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Promising Clinical Trials in 2017

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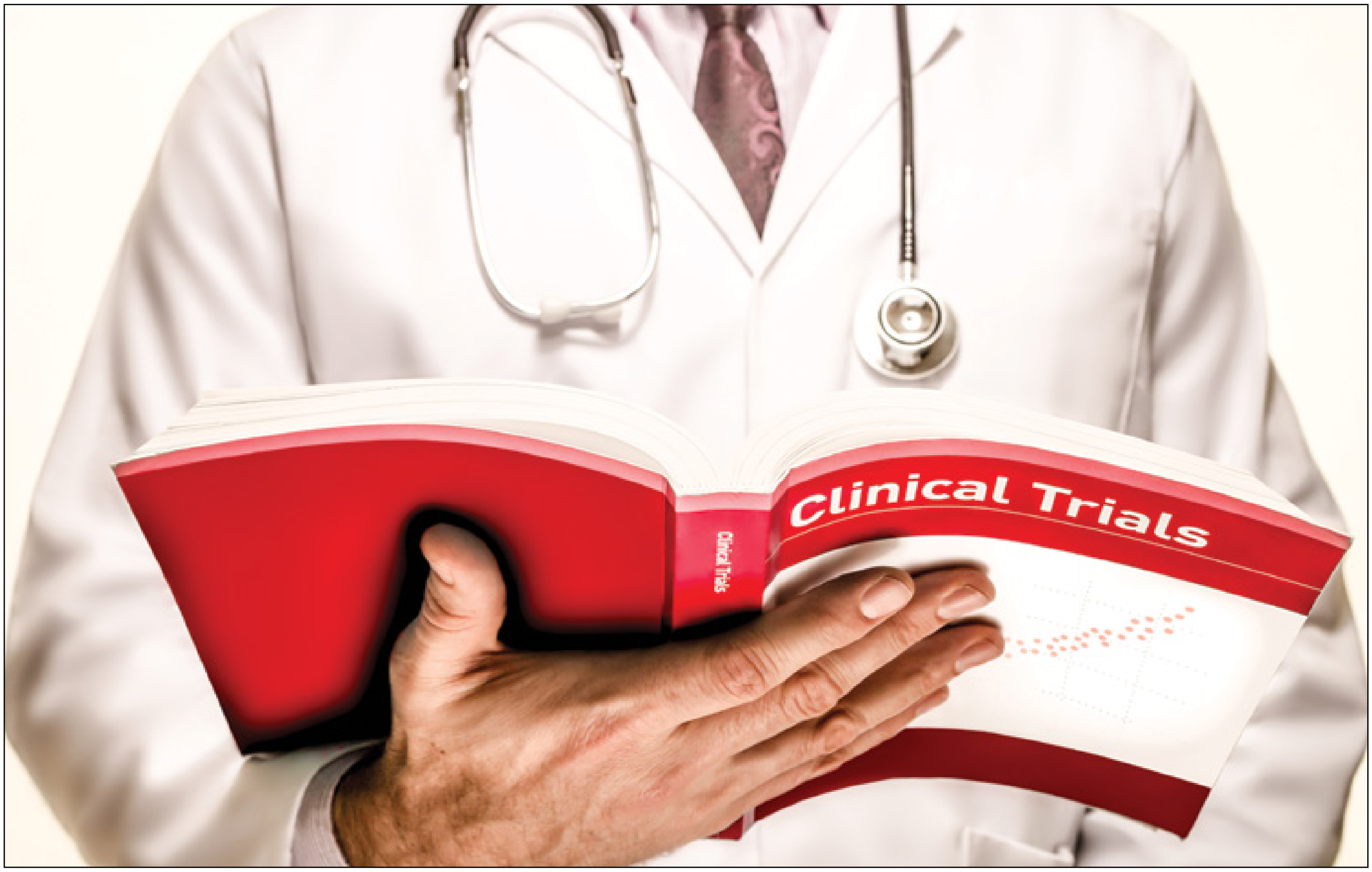

Myeloma treatment armamentarium grows as existing drugs receive expanded approvals, while new agents are explored in clinical trials.

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Dear Reader,

The IMF is about to enter a very busy time, as summer is fast approaching. In June, we will hold two very important annual meetings, the International Myeloma Working Group (IMWG) Summit and the Global Myeloma Action Network (GMAN) Summit, both events to be held just prior to the annual meeting of European Hematology Association (EHA). Each year, EHA is held in a different major European city, and the IMWG and GMAN Summits are held there, too. This year, the three meetings will take place in Madrid, Spain.

So much happens at these three events that is of importance for the myeloma community! These meetings help set the agenda for the remainder of this year and well into 2018. This year I'm especially excited about the GMAN Summit, which will bring together myeloma advocates from around the globe. GMAN is continuing to grow and expand its reach. It now includes 40 member organizations from 37 countries on 5 continents. GMAN's global reach is an opportunity to unite and to work collaboratively with groups that are diverse in many ways, yet are committed to work together on our common goals.

The issues that the GMAN member organizations face depend on the circumstances in their respective countries of origin, and sometimes there are even regional challenges within a country. But one of the biggest obstacles that many myeloma patients face is access to new drugs and/or to long-established myeloma therapies. This is a global problem and we're working together to find solutions.

This year's GMAN Summit agenda will focus on:

- capacity building
- raising global awareness
- advocacy empowerment
- quality of life
- what to do when novel agents are unavailable
- navigating clinical trials

We will keep you updated on GMAN projects and activities. Our global initiatives may have special meaning to you: you may have relatives in GMAN member countries or maybe you are from one of them. If you would like to get involved or need more information, please contact me!

Warm regards,

Susie Novis Durie

Susie Novis Durie, President

Representatives from Global Myeloma Action Network (GMAN) member organizations convened at the 2016 Annual GMAN Summit in Copenhagen, Denmark.

This free issue of *Myeloma Today*© (Volume 17, Number 2) is dated May 15, 2017. *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

Black Swan Research Initiative® Progress Report

By Debbie Birns
IMF Medical Editor

The IMF's signature Black Swan Research Initiative® (BSRI®) is forging ahead at full speed in early 2017, with many accomplishments behind us and many more exciting projects under way. We share with you the current BSRI checklist and a preview of the exciting projects that will unfold this year.

MRD testing

The BSRI team has defined and overcome the first obstacle to finding a cure for myeloma by developing a very sensitive, reliable, standardized, and affordable test to quantify and characterize any myeloma cells that may remain after a patient is in complete response (CR). The new test, known as Next-Generation Flow (NGF), is a flow cytometry technique plus a specialized software package that were developed by researchers in Spain to detect even a single myeloma cell surviving among one million bone marrow cells.

Last October, 120 researchers from myeloma laboratories around the globe gathered in Salamanca, Spain, for intensive training in NGF. Researchers from 60 labs in 26 countries worldwide attended the training workshop in addition to attendees from 12 sites in the US. The BSRI's MRD Consortium represents centers in North and South America, Africa, Asia, Australia, and Europe. Three of the labs in the US – Mayo Clinic (Rochester, MN), Roswell Park Cancer Center (Buffalo, NY), and the SWOG Lab at the Levine Cancer Center (Charlotte, NC) – are reference labs to which patient bone marrow samples can be sent for MRD testing from any other hospital, clinic, or doctor's office.

On March 10, 2017, the journal *Leukemia* published an article by members of the BSRI team on the design and validation of NGF.

iStopMM®

The Icelandic project known as **I**celand **S**creens, **T**reats, **O**r **P**revents **M**ultiple **M**yeloma (iStopMM®) launched officially in November 2017. In just four months since it opened, iStopMM has enrolled more than 70,000 participants! Its aim is to screen approximately 120,000 residents of Iceland who are over 40 years of age for evidence of MGUS, SMM, or myeloma. Researchers, under the direction of principal investigator Dr. Sigurdur Kristinsson, calculate that approximately 4% of those screened will have MGUS, which will add up to over 4,000 MGUS patients with full accrual. This is the largest population-based screening study for myeloma and its earlier disease precursors that has ever been attempted.

Iceland, with its small and networked population and centralized healthcare system, is the ideal place to conduct such a study. Not only will this project allow researchers to observe patterns of occurrence, but they will be able to follow subjects with early disease to see how it progresses. Moreover, monitoring patients with MGUS for many years will demonstrate which prognostic tests are most reliable as indicators of disease progression. We will also learn which patients benefit most from early intervention, as those identified with high-risk smoldering myeloma will be invited to participate in a treatment trial.

Because much of the Icelandic population has already undergone genetic coding, iStopMM researchers will be able to use this genetic data to look for linkages to particular family gene patterns in those with MGUS. The chances are excellent that answers will be found to help the BSRI team understand the biology of why people develop MGUS and how it can be prevented.

The ASCENT trial

The ASCENT trial, headed by Dr. Shaji Kumar of the Mayo Clinic (Rochester, MN), will use a combination of carfilzomib + lenalidomide + dexamethasone + daratumumab with/without stem cell transplant in an attempt to cure patients with high-risk smoldering multiple myeloma (SMM). This trial is scheduled to open in the coming months at the 12 MRD Consortium sites in the US.

Other clinical trials

Multiple clinical trials are being set up in the US, Europe, and the Asia-Pacific region to study and treat patients with MRD-positive disease. These studies will use new therapies to attempt to eliminate resistant MRD myeloma cells. In addition, there are more than 30 BSRI projects under way around the globe to study various aspects of residual disease. There is also an ongoing study of long survivors to better characterize and understand the nature of their disease, treatments, and response to treatment.

The research conducted by BSRI investigators over the course of the past three years is resulting in tangible benefits for patients. With accurate and accessible MRD testing, we have an endpoint to assess deep response; we have clinical trials to attempt to cure early disease; we have a screening trial to understand the causes and biology of precursor disease and to prevent its progression; and we will soon have trials to eradicate MRD. **MT**

Remember to check the BSRI website bsri.myeloma.org for news, information, and site locations for the many upcoming studies.

Promising Clinical Trials in 2017

By Debbie Birns
IMF Medical Editor

The flurry of new drug approvals at the end of 2015 for Darzalex® (daratumumab), Ninlaro® (ixazomib), and Empliciti® (elotuzumab) left the myeloma community wondering what could possibly be next. While there have been no new drug approvals since that 2015 windfall, clinical trials have resulted in expanded indications for previously approved drugs, including:

- **November 2016** – expanded approval of Darzalex, which now includes the combination therapies Darzalex + Velcade® (bortezomib) + dexamethasone (based on the CASTOR trial) and Darzalex + Revlimid® (lenalidomide) + dexamethasone (based on the POLLUX trial) for patients who have had at least one prior therapy.
- **February 2017** – the official approval of Revlimid as post-autologous transplant maintenance therapy both by the FDA in the US and by the European Medicines Agency (EMA) in Europe. The basis for these approvals was overall survival (OS) data from two large randomized trials, one of which was conducted in the US, the other in France.

Now we are focusing not only on expanded approvals for existing drugs, but on potential new approvals for agents still in clinical trials. We are eager to see if they might fill specific "unmet needs" in the myeloma treatment armamentarium. Drugs to treat patients who are "penta-refractory" to Revlimid, Pomalyst® (pomalidomide), Velcade, Kyprolis® (carfilzomib), and an anti-CD 38 monoclonal antibody (either the approved agent Darzalex or the experimental agent isatuximab, also known as SAR650984) are high on the wish list, as are drugs that can target specific high-risk genetic mutations. Trials of combination regimens designed to cure patients with high-risk smoldering multiple myeloma (SMM) are also a priority, and are in process in America and in Europe.

"Cure Trials"

The IMF is proud to be the sponsor of a number of trials that are, or soon will be, taking place in the US, Europe, and Asia to meet unmet needs around the globe. Already under way in multiple centers in Spain through the Spanish clinical trials group PETHEMA is the Black Swan Research Initiative®-sponsored CESAR trial (NCT02415413), a study of Kyprolis + Revlimid + dexamethasone (KRd) followed by high-dose therapy with melphalan and autologous stem cell transplantation (ASCT), followed by consolidation with KRd, and maintenance with Revlimid + dexamethasone in patients under 65 years with high-risk SMM. CESAR is the first of two myeloma "cure trials" that will attempt to treat high-risk SMM early, intensively, and effectively. The goal is for every patient to achieve sustained MRD-negative status. The CESAR trial has been actively accruing patients for almost two years.

The second of the Black Swan-sponsored cure trials for patients with high-risk SMM, the ASCENT trial, is scheduled to open soon at the Mayo Clinic in Rochester, Minnesota. It is not yet listed on the clinicaltrials.gov database. In this two-arm trial all patients will receive four cycles of KRd + daratumumab, and then patients who are eligible for high-dose melphalan with ASCT will proceed to transplant, while those who are ineligible will receive four more cycles of KRd + daratumumab. All patients in both arms of the study will receive another four cycles of KRd + dara at reduced doses as consolidation, and then all patients will receive maintenance therapy for one year with even lower doses of Kyprolis + Revlimid + daratumumab. We will announce the official opening of the trial and the addition of sites via the IMF's weekly e-newsletter *Myeloma Minute*, and via our website myeloma.org.

The IMF is also sponsoring two trials through its Asian Myeloma Network (AMN). Both trials are designed to meet the needs of patients in seven Asian countries/regions plus Australia and New Zealand, where access to treatments is quite limited outside the context of a clinical trial. Planned to launch later in 2017 are two randomized studies for patients with relapsed/refractory myeloma. The first of these is a phase II study of different Kyprolis doses in combination with cyclophosphamide + dexamethasone for patients who have had prior exposure to Velcade. This trial will enroll 50 patients in Asia and 50 patients in Australia and New Zealand. The second randomized trial, which will accrue 120 patients in Asia, is a phase III study comparing Pomalyst + cyclophosphamide + dexamethasone with Pomalyst + dexamethasone.

Venetoclax

AbbVie and Genentech's venetoclax (known as Venclexta® in the US and Venclyxto® in Europe) has been approved as a treatment for CLL patients with the 17p- chromosomal mutation, but is still experimental for patients with myeloma. Data presented on a monotherapy study and a combination study of venetoclax + Velcade at ASH 2016 demonstrated venetoclax's efficacy as a single agent when targeted to myeloma patients with the t(11;14) mutation, making it the first therapy for myeloma that successfully targets a particular genetic mutation. The study of venetoclax + Velcade showed efficacy across a wider spectrum of patients, with a 68% overall response rate (ORR) and a very good partial response (VGPR) rate of 40%.

The largest currently recruiting venetoclax trial is a randomized phase III study of venetoclax + Vd versus Vd for patients with relapsed/refractory myeloma who have either not yet had a proteasome inhibitor or are still sensitive to them. This study is currently accruing patients at 89 sites around the world, including the US, Australia, Brazil, Canada, France, Germany, Hungary, Ireland, Italy, Japan, Republic of Korea, Russian Federation, Spain, Taiwan, and the UK (NCT02755597). A second randomized study of venetoclax in combination with a proteasome inhibitor is the phase II study of venetoclax + Kyprolis + dexamethasone versus Kyprolis + dexamethasone for patients with relapsed/refractory myeloma who have had 1-3 prior lines of therapy and who are proteasome inhibitor-naive or -sensitive.

(continues on next page)

PROMISING CLINICAL TRIALS IN 2017 – CONTINUED FROM PAGE 5

It is currently recruiting patients at seven US sites (NCT02899052).

Small phase I trials of venetoclax in combination with an experimental antibody-drug conjugate (ABBV-838) and as monotherapy for patients with a range of hematologic malignancies are available in Australia (NCT02951117) and Japan (NCT02265731).

Anti-BCMA CAR-T cell therapy

Interest remains high in chimeric antigen-receptor T-cells (CAR-T cell), particularly in those designed to target the B-cell maturation antigen (BCMA), which is heavily expressed on the surface of myeloma cells. While this approach is known to be very effective, it can also trigger an immune system response called cytokine release syndrome (CRS), which, when severe, can be fatal. Six phase I anti-BCMA CAR-T cell trials are currently recruiting patients at sites in the US, Canada, Europe, and China. Sponsors of these trials range from GlaxoSmithKline (GSK2857916; trial identifier NCT02064387) to bluebird bio (bb2121; NCT02658929), to Memorial Sloan-Kettering Cancer Center (EGFR+/BCMA-41BBz CAR T-cell; NCT03070327), to the NCI (cyclophosphamide, fludarabine, and anti-BCMA CAR T-cells; NCT02215967), to the University of Pennsylvania (CART-BCMA, NCT02546167), to Southwest Hospital in Chongqing, China (anti-BCMA-CAR-transduced T-cells; NCT02954445). All but the GSK2857916 and bb2121 trials are single-center studies. GSK2857916 is enrolling patients at five US sites, one site in Canada, and one site in the UK, while the bb2121 study is recruiting patients at nine US sites.

Check-point inhibitors

Because of their striking efficacy in other formerly intractable cancers, hopes have been high that check-point inhibitors, which unleash powerful immune responses, would be equally effective in myeloma. Trials for relapsed and refractory myeloma patients pairing immunomodulatory agents Revlimid or Pomalyst with pembrolizumab were promising, but the results were not comparable to those in advanced melanoma, non-small cell lung cancer, or squamous cell cancer of the head and neck, indications for which pembrolizumab is now approved (with the brand name Keytruda®). Now the University of Michigan and University of Wisconsin are collaborating on a phase II trial using pembrolizumab for six months following ASCT along with ongoing Revlimid maintenance therapy in an attempt to increase response depth and duration (NCT02331368). The trial is open to patients with any stage of myeloma who are ASCT-eligible. The study is currently enrolling patients only at the University of Michigan Comprehensive Cancer Center and the Medical College of Wisconsin.

The other check-point inhibitor trial now being conducted for patients with myeloma is a phase III randomized, but non-blinded, study of combinations of nivolumab (brand name Opdivo®, approved for metastatic melanoma, non-small cell lung cancer, renal cell carcinoma, bladder cancer, Hodgkin lymphoma, and squamous cell carcinoma of the head and neck) + Empliciti (elotuzumab®) + Pomalyst + dexamethasone compared to Pomalyst + dexamethasone (Pd) alone. The trial, called "CheckMate 602" (NCT02726581), is for patients with relapsed/refractory myeloma. Subjects in the control arm (Pd) are allowed to cross over to the exploratory arm (nivolumab + Empliciti + Pd) if their disease progresses. 126 study locations will enroll participants in the US, Austria, Canada, the Czech Republic, Denmark, Germany, Israel, Italy, Mexico, Norway, Poland, Portugal, Puerto Rico, Spain, Sweden, and Switzerland.

Selinexor

Karyopharm Pharmaceuticals' experimental agent, selinexor, is the first in a new drug class that prevents the export of tumor suppressor genes from the nuclei of cancer cells. Approximately 2,000 myeloma patients have been studied thus far in clinical trials with selinexor. Recently, the FDA placed a hold on all trials with selinexor so that all trial-related documents, including the patient informed consent form, can be updated with a more complete list of serious side effects that have occurred during selinexor clinical trials. Side effects, which can be serious, include diarrhea, vomiting, and low blood counts. The trials will re-open if the FDA approves the updated information, which has already been submitted.

Two selinexor trials will be actively recruiting myeloma patients in 2017. The first of these trials is an expansion of the phase II STORM trial, which tested selinexor + dexamethasone in patients who were either quad-refractory (to Velcade, Revlimid, Kyprolis, and Pomalyst) or penta-refractory (to the preceding drugs plus an anti-CD38 monoclonal antibody). The expansion "phase IIb" part of this trial is accruing an additional 122 penta-refractory subjects (those who have exhausted all the most effective approved therapies). STORM is already recruiting at 23 sites in the US. In the coming months, additional trial sites will be opened in the US, as well as in Austria, Belgium, France, Germany, and Greece. For updates, keep checking matrix.myeloma.org and enter the clinicaltrials.gov identifier number NCT02336815 in the search box.

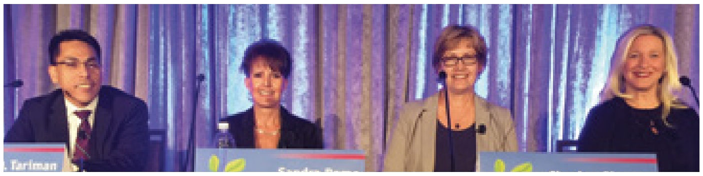
Pending FDA trial design approval, the BOSTON trial will soon be accruing myeloma patients in early relapse. BOSTON is a sequel to the 33-patient, three-arm, phase I STOMP trial, in which selinexor was evaluated in combination with Velcade, Revlimid, or Pomalyst in patients who had heavily pretreated relapsed and/or refractory myeloma. Data from STOMP demonstrated that the combination of selinexor + Velcade + dexamethasone (SVd) is both highly effective and well tolerated: for the 16 heavily pretreated patients in the Velcade + dexamethasone arm of the trial, the overall response rate was 77%; the patients who were not refractory to prior therapy with a proteasome inhibitor had a 100% response rate. The BOSTON trial, in which the plan is to accrue 362 patients who have had at least one prior therapy and randomize them to receive either Velcade + dexamethasone (Vd) or SVd. Both oral selinexor and subcutaneous Velcade will be given once a week, with dexamethasone given at 20mg the day of, and the day after, Velcade. Patients who progress on Vd will be allowed to cross over into the SVd arm of the study. If approved for accrual, trial sites are expected to open in the US and Canada in April; 17 countries in Europe are expected to begin accruing patients in June or July. **MT**

For more information, visit Myeloma Matrix 2.0: Smart Search at matrix.myeloma.org, a tool that makes it possible to search for clinical trials by drug name, drug type, trial phase, and disease status.

Around the World in Three Days

72 Hours, 5 Countries: A Snapshot of the IMF's Global Impact

From May 4th to May 6th, 2017, the International Myeloma Foundation (IMF) made its presence known. From Denver, Colorado, to La Hulpe, Belgium, to Heidelberg, Germany, to São Paulo, Brazil, and Reykjavik, Iceland, the IMF continues to expand our global reach.



Members of the IMF's Nurse Leadership Board presented the latest myeloma research and education at the Oncology Nursing Symposium.

The IMF's Nurse Leadership Board (NLB) symposium at the Oncology Nursing Symposium took place in Denver, Colorado, on May 4. Attended by 835 health-care practitioners, the NLB symposium focused on "Case Studies: Best Practices in Patient Care and Symptom Management." Presenters and NLB members used seven cases to illustrate recommendations throughout the course of the myeloma, from diagnosis to relapse management.

The program was a huge success and is a mainstay of the ONS Annual Congress's program.

Cut to: Across the Pacific Ocean to Heidelberg, Germany

On May 6th, Dr. Brian G.M. Durie presented at the 6th Heidelberg Myeloma Workshop in Germany. Global myeloma experts gathered to discuss everything from the basic science to the newest therapies. A major emphasis was on the search for a cure and, as part of that, Dr. Durie provided an overview of the Black Swan Research Initiative® (BSRI)®.

In addition, results of eight BSRI projects were presented: four from Heidelberg related to imaging, MRD testing, molecular and family studies; one from Australia on blood DNA testing; one by the Spanish team; and two from the US on MRD testing and long-survival analyses. The meeting was really a blockbuster for BSRI!

Close-Up on the 1st Belgian Patient & Family Seminar

IMF team members continue to simulcast our mission in Europe. On May 6th, 2017, the Belgian myeloma support group MYMU and the IMF held the first Patient & Family Seminar in La Hulpe, Belgium. Created in 2006, MYMU is the official French-speaking myeloma support group of Belgium.

The collaboration between the IMF and MYMU brought together more than 200 participants.

Reverse-Cut Back to the Western Hemisphere

During the first weekend of May, a team of myeloma doctors gathered in São Paulo, Brazil, for Janssen's annual hematology meeting – Haimatus.

Drs. Joseph Mikhael, Vania Hungria, Maria-Victoria Mateos, and Angelo Maiolino – all members of the IMF's research arm, the International Myeloma Working Group (IMWG)

Zoom in on the iStopMM Clinic in Reykjavik, Iceland

The much-anticipated iStopMM® project in Reykjavik, Iceland welcomed its first patients to its new clinic just a few days before the IMF swept the globe.

iStopMM team members gear up to use Next Generation Flow technology.

In addition, the facility is now fully prepared to conduct testing for myeloma. A Next Generation Flow cytometry machine arrived at the iStopMM® project lab on May 6, 2017.

Panning Out with a Broadcast from CNN

CNN's "Vital Signs" broadcast (taped in Iceland) aired on Saturday, May 6th, in the US. The segment featured an interview by Dr. Sanjay Gupta with IMF Chairman Dr. Brian Durie and iStopMM Principal Investigator Dr. Sigurdur Kristinsson. Dr. Gupta positions the study as an important part of the immense innovative science taking place on this tiny island nation, referring to iStopMM as an "unprecedented study," and Iceland, the scene of a "research revolution."

CNN Chief Correspondent Dr. Sanjay Gupta seated with Drs. Brian Durie and Sigurdur Kristinsson.

The CNN "Vital Signs" episode will air once again on June 10, 2017. Look to the IMF website (myeloma.org) for scheduled times for the broadcast.

The Closing Shot

IMF Chairman of the Board Dr. Brian Durie reflected on the number of activities the IMF was involved with, commenting, "I realize how lucky we are and how critical it is to be part of so many wonderful and important collaborations. It is all well and good to have brilliant ideas alone in the research lab. But only by linking arms with like-minded people – scientists, patients, caregivers, and advocates will we truly move forward to find the pathway to a cure." **MT**

Drug Access in a Time of Transition

The IMF InfoLine coordinators address your concerns

By Debbie Birns
IMF Medical Editor

Access to expensive medications has always been an issue for myeloma patients, particularly for Medicare patients taking oral medications. Each year, and this year in particular, January brings changes in healthcare coverage that cause uncertainty at best and problems at worst. This is the time of year for updates to insurance plan drug formularies – the official lists of which drugs are and are not covered and, if covered, at what percentage of the total cost. Patients who have rolled over their insurance policies from one year to the next may be surprised to find that a long-used medication now requires pre-authorization, or is covered at a lesser level, requiring a greater share of the cost on the patient's part, or is no longer covered at all. Sometimes patients have enrolled in new insurance plans that go into effect in the new year, only to discover that the new insurer does not cover their long-used treatment. When pharmaceutical companies increase the wholesale price of a needed drug, all or part of that cost increase is passed along to the patient. Whatever the reason for the coverage change, the new year often brings with it hurdles – if not complete barriers – to receiving affordable treatment.

Added to the general state of healthcare anxiety in 2017 are sudden cuts or lapses in funding for patient co-pay foundations, leaving patients without the resources they need to cover their share of the cost for medications. The IMF InfoLine has been receiving an increasing number of calls from distraught patients who are suffering from "financial toxicity" related to their medications.

After hearing from many myeloma patients and support group leaders that some formerly active co-pay assistance foundations no longer had money to help patients, the IMF InfoLine's Judy Webb set out to check with each of the major co-pay foundations to find out what was what. She discovered that at the beginning of 2017, three of the top foundations providing co-pay assistance to myeloma patients had no funds available for myeloma, while three others did. Subsequently, as more patients were driven to the resources, allocated funds dried up. As of this writing, none of the foundations has funds for myeloma patients, but Judy's research provided us with the following information:

- The presence or absence of funds for myeloma co-patients ebbs and flows without warning at the patient assistance foundations;
- Each foundation sets its own standards on income level to qualify for assistance;
- Help with co-payment varies based on which drug(s) the patient is taking;
- Patients who are uninsured may be eligible for more help than those with insurance;
- Patients whose healthcare is covered under a state or federal program may be ineligible for some forms of financial support;
- For Medicare patients, availability of assistance may depend upon whether the drug is covered under Part B (usually an infused drug given at the doctor's office or a clinic) or Part D (for oral drug coverage);
- Patients with commercial insurance have wide access to pharma-sponsored support programs that pay for most or all of the patient's out-of-pocket costs;
- Coverage for drug co-pay assistance may depend upon whether or not your doctor prescribed the drug according to the labeled indication.

Judy compiled an encyclopedia's worth of information about financial support programs for myeloma patients and presented that information in late January on a conference call for myeloma support group leaders across the US. Her bottom line was that there are many avenues to explore, including patient support programs through the pharmaceutical firms, various search engines sponsored by pharmacies to help patients find the cheapest drug prices, co-pay foundations, the State Health Insurance Assistance Programs (SHIP) run by Medicare, and of course the treating physician's office and/or the social worker at the hospital in your community.

Judy suggests the steps listed below if you are seeking financial assistance for your medication.

1. Call the patient support line of the pharmaceutical company or manufacturer of the drug you have been prescribed. Each company – and sometimes each drug within a company – has its own program, or may refer you to a foundation that has funds for their drug. Often this involves a telephone call by the patient or his/her representative to initiate the process. The pharmaceutical company representative will enroll the patient and perform an evaluation of benefits. If the first representative doesn't seem able to help you, ask to speak with a senior patient advocate. Information and/or confirmation will likely be needed from your doctor's office. The pharmaceutical company patient support telephone numbers are:

- **Celgene** – **Revlimid® (lenalidomide)**, **Thalomid® (thalidomide)**, and **Pomalyst® (pomalidomide)**, all are taken orally: 800-931-8691
- **Takeda** – **Velcade® (bortezomib)**, given subcutaneously or by IV: 866-835-2233; **Ninlaro® (ixazomib)**, taken orally: 844-617-6468
- **Janssen** – **Darzalex® (daratumumab)**, given by IV: 844-533-2792
- **Amgen** – **Kyprolis® (carfilzomib)**, given by IV: 855-669-9360
- **Novartis** – **Farydak® (panobinostat)**, taken orally: 844-327-9325
- **Bristol-Myers Squibb** – **Empliciti® (elotuzumab)**, given by IV: 844-367-5424

2. Call or email the patient assistance foundations to see if they have funds for myeloma patients and what their requirements are. Some require a doctor's prescription or confirmation before they will process your request. Below are the six co-pay foundations that have historically had funds for myeloma patients, but may be out of money at any given time.

- **CancerCare Co-Payment Assistance Foundatio**n:
  866-552-6729, *cancercarecopay.org*
- **LLS Co-Pay Assistance Program**:
  877-557-2672,
  lls.org/support/financial-support/co-pay-assistance-program
- **Patient Advocate Foundation (PAF) Co-Pay Relief Program**:
  866-512-3861, *copays.org*
- **GoodDays** (formerly the Chronic Disease Fund):
  877-968- 7233,
  mygooddays.org/en/for-patients/patient-assistance
- **Healthwell Foundation**:
  800-675-8416, *healthwellfoundation.org*
- **Patient Access Network Foundation (PANF)**:
  866-316-7263,
  panfoundation.org/index.php/en/patients/assistance-programs

These foundations calculate eligibility for assistance based on multiples of the federal poverty guidelines (usually 4 or 5 times the listed level). For your reference, see the table of the 2017 poverty guidelines for all states except Alaska and Hawaii. For Alaska and Hawaii, check aspe.hhs.gov/poverty-guidelines

3. There are websites and free apps for your phone or tablet that help patients find the lowest prices for their prescription drugs. They operate by pooling all the available information and finding the lowest prices each day, and refer patients to participating pharmacies with the best pricing and/or find drug discount coupons. *NEVER PAY FOR THIS SERVICE!* All legitimate entities offering this service are FREE:

- **GoodR**x: *goodrx.com*
- **WeRx**: *werx.org*
- **BlinkHealth**: *blinkhealth.com*

While you may not be able to find a cancer therapy through these apps and websites – usually only specialty pharmacies can prescribe cancer medications – it's certainly worth a try for the other prescription medications you use. If you get your myeloma medication through Diplomat Specialty Pharmacy, diplomatpharmacy.com or 877-977-9118, staff members there will provide assistance in trying to find third-party funding for your out-of-pocket drug costs. Pharmacists at cancer centers may also be able to help you.

4. In a category all their own are Needy Meds needymeds.org and Partnership for Prescription Assistance (PPA) pparx.org, non-profit organizations that help find available assistance programs or free drugs for those who qualify. The Needy Meds staff helps patients complete the application forms for assistance and works with physicians who must sign the forms. They also search for local prescription programs in each patient's area and offer counseling and help with all aspects of Medicare and Medicaid. PPA helps qualifying patients without prescription drug coverage get the medicines they need for free or nearly free.

5. The State Health Insurance Assistance Program (SHIP) medicare.gov/Contacts/#resources/ships is a free health benefits counseling service specifically for Medicare beneficiaries and their families or caregivers. SHIP is an independent state-run program funded by federal agencies. It is not affiliated with the insurance industry. Patients who receive Medicare benefits should use SHIP to make sure they are aware of all available options for drug assistance and are choosing the best plans for their needs during open enrollment. SHIP also helps with appeals for coverage if Medicare has denied a claim.

6. Your hematologist/oncologist and the social worker at your cancer center can also help find co-pay assistance. Not only are they specifically trained to deal with drug coverage issues, in some cases the co-pay foundation allows them to complete the required paperwork so you don't have to.

Please visit myeloma.org/patient-resources for the IMF's extensive list of patient resources. **MT**

2017 Poverty Guidelines for the 48 Contiguous States and the District of Columbia

PERSONS IN FAMILY/ HOUSEHOLD*	POVERTY GUIDELINE	PERSONS IN FAMILY/ HOUSEHOLD*	POVERTY GUIDELINE
1	$12,060	5	$28,780
2	$16,240	6	$32,960
3	$20,420	7	$37,140
4	$24,600	8	$41,320

** For households with more than 8 persons, add $4,180 for each additional person.*

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.

March is Myeloma Action Month!

By Robin Tuohy
IMF Senior Director, Support Groups

IMF President Susie Novis Durie first declared March as myeloma awareness month in 2009. Since then, the impact of this annual event has increased exponentially. For Myeloma Action Month 2017, our dedicated patient advocates united to elevate the visibility of the myeloma community by sharing their stories, educating the general public, and advocating for change. Many had a lot of fun doing so – dancing, singing, and tweeting along the way.

Sharing stories and actions

We were deeply moved and inspired by the many myeloma patients who shared their stories on the Myeloma Action Month website mam.myeloma.org. For example, Susan B. of Santa Fe, New Mexico, wrote about the many gifts that have emerged on her myeloma journey. Overwhelmed at first by the diagnosis of this complex disease in 2011, Susan fought her fear with action. She calls the IMF "my second family," and has successfully launched a myeloma support group in New Mexico, which now has more than 30 people who attend its monthly meetings. Susan shares that working with the "truly exceptional and courageous" support group members is yet "another gift." She is currently undergoing an autologous stem cell transplant,

Writing from Dana Point, California, Richard B. shared how "staying positive is the only way to go." Even though he lives in the US, he is still a citizen of the United Kingdom. Without insurance coverage in the States, he had to return to the UK for treatment. He says that the "hardest thing about the myeloma journey was being away from home." As he underwent treatment, he learned that myeloma is "very much a personal journey." He stresses the importance of doing "as much research as you can" and getting a second opinion.

Shan Lin Y. of San Francisco, California, shares how the San Francisco Bay Area Multiple Myeloma Support Group equips her "with very useful knowledge dealing with myeloma." Not long ago, when Shan Lin learned that her friend's brother had also been diagnosed with myeloma, she was "so happy that I had so much information to offer."

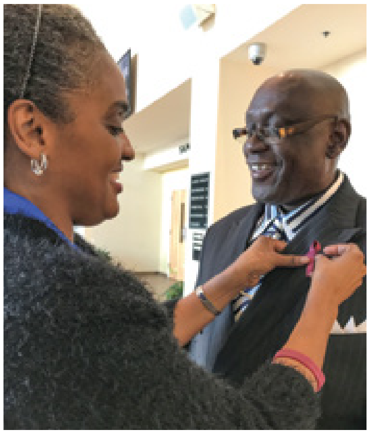
Tiffany Williams, a pediatric nurse practitioner, doctor of nursing practice, and assistant professor, was diagnosed with myeloma in 2013. Today, she is a co-facilitator of the Charleston Area Multiple Myeloma Networking Group. During MAM, Tiffany reached out to local TV affiliates to raise myeloma awareness. She was interviewed on the ABC affiliate WCIV Channel 4 as part of "Good Morning, Charleston," and on the FOX affiliate WTAT Fox 24 Morning News at 7. Tiffany did not stop there; at her local church, she distributed nearly 200 burgundy ribbons during a Sunday service.

These patients are just a few examples of how the IMF community works together to turn fear into hope and action.

Educating the public

As is the tradition with the Myeloma Action Month, the IMF ramped up our educational outreach.

Gearing up for March, the IMF hosted a Regional Community Workshop on February 25 in Seattle, Washington with more than 210 people in attendance. The large-scale IMF Patient & Family Seminar in Boca Raton, Florida kicked off the month with 226 attendees. The "Living Well with Myeloma" teleconference, hosted by Dr. Craig Cole, was accessed by more than 2,100 listeners. Finally, MAM educational events spilled over into the beginning of April with a Patient & Family Seminar in Short Hills, New Jersey, and two



1. Lizzette David (center) with members of the New Bedford Support Group and New Bedford City Council
2. Jack & Linda Huguelet of Walker County with their newly minted Myeloma Action Month Resolution
3. Tiffany Williams pins a burgundy ribbon on a fellow churchgoer.
4. Bill & Jenny Hack with officials of the City of Palm Coast, Florida

Regional Community Workshops, one in Virginia Beach, Virginia, and another in La Jolla, California.

IMF Chairman Dr. Brian G.M. Durie crafted a personal message aimed at US primary care doctors who may not be familiar with myeloma but are on the front lines of potential diagnosis. His letter spells out possible myeloma symptoms and other red flags to look for. We tallied more than 1,500 downloads of Dr. Durie's letter that patients shared with their local doctors.

Advocating for change

The IMF Advocacy team created a Federal Proclamation for Myeloma Action Month. H. Res. 148 was submitted to the U.S. House of Representatives, and an online action campaign was launched to urge representatives to sign the resolution.

In addition, advocates reached out to their local state and city legislators to declare March as Myeloma Action Month. The IMF recognizes the following members for their efforts:

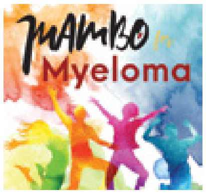
- David Hirsh, Charlotte, North Carolina
- Barbara Max, Richmond, Virigina
- Lizzette David, New Bedford, Massachusetts
- Michelle Keil, Anchorage, Alaska
- Dawn Tomil, Palm Beach County and the cities of Boca Raton, Delray Beach, Ocean Ridge, and West Palm Beach, Florida
- Brett & Brenda Johns, Jacksonville, Florida
- Sue Iwahashi and Joseph Diagonale, Delaware
- Bill & Jenny Hack, Palm Coast, Florida
- Darlene Jesse and Mark McCalman, Johnson City, Tennessee

In addition, patients sent letters to newspapers, and some were published, such as a letter by Tim Gavallas of Watertown, Connecticut.

Lifting our spirits

During Myeloma Action Month, our generous sponsors launched several programs, including the following:

- For every three-point basket made by players of the 17-time champion Boston Celtics, Takeda Oncology made a donation to the IMF. They also played an informational video about myeloma and the IMF at every home game. As a result of the Celtics' nearly 1,000 3-point shots sunk this past season, the IMF was awarded a $25,000 check on center court!
- Also sponsored by Takeda was the Music 2 Fight Myeloma playlist on Spotify. For every person who followed the inspirational playlists curated by members of the myeloma community, Takeda made a donation to the IMF.
- Takeda also donated to the IMF for each tweet that used the hashtag #Music2FightMyeloma.
- Country music star LeAnn Rimes sang live at Music2FightMyeloma to show her support for myeloma awareness.
- Donate a Photo, a mobile app, asked participants to upload pictures to raise funds for myeloma research. For every photo donated, Johnson & Johnson gave $1 to the IMF. For every 25 photos donated, 100 blood samples were able to be collected for myeloma research. This initiative runs until May 20, 2017.
- Sponsored by Amgen and Blood Counts™, social media users were asked to sign-up with their Twitter and Facebook accounts for a Myeloma Action Month Thunderclap. Once participants did so, a myeloma awareness tweet was sent automatically from all of their social media accounts simultaneously at 12 p.m. (Pacific) on March 24th. The total reach was over 450,000!
- Also sponsored by AMGEN and Blood Counts™, NPR's StoryCorps interviewed Michael Tuohy about how his myeloma diagnosis evolved into advocacy work on a national scale. A three-minute clip of the story can be heard at bloodcounts.com.
- For those who preferred to get physically active to take action, the Binding Site sponsored "Mambo for Myeloma." For every video of participants dancing that was uploaded to the Mambo for Myeloma site, the Binding Site made a donation to the IMF.



Music, sports, dance, photography, storytelling, and political advocacy were some of the many ways that the spirited fighters in the myeloma community took action this Myeloma Action Month. The IMF is grateful to all those who joined us to raise myeloma awareness and funds. March may be behind us, but you can still take Action at the IMF website: mam.myeloma.org. **MT**

5. On center court, Robin and Michael Tuohy display the $25,000 check awarded to the IMF as a result of the Boston Celtics' nearly 1000 3-point shots sunk this past season.
6. Country music sensation LeAnn Rimes sang live at Music2FightMyeloma to show her support for myeloma awareness.
7. Michael and Robin Tuohy await their interview outside the StoryCorps mobile bus at the 2016 American Society of Hematology Annual Meeting in San Diego.

NLB Plans to Publish New Best-Practices in Symptom Management and Adherence for Nurses

NLB members Tiffany Richards, Charise Gleason, Tracy King, Beth Faiman, and Donna D. Catamero pose in front of their poster presentation at the IMW in New Delhi, India

By Diane Moran
IMF Senior Vice President, Strategic Planning

The International Myeloma Foundation's Nurse Leadership Board (NLB) recently assessed existing nursing-specific, evidence-based guidelines for the treatment of multiple myeloma. The disease continues to undergo transformation, and each of its treatment regimens potentiate unique side effects that require effective symptom management. Nurses provide a vital link to side effect prevention, symptom management, and education for myeloma patients who are living with uncontrolled or inadequately managed symptoms. As the science of myeloma continues to change rapidly, the NLB recognizes the critical need to improve education for nurses who in turn educate patients and caregivers.

Addressing Unmet Needs

The NLB will soon publish consensus statements for best-practices in symptom management and adherence in myeloma, which will be a CE-accredited supplement to the *Clinical Journal of Oncology Nursing* (CJON), an official publication of the Oncology Nursing Society (ONS). It will provide a comprehensive, timely, and clinically-relevant reference for oncology nurses. Lead Editor, Beth Faiman, PhD, MSN, APRN-BC, AOCN, says, "This publication will provide concise, easy-to-understand recommendations that will set the standard for future nursing care of myeloma patients."

A related project, the NLB's poster presentation "Symptom Management and Adherence in Multiple Myeloma: A Plan to Disseminate Best-Practice Guidelines for Nurses" was recently featured at the 2017 International Myeloma Workshop (IMW) in New Delhi, India.

Conducting Research

As part of this project, members of the NLB conducted a series of teleconferences and face-to-face meetings to determine the following:

- whether critical disease-related and treatment-related symptoms are being addressed,
- whether or not existing guidelines are appropriate for myeloma patient care, and
- whether existing guidelines are sufficient to meet the educational needs of nurses caring for myeloma patients.

To research these criteria, NLB members conducted independent literature reviews on each topic.

Next Steps Toward Creating Best-Practice Guidelines

The literature reviews revealed that publications written by the NLB in 2008 (myelosuppression, venous thromboembolic events, peripheral neuropathy, steroids, and gastrointestinal issues) and in 2011 (renal, bone health, functional mobility, sexuality) must be updated. The research also determined that additional nursing guidelines for managing acute oncologic emergencies, fatigue, depression, and anxiety in the care of myeloma patients are lacking. In addition, there is a clear need to address newly approved drugs, combinations, and clinical indications.

The NLB will update best practices as needed, and create new guidelines to manage symptoms previously not addressed, so that nurses can help improve the outcomes of myeloma patients through education, side effect prevention and management, as well as adherence strategies. **MT**

The IMF Advocacy Team Reports on Federal and State Actions

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

National Institutes of Health Funding Alert for Fiscal Year 2018

Recent discussions regarding proposals that would cut the National Institutes of Health (NIH) and how these cuts could impact cancer research have been a flurry.

Republican and Democratic Congressional leaders recently reached a government funding compromise deal that will last until September. This compromise included $2 billion in new NIH funds, despite fears the agency would receive cuts. Specifically, the bill provides for an additional $476 million to the National Cancer Institute. These increased funds will greatly help Cancer Moonshot efforts.

Even though this increase is encouraging, this deal will only fund the government through September. When that time comes, we will have to fight for NIH funding for FY2018. Sadly, the budget proposal put forth by the Administration for FY2018 includes nearly $6 billion in cuts to NIH. Yet, the initial increase promises hope that Congressional leaders will continue to prioritize cancer research.

While the proposed FY2018 numbers would be devastating to research, individuals like you have some power to halt measures like these. The figure mentioned above is simply the President's proposed dollar amount for this agency. Congress ultimately has the final say on these numbers, which is why your voice matters. Join our advocacy team in fighting these cuts by visiting **advocacy.myeloma.org**. You will be directed to an online form, which allows you to express your opposition to these cuts.

IMF Applauds a New Bill to Improve Access to Oral Anticancer Drugs

On March 7, 2017, Congressman Leonard Lance (R-NJ-7th District) and Brian Higgins (D-NY-26th District) introduced the Cancer Drug Parity Act of 2017, H.R. 1409. A critical step toward improving access to anticancer treatment, this bill requires insurance companies to cover patient-administered and physician-administered anticancer drugs at the same cost to patients.

As the science surrounding cancer treatment improves, the number of chemotherapy drugs that patients can self-administer grows. In some cases, a self-administered drug may be the only drug proven to treat a specific disease setting.

"Insurance coverage for cancer treatments must keep up with innovation. Many patients are now using promising oral treatments but are forced to pay astronomical out-of-pocket costs or forgo treatment altogether. We have to fix this disparity in coverage so cancer patients are making health care decisions based on the best information, not which treatment fits into outdated guidelines," said Congressman Lance, the bill's sponsor and a member of the House Energy and Commerce Health Subcommittee.


Rep. Brian Higgins


Rep. Leonard Lance

To date, insurance coverage policies for these drugs have not kept up with scientific advances. Patients who rely on self-injectable drugs or chemotherapy pills find themselves spending as much as $50,000 a year on out-of-pocket costs because they receive the drugs from a pharmacy, rather than in a doctor's office.

The Cancer Drug Parity Act will dramatically improve the lives of cancer patients. Patients who previously could not afford these treatments will gain access to the life-saving effects of these drugs. Furthermore, by reducing the need to drive long distances for a doctor or nurse to administer treatment, patients living in rural areas will have more practical options.

"Cancer patients should be able focus on their treatment, instead of fighting for adequate coverage for life-saving medications," said Congressman Higgins. "The Cancer Drug Parity Act would ensure that oral chemotherapy treatments are covered at the same rate as more traditional intravenous (IV) and injectable treatments, so that insurance keeps pace with today's medical advances."

To date, 42 states and the District of Columbia have passed similar laws to increase access to these life-saving drugs. To expand this access, we need a federal law so that all cancer patients across all states can access both physician- and patient-administered chemotherapy.

The IMF and the Patients Equal Access Coalition ("PEAC") thanks Congressmen Lance and Higgins for their leadership, and urges Congress to pass the Cancer Drug Parity Act!

Please visit peac.myeloma.org for more information and a list of PEAC members. **MT**

AMN Spearheads First Clinical Trials in Myeloma to Be Conducted Throughout Asia

By Daniel Navid
IMF Senior Vice President, Global Affairs

With leading experts from China, Hong Kong, Japan, Korea, Singapore, Taiwan, and Thailand, the IMF's Asian Myeloma Network (AMN) continues to make strides in myeloma research and to increase patient access to novel therapies.

Myeloma incidence in Asia is beginning to approach that in the West and, due to its large population base, Asia is home to more myeloma cases than any other part of the world. It is encouraging that Asian patients and their families are becoming increasingly knowledgeable about myeloma and its treatment, thanks in no small part to the information provided by the IMF website and IMF's publications.

However, in most Asian countries patients are not yet able to benefit from the many new novel agents to treat myeloma that have recently come onto the market in the United States and other Western countries. These therapies either have not yet been approved in the Asian countries or, if approved, are too expensive for most patients to access, often due to limited health insurance schemes. This is a very serious problem for Asian patients, as well as a moral dilemma for health care providers and organizations.

The AMN is now making a modest contribution to resolving this problem, while also undertaking needed research on myeloma in Asia, by launching the first pan-Asian clinical trials for myeloma treatments already approved in the West. By means of these trials, hundreds of patients are able to access otherwise unavailable effective therapies while IMF is able to gather value data to improve treatment outcomes.

AMN001, the AMN's first clinical trial, led by Dr. Wee Joo Chng with data management provided by the Singapore Clinical Research Institute (SCRI) has recently been successfully completed. It followed up relapsed myeloma patients who had previous exposure to bortezomib and lenalidomide, and were then treated with pomalidomide and dexamethasone. The data demonstrated high response rates and treatment tolerance. A publication of this study is under way.

Four more AMN clinical trials are being launched in 2017:

- AMN002 – A randomized phase II study using different doses of carfilzomib with cyclophosphamide + dexamethasone for relapsed/refractory myeloma patients who had prior exposure to bortezomib. The project will involve 50 patients in Asia and 50 patients in Australia and New Zealand.
- AMN003 – A randomized phase III study comparing the use of pomalidomide + cyclophosphamide + dexamethasone to pomalidomide + dexamethasone in relapsed or refractory myeloma patients. The project will involve 120 patients in Asia.
- AMN004 – A phase II study examining the use of daratumumab in combination with thalidomide + dexamethasone in patients with relapsed and/or refractory myeloma. This study will involve 100 patients in Asia.
- AMN005 – A phase II study will examine the use of durvalumab, pomalidomide, cyclophosphamide, and dexamethasone in patients with relapsed and/or refractory myeloma. It will involve 50 patients in Asia as well as 50 patients in Australia or New Zealand.

Even more AMN trials are being considered for 2017, including a daratumumab study in the frontline setting and a venetoclax study to treat extramedullary myeloma.

All of these AMN studies and their results will be reviewed at the IMF's First Asian Myeloma Network Summit in Seoul, the Republic of Korea. This Summit will be held October 15–17, and we will report on it in the Fall 2017 issue of *Myeloma Today.* **MT**

Members of the IMF's Asian Myeloma Network (AMN) at the American Society of Hematology (ASH) annual meeting in December 2016

Patient and Healthcare Professionals Meetings in Europe

By Nadia Elkebir
IMF Director of Europe and the Middle East

The IMF's 2017 patient and physician education programs in Europe launched in February with a conference for hematologists/oncologists and a seminar for patients and family members in Budapest, Hungary. In Stockholm, Sweden, doctors and government representatives met at Bygget Fest and Konferens, and an IMF Patient & Family Seminar also took place at the Sheraton Hotel. Below is a recap of these events.

Hematologists/Oncologists Attend a Conference at the Science Academy in Budapest

Doctors, nurses, and other health-care practitioners gathered at the prestigious Science Academy of Budapest. Dr. Mikala Gábor opened with an emotional introduction. Following a presentation about the IMF, even though everyone understood the mission and objectives of the IMF, it was great to receive the acknowledgement and support from the audience in Hungary.

Dr. Jean-Luc Harousseau (University of Nantes, France) presented "How to Choose Multiple Novel Agents to Treat Multiple Myeloma." Then, Dr. Gergely Varga spoke about results of autologous stem cell transplants in 548 myeloma patients over 18 years of age. Dr. Harousseau said, "I'm impressed by the results obtained."

Finally, Dr. Váróczy László presented "Challenges in the Success of Autologous Stem Cell Transplant in Myeloma Patients," to which Dr. Harousseau commented, "I am happily surprised by the results of the Hungarian scientists. We should pay more attention to their work." In the coming years, Dr. Harousseau plans to attend more hematologist/oncologist conferences in Hungary.

Dr. Mikala Gábor, Dr. Váróczy László, Prof. Jean-Luc Harousseau

Second IMF Patient & Family Seminar in Budapest, Hungary

Budapest Patient & Family Seminar Presenters

On February 4, more than 220 participants attended the second IMF Patient & Family Seminar in Budapest, held in collaboration with MOHA (Magyar Onkohematológiai Betegekért Alapítvány). Patients, family members, and caregivers quickly filled the room and were abuzz with activity. MOHA's President, Ibolya Kéri, welcomed participants. Four presentations followed:

- Dr. Mikala Gábor presented "Myeloma and Treatment Options;"
- Dr. Szomor Árpád focused on "The Location of Stem Cell Transplantation in Myeloma Therapy;"
- Dr Váróczy László discussed "Prevention of Thrombosis in Patients with Myeloma;"
- And Dr. Modok Szabolcs spoke about "The Importance of Protecting the Kidneys."

OKLEVÉL

One of the most exciting moments of the seminar was when MOHA announced to the audience that the Hungarian government officially recognized MOHA as the fourth most influential foundation in the country and awarded them for their achievements.

First IMF Healthcare Professionals Meeting with Government Representatives at Bygget Fest and Konferens in Stockholm, Sweden

On March 17, the first IMF hematologist/oncologist meeting with government representatives at Bygget Fest and Konferens in Stockholm brought together more than 50 physicians and government representatives to address the issues of drug access in Swedenn. Swedes face the following concerns:

- The governing bodies use a calculation model of "cost efficiency" when considering drug therapies. This model does not focus enough on quality of life, nor does it take into account combination therapies.

(continues on next page)

MEETINGS IN EUROPE – CONTINUED FROM PAGE 15

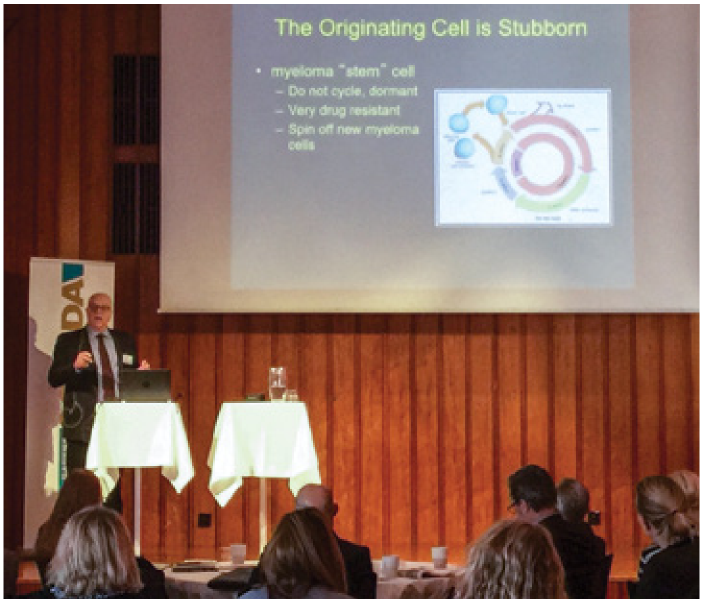
- There is a discrepancy between measured outcomes of clinical trials and patients' needs.
- Within the country, too many municipalities must negotiate individually on various drug prices. These negotiations take a long time, and patients sometimes lose access to drugs during this time.

Lise-Lott Eriksson, President of Blodcancerförbundet, opened the meeting and also introduced a patient, Else-Britt Jarfelt, who shared her story about lack of drug access, asking, "Will I ever have the latest and best medicine?"

Left to right: Lise-Lott Eriksson, President of Blodcancerförbundet, the Swedish patient group; Dr. Hareth Nahi of Karolinska University Hospital; Dr. Rafat Abonour of Indiana University Simon Cancer Center

Other event speakers included Dr. Hareth Nahi (Karolinska University Hospital) and Dr. Bo Björkstrand. Guest speaker Dr. Rafat Abonour (Indiana University-Simon Cancer Center) spoke on combination therapies and what they mean for myeloma patients.

From the TLV (the Dental and Pharmaceutical Benefits Agency of Sweden), Johan Lind-Martinsson asked, "How should we calculate the cost of these combination therapies?"



Dr. Rafat Abonour

The seminar closed with a positive discussion on how to make these drugs available to myeloma patients in Sweden, with commentary by the Swedish governmental bodies TLV and NT-Council (the Swedish council on new drug therapies).

First IMF-Blodcancerförbundet Patient & Family Seminar in Stockholm, Sweden

On March 18, the IMF and Blodcancerförbundet (the Swedish Blood Cancer Association) held their first joint meeting for patients and their families and caregivers in Stockholm. Nearly 180 people attended. The event's guest speaker was Dr. Rafat Abonour (Indiana University-Simon Cancer Center). He spoke about myeloma research and treatments in the US, which was translated to Swedish by Dr. Hareth Nahi (Karolinska Unversity Hospital).

Next, Dr. Nahi spoke on upcoming myeloma treatments and clinical trials in Sweden. In Sweden, nearly 600 people are diagnosed with myeloma each year, and Dr. Nahi pointed out the vital importance of clinical trials. Some of the obstacles Swedes face in obtaining these treatments include the TLV (the Dental and Pharmaceutical Benefits Agency of Sweden), which requires "evidence-based data" to approve certain drug therapies. Furthermore, Swedish hospitals and pharmaceutical companies face restrictions on how they can inform patients about these trials. Fittingly, Martin Irding, a former consultant to the TLV, made the closing presentation at the meeting.

Seminar audience in Stockholm

In Sweden, myeloma drugs are approved, but the rigid governmental structure and lack of knowledge about the efficacy of these drugs are not beneficial to patients. Both the Patient & Family Seminar and the Hematologist/Oncologist meetings were so productive that two meetings are planned in the cities of Stockholm and Göteborg in 2018. **MT**

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

Craig Cole: Doctor, Volunteer, Donor

By Randi Lovett
IMF Director of Development

While Dr. Craig Cole was studying at Michigan State University, his grandmother Vesta announced to the family that she had advanced-stage colon cancer. “I had no intention of going into medicine at the time,” Dr. Cole recollects. “She called and asked me to come to Detroit to drive her to her appointment, and I skipped classes for the day to take her.”

> *“...it’s my job to offer my patients options and to educate them...”*
> **– Dr. Craig Cole**

At the clinic, he was horrified to see how unprofessionally his grandmother was treated. The doctor’s mother was the receptionist, and she told Vesta that if she wanted to be seen on time, she’d have to buy something from a closet full of used clothes.

“My mother bought some shoes for $20, so my grandmother could be seen at her scheduled time,” he says. The doctor told my grandmother, “Your cancer is getting worse, and we’re going to start you on more chemo tomorrow.”

Despite her doctor’s bullying, Vesta refused treatment. After a painful battle, she wanted to spend her remaining days in hospice. Before her passing, Vesta said to Dr. Cole, “I really think you could do better than that.” His life then took a different direction.

The beloved, bow tie-wearing myeloma specialist, who cares for a full slate of patients, also makes time in his schedule to participate in IMF educational programs. “As a physician, it’s my job to offer my patients options and to educate them, but also respect that as informed and empowered patients, their autonomy and wishes supersede my authority.”

At a past IMF Regional Community Workshop, Dr. Cole looked around the room and “realized that for so many patients, this is it. The IMF is the only one reaching out to patients in communities like these.” Today, Dr. Cole is a supporter of the IMF through The Hope Society, a monthly giving club.

When asked about a possible cure, Dr. Cole said, “If you were to ask me 10 years ago about a cure for myeloma, I would have said ‘I don’t know if that’s really possible.’ But there has been so much velocity moving forward toward cure, that now it’s pretty absolute. I am certain that it’s going to happen.”

Dr. Cole has a picture of his grandparents in his clinic, 30 years after visiting the doctor with his grandmother. “When I get off track and frustrated, it reminds me that I went into this line of work to treat people better.”

We applaud Dr. Cole for his dedication as a healthcare professional, volunteer, and donor. **MT**

Tennis Pro Serves Up for the Myeloma Community

By Ilana Kenville
Member Events Associate

When Edward Curtis’ wife Carolyn was diagnosed with multiple myeloma in 2011, they had never heard of the disease. Seeking information and support, the Curtises attended an IMF Patient & Family seminar in Boca Raton, Florida. There, they met Anne Pacowta, the IMF’s Florida Regional Director of Support Groups, and they soon began an IMF Support Group in their hometown of the Villages, Florida.

> *“When you help somebody else, you help yourself.”*
> **– Edward Curtis**

In 2015, after four years of treatments, Carolyn Curtis lost her battle to multiple myeloma. During the four years of Carolyn living with the illness, Edward noted that the two of them made many trips back and forth to Shands Hospital in Gainesville, as well as other medical facilities, adding many miles to the car and lots of gas.

With this in mind, Edward Curtis put his tennis skills toward a good cause. Edward is a certified by The Professional Tennis Registry (PTR) and has been teaching tennis since 1996. He is a USTA Masters Tennis Ambassador and a member of the US Racquet Stringers Association.

Edward presently coordinates a Masters Tennis program and teaches a Basic Tennis clinic at Curtis Tennis in the Villages. He donates all the proceeds from the Masters Tennis program to purchasing gas cards for patients and their families who, too, have to travel back and forth for medical care.

Edward gives back to the myeloma community year-round, not only through his tennis lessons but also by organizing an annual fundraiser, Masters Tennis for Myeloma. Nearly 25 people participated in a round-robin tennis tournament at the most-recent event, raising about $3000 for the IMF.

When asked what motivates him to stay involved, Edward said, “The IMF gave us such helpful guidance. There were many late nights when Carolyn was on the phone with IMF staff members to learn about the available treatments for her myeloma. It is now time to give back.” As a former caregiver, Edward finds it “really rewarding to give back to patients and those involved with them.” **MT**

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– Chip Shanley,
monthly donor

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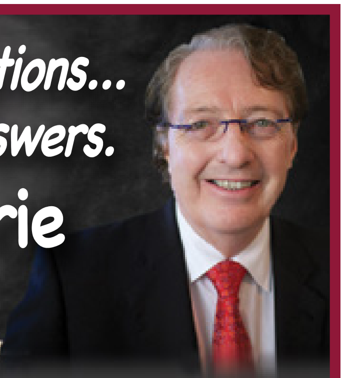

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2017 IMF Calendar of Events

June 2-6	53rd Annual Meeting of the American Society of Clinical Oncology (ASCO) – Chicago, IL
June 10	IMF Regional Community Workshop – Edina, MN
June 10	IMF Patient & Family Seminar – Paris, France
June 17	IMF Regional Community Workshop – Buffalo, NY
June 17-19	Global Myeloma Action Network (GMAN) Annual Summit – Madrid, Spain
June 19-22	8th Annual Summit of the International Myeloma Working Group (IMWG) – Madrid, Spain
June 22-25	22nd Congress of the European Hematology Association (EHA) – Madrid, Spain
June 24	IMF Regional Community Workshop – Dearborn, MI
Aug 18-19	IMF Patient & Family Seminar – Los Angeles, CA
Oct 6-7	IMF Patient & Family Seminar – Dallas, TX
Nov 4	11th Annual Comedy Celebration – Los Angeles, CA
Dec 9-12	59th 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).*
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