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DOCTOR ON CALL: FAMILY MATTERS IN WALDENSTRÖM MACROGLOBULINEMIA

BY DR. MARY MCMASTER



Dr. McMaster at the Chicago Ed Forum

Dr. Mary McMaster received her medical degree from the Wake Forest University Bowman Gray School of Medicine, followed by training in internal medicine and medical oncology at Vanderbilt University Medical Center, where she began to study the genetics of lymphoma. Following postdoctoral training in cellular biology and genetics at the University of North Carolina, she joined the National Institutes of Health. She completed a residency in clinical medical genetics with the National Human Genome Research Institute before moving to the National Cancer Institute (NCI).

At NCI, Dr. McMaster has pursued her long-term interest in cancer genetics. She is especially interested in understanding the basis of susceptibility of certain rare cancers including Waldenström macroglobulinemia (WM) and related blood and lymph node cancers. In

2000 she established a national registry for familial WM, which continues actively to enroll patients and their families. She is active in research consortia related to lymphoid malignancies, and her research encompasses family, genetic, epidemiological, and population-based registry studies. She and her group have characterized the familial risk of WM, identified environmental exposures associated with both familial and non-familial WM, established IgM MGUS as an important component of the familial WM phenotype, and discovered new genetic determinants of susceptibility to WM.

INTRODUCTION

Waldenström macroglobulinemia (WM) is a rare form of malignant lymphoma that arises from a type of immune cell called a B-cell. Only about five persons in one million are diagnosed with this disease each year in the US. WM was first described by Professor Jan Waldenström in 1944. It is very interesting, then, that the first family having more than one relative diagnosed with WM was described less than 20 years later, in 1962. Family studies have been informing our understanding of WM ever since. Families often provide the first clues about aspects of WM biology that have inspired important research about WM in the general population. Over the years we have learned not only about how WM behaves in families but also about susceptibility to WM overall.

*Families often provide the **first clues** about aspects of WM biology that have inspired important research about WM in the **general population**.*

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IS FAMILY HISTORY A RISK FACTOR FOR WALDENSTRÖM MACROGLOBULINEMIA?

Following the description of the original family in 1962, more families were reported in the medical literature. These families usually included multiple relatives with WM, and some families included relatives who had other B-cell tumors. In addition, some families included relatives who had other conditions such as autoimmune diseases. Some natural questions arose. First, is the familial occurrence of WM a coincidence, or does a family history of it increase a person's risk to develop WM? Second, if family history of WM increases risk, does that risk include other B-cell cancers as well as WM? Third, are other diseases part of the familial WM spectrum?

A series of studies has addressed these questions in large populations. Population-based registries in Scandinavia have been useful because they link information about cancer diagnoses, other medical conditions, and family relationships for the entire population. These studies have shown that close relatives (parents, siblings, and children) of WM patients are at increased risk to develop WM or other B-cell cancers, including chronic lymphocytic leukemia, other non-Hodgkin lymphomas, and Hodgkin lymphoma. On the other hand, studies disagree about whether the risk for other forms of leukemia or multiple myeloma is increased in relatives of WM patients. Additional registry-based studies have shown that relatives of WM patients are more likely to be diagnosed with certain autoimmune diseases than relatives of patients without WM.

Registry studies are records-based. Researchers have also used other types of study designs to answer these questions. One study directly asked both WM patients ("cases") and people without WM ("controls") about family history. This case-control study also found that WM patients were more likely to report a family history of hematologic (blood) cancers and certain autoimmune diseases than individuals without WM. Finally, when WM

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patients seen in a large referral hospital were asked about their family history, nearly 20% reported another family member with either WM or a related B-cell cancer. It is important to point out that all these studies have included predominantly white patients with Northern European ancestry. No similar studies have looked at other demographic groups.

HOW DOES IgM MONOCLONAL GAMMOPATHY OF UNDETERMINED SIGNIFICANCE (IgM MGUS) FIT INTO THE WM PICTURE?

The original WM family consisted of two brothers who developed WM. While studying the family, researchers discovered the brothers' mother had IgM monoclonal gammopathy (today termed "monoclonal gammopathy of undetermined significance" or "MGUS"). This was the first indication that IgM MGUS is part of the familial WM spectrum. After that initial finding, researchers began to screen apparently unaffected relatives for MGUS in other families. Several studies reported finding MGUS in otherwise healthy relatives. Whereas IgG MGUS is the most common form of MGUS in the general population, these relatives usually had IgM MGUS. To determine whether this observation was statistically significant and not a coincidence, researchers used the population-based registry studies described above. They found that relatives of WM patients are at significantly increased risk of developing MGUS compared to relatives of people without WM.

A new development began in 1966, when researchers reported a family where one patient had WM and two of his siblings had IgM MGUS. The family was followed over time, and eventually both siblings progressed to WM. This was the first clue that IgM MGUS might be a precursor to WM. Not long afterward, Dr. Robert Kyle confirmed this suggestion by showing that a proportion of all patients with IgM MGUS in his Minnesota study progressed to WM or related B-cell cancers. Further studies have shown that when IgM MGUS occurs in the general population, it progresses to WM at a rate of about 1-2% per year. There are three important points to remember about these results. First, most patients with IgM MGUS do not go on to develop a cancer. Second, these studies again were conducted largely in white Northern European populations, so we cannot generalize the findings globally. Third, we do not yet know whether the rate of progression is different for an IgM MGUS patient who has a family history of WM.

A WORD ABOUT RISK AND INTERPRETATION OF RISK RESEARCH

Interpreting risk-related data is challenging. Unfortunately, most risk data are presented as a "relative risk." In family history studies, this means the risk that person A with a family history of WM will develop WM, compared to the risk that person B without a family history will develop WM. This can be misleading. In contrast, "absolute risk" means the actual risk that a given person will develop WM during his or her lifetime. Clearly, absolute risk is a more meaningful

indicator of individual risk. Absolute risk is influenced by the frequency of a condition in the general population. To relate this to cancer risk, consider how relative risk affects absolute risk for a common cancer (e.g., breast cancer) and a rare cancer such as WM. In the US, about 12% of women will develop breast cancer. Suppose a hypothetical risk factor is associated with a relative risk of 2 (twice as likely to develop cancer). For breast cancer, a relative risk of 2 raises this number to nearly 25%, or 1 in 4 women. In contrast, that same relative risk of 2 increases a person's absolute risk of developing WM next year from about 5 in 1,000,000 to 10 in 1,000,000. The actual calculation is a bit more complicated, but the concept is valid.

ARE THERE GENETIC RISK FACTORS FOR DEVELOPING WM?

The accumulated evidence suggests that there are genetic risk factors for developing WM. Pinpointing those factors has been difficult, however. Genetics could contribute to susceptibility to WM in two main ways. In one scenario, a rare change in a gene important for cell growth and survival could occur. Such a change (called a "variant") would be expected to lead to a high risk for WM and would be present in most or all patients who had an inherited susceptibility to WM. When large-scale genomic sequencing technologies became available, there was hope that it would be possible to discover such a rare "big-effect" gene variant. Instead, WM patients within families share many rare gene variants (as expected), but the same gene variants are not found in different families. This disappointing result caused researchers to change our thinking.

*The accumulated evidence suggests that there are **genetic risk factors** for developing WM.*

In the second scenario, WM susceptibility might be due to variants in the genome that are more common in the general population. Each common genomic variant would contribute only a small increase in risk ("small-effect") in this scenario. A person would need to have several such variants or a combination of genomic variants and specific environmental exposures to develop WM. To search for small-effect, common variants, researchers use a technique to analyze thousands of known common variants to see whether there are differences between WM patients and persons without WM ("controls").

Recently, two regions of the genome were found to be associated with risk for WM. These regions contained common "small-effect" variants that were much more likely to occur in WM patients than in controls. One region is near several genes that are known to be important in B-cell

development and function. Laboratory studies showed that the variant influences cells' ability to grow and divide and affects the function of nearby genes. Importantly, although these regions were discovered in a group that contained many familial WM patients, they were also associated with risk for WM in nonfamilial patients.

WHAT DO THESE RESULTS MEAN FOR ME AND MY FAMILY?

Over the years, I have found patients, families, and caregivers are interested in several questions:

- 1) Can WM run in families? The answer is clearly yes. We now have over 50 years of data in both family and population studies supporting this conclusion. However, because familial WM is an uncommon feature of a rare disease, most WM patients will have no other family members with WM or another B-cell cancer.
- 2) What is my family member's risk to develop WM now that I have been diagnosed? We know that the close relatives of a WM patient are at increased risk to develop WM or another B-cell cancer at some point in their lifetime. We do not know exactly by how much this risk is increased, but the available data suggest that the absolute risk (see discussion of risk, above) for any given individual with a family history of WM is small. We also know that risk increases with age—even with a family history, it is rare for a person to be diagnosed before age 40 and extremely rare for a person to be diagnosed before age 30.
- 3) Can or should my family have a genetic test for WM? As of 2018, the answer is no. The MYD88 gene variant that is characteristic of WM is present only in the WM tumor cells and has never been shown to be passed down from one generation to the next. To date, no single rare “big-effect” gene variant has been conclusively proven to cause WM or found in more than one family, so no gene test of this type is available clinically. The common “small-effect” variants recently discovered are not within genes but may regulate gene function. However, we do not yet understand exactly how they modulate risk or

whether they can increase risk by themselves or need additional gene changes or environmental exposures to influence risk.

- 4) Should my family members be screened for monoclonal gammopathy of undetermined significance? This question is the most difficult, and the answer may be evolving over time. An important consideration is what one wants to accomplish by such testing. We know that MGUS can progress to WM. However, we also know progression can take many years and most MGUS patients will never progress. Moreover, in 2018 there is no treatment that can prevent progression to WM or cure WM once it develops. Meanwhile, the pace of drug discovery is accelerating, and we expect treatment to improve over time.

Further, we know that MGUS, even when part of the familial spectrum, is age-dependent and is virtually never found in childhood, adolescence, or young adulthood. Thus, a family member who does not have MGUS at a young age may be falsely reassured, because they might develop it later in life. These lines of evidence favor an argument to not screen healthy family members for MGUS, except in a research setting. On the other hand, our understanding of MGUS is evolving also. By definition, MGUS has no associated symptoms. However, there is growing evidence that monoclonal gammopathy may have health consequences and in some patients is no longer “of undetermined significance.” Therefore, in 2018, it is reasonable to consider screening for monoclonal gammopathy in adult family members over age 40 who desire screening. However, in general, screening is most appropriate in the research setting.

Clearly, family studies have played a pivotal role in our understanding of Waldenström macroglobulinemia. We owe a huge debt of gratitude to all the WM patients, familial and nonfamilial, who have contributed—and continue to contribute—to WM research!

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 *IWMF Torch* editor Shirley Ganse at shirleyganse@hotmail.com

PRESIDENT'S CORNER

BY CARL HARRINGTON

Traditionally, January is a time to make New Year's resolutions; let me share an inspiring thought:

"The true meaning of life is to plant trees, under whose shade you do not expect to sit." — Nelson Henderson

Now, some of you are probably thinking that's a nice thought. What trees should I plant this year? Others may be thinking

"Who the heck is Nelson Henderson? Am I supposed to know him? Was he Florence Henderson's husband?" No, you are not supposed to know him, and he was not Florence Henderson's husband. He wasn't on *The Brady Bunch* either. So now you're going to have to keep reading to find out the answers to the first and second questions.

Let's look back at 2018 and see some of the trees we planted. Here are few highlights:

- The IWMF invested another \$1,728,000 in research in our search for a cure. This brings our total spending on research to nearly \$14 million since 1999. All financed by fellow WMers and their friends and family. Donate!
- We had record attendance at the 2018 IWMF Educational Forum with 373 attendees and received a rating of 4.82 out of 5! Said another way, we got an A+ with a rating equal to 96 out of 100. Save June 7-9, 2019, for the next Educational Forum in Philadelphia. Come!
- In total about 1,800 WMers attended educational forums in Canada, Germany, Italy, France, Australia, Spain, Rosemont, IL, and New York City. Pretty good for an organization that started with 21 people. Participate!
- Attendance at the two IWMF-CancerCare webinars was over 2,500 from all around the globe. Learn!
- We added two new international affiliates in China and New Zealand, bringing our total to 18. Nearly half of the world's population lives in a country with an IWMF affiliate. Join!
- The IWMF received a coveted 4-star rating from Charity Navigator, the largest evaluator of non-profits. This included a 94.58 overall rating and a 100 rating on accountability and transparency. Give!



- The fourth IWMF-LLS Strategic Research Roadmap Summit in New York on April 6 and 7 – This meeting will include the brightest and best minds in the world of WM. All of them will be donating their time and talent to help us conquer WM.
- A new request for proposals (RFP) on November 15 – We will review those proposals and fund as many of the best as we can afford to get us closer to a cure.
- Our 24th Educational Forum at the DoubleTree by Hilton Philadelphia Center City in downtown Philly on June 7 to 9 – Think seriously about planting yourself at the DoubleTree. Registration information is available on page 25.
- More improved educational publications – They can help you understand your disease and what to ask your medical team.
- A revamped website – It will be even easier and faster to use.
- A new IWMF-CancerCare webinar – Expect to hear more about it soon.

How can you help us plant even more trees?

- Support the IWMF financially. Why do I keep harping on this? Because WM is a rare disease. We get no funding from the US government or any other government. If you want a cure, it's up to YOU. Yes, YOU. Please give as generously as you can. We'll use your donation wisely.
- Ask your friends and family to support the IWMF. At the very least, tell them you don't want anything for your birthday...just their love and a donation to the IWMF.
- Volunteer your talents. Contact Jennifer Silva at jsilva@iwmf.com and tell her how you can help.
- Name the IWMF in your estate. Contact Jason Watkins at jwatkins@iwmf.com. It's really easy; you don't have to create or rewrite your will. It couldn't be more of a "planting" thing to do!
- Share your hard-earned knowledge about WM—what's worked for you and what hasn't—on IWMF Connect, on Facebook, at support group meetings, on LIFELINE, or by telling your Story of Hope. WMers want to know what has helped others.
- Participate in patient registry projects: LLS Patient Registry, WhiMSICAL, and the Rory Morrison Registry project in the UK. There is incredible

So what new trees should you expect to see us plant in 2019?

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power in combined patient data in a rare disease like WM. Help us harvest it!

- Update your contact information to make sure we have your email address, your mailing address, your date of birth, and your date of diagnosis. Contact Jennifer Silva, the IWMF operations manager, at jsilva@iwmf.com. Share your information with us so that we can do the most at the least cost.

So now, stop a moment and look back at that list. How many of those steps are YOU going to take in 2019? Don't wait. Start right now. Working together, we can plant not just a tree or two; we can plant a forest!

And now as a reward for reading all the way to the end, I'll tell you that Nelson Henderson was a second-generation farmer in Manitoba, Canada. As far as I know, he did not have WM. But he was a Wise Man.

Stay well and plant some trees in 2019!

REPORT FROM THE 10TH INTERNATIONAL WORKSHOP ON WALDENSTROM'S MACROGLOBULINEMIA

BY TOM HOFFMANN, MD, IWMF VICE PRESIDENT FOR RESEARCH

The 10th International Workshop on Waldenstrom's Macroglobulinemia (IWWM10) was held on October 11-13, 2018, at the New York Marriott Downtown Hotel and Conference Center. It was coordinated with the 5th International Patient and Physician Summit on Waldenstrom's Macroglobulinemia, which overlapped the workshop on October 13-14 in the same facility (see page 12 of this issue for coverage of the summit).

The co-chairs of the workshop were Lia Palomba, MD, Memorial Sloan Kettering Cancer Center, New York, NY; Richard Furman, MD, Weill Cornell Medicine, New York, NY; Jorge Castillo, MD, Dana-Farber Cancer Institute, Boston, MA; and Steven Treon, MD, PhD, of Dana-Farber Cancer Institute. The workshop secretariat was Chris Patterson of Dana-Farber Cancer Institute.

This workshop broke records not only with the number of attendees but also with the number of research reports and discussions, which included the following:

- 350+ Attendees and speakers
- Opening ceremonies at Ellis Island
- 60 Research presentations
- 7 Keynote lectures
- 5 Panel discussions on treatment approaches to Waldenstrom's
- 79 Poster presentations
- 3 Consensus Panel discussions
- Closing ceremonies at the United Nations

The opening ceremonies at Ellis Island reminded me of our heritage, not only of our personal families but also



Overview of IWWM10 opening ceremonies at Ellis Island

of our Waldenstrom family. I had the joy of talking to Dr. Robert Kyle, Dr. Anders Waldenström (Dr. Jan Gösta Waldenström's son), and Dr. Frank A. Wollheim, who was a resident under Jan Waldenström from 1958 to 1963. We hold these men in highest honor for their work in our disease. During the closing ceremonies, Dr. Anders Waldenström told us about his father's discovery of

our disease at Malmö Hospital in Sweden. None of his colleagues believed that he had really discovered a new disease and thought it was just another variant of multiple myeloma. It apparently became quite contentious among them and took several years for the new disease to be accepted in the medical community.

The Jan Gösta Waldenström Award for Lifetime Contributions to the Study of Waldenstrom's Macroglobulinemia was awarded to Dr. Bart Barlogie during the workshop. He was my oncologist at the Arkansas Myeloma Institute where I was diagnosed in 1999. He is an outside-of-the-box clinician who is always looking forward. He brought me out of my despondent

Report from the 10th, cont. on page 7



Drs. Steven Treon, Tom Hoffmann, Bart Barlogie, and Meletios Dimopoulos at IWWM10 in New York

cancer diagnosis “funk” and treated me with a very questionable drug at that time—rituximab—at a double dose weekly for four weeks. I retired because I thought I would be dead in 3-5 years, as that was the given survival rate at that time. My son was seven years old. Dr. Barlogie pushed me to return to my practice every time I saw him, even during my infusions. Ultimately I took his advice and returned to my patients. Thank goodness! I went into a remission that is still ongoing 19 years later. Dr. Barlogie has received many awards and is now practicing at Mt. Sinai Hospital in New York City.

In addition, during the faculty dinner on Friday evening, Dr. Giampaolo Merlini, University of Pavia, Italy, was awarded the Robert A. Kyle Award for outstanding contributions to Waldenstrom’s macroglobulinemia.

During the IWWM10 closing ceremonies, our humble and gracious IWMF President, Carl Harrington, received one of the first four Peter S. Bing Humanitarian Awards for his work with the IWMF to find a cure for our disease. He stated, “When I was diagnosed with WM in 2006, I never expected to be alive in 2018...I’m very, very happy to be here, among this group...who are making the world a better, safer place for WMers.” Other recipients of the Peter S. Bing Humanitarian Awards were Ranjana Advani, MD, Stanford University; Morton Coleman, MD, Cornell University; and Chris Patterson, administrative director of the Bing Center for WM at Dana-Farber Cancer Institute.

DAY 1 BASIC RESEARCH

Many of the IWWM10 presentations were about research funded by the IWMF. Supporting these researchers to help us find the cure for Waldenstrom’s is the most

important thing that the IWMF does. The basic research presentations were grouped as follows:

Genomics in the Diagnosis and Management of WM

The first session and several others dealt with the MYD88, CXCR4, and other mutations seen in Waldenstrom’s. It is now firmly established that the MYD88^{L265P} mutation is present in almost all WM patients (95-97%) and can be used as a definitive marker for pathologic diagnosis when combined with the typical B-cell phenotype. The few who lack MYD88 mutations have an increased risk of disease transformation to a more aggressive lymphoma. CXCR4 mutations are seen in 30-40% of patients and may predict treatment responses, specifically with ibrutinib, whereas patients with wild type (unmutated) MYD88 do not respond as well to the drug. In one-half of patients with a CXCR4 mutation, the mutation is CXCR4^{S388X} which increases clinical resistance to ibrutinib. It was noted that CXCR4 mutations are associated with patients who have high IgM levels. The MYD88 mutation is also seen in one-half of patients who have IgM monoclonal gammopathy of undetermined significance (MGUS). That has been found to be an independent risk factor for progression to WM, irrespective of IgM level.

*Over **40 mutations** have
been found in **Waldenstrom’s**.*

Predisposition to WM

It was reiterated that the major predisposition to symptomatic WM is smoldering Waldenstrom’s, at a rate of progression of 12% per year for the first five years and then 2% going forward. A family history of Waldenstrom’s also predisposes to WM/lymphoplasmacytic lymphoma (LPL) at a high rate of risk. The triggers for conversion from IgM MGUS to smoldering WM to symptomatic WM are still unknown but probably related to further mutations. Over 40 mutations have been found in Waldenstrom’s. Exposure to some toxins will increase the risk of Waldenstrom’s and other lymphomas. For example, soldiers exposed to Agent Orange in Vietnam have been found to have a 7.1% overall MGUS rate compared to a rate of 3.1% in soldiers not exposed. Interestingly, the firefighters at the 9/11 World Trade Center site were exposed to dioxins (the carcinogenic chemical in Agent Orange). They have developed multiple myeloma and other lymphomas at

Report from the 10th, cont. on page 8

three times the rate in the normal population. They are also being diagnosed decades before the normal onset of these diseases. Their level of MGUS is twice the amount usually seen in the general population.

Disease Presentation in WM

Neuropathy occurs in 30-50% of Waldenstrom's patients. Patients must be screened to be sure that their neuropathy is not from a different cause, such as diabetes, genetic disease, alcohol, vitamin B12 deficiency, chronic inflammatory demyelinating polyneuropathy (CIDP), drug toxicity, and rheumatological disease. Testing is also needed for known IgM antibodies that induce neuropathy, such as anti-myelin-associated glycoprotein (anti-MAG), anti-ganglioside (GQ1b, GM1mGD1a, GD1b, and SGPG), cryoglobulin, and amyloid. Elevated protein and IgM can be found in the spinal fluid. Nerve conduction studies and an electromyogram (EMG) are helpful for diagnosis. Some patients will need a nerve or fat biopsy to make the case for WM neuropathy.

Anti-MAG is an IgM antibody that is prevalent in WM neuropathy. It is difficult to treat, as only 31% of patients with neuropathy responded to rituximab in a large French study. Most feel that these patients must have a treatment that lowers the IgM as much as possible, and some promote treatment of it even in the MGUS state.

Bing Neel is basically Waldenstrom's in the brain and spinal fluid. Magnetic resonance imaging (MRI) of the brain and spinal column as well as a spinal tap is mandatory. The MYD88^{L265P} mutation and IgM can be found in the spinal fluid and disappear with clinical and MRI response.

Emergent hyperviscosity symptoms require emergency plasmapheresis, since acute blindness, hemorrhagic stroke, or other major bleeding can happen without notice. Hyperviscosity syndrome (HVS) is usually not seen until the IgM level is >4,000 mg/dL. Any symptoms suggestive of HVS, even below that level, must be evaluated immediately. Above 4,000 mg/dL, serum viscosity goes up exponentially.

Genomic Landscape of WM

A number of receptors have been found to be possible targets for treatment. We already know about BTK and HCK. Others in focus are BCL2, IRAK4/1, IRAK3, NFkB, and other signaling targets. A tumor-suppressor gene labeled TP53 also has been found to be a mutation in our disease. It is only found in 11% of patients, but it portends a significantly shorter survival rate. Transformation to a more aggressive lymphoma like diffuse large B cell lymphoma (DLBCL) occurs

at a 1% rate. It is associated with a high incidence of MYD88 and CXCR4 mutations, notably with CD79A/B mutations, and transformation risk is also greater in patients treated with high doses of alkylating agents and nucleoside analogs.

*Always consider joining a **clinical trial**.*

Oral Presentations from Selected Abstracts

Polymerase chain reaction (PCR) assays are now able to detect MYD88 mutations in peripheral blood samples. In the future these may actually lower the need for bone marrow biopsies and may eliminate the problem of having incorrect bone marrow biopsies due to uneven dissemination of the tumor cells throughout the marrow.

Progression of asymptomatic WM was found to be associated with the prognostic levels of IgM >5,000 mg/dL, bone marrow infiltration >70%, beta 2 microglobulin (B2M) >4.0 mg/dL, and albumin < 3.5 g/dL. The high risk patients (two or more risk factors) all developed WM by four years. The rates of low risk group patients (0-1 risk factors) developing WM are 42% at four years and 70% at ten years.

CXCR4^{S338X} mutated patients treated with ibrutinib do not fare as well as those with CXCR4^{WT} (wild type). They have lower major response rates (62% vs. 85%). If their CXCR4^{S338X} is higher than 35% of their total WM clone, they also have a lower progression free survival (PFS), 30% vs. 80%. (Note: progression free survival is the length of time during and after treatment that a patient shows no signs or symptoms of the growth or spread of the cancer.)

DAY 2 CLINICAL TREATMENTS

As you read the write-ups below, you will see many different drugs used in many different combinations. It is a tsunami of data hitting the Waldenstrom world right when we need it. Several drugs are seeing second and third generation development before the initial drug is totally studied. It will be very difficult to decide the best regimens for yourself if you look here alone. You should not just pick and choose a treatment based on these numbers. Everyone is different, and it is your entire clinical picture that must be considered so that a drug will fit you. Discuss these issues with your doctor. Always consider joining a clinical trial.

Clinical Trial Updates in WM: Rituximab-Based Therapy

Bendamustine and rituximab is a very good treatment combination as reported by Dr. Veronique Leblond from France. Overall survival (OS) was 97% at two years, PFS was 87% at two years, complete response (CR) rate was 16%, and very good partial response (VGPR) rate was 37%. All but one patient had some type of positive result. Although it has a bad reputation regarding side effects, it has now been found that four courses (four weeks per course) give the same response as a six-course treatment does (87% vs. 88%). Perhaps that will help with the side effects also.

The combination of subcutaneous bortezomib, oral cyclophosphamide, and rituximab was used in previously untreated patients in a Phase II study presented by Dr. Rebecca Auer of the United Kingdom. Overall response rate was 97.6%, and major response rate was 78.6%. Cytopenias (low blood counts) and infections were noted as expected with these drugs. PFS was approximately 65% at 48 months. I can't help but wonder if fewer side effects will be found using bendamustine rather than cyclophosphamide in this "casserole."

The session on rituximab included a vigorous debate concerning whether or not rituximab maintenance should be given to everybody. The consensus was "no." Dr. Treon is still a vigorous supporter of maintenance, and he stated that maintenance increases PFS and possibly overall survival. It will take more time and data before everybody agrees one way or the other. The use of monotherapy rituximab is declining due to its low response rate. It is still used for neuropathy and in some other special cases.

Clinical Trial Updates in WM: Proteasome Inhibitors

A long-term study of bortezomib, dexamethasone, and rituximab in treatment-naïve WM was performed by Dr. Meletios Dimopoulos of Greece. This is a six-year follow-up. The median PFS was 43 months, median duration for those who got at least a partial response was 64.5 months, and the seven year survival was 66%. The majority of those in the study had intermediate/high risk factors. Side effects and neuropathy from bortezomib were not as bad as expected since it was given subcutaneously instead of intravenously.

Carfilzomib and oprozomib are second generation proteasome inhibitors which cause less neuropathy than bortezomib. The carfilzomib study of pre-treated patients showed a very good response rate of 80% with a PFS of 52% at six years. The oprozomib studies had to be stopped due to severe gastrointestinal problems and

probably won't be studied further.

Carfilzomib, rituximab, and dexamethasone (CaRD) treatment in long-term follow-up from Dana-Farber Cancer Institute shows a PFS of 58 months. Those patients with a complete response or very good partial response have not reached their median PFS. Toxicities were moderate.

Ixazomib, rituximab, and dexamethasone (IRD) therapy includes yet another proteasome inhibitor. This study used eight cycles plus rituximab maintenance. Early results showed an 83% response rate, but several patients stopped the regimen because of side effects. The rituximab maintenance was given subcutaneously, which will decrease the need for IVs and ports. The study will continue.

Clinical Trial Updates in WM: BTK Inhibitors

Ibrutinib studies in treatment-naïve and previously treated patients are continuing to show positive results. The PFS is longer than any of our other treatments, but you have to take the drug until disease progression, the occurrence of serious side effects, or the start of a new drug. The PFS and response rates are dependent on the type of mutations that you have in MYD88 and CXCR4. MYD88^{MUT} CXCR4^{WT} reaches major response at two months, and MYD88^{MUT} CXCR4^{MUT} takes six months (see Table 1 at the end). Grade 4 toxicities are rare. There are 10-20% of patients who discontinue the drug because of its side effects. Perhaps lower doses will help alleviate those problems; however, no members of the faculty were willing to push that thought. Ibrutinib-hold recommendations for surgery are: one week for major surgery, three days for minor surgery, and no holds for minor procedures like cataracts, some dental work, colonoscopy without biopsy, and so on. The ibrutinib withdrawal syndrome, which can be severe, is seen in 20-25% of those who hold the drug. Newer second generation drugs (acalabrutinib and zanubrutinib) seem to have fewer side effects with comparable response rates in early trials (see Table 2 at the end). The ibrutinib PFS of 60% at five years also means that 40% of patients will need different treatments in the future. Ibrutinib resistance is being studied, and it has been found that the mutation BTK^{Cys481Ser} is one culprit. BCL2 may also play a role, and venetoclax, an inhibitor of BCL2, is being considered in combination with ibrutinib.

The iNNOVATE study compared ibrutinib/rituximab to rituximab monotherapy. The study found prolonged PFS and increased response with the combination, as

we expected. The third arm of ibrutinib alone showed the same response as IR, but the PFS was shorter (see Table 3 at the end).

Clinical Trial Updates in WM: BCL2 Inhibitors

Venetoclax is the “latest and greatest” WM drug among patients. It appears to give great responses, but the studies are still early and ongoing. There is very little data at this time. The IWWM10 consensus panel discussion did not suggest it for out-of-trial patients at this time as the data is too sparse to determine its safety profile (see Table 4 at the end).

The human CXCR4 inhibitor ulocuplumab will be combined with ibrutinib in a study conducted by Dr. Treon at Dana-Farber Cancer Institute for those with CXCR4 mutations. You can view the trial (identifier number NCT03225716) on www.clinicaltrials.gov.

Daratumumab is an anti-CD38 antibody that will attack the plasma cell portion of the Waldenstrom clone. It will enter a Phase II study at Dana-Farber Cancer Institute. The identifier number on www.clinicaltrials.gov is NCT03187262.

WHAT ABOUT THE FUTURE?

The future is bright for us. Many of the latest drugs and combinations are having excellent results. Previously unidentified mutations and targets as well as other downstream survival signaling pathways like IRAK1 and IRAK4 are being found and studied. Newer generation drugs show promise of decreasing toxic side effects. Combination therapy is promising a one-two punch to our bad cells. Studies are showing which drugs will work best on each of our individual mutational issues. The problem today is that it takes way too long for studies to determine whether a drug is great or not. Four things could help fix that:

- Develop the perfect mouse model. (That currently appears impossible.)

- Have Phase I and Phase II study patients integrated into Phase III studies.
- Change the need for patients to go too far away from home to be in a trial. Use “octopus” trial setups that reach out into patients’ hometowns and allow them to receive treatment there.
- Get more WM patients to sign up for clinical trials. This is the greatest impediment to finding a cure. We must participate. There are several benefits to being in a trial for the patient, and no one is ever given a placebo (sugar pill) as the only treatment.

The 2018 IWWM Workshop has set the groundwork for our future therapies. It will be the opening act in the building of personal treatments based on each individual’s Waldenstrom cell differences. At the core of our abnormal cellular clones are mutational DNA changes that vary from patient to patient and are being identified. We now have the ability to develop drugs that will attack those mutations. We will know which drugs will attack the specific mutations in each patient’s WM cells and which ones won’t. This strategy of individual, targeted therapy transcends the current typical treatments that have low response rates and progression free survival. Newer generations of our current drugs are also reducing the side effect issues.

The chairs of the workshop did an excellent job putting this meeting together, and we appreciate all their work. I would also like to thank Dr. Treon, as he is a leader and a devoted advocate who has moved the needle on Waldenstrom’s treatment. He has an everlasting commitment to us and to this workshop.

Many studies presented here are ongoing, and we will have even more and better results in 2020 at IWWM11, to be held in Madrid, Spain.

Table 1: Ibrutinib

	Treatment Naïve		Previously Treated		
	MYD88 ^{MUT} CXCR4 ^{WT}	MYD88 ^{MUT} CXCR4 ^{MUT}	MYD88 ^{MUT} CXCR4 ^{WT}	MYD88 ^{MUT} CXCR4 ^{MUT}	MYD88 ^{WT} CXCR4 ^{WT}
Overall Response	100%	100%	100%	86%	60%
Major Response	94%	71%	97%	64%	0%
PFS	92% @ 18 Months		73% @ 5 Years	46% @ 5 Years	5 Months
Grade 2-3 Toxicities	7%	7%	-	-	-
Grade 3-4 Toxicities	-	-	about 10%		
Grade 4 Comps	none	none	-	-	-
Time to Major Response	1.8 Months	7.3 Months	2 Months	6 Months	N/A
5 year OS	-	-	93%	80%	N/A
Atrial fib	10%	10%	-	-	-

Table 2: Second Generation BTK Inhibitors

	Acalabrutinib		Zanubrutinib
	Treatment Naïve	Relapsed	1/3 Treatment Naïve and 2/3 Relapsed
Overall Response	93%	93%	92%
Major Response	79%	80%	80%
PFS @ 28 Months	85%	75%	92%
Grade 3-4 Toxicities	43%	54%	32%
Atrial fibrillation	-	-	6%

Table 3: iNOVATE Study

	Ibrutinib/ Rituximab	Rituximab/ Placebo	Ibrutinib Only
PFS	82% @ 30 Months	28% @ 30 Months	56% @ 36 Months
Overall Response (>Min)	92%	47%	90%
Major Response	72%	32%	71%
OS @ 30 Months	94%	92%	-
OS @ 36 Months	-	-	73%
Grade 3-4 Toxicities	60%	61%	40%
Atrial Fibrillation	-	-	0

Table 4: Venetoclax

Prior BTK Inhibitor Treatment	Never	In the Past
Major Response	95%	57%
Grade 3 Toxicities	47%	
Grade 4 Toxicities	10%	
PFS	-	-

REPORT FROM THE 5TH INTERNATIONAL PATIENT AND PHYSICIAN SUMMIT ON WALDENSTROM'S MACROGLOBULINEMIA

BY SHIRLEY GANSE, EDITOR, *IWMF TORCH*

Doctors and patients connected by mutual concerns about WM and its effects often discuss the latest in treatments for this rare disease. This is most often done at the personal or local level, but occasionally they gather together nationally and internationally to discuss not only treatments, but also ongoing research, clinical trials, and specific drugs.

The latest international meeting was the 5th International Patient and Physician Summit, recently convened in New York City and held in conjunction with the 10th International Workshop on Waldenstrom's Macroglobulinemia (IWW10) on October 13 and 14. The IWW10 brought together researchers and clinicians from around the world to present their recent findings (see Dr. Tom Hoffmann's details of this meeting starting on page 6). The summit's one-and-a-half day program benefitted from many of these same specialists speaking and answering questions during the patients' sessions.

Attendance at the summit included 217 patients, caregivers, friends, and family members from 33 states and 21 different

countries, some from as far away as Australia and South Africa. About 85 to 100 researchers and doctors from the IWW10 were present for many of the summit sessions. As the new editor of the *Torch*, I was pleased to be able to attend and learn more about this international gathering.

Such face-to-face meetings can help not only patients and caregivers, but also, by extension, their local oncologists; all can learn about many different perspectives on WM's varying presentations, its diagnosis, management, and treatment decisions. Updates on clinical trials and new drugs in the pipeline are always of great interest to those facing initial or additional treatment.

The same chairs of the IWW10, Drs. Lia Palomba, Richard Furman, Jorge Castillo, and Steven Treon, presided over the summit, and they were joined with presentations by doctors from the UK, the Netherlands, Italy, Sweden, and Greece. Each of the six 45-minute sessions was divided into five to seven categories, all of which further explained

Report from the 5th, cont. on page 13

the session's main topic. Their titles generally followed those of the researchers' meeting and included similar information, although some simplification for a non-medical audience made the mass of data more understandable and useful. Presenters often provided useful "takeaways" for the attendees; however, one clinician said that people should be careful with this information because it can quickly become out-of-date. Much of this data is discussed in Dr. Hoffmann's article.

*As always, the **question-and-answer** periods were a lively part of the discussion.*

As always, the question-and-answer periods were a lively part of the discussion. While the sessions were a review of the researchers' meeting, this was also an opportunity for patients to bring up their concerns, make comments, and ask for clarifications. Some had questions about particular personal situations, while others asked more generic questions; a couple of them were "aha" moments for me. When the subject of Agent Orange, dioxin, and other possible agents of predisposition to WM was discussed, one questioner wondered if glyphosate is in the same category, since it has widespread use in Monsanto's Roundup weed killer and has been implicated in some cancers. That has crossed my mind in the past as well. No definite information about glyphosate was presented, but one clinician emphasized that while measurable levels of dioxin or other agents in the blood may increase the risk for some cancers, this doesn't necessarily dictate one's fate.

Another question, this one in the session on peripheral neuropathy (PN), struck me as surprising. During discussion of common possible causes of PN other than WM, such as diabetes and excess alcohol intake, I was surprised to hear that regularly ingesting more than 200 mg a day of vitamin B6 can also result in PN. We supplement users should list all that we take and discuss them with our doctors; sometimes we can consume more of a vitamin than we realize if we take a multi-vitamin along with individual vitamin supplements. As a side note to that thought, after receiving more than a year of bortezomib treatment in 2013, I now learned that green tea, which I drink every day, can inhibit the effect of that drug. For me, however, it didn't seem to create a problem since it was part of a spectacularly successful treatment.

As usual, questioners wanted to discuss the familiar concern of when to begin treatment for relapsed WM. At what point is this decision made? No single answer can be given for this, since everyone presents the disease so differently. Someone could be anywhere on the scale from asymptomatic to incapacitated, and although no one would wait for the latter,

clinicians seemed to agree that they would consider treatment when the patient is symptomatic, although exceptions to that approach can and do occur.

In addition to speaking to the IWWM10 attendees, both Dr. Anders Waldenström (Dr. Jan Gösta Waldenström's son), and



*Dr. Anders Waldenström, son of
Dr. Jan Gösta Waldenström*

Dr. Frank A. Wollheim, who was a resident under Jan Waldenström from 1958 to 1963, spoke during a session at this meeting. While we often hear about the medical accomplishments of Dr. Jan Waldenström, Dr. Wollheim presented a very personal side to the man, giving insights into their professional relationship and to the close friendship that Waldenström shared with Dag Hammarskjöld. Both came from prominent Swedish families; they

were students together; they shared a love of art, botany, literature, and music; and they exchanged a lifetime of letters, some dating back to 1926 and exhibited in the Hammarskjöld archive in Stockholm. Hammarskjöld went on to become secretary general of the United Nations, and Waldenström was known as a physician and researcher who identified the disease that now bears his name.

The final session presented several case studies and was of great general interest because of the wide variety of



Drs. Steven Treon (US), Jorge Castillo (US), Judith Trotman (Australia), Alessandra Tedeschi (Italy), Eva Kimby (Sweden)

opinions and experiences expressed by doctors from other countries. Dr. Steven Treon (US) was moderator, and Drs. Jorge Castillo (US), Judith Trotman (Australia), Alessandra Tedeschi (Italy), and Eva Kimby (Sweden) formed the panel. For each of four case presentations, the doctors were asked how they would diagnose and treat the patient and why. Their various answers might be the result of differing opinions on the effectiveness of possible treatments, the availability or state approval of certain drugs, or general insurance limitations in each country. The audience had a great opportunity to gain some perspective on how and why WM treatments may differ from one country to another.

Considering the international makeup of the presenters, some discussion followed about the European Consortium for WM (ECWM) and the positive results that occur when so many researchers and clinicians consult and compare notes. Many patients had not been aware of this organization

and were interested in learning about it. Ten European countries are members of ECWM, which is associated with the Australasian Leukaemia & Lymphoma Group, a clinical trial research group. The ECWM is positioned to combine the expertise of clinicians, pathologists, and researchers across Europe and offers clinical trials with novel therapeutic approaches to WM patients. This organization is one more beacon of light that surely gives additional hope to all those in the WM family.

Overall, attendees at the meeting were struck by the excitement and determination of the clinicians and researchers to work on solving the puzzles presented by WM. It was also wonderful to see the extent of collaboration among researchers, not only in the US but worldwide, to pursue better treatments and, eventually, a possible cure. For WM patients, seeing such increased focus on this rare disease is the most gratifying “takeaway” of all.



IWMF DOC STAR: DR. SHUO MA

AS TOLD TO RON TERNOWAY



Dr. Shuo Ma

“It may be a strange thing to say, but while I have this enduring disease, I look forward to my visits with Dr. Ma and am comforted by her ability to care for me.”

These are the words of Greg Ligman, a seven-year WM patient, and his praise is directed towards Dr. Shuo Ma, his hematologist at the Robert H. Lurie Comprehensive Cancer Center at Northwestern University in Chicago, IL.

Greg continues, “It is so reassuring to see and hear how the staff at Northwestern reveres and enjoys working with Dr. Ma. It’s an uplifting experience to be cared for by a team that respects her so much.”

Ligman was diagnosed with accelerated symptoms of WM and with an IgM over 8000. Having worked as an independent contractor in Chicagoland Healthcare for over twenty years, he believed he would receive the best care at Northwestern. He chose to interview Dr. Ma after learning that her specialty was WM; he was impressed by her professionalism and character. Prior to seeing Dr. Ma, Ligman’s disease had just failed to respond to his first-line treatment and he was struggling with hyperviscosity syndrome. Dr. Ma outlined a

treatment plan specific to Ligman’s condition with which he is enjoying a sustained remission for the past six years. She continues to monitor him on a regular basis.

Ligman’s enthusiasm for Dr. Ma is shared by Ed Goldberg, a retired hospital executive, seven-year WM patient, and enthusiastic supporter of the IWMF. When his hematologist retired, he interviewed all listed specialists in Chicago and chose Dr. Ma for a number of reasons. “She is thoroughly knowledgeable about WM and the only investigator for the ibrutinib/rituximab (iNNOVATE) clinical trial in Chicago. She is kind, welcoming, and patient. Dr. Ma has been gracious with her time and spoke to our local IWMF Chicago Support Group, as well as to the Lymphoma Research Foundation meeting in Chicago.”

Shuo Ma was born in China and received her MD at Beijing Medical University in 1994. She completed her PhD in cell and molecular biology at Northwestern University in Chicago in 2000, followed by two years in Boston as a research fellow at the Brigham and Women’s Hospital and Harvard Medical School.

“During this time, I realized how I missed the patient care aspect and decided to advance my medical training in order to pursue a career in academic medicine,” says Dr. Ma. She returned to Chicago and completed residency training in internal medicine at the Resurrection Hospital in 2005 and clinical fellowship training in hematology and medical

IWMF Doc Star, cont. on page 15

oncology at Northwestern University Feinberg School of Medicine in 2008. She stayed on as faculty and is currently associate professor of medicine in the Division of Hematology-Oncology, Department of Medicine, and the Robert H. Lurie Comprehensive Cancer Center at Northwestern.

She has authored over 40 publications in leading medical journals and presented on the topic of current treatment options for WM at the 2018 IWMF Educational Forum in Chicago. A recording of her presentation can be found at <https://youtu.be/GesX8ycWxzw> and the accompanying slides at <https://tinyurl.com/y9lgdq33>.

But how did a young woman from China end up making Chicago her adopted home? She grew up in a medium-sized industrial city in the northeast region of China. Her father is an industrial translator for Russian and English and her mother an accountant. Her parents encouraged their three children to pursue academic excellence. Shuo, the youngest, has traveled the farthest away from home.

Dr. Ma always had a curious mind as a child and loved to learn and discover new things. In her teenage years, she read and was quite inspired by stories of famous scientists and physicians in history who made significant contributions to our understanding of the world and the health of society. She says, “I had debated between a career in astronomy or medical science. It’s my compassion that ultimately made me decide to become a doctor. I wanted to do something that can help to ease human suffering.”

When Dr. Ma first came to the United States, she found many challenges to overcome, including culture shock, the language barrier, and major lifestyle changes. Being young and open-minded, and more importantly, being in a multicultural society and friendly environment, helped to ease the transition.

Dr. Ma considers Chicago her second hometown and has, over the years, established her roots there. She had been at Northwestern through several stages of her career and felt at home there. “I’m proud of our culture here—excellence in patient care along with innovative research,” she relates, and “I’m proud of our team of compassionate and highly motivated healthcare providers and our open and collegial atmosphere.”

Dr. Ma says her greatest professional reward is seeing how her care brings hope and comfort to her patients and how her

research contributes to the advances in the field. She also finds teaching the next generation of physicians very rewarding. Her greatest professional challenge is trying to balance her time and efforts among increasing responsibilities.

“WM is a **chronic illness**, and only symptomatic disease requires treatment.”

When asked what advice she gives to a newly diagnosed patient, she says, “WM is a rare disease with unique features and therefore it’s very important to seek consultation and establish care with a WM expert who has experience in managing this condition. WM is a chronic illness, and only symptomatic disease requires treatment. Even though there is not yet a cure, we do have great treatment options that can effectively control the disease. Stay positive and enjoy life. We are here to help!”

She encourages patients and family to learn more about this disease from reliable resources such as the IWMF, the Lymphoma Research Foundation, and the Leukemia & Lymphoma Society. She cites the IWMF patient support groups as a great resource for patients and their families.

Dr. Ma is grateful for the loving support of her family as she tackles the challenge of work-life balance. “I’m always learning and adjusting, trying to achieve a good work-life balance. I am blessed with a wonderful family, the love of my life.”

She met her husband-to-be in elementary school, and they have been married for over two decades. They carve out time to spend with their three children, two sons and a daughter, and enjoy traveling, hiking, and camping. She also enjoys reading and dancing. This summer her dance group performed traditional Chinese dance at the Millennium Park in Chicago.

Dr. Ma has a final thought for the future of blood cancer patients: “I think that personalized medicine with novel targeted therapies and cellular immunotherapy such as CAR-T will have a major positive influence on future treatment options for WM patients.” That’s a future WMers are very ready to embrace.

In the Torchlight!

New IWMF Vice President for Research

Dr. Tom Hoffmann is the new IWMF vice president for research and chair of the IWMF Research Committee. He recently retired from his practice as a thoracic surgeon and decided to rejoin the IWMF Board of Trustees in August 2018, having previously served on the Board from 2002-2004. Tom is also well known for his sage advice on IWMF Connect.

Tom's extensive medical background will serve him well in his new role. He earned his MD from the University of Arkansas, College of Medicine, served as a resident and thoracic surgeon for over 40 years, and held various committee and leadership positions at Baptist Health Medical Center (in Little Rock, AR) and the University of Arkansas for Medical Sciences.



Dr. Tom Hoffmann

The Board looks forward to Tom's leadership of the IWMF research program. His expertise will advance our efforts to support cutting edge research projects that improve our basic understanding of WM and translate into improving patients' lives.

A World of Thanks to Three Retired Board Members!

How do you thank someone who has worked tirelessly for years to make the world a better, safer place for people diagnosed with an incurable disease? How do you thank someone who has had your back when you needed it the most? How do you thank someone who planted trees for shade in which they didn't expect to sit? A simple thank you isn't enough, so let's try a world of thanks: *thank you, merci, grazie, danke, gracias, xiè xiè, tack, kiitos, takk skal du ha, dank je, go raibh maith agat, dhyanavaad.*

In case you're wondering, those are, according to Google, the Anglicized versions of thank you in the major languages of our affiliates.

So whom do we all need to thank? Here they are:



Dr. Guy Sherwood

Dr. Guy Sherwood was on the IWMF Board of Trustees from 2004-2007 and again from 2009 until August of 2018. Most of you know Guy from his engaging articles in the *IWMF Torch*, in his role as master of ceremonies for the Ask the Doctor session during the most recent IWMF Educational Forums, and for his leadership of Peripheral Neuropathy breakout sessions at the Ed Forum. Guy has served as our vice president of research since late 2013 and spearheaded our recent research expansion under the IWMF-LLS Strategic Research Roadmap. The Board will miss how Guy applied his knowledge as a physician to everything WM, his wit, his outgoing personality, and his undying

dedication to WM patients. Guy stepped down from the Board after the August 2018 meeting when the perils of travel became too great for his immune system.

Sue Herms served on the IWMF Board of Trustees for three terms from 2009 through the end of 2018. Most recently, Sue helped fill in for Guy as administrator of the research program. But you'll also know Sue as the associate editor of the *IWMF Torch* where she writes Medical News Roundup and for her pithy, fact-filled posts on IWMF Connect. You might not know that Sue also serves on

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the Educational Forum and Research Committees. And she reads and edits just about everything the IWMF publishes to make sure it is well-written and grammatically correct. The IWMF Board will miss Sue's background as a lab technologist to help understand the science of WM, as well as her attention to detail, her conscientiousness, and her strong moral compass.

Marcia Klepac served on the IWMF Board of Trustees for two terms from 2012 through the end of 2018. Marcia was coordinator of the Support Group Committee and helped recruit and train all of our incredible support group leaders. Marcia also serves on the LIFELINE, Publications, and Judith May Volunteer Award Committees. Whew!



Marcia Klepac

In all these positions, Marcia applied her background as a registered nurse. The IWMF Board will miss her amazing ability to help WMers under emotional distress, her high emotional IQ, and her sage and practical advice. Lisa Wise will follow Marcia as coordinator of the Support Group Committee.

The good news is that Sue will continue to work on the *IWMF Torch*, the Research and Educational Forum Committees, and as proofreader extraordinaire. Marcia will continue as a volunteer on the Support Group, LIFELINE, and Publications Committees. So while we're not losing their expertise, the members of the Board will miss them and their wise advice at future Board meetings.

We thank each of them from the bottom of our hearts for their extraordinary Board service and accomplishments and most of all for being their wonderful, giving selves.

The Torch Has Been Passed

A tremendous amount of gratitude also goes to **Alice Riginos**, who has retired as *IWMF Torch* editor. Alice was diagnosed with WM in 2003 and began as guest editor in 2007, helping then-editor Don Lindemann. Don became quite ill from WM and sadly passed away in 2008. At that time, Alice graciously agreed to step up and 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 how she did! Among her other accomplishments, she expanded the scope of the magazine; improved its appearance with modern graphics, glossy paper, and a redesigned masthead; used her creativity to constantly look for new ideas for articles; and added regular columns and writers, such as Doctor on Call, Cooks' Happy Hour, International Scene, and In the Torchlight, to name a few. Thanks to Alice, this very public face of the IWMF is a magazine we can all be proud of!

After more than a decade of volunteer service, with this issue Alice passes the *Torch* editorship to Shirley Ganse, support group leader from Seattle.



Sue Herms



Alice Riginos

Peter S. Bing Humanitarian Award

Carl Harrington, IWMF president, received one of the four inaugural Peter S. Bing Humanitarian Awards presented at the closing ceremonies of the 10th International Workshop on WM in New York in October. Peter Bing, MD, is a nationally-



Carl Harrington with Dr. Steven Treon, Lu Kleppinger, Thomas Cavanaugh, and Dr. Peter Bing

renowned philanthropist whose funding support, along with that from the IWMF, made possible the whole genome sequencing project that led to the discovery of the MYD88 mutation in WM.

In his acceptance speech, Carl remarked, “When I was diagnosed with WM in 2006, I never expected to be alive in 2018, let alone become president of the IWMF and be worthy of an award such as this. But I’m very, very happy to be here, among this group of big-hearted geniuses who are making the world a better, safer place for WMers.”

He went on to say: “It is a great honor to accept this award, even more so because it carries the name of Peter Bing. When Steve Treon called me about this award, he described the first visit Dr. Bing made to Dana-Farber. Now, as I think you know, Dr. Bing is a WM patient himself. At the time of his first visit, he was still on watch and wait. After Dr. Bing’s exam, Dr. Treon took him on a tour of the facilities, including the small research lab. At the end of the tour, Dr. Bing wrote Steve a generous check and made a very simple request: ‘Do good work with this and help others with WM’.”

Thanks to Carl and all who tirelessly do good work and help others with WM, we can rest easy knowing that we are the beneficiaries of not only the support of other WMers, but also the continuing progress in research, treatments, and eventually, perhaps, a cure.

MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF RESEARCH COMMITTEE MEMBER

BeiGene Delays New Drug Application Filing for Zanubrutinib in US – The Chinese pharmaceutical company BeiGene has delayed its plans to file a New Drug Application to the US Food and Drug Administration (FDA) for approval of its second generation BTK inhibitor zanubrutinib in B-cell malignancies. The company had been hoping to submit the application to the FDA in the first half of 2019 but announced that the filing is now more likely to occur later in 2019 or in 2020. No reason was given for the delay. Zanubrutinib was

studied in a Phase I clinical trial of WM and is currently in a multi-center international Phase III clinical trial comparing it to ibrutinib (Imbruvica) in WM patients.

Zanubrutinib to Be Tested with New P13K Delta Inhibitor in Phase I Trial for B-Cell Cancers – Meanwhile, a collaboration between MEI Pharma and BeiGene will test a combination of ME-401 and zanubrutinib in patients with

Medical News Roundup, cont. on page 19

B-cell cancers. Under the new partnership, MEI Pharma will amend its Phase Ib trial of ME-401, alone and in combination with rituximab, to include a combination of ME-401 plus zanubrutinib. This trial has enrolled patients with chronic lymphocytic leukemia, small lymphocytic leukemia, and follicular lymphoma. ME-401 is an oral inhibitor of PI3K delta, which is one member in a family of enzymes involved in cellular functions such as growth, proliferation, and survival.

*The US Food and Drug Administration (FDA) has approved a **new drug to treat flu** in patients 12 years of age and older who have been **symptomatic for no more than 48 hours**.*

New Treatment Approved for Flu by US FDA – The US Food and Drug Administration (FDA) has approved a new drug to treat flu in patients 12 years of age and older who have been symptomatic for no more than 48 hours. The drug is baloxavir marboxil and is sold under the trade name Xofluza. Yearly vaccination is still the primary means of preventing and controlling flu outbreaks; however when patients with flu are treated within 48 hours of becoming sick, antiviral drugs can reduce the symptoms and duration of illness. The safety and effectiveness of Xofluza, taken as a single oral dose, were demonstrated in two clinical trials of 1,832 patients. In both trials, patients treated with Xofluza had a shorter time to alleviation of symptoms than patients on placebo. The most common adverse reactions included diarrhea, bronchitis, nausea, and sinusitis. The drug was approved for use in Japan earlier this year and had been fast-tracked by the FDA.

Half-Dose R-CHOP Regimen Effective in WM with Fewer Side Effects Than Full-Dose – While the trend in WM treatment is away from “classic” chemotherapy and toward B-cell pathway inhibitors, Japanese researchers concluded that the classic chemotherapy approach may still be of use to many patients, particularly those who do not have access to novel therapies. This article, published in the journal *Blood Research*, discussed WM treatment with R-CHOP, which is comprised of rituximab, cyclophosphamide, hydroxydoxorubicin, vincristine, and prednisone. The combination, while effective, is typically accompanied by severe bone marrow suppression and high rates of peripheral neuropathy. Therefore, the researchers evaluated the effectiveness and side effects of half-dose CHOP combined with rituximab in a retrospective study that looked at 20 previously untreated symptomatic WM patients from 2011-2016 who were administered the regimen every three weeks for six cycles.

This group achieved a 65% response rate. With a median follow-up of over two years, the progression free survival and overall survival rates were 70% and 93.3%, respectively. Side effects included leukocytopenia (low white blood cell count), neutropenia (low neutrophil count), and mild peripheral neuropathy.

Acalabrutinib Safety Discussed in Pooled Analysis of Clinical Trial Data – The safety profile of acalabrutinib (Calquence) was discussed in a pooled analysis of data published in the journal *Blood*. Acalabrutinib, a second generation BTK inhibitor that purportedly has fewer off-target side effects than ibrutinib, is approved for relapsed/refractory mantle cell lymphoma and is undergoing testing in several clinical trials for other hematologic malignancies. The safety data in this report were collected from 610 patients, including 106 WM patients, who were treated with at least one dose of solo acalabrutinib in seven clinical trials. The median duration of exposure to the drug in these patients was 14.2 months. Adverse events of any grade occurred in 98.9% of patients, although 73% were considered to be treatment-related. The most common adverse events related to treatment were headache, diarrhea, fatigue, nausea, and bruising. Moderate to serious infections were reported in 16.2% of patients, with pneumonia the infection most frequently reported. Atrial fibrillation (Afib) of any grade was reported in 2.3%, and Afib occurred mostly in patients with known risk factors or contributing factors, such as concurrent infections, hypertension (high blood pressure), pre-existing cardiovascular disease, and a history of atrial fibrillation. The majority of adverse events were low grade, with treatment discontinuation due to adverse events occurring in 6.1% of patients.

Phase I Results Reported for New BTK Inhibitor Developed by Merck – Interim results from a Phase I/II clinical trial of a new BTK inhibitor called M7583 were reported at the European Society for Medical Oncology 2018 Congress. In Phase I of this study of relapsed/refractory B-cell malignancies, which included four WM patients, daily dosing started at 80 mg and increased up to 900 mg. M7583 either stopped disease progression or reduced tumor burden in 86% of patients. Overall, adverse events were mild to moderate, with the most common being diarrhea, dizziness, dry skin, fatigue, itchy skin, vomiting, and inflammation of the nasal cavities and throat. Phase I is ongoing, with an additional dose still under investigation. Researchers will soon begin Phase II to continue studying the recommended dose, as determined from Phase I, in patients with relapsed or refractory diffuse large B-cell lymphoma and mantle cell lymphoma.

Duvelisib Approved by FDA for Relapsed/Refractory CLL and Follicular Lymphoma – As anticipated, the US Food and Drug Administration (FDA) approved duvelisib

Medical News Roundup, cont. on page 20

(Copiktra) for the treatment of patients with relapsed/refractory chronic lymphocytic leukemia (CLL) and relapsed/refractory follicular lymphoma. Both indications are for the treatment of patients who have received at least two prior therapies. The approval is based on data from 400 patients in the Phase III DUO and Phase II DYNAMO clinical trials. The overall response rate in CLL was 78% and in follicular lymphoma was 42%. The FDA label for duvelisib includes a Boxed Warning regarding the potential risk of infections, diarrhea or colitis, skin reactions, and pneumonitis. Duvelisib is an oral dual inhibitor of PI3K delta and PI3K gamma and is manufactured by Verastem Oncology.

Venetoclax and Rituximab Combination Regimen Receives European Commission Approval for Previously Treated CLL Patients – Venetoclax plus rituximab has received European Commission approval for the treatment of patients with chronic lymphocytic leukemia (CLL) who have

***Venetoclax plus rituximab** has
received European Commission
approval for the treatment of patients
with chronic lymphocytic leukemia (CLL) who
have received at least one prior therapy.*

received at least one prior therapy. The approval was based on the MURANO Phase III clinical trial of 389 patients, in which venetoclax plus rituximab reduced the risk of disease progression or death by 83% and prolonged overall survival, compared to bendamustine combined with rituximab, which is a standard-of-care chemoimmunotherapy regimen for CLL. A majority of patients (62.4%) treated with venetoclax plus rituximab achieved undetectable minimal residual disease in the peripheral blood, compared to 13.3% treated with bendamustine plus rituximab. The most common adverse reactions for the venetoclax and rituximab combination were neutropenia (low neutrophil count), diarrhea, and upper respiratory tract infections. Venetoclax, also called Venclyxto in Europe and Venclexxa in the US and Canada, is an inhibitor of BCL2.

Long-Term Continuous Venetoclax Monotherapy Well-Tolerated in Relapsed/Refractory CLL – A retrospective safety analysis published in *Clinical Cancer Research* concluded that long-term continuous venetoclax monotherapy is well-tolerated in patients with relapsed or refractory chronic lymphocytic leukemia (CLL). The study, conducted by Dana-Farber Cancer Institute, looked at 350 patients who participated in three Phase I/II studies. The median duration

of exposure to venetoclax treatment was 16 months. The most common adverse events were diarrhea, neutropenia (low neutrophil count), nausea, anemia, fatigue, and upper respiratory tract infections. Using current 5-week ramp-up dosing recommendations, the incidence of tumor lysis syndrome was 1.4%. The researchers also reported that 10% of patients discontinued venetoclax due to adverse events and 8% died while on study, mostly due to disease progression.

Small Pilot Study Looks at Lower Doses of Ibrutinib in CLL Patients – Results of a pilot study of lower doses of ibrutinib in patients with chronic lymphocytic leukemia (CLL) were published in the journal *Blood*. The drug is currently used at a 420 mg daily dose in CLL. This small trial of 11 patients at MD Anderson Cancer Center, nine of whom completed the trial, was designed to systematically reduce ibrutinib dosing over three 28-day cycles, starting at the regular dose and then reducing the dose to 280 mg in cycle two and to 140 mg in cycle three. The rationale used was that BTK levels in CLL cells typically decline after one cycle of ibrutinib, suggesting that the dose could be lowered without loss of effect. By measuring plasma and intracellular BTK occupancy, as well as BTK downstream signaling, the researchers suggested that even the lowest dose of 140 mg was sufficient to occupy more than 95% of BTK. The researchers caution, however, that further studies are needed to systematically evaluate the clinical effect of lowered ibrutinib dosing and that patients should not reduce dosing on their own.

Phase III Results Released for Triple Combination of Ibrutinib, Bendamustine, and Rituximab in Relapsed/Refractory CLL and SLL – Combining ibrutinib with bendamustine and rituximab improved long-term survival in relapsed/refractory patients with chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL), according to updated data released from the Phase III HELIOS study. The 578 study participants received either daily ibrutinib or placebo combined with 28-day cycles of bendamustine plus rituximab for a maximum of six cycles. At the end of the bendamustine and rituximab cycles, patients remained on daily ibrutinib or placebo. Progression free survival at 36 months was 68% for patients on the ibrutinib combination versus 13.9% for patients on the placebo combination. Additionally, overall survival was 34.8% higher for those on ibrutinib. Serious adverse events occurred in 61.3% of patients on ibrutinib, the most common being pneumonia and febrile neutropenia (fever with low neutrophil count). In this same group, 9.8% of patients died as a result of adverse events, mainly infections.

Combination of Rituximab with Novel T-Cell Immunotherapy Results in Some Complete Responses in Phase I Trial of NHL – Unum Therapeutics Inc. announced

that three of six CD20-positive non-Hodgkin's lymphoma patients treated with its T-cell immunotherapy ACTR707 in combination with rituximab achieved a complete response at the first dose level of its Phase I clinical trial. Adverse events included neutropenia (low neutrophil count) and thrombocytopenia (low platelet count); there were no serious adverse events of cytokine release syndrome, neurotoxicity, or autoimmune conditions observed with several other T-cell immunotherapies. Two complete responses remained ongoing at the time these interim results were reported. Enrollment of the second cohort of relapsed/refractory patients has been completed, and dose escalation is proceeding. ACTR707 is based on the company's antibody-coupled T-cell receptor technology.

New Immune Checkpoint Inhibitor Combined with Rituximab in Phase I Trial for B-Cell Lymphomas –

An international multicenter Phase Ib study looked at the monoclonal antibody Hu5F9-G4 combined with rituximab

in 22 relapsed or refractory patients with diffuse large B-cell lymphoma (DLBCL) or follicular lymphoma. The rates of objective (complete and partial) responses were 40% in DLBCL and 71% in follicular lymphoma. Adverse events were mild or moderate and included anemia and infusion-related reactions. Hu5F9-G4 acts as an immune checkpoint inhibitor that blocks CD47 and synergizes with rituximab through enhancement of antibody-dependent destruction of tumor cells by the body's own macrophages. This trial is partially funded by the Leukemia & Lymphoma Society (LLS).

The author gratefully acknowledges the efforts of Grete Cooper, Peter DeNardis, Wanda Huskins, Pavel Illner, Meg Mangin, John Paasch, Colin Perrott, Howard Prestwich, Charles Schafer, Ron Ternoway, and others in disseminating news of interest to the IWMF Connect community. The author can be contacted at suenchas@bellsouth.net for questions or additional information.

TORCH TOON by Linda Pochmerski

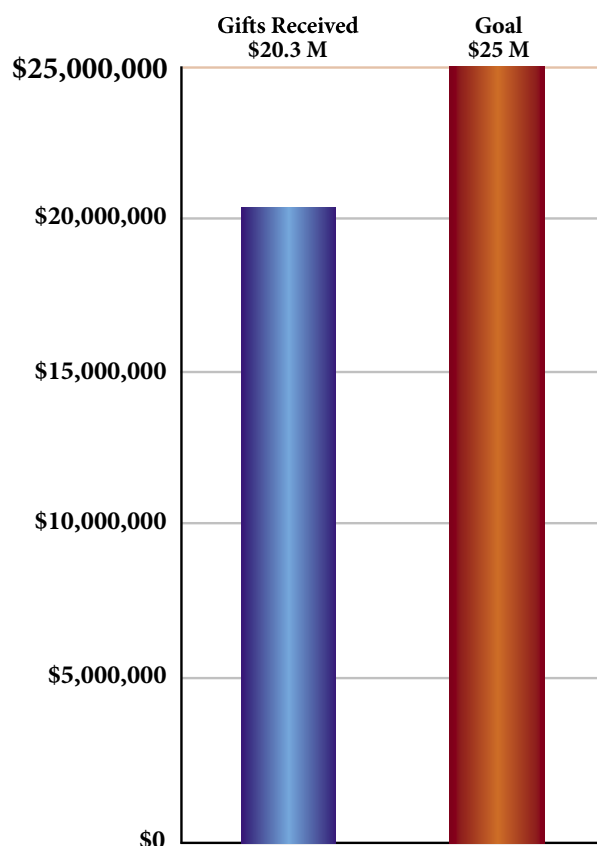


It's well worth the wait for my *IWMF Torch*. I can savor the articles (and highlight items for future reference) with each turn of the page, along with the delicious cup of coffee in my hand.

CELEBRATING TEN YEARS OF GENEROSITY THROUGH THE BEN RUDE HERITAGE SOCIETY

BY MITCH ORFUSS

Imagine a Cure Campaign Progress Report as of November 30, 2018



People with Waldenstrom's macroglobulinemia are some of the most generous people we know. It all started with Arnie Smokler, a retired pharmacist who was diagnosed with WM almost a quarter of a century ago, in 1994. Finding little information available about his disease and knowing no one else with it, Arnie picked up a pen and wrote to the National Organization of Rare Diseases (NORD), requesting the names of patients listed with that organization who had WM. Arnie received contact information for 21 patients, and just that humbly, the seeds of the IWMF were planted.

Founders of promising new organizations attract followers, and for stability, growth, and survival, followers start to organize an expanding list of functions. These are necessary to serve the needs of members who seek knowledge, support, and access to one another and to the small number of doctors who dedicate some or all of their practices to treating our rare disease. There was no cure then (there still isn't, though it is closer than ever!), and treatments worked for some but

not others. It seemed starkly clear that research was badly needed if the lives of patients were to improve and a cure were to become possible. Patients and their families soon realized that funds for expensive scientific research would come only from them. So fundraising efforts were made and money trickled in.

Then—a breakthrough! In 2008 the IWMF Board of Trustees established a legacy society and named it in honor of the Foundation's second president, Ben Rude, for his tireless leadership in growing the IWMF into the most effective organization in the world to help those with WM. The mission of the Ben Rude Heritage Society (BRHS) was to keep Ben's exceptional work thriving into the future for the continued benefit of the growing number of WM patients around the world. Ben's wife Laurie has been the face of the Society since its inception.

What was breakthrough about the BRHS? It created a more powerful way to support the organization—with planned or "legacy" gifts that keep the IWMF stable and functioning into a future that envisions a cure for WM. Legacy gifts come in many forms: bequests through wills or revocable trusts; beneficiary designations through life insurance policies; and IRAs, qualified plan assets, or donor-advised funds directed to the Foundation. These gifts are so meaningful that they have catapulted the IWMF into a position whereby more research can be funded more quickly, leading us in the direction of a cure in ways that couldn't be imagined just a few years ago.

From the time the Ben Rude Heritage Society was launched in 2008 with eleven founding members and just under a quarter-million dollars in future expectancies, the number of members had increased to 48 in 2012, and then almost doubled to 84 in 2018—altogether earmarking \$8.4 million in gift intentions! Of the total, \$1,220,856 was added by five new members of the Ben Rude Heritage Society recognized at the 2018 Educational Forum in Chicago this spring. We welcomed a gift from the estate of Raymond and Bette Fishman and gift intentions from Jane and Ralph Hendrickson, Marcia and Glenn Klepac, Michael and Carol Sesnowitz, and one anonymous family. With these and future gifts, we have confidence that the IWMF will be able to continue, and even increase, the pace of our exceptionally important work.

Over the past 10 years, the IWMF has received roughly \$1.5 million from 34 estates, or an average of \$150,000 a year. All but three of these gifts have come as a surprise to the Foundation. If you've included the IWMF in your estate plans but haven't told us, thank you, and please let us know so that

Celebrating Ten Years, cont. on page 26

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 kept informed of the progress of the research project and will be formally acknowledged by the investigators in their report of the project as well as in any resulting publications. We generally have 4 to 6 research projects underway with new projects under consideration throughout the year.

David and Janet Bingham Research Fund of the IWMF

Elting Family Research Fund of the IWMF

Robert Douglas Hawkins Research Fund of the IWMF

Michael and Rosalie Larsen Research Fund of the IWMF

Carolyn K. Morris Research Fund of the IWMF

K. Edward Jacobi Research Fund of the IWMF

Marcia Wierda Memorial 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.

Baker Family Research Fund of the IWMF

Yoshiko Button Member Services Fund and Research Fund of the IWMF

Friedlander-Scherer Family Research Fund of the IWMF

Dr. Morie A. Gertz Research Fund of the IWMF

Gary Green Research Fund of the IWMF

Dr. Robert Kyle Research Fund of the IWMF

Lynn Martin and Carrie Wells Research Fund of the IWMF

Dennis and Gail Mathisen Research Fund of the IWMF

Gail Murdough Member Services Fund and Research Fund of the IWMF

Sesnowitz Family Research Fund of the IWMF

Donald and Kathryn Wolgemuth 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 and Named Gift Fund opportunities and potential gifting options that might make that possible, please contact Dave Benson, IWMF Senior Development Officer, at (952) 837-9980 or dbenson@iwmf.com

Ben Rude Heritage Society Roster		
*Deceased ♦Founding Member New in 2018		
ANONYMOUS (4)	ELINOR HOWENSTINE*♦	JOEL ROSENBLIT
JEAN-MARC AUDIBERT*	WANDA L. HUSKINS AND JEFFREY A. PRUPIS	LAURIE RUDE-BETTS ♦
BARBARA BACKER	STANLEY KAUFMAN	CYNTHIA RUHL
MARTIN BAER*	SHAN ELIZABETH KEARY*	MICHAEL AND CAROL SESNOWITZ
C. EDWIN BAKER*	NANCY KERR*	ELMO R.* AND DOLORES SCHMID*
JACK BAKER	THOMAS KEYS*	ALLAN SHAW*
DAVE BENSON	EVELYN KLEIN*	DR. GUY SHERWOOD
BEVERLY BLOSS	MARCIA AND GLEN KLEPAC	ELLEN SMITH
VIVIAN AND ROBERT BOAS ♦	GEORGE KNIPELBERG*♦	RAY SOBOROWICZ*
ELSA AND GARY BRADLEY	CHARLES KOCH	KEN AND LINDA SOLOW
LESLEY MOORE BRADSTREET	DR. ROBERT A. AND CHARLENE M. KYLE	CORDELIA AND PETER STEARNS
ARLOU BRAHM*	ROY LANGHANS	JUDITH LEE STERLING AND LESLIE CHARLES WILSON
WILLIAM O. BRESNICK AND ELLEN KANER BRESNICK ♦	JANET LEVY*	JOHN AND DIANE TIPLADY
RUTH L. BROWN*	MICHAEL E. LUTTRELL	RUBEN TROSS*♦
L. DON AND MARY BROWN	LENNY MARTIN	PENNI WISNER
PETER CARR	JUDITH A. MAY	JAMES P YEAGER*
GERALD PRESTON CLANCEY*	KATHARINE E. MCCLEARY AND K. EDWARD JACOBI*	GREGORY FITZWATER AND MARILYN ZOLLNER-FITZWATER
CHRISTINA CONLEY*	KATHLEEN MINER	
IVY COOPER*♦	ANNE AND PETER MITRO ♦	
ROBERT* AND ANNE COULBOURN*	ELEANOR MOORE*	
JAN SOLOMON CRAMER*	RIC MOORE	
NORM CRANDALL	MAYNARD MORRIS	
TONY DYE*	SAM AND GAIL MURDOUGH	
JEAN ELLIS*	BRANDT NORQUIST*	
RAYMOND* AND BETTE FISHMAN*	JIM AND BETTE ORTOLEVA	
MARLYN FRIEDLANDER AND GILBERT SCHERER	ALAN PRESTELL*	
CINDY L. FURST	MARGUERITE C. REGAN, PHD*	
JEB GELBER	PAUL AND JANICE RIPPAS	
LESLIE C. GUTHRIE, JR.*	ROGER AND BARBARA ROBINETTE	
CARL HARRINGTON	MARGARET ROCKELMAN*	
JANE AND RALPH HENDRICKSON		
JAN HERGESHEIMER		
SUZANNE L. HERMS		
ARLENE HINCHCLIFFE		

Come Feel the WM Love...

24th Annual IWMF Educational Forum

June 7-9, 2019

DoubleTree by Hilton Philadelphia Center City Hotel

237 South Broad Street, Philadelphia, PA 19107

** Important: space is limited and we will sell out early!*

Imagine a Cure: The WM Revolution

*So much exciting progress has been made in research and treatment options.
Come join our WM Revolution! We have a space just for you. Register today!*

WHAT IS THE ED FORUM?

Imagine several hundred WMers and caregivers gathering for an information-packed weekend of learning, connecting, and networking. The IWMF Ed Forum offers one-stop shopping for WM patients and caregivers. Be there in person to experience the magic of landing on Planet Waldenstrom and discovering that “You are NOT ALONE!” Participants from across our nation and around the world will be present. We are growing stronger every day!

WHO WILL BE THERE?

The IWMF Ed Forum features the world’s leading medical experts in WM research and clinical care. They are powering our WM Revolution. Enjoy being surrounded by friendly “Waldenfriends” and caregivers who know how it feels to carry the same diagnosis, speak the same disease language, share strategies for symptom management, and swap treatment experiences and lab numbers.

NEWLY DIAGNOSED OR A FIRST-TIMER?

The exciting Early Bird Session on “Basic Training for WMers” is a great introduction for newbies and first-timers, but it is open to ALL ATTENDEES so start your day off with us. Enjoy a continental breakfast before it all begins.

ED FORUM FAVORITES!

Highlights each year include: asking your questions to the lively and ever-popular “Ask the Doctor” panel, mingling at the President’s Reception, enjoying the festive Welcome Dinner alongside IWMF Trustees and world-class physicians, and exploring a plethora of different and diverse breakout sessions addressing multiple issues and hot topics. There is truly something for everyone at the IWMF Ed Forum! Come learn why the WM Revolution is a key to your future progress as a patient or caregiver.



CALLING ALL SUPPORT GROUP LEADERS!

Are you a support group leader? You do not want to miss the exciting, all-new workshop geared just for YOU. Join the other leaders and IWMF Support Group Coordinator Lisa Wise on Thursday, June 6, 2019.

Come be a part of history in the making...

Don't miss this chance to celebrate the progress of the WM Revolution!

Get all the details and register online at

www.iwmf.com/news-and-events/iwmf-educational-forum

OR fill out and send the registration form enclosed with this *Torch* mailing

we can plan more accurately for our organization's financial future. Current future expectancies are \$6.9 million. When the IWMF reaches out to individuals or families for major support for research or when we approach family foundations in search of their supplemental support for the IWMF, they are impressed by the strong future focus that our Ben Rude Heritage Society makes possible.

The roster of the Ben Rude Heritage Society reflects a cross-section of our membership. Few are what you would call wealthy, and most have children and other family to provide for—but all have provided a portion of their estates to the IWMF after they pass away. Gift intentions have ranged from \$1,000 to \$1 million. Now that you know about the

Ben Rude Heritage Society and the huge difference it can make to getting to a cure faster, we hope you will find a way to designate a portion of your estate to the important future work of the IWMF, which has come such a long way since Arnie Smokler reached out in 1994 to those 21 other WM patients.

Membership in the Ben Rude Heritage Society is not based on a binding pledge or commitment to provide future funding, but it is an indication of your intention to support the Foundation as part of your future plans.

Please contact Jason Watkins at jwatkins@iwmf.com or 912-215-2215 or Dave Benson at dbenson@iwmf.com or 952-837-9980 to find out more. Thank you.

CHARLES SCHAFER: A LITTLE LUCK IS A GREAT ASSET IN NAVIGATING LIFE'S JOURNEY—AND WM

AS TOLD TO SHIRLEY GANSE, EDITOR, *IWMF TORCH*

Most of us can look back and probably cite lucky situations that have shaped our lives and how they have orchestrated the course of our personal development. Charles Schafer, retired research scientist and 22-year WM survivor, feels he was blessed with a long string of lucky circumstances, the first of which was being born in the US, and with hard-working parents who provided a safe and stable life for him.

Charles earned a masters degree from New York University in a subset of marine geology called environmental micropaleontology. This specialty deals with living forms of marine micro-organisms that eventually end up as fossils preserved in marine sediments; it was to become the focus of much of his subsequent research.

While at NYU, he became close friends with a Canadian graduate student, which ultimately led to a long-term career at Canada's Bedford Institute of Oceanography (BIO) in Dartmouth, Nova Scotia. Charles calls this connection another lucky circumstance, for after years working stateside, he and his wife Dana moved to Nova Scotia in 1967 for his new job at BIO. He says, "My 28-year-long career working at BIO with a team of about 900 scientists, engineers, support staff, and enthusiastic ship personnel was, for me, a dream come true. In fact, for a while I thought I had gone to heaven."

Extensive travel with BIO projects took him to the Mid-Atlantic Ridge at 45 degrees north latitude to Castries Harbor, St. Lucia, and in 1970 to Tahiti. There Charles joined the Tahiti-Vancouver leg of the Hudson 70 expedition, which was later hailed as the first circumnavigation of the Americas by a research vessel. Its purpose was to give scientists the



Charles Schafer (left) on a 1968 BIO project in St. Lucia

opportunity to study the biology and oceanography of the South Atlantic, the Pacific, and the Arctic, all bodies of water surrounding the Americas.

"My part of that epic journey involved using a specially-designed plankton sampler that could be triggered at various water depths to facilitate mapping the mid-Pacific Ocean distribution of planktic Foraminifera (a marine protozoan). The project yielded a mid-ocean baseline reference of species distributions for the climate of that time," he explains. Interestingly, as late as the 1990s, data from this expedition was still being analyzed and published. In 2012 Charles and Roger Smith published a book entitled *Getting Around the Americas*, which was part of the 40th anniversary celebration of the Hudson 70 expedition.

Charles Schafer, cont. on page 27

Charles retired in 1995 with a generous early retirement package. It gave him research scientist emeritus status, working on and publishing data that had been relegated to the “back burner” during his full-time working years. He has now worked at those tasks for the past 22 years and has participated in volunteer adventures as a member of several government and professional committees.

As his most recent stroke of good luck, Charles says it was not being diagnosed with WM, but rather being diagnosed with it in early 1997, at about the same time that Dr. Arnie Smokler was organizing support groups for WM and setting up the TalkList. “Although I never met Dr. Smokler (despite being only one hour away from Sarasota during my winter visits to Gulfport, FL), I did have several phone calls with him following my diagnosis in 1997. I found him to be very knowledgeable and supportive,” Charles recalls. Many others can also attest to the positive impact Smokler had on their early years of coping with WM.

Charles’s WM was discovered through his company’s yearly blood work requirement when it showed increases in his sedimentation rate over several years. A mention that his elderly mother died from multiple myeloma sent him for more blood work, which showed a high IgM; treatment started soon thereafter.

At the time of his diagnosis, WM had a general life expectancy of about five years.

At the time of his diagnosis, WM had a general life expectancy of about five years. Charles took heart in his oncologist’s remark that with treatment, he probably would die with WM, not of it. He says, “I eventually redeployed my research scientist skills into a mission to learn everything possible about WM that would assist me in negotiating aspects of my treatments to meet my individual needs.” As a result, he admits “I’m an IWmf ‘junkie’ from its very beginning and am exceedingly thankful for all the heavy lifting that current and former staff and volunteers have done to keep all of us abreast of the plethora of new medical research that will one day allow WM patients to achieve an affordable and lasting cure.”



Charles Schafer today

While his diagnosis didn’t directly affect the work he was doing, since he had retired two years previously, it did prevent him from doing part-time work or from living in the United States, because he now had a pre-existing condition. While a pre-existing condition is 100% covered under the Nova Scotia public health care system, Charles felt that health insurance would have been prohibitively expensive in the US if he and his wife

had returned there. So they made their permanent home in Waverley, Nova Scotia.

But for the past 21 years, Charles and Dana have been able to spend their winters in their Gulfport vacation home. Their stay there last winter was shortened because his last treatment generated a persistent case of pneumonia and two separate instances of late onset Rituxan-caused neutropenia. Treatment for that went well, and they are looking forward to their upcoming three months in Florida during which time he will be keeping tabs on his IgM and WBC counts.

When asked about cold weather, Charles says “The relatively mild northern climate of Nova Scotia has not had any discernible effect on my general health. In fact, I would say that steering my snow blower up and down my steep 300-foot-long driveway from time-to-time probably has cardiovascular benefits that are not available to me in the flat setting of Gulfport.”

Charles muses that “I cannot say that any of my current physical activities are ‘taxing’ (fortunately). Of course, at the ripe old age of 79, I do everything slower, including my daily bike rides in Florida and the still doable maintenance chores on my homes in Canada and Florida. My wife and I count six grandchildren that range from pre-school to college age whom we get to see on a fairly regular basis. For us, life is as good as it gets, given our respective advanced ages and medical circumstances.”

You can’t get much luckier than that.

Some details of Charles Schafer’s WM treatments can be found in his 2014 “Story of Hope” at:

<https://www.iwmf.com/get-support/patient-stories/canada-charles-schafer-challenging-career-despite-wm>

FROM IWWMF CONNECT: WINTER 2019

BY JACOB WEINTRAUB, MD

We enter the winter season post-holidays looking for a return to our usual routines. Discussion on IWWMF Connect continues with new members joining, old members adding support, and many of us requesting information and help with questions to ask our own physicians. As always, a multitude of links are posted: some are to human interest articles, some to informational items about WM-related educational events, and others to the newest research in the many treatment options with which we now are blessed. One new treatment, venetoclax, seems very promising. While it may be too early to fully judge it, there has been enough discussion to warrant including it here so that people are made aware of its existence.

HUMAN INTEREST/ARTICLES

IWWMF Connect Manager and IWWMF Trustee Peter DeNardis posted several links of general interest.

One link is to an article about the use of metaphors by non-Hodgkin's lymphoma patients undergoing chemotherapy. Six adult patients undergoing chemotherapy used metaphors 17 times per thousand words to describe their experience. The cited metaphors focused on aspects relating to "war," "prison," and a "journey." While "war" and "journey" concur with other narratives of cancer patients in general, the use of the "prison" metaphor by NHL patients refers particularly to their being isolated for fear of infection while undergoing treatment. The conclusions and summary highlight that metaphors embedded within NHL patients' narratives can provide vital information about their personal experiences. Further, health care professionals should take note of the metaphors that patients with any cancer use in order to give them a common language to enhance the therapeutic relationship. This journal has limited accessibility, so anyone wanting to see the entire article should contact Pete directly through IWWMF Connect. Pete included the abstract of the article in his post on July 18.

<https://www.ncbi.nlm.nih.gov/pubmed/29989199>

Pete posted a link to an article titled "In Praise of Support Groups." More of an opinion article, it reinforces the very reason why we participate in IWWMF Connect and our IWWMF support groups. Pete encouraged everyone to "stay engaged and keep posting, everyone!"

<https://lymphomanewstoday.com/2018/09/07/praise-lymphoma-support-groups-carried-today>

Another link posted by Peter is from a newspaper in Virginia. It is titled "Here, the Big C stands for Courage." This article is about a woman who has had WM since 2013. Her doctors took a long time to figure out what exactly was wrong with her. Then she describes her subsequent experiences and how

her life has been affected by her diagnosis and treatment.
<https://bit.ly/2RToXAa>

Wanda H also posted links to items of interest.

Her first link is to a National Academy of Medicine commentary by Gwen Darian. She has had cancer three times and now has become an advocate by committing herself to improving the lives of cancer patients everywhere.

<https://nam.edu/transformation-my-experience-as-a-patient-and-an-advocate-in-three-chapters/>

Another post from Wanda links to an article based on the National Cancer Patient Experience Survey from England's National Health Service. The article is titled "People with blood cancer less likely to understand their diagnosis." It finds that 59% of blood cancer patients said they completely understood their doctor's explanation of what was wrong with them. This is lower than the average of 73% of patients with other cancers. Only four percent diagnosed with blood cancer left with no understanding of their diagnosis at all.

<https://bit.ly/2FERKC0>

Meg M posted a link to an article about an option to donate leftover chemo pills to needy patients in Tennessee. This is a promising option, and perhaps other states can copy this.

<https://wb.md/2TTZfc8>

VENETOCLAX

Venetoclax is a new treatment, approved for chronic lymphocytic leukemia and being tested in clinical trials for WM. Some people being treated with it are seeing very good responses.

Peter S has posted some of the initial information and treatment experience about venetoclax (Venclexta). He had been treated initially with another drug in a clinical trial, which resulted in a bad outcome. He then enrolled in a venetoclax trial at Dana-Farber Cancer Institute and experienced almost complete resolution of all WM symptoms, with normalization of all the usual blood parameters. He even had resolution of the pleural effusions (fluid buildup between the pleural membranes) that developed during the initial course of treatment with ixazomib, dexamethasone, and rituximab (IDR). He did experience tumor lysis syndrome with venetoclax, but this resolved with a short admission to the hospital for treatment.

From IWWMF Connect, cont. on page 29

Andrew W posted that Australian Professor John Seymour, who is on the IWMF Directory of WM Physicians, has been awarded the Victorian Prize for Life Sciences. The prize was awarded to him and Professor Andrew Roberts, recognizing their collaboration and research to develop venetoclax, which is the first drug in an entirely new class of drugs called BCL2 inhibitors to become routinely available for clinical use. They led the first in-human clinical trial in 2011, with remarkable responses in the first three patients with chemotherapy-resistant leukemia. The first WM patients received this medication in 2013.

Gerry W posted that **Colin P**, one of the frequent IWMF Connect members, was in the first trial and had done very well for a year. At that time Colin posted that he had plateaued on the trial but then had to move on to other treatments.

A follow-up note from **Peter S** indicated that while he himself had a remarkable response to venetoclax, it does appear that venetoclax is not a cure-all. However, Peter still remains virtually disease free after 19 months of treatment, with the duration of the clinical trial being 24 months.

Pat G posted that she is having nausea while taking venetoclax. At first it was mild, then became more severe. She has used Zofran and other treatments, including ginger and mint and ginger tea. She has posted that her initial response has been very good. Her enlarged spleen is getting smaller and lab tests are improving.

Dr. Tom Hoffman, IWMF trustee, commented that while venetoclax does appear to be a great drug, the IWWM10 consensus panel discussion on this drug stated that they will not approve it for WM treatment outside of clinical trials this year. This is because the drug is still being tested in unfinished trials and has not been used enough in WM. Also, the drug does not have an adequate safety profile yet since there is so little data. Optimal dosing still needs to be worked out.

So while we have another very promising treatment in our arsenal of WM medicines, it appears we will have to wait a bit longer for more widespread use.

IBRUTINIB (IMBRUVICA) SIDE EFFECTS

Discussion is ongoing about all the various aspects of ibrutinib treatment, from cost to effectiveness to side effects. Many different perspectives and experiences are reported. This time there was considerable discussion about bleeding, the cause of the bleeding, and how to manage it.

Pavel I posted that at the recent IWWM10 meeting, he posed a question about the need to stop ibrutinib if a person needed emergency surgery. Usually, it is recommended that ibrutinib be discontinued for several days if surgery is needed. Would administering a platelet infusion remedy the situation? No answer was given to his question.

IWMF Trustee Tom Hoffmann suggested that if platelets are infused while a person is still taking ibrutinib, the infused platelets will be affected. However, in an emergency all available help would be needed, so an infusion of platelets likely would be done. Tom later posted that a mandatory seven-day hold of ibrutinib is necessary prior to major surgery to give new platelets enough time to replenish themselves without being exposed to the drug.

Anita L posted that she has been on ibrutinib since 2014. Last year, as the result of two separate falls, she was hospitalized twice. Each time she had two surgeries and multiple transfusions. Ibrutinib was discontinued as soon as she was hospitalized, and surgery was the next day both times. She was on injections of the anticoagulant Lovenox for three weeks and the ibrutinib was not restarted until after that. She fortunately had no excessive bleeding during or after the surgeries.

Kevin H then posted that he had difficulty after prostate surgery. His ibrutinib and anticoagulant were stopped three days before his surgery. He had some bleeding after surgery and then needed a second surgery. Despite being off the drugs for up to 5-6 days post-operation, bleeding recurred when ibrutinib was restarted. Ibrutinib finally was stopped for a full two weeks, and then there was no bleeding when it was restarted.

Vlad N added that the reason for bleeding with ibrutinib is not known, according to the official statement from the pharmaceutical company. So perhaps the reason for bleeding is not the platelet count itself.

Pavel I responded that it is generally thought that ibrutinib interferes with platelet activation by inhibiting collagen, but the exact mechanism still is not known.

MOUTH SORES

This subject comes up for discussion on a regular basis.

Melva G mentioned she has mouth sores after treatment with bendamustine and rituximab. She asked for recommendations to treat them.

Lori P responded that she has had terrible mouth sores also. Nothing seemed to make them heal quickly, but to help numb the area she suggested Magic Mouthwash (prescription) and a Kanka Softbrush, which can be purchased over the counter.

Barrie M suggested the old standard rinse of warm water with salt, which helps him.

Marilyn S recommended a solution that she obtained from one of her husband's oncology nurses and a dental hygienist. It is a tablespoon of milk of magnesia mixed with one tablespoon of children's allergy medicine; it is to be used as a mouth rinse and not to be swallowed.

Dr. Tom Hoffmann offered a link to multiple “Magic Mouthwash” combinations. One can be mixed without a prescription and includes diphenhydramine (Benadryl).
<http://www.drotterholt.com/magicmouthwash.html>

Finally, we said goodbye to an old friend as we learned about the death of Marty Glassman. Marty posted regularly and served on the IWMF Board. **Ron T** said he had the pleasure of working with Marty when Marty was Vice President for Member Services and project manager for an update to the IWMF website. Marty was very committed to the IWMF and had a marvelous sense of humor. He will be missed by the IWMF community.

As always, the discussions and links here represent only a small portion of the wide range of topics discussed. Everyone is invited to join the group. We hope you will participate, but just “lurking” and reading on the sidelines also is welcome. If you have any questions or wish to see more from our discussions on a particular topic, please let me know and I will try to include those discussions in a future column.

I wish you all continued good health.

COOKS' HAPPY HOUR

BY PENNI WISNER



Roasted cauliflower salad adapted from Yotam Ottolenghi's Jerusalem cookbook

No longer just side dishes, vegetables have moved to the center of the plate. A whole roasted carrot becomes a main dish; cauliflower is cut into “steaks” and roasted. Sometimes, the recipes get complicated (in my opinion) with the addition of salsas, relishes, and miscellaneous embellishments. For instance, a cauliflower recipe consistently rebuffs my enthusiasm with its long list of relish ingredients.

Cauliflower and its gorgeous green, whorled cousin, romanesco, can easily be substituted for each other in any recipe, or combined. I am not sure there is a simpler or prettier dish than steamed florets of the two tossed with chopped fresh green herbs such as parsley or tarragon and melted butter. If you must add more flavors, try freshly grated lemon zest, a little mustard, and/or chopped green olives.

Olives, anchovies, and capers are classic companions to cauliflower. They add richness, umami, and snap to what might be considered the bland backdrop of white cauliflower. But if you roast the cauliflower (small heads can be done whole), it can develop an irresistible sweetness. Heat the oven to 425 to 450 degrees F and chop the vegetable into chunks. Do not worry about all the little crumbles that must fall off the larger pieces. Sweep them onto a sheet pan with the rest, toss with salt and a little olive oil, and roast about 20 minutes, until the edges of the pieces are brown. If you want to live on the edge, stir and turn the pieces, and return the pan to the oven until some of the edges get very brown indeed, nearly charred.

Cooks' Happy Hour, cont. on page 31

While the cauliflower roasts, if you watch your salt intake, rinse your anchovies and capers and blot dry before chopping, along with olives and a fat garlic clove. Add these to a large bowl with some freshly grated lemon zest, chopped parsley or mint, and chives or finely sliced scallions. When the cauliflower is done, toss it with the chopped flavorings and taste for seasoning. Adjust with salt and a good pinch of fruity, not-too-spicy chile flakes such as Aleppo pepper. Serve warm or at room temperature.

Yotam Ottolenghi's *Jerusalem* cookbook has a roasted cauliflower salad. Its dressing combines sherry vinegar with fresh herbs, a pinch of cinnamon and allspice, olive oil, toasted hazelnuts for crunch, and pomegranate seeds for color and a sweet/tart crunch. Since I am referencing the book, then I should admit he adds a small splash of maple syrup to the dressing but I've never found that I wanted to follow that advice.

Nik Sharma, whose cookbook, *Season*, has recently been published by Chronicle Books, had a cauliflower recipe in the *San Francisco Chronicle* food section. Briefly (about 5 minutes) blanch a whole romanesco or cauliflower in boiling salted water with a quartered lemon. While the cauliflower drains and cools, pound or chop a handful of raw pistachios with a teaspoon each of chile flakes and poppy seeds, a half teaspoon cumin seeds, and a teaspoon salt until you have a coarse, dry powder. Add 2 tablespoons melted ghee, unsalted butter or olive oil, and smear the paste over the surface of the vegetable. Put it on a baking sheet and roast in a 400 degree F oven until browned and tender throughout when pierced with a knife, about 1 hour. Arrange, whole, on a bed of Greek-style whole milk yogurt mixed with lemon zest, lemon juice, and pressed garlic. Drizzle with a little more melted butter, ghee,

or olive oil and serve warm. Hmmmm, I think I will make this for my next book group meeting.

Since it is winter, you might want to think about turning your cauliflower into soup. I had an amazing one recently at San Francisco's legendary Zuni Café, which, I am very happy to report, is as good as ever. The soup was a creamy mix of cauliflower and celery root. You could roast or steam the cauliflower alone or mixed with cubed celery root tossed with lemon (it can oxidize easily) and mix it with onion, celery, a bay leaf, and stock or water. Puree in a blender for a smooth, frothy soup. Taste and adjust seasoning with salt, pepper, and a touch of cream or milk. Serve with a drizzle of your best olive oil.

One cauliflower soup I especially appreciate uses only water, milk, and spices for a curry-like flavor. In a 4-quart saucepan, cook a chopped onion and 1 or 2 whole garlic cloves in oil until soft. Add a whole head of cauliflower, chopped, and boiling water. Add just enough so the vegetable can cook but not drown. Cover and simmer until the cauliflower is very tender, about 20 minutes. Fill a tea ball with a bay leaf, 3 or 4 each black peppercorns and allspice berries, some parsley stems, and a thyme sprig or two. Add it to the pot with the cauliflower while it cooks. When done, remove the tea ball, and, if you were careful with the amount of water, use a handheld blender to puree the cauliflower. Thin with some whole milk and season with salt and pepper. To serve, drizzle with a seasoned oil made by adding a half teaspoon each of ground black pepper, cumin, coriander, and curry powder, and ¼ teaspoon turmeric to ¼ cup good olive oil.

Our motto: Eat Well to Stay Well

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

Please note: details of support group meetings and other upcoming events are posted on www.iwmf.com under EVENTS CALENDAR. Please check there to confirm details of future events.

ARIZONA

The first support group meeting in Tucson in about five years was held Friday afternoon, November 16, at the University of Arizona Cancer Center-North Campus. Bill Bass and Jim Bushey organized the meeting with the help of Laura Hagerty, clinical social worker at the UA Cancer Center. The meeting began with introductions of the WMers and caregivers present,

followed by a lively discussion of watch and wait, treatments, and current and past treatment options. WMers in attendance included those newly diagnosed to one diagnosed 17 years ago. One very special, "historical" WMer was diagnosed in early 1996 and attended the first WMSG conference in Arlington, VA, in April of 1996, arranged by Arnie Smokler, the founder of the IWmf. The group decided to plan for its next meeting in Tucson in February 2019. The meeting concluded with a DVD viewing of the classic "Weeds in the Garden" presentation by Dr. Morie Gertz of Mayo Clinic.

Support Group News, cont. on page 32



Tucson Support Group

CALIFORNIA

Monterey Bay

The group held its quarterly meeting in early October. Seven attended, including Al and Joanne Holmes, who came all the way from Redding (and included a visit with family locally). They had called Suzie Shook, group facilitator earlier in the week. Amy Bruster from Salinas shared news about her treatment this year with Velcade and Rituxan (successful, no side effects!) and her exciting experience at the IWMF Ed Forum in Chicago. Then the entire group joined in to discuss diagnoses, watch and wait, and possible treatment regimens (both current and future). Online resources, such as lectures available on YouTube, were also shared.



*San Diego Support Group - Elaine Bryan
hosting a talk and tasting of plant-based foods*

San Diego

The group met in the early fall at the University of California San Diego Moores Cancer Center in La Jolla. Elaine Bryan, certified holistic cancer educator, hosted the 14 attendees at the Healing Kitchen. Elaine's talk, entitled "How to Support Your Immune System Naturally," was punctuated by a

delicious array of all plant-based foods for sampling. All left with full, happy tummies! Then in November, seventeen group members met for a "sharing circle" led by Loni Ison, a licensed marriage and family therapist. Participants were instructed to share something they had not previously shared. It was touching and enlightening. Loni's husband, Jack Smith, accompanied her with a guitar solo.



*Colorado and Southern Wyoming - Bill Bass, local co-leader, and three
new attendees: David Christerson, Ed Saboe, and Susan Jackson*

COLORADO / SOUTHERN WYOMING

On a beautiful late fall day, November 10, WMers and caregivers from Colorado and Southern Wyoming were happy to meet and hear from local WM expert, Dr. Jeffrey Matous of the Colorado Blood Cancer Institute in Denver. Fifty-two people showed up to hear him, share a breakfast snack courtesy of the Rocky Mt. Leukemia & Lymphoma Society chapter (LLS), and integrate four newly diagnosed people into the group. All were grateful for the wealth of information, the open sharing of issues such as side effects, new ideas, and hope that the support group provides.



*Colorado and Southern Wyoming Support Group
attendees listening to Dr. Jeffrey Matous*

Dr. Matous had attended the 10th International Workshop on Waldenström's Macroglobulinemia in New York City in October 2018. His talk introduced the group to the newest

Support Group News, cont. on page 33



Connecticut Support Group

revelations and research introduced there, including new diagnosis criteria, the importance of the identified genetic markers (MYD88 and CXCR4), and how these mutations can indicate differences in treatment success. New terms doctors are beginning to use to sort WMers into categories are “wild type” and “mutated.” These categories will help more accurately define the disease and treatment plans. Dr. Matous also discussed recurring topics of concern: WM symptoms, whether or not to treat, and how decision-making for when to treat and what treatment regimen to use must be tailored to each patient individually. He went on to review all the current treatments and their success rates and issues, as well as new drugs coming down the pipeline. He also encouraged group members to take advantage of WM clinical trials available and managed in Denver at the Colorado Blood Cancer Institute. Dr. Matous had prepared about 45 minutes of material, but he was peppered with so many questions that he spoke for nearly 90 minutes. The next meeting is planned for May 4, 2019, at the Rocky Mountain Blood Cancer Conference in Aurora, CO.

CONNECTICUT

In November, 26 patients and caregivers gathered for a light lunch, lively conversation, and inspiration from guest speaker Kerry Coughlin, oncology dietitian at the UConn Cancer Center. She shared information and tips on diet, nutrition, and exercise. She entertained questions from the enthusiastic audience who were also well-informed on current facts and myths about nutrition and diet. The meeting continued with an opportunity for members to share their personal WM stories. Several newcomers gave accounts of their recent WM diagnosis and their gratitude for finding their way to the support group. Everyone benefited from hearing stories from veteran WMers who shared their journey updates. A popular topic of discussion was the use of ibrutinib (Imbruvica) as a treatment of choice. It was interesting to note that almost half of the WMers in attendance were being treated with it. The next meeting is planned for June 22, 2019. Meeting details

are yet to be determined and will be available on the IWMF website EVENTS CALENDAR. Dr. M. Lia Palomba, MD, of Memorial Sloan Kettering Cancer Center, NY, will be the guest speaker. Dr. Palomba is a member of the Waldenström Macroglobulinemia Clinical Trial Group and was also one of the program chairs of the IWWM10 and the 5th International Patient and Physician Summit. Thank you to the IWMF and the LLS for their continued support and to the Westfarms Mall management for use of their community room.

FLORIDA

South Florida

The group held its fall meeting on November 10 at Memorial Hospital West in its new medical education center. Members expressed a general concern regarding the cost of drugs and prescriptions for patients on Imbruvica and the best ways to search for financial assistance. Since Imbruvica now appears to be the go-to therapy for WM, many will face the challenge of paying for this drug for what may be the rest of their lives. The group had a lively and informative discussion on some of the ways to obtain financial assistance. During a complimentary lunch provided by the LLS, attendees discussed a number of questions of mutual interest. After lunch, Dr. Daren Grosman, founding member of Memorial Healthcare System’s Blood Cancers Program, answered questions. Dr. Grosman has been a regular visitor and supporter of the group since its founding 13 years ago.

The next meeting is planned for January 26, 2019. On March 30, 2019, the LLS will hold its annual Florida Blood Cancer Conference with a special session dedicated to WM.

ILLINOIS / SE WISCONSIN

Our Chicago Area Support Group, including all of Illinois and SE Wisconsin, had its annual fall meeting on Saturday, November 3, at Advocate Lutheran General Hospital in Park Ridge. This was a special meeting, as it was the first time



Illinois/SE Wisconsin - Jeff and Janis Atkinson

we had a speaker who was the spouse of a WM patient and member of our support group. Dr. Janis Atkinson, wife of patient Jeff Atkinson, is medical director of the Laboratory at Presence Saint Francis Hospital in Evanston, IL. With over 40 in attendance, Dr. Atkinson gave a wonderful summary of our disease and the blood tests, pathology, and diagnosis related to Waldenstrom's patients.

Many attendees commented on how understandable and how relevant her presentation was for new and veteran patients, who try to understand the laboratory tests that confront them regularly. This was the first pathology-related presentation and hopefully not the last for our group. Janis kindly provided a handout folder including a tabular guide to white cell counts, and guides to CBC and serum protein electrophoresis. We were all very thankful to have her share her knowledge with us.

Our next meeting is scheduled for April 2019. Contact L. Don Brown at Ldonbrown@msn.com for questions.

MICHIGAN

Eastern Lower Peninsula

On the first weekend of November, 18 people, including five first-timers, met at the Henry Ford Hospital (West Bloomfield location). The group liked the new venue very much, and a discussion ensued about the possibility of trying other new locations since this one resulted in attracting new people. Jennifer Goldman, our youngest member, has many contacts with different facilities through her work and has agreed to try to secure a venue further north. The group shared their journeys with Waldenstrom's and the two hours, punctuated by refreshments, went by quickly. A tentative winter meeting is being explored since so many were agreeable to meeting and traveling then. Meanwhile, a May meeting is being planned.

NEW YORK

Northeastern NY/Western New England

The group met in November at the Hope Club of the American Cancer Society in Latham, NY. Although snow meant that some could not make it, a dozen participants (including a couple that joined for the first time) shared in a lively discussion about WM and some of the latest encouraging treatment news. Member Pete Skinner, who was keynote speaker for the meeting, is one of 31 WMers in the 24-month Dana Farber solo venetoclax clinical trial. Pete now has IgM well into the normal range with near 0% bone marrow infiltration. His news, to say the least, was received with enthusiasm and frequent questions from all. He and his partner Betsy Ferris Wyman attended the recent 5th International Patient and



Illinois/SE Wisconsin Support Group



NE New York and W New England - Co-support group leader Pete Skinner and Betsy Ferris Wyman

Physician Summit on WM in New York City and had lots to report, especially about venetoclax. The conversation also included discussion of ibrutinib. Sandy Solomon and Mel Horowitz shared how well they are doing and that the side effects were tolerable and minimal. Some comments about its cost led to a discussion of ways to obtain support to help lower this expense. While some have insurance which covers all but a small co-pay, others are paying thousands each month. The general discussion continued during lunch. It was encouraging to learn that all were doing well. Tentative plans were made for a meeting in March (perhaps with a speaker), a luncheon in April or May, and maybe a summer gathering in Lake Placid.



NE New York and W New England Support Group

Rochester, Western and Central NY

On October 4, the Rochester, Western and Central NY Support Group met at Gilda's Club of Rochester to share lunch and catch up. It was a very productive and positive meeting. The group welcomed a new member who was recently diagnosed and has started treatment. She was very grateful to meet other WMers for the first time. Each attendee updated his/her experience with WM. Newer members welcomed the

opportunity to ask questions and share their concerns. Spouses or significant others shared their feelings and experiences as caregivers. Their insight was most appreciated. Watching a video from the 2018 Ed Forum was on the agenda, but instead, all the time was spent on open discussion.

EASTERN OHIO, WESTERN PENNSYLVANIA, WEST VIRGINIA

Members gathered at an inviting library venue in Parma, OH, for an October educational and sharing meeting. The group was pleased to welcome Dr. Susan McInnes, palliative medicine physician and medical oncologist at the Cleveland Clinic, who presented "Palliative Care and Supportive Oncology for People Living with Waldenstrom's Macroglobulinemia." Dr. McInnes described the components of palliative care throughout the journey of living with a serious illness, including common WM-related issues that may benefit from palliative care approaches. Members appreciated gaining insight into this relatively new medical specialty with its emphasis on quality of life. Dr. McInnes thoughtfully addressed members' questions about care options and accessing services. The focus then turned to group sharing where all, including several new members, discussed their WM stories with related treatment responses, symptoms, and quality of life issues. As WMers shared their experiences, the sense of empowerment was clearly evident! Tasty potluck food contributions energized the group throughout the afternoon.



OR and SW Washington Support Group meeting in progress

OREGON/SOUTHWEST WASHINGTON

Portland

A small but enthusiastic group of twelve met in Portland in September for a delicious potluck lunch and lively conversation. In lieu of a speaker or formal program, members instead shared their various journeys with WM—all so different, but all so connected. Many in the group have become old friends and enjoy just socializing to catch up

Support Group News, cont. on page 36

with each other. As usually happens, one attendee was new to the group as well as a new WM patient. He benefitted from listening to the members' varied experiences and left armed with questions to take to his future medical appointments. A date and speaker for a January 2019 meeting have yet to be determined. Stay tuned.



*Eastern PA Support Group - "Chili in Philly"
get-together at Lisa Wise's home*

PENNSYLVANIA

Susquehanna Valley

In the fall, the group was to be treated to a tai chi demonstration. At the last moment, the speaker could not attend. Instead, Support Group Leader Terrie Eshleman demonstrated some of the forms. She introduced the practice as a wonderful exercise for breath control and focus. The form she learned was designed specifically for older people or those who have difficulty with arthritis. The slow, focused breathing and slow movements engage a meditative state. Terrie did some of the forms while having chemo that lasted for hours. Movement was always good. Even when she was at her most tired, she could still do tai chi. A newly diagnosed WMer, new to the area, attended the meeting; she spends half the year in Florida and was delighted with the help she received on picking a local, WM-savvy oncologist as well as IWFM booklets. A group thank you went to Don and Kate Wolgemuth for their generous donation to the research fund. Also, the group was excited about the next IWFM Ed Forum to be held in Philadelphia, as it would make it so easy for members to attend. The next meeting is planned for March 10, the second Sunday of the month. It will be in the community room at Brethren Village in Lititz from 2 to 4 pm. Speaker TBA.

Philadelphia

In September, Stephanie Fortunato, program specialist and social worker with the Cancer Support Community of Greater Philadelphia, led a discussion about "The Art of Asking for



*Eastern PA Support Group at the
Lankenau Medical Center in Wynnewood, PA*

Help." Twenty-eight participants explored why so many are often more comfortable offering help and assistance than asking for help personally. Stephanie circulated written tips, including: "Rather than viewing vulnerability as a marker of weakness, we can choose to see it as a sign of strength. It takes a lot of courage to ask for help, which is a fact we often recognize in others before ourselves." The group met at Lankenau Medical Center in Wynnewood, PA; shared health news; caught up after the summer; offered each other support; and enjoyed delicious, healthy snacks provided by generous snack volunteers.

In November, the group celebrated the fourth annual "Chili in Philly," a support group meeting and lunch. For this popular event, forty members gathered at the home of Lisa Wise, support group leader, to enjoy seasonal goodies in a welcoming, nurturing atmosphere. Many first-timers attended and felt the "Philly love" that this special meeting offers each fall. Ross Schmucki was wholeheartedly thanked for his four years of dedicated service as an outstanding support group leader. His leadership will be sorely missed by the group, but we look forward to his continuing contributions as an invaluable group member. IWFM President Carl Harrington was joyfully celebrated for receiving one of the inaugural Peter S. Bing Humanitarian Awards at the recent IWWM10! During their time together, each member shared a two minute update that included: year of diagnosis, any treatments, biggest challenges and joys of the past year, and recommendations for any resources that have been useful along their WM journey. In honor of National Family Caregivers Month, the group gave a special salute to the attending caregivers, who give so much with their generous hearts and kind support. To make the event such a success, it really took a whole village. Linda and David Boyer brought gorgeous green plants for everyone in the group to take home; Glenn Cantor and Inge Eriks provided highly informative reports from the 10th International Workshop on Waldenström's Macroglobulinemia and the 5th International Patient and Physician Summit in NYC; and a

whole crew of WMers rolled up their sleeves to help clean up after the event, even scrubbing chili pots together. It was an uplifting way to end 2018 and from which to look forward to an informative and supportive 2019 ahead.

TEXAS

Houston

Very rainy, windy, and cold weather did not deter a small group of support group members from gathering at the home of Dr. Barbara Sunderland Manousso and John Manousso (WMer since 1994) in early November. Thanks to electronic meeting software, Dr. Jorge Castillo, clinical director of the Bing Center for Waldenstrom's Macroglobulinemia at the Dana-Farber Cancer Institute in Boston, MA, was beamed into the living room for an informational update of the newest treatment options and research results on WM. He generously answered individual questions as well. The group enjoyed refreshments and thoughtfully exchanged personal health stories.

NORTHWESTERN WASHINGTON

Seattle

On November 3, more than 60 WMers, friends, and family attended "Updates in Waldenstrom's Macroglobulinemia" at the Fred Hutchinson Cancer Research Center in Seattle. Sponsored by the Seattle Cancer Care Alliance (SCCA), the meeting brought the local WM support group together to hear Dr. Edward Libby, medical oncologist at SCCA, give a very useful, detailed account of the IWWM10 he recently attended in New York. He also conducted an Ask the Doctor session which, as always, was very popular and enlightening. Dr. Julia Ruark, acting assistant professor, University of Washington Medical Center and SCCA, presented "A Psychiatrist's



Dr. Edward Libby and Dr. Julia Ruark

Perspective: How Cancer Impacts Mental Health." She explained that the surging emotions patients often experience around WM are real, not surprising, and treatable. The group then heard about "Integrative Health in Oncology" from Kathleen Sanders, advanced registered nurse practitioner, who suggested different ways we can address those emotions. Many participants seemed ready to slip out of their chairs during her wonderful relaxation exercise. She defined integrative oncology as a patient-centered, evidence-informed field of cancer care that employs mind/body practices, natural products, and lifestyle changes. Members came away from the full day having enjoyed each other's company and the shared knowledge of our presenters.

Videos from this meeting can be found at <https://bit.ly/2QVYLQL>. Then scroll down for links to individual sessions.

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

AUSTRALIA

WMozzies legend tells his story to the Australian Government

Having given his "Story of Hope" to IWWMF in 2015, WMozzies legend Michael van Ewijk, together with Dr. Judith Trotman, was invited to Parliament House, Canberra, in September 2018 to tell his story to Greg Hunt, Australian Minister of Health. In 2014 Michael was the first patient in Australia on ibrutinib. He was in the iNNOVATE clinical trial at Concord Hospital in Sydney under the care of Dr. Trotman. Michael told the Minister of Health about the truly amazing results from the ibrutinib treatment, and about the ClinTrial

Refer app. The app enabled him to locate and join the trial. His story is on a YouTube video at www.youtube.com/watch?v=a9PoV8Jbj7c. The ClinTrial Refer smartphone and iPad/tablet tool provides clinicians, research staff, and patients with instant knowledge of currently recruiting trials. The app was awarded a \$50,000 prize in a worldwide competition for clinical trial innovation.

WMozzies at the Patient Advocate HealtheVoices Event

WMozzies leader Andrew Warden attended with dozens of patient advocates at the HealtheVoices conference sponsored by Janssen in November. The event for health advocates was

International Scene, cont. on page 38

about the power of health advocacy online. It included a range of panel discussions featuring patients, advocates, and other experts. The panels had a significant focus on online patient advocacy, the development of content, and the use of different platforms. Topics covered included:

- Panel on helping, healing, and the risk of hurting discussed how the Internet has changed the way patients connect and interact with each other.
- Patient with a rare condition told about her patient advocacy, leading to wider recognition as an expert voice.
- Health advocate dealt with the challenges of emotional health in online advocacy. How can people balance the benefits of connecting and advocating online while dealing with negative interactions and maintaining boundaries? Communications expert talked on content generation and expanding the reach of advocacy.
- Comedian and patient discussed whether it is okay to make jokes about your own chronic illness. He talked about his own considerations when using humour to describe what can be traumatic patient experiences.
- Panel of three advocates explored the challenge of wearing different “hats” at the same time and balancing what can be competing interests.

Cancer Institute New South Wales Innovations Conference—A WMer’s Story

WhiMSICAL patient investigator and WMozzies leader Andrew Warden shared his personal experience with WhiMSICAL at the conference in Sydney. His personal patient story highlighted the need for WM patients’ de-identified data to be shared.

“Eleven years ago, my treatment resulted in multiple emergency hospitalizations with a week-long stay in an isolation ward. Of my WM friends who had this same treatment, one subsequently died, and one nearly died. None of us were in a clinical trial so our patient experience was not shared widely. Our patient story remained in one hospital’s records. Each of our records was in a virtual silo. Our de-identified experience was not available for research for the benefit of doctors in other hospitals. The WhiMSICAL database is designed to overcome this major shortcoming.”

Andrew Warden, WMOZZIES, reporting

CANADA

Toronto Support Group

The second Toronto Support Group meeting was held at Ellicsr Wellness and Cancer Survivorship Centre in the Toronto General Hospital on September 26. The very engaging speaker at this meeting was Megan Morrison, RD,



Canada, Halifax - Dr. Shirley D'Sa with WM patient Lynn MacDermid

a clinical dietitian specializing in malignant hematology and allogeneic stem cell transplantation at the Princess Margaret Cancer Centre. Although the focus of her presentation was on diet during treatment, she encouraged everyone to maintain a healthy diet to foster overall energy and well-being. A Q & A session was held after the presentation. Megan competently answered many excellent questions from the floor and provided us with a wealth of practical

information. The slides of her presentation can be found at www.wmfc.ca. Following Megan’s presentation there was a round table discussion—a time to share each other’s personal journey with WM. It was a valuable time for newcomers to find out they are not alone.

Halifax Support Group

The Waldenstrom’s Macroglobulinemia Foundation of Canada’s (WMFC) Educational Forum was held for the first time in Halifax, Nova Scotia, on October 27. It provided four dozen patients, family members, and hematology nurses the opportunity to learn from and speak with international and local WM experts and to establish and renew friendships.

IWMF Torch Doc Stars Dr. Shirley D’Sa from University College Hospital London and Dr. Zachary Hunter from The Bing Center for WM in Boston were joined by hematologist Dr. Ismail Sharif and radiation oncologist Dr. Rob Rutledge, both from Dalhousie University in Halifax.

Dr. D’Sa, author of the definitive *Guide to Lymphoplasmacytic Lymphoma and Waldenstrom’s Macroglobulinemia*, kicked off the programme by explaining the basics of WM and the various complications that can arise. She concluded with an analysis of the current situation for WM patients in the United Kingdom (UK), particularly the recent successes in staging WM clinical trials. The development of a patient registry by WM advocacy organization WMUK has resulted in approval of two-year funding for ibrutinib therapy for UK WM patients.

Dr. Sharif explained how patients at the Halifax Hematology Clinic were diagnosed, the current treatment options available in Canada, and the importance of clinical trials to develop new therapies.

Drs. D’Sa and Sharif were joined by Dr. Hunter for a lively Ask the Doctor session, where questions from the audience were supplemented by others submitted in advance.

After lunch, Dr. Rutledge, who has won awards for health promotion with a focus on psychosocial and spiritual oncology, engaged participants' minds and bodies with his presentation, "The Mind-Body-Spirit Connection in your WM Journey." Sleep, diet, exercise, and meditation were highlighted as vital components of our magnificent healing powers.

Dr. Hunter concluded the proceedings with the latest news in WM, including findings from the recent 10th International Workshop on WM, held in New York in mid-October. Highlights included the recommendation to add genetic testing for the MYD88 mutation as a requirement for a definitive diagnosis of WM and the international consensus against rituximab maintenance therapy. He also described current research and clinical trials at The Bing Center, all with the intention of one day rendering WM a chronic, manageable condition at worst, or perhaps leading to a cure.

Calgary Support Group

On Sunday afternoon, October 28, 13 folks gathered at the home of Cam and Jane Fraser. We were pleased to be able to welcome a new member to our group. This was our first meeting since the unfortunate passing in July of one of our original members, Jack Stephens. Jack will surely be missed. We had a discussion on how the group wanted to structure future gatherings—did we want them to be social meetings or should we bring in speakers? Or did the attendees have other thoughts/wishes? We also discussed the possibility of hosting an educational forum in Calgary. We wrapped up our meeting with a brief interactive discussion from each patient on the status of his or her own situation: treatments, response, and so on. As normally happens at our gatherings, the meeting was "sweetened" by cookies and treats brought by attendees.

Vancouver Support Group

In June, a brief meeting was held at the BC Cancer Agency to discuss re-starting the Vancouver Support Group after Dennis and Charlene Kornaga stepped down over a year ago. Kit Schindell agreed to be interim facilitator until a new support group leader could be found. Bill Carbonneau, a WMer, was also very keen to get the group going again. Kit and Bill have stepped up to the plate, and on October 28 they held a meeting at a new venue which Kit was able to find.

Kit reports, "We had eight people show up, with regrets from others indicating they plan to join us at the next meeting. Our group was comprised of five WMers, two spouses, and facilitators. We have been able to get a pleasant, comfortable space with parking, privacy, and tea and coffee, from Fairview Presbyterian Church in central Vancouver at no charge! It was great to see the WM folks support and encourage each other. Some have had multiple treatments over the years. One is on watch and wait. Another was facing his first round of treatment the following week. We are presently working out

how often we should meet and how to make the meetings a good use of our time. We look forward to meeting again in the New Year."

Please note that all Canadian Support Group information can be found on our website at www.wmfc.ca

Betty McPhee, WMFC, reporting



France, Paris - Waldenström France's November meeting at the Musée des Arts Forains

FRANCE

This year the annual patient-doctor day of Waldenström France (WF) was held on November 10, 2018, in Paris. Jean-Paul Favand, a member of Waldenström France, received us in his private Musée des Arts Forains, the fairground arts museum, a marvelous and magical place considered one of the hidden treasures of Paris.

The patient-doctor day is an important and anticipated gathering of Waldenström France members. In the morning, members and their partners meet on a convivial basis, greet new members, and exchange personal experiences. The afternoon is devoted to the presenters.

One hundred and six participants attended this year's meeting and listened to Professor Véronique Leblond, head of the hematology department of the University Hospital La Pitié-Salpêtrière, Paris, and member of the Scientific Advisory Committee of IWMF. Professor Leblond had just returned from the 10th International Workshop on Waldenström's Macroglobulinemia held in New York in October. Professor Leblond spent the afternoon with us, starting with a comprehensive lecture on WM, then explaining the latest research results and answering an avalanche of questions.

The meeting continued with a workshop on a new tool "tableau-analyses," originally created by one of our members, to allow a better follow-up and comprehension of WM patients' medical analyses. The software used, LibreOffice, is free and available to everyone.

The presentation of Professor Leblond was recorded and will be available to the members of the association on the



Germany, Frankfurt am Main - Meeting of the Leukämiehilfe RHEIN-MAIN e.V. (LHRM) Waldenström Forum



India, Bangalore - WM India support group meeting, Jaya Mani and Rajini Seroo

Waldenström France website:

<http://portail.waldenstromfrance.org>

Annick and Rainer Benda, Waldenström France reporting

GERMANY

In early October, the Waldenström support group, Leukämiehilfe RHEIN-MAIN e.V. (LHRM), held a very successful two-day patient and family forum with 74 attendees. Professor Wolfgang Knauf, Frankfurt am Main, Centrum Hämatologie und Onkologie Bethanien, and Dr. Alexander Burchardt, Medizinische Klinik IV, Hämatologie, Uniklinikum Gießen, presented.

Anita Waldmann, LHRM, reporting



Germany, Frankfurt am Main - Anita Waldmann, LHRM chair, and Dr. Alexander Burchardt, Gießen

INDIA

After returning from the wonderful IWMF Ed Forum held this year in May at Rosemont, IL we conducted a support group meeting in Bangalore in June, with two out of four of our regional members attending and sharing significant WM experiences, including those from the Ed Forum. We also held our first support group meeting in Kolkata on November 29 with three members in attendance. We shared our common experiences of attending the Ed Forum in previous years, the evolution in how WM is being treated, and strategies on expanding the membership of the affiliate.



India, Kolkata - Anil Somani, Rajat Saha, and Saurabh Seroo

This year also saw a shift in strategy for the India affiliate with a broader focus on reaching out to WMers across the country through online channels such as WhatsApp and Facebook, with a dedicated website also in the works. We hope that this approach proves to be more scalable in our efforts.

Saurabh Seroo, WM India, reporting

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IWMF Ed Forum 2019

The wait is over! Your 2019 IWMF Educational Forum brochure with registration form is also enclosed!

Planning is well underway, and it's not too early to register for the popular annual event, to be held this year on June 7-9 in Philadelphia, PA.

Information is included on some special options to take place during this exciting and educational weekend, along with instructions for making your room reservations at the Doubletree by Hilton Philadelphia Center City.

The Educational Forum is a unique opportunity for WMers to come together in a very special way and learn from the medical experts and from each other. There's nothing else quite like it!

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