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2015 ASH HIGHLIGHTS

BY SUE HERMS, IWMF TRUSTEE
AND RESEARCH COMMITTEE MEMBER

The 57th American Society of Hematology (ASH) Annual Meeting in Orlando, FL, was recently held on December 5-8, and a number of oral presentations and posters presented at this event focused on or referred to Waldenstrom's macroglobulinemia.

The IWMF staffs a booth each year at this major blood disease conference, which attracts hundreds of clinicians, researchers, and exhibitors from pharmaceutical companies, medical technology industries, and patient advocacy groups. The IWMF was represented by Dr. Robert Kyle, Trustee and Chair of the Scientific Advisory Committee (SAC), President Carl Harrington, and Sara McKinnie and Alan Sachnowski from the Business Office.

The following are summaries of several abstracts of particular interest to WM that were presented at the meeting. They are broadly organized for reading convenience into the following topics: Clinical Trial Results, Genomics and Proteomics, Therapeutic Targets in Preclinical Development, and Disease Complications. These and other ASH abstracts can be viewed online by going to <https://ash.confex.com/ash/2015/webprogram/start.html> and entering "Waldenstrom" in the Search box.

CLINICAL TRIAL RESULTS

Long Term Toxicity and Follow-up of WM Patients After Salvage Treatment with Fludarabine Cyclophosphamide Rituximab [FCR] or Bendamustine and Rituximab [BR], Abstract #3958 – Of the 87 relapsed and refractory WM patients enrolled in this Italian study, 37 received FCR and 50 BR, with both groups undergoing a median of 6 treatment courses. Both regimens led to similar outcomes in terms of overall response rate and major responses, and event-free survival did not differ between the two groups. At 48 months of follow-up, 88% of the patients treated with FCR were free from progression vs. 51% with BR; however, a significantly higher proportion of patients in the FCR group developed a solid tumor or MDS/AML (myelodysplastic syndrome/acute myeloid leukemia) versus those with BR.

The Evolution of Management and Survival Outcomes of WM in the United States, Abstract #882 – Among the 2,666 WM patients analyzed between 1994 and 2011 in this retrospective study, median age was 78 years, and 57% were males. Recorded WM complications at diagnosis in order of prevalence from greatest to least included anemia, transfusions, autoimmune hemolytic anemia, neuropathy, plasmapheresis, and amyloidosis. Between 1994 and 2011, the prevalence of baseline anemia, transfusions, and neuropathy significantly increased, as did the proportion of patients receiving chemotherapy within one year of diagnosis, although mean age at treatment did not change. In the pre-rituximab era, most regimens were purine analog-based or alkylator-based. Since 2000 a majority of patients have received rituximab alone, while purine analog-based therapy is much less used. Overall survival has progressively improved, although anemia, transfusions, plasmapheresis, and/or amyloidosis present at diagnosis were associated with worse overall survival. Patients treated within one year from diagnosis had a worse overall survival than those who were not.

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2015 ASH Highlights, cont. from page 1

Generation of a Large Observational Pan-European Data Platform for Treatment and Outcome Patterns in Patients with WM, Abstract #2096 – This retrospective effort looked at 454 patient records from across Europe during the period 2000-2014. Median age at initiation of front-line treatment was 65 years, and 61% were males. The most common reasons for treatment at diagnosis were constitutional symptoms, cytopenias (reduction in one or more blood cell types) with anemia being the most prevalent cytopenia, and IgM-related symptoms. The use of single-agent therapy of all types decreased, while combination therapy with a monoclonal antibody increased. Rituximab, followed by cyclophosphamide, and to a lesser extent, chlorambucil, fludarabine, vincristine, and bendamustine, were the most common agents used, excluding steroids. Median overall survival was 123 months. Considerable differences in country-specific overall survival were noted, and other malignancies were reported in 12% of patients after diagnosis of WM.

Preliminary Results from a Phase I/II, Open Label, Dose-Escalation Clinical Trial of IMO-8400 in Patients with Relapsed or Refractory WM, Abstract #1540 – When these results were presented, the trial had enrolled 17 patients in three dose cohorts and is continuing to recruit patients with relapsed/refractory WM. The trial identification number on www.clinicaltrials.gov is NCT02092909. The presence of the MYD88 L265P mutation is being assessed in each enrolled patient, who will then be eligible to participate in an extension of the trial upon completion of treatment. The most common adverse events included transient flu-like symptoms and injection site reactions. One serious adverse event was worsening arthritis reported in a patient with a pre-existing history of it. Preliminary evidence of clinical activity was observed in all dose cohorts, with 6 of 15 evaluable patients (40%) achieving an objective response. The highest dosing at 2.4 mg/kg was considered safe for further evaluation, although the maximum tolerated dose has not yet been identified. IMO-8400 is a product of Idera Pharmaceuticals and targets several proteins in the Toll-like receptor (TLR) pathway.

Long-Term Outcome of a Prospective Study of Bortezomib, Dexamethasone, and Rituximab (BDR) in Previously Untreated, Symptomatic Patients with WM, Abstract #1833 – This treatment consisted of bortezomib (Velcade) at 1.3 mg/m² and dexamethasone at 40 mg administered on days 1, 4, 8, and 11 of a 21-day cycle, with rituximab administered at 375 mg/m² on day 11. Initial treatment was for 4 consecutive cycles. Maintenance therapy followed 12 weeks later and consisted of one cycle of BDR therapy every 12 weeks for a total of 4 cycles. The overall and major response rates for the 23 patients in the study were 96% and 91%, respectively. With a median

2015 ASH Highlights, cont. on page 3



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follow-up of 8.5 years, the median time to progression was 5.5 years. The most common toxicities greater than grade 2 were peripheral neuropathy, neutropenia (reduction in neutrophils), infections without neutropenia, thrombocytopenia (reduction in platelets), and steroid-related hyperglycemia (elevated blood sugar levels).

Ibrutinib Therapy in Rituximab-Refractory Patients with WM: Initial Results from an International, Multicenter, Open-Label Phase III Substudy (iNNOVATE™), Abstract #2745 – Symptomatic WM patients were eligible for this trial if they relapsed less than 12 months after rituximab-containing therapy or failed to achieve at least a minor response. The 31 patients received oral ibrutinib at 420 mg/day continuously until progressive disease or unacceptable toxicity. The overall response rate was 84%, with a major response rate of 65% at a median follow-up of 7.7 months. Baseline median hemoglobin increased and baseline median IgM decreased after one cycle, with continued improvement over time. Overall, adverse events of all grades occurred in 94% of patients and included diarrhea, hypertension, neutropenia (reduction in neutrophils), upper respiratory infections, fever, thrombocytopenia (reduction in platelets), and increased tendency to bruise. Dose reductions occurred in 13% of patients, and 2 patients discontinued treatment. Additional data will be provided as the trial continues.

A Phase I Study of Venetoclax (ABT-199/GDC0199) Monotherapy in Patients with Relapsed/Refractory Non-Hodgkin's Lymphoma, Abstract #254 – Venetoclax is an oral inhibitor of BCL-2, which is commonly overexpressed in hematologic malignancies, including non-Hodgkin's lymphoma (NHL). Of 106 patients enrolled, 4 were diagnosed with WM. This analysis focused on patients with follicular lymphoma (FL) and diffuse large B-cell lymphoma (DLBCL). In total, 57 of 70 patients discontinued treatment. The most common adverse events included diarrhea, fatigue, nausea, and vomiting. The overall response rate in FL was

34%, and the median duration of response was 10 months. Eleven FL patients remain in the study. Several DLBCL patients had an initial response, but it was not sustained.

The BTK Inhibitor, BGB-3111, Is Safe, Tolerable, and Highly Active in Patients with Relapsed/Refractory B-Cell Malignancies: Initial Report of a Phase I First-in-Human Trial, Abstract #832 – This trial enrolled 25 patients to test a new BTK inhibitor called BGB-3111. No dose limiting toxicities were encountered, and the maximum tolerated dose was not reached. A recommended Phase II dose of 320 mg/daily was determined as a result of the study. Sixteen patients responded, and potentially drug-related adverse effects included self-limiting neutropenia (reduction of neutrophils) in CLL patients; there were no serious bleeding events and no exacerbation of or new atrial fibrillation events. Twenty-two of 25 patients remain on the treatment, free of progression, at a median of 204 days.

GENOMICS AND PROTEOMICS

Genetic Characterization of Waldenstrom Macroglobulinemia by Next Generation Sequencing: An Analysis of Fourteen Genes in a Series of 61 Patients, Abstract #2971 – Spanish researchers performed a comprehensive analysis of mutations in 12 genes previously described as frequently associated with WM by using next generation (high throughput) DNA sequencing. This cohort of 61 patients included 14 with MGUS, 23 with asymptomatic WM, and 24 with symptomatic WM. Apart from the MYD88 L265P mutation (present in 90%) and the CXCR4^{WHIM} mutation (present in 21%), 23 mutations were found in 18 of the 61 patients. One patient with MGUS demonstrated one additional mutation, while 7 of the asymptomatic and 10 of the symptomatic WM patients demonstrated additional mutations, suggesting an association between the clinical behavior of the disease and a higher number of mutations. Interestingly, patients with wild-type (unmutated) MYD88

2015 ASH Highlights, cont. on page 28

IWMF Fact Sheets are now available in Chinese, Spanish, French and Italian

The IWMF Fact Sheets developed in English are now joined by translations in Chinese, Spanish, French, and Italian. All can be downloaded from iwmf.com MEDIA LIBRARY **DOWNLOADABLE PUBLICATIONS**

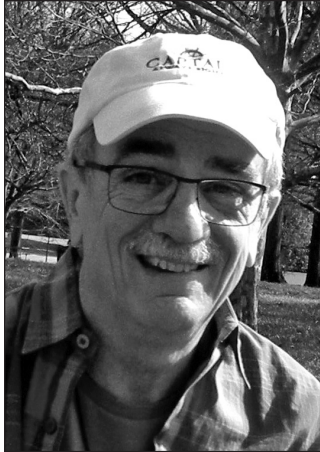
Fact Sheets are short, factual summaries on a specific topic.

About Waldenstrom's Macroglobulinemia – Highlights is a Fact Sheet covering the basic information about the disease and serves as an excellent introduction for both patients and caregivers.

The remaining Fact Sheets give information about five frequently used treatments: bendamustine (Treanda); ibrutinib (Imbruvica); plasmapheresis; Rituxan (rituximab); stem cell transplantation; and velcade (Bortezomib).

Congratulations and our thanks are due to Dr. Jyh-Seng Wang (affiliate leader in Taiwan), Dr. Graciela Molina (affiliate leader in Argentina), Patrice Osterman (affiliate leader in France), Flavia Mammoliti (affiliate leader in Italy) and the many members of their respective groups who gave their time and effort to make the Fact Sheets accessible to many more persons affected by Waldenstrom's macroglobulinemia.

PRESIDENT'S CORNER



What a difference a year makes!

A case in point: My nephew Norman (familiarily known as the Conqueror) was routinely rough on his baby brother, Charlie (as chronicled by their mother on Facebook). Just one year later, Charlie is able to fight back.

What a difference a year makes! And what a difference the past year made in the fight against

WM. When I wrote to you in the January 2015 *Torch*, we were an orphan disease with no drug of our own and no clear plan for making real progress towards a cure.

Surveying the scene in January 2016, we now have a drug approved for WM and we have set in motion a defined plan for WM research in the immediate future. Furthermore, we have watched WM research progress around the world.

1. The drug

- Imbruvica (ibrutinib) was approved in January 2015 by the Food and Drug Administration in the US and in July by the European Medicines Agency in Europe, becoming the first drug therapy ever specifically approved for WM.

2. The plan

- Starting with a meeting in New York City in May, the IWMF and Leukemia & Lymphoma Society (LLS), in combination with the leading WM experts in the world, developed the IWMF-LLS Strategic Research Roadmap for WM. This Roadmap identifies 4 key areas of focus: Bone Marrow/Tumor Microenvironment; Immunotherapy; Signaling; and Genomics/Epigenomics.
- Action taken since the October issue of the *Torch*: In November 2015 we issued a Request for Proposals (RFP) to about 200 researchers worldwide.
- Schedule for 2016: We expect to receive proposals before the February 2016 deadline. We hope to fund 2-4 new research projects between July and October of 2016 at a cost of about \$200,000 apiece per year. The number we are able to fund depends entirely upon the donations we receive.

3. Further progress on the research front in 2015

- The US National Comprehensive Cancer Network (NCCN) Guidelines on WM were updated in



One year ago, Norman had the upper hand.



What a difference a year makes!

September. MYD88 L265P AS-PCR testing of bone marrow at diagnosis has been changed from “useful in certain circumstances” to “essential.” The IWMF helped sponsor the initial study from Dr. Steven Treon of Dana-Farber Cancer Institute that led to the discovery of the MYD88 mutation in WM, a mutation that about 95% of us have, and a target for Imbruvica and other new drugs.

- Researchers from around the world have made enormous progress in WM research. See pages 1-3, 28-29 for a review of WM-related presentations at the American Society of Hematology (ASH) meeting in December.

2015 was also a year of action and accomplishment for the IWMF.

1. Our Member Services were significantly expanded and improved.

At the top of the list is *iwmf.com*, the new IWMF website launched in February.

President's Corner, cont. on page 5

- The new website offers easy access from smart phones and tablets as well as computers and is translatable into over 55 languages to support patients and caregivers who do not speak English.
- We have prominently published on our website inspirational and candid “Stories of Hope” from patients and caregivers worldwide who express in their own words how they have experienced living with Waldenström’s macroglobulinemia and its effects on their health, career, family, and quality of life.
- Our new look features pictures of WM patients from around the globe.

Other Member Services initiatives of 2015 produced improved communication and wider outreach of our services.

- To keep you updated with timely information about WM and the IWWMF, we have implemented a NEWS alert service that delivers e-mail messages directly to your inbox.
- With our focus on supporting everyone affected by WM, we have added affiliates in Argentina, Spain, and Taiwan.
- With the help of our affiliates, many of our booklets and fact sheets have now been translated into Chinese, French, Italian, and Spanish.

2. And there are further indications that 2015 was a vigorous and expansive year for the IWWMF.

- Not only did we expand our partnership with LLS, we also established new partnerships with Lymphoma Research Foundation (LRF), CancerCare, and CURE Magazine. These partnerships enable us to access additional skills and resources and to accomplish more for you for less. See page 16 for a good example: the IWWMF was represented at the LRF Workshop on Oral Therapies held in September 2015.
- We created and implemented a new logo for the IWWMF, as well as new graphics for our patient-friendly publications.

- Our information database also got an update. This new database improves efficiency in the IWWMF Business Office, saving us time and money.

3. We raised a record amount of money in 2015, breaking our year old record from 2014.

Thank you to each of you who contributed!

While 2015 was a great year, now is not the time to rest on our laurels. We need to do more to fight back against WM. We need to make it cry “uncle.” To fund the new Strategic Research Roadmap projects that will get us closer to a cure, we need to **DOUBLE** our research donations in 2016.

Can you double the amount you give to the IWWMF in 2016? I hope so! But if you can’t, look at page 10 to see what Ed Goldberg did. Ed raised nearly \$50,000 for the IWWMF in 2015 by reaching out to his friends, family, and colleagues. Can you make a New Year’s resolution to do the same thing?

The large number of ASH presentations in 2015 relating to WM illustrates the current momentum in WM research. With your support, the IWWMF-LLS Strategic Research Roadmap will lead to more research in the four target areas designated as essential to the deeper understanding of our disease.

Remember that the number of research projects we are able to fund depends upon you. If we have the funds, we’ll be able to support more research and move closer to a cure.

Returning to my rambunctious nephews Norman and Charlie, I’m honored to be their Uncle Carl in a family that laughs and cries together. Within our IWWMF family, we can all support each other and work together to accomplish a great deal in the year ahead.

And in January 2017 I’ll be able to say, “What a difference a year makes!”

Stay well!

Carl

Let’s Keep the Office Database Updated!

The IWWMF Business Office maintains an information database for WMers that includes date of birth, sex, and date of diagnosis. The IWWMF database is a resource for statistical analyses concerning WM. For example, we were recently able to use it to provide information on average age at diagnosis (61.44 years) to our affiliate in the UK, WMUK, to help them gain further approval for ibrutinib (Imbruvica) within the UK.

If you haven’t provided your date of birth, sex, and date of diagnosis, please send this information to office@IWWMF.com. Your personal data will be kept confidential.

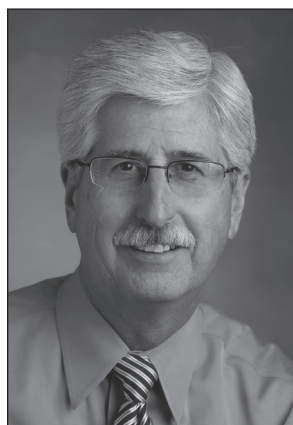
TWO NEW MEMBERS JOIN THE IWMF SCIENTIFIC ADVISORY COMMITTEE

BY SUE HERMS, IWMF TRUSTEE AND RESEARCH COMMITTEE MEMBER

The IWMF is pleased to announce the addition of two new members to its prestigious Scientific Advisory Committee (SAC) chaired by Dr. Robert Kyle of Mayo Clinic in Rochester. Dr. Brian Van Ness from the University of Minnesota and Dr. Surinder Sahota from the University of Southampton in the United Kingdom were invited to participate because of their expertise in focus areas of WM research prioritized by the new IWMF-LLS Strategic Research Roadmap Initiative for WM.

These focus areas include cell signaling, genomics and epigenomics, immunotherapy, and the bone marrow and tumor microenvironment. As a consequence of the Roadmap Initiative, the IWMF sent a Request for Proposals in November to over 200 prominent researchers around the world. The proposals will be evaluated by members of the Scientific Advisory Committee, whose recommendations will be passed to the IWMF Research Committee and to the IWMF Board of Trustees for final selection and approval. Funding of approved proposals is expected to begin in July-October 2016.

For more information about the Roadmap Initiative, please see articles in the July 2015 and October 2015 issues of the *Torch* at iwmf.com/publications/torch-newsletter.



Brian Van Ness, PhD.

Brian Van Ness, PhD

Dr. Brian Van Ness is a professor in the Department of Genetics, Cell Biology and Development at the University of Minnesota Medical School. He served as the Head of the Department and then as a Director of the Institute of Human Genetics and Director of a newly established Division of Medical Genomics. Dr. Van Ness is currently Chair of the University's Advisory Committee for the Genomics Center.

After receiving a bachelor's degree in biology and a master's degree in chemistry from the Indiana University of Pennsylvania, Dr. Van Ness obtained his PhD in biochemistry from the University of Minnesota. He conducted his postdoctoral work in molecular immunology with the Institute for Cancer Research in Fox Chase, PA. His current research focuses on exploring how genetic variations influence disease progression and therapeutic response, particularly with regard to multiple myeloma.

Dr. Van Ness is Founder and CEO of a new company, Target Genomics, LLC, which focuses on guiding healthcare providers on the use of genomics and identifying and

implementing clinical applications of genetics in drug therapies. He has been active in regulatory and legal issues in genomics, both as an expert consultant in patent litigation and as a member of an NIH-supported committee making recommendations on return of genetic results. Dr. Van Ness recently created a joint course with the University of Minnesota Law School entitled "Genetics and Law." In addition to teaching responsibilities for the Medical School and Law School curricula, Dr. Van Ness is a frequent guest speaker on genomics and personalized medicine for continuing medical education programs and patient support groups around the country, including the 2009 and 2012 IWMF Educational Forums.

Recently, Dr. Van Ness and his wife developed a small hobby farm on a 6.5-acre lot, where they keep alpacas and chickens. When the roads are clear of snow, they enjoy biking the many trails of Minnesota and Wisconsin and kayaking the lakes and rivers in the area.



Surinder Sahota, PhD.

Surinder Sahota, PhD

Dr. Surinder Sahota is a Reader in Immunogenetics at the University of Southampton, a position that falls between an associate professorship and a full professorship in the US. He obtained his PhD in microbial biochemistry from the University of London and was a Lecturer at the University of California in Los Angeles. Following his return to the United Kingdom, he undertook cancer research at two medical

schools in London, subsequently receiving his appointment to the Cancer Sciences Academic Unit, Faculty of Medicine, at the University of Southampton.

Dr. Sahota's group has utilized specific genetic imprints and genome-wide whole exome sequencing to examine mutations that define B-cell tumor origins and behavior. Their ongoing research seeks to link those mutations with outcomes. His group is also interested in defining tumor-associated antigens for targeted immunotherapy, which is treatment focused on using the body's own immune system to fight cancer.

Dr. Sahota is married, and his wife is a practicing dentist in Southampton. According to Dr. Sahota, they have two "lively" boys, ages 19 years and 16 years, who share a strong interest in sports with their father. Their family lives in Winchester, the ancient capital of Wessex in the south of Great Britain.

IN MEMORIAM: RONALD A. YEE

1954-2015

BY PETER DENARDIS, IWMF BOARD MEMBER



Ronald A. Yee

On Sunday, November 8, 2015, Ronald (Ron) A. Yee passed away after a long illness, while surrounded by his family at his home in West Chester, Pennsylvania (USA).

Ron earned a Bachelor's of Science in Pharmacy from St. John's University and had a long career in pharmaceutical research and development. He was a caring father and husband – supportive to his wife, Phongsiri (Pook), who is also a pharmacist, and providing ready life lessons, advice, and handyman work for his children, Linh (Danny), Alyssa, and Elizabeth (Liz).

The outpouring of support and remembrance among the IWMF community upon news of his death was nothing short of amazing – and it became quite clear from those messages that Ron Yee was a unique and special person. Each person he encountered was quick to point out his ever-present smile, his boundless energy, and his strong, caring spirit.

One could imagine that he lived his life as if his sole purpose was to be a guardian angel to whomever he encountered. His was (and is) a unique personality – one that exhibited great humanity and generosity of spirit. If there was a door to be opened, a bag to be carried, a car ride to be offered, or a way to be made through a crowd, Ron was there before you even realized there was a need. If you were suffering, Ron was there to bring groceries and provide comfort, even after having worked a 12-hour day himself and facing a two-hour drive to get back home. He would stop, he would be there. Always.

Ron's presence was felt at support group meetings in Philadelphia and in New York, which he attended regularly. He somehow also found time to pursue his passion of taking road trips with friends on his BMW motorcycle, traveling throughout the northeastern US, and taking pictures of the sights and his fellow travelers along the way.

Each notification of the passing of a fellow IWMF member is met, understandably, with great sorrow and reflection on how we've been touched by that person's presence among us. While several wonderful IWMF members passed away in 2015, one in particular deserves special mention for his service as an IWMF volunteer and Board Member and for his outreach to fellow WMers.



Ron at the podium, Ed Forum 2013.

He had been a member of the IWMF Board of Trustees since 2004, serving on the Research Committee, Ed Forum Committee, Finance Committee, Investment Committee, Information Technology Committee, and Judith May Volunteer of the Year Award Committee. He also informally served as the Tech Support person during Board Meetings, as there wasn't an electronic device that Ron couldn't troubleshoot and get back into working order in a matter of minutes.

Seeing him in action, you immediately knew you were in the presence of someone very special. He may be gone physically, but his giving spirit lives on in those of us who were touched by him.

As with the passing of other notable IWMF members before him, the "torch" has now been passed to the rest of us to follow his example – to provide comfort and support to others, to work tirelessly towards a cure for WM, and to live life to the fullest.

Please remember Ron's family in your thoughts and prayers. It should be noted that his family graciously suggested donations to the IWMF as a way to honor and celebrate Ron's life and his generosity to others. We thank them for that, and more importantly, for their having allowed us to be graced by Ron's presence and caring nature, whether it was via a support group meeting, a Board meeting, an Ed Forum, a phone call, a personal visit, or an email.

Author's note: I've had the honor and privilege of serving with Ron on the Board since 2008. In that time, we formed a fast friendship, and I considered him like a brother, as we shared many things in common – both being diagnosed at a relatively young age while working full time and raising a family. Ron had a truly unique giving spirit – always caring for others, always poking fun at himself, always trying to lighten the load for others. He never sought the limelight; he never looked for accolades; he quietly, unfailingly, calmly, lovingly showed complete compassion for everyone he encountered. His life defined compassion. We can only hope to do the same.

THE 2016 EDUCATIONAL FORUM IS JUST AROUND THE CORNER!

BY JIM REED, EDUCATIONAL FORUM COMMITTEE

Last year marked the 20th anniversary of our successful Educational Forums. This year please join us as we start our second 20 years with our Educational Forum in Providence, Rhode Island, on June 10-12. Our theme this year is *Pathways to Progress*.

An exciting new session has been added to the agenda this year. The Forum opens on Friday morning with Newly Diagnosed/First Timers led by Jeffrey Matous, MD, and Megan Anderson, RN, both from the Colorado Blood Cancer Institute and both popular past Ed Forum speakers. Attending this session is an excellent way for first timers at the Forum (and especially for those recently diagnosed with WM) to hear about what may lie ahead on their WM path from a clinician whose busy practice includes a number of WM patients. An added plus is the chance to ask questions in a setting smaller than the general sessions to follow. A continental breakfast will be served, a good opportunity to meet informally with fellow WMers who are embarking on the same path.

Our general sessions open Friday morning at 11 with an opening address by IWMF President Carl Harrington, followed by Dr. Stephen Ansell of Mayo Clinic, who will present an overview of the IWMF Strategic Research Roadmap. Luncheon will follow.

Our other sessions scheduled for Friday and Saturday include:

- Frontline Treatment Options – Jorge Castillo, MD, Dana-Farber Cancer Institute
- Treatment Options for Relapsed/Refractory WM – Jeffrey Matous, MD, Colorado Blood Cancer Institute
- WM and the Eye – Maureen Hanley, OD
- Survivorship – Karen Meneses, PhD, University of Alabama at Birmingham
- Immunotherapy: Killer T-Cells – Edward Stadtmauer, MD, University of Pennsylvania

- Genomics in WM – Zachary Hunter, PhD, Dana-Farber Cancer Institute

The Forum concludes with the ever popular “Ask the Doctor” panel discussion on Sunday morning, moderated by Dr. Robert Kyle of Mayo Clinic.

Friday evening is reserved for the President’s Reception, followed by the Welcome Dinner and President’s Address. Musical entertainment provided by Ali Handal, accomplished musician and WMer, will bring the evening to a close.

As in past years, a number of Breakout Sessions are scheduled throughout the Forum. These informal meetings provide an additional opportunity to ask questions and get firsthand information about a variety of topics of interest to WMers.

Support Group Leaders will again have the opportunity to attend a half-day workshop at the hotel on Thursday, June 9, under the leadership of Marcia Klepac, IWMF Support Group Coordinator.

The 2016 Educational Forum will be held at the Omni Providence Hotel in downtown Providence. The hotel is in a central city location, adjacent to a mall and a number of restaurants within walking distance. See the article about Providence on page 9 to learn more about the area. To make your hotel reservations, call 401-598-8000 or Toll-Free 800-843-6664 by May 20 and mention the code “060516INTWALDEN” in order to receive our special room rate of \$145/night.

Please go to our website iwmf.com for agenda updates and online registration for the Educational Forum or use the enclosed brochure with registration form on the back. Remember to take advantage of our early registration rate of \$199, available through May 1. On May 2, registration will increase to \$250; and at the door, to \$275.

We Get Emails

Dear IWMF *Torch* Team,

I just wanted you to know how much I enjoyed reading Arno’s contribution to the *Torch*. His article was very informative and inspiring.

Thank you,

Casey Miller
Fort Wayne, IN

DOWNTOWN PROVIDENCE: A CITY OF HISTORY ON THE WATER

BY JIM REED, EDUCATIONAL FORUM COMMITTEE

Providence, Rhode Island, home to the 2016 Ed Forum, was founded in 1636 by Roger Williams. Today it is the state's capital and most populous city, boasting eight hospitals and seven institutions of higher learning.

The city proper encloses just 20.5 square miles, with approximately 2.1 square miles of water included in that total. The Providence River, formed by the confluence of the Moshassuck and Woonasquatucket Rivers in the center of the city, runs into Narragansett Bay.

Providence is very compact and densely populated, as is characteristic of eastern seaboard cities that developed prior to the advent of the automobile. The street layout is irregular – over one thousand streets run haphazardly, connecting to and radiating from places traditionally bustling such as Market Square. Downtown Providence boasts numerous 19th century mercantile buildings in the Federal and Victorian architectural styles, as well as several post-modern and modernist buildings located throughout the area.

The Omni Providence Hotel will host the 2016 Ed Forum. At 1 West Exchange Street, the Omni Providence is at the heart of downtown and offers some excellent restaurants. The Providence Place Mall is only a short distance across a convenient skywalk. Also connected to the hotel is the Rhode Island Convention Center.

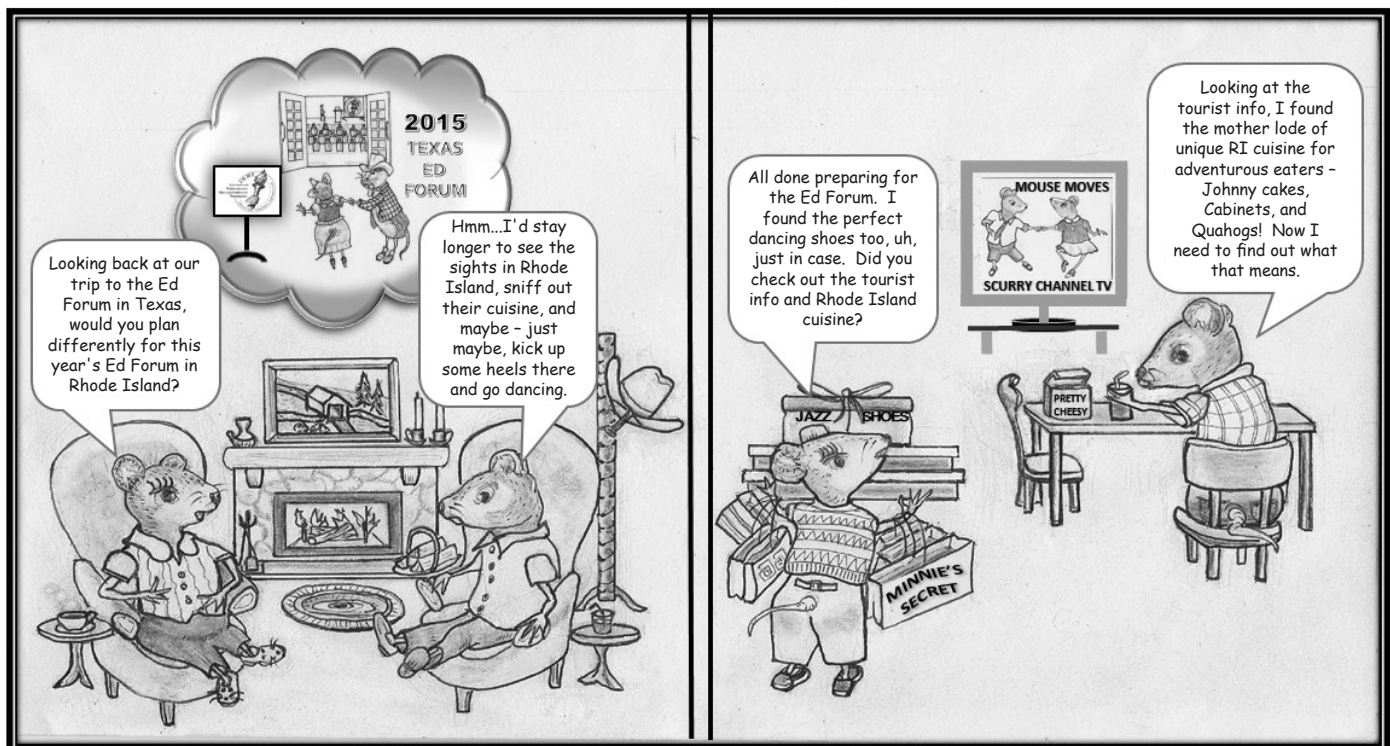
The hotel has easy access to the Waterplace Park and Riverwalk, a collection of cobblestone walkways, plazas, pedestrian bridges, gondolas, and other features intertwined with the rivers flowing through Providence. These features have been central to the revitalization of the downtown Providence area.

During the summer, the city hosts several Waterfire events – environmental art installations consisting of about 100 bonfires that blaze just above the surface of the three rivers passing through the middle of downtown Providence. Displays of public art and musical accompaniment complete the Waterfire experience. The schedule for 2016 will be available in the spring, and we are keeping our fingers crossed that it will include the weekend of the Educational Forum.

If you have an interest in visiting college campuses, Brown University, Providence College, and the Rhode Island School of Design are all within walking distance. The Roger Williams Park Zoo is only four miles from the hotel.

Based on climate data, we can expect an average high temperature of around 75°F and a low of around 58°F during the Ed Forum, ideal for walking and enjoying the sites associated with this old and historic New England city.

WALLY AND WINNIE, WM Model Mice by Linda Pochmerski



ED FORUM 2016 PROVIDENCE RHODE ISLAND

Looking back on the 2015 Ed Forum in Texas, Winnie and Wally reflect on the valuable knowledge they learned about WM. This year they have decided to extend their Ed Forum trip to take advantage of New England's ambiance. Their 2016 Ed Forum trip won't disappoint, Rhode Island's unique cuisine included!

AN OBSESSIVE-COMPULSIVE LUNATIC'S GUIDE TO FUNDRAISING

ED GOLDBERG'S PERSONAL INITIATIVES

AS DESCRIBED TO PENNI WISNER

"It's like living in the Twilight Zone," said Ed Goldberg referring to his life currently, on active treatment with ibrutinib but remaining so severely immunocompromised that he wears a mask and gloves just to visit the pharmacy. Sounding like the healthcare professional he was, he said, "I started ibrutinib on March 18, 2015, at 8:50 pm."



Ed Goldberg

Until November 2012, Ed was the President and CEO of the Chicago-area St. Alexius Medical Center. Ed worked at St. Alexius for 18 years of his 38-year career in hospital administration. His diagnosis in May 2011 and deteriorating health status forced him to resign from a job he loved. His success can be measured in part by his election to the Studer Group Fire Starters Hall of Fame. These are healthcare professionals who "ignite the flames of passion, guide and support an organization's commitment to excellence and impact the lives of employees, physicians, patients, families and students." (studergroup.com/)

"My whole working life I maintained an open-door policy," said Ed. "At St. Alexius, my office had a glass wall, and 2500 employees would walk by every day. They would come in and shake my hand, or give me a hug, or just wave as they went by." Ed continued, "I believe that great leaders lead first by serving. Leading from the bottom up, that was my management style. I was there to support every doctor, nurse, and housekeeper so that they could provide the best care for our patients."

Shortly before his retirement, the hospital leadership approached Ed about a fundraising campaign to honor his contributions to the hospital. Under his leadership, St. Alexius "was named a top 100 hospital in the nation, won the Gallup Great Work Place award for three consecutive years, and received high physician satisfaction scores, among many other successes." (*Daily Herald*, September 6, 2012) There was a stipulation, however: the charitable effort had to fund something for the hospital itself. So Ed's first priority, the IWMF, was temporarily out, but a new inter-faith meditation room was funded with donations totaling \$200,000 within eight weeks. "The Medical Center was a Catholic hospital with a Jewish administrator, and we served a community of Muslims, Buddhists, Sikhs, and various Christian faiths, including a fairly large born-again population," said Ed.

From that experience, "I had a pretty spoiled perspective of what could be accomplished with fundraising. It's been a humbling experience to then raise funds to support research for WM, to spend months on this long road, and to come

nowhere close to \$200,000. But then I was still employed, still a big shot. Now I am retired; I can no longer do favors for others that count."

Despite those beliefs, Ed has continued to use his innovative, person-to person style to raise funds for the IWMF. "It is not that giving is a huge value for me," he admits. When employed by St. Alexius, a nonprofit hospital, fundraising was an important part of his work. He led by example: "We had fundraising goals for the employees every year. If we didn't make that year's target, I would make up the difference. Say the tickets to the hospital's garden ball were \$300. That's a lot for an employee. So I would offer to pay the balance for any employee who could come up with \$150, and the employee could take the full tax credit."

No matter what Ed says about his current health situation, when in conversation, he displays the drive, the passion, the energy that must have made him such a success in his work. "We can't expect the government to pay for research into a disease that affects only five people in a million. Instead, we have to do it ourselves," he says. Ed may claim to be "nobody" these days, but he is an expert in using what he does have to benefit the IWMF.

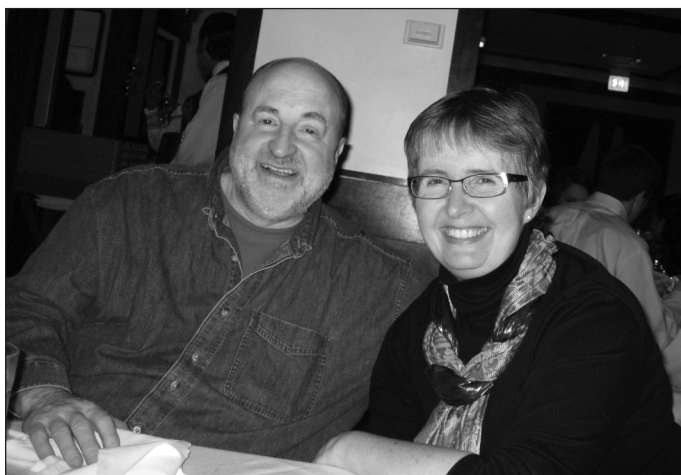
Here's a chronology of his fundraising initiatives (to date. No sooner does he say "I'm done" than another idea occurs to him and he is off again. More about this later.):

"When I started getting serious about this disease, I started preparing. I wrote my eulogy, made arrangements with the funeral home, and wrote my obituaries for both the Chicago, IL, and south Florida papers (Ed spent the first 20 years of his career working in Florida). The obituaries include a request for donations to the IWMF in lieu of flowers. Then I got in touch with the IWMF office and requested a supply of fundraising mailers, both for my own use and a boxful ready to go to the funeral home. Everyone who attends will get one.

"In 2012 I wrote and self-published a book. Some people who want to become doctors read it and occasionally want me to coach them through their medical school applications. I help them develop their personal statements and role play for interviews. I gave the money I earned as a coach from the first four students directly to the IWMF. Now that I am on medical disability, sometimes I give my earnings from coaching (currently I have six students) to the IWMF, sometimes I give it to my close friend who asked that I donate my coaching income to his charity effort, and sometimes I use the money for out-of-pocket medical expenses.

"Then I had the idea that when my wife and I went to dinner with friends we would offer to pay, and our guests would

An Obsessive-Compulsive, cont. on page 11



Ed Goldberg with his wife Linda Trytek
before Ed was diagnosed with WM.

make a donation to the IWMF. At dinner I gave them the IWMF mailer already filled out with their address and the return envelope stamped. All they had to do was to put a check in the envelope and seal it. I think we did this ten times and got ten donations. It got the best result of all my ideas, except the coaching, over which I had total control.”

Asking people for donations reminded Ed of all the people who had asked him to donate to miscellaneous projects: a daughter’s dance-a-thon, a building project for a charity, a son’s school. So Ed drew up a list of as many of these people as he could remember as well as a list of close friends. He composed a fundraising appeal and e-mailed it to all the folks on the list, about 120. E-mail is the most efficient way to contact a large number of people. However, the results, while actually quite good by objective charitable giving standards, disappointed Ed. About 15 of the 120 responded.

In response, Ed dug deeper. He sent out the same e-mail appeal “to every single person I knew, about 300, omitting only the people I had taken out to dinner who had given and those who had responded to the first e-mail appeal. We got about 20 or 25 responses from this second round of e-mails.

My wife looked at all the effort I was putting into the appeals and wondered why I didn’t just give the IWMF \$20,000 and take a rest. But no, I was invested in being an obsessive-compulsive and a lunatic and pressed on.” Ed’s next effort was a personal letter sent through the United States Postal Service. He used the same text as the e-mail appeal but had it typed on letterhead. He then wrote a personal note on each letter and signed each one. The letter went with a completely filled out and stamped IWMF donation envelope. “That was by far the biggest bang for the buck. We sent out around 275 letters and got about 145 responses.

“Because I am at St. Alexius almost every day getting tests or blood work or treatments, I will often see someone who received one of my letters. I ask them: ‘Hey, did you get my letter asking for a donation to the IWMF?’ They might respond that they lost it or something. I respond with a ‘Here’s the information,’ and give them a business card I had

made up. It has a brief donation request on one side and the IWMF contact information for the three ways to give: online, by telephone, and by mail. The flip side says ‘Thank you’ plus my name and contact information. And then I tell them that the IWMF office sends me an e-mail every time a donation comes in, giving me the name of the donor but not the amount. The card has gotten another five or six responses.”

More donations = more research = more and better treatments for WM = longer and better lives for WMers now and in the future. “We need to get more people into the IWMF and more of those members to be active. I would ask them to consider joining the *4 or More* campaign that I’ve come up with. Here are the reasons to do it: Through our research funding, we’ve come up with incredible treatments such as ibrutinib and with more money we can come up with more incredible treatments.

To participate in the *4 or More* campaign, each IWMF member would ask four or more friends to make a donation of \$50. The four might be friends, family, or people who have asked for donations in the past. “How many times have you given \$25 or \$50 to a friend’s pet project? Why not ask them this time around?” mused Ed. *4 or More* uses the multiplier effect: by asking a few friends and family, a small amount can turn into a large amount. If each of four friends gave \$50, the IWMF would receive \$200 instead of a single gift from a member of \$50. An average of \$50 from twenty friends and relatives would raise \$1000, far more than many members can give on their own.

As Thanksgiving approached in 2015, Ed remembered that typically he would send a card to friends on that holiday to say how grateful he was for their friendship. This year the card to those friends came from the IWMF office saying that a donation in their honor had been made to the IWMF. “This is a service the IWMF office will provide to all members,” said Ed. “You could send New Year’s cards, or a birthday card, graduation card, or maybe ‘just-because’ cards to honor your friends and family each with a small donation to the IWMF.

“Yesterday, I was a man who could not go out of the house without protective gloves and a mask. I felt nearly dead. It seemed to me my life was over and my attempts to raise money were so little as to not matter at all. Then I went to our local Chicago support group meeting – without gloves and mask – where we watched Dr. Steven Treon’s talk from the 2015 IWMF Ed Forum. Dr. Treon told the story of how at one point he had no money in his research budget, but he had a big idea. He called Judith May, then the president of the IWMF, who immediately pledged the financial help he needed to pursue his idea. That idea? Genome sequencing of WM patients. This led to the discovery of the MYD88 mutation in WM and then to the decision to test ibrutinib in clinical trials for our disease. Ibrutinib. The drug I take now that is finally making a difference. Dr. Treon then went on to describe all the next generation ideas he has.

“Suddenly, right there in the support group meeting, I felt alive again. We can do this. Little gifts can make a big difference. They can fund big ideas, maybe even the next ibrutinib.”

MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF TRUSTEE AND RESEARCH COMMITTEE MEMBER

Phase II Clinical Trial of Ibrutinib to Open for Previously Untreated WM Patients – Dana-Farber Cancer Institute plans to open a Phase II clinical trial of ibrutinib (Imbruvica) in symptomatic, previously untreated WM patients and will conduct genomic sequencing of patients' WM cells before the start of treatment and 6, 12, 24, 36, and 48 months afterward. The trial will test the drug's safety and efficacy as an option for previously untreated WM patients, while the genomic sequencing will assess which genetic changes affect the action of ibrutinib. The trial identification number on www.clinicaltrials.gov is NCT02604511.

Greek Myeloma Study Group Analyzes Survival Statistics for Symptomatic WM Patients – A study from the Greek Myeloma Study Group analyzed survival statistics for 385 symptomatic WM patients, within the Group's centers, who received therapy from April 1982 until February 2013. The causes of death and relationship to WM were assessed by the treating physicians. WM-related causes of death were those occurring due to progressive disease, transformation to myelodysplastic syndrome (MDS) or diffuse large B-cell lymphoma (DLBCL), infections, or treatment-related complications. Patients who died while their disease was in remission, off treatment, or due to causes such as stroke, heart attack, or a second cancer, and without evidence of disease progression or relapse, were considered WM-unrelated deaths. Survival was calculated from the date of initiation of therapy until date of death or last contact. The 5-year WM-related death rate was 21.4%, and the WM-unrelated death rate was 7.6%; the 8-year WM-related death rate was 32%, and the unrelated death rate was 11.5%. More patients of advanced age are being diagnosed and treated for WM, and the study concluded that WM-unrelated mortality is significant and should be taken into account in the evaluation of long-term outcomes and the design and analysis of clinical trials. The researchers looked at the impact of rituximab-based primary treatment on survival and indicated that it is associated with a reduction in WM-related mortality, independent of other prognostic factors.

Long-Term Outcomes Reported for DRC Therapy in WM – A letter published in the journal *Blood* reported long-term outcomes of a Phase II study of dexamethasone, rituximab, and cyclophosphamide (DRC) in 72 WM patients. The study was conducted with a minimum of 7 years of follow-up by the European Consortium for Waldenström Macroglobulinemia. The study reported that progression-free survival after DRC was about 3 years, and re-treatment was feasible. The overall survival after primary DRC was about 8 years, but approximately 20% of these patients died of unrelated causes. Secondary myelodysplastic syndrome (MDS) and transformation to diffuse large B-cell lymphoma (DLBCL) occurred in 3% and 10% of patients, respectively.

Bing Center Discusses Rituximab Intolerance in WM Patients – In correspondence to the *British Journal of Hematology*, the Bing Center at Dana-Farber Cancer Institute discussed rituximab intolerance in WM patients. Using a database of 1466 patients diagnosed from 2000-2014, 85 patients (7%) were deemed intolerant to rituximab and included in the analysis. The most common symptoms of intolerance were anaphylaxis, chills and rigors, hives, low blood pressure, shortness of breath, itching, and rash. Patients became intolerant while receiving rituximab as a single agent or in combination and while undergoing front-line or maintenance therapy. Intolerance was seen at any level of serum IgM. Approximately 30% of rituximab-intolerant patients went on to receive ofatumumab, which was tolerated and produced a response in 80% of these cases. The rate of rituximab discontinuation due to intolerance may be higher in patients with WM than in patients with other B-cell disorders, and the authors suggest further research to confirm this finding and to clarify the mechanisms behind it.

Phase I Study Looks at New BTK Inhibitor – A multi-center study published in the journal *Blood* included results of a Phase I dose escalation of the oral BTK inhibitor ONO/GS-4059 in 90 patients with relapsed/refractory B-cell malignancies. The drug was well tolerated with significant activity. No maximum tolerated dose was reached in the chronic lymphocytic leukemia (CLL) cohort of the study, which appeared to achieve better results; most adverse events were hematological and resolved spontaneously during ongoing therapy. In the non-Hodgkin's lymphoma (NHL) cohort, the maximum tolerated dose was 480 mg/daily.

New Investigational Drug Combines Anti-CD20 Monoclonal Antibody with Interferon – Valor Therapeutics recently announced that the US Food and Drug Administration has approved a new investigational drug application for IGN002, which consists of an anti-CD20 monoclonal antibody attached to interferon, a hormone-like protein made by white blood cells to help the body's immune system fight disease. This approval allows Valor to initiate a Phase I clinical trial of IGN002 in patients with non-Hodgkin's lymphoma (NHL).

IVIg May Increase Risk of Blood Clotting Events in CLL and MM Patients – A multi-center study reported by the University of Iowa found that administration of IVIg (intravenous immune globulin) to prevent infection may contribute to the risk of thromboembolic events in older patients with hematologic malignancies. Thromboembolic events are caused by blood clots that form in a blood vessel, break loose, and travel through the bloodstream to plug other blood vessels. This retrospective analysis included patients diagnosed with chronic lymphocytic leukemia

Medical News Roundup, cont. on page 13

(CLL) and multiple myeloma (MM) and indicated that the risk was especially higher during the first day following IVIg treatment.

Positive Results Bring Early Stop to Phase III Trial of Idelalisib Combined with Bendamustine and Rituximab in CLL – A Phase III trial of idelalisib (Zydelig) in combination with bendamustine and rituximab (BR) for patients with previously treated chronic lymphocytic leukemia (CLL) was stopped early following a positive interim analysis. Patients in the control arm were then allowed to receive idelalisib. The study enrolled 416 CLL patients, who received 6 cycles of BR with either oral idelalisib administered at 160 mg/ twice daily or placebo. In data from a median follow-up of 12 months, the median progression-free survival was 23 months for BR plus idelalisib compared to 11 months for BR alone. The most common adverse events in the idelalisib arm of the study were neutropenia (reduction in neutrophils), liver enzyme abnormalities, and fevers. Grade 3 or greater diarrhea occurred in 7.2% of idelalisib patients, and pneumonitis in 1.4%. Idelalisib, a PI3K delta inhibitor, was developed by Gilead Sciences, and the company is planning to submit the data to the US Food and Drug Administration and the European Medicines Agency in early 2016.

NIH Study Looks at Association of Shingles with Cancer Occurrence – A poster study presented by the National Institutes of Health suggests that the occurrence of shingles (herpes zoster) may result in a modestly increased risk for several cancers, especially hematologic malignancies. Using the Surveillance, Epidemiology, and End Results (SEER) database, 1,108,986 cases of people 65 years and older with first cancers identified from 1992-2005 were analyzed, with a matching control group of 100,000 cancer-free persons. Significant associations were seen between shingles and oral cavity/pharyngeal, colon, lung, and non-melanoma skin cancers; multiple myeloma (MM); diffuse large B-cell lymphoma (DLBCL); lymphoplasmacytic lymphoma (LPL); and chronic lymphocytic lymphoma (CLL)/small lymphocytic lymphoma (SLL). For LPL, the strongest association occurred when shingles was 60+ months prior to the cancer diagnosis.

The author gratefully acknowledges the efforts of Peter DeNardis, Charles Schafer, John Paasch, Wanda Huskins, Colin Perrott, Howard Prestwich, and others in disseminating news of interest to the IWmf-Talk community. The author can be contacted at suenchas@bellsouth.net for questions or additional information.

FROM IWmf-TALK

BY JACOB WEINTRAUB, MD

Now that winter is here and the holidays are over, we can look at the timely topics that filled the fall season. As always, there was wide ranging discussion from Imbruvica (ibrutinib), to use of intravenous immune globulin (IVIg), to questions about WM from new members just joining our group, to treatment in general and places to find treatment.

HUMAN INTEREST/ARTICLES

IWmf-Talk Manager and Trustee **Peter DeNardis** posted several items of general interest for all readers.

Pete cited a news article from the *Los Angeles Times* about a research study showing that cancer survivors on average eat a less healthy diet than the general population. Especially noted were diets with less fiber and more empty calories. latimes.com/science/sciencenow/la-sci-sn-cancer-survivor-nutrition-20151009-story.html

Pete posted a discussion about financial assistance for US patients taking Imbruvica and other treatments. He noted that the IWmf is aware that the potential cost of novel oral medications such as Imbruvica is a growing concern to the WM community. The Johnson & Johnson Patient Assistance Foundation provides assistance to uninsured US patients with limited financial resources. Their website is www.jjpaf.org

Further, the IWmf website has a link to a website that lists other nonprofit foundations and pharmaceutical companies who also can help patients with limited financial resources to find help with drug co-pays.

<http://www.iwmf.com/get-support/financial-assistance>

Wanda H also brought to our attention a number of articles and websites of general interest and some specifically directed to WM patients.

Wanda noted that Mayo Clinic has a noteworthy blog on living with cancer. The following may be helpful when organizing ideas for a second opinion or if a person is considering transferring care.

mayoclinic.org/diseases-conditions/cancer/expert-blog/cancer-treatment-second-opinion/bgp-20056385/

Another article Wanda recommended is by Toni Bernhard in *KevinMD*. This article shows what it is like to live with a chronic illness and how to adapt. It includes a discussion about friendships, personal judgment, and caregivers, among other aspects of life.

kevinmd.com/blog/2011/08/10-tips-10-years-sick-html

Finally, Wanda posted a link to an article in *Slate* entitled “Winning the Battle Against the Phrase ‘Battle with Cancer’.”

The article cites a press release from the family of actor Roger

From IWmf-Talk, cont. on page 14

Rees who was reported to have passed away after a “brief journey with cancer.” The article related how current bloggers and other writers have moved away from the terminology of “battle,” using other descriptions for a person’s current interactions with his or her cancer. This especially seems to be appropriate to us with WM, who are living for longer and longer periods of time with our disease.

slate.com/blogs/lexicon_valley/2015/07/30/how_battle_with_cancer_is_being_replaced_by_journey_with_cancer.html

IMBRUVICA (IBRUTINIB)

Although Imbruvica is quickly becoming one of the more standard treatments for WM, it is still relatively new and generates significant discussion. The questions raised on IWMF-Talk come from people who have been on other treatments and are now considering a change to Imbruvica (ibrutinib), from others who have not yet had any treatment, and from people who have been taking Imbruvica and have questions about effectiveness, adverse effects, and other aspects of treatment.

Hank S reported that at his annual visit with Dr. Jorge Castillo at Dana-Farber Cancer Institute, Hank was told that taking flaxseed oil supplement was allowed. However, the staff is recommending that patients taking Imbruvica should avoid St John’s Wort, Ginkgo Biloba, and fish oil supplements.

Scott W reported that he has been told that studying the mutations identified by Dr. Treon’s group can now be used to tailor treatment for WM patients. Clinically distinct subgroups of patients are being found. Responses to treatment appear to vary based on molecular signatures, specifically alterations in MYD88 and CXRC4.

<http://www.targetedonc.com/news/waldenstroms-macroglobulinemia-should-be-treated-according-to-genetics>

Delrina C posted a link to an article mainly related to chronic lymphocytic leukemia, but which has the “Top 15 Questions about Ibrutinib.” This includes issues relevant to WM and many of the discussions that have occurred on IWMF-Talk about this med. Questions include those related to bruising, starting at the full dose, holding the med before surgery, development of fatigue, and long term effects. The person answering the questions is Dr. John Byrd of the Ohio State University Medical Center.

<http://cillsociety.org/newsletter/ask-the-doctor/top-15-questions-about-ibrutinib/>

Donna C reported she developed acute liver failure while taking Imbruvica. This appears to be the first case ever reported of liver failure associated with Imbruvica. Donna had been treated in the past with other drugs for WM. When taking Imbruvica she began noticing fatigue, worsening to the point of being “overwhelming,” but it was thought just to be a side effect of the med. Then her condition worsened. She now is completely off Imbruvica and feeling better, and she is expected to make a complete recovery from her liver failure. She will try to stay off all treatment for as long as she is able to do so.

INTRAVENOUS IMMUNE GLOBULIN (IVIg)

Maria C reported that she completed a course of bendamustine and Rituxan 3 years ago and is doing well. However, she has had 2 upper respiratory infections and has needed to be treated with antibiotics. With IgG levels low, she was asking about the need for intravenous immune globulin (IVIg). She had spoken to her oncologist in the past, and he had said then that he will only give it to her if she is very sick.

Dr. Jacob Weintraub responded that Maria should follow her oncologist’s recommendation. She has had only two infections and both responded to antibiotic treatment, although if the infections were viral, the antibiotic would not have made a difference anyway. Just having a low IgG level in the blood is not necessarily a reason for IVIg treatment. Jacob reported that his IgG is very low despite not having had any treatment, and his hematologist at Mayo Clinic won’t begin to consider IVIg unless he starts to develop multiple severe infections. In addition, he noted, IVIg has its own possible severe adverse effects.

John then asked what are some of the possible severe side effects from IVIg. He has had IVIg and did not have any adverse effects except rigors when he did not receive premedications. **Jacob** reported potential adverse effects could include anaphylaxis, thrombosis, other allergic/hypersensitivity reactions, kidney injury, and hemolysis.

Jerry B recalled that after receiving IVIg he had a significant increase in IgM and M-spike. After stopping the IVIg, his IgM and M-spike both went back down to prior levels.

Pat G then reported ongoing significant problems when she received IVIg. With each IVIg dose, her IgM rose, reaching 4250. It went down when IVIg was discontinued for 6

From IWMF-Talk, cont. on page 15

HOW TO JOIN IWMF-TALK

Here are two ways to join:

1. Send a blank e-mail to: iwmf-talk-subscribe-request@lists.psu.edu
Make sure to enter the word “subscribe” as your subject, and do not sign or put anything in the message area (make sure you do not have any signature information in there). Also, do not put a “period” after “edu” or it will reject. Once approved you can post by sending e-mail to iwmf-talk@lists.psu.edu
2. Contact Peter DeNardis at pdenardis@comcast.net and provide your full name

months. She next had IVIg restarted when she developed a new infection. Her IgM went back up above 4000, and her serum viscosity became elevated. After listening to Dr. Ansell's talk at the IWmf Ed Forum, she said that Rituxan binds to monocytes, thereby stimulating the release of IL-6, which in turn binds to WM cells and triggers IgM flare. However, she has not completely ruled out further treatment with IVIg, depending on the severity of her infections.

BENDAMUSTINE

There has not been as much discussion about bendamustine, since Imbruvica has been so prominent. However, "benda" remains a mainstay of current treatment, and many people report very significant responses to treatments that include bendamustine.

Pat G reported she had a significant drop in IgM after only 2 doses of bendamustine at a reduced dosage due to her rocky response to IVIg. She asked if others have had the same result.

John P reported he did not have a flare when Rituxan was given with bendamustine. This was in response to a question about response to treatment from a person who has had significant IgM flare from IVIg. He reported his IgM went down to 647 a couple of months after 6 cycles of treatment. However, he later developed enlarged lymph nodes and currently is taking Imbruvica. He wondered if Imbruvica can be more effective if it follows another form of treatment.

Anita L also reported treatment with bendamustine and Rituxan. Her IgM decreased to a low of around 500. That lasted for about 3 years. She then developed enlarged lymph nodes, resulting in subsequent additional treatment, this time with Imbruvica.

Jim reported a long history of treatment with other meds. He had a significant Rituxan flare and as a result stopped that treatment. His IgM was as high as 9000. After that he was started on treatment with solo bendamustine for 6 months, his IgM then dropping to 800. Treatment was completed in April 2013, and so far he has not needed any further treatment, although his IgM has now started to increase again.

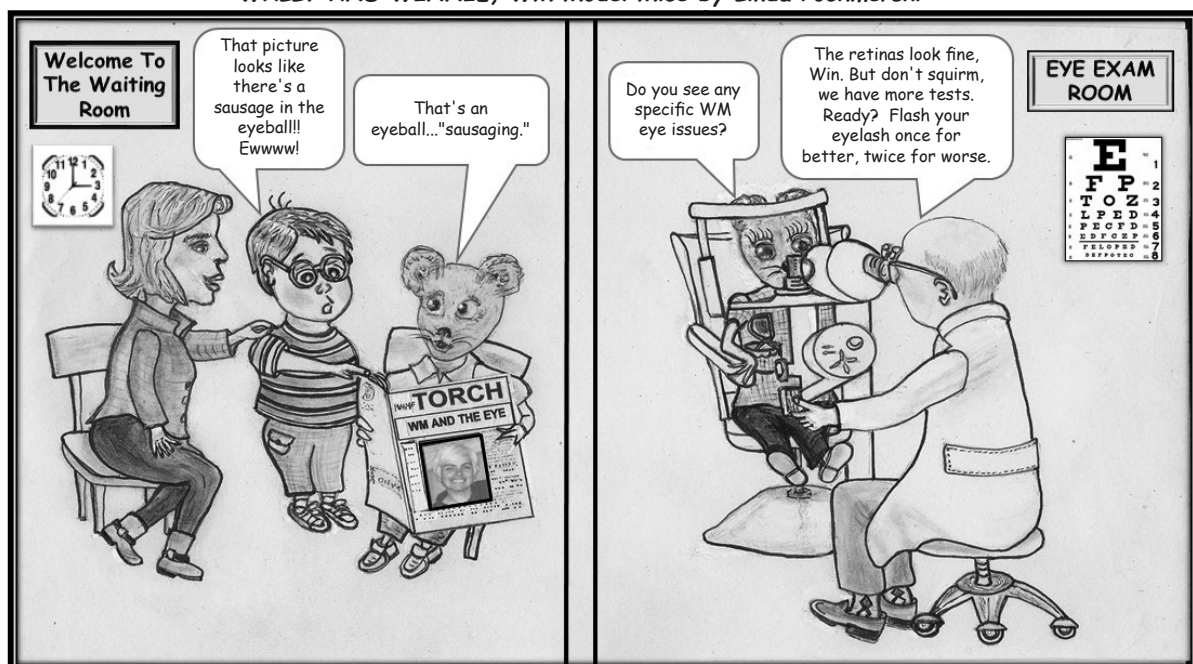
Dr. Jacob Weintraub suggested that Jim's excellent and long response might be, in part, also related to his Rituxan treatment, even though he had a significant flare. Some people have reported very little initial response (or a flare) to Rituxan, but over time a longer, more sustained improvement.

Kenneth L reported he just finished 2 years of Rituxan maintenance after treatment with bendamustine and Rituxan. IgM has been as low as 289, now up to 549, and hemoglobin is 15.7. He has had no significant side effects, only an occasional rash on his feet and hands. The rashes itched but went away after 4 days. Kenneth still feels energetic and "looks like a 60-year old" although he is actually 70.

There was some sad news this month when we learned of the death of long-time IWmf-Talk participant **John Eldridge**. Many IWmf-Talk members voiced fond memories of John's posts and personal communications. He will be missed. Condolences are offered to his family.

In conclusion, the discussion on each of these subjects was far more extensive than can be covered here! Everyone is welcome to join the group, if only to "lurk" and listen, though opinions and shared experiences are always encouraged.

WALLY AND WINNIE, WM Model Mice by Linda Pochmerski



The article "Waldenstrom and the Eye" written by eye care professional Dr. Maureen Hanley (now easily located at iwmf.com BEST OF THE TORCH) discusses what can be done to protect your vision if you are a WM patient. When Wally turns the page to the "graphic eyeball" while waiting for Winnie, the diagram is an "eye opener" for the little boy peeking over his shoulder. Meanwhile Winnie, determined to be vigilant and protect her eyes - and Wally's too - schedules a complete dilated eye exam each year for the pair of them.

LRF WORKSHOP ON ORAL THERAPIES

BY ALICE RIGINOS, TORCH EDITOR

BASED ON REPORTAGE BY ELLY HARRINGTON

The new era of targeted oral therapies for cancer has arrived. Their ongoing development by pharmaceutical companies and their increasing use by lymphoma patients in the clinical setting are prompting lymphoma advocacy organizations to consider and discuss several areas of concern now being raised. WMers are just starting out on a path already broken by other lymphoma communities, some of which have had oral therapies available for ten years.

To address areas of concern, the Lymphoma Research Foundation (LRF) convened the Workshop on Oral Therapies in Lymphoma: Scientific, Policy and Regulatory Considerations on September 10-11 at the Omni Shoreham Hotel in Washington DC.

The Workshop was attended by representatives of some 20 major cancer research centers in the US, 4 pharmaceutical companies, professional medical societies such as the American Society of Hematology (ASH) and the American Society of Clinical Oncology (ASCO), as well as officials of the US Food and Drug Administration (FDA) and members of the United States Congress. Patient advocacy organizations were also represented. President Carl Harrington, Mitch Orfuss, and Elly Harrington represented the IWMF.

The focus of the Workshop was especially timely for the IWMF, since the first drug for WM to be specifically approved (and only in the past year) by the Food and Drug Administration is orally administered Imbruvica (ibrutinib).

Lymphoma communities, to quote the Workshop Overview and Agenda, have “entered a new era in which targeted oral anti-lymphoma agents with substantial clinical activity are quickly changing treatment paradigms and providing a unique opportunity to improve patient outcomes and survival.” Oral cancer therapy is emerging as a viable and important option for patients who can manage the prescribed dosing regimens and recognize possible complications.

The aim of the Workshop was to consider the issues raised by oral therapies for scientists driving research forward, for patients considering access to these new drugs, and for the pharmaceutical companies producing them. As so many diverse organizations were represented, it is not possible to summarize here all the differing positions and opinions advanced by the participants. What follows are the highlights of the Workshop.

Following the opening dinner on Friday, US Congressman Brian Higgins (26th District-New York) and US Congressman Leonard Lance (7th District-New Jersey) spoke of their motivation in sponsoring legislation to provide for equal access to new oral treatments – in other words, oral parity. And welcome words, too, because the adoption of parity for oral drugs would lead to costs comparable to those for intravenous chemotherapeutic drugs administered in a clinical setting. Also noted by the speakers was the fact that many of the new drugs are the product of research funded by the federal government.

Saturday morning’s speakers from the research community spoke of the profound impact of oral therapies on the treatment of lymphoma, especially chronic lymphocytic leukemia (CLL). Several referred to assessing the “value” that a patient places on a course of treatment which has been decided upon after consultation between patient and physician. Value was described as an accumulation of variables: effectiveness, safety, impact on quality of life, convenience, and cost. Patients may select an oral treatment because of the appeal of prolonged response, its convenience, the elimination of frequent clinical visits, and a greater sense of control over their own care. The value of a specific therapeutic regimen needs to be considered in terms of the pros and cons of each variable.

A patient’s perspective on several concerns raised by oral cancer therapies was presented by IWMF patient, support group leader, and advocate Mitch Orfuss. Mitch spoke from his personal experience with ibrutinib in a clinical trial setting. He described his deliberate avoidance of a toxic chemotherapy regimen when he had symptoms needing treatment and his insistence on joining a clinical trial for the targeted oral anti-lymphoma agent ibrutinib, then untested for WM. For Mitch, ibrutinib has provided great value: he feels robust and he maintains his work schedule without interruption. He has no qualms about continuous therapy. However, because he is still on a clinical trial, he has not had to worry about the economic impact of ibrutinib.



At the LRF Workshop, from l. to r.: Mitch Orfuss, Susan Thornton (CLF), Meghan Gutierrez (LRF), Carl Harrington.

The concluding session of the Workshop, however, faced the “bitter pill” to swallow with oral therapy: its cost. What percentage of patients can afford the \$118,000 out-of-pocket cost of ibrutinib? Some patients are known to have economized by reducing the prescribed dosage and taking fewer pills – a very risky practice. Examining the ways in which financial considerations impact patient access and the quality of care, some speakers placed responsibility for this predicament on current “insurance policy trends” and on the limitations on total health spending by the government. The cost of research and development borne by the pharmaceutical industry was also noted.

The LRF Workshop was developed to “set the agenda” for continuing the discussion of oral therapies and establishing the issues which are important from the perspectives of cancer researchers, lymphoma patients, pharmaceutical companies, and legislators. We expect to hear the 2015 LRF Workshop referred to in the future as a milestone in developing this discussion.

IN THE TORCHLIGHT: LARRY ANDERSON, MD



Dr. Anderson at the Grand Finale, a gala celebration when the LLS-sponsored "Man & Woman of the Year" winners are announced.

degree in immunology from MD Anderson Cancer Center and the Graduate School of Biomedical Sciences/Health Science Center, University of Texas at Houston. Dr. Anderson then completed his internship and residency in internal medicine at the Graduate School of Medicine, Mayo Clinic, followed by a fellowship in medical oncology at the University of Washington Medical Center and Fred Hutchinson Cancer Research Center, where he later served as a research associate.

Since 2008 Dr. Anderson is Assistant Professor at the University of Texas, Southwestern Medical Center, Department of Internal Medicine, Division of Hematology/Oncology. A specialist in plasma cell cancers and bone marrow transplantation, Dr. Anderson treats a number of patients with Waldenstrom's macroglobulinemia in his practice at Southwestern Medical Center.

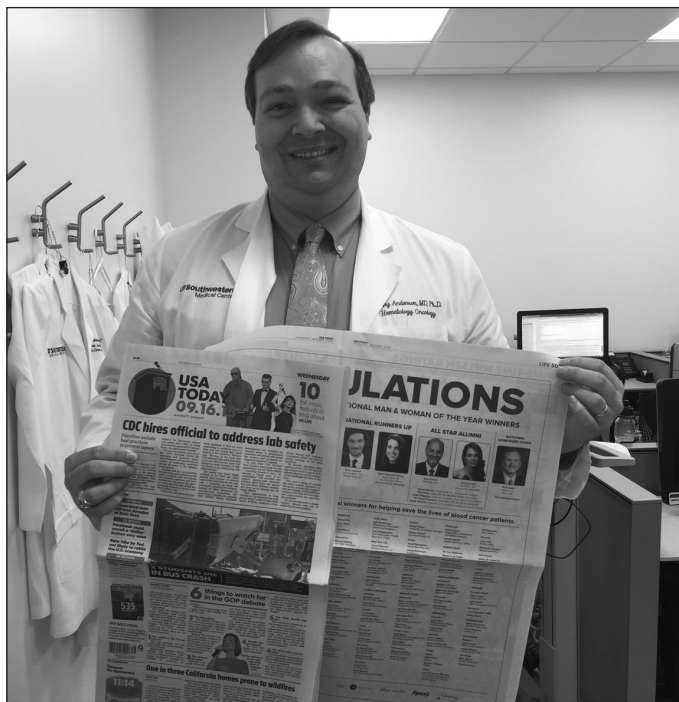
"Man & Woman of the Year" designations are earned by raising funds for LLS to further blood cancer research. Candidates for these titles, as described on the Man & Woman of the Year website (wmoy.org), are "compassionate and relentless in their desire to find cures for blood cancers." Those who achieve the title

When word reached the *Torch* that Dr. Larry Anderson was named 2015 Man of the Year for North Texas by the Leukemia & Lymphoma Society (LLS), it seemed only proper to cast our Torchlight on this outstanding young oncologist who was such a welcome addition to the roster of speakers at the 2015 IWMF Educational Forum.

Dr. Anderson's training began with a medical degree from the University of Texas Medical School at Houston, followed by a doctoral



The celebration in the Medical Center: Dr. Anderson was presented with a beautiful and delectable cake.



Dr. Anderson proudly displays the September 16, 2015, issue of USA Today. Section D, page 5, honors the winners of the "Man & Woman of the Year" competition.

of Man or Woman of the Year are honored in a celebratory event known as the Grand Finale, and they are thanked in a full-page display in USA Today.



To the admiration of the Medical Center staff, Dr. Anderson models a new sporty jacket announcing his title.

More importantly, they have the satisfaction of helping the LLS "invest more than \$1 billion in research to advance breakthrough therapies that are saving lives today and helping us all achieve the LLS goal of a world without blood cancers."

Congratulations, Dr. Anderson! We know you will continue to be both compassionate and relentless in treating your WM patients!

*The video of Dr. Anderson's presentation at the IWMF 2015 Ed Forum, "I Need Treatment – First-Line WM Treatments and Side Effects," as well as "Ask the Doctor" with Dr. Anderson as a participant, can be seen at iwmf.com—**MEDIA LIBRARY—VIDEOS—EDUCATIONAL FORUM VIDEOS***

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE



Thirty members and family members of the Finnish Waldenström's Macroglobulinemia Patients Group met in Lahti in conjunction with the Finnish Cancer Patients Association. On the far left – under the screen image of Jan Waldenström – is Veikko Hoikkala who organized this year's meeting and has been a dynamic presence since the Group's first meeting in 2006.

FINLAND

Wow, has it really been so long? The Finnish Waldenström's Macroglobulinemia Patients Group has been active since its first meeting in Turku in 2006. A lot has happened since, most of it generally good news, though that may not apply for each individual coping with this disease.

We can be pleased in terms of organization, new treatment options, and access to information. Still, there is no reason for complacency. Some of our members did share stories of their individual challenges in getting adequate information from doctors, for example, and some patients' treatment choices had turned into frightening if not life-threatening experiences. These things were discussed as part of the more informal aspect of our gathering at the Salpaus Hotel in Lahti on November 11, 2015. We also had the opportunity to chat during our lunch break at the hotel restaurant.

The formal part of the program included a presentation by Hannele Saloovaara, chairperson of the Lahti District local group of the Finnish Cancer Patients Association, describing the various practical ways that the association supports activities organized by numerous active patient groups like ours. We also had an excellent presentation on WM and its current treatment protocols from Dr. Tuomo Honkanen, whom we have come to rely on as a source of that important information we need in order to have a common language with medical professionals when discussing our treatment options. The importance of this cannot be stressed enough.

This year's meeting, attended by 30 patients and family members, was once again organized by Veikko Hoikkala.

Veikko has been such a dynamic figure in our patient organization, and this year he had some welcome help from Juha Wirekoski. Both Tuomo and Juha now serve on the board of the Finnish Cancer Patients' Association. Though we WM patients are small in numbers, nationally we are well and duly represented!

We also have our "members only" Facebook group for sharing our common concerns and joys and an e-mail list is in the works, so that we can also reach those patients who may not find it convenient to travel to our yearly meetings.

Report and photos by Taina Lukkaroinen, 6th year in remission!



Presenters and organizers of the Educational Forum in Calgary held in September. From left to right: Stu Boland (Calgary support group leader), Dr. Mona Shafey, Dr. Kareem Jamani, Dr. Julie Nielsen, Caitlin Hill, Arlene Hinchcliffe, Dr. Guy Sherwood, Cam Fraser (Calgary support group leader).

CANADA

WM CANADA FOUNDATION (WMFC)

On September 26 we held our very first one-day Educational Forum in Calgary. Held at the Airport Courtyard Marriott, 44 people joined us for a full day of informative presentations. With the help of Stu Boland and Cam Fraser, the support group leaders of Calgary, the event was a great success.

Dr. Guy Sherwood, Vice President for Research of the IWMF, outlined the current research projects that are funded by the IWMF for Waldenström's macroglobulinemia along with the exciting new IWMF-LLS Strategic Research Roadmap initiative to further our knowledge in four key domains of WM research. Dr. Sherwood also shared his journey living with WM from diagnosis, the treatments he chose, and ultimately a bone marrow transplant. Guest comments: Inspirational story of hope! INSPIRING!!!

International Scene, cont. on page 19

Dr. Mona Shafey, Clinical Assistant Professor of the University of Calgary, presented on the risk factors for WM, pathogenesis of WM, and IgM and hyperviscosity syndrome. Dr. Shafey covered the diagnosis of WM and the various tests from blood counts, CT scans, and bone marrow biopsies needed to conclude the presence of WM cells. She outlined treatment options including watchful waiting, plasmapheresis for hyperviscosity, chemoimmunotherapy, and proteasome inhibitors, as well as ibrutinib, which is the first drug approved to treat WM. Ibrutinib is currently awaiting Health Canada approval, which will happen shortly. Guest comments: Well done, topic well covered. Excellent information!

Dr. Julie Nielsen of the British Columbia Cancer Centre gave a recap of the research project the WMFC is presently co-funding on harnessing killer T-cells. They are working on developing an entirely new form of treatment for WM that uses the power of genomics to turn patients' immune system against their cancer. They are particularly interested in the killer T-cells of the immune system. The T-cells are expected to recognize and destroy WM cells throughout the body, leading to improved cancer control. Guest comments: Very exciting, passionate, and optimistic!! Great to hear of research in Canada!

Dr. Kareem Jamani, Specialist in Hematopoietic Stem Cell Transplantation, University of Calgary, addressed the topics of disease transformation and incidence of transformation in WM. Dr. Jamani outlined the procedure for a stem cell transplant and criteria for candidates for this procedure. The last topic discussed was the importance of clinical trials and how one can become a participant, along with the pros and cons. Guest comments: Dynamic speaker!! Very good information and well presented!

Caitlin Hill, MPH, RD, presented an overview on the benefits of a good diet before, during, and after chemotherapy. Ms. Hill discussed how to combat taste changes that occur during treatments, calorie and protein requirements, and nutritional supplements as well as foods that help fight cancer. She also addressed three dietary myths:

Myth #1 sugar feeds cancer: there is no evidence that eliminating sugar from your diet will stop cancer growth. Both cancerous and healthy cells use this energy for nourishment.

Myth #2 the alkaline diet: this diet suggests that cancer cells thrive in an acidic, not an alkaline, environment. Changes in your body pH are life-threatening.

Myth #3 dairy free, gluten free: if you are not experiencing symptoms, there is no reason to avoid any foods.

Guest Comments: Great information, timely and much needed!! Excellent addition to the conference!

The WMFC will continue to reach out to our members across Canada.

Arlene Hinchcliffe, President WMFC, reporting.
wmfc.ca



The Nova Scotia Support Group at their October meeting. First row, from l to r: Joy Tarasuk, Manager of Ambulatory Clinics for the Queen Elizabeth II Health Centre in Halifax NS; Tanya Hastings (LLSC); Arlene Hinchcliffe (WMFC); Dr. Robert Kyle, center row. Dr. Wanda Hasegawa is in the center, second row.

NOVA SCOTIA

Dr. Robert Kyle from the Mayo Clinic, Rochester MN, informed and enlightened members of the Nova Scotia support group in Halifax last October with his presentation on WM. Dr. Kyle was emphatic that it is important to understand your blood tests. Local hematologist Dr. Wanda Hasegawa joined him for an "Ask the Doctor" session.

Arlene Hinchcliffe, president of the WM Foundation of Canada, brought the group up to date on the recent Educational Forum in Calgary and underlined the importance of doing our part to support WM research. We contributed to an In Memory gift for long-time member Judy Greenwood.

Thanks also to the local Leukemia and Lymphoma Society of Canada patient education and services manager Tanya Hastings for her continued organizational and financial support of our group.

Ron Ternoway reporting.

BELGIUM

CMP Flanders, the Belgian Flemish multiple myeloma (MM) and Waldenstrom's macroglobulinemia support group, organizes a major symposium once a year, usually in the spring. In the autumn regional managers of the Flemish regions organize meetings for their local members. This year there were five such meetings.

The volunteers responsible for the Flemish regions (Antwerp, Brussels and Flemish Brabant, East Flanders and West Flanders), are free to organize as they choose. They know that the policy of CMP prioritizes patients' needs. They know better than anyone else their members' wishes and needs.

The region of Flemish Brabant was the first to have a meeting. On September 15, 22 fellow sufferers came together to listen to Herman Baeten, a nurse and nursing instructor. He

International Scene, cont. on page 20

considers it important that the nursing staff try to live in the skin of the patient. Therefore he uses role-playing. Herman Baeten's presentation had four parts: what is pain; causes of undertreatment; treatment; his ten commandments. His final definition of pain is: Pain is what the patient says it is, where it is, and when it is. He insisted that it is important to describe precisely what you feel and to ask for information about the treatment. The audience kept asking questions about their problems. Most were multiple myeloma patients, and they were very grateful for the knowledge imparted about pain and its treatment. Time was too short to fully exchange views and experiences, and everyone agreed to continue the mutual discussions at the next meeting, the symposium planned for 2016. Finally, participants were invited to submit questions in writing to be answered at the next regional meeting.

September 26 was a big day for West Flanders. After some years of profound silence, two courageous volunteers, one for MM and one for WM, made the decision to shake up this region. And they scored with their first attempt. In sunny Ostend, at a spacious and pretty location along the coast, 36 interested people came to listen to Dr. Steven Van Steenweghen who explained how both diseases manifest themselves and are treated. The sessions following such presentations usually give patients the opportunity to exchange comments on their experience with the disease. This time it was conducted in a new format. Without making a distinction between MM and WM, the participants were divided into two groups. The first group, led by the doctor, could submit their special problems for discussion. A second group was led by a clinical onco-psychologist. After the usual presentation, they were asked about restrictions and impediments due to their disease or treatment. They also got a few tips, such as "live consciously," and "believe in yourself and in the future." The psychologist finished by emphasizing the importance of the patient organization.

On the afternoon of October 16, 54 participants gathered in the hospital of Zoersel, a small town in the province of Antwerp. They were warmly received with cake and a drink, met newcomers, and shared experiences. Dr. Greet Bries of the general hospital of Turnhout, who had attended the September international workshop on multiple myeloma in Rome, explained the innovative medications and latest data on MM and WM. Her very interesting presentation was followed by an "Ask the Doctor" session.

East Flanders brought up the rear of the regional meetings. In years past it had become a tradition to hold the meeting in Ghent. Two years ago the leaders decided to choose a different location each year so that the participants were not always the same. On October 17, 60 participants met in Eeklo, and, sure enough, there we found the champion of the Belgian Waldenströmers, a spry 84-year old man, diagnosed in 1995 and still in the wait and watch stage! The center of attention for the day was Professor Dr. Tessa Kerre of the Ghent University Hospital who specializes in allogeneic stem cell transplantation. Dr. Kerre captivated the audience with

her presentation on immunotherapy, what it is, how it works, and how it can make treatment of MM and WM successful in the future. A difficult matter. But everyone understood the essential point: help your own immune system to defeat the cancer. The participants were then divided into smaller groups for the exchange of experiences, one group for WM, three for MM. Under the watchful eye of the regional leaders, many issues were discussed: the disease, the experience with the treatment, CMP Flanders and its collaboration with doctors, hospitals, even the role Europe can play in improving access to and reimbursement of innovative therapies.

The fifth region, Limburg, is a special case. In this region CMP Flanders works with Wildgroei, a support group for people with non-benign hematological diseases. Activities are organized by Wildgroei, but our members are invited and heartily welcomed.

In conclusion, I am very pleased to announce the next symposium of CMP on Saturday, April 16 2016 at Universitair ziekenhuis Brussel - Brussels Health Campus - Laarbeeklaan 101, 1090 Jette - T. 02 477 41 11 - E. info@uzbrussel.be. More information on cmp-vlaanderen.be

Joanna Van Reyn, CMP Vlaanderen, reporting.

ITALY

Less than a year following its inception, WM-IT, the Italian WM patients' group founded on the initiative of Associazione Malattie del Sangue ONLUS (Association of Blood Diseases; AMS) has reached the significant number of 50 members spread throughout the country. Our group has launched numerous initiatives aimed at informing members about AMS volunteer activities and responding to their concerns and questions about the disease WM. Our information exchanges are conducted online with AMS physicians responding to questions from patients about the evolution of the disease and treatment options and offering medical advice. Such information exchanges have allowed patients to become more aware of the manifestations of their disease and to reduce their anxieties.

FUNDRAISING INITIATIVE PROMOTED BY AMS

AMS is an Italian nonprofit organization that aims to support blood disease patients, including WM patients. In addition to voluntary donations, to support its activities the association sponsors numerous fundraising initiatives such as social events, including dinners and concerts.

A major fundraising initiative, thanks to collaboration with the IWMF, was carried out in late 2015, with the support of Janssen Pharmaceutica, a worldwide pharmaceutical company. AMS obtained a donation from Janssen for the translation and publication of IWMF booklets into Italian. Topics covered are basic immunology, medical tests, review of main therapeutic treatments, blood tests, questions and answers, and treatment options. The booklets will be available in 2016. Meanwhile, thanks to the collaboration



A composite photo catches some of the exuberance of the audience at the fundraising event Laugh4Rory, a night of stand-up comedy, put on by leading performers and organized by the late Rory Morrison's BBC radio colleagues.

of many members of the Italian patient group who made it possible to complete the work very quickly, the Fact Sheets with summary information about the characteristics of WM pathology and its current therapies have been translated and can now be downloaded directly from the IWFM website. The initiative is a good example of voluntary cooperation between AMS group members and strengthened the cohesion among the members themselves, thus confirming the fundamental response of the association to its members' needs.

Ermanno Chiavaroli, WM Italy, reporting.

UNITED KINGDOM

Initial assessment for treatment of relapsed WM with ibrutinib by the National Institute for Health and Care Excellence (NICE), the UK drugs gatekeeper, was scheduled for December. Both WMUK patients and doctors contributed to building a case for approval against a background of budget cuts. If successful, a full appraisal meeting will be held in 2016. National Health Service drug approval process is itself changing, and WMUK has input information to try to overcome the current system's discrimination against rarer diseases due to lack of Phase III trials information as currently required.

With clinical trials, the UK position has improved, and we have been able to include a trials page on our website for the first time. The investigator-led R2W trial (BCR versus FCR, led by Drs. Roger Owen and Rebecca Auer) was fully recruited six months ahead of schedule, with a follow up proposed, and one for ACP196 is recruiting very well at six sites. We have also promoted patient sign-ups to a late three-site addition to the Phase III Substudy (iNNOVATE™) ibrutinib trial at the request of Pharmacyclics. There are prospects of more trials in 2016, and WMUK is keen to encourage development of a UK WM trials gateway, as there is great enthusiasm from both patients and doctors to see more.

There is also progress on our registry and tissue biobank, although the latter was slowed by an unrelated accident to the technician. The WMUK board decided in principle that to speed the pace of genetic testing of DNA for mutations, it would raise funds to purchase 1000 kits to distribute to clinicians to take spit samples, this reinforcing the work of

Dr. Roger Owen at Leeds, where WMUK is helping fund a DNA testing postgraduate fellowship. We also agreed to fund up to three travelling fellowships to assist WM doctors to attend events such as IWM9 in Amsterdam. We are also keen to support the doctor-patient day at IWM9 on October 9 when a format has been agreed.

We have scheduled the first UK large scale clinical meeting for WM at the Royal Free Hospital, London, on March 16 and another regional doctor-patient meeting, likely in Bath, in early summer.

There have been two outstanding fundraising events for our research fund. Laugh4Rory (see photo), a night of stand-up comedy, put on by leading performers and organized by the late Rory Morrison's BBC radio colleagues, raised £8,200. A quiz night organised by patient Susan Peire raised over £7,000.

Finally we were delighted to hear that Dr. Surinder Sahota of Southampton had joined Dr. Roger Owen on the IWFM Scientific Advisory Committee. He is one of the UK's most distinguished genetic researchers in WM and multiple myeloma.

Roger Brown, WMUK, reporting from Epping Forest near London!

AUSTRALIA

SYDNEY NOVEMBER 2015 EDUCATION AND SUPPORT MEETING

A star cast and great organization attracted record numbers to the November 2015 Sydney meeting at Concord Repatriation General Hospital. WMozzies greatly appreciate the organizational work done by Madeleine Thompson and her Leukaemia Foundation team in its success. Madeleine specially arranged for the 47 attendees to meet in the University of Sydney Concord Hospital Education Centre. Presentations featured the history of IWFM, US patient experiences, and a specialist haematologist's WM overview. IWFM President Emerita Judith May and husband Michael generously gave up holiday time to attend the WM support meeting. Judith shared her personal insights into the twenty-one year history of IWFM's growth from a support group of 21 to 8,000 members. She told how successive IWFM

International Scene, cont. on page 22

Presidents Smokler, Rude, May, and Harrington's personal passion and energy has been so important to the successful growth of IWMMF. It was an inspiring message as WMozzies' membership of 100 is only 10% of the Australian WM population. WMozzies are greatly indebted to Ben Rude and Judith May in the establishment of WMozzies. Gareth Evans, an Australian member of IWMMF, established WMozzies as an email group in 2003. In 2004 Ben Rude announced that IWMMF would organise and fund the first meeting of WM patients in Australia. On Ben's death in early 2005, Judith became President and confirmed that IWMMF would hold the April 2005 meeting in memory of Ben. Sixty-seven persons attended the meeting in Sydney to hear the world's top three WM experts, Drs. Morie Gertz, Robert Kyle and Steven Treon.

Michael van Ewijk spoke next about his eighteen year WM survival experience. He told how his personal knowledge and involvement in treatment decisions were key in overcoming setbacks. It was particularly interesting to hear his clinical trial experience. Four WMozzies are in a similar clinical trial at Concord Hospital.

The final session was led by Associate Professor Judith Trotman, Senior Staff Specialist and Director of Clinical Research Unit, Department of Haematology, Concord Repatriation General Hospital, Sydney. Dr. Trotman gave an overview of WM diagnosis and treatment and then answered many questions. As well as Principal Investigator on the ibrutinib clinical trial at Concord, she is Principal Investigator in the BGB-3111 trial. One of her BGB-3111 WM patients attending told of his rapid improvement. At the conclusion of the meeting Dr. Trotman introduced Dr. Ibrahim Tohidi, Australia's newest WM researcher.



Judith May and Michael toured the Concord Cancer Centre in Sydney with Dr. Judith Trotman and Dr. Ibrahim Tohidi.

TOUR OF THE CONCORD CANCER CENTRE

Following the meeting, Dr. Trotman gave Judith and Michael a tour of the Concord Cancer Centre accompanied by Dr. Tohidi. Dr. Tohidi has joined the WMozzies CART-WHEEL research project in which Dr. Trotman is Principal

Investigator. The project aims to provide a tool for research analysis of WM patient-submitted details. The project is using the BioGrid computer database at Royal Melbourne Hospital. CART-WHEEL is operationally proven, ethically approved, and easy to use. It covers patient personal and disease history, treatment types and treatment outcomes. It includes key measures of disease progression and adverse events. Dr. Tohidi is involved in the specification of additional requirements and the ethical approval application.



Luncheon at Bondi Icebergs: Judith and Michael with Michael van Ewijk, WMozzies fundraising cyclist (left), and WMozzies leader Andrew Warden (right).

LUNCH AT BONDI ICEBERGS

In appreciation of their generously accepting our invitation to attend WMozzies' meeting during their Sydney holiday, Judith and Michael were hosted to lunch at Bondi Icebergs restaurant overlooking Bondi Beach. Also attending were Madeleine Thompson, Leukaemia Foundation Sydney support coordinator for WMozzies, Nina and Andrew Warden, and Michael van Ewijk. Madeleine was leaving shortly for her flight and her coast-to-coast cruise around the US. Michael van Ewijk and Andrew Warden are in the ibrutinib clinical trial at Concord Cancer Centre. It was good for them to share with Michael their mutual WM treatment experiences.

Michael van Ewijk is the first Australian WM patient in the ibrutinib clinical trial. Michael had returned that morning from a tour including bike riding in Holland and Iceland. In Holland Michael was able to continue his weekly 100 mile regime. Michael is a two-time WM fundraiser with rides in the Tour Down Under in Adelaide (wmozgies.com.au/index.php/about-us/our-history/foundation-gareth-evans) and Canberra to Sydney. He is also featured in the YouTube promotional video for Clinical Trials at the Concord Cancer Centre (youtu.be/M8sjwRAeugc).

Andrew Warden, WMozzies, reporting.

COOKS' HAPPY HOUR

BY PENNI WISNER

Late to the Party

The party began way back in 2010 when Yotam Ottolenghi published his first cookbook, *Plenty*, in the US (Chonicle Books). Then, just a few weeks ago, a friend sent me another of Ottolenghi's books, *Jerusalem* (Ten Speed Press, 2012). So I'm late. But I am now partying hard by cooking my way through *Jerusalem*, referring back to *Plenty*, and wondering about Ottolenghi's and co-author Sam Tamimi's *Plenty More* (Ten Speed Press 2014). If you do not know these books, then I encourage you to join the fun.

Ottolenghi and Tamimi were born the same year in Jerusalem, one on the Jewish west side, the other on the Arab east side. They are business partners in a group of London restaurants as well as writing partners. Take them into the kitchen with you this winter. Let them inspire you with about a gazillion ideas for cooking pumpkins, beets, kohlrabi, and cauliflower. Maybe winter will become your favorite cooking season. No, really! It's possible!

Start here: Take a whole winter squash, maybe the common butternut or something less familiar such as a kuri squash. Stab it a couple of times so it won't explode in the oven. Put it on a cookie sheet and bake it at about 375° F until very soft. When it's cool, scrape the flesh from the skin into a bowl. If your squash was large, you may have quite a lot of cooked flesh. No matter; it freezes perfectly. So. Take some of the cooked squash and put it in a food processor. Add some tahini (start with a tablespoon or so), a clove of garlic, a large pinch of good cinnamon, a large spoonful or so of plain Greek yogurt. Burr it up to a smooth paste and taste for seasoning. Add salt, pepper, more tahini or yogurt, and I like to add a pinch of cayenne. When ready to serve, spread the squash "hummus" on a plate, sprinkle with white (and black if you have them) sesame seeds, and drizzle with date syrup. No, don't get discouraged, you can substitute maple syrup. Serve with crackers or pita. And there you have it: a new winter cocktail partner. You can vary it by using different squashes and different seasonings, for instance adding za'atar instead of cinnamon. You will find the actual recipe on page 69 of *Jerusalem*. The above is my more relaxed adaptation.

The recipes, drawing on Middle Eastern cultures of all kinds including Ottoman, Arab, Jewish, and Italian, display an alchemical combination of Mediterranean flavors made exotic by the addition of Middle Eastern spices such as za'atar (an herb blend including thyme, oregano, sumac, and sesame), sumac (which has a tart, sour flavor not unlike tamarind), pomegranate molasses (you can simply boil down pomegranate juice as a substitute), harissa (a chili paste that includes cumin and caraway), and more. Need I mention

the health benefits of a Mediterranean diet? Heath is not a reason to cook this food: instead, cook it because it is flat-out delicious. (Oh dear, I sound like a tout.)

It used to be a bit of a hunt to track down these ingredients but no longer. Middle Eastern and Israeli cooking is having its moment in the limelight. Last winter I found a four-pack of herbs at Trader Joe's that included za'atar, zhoug, sumac, and pilpelchuma (all used in the Ottolenghi/Tamimi recipes). These blends mix common herbs and spices including cardamom, caraway, cumin, sesame, chiles, paprika, cilantro, thyme, oregano, and others. The books include recipes for the blends which you can then store in the freezer to use when you need "a little something" to jazz up a dish. Just today I plan to cook ahi tuna with a crust of pilpelchuma. You can find the spice mixes at many specialty grocers and online, too, for instance from the spice experts, Penzey's (penzeys.com).

Here's what you might expect if you make "puréed beets with yogurt and za'atar" (page 53 of *Jerusalem*): G, the man of the house here, looks askance at most ethnic cooking that is not recognizably Mexican or Thai. You can imagine his expectation when asked to try the beet dish. Reluctantly game, he dipped his focaccia (topped with za'atar) into the bright pink dip sprinkled with hazelnuts, scallions, and cheese and brought it to his mouth. A change came over his face. He smiled and dipped again. The puree, like many of the dishes in these books, is very simple: baked beets pureed with yogurt, olive oil, date syrup (or maple syrup), garlic, za'atar, salt, and a fresh, hot chile (I used a whole habanero I had on hand – whoops! The cool thing about such a dish is that I could simply add more yogurt to tame the heat and with a day in the refrigerator, the flavors blended and mellowed.)

I have my eye on a kohlrabi salad from the book. My mother loved kohlrabi, and so do I, but most folks are unfamiliar with its fresh crispness and slightly earthy flavor, close to radishes and turnips. The vegetable is cubed and the dressing blends Greek yogurt, sour cream, mascarpone (which is an extra bit of luxury that could be omitted easily), garlic, lemon juice, salt, pepper, and olive oil brightened with dried and fresh mint. The kohlrabi is tossed with the dressing and served with a scattering of winter greens, such as watercress or arugula, and a final dusting of sumac for a bright tartness.

Which brings me to a final point about these books: the photographs are just beautiful. The picture of the kohlrabi salad is what attracted me to the recipe. And here's the thing: when you cook from these books, your dishes will look just like the pictures! No food stylist necessary. There is a lot of good eating between now and spring asparagus, so enjoy.

Our motto: Eat Well to Stay Well

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

Please note!

Contact information for all support groups is found on *iwmf.com* under GET SUPPORT.

Details of support group meetings and other upcoming events are posted on *iwmf.com* under EVENTS.

COLORADO & WYOMING

On Halloween, Dr. Jeffrey Matous of the Colorado Blood Cancer Institute (CBCI) gave an update on WM to a near-capacity crowd at the Presbyterian-St. Luke's Hospital in mid-town Denver. Three attendees were first timers or newly diagnosed. Here's the capsule event summary: Gorgeous day! Fabulous speaker! Great food! Wish you were there! Seriously, all of that was true, and everyone enjoyed the uplifting, informative, and fun group discussion. Dr. Matous covered everything from the new genetic tests for diagnosis and whether they will be given to everyone or just those needing treatment, the success and issues of Imbruvica (ibrutinib), other treatments still doing a fine job of treating WM, and some of the new research for WM that looks promising for the future. Following his hour-long talk, Dr. Matous answered questions for about 45 minutes. Avella Specialty Pharmacy provided the food and drink. Specialty pharmacies like Avella supply oral drugs to many patients who are being prescribed Imbruvica. Such pharmacies also help with financial assistance, insurance company approvals, side effect issues with doctors, and more – lots of help to patients on new, expensive drugs. Five pharmaceutical representatives and nurses also attended. The meeting announcement had been posted at the CBCI and that brought in new people. Representatives from Leukemia & Lymphoma Society (LLS) also attended to update the group members on LLS financial assistance program and the upcoming 2016 Rocky Mt. Blood Cancer Conference, April 16, in Denver. In a wide-ranging discussion, the group also reviewed the 2016 IWMF Ed Forum location and dates, discussed the availability of so many great talks easily accessible on the IWMF website, shared many of the new booklets and the recent *Torch* magazine, and answered questions specifically about the IWMF and how the organization helps WM patients, caregivers, and doctors. New patients had the chance to meet others who live nearby or who are taking the same drugs. The meeting started at 9:30 and ended at 12:15, a very full morning altogether.

CONNECTICUT

Autumn in Connecticut can be quite spectacular. The vibrant rainbow of colorful foliage statewide was especially radiant this year. The display put on by the trees around Covenant Village in Cromwell delighted the 24 group members who met there in October. The meeting was facilitated by co-leaders **Bob Hammond** and **Gail Arcari** and was a mix of



Members of the Connecticut WM Support Group joined together in Cromwell, Connecticut, for a fall meeting with special guest, Jack Whelan (seated second row center).

information sharing, camaraderie, and a lively presentation by special guest speaker, **Jack Whelan**. Copies of The B-Cell, an informative and uplifting newsletter of the CT WM support group (published bi-annually in April and September) were available at the meeting. Support group members were encouraged to submit articles that would interest the WM community. In addition, printed materials about Waldenstrom's, published by the IWMF and LLS, were available as a welcome resource for the 15 members and 9 caregivers who attended the gathering. Gail briefly discussed programs and future events available in the area to WM patients and then introduced Jack Whelan, eight-year WM survivor and cancer research and legislative advocate. Sprinkling his talk with humor, he shared his insights and personal WM journey. Jack's story was featured in *Cancer Today* (Volume 3, Issue 3, Fall 2013) and he generously distributed copies of the magazine to all participants. Jack is the New England support group leader for the IWMF in the group that meets at Dana-Farber Cancer Institute in Boston. He offered valuable advice about being an informed patient in order to become an active participant in treatment decisions. Following Jack's informative talk, each member shared his or her WM journey. After the meeting ended, many of the participants joined together for dinner and conversation. The CT WM support group meets twice yearly in the spring and fall and welcomes all WMers and caregivers in Connecticut and surrounding areas.

ILLINOIS

Chicago Area/SE Wisconsin

Several first-timer families joined Chicago-area members (and some Wisconsin families as well) at the fall meeting held at the Lutheran General Hospital in Park Ridge, IL. The group divided into two breakout sessions, one for patients and one for

Support Group News, cont. on page 25



The Maine support group met for the very first time on October 17 at the Cancer Community Center in South Portland.

caregivers. The patients watched DVDs of two presentations from the 2015 IWMF Educational Forum: “Genomic-Based Treatment Advances” by Dr. Steven Treon of Dana-Farber Cancer Institute and “Diagnosed with WM – What’s Next” by Dr. Joseph R. Mikhael of Mayo Clinic in Arizona. Both videos were very well received. Many members had not heard of Dr. Mikhael prior to the session. Caregivers went to a separate room to discuss their particular issues. This session was led by support group member **Carolyn Hyser**, who is a licensed social worker. Thanks to Carolyn for her kind leadership.

INDIANA

Fifteen patients and caregivers met for a final visit of 2015 on a Saturday morning in early October. They described recent treatments, asked questions, and shared some laughs over coffee and bagels. The group viewed the DVD of the ever-popular “Weeds in the Garden” talk by Dr. Morie Gertz of Mayo Clinic. Afterwards group leader **Gayle Backmeyer** walked the members through the new IWMF website, demonstrating how easy it is to find and watch presentations from the Educational Forums.

MAINE

The new Maine support group was successfully launched on October 17. Dr. Helen Ryan and Tammy Weinberg RN of the New England Cancer Specialists were speakers. Dr. Ryan provided an overview of this rare cancer. She covered epidemiology, etiology, pathogenesis, clinical presentation, laboratory findings, diagnosis, treatment options, and much more. Ms. Weinberg discussed topics including minimizing side effects, navigating treatment, and support from the oncology office. (A copy of Dr. Ryan’s discussion can be

obtained from the support group leader, **Konnie Stinson**.) The meeting was held at the Cancer Community Center in South Portland, Maine. A number of WMers who summer in Maine but are away in the winter were saddened to miss this first meeting. Plans are afoot with the CCC for possible videotaping of future presenters.

NEW YORK

New York City

In November Dr. Lia Palomba of Memorial Sloan-Kettering treated the group to a repeat visit. So much has happened regarding treatments for Waldenstrom’s in the two-and-one-half years since her last visit, perhaps most importantly the arrival and approval of ibrutinib. With that leap forward as a baseline, Dr. Palomba discussed the clinical trials she is opening in the near future that attempt to build on recent successes. Dr. Palomba impressed the attendees with her dedication, kindness, and caring, and she promised to return in the future. Her talk prompted a larger-than-usual turnout of about 40 members. The New York group is fortunate that so many doctors focusing on Waldenstrom’s and other indolent B-cell lymphomas practice nearby and give generously of their time to help inform and educate patients.

Eastern NY/Western New England

In August more than 20 members celebrated summer at the group’s annual picnic at the American Cancer Society’s Hope Club in Latham, NY. Lots of great food fueled animated conversation including general discussion of topics of interest for future programs. One suggestion was to have someone speak about what should be considered ahead of time when

Support Group News, cont. on page 26



The Oregon-Southwest Washington group met in their new location in the Tualatin Community Center.

anticipating a funeral and how to plan for one. This program took place in September when Mike Barna, New York State Licensed Funeral Director and Sanvidge Funeral Home Vice President, gave an informative talk followed by an informal discussion. Everyone really appreciated Mike's presentation and learned a lot. Mike also joined the group for lunch. After lunch, our group leader led a general discussion of how to help those on the group's e-mail list who seldom respond or are unable to attend meetings. Fall plans included reaching out to these members with a survey. Then, in mid-November, the group met again to view DVDs of a couple of the sessions from the 2015 Ed Forum. Unfortunately, technical difficulties torpedoed those plans. Nevertheless, good discussions, followed by the traditional lunch, were greatly enjoyed by all. Several members indicated they would plan to attend the 2016 IWMF Ed Forum in nearby Providence, Rhode Island.

EASTERN OHIO, WESTERN PENNSYLVANIA & WEST VIRGINIA

Marcia and **Glenn Klepac** hosted a late-September get-together. A new member with MGUS attended with a specific goal: to understand the relationship of blood values to the progression from MGUS to WM and to get a sense of what it is like to be a member of the "WM Club." He was pleasantly surprised to find the WMers looking so healthy! A not unexpected result since this is an active group of individuals who enjoy swimming, walking, running, and participating in "Silver Sneakers" exercise programs. Another new member and WMer joined with others in sharing WM updates – most of the members reported the joy of remissions resulting from successful treatments. After viewing the 2015 Ed Forum DVD

"Ask the Doctor," – an informative and fun Q&A session among specialists who spoke at the Forum and moderated by Dr. Robert Kyle – the group enjoyed a variety of delicious potluck creations, followed by **Shari Hall's** yummy apple dumplings à la mode. In November the meeting site moved to the Cleveland area. The Parma Branch Library in Parma, OH, provided a very pleasant setting with state-of-the-art AV capabilities. Clare Grey, an oncological social worker at the Cleveland Clinic, presented a talk entitled: "Life after a Cancer Diagnosis: Strategies for Managing Stress and Finding Balance." Clare offered key suggestions for moderating stress with a focus on developing awareness of personal stressors and effective communication with caregivers. Members, including one new WMer, shared personal examples of stressors and helpful relaxation ideas. Members' concerns were addressed in an atmosphere of mutual help and support. The refreshment break transitioned into a very open sharing of WM status, feelings about treatment, and sorting out WM-related problems from other health issues.

OREGON/SOUTHWEST WASHINGTON

The group found a new home in the Tualatin Community Center. The room has wonderful amenities, plenty of space, privacy, and – best yet – comes free of charge. The community center also provides advertising for the support group meetings. The past two meetings have been spent with members getting acquainted and lots of sharing of WM experiences. New members have thoroughly appreciated the support of more seasoned and experienced members: Some have participated in clinical trials, many are stable after having had treatment, and others remain watching and waiting.



Guest speakers and volunteers at the November meeting of the Washington DC support group. Front row: Tish Davis, Bonnie Beckett, Dr. Clare Sun, Lu Kleppinger (SGL), and Elizabeth Bulatao. Back row: Tony Sablo' (Lu's husband), Jim Black, Dr. Adrian Wiestner, and Carol Mechling Bennett.

WASHINGTON D.C. METROPOLITAN AREA

In November a large group of 40 WMers and caregivers met in Fairfax, VA, to hear about the new National Institutes of Health (NIH) study of Waldenstrom's. Dr. Adrian Wiestner, Senior Investigator, and Dr. Clare Sun, Principal Investigator, of the National Heart, Lung, and Blood Institute (NHLBI) at the NIH, discussed their ambitious natural history study of Waldenstrom's. The goals of this study are to characterize findings that contribute to the disease's course, determine what the genetic events in disease development and progression are, how WM cells affect normal immune cells and vice versa, and how to improve treatments. The NHLBI study, originally designed solely for untreated WM patients, has been expanded to include all WMers. This decision by the Principal Investigators followed a survey of our support group members taken at an earlier meeting. The survey showed that more than half of the membership has been heavily treated. As part of their presentation in November,

Drs. Wiestner and Sun gave an overview of the NIH. As the largest source of medical research funding in the world, the NIH includes an impressive array of 27 research institutions and centers based in Bethesda, MD. Its mission is to provide global leadership for research, training, and educational programs to promote prevention and treatment of disease. Four of the support group members have volunteered to join the Advocacy Committee chaired by President Emerita Judith May to lobby Congress for support of IWMF initiatives. Team member **Bonnie Beckett** provided an excellent report of the Advocacy Committee's progress. She included sample letters group members may use as models to send to their Members of Congress regarding various legislative bills. Discussion touched on topics including insurance issues such as equal coverage of new oral treatments (in particular ibrutinib), Medicare coverage for treatment of Waldenstrom's, and how to promote greater awareness of WM.

Have Your Say

The *Torch* welcomes letters, articles, or suggestions for articles. If you have something you'd like to share with your fellow WMers, please contact *Torch* editor Alice Riginos at ariginos@me.com

showed no additional mutations in any of the studied genes. No relevant differences in progression-free or overall survival were seen in this series based on the presence or absence of mutations. The gene CD79B, which is part of the B-cell receptor pathway, was a frequently mutated gene in this series, emerging as an interesting therapeutic target.

The Clonal Architecture of CXCR4 Mutations in Waldenstrom's Macroglobulinemia Shows Highly Variable Subclonal Distribution, and Multiple Mutations within Individual Patients Indicative of Targeted Genomic Instability, Abstract #1486 – Whole genome sequencing has previously identified CXCR4^{WHIM} mutations in nearly 30% of WM patients, with over 30 different types of mutations described in CXCR4. These almost always occur with MYD88 mutations and impact both disease presentation and treatment outcome. This international multicenter study used both Sanger sequencing and highly sensitive AS-PCR assays to evaluate MYD88 L265P and the most common CXCR4^{WHIM} mutations in samples from 164 WM, 12 IgM MGUS, 20 marginal zone lymphoma, 32 chronic lymphocytic leukemia, 14 multiple myeloma, and 7 non-IgM MGUS patients, along with 32 healthy donors. By using these combined methods, CXCR4^{WHIM} mutations were identified in 43% of untreated WM, 34% of treated WM, 17% of IgM MGUS, and 5% of marginal zone lymphoma patients. They were not identified in the other patient sets or in healthy donors. In addition, multiple CXCR4^{WHIM} mutations were detected in many individual WM and IgM MGUS patients. Taken together, these findings show that CXCR4^{WHIM} mutations are more common in WM patients than previously revealed, and they are primarily subclonal, meaning that they were acquired after the occurrence of the MYD88 L265P mutation in the course of disease development.

Next Generation Sequencing Identifies a Distinct Transcriptional Profile, Including Isoform Dysregulation That Segue with Genomic Alterations in Waldenstrom's Macroglobulinemia, Abstract #128 – Dana-Farber Cancer Institute isolated bone marrow cells from 57 WM patients, as well as memory and non-memory B-cells from 9 healthy donors. An analysis was performed of the MYD88, CXCR4, and ARID1A mutation status, as well as common cytogenetic abnormalities, including amplifications in chromosomes 3q, 4, and 6p and deletions in chromosome 6q. Profiling showed a strong correlation of WM cells with healthy donor memory B-cells, their assumed cell of origin. Controlling for MYD88 and CXCR4 mutation status, the presence of ARID1A mutations and cytogenetic abnormalities generated distinct gene expression profiles and identified subsets of genes strongly associated with bone marrow disease involvement, serum IgM, and hemoglobin levels. Notably, increased bone marrow disease burden was associated with increased CXCL13 and decreased TP53 and RBL1 expression. Likewise, higher levels of serum IgM corresponded with increased IL27RA expression.

Characterization of MYD88 Mutated Lymphoplasmacytic Lymphoma in Comparison to MYD88 Mutated Chronic Lymphocytic Leukemia, Abstract #132 – German researchers analyzed bone marrow samples from 78 lymphoplasmacytic lymphoma (LPL) patients for MYD88 L265P by PCR and by next-generation (high throughput) DNA sequencing for both MYD88 and CXCR4 mutations. For comparison, 784 blood or bone marrow samples from chronic lymphocytic leukemia (CLL) patients were sequenced. In LPL, 87% harbored a MYD88 mutation, one of which was non-L265P; in contrast, only 2% of CLL carried a MYD88 mutation. Interestingly, several of these MYD88 mutations in CLL were non-L265P. Of the MYD88-mutated LPL, 25% also carried a genetic lesion in CXCR4 and 25% had a cytogenetic abnormality such as deletion of 6q (the long arm of chromosome 6). In the MYD88-unmutated LPL, no mutations in CXCR4 or deletions in 6q were identified, suggesting a different genetic driver event in this LPL group. In CLL, those patients with MYD88 mutations had no CXCR4 mutations or deletion of 6q.

THERAPEUTIC TARGETS IN PRECLINICAL DEVELOPMENT

VLX1570, a First in Class Dub Inhibitor, Modulates BCR Signaling and CXCR4 Expression and Demonstrates Significant In Vivo Antitumor Activity in a Murine Model of Human Waldenstrom Macroglobulinemia, Abstract #703 – Abnormal signaling in the B-cell receptor (BCR) and MYD88 cooperatively drive WM tumor cell survival. To sustain BCR-driven growth, WM cells upregulate proteasome function. This multicenter abstract looked at the use of inhibitors to Dub (proteasome-associated deubiquitinating enzymes) to investigate their effect on WM cell growth and survival. Specifically, the Dub inhibitor VLX1570 was tested in three WM cell lines, their drug-resistant derivatives, and bone marrow aspirates from WM patient samples at the Mayo Clinic. In bortezomib- or ibrutinib-resistant WM cells, VLX1570 induced > 50% apoptosis (programmed cell death) and displayed synergistic activity with ibrutinib. VLX1570 treatment also resulted in a significant decrease in CXCR4 expression in all WM cell lines tested and in patient WM cells. VLX1570-treated mice previously transplanted with WM cells demonstrated significantly lower tumor volumes as well as reduced serum human IgM compared to control mice; they also survived longer. These data provide the rationale for a clinical trial of single agent VLX1570 in patients with symptomatic WM.

HCK Is a Highly Relevant Target of Ibrutinib in MYD88 Mutated Waldenstrom's Macroglobulinemia and Diffuse Large B-Cell Lymphoma, Abstract #705 – This study found that HCK, which is a tyrosine kinase protein activated by IL-6, was over-expressed in WM bone marrow cells versus B-cells from healthy donors. It is also more highly expressed

in MYD88-mutated WM and ABC-type diffuse large B-cell lymphoma (DLBCL) cell lines versus wild-type (unmutated) MYD88 cell lines. Screening showed that HCK was a target of ibrutinib and binds robustly to it, thus identifying HCK as a novel and highly relevant target of ibrutinib in MYD88-mutated WM and DLBCL cells. The same was not true for another BTK inhibitor called AVL-292.

Targeting IRAK1/IRAK4 Signaling in Waldenstrom's Macroglobulinemia, Abstract #4004 – MYD88 L265P activates multiple downstream signaling pathways, including BTK and IRAK1/IRAK4, which support malignant cell growth and survival. Analysis of bone marrow cells from WM patients following > 6 months of continued ibrutinib treatment demonstrated highly active IRAK1 and IRAK4, but not BTK, suggesting that IRAK1/IRAK4 signaling may contribute to persistent WM cell survival following ibrutinib treatment. Inhibition of IRAK1 and IRAK4 resulted in reduced tumor cell survival and was more pronounced with IRAK1 inhibition. Combined BTK and IRAK inhibition also leads to decreased NF kappa B signaling and enhanced WM cell killing. This study provides a framework for the development and investigation of IRAK inhibitors, alone and in combination with ibrutinib in WM patients.

Targeting Myddosome Self-Assembly in Waldenstrom's Macroglobulinemia, Abstract #1563 – The Myddosome is a protein complex made up of a ring of six MYD88 proteins and four IL-1R-associated kinases that forms a helix and activates downstream signaling as a key part of the innate immune response. In WM cells, the MYD88 mutation promotes Myddosome self-assembly that triggers NF kappa B-dependent survival. Researchers demonstrated that the use of small peptides to interfere with Myddosome assembly can block downstream signaling, thus reducing NF kappa

B activation and tumor cell growth. The findings provide a framework for direct targeting of the Myddosome in MYD88-mutated WM disease.

DISEASE COMPLICATIONS

Defining the Incidence, Pathology and Clinical Outcomes of Kidney Disease Related to Waldenstrom's Macroglobulinemia and IgM MGUS, Abstract #3926

While kidney disease is a well-described complication of multiple myeloma, its incidence, pathological manifestations, and clinical symptoms in patients with WM or IgM MGUS remain to be clarified. Out of 1,738 patients with WM or IgM MGUS who were evaluated at Dana-Farber Cancer Institute from 2001-2015, this study selected individuals with at least one of the following abnormalities: serum creatinine ≥ 1.3 , estimated glomerular filtration rate (GFR) < 60 , or proteinuria (protein in the urine). A clinical diagnosis of WM/IgM MGUS-associated kidney disease was made in 57 patients (3.3%), of whom 41 had a confirmatory renal biopsy. Renal pathology in the 41 cases showed, in order of frequency from greatest to least: amyloid deposition, parenchymal lymphoplasmacytic infiltration, monoclonal light chain deposition, cryoglobulin deposition, light chain cast nephropathy, monoclonal IgM deposition, thrombotic microangiopathy, and minimal change disease. In 11 cases, multiple abnormalities were present. Patients with either amyloid or light chain deposition showed worse outcomes, including the requirement for dialysis. While treatment was associated with either improved or stable renal function in most patients, the optimal approach to management of WM/IgM MGUS-related kidney disease remains to be determined.

The author can be contacted at suenchas@bellsouth.net for questions or additional information.

Remember: Financial Assistance is Available

Financial assistance is available for qualified WMers through programs offered by the Leukemia & Lymphoma Foundation (LLF) and by the Patient Access Network Foundation (PANF). The qualification requirements and the procedures for application to both programs are laid out in the *Torch* issue 16.3 (July 2015) on pages 6 and 7.

SINCE AUGUST 2015, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION AND THE WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION OF CANADA WERE MADE IN MEMORY OF:

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Paul and Janice Rippas

Elaine Schenker

Jacqueline Brettler

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