IMF's 10th Annual Comedy Celebration
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Myeloma Today

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IMF Presents Highlights of ASH 2016

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Each of the 687 myeloma-specific abstracts presented at ASH oral and poster sessions made a contribution to the expanding body of knowledge about myeloma.

Also in this issue:

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Dear Reader,

Goodbye 2016 – Hello 2017!

This past year was an incredibly busy one, and, most importantly – productive!

One of our most exciting accomplishments is the partnership we established with Iceland. The IMF is funding iStopMM (Iceland Screens Treats Or Prevents Multiple Myeloma), the first large-scale screening to identify and treat the precursor of blood cancer before disease develops. iStopMM is important as it will shed light on how we can stop myeloma at its earliest stage, before it progresses into cancer. To give you some perspective of the scale of this endeavor, Iceland has a total population of 340,000 people and, to date, 60,000 people over the age of 40 have already been screened!

Meanwhile, back at home, I'm very proud and humbled that the City of Los Angeles proclaimed March 30th as "International Myeloma Day" in recognition and in support of the advancements made toward a cure for myeloma. I have to say it was one of the best days in my professional career. Los Angeles truly is the City of Angels.

The IMF is very passionate about ensuring that myeloma patients have access to the drugs they need when they need them! We have been deeply involved in this effort. Our Advocacy Team has formed important alliances and has worked tirelessly across the country, empowering our members to become effective advocates. It's clear they are doing a great job, as the Oral Drug Parity Act has been passed in 42 states plus in the District of Columbia!

The IMF's mission is to find a cure for myeloma – and we are well on our way to accomplishing that. The International Myeloma Working Group (IMWG), the research arm of the IMF, held its annual Summit in Copenhagen, Denmark. More than 50 researchers from 22 countries participated in this important three-day meeting. To name a few, the lectures and discussions included the role of MRD detection, early vs. delayed transplant, new combinations and how best to use them, as well as cost and value in myeloma therapy.

The IMF's 17th annual Support Group Leaders Summit was held once again in Dallas, Texas. 102 group leaders attended, representing 69 groups. Topics included an update on the Black Swan Research Initiative®, how to communicate more effectively with your healthcare team, and a demonstration of the IMF's vastly improved clinical trial search tool, the *Myeloma Matrix: 2.0 Smart Search*! Presentations by our industry partners updated the group leaders on the latest developments in their products.

Patient education has always been first and foremost in my heart. I'm passionate about ensuring that patients are empowered to partner with their physician and help make treatment decisions that are right for them. I truly believe we've changed the landscape for myeloma patients and their families, who aren't afraid to talk to and even challenge their doctor. In 1994, we held the first – ever – Patient & Family Seminar. Since then, the IMF has held countless educational events all over the world. The IMF has always been a global organization and these patient seminars and workshops truly make a difference.

So, thank you to everyone who helped make 2016 a stellar year. Here's to working with all of you in 2017, and making it our best year yet!

Warm regards,

Susie Novis Durie

Susie Novis Durie, President

1. IMF Chairman Dr. Brian G.M. Durie with members of the iStoppMM research team
2. City of Los Angeles proclaims March 30th as International Myeloma Day
3. 2016 is declared the Year of the Advocate by the Global Myeloma Action Network

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Highlights of the 2016 Meeting of the

By Debbie Birns
IMF Medical Editor

The 58th annual meeting of the American Society of Hematology (ASH) brought together more than 20,000 attendees from around the world to share the latest research in blood-related diseases. This year's meeting took place December 3–6 in San Diego, California. Of the 5,000 abstracts accepted, 687 were presented at myeloma-specific oral and poster sessions. Each of these abstracts made a contribution to the expanding body of knowledge about myeloma.

Last year's ASH meeting came on the heels of an unprecedented trio of drug approvals (Darzalex®, Ninlaro®, and Empliciti®) by the US Food and Drug Administration (FDA), two of them myeloma's first monoclonal antibodies. The data from this year's meeting reinforced the value of these newly approved drugs in various disease settings and introduced promising results with other new agents. Attendees gained important insights in autologous transplant, learned about the optimal tests to help diagnose and monitor response, and delved into the results of immunophenotypic and genetic studies as a means to better understand which therapies are best used for which patients at which time points in the disease course.

Abstract numbers are provided in parentheses so you can read further. Go to ash.confex.com/ash/2016/webprogram and use the provided number to locate the abstract that piques your interest.

Disease Biology

A common thread among these studies is that the occurrence and pattern of genetic mutations in myeloma is far more complex than previously reported; much of that genomic complexity can be found as early as the smoldering stage.

- The large, international study of whole-genome sequencing (WGS) in myeloma reported the high prevalence of gene rearrangements at the smoldering stage and in myeloma at diagnosis and a "much more complex genomic landscape than previously thought" (#236). A German study of the evolution of asymptomatic to symptomatic myeloma concluded that "progression is, contrary to current thinking, in the vast majority of patients not driven by *de novo* acquired expressed clonal alterations," but instead can be "predicted by factors [that are] present upfront" (#235). A next-generation sequencing (NGS) study of the evolutionary pattern of myeloma over the course of treatment in 620 patients also revealed the presence of "multiple evolved clonotypes in a substantial percentage of diagnostic MM samples" (#238).
- Two studies (#237 and 373) confirmed that smoldering myeloma is a heterogeneous entity in which some patients are closer to monoclonal gammopathy of undetermined significance (MGUS) and others are closer to myeloma.
- Studying the immune expression of myeloma cells via flow cytometry is an effective and versatile tool, as evidenced by four abstracts:
  - BSRI® Next Generation Flow (NGF) was used to identify patients with an MDS-like [myelodysplastic syndrome, often a precursor to acute myeloid leukemia] phenotype that confers risk of treatment-related hematologic toxicity and poorer survival (#375).
  - NGF used after autologous stem cell transplant showed that patients who are MRD-positive have fewer circulating NK (Natural Killer) cells, demonstrating that the immune systems of these patients is still impaired (#378).
  - Immunophenotyping of plasma cells by flow cytometry was used to identify high-risk smoldering myeloma (HRSMM), perhaps establishing a new, effective testing method that will be universally accepted to determine which patients have HRSMM (#4451).
  - A Mayo Clinic study used flow cytometry to characterize the polyclonal (normal, not monoclonal) plasma cells of patients with relapsing myeloma (#1194). Those with 5% or more normal plasma cells, indicating a more robust immune system, had improved overall survival (OS).
- Underscoring the research linking obesity to myeloma, five abstracts focused on the presence of adipose tissue in the bone marrow and in the circulating blood of patients with MGUS and myeloma (#2055, 2075, 2077, 3262, and 4446).
- The DKK-1 gene associated with myeloma-related bone disease featured in two abstracts, one demonstrating that the presence of DKK-1 in the bone marrow of smoldering myeloma patients is a risk factor for progression (#4452), and the other demonstrating that strong expression of DKK-1 in pretreatment bone marrow biopsy samples is – fortunately for those smoldering patients who progress to active disease – associated with response to Velcade® (#3270).
- A French study of the infectious pathogens found in the monoclonal immunoglobulins of patients with MGUS and myeloma revealed that Epstein-Barr virus, hepatitis C virus, *h. pylori,* herpes virus simplex-1, varicella zoster virus, and cytomegalovirus may be involved in the pathogenesis of MGUS and myeloma.

Tests and Imaging Studies

Minimal Residual Disease (MRD) assessment, its significance, and the various ways to assess MRD remained important topics at ASH once again this year.

- A multi-center European study compared the use of NGF, Next Generation Sequencing (NGS), and PET/CT to assess MRD status in 100 patients who had achieved at least a 90% response to treatment (#377). Their findings were:
  - Almost half the patients who were treated for newly diagnosed myeloma and achieved remission were positive for MRD by NGS.
  - The proportion of patients who had achieved MRD negativity was highest during and after maintenance therapy; thus MRD negativity increases with treatment.

- Relapsed/refractory patients can present with non-secretory focal lesions without any sign of myeloma in the bone marrow aspirate (which is used for NGS and NGF). PET/CT is therefore crucial for the detection and monitoring of their disease.

- A Spanish study of a simplified NGS method to assess MRD status found that failure to reach MRD is a risk factor that is independent of other clinical and biologic variables, including the presence or absence of high-risk cytogenetics (#3283).

- A multi-center study of MRD testing with NGS found that patients with high-risk (HR) disease who do not achieve MRD negativity after their first autologous stem cell transplant (ASCT) have poor prognosis, while standard-risk patients who do not achieve MRD post ASCT tend to have continuing responses to treatment (#2064). For standard-risk patients, MRD testing provides a meaningful prognosis only during maintenance therapy. Like the Spanish study, this study found that molecular testing alone was not sufficient to detect residual myeloma cells in focal lesions, requiring the use of PET/CT or MRI.

"Liquid Biopsy"

- A series of studies looked at circulating myeloma/plasma cells (#800, 801, 996), circulating myeloma cell DNA (#3280 and 4430), and/or circulating myeloma cell RNA (#3286) in the peripheral blood as a "non-invasive biomarker for therapeutic monitoring" of myeloma patients. These analyses of tumor cells and their genetic material in the blood are collectively known as "liquid biopsy," and they will likely one day replace the bone marrow biopsy.

FISH Testing

- The limits of fluorescence *in situ* hybridization (FISH) testing is causing researchers to investigate better ways to assess cytogenetic abnormalities. A study performed at the Translational Genomics Research Institute (TGen) used NGS testing to detect genetic abnormalities within and beyond the range of FISH assays (#374). This new method identified 30 translocations missed by FISH. Another study found that combined genetic and gene expression profiling best identifies patients with ultra-high-risk disease (#4407).

- A study from Germany using FISH at diagnosis and at relapse after ASCT found that the number of high-risk patients was significantly higher after relapse than at diagnosis (#4415). The new cytogenetic abnormalities were 17p deletion and gain of 1q21; none of the relapsing patients developed new t(4;14), t(11;14), or t(14;16) abnormalities. Patients with t(11;14) at baseline were more likely to develop high-risk cytogenetic abnormalities at relapse.

Freelite® Assay

- Patients with light chain or low-secreting myeloma who rely on 24-hour urine collection for urine protein electrophoresis (UPEP) or urine immunofixation electrophoresis (IFE) to assess their monoclonal protein will be happy to know that a pair of studies, one French (#376) and one Japanese (#2074), verified that serum free light chain assay (Freelite, or FLC) responses have greater sensitivity and better concordance with clinical outcomes than those assessed by UPEP or IFE.

(continues on next page)

Members of the IMF International Myeloma Working Group participated in many events

1. Dr. Brian G.M. Durie and Dr. S. Vincent Rajkumar
2. IMF Satellite Symposium
3. Dr. Phillipe Moreau
4. Dr. Rafat Abonour and Dr. Jesús F. San-Miguel
5. Dr. María-Victoria Mateos

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- A study of a sub-group of patients who participated in the large IFM 2009 trial of RVD with/without transplant demonstrated that there was a very low incidence of free light chain escape, a term used to define patients who have no detectable free light chains at diagnosis but who produce them at relapse (#4428). The study authors conclude that the low frequency of light chain escape demonstrates that systematic monitoring by FLC of patients who do not have light chains at diagnosis is not necessary.

Hevylite® Assay

- A French study of the serum samples of 509 patients who were treated in the IFM 2009 trial found that in patients achieving poor or exceptional responses to therapy there was good concordance between the Hevylite test (heavy/light chain assay, or HLC) and standard response assessments (#3245). For patients achieving a VGPR (90% or better reduction in monoclonal protein), however, the HLC had better clinical correlation with outcome than did the tests indicated in the current International Myeloma Working Group (IMWG) criteria for response assessment. An abnormal HLC result after consolidation therapy also had greater concordance with MRD positivity.
- A Japanese study demonstrated that for patients with IgA myeloma, but not IgG myeloma, an abnormal heavy/light chain ratio after treatment is a robust predictor of shorter survival (#3254).
- A small study performed in the UK looked at the reconstitution of immunoglobulins after transplant by means of the HLC and FLC and found that normalization of the HLC and FLC ratios concords with MRD negativity as assessed by multi-parameter flow cytometry (#4633).
- A Spanish study of 309 stored serum samples from patients with MGUS performed HLC analysis of immunosuppression of the normal heavy and light chain pair for MGUS risk stratification (#4454). The results showed that suppression of the normal heavy and light chain pair by more than 50% predicts progression of MGUS to myeloma.

Hemodialysis

- A French randomized study, designed to compare two methods of dialysis in 94 patients with acute kidney injury from myeloma cast nephropathy (MCN), unequivocally demonstrated that in patients with MCN treated with Velcade, intensive high cut-off dialysis resulted in higher rates of renal recovery than standard high-flux hemodialysis (#978).

PET/CT

- Much research has come from Italy on the use of PET/CT in the diagnosis and monitoring of myeloma. The results of a prospective study of PET/CT at diagnosis after four cycles of induction therapy and prior to maintenance therapy in a subgroup of patients who participated in a large Spanish/Dutch treatment trial (#992) confirmed PET/CT to be a reliable predictor of outcome in newly diagnosed, transplant-eligible myeloma patients, no matter which treatment they received. Normalization of PET/CT before maintenance therapy was associated with a significant improvement in progression-free survival (PFS) and OS. It is the preferred imaging technique for evaluating and monitoring response to therapy.

Whole-body low-dose CT (WBLDCT)

- An IMWG study comparing the sensitivity and prognostic significance of WBLDCT and standard skeletal x-ray survey for the detection of bone impairment in monoclonal plasma cell disorders found that WBLDCT shows significantly more sites of bone destruction compared to conventional x-ray imaging, particularly in the iliac bone, thoracic and lumbar spine, and ribs (#4468). More than 20% of patients with smoldering myeloma based on conventional x-rays have active disease that needs treatment based on WBLDCT. This study lays the groundwork for a forthcoming IMWG consensus statement on WBLDCT as the new standard for detection of osteolytic lesions in myeloma.

Drug Trial Results

- An IMWG study of the natural history of patients who are refractory to both immunomodulatory drugs and proteasome inhibitors (PIs) concludes that outcomes for these patients demonstrate increasing drug resistance and decreasing response to sequential therapies (#4414). This study provides the perfect rationale for continuing research in new therapies for relapsed disease.
- Perhaps the biggest story in new drugs for myeloma came from a small Swiss study of the anti-HIV drug nelfinavir in combination with Velcade and dexamethasone for patients with advanced, PI-refractory myeloma (#487). The results among the 34 patients treated were stunning: an overall response rate (ORR; 50% or greater reduction in monoclonal protein) of 65%; for patients with high-risk cytogenetic abnormalities, a surprising 77%; for patients who had had five or more prior lines of therapy, 61%. Clearly there is a need for a larger confirmatory study of this novel combination.
- Venetoclax was tested in patients with relapsed/refractory myeloma both as monotherapy (#488) and in combination with Velcade and dexamethasone (#975). In the monotherapy trial, most responses were seen in patients with the t(11;14) genetic mutation and high expression of the BCL-2 family of proteins. The response rate in that group was 40%; the ORR among all study patients was 21%. Results in the phase I combination study with Velcade and dexamethasone were significantly better, with an ORR of 68% (44 of 65 patients) and a VGPR rate (drop in monoclonal protein of at least 90%) of 40%. Responses in this combination study were not different among patients with or without the t(11;14) abnormality. Adverse events were reported in 99% of patients, most frequently diarrhea, low platelet count, constipation, nausea, insomnia, and peripheral neuropathy.
- The checkpoint inhibitor pembrolizumab made a stunning debut in myeloma at last year's ASH meeting, and figured in one follow-up study presented this year (#490). The PD-1-blocking monoclonal antibody was combined with Pomalyst and dexamethasone in patients with relapsed/refractory disease. With a median follow-up of 10 months, the ORR was 56%, and among double-refractory patients it was 55%. While there were no infusion reactions, there were hematologic toxicities and autoimmune-mediated adverse events.
- Selinexor, the first in a new class of drugs that prevent the export of tumor suppressor genes from tumor cells' nuclei, was featured in four abstracts this year. The top two were the STORM study

of selinexor and dexamethasone in quad- and penta-refractory patients (penta-refractory to Velcade, Revlimid, Pomalyst, Kyprolis, and Darzalex) (#491) and the STOMP study of selinexor in combination with Velcade and dexamethasone (#977).

  - Selinexor + dexamethasone induced at least a partial response (50% or greater drop in monoclonal protein) in 21% of the penta-refractory patients, with a 33% clinical benefit response rate (responses of at least a 25% drop in monoclonal protein or higher). The ORR was 35% in patients with high-risk genetic abnormalities. Side effects were not insignificant, however, and included low platelet counts, fatigue, nausea, and weight loss.
  - Selinexor + Velcade + dexamethasone was tested in refractory patients as part of the STORM trial, which evaluated selinexor in combination with current therapies. 27 of the 33 patients in this arm of the trial had high-risk cytogenetics. The ORR to selinexor + Velcade + dexamethasone was 77%, including patients who were refractory to prior therapy with proteasome inhibitor (PI) Velcade or Kyprolis. The ORR among patients who were not refractory to a PI was 100%.

- A study of 30-minute subcutaneous administration of Darzalex in lieu of a lengthy intravenous infusion has defined a dose at 1800 mg and established its safety, efficacy, and equivalency to the IV infusion (#1149).
- The results of a small, first-in-human study of chimeric antigen-receptor T-cells (CAR T-cells) targeting the B-cell maturation antigen (BCMA) were widely anticipated (#1147). Data was presented on 9 patients, 8 of whom had serious side effects (caused by cytokine release syndrome) but survived. One patient achieved, and maintains, a stringent complete response. Further studies will help to better understand and manage the immune-mediated side effects of this groundbreaking therapy.
- An ongoing study of Empliciti + Revlimid + dexamethasone to treat patients with high-risk smoldering myeloma (HRSMM) is evaluating the effect of using immunotherapy early in the disease course, when patients' immune systems are still relatively unimpaired (#976). Data for the first 47 patients was presented, and thus far results have been excellent, with the therapy well tolerated. No patient has progressed to active myeloma during or after protocol therapy, but longer-term follow-up is needed to fully assess PFS.

Transplant

In recent years, the effectiveness of new therapies cast the need for autologous transplant into question. Emerging data reinforced by several abstracts from this year's ASH has solidified the role of transplant followed by Revlimid (lenalidomide) maintenance therapy as a standard of care for eligible patients, and addressed the questions of the need for consolidation therapy after transplant and the role of tandem transplant.

- The biggest myeloma story of this year's ASH was a late-breaking transplant abstract released just days before the meeting started. The 3-arm StaMINA study (#LBA-1), the largest randomized US transplant trial in myeloma, compared (1) single autologous transplant to (2) tandem autogolous transplant and to (3) autologous transplant followed by four cycles of Revlimid + Velcade + dexamethasone (RVD) consolidation therapy. Patients in all three arms of the study received maintenance therapy with Revlimid until disease progression. The results of this study were surprising: there was no statistical difference among the study arms in either PFS or OS after 38 months of follow-up. Trial participants were randomized so that there were equivalent numbers of high-risk and late-stage patients in each study arm, and an analysis of how these patients fared is being conducted. Study chair Dr. Ed Stadtmauer attributes the trial results to the use of continuous maintenance therapy with

(continues on next page)

1. IMWG Conference series: Drs. Brian G.M. Durie, Joseph R. Mikhael, and Sagar Lonial
2. Dr. Durie's Black Swan Research Initiative® presentation
3. Black Swan Research Initiative investigators

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Revlimid in each of the arms. Patients will be relieved to learn that a single auto transplant plus Revlimid maintenance is as effective as more intensive therapy with higher cost and more side effects.

- A European study of single versus tandem auto transplant in newly diagnosed myeloma patients that was stratified by patient risk status demonstrated the PFS benefit of tandem transplant largely for patients with high-risk and late-stage myeloma (#991). At 27 months of follow-up, there is no difference in OS between patients in the single or tandem transplant arms. Follow-up is ongoing.
- A study of the first use of Kyprolis (carfilzomib) + Revlimid + dexamethasone (KRD) induction before ASCT, and consolidation and maintenance therapy with KRD after ASCT in 76 newly diagnosed myeloma patients resulted in a stringent complete response (sCR) rate of 69% after consolidation (#675). Following an additional 10 cycles of KRD maintenance, the sCR rate was 82%. There were also high rates of MRD negativity among both high-risk and standard-risk patients.
- Three abstracts presented data that underlines the safety and utility of salvage transplant for relapsed disease (#2269, 4626, 4630), and three other abstracts highlighted the safety and efficacy of autologous transplant in older patients (#516, 678, and 3453). Perhaps these studies will encourage Medicare in the US and the European Medicines Agency in Europe to fund salvage transplant for older patients.
- Two presentations provided evidence that myeloma patients with renal insufficiency can safely undergo stem cell transplant, and that a significant proportion of them will regain kidney function with treatment (#994 and 4642). Stem cell transplant should not be withheld from patients with kidney dysfunction.

Plasma Cell Diseases Related to Myeloma

- Plasma cell leukemia can be a primary diagnosis or can arise as a late complication of myeloma. Abstracts from Korea (#4445) and Greece (#4490) report on the ability of novel therapy induction and ASCT to overcome early mortality in primary plasma cell leukemia and to improve OS.
- Patients with AL amyloidosis will be encouraged by the results of several new amyloid treatment studies. For the first time at ASH, there were so many positive amyloid studies this year that amyloidosis earned its own oral session.
  - A new monoclonal antibody, 11-1F4, was able to induce early and sustained organ responses in patients with kidney and heart amyloid deposition (#643). This new treatment was not only effective, but well tolerated.
  - Another monoclonal antibody, NEOD001, is also looking promising (#644 and 647). Given as a monthly IV infusion, NEOD001 was well tolerated and effective, with 53% of cardiac patients and 63% of renal patients meeting the requirements for organ response in an early trial. No patient on the study experienced disease progression. Further studies with this new antibody are ongoing.
  - A first-time trial of Kyprolis in previously-treated AL amyloidosis (#645) demonstrated efficacy even among PI-refractory patients. Caution was expressed about the frequency of cardiac, pulmonary, and renal toxicities in this fragile population that required careful monitoring and appropriate dose reductions.
  - The addition of Velcade to the old standard of care, melphalan + dexamethasone combination therapy, showed more frequent and more profound responses than the older therapy and prevented progression of cardiac dysfunction. This trial demonstrated that the combination of Velcade + melphalan + dexamethasone is the new standard of care in AL amyloidosis (#646).
  - A small (12 patients) study of Darzalex in heavily pretreated cardiac AL amyloidosis demonstrated that the monoclonal antibody is effective in amyloid as well as myeloma (#4525). Darzalex induced rapid and significant responses, paving the way for larger trials with this effective agent.

Miscellanea

Every year ASH presents us with some great tidbits that don't fall into any particular category, and this year was no exception:

- The Mayo Clinic expanded a previous small study that investigated the relationship between propranolol, a beta blocker used to treat heart arrhythmias and prevent heart attacks, and improved survival in myeloma patients. This larger study (#3306) confirmed that myeloma patients who take beta blockers have a reduced risk of death due to myeloma and lower overall mortality compared to myeloma patients who used other types of cardiac drugs or never used cardiac drugs.
- Another Mayo study determined that there is an increased risk of MGUS in first-degree relatives of patients with multiple myeloma (#4425), underscoring the influence of environmental and/or genetic factors that underlie this malignancy.
- Based on indications for FDA approval of Kyprolis as a second-line therapy, most patients are refractory to or intolerant of Velcade by the time they receive Kyprolis. A retrospective study examined the response to proteasome inhibitor therapy used in either of two sequences: Velcade followed by Kyprolis, or Kyprolis followed by Velcade (#4522). Response rates were similar in the two groups, but Velcade in the salvage setting not only induced higher response rates, but deeper responses as well.
- Patients who are dealing with a Revlimid-caused skin rash take heart: a Japanese study demonstrated that PFS and OS are significantly longer in patients who experience a skin rash during Revlimid therapy as compared to those without skin rash (#4532).
- An Icelandic study examined the effect of dietary patterns in early life, midlife, and at study baseline on the risk of MGUS (#3257). They determined that early life adherence to the "old traditional Icelandic diet" of salted/smoked meat and fish, blood and liver sausage, rye bread, milk, oatmeal, and potatoes was associated with decreased risk of MGUS later in life, while high intake of meat and milk and low intake of fish in later life was associated with increased risk of progression from MGUS to myeloma or other lymphoproliferative diseases. If you have MGUS, it's time to quit the steak house and hit the sushi bar! **MT**

Treatment Advances in Multiple Myeloma: Expert Perspectives on Translating Clinical Data to Practice

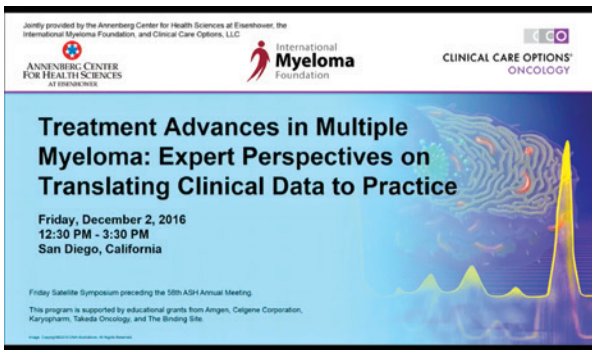
58th annual meeting of ASH kicks off with the IMF's Friday Satellite Symposium

The IMF Satellite Symposium, "Treatment Advances in Multiple Myeloma: Expert Perspectives on Translating Clinical Data to Practice," took place on December 2, preceding the 58th annual meeting of the American Society of Hematology (ASH). The Symposium featured leading international myeloma experts Drs. Brian G.M. Durie, S. Vincent Rajkumar, Shaji Kumar, Bruno Paiva, Jesús F. San-Miguel, and Phillipe Moreau.

The provocative program included interactive case discussions by the panel of renowned myeloma experts who provided varied perspectives on new data, guideline changes, and recommendations for management of patients that can affect therapeutic decisions faced by clinicians treating myeloma. Topics include:

- Diagnosing myeloma: When should treatment be initiated?
- Should we be using risk-adapted therapy in clinical practice?
- How should we use maintenance for patients in clinical practice?
- How do you choose the best treatment regimens for relapsed/refractory disease?
- Where are we now and where are we going with the care of patients with mm?

The IMF Satellite Symposium was livestreamed; the video and accompanying slides are available for viewing on the IMF website at **myeloma.org/videos/ASH-Satellite-Symposium-2016**. **MT**



Generous Donations Help Fund 2017

On December 3rd, the IMF awarded its 2017 Brian D. Novis Research Grants. The grant presentation ceremony was held during the 58th annual meeting of the American Society of Hematology (ASH) in San Diego, California.

For 22 years, the IMF has funded the most promising research in the field of myeloma by leading investigators from institutions around the world. The IMF is proud to support these important projects. In 2017, three Senior Research Grants are being funded at $80,000 each, and five Junior Research Grants are being funded at $50,000 each. These grants are made possible through generous donations from private individuals as well as the proceeds from the IMF's Member Fundraisers program. We are eternally grateful to all who support the Brian D. Novis Research Grants that move us closer to a cure.

The reception was attended by 135 enthusiastic guests who filled the reception hall to capacity. The event created a perfect setting for interaction between the award-winning researchers and the donors who help fund their projects. In several cases, this was the first opportunity for a grant recipient to meet and talk with myeloma patients.

Four of the patients in attendance shared their stories with the guests. In addition, wildlife and conservation filmmaker Hardy Jones sent his speech via video. His powerful "we are all interconnected" message included the story of his discovery that the dolphins he worked with had myeloma. Hardy then learned of his own myeloma diagnosis. Pat Harwood touched everyone's hearts as she spoke about her determined 20-year journey of living with myeloma, despite being widowed 10 days out of transplant and becoming the only parent to her son. Pat's "myeloma doesn't define me" attitude resonated throughout the room. Next, Brian Strickler offered his sincere gratitude to all who are working so hard towards a cure, giving him and other newly diagnosed myeloma patients hope for "a path forward."

Hardy Jones

Patricia Harwood

Brian Strickler

Yelak Biru

Susie Novis Durie, Dr. Robert A. Kyle, and Dr. Karin Vanderkerken

Yelak Biru concluded the patient stories with a moving speech that did not leave a dry eye in the house. Diagnosed while in his first semester of graduate school and newly married, Yelak's story "is still in the making" 21 years later.

As always, the names of the grant recipients as well as the IMF members who are funding each research project were announced by Dr. Robert A. Kyle. The impact upon the researchers of meeting the people who made their work possible was profound, and Dr. Vanderkerken's remark that meeting myeloma patients will fuel her to work harder was echoed by the other grant recipients.

Also in attendance at the event was Kristi Willette of the Willette Charitable Foundation. Earlier that week, she presented Susie Novis Durie (IMF President) and Dr. Brian GM Durie (IMF Chairman) with the first installment of a three-year grant in the amount of $300,000 to support the IMF's Black Swan Research Initiative® (BSRI®) led by Drs. Durie, San Miguel, and Rajkumar. We're so grateful to Kristi and the Willette Charitable Foundation for their vision and continued generosity in support of myeloma research.

"I never doubted that bringing the myeloma community together will lead to a cure, and a cure is right around the corner." said Susie Novis Durie. **MT**

Dr. Bruno Paiva, Kristi Willette, Randi Lovett, Susie Novis Durie, and Dr. Brian Durie

Brian D. Novis Research Grants

2017 Brian D. Novis Senior Grant recipients

Djordje Atanackovic, MD
Huntsman Cancer Institute, University of Utah
Salt Lake City, UT
Anti-CD229 chimeric antigen receptor (CAR) T-Cells for the treatment of multiple myeloma

Felipe Prosper, MD
Foundation for Applied Medical Research (FIMA)
Pamplona, Navarra, Spain
Deciphering the role of eRNAs in the pathogenesis of multiple myeloma

Karin Vanderkerken, PhD
HEIM Myeloma Center, Vrije Universiteit Brussel
Brussels, Belgium
Targeting residual, dormant cancer cells in multiple myeloma: a new approach

2017 Brian D. Novis Junior Grant recipients

Neelam Bhardwaj, PhD
Huntsman Cancer Institute, University of Utah
Salt Lake City, UT
Generation and validation of a monoclonal antibody against VISTA for the immunomodulatory therapy of multiple myeloma

Arnold Bolomsky, PhD
Wilhelminen Cancer Research Institute,
Wilhelminenspital
Vienna, Austria
Targeting of BMI-1 as novel treatment option in multiple myeloma: Examination of PTC-028 as putative anti-myeloma drug in vitro and in vivo

Jesus Delgado-Calle, PhD
Indiana University School of Medicine
Indianapolis, Indiana
Bone/bone marrow-targeted inhibition of Notch signaling in combination with glucocorticoid therapy as a novel approach to treat multiple myeloma

Geoffrey M. Matthews, PhD (second-year funding)
Dana-Farber Cancer Institute
Boston, Massachusetts
Treating multiple myeloma through inducing degradation of BET bromodomain proteins

Alessandra Romano, MD, PhD
Ospedale San Raffaele
Milano, Italy
Exploiting IDO1-GCN2-p62 axis in multiple myeloma microenvironment to trigger myeloid derived suppressors cells

Dr. Robert Kyle, Kim Bradford, and Dr. Djordje Atanackovic.
Kim is supporting Dr. Atanackovic's research in honor of her husband Rob Bradford through the annual Coach Rob's Golf Tournament in Florida

Kent & Candice Oliver, pictured with daughter Annie, are supporting Dr. Romano's research with proceeds from their Laughs 4 Life comedy event in Mississippi

Sheree and Ron Pask are supporting Dr. Vanderkerkin's research with proceeds from their Miracles for Myeloma 5K in New Jersey

Dr. Alessandra Romano

Arnold Bolomsky, PhD

Dr. Karin Vanderkerken

Dr. Jesus Delgado-Calle

Geoffrey M. Matthews, PhD

Dr. Felipe Prosper

2nd International IMF-EuroFlow Workshop

"When it comes to MRD testing, the mantra is 'adopt not adapt.'"

– IMF Chairman of the Board Dr. Brian G.M. Durie

The International Myeloma Foundation and the EuroFlow Consortium hosted the Second Annual MRD Consortium in Myeloma on October 10–11, 2016. Held in Salamanca, Spain, this workshop provided a forum for the update and discussion of the recent advances in myeloma minimal residual disease (MRD) monitoring. The meeting specifically focused on the innovative Next Generation Flow (NGF) approach developed through the collaborative work from the Black Swan Research Initiative®.

The meeting kicked off with the IMF's Chairman of the Board Dr. Brian Durie and the University of Salamanca's Dr. Alberto Orfao welcoming the 124 attendees to this ancient city in northwest Spain. The scale of the event was global, with eager participation from more than 50 institutions representing 25 countries.

The role of MRD in the treatment of myeloma

Dr. María-Victoria Mateos (University of Salamanca) set the stage with the first session that outlined all the new myeloma therapies that will potentially help patients achieve MRD-negative status. During this session, Dr. Brian Durie emphasized the central role of precise MRD testing needed to monitor disease at low levels. Dr. Bruno Paiva reiterated this point, echoing that MRD-negative is an endpoint to achieve the best outcomes for myeloma patients.

The NGF test is being adopted in labs across the globe

How does Next Generation Flow work?

The centerpiece of this two-day workshop was Dr. Alberto Orfao's presentation, "Next generation flow for high-sensitive MRD monitoring in multiple myeloma: an update." Dr. Orfao explained that the ideal antibody "cocktail" necessary to detect myeloma has been determined over the past three years of work. This work identified that the 8-color (antibody) 2-tube method is a very robust myeloma detection panel designed to replace the currently used, less sensitive methods.

Since the 2014 Flow Cytometry workshop, questions emerged about these antibodies and the potential of the NGF method. Over the past two years, test centers have discovered a method that is standardized, reproducible, and remarkably sensitive. But there are still many questions that need to be answered. The focus now is on how to adopt the method using the new multidimensional computer software approach that will automatically select myeloma cells within the bone marrow and/or in blood samples.

Powerful automated computer program

Members of the audience literally gasped when Georgian Grigore of the Salamanca research team demonstrated how simple this automated computer program is for NGF. It will produce a complete printout that shows the number of myeloma cells present at a sensitivity level of 10^{-5} or 10^{-6}, or one myeloma cell in a million cells. Subsequently, attendees took part in hands-on learning about both the antibody methods and computer software – again resulting in a series of discussions and breakout groups.

Advantages of NGF in myeloma testing

So what makes this NGF method so valuable? First, it is sensitive and robust. Impressive correlations with both remission duration and myeloma patient survival have validated the standardization of this NGF method. With a confirmed negative reading, the initial study population has experienced zero relapses within the last two years.

The NGF method is also broadly available and cost-efficient, even for busy labs that now have access to the new software program. Exciting new uses of this new flow cytometry method are testing the blood (in addition to the bone marrow) and immune monitoring.

Diagnostic and prognostic value

Using the NGF method to test the blood reveals two important aspects of myeloma: biology at the early MGUS and SMM stages, and biology at the point of relapse. In both MGUS and SMM, myeloma cells can be detected in the blood. The numbers and nature of the cells will prove to be important diagnostic and prognostic factors.

At relapse, for example, from an MRD-negative to an MRD-positive status, myeloma cells can be measured in the blood. Even though testing cannot be switched over to a standalone blood test yet, the need for bone-marrow testing may eventually be reduced.

Not only are testing methods being streamlined with NGF, but immune monitoring is also advantageous with this method. As Dr. Orfao explained, the NGF method can assess a patient's immune status as MRD-negative or MRD-positive. While it is known that patients with a MRD-negative status can have a good recovery of immune function, a subset of patients who are MRD-positive may also still have favorable immune features. This subset of patients can do extremely well for many years.

Global potential and next steps

NGF is an excellent test that is both sensitive and robust and has sparked enthusiasm globally to adopt the method. The future holds many ongoing research opportunities for NGF, and patients may soon have easy access to it in the US and around the world.

The IMF extends our gratitude to the research teams in Salamanca and Pamplona, who have worked so hard on this. And thanks, as well, to the IMF team and Prof. Jesús San Miguel, one of the founders of the Black Swan Research Initiative®. **MT**

Understanding Statistics in Medical Journal Articles

The IMF InfoLine coordinators answer your questions

By Debbie Birns
IMF Medical Editor

Q. I make a point of reading myeloma-related articles in medical journals, but I have a hard time understanding statistics. Can you help me interpret this information?

A. In the Summer 2016 edition of *Myeloma Today*, the InfoLine column was dedicated to the art of reading medical journalism, offering some tips on how to separate facts from hype in stories that tout a miracle cure or a revolutionary new treatment. Now we turn to the art of reading articles from peer-reviewed medical journals, and how to wade through the jargon of medical statistics to get to the bottom line: Does a particular treatment actually show benefit or not?

Dr. Brian G.M. Durie addressed this issue, focusing on the meaning of p-value, in a March 2016 segment of *Ask Dr. Durie* (visit askdrdurie.myeloma.org). Dr. Durie, like all researchers who conduct and publish results from clinical trials, must use statistical methods to establish the reliability and authenticity of data. Here is an excerpt from a recent article about the VRd versus Rd study published by Durie *et al*. in the pre-eminent hematology journal, *Blood**:

> *The pre-specified significance level of 0.02 was reached in the log rank testing. The stratified hazard ratio (HR) was 0.735 (96% Wald confidence interval: 0.573, 0.941), and the one-sided stratified log rank p-value for PFS (VRd vs. Rd) was 0.00995. The OS was also improved for VRd vs. Rd with HR = 0.666; two-sided log-rank p-value = 0.0114.*

The publication of the SWOG 0777 study of VRD vs. Rd in newly diagnosed myeloma was a highly significant event, providing long-awaited documentation that the three-drug VRd combination of a proteasome inhibitor (Velcade®, bortezomib), an immunomodulatory agent (Revlimid®, lenalidomide), and a steroid (dexamethasone) is more effective than the doublet therapy of Revlimid + dexamethasone (Rd). This study has had, and will continue to have, a major impact on treatment choices around the globe. In presenting the data that demonstrates the significant benefit of adding Velcade to Rd, the authors used abundant and careful statistical methods: Log rank testing (one-sided and two-sided), Hazard Ratio (HR, stratified and not), Confidence Interval (CI), and p-value. (Are you non-statisticians and non-mathematicians lost yet?) Following is a brief explanation of some statistical terms used in the above and other journal articles that may enable you to boldly go where few patients and caregivers (and InfoLine columnists) have gone before.

Long-rank test: A log-rank test is the most popular method of comparing the survival of groups, one which takes the whole follow-up period into account instead of looking at a single time point. An alternate test is the generalized Wilcoxan (Breslow) test, which places emphasis on the early part of the survival curves. The log-rank test puts greater emphasis on the later points of the survival curves and is widely used in clinical trials to establish the efficacy of a new treatment in comparison with a control treatment when the measurement is the time to an event. In the above study, the events measured were progression-free survival (PFS, or the time until relapse) and overall survival (OS, or the time until death). Log-rank tests can be one-sided or two-sided (also called "one-tailed" and "two-tailed"). A one-sided log-rank test will test whether the mean result is *either* significantly greater than *or* significantly less than a given value. A two-sided log-rank test tests whether the mean result is significantly greater than *and* significantly less than a given result. Dr. Durie *et al.* provide both types of log-rank tests to ensure that they have covered all their statistical bases in assessing the differences in PFS and OS with VRd as compared to Rd.

P-value: The "p" in p-value stands for "probability." It is used as a measure of the likeliness that a hypothesis is true. The hypothesis in a clinical trial, for statistical purposes, is usually that there is no difference between two treatments. This is known as the "null hypothesis." The p-value gives the probability that any observed difference between the groups studied could have happened by chance. A p-value of 0.5 means that the probability of a difference this large or larger having happened by chance is 0.5 in 1, or 50:50. A p-value of 0.05 means that the probability of a difference this large or larger having happened by chance is 0.05 in 1, or 1 in 20. The lower the p-value, the less likely it is that the difference in results happened by chance, and so the higher the significance of the finding. P=0.01 (1 in a 100) is considered to be "highly significant." In the VRd vs. Rd article, the p-value for the improved PFS with VRd is very low indeed – 0.00995 – meaning that the odds are even less than 1 in 100 that VRd improved PFS by chance, rather than because of its efficacy. The p-value for OS with VRd is almost as low – 0.0114 – just slightly greater than 1 in 100 that the result could have happened by chance, so the improved OS with VRd is also highly significant.

Stratified: A stratified sample is one that has been split into a number of sub-groups. In the above example, the data were stratified by the stage of each patient's myeloma and whether or not the patient intended to have an autologous stem cell transplant after induction therapy. In other myeloma clinical trials, patients may be stratified by age, by number of prior treatments (in the example above, all patients were newly diagnosed, so none had had any prior treatment), or by

(continues at bottom of page 20)

INTERNATIONAL MYELOMA FOUNDATION

10th Annual Comedy Celebration

honoring **Loraine Alterman Boyle**

benefiting the **Peter Boyle Research Fund** and supporting the **Black Swan Research Initiative®**

IMF President Susie Novis Durie and IMF Chairman Dr. Brian G.M. Durie with Event Chair and the night's honoree, Loraine Alterman Boyle, and Amy Boyle. Ray Romano, comedy legend and the evening's amazing host, has taken part in each of the ten annual Comedy Celebration events.

On Saturday, November 5, 2016, Susie Novis Durie, Founder and President of the International Myeloma Foundation, and Dr. Brian Durie, Chairman of the Board launched the 10th Annual Comedy Celebration at the Wilshire Ebell Theatre in Los Angeles. They opened the night with a map of the Black Swan Research Initiative® projected on screens, showing the 33 countries where the initiative is now active. They then welcomed our gracious supporters, paid tribute to the memory of Peter Boyle, and expressed gratitude to the event's Chair, Loraine Alterman Boyle.

Since the inception of the event ten years ago, Loraine Alterman Boyle has spearheaded efforts to raise nearly $6 million dollars in support of the IMF's research programs, including the groundbreaking Black Swan Research Initiative. While Loraine was humble about her achievements, her daughter Amy perhaps put it best when she said that after the passing of Loraine's husband Peter Boyle to multiple myeloma, Loraine could have easily chosen to forget that the disease myeloma existed. Instead, she has dedicated her time, energy, and passion to continue to contribute to the myeloma community. Amy Boyle also pointed out that even though it has been ten years since her father's passing, the Boyle family is now welcoming a new addition – Amy's sister will be having a baby this winter!

With this, the comedy began with the return of hilarious emcee Ray Romano. Ray not only expressed his love for the memory of Peter Boyle, but also paid tribute to the late Doris Roberts who passed in April 2016. Ray proclaimed himself to be a TV orphan now and offered himself up to the crowd for "adoption." The night continued with comedy greats Fred Willard, JB Smoove, Jeff Garlin, Dom Irrera, Larry Miller, Bill Burr, and Kevin Nealon. The evening concluded with a special musical performance by Oscar-nominated songwriting couple Michael McKean and Annette O'Toole.

The stars shine bright at the Comedy Celebration evening of stand-up comedy and live music

Host Ray Romano was joined by comedians Bill Burr, Jeff Garlin, Dom Irrera, Larry Miller, Kevin Nealon, JB Smoove, Fred Willard, and special musical guests Annette O'Toole and Michael McKean.

(continues on next page)

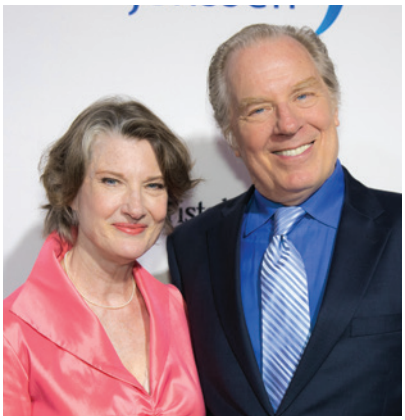
COMEDY CELEBRATION – CONTINUED FROM PAGE 15

On the red carpet

Lanny Kim, Howard Hesseman, Loraine Boyle and Peter Gallagher, Mark Hamill of *Star Wars*, Annette O'Toole and Michael McKean, Lesley Nicol of *Downton Abbey*, Shadidah Omar Brooks and JB Smoove, and Alex Meneses.








The event – complete with red carpet and paparazzi – also featured a silent auction with such stellar items as house seats to see Hamilton at the Pantages Theatre in Los Angeles, an autographed electric guitar signed by legendary musician Joe Walsh with a Skype lesson from the man himself, and a vintage *Star Wars* poster signed by Mark Hamill, who was in attendance at the event. Following the night's comedy, a post-show party kicked off with a live swing band and dancing for VIP ticket holders.

Beginning in 2007, the idea for an Annual Comedy Celebration was sparked by event Chair Loraine Alterman Boyle, who reached out to IMF co-founders Susie Novis Durie and Dr. Brian Durie with a profound desire to make a difference in the lives of people coping with myeloma. Loraine established the Peter Boyle Research Fund, calling upon Peter's friends to join her in raising awareness and money to find a cure. They answered her call without hesitation, and have been donating their time and talents to the cause ever since.

In ten years, the Annual Comedy Celebration has raised over $6 million for the Peter Boyle Research Fund. This year's presenting sponsors included Amgen, Bristol-Myers Squibb, Celgene, and Takeda Oncology. In addition, many other corporate and individual sponsors supported the event through sponsorships, silent auction contributions, and participation in the evening's commemorative tribute journal.

The Annual Comedy Celebration is the IMF's most successful annual fundraiser. On behalf of the International Myeloma Foundation, our esteemed Board of Directors, Scientific Advisors, and the patients we serve, thank you all for supporting this tremendous event! **MT**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1. IMF Director Andrew Kuzneski with Event Chair Laurie Kuzneski
2. IMF Director Yelak Biru with Loul Haug and IMF Chairman Dr. Brian G.M. Durie
3. IMF Director Jason Katz with Sharon Katz and Susan Katz
4. IMF Director John O'Dwyer with wife Dorothy
5. Kristi Willette and Larry Thomas of the Willette Charitable Foundation

We thank our supporters

This year's presenting sponsors included Amgen, Bristol-Myers Squibb, Celgene, Janssen, and Takeda Oncology. In addition, many other corporate and individual sponsors supported the event through sponsorships, auction contributions, and participation in the evening's commemorative tribute journal.

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COMEDY CELEBRATION – CONTINUED FROM PAGE 24

Event Sponsors

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Stephanie Hope Feld

Loraine & Amy Boyle
and
Lucy Boyle & Jesse Wann

Susie Novis Durie &
Dr. Brian G.M. Durie

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Robin Levy

IMF Senior Director of Public Policy and Advocacy

rlevy@myeloma.org

Robin Levy received her Bachelor of Arts degree in Political Science and Jewish Studies from Stockton University in Pomona, New Jersey. She earned her law degree from George Mason University, School of Law in Arlington, Virginia. Robin has more than a decade of experience in policy analysis, advocate and public outreach, and program and budget management. She began her career in the Executive Branch of the federal government, working in the White House Counsel's office during the Clinton Administration. Prior to joining the IMF, Robin was the Director of Public Policy and Advocacy for the Lymphoma Research Foundation as well as the Assistant Regional Director of the Anti-Defamation League, both where she managed the policy and advocacy portfolio.

Jonathan Fitzpatrick

IMF Support Group Coordinator

jfitzpatrick@myeloma.org

Jon Fitzpatrick worked with the IMF for several years as a volunteer before joining our team as the Support Group Coordinator. He is excited to turn his passion for helping others into a career. Jon's interest in working closely with myeloma patients and caregivers was sparked as a result of his experience in the field of emergency response.

Abigail Guzman

IMF Assistant Meeting Planner

aguzman@myeloma.org

Abigail Guzman developed a strong skillset in the hospitality industry through previous work experience and coursework at the University of Johnson & Whales – School of Hospitality. In addition to organizational expertise, Abby possesses a true passion for customer service. Her work behind the scenes ensures every event's success before the customer experience even begins.

Kelley Jones

IMF Advocacy Associate

kjones@myeloma.org

Kelley Jones has joined the IMF to work on federal and state advocacy and policy issues, as well as to help grow our grassroots advocates network. Previously, Kelley worked in the health and wellness community for eight years as a certified Health and Nutrition Coach, Personal Trainer, and Yoga Instructor. She holds a Bachelor of Science degree in Exercise Physiology from Frostburg State University. Kelley resides in Maryland.

March is MYELOMA ACTION MONTH

Visit **mam.myeloma.org** to learn about opportunities to take ACTION to save and improve lives, empower patients, and arm them with knowledge. Awareness of this rare disease may guide someone to ask their doctor to consider myeloma as a possible cause for their symptoms, leading to earlier diagnosis and an improved outcome. **Take Action – It Matters**

What is Multiple Myeloma?

- Second most common blood cancer
- Second most common blood cancer
- Affects 750,000 people worldwide

What are the symptoms?

- Bone pain
- Anemia
- Extreme fatigue

What we do:

- Advocate for needs of the myeloma community
- Foster collaborative research
- Empower people through education
- Provide support for patients and families

Call the IMF Infoline at 800.452.2873
or visit us at myeloma.org

Dr. Joseph Tariman Selected as Fellow of the American Academy of Nursing

Joseph Tariman, PhD, ANP-BC

The IMF congratulates Dr. Joseph Tariman (Assistant Professor, School of Nursing, College of Science and Health, DePaul University, Chicago, Illinois), a member of the IMF's Nurse Leadership Board (NLB) since its inception, on his induction as Fellow to the American Academy of Nursing (AAN). The AAN is a nationally recognized organization that serves the public and the nursing profession by advancing health policy and practice through the generation, synthesis, and dissemination of nursing knowledge.

Dr. Tariman earned his Bachelor of Science in Nursing degree from the University of the Visayas and a Master of Arts in Nursing degree at Cebu Doctors' University, both in the Philippines, and a post-Master's certificate in Adult Health Nurse Practitioner at the University of Miami in Coral Gables, Florida. He then received his PhD at the University of Washington in Seattle, where he completed a research fellowship that was funded by National Institute of Health (NIH) and the Achievement Rewards for College Scientists' Foundation.

In 2010, Dr. Tariman edited a seminal publication on multiple myeloma for the Oncology Nursing Society (ONS). In 2015, he and NLB colleague Dr. Beth Faiman edited *Multiple Myeloma: A Textbook for Nurses. A Treatment-focused and Evidence-based Approach to the Care of Patients with Myeloma, Second Edition*. Dr. Tariman has been an editor for *ONS Connect*, a column writer for *Advance for Nurse Practitioners*, and is an active member of the editorial review boards of *CJON* and *The Oncology Nurse*.

He has received numerous honors, including the 2011 Honored Nurse of the Year Award from the Chicago LLS; the 2012 Nurse of the Year Award from the LRF; and the 2013 ONS Outstanding Achievement for Oncology Nursing Education. The IMF commends Dr. Tariman for his AAN Fellowship. **MT**

UNDERSTANDING STATISTICS – CONTINUED FROM PAGE 13

whether or not they've had certain prior therapies, or by risk status (as determined by the genetics of the myeloma cells). A stratified log-rank test allows researchers to compare treatment groups, but also to adjust for such variables as disease stage, patient age, and so on.

Hazard Ratio (HR): "Hazard" is a statistical euphemism for "death." HR is formed by dividing the hazard (death) rate of the experimental group by that of the control group. A treatment that does better than the control will have a hazard ratio that is less than one.

Kaplan-Meier Survival Curve: Kaplan-Meier survival curves are used to graph the survival of a group of patients. The Y axis of the graph shows cumulative survival, while the X axis shows duration of survival. Each time a death occurs, the curve is adjusted downward to reflect that event at a certain point in time.

Confidence interval: Statisticians can calculate a range (interval) in which we can be fairly sure (confident) that the true value would lie if there were data for the whole population. The larger the number of participants in a study, the narrower the confidence interval. The narrower the confidence interval, the more reliable the study results. In the above VRd vs. Rd study, the confidence interval for the hazard ratio is very narrow: between 0.573 and 0.941.

While these definitions alone will not enable anyone to pass a statistics exam, those of us who have not studied statistics and who read medical literature can, at least, become familiar with some of these difficult terms and read with an eye to narrow confidence intervals, hazard ratios that are less than one, and p-values that are 0.01 or less. For clarification of non-statistical myeloma terms and definitions, visit glossary.myeloma.org or contact the IMF InfoLine. **MT**

Visit myeloma.org for up-to-date information about myeloma and contact the IMF with your myeloma-related questions and concerns. The IMF InfoLine consistently provides callers with the best 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.

* "Bortezomib, Lenalidomide and Dexamethasone Vs. Lenalidomide and Dexamethasone in Patients (Pts) with Previously Untreated Multiple Myeloma without an Intent for Immediate Autologous Stem Cell Transplant (ASCT): Results of the Randomized Phase III Trial SWOG S0777." Brian Durie, Antje Hoering, S. Vincent Rajkumar, Muneer H. Abidi, Joshua Epstein, Stephen P. Kahanic, Mohan C. Thakuri, Frederic J. Reu, Christopher M. Reynolds, Rachael Sexton, Robert Z. Orlowski, Bart Barlogie, Angela Dispenzieri. *Blood* 2015 126:25.

What Does the 21st Century Cures Act Mean to Myeloma?

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

The 21st Century Cures, a wide-ranging bill that authorizes additional cancer research funding as well as funds for the US Food and Drug Administration (FDA) to streamline drug and device approval processes, passed the Senate on December 7 with a bipartisan backing of 94–5 and was signed into law by President Obama on December 13, 2016. While this effort has been lauded as a return to the more traditional give-and-take approach to legislation, many myeloma patients and caregivers remain unclear about how it will affect them. Since its introduction by Rep. Fred Upton (R-MI), much of the bill has been changed, added to or altered, leaving behind those who did not follow the changes closely. The IMF Advocacy Team would like to take this opportunity to highlight some of this bill's main components.

National Institute of Health (NIH) and National Cancer Institute (NCI) Funding: The Bill authorizes $4.976 billion for the NIH Innovation Account over 10 years with $300 million allocated to the NCI for cancer research. This money would fund Vice President Joe Biden's National Cancer Moonshot Initiative, the Precision Medicine and BRAIN Initiatives, and regenerative stem cell research. In a direct endorsement of Biden's moonshot efforts, the first item in the nearly 1,000-page bill is named "Beau Biden Cancer Moonshot and NIH Innovation Projects," an indication that the funds for cancer research are to be used for moonshot priorities.

NIH and NCI are "extremely fortunate" that support for research in Congress is bipartisan, said NCI Acting Director Doug Lowy at a joint meeting of the National Cancer Advisory Board and the Board of Scientific Advisors. "I want to point out that [the Cures Act] includes Blue Ribbon Panel recommendations, but it says specifically, 'Research that has the potential to transform the scientific field that has inherently higher risk and that seeks to address major challenges associated with cancer.' This actually is quite broad," Lowy said at the meeting on December 6.

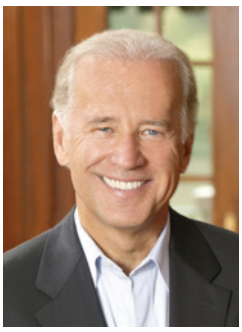
FDA's Accelerated Drug Approvals: Of the $300 million allocated for the NCI, $15 million may be set aside for the FDA Oncology Center of Excellence, a moonshot initiative led by Richard Pazdur, director of the agency's Office of Hematology and Oncology Products. Separately, $500 million has been diverted to the FDA to streamline the drug approval process. In considering whether to approve new drugs or new uses for medications, the bill says, the FDA shall pay more attention to "patient experience data" showing the impact of a disease or treatment on patients' lives, and their treatment preferences.

Scott Whitaker, president and chief executive of the Advanced Medical Technology Association, a trade group for device makers, hailed the bill for creating "an expedited pathway for breakthrough medical technologies – those that offer the best hope for patients with life-threatening diseases" and few treatment options. In reviewing new devices, the bill says, the FDA shall consider the "least burdensome" means of showing their safety.

The approval of the Cures Act represents more than two years of information gathering, collaboration and a commitment from stakeholders across the research enterprise to accelerating medical progress, said Mary Woolley, president and CEO of Research!America. "The bill is a crucial step towards removing barriers to innovation, securing funding for major initiatives like the cancer moonshot and streamlining drug development to ensure more patients benefit more quickly from lifesaving therapies and devices," Woolley said in a statement.

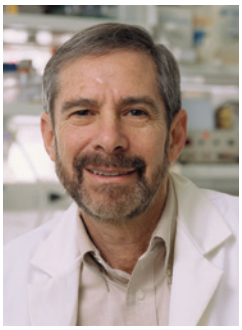
The Cures Act is not perfect, however. Missing from the nearly 1,000-page bill is an attempt to address the rising cost of treatment. "When the cost of our prescription drugs is skyrocketing, this bill does nothing to combat excessive prices," said Rep. Rosa DeLauro (D-CT), the senior Democrat on the Appropriations subcommittee on health and human services. She voted against the measure.

Also missing from the bill is any guarantee of funding for each of the next 10 years. "While the bill authorizes $4.8 billion to the NIH over the next 10 years – on average, a mere $480 million a year – this is barely a quarter per year of what the House passed last year," Ms. DeLauro said. "There is also no guarantee that the appropriators will follow through and provide funding each year." Rep. Kathy Castor (D-FL), who voted for the bill, said she too wished that more of the money had been guaranteed. "Medical research in America today should not be subject to the whims of congressional budget battles or political fights," she said.


Vice President Joe Biden

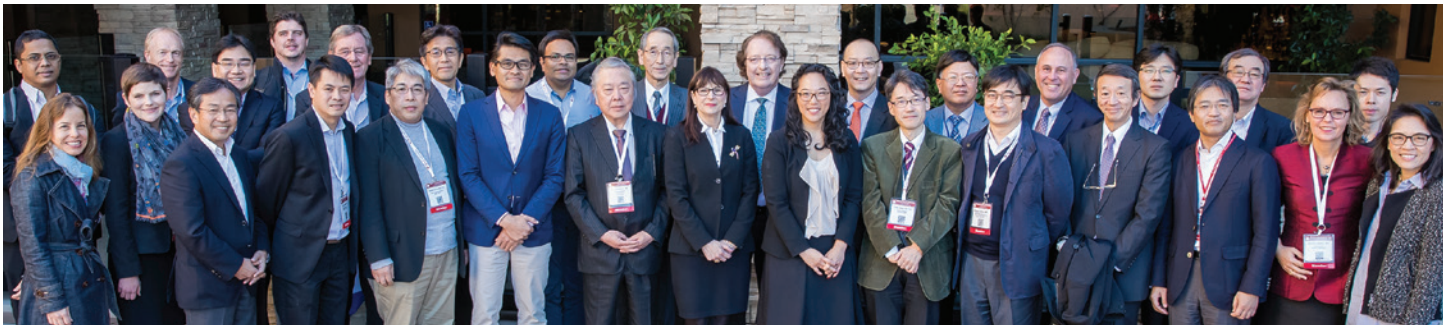

Richard Pazdur


Rep. Fred Upton


Doug Lowy

If you would like more information on the 21st Century Cures Act, or have an interest in getting involved in patient advocacy, please contact Robin Levy, IMF Director of Public Policy and Advocacy, at rlevy@myeloma.org. **MT**

IMF's Asian Myeloma Network Convenes for a Meeting at ASH



Myeloma experts from the Asian Myeloma Network with IMF leadership and industry partners

On December 4, upon the occasion of the annual meeting of the American Society for Hematology (ASH), the IMF convened a session of experts from the Asian Myeloma Network (AMN). The meeting was attended by more than 40 participants from AMN countries and regions: China, Hong Kong, Taiwan, Japan, Korea, Singapore and Thailand. In addition, there were guest observers from industry partners Amgen, Binding Site, Celgene, Janssen, and Takeda.

IMF Chairman Dr. Brian G.M. Durie presided over the session, assisted by Daniel Navid (IMF Senior Vice President, Global Affairs) who is also the IMF's coordinator for the AMN. Two main program activities were the focus of discussion.

Dr. Wee Joo Chng

The first, presented by Dr. Wee Joo Chng of Singapore, was an overview of AMN's clinical trial projects. These were noted to be significant, both because of the data generated and also because clinical trials were one of the few ways to get the more recent novel agents to patients in Asia.

Dr. Chng reported that AMN001, a pomalidomide access project supported by Celgene, has been substantially completed with over 130 of the expected 140 patients recruited. The results of the project were seen to be excellent, with a response rate for the Asian patients exceeding that in the West. It was announced that AMN002, a trial involving carfilzomib supported by Amgen, as well as AMN003, a follow-up pomalidomide trial supported by Celgene, will both begin in early 2017 as all necessary contracts have been concluded for each.

A series of further trial projects were also presented by Dr. Chng and by AMN member Dr. Satish Kumar Gopalakrishnan. The most imminent are likely to be daratumumab studies sponsored by Janssen.

The second main subject for the meeting was a report on the preparations for the First AMN Summit to be held in 2017 in Korea on October 13–15, and Dr. Jae-Hoon Lee and Mr. Navid described the planning to date. The AMN Summit, the first workshop devoted to myeloma priorities in Asia has generated considerable international interest. Following the model of the IMF's International Myeloma Working Group (IMWG) sessions, it was agreed that the AMN Summit will begin with a series of reviews on five focal areas:

Dr. Jae-Hoon Lee

1. Country overviews of myeloma in Asia;
2. MGUS and smoldering myeloma in Asia;
3. Management of newly diagnosed myeloma in Asia;
4. Current and planned clinical trials for newly diagnosed myeloma in Asia; and
5. MRD testing and risk stratification and implementation in Asia.

These would be followed by breakout group discussions with a view to adopt plans of action for the AMN to pursue in the coming year in each of the focal areas. A final session will be devoted to strategic planning for future AMN work.

Dr. Kazuyuki Shimizu

At the ASH meeting, AMN members also discussed other ongoing projects, including the AMN database and the new work being pursued to include cases of MGUS and smoldering myeloma in Asia, the Asian treatment guidelines to be updated during 2017, and the new AMN website.

Dr. Durie concluded the session by congratulating the group for its many successes during 2016 and noting the opportunities that would be presented for expanding the AMN work in 2017. In this regard the International Myeloma Workshop (IMW) to be held in New Delhi in March 2017 was seen to be especially significant. The group agreed to hold its next *ad hoc* meeting at that time. **MT**

Korean Blood Cancer Association Holds Annual Myeloma Patient Seminar

More than 300 patients and caregivers attend the KBCA's most successful event to date

IMF's affiliate partner, the Korean Blood Cancer Association (KBCA), held its 2016 annual myeloma patient meeting on October 29 in Seoul, Korea. With over 300 patients and family members participating, this seminar was KBCA's largest and most successful to date.

Daniel Navid (IMF Senior Vice President, Global Affairs) provided introductory remarks to open the meeting. He presented an overview of the IMF's international programs and stressed the significance of the Global Myeloma Action Network (GMAN) of which the KBCA is a member. He highlighted the role of Korean experts in the IMF's scientific programs, including their participation in the IMF's Asian Myeloma Network (AMN). Mr. Navid assured the Korean patients that they were not alone, being part of the IMF's global network of partners working to enhance myeloma treatment and to achieve a cure.

The seminar then received a series of lectures on aspects of myeloma diagnosis and treatment from several leading Korean specialists. Dr. Jae-Hoon Lee spoke on "What is multiple myeloma?"; Dr. Dong-Yeop Shin reviewed latest developments in "Treatment of newly diagnosed myeloma patients"; Dr. Ki-Hyun Kim presented background information on "What are allogeneic and autologous transplants?"; Dr. Chang-Ki Min provided an update on "Treatment of relapsed/refractory disease"; and Dr. Jin-Seok Kim gave an overview of "Prospects for treatment and clinical research."

The experts were then convened into a panel led by Dr. Je-Jung Lee (President of the Korean Multiple Myeloma Working Group) to consider questions from the audience. Dr. Lee assigned faculty members to each topic, an effective way to cover a wide range of subjects.

Hosts, partners, and faculty of the 2016 annual KBCA myeloma patient meeting

Two of the questions stood out. One patient asked why he had been stricken with myeloma. Dr. Jae-Hoon Lee responded that while there could be various factors, a definitive answer could not be given. He urged that since so many valuable treatment options were now available, it was better to focus upon combating the disease and securing a cure. Another patient then asked why it took so long for new treatments to be approved in Korea, often a delay of years after approval of these same treatments in the US. Dr. Ki-Hyun Kim agreed that delays caused serious problems for patients and stressed the importance of advocacy work by patient associations such as the KBCA in order to convince government administrators of the urgency of taking more rapid approval action. It was noted that the IMF is committed to working with our Korean partners to enhance access to all anti-myeloma therapies. We are very pleased that Korean experts are involved in clinical trials run by the AMN, which provide access to several new treatments to Korean patients.

The IMF looks forward to working with KBCA and our other partners in Asia in 2017, and reporting to you on the activities and advances made in the field of myeloma on behalf of patients and their loved ones. **MT**

The team of volunteers for the event included patients and caregivers

Patient Meetings Across Europe

By Nadia Elkebir
IMF Director of Europe and the Middle East

The IMF's 2016 patient education program in Europe concluded with a series of seminars in October. Some meetings marked the beginning of a new partnership while others felt like a reunion with extended family. An impressive faculty roster included repeat presenters from across Europe as well as guest speaker Dr. Rafat Abonour of the Indiana University Hospital. Below is a brief recap of IMF patient activities this Fall:

Slovakia

The IMF Patient & Family Seminar in Liptovský Ján was held on October 7–8 with 140 patients in attendance. Our friends and partners from the Slovak Myeloma Society (SMS) organized a beautiful event, which started with interesting sessions for both patients and caregivers. Myeloma patient Jozef Novotny and psychologist Zuzana Ondrusová shared their experiences and advice with the participants. Music teacher and myeloma patient Milada Hrianková presented a therapeutic mind-body relaxation technique. Maria Koutoucková reported about the Society for Integrative Oncology, which held a conference in Boston that she had attended. A report on myeloma patient activities in the neighboring Czech Republic was presented by Alice Onderkova and Iveta Mareschova of the Czech Myeloma Group. Maria Svecova and Miroslav Hrianka reported on SMS activities.

Dr. Juraj Chudej

Dr. Ján Sedlák

The next day was devoted to medical lectures: New drugs in myeloma (by Dr. Juraj Chudej), Cytogenetics (by Dr. Zdenka Stefanikova), The role of psychology during treatment (by Prof. Lubos Drgona), Strategic approach to therapy (Dr. Pavel Koutoucek), Patients' role in research (Dr. Ján Sedlák), and Patient rights and the social security system (by Mgr. Daniela Koncierová). During both days, patients were able to have private consults with members of the faculty.

Norway

On October 17, the IMF brought its Patient & Family Seminar program to the beautiful city of Tromsø for our first event above the Arctic Circle! More than 70 patients and caregivers attended the meeting, and the Norwegian support group Blodkreft Foreningen helped make this an absolutely unforgettable event for all. Patients who are so secluded in Northern Norway highly appreciated the efforts to increase their understanding of myeloma, with myeloma experts from Norway being joined by Dr. Rafat Abonour, guest speaker from the US. Dr. Anders Vik presented an overview of myeloma for the patients who are newly diagnosed and those who live secluded villages. Dr. Mats L. Olsen talked about the current treatment in Norway, the national action program for new drugs, and the available clinical trials. Dr. Abonour discussed new drugs and clinical trials in the US, which drew many questions from participants. Physiotherapist Merete Monsen addressed exercise for myeloma patients. Nurse Sigrid Haugland talked about living with myeloma. It was an absolute blessing to meet all the wonderful people who welcomed the IMF so warmly.

Drs. Mats L. Olsen, Rafat Abonour, and Anders Vik

On October 18, more than 110 people attended the IMF Patient & Family Seminar in Trondheim. The IMF has established a great relationship with our Nordic partners, and this is a winning combination for local myeloma patients. The seminar started with an introduction to myeloma; because newly diagnosed patients are part of each meeting, this topic is always helpful. Next, Dr. Tobias Slørdhal talked about the signs and symptoms of relapse. Nurse Turid Almvik talked about the empowering benefits of taking part in a myeloma support group. Dr. Rafat Abonour discussed new drugs and clinical trials in the US. His presentation was translated by Dr. Anders Waage, the head of the department of Biobanking and

The IMF Family now includes many new friends in Tromsø, Norway

Dr. Anders Sundan, Dr. Rafat Abonour (pointing out Tromsø on the map of Norway), and Dr. Anders Waage

clinical studies at St. Olav University Hospital and NTNU, who followed Dr. Abonour's talk with his own discussion of clinical trials in Norway. Dr. Øyvind Hjertner discussed new drugs and current myeloma treatment in Norway. Physiotherapist Elen Stokke covered physical exercise for myeloma patients. As always, Norwegian patients were very involved in the Q&A session and made the most of their interaction with the faculty.

The IMF's third and last 2016 seminar in Norway took place in Oslo on October 20th, and it was the largest, with 200+ people in attendance. Dr. Fredrik Schejsvold opened the meeting with a history of myeloma. Dr. Abonour followed with his talk about new drugs and US clinical trials, and even the doctors had questions for him after his presentation! The Norwegians were also curious about clinical trials and the use of new drugs in Norway. Dr. Nina Gulbrandsen and Dr. Schejsvold addressed the topics of current treatment in Norway and how new drugs can be used. Next, myeloma patient Nina Poulsson shared her story and she was an inspiration for many, especially since she is currently in full remission after a difficult battle. I look forward to returning to Norway with the IMF in 2017 and seeing our colleagues and all the new friends we have made.

Iceland

The first IMF Patient & Family Seminar in Iceland was held in Reykjavik on October 24. This was also a first for Perluvinir, the Icelandic Myeloma Association. I am happy to report that the collaboration was a great success. Myeloma expert Dr. Sigurdur Y. Kristinsson was delighted to have this patient meeting and expressed his gratitude to the IMF. The 65 attendees were all very vocal and asked lots of questions of all speakers. The atmosphere was highly positive and the bad weather had no effect on the mood.

Moderator Gudrún Agnarsdóttir, Dr. Kristinsson, and Kristin Einarsdóttir of Perluvinir

Dr. Sigurdur opened the meeting with a presentation for the newly-diagnosed. Next, physiotherapist Ása Dagny Gunnarsdóttir explained the importance of exercise for myeloma patients, and she received a lot of questions from patients and the six nurses in the audience. Myeloma patient Kjartan Gunnarsson shared his myeloma story with a lot of humor, which had the other patients in stitches. Dr. Kristinsson explained the innovative iStopMM study and how the IMF is giving to the myeloma community in Iceland. Then Dr. Rafat Abonour explained the newly approved drugs and clinical trials in the US. In general, I found that myeloma awareness in Iceland is very high, thanks in part to a steady stream of media coverage.

Myeloma patient Kjartan Gunnarsson and physiotherapist Ása Dagny Gunnarsdóttir

Denmark

The October 27 seminar in Korsør was the 5th IMF patient event in Denmark, and this time was as great an experience as before. As is traditional here, the meeting started with a beautiful biblical song by the faculty and the 215 attendees. Both Bibi Moe and Kaja Schmidt (President, Dansk Myelomatose Forening), the local myeloma foundation, and myeloma expert Dr. Niels Abildgaard expressed gratitude to the IMF for bringing a guest speaker from the US to the meeting. Dr. Henrik Gregersen, a leading researcher in Denmark, started the day with a general introduction of myeloma. Michael Brautsch, a famous motivational speaker in Denmark, received an ovation after his powerful talk. Dr. Ulf Christian Frølund triggered a lot of questions from the participants after his presentations about first- and second-line treatments. Denmark is always a highly anticipated destination for the IMF's educational program, and and this time was no exception! **MT**

Drs. Niels Abildgaard and Ulf Christian Frølund

Just a few of the many new friends the IMF has made in Iceland

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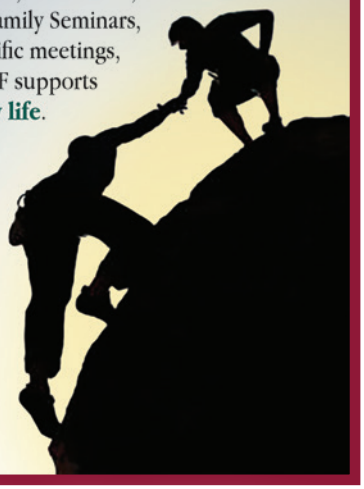

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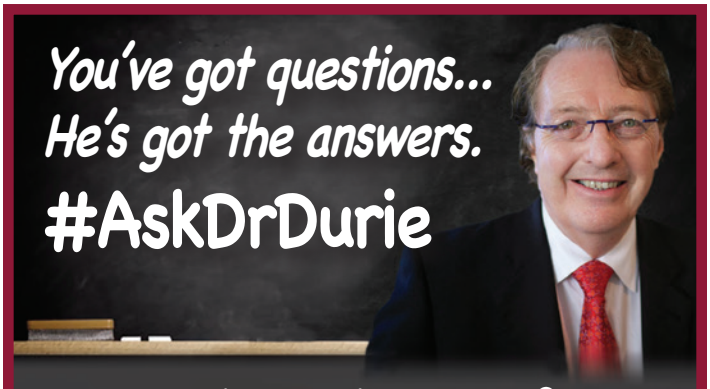
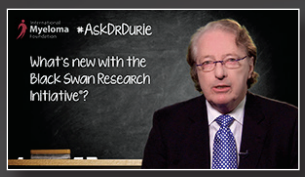
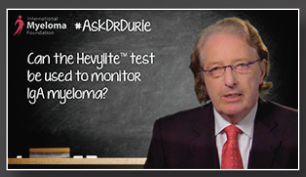
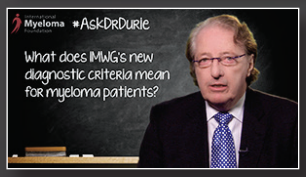


A weekly web series from the International Myeloma Foundation







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2017 IMF Calendar of Events

Feb 3-4	IMF Patient & Family Seminar – Budapest, Hungary
Feb 25	Regional Community Workshop – Seattle, WA
Mar 1-4	16th International Myeloma Workshop (IMW) – New Delhi, India
Mar 17-18	IMF Patient & Family Seminar – Boca Raton, FL
Mar 17-18	IMF Patient & Family Seminar – Stockholm, Sweden
Apr 1	Regional Community Workshop – Virginia Beach, VA
Apr 1-2	IMF Patient & Family Seminar – Schwerin, Germany
Apr 7-8	IMF Patient & Family Seminar – Short Hills, NJ
Apr 15	Regional Community Workshop – La Jolla, CA
May 4-7	42nd Annual Congress of the Oncology Nursing Society (ONS) – Denver, CO
May 6	IMF Patient & Family Seminar – La Hulpe, Belgium
June 2-6	53rd Annual Meeting of the American Society of Clinical Oncology (ASCO) – Chicago, IL
June 10	IMF Patient & Family Seminar – Paris, France
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
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

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