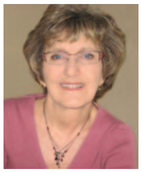
CONTINUES AT TOP OF NEXT PAGE

3. Jerry Walton – *Best Capitol Hill Advocate in Virginia* for visiting the nation's capitol in 2010. Jerry met with Senator Mark Warner, Senator Jim Webb, and Representative Glenn Nye to discuss issues facing his support group and the myeloma community. He is the support group leader from Norfolk, VA / Northeast NC.

4. Caethe Goetz – *Best Advocate in California* for her work on oral parity legislation in California. Caethe provided oral testimony to both the Assembly and Senate committees. The bill passed both Houses! She is the Napa Valley / Sonoma support group leader.

5. Jack Aiello – *Best Capitol Hill Advocate in California* for his work in DC. In 2010, Jack met with Senator Dianne Feinstein, Senator Barbara Boxer, and Representative Zoe Lofgren to discuss legislation important to him and the myeloma community. He is the support group leader from the San Francisco / Greater Bay area.

Two all-star advocates missing from the celebration were Paula Van Riper, Central New Jersey Multiple Myeloma support group leader and Marti Hill, former support group leader from the Tampa/St. Petersburg, Florida group.



In June of this year, Paula testified before the Assembly Health Committee on behalf of oral chemotherapy access legislation in New Jersey. And last year, Marti visited her members of Congress in Washington to discuss issues important to her as a patient and to make some specific requests that would benefit the myeloma community.

The Advocacy team would like to thank all of our all-star advocates for everything they have done and continue to do to help myeloma patients and ALL cancer patients across the nation. And we look forward to next year's ceremony! **MT**

How to contact the IMF Advocacy Team

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

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

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

NLB – SURVIVORSHIP CARE PLAN — continued from page 13

advised to undergo more frequent screening examinations. It is recommended that all hearing screening programs be conducted under the supervision of an audiologist holding the American Speech-Language-Hearing Association's Certificate of Clinical Competence, and that adults be screened at least every decade through age 50 and at 3-year intervals thereafter.

Psychosocial

Depression affects 19 million Americans annually, with most studies indicating that 20-25% of cancer patients will be afflicted at some point in their treatment. Despite the high prevalence of depression in cancer patients, it is often under diagnosed and therefore untreated. Fatigue, pain, and anemia are symptoms that can be related to both treatment of cancer and cancer-related depression. A clinician needs to distinguish the difference between the symptoms associated with the patient's medical illness or treatment and depressive symptoms associated with syndromal depression.

Fatigue in cancer patients can have a major impact on overall quality of life. It can be cumulative as with radiotherapy, or have an acute onset as with chemotherapy. Patients with myeloma often undergo a complicated treatment regimen which may produce fatigue.

Cancer patients may also experience cognitive changes referred to as "chemo brain" that can have an impact on processing, organizational skills, memory, concentration, and attention span. Risk factors include chemotherapy, radiation therapy, and transplant.

Addiction and substance abuse

Cigarette smoking and exposure to environmental tobacco smoke increase the risk of pulmonary infections in general and the risk to contract invasive pneumococcal disease by a factor of 4:1, and for immunocompromised patients with myeloma, avoidance is important. Tobacco use in all forms is the biggest risk factor for oral cancer. Alcohol use combined with tobacco use increases this risk.

Nearly 1 in every 13 American adults abuse alcohol, and more adults engage in risky drinking that could lead to alcohol problems. Alcohol may exacerbate adverse effects of common myeloma therapeutics with a potential for an increase in gastritis, neuropathy, and liver dysfunction. It is important to note that some treatment regimens (e.g., those that contain bortezomib) require dose modifications for individuals with hepatic impairment.

Nutrition

Iron deficiency is the leading cause of anemia. The treatment of iron deficiency begins with identifying the cause. One of the indicators of asymptomatic myeloma is the observation of worsening anemia. Patients initiating or continuing exogenous erythropoietin therapy should be evaluated for adequacy of iron stores.

Obesity can contribute to the development of several chronic diseases from cardiovascular to cancer. All adult patients should be screened for obesity.

Miscellaneous

Myeloma and its treatment can increase a patient's risk of developing an opportunistic infection by interfering with normal immune function. The healthcare team must monitor patients for infection and treat them appropriately. Recommendations to prevent infections may include hand-washing, avoiding anyone with infections, good dental hygiene, and prophylactic antibiotics.

Immunizations are an important primary prevention that should be continued even when on active treatment for cancer. For most myeloma patients who have received their childhood vaccinations, the seasonal influenza vaccine and the pneumococcal vaccine should be administered. Varicella vaccine is currently contraindicated for immunocompromised patients due to immunosuppressive agents and other anti-myeloma therapy. After transplant, patients should follow the recommendations of their transplant center as well as their healthcare provider.

Patients with myeloma receiving bisphosphonate support are at increased risk of ONJ and it is recommended that they maintain good oral hygiene with routine dental evaluation.

Summary

Patients with myeloma are at risk for the illnesses experienced by the general population, as well as at additional risk related to both the disease and its treatment. Patients and caregivers should communicate with their medical teams about health maintenance practices. For more information, please contact the IMF Hotline at TheIMF@myeloma.org or 800-452-CURE (2873). **MT**

UPDATES FROM AROUND THE GLOBE

Advances Against Myeloma in China

By Dan Navid

The fight against multiple myeloma in China received an important boost with the announcement, in Beijing on August 13, 2011, of an affiliation between the IMF and Chinese myeloma experts. Prof. X. Huang of Beijing University is charing the expert group which is part of the IMF's International Myeloma Working Group (IMWG). Co-founders include IMWG members Drs. Wenming Chen and Jian Hou, as well as other experts from key cities across China (Beijing, Shangahi, Chendu, Xian, et. al.).

The Chinese myeloma experts are working with the IMF to initiate a program that will feature national training sessions for Chinese physicians, as well as patient education activities, including the production of information publications and videos, and an annual expert meeting. These activities will integrate with the IMF's Asian Myeloma Network (AMN) overall, which was established to address the growing incidence of myeloma in one of the world's most densely populated regions, and will contribute to the work of IMF's International Myeloma Working Group (IMWG).

The new Chinese affiliation was launched at the outset of the two-day Chinese 2011 Myeloma Forum, co-hosted by Dr. Wenming Chen and featuring the participation of IMF's President, Susie Novis, and IMF's Chairman, Dr. Brian G.M. Durie. More than 200 myeloma doctors from some 50 cities across China joined in this Forum, which was supported by J&J, Celgene, and numerous Chinese industry partners.

Dr. Durie's opened the meeting with a general overview of myeloma. He also led an interactive session on myeloma bone disease diagnosis and management. This opened the discussion on the treatments currently available in China. Velcade® (bortezomib) and a local brand of thalidomide are both available, but Revlimid® (lenalidomide) is not yet approved, and autologous stem cell transplantation (ASCT) is feasible only at a few centers.

The IMF also took part in a meeting of the China Myeloma Patient Club, a 1,500 patient-strong support group. With 40-50 patients in attendance, Dr. Durie responded to questions from patients who seemed truly desperate for advice and comfort. The need for a presence like the IMF in this environment was apparent.

The next day, the IMF met with the representative of the Chinese Health Promotion Foundation (CHPF), with whom we entered into a collaborative agreement earlier this year. We learned of an opportunity to submit a grant request to support educational initiatives for 2012, and we are very excited for the chance to further the IMF's mission to promote patient education and awareness in China.

Shanghai, a city of 30 million people, was next on the itinerary. The IMF team met with Professor Jian Hou of the First Military Hospital, who is the principal investigator for the study that should lead to lenalidomide approval in China by 2013. In addition to a transplant unit plus inpatient and outpatient services, the off-site university translational research center conducts state-of-the-art molecular/genetic research. After touring the facilities, Dr. Durie gave a lecture to 60 Shanghai hematologists. The day culminated in a gala dinner attended by the President of the Chinese Hematology Society. It was a special evening of celebration and the start of ongoing collaborations.

The next IMF meeting in China is planned for May 2012 in Shanghai, and will convene both the Chinese experts and key members of the IMF' s AMN, with participants from six other Asian Countries or territories, including Hong Kong, Chinese Taipei, Japan, Korea, Singapore, and Thailand.

Further meetings of the AMN are taking place in Korea in September, at ASH 2011 in San Diego in December, and in Hong Kong in February 2012. An initial abstract detailing the epidemiology of myeloma in Asia was submitted for the ASH 2011 meeting, outlining early results from Korea and Singapore.

IMF Expands Meetings in Europe

By Gregor Brozeit

In June 2011, the IMF conducted its first Patient & Family Seminar in Norway, with Dr. Robert Kyle headlining the seminar in Oslo as well as two doctors meetings in Trondheim and Bergen.

Dr. Anders Waage of Trondheim – a member of the International Myeloma Working Group (IWMG) – was instrumental in organizing the meetings and participated with Dr. Kyle and host Dr. Nina Guldbrandsen. The meeting featured updates on novel therapies, information about clinical trials in Norway, question and answer periods, as well as breakout sessions for one-on-one interaction between attendees and faculty.

"It is clear that there is a demand among patients and caregivers for updated information about myeloma," said Ann Doeli, a staff member of the Ulleval Hospital who was responsible for the on-site organization of the seminar. "The breakout sessions were an excellent idea and a highlight of the meeting."

Prof. Kyle and Dr. Jakob address Berlin Patient Meeting

Dr. Kyle was also the featured speaker at roundtables for clinicians and researchers in Trondheim and Bergen, hosted by Drs. Waage and Roald Lindås, respectively. He addressed the latest in myeloma research and treatment, and discussed specific local case studies.

Prior to the Norway meetings, Dr. Kyle headlined the second annual patient seminar in Koblenz, Germany. The seminar was co-hosted by Prof. Ralph Naumann, the Koblenz Myeloma Patient Support Group, and the IMF. Prof. Hermann Einsele of Würzburg (IMWG member) and Prof. Rudolf Weide of Koblenz rounded out the faculty. Dr. Kyle then headlined a patient meeting hosted by Dr. Christian Jakob at Berlin's St. Hedwig Clinic. More than 140 patients and family members attended the two meetings in Koblenz and Berlin.

CONTINUES ON PAGE 21

2011 IMF SUPPORT GROUP LEADERS' SUMMIT

By Abbie Rich

Day One

The 12th annual IMF Support Group Leaders' Summit was held July 29–31 at the Four Seasons Resort in Dallas, TX. This special event brought together more than 75 patients and caregivers who lead myeloma support groups around the US, plus two group leaders from Canada. The Summit is organized by the IMF in order to support leaders in addressing the issues they face in running their groups, and to honor these wonderful individuals for their dedication to helping myeloma patients in their communities.

Kati Rosten

It is both great to see the people I met at last year's Summit and to meet so many leaders of recently formed groups. I want to share with you something I heard from Kati Rosten, leader of the group in Redding, CA. She has had a challenging year, but she told me, "I had to come back to this meeting. It just builds me up, and then I can go back and help my group. They lift me too, but this helps me lift them."

After a fun mental exercise led by Summit facilitator, Alan Kumamoto, IMF Chairman Dr. Brian G.M. Durie presented a summary of the 2nd Summit of the International Myeloma Working Group (IMWG), which was recently held in London, United Kingdom. After explaining the value of the collaborative effort that is the IMWG, he talked about the six key issues addressed at that important meeting:

1. Diagnosis and management of high-risk myeloma
2. Sequential vs Curative Strategies: Testing 2- vs 3- vs 4-drug combos
3. Role of early transplant
4. Maintenance or consolidation
5. Integrating new and existing drugs into the myeloma treatment paradigm
6. Risk stratification in myeloma

The support group leaders were very interested in this presentation. I have found that myeloma patients in general and support group leaders in particular are well-informed about all aspects of their disease. Most of the group leaders in attendance at the Summit had been to IMF Patient & Family Seminars, where top myeloma experts present the latest information in a format we all can understand.

What really pricked up the leaders' ears was when Dr. Durie talked about the search for a cure. At the IMWG Summit, Dr. Russell from the Mayo Clinic presented a talk on oncolytic virotherapy, where myeloma cells are killed by a virus assisted by interferon. If using a virus against myeloma can be shown to be effective in mice, we need to follow that possibility and be open to all concepts of finding a cure.

Day Two

The day opened with a "round robin" of groups to hear presentations on available and upcoming myeloma drugs by three myeloma pharmaceutical companies: Celgene, Millennium, and Onyx.

Jeffrey Elbl (Medical Science Liaison, Millennium) gave an update on the VISTA clinical trial of Velcade® (bortezomib) used upfront in newly diagnosed patients – analysis after three years confirms the overall survival benefit of Velcade added to melphalan and prednisone. In addition, the phase III trial of subcutaneous (Sub-Q) Velcade shows that it is equivalent to intravenous (IV) administration in all aspects except that the side effect of peripheral neuropathy (PN) was substantially lower.

Dr. Joseph Leveque (VP of Medical and Scientific Affairs, Onyx) addressed the major benefits of carfilzomib, which is nearly free of PN and has a 19% response in patients refractory to bortezomib. The currently-recruiting phase III clinical trial ASPIRE (carfilzomib, lenalidomide, dexamethasone) is looking at progression-free survival (PFS). Onyx's Jennifer Sharretts talked about patient access as well as their enhanced patients and caregivers service.

I cannot tell you what Mark Allis (President, Celgene) told us, because he asked us not to make it public, but he did stress that Celgene is committed to assisting patients who are having trouble paying for Revlimid® (lenalidomide), and I don't think he would mind me sharing this.

Large Groups/Small Groups

Sometimes the leaders of smaller groups feel intimidated by the accomplishments of the more established groups, so we set about identifying the benefits and the challenges of each type of group. You can read more about these interesting sessions on the IMF web site sglsummit2011.myeloma.org.

How to Be a Good Facilitator

Summit facilitator Alan Kumamoto talked to us about – guess what – facilitating! Sounds easy, but it isn't. His presentation on how to keep a group running smoothly, keep everyone motivated, and keep yourself from going crazy in the process engaged everyone in conversation. Alan talked about the natural progression of a group, from the "Prenatal" stage of someone thinking about forming one through the "Launch" and "Growth" stages to "Maturity" of the group where delegation of responsibility keeps things running smoothly. Groups require planning and organization to keep members energized. Groups need a mission statement, guidelines, and opportunities for rest and recreation, such as a picnic or other joint celebration. There are many ways to make ourselves better leaders.

Tasty Tidbits at Lunch

Box lunches came with an opportunity to ask Dr. Durie questions. He stood at the front of the room answering a stream of inquiries on all kinds of interesting myeloma topics while we chowed down. Everyone wanted this session to go on forever!

Oh, Nurse!

Bonnie Jenkins, a member of the IMF Nurse Leadership Board (NLB) and an integral part of Dr. Bart Barlogie's team at the UAMS Myeloma Institute for Research and Therapy, got a standing ovation for her presentation. She covered many areas of interest, including subcutaneous Velcade, PN, the NLB's Survivorship Care Plan, and "I Will Survive! What do I do now that I forgot to die?" Bonnie made us all stand up and dance to Gloria Gaynor's song "I Will Survive!" and told us to remember that it is all worth it, every single day.

CONTINUES ON PAGE 22

PEOPLE HELPING PEOPLE

You are never alone in your battle against myeloma

The IMF takes this opportunity to highlight two myeloma support groupsin Arizona and one hematological cancer support group in North Carolina. On October 30, an IMF Regional Community Workshop (RCW) will take place in Raleigh-Durham, NC; on November 12, an IMF RCW will take place in Phoenix, AZ. RCWs are half-day meetings designed to provide much of the same information presented at an IMF Patient & Family Seminar, but in a condensed form. RCW faculty consists of local myeloma specialists, a nurse, and a speaker on supportive care issues. The IMF works closely with the local support groups to promote these meetings, and many group members will be in attendance. To view the full schedule of upcoming RCW meetings, as well as information about how to register online, please visit the IMF's website myeloma.org.

Phoenix, AZ


Brenda Gregory

The Phoenix Myeloma Support Group was formed in 1998 by a group of patients and caregivers who met through the IMF. Brenda Gregory, one of the founders, still leads the group 13 years later. “Five or six months after the Phoenix support group was formed, there were enough people driving here from the Tucson area that they started their own group, so we now have two active support groups in Arizona.”

The Phoenix meetings are usually attended by about 30 participants, and Brenda now shares the responsibilities of leading meetings with a professional facilitator. “Our group stresses education, and we always help ‘newbies’ through the maze of dealing with myeloma. But we also share hope. My fellow group members have become my mentors as well as my best friends, so I welcome anyone who reads this to come join us. I know from experience that we all heal better in a group.”

This support group meets on the first Thursday of each month from 10:00 a.m. to 12 noon at the Wellness Community. For more information, please contact Brenda Gregory at bgregory43@yahoo.com or 623-362-0853.

Tucson, AZ

Founded by myeloma patients who initially attended the meetings of the support group in Phoenix, the Southern Arizona Multiple Myeloma Education & Support Group has been active since 1998. The group grew rapidly, thanks in part to one of its co-founders, Larrie Ann Theis, a nurse who was very effective in reaching out both to the patients in the area and to the local medical professionals. “She believed that each member was an integral and contributory part of the group,” says Nancy Ostlund, one of the group's former leaders who continues to participate as a volunteer. “The mission defined in the early days of the group existence continues to motivate us today: to enhance the quality of life of myeloma survivors, their caregivers, and family members by promoting education, self-advocacy, and friendship. I am very proud of our group's camaraderie. It creates a safe setting for members to freely express their thoughts and feelings. Education and the sharing of experiences are equally important to anyone who is living with myeloma.”

As the membership grew, Nancy led the effort to transition the group from meeting at a local church to a new “home” that makes resources more immediately available to members. Since January, the group has been meeting at the Arizona Cancer Center-UMC North, and has benefited from the addition of two new facilitators, social workers Kathleen Pickrel and Lynn Barwick. “The myeloma group is one of our most active support groups,” said Kathleen. “We usually have at least 20 people at each meeting, and our format is designed to best serve the needs of our members. For the first hour, we listen to a presentation by an invited speaker, then take a little break and resume with a second hour dedicated to sharing. Our meetings have recently featured talks by a cancer nutritionist and a radiation oncologist. Next month, a guest will teach us about ‘laughter yoga.’ While our education component is mostly focused on cancer, we must remember the whole person, so we offer resources that are healing on multiple levels.”

This support group meets from 1:00 p.m. to 3:00 p.m on the third Saturday of each month at the Arizona Cancer Center-UMC North. For more information, please contact Kathleen Pickrel, LMSW, at kpickrel@umcaz.edu or 520-694-4786, or Lynn Barwick, LCSW, lbarwick@umcaz.edu or 520-694-1855.

Raleigh-Durham, NC


Patrick Plumeri

“A cancer diagnosis has an impact on both the patient and the caregiver,” says Patrick Plumeri, MS, LMFT, a therapist with the Duke Cancer Patient Support Program (DCPSP) who facilitates the group that serves the local myeloma community. “Our support group started out being exclusively for myeloma patients and caregivers, but has since opened up to welcome individuals coping with other hematological malignancies.”

Patrick ensures that the meetings offer an environment of fellowship and empathy. “We have group members who were recently diagnosed with myeloma, as well as a 14-year survivor, and I have witnessed how beneficial their first-hand interaction has been. Being able to express and share how you feel, physically and emotionally, is crucial to anyone coping with a cancer diagnosis and going through the rigors of treatment. My goal as a facilitator is to present an emotionally safe place for all who attend our meetings.” The group meets over lunch provided by DCPSP in a round-table setting and, upon request from members, occasionally hosts presenters to address specific topics of interest.

This support group meets on the first and third Monday of the month from 11:00 a.m. to 12:30 p.m. at Duke Cancer Institute in Durham, NC. Parking vouchers are available. For more information, please contact group facilitator Patrick Plumeri, MS, LMFT, at Patrick.plumeri@duke.edu or 919-684-4497. **MT**

25 YEARS AND COUNTING...

By Harold Dozier

In 1986, I attempted to be a blood donor but was turned down because my blood counts weren't right. In hindsight, that was my first known symptom of myeloma, but I didn't recognize it. I was experiencing some fatigue, but I simply ignored it. A few weeks later, in July 1986, intense abdominal pain led to a trip to the emergency room. It was likely a kidney stone attack, but a blood test showed that I was was severely anemic. In August, after numerous additional tests, I was admitted to the hospital for diagnostic evaluation. A bone marrow aspiration revealed that I had the IgG form of myeloma. I learned of the diagnosis by peeking inside my medical chart. I had never heard of myeloma previously.

My wife Joan and I were told by the oncologist that myeloma was a treatable cancer, but it was several weeks before I realized that the average life expectancy of a myeloma patient was only two to three years. We had two teenage children. I focused on the treatment, and began monthly oral chemotherapy with melphalan and prednisone. I stayed with this regimen until June 1988 when it became ineffective at controlling the cancer. Next, I received four cycles of my first high-powered chemotherapy: VAD (vincristine, adriamycin, decadron). After numerous side effects, I contracted pneumonia.

From September 1988 until June 1993, I took dexamethasone, a steroid that led to notable mood and energy swings. Then, on Father's Day in 1993, I once again landed in the emergency room with severe abdominal pain. Tests revealed a perforated colon requiring surgery and a colostomy (which was reversed two months later). Chemotherapy was stopped.

I resumed VAD in October but, after two cycles, once again developed a perforated colon requiring two additional surgeries. I remained in the hospital with fever and infection until the end of 1993. In February 1994, I returned to work as an Administrator at the Oklahoma Tax Commission, and VAD treatments were resumed at the end of that month. However, the colon problems returned and led to a second colostomy a month later, my fifth colon surgery in less than a year.

At that point, an autologous stem cell transplant (ASCT) became my best treatment option. Insurance rejected the procedure, but we appealed to the State Insurance Board and to our state senator, and approval was finally granted in Spring of 1995. I was accepted into a SWOG (Southwest Oncology Group) clinical trial and began initial high-dose chemotherapy in July. After being hospitalized in isolation one week due to infection, I was so weak that I had to be wheeled into the Oklahoma Blood Institute 9 times to harvest enough stem cells for the transplant. The transplant oncologist decided to give me extra time at home before returning to the hospital in August for further high-dose chemotherapy. On our wedding anniversary, our Pastor came by the hospital to give us communion. My stem cells were re-infused over the next two days, and I returned home 9 days later!

Following the SWOG protocol, I maintained remission with Alpha Interferon until increased problems with lethargy, light-headedness, and upset stomach led to discontinuation of the injections. I returned to work in 1996 and was happy to take early retirement in April 1999.

Besides the myeloma itself, I have dealt with varying degrees of health issues over the years. I had cervical neck surgery. I have dealt with depression, including a major attack in 2000, and I continue to take anti-depressants. In late 2009, my myeloma relapsed, requiring me to take Velcade® (bortezomib), which caused severe peripheral neuropathy in my hands and feet. Side-effects of long-term chemotherapy may be linked to my heart problems. But there has been much to learn from these experiences, and I'd like to share my lessons with you:

- I am a person of faith, and I know that God is faithful, no matter the circumstance.
- Don't give up when times are tough and there seems to be no hope. Keep a positive attitude and a sense of humor.
- At all times, know what treatments you are receiving and why.
- Maintain a comprehensive medical history, including names of doctors, treatments, allergies, and family background. Bring a copy to doctors' appointments and carry this with you whenever you travel.
- Be your own advocate. Be an active part of your own team. Know when you need help, and make sure you get it.
- Join a support group for fellowship and education. I did not meet another myeloma patient for 8 years after my diagnosis, and I didn't know that there was such a thing as a support group. Now I encourage all long-term survivors to extend themselves to the newly diagnosed.
- Know that more and better treatments are coming your way. I have seen the myeloma treatment options increase significantly since my diagnosis.

I've led an interesting life. I joined the Navy directly after high school. I was with NASA for 15 months, working on communications for Project Mercury, the first US manned spaceflight program. Then I was at the Navy Department, spending the Cuban Missile Crisis in Guantanamo. After I got married, I went to college in Oklahoma, and eventually landed at the State Tax Commission running a department with a staff of almost 140 people. Since my transplant, I have taken 35 trips and flown 90,000 miles as a volunteer courier delivering donor stem cells collected at the Oklahoma Blood Institute. My wonderful, supportive wife and I have celebrated our 49th anniversary. We are grandparents now. My cancer diagnosis is only one part of a much larger story. But it has now been more that 25 years since myeloma came into my life with a prognosis of 2 to 3. Our family and friends have supported us through prayers and gifts of love and grace, and we thank God daily for his blessing of life. My path with this disease has certainly not been smooth, but I've lived the hand that I was dealt. My hope is that my myeloma experiences will in some way help you with yours. I want you to know that you are not alone. **MT**

IMFers RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia

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

Being involved is very fulfilling and empowering. Join us in our search for a cure for myeloma. By organizing an event in your community, you are raising public awareness and helping those whose lives have been touched by this disease. Maybe you want to do something in your community, but deciding on what to do and how to do it can be confusing. That's where we come in! The IMF is here to help you every step of the way. We make it as easy as possible for you to be involved.

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

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

* * *

The RHS Open

Joining the Board of Directors in 2001, Rich Saletan was responsible for the growth of the IMF not only in the amount of revenue but also in the innovating programs he developed. In part, his mission was to put myeloma "out of business" by supporting research aimed at finding a cure. The Saletan Family has carried on that mission in his memory.

The Saletan/Berkman Family with friends and supporters

Organized by Suzanne Saletan and their children Steven and Kim Saletan, Liz and Rich Berkman, and their families, a successful inaugural fundraiser in 2010 raised almost $11,000 for research, setting a high water mark for the 2011 annual RHS Open. This year's golfing event took place on May 14 at the Wycliffe Country Club in Wellington, FL. The full day of activities started with a continental breakfast, followed by the tee-off for nearly 80 golfers, some of whom travelled from far and wide to participate. Lunch for 100 was served following the tournament, and as many as 50 supporters came for dinner at the Saletan Family home.

"It was great to have both our kids and all the grandchildren at the event, along with so many family friends. Even those who could not attend contributed to our success. It was truly a family effort," said Suzanne. "Rich's first love was his family, and his favorite sport was golf, so this was a perfect way to celebrate him, and to share our remembrances. I thought it would be a difficult day for me, but it turned out to be very special. With support from The Ganek Family Foundation and The David Beckerman Foundation, we were able to give more than $16,000 to the IMF, which I hope will help get us closer to a cure for myeloma."

Margie's Road To Recovery

Judy Montgomery's sister Margaret was diagnosed with myeloma in 2010 as a result of a test performed after she was involved in a car accident. "The MRI showed that myeloma had essentially destroyed Margie's femur," said Judy. "We were all devastated to hear that the youngest in our family of four siblings had cancer."

In December, while Margie was in the hospital being prepped for an autologous stem cell transplant, Judy got together with family and friends to plan a show of support for her sister. "Moping around isn't going to change anything, so we decided to hold a party in April at the Clambake Restaurant in Scarborough, ME. We wanted to raise myeloma awareness, support the IMF research program, and help Margie with her medical bills."

Judy was hoping that the event would bring together as many as 100 people. Imagine her surprise when 300 partygoers showed up! "Never in my wildest dreams did I think that so many people would step up to help."

Unfortunately, Margie couldn't attend the event being held in her honor because she was still recovering from her transplant, but she was certainly there in spirit. Instead of margaritas, the venue served a custom drink called the Margie-rita. There were raffles and silent auctions, a live band and dancing. "Everyone had a great time; even our 89-year-old mother got on the dance floor!"

By the end of the evening, with more than $12,000 raised, event organizers decided to turn Margie's Road To Recovery into an annual myeloma awareness and fundraising event. Plans are already underway for 2012.

Bald-4-Bucks

Steven Brown & David Chan

When two good friends, David Chan and Steven Brown, had a casual conversation about raising money for a cancer cause - Dave's father was diagnosed with myeloma in 2010 and Steve's mother is a cancer survivor - the two decided to hold an event to benefit the IMF. To support Brian Chan, who would be losing his hair from chemotherapy prior to his stem cell transplant, Dave and Steve decided to shave their heads to help raise funds for the cause.

From fro to $6800 in dough!

Held on June 2 in New York City, the "Shave Your Fro For Some Dough" event became an unexpected success. In addition to Dave and Steve shaving their heads for donations, there were three additional volunteers. "We thought our goal of raising $5,000 was fairly aggressive, but we were able to reach $6,800! We greatly appreciate the overwhelming generosity and kindness of all our supporters," said Steve. "My father attended the event along with the rest of the family, and he is very proud of what we accomplished," added Dave. "He has now recovered from his transplant and expects to return to work in September."

Senior Project Glee Club

Ally Tuohy's father was diagnosed with myeloma in 2000 when she was 7. By age 12, she was raising funds for the IMF with a lemonade stand. "Now I am 18 and starting college," said Ally. "For our high school Senior Project, my friend Rebecca Norton and I chose to create a Glee Club performance to raise myeloma awareness and to benefit IMF programs and services."

Starting in November 2010, Ally and Rebecca assembled the performers, developed the program, composed the vocals, choreographed the dances, and taught

CONTINUES AT TOP OF NEXT PAGE

Member Events

the music to their cast. "It was a long process, but very rewarding. I was so happy to be able to give back to the IMF. The Foundation has always been there for us and feels like family to me."

(left to right) Samantha Savvidou, Rebecca Norton, Corinne Marshall, Alexa Steinis, Dan Lyons, Ally Tuohy, and music teacher Mr. Lewis, *(back row)* Principal Dr. Frank and Morgan Smith

The show took place on June 3 at Woodland Regional High School, in front of an audience of 100. First, Ally spoke about myeloma and the IMF, and how her Dad has inspired her to help others. Then the WRHS Chamber Choir took the stage, followed by the Glee Club members who performed "covers" of contemporary pop songs.

The Glee Club Performance tickets were free of charge but, with the help of generous sponsors and donors, Ally and Rebecca raised more than $5,565 to support the IMF. **MT**

UPCOMING MEMBER EVENTS

October 9, 2011
7th Annual Walk For Myeloma – Miami, FL
Contact: Denise Vidot, lta.umwalk@gmail.com

October 15, 2011
Monster Miles For A Cause – Dover, DE
Contact: Josephine Diagonale, mmsupportde@comcast.net

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

MYELOMA 200 – CLOSER TO A CURE

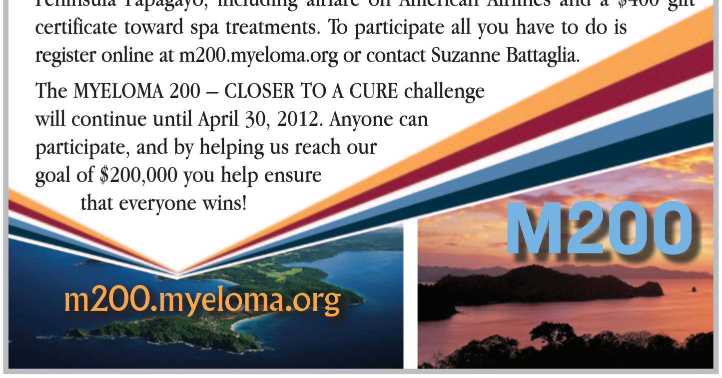
Teamwork makes everything possible. Start your myeloma 200 Fundraising team and help the IMF reach a goal of $200,000 for our Research, Education, Support, and Advocacy Programs.

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

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

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

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



International Affiliates

UPDATES FROM AROUND THE GLOBE— continued from pg 16

Next, Dr. Kyle traveled to Sweden to headline a patent seminar in Gothenburg and physicians' roundtables in Gothenburg and Lund. More than 150 patients and family members attended the Gothenburg seminar that was cosponsored by the IMF and the Swedish Blodcancerforbundet. Speakers included Dr. Ulf-Henrik Mellqvist (IMWG member), other medical faculty, social workers, and a nurse from the Gothenburg University Clinic.

Dr. Kyle's tour closed with a doctors' roundtable at Skåne University Hospital in Lund, the nation's oldest university. Hosted by Prof. Ingmar Turesson (IMWG member) and faculty chair Prof. Stig Lenhoff, the meeting featured a free-ranging discussion of professional and medical issues related to myeloma. According to Dr. Turesson, "The meeting was highly appreciated by the younger doctors who enjoyed the opportunity to listen to an important message from a leading expert in myeloma."

In addition to those meetings, the IMF, together with Prof. Roman Hajek, IMWG member and the founder and chair of the Czech Myeloma Group (CMG), co-hosted a first ever patient workshop in Prague on May 30. The medical faculty, joined by social and legal workers, provided key information to the 65 attendees. The IMF and the CMG have long co-hosted annual Patient & Family Seminars – one will be held in Lednice on September 30 – but this was the first community workshop conducted together.

On June 25, the IMF and the Leipzig Myeloma Support Group, co-hosted their second annual patient meeting, attracting more than 120 attendees. Prof. Dietger Niederwieser and Prof. Wolfram Pönisch of the Leipzig University Clinic, who pioneered much of the research for bendamustine, were joined by Dr. Jens Hillengass from the University of Heidelberg. Dr. Hillengass is recognized as one of the top experts for cancer imaging in Germany. "Albrecht Reissman (founder and president of the Leipzig Support Group) is well recognized as one of the most successful patient leaders in Germany. His organization of the meeting was exceptional and I was honored to be asked to participate," said Dr. Hillengass.

Prof. Sezer, Dr. Salwender, Hamburg SG Leader Rosi Jäger, and Dr. Heiko Dau at Hamburg Seminar

This summer's final IMF patient meeting in Europe was held in Hamburg on June 26. The faculty included Dr. Hans Salwender from Hamburg-Altona, Prof. Nicolaus Kröger and Prof. Orhan Sezer from the Hamburg-Eppendorf University Clinic (both members of the IMWG), and Prof. Martin Gramatzki from the University of Kiel. Dr. Heiko Dau, a retired emergency room surgeon who is also a myeloma patient, spoke about his experience undergoing an allogeneic transplant. He had to give up the practice of medicine following his diagnosis in 2005. Following a number of failed therapies, he was transplanted with cells from a non-related donor in 2006 and was treated with a follow-up regimen. Dr. Dau has been in remission since 2009 and is now engaged in counseling patients in Germany.

The IMF will conduct more patient and doctor meetings in late 2011. In October, Dr. Kyle will headline a patient meeting in Denmark, co-hosted by the IMF and the Danish Myeloma Patient Group. He will also be the keynote speaker for the semi-annual meeting of the Danish Myeloma Study Group before moving on to patient and doctor meetings in Germany and Italy. **MT**

SUPPORT GROUP LEADERS SUMMIT — continued from page 17

The Tough Stuff

To spur an open discussion of the challenging aspects of running a group, David Girard moderated a panel made up of Jack Aiello, Jerry Walton, Susie Novis, and Robin Tuohy.

Jerry addressed the handling of medical information. You almost cannot talk about myeloma without talking about treatment and side effects, and it is understood that people share medical information at support group meetings. So how do you communicate medical info to and within your group if you are not a doctor? Many suggestions were shared: IMF Hotline and publications, and how to find information on the web.

Jack Aiello opened the discussion on finding speakers. Most groups want speakers but they also want time to talk and share among themselves. Jerry Walton commented that Dr. Durie had been a "speaker" at his group's meeting without knowing it – Jerry used a DVD from an IMF Patient & Family Seminar!

Susie Novis addressed dealing with grief. When there is loss in the group, it is important to tell stories and celebrate the person's life. "Hey," she said, "I would want people to talk about me after I'm dead." Schedule a time for celebration and, if people don't want to participate, they don't have to. Invite surviving caregivers. Make a scrapbook with pictures. Just don't ignore the loss.

Robin Tuohy closed the session with a positive spin on the emotional roller coaster that is the myeloma experience: diagnosis, treatment, remission, and relapse. Robin encouraged us to be proactive and not be afraid to ask for help.

She talked about how to keep members coming back to meeting. She also made the point that when patients are doing well, they have an opportunity to help someone by sharing their experience with a "newbie."

Time to Go Home

The Summit closed with an "open mic" session where we shared what the meeting meant to us. If there was a dry eye in the place, I didn't see it. Someone commented that what they found truly amazing was that cancer patients can have fun. Another person said that she didn't want to attend but was now going home re-energized. All of us took away so much from the Summit that I encourage those group leaders who have yet to experience this wonderful annual meeting to join us in 2012.

Until next year…! **MT**

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

NON-PROFIT
ORGANIZATION
U.S. POSTAGE
PAID
N. Hollywood, CA
PERMIT NO. 665

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

2011/2012 IMF Calendar of Events

2011

Oct 12	IMF/DMF Patient & Family Seminar – Nyborg, DENMARK
Oct 16	MM Patient & Family Seminar – Heidelberg, GERMANY
Oct 23	MM Regional Community Workshop – Berlin, GERMANY
Oct 29	IMF Patient & Family Seminar – Ulm, GERMANY
Oct 30	IMF Regional Community Workshop – Raleigh Durham, NC
Nov 5	IMF 5th Annual Comedy Celebration – Los Angeles, CA
Nov 12	IMF Regional Community Workshop – Phoenix, AZ
Nov 19	IMF Regional Community Workshop – Leipzig, GERMANY
Dec 10-13	American Society of Hematology (ASH) – San Diego, CA

2012

Feb 3-4	IMF Patient & Family Seminar – Boca Raton, FL

Additional events/meetings will be posted in later editions of *Myeloma Today* as dates are finalized.
For more information, please visit myeloma.org or call 800-452-CURE (2873).

IMF–Latin America, IMF–Japan and IMF–Israel events are not included above.