IWMF TORCH

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SICK & TIRED OF BEING SICK & TIRED! WHAT TO DO ABOUT FATIGUE ASSOCIATED WITH CANCER AND ITS TREATMENT

RINA S. FOX, PHD, MPH, AND LISA M. WU, PHD

Dr. Rina Fox

Dr. Rina S. Fox is an assistant professor in the College of Nursing at the University of Arizona, an adjunct assistant professor in the Department of Medical Social Sciences at Northwestern University Feinberg School of Medicine, and a licensed clinical psychologist. She researches ways to help improve quality of life and decrease symptoms for adults facing cancer and other chronic illnesses. She has specialized training in treating sleep disorders without medications and is particularly interested in identifying ways that cancer survivors can sleep better and feel less fatigued.

Dr. Lisa Wu

Dr. Lisa M. Wu is an associate professor at the Aarhus Institute of Advanced Studies at Aarhus University in Denmark, adjunct assistant professor in the Department of Medical Social Sciences at Northwestern University Feinberg School of Medicine, and a licensed clinical psychologist. She conducts research in the late effects of cancer and its treatment, including fatigue, cognitive impairment, and sleep disturbances. She has also been investigating circadian rhythm disruption in cancer survivors and the potential benefits of light therapy.

"I just can't get going anymore. I can barely put one foot in front of the other..."

Fatigue is often reported as the most common, most upsetting, and most severe side effect of cancer and its treatment. This is true for all cancers, even ones where fatigue is not one of the primary symptoms of the cancer itself, like it is for Waldenstrom's macroglobulinemia.

Cancer-related fatigue: A different beast than everyday fatigue

Cancer-related fatigue is fatigue associated with cancer and its treatment. It is a different beast from everyday fatigue. According to the National Comprehensive Cancer Network (NCCN), cancer-related fatigue is "a distressing, persistent, subjective sense of *physical, emotional,* and/or *cognitive* tiredness or exhaustion related to cancer treatment that is not proportional to recent activity and interferes with usual functioning." This means that, unlike day-to-day fatigue, cancer-related fatigue is not linked to how active you are, how much rest you get, or how stressed you are. Although most people think of cancer-related fatigue as due to cancer treatment, in reality it can occur at diagnosis, during treatment, and even long after treatment is over. Furthermore, it is the most common side effect of cancer treatment.

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IWMF
International Waldenstrom's Macroglobulinemia Foundation

6144 Clark Center Avenue
Sarasota, FL 34238

Telephone 941-927-4963
Fax 941-927-4467

E-mail: *info@iwmf.com*
Website: *www.iwmf.com*

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EDITOR
Shirley Ganse

ASSOCIATE EDITOR
Sue Herms

SCIENCE EDITOR
Glenn Cantor

INTERNATIONAL CORRESPONDENT
Annette Aburdene

FORMATTING & PRODUCTION
Sara McKinnie

FACEBOOK WM SUPPORT GROUP
Betty Ann Morton

***TORCH* ADVISOR**
Peter DeNardis

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Since cancer-related fatigue can be severe, common, and long-lasting, it can have a powerful impact on your emotions, your thoughts, your relationships with friends and family, and how your body feels. It can also be hard to explain cancer-related fatigue to other people, because it isn't something that your friends and family can see with their own eyes. It is something that can only truly be known by the person experiencing it. So the bottom line is: cancer-related fatigue is common and it is a very real thing.

What causes cancer-related fatigue?
Numerous theories try to explain why cancer-related fatigue might happen to you. Fatigue may be associated with a chronic immune response in your body, changes in your metabolism, anemia, loss of appetite, feeling depressed, having poor sleep, not being very physically active, pain, medications, nutritional deficiencies, and even changes to your daily circadian rhythms. Although there are often clear causes of fatigue, such as in the case of anemia, there are also numerous instances where the causes are not so clear. The good news, though, is that even when the causes of cancer-related fatigue are not apparent, there are several tools available to you to help you manage cancer-related fatigue.

*So the **bottom line** is: cancer-related fatigue is common and it is a very **real thing**.*

What tools are available to help me manage cancer-related fatigue?
The NCCN publishes a document called "Survivorship Care for Cancer-Related Late and Long-Term Effects" (which you can access here: *https://www.nccn.org/patients/guidelines/content/PDF/survivorship-crl-patient.pdf*), and one of the symptoms discussed in this document is cancer-related fatigue. If you read this, you will see that the very first thing they recommend as a strategy to manage cancer-related fatigue is to treat the cause of the fatigue. This is because, sometimes, there are other conditions that are making the fatigue worse. In the context of Waldenstrom's this might be anemia. Or this could be a problem with your thyroid. It is important to check with your medical team to see if there are any other conditions that might be making your fatigue worse and, if so, work with your team to address those. Once that is complete, the NCCN recommends several different techniques to manage fatigue. These include: education and counseling, physical activity, cognitive behavioral therapy (CBT), mindfulness-based stress reduction, supportive expressive therapies, psychoeducational therapy, nutrition counseling, CBT for insomnia, acupuncture, and psychostimulants. Below is some more information about a few of these.

What are specific strategies to combat cancer-related fatigue?
You can begin receiving *education and counseling* about fatigue just by talking to your doctor. This can be especially helpful if you are undergoing or have previously undergone treatments that can make fatigue worse, like radiation therapy or chemotherapy. It is important to remember that fatigue is not necessarily a sign that treatment is not working or that your disease is getting worse. The best thing you can do to make sure everything is going the way it should be is to talk to your doctor.

Once you've spoken with your doctor, a behavioral strategy (meaning a strategy that does not involve changing your medications) that can be useful for conserving energy is *"activity pacing."* This is when you link an activity to time rather than whether it is complete or not. For example, let us say you have a sink full of dishes that all need washing. A typical way to approach this problem would be to go to the sink, start washing, and step away only when all the dishes are clean. However, depending on how many dishes you have, this may take quite some time and might leave you feeling pretty wiped out. Activity pacing involves knowing how long you can do something before it starts making your fatigue worse and then taking a break before that much time has passed. So, you might choose to wash dishes for five minutes and then take a five-minute break, then come back and wash for another five minutes and then take another five-minute break, and so on until all the dishes are done. Even though it may take longer for you to wash all the dishes than it would have if you had just washed them all in one fell swoop, activity pacing can prevent you from becoming totally wiped out, leaving you with more energy to go about the rest of your day. Keeping a fatigue diary can help you figure out how long you can do an activity before you need a break. It can also help you to schedule activities that require the most energy at times

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of the day when you *have* the most energy. It is important to make sure that you schedule plenty of downtime too, and to be sure to be *realistic* in your goals.

Another thing you can do is try to *be more physically active*. Yes, this is counter-intuitive. How can being *more* active be the solution when not having enough energy is the problem? Contrary to what you might expect, there is actually quite a bit of evidence out there showing that more physical activity is related to *lower* levels of cancer-related fatigue. This goes for both supervised and unsupervised training, and has been found for many different types of activities, including walking, yoga, cycling, aerobic training, strength training, flexibility training, and tai chi. In fact, physical activity is the leading evidence-based treatment currently available for cancer-related fatigue. However, please keep in mind that before you start any new type of physical activity it is important to talk to your doctor and make sure there are no restrictions you should be mindful of given your own unique health history.

A different type of approach that can help with cancer-related fatigue is engaging in a psychosocial intervention. This includes things like cognitive behavioral therapy (CBT) and mindfulness-based stress reduction (MBSR). CBT involves learning about the links among your thoughts, feelings, and behaviors, and is often done in collaboration with a psychotherapist. MBSR is a structured eight-week program that is generally completed in a group with a trained instructor. There is research showing that both CBT and MBSR can help with cancer-related fatigue.

One more tool that is newer to the scene is *bright light therapy*. This approach is commonly used to treat seasonal affective disorder, which is when someone has low mood or feels depressed related to the changing of the seasons (meaning depression becomes really impactful, usually during the winter months). Bright light therapy involves using a light box or light goggles for 30 minutes every morning upon awakening. Some recent research has shown that bright light therapy may also be able to help prevent or treat fatigue in people with cancer.

...more ***physical activity*** *is related to lower levels of cancer-related fatigue.*

To sum up

Cancer-related fatigue is real, and it is different from day-to-day fatigue. It can be common, severe, impactful, and long-lasting. While the true underlying causes of cancer-related fatigue remain poorly understood, there are a variety of tools out there that can help with the management of cancer-related fatigue. However, no matter what you decide to do, the first thing should always be to talk to your doctor to determine which tools will be the best ones for you to try first.

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*

TODAY, TOMORROW, AND BEYOND

By Newton Guerin, IWMF President and CEO

Newton Guerin

During a recent presentation to IWMF support group leaders in the US and Canada, Morie Gertz, MD, Mayo Clinic, Rochester, MN, began his comments with, "…given current statistics, we're probably looking at approximately 3,000 newly diagnosed patients with active, not smoldering or MGUS, WM each year." That is double the 1,500 (approximately three to five per million people) that has been commonly used to describe the incidence rate for those newly diagnosed with WM. Dr. Gertz went on to say, "Because of the dramatic advances leading to unbelievable outcomes, this equates to between 40,000 to 50,000 people living with a WM diagnosis in the US at this time."

He also acknowledged the important role IWMF support group leaders play in helping patients access accurate and independent information about treatment options as well as offering encouragement to consider clinical trials. You can view Dr. Gertz's entire video by clicking on *https://iwmf.com/the-waldenstroms-weekly-19/*.

In 2019, the IWMF Board of Trustees crafted a strategic plan outlining six Compelling Intentions to articulate where we want to go and how we plan to get there. With Dr. Gertz's projection in mind, three of those Compelling Intentions will require even more attention and organizational resources going forward:

- Ensure every doctor and nurse worldwide who works in blood cancer knows about the IWMF and the resources we offer.
- Ensure every person diagnosed worldwide with WM knows about the IWMF and the resources we offer.
- Become the global thought leader and authoritative source of information and resources in WM.

This means the IWMF's job is bigger than currently envisioned, and our responsibility to a much larger WM community will require a renewed sense of urgency. Our volunteers and staff must remain focused on supporting an even larger patient and caregiver community.Our Board of Trustees will continue its commitment to do whatever we must to meet the needs of patients and caregivers, not only in the US, but throughout the world. Now we must all invest additional resources of time and talent to accomplish the critical objective of ensuring that we connect with a much larger patient population.

Our network of support groups throughout North America and the world has grown to over 80, and our global presence continues to expand through our 22 international affiliates. This ever-expanding network helps ensure that the IWMF can continue to make a difference in the lives of more people living with WM every day.Our volunteer and staff leaders, who play key roles in providing ongoing information, education, and support through IWMF Connect, Facebook, and other social media platforms have a much greater task ahead in keeping us all connected.

Our annual Ed Forum continues to grow (with 350 attendees at our last in-person event—a far cry from the handful of participants back in 1999). Our first ever Virtual Ed Forum in 2020 was our 25th and by far our largest ever. Attendance exceeded 1,400 participants, representing over 30 countries throughout the world, who joined in to hear uplifting and encouraging updates from leading experts in the field of WM. Our Ed Forum Planning Committee, along with our Publications Committee volunteers, must now be prepared to ensure that the IWMF provides the most current, accurate, and independent information to a more diverse WM community.

Our *Torch* editors and contributors produce our "world class" signature magazine every quarter, reaching over 7,000 subscribers by either email or print. We now have an opportunity to reach a much larger audience by significantly expanding our *Torch* distribution.

The IWMF's newly launched Global WM Patient Initiative will help us reach more people living with WM. This initiative is bringing together key organizations that share common goals to help us all concentrate the global WM community's focus on particular issues or problems, create alliances among those who might not normally work together, and maximize the benefits for WM patients who are struggling with the diagnosis of a rare disease. Our goal here is to ensure that whenever and wherever any WM patient needs information and support, no matter where they live, they will have access to the best information about their disease, treatment options, and support, so they never feel alone.

IWMF volunteers and staff are up to these new challenges, but we will need the entire IWMF community's help! I am confident that by working together, we will find ways to meet the challenges of:

- Increasing our capacity to stay connected to a larger WM community through support groups and LIFELINE volunteers.
- Expanding our social media presence.
- Significantly increasing our Ed Forum participation to reach an even larger percentage of a growing WM community.

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Along with the challenges of expanding our information, education, and support programs to meet the needs of a growing and more diverse WM community, we have new opportunities to make a strong case for an expansion of targeted research on WM. With significantly more people living with WM, there is strength in numbers to help us make an even stronger case for more top-notch research in the mechanisms behind our disease, and in finding better treatments and a cure for WM. The power in numbers will position WM as more "relevant" among the many other types of blood cancers and open new doors to continue to attract the best and brightest clinicians and researchers to the IWMF.

With the new focus on expanding the IWMF's support, education, and research efforts on behalf of a much larger community of patients and caregivers, comes a greater need for financial support to help make that possible.

But we can't do it without you. Please look into your heart and your wallet and consider increasing your support of the IWMF. Visit *https://iwmf.com/ways-to-give/* to see how you might make a difference in the lives of people living with WM.

Thank you for joining us!

CLINICAL TRIALS WITH A COMBINATION OF CXCR4 INHIBITORS AND IBRUTINIB: RESULTS FROM TWO PHASE 1 TRIALS

By Glenn Cantor, Science Editor and IWMF Trustee

In pioneering work, Dr. Steven Treon and his colleagues at the Dana-Farber Cancer Institute at Harvard first identified a mutation in MYD88 in 90-95% of WM patients. A few years later, they found that another protein, called CXCR4, is also mutated in about 30-40% of WM patients.

The CXCR4 protein drives a number of processes that enable cancerous WM cells to survive and proliferate. CXCR4 helps WM cells remain in the bone marrow tumor microenvironment where they grow best. Additionally, CXCR4 signals cause increased WM cell proliferation, reduce the bone marrow's immune response against WM cells, alter the tumor microenvironment within the bone marrow, and promote resistance to some drugs used in cancer therapy. Because of these factors, many patients with CXCR4 mutations have higher serum IgM and increased risk of developing symptomatic hyperviscosity syndrome, as well as delayed or poorer responses to ibrutinib (Imbruvica) therapy.

CXCR4 is a protein that spans the cell membrane that surrounds cells. Parts of the CXCR4 protein are found on the outside of the cell, on the outer surface of the cell membrane, while other parts are found on the inside of the cell, on the inner surface of the cell membrane. The outer portion can interact with signaling molecules that float through the body fluids, while the inner portion sends signals to the inside of the cell. Normally, cell membrane proteins don't last forever. After a while, they are recycled back into the cell and replaced by newly synthesized proteins. One major effect of the CXCR4 mutations in WM patients is that the recycling process is disturbed. Because recycling is slowed down, CXCR4 proteins with mutations remain on the WM cell surface for a long time and continue to be fully active. The increased number of CXCR4 proteins on the cell surface leads to increased WM cell survival and growth.

...Dr. Treon and his group decided to investigate combinations of ***CXCR4 inhibitors*** *with ibrutinib.*

These properties of mutated CXCR4 make it a logical target for WM therapy. Since it is known that CXCR4 mutations inhibit the response to ibrutinib therapy, Dr. Treon and his group decided to investigate combinations of CXCR4 inhibitors with ibrutinib. Results were released recently from two early clinical trials.

The first trial was a Phase 1 study of ulocuplumab with ibrutinib, reported in the journal *Blood* (online publication, July 13, 2021). Results were encouraging. Ulocuplumab is a monoclonal antibody drug that binds to CXCR4, which not only blocks stimulation of CXCR4 but also causes apoptosis (cell death) in cells with excessive CXCR4 expression. A total of 13 WM patients with MYD88 and CXCR4 mutations were treated in a multicenter study, and data from 12 of the patients were evaluable. Nine of the patients were previously untreated, while four had relapsing/refractory WM. Patients were treated with ibrutinib at 420 mg/day, which was continued until intolerance or disease progression, as

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well as the CXCR4 inhibitor ulocuplumab intravenously for six cycles, each cycle of four weeks' duration, at various doses.

The combination of a CXCR4 inhibitor, such as ***mavorixafor****, together with ibrutinib may be a way to achieve a* ***faster and deeper*** *response in CXCR4 mutated patients than with ibrutinib alone.*

The response to therapy was more rapid than is ordinarily seen with ibrutinib alone, although this was not a head-to-head trial, so no formal conclusions can be made about whether the combination was more effective than ibrutinib alone. The median time to a major response was 1.2 months, whereas with ibrutinib alone, the median time to a major response is generally 4.7 to 7.3 months. The major response rate was 100% (defined as partial response or better), with four of the 12 patients achieving a very good partial response (VGPR). Even the highest dose was well tolerated, with no accentuation of the adverse events commonly seen with ibrutinib therapy.

Unfortunately, Bristol-Myers Squibb, the company that makes ulocuplumab, discontinued its development, so a planned Phase 2 study could not be conducted. However, a CXCR4 inhibitor called mavorixafor was available from another company, X4 Pharmaceuticals, so the Dana-Farber group helped X4 initiate a company-sponsored, multicenter study combining mavorixafor with ibrutinib. This was a single-arm study, with the main focus of determining safety and tolerability of the two-drug combination. Interim early results from the mavorixafor-ibrutinib study were first released at the European Hematology Association Congress in June 2021.

In the trial of the mavorixafor-ibrutinib combination, eight patients have been treated to date. Three were previously untreated, and five were relapsing/refractory patients who had received prior treatments. The study is evaluating different doses of mavorixafor taken orally, together with 420 mg ibrutinib per day. To date, low (200 mg/day) and middle (400 mg/day) doses of mavorixafor have been evaluated, and one patient has received the highest dose of 600 mg/day. All patients have experienced a rapid and clinically important decrease in serum IgM and an increase in hemoglobin. Four of the eight patients have now been treated for six months. Of these, two of the four had equal to or greater than 50% reduction in serum IgM from baseline, including one patient with equal to or greater than 90% reduction in serum IgM from baseline. Additional data, including clinical responses based on criteria of the International Workshops on Waldenstrom's Macroglobulinemia (IWWM), are expected later this year. The combination of the two drugs was well tolerated, and there were no serious adverse events as of the cutoff date of April 15, 2021. Two of the eight patients experienced Grade 1 or 2 adverse events (mild or minimal side effects) related to mavorixafor, including nausea, acid reflux, constipation, and worsening pain or numbness in the shoulders, hands, and wrists.

These are encouraging results, although the number of patients treated to date in both studies is small. The combination of a CXCR4 inhibitor, such as mavorixafor, together with ibrutinib may be a way to achieve a faster and deeper response in CXCR4 mutated patients than with ibrutinib alone. Since CXCR4 mutations are so common (30-40%) among WM patients, it is possible that combination therapy will benefit a large number of WM patients. The mavorixafor-ibrutinib study is continuing, and, if successful, will undoubtedly lead to larger studies in the future.

Disclosures: Glenn Cantor is a former employee of Bristol-Myers Squibb Co. and is a consultant to GPCR Therapeutics, Inc.

MICHAEL FARBMAN, JUDITH MAY VOLUNTEER AWARD WINNER

By Peter DeNardis, Chair of the IWMF Board

It is with great pleasure that we announce Michael Farbman as the 2021 recipient of the Judith May Volunteer Award, which will be presented to him in October at the IWMF Educational Forum.

This annual award recognizes the spirit of volunteerism that Judith May so aptly demonstrated throughout her 20+ year career with the IWMF, including leadership in member services, research, advocacy, and as president of the IWMF from 2005 to 2012.

For many years, Michael has been the IWMF's word wizard behind the curtains, copy editing all messages for grammar, syntax, and spelling. If there was an IWMF News item or a Story of Hope that you read, Michael was always there to review it and provide corrections and suggestions to make sure the copy was as professional as possible. His keen eye, insight, and creativity helped ensure that everything communicated was done in an accurate, compelling, and professional manner.

His volunteer journey began when he attended the 2015 IWMF Educational Forum. While talking with an IWMF Board member at the Forum, Michael took the time to point out that, while he appreciated the vast wealth of useful information provided by the website, he found several pages that were sorely in need of some grammatical adjustments. Elena Malunis (a Board member at that time), sensing an opportunity, suggested to him that he should volunteer with the IWMF to do exactly that. And the rest, as they say, is history.

Michael retired in 2008 from the US Foreign Service, having served as a senior foreign service officer for the State Department's US Agency for International Development. His work took him to Washington, DC, and tours of duty in Morocco as the USAID mission director, to Albania as the regional director for the Caucasus, and to Kosovo as mission director. Prior to joining USAID, Michael worked for seven years as an instructor in economics at the University of Glasgow in Scotland.

Michael's WM journey began at diagnosis in 2013. While serving in the Republic of Georgia in the early 2000s, he suspected something was wrong, but it wasn't until 2013 that he was diagnosed. Michael's first treatment (of bendamustine and rituximab) was in 2014, with quarterly infusions of rituximab thereafter for a period of two years, followed by a period since then of a "good partial recovery." However, recent complications have necessitated a consult with the experts at Dana-Farber Cancer Institute and the possibility of another treatment regimen.

Michael Farbman with the Judith May Volunteer Award

Michael has always been available at a moment's notice when urgent, timely messages had to be sent out immediately to notify the global WM community regarding the latest breaking news about a particular new treatment or item of special interest regarding WM. Day or night, regardless of what he may have been doing in his personal and family life, he could be counted on to drop everything and respond within a matter of hours, if not minutes! If you marveled at the precision of the language used and the creativity in the wording of various messages and Stories of Hope, it was usually because of Michael's guidance and input.

Upon notification that he would be receiving the award, Michael was very appreciative and made sure to let us know that he has "loved doing this work, trying to contribute a little creativity (as well as additional precision) to WMers' drafts." And the WM community, in turn, has loved reading the final product of his efforts, each time they opened an email message or visited the website.

It should be noted that Michael stepped down from his volunteer role only recently because of health reasons that hampered his ability to continue proofreading in a timely fashion. The IWMF community is quite fortunate to have had him in this role over the years. Writer Joan Didion once said, "Grammar is a piano I play by ear," and Michael has done just that for us, as a grandmaster pianist with words.

Michael is the perfect example of the many, many unsung heroes in the IWMF community who play critical roles in ensuring that the IWMF continues to excel in its efforts to support everyone around the world affected by WM, while advancing the search for a cure.

MEDICAL NEWS ROUNDUP

By Sue Herms, IWMF Research Committee Member

US FDA Approves Zanubrutinib for WM – The US Food and Drug Administration (FDA) announced on September 1 that it has approved the BTK inhibitor zanubrutinib (Brukinsa) for the treatment of patients with WM. This is the second FDA-approved drug for WM, following ibrutinib (Imbruvica) and its expanded use in combination with rituximab (Rituxan). The decision was primarily based on data from the multicenter Phase 3 ASPEN trial that compared zanubrutinib with ibrutinib in 201 WM patients who were randomly assigned to receive either zanubrutinib at 160 mg twice daily or ibrutinib at 420 mg once daily. The trial's results showed that zanubrutinib was associated with a higher rate of complete or very good partial responses at 28.4%, compared to ibrutinib at 19.2%. Those who received zanubrutinib experienced lower rates of atrial fibrillation, hypertension (high blood pressure), major bleeding, adverse events leading to treatment discontinuation, and toxicity-related death. Although rates of serious infections were comparable between the two, zanubrutinib did have a higher rate of neutropenia (low neutrophil count) than ibrutinib.

NCCN Updates Clinical Practice Guidelines for WM/LPL – The National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines for WM/LPL (lymphoplasmacytic lymphoma) document has been revised as of June 24, 2021. Notable updates from the previous Guidelines include the following: 1) zanubrutinib (Brukinsa) has been added as a preferred regimen for both primary (first-line) and previously treated patients; and 2) R-CHOP (rituximab, cyclophosphamide, doxorubicin, vincristine, prednisone) has been removed as a treatment option from primary therapy.

CDC Issues Guidelines for Additional COVID-19 Vaccine Dose in the Immunocompromised – At press time, the US Centers for Disease Control and Prevention (CDC) was recommending that people whose immune systems are moderately to severely compromised should receive an additional dose of mRNA COVID-19 vaccine (Pfizer or Moderna) after the initial two doses. The recommendation was based on studies indicating that the immunocompromised may not build the same level of immunity from the two-dose series of these vaccines compared to people with normal immune systems. Although an additional dose may improve protection, the immunocompromised should continue to follow infection prevention measures, such as masking, staying six feet apart from others not in their household, avoiding crowds, and handwashing. The CDC recommendation includes immunocompromised people who have 1) recently received or are receiving active cancer treatment for solid tumors or blood cancers; 2) received an organ transplant and are taking medicine to suppress the immune system; 3) received a stem cell transplant within the last two years or are taking medicine to suppress the immune system; 4) moderate or severe primary immunodeficiency, such as DiGeorge or Wiskott-Aldrich syndrome; 5) advanced or untreated HIV infection; and 6) active treatment with high-dose corticosteroids or other drugs that may suppress the immune response. CDC recommends that the additional dose be administered at least four weeks after the second dose of the Pfizer or Moderna vaccine. A third dose of the same vaccine given in the first two doses should be used. If the vaccine given in the first two doses is not available or is unknown, either the Pfizer or Moderna vaccine may be administered. Not enough data were available at press time to determine whether immunocompromised people who received the J&J vaccine should be given another dose.

*The US Food and Drug Administration (FDA) announced... that it has **approved** the BTK inhibitor **zanubrutinib (Brukinsa)** for the treatment of patients with WM.*

LLS Publishes First Analysis in Its Study of Blood Cancer Patients Vaccinated Against COVID-19 – A letter to the journal *Cancer Cell* reported early results from the Leukemia & Lymphoma Society (LLS) study of over 1,400 patients with lymphomas, leukemias, and myelomas to evaluate antibody response to COVID vaccination after a full course (two doses) of the mRNA vaccines, Pfizer and Moderna. Blood cancer patients from the US were recruited for the study and provided their own demographic data, diagnosis, history of treatments, prior COVID infections, vaccine type, dates of vaccine administration, and side effects. Blood samples were collected between March 12 and May 15, 2021, for analysis of antibodies to COVID-19. Overall, approximately 75% of all blood cancer patients were seropositive (produced antibodies) to the Pfizer and Moderna vaccines. Seropositivity varied by blood cancer type and treatment, with chronic lymphocytic leukemia patients less likely to be seropositive while multiple myeloma patients had the highest rates of detectable antibodies. Patients treated with BTK inhibitors, anti-CD20 monoclonal antibodies, or venetoclax, alone and in combination therapies, had lower seropositive rates. For WM patients, the seropositivity rate was 74.2%. A subset analysis that included people with WM found that blood cancer patients were significantly more likely to produce an immune response with Moderna than with Pfizer. The safety profiles of the mRNA vaccines were similar to those

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seen in age-matched healthy individuals. The researchers concluded that a substantial number of vaccinated blood cancer patients may be at high risk of breakthrough COVID-19 infections. This study is ongoing, and additional analyses will be performed, including T cell responses to vaccination.

*...a substantial number of **vaccinated** blood cancer patients may be at **high risk** of breakthrough COVID-19 infections.*

Greek Research Study Reports Neutralizing Antibody Responses After One COVID Vaccine Dose in WM, CLL, and NHL Patients – Greek researchers published a study of protective neutralizing antibody responses to COVID-19 vaccination in 58 patients with WM, chronic lymphocytic leukemia (CLL), or non-Hodgkin's lymphoma (NHL) in the journal *Clinical and Experimental Medicine*. The data were compiled after one dose of the Pfizer and AstraZeneca vaccines. On Day 22 after the first vaccine dose, WM/CLL/NHL patients had lower neutralizing antibody titers compared to normal controls. More specifically, the respective numbers of patients and normal controls who developed titers equal to or greater than 50% (the clinically relevant value for viral inhibition) were 5% and 24%, respectively. These results were independent of vaccine type. The WM patients with titers equal to or greater than 50% were in remission, not receiving current therapy for their disease, off treatment for more than one year, and had normal IgG and IgA levels. The trial also confirmed other reports that patients treated with ibrutinib, venetoclax, and/or anti-CD20 antibodies were unlikely to respond effectively to a single dose of vaccine. The researchers concluded that even though response rates were not optimal, vaccination is still considered essential and should be performed before treatment, if possible. The study is ongoing.

Regeneron Treatment for COVID-19 Can Be Used After Virus Exposure but Prior to a Positive Test – Regeneron announced that its monoclonal antibody cocktail REGEN-COV for COVID-19 treatment can be used in individuals 12 years and older after exposure to the virus but prior to a positive COVID-19 test when they are at increased risk of progressing to severe disease. Previously, the treatment could be used only if an individual tested positive for COVID-19. The new indication is based on results of a Phase 3 trial, in which REGEN-COV reduced the risk of symptomatic infections by 81% when used among household contacts of individuals infected with COVID-19. REGEN-COV can be administered by subcutaneous injection or intravenous infusion and can be repeated monthly for those with ongoing exposure to the virus. Adverse events included mild to moderate injection site reactions in 4% of trial participants.

Pooled Immunoglobulin Used to Boost Low IgG Is Approaching Therapeutic Levels of Neutralizing Antibodies Against COVID-19 – Immunocompromised people with low IgG may receive pooled immunoglobulin, which is a concentrate primarily of IgG derived from 1,000 to 100,000 healthy donors given to boost IgG levels and help prevent a variety of infections. An article published in *The Journal of Infectious Diseases* discussed results of pooled immunoglobulin testing for the presence of protective neutralizing antibodies against the COVID-19 virus. Immunoglobulin lots released since March 2020 were tested for COVID-neutralizing antibodies, with the first positive results determined in September 2020 lots. From there, neutralizing antibody values have steadily increased and were anticipated to have reached a potency of approximately 400 IU/mL by July 2021; at that level, pooled immunoglobulin will have an amount of neutralizing antibodies approaching that seen in convalescent plasma, which has emergency use authorization for the treatment of hospitalized COVID-19 patients.

ASCO Presentation Concludes That Major Response to First-Line Chemoimmunotherapy at Six Months Is Significant Predictor for Survival in WM – A multi-center international group presented an abstract at the American Society of Clinical Oncology (ASCO) Annual Meeting analyzing the depth of response from fixed duration chemoimmunotherapy in WM patients and its impact on survival. The study included 319 WM patients treated with first-line fixed duration therapy consisting of DRC (dexamethasone, rituximab, and cyclophosphamide); BR (bendamustine and rituximab); or BDR (bortezomib, dexamethasone, and rituximab). Response at the completion of six months of therapy was used as a basis for analyzing progression-free survival, time-to-next-treatment, and overall survival. Median follow-up was 63 months. Five-year progression-free survival from completion of therapy for patients who achieved a major response (partial response or better) at six months was 71% vs. 43% for those who did not. Five-year time-to-next-treatment for patients who achieved a major response at six months was 84% vs. 54% for those who did not. Five-year overall survival for patients who achieved a major response at six months was 92% vs. 77% for those who did not. The authors concluded that reaching a major response at six months after first-line chemoimmunotherapy is a significant prognostic factor for survival outcomes in WM patients.

Cellectar Presents Poster on Phase 2 Study of CLR 131 for WM at ASCO Annual Meeting – Cellectar Biosciences presented a poster at the American Society

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of Clinical Oncology (ASCO) Annual Meeting about its targeted radiotherapy drug CLR 131 (now designated iopofosine I-131) used in the Phase 2 CLOVER-1 study of six WM patients. The company reported a 100% overall response rate, with a major response rate of 83.3% (including a complete response rate of 16.7%). The median time-to-initial response was 22 days after the first infusion, with the median time-to-major response (at least a 50% reduction in IgM,) occurring 44 days after the first infusion. Progression-free survival in multi-drug refractory WM patients was 11 months, while it had not been reached after 18 months for other WM patients. The most frequently reported adverse events were cytopenias (low counts of one or more blood cell types). CLR 131 is a small molecule phospholipid drug conjugate intended to provide targeted delivery of iodine-131 directly to cancer cells, while limiting exposure to healthy cells. The company was recently awarded a National Institutes of Health grant to continue development of the drug.

*The **overall survival** for smoldering WM patients was comparable to an age, sex, and calendar-year matched US population...*

Updates Presented for Phase 1/2 Clinical Trial of Pirtobrutinib in Relapsed B Cell Malignancies – Updates were presented in the journal *Lancet* from a Phase 1/2 clinical trial of pirtobrutinib (also known as LOXO-305) in patients with relapsed B cell malignancies. This BRUIN trial enrolled 323 patients, of whom 269 were evaluable and 183 still on treatment by the time of this analysis. To be eligible, participants received two prior treatment regimens that they failed or were intolerant to, or they received a prior BTK-containing regimen as front-line therapy. Patients with BTK C481 mutations that cause resistance to ibrutinib (Imbruvica) were also included. During this study, 87% of adverse events were mild or moderate, while serious neutropenia (low neutrophil count) was observed in 10%. Less than 1% experienced atrial arrhythmias. Of 26 WM patients enrolled, 19 were evaluable for response and had an overall response rate of 68%; those with prior BTK inhibitor therapy had an overall response rate of 69%. The maximum tolerated dose level was not established as there were no incidents of dose-limiting toxicities; however, 200 mg daily was selected as the recommended Phase 2 dose because it achieved a 96% BTK target inhibition.

Mayo Clinic Publishes Study on Progression and Overall Survival in Smoldering WM – Patients with asymptomatic/smoldering WM have a variable risk of progression to active WM. An observational study conducted at the Mayo Clinic and published in the *British Journal of Haematology* evaluated 143 patients with smoldering WM from January 1996-December 2013. With a median follow-up of 9.5 years, the cumulative rate of progression was 11% at one year, 38% at three years, and 55% at five years. At diagnosis, hemoglobin equal to or less than 12.3 g/dL and beta 2 microglobulin equal to or greater than 2.7 mcg/mL were independent predictors of a shorter time-to-progression (TTP). Patients with wild type (unmutated) MYD88 demonstrated a trend toward shorter TTP, while the presence of CXCR4 mutations did not impact TTP. The overall survival for smoldering WM patients was comparable to an age, sex, and calendar-year matched US population, with the researchers suggesting that this argues against pre-emptive treatment intervention in smoldering WM.

China Conditionally Approves Zanubrutinib for Relapsed WM and Researchers Discuss Phase 2 Trial Results for Zanubrutinib in Chinese Patients with WM – BeiGene, Ltd. announced that zanubrutinib (Brukinsa) has received conditional approval from the China National Medical Products Administration for the treatment of adult patients with WM who have received at least one prior therapy. In a separate development, Chinese researchers published data in the journal *Clinical Cancer Research* from their Phase 2 trial of zanubrutinib in 44 Chinese patients with relapsed/refractory WM. Prior to the trial, published data on this treatment in the Asian WM population were scarce. After a median follow-up of 33 months, the major response rate was 69.8%, with 32.6% of these achieving a very good partial response. All mutation groups benefited from zanubrutinib treatment, with a higher major response rate (73%) occurring in patients with the MYD88 L265P mutation; however, a major response rate of 50% was attained in patients with wild-type (unmutated MYD88), even though this group is typically resistant to treatment with ibrutinib (Imbruvica). Median progression-free survival and median duration of major response were not yet reached. The most frequently reported adverse events were decreased neutrophil count, decreased platelet count, and pneumonia; no cases of atrial fibrillation occurred. The drug was discontinued due to adverse events in 13.6% of patients.

US FDA Approves Generic Form of Ibrutinib – The US Food and Drug Administration (FDA) has approved a generic form of ibrutinib (Imbruvica) in 70 mg and 140 mg capsule dosing strengths. The manufacturer, Zydus Cadila, was the first company to submit a complete Abbreviated New Drug Application for generic ibrutinib, making it eligible for 180 days of generic drug exclusivity for marketing the product. It is unclear when a generic drug for ibrutinib will become available in the US, as Pharmacyclics and Janssen Biotech are currently in litigation against Zydus Cadila and other companies for patent infringement.

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Study Discusses Eye Problems in Monoclonal Gammopathy – An article published in the *Journal of Ophthalmology* discussed ocular (eye) problems in people with monoclonal gammopathy. Eighty patients diagnosed with and/or treated for conditions associated with monoclonal gammopathy between 1997 and 2020 were analyzed by Hungarian and German researchers. The group included nine patients with MGUS (monoclonal gammopathy of undetermined significance), 61 with multiple myeloma, six with smoldering multiple myeloma, two with WM, and two with amyloidosis. An age-matched control group of 43 without hematological disease was included. The best-corrected visual acuity was significantly worse in subjects with monoclonal gammopathy than in controls. Among gammopathy subjects, the researchers observed potential corneal immunoglobulin deposition in 3.75% of patients. Ocular surface disease, posterior cortical cataract, and cataract were significantly more common among gammopathy subjects than controls.

The best-corrected ***visual acuity*** *was significantly worse in subjects with* ***monoclonal gammopathy*** *than in controls.*

EHA Presentation Provides Details from Phase 3 Trial Comparing Acalabrutinib to Ibrutinib in Previously Treated CLL – A paper presented during the European Hematology Association (EHA) 2021 Virtual Congress provided details from the Phase 3 ELEVATE-RR clinical trial that compared head-to-head the safety and efficacy of acalabrutinib (Calquence) to ibrutinib (Imbruvica) in 533 patients with previously treated chronic lymphocytic leukemia (CLL). A total of 268 were assigned to the acalabrutinib arm and 265 to the ibrutinib arm; patients had received a median of two prior therapies. At a median follow-up of 40.9 months, the median progression-free survival was 38.4 months in both arms, while the median overall survival was not reached in either arm. The rate of atrial fibrillation of any grade was 9.4% for acalabrutinib and 16.0% for ibrutinib, and the time-to-onset for atrial fibrillation was 28.8 months and 16.0 months, respectively; the condition led to treatment discontinuation in seven patients on ibrutinib and none on acalabrutinib. Headache and cough were more common with acalabrutinib than ibrutinib, and diarrhea, muscle aches, hypertension (high blood pressure), confusion, bleeding, and interstitial lung disease/pneumonia were less common in acalabrutinib. Rates of serious infection were similar. Treatment discontinuation because of adverse events occurred in 14.7% of patients on acalabrutinib and 21.3% of patients on ibrutinib.

Shingrix Vaccine Receives Expanded Approval by US FDA for Immunocompromised Adults 18 Years and Older – Shingrix, the non-live virus vaccine used to help prevent shingles, received expanded approval by the US Food and Drug Administration (FDA) for adults 18 years and older at a greater risk of shingles due to immunosuppression caused by disease or therapy. Shingrix was initially approved in 2017 for adults 50 years and older.

Phase 3 Study Compares Ofatumumab and Bendamustine to Bendamustine Alone in Indolent NHL Patients Unresponsive to Rituximab – A randomized Phase 3 study, designated COMPLEMENT A + B, compared outcomes of the combination of ofatumumab (Arzerra) and bendamustine to bendamustine alone in 346 patients with indolent non-Hodgkin's lymphoma (NHL) who were unresponsive to prior rituximab (Rituxan)-based treatment. Median progression-free survival was 16.7 and 13.8 months in the combination and monotherapy arms, respectively, while median overall survival was 58.2 months and 51.8 months, respectively. However, the study did not meet its primary endpoint of statistically significant improvement in progression-free survival and overall survival in the combination arm. The trial results were published in the *British Journal of Haematology. [Editor's Note: Ofatumumab will no longer be commercially available, although it can still be obtained for clinical use through the Patient Assistance Novartis Oncology (PANO) program.]*

Long-Term Phase 1 Trial Results Presented for Venetoclax in Relapsed/Refractory NHL – An article in the journal *Clinical Cancer Research* reported long-term follow-up results from a Phase 1 trial of patients with relapsed or refractory non-Hodgkin's lymphoma (NHL) treated with venetoclax (Venclexta). All 106 patients received venetoclax in dose cohorts of 200-1200 mg daily until disease progression or unacceptable toxicity. Included in the trial were patients with WM, follicular lymphoma, mantle cell lymphoma, and marginal zone lymphoma. At a median follow-up of 38.5 months, median progression-free survival for the WM patients was 30.4 months, and median duration of response was 25.3 months. The most common hematological adverse events were neutropenia (low neutrophil count), anemia, and thrombocytopenia (low platelet count), while non-hematological adverse events included nausea, diarrhea, and fatigue.

The rate of ***atrial fibrillation*** *of any grade was* ***9.4%*** *for acalabrutinib and* ***16.0%*** *for ibrutinib...*

Interim Results Presented at ASCO for TG-1701 as a Single Agent and as Part of a Triple Combination for NHL and CLL – Interim results were presented from an international Phase 1 study evaluating the BTK inhibitor TG-

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1701 as single agent therapy and as part of a triple combination with the anti-CD20 monoclonal antibody ublituximab and the PI3K inhibitor umbralisib (Ukoniq) in patients with front-line or relapsed/refractory non-Hodgkin's lymphoma (NHL) and chronic lymphocytic leukemia (CLL). The data, presented during the American Society of Clinical Oncology (ASCO) Annual Meeting, included results from 125 patients, all of whom were not previously treated with BTK inhibitors. In the once-daily 200 mg single agent TG-1701 group, the overall response rate for WM was 95%. The triple combination group has so far achieved an overall response rate of 79% for all conditions, with a complete response rate of 21%. Adverse events for single agent TG-1701 included atrial fibrillation and hypertension (high blood pressure), while adverse events for the combination included diarrhea, neutropenia (low neutrophil count), and increases in the liver enzymes ALT and AST. Recruitment for the study is continuing, and its identifier on *www.clinicaltrials.gov* is NCT03671590.

Phase 2 Study Reports Long-Term Results for Combination Ibrutinib and Venetoclax in Newly Diagnosed CLL – Researchers at the MD Anderson Cancer Center reported that the combination of ibrutinib (Imbruvica) and venetoclax (Venclexta) was found to provide lasting disease remission in 80 patients with newly diagnosed chronic lymphocytic leukemia (CLL). This finding from a Phase 2 study was published in the journal *JAMA Oncology* and offered data after median follow-up of 38.5 months. The treatment combination was given for two years and then discontinued. Three-year progression-free survival was 93%, and three-year overall survival was 96%. A total of 75% of patients achieved undetectable minimal residual disease status (U-MRD) in the bone marrow at some point during therapy.

The author gratefully acknowledges the efforts of Glenn Cantor, Grete Cooper, Steven De Cenzo, Peter DeNardis, Julianne Flora-Tostado, Tom Hoffmann, Pavel Illner, Meg Mangin, Colin Perrott, Howard Prestwich, Richard Savoy, Charles Schafer, Ron Ternoway, and others in disseminating research news of interest to the WM community. The author can be contacted at suenchas@bellsouth.net *for questions or additional information.*

Spotlight ON SUPPORT GROUPS

EDITOR'S NOTE:

As the support group section continues to evolve away from individual reports, we begin to spotlight certain groups, activities, or people. As always, for particular information about when and where meetings are being held, go to the Events Calendar at *iwmf.com* for listings: *https://iwmf.com/events-calendar/*

WHAT A SUPPORT GROUP IS NOT

Why I Hated Support Groups Before I Ever Attended One

By Lisa Wise, IWMF Vice Chair, Information and Support

I arrived five minutes early to my very first cancer support group meeting in 2014.

The only problem was that I could not bring myself to get out of the car.

A huge part of me wanted to turn around and head back home to safety. To ease my fears, I promised myself aloud: "If you hate it, you never have to go back!" But it came out a little too cheerleader-ish. I thought of all the negotiations I'd had with my kids throughout the years. Drop-off on the very first day of anything was scary—kindergarten, day camp, music lessons. Beginnings were intimidating. What if the other kids (WM patients) weren't nice? What if I hated the teacher (support group leader)? What if hearing all their stories made me sad? What if I didn't want the "cancer patient" label in my face? I gripped the steering wheel even tighter, affirming my resolve. I wasn't going anywhere. Too scary.

But I was there for a reason. Diagnosed in 2010 at age 45, I had enjoyed four years of living with WM in the laid back, casual "watch and wait" phase. But then I officially shifted into the active and anxious "watch and worry" stage. My numbers were steadily climbing, and my symptoms were slowly increasing. There was no denying disease progression. My oncologist had already begun planting the seeds for future treatment. It was time to seek out support. I needed to find some trustworthy friends on the WM playground who could show me the ropes (*how do I understand my blood results?*), tell me that going down the slide wasn't as scary as it looked (*how would I survive treatment?*) and affirm how high I could climb on the jungle gym (*would the fatigue EVER get better?*). I wanted to know if I could still play despite having the shadow of cancer hanging over my shoulder forever. Would I be brave enough to swing as high as the sky? Could I enjoy life fully after diagnosis? I knew I had a lot of questions. What I didn't know was what it would it be like to ask a room full of total strangers.

Sitting in my car I came up with a workable solution: I would set my phone alarm to ring 17 minutes after the support group began. I carefully chose a ring tone that sounded just like a phone call coming through. That way, when the alarm went off, I could hurriedly rummage through my bag to turn it off and jump up and apologize to everyone for needing to take the call outside. Then I would run like the wind, hop in my car, and high tail it out of cancer support group hell, never to see those sorry folks again. Success! My flawless plan seemed airtight, so I gathered up my courage, set my phone alarm carefully, and walked in the front door, all smiles and sweetness. I was ready and fully present to meet whatever awaited me—for exactly 17 minutes, at the very most.

Then the strangest thing in the world happened. Quite unexpectedly, I fell in love.

I connected with the warm support group leader and friendly group members. I met a fellow newbie who walked in the door with me and became my instant BFF as we grabbed seats next to each other. When IWMF President Carl Harrington gave me the warmest WM welcome in his hip Hawaiian shirt, I knew I'd found home. The meeting was uplifting. The people were impressively well-informed about WM and tremendously thoughtful about their disease management. The leader was empathically compassionate and instinctively knew the perfect balance for group sharing in a healthy, boundaried way. Most surprisingly of all, the snacks were really good! They had me at "hello" (actually, homemade cookies). I admired their wicked senses of humor. This gang knew how to laugh and have fun. I never knew that people laughed during cancer support groups.

I had plenty of pre-conceived notions about what a support group was *supposed* to be. But I had no idea what a support group was actually like. Here are five important things that I've learned about IWMF support groups:

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1. Support groups are NOT downers
WMers worldwide gather to support each other and share their experiences. Conversations typically cover the entire spectrum of topics and emotions, from struggle to celebration, fear to flourishing, worry to relief. People laugh, people cry. There are moments of joy and moments of pain. It is real and honest. Support group members tend to live their lives fully in spite of their WM. There is a constant seeking out and striving to balance WM with the rest of busy, bustling lifestyles. I always leave feeling more uplifted and connected and less alone. It's that powerful.

2. Support groups are NOT only for the very sick
People attend meetings from all across the disease spectrum—newly diagnosed sit beside 20+ year veterans. Some have experienced a plethora of different treatments and clinical trials, while others have been on watch and wait for over a decade. Every WM patient is absolutely unique, bringing his or her own flavor and perspective to the game. Together we share knowledge, experience, and HOPE. Stepping into my first support group meeting, I anticipated entering a sickly-looking "Planet Cancer." I expected a room full of bald heads with no eyebrows, ashen faces with sad looks in their eyes. Instead, I could not tell the difference between the WM patients and their loving care partners. I was shocked to see that WMers looked like regular, run-of-the-mill folks. What a relief. I would not lose my identity entirely. I could be a cancer patient but also keep being "me."

3. Support groups are NOT the same at every meeting
Some groups facilitate informal sharing and caring circles. Some groups invite rockstar WM experts with formal PowerPoint slide presentations. Most groups do a mixture of both, so there's something for every WMer out there! You can learn how to be your own best advocate armed with research, data, and spreadsheets. You can learn how to be your own balanced best friend, with wellness tips, mindfulness, and emotional support. You can have it all—you just have to find the right group of Waldenfriends! Education, information, AND support are the goals!

4. Support groups are NOT a sign of weakness
Participating in a support group is a sign of strength. A community of camaraderie is built by asking each other questions, learning from each other's wisdom, turning toward one another with challenges, celebrating together in times of joy. Every person brings something to offer that makes the group grow stronger.

5. Support groups are NOT meeting in person, but they are THRIVING!
For the past 16 months, all IWMF support groups have been meeting virtually on Zoom. We have safely stayed connected through the pandemic and successfully created community while in lockdown. Who knew that you could offer such heartfelt support through a screen? The IWMF is closely following guidelines from WM experts at Dana-Farber Cancer Institute and Mayo Clinic about resuming in-person meetings safely. In the meantime, group meetings are multiplying and attendance is blossoming! Turns out folks like logging in from the comfort and convenience of their own living room couches! What's more supportive than sweatpants?

Back in that first meeting room, after exactly 17 minutes had passed, my phone rang from the bottom of my purse. I jumped up in my chair, annoyed at the unwanted interruption. I was so involved in the caring circle, so engrossed in the conversation, that I had totally forgotten my escape plan. I quickly silenced the ringer and ignored my faux phone call. I apologized to the group—who were now my new best buddies on Planet WM—and explained that the (phantom) caller would have to wait. THIS conversation was far more important.

I have been attending, leading, and coordinating support groups nationwide since that day in 2014. But I always make a point, before every meeting, to turn off my cell phone. After all, THIS conversation is far more important. No escape hatch needed. I found my WM home. And I hope you do too. For more information about an IWMF support group meeting remotely on Zoom in your area, please visit here: *https://iwmf.com/us-and-international-support-groups/*.

The ever-popular Chili in Philly in November 2019. Now we connect over Zoom!

IWMF BING NEEL SUPPORT GROUP

By Julie Davidson

Bing Neel syndrome (BNS) is a rare, and often for sufferers, lonely disease (Is there anyone else like me? Can anyone really understand how I feel?). If you consider that the incidence of WM is approximately 3-5 people per 1,000,000 and that Bing Neel syndrome may be found in approximately 1% of the WM population, it is easy to understand how alone you might feel.

There is an IWMF support group especially for BNS patients. It is important not to feel alone, and since others struggle with the same thing, it is so much easier when we can reach out to someone else in the same situation.

BNS can present along with the typical signs and symptoms of WM, but more often occurs when they are minimal or absent, and in some patients it may be the first indication that they have WM. It can affect any aspect of the central nervous system (brain and spine), and its presentation can be quite variable, complex, and in need of exquisite investigatory skills. No wonder the person with BNS can feel confused, anxious, misunderstood, and helpless.

However, the lot of the BNS patient has improved and continues to improve. Take, for example, Julie Davidson's story (a BNS patient diagnosed in 2012). When Julie was diagnosed, the survival odds quoted were grim (two years max) and help was limited. As Julie recalls, at that time very little was known about BNS, so she needed to take searching for an answer into her own hands. Julie posted a query on the IWMF Connect precursor and got dead silence. To quote her, "I felt even more alone. Eventually, two men emailed me to say they had it but didn't know of anyone else." Julie found research "challenging—there was very little, and when I found it, the news wasn't good. I felt very alone." Most doctors had never heard of it. As Julie states "When I suspected it, I decided to go see Dr. Steven Treon at Dana-Farber Cancer Institute, who diagnosed my BNS."

Consider Peter Freese, who was diagnosed in 2016 with BNS after being initially told he had "executive stress" and that a few sessions with a psychologist would help. Five years later and after some good treatment, he plays tennis three times a week, volunteers, and generally lives alongside his BNS.

Today we have learned much. The experience of a BNS patient can be much better due to new medicines and interested specialists. There are still more questions than answers. It is very rare and largely unknown to most oncologists. However, the frequency of diagnosis has improved, and more importantly, treatment is better—less toxic, with a marked increase in survival rates. There is improvement.

It is important to seek out a WM specialist to be a part of your medical team, someone who knows and has treated BNS. If that specialist is not available in your area, seek out one of the WM and BNS specialists around the world who can support you. For instance, Dr. Jorge Castillo at Dana-Farber has a particular interest in BNS and either consults globally with other doctors or sees patients in person at Dana-Farber.

In our BNS support group, email addresses are shared, and, sometimes contact information is exchanged, so that members can reach out to each other for support. Periodically, new articles or notices about upcoming events pertaining to BNS are circulated. Recently Zoom get-togethers are being organized, where we might have a speaker or small break-out groups that give us a chance to meet each other.

So! If you have BNS, please join us by reaching out to Julie Davidson, or one of the other IWMF LIFELINE volunteers who also lead the group. You are not alone and you are heard!

Julie Davidson — Tucson, AZ, USA
jefdavidson@icloud.com — 615-429-2017

Peter Freese — Sydney, Australia
peterfreese@bigpond.com — 0429022665

Stuart Quick — London, England
stuartq9961@icloud.com — 0044 07774264805

YOUNG WM SUPPORT GROUP

New Kids On The Block: Meet Our Fabulous Young WMers!

Deborah Kelly, co-leader of Young WM Support Group

The Young WM Support Group held its inaugural meeting on July 19. Eleven attendees got to know each other by sharing histories and discussing what topics the newly established group should prioritize. Ryan Scofield (LIFELINE Volunteer for Young WM) and Deborah Kelly led the discussion with support from Shelly Postek (IWMF manager of Information & Support), Lisa Wise (IWMF vice-chair of Information & Support), and Patience Robinson (IWMF South Bay, CA Support Group leader).

The meeting discussions were well received. The group's goal is to provide much needed support to a subset of WM patients and caregivers who are under the age of 50. Support topics will focus on issues that might be more aligned with young people, such as juggling parenting, work, and WM treatments.

Ryan Scofield, co-leader of Young WM Support Group, and his daughter Gridley

There is a lot of excitement about this unique group, and they look forward to welcoming new faces as they increase participation. Since the group meets online in a virtual setting, all international participants are warmly encouraged to get involved! If you or someone you know has WM and is under 50 years old, please invite them to join!

To join the Young WM Support Group mailing list, contact *office@iwmf.com* or call 941-927-4963.

BRINGING PEOPLE TOGETHER VIA ZOOM

By Cindy Jordan, Oregon/SW Washington Support Group Co-Leader

The word zoom used to mean "to go with great speed," but the pandemic changed all that. In 2020, enter into public consciousness a company that calls itself Zoom, enter a deadly virus that calls itself COVID-19, and a new method of communication catches on and the word zoom assumes an entirely different connotation.

The Zoom software platform developed for remote meetings ushered in a new method of communicating with our local support groups. At first, seeing headshots on a screen seemed awkward compared to an in-person meeting. But over time through Zoom, we became a cohesive group and looked forward to touching base with one another, whether with a speaker or simply having a sharing and caring session.

An added benefit is an acceptable form of Zoom-bombing. WMers who live too far away to attend an in-person meeting can participate. This has been one of the most beneficial aspects of using Zoom. WM patients living where there is no support group (think Kodiak, AK, or wherever a support group may be inactive) are able to engage with another group.

Support group leaders from across the US and Canada now connect face-to-face because of Zoom to share ideas and meeting strategies. Previously, that possibility only existed at an annual IWMF Ed Forum. Our WM support world has grown exponentially because of Zoom.

Many are eager to resume pre-pandemic business as usual. However, until our medical advisors at Dana-Farber and Mayo Clinic tell us we can safely meet in a room together, we will continue to run only Zoom meetings. The IWMF cannot condone in-person meetings before WMers can do so without fear of spreading or contracting the COVID virus. Even then, we will most assuredly continue with a hybrid model, holding both Zoom and in-person gatherings. Though no substitute for meeting face-to-face, Zoom still has tremendous value for bringing our members together.

TRIBUTE TO ROGER L. ROBINETTE

By Jane Loud, South Carolina Support Group Leader

Roger Robinette was a founder and long-term leader of the South Carolina Support Group and long-time supporter of the IWMF. He passed away on June 27, 2021, at the age of 80 from complications from WM.

Roger was diagnosed with WM in 1996 when he was 55. He first sought treatment in Winston-Salem, NC. He soon contacted Arnie Smokler via the internet, which put him on a whole new path. Roger and his wife Barbara attended the IWMF Educational Forum in Richmond, VA, in 1997. This was the first of six conferences they would attend over the years.

Roger and Barbara joined the GA Support Group for several years and would attend "getaway" weekends in Atlanta. Joyce Spencer, the GA leader, was asked to host the Atlanta Forum in 1998. Roger and Barb assisted with planning and registration.

In 2004, Roger contacted John and Paula Austin about starting a SC group. The two couples worked together for many years. Roger and Barb officially became co-leaders after John's passing in the fall of 2013. Jane Loud volunteered in 2019 to assist with the group. Members would meet in person twice a year until the COVID pandemic moved the group virtually to Zoom. Roger and Barb saw many changes over the years and continued to co-lead the SC group until Roger's passing.

Roger was a strong self advocate who actively participated in his treatment decisions. He became known for his spread sheet tracking of his disease progression and would present for every doctor visit with his iPad open to his detailed history. Roger was very happy and proud to be a part of the IWMF.

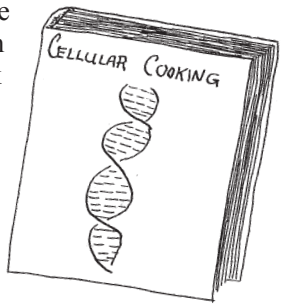
IWMF-FUNDED RESEARCH: THE NEW 2021 GRANT UNDER THE IWMF-LLS STRATEGIC RESEARCH ROADMAP

By Glenn Cantor, IWMF Trustee and Science Editor

Dr. Christopher Oakes, James Comprehensive Cancer Center, The Ohio State University, Columbus, Ohio, USA

Harnessing epigenetic signatures for new insight into the mechanisms and classification of WM

Imagine the DNA sequence (the genes) of a cell as a cookbook, in which the genes instruct a cook (the cell) how to prepare a huge variety of foods. Conceivably, a cook could start at the beginning on page one, follow the recipes on each page, and prepare every dish in the cookbook. The complete cookbook can be seen as the "genome," a complete set of instructions.



But now, imagine that some of the pages are stuck together with tomato paste or honey and are unreadable. The cook can only read recipes (genes) from the pages that are accessible and not stuck together. Perhaps the chapters on lunches are glued together, and only the chapters on breakfast and dinner are available. The cookbook has become modified, and only portions (a subset of genes) can be read. That is the "epigenome" and the study of the epigenome is called "epigenetics."

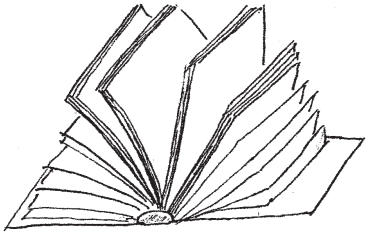
It is easy to imagine how cookbooks can be modified in different ways. Even though each cookbook, when newly purchased from the bookstore, contains exactly the same recipes ("genome"), one family's cookbook might have the lunch chapters glued together and unavailable, while another family's cookbook might have the dinner chapters glued together and unavailable ("epigenome").

Even though every cell contains the complete cookbook, each cell type, such as liver cells, heart cells, and so on, has modified cookbooks. Some of the pages are glued together and some are accessible. That is the normal epigenome, and it helps explain the differences between cell types.

When a normal cell transforms into a cancerous cell, the epigenome changes. A different set of pages in the cookbook are glued together. Some of the pages that were glued together and inaccessible in the normal cells open

IWMF-Funded Research, cont. on page 19

up and become readable in the cancer cells. That change in the epigenome often results in activation of genes that were previously shut off or repressed. Meanwhile, pages that used to be open in the normal, non-cancerous cell might become glued together and inaccessible in the cancer cell. That would result in shutting down some of the normal genes.



The master cook (the chef), who reads and prepares recipes from the open, accessible pages, has assistant cooks or sous-chefs. Each assistant cook has their own responsibilities for a portion of the meal. One might be responsible for preparing vegetables, while another is responsible for baking. Like the master chef, the sous-chefs can only use open pages, but within the open pages, they select and prepare only recipes that fall within their responsibilities. These assistant cooks can be thought of as "transcription factors," regulatory proteins that control and make particular sub-portions of the meal.

Imagine a cancer cell, which has pages that used to be inaccessible in its cookbook, now has pages that are suddenly wide open. The transcription factors (assistant cooks) shift their efforts and start preparing foods that they never were allowed to prepare before. This also suggests possibilities for cancer control. It might not be so easy to re-glue the cookbook and reset the entire epigenome, but what if the restaurant fired the out-of-control, rogue assistant cook? Could a drug be used to inhibit a specific transcription factor?

In the Roadmap Grant awarded in 2021, Dr. Christopher Oakes and his laboratory will investigate how epigenetics and transcription factors affect WM.

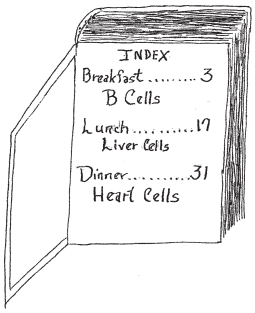
Last year, Dr. Oakes reported two categories of WM patients. In some patients, the pattern of open (available) and closed (unavailable) genes resembled a type of normal cell called the "plasma cell." In other patients, the pattern of open and closed genes was very different and resembled another type of normal cell, called the "memory B cell." For more information, see the article on page 7 in the October 2020 *Torch* (*https://iwmf.wpengine.com/wp-content/uploads/2020/10/torch-oct-2020.pdf*) or Dr. Oakes' 2020 paper in *Blood* (*https://iwmf.wpengine.com/wp-content/uploads/2020/10/methylation_subtypes_WM_Aug2020.pdf*).

In the present grant, Dr. Oakes and his laboratory will dig more deeply into understanding the epigenetic changes of WM cells, including the two types he previously identified. The group will use new technology to study individual cells and even determine epigenetic changes on individual DNA molecules. The ability to analyze individual DNA molecules is an important scientific breakthrough, since previously, most scientists could only analyze large numbers of DNA molecules in their aggregate, studying the average changes among the whole mixture. This work will help better understand which areas of the genome are accessible, leading to gene expression and protein production, and which areas are closed and inaccessible (the pages of the cookbook that are stuck together).

These researchers will also try to better understand exactly what leads to the characteristic epigenetic changes seen in WM cells. They have evidence that these changes are related to the mutated MYD88 protein that is seen in nearly all WM patients, and they will pursue specific signaling pathways that might lead from the mutated MYD88 to epigenetic alterations.

In addition, Dr. Oakes and his group will focus on one of the "assistant cooks" or "sous-chefs," a regulatory protein (transcription factor) called HNF1B. This protein selectively activates a number of genes, and Dr. Oakes and his group will investigate which genes and how they are regulated.

If you don't like the food on your table and want to change it, you need to understand which pages of the cookbook are unavailable, what it is that holds those pages shut, which cook prefers to prepare only certain recipes and not others, and why the cooks and their assistants make the decisions they do.



Similarly, it may be possible to change WM cells into less harmful cells, if scientists could better understand epigenetic changes that make certain areas of the genome open or closed, what drives those epigenetic changes, and how WM cells select specific transcription factors to activate sets of genes within the open areas.

Illustrations by Ginny-Kay Massara

PUTTING THE "I" IN IWMF

BY PAUL KITCHEN, IWMF BOARD MEMBER AND CHAIR OF THE INTERNATIONAL COMMITTEE

Twenty-five countries from around the world are affiliated with the IWMF. Each affiliate has started in much the same way as the IWMF did—with a few WMers getting together. They realized that contact and sharing information with each other was a helpful and a more hopeful path for those diagnosed with our strange and incurable disease. Some affiliates have been in operation for 20 years, while others are newly formed.

Elena Malunis, who retired from the IWMF Board in December 2020, led the growth of our international affiliates. She worked tremendously hard to increase their number and establish personal relationships with all their leaders. Elena kept the "I" in IWMF, and we are looking to springboard off all her efforts as we go forward.

The IWMF Board continues to be committed to offering help and support to all our international affiliates. There is an understanding that the more WM patients we have supporting our search for a cure, the more we can all accomplish. Our vision of a world without WM will be achieved more quickly by all WMers working together.

Each affiliate has a challenge in assisting the WMers in their jurisdictions because of the unique set of circumstances in every country—medical systems are different; some have national health systems, some do not; drug therapy approval is unique to every country; affordability and access to new WM treatments are extremely varied. Some countries allow and support a drug therapy, while others may prevent the therapy from being delivered. Almost all the new small affiliates have the same problems that Arnie Smokler did 25 years ago in the US, trying to gather the names of WMers, trying to establish a way of connecting with each other, and trying to find medical people to take an interest in our rare disease. Finding local medical experts in WM is still a challenge that every IWMF affiliate faces.

The IWMF is constantly looking for ways to support our affiliates and their members. In this last year, Zoom licences have been offered to each affiliate. All affiliates also have access to all of our IWMF publications, which have been translated into eight languages: Chinese, French, German, Italian, Norwegian, Polish, Portuguese, and Spanish.

This spring we began holding Zoom meetings to gather all the affiliates to try to create a better sense of community. It is encouraging and helpful for the leaders of each country's WM group to get to know others who are doing the same thing. We are also able in these Zoom calls to find out what the IWMF can do to help WMers in their countries and assist in their mission. In the past we have offered support to an affiliate leader to attend our annual Ed Forum, and we plan to do the same in Seattle in 2022, when we are, we hope, once again able to hold the event in-person.

Lisa Wise, our vice chair of Information and Support, has graciously offered to help support group leaders from around the world and has invited these leaders to support group leader meetings she holds on a regular basis. A number of affiliates have taken advantage of Lisa's offer and are pleased to learn from her experience.

One of our goals is to continue to increase the number of WM affiliates around the world. As with the IWMF, this often starts with just one person seeking other WMers. Below is a list of the affiliates and their approximate number of members. If you know of a person with WM who lives in a country not listed here, please get in touch with them or with me at *paul@paulkitchen.ca*, and we will see if we can help launch another IWMF affiliate.

Affiliate	Number of Members		Affiliate	Number of Members
Argentina	30		Israel	20
Australia	200		Italy	60
Belgium	30		Mexico	10
Canada	450		Netherlands	70
Chile	10		New Zealand	50
China	30		Norway/Sweden/ Denmark	80
Finland	20		Portugal	10
France	100		South Africa	20
Germany	50		Spain	30
India	50		Taiwan	2
Ireland	40		UK	400

Helping more WM patients to have reliable up-to-date information about WM can make all the difference. Growing the number and membership of worldwide affiliates plays an important role in helping attain the IWMF's vision of a world without WM.

International Scene, cont. on page 21

International Scene, cont. from page 20

AUSTRALIA

COVAX-lymphoma study
By Peter Smallwood

The COVAX-lymphoma study is sponsored by Concord Hospital, Sydney Local Health District, and funded by the IWMF. It involves top specialists in the fields of WM and immunology and is targeted at patients with WM or follicular lymphoma only. Up to 40 WMozzies have signed up, had their blood drawn, and already received their first Pfizer COVID-19 vaccination.

The research is co-ordinated by the Kirby Institute, Sydney. Participant's blood samples will be taken prior to vaccination, 21 days after the first Pfizer jab, and 28 days and 180 days after the second Pfizer jab.

Antibodies to COVID-19 proteins (including the spike, membrane, and nucleocapsid proteins) will be determined. In addition, T cell activation in response to COVID will be measured to see if T helper and T cytotoxic cells have been sensitised by the vaccine to recognise and act against the virus. T cells are particularly important in blood cancer patients as they can provide immunity despite the absence of antibodies. We are fortunate to have access to such sophisticated science, and the results will be fascinating.

Our thanks go to the IWMF and to Prof. Judith Trotman, Dr. Brendan Beaton, Dr. Katherine Rankin, Dr. Juliette Raedemaeker, Dr. Alexander Wong, Andrew Warden (the Concord study team), Prof. Anthony Kelleher, Dr. Sarah Sasson (Kirby Institute), Prof. Stephen Larsen (RPA), and Dr. Orly Lavee (St. Vincent's) for their efforts in making this possible.

Lymphoma Australia webinar
By Michael van Ewijk, WMozzies Committee

Lymphoma Australia (LA) noticed an increasing amount of concern amongst lymphoma and CLL patients in relation to COVID and vaccines. To alleviate this concern, LA hosted a COVID webinar on July 29, 2021. The webinar was led by Prof. Judith Trotman from Concord Hospital in Sydney. She spoke in detail about COVID-19 and its implications for lymphoma and CLL patients. She was followed by Dr. Juliette Raedemaeker, who talked about the latest global data showing vaccine response in these same diseases. The last speaker was Dr. Julianne Falconer, who spoke about the rare but serious issue of blood clots associated with certain COVID vaccinations.

CANADA

Spotlight on the British Columbia Support Group
By Kit Schindell, Co-Leader

Our group started over 50 years ago! Well, not really, but...

In 1966 I met Betty McPhee in Vancouver. Three years later she was married and living in Philadelphia, and I was working on a medical team in West Africa. It was over 40 years later when we met by accident over coffee in a church in Toronto, where Betty and her husband now live. But we had no time to visit—I was flying back to Vancouver later that day. We agreed to connect on Facebook, and that's where Betty later learned that my husband had been diagnosed with a blood cancer.

WMFC
Waldenstrom's Macroglobulinemia Foundation of Canada

Betty knew I was a registered nurse with a long career in health care, and she knew I was familiar with the chemo regimen for WM. I'm not sure if she knew I had a lot of experience leading groups, but nevertheless, she asked me if I would consider facilitating a Vancouver group for WM people. Betty came to Vancouver, and we all met in a room provided by the BC (British Columbia) Cancer Agency. Bill, Brian, and Jimmy (and his wife Janet) were our first group members. That first group was a small cosmos of our present-day group. These three men were all at different stages of their illness; they each had something to offer, and they continue to offer to this day. Bill still exudes hope and calmness; Jimmy's deep, quiet intelligence gives us pause; and Brian's long experience with WM and heartfelt care for everyone in the group is a gift to us. Janet represents every caring spouse standing alongside their WM partner.

We started meeting in the lounge of my church in central Vancouver, kindly offered rent-free with free tea and coffee. Free parking too. But there were downsides—anyone living in the suburbs had a lot of driving to do, and our afternoon meetings meant trying to get home before rush hour. Taking transit was horrible. We could really only meet a couple of times a year.

Then came the pandemic. Obviously, our public meetings were out of the question. We moved to Zoom meetings, new to most of us. Jimmy had a Zoom licence and looked after the technical part. No one had to drive anywhere. No one had to rustle up energy to leave the house. For us, Zoom was a gift.

We had no idea what would happen next. The group blossomed! First, WM people who lived too far away to drive to meetings were suddenly able to access our group. Then we expanded it to the whole province. We started meeting monthly, and not a month has gone by that we haven't welcomed at least one new member. A few months ago, the WM Foundation Canada (WMFC) asked the groups to find a co-leader for each group. Our group chose Brenda Rogers, who is one of our younger group members,

International Scene, cont. on page 22

and we're a good mix. Brenda brought tech knowledge I don't have and whipped us into shape pretty fast. She's opinionated and smart. She brings energy to the group, is utterly knowledgeable about everything happening in the WM world, and generously shares it all. Where I'm quiet and reserved, Brenda is warm and exuberant. I'm old. She's not. We each have different skills and qualities.

Once we were established on Zoom, we were able to welcome Joe Lewicki, a WMFC Board member. I'd been hoping to have Joe as a guest speaker, but instead we have him as a regular group member, which is so great. Joe is a walking encyclopedia of Waldenstrom's. Our gravel-voiced friend knows everything there is to know about this illness and is always willing to share his knowledge. He doesn't pretend to be a doctor. He just shares his vast knowledge and has been hugely helpful to the group in general and individuals in particular. And he has a sense of humour. What more could we ask?

Our group is not a WM group. It's a group comprised of people who have WM—people with hopes, dreams, skills, courage, fears, patience, impatience, life experience. Single people. Married people. Parents. Grandparents. And all with great big hearts.

As I write this, a number of our support group members are facing very critical medical issues. This is a concern for us all, and we continue to meet through the summer because of it.

In closing, this is not a report about a group. This is a warm greeting to you all from a group of people in Vancouver who are facing life in all its richness and all its complexities, one day at a time.

UNITED KINGDOM

By Bob Perry, WMUK Patient Support Manager

Since April we have embarked on raising a number of regional and specialist virtual support groups. We have 13 regional groups covering Wales, Ireland, Scotland, and England. You can find our regional support groups at *https://wmuk.org.uk/support/finding-support/regional-groups/*.

In addition, we have set up five specialist groups: Mums with WM, Dads with WM, Supporters of People Living with WM, Bing Neel Syndrome, and Peripheral Neuropathy. Each group has a volunteer group leader, and the groups are currently meeting every six to eight weeks. You can register to any of our specialist group meetings at *https://wmuk.org.uk/get-involved/whats-on/*.

These meetings have really proved beneficial in taking away the loneliness of living with WM by bringing people together with others in their geographical region or with a special concern or condition. In some cases, COVID permitting, we are seeing people meeting for a coffee and a chat, which is extremely encouraging.

Bob Perry and Clinical Nurse Specialist Julia Darlow with new WM brochure

In addition, we have managed to get four different consultants and three clinical nurse specialists to drop in on the meetings to see what they are about and, where appropriate, give generic advice, counsel, and meaning to some of the topics being discussed. This has proved very popular, and each of these healthcare professionals has expressed an interest in coming back to these meetings when needed. This is extremely encouraging, and our thanks go out to those professionals for giving us their time so freely.

On top of this, our series of live webinars continues with talks about the treatment pathway, clinical trials, Bing Neel syndrome, and medical research. All of these webinars are recorded and available on our website at *https://wmuk.org.uk*, and you can register for future webinars on our What's On pages at the above link. Again, we thank our clinicians for taking the time to do these important webinars.

We also have a live mindfulness class once a month, which is proving to be popular with people logging in from around the world!

I myself have had a go at podcasts, which have been very amusing to make for various reasons (not least the pesky seagull trying to steal our thunder in episode one!). The two that have gone out have been well received: "What is the role of the CNS?" and "Clinical trials—a patient perspective." With more interviews booked in, you can expect to see more episodes coming soon. All episodes are available on Anchor, Spotify, Google Podcasts, Breaker, and RadioPublic.

The first fully-virtual WMUK Patient-Doctor Summit will be happening on 13 November 2021. The WM community

International Scene, cont. on page 23

is invited to join us for a day of informative webinars, chances to meet and video chat with others affected by WM, and a session of mental and physical wellbeing, not to mention a mindfulness class to start the day. The day is open to everyone around the globe; go to *https://wmuk.org.uk/support/2021-wmuk-patient-doctor-summit/* to register for your place.

Work continues on the WMUK website, as we improve navigation and expand our range of information. This work is in direct response to the feedback given to us in our 2021 Patient Survey. For all the updates from the WM, sign up for our monthly newsletter at *https://wmuk.org.uk/get-involved/sign-up/*.

With COVID restrictions being removed in mid-July, it's been a concerning time for those of us classed as "clinically extremely vulnerable." WMUK has been keeping on top of the latest research news around the efficacy of the COVID vaccine for blood cancer patients, as well as lending our voice to the call for the general public to remain vigilant and look out for those who might be more vulnerable to the virus. The latest updates from the UK are all on our website.

Our amazing fundraisers are at it again, with the likes of Helen running 25 miles in August and Vicky taking on the Cheltenham Half Marathon in September. We've also launched our first WMUK fundraising event: Walk for Waldenstrom's. This event asks the community to challenge themselves to walk a distance of their choosing to raise funds for WMUK's Support Line. Learn more about the challenge on our website.

To summarise, we have had a good 2021 so far in raising the awareness, knowledge, and community spirit in WM

Long time WMer Billy King, an avid golfer, succumbed to COVID, so his family held a Golf Day at his club as a fundraiser for WMUK and raised £1500. Pictured from left: Billy's sister-in-law Lisa, Bob Perry, Billy's mother Jean, and brother Chris

world, as we continue to adjust to the new normal brought about by COVID. We look forward to a great end to the year and the exciting plans 2022 brings with it.

We're here for anyone affected by WM, so please don't hesitate to get in touch: *support@wmuk.org.uk*; 0300 303 5870; or join our Facebook group at *https://www.facebook.com/groups/280071106489074/?multi_permalinks=588362438993271*.

FROM THE FACEBOOK WM SUPPORT GROUP: FALL 2021

By Betty Ann Morton

Editor's note: For many years, Dr. Jacob Weintraub summarized the discussions on IWMF Connect for Torch *readers, but he has intended to retire for some time. Since no one has been found to replace him in that job, we now offer summaries from a different platform—the Waldenstrom Macroglobulinemia Support Group on Facebook. With over 4,000 members, this group offers similar perspectives and wide discussions on a variety of WM-related topics. We welcome Betty Ann Morton, editor of this feature, who has agreed to take on this important job.*

Social media is not just a way to relax or waste time. It can be a tool to connect with other WM patients, caregivers, and family members; to learn more about WM; and to give or receive much-needed encouragement.

Since I haven't met many of the WM community in person, let me introduce myself briefly. I was diagnosed with WM twenty years ago. My first tentative diagnosis was multiple myeloma, but it didn't fit. And then my mother said, "Your grandmother had some kind of unusual anemia." Yes, indeed, my grandmother and I were both WMers. I'm a retired high school teacher, wife, mother, and grandmother. We live in the Chicago suburbs and attend Chicago Area Support Group meetings. I love to read and am part of a book club that meets weekly to read books in Spanish and to chat. Since the pandemic shut things down, I've been walking several miles daily. As far as WM goes, I have had several different treatments over the years and have been in good health for most of that time.

About 4,200 of us now belong to the Waldenstrom Macroglobulinemia Support Group on Facebook. This is a private group, so only group members can post or read posts or see who is in the group. WM patients, caregivers, and family members are welcome. To join, search for the group by name, request membership, and answer a couple of simple questions.

*About **4,200** of us now belong to the Waldenstrom Macroglobulinemia Support Group on **Facebook**.*

Especially during this pandemic time, when most of us are staying home much more and having fewer interactions with friends, family, doctors, and our usual support systems, the WM Facebook group has become a community. Of the 4,200 group members, about 2,900 are active, meaning they have posted to the group site, responded to posts, or read posts within the past month. About two-thirds are from the United States, followed by the UK, Canada, and Australia. However, there are WMers from all over Europe, South America, and elsewhere. Facebook translates posts and enables worldwide support.

*"My **attitude** changed because of everyone's comments. I can't thank everyone enough for helping me open my eyes to the **positive side** of treatment."*

Our WM Facebook group is an amazingly kind, supportive, and knowledgeable community. In the words of one member, "This FB group provides comfort, knowledge, and experience for those of us dealing with WM in multiple different ways. I am so grateful!!!" One common post is from someone who is newly diagnosed and has just found the WM Facebook group. They often express their fears about having a cancer diagnosis. Typically, many longtime WMers welcome them and reassure them that many of us are living full lives, despite WM. They post links to resources on the IWMF website and encourage newly diagnosed WMers to see a WM expert doctor.

Recently a group member had just learned that she needed treatment. She explained what her treatment would be and ended by saying, "I'm scared." People started explaining how her treatment would work, what typical side effects would be, and how they had handled them. Soon the original poster commented, "Honestly I'm starting to look forward to treatment. It's been so long since I've felt good that I don't even remember what it's like. That's something I am going to stay focused on." Eight hours and 98 comments after the original post, our formerly scared friend said, "My attitude changed because of everyone's comments. I can't thank everyone enough for helping me open my eyes to the positive side of treatment."

Many questions and discussions have related to COVID-19, including what precautions are wise, experiences of those who have been ill, reactions to vaccines, questions about whether lab results might be affected by either COVID-19 or by vaccination, and whether a third vaccine dose might be beneficial. Frequently questions are answered with links to recordings by WM doctors or studies discussing concerns specifically for immunocompromised people.

Another frequent topic of conversation is the decision to move from watch-and-wait to active treatment. Often

From the IWMF WM Support Group, cont. on page 25

a person describes symptoms and requests input about whether it's time for treatment. Commonly, the responses discuss personal experiences and urge discussing concerns with their own doctor. The community explains that, in WM, doctors treat the symptoms, rather than the numbers. Occasionally the group consensus is that medical care is urgently needed, and they encourage the poster to contact their doctor promptly.

An interesting thread discussed the dilemma of those who are both patients and caregivers. Quite a few WMers in the Facebook group also care for spouses with serious conditions such as dementia. They have been able to encourage each other and also share suggestions from their own experiences, such as compartmentalizing, hiring help, and seeing a therapist.

Often good news is posted: grandchildren born, good treatment results, a retirement or a new job, a move and the need to find a new doctor. Sometimes the news is troubling: a transformation of WM to a more aggressive cancer, a treatment that is not working, serious side effects resulting in hospitalization or even death. In all of these situations, the WM community posts messages of encouragement and understanding. The person posting is no longer alone; their joys, fears, worries, and sorrows are shared by WMers around the world.

Instead of ***struggling with isolation*** *resulting from pandemic restrictions and health conditions, consider becoming a little more connected with a community that will* ***understand*** *and* ***welcome*** *you.*

Facebook is used, along with other methods such as the IWMF emails, IWMF Connect, and the *IWMF Torch* to communicate about various events within the WM community. Starting in May 2021, the IWMF offered a series of chair yoga classes, especially designed for WM patients. Facebook posts helped to spread awareness of WM yoga on Zoom with recordings on YouTube. Taught by professional yoga instructor and volunteer Ann Grace MacMullan, daughter of a WMer, the yoga class includes stretching, breathing, balance work, and some weight-bearing poses. Ann is skilled at helping people to adapt the basic moves to fit their individual needs and limitations. At a recent class, she encouraged everyone to swing their opposite arm when walking for better stability. One participant commented on Ann's calming demeanor; another added that even her dog gets calm after yoga. During after-class conversation, someone observed that WM yoga was a highlight of her week; others concurred. Good news: chair yoga will continue, at least through the rest of 2021. To request the yoga class link, email Michelle Postek from the IWMF office at *mpostek@iwmf.com*.

Ann Grace MacMullan, WM yoga instructor on Facebook

Instead of struggling with isolation resulting from pandemic restrictions and health conditions, consider becoming a little more connected with a community that will understand and welcome you. The Waldenstrom Macroglobulinemia Support Group on Facebook and IWMF chair yoga are always open to new participants.

Since I am just getting started as a "columnist," ideas for future columns are floating around in my head. They will probably include more specific information about what WM Facebook participants have asked, shared, and learned. See you in the *IWMF Torch* in January or on Facebook today.

WM HIGHLIGHTS FROM THE EUROPEAN HEMATOLOGY ASSOCIATION 26th CONGRESS, 2021

BY GLENN CANTOR, SCIENCE EDITOR AND IWMF TRUSTEE

Karima Amaador (Amsterdam UMC), T Cell Subset Composition and Functionality in Patients with WM

T cells are critically important cells in the immune system. There is a wide variety of different types of T cells ("subsets") with various functions in protecting the body against infections. Recently, considerable attention has focused on emerging therapies that enhance the ability of T cells to kill tumor cells and help control certain types of cancer.

In chronic lymphocytic leukemia (CLL), a blood cancer that shares some characteristics with WM, there are extensive abnormalities in the distribution of T cell subsets and function. This has led to disappointing results when the T cell-enhancing therapies that are successful in other cancers are applied to CLL. Accordingly, the WM group at Amsterdam UMC asked whether T cell abnormalities similar to those in CLL patients are also seen in WM patients.

Fortunately, the answer is no. By all the measures that Dr. Amaador explored, T cell subsets and function in WM patients were similar to T cells in healthy people. The investigators compared T cells from three groups: 26 WM patients (including 16 treatment-naïve and 10 relapsed/refractory), 21 healthy ("control") people, and 17 CLL patients. They used a technique called flow cytometry to evaluate the number and percentages of T cells in different subsets and stages of differentiation. They also evaluated several functions of the T cells, including their ability to respond to stimulation by producing cytokines and their potential to kill tumor cells. They confirmed the previously reported T cell abnormalities in the CLL patients. Importantly, the T cells from the WM patients, even those with high disease burden before their treatment, behaved similarly to the T cells of the healthy control people.

They concluded that changes in the immune system seen in CLL are not found in WM. These findings are encouraging for the application of T cell-targeting treatments in WM, especially for the management of relapsed/refractory WM.

Jorge Castillo (Dana-Farber Cancer Institute, Harvard University), Cost Effectiveness of Zanubrutinib vs. Ibrutinib in Adult Patients with WM

Zanubrutinib is now approved for treatment of WM in Canada and the US, and conditionally, in China; applications are under review by regulators in Europe. Whenever a new drug becomes available, formulary decision makers and governmental agencies that pay for drugs want to know if the drug is cost effective—do patients, on the average, get their money's worth?

When researchers conducted a cost-effectiveness analysis using data from the recent Phase 3 ASPEN trial that compared zanubrutinib to ibrutinib head-to-head, their data suggested that WM patients given zanubrutinib lived for 0.94 years longer than patients given ibrutinib. Another measure used was years of quality-adjusted life-year. In that measure, zanubrutinib-treated patients were expected to have 0.84 years more quality-adjusted life-years.

The investigators then compared the cost of the two drugs (referenced by the drug pricing database called the Red Book), together with the cost of routine patient care, management of patients' side effects, patient care during severe illness, and end-of-life care. Because there are fewer side effects with zanubrutinib vs. ibrutinib, patients tend to discontinue zanubrutinib less often than patients treated with ibrutinib. Since patients on zanubrutinib have a longer time-to-treatment-failure than those on ibrutinib, the cost of zanubrutinib is slightly higher than ibrutinib ($11,000 spread over the 30-year course of a patient's lifetime). However, this increase is partially offset by the lower monthly drug cost, reduced cost of routine care, and lower terminal care cost of zanubrutinib compared to ibrutinib.

When all these factors were considered together, the incremental cost-effectiveness ratio (ICER) of zanubrutinib was $13,205 per quality-adjusted life-year gained. The investigators concluded that zanubrutinib appears to be a cost-effective drug compared with ibrutinib for treatment of patients with WM in the US.

By all the measures that Dr. Amaador explored, ***T cell subsets*** *and function in WM patients were* ***similar*** *to T cells in healthy people.*

Karima Amaador (Amsterdam UMC), Conditional Relative Survival in LPL/WM Patients: A Population-Based Study in the Netherlands

When patients are diagnosed with WM, they often ask their doctors how long they have to live. Of course, it is impossible for doctors to predict this on an individual patient basis, but they can try to explain survival of WM patients in a general way. Fortunately, with the advent of better drugs, survival has improved greatly. Many WMers have heard from their doctors that "most patients with WM have long lives and die of causes other than WM."

WM Highlights, cont. on page 27

Investigators at the Amsterdam UMC took a different approach to the question. Instead of presenting survival estimates that are measured from the time of diagnosis, which provide the prognosis for newly diagnosed WM patients, they calculated the "conditional relative survival." This is a concept that gives an estimate of the likelihood of surviving into the future after a WM patient has survived from a specified time since diagnosis, relative to the survival of similar people from the general population.

So, for instance, "conditional relative survival" tells a WM patient who has already survived five years after his diagnosis, what his chances are for surviving an additional five years. This can therefore predict survival better for individual patients.

Generally, you would expect that "conditional relative survival" for cancer would increase with increasing years already survived, due to the share of "cured" patients that is increasing. Unfortunately, this is not the case for WM, because WM is currently an incurable disease. They found that for WM patients diagnosed in the Netherlands, despite having survived their disease from a specified time since diagnosis and the impressive treatment advances, the life expectancy still does not equal that of the general population.

This information can be used by physicians to tailor their surveillance and follow-up activities to different WM patients.

...the relative ***survival of WM patients*** *in the Netherlands greatly improved over the last 30 years for patients in all age groups since* ***rituximab-containing therapy*** *was widely implemented.*

Karima Amaador (Amsterdam UMC), Primary Therapy and Relative Survival in LPL/WM Patients: A Population-Based Study in the Netherlands, 1989-2018

The general population has a certain probability of dying, based on age. Obviously, the life expectancy of 80 year olds is less than the life expectancy of 50 year olds. Dr. Amaador and her group calculated WM patients' "relative survival"—what is the observed survival of WM patients compared to expected survival of people of the same age and sex from the general population. They also corrected for "calendar year" since survival is different now than it was, say, 20 years ago. They used a large database of patient health outcomes from the Netherlands Cancer Registry to determine relative survival at different ages. They also compared different time periods—WMers diagnosed in 1989-1996, for example, when drug therapy was quite different than it is now, vs. 2011-2018.

Relative survival is calculated to estimate the survival, in this case of WM patients, when the cause of death is unknown. When considering death from any cause, they found that in the Netherlands, during the first year after diagnosis, if a WM patient younger than 65 years asks what the survival is for the next five years, WMers in this age group have a relative survival of 93% compared to the general population in 2011-2018. The relative survival 15 years after diagnosis was 69% in 2003-2010 compared to the general population.

They demonstrated that the relative survival of WM patients in the Netherlands greatly improved over the last 30 years for patients in all age groups since rituximab-containing therapy was widely implemented.

These numbers are based on data from the Netherlands, and they reflect the state of WM treatments and all other aspects of medicine in that country. Obviously, the numbers would differ from country to country; however, the researchers found similar patterns in relative survival in Sweden and the United States when comparing their study with the available population-based studies from these countries. Also, these numbers may change as new WM treatments are introduced. Still, the idea of considering all causes of death and calculating "relative survival" seems like a useful approach.

Steven Treon (Dana-Farber Cancer Institute, Harvard University), Preliminary Clinical Data from a Phase 1b Study of Mavorixafor and Ibrutinib in Patients with WM with MYD88 and CXCR4 Mutations

The European Hematology Association Congress saw the first disclosure of data from the Dana-Farber Cancer Institute's clinical trial with the combination of mavorixafor, an oral CXCR4 inhibitor, and ibrutinib, a BTK inhibitor. See the article on page 6 in this issue of the *Torch*.

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6144 Clark Center Avenue
Sarasota, FL 34238

Telephone 941-927-4963 · Fax 941-927-4467
E-mail: info@iwmf.com · www.iwmf.com
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