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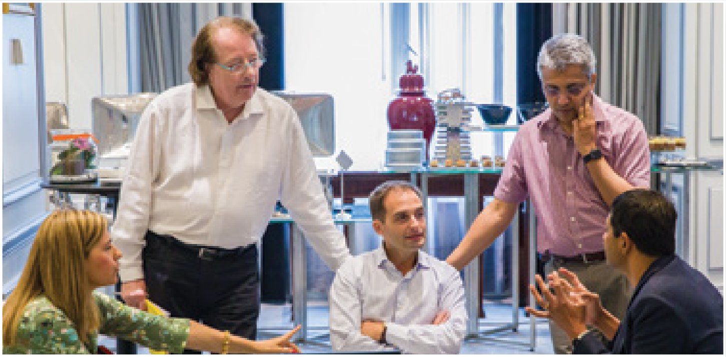
2017 IMWG Summit



More than 100 members of the International Myeloma Working Group met to review, support, and implement the most promising myeloma research.

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A Message from the IMF President

Dear Reader,

The past few months at the IMF have been very busy and very productive. June was especially busy as the annual International Myeloma Working Group (IMWG) Summit was held June 19th–21st in Madrid, Spain. The IMWG consists of 226 leading myeloma researchers from around the world who collaborate on a broad range of myeloma research projects. With a goal to improve myeloma treatment options and diagnostic systems, their work focuses on protocols to provide more durable remissions for myeloma patients while improving quality of life. About 100 IMWG members attended this year's Summit, co-chaired by Drs. Brian G.M. Durie, Philippe Moreau, S. Vincent Rajkumar, and Jesús F. San Miguel. The agenda included important topics including Frontline Therapy for Myeloma, Role of MRD Assessment in Myeloma, Drug Access, and the Costs of Myeloma Care to name a few. Needless to say, it was a very active and impassioned summit, with plenty of discussion and debate.

A highlight of the IMWG Summit is the Robert A. Kyle Lifetime Achievement Award. Established in 2003, the award is presented to a physician whose work against myeloma has made significant advances in areas including research and clinical treatment. The 15th Robert A. Kyle Lifetime Achievement Award was presented to Dr. Paul Richardson of the Dana-Farber Cancer Institute. Dr. Richardson holds leadership positions in several professional bodies and serves on the Editorial Board of the *Journal of Clinical Oncology*, the *Journal of Oncology*, and the *British Journal of Hematology* to name a few. He as published more than 320 original articles and more than 200 reviews, chapters, and editorials in leading peer-reviewed journals. Currently he is leading multiple efforts studying the use of combination therapies in relapsed/refractory myeloma.

The other highlight that took place in Madrid, was the 5th annual meeting of the Global Myeloma Action Network (GMAN). A welcome reception kicked off the two-day summit, with 34 members gathered from around the world for a very active and productive meeting. The Summit began with opening remarks from Marya Kazakova – GMAN Director. Nadia Elkebir, Sr. Director Global Patient Relations, presented an overview of prior year's GMAN activities and Yelak Biru, IMF Board member, presented GMAN's mission and objectives, as well as drug approval process and availability in various countries. IMF Board Director and GMAN member Christine Battistini discussed capacity building.

The agenda included presentations from myeloma experts, Prof. Jean-Luc Harousseau, Dr. Rafat Abonour, and Dr. Durhane Wong-Rieger. Patient advocate and GMAN member Jack Aiello demonstrated how to navigate clinical trials for access to novel therapies.

A highlight of the Summit was awarding three Susie Novis Durie grants to GMAN members. We were proud to be able to present these grants to the following recipients to support outstanding projects in their respective countries. The grant recipients are: Fundación Argentina de Mieloma Multiple, Myeloma and Lymphoma Association of Austria, and Myeloma Euronet Romania.

Needless to say, June was a very active and productive month, reflecting the heart of our mission – to bring together the myeloma community, and empower patients, doctors, nurses, and researchers with a common goal – to find a cure.

Warm regards,

Susie Novis Durie

Susie Novis Durie, President & CEO

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Report from the 2017 Summit of the International Myeloma Working Group

By Debbie Birns
IMF Medical Editor

The 8th annual Summit of the International Myeloma Working Group (IMWG) took place in Madrid, Spain, from June 19th-21st. More than 100 of the world's top myeloma specialists gathered to review the IMWG's recent achievements, address problems, and set an agenda for the coming year's research. Unlike the annual meetings of EHA, ASH (American Society of Hematology), and ASCO (American Society of Clinical Oncology) – huge conferences that focus on research results – the IMWG Summit is a true workshop meant to encourage lively discussion and brainstorming.

Pathogenesis of myeloma: current concepts

Dr. Leif Bergsagel (Mayo Clinic, Scottsdale, AZ) started the meeting with a presentation on new concepts in the pathogenesis of myeloma. He contends that myeloma only appears to be highly heterogeneous, but can actually be seen as only one of two types (hyperdiploid or non-hyperdiploid) based on the oncogenes that drive myeloma to proliferate and the enhancer proteins that drive those oncogenes. Dr. Bergsagel believes the way forward is to target the enhancers. Panelists Drs. Wee Joo Chng and Bruno Paiva provided guidance for a discussion of possible treatment strategies and targets for new drugs.

VRd as standard of care for frontline therapy?

Dr. Brian Durie's publication of the SWOG 0777 study, which showed VRd (Velcade + Revlimid + low-dose dexamethasone) was significantly more effective than Rd (Revlimid + dex), was the basis for a discussion of frontline treatment options. Is VRd significantly superior to VCd (Velcade + Cytoxan + dex) or VTd (Velcade + Thalomid + dex)? There are no head-to-head survival comparisons, so we don't know the answer to this question. Some patients are able to do well simply with continuous Rd. If a triplet regimen is preferred, cost and availability of drugs can help discriminate which regimen to use. The currently-enrolling, multi-center, US cooperative group ENDURANCE trial compares frontline VRd to KRd (Kyprolis + Revlimid + dex), which may be a better option for high-risk patients. Since VRd is not available in much of the world and is very expensive, a consensus was reached that VRd is the current standard of care for frontline therapy where available.

Role of transplant in myeloma

Dr. Gordon Cook (University of Leeds, UK) accompanied by panelists Drs. Morie Gertz (Mayo Clinic, Rochester, MN), Pieter Sonneveld (University of Utrecht, the Netherlands), and Sergio


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Giralt (Memorial Sloan-Kettering, New York), stated his fervent hope that this would be the last time the role of transplant in myeloma would need to be validated with further large clinical trials or discussed at the IMWG meeting. Data from the three large transplant trials – IFM 2009, CTN0702, and EMN02/HO95 – overwhelmingly demonstrate the benefit of upfront transplant for almost all subgroups of patients. All concurred that autologous stem cell transplant remains an important treatment and that not enough US patients are opting for it. A remaining issue in the US is the need to make it possible for patients to store stem cells for later use.

MRD assessment in myeloma

Drs. Hervé Avet-Loiseau (University of Toulouse, France) and Dr. Jesús San Miguel (University of Navarra, Pamplona, Spain) presented data from French and Spanish trials that incorporated MRD testing as a measure of treatment response and discussed the two competing methods of assessing MRD status. Areas of consensus were that while both NGF (next-generation flow) and NGS (next-generation sequencing) have their pros and cons, both methods are sensitive enough to detect one myeloma cell among one million sampled bone marrow cells, and that MRD negativity is a clear indication of superior remission duration and overall survival. There was also consensus that some patients who are MRD-positive after therapy can still have long survival because they have excellent immune recovery.

High-priority questions about MRD status need to be resolved in future trials: Should patients who are MRD- continue or discontinue therapy? Should therapy be changed for patients who are MRD+? When should MRD testing occur after treatment and how often should MRD status be monitored thereafter? All discussants agreed that MRD testing can become the official measure of treatment response in myeloma clinical trials.

Monoclonal antibodies

Dr. Meletios Dimopoulos (University of Athens, Greece) accompanied by panelists Drs. Saad Usmani (Levine Cancer Center, Charlotte, NC) and Ken Anderson (Dana-Farber Cancer Institute, Boston, MA) led a discussion of therapy with approved and experimental monoclonal antibodies. As this new treatment area grows, many questions and some new answers are emerging. We are beginning to see that these antibodies produce late effects on the immune system, with deepening responses over time. While patients who were treated later in the disease course seemed to do better with Empliciti® (elotuzumab) than those treated at first relapse, it doesn't seem to matter which relapse is treated with Darzalex® (daratumumab) + Rd, as responses are good at any time. There was consensus on these issues:

- Prior treatment history influences the choice of daratumumab combination therapy: patients who are refractory to a proteasome inhibitor should get daratumumab + Rd (DRd), and those who are refractory to IMiDs should get daratumumab + Vd (DVd).
- High-risk patients do better with daratumumab than with elotuzumab.

Questions that remain to be resolved are:

- What is the best drug partner for each monoclonal antibody?
- Should we combine monoclonal antibodies?
- How can we treat patients who are refractory to daratumumab?

(continues on next page)


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1. Robert A. Kyle
2. Brian G.M. Durie
3. Joan Bladé
4. S. Vincent Rajkumar
5. Dr. Durie with members of the Asian Myeloma Network (AMN)
6. Susie Novis Durie & Brian G.M. Durie
7. María-Victoria Mateos
8. Bruno Paiva
9. Irene Ghobrial
10. Sagar Lonial, Philippe Moreau, and Brian G.M. Durie
11. Behind the scenes during the filming of the IMWG Conference Series

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IMWG 2017 SUMMIT – CONTINUED FROM PAGE 5

- What kind of T-cells are activated by these drugs? Can we augment the ability of immune cells to persist over time?
- What is the proper sequencing of treatments? What should be used first, second, third or fourth?

Breakout Sessions

Breakout sessions focused on four substantive topics requiring action plans, and IMWG members came armed with ideas. The chair of each breakout session presented the participants' action plans the following morning.

Breakout 1: Drug Access and the Cost of Myeloma Care

Prof. Jean-Luc Harousseau (University of Nantes, France), who led the discussio, stated that this is a complex topic, made more difficult to resolve by the differences in healthcare systems, drug costs, and drug availability around the globe. While we know that drug pricing is only one part of soaring healthcare costs, drug costs are the fastest-rising component of the cost of care. The cost of combination therapies, particularly as we add new immunotherapies to the regimens, will ultimately be unsustainable. Even the costs of older drugs continue to rise. The major problem in the US is that Medicare and Medicaid are not allowed by law to negotiate drug prices, while countries with government-provided healthcare have limited resources. Lower-income countries can't afford drugs, and in some places, there are problems more pressing than healthcare. Suggestions to improve this situation involved payors (insurance companies and governmental agencies), physicians, and patient advocacy groups. There was strong consensus that all stakeholders must sit at the same table – pharmaceutical companies, regulatory agencies, patients, legislators, and doctors.

Breakout 2: Bone and Imaging

Drs. Evangelos Terpos (University of Athens) and Elena Zamagni (University of Bologna, Italy), both of whom have published extensively on this topic, led a discussion of a research project proposal to include a comparison of DWI (diffusion-weighted imaging) MRI versus PET-CT to assess response and MRD status in an autologous transplant treatment trial. The endpoint of the trial would be the non-inferiority of DWI MRI as compared to PET-CT. They are hoping that DWI MRI is non-inferior to PET-CT because CT exposes patients to radiation, while DWI MRI does not. Moreover, DWI MRI images focal lesions very well, shows mixed patterns of diffuse and focal lesions, and shows what is necrotic bone and what is active disease. Results of the trial will enable the publication of standardized procedures for both imaging techniques. Doctors from 12 centers in North and South America and Europe will participate in the proposed trial.

Another project for the coming year is the creation for new IMWG guidelines for the management of myeloma bone disease. Issues to be clarified include the use of whole-body low-dose CT in lieu of whole-body x-ray survey as the standard bone assessment tool, the proper duration and spacing of bisphosphonate therapy, and the use of Xgeva® (denosumab) for a subset of myeloma patients with kidney damage.


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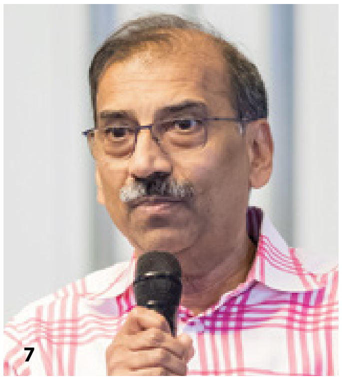
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Breakout 3: Immunotherapy

Drs. Irene Ghobrial (Dana-Farber Cancer Institute) and Adam Cohen (University of Pennsylvania, Philadelphia, PA) presented questions that must be resolved as we await further data from clinical trials, particularly with checkpoint inhibitors and CAR T-cells.

For **checkpoint inhibitors**, the questions are:

- Which patients benefit from these therapies?
- Should we adjust the response criteria to include measures of immune status?
- When should these agents best be used? In the newly diagnosed or relapse setting?
- What are the unique toxicities that occur when these agents are combined with IMiDs?

For **CAR T-cell therapies**, the outstanding issues are:

- Response rates have varied from 44% to 100% in different trials.
- Most of the follow-up is short.
- Cytokine release syndrome remains a concern.
- Can CAR T-cell therapy be combined with checkpoint inhibitors or other immunotherapies?
- Will CAR T-cell therapy take the place of allogeneic transplant?

We will certainly know a lot more a year from now when we have data from the ongoing trials.

Breakout 4: Smoldering Myeloma

Drs. María-Victoria Mateos (University of Salamanca, Spain) and Shaji Kumar (Mayo Clinic, Rochester) have both pioneered studies of treatment of smoldering multiple myeloma (SMM) and have been involved in trying to best define the criteria for high-risk SMM. Dr. Kumar presented their group's consensus on outstanding issues:

- A new risk model for progression of SMM needs to be created.
- Sensitive imaging can reveal that up to 35% of patients thought to have SMM actually have active disease.
- We need to identify which patients are at a lower risk of progression so we don't intervene too early.
- We need to demonstrate that early intervention does not cause treatment-related mortality and preserves quality of life.
- We need to identify genetic and microenvironment triggers for disease progression.
- Dr. Ray Comenzo (Tufts University Medical Center, Boston, MA) announced that he is leading a clinical trial for patients who have lambda light chain-type SMM to determine the risk of progression to AL amyloidosis.

How to Treat High-Risk Myeloma

Dr. Usmani addressed the issue of how best to treat high-risk myeloma, for which there is no current standard of care. He outlined current challenges and what we know so far:

- Ultra-high-risk myeloma can be characterized by two or more adverse cytogenetic features, a high number of circulating plasma cells, and failure to respond to therapy.
- While Velcade, Revlimid, and Pomalyst are currently available therapies that can help overcome some of the high-risk cytogenetic abnormalities, new treatments are needed.
- Current trials with KRd + daratumumab ; venetoclax; selinexor; the BCMA drug conjugate; CAR T-cells; and new monoclonal antibodies may offer some promise.

Dr. Usmani's summary of trials and his call for new approaches was the perfect introduction to the meeting's last presentation: a summary of the current portfolio of phase III myeloma clinical trials by Dr. Vincent Rajkumar (Mayo Clinic, Rochester). Among the trial highlights are the following:

- Six randomized trials now include MRD testing.
- Some trials are looking at the need for, and duration of, maintenance therapy among patients who are MRD-positive and MRD-negative.
- Two trials, one in the UK and one in Spain, are aimed at treatments for frail patients.
- A trial in the UK is using risk-adapted therapy after stem cell transplant depending on patients' MRD status.

As the IMWG Summit drew to a close, Dr. Robert Kyle commended the meeting's organizers for their leadership, for the meeting's content, and for their eagerness to listen to a younger generation of doctors in the IMWG. The modest and wise Dr. Kyle advised them always to "Hire the young person who is smarter than you are." We can rest assured that the future of the myeloma brain-trust is secure. **MT**


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1. Shaji Kumar
2. Michele Cavo and Elena Zamagni
3. Dorotea Fantl and Amara Nouel
4. Jens Hillengass
5. Suzanne Lentzsch
6. Yelak Biru
7. Sundar Jagannath
8. Sonja Zweegman
9. Jesús F. San Miguel
10. Susie Novis Durie

Two New Clinical Trials are Accruing Patients for Studies of the Role of Selinexor in Myeloma

Selinexor is a novel, first-in-class, orally administered "Selective Inhibitor of Nuclear Export" (SINE™) compound. Selinexor blocks the ability of cancer cells to export tumor suppressor proteins from their cell nuclei. This restores the tumor suppressor proteins' ability to detect cancerous DNA changes and induce cancer cell death. Selinexor also reduces levels of key proteins that promote cancer cell growth.

Selinexor STORM study

The STORM clinical trial of selinexor is for eligible patients who are "penta-refractory" to Velcade® (bortezomib), Kyprolis® (carfilzomib), Revlimid® (lenalidomide), Pomalyst® (pomalidomide), and Darzalex® (daratumumab). This trial is for heavily pretreated myeloma patients with relapsed, refractory disease. Patients must have disease that progressed during, or within 60 days after completing therapy with steroids (dexamethasone, prednisone, or methylprednisolone), an immunomodulatory agent, a proteasome inhibitor, and an anti-CD38 monoclonal antibody.

STORM study participants will receive treatment until their myeloma progresses or until they are unable to tolerate the regimen. Patients may decide not to participate and withdraw their consent at any time, for any reason. STORM is currently enrolling patients at more than 20 US sites. In the coming months, the STORM study will be opening in additional US sites and also in Europe. For the most up-to-date information on the STORM study, please visit ClinicalTrials.gov and enter identifier NCT02336815 in the search box.

Selinexor BOSTON study

The objective of the BOSTON clinical trial is to compare the effectiveness and safety of selinexor + Velcade + low-dose dexamethasone (SVd) to Velcade + low-dose dexamethasone (Vd) , and to compare the health-related quality of life of patients receiving each regimen. Approximately 364 myeloma patients who have been treated with 1 to 3 prior anti-myeloma regimens and have disease that has progressed during or within 60 days after prior treatment will be randomly assigned by a computer to receive either SVd or Vd. Trial participants will know whether they are receiving SVd or Vd. Patients in the Vd arm of the study whose disease progression is confirmed by an independent review committee may cross over to receive SVd treatment. **MT**

Selinexor investigator perspectives

"Early clinical results with Selinexor are encouraging, even in patients who have been treated with all available myeloma drugs. The STORM and BOSTON trials will help define in larger populations of patients the effectiveness of Selinexor and will determine whether or not this drug should move towards regulatory approval."

Keith Stewart, MD
Mayo Clinic

"The STORM trial represents an important opportunity for patients with myeloma who have been treated with all available agents and still have disease. This is a very important trial for heavily pretreated myeloma patients based on the phase II data indicating that up to 30% of patients may have responses to Selinexor and dexamethasone."

Raymond L. Comenzo, MD
Tufts University School of Medicine

New Clinical Trial for Patients with Solitary Plasmacytoma of Bone

The Alliance for Clinical Trials in Oncology, a national clinical trials network supported by the National Cancer Institute (NCI), is sponsoring a clinical trial for patients with solitary plasmacytoma of bone (SPB). SPB is a rare (less than 450 cases annually in the US) occurrence of myeloma in a single bone without evidence of myeloma elsewhere in the body (absence of monoclonal plasma cells in a random sample of bone marrow and no evidence of anemia, hypercalcemia, or renal involvement – that is, no CRAB criteria).

Approximately 30% of patients with SPB will develop active systemic myeloma. The current standard of care for SPB is radiation therapy followed by regularly scheduled follow-up appointments to check for signs of more widespread disease. A deeper understanding of disease biology in recent years has led to treatment studies for patients with high-risk smoldering multiple myeloma (SMM), early-stage myeloma or disease that presents no signs or symptoms, and now for SPB as well.

The new SPB clinical trial is titled "Ixazomib Citrate [Ninlaro®], Lenalidomide [Revlimid®], Dexamethasone, and Zoledronic Acid [Zometa®] or Zoledronic Acid Alone After Radiation Therapy in Treating Patients with Solitary Plasmacytoma of Bone." For more details about this study, please visit clinicaltrials.gov and search for this trial by its identifier, NCT02516423. This is a phase III clinical trial in which patients will be randomized to receive either a triplet therapy plus Zometa, or Zometa alone, within three months after they have been treated with radiation therapy, the current standard of care. For further information or to register for this clinical trial, please contact principal investigator Dr. Anuj Mahindra at mahindra.anuj@scrippshealth.org. **MT**

ASCO 2017 Highlights

By Debbie Birns
IMF Medical Editor

The annual meeting of the American Society of Clinical Oncology (ASCO), held each June in Chicago, featured nine oral presentations in myeloma this year. ASCO is always a good indicator of the hot topics in myeloma, and this year was no exception. ASCO 2017 highlighted three themes that have emerged in myeloma treatment:

1. monoclonal antibodies show benefit as frontline therapies as well as treatments for relapsed disease;
2. given the number of new and emerging treatments for myeloma, we must urge approval of new therapies that are not only effective, but preserve quality of life; and
3. therapies must not only be effective and safe, but must be cost-effective as well.

The following myeloma abstracts were the most important and most widely discussed of the meeting.

Newly-diagnosed myeloma

- **Abstract #8000**: This phase Ib study of low-dose dexamethasone plus Darzalex® (the anti-CD38 monoclonal antibody daratumumab) in 21 newly-diagnosed patients was presented by Dr. Andrzej Jakubowiak (University of Chicago). This trial will be of particular interest to patients with high-risk smoldering myeloma who wish to participate in the soon-to-open IMF-sponsored ASCENT trial, which uses the Kyprolis® (carfilzomib) + Revlimid® (lenalidomide) + low-dose dexamethasone + Darzalex regimen. The regimen produced a 100% response rate and median progression-free survival (PFS) of 100% at six months, with follow-up continuing. KRd +D was fairly well tolerated, with 46% of patients experiencing a serious side effect. There was one serious cardiac event that resolved with Kyprolis dose reduction.
- **Abstract #8003**: Dr. Francesa Gay (University of Torino, Italy) presented a phase III study of induction therapy with Kyprolis + Revlimid + dexamethasone (KRd) versus Kyprolis + Cytoxan® (cyclophosphamide) + dexamethasone (KCd) in 281 newly-diagnosed, transplant-eligible patients. While response rates of at least a 50% drop in monoclonal protein were similar between the two regimens (95% for KRd and 92% for KCd), the VGPR or better rate (very good partial response: at least a 90% drop in monoclonal protein) was higher for KRd than for KCd (74% vs. 61%). There were more serious side effects for KRd than for KCd, and 14% more of the patients in the KRd study arm than in the KCd arm required the stem cell mobilizer Mozobil® (plerixafor) to harvest stem cells for transplant, adding to the already high cost of KRd therapy.

Relapsed/refractory myeloma

- **Abstract #8007**: A phase Ib study of isatuximab (formerly known as SAR650984) in combination with Pomalyst® (pomalidomide) + dexamethasone (Pd) in patients who had had a median of four prior treatment regimens was presented by Dr. Joseph Mikhael (Mayo Clinic, Scottsdale, Arizona). Of the 26 patients in the study, 20 were refractory to Revlimid and/or thalidomide. 60% of the patients who were refractory to Revlimid responded to this new combination regimen. Infusion reactions (IR) occurred in 12 of the 26 patients; in 9 of those 12, IR were confined to the first infusion. Approximately 3/4 of the patients had at least a minimal response to treatment (at least a 25% drop in monoclonal protein). Infusion of isatuximab requires approximately half the time currently required for Darzalex. A phase III trial comparing Pd to isatuximab + Pd is now under way, with plans to submit data from that study to the FDA for approval of the regimen.

- **Abstract #8006**: A study of patients with high-risk cytogenetic abnormalities who participated in the CASTOR (Darzalex + Velcade + dexamethasone) and POLLUX (Darzalex + Revlimid + dexamethasone) studies was presented by Dr. Katja Weisel (University of Tübingen, Germany). Both of these Darzalex-containing regimens were found to improve response and PFS rates regardless of cytogenetic risk status. It is still too early to assess overall survival.
- **Abstract LBA3001**: There has been a great deal of buildup to a late-breaking oral presentation by Dr. Wanhong Zhao (Second Affiliated Hospital of Xi'an Jiaotong University) on CAR T-cell therapy targeted to the B-cell maturation antigen (BCMA). The very short follow-up period after treatment reported for this study and the high-risk immune-related side effects suggest we await further data before drawing conclusions about efficacy and safety.

Supportive care

- **Abstract #8005**: A 1700-patient phase III study comparing Xgeva® (denosumab), a new therapy to prevent bone disease, to Zometa® (zoledronic acid) was presented by Dr. Noopur Raje (Massachusetts General Hospital, Boston). The trial demonstrated that Xgeva is "non-inferior" to Zometa in prevention/delay of bone disease and provides equal rates of survival, but causes a significantly lower rate of kidney side effects than Zometa. Of particular note is that kidney side effects were twice as low among patients in the Xgeva arm of the study who already had renal insufficiency before entering the trial.

Putting the results in context

ASCO provides a Highlights of the Day session to which they "invite expert discussants to present key findings, place abstracts into clinical context, and provide an overview of the previous day's Oral Abstract Sessions." Dr. S. Vincent Rajkumar (Mayo Clinic, Rochester, Minnesota) was asked to discuss the myeloma oral abstracts. He focused on four abstracts, all of them included in this article. Dr. Rajkumar's conclusion was that three of these selected abstracts should not change current clinical practice. Citing concerns about safety, toxicity, convenience, and cost, he urged clinicians to reserve frontline KRd and supportive care Xgeva only for selected patients, high-risk patients in the case of KRd and patients with renal insufficiency in the case of denosumab. Dr. Rajkumar urged the gathered doctors to systematically study quality of life in treatment trials, and to select treatments with an eye to all toxicities, including those that are financial. **MT**

IMF Honors Dr. Paul G. Richardson

The International Myeloma Foundation (IMF) presented the 15th annual Robert A. Kyle Lifetime Achievement Award to Dr. Paul G. Richardson during the award ceremony in Madrid, Spain, on June 20, 2017. 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.

The ceremony took place during the IMF's annual International Myeloma Working Group (IMWG) Summit, and the event was held at the beautiful Royal Tapestry Factory, which was founded in 1720 by Philip V. Unfortunately, Dr. Richardson was not able to attend the ceremony in person due to a family medical emergency. However, his warm reception speech was shared with the audience as a pre-recorded video.

Dr. Richardson said, "All of this means so much to me because it embodies everything I think we are about in the myeloma research community. This extraordinary group of colleagues – men and women from all across the world – working in laboratories and clinics together to translate our advances from the bench to the bedside, and bringing meaningful benefit to our patients. And in that spirit, it's particularly lovely to welcome our patients who are with us tonight." Dr. Richardson then named the patients who were in attendance at the Summit, and reminded the audience that myeloma patients are "the reason why we are all here tonight."

Dr. Richardson expressed gratitude to his colleagues, his mentors, including Dr. Robert A. Kyle, colleagues at the Dana-Farber Cancer Institute (DFCI), and to pharmaceutical company partners. He concluded his speech with this comment, "And it's that spirit that I think embodies the real message of the Robert A. Kyle Lifetime Achievement Award – it reflects everyone's contributions."

The evening's speakers included the award's namesake, Dr. Robert A. Kyle, IMF Chairman Dr. Brian G.M. Durie, Dr. Kenneth Anderson, Prof. Jean-Luc Harousseau, Prof. Joan Bladé, and Dr. Antonio Palumbo.

Dr. Brian G.M. Durie and
Susie Novis Durie welcome the guests

Dr. Kenneth Anderson accepted the award on behalf of Dr. Richardson, calling him "a wonderful teacher and mentor, and an inspiring leader." Dr. Richardson "treats his patients like his family," according to Dr. Anderson. Indeed, several

Dr. Richardson addressing his friends and colleagues via video

Dr. Robert A. Kyle with Dr. Kenneth Anderson and Dana-Farber Cancer Institute colleagues, who accepted the award on Dr. Richardson's behalf

members of Dr. Richardson's "patient family" trekked from the US to Spain to honor their beloved doctor.

Prof. Bladé, who received the Kyle Award in 2010, testified to Dr. Richardson's legendary enthusiasm. "Paul is not only a very hard worker, but so polite – everything is 'lovely,' 'super,' and he says, 'Thank you' so much!"

Having received his medical degree from the Medical College of St. Bartholomew's Hospital in London, Dr. Richardson completed fellowships in hematology/oncology and medical oncology at Tufts University School of Medicine, Baystate Medical Center, and Harvard Medical School, Dana-Farber Cancer Institute before joining the DFCI staff as an attending physician in1994.

He currently holds leadership positions in several professional bodies and has served on the editorial boards of the *Journal of Clinical Oncology*, the *Journal of Oncology*, *The Oncologist*, *Clinical Cancer Research*, and the *British Journal of Hematology*. He chairs the Multiple Myeloma Committee for the Alliance for Clinical Trials in Oncology. Dr. Richardson's honors include several Massachusetts General Hospital, Brigham and Women's Hospital, and Dana-Farber Partners in Excellence Awards; the Brigham and Women's Hospital Teaching Scholars Award; the Tisch Outstanding Achievement Award for Clinical Research; and DFCI's George Canellos Award for Excellence in Clinical Research and Patient Care. For his contributions in hematology and oncology, and in myeloma in particular, he was awarded an honorary Fellowship of the Royal College of Physicians in 2009, was a co-recipient of the prestigious Warren Alpert Foundation Prize in 2012, and received the Ernest Beutler Prize at the 2015 Annual Meeting of the American Society of Hematology (ASH). He most recently received the COMy Prize for global contributions in myeloma research at the annual meeting held in Paris last year.

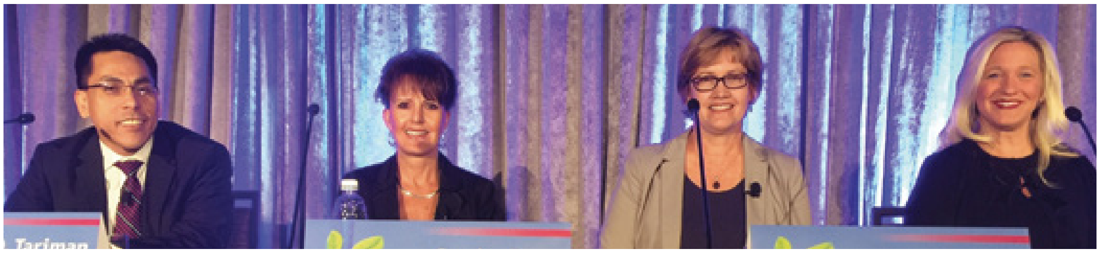
Past recipients of the Robert A. Kyle Lifetime Achievement Award:
Drs. Jesús San Miguel, Pieter Sonneveld, Robert A. Kyle, Gösta Gahrton, Brian G.M. Durie, Kenneth Anderson, Heinz Ludwig, Joan Bladé, Jean-Luc Harousseau, S. Vincent Rajkumar, and Dr. Antonio Palumbo.

Dr. Richardson has published more than 320 original articles, and over 200 reviews, chapters, and editorials in leading peer-reviewed journals, including *The New England Journal of Medicine*, *Blood*, *Journal of Clinical Oncology*, *Leukemia*, *Clinical Cancer Research*, and *British Journal of Haematology*. His primary research interest is in novel therapies for the treatment of myeloma, and he has been a leader in the clinical development of bortezomib, lenalidomide, panobinostat, elotuzumab, daratumumab, and pomalidomide. He pioneered the development of RVD (lenalidomide + bortezomib + dexamethasone), which is now one of the most widely used combinations in the upfront treatment of myeloma patients in the US and elsewhere. Currently, he leads multiple efforts studying the use of combination therapies in relapsed and refractory myeloma.

Dr. Richardson could not express his gratitude more, when he commented on how this honor "reflects the privilege of working with my phenomenal team, and, the greatest privilege of all, to have made a meaningful difference in the care of our patients. I, therefore, am truly honored to receive this award and deeply grateful for all that it means." **MT**

ONS 2017 Satellite Symposium

Case Studies in Multiple Myeloma: Best Practices in Patient Care and Symptom Management



NLB members *(left to right)* Dr. Joseph Tariman, Sandra Rome, Charise Gleason, and Dr. Beth Faiman

By Diane Moran
IMF Senior Vice President, Strategic Planning

The IMF Nurse Leadership Board (NLB) satellite symposium at the Oncology Nursing Society (ONS) 2017 Annual Congress was attended by 835 nurses. Held on May 4 in Denver, Colorado, the successful event featured a presentation on “Case Studies in Multiple Myeloma: Best Practices in Patient Care and Symptom Management.”

This symposium was designed to meet the educational needs of oncology nurses in community and academic settings who are involved in the care of patients with myeloma. The distinguished panel included NLB members: Co-Chairs Beth Faiman, PhD, RN, MSN, APRN-BC, AOCN® and Joseph D. Tariman, PhD, RN, ANP-BC, FAAN; and NLB faculty members Sandra Rome, RN, MN, AOCN®, CNS, and Charise Gleason, MSN, NP-BC, AOCNP®.

Dr. Joseph Tariman opened the symposium by providing background on myeloma. His lecture was followed by seven HIPAA-compliant case studies that illustrated patients at various stages on the disease spectrum and to show various care approaches and treatment options with nursing implications. Cornerstone therapies of myeloma, bortezomib, lenalidomide, steroids, and transplantation were woven through the cases as well as information on immuno-oncology as an emerging field and clinical pearls for therapies including carfilzomib, daratumumab, elotuzumab, ixazomib, and pomalidomide. Throughout the symposium, numerous illustrated IMF patient educational materials supported the nurse-patient educational interaction.

Case No. 1: Diagnostic Criteria, Shared Decision-Making, Clonal Evolution, Clinical Trials

Dr. Beth Faiman presented on the immunologic basis of disease of patients with myeloma. As part of a comprehensive description of the diagnostic workup, she shared the updated IMWG myeloma criteria for diagnosis used to determine when and when not to treat patients.

Dr. Tariman presented the model of shared decision-making model. He described the consideration of factors including a clinicians’ experience, data from medical research, and patients’ preferences for their own care as a model for treatment decision-making.

One key concept illustrated was nurses’ sphere of influence on patients, which included the areas of patient advocacy, disease assessment, monitoring and management of side effects, psychological support, treatment outcomes evaluation, and the coordination of multidisciplinary teams.

Case No. 2: Newly Diagnosed Myeloma, Response, Bone Health, Renal Health, Minimal Residual Disease, Adherence, Survivorship Care

During this segment, the audience learned that myeloma patients are in some cases living 10 years and more. Bone health was discussed and the implications of treatment with bisphosphonates. The speakers examined transplant-eligible versus non-transplant-eligible patient profiles, and Dr. Faiman described, “the cornucopia of drug treatment options for patients with newly diagnosed myeloma.” She also commented on maintenance options for patients who undergo autologous stem cell transplant. She referred clinicians to the IMWG Response Criteria to assess treatment response, and explained minimal residual disease (MRD).

Sandra Rome followed up with clinical pearls for transplant patients based on the Clinical Journal of Oncology Nursing (CJON) supplement on transplantation. She touched upon infection prevention, especially since infection and/or sepsis are the number one causes of mortality in cancer patients. Because up to 50% of myeloma patients will have renal complications, she emphasized the importance of discussing patients’ renal health. This segment concluded with discussion of the importance

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IMF TV! One of the IMF’s Best Educational Resources – Check It Out!

By Debbie Birns
IMF Medical Editor

IMF TV is a fantastic resource for the entire myeloma community. Whether you’re a newly di.agnosed patient or a long-term survivor who has been living with myeloma for many years, a caregiver or a member of the healthcare profession, **IMF TV** is a rich repository of myeloma wisdom.

IMF TV is a treasure chest of myeloma gems. It is available on the IMF website myeloma.org, and you’ll find it by clicking on the words “Education & Publications” at the upper right of the IMF website’s home page. When you click, you’ll find a list of red buttons, the second of which reads “**IMF TV**.”

IMF TV is the section of the IMF website that functions as a repository for all the IMF’s educational videos. Click on “**IMF TV**” to reveal nine topics full of video content.

What’s on IMF TV?

- **Ask Dr. Durie** is a TV series comprised of short talks given by the very personable Dr. Brian G.M. Durie that appear each Friday in response to questions submitted by myeloma patients. Notable topics include genetics and maintenance therapy, use of supplements while on Velcade® (bortezomib), smoldering myeloma and bone density, and the cost of cancer drugs.
- **Black Swan Research Initiative**® videos explain and keep you updated on the many projects of the IMF’s largest research program.
- Archived slides and audio from our teleconference and webinar series, **Living Well with Myeloma**, featuring noted myeloma specialists, nurses from the IMF’s Nurse Leadership Board, and experts from such fields as diverse as veterans’ affairs and cancer nutrition, with topics ranging from managing treatment side effects to the latest T-cell therapies.
- Archived videos of The **IMWG Conference Series** – the International Myeloma Working Group is our worldwide consortium of myeloma experts – are recorded twice annually following each year’s American Society of Hematology (ASH) meeting in December and the June IMWG Summit. These videos feature myeloma experts reviewing the advances in care and debating the issues that have emerged during these important meetings.
- Videos of faculty presentations at **IMF Patient & Family Seminars** bring you the latest information on best frontline therapies, best therapies for patients opting for transplant, management of bone disease, drugs in clinical trials, how to manage side effects of treatment, and how to understand and follow the results tests.
- Videos in the **Medical Meetings** category are a storehouse of interviews with the world’s leading researchers in myeloma, filmed at each year’s ASH and American Society of Clinical Oncology (ASCO) meetings. Not only do the experts provide summaries of their own new research and the results of their clinical trials, but many of them present overviews of the most promising research presented at that year’s meeting, including summaries in several foreign languages.
- The IMF also films the **NLB Satellite Symposium**, the most sought-after educational meeting at the annual congress of the Oncology Nursing Society (ONS). Conducted by members of the elite IMF Nurse Leadership Board (NLB), this symposium features a series of case studies to shed light on such topics as diagnostic and response criteria, treatment for newly diagnosed and relapsed myeloma, drugs in development, minimal residual disease, and clonal evolution.
- **Myeloma Voices** is a collection of audio interviews that provides insight into the trials and triumphs of patients and caregivers. If you are a newly diagnosed or relapsed patient searching for some good advice and inspiration, Myeloma Voices is a must.
- Finally, the **About the IMF** videos actually do contain a bit of “real” TV: a CNN segment featuring Drs. Brian Durie and Sigurdur Kristinsson discussing the IMF-funded iStopMM research project, and interviews from the IMF’s annual Comedy Celebration featuring *Everybody Loves Raymond’s* Ray Romano. Other videos include interviews with recipients of the Brian D. Novis research grant and a moving series of conversations with recipients of the Robert A. Kyle Lifetime Achievement Award, which recognizes the best myeloma doctors around the world for their outstanding contributions to research, treatment, and patient care.

As always, you can also contribute to your myeloma knowledge by calling or emailing the IMF InfoLine. **MT**

The IMF and our InfoLine Coordinators are here to help with your myeloma-related questions and concerns. The IMF InfoLine consistently provides callers with up-to-date information about myeloma in a caring and compassionate manner. InfoLine specialists Paul Hewitt, Missy Klepetar, and Judy Webb can be reached at 800-452-CURE (2873) in the US and Canada, or 818-487-7455 worldwide. Phone lines are open Monday through Friday, 9 a.m. to 4 p.m. (Pacific). To submit your query electronically, please email InfoLine@myeloma.org.

Fifth Annual GMAN Summit

By Marya Kazakova
IMF Director, Global Advocacy

The fifth annual Summit of the IMF's Global Myeloma Action Network (GMAN) took place June 17-19 in Madrid, Spain. The meeting immediately preceded the annual Summit of the IMF's International Myeloma Working Group (IMWG). The 2017 GMAN Summit garnered the participation of 35 advocates representing organizations from 25 countries, as well as an umbrella organization of myeloma patient groups and associations from across Europe.

The GMAN Summit provides an annual opportunity for members to meet in person to advance GMAN's mission to improve the lives of myeloma patients around the world by raising the profile and building the capabilities of patient advocacy groups, increasing myeloma awareness, and improving access to myeloma treatments. The Summit is a unique forum that brings together diverse and dynamic advocates, myeloma experts, and industry partners to address issues that affect the myeloma community on a global level.

The Summit's presentations, discussions, and breakout sessions reflected the areas of focus for GMAN member organizations:

A complex part of the access paradigm was addressed by Dr. Jean-Luc Harousseau in his **"The Cost of New Myeloma Treatments"** presentation. Dr. Harousseau is Professor of Hematology at the University of Nantes, IMF's Medical and Scientific Advisor, member of the IMWG, past President of the Haute Autorité de Santé (HAS, the French Healthcare High Authority) and Chair of the HAS Economic and Public Health Evaluation Committee, recipient of the 2009 Robert A. Kyle Lifetime Achievement Award, and a key figure in myeloma research for the past 30 years. The exchange that followed Dr. Harousseau's afternoon talk could have continued well into the evening, and GMAN members were highly appreciative to see Dr. Harousseau return to the Summit the following day to answer more questions and contribute to the continuing examination of the issue.

The aim of the advocacy component of the Summit was to aid members to be more effective advocates. Dr. Durhane Wong-Rieger discussed **"Real World Advocacy: Advancing Research and Access"** and led a training session on **"Advancing Public Policies That Support Research, Improve Access to Treatments, and Yield Real Results."** Dr. Wong-Rieger is President and CEO of the Institute for Optimizing Health Outcomes, President of the Canadian Organization for Rare Disorders, and Head of the Consumer AdvoCare Network. Internationally, she is immediate Past-Chair of the International Alliance of Patient Organization. She is a certified Health Coach and a licensed T-Trainer with the Stanford-based Living A Healthy Life with Chronic Conditions.

Robust discussions of myeloma included an Open Forum led by Dr. Rafat Abonour, with no topics off bounds, as well as his breakout session on what to do if access to novel therapies is unavailable, an issue that resonates for GMAN representative from countries where

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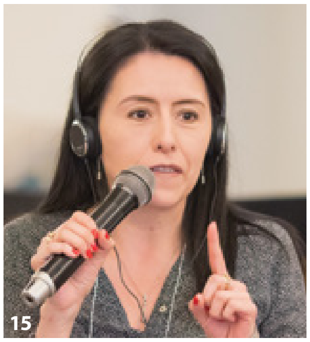
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1. Durhane Wong-Rieger, PhD
2. Rafat Abonour, MD
3. Jean-Luc Harousseau, MD
4. IMF team: Marya Kazakova, Susie Novis Durie, Yelak Biru, and Nadia Elkebir
5. Christine Battistini (IMF Latin America)
6. Sofia Sá Cardoso (Associação Portuguesa Contra a Leucemia) and Felice Bombaci (Associazione Italiana contro le leucemie-linfomi e myeloma)
7. Yervand Hakobyan, MD (Armenian Hematology Association)
8. Mira Amour (Mijelom CRO, Croatia)
9. Alfonso Aguarón (Myeloma Patients Europe)
10. Catherine Davignon (MyMu Wallonie-Bruxelles) and Lise-lott Eriksson (Blodcancerförbundet, Sweden)
11. Doreen Bruno (Malta Health Network & Lumière MM Support Group)
12. Kristín Einarsdóttir and Kjartan Gunnarsson (Perluvinir, Iceland)
13. S. Vincent Rajkumar, MD (Mayo Clinic, USA), Lisa Paik (Senior VP, IMF Clinical Education & Research Initiatives), Chul Hwan Lee and Suji Yoon (Korea Blood Cancer Association), and Jack Aiello (San Francisco Bay Area MM Support Group, USA)
14. Steve Roach (Myeloma Foundation of Australia)
15. Yolima Camacho (Fundación Colombiana de Leucemia y Linfoma)
16. Kurt Petersen (Dansk Myelomatose Forening, Denmark), Barbro Hardersen (Blodkreftforeningen, Norway), and Bibi Moe (Dansk Myelomatose Forening)
17. Aldo Del Col (Myeloma Canada), Dr. Wong-Rieger, and Martine Elias (Myeloma Canada)


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2017 Susie Novis Durie Grants Awarded

In 2016, the IMF's Global Myeloma Action Network (GMAN) launched the Susie Novis Durie Grant program to honor IMF President and Founder, Susie Novis Durie, for her tireless efforts to develop and implement innovative patient programs in the area of myeloma. These merit-based Grants provide funding to GMAN member organizations to support projects that advance the GMAN mission to improve the lives of myeloma patients around the world by raising the profile and enhancing the capabilities of patient advocacy groups, increasing myeloma awareness, and improving patients' access to myeloma treatments Three 2017 Grants were awarded to organizations in Argentina, Austria, and Romania.

Fundación Argentina de Mieloma

While the law in Argentina grants equal rights to all, not all myeloma patients have equal access to the same treatment options. Fundación Argentina de Mieloma (FAM) seeks to achieve equality of care for all people with myeloma, empowering patients and caregivers to overcome avoidable obstacles on the path to treatment. The 2017 Susie Novis Durie Grant will enable FAM to train an educator who will travel to remote regions of low economic resources and lack of access to means of communication, to deploy this educator to 5 identified regions to visit local patients and medical treatment centers, and to organize regional meetings for patients and caregivers with the participation of local healthcare professionals. FAM staff will continue to offer support and assistance to this newly formed network of myeloma patients and healthcare providers from FAM's headquarters in Buenos Aires.

Myelom- und Lymphomhilfe Österreich

Improving and enhancing the comprehension and assimilation of medical information about myeloma is an important contributing factor to patient outcomes and quality of life. Myeloma patients who are well-informed about their multifaceted disease are better able to take a participatory role in their medical care and have a voice in making treatment decisions in partnership with their healthcare team. In Austria, there is a pressing need to ensure that the education of myeloma patients and their loved ones is made as easily accessible and digestible as possible. This project will create and produce an engaging, user-friendly, web-based lesson plan about the many aspects of myeloma and its treatment, thereby raising awareness and facilitating the integration of myeloma education into the challenging daily lives of patients and caregivers. This innovative approach to myeloma patient education aims to set a new model that can be adopted and adapted as needed by other myeloma organizations around the world.

IMF President and Founder, Susie Novis Durie *(second from left)* with Elfi Jirsa of Myelom- und Lymphomhilfe Österreich, Mariana Auad of Fundacion Argentina de Mieloma, and Viorica Cursaru of Myeloma Euronet Romania

Myeloma Euronet Romania

This 2017 Susie Novis Durie Grant will support the implementation of a capacity building program by Myeloma Euronet Romania (MER). The program's objective is to provide myeloma-specific education to Romania's medical nurses. Due to the current struggle with a shortage of medical doctors to provide adequate care to patients with myeloma, the role of medical nurses in Romania is progressively more essential to both the quality of care and the quality of life of patients with myeloma. This project will build the professional capacity of nurses by supporting a formal, expert-driven, two-day training session for nurses, while also addressing improving the relationship between nurses and patients in alignment with EU medical and ethical standards. This program will launch during the Oncology Congress in Romania, held on November 23 and 24, followed by the Patients Day on November 25. The events will take place in Iasi, located in the Eastern part of Romania, a region from which many physicians have migrated to the West for economic reasons, leaving many patients without doctor care. The nurse training for the MER program will be provided by the University Hospital from Zurich, Switzerland.

The leaders of these three innovative programs will report their outcomes at the 2018 GMAN Summit. **MT**

GMAN SUMMIT – CONTINUED FROM PAGE 14

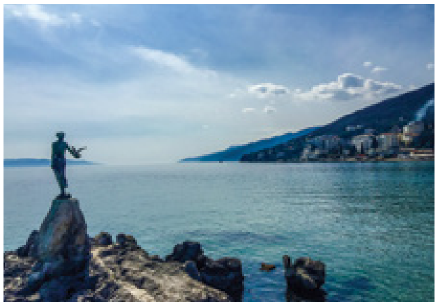
myeloma treatment options are limited. Dr. Abonour is Professor of Pathology & Laboratory Medicine, Medical Director of the Bone Marrow Transplant Program, and Medical Director of the Stem Cell Laboratory at Indiana University in Indianapolis, Indiana. He is an investigator of several ongoing clinical trials and has travelled to numerous countries to update myeloma physicians, nurses, and patients on the latest scientific and clinical advances in the field.

The Summit agenda also included a session on navigating clinical trials for access to novel therapies, as well as presentations by representatives of eight member organizations from Asia, Europe, Latin America, and North America. The interaction among members in attendance, and between members and GMAN partners and guests, is one of the key aspects of this important annual event. GMAN remains a unique global myeloma advocacy initiative, and its annual Summit fosters an environment that supports the strengthening of existing relationships and the development of new ones. The IMF team is grateful to our members, faculty, and sponsors for a successful and productive 2017 Summit, and we look forward to our continued collaboration. **MT**

IMF Patient & Family Seminars in Europe

By Nadia Elkebir
Senior Director of Global Advocacy, Europe & Middle East

1st IMF Patient & Family Seminar in Croatia



Cvijeta-Kongresi – the location of the first Croatian Patient & Family Seminar

On March 25, 2017, the IMF and Mijelom CRO hosted the very first Croatian Patient & Family Seminar in the beautiful city of Opatija. Mijelom CRO was founded by Mira Armour, Director of the organization; her brother Goran Tudor, the President; and her sister Ana Tudor; Honorary Secretary. After their mother passed from multiple myeloma in 2011, they decided, as former caregivers, to create Mijelom CRO to support others in their myeloma journeys. Since then they have been doing tremendous work all over the country, including for emerging programs in neighboring Bosnia and Herzegovina.

MijelomCRO is led by siblings *(from left to right)* Ana Tudor, Secretary; Goran Tudor, President; and Mira Armour, Director.

Goran Tudor welcomed participants to the meeting. Throughout the event, a number of faculty members presented informative panels. Professor Toni Valković from Rijeka Clinic Hospital spoke on “An Introduction of the Disease and An Overall Strategy for Treating Myeloma.” Next, Dr. Verica Lazić-Prodan from Pula General Hospital discussed “Complications Associated with Multiple Myeloma – How to Recognize and Prevent Them.” Finally, Nurse Vanja Toric of Rijeka Hospital related how nurses can integrate their duties with good listening skills for all patients.

Mijelom CRO’s Director Mira Armour and her family go way beyond the needs of myeloma patients in their country. It is overwhelming to be part of this success which is largely deserved, and I look forward to our next collaboration.

(From left to right) Prof. Toni Valković, Dr. Verica Lazić-Prodan, Dr. Duskco Pertanovic, and Nurse Vanja Toric]

IMF Patient & Family Seminar in Belgium

The Belgian multiple myeloma support group MYMU (Wallonie Bruxelles) and the IMF held their first Patient & Family Seminar in La Hulpe, Belgium on May 6, 2017. The event was attended by 200 participants, and featured speakers Dr. Rafat Abonour (Indiana University), Dr. Jean-Luc Harousseau (University of Nantes), Dr. Chantal Doyen (Namur Hospital), Dr. Marie-Christiane Veekmans (Saint Luc Universitaires), Dr. Khalil Kerkar (CHwapi Tournai), and psychologist Mina Milani (CHwapi Tournai). Created in 2006, MYMU is the official French-speaking myeloma support

Dr. Rafat Abonour presents to Belgian patients and families.

(continues on page 18)

MijelomCRO members partner with the International Myeloma Foundation to host the first Croatian Patient & Family Seminar.

P&F SEMINARS IN EUROPE – CONTINUED FROM PAGE 12

group of Belgium. Currently, Belgium participates in a national study for myeloma treatments that has so far accrued more than 250 myeloma patients.

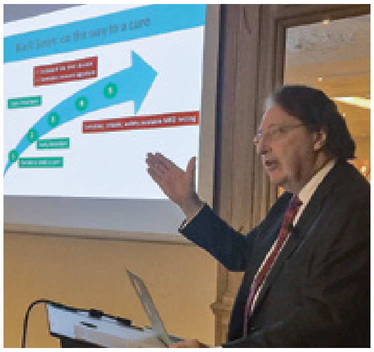
Another Successful Croatian IMF Seminar

Pictured in Zagreb are members of both the Croatian and Bosnian support groups.

On May 27, 2017, the IMF and the Croatia's Mijelom CRO held the second Patient & Family Seminar in Croatia – this time in capital city Zagreb. Five speakers presented on the most important myeloma topics to a group of 76 participants. Of note, the Bosnian patient support group – created in solidarity with Mijelom CRO – attended. The successful collaboration between Mijelom CRO and the new Bosnian group (Mijelom BIH) triggered plans for another Patient & Family Seminar in Croatia and for the first time in Sarajevo, the capital city of Bosnia and Herzegovina.

IMF and AF3M Collaborate Once Again

Marking 15 years of collaboration, the IMF and the Association Française des Malades du Myélome Multiple hosted another successful Patient & Family Seminar on June 10 in Paris, France. The event's speakers included Dr. Brian Durie (Cedars-Sinai Hospital, Los Angeles), Dr. Jean-Luc Harousseau (University of Nantes, France), Dr. Xavier Leleu (Poitiers Hospital, France), and Mr. Daniel Chauvet from the Binding Site. Special guest Dr. Christoph Driessen (St. Gallen, Switzerland) presented positive news about the combination of bortezomib and nelfinavir. The attendees were eager to learn about sensitive topics such as new drugs and the challenges for access to these drugs in France. They also listened attentively to the latest updates from the Black Swan Research Initiative®. **MT**



IMF Chairman of the Board Dr. Brian Durie leads a presentation at the Paris Patient & Family Seminar.

To learn about upcoming events in Europe, please see the IMF Calendar on the back cover or contact Nadia Elkebir at **nelkebir@myeloma.org.**

The Belgian Patient & Family Seminar, attended by more than 200 participants, was a great success!

NLB – CONTINUED FROM PAGE 12

of a Survivorship Care Plan for survivors and their primary care providers.

Case No. 3: Relapsed Myeloma, Multiple Therapeutic Options, Immunotherapy Considerations

Dr. Beth Faiman pointed to the many, many choices at relapse after a myeloma patient has had one or more prior therapies and reiterated the importance of shared decision-making at relapse.

Case Nos. 4, 5, 6, & 7: Relapsed Myeloma, Treatment for Relapsed Myeloma, Frailty as a Consideration in Treatment

Charise Gleason discussed how treatment decisions are generally approached during relapse since there is no standard of care and many potential therapies. She discussed the Charlson Comorbidity Index for clinicians, a tool to address the needs of frailer myeloma patients with comorbidities. In the discussion of patient frailty, dosing recommendations based on Dr. Antonio Palumbo's frailty/risk scores were referenced. Also addressed in this segment were the topics of patient adherence to oral therapies as well as directing patients to financial resources to obtain such therapies.

The closing notes were on new drug developments in multiple myeloma, and a reiteration of the IMF's mission to find a cure.

Slides and a video for replay from the ONS Satellite Symposium are available in their entirety at imf-ons.myeloma.org. **MT**

Healthcare... What's Next?

By Robin Roland Levy
IMF Senior Director, Public Policy & Advocacy

A lot has been going on in the world of healthcare policy. With so much activity, it is more important than ever for patients and their families to be informed and engaged in the process. While healthcare reform is being discussed in the media right now, numerous pieces of legislation that could impact cancer patients are being actively debated in both US Congress and State Legislatures across the nation.

The IMF has monitored oral parity legislation for years, and these bills ensure insurance benefits are meeting up properly with innovation. The bipartisan H.R.1409 Cancer Drug Parity Act would make it so that cancer patients who are prescribed chemotherapy drugs do not have to face enormous copays just because the drug they need is not traditional intravenous chemotherapy. If you or one of your family members receive chemotherapy in the form of a pill or injection at home, this legislation could help ensure that you are being treated fairly. In addition, several states have active oral parity campaigns. This year, the IMF has advocated for the oral parity legislation in North Carolina, Tennessee, and Michigan. In April of this year, the oral parity bill successfully became law in Arkansas. The IMF advocacy team has closely followed and advocated for out-of-pocket legislation at the state level, including in New Jersey and in Minnesota where it was passed unanimously into law.

The IMF also closely follows healthcare reform legislation. Right now, reform efforts seem to be dwindling, but in Washington things can change quickly. We will continue to monitor the proposals being put forth by Congress to see to it that patients are protected. We think it is important for members of Congress on both sides of the aisle to not only know about the challenges myeloma patients face, but for them to come together to address these problems.

The IMF also recognizes the importance of myeloma awareness: simply knowing about a disease can help a decision maker help patients. If your legislators do not know the challenges myeloma patients face, how can they construct policies that will help our community? That is why we support H.Res.148 which designates March as "Myeloma Awareness Month." This past March, the IMF participated in this initiative and some of our advocacy actions included a federal proclamation, letters to the editor, and providing toolkits on how to advocate for the myeloma community.

Not only are we engaged in the aforementioned legislative efforts, we also continually strive to protect patients. For example, we collaborate with other cancer and disease advocacy groups to ensure the Congressionally Directed Medical Research Program continues to be successful. This program allows the Department of Defense to provide research specific to veterans fighting myeloma. We also ensure the National Institutes of Health and other agencies working to cure cancer are well funded. Additionally, we work to help myeloma patients who are Medicare beneficiaries. We also cultivate legislative solutions reexamining Medicare policies, specifically Medicare's specialty tiers. We want to make certain patients on Medicare also have access to the right drugs and therapies when they need them.

These initiatives are all great opportunities for you and your network of friends and family to get involved. You can visit our action center at advocacy.myeloma.org and easily lend your support to one or more of these issues. We can also assist you by setting up a time to speak with your legislator, whether by phone or in person. We are happy to set up meetings for you in your Congressman's local office, and we can provide a policy expert to help coach and prepare you for the event. **MT**

A Tale of Two Cancers

By René Hicks
Vallejo, California

When diagnosed with smoldering multiple myeloma, my oncologist told me that because I was so healthy and had such a positive outlook, I would likely die of old age, not myeloma.

Because I didn't expect myeloma to have any real effect on my life, I didn't even seek information about it. I remember thinking "smoldering" sounded sorta sexy – until the fanning of the embers ignited into flames of myeloma. And when my oncologist started talking about the need for a bone marrow transplant, I became a full-blown cancer patient. Cancer patient and sexy are as incongruent as you can get.

The mere mention of cancer conjures up fear. It carries a power like no other disease – it crosses all human boundaries – no one is exempt – no matter how rich or how good-looking or athletic – anyone can be diagnosed with it and sometimes be diagnosed more than once. I know this because myeloma is not my first ride on the cancer roller coaster.

With Cancer – the Sequel, I have to sit in a room with other cancer patients, wait for the nurse to poke around to find a usable vein so I can be hooked up to an IV, spend up to 3 hours getting infusions, and now I'm prepping for a bone marrow transplant. After which, I could go on maintenance with more oral chemotherapy treatment. And, heaven forbid, I may have to have another transplant. This is definitely having cancer, and myeloma is a cancer that many have never even heard of.

Now let's rewind to my first run-in with cancer: lung cancer. I had never smoked, but I had spent many years performing stand-up comedy in smoky venues – thus a victim of second-hand smoke. They removed the lower right lobe of my lung and all the surrounding lymph nodes – no other treatment – no chemo, no radiation, no medication – nothing like myeloma.

A lot of people get lung cancer from smoking, but my situation really got people's attention. It was the shock of hearing my story of being a multi-sport athlete, including being a ranked distance runner, and an award-winning comedian who had performed all over the world – much of the time in smoke-filled venues – never having smoked, but getting lung cancer from second-hand smoke.

As a lifelong advocate for social issues, using my ability to make people laugh to get messages across, I started speaking out for the right to clean air and against the tobacco companies, for patient empowerment, cancer awareness, and the need for increased cancer research funding. I spoke all over the country, doing Grand Rounds at prestigious medical hospitals and medical schools, colleges, and universities. I gave keynote speeches at medical, cancer, pharmaceutical, and tobacco prevention conferences. I taped Public Service Announcements that won the highest awards. I taped interviews that ran on the Centers for Disease Control (CDC) website. I lobbied on Capitol Hill and met with prominent Senators and Congressional members. I did hundreds of town hall meetings to get smoke-free laws passed. I ran workshops and weekend retreats. I gave thousands of TV, radio, and news interviews. I was on a nonstop mission to enhance and save people's lives. My lung cancer turned into a heroic, noble cause – reaching out and inspiring people worldwide to take action for themselves and for others.

Having myeloma is nothing like that. It feels like I'm fighting cancer, not fighting to prevent people from dying of cancer. But when people ask me if I am as funny with myeloma, I tell them there's nothing about life – good or bad – that I can't apply humor to. If my myeloma can't be sexy, it can at least be funny. Myeloma is the least known of the blood cancers; it's like being the red-headed step-child, having a bad hair day. However, having been a Black person, "Myeloma" sounds like the name of a girl that I went to high school with. Sure, she had an older brother Leukemia and an older sister Lymphoma, but Myeloma was the popular one.

This time around, I have years of experience in successfully making people laugh while making them aware of the challenges of living with cancer, and I also possess the sharply honed skills of using funny to get funding by making the "deep pockets" laugh, but also understand the need for research funding is no joke. I don't think it's a coincidence that these two experiences – cancer and laughter – are universal. Not everyone likes the same music or food or books, but cancer and laughter have the power to profoundly affect the lives of everyone in the world. **MT**

Sharing Stories of Hope

As the IMF President and Founder Susie Novis Durie says, "The telling of stories goes back thousands of years, and most of us have memories of listening to a story with rapt attention. It takes us to another place. Sharing experiences through storytelling is a powerful tool for the myeloma community." That's why the IMF website features an audio archive known as **Myeloma Voices**.

In this archive, you will hear from myeloma patients and caregivers from all walks of life and in all different stages of the disease. These individuals share how a myeloma diagnosis changed their lives and how they live with their illness on a daily basis. For example, patient Joe Petty, a self-described "car nut" whose myeloma is now in remission, spends his spare time fixing old cars and traveling with his wife Patricia, as the two try "to live as normal a life as possible." Tune in at **myelomavoices.myeloma.org**.

In addition, as part of the annual March **Myeloma Action Month** initiative in March, patients and caregivers share their stories on **mam.myeloma.org**, and we invite you to listen or add your story.

Miles for Myeloma 5K Raises Nearly $100,000 for the IMF

By Suzanne Battaglia
IMF Director, Member Events

From an initial meeting around a kitchen table, Marilyn Alexander and her twin sister, Sharon, along with Phil Falkowitz and his wife Barbara, launched the Philadelphia Multiple Myeloma Networking Group. Through trial and error, the PMMNG has become a great resource of support and education for the local myeloma community.


Co-founders of the Philadelphia Multiple Myeloma Networking Group, Phil and Barbara Falkowitz

Over the years, many PMMNG members have attended the IMF's annual Support Group Leaders Summit, and group facilitator Maddie Hunter credits the IMF's stewardship for helping the leaders of their group to become trained to address issues faced by the members.

Maddie Hunter at the most recent Miles for Myeloma race

The IMF's support of the PMMNG was one of the reasons that the group's 2017 Miles for Myeloma 5K Run/Walk fundraising effort benefitted the IMF. According to Maddie Hunter, "The IMF is the backbone of so much of what happens, not just in our support group, but in support groups in general. We look to the IMF as a surrogate guide, mentor, and coach that has allowed our group to be sustainable." The 2017 Miles for Myeloma 5K Run/Walk raised nearly $100,000 for the IMF's research initiatives and patient support programs. The course was USA Track &Field/ RRTC-Certified, with beautiful views of Philadelphia's historic Please Touch Museum and the Horticultural Center's Japanese Garden.

Since its inception in 2008, the PMMNG's annual Miles for Myeloma 5K Run/Walk event has raised more than $1 million for blood cancer organizations while also building awareness and community around myeloma. At first, a PMMNG member who was a professional event planner provided much-needed expertise, then the PMMNG hired a 5K event coordinator to delegate tasks to members and lead the organization to race day. Maddie Hunter shared this because she wants other groups to realize that fundraising takes time, effort, and resources. Yet, she encourages all groups out there to not be daunted by the task. She recommends, "Choose to organize an event that matches the scale of your resources. Choose what you can follow-through on! The inspiring thing is to raise money and find a way that works for you."

Hundreds of runners at the starting line of the 2017 Miles for Myeloma

The PMMNG's Miles for Myeloma 5K Run/Walk event has been attended multiple times by the Mayor of Philadelphia, garners huge banners in the city's center, and attracts accomplished runners. As Maddie Hunter explained, "The Miles for Myeloma 5K Run/Walk really has made the people of Philadelphia familiar with myeloma. Some of the attendees are elite runners who may not be related to a myeloma patient. As a result of attending the event, they are educated about the disease."


Runners celebrate in front of Philadelphia's Please Touch Museum.

But perhaps the most inspiring message of the 2017 Miles for Myeloma 5K Run/Walk is that of hope. Diagnosed with myeloma in 2001, Maddie Hunter says events like these raise myeloma awareness and decrease the understandable fears that arise upon diagnosis. As Maddie says, "I'm living a great life, and I have myeloma." Even though she knows that may not be the case for all patients, she hopes that the efforts of the PMMNG help other patients "find a way to a new normal to continue their lives."

The IMF congratulates the patients, caregivers, and volunteers of PMMNG for their tremendous accomplishments, including the organization of a citywide event like Miles for Myeloma. **MT**

Myeloma #AskDrDurie
What's new with the Black Swan Research Initiative?
Myeloma #AskDrDurie
Can the Hevylite™ test be used to monitor IgA myeloma?
Myeloma #AskDrDurie
Is it possible to have short remissions without high-risk features?
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What does IMWG's new diagnostic criteria mean for myeloma patients?

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Trial in Relapsed Myeloma

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vs Bortezomib and Dexamethasone
Trial in Relapsed Myeloma

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2017 IMF Calendar of Events

Aug 18-19	IMF Patient & Family Seminar – Los Angeles, CA
Sep 8-9	IMF Patient & Family Seminar – Liptovský Ján, Slovakia
Sep 9	IMF Regional Community Workshop – Overland Park, KS
Sep 15-16	IMF Patient & Family Seminar – Mikulov, Czech Republic
Sep 23	IMF Regional Community Workshop – Charlotte, NC
Sep 23	IMF Patient & Family Seminar – Heidelberg, Germany
Sept 30	IMF Regional Community Workshop – Ft. Wayne, IN
Oct 6-7	IMF Patient & Family Seminar – Dallas, TX
Oct 28-29	IMF Patient & Family Seminar – Helsinki, Finland
Nov 1	IMF Patient & Family Seminar – Oslo, Norway
Nov 3	IMF Patient & Family Seminar – Trondheim, Norway
Nov 4	11th Annual Comedy Celebration – Los Angeles, CA
Nov 6	IMF Patient & Family Seminar – Stavanger, Norway
Nov 10	IMF Patient & Family Seminar – Reykjavik, Iceland
Nov 11	IMF Regional Community Workshop – Raleigh, NC
Nov 16	IMF Patient & Family Seminar – Nyborg, Denmark
Nov 20	IMF Patient & Family Seminar – Lisbon, Portugal
Nov 23-24	IMF Patient & Family Seminar – Iasi, Romania
Dec 9-12	59th American Society of Hematology (ASH) Annual Meeting and Exposition – Atlanta, GA

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 **myeloma.org/events/all** *or call* **800-452-CURE** *(2873).*
For information on activities in Australia, Canada, Israel, Japan, or Latin America, please visit:
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