



Improving Lives • Finding the Cure™

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

Scientific & Clinical News



The Black Swan Research Initiative™ (BSRI™) work is accelerating rapidly. As Dr. Durie explains, the BSRI team has already completed work on how to define and identify minimal residual disease, MRD-Zero™, clinically. Around the world, BSRI team members are designing clinical trials, analyzing data from thousands of myeloma patients, and standardizing the sophisticated testing techniques that will tell us when no minimal residual disease remains (MRD-Zero). By the end of the year, the BSRI team will begin testing multiple treatment approaches simultaneously, incorporating new therapies into trials as they are approved. **PAGE 5**



Dr. Brian G.M. Durie, IMF Chairman and Co-founder, shares highlights from the 4th Annual IMWG Summit. More than 70 leading myeloma researchers from around the world gathered in Stockholm to grapple with subjects of vital concern to the myeloma community. He notes that IMWG attendees discussed the need to arrive at a consensus for a definition of “early myeloma” and debated how early to begin myeloma treatment. A presentation from Dr. Maria-Victoria Mateos on the University of Salamanca’s high-risk smoldering myeloma trial spurred discussion. **PAGE 4**



Henk Lokhorst, MD, Professor of Haematology at University Hospital Utrecht in the Netherlands, reviews results of a Phase I/II clinical trial of the monoclonal antibody daratumumab in myeloma patients. Daratumumab is directed against CD38, a protein that is present on the surface of myeloma plasma cells. Data from the Phase I clinical trial were encouraging, and further studies are underway. Daratumumab has been granted breakthrough therapy designation by the FDA. **PAGE 7**

Special Event



Prof. Gösta Gahrton, a leading Swedish hematologist and professor of medicine at the Karolinska Institutet, was honored with the IMF’s 11th Annual Robert A. Kyle Lifetime Achievement Award. More than 140 attendees gathered in Stockholm’s Grand Hotel to pay tribute to Prof. Gahrton for his contributions to the field of multiple myeloma as a pioneer in bone marrow transplants, renowned investigator into the use of cell and gene therapy for the treatment of hematological disorders, and author of hundreds of scientific articles. **PAGE 6**

Special Meetings



The IMF, in conjunction with Myeloma Club, the myeloma patient association of the Czech Republic, and the Czech Myeloma Group, hosted a patient meeting that welcomed over 100 attendees, including myeloma physicians, patients, and family members. Speakers included Czech myeloma physicians who updated attendees on the myeloma treatment landscape and clinical research, patients who discussed living active lives with myeloma, and leaders from Myeloma Club and the Slovakia Myeloma Society. **PAGE 9**



The 2013 IMF Support Group Leaders Summit brought together myeloma support group leaders from across the US, Canada, and Australia to learn from each other and myeloma experts. A record number of first-time attendees joined this year’s Summit. New and returning attendees shared tips for running their groups and supporting their members, while forging bonds with fellow support group leaders and the IMF Support Group Team. **PAGE 10**

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(We have 9 additional RCW/MCW seminars in the works for 2014. They will be listed on our website as soon as we confirm dates.)

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Chief Financial Officer
Jennifer Scarne
jscarne@myeloma.org

**Senior Vice President,
Clinical Education & Research Initiatives**
Lisa Paik
lpaik@myeloma.org

IMF Executive Team

**Executive Vice President,
Development**
Heather Cooper Ortner
bortner@myeloma.org

**Vice President,
Global Affairs**
Dan Navid
dnavid@myeloma.org

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

**Vice President,
Global Advocacy**
Arin Assero
aassero@myeloma.org

IMF Staff

Database & Inventory Control
Betty Arevalo
marevalo@myeloma.org

Director, Member Events
Suzanne Battaglia
sbattaglia@myeloma.org

Hotline Coordinator
Debbie Birns
dbirns@myeloma.org

**Southeast Regional Director,
Support Groups**
Nancy Bruno
nbruno@myeloma.org

Director, US Advocacy
Meghan Buzby
mbuzby@myeloma.org

National State Affairs Consultant
Zina Cary
zcary@myeloma.org

Development Assistant
Sharon Chow
schow@myeloma.org

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

**Director, Europe
& the Middle East**
Nadia Elkebir
nelkebir@myeloma.org

**Midwest Regional Director,
Support Groups**
Sue Enright
senright@myeloma.org

Hotline Coordinator
Paul Hewitt
phewitt@myeloma.org

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

Hotline Coordinator
Missy Klepetar
mklepetar@myeloma.org

Accountant
Phil Lange
plange@myeloma.org

**Director, Annual Giving
& Social Media**
Randi Lovett
rlovett@myeloma.org

Research Project Coordinator
Danielle Loi
dloi@myeloma.org

Grassroots Liaison
Aimee Martin
amartin@myeloma.org

Publication Design
Jim Needham
jneedham@myeloma.org

**Florida Regional Director,
Support Groups**
Anne Pacowta
apacowta@myeloma.org

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

Assistant to the President
Chelsea Proctor
cproctor@myeloma.org

Webmaster
Kelly Quiggle
kquiggle@myeloma.org

Meeting Coordinator
Annabel Reardon
areardon@myeloma.org

Web Producer
Miko Santos
msantos@myeloma.org

IT Systems Admin
Thomas Shin
tsbin@myeloma.org

Distribution
Brando Sordoni
bsordoni@myeloma.org

**Senior Director,
Support Groups**
Robin Tuohy
rtuohy@myeloma.org

Hotline Coordinator
Judy Webb
jwebb@myeloma.org

A Message from the President

Dear Reader,

We may live in a digital world, but IMF events this summer showed me that the most valuable experiences will always be face-to-face.

The power of real world encounters really hit home in June at the 2013 International Myeloma Working Group Summit in Stockholm and again in July at the 2013 Support Group Leaders Summit in Dallas. When the IMF brings together myeloma patients, caregivers, researchers, and advocates under one roof, the sparks fly, the adrenalin flows, and new ideas are born!

The world's top myeloma researchers listened attentively during the IMWG scientific presentations in the auditorium. But at break time, the air buzzed with the sounds of people sharing ideas and opinions about what they had just heard.

Even though they keep in touch electronically, it's always better face-to-face. The attendees clearly connected with Prof. Jesús San Miguel of Spain, one of 70 IMWG members from around the world attending the Stockholm meeting, when he noted that the Summit is "a tremendous opportunity to know how the other people think, how they create new ideas." Prof. San Miguel also posed an important question to his colleagues, asking, "What is going to be the next step in myeloma?"

That's exactly what myeloma patients long to hear, especially now that we're actually talking about a pathway to a cure. Many of them heard that information first-hand: this year, for the first time, representatives of myeloma patient organizations attended the IMWG Summit. At break-out sessions, patients got to witness small groups of researchers grappling with the most pressing questions in myeloma research and treatment.

Seeing researchers passionately engaged in debating how best to diagnose and when to treat myeloma, and what sequence of drugs to use to get the best long-term results, lets patients know that we're really making progress. That includes attendees like Myeloma Canada's Aldo Del Col, for whom the high point of the Summit was "listening in on the discussions and debates about clinical practice and new therapies."

A month later I again heard the familiar buzz of excitement as patients and caregivers connected at the Support Group Leaders Summit in Dallas. They exchanged not only phone numbers, but experiences – new leaders and seasoned "vets" traded advice, shared laughs, and embraced in big bear hugs. A virtual experience could never generate the kind of positive energy that filled the room that weekend.

Jan Martin Bopp, who recently started a myeloma support group in Vermont, said he was moved by the generosity he found among support group leaders. "There was such a familial quality," he said. "Leaders gladly shared whatever they could."

The support group leaders who connected at the Summit will almost certainly stay in touch using the iPads that the IMF provided. What always strikes me attending the annual Summit is the honesty of emotions that the leaders are able to share with one another. The triumphs and the many challenges they face as leaders, and the love, friendship, trust, and camaraderie they so willingly share with one another. The jam-packed weekend of "face time" definitely boosted their spirits, and gave them the skills and confidence they need as support group leaders.

So while the IMF has dramatically expanded our online reach into the myeloma community through teleconferences, live webcasting, Twitter, Facebook, YouTube and You-Name-It, I firmly believe that meeting people face-to-face will always be the best way to communicate – true "face time" still matters. Especially when it comes to enriching our lives and finding a cure.

Warmly,

Susie Novis, President



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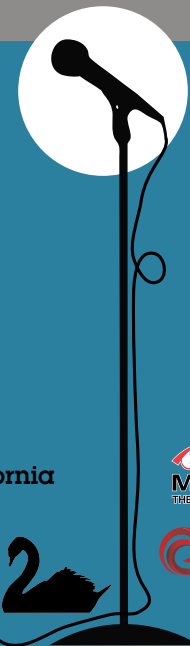
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IMWG RESEARCH TAKES CENTER STAGE AT SUMMIT IN STOCKHOLM

by Brian G.M. Durie, MD



More than 70 of the world's leading myeloma experts from 29 countries gathered in Stockholm June 11 for the 4th Annual International Myeloma Working Group (IMWG) Summit. Each year, the Summit, organized by the International Myeloma Foundation, brings together

researchers from around the world to grapple with subjects of vital concern to the myeloma community.

This year, a format change stimulated more brainstorming among attendees than ever before. From the main auditorium, where the formal IMWG program was held, everyone dispersed to the more intimate conference rooms nearby. There, the researchers enthusiastically shared ideas about key questions in myeloma – frontline therapy, maintenance therapy, transplant, and CR assessment and MRD.

One of the most popular subjects this year in both IMWG Summit settings was the need to arrive at a consensus for a definition of “early myeloma.” A close second was the question of how early to begin myeloma treatment. A highly anticipated presentation may have helped us get closer to some possible answers.

Dr. Maria-Victoria Mateos reported on the results of the University of Salamanca's randomized High-Risk Smoldering Myeloma trial, which showed survival benefit for high-risk smoldering myeloma patients receiving lenalidomide-dexamethasone therapy versus patients without therapy. The focus of discussion was on how to identify patients who can be classified as having “early active myeloma,” and select therapy appropriate for typical “symptomatic,” or “CRAB positive,” myeloma. This would mean that lower-level smoldering patients would not be treated.



Dr. Maria-Victoria Mateos presents results of a highly anticipated high-risk smoldering myeloma trial

The two important questions the study raises are: 1) How do we define what is now being called “CRAB negative” myeloma, and should it be renamed “early active myeloma”? And 2) Is normal myeloma therapy to be recommended for this new “CRAB negative” subgroup? This is when the discussion format – both in the open sessions and work groups – proved effective in soliciting the maximum input from the myeloma experts. Fortunately, there have been pertinent studies and publications to guide the way, especially from the Mayo Clinic and the University of Salamanca teams, as well as corroboration by teams from the US, NCI, and the University of Athens.

Summit participants agreed that it is a priority to consider all these and additional parameters carefully as a basis to clearly define “early active myeloma” as soon as possible, using widely available testing procedures.

There was also consensus among IMWG members that this subgroup is one of those most amenable to curative approaches to therapy, linking directly with the IMF's Black Swan Research Initiative™.



Researchers from around the world gather in Stockholm for the 4th Annual IMWG Summit to grapple with subjects of vital concern to the myeloma community

Myeloma researchers and patients around the world were able to sample some of the findings and excitement generated at the IMWG Summit through the magic of modern technology. I had the pleasure of moderating the third in the IMWG Conference Series “Making Sense of Treatment,” a live-streamed panel discussion that included Drs. Antonio Palumbo, Ola Landgren, and Joseph Mikhael. The topics we covered on the webcast (*archived at <http://tinyurl.com/IMWGW2013webcast>*) ranged from frontline treatment options to maintenance, second primary malignancies to everyone's perspective on new ideas for the future. In other words, lots of ground to cover. Fortunately, a wonderful trio of researchers weighed in on these topics for viewers who had tuned in from around the world.

During the webcast, a seminal question was raised: “If we were to identify myeloma patients for potential therapy before CRAB (clinical) features emerged, what category would this pre-CRAB group be?” The answer from Dr. Joseph Mikhael of “LOBSTER” brought waves of laughter from the panel and audience and was a fitting place to close as Dr. Mikhael pondered the details of this potential acronym!



Drs. Brian Durie, Ola Landgren, Joseph Mikhael, Antonio Palumbo during the conference series webcast

The next evening, international reporters and patient representatives gathered to hear the latest news about myeloma research and treatment at the International Journalists' Workshop, presented by the IMF and Myeloma Canada, and held at the spectacular Swedish Museum of Photography, a restored customs house on the water's edge in Stockholm. (*Archived here: <http://tinyurl.com/IJW-2013>*.)

The panel for the evening included IMF President Susie Novis, Aldo Del Col (Myeloma Canada), myself, Dr. Paul Richardson (Dana-Farber Cancer Institute), and Dr. Xavier Leleu (Lille, France). The theme for the workshop was “the impact of innovation.” I started by illustrating the impact of penicillin in the area of infectious diseases. From that, I summarized the doubling of myeloma survival (average now more than seven years)

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by Brian G.M. Durie, MD

EXCITING MONTHS AHEAD FOR THE IMF BLACK SWAN RESEARCH INITIATIVE



This fall has been a busy time for the International Myeloma Foundation's Black Swan Research Initiative™ (BSRI™) team. We are working behind the scenes to lay the groundwork critical to moving ahead rapidly in what will be an exciting next few months.

In cities around the world, BSRI team members are designing clinical trials, analyzing data from thousands of myeloma patients, and standardizing the sophisticated testing techniques that will tell us when no minimal residual disease remains, MRD-Zero™.

We have already completed our work on how to define and identify MRD-Zero clinically. We are now looking back over previous studies to glean new information about MRD-Zero and responses to treatment that may point toward a cure.

On October 25, several members of the BSRI team will gather in New York for a mini-summit to report on progress and lay out the next steps in our research initiative. And the full BSRI team will convene at a meeting in December ahead of the 2013 Annual Meeting of the American Society of Hematology (ASH). While we work together continuously via phone and email, these face-to-face meetings give us the opportunity to exchange ideas, challenge concepts, and drive the project forward.

By the end of the year, the BSRI team is poised to begin testing multiple treatment approaches simultaneously, incorporating new therapies into the trials as they are approved. We are also looking at new drug combinations already in clinical trials as a guide for our own next steps to find the cure.

Following in our footsteps, others are ramping up their myeloma research efforts as well. This is great news for myeloma patients, and in science it's particularly useful to have lots of people examining data in different ways. But BSRI stands apart as an actual research project aimed at finding a functional cure for myeloma, not an open-access platform to support external research.

Its unique approach differs from other myeloma research efforts in some fundamental ways:

- A core tenet of BSRI is that many patients might be cured and don't know it – because previously we have lacked the sophisticated tests necessary to determine that MRD-Zero has been achieved. Using the latest procedures involving flow cytometry and full DNA sequencing, we will be able to detect down to less than one cell per million of myeloma. Thus, we can identify who has been cured, and what combinations of therapies led to that cure.
- Using Big Data to look for individual *differences*, as others are doing, is expensive, difficult and time-consuming. What makes more sense is BSRI's strategy of using Big Data to find the *similarities* among patients. If the BSRI testing protocols find, for example, a patient with "Category A" characteristics has reached MRD-Zero, then the same treatment course can be applied to others in Category A. Will the cured patient's therapy regime work on all similar patients? No – but when it *does* work that will yield a new, more refined set of characteristics, a "Category A-1" that responds in like manner. And so on.
- Others are attempting to use individual molecular data to develop new targets for drugs. In other words, find a mutation, target the mutation. Better to avoid the mutations that occur in myeloma cells over time by treating the myeloma early. BSRI proposes administering therapy that is known to work in combinations of multiple mechanisms, then applying improved detection techniques to monitor that therapy – and determine what's working – from an early point in the disease.

Comprehensive global research and development is expensive. This month we are finalizing contracts for partial funding necessary to acquire the most sophisticated analytical equipment needed for our research, and to support the teams of researchers.

Personal donations are still the mainstay of the work at the IMF and we are planning to include BSRI at our annual fundraising gala in November.

Also, we hope you will please consider donating to the Black Swan Research Initiative. With your help, we will soon bridge the gap from long-term remission to cure. **MT**

IMWG SUMMIT IN STOCKHOLM — continued from page 4



Myeloma experts Dr. Xavier Leleu and Dr. Sagar Lonial engage in discussion during one of the IMWG Summit's smaller breakout sessions

with the advent of novel therapies: thalidomide, Velcade, Revlimid, plus the more recent additions to the myeloma armamentarium.

Dr. Leleu summarized the amazingly positive results with the new IMiD pomalidomide (Pomalyst®), which led to FDA approval early in 2013 and European approval (EMA) this summer. Dr. Richardson focused on

results with the proteasome inhibitors (Velcade® and carfilzomib [Kyprolis®]), emphasizing the very encouraging results with Kyprolis, which led to the FDA approval for that agent. He also reviewed the range of new agents moving forward in drug development, especially elotuzumab, HDAC inhibitors, and anti-CD38 inhibitor compounds – recently granted special accelerated or "breakthrough" review status by the FDA.

As the wonderful and thought-provoking presentations and discussions wound down in Stockholm, a definite sense of accomplishment filled the air. But as with all scientific endeavors, the more we know, the more questions arise. Fortunately, discussions among the group will continue at the IMWG Breakfast Meeting at the American Society of Hematology (ASH) annual meeting in New Orleans in December this year and at the 5th Annual IMWG Summit in Milan, Italy in 2014. **MT**



Dr. Brian Durie describes the impact of innovation on myeloma treatment before an audience of international journalists gathered at Stockholm's Swedish Museum of Photography

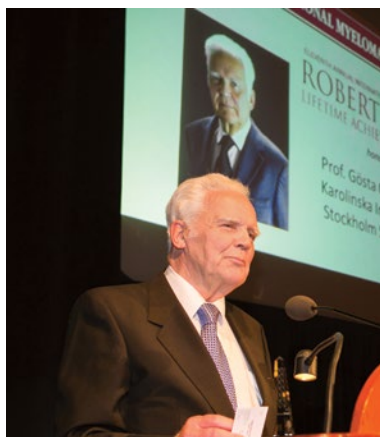
PROFESSOR GÖSTA GAHRTON RECEIVES THE 11th ROBERT A. KYLE LIFETIME ACHIEVEMENT AWARD

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ROBERT A. KYLE
LIFETIME ACHIEVEMENT AWARD

2013 Robert A. Kyle Lifetime Achievement Award Honors Prof. Gösta Gahrton

Stockholm's Grand Hotel, where the Nobel Prize was awarded in the early 20th Century, was the historic setting for the International Myeloma Foundation's 11th Annual Robert A. Kyle Lifetime Achievement Award ceremony on June 11th honoring leading Swedish hematologist Prof. Gösta Gahrton.



Prof. Gösta Gahrton thanks 'all the people I've collaborated with' in his speech accepting the Robert A. Kyle Lifetime Achievement Award

"It's wonderful to be in a place where so many medical milestones took place," said Susie Novis, President and Co-founder of the IMF, kicking off the gala evening. "We applaud Dr. Gahrton's accomplishments and decades-long contributions to improving the lives of myeloma patients."

Dr. Brian Durie, Chairman and Co-founder of the IMF, welcomed the audience of 144 attendees who had gathered to pay tribute to Prof. Gahrton for his contributions to the field of multiple myeloma. Among them were eight previous Kyle Award winners – the award's namesake, Dr. Robert Kyle, Dr. Ken Anderson, Dr. Heinz Ludwig, Dr. Mario Boccadoro, Dr. Jesús San Miguel, Prof. Douglas Joshua, Dr. Joan Bladé and Dr. Brian Durie.

The Robert A. Kyle Lifetime Achievement Award pays homage to the man considered to be the "grandfather" of myeloma treatment. In his more than 40 years at the Mayo Clinic, Dr. Kyle has gained worldwide recognition as a pioneer and respected leader in the advancement of research, clinical treatment, and education about myeloma. Kyle Award honorees are individuals whose work in the field of myeloma has resulted in significant advances in research, treatment and care of myeloma patients.

In his introductory remarks, Dr. Durie recalled meeting Dr. Robert Kyle early in his own medical career. "I was a young guy coming from Scotland to the Mayo Clinic – and who do I get as a mentor but Dr. Kyle?



Dr. Robert A. Kyle presents the KLA Award to Prof. Gösta Gahrton

This fortuitous event led to being mentored by him, and to being a friend of Dr. Kyle's. To be able to give this award tonight is an honor."

Dr. Christer Paul, a professor of hematology at the Karolinska Institutet, offered some personal reflections and humorous insights about Prof. Gahrton, his longtime friend and co-worker at the Karolinska Institutet. "He's like a big brother," Prof. Paul observed. "I'm always looking up to him – and sometimes fighting with him like a big brother."

He went on to describe Prof. Gahrton's many professional accomplishments: "He's been a professor of medicine for many years. He is a member of the Nobel Prize committee – and in some ways was instrumental when Don Thomas received the Nobel Prize [in 1990, for the development of cell and organ transplantation]. But," Prof. Paul noted, "there are other strings on his bow. He is a mountain climber, a very good tennis player and a great hunter."

Dr. Ray Powles, Head of Hematology and Oncology at Cancer Centre London, echoed the praise for Prof. Gahrton, whom he said he has known for 42 years. A touching video chronicled Dr. Gahrton's career as a pioneer in bone marrow transplants, investigator into the use of cell and gene therapy for the treatment of hematological disorders, and author of hundreds of scientific articles. In it were heartfelt tributes by colleagues and lovely images of his family.

In accepting the award, Dr. Gahrton appeared to be amused by the accolades. "At times like this, maybe you have to take all this with a grain of salt," he said with a smile. Then, he, too, reflected on his history with Dr. Kyle. "I recall when we were in Poland and we sneaked away from a meeting and took a boat out on the river. We got to know each other very well."

He graciously thanked "all the people I've collaborated with – lab technicians and people in the hospitals," and his family ("Without my wife Astrid,



In the early 20th Century, Stockholm's Grand Hotel hosted the Nobel Prize award ceremony



IMF President Susie Novis, Kyle Award winner Prof. Gösta Gahrton and his wife, Astrid, and IMF Chairman Dr. Brian Durie

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DARATUMUMAB: A NEW PROMISING DRUG FOR MULTIPLE MYELOMA

by Henk Lokhorst
Professor of Haematology, University Hospital Utrecht, The Netherlands

Daratumumab is a monoclonal antibody that has been developed for the treatment of multiple myeloma. The antibody is directed against CD38, a protein that is present on the surface of myeloma plasma cells. Studies in the laboratory have shown that myeloma plasma cells can be efficiently killed by the antibody by five different mechanisms. These include i.a. CDC (complement dependent cytotoxicity) and ADCC (antibody dependent cellular cytotoxicity). ADCC occurs when the antibody binds to its target, CD38, and then activates the patient's immune cells (the natural killer cells; NK cells) to specifically kill the CD38-expressing myeloma cells.

Based on the high killing efficacy found in the lab against the myeloma cells, a Phase I/II study was initiated in several European centers, including our hospital and the Dana-Farber Cancer Institute (Boston). In the Phase I study, several dosages of the antibody were tested, starting at very low dosages (0.005 mg/kg) and after proven to be safe gradually increased in the next patients up to very high dosages (24 mg/kg). Patients were given eight infusions of the antibody. The first two infusions were separated by three weeks; the remaining six infusions were administered weekly. All patients had received prior treatment with bortezomib and lenalidomide and/or thalidomide, of which approximately 75% were refractory to both bortezomib and lenalidomide.

The results of this Phase I portion of the Phase I/II study were remarkable. When given at dosages up to 24 mg/kg, no significant side effects were observed. More importantly, this group of patients was very heavily pre-treated with no further treatment options, and daratumumab induced tumor responses. When evaluated according to the official (IMWG) response criteria, about one-third of the 32 patients achieved a response (MR or better). Approximately two-thirds of the patients achieved a response when administered higher dosages of the drug (4–24 mg/kg) that resulted in adequate concentrations of the drug in the blood of the patients. Such high efficacy is very unusual in a Phase I study, the main focus of which is to determine the safety of a drug.

At this moment, the Phase II part of the study is underway to determine the optimal dose and schedule to apply the drug, and optimal pre-medications. Based on these preliminary results, daratumumab was granted a breakthrough therapy designation by the FDA.

Studies in our lab have also shown that lenalidomide may improve the efficacy of daratumumab. As mentioned above, ADCC with recruitment of NK cells is probably one of the major mechanisms of killing by daratumumab. As lenalidomide stimulates NK cells it seemed logical to give daratumumab in combination with lenalidomide to patients. Currently, a Phase I/II study with this combination is running in Europe and at Dana-Farber. The first results of this study will be presented at ASH 2013 in New Orleans.

In my opinion, monoclonal antibody therapy, of which daratumumab may be the most promising, will completely change the landscape of myeloma therapy. After the introduction of proteasome inhibition and several generations of IMiDs, a major improvement in the life expectation of myeloma patients may come from the application of monoclonal antibody therapy, most likely in combination with established myeloma drugs like lenalidomide and or bortezomib. **MT**



Related IMF Videos

Watch Prof. Henk Lokhorst discuss daratumumab:
<http://tinyurl.com/Lokhurst-dara>

Watch Dr. Brian Durie discuss antibody therapy in myeloma:
<http://tinyurl.com/Durie-mab>

KLAA — continued from page 6

I couldn't do anything!"), as well as "the whole myeloma community!"

Prof. Gahrton praised the IMF and Susie Novis, as well. "I appreciate your honesty and integrity. I appreciate all that you have done," he said, adding, "Susie, you are a wonderful lady. Who else could have built an organization like this?"

A chamber trio played as all nine of the Kyle Award winners gathered on the stage for photos and easy conversation. The spirit of scientific achievement seemed to fill this beautiful room once again. **MT**



Eight winners of the Robert A Kyle Lifetime Achievement Award take the stage in Stockholm: (l-r) Drs. Brian Durie, Robert Kyle, Gösta Gahrton, Ken Anderson, Jesús San Miguel, Joan Bladé, Heinz Ludwig, and Douglas Joshua

GLOBAL COLLABORATION STRENGTHENS PATIENT ADVOCACY



by Arin Assero
IMF Vice President, Global Advocacy

On Thursday, June 13, in Stockholm, Sweden, I had the honor of hosting the International Myeloma Foundation's inaugural Global Leaders Summit (GLS), which brought together patient advocacy group leaders from Canada, Israel, Italy, Korea, Latin America, Spain, Sweden, Turkey, the United Kingdom, and the United States. Our goal was



Patient representatives from ten countries met at the inaugural IMF's Global Leaders Summit in Stockholm

to assess the most critical issues facing patients around the world and launch a collaboration to help find solutions. Summit participants were excited to meet with other myeloma and blood cancer patient advocacy leaders who share common missions and goals. All organizations represented focus their work on the same four areas: education, research, advocacy, and patient support. And while the leaders possess varying degrees of expertise, the patients they serve share the same concerns – a need for early diagnosis; access to myeloma specialists; access to novel therapies and supportive care; help coping with the side effects of treatment and psychosocial issues; and help with the financial impact myeloma has on patients and their families.

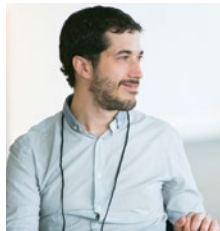
After introductions and general discussion, it was time to brainstorm. Participants divided into small work groups, where robust conversations centered on early diagnosis, access to treatment, and disease awareness. Each group identified possible solutions and opportunities to address these issues in a collaborative way. We made some progress, but it was clear that there was not enough time to decide where to begin our work, and getting organized as a group would be essential to our success moving forward.



Chul Hwan Lee, Korean Blood Cancer Association Executive Director

With that in mind, we wasted no time establishing the Global Myeloma Alliance (GMA) to strengthen the voice of the myeloma community internationally. Our mission is to work together to improve the quality of life for patients through advocacy, support for new drug approvals and expanded access to treatment. We will also exchange best practices among patient groups to raise awareness of multiple myeloma and the impact it has on the lives of patients and their families around the world.

The GMA will convene again in New Orleans this December to discuss the next steps and plans for our first collaborative project. With the knowledge, expertise, and dedication of our international colleagues,



Diego Villalón García,
from AEAL, Madrid, Spain

I am confident that we will have a positive impact on the lives of myeloma patients around the world.

I'd like to thank all those who participated in the GLS in Stockholm – your passion and commitment to patients is truly inspiring!

Many thanks to: Asli Ortakmac and Serdar Erdogan (*Miyelomla Yaşam, Turkey*); Eric Low (*Chief Executive, Myeloma UK*); Chul Hwan Lee (*Executive Director, Korean Blood Cancer Association*); Jung Suk Park (*Director, Korean Blood Cancer Association*); Christine Battistini (*President, IMF Latin America*); Diego Villalón García (*Volunteer Coordinator, Asociación Linfoma Mieloma y Leucemia/Psychosocial Area Director, GePac*); Aldo Del Col (*Myeloma Canada*); Maria Rita Grattarola (*Chief, Patient Division, Associazione Italiana contro le Leucemie, Linfomi e Mieloma*); Felice Bombaci (*Gruppo AIL Pazienti LMC*); Kerstin Holmberg (*Chairwoman, Blodcancerförbundet*); Hasse Sandberg (*Secretary, Blodcancerförbundet*); Jack Aiello (*Co-Leader, San Francisco Bay Area Myeloma Support Group*); and Paula Asulay (*AMEN, Israel*).



Arin Assero, IMF Vice President of Global Advocacy, leads Global Leaders Summit in Stockholm

US ADVOCACY NEWS

IMF Hosts Educational Seminars and Forums Explaining the Affordable Care Act

by Meghan Buzby, Director, US Advocacy

This summer, the International Myeloma Foundation (IMF) reached more than 400 patients, caregivers, and family members with its patient education series, "Health Care Reform and You: Navigating the Changing Health Insurance System." Online seminars and in-person forums in California, New Jersey, and Illinois explained what the Affordable Care Act (ACA) is and how the law can benefit patients. Attendees heard from experts from the regional offices of the American Cancer Society Cancer Action Network, Centers of Medicare and Medicaid, and State Health Insurance Marketplaces.



IMF patient education attendees listen to Blair Horner, Vice President for Advocacy, American Cancer Society Cancer Action Network, New York & New Jersey.

Topics reviewed at the patient education events included the ACA's new patient protections, changes to Medicare, and the new health insurance marketplaces/exchanges, which allow people who are uninsured and under-insured to purchase health insurance starting October 1. Terms such as "Essential Health Benefits," "Qualified Health Plans," and "Out-of-Pocket Limits" were defined and explained, and many questions and concerns were answered.

Thanks to everyone who participated! **MT**

IMF IN THE CZECH REPUBLIC



by Nadia Elkebir
IMF Director Europe/Middle East
Medical Education & Patient Liaison

The International Myeloma Foundation, in conjunction with Mnohočetný Myelom Klub Pacientů (“Myeloma Club,” the myeloma patient association of the Czech Republic) and the Czech Myeloma Group, hosted a patient meeting in Mikoluv, Czech Republic in September. The two-day meeting welcomed over 100 attendees, including myeloma physicians, patients, and family members.



The Czech myeloma patient meeting was attended by more than 100 physicians, patients and family members

A speech by Dr. Roman Hájek opened the meeting, which included medical update presentations from myeloma specialists from the Czech Myeloma Group, a medical association of myeloma specialists advancing treatment and research that will celebrate its 10th anniversary in 2014.

Josef Hájek, President of the Myeloma Club and a myeloma patient, shared updates on Czech patient activities and provided inspiration to those in



Josef Hájek, President of the Myeloma Club, toasts a patient before meeting begins



Miroslav Hrianka, of the Slovak Patient Association

attendance. Although his own prognosis is poor, he was extremely upbeat. The work he does to support other patients and encourage the advancement of myeloma treatment in the Czech Republic is extremely impressive.

Dr. Miroslav Hrianka, president of the



Opening speech with patient group manager Iveta Mareshova, Dr. Roman Hájek, Dr. Miroslav Hrianka, and Nadia Elkebir

Slovakia Myeloma Society also attended the meeting and spoke about his group’s activities and the treatment landscape for patients in Slovakia. It is wonderful to see how the myeloma communities from the Czech Republic and Slovakia support each other and work together.

Other highlights of the meeting included talks from three patients living with myeloma. Their stories of enjoying their lives and experiencing new things were inspirational to all in attendance. In keeping with the theme of living an active life, there was also a presentation on the benefits of yoga classes for myeloma patients – for the mind, body, and as an opportunity to meet and be active with other patients.



Musicians in costume performed at the meeting

In addition to the messages of hope and many lively talks throughout the meeting, a live performance by traditional Czech musicians and dancing ensured all in attendance had a wonderful time!



Patients get into the spirit of the event

We are already looking forward to working closely with the Czech and Slovakia myeloma groups to plan next year’s meeting. **MT**

MYELOMA SUPPORT GROUP LEADERS



by Robin Tuohy
Senior Director, Support Groups

The International Myeloma Foundation's 14th Annual Support Group Leaders Summit brought together 80 support group leaders from cities across the US, Canada, and even Australia. The 2013 Summit welcomed 28 first-time attendees, more than ever before! During this year, a record 23 new local support groups have been established, making 2013 a banner year for support groups.

The 14th Annual Summit, held in Dallas, Texas, provided support group leaders with an information-packed three-day program. Dr. Brian G.M. Durie, Chairman and Co-founder of the IMF, presented updates on the latest myeloma treatments and research, including the IMF's Black Swan Research Initiative™. Tiffany Richards, RN, of MD Anderson Cancer Center, spoke about the work of the IMF's Nurse Leadership Board.

Other memorable sessions included Support for Support Group Leaders, a panel that presented case studies and advice from leaders who had experienced issues such as "leader burnout." The Top Ten Topics discussion session, during which we broke into small groups to discuss one of the 10 issues the whole group identified as most relevant, was another highlight. Topics included Programming and Meeting Dynamics; Outreach, Publicity and Myeloma Awareness; and Providing Support for Caregivers.

A major theme of this year's Summit was technology. At the 2012 Summit, leaders received iPads for their groups and were introduced to the



Myeloma Post app, available to everyone. This year, we unveiled a new app just for support group leaders – the Support Group Leaders Toolkit. The Toolkit app augments the IMF Support Group Team's individual assistance, placing information at support group leaders' fingertips during meetings and meeting prep.

We asked several leaders who attended the Summit to share what they considered to be the highlights of the event. Some were Summit first-timers, while others were veterans. All were enthusiastic about what they had learned in Dallas.



At a panel entitled "Support for Support Group Leaders," new leaders get pointers from veteran leaders on the importance of sharing responsibilities. Participants include: Summit Facilitator Alan Kumamoto; Robin Tuohy, IMF Senior Director, Support Groups; Sue Enright, IMF Midwest Regional Director, Support Groups; Anne Pacowta, IMF Florida Regional Director, Support Groups; Nancy Bruno, IMF Southeast Regional Director, Support Groups; Arlene Preisendorf, Co-leader of Grand Island, Nebraska Support Group; Paula Van Riper, Founder/Leader of Central New Jersey Support Group; Kelly Cox, IMF Director, Support Groups & Regional Community Workshops; and Joanie Borbely, IMF Special Projects, Support Groups

Look-alike support group leaders Mike Katz (NYC & White Plains) and Charlie Mooney (Staten Island)



IMF Webmaster Kelly Quiggle advises Josephine Diagonale on fine points of iPad



Dr. Brian Durie, Tackle Cancer's Kim Alexander, Kelly Cox, Anne Pacowta, Susie Novis



Great friendships are launched at IMF's annual Support Group Leaders Summit

GATHER FOR 14TH ANNUAL SUMMIT

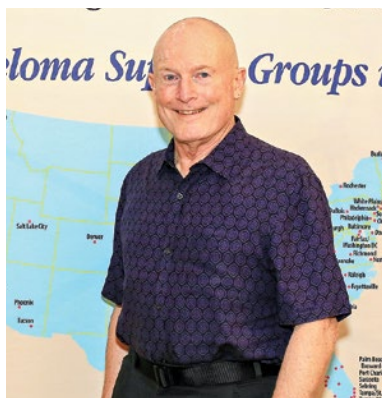


Meeting other group leaders was inspiring; this is a group of such self-sacrificing individuals, and many of them are struggling with the disease. As I said to my husband at the end of the Summit, 'Now we have to come every year!' Where would we be without the IMF? Look at all they have accom-

plished and how they have helped educate and support patients.

This Summit really helped me to see how important it is to have involvement from other members of the group – having others take responsibility for various roles can allow the group to grow and continue to thrive. I particularly enjoyed the session when we broke down into smaller groups; this really allowed us to get to know others more intimately and to talk more closely about their groups and the different ways they conduct them.

– Laura Mooney, first-time attendee
Staten Island, NY
Founded group in January 2013



Attending the 14th Annual Support Group Leader Summit was a wonderfully rich, life-changing and empowering experience for me. I now feel like an invested member of the IMF family. My first impression was how immediately warmly welcoming, inviting, and approachable everyone was, both attendees and IMF staff. Everyone was

so willing to include me, to share with me, and to offer assistance in establishing my new, small support group in the southwestern Vermont region. Nothing seemed proprietary; leaders would gladly share whatever they could. What I received from others boosted my confidence to overcome the challenges of growing a group from seed.

What excited me most that I could bring back to my group is what I gleaned from the powerful presentations by Dr. Durie (including discussion), the personal experiences of attendees regarding their treatments, and the heartening prospects for newer, more effective drugs, increased personal longevity/survival, and a cure for some within the foreseeable future!

– Jan Martin Bopp, first-time attendee
Bennington, VT
Founded group in June 2013



One of the highlights of this year's SGLS was the unveiling of The Support Group Leaders Toolkit app for our iPads. This app puts all the information and resources you will need as a leader right at your fingertips. What I believe is one of the most helpful features of this

app is sharing resources with a group member is just two clicks away. I can pull up a page in one click and email it to a member in the second click! The Toolkit offers sample meeting agendas and group surveys, as well as videos, blogs, webcasts and slide presentations that can be used as springboards to start a meeting or to revisit a topic. The Toolkit also provides information on currently available treatment options and clinical trials. The Support Group Leaders Toolkit app, along with the Myeloma Post app, allows me to be confident that the information I am providing our group members is accurate and up-to-date.

– Cindy Chmielewski, veteran attendee
Philadelphia, PA
Group founded in 1995



Hearing Dr. Durie provide us with a myeloma update was one of the meeting highlights for me. And this year we learned about the Black Swan Research Initiative, which actually mentions the word 'cure' for some myeloma patients.

While I feel confident as a group facilitator, I'm always looking for ideas and hints to make support group meetings a great experience.

I was reminded that more frequent communication with our group members is beneficial.

– Jack Aiello, veteran attendee
San Francisco, CA
Group founded in 1991



The comprehensive Top Ten Topics session was a highlight – it covered the broad range of issues important to group leaders. We broke up into smaller groups and shared sub-group discussion results to ensure everyone heard all the key recommendations covering group, patient and caregiver needs. Leaders could focus on and take back information on the issues most relevant to their group.

– Jerry Walton, veteran attendee
Norfolk, VA
Founded group in 2007

IMFers RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY



By Suzanne Battaglia

IMF members are raising funds to support essential multiple myeloma research while also raising awareness. Fundraisers as diverse as garage and bake sales, community walks and marathons, parties and entertainment events, sports tournaments, and countless other fundraisers are taking place across the country. Most of these activities start with a call to the IMF and one simple question – “What can I do?” Those who become involved find their efforts to be not only fulfilling but also incredibly empowering.

The IMF’s FUNdraising program is fun and easy, and brings with it the satisfaction of knowing that YOU are making a difference in many lives.

A Delicious Day in Virginia’s Wine Country

A wine tasting tour, a gourmet lunch in a historic restaurant, views of Virginia’s beautiful wine country on a late summer day, and the company of good friends, new and old – who wouldn’t sign up for that? Over 40 people did, exceeding the expectations of the Greater Richmond Multiple Myeloma Support Group that organized the event.



When the group set out to plan a fundraiser to benefit the IMF, members discussed activities they liked to do, and it was decided that a wine tour would be the perfect fit. A handful of support group members interested in organizing the fundraiser formed a committee and met several times to plan the event. The organizers were support group leader Barbara Marx, Nancy Raible, Mindy Fast, and Regina Leftwich.

Nancy Raible, whose son was diagnosed with myeloma, said she wanted to organize a benefit because, “I just love the IMF. It has been such a wonderful resource for us. We wanted to raise money

top row: Jo Smith, Nancy Bruno, Nancy Raible, Claude Raible, Regina Leftwich; bottom row: Barbara Marx, Mindy Fast

to support the IMF and encourage more research.”

Many of the wine tour’s attendees had heard of myeloma, but did not know much about it. During the bus ride to the wineries, Nancy Bruno, the IMF’s Southeast Regional Director of Support Groups, spoke about myeloma and the work of the IMF. In addition to their education on myeloma, attendees learned about the wine-making process in an extensive tour of one of the wineries’ facilities. Educational, fun, and delicious – the recipe for a successful event!



Where’s the wine?!!

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 events...

to support the IMF and encourage more research.”

Many of the wine tour’s attendees had heard of myeloma, but did not know much about it. During the bus ride to the wineries, Nancy Bruno, the IMF’s Southeast Regional Director of Support Groups, spoke about myeloma and the work of the IMF. In addition to their education on myeloma, attendees learned about the wine-making process in an extensive tour of one of the wineries’ facilities. Educational, fun, and delicious – the recipe for a successful event!

to support the IMF and encourage more research.”



Birthday Party Celebrates Supporters & Supports IMF

Mary Burkard and her husband Jim both turned 50 in the hospital while Mary was undergoing myeloma treatment. Jim’s birthday fell during stem cell collection for Mary’s autologous stem cell transplant, and Mary’s fell during the transplant. After the process was through, Mary and Jim threw a party this summer to celebrate their birthdays, the successful transplant, and the love and support of their family and friends who had helped them throughout Mary’s treatment.



Mary and Jim Burkard with daughters Lauren, Melanie, and Julianna

As if that weren’t enough, the Burkards also wanted to give back to the IMF. “This was a big ‘thank you’ party. We wanted to give back because

CONTINUES ON NEXT PAGE

Member Events



friends, family, and the IMF did so much for me while I was sick,” Mary explained.

Instead of gifts, guests could fill out a donation form for the IMF in Mary’s honor at the party. Mary says the process was very easy, explaining, “The

whole process was wonderful – I wrote my name on envelopes the IMF sent me and displayed IMF information on a table. After the party, I just had to collect all the envelopes, put them in a package and mail them to Suzanne Battaglia. It was very easy!”

On doing her part to support the IMF, Mary reflected, “It felt good to be able to do something to help the IMF advance their quest to find a cure for myeloma. This was a great experience, and I would recommend setting up a similar fundraiser to anyone looking for ways to support the IMF.”

Annual Swim Race Benefits IMF

Doug and Kate Farrell have organized several fundraisers for the IMF, including their very successful bi-annual *A Song for Ireland* event in Philadelphia. This summer, Doug found a new opportunity for the IMF

to benefit from an event he has participated in for more than 15 years in Longport, New Jersey, the beach town where his family vacations.

Along the south Jersey shore, it is a longstanding tradition for many towns to hold



Doug and Kate Farrell with children and grandchildren

annual “Ocean Swim” open water races. The events sometimes benefit local organizations, and Doug asked himself why an Ocean Swim couldn’t benefit the IMF. So he took action and asked the organizers of the Capt. Turner Ocean Swim in Longport, New Jersey if the 2013 race could benefit the IMF, along with another cancer organization. With a great idea and determination, Doug became involved with the organization of the Ocean Swim, had a great time working with friends who were fellow organizers, and raised money for the IMF!

Doug, who spoke about his myeloma and the work of the IMF at the Ocean Swim, said the community was happy to support the IMF. He explained, “Being a small community, everyone knows each other and people really want to support each other.”

Supporting the IMF is important to Doug because of the support he has gotten from the IMF since his myeloma diagnosis in 2006. He said, “Fundraising is so important to me and my wife Kate – it allows the IMF

to do all the work it does that’s so important to us: the hotline, support groups, patient and family seminars, and now the Black Swan Research Initiative™.”

The Farrells look forward to working on next year’s Capt. Turner Ocean Swim in Longport, and hope to grow the event and get even more of the local community involved! **MT**



Calendar of Upcoming Events

October 20 & 21, 2013

Coach Rob’s Benefit Bash & Golf Tournament – Apopka, FL
Contact: Rob Bradford at rbradford@crothall.com

October 22, 2013

Music Against Myeloma – New York, NY
Contact: Slava Rubin at slava@indiegogo.com

October 26, 2013

Wayne Hamby Memorial Golf Tournament – Bluffton, SC
Contact: Andrew Bertram at abertram@yahoo.com or 843-757-2322

October 27, 2013

Scare Away Cancer, a Halloween Celebration – La Quinta, CA
Contact: Amanda Miller at scareawaycancer@gmail.com

November 9, 2013

7th Annual Comedy Celebration – Los Angeles, CA
Buy tickets at: comedy.myeloma.org or call (800) 452-2873

Modern Art Against Myeloma – Williamsport, PA
Contact: John Bianco at jbianco9@comcast.net

November 2, 2013

Texas Hold ‘Em Benefit Bash – San Jose, CA
Contact: Jack Aiello at jackaiello@comcast.net or 408-264-7609

Shop for the Cure

Shop with the leading merchants on the Internet, receive the same price as anyone else visiting their sites, and support the IMF at the same time! Visit the merchants using the links at shop.myeloma.org and, if you make a purchase, a percentage goes to support the IMF. Please remember that the IMF receives a donation only if you use the links on the shop.myeloma.org page, so please bookmark this page to ensure that when you are shopping your purchases are properly credited. E-commerce vendors include Amazon, Macy’s, Walmart, iTunes, 1-800-Flowers, Hotwire, The Sharper Image, Omaha Steaks, Dollar and Thrifty Car Rental, and many others. Keep checking back as we regularly add new stores to our mall. Thanks for your support!

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A LASTING LEGACY



Kenneth Kochmann, MD

On March 8, 2013, Dr. Kenneth B. Kochmann of Baltimore, MD, left a generous bequest to the International Myeloma Foundation (IMF) when he lost his battle with myeloma. He believed a cure was just around the corner and if he could just hold on, he would meet that cure. But it was not to be.

However, Dr. Kochmann's \$50,000 donation will have a lasting impact on others who are still fighting the

disease. With his support of the IMF, he will always be remembered as a man whose deep compassion for others extended to his fellow myeloma patients.

Diagnosed in 2003, he had completed several rounds of chemotherapy and had had two stem cell transplants. Yet, "he never complained, and to the very end, always maintained his puckish sense of humor, affable sunny demeanor, and was determined to beat the disease," Dr. Kochmann's sister, Carol Kochmann, said in an obituary in *The Baltimore Sun*.

In life, Ken Kochmann was a believer. He believed in helping people. So, after receiving both his undergraduate and master's degrees in philosophy, he started his professional life as a social worker in Newark, N.J.



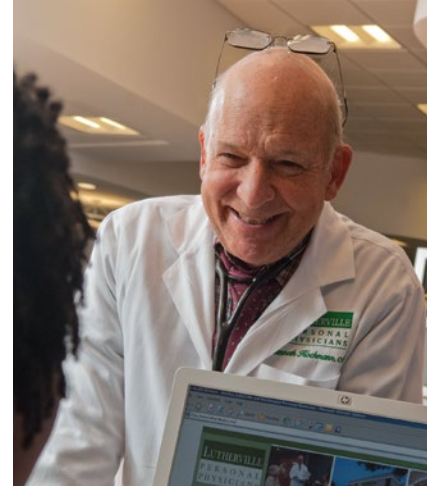
Co-worker Michele Alessi, Dr. Kochmann, and his sister Jill Blumkin. Michele was a good friend of Dr. Kochmann and had been the main organizer of the Kenny B. Kochmann Multiple Myeloma Foundation fundraiser

When a move to Baltimore found him behind a desk at the federal Office of Management and Budget, he believed he should – could – change his life. He was drawn to and considered genetic research, but when one of his sisters reminded him that he was so generous with others, and cared so much about people, not to mention being such a great listener, he chose to become a doctor. So in his late thirties, he went back to medical school – the oldest in his class – and re-started his professional life as a family practice physician.

For over twenty years, the now *Dr.* Kochmann believed that you care for your patients by caring about your patients. After his death, his sisters, Carol and Jill Blumkin, found hundreds of letters from his patients, who

had affectionately called him "Dr. K," thanking him for being the best listener and the best doctor they had ever had. He loved his patients and saw them until three weeks before his death.

A man armed with a wicked sense of humor, he believed in its power over the absurdities of life. When he and



Dr. Kochmann's patients adored him, and dubbed him "Dr. K."

his sister Jill visited a holistic clinic during his myeloma treatment, a nurse at the clinic said that there was no

such thing as AIDS – it was a hoax perpetrated by conventional medicine to make money. Jill asked the clinic director if he agreed with what the nurse had said. He did, he said, except she had forgotten to mention the therapeutic power of ozone enemas. For the next ten years, every time there was a setback in his treatment or some other life challenge presented itself, Dr. Kochmann would wryly comment that what was really needed here was an ozone enema.

Despite choosing clinical practice over the genetics lab, Dr. Kochmann continued to believe in the power of research. He co-authored a paper on "A Prototypical Community Model for Training of the Clinical Pharmacopsychologist," which presented a model for the clinical training of what could become a prescribing psychologist. But nowhere was his belief in research more evident than in his ten-year battle with myeloma. A voracious reader, he did his research and became an active participant in his treatment decisions, often to the consternation of his doctors. He hoped for a cure, but it wasn't coming soon enough.

As he and his sisters filled out the *Five Wishes* form in the last weeks of his life, they laughed together over the questions and his answers to them. But when they got to *Wish Five: My Wish for What I Want My Loved Ones to Know*, he teasingly answered the question: "If anyone asks how I want to be remembered, please say the following about me" with "I want to be remembered as the man who cured multiple myeloma."

Funny to the end, with his generous bequest to the IMF, Dr. Kochmann's wish may be closer to the truth than he could know. **MT**



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He's got the answers.

#AskDrDurie

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International Myeloma Foundation



YouTube.com/IMFmyeloma

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2013 / 2014 IMF Calendar of Events

- 2013**
- Sep 13-15 IMF Patient & Family Seminar (PFS) – Mikulov, Czech Republic
 - Sep 26 IMF Patient & Family Seminar (PFS) – Ancona, Italy
 - Sep 28 IMF Patient & Family Seminar (PFS) – Roma, Italy
 - Oct 9-13 Eurasian Hematology Congress – Antalya, Turkey
 - Oct 12 IMF Regional Community Workshop (RCW) – St. Louis, MO
 - Oct 18-20 IMF Nurse Leadership Board Meeting – Short Hills, NJ
 - Oct 27 IMF Asian Pacific Physician Regional Training Meeting – Shanghai, China
 - Oct 28 IMF Physician Community Workshop – Oslo, Norway
 - Oct 30 IMF Physician Community Workshop – Odense, Denmark
 - Oct 31 IMF Patient & Family Seminar (PFS) – Middelfart, Denmark
 - Nov 9 **IMF 7th Annual Comedy Celebration** – Los Angeles, CA
 - Nov 13 IMF Living Well Series Teleconference – *Complementary and Alternative Medicine: What Patients and Caregivers Need to Know* *
 - Nov 21 IMF Webinar – *Health Reform and You: Health Insurance Marketplaces***
 - Nov 22 IMF Myeloma Center Workshop (MCW) – Raleigh-Durham, NC
 - Dec 6-9 55th Annual Meeting & Exposition of the American Society of Hematology (ASH) – New Orleans, LA
 - Dec 6 IMF Friday Satellite Symposia “Critical Issues Need Answers: Providing Best Options for Myeloma Treatment in 2013” – New Orleans, LA
 - Dec 7 IMF Brian D. Novis Senior & Junior Research Grant Awards Reception – New Orleans, LA
 - Dec 9 IMF International Myeloma Working Group Conference Series “Making Sense of Treatment” – New Orleans, LA
- 2014**
- Feb 1 IMF Myeloma Center Workshop (MCW) – Denver, CO
 - Feb 28-Mar 1 IMF Patient & Family Seminar (PFS) – Boca Raton, FL
 - March 8 IMF Regional Community Workshop (RCW) – Portland, OR
 - April 26 IMF Regional Community Workshop (RCW) – Norfolk, VA
 - May 16-17 IMF Patient & Family Seminar (PFS) – Atlanta, GA
 - June 14 IMF Myeloma Center Workshop (MCW) – Minneapolis, MN
 - Aug 22-23 IMF Patient & Family Seminar (PFS) – Los Angeles, CA
 - Oct 10-11 IMF Patient & Family Seminar (PFS) – Short Hills, NJ

The IMF is proud to work with our global partners. We thank them for supporting our international meetings.

For more information about upcoming events, please visit calendar.myeloma.org or call 800-452-CURE (2873).

For information on activities in Australia, Canada, Israel, Japan, or Latin America, please visit:

Australia www.myeloma.org.au • Canada myelomacanada.ca • Israel amen.org.il • Japan myeloma.gr.jp • Latin America mielomabrasil.org

* Pre-register for this FREE teleconference on the IMF website: myeloma.org. This 60-minute, Living Well Series teleconference starts at 4 p.m. Pacific/7:00 p.m. Eastern.

** Pre-register for this FREE webinar via email to Aimee Martin at amartin@myeloma.org. This webinar starts at 4 p.m. Pacific/7:00 p.m. Eastern.