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INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION

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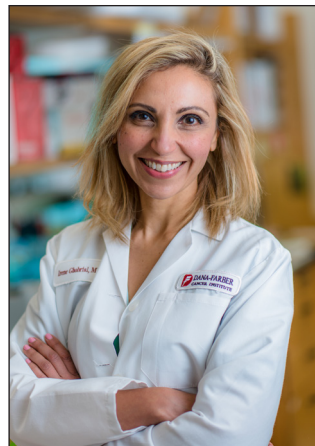
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FROM PRECURSORS TO PROGRESSION: THE NEED FOR MORE RESEARCH

BY DR. IRENE GHOBRIAL, MD; ANNIE COWAN;
DR. CATHERINE MARINAC, PHD; NADER SHAYEGH



Dr. Irene Ghobrial

Dr. Irene Ghobrial is a professor at Dana-Farber Cancer Institute (DFCI), Harvard Medical School, Boston, MA, and an associate member of the Broad Institute, Cambridge, MA. She is the director of the Clinical Investigator Research Program at Dana-Farber Cancer Institute, co-director of the Center for Prevention of Progression, and co-leader of the Blood Cancer Research Partnership. She is also the director of the Michele & Stephen Kirsch Laboratory.

She has authored or co-authored over 250 publications and book chapters and has received funding support from the National Cancer Institute as well as multiple foundations, including the IWMF, Stand Up To Cancer, Leukemia & Lymphoma Society, Multiple Myeloma Research Foundation, and International Myeloma Foundation. She has received multiple awards, including the Ken Anderson Young Investigator Award, Robert A. Kyle Award for Research in Waldenstrom Macroglobulinemia, and Mentor of the Year Award at DFCI.

Imagine you have boarded an airplane for a trip across the country. If you've flown before, you know exactly what to expect. You'll settle into your seat as the pilot introduces himself and the flight attendants check your seatbelt. Then, you'll be throttling down the runway, lifting suddenly off the ground with a lurch. It will take a while to reach cruising altitude. When you do, you're offered a cup of water and snacks as you weather through some turbulence. The pilot comes over the intercom to let you know when to put your seatbelt back on; the descent begins. It is a bit of a relief when you finally touch ground.

For those afflicted with Waldenstrom's macroglobulinemia (WM), the diagnosis, treatment, and (hopefully) remission process can be quite long, much like a flight. For some, it initially involves the diagnosis of a "precursor" condition, or one that can develop into WM. Specifically,

From Precursors to Progression, cont. on page 3

2020 Vision: A World Without WM

This issue of the *IWMF Torch* features the announcement about the exciting 25th anniversary of the Ed Forum! For more information about the upcoming Ed Forum, see page 16 and the 2-sided insert located inside.

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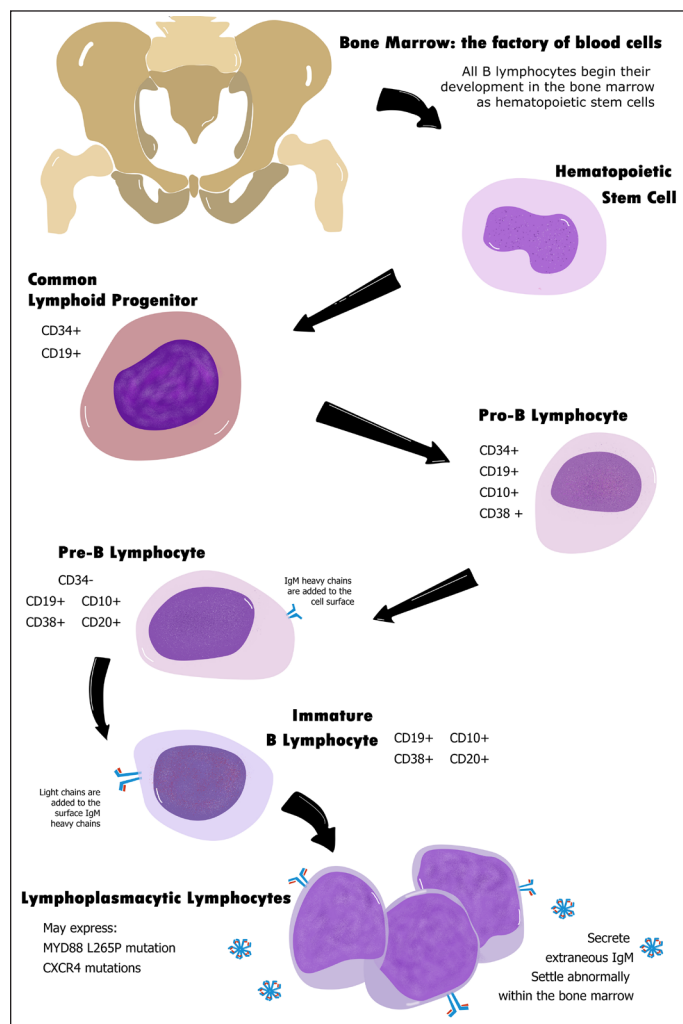
IWMF is a 501(c)(3) tax exempt non-profit organization Fed ID #54-1784426. Waldenstrom's macroglobulinemia is coded 273.3 in the International Classification of Diseases (ICD) of the World Health Organization.

WM always evolves from the premalignant conditions of IgM monoclonal gammopathy of undetermined significance (MGUS), and smoldering WM (SWM). These precursor conditions are often asymptomatic, and their diagnosis may feel like they have come out of thin air, suddenly, like the lifting of the wheels off the tarmac. Patients with a diagnosis of IgM MGUS or SWM want to know if or when they will “reach altitude” and be diagnosed with symptomatic WM—and if treatment should begin before that point is reached, thus preventing the dreaded “watch-and-wait” ascent and the turbulence that can come with a cancer diagnosis. As the medical community learns more about the precursor conditions which precede WM, we are approaching a crossroads in the discussion of WM prevention and clinical care—one in which the question of early treatment enters center stage. Before this critical conversation can proceed, it is important for us to define these precursor conditions and examine how and why progression to WM may occur in the first place.

Waldenstrom’s Macroglobulinemia and the Evolution of the B-Lymphocyte

WM is a non-Hodgkin’s lymphoma of the bone marrow defined by the abnormal development of B-lymphocytes (B-cells) and the extraneous secretion of IgM monoclonal protein. Because WM cells have features of lymphocytes and plasma cells, WM is sometimes referred to as a “lymphoplasmacytic lymphoma.” We can illustrate the origination of WM by walking through the development of a healthy B-lymphocyte, examining when and how alterations to this developmental process result in the evolution of tumor cells.

Bone marrow is the spongy tissue located, in adults, within the interior of the larger bones of the body and is known colloquially as the “factory of blood cells.” A single type of cell, deemed the hematopoietic stem cell, produces the three cell types present in blood: white blood cells, red blood cells, and platelets. Platelets are involved in the blood-clotting process and are essential to the healing of wounds. Red blood cells carry oxygen and are involved in respiration. White blood cells comprise the body’s immune system and include, among other infection-fighting cells, B-lymphocytes and plasma cells, the two cells associated with WM.



WM cell evolution

starting point for all blood cells. An important note about the developmental process is that cells are identified by the presence or absence of specific receptors on their surface called “clusters of differentiation” (CD). CDs are protein units that help cells attach to one another, “talk” with one another, and identify foreign elements, such as bacteria and viruses. Researchers are able to define the developmental pathway of the plasma cell by examining the changes in the type and number of CDs present on the cell surface; a change in CD pattern indicates the development of a new cell type.

In WM, B-lymphocyte maturation begins normally with the hematopoietic stem cell differentiating into a common lymphoid progenitor (or precursor) with CD34 and CD19 receptors. The common lymphoid progenitor cell then differentiates into a new cell type called the pro-B-cell with CD34, CD19, CD10, and CD38 receptors. The pro-B-cell develops into a pre-B-cell when the CD34 receptors are lost from the cell surface, CD20 receptors are gained, and, importantly, the cell begins to express heavy-chain IgM antibodies (or immunoglobulins) on its surface. The switch

From Precursors to Progression, cont. on page 4

Researchers are able to **define the developmental pathway** of the plasma cell...

The hematopoietic stem cell is capable of dividing for a prolonged period of time without differentiating or developing into a more specialized blood cell. Because these stem cells have the ability to propagate indefinitely, they serve as the

from pro-B-cell to pre-B-cell occurs as the cell begins to generate an enormous repertoire of unique antibodies that the cell will eventually use to recognize foreign material (this process is called VDJ recombination). Pre-B-cells develop into immature B-lymphocytes when light chains are added to their membrane-bound IgM heavy chains.

Immature B-lymphocytes move out of the bone marrow and into the body's circulation. There, they interact with foreign materials such as viruses and bacteria, identify them as foreign, and become "educated" to that foreignness. Once educated, the B-lymphocyte is mature, loses its enormous repertoire of antibodies, and begins producing only one unique antibody shaped perfectly to match and identify the foreign material to which it was educated; at this point, the B-lymphocyte has officially become a plasma cell. As part of its development into a plasma cell, the B-lymphocyte must go through a process known as "class switching" where the immunoglobulin heavy-chain class on the B-lymphocyte is changed from IgM to IgG, IgA, or IgE. The plasma cell is then able to clone rapidly and produce large amounts of unique immunoglobulin with heavy and light chains, thus spreading the message of the foreign material quickly throughout the body to fight the infection.

The Pathophysiology of IgM MGUS and SWM

The immunophenotypic (or surface protein expression) profile of a WM cell is unique from normal lymphoid cells as it resides in some intermediate state between the B-lymphocyte and the plasma cell. In simpler terms, this means that the malignant cells involved in WM look structurally like plasma, lymphocyte, *and* lymphoplasmacytic cells with varied patterns of cell-specific receptors. Because this developmental interruption occurs prior to or independent of class switching, WM malignant plasma cells only produce IgM immunoglobulin. Consequently, IgM is secreted prematurely, in the bone marrow and in abundant quantities, leading to several of the symptoms commonly associated with WM, including hyperviscosity ("thick" blood) and anemia.

The evolution of IgM MGUS to symptomatic WM is the consequence of an accumulation of mutations that drive cell division and prevent cell death. MYD88 is an adaptor protein that functions as the connection between two other proteins within a cellular pathway. Crucially, MYD88 operates in a critical signaling pathway in B-lymphocytes that promotes proliferation and cell survival. Recent research has shown that in many IgM MGUS, SWM, and WM clinical cases, a single amino acid of the MYD88 protein is mutated from a leucine (L) to a proline (P) at position 265. This MYD88 L265P mutation results in the overactivation of the MYD88 protein, the overstimulation of the signaling pathway, and the corresponding proliferation of the cell. Mutations in the CXCR4 protein are also common in IgM MGUS, SWM, and WM. CXCR4 is a cell surface receptor that helps to

facilitate cell migration; abnormal forms of CXCR4 found in WM cause WM cells to migrate to and take up residence in the bone marrow where they continue to expand. While the MYD88 L265P mutation occurs in about 50% and CXCR4 mutations in about 15% of IgM MGUS cases, abnormal forms of these proteins appear in even higher rates in SWM, about 80% and 24%, respectively, and in WM, 90% and 27%, respectively. This suggests not only that the presence of these mutations in IgM MGUS and SWM increases the risk of progression, but also that combinations of these mutations may multiply that risk.

*Current algorithms or formulas to determine the **risk of progression** utilize standard clinical information...*

At this point in the history of WM (discovered by Dr. Jan Waldenström in 1944) and the even younger history of IgM MGUS (discovered by Dr. Robert Kyle of the Mayo Clinic in 1978), there is enough clinical data to group patients based on their probability of progressing to WM. Current algorithms or formulas to determine the risk of progression utilize standard clinical information, including bone marrow infiltration and IgM, beta-2 microglobulin, and albumin volume. Recently, a team from the Dana-Farber Cancer Institute designed an asymptomatic WM (AWM) risk calculator for both patients and physicians to use to identify their progression risk based on those variables; this calculator is available online at www.awmrisk.com. Progression risk algorithms like these may help hematologist-oncologists make decisions about when treatment should begin and are an important clinical component of an IgM MGUS and SWM diagnosis. Incorporating the genetic profile of a patient's specific disease will have an impact on classification systems of high-, intermediate-, and low-risk and thus will likely become a critical variable for improving progression risk classification moving forward.

What Can You Do?

In the general population, IgM MGUS and SWM have been shown to progress at rates of around 1.5% and 12%, respectively, per year, with most IgM MGUS patients never developing symptomatic WM. Specifically, Dr. Robert Kyle, the Mayo Clinic physician who discovered and coined the term MGUS, recently published an analysis on the risk of IgM MGUS disease progression in *The New England Journal of Medicine*. This work found that progression risk is directly tied to M-protein and serum free light chain volume, with the risk of progression at 2% per year for the first ten years following the diagnosis and dropping to 1% per year after that

From Precursors to Progression, cont. on page 5

point. But percentages are often difficult to extrapolate to real life, and patients would prefer to be told their personalized risk of progression as well as how to diminish that risk. As our research community works on better describing the variables which impact progression, here are some lifestyle changes you can make following a diagnosis.

1. **Eat well and take care of your body.** A common question that newly-diagnosed IgM MGUS and SWM patients have is how diet impacts progression. While there is research connecting high body mass index to an increased risk of progression from MGUS to lymphoproliferative diseases like WM, there is no special diet or exercise plan that has been shown to specifically counteract progression. As with any chronic condition, the best advice that hematologist-oncologists can give is to eat healthy and exercise daily. Work with your support team to develop better lifestyle habits, such as minimizing sugar, getting at least 150 minutes of moderate intensity or 75 minutes of vigorous intensity exercise (or a combination of both) per week, and sticking to a schedule that includes 7-9 hours of sleep per day.
2. **Visit a hematologist-oncologist every 6-12 months (for IgM MGUS) and 3-4 months (for SWM) to monitor your numbers.** Research has shown that simply visiting a hematologist-oncologist regularly improves prognosis for patients with hematological precursor conditions. Regular visits to a hematologist-oncologist will ensure that lab result trends are supervised over time and new or worsening symptoms are attended to.
3. **Seek therapy and/or learn a stress management technique to deal with anxiety.** Precursor conditions and “watch and wait” treatment approaches can be difficult to process and may negatively impact mental health. Now is a great time to incorporate stress management techniques into your daily life, such as finding a therapist, picking up meditation, or journaling. You may be surprised how these routines help with other parts of your life as well!
4. **Talk with your hematologist-oncologist about treatment options before symptoms begin.** Communicating with your oncologist about when treatment is expected to begin (if ever) and what treatment options are available can help patients better understand what to expect after a new diagnosis. This conversation will also help your physician select clinical trials and/or treatment plans that will work best for you.

The Imperative Need for Research

While the past decade has provided enormous developments

in our understanding of WM biology and treatment, there is still much that is poorly understood about the evolution of the disease. Importantly, many clinical trials focus on the treatment of symptomatic WM, with few enrolling IgM MGUS and SWM patients. For example, while there are many clinical trials offered at the Dana-Farber Cancer Institute and other large cancer centers for asymptomatic smoldering multiple myeloma, trials for high-risk SWM are only just beginning. It is crucial that the medical community increase support to IgM MGUS and SWM patient populations by leading and encouraging participation in research studies. Such research may not only provide the basis for developing new therapies to prevent WM in patients with these early precursor conditions, but may also facilitate advanced screening techniques for early diagnosis and allow us to continue to improve the algorithms we use to predict the risk of progression to WM.



*The best way for patients **to contribute...**
is **to participate** in a research project...*

Importantly, patients with hematological precursor conditions often require unique clinical management compared to those patients with an active cancer diagnosis. The Dana-Farber Cancer Institute Center for Prevention of Progression of Blood Cancers (the CPOP Clinic) was established to provide multidisciplinary care for patients with hematological precursor conditions like IgM MGUS and SWM. The genetic risk factors, lifestyle, and psychology of patients with precursor conditions can vary immensely across individuals and have a tangible impact on prognosis. The CPOP Clinic allows physicians who specialize in precursor conditions to refer patients to expert cardiologists, psychologists, social workers, and genetic counselors and thus create tailor-made experiences for each patient to improve health outcomes and quality of life. Individuals with precursor conditions deemed higher risk have the opportunity to participate in the latest treatment options and clinical trials. Tissue banking studies are also available to help improve our understanding of precursor conditions such as IgM MGUS and SWM and how we can prevent them from progressing. The best way for patients to contribute to these advances is to participate in a research project, such as the PCROWD Study and the PROMISE Study, which are further described below.

From Precursors to Progression, cont. on page 6

The PCROWD Study is an international tissue banking project that works with patients diagnosed with hematological precursor conditions, including IgM MGUS and SWM, to generate a database of samples for a wide variety of research projects. Importantly, the PCROWD Study allows researchers to evaluate how these conditions and other monoclonal protein disorders evolve over time. The PCROWD Study supports several progressive projects that are designed to enhance the understanding of WM biology and treatment, including studies that analyze and compare the genetic information of different cell types by using a technology called single-cell sequencing. This is one example of a technology that may help researchers understand how cancer cells interact with other cells in their environment (e.g., the bone marrow) to influence prognosis, as well as how different cells in the body respond to treatment. Patients can join the PCROWD Study by enrolling online at <https://pcrowd.dana-farber.org/>.

Because research has shown that families with a history of WM or IgM MGUS have a significantly increased risk of developing WM or a related blood condition, there may be a benefit for first-degree family members (parents, siblings, and children) to undergo screening for these conditions. The PROMISE Study is a national screening study led by the Dana-Farber Cancer Institute and funded by Stand Up to Cancer that was designed to give family members of patients with

WM, multiple myeloma, and their precursor conditions the opportunity to screen for the asymptomatic blood conditions, including IgM MGUS and SWM, that may develop into cancer. Individuals between the ages of 40 and 75 with a first-degree relative with a diagnosis of WM, multiple myeloma, or their precursor conditions, but without a diagnosis themselves, are eligible to participate. Participants who are eligible can enroll online and are sent the necessary instructions and materials to collect their blood for free at a local lab and send it back to the research team. Blood samples are screened for the presence of a monoclonal protein which may indicate the individuals have a precursor condition like IgM MGUS or SWM; those who test positive are assisted with finding a local hematologist-oncologist so that they can receive appropriate clinical follow up, and those who test negative remain in the study and are rescreened every three years. If your parents, siblings, or children qualify for the PROMISE Study and would like to contribute to WM research, they can register online at www.enroll.promisestudy.org.

Large research initiatives such as the PCROWD and PROMISE generate the data that researchers and physicians need to advance the understanding of an intricate disease like WM. The precursor patient community is ready to learn more, and our research teams are determined to help. Together, we can work to stop WM before it starts!

CHAIRMAN'S CORNER

BY CARL HARRINGTON



Vision without action is merely a dream. Action without vision is just passing the time. Vision with action will change the world.

Joel Barker, Futurist

Welcome to 2020! Did you make any New Year's resolutions? At the IWFMF, we went far beyond that. We created a strategic plan that will guide us for the next 3-5 years. Playing off the

year 2020, this "IWFMF Strategic Plan" gives us 20/20 vision regarding what we want to accomplish on behalf of WMers everywhere.

Please reread that opening quotation.

The intention of the IWFMF Board of Trustees is to change the world, specifically, the world of WM through our new "IWFMF Strategic Plan." This "Strategic Plan" lays out our vision of

where we want to end up, and it includes: our mission, or what we'll do on our way to the vision; our values; and our compelling intentions, or the things we will focus on to get us to the vision. The IWFMF vision is:

IWFMF Vision: *A world without WM (Waldenstrom's macroglobulinemia)*

A world without WM is a world where no one relapses, no one is refractory, no one worries about his or her kids getting WM, and no one suffers from side effects from WM or its treatment. While we are striving to achieve this vision, we'll focus on our mission—meaning what we do every single day.

IWFMF Mission: *Support and educate everyone affected by Waldenstrom's macroglobulinemia (WM) while advancing the search for a cure.*

With the IWFMF, no one is alone. It doesn't matter who you are or where you live. If you have WM or someone you love has WM, we're here to help. Although WM is a rare disease, the IWFMF is here for you.

Chairman's Corner, cont. on page 7

IWMF Values: The values we live by are what we ask our Board, our office staff, our volunteers, and WMers to stay true to in interactions with other WMers—in support groups, at the IWMF Educational Forum, online at IWMF Connect, on LIFELINE calls, with our partners, and everywhere else. These values are:

Behavior:

- Community – We believe in engaging the WM community by sharing information, providing support, and working together to eradicate the disease.
- Teamwork – We work as a team that includes all WM stakeholders.
- Integrity – We care about the WM community and commit to the highest financial and ethical standards, with transparency in all that we do.

Execution:

- Focus – We are fiercely dedicated to providing support and education for those affected by WM, to supporting research to improve and extend lives, and to finding a cure for the disease.
- Collaboration – We leverage the collective passion and genius of other blood cancer organizations and the medical and research communities.
- Accountability – We are transparent and accountable at every level to the WM community and to the general public.

As you probably know, our Charity Navigator (the largest rater of nonprofits in the US) score on accountability and transparency is a perfect 100, which suggests we're doing pretty darn well in those areas.

To get to our vision, we identified the following compelling intentions that will drive what we do.

Our Compelling Intentions:

1. Assume leadership to significantly increase the number, scope, and coordination of global WM research projects.
2. Become the global thought leader and authoritative source of information and resources in WM.
3. Ensure that every doctor and nurse worldwide who works in blood cancer knows about the IWMF and the resources we offer.
4. Ensure that every person diagnosed worldwide with WM knows about the IWMF and the resources we offer.
5. Expand worldwide awareness of WM and the IWMF.
6. Significantly increase and diversify our sources of funding to support our mission.

To accomplish these intentions over the next 3-5 years, we need your help. As a first step, for everyone who gets a paper *IWMF Torch*, look for the "About the IWMF" brochure that is inserted into this issue. For those of you who get the *IWMF Torch* electronically, go to <https://www.iwmf.com/sites/default/files/docs/publications/IWMF%20brochure.pdf> to download the brochure. This brochure is designed to let everyone know what the IWMF does. Please share it with your health care team, with your caregiver, and with your family and friends. If you want more copies, you can either print them or email Michelle Postek at the IWMF Office at mpostek@iwmf.com or call her at 941-927-4963.

For more information about how you can help fund the IWMF mission in 2020 and beyond, see the article on page 20. We have the vision, but we need your help to share it. We are taking action, and we can't do it without you. Working together, we will put our vision into action and change the world into a world without WM!



*In Memorium of Our
Dear Friend, Alice Riginos*

Editor's note: As this issue was going to press, we learned of the passing of Alice Riginos, the well-known and respected editor of the *IWMF Torch* from 2008 to 2018. She brought to life her vision of a magazine that is both beautiful and extremely useful to WMers around the world. We will cover Alice's legacy to the IWMF in the April issue. We send our sincere condolences to her family and friends.

FROM PATIENT TO PATIENT ADVOCATE

BY BONNIE BECKETT, IWMF PATIENT ADVOCATE

I Have What???

My diagnostic journey was much shorter than the typical Waldenstrom's patient. I had a diagnosis two months after the discovery of some odd markers of inflammation at my annual physical in 2012. Dr. John Feigert, a hematological oncologist at Virginia Hospital Center two blocks from my home, reviewed the prior blood tests done by my primary care doctor and a rheumatologist. Although not a WM specialist, he had about a dozen other WM patients, one for more than 14 years, and was already working closely with Dr. Treon. Additional blood tests showed slightly elevated IgM (529) and other blood markers confirming the WM diagnosis. He patiently spelled out the disease name, explained its generally indolent nature, said that with no symptoms I would not need any treatment for now, and told me to come back in six months.

I walked home in a daze, told my husband I had cancer, made myself some tea, and went on the Internet. I found the IWMF, printed masses of information, and read for days. Within a week I had three pages of questions for Dr. Feigert and asked to see him again. Isn't it really monoclonal gammopathy of undetermined significance (MGUS)? Why didn't you do a bone marrow biopsy (BMB) or CT scan? I knew he was the right doctor when he saw me again promptly, patiently answered every question, offered to do the BMB and CT scan, but pointed out that we wouldn't be doing anything differently—no symptoms, no treatment. As a confirmed pain wimp who had seen the “treat the symptoms not the numbers” mantra repeatedly on the IWMF site, I readily agreed to that approach.

Helping to Advance Science

I spent the next three years educating myself about WM. I read Talk List (now IWMF Connect) posts and research articles linked there, attended my local support group and the Ed Forums in Tampa and Chicago, and participated in the Rare Disease Legislative Advocate's (RDLA) Rare Disease Week on Capitol Hill. When I learned that the nearby National Institutes of Health (NIH) was seeking volunteers for a natural history study of WM, I volunteered in 2015. Nine vials of blood, a CT scan, and a near-painless BMB later, NIH gave me the good news (no evidence of WM cells in my bone marrow) and the bad news (I had MGUS and had flunked out of the study because I don't meet the technical definition of 10% WM cells in the bone marrow). NIH did find that I have the MYD88 mutation at just above the detection level. Drs. McMaster, Wiestner, and Sun hope to add MGUS patients like me to the study to gain an understanding of how and why we do or don't progress to full-blown WM. I wish my mother, who had many of the classic WM symptoms and was a four-time cancer survivor, had been tested for elevated IgM and the mutations before her death at 97.



Bonnie Beckett on her way to congressional meetings during Rare Disease Week

I would have to find other ways to support WM patients with the disease that I no longer officially had.

The Formation of the IWMF Advocacy Committee

In 2015 former IWMF President Judith May and members Pat Getz, Chuck Ross, and I formed the IWMF Advocacy Committee to track and alert US members to legislation that could have an impact on WM patients. WMers frequently expressed concerns about the availability and affordability of insurance, especially for those with pre-existing conditions; the need to foster drug innovation; and the accessibility and affordability of drugs, including legislation preventing Medicare from negotiating drug prices. We developed a process for putting out legislative alerts to US members while maintaining the IWMF's political neutrality. The process was time consuming, involved multiple layers of review and editing, and generated limited response.

*...research and development of therapies
addressing **rare diseases** have resulted in
more than 750 **new therapies**...*

I spent many hours developing a spreadsheet of many relevant House and Senate bills, tracked and updated those, but found that many had insufficient congressional support to move out of committee. Even bills with broad bipartisan and rare disease community support languished unpassed.

From Patient to Patient Advocate, cont. on page 9

For example, the Orphan Products Extension Now Act, to continue fostering the development and repurposing of drugs to treat rare diseases, had strong bipartisan support and passed the House, but was dropped from the final version of the Affordable Care Act. The original Orphan Drug Act (Public Law 97-414) was enacted to provide research and development incentives to encourage the development of new therapies for diseases affecting fewer than 200,000 people in the United States. In the ten years prior its enactment, only ten therapies for rare diseases were developed by private industry and approved by the Food and Drug Administration (FDA). Since its enactment, research and development of therapies addressing rare diseases have resulted in more than 750 new therapies for rare diseases.

I found that my prior training is a natural fit for speaking out about WM and tracking relevant legislation. While my academic training was in literature and foreign languages, I had worked both as a university professor and, for over 25 years, for the US Government Accountability Office (GAO), the agency that reviews federal programs in response to congressional requests and mandates. I had written numerous reports and testimonies for Congress on everything from Superfund hazardous waste cleanup to aviation safety and security before and after 9/11. I had also developed an aversion to meetings and to bureaucratic layers of review and found myself frustrated by the process we had created and my wasted efforts tracking legislation that went nowhere. With the other three committee members facing some health issues and two of them located in the western US, the formal IWMF Advocacy Committee faded away.

Informal Advocacy Continues

Since Chuck and I are located in Virginia just across the river from Washington DC, we continued to represent the IWMF and advocate for key legislation. We've attended RDLA's Rare Disease Week on Capitol Hill several times, joining other rare disease patients and their caregivers for updates on legislation and briefings on NIH breakthroughs, along with training on lobbying members of Congress followed by meetings with our members and their staffs. Through RDLA I've met patients with a wide variety of rare diseases, many of whom have greater disease burdens than most of us but share our concerns about access to insurance and the affordability of treatments.

We've also represented the IWMF at the World Orphan Drug Congress, a gathering of scientists, pharmaceutical representatives, and patient advocates specializing in rare diseases. Chuck focused on sessions dealing with scientific breakthroughs. I attended sessions for representatives of the pharmaceutical industry on drug innovation and pricing. I learned that drug prices have little to do with the costs to develop and produce a specific drug and a lot to do with the size of the potential patient population, the impact the drug will have on the patient's quality of life, and mostly on how



Nita Somasundaram (center) of Congressman Don Beyer's staff

many new drug trials the company plans to start in the next year or two.

I've also staffed the IWMF booth at the National Organization for Rare Disorders (NORD) Rare Diseases and Orphan Products Breakthrough Summit the past two years. There I met newly diagnosed patients and provided them with encouragement and IWMF publications. I had long discussions with medical and pharmacy students about the IWMF's Strategic Research Roadmap, and how genetic testing is now helping to direct our treatment choices. I also increased our disease visibility with researchers, pharma companies, and other patient organizations. Representing the IWMF at Janssen Pharmaceutical's session on drug pricing transparency allowed me to speak up about the impact of high drug prices on our members, especially those on Medicare who cannot take advantage of the compassionate use prices for Janssen's Imbruvica and other medications.

I've shifted my informal advocacy role to alerting our members on a variety of fronts. I now regularly pass on information about upcoming events and free webinars by



Meeting with Amanda Haverkamp (far left) of Senator Mark Warner's staff

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Rachel Reibach (right) of Senator Tim Kaine's staff

other groups like the Leukemia & Lymphoma Society (LLS) and NORD on topics of potential interest. I will continue to alert our US members on IWCF Connect to legislation that is moving forward and encourage them to make their views known to their members of Congress.

How Can US IWCF Members Have an Impact on Key Legislation?

To have an impact on legislation, you need to make your views known to your members of Congress. The most effective way is in person, but not everyone can travel to one of their offices or town halls or get an appointment with their senator, representative, or someone on their staff. Letters, emails, and phone calls also have an impact, especially when you explain the connection between WM and a specific piece of legislation or issue, and that you are a constituent. The best site for information on how to contact members, track specific pieces of legislation, and find out whether your member is a cosponsor of a bill is <https://www.congress.gov/>. The site can help you identify your members and direct you to their websites that have phone, address, and email contact information. The US Capitol switchboard can also connect you to your member's office: 202-224-3121.

You can also encourage your members of Congress to join the Rare Disease Legislative Caucus, a bipartisan, bicameral group that meets quarterly to support rare disease patients. These meetings, which I frequently attend, include patients, pharmaceutical company representatives, key staff from the FDA and NIH, and senators and representatives. They share a commitment to understanding the needs of the rare disease community and working together to pass legislation that will help patients and caregivers. You may go to this link to see

whether your senators and representatives are members of the Caucus: <https://rareadvocates.org/rarecaucus/>.

We can also have a greater impact working in concert with other rare disease and blood cancer organizations, including LLS, RDLA, and NORD. RDLA and NORD have put great emphasis on legislation important to WM patients in the past, specifically the Orphan Drug Act to foster drug development and innovation for all rare diseases by offering drug companies extensions of patent exclusivity to encourage the repurposing of existing drugs for the treatment of rare diseases. However, abuses of this exclusivity have left enough members wary of this approach that the legislation to reauthorize this act has not yet been reintroduced. In 2019 RDLA focused its Rare Disease Week on Capitol Hill on other very worthy legislation that is not relevant to WM, for example, the reauthorization of the Newborn Screening Act, the Medical Nutrition Act, and the Ensuring Lasting Smiles Act.

Critical Legislative Issues

At present I'm tracking over 30 House and Senate bills on issues critical to WMers. These include: the affordability and availability of insurance, especially for those with preexisting conditions; drug prices and changing the rules so Medicare can negotiate drug prices the way the Veterans Administration and private insurance companies can; fostering drug innovation and the search for cures; expanding the availability of Medicare to more people at an earlier age; and oral parity—having insurance cover oral cancer medications the same way that it covers infusions in order to reduce co-pays. Anyone interested in the list of bills with brief summaries and my periodic updates on the status of bills that are making progress toward passage may contact me at bonnie_beckett@hotmail.com to be added to my mailing list.

Unfortunately, as of fall 2019 few of these bills have sufficient congressional support to move out of committee, let alone pass the House, move forward for Senate consideration, and then go to the President for signature. The House and Senate continue to work on proposals to reduce the cost of prescription drugs for consumers. The Senate Finance Committee passed the Prescription Drug Pricing Reduction Act (S. 102, H.R. 465). This Act proposes changes to Medicare to limit the out-of-pocket costs to beneficiaries to a maximum of \$3,100 in 2022. Two critical bills that passed the House are languishing in the Senate: Strengthening Health Care and Lowering Prescription Drug Costs Act (H.R. 987) and Protecting Americans with Preexisting Conditions Act of 2019 (H.R. 986). A separate Senate Resolution (S.J. Res 52) to maintain current requirements for insurance policies under the Affordable Care Act and not grant waivers to exclude those with preexisting conditions failed along strictly party lines, with all Senate Democrats supporting the resolution and virtually every Republican opposing the resolution.

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Given the widespread concerns about the cost of healthcare among Americans, the lack of progress on these issues is discouraging.

Editors Note: Group photographs were taken of Rare Disease Week meetings on Capitol Hill with Congressional staff; these meetings included other rare disease patient advocates.



MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF RESEARCH COMMITTEE MEMBER

Mayo Clinic Study Evaluates Ibrutinib Therapy for WM Outside of the Clinical Trial Setting – The *British Journal of Haematology* published a report from the Mayo Clinic that looked at ibrutinib (Imbruvica) monotherapy for WM outside of the clinical trial setting. Eighty patients (67 previously treated and 13 previously untreated) who were consecutively treated with ibrutinib off-study were evaluated. With a median follow-up of 19 months, the overall response rate to ibrutinib was 91%, with a major response rate of 78%. The median time-to-first-response and median time-to-best-response were 2.9 months and 5.7 months, respectively. The median duration of response was 32 months. At last follow-up, 31% had discontinued therapy, the majority due to treatment-related toxicities, and 18% required dose reduction. Fatigue and atrial fibrillation were common non-hematological toxicities, and IgM rebound occurred in 36% of patients who abruptly discontinued ibrutinib. Following ibrutinib discontinuation, patients who received subsequent therapy achieved an overall response rate of 57% and a major response rate of 50%, with a median progression-free survival of 18 months.

*The two-year **progression-free** survival rate [for venetoclax] was 76%.*

Results Updated for Phase 2 Trial of Venetoclax in WM – Results from the multicenter Phase 2 clinical trial of venetoclax (Venclexta) in 31 previously treated WM patients were updated during the 17th International Myeloma Workshop in Boston. All patients were successfully escalated to the target dose of 800 mg. At 12 months, serum IgM declined to 1,071 mg/dL, bone marrow involvement declined to 3%, and hemoglobin increased to 13.1 g/dL. A very good partial response was attained in 19%, partial response in 61%, minor response in 6%, stable disease in 10%, and no response in 3% of patients. Median time to response was 1.9 months and was slower in patients with prior exposure to BTK inhibitors such as ibrutinib (Imbruvica). The two-year progression-free survival rate was 76%. Severe adverse events included neutropenia

(low neutrophil count), anemia, and diarrhea. One instance of laboratory tumor lysis syndrome occurred.

Clinical Trial Available to Provide Continued Access to Ibrutinib for Patients Completing Other Clinical Trials of the Drug – A multicenter clinical trial at 85 locations worldwide is available to provide continued access to ibrutinib (Imbruvica) for patients who have completed other clinical trials of ibrutinib, are still benefitting from it, and have no access to commercial ibrutinib within their geographical area. The estimated enrollment is 500, and participants receive oral continuous dosing with ibrutinib at the same dose and schedule they were receiving at the end of their original clinical trial. Treatment may be continued as long as participants continue to derive benefit from treatment, until such time that ibrutinib becomes commercially available in their area. The identifier number on www.clinicaltrials.gov is NCT03229200.

Dana-Farber Cancer Institute to Open Phase 1 Study for WM Patients Experiencing Disease Progression on Ibrutinib Therapy – At press time, Dana-Farber Cancer Institute was anticipated to open a small Phase 1 pilot study of dasatinib (Sprycel) in symptomatic WM patients who are experiencing disease progression on ibrutinib (Imbruvica) and have BTK or PLCG2 mutations. Dasatinib is an oral tyrosine kinase inhibitor that blocks members of the SRC kinase family and is approved for the treatment of chronic myelogenous leukemia and acute lymphoblastic leukemia. On www.clinicaltrials.gov, the identifier number is NCT04115059.

Emory University Opens Trial for Patients with Monoclonal Gammopathies – Emory University in Atlanta has recently opened a clinical trial for patients with monoclonal gammopathies, including IgM MGUS and smoldering WM, who will receive a 2-week course of an antibiotic called rifaximin to alter the intestinal flora with the goal of determining if the abnormal monoclonal protein is subsequently reduced. The idea behind the trial comes from preliminary data indicating that the cell walls of certain gut bacteria may stimulate development of clonal gammopathies. Patients will receive rifaximin orally three

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times daily on days 1-14. Following completion, patients will be followed for eight weeks. The trial is anticipated to enroll 48 participants, and the identifier on www.clinicaltrials.gov is NCT03820817. The study is co-sponsored by the Leukemia & Lymphoma Society.

Phase I Trial Opens for Novel Bispecific IgM Antibody Therapy in Patients with Relapsed/Refractory NHL – IGM Biosciences announced the opening of a Phase 1 clinical trial evaluating IGM-2323, the company's CD20/CD3 bispecific IgM antibody therapy, in patients with relapsed/refractory B-cell non-Hodgkin's lymphoma (NHL). IGM-2323 is able to eliminate CD20-positive lymphoma cells by engaging one's own T-cells and the immune system protein complement. The identifier number on www.clinicaltrials.gov is NCT04082936, and the trial expects to enroll 160 participants. IGM Biosciences focuses on creating and developing engineered IgM antibodies for the treatment of cancer patients.

Phase 1/2 Trial Begins for SYK Inhibitor in Patients with Relapsed/Refractory NHL – Hutchison China MediTech Limited has initiated a Phase 1/2 study of HMPL-523, its novel spleen tyrosine kinase (SYK) inhibitor, in patients with relapsed or refractory non-Hodgkin's lymphoma (NHL). The study is anticipated to enroll 80 patients in several US and European locations. On www.clinicaltrials.gov, the identifier number is NCT03779113.

Familial Risks Discussed for Blood Cancer Types – To gain insight into the familial risk of the different blood cancers and their possible inter-relationship, researchers performed an analysis of 153,115 records of these cancers from the Swedish Family-Cancer Database that were diagnosed between 1958 and 2015. Overall, 4.1% of diagnoses were familial cases; however, the analysis revealed that LPL (lymphoplasmacytic lymphoma)/WM was associated with a familial relative risk of 15.8%, second highest of the tumor types studied. The risks for LPL appeared stronger with parent-child relationships than with sibling relationships. Close relatives of LPL/WM patients had the strongest risks for development of LPL/WM, mantle cell lymphoma, small lymphocytic lymphoma, and nodular sclerosis Hodgkin's lymphoma. The analysis was published in the journal *Blood*.

Study Focuses on Cardiovascular Toxicities During Ibrutinib Treatment – A multicenter research team utilized a global database of drug complications, called VigiBase and maintained by the World Health Organization, to analyze deaths associated with ibrutinib (Imbruvica). The death rate for ibrutinib was 7% compared to 1% for chemotherapy during treatment or within 30 days afterward. The study, published in *The New England Journal of Medicine* and the *Journal of the American College of Cardiology*, discussed several cardiovascular toxicities associated with ibrutinib, including supraventricular arrhythmias, central nervous system hemorrhagic events, heart failure, ventricular arrhythmias,

..clear and pressing need to **improve**
management of patients on ibrutinib...

conduction disorders, ischemic strokes, and organ damage related to hypertension. The analysis also revealed that cardiovascular adverse reactions occurred steadily in the year following initiation of ibrutinib therapy. Conduction disorders developed within the first 30 days of treatment, while the time to onset of atrial fibrillation, ventricular arrhythmias, or heart failure peaked after two-three months of treatment. Hypertension tended to occur four-five months after the first dose of ibrutinib. All cancer types, including WM, were affected by higher rates of cardiovascular adverse events. The researchers concluded that there is a clear and pressing need to improve management of patients on ibrutinib and that careful cardiac evaluation and electrocardiogram monitoring should be considered during therapy because patients may be asymptomatic despite arrhythmias or developing heart failure.

Another Study Discusses Risk of Hypertension During Ibrutinib Therapy – Meanwhile, The Ohio State University focused its study on the incidence of hypertension (high blood pressure) following ibrutinib (Imbruvica) therapy in patients with B-cell malignancies. This study, published in the journal *Blood*, included 562 consecutive patients treated with ibrutinib between 2009 and 2016 and assessed the incidence of new hypertension (defined as systolic pressure greater than 130 mmHg) or worsened hypertension (defined as systolic pressure increase of 5.2 mmHg or more). Overall, 78.3% of ibrutinib users developed new or worsened hypertension over a median time period of 30 months. Among those without preceding hypertension, 17.7% developed high-grade hypertension (defined as 160/100 mmHg).

US, Canada, and Australia Approve Acalabrutinib for CLL and SLL Patients – Acalabrutinib (Calquence) has been approved in the US, Canada, and Australia for patients with chronic lymphocytic leukemia (CLL) and small lymphocytic lymphoma (SLL). The accelerated approval of this BTK inhibitor was a cooperative effort by the US Food and Drug Administration (FDA), Health Canada, and the Australian Therapeutic Goods Administration, only the second time that all three agencies have cooperated in a new drug approval. The approval is based on positive results from the interim analyses of two Phase 3 clinical trials in patients with previously untreated and relapsed/refractory CLL. Serious adverse events in the trial patients included infections in 19%, major hemorrhage in 3%, and atrial fibrillation in 1.1%. Second primary malignancies, including skin cancers, occurred in 12% of patients. Continued approval is contingent upon verification of clinical benefit in confirmatory trials.

The drug was previously approved by the FDA for mantle cell lymphoma and has been tested in trials with WM patients.

Zanubrutinib has been and is being used in ***clinical trials*** of WM patients.

FDA Grants Approval to Zanubrutinib for Relapsed/Refractory Mantle Cell Lymphoma – The US Food and Drug Administration (FDA) has granted accelerated approval of the BTK inhibitor zanubrutinib (Brukinsa) for relapsed/refractory mantle cell lymphoma—the first FDA approval for the drug, which is also the first cancer drug developed in China to receive such approval. Supporting evidence for the approval came primarily from a Phase 2 trial of 86 previously treated Chinese patients who achieved a response rate of 84% with a median duration of response of 19.5 months. Common side effects of zanubrutinib in the trials included decreased neutrophil count, decreased platelet count, upper respiratory tract infection, decreased white blood cell count, decreased hemoglobin, rash, bruising, diarrhea, and cough. As a condition of accelerated approval, the company must conduct additional studies to confirm the results used to support the approval. Zanubrutinib has been and is being used in clinical trials of WM patients.

Results Updated for Phase 2 Trial of Ibrutinib Plus Venetoclax in Relapsed/Refractory CLL – Results from the Phase 2 CLARITY study of 53 relapsed or refractory chronic lymphocytic leukemia (CLL) patients were updated. The goal of the combination was to eradicate detectable CLL with the intention of stopping therapy, rather than treating continuously. The data showed that after 12 months of ibrutinib (Imbruvica) plus venetoclax (Venclexta) combination therapy, 89% responded. Minimal residual disease negativity (undetectable disease) was achieved in the blood of 53% of patients and in the bone marrow of 36%. After a median follow-up of 21.1 months, one patient progressed, and all patients were alive. There were no significant additional adverse events with the combination compared with published data on either drug alone. The study was reported in the *Journal of Clinical Oncology*.

Phase 2 Results Updated for Umbralisib in CLL Patients Intolerant to Prior BTK or PI3K Inhibitor Therapy – Results were updated for the Phase 2 clinical trial of the oral PI3K-delta inhibitor umbralisib in patients with chronic lymphocytic leukemia (CLL) who were intolerant to prior BTK or PI3K inhibitor therapy. The study enrolled 51 patients, of whom 50 were evaluable. With a median follow-up of 15.7 months, the estimated progression-free survival was 23.5 months. The most common adverse events reported included diarrhea, nausea, thrombocytopenia (low platelet count), fatigue, and insomnia. No adverse events led to fatality, 16%

of patients required dose reductions, and 12% of patients discontinued treatment because of adverse events.

The following are summaries of selected abstracts about clinical trial results and survival trends for WM presented at the 2019 ASH Annual Meeting on December 7-10, 2019, in Orlando, FL. Summaries of selected abstracts pertaining to basic research will be included in this column in the spring 2020 issue of the Torch. The abstracts are online at <https://ash.confex.com/ash/2019/webprogram/start.html>. To read a specific abstract, type part or all of its title into the Search box; for a general search of all abstracts pertaining to or including WM, type “waldenstrom” into the Search box.

Two Years Rituximab Maintenance Vs. Observation after First Line Treatment with Bendamustine Plus Rituximab (B-R) in Patients with Waldenstrom’s Macroglobulinemia (MW): Results of a Prospective, Randomized, Multicenter Phase 3 Study (the StiL NHL7-2008 MAINTAIN trial) (Abstract 343) – This much-anticipated trial in Germany reported interim results on the role of rituximab (Rituxan) maintenance in WM therapy by comparing the effect of two years of maintenance vs. observation after first line treatment with bendamustine and rituximab (B-R). At the time of this analysis, the median follow-up was 70.2 months. Following B-R therapy, 109 patients were randomized to maintenance every two months for two years, and 109 were randomized to observation. The two-year maintenance provided better disease control, with a median progression-free survival of 101 months compared to 83 months in the observation group; however, this difference was not deemed statistically significant. There was no difference in overall survival between the two groups. The trial is ongoing.

Ixazomib, Rituximab and Dexamethasone (IRD) in Patients with Relapsed or Progressive Waldenstrom’s Macroglobulinemia: Results of the Prospective Phase I/II HOVON 124/Ecwm-R2 Trial (Abstract 344) – This multicenter European study explored the use of the oral proteasome inhibitor ixazomib (Ninlaro) with dexamethasone and subcutaneous administration of rituximab (Rituxan). Preliminary results were reported for 50 relapsed WM patients, 39 of whom completed eight cycles of therapy. Treatment in the first and second cycles consisted of ixazomib at 4 mg orally on days 1, 8, and 15 plus dexamethasone on days 1, 8, 15, and 22; in cycle three, rituximab was added intravenously on the first day of the cycle and then subcutaneously on the first day of the remaining cycles. Subsequently, patients with at least a partial response received two years of rituximab maintenance subcutaneously once every three months. The best overall response rate was 88%. With a median follow-up of 19.5 months, the median duration of response and median progression-free survival were not reached. A rapid and significant decrease in IgM levels was seen after cycle two, accompanied by a rapid increase in hemoglobin levels,

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and the depth of response continued to increase until month 12. Two patients had an infusion-related reaction to the first intravenous dose of rituximab; subsequent subcutaneous dosing was well tolerated in all patients. The most common serious adverse events were infections.

Phase 2 Study of Tirabrutinib (ONO/GS-4059), a Second-Generation Bruton's Tyrosine Kinase Inhibitor, Monotherapy in Patients with Treatment-Naïve or Relapsed/Refractory Waldenström Macroglobulinemia (Abstract 345) – This Phase 2 multicenter Japanese trial treated 27 treatment-naïve or relapsed/refractory WM patients with the second generation BTK inhibitor tirabrutinib at 480 mg once daily. With a short median follow-up of six months, the overall response rate was 94.4% in treatment-naïve and 100% in relapsed/refractory patients, while the major response rate was 77.8% in treatment-naïve and 88.9% in relapsed/refractory patients. The most common adverse events of any grade were rash, neutropenia (low neutrophil count), and leukopenia (low white blood cell count). The trial is ongoing.

Open Label Non-Randomized Phase II Study Exploring <<Chemo-Free>> Treatment Association with Idelalisib + Obinutuzumab in Patients with Relapsed/Refractory (R/R) Waldenström's Macroglobulinemia (MW), A Filo Trial: Results of the Intermediary Analysis of the Induction Phase (Abstract 346) – The French Innovative Leukemia Organization (Filo) initiated a clinical trial to evaluate the efficacy and safety of the oral PI3K inhibitor idelalisib (Zydelig) in combination with the anti-CD20 monoclonal antibody obinutuzumab (Gazyva) in patients with relapsed/refractory WM. Idelalisib was given at 150 mg twice daily, and obinutuzumab was administered intravenously. After six cycles, idelalisib was given alone as maintenance therapy for two years. Fifty patients were enrolled; with a median follow-up of 18.3 months, the overall response rate was 90% and the major response rate was 76%. Median progression-free survival was 25.2 months. Adverse events that occurred most frequently were hepatotoxicity (liver injury), diarrhea, skin rashes, infections, neutropenia (low neutrophil count), anemia, and thrombocytopenia (low platelet count). The trial is ongoing with 29 patients who started idelalisib maintenance.

Waldenström Macroglobulinemia with Excess Plasma Cells: Is It a Distinct Entity? (Abstract 1532) – The Mayo Clinic in Rochester examined WM patients seen at its facility between January 2001 and December 2017 with a bone marrow biopsy and a corresponding serum free light chain examination at diagnosis. The percentage of lymphocytes and plasma cells in the marrow biopsy was determined. Patients with 10% or more plasma cells were considered to have WM with excess plasma cells, while those with less than 10% plasma cells were considered to have lymphocytic WM. Of 228 evaluable patients, 147 had excess plasma cells. These

patients had lower bone marrow infiltration at diagnosis, but the rate of symptomatic hyperviscosity was higher during the disease course. The time-to-next-treatment was shorter for these patients (2.6 years) than those with lymphocytic WM (4.5 years), although it did not reach statistical significance. There was also a trend towards shorter overall survival in patients with excess plasma cells. In those for whom treatment data were available, the rate of partial response or better with frontline therapy was lower in those with excess plasma cells, although the excess plasma cell cohort had a higher rate of partial response or better with proteasome inhibitor-based or immunomodulatory-based combinations than with other therapies for frontline treatment.

Waldenström Macroglobulinemia in Young Patients Treated in the Modern Era: A Multi-Institutional Italian Study (Abstract 1539) – Less than 10% of WM patients are diagnosed younger than 55 years of age, and few studies have addressed their outcomes in the era of immunotherapy and targeted therapies. This Italian study analyzed 129 patients diagnosed at a median age of 50 between 2000 and 2018. With a median follow-up of 5.6 years, 59% had been treated. Frontline therapy included rituximab (Rituxan) in 93% of treated patients, mainly in combination with chemotherapy. The overall response rate for first line therapy was 85%, and the median progression-free survival afterward was 76 months. During follow-up, 5% developed a solid cancer, and 2.6% a second blood cancer. The five-year and ten-year overall survival rates from diagnosis were 99% and 96%, respectively. The overall survival of young WM patients was not significantly reduced compared to a control group from the general population matched to age, sex, and calendar year.

*The **PFS risk score** showed **consistent results** whether evaluating relapsed/refractory or previously untreated patients on **ibrutinib**.*

Clinical and Genomic Factors Are Predictive of Response and Prognostic of Progression-Free Survival in Patients with Waldenström Macroglobulinemia Treated with Ibrutinib (Abstract 2823) – The Bing Center for WM at Dana-Farber Cancer Institute assessed WM patients treated with ibrutinib (Imbruvica) monotherapy at its institution from January 2012 through March 2019. Patients with Bing-Neel syndrome were excluded, resulting in a total of 252 patients included in the analysis. MYD88 L265P and CXCR4 mutations were detected in 98% and 38% of patients, respectively. At six months, 71% of patients attained a partial response and 17% a very good partial response. Worse outcomes were seen

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with CXCR4 mutations and serum albumin levels less than 3.5 g/dL. A PFS risk score was designed using both CXCR4 mutational status and serum albumin, which divided patients into three distinct risk groups: low risk (no risk factors yielded 5-year PFS of 81%); intermediate risk (one risk factor yielded 5-year PFS of 51%); and high risk (both risk factors yielded PFS of 25 months). The PFS risk score showed consistent results whether evaluating relapsed/refractory or previously untreated patients on ibrutinib.

CXCR4 Mutational Status Does Not Impact Outcomes in Patients with Waldenstrom Macroglobulinemia Treated with Proteasome Inhibitors (Abstract 2830) – The Bing Center for WM at Dana-Farber Cancer Institute evaluated the impact of CXCR4 mutations and mutation subtypes on response, progression-free survival, and overall survival after frontline treatment of 76 WM patients in clinical trials who received proteasome inhibitor-based therapy, including bortezomib (Velcade), carfilzomib (Kyprolis), or ixazomib (Ninlaro). In the combined analysis, 36 patients did not have CXCR4 mutations, and 29 did; of those who did, 16 had nonsense and 13 had frameshift mutations. In 11 patients, CXCR4 mutational status was not determined. This study showed no detectable differences in the major response rate at six months and 12 months in patients with and without CXCR4 mutations. Frameshift CXCR4 mutations were associated with better progression-free survival than nonsense CXCR4 mutations. After frontline treatments, patients with CXCR4 mutations had a 10-year survival rate of 75% versus 83% in patients without CXCR4 mutations, which was not deemed statistically significant.

Preliminary Results from a Phase I Study of SHC014748M in Patients with Relapsed or Refractory Indolent B-Cell Lymphomas (Abstract 4000) – SHC014748M is an oral inhibitor of PI3K-delta, and this Chinese trial of the drug included 38 patients with relapsed or refractory indolent B-cell lymphomas, three of whom had WM. The most common adverse reactions were neutropenia (low neutrophil count), fatigue, thrombocytopenia (low platelet count), diarrhea, pneumonia, cough, lymphopenia (low lymphocyte count), anemia, and rash. One of the WM patients had a partial response and two had a minor response to treatment.

Long-Term Follow-up of Idelalisib Monotherapy in Patients with Double-Refractory Marginal Zone Lymphoma or Lymphoplasmacytic Lymphoma/Waldenstrom's Macroglobulinemia (Abstract 4006) – This multicenter international abstract focused on LPL/WM and marginal zone lymphoma patients who were part of a Phase 2 trial for indolent non-Hodgkin's lymphoma refractory to both rituximab (Rituxan) and an alkylating agent. These patients received the oral PI3K inhibitor idelalisib (Zydelig) at 150 mg twice daily until disease progression or intolerance. Of the ten LPL/WM patients included in the study, the overall response rate was 80%, with a median duration of therapy

*The median age at **diagnosis** was 64, with a **third of patients** diagnosed under the age of 60.*

of 29 months. The median progression-free survival was 22 months. All patients had at least one adverse event, which included neutropenia (low neutrophil count), diarrhea, elevated liver enzyme called alanine aminotransferase (ALT), weakness, and pneumonia. All patients eventually discontinued treatment, primarily because of disease progression or an adverse event.

An Analysis from the WM UK Rory Morrison Registry: Waldenström's Macroglobulinaemia Patient Demographics, Disease Characteristics and Evolving Treatment Choices (Abstract 4016) – The Rory Morrison Registry in the United Kingdom was searched for all patients with a diagnosis of WM, and 671 patients were identified, with years of diagnosis from 1978 to 2019. The median age at diagnosis was 64, with a third of patients diagnosed under the age of 60. Peripheral neuropathy was seen in 74 patients at diagnosis; other manifestations at diagnosis included cryoglobulinemia in 26 patients, amyloidosis in 12 patients, and Schnitzler's syndrome in 7 patients. Of these patients, 440 (65.6%) had received treatment, with a median time from diagnosis to treatment of two months. At treatment, 47% of patients had a hemoglobin less than 100 g/L (10 g/dL). Hyperviscosity was the indication for treatment in 24.8% of patients, fatigue in 21.6%, and peripheral neuropathy in 9.8%. In the past decade, the most frequent first line treatment regimens were, in order: DRC (dexamethasone, Rituxan, Cytoxan); R-bendamustine (Rituxan, bendamustine); Rituxan monotherapy; R-CHOP (Rituxan-Cytoxan, hydroxydaunorubicin, Oncovin, prednisone); bortezomib (Velcade) regimens; and varying combinations. Before 2010, chlorambucil, R-CHOP, and FC (fludarabine, Cytoxan) were the most frequently used first line treatments. BTK inhibitors have become the most commonly used second line therapy since 2010. Of the total number of WM patients identified, 118 were deceased. Five-year and ten-year overall survival rates were 90.5% and 79.4%, respectively. There was a trend towards somewhat poorer overall survival among MYD88 wild-type patients, while CXCR4 status did not impact overall survival.

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2020 Vision: A World Without WM

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The IWMF Ed Forum features the world’s leading medical experts in WM research and clinical care. 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.

GET AN EARLY START!

Hit the road running: ALL Ed Forum attendees are invited to a continental breakfast on Friday, June 5, with two different Early Bird Sessions offered. Choose between “Getting to Know WM: Basics & Beyond” OR “A Deeper Dive into WM Genomics.”

ED FORUM FAVORITES!

Don’t miss our classic highlights, including: asking your questions for the lively and ever-popular “Ask the Doctor” panel, rubbing elbows at the President’s Reception, enjoying the festive Welcome Dinner alongside IWMF Trustees and world-class physicians, and exploring an array of diverse breakout sessions addressing multiple issues and hot topics. There is truly something for everyone at the IWMF Ed Forum.

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IWMF DOC STAR: DR. ASHER CHANAN-KHAN

AS TOLD TO RON TERNOWAY



Dr. Chanan-Khan and his son Matthew

Dr. Asher Chanan-Khan is a clinician, researcher, and former chair of Hematology and Oncology at the Mayo Clinic Jacksonville, in Florida. He specializes in the treatment of multiple myeloma, chronic lymphocytic leukemia, and Waldenstrom's macroglobulinemia (WM). He led the project which developed RPCI-WM1, one of the first cell lines to be derived directly from a WM patient.

Chanan-Khan was born in Lahore, Pakistan, where his father's career in the Air Force offered many opportunities for travel within Pakistan and abroad. His paternal grandmother Angelina, "a devoted, selfless, caring, and compassionate physician," was Asher's inspiration to become a doctor. "She was a pioneer of her time, as very few women had the courage to go into medicine, let alone practice in remote, under-served areas of the country. She left her home at odd hours, traveling great distances in a horse and buggy to care for the poorest people in the villages. She was in her 80s when she passed, but to the very last week she served her patients, never complaining and never shying away from sharing the talent God had blessed her with."

Chanan-Khan completed his medical training at Allama Iqbal Medical College, Punjab University. His best friend's father, Professor Dr. Hannan Nagi, inspired him to excel in the field of medicine and to serve patients, irrespective of who they are or what they have to offer. "Dr. Nagi's stellar career in academia directed my path to be a researcher and teacher, mentoring the next generation of cancer researchers in the USA."

Chanan-Khan completed his internship and residency at the Harlem Hospital Center of Columbia University in New York, followed by clinical and research fellowships in hematology at New York University School of Medicine. "I credit Dr. Kenichi Takeshita for changing my mind and changing my path in life," he said. "I was a fellow in hematology and joined Takeshita's lab for training in translational cancer medicine. Ken trained me how to ask a question, and then how to find a way to answer it. His manner was always subtle, persistent, and intentional. His goal was always to build me up with a gentle nudge, empathy, and encouragement when required, and polite sternness when essential to get me back on track."

RPCI-WM1 is the designation for a WM cell line developed in Chanan-Khan's research laboratory at Roswell Park Cancer Institute in Buffalo, NY. It is one of the only cell lines that was directly developed from patient WM cells without the need of transfection with a retrovirus. *[Editor's note: Transfection can be used to modify the characteristics of a cell line by introducing foreign DNA or RNA into it, often by means of a virus. The absence of a transfecting virus makes the cell line more authentic for researchers studying its genome.]*

*"Her heart was so big, and she
was **never afraid** of the disease."*

"Michelle was a patient of mine whom I took care of for many years. She was an amazing lady. Her heart was so big, and she was never afraid of the disease. When the time came for her to pass, she was adamant to continue the fight beyond her existence. She and her loving husband committed to giving my team her body the very moment she stopped breathing."

The 2:00am call from her husband galvanized the Roswell Park team into action. Her body was immediately transported to the cancer center, where a team of surgeons diligently and expeditiously removed all cancerous tissue, then rushed it to Chanan-Khan's laboratory. A group of dedicated scientists led by Aneel Paulus and Kasyapa Chitta painstakingly

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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

implanted some cancer cells in mice and cleaned and sorted others destined to grow in tissue flasks.

It took several months before the WM cells started growing in the laboratory and in the mice. WM researchers from around the world now have access to the RPCI-WM1 and other cell lines to propel the search for a cure. Novel drugs can be tested in the test tube or in mice prior to launching clinical trials on human subjects.

As a clinician, Dr. Chanan-Khan has a special relationship with cancer patients because he has been one. In 2005, he was diagnosed with thymic carcinoma in the chest. It had invaded his heart membranes, and his doctor predicted a 90% chance of death within two years.

“However, God had other plans for me,” he said. “I went to Memorial Sloan Kettering Cancer Center in New York, which remains one of the best places for cancer [treatment] in the country. I was operated on by Dr. Manjeet Bain, one of the most compassionate, talented, and kind surgeons whom I have ever met in my personal and professional life. I am now 15 years out and still going strong. I felt mortality closely, and this experience made me realize how vulnerable we all are.

*“I learned how **my patients** must
feel when they sit in front of me.”*

“I learned how my patients must feel when they sit in front of me. I can palpate their fears, touch their anxieties, sense their frustrations, and empathize with the flood of emotions that they so bravely grapple with. I try hard to remind myself, every time I see my patient, that I was him or her. I try never to forget those moments of my life, so that I can be a better physician to my own patients, that my eyes extend them the comfort they are searching for, and my ears intently listen to their plight in life. I remind them that God is great, and He has a plan for them. I share that statistics are meaningless to an individual patient, and that miracles abound in God’s world: I am one of those.”

Chanan-Khan has taken on the mission of serving the community beyond the walls of the Mayo Clinic Jacksonville. He was a driving force and an integral part of the team that brought about a unique collaboration, wherein the world-renowned experts of Mayo Clinic Jacksonville have seen patients at St. Vincent’s Hospital Riverside since 2016. “This is so near and dear to my heart, as the patient population at St. Vincent’s represents minority and vulnerable members of our society. They are often of the low socioeconomic strata of our community, and their insurances or personal resources can

limit access to the tertiary care facilities like Mayo Clinic. Through this collaboration I can now also help these patients.”

When asked what advice he gives to newly diagnosed WM patients, Chanan-Khan said, “My most sincere advice is that they should always seek a second opinion. Although the IWMF provides immense knowledge on WM, direct clinical experience with this disease is invaluable. Seeing a WM expert in order to understand the nature and character of your own version of WM is essential in order to formulate a good long-term plan. I typically do not recommend jumping to treatment unless two WM experts agree with such an approach.”

Nearly every IWMF Doc Star in this series has confessed that they do an absolutely terrible job of work-life balance, driven by the demands of their professional calling. Not so for Asher Chanan-Khan, father, coach, barista, advocate, evangelist, musician, humanitarian, and healer.

“My son (Matthew, age 10) has become an amazing source of personal development. He has taught me so much and every day inspires me to be a better person. We love our time together. We are avid soccer fans, and he is an amazing soccer player. It is because of him that I became a soccer coach and have my own team.”

On weekends you can find Chanan-Khan doing dishes at Cup of Job in between making specialty coffees and sandwiches for customers. The profits from this café help rehabilitate homeless members of the Jacksonville community.

Or perhaps father and son will be feeding the penguins at the Jacksonville Zoo. Chanan-Khan helps the zoo with animal welfare and other strategic needs that provide opportunities for improved animal care, as well advancing the zoo’s conservation mission.

The final words from the good doctor on life, the Universe, and everything: “I must say I have no work-life balance issues. It all came together when I realized that my medical practice is my most favorite hobby, and that it brings me the most joy (well, I guess, a step after the joy of playing with my son!).

“Being able to tell another human being that life will be OK, and that I will be there all through their cancer journey regardless of the outcome is an amazing privilege that God has blessed me with—it is not work at all!

“I feel complete. My completeness in myself comes from my faith in Jesus; my love for my son, family, and friends; the warmth and commitment I feel for those who allow me to be their physician; the passion of science and quest for the cure; and the cohesiveness of the life I live through all these paths.”

COOKS' HAPPY HOUR

BY PENNI WISNER



Kale salad is part of a healthy diet.

While considering what can be found in farmers markets in January, I landed on carrots and other orange vegetables plus citrus. But my list of column contents says these subjects have been covered too recently. Which leaves, in my mind anyway, greens. Therefore, all these years later, well after kale became a meme and is now boring, it is time to finally discuss raw kale salads. And maybe remind you about kale pesto.

For years, while cooking for the University of California San Francisco Cancer Survivorship Days, I demonstrated a raw kale salad. Over that time, my methods became simplified. First, start with Lacinato or dinosaur kale. It's the one with the long leaves covered with deep "wrinkles" that make it look like thick dinosaur skin. And the kale can be tough so you want to choose the freshest, tenderest kale you can find. This might fall into the too-much-information category, but you do need to like to chew.

Caveats revealed, let's move on to the fun parts of making this salad. First, strip the leaves off the stems. It can give you a great sense of accomplishment and is done in a jiffy; using your hands is much faster than using a knife. The thickest part of the stems has just a thin frill of green leaf on each side. Pinch the stem and strip those off toward the base of the stem. Rotate the stem and strip off the wider part of the leaf, this time toward the tip. The stem will break off where it is finally tender. Rip, rip! And your stem is stripped clean. Save the stems for green smoothies, or chop and braise them, or chop and feed them to your worms for compost.

Now stack the leaves and cut them crosswise into strips. The tougher you think the greens are, the thinner the strips should be. Or, you can simply tear the leaves into small pieces. Drop

the prepared kale into a bowl of water and wash thoroughly, then spin dry.

While you prepare the kale, put a handful of dried cranberries and/or raisins in a small bowl and moisten with balsamic or unseasoned rice vinegar. Leave to soak and soften. You can omit this step if the dried fruits are moist and plump.

Finely chop a small shallot or half a small red onion and a clove of garlic. Put them in a jar with a small spoonful of mustard. Add the vinegar from the soaked dried fruit (if used) or fresh vinegar. You don't need to be very precise with amounts here: start with an approximate several tablespoonsful. Shake very well. Season with salt and freshly ground pepper and shake again. Add about twice the amount of oil and shake again. The mustard should keep the oil in suspension. Dip a leaf of the kale into the dressing and taste. Adjust with salt, pepper, vinegar, oil.

...kale is so sturdy, you can make a huge bowlful and refrigerate leftovers.

Pile the kale in a bowl and pour far less of the dressing over it than you think you might need. The salt in the dressing begins to wilt the kale, and I cannot count the number of times I've overdressed the salad. You don't want to do that, believe me. Toss well with your hands, tongs, or salad servers. Add the soaked (or not) cranberries; some toasted, slivered almonds; and toss again. Stop right there if you want a vegan salad. Or add little cubes of sautéed tofu to make a main dish salad. You could add cubes of feta or freshly grated Parmesan. A great thing about this salad is that the kale is so sturdy, you can make a huge bowlful and refrigerate leftovers. It will keep for several days.

You can also change the dressing by using sesame oil (not toasted!), unseasoned rice vinegar, and lots of minced garlic. If you find looking at a bowlful of kale slightly intimidating, cut equal amounts of romaine as kale, and toss it all together. Romaine is sturdy but less so than kale, so your salad will not last as long.

Here are a couple of reminders of other things to do with kale: make your own kale chips since, it seems to me anyway, that half a bag of commercially produced kale chips is dust by the time it gets home. If made at home, they can be flavored to your liking: tossed with coconut oil or olive oil before roasting; seasoned with salt and Parmesan or nutritional

Cooks' Happy Hour, cont. on page 20

yeast. (Have I confessed to my love of popcorn tossed with salt and nutritional yeast? Now that would be an excellent snack for dark, long, winter afternoons or evenings.)

One of the best ways (as the author here, I control good, better, and best) to take advantage of kale is to blend it into a pesto after a quick blanching in salted water just until tender. Add garlic, salt, pepper, lemon zest, maybe a little lemon juice, a pinch of cayenne, and olive oil. Then toss your pesto with hot

pasta and cubes of roasted squash. You will have the best of winter's offerings all on a single plate.

Oh! About that citrus: here is an amazing and amazingly simple dish: Peel oranges down to the flesh and slice into rounds. Top each with a small spoonful of finely chopped olives (or a spoonful of tapenade) and a sprinkling of finely sliced red onion. Sweet, salt, crunch, and tender all at once.

Our motto: Eat Well to Live Well

FROM IWmf CONNECT: WINTER 2020

BY JACOB WEINTRAUB, MD

We are past the holidays and into the new year. It is time to reassess ourselves and our status and hopes for the coming year. Discussion on IWmf Connect reflects this and more. As always, there are multiple links to human interest articles, scientific studies, and other important issues. Multiple issues are discussed, and even old topics are presented with new twists or just reminders of information we may have forgotten.

*..links to human interest stories that **resonate** with the **WM community** and to issues we deal with on a regular basis.*

Peter DeNardis, IWmf Connect manager and IWmf Trustee, posted links to several items. Some were scientific and clinical studies, and many were links to human interest stories that resonate with the WM community and to issues we deal with on a regular basis.

Peter posted a link to an article by a breast cancer patient who also happened to be a health care reporter for some time before she was diagnosed with breast cancer. The article, titled "I Thought Being a Health Care Reporter Would Make Cancer Easier. I Was Wrong," presents her realization that one doesn't fully grasp the enormity of living with cancer until one is face up against it. Her honesty and fortitude shine through. The importance of being able to rely on a "cancer club" for support and suggestions also shine through in her article, adding weight to our own support group on IWmf Connect.

<https://www.politico.com/magazine/story/2019/11/10/cancer-health-care-reporter-229889>

A subject that is discussed on occasion is how cancer has changed the way we live our lives. Peter posted a link to an article in *Cure* magazine titled "How Has Cancer Changed

the Way Patients Live Their Lives?"

<https://www.curetoday.com/articles/how-has-cancer-changed-the-way-patients-live-their-lives>

Finally, Peter posted a link to an article titled "I am not a fighter because I survived cancer at 19." This is another perspective on living with lymphoma. It helps to read about the experiences of other people, sometimes just to affirm how you approach your own WM, sometimes to get a new perspective on how to deal with the enormity of having WM. Many will recognize a variant of a subject discussed in this forum with regard to how we view our relationship with our own cancer. Do we "battle," live in harmony, or have some other descriptive term?

<https://www.washingtonpost.com/outlook/2019/08/21/i-am-not-fighter-because-i-survived-cancer-nineteen/>

Wanda H posted a link to an article with advice that is relevant for all of us: "What To Say—And What Not To Say—To a Friend or Loved One With Cancer." She felt that perhaps of more importance is the need for cancer patients to become transparent and direct with family and friends, so they can offer the support we each need as individuals. I imagine many of us could write our own list of things we would either like or not like to hear.

<https://www.curetoday.com/articles/what-to-say--and-what-not-to-say--to-a-friend-or-loved-one-with-cancer>

Wanda also posted a link to an article that deals with a subject that all of us have pondered during our WM journey: "'How Do You Really Feel?': A Question to Ask Cancer Survivors" Here a cancer patient shares suggestions on improving the content behind this question.

<https://www.curetoday.com/community/jane-biehl/2019/08/how-do-you-really-feel-a-question-to-ask-cancer-survivors>

Sara W posted that she loves this article. The first time a nurse posed that question to her, she surprised herself by starting to

From IWmf Connect, cont. on page 25

FUNDING THE IWMF MISSION IN 2020 AND BEYOND

BY NEWTON GUERIN, IWMF CHIEF DEVELOPMENT OFFICER

As the new chief development officer, I have joined the IWMF at a very exciting time. We have many great opportunities to impact the lives of people with WM as well as their caregivers. We also face significant challenges. At its August meeting, the IWMF Board of Trustees began a discussion and debate around organizational priorities. It became clear to the IWMF leadership, volunteers, and staff that there was much more that could be done with additional resources and a renewed sense of urgency.

As part of the "Strategic Plan," IWMF Leadership crafted six compelling intentions to articulate where we want to go and how we plan to get there (see page 7 for these six intentions).

The resulting list goes on to spell out crucial objectives, along with specific priorities for 2020. It tells our story to all IWMF stakeholders: patients, caregivers, donors, volunteers, Board members, corporate partners, and the research and medical communities. It talks about big ideas; it's simple to understand, it's optimistic, and it focuses on the future. Like the old saying goes, "Without a good plan, someday will never come."

As the IWMF Board of Trustees and management team undertake the 2020 planning and budgeting process, "Our Compelling Intentions" provides guidance and direction and reminds us that our ability and capacity to undertake these important goals is dependent on how well we "significantly increase and diversify our sources of funding to support our mission" ("Our Compelling Intentions" #6). Determining specific performance metrics to measure our results and tell us how we're doing is an important next step. Specifically, in the area of resource development in 2020, we will look at four areas that could significantly increase our revenue:

- **Corporate/pharmaceutical partnerships:** As a direct result of Chair of the IWMF Board of Trustees Carl Harrington's extensive outreach efforts and relationship building with our corporate partners, revenue from these partnerships in 2019 will exceed \$300,000.
- **Traditional donor development:** We must implement relationship enhancement strategies and practices with donors at all giving levels.

- **Online giving and social media outreach:** We have engaged a website design firm to do a complete redesign of our existing IWMF website. Our new website will focus on patients and caregivers as the primary audience and will promote social media interaction. The new design will balance messaging to help reinforce the importance of increasing and diversifying our sources of funding to support our mission.
- **Creation and launch of an IWMF Signature Event:** To maximize its impact on the IWMF, this event should be memorable, low cost and low risk, result in attracting new volunteers and donors, and enhance brand awareness.

With each of these resource development strategies, we will continue our strong commitment to good stewardship of our donor dollars. We are extremely proud of our ratings with watchdog agencies. Our reputation is one of our greatest assets.

Like any good plan, "Our Compelling Intentions" encompasses four areas of focus that any well-run organization must address:

- Communicating and delivering the mission
- Developing human and financial resources
- Managing business practices
- Fostering growth and innovation

Good leaders and good fundraisers have a vision for their organization and can articulate it effectively. Now we have the framework to help make that happen. Going forward, it is critical that we tell our story to all IWMF stakeholders on a regular basis. Our donors expect to hear from us about the progress we are making, the challenges we are facing, as well as new opportunities as they arise.

As I move forward in my new role as CDO, I welcome your advice and guidance along the way. Please reach out to me whenever you want. I can be reached by email at nguerin@iwmf.com or by telephone at 941-927-4963.

Your Legacy is Important

That's why you take time to plan and provide for the people and causes that mean the most to you. If you've included our organization in your will, trust, or other planned gift, please let us know. We want to honor you with membership in our legacy society, and more importantly, we want to make sure you're thanked today, and your legacy is honored tomorrow.

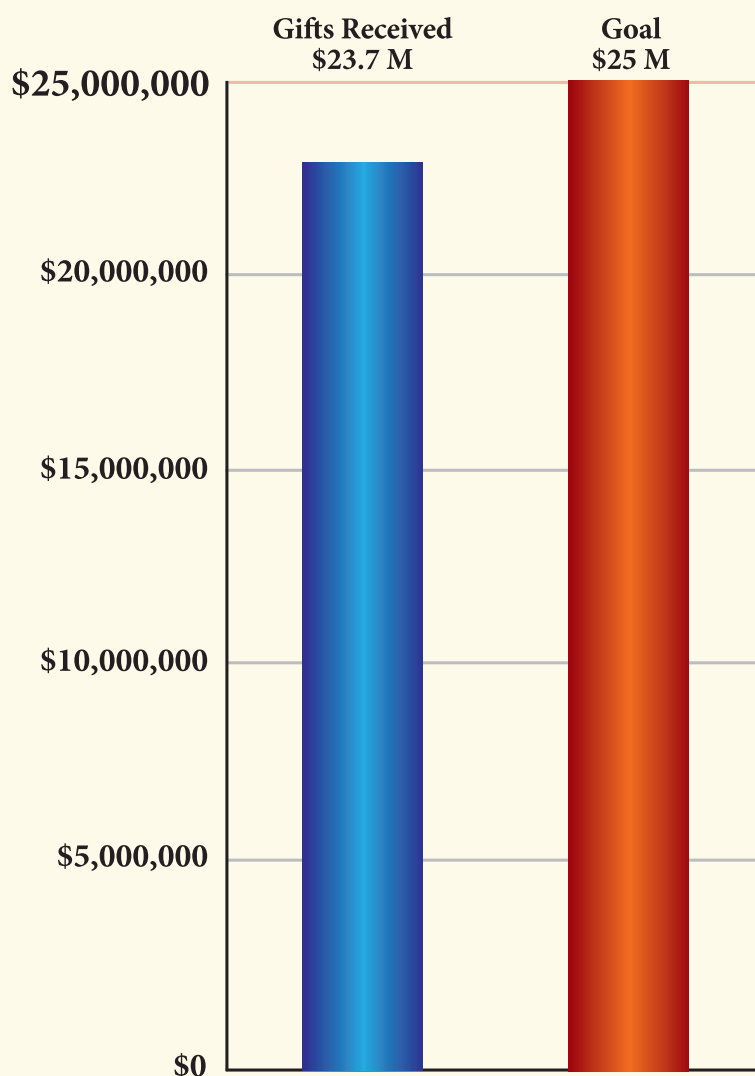


Ending the Year Well

Get a head start now on your year-end tax planning. Do you own an IRA and/or a 401(k)? Are you age 70½ or older? Do you expect to be in a higher tax bracket?

There are several ways that you can shift tax dollars to charitable dollars and support the IWMF's mission at the same time. These include a zero tax gift and sale, a donor-advised fund, the outright gift of an asset, or an IRA charitable rollover. As you think about tax planning, this may also be an appropriate time to think longer-term about a legacy gift to the IWMF.

Imagine a Cure Campaign Progress Report as of December 20, 2019



The Ben Rude Heritage Society for Legacy Gifts to the IWMF

The IWMF has a special club for those who name the IWMF as a beneficiary of their estate plan—the Ben Rude Heritage Society. No gift is too small for membership! If you have already made a provision for the IWMF in your will, trust, life insurance, or as a beneficiary of your IRA, please let us know, and we'll enroll you in the Ben Rude Heritage Society. You can remain anonymous if you prefer. Either way, we would like to say thank you and keep you in the loop with all things IWMF-related. For more information on estate gifts or to join the Ben Rude Heritage Society, call or email the IWMF office or contact our **Chief Development Officer Newton Guerin at 703-986-3549 or nguerin@iwmf.com**.

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 10 to 12 research projects underway with new projects under consideration each 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

K. Edward Jacobi Research Fund of the IWMF

Ed and Toni Saboe Research Fund of the IWMF

Carolyn Morris Research Fund of the IWMF

Yang Family 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 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 please contact Newton Guerin, IWMF Chief Development Officer, at nguerin@iwmf.com or 540-308-1231.

Ben Rude Heritage Society Roster

*Deceased ♦Founding Member New in 2019

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

cry, even though she does not cry often. However, something about a person wanting to be there enough to scratch below the surface made her feel relieved and cared for.

Finally, two articles posted by Peter generated a long discussion about exercise and fatigue in people with cancer. Generally, depending on our disease state, exercise can be difficult, but any type of movement is helpful.

“Exercise on quality of life and cancer-related fatigue for lymphoma survivors: A systematic review and meta-analysis.” This is an abstract; for the full article, contact Peter Denardis at pdenardis@gmail.com.

<https://www.mdlinx.com/journal-summaries/exercise-randomized-controlled-trial-quality-of/2019/10/24/7582956/?spec=oncology>

“Cancer care: Are personalized exercise prescriptions the future?”

<https://www.medicalnewstoday.com/articles/326765.php>

Glenn C noted that his fitness center started a class on indoor cycling for cancer survivors. The instructor is a physician who thought of this class and persuaded the city parks and recreation department to let her run the class. The instructor provides lots of introductory instruction to people who are unfamiliar with or are intimidated by bicycle spin machines. She also provides alternatives for people who don't feel up

to particular sections. Everyone seems to enjoy it so far and thinks it is valuable.

Betty Ann B added that she is 77 and starting her eighth month of chemo and has been going to a yoga class twice a week for several years. Going to these classes has helped so much during treatment. The class is called “Gentle Yoga” and is free. It is sponsored by the Silver Sneakers Association. Most gyms have these classes. She feels that as we age, it helps to stay flexible and to be able to set and achieve small strength and flexibility goals.

However, **Pat G** commented that cycling is great exercise, but it is not weight bearing. As we age, it is particularly important to do weight bearing exercise. Walking, running, hiking, dancing, stair climbing and weight lifting are all weight bearing exercises. Pat walks her dog half an hour daily and she is trying to get back to the gym two to three times a week to walk on the indoor track and lift some weights. She has more fatigue now and says it is important to do as much as we can.

Karen R agreed that we “just gotta keep moving.” Exercise not only strengthens our bodies, but it releases endorphins that can help improve our mood. As we all age, it can be tougher to get motivated because many develop arthritis and

From IWMF Connect, cont. on page 26

Torch Toon by Linda Pochmerski



If there are multiple options offered, you may want to take the lead, maybe share in the decision making, or let others decide. It's your choice.

other ailments. She may hurt in places in the morning, but once she gets moving, everything loosens up and she feels better. When her energy levels are low, she still tries to take at least a 20-30 minute walk, though at a slower pace than usual, and she always feels better after. She also found that when she was in treatment, she felt better after taking a walk, even at a slow pace.

Finally, **Elizabeth D** echoed other comments. She is now in treatment. After the first round she was fatigued, depleted, and depressed. Her biggest concern about exercising was to find a clean and safe place to strengthen between infusions, so her local gym was off the table. She was fortunate to have a nearby physical therapy establishment that she visits three times a week to build her strength. Her insurance pays for these visits, and she works with professionals on core, balance, and strength training. Also, there is less worry about staying safe and clean.

***Ibrutinib** has become a mainstay of WM treatment.*

Ibrutinib (Imbruvica)

Ibrutinib has become a mainstay of WM treatment. However, as it gains wider use, some adverse effects are becoming apparent that were not previously reported. The discussion here relates to gastrointestinal (GI) symptoms related to WM itself, as well as to treatment with ibrutinib.

Richard M asked about this med. He will be starting ibrutinib soon and he understands that a high percentage of people at first have diarrhea and nausea, and then it gradually disappears. He asked for experiences and ways to deal with this problem.

Barbara posted that she has been taking ibrutinib for three years. She had diarrhea and some nausea off and on for over two years. Imodium helped a lot; she took it only when needed.

Pavel I posted an article that presented a case report of a man who presented with WM who initially had chronic watery diarrhea. The diarrhea resolved when his WM was treated with bendamustine and a steroid, budesonide, though it returned in two months while the man was still taking budesonide. After further treatment for WM, the diarrhea resolved. A conclusion is that WM itself can present with GI symptoms.

Another member posted about having had many GI-related issues. A full GI workup has been negative for intestinal disease. Rituxan treatment seems to help.

Marlene D stated that she has been complaining of GI issues for years, only to be told it is not related to her WM by both her primary care doctor and her oncologist.

Cleo L added that she has been taking Imbruvica 420 mg since April 2019 and has been complaining of chronic stomach issues, heartburn and pains. Her doctor keeps asking if she has diarrhea, but she does not. Doctor then says symptoms has nothing to do with Imbruvica. She will start a lower dose of Imbruvica next week.

Patrick N reported that his wife's major complaint leading to her WM diagnosis was severe GI problems. She has continued to have stomach issues while on ibrutinib therapy.

IWMF Trustee **Dr. Tom Hoffmann** posted that all of the stomach and also skin issues that have been discussed in the past are due to the inhibiting effect of ibrutinib on our epithelial growth factor receptor (EGFR). While this is good for our WM, lowering our epithelial growth factor results in multiple skin and mucosal tissue problems, from our nose to the end of our colon. Tom cited an article that said this blocking of EGFR could be the cause of adverse effects like diarrhea.

Finally, we occasionally get into discussion about the group itself and best ways to communicate, as well as civility.

*...there is something **truly special** about us that
fosters amazing **sharing** and **candor**.*

During one such discussion, **Peter S** commented that there is something truly special about us that fosters amazing sharing and candor. Without IWMF Connect, our ability to make sense of the jargon and put context on rosy reports of response would be hobbled.

Brad S added that three years ago, his primary care physician, who was both conscientious and a personal friend, forwarded to Brad an article with the latest findings about ibrutinib. Brad told him the same information in the article had been a hot topic on IWMF Connect, and added a couple of other insights he had learned here. His doctor commented that he was impressed, and that Brad and the discussion group know more about WM than most doctors.

Barbara L posted that the IWMF and forums like this one are islands of information and knowledge on Waldenstrom's amidst a sea of detritus that is the Internet. There is literally nowhere that one who is newly diagnosed can reliably turn to other than these groups to receive correct information on our disease.

From IWMF Connect, cont. on page 27

As always, the discussions and links here represent only a small portion of the wide range of topics discussed. Everyone is invited to join in the group. We hope you will participate, but just “lurking” and reading on the sidelines also are

welcomed. 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.

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

PLEASE NOTE

Contact information for all support groups is available at www.iwmf.com/get-support/us-and-international-support-groups

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



N. California Group members at the November meeting in Napa, CA

CALIFORNIA

Northern California

In early November, the group met at the Methodist church in the town of Napa. Sixteen attended, three of whom were diagnosed in 2019 and one within two weeks of the meeting. Most of the meeting time was devoted to sharing of experiences and learning from each other. Marilyn and John Tinsley reported on the 2019 IWMF Educational Forum in Philadelphia. Support group members were encouraged to attend the 2020 Ed Forum in Seattle. At the close of the meeting, members expressed appreciation for the opportunity to meet and network with others affected by this rare disease.

Orange and San Diego Counties

The group honored Kathleen Battle, RN, who led the group for some years and died in September 2019. The memorial was followed by a lecture about “Nutrition and Cancer” by Patrick Pablo, RD, from the University of California, San Diego. He focused on fatigue, diet, and food safety when immunity is low. His lecture ended with a “theory in action”



Former San Diego Support Group Leader Kathleen Battle, RN, died in September.



San Diego Support Group members

Support Group News, cont. on page 28

piece: his handmade power bites and green smoothies—plus recipes.

COLORADO/S. WYOMING

It was 75 degrees and sunny on a gorgeous late fall day in Colorado when 57 WMers and their caregivers gathered at Presbyterian/St. Luke's Hospital in Denver to hear Dr. Jeffrey Matous of the Colorado Blood Cancer Institute speak. He is a regular at Colorado Support Group meetings and always draws a big audience. The meeting opened at 9:00am for socializing and connection with others. Eight new patients arrived with lots of questions and received support from more experienced members. The breakfast pastries, fruit, and coffee provided by the Leukemia & Lymphoma Society were much appreciated by all. Announcements were made about upcoming WM learning events: the Rocky Mountain Blood Cancer Conference on April 4, and the IWMF Ed Forum in Seattle in June. Since Dr. Matous is originally from Seattle, he will definitely be attending and making a presentation. Dr. Matous began his talk by reviewing what has changed in the last year, both on the diagnostic and treatment fronts. WM

*WM patients can currently be sorted into four possible “**buckets**” based on **genetic markers**.*

patients can currently be sorted into four possible “buckets” based on genetic markers. Doctors can better predict an individual's success with various drugs and make more educated guesses of symptoms, etc. Testing capabilities are limited and not done on a regular basis unless the patient must make a treatment decision. Factors governing treatment decisions garnered much general discussion. The financial impacts were also much discussed, as well as how to find grants to defray costs. The military veterans in the room had a lively discussion about getting VA disability for WM, and most felt they were getting or are almost ready to receive disability payments from the government because of their WM diagnosis. They helped each other understand how to apply. Dr. Matous showed everyone the IWMF website and went to each appropriate video to show where all the answers are to each question or topic. Members recommended their favorite videos to watch, especially for those who have not attended an IWMF Ed Forum. A lively Q&A continued until all questions were answered. The newest members were surprised that such an informative group exists and left with lots of contacts to help them along their WM journey.



Connecticut Support Group members

CONNECTICUT

The Connecticut Support Group met the first Sunday of November at the Westfarms Mall community meeting room in Farmington, CT. A half-hour informal mingle and a pizza lunch provided by a nearby shop opened the meeting. After lunch, the group watched the most recent video presentation by Dana-Farber Cancer Institute's Dr. Jorge Castillo, called “The Revolution in WM Treatment and What's on the Horizon.” It was filmed at the IWMF's 2019 Ed Forum in Philadelphia. The presentation was very informative and encouraging, especially as no one had attended the Ed Forum in person. Following a short break, the members shared individual WM stories and treatments. Approximately 20 attended, equally divided between patients and supporters. The next meeting is planned for May 2020.

FLORIDA

Sarasota

On Saturday, November 2, the Sarasota group held its second meeting. They invited board-certified hematologist and medical oncologist Dr. Rachid Baz from Moffitt Cancer Center as the guest speaker. (He is listed in the IWMF Physicians Directory.) Dr. Baz spoke at length about trending treatments for WM, shared updates about WM symptoms and diagnosis, and led a lively Q&A session. Thirty attendees, some from as far away as Canada, were delighted to connect with a WM expert. Several local businesses donated refreshments, which



Dr. Rachid Baz (center, white shirt), Cleo Lowe (center, flowered shirt), and Michelle Postek (far right) all collaborated to make the Sarasota WM meeting a success!

Support Group News, cont. on page 29

were enjoyed by all. A special thanks to Cleo Lowe, IWFM member, who graciously arranged the event location at her community's clubhouse, which overlooks a beautiful marina in Osprey, FL.

INDIANA

Long-time Indiana Support Group Leader Gayle Backmeyer chaired her last meeting in October. Thirteen members (nine of them who have attended since the group's first meeting in 2011) gathered for a discussion on palliative and hospice care. Information was also presented on Indiana state laws regarding advanced directives and power of attorney for health care decisions. Although not legally binding in Indiana, the advance directive legal document, "Five Wishes," was distributed to participants as a guide for end-of-life planning. The topic generated much discussion, and participants shared their experiences and resources. It was agreed that this was important information for everyone. Plans are to take the winter off and reconvene in the spring with a new group leader.



Massachusetts Support Group members with Dr. Jorge Castillo (center), of Dana-Farber Cancer Institute

MASSACHUSETTS

Eastern Massachusetts

The group is indeed lucky to be so close to Dana-Farber Cancer Institute. In fact, meetings are held at Dana-Farber and are organized with the help of Chris Patterson of the Bing Center for WM located there. In June, Dr. Jorge Castillo spoke to the group about advances in the ability of WM doctors to assess and recommend treatments tailored to individuals rather than to treat all patients as if WM presented exactly the same way for each. In September Dr. Zachary Hunter of Dana-Farber updated the group on the genomics of WM. He has been in the forefront of the research arm for WM at Dana-Farber for years. Both he and Dr. Castillo have a gift for explaining things in ways that "ordinary" humans can understand. All meetings begin with sharing and welcoming of new members. And there are always plenty of snacks. Some people confess that they come for the cookies made by group leader Eileen Sullivan. (Her current "go to" cookbook is *Flour*, by Joanne Chang, a local Boston bakery owner.

Eileen will adjust the recipes somewhat, in an effort to make them "relatively healthy," and there is always fruit as well.)

MICHIGAN

Twenty-four people (including seven first timers) from the Lower Eastern Michigan Support Group met in August at the Henry Ford Hospital West Bloomfield location. Two hours flew by while members shared their journeys with Waldenstrom's. For the mid-November meeting, Bob Jenkins secured his workplace in Plymouth as the location for the 13 members who attended. April 19 from 2:00-4:00pm is the scheduled date for the next gathering. Dr. Christine Ye will return as the speaker, and she plans a far-ranging Q&A. She is a hematologist-oncologist at University of Michigan Hospital and has presented previously. The meeting is currently planned to take place in Ann Arbor. Details will be available later.

*"When I was **diagnosed** with Waldenstrom's in 2015, one of the **first things** I did was to **search online** for information about the disease. This led me to the **IWMF website**..."*

Jennifer Goldman has joined Janice Wheeler as the group's co-leader. She explains how she came to be involved with the IWFM: "When I was diagnosed with Waldenstrom's in 2015, one of the first things I did was to search online for information about the disease. This led me to the IWFM website where I was linked to the then Michigan support group leader. He returned my call within 24 hours and provided me with all the basic information I needed to begin to understand my diagnosis and how to approach it. Since then, I have made sure to attend as many support group meetings as possible, so that I can share my experiences and learn from others. The support group leader was such a fundamental part of my early journey. As time went on and I learned more about the disease, the research, and the treatments, I wanted to help others the way I had been helped. When Jan (my co-leader) asked if I wanted to join her, it was an easy decision! I grew up in Baltimore and moved to Michigan, where I married my husband Ezra in the late 1990s; we have three children. I have a background in counseling psychology but have taken the last several years off. During that time, I became very active in legislative advocacy on behalf of patients with cancers and rare diseases. I am planning to return to school in January to pursue a master's degree in public administration with a concentration in health and human services. My hope is to use those skills to improve the lives of patients in Michigan and across the country."

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MINNESOTA/WESTERN WISCONSIN

The group changed its format for the October meeting. Members broke into two groups (12 patients in one group, six care partners in the other). This format provided the opportunity for more candid sharing of the unique experiences and concerns of each group. As different as each situation is, there is also common ground. These meetings reinforce the importance of drawing on the excellent resources that exist, including one another. After the separate discussions, the group reconvened for a little more social time before adjourning. The next get-together is planned for the spring.

NEW MEXICO

Santa Fe/Northern New Mexico

September's inaugural meeting drew attendees from Santa Fe and Albuquerque. The second meeting featured Dr. Andrea Teague, oncologist and hematologist with Christus St. Vincent Cancer Care, a division of Christus St. Vincent Hospital in Santa Fe. Dr. Teague treats WM patients as well as those with other blood cancers. She discussed the differences and similarities in WM patients and their symptoms, when to treat, and the various treatments she uses in her practice, and she followed with Q&A time. Future speakers will include Karen Gano, LCSW, an oncology social worker; other speakers will discuss finances and insurance.

*"The treatment has **helped me** so much that I decided it is **time to begin** a local group."*

Pat Getz volunteered to start and lead the group in summer 2019. She says: "I discovered the IWMF so long ago I can't remember how I found out about it. But once I did, it became my lifeline. I had hoped for a local IWMF support group, but there was none, and for a long time I was not well enough to even think of starting one. Then, I began a new treatment I first learned about by reading IWMF Connect posts, following the reported research developments, and attending the IWMF Ed Forums. The treatment has helped me so much that I decided it is time to begin a local group. I have an MSW in clinical social work, several therapy specialty certifications, and worked in the mental health field many years ago. I've also worked as a realtor, an insurance broker, a New York model (back in the day), and was a volunteer for the internationally active Greyhound Protection League and Greyhound Companions, a local New Mexico greyhound rescue and adoption organization. When I was no longer able to work because of worsening WM complications, I volunteered for local American Cancer Society events, the Christus St. Vincent Hospital Foundation galas, a Santa Fe cultural center (The Lensic), the Santa Fe Animal Shelter events, and several

music and art organization events. My life companion is my greyhound Galina. She is the only one who lives with me as my two sons are living in San Diego and Bangkok, Thailand. When I wake each morning, I grab a cup of black coffee and bring it and my laptop to my sofa where I read the morning's news, spend an hour or so reading the latest IWMF Connect posts, and go to the links provided to learn about recently published research articles. What would round all this out? A Santa Fe Support Group for Wallies! There is so much about our illness to learn and so much each of us might share with others who know how unique this illness can be and are looking for information and support. I am so looking forward to this."



Eastern NY Support Group members with Dr. Jorge Castillo and his children in Lake Placid.



Dr. Jorge Castillo meets informally with members in Lake Placid, NY.

NEW YORK

Eastern NY/Western New England

Technology helps spread the good word: for the group's November meeting featuring Dr. Jorge Castillo, some members used the video conferencing application Zoom to join the meeting, making Dr. Castillo's presentation available live worldwide. IWMF viewers from as far as the Netherlands participated. Those viewing it live were even able to connect with the group at Lake Placid, NY, and submit questions.

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Members of Western NY Support Group

The video is still available for those interested in seeing the presentation. It might have been the first use of this platform for WM meetings and will not be the last.

Rochester, Western and Central NY

Members enjoyed lunch and catching up with each other at the fall meeting on the Nazareth College Campus in Rochester, NY. As the group continues to grow, members find the opportunity to share their stories and hear those of other WMers to be most valuable. Time flew as members engaged in asking questions of one another, offering advice, and sharing information. A number of topics were touched upon, several prompted by a summary of Dr. Castillo's presentation in Lake Placid to the Eastern NY Support Group. Winters in the Rochester area have been considerably milder in recent years, so the group plans to meet again in early January.



Dr. Danielle Brander (right) has the attendees' attention for her response to a question at the meeting in Durham, NC.

NORTH CAROLINA

Quite a few participants came to a summer get-together in Durham, NC, to hear two speakers. Dr. Danielle Brander,

hematologist-oncologist, and Jennifer Snyder, nurse practitioner, both from the Duke Cancer Center, did an outstanding job answering tough questions. Questions asked were about trials, new drugs, IVIG infusions, and doctor/patient treatment procedures.

EASTERN OHIO/WESTERN PENNSYLVANIA/WEST VIRGINIA

On a late September afternoon, members met at the home of Marcia and Glenn Klepac in Pittsburgh for an informal meeting and potluck. The afternoon began with all enjoying the delicious lunch while catching up with each other. The conversation's focus then turned to WM and the experience of living with this rare disease. Although each patient must deal with his or her own unique WM situation, all agreed that treatment decisions are difficult and require careful consideration guided by expert opinion. Common quality of life issues identified among members were neuropathy and fatigue, which triggered discussion of managing these problems with medications and/or supplements, nutrition, and exercise. Thoughts about the difficulty in accepting activity adjustments due to fatigue were shared. Members reflected on the challenging goal of keeping WM in perspective while enjoying life and offered their insights and personal strategies. The afternoon of support and sharing ended on a high note with special desserts!

OREGON/SOUTHWEST WASHINGTON

On a sunny, warm Sunday in early September, Oregon/Southwest Washington Support Group members drove along the gorgeous Columbia River Gorge and through the Oregon countryside to meet up with fellow Waldenstrom's friends and caregivers at the lovely woodland home of Cindy Fahey

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OR/SW WA Support Group Co-leaders Marie Navarra (front row, second from left), Joel Rosenblit (front row, first on right), Cindy Jordan (standing on left), and hostess Cindy Fahy (middle row, first on right)

and husband, Bob Jansen. Their cozy home and property were pleasant changes from window-less conference room meeting locations. After feeding the group a nutritious lunch, Cindy gathered the group outside on the deck to share sunshine and individual WM stories and treatment paths. Three new WMers joined, which gave everyone an opportunity to offer knowledge and support. The group benefits from the membership of several former nurses. They help navigate medical terminology and “doctor speak.” Everyone chimes in with caring and empowering advice for treatment plans and questions to ask one’s personal medical team. What is always difficult, however, is learning of a complication in a WM friend’s health situation. The group is thrilled that the 2020 Ed Forum is on the West Coast and within easy driving distance for members. The next meeting is planned for mid-January in Lake Oswego, OR.

PENNSYLVANIA

Southeast PA/Harrisburg

A small group gathered in November at Brethren Village to discuss personal and current WM topics. The next meeting is planned for Sunday, March 8, 2020, at the Brethren Village of Lititz.

Philadelphia

On September 8, despite competing with several critical football games being aired that afternoon, over 30 dedicated and passionate WMers gathered for a very special presentation on “Insurance and Financial Essentials for People with Cancer.” Who knew that learning about health insurance could be so much fun? The stellar presenter, Christina Bach, an oncology social worker at the University of Pennsylvania and educational content specialist and psychosocial content editor of *OncoLink*, shared a highly informative PowerPoint presentation. She introduced some fascinating blogs on financial issues (included below), and answered all the group’s burning fiscal questions. Christina handed out a two-page Cancer Insurance Checklist for us to complete (<https://cancerinsurancechecklist.org/>). “Hippie



Plants from David and Michelle Boyer were distributed to Philly members to take home to nurture – always given with a smile, a hopeful message, and lots of love!

Honeymooners” Linda and David Boyer once again gifted everyone with beautiful flowering plants and sweet-smelling lavender. Their uplifting message of hope—nurturing “old seeds” into vibrant, healthy, strong plants—inspires attendees at every meeting.

The *OncoLink* “Health Insurance Webinar Series” has been updated for 2020 and is now available for on-demand listening at www.oncolink.org/insurance. Printable articles focusing on financial, legal, insurance, and employment issues are available at www.oncolink.org/support/insurance-legal-employment-financial-concerns.



Everyone enjoys the annual Chili in Philly get-together.

Crisp autumn air, golden sunlight, and a carpet of freshly fallen leaves were the perfect backdrop as 32 WMers made their way up the path to the 5th Annual “Chili in Philly.” This favorite meeting of the year was held on Sunday, November 6, at the home of Lisa Wise, Philly’s WM support group leader. Old and new Waldenfriends gathered to share their WM experiences, update each other on their latest medical news, learn about exciting IWMAF developments from IWMAF Board Chair Carl Harrington, and warmly welcome a brand new member and family to our supportive group. Sweet apple

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cider was flowing, and a festive buffet offered vegetarian chili, gluten-free cornbread, crudité and hummus, vegetable salad, fruit salad, blueberry-chocolate chip biscotti, and blondies. While munching and sipping contentedly, folks expressed their gratitude for the warmly connected “WM family” here in Philly. Carl shared news about the IWMF’s recent IVIG fact sheet (at www.iwmf.com/system/files/IVIG_FactSheet-English.pdf) and a “hot off the press” venetoclax fact sheet (at www.iwmf.com/system/files/VenetoclaxFactSheet-English.pdf). Several members of the group have already begun thinking about travel plans to the 2020 IWMF Educational Forum at the scenic Hyatt Regency Lake Washington in Renton, WA, from June 5-7. After a compassionate, honest, and supportive sharing circle experience, the afternoon ended with friendly goodbyes and goody bags from the buffet table for all to take home.

SOUTH CAROLINA

The South Carolina group met at Leeza’s Care Connection (Michael J. and Mary Meech Mungo Home) in Columbia, SC, in early November. Of the seven with WM, two were attending for the first time but were not recently diagnosed. After the group shared stories, members discussed what future meeting content would be most helpful, and group sharing topped the priority list. The next meeting is planned for the spring in Charleston.

TEXAS

Dallas/Northern Texas

The final meeting of 2019 took place in October. Judy Francis and Steve Pine, co-leaders of the group, made everyone feel welcome and comfortable. Steve explained that the overarching goals of meeting are the continued support and education of North Texas WMers and the mutual exchange of information regarding WM and related health issues. Additionally, Steve reinforced the wealth of information and utility of the IWMF and its website for both caregivers and those managing Waldenstrom’s. The first order of business was an update on those not in attendance. The group was reassured when told that vacations, personal commitments, and active lifestyles prevented their attendance. During the caring and sharing time, a few golden nuggets surfaced that may be of value:

- Shingle vaccines are important! Consult your physician regarding the safer, two-shot option and steer away from the live virus vaccination.
- When considering expensive medications, consult your physician for the right insurance coding. Stating a diagnosis of WM may result in insurance denying coverage for needed medications. Coding as non-Hodgkin’s B-cell lymphoma or lymphoplasmacytic lymphoma can often jump the hurdles and drive significant cost savings.

- Currently doctors treat the symptoms of WM, and there is no cure. However, continue to educate yourself and stay connected to take advantage of the newest research.
- Exercise is important. When you feel the least desire to exercise may be when you’ll benefit most!
- Doctors and patients often follow the paraprotein levels along with IgM to help guide them through medical decisions.
- Your body’s defense system to seasonal allergies, colds, and the flu may cause your total IgM to rise because of a normal immune response, possibly resulting in seasonal fatigue or other symptoms. Be aware of this should you see an increase in some of your numbers.

The second half of the meeting included a “working lunch” provided by the Cvetko Patient Education Center. During lunch, the group viewed a 30-minute video, “The Great Debates – Rituxan Maintenance vs. No Maintenance and Limited Treatment Duration vs. Continuous Pill” (at <https://youtu.be/ijMKfyiJG68>) from the 2019 IWMF Ed Forum. The video consists of two debates regarding treatment options and is highly recommended.



Denton Support Group members

Denton

Eleven people gathered in mid-November, including six WM patients, four care partners, and the speaker. After an hour of socializing and sharing, Dr. Ankit Kansagra from University of Texas Southwestern Medical Center in Dallas, TX, joined the group. He works in close collaboration with Dr. Larry Anderson, also of UT Southwestern, and specializes in stem cell transplants and CAR-T therapy with particular expertise in plasma cell disorders, including WM. After his presentation, a lively discussion followed with many questions from the group and clear and thorough responses from Dr. Kansagra.



Houston Support Group members enjoy a Greek lunch after their meeting and presentation.

Houston

In mid-September, the group had a wonderful meeting when some attendees drove three hours from the Texas Hill Country to hear from Dr. Peggy Determyer of St. Martin's Center for Health and Healing. She spoke on grief when faced with illness. Many members stayed for Greek salad and pastitio at the home of co-leaders Dr. Barbara and John Manoussos. The group will kick off the new year on Sunday, January 25, at 3:00pm, again at the home of the Manoussos. The address is 21 Briar Hollow Lane, Houston, TX 77027. The speaker will be a nutritionist from the Houston Cancer Institute, and there will also be time for group health updates and information sharing.



Houston Support Group members in relaxed conversation.

NORTHERN VIRGINIA/WASHINGTON DC/ WESTERN MARYLAND

Celebrating its five-year anniversary, the group co-sponsored a November meeting in Fairfax at the long-term venue, INOVA Schar Cancer Institute. The guest speaker was Drucilla Brethwaite, director of all six INOVA Life with Cancer locations, licensed clinical social worker, and certified oncology social worker. She provides free counseling services to all interested cancer patients in the area. "Building Resilience: Living Well in Survivorship" was her topic. Her goal is to promote adjustment to illness and improved quality of life for cancer patients and care partners. She opened by talking about the brain and resiliency. When we are overwhelmed with strong emotions and perceive a threat, the brain reacts quickly and sends us a chemical message. Models of resiliency and positive psychology can



Wash DC: Left to right: Catherine Intartaglia, Drucilla Brethwaite, and Support Group Leader Lu Kleppinger

help overcome our despair. Ms. Brethwaite coached us on how to accomplish resiliency, including leading a meaningful life with a sense of purpose, focusing on goals, being self-reliant, and being comfortable with who we are. Thankfulness was one of her strongest points, and she advised to connect to others to be resilient.

IWMF Board Trustee Ron Branscome elaborated on the IWMF services available to support groups. Also, we welcomed fellow Virginian Newton Guerin, the IWMF's new chief development officer, to our group. Guests enjoyed mingling with both of them after the presentation.

WASHINGTON

Olympic Peninsula

"I'm Jim Nelson, the new IWMF Support Group leader for Washington State west of Puget Sound. I am a retired chemical engineer and my wife is a retired geologist. We spent most of our careers working on environmental cleanup at the Hanford site in southeastern Washington. In 2015 we retired to the beautiful Olympic Peninsula of Washington state, a relatively remote area. When I was diagnosed in the summer of 2018, my local oncologist was largely unfamiliar with WM and encouraged me to seek a second opinion in Seattle. My new doctor, who specializes in WM and actively participates in the IWMF, referred me to the local support group. In the early stages of trying to understand my experience of WM, I took great comfort from hearing the experiences of others who were further along the same path of discovery. As time progressed, I found I had something to offer new people joining the support group.

It appeared that the extreme western region of Washington State was disadvantaged for support from the IWMF owing to the geographic barrier of Puget Sound. It was easy to believe I could offer help to others who could not make the longer journey to the larger population area served by the existing support group. I hope to serve the western Washington counties of Clallam, Jefferson, Kitsap, and Mason by providing a forum for information exchange, support, and

fellowship in this area. WM patients, caregivers, and friends are all welcome. I am looking forward to a first meeting in the early spring of 2020 in the Silverdale area where we can share experiences and knowledge. As needs and interests are identified, I hope over time to organize more formal presentations involving regional professionals or prepared materials.”

Seattle Area

On a Saturday morning in November, the Seattle Area Support Group and the Seattle Cancer Care Alliance hosted 46 attendees at the Fred Hutchinson Cancer Research Center for socializing, sharing common experiences, and learning a great deal about WM. After a continental breakfast, Dr. Ed Libby gave a detailed presentation about WM, past, present, and future. Clear explanations about various current and potential future treatments and how they work were very useful to all of us, especially a couple of newly diagnosed members. After a boxed lunch, Dr. Libby held a Q&A and answered all questions; as usual, wide-ranging topics made



Good conversations at the Seattle area meeting in November

it a particularly interesting session. Kudos to Dr. Libby for spending his Saturday with us!

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

AUSTRALIA

Brisbane Patient Meeting

On 7 September, to mark World Lymphoma Awareness Day, The Leukaemia Foundation held a workshop for lymphoma patients at the ESA Village at Dutton Park. Arthur Alexander presented “Bouncing Back—Using the Diagnosis to Reset Your Life.” The workshop examined how to build resilience and claim the fullness of life, regardless of age, state of health, or what people perceive as weakness or past failures. It showed how to improve capacity for resilience at any time of your life. This was built on three evidence-based disciplines—neuroscience, psychology, and contemplative practice.

Sydney, NSW Patient Meeting

A World Lymphoma Day seminar was held in Sydney on 9 October 2019.

The speakers were:

Senator The Hon Arthur Sinodinos - The senator for NSW discussed his lymphoma patient experience.

Associate Professor Christina Brown - Haematologist Royal Prince Alfred Hospital & Chris O'Brien Life House

Senior Clinical Dietician Jessica Cheng - Bone Marrow Transplant & Haematology, St Vincent's Public Hospital

Andrew Warden, WMozzies, reporting

CANADA

Thanks to the generosity of our members and special donors, we are proud to invest in three significant research projects. First, we are continuing to fund a project in which Dr. Ruben Carrasco from Dana-Farber Cancer Institute (DFCI) is the lead investigator. This project is to develop a mouse genetic model of WM. Second, we are funding another DFCI project on the development of a comprehensive epigenetic roadmap of WM, and Dr. Steven Treon is the lead investigator. Finally, the third project concerns the use of peripheral blood cell-free DNA for genetic profiling in patients with WM. This will potentially lead to a non-invasive platform for mutation detection at the time of diagnosis, replacing the bone marrow test. The lead investigator is Dr. Christine Chen at Princess Margaret Hospital/University Health Network in Toronto. The total amount of these three projects is CN \$402,847.

Vancouver, British Columbia

Dr. Jorge Castillo, while on a west coast speaking engagement to the medical community, agreed to add one more stop to address WMers in the Vancouver area on November 8. Hosted by Lymphoma Canada, with assistance from the

International Scene, cont. on page 36



The Halifax Support Group meeting attracted attendees from Nova Scotia, New Brunswick, and Prince Edward Island.

WM Foundation of Canada (WMFC), Dr. Castillo met with a group of 25-30 WMers and discussed future treatments of WM currently in research at Dana-Farber Cancer Institute in Boston. He set out the parameters and rationale for research behind the many new drugs which are focused on the two new pathways created by the discovery of the MYD88 and CXCR4 genetic mutations in WM. This led to an hour-long Q & A period around the availability of clinical trials, advancing the research in nontoxic treatments for WM, advantages of genetic testing and how to access this testing, as well as a discussion of the availability of these new treatments in Canada. It was a fascinating two hours from one of the leading clinicians in WM research about the future of WM treatments, which was really appreciated by the local WMers. Cam Fraser, WMFC Board member, closed the evening by making a brief presentation to the group outlining the benefits of participation and membership within the WMFC and strongly encouraging future collaboration with Lymphoma Canada in our mutual goal of education and research into seeking a cure for WM. Participants were encouraged to attend the next WMFC Vancouver Support Group meeting.

Halifax, Nova Scotia

Twenty Wallies and care partners from Nova Scotia, New Brunswick, and Prince Edward Island met for food, fellowship, sharing, and caring on October 19. The hosts were Support Group Co-Leaders Jim Mason and his wife Jill. WMFC Board Chair Paul Kitchen spoke of initiatives to increase the frequency and quality of WMFC communications. He also reported that a new WMFC website is in development and scheduled for launch mid-2020. With all tasks being handled by volunteers, virtually all WMFC funds go to WM research

and support for the Canadian WM community. Paul asked anyone with time and skills to devote to WMFC to contact him at paul.kitchen@wmfc.ca.

The guest speaker was the Reverend David Maginley, interfaith spiritual counsellor at the QEII Health Sciences Centre, four-time cancer survivor and author of *Beyond Surviving—Cancer and Your Spiritual Journey*. As always, the opportunity to share stories and to seek advice and support from fellow travellers concluded the meeting. Following the meeting, Team Wallie joined hundreds of blood cancer survivors, family, and friends on a marvelous fall evening for the LLSC Halifax Light the Night Walk, which raised more than CN \$750.

Montreal, Quebec

Dr. Steven Treon was in Montreal to speak to groups of physicians at four major hospitals for a week in November. He graciously took time from his very busy schedule to speak to a patient group at the Jewish General Hospital on November 7. About 25 WM patients attended, and it started with a wonderful continental breakfast, which, of course, included Montreal bagels! Dr. Treon spoke on “Updates on the Genomics and Treatments of Waldenström’s Macroglobulinemia” with ample time for a Q & A. Everyone appreciated the opportunity to hear “the” WM expert. Although many excellent hematologists are in the Montreal area, few have the experience and expertise that Dr. Treon has. Participants were especially grateful that WMFC was able to provide interpreters to make this presentation accessible to the French community. Dr. Treon’s presentation can be found on our website www.wmfc.ca.

This event was a unique opportunity, since there is no WMFC Support Group in Montreal at the present time. The hope of the WMFC was to provide an opportunity for Montrealers to get up-to-date information on WM treatments from a renowned expert and to network with others who share the same disease. The feedback after the presentation indicated that more than ten people are interested in starting a Montreal Support Group, including one volunteer to help lead the group. We look forward to the official launch in the very near future!

Betty McPhee, WMFC, reporting



Dr. Steve Treon (center), with Dr. Hou Jian on his right and Chris Patterson on his left, at Renji Hospital in Shanghai, China.

CHINA

On October 18, 2019, the second educational meeting for Waldenström's macroglobulinemia (WM) patients in China was held in Shanghai Renji hospital. Forty WM patients and caregivers attended this meeting.

Dr. Steven Treon from Dana-Farber Cancer Institute, and Dr. Hou Jian and Dr. Huang Honghui from Renji Hospital gave lectures focusing on different aspects of WM and lymphoma. Dr. Treon introduced the history of WM, diagnosis and genetics, pros and cons for different treatments, as well as the outlook of new treatment research. He also mentioned that Chinese researchers in the US have made big contributions in the WM field, and he welcomed more Chinese hematologists to attend the IWMF Ed Forum. Dr. Wang Ting from Renji Hospital served as interpreter during Dr. Treon's lecture. Dr. Hou Jian's lecture concentrated on the topics of daily life for WM and lymphoma patients, while Dr. Huang Honghui talked broadly about different medicines and treatments and their side-effects for different kinds of lymphoma.

A question and answer session followed the lectures; questions collected by the WM support group were answered by the doctors. After that, doctors from Renji Hospital provided one-on-one consultation to patients and caregivers. The lectures were recorded by WM support group volunteers and



WM educational meeting at Renji Hospital in Shanghai.

the videos of lectures were shared online and on the support group WECHAT official account for those who were not able to attend this meeting.

Roger Yao, WM-China, reporting



Professor Gilles Salles, head of the Hematology Department of the University Hospitals at Lyon-Sud. The four people on the panel (from left to right) are Dr. Chloé Herledan (chief chemist of the hospital), Dr. Anne Lazareth (hematologist), Dr. Pierre Sujobert (hematologist and research scientist), and Mrs. Frédérique Gibert (psychologist).

FRANCE

This year the annual patient-doctor day of Waldenström France was held on September 28, 2019, in Lyon. We assembled in the very modern lecture hall of the Institute for Cognitive Sciences of the CNRS, a research institute integrated into the medical campus of Lyon-Sud. As usual, the morning was dedicated to our association, the introduction of the Board President Denis Beugeard, meet and greet with members and their partners, welcome of new members, exchange of personal experiences, and then a very convivial catered lunch on the sunny terrace of the institute. Sixty-five patients and caregivers from all over France attended.

International Scene, cont. on page 38

The afternoon program consisted of two parts: Professor Gilles Salles, head of the Hematology Department of the University Hospitals at Lyon-Sud, gave a comprehensive lecture on Waldenström macroglobulinemia. He integrated in his presentation answers and comments on questions we had sent him before. Professor Salles brought with him four coworkers: Dr. Anne Lazareth, hematologist, Dr. Pierre Sujobert, hematologist and research scientist, Dr. Chloé Herledan, chief chemist of the hospital, and Mrs. Frédérique Gibert, a psychologist. We engaged in very lively discussions covering a multitude of patient and caregiver questions and comments and received appropriate answers from the presenters.

We would like to repeat this exercise at our 2020 meeting at Paris. The presentation of Professor Salles and the discussions have been recorded and will be available to the members of the association on the Waldenström France website: <http://portail.waldenstromfrance.org/>

Rainer Benda, Waldenström France, reporting

SCANDINAVIA

3rd WM Scandinavia Meeting

The meeting was held 14 September at ABF Stockholm (a non-profit Union educational association) in the center of the Swedish capital. We were close to 50 participants, who gathered to spend an exciting day together. The meeting was a great success. The participants were most grateful for the opportunity to meet and learn more about WM. It was a good opportunity for making new friends and sharing experiences and knowledge. It's impossible to make a report that covers everything that happened, but this is a high-level summary.

Susanne Öhrn, patient and founder of WM Scandinavia, and Ulf Persson, patient and volunteer, welcomed the participants with registration, coffee, and some fruit. Ulf reviewed the agenda of the day, while Susanne presented the development of WM Scandinavia. The group was started in May 2016, and we had 221 members in the Facebook group the day

of the meeting. We have grown by 56 people this past year. The allocation among the various Scandinavian countries is approximately 50% Swedes and 25% each from Norway and Denmark. Among our members, 90% have been active on our Facebook site the last 60 days—which is unique! That clearly shows how important this channel is for WM patients and their relatives in Scandinavia. But this can't be managed by just one person alone, more volunteers are needed.

Olga Strömberg, chief hematology physician at Södersjukhuset in Stockholm, provided us with very good and easy-to-understand information about the complexity of WM, diagnostics, symptoms, and treatment. She held a very informative lecture in immunology and vaccines. She also pointed out the relationships between WM and autoimmune diseases and various other conditions. She also answered a lot of questions during her presentation.



Owe Salvén tells about his experience at the IWMF Ed Forum in Philadelphia.

Owe Salvén, WM patient, gave us a taste of his experiences from the IWMF Educational Forum in Philadelphia earlier this year. He was very impressed by the Forum and the IWMF, the organization, the people, the lectures, and opportunities to meet all the famous doctors. He really convinced us all to go to the next Ed forum.

Eva Kimby, Professor Emerita, Hematology Center at Karolinska, talked about new gene diagnostics that now will be used in Sweden. She also presented new medicine trials. There is also a study conducted at Karolinska where they continue to recruit patients. Furthermore, she showed that overall survival has improved a lot lately. Facts show that some of those with WM live longer than the control group without WM, thanks to more focus on healthy living and close medical checks. Sadly, new research shows that we in Sweden are at higher risk than the average in the world of



Eva Kimby (right) and Olga Strömberg (left) received from Susanne Öhrn this year's WM Scandinavian raku sculptures as an appreciation for their participation in the WM meeting.



Eva Kimby and Olga Strömberg answer questions in the "Ask the Doctors" session.

being affected by WM, and the worst is for those living in the northern part of Sweden. Furthermore, some ongoing research of a few families shows that they appear to be affected by a hereditary form of WM.

Eva Kimby and Olga Strömberg together answered questions from the patients. It was extremely informative, and the two doctors complemented each other, as one is a practicing doctor and one works with research. Much was clarified, and everyone had the opportunity to ask their questions. Here, the doctors came up with a very creative idea for the next meeting: a model that would give us a more direct personal feedback on an individual level. It sounded incredibly exciting. We will, of course, take a closer look at this method before the next meeting.

In the meeting summary, the only improvement that was presented was that we should have a microphone for those who ask questions for the next meeting. Otherwise, participants were very satisfied with the organization, the presentations, the information shared at the meeting, and the premises. In addition, we pleaded that more people should take their responsibility and sign up to volunteer for WM Scandinavia. Fortunately, there were some who signed up as volunteers during the meeting, which may lead to finally being able to create a website for the group. And we may be able to form a formal association so that we can better handle membership fees, make fundraisers, buy services, and so on.

A very special thanks to our sponsors: Janssen, Blood Cancer Association in Stockholm, and ABE.

Susanne Öhrn, WM Scandinavia, reporting from Sweden

UNITED KINGDOM

Changes at WMUK

Lots of new things are happening at WMUK. We recently said farewell to WMUK's founder, trustee, and WM patient, Roger Brown, who has retired from the day-to-day running of the charity and from the Board of Trustees. Roger established



The closing discussion for the meeting was held by Susanne Öhrn and Ulf Persson.

WMUK and dedicated his life to others with WM, whilst also coping with his own health problems. He had indicated in 2018 that he wished to retire, and plans had been put in place to enable Roger to do this; the transition has now been achieved. A huge thank you to Roger and his wife, Alison, for their dedication to the WM community over many years. WMUK's current chair of trustees is Will Franks, a WM patient. Our board is a strong combination of doctors, patients, and experts from relevant health industries, supported by a small professional team of Chief Executive Lindsey Bennister and new Operations Manager Leigh Hibberdine. Leigh joined WMUK in November and brings her professional background in administration, as well as personal experience in the rare cancer charity world as a trustee, volunteer, and parent carer.

We have new contact details for WMUK: info@wmuk.org.uk
Tel: +44 20 3096 7858

Address: c/o CAN Mezzanine, 7-14 Great Dover Street, London SE1 4YR.

WMUK will launch a new website in March 2020. Work is currently underway to redesign our website and produce new content. Watch this space.

Ibrutinib Update

Currently, ibrutinib is available to patients at no cost through the National Health Service (NHS) in England for eligible WM patients who have received at least one prior therapy. This is for a time-limited period whilst more data are collected by the manufacturer, in clinical trials, and via NHS data collection methods. The long-term funding of ibrutinib by the NHS in England will be decided in the next two years. The process of re-appraising ibrutinib by the UK regulatory body, the National Institute for Care and Health Excellence (NICE), will start in 2020, and WMUK is contributing to the data collection through the Rory Morrison Registry, which is collecting detailed data from patients taking ibrutinib. We will be making as strong a case as possible to support the



Dr. Helen McCarthy presents at the BAD WMers Support Group meeting in November 2019.

continued availability of this treatment for WM patients in the UK.

Research

WMUK has been facilitating the collection of saliva samples from patients for our biobank project operated through University College London. We are pleased that these donated samples are now being used as part of a project with the National Institutes of Health in the United States, which will be analyzing over 100 of our samples in order to look for previously undiscovered genetic causes of WM, in particular familial cases of WM. This is a fantastic example of what can be achieved through international research collaborations that involve patients and clinicians working together.

New Clinical Trials in the UK

The Pembro WM trial has just opened in the UK and will investigate the use of the pembrolizumab/rituximab combination in patients with relapsed WM who have already received at least one other treatment line. Pembrolizumab has previously been used for several other conditions and has shown early promise in WM; this trial will explore its effectiveness for WM. This trial is being run in eight centres across the UK.

The RAINBOW trial aims to assess chemotherapy-free first line treatment for WM. Currently, ibrutinib is only being used as single agent for patients who have already had chemotherapy. This trial will compare the existing combination chemotherapy option of dexamethasone,

rituximab and cyclophosphamide (DRC) with the non-chemotherapy combination of rituximab and ibrutinib (RI) for patients who have not previously had any treatment. It focuses on assessing safety and effectiveness and offers patients a chance to receive this novel combination. This trial will run in several centres in the UK.

Support Group Events

Following in the long tradition of the IWFM, WMUK held a social “walk for health” on Friday, October 18. It was a great opportunity for patients and their partners to meet socially and enjoy a guided tour of the sights of London, including St Paul’s Cathedral. The walk was co-hosted by Maggie’s Centre Barts, a beautiful architect-designed centre on the grounds of St Bartholomew’s Hospital, London. Participants enjoyed the relaxed environment and the chance to talk informally about their experiences of WM whilst they were walking. Another “walk for health” is planned for spring 2020.

The Bournemouth and District WM Support Group (BAD WMers) took to the road on Saturday, November 23, meeting in a community centre in Winchester. Over 35 people attended to hear Dr. Helen McCarthy, WM expert at Royal Bournemouth Hospital, talk about WM and the immune system. Patients and their supporters travelled from the Midlands and even the north of England to attend, and for many, this was their first time to meet others with WM.

Lindsey Bennister, WMUK, reporting

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Thank you~

Kudos and Best Wishes to Penni Wisner

Penni Wisner has been the *IWMF Torch* support group correspondent and author of “Cooks’ Happy Hour” for over ten years. With Penni's well-deserved retirement, the editors of the *Torch* are now looking for two people to do these two columns. Here is your chance to give some of your time to the WM cause! If you are interested in volunteering as the support group correspondent for the *Torch*, you will collect and assemble group reports and photographs four times a year and forward them to the editor. If you are really into healthy eating, enjoy writing about food and how to prepare it, you might be the perfect author for our food column. So if you are interested in doing either of these, please contact the editor at shirleyganse@hotmail.com.

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