IWMF TORCH

April 2026

Issue 27.2 International Waldenstrom's Macroglobulinemia Foundation

INSIDE THIS ISSUE

BCL2 INHIBITION IN WALDENSTROM MACROGLOBULINEMIA: WHAT PATIENTS SHOULD KNOW

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For the majority of patients with Waldenstrom macroglobulinemia (WM), our most commonly employed treatments (for example, chemoimmunotherapy and BTK inhibitors) work really well, resulting in improvement of symptoms and many years of stable disease control with good quality of life. However, these treatments are sometimes not tolerated very well or quit working (treatment resistance). Additionally, BTK inhibitors require continuing therapy indefinitely, which may not appeal to some patients. Therefore, we are always looking not only to improve the effectiveness and tolerability of treatments which we can offer to our patients, but also to develop new therapies for patients in whom our standard treatments are either poorly tolerated or are no longer effective.

Fortunately, the treatment landscape for WM continues to expand, offering patients more options than ever before. WM researchers are also testing a variety of promising new therapies such as non-covalent BTK inhibitors, BTK degraders, antibody-drug conjugates, and immune therapies like T cell redirecting antibodies, which all hold substantial promise. Check out some of these ongoing clinical trials through the WM-Net clinical trial network (*https://www.wm-net.org/*) or the European Consortium for Waldenstrom's Macroglobulinemia (*https://www.ecwm.eu/*).

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The *IWMF Torch* is a publication of IWMF. This publication is designed to provide information about the disease Waldenstrom's macroglobulinemia. It is distributed as a member service by the International Waldenstrom's Macroglobulinemia Foundation, Inc., to those who seek information on Waldenstrom's macroglobulinemia with the understanding that the Foundation is not engaged in rendering medical advice or other professional medical services.

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

In this issue of the *Torch*, we are going to review a class of drugs called B cell lymphoma 2 (BCL2) inhibitors, which hold significant promise in the treatment of WM.

Readers of the *Torch* are likely familiar with the concept of targeted therapy: drugs designed to interfere with specific pathways that cancer cells rely on to survive. The most notable example of targeted therapy in WM is disrupting activation of the BTK pathway with BTK inhibitors such as ibrutinib, acalabrutinib, and zanubrutinib. Beyond BTK, BCL2 represents another potentially exploitable pathway. All normal cells in our body live their lifespan, then die and are replaced. The BCL2 protein is part of this process of what we term "programmed cell death" or "apoptosis" (Greek for "falling off"). Many cancers, including WM, are in part driven by the excess accumulation of BCL2 protein inside the malignant cells, thereby allowing them to evade death. Naturally, searching for treatments that will coerce these malignant cells to follow a more normal fate and die when they are supposed to is a priority for cancer researchers.

Many cancers, including WM, are in part driven by the excess accumulation of BCL2 protein...

Venetoclax, an oral BCL2 inhibitor, was the first drug developed to block this survival signal and restore the natural process of cell death. Over the past decade, venetoclax has become an established and highly effective therapy in several blood cancers, particularly chronic lymphocytic leukemia (CLL) and acute myeloid leukemia (AML). In CLL, venetoclax-based combinations have enabled many patients to achieve deep remissions with time-limited treatment, an approach that has been especially appealing to patients wishing to avoid indefinite therapy. The potential for BCL2 inhibitors to allow treatment protocols with fixed periods of dosing may also be an appealing consideration in WM, where current targeted therapy options like BTK inhibitors generally require indefinite dosing.

Given its success in related diseases, venetoclax has been studied in WM, primarily in patients whose disease has returned after prior treatments. Dr. Jorge Castillo, from the Dana-Farber Cancer Institute, has been at the fore in this research. Dr. Castillo led a multi-institutional study of venetoclax therapy in 32 previously treated WM patients, who received the drug orally as a single agent daily, for a total of 24 months. It worked very well, with 81% of patients achieving at least a partial response (a greater than or equal to 50% reduction in WM burden) and 19% achieving a very good partial response (a greater than or equal to 90% reduction). One half of the patients remained in remission at three years. (Castillo et al. *Blood Advances*, 2025, 9 (19): 4842-4847).

Importantly, in this trial, responses with venetoclax were observed even in patients previously treated with BTK inhibitors, suggesting that BCL2 inhibition works through a distinct and complementary mechanism. Venetoclax activity also appears to be largely independent of common WM genetic features such as *MYD88* and *CXCR4* mutations, an encouraging finding for a genetically diverse patient population.

The side effects identified with venetoclax in WM are generally consistent with those reported in other similar blood cancers. Low blood counts and infections are the most common concerns and require careful monitoring by the healthcare team. One potential risk, tumor lysis syndrome (TLS), caused by rapid breakdown of cancer cells during the start of therapy, has been a concern in the use of venetoclax across blood cancers. Risk for TLS may differ in different types of blood cancers, and it has been uncommon in WM when standard precautions are followed. The precautions include planned dose escalation, good hydration during initial doses, and close initial laboratory monitoring. In general, venetoclax has shown to be a relatively well-tolerated treatment for WM with a well-described safety profile.

Researchers are now exploring whether venetoclax

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may be even more effective when combined with other treatments. One such study, again conducted by Dr. Castillo and colleagues, combined venetoclax with the BTK inhibitor ibrutinib in patients who had not been previously treated for their WM. (reference PMID: 37971194 on PubMed at *https://pubmed.ncbi.nlm.nih.gov/*) It was extremely effective. However, the study terminated early because two of the 42 patients developed fatal ventricular arrythmias. Both patients were men over 65 years old with cardiac risk factors. Presently, the same team is now studying a newer non-covalent BTK inhibitor, pirtobrutinib, which has less potential to contribute to cardiac arrhythmias, in combination with venetoclax in patients who primarily had one previous WM treatment. It has so far shown to be very effective, with fast and deep responses and appears to be safe (Castillo, American Society of Hematology Annual Meeting 2025).

Other combinations, including venetoclax with anti-CD20 antibodies, such as rituximab, are also under investigation. One example is a multicenter randomized Phase 2 study evaluating ibrutinib plus rituximab or single-agent zanubrutinib versus venetoclax plus rituximab for treatment naïve WM/LPL (lymphoplasmacytic lymphoma). The trial identifier is NCT04840602 on *www.clinicaltrials.gov*.

These approaches remain experimental, but they reflect a broader trend toward thoughtfully designed combinations that aim to maximize benefit while limiting long-term toxicities and treatment burden.

In addition to venetoclax, newer BCL2 inhibitors are beginning to enter clinical trials, most notably sonrotoclax. Sonrotoclax is designed to bind BCL2 with high precision and may offer advantages in potency and resistance profile compared with first-generation inhibitors such as venetoclax. Sonrotoclax inhibits BCL2 with greater than 10-fold potency compared to venetoclax and exhibits better "in vitro" (in a laboratory setting) activity against certain BCL2 mutations, including BCL2 G101V, which can be an issue with causing resistance to venetoclax.

In addition to venetoclax, newer BCL2 inhibitors are beginning to enter clinical trials, most notably sonrotoclax.

Studies of sonrotoclax in other B cell malignancies have shown promising activity, including in some patients who previously received venetoclax. The experience with sonrotoclax is more advanced in other blood cancers such as CLL but is growing in WM, as well as in other less common lymphomas. While still investigational, sonrotoclax represents an exciting next step in refining BCL2-targeted therapy. This excitement may include an improvement in safety profile and tolerability in comparison to venetoclax. One notable finding to date has been that no episodes of tumor lysis syndrome are being described with sonrotoclax, which might make starting treatment safer and straightforward.

At the Colorado Blood Cancer Institute, we have been participating in a clinical trial evaluating sonrotoclax in WM. This study (along with others in different lymphomas) is focused on determining the safest dosing, understanding side effects, and assessing early signs of effectiveness. Some trials are testing sonrotoclax alone, while others are pairing it with BTK inhibitors such as zanubrutinib or with monoclonal antibodies. Early results demonstrate high rates of deep responses and so far good tolerability, and we look forward to seeing these initial results presented at upcoming meetings.

To summarize, BCL2 inhibition is just one example of the broader wave of innovation now underway in WM research. Non-covalent BTK inhibitors, which may remain effective after resistance develops to current BTK inhibitors, and BTK degraders, which remove the BTK protein altogether, are also being actively studied. Altogether, these advances highlight a hopeful reality for the WM community: progress is accelerating. While challenges remain, the expanding pipeline of targeted therapies including venetoclax and emerging agents like sonrotoclax offers renewed optimism that patients will continue to see improvements in disease control, tolerability, and quality of life.

FROM DIAGNOSIS TO ADVOCACY: STEVE PINE AND THE POWER OF EDUCATION

By Art Brewer, Features Correspondent

When Steve Pine was diagnosed with Waldenstrom's macroglobulinemia (WM) in September 2005, he was only 47 years old—young by WM standards. "Everything was pointing to Waldenstrom's," he recalls, "but my oncologist told me he didn't think it could be WM because I was too young."

That moment marked the beginning of a journey that would stretch across two decades and be defined not only by careful medical decision-making, but also by education, self-advocacy, and a deep commitment to helping others navigate this rare disease.

A diagnosis that didn't start with cancer

Steve's diagnosis did not begin with alarming lab results or a medical emergency. Like many WM patients, his story started quietly, during a routine annual physical. He mentioned a few nagging issues to his general practitioner: occasional balance problems in the shower, a mild back issue that felt like sciatica. Nothing seemed urgent.

But during the physical exam, something unusual emerged. When Steve's doctor tested his reflexes, they were completely absent. "He checked again. And again," Steve remembers. "Then he said, 'You don't have any reflexes.'"

That finding set off a cascade of referrals and tests, eventually landing Steve in a neurologist's office. After extensive evaluation, he was initially diagnosed with chronic inflammatory demyelinating polyneuropathy (CIDP), a rare neurological disorder with no clear cause. But further blood work revealed abnormal proteins, prompting a referral to a hematologist and a phone call Steve still remembers vividly.

"When they answered the phone, they said, 'Lake Vista Cancer Center,'" he says. "I was speechless."

What followed was a familiar experience to many WM patients: inconclusive tests, multiple possible diagnoses, and mounting anxiety. A bone marrow biopsy suggested either lymphoplasmacytic lymphoma or marginal zone lymphoma, closely related conditions that Steve, like many patients, had never heard of before.

Unsatisfied and eager for clarity, Steve sought a second opinion at MD Anderson Cancer Center in Texas. There, after repeat testing, he finally heard the words: Waldenstrom's macroglobulinemia.

Steve and Alyce Pine

But even then, Steve's story took a less common turn. The initial recommendation from the non-WM specialist came with a treatment plan that Steve wasn't convinced he needed. Armed with research, support from information provided by IWMF, and a growing understanding of the disease, he advocated for a watch-and-wait approach.

"I wrote a two-page letter explaining everything I'd learned, asking to see the WM specialist," he says. "And when I finally met with her, she walked in and said, 'I agree with you. You don't need treatment.'"

For Steve, treatment decisions have always been guided by quality of life. His primary symptom, peripheral neuropathy, progressed slowly. Once he learned how balance, vision, and sensation work

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together, he adapted. "If my feet are numb and my eyes are closed, of course I'm going to feel off balance," he explained.

He waited until 2008, when neuropathy began interfering with fine motor skills, before starting treatment. He received four doses of rituximab followed by another four a month later. The results were remarkable: his IgM levels dropped significantly, and he enjoyed more than 15 years without additional therapy.

In late 2025/early 2026, two decades after diagnosis, Steve completed a second eight-dose course of rituximab. While the response has been gradual, his numbers are trending in the right direction. "You notice little things," he says. "Zippers. Signing your name. Picking things up off the floor."

Becoming an advocate and a leader

Steve's commitment to education and advocacy deepened soon after his diagnosis, when he attended his first IWMF support group meeting. Initially, he wasn't sure it was for him. "I'm not really a touchy-feely person," he says. "For me, it was about learning."

What kept him coming back was the realization that he could help others. With a knack for research and an ability to translate complex medical information into plain language, Steve became a trusted voice within the group. In 2010, after the group's leader passed away, Steve stepped into a co-leadership role and has held that role ever since. "I don't go to the support group for me," he says plainly. "I go to help others."

"I don't go to the support group for me…I go to help others."

Over the years, Steve has helped guide countless newly diagnosed patients through fear and confusion, reassuring them that WM is manageable. His experience as a patient and a leader has given him a steady perspective that only time can provide.

Steve has also played a key role in shaping how IWMF support groups operate in the digital age. When COVID disrupted in-person meetings, he helped reimagine programming, including a highly successful virtual event last year featuring Dr. Jorge Castillo. The concept was simple but powerful: bring everyone together for a high-quality educational presentation, then break into smaller groups for discussion. The idea was widely embraced by support group leaders and participants alike.

"Education is the key with this disease," Steve says. "You have to know what's happening in your body, understand the treatments, and be able to have real conversations with your doctors."

"Education is the key with this disease…"

In addition to his support group leadership, Steve is also an IWMF LIFELINE volunteer, offering one-on-one support to patients, often newly diagnosed, who need reassurance, perspective, and guidance toward reliable resources.

As if advocacy within the WM community weren't enough, Steve also serves his local community as mayor of Caney City, TX, a small town of fewer than 200 residents. Elected to the city council in 2022 and becoming mayor in 2023, Steve has helped bring financial stability, transparency, and improved infrastructure to the town, all as an unpaid volunteer.

His impact is undeniable. Under his leadership, the city corrected years of accounting errors, renegotiated contracts, stabilized emergency services, and significantly increased its road maintenance budget. It's no surprise he has run unopposed in every election.

Words for the newly diagnosed

When asked what message he most wants newly diagnosed patients to hear, Steve doesn't hesitate. "You, or someone in your family, has to be an

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advocate," he says. "You have to be educated about the disease. Every one of us is unique in how WM shows up and progresses."

He credits IWMF with making that education possible. "We have access to resources and experts that most diseases simply don't," he says. "That's remarkable, and it's something people shouldn't take for granted."

When he's not volunteering, leading, or governing, Steve enjoys fishing, working outdoors, and spending time on the lake. He's also hoping to return to an old hobby: brewing beer. "Now that things are more settled," he says with a laugh, "I'm hoping to get back to that."

After more than 20 years with Waldenstrom's, Steve Pine embodies what long-term survivorship can look like: informed, engaged, realistic, and hopeful. Through advocacy, education, and service, he continues to pass the torch to others, lighting the way forward for the WM community.

Steve Pine and support group members at lunch

WM-Net Clinical Trial Network Is Recruiting Patients for Novel Phase 2 Trial – The WM-Net clinical trial network has begun to recruit treatment naïve patients with WM/lymphoplasmacytic lymphoma (LPL) for a Phase 2, time-limited clinical trial of pirtobrutinib (Jaypirca), venetoclax, and rituximab. This designated PROVEN trial represents the first for WM to use a non-chemotherapy, fixed duration, triple combination therapy. Enrollment of 40 participants is expected. Patients receive pirtobrutinib and venetoclax orally once daily on days 1-28 of each cycle (with venetoclax starting in cycle 2), along with intravenous rituximab on day 1 of cycles 4-9. Cycles repeat every 28 days for up to 24 cycles, unless there is disease progression or unacceptable toxicity. The primary objective is to evaluate the very good partial response (VGPR) or better rate. The trial identifier is NCT07231952 on *www.clinicaltrials.gov*.

...PROVEN trial represents the first for WM to use a non-chemotherapy, fixed duration, triple combination therapy.

Results Announced for CD19 CAR-NK Therapy in Relapsed or Refractory WM – ImmunityBio announced updated durable response results for the relapsed or refractory WM patients included in its QUILT-106 clinical trial of off-the-shelf allogeneic CD19 chimeric antigen receptor therapy. This therapy uses natural killer (NK) cells instead of T cells, and the NK cells come from a healthy donor rather than from the patient. It was administered with rituximab for a total of eight doses—two doses per every 21-day cycle for four cycles. Four WM patients were enrolled in this trial for indolent lymphomas; two of them were evaluable for long-term follow-up and continued to demonstrate complete remission at seven and at 15 months. Enrollment is continuing in the trial, and its identifier number on *www.clinicaltrials.gov* is NCT06334991. Based on these results, ImmunityBio recently announced that it expects to launch a Phase 2 clinical trial of this CD19 CAR-NK therapy and rituximab combined with an immune system booster called Anktiva for patients with relapsed or refractory indolent B cell non-Hodgkin's lymphoma, including WM, who have had at least two previous lines of treatment.

Researchers Discuss Late Toxicity and Long-Term Effectiveness of Bendamustine and Rituximab Therapy for WM – A letter to the journal *Leukemia* from the French Innovative Leukemia Organization (FILO) discussed late toxicity and long-term effectiveness of first-line bendamustine and rituximab combination therapy in WM patients. This research group presented updated data after 97 months from a study of 69 WM patients treated with first-line bendamustine and rituximab. For the group as a whole, the median progression-free survival was 82.2 months, and the median overall survival was not reached. For the six *MYD88* wild-type (unmutated) patients in the study, the median progression-free survival was 25.3 months vs. 83.6 months for the *MYD88* mutated patients, while median overall survival for the *MYD88* wild-type patients was 27.4 months vs. not reached for the *MYD88* mutated patients. Median progression-fee survival for patients with unmutated *CXCR4* was 81.5 months vs. 83.6 months for those with mutated *CXCR4*, while median overall survival was not reached regardless of *CXCR4* status. Second primary cancers were observed in 12 patients—nine developed solid tumors and three developed myelodysplastic syndromes, which progressed to acute myeloid leukemia in two patients. The cumulative incidence of second primary cancers was 2.9%, 5.8%, 10.5%, and 17.6% at 12, 24, 48, and 96 months, respectively. A total of 29 patients died, eight from progressing WM, two from therapy-related acute myeloid leukemia, nine from second

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primary solid tumors, two from unknown causes, and eight from other non-WM-related causes, including hemorrhage, thrombosis, infection, pulmonary fibrosis, chronic obstructive pulmonary disease, and cardiac failure.

Disease Progression Within 24 Months Is Prognosis Factor in Frontline BR Therapy for WM – In an article appearing in the journal *Blood Advances*, a group of international researchers noted that progression of disease with 24 months, referred to as POD24, is an established negative prognosis factor in several types of indolent lymphomas; however, the data have been lacking in WM. This study followed 253 WM patients receiving frontline fixed-duration therapy with bendamustine and rituximab (BR) to evaluate POD24 as a prognosis factor. In this study, BR was effective regardless of *MYD88* status; among 89 patients with known *CXCR4* mutation status, those with *CXCR4* mutations had shorter progression-free and overall survival that those without such mutations. POD24 occurred in 11.5% of patients, who demonstrated inferior overall five-year survival (71%), compared to the non-POD24 group (86%). The researchers concluded that POD24 after BR therapy can serve as an early marker to identify patients with inferior prognosis.

Prognostic Impacts Reported for *CXCR4* and *TP53* Alterations in WM Patients Treated with Zanubrutinib – Zanubrutinib (Brukinsa) has recently replaced ibrutinib (Imbruvica) as the preferred BTK inhibitor for WM treatment, largely based on results from the Phase 3 ASPEN clinical trial comparing the two therapies. In a letter to the journal *Leukemia*, researchers from Dana-Farber Cancer Institute (DFCI), Massachusetts General Hospital, and Harvard Medical School reported the prognostic impacts of *CXCR4* and *TP53* alterations in WM patients who were treated with zanubrutinib outside of clinical trials. They performed genetic testing on 236 consecutive patients treated with zanubrutinib at DFCI, excluding patients who transitioned from ibrutinib because of side effects. In these patients, 98% had *MYD88* mutations, 35% had *CXCR4* mutations, and 12% had *TP53* alterations. For those with *CXCR4* mutations, 26% achieved a very good partial response (VGPR), compared to 40% without *CXCR4* mutations, and they took longer to achieve VGPR; however, 24-month progression-free survival was similar between the two groups. Notably, patients with *CXCR4* frameshift mutations experienced a significantly longer time to VGPR than those with *CXCR4* nonsense mutations—this was the opposite of what has been observed in ibrutinib-treated patients. Researchers could not conclude whether this represented a true difference between the two treatments or whether the high sensitivity of their PCR test method for nonsense mutations may have skewed this observation. For all patients with *TP53* alterations, 26% achieved VGPR, compared to 38% without *TP53* alterations, but this was not statistically significant; there was no difference in the time to achieve VGPR between the two groups. The overall 24-month progression-free survival was 62% in *TP53*-altered patients and 89% in *TP53*-unaltered patients, but it was noted that *TP53*-altered patients who received zanubrutinib as first-line therapy showed better outcomes than patients who received it as relapsed or refractory therapy.

Zanubrutinib (Brukinsa) has recently replaced ibrutinib (Imbruvica) as the preferred BTK inhibitor for WM treatment.

Time-to-Next Treatment Within 24 Months of First Treatment May Be Survival Predictor in WM/LPL – A Danish study, published in the *European Journal of Haematology*, suggested that time-to-next-treatment within 24 months (TTNT24) after first-line treatment is a predictor of survival in WM/lymphoplasmacytic lymphoma (LPL). In this retrospective study, 526 Danish patients diagnosed with WM/LPL between 2000-2023 in southern Denmark were identified by using national registries and health records. TTNT24 was defined

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as the beginning of second-line treatment within 24 months of first-line therapy. Out of 218 symptomatic patients requiring first-line treatment, 33 (15%) received second-line treatment with 24 months and were designated TTNT24-positive; 185 (85%) were treated later than 24 months or not yet treated beyond first-line therapy and were designated TTNT24-negative. Baseline clinical and prognostic characteristics were similar between the two groups, as was the time from diagnosis to the beginning of first-line treatment. Median overall survival was shorter in the TTNT24-positive group at 80 months vs. 122 months for the TTNT24-negative group. The researchers noted, however, that many of these study patients were treated before more recent therapy advances, and a substantial portion did not receive therapies considered standard today. Moreover, treatment selection may have been influenced by patient age, co-existing health conditions, and physician preferences, all of which warrant a cautious interpretation of these findings.

...no significant differences in overall survival were observed between the [high and low disease burden] subgroups.

Extent of Bone Marrow Infiltration Predicts Disease Progression in Asymptomatic WM – Italian researchers looked at the extent of bone marrow infiltration in asymptomatic WM patients to see how it predicts progression to symptomatic disease. Using the amount of bone marrow infiltration with WM cells at 25% as a dividing line, the researchers separated a group of 150 asymptomatic WM patients into high- and low-disease burden subgroups. The high-disease burden subgroup (equal to or greater than 25% infiltration) exhibited certain distinct features, including lower hemoglobin levels, higher serum IgM concentrations, increased monoclonal IgM, and a lower prevalence of peripheral neuropathy than the low-disease burden subgroup (less than 25% infiltration); the high-disease burden group also demonstrated a significantly shorter median time-to-progression of 64 months from asymptomatic to symptomatic WM, compared to 137 months for the low-disease burden subgroup. However, no significant differences in overall survival were observed between the two subgroups. This study appeared in the journal *Discover Oncology*.

Measuring Mutation Levels in Peripheral Blood Rather Than Serum IgM May Improve Clinical Trial Assessments in WM – Serum IgM measurements are the gold standard for assessing treatment response in WM. However, several therapies used to treat WM can raise or lower serum IgM levels without significantly impacting the underlying disease in the bone marrow, making it difficult to assess clinical trial responses. A letter to the journal *Blood Advances* from researchers at Dana-Farber Cancer Institute and Massachusetts General Hospital suggested that quantitative measurement of *MYD88 L265P* and *CXCR4 S3338X* mutations by allele-specific PCR testing in peripheral blood may be a better measurement than serum IgM of clinical trial performance in WM patients. Using samples from five clinical trial therapies of WM patients that included 1) ibrutinib, 2) venetoclax, 3) ibrutinib + venetoclax, 4) ibrutinib + the anti-*CXCR4* monoclonal antibody ulocuplumab, or 5) ixazomib + dexamethasone + rituximab, they compared changes in IgM levels, bone marrow involvement, and *MYD88* and *CXCR4* mutation levels in peripheral blood. All treatments lowered IgM levels, but some treatments (such as the venetoclax and ixazomib regimens) reduced the number of WM cells in the bone marrow more than others (such as the ibrutinib regimen). Mutation levels in the peripheral blood generally tracked better with what was seen in the bone marrow than serum IgM levels, suggesting that blood tests of mutation levels may

..PCR testing in peripheral blood may be a better measurement than serum IgM...

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reduce the need for repeated bone marrow biopsies in clinical trial participants.

Chinese Researchers Examine Cause of Death in WM Patients – Chinese researchers used the US Surveillance, Epidemiology, and End Results (SEER) database to explore cause of death in WM patients. Data from 8,894 patients diagnosed with WM from 1980 to 2016 were used to compare their relative risk of death with that of the general US population. The five-year cumulative incidence of death from WM itself was 8.6%, from second cancers was 10.02%, and from non-cancer causes was 16.14%. Their highest risk of death from WM occurred in the first year after diagnosis and declined thereafter. Among deaths from second cancers, other blood cancer malignancies were notably increased, whereas solid cancer deaths were elevated only ten years after WM diagnosis. The authors noted that the current risk of non-cancer-related deaths (mainly cardiovascular disease) exceeded that of cancer-related deaths among WM patients. This study appeared in the journal *Clinical Lymphoma Myeloma and Leukemia*.

...the current risk of non-cancer-related deaths (mainly cardiovascular disease) exceeded that of cancer-related deaths among WM patients.

Researchers Study Disease Characteristics of Non-IgM LPL – Lymphoplasmacytic lymphoma (LPL) is the underlying cancer cell type in WM, with monoclonal IgM the additional requirement needed for diagnosis. However, LPL that secretes monoclonal IgA or IgG instead or does not secrete a monoclonal protein at all is rare and poorly understood. A study from Pakistani researchers, published in the *Journal of Population Therapeutics & Clinical Pharmacology*, compared 47 IgM-negative LPL patients and 42 WM patients, all diagnosed between March 2024 and July 2025, to determine important characteristics between the two groups. The IgM-negative LPL group exhibited significantly more aggressive disease characteristics, including high rates of splenomegaly (enlarged spleen), lower platelet counts, and higher serum creatinine (a concerning marker of kidney health). The *MYD88 L265P* mutation was less prevalent (63.8%) in IgM-negative LPL, compared to WM (95.6%). Within the IgM-negative group, *MYD88* wild-type (unmutated) status was associated with lower blood counts and kidney impairment. With a median follow-up of 14 months, overall survival at 85% was less for IgM-negative LPL patients, compared to 98% for WM patients.

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

Telehealth in the US

Telehealth has strong bipartisan support in the US Congress, and its reimbursement by Medicare has been extended through December 2027. Telehealth, whereby patients can consult with their doctors online, was highly successful during the COVID pandemic. It brought medical access to many patients living in rural areas, at a distance from specialists, or with mobility or transportation issues. While healthcare providers participating in telehealth generally need to be licensed to practice in the state where patients are located, some states have reciprocal licensing agreements. There is a broad consensus to provide permanent telehealth access for Medicare recipients.

FROM THE FACEBOOK WM SUPPORT GROUP: SPRING 2026

By Betty Ann Morton, Editor

It's not unusual for new members of the Facebook WM Support Group to feel a sense of relief. They have finally found people who understand their feelings and situations, people who can also answer questions about WM and give guidance.

LKO recently posted, "I'm feeling so grateful that I found this group. I am 64 and live in Minnesota. I was diagnosed in December, so I'm new to all of this. I've been on Brukinsa (zanubrutinib) for one month and am starting to feel my brain fog lifting. I suffer from severe neuropathy and am hoping this will help with that as well. The group has me feeling really empowered, and I'm getting so much good information. I'm thinking of going to the Mayo Clinic in Rochester for treatment. It's only an hour away. I realize now that I need a doctor who is familiar with this cancer. Thank you all!"

JJ turned to the group for support in a difficult situation. "Hello all. We are based in the UK in North Wales. My husband is the WM sufferer, diagnosed in May 2025. He has been on watch-and-wait with three monthly blood tests and appointments since then. Back in September, during a routine eye test, a bleed was seen in my husband's eye; he had a retinal examination with the results sent on to our GP. We requested that the GP send these results to my husband's haematology consultant, and we also asked the consultant to request them from the GP. The consultant didn't seem worried about the bleed. When my husband mentioned at his appointment in early December 2025 that his eye felt more blurry, she told him to go back to the opticians to get it checked out if he was worried, but that it was unlikely to be connected to LPL/WM. On Monday, my husband had another retinal exam at his request, and they have referred him urgently to the eye hospital as the haemorrhaging is worse, and his eye is also swollen at the back, putting him at risk of a detached retina and loss of vision. They told my husband that he should have been referred by our GP or consultant back in September when the bleed was first seen! I called our CNS (Clinical Nurse Specialist) yesterday afternoon to let her know, and she called me back to say that the doctor didn't think it was anything to do with LPL/WM as his numbers are OK, and that it is something completely separate.

"I have done some research and believe that it is very definitely connected and that sometimes symptoms are more important than numbers with this disease. This has caused us to lose confidence in the doctor. We are seriously considering requesting a second opinion with a consultant who specializes in WM. There aren't any in Wales, and we don't have the right to refer outside of Wales, so it is likely to be an IPFR (individual patient funding request), which will have to go to the Health Board for approval. I would be grateful for any thoughts or similar experiences."

Another group member, **JL**, wrote, "The first thing my WM oncologist recommended was to see an ophthalmologist on a regular basis, since the blood vessels in the back of the eye are very thin and could indicate progression of symptoms of WM. Of course, it could be something else! I have age-related wet macular degeneration. It has nothing to do with my WM, but it was caught early by going to the ophthalmologist routinely! Good luck and prayers for his recovery."

GF related his experiences with eye issues. "I had blood vessels breaking in my eyes about every six months. I had my WM treatment over three years ago (B&R or bendamustine and Rituxan) and have not had an eye problem in those three years. So I am pretty sure WM will and does cause eye problems, with high viscosity being the cause."

CP steered the original poster **JJ** to local support. "I'm not sure if you're aware, but WMUK has a Welsh support group, details of which can be found here: *https://www.wmuk.org.uk/giving.../national-support-groups/*. There is also a UK-based Facebook group called WMUK Community Support Group." **JJ** responded, "I had absolutely no idea, thank you so much."

From the Facebook WM Support Group, cont. on page 13

In addition, one of our group experts, **MCM**, responded, "Your husband is in a difficult situation. Because you're in Wales I asked ChatGPT for advice:

'What I would strongly recommend you do next (practically, in Wales), eye care comes first — urgently. The optician referral to the eye hospital is absolutely appropriate. Ask ophthalmology directly: Are the retinal findings consistent with hyperviscosity or IgM-mediated disease? Do they recommend urgent liaison with haematology? Ophthalmologists recognise WM-related retinal disease, often better than general haematologists.'"

Several days later **JJ** posted again, "Update to my post on Wednesday. My husband had an urgent appointment at the eye clinic yesterday, who, following tests, referred him straight to the clinical team in A&E (Emergency Medicine), where we have been ever since—over 20 hours now. Why they didn't let him go home and come back this morning is beyond me! I brought in the notes that **MCM** very kindly took the time to put together for me. The ophthalmologist, who knew nothing about WM, listened and was fantastic, and she ordered a serum viscosity test. The clinical team also admitted that they knew nothing about WM and considered a brain tumour or clot first. A brain scan last night was clear, and this morning they are finally considering that the retinal bleed and swelling may be caused by hyperviscosity, which I have been suggesting all along. We are now waiting for him to have more blood tests and to see his haematologist, who at both of his appointments in September and December had been adamant that WM had nothing to do with the eye issues. I'm so cross; had this been referred as it should have been back in September by our GP or haematologist, this whole experience may well have been avoided. He is now waiting for a bed on the cancer ward, and we are told the haematologist will decide on treatment now, which worries me enormously for obvious reasons! Should we insist on a second option from a WM specialist at this stage?"

MCM replied, "Hi **JJ**, thanks for the update. Your advocating worked! Patients with serious hyperviscosity symptoms are usually treated initially with plasmapheresis to get the IgM down quickly. After that, they usually receive chemo-immunotherapy or a BTK inhibitor. Good luck to him."

Those who have had one cancer are at increased risk for another cancer diagnosis. In such situations, the Facebook WM Support Group listens to the feelings and encourages the person. **AFH** wrote to a fellow patient who received an additional cancer diagnosis recently, "I want so much to have the magic words. To change everything back to life before cancer. I don't have those words. But I do understand. WM is my fourth cancer. Does it help to say you're not alone? Does it help to say that expressing your feelings is much healthier than bottling them up? We are the perfect place to vent because we understand a lot."

SAP added, "Scream, yell, vent all you want. We are here for you. I know you have the inner strength (though I am sure at times it's hard to muster up) to face what you have to face, but it is so hard to fathom at the same time. Truly, I'm sorry to hear what is in front of you."

MC responded, "Your post tells me you know that talking about this journey helps lighten the load. Sending you strength and some moments during each 24 hours when you don't think about it at all. I try to stop the worry about the next test until I am getting in the car. It's hard. We are here for you."

Sometimes WM patients ask for explanations and suggestions regarding symptoms. **TP** recently posted, "What's wrong with me? My IgM on the blood test this week was 187 mg/dL. That's just about perfect! I started Brukinsa 16 months ago; IgM was about 1,300. Actually, my neurologist prescribed Brukinsa to lower anti-MAG from 40,000 to 19,000.

"These are remarkable results. But why do I still feel bad? Fatigue is still huge, despite routine workouts. Yes, hemoglobin, RDW (red cell distribution width), and associated tests are still out of bounds. My body aches, and neuropathy is still a pain. In short, I don't feel much different than when first diagnosed. Is there a lag time between numbers and body function? Doc says to remember you're 76 and the body doesn't heal as fast as it used to."

From the Facebook WM Support Group, cont. on page 14

HW had a suggestion. "Have you had your thyroid hormone levels checked? It is not unusual for people with WM to have hypothyroidism. This would explain the continued fatigue."

GR added more ideas. "Sorry to hear that you aren't feeling great. Hemoglobin should be good after 16 months on zanubrutinib. Are your ferritin and iron levels adequate? Are you getting sufficient protein and carbs? I eat high protein (at 120 lbs, I try to get at least 80 g), low fat, zero sugar (or alcohol), and lots of fresh fruit and vegetables. Do you have anything viral or bacterial going on long-term? For me, I started to feel better within 24 hours, and as for age, I'm 71, so I wouldn't attribute feeling lousy to age if you are the active type."

If you would like to become more connected with the WM community and join the Facebook WM Support Group, go to *https://facebook.com/groups/wmsupportgroup*. In order to join, people must answer two membership questions. Since the group is private, only group members are able to see the posts. If you need additional help with the process, please contact the IWMF office at 941-927-4963 or email to *office@iwmf.com*.

DID YOU KNOW?

YOU CAN CREATE A FACEBOOK FUNDRAISER FOR IWMF

Celebrate your birthday, anniversary, or other special event while accelerating the search for a WM cure! IWMF has put together a step-by-step guide for setting up a Facebook fundraiser to share with your family, friends, and co-workers. All the donations go to IWMF. You can see the guide on our website at *https://iwmf.com/facebook-fundraiser/*. Or for more information, contact IWMF office at 941-927-4963.

SUMMARIES OF SELECTED ABSTRACTS FROM THE 67TH ASH ANNUAL MEETING

By Sue Herms, IWMF Research Committee Member

The 67th American Society of Hematology (ASH) Annual Meeting in Orlando, FL, was attended by more than 30,000 hematology professionals from around the world, as well as by representatives from businesses in the biomedical field and from patient advocacy groups, including IWMF. This premier event was held on December 6-9, 2025, and presented new research and medical practice innovations aimed at improving care for people with blood and bone marrow diseases. Some 8,200 research abstracts—a record number—were included, along with hundreds of exhibits. The following are summaries of selected abstracts about treatment outcomes for WM patients and are part of the total number of WM abstracts presented during the meeting. The author can be contacted at suenchas@bellsouth.net *for questions or additional information.*

Pirtobrutinib in relapsed/refractory (r/r) Waldenstrom macroglobulinemia (WM): up to five years of follow-up from the Phase 1/2 BRUIN study – A multicenter international abstract reported final results with up to five years of follow-up for the group of 80 relapsed or refractory WM patients who received the non-covalent BTK inhibitor pirtobrutinib as part of the BRUIN clinical trial. Non-covalent pirtobrutinib binds in a different way to the BTK molecule than covalent BTK inhibitors like ibrutinib, acalabrutinib, and zanubrutinib. Among all WM patients, the response rate to pirtobrutinib was 83%, including a complete response (CR) rate of 1% and a very good partial response (VGPR) rate of 26%. The median progression-free survival was 36 months, and the median overall survival rate at 36 months was 67%. In the group of patients who had previously received covalent BTK inhibitor therapy, the overall response rate was 81%, including a CR rate of 2% and a VGPR rate of 24%; the median progression-free survival was 20 months, and the median overall survival rate at 36 months was 64%. Among all patients, the most frequent treatment-related side effects were COVID-19 infection, diarrhea, anemia, headache, fatigue, and low neutrophil counts. Side effects led to 5% of patients stopping treatment and 2.5% receiving dose reductions.

High VGPR/CR rates with pirtobrutinib plus venetoclax in previously treated Waldenstrom macroglobulinemia: results from a multicenter Phase 2 study – This ongoing clinical trial conducted by the Bing Center at Dana-Farber Cancer Institute and Massachusetts General Hospital evaluated the combination of the non-covalent BTK inhibitor pirtobrutinib with the BCL-2 antagonist venetoclax as a fixed-duration treatment of 24 months for previously treated WM patients. Therapy consists of pirtobrutinib at 200 mg/day during all 28-day cycles, with venetoclax added during cycle 2 at 100 mg/day for one week and incrementally increased to 400 mg/day for the remaining cycles. Between May 2023 and July 2025, 38 patients were enrolled; of the 29 who had completed at least six months on the study and were eligible for response evaluation, 27 were *MYD88* mutated, 12 were *CXCR4* mutated, and five were *TP53* mutated. The overall response rate was 100%, with a combined very good partial response plus complete response (VGPR/CR) rate of 56%. *CXCR4* mutations, *TP53* mutations, and previous covalent BTK inhibitor treatment (such as ibrutinib, acalabrutinib, or zanubrutinib) were associated with longer times to response and lower VGPR/CR rates. Among all patients, the 12-month progression-free survival rate was 94%, and the 12-month overall survival rate was 100%. The two *MYD88* wild-type (unmutated) patients attained a minor response and partial response, with one progressing at two months, and the other at five months. Subsequently, the trial protocol was changed to include only *MYD88* mutated patients. The most common Grade 3 or greater (severe) side effects were low neutrophil counts, anemia, low platelet counts, respiratory infections, diarrhea, headache, increase in the liver enzyme AST, muscle aches, and fatigue. No heart arrhythmias or tumor lysis events occurred. This still-recruiting study is posted on *www.clinicaltrials.com* as NCT05734495.

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Deep responses following treatment with loncastuximab tesirine (WM-Net1 trial) in patients with relapsed/refractory WM including those with high-risk, *TP53*-altered Waldenstrom macroglobulinemia – Alterations in the *TP53* gene are reported to occur in up to 25% of WM patients, especially those previously treated with chemotherapy agents; such alterations are associated with a shorter time to disease progression and worse overall survival. This multicenter US clinical trial of loncastuximab tesirine is analyzing its effectiveness and safety in previously treated patients, including those with altered *TP53* status. Loncastuximab tesirine is a humanized monoclonal antibody targeted to the CD19 receptor on B cells combined with an agent that is highly toxic to these targeted cells. Loncastuximab tesirine is administered intravenously for up to six monthly cycles. Of the 14 patients enrolled so far who completed therapy, 12 were *MYD88* mutated, eight were *CXCR4* mutated, and eight were *TP53* altered. No IgM flare or infusion reactions occurred. The overall response rate was 93%, with a combined very good partial response and complete response (VGPR/CR) rate of 71%. For those with *TP53* alterations, the overall response rate was 100%, and the VGPR/CR rate was 89%. The trial identifier on *www.clinicaltrials.gov* is NCT05190705.

Updated efficacy and safety results of the Bruton tyrosine kinase degrader BGB-16673 in patients with relapsed/refractory Waldenstrom macroglobulinemia from the ongoing Phase 1 CaDAnCe 101 study – BGB-16673 is an oral drug that blocks BTK signaling by tagging the BTK protein for degradation or breakdown by the cell's proteasome pathway. At the time of abstract submission, 42 WM patients were enrolled and treated in this multicenter international trial, and median follow-up was 8.8 months. Eligible participants must have already received treatment with an anti-CD20 antibody such as rituximab or obinutuzumab; in the US, Japan, and the European Union, participants must have also been treated with a covalent BTK inhibitor such as ibrutinib, acalabrutinib, or zanubrutinib. Overall, 97.6% of patients experienced side effects of any severity, the most common being low neutrophil counts, diarrhea, bruising, and low platelet counts. No atrial fibrillation was observed. Side effects led to two deaths, treatment stoppage in three patients, and dose reductions in two patients. The overall response rate was 83.3%, and the very good partial response rate was 26.2%. Responses were seen in patients previously treated with BTK inhibitors and were independent of mutations in the genes *BTK*, *MYD88*, *CXCR4*, *TP53*, and *PLCG2*. The nine-month duration of response rate was 84.1%. Enrollment is ongoing in the Phase 2 portion of this trial, identified on *www.clinicaltrials.gov* as NCT05006716.

Bexobrutideg (NX-5948), a novel Bruton's tyrosine kinase (BTK) degrader, shows high clinical activity and tolerable safety in patients with Waldenstrom macroglobulinemia: updated results from an ongoing Phase 1a/b study – Bexobrutideg is another oral drug that degrades or breaks down the BTK protein through the cell's proteasome pathway. At the time of abstract submission, a multicenter international trial had enrolled 27 relapsed or refractory WM patients. They were treated with a median of three previous lines of therapy, including BTK inhibitors; two had Bing-Neel syndrome, which is central nervous system involvement from WM. In the 20 patients evaluable for a response at a median follow-up of 7.3 months, the overall response rate was 85%, including a very good partial response rate of 15%. Both Bing-Neel participants achieved disease stabilization. The most common treatment-related side effects were diarrhea, petechiae (small spots of bleeding under the skin), bruising, low neutrophil counts, and upper respiratory tract infections. The study is still recruiting participants and is identified on *www.clinicaltrials.gov* as NCT05131022.

SGR-1505, a potent and selective MALT1 inhibitor with preliminary efficacy in BTKi-exposed Waldenstrom macroglobulinemia (WM) and "double-exposed" CLL/SLL – MALT1 plays an essential role in the NF-kappa B pathway downstream of BTK and promotes growth and survival of B cell cancers. SGR-1505 is a MALT1 inhibitor being evaluated in a Phase 1 dose escalation clinical trial of 49 patients with B cell cancers, including six WM patients who were relapsed or refractory to BTK

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inhibitor treatment. The drug is given orally and administered for up to two years in the trial. This summary focuses on data reported for the WM patients, who had a median number of two previous lines of therapy, including a BTK inhibitor as their last previous therapy to which they developed treatment resistance. This early preliminary report noted that all six WM patients experienced rapid IgM decreases, with three achieving minor and three achieving partial responses. On *www.clinicaltrials.gov*, the trial identifier is NCT05544019.

Docirbrutinib (AS-1763), a novel non-covalent pan-mutant BTK inhibitor, demonstrates durable clinical responses in patients with previously treated B-cell malignancies: data from an ongoing Phase 1b study – The long-term effectiveness of BTK inhibitors is limited because of off-target side effects and acquired mutations that cause cancer cells to become resistant to them. Docirbrutinib is a non-covalent BTK inhibitor that demonstrated strong anti-tumor activity in B cell lymphoma cell lines with BTK resistance mutations and is being studied in a Phase 1b dose escalation clinical trial of patients with various B cell cancers. As of the abstract cut-off date, 31 patients, including three with WM, were enrolled; all patients had received two or more prior therapies, including both covalent and non-covalent BTK inhibitors. Docirbrutinib was orally administered twice daily, and median treatment duration was six months at the time of this report. No drug-related atrial fibrillation or hypertension was observed; drug-related side effects included decreased neutrophil counts, increased ALT/AST enzyme levels, anemia, and bleeding. Of the two WM patients who were eligible for response assessment, one achieved a partial response and one a minor response; all WM patients were still on treatment at the time of abstract deadline. This trial's identifier on *www.clinicaltrials.gov* is NCT05602363.

The long-term effectiveness of BTK inhibitors is limited because of off-target side effects and acquired mutations...

Efficacy and tolerability of bendamustine, rituximab and acalabrutinib in elderly treatment naïve Waldenstrom's macroglobulinemia – This analysis, performed as part of the Canadian BRAWN clinical trial of the three-drug combination of bendamustine, rituximab, and acalabrutinib, evaluated the combination's effectiveness, tolerability, and dose intensity in two age groups: those less than 70 years old and those 70 years and older. The BTK inhibitor acalabrutinib was taken at 100 mg/twice daily for twelve 28-day cycles, with bendamustine and rituximab also administered during the first six cycles. Of the 63 trial participants, 31 were in the 70 years and older group, with those up to age 85 treated. By cycle 7, the combined complete response and very good partial response (CR/VGPR) rates were very similar between the two age groups, at 59.4% in those less than 70 years old and 58.1% in those 70 years and older. With respect to dose intensity, both age groups were able to tolerate similar doses of bendamustine and acalabrutinib, but the older patients received a slightly lower mean number of bendamustine cycles. Although more of the older patients discontinued bendamustine because of side effects, this did not appear to compromise the overall effectiveness of the regimen. The side effect profile in the two age groups was very similar. The authors concluded that age does not appear to be a limitation for using this treatment.

Final report of a Phase 2 study of ibrutinib and venetoclax in previously untreated Waldenstrom macroglobulinemia – This trial, conducted by Dana-Farber Cancer Institute, evaluated the first chemotherapy-free, fixed-duration oral regimen in WM. The intended therapy consisted of 24 four-week cycles of ibrutinib at 420 mg/day, with venetoclax added in stepwise fashion in cycle 2 up to 400 mg/day and continuing for the duration of treatment. After enrolling 45 patients, therapy was stopped early on March 31, 2022, because of four ventricular arrhythmia events, including two that resulted in death. However, enrolled patients continued to

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be followed for a median time of 49 months from treatment start. Their median time on treatment was ten months; at best response, 42% achieved a very good partial response, 24% a partial response, and 4% a minor response. During follow-up, 60% experienced disease progression, 24% started a new treatment, and four patients died. The median progression-free survival was 36 months, with median overall survival not reached. Low platelet counts and high serum lactate dehydrogenase (LDH) levels were associated with inferior progression-free survival. *CXCR4* mutations did not impact survival outcomes. Of the patients who began a new treatment, all responded to a variety of subsequent therapies, including solo zanubrutinib, solo venetoclax, bendamustine and rituximab, R-CHOP, and clinical trial treatments.

Dexamethasone, rituximab and cyclophosphamide with bortezomib is a rapidly acting and highly efficient first-line treatment in Waldenstrom's macroglobulinemia: final analysis of ECWM-1 trial of the European Consortium for Waldenstrom's Macroglobulinemia (ECWM) – The chemoimmunotherapy combination of dexamethasone, rituximab and cyclophosphamide (DRC) therapy is still used as first-line treatment for WM patients. The ECWM performed a first-line clinical trial aimed at improving the outcomes of DRC by adding bortezomib and comparing it to DRC alone. This final analysis from the trial reported treatment outcomes and long-term safety after a median follow-up of 68.8 months. The DRC arm included 100 patients, while the bortezomib-added arm, designated B-DRC, included 102 patients. The combined complete and very good partial response rate was 35.4% for B-DRC, compared to 22.2% for DRC. The median progression-free survival was 56.7 months for B-DRC and 50.1 months for DRC and was not influenced by either *MYD88* or *CXCR4* mutation status. The five-year overall survival rate was similar at 89% for B-DRC and 91% for DRC. Grade 3 or greater (severe) side effects were recorded in 52% of B-DRC and 49% of DRC patients and mainly affected blood counts. Drug-related peripheral neuropathy occurred in 50% of B-DRC and 20% of DRC patients.

Anti-CD19 chimeric antigen receptor T cell therapy for transformed Waldenstrom macroglobulinemia/lymphoplasmacytic lymphoma: a DESCAR-T Registry and international collaborative study – The prognosis of WM patients who have transformed to a more aggressive lymphoma (such as diffuse large B cell lymphoma) remains poor with standard chemoimmunotherapy.

The prognosis of WM patients who have transformed to a more aggressive lymphoma…remains poor with standard chemoimmunotherapy.

This retrospective study evaluated a group of 50 transformed patients who had been treated with CAR T cell therapy in the French DESCAR-T registry and at four centers each from the European Consortium for Waldenstrom's Macroglobulinemia and the US. Their median age at WM diagnosis was 60 years and at CAR T therapy was 68 years. For those with available data, the *MYD88 L265P* mutation was present in 79%, and *CXCR4* mutations were present in 15%. The best overall response rate to CAR T therapy was 94%, with 88% reaching a complete response. With a median follow-up of 25.7 months from CAR T infusion, the median progression-free survival was 1.2 years, and median overall survival was 4.2 years. Typical CAR T-related side effects included cytokine release syndrome (CRS) in 76%, immune effector cell-associated neurotoxicity syndrome (ICANS) in 45%, infections in 35%, and prolonged low blood counts in 43%. Among 19 patients who died, 74% of deaths occurred because of progressive disease and 26% because of infections. Central nervous system involvement from transformed disease was present in 22% at the time of CAR T therapy; their best overall response was 91%, with median progression-free survival of 1.2 years and median overall survival not reached. Only elevated levels of the enzyme lactate dehydrogenase were correlated with worse progression-free and overall survival in all patients. Other variables, such as *MYD88* mutation status,

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number of lines of previous therapy, central nervous system involvement, lack of response to previous treatment, and type of CAR T cell therapy received, were not associated with inferior survival outcomes.

WM-VOICE: An international discrete choice experiment on treatment preferences in 1,455 patients with Waldenstrom macroglobulinemia – This study was conducted with WM patients in Australia, Canada, the Netherlands, the United Kingdom, and the US and was designed to determine international patient preferences for treatment through the use of a series of questions. Most participants were 61-80 years old and male. With a median time since diagnosis of six years, 79% had been previously treated for WM. Preferences were largely consistent across all five countries. Duration of response to treatment and temporary side effects were of highest importance at 29.7% and 25.6%, respectively, followed by concerns for the risk of second malignancy (17.7%) and persistent side effects (17.4%). The treatment administration method and treatment duration were less concerning, with oral treatment at home preferred over hospital infusions in 4.9% of surveyed patients and fixed-duration therapy preferred over ongoing therapy in 4.6%. Experience with prior BTK inhibitor treatment significantly increased patient preference for oral over intravenous therapy. Other patient characteristics, such as sex, age, treatment status, prior chemotherapy, travel time to treatment, and educational level, did not impact treatment preferences.

ROOTED IN COMMUNITY: STRONGER TOGETHER

By Ann Grace MacMullan
IWMF Director of Integrative Wellness and Patient Communications

In nature, some of the world's largest and longest-living organisms thrive not because they stand alone, but because they are deeply connected. Giant aspen colonies and vast fungal networks span great distances underground, sharing resources and communicating through intricate root-like systems.

Fungi form mycelial webs beneath the earth—threadlike tendrils often compared to neurons in the human brain. Forests also rely on these networks: beech trees exchange carbon, water, and nutrients through a "wood wide web" of mycorrhizal fungi. These ancient systems promote resilience, longevity, and health.

This astonishing connectivity, associated with longevity and resilience in the natural world, is a powerful metaphor for how the IWMF wellness community functions—and we actively draw on its symbolism to heal together.

What began as a donated chair yoga class has grown into a global IWMF Integrative Wellness program connecting WM friends across time zones and continents. We now offer yoga, fitness, meditation, and relaxation guidance, t'ai chi and qigong, art and dance therapy, and more, all tailored to the WM journey and delivered through Zoom.

After many classes, we stay and talk. In those moments, I've witnessed an extraordinary outpouring of support, compassion, and love. The connection is so profound that sometimes we wonder: "Is this even real?"

I believe it is. A 2008 study found that compassionate intention, offered as a therapeutic intervention by partners of cancer patients, can activate the patient's autonomic nervous system—showing measurable physiological responses, even across distance. Even more remarkably, nervous system signals synchronized with those of a loved one at a remote location.

We practice compassionate intention together in many of my classes, across time zones and geographic distance. You can try it now:

1. Place your hands over your heart and take a few easy breaths.
2. Imagine sending roots down into the earth, spreading wide and connecting with others in the WM community around the world.
3. As you breathe in, draw up nourishment, understanding, and belonging; as you breathe out, send compassionate support through this interconnected network until a sense of calm vitality washes over you.

Our community is anchored by this shared interconnectedness—a living network of healing across time and distance, accessible anytime and anywhere through mindful presence.

For many of us, me included, this community is more than support. It is connection and continuity, a steady reminder that none of us walk this path alone. Like an unseen root system beneath the earth, we sustain one another with compassion, strength, and hope. May our roots continue to deepen, our branches reach wider, and our beautiful WM community flourish together for many years to come.

Editor's note: For more information on the IWMF Integrative Wellness program, contact Ann at anngrace@iwmf.com*. Ann's mission is to empower WM patients to participate their own well-being, and to improve quality of life and patient outcomes. Her father was diagnosed with WM in 2019 and passed away in June of 2025.*

ARTISTIC EXPRESSIONS OF WM

By Diane Mazza

Editor's note: Comments have been edited for length and clarity. Some photos have been replaced with similar ones that are not under copyright.

In early January, *Torch* Editor Shirley Ganse contacted me and asked for more artwork for the *Torch*. I kept trying to think of what I'd like to do, but it was challenging. Then I had the idea of asking members of the Facebook WM Support Group for help. This is what I posted:

"I'm working on a project related to what represents WM in an artistic way. I am looking for suggestions on how to do some artwork that represents how we feel about WM. For example, does it look like a glass half full (representing the fact that WM never goes completely away), a hibernating bear (representing watch-and-wait), a snowball in hell (representing WM as a rare disease)? The sky is the limit. Please submit your ideas and explain why you think it relates to WM."

I was amazed at the number of creative responses! Some even added images to their post. Here is how they responded:

Rick Savoy
Brain fog

Richard Hayden
To me it's mostly just annoying, a nuisance, like having to constantly shoo away flies.

Yvonne Dutton
To me it should represent Life and Living. Positivity.

Staci Leach
Since it is a blood cancer, I see it as an ocean tide with an ebb and flow to its on and off nature.

Linda Goodman
I see it as an uninvited guest. Having a new, perplexing symptom often for no rhyme or reason. A lesson to live in the moment and treasure each day.

Carol J. Hesse
To me it is haunting. Will it get worse, will I go into remission, what other issues will arise?

Kathryn Campbell
A child looking into a dark closet.

Nancy Miller
Swarm of bees stinging my feet, neuropathy.

Sherri Pence Milbank
To me, my WM was the silver lining on a beautiful cloud, because without it and the constant monitoring, they wouldn't have caught my lung cancer at an early stage 1, which we cured five years ago with a lobectomy. My biggest fear in life was getting lung cancer or running out of air, so WM saved me from that. It also brought me closer to God.

Corrie Kossow Garrison
I started out tilting at windmills, wishing to believe in magic, illusions, and magical elixirs.

Artistic Expressions of WM, cont. on page 22

Now my rose-colored glasses are dirty and broken. Reality has settled in for the long haul. I listen to the advice of the whispers my body gives me instead of waiting for the bricks to start flinging at my head again. I eat the greens and skip the ice cream. Reality isn't much fun and tastes like dirt.

Margi Moore
If I had to give WM a name, I would name it Gulliver.

Tammy Schlabach
Rollercoaster comes to my mind...weeeee...

Maureen Wood
Blood cells surrounding a small bomb, some black (sinister) cells amongst them...perhaps some hypodermic needles pointing in at one side surrounded by sunlight and spring shoots representing hope and a new start.

Renee Bennett
A garden with some thriving plants and some struggling to survive and some uncertain as to their future

Elizabeth O'Connell
When I was first diagnosed, I called a friend who had lost his leg in Afghanistan and also had some medical issues with his blood. I called him to discuss my new diagnosis. He said to me:

The one thing I learned is that none of us are getting out of here alive. With this diagnosis, I have a little better idea of how I might go, but no one knows for sure. I choose to make the most of the time I have. (Paraphrased as I remember.)

I picture a person with a clock ticking or an hourglass, as it is always present in our minds, but looking into a crystal ball or out a window or even a fork in the road and choosing happiness and life. Maybe a beautiful sunrise. You could put some obstacles in the way. Not sure if this is clear, but his words did and still do give me comfort. Nothing is certain or promised. We live with a monkey on our back for sure, but from what I have learned from this group, we are all fighters and all doing the best we can with our diagnosis. With this diagnosis comes incredible uncertainty. Maybe someone jumping away from a timing device upwards (showing the struggle) but towards something promising and beautiful. Toward hope.

Philippe Bauer
Waldenström's disease: an enigmatic and unexpected symptom suddenly appears, a mixture of life and death.

© Philippe BAUER

Artistic Expressions of WM, cont. on page 23

Jesper Leonhardt Svensson
I think it is so hard to answer, because there are so many aspects to WM.

If I try to compress it, I will say gratitude. WM has gotten me in contact with so many fantastic people, from this group, the Danish counterpart, the healthcare persons, and so on. All in, I want to focus on the positive things, but make that into an art piece.

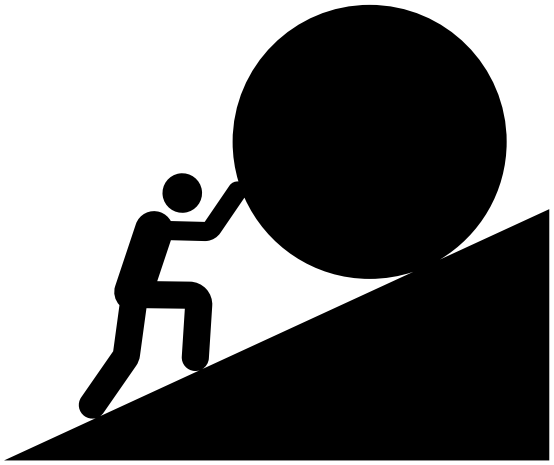
I have asked a friend of mine, who is a tattoo artist, to make something for me that represents the cancer, my family and so on, in a positive way. What we have boiled it down to is something with a guardian angel, blood veins that are turning from red to black, visible heart, and possibly one wing withered. BUT it should still show force and determination. Still undecided how it is going to be. Will know in week 8.

Barry A. VerMeulen
Magic 8 Ball.

Cindy Luce
The bogeyman under the bed. Are you imagining he's there? Most of the time he doesn't bother you, but all it takes is one big scare and he's very real…reminds me of symptoms that pop up over time, leading to treatment.

Phillip M. Filipovski
I would definitely recommend something abstract, with red representing blood, green for poison, blue for peace, and something else for conflict and despair.

Sharon Axelrod Piotrowski
I was involved in a project with some other WM patients with a marketing company that was hired by a drug company. They showed us images. This one resonated with me. But it did show the other side of the hill which represented to me the battles going up and relief going down.



Patricia Verdolino
A small person wearing a tin suit with a huge heavy backpack on, but somehow, they have not fallen down. Early stage feelings of being heavy, bones stiff, pushing forward, body not working but STILL climbing up the mountain.

Ann F. Hammond
A marathon, not a sprint. There are hurdles and pits and other obstacles in the path, but always another runner is along to help.

Patricia Quick
Sounds like a fun project. For me, I've been with WM since 2023, and I just have the memory that I have it just so often. I can go from one to three or four days of no thoughts of it whatsoever.

Elaine Clinton
There are many aspects, aren't there? I like the concept of "the elephant in the room," maybe hiding in a corner, could be behind a tree, as some friends and relatives are not comfortable to ask or even hear about it. It then also represents the worry, maybe not for all, of the possibility of more treatment, the unknown reinfections and the "what happens next?"

However, I think there needs to be a focus on positivity and the future is looking always brighter—

Artistic Expressions of WM, cont. on page 24

retreatments and ultimately a cure. So, an eagle soaring high springs to mind. Hence the suggestion of an elephant behind the tree as opposed to in a room. Maybe a rainbow arching over it all? Sorry, these are early morning random thoughts!!

Linda Trytek
Tunnel with light—all of the people who have helped along the way.

Deborah Carr Hollingsworth
Me, standing still, at peace, perhaps eyes downward or closed, like in yoga. While a tornado like whirlwind completely swirls all around me. Golden colors.

Eva Cameron
Living with a tiger on a boat adrift at sea.

Sheila Knutson
A rat peeking out of a mouse hole.

Edward Goldberg
Those are some good ones. The one I always liked is if you've seen one WM patient you've seen one WM patient. Take care.

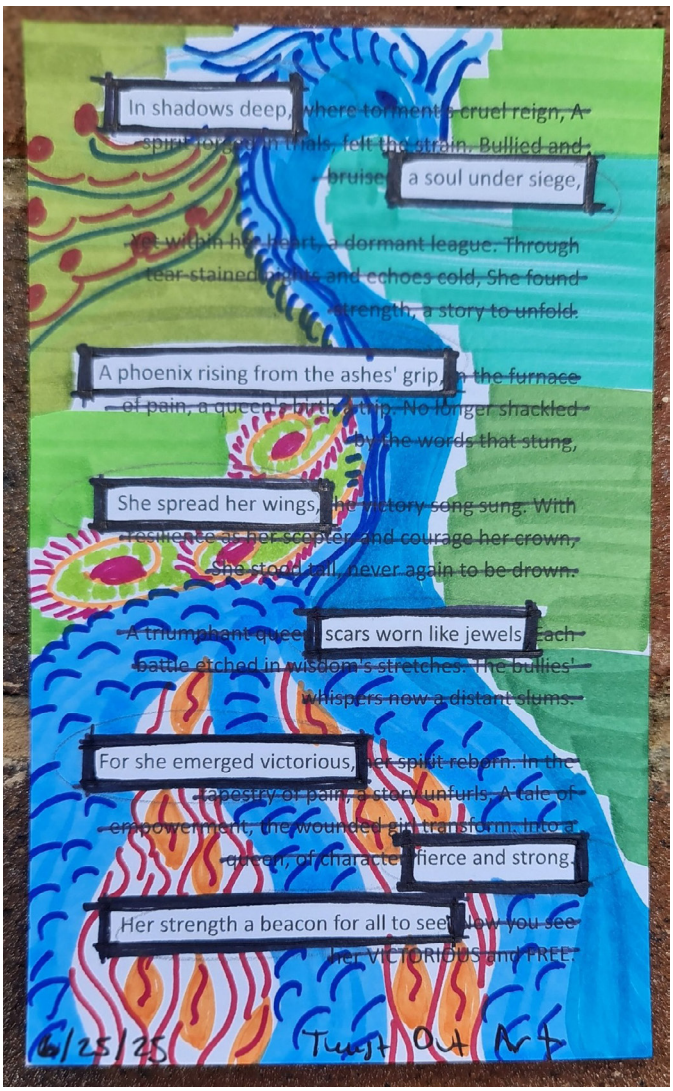
Karen Harman
It's different for everyone. That element of complex diversity needs to be there!

Lisa J. K. Stacholy
The diagnosis of WM was 2/14/24...nearly four years of doc saying "Gee, let's try some iron? Let's try some B12? Oh, meh, come back in three months for more bloodletting...Oh, gee, still anemic. HUH, that's odd...." so I'm a bit jaded.

BUT, ultimately not getting diagnosed right away was sort of ok, because I was non-official "watch-and-wait" (btw, I HATE that term...waiting for what? the bottom to fall out? the shoes to fall from the sky???).

...I re-found the joy of quiet time doing artwork, I held my family closer, got more dog hugs, and spent more time in the saddle riding into the woods to lose my mind and find myself again. I learned to breathe again.

...Art therapy is a great resource to sort things out. In a single word, WM to me is "Phoenix." The best representation I think I've made so far is a Blank Out poetry piece (well, at least it made me feel so much better). Original poem is "The Warrior Queen" by Maria Diana Torres.



By Lisa J. K. Stacholy

Artistic Expressions of WM, cont. on page 25

Andi Gold
Me peeking out a door to see what kind of day it will be. One window sunny and the other dreary. Never knowing how the energy level will be.

Allan Pryer
Perhaps a dark shadowy presence with its hand on my shoulder and me doing my best Tay Tay "shake it off" impression!

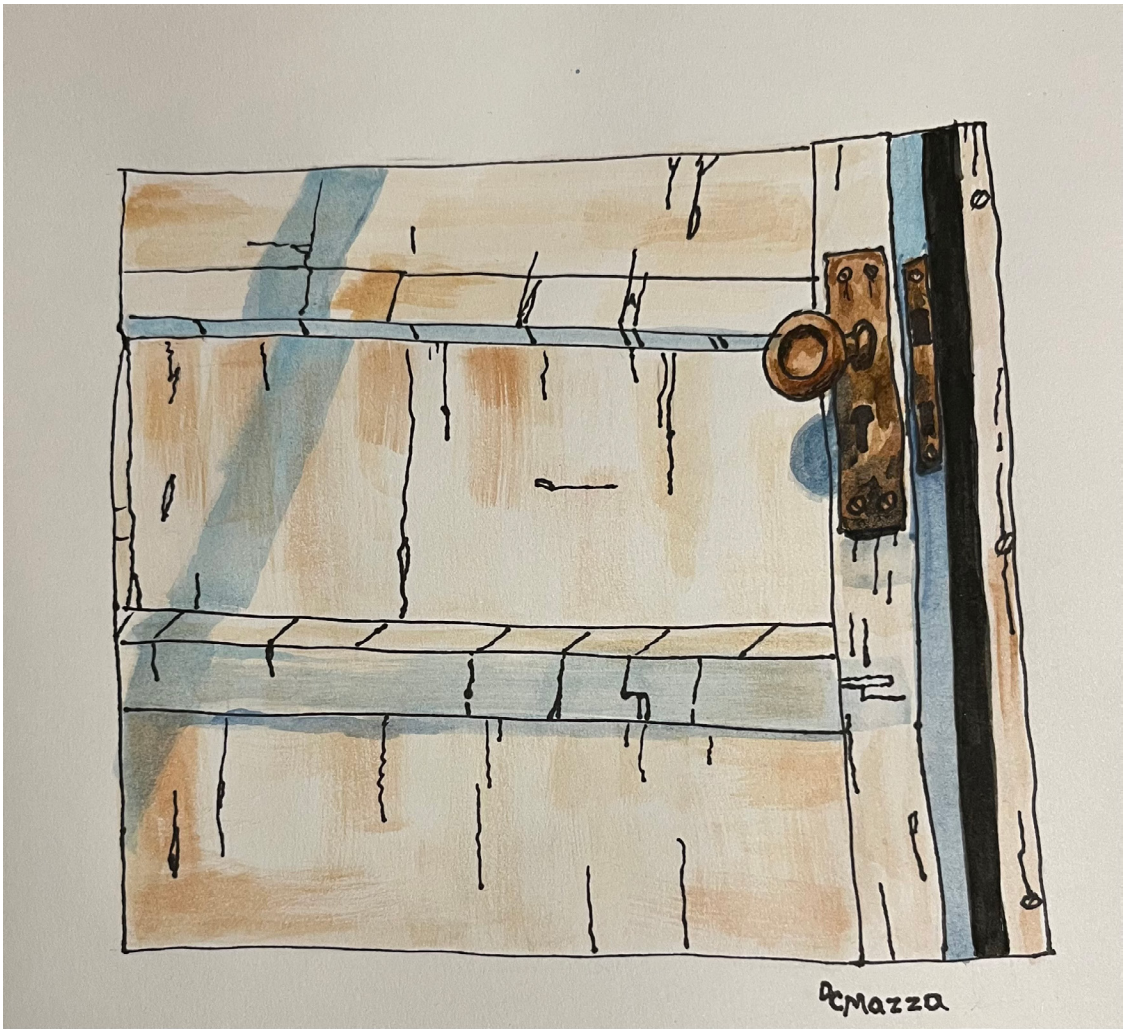
Diane Mazza - closing thoughts
With my limited artistic ability, I tried to develop some art to address a few of the descriptions. But I had a tough time. At this point, I thought I'd challenge the group to put their words into creating their own artwork. So, I posted again, but there seemed to be no one who wanted to take up the challenge.

I continued. One of the postings hit home to me: the one by Kathryn Campbell, who said "A child looking into a dark closet."

I'm not good at drawing people, so I took out the child and created this image. To me, the old door represents the average population of patients with WM, who are older (or should I say more mature). The dark, partial opening of the door represents many things.

It could mean the fear of the unknown. It could be what the diagnosis means for our lives, our survival. It could mean the sliver of hope that this door will not open any time soon, similar to how people stay on watch-and-wait for many years. It may mean peeking into the room and finding an effective treatment but being afraid of the unknown side effects.

But most of all to me, it is a representation of what it feels like when waiting for test results, waiting for an appointment to see the doctor, and the waiting to begin treatment. You know it's coming, but you don't want to walk through that door.



Artwork by Diane Mazza

NEW SUPPORT GROUP LEADERS

Compiled by Sharon Rivet, Support Group News Editor

Ann MacMullan, Co-Leader, WM Caregivers Support Group

My father, Hugh MacMullan, was diagnosed with WM in 2019. I started my journey of WM caregiving then, learning everything I could about WM, wanting to help him be as healthy as possible. And that further aligned with my purpose—to use what I learned to help others.

This past year, my father died from prostate cancer (though WM caused its fair share of issues). Helping him through the final year of his life was a profound blessing, but I've had to learn the hardest caregiving lesson of all: letting go. And I'll be honest; it's going to take some time.

In his honor, and for my own healing, I wanted to create space for other caregivers to connect and support each other through the fluctuations of WM. In our first two WM Caregivers Support Group meetings, we've had an incredible outpouring of sharing. Some of our members even have WM themselves and are caregiving their loved ones! We've been fortunate to find Linda Trytek to co-lead; her positive outlook and years of experience add depth and compassion to our group.

When I am not working, you can find me on the yoga mat, in the woods, or playing guitar.

Linda Trytek, Co-Leader, WM Caregivers Support Group

My wonderful husband, Ed Goldberg, was diagnosed with WM in 2011. He expected to live about five years, and he put his affairs in order. We were scared! We found IWMF at a Chicago conference of the Leukemia & Lymphoma Society (now named Blood Cancer United). A WM breakout group led us to outstanding doctors specializing in WM. Our local support group and Don and Mary Brown made us feel that we were not alone and that there was hope and life beyond a WM diagnosis.

Caregivers are the silent glue that can hold everything together in these journeys. Sometimes you just need someone to talk to who understands what you are going through. I want to extend that safe space to other caregivers.

I am retired now, but I worked as a programmer/analyst, psychiatric social worker, hospital administrator, and preschool teacher. I find joy in our two beautiful daughters, their wonderful husbands, and our amazing granddaughter. For fun I play and sing in two ukulele bands and exhibit my photography. Taking daily walks with my beloved husband improves my outlook a great deal.

New Support Group Leaders, cont. on page 27

Deborah Tayloe, Co-Leader, North Carolina Support Group

I am honored to serve as the new North Carolina Support Group Co-Leader, along with Jennifer Hervey. My connection to WM began when my husband Randy was diagnosed in May 2025 (he's now in remission). As a caregiver, I quickly learned how isolating a rare diagnosis can feel—especially when you are trying to stay strong for someone you love while still processing everything yourself.

I became involved with IWMF as a care partner, seeking clear, reliable information and reassurance during an uncertain time. IWMF has been an essential resource for our family, helping us better understand WM and reminding us that we are not walking this road alone.

I volunteered to become a support group leader because every patient and caregiver needs the support of others who understand the balancing act of appointments, decisions, daily life, and quiet worry. I hope to help create a welcoming, down-to-earth space where caregivers and patients alike can connect, share experiences, and feel heard.

Outside of WM advocacy, I am a serial entrepreneur. My husband and I own and operate a landscaping company, a custom apparel printing shop, and an Etsy business. I live and work in Aulander, NC. Life here keeps us grounded, and I recharge by serving my church community and spending time with my rescue pets.

I look forward to walking alongside others in this role.

Jennifer Hervey, Co-Leader, North Carolina Support Group

I was diagnosed in February 2024, at age 50, with lymphoplasmacytic lymphoma. For two years before, I just thought it was perimenopause. Zanubrutinib was my initial treatment, but I developed chronic pneumonitis. Next treatment was bendamustine, dexamethasone, and rituximab. Current treatment is pirtobrutinib. I hope this will do the trick!

When I first was diagnosed, I sought out every resource I could find, including IWMF, support groups, and the Facebook WM Support Group. The Facebook page has extremely helpful information, and I highly recommend it to everyone. I want to be in an active support group in North Carolina to find connections and share resources, so I volunteered to co-lead the North Carolina group with Deborah Tayloe. Our last leaders gave many years to our group, and I'm very grateful for their time.

I am a wife, mother, and nurse. I have been married to my husband Doug for 26 years, and we have two children. Our daughter Katie is 23 years old and a fully employed college graduate. Carson, our son, is 19 years old and enjoying college life at Virginia Tech. I, however, fully bleed Duke blue. I have worked in various areas within Duke University Medical Center for the last 29 years. Currently I am working with research trials as a project manager. Watching Duke basketball, tennis, pickleball, hiking, knitting, reading, and traveling are just some of my hobbies.

New Support Group Leaders, cont. on page 28

Sandy Dochen, Co-Leader, Central Texas Support Group

After being diagnosed with MGUS (monoclonal gammopathy of undetermined significance) about 17 years ago, I "crossed over" to the WM "exclusive club" almost two years ago. Except for a daily iron supplement and some IVIG infusions last year, I'm in watch-and-wait—and feeling energetic and positive. I supplement my local oncologist visit with a trip to the amazing MD Anderson Cancer Center in Houston.

Attending my first IWMF Ed Forum last year inspired me to get more engaged. I live in Austin, and Shelly Postek, IWMF's Director of Information & Support, helped me create a Central Texas Support Group. Soon after, Steve Sundby, who lives near San Antonio, offered to help co-lead our group. We held an introductory Zoom call last October and got together for pizza and conversation in January. It was empowering to hear stories and compare notes—and even swap some advice.

I spent most of my career in corporate social responsibility and government/community relations at IBM, the Austin Chamber of Commerce, and two other technology companies. Policy "wonking" and community volunteering are my passions. My wife and I have been married 47 years, have two terrific children and the cutest two-year-old red curly-headed granddaughter on earth. Grandchildren are our best medicine!

Cathy Zimmerman, Co-Leader, Colorado/Wyoming Support Group

I was diagnosed in 2019 after having low blood counts and anemia, followed by confirmation of WM by a bone marrow biopsy. I went through six rounds of bendamustine and Rituxan (B&R), followed by four months of Rituxan only, and I have been on watch-and-wait since completion of those in 2020.

For me, IWMF has been a support system like no other. After attending the Ed Forum last year, I was encouraged by Shelly Postek and Robin Tucker (my co-Leader) at IWMF and by Jane Cox (Support Group Leader for Northern Virginia/Washington DC/Maryland) to start a virtual support group for the CO/WY area. We have had two virtual meetings so far, and Robin and I will also be taking over for Bill Bass, who led the in-person meetings for many years. We are so grateful for the foundation Bill has built here in the CO/WY area.

We all have slightly different stories on how we arrived at this spot in our WM journey, but in the time that we meet, we are stepping out onto the exact same floor as we face our shared challenges together.

In Memoriam: Elsa Bradley - A Decade of Devotion

IWMF celebrates the memory of Elsa Bradley, co-leader of the Colorado/Wyoming Support Group for nearly ten years. Elsa was a true champion for those living with Waldenstrom macroglobulinemia, not only through her years of local leadership but also through her support as a member of the Ben Rude Heritage Society. Her legacy of care and commitment leaves a lasting impact on the WM community.

WM-NET CLINICAL TRIAL NETWORK LAUNCHES WEBSITE

WM-Net, the US clinical trial network dedicated solely to providing advanced, innovative therapies for WM patients, recently launched its website at *www.WM-Net.org*.

WM-Net was established in 2024 under the leadership of Dr. Jorge Castillo of Dana-Farber Cancer Institute in Boston, with original funding and continuing support provided by IWMF. Its premise is to improve outcomes for people living with WM today and in the future through rapid activation of new clinical trials at multiple locations, faster patient access to new therapies, broader participation in clinical trials, and sharing of data and best practices.

Today, this network includes 24 leading academic medical centers across the US: Fred Hutchinson Cancer Center, Stanford University, City of Hope, University of California San Diego, Huntsman Cancer Center, Colorado Blood Cancer Institute, Mayo Clinic, Northwestern University, University of Texas Southwestern Medical Center, MD Anderson Cancer Center, Cleveland Clinic, The Ohio State University, Memorial Sloan Kettering Cancer Center, Dana-Farber Cancer Institute, University of North Carolina, Massachusetts General Hospital, Beth Israel Deaconess Medical Center, Emory University, Moffitt Cancer Center, University of Miami, Vanderbilt Health, Perelman School of Medicine, University of Maryland, and Levine Cancer Center.

The investigators involved in WM-Net are actively working to identify the most important unanswered questions in WM and design studies to address them. These five clinical trials are either enrolling participants now or about to begin:

WM-Net 1 – Loncastuximab tesirine in previously treated WM – first trial in the world to use an antibody-drug conjugate for WM.

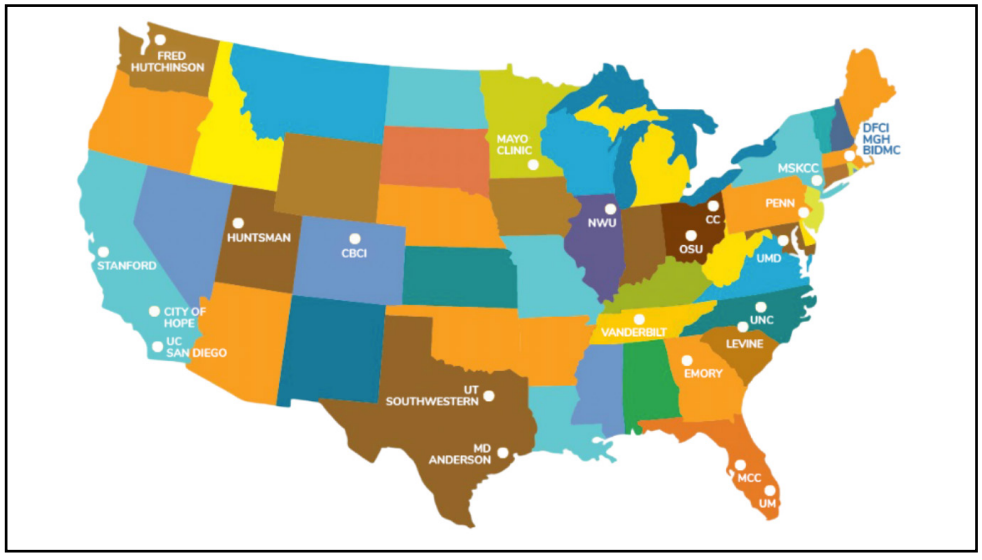
WM-Net 2 – Zanubrutinib, bendamustine, and rituximab (ZEBRA) in previously untreated WM – first trial in the US to use a triple combination for WM.

WM-Net 3 – Epcoritamab in previously treated WM – first trial in the world to use an anti-CD20 bispecific antibody for WM.

WM-Net 4 – Pirtobrutinib, venetoclax, and rituximab (PROVEN) in previously untreated WM – first trial in the world to use a non-chemotherapy, fixed duration, triple combination for WM.

WM-Net 5 – Etentamig in previously treated WM – first trial in the world to use an anti-BCMA bispecific antibody for WM.

To read more about WM-Net and see the details for participation in these clinical trials, visit *www.WM-Net.org* and check back periodically for updates.



The 24 clinical trial venues of WM-Net

WMOZZIES LOOK TO THE FUTURE

Since the early 2000s, WMozzies has worked to participate in activities that support and improve the experience of those with WM in Australia. The development of WMozzies and its value to those who support individuals with WM has been possible because of its changing leadership at different junctures in the journey.

In the early years, leadership for WMozzies was provided by Gareth Evans in collaboration with Ben Rude, then President of IWMF. In recent years it was led by the ever-committed Andrew Warden and, most recently, by David Young.

David is now stepping away from the role of WMozzies leader to focus on a broader set of goals. In his final communication, David said, "It has been an honour and meaningful experience over this time to lead WMozzies. It is time for me to move on to further participate in the growing world of cancer consumer advocacy." WMozzies is grateful to David for his contributions to the group.

Following David's departure, it is now appropriate to welcome and pass the torch to Peter Freese as he takes on the role of Global Partner Leader for WMozzies. Although Peter will head WMozzies, the value and experience that Andrew and David offer will not be lost. They will both continue to participate in various projects as members of WMozzies—such is their passion for WMozzies and its goals.

Peter has been a longstanding member of WMozzies and the broader IWMF community. Having been diagnosed with WM in 2014 and Bing-Neel syndrome (BNS) in 2016, he has participated as a patient in a number of WM research activities such as the COVAX - Lymphoma study, WM-Voice study, and the zanubrutinib trials, as well as being a participant in an upcoming Australian-led international WM clinical trial. Currently Peter is an IWMF LIFELINE volunteer for BNS, and, alongside stalwarts Eileen Sullivan and Julie Davidson, co-facilitates the IWMF BNS Affiliate Group.

Looking to the future, WMozzies has begun its 2026 planning process with the intent to capitalise on all the good work of recent years. It is essential that in 2026 we work to consolidate the value of existing initiatives whilst participating in the new opportunities that are emerging. We will do this by giving priority to growing the participation and engagement of our current membership and those individuals with WM who are yet to be members.

Central to meeting the needs of our members will be to clearly understand and prioritise those needs and to direct our energy toward value-adding activities. As such we will continue to develop and improve patient-centred tools and databases such as WhiMSICAL. Finally, as much as Australia is an island continent, WMozzies can't afford to be that. Since inception, our growth has depended on the relationships we have developed with like-minded individuals and organisations. In 2026, we will give priority to strengthening the collaboration with Australian and international organisations such as IWMF, LF Australia, Lymphoma Australia, and more.

On World Cancer Day, 4 February 2026, three WMozzies leaders met at historic Pyrmont on Sydney harbourside. Left to right, with leadership dates: Andrew Warden (2013-20), David Young (2020-26), Peter Freese (2026-)

DANA-FARBER CANCER INSTITUTE RECEIVES MAJOR GIFT FOR WM RESEARCH

Dana-Farber Cancer Institute has received an anonymous gift to advance understanding of Waldenström macroglobulinemia (WM). This visionary gift establishes both the Robert F. Tannenhauser Chair for Waldenström's Research at Dana-Farber, with Steven P. Treon, MD, PhD, serving as the first incumbent, and the Steven Treon, MD, PhD, Fund for Advancing Waldenström's Research.

The newly endowed chair is named in memory of Robert F. "Bobby" Tannenhauser, a beloved WM community member with a deep commitment to serving others, who passed away on April 25, 2025. Dana-Farber is proud to carry forward Bobby's inspiring legacy; he lived with WM for nearly four decades and was an early participant in familial WM studies—reflecting the enduring impact patients and families can have when they partner with physician-scientists to advance discovery for future generations.

Dr. Treon, who will carry this work forward, is the Director of the Bing Center for Waldenström's Macroglobulinemia. He is a senior physician at Dana-Farber and a Professor of Medicine at Harvard Medical School. Since founding the WM program at Dana-Farber in 1999, the Bing Center clinical team has cared for nearly 2,500 WM patients annually, making it the world's leading center for WM care and research.

Dr. Treon has had a transformative impact on the treatment of WM. He organized and serves as Chair of the WM Clinical Trials Group, bringing together investigators in the US, Canada, and Europe, and served as Principal Investigator for numerous prospective clinical trials which introduced many novel therapies to WM. Over the past two decades, he and his colleagues at the Bing Center have mapped the genetic blueprint of WM—including landmark discoveries involving the *MYD88* and *CXCR4* genes—and translated those findings into the use of new targeted treatments for WM, including the BTK inhibitor ibrutinib as the first FDA-approved treatment for WM. Building on this progress, the team continues to study these and other therapies and the use of genomics to refine how they are used and better match treatments to patients. Together these discoveries have contributed to improving survival for many people with WM from three to five years to decades.

In addition to authoring more than 300 research papers in prestigious journals, Dr. Treon has earned numerous honors for his contributions to WM research, including the Jan Gösta Waldenstrom Lifetime Achievement Award, the Robert A. Kyle Award for Waldenström's Macroglobulinemia, and the Medical Discovery Award from Dana-Farber.

Steven Treon, MD, PhD

The Robert F. Tannenhauser Chair will provide sustained support to advance bold, high-impact WM research, and the Steven Treon, MD, PhD, Fund for Advancing Waldenström's Research will help launch and sustain a comprehensive, long-term effort to follow families affected by WM and track genomic and immune-cell changes over time—work aimed at identifying the earliest signals of disease development and leading to earlier intervention.

Congratulations to Dr. Treon on this well-deserved honor, and many thanks to the anonymous donor for a significant investment in Dana-Farber's mission and in the WM community.

HEALTHWELL FOUNDATION®

www.HealthWellFoundation.org

HEALTHWELL FOUNDATION: FINANCIAL RELIEF FOR CHRONIC DISEASE TREATMENT

Managing a chronic illness presents daily challenges—not only in addressing physical symptoms and emotional strain, but also in confronting the financial burden that comes with long-term treatment. High out-of-pocket costs for medications, specialist visits, and essential therapies can overwhelm patients and their families.

The HealthWell Foundation was created to help improve the financial well-being of people with chronic diseases. A nationally recognized, independent non-profit organization founded in 2003, HealthWell has served as a safety net for more than 1.1 million underinsured US patients by providing access to life-changing medical treatments they otherwise would not be able to afford. The Foundation provides financial assistance to adults and children facing medical hardship resulting from gaps in their insurance that cause out-of-pocket medical expenses to escalate rapidly. Through the Foundation's Waldenstrom Macroglobulinemia Fund, eligible patients may receive up to $8,000 in medication copayment or Medicare Part B insurance premium assistance to support treatment and management of their WM.

HealthWell recognizes that the impact of cancer goes beyond medical expenses. Additional resources include:

Cancer-Related Behavioral Health Fund – Assists with prescription drugs, counseling services, Cognitive Behavioral Therapy, and transportation needed to support cancer-related behavioral health and well-being.

Oncology Caregiver Behavioral Health Fund – Assists with prescription drugs, counseling services, psychotherapy, and transportation costs needed to treat or manage behavioral health and well-being for a family member who is providing care to a cancer patient with an active HealthWell grant.

Cancer Home Care Services Fund – Assists with out-of-pocket expenses for home care services and durable medical equipment for active or former HealthWell oncology grant recipients who are managing a cancer treatment.

For individuals or caregivers facing financial barriers to treatment, HealthWell offers an application that takes less than ten minutes to complete. Patients may apply online or reach out directly to the Foundation's support team for personal assistance. To explore available funds, eligibility requirements, or program details, one can visit the HealthWell Foundation website at *www.healthwellfoundation.org* or call 800-675-8416, Monday-Friday, 9am to 5pm ET.

BEN RUDE HERITAGE SOCIETY

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

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JANE BALLARD IN HONOR OF SHIRLEY GANSE
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