IWMF TORCH

July 2023

Issue 24.3 International Waldenstrom's Macroglobulinemia Foundation

INSIDE THIS ISSUE

THE 2023 ED FORUM IN ST. LOUIS

By Pete DeNardis, AKA Secret Wallie

Pete DeNardis

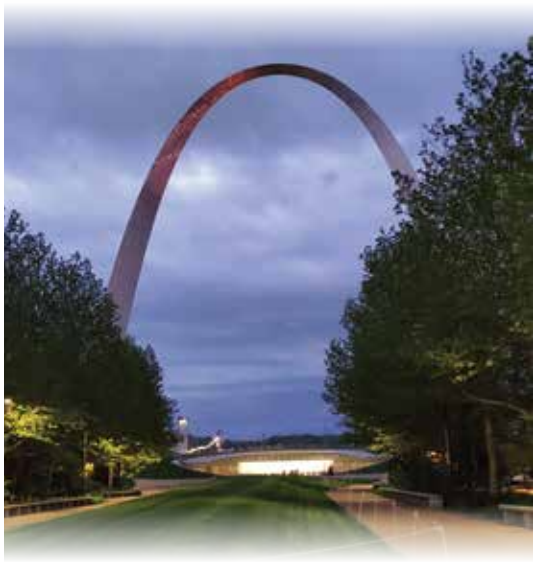
Who is Secret Wallie, you might ask? I had been involved with the Ed Forum for many years, working behind the scenes as a technical volunteer. Each year, those more scientifically astute than I would provide detailed summaries of the presentations, which were shared with the global WM community. But I noticed something was missing—a first-hand account of what makes attending an Ed Forum in person such an amazing experience. Anyone who has attended will tell you that it's so much more than just listening to top quality presentations from world-renowned WM experts, and I wanted to relay that first-hand experience to those who are not able to attend in person.

That's how Secret Wallie came into existence. I thought that it would be fun to anonymize the person relaying what it's like to be at an Ed Forum to make the reflection more compelling in the process. And even though people eventually figured it out, I'm still Secret Wallie at heart when I attend the Ed Forums, no matter what my role is. So here is Secret Wallie's account of the St. Louis Ed Forum and activities outside the presentation rooms.

The 28th Annual Educational Forum, held in April, was a hybrid event, with folks being able to attend either in person or virtually, and it was the first time many of us have been together in person since 2019. The in-person attendance was 185, and 610 attended virtually, although not all at the same time. Virtually and in-person, representatives from 31 countries attended!

Pre-Ed Forum Activities

On Thursday, the day before the official start of the Ed Forum, the first thing that struck me was the Gateway Arch, since our hotel was a short distance away from it. It's an impressive structure, and Secret Wallie and others rode in the space capsule-sized tram cars to get to the top of the arch and view the sights of the city, including Busch Stadium (home of the St. Louis Cardinals baseball team).



A few WMers arrived a day earlier to take in a baseball game before the Ed Forum—and started the Ed Forum weekend off on a high note with a win for the Cardinals! Others took advantage of the opportunity to venture nearby to see the sights and attractions the city had to offer. Even before the Ed Forum began, there was a note of fellowship in the air. Pockets of folks were arriving in the lobby, hanging out in the lounge area, and bumping into each other in the city streets. Each encounter was met with a nod, or perhaps a fist or elbow bump, and occasionally a brief hug hello, followed by spirited conversation to give a warm welcome to each other and share travel and WM stories.

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IWMF
International Waldenstrom's Macroglobulinemia Foundation

6144 Clark Center Avenue
Sarasota, FL 34238

Telephone 941-927-4963
Fax 941-927-4467

E-mail: *info@iwmf.com*
Website: *iwmf.com*

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

EDITOR
Shirley Ganse

ASSOCIATE EDITOR
Sue Herms

SCIENCE EDITOR
Glenn Cantor

INTERNATIONAL CORRESPONDENT
Annette Aburdene

FORMATTING & PRODUCTION
Sara McKinnie

FACEBOOK WM SUPPORT GROUP
Betty Ann Morton

***TORCH* ADVISOR**
Peter DeNardis

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

Even before the Ed Forum started, if one happened to walk past the meeting room area, one would see a buzz of activity, with the IWMF's Manager of Meetings & Partner Engagement, Sara McKinnie (who's been with the IWMF since the very early days), directing volunteer traffic and providing instructions to each person to ensure that the Forum would be a fantastic experience for everyone. And the video, sound, and lighting crews were busy setting up the necessary equipment in each meeting room. Of course, there was also a lot of activity leading up to the weekend, with a committee of dedicated volunteers working hard over the past year to iron out the agenda and activities for the weekend.

Every trip through the hotel lobby led to an encounter with fellow WMers checking in and a chance to say hello to each other. One could sense the building air of anticipation for the coming days. It should be noted that many folks did arrive at the hotel wearing masks to protect themselves, and when they entered the hotel's Ed Forum area, they had to provide proof of at least the first two vaccinations before attending the Forum. At that point, the IWMF strongly encouraged wearing masks, but did not require it; throughout the meetings, some wore masks, and most did not.

Thursday evening was an unofficial start to the festivities, with a reception held in the hotel for the international affiliate leaders, support group leaders, and LIFELINE volunteers (and their care partners) who came to St. Louis. The IWMF's Manager of Information & Support, Michelle Postek, along with the Board Chair (me) and IWMF CEO Newton Guerin, formally introduced themselves and expressed their heartfelt gratitude to everyone for the amazing volunteer work that they provide throughout the year. It was especially noted—and cannot be stressed strongly enough—that what makes the IWMF unique among cancer patient organizations is the atmosphere of fellowship and the strong bond patients, caregivers, medical professionals, and volunteers have in their commitment to making life with WM better for each other!

Friday, April 21

The much-anticipated day is here! The day started with folks getting their morning coffee or tea fix and some breakfast to gear up for the day's presentations. The meeting began with brief introductions by Newton and me, followed by presentations by each of the 2022 Kyle Career Development Award Recipients (the Kyle award is in honor of Dr. Robert Kyle and is presented to young WM investigators who are in a mentoring environment. You can read more about the awardees in the April 2023 issue of the *IWMF Torch*.) The awardees, Dr. Simone Ferrero (University of Torino, Italy) and Dr. Signy Chow (University of Toronto, Canada), provided brief descriptions of the WM research they are conducting. The presentations were quite informative, and patients and caregivers immediately recognized why these two received the awards. We all listened intently to attempt to grasp at least a passing understanding of the level of knowledge and effort these two young doctors are putting forth to understand the progression of WM disease in patients. They truly represent the future of WM research and will help guide research further in the coming years!

A representative from one of the Ed Forum sponsors, BeiGene, then spoke briefly about their commitment to WM patients. BeiGene is the company behind zanubrutinib (Brukinsa), and they introduced a new initiative, called "myBeiGene," designed to provide information and assistance to patients taking the medication.

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At that point, attendees had the option of attending either the WM Basic Training session with Dr. Andrew Branagan, or the Experienced—Living Longer with WM session with Dr. Prashant Kapoor. Each presenter did an excellent job at bringing the attendees up to speed on the latest about WM, whether from a new patient or a veteran patient perspective.

Throughout the Ed Forum, Ann Grace MacMullan, caregiver to her father who has WM, led attendees through stretching and yoga breaks, while Tom Shyver, a WM patient, could be found wandering the meeting rooms and hallways with a camera in hand, as he was the official Ed Forum photographer again this year.

The next session was Current Treatment Options and New Therapies presented by Dr. Jonas Paludo. This is obviously one of the more popular topics, since it helps to hear what the latest information is regarding treatments for WM.

After lunch, Dr. Branagan provided a useful presentation called Infection Prevention, IVIG, and COVID Vaccinations. The Q&A afterwards was quite interesting, with questions arising as to whether attendees should be wearing masks at the Ed Forum and elsewhere.

Then, a new option was provided for the remainder of the afternoon: simultaneous sessions from which attendees had to select which they wished to attend:

- I Just Want to Meet Other WM Patients, where co-hosts Sharon Rivet and Bob Perry guided attendees through a "speed dating" experience, where, in round-robin style, each participant had two minutes to do an introduction before moving on to the next participant. This was a unique way to accomplish such a task with a fairly large group in attendance, and the participants really enjoyed the experience!
- Young WM: Under 50, hosted by Jason Euzokinis, was devoted to providing information and support to those diagnosed with WM under the age of 50. It's a relatively small group, but a number of them are trying to navigate work, treatments, raising a family, and other issues that younger WMers face on a daily basis.
- Caregivers: You are Not Alone was co-hosted by Jennifer Bires and Michelle Postek, in which caregivers were given the opportunity to share their experiences and provide guidance to each other.
- Rare Complications: Wacky WM was co-hosted by Eileen Sullivan and Dr. Shirley D'Sa, who provided information regarding the various unusual complications that WMers may face during their disease course, and what is (or isn't) available to deal with those situations.
- Sound Meditation with Singing Bowls was hosted by Ann Grace MacMullan. Attendees found this to be a fantastic introduction or re-introduction to an effective technique for relaxation and to deepen meditation.
- Virtual attendees also had a session of their own, led by Suzie Shook and Lisa Wise. They all got to talk with each other and discuss the presentations thus far. There were many questions, and folks enjoyed it so much that the discussion could have gone on much longer than the time allotted!

At this point, folks then were free for a couple of hours before the welcome reception and dinner in the evening. Some took advantage of the opportunity to join me and others in a leisure walk to the Gateway Arch National Park, while others either found themselves having discussions with the doctors and researchers in attendance or with their WM friends, both old and new!

Michelle Postek and I kicked off the welcome reception. It was my honor and privilege to present the 2023 Judith

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May Volunteer Award to three recipients this year, in recognition of their many years of service to the global WM community. You can read more about them in this issue on page 9. Recipients are: Elena Malunis, Guy Sherwood, MD, and Eileen Sullivan.

After a long first day of presentations, many folks headed up to their hotel room to get some rest for the next day. And yet, if you lingered long enough in the hotel lobby area, you'd find that a group of WMers had pushed lounge chairs and sofas together in a big circle and were just sitting together chatting the night away. It was heartening to see so many enjoying each other's company, knowing that they fully understand what they are contending with and finding time to lift each other's spirits.

Saturday, April 22

The day began with a few early birds joining me for an early morning leisure walk through the Gateway Arch National Park (this time in a different direction), and others participated in the morning stretch activity with Ann Grace MacMullen. Each event provided the opportunity to energize the body before the mind got filled with much more information during the day.

After breakfast, Laurie Rude-Betts, widow of the second IWMF President, Ben Rude, introduced the newest members of the Ben Rude Heritage Society (see the IWMF website for more information about how you can participate) and spoke briefly about her husband's legacy. Each year, you can count on seeing Laurie helping at the registration desk and other activities throughout the Ed Forum.

At that point, the presentation sessions commenced, first with an overview of the IWMF's Global Patient Initiative, which is devoted to improving the means by which information is provided consistently to WM patients, caregivers, and medical professionals around the world.

The popular Great Debate session followed. Dr. Jeffrey Matous and Dr. Stephen Ansell debated the use of bendamustine/rituximab versus BTK inhibitors as a frontline induction regimen for WM patients. Carl Harrington, Board Chair Emeritus, officiated the debate wearing a referee's shirt, and the doctors had a great time engaging light-heartedly with each other, while also presenting vital information regarding various treatment options. Dr. Ansell then presented the latest developments in IWMF-funded research activities.

In the last morning session, Dr. Ansell discussed how to manage complications secondary to WM and provided advice and guidance in this area. Much information was presented during the morning, and attendees were ready for a break for lunch to help digest what they had learned over the past few hours and to digest the food too!

As in years past, people lined up to ask questions during the Q&A sessions at the end of each presentation, and then with individual doctors either in the back of the room or out in the hallway, as they still had more questions. The doctors made sure to make themselves available to provide assistance where possible. This is an amazing testament to the doctors' dedication to helping WM patients; they come to the Ed Forum on their own time and take the time to not only prepare and deliver presentations, but also to spend extra time to talk with WM patients and caregivers one-on-one. We are fortunate to have such experts who are amazing at what they do and are deeply caring individuals!

After lunch, there was a presentation by Jennifer Bires on WM survivorship, followed by Dr. Steven Treon providing

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updates on what was discussed during the IWWM11 meeting in Madrid in October 2022. He highlighted the latest information regarding treatment options and the findings of the various consensus panels comprised of WM experts from around the world.

After this last presentation of the day, groups of WMers had the opportunity to go on a tour of Busch Stadium to see a lot of the behind-the-scenes activities that take place during a baseball game. It seems that in each tour group (we had several), a WMer who was a true baseball aficionado would verbally spar (lightheartedly, of course) with the tour guide to point out that there are favorite teams other than the St. Louis Cardinals.

Following the tour, folks gathered on their own in groups to have dinner together at various locations nearby. Many could be seen walking out with friends old and new to share the evening together. Afterwards, another group of WMers gathered in the lobby to just sit together and share some stories and laughs together.

Sunday, April 23

The last day is always bittersweet and filled with anticipation for one of the signature events—the Ask the Doctors session.

The day began with simultaneous breakout sessions on peripheral neuropathy (Dr. Shirley D'Sa), fatigue (Cathy Skinner), patient-doctor shared decision making (Dr. Shayna Sarosiek), and nutrition (Margaret Martin). Each session was well attended, and each of the presenters provided valuable information and advice to the attendees.

The presentations, and the Ed Forum itself, ended with the Ask the Doctors session, an hour and a half of the emcee, IWMF Trustee Dr. Tom Hoffmann, posing questions to the panelists comprised of Dr. Christian Buske, Dr. Jeffrey Matous, Dr. Shirley D'Sa, and Dr. Shayna Sarosiek. Dr. Hoffmann selected from many questions provided by participants of IWMF Connect, the Facebook WM Support Group, and the Ed Forum attendees (including virtual) from previous days, and each doctor had opportunities to respond to the question and to each other. It's always interesting to see the interchanges among the doctors, and even when they disagree, they do so collegially; at times, they even come around to agreeing with each other's positions. In the end, it's we, the WM community, who gain by this interchange, taking away valuable information that we otherwise would not obtain.

At that point, the 2023 IWMF Educational Forum was over. Folks could be seen giving each other either goodbye nods, fist bumps, elbow bumps, or hugs in appreciation of having had the opportunity to spend time together over the past couple of days and in appreciation of having been able to connect physically with an old, or perhaps new, WM friend. Some traded email addresses and phone numbers, promising to keep in contact well after the Ed Forum.

Also, in case you're wondering, next year, May 3-5, 2024, the IWMF Education Forum will be at the Hyatt Lake Washington in Renton, WA (about a 25-minute drive from Seattle). Secret Wallie is looking forward to seeing many of you there next year!

Have Your Say

The *Torch* welcomes letters, articles, or suggestions for articles. If you have something you'd like to share with your fellow WMers, please contact *IWMF Torch* editor Shirley Ganse at *shirleyganse@hotmail.com*

"SPEED DATING" AT THE IWMF ED FORUM, OR "I JUST WANT TO MEET OTHER WMERS"

By Diane Mazza

"Speak fast, you each have one minute!"

As a first-time attendee at the IWMF Educational Forum, I thought the breakout session to meet other WMers would help me connect with more people. I was a bit afraid this Forum would be a gathering of repeat attendees excited to see each other after a three-year COVID hiatus. I didn't want to force my way into groups to introduce myself, so this seemed like a good fit.

When I walked in the door, people were milling around the center of the room. I spotted two rows of chairs along the walls of the room facing each other. Hmmm, what was this all about? One of the moderators explained that we were going to use the speed dating format! What? I certainly haven't done that before. I haven't dated in over 40 years! We would sit in the chairs facing each other and have a total of two minutes to tell each other about our experience with WM. A bell would ring to tell each person in one row to move one seat to the left, and we would begin again. Oh boy. How could I tell my story in one minute? Deep breath, give it a try.

The bell sounded and we started talking—fast. "Hi, you go first; no, you go first." "Where are you from?" "How long have you had WM?" "Have you had treatment?" Ding!

We had to pack our story into Cliff Notes to get it all in.

I had heard that saying, "If you've seen one WMer, you've seen one WMer." Well, that certainly was evident during this session. Such diverse stories!

There were times when we got so engrossed in our conversations, we practically had to be pushed out of our seats to move to the next one!

By the time we got to the end of the session, our discussions graduated to connecting in additional ways. We delighted in hearing about the personal side of life. I met one person who was a chef specializing in BBQ. How fitting to find him in St. Louis! He gave me tips about the different kinds of BBQ to try. My mouth began to water. Mmmmm. Another had a husband who was a mixologist. We talked about different kinds of drinks we liked and others we wanted to try. Another gave me great tips on how to manage my peripheral neuropathy. I met Meg Cyr Mangin—something I specifically wanted to do during the Forum. As one of the administrators of the IWMF Facebook page, she practically scraped me off the ceiling when I was first diagnosed and so anxious. She gave wonderful advice and evidence-based resources to help me understand my own experience with the disease.

I came away from this session feeling connected to more people than I ever expected just by attending this one session.

Would I do this again? I sure would!

A FIRST-TIME ATTENDEE'S THOUGHTS ON THE ED FORUM

By Danna Powers

My journey with Waldenstrom's macroglobulinemia (WM) began the spring of 2021. After nearly eight months, several emergency room visits, multiple lab tests, CTs, and MRIs to investigate severe headaches, chest pain, and fatigue, I received a misdiagnosis of bilateral temporal arteritis. The rheumatologist I was referred to ordered a protein electrophoresis, which showed an abnormal IgM.

I then got an appointment with a local hematologist/oncologist (H/O). My symptoms had continued to progress and now included enlarged lymph nodes. I received a bone marrow biopsy; the results confirmed WM. I had six bendamustine and rituximab infusions and four rituximab maintenance doses. In December of 2022, I followed up with Dr. Stephen Ansell at Mayo Clinic Rochester. We discussed the risks and benefits of continued rituximab maintenance. He felt that my response to treatment had been strong enough that the maintenance was stopped. I am now on watch-and-wait and have appointments every three months with my local H/O.

My local H/O's website included the Cancer*Care* site, which had a link to the IWMF. I then joined the Facebook WM Support Group page. Through this page, I found a fellow WMer, Judy Johnson Martin, living just 20 miles away. While we were messaging each other, Judy shared that she had gone to an IWMF Educational Forum when first diagnosed and highly recommended I attend. Judy graciously invited me to travel with her. Since we are two hours from St Louis, I worried that I might have difficulty making conversation with a near total stranger for that length of time. It wasn't a problem, as our common bond provided more than adequate topics for discussion.

The Ed Forum check-in was well organized. Photos were taken, badges were distributed, and in my case an orange "FIRST TIMER" ribbon was added. Little did I know how big a part that ribbon would play in the rest of my weekend. So many long-term WMers stopped and talked with me, sharing their stories and giving me so much encouragement. I was approached at the reception dinner, while standing in lines, at meals while sharing a table, and at breaks during the sessions. Each person took the time to give support to a First-Timer. They were all walking, living, breathing proof that you can have a complete and full life that includes WM.

As a first-time attendee, I found the sessions to be very informative. Of particular interest were the discussions of WM definitions, diagnosis and disease management, available therapies, and management of possible complications. Knowing that relapse will likely occur, I find it reassuring to know that multiple therapies are currently available, and research is ongoing for yet more options. I appreciated the inclusion of alternative therapies for self-care such as yoga, sound meditation, nutrition, exercise, and tools for enhancing mental well-being.

Back: Donna Jones Sheets, Judy Johnson Martin.
Front: Danna Powers

The sessions I attended gave me knowledge, facts I can hold on to so that I can make more informed decisions in collaboration with my WM team. I learned that the IWMF is there for us to answer questions and address concerns with the most current information. They are the definitive resource.

Someone said you only retain about 10% of the information you receive. I'm not sure what 10% of the sessions I retained, but I am 100% sure that attending the Ed Forum was the best thing I could have done for myself. Yes, I gained knowledge, but of equal or perhaps greater value was the interaction with fellow WMers. I am not alone. There are others who have this cancer.

I would highly recommend anyone with WM attend the Educational Forum. Experience first-hand the feeling of caring and concern from our experts as they conduct the sessions and the atmosphere of hope, the encouragement, the support, and camaraderie of fellow attendees.

2023 JUDITH MAY VOLUNTEER AWARD WINNERS

The IWMF is a patient-driven organization, and as such, several years ago it instituted a yearly award to recognize the spirit of volunteerism which IWMF President Emerita Judith May so aptly demonstrated throughout her career with the Foundation. Judith spent 15 years on the Board, eight of them as President (from 2005-2012), and she has been President Emerita since 2013.

The Judith May Volunteer Award Committee is comprised of designated Board members, the Chair of which sends a request for nominees (with supporting rationale) to Board members and key IWMF staff who work with volunteers. The nominees are voted on by the Board. The selection criteria include:

- recognition that the nominee is a dedicated volunteer among the general IWMF community;
- consideration of a nominee's significant contribution to the furtherance of the IWMF mission; and
- positive impact on the well-being of the IWMF community.

The IWMF is fortunate to have a great number of dedicated volunteers, who spend countless hours to help the organization educate and support the WM community and fund WM research. So, it's not surprising that for 2023, the Board determined that not one, but three, volunteers are deserving of the recognition of this Award. The three volunteers are:

Elena Malunis

Elena was one of the first care partners to join the Board (her husband Gary is the WM patient, has been treated in the past, and is currently on watch-and-wait status). She was a retired executive from IBM and, initially, was a volunteer on the Publications Committee; she then joined the IWMF Board in 2012.

Elena Malunis

She was instrumental in coordinating the IWMF's communication and publication activities and made it her mission to ensure that booklets and other publications would have a more patient-friendly focus and wording. She also established processes by which many of the publications could be translated into multiple languages—thereby extending the educational and support reach of the IWMF.

Also, she was instrumental in expanding the international activities of the IWMF, instituting a more formalized network of WM affiliate organizations in various countries. One of the other 2023 awardees initiated the development of international affiliates in Canada, the UK, the Netherlands, France, and Australia. But Elena saw that as just a starting point and sought out and identified opportunities to help volunteers establish organizations in 18 countries in five of the six continents on the globe. It was her energy, willingness to collaborate, and guiding hand that helped propel the IWMF to be more truly international in focus.

Elena stepped down from her Board position in 2021 but continues to volunteer on the Publications Committee and other projects.

Guy Sherwood

Guy, an MD by training, was first diagnosed in 2000 and underwent an autologous stem cell transplant in 2008. Guy joined the Board in 2004, took a year off in 2008 for work and personal matters, and rejoined in 2009. At the time, he was living and working in the US (Muncie, IN) but moved back to his home country of Canada in 2014, where he has been working on rebuilding his family homestead and farm (planting over 1,000 trees in the process).

Guy Sherwood, MD, and his wife, Faith

Guy's volunteer activities have been varied. He initiated the International Committee and was instrumental in helping the UK, France, and the Netherlands develop their first Ed Forums. He was also the first official Vice President for Member Services, where his focus was on developing and establishing the first set of booklets for the WM patient community (you'll see his name as an author on many of them). His passion was member education, and his focus was on expanding the outreach of the IWMF's educational services. From that position, he took on the role of Vice President for Research after a fellow Board member stepped down from that position. Guy left the Board in 2016.

For many years, Guy was the "peripheral neuropathy" guy because he did presentations at the Ed Forum on that always popular topic. WM-wise, most recently he underwent Rituxan and bendamustine therapy, with two years of Rituxan maintenance. It's been a year since then, he's feeling quite well, and he and his wife Faith attended the Ed Forum in St. Louis.

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Eileen Sullivan

Eileen Sullivan

Eileen is the earliest diagnosed of the three awardees and the force behind several of the most recent IWMF activities. Eileen was diagnosed with WM in the summer of 1995 and was on watch-and-wait until 2003, when her WM kicked into high gear and treatment was needed. Over the years, she's had a multitude of complications, including rare WM extramedullary tumors that have appeared in various parts of her body, requiring some form of treatment.

Eileen has been a participant in the Massachusetts Support Group since its inception, when it was first run by Dana-Farber Cancer Institute. She took over as support group leader in 2016 after Jack Whelan stepped down. Over the years, Eileen has volunteered to work the registration table at the Ed Forum and at local Lymphoma Research Foundation (LRF) workshops.

More recently, many of you may recognize Eileen from the IWMF Zoom meetings and webinars held during the past four years, since the COVID pandemic started. In fact, with Shelly Postek's help and Lisa Wise's prodding, she was the first support group leader to hold a Zoom meeting. She has also had a hand in setting up international special purpose support groups and meetings on a variety of topics, ranging from Bing-Neel (with the participation of both Dr. Steven Treon and Dr. Jorge Castillo), to peripheral neuropathy, to extramedullary disease. Through her efforts, not only has the IWMF presented webinars on these topics, but there are now special support groups that meet on a regular basis to discuss topics such as these—and the IWMF has been able to raise awareness of those manifestations among the WM community.

The IWMF owes a debt of gratitude to these three stand-out volunteers (and all IWMF volunteers!) for the time and energy they donate to the good of the greater WM community. In the words of Judith May: "The greatest of all human needs is to be a part of something larger than the self. The IWMF has been perhaps the strongest commitment of my life. We all work tirelessly with one thought in mind—to make this Foundation stronger, sustainable, and relevant."

President Emerita Judith May attended the Ed Forum in St. Louis.
Left to right: Pete DeNardis, Laurie Rude-Betts, Judith May, Carl Harrington, Michael Luttrell

WHY CAN'T I EAT GRAPEFRUIT?

By Glenn Cantor, *Torch* Science Editor and IWMF Trustee

You are a WMer who is successfully controlling your disease with daily ibrutinib pills. You are on vacation and wake up to a delicious breakfast buffet with all sorts of luscious fruits, including fresh, juicy grapefruit. But then, you remember that your doctor said not to eat grapefruit or drink grapefruit juice while taking ibrutinib. Why is that? Who comes up with these strange recommendations?

The answer lies in our ancient past.

*As **humans,** we evolved the **ability** to **break down drugs** from our plant-eating ancestors.*

Hundreds of millions of years ago, some plants evolved ways to defend themselves against being eaten by animals. They began to assemble chemicals that tasted bad or were poisonous to the animals who tried to eat them. Most animals avoided these plants, and the plants that made these defensive molecules thrived. But, over time, evolution continued. While the vast majority of animals could only eat plants without chemical defenses, a few animals developed the ability to dodge those defenses. This opened new frontiers for those lucky animals. They could enjoy lunching on fields of leafy greens that were untouched by other animals. In turn, that put pressure on the plants that were now under attack. After a while, the plants developed the ability to make new chemicals to discourage animals from eating them. And then, some animals developed ways to break down those new chemical defenses. And so it went…

Some animals went even one step further. Instead of developing ways to cope with only the existing plant toxins, they came up with ways to defend themselves against future chemicals that a plant might conceivably develop. That way, they could stay ahead of the game. To do this, they evolved ways to break down whole categories of plant chemicals, not just the specific ones they had encountered in the past.

The result of this ancient competition between plants and animals is that many modern animals—including human beings—have elaborate systems for changing the chemistry of things that they eat. Sometimes, a defensive plant molecule that could be harmful is cut in half, resulting in two harmless pieces. Other times, a little piece of the harmful molecule is removed, rendering it inactive. In other situations, the animal attaches an extra piece onto the harmful molecule, which keeps it from being active or steers it out of the body.

What does all this history have to do with drugs that we take? When modern chemists began to invent synthetic drugs (sometimes called "molecules"), many people already had the ability to rapidly break down the new molecules. From the human body's perspective, a modern drug was just one more plant molecule, intended to deter animals from eating the plant. As humans, we evolved the ability to break down drugs from our plant-eating ancestors. Actually, that's a good thing…you wouldn't want to take one single pill that stayed in the body forever. If such a "forever pill" caused harmful side effects, there would be no way to stop the side effects and feel better.

Medicinal chemists had to find the right balance. If a novel drug is broken down too rapidly, patients would have to take the pill every few hours, which would be terribly inconvenient (and expensive). As drug discoverers sort through myriads of candidate drugs, they try to choose the ones that stay in the body for just the right amount of time.

But not everybody is the same. Some people are able to alter (or "metabolize") certain chemicals rapidly; others alter the chemicals slowly (or not at all). As new drugs are discovered and subjected to testing, scientists and physicians have to find the right dosing schedule for the majority of people. If a drug is not broken down properly, even by a small number of people, it can accumulate to harmful levels and cause dangerous side effects in those people. That needs to be avoided. Some drugs can be particularly toxic at high levels, so doctors may need to measure the amount of drug in the blood of each individual patient to avoid this kind of problem. In other situations, the scientists who are trying to develop a new drug must throw it away and go back to the drawing board to design a different drug that is altered or metabolized more uniformly.

It's not just a matter of breaking down a drug into inactive pieces that are eliminated from the body. Sometimes when the body alters a chemical, it creates a new chemical that is even more active than the original. This can be a good thing—some drugs are inactive in their original form but are activated within the body. In other cases, though, it can be bad. Sometimes, when a drug is broken down or changed, the newly created molecules are harmful. During drug development, this possibility needs to be carefully assessed and avoided.

So far, I've described an unchanging picture. Humans, like all animals, break down foreign chemicals such as plant

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defenses or drugs. Scientists and physicians need to figure out the right balance so that medicines are broken down at just the right speed. But it's not so simple! Many foods and drugs can alter this balance. This ability to "rock the boat" and change the balance is the core idea of what is called a "drug-drug interaction."

Why is this important to understanding why we shouldn't eat grapefruit if we are taking ibrutinib? Let's go back to our primitive plants and animals. From a plant's point of view, it takes a lot of energy to make chemicals. Energy that the plant could use to grow taller or make more leaves or sprout deeper roots is diverted into making defensive chemicals. That is an unnecessary waste of resources, if plant-eating animals are not present. Gradually, some plants evolved a way to solve the problem. Instead of wasting energy making their full array of defensive chemicals at all times, they made defensive chemicals only at certain times. Perhaps in the mid-summer drought, when grazing animals are especially prone to eat certain plants, those plants produced higher levels of defensive chemicals. Or, in an even more clever adaptation, some plants quickly start manufacturing their defensive chemicals when only a few leaves are nibbled.

Animals (and people) have a similar problem. It costs valuable energy for the body to maintain the ability to break down lots and lots of potential plant chemicals. Instead, many animals lay low, producing just a minimum needed to break down noxious plant chemicals. Only when they are exposed to a plant chemical do they rapidly increase their ability to change or break down the foreign chemical. This on-demand system, when the ability to break down drugs is increased only when it is needed, is called "induction."

*Scientists and physicians need to **figure** out the **right balance** so that **medicines** are broken down at just the right speed.*

In the ongoing evolutionary back-and-forth between animals and plants, some plants managed to avoid that trick. Those lucky plants evolved chemicals which could interfere with the animals' ability to break down plant chemicals. When the animals express molecules to alter the plant's defense, the plant makes a new chemical to stop the animals from doing so. Turning the system off is referred to as "inhibition."

Scientists many years ago began to discover the specific ways that animals broke down plant chemicals. They found large families of related proteins inside animal cells. Some broke down certain types of plant chemicals; others broke down other types. Unfortunately for us, these scientists gave their newly discovered animal proteins some pretty strange names, such as one extensive family called "Cytochrome P450." Then, they applied various letters and numbers to the specific proteins in the family: Cytochrome P450 3A4, Cytochrome P450 1A2, Cytochrome 2C9, and so on. With time, these long, awkward names became shortened, and they are now collectively known as "Cyps." Each specific Cyp has numbers and letters, such as CYP 3A4, CYP 1A2, CYP 2C9, and many more.

Cyps are especially expressed in liver cells. When you eat food, the food is digested and chemicals inside the food are absorbed and sent to the liver, which screens the chemicals for danger before release into the rest of the body. When liver cells detect harmful chemicals, the Cyps inside the liver cells break down the harmful chemicals. Other Cyps are expressed elsewhere in the body such as the nose, where harmful chemicals in the air might be encountered, or in cells that directly line the intestines, preventing chemicals from being absorbed into the body in the first place.

*It **costs** valuable **energy** for the body to maintain the ability **to break down** lots and lots of potential plant **chemicals.***

Identification of these Cyps, as well as the genes that encode them, has allowed scientists to probe drugs much more rapidly and efficiently. Tens of thousands of prospective new drug candidates can be tested quickly, and only the best ones chosen for further investigation. Drug-hunting scientists can figure out which Cyps break down the new molecules and what the speed of breakdown is. Ideally, a drug would be broken down by a variety of Cyps, not just one, so that if one Cyp is impaired, the drug still has other ways of being metabolized (the "don't put all your eggs in one basket" approach). The scientists also can determine if new molecules induce Cyps (make them more active) or inhibit Cyps (make them less active).

Knowing the specific Cyps that break down each drug, as well as which drugs induce or inhibit those Cyps, allows doctors and pharmacists to avoid the "drug-drug interactions" discussed above. If one drug, say for example a heart medication, causes a particular Cyp to be inhibited or less active, it may be inadvisable to take a second drug, such as a cancer drug, which is uniquely broken down by that same specific Cyp. The thinking is that because the

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Cyp is less active, the second drug, the cancer drug, would not be broken down as quickly as it should be. If that happened, the drug could then accumulate to toxic levels in the body.

So where do grapefruit come into this? Animals (and people) have re-purposed some of the chemicals that plants have evolved to defend themselves against being eaten. Rather than serving as noxious defenses, these chemicals are now detected as pleasant flavors instead. A prominent example is the chemical group called capsaicins that make hot peppers hot. These are defensive compounds, yet many people, including myself, enjoy the stingy sensation in their mouths that hot peppers provide. But more broadly, most of the unique flavors of our plant-based foods are provided by chemicals that were once evolved as plant defenses. Without these plant chemicals, our diets would be very bland indeed.

In the case of grapefruit, there are chemicals in grapefruit juice that inhibit a particular Cyp called CYP3A4. This happens to be the main Cyp that is responsible for breaking down ibrutinib in the body. If ibrutinib is not broken down at the expected rate, it can accumulate in a person's blood. Too much ibrutinib can lead to many of the undesirable side effects that WMers are well aware of.

Over time, scientists and physicians have discovered a huge number of foods, dietary supplements, teas, herbs, and drugs that can alter the levels of various medicines. It is not the purpose of this article to list or discuss the large number of materials that a person should or should not avoid while taking specific drugs. By studying Cyps and other metabolizing proteins, doctors and pharmacists have developed lengthy lists of possible drug-drug interactions, drugs to avoid taking together with other drugs.

Doctors warn patients about this, and pharmacists are particularly knowledgeable in cautioning and advising their patients. Patients have a key role too. You should maintain a list of all the different drugs you are taking, especially if you see different specialists or use a variety of pharmacies. You can learn about drug-drug interactions yourself by referring to the prescribing information sheets that pharmacies give patients. Even topical medications (creams applied to the skin) sometimes can be absorbed enough that they should be included in your list. In addition to standard drugs, it is important to tell your doctor and pharmacist if you are taking dietary supplements or herbal medicines, since many of these also contain ingredients that affect drug levels. This information is particularly necessary when starting any new drug. As with the rest of WM management, it is critically important to use a team approach, involving your doctors (all your doctors, not just your WM doctor), nurses, pharmacists, and your own knowledge and awareness.

This article is not intended to provide specific medical advice. For medical advice, consult your medical team.

THE TORCHBEARER REPORT

By Linda Nelson, IWMF Trustee and Chair, Publications Committee

STAND UP AND BE COUNTED

Editor's note: Linda Nelson has been a Trustee of the IWMF since 2016. As someone who likes to work behind the scenes, she is the Chair of the IWMF Publications Committee and serves on the Research Committee. She, along with other members of the Publications Committee, is the author of many of the IWMF booklets, Fact Sheets, and Info Paks for the newly diagnosed.

My back story

My journey with WM began in 1987 when my mother was diagnosed with chronic lymphocytic leukemia (CLL) and then Waldenstrom's macroglobulinemia (WM). I went with her to her initial visit to the oncologist, and I remember sitting there thinking, "OK, I know what CLL is, but what is this other diagnosis that I've never heard of, let alone can hardly pronounce?" My mother was listening intently but only heard the doctor say that she had an incurable disease and that she would likely die from something other than her CLL or WM. This was her mantra during five years of plasmapheresis and cyclophosphamide therapy, and true to his words, she died from another cause, not WM.

As we now understand it, blood relatives in a WM patient's immediate family are slightly more likely to develop WM or another kind of B cell lymphoma. Of five siblings, she had CLL/WM, her younger brother subsequently was diagnosed with CLL/WM, and an older sister was diagnosed with lymphosarcoma, another B cell malignancy. All of us in the family knew she had a non-Hodgkin lymphoma that was incurable, but we really did not understand anything about WM, other than having high IgM was a bad thing. My mother called them her "iggums." Only one treatment regimen other than bone marrow transplant was available. There was no IWMF or IWMF Ed Forum…no website, no support groups, no LIFELINE, no *Torch* magazine, and there was nothing to explain in lay terms what WM was. We felt like we were truly all alone, and we depended on the oncologist to explain everything to us. But, honestly, he had trouble simplifying the science, which was still new back then.

Fast forward twenty years, and I was approaching the age at which my mother was diagnosed. I asked my internal medicine doctor to check my IgM level because of her diagnoses. He refused, saying that my blood profile was within normal limits, and that I had no symptoms. I continued to hound him during each of my yearly visits, and I think he got tired of my asking and eventually ran the immunoglobulins test—lo and behold, my IgM number was twice the high normal level.

I was referred to Dana-Farber Cancer Institute, where I was diagnosed with IgM MGUS and sent home with a packet of information that would answer my myriad questions. I was to return in one year. I remember clutching these booklets on my way home. Why wasn't I going to get treatment? Wasn't the prognosis better if you catch a cancer early and start treatment right away? I poured over the IWMF booklets that were available at that time. I read them and re-read them. I'd put them away for a while and then read them again and again. I looked up the terms I did not know. I joined IWMF Connect and went to Ed Forums. Knowledge really is power. I was starting to sleep through the night again. I encouraged my husband to volunteer as the IWMF webmaster, and eventually I volunteered to be part of the Research Committee. I then became a Trustee and chaired the Publications Committee. The more I volunteered, the more I learned about the disease and the IWMF's role in achieving a cure.

Our aim is to have all of our ***publications*** *be* ***medically accurate*** *but* ***at different levels*** *of understanding...*

Giving back to the IWMF community

I wear a couple of different hats for the IWMF, but one of my most important roles is Chair of the Publications Committee. I, along with Sue Herms (former Chair extraordinaire of this Committee and Committee consultant), Dr. Glenn Cantor (Committee consultant), Dr. Tom Hoffmann, Elena Malunis, Marcia Klepac, and Peter DeNardis, translate the dense scientific papers on WM into (hopefully) understandable IWMF booklets, Fact Sheets, Treatment Options Guides, and Info Paks for the newly diagnosed. Our aim is to have all of our publications be medically accurate but at different levels of understanding, as needed, for our community. We strive for a two-tiered level of comprehension for our copy; one for someone with a basic, high school knowledge of biology and the other for someone with an advanced, in-depth grasp of the subject matter.

Updating or revising our publications is a tricky balance. On the one hand, we want to give the community the latest and most important research findings; but on the other hand, we have the significant cost of translating our publications into the nine languages (traditional Chinese, simplified Chinese, German, Spanish, French, Italian, Norwegian, Polish, Portuguese, Finnish) that our international affiliates have requested. We are quite lucky that our French affiliate

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translates some of our publications for us. We reach a balance by waiting until enough new findings justify a revision. Sometimes our medical experts weigh in and tell us to wait until new findings are published. Over the years, we have worked quite closely with the oncologists from the Mayo Clinic and the Dana-Farber Cancer Institute.

Another important responsibility of the Publications Chair is to maintain the IWMF website's library of peer-reviewed medical papers on WM (*https://iwmf.com/wm-medical-practice-guidelines-research-articles/*). These papers include recommendations and guidelines from the International Workshops on WM (IWWM) and the National Comprehensive Cancer Network's Guidelines for patients with WM, as well as a separate section for physicians (*https://iwmf.com/for-medical-providers/*). The library does not contain all the papers written about WM but does include ones we think are significant. You can click on the description of the paper or go to the link to access the actual paper. The webpage also highlights research papers that were written as a result of IWMF research grants. These are highlighted with an asterisk.

IWMF publications

A lot of people ask how the topics of IWMF publications are chosen. Very often the ideas come from individuals within the support groups, IWMF Connect (one of our online communities), the Board of Trustees, or the greater IWMF community. The knowledge gap is identified and communicated through the Board to the Publications Committee. The Chair, one of the members of the Committee, or an invited medical expert reviews the literature and determines if there are enough peer-reviewed medical papers on the topic to warrant a publication. Some new therapies are "hot items" on Connect or in support groups, but without enough peer-reviewed published papers on the treatment and WM, we cannot write a credible Fact Sheet. In conjunction with our medical experts, we determine when it is time to write a Fact Sheet on the hot topic.

Peer review is key because it means that multiple medical experts in the field have reviewed the author(s) methodology and results and have deemed them publishable. A draft is submitted to a small subset of the Committee, then revised multiple times, and finally the whole Publications Committee weighs in; after that, it is sent out for final review by a medical expert. After the 3-6 months of drafts and reviews, a new or revised booklet, Fact Sheet, or Treatment Options Guide is placed on the IWMF Publications webpage (*https://iwmf.com/publications/*). It is usually the length of the publication that determines if it becomes a booklet or a Fact Sheet.

The current IWMF Info Pak for the newly diagnosed was a brainchild of Elena Malunis and Carl Harrington. It is our most requested packet of publications *(https://iwmf.com/iwmf-info-for-patients-and-caregivers/),* and it is translated into multiple languages. The content is intended for those with a new diagnosis of WM and their caregivers, but sometimes those who have had the diagnosis for years request the Info Pak for a refresher.

The Info Pak includes a letter of introduction from the IWMF President and CEO Newton Guerin, "About WM Expanded Fact Sheet," "About the IWMF" brochure, "Frequently Asked Questions" booklet, "WM Medical Tests" booklet, "Treatment Options Guides" (a series of four pamphlets written by Sue Herms), an explanation of the "Directory of Physicians" (who have expertise in WM), information about support groups, LIFELINE, the annual Educational Forum, and other services available to members and friends of the IWMF. We also include two useful *IWMF Torch* articles by Morie Gertz, MD: "Should I Get a Second Opinion" and "Getting the Most from My Provider Visit." It also contains links to pertinent videos from IWMF Educational Forums, such as "The Garden Talk," "I've Been Diagnosed with WM," "Doctor, How Long Am I Going to Live?" and "WM: An Exciting Upbeat Story." The Info Pak evolves over time and tries to answer the most pressing questions that someone newly diagnosed with WM may have or poses questions that they had not considered.

My most powerful moment

In Dallas, at my first Ed Forum. Carl Harrington, who was then President of the Board, asked for those in the audience to stand if they were diagnosed with WM 5 years ago, 10 years, 15 years, 20 years, 25 years, and so on. I stood up with a bunch of folks at the call for 5 years out from diagnosis, but I saw how many people in this enormous ballroom with over 350 people were still alive and "thriving" with WM at 15, 20, and even 25 years out from their initial diagnosis! It was such a powerful moment for me. I turned around and saw this huge community of people who were just like my mom and me. It brought me to tears thinking back to the dearth of information and lack of support available to her and our family thirty years ago. It was profoundly meaningful to me to stand up among this little community of my WM peers and be counted as a "thriver."

Linda Nelson, IWMF Trustee and a biking enthusiast, has ridden her bike in the Pan Mass Challenge ride each August for 27 years to raise money for the Bing Center for WM at the Dana-Farber Cancer Institute—it's one of many ways she helps the WM community

IWMF APPROVES $2.4 MILLION FOR NEW 2023 RESEARCH GRANTS

The IWMF is pleased to announce the selection of its 2023 research grant awards. This year, the IWMF Board of Trustees approved funding for eight new research grants to WM scientists in four different countries. This represents a commitment of nearly $2.4 million over the next two years.

Researchers from around the world responded to the IWMF Requests for Proposals. The proposals were evaluated and scored in a rigorous and competitive process, first by detailed, in-depth reviews by scientists who were selected from the IWMF Scientific Advisory Committee (SAC) or who were prior WM research grantees, followed by discussion and debate by the entire SAC.

The research grants fall into three categories:

1. IWMF-LLS Strategic Research Roadmap Initiative grants, which are major, highly competitive awards for up to $480,000 in targeted research areas that have been identified through strategic discussions with WM experts, the IWMF, and the Leukemia & Lymphoma Society.
2. Research Seed Money Initiative grants, which are designed to enable investigators to test innovative, new hypotheses or ideas during a one-year period and potentially generate preliminary data that lead to major proposals for future research funding (funding for up to $90,000).
3. Robert A. Kyle Career Development Award Program grants, which are given to talented, young junior faculty members or postdoctoral fellows to enable them to perform WM research in a mentored environment, with the hope of fostering a new generation of WM researchers (funding for up to $157,500).

The new 2023 research grants are awarded to:

DR. ZACHARY HUNTER

Dana-Farber Cancer Institute, Harvard University, Boston, MA, USA.

Characterization of isoform usage, novel isoforms, and tumor evolution in WM
(Roadmap Grant, $480,000)

DR. PATRIZIA MONDELLO

Mayo Clinic, Rochester, MN, USA.

Identifying the oncogenic cooperation between IRF4 and MYD88 L265P and their impact on the tumor microenvironment of WM
(Roadmap Grant, $480,000)

DR. MARCEL SPAARGAREN

Amsterdam UMC, University of Amsterdam, the Netherlands.

Towards a rational targeted combination therapy for WM by venetoclax sensitizer CRISPR screens
(Roadmap Grant, $476,000)

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DRS. TINA BAGRATUNI AND MELETIOS DIMOPOULOS

National and Kapodistrian University of Athens, Greece.

Genomic characterization of ibrutinib-resistant WM
(Roadmap Grant, $400,000)

DR. MARION ESPÉLI

Inserm U1160, Institut de Recherche Saint Louis, Paris, France.

Impact of MYD88 and CXCR4 mutations on age-associated B cells at steady state and in the course of Waldenström's macroglobulinemia
(Seed Money Grant, $90,000)

DR. JITHMA PRASAD ABEYKOON

Mayo Clinic, Rochester, MN, USA.

Defining the prognostic significance of TP53 alterations in WM and exploiting them for therapeutic benefit
(Robert A. Kyle Career Development Award, $157,500)

DR. MARIA LUISA GUERRERA

Dana-Farber Cancer Institute, Harvard University, Boston, MA, USA.

Characterizing the role of the ERK1/2 regulator WNK2 as a novel target in the disease progression of MYD88 mutated WM
(Robert A. Kyle Career Development Award, $157,500)

DR. CHRISTELLE VINCENT-FABERT

Centre de Biologie et de Recherche en Santé (CBRS), Inserm 1262, Limoges, France.

Study of immune microenvironment and BCR signaling in a WM-like mouse model
(Robert A. Kyle Career Development Award, $157,500)

Pete DeNardis, Chair of the IWMF Board of Trustees, said that the additional funding for the 2023 IWMF research grant awards now brings the grand total of funds earmarked by the IWMF for WM-specific research to $23 million since 2000. That amount of funding has led to significant discoveries that benefit the global WM community—discoveries that wouldn't happen without the IWMF's involvement and without the generosity of donors to the IWMF to support its research mission. These new grants enable the IWMF to continue to work toward accomplishing its vision of a world without WM!

LIVING WELL WITH WM
Financial Wellness and Assistance

By Carl Harrington, Peter DeNardis, Newton Guerin, and Paul Kitchen
IWMF Education Committee Financial Concerns Subgroup

When the IWMF was founded, no one really knew what life expectancy was for newly diagnosed patients. When Pete, Paul, and Carl were diagnosed in 2003, 2014, and 2006 respectively, they were told their life expectancy was 3-5 years. Now leading WM experts are saying 15-20 years from diagnosis. What a change!

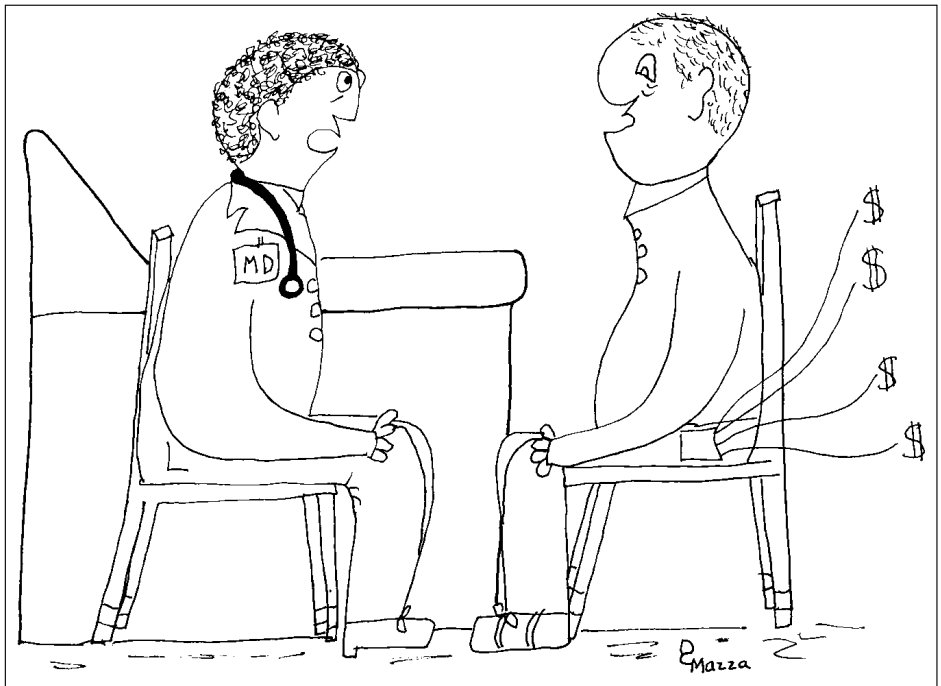
Since many people diagnosed with WM now live longer lives with fewer treatment side effects, the IWMF Board of Trustees formed an Education Committee to explore how to help patients live well with WM. The Committee's Physical Wellness subgroup provided an initial article that focused on aspects of living well, such as nutrition, dietary supplements, and physical fitness in the April 2023 *IWMF Torch* (see *https://iwmf.com/iwmf-torch*/, pages 17-18.)

To live well with WM, the Financial Concerns subgroup has been studying ways to alleviate the stress of worrying about how to pay for medical care. We worked with our non-profit partners, as well as the pharmaceutical industry, to identify possible sources of financial assistance. The good news is that there are many resources available to us. The ultimate goal is that no one chooses a treatment based upon cost; the only determining factor should be to select the treatment option that is best based on the patient's individual situation. This article provides highlights of the financial resources available. You can find the entire list and the full details here *https://iwmf.com/financial-assistance/* on the IWMF website.

Get Started: What Do You Need Help With?
Do you need assistance with the cost of the drugs you have been prescribed or with affording your co-payments? Are you worried about the costs of traveling to get a second opinion, paying others to tend to responsibilities at home while you are away, or some other kind of cost assistance? Maybe you need help understanding and navigating the whole system?

It's important to note that financial assistance resources can vary from country to country. No one country has the best drugs at the cheapest price. In the US, we may have the most current treatments, but they are also the most expensive.

Note: The information below focuses primarily on resources available to patients and caregivers in the United States. Those living in other countries should reach out to their country's IWMF affiliate (https://iwmf.com/international-affiliates/) *for information pertinent to their national policies, protocols, and offerings.*



You have been diagnosed with significant out-of-pocket expenses

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Travel for a Second Opinion?
The new Travel and Lodging Financial Assistance program, funded solely by the IWMF, helps individuals travel for second opinions for diagnosis or treatment. Even though this program was developed with our US partner National Organization for Rare Disorders (NORD) and is administrated by NORD, its benefits are available globally. Like all assistance programs, funding is limited and may run out. Of course, we gratefully accept contributions to keep this program ready to cover the requested funds. Anyone in the WM community who wants to provide financial support to this fund should contact the IWMF office.

To apply for assistance, you must have a confirmed WM diagnosis or verification of the need for a second opinion to confirm a diagnosis of Waldenstrom's macroglobulinemia. Importantly, the program is available to individuals both inside and outside of the US, except those residing in a country subject to US sanctions per the US Department of Treasury Sanctions Program. With an award cap of $1,500, this program provides economy class airfare for the patient as well as one traveling companion and up to two nights of hotel accommodations. Also, for those driving (distances of two hours or more), reimbursement of a flat amount of $200 after the visit has occurred will cover mileage, tolls, and parking.

Cast a Wider Net
This article can't cover everything that is available, so please go to *https://iwmf.com/financial-assistance/* to learn more. Start by looking beyond WM-specific financial resources to blood cancer and cancer in general**.** A great publication (which is also free) from the Leukemia & Lymphoma Society (LLS), "Cancer and Your Finances," describes health insurance options and coverage. Furthermore, it provides worksheets and checklists to help you stay organized. It will empower you to recognize and understand costs, and it provides tips and resources. You can download it at *https://www.lls.org/booklet/cancer-and-your-finances.*

Get Personal Guidance
If you need help and wish to talk to a real person, try these IWMF partners:

- Triage Cancer is a national, nonprofit organization that provides free education on the legal and practical issues that may impact individuals diagnosed with cancer and their caregivers through events, materials, and resources. Their resources are listed here: *https://triagecancer.org/legal-and-financial-navigation-program.*
- The Leukemia & Lymphoma Society lets you speak one-on-one with an LLS Information Specialist. These folks are highly trained oncology social workers and nurses. They can assist you through cancer treatment as well as financial and social challenges. In addition, they provide accurate, up-to-date disease, treatment, and support information. Visit *https://www.lls.org/support-resources/information-specialists* and learn how to reach them by phone, chat, email, or by leaving a message for a call-back.
- Cancer Support Community is a global non-profit network that delivers free emotional support and navigation services to patients and families impacted by cancer. See *https://www.cancersupportcommunity.org/* for their many services.

Can't find exactly what you're looking for? Feel free to call the IWMF office for additional help, at 1-941-927-4963 or send your questions to *info@iwmf.com*.

*The **IWMF** now **participates in** four US **co-pay assistance** programs.*

Look for Co-Pay Assistance
The IWMF now participates in four US co-pay assistance programs. Funding is not always available at any given fund, so you may need to apply to more than one. In general, you may qualify for $7,000-10,000, depending upon your finances. Details for each program are on our website at *https://iwmf.com/financial-assistance/.*

- The Leukemia & Lymphoma Society (LLS) Co-Pay Assistance Program
- Cancer*Care*
- PAN Foundation WM Assistance Program
- HealthWell Foundation

Travel to Clinical Trials
Usually, all expenses, including travel to clinical trials, are covered by the organization sponsoring the clinical trial. If travel is not covered, check the resources on our website. You might be able to get a free flight.

More Services from Nonprofits
Our website covers another half dozen nonprofits which can help. Here are two examples:

National Comprehensive Cancer Network (NCCN) NCCN maintains a list of patient and caregiver resources in its Virtual Reimbursement Resource Room Guide. It also provides a smart phone app to assist patients in navigating through the available resources: *https://www.nccn.org/business-policy/business/virtual-reimbursement-resource-room-and-app.*

Financial Wellness and Assistance, cont. on page 20

Cancer Financial Assistance Coalition (CFAC) This group offers a one-stop method of searching for aid from its 14-member alliance. The site's homepage allows searches by diagnosis, zip code, and type of service needed: *https://www.cancerfac.org/.*

Local Resources
When a WM diagnosis raises a wide range of challenges and concerns, it's good to have local resources to assist you. It's usually a good idea to check with your doctor and with a social worker at your hospital before exploring other options.

The **Cancer*Care* fact sheet** describes many kinds of services available locally to people with cancer and how to find the help you need: *https://www.cancercare.org/publications/60-finding_resources_in_your_community.*

Cancer.net, from the American Society of Clinical Oncology (ASCO), is a patient information website which includes a guide and list of links to national and local financial resources:
https://www.cancer.net/navigating-cancer-care/financial-considerations/financial-resources.

The **American Cancer Society** provides a list of national and local programs and resources to help with cancer-related expenses: *https://www.cancer.org/support-programs-and-services.html.*

Other global regions and other countries may also have information specific for WM patients – check with the IWMF international affiliate nearest you for further information.

Pharmaceutical Companies Can Help With Industry-Wide Information

The Partnership for Prescription Assistance (PPA) brings pharmaceutical companies, doctors, other healthcare providers, and patient advocacy and community groups together to help eligible patients who don't have prescription drug coverage get their medicines for little or no cost. See:
https://screening.mhanational.org/content/partnership-prescription-assistance/?layout=actions_neutral.

The Pharmaceutical Research and Manufacturers of America (PhRMA) maintains a directory of patient assistance programs for prescription drugs. PhRMA's Medicine Assistance Tool (MAT) is a search engine designed to help patients, caregivers, and health care providers learn about the resources available through biopharmaceutical industry programs. You can use it to determine if you are eligible to participate in any of more than 475 different assistance programs. See: *https://phrma.org/patient-support.*

Specific Pharmaceutical Company Info
On *https://iwmf.com/publications/* you'll find fact sheets on specific drugs, including:

- Imbruvica (ibrutinib) from Johnson & Johnson and Pharmacyclics
- Brukinsa (zanubrutinib) from BeiGene
- Calquence (acalabrutinib) from AstraZeneca
- Bendeka (bendamustine) from Teva Pharmaceuticals

Wrap Up
The IWMF's mission is to "Support and educate everyone affected by Waldenstrom's macroglobulinemia (WM) to improve patient outcomes while advancing the search for a cure." This support extends to putting financial concerns in the back seat and letting the goal of quality health and wellness drive your treatment decisions. Remember, with the IWMF, you are never alone!

MEDICAL NEWS ROUNDUP

By Sue Herms, IWMF Research Committee Member

Consensus Panel Statements from IWWM11 Are Published – As a result of the 11th International Workshop on Waldenstrom's Macroglobulinemia (IWWM11), held in October 2022 in Madrid, seven Consensus Panel statements have been published on various aspects of diagnosing and managing WM. The Consensus Panel statements include: Consensus Panel 1 on the Management of Symptomatic, Treatment-Naïve Patients; Consensus Panel 2 on the Management of Relapsed or Refractory WM Patients; Consensus Panel 3 on Recommendations for Molecular Diagnosis in WM; Consensus Panel 4 on Diagnostic and Response Criteria; Consensus Panel 5 on COVID-19 Prophylaxis and Management; Consensus Panel 6 on Management of WM Related Amyloidosis; and Consensus Panel 7 on Priorities for Novel Clinical Trials. These are available on the IWMF website at *https://iwmf.com/wm-medical-practice-guidelines-research-articles/*.

European Consortium for WM Conducts Trial of First-Line Therapy with Bortezomib Plus DRC – Investigators in the European Consortium for WM discussed the results of a trial using bortezomib (Velcade) plus dexamethasone, rituximab (Rituxan), and cyclophosphamide (B-DRC) as first-line treatment. There were 204 participants, randomized to receive either B-DRC or DRC only for six cycles. The major response rate from B-DRC was 80.6% vs. 69.9% for DRC; at median follow-up of 27.5 months, the estimated two-year progression-free survival was 80.6% for B-DRC vs. 72.8% for DRC. The median time-to-first-response was shorter for B-DRC. Grade 3 or greater (moderate-to-severe) adverse events occurred in 49.2% of all patients, with a similar incidence in both groups; however, grade 3 or greater peripheral neuropathy occurred in two patients treated with B-DRC but in none treated with DRC. The results appeared in the *Journal of Clinical Oncology*.

EHA Abstract Reports Early Phase 1/2 Trial Results for MB-106 in WM – An abstract from the 2023 European Hematology Association (EHA) Annual Congress reported early results of a Phase 1/2 clinical trial of MB-106 in WM/lymphoplasmacytic lymphoma patients who were relapsed/refractory to BTK inhibitor therapy. MB-106 is a CD20-targeted CAR T cell therapy. The trial was conducted at the Fred Hutchinson Cancer Center from July 2021-February 2023. Of the six patients enrolled, all were MYD88 mutated. Four patients were eligible for response assessment at data cut-off. All developed mild or moderate cytokine release syndrome, which is an acute systemic inflammatory condition characterized by fever and multiple organ dysfunction and can be associated with CAR T cell therapy. None experienced IgM flare from targeting CD20. All four patients responded by Day 28, with two of them in complete response, and all exhibited no remaining detectable abnormal B cells in their bone marrow. One died from complications of COVID-19, while the other three are free of progression at 1.5+, 3+, and 19+ months.

Preliminary Data Reported from Phase 1b/2 Trial of

...seven ***Consensus Panel statements*** *have been* ***published*** *on various aspects of diagnosing and managing WM.*

BCL-2 Inhibitor Lisaftoclax in WM – Preliminary data from a Phase 1b/2 study of the BCL-2 inhibitor lisaftoclax, alone or in combination with ibrutinib or rituximab, was reported from 46 WM trial participants during the 2023 ASCO (American Society of Clinical Oncology) Annual Meeting. This global multicenter trial enrolled patients in three dose escalation arms: Arm A) lisaftoclax alone in patients who were resistant or intolerant to BTK inhibitors; Arm B) lisaftoclax plus ibrutinib (Imbruvica) in treatment-naïve patients; and Arm C) lisaftoclax plus rituximab (Rituxan) in relapsed/refractory patients not previously treated with BTK inhibitors. At data cut-off for the report, the median treatment duration for Arm A was six months, for Arm B was 14 months, and for Arm C was eight months. The overall response rates were 25%, 90.9%, and 37.5% for Arms A, B, and C, respectively. No significant difference was observed between patients with and without CXCR4 mutations. Moderate-to-severe adverse events included neutropenia (low neutrophil count), leukocytopenia (low white blood cell count), anemia, weight loss, and septic shock. Ventricular arrhythmias were not observed. A total of 14 patients discontinued the study treatment because of disease progression or adverse events.

ASCO Abstract Discusses Incidence of Solid Tissue Cancers in WM Patients – An abstract from the 2023 ASCO (American Society of Clinical Oncology) Annual Meeting discussed the incidence of solid tissue cancers among patients with WM. The US multicenter abstract used the SEER (Surveillance, Epidemiology, and End Results) database from 2000-2019 to identify 8,099 WM patients, of whom 794 (9.8%) developed a subsequent solid tissue cancer. In these patients, WM was diagnosed at a median age of 70, while subsequent solid tissue cancers were diagnosed at a median age of 74. The most common sites of solid tissue cancers in older male WM

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patients (60 years and older) were, in order, the prostate, the lung/bronchus, the urinary bladder, skin melanoma, and kidney. In younger male patients (less than 60 years old), the same was true except that skin melanoma was more common than cancer of the urinary bladder. In older female WM patients, the most common sites were the lung/bronchus, the breast, and the urinary bladder, while in younger female patients, the most common sites were the breast, the lung/bronchus, the thyroid, and skin melanoma. Overall survival was poorest for those who developed lung/bronchus cancers.

*The overall **risk** of developing **aggressive skin cancer** was significantly **higher in WM** patients as compared to the general population.*

ASCO Abstract Analyzes Aggressive Skin Cancers Among WM Patients – Another US multicenter abstract from the 2023 ASCO (American Society of Clinical Oncology) Annual Meeting analyzed the incidence of aggressive skin cancers among WM patients, using the SEER (Surveillance, Epidemiology, and End Results) database from 2000-2019. Of the 8,099 WM patients identified, 68 (0.84%) were subsequently diagnosed with an aggressive skin cancer (excluding basal cell and squamous cell cancers). The most common such cancers were malignant melanoma and Merkel cell carcinoma. The overall risk of developing aggressive skin cancer was significantly higher in WM patients as compared to the general population. The median survival after aggressive skin cancers was 68 months. The researchers suggested that these data highlight the need for screening and counseling for skin cancers in WM patients.

Researchers Present Information About Outcomes in Hispanics with WM/LPL – Little is known about the outcomes of WM/LPL in ethnic minorities. Researchers from University of Texas Health in San Antonio, TX, presented information about outcomes in Hispanic patients diagnosed with WM/lymphoplasmacytic lymphoma (LPL) at the 2023 ASCO (American Society of Clinical Oncology) Annual Meeting. Information was collected from the SEER (Surveillance, Epidemiology, and End Results) database; according to the database, Hispanics were diagnosed at a younger median age than non-Hispanics, with a higher percentage of Hispanic patients diagnosed before the age of 60. The survival probability for Hispanics at two, five, and ten years was similar to that of non-Hispanics, and there was no overall survival difference favoring one group over the other. The researchers suggested that further studies are needed to explore biological differences that may explain the earlier diagnosis of WM/LPL in Hispanics.

Pooled Data Analysis Looks at Impact of Ibrutinib Dose Reductions for Cardiac Adverse Events in B Cell Cancers – An international group of researchers pooled data from ten clinical trials to evaluate the outcomes of patients with B cell cancers on ibrutinib (Imbruvica) therapy who had dose reductions because of cardiac toxicities. Clinical trials with WM patients were included. Overall, of 1,263 patients with B cell cancers on ibrutinib, 234 (19%) had cardiac adverse events of any severity grade. Among patients with cardiac adverse events who started with a 420 mg ibrutinib dose (which includes most WM patients), no cardiac adverse events recurred at the same or worse severity when the dosage was reduced. Progression-free survival was not negatively impacted by dose reduction. The data were presented during the 2023 ASCO (American Society of Clinical Oncology) Annual Meeting.

Japanese Researchers Examine Risks of Second Cancer and Infection in Indolent Lymphoma Treated with First-Line Bendamustine and Rituximab – A retrospective examination by Japanese researchers in the journal *Hematological Oncology* compared the risk of second cancer and infection in indolent B cell lymphoma patients treated with first-line bendamustine and rituximab. This analysis of a medical claims database included 5,234 patients who were diagnosed with various types of indolent B cell lymphoma between 2009 and 2020. Of this number, there were 589 second primary cancers, of which myelodysplastic syndromes were the most common (1.7%). Myelodysplastic syndromes are a group of bone marrow cancers that affect the immature myeloid blood cells, preventing them from developing into healthy blood cells. The incidence of second cancers at five years was significantly higher in patients treated with bendamustine and rituximab, at 18.1%, compared to those treated with rituximab only at 12.5% or with RCHOP (rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone) and similar therapies at 12.9%. The risk of infections in those receiving first-line bendamustine and rituximab was higher for cytomegalovirus and lower for pneumocystis pneumonia than it was for patients receiving RCHOP and similar therapies. However, this study found no significant difference in overall survival between the bendamustine and rituximab group and the RCHOP and similar therapies group.

Japanese Study Suggests that WM and Non-IgM LPL Are Genetically Similar – A Japanese study published in the journal *Acta Hematologica* evaluated common genetic mutations in WM, which is a subset of lymphoplasmacytic lymphoma (LPL) that secretes IgM, and compared them

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to mutations in non-IgM-secreting lymphoplasmacytic lymphoma. The researchers used targeted next-generation sequencing in 20 patients, ten with WM and ten with non-IgM LPL. Mutations in WM patients were detected in the genes MYD88 (90%), CXCR4 (20%), ARID1A (10%), and KMT2D (0%). In non-IgM LPL patients, the mutations detected were MYD88 (70%), CXCR4 (20%), ARID1A (10%), and KMT2D (10%). In the study participants, no mutations were detected in NOTCH2, PRDM1, PD-L1, PD-L2, RAG2, MYBBP1A, TP53, or CD79B. No significant mutational differences were identified between the two subsets of LPL, suggesting genetic similarities between them.

Italian Researchers Analyze Mutational Profile of Patients with Anti-MAG Neuropathy – Italian researchers analyzed the prevalence of MYD88 L265P and CXCR4 S338X gene mutations in 75 patients with anti-myelin associated glycoprotein (anti-MAG) neuropathy. Among them, 38 had IgM MGUS (monoclonal gammopathy of undetermined significance), 29 had WM, and eight had chronic lymphocytic leukemia/marginal zone lymphoma/hairy cell leukemia. Of these patients, 50 carried the MYD88 L265P mutation, with a higher frequency in those with WM than with the other conditions. No patients harbored the CXCR4 S338X mutation. Of those who were treated for their neuropathy, 45 received rituximab, six received ibrutinib, three received venetoclax-based therapy, and two received obinutuzumab and chlorambucil. There were no significant differences in IgM levels, monoclonal protein levels, anti-MAG antibody titers, neuropathy severity, or response to rituximab therapy in the MYD88 L265P-mutated patients vs. those without the mutation. Since nine of the 11 patients treated with either ibrutinib or venetoclax-based therapy had some improvement in their neuropathy, the researchers suggested that patients who do not show improvement with rituximab or become refractory to it should consider one of these targeted therapies. The study was published in the journal *Neurology Neuroimmunology & Neuroinflammation*.

...nine of the 11 patients treated with either ***ibrutinib or venetoclax****-based therapy had some* ***improvement*** *in their* ***neuropathy****...*

Phase 1 Trial Planned of Novel CAR T Cell Therapy in B Cell Malignancies – A Phase 1 clinical trial of a novel CAR T cell therapy for treating B cell malignancies was to begin recruitment at press time. The trial, located at the National Cancer Institute, features CAR T cells that target both the CD19 and CD20 surface antigens found on B cells. The trial is open to adults with B cell cancers that have not been controlled with standard therapies, and WM patients are eligible to participate if they have been previously treated with at least two regimens that included a monoclonal antibody, a BTK inhibitor, and chemotherapy. The trial identifier on *www.clinicaltrials.gov* is NCT05797233.

Immunocompromised *adults now have the* ***option*** *to receive one or more* ***additional booster*** *doses of bivalent Pfizer or Moderna.*

US End to Public Health Emergency for COVID Results in Some Medicare Changes – The United States ended the Public Health Emergency for COVID-19 on May 11. For those on Medicare, the program will still cover the cost of COVID vaccination. Medicare Part B will cover the cost of COVID testing only if it is ordered by a doctor and performed by a laboratory, but Medicare Advantage Plans may require some cost sharing even in this circumstance. Medicare B will no longer pay for over-the-counter COVID test kits, but some Medicare Advantage Plans may do so. Expanded telehealth services under Medicare that were instituted during the Public Health Emergency will remain in effect until December 31, 2024.

CDC Updates COVID-19 Vaccination Guidance for Immunocompromised Adults – The US Centers for Disease Control and Prevention (CDC) has issued new recommendations for COVID-19 vaccination for immunocompromised people. To view the complete guidelines for the immunocompromised, including the timing of doses, go to *https://www.cdc.gov/vaccines/covid-19/clinical-considerations/covid-19-vaccines-us.html#considerations-covid19-vax*, scroll down to the section "COVID-19 Vaccines, Recommendations, and Schedules," and click on the heading "Guidance for people who are immunocompromised." In brief, these are the new recommendations:

- Immunocompromised adults now have the option to receive one or more additional booster doses of bivalent Pfizer or Moderna. This follows their eligibility for a first bivalent Pfizer or Moderna booster in fall 2022.
- Additional booster doses may be administered at the discretion of healthcare providers, but the time interval between each booster dose should be at least two months.
- The older monovalent Pfizer and Moderna vaccines are no longer available in the US, nor is the J&J vaccine. Consequently, primary vaccination for immunocompromised adults will be with three doses

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of bivalent Pfizer or Moderna or with two doses of Novavax.

US FDA Authorizes New Monoclonal Antibody Treatment for Severe COVID Infection – The US Food and Drug Administration (FDA) has issued an emergency use authorization for vilobelimab, also known as Gohibic, to treat COVID-19 in hospitalized adults with severe COVID disease when treatment is initiated within 48 hours of receiving invasive mechanical ventilation or extracorporeal member oxygenation (ECMO). The drug is a monoclonal antibody which works to control an immune system protein called complement that is thought to lead to inflammation and COVID disease progression.

AstraZeneca Recruiting Participants for Phase 3 Study of New COVID Preventative for the Immunocompromised – AstraZeneca is conducting a Phase 3 randomized, double blinded clinical trial of its drug AZD3152 for the pre-exposure prevention of COVID infection in immunocompromised adolescents and adults. Since authorization for Evusheld was withdrawn in January 2023, no prophylactic treatment to prevent COVID infection in the immunocompromised has been available. AZD3152 is a next-generation long-lasting monoclonal antibody that has been shown in pre-clinical studies to have broad and potent activity against all known COVID-19 variants of concern to date. The trial, called SUPERNOVA, plans to enroll approximately 3,200 immunocompromised participants in 20 countries, who will receive either the study drug AZD3152 or Evusheld (as a comparison arm). On *www.clinicaltrials.gov*, the trial identifier is NCT05648110.

First Vaccines for RSV Are Approved for Older Adults – The US Food and Drug Administration has approved the first two vaccines to protect against respiratory syncytial virus (RSV). The vaccines are Arexvy from GlaxoSmithKline and Abrysvo from Pfizer and are for adults 60 years and older. Although RSV is often associated with babies and young children, it can also be dangerous for older adults, especially those with underlying health conditions such as heart or lung disease or with weakened immune systems. At press time, the CDC was soon expected to review the approvals and recommend them for routine use, in which case they will be available at no out-of-pocket cost for most older Americans covered by Medicare. Both are expected to be available this fall.

AbbVie Withdraws Sale of Ibrutinib for Mantle Cell and Marginal Zone Lymphomas – AbbVie has voluntarily withdrawn the sale of ibrutinib (Imbruvica) for both mantle cell lymphoma and marginal zone lymphoma. The drugs were originally approved for these two indications under "accelerated" clearances that had to be confirmed with additional testing. While a follow-up study in mantle cell lymphoma met its main goal of slowing tumor progression, it did not extend survival and was associated with serious grades of adverse reactions. The confirmatory study in marginal zone lymphoma did not succeed. This decision does not impact any of ibrutinib's other approvals.

The author gratefully acknowledges the efforts of Grete Cooper, Steven De Cenzo, 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.*

Spotlight ON SUPPORT GROUPS

EDITOR'S NOTE:

As the support group section continues to evolve away from individual reports, we begin to spotlight certain groups, activities, or people. As always, for particular information about when and where meetings are being held, go to the Events Calendar for listings: ***https://iwmf.com/events-calendar/***

THE SECRET INGREDIENT TO TWO YEARS OF WM WELLNESS

By Ann Grace MacMullan, E-RYT 500, C-IAYT
WM Community Yoga Instructor

Editor's note: Ann Grace is a certified yoga therapist who enjoys connecting the WM community through movement, breath, and sound. Her father was diagnosed with WM in 2019.

After a recent virtual WM Chair Yoga class with a record high of 30 folks in attendance, a participant named Diane from Florida asked a great question: "What makes this yoga class specifically for those of us with Waldenstrom's?"

The first sentence out of my mouth was, "You are in a yoga class where everyone else has the same rare diagnosis as you." The rarity of Waldenstrom's means you may never meet anyone else with your diagnosis, but in this class, you're surrounded by people you don't have to explain anything to and who may more compassionately understand symptoms like fatigue, recurring infections, anxiety, or how challenging it can be to advocate for medical care. They may also provide personal anecdotal evidence that helps you navigate your own journey in the support chat after our movement practice. Having that sense of "we're all in it together" also creates a safe space where your nervous system can relax, while providing a fundamental human need: a sense of community, of belonging.

However, when this class began back in May 2021 with only about 12 participants, my answer to that question might have been a bit different. As a yoga therapist in my second year of training, I might have said something like, "This class is designed for Waldenstrom's because it uses the tools of yoga to address symptoms such as fatigue, peripheral neuropathy, decreased bone mineral density, immune system health, stress, and anxiety that you might experience either as a result of WM or WM treatments."

Because of the diversity of how WM presents and is treated, yoga therapy is an excellent holistic intervention, addressing the multiple layers of mind, body, and spirit through tools such as physical postures, breathing techniques, and meditation tailored to an individual or to the group. While there is plenty of research to back up the claim that yoga can help those affected by cancer in a myriad of ways, our classes have provided anecdotal evidence that yoga can help with Waldenstrom's in particular.

Ann Grace MacMullan, IWMF yoga classes instructor

Here is the real two-year kernel of learning for me, though. Beyond the actual poses, breathing, and meditation—which all do a great deal of good—it's the *community* that provides the stable, safe base for true healing. Knowing you are not alone, that you are part of something larger than yourself, can be just as therapeutic as the yoga practice. In my clinical practicum, the culmination of my yoga therapy training, I focused on developing a group yoga therapy curriculum as an intervention for Waldenstrom's. Here's an excerpt from my conclusion:

> The word Yoga translates as "to yoke or join," and this can mean connecting mind, body, and spirit, or connecting our individual consciousness with a universal consciousness. In particular for this specialty population, yoga has come to mean

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connecting with each other—rendered even more important when being with others is challenged due to pandemic and post-pandemic protocols for this oft-immunocompromised population.

Wellness Class participants share that our practice helps them breathe better, feel more relaxed, balanced and flexible…and they feel more connected. It is important to note that sequencing is integral to the general success of the curriculum. The movement practice prior to the Support Chat helps to "soften the matrix" or relax the nervous system; I would offer that feeling more open in the body may result in feeling more open to sharing and listening.

I have learned so much from this rich experience, both for my Dad's benefit, and for advancing my knowledge as a yoga therapist. I hope that this curriculum can serve as a stepping-stone for other yoga therapists looking to serve a specialty population, especially in the field of integrative cancer care.

We can do all the yoga, all the time, but that supportive relationship with the community that develops naturally over time is foundational. It's like a beautifully complex system of tree roots, growing out wide and intertwining with other root systems until we are one network of souls and bodies with a shared goal: to live well with WM. And friends, *that* is the very definition of yoga.

DALLAS SUPPORT GROUP HOLDS FIRST IN-PERSON MEETING IN THREE YEARS

By Steve Pine

On April 15, 2023, members of the Dallas Area WM Support group met for the first time in person since February 2020. The meeting was set up as a social event, no educational agenda but just an opportunity to visit with other members old and new.

Our in-person gathering was held at the Truck Yard near downtown Dallas, a dog and family friendly outdoor venue. Each year, the Truck Yard donates a portion of sales to the Truck Yard Nursing Scholarship, as part of the Advancing Nursing Excellence scholarship program at Baylor Scott & White North Texas.

Known for in-house cheesesteaks, Airstream trailer, and treehouse bars, along with a relaxed backyard vibe, food trucks, and live music, it was the perfect setting to scratch the itch to visit with old WM friends and meet face-to-face with new ones after more than three years of Zoom meetings. A toddler grandchild and our dog, Shorty, were included in our group.

We also took the opportunity to catch up with how everyone is doing with their WM, and the more seasoned members were able to pass on their knowledge and experiences to the more recently treated and diagnosed. The Educational Forum the following weekend and the Consensus Panel reports from the 11th International Workshop for Waldenstrom's Macroglobulinemia were also hot topics of conversation.

Steve Pine, Co-leader, Dallas Area WM Support Group

Meeting virtually has been a double-edged sword for our support group. Zoom does not know distance. We now have members who regularly participate from all parts of Texas and, from time-to-time, other parts of the US. The importance of meeting in person was confirmed by our experience at this gathering and during the recent Educational Forum. Going forward, the Dallas Area Support Group plans to continue meeting virtually every other month and hopes to have regional social meet-ups in the off months to fulfill our desire to visit with each other in person.

FROM THE FACEBOOK WM SUPPORT GROUP: SUMMER 2023

EDITED BY BETTY ANN MORTON

Spring 2023 was a busy and productive time for the entire IWMF community, particularly leading up to the Ed Forum. On an average day, there are ten new posts on our Facebook WM Support Group page, 145 comments made regarding posts, and 470 reactions (such as "likes"). This is an active group.

In the weeks leading to the 2023 Ed Forum in St. Louis, members discussed who would be attending. Those who could not attend in person were delighted to learn that they could attend the presentations online—and for free. During the weekend, many who were in St. Louis shared photos and comments about the sessions, giving a taste of the experience. Although the vast majority of the 5,800 members of the Facebook WM Support Group did not attend the Ed Forum in person, posts discussed the presentations and the implications for each individual's own health.

Sharon Axelrod Piotrowski summarized what she learned. Sharon is a WM patient, diagnosed in July 2019. She is a co-leader of the Sarasota Support Group and also a LIFELINE Volunteer. She wrote, "I recently attended the IWMF Ed Forum in April. So much to digest (and I want to watch the videos), but my take-away from meeting people and listening to the experts is that:

1. Mostly, we have different journeys to our diagnoses.
2. Some WM patients do well on a treatment and others not so much, even with the same treatment.
3. Some have long watch-and-wait times between treatments, and others don't.
4. Doctors can't predict how a drug will work for an individual patient. Doctors and patients need to evaluate the patient's own health issues, life choices, and ultimately what a patient would prefer as treatment.
5. Treat the symptoms, not necessarily the blood numbers/IgM. During the Ask the Doctors session, a specialist said that in the absence of symptoms, treatment may not be needed even if IgM levels are over 6,000 mg/dL. However, in such situations, the oncologist recommended following the patient closely and watching for bleeding or other problems.
6. Doctors can't predict how long it will take for a patient to relapse after treatment. Some patients' responses last a long time, others not long.
7. BTK-I (BTK inhibitor) versus B&R (bendamustine and rituximab): Besides evaluating possible health issues that may impact the decision to use one of these treatments, it comes down to whether the patient prefers being on a continuous oral treatment or receiving intravenous treatment for shorter duration.
8. Zanubrutinib seems to be the preferred choice over ibrutinib for oral medication. But if one is doing well on ibrutinib, there is no need to switch.
9. All drugs have their own toxicity and side effects, so you might drive yourself crazy thinking about them.
10. The experts can guide us and provide research, but in the end they don't have a crystal ball to give us definitive answers on treatment choices or length between treatments.

"I am most grateful for a weekend where I felt like I was around people who just…get me."

DJS wrote, "I so enjoyed meeting my 'neighbors' from Illinois at the Forum; I am from Indiana. So enjoyed our time together and getting to know each other." Her new friend **DP** added, "A wonderful experience from beginning to end. Where else would I go home with new Wally friends?"

*"I am most **grateful for** a weekend where I felt like I was around **people who** just…**get me.**"*

Our WM yoga teacher **Ann Grace** commented, "Oh so wonderful to be here, meeting friends and making new ones. IWMF rocks—what an awesome team! Meeting those affected by WM in person is a treasure—truly an amazing community." **DCH** responded, "Hi Ann! I'm doing the next best thing, stretching and yoga moves while listening to the podcast!...will meet everyone maybe next year?"

NB posted, "Hello everyone, this is my first post on here. My husband was diagnosed with WM late last year; he's 58 years old. I've joined the group so I can chat with people that understand/experience similar issues as we are. I really would like to get an idea of where everyone lives to see if anyone might be in the area that we're in. We live in Western Australia. Thank you in advance to everyone that responds to my post."

Many of the group members request information or support regarding their own situation. **SC** wrote, "This has been a challenging couple of weeks for me. Diagnosis was

From the Facebook WM Support Group, cont. on page 28

January this year. I mentioned in a previous post about my right foot feeling like a cell phone on vibrate was attached to it. Big toe area was sore and beginning to cause a limp. There was a Friday night with severe pains in my right arm joints (shoulder, elbow, and hand). Those have reduced significantly, even the buzzing foot. Weird. My fatigue is the worst it's been since diagnosis. My journey started last summer with blood tests revealing my anemia...My hobby is riding my bikes and commuting to the bike shop I work at in my semi-retirement. The last couple of weeks I've barely ridden. No commutes at all. Just too tired…My second oncologist appointment is soon. At this rate I'm kind of hoping to be closer to the start line for treatment than I was in January."

***Understanding WM** is a **challenge** even for our expert doctors, and WMers often **ask for help** in understanding what is happening.*

BB noted, "I woke up this morning with a sharp abdominal pain on left upper quadrant under my rib cage, and it's uncomfortable if I press on the area. I hadn't had that pain before. Online, Dr. Google says spleen. My doctor has not noted any enlargement of my spleen nor lymph nodes. I see her in a month. I'm not running in at the first sign of discomfort but will call if it continues. I just wanted to see if I should be more worried about this…" **BB** was advised by several to contact her doctor to let about this new symptom and seek guidance. Her oncologist requested her to see her PCP to rule out any acute cause.

Understanding WM is a challenge even for our expert doctors, and WMers often ask for help in understanding what is happening. The Facebook WM Support Group has several individuals who are designated as "group experts;" other group members also share their knowledge and personal experiences. When **TS** posted, "I have perhaps a dumb question. I was diagnosed in October 2021 via bone marrow biopsy. I also had a full CT scan that indicated lymph node involvement. I'm confused that some people only have marrow involvement. Is this indicative of progression? My treatment was successful in that I feel better but I still have enlarged lymph nodes. Should I be concerned? I just had my check up with my oncologist and he is not concerned and I'm feeling good. I just now realized that not everyone has lymph node involvement..."

After reassuring the poster that her questions were not dumb, fellow WMers explained that lymph node involvement is another way in which we vary. Although many of us have enlarged lymph nodes, as well as enlarged spleen, those symptoms are not universal. **JPW** wrote about her own experiences. "I was diagnosed because of a swollen lymph node in my groin. I thought I had a yeast infection because I had that issue before, but when it wouldn't resolve I saw the doctor. They did ultrasound, bloodwork, and scheduled the biopsy. Upon removal of the swollen node they discovered it was wrapped in tumor. This prompted further investigation which found that it has spread through the iliac chain as well. The bone marrow biopsy confirmed WM but there was low marrow involvement. My oncologist/hematologist checks when I see him because of pressure in my arm pit and groin area. I'm still on watch and wait."

The most common suggestions on our Facebook page are to read/watch IWMF publications and videos, check with your doctor, and consider getting a second opinion with a WM expert doctor. **KC** reported on a recent experience with getting a second opinion. "Mom's appointment today at Dana-Farber was WORTH THE TRIP! If you get a chance…just go!! Dr. Castillo validated my concerns for mom, and reassured me that my research (much of what was initiated here in this group) was right on track! For us, it was a game changer. Knowing we have access to him going forward through email/phone/visits is peacefully reassuring."

Another positive outcome of the Facebook group is connecting people with resources they had been unaware of. Recently the child of a WMer from India joined the group, seeking help in understanding watch-and-wait and when treatment is needed. Along with links to helpful articles and videos, this message was posted: "Hi, welcome to our support group. You can contact us on *https://www.wmindia.org/*. We are India's support group and we're the affiliate leaders of IWMF. I've also been on wait-and-watch for many years."

I recently posted, "I had a checkup with my PCP yesterday and took her two booklets I picked up at the Ed Forum, thinking she might read them and learn information that would help her to treat me. It turned out that she has another patient with WM that she has concerns about. I gave her permission to give that person my contact information, and I highly recommended IWMF, as well as our local support group and this Facebook page. We'll see what happens." This is another way WMers can help to spread the news about the IWMF's excellent resources to the medical community and to the newly diagnosed.

Note: WMers 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*.

A WM VOICE FROM SWEDEN

By Susanne Öhrn, Founder/Leader
WM Skandinavien


Susanne Öhrn

In April I had the honor and the great privilege to attend the IWMF's Educational Forum in St. Louis, MO.

For me as a European coming from the Nordics/Scandinavia/Sweden, it was an extra awesome experience. This was the first time in my 63-year-old life that I visited the US. It felt like I had the opportunity to experience much more of the US than just Missouri, since there were people at the Ed Forum from pretty much every state in the US (like a little US in miniature), plus people from Canada, the UK, and Germany.

It was great to meet such interesting, nice, and knowledgeable people. And the conference was incredibly well-organized! This was thanks to all the amazing people from the IWMF, both employees and volunteers, who made the experience outstanding. In addition, they managed to recruit many talented doctors to present the latest on WM. The information was packaged in a way that everyone could learn according to the level of their own WM journeys.

Many opportunities were given to meet, talk, eat together, and make new friends, which I greatly appreciated. In addition to this, I had the opportunity to meet with the Board of the IWMF and give them a small talk. The information I presented to them was about the Nordics/Scandinavian health care system and "WM Skandinavien." Health care clearly works differently in the US compared to the Nordics, without putting any value judgments into either system.

Nordic health systems

The Nordics have a high standard of living and a long life expectancy.

The Nordic health systems are government-financed through tax revenue. Most of us accept our payment of taxes, considering it a "mandatory insurance" which provides us with health care, medicine, sickness benefit, parental leave, guaranteed pension, free college and universities, and much more. The discussion in the Nordic countries is **not if** we should pay the taxes—but rather sometimes the tax level and how the tax should be calculated.

Patients in the Nordics also have the right to seek care in other Nordic and European Union (EU) countries if they can't get it in their own country. This has been consolidated in legislation and in decisions of the EU Court of Justice (the UK is not part of the EU).The health systems are based on three main pillars:

- **General and equal care:** All citizens have access to health care services and medicine, at low or no cost at all.
- **Availability:** The health systems are available in both urban and rural areas. Local care is of great importance in preventive care and early detection of diseases.
- **Quality:** The health care systems are composed of highly educated staff, who use advanced technology and prioritize care closest to the patient. Focus is on preventive care and promoting a healthy lifestyle for healthier lives. For example, we have extensive national vaccination programs and some of the strictest tobacco laws in the world.

The Nordic health systems challenges

An aging population and long life require a lot of resources. The costs for new medicines, personalized medication, and new medical technology are increasing.

Private health care providers have entered the market and can be chosen by patients with private insurance and/or as subcontractors to the government health care system. The competition to win tenders to offer health care at the lowest cost makes it difficult to spend resources on clinical research. Private health care and personnel moving abroad drain the public care of staff and specialists

Despite challenges, the Nordic health systems have shown resilience; they are still developing and changing with new demands.

WM Skandinavien

I started WM Skandinavien in 2016. For the moment I'm still the sole administrator, but I am looking for volunteers.

We are not yet registered as an association in any of the Scandinavian countries because this would require that more members are willing to work for the group. We are now 400 members from the Nordics and some from other countries (Sweden 247, Denmark 65, Norway 32, Finland 14, The Faroe Islands 2). Interest in what is happening on our Facebook page is very high. Over three-quarters of the members are active, making comments, using "like" symbols, or just reading.

We have, over the years, had several physical and digital doctor/patient meetings along with several Zoom meetings and local "*fika*" (casual social) meetings.

I'm also a patient representative in the Nationellt vårdprogram Waldenströms makroglobulinemia, the care program that produces the national WM guidelines

International Scene, cont. on page 30

International Scene, cont. from page 29

Susanne and her grandson

in Sweden. This national working group's mission is to meet challenges and demands in tomorrow's cancer care through outreach and cooperative work. It is composed of representatives of the different levels of patient care, and also includes patients. That's me!

Support is local

It is difficult to get qualified information about rare diseases, such as WM, through local doctors, hospitals, or organizations. The area of the Nordics is quite large, and the population density is low, except for Denmark.

We also have to consider the language barrier—many people in Scandinavia can manage only "holiday English" or "old school English." This is a concern, especially when it comes to elderly patients, and why information in their own language is necessary. People also want to discuss difficult topics and feelings in their mother tongue.

There are also groups of people who have low information technology knowledge. So the use of well-known, simple, and easy-to-use communication is the reason we use Facebook as the main source.

WM Skandinavien challenges

It's hard to get commitment from volunteers on a more regular basis. Traditionally, Scandinavians are not used to volunteer work in the health care sector. Many believe that even WM Skandinavien is state-funded—or should be.

Scandinavians trust their health care system. They expect to receive all information and help through the health care system without any effort on their part. But, after being diagnosed with WM, this belief has often been replaced by doubt.

The local blood cancer associations regard WM Skandinavien as a competitor/threat, not as a potential cooperation partner.

Many patients believe that it is enough to pay a small sum per year to join the national blood cancer association. For this, they expect information, support, meetings, and help. The low cost is because the blood cancer associations often receive government support and/or grants from the national cancer organizations.

In Scandinavia we are not used to donating money to other than very well-established national organizations or UN-supported fundraisers. But that is slowly changing.

Lymphoma research is ongoing in the Nordics, with the goal of improving survival and quality of life for patients. Along with studies of length of treatment and its long-term effects, population-based studies are done as well, for northern Sweden's rate of the incidence of WM is three times higher that of most other countries. This is true of some other diseases too.

My hope is that this research on WM will continue and create more interest in supporting WM patients as well as medical colleagues who do not have WM as a special interest.

I will try to organize a patient-doctor meeting in the fall. Perhaps I will be able to attract some of the doctors who are part of the WM group to participate. Whether this will be a physical or a digital meeting remains to be seen.

WM UNITED KINGDOM – WMUK

By Kat Tucker, Information and Support Manager

It has been a busy quarter for the WMUK team, with the charity jumping into spring with a fresh new look and even fresher new website.

The team members have worked extremely hard over the past year alongside patients and experts to produce a website that has even more information and is easily accessible. Simply click where you are on your WM journey, and you will find the information that is relevant to you, from newly diagnosed FAQs, to the different treatments you might come across, to related conditions that might develop with WM. All the information has been informed by clinicians, and we hope it helps people living with WM feel more confident and knowledgeable about the condition.

We have regular webinars running, with our most recent webinars ("Getting the Most from your Consultation," "Emotional Wellbeing and Resilience," "Benefits and Employment Rights," and "COVID and Vaccines Update") all available to (re)watch on our YouTube channel: *https://www.youtube.com/@wmuk9147* Coming up in the next months we have:

- 12 July – "Complications of WM – Bing Neel Syndrome and Amyloidosis"
- 13 September – "WM for Beginners"
- 12 October – "Menopause/Women's Health"

You can register for these on our website: *https://www.wmuk.org.uk/waldenstroms-macroglobulinaemia-giving-you-support.*

International Scene, cont. on page 31

The cost of living continues to rise, and we understand that this might affect people with WM even more. Due to the generosity of our supporters, we are delighted to be able to open up the WMUK Patient Assistance Fund to WM patients in the UK to help with the financial burden. The fund grants every patient a one-off amount of £100, no matter their circumstances. To apply, please see our website or contact us at *info@wmuk.org.uk.*

Our Support Line continues to be a vital lifeline for anyone affected by WM. Whether you have just been diagnosed, have been living with the disease for years, or are a family member or carer, our cancer nurse, Alison, is there to answer questions, provide personal support, and be a listening ear. You can get in touch with Alison Monday-Thursday, 9-5, at *support@wmuk.org.uk* or by calling 0300 373 8500.

Plans for the 2023 Patient-Doctor Summit are well underway, and we will soon be releasing our early-bird tickets. Block out 23 September in your diary and come join us for a day of learning, community, and collaboration.

Our incredible Wheels for Waldenstrom's team have been training hard, meeting up for gruelling rides across the UK, and even taking their bikes on trips abroad. The team—a mix of WM patients, families, and healthcare professionals—will be cycling from London to Paris this August to raise funds and awareness for WM. Their efforts have only just started, but they have already raised a whopping £10,000! If you would like to support them, you can donate here: *https://www.justgiving.com/campaign/wheelsforwaldenstroms23.*

Finally, we want to say a huge thank you to everyone who completed our Patient Survey. Over 300 of you took the time to provide feedback regarding your experiences and opinions, all of which we are currently taking on board to improve and grow our services. Every response will help people living with WM.

WM NEWS FROM CHINA

By Roger Yao, WM-China

WM online lecture for the 29th National Cancer Awareness Week

The week of April 15-21, 2023, is the 29th National Cancer Awareness Week in China. The biggest patient organization in China for lymphoma disease, House086, held a series of caring events for lymphoma patients.

Among these events, House086, the First Hospital of Zhejiang University, and WM-China worked together to have a special online educational lecture for WM topics the evening of April 20, and more than 600 WM patients and family caregivers participated virtually.

Two hematologists, Dr. Cai Zheng and Dr. Yang Yang, gave the lectures with the topics of "Diagnosis and Treatment for WM" and "Follow-up Management for WM Treatment," respectively. Roger Yao, from WM-China, shared his own experience of effective ways of communicating with doctors and how to collect routine blood test historical results and make them into an Excel sheet for follow up.

For the Ask the Doctor session at the end, more than 20 patients prepared their questions and sent them to Ms. Juan Juan from House086; Dr. Yang Yang then gave detailed answers and explanations online.

Zanubrutinib approvals

BeiGene announced the China National Medical Products Administration (NMPA) approved four applications for Brukinsa (zanubrutinib), the company's Bruton's tyrosine kinase inhibitor (BTKi), including two Supplemental New Drug Applications for treatment-naïve adults with chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL) and Waldenström's macroglobulinemia (WM) and two Supplemental Applications for conversions from conditional approval to regular approval.

Dr. Cai Zhen and Dr. Yang Yang

International Scene, cont. on page 32

International Scene, cont. from page 31

Dave Johnston with his granddaughter

DAVE JOHNSTON'S LONG ACQUAINTANCE WITH WM AND THE WM FOUNDATION OF CANADA (WMFC)

by Kirsten Johnston

In May 1998 David attributed his unexplained weight loss to the considerable physical effort he put in over several weeks cleaning up fallen branches on the grounds of his beloved family cottage which, along with huge swaths of Eastern Ontario and Western Quebec, had been hit by a catastrophic ice storm a few months earlier.

However, around the same time, David's GP observed that his hemoglobin had dropped below normal levels to 122 g/L (12.2 g/dL), and proceeded to look for a possible cause. Unable to find anything specific, in 2000 the GP referred him to a hematologist, who quickly determined that David had an extra protein in his blood, but that it was of unknown significance. The doctor was trying to tell him that he had MGUS. Further testing in 2002 confirmed that he had an IgM abnormality. When the hematologist moved away, David was without specialist care, until he was finally referred to a new hematologist in 2004, who told him for the first time that his IgM abnormality was in fact because of Waldenstrom's macroglobulinemia (WM).

At that time, David, now aged 73, was still fully engaged in a second career as a life insurance actuary, having earlier retired from his position as Senior Vice President and Actuary of a major Canadian life insurance company. At every opportunity, he and his wife, Kirsten, traveled to visit her family in Denmark and to explore many other parts of Europe, with Tuscany being a favourite destination. Combined with family time at the cottage every summer and the sport of curling in a senior's league all winter, it made for a busy, active life.

By 2005 his IgM approached 40 g/L (4,000 mg/dL), and treatment was becoming necessary. The hematologist, who was unfamiliar with any specific WM treatment, prescribed an out-of-date chemotherapy treatment with chlorambucil and a low-dose steroid, both taken in pill form daily for 18 months. This brought his IgM down to 11 g/L (1,100 mg/dL.

During this time, David discovered a WM support group in Oakville, a suburb of Toronto, where he lives. The group was organized and run by Arlene Hinchcliffe in tribute to her father, who had succumbed to WM, and it quickly became an important source of help and information for him. One member in particular, Betty McPhee, encouraged him to transfer to a more expert hematologist. At her urging, he arranged for his GP to get him transferred to a hematologist at Sunnybrook Hospital in Toronto in 2007, where he remains under care. This community of fellow WMers continues to be an ongoing source of support and information for David to this day. He has reciprocated by applying his own considerable knowledge of WM and its various treatment protocols to help newly diagnosed members understand their condition better and to reassure them that life does go on after diagnosis.

His remission following his first round of treatment continued for almost four years, but in 2010 his IgM again approached 40 g/L (4,000 mg/dL). By that time rituximab and chemo had become the standard of care. Since chlorambucil had worked well before, it was chosen as the companion chemo to rituximab for the first six months of treatment, followed by 24 months of maintenance rituximab, all of which David tolerated quite well. This treatment was extremely effective and brought his WM into remission until late 2021.

In December of that year, David began treatment with zanubrutinib with mixed results. Although the IgM has been knocked down, he has experienced concerning side effects, and the dosage has been reduced a couple of times in an attempt to maintain the therapeutic benefit while minimizing the side effects. He is not yet sure that this drug is right for him.

Dave and Kirsten Johnston

International Scene, cont. on page 33

David's involvement in the management of the support group in Oakville began in 2010, when he volunteered to become a trustee (known then as a statutory member). In 2006, at age 75, he had finally retired from his second career and had more time to devote to volunteer activities. When a director resigned from the WMFC Board in 2011 due to ill health, David stepped in to take his place. He was soon appointed secretary of the Board, and in 2013 he took on the additional role of treasurer, holding both positions until 2020. Since then, he has continued as a regular member of the Board but will be leaving this position at the time of the Annual Meeting in May 2023, right around his 92nd birthday.

An open letter from the founder of the WMFC, Arlene Hinchcliffe, to David

Dear David,

As a volunteer WMFC Board member for over 13 years you were a most valuable contributor to the success of the WMFC. You have held several positions over the years, most notably as treasurer and secretary, and I personally thank you for the support and guidance you gave to me and the other Board members. Without volunteers like you the WMFC could not have become what it is today.

You showed so much compassion and gave guidance to newly diagnosed patients. You were always there for them to answer any questions and to share your experiences living with WM. I know you helped all of them to navigate the services offered by both the WMFC and the IWMF and eased their fears along the way.

On behalf of all of us we thank you so much for your dedication over the years and wish you the very best.

Sincerely,

Arlene Hinchcliffe

Beth Mitchell

THE IWMF WELCOMES ITS FIRST INTERNATIONAL EMPLOYEES

Hannah Syed

We are delighted to welcome the IWMF's first international employees, Beth Mitchell and Hannah Syed, who joined the IMWF team in April as Managers of Affiliate and Global Partner Engagement. Beth explains, "Our initial focus is providing hands-on support to serve and strengthen the efforts of the IWMF international affiliates throughout Europe and beyond."

With a combined total of 14 years medical education and pharmaceutical communications experience, Beth and Hannah will create and implement individualised support plans for affiliates to continue supporting the WM community globally. Both Beth and Hannah helped support the launch of the WM Global Awareness Initiative with the IWMF and Scientific Education Support and have been collaborating with the IWMF for the last year.

Based in London, UK, our new team members are also keeping active with fundraising activities. Hannah has recently taken part in the Lymphoma Action Bridges of London charity walk. Beth will be joining the WMUK team cycling from London to Paris this August to raise awareness of WM. Good luck Beth and the team, we wish you all the best!

Kicking off our European events, Beth and Hannah will have responsibility to manage the Affiliate/ Global Partner Leadership Meeting and Ed Forum in Amsterdam, 20-21 October 2023. Working together with affiliates, the team will plan and carry out a high-quality program that ensures a great learning and networking experience for everyone attending!

Hannah expresses, "We are excited to expand our team and connect with our European and global partners to support WM patients and caregivers worldwide."

TOP TEN REASONS TO DONATE TO THE IWMF

By Annette Preston, Director, IWMF Donor Engagement

With 2023 solidly underway, you may be focusing on your charitable giving goals for the year and how you can positively impact your charities of choice. Perhaps you are considering making a donation to the International Waldenstrom's Macroglobulinemia Foundation (IWMF) but would like to know more about the advantages of giving. The IWMF wants to make your decision as easy as possible. Here are ten reasons why people donate and how your donations to the IWMF help us carry out our Vision and Mission:

1. Your donations fund groundbreaking research into WM. The IWMF just announced eight new research grants for 2023, a commitment of $2.4 million dollars over the next two years (for more, see page 16 of this *Torch* issue).
2. Your donations help us to expand our vital information, education, and support programs. The most recent example is the IWMF's partnership with the National Organization for Rare Disorders (NORD) to provide financial assistance for travel and lodging expenses incurred by individuals who want to seek a second opinion about their WM diagnosis.
3. Your donations help us to improve awareness of WM. As only 1,500 people are diagnosed with WM each year in the US, with a similar number in Europe, promoting awareness is crucial to find and help others with WM.
4. Your donations to the IWMF not only help today, but tomorrow and beyond. Consider making a recurring donation each month to help us plan for the future. You can also include the IWMF in your estate planning.
5. Your donations encourage others to follow your example. When your family and friends see how important the IWMF is to you, they will be more inclined toward giving.
6. Your donations count, no matter their size. You do not need to donate thousands of dollars to make a difference, and the IWMF is grateful for all donations.
7. Your donations give you the opportunity to express your feelings of gratitude for the amazing work that the IWMF continues to do each and every day.
8. Your donations strengthen your personal values by giving you the power to improve the lives of others.
9. Your donations of money or time increase your sense of personal satisfaction and give additional meaning to your life.
10. Your donations are tax-deductible.

These are only a few reasons why giving to the IWMF can provide you and others with many benefits. The IWMF is proud of the community we have built, and our initiatives continue to grow thanks to our amazing donors. With your help, the IWMF can continue to improve the quality of life for WM patients, build an even stronger WM community, and support those who are in need.

If you have any questions, please do not hesitate to reach out to me, Annette Preston, at *apreston@iwmf.com* or 317-919-8238.

The IWMF Vision: A World without Waldenstrom's macroglobulinemia (WM).

The IWMF Mission: Support and educate everyone affected by Waldenstrom's macroglobulinemia (WM) to improve patient outcomes while advancing the search for a cure.

"During my 28-year Waldenstrom journey there has been one knowledgeable and consistent guide—the IWMF. Each of the many treatments I've received were initially learned of via this resource, long before my local oncologist knew of their existence. It's very apparent that the IWMF uses every donation to further research and education, which directly benefit the patients of this orphan disease. In giving, we receive so much, and expand the possibility of a cure."

– Jennifer Hoegerman

Jennifer and Robin Hoegerman

Join us to raise awareness and support for the International Waldenstrom's Macroglobulinemia Foundation (IWMF).

Join the Walk for Waldenstrom's from anywhere in the world anytime in the month of September.

Walk for Waldenstrom's is a one-mile walk/run virtual or in-person fundraising and awareness event for the IWMF and global WM community.

Walk in a park, on the beach, on a treadmill, in your neighborhood (bring the dog), or even from the comfort of your own home.

Don't want to walk? No problem!
Pick an activity you enjoy...pickleball, bridge, even reading a book.

We will help you create your own fundraising page.

Please reach out to your friends and family for support, or you can even sponsor another Walk participant.

Contact Annette Preston at *apreston@iwmf.com* or 317-919-8238 for more information.

IWMF
International Waldenstrom's Macroglobulinemia Foundation

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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ANONYMOUS
JEAN-MARC* AND SARAH AUDIBERT
PAUL AWES
C. EDWIN BAKER*
JACK BAKER
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DAVID M. BENSON
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LISA WILSON
LISA WISE
PENNI WISNER
JAMES P. YEAGER*
RALPH ZUCKERMAN*

* Deceased ◊ Founding Member

RESEARCH PARTNERS

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 has supported the following research projects:

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

Elting Family Research Fund of the IWMF has supported the following research projects:

- Dr. Marzia Varettoni, Fondazione Italiana Linfomi Onlus, *Non-invasive diagnostics and monitoring of MRD and clonal evolution in Waldenstrom's Macroglobulinemia*
- 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*
- Sherie L Morrison, PhD, The Regents of the University of California, *Novel antibody-targeted interferons in combinational therapies for Waldenstrom's Macroglobulinemia*
- Shahrzad Jalali, PhD, Mayo Clinic, *Modulation of T-cell function by metabolomic signature of the bone marrow microenvironment in Waldenstrom's Macroglobulinemia*
- 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*
- Dr. Gareth Morgan, New York University Grossman School of Medicine, *Using mutographs to define the molecular landscape and cell of origin of Waldenstrom's Macroglobulinemia*

Hamberg Family Research Fund of the IWMF

Robert Douglas Hawkins Research Fund of the IWMF

The Lynn M. Fischer Research Fund of the IWMF

Michael and Rosalie Larsen Research Fund of the IWMF

Leukaemia Foundation of Australia has supported the following research projects:

- 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*
- 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*

K. Edward Jacobi Research Fund of the IWMF has supported the following research projects:

- 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*

Carolyn K. Morris Research Fund of the IWMF

The Poh Family Research Fund of the IWMF has supported the following research projects:

- 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*

Ed and Toni Saboe Research Fund of the IWMF has supported the following research projects:

- 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*

The Paul and Ronnie Siegel Family Research Fund of the IWMF

Waldenstrom's Macroglobulinemia Foundation of Canada has supported the following research projects:

- 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*
- 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*

Robert and Nadeline White Family Research Fund of the IWMF has supported the following research projects:

- Steven Treon, MD, PhD, Dana-Farber Cancer Institute, *Targeting MYD88 in Waldenstrom's Macroglobulinemia*

Marcia Wierda Memorial Research Fund of the IWMF

Yang Family Research Fund of the IWMF has supported the following research projects:

- Steven Treon, MD, PhD, Dana-Farber Cancer Institute, *Targeting MYD88 in Waldenstrom's Macroglobulinemia*
- 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*

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:

Baker Family
Research Fund of the IWMF

David and Lois Baru and Family
Research Fund of the IWMF

Yoshiko Button
Mission Support Fund of the IWMF

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International Waldenstrom's
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6144 Clark Center Avenue
Sarasota, FL 34238

Telephone 941-927-4963 · Fax 941-927-4467
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