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INSIDE THIS ISSUE

THE 11TH ANNUAL ECWM IN ATHENS: A MEETING CENTERED AROUND THE MEANING OF TIME

By Lisa Marie Kaiser

Lisa Marie Kaiser and Prof. Christian Buske

Lisa Marie Kaiser is a German biomedical researcher affiliated with the University Hospital Ulm, Germany. Her work focuses on B cell malignancies, especially Waldenström's macroglobulinemia, including translational and therapeutic approaches in hematologic cancers. Together with Prof. Christian Buske, she is also involved with the European Consortium for Waldenström's Macroglobulinemia (ECWM), where she serves as Administrative Director, supporting international collaboration and coordination in Waldenström's research.

The 2026 European Consortium for Waldenström's Macroglobulinemia meeting in Athens, Greece, brought together 81 physicians and researchers from across Europe and the United States, united by a single, powerful theme: *chronos*—time as the key factor in the management of WM. Hosted at the Athens Capital Hotel, the venue offered breathtaking rooftop views of the Acropolis, as well as a curated art collection reflecting Greek culture and creativity.

The meeting was opened by Prof. Christian Buske, coordinator of the ECWM, together with Lisa Marie Kaiser, whose dedication was instrumental in organizing the event. Their remarks set the tone for a meeting shaped by the concept of time. As Aristotle defined it, time is "the number of motion in respect of before and after"—a notion closely aligned with *chronos*, the measurable progression of events. In this sense, time is not a substance in itself, but a way of describing change. Yet Greek thought goes further, distinguishing not only measurable time but also the right moment and the broader flow of existence.

A particularly memorable opening came from Steve Kershaw, whose Vision talk drew not only on Greek mythology to frame the meeting's theme, but also on Pallas Athena, the patron goddess of the city. Kershaw, a classicist and scholar based in Oxford, UK, doesn't just recount myths—he explores what they mean, and why they still matter. We learned more about *chronos*, the linear, measurable

The 11th Annual ECWM in Athens, cont. on page 3

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The 11th Annual ECWM in Athens, cont. from page 1

progression of time; *kairos*, the opportune moment for decisive action; and *aion*, representing eternal or cyclical time. This distinction was central in Greek rhetoric, tragedy, and ethics. A physician such as Hippocrates, for instance, would think in *kairos* terms when deciding the exact moment for intervention.

Together, these concepts provided a compelling metaphor for WM care and fueled the discussions with central questions, such as focus on duration and change in patient care (*chronos*). How long should we observe in a watch-and-wait phase? What is the optimal length of treatment? And how can treatment-free intervals be extended and optimized through different strategies and sequences? *Kairos* (interlinked with *chronos*) focuses on choosing the right moment to intervene. When is the right time to start, stop, or change a therapy? And how should treatments be sequenced to best align with these key decision points? And, most importantly, how can we appreciate the long-term journey of patients over time? *Aion*—lifetime, continuity, and eternity—brings the broader perspective. How can we maximize both survival and quality of life and move closer to the goal of cure? With this adding a deeper philosophical dimension, it gently reminds physicians of something essential: their shared humanity and their responsibility to use knowledge and intelligence not only to understand disease, but to serve the people living with it.

One of the most emotional moments of the meeting was the standing ovation for Paul Kitchen, who presented the perspective of International Waldenstrom's Macroglobulinemia Foundation (IWMF) and his own story during the session "*Chronos*: giving time to our patients." His remarks reinforced the central theme: that beyond science and data, time is ultimately about the lived experience, the journey of patients and their families.

Panel for the session "The Future: The Young ECWM"

Predicting progression to symptomatic WM

A major focus of discussion was the prediction of progression from IgM MGUS to symptomatic WM. While multiple prognostic scoring systems exist, they remain heterogeneous—largely due to inconsistent definitions distinguishing IgM MGUS from asymptomatic (smoldering) WM—and currently lack clear clinical utility. A key proposal emerged: to develop a unified prognostic model encompassing all asymptomatic patients, grouping IgM MGUS and asymptomatic WM together. Such

The 11th Annual ECWM in Athens, cont. on page 4

a tool could offer patients a clearer expectation of when symptoms—and therefore treatment—might arise. This initiative is being led by Prof. Monique Minnema from the Netherlands and Dr. Saemundur Rögnvaldsson from Iceland, with further discussions planned at the International Workshop on Waldenström's Macroglobulinemia (IWWM-13) in Palm Springs (October 2026) and a manuscript already in preparation on behalf of the ECWM.

Clinical trial updates

Clinical trial ECWM-1 demonstrated that *TP53* mutations predict inferior outcomes across treatment modalities, including R (rituximab)-chemotherapy and bortezomib-based regimens. At the same time, DRC (dexamethasone, rituximab, cyclophosphamide) ± bortezomib emerged as a highly effective and generally well-tolerated approach, capable of inducing long treatment-free intervals and excellent overall survival.

ECWM-2 showed that combining bortezomib with the covalent BTK inhibitor ibrutinib and the monoclonal antibody rituximab leads to remarkable disease control, with very few progressions after approximately 50 months of follow-up. Notably, some patients discontinuing ibrutinib because of side effects maintained remission without requiring further therapy.

ECWM

European Consortium for
Waldenström´s Macroglobulinemia

The CZAR-1 and VIWA-1 trials highlighted two important directions in WM research. The CZAR trial, studying the combination of carfilzomib and ibrutinib, focuses on a smarter combination of covalent BTK inhibitor and proteasome inhibitor, avoiding the potential nerve damage of bortezomib but keeping the very high efficacy seen in the ECWM-2 trial. The actively recruiting VIWA-1 trial is the first worldwide to compare classic time-limited R-chemotherapy with a fixed duration, chemo-free approach (rituximab plus the BCL2 inhibitor venetoclax) in a randomized prospective trial. This trial will be pivotal for understanding the role of chemotherapy-free regimens given for a limited pre-defined time period in the first-line management of WM, in which R-chemotherapy is still widely used.

Emerging therapies

Emerging therapies were also discussed, including epcoritamab (bispecific antibody immunotherapy) and CAR T cell approaches. Early data on epcoritamab—though limited to just four evaluable patients—show promising responses without significant toxicity signals. However, these findings remain preliminary, and a critical gap persists: there is currently no active CAR T cell program specifically for WM. The meeting emphasized the urgent need for collaborative clinical trials with industry partners to advance this field.

The role of *TP53* alterations

Another evolving area is the role of *TP53* alterations in high-risk WM. Evidence continues to accumulate that these mutations confer poorer outcomes not only with R-chemotherapy but also with covalent BTK inhibitors. This has sparked ongoing debate about whether *TP53* testing should become routine in clinical practice. However, despite these inferior outcomes, BTK inhibitor-based therapy may still perform better than R-chemotherapy in this subgroup, which is why there is interest in whether these patients should preferentially receive BTK inhibitor-based approaches.

Collaboration and the future

A central theme of the meeting was harmonization of global efforts. The ECWM and the US-based clinical trial group WM-Net are actively working toward closer collaboration, including the formation of a joint steering board to develop a global translational and clinical roadmap for WM. The steering board is already being established, consisting of four members from the ECWM, four members from WM-Net, and two delegates from IWMF.

The 11th Annual ECWM in Athens, cont. on page 5

The Grand Debate: Steve Treon, Troels Hammer, Damien Roos-Weil, Stathis Kastritis, Josephine Vos, Prashant Kapoor, Lia Palomba, Jorge Castillo, Sheeba Thomas, Christian Buske

This spirit of cooperation culminated in the Grand Debate between the two groups, addressing the question: Where are we now, and where should we go? The discussion, led by Prof. Buske and by Dr. Steven Treon from Dana-Farber Cancer Institute in the US, underscored the importance of transatlantic alignment in both research and patient care. Both doctors play a key role in strengthening the transatlantic partnership in the interest of patients worldwide.

One funny moment came at one of the brainstorming sessions, after hearing all the future concepts and clinical trials, when the panelists were asked which future treatment concept from the ECWM they would support. They went through the experts one by one, and every single person answered "MOZART," which was amusing because, despite the "Debate" format, there was no debate, everyone ultimately agreed to the concept. The W-MOZART trial was presented by Prof. Buske as a particularly promising future concept. The idea is to combine two potentially powerful therapeutic classes, including bispecific antibodies and BTK inhibitors, with the goal of improving efficacy while also converting continuous BTK inhibitor therapy into a fixed-duration, two-year treatment approach. Another important concept is the possibility that combining bispecific antibodies with zanubrutinib could help reduce some of the toxicities associated with the bispecifics.

What stood out during the discussion was the remarkable level of consensus among the experts as described above. It was clearly important for the participating pharmaceutical companies to hear such a unified voice supporting this as a promising future direction. We need to speak with one voice in order to move forward!

Looking ahead, one of the most inspiring moments was "The Future: The Young ECWM." Thirteen young investigators entered the room to applause and the iconic strains of "We Will Rock You" by the music group Queen, symbolizing the next generation's commitment to advancing WM research and care. The group, founded in 2025 by Lisa Marie Kaiser, has quickly become a vital cadre of young, devoted physicians and researchers that meets regularly and shares ideas and collaborations across Europe.

Shared experiences beyond the meeting

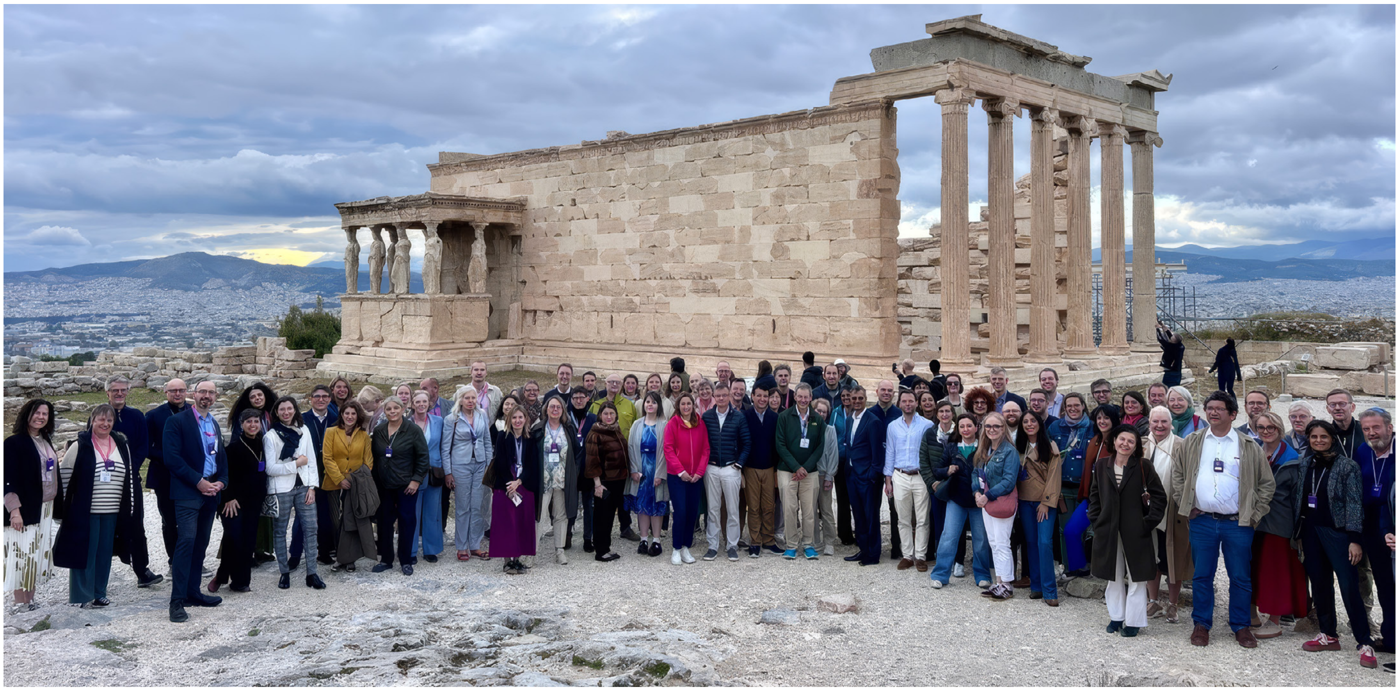
The social program added a special dimension to

The 11th Annual ECWM in Athens, cont. on page 6

the event. Participants explored the Acropolis of Athens on a guided tour, deepening their connection to the city's history. The highlight for many was an unforgettable dinner beneath the Parthenon, where colleagues shared ideas and experiences under the illuminated monument—an inspiring setting that perfectly captured the meeting's blend of science and humanity.

A lasting impression

The ECWM Athens 2026 meeting was, by every measure, a success. It combined scientific rigor with philosophical depth, always keeping patients at the center. With the European Educational Forum directly integrated into the meeting, the message was clear: time in WM is not just about disease biology—it is about people. What made this gathering truly stand out was its sense of connection: between physicians, researchers, and patients; between science and philosophy; and between individuals united by a shared goal—to make a meaningful difference. Progress in WM is not only about new discoveries, but also about how we use time—how we understand it, measure it, and, most importantly, give it to patients.



ECWM attendees at the Erechtheion, on the Acropolis, Athens

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CHRONOS AND CONNECTION: THE EUROPEAN EDUCATIONAL FORUM

By Hannah Mobarak, IWMF Global Partner Manager

Chronos, the ancient Greek word for time, proved a fitting lens for our 4th Annual European Educational Forum (EEF), held on 24 April in Athens, Greece. The concept of time—how it is understood, managed, and ultimately returned to patients—ran as a subtle but constant thread throughout the meeting. In WM it is more than a measure; it shapes care, influences decisions, and affects quality of life.

European
Educational
FORUM

It was a privilege to once again convene the international WM community—patients, carers, clinicians, and researchers—creating space to learn, connect, and strengthen the collaboration that defines this field. As in previous years, we partnered with the European Consortium for Waldenström's Macroglobulinemia (ECWM), aligning our Forum alongside their annual meeting of leading experts. Inspired by ECWM's focus on time, we reflected this theme across our own programme. Close collaboration with Lisa Kaiser and Prof. Christian Buske ensured a balance of scientific excellence and community relevance, and their guidance was instrumental in delivering a successful and meaningful event.

What stood out immediately was the breadth of our community. Attendees travelled from across Europe and beyond—including Greece, Germany, UK, US, France, Denmark, Switzerland, Spain, Türkiye, Sweden, Finland, Italy, the Netherlands, Canada, and Chile—making this our most internationally diverse EEF to date. This diversity reinforced a powerful truth: while WM is a rare condition, the global commitment to improving patient outcomes is vast and deeply connected.

We were honoured to welcome Delora Senft, President and CEO of IWMF, who was attending for the first time. Opening the session, she spoke to patients, carers, and clinicians, emphasising the importance of coming together in person—of sharing time, knowledge, and lived experience. She highlighted the global impact of IWMF, and alongside Paul Kitchen, IWMF Board Chair, presented the IWMF Impact Awards, recognising outstanding contributions in patient support, research, and partnership.

Prof. Buske introduced the work of the ECWM, a network of experts spanning 17 European countries. Hearing about their collaborative efforts—and witnessing them firsthand during the preceding ECWM meeting in Athens—was truly inspiring. The strength of collective endeavour, including the emerging contributions of the Young ECWM group, signals a future where research and care continue to accelerate. Their invitation to future meetings, including Oxford, England, in 2027 and the International Workshop on WM (IWWM-13) in Palm Springs, CA, reflects an ongoing commitment to shared progress.

One of the most dynamic elements of the day was the interactive research poster walk. Young ECWM researchers presented their work directly to attendees, creating space for dialogue and curiosity. From insights into familial WM and genetic risk to patient perspectives shaping treatment decisions, these sessions demonstrated how the next generation of researchers is already influencing the trajectory of WM care. Their work is not only advancing science—it is reshaping how time is experienced by patients, from earlier diagnosis to more personalised treatment pathways.

Sessions addressing associated conditions provided valuable clinical insight. Under the title "When Time Complicates the Picture," Prof. Monique Minnema and Dr. Efstathios Kastritis explored complications

Chronos and Connection, cont. on page 8

Chronos and Connection, cont. from page 7

such as peripheral neuropathy, cryoglobulinemia, amyloidosis, and Bing-Neel syndrome. These discussions highlighted the complexity of managing these conditions and their impact on the patient experience and overall outcomes.

Equally impactful were the sessions grounded in lived experience. Paul Kitchen's personal treatment journey illustrated the realities of navigating WM over time, complemented by clinical insights from experts including Jennifer Russell, Prof. Buske, and Prof. Shirley D'Sa. Meanwhile, the support group session with Global Partner patient advocates Bob Perry (WM Ireland), Susanne Öhrn (WM Scandinavia), Michael Bentley (Hematon of the Netherlands), and Gloria McNeill (WMFC of Canada) highlighted the essential role of community—how connection can transform the passage of time for those living with WM, offering understanding, reassurance, and shared strength.

Looking ahead, discussions on clinical trials and future therapies brought a forward-looking dimension to the programme. Prof. Maria Gavriatopolou emphasised the importance of clinical trial participation, while Dr. Steven Treon shared developments in next-generation treatments currently under investigation. These sessions reminded us that time is also about progress—about the therapies on the horizon that may redefine what it means to live with WM.

The "Ask the HCP" panel brought together leading experts Dr. Treon, Prof. Gavriatopolou, Prof. Minnema and Prof. Buske to discuss real clinical cases and questions, bridging the gap between research and practice. It was a fitting reflection of the Forum's purpose: to create space where knowledge is exchanged openly and meaningfully.

As organisers, we were deeply grateful to every speaker who contributed their time and expertise. The richness of perspectives—from seasoned clinicians to emerging researchers, from specialist nurses to patient advocates—made the meeting informative and diverse.

The day concluded with a networking dinner in a beautiful Athenian setting, offering a final opportunity to connect. These informal moments are often where the theme of *chronos* feels most present—where time slows, conversations deepen, and relationships are formed that will carry forward into future collaborations.

In many ways, this Forum was about reclaiming time—through knowledge, through innovation, and through community. In WM, where time can often feel uncertain, gatherings like this remind us that we are not navigating it alone.

We are already looking ahead. Our next EEF will take place on Thursday 15 April 2027 in Oxford, UK. We warmly invite you to join us once again—to learn, to connect, and to continue shaping the future of WM together.

Dr. Steven Treon explains future therapies for WM.

A PATIENT'S PERSPECTIVE ON THE 2026 EUROPEAN EDUCATIONAL FORUM

By Michael Bentley

I had three reasons for wanting to attend the European Educational Forum. First, I am a WM patient, diagnosed in April 2024. I am currently asymptomatic and enjoying life. Second, I volunteer for both IWMF and Hematon, the Dutch organisation for people with blood cancers. And lastly, I had never been to Greece.

Having attended my first Ed Forum in 2025, I knew the event would be valuable and well worth the effort.

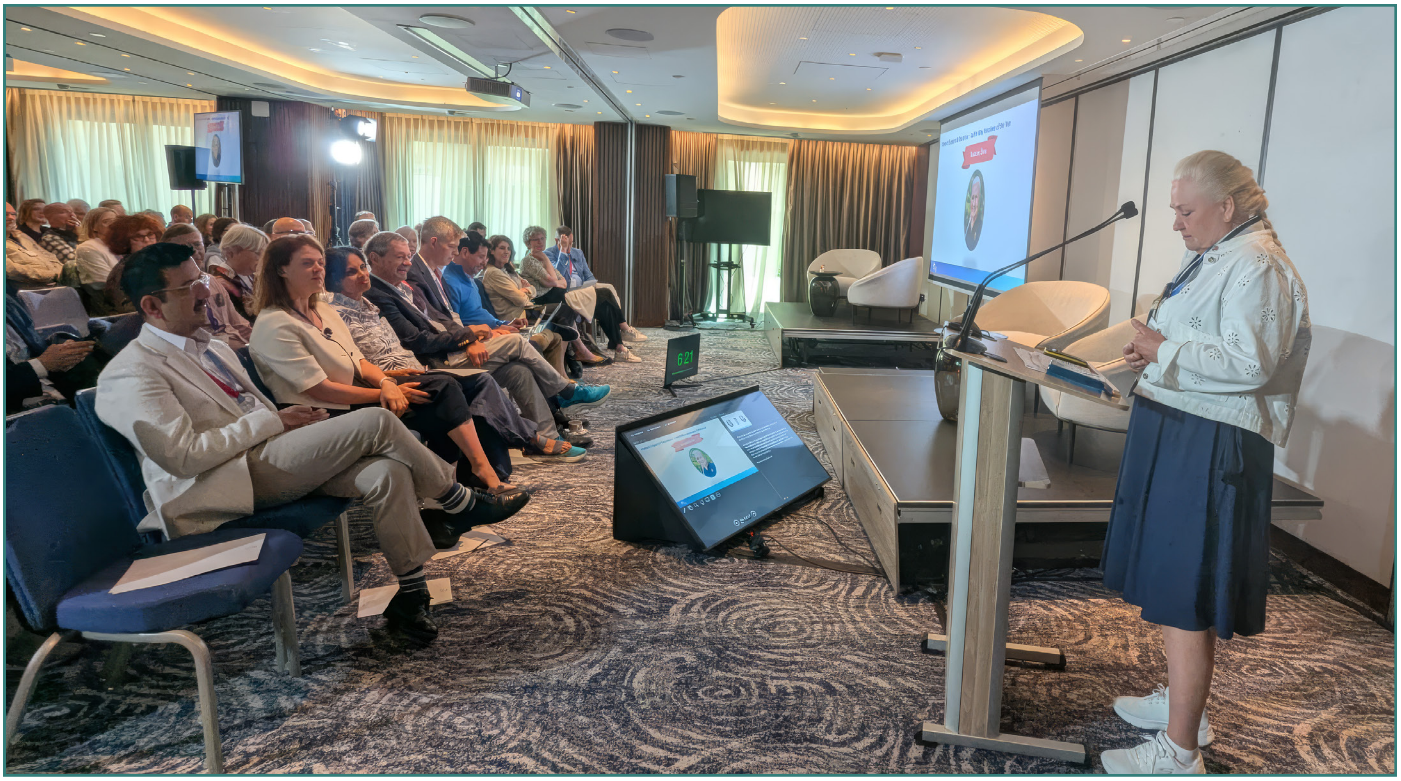
My journey began with a hiccup: my flight was cancelled at the last minute, and I was rebooked onto a later one, meaning I missed the guided tour of the Acropolis. I did, however, arrive in time for the ECWM dinner on Thursday evening. It was an excellent opportunity—both as a Hematon patient advocate and as an IWMF volunteer—to connect with clinicians and senior IWMF members. The restaurant, located at the foot of the Acropolis, offered a stunning setting, delicious food, and engaging company.

Friday: the main event

Friday was the most important day for me, both as a patient and as part of the IWMF Global Support Network. After breakfast, the global support volunteers who had travelled to Athens met with IWMF President and CEO Delora Senft and IWMF Global Partner Manager Hannah Mobarak. We discussed ways to strengthen and mature the support network and heard more about their vision for the coming years.

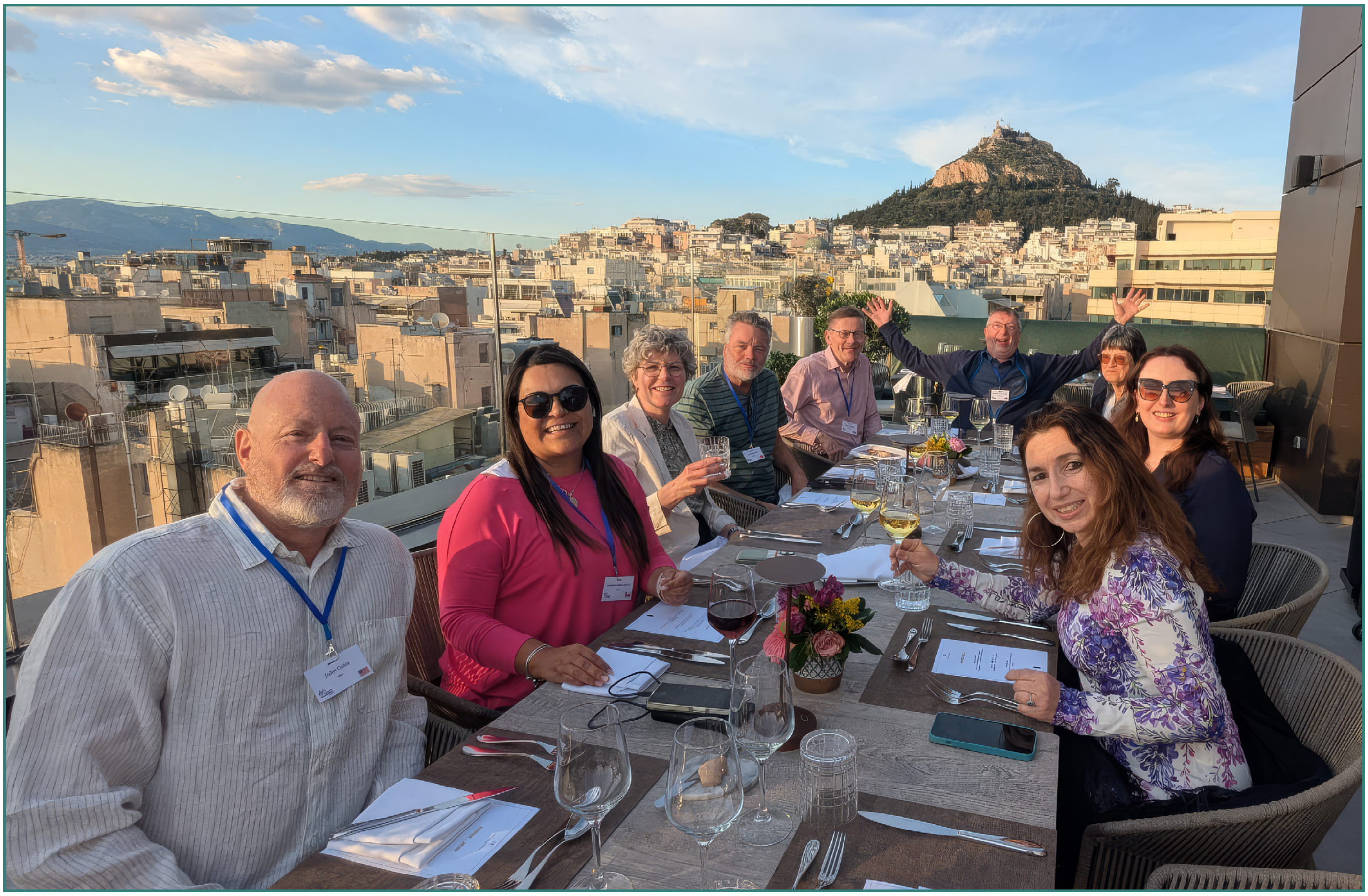
The morning programme offered a mix of presentations. I particularly enjoyed the opening session on "Giving Time Back to Patients," co-hosted by Delora and Prof. Christian Buske.

During lunch, several researchers presented their work at the research poster walk. I was especially interested in the WM VOICE survey, having participated myself. I remembered how complex the questions were and how none of the answers felt ideal. Dr. Anne Marie Becking from Amsterdam



Susanne Öhrn accepts IWMF's Judith May Volunteer Award.

A Patient's Perspective, cont. on page 10



EEF attendees enjoy a networking dinner.

UMC kindly took the time to explain the survey's goals and findings.

I was delighted to see so many Dutch clinicians and researchers present. It was also during the poster walk that I met two other Dutch patients. Stepping into my Hematon advocacy role, I spoke with them about the proposed partnership between Hematon and IWMF—something they greatly appreciated.

Afternoon sessions

After lunch, I was keen to attend "When Time Complicates the Picture – Associated Conditions" by Prof. Monique Minnema (UMC Utrecht) and Dr. Efstathios Kastritis, followed by "The WM VOICE Analysis" by Dr. Anne Marie Becking.

Just before the coffee break, I participated in a role play session designed for patients who are not yet part of a WM support group. This was a joint effort with colleagues from the UK, Sweden, and Canada.

After the break, Dr. Steven Treon and Dr. Maria Gavriatopoulou delivered an insightful talk on "What's Coming Next – Clinical Trials & Future Treatments." As an asymptomatic patient with both MYD88 and CXCR4 mutations, I am always eager to understand what future treatments may mean for me.

Closing the day

We ended the day with dinner on the hotel's rooftop terrace. The evening began sunny with a pleasant breeze, but once the sun set it quickly became cold. It was amusing to watch people quietly disappear and return wrapped in jumpers, coats, hats, and blankets. Despite the chill, the company was warm and the food excellent.

In conclusion

IWMF organised, managed, and hosted a highly successful event. As both a Hematon patient advocate and a WM patient, the next European Ed Forum—Oxford, UK—is already in my diary.

Thank you to IWMF for delivering such a meaningful and well run event.

NORTH AMERICAN EDUCATIONAL FORUM 2026 COLUMBUS, OH

By Pete DeNardis

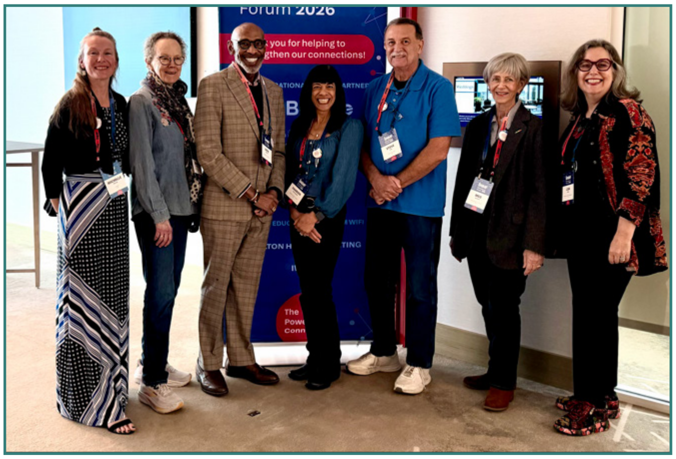
The North American Educational Forum is a signature event for WM patients and care partners from around the world. Each year, its attendees, whether in person or virtual, are provided the most up-to-date information regarding the optimal current and upcoming treatment options for WM.

While that information alone is well worth spending a few hours or a few days participating in the Forum, the added bonus of attending in person is the opportunity to meet with hundreds of fellow WMers traveling the same journey—to share experiences with each other and to know that we are not alone in the journey. There are several events intended to specifically provide the opportunity to engage with fellow attendees in one-on-one activities and in wellness activities (which included yoga, exercise, and leisure walks).

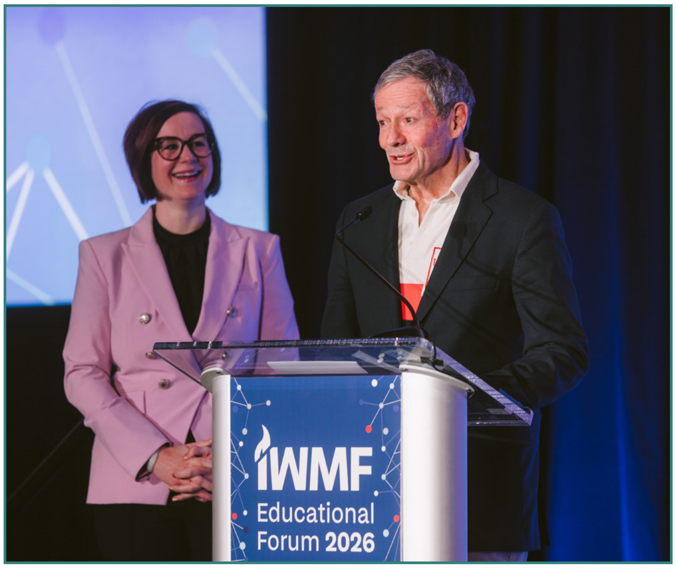
Each year IWMF and top researchers and clinicians from around the world provide information that has us moving much closer to a functional cure for the disease, and this year's event at the Hilton Columbus Downtown was no different!

April 30

The first "official" Ed Forum event was the Support Group Leaders Workshop, where leaders are provided specialized training in how best to guide their groups. It's also an opportunity for them to share their "best practices" with each other and to interact with the IWMF staff, who are always available to provide assistance.



Support Group Leaders Workshop panel: Michelle Postek, Eileen Sullivan, Gene Batiste, Sharon Piotrowski, Steve Pine, Meg Mangin, and Lisa Wise



Delora Senft and Paul Kitchen welcome attendees.

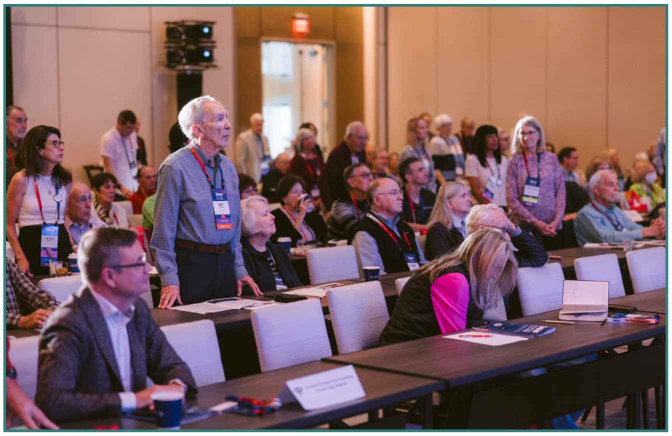
May 1

The first day of the Ed Forum provided a primer on what WM is, how it's diagnosed, and the various treatment options available when diagnosed (including, at times, no treatment at all). After those initial sessions, others focused on how to navigate the need for retreatment and the options available if the initial treatment is no longer effective.

Each year, the presenters always stress that they treat the symptoms and not necessarily the numbers; at times, it may be several years before a diagnosed patient is treated. The other takeaway is that, as I like to say, "when you've seen one WM patient, you've seen one WM patient." Each of us, even though we share the same disease, is affected differently by it—some experience significant symptoms at relatively low levels of IgM in their blood, while others don't experience symptoms at much higher levels. It's important to always be in communication with your healthcare team to assess your symptoms and status.

North American Educational Forum 2026, cont. on page 12

North American Educational Forum 2026, cont. from page 11



Patients stand and sit depending on how long they have had WM.

During the first session of the day, Prof. Christian Buske, a noted WM expert from University Hospital Ulm, Germany, stressed how truly unique our patient/caregiver community and IWMF are when compared to other blood cancers. Prof. Buske, who also chairs the European Consortium for WM, stated that "collectively, the IWMF community members know more about their disease, and they help fund more research into more and better treatments that just would not happen otherwise." As he stated, we truly are a caring and sharing community!

Later that day, in a review of the latest IWMF-funded research, Dr. Zachary Hunter of Dana-Farber Cancer Institute noted that over the past 20 years, great advancements have been made. He also went on to say that some reports state overall survival has TRIPLED, but it's actually better than that. And better treatments are on the horizon, all made possible by funding from IWMF. He went on to say that "We are at a point where we're not just focusing on keeping people alive, but also on improving their quality of life as they live longer!"

Dr. Brad Nieder, The Healthy Humorist, entertains at Friday's dinner.

The day ended with a special reception for first-time attendees to provide guidance and support to them throughout the weekend, followed by the Ed Forum dinner reception, which this year had Dr. Brad Nieder, "The Healthy Humorist," as a keynote speaker. His funny take on the medical world kept people laughing. (Each Forum has a different type of keynote event—who knows what next year will bring?)

May 2

Attendees began the day seeking both old and new friends for breakfast, discussing what they learned the day before and what to expect from the day's presentations.

The day began with a session about the use of AI tools by patients, care partners, and medical professionals. While many folks use tools like ChatGPT, the medical community uses OpenEvidence, which tends to produce more accurate results. Still, one should use such tools with caution. It's important to always have the perspective that you are the CEO of your medical team and should confer with them to assess the best possible options at a given point in time.

Dr. Stephen Ansell discusses WM's ripple effects.

Dr. Stephen Ansell (Mayo Clinic) then presented the many complications that can arise due to WM and to its treatments and how they are addressed. His explanations of medical jargon always distill things in a way that anyone can understand. Dr. Ansell also allowed extra time for fielding questions from the audience, truly making it more of a conversation than just a presentation.

That was followed by a breakout session on tackling depression and anxiety, with another on peripheral neuropathy (PN) presented by Prof. Shirley D'Sa

North American Educational Forum 2026, cont. on page 13

North American Educational Forum 2026, cont. from page 12

(University College London Hospitals), who is a noted WM and PN expert.

The day also included a presentation on clinical trials led by Dr. Jorge Castillo (Dana-Farber Cancer Institute), explaining the many promising trials that are in progress across the US as part of WM-Net (a US clinical trial network supported by IWMF). Patients Lisa Wise, Paul Kitchen, and Marcia Klepac relayed their experiences in participating in clinical trials. A Blood Cancer United representative was on hand also to discuss its clinical trials navigator service.

The last session of the day was one of the highlight events at each Ed Forum—Dr. Steven Treon of Dana-Farber Cancer Institute providing the latest information regarding the current and upcoming treatment options for WM patients. His presentations are always fully loaded with the latest trial results and therapies holding promise in the near future for WM.

Throughout the day, even more than in previous years, each presentation highlighted the distinct possibility of having a functional cure for WM and the critical role that IWMF funding is making in that effort.

I know I, for one, am grateful for those fellow patients and care partners who have given generously to IWMF-funded research! Together, we CAN and DO make a difference in our lives!

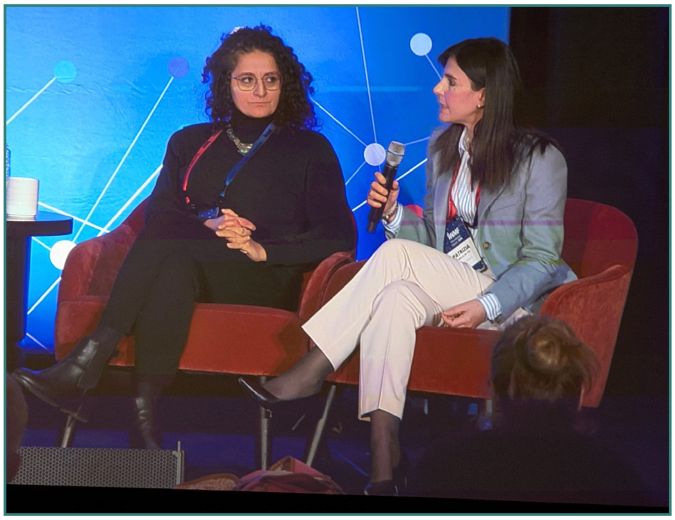
Throughout the day, before and after each session, patients were seen gathering together with old and new friends and in deep discussions with the clinicians who were in attendance.

The evening of the second day typically provides an opportunity to experience the city that the event is held in, to go out to dinner with friends, and this year, to spend time at a special dinner gathering for attendees (which was optional).

May 3
The final day of the Ed Forum is always bittersweet.

There's the excitement of looking forward to more educational presentations, the highly anticipated "Ask the Doctors" session, and opportunities to start the day off on the right foot with wellness activities. Yet, there's also the realization that this is the final day to get together with fellow WM patients and caregivers that you've been bonding with over the past weekend. As I stated earlier, one of the most special aspects of an Ed Forum is being able to share stories and life experiences and to provide support to people from around the world that you otherwise would not have met…and all with different, but similar, journeys with WM.

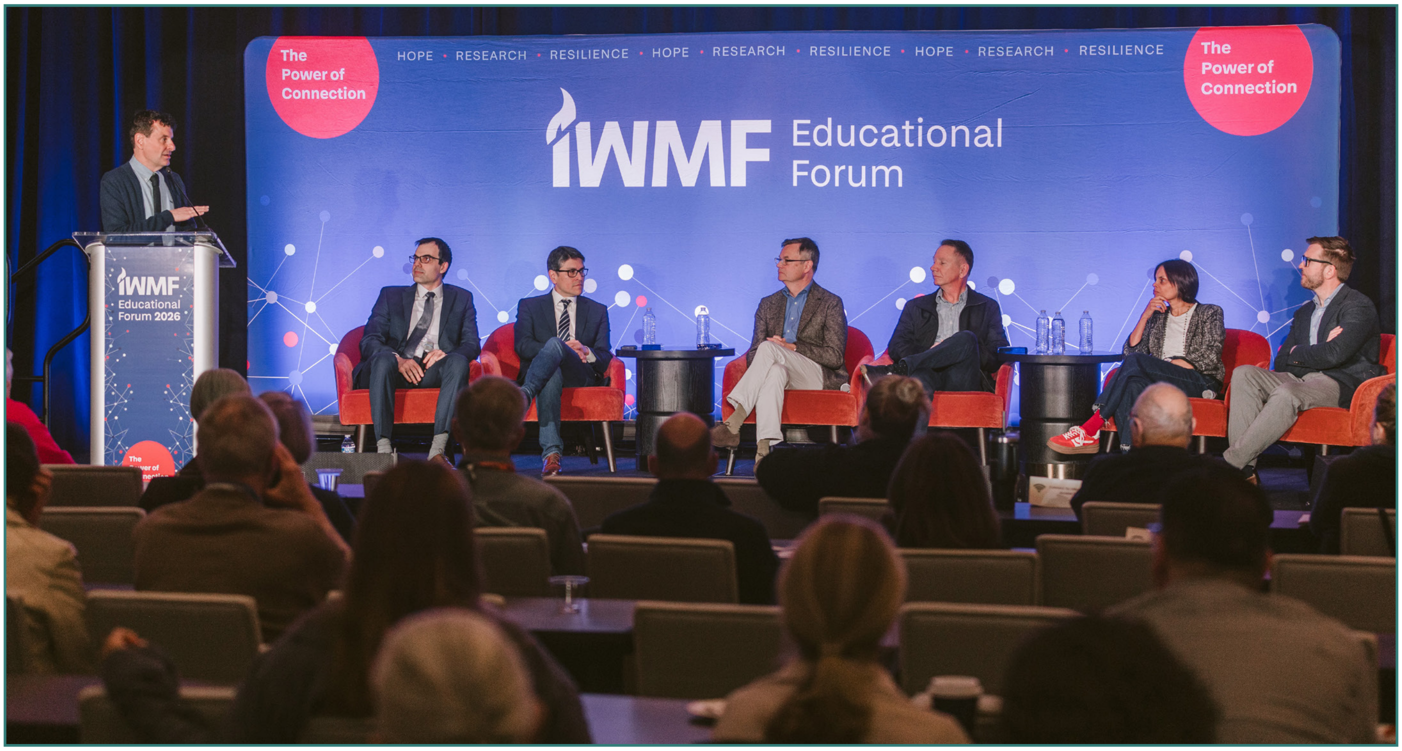
The day started with wellness offerings—a leisure walk that took folks past the Arnold Schwarzenegger statue (he won the Mr. World Bodybuilding Contest in Columbus in 1980) and yoga with Ann Grace MacMullan. You could see folks sitting together with other patients, care partners, WM staff members, and many of the researchers and doctors in attendance (it's amazing how approachable the doctors are at these events).



Dr. Maria Luisa Guerrera of Dana-Farber Cancer Institute and Dr. Patrizia Mondello of Mayo Clinic on the panel for "The Next Frontier in WM."

The presentations began with Dr. Treon and Dr. Hunter addressing what direction WM research and treatments are heading, with talks by Dr. Patrizia Mondello of Mayo Clinic, Dr. Maria Luisa Guerrera of Dana-Farber Cancer Institute, and Dr. Tarek Mouhieddine of Dana-Farber. Each provided a perspective on the biology of treatment pathways and what the future holds for all of us. Dr. Guerrera

North American Educational Forum 2026, cont. on page 14



"Ask the Doctor" panel: Dr. Steven Treon, moderator, Dr. Yazeed Sawalha, Dr. Jorge Castillo, Prof. Christian Buske, Dr. Stephen Ansell, Prof. Shirley D'Sa, Dr. Peter Forsberg

and Dr. Treon made brief mentions about the importance of basic science research and the impact of fundamental work done by young investigators and others, both of which are critical to finding more and better treatments in the future.

And then, the final event—"Ask the Doctors." Dr. Treon moderated the session, asking questions that had been submitted by the WM community in advance of, and during, the Ed Forum. Topics ranged from their thoughts on what first-line treatment they would recommend; what the exciting areas of research are right now for WM; what role watch-and-wait should play; what part bone marrow involvement plays in determining whether it's time to treat; and what their message of hope is for WM patients.

I encourage folks to visit the IWMF website at *www.iwmf.com* and the IWMF YouTube channel at *https://www.youtube.com/user/IWMFVideos* to view the videos from the Ed Forum that will be available soon.

At the meeting's end there were head nods, hand waves, handshakes, and hugs among participants getting ready to head back home—more knowledgeable about their disease, more hopeful for continued advancements in the near future, and more at ease, knowing that we are truly on a path to a functional cure within the next few years.

The treatment landscape has improved significantly over the years, yet the pace of research and discovery continues to accelerate, thanks to dedicated researchers and the IWMF funding for their efforts!

It was an amazing event, and the IWMF staff and volunteers are to be commended for their efforts to make it such a special event for everyone. And a special note of gratitude on behalf of all WM patients and caregivers around the world goes to all the presenters, doctors, researchers, and clinicians who took time out of their weekend to meet with us and share the latest information about our disease and how best to treat it!

Mark your calendars! Next year the North American Ed Forum will be at the Renaissance Dallas Hotel in Dallas, TX, September 10-12.

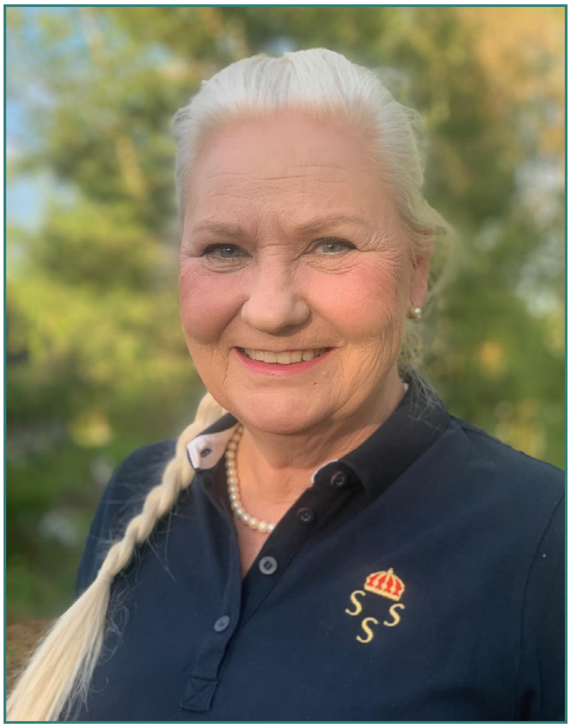
We do hope that many of you can make it in person!

THE IWMF IMPACT AWARDS

At the heart of IWMF is a commitment to celebrate the extraordinary people who move our mission forward. The IWMF Impact Awards honor those whose contributions embody our promise to educate, empower, and support every person affected by WM, while relentlessly pursuing a cure.

As we look toward the future, these awards reflect the powerful momentum across our strategic pillars: Patient Support and Education, Research, and Partnership. We are honored to recognize the following awardees, who were celebrated at both our 2026 European and North American Educational Forums.

Judith May Volunteer Award
Honoree: Susanne Öhrn, Täby, Sweden
The Judith May Volunteer Award was established to recognize the spirit of volunteerism, which President Emerita Judith May so aptly demonstrated throughout her career with IWMF. This year, we are honored to recognize Susanne Öhrn, who, for almost a decade, has led WM Scandinavia single-handedly.



Susanne Őhrn

Since September 2019, the group has grown from 221 members to nearly 700—an incredible testament to the trust, community, and support that have flourished under Susanne's leadership. From managing the WM Scandinavia support group and providing vital translations to hosting "fika" gatherings and contributing to our Global Partners group, Susanne is a true pillar of the international WM community.

Research Impact Award
Honorees: Prof. Christian Buske, University Hospital Ulm, Germany; Dr. Steven Treon, Dana-Farber Cancer Institute, US; and Dr. Stephen Ansell, Mayo Clinic Rochester, US

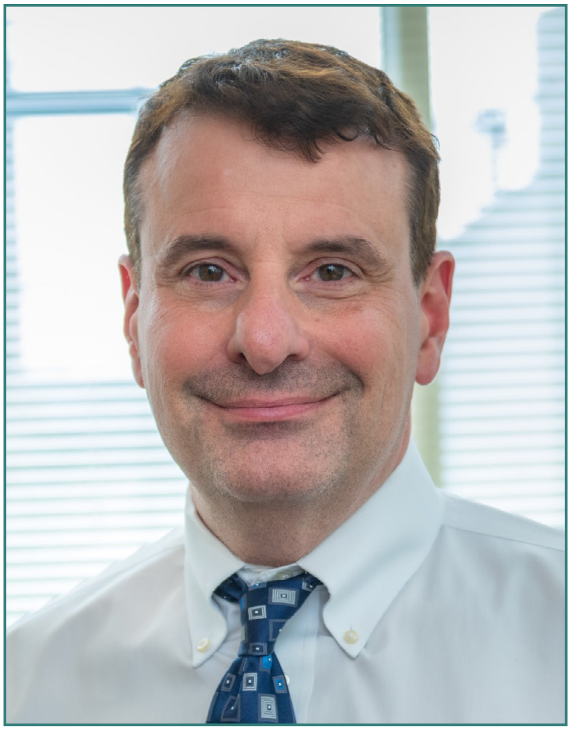
Prof. Christian Buske

This year, IWMF is proud to recognize three pioneers who have shaped the landscape of next-generation research and clinical excellence. Their combined lifelong dedication has transformed WM from a poorly understood disease into a field of highly targeted, life-saving therapies.

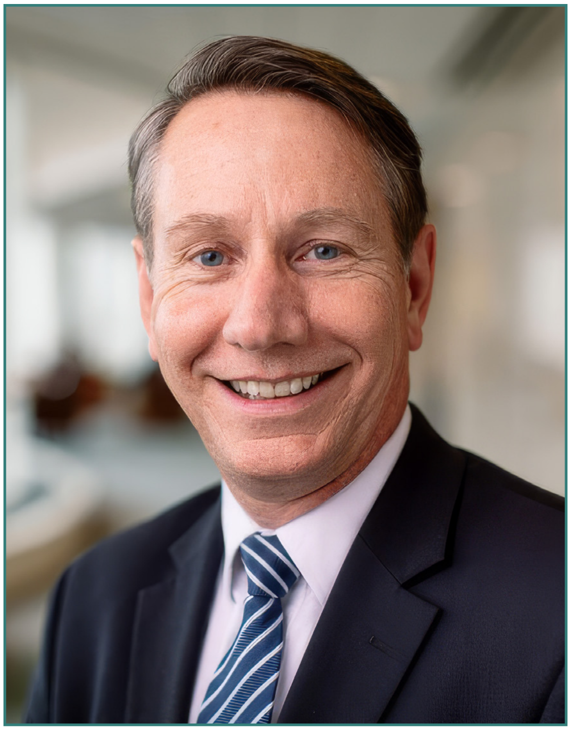
As Delora Senft, IWMF President and CEO, noted: "I think we can all agree that we would not be where we are without 'The Three Amigos,' as they have been affectionately coined within our community."

We are deeply grateful to these three visionaries whose collaborative spirit continues to bring hope,

The IWMF Impact Awards, cont. on page 16



Dr. Steven Treon



Dr. Stephen Ansell

better outcomes, and closer proximity to a cure for WM patients worldwide.

Partnership Award
Honoree: Christopher Patterson,
Dana-Farber Cancer Institute, US

A new Impact Award for 2026 recognizes excellence in partnership and involvement. Since its inception in 2000, the International Workshop on Waldenström's Macroglobulinemia (IWWM) has grown substantially, now engaging investigators from more than 35 countries and contributing to over 6,500 publications—many of which originated from the Workshops themselves.

We present this award to Christopher Patterson for his masterful leadership in organizing and managing the IWWM. His work has created the infrastructure that allows global experts to collaborate, innovate, and bring us closer to a cure.

Beyond his global impact, Christopher is deeply involved on a local level through his invaluable partnership with our Eastern Massachusetts Support Group. He also has been instrumental in managing logistics for IWMF support group meetings at Dana-Farber Cancer Institute.

Christopher Patterson

MEDICAL NEWS ROUNDUP

By Sue Herms, IWMF Research Committee Member

Acalabrutinib Treatment for WM Evaluated After Five Years of Follow-Up – The journal *Blood Advances* published an evaluation of acalabrutinib (Calquence) treatment after five years of follow-up in both treatment naïve and relapsed or refractory WM patients who were enrolled in a Phase 2 international clinical trial called ACE-WM-001. Of 106 patients treated, 52.8% discontinued therapy at some point, most commonly because of disease progression or adverse side effects. The overall response rates were 92.9% in treatment naïve patients and 94.6% in relapsed/refractory patients, with major response rates of 78.6% and 81.5%, respectively, in the two groups. The estimated 66-month progression-free survival rates were 83.6% in the treatment naïve group and 52.0% in the relapsed/refractory group, while estimated 66-month overall survival rates were 90.9% and 71.2%, respectively. Cardiac events occurred in 20.8% of patients.

Cellectar Provides 12-Month Update on Iopofosine I 131 Treatment at FDA Request – At the request of the US Food and Drug Administration (FDA), Cellectar Biosciences updated results from iopofosine I 131 therapy after at least 12 months of follow-up for 55 relapsed/refractory WM patients who participated in the Phase 2b CLOVER WaM clinical trial. The FDA request was made to position the drug for consideration of accelerated approval in relapsed or refractory WM. Iopofosine I 131 is a novel agent that combines a phospholipid ether molecule targeted to the cancer cells and radioactive iodine to cause cancer cell death. During the clinical trial, participants received intravenous iopofosine I 131 on days 1 and 15 of cycle one; six weeks later, they received the final two doses on days 1 and 15 of cycle two. The trial participants had a median of four previous therapies, and the update reported an overall response rate of 83.6%, including a major response rate of 61.8%. The median duration of response was 17.8 months. During the recent 2026 American Society of Clinical Oncology Annual Meeting, Cellectar also updated results for the subset of patients who had received BTK inhibitor therapy just prior to iopofosine treatment. In these patients, for whom there is no current standard therapy after BTK discontinuation, the overall response rate was 86.4%, with a major response rate of 68.2%. Median progression-free survival was 12 months. Grade 3 (severe) treatment-related adverse events occurring in more than 10% of patients included anemia, low white blood cell counts, low neutrophil counts, and low platelet counts.

Long-Term Results from Carfilzomib-Based Regimens Reported During 2026 ASCO Annual Meeting – The John Theurer Cancer Center at Hackensack University in New Jersey performed a single-center retrospective study of 43 WM patients treated with carfilzomib-based regimens from July 2012 to January 2026 and presented its findings during the recent 2026 American Society of Clinical Oncology (ASCO) Annual Meeting. Carfilzomib (Kyprolis) is a second-generation proteosome inhibitor in the same class as bortezomib (Velcade). The overall response rate was 93%, with a complete response rate of 6.9%, a very good partial response rate of 41.9%, and a partial response rate of 41.9%. Median IgM after treatment was 161.5 mg/dL. One patient developed atrial fibrillation and one developed heart failure that resolved after carfilzomib withdrawal. The incidence of peripheral neuropathy attributed to carfilzomib was 6.9%. Two patients stopped treatment because of toxicity, one heart-related and one not.

Update Provided for Phase 1 Clinical Trial of BGB-16673 in Relapsed or Refractory WM – During the European Hematology Association 2026 Congress, international researchers provided an update to the Phase 1 portion of the CaDAnCe-101 clinical trial of the BTK degrader BGB-16673 that enrolled 43 relapsed or refractory WM participants. BGB-16673 is an oral drug that blocks BTK signaling by tagging the BTK protein for degradation or breakdown by the

Medical News Roundup, cont. on page 18

cell's proteasome pathway. Eligible participants were required to have had at least two prior therapies, including an anti-CD20 monoclonal antibody such as rituximab and a covalent BTK inhibitor such as ibrutinib, acalabrutinib, or zanubrutinib. Among the 42 evaluable patients, the overall response rate was 85.7%, the major response rate was 76.2%, and the very good partial response rate was 31.0%. The estimated 15-month progression-free survival rate was 70.4%. Responses were observed in patients with high-risk features, including those with mutations in the *BTK* gene and those who had discontinued BTK inhibitors because of progressing disease. Overall, 95.3% of participants experienced any grade of adverse events, the most common being decreased neutrophil counts, diarrhea, and bruising. No atrial fibrillation occurred. At data cutoff, 26 patients remained on treatment; of the 17 patients who discontinued treatment, progressing disease (in six patients) was the primary reason for discontinuation. The Phase 2 part of the trial is currently enrolling participants; on *www.clinicaltrials.gov*, the trial identifier is NCT05006716.

> ***...Greek researchers attempted to characterize the factors that enabled WM patients to achieve a "functional cure,"...***

Greek Researchers Characterize "Functional Cure" in WM Study – In a poster abstract at the European Hematology Association 2026 Congress, Greek researchers attempted to characterize the factors that enabled WM patients to achieve a "functional cure," which they defined as exceeding 10 years of progression-free survival (PFS). Their retrospective analysis included 326 newly diagnosed WM patients who began frontline therapy between 2002-2016. Among the study patients, 39 (12%) achieved a PFS of more than 10 years. Additionally, with a median follow-up of 15.8 years, the "functional cure" subset achieved 15-year overall survival and PFS rates of 59.5% and 36.5%, respectively. A higher proportion of these patients were younger at diagnosis and were female, compared to the study group as a whole; they were also at lower risk of the following: severe hypoalbuminemia (very low serum albumin), high beta 2-microglobulin levels, and high lactase dehydrogenase levels. In this study, the specific type of frontline treatment regimen was not a determining factor in achieving long-term PFS.

DFCI Researchers Compare Venetoclax to Pirtobrutinib as Chemo-Free Options for Relapsed or Refractory WM – Venetoclax (Venclexta) and pirtobrutinib (Jaypirca) have emerged as two chemotherapy-free options for relapsed or refractory WM, but there has been little evidence to guide which patients would be more likely to benefit from either agent. Researchers at the Dana-Farber Cancer Institute (DFCI) retrospectively evaluated consecutive WM patients treated with venetoclax or pirtobrutinib at its facility and published their results in the *American Journal of Hematology.* Among 91 treatment episodes (64 venetoclax and 27 pirtobrutinib) across 80 patients, treatment discontinuation because of adverse effects occurred in 19% treated with venetoclax and in none treated with pirtobrutinib. In the venetoclax group, alterations in the *TP53* gene were associated with shorter progression-free survival at 10 months, compared to 35.6 months for unaltered *TP53*. In the pirtobrutinib group, *CXCR4* mutations predicted lower major response rates (40% vs. 91%) and shorter progression-free survival (8.3 months vs. not reached) than wild-type (unmutated) *CXCR4*. When switching from a covalent BTK inhibitor therapy like ibrutinib or zanubrutinib, IgM rebound (a potentially dangerous spike in IgM level), occurred in 62% of patients beginning venetoclax when there was no overlap therapy between the previous treatment and venetoclax. (Overlap therapy refers to using the two medications simultaneously for a short time to ensure effectiveness and safety during transitions between therapies.) However, no IgM rebound occurred when switching from a covalent BTK inhibitor therapy to pirtobrutinib or when overlap

Medical News Roundup, cont. on page 19

therapy was used while switching from covalent BTK inhibitor treatment to venetoclax. The researchers noted that the study size was relatively small, and they encouraged the development of clinical trials with more patients to confirm their findings.

Mayo Clinic Abstract Indicates Improved Cause-Specific Survival in WM – A poster abstract from Mayo Clinic included at the European Hematology Association 2026 Congress looked at the impact of treatment advances on improved survival in those with active WM. The single-center retrospective study identified 1,020 patients diagnosed between January 1996 and December 2018 with active disease, which was defined by symptoms or organ dysfunction attributable to WM. Patients were grouped into time periods, with the two major groups consisting of those diagnosed between 1996-2005 and those diagnosed after 2006. Median follow-up was 20.5 years for the 1996-2005 patient group and 11.3 years for the after-2006 patient group. Patients treated in more recent years tended to be older, with a higher proportion aged 65 years or more. Overall survival was similar between the earlier and later time frames at 10.9 years for the 1996-2005 group and 11.9 years for the after-2006 group; however, cause-specific survival, which is the length of time from diagnosis to death as a result of WM (and not from other causes), improved significantly in the era of novel therapies, from 15.6 years in the 1996-2005 group to 18.9 years in the after-2006 group.

> ***...renal impairment at diagnosis may represent an underrecognized adverse prognostic factor in symptomatic WM patients.***

Impaired Renal Function Is Adverse Prognostic Factor in WM Survival – An Italian study, published in the *British Journal of Haematology,* looked at the prognostic significance of impaired renal (kidney) function in WM. A country-wide multicenter study analyzed 402 symptomatic WM patients based on their renal function at diagnosis. The study researchers used creatinine clearance as their criterion, with a value of less than 60 mL/min/1.73m^2 considered to be a sign of reduced renal function; they identified 119 patients who met that criterion. Patients with impaired renal function tended to be older (median age of 76 years) with lower hemoglobin levels (median 10.8 g/dL), and higher 24-hour protein level in the urine (median 0.29 g). Renal impairment was associated with lower median overall survival (139 vs. 203 months) and lower progression-free survival (80 vs. 106 months). For these patients, first-line treatment with chemoimmunotherapy was associated with improved median progression-free survival. The researchers concluded that renal impairment at diagnosis may represent an underrecognized adverse prognostic factor in symptomatic WM patients.

Retrospective Study Looks at Two Bispecific Antibody Therapies for Transformed WM – A retrospective study reported in correspondence to the journal *HemaSphere* assessed the use of bispecific antibodies to treat transformed WM, which occurs when the WM cells mutate into a more aggressive lymphoma, typically with a poor prognosis. Bispecific antibodies are monoclonal antibody treatments similar to rituximab, but they bind to two different targets at the same time, unlike rituximab with one target. In bispecific antibodies used to treat B cell lymphomas, one part of the antibody binds to a protein target on the cancerous B cell, while the other part binds to the surface target CD3 on a T cell; this connection brings the T cell close to the cancer cell, thereby triggering the T cell to destroy the cancer cell. Because no previous data have been published on the use of bispecific antibodies in transformed WM, researchers performed a retrospective study of 20 transformed WM patients who were treated at several European and US centers from February 2023-May 2025 with epcoritamab or glofitamab, both of which target CD20 on B cells and CD3 on T cells, and have been used to treat other lymphomas.

Medical News Roundup, cont. on page 20

These patients had received a median of three prior lines of treatment, including BTK inhibitors and CAR T cell therapy. Their median time from WM diagnosis to transformation diagnosis was 3.3 years. Their best overall response rate was 80%, including 45% complete responses. With a median follow-up of eleven months, 60% were still alive. The estimated progression-free survival and estimated overall survival rates at one year were 51% and 57%, respectively. Fifteen patients (75%) experienced the side effect called cytokine release syndrome (CRS) that occurs when a large number of cancer cells are killed and release inflammatory chemicals that can potentially cause damage to tissues and organs, while 15% experienced ICANS, or toxicity to the central nervous system. Both conditions range from mild-to-severe but can be treated successfully with supportive therapy. Infections occurred in 45% of patients. The researchers suggested that the study data support the use of bispecific antibodies in difficult-to-treat WM transformation but need to be confirmed in a larger group of patients with longer follow-up.

International Study Discusses Zanubrutinib as Treatment for IgM-Associated AL Amyloidosis – Correspondence to the *American Journal of Hematology* from a multicenter international study discussed IgM-associated light chain (AL) amyloidosis, a rare disorder in which misfolded light chains from the monoclonal IgM antibody deposit within organs, resulting in organ damage. When it occurs with WM, treatment options have included bendamustine and rituximab, with or without autologous stem cell transplant (using one’s own stem cells). However, these treatments are not always feasible because of advanced patient age and co-existing medical conditions or because they may not keep the amyloidosis under control and prevent further organ damage. Previous studies of treatment with the BTK inhibitor ibrutinib (Imbruvica) resulted in severe cardiac toxicity and low responses in IgM-associated AL amyloidosis patients, resulting in poor outcomes. This retrospective study was undertaken to see if the BTK inhibitor zanubrutinib (Brukinsa) may be a more effective approach. Eleven centers in the UK, US, Germany, Denmark, and the Netherlands analyzed all consecutive IgM amyloidosis patients with underlying WM or another B cell disorder who received zanubrutinib at some point between November 2020 and December 2024, identifying 21 patients. Median time on zanubrutinib was 7.9 months, with nine patients (43%) still on therapy at the time of data collection. Nineteen of the 21 patients were evaluable for a response. Median follow-up was 14.2 months. Responses were observed in eight patients (42%), with four of these achieving a very good partial response. The median duration of response was 18.4 months. Three patients died while on therapy because of progressing amyloidosis, and two died from other causes after stopping zanubrutinib. One-year overall survival was 90%. Grade 3 or greater (severe) side effects occurred in 57%, mostly low neutrophil counts, infections, and bleeding. Cardiac side effects were observed in three patients (14%), two of whom died; it is unknown to what extent this was related to their pre-existing cardiac amyloidosis or to zanubrutinib. Although not directly compared to ibrutinib in this study, zanubrutinib showed better tolerability, less cardiac toxicity, and higher response rates than have been reported for ibrutinib. The authors concluded that zanubrutinib might be feasible for IgM amyloidosis patients with underlying B cell disorders who cannot tolerate more intensive treatment or could be considered as part of a combination therapy.

> ***....the study data support the use of bispecific antibodies in difficult-to-treat WM transformation...***

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

THE TORCHBEARER REPORT: A REMARKABLE TIME FOR WM PATIENTS

By Delora Senft, IWMF President and CEO, and
Paul Kitchen, Chair of the IWMF Board

This April in Athens, Greece, the European Consortium for Waldenström Macroglobulinemia (ECWM) invited IWMF to share its perspective on time—a perspective shaped not just by history, but by lived experience.

Two and a half millennia ago in Greece, and even until fairly recently, people dying from what we now know as cancer faced a stark reality: no treatments, no answers, just uncertainty. With continuing progress in nutrition, shelter, hygiene, and medicine, people with cancer began to live longer. As survival improved, patterns started to emerge, and in 1942, Dr. Jan Waldenström was able to identify and describe one of those cancers: Waldenstrom macroglobulinemia. Yet, a global consensus on diagnosis and treatment wouldn't come until the second International Workshop on Waldenström's Macroglobulinemia (IWWM-2) in 2004.

For IWMF, these milestones aren't just history. They're personal. In 1975, Paul Kitchen's mother was diagnosed with WM. By 1983, she had passed away—without a single effective treatment available. She lived longer than her ancient Greek counterparts, but her options were no better. For a long time, there was no real progress in treating WM. This is why our urgency is earned, our commitment personal, and our mission relentless.

IWMF is not an institution watching from afar. We were founded by patients, for patients—because they refused to accept a future without answers. Our mission is lived every day. Since 1999, IWMF has sponsored 116 research projects. Progress was slow at first—just a handful of harsh treatments were available in the early 2000s. Today, there are more than 80 treatment options, many using combination protocols. Because we are both the community and the driver of scientific discovery, the pace of change has picked up dramatically. We don't just fund research; we accelerate it, and we're determined to make sure it positively impacts every life touched by WM.

Our top priority is clear: find a cure (or cures) for WM, so patients can live fully and freely. The timeline for a cure is no longer measured in millennia, or even decades. The time for a cure is now.

Impact events

Recently that sense of urgency and hope was everywhere. In late March in Boston, MA, Tim and Ginny Bliss sponsored the Cellular Therapies Conference for WM, organized by Dr. Steven Treon. Experts from around the globe came together, and we listened to insights from the field of multiple myeloma. For WM, cellular therapies such as CAR T cells or CAR NK cells are just beginning, and there's hope that lessons learned from multiple myeloma will accelerate progress for our community. The conference ended with the Bliss family announcing a $3 million gift to IWMF to fund cellular therapy research for WM (see page 23).

Soon, IWMF will publish the Request for Proposals (RFP) for the Bliss Family Cellular Therapies Grants. By early fall, we expect to receive research proposals in this promising new field. Many experts believe the first cures for WM may emerge from these cellular therapies. "We don't wait for answers. We fund them." That's not just a tagline—it's our truth.

After Boston we headed to Athens, where we joined the ECWM and IWMF European Educational Forum, gathering patients and experts from across Europe—and even one adventurous patient from California. The excitement for new treatments and the drive to accelerate progress was palpable. Over 15 countries were represented, with more than 80 clinicians and researchers present. We are stronger together, wherever we are.

Next, in Columbus, OH, over 300 people gathered for the North American Educational Forum. There

The Torchbearer Report, cont. on page 22

were interactive panels and presentations covering everything from understanding WM to exploring the next frontier in treatment. Most importantly, there was a chance for our community to connect, support, and empower each other. Our journey is personal, and we stand with every patient, every step.

Next steps

Looking ahead, IWMF will soon award the 2026 research grants, which, for the first time, will include pilot clinical trials. Our RFPs have changed to emphasize translational research with the goal of shifting clinical practice within three to five years. These grants are for today's WM patients—and for tomorrow's breakthroughs.

With so much new research underway and recent study results emerging, the upcoming IWWM-13 in Palm Springs, CA, October 14-16, promises to be an exciting event. On Saturday morning, October 17, there will be a patient forum featuring a comprehensive review of the research and treatments discussed at IWWM-13. Patients will gather immediately after the conclusion of the Workshop's scientific sessions, receiving real-time updates and renewed hope.

Science fueled by humanity: this is what sets IWMF apart. We don't just observe—we participate, we lead, and we care. Every step forward is powered by the urgency of lived experience and the momentum of a truly global, patient-powered community.

These recent events have shown just how far we've come—and how much closer we are to a cure. For thousands of years, WM patients lived in the shadows of uncertainty. Today, hope is real, progress is accelerating, and the community is united in determination. With every new grant, every new study, and every gathering of patients and experts, we move closer to the day when WM is not just treatable, but curable.

The time for a cure is now—and together, we're making it happen.

Financial and other information about The International Waldenstrom's Macroglobulinemia Foundation, Inc. can be obtained by writing the Foundation at 1449 S Michigan Ave, STE 13329 Chicago, IL 60605. In addition, several states where The International Waldenstrom's Macroglobulinemia Foundation, Inc. is required to file financial information each year also require the following disclosures: Colorado: Colorado residents may obtain copies of registration and financial documents from the office of the Secretary of State, (303) 894-2680, http://www.sos.state.co.us/. **Florida**: Registration No. CH33403. A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE, WITHIN THE STATE, 1-800-HELP-FLA OR VIA THE INTERNET AT http://www.FloridaConsumerHelp.com. **Georgia**: A full and fair description of the programs and activities of The International Waldenstrom's Macroglobulinemia Foundation, Inc. and its financial statements are available upon request at the address indicated above. **Maryland**: For the cost of postage and copying, documents and information filed under the Maryland charitable solicitation law can be obtained from the Secretary of State, Charitable Division, State House, Annapolis, MD 21401, (800) 825-4510. **Michigan**: MICS No. 45029. **Mississippi**: The official registration and financial information of The International Waldenstrom's Macroglobulinemia Foundation, Inc. may be obtained from the Mississippi Secretary of State's Office by calling 1-888-236-6167. Registration with the Secretary of State does not imply endorsement by the Secretary of State. **New Jersey**: INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION AND THE PERCENTAGE OF CONTRIBUTIONS RECEIVED BY THE CHARITY DURING THE LAST REPORTING PERIOD THAT WERE DEDICATED TO THE CHARITABLE PURPOSE MAY BE OBTAINED FROM THEB ATTORNEY GENERAL BY CALLING (973) 504-6215 AND IS AVAILABLE ON THE INTERNET AT www.njconsumeraffairs.gov/ocp.htm#charity. REGISTRATION WITH THE ATTORNEY GENERAL DOES NOT IMPLY ENDORSEMENT. **New York: A copy of the latest annual report can be obtained from the organization or from the Office of the Attorney General by writing the Charities Bureau, 120 Broadway, New York, NY 10271. North Carolina**: Financial information about this organization and a copy of its license are available from the State Solicitation Licensing Branch at 1-888-830-4989 (within North Carolina) or 919-807-2214 (outside of North Carolina). The license is not an endorsement by the State. **Pennsylvania**: The official registration and financial information of The International Waldenstrom's Macroglobulinemia Foundation, Inc. may be obtained from the Pennsylvania Department of State by calling toll-free, within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement. **Virginia**: Financial statements are available from the State Office of Consumer Affairs, P.O. Box 1163, Richmond, VA 23218. **Washington**: The notice of solicitation required by the Charitable Solicitation Act is on file with the Washington Secretary of State, and information relating to financial affairs of The International Waldenstrom's Macroglobulinemia Foundation, Inc. is available from the Secretary of State, and the toll-free number for Washington residents: 1-800-332-4483. **West Virginia**: West Virginia residents may obtain a summary of the registration and financial documents from the Secretary of State, State Capitol, Charleston, WV 25305. **REGISTRATION IN THE ABOVE STATES DOES NOT IMPLY ENDORSEMENT, APPROVAL, OR RECOMMENDATION OF THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION, INC. BY THE STATE.**

THE BLISS FAMILY FUND SUPERCHARGES CELLULAR THERAPY RESEARCH IN WM

Tim and Ginny Bliss have pledged $3 million to IWMF, the largest single gift in the Foundation's history, to jumpstart research into cellular therapies for WM.

At the end of March in Boston, Dr. Steven Treon of Dana-Farber Cancer Institute brought together a powerhouse group for an intensive two-day summit focused on the future of cellular therapies for Waldenstrom macroglobulinemia. Cellular therapies include CAR T cells and bispecific T cell engagers that harness the power of the immune system to target and eliminate cancer cells.

The meeting room was buzzing with possibility, as top clinicians in multiple myeloma—already veterans in deploying cellular therapies—shared their insights with leading WM experts eager to adapt these breakthroughs for their own patients. That excitement was matched only by the announcement of the major Bliss donation that closed the meeting.

"As both a patient and IWMF's Board Chair, I know firsthand how much hope this gift brings. The Bliss Family Fund's $3 million commitment means more than just financial support—it's a beacon for every WM patient and researcher," declared Paul Kitchen.

This landmark donation will establish the **Bliss Family Fund to Advance Cellular Therapies for WM**, administered by IWMF, to accelerate the development and clinical application of cellular therapies. IWMF is already fielding questions about the forthcoming RFP (Request for Proposals), which will offer a unique, rolling opportunity—researchers can apply at any time, with no deadlines, thus ensuring the most promising ideas can be supported as soon as they arise.

"Cellular therapies have transformed the outlook for myeloma and other lymphoma patients. With the Bliss family's incredible generosity, we can now pursue this same promise for those living with WM," noted Dr. Treon.

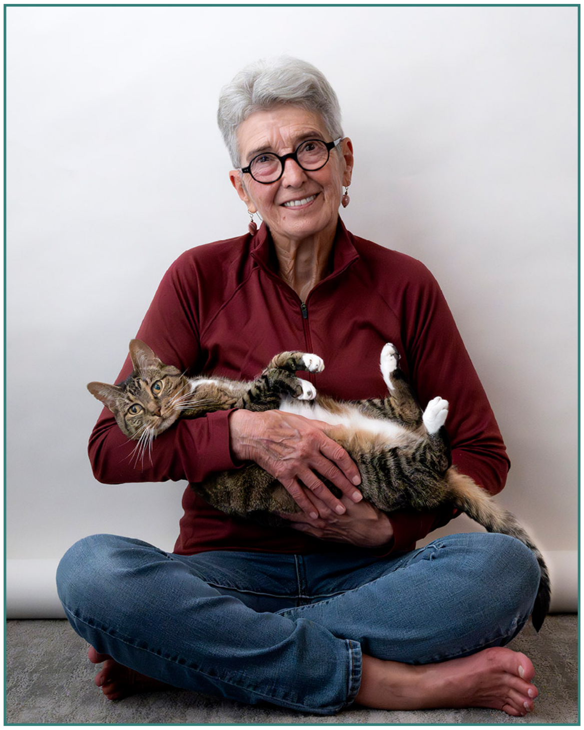
IWMF is deeply grateful for the Bliss family's vision and generosity. This historic gift sets a new standard for what's possible in WM research, opening the door to innovative treatments and, ultimately, better lives for patients everywhere.

EVERY DONATION GETS US CLOSER TO A CURE

By Sue Sherwin

Greetings from Bedford, Texas! Bedford is a suburb of the Dallas – Fort Worth metroplex and is home to electric infrastructure failures, tornadoes, softball sized hail, frog-strangling downpours, and, best of all, America's Team—the Pittsburgh Steelers. Oops, wrong city, right team. Can you guess where I grew up?

My Waldenstrom's journey is similar to most. It began with routine bloodwork showing an increased total protein. A serum protein electrophoresis revealed the dreaded M-spike, and a preliminary diagnosis of smoldering multiple myeloma (MM) was made by my internist. I am a retired clinical chemist and could analyze my bloodwork as it became available. My initial IgM was 5,500 mg/dL, and I immediately knew that this was probably not MM. Dr. Google led me to Waldenstrom's and the journey began.



Sue and her cat Watson

Since my story is not unique, I'll stop my tale here. What I really want to convey is for everyone to understand why I LOVE IWMF, how it has helped me in ways that I could never have imagined, and why I urge everyone to donate, donate, donate.

My cat, Watson, and I manage a Facebook page which supports the Bedford Animal Shelter, so I am very social media savvy. My first and best thought was to search Facebook for Waldenstrom's macroglobulinemia, and I was thrilled when the IWMF page popped up. I'll never forget typing "I think I have Waldenstrom's" for permission to become a member. I then spent hours reading posts, learning about treatments, and, most importantly, learning that this was not a death sentence. (Another plus was reading every post by Peter DeNardis and enjoying all the pictures of my old stomping grounds in Pittsburgh, Oakland, and Shadyside. Keep those pictures coming, Peter!). Meg Mangin, or one of the other great Facebook page admins, always provides a link to the IWMF website, and, of course, that was my next stop. I read almost everything available and was prepared for the future. The most important remaining obstacle was to figure out a way to tell my brother that I have cancer.

My brother, Jack, and I grew up in Oakmont, PA, a suburb of Pittsburgh. When my husband, Andy, was transferred to Irving, TX, in 1987 we didn't see each other often but chatted by phone for about an hour every Sunday afternoon. In the fall we would be watching Steelers games and cheering them on while discussing life and just enjoying our chats.

I was officially diagnosed in July 2021 and immediately started Brukinsa (zanubrutinib), due to a significantly elevated serum viscosity, but it was months before I told Jack. How do you convince someone not to worry about his kid sister when you are 1,400 miles away and aren't traveling because of COVID? My plan was to wait until my numbers improved and I had facts and data to show that my Brukinsa was working. By October 2021, my IgM had decreased to the 800s (WOW!) but I still had concerns. Then I remembered the wealth of information on the IWMF website. I confessed to Jack in October, emailed my bloodwork and a link to the website, and hoped for the best. Jack read and digested everything and was very relieved that I would probably have a normal life expectancy. All thanks to the information provided by the IWMF website.

Every Donation Gets Us Closer to a Cure, cont. on page 25

Jack died unexpectedly in March 2022. COVID omicron was rampant, which made being executor of his estate very trying and difficult, but through perseverance and help from his many friends in Harrisburg, PA, we succeeded in meeting Pennsylvania's requirements. After all the trials and tribulations (estate settlement in PA is NOT easy!), I spent much time deciding how to honor Jack with a significant donation in his memory from my inheritance. I then remembered that his final months were not spent worrying about me because of IWMF, and my decision was made. I know that Jack smiles every year when Andy and I donate our IRA required minimum distributions (RMDs) to IWMF, made possible by Jack Sherwin.

A few times a year Andy and I Zoom with Carl Harrington and Paul Kitchen. Last fall Carl and I discussed the percentage of people benefiting from IWMF who also donate. In the US, approximately 50% of all people who use IWMF services are donors, while 19% of new users are donors. According to Carl, this is really good participation. I think that we can do better! According to Google, an inexpensive Starbucks coffee is around $5, and a Big Mac and fries is around $10. If all US members donated the value of one Starbucks coffee, IWMF would receive about $70,000! Double that for a $10 donation! Just think how those funds could get us closer to a cure. I'll give up a couple of Starbucks for a cure! How about you?

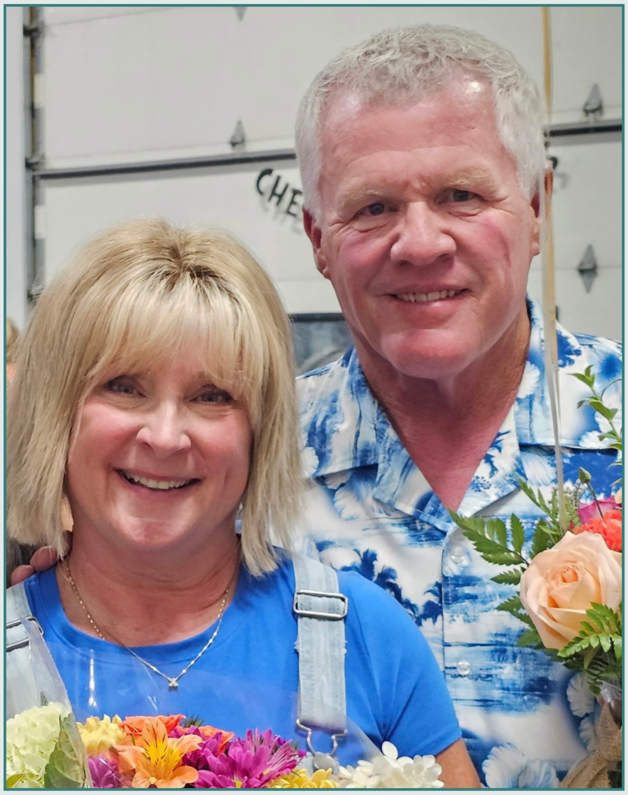
I know that the cost of living has dramatically increased and that funds are tight, but remember how much IWMF gives us. Meg and the other Facebook admins work full time helping us and easing our minds. IWMF provides a wealth of information to educate us and find Waldenstrom experts. This is all free! I'm writing this article while listening to Dr. Steve Ansell speak at the 2026 Ed Forum. How cool is that? Many cancer patients lack access to expert guidance about their disease; IWMF gives us that access. And don't forget about all the other ways to donate. Include IWMF in your will and join the Ben Rude Heritage Society, or you can easily add IWMF as a beneficiary of your investment accounts. Finally, plan to participate in the 2026 IWMF Giving Challenge happening later this year.

Thank you, IWMF, for everything that you provide for us!

Sue and her brother Jack Sherwin in 2013

NEW SUPPORT GROUP LEADERS

Compiled by Sharon Rivet, Support Group News Editor



Janie Peterson, Leader
Heartland Nebraska/Iowa Support Group

Hello all my fellow Wallies! I'd like to help begin a WM support group in the Nebraska and Iowa area. Let's call it Heartland Nebraska/Iowa Support Group.

A little introduction: Janie Peterson here. I have been married to my best friend, Roger, for 45 years and am a mother of two daughters. I also have two sons-in-law and five amazing grandchildren. We all live on a 10-acre "compound" in Valley, NE. I love keeping active with golf, painting, CrossFit, shopping, baking/cooking, pickleball, RVing, traveling, and watching our athletic grandchildren compete in softball, soccer, golf, and more. Rog and I have been retired for four plus years, we are loving life, and I celebrated my 70th birthday in 2025. Oh yes, one more detail…I have Waldenstrom's.

I have lived uneventfully with MGUS for 14 years, but 2025 began quite a journey of healing and learning. I was diagnosed with the flu, which wouldn't go away, leading to many tests. The tests discovered non-Hodgkin lymphoma, which led to more tests. These tests discovered Waldenstrom's and diverticulitis. Whew! Luckily, I have great doctors in Omaha who were persistent in finding out why I was so sick. I also found a WM expert doctor at Mayo Clinic in 2025. I have taken a lot of medicines, endured radiation, survived surgery, awaited results, and survived to be on watch-and-wait. But I made it!

My journey has been short—just one year—but I have learned so much. One of the most helpful lifesaving events of my WM journey was reading the Facebook WM Support Group page. IWMF provided valuable knowledge that helped me/us make a critical decision to seek a second opinion at Mayo. There were too many contradictory plans being made for my treatment here in Nebraska that didn't align with what the experts and other patients wrote about in IWMF communications. I would love to help others on their journey find hope and support through a local NE/IA support group. Please share this information if you know of someone within our region! You can contact me, as well as other support group leaders, on the IWMF website at *https://iwmf.com/us-and-international-support-groups/*.

New Support Group Leaders, cont. on page 27

Jane Cox, Support Group Co-Leader
Northern Virginia/Washington DC/Maryland;
Leader for Proposed TP53 Affinity Group

My WM diagnosis, followed by bendamustine and Rituxan treatment, started in 2017. Then in 2025, my new oncologist conducted genetic testing, and I was diagnosed with the *TP53* mutation. To say I was overwhelmed with my *TP53* mutation diagnosis is an understatement, for there was so little information on the topic as it relates to Waldenstrom's. At the Ed Forum last year, I was desperate for information and repeatedly received the same answer, "Patients with the *TP53* can expect a poorer outcome," with no other information or qualifiers. As a result, I discussed with Shelly Postek, IWMF Director, Community Engagement and Support, the possibility of starting a *TP53* Mutation Support Group. I recently held a "meetup" for people with the *TP53* mutation to check for interest. We had ten people attend, and many people have contacted me since. This is still an area where there is little information available, and the people who attended were so happy to be meeting with others with the mutation.

Wow, a lot can change in a year! This year at the Ed Forum, I personally spoke to at least five oncologists who had much more to say about *TP53*. Dr. Steven Treon even asked the panel in the "Ask the Doctors" session about how mutation results influence their decisions with treatment. A large portion of the discussion was about *TP53* mutation and the 17p deletion. Dr. Castillo told me there are more clinical trials that will focus on the *TP53* mutation and deletion, particularly in Europe during the next year. He believed that there will be more data to report next year.

I am very hopeful. I encourage anyone affected by the mutation or deletion to watch that session on the IWMF YouTube channel at *www.youtube.com/@IWMFVideos*. If you have the *TP53* mutation/deletion and would like to join our proposed *TP53* Affinity Group, please contact the office at *office@iwmf.com* to be notified when we are meeting.

IWMF AFFINITY SUPPORT GROUPS

If you are interested in joining any of these groups, please contact *office@iwmf.com*.

LGBTQ+

The LGBTQ+ Affinity Group is for individuals diagnosed with WM who identify as LGBTQ+, their partners, and their caregivers. It provides a safe and unique space where members can be their authentic selves while coping with the challenges of living and thriving with WM through an LGBTQ+ lens.

Young WM

The Young WM Affinity Group is specifically designed for patients and caregivers in the pre-retirement stage of life (age 50 and under). Discussions center on the issues most relevant to younger patients and caregivers, including navigating workplace transitions and family dynamics while undergoing treatment. Join a community that understands the complexities of juggling it all.

WM Military Veterans

Supporting those who served, our WM Military Veterans Affinity Group provides a dedicated space for veterans to connect and share their unique perspectives. Meetings cover a range of essential topics, from personal experience-sharing to practical advice on navigating the Veterans Administration (VA) system. The group is led by a Vietnam veteran.

Bing-Neel Syndrome

The Bing-Neel Syndrome Affinity Group offers an invaluable opportunity for WM patients with this rare syndrome and their care partners to “meet” one another virtually from across the globe. This group also hosts a private Facebook group for Bing-Neel community members to discuss important topics at *https://www.facebook.com/groups/3439253813014235*.

WM Caregivers

Launched in 2025, the WM Caregivers Affinity Group is a vital space dedicated to the heart of our community: WM care partners. Whether supporting a loved one with WM or managing a WM diagnosis while caring for another, this group is open to everyone needing support. Join the group to share your journey, find helpful resources, or simply listen in a supportive environment. Sign up for meeting notices at *https://lp.constantcontactpages.com/sl/dTXlHts/WMCaregivers*.

WM People of Color

Since the spring of 2021, our WM People of Color (POC) Affinity Group has been a dedicated force in closing the gap in healthcare disparities and resources for people of color with WM. This group provides a vital space for connection, advocacy, and shared support. Join on Zoom every other month on the first Friday from 1:00pm-2:00pm ET.

WALDENSTRÖM FRANCE'S
WM WORLD AWARENESS DAY ACTIVITIES
FIVE GATHERINGS, ONE SHARED ENERGY

By Valerie Debaix-Politano, President of Waldenström France, and
Alain Pleskof, Director of International Relations

Waldenström France has regional delegates who are members of our association. Each region has one or more delegates, depending on the size and importance of that region. These delegates are responsible for creating friendly connections between members who wish to interact, for organizing meetings or gatherings, and for informing newly diagnosed patients about hematologists familiar with Waldenström (WM) in their area.

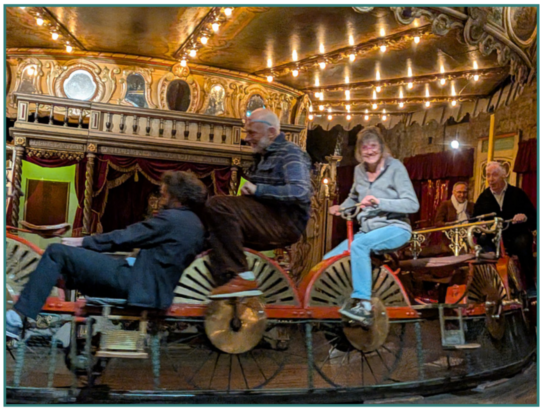
We have 12 delegates, representing seven different regions around France. They meet face-to-face once or twice a year, changing the place of the meeting to allow the largest number of members to attend, and regularly, sometimes once a month, meeting through video conference. Apart from that, any one of our members can be contacted anytime by phone, if needed.

April 17 was WM World Awareness Day, and it was celebrated across France, with five gatherings that were as warm as they were unforgettable. From Parisian magic to the friendliness of Mayenne, the Alsacian atmosphere, and the warmth of Bordeaux and Quimper, our members turned this day into a moment of sharing, laughter, and mutual support. Here is a quick look back at these precious moments that touched our hearts.

Paris: An enchanting journey at the Museum of Fairground Arts

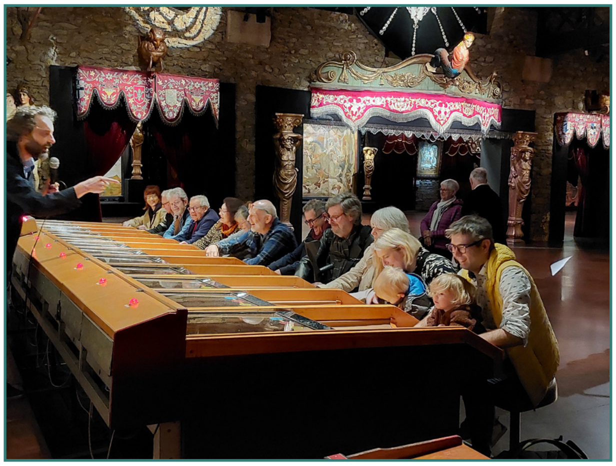
Our first adventure began at 10am in front of the Museum of Fairground Arts in Paris's 12th district. From the moment we arrived, our guide—both passionate and captivating—immersed us in the fascinating history of this unique place. From the very first steps, the magic began.

We discovered the Venetian Museum, a sumptuous setting where every detail transported us to another era. Then it was time for the rides! Who didn't smile when rediscovering wooden horses? These moments delighted young and old alike, reminding us all that joy has no age.



Cyclopèdes, a fun carousel ride in Paris

We also experienced the "cyclopèdes" carousel—an exhilarating experience! Between the rotation of the bicycles and the opposite movement of the tent, the illusion of speed was so strong that some of us came out a little dizzy, but delighted! And how could we forget the horse- racing game? This game of skill sparked friendly competition—and plenty of laughter! This day was made even more special by the presence of Dr. Pierre-Edouard Debureaux, a researcher at Saint-Louis Institute in Paris, who was accompanied by his charming family. His commitment alongside us was greatly appreciated.



A horse racing game played by the Paris group

WM World Awareness Day in France, cont. on page 30

At the end of the visit, Jean-Paul Favand, the Museum's founder, opened the doors to his secret storage rooms. A true hidden treasure: merry-go-rounds, figurines, paintings, games—a giant collection of odds and ends that amazed both children and adults. Then at 12:30pm, we headed to the Auberge Aveyronnaise for a warm welcome and a delicious meal. Between hearty dishes and lively conversations, this break was an opportunity for reunions and new exchanges.

Mayenne: An intimate gathering at the restaurant L'Antiquaire

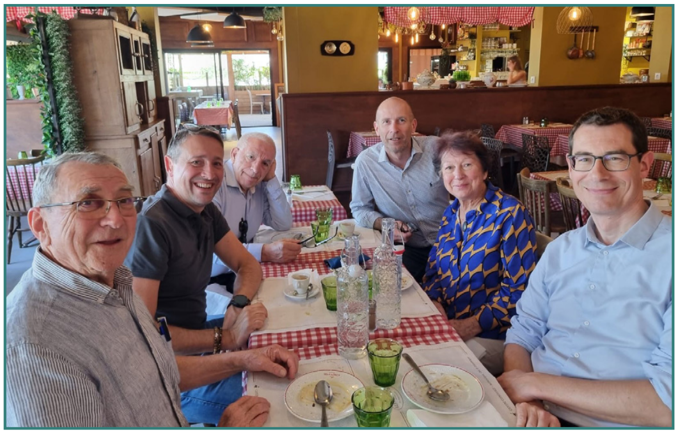
In Mayenne, Isabelle, Lionnel, Sylvie, and Jean-Paul met at the restaurant L'Antiquaire for a friendly get-together. In a warm atmosphere, these conversations helped strengthen the bonds among the participants.

Colmar: An Alsacian gathering

In Alsace, Laurence, our Grand Est representative, organized and hosted a meal in Colmar with nine guests. Thank you, Laurence, for this initiative, which delighted all the participants.

Saint-Médard-en-Jalles: A Bordeaux-style atmosphere

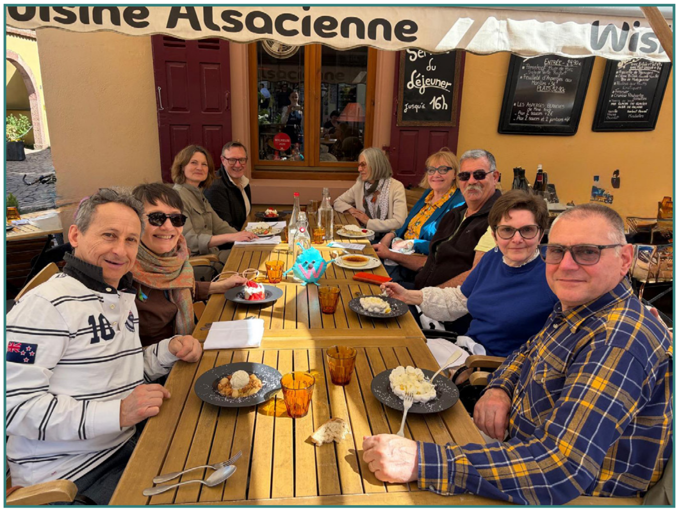
In western France, Pierre, our New Aquitaine delegate, brought together Gérard, Olivier, Joël, Philippe, Françoise, and himself around a table in Saint-Médard-en-Jalles. It was a "really great day," he said.



Dinner in Colmar, Alsace

Quimper: A warm Breton meeting, rich in exchange

In Brittany, 13 Walds and caregivers from Ille-et-Vilaine, Morbihan, and Finistère gathered with Michel. As is always the case with these informal meetings, the atmosphere was friendly and welcoming. Naturally, many discussions took place about each person's journey with the illness—but not only that. The seating arrangement also allowed caregivers to share their experiences of supporting their spouse or partner.



A group outing, Saint-Médard-en-Jalles, near Bordeaux

The discussions enabled Michel to gather the names of competent hematologists. They will be added to the list we keep up-to-date, so that we can offer recommendations to others. We will also send our brochures to hematologists, so that they can share information about WM and raise awareness of our organization. A big thank you to Michel and all the participants for this shared moment.

Supporting each other, no matter what happens!

Whether in Paris, Mayenne, Colmar, or near Bordeaux, the spirit of the day was the same: coming together, sharing, and supporting one another. As Jacques Dufour, our Île-de-France representative, so aptly said, "The formula was appreciated," and now the challenge is to maintain this level for future meetings. We parted with these simple but powerful words:

"Supporting each other, no matter what happens!" This perfectly captures the spirit of our association: solidarity, mutual aid, and joy of life, despite the challenges we face.

See you soon for new adventures!

FROM THE FACEBOOK WM SUPPORT GROUP: SUMMER 2026

By Betty Ann Morton, Editor

The Facebook WM Support Group remains active, with members asking questions about WM and sharing information and experiences. WMers and caregivers from around the world are welcome to join the 9,000 of us who already participate.

Here's a short conversation that may reassure WMers considering joining the Facebook group. **MP** wrote, "Quick question for this page administrator: Is this a public or private group? I'm questioning because Facebook can and does send email notifications to friends of posters/commenters of public groups. I assume it's a private group, but I would like to know. Sorry if it's a dumb question, I rarely post or comment on Facebook, but this WM group is very important to me. Thank you!"

Administrator **RS** responded promptly, "Yes, it is private. Your FB friends will not see any posts from this page unless they belong to the Facebook WM Support Group."

WM and kidney involvement was **MH**'s concern. "I was diagnosed with WM two years ago. Last year, it attacked my kidneys. I had kidney dialysis for 4.5 months along with chemotherapy, and my kidneys' GFR went up to 30 mL/min/1.73 m^2, which my kidney doctor was comfortable with. *[Editor's note: GFR is glomerular filtration rate, which measures how well kidneys remove waste from the blood.]* A year later, my kidney GFR is at 22, and she is sending me for a kidney biopsy to see if the cancer has returned and is attacking my kidneys again. Has anyone else had their WM attack their kidneys? I am in British Columbia, Canada."

RS responded, "Is this what you are referring to when you say WM in the kidneys? AL amyloidosis: The most common form of kidney involvement, where abnormal proteins (amyloid fibrils) build up in the kidney tissue and interfere with its ability to filter blood." **RS** also posted a link to an article about amyloidosis from the *IWMF Torch* at *https://iwmf.com/wp-content/uploads/2022/01/Torch-Jan-2022_final_web.pdf*

AJ shared her own experience. "I don't know if it's similar to you, but after a couple of years on watch-and-wait, I started to get frothy urine, which resulted in a biopsy of my kidneys to see if WM was causing the proteinuria. My kidney function was normal otherwise, and the biopsy did show WM infiltration, so I've done 6x cycles of bendamustine and rituximab, which brought my kidney function back to normal for now, and I hope for a long while."

TM introduced a new topic by writing, "This might be a silly question, but does WM have staging like all other cancers? I was just asked if I'm considered stage 1 since I'm watch-and-wait and am asymptomatic at this time."

It turns out that this question is one that many WMers wonder about. **MCM** explained, "Not silly at all. 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 has progressed to the bone marrow. WM always begins in the bone marrow, so labeling WM as a stage 4 cancer creates unnecessary panic."

JR said, "I was told stage 4."

MCM's response was, "Your doctor may have told you your WM is 'stage 4,' but WM isn't staged."

JR wrote back, "The explanation was that if bone marrow is involved, it's stage 4."

ES added, "You may want to give your doctor some current information. If the doctor insists on staging a lymphoma that isn't staged, I think it would actually be considered stage 1, because it STARTS in the bone marrow, and that's where it belongs! If lung cancer or breast cancer or many other lymphomas spread to the bone marrow, that's considered stage

From the Facebook WM Support Group, cont. on page 32

4, and that’s not a good place to be. Don’t be afraid to educate your doctor. If she/he doesn’t want to learn, that’s not a good omen. We all need to advocate for ourselves, as WM is so rare.”

RW expressed the thoughts of many WMers, “This is all such great information and explains it so well. I wish I could remember all this when I need to explain it to people.”

EM wrote about struggles with the side effects of treatment. “Do the treatments we have lengthen life expectancy? We all have a limited time, but we WMers lose whole days/weeks/months to the side effects of treatment, experiencing a low quality of life during that time. So, to make it work out for me, bendamustine owes me at least a week of good-enough days at some point. I've had relentless headaches, shivers, low-grade temperature, sweats on repeat. I can't even enjoy my books or other housebound hobbies. Please understand I'm really trying to hang tough.”

KK’s perspective was, “It is dependent on age and fragility and how advanced the cancer is. Treatment can definitely extend life and quality of life for the large majority of us. At 54 I was diagnosed with advanced disease. Without treatment, I'd have likely passed by now. Instead, a year later I have a good prognosis of lasting many more productive years of paying taxes.”

KH asked, “Are you still in active treatment? I'm six months post-treatment, and my quality of life has been greatly improved! It's worth it in my opinion. I'm having to manage my energy, but I wake up each day feeling like myself.”

BAM added, “Another part of the equation is whether the treatment alleviates the symptoms that led to a treatment decision. In my case, for example, WM with high IgM levels was subtly affecting my thinking speed and ability to make connections. Treatment brought me back, and that's worth a few days of side effects. If it extends my life, that's a bonus, but quality of life matters more to me.”

The original poster **EM** responded, “Getting your brain back is a great feeling. I'm hoping for both longer life and better quality of life.”

Another common topic of conversation centers around various treatment possibilities. **MB** started a conversation recently, writing, “I've been on Brukinsa (zanubrutinib) for a couple of years. It had brought my IgM down some, but now it is climbing back up again. My oncologist said they will likely change to something else in a few months. What have others gone to after Brukinsa?”

MCM suggested, “Jaypirca (pirtobrutinib) may be an option when Brukinsa stops working.” She posted a link to the Pirtobrutinib (Jaypirca) Fact Sheet on the IWMF website at *https://iwmf.com/publications/*. Fact sheets about the common WM treatments are downloadable in many languages.

SAP wrote, “Be sure to see how the symptoms that brought you to treatment track with your bloodwork. For me, my symptoms will come back (I’ve had two relapses), and my doctors and I watch to see if the IgM changes over 2-4 months. I am two years out from B&R or bendamustine and Rituxan (and Brukinsa before that). My IgM has been steadily rising, but symptoms are stable. For me and my WM specialist and local oncologists to treat again, we need to see my symptoms coming back. If you haven’t had B&R, that’s another option. Out of the three treatments I had in five years, B&R has given me the longest time between treatments. But each person can be different. I hope this helps as you think about whether you need another treatment.”

There are more suggestions, support, encouragement, and fellowship in the Facebook WM Support Group. 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*.

GET CREATIVE WITH DANA KUEHN
A CLASS IN THE IWMF INTEGRATIVE WELLNESS PROGRAM

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

Sometimes healing begins not with words, but with color, movement, music, and quiet moments of self-expression. IWMF's "Get Creative with Dana Kuehn" offers members a gentle space to slow down, explore, and reconnect with deeper parts of themselves through the expressive arts.

In fact, this class itself grew directly from the WM community: a WM patient who had previously participated in Dana's workshops elsewhere recommended her to the IWMF team. That spirit of collaboration and shared wisdom has helped shape the entire Integrative Wellness Program, with many offerings inspired by the experiences, interests, and suggestions of WM patients and caregivers themselves.

Led by expressive arts therapist and breast cancer survivor Dana Kuehn, this welcoming class invites participants to engage in simple, guided creative exercises designed to foster mindfulness, emotional restoration, and self-discovery. No artistic experience is needed—the focus is on the healing power of the creative process, not technical skill.

To help participants begin their creative journey, the IWMF Integrative Wellness Program recently offered a special art supply giveaway, covering the cost of six art supply gifts for WM patients and caregivers. Dana recommends easy, playful materials such as Jupitearth Tempera Paint Sticks or Faber-Castell Gelato Pens to help participants jump into the creative process without pressure or perfectionism.

The responses from community members revealed just how deeply many are longing to reconnect with creativity during treatment and caregiving:

"I've had a yearning to rediscover my abilities. I used to live to sketch but I have neglected that for a long time. I thought that while I am in treatment I could focus on the things that have brought me joy."

"I have always wanted to explore art as a hobby. Drawing and creating things helps decrease my anxiety."

"I am not doing enough with creativity and struggling with anxiety. I've been told art therapy could be very helpful. I have fond memories of art classes as a child and would love to rediscover that joy."

These reflections beautifully capture the heart of the program: creativity as a pathway back to joy, calm, connection, and self-expression.

The two art pieces accompanying this article were created during a special Earth Day-themed session, when participants were invited to reflect on something in nature that inspires gratitude. Several participants chose to draw the trees visible from their windows—steady, familiar presences that offer shade, beauty, comfort, and a grounding sense of connection to the world around them. Their artwork serves as a reminder that even small moments of noticing and creating can nurture healing and presence.

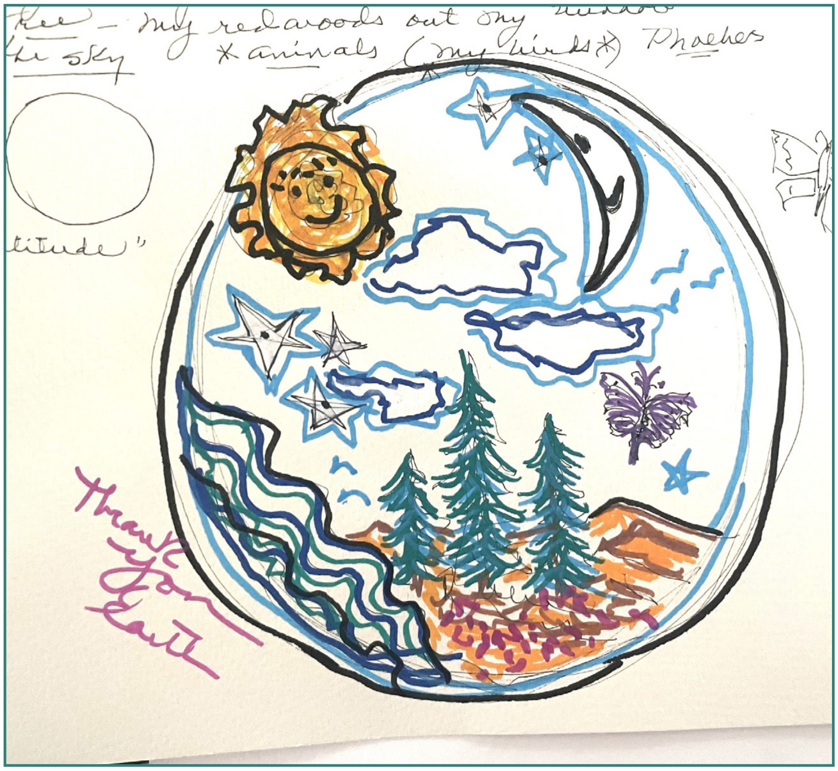
Drawing, painting, collage, movement, and reflection all become avenues for healing within the supportive WM community. Participants often discover that creativity opens doors to feelings, insights, and inner resilience that can be difficult to access in everyday life—especially while navigating Waldenstrom's.

Dana brings warmth, compassion, and decades of therapeutic experience to each session, blending expressive arts, nature therapy, and a deep belief in the restorative power of creativity.

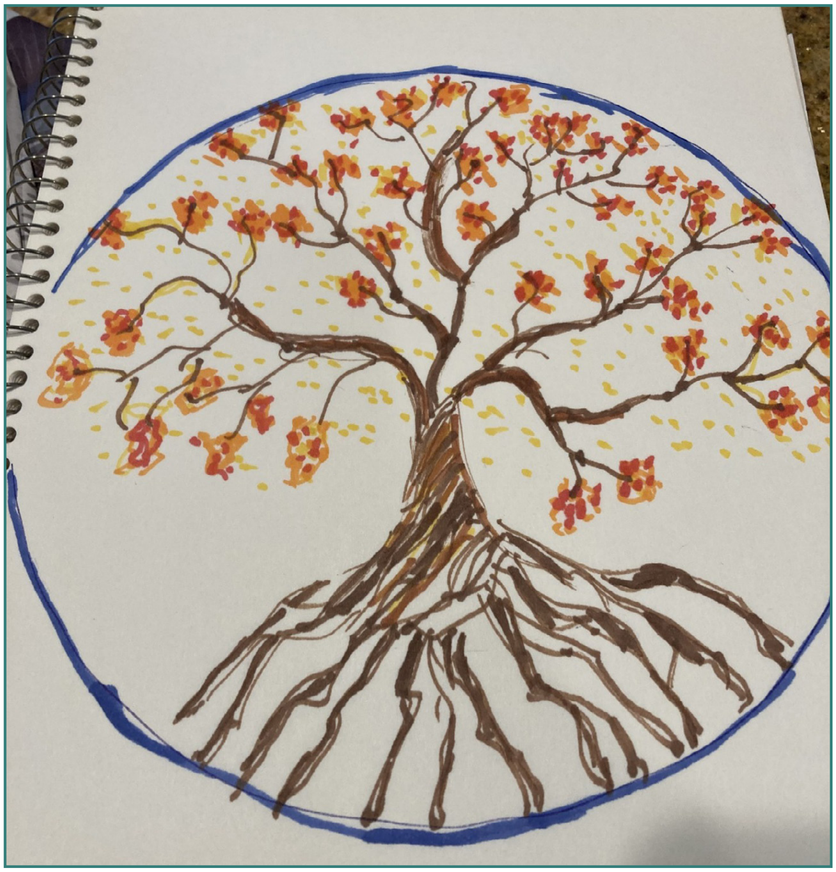
"Get Creative with Dana Kuehn" meets every other month at 12 noon ET on August 18, October 20, and December 22.

Get Creative with Dana Kuehn, cont. on page 34

To learn more, visit the IWMF Event Calendar on *www.iwmf.com* or contact *anngrace@iwmf.com*.



Earth Day drawing



Earth Day drawing

MEET KATIE WARRENSFORD
NEW IWMF CHIEF DEVELOPMENT OFFICER

IWMF is delighted to welcome Katie Warrensford as its new Chief Development Officer.

Katie is a dynamic nonprofit executive with more than 20 years of experience driving revenue growth and delivering measurable impact across mission-driven organizations. She has held senior leadership roles at both Blood Cancer United (formerly The Leukemia & Lymphoma Society or LLS) and the American Heart Association.

Katie brings deep expertise in strategic leadership, major gifts, and stakeholder alignment, along with a reputation for innovative solutions and inclusive practices. Her commitment to measurable results and her passion for patient-centered missions make her an exceptional addition to our team.

Here is Katie's message to the IWMF community:

Katie Warrensford

"There is something incredibly special about organizations built not only around a mission, but around people. From my very first conversations with the IWMF community, it became clear to me that this Foundation is powered by compassion, connection, and a shared commitment to creating hope for those affected by WM.

"It is truly an honor to join IWMF as Chief Development Officer and become part of a community that means so much to so many. Throughout my career, I have been drawn to mission-driven organizations where partnership, purpose, and people are at the center of the work. IWMF embodies all of those things in a remarkable way.

"While my professional background has centered around advancing nonprofit missions and building strong philanthropic partnerships, my connection to this work is also deeply personal. As the caregiver to my husband, who was diagnosed with a rare cancer, I understand the uncertainty and isolation that can come with navigating a rare disease diagnosis. Since joining IWMF, one of the things that has impacted me most is witnessing the strength of this community and realizing what an incredible gift it is for patients and families to have a place where they feel supported, understood, and connected.

"Even in my first month with the organization, I have already had the privilege of meeting patients, caregivers, donors, volunteers, researchers, and advocates whose passion and generosity continue to move this mission forward every day. Their stories are powerful reminders that the impact of IWMF extends far beyond programs and research initiatives — it reaches individuals and families searching for support, answers, and hope.

"As I begin this journey with IWMF, I do so with tremendous optimism for the future. There is meaningful momentum surrounding research, education, patient support, and community engagement, and I am excited to work alongside our staff team, Board of Trustees, volunteers, and supporters to continue building opportunities for impact, connection, and hope.

"I am deeply grateful for the warm welcome I have already received and look forward to building relationships throughout this remarkable community in the months and years ahead. Thank you for the trust, generosity, and dedication that continue to make the work of IWMF possible.

"I truly believe there are great things ahead for IWMF, and I am honored to be part of this journey with all of you."

TOTALASSIST: CONNECTING WM PATIENTS WITH THE CARE THEY NEED

By Maureen Iselin, Director of Communications, Patient Advocate Foundation

As patients across the country face rising barriers to care, growing affordability challenges, and a weakened healthcare safety net, the need for support has never been greater. That's why Patient Advocate Foundation—which announced a strategic merger with the PAN Foundation in March 2026—is proud to have launched TotalAssist on July 1, 2026.

As the nation's largest, most comprehensive charitable patient assistance portfolio, Patient Advocate Foundation's TotalAssist program offers over 140 disease-specific and health equity financial assistance funds. These funds support patients across a wide range of conditions—from chronic and rare diseases to cancers, including WM.

Immediate financial assistance for WM patients

Through a dedicated WM TotalAssist fund, we have immediate financial assistance of up to $9,500 per year for WM patients. If you or a loved one is living with WM, you could be eligible to receive a TotalAssist grant.

How TotalAssist works

Through financial assistance programs like Patient Advocate Foundation's TotalAssist, individuals who meet eligibility guidelines can receive free grants to help cover their out-of-pocket expenses.

Patients can use their TotalAssist grants for:

- Medication copays, coinsurance, and deductibles
- Health insurance premiums
- Office visit charges the day of treatment
- Administration charges related to treatment

By giving patients the flexibility to choose how they use their grant, this comprehensive approach reflects how patients actually experience care.

Eligibility criteria

While eligibility for TotalAssist grants vary by fund, to qualify for our WM fund you must:

- Be diagnosed with and in active treatment for WM.
- Legal resident of and receive treatment in the US or a US territory.
- Have health insurance that covers your prescribed WM medication.
- Be prescribed a medication on the TotalAssist approved medication list for WM (TotalAssist covers all treatments that are FDA-approved, listed in official compendia, or listed in published evidence-based or clinical guidelines).
- Have a household income at or below 500% of the Federal Poverty Level (adjusted for the Cost-of-Living Index and the number of people in your household).

How to enroll

Funds are available immediately, and the application process is fast and straightforward—it takes under ten minutes. Once approved, you can begin using funds right away, with a six-month lookback period. This means that your grant can be applied to expenses incurred up to six months prior to enrollment, depending on your date of diagnosis.

TotalAssist: Connecting WM Patients, cont. on page 37

TotalAssist: Connecting WM Patients, cont. from page 36

TotalAssist Fund Notification System

We are also pleased to launch our TotalAssist Fund Notification System. Through this user-friendly system, you can be notified as soon as a TotalAssist disease fund opens. The new system will allow you to:

- Select the communication delivery method(s) you prefer, email, SMS text, and/or automated phone call. You can select multiple communication options.
- Receive notifications for one fund, multiple funds, or all funds.
- Update your settings and preferences at any time.
- Unsubscribe at any time.

To learn more and sign up, visit *TotalAssist.org/notify*.

Additional TotalAssist resources

- **Website:** *TotalAssist.org*
- **Phone:** 1-866-512-3861
  (Monday through Friday, 8:30am-5:30pm ET)
- **Online help center:**
  https://uniting.patientadvocate.org/help/

We want to help you focus on what matters most—your health and well-being. We encourage you to apply today and thank you for trusting us with your healthcare journey.

IWWM
INTERNATIONAL WORKSHOP ON
Waldenström's Macroglobulinemia
2026

SAVE THE DATE

OCTOBER 17, 2026

9:00 AM – 12:00 PM
Networking Breakfast: 8:00 AM – 9:00 AM
Lunch: 12:00 PM – 2:00 PM

Renaissance Hotel
Palm Springs, CA

Waldenström's Macroglobulinemia
Patient-Focused Recap Session of IWWM-13

More details coming soon

Scan to register!

waldenstromsworkshop.org

BETWEEN MARCH 6, 2026, AND MAY 31, 2026, CONTRIBUTIONS TO INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF

5 year Wellness Anniversary
Ann Grace and IWMF Wellness Program
Bob Ulkus
Carl Harrington
Charles Caroselli
Dean Hill's Birthday
Dr. Jorge Castillo
Edward Goldberg
Edward Goldberg's Birthday
Eileen Sullivan's Birthday
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Jane Dutkowsky's Birthday
Janet Livingston
Janet Louise Livingston
Jay Singer
Kevin Toler's Birthday
Lisa Wise
Loretta Traphagen
Marcia Wierda
Margret Koch's Birthday
Meg Cyr Mangin's Birthday
Mike Gluhanich
Pat Hasler's Birthday
Patricia Oliver Ball's Birthday
Paul Bryan's Birthday
Peter DeNardis
Rubina Panariello's Birthday
Santi Vorster's Birthday
Sending Love to All of You
Sharon Piotrowski's 65th Birthday
Tarek Mouhieddine
The WM Wellness Program
Thomas O'Brien
5 year Wellness Anniversary, Ann Grace and IWMF Wellness Program
Delora Senft, Dr. Jorge Castillo and Paul Kitchen

BETWEEN MARCH 6, 2026, AND MAY 31, 2026, CONTRIBUTIONS TO INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF

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Laurie Ach
Lawrence Bonney
Lorraine Harkness Wynn
Marlene Terry
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Trey Levy
William A.S. Akana

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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IWMF
International Waldenstrom's
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2027
NORTH AMERICAN EDUCATIONAL FORUM

One Community. One Mission.

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Thursday, 15 April 2027

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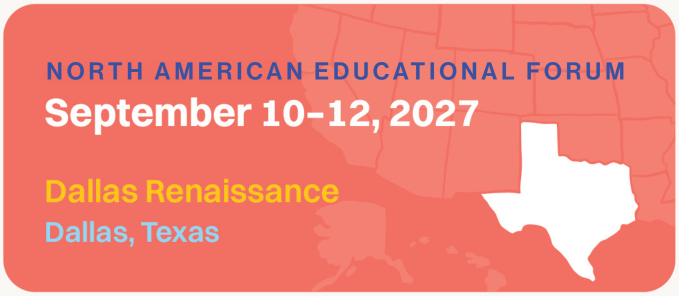

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