IWMF TORCH

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INSIDE THIS ISSUE

A LETTER FROM IWMF'S PRESIDENT AND CEO

BY DELORA SENFT

Delora Senft

Editor's note: With the hiring of Delora Senft, the new IWMF President and CEO who began work last August, IWMF enters 2026 filled with new insights, new ideas, and new approaches for the ongoing success of its mission to advance the search for a cure while supporting those affected by WM.

What led me to IWMF

My path here has always been driven by a need to make a difference—a path rooted in data, partnership, and a belief in what people working together can do. I built my career around collaboration, often coaxing teams from different worlds to see one another, connect resources, and pull big ideas off the page.

In my previous position, I led Gateway for Cancer Research's scientific programming and partnerships, overseeing multimillion-dollar research initiatives and helping generate millions in funding by connecting compelling patient narratives with rigorous, evidence-based science. I built and restructured teams, nurtured global research collaborations, and translated complex scientific outcomes into stories that moved people to act. That work taught me what it means to make every single dollar count and to ensure that investments truly reach the patients who need them most.

My academic background instilled in me a deep respect for quantitative analysis, sustainable growth, and clear communication, principles that continue to serve me well. Those skills inform how I approach everything from optimizing a research portfolio to crafting a pitch that brings a new partner to the table. More importantly, they shaped my belief that mission and measurement must go hand in hand if we want to create lasting change.

My younger brother, Nate, and I at my wedding. He was diagnosed three months before I got married. His oncologist said, "You plan your wedding, and I will get him there."

However, my motivation runs deeper than my resume. I joined IWMF because I lost my younger brother to a rare cancer. In his final days, he asked me to help

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IWMF Board members at the Board retreat in Chicago

others avoid the pain we endured. This is personal. It's my mission to help bring resources to families who are counting on it. I'm here as a servant leader, holding my head and heart together—because I know, intimately, what's at stake.

Stepping into the new role

All of this experience led me here, and as I stepped into the role of President and CEO at IWMF, I brought not only that professional history but a personal commitment to advancing research, supporting the WM community, and expanding global impact. I thrive when working at the intersection of science, philanthropy, and human stories—and this community embodies that intersection more than any other I've served.

Since joining IWMF in August, I've met people whose lives have been changed by WM: patients searching for answers, families doing everything they can, and scientists determined to make progress. Every conversation reminds me why IWMF was founded: we are a community built by patients, for patients, powered by urgency and hope.

The first month to first 90 days

During my first month, I focused on meeting with Trustees, advisors, and, most importantly, our dedicated IWMF team. These conversations offered invaluable insight into the depth and reach of our work and reminded me how interconnected and mission-driven this organization truly is. By the 60-day mark, I expanded these meetings to include donors, volunteers, partners, and members of the scientific community so that I could understand our mission from every angle and hear directly from those who help shape it.

As I approached the end of my first 90 days, it became clear that this was the right moment to begin charting our future. In Chicago, during our strategic Board retreat, we partnered with a skilled nonprofit facilitator to revisit and strengthen our vision, mission, and global imperatives. What emerged from that retreat was a unified commitment to building a stronger, more strategic path forward—and the confidence that we have the leadership, expertise, and passion to achieve it.

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Community achievements in 2025

I would be remiss not to highlight a few of the milestones our community achieved in 2025:

- A record year of fundraising, which included a 41% increase in our annual Giving Challenge;
- Launch of the new Strategic Research Agenda, designed to accelerate the translation of research discoveries into transformative therapies;
- Our first-ever support group webinar, "Waldenstrom's Unplugged," which brought together over 300 participants;
- Educational Forums in Florida and France, where over 300 attendees from 17 countries gathered to learn, share, and connect;
- Six new regional support groups started, plus one new caregiver group, and a record year of 500 LIFELINE touches with patients;
- Integrative Wellness program expanded, with a diverse range of offerings for the WM community, new instructors, and classes aimed at improving quality of life;
- Fifteen grants given to patients and their families to support travel and lodging for second opinions and clinical trial eligibility.

The year ahead

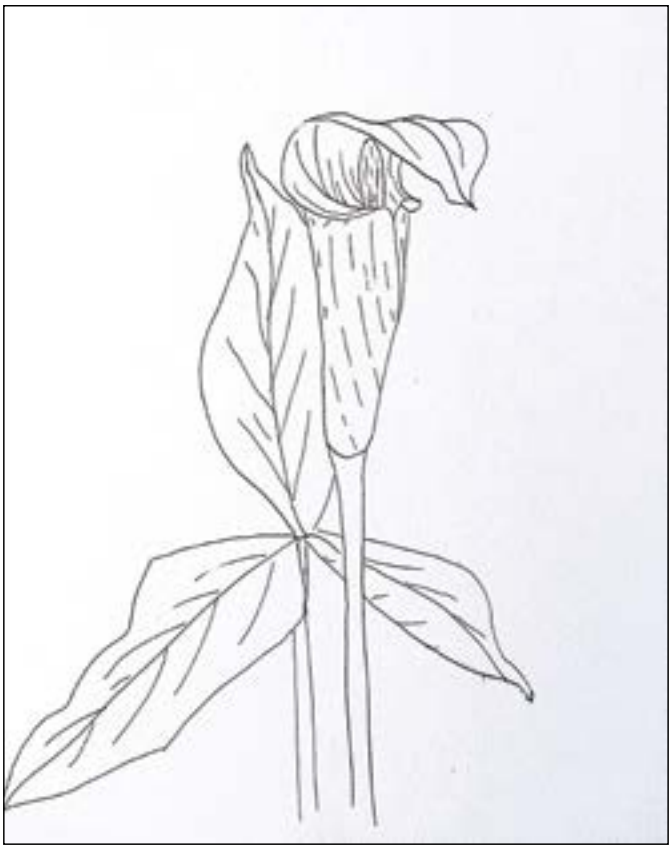
Looking ahead to 2026, we are focused and ready:

- We are directing funding to top research centers so that discoveries can become treatments faster.
- We are setting measurable goals to ensure investments directly improve care and outcomes for people with WM.
- We are supporting and attracting leading scientists—and cultivating the next generation—to keep innovation moving forward.
- We are strengthening global partnerships to ensure that every person with WM has more resources and support than ever before.
- We are maximizing technological optimization to increase awareness of IWMF services to all patients.
- We are working for another record year of fundraising to enable us to continue to fund all our critical programs now and beyond.

At IWMF, our mission isn't something we simply talk about—it's something we live. We bring families, researchers, and advocates together to drive research, share trusted information, and provide support that is both practical and deeply compassionate.

I am truly grateful for the connections I've made so far, and I'm energized by the work ahead. I look forward to a full year of impact and meeting even more members of our community. I'm proud to keep my promise to my brother—serving others and living my purpose in this community. Thank you for being part of this journey, for believing in progress, and for helping us turn lived experience into lasting change.

We want to hear from you! Please look for a survey in your email or the "Waldenstrom's Weekly" on how we can communicate more efficiently and provide you with the resources you need!



"*Jack in the Pulpit*" by Diane Mazza
"*It's a good representation of WM because it is rare, takes a long time to grow, and is often hard to find or diagnose.*"

LET'S ACCELERATE THE CURE: A NEW RESEARCH ROADMAP

IWMF is leading a global mission to transform WM from an incurable cancer into a disease we can fully eradicate.

A cure is more than remission. It's a healthy, treatment-free life with no trace of disease anywhere in the body. Today, these complete responses in WM remain rare, and even with the best novel drug therapies, relapses are expected. That's why IWMF undertook a year-long process to design a new Roadmap for research investment—one that pushes discoveries faster from the lab to the clinic.

We consulted with experts, and our process included workshops, interviews, and external input from both scientific leaders and pharmaceutical partners. The new Research Roadmap pinpoints the most urgent gaps in WM research and highlights opportunities for translational research—scientific discoveries that can be turned into treatments for patients to use.

In September 2025, we launched this new Roadmap, defining five grant categories for our 2026 grant funding cycle:

Pilot Clinical Trials Grants: We are inviting proposals for pilot clinical trials of novel agents with a strong potential to change the standard of care for patients, grouped by genetic subtypes of WM.

Companion Grants: When pharmaceutical or biotech companies sponsor a clinical trial, we want to sponsor academic investigators to harvest tissue samples for study of treatment resistance mechanisms and disease biomarkers. While the industry may focus on a winning therapy, we want to know why a treatment works or doesn't. These critical questions are rarely funded by the pharmaceutical industry, yet they are essential to advancing the field.

Translational Grants: We are giving priority to proposals that enable translation of a lab discovery to a clinical trial within three years. These projects may propose ways to interfere with the underlying cancer process, address resistance to therapy, or develop a novel target or treatment.

Acceleration/Expansion Grants: These grants accelerate prior IWMF-funded projects toward a clinical application. They may also expand the projects to new translational hypotheses and apply new cutting-edge approaches.

The Robert A. Kyle Career Development Award Grants: We are continuing these highly impactful awards to young investigators working alongside WM experts, as they pursue translational research in WM and related B cell malignancies.

Most grants will run two to four years. The more our donors invest, the faster this Roadmap expands—and the sooner discoveries reach patients.

Our Scientific Advisory Committee Co-Chairs, Dr. Steven Treon and Dr. Stephen Ansell, emphasize the unprecedented opportunity before us. A technological revolution of gene editing, AI-driven analytics, and advanced tools to study the bone marrow microenvironment are giving us new power to attack WM. By focusing on translational research, we can disrupt how WM cells hide from the immune system or cut off the survival signals the cells depend on in their environment.

Past grants built the foundation for understanding WM biology. Future grants will more directly transform patient lives. Beginning with the 2026 awards, every project we fund must chart a clear path to improved treatment, quality of life, or survival within three years.

This is not business as usual. It is a new era of grantmaking with one aim: to shorten the time between discovery and a cure. Or said another way, our aim is to Accelerate the Cure.

THOUGHTS ON PROBLEM-SOLVING

By John Gallagher, Member, Southern NJ, Eastern PA Support Group

John Gallagher

Some people have serious problems, not shared by the majority, which require a solution. These few people cannot solve their problems, since the solution requires specialized knowledge they do not possess. What can they do?

Some people may have the knowledge to solve these problems, but they may not have any interest or incentive to attempt to solve problems only a few people have. How can they be convinced to spend their time and energy in solving them?

In the past these unique problems would remain unsolved because of the lack of communication technology. But over time, communication has improved, and more knowledgeable solvers have been made aware of the problems. Slowly a knowledge base begins to form, shared by a small group who usually speak the same language and who share the same occupation. But the solution remains elusive. How can this small group of solvers be expanded to include others from different countries, speaking different languages, and from different disciplines?

Communication technology today has made this expansion of the small group possible. But such expansion requires a quarterback or facilitator to bring the solvers together, give them incentives, and have them work efficiently and cohesively to achieve a solution.

Where would one find such a quarterback or facilitator? A single person may not have the time, expertise, or resources to accomplish the goal. What is needed is a group of like-minded people, collectively possessing the requisite qualities and knowledge.

Let me stop now with the above narrative and introduce you to the real-life group created to solve the real-life unique problems highlighted in this imagined story.

Enter IWMF.

IWMF evolved from Arnie Smokler and a small group of WM patients living the story you just read. Thankfully, they had the energy and initiative to give birth to the Foundation, which is the perfect vehicle (quarterback and facilitator) to find, nurture, incentivize, and direct the many knowledgeable solvers who are every day at work moving closer and closer to a cure for our disease.

IWMF needs to keep doing what only it can do. Progress has been great in the last ten years, but it's not time to rest and pat ourselves on the back for past effort and successes. Victory is in sight, but, as a quarterback will tell you, the last few yards before the goal can be the toughest. IWMF will need your support to reach its goal to forever banish WM from the playing field.

This article did not start out as a fundraising request, but as I was writing, it dawned on me that while only a few can do the technical work that IWMF requires, everyone can help in other ways. All can help by donating money, which I just did, because in reviewing the various ways I could spend my money, one stood head and shoulders above the rest. One recipient of my money could lengthen my life by curing or at least containing my WM. So I asked myself, "What is an extra year (or years) of health worth to me?" I won't share my answer with you here, but I will tell you that I never donated money more willingly, or with more assurance that I was making a great investment, than when I wrote a check to IWMF.

Most of my charitable donations are for public benefit. This one is different. This one is personal. I, along with all WM patients, have a personal stake in the success of IWMF. But this self-interest does not make a donation to IWMF a selfish act. While it's true a donation to IWMF will benefit me directly—unlike most of my other donations—it also benefits many other people as well.

Thoughts on Problem-Solving, cont. on page 7

So be selfish and selfless at the same time by donating to IWMF. It will benefit all WM patients as well as you, give young doctors and investigators interesting and important projects to begin their careers, and allow more seasoned medical practitioners to pull all of their discoveries together to produce a cure for WM. This would show the world what can be attained when the energy and knowledge of a few people are used and directed toward accomplishing a worldwide goal. How great is that?

RESEARCHER SPOTLIGHT: HOW WM ADAPTS—AND HOW THE IMMUNE SYSTEM FIGHTS BACK

Dr. Pieter Langerhorst, recipient of a Robert A. Kyle Career Development Award, is using proteomics—the study of proteins, which are the dynamic molecules that carry out our genetic instructions—to analyze and track biological changes in the proteins found in the blood and bone marrow of WM patients.

Dr. Pieter Langerhorst

No two patients with WM experience the same journey. Some live for decades with few symptoms. Others face rapid progression, treatment resistance, or unpredictable relapses. Genetics explains part of this—but not all. Key mutations like *MYD88* and *CXCR4* shed light, yet they fall short of fully predicting how the disease will behave. That's where Dr. Langerhorst's research breaks new ground.

A physician-scientist based at the Sanquin Blood Bank in the Netherlands, Dr. Langerhorst has eight years of experience in plasma cell disorders and a deep background in analytical chemistry. As founder and chair of the Young Dutch Society of Mass Spectrometry, he's a rising leader in proteomics.

Dr. Langerhorst's award is part of a two-year IWMF grant initiative that supports exceptional post-doctoral researchers and junior faculty who are advancing the science of WM. The program was named in honor of Dr. Robert A. Kyle of the Mayo Clinic, whose decades of insight have shaped the field of WM.

Why do patients with similar genetics have different experiences with the disease?

Dr. Langerhorst is exploring one of the most frustrating mysteries in WM. The biology driving WM disease variability is still largely unknown, but this project aims to change that. With the mass spectrometer, Dr. Langerhorst will analyze proteins in both blood and bone marrow—hundreds to thousands of proteins from WM patients across different genetic subtypes and disease stages. Thanks to major advances in mass spectrometry hardware and software, he can now extract deep protein data from just a single drop of blood, processing 60 samples a day with precision.

His goal is to identify new biomarkers that can predict disease behavior, track treatment responses, and guide therapy choices—based not just on genetics, but on the real-time biology of the disease. Dr. Langerhorst's work will also dig into the role of inflammation, which may be a key but underexplored factor in WM's progression. If successful, this study could spotlight inflammatory proteins as both prognostic tools and therapeutic targets.

This project tackles three of the toughest unanswered questions in WM.

1. **What drives different outcomes in patients with the same genetic subtype?** Dr. Langerhorst is analyzing serum from 120 patients with known genetic mutations to determine whether distinct protein "signatures" can better predict

Researcher Spotlight, cont. on page 8

progression, relapse, or resistance—beyond what genetics can reveal.

2. **Can we track treatment response by watching changes in proteins?** Dr. Langerhorst is studying 111 plasma samples from 36 patients at multiple stages of treatment, looking at how therapy reshapes inflammatory and signaling proteins—and whether those changes can forecast who will respond.
3. **Who will progress from IgM MGUS to full-blown WM?** This is one of the most urgent questions for newly diagnosed patients. He will compare blood samples of those who progressed to WM with those who stayed stable, aiming to identify the earliest warning signs of progression at the protein level.

As a Kyle Development Award winner, Dr. Langerhorst is not conducting this research alone. His principal mentor, Dr. Zachary Hunter at Dana-Farber Cancer Institute, is one of the world's foremost experts in WM biology. Dr. Hunter played a pivotal role in discovering the *MYD88* and *CXCR4* mutations that redefined the genetic landscape of WM, enabling more precise diagnosis, risk stratification, and treatment targeting. Dr. Langerhorst is also working closely with Dr. Saemundur Rognvaldsson and Professor Sigurdur Yngvi Kristinsson at the University of Iceland, who are leaders in the study of B cell cancers and whose biobank has powered some of the largest and most informative long-term population studies of patients with blood cancers.

This is exactly the kind of science that IWMF is proud to support, and this is what donor dollars make possible.

RESEARCHER SPOTLIGHT: TRANSCRIPTION FACTOR NETWORKS THAT ARE CRITICAL FOR WM CELLS

In a project that is part of the Strategic Research Roadmap Initiative, Dr. Constantine Mitsiades of Dana-Farber Cancer Institute is using CRISPR-based gene editing to identify transcription factors that are critical for the survival of WM cells.

Dr. Constantine Mitsiades

The challenge

Despite therapeutic advances, WM remains incurable. Many drugs hit downstream targets—typically proteins on the surface of or inside WM cells. But what if we could go straight to the source?

Dr. Constantine Mitsiades is doing just that by systematically studying transcription factors (TFs), or the proteins that regulate the expression of genes and control which genetic programs are turned on or off in each cell. These factors determine how cells divide, differentiate, migrate—or die. Some are shared across several cancers, while others appear uniquely critical to WM. These "master switches" have historically been considered undruggable—not suitable for conventional therapies. But that is changing. Emerging therapies such as targeted protein degraders and synthetic lethal approaches can now go after TFs directly or disable their partner proteins called co-factors.

Using CRISPR gene editing, the Mitsiades team has uncovered more than 60 TFs that WM cells rely on for survival. They don't show up in conventional tumor sequencing, but through CRISPR screening, the team is revealing just how essential they are.

The research plan

The researchers will use advanced gene-editing tools to turn off specific TFs one-by-one and see how that affects WM cell survival. First, they'll do testing in lab-grown WM cells. Then, they'll move to special mouse models that include human bone marrow cells to better reflect how WM behaves in the body.

To go deeper, they'll use a technique called CROP-seq, which lets them see how turning off each gene changes what the cell is doing, at the level of individual cells. This will help them map how each transcription factor controls the cell's behavior.

Cancer doesn't run on a single switch. It operates as a network of backups and feedback loops. The team will uncover which TFs work together and which combinations make WM cells especially vulnerable. This may reveal synergistic targets, or weak spots that only emerge when two TFs are hit at once.

They'll also explore how disrupting these TFs affects WM's response to 1) current drugs like BTK and BCL-2 inhibitors and 2) immune therapies such as CAR T.

This changes the model for treatment possibilities

Most drug development chases mutated genes or their resulting proteins. Instead, this project focuses on functional targets that matter because WM cells can't live without them, not because they're genetically altered. We expect to unveil new therapeutic paths. Even if a TF can't be directly inhibited, its co-factors may be within our reach. Dr. Mitsiades and his team have experience making the "undruggable" druggable.

The whole WM field can use this research because it will generate detailed maps of WM transcriptional networks—maps that can guide future drug development, rational treatment combinations, and biomarker discoveries.

This is bold, foundational work. By targeting the control centers—not just the foot soldiers—of WM biology, we will open new therapeutic frontiers. And with the power of CRISPR, the researchers are doing it at unprecedented scale and precision.

This is exactly the kind of high-impact science that the IWMF Strategic Research Roadmap is designed to fund.

MAKING MONSTERS, FINDING JOY: HOW JOE WELSH TURNED A WM DIAGNOSIS INTO A FAMILY ADVENTURE

By Art Brewer, Features Correspondent

When Joe Welsh was diagnosed with Waldenstrom's macroglobulinemia (WM) in late 2022, his world stopped cold. Just 46 at the time, he was a husband, a father of two young daughters, and a man whose life had been defined by adventure and achievement. Suddenly, the horizon ahead was full of uncertainty. Now 49, Joe lives in Chapel Hill, North Carolina, with his wife of 16 years and their daughters, ages 12 and 8. His journey from the shock of diagnosis to rediscovering purpose has been marked by strength, creativity, and a surprising source of hope—a board game called "Making Monsters."

Joe Welsh and his family

Raised in Los Altos, California, Joe earned an MBA from UCLA and built a varied career that took him from Silicon Valley to Africa and Europe. He held technical sales and leadership roles with major corporations, including IBM. Then he spent seven years in the US diplomatic corps as a foreign service officer, serving in Norway and Togo. He already spoke Spanish before joining but added Norwegian and French to his repertoire and even tried to teach himself Arabic and Russian.

Later, seeking a new challenge, Joe co-founded a robotics company in Colorado with his best friend. For seven years, the two worked on cutting-edge technology, developing autonomous robots that move trailers around shipping yards. It was fast-paced and innovative work, but also exhausting. By the time WM entered his life, Joe was already burned out from the relentless pressure of running a startup.

The diagnosis and concomitant restrictions were a crushing blow to this former college water polo player. Joe learned that he had a rare form of WM complicated by monoclonal immunoglobulin deposition disease (MIDD) and cryoglobulinemia, both of them serious conditions that cause damage to the nerves and organs. Within months, the neuropathy in his legs and ankles made movement difficult. "Treatment was brutal," he said. "Chemo. Nerve damage. Most days, even walking was hard."

After undergoing a course of chemotherapy with bendamustine and rituximab, Joe began intravenous immunoglobulin (IVIG) therapy to help manage his neuropathy, one of the most painful and debilitating symptoms of his condition. IVIG is a treatment in which purified antibodies, known as immunoglobulin G (IgG), are infused directly into the bloodstream. In Joe's case, the therapy helps regulate an overactive immune system and protect nerve cells from further damage.

Every month, Joe spends four consecutive days undergoing six-hour IVIG sessions. Over time, the treatment has reduced his pain and enabled him to move more comfortably. Despite the physical toll, Joe is grateful and pleased for how effective it has been. "I can't stress enough how much this treatment has helped, and I want to encourage others suffering from neuropathy to explore it as an option," he said. Joe hopes in time to reduce the frequency of his sessions from four days a month to two.

Blood cancers run in Joe's family. His father has myelodysplasia, a bone marrow disease that required a transplant, and his cousin was diagnosed with multiple myeloma. Joe considers himself fortunate that WM, while serious, is treatable and manageable over the long term.

After his diagnosis, Joe slowly stepped away from his robotics company. He and his family relocated to Chapel Hill in 2024 to be closer to his sister and her

Making Monsters, Finding Joy, cont. on page 11

family. The move brought new energy and emotional support, and it gave Joe the opportunity to be a more present uncle and father. "Now I'm surrounded by five girls—my two daughters and three nieces—from second through ninth grade," he said.

As his body struggled through recovery, Joe searched for something to fill the long hours at home. The answer arrived in the form of a family pastime that had always brought joy: board games. At first, he and his family played simply to pass the time and avoid being in front of a screen. Gradually, those times around the table became a way to reconnect, laugh, and feel normal again.

That spark of joy eventually led Joe in an unexpected direction. A lifelong gamer and strategist who has always loved chess and complex board games, Joe began tinkering with ideas of his own. He tried designing games but soon realized that what he really loved was the process of helping others create and share their work. At a local game night, he overheard a group of designers venting about how difficult it was to get their games published. "That's when something clicked," he recalled. "I've built companies. I know how to manage complexity. Maybe this was where I could help."

Not long after, Joe discovered a family-friendly game called "Making Monsters" created by two of the best designers in the business. The concept immediately appealed to him: players compete at a "Mad Science Fair" to build the best monsters

Family play test for the "Making Monsters" game

from random body parts drawn from a bag. The game had been shelved by another publisher, so Joe reached out to the designers, negotiated the license, and decided to publish it himself.

He enlisted his daughters and nieces to help test and refine the game. Together, they reworked rules, came up with monster names, and developed the art and humor that give "Making Monsters" its quirky charm. "It became a shared creative escape during one of the hardest years of my life," Joe said. "It was a labor of love."

The family's enthusiasm was infectious. A campaign for the game was launched on Kickstarter, a platform where creators share new visions for creative work with the communities that come together to fund them. The campaign received an overwhelming response, raising nearly $100,000 in preorders. The game is now in production and slated for release

The girls' favorite monsters

in March 2026, with national distribution through Barnes & Noble later in the year. At conventions, "Making Monsters" has already attracted strong buzz.

For Joe, the success of the project is deeply personal. It represents not just a creative venture, but a path toward healing. "Making Monsters" has given him purpose during recovery and a way to transform pain into joy. Most importantly, he remains focused on what really matters: family connections and the moments that make life feel whole. He, his daughters, and his nieces play games several times a week. "Any chance to spend time with my kids is great," he said.

Joe approaches each day with a renewed perspective shaped by gratitude and creativity. He encourages others facing chronic illness to find a personal source of joy and connection with family, whatever form it takes. "It doesn't have to be a board game," he said. "What matters is that it's yours, and that you do it together."

As he continues his treatment, Joe is determined to keep making both monsters and memories.

Phase 2 Trial Is Recruiting Relapsed or Refractory WM Patients for Pacritinib Therapy – A Phase 2 clinical trial is recruiting relapsed or refractory WM patients to evaluate the safety and effectiveness of oral pacritinib (Vonjo) as a possible treatment. Pacritinib is a kinase inhibitor that blocks the proteins JAK2 and IRAK1, both of which are important for the survival of WM cells, and the drug has already been FDA-approved for a rare cancer of the bone marrow known as myelofibrosis. Participants will receive study treatment for up to four years and followed for two years or until there is need for a new treatment. Approximately 30 participants are anticipated for the trial, which is being conducted at Dana-Farber Cancer Institute (DFCI). On *www.clinicaltrials.gov*, the trial identifier is NCT06986174.

DFCI Studies Real-World Outcomes of Zanubrutinib Dosing and Patient Mutations in WM – Researchers at Dana-Farber Cancer Institute (DFCI) looked at the real-world impacts of zanubrutinib (Brukinsa) dosing and patient mutational status on treatment responses and outcomes in WM. This study retrospectively analyzed 177 *MYD88*-mutated patients treated between 2018-2025 at DFCI who had not received their zanubrutinib therapy in a clinical trial setting. Initial dosing was 160 mg twice daily in 77% of patients, 320 mg once daily in 11%, and reduced dosing (80 mg twice daily or 160 mg once daily) in 12%. Of these patients, 53% had been previously treated, 41% had mutations in the gene *CXCR4*, and 15% had mutations in the gene *TP53*. After a median follow-up of 28 months, the very good partial response (VGPR) and 24-month progression-free survival (PFS) rates were comparable between the 160 mg twice daily and 320 mg once daily groups; however, reduced zanubrutinib dosing resulted in lower VGPR (23% vs. 41%) and lower PFS (61% vs. 85%) rates. *CXCR4* mutations were associated with lower VGPR, shallower IgM reductions, and delayed responses, but they did not impact PFS. TP53 mutations and prior therapy were independently associated with inferior PFS. This study was published in the journal *Clinical Lymphoma Myeloma and Leukemia.*

Real-World Study Compares Outcomes in WM Patients Treated with Second- vs. First-Generation BTK Inhibitors – A real-world study published in the journal *Clinical Lymphoma Myeloma and Leukemia* compared outcomes in WM patients treated with the second-generation BTK inhibitors zanubrutinib (Brukinsa) or acalabrutinib (Calquence), compared to the first-generation BTK inhibitor ibrutinib (Imbruvica). Scientists in the TriNetX global research network identified WM patients in the network's database treated with either generation of BTK inhibitors, and their outcomes were assessed over a maximum five-year period. Treatment with second-generation BTK inhibitors resulted in significantly lower mortality compared to ibrutinib (10.6% vs. 28.9%, respectively). Second-generation BTK inhibitors were associated with reduced risks of low neutrophil counts, anemia, and low platelet counts, as well as reduced incidences of pneumonia, viral infections, and sepsis (a life-threatening response to infection). Gastrointestinal events with second-generation BTK inhibitors were also reduced, with less diarrhea and nausea/vomiting. There were no statistically significant differences in the rates of pulmonary embolism, deep vein thrombosis, cardiac arrest, heart failure, or second cancers between the two groups.

...second-generation BTK inhibitors resulted in significantly lower mortality compared to ibrutinib...

Extension Study Reports Outcomes of WM Patients Transitioning from Ibrutinib to Zanubrutinib – A long-term international extension study, begun after the Phase 3 ASPEN trial for WM that compared zanubrutinib (Brukinsa) to ibrutinib (Imbruvica), has enrolled eligible ASPEN patients for the continuing collection of data. This study, called BGB-3111-LTE1, included 47 WM patients from the ASPEN trial who chose to

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transition from ibrutinib to zanubrutinib therapy. Upon enrollment in the LTE1 study, participants started zanubrutinib at 160 mg twice daily. The trial protocol was later amended to allow the choice of either 160 mg twice daily or 320 mg once daily to improve flexibility and convenience for study patients. At a median follow-up of 15.3 months, 85% remained on zanubrutinib. Despite the increasing age of patients as the study has proceeded, most of the adverse events seen during ibrutinib therapy have not recurred or worsened with the change to zanubrutinib. Disease response has been maintained or improved in 96% of evaluable patients. The data were published in the journal *Blood Advances*, and study follow-up is continuing.

Retrospective Study Analyzes Solo Ibrutinib Compared to Ibrutinib Plus Rituximab in WM – Ibrutinib (Imbruvica) and ibrutinib plus rituximab are both highly effective in treating WM; however, the benefit of adding rituximab has been unclear, and a clinical trial to compare the two regimens head-to-head has not been undertaken. Researchers at Dana-Farber Cancer Institute instead performed an analysis of three clinical trials that used either ibrutinib alone (designated I) or ibrutinib plus rituximab (designated I+R) to compare their effectiveness. The analysis, published in the journal *Blood Advances*, excluded those without *MYD88* mutations. Among 174 patients (58 treated with I+R and 116 treated with I), the overall very good partial response (VGPR) rate was comparable between the two regimens, as were the 48-month progression-free survival (PFS) and overall survival (OS) rates. However, in the subgroup of patients with *CXCR4* mutations, the I+R regimen trended toward a higher VGPR, although it was not statistically significant, and demonstrated a superior 48-month PFS (72%) compared to the I regimen (43%). The researchers emphasized the importance of CXCR4 mutation testing in WM patients considering treatment with BTK inhibitors; they also suggested that randomized prospective clinical trials are needed to compare solo BTK inhibitors to the combination of BTK inhibitors and rituximab to better characterize patient outcomes.

Phase 2 Trial Results Reported for Obinutuzumab (Gazyva) in Relapsed or Refractory WM – A Phase 2 clinical trial in Poland assessed the effectiveness and toxicity of the humanized anti-CD20 monoclonal antibody called obinutuzumab (Gazyva) for treating relapsed or refractory WM. The trial enrolled 23 participants, who received infusions of obinutuzumab at 1,000 mg on days 1, 8, and 15 during their first treatment cycle, followed by five more cycles of infusions on day 1. Patients with a response of stable disease or better entered a two-year maintenance treatment of obinutuzumab at 1,000 mg every eight weeks, followed by observation. The median duration of follow-up was 3.8 years. The overall response rate at the end of the study was 65%, with a very good partial response rate of 26% and a complete response rate of 4%. Progression-free survival was 65%, and overall survival was 74%. Serious adverse events occurred in 34.8% of patients, with infections being the most common.

…clinical trials are needed to compare solo BTK inhibitors to the combination of BTK inhibitors and rituximab…

Hungarian Study Analyses One-Day vs. Standard Two-Day Bendamustine Therapy Dosing in Indolent Lymphomas – Hungarian researchers conducted a retrospective analysis of 144 patients with indolent lymphomas, including WM, to explore the use of one-day bendamustine dosing compared to the standard two-day dosing schedule. One-day dosing was begun during the COVID-19 pandemic to reduce hospital visits for these immunosuppressed individuals. All patients during the period between 2015-2023 received bendamustine combined with either rituximab or obinutuzumab (Gazyva). Despite receiving a significantly lower cumulative bendamustine dose and being significantly older, study patients in the one-day group had similar progression-free survival, and there was no significant difference in their overall survival compared to that

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of the two-day group. Adverse events, particularly low neutrophil counts, were more frequent in the two-day group. This study was reported in the journal *Pathology & Oncology Research*.

Italian Study Determines Role of Serum Free Light Chain Ratio in Progression to Symptomatic WM – A study from Italy, presented during the 18th International Conference on Malignant Lymphoma, determined that the serum free light chain ratio is an independent risk factor for progression from the earlier stages of IgM MGUS or asymptomatic WM to symptomatic disease. This study used two Italian databases, with 613 patients diagnosed and followed between 2000-2023; patients were classified as IgM MGUS/IgM-related disorders, asymptomatic (smoldering) WM, or symptomatic (active) WM. Progression was defined as the time between diagnosis to symptomatic WM or death/last follow-up. Baseline serum free light chain results were available for 402 patients, with a normal free light chain kappa/lambda ratio designated as 0.26-1.65. The predominant (79.6%) light chain in these study patients was kappa type. An abnormal free light chain ratio was detected in 33% of patients with IgM MGUS/IgM-related disorders, in 73% of patients with asymptomatic WM, and in 77.5% of patients with symptomatic WM. With a median follow-up of 6.5 years, a higher risk of progression to symptomatic disease was seen in the earlier-stage patients who had an abnormal free light chain ratio, and this risk factor was independent of other risk factors such as lactate dehydrogenase (LDH) level, hemoglobin, and serum albumin level.

Greek Researchers Analyze Database to Determine Significance of Lymphadenopathy in WM – *The British Journal of Haematology* published a letter from a Greek research group who studied their WM database to determine the prognostic significance and clinical impact of lymphadenopathy (enlarged lymph nodes) in the disease. Their analysis included newly diagnosed and treatment-naïve patients with symptomatic WM who received treatment between 1977-2024. The presence of lymphadenopathy was assessed through clinical examination and computed tomography (CT) scans. Of a total of 707 patients with symptomatic WM, lymphadenopathy at diagnosis was present in 32.8%. Median follow-up was about 10.4 years for the group as a whole. There were no statistically significant differences at diagnosis between patients with and without lymphadenopathy in terms of age, presence of *MYD88 L265P* and *CXCR4* mutations, B cell symptoms (fevers, night sweats, weight loss, fatigue), and anemia, although the number of women was lower in the subgroup with lymphadenopathy. Median progression-free survival was lower among patients with lymphadenopathy at diagnosis (about 3.2 years), compared to those without (about 5.4 years). Overall survival was also inferior for patients with lymphadenopathy compared to those without (8.8 years vs.10.0 years, respectively).

Median progression-free survival was lower among patients with lymphadenopathy at diagnosis...

A Study from Greece Looks at Second Primary Cancers and Transformation in Symptomatic WM Patients – Greek researchers published data in the journal *Clinical Lymphoma, Myeloma and Leukemia* on the occurrence of both second primary cancers and transformation to aggressive B cell lymphoma in WM patients. This was a retrospective analysis of their database and included 677 symptomatic WM patients who were diagnosed, treated, and followed up between January 1990 and May 2024. In patients whose mutation status was available, 80.2% carried the *MYD88 L265P* mutation, and 23.2% carried mutations in *CXCR4*. The most-used treatment was rituximab with or without chemotherapy. Over a median follow-up period of 5.3 years, 8.6% were diagnosed with a second primary cancer (a new, unrelated cancer in someone previously diagnosed with cancer). The most common was lung cancer, followed by other blood cancers, colorectal cancer, gastrointestinal cancer, prostate cancer, invasive skin cancers, breast cancer, central nervous system

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cancers, head and neck cancers, and urinary tract cancers. Additionally, 3.4% developed transformation of their WM to a more aggressive lymphoma, such as diffuse large B cell lymphoma. The researchers concluded that these findings highlight the need for vigilant long-term monitoring of WM patients, even if their WM remains in remission.

US Study Looks at Underlying Cause of Death in WM Patients – The underlying cause of death in WM patients in the US was analyzed using a database from the US Centers for Disease Control and Prevention (CDC). The study, published in the journal *Clinical Lymphoma Myeloma and Leukemia*, reported that there were 11,393 deaths of WM patients between 1999 and 2020. Most died in inpatient medical facilities or in their homes. The most common cause of death was from WM (approximately 82.9%), with other leading causes including cardiovascular diseases (8.3%), chronic lower respiratory diseases (1.7%), cerebrovascular diseases (1.4%), accidental injuries (1.1%), Alzheimer's disease (0.8%), and other tumors (0.8%).

Chinese Researchers Identify Surface Marker That Distinguishes WM/LPL from Marginal Zone Lymphoma – A study from China attempted to provide more precise differential diagnosis criteria between WM/LPL (lymphoplasmacytic lymphoma) and marginal zone lymphoma, a situation which is sometimes challenging because of clinical and pathological similarities between the two blood cancers. The research, published in the journal *Modern Pathology*, looked for the expression of the surface marker CD180 on cancerous B cells in 26 WM/LPL patients and 50 marginal zone lymphoma patients. Results of flow cytometry testing indicated that WM cases exhibited a complete absence of CD180 expression, whereas marginal zone lymphoma cases, as well as normal controls, showed robust CD180 expression.

...WM cases exhibited a complete absence of CD180 expression, whereas marginal zone lymphoma cases,... showed robust CD180 expression.

Medicare Announces Second Round of Drug Price Reductions – Negotiations between the US Centers for Medicare & Medicaid Services and several pharmaceutical companies over the monthly prices of 15 common medications have concluded for the second year that the negotiation requirement has been in effect. This second round of price reductions will go into effect in January 2027 and must apply to any of these drugs available in stand-alone Part D drug plans for people with original Medicare and Medicare Advantage. The lower prices are expected to save Medicare an estimated $8.5 billion to $12 billion a year. Of particular interest to people with WM is the new maximum monthly price for acalabrutinib (Calquence) of $8,600. Other medications and their new maximum monthly prices are the following: Janumet, Janumet XR - $80; Tradjenta - $78; Breo Ellipta - $67; Linzess - $136; Trelegy Ellipta - $175; Ozempic, Rybelsus, Wegovy - $274; Otezla - $1,650; Xifaxan - $1,000; Pomalyst - $8,650; Ibrance - $7,871; Ofev - $6,350; Xtandi - $7,004; Vraylar - $770; and Austedo, Austedo XR - $4,093. Another 15 drugs will be selected for 2028, with 20 more to follow in 2029.

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.

WM UNPLUGGED: A CONVERSATION WITH DR. JORGE CASTILLO

Dr. Jorge Castillo

IWMF kicked off a new era of global connection on October 23, 2025, with its inaugural "Waldenstrom's Unplugged" webinar. Bringing together over 300 community members and global partners from around the world, this monumental virtual event successfully merged expert medical insight with essential peer-to-peer connection.

This vision was first brought to life by Steve Pine, IWMF Support Group Leader from Dallas, Texas. The IWMF Support Group Leadership Committee, including Lisa Wise, Gene Batiste, Steve Pine, Sharon Rivet, Sharon Piotrowski, Meg Mangin, Eileen Sullivan, and Shelly Postek, collaborated for months to curate a blend of personal and medical questions, ensuring a truly intimate and informative Q&A session.

A fireside chat with a WM rockstar doc

The session featured a comprehensive Q&A with Dr. Jorge Castillo of Dana-Farber Cancer Institute, one of the world's leading experts in WM. After warm welcomes from Lisa Wise (Vice-Chair of Information & Support) and Delora Senft (IWMF President & CEO), the conversation got personal. Dr. Castillo opened up about his journey from Peru and Mexico City to Dana-Farber, sharing a humbling anecdote that he never imagined reaching his current position, having once cared for rural populations "on the back of a donkey."

Moderators Gene Batiste, Sharon P., and Sharon R. took turns asking Dr. Castillo pre-submitted questions on general topics, current treatments, and treatments on the horizon. Key takeaways from the Q&A included the following:

- **Treatment philosophy:** Dr. Castillo stressed that for WM, "it's not which treatment you choose, but which treatment to choose first," emphasizing that the goal of standard care is to improve a patient's quality of life and manage symptoms. He advocates for tailoring treatment based on patient goals, other health conditions, and genomics.
- **The power of self-advocacy:** Dr. Castillo shared a powerful message for every patient, telling attendees: "You and your family are your own best advocates. You will know more about your disease than most of the doctors you will meet in your lifetime." He stressed the importance of being heard, building a supportive care team, and not going through the journey alone.
- **Research on the horizon:** Dr. Castillo provided an exciting look at the future of WM research, including new standard treatment options like non-covalent BTK inhibitors (such as pirtobrutinib) and BCL-2 inhibitors (such as venetoclax). He also shared updates on the IWMF-supported WM Clinical Trials Network (WM-NET), which is driving forward novel clinical trials using revolutionary agents like bispecific antibodies, as well as the ongoing development of a CAR T cell program.

The power of community connection

Following the main presentation, participants transitioned into 26 virtual breakout groups pre-assigned by US region, global partner, or affinity group. These groups offered a unique support setting where members could discuss the medical takeaways from Dr. Castillo's session, share their personal experiences, and offer mutual community support.

Want to learn more?

If you want to hear Dr. Castillo's journey to Dana-Farber, his advice for newly diagnosed patients, and important treatment and research updates, check out the recording today! Go to "Waldenstrom's Unplugged: A Conversation with Dr. Jorge Castillo" at *http://www.youtube.com/watch?v=ev3tFdKWPf0*.

FROM THE FACEBOOK WM SUPPORT GROUP: WINTER 2026

By Betty Ann Morton, Editor

Welcome back to a new episode of the Facebook WM Support Group saga. WM patients from all around the world (8,200 at last count) meet on Facebook at any time of the day or night to learn more about WM, to ask questions, to seek and give support and encouragement. You're welcome to join the conversation. Here is a glimpse of what has been happening in that space.

JP started a lively conversation recently. "So I did a thing here in Nebraska…I cancelled (postponed) my B&R (bendamustine and rituximab) chemo and then booked a visit to Mayo Clinic in Minnesota. After reading the information provided by the great administrators on this site and listening to everyone advising me 'to be my own advocate,' going to Mayo Clinic was the obvious choice. Too many treatments had been prescribed that conflicted with NCCN/IWMF articles. (The National Comprehensive Cancer Network publishes *NCCN Clinical Practice Guidelines in Oncology*.) When I asked my current hematologist/oncologist how many WM patients he sees, he stated 1-2 a year. NOPE! Thank you again for this site!"

JP elaborated. "The straw that broke the camel's back was that my IgM was listed as greater than 5,850 mg/dL. If 5,850 was the machine's top measure, how were they going to determine if I had an IgM flare during B&R treatment? Could they determine whether the IgM was decreasing? I loved my doctor. He was caring and knowledgeable, and the staff were professional and very helpful. But too many things didn't line up."

GP wrote back, "Hi **JP**! When I asked my doctor how many other WM patients he had, I got a vague reply that I interpreted as 'not many.' Because I was gifted a tumor (now gone) by my WM after 11 plus years of no overt symptoms, it dawned on me that I didn't know a lot about this diagnosis. Not long afterwards I found this fantastic group. Besides learning so much, I now know there is a WM specialist close to where we will be moving next year. You did indeed make the right decision. Best of luck at Mayo."

KH added her own personal experience at Mayo. "I went to Mayo in September mainly for a non-WM reason, but while there I also saw Dr. N. Nora Bennani, a hematologist who is very knowledgeable about WM, as well as another oncologist. I already had faith in my local team, and both Mayo oncologists reaffirmed that my local team is on the right path and said, 'Relax: you don't need treatment yet and don't be concerned about what meds you may need if or when it may happen.' New meds for treatment are changing and what works today may be totally different for me tomorrow. Good luck. You will love it. There are some good restaurants there too. My sisters and I were partial to the Irish Pub. Personally, I could have eaten at Victoria's (Italian) every day…"

JY added a unique endorsement. "Excellent! Wise choice. The physicians work together. They go over the cases together. I know from personal experience, and I worked there for over 20 years." **PH** contributed another perspective about placing priority on expert medical care. "I moved across the country for a similar reason. My small hospital back East, in the mountains, might have had 2-3 oncologists who had to deal with every cancer that walked in. I decided to move to the Seattle area for The Hutch (Fred Hutchinson Cancer Center in Seattle, Washington). I had kids out here so that made it an easy choice. Good luck in Minnesota!"

A few weeks later, **JP** posted again. "Update on my trip to Mayo Clinic. I posted several weeks ago that I was headed to Mayo because some of the information I was getting from my doc in Omaha didn't match what I was learning here on this site and what I read from IWMF. Mayo was hard…so many tests; with my symptoms of anemia, PN (peripheral neuropathy), and more, it wore me down. But today the doc at Mayo recommended WATCH-and-WAIT on the Waldenstrom. NO CHEMO AT THIS TIME!!!! To think I was scheduled for November 11 for my first round in Omaha. The Mayo doctor was worried I had another cancer. He needed to rule out many things. Diagnosis

From the Facebook WM Support Group, cont. on page 18

is iron deficiency that is causing symptoms. Things like the low (20%) bone marrow involvement and the consistent IgM, although highish (around 3,000 mg/dL) and normal platelet numbers, to list a few, led him to look for more information. The moral to the story: Trust your gut! Be your own advocate! Read! Read! Read!! Seek out experienced Waldenstrom doctors!! And pray."

WM patients discuss their health concerns often, and not just WM. Although WM is the primary focus, group members frequently have questions about other health issues and how WM might impact possible treatment—or vice versa. For example, **KG** recently posted this question: "Has anyone in watch-and-wait stage had cataract surgery, or is that not advisable?" A quick response from **AMDV** read, "I had it on watch-and-wait with no issues. Please consult with your doctor first though." Patients generally agreed that their experiences had been positive. **BAM** wrote, "WM is not usually a barrier to cataract surgery. I was in treatment when I had my cataract surgery without problems. Do check with your doctor to be sure there's nothing unique about your situation which could cause problems and let the ophthalmologist know you have WM. Enjoy your improved vision."

Some WM patients had more challenging experiences with cataract surgery. **DDM** said, "I just had one eye done. The meds messed me up a bit; I didn't want to wake up. I guess that's what happens when you're anemic." **ZB** wrote, "I was recommended for cataract surgery three years ago. But due to my situation, all felt a specialist was needed. So, ask questions and talk to your doctors about your specific needs."

ND had a minor complication that developed later. "I had both eyes done following four rounds of B&R. Two years later I had both eyes lasered due to scar tissue. Apparently, that is typical, so keep it in mind. I had no issues with either procedure."

Medication side effects are often discussed. **JLG** wrote, "I'm a man in my 70s. I have been on Brukinsa (zanubrutinib) for six months and feel much better. However, I have noticed that I bruise and bleed much easier. Skin breaks easily and just removing tape from my skin leaves significant bruises. Anyone else experienced this?"

ES wrote, "Although Brukinsa is not a blood thinner, it 'messes with' platelet function, so it is famous for causing easy bruising. I'm surprised that they didn't advise you in advance." **GR** had similar experiences. "Yes, I find bruises even when I don't remember bumping myself. My body looks a mess at times, especially after rock climbing and I don't even realize at the time that I am getting battered about. Brukinsa is my wonder drug though, and I don't mind the bleeding and bruises because I feel so healthy on it. One reason we bruise and bleed is because it decreases platelets which we need for blood clotting."

MCM added, "BTK (Bruton's tyrosine kinase) is crucial for platelet signaling. Platelets use BTK as part of their signaling cascade for activation and aggregation in response to vascular injury. By inhibiting BTK, zanubrutinib impairs platelet function even though it does not reduce platelet count." **GR** continued the conversation, saying, "**MCM**, my platelets dropped from 579 to 281 within a month of starting zanubrutinib. They are now stable at a 'normal' 329, though I agree that the clotting factors don't work very well."

MCM replied, "**GR**, thanks. I'll correct my information." Then **MCM** addressed the original poster. "**JLG**, bruising is a common (25%) hematologic side effect of Brukinsa. If you can't tolerate this side effect, ask your doc about a dose reduction. Side effects often go away, or lessen, after decreasing the dosage." **MCM** later commented in an email to **BAM**, "Until **GR** mentioned it and I checked it out, I thought BTK inhibitors didn't reduce the platelet count. It's a good example of how we all learn from each other." Even longtime WMers learn from our Facebook Support Group's conversations!

Because WM is so different from other cancers, there is much to learn and group members answer many basic questions. Recently **AW** wrote, "My husband has WM fourth stage because it is in the bone marrow. Does that mean it should be treated?" **JBS** wrote, "The doctor told my hubby the same thing

From the Facebook WM Support Group, cont. on page 19

about his WM: Stage 4, but it isn't like other cancers so that's not a death sentence like it sounds." **RS** quickly explained, "WM starts in the bone marrow. There are no stages for WM. If your husband isn't experiencing symptoms, treatment isn't usually recommended."

CS agreed. "My Dad had his initial oncologist panic about WM being in the bone marrow and recommended treatment. We found a new oncologist through *www.iwmf.com* who said the same thing you did, **RS**. He's now been on watch-and-wait for about a year. I'd recommend the original poster get a second opinion—preferably from someone recommended through IWMF." **MCM** summed up the situation for the original poster. "His doctor may have told him that his WM is "stage 4," but WM isn't staged. Staging a cancer diagnosis refers to the extent of the disease, such as how large the tumor is and if the cancer has spread from the original site. Other cancers are staged to determine the need to treat and the chances of survival. But WM is a lymphoma that is a 'liquid' tumor; it affects the blood, bone marrow, lymph, and lymphatic system, so it's not staged in this way. Stage 4 in other lymphomas means it's progressed to the bone marrow, and WM always begins in the bone marrow, so labeling WM as a stage 4 cancer creates unnecessary panic."

Note: The Facebook WM Support group is open to WM patients and their family members and other support people. 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 941-927-4963 or email to *office@iwmf.com.*

NEW SUPPORT GROUP LEADERS

Compiled by Sharon Rivet, Support Group News Editor

Tania Soussan-Watt, Leader, New Mexico Support Group

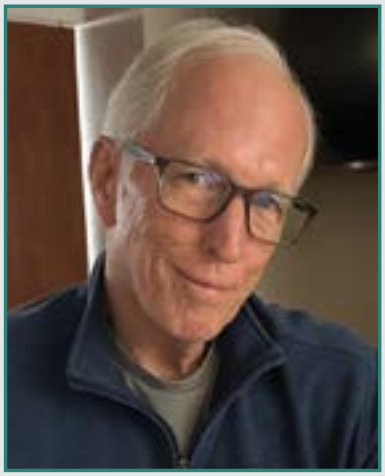
Like so many others, I was diagnosed with WM after bloodwork ordered for other reasons detected M protein. That diagnosis in March 2021 was very scary, and good information seemed nonexistent. Even my doctors had no clear answers.

It was such a relief to find IWMF. The resources on the website, Connect, and Facebook groups helped me to finally feel a little less alone and more hopeful. What has been missing for me is a group where I could talk more directly with other WM patients. My hope is that starting a New Mexico support group will give others in the state a place to find connection and to share stories and resources.

A little background about me: I worked for 20 years as a newspaper journalist and then switched to freelancing editing and writing. I also work part time from home as a writer for an energy and sustainability consulting company. My daughter is in her first year of college, and my husband (a retired photographer) and I are adjusting to life without her around. When I'm not working, I enjoy hiking, making stained glass, reading, and baking.

Steve Sundsby, Co-Leader, Central Texas Support Group

"Something is wrong with your blood." In the fall of 2024, that started my journey with WM.



I'm Steve, a 72-year-old retired business executive. After learning that I had WM, I undertook a project to learn all I could about the disease. It did not take long to find IWMF. What a resource! It is the gateway into a world of biology, pharmacology, and case studies to give me hope that I will die with WM, but not necessarily because of it.

My wife of 50 years, who has been beating multiple myeloma since 2017, lives with me on our ranch in the Texas Hill Country. I stay busy on our property but have always been athletic and still hike, work out, attend yoga sessions, hunt, and ski. I have not started treatment yet and have had only slight symptoms, but I am educating myself to be ready for it. In that regard, IWMF Connect (an online IWMF discussion forum) is a wonderful way to learn about real patients' experiences with WM and their treatment regimens.

I reached out to IWMF to learn if there is a support group in San Antonio. An Austin group was recently formed, and I volunteered to help lead the new Central Texas Support Group. I look forward to sharing information, concerns, and support with my fellow WM wayfarers.

New Support Group Leaders, cont. on page 21

Gene Batiste, Co-Founder, LGBTQ Affinity Group One year and two months ago, I boarded a flight as I had countless times before—briefcase in hand, mind already on the work waiting for me when I landed. But that day, May 9, 2024, as I was attempting to put my bag in overhead storage, I received news that quietly redrew the contours of my life: you have Waldenstrom macroglobulinemia (WM).

The words felt almost abstract at first. I was asymptomatic, healthy in every way I could measure. No aches, no fatigue, no outward sign that something rare and unseen had taken root in me. And so, I carried that diagnosis onto the plane, tucked into the same pocket as my boarding pass, and sat with it in silence at 30,000 feet. Just over a month before this experience, I was hospitalized with acute anemia which involved tests, a blood transfusion, and later, an iron infusion.

Since then, I've often described my life since my diagnosis as being strapped into a roller coaster I didn't ask to ride. There are climbs of hope, plunges of fear, loops of uncertainty—and yet also surprising vistas of beauty when the car slows and I can look around at who is beside me.

Within two months of that flight, I found IWMF, and through it, a community of people who understood this strange new world. Their presence helped me replace isolation with connection. I joined the Northern Virginia, Washington, DC, and Maryland Support Group and the WM People of Color Affinity Group, where I heard stories that mirrored and expanded my own. And, with encouragement, I co-founded the WM International LGBTQ Affinity Group—because living fully with this disease also means honoring every part of who we are.

I have not walked—or ridden—this metaphorical roller coaster alone. My husband, my family, and my closest friends have been the ones who steady me when the ride lurches, who laugh with me when I need lightness, and who remind me that love is stronger than fear.

Living with WM is not about denying the diagnosis or minimizing the roller coaster of emotions. It is about learning to ride with both hands open—sometimes gripping tightly, sometimes letting go, and always looking for moments of grace in the turns.

And perhaps, in the end, this is what any of us can hope for: to discover that even when life takes us on an unexpected ride, we are never truly alone.

NEWS FROM THE NORTH: THE CANADA REPORT

By Anne Moffat, Waldenström's Macroglobulinemia Foundation of Canada (WMFC)

A record number of Canadians with WM registered for sessions in both French and English at the recent WMFC 2025 Virtual Education Forum, held in Toronto. Nearly 300 registrants eagerly absorbed the following presentations from renowned WM experts:

- An updated overview of WM from Dr. Christine Chen at Princess Margaret Cancer Centre in Toronto and Dr. Rayan Kaedbey of Quebec;
- A talk on the latest and future research in WM by Dr. Steven Treon from Dana-Farber Cancer Institute in Boston, and Dr. Patrizia Mondello of the Mayo Clinic in Rochester;
- Inspiring suggestions for living well with WM by Dr. Shirley D'Sa of University College Hospital in London;
- A description of the patient experience, including participation in clinical trials, by Dr. Neil Berinstein, lead researcher of the BRAWM clinical trial at Sunnybrook Hospital in Toronto;
- A discussion by Dr. Christopher Venner from British Columbia of "the weird stuff" in WM: Bing Neel syndrome, amyloidosis, cold agglutinin disease, peripheral neuropathy, and transformation to diffuse large B cell lymphoma;
- An outline of treatments for WM available across Canada's ten provinces by Dr. Carolyn Owen of Alberta and Dr. Jean Sebastien Claveau of Quebec;
- Answers to patient questions fielded by Drs. Steven Treon, Neil Berinstein, and David MacDonald in an "Ask the Doctor" session.

Videos of these presentations are now available at *www.wmfc.ca.*

Getting the word out to Canadian doctors

In Canada, most oncologists treat very few WM patients but treat many more patients with related blood disorders like multiple myeloma and chronic lymphocytic leukaemia (CLL). In an effort to increase physician awareness of our disease and improve treatment for Canadian WM patients, WMFC Board Member Gloria McNeill attended the International Myeloma Symposium (IMS) held at the Toronto Convention Centre last September. Gloria volunteered in Dr. Steven Treon's booth "Waldenström's Workshop 2026" along with Chris Patterson from the Dana-Farber Cancer Institute.

During the IMS, Gloria met and talked with many Canadian doctors who either treat WM or do research on WM. Additionally, she distributed WMFC brochures and handouts announcing the WMFC Educational Forum, in expectation that the doctors would pass along the information to their patients, and they did! Thanks to Gloria for getting the word out to Canadian doctors.

Dr. Steven Treon

Coming up in Canada

Learn more about your immune system from Haematology Consultant Dr. Dima El-Sharkawi, of The Royal Marsden NHS Foundation Trust, The Institute of Cancer Research, London, who will talk about "Waldenström's and Your Immune System" in a webinar on January 22, 2026.

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Dr. El-Sharkawi's special interests are in lymphoma, CLL, and the mature lymphoid leukaemias. She is the lead for the clinical advisory group for WMUK, the United Kingdom support organization, and an author on the British guidelines for the diagnosis and management of WM. See *www.wmfc.ca* for more information.

Chris Patterson, Gloria McNeill, and Dr. Steven Treon at the IMS conference

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.

A REPORT FROM WALDENSTRÖM FINLAND

By Jukka Sneck

Waldenström Finland, a national organization founded and led by patients, was launched six years ago. We bring together patients living with Waldenström macroglobulinemia (WM) and their relatives, working together to improve the lives of all those living with WM in Finland.

Finland has about 350 WM patients. Our association has about 50 members; most are patients, some are family members, and others are business support members. Our Board has seven members, and their responsibilities are divided: chairperson, secretary, accountant, and those responsible for membership, a Facebook group, and so on. We meet about once a month to plan and implement our activities.

Juha Wirekoski and Jukka Sneck

Our activities

We have monthly online peer support meetings, our own closed Facebook group, and a WhatsApp community with some subgroups. We had a temporary fundraising campaign last spring, and the result exceeded expectations.

Our most-liked activity is our annual full day, face-to-face meeting. Since the pandemic closure, we have had four of these meetings. Our objective is to bring together WM patients, all in different phases of their WM, to discuss their concerns with each other.

The following agenda of the meetings has been much appreciated:

- Opening the event and presenting the speakers
- Check-in round, when each participant gives a short 1-2 minute presentation about her/himself
- Welcome lunch – discussions have always been lively in the lunchroom
- Expert lecture and discussion on topics such as latest treatment options, nutrition, exercise
- News from IWMF – Hannah Syed, IWMF Global Partner Engagement Consultant, has joined our meetings. This is important to us to help feel we are not alone in the world with WM.
- Discussions in small groups while having afternoon coffee and refreshments
- Conclusions of group discussions presented in a meeting of all attendees
- Written feedback of the day on sticky notes
- Check-out round, with each participant describing his or her feelings about the day

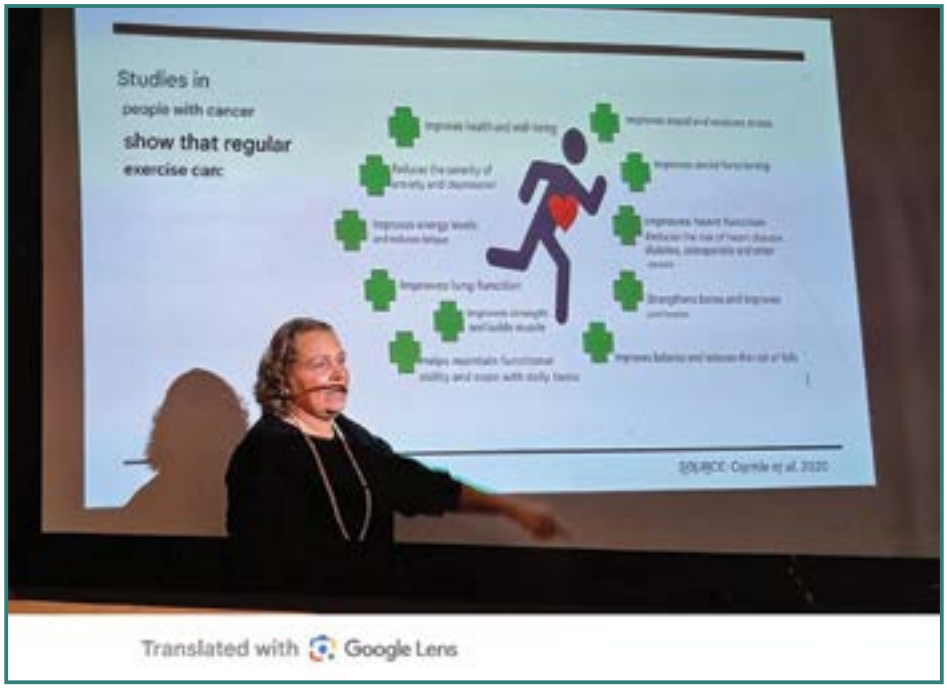
The August 2025 meeting

The latest face-to-face meeting was held in August 2025, and 30 people attended. The event was led by Juha Wirekoski and Jukka Sneck.

The topic of the expert lecture was exercise, presented by Mari Koski. She noted that any exercise, even a little, is better than none and promotes health. Likewise, you don't need expensive equipment if you just want to move. You must exercise according to your own abilities, and you need to be kind to yourself. Don't demand too much. Many effects of exercise, both psychological and physical, were also highlighted. Humans are holistic beings.

The discussions in small groups were fruitful. We heard many new ideas, both personally for

A Report from Waldenström Finland, cont. on page 25



Mari Koski

living with WM and for developing the activities of Waldenström Finland.

Future event

We have started to plan our next face-to-face meeting; preliminary dates are August 18-19, 2026. We are planning to have a two-day meeting, and the first day will follow the agenda described above. The evening of the first day and the forenoon of the second day will be less organised, with more free time together. This is our plan, and while financing the event might be a problem, we are working to solve it.

Waldenström Finland wishes all the best to all WMers around the globe.

Some of Waldenström Finland's active volunteers

THE IWMF GOLF CLASSIC

By Tom Allen

When the idea of an IWMF golf fundraiser was conceived by three childhood friends from Pennsylvania, no one imagined it would lead to the extraordinary result achieved at Saucon Valley Country Club's Weyhill Course, September 11, in Bethlehem, PA. The commitment of friends Scott Heiser, Tom Allen, and Scott Noga and the adventurous spirit of former IWMF CEO Newton Guerin and IWMF Board Member Craig Prizant led to the IWMF Golf Classic raising more than $47,000 for the Accelerate the Cure campaign.

The golf course had always been a hallowed place for these three friends, and it is where Tom Allen shared his WM diagnosis. As Tom was the highest handicap of the trio, Scott Heiser and Scott Noga suggested in jest a fundraiser to further WM research and keep Tom healthy to ensure they would always have an easy win on the course. With that joke, the golf tournament fundraising idea was born.

Planning commenced in 2024 with Scott Heiser, a Saucon Valley member, securing a coveted charitable tournament allocation from the club, and approval was given by Newton Guerin and IWMF Vice Chair Carl Harrington. As the event drew nearer, additional committee members were recruited to see everything to fruition: IWMF staff members Kellye Jacob and Robin Tucker, Craig Prizant, Tom's wife Jamie Huffcut, and their family friends Lynne Tracy and Pat Flannery. An additional nine friends assisted in marketing the tournament.

Craig Prizant and Pat Flannery's non-profit fundraising counsel proved invaluable during the eight-month marketing campaign. All 72 golfing spots were sold, and 61 company and individual tournament sponsors were secured for the event. Ninety percent of all sponsorship funds contributed came from people or companies not affected by WM. Lead sponsors included the Select Equity Foundation, DeBenedictis Family Foundation, and Johnson Controls, Inc.

Scott Noga

The IWMF Golf Classic, cont. on page 27

The tournament was played in a team format among foursomes. The foursome from Washington, DC, real estate developer Renaissance Centro was victorious with a score of nine under par. In addition to the foursome competition, all golfers took part in five contests, including two long drive competitions and two closest-to-the-pin competitions. The winners were rewarded with gift cards to Saucon Valley's pro shop. A hole-in-one contest also took place on Weyhill's signature hole, the iconic par-3 14th that requires golfers to hit over an old limestone quarry from 175 yards away. The contest prize was a trip for two to the 2026 Master's Tournament. In riveting play, three golfers came within two feet of the pin, but no one took the enviable prize in the end. Thanks to generous sponsors, all golfers walked away with a Saucon Valley golf cap and a dozen Titleist Pro-V1 golf balls emblazoned with IWMF and Select Equity Foundation logos. Sponsors also treated the golfers to lunch, on-course snacks, and endless beverages of their choice.

The memorable day culminated with a sunset cocktail reception and awards dinner at the main clubhouse, overlooking Saucon Valley's three championship courses. Carl Harrington awarded the prizes as photos from the day filled the screens. Carl's thankful message to the golfers, sponsors, and volunteers radiated hope for the future. And while only two individuals at the entire event carried a WM diagnosis (Carl and Tom), the WM community can now take comfort that regardless of never having heard of WM prior to the tournament, a whole new audience stood up to learn about WM and join IWMF in accelerating the cure, with just the swing of a club.

Winning foursome from Renaissance Centro

WALDENSTRÖM FRANCE'S WEBINAR AND RARE DISEASE MARCH

On October 16, 2025, Waldenström France (WF) organized an engaging and informative webinar entitled "Everything You Always Wanted to Know About Waldenström Disease (But Were Afraid to Ask)."

This event welcomed over 90 participants, including patients, caregivers, and healthcare professionals eager to improve their understanding of Waldenström macroglobulinemia (WM).

The session was divided into three parts. First, Mme Valérie Debaix, President of WF, gave a short introduction, explaining the outline of the meeting and providing some technical details for the use of Zoom.

Then, a 30-minute presentation by Dr. Pierre-Edouard Debureaux, clinician and researcher at Saint Louis Research Institute, Paris, offered a clear and accessible explanation of WM, its mechanisms, and current treatment options.

Last but not least, this presentation was followed by a 60-minute Q&A session, in which participants asked numerous questions about diagnosis, daily life with WM, and emerging therapies. All those questions were answered with clarity and empathy by Dr. Debureaux, highlighting the role of psychological support and patient engagement in care.

This webinar was a success, combining medical expertise and clear explanations. It reaffirmed Waldenström France's commitment to supporting patients through information, education, and dialogue.

In other news, on December 6, 2025, the Waldenström France Association joined the Rare Disease March in Paris organized by the Alliance for Rare Diseases as part of their telethon.

In mild weather, more than 2,000 people walked the seven-kilometer route starting from the Luxembourg Gardens, making their way through the streets of Paris and passing not far from Notre Dame. This participation aimed to raise awareness of Waldenström France (WF)—1,300 new patients every year in France—and to raise funds for the telethon.

Waldenström France members at the Rare Disease March

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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