Improving Lives • Finding the Cure

MYELOMA TODAY

SUMMER 2012
VOLUME 9 NUMBER 2

A Publication of the International Myeloma Foundation

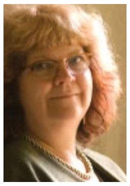
Dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure.

Scientific & Clinical News

Dr. Brian G.M. Durie (Chairman, IMF Board of Directors; Cedars-Sinai Comprehensive Cancer Center, Los Angeles, CA) highlights important myeloma news from the annual meeting of the American Society of Clinical Oncology (ASCO), which took place June 2-4, 2012, in Chicago, Illinois. At this major medical meeting, there were several important presentations demonstrating the benefits of combination therapies with the second-line proteasome inhibitor carfilzomib (Kyprolis®) in the frontline setting, as well as investigations of single agents and combinations in the relapsed/refractory setting, and other abstracts of interest to members of the myeloma community. ***PAGE 4***

Patient & Caregiver Experiences

Dr. Jim Omel, a physician who is also a patient, shares the challenges of arriving at his own diagnosis. Since myeloma can masquerade as more common ailments with seemingly benign symptoms, even a doctor with 25 years of experience can misdiagnose himself. A few tests could have established the diagnosis a full nine months prior, but Dr. Omel explains how difficult it can be to spot a zebra hiding among many horses. As he looks back on his 15 years with myeloma, Dr. Omel shares his experience of living with the zebra. ***PAGE 15***



Kim McLaughlin, a caregiver wife whose blog has become a popular feature of the IMF's *Myeloma Minute.* Kim shares her experiences on a journey she would have never chosen, even though the gifts along the way have exceeded the challenges of choosing to accompany someone on this precarious path. She writes about some of the people she has met in her six-plus-year odyssey as a caregiver to her husband Alan, what they have learned from their fellow travelers, and how they have now become a resource for other couples coping with myeloma. ***PAGE 16***

Supportive Care

IMF Hotline Coordinators answer a question from a newly diagnosed patient about absorbing and processing the mass of available information about myeloma. How does a patient learn what to learn? What should be done first? And next? The questions and answers seem endless, and confront patients at every step of the way. The IMF helps organize the information you need to answer all your questions with "The 10 Steps to Better Care™," a unique tool designed to help both patients and physicians better navigate the course of myeloma, from diagnosis through long-term survival. ***PAGE 6***

10 Steps to Seeking a Second Opinion, a summary by Dr. Brian G.M. Durie, attempts to answer the "ifs, whens, and hows" related to considering your medical options. Whether it is a telephone "consult" or a complete re-evaluation with testing and recommendations provided, crucial medical questions often deserve and require a careful discussion and a second opinion. Not only is it rare for a primary doctor to object to their patient seeking a second opinion, but the willingness to support the search for available options often strengthens the relationship between patient and physician. ***PAGE 7***

IMF's Nurse Leadership Board (NLB) presented a Satellite Symposium – "Multiple Myeloma: The Patient's Journey Through Survivorship" – at the 37th Annual Congress of the Oncology Nursing Society (ONS), which took place on May 3, 2012, in New Orleans, Louisiana. More than 600 nurses attended this educational program, which was designed to improve nurse management of myeloma patients through all stages of survivorship. In the context of the expanded approved therapeutic options for myeloma, as well as the many new agents currently in development, symposium presentations included case studies with discussions of available treatment options, complications and comorbidities, and supportive care and relapse. ***PAGE 8***

Special Event

The IMF team returned to Asia in May 2012. The visit to Shanghai, China, included the 2nd Chinese National Myeloma Conference, an amazing tour of Shanghai Changzheng University Hospital, a productive meeting with the China Health Promotion Foundation (CHPF), the first Shanghai Regional Myeloma Patient Forum, and the 2012 annual meeting of the Asian Myeloma Network (AMN) with representatives from each of the seven member regions (Hong Kong, Taipei, Japan, Korea, Singapore, Thailand, Taiwan). ***PAGE 12***

Also in this issue…

What you get at an IMF Patient & Family Seminar

- ***Education***
- ***Access to Experts***
- ***Camaraderie***

Upcoming P&F Seminars
Los Angeles, CA
August 10-11, 2012
Boston, MA
August 24-25, 2012

Go to **myeloma.org** *and click on the "Seminars and Meetings" tab.*

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

International Myeloma Foundation

Founder
Brian D. Novis

President
Susie Novis

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

Prof. Dr. Mario Boccadoro
Loraine Boyle
Mark Di Cicilia
Donna Feig
Michael S. Katz
Benson Klein
Andrew Kuzneski, III
Dr. Robert A. Kyle
Prof. Dr. Heinz Ludwig
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

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
Ola Landgren, USA
Henk M. Lokhorst, The Netherlands
Sagar Lonial, USA
Heinz Ludwig, Austria
Jayesh Mehta, USA
Håkan Mellstedt, Sweden
GiamPaolo Merlini, Italy
Angelina Rodríguez Morales, Venezuela
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
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

Scientific Advisors Emeriti
Raymond Alexanian, USA
Y.C. Chen, Republic of China
Ian Franklin, Scotland
Tadamitsu Kishimoto, Japan
Ian MacLennan, England
James S. Malpas, England
Martin M. Oken, USA

IMF Staff

Chief Financial Officer
Jennifer Scarne
jscarne@myeloma.org

Senior Vice President, Asia
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 of Support Groups
Joanie Borbely
jborbely@myeloma.org

European Programs
Gregor Brozeit
greg.brozeit@sbcglobal.net

State Government Affairs
Meghan Buzby
mbuzby@myeloma.org

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

Auction & Development Associate
Janice Marie Estrada
jestrada@myeloma.org

Hotline Coordinator
Paul Hewitt
phewitt@myeloma.org

Meeting & Event Services
Spencer Howard
SHoward@SignatureEventsLA.com

Editor-in-Chief, Publications
Marya Kazakova
mkazakova@myeloma.org

Hotline Coordinator
Missy Klepetar
mklepetar@myeloma.org

Accountant
Phil Lange
plange@myeloma.org

Regional Director of 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

Grassroots Liaison
Aimee Martin
amartin@myeloma.org

Publication Design
Jim Needham
jneedham@myeloma.org

Regional Director of Support Groups
Anne Pacowta
apacowta@myeloma.org

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

Executive Assistant
Chelsea Proctor
cproctor@myeloma.org

Web Producer
Abbie Rich
arich@myeloma.org

IT Systems Admin
Thomas Shin
tshin@myeloma.org

Director of Support Groups
Robin Tuohy
tuohy@snet.net

Hotline Coordinator
Judy Webb
jwebb@myeloma.org

A Message from the President

Dear Reader,

In the late 1990s, I would occasionally tell a story at patient events that living with myeloma was like living with a terrorist, an analogy that became inappropriate after September 11th. I had forgotten about it until very recently when it occurred to me that living with myeloma is less like living with a terrorist and more like living with a bad neighbor.

More than a dozen years ago, thalidomide was a relatively new term for most of us. There were only about fifteen myeloma support groups in the United States. The IMF had just embarked on publishing a wide range of patient information materials. And the mantra for diagnosed patients was, "three-to-five years."

So it seemed very much like being under the control of a terrorist – constantly in fear, never knowing what the future might hold. The fear part was real – fear of having the disease become more active than last time; fear of not seeing once-in-a-lifetime experiences like graduations, weddings, and family vacations; fear of having passed on the genetics of the disease to a loved one.

Reconsidering that analogy after it had been shelved for more than a decade makes me realize how much has changed. It's like the difference between being with someone over a period of ten years and seeing someone for the first time after ten years. If you're the latter, you have greater awareness of the changes.

That's when I realized that the terrorist analogy no longer applies for myeloma patients. Times have gotten significantly better for the community. For some, living with myeloma is easy. For others, it is still a struggle every minute of the day. But by in large, instead of being under the control of a terrorist, living with myeloma is more like living with a bad neighbor.

For more and more patients, that bad neighbor is not so bad. For these patients, living with myeloma as a chronic disease might mean making peace with a bad neighbor. You make adjustments in your treatment as you would in your lives. You keep the blinds shut during the part of the day that Mr. Smith likes to take his afternoon backyard stroll in his altogether. Or your neighbor agrees to turn down the Aerosmith music after midnight. Sometimes – rarely to be sure – you learn to accept and live with theses quirks.

For others of us, we know what is meant by a "neighbor from hell" who seriously impedes our quality of life and, in extreme cases, our finances and health. This neighbor can truly make life miserable. You need to call the police…often. Your property value suffers even more than it would anyway in this economic downturn. You begin to lose much sleep and your health deteriorates.

Thankfully, most of us who have bad neighbors have the tolerable kind. That's a lot like it is for most myeloma patients today. As knowledge of diagnosis, therapies, and medications grows, these bad neighbors will become more tolerable, if not almost forgotten. As myeloma becomes more and more of a chronic condition – something that was inconceivable to anyone but the top experts just a few short years ago – the stress of living with it and the fear of dying from it should diminish.

Although the bad, malignant neighbor might not be manageable for everyone, there will be fewer of them in the foreseeable future. Just know there's one thing every newly diagnosed patient should understand immediately – you don't have to be terrorized by myeloma.

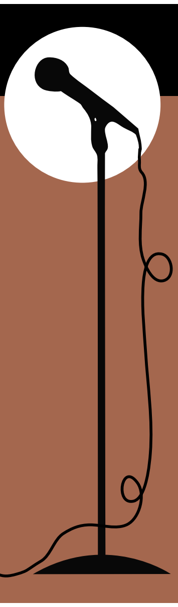
There's a good chance it may become a mildly annoying neighbor. And that chance is getter better all the time.

Warmly,

Susie Novis

Susie Novis, President

SAVE THE DATE



INTERNATIONAL MYELOMA FOUNDATION

6th Annual

Comedy Celebration

benefiting the Peter Boyle Research Fund

Hosted by **Ray Romano**

(additional performances to be announced)

Saturday, October 27, 2012

The Wilshire Ebell Theatre & Club in Los Angeles, California

For information about sponsorship opportunities, please call (818) 487-7455 or email: events@myeloma.org or visit: comedy.myeloma.org

This free issue of *Myeloma Today*© (Volume 9, Number 2) is dated June 1, 2012. *Myeloma Today*© is a quarterly (Spring, Summer, Fall, and Winter) publication of the International Myeloma Foundation, located at 12650 Riverside Drive, Suite 206, North Hollywood, CA 91607 USA.

REPORT FROM ASCO 2012: NEW RESULTS IN FRONTLINE AND AT RELAPSE

Dr. Brian G.M. Durie highlights important myeloma news from the annual meeting of the American Society of Clinical Oncology

By Dr. Brian G.M. Durie

Although the annual meeting of the American Society of Clinical Oncology (ASCO) – held in June 2012 – did not have the number or scope of abstracts presented at the meeting of the American Society of Hematology (ASH) in December 2011, there were nonetheless several important presentations of interest to members of the myeloma community.

Three presentations in the frontline setting demonstrated the remarkable benefits of combination therapies with the second-line proteasome inhibitor carfilzomib (Kyprolis®):

Phase I/II study of carfilzomib plus melphalan-prednisone (CMP) in elderly patients with de novo multiple myeloma

Abstract 8009 from the French IFM group summarized results with carfilzomib plus melphalan and prednisone (CMP), which can be compared with the extensive prior data with Velcade® (bortezomib) plus MP (VMP). The objective response rate (ORR) (>50% regression) with CMP was an impressive 92% (versus 71% with VMP), with 42% having at least a very good partial response (VGPR) rate with CMP.

Brigitte Kolb of the Institute for Myeloma and Bone Cancer Research (West Hollywood, CA) evaluated toxicity and effectiveness of CMP in an elderly population – a group that cannot engage in high-dose treatment. Twenty-four patients enrolled in phase I were given varying levels of carfilzomib to assess maximum tolerated dose (MTD). To determine MTD, dosage level of carfilzomib was increased over three cohorts and toxicities/response rates were evaluated. An additional 16 patients were included in phase II, assessing effectiveness of level 3 carfilzomib (which was given at 36mg/m^2 per dose). Altogether, 43 patients have been enrolled in the phase I/II studies; ORR was 89%, including 40% at least VGPR. Event-free survival was estimated at 80%, with toxicity levels estimated at 6%. Efficacy in high-risk patients and longer follow-up data will be reported in the next year.

Phase I/II trial of cyclophosphamide, carfilzomib, thalidomide, and dexamethasone (CYCLONE) in patients with newly diagnosed multiple myeloma

Abstract 8010 was presented by Joseph Mikhael from the Mayo Clinic group in Scottsdale, AZ, who looked at a new regimen called CYCLONE, incorporating carfilzomib, cyclophosphamide, thalidomide, and dexamethasone. At the early phase of this study all patients had responded, with 83% achieving VGPR with a combination that appeared to be reasonably well tolerated.

In phase I, three patients were treated with CYCLONE (carfilzomib is given intravenously; the other three orally) and all responded well. Data from 27 enrollees from phase II have been collected; a 96% ORR was reported, with 75% having a VGPR. Grade 3 toxicities were reported in 50% of patients; grade 4 toxicities were reported in 20% (these included arhythmea, fatigue, muscle weakness, neutropenia, lymphopenia and thrombocytopenia). Twenty-six out of 27 patients are still alive. All patients advancing to stem cell harvest successfully collected stem cells (14 total). Seven cases of grade 1 peripheral neuropathy (PN) were reported. An even further depth of response was seen in patients post-transplant. In future work, the carfilzomib dose will be increased, as MTD was not reached in this trial.

CONTINUES ON NEXT PAGE

Launched in 2001, the International Myeloma Working Group (IMWG) – the research arm of the International Myeloma Foundation (IMF) — has had many successes that have changed the landscape of myeloma research. Through the collaboration of 159 world-renowned myeloma researchers, the IMWG has revolutionized the way myeloma is diagnosed, treated, and managed.

But these experts don't always agree...

On June 13, the inaugural IMWG Conference Series kicked off with a debate between world-recognized experts from the United States and Europe taking on the first topic of the series: Making Sense of Treatment.

Those who were unable to attend this groundbreaking debate in person or witness the event as it was livestreamed on the IMF website are encouraged to view the archived video. In fact, the entire IMWG Conference Series will be available for viewing on the IMF website. Just go to myeloma.org and click on the "webcasts" tab for the drop-down menu.

This is one conference you won't want to miss!

Stringent complete response in patients with newly diagnosed multiple myeloma treated with carfilzomib, lenalidomide, and dexamethasone.

Abstract 8011 from Andrzej Jakubowiak and colleagues at his former institution, the University of Chicago Medical Center, provided data utilizing his frontline combination of carfilzomib and Revlimid® (lenalidomide) plus dexamethasone. Emphasis was placed upon the fact that 42% of patients achieved stringent complete response (sCR). Progression-free survival (PFS) was 97% at 12 months and 92% at 24 months, indicating ongoing treatment benefit.

Dr. Jakubowiak, who is currently at the University of Iowa (Iowa City, IA) examined long follow-up responses to the combination treatment in 53 newly diagnosed MM patients who were treated in a 28-day cycle with carfilzomib (20–36 mg/m^2 intravenously on days 1, 2, 8, 9, 15, 16), lenalidomide (25 mg orally, days 1 through 21) and dexamethasone (40/20mg orally, weekly). After four cycles of this treatment patients achieving a positive result could collect stem cells (and 35 patients did). After 8 cycles patients received 16 maintenance therapy cycles (with modified carfilzomib). All 53 patients were evaluable; 81% were achieving VGPR or better, 62% were achieving complete response (CR), and 42% were achieving stringent complete response (sCR). The most common all-grade adverse events included lymphopenia (30%), leukopenia (26%), fatigue (25%), and PN (11%). Extended carfilzomib, lenalidomide, and dexamethasone is well tolerated and resulted in deep response.

In contrast, **Abstract 8096** from the Mayo Clinic team in Rochester, MN, detailed the longer-term outcomes with the two-drug combination of lenalidomide plus dexamethasone as first therapy. Tracking 286 consecutive patients, the median survival was approximately 8 years, reflecting both induction and follow-up therapy.

Clearly, it will take some time to assess which is the ideal combination to achieve excellent early results, acceptable toxicity, and the best longer-term benefit.

In the relapsed/refractory setting, many single agents and combinations were evaluated. Of the single agents, both pomalidomide and carfilzomib demonstrated expected efficacy, with ORRs of about 30% or better. It is hoped that both will soon be approved by the Food and Drug Administration (FDA). The favourable vote for carfilzomib at the June 20th Oncologic Drugs Advisory Committee (ODAC) hearing was a key step towards likely final approval later in July.

Of the newer agents, both elotuzumab and MLN9708 (an oral proteasome inhibitor) continued to show promising results.

Among agents at an early stage of development, results were rather disappointing. Obatolclax (anti-BCL-2; **Abstract 8013**) and siltuximab (anti-IL-6; **Abstract 8018**); showed limited evidence of efficacy. Daratumumab (anti-CD38; **Abstract 8018**) was the only one of the new agents to produce any single-agent responses at the partial response (PR) level.

2012 Myeloma Updates from ASCO, EHA, and IMWG Summit

SPEAKER **Brian G.M. Durie, MD**

This June 28th teleconference for patients, family members, caregivers, and healthcare professionals features news from the 2012 annual meetings of the American Society of Clinical Oncology (ASCO) and the European Hematology Association (EHA), as well as the International Myeloma Working Group (IMWG) Summit.

The 60-minute recording of the teleconference is available on the IMF website myeloma.org. Go to the "webcasts" tab on the home page and select "teleconferences" from the drop-down menu.

ASCO American Society of Clinical Oncology

EHA EUROPEAN HEMATOLOGY ASSOCIATION

International Myeloma Working Group 2012 Summit

In **Abstract 8038**, a retrospective analysis of 841 consecutive patients from the City of Hope (Duarte, CA) showed that the primary correlates for development of second primary malignancies (SPMs) were older age (>55 years) and non-Hispanic white race.

There were several interesting abstracts that will undoubtedly give rise to further research. Among them, **Abstract 8040** suggested that t(11;14), commonly thought to be a "good-risk" translocation, may have a negative impact related to autologous stem cell transplantation (ASCT). **Abstract 8097** presented results of a large analysis demonstrating a different pattern of disease and outcomes in Asian patients, and **Abstract 8088** presented inconsistencies in systems used to assess risk progression in smoldering multiple myeloma (SMM).

The IMF has summarized all of the important abstracts in the *ASCO 2012 Multiple Myeloma Highlights* publication, available in hard copy by request, and in electronic version on the IMF website myeloma.org. In addition, the IMF has interviewed the lead myeloma investigators, and these online webcasts are available for viewing on the IMF website.

As always, new data are moving the field forward and helping to identify the best approaches to diagnosis and therapy for myeloma patients worldwide. Please stay tuned for the next edition of *Myeloma Today*, subscribe to the Myeloma Minute weekly e-newsletter, download the IMF's *Myeloma Post* iPad app from the iTunes store, and/or visit the IMF website directly at myeloma.org to get all the latest information. If you need more specific advice in your case, please do not hesitate to contact the IMF Hotline at 800-452-CURE (2873). **MT**

AN INTRODUCTION TO THE 10 STEPS TO BETTER CARE™

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.

Paul Hewitt, Judy Webb, Debbie Birns, and Missy Klepetar

I was recently diagnosed with multiple myeloma, a disease I had never even heard of. Now I feel like there is so much new information to absorb and process that I don't even know where or how to begin. What's a "newbie" like me to do?

Do you ever feel like you're living in the age of "TMI"— too much information? If you are a newly diagnosed myeloma patient, the mass of information about this little-known disease can be absolutely overwhelming. How does a newly diagnosed myeloma patient learn what to learn? What should be done first? And next? What tests should be performed? How often? What can be done if a patient can't afford a co-payment for treatment? What are the options for treatment if the disease relapses? Which drugs in clinical trials are for the newly diagnosed and which are for relapsed myeloma?

The questions and answers seem endless, and confront patients at every step of the way. The IMF, always the source of the world's most reliable information about myeloma, has organized the information you need to answer all your questions, whether you are a newly diagnosed patient or a long-term survivor.

The IMF, with the inspiration and guidance of Dr. Brian G.M. Durie, has adopted a new organizing principle for its website and its array of patient publications. "The 10 Steps to Better Care™," a unique tool for diagnostic and treatment information, is designed to help both patients and physicians better navigate the course of myeloma, from diagnosis through long-term survival. By breaking a large body of information into 10 discreet segments, the IMF hopes to make it easy to hone in on the information that patients, their caregivers, and their healthcare providers need at any particular time.

For those who have not yet visited the IMF website to become acquainted with the 10 Steps to Better Care™, here they are:

1. **Know what you're dealing with: Get the correct diagnosis**
2. **Tests you really need**
3. **Initial treatment options**
4. **Supportive care and how to get it**
5. **Transplant: Do you need one?**
6. **Response assessment**
7. **Consolidation and/or maintenance**
8. **Monitoring without mystery**
9. **Relapse: Do you need a change in treatment?**
10. **New Trials: How to find them**

The best current treatment information is included for each step, including IMF publications and guidelines developed by the IMF's International Myeloma Working Group (IMWG).

In addition to organizing the IMF website around The 10 Steps, the IMF has released a ne iPad application called The Myeloma Post, which is organized in the same user-friendly format. Each of our printed booklets is also being updated to include information about where they fit in The 10 Steps.

As always, we encourage you to visit our web site for the best and most up-to-date information about myeloma, now organized into The 10 Steps to Better Care, and to call the IMF Hotline at 800-452-CURE (2873) with all your myeloma-related questions. **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 & 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

10 STEPS TO SEEKING A SECOND OPINION

By Dr. Brian G.M. Durie, Chairman, IMF Board of Directors

Whether or not to seek a second opinion is a key question for all patients with multiple myeloma (MM). This 10-step summary attempts to answer the "ifs, whens, and hows" related to seeking a second opinion.

1. Should you consider a second opinion?

It is essential to realize that a second opinion is always an option, whether it is a telephone "consult" or a complete re-evaluation with testing and recommendations provided. The urgency varies, as does the ability to travel and absorb the added expense. If in doubt, call the IMF Hotline at 800-452-CURE (2873) to discuss options and potential help available.

2. Do you need a second opinion right now?

Crucial questions that often deserve and require a second opinion are:

- Do I have active MM needing immediate treatment? Or do I have MGUS or smoldering myeloma (SMM), for which observation is the answer?
- What is the best first treatment in my case?
- Am I really relapsing and do I need new therapy?

At the very least, these questions require careful discussion, if not input from a myeloma expert.

3. What should you do if treatment is planned?

In general, urgent issues should be treated immediately. However, if the recommendations include…

- Major surgery
- Delay in potentially crucial supportive care (such as dialysis for kidney failure, IVIG for infection, or kyphoplasty for severe pain/vertebral collapse)

…then reach out for help and advice. Beyond urgent issues, there is usually time to assess treatment options for MM. This is an ideal time to get a second opinion.

4. What about your main treating doctor?

Even if your main doctor is experienced in the diagnosis and treatment of MM, be aware that there are always differences in philosophy and opinion. The major difference is the "watch and wait approach" versus the "treat aggressively now" approach. Along the same lines is the "control versus cure" controversy. Does one aim for chronic disease control or does one attempt to achieve a cure? If you and your doctor share the same philosophy, a single opinion can be fine. However, even then, it can be enlightening to hear and discuss the opposite philosophy before reaching a final decision.

5. Is getting a second opinion rude or inappropriate?

It is rare for a primary physician to object strongly to a patient seeking a second opinion. In fact, the willingness to support the search for available options often strengthens the relationship with the primary doctor. Nonetheless, it is wise and polite to openly discuss the desire for a further opinion to avoid any misunderstandings. Couching the discussion in terms of "I think you are a great doctor..." (if true) or "we are concerned that you do not see that many myeloma patients..." (if this is the case) "but/so, we would like to seek a second opinion" is helpful. You can proceed from there.

6. Which expert should I see?

This is a key question, and the IMF Hotline Coordinators are well prepared to help you. For example, it is well known that certain centers are very well equipped to do specialized testing to ensure a correct diagnosis and/or to ensure that baseline prognostic factors such as FISH results have been established. The choice of where to seek treatment may be influenced by such practical concerns as local convenience or the availability (or not) of reimbursement by your healthcare plan. Obviously, you may choose to pay out of pocket, if necessary.

7. What is expected from a second opinion consultation?

Important considerations are:

- Do I just want advice, or do I plan to receive treatment there as well?
- Am I planning to go to a center for treatment such as transplant or to receive a new drug in a clinical trial setting?
- Will I continue to see my primary physician? This is typically the case. After advice is received or new treatment completed, it is most common for patients to return to their local doctor's care.
- Will I plan to return for periodic review? Again, it is common practice to see the specialist to get follow-up advice for the local MD.

8. When is the best time for a second option?

In general, early in the disease course is an excellent time to make sure the diagnosis is confirmed and initial treatment decisions are the best possible. However, later can also be very helpful, especially at the point of MM relapse when new drugs are needed.

9. How do I decide about one medical center versus another?

The best center for you depends upon the questions or needs, whether that be a one-time consult, or ongoing care, or the need for a transplant, or the need for a particular new drug available only in clinical trials. For example, gaining access to pomolidamide, carfilzomib, and/or elotuzimab could be very important.

10. What about follow-up?

At the time of a second opinion, recommendations are made and typically the "myeloma expert" will call your local MD and/or send a summary report. It may be possible to proceed with a new course of action, or no changes may be required, or perhaps additional testing is needed. Frequently, the initial consultation is followed by an ongoing relationship between the "myeloma expert" and your local MD. This is ideal. It may be that you have to work with both doctors to make the partnership run smoothly and to your advantage. It is worth the effort and many times produces the best outcomes.

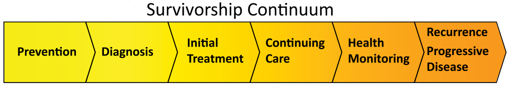
So there you have it! I hope that these perspectives and suggestions will guide your decisions in thinking about seeking a second opinion. If you need more specific advice in your case, please do not hesitate to contact the IMF at 800-452-CURE (2873). **MT**

Editor's Note: To read Dr. Brian Durie's blog entries as they are published, follow him on Twitter @BrianDurieMD or subscribe to the weekly *Myeloma Minute* e-newsletter. To read archived blogs, please visit myeloma.org.

THE PATIENT'S JOURNEY THROUGH SURVIVORSHIP

IMF's Nurse Leadership Board presents ONS Satellite Symposium

More than 600 nurses attended the IMF's Nurse Leadership Board (NLB) Satellite Symposium at the 37th Annual Congress of the Oncology Nursing Society (ONS) in New Orleans on May 3, 2012. After a warm welcome, symposium chairman Joseph Tariman shared a brief overview of the learning objectives for the "Multiple Myeloma: The Patient Journey Through Survivorship" symposium, a program designed to improve nurse management of multiple myeloma (MM) patients through all stages of survivorship.


Survivorship Continuum
Prevention → Diagnosis → Initial Treatment → Continuing Care → Health Monitoring → Recurrence Progressive Disease

Treatment Plans

Joseph Tariman and Beth Faiman presented a case study of "Mary Brown" (using HIPPA compliant patient details modified to protect privacy), a 55-year-old African American female with an abnormal protein. Joseph explained the process that led to Mary's diagnosis with smoldering multiple myeloma (SMM). Beth and Joseph reviewed Mary's options when she unfortunately progressed to active ISS stage II disease, as well as how Mary was able to achieve remission with induction therapy and a stem cell transplant.

"Richard," a 74-year-old Caucasian male was hospitalized with a medical emergency, kidney failure. He is one of less than 10% of patients with MM who have severe renal failure at presentation, but 30-40% of patients have elevated serum creatinine and 25-50% have renal impairment during the course of their disease. Richard was hydrated, treated with a Velcade® (bortezomib) combination regimen, and received plasmapheresis and a thorough myeloma work-up. Approximately 85% of MM patients have bone disease, which may lead to hypercalcemia and contribute to renal impairment. Luckily, no lesions were found in Richard's skeletal survey and he was released from the hospital.

Next, Teresa Miceli and Beth Faiman reviewed the available treatment options, which have improved dramatically over the past decade for MM patients. Teresa discussed the case of "Judy," a 66-year-old Japanese woman in good general health. At age 2, she was exposed to radiation during the bombing of Nagasaki. In 2009, she was diagnosed with ISS stage III myeloma. Judy attended an IMF Patient & Family Seminar and realized that she was not too old to have a transplant. Candidacy for transplantation depends on multiple factors, not just age. With mobilization, Judy was successful in collecting enough stem cells for one transplant and achieved a very good partial response (VGPR).


Joseph Tariman


Beth Faiman


Teresa Miceli


Tiffany Richards

"Hank," a 62-year-old rural Texan rancher, was admitted to hospital with fever, cough, back and rib pain. Chest x-ray revealed pneumonia, rib fractures, lytic lesions, and vertebral compression fracture. A heavy smoker with COPD, Hank is a Vietnam veteran with possible exposure to Agent Orange. Diagnosed with ISS stage II, high-risk myeloma, Hank was not transplant-eligible based on comorbidities and insurance coverage, so a three-drug combination therapy was initiated. Due to steroid-related side effects, Hank was switched to steroid-sparing treatment. Due to recurrent pneumonia, he was readmitted to the hospital, where it was determined that his MM had relapsed. At this point, a range of treatments options must be considered.

Patients are still grouped as transplant-eligible or -ineligible, with stem cell-sparing treatment in transplant-eligible patients, and consolidation and/or maintenance therapies improving outcomes for both transplant-eligible and -ineligible patients. The expansion in therapeutic options for MM in past decade has resulted in improved response rates, improved progression-free survival and/or overall survival, and depth and length of response. Many new agents currently in development are expected to become available in the coming years, further improving the outlook for patients.

Supportive Care and Relapse

Approximately 90% of patients develop osteolytic lesions from disease, treatment, and age. Bone health can be improved by multiple techniques, including surgery or pharmaceutical agents. Residual disease is a prognostic factor for future relapse. Tiffany Richards and Beth Faiman discussed caring for MM patients as being more than just treating the disease. Quality of life is very important. Health maintenance must be an integral part of the care plan for all MM patients, as many experience multiple rounds of treatment, remission, and relapse. Caregivers are essential to helping patients in their journey, but they must also take care of themselves.

CONTINUES ON NEXT PAGE

News & Notes

Just released: the IMF iPad app

The has IMF unveiled its first iPad application, the *Myeloma Post*. The *Myeloma Post* is the first comprehensive disease-specific cancer app available for patients, doctors, and caregivers. It was developed by the IMF to serve as a mobile gateway to the educational, research, support, and advocacy programs and information found on the IMF's website myeloma.org.

Updates posted to the IMF website provide access to medical news, educational programs, quality-of-life support resources, and advocacy activities, as well as patient, caregiver, and medical blogs and communities. The creation of the *Myeloma Post* mobile app was a natural evolution of our longstanding history of finding new and better ways to keep the myeloma community well informed and up-to-date.

The *Myeloma Post* iPad app is an instrumental educational tool for patients, their families and caregivers, and others whose lives have been touched by myeloma. The app can be easily customized from the IMF website for specific groups within the myeloma community. For example, our extensive network of volunteer Myeloma Support Group Leaders now has a version of the app that directly serves their unique needs.

The *Myeloma Post* iPad app joins the long list of programs developed by the IMF to benefit you, our members. This includes the IMF Patient & Family Seminars, which present vital information, provide time with premier myeloma specialists, and allow participants to share personal experiences and support. The IMF Regional Community Workshops are condensed seminars that expand the reach of IMF programs to a wider audience in smaller cities. The IMF's toll-free Hotline 800-452-CURE offers support from highly trained specialists. Like these and other IMF services, the *Myeloma Post* iPad app is free of charge. Download the app from the iTunes Store and take advantage of this new mobile gateway to IMF information!

REFERRAL Study

Major advances have occurred in the diagnosis and treatment of multiple myeloma in the last decade, but more needs to be done. The purpose of the Race, Ethnicity, and Familial Etiologic Relationship, Risk Association, and Linkage (REFERRAL) study is to determine the underlying reasons for the increased risk of myeloma in certain races and in family members, as well as to understand whether the subtypes of myeloma occur more commonly in one group over the other. There are many subtypes of myeloma, and there is an increased risk of myeloma in African Americans and in close family members. The REFERRAL study will provide important information that will help all patients with myeloma.

To participate in this study, you do not need to reveal any identifying information. The study consists of a simple survey, which will only take a few minutes of your time to complete. The study survey can be accessed at survey.myeloma.org.

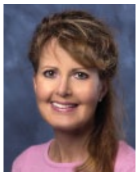
If you have questions about the survey, please contact Danielle Loi at the IMF at 800-452-CURE (2873) or 818-487-7455, or email us at IMF-fish@myeloma.org. Please do not take the survey again if you have already taken it.

IMF Board Member Receives 2012 ASCO Humanitarian Award

IMF Board member Dr. Edith Mitchell, a medical oncologist at Thomas Jefferson University Hospital and Kimmel Cancer Center (KCC), is the 2012 recipient of the American Society of Clinical Oncology (ASCO) Humanitarian Award for her personification of the society's mission and values, and for going above and beyond the call of duty in providing outstanding patient care. "A big part of my work over the course of my career has focused on helping those in need of medical care—to reach those who have no access to it, who have no opportunities for health, and no means to seek out conventional medical advice," said Dr. Mitchell, who has spent her medical career helping individuals in medically underserved areas and demonstrating the importance of community service and outreach. For her efforts, Dr. Mitchell was presented with the award during the opening session of the ASCO Annual Meeting on June 2, 2012.

IMF Nurse Leadership Board Members Honored

Beth Faiman, member of the IMF Nurse Leadership Board (NLB), has received the 2012 Excellence in Medical Oncology Award from the Oncology Nursing Society (ONS). A certified nurse practitioner at the Cleveland Clinic, Beth is also a full-time pre-doctoral research fellow at Case Western Reserve University in Cleveland, OH.



NLB member Sandra Rome, a clinical nurse specialist in hematology and oncology at the Cedars-Sinai Samuel Oschin Comprehensive Cancer Institute in Los Angeles, has received the Distinguished Alumni Award from the UCLA School of Nursing. Sandra, who currently oversees about 100 nurses on the Medical Oncology and Bone Marrow Transplant Unit, received the top honor for her inspiring efforts to transform the nursing profession and to raise public awareness of the crucial role that nurses play in the nation's healthcare system. **MT**

NLB — continued from page 8

Conclusion

Patient education is imperative throughout the survivorship continuum. MM patients are living longer and they are living better, and it is important to remind them of the steady improvements being made in treatment, survival, and quality of life. Collaborative care remains key to long-term patient management, and NLB symposium participants took away with them an enhanced ability to manage their patients through all stages of MM survivorship. **MT**

Editor's Note: A recording of the ONS symposium is available on the IMF website myeloma.org, which has a wealth of resources for nurses, doctors, patients, and caregivers.

COMING SOON

Take Action Against Myeloma Weekend

Mark your calendars, September 7–10th

Nationwide, people will unite and take action against myeloma by hosting a personalized fundraiser.

Garage sale, car wash, benefit dance, costume party… if you can envision it, you can put it into action!

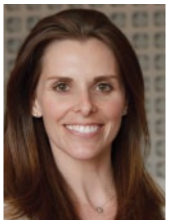
Now is your chance to raise awareness.

To take action today, contact Janice Estrada at jestrada@myeloma.org or 818-487-7455, x234

Additional details underway

SPOTLIGHT ON ADVOCACY

Happenings on the Hill and Across the Country



By Arin Assero

How a Bill Becomes a Law

How many of you recall hearing the catchy little "I'm Just a Bill" tune on Saturday morning television back in the mid-70s?

"I'm just a bill.
Yes, I'm only a bill.
And I'm sitting here on Capitol Hill.
Well, it's a long, long journey
To the capital city.
It's a long, long wait
While I'm sitting in committee,
But I know I'll be a law someday
At least I hope and pray that I will,
But today I am still just a bill."

© 1975, Schoolhouse Rock

Is it coming back to you now? The *Schoolhouse Rock* television series, which aired in 1975 in preparation for the upcoming United States bicentennial, was part of an effort to educate children on the structure of government. While I was only seven years old when I first heard that song, I never imagined that I'd have the opportunity as an adult to play an integral role in the process of how a bill becomes a law.

Now, I'd like to preface this story by saying I'm not drinking from the fountain of eternal optimism (at least not every day). I'm simply sharing a story that isn't about partisan politics or upcoming elections. I think we could all use a healthy dose of good news that may renew our faith in the system.

If you've been following the progress being made by the IMF's Advocacy Team, you know that we've been quite active in many states, urging policy makers to ensure access to treatment for patients through various chemotherapy parity bills. In one of the most recent states to sign their bill into law – Delaware – the IMF led the charge from day one. So, here is our story of *How a Bill Becomes a Law*…

In July of 2011, Representative Deborah Hudson heard me give a talk on why access to oral treatments is such an issue for cancer patients. Shortly after that talk, Rep. Hudson contacted me and said, "We need to make sure this isn't an issue for patients in Delaware. Let's get moving. I don't want to waste any more time." I knew she meant business and wasn't going to let anything stand in our way.

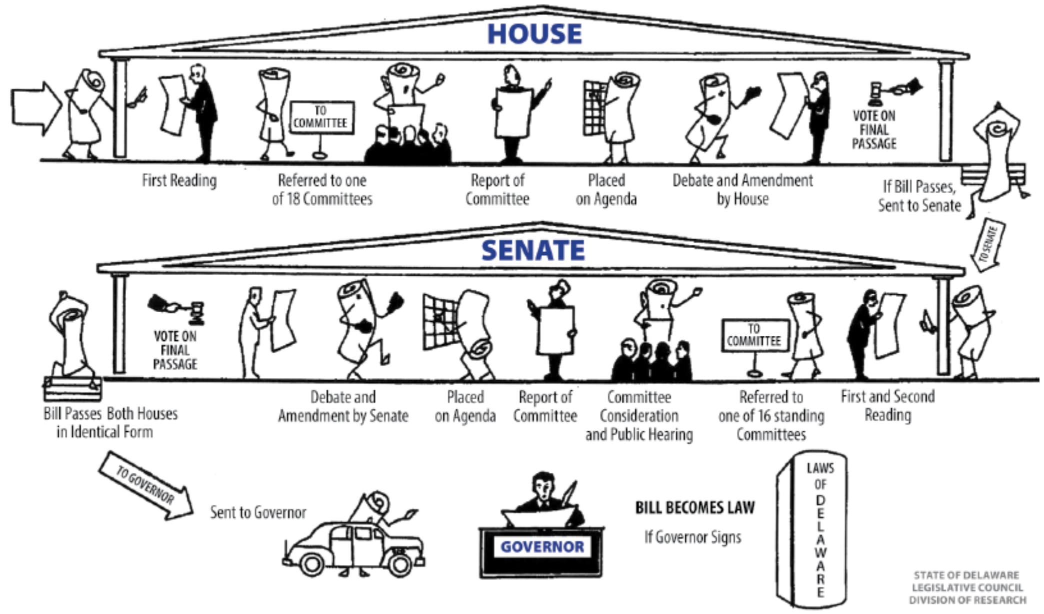
While Rep. Hudson worked with her staff to write the legislation, the IMF was organizing and activating a huge grassroots movement. With IMF's Meghan Buzby working on the ground in Delaware, the IMF formed the Delaware Cancer Treatment Access Coalition, a coalition of patient advocate groups and healthcare providers that believe every cancer patient should have access to the treatments recommended by their physicians. No patient should suffer from cost discrimination based on the type of therapy provided or the mechanism of delivery for that therapy.

Armed with a good bill and a foundation of support, we were ready to go!

Step One: Introduction and Assignment to Committee

On January 25, 2012, Rep. Hudson and her colleagues – Representatives Ruth Briggs-King and Bryon Short, and Senators Patricia Blevins and Liane Sorenson – introduced HB 265, a bi-partisan bill which would require health insurance plans in Delaware that cover cancer treatments to provide coverage for orally administered anti-cancer medications on a basis no less favorable than coverage for intravenously administered or injected anti-cancer medications. HB 265, otherwise known as The Delaware Cancer Treatment Access Act was assigned to the Economic Development/Banking/Insurance/Commerce Committee in the House.

HOW A BILL BECOMES A LAW IN DELAWARE



STATE OF DELAWARE LEGISLATIVE COUNCIL DIVISION OF RESEARCH

At a press conference held to announce the introduction of The Delaware Cancer Treatment Access Act (HB 265), IMF's Meghan Buzby and Delaware MM support group leader Josephine Diagonale addressed legislators, supporters, and members of the media.

Josephine Diagonale at the Press Conference in January 2012

Step Two: Committee Hearing in the House

On March 14, Rep. Hudson, a physician, myself, and IMF patient advocate Kelley Campbell testified in front of

Arin Assero, Rep. Deborah Hudson, Tayler, Ryan and Kelley Campbell at the Hearing

the Economic Development/Banking/Insurance/Commerce Committee on behalf of the bill.

Kelley drove to Dover with her granddaughters, Ryan and Tayler, to participate in the hearing. "I was nervous to testify," recalled Kelley. "But I knew that after all I'd been through to get the medication I needed, I just had to testify. I wasn't just testifying for myself, but for lots of cancer patients who have insurance but still don't have access to the anticancer drugs they need." Kelley eloquently shared her story about how scared she had been when she was not able to afford the co-pay for her anti-myeloma therapy Revlimid® (lenalidomide).

Members of the Delaware Cancer Treatment Access Coalition after the Bill Passed the House Committee

HB 265 is reported favorably out of committee: 8 Favorable, 3 On Its Merits.

"On its merits" is one of the options for voting a bill out of committee. It means the legislator voted it out of committee on the merits of the bill (not necessarily because they were in favor of the bill.) We were a tad worried something would happen and it would not make it out of the committee, but Rep. Hudson stayed firm and pressed hard on her colleagues to help all cancer patients in Delaware.

Step Three: HB 265 Goes to the Full House for a Vote

IMF advocates flooded the Delaware House of Representatives with letters of support via the IMF Action Center. You, too, can easily contact your legislator by visiting our Action Center at advocacy.myeloma.org.

On March 20, the bill passed unanimously by the Delaware House of Representatives. Votes: 41 Yes, 0 No, 0 Not Voting, 0 Absent, 0 Vacant.

On March 22, HB 265 was assigned to Insurance Committee in Senate.

Left to Right: Advocate Kelley Campbell, Rep. Debroah Hudson, Aimee Martin, Governor Jack Markell, and Advocate Josephine Diagonale

"IMF Thanks Governor Markell"

Step Four: Committee Hearing in the Senate

On March 28, the bill was heard in the Senate Insurance Committee. Rep. Hudson and Jeanne Chiquoine testified on behalf of the Delaware Cancer Access Treatment Coalition.

The bill was reported favorably out of committee: 1 Favorable, 3 On Its Merits.

Step Four: HB 265 Goes to the Full Senate for a Vote

Our advocates once again flooded the Delaware State Senate with letters of support urging their members to vote in favor of the bill.

On April 3, the Delaware State Senate passed the bill unanimously 21-0.

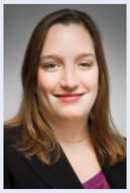
Step Five: HB 265 Heads to the Governor for a Final Decision

The IMF's grassroots network got busy with our "Postcards for Parity" program sending almost a hundred postcards to Governor Jack Markell asking him to sign the bill! We have launched this program now in all fifty states to provide another great way for folks to contact their state and federal legislators on this import topic. To learn more about the "Postcards for Parity" program and get involved, email IMF's Aimee Martin at amartin@myeloma.org.

Crossing the Finish Line

On May 01, HB 265 was signed into law by the Honorable Jack Markell!! **MT**

Gov. Markell Signs HB 265 into Law



Capitol Hill Bulletin

By Johanna Gray

In addition to our work in Delaware on the oral parity legislation, the IMF advocacy team continues our efforts on the federal level. The IMF formed the Patients Equal Access Coalition (PEAC), a partnership of organizations representing patients, healthcare professionals, care centers, and industry. This collaboration aims to ensure that cancer patients have equality of access (and equality of insurance coverage) to all approved anticancer regimens, including oral and intravenous drugs, injections, surgery, radiation, and transplantation.

PEAC believes that all cancer patients should have access to the anticancer regimens recommended by their physicians. Patients should not suffer from cost discrimination based on either the type of therapy provided or the mechanism of delivery. Working with the PEAC to build support for HR 2746, the Cancer Drug Coverage Parity Act has been a high priority for the IMF. HR 2746 would help patients who have not been able to benefit from the states' bills, including federally regulated ERISA (The Employee Retirement Income Security Act of 1974) insurance plans, and patients who live in states that have not yet passed a bill addressing this issue. ERISA, a federal law that established minimum standards for pension plans in private industry, was enacted to protect the interests of employee benefit plan participants and their beneficiaries. Through efforts led by PEAC, there are now more than 30 bi-partisan co-sponsors of HR 2746. We hope to gain even more supporters this summer after our coalition lobby day in June 2012.

How to contact the IMF Advocacy Team

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

Meghan Buzby – *State Government Affairs*
phone: 410-252-3457
email: mbuzby@myeloma.org

Aimee Martin – *Grassroots Liaison*
phone: 800-452-CURE (2873) ext. 242
fax: 818-487-7454
email: amartin@myeloma.org

Johanna Gray – *Fed.Gov't Affairs Consultant*
phone: 202-484-1100
email: jgray@dc-crd.com

Jennifer Leib – *Fed.Gov't Affairs Consultant*
phone: 202-484-1100
email: jleib@dc-crd.com

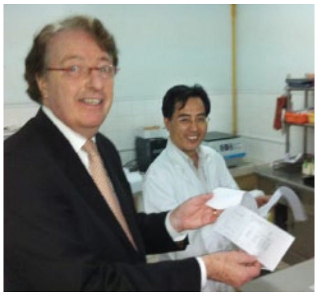
UPDATES FROM AROUND THE GLOBE

Shanghai Revisited: An Environment of Hope

By Dr. Brian G.M. Durie,
Chairman, IMF Board of Directors

A return visit to Asia by the IMF team – Susie Novis, Dan Navid, and me – in May 2012 was an exhilarating blur of activities that instructed, impressed, and touched us deeply.

On the morning of May 10, we visited the sponsoring institution – Shanghai Changzheng University Hospital – with Prof. Jian Hou, head of the Myeloma Unit. Dr. Weijun Fu, one of Prof. Hou's assistants, showed us the laboratory facilities. On this amazing tour we saw the SPEP/UPEP and IFE testing laboratory, then the outpatient clinic.



The testing lab was in the basement and reached by an elevator packed with sick patients and family members. In the corridor, we were greeted by a large picture of an electrophoresis (SP) gel (SPEP), commemorating the professor who established this pioneering unit in Shanghai. Here, samples for testing arrive in a drop-off box: reports on tiny pieces of white paper are sent to the patient's chart or mailed back to the referring hospital by regular post. In addition to the electrophoresis laboratory, we saw the whole range of clinical pathology laboratories plus the Blood Bank – all with gleaming new equipment of every conceivable type.

The outpatient area looked like New York's Grand Central Station. Hundreds of patients lined up for appointments in the hospital lobby, where patients also picked up prescriptions (free with SS#) at the huge pharmacy sections.

A very efficient dedicated testing area consisted of a series of rooms in which myeloma patients had their blood tested and their bone marrow sampled (right there off the clinic), and received an immediate morphology review and FISH (chromosome) testing. About half a dozen doctors cope with 30-40 patients daily.

The next morning, we headed to a Howard Johnson's Hotel – strange to see in China – where we reviewed our cooperative agreement with the China Health Promotion Foundation (CHPF), with whom educational activities are authorized and planned. We discussed potential upcoming activities with the leading myeloma experts in China, Prof. Wen-Ming Chen from Beijing and Prof. Hou from Shanghai.

Myeloma investigators flew in from seven countries (Hong Kong, Taipei, Japan, Korea, Singapore, Thailand, Taiwan) to participate in our Asian Myeloma Network (AMN) meeting, which followed. On behalf of Prof. Lee and the Korean team, Prof. Kim presented the results of our database project, which was presented in abstract form at both ASCO and EHA in 2012.

At the AMN meeting, there was much interested discussion comparing Asian with US (Mayo Clinic, for example) and European datasets. Of note, Asian patients are younger and have different disease patterns, such as more frequent plasma cell leukemia, extramedullary disease, as well as IgD type myeloma. Despite limited access to many diagnostic facilities and therapies in many of the countries – including, for example, autologous stem cell transplant (ASCT) in China – the overall survival was a very respectable 52 months. This is not too dissimilar from general outcomes elsewhere.

Plans for new clinical trials in Asia were discussed, with specific protocol suggestions presented by Dr. Wee Joo Chng from Singapore. Each country has different issues for drug access and approval. Nonetheless, potential protocols in both the frontline and relapse settings were favorably received. With incorporation of the feedback and suggestions, it seems likely that agreement will be reached to initiate new Asian trials – a first in the region.

Follow-up plans were made. A very enthusiastic and positive meeting.

That evening, the opening ceremony for the 2nd Chinese Myeloma/ Lymphoma Congress was hosted by Prof. Hou. The 1st Congress was held in Beijing last year, hosted by Prof. Chen. This 2nd opening ceremony was a lively affair, including a gymnastic performance (think Cirque du Soleil) and the normal "toasting," which involves everyone going from table to table meeting prominent invited guests and toasting with Great Wall of China red wine. This is when a lot of contacts and discussions occur – especially before too much toasting has happened!

After an exhausting day, we slept soundly to be up for an early start. At 8 a.m., I gave the lead-off lecture back at the Howard Johnson's Hotel, which was followed by a number of international guests, including International Myeloma Working Group (IMWG) member Dr. Douglas Joshua from Sydney, Australia. At the first coffee break, we were very excited to meet five of the seven Chinese physicians who will be travelling to Los Angeles in August to participate in a tailored two-week myeloma educational course hosted by the IMF. All attendees are very excited about this opportunity, which the IMF is in the midst of planning

On May 13, the final event of our visit was the Myeloma Patient Forum. More than 120 Chinese patients attended the event, held in a transformed lobby area of Changzheng Hospital using one wall as a huge screen with multiple TV panels. I co-hosted with Dr. Fu, and one of his colleagues gave an excellent lead-off "Myeloma 101" talk illustrated with beautiful, up-to-date slides.

This was followed by what started as a "free for all" of questions, with everyone keen to have theirs answered first. This was when Susie stepped in to restore order by taking questions row by row. Through an interpreter and with the help of Dr. Fu, over two hours of questions ensued. We heard very emotional and sometimes tragic stories. Everyone did their best to give helpful advice as well as what was equally important – the support coming from reaching out in an environment of hope.

CONTINUES ON PAGE 13

UPDATES FROM AROUND THE GLOBE

The IMF Team Returns to China

By Dan Navid,
Senior Vice President, Asia

With possibly more myeloma patients than in all other countries combined, it is only natural that the IMF continues to devote its attention to China. The IMF-China prog With possibly more myeloma patients than in all other countries combined, it is only natural that the IMF continues to devote its attention to China. The IMF-China program continues to grow with the dual goals of assisting Chinese physicians and supporting Chinese myeloma patients.

In Shanghai during the weekend of May 11-13, major steps forward in the IMF-China relationship included holding the 2nd Chinese National Myeloma Conference, the 2012 annual meeting of the Asian Myeloma Network (AMN), and a first Shanghai regional Myeloma Patient Forum.

IMF's President, Susie Novis, and IMF's Chairman, Dr. Brian G.M. Durie represented the Foundation at these events and also held talks with industry partners and key opinion leaders to develop further the IMF-China programs and projects for the coming three years.

Dr. Durie was the keynote speaker at the 2nd Chinese National Myeloma Conference, a gathering of more than 200 hematologists from across China. This conference provides a forum to exchange information about the latest developments in the field of myeloma.

Dr. Durie introduced the conference participants to the IMF's concept of 10 Steps to Better CareTM, a unique tool of diagnostic and treatment information that serves as a guide through the myeloma journey, from diagnosis to long-term survival. Dr. Hou Jian, the organizer of the 2nd Chinese National Myeloma Conference and a member of the IMF's International Myeloma Working Group (IMWG), indicated that translating the IMF's 10 Steps tool would be especially important for the Chinese physicians who are seeing increased numbers of patients.

The 2012 annual meeting of the Asian Myeloma Network (AMN) was attended by representatives from each of the seven regions with members on the panel, along with observers from industry partners and an invited expert, Dr. Douglas Joshua from Australia. The group reviewed the success of the recently launched IMF Asian Myeloma Data Base, which already has more than 3000 patient entries. Dr. Kihyun Kim of Korea, the leader of the project along with Dr. Jae Hoon Lee, provided an interesting initial analysis which suggests important differences between myeloma patients in Asia and in western countries. The group noted that this could have significant implications for treatment regimes for Asian patients. AMN members discussed potential publications and other means of disseminatiing this useful data, which is nowhere else available.

As a next project, the AMN considered options for multi-country clinical trials in Asia. Proposals were tabled for possible clinical trials both for newly diagnosed and for relapsed/refractory patients. Following the meeting, it was agreed that Dr. Wee Joo Chng of Singapore should further refine the discussed proposals for approval by AMN membership.

AMN members next reviewed training priorities for Asian physicians. Dr. Wenming Chen reported on the extensive efforts being made in China for the training of hematologists, including initiatives such as the current national conference. Great strides are being made in this regard both within China and for Chinese doctors abroad, and this could be a model for other Asian countries.

Dr. Kazuyuki Shimizu, AMN member and President of the International Myeloma Workshop (IMW), presented the IMW program for Kyoto in April 2013. In addition to a very extensive global scientific program, a special "Myeloma in Asia" session will be held in Kyoto, featuring speakers from the AMN presenting their national experiences. The 2013 annual AMN meeting will also be held in Kyoto in conjunction with the IMW.

IMF was delighted to have the opportunity to join in the first educational seminar for myeloma patients in the Shanghai region. The forum was supported by Xian-Janssen, with staff from this company providing extensive technical and organizational support. The forum covered a broad range of topics of interest to myeloma patients, and closed with an extensive question and answer session. At the conclusion of the forum, Susie Novis shared a message of encouragement and hope for the future, which was most gratefully and enthusiastically received by the participants.

Patient support in the form of making IMF educational materials and publications available in the Chinese language is being planned. Additional patient forums and seminars will also be organized.

For more information, please read Dr. Durie's article – Shanghai Revisited: An Environment of Hope – on page 12 and stay tuned for updates in future editions of *Myeloma Today*. **MT**

SHANGHAI — continued from page 12

Numerous contacts were made, and there will be much follow-up. Again, it was an exhausting day, but incredibly rewarding for all.

After what seemed like a blur of activity it was time to catch a direct flight back to the US. Pondering great plans for the future, we took off at 9:35 p.m. from Shanghai and arrived in Los Angeles at 6:10 p.m. the same day – before we took off! We saved a day on our way back, which we certainly needed for our recovery!

Editor's Note: To read Dr. Durie's earlier reports about the IMF's visits to Asia, please visit the blogs section of the IMF website myeloma.org.

PEOPLE HELPING PEOPLE

You are never alone in your battle against myeloma

Richmond, KY

Although Modenia Black suffered with anemia since childhood, she was usually a very energetic person. In 2005, when her fatigue got so bad that she had to nap during her lunch hour at work, it was time to see a doctor. The myeloma diagnosis, which was confirmed in 2006, was a complete shock. "I remember feeling like a stranger in a strange land," she recalled. But Modenia is a fighter, so she braved chemotherapy and prepared for her stem cell transplant.

For her transplant, Modenia traveled from Nevada, where she was living and working, to Arizona. Her stay there lasted for almost two months. "There were times I wanted to give up," said Modenia. "But my family wouldn't let me." When she was finally ready to leave Arizona, Modenia's brother and cousin drove her to Kentucky, which has always been her true home.

In 2010, Modenia started a support group in Richmond with the assistance of the IMF. "I think of it as IMF giving me my 'Field of Dreams' – the IMF helped me build it, and people came. Myeloma may be my journey, but I found my purpose in my support group. I had a calling to help people, but I also needed help with lifting my own spirits. Now I am happy and my spirit is as high as the clouds. Our group is 15 members strong and we call ourselves 'Fearless in Flight'– a name that came to me at an IMF Support Group Leaders Summit I attended – because we refuse to let fear get us down."

At each meeting, group members "fly" to a destination selected by one of its members. It can be a favorite place or somewhere they wish they could visit. They decorate the meeting room accordingly and prepare food that reflects the chosen destination. So far, they have "flown" to Europe, Africa, and across the US. The numbered "boarding pass" each group member receives upon arrival also serves as a ticket for raffle prizes.

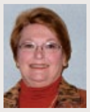
"We plan to live with this disease, not die from it," said Modenia in conclusion. "Our group members share more than support. We share joy and hope, and we welcome all newcomers with love and open arms." **MT**

The "Fearless in Flight" group meets on the second Saturday of each month from 1:00 to 3:00 p.m. at the First Baptist Church in Richmond, KY. Contact Modenia at modeniablack@yahoo.com or 859-623-1684.

How to contact the IMF Support Group Team

Robin Tuohy – *Director of Support Groups*
phone: 203-206-3536
email: Tuohy@snet.net

Kelly Cox – *Regional Director of Support Groups and Regional Community Workshops*
phone: 800-452-CURE (2873)
email: kcox@myeloma.org



Anne Pacowta – *Regional Director of Support Groups*
phone: 203-233-5813
email: apacowta@myeloma.org

Andrew Lebkuecher – *Regional Director of Support Groups*
phone: 404-353-7127
fax: 678-546-3045
email: alebkuecher@myeloma.org

Gregor Brozeit – *European Programs*
email: greg.brozeit@sbcglobal.net

Ann Arbor, MI

The Ann Arbor MM Support Group was founded in October 2006, three years after Jewells Nagy was diagnosed with myeloma. Along with Diane Nagy and IMF Board of Directors member Chuck Newman, two more people attended the first meeting. Over the next five years, the group's membership grew from 5 to 100. Up to 20 members come to most meeting, and as many as 50 have attended meetings featuring invited speakers.

The group has several supporters in the healthcare community and it is not unusual for meetings to feature presentations on a variety of medical topics. "We schedule one speaker every quarter," clarified Jewells. "The other meetings are about an exchange of information among our members. We have a knowledgeable group and we make sure that the newly diagnosed get the time they need to get their questions answered. When new members return to our meetings again and again, it confirms that we are serving a need of the myeloma community in southeast Michigan."

The group's focus has always been on patient education. "The more we know, the better able we are to make informed decisions about our treatment and care," said Jewells. "In that regard, the IMF has been invaluable to our group. We received a lot of support from the IMF during the group's early days and continue to benefit from our relationship with the IMF. They send us educational materials and we've had several visits, including during the cross-country Myeloma Mobile trek made by the Tuohy Family, plus the 2011 Michigan RCW (Regional Community Workshop). In addition, we attend the IMF's annual Support Group Leaders' Summit and we've been invited by the IMF to ASH, the Annual Meeting and Exposition of the American Society of Hematology – a very informative look behind the scenes at the medical progress being made in the field."

Last December, the Ann Arbor group celebrated its 5-year anniversary. Group members organized a surprise for Jewells and Diane, presenting them with a plaque as a token of appreciation for their care and steadfast leadership. "Diane and I have accomplished a lot in our lives," said Jewells in closing. "But starting this support group has been the most gratifying and enriching experience we've ever had."

The Ann Arbor MM Support Group meets the first Tuesday of each month at St. Joseph Hospital in Ypsilanti, MI. Contact Jewells at 810-923-9809, Diane at 248-417-6313, or email annarbormyelomagroup@yahoo.com.

The IMF welcomes new MM support groups

CALIFORNIA – San Fernando Valley (LA area) MM Support Group held its first meeting on June 13, 2012. The group meets from 7:00 to 9:00 p.m. at Temple Judea, 5429 Lindley Ave, Tarzana, CA. Contact Malcolm at SFVMMgroup@gmail.com or call 818-515-6060.

MARYLAND – The Chesapeake MM Network, founded in February 2012, meets quarterly on the first Saturday of May, August, November, and February from 4:00 to 5:30 p.m. at the Easton Bank & Trust Co. Contact Robert Kelly at kellyrf@lemoyne.edu or 410-226-5345, or Midge Menzies at 410-822-6663, or René Fuentes RRFuentes46@gmail.com.

OHIO – The Toledo Area MM Support Group meets on the third Tuesday of each month from 2:00 to 4:00 p.m. at the Perrysburg Way Public Library in Perrysburg. Contact Inge Lanzenberger at inge1028@gmail.com.

TEXAS – The Kingwood Area MM Support Group meets quarterly on the 3rd Saturday of January, April, July and October from 10:00 a.m. to 12:00 noon at the YMCA in Kingwood. Contact Mike Boyd at mboyd4814@gmail.com or 281-360-9267.

A ZEBRA AMONG HORSES

By Jim Omel, MD

The MM Masquerade

Myeloma can be challenging to diagnose since it masquerades as much more common ailments. When cancer presents with seemingly benign symptoms, even a doctor can misdiagnose himself. As a physician who is also a patient, I hope that my experience can help others understand why their doctor took so long to make their diagnosis. If I could miss my OWN diagnosis for nine months, patients should consider how difficult it can be to spot a zebra hiding among many horses.

After 25 years in family practice, I had come to believe the principle of diagnosis taught to me in medical school: "When you hear the sound of hoof beats, think horses, not zebras." The most common conditions will be the most common diagnoses for a set of symptoms. A baby with feeding problems and vomiting most likely has colic – not pyloric stenosis (a stomach blockage that requires urgent surgery). Likewise, most working people with painful backs have muscle or ligament strain, not cancer.

For 49 years I had been in excellent health. Surely the nagging ache in my back was just another unfortunate consequence of my 50th birthday, like the black balloons from my nurses. That's it, I thought: I'm just getting old. Or perhaps the growing discomfort was from lifting my wife incorrectly. Her multiple sclerosis had progressed to the point where she needed more and more help. Along with frequent ibuprofen and my nightly heating pad, I resolved to exercise more faithfully. But the pain grew worse. Pondering my medical history, I concluded that the pain just had to be a recurring strain injury. I resolved to use better lifting techniques as I helped my wife into bed each night, to do more sit-ups, and even to start some physical therapy.

Stronger medicine and the physical therapy brought some improvement, assuring me of my proper diagnosis. Every patient I treated for moderate back strain who improved convinced me that time and exercise would help my own misery as well. Still, the pain grew worse. By now my wife and office nurses were quite concerned, so I prescribed myself some rudimentary lab tests and an x-ray of the lower back. The normal results confirmed to me that I was a wimp. I resolved again to be extra careful when moving my wife, faithfully exercise to strengthen my back muscles, and wait for this common horse to get better.

It was the night before Thanksgiving when I felt something give way. Halfway through a sit-up, lancing pain convinced me I'd torn something. After a painful, sleepless night I drove our handicap van to the hospital. It was Thanksgiving, and I was on call, so I tried in vain to make hospital rounds on my wife's electric scooter. Finally, another doctor stopped me and said, "Jim, it's time you stop being a doctor and start being a patient."

I crawled into an MRI scanner and heard, for the first time, its knock knock knock, ca-dong ca-dong, click click click. I recalled dozens of MRIs I had ordered and considered how confined my patients must have felt. Later, I stared at the pictures with the radiologist. A compressed mass of bone fragments filled the narrow space that used to be occupied by the 10th thoracic vertebra. My brain would not accept what my trained eye was seeing. It was then I realized what a fool I had had for a doctor.

A few tests at a cumulative cost of under $2000 would have established the MM diagnosis nine months prior. But should every patient with chronic back pain have these tests and add to the ballooning cost of health care? Consider the majority of 'normal' results and the payment denial letters from insurance carriers decrying such a waste of resources. Also consider the specter of malpractice lawyers waiting for one wrong medical decision. Patients dismayed by the time required to diagnose cancer might not understand the innumerable possible diagnoses associated with their symptoms… especially with the perfect vision of hindsight.

It was time to share the grim prognosis with my family. I had handled moments like this dozens of times with patients and their families. I began calmly but quickly lost my equanimity when telling them my life expectancy was about 36 months. The powerful emotions of that moment fully 15 years ago are still as vivid as ever. I recall the tears shed with my two daughters and the hugs of my two tall sons, hugs which were firm but strangely gentle as they were aware of the pain deep in my bones.

This was in 1997, when thalidomide was first being tried in a few MM patients. A 'pipeline' for new myeloma drugs simply did not yet exist. I could give my family very little reason for optimism, and every medical article I read shouted the awful word INCURABLE.

Our local radiation oncologist, a colleague and friend, told me of a lady who had MM for 15 years. Mark said it could be controlled if not cured, and to think of it as a chronic disease. In my anguish I found his words to be patronizing. They didn't mesh with my personal pity party. I considered how many times I'd tried to comfort a frightened patient and now realized the only word they heard, the only word they remembered, was "cancer!"

I planned to die and acted accordingly, selling my coin collection, several limited partnership investments, and a valuable collection of rare pharmacy proprietary products and bottles for a fraction of their worth. I shortened the maturity of numerous bond holdings and did whatever I could to ease the financial decisions which my wife would have to make. But a funny thing happened on my way to dying…..I lived!

Living with the Zebra

Initial treatment with chemotherapy and radiation brought remission, but in two years the MM returned. An autologous stem cell transplant achieved the second remission, which took me well beyond my original life expectancy. Since then, I've had more MM relapses and I am currently making the most of another remission.

As I look back on my 15 years with MM, it has indeed become a chronic disease. Those years have included fractured bones, 14 months with exposed mandible resulting from osteonecrosis of the jaw caused by bisphosphonates, worrisome myelosuppression, and long lonely IV infusions.

The past 15 years have also included many new friends I wouldn't have otherwise met, a great support group to lead every month, and exhilarating advocacy work at the U.S. Food and Drug Administration (FDA) and the National Cancer Institute (NCI).

At one point, I chose not to seek a 4-year position on NCI's advocacy board DCLG, fearing myeloma death or treatment side-effects. In sharp contradistinction and demonstrative of a sea-change in my personal thoughts about cancer, I later accepted an invitation from Dr. John Niederhuber, the 13th director of the NCI, to serve on NCI's Board of Scientific Advisors (BSA). My 5-year BSA term will conclude in 2012. I have the distinct honor and responsibility to represent MM patients on FDA's Oncologic Drugs Advisory Committee (ODAC) review of carfilzomib for relapsed and refractory MM, a new drug with promising clinical trial results.

CONTINUES ON PAGE 16

MYELOMA CAREGIVER WIFE

By Kim McLaughlin

Diving into Love with Eyes Wide Open

It's a journey I would have never chosen. This is true, even though some gifts from being on this path have been huge. I wanted to write about some people I have met in my six-plus-year odyssey as a caregiver wife, who DID choose this journey.

My husband, Alan, was diagnosed with myeloma in September 2005. I jumped into the search for resources. The IMF was one of those resources. I remember the arrival of the IMF InfoPack, including the card for an IMF Patient & Family Seminar in San Francisco. That seminar happened to hit on the day of my 50th birthday. We traveled from Portland to San Francisco, and were like sponges absorbing information. I remember the rush of calm when a patient panel included a 28-year survivor.

At a cocktail party that evening my extremely introverted husband whispered to me "Don't make eye contact!" He was shy in a room full of strangers. But Alan married an extreme extrovert, so of course I made eye contact, and invited a couple looking for a place to sit to join us.

It was Ms. J and Mr. J from Medford. They were delightful. Alan was immediately fascinated with Mr. J's extensive notebook of years of lab results. They were both "engineer" types, and Alan started keeping similar spreadsheets of his lab results when we returned to Portland.

I've held onto this couple's story for years. They were older than us and had been dating for a long time before Ms. J said "yes" to a marriage proposal. The wedding was just weeks away when the MM diagnosis came. There was a lot of pressure from her family to call it off and to avoid a marriage as a caregiver to a patient. But she didn't back out.

How hard it must have been to choose to say "yes," to an uncertain future, and with well-meaning family trying to dissuade you. By the time we met them, things had developed into a pretty nice routine of golf and clinic appointments, and the marriage was a treasure to both.

We threw ourselves into our local MM community. Because of this, when friends had a family member who had been diagnosed with MM, we often found ourselves connected with them to "show them the ropes." This was how I met Ms. C, who was gathering information after her fiancé was diagnosed with MM. She was in her 40s and finishing a medical program, and he was approaching 50. She wanted to talk about marriage to someone with a myeloma diagnosis. I shared what I could.

Ms. C also chose to be the wife of a myeloma patient. In the brief window before her new husband began Revlimid treatment, she became pregnant. The couple's little son has the widest smile I have ever seen on any human being, and is the center of their universe.

Two weeks ago, I was at the IMF's Patient and family seminar in Seattle, and met Ms. S, whose boyfriend of almost five years was recently diagnosed. She is selling her house, and he is packing up his, to move to the East Coast together, where they have decided his treatment will be handled. Her sweetheart asked Ms. S not to share his diagnosis with friends and family, partially, I think, out of worry over the judgments they might make on her choosing to accompany him on his challenging future. But she is smart, loves him, and is choosing with her eyes open.

I hope all of these caregivers find gifts along the way that exceed the challenge of choosing to accompany someone with myeloma on this precarious path. If your story is similar, you, too, have my extra admiration.

Riding Tandem

In the Fall of 2004, Charles and Marie were riding a bicycle built for two around Greece, celebrating Marie's return to health and strength after her MM diagnosis in 1999 and her stem cell transplant in 2000.

Alan and I were in Greece at the same time, celebrating our 15th wedding anniversary. But we hadn't yet met Charles and Marie, and hadn't ever heard of MM. For us, those two things wouldn't happen for another year, when in Fall of 2005, Alan was also diagnosed with MM.

In 1999, Marie was diagnosed with MM after several of her vertebrae collapsed when she was moving a large vase in their home. Charles launched himself into the battle to save his wife, who at the time was given a 6-month prognosis. He did a lot of research, collecting 7 binders of notes. Charles is a "Caregiver's Caregiver." In 2000, when they determined that their best option was a stem cell transplant – a relatively new and experimental process in Portland, Charles offered to buy their local hospital the equipment to harvest the stem cells. For Charles and Marie, the transplant was victory: It's now been 12 years since Marie had hers, with no follow-up drugs or treatment.

Through a serendipitous connection, Charles and Marie became the first fellow travelers Alan and I met after Alan's diagnosis, and became our first guides. They invited us to their home to share their story and answer questions. During that evening of listening to their saga, and wealth of fascinating anecdotes, they shared a warning with us: After the successful treatment, with so much to celebrate and be thankful for, they nearly divorced. The intensity of the medical crisis had left them in very different places. Charles was vehemently protective and Marie was withdrawn and overwhelmed by what she had been through.

All of us become caught up in the battle with MM. We fight for our partners and for ourselves. Caregivers become hyper-vigilant, and assume patients will always be grateful for the help and love they receive, but it isn't simple for any of us. Often we become so accustomed to our roles that we can't re-adjust when it's time to resume "normal" life. Charles and Marie saw how behavior patterns that were necessary in the time of distress were pulling their marriage apart when the need for struggle was over. Fortunately, they recognized this and were able to talk about it. They found a support group and got help from a cancer social worker.

Many of us don't get to that safe place where the MM is no longer the biggest fight of our lives. We move forward to keep from falling, seeking that balance, and a way to ride tandem for the the trip. We both are pulling more weight than we ever thought we could as we negotiate the road ahead together. As Lance Armstrong said, "It's not about the bike." **MT**

Editor's Note: Kim McLaughlin's cargiver blog is a regular feature of the IMF Myeloma Minute (minute.myeloma.org).

A ZEBRA AMONG HORSES — continued from page 15

I am thrilled every time I add a new 'survivors' shirt to my growing Relay for Life collection each year, and agree with the sign above my desk – *Getting Older is Wonderful*. Each birthday is a triumph and each grandchild is a blessing. My wife and I are now grandparents of 13 children and have identical twin GREAT granddaughters. In my wildest dreams, I would never have imagined those things happening in the horrible, painful, dark days of 1997! **MT**

Editor's Note: In 2000, Dr. Omel retired from active practice in Grand Island, NE. He is devoting his life to cancer patient advocacy.

IMFers RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

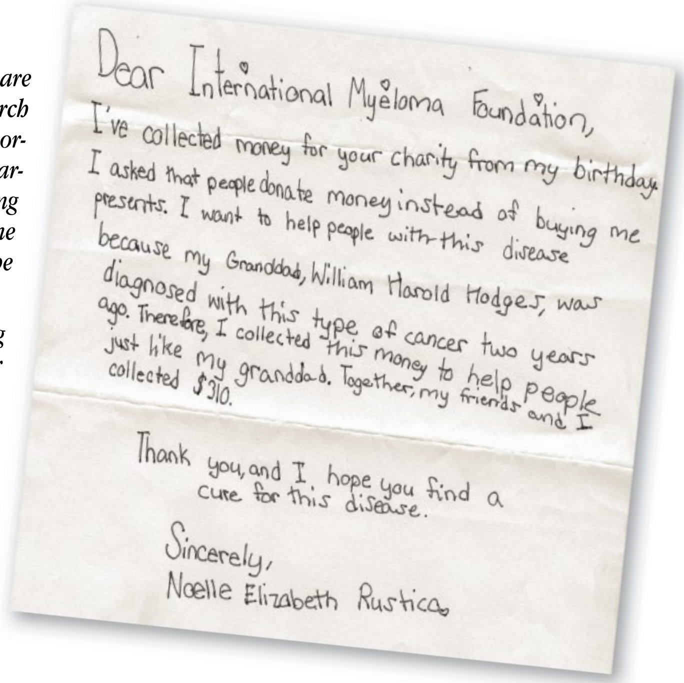
By Suzanne Battaglia

2012 promises to be a very successful year for IMF members who are raising funds to support essential multiple myeloma (MM) research while also raising MM awareness. Fundraisers as diverse as neighborhood garage and bake sales, community marathons and walks, parties and entertainment events, sports tournaments and countless other events are taking place across the country. Most of these events start with a phone call to the IMF and one simple question – "What can I do?" Those who became involved find their activities to be not only fulfilling but also incredibly empowering.

Our FUNdraising program is fun and easy, and brings with it the satisfaction of knowing that YOU are making a difference in many lives. Choose an established event model or create your own. ***No idea is too large or too small!*** *The IMF provides you with tools and assistance to make your event a success, and promotes your efforts through our website and social media outlets. Please contact me, Suzanne Battaglia, at sbattaglia@myeloma.org or 800-452-CURE (2873) to chat about any ideas you might have.*

The moneys raised by individuals like you help support cutting-edge MM research funded by the IMF. Become a part of making miracles happen! Join us in working together toward our common goal… a CURE.

Here are some examples of recent events…



Dear International Myeloma Foundation,

I've collected money for your charity from my birthday. I asked that people donate money instead of buying me presents. I want to help people with this disease because my Granddad, William Harold Hodges, was diagnosed with this type of cancer two years ago. Therefore, I collected this money to help people just like my granddad. Together, my friends and I collected $310.

Thank you, and I hope you find a cure for this disease.

Sincerely,
Noelle Elizabeth Rustica

The Meier/Grammel Family Run

In October 2009, when Dr. Chris Meier started experiencing heavy fatigue, he assumed this was due to the demands of his medical practice. But when he awoke one morning with a sizeable bruise on his back, he knew something was wrong. The results of blood labs and other testing confirmed the MM diagnosis. In addition, a CT scan revealed renal cell carcinoma, kidney cancer that later resulted in the removal of one kidney.

Dr. Chris Meier with daughters Ellen Grammel and Teresa Meier

"Regardless of all the challenges my Dad has faced since his cancer diagnoses, he has continued to take care of his patients," said Dr. Meier's daughter Ellen Grammel. "He is such a positive person. I really admire him and am inspired by him." Along with her sister, Teresa Meier, Ellen decided to run the Flying Pig Marathon, an event well-known in Cincinnati for supporting charities. The Meier/Grammel Family wanted to raise funds for the IMF while raising awareness of myeloma in their local community. While Ellen and Teresa trained for the marathon, donations in honor of Dr. Meier started to come in via a web page they set up on the IMF site.

The Meier/Grammel Family

On the day of the marathon, Dr. Meier and his wife Nancy, along with their three other children and their families, staked out several sections along the event's route to cheer on Ellen and Teresa as they completed the course. "Teresa and I didn't know we had it in us to run a marathon, but we were so determined to show support for our Dad while helping raise MM awareness, that it really motivated and pushed us forward. In the end, we accomplished our goals and were so excited to raise $1,500 in our father's honor. This was such a great experience."

MYELOMA 200 – Closer To A Cure

Over the years, MYELOMA 200 – CLOSER TO A CURE (M200) has been one of the IMF's most successful fundraisers. Every $200 given or raised by a participant yields one entry in the M200 Challenge drawing to win a fabulous vacation getaway for two. The lucky winner of the IMF's recent M200 drawing for a trip to Costa Rica is Yelena Kotlyar. Yelena and her husband Vadim will enjoy 7 days and 6 nights at the beautiful Four Seasons Costa Rica at Peninsula Papagayo. The prize package also includes airfare on American Airlines and a $400 Four Seasons Gift Card for spa services.

Vadim & Yelena Kotlyar with son Gene and daughter Vanessa

Vadim Kotlyar suffered for many years with persistent back and rib pain, colds and flu, and frequent nose bleeds before being diagnosed with multiple myeloma (MM). As soon as her husband's diagnosis was confirmed, Yelena started to learn all she could about MM and quickly found a myeloma specialist to manage Vadim's medical care. After undergoing a transplant in the Summer of 2011, Vadim achieved a complete remission. "Our family is so fortunate and grateful," said Yelena. "And we are hoping for the best!"

"The M200 Challenge campaign was created with the goal of raising $200,000 for IMF Research, Education, Support, and Advocacy Programs," continued Yelena. "If the IMF reaches this goal, everyone wins. So we created a family webpage and were able to raise $1,900 with the support of friends and colleagues. Our M200 experience was rewarding all on its own, and winning the Grand Prize is a very unexpected bonus. I am sure we will enjoy and remember this for many years to come." **MT**

Letters to the IMF

The IMF's new 'Myeloma Post' App

I am a 12-year MM survivor, and a support group leader. I know personally how important it is to have MM information readily available and flexible enough to meet specific needs. And as a father of active teenagers, I know managing MM is just one part of a busy day, so having the information easily accessible and portable is also essential. The IMF's new iPad application, the Myeloma Post, gives me fast and easy access to IMF's website so I can stay informed of all medical news and other developments. It's a great addition to the array of educational tools made available by the IMF.

Michael Tuohy

Regional Community Workshops

The IMF's Regional Community Workshop (RCW) in Kansas City was highly successful thanks to Kelly Cox and other IMF staffers who worked diligently to bring in Dr. Hari (Medical College of Wisconsin), Dr. Abhyankar (University of Kansas Bone Marrow Transplant Center), and Nadine Baxter-Hale (University of Arkansas for Medical Sciences, Myeloma Institute of Research and Therapy).

This was the third year the IMF partnered with the Health and Human Services division of Johnson County Community College to bring together myeloma experts with myeloma patients and their supporters, as well as local medical professionals, to hear the latest information about this disease. With over 80 people attending, the workshop demonstrated the impact the IMF has on so many people living with myeloma.

Cindy Ralston

Many thanks to the IMF for the terrific Regional Community Workshop (RCW) held in Indianapolis, IN. To attend the RCW, my husband and I traveled to Indy from Cincinnati, OH. The meeting was very informative and gave us – patients with multiple myeloma – a chance to ask questions of the doctors without having to worry about appointments and time constraints.

One of the faculty members, Dr. Rafat Abonour, is my doctor and he is always a great presenter, as well as a very caring human being. The RCW was also a wonderful opportunity to listen to Dr. Robert Kyle, who has such a caring way of talking to us about myeloma while giving us lots of information. I want the doctors to know how much their time and efforts are appreciated by patients and our families. These two doctors, in particular, have a special way of presenting tough information to us in a personal way with warmth and humor. They give us hope as we deal with the frightening and overwhelming problems of MM.

My husband and I are very grateful to Dr. Brian Durie and Susie Novis and the rest of the IMF team for making the RCW events available to us.

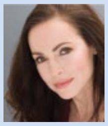
Suzie Schreiber

Advocacy

I just wanted to take a moment to thank IMF's grassroots liaison Aimee Martin for spending so much time with me during my visit to the IMF headquarters in Los Angeles. I enjoyed getting to know her and learning more about the IMF. It was great to meet someone who is so smart, passionate, and dedicated. I know that the myeloma community is all the better for having her on our team. I also appreciated the time she took in showing me around the offices and introducing me to many of the people who work so hard on our behalf. I look forward to testifying before the Senate Health Committee in California, and continuing to work with the IMF to help get the legal changes we MM patients need enacted.

Robert Adler

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

IMF Staff Updates

Anne Pacowta

Regional Director, Support Groups

Anne Pacowta was born and educated in Pennsylvania, where she earned a Bachelor of Science degree from Marywood College. She moved to Connecticut to teach, where she married and spent the next 38 years with her husband Jack. She raised three children and maintained active involvement in community activities, including being a Scout leader, religious education instructor, Parent-Teacher Organization officer, and school volunteer.

Anne and Jack were well into enjoying grandparenthood when Jack was diagnosed with multiple myeloma. They joined a myeloma support group in Connecticut, but later relocated to an area of Florida where they found themselves without that source of education, friendship, and community. In 2007, Anne and Jack founded the North Florida MM Support Group. The first meeting, held in a small library room, was attended by 12 people.

After Jack lost his battle with MM in 2008, Anne continued to keep his legacy alive with group co-leaders, Hunter and Dianna Chiles. The North Florida MM Support Group now has over 40 registered members. "I am gratified to have been able to help our support group members with their journey on the myeloma road and will continue to do so as I embark on my new position with IMF," said Anne. "I look forward to this new opportunity and the chance to reach many more people with help, education, and support." Anne can be reached at apacowta@myeloma.org.

Janice Marie Estrada

Auction and Development Associate

Janice Marie Estrada holds a Master of Arts degree in Theater from California State University Northridge. She also holds a Bachelor of Science degree in Recreational Management with an emphasis in Non-Profit Development and Program Planning. With more than eight years professional experience working in the non-profit sector, Janice comes to the IMF with knowledge in donor relations, advocacy, and event fundraising. Janice is responsible for all public relations pertaining to the IMF's annual silent auction, as well as the development of external fundraising campaigns. Janice can be reached at jestrada@myeloma.org.

We're here for a reason.

To transform lives by transforming medicine.

At Onyx, this is the guiding principle that drives both our scientific innovation and our dedication to deliver novel therapies to patients with multiple myeloma.

LEARN MORE AT
onyx.com

ONYX
PHARMACEUTICALS

Times Change

Technology has Evolved. So has Myeloma Diagnosis.

Freelite® polyclonal serum free light chain assays are highly sensitive and specific tumor markers for the diagnosis and monitoring of Multiple Myeloma.

The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) recommend the use of polyclonal serum free light chain assays (**Freelite**) in the initial diagnostic workup of myeloma and related disorders.[1]

1. Referenced with permission from The NCCN Clinical Practice Guidelines in Oncology® for Multiple Myeloma V.1.2012. © National Comprehensive Cancer Network, Inc 2011. All rights reserved. Accessed March 21, 2012. To view the most recent and complete version of the guideline, go online to www.nccn.org. NATIONAL COMPREHENSIVE CANCER NETWORK®, NCCN®, NCCN GUIDELINES®, and all other NCCN Content are trademarks owned by the National Comprehensive Cancer Network, Inc.

In Europe and the USA, **Freelite**® is a registered trademark of The Binding Site Group Ltd, Birmingham, UK.

Call: 1-800-633-4484
Email: info@thebindingsite.com
www.thebindingsite.com

Binding Site

One mission: to deliver extraordinary medicines to patients with cancer worldwide through our science, innovation and passion.

Takeda
MILLENNIUM
THE TAKEDA ONCOLOGY COMPANY

To learn more, visit us at ***millennium.com.***

©2012 Millennium Pharmaceuticals, Inc. All rights reserved.

MILLENNIUM SALUTES THE INTERNATIONAL MYELOMA FOUNDATION

Improving Lives • Finding the Cure

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

2012 IMF Calendar of Events

June 7	IMF/AF3M 10th Annual Patient & Family Seminar (PFS) – Paris, FRANCE
June 9	WüUC/IMF Patient & Family Seminar (PFS) – Würzburg, GERMANY
June 10	Koblenz SG/IMF Regional Community Workshop (RCW) – Koblenz, GERMANY
June 11-13	International Myeloma Working Group (IMWG) Summit III – Amsterdam, THE NETHERLANDS
June 12	Robert A. Kyle Lifetime Achievement Award Dinner – Amsterdam, THE NETHERLANDS
June 14-17	European Hematology Association (EHA) 17th congress – Amsterdam, THE NETHERLANDS
June 16	Munich SG Patient & Family Seminar (PFS) – Munich, GERMANY
June 17	Leipzig SG/IMF Regional Community Workshop (RCW) – Leipzig, GERMANY
June 20	Berlin SG/IMF Regional Community Workshop (RCW) – Berlin, GERMANY
June 23	MLÖ/IMF Patient & Family Seminar (PFS) – Vienna, AUSTRIA
July 27-29	IMF Support Group Leaders' Annual Summit – Dallas, TX
Aug 10-11	IMF Patient & Family Seminar (PFS) – Los Angeles, CA
Aug 18	IMF Regional Community Workshop (RCW) – San Marcus, TX
Aug 24-25	IMF Patient & Family Seminar (PFS) – Boston, MA
Sept 12	DMG/IMF Patient & Family Seminar (PFS) – Nyborg, DENMARK
Sept 15	Myeloma Center Workshop (MCW) at Emory University – Atlanta, GA
Sept 15	TUC/IMF Patient & Family Seminar (PFS) – Trondheim, NORWAY
Sept 16	UH/IMF Patient & Family Seminar (PFS) – Oslo, NORWAY
Sept 21-22	CMG/IMF Patient & Family Seminar (PFS) – Lazne Belorad, CZECH REPUBLIC
Sept 22	AIL/IMF Patient & Family Seminar (PFS) – Catania, ITALY
Sept 24	AIL/IMF Patient & Family Seminar (PFS) – Torino, ITALY
Sept 30	IMF Patient & Family Seminar (PFS) – Heidelberg, GERMANY
Oct 5	Myeloma Center Workshop (MCW) at UNC/Duke University – Raleigh-Durham, NC
Oct 27	6th Annual Comedy Celebration – Los Angeles, CA
Nov 3	IMF Regional Community Workshop (RCW) – Sacramento, CA
Nov 10	Myeloma Center Workshop (MCW) at Mayo Clinic – Scottsdale, AZ
Dec 8-11	American Society of Hematology (ASH) annual meeting – Atlanta, GA

The IMF is proud to work with our global partners.
For more information about upcoming events, please visit myeloma.org or call 800-452-CURE (2873).
IMF–Latin America, IMF–Japan and IMF–Israel events are not included above.