IMF's 11th Annual Comedy Celebration PAGE 14

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Myeloma Today

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IMF Presents Highlights From ASH 2017

This year's meeting offered presentations that deepened our knowledge of disease biology and provided glimpses of promising new approaches to treatment. PAGE 6

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This free issue of *Myeloma Today*© (Volume 18, Number 1) is dated January 15, 2018. *Myeloma Today*© is a quarterly (Spring, Summer, Fall, and Winter) publication of the International Myeloma Foundation, located at 12650 Riverside Drive, Suite 206, North Hollywood, CA 91607 USA

Dear Reader,

A new year is often characterized by renewed hope, promises kept, and a sense of energy and purpose. In the world of nonprofit cancer research, it is all this and so much more. It is also an opportune time to accelerate progress toward our ultimate goal: finding the cure.

The International Myeloma Foundation launched headfirst into 2018, building upon the successes achieved in the past 12 months and – as always – learning from the challenges.

Our commitment has always been to put an end to myeloma, and we're thrilled that we are now able to say that we are on the cusp of finding that elusive cure for this disease. It's also important to recognize that a cure will not look the same for every patient. As we've discovered, the "multiple" in multiple myeloma refers to the various forms this complex disease can take, and there will not be a one-size-fits-all cure.

For some, a cure may come from early detection and prevention, which is the focus of the iStopMM project funded through the IMF's Black Swan Research Initiative.® In 2017, this project celebrated its one-year anniversary. Since its launch in October 2016, over 80,000 Icelanders enthusiastically opted in to participate in the study and approximately 1,000 new cases of MGUS (monoclonal gammopathy of undetermined significance) were diagnosed.

For others, the cure may be a three-drug cocktail that results in zero Minimal Residual Disease (MRD) after treatment – a feat which our researchers are hoping to prove as a surrogate endpoint to cure. The IMF-funded CESAR "cure" trial in Spain has fully accrued and demonstrated that Kyprolis® (carfilzomib) + Revlimid® (lenalidomide) + dexamethasone (KRd) and autologous stem cell transplant (ASCT) in high-risk smoldering myeloma has been well tolerated with 100% response rate.

In addition, IMF is funding another "cure" trial – the ASCENT trial, which is taking place in the United States, and is about to begin under the direction of Dr. Shaji Kumar of the Mayo Clinic, who is also a prominent member of the International Myeloma Working Group and BSRI research team. This trial will test KRd + Darzalex® (daratumamab) with/without ASCT in high-risk smoldering patients. We are excited to launch this critical study and compare the results with those from the CESAR trial.

This past year marked a major milestone in IMF research towards a cure. We have launched over 40 simultaneous research projects – outlined as part of phase II of the IMF's Black Swan Research Initiative. In 2018, the IMF will launch into phase III of BSRI, which is extremely important, as it's the study of resistant disease.

All of this is possible thanks to your overwhelming generosity – sharing our passion and supporting our mission to find the cure! As we move forward into 2018, you will see other advances at the IMF. We will continue to excel and further our reach in the areas of myeloma research, patient education, and support, and we'll be timely in communicating our progress with you.

We want to hear from you. Your feedback is important – so whether you engage with us on social media, submit feedback about any of our educational events, or call the IMF to speak with our InfoLine team, we welcome your thoughts and comments. You are the driving force behind the IMF's mission.

Thanks to your support, 2018 will be a year of great progress!

Warm regards,

Susie Durie

Susie Durie, President & CEO

Dr. Joseph Mikhael Joins the IMF as Chief Medical Officer

The International Myeloma Foundation (IMF) is pleased to announce that world-renowned myeloma expert Dr. Joseph Mikhael has joined the IMF as Chief Medical Officer. He will work closely with the IMF's Chairman of the Board, Dr. Brian G.M. Durie, to advance the mission of the organization in research, education, advocacy, and patient care to improve lives of patients with myeloma.

"Dr. Mikhael has a tremendous passion for education and travels the world lecturing and developing collaborations in the myeloma community," said Susie Durie, the IMF's President and CEO. "He is the ideal fit to be our CMO, and we are excited to have him join the team."

Having been a Professor of Medicine at the Mayo Clinic, Dr. Mikhael brings a wealth of experience to this new role. He has conducted dozens of clinical trials in the field of myeloma and has contributed to the development of many novel drugs. He also served as an Associate Dean at the Mayo Clinic School of Graduate Medical Education and as the Deputy Director of Education at the Mayo Clinic Cancer Center.

"Dr. Mikhael brings extensive experience in myeloma treatment and research to his new position with the IMF," said Dr. Durie. "In addition, his experience on the global stage makes him perfectly suited to playing an important role in our growing research efforts around the world."

Dr. Mikhael also serves as a councillor on the American Society of Hematology (ASH) Executive Committee and is involved in mentoring the next generation of hematologists. He did his medical training in Canada, having completed medical school at the University of Ottawa, his hematology training at the University of Toronto, and a Multiple Myeloma Fellowship at Princess Margaret Hospital. He also has a master's degree in education from the University of Toronto.

Dr. Mikhael will remain in clinical and academic medicine with City of Hope Cancer Center in California. **MT**

2018 IMF Brian D. Novis Research Grants

Research projects focus on deepening the knowledge of myeloma and developing future therapies

By Susie Durie
IMF President & CEO

For 23 years, the IMF has proudly funded the most promising myeloma research by talented investigators from the leading institutions around the world. On December 9, 2017, the IMF awarded its 2018 Brian D. Novis Research Grants at a presentation ceremony held during the 59th annual meeting and exposition of the American Society of Hematology (ASH) in Atlanta, Georgia.

The Brian D. Novis Research Grant program was established in 1995 in memory of the IMF co-founder with the goal of improving patient outcomes by furthering research in all areas of myeloma. To date, the IMF has funded more than 100 projects by both senior and junior investigators. The IMF is proud of our long history of supporting myeloma research.

Six important research projects are being funded for 2018, three Senior Research Grants at $80,000 each and three Junior Research Grants at $50,000 each. The grants are made possible through the proceeds from the IMF's Member Fundraisers program as well as generous donations from private individuals. The research projects supported by the Brian D. Novis grants are bringing us closer to finding a cure for myeloma, and we are deeply grateful to all who support this valuable program.

1. Dr Brian G.M. Durie & Susie Durie
2. Michael & Robin Tuohy
3. Kenton Hofmeister
4. Todd & Debbie Bater
5. Tamara Wyche Mobley
6. Speeches during the award presentation ceremony brought smiles to everyone

Dr. Robert A. Kyle opened the award presentation ceremony with an overview of the 23-year history of this vital IMF program. He announced the names of the grant recipients and presented their awards, and I introduced the donors who are funding each research project. For the researchers, meeting the people who make their work possible always makes a profound impact.

For the members of the myeloma community, their direct interaction with myeloma researchers is equally rewarding.

To celebrate the patients who are benefiting from the new treatment options that are available today, the theme of the evening was "Living Well With Myeloma." Four of the myeloma patients in attendance had the opportunity to share their stories with the event's guests, and their moving journeys made a huge impact on all in attendance. Here are brief excerpts of each story:

Michael Tuohy

"I honor the patients who came before me. They remain a force in my mind to be strong, to learn, to help others. But most importantly, to be thankful. And to have hope. My daughter Ally was seven when I was diagnosed, and I wondered if I would someday walk her down the aisle to be married. Well, this summer, I'll get to do that, and I'm thrilled. But now I also want much more."

Kenton Hofmeister

"Ever since my first IMF Patient & Family Seminar, my strategy has been to accept that while I was powerless over the diagnosis, I was not powerless over my prognosis. I had choices. I had positive choices."

Todd Bater

"I feel blessed to be here, for what I have in my life, and what I can do with my life. With my myeloma managed, my life is still about appreciating every moment. This appreciation is enriched now, while it has simultaneously been modified. Because living well now means living well with myeloma."

Tamara Wyche Mobley

"I've made the decision that myeloma doesn't have to rule my life. I'm doing the same things I always thought I'd do, but I'm also more aware now that what I say is just as powerful as what I do. Especially when I wake up not feeling my best, I actually say out loud, 'Get it together Tammy, you got things to do.'"

Brian Novis would often say, "One person can make a difference, but two can make a miracle." His message continues to resonate loud and clear, and the remarkable individuals I am proud to know demonstrate this on a daily basis. The IMF has brought the myeloma community together in a very profound way. Patients are proactively engaged in supporting important research, and researchers around the world are working collaboratively and making significant advances towards a cure. I truly believe that once we "kick" that door to a cure open, miracles will happen. **MT**

2018 Brian D. Novis Senior Grant recipients

Sophia Adamia, PhD
Dana-Farber Cancer Institute and
Harvard Medical School – Boston, Massachusetts
Identifying the causes and consequences of epigenetic alterations (mRNA splicing) in myeloma cells.
Funded by **Miracles for Myeloma 5K**

Nicola Giuliani, MD, PhD
University of Parma
Parma, Italy
Investigating the role of metabolic alterations in the pathophysiology of myeloma bone disease.
Funded by **Miles for Myeloma 5K**

Eline Menu, MD
Vrije Universiteit Brussel
Brussels, Belgium
Finding novel ways to treat myeloma by examining how myeloma cells "digest" nutrients to produce energy.
Funded by **Laughs 4 Life**

2018 Brian D. Novis Junior Grant recipients

Elka De Bruyne, PhD
Vrije Universiteit Brussel
Brussels, Belgium
Investigating the role of PRMT5 in genomic instability, drug resistance, and myeloma progression.
Funded by **Chek Fest Golf Outing**

Jacqui McGovern, PhD
QUT Institute of Health and Biomedical Innovation
Brisbane, Australia
The development of a humanized animal model to increase knowledge and find new therapeutic strategies for myeloma.
Funded by **J.C. Golf Tournament**

Simona Segalla, PhD
Functional Genomics of Cancer Unit,
Division of Experimental Oncology
Ospedale San Raffaele – Milano, Italy
Increasing the knowledge of the DIS3 oncogenic mechanisms to provide a framework for the development of individualized, molecularly based therapies.
Funded by **Hamby Memorial Golf Tournament**

The "Miracles for Myeloma 5K" event in New Jersey is now in its fifth year. Proceeds from this fundraiser have supported six Brian D. Novis Grants, three of which have been Senior Grants. The event was started by three people who had no prior fundraising experience. Five years later, Ron and Sheree Pask were in attendance in Atlanta as their third Senior Grant was awarded to Dr. Sophia Adamia.

After many successful years, the "Miles for Myeloma 5K" in Pennsylvania is funding its sixth Research Grant, with a Senior Grant being awarded this year to Dr. Nicola Giuliani. Presenting the award on behalf of the Philadelphia Multiple Myeloma Networking Group is support group member Cindy Chmielewski.

Kent Oliver was diagnosed with myeloma at age 26. A year ago, at age 34, he got involved in raising public awareness about myeloma and raising funds for research. His inaugural "Laughs 4 Life" event in Mississippi raised $60,000 and funded a Junior Grant. This year, Kent and Candace Oliver are funding the Senior Grant awarded to Dr. Eline Menu, PhD. Dr. Karin Vanderkerken of VUB accepted the award on the behalf of Dr. Menu.

For 18 years, the annual "J.C. Golf Tournament" has been held in Minnesota in memory of the late J.C. Johnson, loving wife of David Johnson, and the whole community comes out to honor and celebrate J.C. This year, yet another Research Grant has been funded by the family and friends of J.C., this year to Dr. Jacqui McGovern. Bev Lundorff attended the reception on behalf of the tournament.

Highlights of the 2017 Annual Meeting of the American Society of Hematology

By Debbie Birns
IMF Medical Editor

The American Society of Hematology (ASH) Annual Meeting and Exposition, host to over 20,000 attendees each December, is the world's largest annual gathering of researchers, clinicians, and others involved in blood-related diseases. This year's meeting, which was held in an unusually snowy Atlanta, Georgia, offered its usual windfall of myeloma-related oral and poster presentations that deepened our knowledge of disease biology, provided glimpses of promising new approaches to treatment, evaluated the demographics and economics of healthcare, and provided some clinical gems. The ASH meeting provides a large dose of optimism each year as researchers move ever closer to discovering the keys to this complex disease and its treatment.

Abstract numbers for the oral and poster presentations mentioned below are provided so that you can read further, if you wish. Go to **ash.confex.com/ash/2017/webprogram/start.html** and use the provided number to locate the abstract that piques your interest.

Disease biology

Studies of genetic mutations driving disease evolution and research in the area of circulating tumor cells were among the highlights of the many biology and pathophysiology sessions this year. Oral and poster presentations on disease biology and pathophysiology by far outnumbered those on treatment.

- Mutations in so-called "driver genes," or oncogenes, increase the growth of cancer cells, propelling the transitions from early to advanced disease. Much research has been devoted to identifying the driver genes in myeloma that cause clonal evolution and make myeloma cells ever more difficult to kill. Several presentations (#64, 65, and 393) focused on the myeloma driver gene known as MYC, elucidating which factors turn it on, which enhance its activity, and which other genes they regulate. One study (#393) confirmed that translocations in MYC are a genetic marker of, and likely cause of, progression to myeloma.
- French researchers used CRISPR/Cas9 technology to delete a particular sequence of non-coding RNA (called CRNDE) from myeloma cell lines and found that CRNDE deletion suppressed myeloma cell growth (#4357). Further research revealed that CRNDE in myeloma cells increases with disease progression from monoclonal gammopathy of undetermined significance (MGUS) through smoldering multiple myeloma (SMM) and reaches its peak at progression to overt symptomatic myeloma.

Several research groups presented data focused on the significance of myeloma cells in the circulating blood, known as "circulating tumor cells" or "circulating clonal plasma cells (cPCs)."

- A group in Japan analyzed the prognostic significance of cPCs in patients with newly diagnosed myeloma receiving novel-agent induction therapies (#4354). They determined that patients at highest risk of disease progression within three years had at least 500 cPCs per 500,000 blood cells. This result correlated with all other prognostic factors of high risk and is also an independent prognostic predictor.
- A German study (#4359) determined that cPCs are a surrogate marker for bone marrow minimal residual disease (MRD) after autologous stem cell transplant (ASCT). The presence of cPCs post-transplant predicts for poor overall survival (OS).

Smoldering myeloma

Increasing knowledge of disease biology and disease evolution has led to clinical trials to treat SMM patients before they develop organ damage to the bones, kidneys, and blood cells.

- The CENTAURUS clinical trial, an international, multi-center, phase II study of daratumumab (Darzalex®) given in three different 8-week schedules for treatment of intermediate or high-risk SMM demonstrated that the long, intense dosing schedule was well tolerated, and the overall response rate and estimated 12-month progression-free survival (PFS) rate were highest, at 95%, among patients who had received Darzalex on that schedule (#510). A phase III study is planned to evaluate the long, intense dosing schedule with subcutaneous administration of Darzalex in high-risk SMM patients.
- As part of the IMF's Black Swan Research Initiative®, the Spanish myeloma group is conducting the CESAR study (#402), a curative strategy for high-risk SMM with carfilzomib (Kyprolis®) + lenalidomide (Revlimid®) + dexamethasone (KRd) as induction, followed by high-dose therapy (HDT) with ASCT, consolidation with KRd, and maintenance with Rd. Dr. María-Victoria Mateos from the University of Salamanca presented data demonstrating that at 13 months' median follow-up, 99% of the patients are alive and free of progression. Responses have deepened with duration of therapy. One patient died of a stroke. 60% of the patients were MRD-negative by Next Generation Flow (NGF) following consolidation therapy and before maintenance therapy.

New therapies

Perhaps the hottest topic in new treatment for myeloma as well as the other hematologic cancers is CAR T cells. Many companies have CAR T products in myeloma clinical trials, and ASH attendees eagerly awaited reports of their interim data.

- A University of Pennsylvania study of two dose levels of Novartis's B cell maturation antigen- (BCMA-) targeted CAR T cells (CART-BCMA) with and without cyclophosphamide conditioning (#505) reports on treatment of 24 eligible patients, all of whom were heavily pretreated, and 95% of whom have high-risk cytogenetics. It takes three to four weeks to engineer the patient's T cells before the targeted T cells can be reinfused. Cytokine release syndrome (CRS) remains a common but manageable toxicity. There was one case of encephalopathy that was life-threatening, and one patient died in the lowest-dose cohort. One patient at the higher dose level without cyclophosphamide conditioning is in ongoing stringent complete response (sCR) at 24 months. Eleven of the 24 dosed patients had at least a partial response (PR, 50% or greater drop in M protein), for an overall response rate (ORR) of 46%.

- A new CAR T product from Shanghai Unicar-Therapy in China combines infused CD19 and BCMA-specific CAR T cells (#506). Thus far, only eight patients in the first dosing cohort have completed the CAR T cell infusion. The ORR is 90%, with 30% having at least a very good partial response (VGPR, 50% or greater drop in M protein). All eight patients had CRS but recovered. There were no neurological complications. With one year since infusion of the engineered T cells, the average response has been seven months.
- Last year's late-breaking abstract on CAR T cell therapy from China's Nanjing Legend Biotech raised eyebrows and hopes. This year's more mature data on the five patients treated were presented in a poster, complete with photographs showing disappearance of outwardly visible extramedullary plasmacytomas from the forehead of one patient and the lower jaw of another (#3115). Data were only reported for the first two months after treatment. One patient was in CR and MRD-negative, one had a VGPR, and the other three had PR. There were no dose-limiting toxicities and no deaths; CRS was manageable.
- Among the most highly anticipated CAR T cell trial results this year were those of 21 relapsed/refractory patients treated at eight US sites with anti-BCMA CAR T cell therapy bb2121 (#740), which was granted "breakthrough therapy" status by the US Food and Drug Administration (FDA) in November 2017. Three of the 21 patients had progressive disease and died before their T cells were available for dosing. CRS occurred in 71% of the remaining 18 patients, two of whom had severe cases. There were five on-study deaths: three from progressive disease, one from myelodysplastic syndrome, and one from cardiac arrest. One 46-year-old patient had a grade 4 neurotoxicity compounded by tumor lysis syndrome. She was treated with steroids, tocilizumab, and hemodialysis, and recovered. 100% of the patients treated at the higher dose levels responded. 56% of patients had at least a complete response (CR). Four patients had progressive disease after treatment. PFS was 71% at nine months. Four patients available for analysis by Next Generation Sequencing (NGS) were MRD-negative.

Other meeting highlights in new approaches to therapy included presentations on GSK2857916 and selinexor.

- Current data was presented on 35 relapsed/refractory patients treated in the second part of an ongoing phase I study of GSK2857916 (#741). This very promising new bi-specific antibody-drug conjugate was granted "breakthrough therapy" designation by the FDA and "PRIME" designation by the European Medicines Agency (EMA) in November. GSK2857916 works by binding to B cell maturation antigen (BCMA) on the surface of myeloma cells and then releasing a chemotherapy agent that is rapidly internalized in those cells, which kills them. There is some evidence that this drug also activates an immune system response against the myeloma cells. ORR to single-agent GSK2857916 was a robust 60% of patients with at least a VGPR, with a median PFS of 7.9 months. The most common side effects were ocular (blurred vision, dry eye, sensitivity to light).

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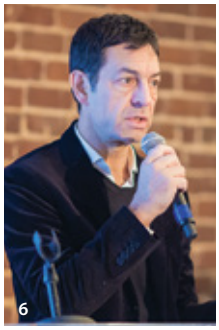

The IMF's International Myeloma Working Group (IMWG), a collaboration of more than 200 leading myeloma researchers from around the world, has changed the landscape of myeloma since it was founded in 2001. The IMWG has brought about breakthroughs in treatment options and diagnostic systems that prolong lives. On December 9th, members of the IMWG met in Atlanta to discuss the needs of both myeloma patients and the physicians who treat them.

1. Dr. Brian G.M. Durie presents at an International Myeloma Working Group function
2. Dr. Robert A. Kyle with Dr. Simon Rögnvaldsson
3. Dr. María-Victoria Mateos
4. Dr. S. Vincent Rajkumar and Dr. Brian G.M. Durie
5. Dr. Suzanne Lentzsch
6. Dr. Philippe Moreau
7. Drs. Evangelos Terpos, Jean-Luc Harousseau, Meletios A. Dimopoulos, and William Bensinger
8. Dr. Jesús San Miguel with Susie Durie and Dr. Brian G.M. Durie

ASH HIGHLIGHTS – CONTINUED FROM PAGE 7

Steroid and lubricant eye drops and cooling masks over the eyes are used to help minimize this side effect. Hematologic side effects were low platelet counts and anemia.

- Promising data from small, early-phase clinical trials with selinexor triplet therapies were featured in several posters this year, including selinexor + Velcade® + dexamethasone (SVd) (#3135), selinexor + Revlimid + dexamethasone (SRd) (#1861), selinexor + pomalidomide (Pomalyst®) + dexamethasone (SPd) (#3136), and selinexor + Darzalex + dexamethasone (SDd) (#3100). All combinations were found to be safe. The ORR to SVd in patients who had had one to three prior therapies and were not refractory to Velcade was 83%; to SRd in patients who had had one to three prior therapies and were not refractory to Revlimid was 91%; to SPd in patients who had two or more prior therapies including Revlimid and a proteasome inhibitor was 54%. Response data for SDd in patients who have relapsed/refractory myeloma and have had at least three prior therapies, including an immunomodulatory drug (thalidomide, Revlimid, or Pomalyst) and a proteasome inhibitor (Velcade, Ninlaro®[ixazomib], or Kyprolis), are still very early and are limited to only three patients, all of whom have responded.

Darzalex (daratumumab, DARA)

Darzalex remains a topic of high interest two years after its approval as a single agent. In addition to follow-up studies on such approved regimens as Darzalex + Revlimid + dexamethasone (#739, #1883) and Darzalex + Velcade + dexamethasone (#1852, #3145), studies of new combination therapies with Darzalex, administration of Darzalex by subcutaneous injection rather than intravenous infusion, and use in the newly diagnosed setting sparked high interest.

- An early-phase study of the combination Darzalex + Kyprolis + dexamethasone (DKd) in 85 heavily-pretreated patients with relapsed myeloma (#1869) found that the combination was effective (84% ORR with 4% sCR) and durable. Side effects were consistent with those of the individual therapies. A phase III trial of KRd versus Kd (CANDOR) is ongoing.
- A small phase I study introduced the quadruplet combination of Darzalex + Kyprolis + Revlimid + dexamethasone (DARA-KRd) in 22 patients with newly diagnosed, transplant-eligible myeloma (#3110). While the most common side effects were low blood cell counts, the most common serious side effect was pulmonary embolism, which occurred in three patients. ORR was 100%, with 40% sCR and 20% CR in patients who did not opt to go on to stem cell transplant, and 43% sCR and 14% CR in patients who did undergo stem cell transplant. The 12-month PFS rate is 100%.
- A dose-escalation study of subcutaneously administered Darzalex with hyaluronic acid in patients with relapsed/refractory myeloma (#838) found that it was well tolerated, and that infusion-related reactions were lowest among patients who received the 1800 mg dose administered over only three to five minutes. The preliminary ORR in that cohort of patients is 42%.

Imaging studies

Studies of whole-body low-dose CT (WB-LDCT) continue to demonstrate its superiority over the conventional X-ray skeletal survey that is the current standard of care for assessing bone disease in myeloma.

- A team of researchers in Japan found that using WB-LDCT to detect the presence of abnormal bone marrow lesions in the appendicular skeleton (arms, legs, clavicle, scapula, pelvis, hip bone) is not only valuable for diagnostic purposes, but is prognostic of poorer OS among patients who have a diffuse high-density area in the marrow compared to those with a circumscribed focal pattern (#1763).
- A study at the University of Padova in Italy (#1788) followed newly diagnosed patients who were given both WB-LDCT and PET-MRI scans as baseline studies. The researchers concluded that WB-LDCT was able to identify a distinct pattern of lytic lesions that was not observable with PET-MRI. The researchers found that WB-LDCT adds crucial and specific information in newly diagnosed patients. This study adds further evidence that the skeletal survey performed with X-rays, the current standard of practice, should be replaced by WB-LDCT.

MRD assessment

MRD status remains a topic of the utmost importance at ASH. A growing body of evidence is validating MRD testing's effectiveness in evaluating response to treatment and in predicting relapse and OS. Studies from France (#435), Spain (#1783, #905), the Russian Federation (#3097), Greece (#3088), and the UK (#904) added significantly to our knowledge of the power of MRD and its role as an endpoint in clinical trials.

- Two large clinical trials into which MRD testing was incorporated (#435 and #905) demonstrated that MRD assessment is feasible in large multicenter trials, is highly sensitive, is the most relevant clinical endpoint for both standard and high-risk patients, should be accompanied by imaging for extramedullary disease, and should be the new surrogate marker for evaluation of treatment in clinical trials.
- A comparative study done in Spain showed that both next-generation flow cytometry (NGF) and next-generation (DNA) sequencing (NGS) techniques are highly accurate and correlate well with each other (#1783).
- A large study of post-autologous transplant Revlimid maintenance therapy performed in the UK demonstrated that MRD testing "is a particularly powerful predictor of outcome in the maintenance setting" and should be used to monitor MRD status in clinical trials of maintenance therapy (#904).

Transplant

Last year's ASH brought us the formidable STAMINA trial results, which demonstrated that at a median of 38 months of follow-up in the largest transplant trial ever conducted, OS was the same whether patients had single autologous transplant with Revlimid maintenance, tandem autologous transplants with Revlimid maintenance, or single autologous transplant followed by four cycles of RVd consolidation and Revlimid maintenance. While these data seemed to put to an end the debate about which transplant approach is best in the age of novel therapies, the debate nevertheless rages on.

- This ASH brought us an Italian-Dutch rebuttal to STAMINA in favor of tandem ASCT followed by Revlimid maintenance (#401). Patients were treated with cyclophosphamide + Velcade + dexamethasone and then randomized to one of three trial arms to receive

intensification with either four cycles of VMP, a single ASCT, or a tandem auto transplant. With a much smaller patient population than the STAMINA trial, the data from this European trial demonstrated that at a median 38 months of follow-up, OS was 89% for patients who had had tandem transplants, and 82% for those who had had single ASCT.

- A study from Hackensack Medical Center in New Jersey (#2013) elucidates transplant outcomes for patients 75 to 81 years of age, a population not traditionally thought of as eligible for transplant. Although 2 of 24 patients died before day 100 post-transplant, at five years of follow-up, PFS was 40% and OS was 56%. The researchers conclude that there was no difference in OS for patients 75 years and older at the time of transplant compared to patients younger than age 75, providing some inspiration for fit older patients.
- Another study from Hackensack (#4538) gives new life to an old debate in stem cell transplant: Does depth of response to induction therapy influence the depth of response after autologous stem cell transplant or not? A study of 496 transplant patients who received 596 transplants at Hackensack between 2005 and 2015 led the researchers to conclude that while having progressive disease at the time of transplant predicts for poorer OS, all other responses – CR, VGPR, PR, and stable disease (SD) – did not lead to statistically significant differences in OS. Attempting to deepen pre-transplant response with different therapy does not improve OS unless the patient has progressive disease. They advise all patients who do not have progressive disease after induction therapy to proceed directly to transplant.

Maintenance therapy

The benefit of maintenance therapy with Revlimid, both post-ASCT and as continuous therapy for non-transplant-eligible patients, has been amply demonstrated. This ASH brought us information about the impact of Revlimid maintenance on high-risk patients and on MRD status and provided data on a new player in the realm of maintenance therapy, Ninlaro.

- A large UK maintenance therapy study of 1970 patients, 1247 transplant-eligible and 723 ineligible for transplant, concluded that Revlimid maintenance versus no maintenance significantly improves both PFS and OS regardless of the patient's cytogenetic risk status (#436).
- A Spanish study (#3098) identified 87 patients who received Revlimid maintenance therapy and collected data on their baseline variables, clinical and biological parameters, therapy, and flow cytometry and PET-CT results. They concluded that Revlimid maintenance increases the proportion of patients who are MRD-negative by both flow cytometry and PET-CT scan, and that their prognosis is significantly superior to that of other patients.
- An integrated analysis of the data from 121 newly diagnosed patients in four early-phase Ninlaro maintenance/continuous therapy studies (1) weekly Ninlaro + Revlimid + dexamethasone (IRd); (2) twice-weekly IRd; (3) Ninlaro + melphalan + prednisone (IMP); and (4) Ninlaro + cyclophosphamide + dexamethasone (ICd) (#902) showed that patients who continued on single-agent Ninlaro following a Ninlaro-based induction regimen had deepening of responses and good long-term outcomes, with median PFS of 21.4 months. There were no serious side effects that occurred in more than 2% of patients.

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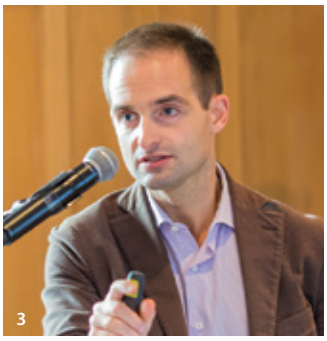
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The IMF's signature Black Swan Research Initiative® (BSRI®) is forging ahead at full with many exciting projects. On December 7th, the BSRI Investigators Meeting focused on MRD testing, the progress being made through the iStopMM® (Iceland Screens, Treats, Or Prevents Multiple Myeloma) project, the ASCENT trial headed by Dr. Shaji Kumar of the Mayo Clinic (Rochester, MN) that will attempt to cure patients with high-risk smoldering multiple myeloma (SMM), and other clinical trials in the US, Europe, and the Asia-Pacific region.

1. Dr. Brian G.M. Durie
2. Sigurdur Kristinsson
4. Dr. Bruno Paiva
5. Dr. Mario Boccadoro
6. Hartmut Goldschmidt
7. Jens Hillengass
8. Dr. Heinz Ludwig and Dr. Philip McCarthy

ASH HIGHLIGHTS – CONTINUED FROM PAGE 9

AL amyloidosis

Last year, the ASH organizing committee devoted an entire oral session to presentations about treatment of immunoglobulin light chain amyloidosis, also known as AL amyloidosis. This year, three oral presentations on AL amyloidosis were grouped together in a session on immunotherapy for myeloma, reflecting the importance of this new approach to treatment.

- Darzalex is making strides in the treatment of amyloidosis, just as it has for myeloma. Two phase II studies of Darzalex for patients who have relapsed after at least one therapy for light chain amyloidosis and have involvement of at least one vital organ were conducted by researchers at Boston Medical Center (#507) and at nine French centers (#508). The data thus far for these trials show that Darzalex is safe and well tolerated for this population of patients, infusion reactions have been minimal, and deep responses were seen among patients in both trials after just one dose of Darzalex.
- The final analysis of a phase I trial at New York's Columbia University Medical Center of the first-in-class fibril-reactive monoclonal antibody 11-1F4 (#509) for patients with relapsed or refractory AL amyloidosis determined that the monoclonal antibody is well tolerated and safe and that it leads to fast, early, and sustained organ response. Larger randomized trials with mAb 11-1F4 are planned.

Racial disparities

Racial disparities were the focus of presentations in disease biology as well as health services.

- A large genome-wide association study conducted by researchers at 48 US institutions (#3058) found that genetic loci associated with myeloma risk in African-Americans appear distinct from risk loci identified in European-Americans. The researchers postulate that this may explain some of the disparity for myeloma risk in these two populations.
- Hispanics have the worst OS in myeloma, but previously there has been no documentation of clinical or cytogenetic abnormalities that might explain their poorer survival rates. Researchers examined the data from 266 Hispanic patients seen at the Florida and Arizona branches of Mayo Clinic and found some significant differences (#864). These include younger age at diagnosis, higher rates of female patients, higher rates of lytic bone disease, and lower rates of two high-risk genetic abnormalities – t(4;14 and del 13q – in Hispanics as compared to white patients. Unfortunately, none of these disparities clearly explains their inferior OS. The researchers propose delving into larger institutional and public databases and examining healthcare access and utilization in the Hispanic population. **MT**

The IMF's Asian Myeloma Network (AMN) met at ASH to review projects from the first AMN Summit held in Seoul in October 2017. Members discussed Asian-wide clinical trials, myeloma treatment guidelines in Asia, and Asian-based physician training programs. Members also made plans for the second AMN Summit in Beijing in October 2018 and the third summit in Tokyo in October 2019. Lastly, nominations were received to expand the AMN membership as the network continues to grow and flourish.

1. Dr. Wenming Chen (China)
2. Dr. Kazuyuki Shimizu (Japan)
3. Dr. Wee Joo Chng (Singapore)
4. Dr. Juan Du (China)
5. Dr. Tadao Ishida (Japan)
6. Dr. Kihyun Kim (Korea)
7. IMF Asian Myeloma Network meeting in Atlanta on December 10, 2017

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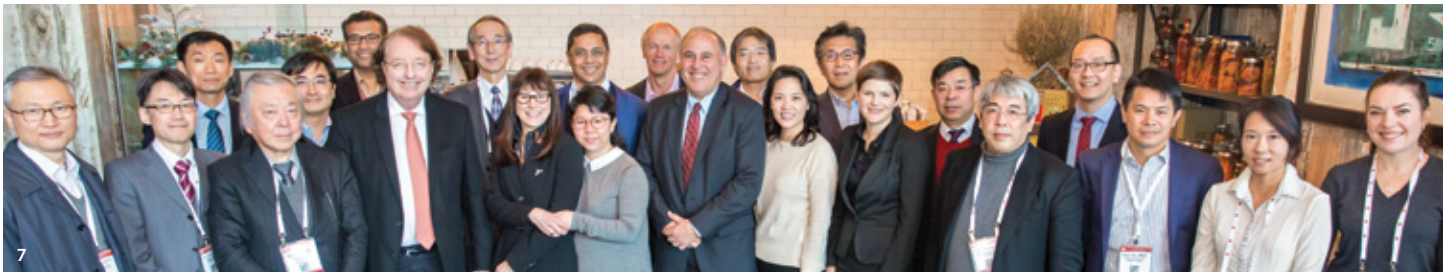
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Getting Answers to Complex Treatment Challenges in Multiple Myeloma

2017 ASH kicks off with the IMF's Friday Satellite Symposium

By Debbie Birns
IMF Medical Editor

It was standing-room-only crowd of over 1,000 attendees once again at the IMF's ASH Satellite Symposium, a continuing medical education (CME) program for physicians attending the American Society of Hematology (ASH) annual meeting and exposition in December in Atlanta. This year's symposium, "Getting Answers to Complex Treatment Challenges in Multiple Myeloma," featured leading myeloma experts Drs. Brian G.M. Durie, S. Vincent Rajkumar, Shaji Kumar, Philippe Moreau, Jesús San Miguel, and Bruno Paiva.

The IMF's ASH Satellite Symposium is presented as a series of case studies. Each audience member is given a remote-control device and is asked to respond to the same set of questions before and after each presentation to see if opinions have changed after the discussion of medical data. It's always interesting to see if – and how much – the voting changes after the presentations have been made and the panel of experts has had its say. Attendees voted – and often disagreed – on such topics as "Which is the preferred regimen for treatment of late relapse?" and "Are we currently curing myeloma?"

Topics this year included:

- Accurately Diagnosing Multiple Myeloma: When Should Systemic Treatment Be Initiated? (Dr. Paiva)
- Individualized Approaches to Treatment Selection for Induction Therapy (Dr. Rajkumar)
- Transplant, Consolidation, and Maintenance: The Role of MRD in Monitoring (Dr. Moreau)
- Therapeutic Strategies After First Relapse Following Initial Therapy (Dr. San Miguel)
- Current and Future Options for Therapy in Patients with Late Relapse (Dr. Durie)
- Review of a 2018 Treatment Algorithm for Multiple Myeloma (Dr. Rajkumar).

The IMF Satellite Symposium was livestreamed; the video and accompanying slides are available for viewing on the IMF website at **ASHsymposium2017.myeloma.org** for a crash course in best treatment practices. **MT**

1. The IMF's ASH Satellite Symposium drew more than 1,000 attendees.
2. Dr. Jesús San Miguel, S. Vincent Rajkumar, Bruno Paiva, Brian G.M. Durie, and Philippe Moreau
3. Drs. Rajkumar and Paiva
4. Dr. Vania Hungria and Dr. Jesús San Miguel
5. Dr. Durie during media interviews
6. An audience member posed a question for the panel of myeloma experts.

Myeloma Support Group Leaders at ASH

Nancy Bruno, Cindy Chmielewski, Linda Huguelet, Teresa Miceli, Jack Aiello, Robin Tuohy, Michael Tuohy, Tiffany Williams, John DeFlice, Laura Mooney, and Yelak Biru.

Support group leaders and myeloma patients and caregivers attended the 59th annaual meeting and exposition of the American Society of Hematology (ASH) as a group. They shared their experiences about the conference on blog posts at **ash2017blogs.myeloma.org** and on social media. "Our perspective is very personal," noted Robin Tuohy, IMF Senior Director of Support Groups, in her ASH blog. Read excerpts of the support group leaders' insights about ASH below:

Robin Tuohy
IMF Senior Director of Support Groups

"I'm thankful and proud of the leaders who attended ASH with the IMF to share their perspectives through blogs and social media. Peer-to-peer sharing and learning contributes to the key conversations we hold with our healthcare teams, and this enhances shared decision-making."

Jack Aiello
San Francisco Bay Area Myeloma Support Group

"When you attend ASH, you begin to learn the formula of a presentation. It's like football. If you understand how the game is played, you know what's happening. Understanding the rules makes a big difference in getting as much possible out of a presentation."

Nancy Bruno
IMF Southeast Regional Director of Support Groups

"I felt fortunate to be among so many knowledgeable professionals. I knew that I could not absorb all the details, but hearing the general tone and direction of the discussions was so valuable."

Cindy Chmielewski
Philadelphia Multiple Myeloma Networking Group

"While I was at ASH, I got a direct message on Twitter from a medical professional thanking me for sending out live tweets about sessions he had missed. That made me realize what I was doing was important."

John DeFlice
Land of Enchantment Multiple Myeloma Support Group

"I was in awe of people who are doing incredible work on genetics or clinical studies and seeing the enthusiasm they have in trying to find a cure. The amount of brainpower they put into myeloma is so impressive."

Tiffany Williams
Charleston Area Multiple Myeloma Networking Group

"There were several presentations on disparities in myeloma this year. In my effort to increase awareness, I have to address that, and we have to have the conversation to eliminate some of those disparities."

Yelak Biru
IMF Board Member, North Texas Myeloma Support Group

"There have been many life-altering treatment options reported at ASH since I first started attending in 2006. But, as evidenced by the IMF's Satellite Symposium, even though progress has been made in the treatment of myeloma over the last decade, there are still many exciting opportunities in the pipeline."

Linda Huguelet
Chattanooga Multiple Myeloma Networking Group

"ASH is one of the most encouraging experiences from a patient standpoint. When researchers present their work, they put up a slide with the names of 200 team members who helped on a project, and I'd think, 'Gosh, all these people are working either to find a better treatment or cure for myeloma.'"

Teresa Miceli
Rochester Multiple Myeloma Sharing Sessions in Minnesota

"As a nurse, I'm always focusing on supportive care, so I attended an ASH session about influenza vaccine trials for people who are immunocompromised. There are everyday type things that can be done to improve quality of life and prevent death for patients with myeloma."

Laura Mooney
Staten Island Multiple Myeloma Support Group

"As a first-time attendee of ASH, I couldn't believe the size of the crowd. It gave me a much larger view of how much interest there is in myeloma and how much they want to move forward and find a cure."

Michael Tuohy
Connecticut Multiple Myeloma Fighters Information Group

"Thanks to the IMF for their long-term commitment and providing junior and senior grants to researchers! It was an honor to share my story at this event at ASH and to have the opportunity to talk with researchers and donors."

(continues on next page)

FDA Expands the Use of Xgeva for Myeloma

The US Food and Drug Administration (FDA) has expanded the approval of Xgeva® (denosumab) to include the prevention of skeletal-related events (SREs) in patients with myeloma. The expanded approval is based on randomized phase III clinical trial data that illustrated lesser renal (kidney) toxicities with denosumab. In an IMF video filmed at the American Society of Clinical Oncology (ASCO) annual meeting in June 2017, Dr. Noopur S. Raje (Massachusetts General Hospital Cancer Center), the study's principal investigator, discussed the impact of denosumab compared with zoledronic acid (Zometa®) on renal function in the treatment of myeloma bone disease. "We saw a very encouraging progression-free survival benefit of close to 11 months for denosumab," Dr. Raje said. "More importantly, we also saw improvements in terms of renal toxicity side effects in denosumab as opposed to zoledronic acid." **MT**

Best of ASH Teleconference – Now Available

Dr. Brian G.M. Durie discussed key takeaways from the 59th meeting and exposition of the American Society of Hematology (ASH) during a teleconference on January 11, 2018. If you missed Dr. Durie's discussion of new and important information that could have an impact on myeloma patient care, watch a replay with slides at **myeloma.org/videos/best-ash-2017**. **MT**

SUPPORT GROUP LEADERS AT ASH – CONTINUED FROM PREVIOUS PAGE

In addition to leaders of US myeloma support groups, ASH was also attended by representatives of IMF affiliates in Australia, Canada, Korea, and Latin America. The IMF successfully fostered an environment that made it possible for leaders of the myeloma patient communities to engage with each other and with myeloma experts in a meaningful way, and to bring key takeaways back home to their local groups. **MT**


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1. The team from Myeloma Australia: Nella Combe, Steve Roach, Haley Beer, and Brian Rosengarten
2. Yelak Biru, Linda Huguelet, Cindy Chmielewski, Teresa Miceli, Tiffany Williams, and Dr. Rafat Abonour
3. Support group leaders listening to a myeloma researcher at the 2018 Brian D. Novis Grants reception
4. Danielle Doheny and Robin Levy of the IMF's Advocacy team meet with Laura Mooney and Nancy Bruno

NLB Authors 'Multiple Myeloma' Supplement in CJON

By Diane Moran
IMF Senior Vice President, Strategic Planning

On October 1, 2017, the *Clinical Journal of Nursing Oncology* (CJON) published a "Multiple Myeloma" supplement authored by the International Myeloma Foundation's Nurse Leadership Board (NLB). It's a major achievement for the NLB, which was an outcome from work at previous annual meetings.

"CJON is a peer-reviewed journal, and it reaches the nurses who are taking care of the patients," said Beth Faiman, PhD, APRN-BC, AOCN, certified nurse practitioner at Cleveland Clinic, and NLB member. Faiman was a guest editor of the supplement.

The supplement's research-based articles focus on myeloma symptoms and complications and their management. Each article also includes an activity for Continuing Nursing Education (CNE) credit and educational tips sheets for patients and healthcare providers. Learn more about the supplement's articles below:

Disease and symptom care

The first article to the supplement focuses on the specific needs of patients with myeloma, who often deal with short- and long-term side effects of treatment and consequences of the disease itself. This article emphasizes "the importance of effective symptom management, which helps people stay on treatment," Faiman said.

Distress, fatigue, and sexuality

The second article points out how the psychological needs of myeloma patients and their caregivers might be overlooked. As a result, patients may experience distress and suffer compromising outcomes. If these psychological needs are untreated, a patient's ability to make decisions and adhere to treatment could be impaired. The article aims to guide oncology nurses to recognize and manage distress, fatigue, and sexual dysfunction in patients with myeloma.

"If an infusion nurse is giving chemo to a patient and discussing their symptoms such as fatigue, they might be able to say, 'I'm hearing you're tired all the time, and it bothers you quite a bit. Here are some tip sheets from the IMF that might help you manage some of this,'" Faiman explained.

Renal, GI, and peripheral nerves

The third article discusses how many myeloma patients may experience damage to the kidneys and peripheral nerves at diagnosis or throughout the course of the disease. "We provide recommendations for how the patient can take hold of their health and protect themselves from organ and nerve damage," Faiman said.

Heart and lung complications

Myeloma patients may experience venous thromboembolism (VTE) and cardiovascular (CV) disease. The fourth article describes the influence of CV disease on patients with myeloma and reviews how to identify and treat these common conditions. "When you have myeloma, you are at an increased risk of blood clots due to a variety of factors, and it can affect your health for years," Faiman said. Tips for reducing your risk of blood clots are highlighted in this article.

Bone health, pain, and mobility

About 85% of myeloma patients develop bone disease characterized by the presence of lytic bone lesions. The fifth article guides nurses in the assessment and management of bone disease, pain, and mobility in patients with myeloma at varying points in their disease trajectory. "We wanted to shed light on people who oftentimes suffer silently," Faiman said. "If there's new pain, we need to look for new lesions, or the pain may be due to something other than active myeloma."

Oncology emergencies in myeloma

Myeloma and its treatment may lead to potentially life-threatening conditions that require immediate medical attention. The sixth article reviews the pathophysiology of these myeloma-associated oncology emergencies and provides a framework for assessment and effective intervention. "Oncological emergencies are well known to nurses in lung cancer, lymphoma, and other disease states, but we really haven't really talked about it too much in myeloma," Faiman said. "So we highlight some of the emergencies the nurses need to know about and act on right away, while providing tips for patients on what serious conditions to look for." **MT**

Read the NLB's 'Multiple Myeloma' supplement in CJON online at
https://cjon.ons.org/cjon/21/5/supplement

11th Annual Comedy Celebration Brings Laughter and a Sense of Community

By Randi Lovett
IMF Senior Director, Development

Ray Romano didn't let 2,797 miles stop him from hosting the International Myeloma Foundation's 11th Annual Comedy Celebration on November 4, 2017. He caught a morning flight that day from New York City, where he's shooting a film with Oscar Award-winning director Martin Scorsese, so he could be on the stage at the Wilshire Ebell Theatre in Los Angeles later that evening.

"Every charity is special, and I do a bunch of them," Romano said. "But this one hits closest to home because it's for my great friend Peter Boyle who lost his life to myeloma."

Since 2007, the IMF's Annual Comedy Celebration has raised more than $6 million to benefit the Peter Boyle Research Fund, named for Romano's beloved co-star from "Everybody Loves Raymond," and the IMF's signature Black Swan Research Initiative®, a groundbreaking and collaborative global project aimed at developing the first definitive cure for myeloma.

Comedian René Hicks, a myeloma patient and lung cancer survivor, kicked off the night with an inspirational set by saying, "It's Mark Twain who said that the human race has one really effective weapon and that's laughter. And we are going to use that weapon tonight to aid the IMF and, in conjunction with the Peter Boyle Research Foundation, to help that weapon combat myeloma – along with your support."

Plenty of laughter followed as Romano returned to the stage to emcee a show featuring Hannibal Buress, Rachel Feinstein, Nikki Glaser, Robert Klein, Marc Maron, Iliza Shlesinger, and Fred Willard. While the comedians had hilarious takes on a variety of topics, including dating, teenagers, and traffic, they were all at the event for the same reason – because Romano asked them to be there.

"Comics are like superheroes. When we get the call, we show up, make people laugh, they don't realize they're spending money, and then everybody wins in the end," Shlesinger said on the red carpet.

And for the first time, the event featured an exclusive live stream of the red carpet arrivals and silent auction, which generated more than

35,000 views on Facebook and through AmpLive. Co-hosts Miss Black USA Daphne Lee and TV personality Alie Ward, who both have a parent with myeloma, interviewed celebrities, comedians, and VIP guests on the red carpet and silent auction area, where items such as tickets to "Saturday Night Live" and "The Late Late Show With James Corden" were up for bid.

"It's one of those events that's very positive because they're actually making real, real headway to finding a cure," actress Lesley Nicol of "Downton Abbey" fame told Ward on the red carpet.

The silent auction was also available online at 501 Auctions and then on Charitybuzz after the show ended. Watch a replay of the live stream at facebook.com/myeloma/.

Amgen, Celgene, Janssen, and Takeda Oncology played key roles in the night's festivities as the presenting sponsors, while the San Fernando Valley Multiple Myeloma Support Group and other

(continues on next page)

Red carpet arrivals

From left to right, top: Comedian René Hicks and live stream show co-hosts Miss Black USA Daphne Lee and TV personality Alie Ward. From left to right, bottom: Ray Romano, Loraine Alterman Boyle, Susie Durie, Dr. Brian G.M. Durie, Lesley Nicol , Lanny Joon, Patricia Heaton, and Howard Hesseman.








COMEDY CELEBRATION – CONTINUED FROM PAGE 15

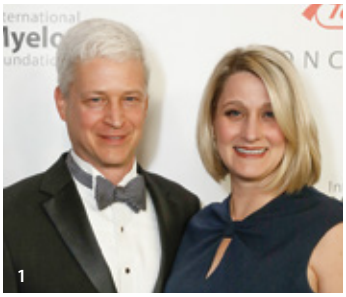
corporations and individuals supported the event through sponsorships, silent auction bids, and participation in the evening's commemorative tribute journal.

Amid the laughter, there was also an unmistakable sense of community as guests erupted in applause and cheered when Susie Durie, IMF President and CEO, and Dr. Brian G.M. Durie, IMF Chairman, opened the show by talking about the C-word – the cure.

"For the first time, we have completed a cure trial," Dr. Durie told the audience. "Ninety patients with early disease have been treated. They received a novel combo plus a transplant and the response has been really good."

That sense of community only grew stronger throughout the night as guests applauded the work of the IMF, the comedians, and stories about Peter Boyle.

"Hard to believe it's been so long since Peter's gone, but this is keeping his memory alive for us, and hopefully we're going to get to that cure," Loraine Alterman Boyle, Peter Boyle's widow and the Event Chair, said to close the night. **MT**



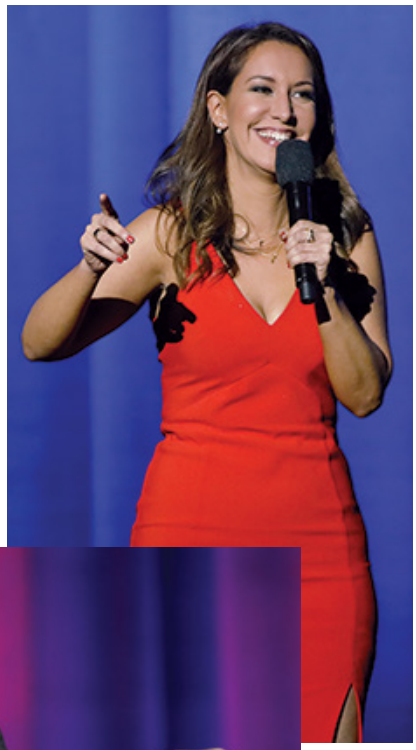




1. IMF Board Member Andrew Kuzneski with Event Vice Chair Laurie Kuzneski
2. IMF Board Member Matthew Robinson
3. Candace and Kent Oliver
4. IMF Board Member Dr. S. Vincent Rajkumar
5. IMF Board Member George T. Hayum and Carole Thompson
6. Attendees considered making a bid at the silent auction.
7. From left to right, top: Jake Smollett and Grace Gibson. From left to right, bottom: Caroline Ducrocq, Howard Hesseman, Daniela Wood, Carl Gottlieb

Ray Romano and comedians make a difference for the myeloma community through laughter

The comedians all appeared at the Comedy Celebration for the same reason – because Ray Romano asked them to be there. Clockwise from top left: Iliza Shlesinger, Rachel Feinstein, Ray Romano, Fred Willard, Hannibal Buress, Nikki Glaser, Marc Maron, and Robert Klein.



We thank our supporters

This year's presenting sponsors included Amgen Oncology, Celgene, Janssen Oncology, and Takeda Oncology. In addition, the San Fernando Valley Multiple Myeloma Support Group and other corporations and individuals supported the event through sponsorships, silent auction bids, and participation in the evening's commemorative tribute journal.

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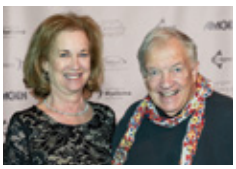

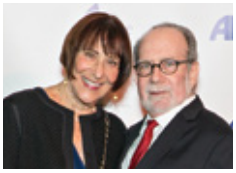

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Advocacy Team Gives Greater Voice to Myeloma Patients' Needs

By Raymond L. Wezik, JD
IMF Director, Public Policy & Advocacy

The IMF Advocacy Team is often asked what, exactly, it is that we do. I am always tempted to respond with what we do not do so as to shorten the response. In any given year we track and cover a multitude of issues, and 2017 was especially busy as it brought a new administration and new challenges into play. The healthcare debate raged through the spring and summer, appropriations for research funds found themselves on the chopping block once again and the fight for federal anticancer treatment parity began anew in the 115th Congress. The Advocacy Team engages in these topics while remaining a powerful non-partisan voice for the needs of patients with myeloma; that is what we do.

In March 2017, the House of Representatives proposed the American Health Care Act (AHCA), and later the Senate with the Better Care Reconciliation Act (BCRA), as a direct replacement for the Affordable Care Act (ACA), also known as Obamacare. The bills were hotly debated in the public forum and in Congress with the IMF Advocacy Team taking part through discussions with Republicans and Democrats on the specific provisions and changes that would hurt or help myeloma patients without delving into party politics.

While both bills eventually failed to pass, the concerns of myeloma and other cancer patients was well understood on both sides of the aisle, and amendments proposed to both bills on these issues were a direct reflection of the efforts of the IMF Advocacy Team and other organizations from across the US.

Also in March, the Patient Equal Access Coalition (PEAC), which is led by the IMF Advocacy Team, worked with a bipartisan group of legislators to reintroduce the *Cancer Drug Parity Act of 2017*, H.R. 1409, with the goal of bringing equitable cost sharing to all available anticancer treatments. Oral and self-injectable anticancer treatments are typically covered under an individual's prescription drug benefit, unlike traditional IV therapy, and often a large percentage of that cost is passed on to the patient from the insurer.

For many patients, the cost burden is so large that they can't afford the treatment. H.R. 1409 will bring the issue of anticancer parity to those on federally regulated health plans, such as those on large self-funded insurer plans. Currently, 43 states plus the District of Columbia have some form of oral parity laws enacted thanks in large part to the efforts of the IMF Advocacy Team at the state level.

In an effort to increase co-sponsors and push for passage of the federal bill, members of PEAC, including the IMF Advocacy team, along with Rep. Leonard Lance (R-NJ) and Rep. Brian Higgins (D-NY), hosted an informational congressional briefing on November 8, 2017. This effort was a success, as the bill currently has 122 co-sponsors in the House after just nine months and is evenly split between 61 Republicans and 61 Democrats.

The IMF's Advocacy Team outside the briefing with congressional staffers on Capitol Hill on November 8, 2017: Raymond Wezik, Danielle Doheny, Kelley Sidorowicz, and Robin Levy

The Peer Reviewed Cancer Research Program (PRCRP) under the Congressionally Directed Medical Research Program (CDMRP) is an important tool for the Department of Defense (DoD) to address service-connected diseases, such as myeloma, and show a continued commitment to service members beyond their time in the armed forces.

In the FY 2018 National Defense Authorization Act (NDAA), CDMRP found itself on the verge of virtual elimination with a proposal to send the program to the National Institute of Health (NIH) without the matching funds. The result would have been the slow death of CDMRP.

The Advocacy Team, along with a coalition of other likeminded groups, was able to rapidly bring the necessity of CDMRP and the threat to its existence to members of Congress. Veterans Against Myeloma (VAM), a veteran-specific program under the IMF Advocacy Team, was also alerted about the issue so that VAM members could contact their representatives. Sen. Dick Durbin (D-IL) and Sen. Roy Blunt (R-MO) introduced an amendment that had heavy bi-partisan support to keep CDMRP under the DoD, and the provision to eliminate the program was eventually removed in the final version of the NDAA.

While these are just three issue areas, the IMF Advocacy Team is engaged in many similar topics of discussion, including comments on proposed regulation for various agencies such as Centers for Medicare and Medicaid Services (CMS), engagement with specific veteran issues through the Department of Veterans Affairs (VA), and monitoring legislation changes in Congress. In addition to state oral parity campaigns, the IMF Advocacy Team closely follows state issues that include out-of-pocket cost legislation. The most important job of the Advocacy Team is to make sure the interests and needs of the myeloma patient are understood and met. **MT**

Please contact **advocacy@myeloma.org** *if you wish to get involved with advocacy or have an issue you would like to bring to the IMF Advocacy Team's attention.*

IMF Holds First AMN Summit in South Korea

By Daniel Navid
IMF Senior Vice President, Global Affairs

On October 13–15, 2017, the first IMF Asian Myeloma Network (AMN) Summit brought together 100 of the leading myeloma specialists to Seoul, South Korea, for an interactive workshop designed to identify pressing myeloma treatment and research needs for Asia.

Created by the IMF in 2011, the AMN comprised of top hematologists from seven Asian countries and regions: China, Hong Kong, Taiwan, Japan, Korea, Singapore, and Thailand. The AMN carries out research projects, including clinical trials and physician education, throughout Asia.

The AMN Summit opened with member presentations about myeloma incidence and treatment options in the region. Presentations by Dr. Jin Lu (China), Dr. James Chim (Hong Kong), Dr. Shuji Ozaki (Japan), Dr. Jin-Seok Kim (Korea), Dr. Chandramouli Nagarajan (Singapore), Dr. Jeffrey Huang (Taiwan), Dr. Weerasak Nawarawong (Thailand), and Dr. Tan Sen Mui (for non-AMN member Malaysia) showed that there is a wide disparity in resources in different parts of Asia.

This was followed by background sessions on monoclonal gammopathy of undetermined significance (MGUS), smoldering multiple myeloma (SMM), newly diagnosed myeloma, and minimal residual disease (MRD) risk stratification.

Dr. María-Victoria Mateos (Spain) presented an overview of MGUS and SMM, which was followed by a presentation on the IMF/AMN smoldering myeloma project by Dr. Tadao Ishida (Japan) and a study of MGUS by Dr. Byung Su Kim (Korean).

Dr. Daryl Tan (Singapore) discussed newly diagnosed myeloma, followed by an overview of new imaging techniques by Dr. Evangelos Terpos (Greece).

In the session on MRD risk stratification, Dr. Wee Joo Chng (Singapore) provided an overview on potential future directions, while Dr. Bruno Paiva (Spain) reviewed MRD and Dr. Hiroyuki Takamatsu (Japan) described implementation of MRD (next generation flow/next generation sequencing for myeloma in Asia.

The participants then divided into four breakout groups to focus on stratified treatment guidelines, risk stratification, integration of novel agents into the standard treatment paradigm, and the application of MRD in myeloma.

Several follow-up projects were proposed for implementation by the AMN, including the finalization and publication of revised AMN Asian treatment guidelines, new AMN clinical trials to gather research data and to allow for increased access to novel agents, information and advocacy actions to improve access to novel agents, and further MRD training for physicians.

To conclude the summit, a session was held on new targets and exciting areas for drug developments in the near future. Dr. Melissa Ooi (Singapore) reported on IMiD/PI and new targeted agents, Dr. James Chim (Hong Kong) presented an update on monoclonal antibodies, Dr. Je-Jung Lee (Korea) explained new developments in immunotherapy, Dr. Chng recalled AMN's clinical trial work with seven projects either implemented or under development, Dr. Wenming Chen (China) spoke on recent TRIAL results for the treatment of relapsed/refractory myeloma, Dr. Ken Ohmine (Japan) explained advances in the development of CAR T-cell therapy for myeloma, and Dr. Sung Soo Yoon (Korea) presented study projects for two new treatment approaches.

In summarizing the results of the AMN Summit, IMF Chairman Dr. Brian G.M. Durie noted that myeloma work had certainly come of age in Asia. Experts were world class and the opportunities to make significant contributions to improving the life of myeloma patients both in Asia and throughout the world were plentiful. In thanking the participants and the supporting partners, Dr. Durie pledged the continued support of the IMF for the further work of the AMN.

Platinum sponsorship for the summit was provided by Amgen, Celgene, Janssen, Sanofi, and Takeda and silver sponsorship from the Binding Site.

The second AMN Summit will be held in Beijing, China, on October 19–21, 2018. **MT**

More than 60 top hematologists from seven Asian countries and regions attended the first-ever IMF Asian Myeloma Network Summit in Seoul, South Korea.

Patient & Family Seminar Comes to Finland for the First Time

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

Finland

The first Patient & Family Seminar in Finland was held in Helsinki on October 28–29, 2017, to an audience of 200 participants. Dr. Raija Silvennoinen, an International Myeloma Working Group (IMWG) member, led the meeting and panel discussion, while guest speaker Dr. Rafat Abonour (Simon Cancer Center, Indiana University, US) held a presentation about myeloma treatments.

The first meeting by the IMF and "Suomen Syöpäpotilaat" – the Finnish support group – is just the beginning of many more successful collaborations.

In addition, Dr. Caroline Heckman (Principal Investigator and Group Leader, FIMM – Institute for Molecular Medicine Finland), conducted a tour of the prestigious FIMM, where more than 400 patients are taking part in myeloma research.

Norway

More than 500 patients in Norway attended Patient & Family Seminars in Oslo, Trondheim, and Stavanger last November. Dr. Nina Gulbrandsen (Oslo University Hospital) oversaw the seminar in Oslo, and guest speaker Dr. Sundar Jagannath (Mount Sinai Hospital, New York City) shared a presentation titled "Drugs and Treatments for the Future." Twenty doctors also met at Oslo University Hospital, where Dr. Jagannath discussed the latest therapies in the US. Dr. Anders Waage from Trondheim and Dr. Einar Haukås from Stavanger led seminars in their respective cities.

Attendees listened to a presentation during a Patient & Family Seminar in Oslo, Norway.

Iceland

The second Patient & Family Seminar in Reykjavik, Iceland, which took place on November 10, 2017, almost doubled the attendance of last year's event.

Dr. Jean-Luc Harousseau (University of Nantes, France) was a guest speaker and presented "Recent Advances and Future Hopes in the Treatment of Myeloma," followed by Dr. Sigurdur Yngvi Kristinsson (University of Iceland, Reykjavik) who updated the audience about the progress of iStopMM (Iceland Screens Treats Or Prevents Multiple Myeloma) study.

Because of iStopMM, a thousand new cases of monoclonal gammopathy of undetermined significance (MGUS) were diagnosed this year in Iceland and are currently being followed. **MT**

Dr. Jean-Luc Harousseau, second from left, and Dr. Sigurdur Yngvi Kristinsson, right, with leaders of the support group Perluvinir in Reykjavik, Iceland.

Dr. Anders Waage, Tone Hansen (the support group president), Dr. Sundar Jagannath, and Dr. Einar Haukås in Stavanger, Norway.

Dr. Rafat Abonour, center, met with a group of nurses in Helsinki, Finland.

International Myeloma Foundation®

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2018 IMF Calendar of Events

Feb 3	IMF Regional Community Workshop – Raleigh, NC
Feb 9-10	IMF Patient & Family Seminar – San Francisco Bay Area (Redwood City), CA
Mar 10	IMF Regional Community Workshop – Denver, CO
Mar 16-17	IMF Patient & Family Seminar – Boca Raton, FL
April 21	IMF Regional Community Workshop – Nashville, TN
May 17-20	43rd Annual Congress of the Oncology Nursing Society (ONS) – Washington, DC
June 1-5	53rd Annual Meeting of the American Society of Clinical Oncology (ASCO) – Chicago, IL
June 9	IMF Regional Community Workshop – Indianapolis, IN
June 11-13	9th Annual Summit of the International Myeloma Working Group (IMWG) – Stockholm, Sweden
June 14-17	23rd Congress of the European Hematology Association (EHA) – Stockholm, Sweden
June 17-19	Global Myeloma Action Network (GMAN) Annual Summit – Stockholm, Sweden
June 30	IMF Regional Community Workshop – Ann Arbor, MI
July 21	IMF Regional Community Workshop – Minneapolis, MN
Aug 24-25	IMF Patient & Family Seminar – Los Angeles, CA
Oct 12-13	IMF Patient & Family Seminar – Philadelphia, PA
Oct 19-21	Asian Myeloma Network (AMN) Summit – Beijing, China
Nov 3	12th Annual Comedy Celebration – Los Angeles, CA
Dec 1-4	60th American Society of Hematology (ASH) Annual Meeting and Exposition – San Diego, CA

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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