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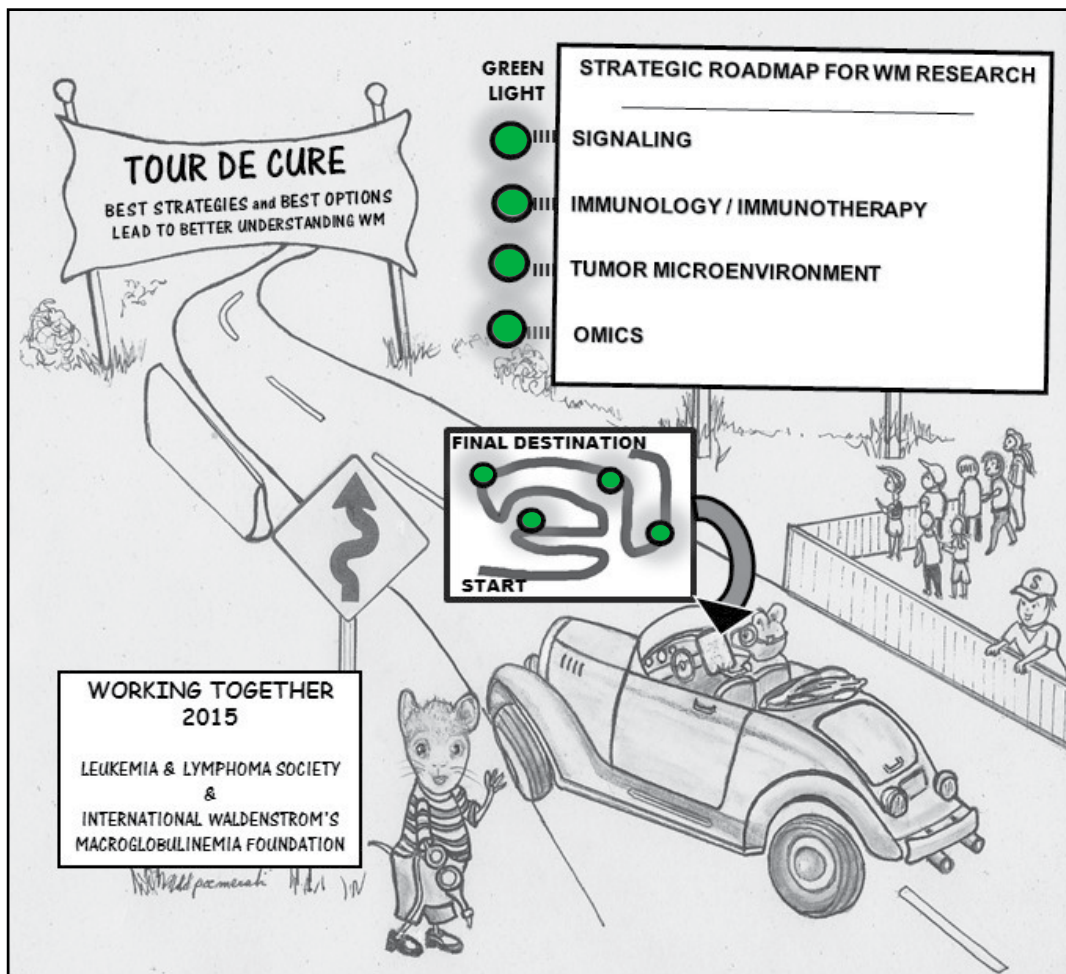
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## MAPPING THE WAY TO A CURE THE STRATEGIC RESEARCH ROADMAP CONFERENCE

BY CARL HARRINGTON, IWMF PRESIDENT

The Strategic Research Roadmap Conference was held on May 16 and 17 at Memorial Sloan Kettering Cancer Center in New York City. Partnering with the IWMF for this meeting was the Leukemia & Lymphoma Society (LLS), and the goal was to form a plan or roadmap for future research leading to a cure in Waldenstrom's macroglobulinemia. At first glance this partnership might seem surprising. After all, in the United States alone 156,420 new cases of leukemia, lymphoma, and myeloma are diagnosed each year, but of this number only 1,500 are new cases of WM.

MOUSE MODELS WALLY AND WINNIE ARE READY TO HIT THE ROAD



*The Strategic Roadmap for WM Research has now been declared and given the green light. Using the known pathways and navigational compass, we'll focus on the final destination: to complete our knowledge of what is unique to WM.*

*Mapping the Way, cont. on page 2*

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## Mapping the Way, cont. from page 1

Since WM represents less than 1% of blood cancers under the LLS umbrella, why would this much larger and more established organization be interested in WM? Here's why:

- There has been tremendous recent progress in understanding blood cancers related to WM and in understanding cancer in general, with results that seem applicable to WM.
- Recent progress in understanding WM, primarily identification of the MYD88 L265P genetic mutation found in 90%+ of us, indicates a clear objective that is applicable to almost all WM patients, in contrast to many other cancers.
- The IWMF and the LLS have a strong history of past partnership and an active current one.
- The IWMF community is very cohesive, well educated in its disease, and willing to contribute time and money and to enroll in clinical trials necessary to find the cure.

Now let me share what went on at the meeting:

### Who was there?

The attendees were a virtual Who's Who among WM researchers and clinicians. See page 4 for the list of illustrious attendees. Once again, WM researchers demonstrated their extraordinary commitment by giving up yet another weekend to come to the meeting with no compensation. And, as you'll see from the list, many traveled thousands of miles to attend.

### Who led the meeting?

Dr. Lee Greenberger, Chief Scientific Officer of LLS, presided over the meeting. The two scientific leads were Dr. Steven Treon and Dr. Stephen Ansell.

### What were the four research targets discussed at the conference?

The conference was divided into four sections corresponding to the research targets that have been "given the green light" for WM. Teams of two WM specialists led the discussion in each section:

- *Signaling*: What are the pathways that WM cells use for communication?  
Dr. Steven Treon; Dr. Richard Furman.
- *Immunology/Immunotherapy*: How can we better use our own immune system to fight WM?  
Dr. Stephen Ansell; Dr. M. Lia Palomba

*Mapping the Way, cont. on page 3*



The IWMF Torch is a publication of:

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- **Tumor Microenvironment:** How does the bone marrow environment affect WM cells?  
Dr. Irene Ghobrial; Dr. Asher Chanan-Khan.
- **Omic:** What else can we learn about genomics, epigenomics, and WM mutations?  
Dr. Ari Melnick; Dr. Zachary Hunter.

### Pharmaceutical company presentations:

On Sunday, the following pharmaceutical companies presented current projects, one at a time, to the “WM brain trust”: Vivolux, Pharmacyclics, Nimbus, arGEN-X, Genentech/Roche, and Idera.

Before I tell you the results of these two days of intense discussion, let me remind you that we held a similar meeting in 2008. At that time we identified the need for a WM tissue bank, a WM mouse model, and a WM cell line. Thanks to funding from LLS and the IWMF, we now have three WM cell lines with a fourth on the way; a WM mouse model; and two WM tissue banks, one in the United States at the Dana-Farber Cancer Institute under the leadership of Dr. Irene Ghobrial and the second in the United Kingdom at University College London under the leadership of Dr. Shirley D’Sa. All of the goals outlined in 2008 by the LLS-IWMF partnership have been realized.

What did we accomplish at the 2015 meeting? Identified at the IWMF/LLS Strategic Research Roadmap Conference were the following five requirements needed to support research in the four target areas listed above:

- The identification of the knowledge gaps that are holding us back in each of the four topic areas (outlined above).
- A prioritized list of key needs and a rough estimate of the funding needed in each area.
- The formation of a subcommittee to identify the animal models needed to expedite FDA approval of future treatments.
- The formation of a subcommittee to identify the prioritized clinical trials needed to advance research to a cure.
- A request to hold this Strategic Research Roadmap Conference yearly. (Believe it or not, Dr. Treon was pleading with Dr. Greenberger of LLS and me to hold this meeting annually! I thought in jest to myself that

maybe he has too many free weekends!) But really, this request underscores the commitment on the part of our researchers. Since the IWMF was the primary sponsor of the meeting, we will need to secure the necessary funds and build this critical meeting into our yearly budget.

### What can we all do now?

We can all feel confident that we are on the road to understanding the biological mechanisms of WM, with the ultimate goal of finding a cure. You personally can help with two of the biggest constraints holding us back from continuing research in the four key research targets that have now been given the “green light.”

- The first is **money**. Please donate as generously as you can to the IWMF. Remember, 100% of all IWMF Research Funds go to research. Not a single penny goes elsewhere. It’s pretty simple . . . the more money we have, the more research we can fund . . . the more research we fund, the faster the road to a cure.
- The second is **participation in clinical trials**. The reason we have Imbruvica and the reason that control of our disease is within sight is because 63 WMers participated in the Imbruvica clinical trial. We are going to need a **much larger number of clinical trial participants to get to a cure**. Even if our brilliant and dedicated WM research community is successful in meeting these needs, new drugs and a cure cannot and will not be approved by the FDA, the EMA (European Medicines Agency), and other regulatory bodies without proof from clinical trials. Only you can provide that proof by participating.

In closing this report I will mention the wonderful news that Dr. Lee Greenberger announced at the recent IWMF Educational Forum: LLS has committed \$250,000 in incremental support for WM research by pledging \$125,000 in 2015 and another \$125,000 in 2016 to a designated project jointly selected by LLS and the IWMF, with the approval of our Scientific Advisory Committee.

What a terrific way to seal this new partnership between LLS and the IWMF! The Roadmap is now set and we are ready to go.

## 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](mailto:ariginos@me.com)



## Attendees at the 2015 IWMF/LLS Strategic Research Roadmap Conference

### *WM Researchers/Clinicians*

Dr. Ranjana Advani, Stanford University, Stanford, CA  
Dr. Stephen Ansell, Mayo Clinic, Rochester, MN\*  
Dr. Asher Chanan-Khan, Mayo Clinic, Jacksonville, FL  
Dr. Morton Coleman, New York-Presbyterian Hospital/Weill Cornell Medical Center, New York, NY\*  
Dr. Shirley D'Sa, University College, London, United Kingdom  
Dr. Richard Furman, New York-Presbyterian Hospital/Weill Cornell Medical Center, New York, NY  
Dr. Irene Ghobrial, Dana-Farber Cancer Institute, Boston, MA\*  
Dr. Zachary Hunter, Dana-Farber Cancer Institute, Boston, MA  
Dr. Larry Kwak, City of Hope, Duarte, CA  
Dr. Robert Kyle, Mayo Clinic, Rochester, MN, and Chair of the IWMF SAC \*  
Dr. Ari Melnick, New York-Presbyterian Hospital/Weill Cornell Medical Center, New York, NY  
Dr. M. Lia Palomba, Memorial Sloan Kettering Cancer Center, New York, NY  
Dr. Roger Owen, St. James's Institute of Oncology, Leeds, United Kingdom\*  
Dr. Steven Treon, Dana-Farber Cancer Institute, Boston, MA\*

### *Young Investigators*

Dr. Kimon Argyropoulos, Memorial Sloan Kettering Cancer Center, New York, NY  
Dr. Eric Smith, Memorial Sloan Kettering Cancer Center, New York, NY  
Dr. Aneel Paulus, Mayo Clinic, Jacksonville, FL

### *LLS and IWMF*

Dr. Lee Greenberger, Chief Scientific Officer, LLS, White Plains, NY  
Carl Harrington, President IWMF, Philadelphia, PA  
Dr. Erik Nelson, Director of Research Programs, LLS, White Plains, NY  
Dr. Guy Sherwood, VP Research IWMF, Winnipeg, Manitoba, Canada\*  
Dr. Yixian Zhang, Executive Research Director, LLS, White Plains, NY

\* Member of the IWMF Scientific Advisory Committee

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## DOCTOR ON CALL: IRENE M. GHOBRIAL, MD

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### THE NEW PARADIGM: SHOULD WE TREAT PRECURSOR CONDITIONS FOR BLOOD CANCER?



Dr. Irene M. Ghobrial

*Irene M. Ghobrial is an Associate Professor of Medicine at Dana-Farber Cancer Institute, Harvard Medical School, Boston, MA, where she specializes in multiple myeloma and Waldenstrom macroglobulinemia, specifically in the precursor conditions of MGUS and smoldering disease.*

*Dr. Ghobrial completed her medical studies at Cairo University, Cairo, Egypt, followed by an externship at the Wellesley Hospital, University of Toronto, Canada. Her residencies were first at Cairo University Hospitals in pediatrics and then at Wayne State University and Sinai-Grace Hospitals, Detroit, MI, in internal medicine. A fellowship in hematology/oncology followed at the Mayo Clinic, Rochester, MN, where she was named Outstanding Fellow in 2004. Dr. Ghobrial's affiliation with Harvard Medical School began in 2005.*

*In 2010 she received the Robert A. Kyle award at the International Workshop on Waldenstrom's Macroglobulinemia for research in Waldenstrom's macroglobulinemia.*

*Doctor on Call, cont. on page 5*





## CURRENT APPROACH TO PRECURSOR CONDITIONS FOR BLOOD CANCERS

**What is the problem?** Each year, thousands of people learn – usually after a routine blood test – that they have a condition that may develop into a blood cancer such as leukemia or lymphoma. That news is often followed by an equally surprising addendum: they are put on “watch and wait,” meaning the condition will not be treated until it becomes a full-fledged cancer. The lack of treatments for such “precursor conditions” places patients in an awkward limbo – seemingly healthy but waiting for their disease to progress to the point where it requires treatment. Scientists, including those at Dana-Farber Cancer Institute, have puzzled over why some people with these conditions go on to develop cancer quickly, while others never do, and whether treatment could arrest the disease at the precursor stage.

**How big is the problem?** Hematological malignancies including Waldenström macroglobulinemia (WM), multiple myeloma (MM), and acute myeloid leukemia (AML) are almost always preceded by clonal states that then progress to one of these diseases. Well-recognized precursor conditions, such as monoclonal gammopathy of undetermined significance (MGUS) and myelodysplastic syndromes (MDS) or the newly discovered clonal hematopoiesis of indeterminate potential (CHIP), increase in incidence with age. The incidence of MGUS is 3% in the general population over the age of 50, or approximately 3 million people in the US. Similarly, a recent study led by Benjamin L. Ebert, MD, PhD, and other Dana-Farber investigators showed that normal individuals also have mutations present in their peripheral blood that could lead to the development of MDS or leukemia and are associated with higher mortality. These mutations increase with age and are present in 9% of the population over the age of 70, or approximately 2.5 million people in the US (*New England Journal of Medicine*, December 2014). These studies of MGUS and CHIP indicate that precursor conditions to leukemia, lymphoma, and MM can be easily detected early if a screening method was implemented. Unfortunately, there are no current screening studies to detect these conditions in the larger population.

**Current management is watch and wait.** Screening and early therapeutic interventions for breast and colon cancer in high risk populations have significantly impacted the outcome of these patients with improved survival, decreased morbidity, and lower cost of care. Yet no such effort has been undertaken to diagnose and prevent the occurrence of WM, MM, and AML. Instead, as noted above, the standard of care for these patients once diagnosed is observation or “watch and wait” until quality of life is impacted or hematological end organ damage occurs, including acute leukemia, bone fractures, and renal failure. This concept of initiating therapy at the time of symptomatic disease is equivalent to initiating therapy in patients with solid tumors only after the

development of measurable metastatic disease. It is therefore not surprising that, even with the best combinations of agents that are currently available, cure has yet to be achieved for most patients with WM, MM, or AML. We anticipate that our efforts in early screening and intervention, described below, will lead to a major paradigm shift in the management of these patients.

By identifying patients early and preventing organ damage and time spent in the health care system with multiple admissions and complications related to therapy, we will not only save lives and significantly impact morbidity but also have a major impact on health care costs and the productivity of these patients in the work force.

**How Dana-Farber plans to tackle the problem.** At Dana-Farber, we believe that WM, MM, and AML *can* be preventable or curable diseases if detected and treated at early precursor stages. Advances in genomic technology have given us the tools to study the switch from precursor conditions to cancer in unprecedented detail. By understanding the fundamental changes that occur in cellular DNA – and when those changes occur – we hope to break the process down to its key components and, ultimately, develop targeted therapies capable of halting the process.

The focus of our research is to 1) identify molecular markers of progression for patients with precursor conditions in order to define who will go on to develop WM, MM, or AML at a fast pace and who will not; 2) develop tools for screening of high risk individuals that can impact the survival of patients with WM, MM, and AML by early detection and treatment; and 3) develop therapies to prevent or delay progression in these patients. To facilitate this research, we have developed the Blood Cancer Prevention of Progression Clinic.

### FIRST IN THE NATION: DANA-FARBER'S BLOOD CANCER PREVENTION OF PROGRESSION CLINIC

Launched in the fall of 2014, Dana-Farber established the Blood Cancer Prevention of Progression Clinic (BCPC). The first mission of the Clinic is to develop a large database of clinical information and tissue samples from US patients who are diagnosed with MGUS, smoldering WM and MM, and early MDS so that we can perform next generation sequencing studies. We are naming this tissue bank “Pcrowd.”

This invaluable resource of patient samples will help inform genomic and epigenetic studies, define molecular markers of progression, and identify novel therapeutic options to prevent or delay disease progression. Open and available to our scientific collaborators, this resource has potential to lead to significant progress in how we conquer blood cancers. While prospective studies that could lead to meaningful results are endless, examples of projects that we are poised to investigate include the following:



- Exploring genomic and epigenetic factors that influence progression along with age, race, gender, obesity, metabolic and environmental factors.
- Examining clonal evolution and heterogeneity during progression.
- Determining whether changes in the bone marrow microenvironment and the immune system are critical for the regulation of tumor progression.

Comprised of experts in a variety of hematological disorders, the BCPC has begun collecting tissue samples at Dana-Farber from patients with precursor conditions. The samples are already being analyzed to tease out genomic differences between early- and later-stage disorders to identify which ones lead the march toward cancer. With the support of Edward J. Benz, Jr., MD, President and Chief Executive Officer of Dana-Farber, and seed funding from the Division of Hematologic Malignancies, we have started to develop the necessary infrastructure for the Clinic's effort to collect clinical and epidemiological information. Today, we have over 300 samples from patients seen at Dana-Farber Cancer Institute, and our goal is to collect data and samples from 10,000 individuals once a year during a 10-year follow up period. Tissue collection, annotation, and storage of these samples are required to perform the sequencing and molecular studies. This initiative by Dana-Farber is the first in the world to attempt to change the paradigm of management of patients with precursor conditions for hematological malignancies.

By harnessing this resource, we will be able to leverage the expertise and discoveries from each disease to make insights of general relevance to the field. The work at the Clinic will also help identify common pathways that can be targeted by therapeutic agents in different clinical settings. It is our ultimate goal to use these samples to develop clinical trials to therapeutically target pathways that prevent disease progression or cure patients at early disease states before clonal heterogeneity occurs.

### **THE BLOOD CANCER PREVENTION OF PROGRESSION CLINIC NEEDS YOUR HELP**

Dana-Farber is positioned to be a leader in the early detection and treatment of precursor conditions that commonly lead to hematologic cancers. Its mission and budget are split 50/50 between scientific research and clinical care. It collaborates with all Harvard-affiliated hospitals, Harvard Medical School, Harvard University, the Harvard School of Public Health, the Broad Institute of MIT and Harvard, and the David H. Koch Institute for Integrative Cancer Research at MIT. These strategic partnerships provide Dana-Farber with a wealth of clinical data and access to powerful technologies. Still, we cannot do it alone.

The process is well underway, and the expansion of the Pcrowd tissue bank is a critical component of the effort. To reach the BCPC's goal of obtaining samples from 10,000 patients across the US, we need the key component without which none of this would be possible: **patient participation.**

**Eligibility.** Patients with known or suspected precursor conditions in the following hematological disease subgroups are eligible to participate in this study:

- Asymptomatic Waldenström macroglobulinemia and multiple myeloma, such as monoclonal gammopathy of undetermined significance (MGUS) or smoldering Waldenström or MM.
- Early MDS, including pathologically-confirmed MDS and idiopathic cytopenias of undetermined significance (ICUS).
- Myeloproliferative neoplasms (MPN).
- Early stage asymptomatic low-grade lymphomas.
- Monoclonal B cell lymphocytosis (MBL).
- Other precursor conditions or clonal genetic abnormalities of the blood or bone marrow that do not meet criteria for symptomatic hematological malignancy or patients exposed to prior chemotherapies (e. g., alkylating agents, platinum derivatives, taxanes, topo-2 inhibitors, anti-metabolites, systemic radioisotopes).

Note: Patients with evidence of symptomatic or active hematological malignancy requiring active therapy are not eligible to participate in this study.

### **CONCLUSION**

This is a very exciting time in the history of cancer research. We can and must win the fight against cancer, and through the BCPC, Dana-Farber is taking the initiative to strengthen the connection between laboratory and clinic to significantly improve research and treatment for blood cancer patients. Patient participation in studies such as the Blood Cancer Prevention of Progression Clinic is critical to realize the dream to conquer these cancers.

### **CONTACT INFORMATION**

If you are interested in learning more about the BCPC initiative, contact:

Adriana Perilla-Glen

Phone: 617-582-8664

Email: [precursor@partners.org](mailto:precursor@partners.org)

Fax: 617-394-2603

Website: [www.dana-farber.org/bcpc](http://www.dana-farber.org/bcpc)



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## PRESIDENT'S CORNER

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My wife and I often joke, yes, and even argue at times about car trips. I happen to have a keen geographic memory: if I've been somewhere before, I can usually find it again. My wife's many talents lie elsewhere, and when she's giving directions, her success rate is about 50-50. Map reading is not one of her strengths, but with the support of a GPS in our car

and Google maps on her smart phone, she gets the support she needs to help us reach our goal.

In a similar way, all of us affected by Waldenstrom's macroglobulinemia turn to the IWMF for support on the way to our common goal: a cure. And we on your volunteer Board of Trustees do our best every day to realize that vision in ways that are smart, strategic, and proactive.

**Support** was at the forefront of the 20th IWMF Educational Forum in Dallas. The theme was *Imagine a Cure: Parade of Hope*. Within that theme, we delivered two important messages:

1. *You are not alone.* Although WM is a rare disease, the IWMF is there to support everyone affected by the disease, from patients to caregivers to the medical community. If you need information about WM, turn to the IWMF website, the *Torch*, the annual Educational Forum and our booklets. If you need support, reach out to others via IWMF-Talk, the LIFELINE, and the IWMF Support Group that is nearest to your home or the IWMF affiliate in your own country.

No matter where you are in your journey with WM, there is probably someone who has experience that would be helpful to you. No one has more experience than Emil Parente, who has been living with WM for over 35 years. As an example of how caring the WM "family" is, Emil attended the Newly Diagnosed breakout session that Peter DeNardis and I ran at the Ed Forum and shared his experience with our "newbies." What a tremendous gift and source of hope for each of them!

2. *We are not alone.* The IWMF has powerful allies in our determination to find a cure:
  - a. *Non-profit partners* such as: Leukemia & Lymphoma Society (LLS), Lymphoma Research Foundation (LRF), CancerCare, National

Organization of Rare Diseases (NORD), and many more.

- b. *Medical and research organizations* such as: Dana-Farber Cancer Institute, the Mayo Clinic, Memorial Sloan Kettering Cancer Center, Weill Cornell, MD Anderson Cancer Center, and many more.
- c. *Pharmaceutical partners* such as the sponsors of our Educational Forum: Acerta Pharma, LLC; Biologics, Inc.; Celgene Corporation; Gilead Sciences, Inc.; Idera Pharmaceutical; Millennium Pharmaceuticals, Inc.; Novartis Pharmaceuticals Corporation; Onyx Pharmaceuticals, Inc., a subsidiary of Amgen, Inc.; Pharmacyclics, Inc.

**Progress** was another theme linked to our Parade of Hope at the 20th IWMF Educational Forum. Taking a long look back to 1995, we can today see progress in every direction.

1. *Member Services.* In 1995 Arnie Smokler first began mailing a monthly newsletter to 125 WM patients in the Waldenstrom's Macroglobulinemia Support Group, the forerunner of the IWMF, and he also established the Waldenstrom's macroglobulinemia website. A newsletter and a website were the first services for members – how that list of Member Services has expanded in 20 years!
2. *Research Program.* A fund to support ongoing research in WM? Wishful thinking 20 years ago! But in 1998 at their first meeting, the IWMF Board of Trustees made a commitment to support an active research program, and in 1999 the first research project was funded with contributions from IWMF members. From 1999 until today the IWMF Research Fund has grown, largely from contributions made by you and me and other IWMF members. To date we've invested over \$8.1 million in WM research. Our funding has played a critical role in creating WM mouse models, WM cell lines, and WM tissue banks; in discovering mutations such as the MYD88 mutation and the CXCR4 mutation; in exploring signaling pathways within the bone marrow; and much more!
3. *Treatments.* How many treatments were available to WMers 20 years ago? Four. How many pharmaceutical options do we have now? Forty-two. And, not only do we have more treatments, we have better treatments today, better treatments that yield better results and cause fewer side effects. And we now have "a drug of our own" since Imbruvica

*President's Corner, cont. on page 8*



(ibrutinib) was approved earlier this year by the FDA for Waldenström's macroglobulinemia.

When we speak of progress over the past 20 years, we realize that the whole world of WM has changed for the better. Not only do we have more and better treatments, but life expectancy is also increasing for WMers, and our quality of life is improving. With so much progress accomplished in 20 short years, several presenters spoke about the possibility of WM becoming a controllable disease (comparable to high blood pressure or diabetes) for many WMers; but we won't

stop there because a cure for WM, while further out, may be within reach.

Imagine it! A cure for WM!

Stay well,  
Carl

I'm pleased to announce that the 2016 Educational Forum will be in Providence, RI, at the Omni Hotel from June 10 to June 12. Write down these dates and put them on your calendar!

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## TREASURER'S REPORT

BY CYNTHIA RUHL, IWmf SECRETARY AND TREASURER

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The finances of the IWmf are accounted for through two separate funds. The Research Fund is used solely to provide research grants for projects that our Research Committee has reviewed and recommended. Our Member Services Fund provides for all of our outstanding services for members, including the Educational Forum, the website, and the *Torch*. Both funds are critically important to the work of the IWmf.

The following is a summary of the financial results for 2014. The amounts are rounded to the nearest thousand and have not yet been audited. We are expecting the audited financial statements to be completed by the end of June, and they will be posted on the website when available. However, I wanted to share with you where the IWmf stands financially through 2014.

As a result of your generous support in 2014 we were able to publish the *Torch* four times, update some of our literature, upgrade the IWmf website, produce the annual Educational Forum, and fund four new research grants!

At the end of December 2014, our cash reserves for the Research Fund were \$735,000 and for the Member Services Fund were \$547,000.

We have \$1,698,000 obligated in future payments of research grants that have been approved by both the Board and the Research Committee. Clearly, we are counting on your future support in keeping this important research moving forward. I can assure you that the Board does their very best to make certain that every dollar given is wisely spent on serving you, our members. Thank you for your continued support.

	Research	Member Services	Total
Revenue	\$ 758,000	\$ 917,000	\$ 1,675,000
Expenditures	\$ 808,000	\$ 712,000	\$ 1,520,000
Net Income	\$ (50,000)	\$ 205,000	\$ 155,000





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# ED FORUM 2015

BY SECRET WALLIE

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## THURSDAY APRIL 30

It's the day before the "official" Ed Forum activities begin. Even so, there's a lot of activity in the hotel . . . volunteers are setting up tables, organizing folders, handing out registration packets to attendees, and ensuring that the AV equipment works. As one can imagine, a lot of "behind the scenes" work takes place before the meeting even begins . . . and volunteers are hard at work actually months before the event even takes place!

This is also the day that, traditionally, the Support Group Leaders Workshop takes place, where advice and suggestions are made and best practices are shared regarding how to maintain and run effective support groups. Representatives were on hand from over 21 different support groups.

At various locations in the lobby, on the airport shuttle, and in the hallways, one could see repeat attendees greeting each other as if they were long lost friends – catching up on what's happened in each other's lives since the last time they attended an Ed Forum together. To be honest, it's quite difficult to tell who is the caregiver and who is the patient among those that will be attending the sessions!

Upon entry into the ballroom, one could see displayed on the projection screens photos of attendees, sorted in order by years since diagnosis (newly diagnosed, 1-4 years, 5-9 years, 10-14 years, 15-19 years, and 20+ years). It was encouraging to see so many people in the 10+ category, especially since not too long ago the projected median life expectancy was only 5-7 years! Also, the IWMF provided a selection of country songs to set the mood for the session in Dallas.

## FRIDAY MAY 1

Following introductory remarks by IWMF President Carl Harrington, Ed Forum 2015 opened with a very full day of talks and breakout sessions. A number of the presentations on Friday were aimed at the newly diagnosed among us as well as those heading for treatment for the first time.

**Readers take note:** It would be a hard for me to recap accurately and completely the information I heard in so many talks by the experts packed into two and a half days. I will therefore stick to the Forum schedule in my report and list the speakers and their topics in the order they presented, but I won't attempt to give you all the details. The PowerPoint slides shown at the Forum and select videos of the presentations are available to you at: [iwmf.com/publications/educational-forum/educational-forum-presentations-and-videos](http://iwmf.com/publications/educational-forum/educational-forum-presentations-and-videos)

### Morning session

Dr. Joseph Mikhael, Mayo Clinic: "I've Been Diagnosed with WM – What Happens Now?" **Video available at [iwmf.com](http://iwmf.com)**

Dr. Mikhael is an excellent speaker and provided much valuable information and useful advice for the newly

diagnosed WM patient.

Dr. Claudia Harsh, Baylor Sammons Cancer Center: "Integrative Oncology."

Dr. Harsh spoke to us regarding alternative methods possible for treating cancer, outlining tools to balance emotional, mental, physical, and spiritual health during and after treatment. Included were acupuncture, supplements, and relaxation exercises.

### Afternoon session

Dr. Larry Anderson, University of Texas Southwestern Medical Center: "I Need Treatment – First-Line Treatments and Side Effects." **Video available at [iwmf.com](http://iwmf.com)**

Dr. Anderson gave a summary of the different ways a patient could be diagnosed and discussed the signs and symptoms that indicate the need for treatment. He then reviewed the treatment options for symptomatic disease and explained the criteria commonly used when indicating a range in response to treatment.

Dr. Sheeba Thomas, M.D. Anderson Cancer Center: "My WM is Back – Relapsed/Refractory Treatments."

**Video available at [iwmf.com](http://iwmf.com)**

Dr. Thomas presented a very thorough review of the options available to the patient who has relapsed WM.

### Breakout Sessions

After a full day of intense medical-ese, patients and caregivers had an opportunity to attend one of several breakout sessions on the more "popular" forms of treatment for WM including bendamustine, ibrutinib, Rituxan, Velcade, plasmapheresis, and stem cell transplantation.

### Friday Evening

Traditionally, the Friday evening of the Ed Forum is given over to the social side, beginning with the President's Reception followed by the Welcome Dinner with its keynote event. It was a lovely cool evening and the President's Reception was held outside on the patio, where one could see researchers swapping stories with each other, patients swapping stories with each other, and patients and researchers toasting to each other's good health. One could feel an air of both optimism in the group and of companionship. Of course, lots of resveratrol was being "prescribed" during this event! After all, we were in GRAPEVINE, Texas.

The Welcome Dinner was an occasion for attendees to once again get together and learn more about each of their newfound friends at the conference and for IWMF President, Carl Harrington, to officially welcome everyone to the Ed Forum. Carl's Welcome Address focused on the theme "Parade of Hope," and he recounted his boyhood days in upstate New

*Ed Forum 2015, cont. on page 10*



York watching parades in his small hometown and brought that around to reflect on the progress that's been made, and the evolution of the IWMF itself since its establishment . . . a true parade of progress and hope! When the IWMF was first formed, there were 4 primary forms of treatment; today there are 42 possibilities! Also, one can find over 70 clinical trials in which WM patients can participate. In the early days, in the mid-nineties, the IWMF did not fund basic research in WM, while today we are able to fund \$8 million in research (thanks to the generosity of IWMF donors)! Carl then went on to provide some statistics of the attendees present, to note that patients are living longer, and to recognize patients in various "categories" of longevity. He closed with an appeal for all WMers (patients and caregivers) to provide support – whether in the form of time, skills, donations, or participation in clinical trials – to help to finally take the "in" out of "incurable"!

The Welcome Dinner is traditionally the opportunity for a keynote event, whereby attendees are treated to a presentation that is particularly inspirational, entertaining, or educational. This year we had the honor of having Dr. Kenneth Anderson of Dana-Farber Cancer Institute address us on recent developments in the treatment of multiple myeloma and Waldenstrom's. Not only is Dr. Anderson a noted and highly regarded researcher in MM and WM, he also is the president-elect of the American Society of Hematology. His talk focused on the advances being made in both MM treatments and WM treatments, and he interspersed stories about his own experiences treating high-profile patients such as Tom Brokaw (noted US TV News personality). He specifically stated that "we are in a new world of treatment for WM – where patients can be treated with oral regimens rather than IV forms of chemotherapy" – which are also less toxic than previous forms of treatment. His talk also focused on different forms of inhibitors and mechanisms to turn cancer cells against themselves. In closing, he spoke about one of his more "prominent" patients (of course, every patient is important to a doctor), Tom Brokaw (who gave a talk recently about "big events" in his life, including diagnosis with multiple myeloma), and encouraged us to read Mr. Brokaw's book *A Lucky Life Interrupted*. Dr. Anderson stated that we all need a "big event" in cancer – a cure – and we all need to be on the team to help make that happen!

With that, the first day ended; it was a long but very educational day. One could sense an air of optimism and hope that was more prevalent than at Ed Forums in the past – namely a feeling that we (all of us as members of the WM community and the IWMF) are on the verge of WM becoming a chronic, manageable disease in the next few years. Interspersed through many talks in the day were the comments that it's not inconceivable that WM could become a disease that is manageable via lifetime administration of oral medication much like diabetes or high blood pressure . . . this was not possible in years past.

## SATURDAY, MAY 2

### IWMF-Talk Meet and Greet

Saturday promised another full schedule of speakers and the day began with a fortifying buffet breakfast for everyone in attendance – with an area in the ballroom reserved for the IWMF-Talk folks to get together. One could see them seated around the table, enjoying the opportunity to match faces with names and meet fellow talkers in person.

### Morning Session

Dr. Morie A. Gertz, Mayo Clinic: "The Garden Talk."

**Video available at [iwmf.com](http://iwmf.com)**

The Garden Talk remains as one of the more popular presentations at Ed Forums – both for the means by which it distills complex scientific and medical concepts into common layman terms that are easy to grasp and remember and for the witty delivery style of Dr. Morie Gertz.

Dr. Stephen M. Ansell, Mayo Clinic: "How B-Cells Work and Talk to Each Other." **Video available at [iwmf.com](http://iwmf.com)**

Dr. Ansell explained the process of how our B-cells communicate and work together. His charts and diagrams helped guide us along the pathway (see the PowerPoint slides on the IWMF website), and he provided a layman's summary of how the entire process works and where the issues occur with regard to WM. Dr. Ansell's current research is funded by the IWMF.

Dr. Julie Nielsen, Deeley Research Centre, BC Cancer Agency: "Harnessing Killer T-Cells."

Dr. Nielsen provided an explanation of what T-cells are and how they work in immune-based therapies for cancer, using T-cells to target patient-specific mutations such as MYD88. Dr. Nielsen's current research is funded by the IWMF and the Waldenstrom Macroglobulinemia Foundation of Canada.

Dr. Mary Lou McMaster, National Cancer Institute: "Familial Studies in WM."

Dr. McMaster has been on the familial studies quest in WM for several years now, and she presented her interesting findings to the audience. The questions she is working to answer are: Why does WM sometimes cluster in families? Is WM in families different from non-familial WM? Why are some people susceptible to WM? Are there factors that increase risk for WM? Genetic? Environmental? Lifestyle? Dr. McMaster encouraged those interested in participating in the NCI Family Study to contact her directly (and she added that she answers her own phone): 240-276-7248 or [mary.mcmaster@nih.hhs.gov](mailto:mary.mcmaster@nih.hhs.gov)

**Saturday Luncheon: Board of Trustees Reports, Ben Rude Heritage Society Report, Judith May Volunteer of the Year Award.**

Lunch on the second day also includes the official IWMF Board Report to the members of the IWMF. While folks



Wally and Winnie saw a light under the door of Secret Wallie's room at the Hilton and scampered in to pay their respects.



As the notable Secret Wallie was preparing his running account of events of the Ed Forum in Dallas to send to IWMF's Stay in Touch TALKLIST, TWITTER, and FACEBOOK, Winnie and Wally weren't about to take a tater and wait, so to speak, so they seized the opportunity right away to introduce themselves.

were breaking bread, sharing stories with old friends and newfound friends, President Carl Harrington, Secretary/Treasurer Cynthia Ruhl, and Vice President for Fundraising Michael Sesnowitz presented the state of the IWMF. It was encouraging to hear that the IWMF is in good financial shape, that 100% of all donations earmarked for research go directly to research, and that the generous donations of IWMF members are leading to exciting new discoveries, better treatments for WM, and the wonderful support and education efforts by the IWMF (including the Ed Forum!). After the Board reports, Laurie Rude-Betts announced the names of 3 new members of the Ben Rude Heritage Society and noted that in the 7 years since it was established the Society has enrolled 66 members and has received \$3.3 million in commitments.

The luncheon concluded with the presentation of the third Judith May Volunteer of the Year Award. On behalf of the IWMF, Judith May presented a beautiful engraved crystal prism to awardee Alice Riginos. Alice has been the IWMF *Torch* editor for seven years, and it is under her stewardship that the *Torch* has become the professional publication that it is today. See more on page 14.

#### **Saturday Afternoon: the Parade of Hope continued to march onward!**

Dr. Zachary Hunter, Dana-Farber Cancer Institute: "Genomic Landscape of WM."

Dr. Hunter laid out the various aspects of studying the genetics of WM. He began by explaining what genetics is and why it is important. The hope is that the study of genetics can: Help

*Ed Forum 2015, cont. on page 12*





find new targets like MYD99 to create new target therapies; Help determine how aggressive or indolent the disease may be, which can in turn impact care and treatment; Predict the response to therapy and allow for individualized treatment plans; Study family inheritance and ways to mitigate factors to prevent disease. Dr. Hunter's current research is funded by the IWmf.

Dr. Steven P. Treon, Dana-Farber Cancer Institute. "Targeted Therapies for WM." **Video available at [iwmf.com](#)**

In this wide-ranging discussion Dr. Treon covered the significance of the MYD88 L265P and CXCR4 mutations, the timeline and steps from the discovery of the MYD88 mutation to the development of ibrutinib (Imbruvica). He reported on both the efficacy of ibrutinib and its adverse effects noted thus far. Dr. Treon also outlined directions for future research to unlock more of the WM mysteries and looked ahead to future acceptance of drugs now making their way through clinical trials. Dr. Treon's current research is funded by the IWmf.

### Break Out Sessions

Several "break out" sessions ended the day. Attendees were able to select from among one of several running concurrently, and presented by medical experts and fellow patients with a particular knowledge of the topics: Coping with Cancer-Associated Fatigue, Clinical Trials, Newly Diagnosed, and Peripheral Neuropathy. Also, due to popular demand, another special session was added – one specifically for caregivers to get together and share their experiences and stories, without the "caregiver" being with them.

To wind up for Saturday, did I mention that after each session one could see a line of WMers queued up in front of the presenter either in the back of the ballroom or in the hallway, often to ask questions for clarification on certain points and often to ask questions specific to one's own personal condition? And that each doctor patiently and gladly took the time to properly respond to each question and assist each WMer? One can easily see that we are fortunate to have such a collection of caring, committed researchers and clinicians!

Tomorrow is the final day of the Ed Forum . . . it promises to bring the second annual IWmf Walk and the much anticipated "Ask the Doctor" session, along with Dr. Gertz's carefully designed answers to the "burning questions" about WM.

### SUNDAY MAY 3

Here it is...the third and final day of the 2015 Ed Forum. We've tried our best to soak up and understand all the information about the biology of WM, the latest treatment methods, and new treatment options that are available. And, by this point, we've shared our stories and experiences with fellow patients and caregivers and learned much from their stories and experiences. We look at the agenda with hope and with a bittersweet feeling, knowing that in a few hours another Ed Forum will be over, and we'll all be going our separate ways. But we all know that we'll be able to stay in contact by phone, by e-mail, by attending support group meetings, or even by

an in-person visit. There's nothing quite like getting together with people who are pursuing the same path in life.

### The Walk

Pete DeNardis led a group of about 20 early risers at 6:30 am (yes, the sun was out at that time of the morning) to walk the trails around the hotel grounds, where they encountered herons, horses, and even a covered wagon. The sky was clear and the air was warm as they paraded around on the trails amid the woods and lake, sharing bits of information about their lives, their families, and their experiences with WM.

### Morning Session

Dr. Morie A. Gertz, Mayo Clinic: "The Burning Questions about WM." **Video available at [iwmf.com](#)**

Dr. Gertz first tackled this topic last year – providing answers to questions that are of particular importance to inquisitive WM patients and caregivers.

Dr. Lee Greenberger, Leukemia & Lymphoma Society: "The Strategic Research Roadmap for WM."

Dr. Greenberger, Chief Scientific Officer of the LLS, spoke to the 2015 attendees as LLS and the IWmf prepared to enter on a new partnership to pursue set objectives in WM research which, when achieved, will bring research in WM closer to our ultimate and mutual objective – a cure. Dr. Greenberger reminded us that LLS is the third largest cancer foundation in the US, its focus is on blood cancers, it funds research that is "cutting edge," and it has over 300 grants currently active. Next he asked the question many of us were thinking about: Why is LLS interested in WM at this time? The answer, said Dr. Greenberger, is that research in WM has a lead over other blood cancers because a start in understanding its genetic basis has begun and right now there's a huge opportunity for progress with novel therapies. [See Carl Harrington's report beginning on page 1 of this issue for the details of the Roadmap Conference convened by LLS and the IWmf that took place May 16-17.] Dr. Greenberger finished by listing the monetary support that LLS will be offering to the IWmf in addition to direct funding for WM research. He announced that soon LLS will be providing co-pay assistance for WM patients (see page 17) and pledged additional grant money for a project partnered with the IWmf at \$125,000 per year for 2015 and 2016. The Parade of Hope will soon be marching with the Roadmap!

Doctors Treon, Gertz, McMasters, and Larry Anderson, with Dr. Robert A. Kyle moderating.

"Ask the Doctor." **Video available at [iwmf.com](#)**

A wide-ranging discussion filled with insights from the specialists. View the video and share in the wisdom and the spirit imparted by our WM experts!

The ever-popular finale of an IWmf Ed Forum! Questions from Forum attendees (and this year also by IWmf-Talk folks) are submitted in advance to Dr. Kyle to be answered by

*Ed Forum 2015, cont. on page 14*





# AN ED FORUM ALBUM: DALLAS 2015



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# ALICE RIGINOS: 2015 JUDITH A. MAY VOLUNTEER OF THE YEAR

BY JUDITH MAY, IWMF PRESIDENT EMERITA

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*The third Judith May Volunteer of the Year Award was presented by President Emerita Judith May to Alice Riginos, editor of the IWMF Torch for the past seven years.*

At the recent IWMF Ed Forum in Dallas, I was very pleased to present the 2015 Judith A. May Volunteer of the Year Award to Alice Riginos, who was honored for her seven years of volunteer work as Editor of our *Torch* newsletter.

The IWMF runs on volunteers who dedicate their time and skills to serve WM patients and caregivers. In 2012 the IWMF Board established this award to annually recognize a single volunteer for his or her outstanding dedication to and support for Waldenstrom's patients.

Alice has had and continues to have a most interesting and exciting life.

She had a classical education, earning a BA in Ancient and Medieval History and MA in Classical Archeology at the University of Chicago. Alice went on to receive a PhD in Greek and Latin Languages and Literatures at Columbia University in New York. She taught for 27 years in the Classics Department of Howard University in Washington DC, and for many years she taught an intensive writing course designed to enhance composition skills.

Alice is married to Vasilis Riginos, and they have two adult daughters and three grandchildren. Alice and Vasilis spend

part of each year in Greece where they have a second home, and during those months she produces the *Torch* from Greece.

Alice was diagnosed with WM in 2003 – 12 years ago – and although she has been through several treatments, she has continued her volunteer work for the IWMF. She began as Guest Editor in 2007, helping then-Editor Don Lindemann, whom many of us remember very fondly. Don became quite ill from WM and sadly passed away in 2008. At that time, Alice graciously agreed to become the new *Torch* Editor.

With Alice's interests, education, and experience as a published writer, she focused on how to improve the *Torch*. And she did! We owe a great deal to Alice for the changes she has made to the *Torch*, which is a very public face of the IWMF.

Since becoming Editor, she has, among other accomplishments –

- expanded the scope of the *Torch*;
- improved its appearance with modern graphics, glossy paper, and a redesigned masthead;
- used her creativity to constantly look for new ideas for articles;
- added regular columns and writers, such as Doctor on Call, Cooks' Happy Hour, International Scene, and In the Torchlight, to name a few.

Under her leadership, the *Torch* has become a very professional publication, and in the 2012 Member Satisfaction Survey of IWMF services, the *Torch* was listed as Number One.

Alice's editorial standards are very high, and she is of invaluable assistance to Trustee Sue Herms on the Publications Committee in proofing revisions to our IWMF booklets. Alice and Vasilis also created a "Best of the *Torch*" section for our recently revamped IWMF website.

On behalf of all WM patients and the IWMF Board of Trustees, I was delighted to honor her in this way, and I know I speak for everyone when I say that we are so thankful for Alice's masterful management of the *Torch* for the past seven years.

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## *Ed Forum 2015, cont. from page 12*

a select set of WM luminaries. In a sense, these are the really "Burning Questions" that participants have this particular weekend. While there is often agreement among the panel of experts, when there is disagreement they do not hesitate to voice an opposing opinion.

### **Closing Notes: Secret Wallie, from his Hilton hotel room.**

The Ask the Doctor session was the last of the event for 2015. Already the particulars of the 2016 Ed Forum have been announced: June 10-12 in Providence, Rhode Island, at the Omni Hotel.

One could see groups of patients gathered at various points in the hallways and lobby area, saying final goodbyes to each other, and sharing contact information. Bittersweet moments, indeed.

Suffice it to say that I will miss many of the fine people I met during this year's Ed Forum, and I look forward to the possibility of meeting up with some of them in the coming months, and hopefully also at next year's Ed Forum.

This year, we had several corporate sponsors who provided funding to help offset the cost of the Ed Forum, including

*Ed Forum 2015, cont. on page 15*





Acerta Pharma, Biologics, Celgene, Gilead, Idera, LLS, Millennium, Novartis, Onyx, Pharmacyclics.

The common theme I heard from sponsors and presenters that I ran into was “the IWmf is quite a unique patient organization; it is highly organized, provides a wealth of information to its membership, and is almost entirely run by volunteers. And, WM patients are very knowledgeable about their disease.” I can’t say we’re fortunate to have to deal with WM, but what I can say, unequivocally, is that we’re quite fortunate that we have a form of cancer that is so well supported and where there are so many resources dedicated to our disease.

Our sponsors also stated that they caught an atmosphere of optimism and hope among those in attendance, more so than in previous years and more so than at other cancer support organizations. The IWmf strikes up the band so that we truly can all be part of the ongoing Parade of Hope!

Best of health to all, Secret Wallie

PS: And, if you haven’t already viewed them – see photos from the Ed Forum, [2015iwmfedforum.shutterfly.com/](http://2015iwmfedforum.shutterfly.com/) (password is iwmf2015).

Thanks to the terrific folks from the IWmf Dallas Support Group who volunteered to pitch in and take many of the wonderful pictures!

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## MY RED BADGE OF COURAGE

BY LISA WISE, M ED

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*Lisa Wise attended the Dallas Ed Forum as a “newbie” and wrote up her enthusiastic impressions as soon as she returned home.*

The instructions were clear. At the end of the Ed Forum, before leaving the hotel, kindly drop your name badge in the return boxes so that they may be recycled. Seemed simple enough. I whipped my name badge off as I ran to catch the shuttle to the airport. But then I froze, unexpectedly, mid-air. My name badge hovered awkwardly over the box. My fingers were unwilling to let it drop. I was not ready to let go.

A woman walked by and dropped her badge in the box. I was still standing there, frozen. Our eyes locked for a moment. She smiled. “I’m having trouble letting my badge go,” I explained, realizing that I might look a bit off. “I’m not ready to say goodbye to it.” She responded warmly and knowingly: “Is this your first Ed Forum?” I nodded, impressed that she was clairvoyant. “Amazing, isn’t it?” she exclaimed. And with that we began to chat, and I dropped my badge in the box, whispering, “Goodbye, Badge,” so that I could stroll away with her. “They only get better and better each year,” she assured me. “As you learn more about your disease, you will understand more information each time. As you are exposed to all the newest, exciting discoveries, you will absorb more and more at every Ed Forum. It just keeps getting better and better,” she promised.

My badge only shared five little pieces of information about me and my story. But for three glorious days, those five facts were the truest parts that I wanted to highlight and focus on completely: my name, my city, my “first timer” status, the five years under my belt, and – most importantly – that

unmistakably bright red string that announced to all that I was a WM patient. My diagnosis is something that I work very hard, every single day, **not** to announce to the world while I silently fight the fatigue, night sweats, anemia, rashes, peripheral neuropathy, and a host of other symptoms that have snuck up on me as my IgM slowly creeps up over the years. But here, on Planet Waldenstrom, that badge represented a five-note song that I had enjoyed playing over and over again throughout this life-changing Ed Forum. Just a few short days, but I was *transformed*. I reaped the enormous benefits of sharing my story, hearing other patients’ inspiring stories, listening to top researchers wow me with their passion, drive, and breakthroughs, and was able to step into and live in this supportive, altered universe for a whole weekend. It was the most freeing and uplifting experience I have enjoyed since diagnosis. Carl Harrington, the IWmf President, promised us the very first day of the Forum: “You are not alone.” Indeed, I am not alone.

It was time to dash to the airport, so I hurriedly said goodbye to my new (millionth) Ed Forum Best Friend Forever. As she walked away, I froze in a panicked realization. I wanted to shout out: “WAIT!” as anxiety washed over me. We were no longer wearing our badges so I didn’t know her name. I didn’t know where she was from. I didn’t even know if she was a *patient* or how many years she had under her belt. And that’s when it hit me: *it didn’t really matter*. We had connected. We had shared a moment. She understood me, supported me, allowed me to let go for now, and would see me at the next Ed Forum in Providence, RI. And that was all that really mattered. The rest was just background music. Now I was ready to get on that plane home and re-enter the (real?) world. And I was leaving my “red badge of courage” behind. I was still me, a WMer of five years and counting, very much still the “first timer new kid on the block”. But oh, had this kid grown up and changed in so many ways. And I just couldn’t wait to get out there to tell the whole world all about it...

*Lisa Wise is co-leader of the Philadelphia support group.*



# PANF ASSISTANCE FOR WM PATIENTS IN THE US

WM patients in the US may be eligible to receive financial assistance from the Patient Access Network Foundation (PANF) to help with high prescription co-pays and deductibles. The PANF is a national 501 (c)(3) charitable not-for-profit organization.

PANF was established in 2004 to provide financial assistance to patients with chronic or life-threatening illnesses who are underinsured and need help to cover out-of-pocket medical expenses for certain forms of cancer, chronic illnesses, and rare diseases. Since that time, PANF has provided more than \$880 million to over 420,000 underinsured patients.

WM patients can qualify for PANF assistance as part of its Non-Hodgkin's Lymphoma Program, which allows a maximum award of \$7,500 over 12 months for prescription cancer treatment. PANF is currently accepting applications for new and renewal patients. Eligibility criteria include the following:

- The patient should be insured, and insurance must cover the medication for which the patient seeks assistance.
- The medication must treat the illness directly.
- The patient must reside in and receive treatment in the United States.
- The patient's income must fall below 400% of the Federal Poverty Level. 2015 Federal Poverty Levels can be viewed at [aspe.hhs.gov/poverty/15poverty.cfm](http://aspe.hhs.gov/poverty/15poverty.cfm).

Using Federal Poverty Levels for one-person and two-person households in the contiguous 48 States and the District of Columbia would allow income levels up to \$47,080 and

\$63,720, respectively. Levels are slightly higher in Alaska and Hawaii. Income includes wages, tips, salaries, IRA distributions, pensions, annuities, Social Security benefits, and other income (alimony, rental income, child support, etc.).

In order to apply, you will need income, insurance, and doctor information.

To apply for assistance, you can visit the PANF website at [www.panfoundation.org](http://www.panfoundation.org). Apply online by selecting Online Application from the top menu, or you may also phone 1-866-316-7263 to speak to a Call Center Representative. Eligibility is determined almost immediately after submitting fully completed online or phone applications. If you qualify, PANF will send you an approval letter that includes details such as your award amount and your eligibility dates. You will also receive a separate letter containing a plastic pharmacy card to be used for any qualifying prescription drugs.

If a provider/pharmacist is applying on your behalf, that person can register and submit applications easily through the provider and pharmacy portals on the PANF website.

Assistance begins on your approval date and continues for 12 months. During your first eligibility period, eligible expenses incurred up to 90 days prior to your approval date may also be submitted. Payment is made to the physician, pharmacy, or health care provider who supplies the treatment. In cases where you have already paid out-of-pocket for eligible expenses, reimbursement will be paid directly to you, upon approval of receipts. Following the first 12 months of eligibility, you may apply for a second grant, contingent upon availability of funds.

## ONE PATIENT'S EXPERIENCE WITH PANF

When it was decided that I was going to use ibrutinib/Imbruvica, it was suggested that I call the Patient Access Network Foundation for the possibility of financial assistance.

In mid-February I called and found the people at PANF to be positive, friendly, and cooperative. I was approved for ibrutinib over the phone quickly. Approval, that is, in the following sense: "tell the MD to order the meds."

My first order was for two weeks' worth. This immediately put me "down the slopes of Medicare's donut hole," and began a paperwork/phone calling education. I mailed the billing paperwork to PANF using my name, Richard, which for data inputers is a problem since it is my middle name. But what with phone calls, the right PANF patient ID numbers, and using FAX rather than mail, the ball finally got rolling, which was helpful since the second two weeks of ibrutinib put me at the bottom of the donut hole. Two weeks later I got a one-month supply of the drug and was on the way "out of the hole." All paperwork with receipts was finally FAXed. In mid-April I received a check for all three prescriptions.

The report above does not describe the cooperation of the people I spoke with or the phone calls not returned. One of

the major problems, other than my middle name, was even though my medical provider Kaiser Permanente's people are helpful, the Kaiser pharmaceutical system is designed not to work with outside organizations. A representative of PANF tried to set up a conference call between himself, myself, and Kaiser. It didn't work, but the PANF rep tried. PANF is willing to work directly with the providers if the providers are willing. When that works, there is no out of pocket expense for the patient. When it doesn't work, the patient is reimbursed – as long as the required receipts can be submitted.

Registration with PANF is good for a year and meds purchased within three months prior to initial approval are covered. The wife of a friend of mine has multiple sclerosis, and they began using PANF this year. They used the on-line application and were happy with it. My friend is also pleased with the personnel. When he had not placed an order with PANF for 60 days, he received a phone call, and when he said that he was planning to use PANF again, approval was extended.

All-in-all, I am happy with PANF.

Richard Black





# LLS OFFERS NEW CO-PAY ASSISTANCE PROGRAM FOR WM PATIENTS

On May 15, the Leukemia & Lymphoma Society (LLS) announced a new WM-specific Co-Pay Assistance Program to offer financial help toward treatment-related co-payments, premiums for private health insurance, and premiums and co-pay obligations for Medicare Part B, Medicare Plan D, Medicare Supplementary Health Insurance, Medicare Advantage, and Medicaid Spend-down.

The assistance for WM patients is available for up to \$5,000 for a 12-month coverage period. To be eligible, a patient must meet the following requirements:

- Have a household income that is at or below 500% of the Federal Poverty Guidelines as adjusted by the Cost of Living Index (COLI). 2015 Federal Poverty Levels can be viewed at [aspe.hhs.gov/poverty/15poverty.cfm](http://aspe.hhs.gov/poverty/15poverty.cfm).
- Be a US citizen or permanent resident of the US or Puerto Rico and be medically and financially qualified.
- Have prescription insurance coverage.
- Have a WM diagnosis confirmed by a doctor.

Using Federal Poverty Guidelines for one-person and two-person households in the contiguous 48 States, the District of Columbia, and Puerto Rico, the LLS Co-Pay Assistance Program would allow household income levels up to \$58,850 and \$79,650, respectively. Levels are slightly higher in Alaska and Hawaii.

Patients and caregivers can submit online Co-Pay Assistance Program applications by going to [www.lls.org/support/](http://www.lls.org/support/)

[financial-support/co-pay-assistance-program/for-patients](http://financial-support/co-pay-assistance-program/for-patients), while pharmacies and healthcare providers can go to [www.lls.org/support/financial-support/co-pay-assistance-program/for-providers](http://www.lls.org/support/financial-support/co-pay-assistance-program/for-providers). Or they may apply or get more information about the Co-Pay Assistance Program by calling 1-877-557-2672 to speak with a specialist who will provide personalized service throughout the application process.

Enrolled patients have the freedom to choose doctors, providers, suppliers, insurance companies, and/or treatment-related medications and can make changes in any of the above without affecting their continued eligibility. Services not covered include prescribed devices such as eyeglasses, wheelchairs, etc.; diagnostic procedures such as PET/CT/MRI scans and X-rays; and laboratory services including blood work, biopsies, etc.

All applicants will receive a “Determination” letter approximately 7-10 business days after the application is received. Approved patients will be sent a Letter of Approval with directions on how to request assistance from the Program.

In most cases, the payment will be sent directly to the pharmaceutical supplier, hospital, doctor, and less commonly, directly to the patient. Claim requests for less than \$20 will not be processed.

For more information about the program, including a list of covered and non-covered expenses, visit [www.lls.org/support/financial-support/co-pay-assistance-program](http://www.lls.org/support/financial-support/co-pay-assistance-program).

## ADVICE FOR PROSPECTIVE LLS APPLICANTS

Three participants on IWMF-Talk responded to a request from the *Torch* for comments from successful applicants to the LLS Co-Pay Assistance Program.

Two responders were successful applicants to LLS prior to the May 15 announcement of the program reserved for WM patients. One provided information that is useful for those thinking of applying now: LLS requires certification from your doctor that you are a Waldenstrom’s patient based on your medical condition and that you meet international criteria for determination of this diagnosis. In addition, together with your application, you are asked to provide your prior year’s income tax return. Once the application

has been submitted, the “process goes very smoothly.”

Ralph Applegate wrote to say that he had applied to the new program and on May 28 he was informed by telephone that his application was successful and that he would soon receive an information packet in the mail.

One further bit of advice for those whose applications are successful: to re-apply to LLS you must wait each year for the same month start date before you will be provided the application and allowed to begin the process once more.



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# IMAGINE A CURE CAMPAIGN PROGRESS REPORT

## AS OF APRIL 30, 2015

### THE VISION OF THE IWMF

*To support everyone affected by Waldenstrom's macroglobulinemia while advancing the search for a cure.*

### THE MISSION OF THE IWMF

*To offer means of mutual support and encouragement for those with Waldenstrom's macroglobulinemia, their family members, and others with an interest in the disease.*

*To provide information and educational programs that address patients' concerns.*

*To promote and support research leading to a cure.*

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As most of you know, providing support to those affected by Waldenstrom's macroglobulinemia was the aim of Arnold Smokler when he formed the WM Support Group in 1995. In 1999 the newly-founded IWMF expanded its mission and began funding research into this incurable blood cancer. In the years since its founding, the IWMF has provided comfort and support to thousands of patients and their families and has awarded millions of dollars to support the work of many of the world's most prominent WM researchers.

Most of you know just how the IWMF has been living its mission. Those of us affected by WM learn so much about our disease from the IWMF website, by reading IWMF publications, and by attending Ed Forums where we hear about new research developments from those who are actually doing the research. We also learn from, and aid, each other through the extensive support group network, IWMF-Talk, and the LIFELINE.

A recent post on IWMF-Talk attests to just how valuable the IWMF services are to our members:

"My dear wife was diagnosed with WM nearly a year ago and although the road has been rough from time to time, I cannot imagine how it would be if *iwmf.com* were not such a helpful resource to us on so many occasions."

Those of you who have been diagnosed recently know how valuable the IWMF member services are, but you might not be aware of just how much the IWMF has contributed to the advancement of knowledge about WM through our Research Fund. The treatment options available today are vastly superior to what was available just a few years ago, and the IWMF has been instrumental in funding research that has led to these improved treatments. Because of these advances we are closer to a cure.

But because we aren't yet there, we must continue our mission. All that we do is possible only because our members have generously supported our efforts through their donations of time and money. Donations account for almost all of our revenues, so without them we would cease to exist.

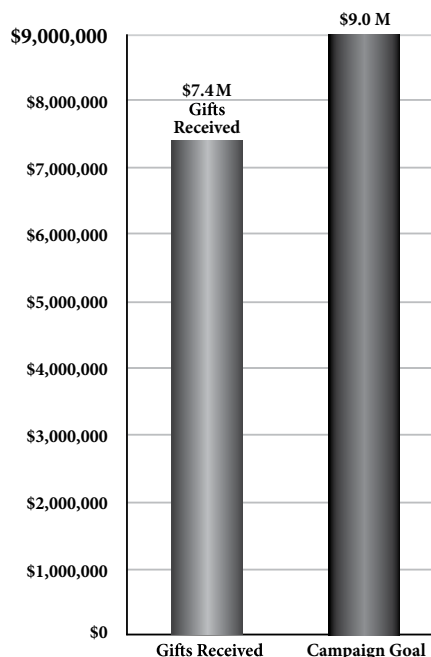
To this end, the Imagine a Cure Campaign was announced at the 2013 Ed Forum in San Diego. The goal of the campaign

was to raise \$9,000,000 over a five year period to help continue the search for better treatments and a cure for WM, as well as to continue to provide vital support services to our members and their families.

How are we doing? As of April 30, 2015, the Imagine a Cure Campaign received commitments of \$7,448,979 or 82.8 percent of the goal. More than 4,400 donors have participated in the Campaign, with gifts ranging from \$1 to \$750,000. If you have contributed to the Campaign, we thank you for your generosity and hope that you will continue to give. If you have not yet participated, we hope you will do so this year.

Multi-year pledges are particularly important because they allow us to fund multi-year research projects. Please visit our website ([iwmf.com/research/current-recipients](http://iwmf.com/research/current-recipients)) to read about some of the exciting new projects that your dollars are funding.

Together we are making a difference. Let's all continue to do so.



*The total amount for Gifts Received includes all gifts to the Member Services Fund and the Research Fund, pledges made over a five year period, and planned legacy gifts.*



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## MAJOR GIFTS TO THE IWMF

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**RESEARCH PARTNERS:** For a commitment of \$50,000 per year for a minimum of two years, or a lump sum of \$100,000 or more, you can become a Research Partner supporting a specific IWMF research project approved by our Scientific Advisory and Research Committees. Research Partners will have an opportunity to be informed regarding the research project and will be formally acknowledged by the investigators in their report of the project as well as in any resulting publications. The IWMF typically has 4 to 6 research projects underway, with new projects under consideration throughout the year.

### RESEARCH PARTNERS

David & Janet Bingham Research Fund of the IWMF

Michael & Rosalie Larsen Research Fund of the IWMF

Maynard Morris & Carolyn K. Morris Research Fund of the IWMF

W. Thomas Myers Research Fund of the IWMF

**NAMED GIFT FUNDS:** For a commitment of \$10,000 per year for five years, or a lump sum of \$50,000 or more, you can establish a named fund at the IWMF in your own name or in

the name of someone you wish to honor. This fund may support member services or research or a combination of the two.

### NAMED GIFT FUNDS

Baker Family Research Fund of the IWMF

Dr. Morie A. Gertz Research Fund of the IWMF

Gary Green Research Fund of the IWMF

Caroline & Harry McPherson Research Fund of the IWMF

Lynn & Carrie Martin Research Fund of the IWMF

Gail & Sam Murdough Research Fund of the IWMF

Sesnowitz Family Research Fund of the IWMF

If you have discretionary giving power and would like to help move our research program forward in a special way, we invite you to join those listed above. For more information about Research Partners, Named Gift Fund opportunities, and other possible giving options, please contact Dave Benson, IWMF Senior Development Officer at (952) 837-9980 or [dave@dbenson.com](mailto:dave@dbenson.com)

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## 2015 BEN RUDE HERITAGE SOCIETY REPORT

BY LAURIE RUDE-BETTS

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In 2008 I was thrilled when the Board of Trustees established the Ben Rude Heritage Society, a group of individuals who are remembering the IWMF in their wills and giving their legacy an opportunity to live on through the IWMF. The Society honors my late husband, Ben Rude, the second president of the IWMF, in recognition of his leadership legacy. Ben Rude Society members are generous individuals who have made provisions for the IWMF through bequests, gift annuities, trusts, insurance policies, or similarly planned gifts.

In 2008, the Society started with 11 members and \$250,000 in commitments. In only 7 years, those numbers are up to 66 members and \$3.3 million, so it is really making a difference!

Three new inductees for 2015 were announced at the Ed Forum: Jan Solomon Cramer, who donated in memory of Mathilde Johanna Van Gogh; Marguerite C. Regan, PhD; and Thomas Keys.

We thank these donors and their families for their generous gifts and for their support of the Ben Rude Heritage Society!

Legacy provisions are a meaningful part of the IWMF's future and for that reason the legacy portion represents 20% of the Imagine a Cure Campaign. If you are thinking about your personal estate planning and can find a way to donate to enable the IWMF to continue serving members and to support research, please contact Dave Benson at (952) 837-9980 or [dave@dbenson.com](mailto:dave@dbenson.com) or visit the planned giving section of the IWMF website at [iwmf.giftlegacy.com](http://iwmf.giftlegacy.com)

**LYMPHOMA  
COALITION**

Worldwide Network of  
Lymphoma Patient Groups



**September 15th is  
World Lymphoma Awareness Day**

For more information, visit the Lymphoma Coalition website  
[www.lymphomacoalition.org](http://www.lymphomacoalition.org)





Dr. Eric L. Smith

Dr. Eric L. Smith was one of four researchers granted a Young Investigator Award to attend IWWM8, the International Workshop on Waldenström's Macroglobulinemia held in London, August 2014. He presented his current research in a poster session under the title *CD 19 Targeted Chimeric Antigen modified (CAR) T-cells for the treatment of WM*. The accompanying article is the second in a planned series of interviews with young cancer researchers whose cutting-edge and innovative work may well culminate in a new understanding of Waldenström's macroglobulinemia and potential new therapeutic regimens.

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## INTRODUCING YOUNG INVESTIGATOR AWARDEE ERIC L. SMITH, MD, PHD

AS TOLD TO PENNI WISNER

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To talk with Dr. Eric Smith, a third-year oncology fellow and cancer researcher at Memorial Sloan Kettering in New York, is to begin to understand just how he has accomplished so much so young: He talks extremely fast with passion and thoroughness. His drive and focus apply equally to work and family life. He and his wife have two young daughters. Dr. Smith admits: "I don't have very much time for hobbies. So when I am at work, that's where my focus is, and when not at work, I want to maximize my time with my family."

After twelve years living in Manhattan, the Smiths decamped for Westchester County in 2014 when his older daughter started kindergarten. Their first winter in the country provided many opportunities for building snowmen and going sledding. This spring, Dr. Smith volunteered to coach his daughter's softball team: "It's not that big a commitment to coach five-year-olds." An avid bike rider, Dr. Smith rides to and from the train for his daily commute to New York City: "As I ride my bike back and forth to the train every day, it gives me a small decompression – going from work mode to family mode and vice versa."

Dr. Smith looks forward to going to work every day. "Growing up, I wanted to be a doctor. But during college, I got into research (on *C. elegans*, studying how neurons grow and nerve generation) and it opened my eyes to how exciting it can be to draw up hypotheses and test them. It is a way to help more than the one person in front of you."

In his second year of medical school at the Icahn School of Medicine at Mount Sinai, Dr. Smith saw an opportunity to help the community surrounding the hospital. "My grandparents were Holocaust survivors who immigrated to the USA after the war. They did not speak any English at all. My mother was born shortly after they arrived, grew up in the Bronx, and was the only person in her family to go to college. She ultimately got a Master's in education and later in her career became an assistant principal. While she could have taken a job in the suburbs, instead she commuted to the South Bronx every day. She felt she could do the most good helping the immigrant community there. In medical school in East Harlem, surrounded by opportunities to volunteer with immigrant populations, I wanted to be a part of that."

He was one of the founding members of the East Harlem Health Outreach Program, a student-run, physician-supervised, free clinic for uninsured adults. "I had every position imaginable there from junior clinician, clinic manager, and finally clinic chair, the highest

student position. I held that position, off and on, for several years. I also wrote and oversaw several grants and initiated and ran a national conference. Every year I was involved, we would add new services and increase the numbers of patients we served. But back then we were just getting off the ground. Today, EHHOP is thriving beyond my wildest expectations. In the time since I graduated medical school the student leaders have continued to expand it at the same remarkable pace."

While pursuing the PhD portion of his combined medical studies program, Dr. Smith worked in a laboratory studying Niemann-Pick disease in which an infant is born missing an enzyme that degrades lipids. "During my time there, we started clinical trials to test a recombinant enzyme. I got to see and work with some of the children with the disease. The work led to my interest in cancer because the pathway involved in these lipids is also important in cell death."

After completing his PhD and then his medical training at Mt. Sinai including two years as a resident in internal medicine, Dr. Smith moved to Sloan Kettering for a four-year oncology fellowship where he is currently completing his third year. His laboratory mentor at Sloan Kettering is Renier Brentjens, MD, PhD, a pioneer of chimeric antigen receptor (CAR) T-cell therapy.

"'Chimeric' means that we take parts of different genes and put them together. What we are using in patients now is essentially a synthetic gene that we 'sewed' together from three different genes. Two parts of our synthetic gene are human and signal T-cells to become active (to kill whatever cells they are engineered to target and to reproduce themselves). These are the parts of the CAR that are inside the cell and become incorporated into its functional apparatus. The third part of our synthetic gene

*Introducing Young Investigator, cont. on page 21*





extends outside the cell. Technically, it is called a “single-chain variable fragment.” This fragment recognizes the target, which is an antigen expressed on the cancer cell—in this case, the CD19 antigen found on WM cells (and most B-cells). This fragment binds to the antigen and causes the other two functional parts of the gene to begin a cascade of signaling inside the cell to not only kill the targeted cells but also to reproduce more T-cells. These newly reproducing T-cells also include the synthetic CAR gene.

“The therapy takes advantage of what is a natural pathway for T-cells. We ‘teach’ the T-cells outside the body (by altering them in the laboratory) to recognize a protein such as CD19 and attack it. Normally the T-cells would treat CD19-expressing B-cells as ‘self.’ But now the altered T-cells will effectively kill all CD19-expressing B-cells.” Advances in gene therapy over the last decade have allowed the development of gene-transfer technology. The technology is so important that the December 2013 issue of the journal



*The laboratory group at Sloan Kettering of Renier Brentjens, MD, PhD. Dr. Brentjens (at center) is a pioneer of chimeric antigen receptor (CAR) T-cell therapy and mentor of Dr. Smith. Dr. Smith stands at the far left.*

*Science* named cancer immunotherapy the breakthrough of the year, in large part because of advances and results in patients using this technology. “We are getting responses and potentially cures for diseases that were previously thought incurable.”

Responses can be dramatically rapid. “Our biggest success story so far, and most of our experience, has been with acute lymphocytic leukemia (ALL). In relapsed, refractory ALL, where there are really no other efficacious treatment options, we have had rapid, complete responses in 90% of patients. It is just incredible to be part of this project and to see such startling results. We are still following these patients to see how many, if any, are cured. Some, because there are no other treatment options, go on to have donor bone marrow transplants. We are learning slowly. That is why we are interested in doing more T-cell work: to get the CAR T-cells to function better, persist longer, and to turn remissions into cures.”

The CAR T-cell therapy must be developed for each patient. The synthetic CAR gene developed in Dr. Smith’s lab is the same from patient to patient. But the finished treatment product must be manufactured from each patient’s T-cells at Sloan Kettering’s FDA-approved gene-transfer facility before being transfused back into the patient. (“We are lucky to have this enormous facility on hand.”) It takes less than two weeks to do the manufacture and then another one to two weeks to test the product: making sure the T-cells are clean – free of any bacteria or viruses that could be picked up during the manufacturing process. The process has gotten faster and faster; a couple of years ago, this would not even have been possible.

“We have clinical trials for ALL, chronic lymphocytic leukemia (CLL) and aggressive lymphomas at Sloan Kettering. In addition, I am involved in a new trial that focuses specifically on WM. I am particularly interested in exploring T-cell therapy in WM because, unlike many other B-cell cancers, WM is predominantly a bone marrow disease like ALL. So I draw a parallel there.

“I think there is a strong chance that we would see results in WM similar to those we achieved with ALL. The trial is open now only at Sloan Kettering. We hope to initially sign up at least nine patients. So far, none have been treated, but for a good reason. Unlike ALL patients, many WMers can live a long, good life, either without treatment, or do very well on current treatments. It would not be appropriate to try this new therapy on such people. We are therefore trying to find patients who have failed or are intolerant of ibrutinib. Ibrutinib is such a good treatment for WM – it works really well and is well tolerated – but has not yet been shown to be curative. So patients should really try ibrutinib first, if possible.”

Dr. Smith adds, “I am happy to talk to any patient who either has failed or cannot be on ibrutinib for any reason and who is considering a trip to Sloan Kettering for the trial to see if it will be worth their time.”

*The Phase I/IIa CAR T-cell trial for WM patients at Memorial Sloan Kettering Cancer Center is being managed by Dr. Jae Park, Principal Investigator, and Dr. M. Lia Palomba, Co-Principal Investigator. WM patients who might be interested in the trial should contact Yvette J. Bernal, Research Project Coordinator, Memorial Sloan Kettering Cancer Center at (212) 639-8047 or e-mail [bernal@mskcc.org](mailto:bernal@mskcc.org).*

*Dr. Smith’s contact information is: Eric Smith, MD, PhD; Medical Oncology Fellow; Memorial Sloan Kettering Cancer Center; (lab) 212-639-3007.*

*Upon request, Dr. Smith will send inquirers a detailed description of the Phase I/IIa CAR T-cell trial written in a straightforward way for the non-professional reader.*

Further information about the IWMF Young Investigator Award program is found on pages 8-10 of the January 2015 *Torch*, issue 16.1.

Readers interested in further information about the East Harlem Health Outreach Program are referred to EHHOP, [icahn.mssm.edu/education/medical/student-engagement/east-harlem-health](http://icahn.mssm.edu/education/medical/student-engagement/east-harlem-health)



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# MEDICAL NEWS ROUNDUP

BY SUE HERMS

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**Seminal Phase II Trial Results Reported for Imbruvica in Relapsed WM** – *The New England Journal of Medicine* included an article with results of the multicenter Phase II trial of Imbruvica (ibrutinib) that was instrumental in obtaining FDA approval of Imbruvica for WM patients. This study of 63 previously treated symptomatic WM patients was conducted at Dana-Farber Cancer Institute, Memorial Sloan Kettering Cancer Center, and Stanford University Medical Center. Imbruvica at a daily dose of 420 mg was administered orally until disease progression or the development of unacceptable toxic side effects. After the patients received Imbruvica, median serum IgM levels decreased from 3520 mg/dL to 880 mg/dL, median hemoglobin levels increased from 10.5 g/dL to 13.8 g/dL, and bone marrow involvement decreased from 60% to 25%. The median time to at least a minor response was 4 weeks. The overall response rate was 90.5%, and the major response rate was 73%. Response rates were highest among patients with the MYD88 L265P mutation/wild-type CXCR4, followed by patients with the MYD88 L265P mutation/CXCR4 WHIM mutation, and patients with wild-type MYD88/wild-type CXCR4. The estimated 2-year progression-free and overall survival rates among all treated patients were 69.1% and 95.2%, respectively. Treatment-related side effects included neutropenia (decreased neutrophils), thrombocytopenia (decreased platelets), post-procedural bleeding, nosebleeds associated with the use of fish oil supplements, and atrial fibrillation associated with a history of arrhythmia.

**Imbruvica Advances Through Approval Process for WM in the European Union** – Meanwhile, Pharmacyclics, Inc. announced that the Committee for Medicinal Products for Human Use of the European Medicines Agency (EMA) has issued a positive opinion recommending that Imbruvica (ibrutinib) be approved to treat WM patients who have received at least one prior therapy or as first line treatment for WM patients unsuitable for chemo-immunotherapy. The EMA is an agency of the European Union responsible for the scientific evaluation of medicines used in the 28 countries of the European Union. The opinion of the Committee will be reviewed by the EMA, and a final decision is anticipated in the second half of 2015. If the final decision is positive, this would mark the first EMA-approved therapy for WM patients in Europe.

**New Clinical Trial for Relapsed/Refractory CLL and Indolent B-Cell Lymphoma Patients Utilizes CAR Modified T-Cell Immunotherapy** – Patients with relapsed, refractory, or residual WM are eligible to be included in a Phase I/IIa clinical trial at Memorial Sloan Kettering Cancer Center that includes a single dose of cyclophosphamide preconditioning followed by an infusion of 19-28z CAR modified autologous T-cells. This trial will utilize the

principle of immunotherapy: T-cells from study patients will be collected, genetically modified so that they are able to recognize a target on cancer cells (in this case the CD19 antigen on B-cells), and then re-infused into the patients in large numbers in order to effectively kill the targeted cells. Further details of this trial (identification number NCT00466531) can be found on [www.clinicaltrials.gov](http://www.clinicaltrials.gov). For more information about CAR-T immunotherapy, see page 20 of this *Torch* issue for an article about Dr. Eric Smith, who received a Young Investigator Award at the 8th International Workshop on WM for his research in this area.

**Novel Proteasome Inhibitor Ixazomib Enters Phase II Trial in Combination Therapy for WM Patients** – Dana-Farber Cancer Institute is opening a Phase II trial for the combination of ixazomib, dexamethasone, and rituximab in previously untreated WM patients. Ixazomib is a novel oral proteasome inhibitor. This so-called IDR combination will be evaluated for safety and effectiveness; the trial identification number on [www.clinicaltrials.gov](http://www.clinicaltrials.gov) is NCT02400437.

**Zydelig (Idelalisib) to Enter Phase II Trial for Relapsed/Refractory WM** – Dana-Farber Cancer Institute was scheduled to open a Phase II trial of Zydelig (also called idelalisib, GS-1101, or CAL-101) in May for relapsed/refractory WM. Idelalisib is an oral PI3K inhibitor that has already been approved in the US by the FDA to treat patients with relapsed chronic lymphocytic leukemia, follicular lymphoma and small lymphocytic lymphoma. On [www.clinicaltrials.gov](http://www.clinicaltrials.gov), the trial identification number is NCT02439138.

**Idera Pharmaceuticals Expects to Add Additional Patients to Phase I/II Trial of IMO-8400 in Relapsed/Refractory WM** – As part of the ongoing Phase I/II clinical trial of IMO-8400 in relapsed/refractory WM, Idera Pharmaceuticals has enrolled the targeted number of patients at each of the three dose levels to fulfill the requirements for a data review by an independent safety data monitoring committee; in June, Idera expects to open an additional cohort to allow more patients to enroll in the study. IMO-8400 is an investigational new drug designed to target the Toll-like receptor (TLR) signaling pathway, which is over-activated in WM patients who have the MYD88 L265P mutation (approximately 90% of WM patients). The ongoing trial is designed to evaluate the safety and clinical activity of three escalating dose levels of IMO-8400. The trial identification number on [www.clinicaltrials.gov](http://www.clinicaltrials.gov) is NCT02092909.

**United Kingdom Study to Test Anti-CD19 Monoclonal Antibody in Patients with B-Cell Malignancies** – A Phase I clinical trial in the United Kingdom will determine the maximum dose and potential side effects of the monoclonal antibody DI-B4 that can safely be given to patients with

*Medical News Roundup, cont. on page 23*



indolent B-cell malignancies, including WM. DI-B4 targets the CD19 antigen found on the surface of almost all B-cells. DI-B4 will be given intravenously once a week for four weeks. The trial identification number on [www.clinicaltrials.gov](http://www.clinicaltrials.gov) is NCT01805375.

**Spanish Researchers Investigate WM Cell of Origin and Pathogenesis** – A multicenter group of Spanish researchers reported in *Blood* their approach to determine the cell of origin and the molecular pathogenesis behind WM development from IgM MGUS. By utilizing flow cytometry, the researchers noted a significant overlap in the profiles for clonal B-cells from IgM MGUS, smoldering, and symptomatic WM patients, suggesting that IgM MGUS and smoldering WM cells already harbor many of the genetic characteristics of aggressive disease. But the frequency of specific copy number abnormalities in certain genes progressively increased as the disease progressed, suggesting a multistep transformation of clonal B-cells from the benign IgM MGUS to symptomatic WM. The researchers also proposed the cell of origin for WM as CD25+ CD22<sup>low</sup> activated B-cells.

**DFCI Study Looks at Secondary Malignancies in WM Patients** – A retrospective study utilizing the SEER (Surveillance, Epidemiology and End Results) database was conducted by Dana-Farber Cancer Institute to look at the incidence of secondary malignancies in WM patients. The SEER data covered 4,676 WM patients from the years 1992-2011; of this number, 681 reported secondary malignancies. The study concluded that patients with WM had a 49% higher risk of secondary malignancies than the general population, regardless of age, sex, race, or year of diagnosis. The risk was significantly increased for solid cancers of the lungs, urinary tract, and thyroid; melanoma; aggressive lymphoma; and acute leukemia. A separate, related study by DFCI looked at survival outcomes of WM patients who subsequently developed secondary malignancies and found that those patients were older than population controls with the same cancers who did not have WM. In addition, WM patients with colorectal cancer, melanoma, and diffuse large B-cell lymphoma tended to have worse overall survival than controls. The group's conclusion is that those outcomes argue in favor of continuing to pursue age-appropriate screening for other types of cancer in WM patients.

**Study Reports Impact of Family History of B-Cell Cancers on Overall Survival of LPL/WM Patients** – A population-based retrospective report from the University of Iceland, Skane University Hospital in Sweden, and the National Cancer Institute in the US examined the impact of having a family history of B-cell malignancy on overall survival of LPL/WM patients. In this case, nationwide Swedish registries identified 2,185 LPL/WM patients diagnosed from 1958-2007 and their 6,460 first-degree relatives. Overall, LPL/WM patients with a family history of any lymphoproliferative disorder had an increased risk

of death compared to those with no family history of such disorders. The report concluded that these results support the theory that genetic susceptibility predisposes patients to a more severe form of LPL/WM; however, it also pointed out that the follow-up time through 2007 was not able to evaluate the impact of novel agents that might alleviate the negative prognostic impact of familial disease.

**Farydak (Panobinostat) Combination Therapy Approved for Multiple Myeloma** – The US Food and Drug Administration has approved oral Farydak (panobinostat) in combination with bortezomib and dexamethasone for the treatment of patients with relapsed multiple myeloma. In clinical trials, patients receiving this Farydak combination saw an improved response rate and a delay in their disease progression, compared to participants treated with bortezomib and dexamethasone only. The most common side effects included diarrhea, nausea, arm or leg swelling, decreased appetite, fever, vomiting, and weakness. The drug has a Boxed Warning of possible severe diarrhea and severe cardiac events. Farydak works by inhibiting the activity of certain enzymes, known as histone deacetylases (HDACs), and is marketed by Novartis Pharmaceuticals.

**Vorinostat Evaluated in Phase II Trial for Indolent Non-Hodgkin's Lymphoma** – Another oral HDAC inhibitor called vorinostat, in combination with rituximab, was evaluated in a Phase II clinical trial for newly diagnosed and relapsed/refractory indolent non-Hodgkin's lymphoma patients. The overall response rate was 46% for all patients – 67% for previously untreated and 41% for relapsed/refractory patients. Median progression-free survival was 29.2 months for all patients – not reached for previously untreated and 18.8 months for relapsed/refractory patients. The most common adverse events were thrombosis (blood clots), neutropenia (decreased neutrophils), thrombocytopenia (decreased platelets), lymphopenia (decreased lymphocytes), and fatigue.

**Phase III Trial Compares Kyprolis to Velcade in Multiple Myeloma** – A Phase III clinical trial of 929 multiple myeloma patients evaluated Kyprolis (carfilzomib) and dexamethasone vs. Velcade (bortezomib) and dexamethasone and concluded that the Kyprolis combination significantly increased progression-free survival and resulted in a higher overall response rate and lower neuropathy events. Kyprolis is a second generation proteasome inhibitor. This so-called ENDEAVOR study is continuing to evaluate the effect of the Kyprolis combination on overall survival in these patients. Treatment discontinuation due to adverse events was comparable between the two arms, although the rates for cardiac and renal events, hypertension, and dyspnea (shortness of breath) were greater in the Kyprolis arm. Kyprolis is marketed by Onyx Pharmaceuticals.

**Rapid-Infusion Bendamustine Advances Through Approval Process** – Eagle Pharmaceuticals Inc. has submitted





a new drug application for EP-3102 to the US Food and Drug Administration. EP-3102 is a rapid-infusion product similar to Treanda (bendamustine). Teva Pharmaceutical Industries Ltd., the manufacturer of Treanda, has entered into a licensing agreement with Eagle Pharmaceuticals to allow Teva to promote and distribute EP-3102, and Teva will waive its orphan drug exclusivities, which should allow EP-3102 to come to market sooner.

**Tyrosine Kinase Inhibitor Called Entospletinib Tested in CLL and NHL** – A multi-center Phase II trial, reported by Willamette Valley Cancer Institute and Research Center/US Oncology Research, studied an oral small molecule tyrosine kinase (Syk) inhibitor called entospletinib (GS-9973) in patients with chronic lymphocytic leukemia and non-Hodgkin's lymphoma. Patients received 800 mg twice daily. The objective response rate was 61%, and 29% of patients had adverse events, including shortness of breath, pneumonia, neutropenia (reduced neutrophils), dehydration, fever, and reversible elevations in liver enzymes.

**New PI3K Inhibitor for Indolent NHL to Enter Phase III Clinical Trials** – Bayer HealthCare is expanding its study of intravenous copanlisib (BAY 80-6946) by opening two new Phase III trials for indolent non-Hodgkin's lymphoma (NHL). Copanlisib is an inhibitor of PI3K, which is one of the most frequently altered pathways in cancer, and was recently granted Orphan Drug Designation for follicular lymphoma. The new trials will open for enrollment in mid-2015: one trial will evaluate copanlisib in rituximab refractory indolent NHL patients who have previously been treated with rituximab and alkylating agents, and the other trial will use copanlisib in combination with rituximab vs. single-agent rituximab in patients with relapsed NHL.

**Phase III Results Reported for Imbruvica, Bendamustine, and Rituximab Combination in CLL and SLL** – Pharmacyclics reported Phase III study results evaluating Imbruvica (ibrutinib) in combination with bendamustine and rituximab vs. placebo in combination with bendamustine and rituximab in patients with relapsed chronic lymphocytic leukemia (CLL) and small lymphocytic leukemia (SLL). The study met its primary endpoint, demonstrating a statistically significant improvement in progression-free survival for

the Imbruvica combination arm. This study enrolled 578 patients.

**Biosimilar to Neupogen Receives FDA Approval** – The US Food and Drug Administration has approved Zarxio, a biosimilar of Neupogen that boosts the production of white blood cells and helps to ward off infection in patients receiving strong chemotherapy. Approval of a biosimilar is based on data that demonstrate that the biosimilar is highly similar to an already approved biological product, known as a reference product. The biosimilar must also show that it has no clinically meaningful differences in terms of safety and effectiveness from the reference product. It is hoped that the introduction of biosimilars in the US could lead to decreased drug costs. The most common expected adverse events of Zarxio are aching in the bones or muscles and redness, swelling, or itching at the injection site, as well as allergic reactions. Zarxio is manufactured by Sandoz and is marketed under the name Zarzio outside of the US.

**Novel Bispecific Toxin Targets CD22 and CD19 in Refractory B-Cell Cancers** – A multicenter Phase I study reported by the University of Minnesota looked at a novel bispecific ligand-directed toxin targeting CD22 and CD19 in refractory B-cell malignancies. The treatment consists of a fusion between parts of the diphtheria toxin and fragments of monoclonal antibodies that target both CD19 and CD22, which are antigens found on B-cells. The treatment, designated DT2219, was administered at one dose intravenously in several different strengths, and the trial was designed to determine safety, maximum tolerated dose, and preliminary efficacy. The most common adverse effects were weight gain, low albumin, transaminitis (increased liver enzymes), and fever. An objective response occurred in 2 of 25 study patients. The maximum tolerated dose was established for a Phase II study exploring repetitive doses of DT2219.

*The author gratefully acknowledges the efforts of Peter DeNardis, Charles Schafer, John Paasch, Wanda Huskins, Colin Perrott, and others in disseminating news of interest to the IWMMF-Talk community. The author can be contacted at [suenchas@bellsouth.net](mailto:suenchas@bellsouth.net) for questions or additional information.*





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# FROM IWMF-TALK

BY JACOB WEINTRAUB, MD

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The Ed Forum in Dallas produced several postings from “Secret Wallie,” keeping the IWMF-Talk participants up-to-date on the proceedings. The postings were informative and entertaining. Watch for the speakers’ slide presentations and selected videos on the IWMF website ([www.iwmf.com](http://www.iwmf.com)) and see page 8 in this issue of the *Torch* for Ed Forum coverage.

Other than a brief lull during the Ed Forum, the ongoing discussions continued to be lively. Ibrutinib discussion was prominent, with postings about results, doses, side effects, and insurance coverage. There were also postings with links to a variety of human interest articles and a very information-filled discussion about travel.

## HUMAN INTEREST ITEMS

As usual, IWMF-Talk Manager and Trustee **Peter DeNardis** posted several items of more general interest for all readers.

Peter posted a link to a video about transition from cancer patient to survivor. Although it deals with a slightly different situation than is common to WM patients, the video still addresses many issues that we experience, including how to deal with treatment and side effects and long term care with follow up. [vimeo.com/15988236](http://vimeo.com/15988236)

Another article presented the perspective of a leukemia patient facing life post-treatment, including continued care after treatment to improve quality of life. Peter quoted the author’s viewpoint that all people hold a dual citizenship, in the kingdom of the well and also the kingdom of the sick, with some people, like us, who are neither sick nor well. [well.blogs.nytimes.com/2015/03/16/lost-in-transition-after-cancer](http://well.blogs.nytimes.com/2015/03/16/lost-in-transition-after-cancer)

Peter also posted a link to an article that focuses on cancer patients and how doctors are involving them more directly as partners in decision-making about treatment – something that has been discussed extensively on IWMF-Talk. The article also reported a program at the University of California, San Francisco, where patients are paired with college students or recent grads who help the patients make a list of questions for their doctors before appointments. The students then record the visit and type notes for the patients.

[www.huffingtonpost.com/2015/03/23/inviting-patients-to-decide\\_n\\_6890324.html](http://www.huffingtonpost.com/2015/03/23/inviting-patients-to-decide_n_6890324.html)

**Wanda H** also posted several links to articles of general interest.

One article was about a man who was caregiver to his wife for 17 years after her cancer diagnosis. This is an emotional article and presents a somewhat different perspective from what we usually hear. The author also cites a book he wrote called *Still Have Faith*.

[goodmenproject.com/featured-content/keeping-it-together-when-your-wife-has-cancer-dg](http://goodmenproject.com/featured-content/keeping-it-together-when-your-wife-has-cancer-dg)

Wanda also posted a link to an article about insomnia in cancer patients and survivors. The article from Dana-Farber Cancer Institute notes that insomnia is a common side effect of living with cancer – “possibly triggered by several factors, including the cancer diagnosis, side effects of treatment, hospitalization or chronic pain.” Insomnia affects about one in four survivors. The article outlines a program by Eric Zhou, PhD, that helps many people with this problem, not just people with cancer.

[blog.dana-farber.org/insight/2015/03/helping-cancer-survivors-get-a-good-nights-sleep](http://blog.dana-farber.org/insight/2015/03/helping-cancer-survivors-get-a-good-nights-sleep)

Finally, Wanda posted a link to an article that generated considerable discussion. The article was about physical activity and the possibility that it offers some protection from developing non-Hodgkin lymphomas (NHL). It suggests that performing vigorous activity over one’s lifetime may lower risk for NHL. The results were based on a questionnaire given to 820 NHL patients and an equal number of controls. Patients who engaged in vigorously intense physical activity performance had about a 25-30% lower risk for NHL. Wanda observed this article with a “smirk” because she has “been a gym rat all her life.”

[www.sciencedaily.com/releases/2015/05/150501081838.htm](http://www.sciencedaily.com/releases/2015/05/150501081838.htm)

Other members added their experiences about having been very active and whether or not exercise might have an effect on NHL.

**Joe M** reported that he worked out all his life and still does but thinks that exercise is not a key determinant as to whether one gets NHL.

**Ginger H** stated that she has always included exercise in her life and has eaten a fairly well-balanced diet. She still needed a stent in the past but feels that diet and exercise made a difference in how she got through the past year since diagnosis and treatment of her WM.

**Dr. Jacob Weintraub** remembered past discussions about athletes who participate in extreme exercise and exertions that somehow result in a suppressive effect on their immune system and make development of cancer more likely. He further added that the article suggests people who exercise lower their risk for NHL, but exercise does not necessarily prevent it. He opined that genetics and environment likely are significant factors, too. He agreed that a good diet and exercise are better for our overall health.

**Colin P** agreed with the idea that extreme physical exertion somehow suppresses the immune system. He cited his own past experience of running marathons, thereby pushing

*From IWMF-Talk, cont. on page 26*



his body beyond its capabilities, and thinks the exertion in combination with environment and genetics might have influenced his development of WM.

There was a discussion about overall survival and risk of death in WM patients. The current thoughts related to “median survival” were considered, and there have been many different articles and comments from WM experts about this, ranging from 5 to 7 years to more than 10 years.

**Dr. Jacob Weintraub** posted a link to an article that has been referenced in the past, but one that he feels is still relevant. It is the printed version of a lecture given by Jay Gould, a college professor who was diagnosed with an aggressive cancer and was told the median survival was only 8 months. “The Median Isn’t the Message” was the title of lecture. However, Jay Gould lived for another 20 years and died of something completely different from his original cancer. This was not only an inspiring lecture but also an informative one regarding how to consider all the varying “median survival” times that we see.

[cancerguide.org/median\\_not\\_msg.html](http://cancerguide.org/median_not_msg.html)

## TRAVEL

An item in the news about a cancer patient who was denied travel on an airplane generated a discussion about rights of passengers, means of protection when traveling, and even some technical posts about air circulation in airplanes.

**Scott W** posted that the Air Carrier Access Act prohibits discrimination on the basis of disability in air travel and requires air carriers to accommodate the needs of passengers with disabilities. He also included a link to the Act. [www.disabilitytravel.com/airlines/air\\_carrier\\_act.htm](http://www.disabilitytravel.com/airlines/air_carrier_act.htm)

**Dr. Tom Hoffmann** reported that while airlines have to accommodate passengers, some forethought and advance planning are needed. Airlines do not keep extra oxygen bottles on hand, and a traveler would need to contact the airline ahead of time to make arrangements for an airline to provide an oxygen supply or for the use of a personal supply.

**Peter DeNardis** posted a link to an article in *Cure* magazine that had some useful tips for flying.

[www.curetoday.com/community/janet-freeman-daily/2015/04/can-i-fly-when-i-have-cancer](http://www.curetoday.com/community/janet-freeman-daily/2015/04/can-i-fly-when-i-have-cancer)

There was some discussion about the use of face masks on airplanes during travel.

**Michael L** suggested that pathogens are short-lived in air, and we need to pay more attention to what may be on surfaces. He suggested that airlines use a mix of outside and recirculated air and highly efficient HEPA filters, rendering the air we breathe on an airplane cleaner than we might find in other places.

**Dr. Tom Hoffmann** noted that masks can be helpful but do not supplant proper hygiene or vigilance. We can infect

ourselves if we touch a contaminated surface and then touch our faces or mouths. A mask would prevent us from doing this and would also protect us from bacteria or viruses from a sneeze or cough nearby.

**Fay L** was told by a physician at Mayo Clinic, Jacksonville, that for flying, the dark blue, half circle-shaped face mask is far superior to the soft accordion type face mask that is often handed out. When she went on a trip this year, she was able to select a location that offered a nonstop flight short enough to allow her to keep the mask on for the entire flight.

**Lydia M** reported on this topic as a certified airline pilot. She stated that there is no difference between airlines in their air recirculation systems, nor is there significant difference between airplanes. Air on airplanes is much better than most people are led to believe. The problem with air travel has more to do with contact with dirty surfaces and close proximity to other people.

Finally, **John E** stated that he was wearing gloves and not touching his face as he responded to the thread. His laptop fan pulls in fresh air which is sanitized by the heat of the electronics.

## IBRUTINIB/IMBRUVICA

The discussion continues about the newest addition to the WM treatment universe. Some aspects of ibrutinib have been reported in past issues of the *Torch*. The online discussions continue to address old issues, and sometimes new concerns and topics are discussed.

**Scott K** reported that he wore a heart monitoring unit for 40 days to detect atrial fibrillation (A-fib). He had to push a button to record his rhythm. He hadn’t realized his heart fluttering was a sign of A-fib, but the monitor recorded well enough that the cardiologist called Scott to ask if he had passed out.

**Michael L** reported that his A-fib was detected 3 months after ibrutinib was started. He had a small stroke, from which he has recovered. He stated that the company producing ibrutinib is reporting an incidence of 5% in patients taking the medication. This number is not age-adjusted, and it is known that A-fib has a higher incidence in people over age 50. He was told treatment is with an anticoagulant first, then other modalities such as ablation.

**Dr. Tom Hoffmann** added that if not adequately treated, A-fib can cause clots, strokes, and loss of stamina. Other treatment modalities are medications other than anticoagulants, cardioversion, and cardiac surgery. The longer a person has A-fib, the more difficult it is to get back to normal rhythm. It could become permanent.

Members continue to report excellent results from Imbruvica.

**Bob H** has been on the Dana-Farber ibrutinib trial for 35



cycles. His bone marrow at start showed 95% involvement. Although the marrow involvement continued at 95%, his IgM dropped from 3500 to 175 with no upward movement over the time on the trial. Finally, at two years into the trial, his bone marrow involvement showed a decline, now at 20%.

Others are starting to report that response is slow or that they have reached a plateau in treatment.

**Ruth S** said she is now on her sixth month of ibrutinib and has not seen any improvement in her lab values. She also takes lenalidomide. She developed a rash, had to have her dose reduced, and may need to consider getting out of the trial.

Finally, in a discussion about the MYD88 and CXCR4

mutations, **Jeanne H** reported that her husband has been tested and has both mutations. However, despite others' reporting of poor response to treatment if they have the CXCR4 mutation, her husband has had a very good response to ibrutinib. She added that his response may not be as good as those reported by others, but his IgM has decreased from 4700 to 3000 and has plateaued. However, all his other labs are in the normal range, and his oncologists plan to continue the treatment.

There were more in-depth discussions than can be recounted here. Everyone is welcome to join IWMF-Talk, even if only to "lurk" and learn, although comments and questions are always welcome.

## 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](mailto: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](mailto:iwmf-talk@lists.psu.edu)

2. Contact Peter DeNardis at [pdenardis@comcast.net](mailto:pdenardis@comcast.net) and provide your full name

## COOKS' HAPPY HOUR

BY PENNI WISNER

By the time you read this, you may already have had your fill of zucchini. As I write, it is the end of May and the single zucchini plant is already in abundant production. The challenge – should you choose to accept it – is to discover how many ways to cook it. Perhaps together we can brainstorm enough ideas to inspire us and thus save the neighbors from brown bags full of zucchini left on their doorsteps in the dead of night. (Oh dear, am I being too negative? And it is only just the start of the season!)

Here are some of my ideas and I hope you will chime in with yours. First, the easiest way to enjoy zucchini (in my opinion and I am sticking to it) is to choose young, slender vegetables and slice them into thin rounds with a mandoline (Remember we talked about those convenient handheld mandolines some time ago?) or cut them into a small dice and add them to salads for crunch and a delicate, sweet flavor. To make a very good salad made with raw zucchini, use the mandoline to slice the zucchini lengthwise. Dress them simply with salt, pepper, fresh lemon juice, very good olive oil, and a sprinkling of chopped fresh mint.

If you have the grill going, and since it is July, you very well might, grilling zucchini gives it great flavor. The same could be said for just about any vegetable, meat, or fish. By the

way, have you tried grilling avocado? I learned the trick years ago from Michael Chiarello. Oil the grate well and grill very thick slices or halves only until they just take on grill marks. Turn and repeat. Salt and pepper them and smear them on grilled bread and dust with paprika, preferably (to me) hot, smoked paprika. Or grill husked corn over indirect heat until lightly browned all over. Then douse with fresh lime juice and again, hot paprika or mild to medium chile powder. (Whoops, I have gone far afield from my subject – but you did light the grill after all.) As for those grilled zucchini: again cut them lengthwise with a mandoline (the size helps prevent them falling through the grate), brush them with olive oil, salt, and pepper, and grill on both sides until browned and tender. You can make a game of it: challenge yourself to see how many slices you can produce with crosshatched grill marks.

There are any number of ways to serve these. Sprinkle them lightly with truffle salt (It makes nearly everything taste better – slightly exotic and haunting.), roll them up and secure them with skewers. Serve with chilled Lillet Blanc or Rosé. Or, before rolling, spread the slices gently with Greek yogurt or fresh goat cheese mixed with pressed garlic, a touch of lemon and olive oil, salt, pepper, and chopped herbs of your choice. Need I mention smearing them with pesto?

*Our motto: Eat Well to Stay Well*





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# SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

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



*The Sacramento-Bay Area support group was well represented at the Ed Forum in Dallas. Dallas attendees, from l to r, are: Terry Rossow, Albert Semtner, Alyce Rossow, Judith May, Michael Luttrell, Jill and Larry Myers, and Kris and Steven Satterwhite. Also attending the Forum but not pictured were Jennifer and Robin Hoegerman and Tom White.*

## CALIFORNIA

### *Sacramento and Bay Area*

The group met in early June at its long-time meeting space, the Kaiser Foundation Hospital in Vallejo. Several members who had attended the May IWMF Educational Forum in Dallas were on hand to report on what they learned there. The group also talked about personal experiences with WM and enjoyed bountiful finger-food snacks.

## COLORADO & WYOMING

In April, the Rocky Mountain Blood Cancer Conference, put on by the Leukemia & Lymphoma Society (LLS), provided an opportunity for a separate support group meeting. The conference was a fabulous event, free, and conveniently located near Denver International Airport. The group staffed an IWMF table for outreach to the almost 200 nurses and others in attendance. There were about 300 patients, including 20 WMers and caregivers. Three breakout sessions proved of particular interest: Complementary & Integrative Medicine, How to Communicate with your Doctor, and Treatments for Indolent Non-Hodgkins Lymphomas. Attendees could attend their choice of the 12 different sessions. The keynote speaker, Ethan Zohn, won Survivor Africa in 2001 (and \$1 Million!) and then became a two-time lymphoma patient.



*Ethan Zohn, keynote speaker at the larger Rocky Mountain Blood Cancer Conference organized by the LLS, with Colorado WMers Sheila Lammers (l) and Cindy Furst (r).*

He survived two different transplants, one each of allogenic (donor) and autologous (from self), and four to five years of various treatments, including several that did not work. He talked about how the experiences of both “really good” and “really bad” had changed him forever and shown him that giving back and helping others with cancer is the best

*Support Group News, cont. on page 29*







One of two tables reserved for WMers at lunch, from l to r: Tina Phillips, Susan Mollner, Gary and Elsa Bradley, Cliff and Gail Baker, and Ed and Linda Fritchie.



At the Rocky Mountain Blood Conference support group leader Bill Bass with Dr. Jeffery Matous of the Colorado Blood Cancer Center.

he could do to make a positive impact on the world. During lunch, the WMers congregated at two large tables at the back of the room for an impromptu “support group” at which four newly diagnosed WMers introduced themselves while everyone shared WM experiences. Discussions centered around oncologists practising in the various cities members are from, as well as the expanding treatment choices currently available. Also attending was the new IWWMF support group leader from Albuquerque, **Ginny-Kay Massara**, who is planning her first meeting.

## CONNECTICUT

The Westport Library in Westport, CT, provided the meeting space for the April meeting facilitated by co-leader **Bob Hammond**. Each member shared his/her personal journey living with WM. Of particular interest was the recent US FDA approval of ibrutinib (Imbruvica) to treat patients with Waldenstrom’s macroglobulinemia. One member of the group was part of the clinical trial and reported that he



The “B-Cell” is a volunteer effort published biannually by members of the Waldenstrom’s community in Connecticut for the purpose of sharing news and information.

experienced a very favorable result. Other members in the “watch and wait” stage discussed other clinical trials in the pipeline. This information-sharing session left the group hopeful that the continued efforts of researchers will soon result in a new array of targeted therapies for WM. The group will continue to meet twice yearly. Meeting details will be

Support Group News, cont. on page 30



announced in the fall issue of “The B-Cell,” the Connecticut WM newsletter. During its first year of publication, “The B-Cell” has received an enthusiastic response by support group members. Beginning in September 2015, it will be published twice a year – spring and fall – to coincide with meeting dates. Request PDF copies of “The B-Cell” from Bob Hammond at [rhamm7@aol.com](mailto:rhamm7@aol.com).

### ILLINOIS

*Chicago Area/SE Wisconsin*

The group held its annual spring meeting at Lutheran General Hospital on a Saturday in April. It was a special meeting with our guest speaker, Dr. Christine Winter, who retired in 2014 after treating many patients, including WMers, for many years. Her dedication to patients was still apparent. She received a spontaneous round of applause from the group of over forty attendees when a member remarked how understandable her talk was.

### INDIANA

An enthusiastic, although smaller-than-usual, group gathered at the LLS office in Indianapolis on April 18 for a meeting. Stacey Koleszar, Patient Access and Education Manager, spoke to the group about the LLS and its many programs to benefit patients. After the presentation there was group sharing. There was a special interest in ibrutinib; many questions were asked about first-line treatment and side effects. Coffee and breakfast snacks were served.

### NEW YORK

*New York City*

The most beautiful late-spring day of the year coincided with the group’s meeting date and probably accounted for the uncharacteristically low turnout – either that or our group is just generally feeling pretty well and members chose to soak in the especially great weather. One “newbie” attended, and the group helped orient him to the hopeful road ahead. He had already done a lot of reading on the IWmf website, so the conversation went smoothly and quickly. The rest of the meeting was a wide-ranging discussion of the current status of four or five of our long-time regular attendees who were dealing with the usual range of pesky symptoms and challenges concerning what to do next time treatment becomes un-push-off-able. A core group has been convening at meetings six times a year for the past five to ten-plus years, so there is a lot of built-up trust, comfort, and good will in the room – and humor: a really wonderful bunch of friends found unexpectedly.

*Rochester, Western and Central NY*

The group assembled for a lunch in May at a local restaurant where they shared their personal journeys with WM. New attendees found comfort in the mutual understanding and experience of the group.

### EASTERN OHIO, WESTERN PENNSYLVANIA, & WEST VIRGINIA

**Marcia** and **Glenn Klepac** hosted the April meeting at their home in Pittsburgh, PA. In the general sharing discussion, treatment side effects were a concern for a couple of members: one chose to reduce the treatment dosage and another stopped maintenance therapy because of quality-of-life issues. The current bestseller, *Being Mortal*, by Atul Gawande, was briefly discussed as helpful in making meaningful treatment and end-of-life decisions. Several members were pleased to report great remissions. Discussion continued on to options for local WM care and getting second opinions, a frequent topic of interest. Texting facilitated long-distance support to a new member in Pittsburgh, who texted her sister, a WM patient in Los Angeles, the group’s input regarding ibrutinib. Next time, the group hopes to make more personal contact through Skype or FaceTime. Members enjoyed culinary potluck delights while “catching up” on personal news.

### OREGON/SOUTHWEST WASHINGTON

**Marie Navarra** is a new support group leader for the area along with **Joel Rosenblit** and **Carol Auger**. Marie was diagnosed with WM in 2009; her research led to the discovery of the IWmf and LLS patient support programs. She retired as a home health nurse in 2011, the same year she started treatment for WM. Marie has had a long, wide ranging nursing career spanning many years. She began as a critical care nurse in a large Portland hospital and moved on to become a medical case manager for Oregon Workers’ Compensation Division. She owned her own business and found it rewarding to work with injured workers out in the field and in rural areas, facilitating appropriate care for injuries that were at times catastrophic. Just before retiring, Marie worked as a communicable disease nurse for the Public Health Department, Polk County, Oregon. She has had just as active a volunteer life, first as a soccer coach for sixteen years. When her three-year-old daughter was diagnosed with acute lymphocytic leukemia (ALL), she started the parent support group called “Candlelighters.” She also served on the board of directors and as president of the local Ronald McDonald House. Since Oregon has a small population, WM group members are spread over a very large geographic area. Some drive more than three hours each way to attend meetings at which they bond quickly and look forward to reuniting at subsequent meetings.





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# INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

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*The capacity audience at WMUK's first regional meeting, held in the new library of Birmingham.*



*Dr. Roger Owen received the Robert A. Kyle Award in 2014. WMUK has announced a new research fellowship jointly with Leeds Teaching Hospital under the direction of Dr. Owen for DNA analysis of WM tissue samples.*

## UNITED KINGDOM

WMUK has been very busy, with progress on the Registry and University College London Hospitals (UCLH) biobank, which is 50% funded by IWME, and the announcement of a new research fellowship jointly with Leeds Teaching Hospital under Dr. Roger Owen, the Robert A. Kyle award holder in 2014, for DNA analysis of WM tissue samples.

WMUK also held its first regional meeting in April in the amazing new library of Birmingham, where Drs. Guy Pratt, Shirley D'Sa, Roger Owen, Simon

Wagner, and Derallyn Hughes spoke to a capacity audience, with the more intimate setting leading to a very enthusiastic and positive meeting – one of the new highlights being four patients speaking from the heart about their WM journey.

WMUK is also developing a strong working relationship with the Lymphoma Association which has particular strengths in clinical nurse specialist education and works through many local groups.



*At the British Society of Haematology's annual meeting in Edinburgh in April, a physician completes on the stand WMUK's newly re-launched online doctor treatment survey.*

On the treatment front, ibrutinib was approved for relapsed mantle cell lymphoma, a rarer and more aggressive non-Hodgkins lymphoma, by the Cancer Drugs Fund at the end of 2014, and this *may* mean limited use in relapsed WM by the end of 2015 if sufficient data is forthcoming to impress the European Medicines Agency (EMA), the National Institute for Health and Care Excellence (NICE), and the Fund.

UK has seen a dearth of trials for WM patients, but this summer sees encouraging additions to the already very successfully recruiting multi-centre R2W trial (BCR v FCR). Ibrutinib, ACP196, and the European ECWM1 trials are all starting up.

*International Scene, cont. on page 32*





WMUK attended the British Society of Haematology annual meeting in Edinburgh in April to raise its doctor profile and re-launched its online doctor treatment survey which could be completed on the stand. We also attended several B-cell lymphoma lectures, and the range of new therapies evolving is very impressive. Next year, in Glasgow, there hopefully will be a greater WM component. Dr. Steven Treon's presentation on WM this year was very well received.

In the future we are looking forward to working with Dana-Farber Cancer Institute, the IWFM, and local chairs over the patient component of IWM9 in Amsterdam (for patients: October 9, 2016) and intend to gather as large a group as possible of UK patients to attend. IWM9 details are available at <http://www.wmworkshop.org/conferences/amsterdam-2016>

Finally, an important diary date: the **Laugh4Rory** comedy event on October 10, 2015, at the Bloomsbury Theatre in London. This is being organised by the late Rory Morrison's BBC colleagues to raise money for WM research in the UK, and some of the UK's leading radio comedians have already volunteered their services. More details will be available at [www.wmuk.org.uk](http://www.wmuk.org.uk)

We moved offices in May to North London and we can be found at 44 Beresford Road, Chingford, London E4 6EE. Phone: 0208 2816477

**Roger Brown, WMUK reporting.**

### IRELAND

The WM Support Group Ireland held its annual general meeting at the Rochestown Park Hotel in Cork on March 22. The meeting was held over lunch and was informal in nature. Our group has thirteen members of which five attended, two excused themselves, and six were unable or unwilling to attend. Three of our members had attended the WMUK Doctor/Patient Forum held in London last August, and they agreed that they had found it very useful and informative. The next IWFM meeting to be held in Europe will be in Holland in 2016. One patient was planning to attend the WMUK regional meeting in Birmingham this April. She also reported that WM Support Group Ireland has recently attempted to get in touch with the Rare Diseases Ireland organization. We then talked about our experience with treatments: a stem cell harvest, bendamustine treatment, and another planned stem cell harvest. We discussed the drug ibrutinib and the research that Doctor Treon is carrying out in relation to the MYD88 gene mutation. We look forward to ibrutinib being available

in Ireland for the treatment of WM. We wished each other well and look forward to meeting up again next year.

**Sheila Thomson, WM Support Group Ireland, reporting.**

### BELGIUM (FLANDERS)

CMP Flanders is a patient organization for two diseases, multiple myeloma and Waldenstrom's macroglobulinemia. In prior symposia we had tried to put issues on the agenda that concerned both disorders but found that the speakers had very little or no information for WM. Therefore we began organizing our symposia with two simultaneous separate meetings for both diseases.

After the successful symposium of November 2014, which took place in Leuven, we decided to organize the May 9, 2015, conference in Roeselare, a town centrally located in the Belgian province of West Flanders. The city has about 60,000 inhabitants and presents itself as a very lively and industrious town. It has some well-known hospitals that recently merged into AZ Delta. As a result of this merger and the construction of a brand new hospital, AZ Delta does not yet have an auditorium but hosted us in the nearby Vives College.



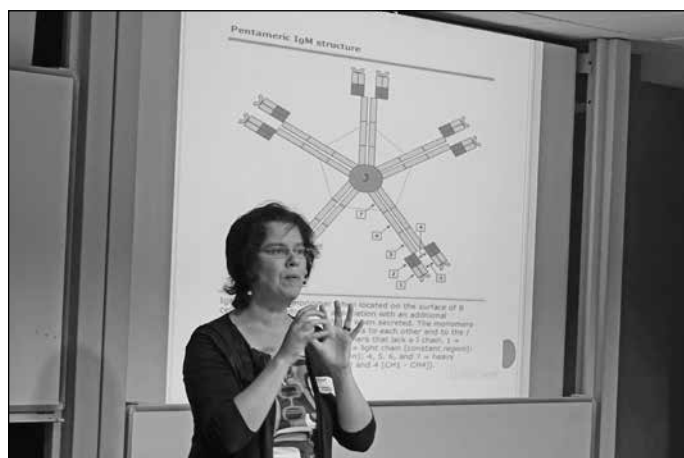
*The banner of our contact group CMP Flanders is always displayed at every event.*

*International Scene, cont. on page 33*

## The IWFM's First Affiliate/Support Group in Asia

The IWFM is pleased to welcome its newest International Affiliate and the first in Asia. The IWFM Support Group-Taiwan was established under the leadership of Jyh-Seng Wang, MD, from Kaohsiung Veterans General Hospital to reach out to serve those in Taiwan touched by Waldenstrom's macroglobulinemia.





*Doctor Liesbeth Schauvliege explains the 'big' IgM pentamer in her first presentation of the day.*

Roeselare is located in the centre of West-Flanders, a province situated on the coast, not at all in the centre of Flanders. That's why we feared for a poor attendance, in contrast to previous symposia. On the other hand, we wanted to offer our fellow sufferers who live in this out-of-the-way corner of Flanders the opportunity to attend a symposium in their own backyard. Only 26 participants attended, most of them coming from the provinces of East and West Flanders. They did the right thing!

We had invited two haematologists. Dr. Liesbeth Schauvliege of the haematological department of AZ Delta and St. Joseph Clinic in Izegem was the first presenter of this inspiring day. It was the third time that Dr. Schauvliege gave a presentation to our fellow sufferers. In the morning she talked about the disease, its symptoms, diagnosis, and primary treatment. After lunch she captivated the attentive listeners describing the course of disease and treatment based on examples from her practice.

The second speaker of the day was a young haematologist, Dr. Dominiek Mazure, staff member resident at the University Hospital Ghent and consultant haematologist at the oncology department of the AZ Damiaan Hospital in Ostend. She approached a very difficult matter in a comprehensive manner, explaining the newer treatments for WM and the place of stem cell transplantation in the treatment of the disease.

Those present were newly diagnosed patients who were in the phase of wait and watch, patients who had undergone one or more treatments, and partners or friends. All were unanimous that the information handed to them was on a human scale, clear and understandable. Unfortunately neither a nurse nor a pharmaceutical company representative was present at the WM presentations. They still are more interested in multiple myeloma.

Belgium has been and still remains a country where the repayment of a lot of drugs for rare diseases such as WM has

not been approved. Fortunately the treating physicians can work around the restrictions. This is in striking contrast to a few years ago in that today some doctors dare mention this unfortunate and difficult 'therapeutic' situation in guarded language and in a limited group. So there is still work to do for CMP Flanders in Belgium: defending the interests of WM patients by eliminating the painful discrepancy regarding treatment and scientific research.

The last session of the afternoon was reserved for patient exchange of experiences and contact with fellow sufferers. This contact is so warm, so encouraging, so comforting. It is almost touching to hear how freely patients talk about the way they live with Waldenstrom's and deal with the disease. That makes the commitment of the volunteers, also patients for the most part, so valuable and precious.



*Although this year CMP Flanders organized its symposium with two simultaneous and separate meetings for MM and WM, multiple myeloma and Waldenstrom patients sat "fraternally" together in the restaurant for luncheon.*

Finally, we had an unusual guest speaker. A Waldenstrom's patient, until recently an active member of an amateur cycling club, reported that his friends in the club will participate in the "1000 km biking against cancer," an event that lasts four days from May 14 through 17. One can participate in a team of eight cyclists and start when an amount of Euros 5,000 is paid to the Flemish League against Cancer. This money is used for scientific research. Not for us, you might think. But prior to the start there was already a radio interview with the patient, a former participant in the race, and at the finish, a television interview. Waldenstrom's name has resounded in Flemish households!

In the late afternoon after refreshments had been served, participants went home, tired but made happy by the reunion with fellow sufferers and reassured by the message from the speakers. They departed with a hearty "au revoir" and wishes for Mother's Day, to be celebrated the following day.

**Joanna van Reyn, CMP Vlaanderen, reporting.**

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