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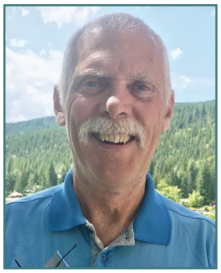
IWMF'S NORTHERN PARTNER: CANADA'S WMFC

By Cam Fraser, WMFC Board Chair



Cam Fraser

WMFC
Waldenstrom's Macroglobulinemia Foundation of Canada

(Editor's note: We have never had a comprehensive look at the WM activities and challenges of our large neighbor to the north, and it is time we do so. Cam Fraser was diagnosed with WM, watch-and-wait, in 2003, and in 2007 he retired as a VP business development, working with various oil and gas companies. He started a WM support group in Calgary in 2012 and had bendamustine and rituximab treatment the following year. He was appointed a Director of WMFC in 2019 and became Chair in 2021. He is happy his WM is now stable, and he can continue to work to make the WMFC a vital support system for Canadians with WM.)

At the recent IWMF Ed Forum, the Waldenstrom's Macroglobulinemia Foundation of Canada (WMFC) was invited to give a presentation to the IWMF Board. The following is a summary of my presentation—a brief update on our recent accomplishments and how we came to be.

Over the past three years, the WMFC has become very research project oriented, partly because of a new relationship with Pharma. Our revenues in 2023 have risen to $255,000, and we have issued an additional $300,000 in new research grants, all rated through the IWMF Scientific Review Committee's recommendation process. Some of our projects are listed below:

- We have expanded and updated our website at *www.wmfc.ca* and made it very user friendly and bilingual, as well as using both of our national languages of English and French in our communication to members.
- Labour has been significantly reduced through improvements in online processes with respect to donations and receipts and managing our membership.
- We have held three national Zoom presentations for oncologists in Canada by Dr. Steven Treon of Dana-Farber Cancer Institute.
- We hold 3-4 national Zoom meetings each year on various WM topics. Speakers are typically Canadian and US experts in WM.
- In November 2023, we held a Virtual Ed Forum with over 160 registered attendees, which was exceptional participation (30%) for Canadian people with WM.
- In partnership with BeiGene, Dr. Neil Berinstein, and CTC Communications, we have created an excellent, animated four-video set for the newly diagnosed (*https://www.wmfc.ca/videos-for-the-newly-diagnosed/*). Dr. Treon saw the video at the St. Louis IWMF Ed Forum in 2023 and was thrilled; the IWMF is considering an edited version for global distribution. Subsequently we created a second video: "Who is the WMFC?" (*https://www.wmfc.ca/who-we-are/*).
- We edited and redesigned two IWMF "Essential Information" booklets and distributed them to our current membership as well as to each new member, with amazing positive feedback. We are grateful to the IWMF for allowing us to adapt these booklets for distribution in Canada.

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Left to right: Joe Lewicki, Science Director; Rafaela Mercurio, Member Services Director; Cam Fraser, Board Chair

Our support groups are typically run by two co-leaders, and meetings are held 3-4 times each year. Our Zoom meetings have allowed us to expand geographically, with little interest, it seems, in a return to in-person meetings by our membership. The year 2024 has been deemed the "Year of the Support Group," and we are trying to fill our leadership vacancies and do our best to update and offer training to our existing leaders. We have one group operating in French in Montreal, Quebec. We may have the ability to expand the number of support groups by possibly one or two in the coming years. We are very appreciative of the things that the IWMF does to assist us in the managing and training of our support groups.

WM research in Canada has proved a challenge. We have partnered with the Leukemia & Lymphoma Society of Canada (LLSC) and issued two Requests for Proposals for Research in Canada to be funded 50/50 between LLSC and WMFC. Unfortunately, no acceptable proposals have been received after our two attempts. There appear to be a lack of WM researchers in Canada as well as a shortage of WM patient samples. However, we do have one very exciting clinical trial in Canada, the BRAWM trial, where researchers are treating up to 66 newly diagnosed patients with acalabrutinib, bendamustine, and rituximab. The Principal Investigator is Dr. Neil Berinstein of the Sunnybrook Hospital in Toronto, Ontario, and it is being run in nine centres across Canada. With the trial nearing completion, the initial results are very encouraging.

The WMFC is currently funding three new WM research projects. These include a $100,000 project from Dr. Signy Chow of Sunnybrook Health Sciences Centre, which is performing gene panel studies of samples from the BRAWM trial, as well as projects from Dr. Zachary Hunter of Dana-Farber and from Dr. Patrizia Mondello of the Mayo Clinic, each for $100,000. With the current fast pace of new genomic drug research, the WMFC is excited to continue partnering with the IWMF in supporting WM patients and ultimately finding a cure.

For those of you who are unfamiliar with Canada, we are a vast country, second largest in the world. We touch three oceans, the Atlantic, the Pacific and the Arctic. We have ten provinces and three Northern Territories with a total population in excess of 40 million people, including more than one million immigrants last year. We have two official languages, English and French, with English as the mother tongue of approximately 56% of Canadians while French is about 23%, with most French speakers, but not all, in the province of Quebec. Canada and the US share one of the largest trading relationships in the world.

We do have some challenges in Canada:

- There are approximately 2,000 WM patients in Canada. How do we reach the other 1,500 who are not currently members?
- It is difficult to find volunteers, both to co-chair our support groups and become Board members.
- Ideally, we would like to create a Centre of Excellence for WM in Canada, but as it stands now, doctors are scattered across Canada, and most see only a very small number of WM patients during their careers.
- Canadian research seems focused primarily on higher frequency conditions like chronic lymphocytic leukemia and multiple myeloma.
- How can we develop a sustainable revenue flow from donations?
- How can we simplify Canadian participation in US clinical trials?
- Drug approval is slow as each province must approve payments.
- We have approximately 450 hematologists in Canada, but only about 20% work on blood cancers.

The Waldenstrom's Macroglobulinemia Foundation of Canada (WMFC) was founded in 2000 by Arlene Hinchliffe. She did not have WM, but her father did, so she started WMFC because of the lack of WM support in Canada. It received its Canadian Charitable status for tax receipts in 2002. The WMFC is an all-volunteer foundation supporting WM patients across Canada. Arlene as Chair, along with a small board, directed operations over the next 16 years, managing 3-4 support groups, with average donations between $30,000 -$50,000 per year. An in-person Ed Forum was held in various cities across Canada each year. When Arlene retired in 2018, we had approximately 250 members. We owe Arlene a tremendous debt of gratitude for her years of outstanding service with the WMFC.

In 2018, Paul Kitchen became Chair. During his time with the WMFC, he expanded and diversified the Board to eight members and developed a new strategic plan for the WMFC. Donations rose to approximately $75,000 per year, and the number of support groups expanded to seven.

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He initiated the WMFC's first $200,000 research grant with the IWMF to fund a three-year project with Dana-Farber Cancer Institute and Dr. Zachary Hunter. No Ed Forums were held during the pandemic, and support groups switched to Zoom meetings, with our membership growing to about 350 members. Paul retired in 2021; during his time as Chair, he provided tremendous leadership through implementation of the new strategic plan. He currently is serving as a Trustee with the IWMF.

We now have 550 members and manage nine support groups located in most major cities across Canada. We are looking forward to our 25th anniversary as a charity in 2027. Although we have our challenges, we are also now focused firmly on the future, by finding new methods to connect with more Canadians with WM; improving both the WM patient's and the Canadian medical system's knowledge of the diagnosis and treatment of WM; and increasing our contributions to research to improve treatments and find a cure.

2024 IWMF ED FORUM RECAP

BY PETE DENARDIS, CHAIR OF THE IWMF BOARD OF TRUSTEES

The 29th Annual Educational Forum, held in May in Renton, Washington (near Seattle) in the US, was a hybrid event, with folks being able to attend either in person or virtually. The in-person attendance was 210, and 649 attended virtually. Virtually and in-person, 25 countries were represented.

Pre-Ed Forum activities

Upon landing at the Seattle airport, I was first struck by the image of Mount Rainier looming in the distance. Snow and glaciation atop its 14,000-foot peak belie the fact that it is an active volcano. The site of this year's IWMF Educational Forum was a short distance away, on the banks of Lake Washington, and provided ample opportunity to stroll along the lake front.

As I was entering the hotel, I could see IWMF staff, hotel staff, and videographers hard at work setting up for the weekend's meetings and activities. As attendees checked into the hotel, they invariably encountered fellow attendees they may have met in prior years or recognized from a photo via the IWMF website and social media postings. In each case, warm greetings were extended, and the atmosphere was more of a celebration of being together rather than a concentration on learning how best to cope with a rare, incurable blood cancer. Of course, there were to be many sessions on the latter—but the surprising aspect was just how excited folks were to see each other and to have the opportunity to share their stories.

In the afternoon on Thursday (or "Day 0"), there was a Support Group Leader Workshop, with SG leaders and affiliate leaders from around the world in attendance to gain insights and tips on how best to manage meetings and interactions with members. They were actively participating in a "hands on" presentation by Bethanie Mills, Senior Manager of Patient and Community Outreach at the Leukemia & Lymphoma Society, who shared her tips on strategies and support for peer support mentors, and at the end, the leaders shared best practices with each other.

Day one

Day one, Friday, was a day of surprises. It began early with a centering meditation led by the IWMF's Ann Grace MacMullan and breakfast next to the main ballroom.

View of Seattle beyond Lake Washington from the hotel's dock

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Sara McKinnie and Ann Grace MacMullan

Throughout the day, attendees were walking along the path that winds around the lake, and rock star doctors like Dr. Stephen Ansell were seen running along the path, while Dr. Jeffrey Matous was coming back from a 50-mile bicycle ride in the area!

The sessions began with opening remarks by IWMF CEO and President Newton Guerin and me. We thanked the Ed Forum Committee and the IWMF staff for their hard work putting together this year's Ed Forum and the many speakers who took time out of their busy schedules to attend.

The day's first session was led by Dr. Jeffrey Matous and one of his patients, Elsa Bradley. Dr. Matous is a clinician/researcher from Colorado Blood Cancer Institute and has been a featured speaker at several IWMF Ed Forums, while Elsa Bradley has had WM for over 17 years. Their dialogue focused on the importance of forging a strong relationship between the doctor and the patient. They agreed that, while it is ideal for patients to seek out doctors familiar with WM, one should at least find someone who is willing to communicate and talk with an expert. The important take-away is that the visit with the doctor is not a "once and done event." The relationship is one that must be built and maintained over the long term.

Ensuing sessions included Dr. Mary Kwok of Fred Hutchinson Cancer Center on the basics of WM, Dr. Zachary Hunter of Dana-Farber Cancer Institute on WM genomics, and Dr. Steven Treon from Dana-Farber on novel strategies to treat WM. Dr. Treon always can be counted on to provide an insightful perspective about just how far WM research has come over the years and how important the researchers and the IWMF are to the efforts to arrive at better treatments for the disease.

All participants were treated to a buffet lunch, followed by breakout sessions on "speed networking" (meeting fellow patients and caregivers), healthy cooking, resources provided by the IWMF, sound meditation, and a guide to all the services provided by the IWMF. Extra attention was devoted this year to the aspect of wellness and living well with WM, thanks to a relatively new staff member, Ann Grace MacMullan, and others.

After the presentations, a large group of attendees took advantage of the opportunity to participate in a leisure walk along the lake front. But the day was not over yet, as the last event was the Welcome Reception and Awards Dinner. And here's where additional surprises occurred.

The first was the announcement of the recipient of this year's Judith May Volunteer Award—Rick Savoy (see accompanying story on page 10). Although Rick was not able to attend in person, he did record a short video acceptance speech.

This was followed by a surprise presentation to Sara McKinnie, who has been the voice and face of the IWMF since its inception. IWMF founder Dr. Arnie Smokler hired her to help manage and coordinate communications with WM patients in the US and around the world, organize annual patient education forums, and develop relationships with top WM researchers and clinicians. Sara has been with the IWMF for 25 years and will be retiring at the end of May. Several people in attendance spoke about her, including Laurie Rude Betts (whose late husband was a past President of the IWMF and who has been an attendee and volunteer at the Ed Forum each year), Dr. Steven Treon and Chris Patterson of Dana-Farber, Dr. Stephen Ansell of Mayo Clinic, and me. A video tribute to Sara was then played, in which Dr. Morie Gertz and Dr. Robert Kyle (both of Mayo Clinic) each spoke of their admiration for Sara's dedication to the IWMF community. Then, Newton Guerin and I presented her with an award. Sara responded with heartfelt gratitude to everyone for their kind words.

Then, something a bit different took place to close out the day—a West Coast Swing dance demonstration led by IWMF Board member and *Torch* Editor Shirley Ganse and her fellow dancers. Shirley and her colleagues gave an impressive display of dancing techniques, and then, as the music continued, others got up to dance and try their hand at West Coast Swing dancing—or just dancing in whatever fashion suited them best (even Dr. Judith Trotman was encouraging

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me to join her!). It was a very special way to end the first day of the IWMF Education Forum.

Day two

Saturday morning began with a leisure walk, as I led a small group of attendees on the path along the lake. After a few minutes, the drizzle stopped, and folks were able to continue their journey of walking, talking, and sharing experiences with each other. Others chose to head to the buffet breakfast (the buffet food options were fantastic this weekend!) or to the morning centering meditation led by Ann Grace MacMullan.

The presentations for the day began with Todd Zimmerman, Medical Director from Beigene, speaking about advances in the last 25 years, noting that the IWMF is the glue that helped make the researchers, pharma, and clinicians work together to develop better treatments for WM. He also spoke about Beigene's campaign to focus on mental health among cancer patients.

The first official presentation of the day was by Dr. Stephen Ansell, who spoke about the IWMF research grant program, including the Robert Kyle Career Development Awards and the new Glenn Cantor Early Career Researcher Fund. The two invited Kyle Career Development awardees (Dr. Jithma Abeykoon of Mayo Clinic and Dr. Maria Luisa Guerrera of Dana-Farber Cancer Institute) provided insights into their research and background and gave everyone a glimpse of what the future holds for the global WM community. Dr. Ansell spoke about Dr. Glenn Cantor, former IWMF Board member who passed away unexpectedly a few months ago, and thanked his family for setting up the IWMF Glenn Cantor Early Career Researcher Fund (to which we can all contribute). It should be noted that Dr. Treon, in his presentation on the previous day, also spoke about the tremendous contributions that Glenn made to WM research initiatives.

Dr. Stephen Ansell and Dr. Guy Sherwood

This was followed by a new concept at this year's conference, a series of brief case studies presented by Board member Meg Mangin to a panel of doctors, each of whom provided their perspective on how best to treat the patient in question. It provided a glimpse into the thought process of each doctor and confirmed just how important it is to have a good relationship with your doctor and to seek out second opinions whenever possible. The morning sessions concluded with a presentation on WM treatment options by Dr. Judith Trotman from Concord Repatriation General Hospital, University of Sydney, Australia.

Buffet lunch was next on the agenda with great food options yet again (and they were quite tasty). Throughout the morning activities, attendees approached the doctors after each session to relay their own stories and get each doctor's perspective or just to thank them personally. The atmosphere was one of excitement and fellowship, with a unique vibe of togetherness and compassion.

After lunch were the last sessions for the day: one on wellness by Julie Larson and another by Dr. Jorge Castillo of Dana-Farber on the newly established clinical trials network called WM-NET, which promises to make clinical trials more readily available to patients in the US (and around the world in the future).

Once the two sessions were completed, several folks headed off to the WM Wellness and Community Yoga session, led by Ann Grace MacMullan, while others could be seen making dinner plans with each other and considering seeing some of the sights in Seattle for the evening.

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Day three

The last day (Sunday) began with several concurrent sessions:

- "All Things Anemia," presented by Dr. Mary Kwok, Fred Hutchinson Cancer Center
- "Peripheral Neuropathy," presented by Dr. Shirley D'Sa, University College London Cancer Institute, London, England
- "Preventing or Minimizing Financial Toxicity and Hardship," presented by Joanna Doran, Triage Cancer
- "Science of Cooking: Eating for a Healthier Lifestyle," presented by Christine Zoumas, UC San Diego
- "Unusual WM Complications," presented by Dr. Jeffrey Matous, Colorado Blood Cancer Institute
- "Zoom Community Discussion" for virtual attendees, conducted by Lisa Wise, IWMF Vice Chair for Information & Support

After the concurrent sessions was a presentation by Carl Harrington, IWMF Vice Chair for Fundraising, while Newton Guerin presented and explained several initiatives that are underway at the IWMF to raise funds to support more groundbreaking research.

At this point, it was time for the much anticipated "Ask the Doctors" session. The doctors on the stage were Jeffrey Matous, Judith Trotman, Sheeba Thomas (University of Texas MD Anderson Cancer Center), and Jorge Castillo. Dr. Shirley D'Sa and Dr. Mary Kwok were asked to participate from the front row of the audience.

Early morning walk for attendees

On the back end of things, Meg Mangin read through the almost 200 questions that were submitted for this session and placed them into categories, so that Lisa Wise and I could more easily select appropriate questions to present to the doctors.

As is usually the case, the questions were thought-provoking, and the answers were enlightening; there simply wasn't enough time to address all the questions that were submitted. Yet, everyone came away a good bit more knowledgeable about WM and their current health condition.

At the end, Lisa and I led the audience in a standing ovation for the doctors who took time out of their busy schedules to attend the Ed Forum and speak to us. At this point, Newton Guerin closed out the Ed Forum and thanked everyone who

"Ask the Doctors" panel: Drs. Judith Trotman, Jeffrey Matous, Jorge Castillo, and Sheeba Thomas, with Lisa Wise as moderator

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attended, everyone involved in planning and executing the Ed Forum, and all the doctors and researchers who came to be with the WM patients and families throughout the weekend. He also announced the site of next year's Ed Forum, which will be held at the Sawgrass Marriott Golf Resort and Spa in Ponte Vedra, Florida (near Jacksonville).

As folks were filing out of the ballroom, I could see many hugs, handshakes, fist bumps, and head nods as attendees said their goodbyes to each other. Everyone came away energized with the hope for a brighter future for living with the disease and with a warm glow in their hearts after sharing the weekend with people who are travelling the same life journey, dealing with the impact of WM.

P.S. Photos from the weekend can be seen at: *http://www.bit.ly/2024IWMF*. While a few participants shared their photos, it should be noted that most photos were taken by Tom Shyver, fellow WM patient, who has been the "official" photographer for the Ed Forum for the past few years—a huge note of thanks to him for taking on that volunteer role.

A joyful ending to the Ed Forum: Dr. Jorge Castillo, Dr. Jeffrey Matous, Dr. Shirley D'Sa, Pete DeNardis, Dr. Judith Trotman, Newton Guerin, and Dr. Mary Kwok

A FIRST-TIMER AT THE FORUM

By Chuck Moores

My wife Laura and I live in Sacramento, CA. I was diagnosed with WM in 2023...and that was a shock! Before my diagnosis we had never heard of WM, and because of my severe symptoms, we thought my days were numbered. We didn't know anyone else with this rare cancer, and if it weren't for my strong faith and wonderful wife, I probably would have fallen into depression.

So, Laura and I turned to the internet for information, but that resulted in a roller coaster of emotions. Shortly after the diagnosis, my oncologist started me on bendamustine and rituximab for six cycles. Laura put us on a whole food, plant-based vegan diet with no processed foods, sugar, or oil. In addition, we eliminated as many toxic products from our home as possible. However, we felt like we were fighting this battle alone with no place to go for support and no one to answer our questions.

Then in March of this year we found the IWMF website. We began realizing there are others like us out there who know what we've been going through. We aren't alone! It was through the website that we learned about the 29th Annual IWMF Educational Forum in Renton, Washington. Not only was this near my old hometown, but right next to the airport where I learned to fly. We didn't have to think twice about attending, and we are so glad that we did!

From the moment we signed in we could tell this event was well planned and very organized. The IWMF staff thought of so many wonderful details, like decent-sized name tags that were easy to read and provided additional information such as patient, caregiver, doctor, and a colored ribbon with the number of years since WM diagnosis. We found this information useful as we interacted with other attendees. To see ribbons with 5, 10, 15 and even 20 years survival rate was a huge inspiration and gave us hope. It was invaluable to mingle with others who have WM and share experiences, and we made so many new friends. Everyone was so easy to talk with: staff, patients, caregivers, and doctors.

At the Saturday morning breakfast, Laura and I happened to sit with Dr. Jithma Abeykoon from the Mayo Clinic. At the time we didn't know who he was. We just thought he was a very young man to have WM! As it turned out, we learned he was a hematologist specializing in WM research, and later that day was presented the prestigious Kyle Career Development Award. I mentioned to him that I have had WM for one year, and my oncologist would never explain my bone marrow biopsies or my lab results. Then, when I told him I had my results with me, he enthusiastically spent the next 30 minutes reviewing, interpreting, and educating us on WM, and where I stood as a result of my treatments. THAT WAS WORTH THE WHOLE TRIP! It's obvious he loves his job and is very dedicated, as were all the WM doctors attending. He even told me what other tests I needed to ask my oncologist to perform and why.

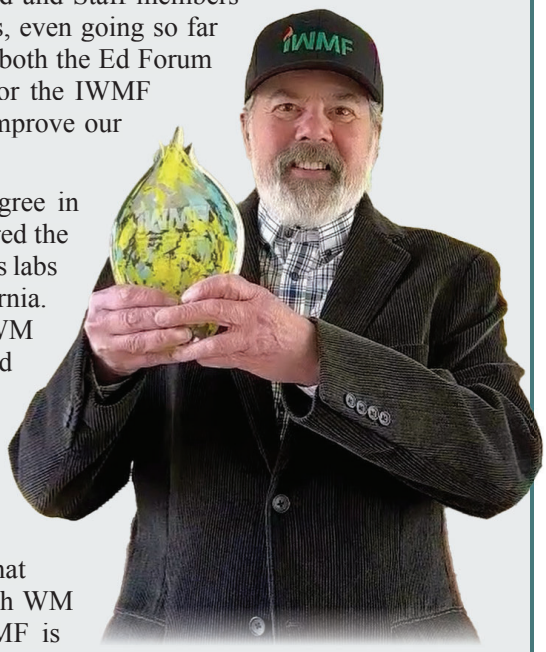
From that point on, my wife and I felt empowered, because now we had a better knowledge of the dynamics of the disease and the terms and words that define it. There was so much great information being shared during the breakout sessions, and we didn't want to miss any of it, so Laura and I decided to attend different sessions. Being immersed for three days with information about the latest research, treatment advancements, symptoms, ways to improve quality of life, patient interaction, and networking with others is best achieved by attending in-person. You could feel the positive energy in the air, and everyone was so eager to share, educate, and provide encouragement. This truly is a unique group of people. Thank you, IWMF, for hosting this invaluable Forum. We are planning to attend again next year, and if you've never been to an IWMF Educational Forum, I hope you will consider attending. See YOU there in 2025 at the Marriott Sawgrass in Ponte Vedra Beach, FL! Please make a point to come up to us and say "Hello my name is ____, and my IgM is ____."

Left to right: Dr. Jithma Abeykoon of Mayo Clinic, Chuck Moores, Laura Moores

AND THE JUDITH MAY VOLUNTEER AWARD WINNER IS…

Each year the winner of the IWMF's Judith May Volunteer Award is announced during the Ed Forum Friday night dinner, and this year's deserving recipient is Richard (Rick) Savoy.

Rick is the classic example of a "behind the scenes" volunteer. While he actively posts research articles and helpful information on both the IWMF Connect internet discussion group and the Facebook WM Support Group, much of his work for the IWMF has taken place under the radar. Rick is a "technical guy," and that was never more apparent—or more appreciated—than in 2020 when COVID hit, and the IWMF had to quickly switch gears and find a way to provide the next Ed Forum experience virtually. After the IWMF Board and Staff members chose a virtual platform, Rick was the one who dove into its mechanics, even going so far as to edit video recordings and stitch together multiple short videos for both the Ed Forum and the IWMF webinars—all from his home. Rick's technical work for the IWMF continues: he is always ready to provide constructive tips on how to improve our recordings, social media platforms, and website environment.



Rick Savoy

Rick is a native of Athol, Massachusetts, in the US. He earned a degree in electrical engineering from Wentworth Institute in Boston and then entered the US Air Force. After completing his service, he worked at various materials labs and analytical engineering labs in Massachusetts, New York, and California. He returned to Massachusetts, retiring in 2015, two years after his WM diagnosis. Rick is married to Joyce, and they have two children and three grandchildren. In his spare time, he enjoys hiking, bird watching, spending time in Boston, and, of course…editing videos for the IWMF.

The Judith May Volunteer Award is named in honor of past President (and now President Emerita), Judith May. It recognizes the spirit of volunteerism that Judith so aptly demonstrated throughout her career with the IWMF. The Award's recipients, current and past, are proof that working together, volunteers CAN make a difference for all people with WM around the world. Anyone who would like to volunteer for the IWMF is encouraged to go to: *https://iwmf.com/volunteerism/*.

Have Your Say

The *Torch* welcomes letters, articles, or suggestions for articles. Please contact *IWMF Torch* editor Shirley Ganse at *shirleyganse@hotmail.com*

MEDICAL NEWS ROUNDUP

By Sue Herms, IWMF Research Committee Member

Long-Term Results Published from French Clinical Trial of Bendamustine and Rituximab Therapy in Treatment Naïve WM – *The British Journal of Haematology* has published an update with long-term results from the 2013-2017 clinical trial of bendamustine and rituximab therapy in 69 treatment naïve WM patients that was conducted by the French Innovative Leukemia Organization (FILO). With a median follow-up of 76.1 months, the five-year progression-free survival rate was 66.63%, and the overall survival rate was 80.01%. Nineteen patients died—six from disease progression (including aggressive B cell transformation and amyloidosis), two from acute myeloid leukemia, five from solid cancers, and six from other causes (including brain hemorrhage, cardiac failure, organ failure, lung fibrosis, and flu). Sixteen patients relapsed, with a median time of 35.3 months from the end of first treatment to initiation of second treatment. Ibrutinib-based second-line therapy was more efficient than other second-line approaches, with a median progression-free survival of 45 months as compared with the whole group of relapsed patients who had a median progression-free survival of 21 months after second-line therapy with other drugs. Persistent toxicity from bendamustine and rituximab therapy was primarily from low blood counts, which were observed in 51% of patients, and included neutropenia (low neutrophil count), anemia, and thrombocytopenia (low platelet count); the median duration of low blood counts was less than one year. The rate of secondary cancers was 17.66% at 66 months. Although a lower overall survival was observed for the six patients in the study who did not have an MYD88 mutation, it was not statistically significant. Similarly, while CXCR4-mutated patients fared somewhat less well, this too did not reach statistical significance.

Chinese Researchers Look at Survival Effect of Early Progression in WM Patients – Researchers from the Chinese Working Group of Waldenström Macroglobulinemia performed a retrospective analysis of WM patients from the database of the Chinese Registration Network for WM to determine the outcomes on prognosis and survival of early disease progression, defined as progression that occurs within 24 months of diagnosis and first-line treatment. All 373 WM patients in the study received 3-10 courses of first-line therapy, including 143 with rituximab-based chemotherapy, 51 with bortezomib (Velcade)-based therapy, eight with BTK inhibitors, and 171 with traditional chemotherapy such as fludarabine with or without cyclophosphamide, chlorambucil alone, or cyclophosphamide with vincristine and prednisone. Progression within 24 months after diagnosis and treatment occurred in 98 patients (26.3%). The median overall survival was 40 months in these patients, which was significantly shorter than the 156 months achieved by patients who had not progressed with 24 months of diagnosis and first-line treatment. The researchers noted some limitations to their study, including the fact that BTK inhibitors and bendamustine-based treatments have only recently been available in China. Also, genetic characteristics of these patients (including MYD88 and CXCR4 mutation status) were not available, and their impact on prognosis and survival could not be analyzed. This research was published in the journal *Holistic Integrative Oncology*.

*Median **progression-free survival** was **less** in patients **with chromosome abnormalities** compared to those with normal chromosomes...*

Researchers from Italy Study Impact of Chromosome Abnormalities on Clinical Outcomes in WM – Italian researchers looked at how the presence and number of chromosomal abnormalities in WM cells affected clinical outcomes in WM patients. This retrospective study was based on a group of WM patients diagnosed between 2000 and 2023 at the University of Padua, 64 of whom had chromosome analyses (called karyotypes) of their cancer cells and were followed up for a median of 51 months. It was determined that 30 of the 64 (46.9%) had some abnormality of their chromosomes, either in their number or structure. A majority had one abnormality, but there were several with multiple abnormalities. The most frequent abnormalities included the 6q deletion (a missing part of the genetic material in the long arm of chromosome 6); trisomy of chromosome 3 (three instead of the normal number of two chromosomes); and the 11q deletion (a missing part of the genetic material in the long arm of chromosome 11). Loss of the Y chromosome was also detected. These patients tended to be older at diagnosis, suggesting a correlation between older age and higher prevalence of chromosome abnormalities. The researchers also observed a higher prevalence of secondary cancers in patients with chromosome abnormalities. Major response rates to first-line therapy tended to be less in those with abnormal chromosomes than in those with normal chromosomes, although statistical significance was not reached. Median progression-free survival was less in patients with chromosome abnormalities compared to those with normal chromosomes (65.8 months vs. 117.8 months, respectively); similarly, median overall survival was less in patients with chromosome abnormalities (76.1 months vs 167.7 months, respectively). This study was published in the journal *Annals of Hematology*.

Medical News Roundup, cont. on page 12

NCI Researchers Analyze Genes from WM Family Pedigrees – It is known that the risk for WM is elevated among first-degree relatives (parents, siblings, and children) of WM patients; however, the list of genes and their variants that cause genetic susceptibility to WM is incomplete. Researchers from the US National Cancer Institute (NCI) performed genetic sequencing of 64 WM family pedigrees, most of which had at least three members with WM, to look for evidence of the genes and gene variants that cause susceptibility to the disease. This study, published in the journal *Blood Neoplasia*, identified several genes and gene variants that were pathogenic or likely to be pathogenic in each family pedigree. Variants seen in a few family pedigrees that may warrant further investigation were identified in two genes, TREX1 and SAMHD1. In addition, the researchers identified other cancer pre-disposing genes of interest, such as POT1, RECQL4, PTPN11, and PMS2, that play a role in the regulation of the immune response, DNA repair, and the maintenance of telomeres (sections of DNA at the ends of the chromosomes that protect chromosomes from damage). However, the overlap of these genes between different WM families was modest, indicating that each WM family pedigree is largely unique and that multiple genes are likely to be involved in the pathogenesis of WM.

*It is known that the **risk** for **WM** is **elevated** among **first-degree relatives** (parents, siblings, and children) of WM patients...*

Texas Study Compares Survival Outcomes in Hispanic and Non-Hispanic Patients with LPL/WM – A study presented by the University of Texas Health Science Center at the 2024 American Association of Cancer Research (AACR) Annual Meeting examined patient characteristics, treatment, and survival patterns in Hispanic vs. non-Hispanic patients with lymphoplasmacytic lymphoma (LPL)/WM. Data reported to the National Cancer Database were analyzed from 2004-2019 and identified 17,915 such patients, 3% of whom were Hispanic and 92% non-Hispanic. Hispanic patients were mostly male, as were non-Hispanics, and the median age at diagnosis for Hispanics was 68 years, compared to non-Hispanics at 71 years. Education levels and income tended to be less for Hispanics than non-Hispanics. More Hispanics were uninsured and were less likely to have government-sponsored insurance. During this period, 68% of Hispanics and 62% of non-Hispanics received treatment, and most Hispanics were treated at academic/research centers, while most non-Hispanics received treatment from community cancer centers. There was no difference in overall survival between the two groups, and there were no independent factors in either group associated with better or worse overall survival.

Phase 2 Trial of Loncastuximab Tesirine for Relapsed or Refractory WM is First Trial in WM-NET Clinical Trials Network – A Phase 2 clinical trial of the drug loncastuximab tesirine (Zynlonta) for relapsed or refractory WM is the first trial to be included in the newly formed WM-NET clinical trial network established by the Dana-Farber Cancer Institute and funded by the IWMF. The drug, already approved by the US Food and Drug Administration for diffuse large B cell lymphoma, will be available to WM participants who have received at least two prior treatments, including an anti-CD20 antibody such as rituximab and a BTK inhibitor such as ibrutinib (Imbruvica). Loncastuximab tesirine is an antibody drug conjugate that combines a monoclonal antibody (in this case an anti-CD19 antibody) with a toxin in order to deliver the killing toxin directly to the cancer cells. The trial will be conducted at Dana-Farber Cancer Institute, Mayo Clinic, and Fred Hutchinson Cancer Center. The trial identifier on *www.clinicaltrials.gov* is NCT05190705. For more information on WM-NET, see the article "WM-NET: A New Solution to the Clinical Trial Challenges in WM" on page 5 of the January 2024 *Torch* at *https://iwmf.com/wp-content/uploads/2024/01/N52606-Torch-January-2024_web.pdf*.

Phase 2 Trial Available for Newer BCL-2 Inhibitor Therapy in Relapsed or Refractory WM – BeiGene is sponsoring a Phase 2 clinical trial to evaluate the safety and effectiveness of its oral BCL-2 inhibitor called BGB-11417 (Sonrotoclax) in patients with relapsed or refractory WM. The trial, which expects to enroll approximately 85 participants, is open at 31 locations in the US, Australia, China, France, Spain, and the United Kingdom. BGB-11417 is a second-generation drug in the same drug class as venetoclax (Venclexta). On *www.clinicaltrials.gov*, the trial identifier is NCT05952037.

Article Compares Immunoglobulin Replacement Therapy to Prophylactic Antibiotics in Blood Cancer Patients with Hypogammaglobulinemia – An article in the journal *Blood Advances* compared immunoglobin replacement therapy to prophylactic antibiotics to treat hypogammaglobulinemia (low levels of normal antibodies) in people with blood cancers. Hypogammaglobulinemia may put one at a greater risk of getting infections. This trial, conducted in seven hospitals in Australia and New Zealand from August 2017-April 2019, enrolled 63 patients with either a history of repeated serious infections or IgG levels less than 400 mg/dL (4 g/L). Participants were randomized to receive intravenous IgG every four weeks or daily antibiotics (either trimethoprim-sulfamethoxazole or doxycycline) for a total of 12 months. The primary outcome was the proportion of patients alive on the assigned treatment at 12 months; 76% in the immunoglobulin replacement arm and

Medical News Roundup, cont. on page 13

71% in the antibiotic arm achieved this result. The lowest time point to first major infection was 11.1 months for the immunoglobulin replacement group and 9.7 months for the antibiotic arm. The rates of major infections were similar in both arms. Three participants in the immunoglobulin replacement arm and two in the antibiotic arm experienced Grade 3 or greater (severe to life threatening to causing death) treatment-related adverse events.

***BI-1206** targets a mechanism of resistance to rituximab therapy and **aims to restore rituximab's benefit** to patients who are demonstrating resistance to therapy.*

Early Phase 1 Data Available for Novel Monoclonal Antibody Combined with Rituximab for Relapsed/Refractory NHL – Early data are available from a Phase 1 clinical trial of the monoclonal antibody BI-1206 in combination with rituximab for the treatment of relapsed or refractory non-Hodgkin's lymphoma (NHL). BI-1206 targets a mechanism of resistance to rituximab therapy and aims to restore rituximab's benefit to patients who are demonstrating resistance to therapy. Among eight patients evaluated, there were four partial responses and one complete response (by a patient with marginal zone lymphoma).

Phase 1 Trial Reports First Results for BTK Degrader Used in Blood Cancer Patients with CNS Involvement – Nurix Therapeutics announced its first response results in patients with B cell blood cancers who had central nervous system (brain and spinal cord) involvement and were treated in a Phase 1 clinical trial with its oral BTK degrader called NX-5948. NX-5948 was detected in all spinal fluid samples available from treated patients, demonstrating that the drug was able to cross the blood-brain barrier. The company's presentation included case studies of two patients who had progressed after multiple lines of previous treatment, one with chronic lymphocytic leukemia (CLL) and one with aggressive primary central nervous system lymphoma (PCNSL). Both patients had complete responses to NX-5948 therapy in their brain scans and spinal fluid. While the CLL patient remained in response at the time of this report, the PCNSL patient developed a new brain lesion. The findings were presented during the 2024 American Association of Cancer Research (AACR) Annual Meeting.

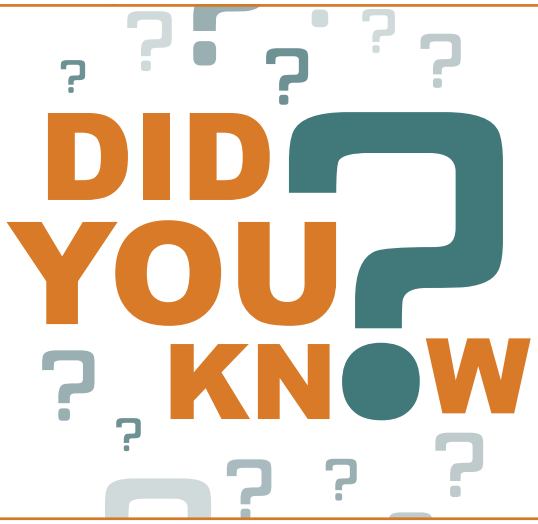
The author gratefully acknowledges the efforts of Grete Cooper, Peter DeNardis, Julianne Flora-Tostado, Tom Hoffmann, Richard Savoy, and others in disseminating research news of interest to the WM community. The author can be contacted at suenchas@bellsouth.net *for questions or additional information.*

THE IWMF NAMES NEW BOARD MEMBERS

The IWMF continues to maintain its strength and scope by encouraging Board members to serve one or two three-year terms and then consider making way for new members. As needs, resources, and geographic areas expand, the Board is then able to be refreshed with new expertise, life experiences, and a variety of personalities. Two new members were recently appointed, and they are:

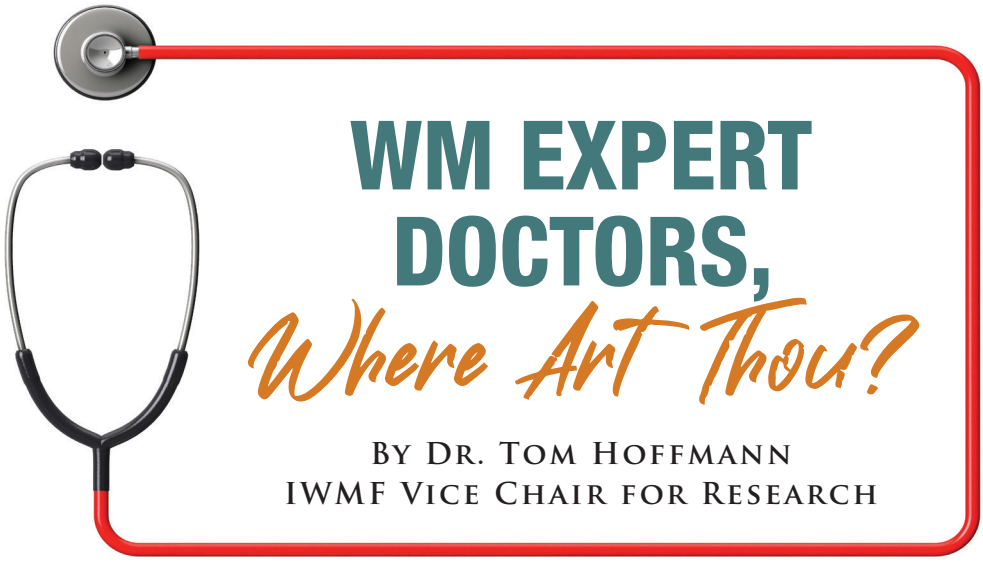
Eileen Sullivan, a WM patient, was diagnosed in 1995 and is well known across the WM community for her volunteerism. She specializes in support and education, as she has a strong professional background in education planning and delivery. Her many WM-related activities include being the current Eastern MA Support Group Leader; working on the annual IWMF Ed Forum Committee; providing tech support for international meetings for Bing-Neel Syndrome and Peripheral Neuropathy Support Groups; and being an active contributor to the IWMF's Facebook and Connect groups online. She has also taken a lead role in developing an IWMF Support Group for Extramedullary Disease and continues to press for more attention to it.

Craig Prizant, whose sister has WM, is a cancer survivor. He is serving on the IWMF Fundraising Committee. He is the Chief Development, Marketing, and Leadership Officer at Vista Del Mar Child and Family Services, a premier mental health children and family services agency. He has been there for over ten years. Craig has spent the past 17 years in the not-for-profit world guiding some of the largest charities in terms of raising money, branding, and identifying key volunteer leadership. Prior to his not-for-profit work, Craig was one of the foremost authorities on branding global corporations at Saatchi & Saatchi Advertising. He has raised over $1 billion in charitable gifts in his career. He has also offered the resources and staff of his fundraising team, including in the areas of public relations, grant writing, and data analysis, to help augment the IWMF's fundraising capabilities.



THE IWMF SPONSORS ONLINE HEALTH AND WELLNESS CLASSES

The IWMF offers online health and wellness classes and webinars to improve the quality of life for people with WM. Regular classes include chair yoga, yoga nidra, strength training, sound meditation, cardio flow, tai chi, and qi gong, while recent webinars have included topics on how to improve sleep and reduce fatigue and strategies to manage peripheral neuropathy. For more information, contact: Ann Grace MacMullan, IWMF Wellness Program Coordinator, at *anngrace@iwmf.com*



WM EXPERT DOCTORS, *Where Art Thou?*

By Dr. Tom Hoffmann
IWMF Vice Chair for Research

As we all know, very few doctors are aware of Waldenstrom macroglobulinemia (WM), much less know about the treatments for it. When primary care physicians finish their training after four years of medical school plus 2-4 years of a family practice residency, they may not have heard even once about WM. The next level are doctors in internal medicine. They also know little to nothing about WM after 7-8 years of training. Even an oncologist who has heard about WM in his training may have never seen a patient or be able to manage the work-up and treatment.

This is a terrible problem for someone who is newly diagnosed with WM who goes to a family physician with his symptoms. The physician has probably never seen a WM patient and doesn't order the proper blood tests. He may say "let's give it a few months." If he remembered WM from medical school, he might say that you will die in 2-5 years. That was accurate in the 1990s and continued to be used for a decade. Doctors cannot keep up with everything about every disease, especially rare diseases. It is out of their realm.

In time, a patient will be sent to see a local oncologist. The oncologist may not have ever seen WM either. I went to the American Society of Hematology medical meeting last year, which more than 35,000 doctors, mostly oncologists, attended. One of the discussions was in a room full of thousands of oncologists, with others standing in the back. It was about breast cancer. Next was a WM discussion; only 35 people were in the room.

The IWMF is doing as much as possible to get the word out to all doctors and patients. We have multiple publications to help patients, nurses, and doctors at *https://iwmf.com/publications/*. We have even mailed hundreds of these to doctors and nurses. But the problem continues because we are one of more than 300 rare cancers. Nobody can remember them all.

The IWMF has a list of WM expert doctors on its website. These doctors see many WM patients, have performed WM research projects, specialize in WM, and are used for second opinions. There are many in the country but not in all states. This list can be accessed at *https://iwmf.com/wp-content/uploads/2023/10/IWMF_PHYSICIANS_DIRECTORY.pdf.*

As I mentioned, finding a local oncologist who is familiar with WM is a big problem for newly diagnosed patients. While they might have gotten a diagnosis, they still will need a local oncologist for ongoing care. The IWMF cannot reach all of them, and they may flounder with their non-WM doctors. So they need to be proactive in asking a potential oncologist several questions:

1. How many WM patients do you see per year?
2. Will you mind if I get a second opinion from time to time from a WM expert?
3. Will you follow the expert's advice and/or use the NCCN clinical guidelines for treating my WM?

It is also important that a local oncologist is willing to answer questions, offer explanations, and be open to discussions about treatments and other associated medical issues. While these precautions might not guarantee finding an oncologist who will exactly fit their needs, it is a good place for newly diagnosed patients to start. Locating a nearby IWMF support group could also be helpful, for sharing information about local resources among members is a good way to learn who the doctors are and what options are available in the area.

INDIA UPDATE

By Saurabh Seroo, IWMF Trustee and Co-Leader of WM India

Waldenstrom India

On March 29, 2024, Saurabh Seroo signed an Agreement or "Memorandum of Understanding" on behalf of the IWMF with the Indian Myeloma Academic Groupe (IMAGe).

As part of the Agreement, the IWMF and IMAGe will collaborate on pan-India educational initiatives; patient-centric activities such as support groups and annual educational meetings; and research and epidemiological studies to enhance knowledge and treatment outcomes in the field of WM in India.

This is a significant step forward for the WM community in India, because it signifies the importance with which WM is being viewed by practitioners in large and important hospitals across the country.

As part of our joint initiatives, WM India and IMAGe held the first national support group meeting on May 19, 2024, over Zoom. The meeting was headed by two stalwarts in the field of hematology in the country: Dr. Hari Menon of St John's Hospital, Bangalore, and Col. Dr. Uday Yanamandra of Armed Forces Medical College, Pune.

The inaugural meeting was a successful first step toward disseminating knowledge and enhancing WM patient care in the country. We plan to have more such meetings with some of India's best doctors, and we count ourselves lucky to have them focus their efforts on WM.

Left to right: Saurabh Seroo; Dr. Pankaj Malhotra of PGIMER, Chandigarh; Dr. Hari Menon of St John's Hospital, Bangalore; Col. Dr. Uday Yanamandra of Armed Forces Medical College, Pune

THE LONG VIEW

By Carole Zavala

Carole Zavala and her artwork

"You have, I suspect, a marginal B cell lymphoma," Dr. Jacobs said after checking out a small, salmon colored lump under my right eyelid. "What?" I asked, having been told for several years that this slight lump was the product of an allergic reaction to a hair product or something in the air. "What is that?"

"I'll send you to a specialist for a biopsy, but it's a form of cancer," he replied. My disbelief and shock are no stranger to any of you, I'm sure. A biopsy revealed the truth of his words. A subsequent meeting with an oncologist not only confirmed that news, but further scans revealed tumors throughout my body. I didn't have a bone marrow biopsy, but a year later, two more lumps in the ocular area were biopsied and found to contain the evidence of Waldenstrom's. Another layer of shock and denial arose. "Jeesh, what the heck is that," I asked, and was reassuringly told that it was a rare blood cancer with no cure, but was treatable. The following statement was meant for comfort: "If you have to have cancer, this is the best one to have. It won't kill you, especially at your age."

Thus, my entry into the world of WM. I'll cut to the chase here. I am blessed with a terrific oncologist, Dr. Lauren Pinter Brown of UCI in Orange, CA. She didn't mind being rigorously interviewed as to her qualifications, to my future, and to my ongoing requests to modify treatment dates, treatments, and options.

I was no stranger to what might be ahead. My partner was in his fourth year of treatment for colon cancer. I had shaved clumps of his greying hair as it began to fall out. He wasn't even 70 when it started. I had researched diet options for side effects and scoured sources for soothing treatments for sores. No way was I going to put myself through this scenario.

Besides, he had an almost meditative approach to his cancer. He seldom ever complained, spent quiet hours sleeping during chemo (while I never even closed my eyes), and only during the last weeks of his life talked about things he missed doing. He never whined! I whine regularly.

Fortunately, I didn't have to suffer as he did. Rituxan proved to have very minimal side effects, and I used the 3-4 hours to write, sketch, or read. But fatigue found me an unwilling victim. I continued to run a weekly art program for the City of Laguna Beach, do career coaching, and travel. I lived my dream of getting to Egypt in 2019 before COVID hit, and this year I published a fantasy novel for young girls that I'd been writing since 1964 when teaching in East Los Angeles.

I truly credit part of my good fortune to being "upright and taking nourishment" at 85 from the IWMF and its excellent resources, especially the Wellness Program by Ann Grace MacMullan. I've done yoga since the 70s and hated giving that up due to dicey knees, fatigue, and COVID. Thanks to Ann, I discovered not only a reasonable approach to yoga, but an amazing support group of international participants. Bonus features are yoga nidra, sound meditations, and now access to a host of WM experts.

I still get "whiny" about the routine of bloodwork, doctor visits, and occasional rounds of chemo, but gratitude waltzes in more often than not and gives me a reality check. My doctor suggests I modify my schedule to reduce fatigue, but I resist until I can't get my head up off the pillow. Who wants to miss another chance to walk the beach, have dinner with friends, or visit an art gallery? Not me!

The Buddhists encourage embracing difficult times with curiosity or even "friendliness," as meditation teacher and psychologist Tara Brach suggests. I find this a fascinating approach and difficult to do, but it has some validity. Everything changes and impermanence is a concept I'm trying to get comfy with. But on a day when I'm feeling reasonably strong and energetic, I understand the concept. And on the days when I'm not, I try to remember it could all change at any moment.

I try to stay in the present, maintain an irreverent sense of humor, rely on Buddhist teachings, and not ponder much about the future. But there are moments, and I'm sure you know this, when even the smallest discomfort can trigger fear and anxiety about "What's next?" or "How much more can I handle?" That is when I try to remember advice from Ann Grace and people with WM to breathe and just take it one moment at a time. A fellow colleague, who taught fitness classes up until her 80th birthday this last April, always ended her classes with the reminder, "It's good to have a pulse. Consider the option!"

"The Long View" by Carole Zavala, acrylic on canvas

HAEMATOLOGY PATIENT AND CARER CONFERENCE, LONDON

HANNAH SYED, AFFILIATE AND GLOBAL ENGAGEMENT

The IWMF Europe team was fortunate to be invited by Dr. Shirley D'Sa to attend the inaugural Haematology Patient & Carer Conference (HPCC) held recently in Westminster, London. This meeting gave a unique opportunity for patients and carers to connect with people living with similar conditions and hear from clinicians, National Health Service (NHS) executives, industry partners, and patient organizations in one space.

Orlando Agrippa, Founder and CEO of Sanius Health

With a packed agenda, the day was kicked off by a welcome from Orlando Agrippa, the Founder and CEO of Sanius Health. Sanius Health was the host of the HPCC meeting, and Agrippa previously presented at our European WM Patient Forum (EWMPF), when Sanius launched wearable technology to support people living with WM in the UK. This EWMPF session can be viewed on the IWMF YouTube channel at *https://youtu.be/rc3U3VA4-30?si=YOP3HfZ3xBnNw2ka.*

Agrippa spoke on the importance of value-based care and improving the quality and experience of patient care and outcomes, with a focus on rare and chronic diseases. Later, a unique panel session was held with a range of executives from hospitals and the National Health Service Trusts across the country. The session was chaired by Dr. Shirley D'Sa, Consultant Haematologist and Clinical Lead at the University College London Hospitals Centre for WM and Associated Disorders, and Claire Harrison, Professor and CMO at Guy's and St. Thomas' Hospital.

This panel session was an opportunity to gain an insight into the challenges of efficiently managing healthcare. Questions posed to the panel included "What does good healthcare look like?" A consistent message from this session was that there needs to be a change to prioritize putting patients at the center of managing their condition. It was discussed that in the UK, and I would imagine this would be relevant in many countries, we do not have a "health service" but rather a "sickness service." Where currently we have a very reactive system, we need to have a focus on prevention. Patients also need to be empowered with the knowledge about their health and condition to work with their healthcare team and manage this effectively. Healthcare should be seen as a team sport, in which a community collaboration between the multidisciplinary healthcare professionals and their patients creates a level of personalization of care. The speakers were challenged about how these values could be implemented. They recognized there would be a journey to make these changes; however, they hoped that the leaders and executives within the healthcare system recognized that to improve

Left to right: Vincent Sai, CEO of Modality Partnership; Dr. Claire Harrison, Professor and Clinical Director at Guy's and St. Thomas' Hospital NHS Foundation Trust; Dr. Shirley D'Sa, Consultant Haematologist and Clinical Lead at UCLH NHS Foundation Trust; Sir James Mackey, CEO of Northumbria NHS Foundation Trust; David Probert, CEO of UCL Hospitals; Orlando Agrippa, Founder and CEO of Sanius Health

Haematology Patient and Carer Conference, cont. on page 19

patient outcomes, patients need to be put at the center of their care, empowering them and understanding that this is the direction the future of healthcare should be heading.

The range of haematological conditions represented at the meeting was also reflected in having a diverse audience and speakers. It was very insightful and moving to hear from a young man speaking about his sickle cell anaemia diagnosis, living and managing his condition with the support of his community and healthcare team.

The afternoon was divided into plenary sessions and workshops—a great way to cater to different levels of knowledge and interests within haematology. Plenary sessions included topics such as innovative trials, treatment challenges, and shared decision-making. Workshop topics included a guide to understanding bone marrow, exercise, and nutrition. The session on patient empowerment was very encouraging for patients to realize they are the "experts in their condition." It was discussed how being involved with (Phase III) clinical trials does not mean you are a "guinea pig," but rather it helps researchers understand which treatment is better for patient quality of life. The importance of clinical trails being representative of the patient population was also emphasized, as an underrepresentation will result in developing medication suitable for only some members of the community.

This meeting was a fantastic opportunity to meet people living with WM in the UK, in person. Many were very excited to attend the event, to reunite with their support group members, connect with new members of the WM community, and meet the UK expert in WM, Dr. Shirley D'Sa.

Overall it was a fantastic meeting. The date for the next HPCC meeting is already set for May 16, 2025, and I very much look forward to attending next year.

Attendees with an interest in WM at the HPCC meeting

ACTIVE MONITORING: PAVING THE WAY FOR A STANDARD OF CARE PATHWAY IN THE UK

By Kat Tucker, WMUK

Earlier this spring, WMUK was proud to launch the Active Monitoring Checklist—a resource to help both patients and healthcare professionals navigate conversations around Active Monitoring (AM) and improve care during this period of time for people with WM. *(Editor's note: AM is also called "watch-and-wait.")*

Alongside the Checklist, the charity also launched a series of videos for people on AM, showing what consultations on AM should look like, as well as patients sharing their own experiences of care whilst on AM.

The work was the product of a need to improve the patient AM experience. WM patients reported feeling stressed and anxious during this time, with many patients and family members often feeling confused as to why they weren't going on treatment.

As one commenter on social media said: "When a doctor says you have cancer, the first thing you want is treatment to cure it. It's difficult for a patient to accept that watchful waiting (AM) can be the correct treatment for this very rare, incurable cancer."

Together with a working group of clinicians, patients, and other stakeholders, we gathered the opinions of almost 200 patients and clinicians, whose responses to our survey produced a strong consensus on how AM should be communicated and explained. These results fed into the AM Checklist.

The videos supporting the campaign have also helped people on AM feel heard and understood. One viewer of a patient story video said: "It is quite reassuring to hear about others with the same condition."

A series of educational videos for healthcare professionals was also rolled out, with Dr. Roger Owen and clinical nurse specialist Charlotte Bloodworth giving guidance and advice on navigating what can be difficult conversations and consultations with patients.

Patients are already reporting back how useful the Checklist has been when talking with their clinicians. It is the first step toward creating a standard of care pathway for people with WM, ensuring that no matter where they are treated in the UK, they receive the same expert care. WMUK is raising money to help drive this work, and you can contribute here: *justgiving.com/campaign/wmactivemonitoring.*

You can find the AM Checklist and our other video resources here: *wmuk.org.uk/waldenstroms-macroglobulinaemia-active-monitoring*.

MEETING OF THE WALDENSTROM SUPPORT GROUP IN ULM, GERMANY

MARCH 21-23, 2024

In comparing the recently distributed agenda for the patient conference in June 2024 in Hamburg (Germany), organized by the German Leukemia Support Group (DLH), one has to admit that the meeting of the Waldenstrom Group in Ulm is more comparable to a very intimate family reunion.

It's worth sharing a few thoughts about the value of this group and its annual meetings for its members. The group, founded by Uwe Kerscher from Regensburg in April 2021, grew within three years to the remarkable size of 87 members spread over Austria, Bulgaria, Germany, Switzerland, and the US.

The communication takes place mainly via WhatsApp, sometimes by using emails. To establish the WhatsApp group structure, subgroups focusing on specific topics were founded and are meanwhile well accepted. With those tools and the appropriate mindset of all members, an outstanding, efficient, and open discussion culture emerged. Regarding issues in conjunction with our disease, someone in our group responds and has a helping proposal or reports from his own experiences. It is always astonishing what open and fearless exchange of very personal information is possible between people who never met before.

Lucky as we are, we have a physician in our group; she knows both sides as a physician and as a patient. A special gift for the group is the fact we also can call Prof. Christian Buske, our mentor, as he supports us through one-to-one discussions as well with regular presentations during our annual meetings in Ulm.

With all those communications and presentations, we learn a lot about our disease and the different symptoms and side effects of the potential treatments. Knowledge is the key word to get along with almost every challenge.

Prof. Buske is the reason why we come together for personal meetings in Ulm. All presentations are recorded and available at our internet page, but they can also be followed in real time through video conference by those who cannot make it to Ulm.

This year's meeting in Ulm started with a lecture from Uwe Kerscher about his personal experience with medical cannabis as a pain-relieving treatment. Barbara Scheerer (Munich) followed with an instructive overview on nutrition recommendations for cancer patients. The afternoon brought us back into the center of Waldenstrom research. Prof. Ute Hegenbart (Heidelberg) pointed out that light chain amyloidosis is rarely triggered by Waldenstrom's, but she gave us an understandable presentation of the background and treatment of this disease. Finally, newest research results were explained by Prof Buske, who also took us through the achievement of establishing the European Consortium for Waldenström's Macroglobulinemia (ECWM), which for now mainly brings researchers together; however, it is also to include patients. Before the social part of the meeting started, Annedore Klinksiek-Bruegel, a member of our group, introduced us to yoga exercises. It turned out to be an extraordinary experience on how to relax with a few smart movements after a day of presentations and discussions.

Time for private talks was sufficiently available during our joint dinner in the evening and while walking through the city of Ulm on the following day. This walk was under the guidance of Daniela, a most experienced guest leader, whose expertise we enjoyed for the third time.

Yes, it remains a challenge when we look at the broad program of the DLH Conference in Hamburg. However, we decided to stick to our family reunion approach and are not planning to compete with such spectacular conferences.

Spotlight ON SUPPORT GROUPS

Edited by Sharon Rivet

EDITOR'S NOTE:

Please send ideas for future stories about your support group and its members and activities to Sharon Rivet at shaycr62@gmail.com*. We'd like to read more about groups we've never heard from!*

SIX YEARS MAKE A DIFFERENCE

By Sharon Rivet

Six years ago…

Like most of us, I was stunned to hear the words, "You have cancer." What the heck, I had just retired, and I felt fine! As I reflect on the last six years, I recall the "treatment" year, the COVID year, the "I am always sick and need IVIG" year. I also reflect on finding the IWMF, finding a support group, and finding how I could support others.

Sharon Rivet

It was as simple as clicking on "GET INVOLVED" from our IWMF website. From that click forward, I have had many opportunities to become involved, from working on the Ed Forum planning committee to participating on the BeiGene Patient Advocacy Council as a person with Waldenstrom's.

Six years later…

One role that I have found extremely rewarding is acting as Regional Contact for the New York/Western Massachusetts area. While I do not have a dedicated support group, it has allowed me to speak with people who, like me six years ago, are going through the period of disbelief, of not understanding treatment options, or of being afraid for their future. I can direct them to the IWMF and a support group.

Through this role, I have had the opportunity to meet support group leaders (SGLs) from the United States and our international affiliates, and at a meeting for SGLs during the Seattle Ed Forum recently, I had the pleasure to meet with many in person. During the group presentation, the phrase, "positive problem solving" was intertwined throughout many of our discussions. I listened to the SGL discussions around how to navigate in the post-COVID world of Zoom, versus in-person, versus hybrid meetings, or how to make sure a person who is newly diagnosed feels welcome and safe, just to highlight a few of the many topics.

Like you and me, most of our SGLs are also Waldenstrom patients who may be experiencing symptoms, treatments, and so on. It is a testament to how important and committed our SGLs are as they continually look for ways to build the power of our support groups—positive problem solving. Of course, support group meetings would not be possible without the IWMF, Shelly Postek, and Lisa Wise! So, what is the point of this story?

Reflecting back, I have learned that regardless of where I am on any given day, I know I can find support at a meeting, on Facebook, Connect, LIFELINE, or through a phone call, and this is my thank you to all our many positive problem solvers. It is also my challenge to you that if it has briefly crossed your mind to volunteer, even if you have limited time to offer, just click GET INVOLVED.

A JOURNEY YOU DON'T SEE COMING

By Howard Sholkin

I am a lifelong resident of Newton, MA, where my two adult children are fourth generation Newtonians. My career began exactly as I expected when I was a child, but it didn't last. I wanted to be a broadcast journalist, and I graduated from one of the best schools for it: Syracuse University's Newhouse School. After nine years at WCVB-TV in Boston, I switched to the growing high technology industry in 1981. As it grew, so did my resume in marketing communication, as I worked at eight tech companies over several years. When I ended full-time corporate work, I moved into higher education. For several years, I taught marketing communication and media at Boston University and Lasell University.

This is the third year of my WM journey that I didn't see coming. I had one symptom that two primary care doctors missed: persistent anemia. I was a regular blood donor for a few decades, and several years ago I started failing iron tests, even though I was taking iron pills for several years.

I had two misses by doctors before I was diagnosed. When my primary care doctor left the practice, I found another one. At my first visit, this doctor was suspicious of the persistent anemia and some blood test results. It also turned out she had worked at Dana-Farber Cancer Institute, where I'm now

Spotlight on Support Groups, cont. on page 23

being treated by Dr. Shayna Sarosiek. A few months after seeing me, Dr. Saroseik said it was time to be treated. She gave me a menu of choices, and I selected a clinical trial of ibrutinib and venetoclax.

IWMF helped me find clinical trial participants

That's when I first learned of the IWMF during my research. I wanted to meet the trial participants and asked Dana-Farber if I could. I could not do that through the hospital, so I turned to the IWMF. I posted a request on IWMF Connect and on the Facebook WM Support Group. About 15 of the 60 participants from around the US and one other country (not in the trial but taking the meds) wanted to talk. We had a few very informative talks, and then the trial stopped suddenly because of serious adverse side effects among several participants.

I developed A-fib shortly after taking ibrutinib; I now take medications for it, and I have no A-fib symptoms. The good news is that after only eight months of the scheduled two-year trial, my WM is under control more than two years after I stopped the trial drugs!

For the past 30 years, I have worked out one hour, three days a week. Based on Dr. Sarosiek's orders to remain healthy and fit to counteract WM, I have continued that schedule. Sometimes I am more tired during my exercise regimen, so I take a short break. If I didn't work out, I'd probably be 30 pounds heavier, so that's another motivation!

Making local connections with an IWMF support group

I'm a natural connector, so I found the Eastern Massachusetts Support Group of the IWMF in early 2021. Our leader, Eileen Sullivan, is a thriver since the 1990s, when she was told she had five years to live. She confirmed what I had been told—that one usually dies with WM and not from it. Since COVID, group members from across New England have met on Zoom. There are usually 10-15 participants on Sundays every few months. We had our first in-person meeting in October of 2023, gathering for a picnic in Waltham, MA.

My life with WM

WM hasn't significantly interfered with my life, and I am very grateful, for I know some people cannot say that. Just

Howard Sholkin and the Red Sox World Series trophy at Fenway Park in Boston

a few months before I was diagnosed in February 2021, I retired as adjunct faculty at Boston University, where I taught in the Communication College. As a serial volunteer, I have since joined four non-profit boards spanning religion, business, arts/culture/beautification, and local online media. In my spare time, I help at two food pantries and guide a Syrian family through life in America.

The IWMF is one of the most important non-profits that I help with fundraising each year. When I join an organization, I like to be an active participant, and in my first year, I collected enough IWMF donations to earn a complimentary pass to the annual Educational Forum held last year in St. Louis!

While I know WM is with me all the time, I do not let it rule my life. I feel fortunate that I have friends in the IWMF, doctors at Dana-Farber just a short distance from my home, and a cancer that is very treatable.

FROM THE FACEBOOK WM SUPPORT GROUP: SUMMER 2024

By Betty Ann Morton

Greetings to our international WM community! I'm recently back from the 29th IWMF Educational Forum in Seattle where I was able to meet some of the world's leading experts in Waldenstrom's macroglobulinemia. I practiced yoga next to Dr. Judith Trotman from Australia; had a conversation with Dr. Shirley D'Sa from the UK about peripheral neuropathy; coincidentally sat with the parents of Dr. Zachary Hunter (from Dana-Farber Cancer Institute) during his presentation about WM genomics; and learned from social worker and presenter Julie Larson, LCSW that she had brought her young daughter along from Iowa for a special girls' weekend in Seattle.

Although most members of the Facebook WM Support Group were unable to attend the Ed Forum in person, members watched the virtual presentation and have been anxious to view recordings of sessions they had missed. **LS** wrote, "Hi everyone, I registered for the 2024 IWMF conference in Seattle, but as I live in Australia it was difficult to watch because of the time zones. I thought that the sessions were recorded, but I've been unable to find where/how to watch them. I'm particularly interested in "Pick Your Poison: Treatment Options" and "Ask the Doctors," because they include Prof. Judith Trotman, who is my haematologist." **LS** was pleased to learn that after a little editing, the Ed Forum recordings have been posted on the IWMF website (see *https://iwmf.com/educational-forum-multimedia-2/*).

*I **de-stress in nature** and have forced myself to **be present in the things I do** instead of just 'doing them' on auto pilot.*

Stress plays a major part in WM patients' quality of life. Most of us had serious stress at diagnosis; it's common to feel some of that stress again when waiting for test results or when making treatment decisions. **AM-J** posted, "Has anyone found that stress plays a part in the course of the illness? How do you handle it please?" **LJ-KS**'s request was very similar. "I was diagnosed on 2/15/24, a few weeks before I turned 60 (that really sucked!). The mental part has been the hardest—just not knowing what all of this means! I say all the info I've been bombarded with is like trying to drink from a fire hose! (Humor helps me a lot.) If anyone has any particular advice on how to keep this demon from whispering in my ear and ruining the positive mental part of how I live my happy life, I'd be really grateful for suggestions."

BAM said, "I haven't personally found a correlation between stress and the course of my WM. However, stress does intensify how much I notice various symptoms and how much I worry. When I'm stressed, I'm more likely to obsess about things. Is this cancer-related fatigue or do I just need to turn the light out earlier? For me, exercise is most helpful in handling stress: anything from going for a walk to a strenuous exercise class. I find WM yoga classes (and the post-class conversation) to be stress-reducing."

AGC responded, "I do the same thing…ask myself all the time…could this be part of the WM? I de-stress in nature and have forced myself to be present in the things I do instead of just 'doing them' on auto pilot. Meditation has helped A LOT!" **TB** added, "Exercise, listen to music, plant a garden...any kind of hobby you love. Do that. Call people who make you laugh or watch cat videos on YouTube. Bake, volunteer, be kind to yourself." **CBM** added, "I've had to learn to change my attitude. I think the stress I dealt with in the past may have lowered my immunity. WM snuck past my immune system is how Dr. Ansell explained it to me. I too do WM yoga, walk, listen to music. Dance and pray. I try to stay as calm as possible since the treatments six years ago." **MCM** suggested Julie Larson's virtual 2021 Ed Forum presentation "Dealing with the Stress of Medical Uncertainty" (*https://www.youtube.com/watch?v=vhsb-OXxJqw*). More of Julie Larson's wisdom is in "Finding Wellness in a Wacky World" from the 2024 Ed Forum: (*https://www.youtube.com/watch?v=d3LSzXdygBA&list=PL8DMfoyQZpOqhW1N85xJb9OKkk2oS-bt9&index=7*).

As usual, there has been much discussion within the Facebook WM Support Group about troubling symptoms, often looking for help with fatigue. **KGG** lamented, "Does the fatigue ever get better??? It's been a week and a half since my final Rituxan treatment, all my labs look amazing, but by 12pm I am utterly exhausted." **BD** replied, "Fatigue hasn't been better for me. I ended bendamustine and Rituxan treatments 16 months ago. It seems to get worse actually." **SR** wrote, "No, it doesn't (get better). When I have energy, I take advantage and often overdo it. I always hit a wall when my body says enough!"

Continuing the discussion about fatigue, **JJ** posted, "I've had to learn how to pace myself. When I'm feeling great, I still take it easy. If I do too much, I have a rebound effect the next day, and I'm like a zombie. As a general rule, I do half as much as I used to, and I build in time during the day to rest and relax. It's my new normal, and it's working well. I only nap two or three times a week now—whereas post-treatment I was still napping daily, so it's an improvement." **MCM** agreed, "Fatigue has been part of my life for many years, and I expect it to continue. I am involved in many activities, but I pace myself carefully, and I participate in regular exercise."

From the Facebook WM Support Group, cont. on page 25

The Facebook WM Support Group serves as an always available listening ear—and a best friend's common sense, knowledge, and experience. Many times, WM patients ask questions about medical concerns. People have posted quite a variety of questions. **LT** wondered, "Can Brukinsa (zanubrutinib) cause low blood pressure? My pressure went down to 85 over 50. I had to go to the hospital to get checked out." **MCM** responded, "High blood pressure is a side effect of Brukinsa. What was your sodium level? Were you referred to a specialist to determine the underlying cause?"

JM wrote, "I have had a mouth sore (canker sore) on the very back of my tongue since January. I have seen my PCP who advised triamcinolone dental paste. Still not healing. It hurts to swallow. Has anyone ever dealt with ongoing mouth sores?" That was the beginning of a lengthy discussion about people's experiences with mouth sores and suggestions for dealing with them, with some members having found solutions for their sores while others were still searching.

JWJ worried about rising IgM levels. "If I'm on zanubrutinib and my IgM is rising, does that mean the treatment is not working anymore?" **DS** responded, "It depends on what you mean by rising. If there is a significant increase in IgM, then you should discuss it with your consultant. If it is a small increase, I wouldn't worry. There can always be a fluctuation in test results."

HMS posted, "Does anyone experience a dry nose with Waldenstrom's? I can't tell if it is seasonal allergies or coming from WM. Some minor bleeding. I just had a PET scan yesterday and will see my hematologist in June for an IgM in the 5,000 (mg/dL) range. It jumped from the 3,000 range in December. My hemoglobin is in the normal range. I did read that WM can cause nose bleeds or nose irritation." **MCM** replied, "Your IgM and nosebleeds suggest hyperviscosity. A rapid increase in IgM suggests progressive disease. Depending on symptoms and PET scan results, doc may want to see you sooner." **KL** added, "You might want to get a dilated retinal exam with an IgM that high."

PS wondered, "Has anyone had kidney or gallbladder issues since being on B/R (bendamustine and Rituxan)?" **MP** responded, "I had to have my gallbladder removed, not because of stones, after three Rituxan treatments. After my gallbladder was removed, I went on to have the fourth Rituxan treatment and have been on Imbruvica since then. No other problems. My oncologist said she couldn't find any connection with Rituxan in the literature."

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

GLENN CANTOR MEMORIAL EARLY CAREER RESEARCHER FUND

Dr. Glenn Cantor was a tireless advocate for finding and engaging the best and brightest next generation researchers for WM.

Glenn joined the IWMF Board of Trustees in 2020, served on the IWMF Scientific Advisory Committee (SAC) and Research Grants Review Committee and was Science Editor for the *IWMF Torch* magazine.

In early May 2024, his family announced the creation of the Glenn Cantor Memorial Early Career Researcher Fund. This effort will help ensure that the IWMF will continue to attract the best and brightest next generation researchers to WM.

Thank you to the Cantor Family for helping ensure future WM research.

Glenn and Inge Cantor

If you are interested in learning more about IWMF Named Gift Funds or Named Research Funds, please contact Annette Preston, Director, Donor Engagement, at *apreston@iwmf.com* or 941-927-4963.

SUPPORT AND FINANCIAL ASSISTANCE AVAILABLE FROM THE PAN FOUNDATION

By Amy Niles, Chief Mission Officer, PAN Foundation

Eric Douglass lives in Virginia, where he enjoys spending time with his kids and hiking in the Shenandoah Mountains whenever he can.

Eric is also living with Waldenstrom's macroglobulinemia, and for a time, he was overwhelmed by the cost of his care and managing his condition. Financial assistance from the PAN Foundation changed that.

"Without PAN's assistance, I would have stayed home and worried not just about cancer issues, but about money issues," he said. "PAN has successfully removed one of these, so that there is less on my plate. I have nothing but gratitude for PAN."

As the Chief Mission Officer at PAN, I am proud to be a part of a national charitable assistance and healthcare advocacy organization that has helped more than 1.1 million people like Eric, who are living with chronic, rare, and life-threatening conditions.

Our financial assistance programs help people afford their premiums, copays, and other treatment costs, as well as transportation to support their care. And through our advocacy initiatives, we're helping to educate patients, healthcare professionals, and policymakers about the legislation that will make equitable and affordable healthcare a reality for all.

How our financial assistance works

PAN provides patient assistance grants for more than 70 diagnoses, including Waldenstrom's macroglobulinemia. Through these grants, we offer a fast, reliable way for eligible patients to get help paying for out-of-pocket prescription medication costs, health insurance premiums, and transportation expenses. Our online eligibility checker at *https://www.panfoundation.org/apply-and-manage-grants/applying-for-grants/* helps you find out whether you qualify for any of these funds in minutes.

Our grants often cover 100% of your out-of-pocket costs. And we cover products that are FDA-approved or listed in an official compendia or evidence-based guidelines for each disease. This includes brand and generic medications.

If you have previously applied for a PAN grant or joined one of our disease fund wait lists, you can apply online through the PAN portal at *https://panfoundation.my.site.com/s/login* or by phone. If you're new to PAN, please apply by phone. To apply by phone, call us at 1-866-316-7263 Monday through Friday, 9am to 5:30pm. ET. In most cases, approved applicants can begin using their grants immediately.

Our Waldenstrom's macroglobulinemia fund's assistance amount is $3,250 per year, and 61 medications are covered.

To get financial assistance, you must:

- Be getting treatment for WM;
- Reside in the United States or US territories (US citizenship not required);
- Have health insurance to cover your qualifying medication or product;
- Be prescribed a medication or product on PAN's list of covered medications; and
- Have an income that falls at or below 500% of the federal poverty level (see *https://www.needymeds.org/poverty-guidelines-percents),* or $75,300 annually for a single person household.

Use our disease fund wait list

We do our best to keep our disease funds open all year round based on support from our generous donors. However, if the fund you would like to apply for is closed, we recommend signing up for the wait list at *https://www.panfoundation.org/apply-and-manage-grants/wait-lists/*. Our wait list system allows prospective grantees to get the first chance to apply for assistance when funding becomes available. Our website also tracks available funding at other charitable organizations, so even if our fund is closed, you'll be able to quickly see whether help is available somewhere else. Our goal is to help patients in need find help, regardless of the source.

Sign up for FundFinder to get real-time funding alerts

We also recognize that searching the internet for open funds, whether at PAN or another organization, can be challenging and time-consuming. That's why we developed the first patient assistance app, FundFinder, which allows users to sign up for notifications for 200 funds across nine different charitable organizations. Our award-winning app also allows users to connect with nearly 150 support organizations that may have peer support, educational resources, and other helpful offerings. It's free to use and anyone can sign up. Check it out at *fundfinder.panfoundation.org.*

Learn more

To learn more about the PAN Foundation or apply for financial assistance, visit *www.panfoundation.org.*

BEN RUDE HERITAGE SOCIETY

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

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

David and Janet Bingham Research Fund of the IWMF

- Aldo M Roccaro MD, PhD, Dana-Farber Cancer Institute, *Further genomic characterization of Waldenstrom's Macroglobulinemia: unveiling the role of the CXCR4 somatic mutation, a crucial regulator of pathogenesis and important targets for therapy,* 03/01/14 - 02/28/16
- Brad H Nelson PhD & Julie S Nielsen PhD, Deeley Research Centre, *Mutant MYD88: A target for adoptive T cell therapy of WM,* 10/01/14 - 09/30/16

Elting Family Research Fund of the IWMF

- Dr. Marzia Varettoni, Fondazione Italiana Linfomi Onlus, *Non-invasive diagnostics and monitoring of MRD and clonal evolution in Waldenstrom's Macroglobulinemia,* 10/15/17 - 10/15/19
- Larry W Kwak, MD, PhD, Beckman Research Institute of the City of Hope, *Anti-tumor and immune microenvironment responses following a first in-human DNA fusion vaccine for asymptomatic WM,* 10/15/17 - 10/15/21
- Sherie L Morrison, PhD, The Regents of the University of California, *Novel antibody-targeted interferons in combinational therapies for Waldenstrom's Macroglobulinemia,* 10/15/17 - 10/15/20
- Shahrzad Jalali, PhD, Mayo Clinic, *Modulation of T-cell function by metabolomic signature of the bone marrow microenvironment in Waldenstrom's Macroglobulinemia,* 09/15/17 - 09/15/19
- Dr. Bruno Paiva & Dr. Jose Angel Martinez Climent, Clinica University of Navarra, *Single-cell next-generation flow and sequencing to unravel the pathogenesis of Waldenstrom's Macroglobulinemia and to design genetically driven human-like experimental models,* 09/15/17 - 09/15/19
- New York University Grossman School of Medicine, Dr. Gareth Morgan, *Using mutographs to define the molecular landscape and cell of origin of Waldenstrom's Macroglobulinemia,* 01/01/23 - 12/31/25

The Lynn M. Fischer Research Fund of the IWMF

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Robert Douglas Hawkins Research Fund of the IWMF

K. Edward Jacobi Research Fund of the IWMF

- Dr. Morie Gertz, Mayo Clinic, *Biology to Treatment: Prognostic factors, Bone Marrow Microenvironment, Genomic and Proteomic Profile of Light Chain Amyloidosis in Waldenstrom's Macroglobulinemia,* 10/01/17 - 10/01/19

Michael and Rosalie Larsen Research Fund of the IWMF

Leukaemia Foundation of Australia

- Zachary Hunter, PhD, Dana-Farber Cancer Institute, *Multiomic analysis of DNA, RNA and epigenomic networks for prognostication and novel target identification in Waldenstrom's Macroglobulinemia,* 09/01/20 - 09/01/22
- Gareth J Morgan, PhD, New York University Grossman School of Medicine, *Using mutographs to define the molecular landscape and cell of the origin of Waldenstrom's Macroglobulinemia,* 09/30/22 - 09/26/24

Carolyn K. Morris Research Fund of the IWMF

Pharmacyclics LLC

The Poh Family Research Fund of the IWMF

- Dr. Signy Chow, Sunnybrook Research Institute, *Characterization of Genomic Alterations in Treatment Naive Patients with Waldenstrom's Macroglobulinemia Through a Course of Targeted Treatment and Disease Progression,* 09/01/22 – 08/31/24

Ed and Toni Saboe Research Fund of the IWMF

- Larry W Kwak, MD, PhD, Beckman Research Institute of the City of Hope, *Anti-tumor and immune microenvironment responses following a first in-human DNA fusion vaccine for asymptomatic WM,* 10/15/17 - 10/15/21

The Paul and Ronnie Siegel Family Research Fund of the IWMF

Waldenstrom's Macroglobulinemia Foundation of Canada

- Zachary Hunter, PhD, Dana-Farber Cancer Institute, *Multiomic analysis of DNA, RNA and epigenomic networks for prognostication and novel target identification in Waldenstrom's Macroglobulinemia,* 09/01/20 - 09/01/22
- Dr. Signy Chow, Sunnybrook Research Institute, *Characterization of Genomic Alterations in Treatment Naive Patients with Waldenstrom's Macroglobulinemia Through a Course of Targeted Treatment and Disease Progression,* 09/30/22 - 09/29/24
- Zachary Hunter, PhD, Dana-Farber Cancer Institute, *Characterization of Isoform Usage, Novel Isoforms, and Tumor Evolution in WM,* 07/01/23 - 06/30/25
- Patrizia Mondello, M.D. PhD, Mayo Clinic, *Identifying the oncogenic cooperation between IRF4 and MYD88 L265P and their impact on the Tumor Microenvironment of Waldenstrom Macroglobulinemia,* 08/21/23 - 08/20/25

Robert and Nadeline White Family Research Fund of the IWMF

- Steven Treon, MD, PhD, Dana-Farber Cancer Institute, *Targeting MYD88 in Waldenstrom's Macroglobulinemia,* 09/01/18 - 08/31/20

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- Steven Treon, MD, PhD, Dana-Farber Cancer Institute, *Targeting MYD88 in Waldenstrom's Macroglobulinemia,* 09/1/18 - 08/31/20
- Zachary Hunter, PhD, Dana-Farber Cancer Institute, *Multiomic analysis of DNA, RNA and epigenomic networks for prognostication and novel target identification in Waldenstrom's Macroglobulinemia,* 09/01/20 - 09/01/22

NAMED GIFT FUNDS

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

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