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PIRTOBRUTINIB IN WM

BY CAMILLE V. EDWARDS, MD, DANA-FARBER CANCER INSTITUTE



Dr. Camille Edwards

Camille V. Edwards, MD, is a physician at the Dana-Farber Cancer Institute and a faculty member at Harvard Medical School. In her current role at the Bing Center for Waldenström's Macroglobulinemia at Dana-Farber, Dr. Edwards is involved in clinical care and research, including understanding disease biology in a socioenvironmental context, emphasizing health-related quality of life, and developing novel therapies for patients with Waldenström macroglobulinemia (WM).

Although WM remains a disease we cannot yet cure, patients are living longer and with better quality of life because we now have a better understanding of its biology. For decades, treatment involved chemoimmunotherapy, that is, chemotherapy paired with an antibody to CD20 (a marker present on WM cells)—the usual antibody being rituximab.

While these regimens play an important role in WM treatment, the treatment armamentarium has expanded significantly since the discovery that most WM cells carry a mutation in the gene *MYD88*. Mutated *MYD88* tells WM cells to stay alive through the permanent activation of Bruton tyrosine kinase (BTK). In roughly two-thirds of patients, WM cells carry another mutation, *CXCR4*, which provides a complementary mechanism to the *MYD88* pathway. In a small group of patients, WM cells carry a variety of changes in *TP53*, a gene that normally helps damaged cells self-destruct. Knowing which of these a person's disease has, now shapes the discussion on treatment options.

Importantly, targeted therapies have been developed to disrupt the abnormal activation signals in WM cells. The first drug developed to do this was ibrutinib (Imbruvica), which works by latching permanently to a specific area on the BTK protein called C481. This permanent latching is referred to as covalent bonding. In the first trial of 63 previously treated patients, 91% of patients had a disease response, and 79% achieved a major response, meaning their IgM declined by at least half. The responses also came quickly, with the first signs of improvement

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at about four weeks; at five years, just over half of patients still did not have disease progression.

Ibrutinib was followed by second-generation covalent BTK inhibitors, zanubrutinib (Brukinsa) and acalabrutinib (Calquence), designed to target BTK more precisely and spare binding to other proteins that lead to most of the known side effects of ibrutinib. Zanubrutinib was compared with ibrutinib in the randomized ASPEN clinical trial. The two drugs worked equally well, but zanubrutinib was easier to tolerate, with markedly less atrial fibrillation (8% vs. 24%) and less high blood pressure (15% vs. 26%). Neutropenia (low levels of infection-fighting white cells) was more common with zanubrutinib (35% vs. 20%), but this did not translate into more infections. Zanubrutinib also performed better in patients with *CXCR4* mutations. Acalabrutinib has shown strong activity with a 93% response rate in a Phase 2 clinical trial. There was also a low rate of atrial fibrillation, but because it is not FDA-approved for WM, it is used less often. Orelabrutinib and tirabrutinib are used in some countries but are not available in the US. Therefore, while both ibrutinib (alone or with rituximab) and zanubrutinib are FDA-approved for WM, zanubrutinib is the preferred covalent BTK inhibitor for most US patients. One practical point worth knowing: BTK inhibitors can cross into the brain and spinal fluid, making them the treatment of choice for Bing-Neel syndrome, a rare form of WM that involves the central nervous system.

Covalent BTK inhibitors are usually taken indefinitely, and for many people they work for years. However, in most patients, WM cells eventually escape BTK inhibition through mutations that disrupt drug binding or through alternate pathways that bypass the blocked BTK growth signal. As a result, researchers developed alternative BTK inhibitors such as pirtobrutinib (Jaypirca).

Pirtobrutinib binds reversibly, not permanently, to both normal and mutated BTK. This is called noncovalent bonding. Pirtobrutinib was first evaluated in the BRUIN clinical trial in 80 people

with relapsed or refractory WM who had multiple prior treatments, including 79% of patients who had already received a covalent BTK inhibitor, such as ibrutinib or zanubrutinib. Most patients (83%) had a disease response to treatment, and 73% achieved a major response, including those with prior BTK inhibitor use and limited treatment options. Pirtobrutinib's side effect profile closely resembles that of the covalent BTK inhibitors, including fatigue, low blood counts (neutropenia and anemia), bruising, diarrhea, and rash. Pirtobrutinib is also associated with a lower frequency of cardiac side effects, including atrial fibrillation.

Currently, pirtobrutinib is FDA-approved for mantle cell lymphoma and relapsed or refractory chronic lymphocytic leukemia/small lymphocytic lymphoma (CLL/SLL) in patients previously treated with a covalent BTK inhibitor, but it is not yet FDA-approved for WM. Nonetheless, the need for therapies after covalent BTK inhibitor failure is evident. In the US, pirtobrutinib is currently used off-label, which usually means a conversation with your doctor and insurer. Internationally, access varies considerably, and in several countries, it may be available only through a clinical trial or a patient program. Pirtobrutinib is recognized in the newest version of the NCCN Clinical Practice Guidelines (Version 1.2027) as a preferred treatment for relapsed or refractory WM if previously treated with a BTK inhibitor. Mature data from the BRUIN trial and pirtobrutinib's use in clinical trials of combination therapy for WM support the push for wider availability and could potentially become the route by which it gains FDA approval.

One of the unanswered questions in WM, however, is when to use pirtobrutinib in the relapsed or refractory setting, given other potential treatment options available. This is exactly the kind of question that prospective clinical trials could seek to answer. In WM, however, evidence in this area is still under development and mostly retrospective in nature, meaning that the data were collected by looking back at patients treated in the past with a drug off-trial. A recent retrospective analysis of

patients with relapsed or refractory WM at our center compared pirtobrutinib to venetoclax—a drug that blocks a different survival protein in WM cells called BCL2. While both treatments worked equally well, venetoclax given after a covalent BTK inhibitor therapy was more often complicated by an IgM rebound (an elevation in IgM after stopping

The first attempt at using a BTK inhibitor with another targeted therapy for WM was the combination of ibrutinib and venetoclax given for two years to 45 previously untreated patients. The combination worked well (100% of patients had improvement in their disease, and 96% achieved a major response), and responses came within

about one month. The study was stopped early because of an unexpected number of patients having abnormal heart rhythms, which were fatal in two participants. The ongoing Phase 2 study combining the more selective BTK inhibitor pirtobrutinib and venetoclax in previously treated WM sought to maintain this high efficacy while lessening the adverse cardiac effects. Early results are encouraging: of the 27 patients with MYD88-

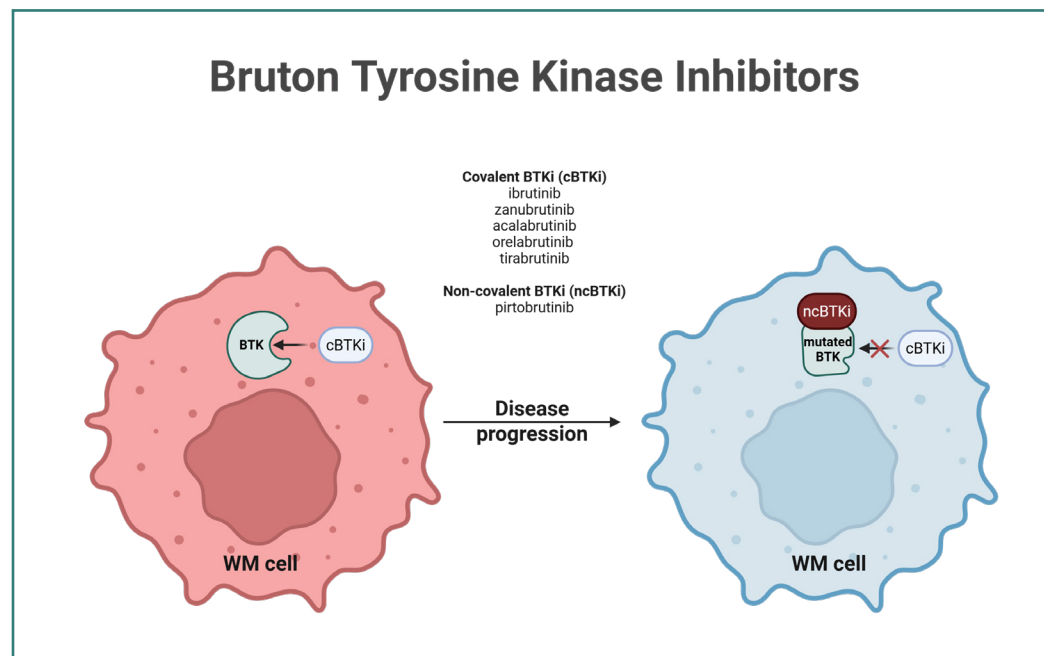


Figure 1: Covalent BTK inhibitors (cBTKi) work by latching permanently to a specific area on the BTK protein called C481. This permanent latching is referred to as covalent bonding. Noncovalent BTK inhibitors (ncBTKi) bind reversibly, not permanently, to both normal and mutated BTK. Created in BioRender. Edwards, C. (2026) <https://BioRender.com/i0r3r0t>.

a BTK inhibitor) and by side effects that led to early treatment discontinuation. However, no IgM rebound occurred when pirtobrutinib was given after a covalent BTK inhibitor, suggesting that sequencing pirtobrutinib first and using venetoclax later may be more feasible and acceptable. The study also highlighted that the genetics of WM cells matter. *TP53* abnormalities were associated with poorer outcomes on venetoclax, while *CXCR4* mutations were associated with poorer outcomes on pirtobrutinib.

Beyond investigations for optimal treatment sequencing, combination regimens including pirtobrutinib are also being explored with the rationale that targeting WM cells in two or more places at once could lead to deeper responses and make it possible to stop treatment rather than remain on treatment indefinitely.

mutated disease who completed six months of treatment, 100% had improvement in their disease (96% achieved a major response), with no abnormal heart rhythms detected to date. Building on this success, the PROVEN clinical trial (also designated WM-NET 4) is now evaluating pirtobrutinib, venetoclax, and rituximab together as a fixed-duration, chemotherapy-free, mostly oral regimen for patients who have never been treated for WM. The trial is currently enrolling at Memorial Sloan Kettering, Dana-Farber Cancer Institute, and Beth Israel Deaconess Medical Center. The trial identifier is NCT07231952 on www.clinicaltrials.gov.

Beyond pirtobrutinib and pirtobrutinib-based combinations, other noncovalent BTK inhibitors, including nemtabrutinib, are in development. Moreover, BTK degraders, which tag the BTK protein

for destruction and remove it entirely rather than blocking it, are also in development and can be used in patients with *BTK* mutations. BGB-16673 has produced responses in roughly 83% of heavily pre-treated WM patients, including those who had already been exposed to both covalent and noncovalent *BTK* inhibitors. NX-5948 can cross into the brain and spinal fluid and is being studied in WM, including patients with Bing-Neel syndrome, with a disease response of 85%. Finally, T cell engaging therapies, including antibodies such as epcoritamab targeting CD20 (NCT06510491), etentamig targeting BCMA (NCT07420959), and surovatamig targeting CD19, recruit the immune system to kill WM cells directly. All three of these agents are in development for previously treated WM.

In summary, the development of pirtobrutinib addresses a specific situation in WM: treatment options after a covalent *BTK* inhibitor stops working. Its broader significance is still being investigated, including whether pirtobrutinib-based combinations are safe and effective fixed-duration treatments for patients who were previously treated for WM or who have never been treated. If you are approaching disease progression on a *BTK* inhibitor, two important questions worth raising with your oncologist include whether your disease can be retested for *BTK*, *CXCR4*, and *TP53* mutations, and whether a clinical trial is available to you.

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BETH GRANT: “WALDENSTROM’S HAS BEEN THE BEST THING THAT EVER HAPPENED TO ME”

BY ART BREWER, FEATURES CORRESPONDENT



Acclaimed actress Beth Grant has built a memorable career spanning film, television, and theater.

Actress Beth Grant learned she had WM in January 2018 while preparing to film “A Series of Unfortunate Events” in Vancouver, Canada. Standing with her arms outstretched like a scarecrow in a man’s tweed suit with wingtip shoes and wearing an upside-down beard and mustache perched on top of her head, she answered a phone call from her husband, Michael, who was relaying the results of her bone marrow biopsy. “Sweetheart,” he said, “it’s the Waldenstrom’s.” In an instant, an ordinary day on set became one she would never forget.

Grant, whose career spans more than four decades and includes memorable roles in “No Country for Old Men,” “Little Miss Sunshine,” “Donnie Darko,” “Speed,” “The Mindy Project,” and most recently, Netflix’s “Remarkably Bright Creatures,” was stunned. She suddenly found herself confronting a rare blood cancer while preparing to step in front of the camera.

Grant immediately shared the diagnosis with the costume designer and seamstress. To her

surprise, they began crying before she did. Their tears brought her own. Still shaken, Grant later confided in the makeup artist preparing her for a camera test. As she gently applied Grant’s makeup, the artist tearfully repeated the same reassuring words over and over like a mantra: “It’s going to be okay. It’s going to be okay.” Grant embraced those words, accepted the support surrounding her, and continued with the production.

Today she continues to work steadily in film and television at 77 years old while sharing an inspiring message with others living with WM: life doesn’t stop after diagnosis. “I don’t say I’m battling cancer,” she said. “I’m living with cancer. And cancer has been a gift to me.”

A diagnosis years in the making

Looking back, Grant realizes her body had been sending warning signs long before her diagnosis in early 2018. It began with unexplained shortness of breath while climbing subway stairs in New York. Then came crushing fatigue, severe leg cramps, chronic sinus infections, dizziness, and Raynaud’s syndrome, which caused painfully cold hands and feet. “There were all these little things sitting in the back of my mind that weren’t quite like me,” she recalled.

During a film shoot in Paris of “Jackie,” the biographical drama about Jacqueline Kennedy starring Natalie Portman, she found herself unusually fatigued. On a scheduled day off, her husband and daughter planned an excursion to the Palace of Versailles, but she declined because she didn’t have the energy. “I didn’t want to tell them I didn’t feel like it,” she recalled. “I just said I’d stay behind and go over my lines.” And at a holiday party, she became so dizzy while speaking with a television executive that she had to stop the conversation and sit down. “I was embarrassed,” she said. “I’d never experienced anything like that.”

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Routine blood work eventually revealed anemia and abnormalities affecting several blood counts. Her primary care physician referred her to a hematologist, and after additional testing, including a PET scan and bone marrow biopsy, she received the diagnosis of WM.

Like many newly diagnosed patients, Grant immediately searched online. "You read 'five-year life expectancy' and you think the worst," she said. "I was terrified."

Finding the right specialist

Grant's first hematologist had treated very few WM patients and recommended treatment with bortezomib (Velcade) and rituximab (Rituxan). Before beginning therapy, however, she sought a second opinion from Dr. Herbert Eradat at UCLA, a WM specialist listed in the IWMP's Directory of WM Physicians.

She also consulted Dr. Stephen Lottenberg of the Simms/Mann UCLA Center for Integrative Oncology, whom actor friends Rachelle Carson-Begley and Nancy Allen had recommended. During a 45-minute phone conversation shortly after her diagnosis, he introduced her to a newer treatment called ibrutinib (Imbruvica) that was just beginning to transform care for many patients. "He called it a 'silver bullet,'" Grant recalled.

After discussing the options with Dr. Eradat, she began treatment with ibrutinib, delaying therapy only long enough to complete her filming schedule. "No one told me I had to stop working," she said. "They told me, 'Finish the job. This is an indolent disease.'"

Continuing to do what she loves

Grant has worked almost continuously since her diagnosis. She completed "A Series of Unfortunate Events," starred alongside Billy Bob Thornton in "Goliath," and appeared in "Grace and Frankie," "Mayfair Witches," "The Bondsman" with Kevin Bacon, and numerous films. Most recently, she appeared in Netflix's "Remarkably Bright Creatures" with Sally Field. "I've continued to work on projects I'm proud of," she said. "I love acting so much."

She credits careful planning, guidance from her medical team, and strict precautions, particularly

during COVID, for allowing her to keep doing the work she loves. While filming "Goliath," Grant took extraordinary measures to protect herself. "I probably was safer on that set than I would have been going to the grocery store," she said. "Everyone wore masks. I did my own hair and makeup. They isolated the actors." After the director contracted COVID, he continued directing remotely via Zoom. Grant, who has never had COVID, credits those precautions and her own vigilance with allowing her to continue working safely throughout the pandemic.

A remarkable remission

Ibrutinib proved highly effective, although Grant experienced occasional episodes of chest pain. While cardiac testing revealed no problems, her oncologist recommended switching her to the newer BTK inhibitor zanubrutinib (Brukinsa), which had a remarkable effect. Her IgM levels returned to normal, and her monoclonal protein disappeared.



Beth Grant, left, with country music legend Dolly Parton in the 1999 television movie "Blue Valley Songbird."

Encouraged by her response, her physician eventually suggested an unusual possibility: stopping treatment to see whether her functional remission could be maintained, as he had observed in some other UCLA patients. The understanding was that if her IgM levels began to rise, she would immediately resume zanubrutinib. Grant was delighted to take the chance, and it paid off. "I stayed off treatment for almost four years," she said.

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Earlier this year, however, she experienced anemia, rising IgM levels, worsening Raynaud's symptoms, unusual bruising, and a diagnosis of livedo reticularis—a condition that caused a lace-like rash on her legs and can be associated with underlying disorders, including WM. Together, those developments prompted her physician to recommend restarting therapy. Three weeks before her *Torch* interview, she resumed treatment with zanubrutinib. Although she hasn't noticed any improvement yet, she remains optimistic. "Compared to what?" she said with a laugh. "I'm doing great."

More than medicine

Grant said living with WM has occasionally required her to adapt her work commitments, particularly when managing the fatigue that can accompany the disease. She completed "A Series of Unfortunate Events" while experiencing symptoms, relying on the ability of actors to summon the energy needed once the camera starts rolling. "We call it 'Dr. Theatre,'" she laughed.

Today, Grant is more intentional about preparing for physically demanding roles and believes medicine is only one part of living well with WM. She exercises nearly every day, alternating swimming, walking, chair yoga, tai chi, and strength training. During filming of "Remarkably Bright Creatures," she completed an IWMF wellness exercise video every morning before heading to the set. "I'd go to work feeling good," she said.

She also follows a largely plant-based diet, emphasizing vegetables, fruit, whole grains, and protein while limiting processed foods and sugar. "I've learned to take much better care of myself," she said. "I'm maintaining a healthy weight, and I feel better than I have in years."

Finding her community

Initially, Grant hesitated to speak publicly about her diagnosis, fearing it might affect her acting

career. "I was afraid people would be afraid of disease," she said. Over time, however, she became more comfortable sharing her story and discovered an unexpected source of strength through the IWMF community. After finding one of Ann Grace MacMullan's chair yoga videos, she enrolled in additional classes and became increasingly involved in the IWMF Wellness Program. The experience deepened her connection to IWMF and introduced her to a network of support that has become central to her journey. She loves



Beth Grant, with co-stars Sally Field, Joan Chen, and Kathy Baker in the Netflix film "Remarkably Bright Creatures." Clockwise from top left: Chen, Baker, Grant, and Field.

and appreciates the support groups, educational webinars, Connect forum, Facebook community, and one-on-one conversations with fellow patients. "There's just nothing like talking to somebody else who has Waldenstrom's," she said.

She especially values the Wellness Program's chair yoga, tai chi, meditation, and relaxation sessions, which have helped improve both her physical health and emotional well-being.

"The people are so informed," she said. "They're positive. They're doing something to enjoy their lives." Grant also volunteers on the IWMF LIFELINE

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and regularly contributes to fundraising efforts for the Foundation.

Perhaps the biggest transformation has been personal. Grant says WM has made her more vulnerable, empathetic, and appreciative of the people around her. "It has brought me closer to my husband than we've ever been," she said. She recalls the kindness of coworkers who comforted her after her diagnosis and the friends who helped her find specialists and treatments. Those moments changed her.

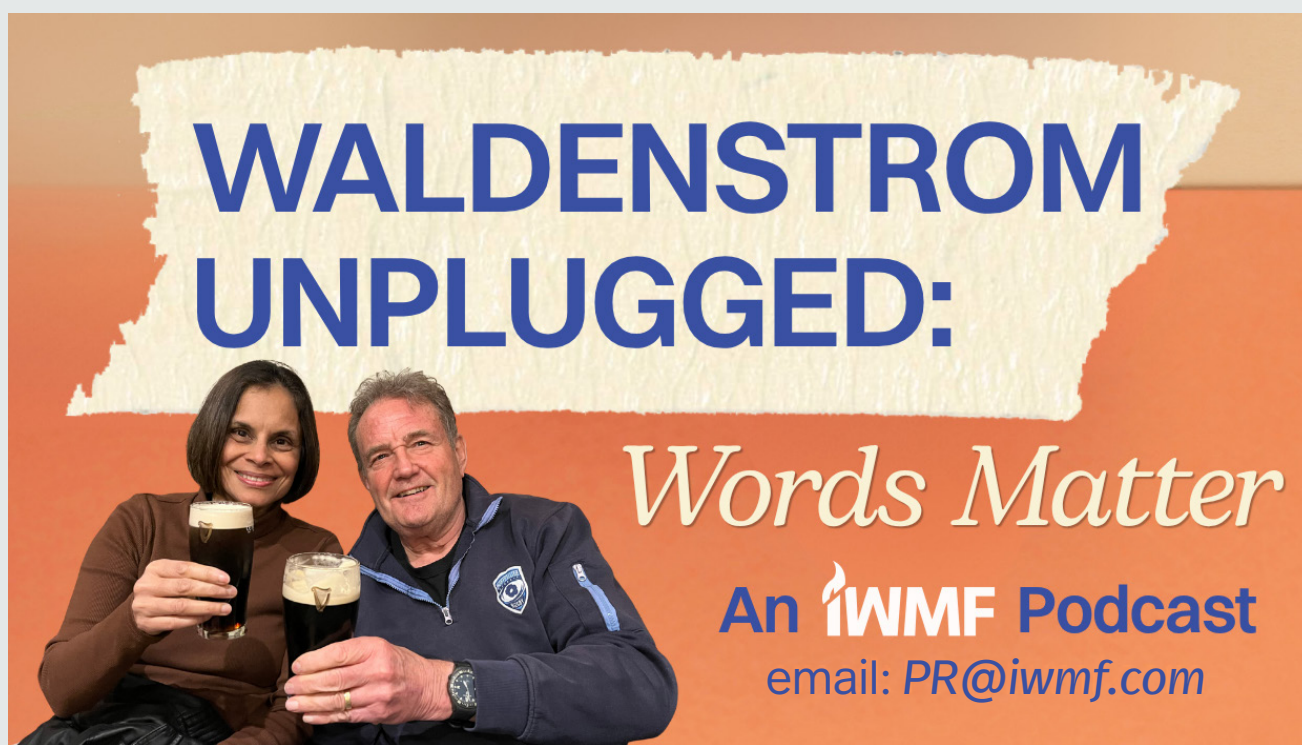
Advice for the newly diagnosed

For those just beginning their own WM journey, Grant encourages patients to become active participants in their care and to seek treatment from a WM specialist or ensure their local hematologist consults regularly with one. Grant also encourages

patients to watch educational presentations, follow emerging research, and remain open to new treatments. "Make sure you're getting the latest information," she said.

Reflecting on eight years of living with Waldenstrom's, Grant acknowledges there have been difficult days, but she refuses to let the disease define her. Instead, she measures her life by the relationships it has deepened, the gratitude it has cultivated, and the opportunities it has given her to encourage others. "I really believe a cure is just around the corner," she said. "Science keeps moving forward."

And then she offered the message she hopes every person diagnosed with WM will hear: "This is not a death sentence. Life goes on. You can still work. You can still love. You can still laugh. And you can still live a beautiful life."



IWMF's new podcast, "Waldenstrom Unplugged: Words Matter," has launched! Featuring two well-known WM voices, Prof. Shirley D'Sa and patient advocate Bob Perry, the podcast brings together expert insight and lived experience to make WM clearer, more relatable, and easier to navigate.

Have a question? Send it to PR@IWMF.com to be featured on the podcast. Listen wherever you get your podcasts, or go to IWMF.com for more information.

IWMF WELCOMES NEW STAFF MEMBERS

IWMF is pleased to welcome three new staff members whose experience, leadership, and commitment to service will strengthen the Foundation's ability to support the WM community.

"I couldn't be more excited to welcome Whitney, Faith, and Kim to the IWMF family. Each of them brings not only incredible expertise, but a genuine passion for making a difference in people's lives," said Delora Senft, IWMF President and CEO. "As we work to support the WM community, I know their warmth, dedication, and collaborative spirit will be felt by everyone—patients, care partners, staff, volunteers, and our research partners alike. I feel so grateful to have them join us, and I can't wait to see the positive impact they'll have as part of our team."



Whitney Musitano, Vice President of Donor and Volunteer Engagement

Whitney Musitano brings more than 20 years of nonprofit leadership experience across fundraising, volunteer engagement, board development, and organizational growth.

"My career has been dedicated to work in the blood cancer community and has given me a deep appreciation for the importance of patient support and research," said Whitney. "IWMF's unwavering commitment to serving the WM community is both inspiring and motivating, and I look forward to

helping expand its impact for patients and families around the world."

Most recently, Whitney served as Vice President of Community Engagement & Stewardship at Blood Cancer United, formerly The Leukemia & Lymphoma Society, where she led volunteer engagement strategy for a nationwide network of more than 300,000 volunteers. Known for her collaborative leadership style and strategic vision, Whitney is passionate about connecting donors, volunteers, and community leaders to meaningful opportunities for impact. Whitney lives in Austin, TX, with her husband, Mike, and two daughters, Olivia and Eva.



Faith Bone, Senior Manager, Executive Operations and Governance

Faith Bone has more than 20 years of leadership experience spanning executive operations, governance, human resources, organizational development, and strategic planning across the nonprofit, higher education, government, and private sectors.

"I'm excited to be part of a team that's making such a meaningful difference for patients and families affected by WM. Having worked with cancer-focused

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nonprofits, I'm passionate about supporting research that brings us closer to better treatments—and ultimately a cure,” Faith said. “I’m grateful for the opportunity to use my experience to help strengthen the organization and advance its mission.”

Before joining IWMF, Faith served as Director of Strategic Development at Amanda Hope Rainbow Angels, where she supported organizational operations, strategic planning, fundraising initiatives, donor and corporate partnerships, process improvement, and CRM optimization (CRM is a centralized system for managing nonprofit relationships and engagement). She brings deep expertise in board governance, policy development, operational management, technology implementation, and cross-functional alignment. Faith and her husband live in Scottsdale, AZ.



Kim Schwartz, Grants and Contracts Administrator

Kim adds a strong track record of improving processes and strengthening cross-functional collaboration, and more than six years of nonprofit grants management experience.

Most recently, Kim served at Gateway for Cancer Research, where she held multiple roles over nearly eight years, including Grants Program Manager. In that role, she helped strengthen grantmaking programs, manage pre- and post-award processes,

and support the Board of Directors as well as scientific and strategic research partnerships.

Known for streamlining complex systems, building trusted relationships across teams and stakeholders, and serving as a reliable connection point between internal departments, donors, and external partners, Kim brings broad experience across nonprofit and corporate environments, including research administration, project management, and sales operations. Kim and her husband live in Northern Illinois.

Together, these new team members bring a range of skills that will help IWMF deepen engagement, strengthen operations, support research partnerships, and advance the Foundation’s mission. Their combined experience reflects IWMF’s ongoing commitment to building a strong, responsive organization centered on the needs of the WM community.

SUPPORT THE ORGANIZATION THAT SUPPORTS US: IWMMF

BY MONICA BLACKMAN



Monica Blackman

Hello from lovely Morris County, NJ. We are in the northern part of the state, about halfway between New York City and the Delaware Water Gap (Pennsylvania). Things have calmed down quite a bit since the excitement of the World Cup games, and we are back to “enjoying” the hot humid days of summer.

Like some of you, I had never heard of WM until I was told that I had it. At my annual physical in 2022, my hemoglobin was low on my routine blood work. My doctor wasn't alarmed and thought it might be a passing thing. After another blood test, a bottle of iron supplements, and a third blood test, it was still low. So, she recommended I see a hematologist. I made an appointment with a local hematology group. When I showed up for my appointment, I noticed it said Oncology/Hematology on the door. Oncology? That was unsettling! I met with a young doctor who ordered a bunch of blood tests and told me to come back in three weeks. When I returned, he said, “Now I want you to have a nuclear PET scan and a bone marrow biopsy.” This is serious! The next time we met he had a diagnosis of Waldenstrom's. On a sheet of paper, he explained the disease, the possible symptoms and treatments. Not much sank in. I left

his office with a cute little diagram that he drew as he explained this rare disease that I had never heard of. So, I went home to consult with Dr. Google.

My Google search led me to the IWMMF website. IWMMF is, by leaps and bounds, the best resource for people with WM and their caregivers. I explored every corner of the website. I read the brochures. I watched the recordings of the Ed Forums. I read issues of the *Torch*. I signed up for the “Weekly” (now the “Digest”). I've sat in on online education and support sessions. I was amazed and heartened by how many caring people are part of this organization. Hearing about other people's experiences with Waldenstrom's and learning about ongoing research has given me hope and relieved my fears of having this currently incurable but manageable disease.

For two years after my diagnosis, I was in “watch-and-wait” mode. By November of 2024, my weight had dropped significantly, and I was starting to see some swollen lymph nodes. My doctor and I agreed that I needed to start treatment. That was a tough decision, Did I want to go through chemoimmunotherapy for six months and maybe be done? Or, did I want to take an oral medication indefinitely? Again, the IWMMF website was so helpful. I read as much as I could about the treatments and decided, with my doctor, that the BTK inhibitor zanubrutinib was the right treatment for me. I have been on it for 18 months. My IgM is down significantly. My weight is back to normal, and my lymph nodes have retreated. I have no side effects, and I feel 100% better. I made the right choice for me.

I am so grateful to IWMMF for the education and support they have provided me. Like all non-profits, IWMMF relies on donations to provide the services we enjoy. It also helps fund research so that, hopefully one day, we can say that we are cured. If you are able, please consider donating to IWMMF. A simple donation, a company match, or a Qualified Charitable Distribution from your IRA can make a difference: You can make a donation at <https://wl.donorperfect.net/weblink/WebLink.aspx?name=E189844&id=6>.

IN MEMORIAM – ROBERT A. KYLE, MD



IWMF and the entire WM community mourn the passing of Dr. Robert A. Kyle, a true visionary and friend. Dr. Kyle, who died on September 2, was born in Bottineau, North Dakota, in 1928. After graduating from Northwestern University Medical School in Chicago in 1952, he accepted a fellowship at Mayo Clinic in Rochester, Minnesota, in 1953. Following military service and a hematology fellowship at Tufts University in Boston, he returned to Mayo Clinic in 1961, where he moved up the ladder to become Chair of the Division of Hematology. Among many highlights of a distinguished career, he was a Master of the American College of Physicians and an honorary member of the Royal Society of Pathologists in London.

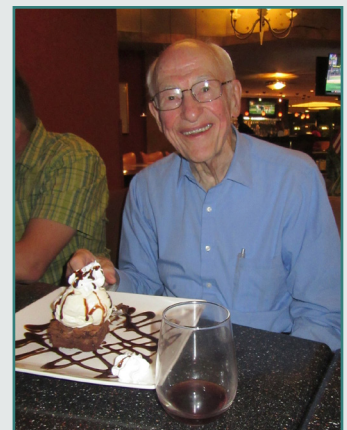
Early in his work at Mayo, Dr. Kyle focused on multiple myeloma and made numerous achievements in that field, ultimately becoming known as the “Father of Myeloma.” His expanded interests included amyloidosis, Waldenstrom macroglobulinemia (WM), and MGUS, which is a term he coined in 1978 and stands for monoclonal gammopathy of undetermined significance. Indeed, Dr. Kyle knew Dr. Jan Waldenström, the Swedish physician who first described WM in 1944.

Dr. Kyle joined the IWMF Board of Trustees in 2004 and served as a Trustee until 2019, also acting as Chair of its Scientific Advisory Committee. His counsel on the Board was always concise, accurate, and wise. Several years ago in his honor, IWMF established a research grant program, known as the Robert A. Kyle Career Development Awards, to acknowledge the crucial role of nurturing a new generation of researchers to study WM and ensure continuous progress in the field.

The International Workshop on Waldenstrom’s Macroglobulinemia (IWWM), the world’s premier hematology/oncology meeting dedicated to WM, also recognizes Dr. Kyle with the Robert A. Kyle Award, given to those who have made outstanding contributions to scientific and medical advancements in WM. For years, the award has been presented during each biennial meeting of IWWM.

Dr. Kyle traveled widely to share his knowledge through attendance at meetings and lectures and for many years was a fixture during IWMF Educational Forums, where he moderated the popular “Ask the Doctor” panel session. His philosophy of travel for meetings was to always go a day early or stay a day late so that he would have a chance to learn something about the area. His curiosity was boundless, and his recollection of stories, adventures, and historical events was unparalleled. Many who had the pleasure of sharing a meal with Dr. Kyle not only enjoyed the conversation but also learned about his love of chocolate—there was no such thing as too big a piece of chocolate cake for dessert!

Dr. Kyle published widely and contributed over 1,050 articles and book chapters and over 1,350 abstracts to the medical literature. He was a true gentleman and a mentor to many distinguished physicians. The WM community is forever grateful for his interest in and his concern about improving their lives and their futures.



WHERE BLOOD MEETS NERVE: A DAY IN THE QUEEN SQUARE NEUROHAEMATOLOGY CLINIC, LONDON, UK

BY PROFESSOR SHIRLEY D'SA

ON BEHALF OF THE UCLH–QUEEN SQUARE JOINT NEUROHAEMATOLOGY CLINIC

Introduction

I have been caring for patients affected by WM for more than 20 years, and one of the commonest topics to arise is neuropathy. Neuropathy means different things to different people. The additional term “peripheral” refers to the part of the nervous system affected—namely *outside* the brain and spinal cord (central nervous system or CNS). Technically speaking, peripheral neuropathy (PN) refers to “pathology” or disease (patho) of the peripheral nerves (neuro). PN is said to be frequently associated with WM and IgM paraproteins (also referred to as monoclonal proteins) based on a number of clinical studies and observations.

Many persons experience symptoms such as tingling, numbness, pain, weakness, or instability at some point in their lives. There are many causes of such symptoms, ranging from alcohol excess to zinc excess. The most common causes overall are diabetes, alcohol, vitamin B12 deficiency, medications/chemotherapy, hereditary neuropathies, and idiopathic (no cause found) neuropathy.

Through our work at University College London Hospitals—specifically our Joint Neurohaematology Clinic based at the National Hospital for Neurology and Neurosurgery, Queen Square, London—it is crystal clear to us that deciphering exactly what is going on when someone has WM/IgM paraprotein is crucial to making the correct choices around treatment or management. “Queen Square” is more than a London address. It is shorthand for the National Hospital for Neurology and Neurosurgery, one of the world’s oldest and best-known specialist

neuroscience centres. The hospital was founded in 1859 by sisters Johanna and Louisa Chandler, inspired by their experience of caring for their grandmother after she became paralysed. Its creation coincided with the emergence of neurology as a distinct medical specialty. The importance of Queen Square lay not only in individual discoveries but also in its method: careful listening, detailed bedside examination, repeated observation over time, and the linking of a patient’s symptoms to anatomy and pathology. These principles helped transform neurology into a disciplined clinical science.

The hospital expanded across Queen Square, survived damage during the Second World War, and joined the newly created British National Health Service in 1948. It later merged with the Maida Vale Hospital for Nervous Diseases and adopted its present name in 1990. Since 1996 it has formed part of University College London Hospitals (UCLH) NHS Foundation Trust.

Today, the National Hospital works closely with the UCLH Queen Square Institute of Neurology, bringing highly

specialised patient care, laboratory science, imaging, and clinical research together on one campus. Patients are referred from across the United Kingdom and internationally, often with uncommon, diagnostically difficult, or treatment-resistant neurological diseases.

That history matters to our Joint Neurohaematology Clinic. The Clinic stands within a tradition in which difficult neurological problems are



Main Entrance, National Hospital for Neurology and Neurosurgery, Queen Square

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approached through detailed clinical observation and multidisciplinary thinking. Yet it also adds something distinctly modern: neurologists and haematologists examining the patient together, particularly where a blood or immune disorder may be injuring the peripheral nerves.

Who makes up the Queen Square Joint Neurohaematology Clinic team?

The Clinic brings together specialists from neurology and haematology who examine each patient's illness from different but complementary perspectives.

Professor Michael Lunn, consultant neurologist, brings particular expertise in peripheral nerve and immune-mediated neurological disorders. Professor Shirley D'Sa, consultant haematologist, specialises in WM, monoclonal IgM proteins, and the wide range of clinical disorders these proteins can cause. They have worked together for more than two decades, developing a shared approach to patients whose conditions do not fit neatly within a single specialty.



Prof. Shirley D'Sa and Prof. Michael Lunn – clinical leads of the neurohaematology service

The team includes Dr. Junie Koay, consultant neurologist, and Dr. Jin Lindsay, consultant haematologist, who contribute their respective neurological and haematological expertise while helping to develop the Clinic for the future. Dr.

Chandra Hosokote is a vital member of the team, bringing neuroradiology expertise to interpretation of the MRI scans, while Dr. Simon Wan is a consultant in Nuclear Medicine and CT and interprets our PET-CT scans during our weekly multidisciplinary meetings. Nicole Japzon, Physician Associate, coordinates clinical assessment and is highly experienced in performing lumbar punctures as well as ensuring the correct samples get to the right labs, providing an important element of continuity across what can be a complicated patient journey.

From referral to a coordinated plan

Patients are referred to the Queen Square Neurohaematology Clinic from across the United Kingdom, often after months or years of investigation in several different specialties. Some have a recognised blood disorder, such as WM, IgM MGUS, lymphoma, or amyloidosis, and have subsequently developed neurological symptoms. Others are referred because an unexplained neuropathy has led to the discovery of a monoclonal

protein. The diagnoses considered include anti-MAG neuropathy, chronic inflammatory demyelinating polyneuropathy (CIDP), cryoglobulinaemic or vasculitic neuropathy, AL or transthyretin amyloidosis, Bing-Neel syndrome and direct infiltration of the peripheral nerves by lymphoma. In some patients, the eventual conclusion is that the neuropathy and the blood abnormality are coincidental rather than causally related—an equally important distinction because it can prevent unnecessary treatment.

Referrals are reviewed in advance so that each patient can be directed to the most appropriate setting. Many are assessed as outpatients. Those requiring several investigations may attend as a day case, allowing tests and specialist reviews to be coordinated during a single visit. Patients who are acutely unwell, deteriorating rapidly, or requiring urgent investigation and treatment may be admitted to the hospital.

The assessment is deliberately systematic. The team documents the pattern, tempo, and severity of the neurological symptoms; examines strength, sensation, reflexes, balance, and gait; and reviews nerve conduction studies in detail. At the same time, the haematological context is reconstructed: the type and quantity of monoclonal protein, bone-marrow findings, molecular characteristics of the clone, previous treatments, and whether the blood disorder is otherwise stable or progressing. This combined assessment helps the team determine



Drs. Junie Koay (neurologist) and Jin Lindsay (haematologist) pondering a case in the clinic

whether the paraprotein is a probable cause, a possible contributor, or simply an incidental finding.

Investigations are then tailored for the individual patient rather than ordered as an indiscriminate panel. They may include MRI or (PET)CT cross-sectional imaging to look for lymph node, organ, bone, nerve root, or central nervous system involvement. When disease affecting the brain, spinal cord, nerve roots, or brain covering is suspected, a lumbar puncture may be performed. The cerebrospinal fluid (CSF) is examined not only for its cell count and protein concentration, but also by specialist flow cytometry and molecular tests—such as *MYD88* analysis—to search for very small populations of abnormal cells.

Specialist neuroimmunology blood tests may include antibodies against parts of the nerve or nerve covering, such as myelin-associated glycoprotein (MAG) and gangliosides, alongside cryoglobulins, complement studies and other markers selected

according to the clinical picture. Testing for diabetes, vitamin deficiencies, renal or thyroid disease, infection, medications, and hereditary neuropathy remains essential: the presence of an IgM protein does not remove the need to search for more common or treatable explanations.

The goal is not simply to accumulate results. It is to bring the neurological signs and symptoms, electrophysiology, imaging, CSF findings, and biology of the blood disorder into a single explanation, and from that explanation, to develop a treatment and monitoring plan that is proportionate, evidence-based, and meaningful to the patient.

So what does the Joint Neurohaematology Clinic add to the care of someone with WM or a related disorder?

It is more than having a neurologist and haematologist in the same room. The real value comes when we have to decide whether a neurological problem is being caused by the blood disorder, its treatment, an entirely separate neurological disease—or sometimes a combination of these.

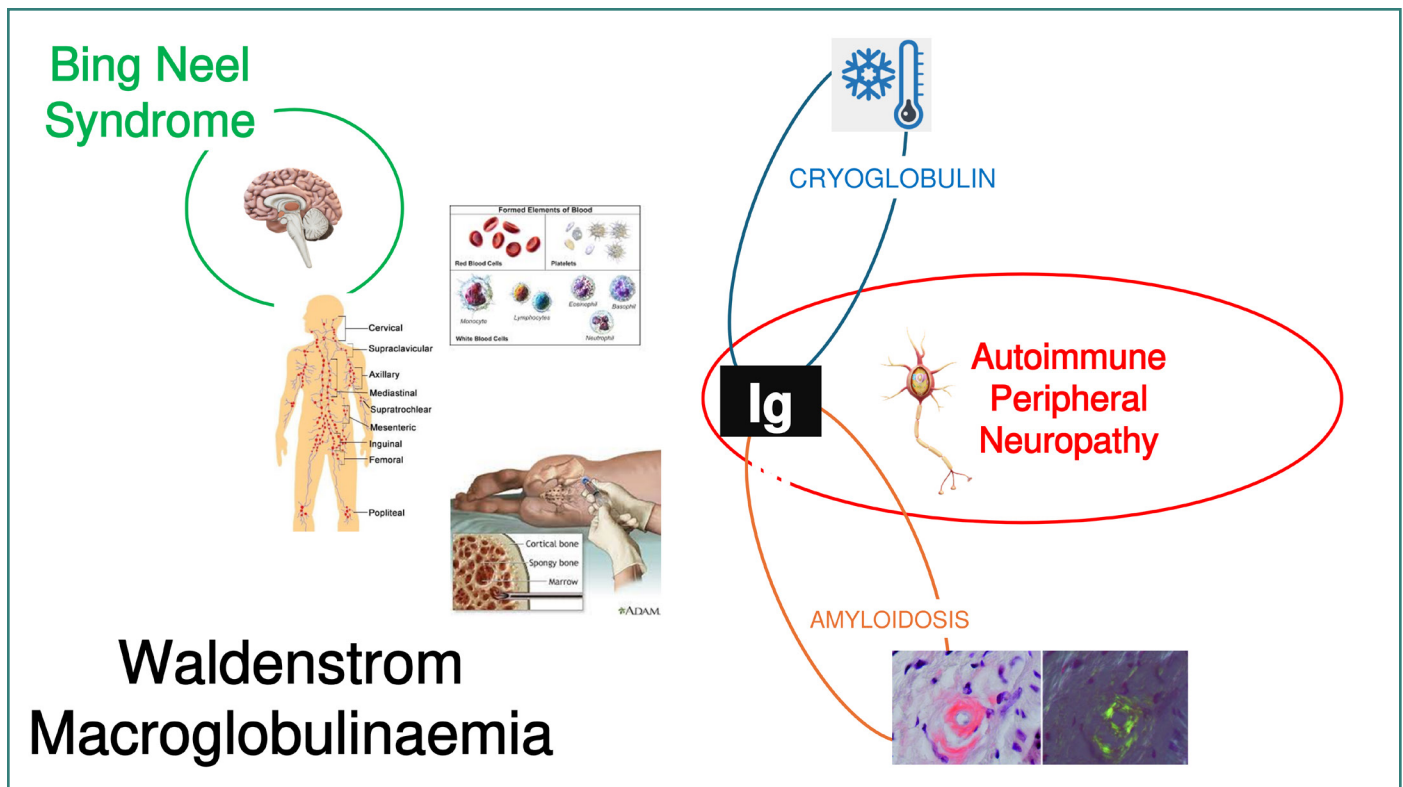
Two patients from our clinic illustrate why that distinction matters.

When treatment has to reach the brain

Our first patient illustrates a very different problem: how do we prove that WM itself has entered the nervous system? He had already been through a remarkable amount of treatment for WM following diagnosis in 2017. He was referred to us in 2021 with severe back pain and numbness and tingling in the toes and hands. When he was investigated, his bone marrow was extensively infiltrated by lymphoplasmacytic lymphoma and contained the characteristic *MYD88 L265P* mutation. At the same time, his MRI showed striking abnormalities involving the spinal cord.

The crucial evidence came from examining his CSF, obtained by lumbar puncture. Flow cytometry demonstrated an abnormal population of B cells, while molecular testing detected the *MYD88 L265P* mutation. Taken together with the MRI and clinical picture, this established Bing-Neel syndrome—WM involving the central nervous system.

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He subsequently received intensive CNS-directed chemotherapy followed by an autologous stem cell transplant in 2022. Small amounts of disease remained detectable in the CSF, so he was maintained on zanubrutinib (Brukinsa), a BTK inhibitor that can penetrate the central nervous system.

Then, in 2024, the different pieces began moving in the wrong direction again. His IgM rose, his marrow showed increasing WM, MRI demonstrated increasing disease affecting the covering of the brain, and lymphocytes reappeared in his CSF. He developed headaches, weight loss, night sweats, and unusual cramping in his feet.

His treatment options were now limited: he had already received many of the conventional drugs capable of treating disease within the CNS. We therefore referred him for a clinical trial of an investigational treatment with a BTK degrader, now known as bexobrutideg.

The improvement was rapid. His cramps largely disappeared and he felt “a lot better.” Even more reassuringly, serial CSF samples showed the previously abnormal measurements moving toward normal. More than a year later he remains

well on the study, with his latest CSF containing only three white cells.

His story demonstrates why Bing-Neel syndrome cannot be managed by following the blood IgM alone. We have to follow several compartments simultaneously—the patient, the blood and marrow, the MRI, and the CSF, and periodically ask whether they are all telling us the same story.

When the paraprotein isn't the problem

Sometimes the most useful thing our clinic does is decide not to treat the blood disorder.

One woman was referred with progressive neurological symptoms, a small IgM paraprotein, and a very high level of anti-MAG antibodies. She had already received rituximab without improvement, and the possibility of treatment with a BTK inhibitor had been explored. On paper, IgM-related neuropathy seemed an obvious explanation.

But seeing the patient neurologically changed the picture.

Her pattern of symptoms and signs suggested that at least much of the problem might be mechanical

rather than paraprotein-related. MRI demonstrated substantial lumbar scoliosis with narrowing around several nerve roots, providing an anatomical explanation for her lower limb symptoms. Her upper limb symptoms also raised the possibility of cervical degenerative disease. Nerve conduction studies and electromyography (EMG) were arranged to look for evidence of a generalized peripheral neuropathy and radiculopathy (compression or irritation of the nerve root).

Instead of escalating WM-directed treatment, the emphasis shifted towards treating the problems actually causing her symptoms: physiotherapy and core strengthening, optimising neuropathic pain medication, and addressing her spinal disease. Her small paraprotein could simply be monitored.



The all-important model of the lower back to show a patient how nerve roots can be affected by wear and tear

This illustrates one of our most important rules: association is not causation. IgM paraproteins become increasingly common as we age. Even a positive anti-MAG antibody test should not replace careful neurological assessment.

Sometimes the best outcome of a specialist clinic is preventing treatment that a patient did not need.

The question we keep asking

These two cases are very different, but the same question runs through our clinic: What is causing this patient's neurological problem now?



The weekly multidisciplinary team meeting, in which we review neurohaematology cases from across the UK

Conclusion: putting the pieces together

For patients, neurological symptoms can be frightening, particularly when they occur alongside WM or an IgM paraprotein. It is tempting to assume that the two must be connected. Sometimes they are. Sometimes they are not.

That uncertainty is precisely where the Joint Neurohaematology Clinic can make a difference. By bringing neurological and haematological expertise together, we can look beyond an individual blood result, scan, or antibody test and ask a more important question: *What is actually causing this person's symptoms, and what can we do about it?*

As our two patients illustrate, the answer can lead in very different directions. For one, careful integration of symptoms, MRI, and sophisticated analysis of the spinal fluid confirmed WM within the nervous system and ultimately opened the door to an innovative treatment when conventional options were running out. For the other, specialist assessment showed that an apparently convincing IgM and anti-MAG story was not the explanation for her symptoms, sparing her further unnecessary treatment and redirecting attention to a problem that could be managed quite differently.

Perhaps that is the most important lesson from a day in our clinic. *The aim is not always to find another treatment. It is to find the right explanation. And when the story changes, we look again.*



MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF RESEARCH COMMITTEE MEMBER

Updated Version Available of NCCN Clinical Practice Guidelines for WM/LPL – The previous version of the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Waldenström Macroglobulinemia/Lymphoplasmacytic Lymphoma has been updated to Version 1.2027. Among several changes from the previous version, notable ones include the following: 1) as part of the essential diagnostic workup, a recommendation has been added to consider *CXCR4* and *TP53* gene mutation testing by next-generation sequencing and del(17p) testing by FISH (fluorescence in situ hybridization); 2) the therapy table for previously treated WM/LPL has been modified to account for differing recommendations for patients previously treated with a BTK inhibitor or with contraindications for BTK inhibitor therapy and for patients not previously treated with a covalent BTK inhibitor; 3) a new page has been added to include therapy recommendations for WM-related systemic light chain amyloidosis; and 4) for Bing-Neel syndrome, pirtobrutinib (Jaypirca) has been added to the list of Other Recommended Regimens, and methotrexate has been moved to the list of Useful in Certain Circumstances. After establishing a login, one can view the complete guidelines at https://www.nccn.org/professionals/physician_gls/pdf/waldenstroms.pdf.

Phase 1/2 Clinical Trial Results Published for Pirtobrutinib in Relapsed or Refractory WM – Results from the international Phase 1/2 BRUIN clinical trial evaluating the noncovalent BTK inhibitor pirtobrutinib (Jaypirca) in 80 patients with relapsed or refractory WM were published in the journal *The Lancet Haematology*. This subset of WM patients was part of the larger trial that enrolled patients with several types of relapsed or refractory B cell cancers. The median number of previous therapies in WM participants was three, with 79% having received covalent BTK inhibitors such as ibrutinib, zanubrutinib, or acalabrutinib. With a median follow-up of 35 months, the overall response rate was 82.5%, while the combined rate of

partial, very good partial, and complete responses was 72.5%. In WM patients previously treated with covalent BTK inhibitors, the overall response rate was 81%, and in patients not treated with covalent BTK inhibitors, it was 88.2%. The median progression-free survival was 35.9 months, and the median overall survival was not reached. Grade 3 or greater (severe) side effects occurred in 71%, the most common being decreased neutrophil counts and anemia. Side effects led to dose reductions in 5% and treatment discontinuation in 15%.

Clinical Trial Results Presented for Four-Drug Combination in Elderly WM Patients with an Unfavorable Prognosis – Russian clinical trial results presented during the European Hematology Association 2026 Congress discussed a combination therapy of rituximab, bortezomib (Velcade), bendamustine, and dexamethasone (RBBd) in WM patients over 65 years of age with unfavorable prognostic factors. The average age of the 34 participants treated during the trial period from 2018-2025 was 68, and most had severe anemia. Other high-risk signs and symptoms included hyperviscosity syndrome, low platelet counts, high lactate dehydrogenase levels, low albumin levels, and high beta-2-microglobulin levels. Two patients had kidney failure. The rates of overall response, partial response, very good partial response, and complete response were 100%, 41%, 28.2%, and 30.8% respectively. Kidney function was restored in one patient. The five-year progression-free survival rate was 75%, and the five-year overall survival rate was 90%.

British Researchers Report the Use of Bortezomib Therapy After Failure of BTK Inhibitors in WM – Treatment options after failure of covalent BTK inhibitor therapies in WM patients are limited, and while encouraging strategies—such as noncovalent BTK inhibitors and BTK degraders—are being investigated, these drugs are limited or unavailable in many countries. The

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journal *Hematology Reports* included an article from researchers at University College London Hospitals that retrospectively studied the use of bortezomib (Velcade) after BTK inhibitor failure, noting that scant data are available regarding bortezomib use in this situation. The small study included 17 patients who were treated at the center between 2018-2025. Patients were pretreated with a median of four lines of therapy, including chemoimmunotherapy and BTK inhibitors; most patients had received ibrutinib as their BTK inhibitor therapy, with a few on zanubrutinib, acalabrutinib, or pirtobrutinib.

The latest clinical trial in the WM clinical trial network called WM-Net is expected to begin recruitment soon.

Their median duration of BTK inhibitor therapy had been 11 months, and reasons for treatment failure included disease progression in 59% and drug intolerance in 41%. Bortezomib was delivered as combination therapy that variously included one or more agents such as dexamethasone, rituximab, cyclophosphamide, and daratumumab. The best overall response rate was 88%, including a very good partial response rate of 18%. At a median follow-up of 39 months, median overall survival in these heavily pretreated patients was 22 months, resulting in an estimated two-year survival rate of 47%. The most common side effects included low neutrophil counts, low platelet counts, and mild-to-moderate neuropathy.

Huntsman Cancer Center to Recruit Relapsed or Refractory WM Patients for Trial of Novel Combination Therapy – The Huntsman Cancer Institute in Utah will soon begin recruiting participants with relapsed or refractory WM for a Phase 2 clinical trial of mosunetuzumab (Lunsumio) in combination with the noncovalent BTK inhibitor pirtobrutinib (Jaypirca). Mosunetuzumab is a bispecific antibody that binds to both the CD20 surface antigen on B cells and the CD3 surface

antigen on T cells, bringing the B cells in close contact with T cells and activating the T cells to mount an immune response against the targeted B cells. This trial, designated MPOWER, is expected to enroll 25 participants, who will receive one of two dosing strategies. In both strategies, pirtobrutinib is taken at 200 mg daily on days 1-21 of 21-day cycles. Mosunetuzumab will be administered subcutaneously starting on the first day of either cycle 2 or cycle 3 and continuing to cycle 9. Patients who achieve a complete response after cycle 9 will continue on pirtobrutinib only for a total of either 18 or 19 cycles, depending upon what cycle they began mosunetuzumab. Patients who achieve a very good partial response or less after cycle 9 will continue to receive both drugs for a total of 18 or 19 cycles, again depending upon the start of mosunetuzumab. On www.clinicaltrials.gov, the identifier number is NCT07548450.

Phase 1/2 Trial of Ententamig in Relapsed or Refractory WM to Begin Soon – The latest clinical trial in the WM clinical trial network called WM-Net is expected to begin recruitment soon. This is a Phase 1/2 trial of ententamig (ABBV-383) for relapsed or refractory WM patients. Ententamig is a bispecific antibody that binds to both the BCMA surface antigen on WM cells and the CD3 surface antigen on T cells, bringing the WM cells in close contact with T cells and activating the T cells to mount an immune response against the targeted WM cells. Participants will receive an IV infusion of ententamig on days one and four of cycle 1 and on day one of subsequent cycles. Cycles repeat every 28 days for up to 12 cycles. The trial, expected to enroll 38 patients, is identified as NCT07420959 on www.clinicaltrials.gov.

Danish Study Analyzes Risk of Second Primary Cancers in LPL/WM Patients – An increased risk of second primary cancers (SPCs) has been consistently reported with lymphomas, including LPL (lymphoplasmacytic lymphoma)/WM. Researchers in Denmark retrospectively analyzed 521 Danish people diagnosed with LPL/WM from January

2000-December 2023 for their risk of SPCs and compared their risk to that of the general population. This study defined SPCs as cancers diagnosed at least six months after an LPL/WM diagnosis, but with the following exceptions that were not considered SPCs and excluded: relapses of LPL/WM after treatment, histological transformation of LPL/WM to a more aggressive lymphoma, recurrence of a previously diagnosed cancer, and non-melanoma skin cancers. During a median follow-up of 8.1 years, 31.9% died without developing SPCs; meanwhile, 13.1% developed at least one SPC during this period, with a median time from the diagnosis of LPL/WM to SPC of 4.1 years. There was a continuous increase in SPC risk over time, reaching an estimated 15% of patients at 10 years, with most SPCs being solid

***Dana-Farber Cancer Institute (DFCI)
has developed a trispecific antibody
drug called a TriTE...***

tumors such as lung cancer, colorectal cancer, head and neck cancer, urinary tract cancer, and melanoma. Compared to the general population, the overall solid tumor SPC risk for those with LPL/WM was not significantly increased. However, the risk for other blood cancers, particularly acute myeloid leukemia and myelodysplastic syndrome, did show a borderline increase for LPL/WM patients compared to the general population. Among the 11 patients who developed these blood cancers, ten had received previous chemotherapy, including seven treated with bendamustine and seven treated with alkylating agents like cyclophosphamide or purine nucleoside analogs like fludarabine. The study was too small to establish statistically whether treatment caused these cancers. The researchers indicated that these findings support the need for LPL/WM patients to continue to receive standard age- and sex-appropriate cancer screenings, while physicians should be aware of possible therapy-related blood cancers during long-term follow-up. This study was reported in the *British Journal of Haematology*.

DFCI Researchers Develop Trispecific Antibody That Targets Multiple Myeloma and WM Cells – Dana-Farber Cancer Institute (DFCI) has developed a trispecific antibody drug called a TriTE, which stands for trispecific T cell engager. The new antibody, still in preclinical development, binds to BCMA (B cell maturation antigen), expressed on multiple myeloma and WM cells, and to FcRL5, a surface antigen that promotes the differentiation of B cells into plasma cells and is also expressed on both types of cells. It brings these cells into close contact with the T cells of the body's immune system by means of attachment to the CD3 surface antigen on T cells, thereby activating the T cells to attack the targeted cells. In WM cell lines and in cells collected from WM patients, the new antibody improved WM cell killing and T cell immune responses when compared to bispecific antibodies targeting BCMA only. The researchers, who presented these results during the European Hematology Association 2026 Congress, suggested that these results support further development of the TriTE antibody.

Real-World French Study Compares A-Fib Rates of BTK Inhibitors – French researchers performed a nationwide real-world study to compare atrial fibrillation (A-fib) rates for various BTK inhibitor therapies in patients with B cell cancers. Patients treated with venetoclax were used as baseline comparison controls because that drug is not associated with A-fib. Using a French national health insurance database from 2015-2024 and excluding those with pre-existing A-fib, the researchers identified 26,393 patients: 16,375 treated with ibrutinib, 2,431 with acalabrutinib, 1,116 with zanubrutinib, and 6,471 with venetoclax. Chronic lymphocytic leukemia was the most frequent disease indication at 47%, followed by WM at 9%. The primary outcome measured was A-fib requiring hospitalization. Median follow-up ranged from 167 days for those on zanubrutinib to 526 days for those on ibrutinib. New ibrutinib users peaked around 2021, followed by an increasing shift toward second-generation BTK inhibitors. In this study, more than 60% of patients newly treated with BTK inhibitors

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had pre-existing cardiovascular conditions, which are known to increase the risk of A-fib. Ibrutinib was associated with a one-year risk of hospitalization for A-fib at 2.3%, substantially higher than the risk with acalabrutinib at 0.9%, zanubrutinib at 0.7%, and venetoclax at 0.5%. The researchers suggested that these results support the preferential use of second-generation BTK inhibitors or venetoclax in B cell cancer patients with an elevated A-fib risk; they also underscored the need for cardiovascular assessment before starting therapy, along with enhanced cardiovascular monitoring during therapy for those on ibrutinib. The study was reported in the *British Journal of Haematology*.

Newly-Discovered Mutation in CLL Patients Causes Resistance to BTK Degraders and BTK Inhibitors

Early-phase clinical trials of the emerging class of BTK degrader drugs, such as bexobrutideg (NX-5948), are demonstrating effectiveness in B cell cancer patients who have become resistant to the BTK inhibitors ibrutinib, zanubrutinib, and acalabrutinib. However, resistance to BTK degraders has also been observed, although the reasons for resistance have been largely unknown. The journal *Cancer Discovery* recently included an article from collaborating researchers in several US centers reporting a mutation called *BTK A428D* in chronic lymphocytic leukemia (CLL) patients who developed resistance to BTK degraders; this mutation was also observed to cause resistance to BTK inhibitors, although its frequency was low in patients on BTK inhibitors. The mutation appears to be a pre-existing one, and treatment with BTK-targeted drugs causes expansion of the cancer cells carrying the mutation, leading to the eventual development of therapy resistance. The mutation itself changes the structure of the BTK molecule so that BTK inhibitors and degraders can no longer form essential contact with the BTK protein. As of now, the researchers cannot determine how predominant the *BTK A428D* mutation may become in patients on BTK degrader therapy; however, they did suggest that time-limited and/or combination therapies of BTK degraders with other drugs may be a way to delay or prevent the development of resistance.

US CDC Issues Health Advisory About Arboviral Risk for Patients on Anti-CD20 Monoclonal Antibody Therapies

The US Centers for Disease Control and Prevention (CDC) has issued a health advisory about the risk of severe arboviral diseases in patients who are receiving anti-CD20 monoclonal antibody therapies such as rituximab and its biosimilars, obinutuzumab (Gazyva), ofatumumab (Kesimpta), and others. Arboviruses are transmitted by biting insects, most commonly mosquitoes and ticks, which are active during late spring through early fall in the US. The arboviruses include West Nile, eastern equine encephalitis, Powassan, Jamestown Canyon, La Crosse, Cache Valley, and Potosi. Although these infections are not symptomatic in many people, they can cause acute fevers or neurologic illnesses such as meningitis or encephalitis. Anti-CD20 monoclonal antibody therapies deplete B cells, increasing the risk of serious complications from these diseases; in fact, the overall mortality rate from arboviral diseases was 40% in people on these therapies, and most survivors experienced long-term neurologic damage. Since there are no preventatives or approved treatments for arboviral diseases, people on these monoclonal antibody therapies are urged to use personal protective measures to prevent mosquito and tick bites.

Anti-CD20 monoclonal antibody therapies deplete B cells, increasing the risk of serious complications from [arboviral] diseases...

The author gratefully acknowledges the efforts of Grete Cooper, Peter DeNardis, Dr. Tom Hoffmann, Richard Savoy, and others in communicating research news of interest to the WM community. The author can be contacted at suenchas@bellsouth.net for questions or additional information.

WMOZZIES AND WALDOSNZ TOGETHER BUILD WM CARE COMMUNITIES

BY PETER FREESE, WMOZZIES, AND MEL ARNOLD, WALDOSNZ

A warm hello from WMozzies in Australia and WaldosNZ in New Zealand! We're delighted to connect and share some exciting news about the changes happening within our groups.

With Mel Arnold now leading Waldos in New Zealand and Peter Freese at the helm of WMozzies in Australia, both teams are working closely together to strengthen our local presence and community engagement.

One of our main projects is to enhance the existing feeling of community within our member groups, their carers, and health providers. A key project is the reinstatement of our joint local newsletter, "The Beacon." Our goal with this revived publication is to provide our Australian and New Zealand communities with more tailored updates and insights into what's happening in our regions. At the same time, we want to highlight the valuable opportunities and resources offered by partners like IWmf, Blood Cancer New Zealand, and Lymphoma Australia.

While WaldosNZ already has a small committee, WMozzies is looking to invite members to join in

the formation of a new management team to enhance our reach and support throughout our countries. We're also both reaching out looking for volunteers to support our wider WM community through regional support roles.



Mel Arnold



Peter Freese

We are also excited about the educational opportunities that will be delivered to both the Australian and New Zealand members toward the end of the year 2026. With the support of IWmf and local practitioners, we are aiming to make these available to our members in a face-to-face format and/or through digital means. In October this year in Auckland, New Zealand, with the support of IWmf and Blood Cancer New Zealand, we will host a patient forum, available both in person and online. Dr. Judith Trotman and Prof. Shirley D'Sa will each present on topics relevant to the WM community, followed by an interactive patient Q&A session. WMozzies is also working to facilitate an educational forum in November 2026, date to be confirmed and communicated.

The close collaboration between WaldosNZ and WMozzies has strengthened our cross-Tasman partnership, enabling us to share information, resources, and ideas to better support our WM communities. We're enthusiastic about these new steps and look forward to keeping everyone informed and connected. Please feel free to reach out if you have any questions or would like to get involved in any of our activities. Thanks for your ongoing support!



Mel Arnold and family

FIFTH ANNUAL MEETING OF THE WALDI GROUP IN ULM, GERMANY

BY BETTINA SCHWETHELM

In Germany, there are two main groups that provide information and support to individuals dealing with WM and MGUS. The group associated with Deutsche Leukämie- & Lymphom-Hilfe (DLH) meets every other month online for membership exchange and presentations by experts. The WhatsApp group is affectionately named “Waldi” by its almost 300 members (“waldi” is a name often used for the little German dachshund). It has various WhatsApp groups, including a general one, groups by regions of Germany, a watch-and-wait group, and a group on neuropathy; it has put together a “Waldipedia” of them. Membership is restricted to individuals affected by WM and family members.

The Waldi group met this year for the fifth time in the beautiful city of Ulm, the location of the research of Prof. Christian Buske and his team. The purpose of the meeting is to learn, provide support to each other, and have fun together. For me, until recently a member of only the DLH group and a participant in three of the four IWMF European Educational Forums, this was a first time in Ulm. Preparations started with some excitement, for all local public transport was to go on strike the day we were supposed to take the tram up to the University campus, but it was called off just the day before. We figured the union did not want to further risk the health of some 70 “Waldis” that had come from all over Germany, Switzerland, Austria, and even Denmark.

The meeting started with a dinner the night before. It was obvious that many participants were happy to see each other again; others were able to put faces to the names in the WhatsApp exchanges. The next day—thanks to no strike—we took a tram up to the campus and arrived quickly in our beautiful meeting place.

The organizers scheduled four major learning sessions. Dr. Michaela Sternke, a doctor and patient who provides ongoing technical inputs and corrections to WhatsApp content that has “gone

astray,” provided us with a deep dive into all the different blood tests we should be knowledgeable about. Those of us with less medical knowledge will probably still want additional explanations of what is most relevant in our individual cases.

Prof. Buske mentioned that our WhatsApp group is one of the most active patient groups and has grown enormously. He then took us through some of the history in treating WM. While the combination of chemotherapy and rituximab is still standard, particularly for fit patients, the move is toward chemo-free therapies, i.e. ibrutinib with or without rituximab or zanubrutinib. He showed how progression-free survival can be affected by *MYD88* and *CXCR4* mutation status for those on ibrutinib—patients who are wild-type (unmutated) for both have the shortest progression-free survival (PFS). However, when combining ibrutinib with rituximab, progression-free survival is independent of genotype. Zanubrutinib compared to ibrutinib has a better combined complete response (CR) and very good partial response (VGPR) rate and fewer side effects, particularly atrial fibrillation.

The guidelines for new and for relapsed patients provide some possibility to adapt treatment to patient needs and preferences, and they are the same for Germany, Switzerland, and Austria. Interestingly, he mentioned that patients tend to stay with the same group of symptoms when relapsing, so I am guessing this means that my neuropathy will continue to accompany me. Prof. Buske emphasized again that in addition to finding a cure, the focus is on giving patients quality time **without being on therapy**, and there are efforts to see how treatment with BTK inhibitors can be time-limited. He explained that the VIVA-1 clinical trial at 14 sites in Germany and several other countries is comparing dexamethasone, rituximab, and cyclophosphamide (DRC) to venetoclax and rituximab and is still recruiting.

Waldi Group – Ulm, Germany, cont. on page 25

The session on fatigue by Dr. Jetta Hübner, professor for integrative oncology, University of Jena, and founder of Stiftung Perspektiven (<https://stiftung-perspektiven.de>) and her therapy dog (who contributed frequently to the presentation) explained the difference between exhaustion and fatigue. Patients may suffer from exhaustion due to nutritional, hormonal, or glandular activity without suffering from fatigue. Blood values are needed for a better determination. Therapy side effects can lead to poor nutrition and low levels of activity, further resulting in a reduction in muscle mass, also affecting mood. Her emphasis is on helping patients take charge of their situation. She provided practical tips on how to integrate even small or short individually-adapted activities into daily life by engaging in enjoyable activities and routine tasks, and by adding small elements that increase movement and strength. This can include household tasks, gardening, dance, making music, or singing.

The fourth session, online with Dr. Mouhamad Khouja (Universität Kiel), explained the genetic and familial disposition of WM. His statement that WM develops mostly through mutations in blood stem cells during one's lifetime and not from inherited gene defects probably provided relief to many listeners concerned about the risk of WM to their children. In around 20% of cases, first-line relatives (parents, siblings, and children) have about 20 times increased risk. Because of the generally late diagnosis of WM, Dr. Khouja recommends screening (bloodwork) for first-line relatives at 40-50 years of age. Individuals with familial WM have somewhat poorer outcomes. The open questions for research were also interesting:

- Do women have other or atypical symptoms with WM?
- Does frequency of the mutations *MYD88* and *CXCR4* differ by gender?
- Do women react differently to the common therapies? Do current treatment results differ by gender?
- Does risk for progression differ by gender?

- Are women diagnosed late due to atypical symptoms (men are diagnosed 3.2 times more frequently)?
- What are the hormonal effects (estrogen, testosterone) on WM?

The group met again for dinner with more opportunities to ask brief questions to Prof. Buske and Dr. Hübner and getting to know each other. The group also discussed one of the next challenges, the "retirement" of one of the two prime movers of this group, Jürgen Goetz.

The next day, most participants took the opportunity to participate in a walking tour of Ulm despite the exceedingly high temperatures. The 45-minute introduction to the city was given in the beautiful Münster, the church with the now second highest church tower globally. As old churches usually do, the Münster cooled us down to a semi-frozen state, allowing us to enjoy walking about the town without suffering from the heat.

Author Bettina Schwethelm's WM journey

My first encounter with WM dates to 2009, when I had strange sensations in my feet. The blood tests taken during that time showed a clear IgM spike but was never followed up by my family doctor. Today, I am immensely grateful for his omission, as I was working in international health, my great passion, traveling extensively, and raising my two US-born sons in Switzerland.

The persistent neuropathy in my feet then led to a diagnosis of WM in 2020 by the local haematologist, and again, I had no time and energy for it, because I was dissolving the family home to move back to Germany after some 50 years.

Coming from an English-speaking health setting, I googled and immediately landed on the IWMF website, where I learned (among much other helpful information) that a bone marrow biopsy was one of the three criteria for a WM diagnosis. When my haematologist explained he would perform one only before starting treatment, I was glad to move on to Bonn, Germany. There, after some research, I

found a wonderful haematologist at the university hospital who revised the diagnosis to MGUS and “watch-and-wait.”

Since then, I have tried to learn more about my medical issues: small fiber neuropathy, not anti-MAG, double wild type, and am dealing with increasingly annoying symptoms, particularly at night and during the colder seasons. Two courses of IVIG so far, thanks to the second opinion of our national expert Professor Christian Buske, provided some relief, but then my haematologist left Germany, and her replacement is focused on my IgM values.

In my new life in Germany, I have participated in many IWMMF online seminars and wellness sessions and have been to three of the four meetings of the European Educational Forum. Because it is so

challenging to explain my difficulties to those not affected, I enjoy being with others dealing with diverse issues related to WM. I am also active in the DHL online patient group and the German WhatsApp Group. What I miss most, particularly here in Germany, is an integrated approach to treating complex and chronic health issues such as ours—to have a haematologist who actively coordinates with a neurologist and other specialists, as needed, to maintain or improve our quality of life.

Lest you think I spend much of my time thinking about WM, my real life focuses on family and friends and being active outdoors. I jog, bike, swim, hike, read, and explore Germany, a country that has changed tremendously in my 50 years of living abroad.

DID YOU KNOW?

THE IWMMF BOARD OF TRUSTEES HAS APPROVED ALMOST \$4.4 MILLION IN NEW RESEARCH FUNDING!



Requests for grant proposals were sent in September 2025, with a record 37 applications received from researchers in the US, Canada, Italy, Germany, the Netherlands, France, Spain, Greece, and England. Following a thorough review, 11 grants were approved, broken down into these funding categories:

Pilot Clinical Trials – two grants, totaling \$1,993,380

Translational Research – one grant, totaling \$750,000

Correlative Companion Research – two grants, totaling \$500,000

Acceleration and Expansion Research – two grants, totaling \$500,000

Robert A. Kyle Career Development Award – four grants, totaling \$640,000

A sincere thanks to all our donors for making this research funding possible! Look for additional details about the approved grants to appear in the next *Torch* in January.

A TALE OF TWO WM SUPPORT GROUPS

BY BOB PERRY

How lucky I am to be the Support Group Leader for not one but two WM support groups! First, I am the IWMF Global Partner for the Island of Ireland Support Group, a role I took on a temporary basis about five years ago and am still doing, despite living in the South of England. Second, I run the Bournemouth and District WM Support Group (BAD WMers!!) for WMUK, a group I set up back in 2017, two years after my diagnosis in 2015.

Whereas like most groups, we meet on Zoom roughly every three months, I decided to try to arrange a face-to-face group meeting for both of my groups this year. This follows an inaugural Ireland meeting in Dublin last year which was an amazing success; we saw the very real benefits of meeting in person.

So on June 20 this year, we held our second Island of Ireland Support Group meeting in Portlaoise at an amazing location called The Cuisle Cancer Support Centre (<http://www.cuislecancersupport.com>). This beautiful building set in gorgeous gardens and surroundings was perfect for a support group meeting, as well as being central for most of the group.

We were joined by Dr. Carmel Waldron, Consultant Haematologist and WM expert from St. James Hospital, Dublin, together with her Clinical Nurse Specialist Melissa Martin, both of whom gave their time freely to join us on a Saturday. In addition, I was accompanied by Hannah Mobarak, Director, IWMF Global Partners.

Eight patients attended, and it really was a special group for two reasons. First, most of the group had never met each other in person, even though they discovered that they didn't live too far from each other. Second, there was an amazing range of

where people were in their WM journey, from newly diagnosed and on active monitoring, to having had one or more courses of treatment, to two of the group having experienced stem cell therapies. This collective experience was very important to the



Dr. Carmel Waldron (second from left) and Clinical Nurse Specialist Melissa Martin (third from left) with the Island of Ireland Support Group

group, and it opened avenues for so many important questions to each other. In addition, Dr. Waldron and Melissa were totally engaged in answering the clinical questions as they arose, and they gave their informed opinions about any concerns the group had.

I have to give a very special mention to local WM patient Mary Sexton, who arranged not only the amazing location but also the incredible buffet lunch from a local supplier.

This was truly a much-needed group meeting, and we have agreed to try to follow up next year back in Dublin.

Hot on the undoubted success of that meeting and full of enthusiasm for my UK group, I was fortunate to come into contact with a local man,

A Tale of Two WM Support Groups, cont. on page 28

Layne Hamerston, in Bournemouth, who is the custodian for an area of the New Forest, which is privately owned and absolutely stunning. Layne runs wellbeing projects in this woodland area, and I asked if it might be possible to run a face-to-face group session there for my WMUK BAD WMers group. He jumped at the chance to let us use the site.

Therefore, on Saturday, 8 August, in private woodland near Bransgore, New Forest, 25 of us met for a three-hour meeting. Once again this truly was a stunningly beautiful location right in the middle of nature and just so perfect for a mindful meeting. This time we were joined by my very own Dr. Helen McCarthy, Consultant Haematologist at University Hospital Dorset, in Bournemouth. Helen is a well-known WM specialist in the UK and is so generous with her time. (Look for her at the International Workshop on WM in Palm Springs in October where she is presenting an abstract.)

The meeting started with a short mindfulness session given by Layne and introductions from

those present. Then Dr. McCarthy spoke for about an hour about developments in the WM world, including research, new treatments, and what the future might hold for WM patients. She also took generic questions from the group.

We then mingled as a group and really got to know each other; again, it is such a pleasure to see people with a common interest who have never met each other really bond when meeting in person.

The meeting was such a success we will definitely be returning again next summer, and I think I may have tempted the London Support Group to meet at the same location next year as well—maybe a coach trip to the country!

So there we have it, “A Tale of Two WM Support Groups.” I feel so privileged to have been at both meetings, and I hope we can progress and expand them.



New Forest meeting: Dr. Helen McCarthy (center, in long dress) with the Bournemouth and District Support Group

WALDENSTRÖM FINLAND RY: A PEACEFUL RETREAT

Editor's note: The Board of Waldenström Finland ry consists of eight persons. Two of these, Jukka Sneck and Rauna Korhonen, represent Waldenström Finland ry in the IWMF Global Partner community.

Jukka Sneck, Global Partner

I am over 70, I retired about ten years ago, I live in Espoo. In January 2020 I had an infection called erysipelas. After the infection was over, my blood test results did not return to normal. Finally, after many turns, I got my WM diagnosis in January 2021. Fortunately for me, I have never had any WM symptoms, and I have not needed any treatment. I am in “watch and live” status, regular tests are taken twice a year. It is even possible I will never have any WM symptoms.

After getting the diagnosis, I was scrolling the internet and found our patient-driven support group Waldenström Finland ry. I joined the association, and I was elected to the board.

My wife and I have two children and four grandchildren, fortunately both families live near us, we are in close contact. In summer we do rowing, swimming, and kayaking at our leisure house; in winter I join them in downhill skiing.



Jukka Sneck and Valamo Monastery

Rauna Korhonen, Global Partner

I am a 60-year-old lawyer living in Helsinki, Finland. My journey with WM started at a routine

occupational health check-up 2022. All my blood test results were poor and I had severe anemia. I



Rauna Korhonen

hadn't noticed any specific symptoms and I didn't feel sick. A little tired maybe, cycling uphill was a little harder than before, but not fatigue. I was sent to the hospital for further tests and was diagnosed with WM in February 2022.

Like so many others I had never heard of WM. The whole thing felt unreal—I had never been ill or in the hospital and now I have cancer. DRC (dexamethasone, rituximab, cyclophosphamide) treatment was started shortly after diagnosis and made WM a real part of my life. Fortunately, the treatments worked as intended, and I have lived a fairly normal life for over three years now. Blood tests are taken twice a year, otherwise I do the same activities as before, including cycling (even uphill), hiking, and long walks.

Waldenström Finland ry member meeting at Valamo Monastery.

Valamo Monastery is a living center of Orthodox spiritual life and culture and a unique destination. Valamo Monastery belongs to the Orthodox Church of Finland, which is an autonomous church under the Ecumenical Patriarchate of Constantinople. The

Waldenström Finland ry: A Peaceful Retreat, cont. on page 30

Monastery, located in Heinävesi, Eastern Finland, is open to visitors year-round. Valamo Monastery offers meeting facilities, accommodation, and a peaceful atmosphere with surrounding nature, far from all the hustle and bustle.

This Monastery was the place for Waldenström Finland's member meeting in April 2026. Two days without PowerPoint presentations, laptops, expert lectures, strict agenda, or time schedule. Two days to get to know each other better and share experiences. How did that succeed?

Twenty patients and relatives were present. The number is approximately one-third of the association's membership. Many had had a long journey to get there, and we started with a joint lunch. After lunch we moved to a classroom where the chairs were arranged in a circle so that everyone had the opportunity for eye contact. Everyone told their own WM story in the way and with the details they chose. Among the participants were people who had received a diagnosis decades ago and others who had received one just a few months ago. Some had received several treatments, others none at all. For once, there was enough time for everyone's story.

We also had time for the Monastery's art exhibition, which featured old Finnish fairy tale illustrations,

health walks on forest paths, a visit to the Monastery church, and a joint dinner. The first day ended in the Monastery's sauna facilities.

The next morning, we continued our discussions in small groups about what we expect from the association and how those expectations could be met. For example, regular newsletters, easy-to-understand information about WM, meetings with doctors and other WM experts, support group meetings, and ad hoc discussions on specific topics were on the wish list.

The feedback on the meeting was positive. Many appreciated the peaceful atmosphere and informal agenda. "The next morning after good night's sleep, I felt like I was in heaven. A pleasant surprise that instead of strict schedules, everyone got to tell their WM story. The atmosphere was truly heartwarming and rare," one participant commented. Many said they had gained new information about the disease from others' stories.

The weekend at Valamo Monastery was a different but successful face-to-face meeting and a good basis for planning our future meetings.



Member meeting at Valamo Monastery

REIKI AND WM: THE RESEARCH AND EXPERIENCE

BY ANN GRACE MACMULLAN, IWMF DIRECTOR OF INTEGRATIVE WELLNESS
AND COMMUNITY SUPPORT

Living with WM involves more than treating the disease. It also means finding ways to care for your whole self. Reiki is one complementary practice that some people turn to for relaxation and well-being. Research is beginning to explore its potential, while two members of our own WM community, both Reiki practitioners, share what the practice has meant in their lives.

What is Reiki?

Reiki (pronounced ray-key) is a Japanese complementary practice developed in the early 20th century. Since Mikao Usui began teaching his system in the 1920s, numerous traditions and lineages have emerged, with training and practices varying among practitioners. The word Reiki is commonly described as combining the Japanese words *rei*, referring to spirit or universal wisdom, and *ki*, referring to life energy.

According to Reiki practitioners, the practitioner acts as a conduit for what is traditionally referred to as universal life energy. Most Reiki traditions describe physical or emotional distress as creating imbalances or blockages in the flow of life energy. Reiki is intended to support the balanced flow of this life energy, although this proposed energy mechanism has not been established scientifically. People who receive Reiki often describe the experience as calming or deeply relaxing, and some report sensations of warmth or other physical or emotional responses during a session.

During a session, a practitioner typically places their hands lightly on or just above different areas of the body while the recipient remains fully clothed and comfortably seated or lying down. Sessions are generally quiet and may last 30–60 minutes. Many practitioners also offer distance or remote Reiki through video or telephone sessions, allowing people to participate from home. This approach is part of some Reiki traditions and may appeal to people who prefer or need to receive care remotely. The Cleveland Clinic offers a helpful, patient-

friendly overview of Reiki and what to expect from a session. See <https://health.clevelandclinic.org/reiki>.

What does the research tell us about Reiki?

Research on Reiki and cancer is still developing, but some studies suggest it may help with symptoms such as pain, anxiety, stress, fatigue, and overall quality of life. A 2023 systematic review published in *Integrative Cancer Therapies* (<https://pubmed.ncbi.nlm.nih.gov/37595119/>) examined seven studies involving 572 people with cancer. Most reported reductions in pain, although the researchers noted that more high-quality research is needed (this review also included one study of distance Reiki.)

A 2025 randomized controlled trial involving 58 people with cancer found reductions in pain and anxiety over time among those receiving Reiki, along with lower perceived stress at three months. Another recent study of Reiki provided during cancer infusion treatments found that patients reported improvements in pain, fatigue, anxiety, nausea, and overall well-being following their sessions.

It's worth noting that studies on Reiki have often been small, have used different methods, and have not been specific to WM. While more research is needed, Reiki is being used as a complementary approach to support relaxation, stress management, and emotional well-being in cancer care.

Reiki is also being incorporated into integrative care at several major cancer centers. Dana-Farber Cancer Institute's Zakim Center offers Reiki alongside services such as acupuncture, massage, movement, and meditation. Memorial Sloan Kettering Cancer Center's Integrative Medicine Service also incorporates Reiki among its complementary therapies, and Mayo Clinic's Integrative Oncology program lists Reiki as one of its complementary approaches.

What might Reiki offer someone living with WM?

For some people, the experience is simply one of quiet, focused attention and relaxation. And

Reiki and WM: The Research and Experience, cont. on page 32

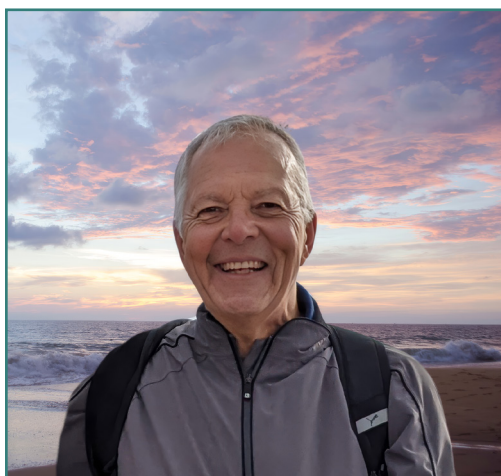
those experiences matter. Living with WM can involve ongoing monitoring, treatment decisions, fatigue, symptoms, uncertainty, and the emotional weight of living with a chronic cancer. Creating time to slow down, relax, and simply receive care can be meaningful. Reiki should be viewed as complementary, not alternative, care. It should never replace medical treatment or be used as a reason to delay or discontinue therapy.

Two people living with WM share their Reiki experiences

Ron Ternoway first experienced Reiki as a WM patient in his local hospital about ten years ago. “I was astounded by the experience—the feeling of lightness, calm and serenity in only a few minutes.” After completing Reiki training, Ron began practicing self-Reiki every day. He also describes improvement in his motor and sensory peripheral neuropathy over a three-year period, as measured by neurological testing. While he cannot say Reiki caused that improvement, the experience strengthened his commitment to the practice.

Today, Ron volunteers as a Reiki practitioner in the Sunshine Room at his hospital in Halifax, Nova Scotia, where people receiving cancer treatment and their support teams can receive complementary therapies. “It is so rewarding to see someone who entered the treatment room full of stress, anxiety and sometimes pain leave 30 minutes later figuratively walking on air.”

Ron also practices distance Reiki for friends and family upon request. While the idea of sharing Reiki



Ron Ternoway

across thousands of miles may test your credulity, he finds it especially powerful for emotional healing.

Sharon Rivet discovered Reiki during yoga teacher training, several years before her WM diagnosis. She went on to complete multiple levels of Reiki training and incorporate the practice into her work with yoga students. After her WM diagnosis in 2018, Reiki became an important part of her own wellness practice. “This deepened my personal practice, which was key from the day of WM diagnosis through bendamustine and rituximab (B&R) treatment for anxiety, awareness, and finding relaxation.”

Sharon has also shared her experience with the WM community, presenting IWMF’s 2024 Wellness Webinar, “Reiki for Cancer Care” at <https://www.youtube.com/watch?v=3RooiNZKiRc>. You can also connect with Sharon through her IWMF wellness classes, including Chair Yoga and Slow Flow Yoga.

Sharon’s practice has touched my family as well. When my father (diagnosed with WM in 2019) was experiencing considerable distress from symptoms such as nausea and fatigue, Sharon sent him distance Reiki. Later, he told me, “I don’t know what that was, but I feel immeasurably better.” Maybe he was humoring me. But he looked better to me, and the moment stayed with me.

For Sharon, Reiki and yoga offer practical tools for relaxation, awareness, and self-care throughout the cancer journey.

Finding a reputable Reiki practitioner

If you’re considering Reiki, particularly while undergoing cancer treatment, look for a practitioner who

- Has completed formal Reiki training and can explain their training and lineage.
- Has substantial hands-on experience.
- Has experience working with people affected by cancer or serious illness.
- Carries professional liability insurance and appropriate general liability coverage.
- Follows a professional code of ethics and

maintains appropriate boundaries.

- Explains what will happen during a session and respects your preferences regarding touch.
- Understands that Reiki is complementary care and never suggests replacing or changing medical treatment.



Sharon Rivet giving Reiki session

Watch for red flags

Be cautious of anyone who claims Reiki can cure cancer, eliminate cancer cells, control WM, replace cancer treatment, or guarantee a particular outcome. A reputable practitioner should be comfortable saying that Reiki is one complementary tool for supporting well-being, not a treatment for cancer. For readers who want to learn more, visit the International Center for Reiki Training (ICRT)

at www.reiki.org or the Reiki Council website, www.reikicouncil.org.uk/.

Caring for the whole person

There is still much to learn about Reiki, and more rigorous research is needed. But Reiki is finding a place in integrative cancer care, including at major cancer centers. For some people, it may offer a quiet opportunity to relax, manage stress, and reconnect with a sense of well-being.

For Ron and Sharon, Reiki has become one way to care for themselves while living with WM and to support others along the cancer journey. Reiki doesn't treat WM. But caring for the person who lives with WM is an integral part of whole-person care.

Curious about Reiki? Try it for yourself. Consider yourself your own science experiment. Notice how you feel before a session, how you feel afterward, and whether you notice any changes over time. There's no single right experience. Stay curious and discover what supports your own well-being. You may find that a little time to pause, breathe, and simply be is exactly what you need.

The author gratefully acknowledges the input of Sharon Rivet and Ron Ternoway, WM patients and Reiki practitioners, for this piece. For additional wellness information or suggestions, contact the author at anngrace@iwmf.com.

FEAR TO RELIEF

BY RAYMOND ADAMIEC, CAREGIVER

At a recent IWMF Ed Forum, one speaker discussed the subject of fear. As someone who spent 37 years in the Marine Corps and is the husband of a WM patient, I would like to share a few thoughts on that topic and explain how to convert fear to relief.

Psychologists often distinguish between two types of fear: rational and irrational.

A **rational fear** is triggered by a genuine danger or significant risk. It is roughly proportional to the likelihood and severity of harm, it is responsive to evidence (it lessens when the danger decreases), and it potentially is useful because it motivates protective behavior.

Some examples include feeling anxious when driving on icy roads, being concerned about when a bear confronts you in the forest, encountering a large aggressive dog off leash, and being in combat with an enemy firing at you.

An **irrational fear** is disproportionate to the actual level of danger. It is based largely on **False Expectations of Anticipated Results (F.E.A.R.)**. It is persistent despite contrary evidence and often interferes with daily life or leads to excessive avoidance.

Examples of irrational fear include being convinced an airplane will crash despite air travel being statistically very safe, avoiding all social situations because of certainty that everyone will ridicule you, or panicking at the sight of a harmless spider in a region where dangerous spiders are extremely rare.

Evaluating fear

If the fear prompts appropriate precautions and remains flexible in light of new information, it is more likely rational. If it persists despite strong evidence to the contrary and significantly restricts life, it is more likely irrational or at least disproportionate.

Given the above, I would like to focus on irrational fear. More often than not, such fear unleashes a flood of powerful emotions. These emotional responses cloud judgment and have a serious impact on a person's well-being. For the first few seconds after

exposure to a situation that causes a person to be afraid, there are two immediate responses—fight or flight. Then the rational brain kicks in and not only assesses which of those responses is best for the situation, but also judges whether the fear is rational or irrational. It should be noted that the difference between rational and irrational is not black and white but rather a spectrum. People who are afraid of heights and have trouble looking out of a skyscraper's window know their fear is irrational; nonetheless, it causes them anxiety and an immediate desire to flee the situation. They simply have **False Expectations of Anticipated Results**. They are in no physical danger, but it takes time for knowledge to replace emotion.

When my wife, Cathy, was diagnosed with cancer in 2012, my immediate reaction was to envision her imminent death. That thought produced an overwhelming surge of fear and uncertainty. The diagnosis was unexpected. She had been experiencing flu-like symptoms regularly every 3-4 months. During an annual physical, she casually mentioned it to her doctor. He was skeptical it was the flu and had her undergo numerous tests, starting with more bloodwork that showed an elevated sedimentation rate and a CT scan that showed nothing. He decided to send her to an infectious diseases specialist. Those tests were all negative, and then she had a battery of tests initiated by a rheumatologist.

Concurrently, she was undergoing imaging for back pain. The imaging indicated numerous issues with her back but also "unusual activity in her bone marrow." This is when her doctor called and indicated it was most likely a blood cancer, and she would need a bone marrow biopsy. The result was the WM diagnosis. The initial review of WM survival at that time was five years! In hindsight, I realized that I had anticipated an outcome without a full understanding of the diagnosis. My mind had raced ahead to the worst possible conclusion. (F.E.A.R.).

Unexpected events, particularly those that threaten me or someone I love, activate the instinctive part of

Fear to Relief, cont. on page 35

my brain. For a moment, I felt paralyzed, only to be propelled into the familiar fight-or-flight response, verging on a panic attack. While this response is natural and has evolved to protect us from danger and ensure survival, it can also lead us to make assumptions, decisions, or take actions that are neither necessary nor helpful.

Learning to recognize the difference between rational concern and irrational fear can help us respond more thoughtfully to difficult news. Fear motivates us to gather information, seek support, engage in seeking knowledge, and focus on making informed decisions. In my case I researched to find out who was the expert in WM and contacted Dr. Steven Treon's office at Dana-Farber Cancer Institute to get unbiased information. There I found out about IWmf and how to get engaged in helping to find a cure. Had I succumbed to fear, I would have been robbed of the proper perspective and suffered mentally from outcomes that may never occur. Instead, IWmf provided me with a sense of relief. Learning that an organization like IWmf existed and was working hard to find a cure turned fear into relief. Recognizing this distinction has helped me better support my wife and navigate the uncertainties that

accompany living with WM. I'm happy to report that she is doing very well. She's taking Calquence (acalabrutinib) daily with no problem, and her bloodwork is better on this medication than when



Cathleen and Raymond Adamiec

she received a more traditional chemotherapy several times in the past.

Bottom Line: It's time to turn **False Expectations of Anticipated Results (F.E.A.R.)** into **Relax Exhale Learn Information Engage Focus (R.E.L.I.E.F.)**.

HAVE YOUR SAY

The *Torch* welcomes letters, articles, or suggestions for articles.

Please contact *IWmf Torch* at PR@iwmf.com.

NEW SUPPORT GROUP LEADERS

COMPILED BY SHARON RIVET, SUPPORT GROUP NEWS EDITOR



Laura Brice, Co-Leader, CO/WY Support Group

My husband and I are both retired from our CPA/oil and gas auditing and consulting business which we had for more than 30 years.

My journey with WM started in April 2025 when my primary care physician thought further testing was required because my protein level had been elevated for several years. After additional blood work and a bone marrow biopsy, I was diagnosed with WM in June. My doctor provided literature on IWmf that was extremely helpful.

I was still asymptomatic and had been hiking 10-11 miles in the mountains near my home south of Steamboat Springs, CO. That level of activity didn't last long because, by October, I was anemic and having a hard time walking, which is when I began Brukinsa. My improvement was initially very slow (because of the *CXCR4* and *TP53* mutations) but it continues to improve. I started hiking again and staying active, which has always been my lifestyle. It fills my soul.

My husband encouraged us to attend an in-person IWmf CO/WY Support Group meeting that was held a month later. I am so glad we did. I met other WM patients and felt I had found a great community. At the end of the year, a virtual group was initiated, and I began attending early this year.

I am so happy to be able to contribute to the IWmf/WM community by being a co-leader, along with Cathy Zimmerman. It has already provided me with so much support in the first year of my WM journey.



Sharon Rivet, Leader, Eastern NY/Western New England/Vermont Support Group

I was diagnosed in 2018, like so many others during a routine physical, and also like so many others, I experienced an extremely scary, nerve-wrecking time. It wasn't until 2019, after I started treatment (B&R), that I found IWmf, and my world changed. Not only did I have access to (at the time) an overwhelming amount of information, I also found others with WM, from newbies like me to those who had it for 20+ years. The resources and contacts have been invaluable to me. Over the last six years, I have been volunteering at IWmf, supporting the

North American Ed Forum, writing for the *Torch*, teaching yoga for our Wellness community, and attending the BeOne Patient Advocacy Council.

As a member of the Eastern MA Support Group, I have truly appreciated Eileen Sullivan (the SGL) and all the people in our group as we share and learn from each other. This past May, I was tapped to consider rebooting the Eastern NY/Western New England/Vermont Support Group. Knowing how important it is for me to have opportunities to talk with others in this WM world, I agreed and am excited to connect, support, and share with others in this area.

Since retiring, I love spending time with my grandchildren and great-grandchildren making cookies or riding roller coasters. I also teach yoga locally and travel with my husband whenever we have the opportunity and are not in the kitchen cooking.

FROM THE FACEBOOK WM SUPPORT GROUP: OCTOBER 2026

BY BETTY ANN MORTON, EDITOR



Recent conversations in the Facebook WM Support Group cover a wide range of topics, including how to find a knowledgeable doctor, whether a particular symptom may be connected to WM, questions about specific treatments and people's experiences with them, and our joys and fears. Here are some excerpts from those discussions.

MS recently needed a new doctor. "My local oncologist has retired. What's the best way to pick a new one from the local (name of a large oncology group) office?"

CBC knew doctors in the area and responded, "You can check the IWMF website for those specializing in WM. If you are near (name of city), I recommend Dr. (name) at (location of practice). He's spoken to our group before too." Group members posted links to the IWMF physician list at <https://iwmf.com/wp-content/uploads/2025/04/IWMF-DIRECTORY-OF-WM-PHYSICIANS-Final.pdf>.

MT wondered, "Maybe your oncologist will recommend a new oncologist. Did they give you any suggestions?" **BR** added, "I use two, a local doctor and another who is a specialist (on the IWMF list). She really knows her stuff about WM." **BAM** had another suggestion, "Are you in a local support group? If so, you might ask the leader and/or members for recommendations."

Decisions about treatments are important, and group members frequently ask about specific treatments, their effectiveness, and their side effects. **KR** posted, "After more than nine years of being on watch-and-wait, my IgM has gone over 5,000 mg/dL. I will see my oncologist this week. He has already told me that he wants to start me on zanubrutinib (Brukinsa). I'm 73 with a mildly enlarged spleen and mild anemia, but no troubling symptoms to complain about. I thought I wanted to do rituximab and bendamustine, instead of oral meds forever. What are compelling reasons to choose one or the other? Are there any advantages to choosing one over the other as the initial treatment?"

MCM posted a lengthy response, "There are lots of things to consider when deciding on a treatment.

BTK inhibitors and chemoimmunotherapy infusions usually result in similar outcomes, but their efficacy has not been compared in a head-to-head study. Patients (in consultation with their doctor) should carefully consider the advantages and disadvantages of each treatment to decide which is the right one for them.

"Some people like the convenience of an oral BTK inhibitor (ibrutinib, acalabrutinib, zanubrutinib) even though they must be taken once or twice a day until they're no longer effective (they often stop working after several years and then another treatment must be started). They have some restrictions (i.e., food and drug interactions) that may be inconvenient. They must be stopped briefly for procedures that may involve bleeding, during which time IgM may rebound. They have many side effects; most are minor and tolerable, but some are serious (e.g., bleeding, hypertension, atrial fibrillation, etc.). Immunosuppression is ongoing. The patient's medical history should be considered, especially regarding those issues a BTK inhibitor might affect (e.g., joint pain, cardiac arrhythmia, bleeding, upper respiratory infections, etc.). The cost of BTKi's can be an issue for some, but they're now reasonable in the US under Medicare, and financial assistance is available.

"Chemoimmunotherapy (e.g., bendamustine/rituximab or B&R, cyclophosphamide/rituximab, etc.) is a short-term intravenous infusion. Side effects (e.g., nausea, fatigue, constipation, rituximab reaction) can be unpleasant but usually only last for a few days post-infusion. Immunosuppression subsides a few months after treatment is complete. Venous access may be uncomfortable and require a temporary catheter (PICC line) or an indwelling port. The need to take time off from work for infusion days may be an issue for some. In the US, IV therapy is paid for by Medicare Part B and most private insurers. The most popular selling point is that after completion of treatment, many people have a treatment 'holiday' of several years."

From the Facebook WM Support Group, cont. on page 38

Please note that there is bias when asking for opinions and experiences. WM is a very quirky disease, and each of us is different. One person's story of no adverse effects and great results from a particular treatment is no guarantee you'll have the same result.

In the "Great Debate: BTKi versus CIT" at the 2023 Ed Forum, WM expert doctors discussed long duration versus short duration therapy. <https://youtu.be/AdbXF2MGxrA>

JCD replied, "**MCM**, this is the most succinct and informatively written explanation I have read. I did B&R eight years ago, and my IgM has remained under 300 mg/dL, spleen and liver recovered, no more anemia or night sweats, and my immune system is great. I don't know how long my good fortune will last, but it's been a nice holiday. I will definitely ask to repeat it. Hopefully, **KR** will have a nice holiday as well after choosing her treatment options, whichever she prefers (not anyone else's choice, including her doctors).

"Self-advocacy is SO important. I'm not sure how it works for everyone based on insurance coverage and geographical location, but I believe in my right to choose for myself. And that was exactly what I did with both WM and with breast cancer. It's been 13 years since my choice to have a bilateral mastectomy, and I had to fight five doctors. I have zero regrets. B&R was my choice of treatment for WM and no one fought me. My oncologist helped me by telling me what he would do for himself in my place when I asked him. I still favor B&R after joining this group and reading all the comments."

BH added, "My reasoning was simple—I'd much rather take a pill every day than have to sit with an IV for hours, even if it was only twice a month."

KG wrote about her family's experience. "I am so glad you are reaching out with questions! Ask your oncologist if there are other health concerns for you. It could be why they are recommending oral meds. Hubby hands down will take oral meds over chemo. He is 15 years in, will turn 60 this year and much prefers to take a pill, do his thing, and have less of his life spent in a medical facility. He also has acquired heart failure from chemo; vision defect from high steroid use during chemo (now terrified to take any

steroids); his thyroid doesn't work (unknown what caused that issue). And the never-ending fatigue requiring two 2-hour naps per day. By the way, all his CBC (complete blood count) numbers are in the normal range (no anemia).

"I strongly suspect his disease path is a unicorn, based on other people's experiences. I am so grateful this disease allows people time to ask questions and get second opinions! Sounds crazy, but..."

CM expressed her preference. "I chose B&R for a couple of reasons. 1) I'd prefer to delay a lifelong pill for as long as possible. 2) Not knowing how long the results from B&R would last, I wanted to "save" oral treatments for when I'm older (if I need them). It's been exactly three years since my B&R. It was very effective and still holding. I feel great. The side effects for me were manageable, and the six months went by quickly!"

ES wrote, "My only additional comment is that when you're choosing therapy (your choice, not the doctor's), to dismiss oral treatment because it's 'for the rest of your life' might need more thought. You will (unless we find a cure) have WM for the rest of your life. I take daily blood pressure, thyroid, and cholesterol meds, likely for the rest of my life, so, to me, one more pill is not a deal breaker."

RS added, "Knowing how many chemotherapy-free treatments are in development, I would consider choosing a chemo-free option such as Brukinsa for my initial treatment. By the time Brukinsa is no longer effective, other chemotherapy-free treatments—such as CAR T cell therapy or bispecific antibodies—may be available."

Although there is no consensus among the WM community about which initial treatment to use, knowing the pros and cons of various treatments may help us make wiser decisions.

The emotional aspect of a cancer diagnosis is also important to members of the Facebook WM Support Group. **WR** started a recent conversation with this post: "Nothing earth-shattering and not meant to criticize, but more of an observation. Ever since my friends have found out I have WM, I have discovered

From the Facebook WM Support Group, cont. on page 39

that they all have MDs after their names or PhDs in nutrition, and they all have cures. I know they mean well and are sincere, but sometimes I get tired of getting free medical advice.”

TG wrote, “One friend talked to a nutritionist who gave her tons of recipes that I ‘had to try.’ Another talked to his friend who is maybe an MD, ‘Take this cocktail of vitamins.’ My oncologist said not while on chemo and that we aren’t trying to make the chemo take longer.”

PPVP responded, “Ah yes. It’s great that, despite being the one with the illness, you are aware of your friends’ urgent need to help. They probably feel a bit helpless and are having a hard time with that. Generally, taking care of yourself will probably make anything you encounter in life a bit better. But outside of that, we and your expert doctors are here for you!”

“At least they care and didn’t disappear,” added **PF**. **PH** expressed empathy. “Yes....and I’ve had THAT happen too, the disappearing.”

GR struggled with a relative who didn’t understand. “My sister drove me to the point of depression. All the YouTube influencers, with no qualifications, but so much advice. My sister didn’t want me to do chemo or take prescription medications. I was told to choose [alternative treatments] and refuse oncology. I was flooded with YouTube videos by the likes of ‘Dr. Blank’ (not a medical doctor), etc. She got angry that I wouldn’t go down this path, and she made my life miserable. When it became clear that I was going to see an oncologist and accept treatment, she wrote me off.”

JM explained her experiences. “I have had two people do this to me, both completely unqualified. Enough said. I don’t tell people other than close family that I have WM. I don’t want to hear their medical opinions, and I think that has helped me a lot. We have a friend who was diagnosed with an aggressive cancer. He sent out an email to family and friends telling them about his diagnosis and told them please not to offer any well-meaning medical/health advice, that he’s got the best doctors in the country. I think that was very smart.”

LM wrote, “One friend I asked politely not to keep sending YouTube and other videos and links, but she keeps sending them. I just ignore them and don’t respond. Maybe just a polite, ‘My medical doctors are managing my condition, but thank you for being concerned,’ might help?”

DLC’s perspective was, “I would just tell them that, while it’s very touching and you appreciate their support and how much they care about you and how much your diagnosis obviously weighs on them...it’s unfortunately adding unnecessary and unintentional stress. That you spend enough time thinking about it and talking to doctors about it...you would much prefer time spent with friends...time to hang out, laugh, be silly, gossip and make new memories... THAT is what you would find helpful, uplifting and the best therapy!!!! They can be the mental break and escape from everything you have to think about and discuss the rest of the time. You feel you’re in very good hands with your doctors and want friend time to be just that...no medical discussions. Remind them you are still you and you are not your diagnosis! Reassure them that if you ever have a question or need advice or input, they will be the first to know... and if they have any questions, they are free to ask... but medical advice and ideas are overwhelming even though it’s from a place of care and concern.”

HBS had a gentle approach. “Your friends care about you and want to help. It can be worth exploring and listening to the advice they give before dismissing them.” **LJ** posted, “Oh, yes. I just state calmly that I have a great team at MD Anderson and trust them completely.”

To join the 9,300 WM patients and their loved ones in the WM Facebook Support Group, look for us at <https://www.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 at 941-927-4963 or email to office@iwmf.com.

NW/SEATTLE AREA SUPPORT GROUP WELCOMES DELORA SENFT AND KATIE WARRENSFORD

BY RICHARD DAVIS, MEMBER

Twenty people attended the annual NW/Seattle Area Support Group picnic this year at the Kirkland, WA, home of Co-Leader Nancy and Mark Nelson. Ten of those present were WM patients—three men and seven women—the earliest of whom was diagnosed in 2010 and the latest in 2025, and they were accompanied by their partners or friends. Two of the attendees had never met another WM patient in person before. This is really what IWWMF is all about, helping each other navigate and understand our rare disease.

Warrensford. Delora explained that since starting in August of 2025 she has been trying to attend in-person meetings of WM support groups around the world to hear patients' stories. So why not invite her to attend a future meeting of your support group, especially if your group is near a major cancer center? Delora is passionate about getting a feel for our experiences as we navigate the healthcare field. Some of us told our complicated stories to the group or individually to each other. As you may imagine, they were all different.



NW/Seattle Area Support Group picnic attendees

It was a beautiful sunny day, and we enjoyed a delicious potluck lunch and meeting in person our WM friends whom we usually see only at our quarterly Zoom meetings. Online meetings can be a lifeline, for some of our group members live in Hawaii, Alaska, and Idaho, where local groups are few and far between.

Special IWWMF guests at our picnic this year were President & CEO Delora Senft and her husband, John, and IWWMF's Chief Development Officer, Katie

Katie is responsible not only for fundraising, but also in creating key partnerships and ensuring patients have access to WM clinical trials. Their other aim here in Seattle was to visit our premier Fred Hutchinson Cancer Center.

IWWMF is using your donations, along with help from pharmaceutical companies, to further research toward a cure for WM by helping to fund our new research grants including our first ever pilot clinical trials. However, IWWMF must get the news out that these funds are available

to cancer researchers, which is one reason why Delora and Katie met with researchers and executives at the Fred Hutchinson Cancer Center. Dr. Mary Kwok, Dr. Vikram Raghunathan, Dr. Mazyar Shadman, and Dr. Stephen Smith all expressed the wish that more WM patients had joined some of their previous trials and asked that IWWMF continue to work on facilitating greater patient participation in clinical trials.

SOMETIMES IT'S ZEBRAS

BY EILEEN SULLIVAN AND PETE DENARDIS

Most of you have heard the mantra that most doctors learn in medical school. “When you hear hoofbeats, think horses, not zebras.” This article is about those times when it turns out to be zebras.



Pete DeNardis and Eileen Sullivan, both WM long-timers, have experienced this firsthand and have long had an interest in spreading the word to the WM community, including doctors, that WM can find its way into just about any organ in the body and can be tricky to sort out when it does.

At the recent North American Ed Forum in Ohio, both Pete and Eileen had an opportunity to meet with Prof. Shirley D'Sa, a WM expert from University College London Hospitals, who has treated many WM “zebras” in her practice. They asked if she might be willing to give a presentation on the topic to the international WM community.

When WM is found outside its normal location in the bone marrow, it's called extramedullary WM, and it's quite rare, hence the zebra moniker. Sites for extramedullary lesions or masses can include the lungs, soft tissue, cerebrospinal fluid, lumbosacral region, breast, eyes, skin, prostate, and bones, but there are reports of it showing up in just about every possible organ.



As of this writing, little, if anything, is known about why this happens for some patients. For both Pete and Eileen, this change happened after chemotherapy

many years ago, but for other patients, it is the first indication of WM and sometimes the symptom that leads to the initial diagnosis.

Prof. D'Sa agreed to participate in an IWMF webinar-style support group meeting for patients interested in learning more about this rare complication.

She prepared an informative slide presentation which was prerecorded, and it included a Q&A discussion at the end with Pete and Eileen asking clarifying questions. The video was presented in April of 2026 as a webinar



with international participants who signed up via IWMF. It is available on the IWMF YouTube channel at <https://tinyurl.com/WMExtramedullary>.

After the recorded session, those attending had an opportunity to discuss what they had learned and to share their own experiences (Pete and Eileen moderated this part also). There was interest in a follow-up support group-style meeting during which we would have more time for participants to share their WM journeys and complications with one another—and that will happen in the future. Anyone interested in learning more about upcoming meetings should send a note to info@iwmf.com.

We look forward to continuing research into these rare WM complications to identify the most effective treatment methods and raise awareness in the larger community that zebras do exist.

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