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BEATING THE BRUTON'S TYROSINE KINASE BLUES

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Bruton's tyrosine kinase (BTK) inhibitors play a major role in the treatment of Waldenström macroglobulinemia (WM). They can be used either as a first line of therapy or after other lines of treatment when WM relapses. They work by blocking Bruton's tyrosine kinase, an enzyme which plays an essential role in the survival of cancerous B cells in WM. When BTK is blocked, the cancerous B cells are unable to multiply and grow. Unfortunately, BTK inhibitors are unable to eradicate cancerous cells and therefore cannot cure WM. However, by keeping the growth and survival pathways of cancerous cells in check, BTK inhibitors aid in decreasing the levels of the circulating immunoglobulin (IgM) and cytokines. As a result, the patients feel symptomatically better within a few weeks of starting their medication. There are currently four BTK inhibitors available in the United States, including ibrutinib, acalabrutinib, zanubrutinib, and the newest addition, pirtobrutinib. Only ibrutinib (Imbruvica) and zanubrutinib (Brukinsa) are currently approved for use in WM in the US. Tirabrutinib (Velexbru) is approved for use in WM patients in Japan.

BTK inhibitors come with a wide range of potential side effects, including low blood counts, increased risk of bleeding, increased infection risk, fatigue, diarrhea, headache, high blood pressure, atrial fibrillation, muscle and joint aches, and changes in skin, hair, and nails. When stopping a BTK inhibitor abruptly, there is also a risk of experiencing withdrawal symptoms and a rebound increase in the IgM level; if a BTK inhibitor needs to be stopped, it should be done under the supervision of a health care provider, with close monitoring of symptoms and blood

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tests, including IgM levels. The side effects can often be managed by adjusting the dose or using supportive therapies. BTK inhibitors are given daily on a continuous basis until WM relapses or the side effects become intolerable. It can be rather disappointing to stop treatment because of side effects if it is otherwise working well. Therefore, both patients and clinicians need to focus on strategies to reduce BTK inhibitor-associated toxicities and maximize benefit from these effective medications. Understanding what to expect from treatment with BTK inhibitors and how to manage these side effects may help you feel empowered to improve their tolerability, allowing you to potentially benefit from continuous treatment for a longer period of time.

There are a few universal actions that every patient can do to limit side effects from most cancer treatments. All patients should strive for a healthy lifestyle that includes quitting smoking, staying away from tobacco products, limiting sun exposure and using a broad-spectrum sunscreen, eating a diet rich in vegetables and fruits (avoid grapefruit, star fruit, and Seville oranges while on BTK inhibitors due to potential interactions), and participating in moderate-intensity exercises. These healthy activities may reduce the risk for second cancers as well.

*Sometimes **dealing with side effects** is a **long process** of trial-and-error.*

There is no one-size-fits-all solution for side effects from cancer treatment, so it's important that you have a good relationship with your health care team if problems arise. Management of one side effect may make a different side effect worse. A good example of this might be a recommendation to avoid caffeine to improve sleep quality, even though caffeine is frequently recommended to manage headaches caused by BTK inhibitors. Sometimes dealing with side effects is a long process of trial-and-error. Try not to get discouraged! Letting your health care team know what has and hasn't worked for you is like gold because they can make more specific recommendations and adjustments to personalize your care.

Low Blood Counts, Bleeding, and Infections

Low blood counts are common with BTK inhibitors and may require holding doses or dose reductions. All three major blood cell lines, including red blood cells, platelets, and white blood cells, are at risk of declining.

Hemoglobin, which is the oxygen-carrying component of the red blood cell, is regularly monitored to assess a drop in red cells. If your hemoglobin is low, you may experience fatigue, pale skin, lightheadedness, and shortness of breath with activity. If hemoglobin is substantially low, red blood cell transfusions may be considered. Discuss with your doctor about checking your baseline iron stores. Within weeks of starting treatment, your hemoglobin should improve, provided the iron stores in your body are sufficient. Eating foods rich in iron (patients with WM may have coexisting iron deficiency that is unrelated to BTK inhibitor therapy use) and B vitamins, such as organ meats, beans, nuts, green vegetables, whole grains, and enriched cereals, may help improve anemia.

Platelets help the blood to clot, and when low, can increase the risk of bleeding. Regardless of the platelet count, BTK inhibitors can increase the bleeding risk by impairing the ability of platelets to clump together and form clots. Because of the higher risk of bleeding and the ability of these drugs to slow wound healing, it is advisable to temporarily hold BTK inhibitors before any planned surgeries or procedures. It is recommended to hold BTK inhibitors typically for three days before a minor surgical procedure and seven days before a major surgery. After the procedure, the duration of the hold varies from one day up to seven days, depending on the potential risk of bleeding associated with the surgical intervention. This break allows new platelets with preserved function to regenerate and prevent bleeding during and after procedures. While taking a BTK inhibitor, avoid contact sports or activities with increased risk of injury, maintain good oral care, consider use of an electric razor while shaving, avoid fish oil supplements, and apply ice or pressure to wounds to stop bleeding. Bruising is frequently seen but does not warrant stopping treatment and is not associated with a higher risk of major bleeding. Avoid using blood thinners unless you absolutely need them for another condition. Discuss which blood thinner is right for you. Apixaban (Eliquis) may be preferred over other blood thinners when used with a BTK inhibitor. Besides increased bruising, signs of minor bleeding include more frequent nose bleeds and bleeding gums when brushing or flossing. Note that spontaneous nose or gum bleeds can also encountered with hyperviscosity syndrome, associated with thick blood. This can occur if the BTK inhibitor is either no longer effective or has been abruptly stopped, leading to IgM rebound.

White blood cells fight infection, and when low, will put patients at an increased risk of infection. When white blood cells, especially neutrophils, are low, avoid known sick contacts and consider masking in public. Wash your hands regularly and maintain good oral hygiene. Stay up-to-date on vaccines recommended by your health care provider. Seek medical care for persistent fever over 100.4°F (38°C) as infections can progress quickly to become life-threatening in immunocompromised patients, such as those with WM. Infections require prompt work-up and appropriate treatment. If the white blood cell count remains low, patients

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may receive a growth factor shot to boost production of new cells. Patients taking BTK inhibitors may have more frequent infections, even if their white blood cell count is normal. Report any signs of infection to your health care provider, including fevers, chills, cough, shortness of breath, pain or burning with urination, or skin wounds. Your health care provider may give you additional antiviral or antibiotic medications to prevent infection, based on your treatment history. Patients with recurrent serious infections may require intravenous (injected into a vein) or subcutaneous (injected under the skin) IgG to prevent infections in the future.

*Patients taking **BTK inhibitors** may have more frequent **infections, even if** their white blood **cell count** is **normal.***

Fatigue

While taking a BTK inhibitor, you may feel more tired and struggle with lack of energy. This can be related to both the medication and the disease state, especially if your hemoglobin is low. Generally, dose reduction for fatigue early in the course of BTK inhibitor-based treatment is avoided. To combat daytime fatigue, take steps to ensure you are getting a good night's sleep. To improve sleep duration and quality, it is important to establish a calming bedtime routine which would avoid exposure to blue light from electronic devices. Give yourself time to slow down and relax at the end of the day and consider light reading, warm baths, or listening to soft music. Avoid caffeinated beverages after 3pm. Throughout the day, try to include extra activity to get moving and help perk yourself up. This could include a short walk around the office or your home at least every hour. If you're able, you can consider a short afternoon nap or rest to recharge but avoid sitting and resting for long periods throughout the day. If fatigue and daytime sleepiness are affecting your ability to perform daily activities, contact your doctor to discuss options for management.

Diarrhea

Diarrhea is common with these medications and most often appears when first starting treatment. Symptoms tend to improve over time, but if you're experiencing multiple loose or watery bowel movements per day you should contact your doctor. He or she may want to test the stool for infection before starting anti-diarrheal (anti-motility) medications. When diarrhea is present, avoid foods with excess fiber, dairy products, caffeine, alcohol, and foods high in fats and sugars and stay well-hydrated. Consider a diet of bland foods, which includes bananas, rice, apples, and toast (called the BRAT diet), until symptoms have improved. Over-the-counter loperamide (Imodium) may be used if no signs of infection are present. Seek immediate medical care if you experience any dizziness, racing heart rate or changes in heart beats, falls, severe abdominal pain, or blood in the stool. For medications such as ibrutinib, changing to evening dosing may help improve symptoms.

Constipation

Constipation occurs less often than diarrhea, but it is still possible with BTK inhibitors. To prevent constipation, be sure to drink at least eight glasses of water daily and eat fiber-rich foods such as beans, fruits, vegetables, nuts, and seeds. Daily activity can also decrease your risk of developing constipation. If lifestyle modifications are not enough to prevent constipation, there are several over-the-counter options that can relieve symptoms. Fiber supplements can be considered but make sure to drink plenty of water and only use the recommended amount on the label because they can worsen constipation if you use too much and aren't drinking enough fluids. Laxatives and stool softeners can also be used when needed. If you're having trouble with constipation, contact your health care team to assist with product selection and dose modifications. If you develop diarrhea while taking medications for constipation, hold the dose and reach out to your team for medication adjustments.

Headaches

Acalabrutinib (Calquence) often causes more headaches than the other BTK inhibitors; however, this side effect can be present with any of them. It often occurs in the first 1-2 weeks of treatment and fortunately resolves over time. When starting treatment, maintain good hydration by drinking at least eight glasses of water daily. Headaches may be treated with acetaminophen and caffeine. Avoid NSAIDs such as ibuprofen, naproxen, or aspirin because of the increased risk of bleeding with these medications.

High Blood Pressure and Atrial Fibrillation

Increased blood pressure can occur and is often more common if you have a history of high blood pressure. Before starting a BTK inhibitor, your doctor will check to make sure your blood pressure is well controlled. If not, he or she will likely start blood pressure lowering medication(s) that may need to be adjusted while on the BTK inhibitor. Routine blood pressure monitoring will ensure proper management, avoid complications, and help your doctor know if changes to the blood pressure medications are needed. Remember to ask your nurse about your blood pressure and pulse readings at every visit to the doctor's office.

Atrial fibrillation is a condition with irregular heart beat that tends to be more common with ibrutinib but may occur with any BTK inhibitor. Doctors typically assess for risk factors for developing atrial fibrillation before starting a BTK inhibitor. Tell your doctor immediately if you notice any dizziness, lightheadedness, shortness of breath, palpitations, and rapid

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or skipped heart beats. Your medical team will pay special attention to drug interactions if starting medicines to treat atrial fibrillation. Blood thinners are often used cautiously to prevent strokes in patients with atrial fibrillation, and your doctor will carefully consider bleeding risks when blood thinners are used with BTK inhibitors. If you need to be on a blood thinner to prevent stroke from atrial fibrillation, discuss which one is right for you with your doctor as some agents are preferred over others. BTK inhibitors may need to be temporarily held until atrial fibrillation is well controlled. Ventricular arrhythmias are potentially serious rhythm problems involving the lower chambers of the heart but fortunately are uncommon. Patients and family members should remain vigilant for the development of new symptoms, including fast or dropped heart beats, sudden loss of consciousness, and lightheadedness. The incidence of heart-related complications is lower with newer BTK inhibitors such as zanubrutinib and pirtobrutinib (Jaypirca).

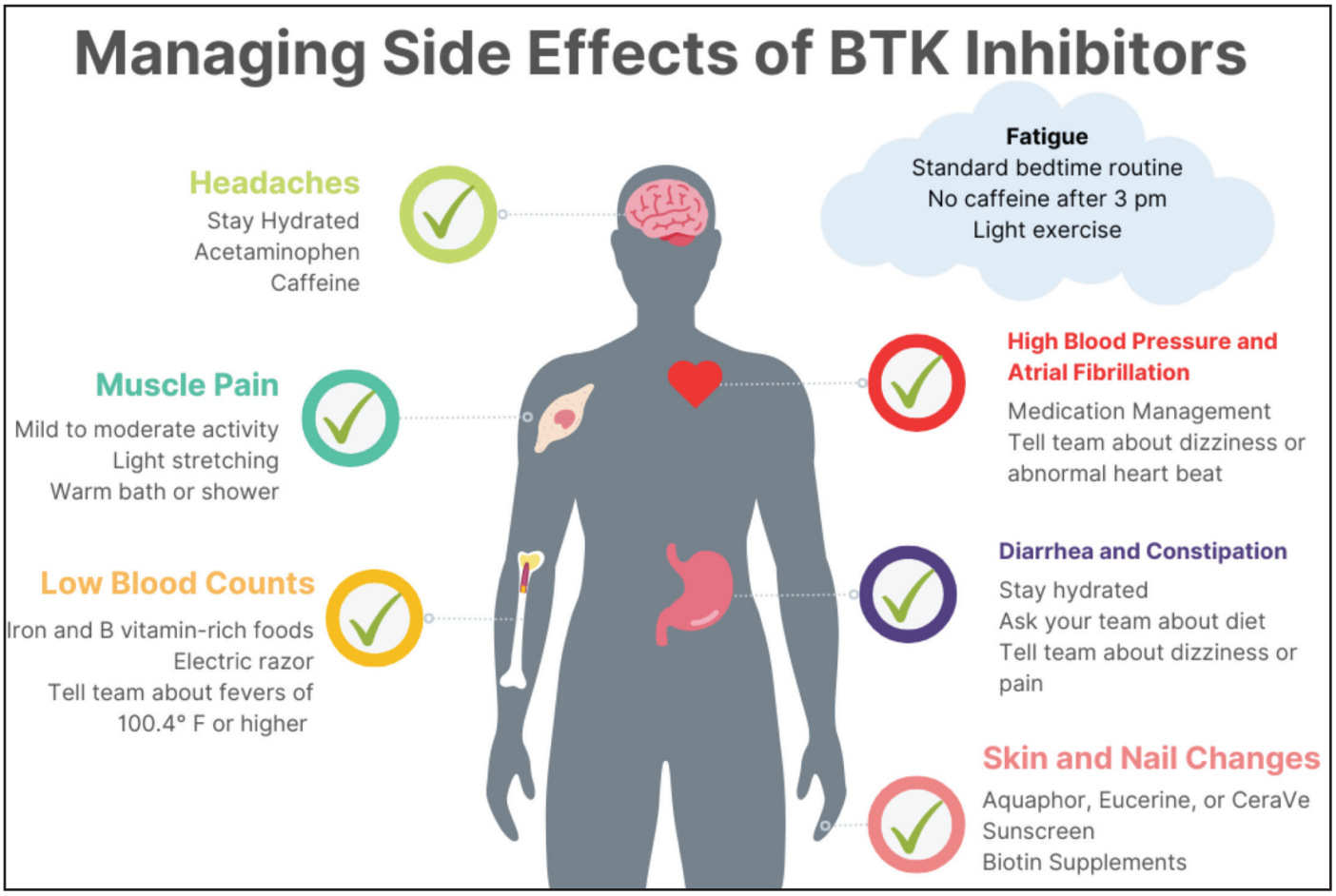
Muscle and Joint Pains

You may experience general aches and pains while taking these medications. Muscles may feel sore after gentle activity. Joint stiffness and pain are also seen, especially upon waking in the morning. Maintaining mild to moderate activity throughout the day with gentle stretching before bed can help prevent or improve these symptoms. A warm bath or shower at the end of the day may also help loosen stiff muscles and joints. Acetaminophen may be used to help with muscle and joint pains, but NSAIDS like ibuprofen and naproxen should be avoided due to increased risk of bleeding. If you have significant muscle or joint pain, a short course of steroids such as prednisone may be helpful. Contact your provider if you experience any pain, swelling, or warmth in your joints.

Skin, Hair, and Nail Changes

Skin changes can consist of rashes, dry flaky skin, and dry cracked skin. Dry skin is often most noticeable on the palms of the hands and soles of the feet. To prevent dryness and cracking, use an unscented glycerin-based cream such as Aquaphor, Eucerin, or CeraVe twice daily. Avoid sun exposure during peak periods between 11am and 2pm. Wear sunscreen with SPF 30 or greater. Use mild soaps and avoid corn starch or baby powders. Contact your provider if you notice any rashes. These often resolve after holding therapy and may require topical or oral steroids. If there is an active rash or any broken skin, avoid swimming in lakes, chlorinated pools, hot tubs, or saunas.

Texture of hair and nails may change while taking a BTK inhibitor. Nails may become brittle or thin and break easily. Nail oils may help with softening brittle nails, and



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strengthening polishes may prevent excess breaking. Avoid nail soaks as they may increase the risk of fungal nail infections. Biotin supplementation may provide benefit in strengthening hair and nails.

Withdrawal Symptoms

When stopping or holding BTK inhibitor treatment, it is possible to experience withdrawal symptoms. These symptoms take about 2-3 days (range: 0-5 days) to show up after stopping the BTK inhibitor. Most patients (about 80%) will not experience this complication, but symptoms can include fevers, chills, body aches, night sweats, headaches, and fatigue. In one study, patients who experienced the withdrawal symptoms were more likely to be in deep remission when ibrutinib was held. The presence of withdrawal symptoms is generally not a sign of disease progression, but you should contact your provider promptly if you experience these symptoms. Withdrawal symptoms may be treated with steroids, acetaminophen, restarting the BTK inhibitor (typically symptoms resolve within a day of restarting the BTK inhibitor) or a change in WM treatment.

When you stop taking a BTK inhibitor, there is also a chance of IgM rebound, which is associated with a rapid IgM increase shortly after the drug discontinuation. This can cause hyperviscosity symptoms associated with WM and requires treatment by your doctor. Hyperviscosity symptoms can include headache, dizziness, blurred vision, nosebleeds, bleeding gums, and shortness of breath. It's very important to seek input from your doctor before you stop BTK inhibitors so that these unwanted symptoms can be prevented and managed appropriately.

Conclusion

While BTK inhibitors can cause a wide range of side effects that potentially impact your quality of life, there are many ways to make them more manageable. Work closely with your health care team and be open about any side effects that you may be experiencing. As you may have noticed, treatments for some side effects can worsen other side effects from your medications. If you feel confused or overwhelmed by your medication list, be sure to discuss your concerns with your hematology team. Your team is there to support you through treatment and would not want you to suffer in silence. There are many side effects that can be managed at home, but some may require prescription medications, so maintain regular visits with your hematology team to ensure that the side effects are tackled in the safest way possible.

Additionally, studies have shown that when patients who responded to, but were intolerant of, ibrutinib or acalabrutinib were switched to zanubrutinib, the intolerant event did not recur in most patients, and they continued to derive the benefits of BTK inhibition. In the future, newer BTK agents with fewer toxicities, such as pirtobrutinib, and results from studies that propose limiting the duration of treatment with BTK inhibitors should be helpful.

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*

A NEW, YET FAMILIAR, PATHWAY

By Susan Kitazawa

Susan Kitazawa

I'd never heard of Waldenstrom macroglobulinemia despite having worked as an RN for 25 years. Yet the diagnosis of this cancer was oddly comforting after months of numbing fatigue and mystery weight loss. At least my problem had a name, albeit a long and cumbersome one.

Within weeks of finding I was going to live with this rare cancer, this new experience began to seem strangely familiar, as if "I've been here before." It was something I didn't sign up to do. It was something that was going to be tough at times. And it was something that would become part of me if I was going to continue to live a full and meaningful life.

I was born an American of Japanese descent two years after my parents and other family had been released from World War II incarceration by our own US government. We lived in small East Coast towns, and it felt like being Muslim American after 9/11. No one around us looked like us. We hadn't chosen to be different, but we were.

Growing up, I learned that other "outsider" allies made it easier to get through hard times. We could understand and support each other,

The importance of sympathetic allies rose up again, in my fifties, when I received news that a somewhat rare eye disease would gradually destroy my eyesight. I went forward with my work and family tasks. But, each evening, I cried in solitude, feeling that my life was ruined.

One evening, after six weeks, I thought, "Hold on, Susan, you're a nurse. What would you say to a patient with this diagnosis?" I knew what I had to do. The next day I began searching for others who were losing their eyesight or who were already totally blind. An older man, well ahead of me on the road to blindness, became a delightful ally and mentor.

Unable to find a local support group, another blind peer and I started a peer vision loss support group. Everyone could share their struggles and their strategies.

I live, on my own, with limited and ever diminishing eyesight. I struggle at times with day-to-day tasks. I can't drive. I can't see my granddaughters' faces. I worry at times how it will be when I lose my remaining vision.

But there's still so much I *can* do. Peer support has made all the difference. I traveled alone to visit several cities in Japan after a totally blind peer told me he had done this. Neither he nor I speak Japanese. It wasn't easy, but then life often isn't easy.

I went white water rafting with a group of blind teenagers when I heard the youth program director put out an announcement saying the trip was "for ages 14 and up." Since I was in my sixties then, I figured I qualified, even though it really was a teen trip. The youth director let me come along. It was terrifying and great fun. We went over Class 3 rapids!

I wouldn't have signed up for growing up as an American minority person or for going blind. None of us signed up for WM.

As I write this, I'm just two months out from listening to my bone marrow biopsy results online and realizing that I was about to embark on this new journey. I cried for six weeks over the news that I would be losing my eyesight. It was only six *days* after my WM diagnosis when I typed the words "Waldenstrom macroglobulinemia peer support" to begin an internet search. I didn't know if I'd come up with anything, given how rare WM is.

Lo and behold! The International Waldenstrom's Macroglobulinemia Foundation popped up on the screen. Wonder of wonders, the website turned out to be very compatible with blind screen reading software. I could listen to all that great information without needing to try to read it with my eyes. And I marveled at finding a whole list of support groups including one for POC, people of color.

Even though I'm a newcomer to the Waldenstrom world, this feels like a familiar pathway in many ways. It's going to have its ups and downs. It's going to feel like very bad luck at times. Still it's going to be an interesting and hopefully fulfilling journey.

I'm deeply grateful for everyone in the IWMF who is welcoming me in traveling this new, yet familiar, pathway.

Susan and fellow white-water rafters

2023 CONSENSUS PANEL REPORTS FROM THE 11TH INTERNATIONAL WORKSHOP ON WM

By Glenn Cantor, Torch Science Editor and IWMF Trustee

There has been extraordinary progress in recent years in the treatment and management of WM. At the recent 11th International Workshop on Waldenstrom's Macroglobulinemia (IWWM-11), over 400 physicians and researchers met in Madrid, Spain [described in the January 2023 *Torch*]. Many of these individuals, who are clinical experts in WM, participated on seven consensus panels that updated the management of WM, constituting the most comprehensive overhaul since the first consensus recommendations were published in 2003. This large effort resulted in the recent publication of seven papers in *Seminars in Hematology*. Here, we summarize some of the major recommendations. It is impossible to discuss each point; for more information, you can access the full text of each paper at *https://iwmf.com/wm-medical-practice-guidelines-research-articles/*. For a more detailed summary of the highlights, go to *https://www.sciencedirect.com/science/article/pii/S0037196323000380?via%3Dihub.*

Please note that the consensus panel reports are overall recommendations for doctors to consider; they should not be construed as offering specific medical advice for individual patients.

Consensus Panel 1: Management of symptomatic, treatment-naïve patients. Christian Buske (Germany), Jorge Castillo (US), Judith Trotman (Australia), and many more authors.

This panel addressed selection of treatment for patients who have never been treated for WM before, often referred to as first-line or treatment-naïve. Before deciding to treat, the panel emphasized that if a patient does not have symptoms, watchful waiting remains the gold standard, as long as the patient does not have critically elevated IgM or other major blood problems. Frequent monitoring of blood values and symptoms is important.

When the first treatment is needed, many WMers ask which is best, the bendamustine-rituximab combination (BR or Benda-R, also called chemoimmunotherapy or CIT) or pills such as ibrutinib or zanubrutinib (also known as BTK inhibitors). The panel concluded that either BR or a BTK inhibitor is suitable for treatment-naïve patients. They are both reasonable choices with similar efficacy. The authors also said that a third option, dexamethasone, cyclophosphamide, and rituximab (a chemoimmunotherapy called DRC) is suitable, especially for less fit patients with lower tumor burden.

Both chemoimmunotherapy regimens, BR or DRC, are effective, of fixed duration (which is important to many patients), generally well-tolerated, and less costly. The BTK inhibitors are also generally well-tolerated and are especially useful if patients are unsuitable for BR or DRC because they are too frail or have too many other medical problems. BTK inhibitors are an important option for young patients, since BR may carry the risk of damaging DNA and causing additional blood cancers in the future. The panel pointed out that zanubrutinib (Brukinsa), a second-generation BTK inhibitor, shows less risk for causing atrial fibrillation than ibrutinib (Imbruvica) and induces deeper remissions. Other chemotherapy treatments used in the past, including R-CHOP, R-CVP, fludarabine, or cladribine-based treatments, are not preferred in first-line treatment of WM because of higher toxicity, without evidence of long-term benefit, compared with BR or DRC.

If therapy with ibrutinib or zanubrutinib is chosen, the panel recommended testing the mutational status of MYD88 and CXCR4, if possible, since that information is helpful in predicting how well the therapy will work. For example, if CXCR4 is mutated, zanubrutinib results in faster and deeper responses than ibrutinib. There has been increased attention recently on mutations of another gene, called TP53. The panel concluded that the impact of TP53 mutations on treatment outcomes for treatment-naïve WM patients is not yet known.

The panel also considered proteasome inhibitor-based therapy, such as bortezomib (Velcade) or the newer drugs, ixazomib (Ninlaro) or carfilzomib (Kyprolis). These drugs are often used in combination with other drugs. A problem with bortezomib is that it can cause neurotoxicity, especially peripheral neuropathy, and possibly lead to increased infections. The use of subcutaneous rather than IV bortezomib reduces the neuropathy risk. Carfilzomib or ixazomib, in combination with rituximab and dexamethasone, are effective in treatment-naïve patients. This type of regimen may be appropriate for WM patients with amyloidosis. Carfilzomib should be avoided in patients with cardiopulmonary disease.

The panel addressed treatment for WM-associated cryoglobulinemia, cold agglutinins, Bing-Neel syndrome, peripheral neuropathy, and hyperviscosity and said that the basic practice should be to treat for WM to reduce the tumor burden and the IgM level rapidly and deeply. In Bing- Neel, ibrutinib can be highly active and produce durable responses. For amyloidosis, a serious complication of WM, BTK inhibitors are not recommended.

Consensus Panel 2: Management of relapsed or refractory (RR) WM patients. Shirley D'Sa (UK), Jeffrey Matous (US), Efstathios Kastritis (Greece), and many more authors.

Relapsed patients are those who responded initially to treatment but then develop active disease again. Refractory

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patients are those who do not respond to their treatment. BR, DRC, or BTK inhibitors are all important options. There is no one, single recommendation for a drug for RR WM patients. Often, choice is guided by what the patient was treated with before, how well they responded to their prior treatment, and what type of toxicities they encountered. Many other factors need to be considered, including the nature of the relapse (rapid vs. more gradual onset), biological age (not just year of birth, but how old a patient looks and feels), other medical problems (called co-morbidities), overall fitness, symptoms, and blood values, and whether there are WM-related complications. The choice also depends on guidelines and reimbursement arrangements in different countries. Patient preferences are important, and it is helpful for doctors to have a detailed discussion with patients of the advantages and disadvantages of the treatment options.

When considering using a BTK inhibitor, doctors should take into account cardiovascular problems, such as atrial fibrillation or other disturbances of heart rhythm, bleeding risk, and other medications that the patient is taking. The MYD88 and CXCR4 mutational status should be considered, since some types of CXCR4 mutations reduce the response to ibrutinib. New data presented at the meeting discussed mutations in another gene called TP53. TP53 mutations are much more common in WM patients than previously appreciated. Data updated at IWWM-11 from the ASPEN study showed that patients carrying both MYD88 and TP53 mutations had poorer responses, regardless of whether they received ibrutinib or zanubrutinib, compared to those patients who were MYD88-mutated and had no TP53 mutations. Fewer major responses to ibrutinib were also seen compared with zanubrutinib in patients with TP53 mutations. The panel concluded, though, that the impact of TP53 mutations would require further study and cannot guide one choice of treatment over another at this time.

A number of treatment options are possible: switching to a treatment that the patient has not been exposed to before, adding rituximab to the BTK inhibitor regimen, switching to a newer BTK inhibitor such as zanubrutinib or pirtobrutinib (Jaypirca), proteasome inhibitors such as bortezomib or ixazomib, or BCL-2 inhibitors such as venetoclax (Venclexta). In some patients with iron deficiency, IV iron may correct anemia and improve well-being, which reduce the urgency to start treatment. The panel also emphasized that all relapsed or refractory WM patients should be encouraged to participate in clinical trials.

Consensus Panel 3: Recommendations for molecular diagnosis in WM. Ramón Garcia-Sanz (Spain), Marzia Varettoni (Italy), Zachary Hunter (US), and many more authors.

The panel reiterated the importance of a bone marrow biopsy when making the initial diagnosis of WM to avoid confusing it with other diseases. They recommended that when bone marrow biopsies are performed, samples should be sent to specialized centers for diagnostic workup. The molecular studies should include MYD88, CXCR4, TP53, and an assessment of portions of two chromosomes, called 6q and 17p, which are sometimes deleted in WM. CXCR4 testing is particularly recommended when considering ibrutinib treatment, since patients with certain CXCR4 mutations such as the S338X mutation have lower odds of responding well to ibrutinib.

Each panel presented key questions and listened to input from the entire Workshop on additional questions and comments. Shown here is Panel 7, Priorities for Novel Clinical Trials. Left to right: Drs. Steven Treon (US), Meletios Dimopoulos (Greece), Prashant Kapoor (US), MJ Kersten (Netherlands), Glenn Cantor (US), Constantine Tam (Australia) - photo by Dr. Karima Amaador

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Consensus Panel 4: Diagnostic and response criteria. Steven Treon (US), Alessandra Tedeschi (Italy), Roger Owen (UK), and many more authors.

When diagnosing WM, the panel reiterated that there are multiple criteria that must be considered, not just a certain arbitrary level of IgM or percentage of bone marrow infiltration. The panel also discussed standardized criteria of response, which are important when evaluating and comparing clinical trial results. A new response assessment was endorsed which utilizes serial IgM measurements to assess most categories of response. The use of previously-mandated serial CT scans was only endorsed for determining if a patient has achieved a complete response or has suspected progression of disease.

Consensus Panel 5: COVID-19 prophylaxis and management. Evangelos Terpos (Greece), Andrew Branagan (US), Véronique Leblond (France), and many more authors.

The panel made a series of recommendations, including booster COVID vaccines for all WM patients and new variant-specific boosters as they become available. Because patients under treatment with rituximab or BTK inhibitors have lower antibody responses to the vaccine, those patients should continue to follow preventive measures such as masking and avoiding crowded places. Pre-exposure prophylaxis should be considered if available, especially for patients being treated with rituximab or BTK inhibitors, depending on which strains of COVID are currently circulating in the community. Oral antiviral medication such as Paxlovid should be offered to all symptomatic and high-risk asymptomatic WM patients with mild to moderate COVID disease, regardless of their vaccination or treatment status, as soon as possible after a positive test and within five days of symptom onset. It is not recommended to take Paxlovid in combination with some drugs, including ibrutinib. The panel made recommendations on how to tailor the drug regimen on a case-by-case basis. The panel also recommended that WM patients should receive two high-dose influenza vaccinations, separated by at least 30 days, rather than a single influenza vaccination.

Consensus Panel 6: WM-related amyloidosis. Monique Minnema (Netherlands), Shayna Sarosiek (US), Giampaolo Merlini (Italy), and many more authors.

Amyloidosis is a serious, potentially life-threatening complication of WM in some patients. The panel made several recommendations for tests to improve the diagnosis of amyloidosis, which may affect the kidneys, heart, lungs, liver, or other organs. There are different types of amyloidosis, so there is a need to determine which type a specific patient has. The goal of treatment is to control WM as soon as possible. Autologous stem cell transplant should be considered, even as first-line treatment, or bendamustine-rituximab if stem cell transplantation is not feasible.

Consensus Panel 7: Priorities for Novel Clinical Trials. MJ Kersten (Netherlands), Prashant Kapoor (US), Constantine Tam (Australia), and many more authors.

The panel made a series of recommendations for future clinical trials. A key need is to discover limited duration drug combinations that do not need to be continued indefinitely. The panel also discussed the importance of designing comparative trials, where a new treatment is compared to a known standard-of-care treatment (such as BR, DRC, ibrutinib, ibrutinib/rituximab combination, or zanubrutinib) to see if the new treatment is better or not. They also discussed better ways to standardize the trials, so that trial results can be compared with each other in a more meaningful way.

Thanks to Dr Steven Treon, not only for organizing the consensus panels, but also for his cogent summary of the panel results, which was enormously helpful to me when I wrote this article, and for his careful review of this article. I thank Chris Patterson for all his behind-the-scenes organizing work. *I emphasize again that this article does not address all the recommendations of the panels; for more information, you can read the publications cited above. Information here should not be substituted for medical advice, which should be obtained from your oncologist.*

LIVING WELL WITH WM
Emotional Aspects of Living with WM

By Michelle Postek and the IWMF Education Committee
Emotional Aspects Subgroup

Earlier this year, the IWMF Board of Trustees created an Education Committee, with a focus on living well with WM. I was appointed the group lead, and it was an honor to work alongside Julianne Flora-Tostado, Marcia Klepac, Meg Mangin, and Lisa Wise. All of us provide support to the WM community, either as staff or in a volunteer capacity. Our goal was to punch up the IWMF website with a new webpage on emotional wellness resources. We compiled all our selected resources, then we divided the resource list into seven categories: Adjusting to a WM Diagnosis, Coping with Watch-and-Wait Stage, Coping with Treatment and Beyond, Coping with Relapse and Recurrence, Gaining Support, Self-Care, and Gaining Empowerment. Please see each category below with selected resources from our group. They offer support through every phase of one's journey with WM. The full list of resources is available at *https://iwmf.com/emotional-wellness-in-wm/*.

Adjusting to a WM Diagnosis

Being diagnosed with Waldenstrom's, an indolent, incurable but treatable rare lymphoma, may disrupt one's sense of normalcy and cause stress for both patients and loved ones. Uncertainty about the future and a whole array of emotions can cycle through the adjustment process. Many questions often surface, such as: "Why me? How did this happen? How long will I live? How will my life, work, relationships change? Will I be around to see my children grow up?" Over time, WM patients find a way to adjust to the diagnosis and move forward with their lives with purpose, strength, and hope.

The National Cancer Institute article titled "Emotions and Cancer" covers the various emotions one may experience with a WM diagnosis, and offers ways to cope: *https://www.cancer.gov/about-cancer/coping/feelings*

Personal stories of how WM patients faced the challenges and successes of their WM diagnosis can offer tremendous support. For a dose of inspiration and validation of your feelings, read the IWMF Stories of Hope and watch the Patient Perspective videos. They are filled with honest reflections and inspiring tales of living fully and thriving with WM:

https://iwmf.com/stories-of-hope/

https://www.youtube.com/playlist?list=PL8DMfoyQZpOrMq8Bqtb_dODQhMbRxwZSE

GRYT Health's presentation titled "How Are You Really? A Mental Health Series – Frankly Speaking About Cancer: Why Can't I Stay Positive?" explores the top concerns related to cancer and strategies to overcome various issues while learning ways to stay positive: *https://www.youtube.com/watch?v=NaykDQCnS44*

Coping with Watch-and-Wait Stage

When no significant WM symptoms are present and treatment is not recommended, that time is called watch-and-wait. During that period, it is important to monitor disease status so that treatment begins at the right time, when and if it is needed. Some find this period unsettling because of the lack of action and prefer to call it more accurately watch-and-worry. Others feel a sense of relief at being free from the demands of treatment and view it more welcomingly as watch-and-live. There are many ways patients can take control during this time to improve their physical fitness, emotional health, and overall well-being.

The Leukemia & Lymphoma Society article, "Watch and Wait," suggests helpful action steps you can take during this time:

https://www.lls.org/treatment/types-treatment/watch-and-wait

The Fred Hutchinson Cancer Center article, "The Cancer Waiting Game: When the Recommended Treatment Is Nothing," provides a detailed description of this approach and the different emotional reactions experienced by patients: *https://www.fredhutch.org/en/news/center-news/2016/10/cancer-waiting-game-when-the-recommended-treatment-is-watch-and-wait.html*

Living Well with WM, cont. on page 12

Living Well with WM, cont. from page 11

Coping with Treatment and Beyond

Many emotions can arise during treatment and continue even after it ends. Finding the right kind of support—at the right moment—that best fits one's personal needs is key. Experiencing many different feelings, even all at once, is an expected part of the cancer experience. Patience, understanding, and self-compassion are tools that can help navigate each new stage of our disease. Joining a support group, calling a friend or family member, reaching out to a spiritual or community leader, or seeking professional help from a licensed therapist can be important coping strategies.

The Cancer*Care* fact sheet, "Coping with Sadness Throughout and After Treatment," focuses on ways to recognize emotional changes that may occur and tips to care for oneself:
https://media.cancercare.org/publications/original/279-2022_Coping_with_Sadness_Throughout_and_After_Treatment.pdf

The Leonard P. Zakim Center for Integrative Therapies and Healthy Living at Dana-Farber Cancer Institute offers an array of wellness videos on its YouTube channel that address topics such as nutrition and exercise:
https://www.youtube.com/playlist?list=PLPLXayOtubE2uosxnLNZaE-nJ0dY9Q1rp

The *IWMF Torch* article by Wanda Huskins (October 2012, page 12) addresses the "Psychological and Social Needs of Cancer Patients: Scope of the Problem" *https://iwmf.com/wp-content/uploads/2020/10/Torch-Oct-2012.pdf*

A comprehensive overview of depression can be read in the *IWMF Torch* article (January 2023, page 1), "Depression – A Very Treatable Illness," by Dr. Marshall Lewis:
https://iwmf.com/wp-content/uploads/2022/12/N35555-Torch-January-2023_web.pdf

A companion piece to the above article by Dr. Julianne Flora-Tostado is included on page 4 and is about her experience as a care partner to her husband with WM and her own experience helping patients as a psychologist and psychotherapist; it is titled "Depression – Some Personal Perspectives."

Coping with Relapse and Recurrence

Waldenstrom's is very treatable but tends to relapse or recur after treatment within a wide range of time frames. This uncertainty can lead to anxiety and other negative emotions but is also an incentive to make personally meaningful life choices and to adopt a "live in the moment" way of being. Becoming educated about promising treatment options can help to reduce anxiety and promote a sense of control.

The Cancer*Care* article titled "Coping with the Fear of Cancer Returning" offers helpful ideas for managing anxiety about cancer recurrence:
https://www.cancercare.org/publications/253-coping_with_the_fear_of_recurrence

In this Cancer*Care* workshop recording, a panel of experts (including a blood cancer patient) provides insight and inspiration in a discussion titled "Fear of Recurrence and Late Effects: Living with Uncertainty."
https://www.cancercare.org/connect_workshops/2-cancer_fear_recurrence_2011-07-12

*It is important to **reach out** for **help** when **needing support** with a WM diagnosis.*

Gaining Support

It is important to reach out for help when needing support with a WM diagnosis. With the IWMF, you are never alone. The IWMF offers support resources, including a 1:1 phone call/email resource, support groups, and online discussion groups for which you will find links below designated with an asterisk (*). Many of our partner organizations offer emotional wellness resources as well.

Outside of the IWMF, patients may also find it helpful to find a private psychotherapist who is trained to address coping with anxiety and depression. *Psychology Today* is one example of an online service designed to help you find a licensed, private psychologist:
https://www.psychologytoday.com/us

Your hospital team may have a social worker you could meet with for therapeutic sessions. These social workers can also refer you to local resources for longer-term care.

Your medical insurance company will also have a list of licensed therapists who serve patients in your community.

In various states the license title may be different, but your company will have a list of verified therapists who are registered or licensed and experienced as clinical social workers, counseling, health, or clinical psychologists, or perhaps marriage and family therapists.

Aging Life Care Managers can help with coordinating daily living tasks and treatment demands:
https://www.aginglifecare.org/

*Over 70 IWMF Support Groups and International Affiliates offer local support throughout the world:
https://iwmf.com/us-and-international-support-groups/

*IWMF LIFELINE is a telephone and email support program offered by volunteer WM patient and caregivers to share their experiences categorized by topics related to WM:
https://iwmf.com/lifeline-and-one-on-one-support/

*IWMF Online Discussion Forums are available 24/7, where you can ask a question to thousands of WM community

Living Well with WM, cont. on page 13

members in real time or search topics previously asked by fellow patients and caregivers:

IWMF Connect:
https://iwmf.com/iwmf-connect-and-online-discussion-forums/

Facebook Waldenstrom Macroglobulinemia Support Group (a private discussion group):
https://www.facebook.com/groups/wmsupportgroup

The Leukemia & Lymphoma Society has Information Specialists to offer support and share their resources, which include support groups (social workers and nurses) with language interpreters for 350 different languages:
https://www.lls.org/support-resources/information-specialists

Cancer*Care* has professional oncology social workers on staff to provide free emotional and practical support for people with cancer, caregivers, loved ones and the bereaved:
https://cancercare.org/services

Cancer Support Community has a helpline with a range of support services with over-the-phone translation support in over 200 languages:
https://www.cancersupportcommunity.org/cancer-support-helpline

Self-Care

Taking thoughtful, gentle care of ourselves can be a new skill to acquire. The IWMF offers a wellness program and a plethora of resources to support these efforts. There are many helpful online videos and resources to explore. If you are finding it hard to take the first step, imagine what you would say and do for your best friend if they were hurting or in need. Then try offering that exact same gracious support and kindness to your own precious self.

The IWMF Wellness Community features a range of group classes on Zoom to address common issues related to WM and to provide our members with an enhanced quality of life. The classes meet live and feature an optional support chat afterwards. Some find that being in a shared space with others who have their rare diagnosis is as therapeutic as the class itself. Recordings are posted soon after the class ends, but the support chat is not recorded. You can check out upcoming sessions on the IWMF website calendar:
https://iwmf.com/events-calendar/

Chair Yoga for WM YouTube Playlist:
https://www.youtube.com/playlist?list=PLgZibbDA48mSMZ1Nhn1X6EJPfEBJT59dh

Sound Meditation for WM sessions offered monthly:
https://www.youtube.com/watch?v=8qy2aGyWgYA

Cardio Flow for WM YouTube Playlist:
https://youtube.com/playlist?list=PLgZibbDA48mRmMDwUq_a4tuWN9Wd_3P-s

Yoga Nidra Playlist:
https://www.youtube.com/playlist?list=PLgZibbDA48mQIa-sdBMMMYqWIpEPDxQs8

The IWMF Torch article (April 2013, Page 18) titled "A Self-Care Approach to Living Well with Waldenstrom Macroglobulinemia" by Wanda Huskins explores the array of self-care methods at our disposal and emphasizes that self-care varies from individual to individual:
https://iwmf.com/wp-content/uploads/2020/10/Torch-April-2013.pdf

The Leonard P. Zakim Center for Integrative Medicine and Healthy Living has a Sleep & Relaxation Toolkit video series demonstrating evidence-based techniques for reducing stress and anxiety, calming the nervous system, and promoting relaxation:
https://myzakim.dana-farber.org/sleep-relaxation-toolkit

Cancer*Care* offers an audio recorded presentation with two doctors discussing the impact of stress on well-being and using "Mind Body Techniques to Cope with the Stresses of Cancer"
https://www.cancercare.org/connect_workshops/619-mind_body_techniques_cope_stresses_cancer_2017-11-15

Gaining Empowerment

Gaining empowerment or a sense of control in living with and managing Waldenstrom's will help patients become active participants in their health care at a personally acceptable level of involvement. Key steps in the empowerment process include gaining knowledge and support and partnering with health care professionals through effective communication and decision making. Empowerment builds self-confidence and promotes better health outcomes.

The Patient Empowerment Network (PEN) is an organization dedicated to providing resources to empower patients and care partners on their cancer journeys. PEN has developed animated videos and resource guides that provide rationale and tips for patients to actively participate in their cancer care:
https://powerfulpatients.org/becoming empowered/#guides

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Shared decision making is a key component of patient-centered healthcare that balances risks and expected outcomes with patient preferences and values. Below are resources addressing this topic:

The IWMF Ed Forum 2023 video, "Patient-Doctor Shared Decision Making" with Dr. Shayna Sarosiek of Dana-Farber Cancer Institute:
https://youtu.be/XEW-Gv1WIBs

"The Bloodline with LLS" podcast – "Patient-Doctor Perspectives: Shared Decision-Making" discusses how a doctor and patient worked together to determine the best treatment course for the patient:
https://thebloodline.org/TBL/112e113/

In September 2023, the IWMF launched a Living Well with WM monthly community gathering hosted by IWMF Wellness Program Coordinator Ann Grace MacMullan. We also look forward to expanding our wellness programming in other ways, such as adding new exercise class opportunities to offer exclusive support to WM community members. If you have any questions about the resources shared, please feel free to contact Michelle Postek at *mpostek@iwmf.com*. Stay tuned for more exciting offerings from the IWMF!

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

AUSTRALIA

In Memorium Michael Van Ewijk, WMozzie

Michael van Ewijk's life was celebrated by his family and friends in his historic home town of Milton, NSW Australia. He was particularly well known to his Australian WM fellow travellers for his inspirational contributions over many years.

Michael was the first Australian WM patient to receive ibrutinib on the iNNOVATE trial at Concord Hospital under Prof. Judith Trotman in 2014. He realized his luck that his incurable cancer had not really affected his life because of good care and treatments and his three-decade passion for bike riding.

Last September he was invited, with Prof. Judith Trotman, to Parliament House Canberra to tell his WM survivor story to the Australian Government Minister of Health to support Pharmaceutical Benefits Scheme (PBS) funding for new treatments for WMozzies.

Michael van Ewijk, Prof. Judith Trotman, Hon. Greg Hunt MHR

Michael on his 702km WM fundraising ride, October 2020

He raised over A$11,000 for the IWMF-LLS Strategic Research Roadmap Initiative with a mighty bike ride—702 km from Balranald to Wagga Wagga to celebrate his 70th birthday. This achievement was celebrated in the January 2021 issue of the *IWMF Torch*: *https://iwmf.com/wp-content/uploads/2021/01/Torch-Jan-2021_final-web.pdf.*

WMOZZIES
Australian patient support group for Waldenström's Macroglobulinemia

Michael was founding editor of A*NZ Beacon Newsletter for WMozzies, with four editions 2018-22. He also created the logo of WMozzies and was Australian contributing reporter for the *Torch.* See his profile, reprinted from the Leukaemia Foundation of Australia's *Lymphoma News,* at *https://iwmf.com/michael-van-ewijk-5-years-on-ibrutinib-and-still-going-strong/.*

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CANADA

In Memoriam Betty McPhee

Betty McPhee

Betty McPhee of Toronto, Ontario, Canada, played many roles in making the Waldenstrom's Macroglobulinemia Foundation of Canada (WMFC) what it is today. She served as a Vice Chair of the Board and as Chair of the Membership Services. She not only was Co-Leader of the Toronto Support Group but also had a major role in starting support groups across Canada. She was a very welcoming person and always ready to help others navigate their WM journey by providing insightful suggestions. She was an amazing and dedicated individual who did so much for patients impacted by WM. Betty will be greatly missed by the WM community.

Negotiating WM in Two Countries and in Two Languages

By Francine Blackburn, Montreal, Canada

After two years of my testing slightly anemic at my annual physical, my Canadian doctor in Montreal recommended that I see a hematologist. The Canadian health care system can be very slow when there is no known urgency, so it was a one-year wait time on the public side of Quebec's health care system, or two weeks on the private side where you pay out-of-pocket. Quebec has a growing private health care system, given the difficulty in getting medical attention because of long wait times and a shortage of doctors. I was diagnosed with a vitamin B12 deficiency. The hematologist prescribed B12 supplements and told me to redo more detailed bloodwork in about a month to see how I did.

The day after I arrived in Florida for the winter, I received a call from my Canadian hematologist to the effect that she suspected I had Waldenstrom, given my high IgM. She recommended a few more tests (bloodwork, CT scan, and biopsy). For the scan and biopsy, she would have to refer me to a public side oncologist who would schedule the initial consultation and subsequently order the tests. This would be a long process, as I was not yet on an urgent list. I decided to stay in Florida to do all tests. I contacted my travel insurer, as initial diagnostics while traveling are supposed to be insured, but they have proven to be a big disappointment and a pain to deal with. So after spending tens of hours on the phone with them, I decided that it was best for my mental wellbeing to no longer deal with them and absorb the costs.

As expected, no facility in Florida was willing to perform tests unless requested by a US doctor. It took visits to a hospital emergency department and then again to an Urgent Care facility to get the required referrals to cancer clinics. I tried to get an appointment with five cancer care facilities over a three-week period before Florida Cancer Specialists in Estero gave me an appointment with an oncologist for two weeks later. One of my problems was that the requisitions from my Canadian doctor were on forms printed in French, although the requested tests were written in English. I was told multiple times that they would need to send the forms for translation, while my Canadian doctor wasn't helpful to send English forms. I took note that when I returned to Montreal, I would seek medical treatments from an English-speaking oncologist, so my files could go back and forth between my home in Quebec and my home in Florida.

This was a very difficult time for my husband and me. We did not sleep well during this period, as we had no information other than what we could find on the internet, and based on symptoms, I was convinced that I had three years to live! From the time I saw my Florida hematologist/oncologist, I started receiving a more positive prognosis and was then told that I had ten years to live, as I was assessed as low risk (of course, I now know it can be substantially more). She said I had lymphoplasmacytic lymphoma (LPL), yet she didn't want to confirm WM; this was very confusing, as I read they were the same. Two-and-a-half months after the initial call, I had enough information to stop rehearsing in my head and finally tell my kids, my mother, and my sisters. My daughter lives in England, so this was a difficult conversation, but we had a positive spin to our message so it went well.

My husband and I went to St. Louis at the end of April for the IWMF Ed Forum. It was an eye opener for us, and we were so pleased to meet people who have had WM for 10, 15, 20, and even 30 years! We received much better information about WM and joined IWMF Connect and the Facebook WM Support Group, where the WM community shares so much helpful information. At the Forum, I met Dr. Steven Treon, and he was kind enough to put me in contact

Francine and Mike Blackburn

International Scene, cont. on page 16

with a public-side oncologist in Montreal associated with the McGill University Health Center, with whom he had worked in the past.

Four months after my initial visit with my Florida oncologist, it was time to go back home.

A few weeks after I returned home, I met with my hematologist on the private side to thank her for her initial diagnostic workup. I asked to be referred to a neurologist, as I suspected I had neuropathy. I first heard of it when I attended the Forum in St. Louis and started suspecting that pain in my feet and hands for the past seven years were not due to arthritis or mechanical issues, but to neuropathy.

I should state that I had two surgeries on each foot since 2018 starting with bunion surgery. While the bunions were not overly bad, the surgeon performed the surgery, as I was under immense pain. With the pain getting worse following surgery, another surgeon thought it was because of other issues in my toes, so I had surgery on both feet again last September. Ever since, the pain became such that I had difficulty sleeping. Given a confirmed WM diagnosis, I was able to get an appointment within a month at The Neuro (Montreal Neurological Institute-Hospital) where neuropathy was confirmed.

I am still awaiting results from my anti-MAG antibodies test to help determine if it is WM-related. I was told it would take two months to get results, as my blood samples were sent to another province. Given WM's rarity in Canada, they are waiting for more specimens to be received before proceeding with the analysis. I was very upset with the neuropathy confirmation, thinking that it could mean that WM had already started causing damage to my body. I also wonder whether any of my foot surgeries were ever needed, given that the pain was due to neuropathy. At my last appointment with my neurologist, he said that since my neuropathy is still relatively mild (notwithstanding the pain), starting cancer treatment would be like using a cannon to kill a fly. He also shared the fact that there are disagreements between hematologist/oncologists and neurologists on the benefits of cancer treatments to address neuropathy.

Around the same time as my neurology appointments, I contacted Dr. Treon's referral, and given my Florida cancer diagnosis, I was able to get an appointment within a few weeks. My new hematologist/oncologist believes that I do not have WM but MGUS. I am scheduled to see him again in two months. Meanwhile, I continue to be on watch-and-wait.

My husband and I believe that we have been on a roller coaster over the past nine months. I feel grateful that I am being followed by specialists in Montreal, but I am finding the doctors' conflicting diagnoses confusing. I plan to go to Dana-Farber Cancer Institute in the fall for a second (or third) opinion...at least we know they are familiar with WM. Meanwhile, my husband and I try to remain active, playing tennis, golfing, swimming, and walking the dogs.

Waldenström France

FRANCE

Our 11th Patient-Doctor Meeting of Waldenström France was held June 10 in Paris at the Musée des Arts Forains. It was with great pleasure that Jean-Paul Favand and his team once again welcomed us to this unique place. We are a bit at home there now.

Waldenström France attendees enjoyed dinner after the meeting.

It was the first face-to-face meeting organized by the new Board of Directors. They were recently elected, and the Board has expanded with the arrival of four new members. It was therefore an opportunity to put a face to those who work to provide support and information throughout the year.

We were also lucky to welcome Hannah Syed and Bob Perry, both English representatives of the IWMF, our partner.

Almost 80 attendees came to listen to our three speakers:

> Prof. Olivier Tournilhac, Service d'Hématologie et de Thérapie Cellulaire, CHU de Clermont-Ferrand, "WM Diagnosis: State of Knowledge"
>
> Dr. Damien Roos Weil, APHP Pitié Salpêtrière, "When and How to Treat Waldenström"
>
> Dr. Rabab Deb, Clinical Neurophysiology Service, Pitié Salpêtrière, Paris, "Neuropathy and Waldenström"

There were two major firsts this year:

> The testimonies of Sylvie and Louise, helping and accompanying carers, provided very emotional moments; and
>
> The presentation of Dr. Rabab Debs, neurologist, who allowed us to better understand the links between Waldenström and neuropathies. It appears that these links are very complex. Dr. Debs therefore agrees to appear on the scientific page of our site in order to be consulted if necessary, and we thank him for this.

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Waldenström France's Patient-Doctor Meeting was held at the Musée des Arts Forains in Paris.

As at each of our meetings, the discussions went well, and the day went by too quickly. It then ended at a restaurant with an optional dinner for attendees.

Editor's note: Article and photographs translated from https://portail.waldenstromfrance.org/11ieme-rencontre-patients-medecins-waldenstrom-france-10-juin-2023

INDIA

By Saurabh Seroo, WM India Co-Leader

WM India conducted its in-person support group meeting in Bangalore in August 2023. We were fortunate to have one of our oldest members join us and share her experience and deep knowledge of the disease and its manifestations.

As we shared our stories of overcoming Waldenstrom's, it was sad to note the second order effects of the pandemic and its impact on our lives. We noticed how our underlying WM numbers had been impacted after contracting coronavirus and how the disease had progressed since then.

Those who had been asymptomatic or in remission were now on the verge of treatment, after an uncharacteristic increase in their immunoglobulin counts. On a positive note, treatment options have continuously improved in India over this period, and most patients have access to the latest protocols, regardless of where they live in the country.

Our support group also saw an increase in our membership, as more patients and caregivers reached out to us. This could be attributed to our new online presence—something that has enabled us to rank higher up on Google and be displayed organically when patients in India search about WM.

One of the privileges of our role as support group leaders is the opportunity to speak to newly diagnosed patients. We cherish this first conversation, as it is an opportunity to impart everything we have learned in our journey in a cogent, hopeful, and optimistic manner. It is important for patients and caregivers to know that there is hope at the end of the tunnel and no reason to catastrophize or spiral.

Of all the lessons we have taken away in our journey leading WM India, the singular one has been the role of a positive mindset through this journey and the determination to live better lives, despite the obstacles that come.

Left to right: Co-Leader Rajini Seroo, patient and group member Jaya Mani, Co-Leader Serabh Seroo

International Scene, cont. on page 18

WMUK
Wheels for Waldenstrom's
By Rebecca Milburn

Editor's note: For three days in August, 20 riders took on the incredible challenge of cycling from London to the heart of Paris to support the work of WMUK. Rebecca Milburn, whose mother has WM, explains how the ride raised £70,000 by uniting the team in a common purpose.

Our journey together began in London's Crystal Palace, and it is fair to say we were an eclectic group. There were WM experts, patients, and family members, and we were delighted that London-based Beth Mitchell from the IWMF could join us too. Most had never done anything quite as crazy as a 200-mile cycle ride, so anticipation and nerves were high.

However, for those of us who live with WM or are supporting loved ones, adversity is nothing new. We've all been on the diagnostic odyssey and continue to battle the uncertainty of symptoms, pain, and treatment options. Along the way, we've all built resilience.

Indeed, it was patients' resilience that inspired this whole cycling challenge. Dr. Helen McCarthy, WMUK Clinical Advisory Board member, is who we had to blame. She was inspired by a WM patient who cycled from Land's End to John O'Groats just months after a gruelling session of chemotherapy, so she approached WMUK about doing a similar challenge. She told me, "I thought if he can do it after chemotherapy, it would be a wonderful challenge for us doctors."

Dr. Shirley D'Sa, known world-wide as a WM expert, a founder and major supporter of WMUK, said, "I have taken up cycling again after 30 years to take part in this fundraising event. A patient and I set up this charity some ten years ago, and it has gone from strength to strength! I am very proud of what we have accomplished so far, but in order to achieve our important goals going forward to support people affected by WM, we need to raise funds to make this possible."

Growing Camaraderie

With Helen to blame, we set off with eager anticipation and the port of Newhaven on the south coast in our sights. While there was no time pressure for our 11pm ferry, there were certainly plenty of hills to contend with, not to mention the odd puncture and the growing sense of discomfort from so many hours in the saddle.

Plenty of research shows that human beings can endure far more pain when in the company of others. The ride was certainly proof of that. The thigh-burning gradient of Turners Hill in West Sussex caused us to curse Helen and her crazy ideas, but together we conquered it.

It was in the dark moments that the firm friendships were formed. That, and onboard the Newhaven to Dieppe Ferry where those of us who were looking forward to a long soak in a hot bath followed by the luxury of an eiderdown duvet were sorely disappointed!

It was past midnight before my head finally hit the pillow in a cramped berth. After what felt like mere seconds, I was jolted from my not so peaceful sleep at 4am. Bleary eyed and coffee-fuelled, we set off for day two.

Creating Memories

Our reward was a beautiful stretch of cycle path known locally as the Avenue Vert. As the name suggests, this is a dedicated cycle path stretching through the beautiful French countryside. Not a hill in sight (or another human being at the unearthly hour of 6am).

We are all guilty of pre-judging people, and I must confess that before the ride I was a little apprehensive about cycling

The WM "peloton"

International Scene, cont. on page 19

Left to right: Dr. Shirley D'Sa, Beth Mitchell, Rebecca Millburn

with such experienced consultants. We tend to hold medical professionals on a pedestal, but events like this are such a leveller. The very ethos of WMUK is to unite people with different experiences of WM, with a focus on improving life. The ride did just that, and on the long flat stretches of path, conversations flowed.

One of the most beautiful memories I have is from the second day where we stopped in the most picturesque French village. I sat sipping coffee and indulging (guilt-free) in the most exquisite croissants while discussing the merits of ear plugs with leading WM consultants, patients, and their families. It just summed up the camaraderie of the group.

Tackling the Real Challenge

By the start of day three, what had seemed like an unsurmountable challenge was now within our grasp. It had gone by in a flash, and yet the team had jelled together like friends who had been on the journey together forever.

As we set off with visions of the Eiffel Tower, the hard work and dedication of the support crew really came to the fore. The team of mechanics, medics, guides, and their endless supply of ibuprofen gel and jelly babies, got us through those last few tough miles.

Nothing quite prepares you for the sight of the Eiffel Tower rising majestically into the Parisian sky. Tracy Paulin, a WM patient cycling in the group, told me, "Everyone had been saying 'well done for doing this,' so I felt like I finally deserved the sponsorship." We may have had sore derrieres, but we had huge smiles on our faces.

The metaphor of a journey is an overused cliché, but so much of the cycle challenge seemed to mirror the daily struggles we all face. It wasn't easy. There are parts of the journey we'd rather forget, and moments we'll remember forever. But what got us through was the team around us.

The £70,000 we raised for WMUK will ensure that more people living with WM can get the support they need to live well. As Helen said, "WMUK is such a fantastic charity, and it's actually just a great family."

My fellow riders and I hope that more people living with and impacted by WM can be part of this fantastic family as a result of cycling endeavours.

If you would like to be part of next year's Wheels for Waldenstrom's London to Paris Cycle Challenge from 23-25 August 2024, visit *https://www.my-cycle.co.uk/london-to-paris-wmuk.*

Final stop, Paris

MEDICAL NEWS ROUNDUP

By Sue Herms, IWMF Research Committee Member

Final Analysis Published for Pivotal Phase 3 ASPEN Trial in WM – The final analysis from the pivotal Phase 3 ASPEN trial comparing zanubrutinib (Brukinsa) to ibrutinib (Imbruvica) in symptomatic WM patients has been published in the *Journal of Clinical Oncology*. Cohort 1 of the trial had 201 participants with mutated MYD88, 102 of whom received zanubrutinib and 99 of whom received ibrutinib; Cohort 2 had 28 participants with wild-type (unmutated) MYD88, all treated with zanubrutinib. The sum of the very good partial response (VGPR) rate plus the complete response (CR) rate was chosen as the primary end point for this study because response rates and depth of response are associated with progression-free survival and time-to-next-treatment. At a median follow-up of 44.4 months, the VGPR + CR rate in Cohort 1 was 36.3% with zanubrutinib vs. 25.3% with ibrutinib. In addition, Cohort 1 participants who also had CXCR4 mutations demonstrated a VGPR + CR rate of 21.2% with zanubrutinib vs. 10.0% with ibrutinib. In Cohort 2, the VGPR + CR rate with zanubrutinib was 30.8%. This rate increased over time and was numerically higher for zanubrutinib than ibrutinib at all time points during follow-up. The median times to overall response (minor response or better) or major response (partial response or better) were similar with both drugs, but the median time to VGPR + CR was faster for patients on zanubrutinib (6.7 months) vs. ibrutinib (16.6 months). Median duration of response was not reached in either drug arm. Participants with enlarged lymph nodes and/or enlarged spleen saw a greater reduction in size with zanubrutinib. Adverse events for zanubrutinib vs. ibrutinib, respectively, included: diarrhea (22.8% vs. 34.7%), muscle spasms (11.9% vs. 28.6%), hypertension (14.9% vs. 25.5%), atrial fibrillation/flutter (7.9% vs. 23.5%), pneumonia (5.0% vs. 18.4%), and neutropenia (34.7% vs. 20.4%), with neutropenia being the only adverse event that was greater for zanubrutinib—although it was not associated with a higher infection rate. Overall, zanubrutinib was associated with a lower risk of treatment discontinuation because of adverse events.

Study Looks at Immune Responses to Shingrix Vaccination in Patients with CLL and LPL/WM on BTK Inhibitor Therapy – A discussion by researchers from the University of Rochester in New York looked at whether vaccination with Shingrix (to prevent herpes zoster, also called shingles) is effective in patients with chronic lymphocytic leukemia (CLL) or lymphoplasmacytic lymphoma (LPL)/WM who are on BTK inhibitor therapy. Their pilot study, published in the *American Journal of Hematology*, enrolled 32 patients, 22 with CLL and 10 with LPL/WM, who had been on BTK inhibitor therapy for at least three months. The patients were followed for 24 months after their second Shingrix dose and were tested for at least a four-fold increase in the titer of IgG antibodies specific for herpes zoster. T cell immune responses were measured by counting the number of CD4 + T cells specific for herpes zoster. Seventy-five percent of all patients had an antibody response to vaccination at four weeks; in these responding patients, 56.5% had a sustained antibody response 24 months after vaccination. A T cell response was achieved in 81.3% of patients four weeks after vaccination; in these responding patients, 65.4% showed a sustained T cell response 24 months after vaccination. Compared to 24-month Shingrix vaccine responses in healthy subjects from previously reported studies, the antibody response rate in these current study patients was less, but the T cell response rate was similar. Interestingly, T cell response is thought to be the primary method of protection against shingles.

*...**zanubrutinib** was associated with a **lower risk** of **treatment discontinuation** [than ibrutinib] because of adverse events.*

Chinese Study Analyses Retinopathy in WM Patients – Chinese researchers performed a retrospective analysis of retinopathy (damage to the retina) in WM patients through the use of several imaging methods and reported their results in the *American Journal of Ophthalmology*. Of the 50 patients in this study, 28 had retinopathy in at least one eye, characterized by tortuous retinal vessels, extensive retinal hemorrhage, and macular edema (swelling from fluid accumulation in the central part of the retina). Retinopathy from WM is related to increased blood viscosity caused by high IgM levels. In addition, WM patients often show accompanying anemia and low platelet counts, which can aggravate the condition. This study found that a serum monoclonal IgM protein level of 26.2 g/L (2,620 mg/dL) or serum quantitative IgM level of 5.10 g/L (5,100 mg/dL) were important cutoff points for predicting WM retinopathy, with the serum quantitative IgM level being the preferred unit of measurement. The researchers recommended that patients with these IgM levels should undergo retinal imaging studies to determine if retinopathy is present. Plasmapheresis rapidly reduces IgM levels, helping to reverse WM retinopathy; the use of bevacizumab (Avastin) injections has also been reported to be of some benefit. Serum viscosity was not measured in this study because the researchers suggested that in actual clinical practice, results are often slow to be reported, not reproducible, and may lack good correlation with serum IgM levels.

Medical News Roundup, cont. on page 21

Study Looks at Risk of Treatment-Related MDS/AML in Lymphoma Patients – Historically, survivors of lymphoma have had increased risks for treatment-related myelodysplastic syndrome and acute myeloid leukemia (tMDS/AML), which are cancers that affect myeloid-derived blood cells such as neutrophils, platelets, red blood cells, and monocytes. These cancers can occur because chemotherapy and radiation treatment for lymphomas have the potential to damage the DNA of bone marrow stem cells. A multicenter US study looked at cancer registries from 2000-2018 and identified 1,496 cases of tMDS/AML among 186,503 adults with lymphoma who were treated with frontline chemotherapy or chemoimmunotherapy and survived at least one year. The researchers estimated the relative risk of tMDS/AML by comparing its incidence in the lymphoma patients to its expected incidence in the general population by means of a statistical term called the standardized incidence ratio (SIR). Some of the higher rates of tMDS/AML were seen in patients with Burkitt's lymphoma (SIR of 20), peripheral T cell lymphoma (SIR of 12), chronic lymphocytic leukemia/small lymphocytic lymphoma (SIR of 9), and mantle cell lymphoma (SIR of 8.5). LPL (lymphoplasmacytic lymphoma)/WM patients were also at an elevated risk, but their risk rate was lower (SIR of 6.9). Median survival after the diagnosis of tMDS/AML was eight months. The researchers observed a lower risk for tMDS/AML in more recently treated lymphoma patients, notably including those with LPL/WM; Although the condition is rare, the poor prognosis following tMDS/AML emphasizes the importance of continued efforts to reduce chemotherapy-related toxicity to the bone marrow of lymphoma patients. The study was published in the journal *eClinicalMedicine*.

Greek Researchers Discuss Monoclonal Gammopathy of Clinical Significance – Monoclonal gammopathy, or the presence of a monoclonal protein in the blood, is a common condition among the elderly and is typically referred to as a monoclonal gammopathy of undetermined significance (MGUS), which usually is asymptomatic. MGUS may progress over time to become multiple myeloma, WM, or light chain amyloidosis. Even in cases where monoclonal gammopathies have not progressed, they can be associated with a variety of conditions involving the kidneys, peripheral nerves, skin, or less commonly, other organs. These symptomatic syndromes do not fulfill the typical criteria for the diagnosis of multiple myeloma or WM and have been termed monoclonal gammopathy of clinical significance (MGCS). A study from researchers in Greece attempted to provide an estimate of the prevalence of MGCS among all patients with monoclonal gammopathies by analyzing a database at the Plasma Cell Dyscrasia Unit of the National and Kapodistrian University of Athens, Greece. Between January 2010 and December 2021, the researchers looked at 3,138 patients diagnosed with a monoclonal gammopathy and found that 135 (4.3%) patients were ultimately diagnosed with MGCS, with the two most commonly affected organs being the kidneys or the peripheral nerves. The median baseline level of monoclonal protein among MGCS patients was low at 0.4 g/dL, and the median bone marrow infiltration by clonal cells was 10%. The monoclonal protein was of the kappa light chain type in 56%, lambda light chain type in 42%, and biclonal (presence of two monoclonal proteins) in 2%. In patients with B cell clones, therapy for MGCS was primarily rituximab-based, although a significant proportion of patients with IgM-related neuropathy received only supportive therapy. The researchers noted that, given the prevalence of monoclonal gammopathies in the general population and the differing clinical presentations when symptoms are present, there is probably a significant number of undiagnosed patients with MGCS. As well, the causal link of a monoclonal gammopathy with a condition is often difficult to prove. This study was published in the journal *HemaSphere*.

Novel CAR Therapy in Phase 1 Testing for Relapsed/Refractory NHL – Most chimeric antigen receptor (CAR) therapies currently use T cells, but a novel CAR therapy using natural killer cells (NK cells) that target surface marker CD19 on B cells is undergoing Phase 1 testing in patients with relapsed/refractory non-Hodgkin's lymphoma (NHL), including WM. The therapy is called NKX019, and the trial sponsor, Nkarta Inc., plans to enroll 150 participants in the US and Australia. Its identifier on *www.clinicaltrials.gov* is NCT05020678.

Phase 2 Trial of Nemtabrutinib Is Enrolling Patients with B Cell Cancers – A Phase 2 trial called BELLWAVE-003 is enrolling participants for the study of nemtabrutinib (formerly called ARQ 531) in B cell cancers, including relapsed/refractory WM. Nemtabrutinib is a noncovalent BTK inhibitor of both wild-type (unmutated) and C481S-mutant BTK. The trial expects to enroll a total of 450 patients at several US and international locations and is listed on *www.clinicaltrials.gov* as NCT04728893.

*...the **causal link** of a monoclonal gammopathy with a condition is often **difficult to prove**.*

Phase 1a/b Study Begins of IRAK4 Degrader for Relapsed/Refractory B Cell Lymphomas – A Phase 1a/b study of KT-413 for relapsed or refractory B cell non-Hodgkin's lymphomas, including WM, has enrolled its first patients. KT-413 is an intravenous small molecule degrader of IRAK4, as well IRF4, both of which activate the NF-kappa B pathway and thereby prevent cell death. This US-based trial plans to enroll 80 participants. The trial designation on *www.clinicaltrials.gov* is NCT05233033.

Medical News Roundup, cont. on page 22

First Patient Dosed in Phase 1 Trial of BTK Degrader AC676 – Accutar Biotechnology has dosed its first patient in a Phase 1 trial of AC676 in patients with relapsed/refractory B cell malignancies, including WM. The drug is a pill that works differently from BTK inhibitors—instead of binding to and blocking the BTK protein, it degrades or breaks it down. AC676 degrades both wild-type (unmutated) BTK and mutated BTK, including the C481S mutation that can lead to resistance to first- and second-generation BTK inhibitors like ibrutinib (Imbruvica), acalabrutinib (Calquence), and zanubrutinib (Brukinsa). The trial plans to enroll 60 patients. The trial identifier on *www.clinicaltrials.gov* is NCT05780034.

*The **vaccines**, approved for everyone over the age of six months, **target** the XBB.1.5 COVID **variant** that was **dominant** in the **spring**;...*

US Will Continue to Provide Free COVID Vaccination to Uninsured and Underinsured Adults During Transition to Commercial Market – Because COVID-19 vaccines in the US are transitioning from a government-run access program to the commercial market this fall, the Centers for Disease Control and Prevention (CDC) has launched the Bridge Access Program to allow adults who are uninsured or underinsured to continue to receive free COVID-19 vaccination. The CDC will purchase COVID-19 vaccines and allocate them to participating community-based providers, including local health departments and retail pharmacies. The Bridge Access Program is temporary and will expire in December 2024, at which time a permanent solution called Vaccines for Adults (VFA) has been proposed, although not yet enacted into law. More information on the Bridge Access Program can be found at *https://www.cdc.gov/vaccines/programs/bridge/index.html*.

New COVID Vaccines Approved in US – At *Torch* press time, the US Food and Drug Administration and the US Centers for Disease Control and Prevention approved new COVID-19 vaccines from Pfizer and Moderna, along with guidelines for their use. Approval of a new vaccine from Novavax was also expected, with the vaccines becoming available in September. The vaccines, approved for everyone over the age of six months, target the XBB.1.5 COVID variant that was dominant in the spring; other variants have since emerged, but experts say that the new vaccines are also protective against these variants. To view the complete guidelines for adults who are immunocompromised, including the timing of doses, go to *https://www.cdc.gov/vaccines/covid-19/clinical-considerations/covid-19-vaccines-us.html#considerations-covid19-vax*, scroll down to the section "COVID-19 Vaccines, Recommendations, and Schedules," and click on the heading "Guidance for people who are immunocompromised.

New Medicare Initiative to Negotiate Prescription Drug Prices Has Begun – A new initiative for making prescription drugs less expensive for Medicare Part D and its beneficiaries has begun, now that the US Department of Health and Human Services has been instructed to negotiate pricing of ten drugs directly with their manufacturers. The ten drugs named in the first round of price negotiating include: Eliquis, Xarelto, Januvia, Jardiance, Enbrel, Imbruvica, Farxiga, Entresto, Stelara, and Fiasp or NovoLog. Imbruvica was the only cancer drug to make the list. Together, these drugs accounted for $50.5 billion (or about 20%) of Medicare Part D spending from June 2022 to May 2023. Governments of other economically advanced countries have long set drug prices through some sort of negotiation or direct regulation; the US government has now joined this group, although the newly discounted drug pricing won't take effect until January 2026. The initiative is the result of the Inflation Reduction Act, signed into law in 2022. Under the Act, more prescription drugs will be added over successive years, with the focus on drugs that are costing Medicare and its beneficiaries the most money.

The author gratefully acknowledges the efforts of Grete Cooper, Steven De Cenzo, Peter DeNardis, Julianne Flora-Tostado, Tom Hoffmann, Richard Savoy, 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

EDITED BY SHARON RIVET

EDITOR'S NOTE:

After a year-long search, the Torch *welcomes Sharon Rivet as the new Editor of Support Group News. Please send ideas for future stories about your support group and its members and activities to Sharon at* shaycr62@gmail.com. *We look forward to reading more about IWMF support groups, perhaps also some that we haven't heard from before!*

SUMMER PICNIC!

BY SHIRLEY GANSE, SEATTLE AREA SUPPORT GROUP LEADER

Everyone loves a picnic, especially when the weather is in the mid-70s, the sun is shining, and the view is terrific. The Seattle Area Support Group had not gotten together in person for three years, and since we are lucky to have some of the best weather in the country this summer, we decided to take advantage of it and have a picnic!

Fifteen members of the group converged on the lakeside home of Nancy and Mark Nelson, and our potluck fare was truly amazing; I felt like I was eating a meal somewhere on the Mediterranean! We gathered outside on the covered patio and under umbrellas on the lawn, enjoying good conversation, good company, and good food.

Nancy commented, "Thanks to the IWMF, on July 29 I enjoyed a picnic and enriching conversations with other Seattle area Waldenstrom patients. Each person provided knowledge, information, and hope concerning their journey with Waldenstrom. I look forward to making this an annual event!"

Janet McIntosh said, "I thoroughly enjoyed sharing a delicious potluck lunch with local WMers at the Nelsons' beautiful Lake Washington home. After three years of Zoom, it was very rewarding to make a personal connection with those newly diagnosed as well as WM veterans, gain insight from other's experiences, and share my ten-year journey and recent 3½ year success on zanubrutinib."

Perfect weather for an outdoor meeting

David Cohen also added that he "…enjoys attending the support group meetings and getting other people's perspective on living with WM."

I'm sure the group is happy to hear that we can look forward to another picnic at the Nelsons' next summer!

Janet McIntosh and David Cohen find time for some one-on-one discussion.

Attendees gather under umbrellas to enjoy each other's company

Spotlight on Support Groups, cont. on page 24

FACEBOOK SUPPORT HELPS WMer TO WATCH-AND-LIVE

By Tina Regester

On July 19, 2021, exactly two weeks after I had a bone marrow biopsy to determine why my IgM levels were so high, I received the results on my online health portal. Lymphoplasmacytic lymphoma. I knew lymphoma was a type of cancer. Then my cell phone rang, the doctor's office asking if I could come in the next day.

I left work in a state of shock and fear. I've got it—cancer. My young adult daughter was home that day and was leaving for a flight in the afternoon, so I sat in my car in the parking lot until I knew she would be gone. I sobbed uncontrollably, asking "Why? Why?" Then, I started looking online. Rare cancer, 5-8 years. I was only 52 years old, with two small grandchildren. How could I not be here to see them grow up or to see two of my unmarried daughters wed?

When I arrived at home with my husband minutes behind me, he held me tight, and we cried together for hours. When the tears wouldn't come any more, I started looking online again for any information that would provide some glimpse of hope. Somewhere along my search, I made it to the Waldenstrom Macroglobulinemia Support Group Facebook page.

I wasn't sure what I'd find, but I don't remember reading anything about people dying. People seemed to be living with this rare disease. I started reading as much of the literature posted on the page as I could that night. People were living with WM for decades.

By the next morning, I walked into the hematologist's office concerned and nervous, but no longer in a state of panic. Some things he was explaining to me I had already read the night before on the WM Facebook page. I even had a set of questions to ask him that I found on the page. I felt empowered, and I think he was even a little impressed.

I went home and continued to read the FB posts. I couldn't stop. I was reading posts out loud to my husband and kept saying "Listen to this one." WM was in my every thought as I fell asleep that night.

The next day, I sent my first post to the group page, "You are all so positive and are living with WM. Any initial advice you can lend on how you cope? Will it come to a point where I can wake up and not think about this first thing in the morning or constantly throughout the day, or will it always be in the forefront of my thoughts? My doctor said to try to think of it as having a chronic disease, such as high blood pressure. Will this ever happen with WM, so I can learn to live with it?"

Comments started pouring in within minutes. One person said she cried when she read my post, because she felt the same way when diagnosed. She and more than 100 others

Tina and granddaughter Alora

reassured me that eventually I would wake up, and WM wouldn't be my first thought.

They were right. It was my first thought for at least several weeks, but thanks to members of the WM Facebook page, they weren't fearful thoughts. Today, I'm still what some call "watch-and-wait." My oncologist calls it "watch-and-observe." I prefer to call it "watch-and-live," because I'm living a relatively great life. I'm thinking about retirement in ten years instead of wondering if I will live long enough to retire.

I still think of WM throughout my day, but it's just part of my life. No sadness; no despair. I visit the WM FB page at least once a day for factual information, inspiration, hope, and a chance to provide support to others who may be struggling. I've read posts from others who were diagnosed after me, and they sounded just like me when I was diagnosed. It's amazing how, as time goes by, they are providing comfort to those diagnosed after them.

I would encourage all of the newly diagnosed and their families to join the WM Facebook page. I can't imagine not having this support system from people who truly understand. I wouldn't be "watching-and-living." I'd be "watching-in-fear."

FROM THE FACEBOOK WM SUPPORT GROUP: FALL 2023

EDITED BY BETTY ANN MORTON

Having a rare disease like ours means that few of us have close friends who can even pronounce Waldenstrom macroglobulinemia, much less understand what WM is or how it affects our lives. A knowledgeable and caring medical team is a true gift. Some of us have family or friends who are willing to learn and care in helpful ways. We all need support because having WM can be lonely and perhaps scary.

Because "one size doesn't fit all," the IWMF has many support methods, from geographic support groups to special interest on-line groups, such as Young WMers, Military Veterans, People of Color, or WM Chair Yoga. Our Waldenstrom Macroglobulinemia Facebook Support Group is one of the most accessible. The 6,000 members of our Facebook support group have around-the-clock access to others who know about WM. Posts asking for information about a treatment, wondering how to get a second opinion, or just expressing feelings get quick responses. Since this is 2023, Facebook translates posts into the reader's language (although translation of medical terms can be problematic). The speed and quality of the support is extraordinary.

In order to join the Facebook group, potential members are asked, "Why are you seeking to join this group?" Recent responses include:

- I have WM and am looking to connect with others.
- I was diagnosed with Waldenstrom. Seek information and networking.
- In January 2023 I was diagnosed with WM and just completed six treatments of chemo two weeks ago. I live in the -- area and do not know anyone who has WM.

Quality of life is important to WMers; the emotions that surround being diagnosed with cancer and then learning to live with it are major issues. **CJA** posted, "Sorry for Google translate. For two years I have had problems telling my wife, my friends about my illness. And that it is chronic. Stresses me mentally. Anxiety. Death. Treatment. I have had my granddaughter visiting for eight days. Hard. I'm tired, but friendly friends invite me to lunch. I'm tired. I have not the energy. Cancellation of social activity. It would then have been easier to explain other forms of cancer. I feel a lack of respect for my Waldenstrom or I'm just a pessimist."

CC responded, "I understand how you feel. WM is to most an invisible illness. Some people understand, and some people do not. For all of us it is a balancing act. I just tell people that I have a very rare type of blood cancer, and both my cancer and the therapy cause me great fatigue. I have learnt to tell people that my participation in certain activities must be short. And I hate it when I do not feel well, and I get the following response: 'But you look good.' I did seek help from a counselor to help me deal with all the various ramifications of having this cancer, and found it helpful. I also show them the IWMF website, and suggest that they get better informed."

DNV wrote, "We have the opposite problem. My Wallie seems to think he can get back to normal activities now that he is done with BR (bendamustine and rituximab) and is ignoring his body's signals. He climbed a ladder recently, even though he was feeling tired, and there was no one home to help or notice if he fell. Our family has enough experience with other cancers that we do not assume he will ever be back to 100%. Perhaps tell them 'I will always have this cancer. It may not kill me, but it will keep me more tired and achy than before. Thank you for wanting to include me, but I just do not have the energy for my old, active life.'"

PH described her own experiences: "Very similar with family. Suspicion amongst neighbours that it is all invented. They are so used to people with tumours that the blood cancer group passes them by, especially non-Hodgkin lymphomas."

Group members sometimes ask for emotional support when they are going through a health crisis. The WM Facebook group has members in many different countries, so responses are generally quick, even to posts written in the middle of the night.

CC lamented, "I am utterly devastated…I am being admitted for surgery...bowel obstruction." She received many encouraging responses and commented how helpful it is to know that others care. For example, **AN** posted, "I'm so sorry. I went through that a couple of years ago. No fun. Take good care and hope things get working soon." "So very sorry. I hope each day shows improvement," commented **LG**. When **CC** posted that the obstruction had resolved after several days, without surgery, the group rejoiced.

JS wrote, "After five years of watch-and-wait, I begin BR treatment tomorrow. Currently targeting four treatments vs. six but may adjust if targeted response is not obtained. Thanks to everyone who shares their experiences with this support group (and to my brother who was treated in 2020). I know treatment plans, treatment response, etc., vary by individual, but it's still good to hear and learn from others that are starting their journey, in the middle of their journey, or those that have persevered for a long journey."

DAF replied, "You articulated well my sentiments about the value of sharing our journeys and supporting one another along the way! As someone who was recently diagnosed and is on watch-and-wait, I will be closely following your story. Thank you for sharing your life with us!"

From the Facebook WM Support Group, cont. on page 26

NL said, "*Bon courage! Tout s'est très bien passé pour moi… ça fait 3 ans maintenant et mes résultats sont toujours très bons*…(Good luck! Everything turned out pretty well for me...it's been three years now and my results are still very good...)"

New member **MS** expressed many worries about a future with WM. "My questions are more about how one lives their life. My doctors talk about immunosuppression and the risk of infections from within my own body, and, of course, from others. Also, I still wear a N95 mask when indoors or in crowds, which I try to avoid to the best of my ability. I don't feel comfortable eating around a stranger indoors or with someone who refuses to rapid test for COVID.

"I've been told that after treatment is completed, I will still be at risk from internal infections, etc., and from others for up to one year. I was quite active…traveling, playing indoor handball, going to gym 3-5 times/week, dinners, theater, etc. I miss being as active, yes, I walk everyday near sunset, 1-4 miles, and lift light weights, and see a film now and then, sitting in the corner of the theater during an early show wearing my mask, but I'm very cautious while undergoing treatment.

"Is this normal? Am I being too cautious? What should I avoid? Is it OK to get on an airplane wearing a mask after treatment is completed? Do I need to wear UV shirts if out in the direct sun for long periods? Yes, I know what the doctors have advised me, but I'd like your opinions. Be harsh and true."

This post spurred a lively conversation. **SAP** wrote, "In terms of how to live one's life having a rare immunity type cancer is a personal choice. I go out to restaurants, shopping, and airplanes and just went to my daughter's wedding and a vacation to the national parks and am no longer wearing a mask. I also go to a group fitness gym. That one was hard because everyone touches equipment and we are sweating. This works for me and my state of mind. In the end do what feels comfortable for you."

PD's thoughts were, "Your questions are very reasonable. You will eventually find equilibrium where you comfortably live. You have had a very active life. Hang on to that in a gentler way. I remember the first year of uncertainty, but I became more at ease. For everything that you might put aside, another interest might replace it."

DC shared from personal experiences, "I am immunocompromised according to the numbers but have experienced no infections. As a result, I sometimes feel at a loss as to how much I should be protecting myself, because I don't feel as if there is anything wrong with me. I live in the tropics of Australia, so sun protection has always been part of life for me and, early in the pandemic, I was much more careful, but now I really only wear masks on planes, or if I go to the theatre, cinema, or to a big sporting event where I am part of a crowd (I always carry a mask with me).

Bill Pappas posted a photo of a crocheted WM infusion buddy his daughter made for him. A WM blood drop she named Bob looks on with a concerned look.

I think everyone must find their 'comfort level' and this can change as you come to terms with your situation. I know if I get that nervous feeling when I go somewhere that is a sign to pull out the mask. Otherwise I am trying to live my life as normally as I can. Good luck with your journey."

TMR shared, "Never thought I would say this two years and two days ago, but two days ago came and went, and I forgot it was my two-year anniversary of my WM diagnosis. I'm sharing this for anyone recently diagnosed who is wondering if there will ever be a day when WM doesn't consume your thoughts. I hope that will come for you."

That's the WM Facebook Support group's wish for each of you. Come join us! Whether we are newly diagnosed or veteran WMers, some days we each need the reassurance that we're not alone, but rather part of a community that understands our struggles and worries. The WM community is full of people who are willing to share knowledge and experiences and to comfort those who are feeling scared or down. Some days I'm the one who needs help; other days I feel strong enough to care for someone else.

Note: WMers and their family members and support people are welcome to join this group. We all need friends. To join the Facebook WM Support Group, go to *https://facebook.com/groups/wmsupportgroup*. In order to join, people must answer two membership questions. Since the group is private, only group members are able to see the posts. If you need additional help with the process, please contact the IWMF office 941-927-4963 or email to *office@iwmf.com*.

GIVING TUESDAY
Make a Difference for the IWMF!

During the busy holiday season, it's easy to lose sight of things beyond hosting family, making travel plans, and finding perfect gifts for everyone on your list. But one of the most impactful gifts you can give this season is a donation to the IWMF. A contribution, no matter the size, is integral to all nonprofits working toward the greater good.

Giving Tuesday is a global movement that has unleashed the power of generosity. Starting in 2012, Giving Tuesday was a simple idea: a day to encourage people to do good. In 2022, donors in the US gave over $3 million in gifts to nonprofits in just 24 hours. Giving Tuesday is celebrating its 11th anniversary this year on November 28. This day of global generosity is the perfect opportunity to support the IWMF. If you're unable to give a monetary donation, please consider giving your time as a volunteer or lending your voice as an advocate for our cause.

It may not seem like your gift of $100, $50, or even $25 will make much of an impact, but this broad support from our donors is critical to the continued operations of the IWMF. These gifts also help the IWMF cover administrative costs, which are essential for us to remain impactful and financially sustainable.

Giving also doesn't have to be seasonal. The IWMF offers the option to give monthly through recurring electronic donations. Monthly donations give us peace of mind knowing we can count on your support month after month. If you already make a recurring donation, please consider increasing the amount by a few dollars each month to offset the impacts of inflation.

If you have questions regarding Giving Tuesday or other ways you can help support the IWMF, please reach out to Annette Preston, Director of Donor Engagement, at 317-919-8238 or *apreston@iwmf.com*.

The IWMF is grateful for all your support—and your donations (or acts of support) make a big impact.

BEN RUDE HERITAGE SOCIETY

The Ben Rude Heritage Society recognizes those who have made provisions for a future gift to the IWMF, such as a bequest, listing the IWMF as a beneficiary for a life insurance policy or qualified planned asset (such as 401k or IRA), or a life income agreement, such as a Charitable Remainder Trust. Legacy gifts represent an important component of the IWMF's financial future. There are many ways to support the IWMF through a planned gift, but a bequest is perhaps the easiest and most tangible way to leave a lasting impact. The following supporters are members of the Ben Rude Heritage Society:

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RESEARCH PARTNERS

For a commitment of $50,000 per year for a minimum of two years, or a lump sum of $100,000 or more, you can become a research partner supporting a specific IWMF research project approved by the IWMF's Scientific Advisory and Research Committees. Research Partners will have an opportunity to be kept informed of the progress of the research project and will be formally acknowledged by the investigators in their report of the project as well as in any resulting publications. Generally 10 to 12 research projects are underway with new projects under consideration each year. The following funds support current IWMF research:

David and Janet Bingham Research Fund of the IWMF has supported the following research projects:

- Aldo M Roccaro MD, PhD, Dana-Farber Cancer Institute, F*urther genomic characterization of Waldenstrom's Macroglobulinemia: unveiling the role of the CXCR4 somatic mutation, a crucial regulator of pathogenesis and important targets for therapy*
- Brad H Nelson PhD & Julie S Nielsen PhD, Deeley Research Centre, *Mutant MYD88: A target for adoptive T cell therapy of WM*

Elting Family Research Fund of the IWMF has supported the following research projects:

- Dr. Marzia Varettoni, Fondazione Italiana Linfomi Onlus, *Non-invasive diagnostics and monitoring of MRD and clonal evolution in Waldenstrom's Macroglobulinemia*
- Larry W Kwak, MD, PhD, Beckman Research Institute of the City of Hope, *Anti-tumor and immune microenvironment responses following a first in-human DNA fusion vaccine for asymptomatic WM*
- Sherie L Morrison, PhD, The Regents of the University of California, *Novel antibody-targeted interferons in combinational therapies for Waldenstrom's Macroglobulinemia*
- Shahrzad Jalali, PhD, Mayo Clinic, *Modulation of T-cell function by metabolomic signature of the bone marrow microenvironment in Waldenstrom's Macroglobulinemia*
- Dr. Bruno Paiva & Dr. Jose Angel Martinez Climent, Clinica University of Navarra, *Single-cell next-generation flow and sequencing to unravel the pathogenesis of Waldenstrom's Macroglobulinemia and to design genetically driven human-like experimental models*
- Dr. Gareth Morgan, New York University Grossman School of Medicine, *Using mutographs to define the molecular landscape and cell of origin of Waldenstrom's Macroglobulinemia*

Hamberg Family Research Fund of the IWMF

Robert Douglas Hawkins Research Fund of the IWMF

The Lynn M. Fischer Research Fund of the IWMF

Michael and Rosalie Larsen Research Fund of the IWMF

Leukaemia Foundation of Australia has supported the following research projects:

- Zachary Hunter, PhD, Dana-Farber Cancer Institute, *Multiomic analysis of DNA, RNA and epigenomic networks for prognostication and novel target identification in Waldenstrom's Macroglobulinemia*
- Gareth J Morgan, PhD, New York University Grossman School of Medicine, *Using mutographs to define the molecular landscape and cell of the origin of Waldenstrom's Macroglobulinemia*

K. Edward Jacobi Research Fund of the IWMF has supported the following research projects:

- Dr. Morie Gertz, Mayo Clinic, *Biology to Treatment: Prognostic factors, Bone Marrow Microenvironment, Genomic and Proteomic Profile of Light Chain Amyloidosis in Waldenstrom's Macroglobulinemia*

Carolyn K. Morris Research Fund of the IWMF

The Poh Family Research Fund of the IWMF has supported the following research projects:

- Dr. Signy Chow, Sunnybrook Research Institute, *Characterization of Genomic Alterations in Treatment Naive Patients with Waldenstrom's Macroglobulinemia Through a Course of Targeted Treatment and Disease Progression*

Ed and Toni Saboe Research Fund of the IWMF has supported the following research projects:

- Larry W Kwak, MD, PhD, Beckman Research Institute of the City of Hope, *Anti-tumor and immune microenvironment responses following a first in-human DNA fusion vaccine for asymptomatic WM*

The Paul and Ronnie Siegel Family Research Fund of the IWMF

Waldenstrom's Macroglobulinemia Foundation of Canada has supported the following research projects:

- Zachary Hunter, PhD, Dana-Farber Cancer Institute, *Multiomic analysis of DNA, RNA and epigenomic networks for prognostication and novel target identification in Waldenstrom's Macroglobulinemia*
- Dr. Signy Chow, Sunnybrook Research Institute, *Characterization of Genomic Alterations in Treatment Naive Patients with Waldenstrom's Macroglobulinemia Through a Course of Targeted Treatment and Disease Progression*

Robert and Nadeline White Family Research Fund of the IWMF has supported the following research projects:

- Steven Treon, MD, PhD, Dana-Farber Cancer Institute, *Targeting MYD88 in Waldenstrom's Macroglobulinemia*

Marcia Wierda Memorial Research Fund of the IWMF

Yang Family Research Fund of the IWMF has supported the following research projects:

- Steven Treon, MD, PhD, Dana-Farber Cancer Institute, *Targeting MYD88 in Waldenstrom's Macroglobulinemia*
- Zachary Hunter, PhD, Dana-Farber Cancer Institute, *Multiomic analysis of DNA, RNA and epigenomic networks for prognostication and novel target identification in Waldenstrom's Macroglobulinemia*

NAMED GIFT FUNDS

For a commitment of $10,000 per year for five years, or a lump sum of $50,000 or more, you can establish a named fund at the IWMF in your own name or in the name of someone you wish to honor. The following funds support information, education, mission programs, research, or a combination of each:

Baker Family
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David and Lois Baru and Family
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Mission Support Fund of the IWMF

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If you have discretionary giving power and would like to help move our research program forward in a special way, we invite you to join those listed above. For more information about Research Partners and Named Gift Fund opportunities and potential gifting options that might make that possible, please contact Annette Preston, Director, Donor Engagement, *apreston@iwmf.com*.

BETWEEN JUNE 1, 2023, AND AUGUST 31, 2023, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

Dwight W. Anderson
Louise Anderson

Jean Biederman
Cheryl Lerchin

William Block
Suzanne L. Herms

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Macroglobulinemia Foundation

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