IWMF TORCH

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INSIDE THIS ISSUE

LEST WE FORGET – A PANDEMIC PERSPECTIVE FROM INDIA

By Jaya Mani, Bangalore

Member of Waldenstrom India | June 2021

Editor's note: In the interest of introducing our readers to more of the worldwide WM community, in this issue we feature the first-hand experience of a WMer in Bangalore, India. We've all watched aghast as India has suffered major COVID trauma, and with Ms. Mani's description of what she sees around her, we understand a bit better how the pandemic has affected her, as a WMer, in her country. Many thanks to Waldenstrom India Affiliate Leader Saurabh Seroo, for his help.

Ms. Jaya Mani

Jaya Mani lives in Bangalore, India, where her boutique, Ambara, promotes the work of artisans in the handloom and handicraft sectors. She also curates art shows through her gallery, Dravidam. Her interests lie in the visual and performing arts. At the age of 61 in 2010, she was diagnosed with WM. Travel continues to be an indulgence.

A few months ago, India was lauded for having controlled the spread of COVID-19. What were we doing right that, despite being a relatively small country with the highest population density per square kilometre, it seemed like we contained the virus? This was a question being raised on international forums and by the media.

Health workers wearing protective gear monitor the body temperature of people during a health check-up camp in Mumbai.

Sadly, this good fortune did not last long, and here we are, having slipped into despair. The country has now hit a world record for the highest number of cases and mortality. Given the density of our almost 1.39 billion population (projected to overtake China soon) and our socio-economic disparity, the pandemic seems to have slipped out of control.

Much of rural India was already suffering from mind-boggling poverty. The pandemic has now spread its tentacles into the countryside and has thrown open the glaring lack of medical facilities, oxygen, vaccines, and medical personnel in villages. Across the country, in cities and towns, we are hopeless spectators to what appears to be an uncontrollable avalanche. As the news of the death of yet another friend, relative, acquaintance, or the loved one of a loved one hits home

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every day, we are but mute bystanders. The wily virus mutates faster than we can keep track of, and recent horrific reports of associated black and white fungus infections and the prospect of a possible third wave hitting children more than the adult population are terrifying.

So, where did we go wrong, and how have we come to this? The answer is simple. We got complacent. Amidst news that the pandemic was finally under control, most people divested themselves of masks or retired them to their chins and necks. Social distancing was shelved. We lived in the false belief that we were invincible. After all, supposedly, most Indians have natural immunity, as we are exposed to infectious diseases from childhood. But COVID-19 proved us wrong.

Religious festivals and political gatherings are woven into the socio-political fabric of this nation. India is a country with multiple religions, and each religion has various festivals. We probably have more holidays for religious festivals than any other country in the world. Our weddings are attended by hundreds and sometimes even thousands of guests. Celebrations continue for days with feasting, drinking, and revelry. Political election rallies, which continue for weeks, are attended by millions of slogan-shouting unmasked supporters. In March and April of this year, the virus made the most of a spate of religious events and political rallies. These events turned into breeding grounds for the fast-mutating virus. Although India is a prominent manufacturer and exporter of vaccines and has, for decades, run vaccination drives that have successfully eradicated diseases like smallpox and polio and controlled malaria and HIV, we were caught on the back foot.

Amidst complacency and congratulatory backslapping, our vaccines were exported, and our masks slipped while social distancing norms were flouted. We did not anticipate the need for additional oxygen supplies or ICU beds and ventilators. In some rural areas, patients

Health workers wearing personal protective equipment arrive to take part in a check-up camp at a slum in Malad.

Migrant workers walk on the highway on their journey back home during a nationwide lockdown to fight the spread of the COVID-19 coronavirus.

lie on makeshift beds under the scanty shade of trees in the scorching summer heat with IV drips strung from branches, while helpless family members take turns being caregivers. There is a dearth of doctors and nurses across the country, and the endurance of frontline workers is being stretched to the maximum. Crematoriums and graveyards have long run out of space.

One of our foremost doctors, Dr. Devi Shetty, recently emphasized the need for an immediate increase of medical personnel, especially the nursing staff. The government has heeded his advice, and plans are afoot to recruit doctors and nurses from the ranks of those who have completed the final year of their degree course, allowing them to do a year of coronavirus duty in lieu of residency. This should ease the pressure on a faltering healthcare system.

As a WMer, I wait and watch the journey of the virus and wish upon us a Saint George-like strength to slay the coronavirus dragon. As a senior citizen with comorbidity, I am distanced from the ground reality. Yet, despite being in the priority group for vaccination, even I await my second dose because there are simply not enough vaccines to go around.

Saleela and Kabeer before COVID photo by Jaya Mani

At times, even the passing of someone we knew on the periphery has the incredible ability to shake the

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core of our being. Last week, I chanced upon a friend's Facebook post on the demise of a vegetable vendor and his wife, whom we knew. More than news of other deaths, this post strangely shook me, and I lay awake at night thinking of their two young daughters who must feel so rudderless. Kabeer was a poor vegetable vendor whose stall I have shopped at for years. Although he had a conservative upbringing, he encouraged his wife to put aside her burkha and help him with his small enterprise. Saleela loved following the latest fashion trends. She was full of the joy of life. They worked hard to better their lives and to educate their two daughters at private schools. Anisha, the older of the two, is a bright student and recently graduated medical school with a full scholarship. Her parents were so proud of her and would share news of her awards or promotions with their customers. Sadly, Saleela contracted COVID, and a few days later, Kabeer followed her to the hospital. They deteriorated, and since Bangalore was overrun with cases and the medical system was under pressure, they were moved to their hometown in Kerala, a nine-hour journey by ambulance. Saleela departed life four days later, soon to be followed by Kabeer. The family had begged and borrowed to pay their medical bills, and yet they were gone. The girls are left orphaned. Despite being a doctor, Anisha could not save her parents—all she could do was go to the hospital to collect their death certificates.

Anisha at her graduation with her late mother, Saleela photo by Jaya Mani

At a time when most of us need a loving hug or a reassuring shoulder to cry on or a comforting hand upon a fevered brow, even that is denied to us, thanks to the social distancing we must maintain. Hopefully, this too shall pass, and the fabled Indian resilience will see us through this darkest tunnel.

Good Samaritans emerge, especially in adversity. The Sikh community provides free oxygen cylinders to those unable to get oxygen, free food kitchen chains are operated by volunteers in cities, homemakers cook food to be delivered to COVID patients at their doorsteps, tech-savvy citizens are putting together apps and portals to get COVID information and assistance to people in need, and doctors offer free consultations online. Perhaps working and learning from home has its advantages. Family bonds have grown more robust, and parents spend more time with their children. Times are complex, and we learn to live less materially and to recycle. With less traffic on the roads, air pollution is significantly reduced, and Mother Nature is getting time to repair. The pandemic has taught us valuable lessons—lessons we must never, ever forget.

Except where otherwise noted, photographs are from Manoej Paateel / Shutterstock.com.

The following statistics for India were provided by Saurabh Seroo and collected from the Government of India Ministry of Health and Family Welfare and the Government of India 2001 Census of India report.

Population: 1,332,900,000

Area: 1,269,210 square miles

Density: 1,050 people per square mile

Confirmed cases: April 1, 2020 – 2,059
January 1, 2021 – 10,306,471
May 1, 2021 – 19,549,772
June 9, 2021 – 29,182,127

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*

TODAY, TOMORROW, AND BEYOND

By Newton Guerin, IWMF President and CEO

Newton Guerin

We have seen incredible change over the last eighteen months, with uncertainty everywhere around us. Despite all of this, the spirit of the IWMF community remains vibrant. Our Board of Trustees continues its commitment to do whatever we must to meet the needs of patients and caregivers, not only here in the US, but throughout the world. Our Board is always eager to invest additional resources of time, talent, and treasure to ensure that we remain connected to those we're here to serve. Our support group leaders and LIFELINE volunteers make a huge difference in the lives of people living with WM every day! Each of these individuals, along with volunteer leaders who play key roles in providing ongoing education, information, and support through IWMF Connect and other social media platforms, truly do keep us all connected. The Ed Forum Planning Committee, along with our Publications Committee volunteers, work extremely hard to ensure that the IWMF is always here for you by providing the most current, accurate, and independent information about WM. Our *Torch* editors and contributors produce our "world class" signature magazine every quarter.

Our home office staff has the distinct privilege of partnering everyday with IWMF volunteer leaders worldwide to provide a wide array of critically important programs to patients and caregivers:

- **Information** from our website and our publications, written in a patient-friendly way to promote understanding of our rare disease
- **Education** at our annual Educational Forum to help patients and caregivers learn about our disease from WM researchers and clinicians
- **Periodic global webinars** on topics of interest to the WM community and on advances in the treatment of WM
- **On-going updates** about WM and the IWMF sent through our eNEWS releases.
- **Peer support** for individuals with WM
- **Information** for medical professionals who may have limited experience with our rare disease

These programs, along with IWMF research directed to finding better treatments while we continue to search for a cure, require funding. Working together with our Fundraising Committee, staff conduct a comprehensive fundraising program including individual and corporate donor development, planned giving, and the Walk for Waldenstrom's, our signature fundraising event.

So that you can know whom to turn to for information or help, here's a quick introduction of each of our staff and a brief description of "who does what" at the home office:

Manager, Digital & Creative Services
Maureen Baeck: *(mbaeck@iwmf.com)*
Maureen's responsibilities include:

- Managing and maintaining our website, *iwmf.com*.
- Creating and fostering a robust social media presence.
- Serving as technology lead for all virtual programs, including the Ed Forum and Global Webinar Series.

Office & Project Manager Donna Cutillo:
(dcutillo@iwmf.com)
Donna's responsibilities include:

- Answering incoming telephone calls, greeting visitors, responding to inquiries and questions and connecting folks to whomever they may need. I like to refer to this critically important role as the "VP for First Impressions."
- Managing overall administrative functions at the home office and providing support to staff and leadership volunteers, including support group leaders.
- Developing and updating administrative systems and resolving any related problems.
- Mailing Info Paks and other publications as requested via website, phone calls, and email.
- Updating IWMF events calendar by posting partner events.

Director, Development & Communications
Jeremy Dictor: *(jdictor@iwmf.com)*
Jeremy's responsibilities include:

- Leading all IWMF fundraising activities as described above along with cultivation of relationships with our pharma and foundation partners.
- Planning and carrying out a comprehensive year-round communication strategy and plan including regular mail, email, eNews, social media, and our website *www.iwmf.com*.

Development Associate Fallon Markwell:
(fmarkwell@iwmf.com)
Fallon's responsibilities include:

- Maintaining and managing our database and processing all donor acknowledgements.
- Assisting with donor cultivation and recognition efforts.
- Supporting individual social media fundraising efforts and the Walk for Waldenstrom's.

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Manager, Meetings & Partner Engagement
Sara McKinnie: *(smckinnie@iwmf.com)*
Sara's responsibilities include:

- Leading the annual Ed Forum and Global Webinar Series planning and implementation process to deliver high-quality programs that ensure positive learning and networking experiences for all participants.
- Managing and building relationships with external partners/patient advocacy organizations.

Manager, Information & Support
Michelle Postek: *(mpostek@iwmf.com)*
Shelly's responsibilities include:

- Serving as home office information and support specialist to help patients and caregivers when they contact us.
- Working in partnership with the chairs of US support groups, LIFELINE, and International Committees to enhance the IWMF community experience worldwide.
- Partnering with the US support group chair to plan and conduct training and networking opportunities tailored to meet the needs of support group leaders and LIFELINE volunteers.
- Creating and publishing Stories of Hope via Constant Contact, website, and Facebook.
- Partnering with the IWMF Publications Committee to ensure that all IWMF publications are accurate and accessible to the IWMF community.
- Updating IWMF events calendar by posting support group meetings.

Finance Manager Robin Tucker: *(rtucker@iwmf.com)*
Robin's responsibilities include:

- Directing and coordinating overall financial management functions, including cash management, banking, tax and regulatory compliance, accounting, and reporting,
- Managing human resource functions, including payroll and employee benefits.

Our staff operate as a highly effective, engaged, and empowered team with a culture of dignity and mutual respect. They have created a work environment of honesty, accountability, and a sense of "ownership" of responsibilities. Home office operations continued uninterrupted throughout the pandemic. On their own, our staff made a commitment to ensure that our office would not close its doors and that "with the IWMF, you are never alone."

I am proud to be part of this great team!

ROBERT A. KYLE CAREER DEVELOPMENT AWARDS

To achieve its strategic vision, the IWMF recognizes it is vital to provide funding to support the career development of next-generation researchers for WM. The IWMF is therefore proud to announce the establishment of the Robert A. Kyle Career Development Awards for WM. The Awards recognize the 50+ years of impactful contributions by Dr. Robert Kyle to the field of plasma cell disorders and WM.

In 2021, the first year of these awards, the IWMF has conferred research grants to two young investigators in the amount of $75,000 each year for a two-year project. A young investigator is defined as a junior faculty member (instructor or assistant professor) and/or postdoctoral fellow who has a focus in clinical research in the field of B cell or plasma cell malignancies. His or her program must have a teaching curriculum and mentoring with well-established investigators with track records in the B cell malignancy or plasma cell malignancy field.

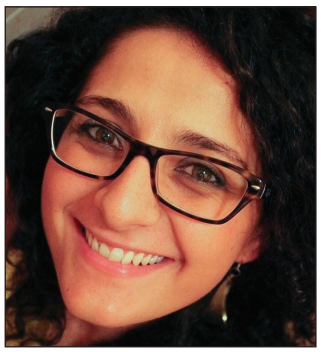
Dr. Tom Hoffman, IWMF vice president for Research and chair of the Research Committee, said "The IWMF has a long history of finding the best WM researchers in the world to do WM basic science research projects. Many of the drugs we have now are due to our past projects. In order to find newer drugs and possibly find a cure, we need to inject Dr. Kyle's work effort and excitement into the younger group of researchers. The Kyle award is an excellent way to do that. The two recipients we have chosen this year are the cream of the crop: Dr. Maria Luisa Guerrera and Dr. Romanos Sklavenitis-Pistofidis."

2021 ROBERT A. KYLE CAREER DEVELOPMENT AWARDS – RESEARCH SUMMARIES

By Glenn Cantor, IWMF Trustee and Science Editor

Maria Luisa Guerrera, MD, Dana-Farber Cancer Institute, Harvard University, Boston, MA

Isolation and spatial characterization of 6q deletions and CXCR4 mutations using novel biomarkers in WM



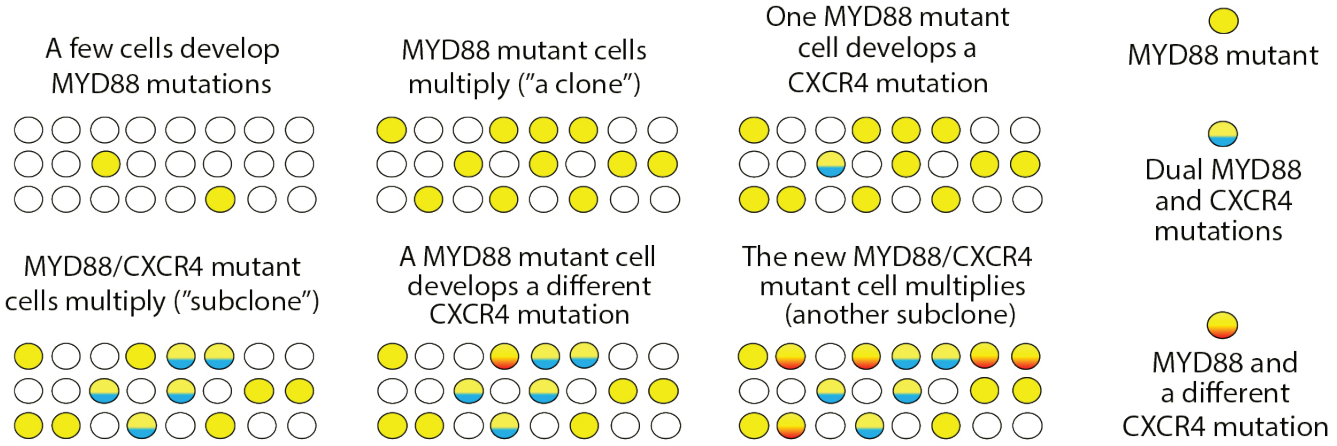
Dr. Maria Louisa Guererra

Cell division isn't a perfect process. In order for a cell to divide into two new cells, the original cell must duplicate its DNA, so that it can pass on a complete set of DNA to each of the new cells. As cells make new DNA, they sometimes make mistakes. Fortunately, cells can repair most of the mistakes in DNA. Many mutant cells are either poorly viable or are eliminated by the immune system. Sometimes, though, as a cell makes new DNA and divides, the mistakes affecting specific genes, called mutations, are passed on to the next generation of cells.

First, one cell has a mutation. Then, when it divides, two cells have the mutation. When each of those two cells divide, four cells have the mutation…and so on. Eventually, a large number of cells have the same mutation. These cells, which all share the same mutation, are called a clone. But the cells in a clone keep dividing. Eventually, one of the cells in a clone makes a mistake in a different area of DNA and develops a new mutation. Soon some of the cells from the original clone—but not all of them—have the new mutation. This is called a subclone.

The existence of subclones makes WM complicated. In most WMers, the MYD88 gene is mutated. However, if a scientist analyzes every one of the WM cells in a patient's body, they may find some WM cells that also have a second mutation, such as a mutation in a particular part of the CXCR4 gene. In some patients, there are subclones of different CXCR4 mutations. Some cells have one particular alteration in the CXCR4 gene, while other cells—in the same patient—have another alteration in the CXCR4 gene. On top of that, there may be subclones with third, fourth, or fifth mutations. Some subclones may have

PROGRESSION OF WM CLONES



Each circle represents a cell; each group of circles represents a number of cells in a WM patient at a certain time. Initially, there are only a few cells with the MYD88 mutation. Gradually, the MYD88 cells proliferate, forming a clone. Later, a cell with the MYD88 mutation develops a second mutation, in the CXCR4 gene. Cells with both the MYD88 and CXCR4 mutations proliferate, forming a subclone. Sometimes, another cell with the MYD88 mutation will develop an independent CXCR4 mutation in a different part of the CXCR4 gene. As these cells proliferate, the patient can have a second subclone, consisting of cells with the MYD88 mutation plus the second CXCR4 mutation. Not shown in this diagram are patients with a different gene alteration, deletions of the long arm of chromosome 6. Subclones can occur with MYD88 mutation and deletions in the 6th chromosome.

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other DNA modifications, such as deletions of certain areas of DNA which contain a large number of genes. A common deletion in many WM patients is in the long arm (called "q") of chromosome 6 and is called a 6q deletion.

Dr. Guerrera's project is to study subclones in WM patients. If a person has multiple subclones, each with different mutations or other DNA alterations, how does that affect the disease? Does one subclone of WM cells influence the growth of another separate subclone of WM cells? There is evidence that this happens. How can different subclones be separately identified in the best way, when they are all mixed together in the same patient's body? One of Dr. Guerrera's goals is to identify new biomarkers that laboratories can use to identify and isolate different subclones within a patient. And what about treatment? If a drug kills WM cells from one subclone, what about the other subclones? Is it a good idea to use combination treatments with one or more drugs? If so, which combinations, in which patients? How do the different WM subclones interact with the surrounding bone marrow microenvironment?

A principal goal of the Kyle Awards is to encourage and mentor young investigators so that a high level of WM research will continue in the future. Dr. Guerrera is a board-certified MD hematologist, currently in the fourth year of her postdoctoral research fellowship. She is working in Dr. Steven Treon's group at Dana-Farber, where she is also mentored by Drs. Zachary Hunter, Guang Yang, and Jorge Castillo. This rich environment gives her mentoring in molecular biology, computer analyses (called bioinformatics), clinical research, and clinical medicine, from some of the top people in the WM field.

Romanos Sklavenitis-Pistofidis, MD, Dana-Farber Cancer Institute, Harvard University, Boston, MA

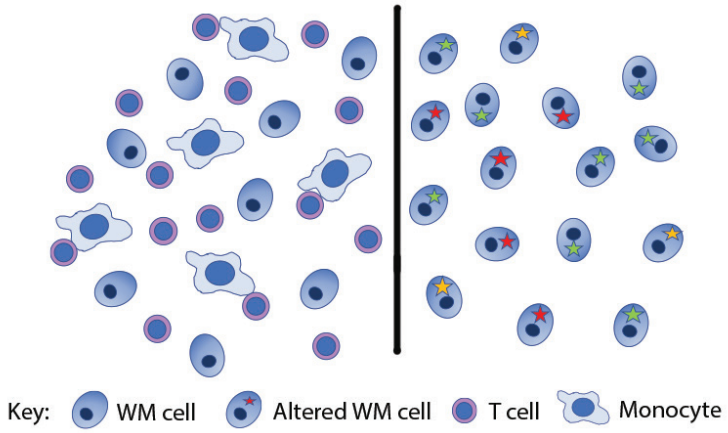
Dr. Romanos Sklavenitis-Pistofidis

Genomic and immune biomarkers of progression from IgM MGUS to WM

A common benign precursor to WM is called IgM-MGUS (monoclonal gammopathy of undetermined significance). Of all the people with IgM-MGUS, a small proportion will progress to WM. Many patients with WM are first detected before they show significant disease symptoms. The disease at this stage is sometimes called "asymptomatic WM" or "smoldering WM." The patients are monitored for disease progression without being treated, a strategy called "watch-and-wait."

Some IgM-MGUS or watch-and-wait WM patients never progress to symptomatic WM, or only progress after many years. Others, however, are not so fortunate and progress more rapidly to active, symptomatic disease that requires

HYPOTHESIS OF HOW WM INTERACTS WITH THE IMMUNE SYSTEM IN BONE MARROW – A HIGHLY SIMPLIFIED MODEL



Left: WM is well controlled in some asymptomatic patients. The immune system (monocytes and T cells) responds to the tumor. Right: In other asymptomatic patients, there is an "immunological desert," for which Dr. Sklavenitis-Pistofidis hypothesizes that some immune cell types such as monocytes and T cells are underrepresented in the bone marrow microenvironment, leading to immune evasion and disease progression. This may be due to alterations in the tumor cells, such as genetic, epigenetic, or transcriptomic changes, that help them evade an immune response. Different types of WM cell alterations are depicted by different colored stars. These patients may be the ones who progress to active WM.

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treatment. Which of these watch-and-wait patients are at high risk of progression and which are not?

Dr. Irene Ghobrial at Dana-Farber Cancer Institute at Harvard has hypothesized that these high-risk watch-and-wait WM patients might benefit from early treatment, to prevent progression to more active WM (for more details, see her article in the January, 2020 issue of the *Torch, https://iwmf.wpengine.com/wp-content/uploads/2020/10/Torch_January2020.pdf*). A key piece in this strategy would be to accurately identify which watch-and-wait patients are at high risk of progression to WM and which are not.

Several years ago, Drs. Sklavenitis-Pistofidis, Mark Bustoros, and Ghobrial published a system for predicting which watch-and-wait patients are at higher risk of progression to symptomatic WM *(https://iwmf.wpengine.com/wp-content/uploads/2020/10/Progression_risk_stratification_asymptomatic_WM.pdf)*. This system relied on clinical biomarkers such as the degree of bone marrow infiltration and the patients' levels of abnormal serum IgM. In the present proposal, Dr. Sklavenitis-Pistofidis will further refine their 2019 model, with the addition of genomic and immune biomarkers for better, more accurate prediction.

Specifically, Dr. Sklavenitis-Pistofidis will examine the WM tumor cells and their immune microenvironment in samples from bone marrow and blood from IgM-MGUS and watch-and-wait WM patients. The problem is that in the early stages, WM tumor cells are found only in small numbers, making it difficult to find and identify the tumor cells. To get around this problem, he will use advanced technologies such as genome sequencing, single-cell sequencing, and imaging cytometry to characterize patients' tumor and immune cells. He will also study the tumor cells' spatial interactions, to see which immune cells are close to the tumor cells within the bone marrow microenvironment. The study will use samples from the PCROWD project, a project run by Dr. Ghobrial that has been collecting samples and clinical information contributed by a large number of MGUS and watch-and-wait patients since 2014.

The goal of this work is to create a next-generation model to predict which IgM-MGUS or watch-and-wait WM patients will progress to more active, symptomatic WM. The model will incorporate clinical, genomic, and immune biomarkers. This information could be used to design a clinical trial to test whether these patients would benefit from earlier drug treatment. Furthermore, understanding the genetic changes and signaling alterations in the tumor and its surrounding immune cells in IgM-MGUS and early, asymptomatic WM may lead to more targeted drug therapy.

Dr. Romanos Sklavenitis-Pistofidis is a physician-scientist with expertise in molecular and computational biology and extensive research experience in the fields of multiple myeloma and WM. He is an instructor in Medicine at Dana-Farber Cancer Institute, at Harvard Medical School, and the Broad Institute at MIT and Harvard, where he leads a team in the laboratories of Drs. Irene Ghobrial and Gad Getz, who will serve as mentors for the project.

US LEGISLATIVE UPDATE

By Bonnie Beckett, IWMF Patient Advocate

The US legislative landscape for healthcare remains a moving target with a variety of bills introduced, some gaining more traction as they pick up co-sponsors in the House or Senate. The bills most likely to pass eventually first garner significant bipartisan support—a challenge in the current political climate. Information on bill status and co-sponsors changes frequently and would be outdated by the *Torch* publication date. Current information can be found at *www.Congress.gov* by entering the bill number, following the link to that bill, and selecting the appropriate tab to see a summary, the full text, the Congressional actions to date, and the number and identities of the co-sponsors. The STAT Act discussed in the last *Torch* issue's article has been introduced in the House and Senate (H.R. 1730, S. 670), and other legislation discussed below may directly affect many WM patients.

Bonnie Beckett on Capitol Hill

Drug pricing and Medicare update

One of the biggest concerns voiced by IWMF members in our Connect and Facebook groups is the high cost of prescription drugs, especially for those US members relying on Medicare. Given the typically older onset age of WM, Medicare is the primary or sole form of health insurance for many US members. Under current law, Medicare may not negotiate the price of prescription drugs for its beneficiaries, in contrast to private insurance companies and the Veterans Administration. The high cost of prescription drugs in the US has been the subject of

US Legislative Update, cont. on page 10

congressional hearings and also a key study by the US Government Accountability Office (a summary of which can be found at *https://www.gao.gov/assets/gao-21-282-highlights.pdf*).

[Medicare] ***Part D*** *has not kept pace with the needs of patients with life-threatening, chronic, and* ***rare diseases****.*

The US House and Senate have proposals for addressing these and other healthcare issues. The primary bills are the Lower Drug Costs Now Act (H.R. 3) proposed by the Democrats and the Lower Costs, More Cures Act (H.R. 19) proposed by the Republicans. Senator Bernie Sanders has also introduced three bills that cover international reference pricing (S. 909), drug importation (S. 920), and Medicare direct price negotiation (S. 908). President Biden mentioned Medicare negotiating drug prices in his joint address to Congress and has supported Medicare expansion to age 60, but these have not been included in his broad plans as of May.

A recent editorial by Amy Niles (vice president for Patient Access Network Foundation) and Michael Ward (vice president for Public Policy at the Alliance for Aging Research) offered some perspective on Medicare's prescription drug price benefit (Part D), which was created 15 years ago and is relied on by 46 million people. Part D has not kept pace with the needs of patients with life-threatening, chronic, and rare diseases. Medicare leaves many patients facing substantial out-of-pocket costs for physician visits, hospital stays, medical devices, and non-covered but essential services such as vision, dental, and hearing-related care. They cited a 2019 Kaiser Family Foundation study that showed an annual out-of-pocket cost of more than $8,000 for patients requiring a special medication.

Congress has considered in the past and is currently contemplating a number of options for addressing patient costs under Medicare.

1. **Capping** - Other US insurance beneficiaries have an annual cap or limit on what they owe out-of-pocket for their medications. Medicare has no cap. Various past and current proposals for limits have bipartisan support but offer differing cap levels (e.g., $2,000 or $3,100).
2. **Smoothing** - Part D results in high out-of-pocket costs at the beginning of the calendar year, leaving some patients unable to pay for medications. Smoothing would give the option of spreading these payments out in installments over the calendar year. This would potentially lead to better adherence to prescribed medication and reduced costs for hospitalizations and emergency care.
3. **Allowing Medicare to Negotiate Drug Prices** - Several Democratic proposals (H.R. 3, S. 352, and S. 833) would require the Department of Health and Human Services (HHS) to negotiate prices for certain drugs and establish rules for the negotiation process. A Republican-proposed bill (H.R. 19) opposes Medicare price negotiation, believing that it will lead to fewer cures and lifesaving medical breakthroughs by pharmacy companies.

While Democratic and Republican proposals contain some common features, fundamental differences make comprehensive changes unlikely in the near future. Even if agreement can be reached and legislation passed this year on areas of general agreement such as capping and smoothing, implementation is not likely before January 1, 2024.

Telehealth

Telehealth regulations also concern WMers, especially those on Medicare, who rely on seeing specialists and who have used telehealth during the pandemic. This concern extends to our members outside of the US who seek consultations with US specialists.

US federal involvement in telehealth mostly concerns Medicare. Prior to the pandemic, telehealth was limited to serving those in rural areas (originating site requirements), to certain providers, and under certain conditions. The pandemic's Public Health Emergency gave HHS and the Centers for Medicare and Medicaid Services (CMS) broad waiver authority, which was used to waive originating site restrictions and allow new patients to use telehealth, to add services, and more. HHS plans to ramp down the Public Health Emergency and end the waivers providing 60-days' notice, possibly by the end of 2021.

Many ***patients, providers,*** *and* ***Members of Congress*** *saw the benefits of* ***telehealth*** *during the pandemic...*

Many patients, providers, and Members of Congress saw the benefits of telehealth during the pandemic and would like to see some of the waivers made permanent. Three bills have been introduced in Congress that would make most waivers permanent and that have some bipartisan support:

- Creating Opportunities Now for Necessary and Effective Care Technologies (CONNECT) for Health Act (H.R. 2903, S. 1512)
- Telehealth Modernization Act (H.R. 1332, S. 368)

US Legislative Update, cont. on page 11

- Protecting Access to Post-COVID Telehealth Act (H.R. 366)

Extending the ability of physicians to practice across state lines raises more complex issues of safety and accountability. Currently state medical boards license physicians, nurses, psychiatrists, and other medical personnel to practice in that state. During the pandemic, some states granted temporary waivers for physicians licensed in other states to practice medicine in the state. As the pandemic wanes, many state boards are terminating the temporary waivers. These waivers, combined with telehealth options, meant that WM patients and others could, in many instances, be seen by WM specialists in other states via telehealth visits, even as new patients. Already some states and specialists have begun notifying WM patients that they can no longer use telehealth visits. Additional legislation addresses the issue of reciprocal licensing of physicians across states but faces many questions and concerns: Temporary Reciprocity to Ensure Access to Treatment (TREAT) Act (S. 168).

Several of the primary US treatment centers for Waldenstrom's continue to offer options for consultation to both US and international patients. Options that existed during the pandemic may no longer be available, so it is best to direct questions to the specific treatment center to verify current options for new vs. existing patients, consultation by your local physician with the WM specialist, consultation by the patient directly with the WM specialist, and so on.

BENEFIT Act

The Better Empowerment Now to Enhance Framework and Improve Treatments Act of 2021 (BENEFIT Act, S. 373) requires the Food and Drug Administration to consider patient experience, patient-focused drug development, and related data as part of its risk-benefit assessment for new drugs. This would include information developed by a product sponsor or a third party, such as a patient advocacy organization or academic institution. This action would send an important signal to all stakeholders that patient experience and data will be fully incorporated into the agency's review process and will encourage such entities to develop scientifically rigorous and meaningful tools and data. Updates to the Prescription Drug User Fee Act and several provisions in the 21st Century Cures Act helped ensure that the FDA has a number of programs and policies in place to evaluate the benefits and risks of potential therapies and to gather and assess patient perspectives.

MEDICAL NEWS ROUNDUP

By Sue Herms, IWMF Research Committee Member

Phase 2 Trial Begins for Ibrutinib, Rituximab, and Venetoclax Combination in Treatment Naïve WM/LPL – At press time, the US National Cancer Institute was anticipating the start of a Phase 2 randomized trial comparing the combination of ibrutinib (Imbruvica), rituximab (Rituxan), and venetoclax (Venclexta) to ibrutinib and rituximab in previously untreated patients with WM/lymphoplasmacytic lymphoma (LPL). The primary objective will compare the rate of complete responses in the two study arms. In both arms, ibrutinib will be dosed daily for 24 monthly cycles, while intravenous rituximab dosing will occur during cycles one and five. Those in the study arm with venetoclax added are to be dosed daily from cycles 2-24. After completion of study treatment, patients will be followed every three months for two years and then every six months for up to five years. The trial identifier on *www.clinicaltrials.gov* is NCT04840602.

French Researchers Analyze Phase 2 Trial of Obinutuzumab and Idelalisib in Relapsed/Refractory WM – A multicenter Phase 2 study from France analyzed the fixed-duration combination of obinutuzumab (Gazyva) and idelalisib (Zydelig) in symptomatic patients with relapsed or refractory WM. Obinutuzumab is an anti-CD20 antibody, while idelalisib is a PI3K inhibitor. Patients received the combination for six cycles, followed by a maintenance phase with idelalisib alone for a maximum of two years. Forty-eight patients were treated with the combination, with 27 patients participating in the maintenance phase. The best responses were reached after a median of 6.5 months, with an estimated overall response rate and major response rate of 71.4% and 63.3%, respectively. Median progression-free survival was 25.4 months. CXCR4 mutations had no significant impact on responses and survival, but TP53 mutations appeared to have an adverse impact on survival. The most frequent side effects were neutropenia (low neutrophil count), diarrhea, and liver toxicity, and 26 patients were removed from the study because of side effects. The study was published in the journal *Blood Advances*.

Preliminary Phase 1b Study Data Released for Combination of Mavorixafor and Ibrutinib in WM – X4 Pharmaceuticals released preliminary data from a small group of patients in its ongoing multicenter Phase 1b clinical trial of mavorixafor combined with ibrutinib (Imbruvica) in

Medical News Roundup, cont. on page 12

WM patients who have both MYD88 L265P and CXCR4 mutations. Mavorixafor is an oral small molecule antagonist of the CXCR4 receptor; in preclinical studies this drug was shown to sensitize WM cells expressing WHIM-type CXCR4 mutations to the use of BTK inhibitors. Of the seven patients enrolled, six showed a decrease in IgM after one cycle. At the time of this announcement, four patients had been treated for at least three cycles and experienced rapid decreases in IgM levels, achieving a median decrease of 51%. No serious adverse events were identified or led to study discontinuation, although one adverse event did result in dose reduction. Additional data are being presented at this year's European Hematology Association Annual Congress. The trial identifier on *www.clinicaltrials.gov* is NCT04274738.

Mavorixafor** is an oral small molecule antagonist of the **CXCR4 receptor**...this drug was shown to sensitize WM cells to the use of **BTK inibitors.

Treatment Patterns and Outcomes Discussed in Veterans Administration Study of Military Veterans with WM – A study from the Veterans Health Administration, published in the *American Journal of Hematology*, looked at real-world treatment patterns and outcomes in military veterans with WM from 2006-2019, separating them into two eras: early (2006-2012) and modern (2013-2019). A total of 318 patients were followed from first-line treatment until loss to follow-up, death, or the end of the study period, with 138 beginning therapy during the early era and 180 during the modern era. Few differences were noted in the demographic and disease-specific characteristics between the two eras, although modern-era patients had a higher level of co-morbidities. Overall, single-agent rituximab was the most common first-line therapy. Nucleoside analog-based and alkylating agent-based treatments and single-agent rituximab (Rituxan) dominated the early treatment landscape, but patterns after 2013 favored bendamustine-based and targeted therapy-based agents, with significant decreases noted in the use of bortezomib (Velcade)-based therapy and single-agent rituximab. The early era overall response rate was 70.0%, compared to the modern era at 74.1%. Median overall survival was 92.1 months for early era patients and was not yet achieved in modern era patients. Median progression-free survival was 43.8 months in the early era, compared to 52.8 months in the modern era.

University of Pittsburgh Medical Center Study Indicates Blood and Bone Marrow Cancer Patients Are at Elevated Risk of COVID-19 Vaccine Failure – An analysis by the University of Pittsburgh Medical Center has indicated that people with cancer affecting the blood, bone marrow, or lymph nodes are at elevated risk of COVID-19 vaccine failure and should continue wearing masks and practicing social distancing, even after full vaccination. Three weeks after their final vaccination, 67 patients with blood cancers who had been vaccinated with either the Pfizer or Moderna COVID-19 two-dose vaccines were tested, showing that more than 46% of the participants had not produced an antibody response. However, the research team also cautioned that a negative antibody test does not necessarily mean that the patient lacks all protection from the virus. The researchers also indicated that it is critically important for such patients to be aware of their continued risk and to seek prompt medical attention if they have COVID-19 symptoms, even after vaccination, and that they may benefit from outpatient treatments with monoclonal antibodies [such as Regeneron]. At press time, this analysis had not yet been published as a peer-reviewed journal article.

Clinical Trial to Analyze COVID-19 Vaccine Response in Multiple Myeloma and WM – Massachusetts General Hospital is sponsoring a clinical trial of COVID-19 vaccine responsiveness in patients with multiple myeloma or WM, slated to begin in September 2021 with 160 anticipated participants. The primary endpoint of the trial will be the effective immune response rate at 28 days following the second or final vaccine dose, as defined by a positive SARS-CoV-2 spike antibody test. WM participants will be categorized as to whether they are treatment naïve, actively receiving BTK inhibitor therapy, or are currently or previously treated with another therapy. On *www.clinicaltrials.gov*, the identifier number is NCT04830046.

LLS Study Is Looking at COVID-19 Vaccine Effectiveness in US Blood Cancer Patients – The Leukemia & Lymphoma Society (LLS) is collecting data on COVID-19 vaccine response in US blood cancer patients. Participants may sign up online and are asked to provide blood samples that will be drawn and tested for antibodies by LabCorp at any of its service centers—testing is free to participants, and the number of blood tests performed will depend upon the number of vaccine doses an individual has received. LabCorp will report results to LLS researchers and will make them available directly to participants. WM patients are eligible to participate, and the link to join the study is *https://www.ciitizen.com/LLSCOVIDStudy/*.

*...people **with cancer** affecting the blood, bone marrow, or lymph nodes are at **elevated risk** of COVID-19 **vaccine failure**...*

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NIH to Begin Clinical Trial of Immunocompromised to Assess Response to COVID-19 Vaccination – Meanwhile, the National Institutes of Health (NIH) in the US has begun a clinical trial of people with immune system deficiencies or dysregulations to assess how they respond to COVID-19 vaccination and anticipates enrollment of 500 participants, 400 with primary or secondary immune system disorders and 100 without such conditions to serve as a control group. All study visits can be conducted either in person at the NIH Clinical Center in Bethesda, MD, or remotely. Participants may be enrolled if they are completely or partially vaccinated against COVID-19, or if they intend to be vaccinated. If a participant has not yet been vaccinated, he or she will provide a blood sample to investigators seven days prior to receipt of an FDA-authorized COVID-19 vaccine. Study participants can receive any authorized COVID-19 vaccine in their local communities. Depending upon which manufacturer's vaccine a participant receives, additional blood samples will be collected between 14 and 28 days after the first dose. If a two-dose vaccine is received, repeat blood draws will occur after 3-4 weeks. Participants have the option to provide additional samples approximately six, 12, and 24 months after the last dose. These samples will permit the researchers to assess the persistence of vaccine-induced antibodies and T cell responses and to compare responses made by people with and without immune system disorders. If vaccine "booster" injections are recommended in the future, volunteers may choose to provide additional blood samples following those booster vaccines. On *www.clinicaltrials.gov*, the identifier number is NCT04852276.

Results Presented for Phase 3 Study of Copanlisib and Rituximab in Patients with Relapsed Indolent Non-Hodgkin's B Cell Lymphoma – Results were presented at the American Association for Cancer Research Annual Meeting 2021 from the Phase 3 CHRONOS-3 study of the PI3K inhibitor copanlisib (Aliqopa) combined with rituximab (Rituxan) and compared to rituximab plus placebo in patients with relapsed indolent non-Hodgkin's B cell lymphoma. Of the 458 participants, 307 received copanlisib/rituximab, and 151 received rituximab/placebo; the disease subtypes in the study included follicular lymphoma, marginal zone lymphoma, small lymphocytic lymphoma, and lymphoplasmacytic lymphoma/WM. Participants had relapsed following previous treatment with rituximab, a rituximab biosimilar, or another anti-CD20 monoclonal antibody. Patients also needed to be treatment free for at least one year since their last rituximab-containing regimen or treatment free for at least six months and unwilling or unfit to receive chemotherapy. At a median follow-up of 19.2 months, median progression-free survival with copanlisib/rituximab was 21.5 months, compared with 13.8 months in the rituximab/placebo arm. Progression-free survival benefit was observed across all disease subtypes. Adverse events occurred in 100% and 91.8% of patients on copanlisib/rituximab and rituximab/placebo, respectively. The most common such events in the copanlisib/rituximab arm were hyperglycemia (high blood sugar) at 69.4% and hypertension (high blood pressure) at 49.2%; serious neutropenia (low neutrophil count) occurred in 8.8% and pneumonitis in 6.8%.

First CAR T Cell Therapy Approved by US FDA for Relapsed Multiple Myeloma – The US Food and Drug Administration (FDA) has approved the first CAR T cell therapy for relapsed multiple myeloma. While prior such therapies have primarily targeted the engineered T cells to the CD19 marker, this is the first approval targeted to a marker called BCMA (B cell maturation antigen). The therapy is designated ide-cel (Abecma). The approval was based on results from the Phase 2 KarMMa clinical trial, which treated 127 relapsed/refractory multiple myeloma patients; 72% of patients in the trial partially or completely responded to ide-cel treatment, with 28% achieving a complete response. The expected side effects included cytokine release syndrome and neurotoxicity, occurring in 85% and 28% of patients, respectively, both of which were usually transient.

***Anktiva** is being explored to enhance the tumor targeting of **anti-CD20** monoclonal antibodies...*

New Agent Aims to Improve Rituximab Efficacy in Patients with Relapsed or Refractory Non-Hodgkin's Lymphoma – ImmunityBio, Inc. published results in the journal *Clinical Cancer Research* from its Phase 1 study evaluating the IL-15 therapeutic agent called Anktiva in combination with rituximab (Rituxan) in patients with relapsed or refractory indolent non-Hodgkin's lymphoma. The study enrolled patients with follicular lymphoma, marginal zone lymphoma, small lymphocytic lymphoma, and lymphoplasmacytic lymphoma who had received two or more prior lines of therapy. Anktiva is being explored to enhance the tumor targeting of anti-CD20 monoclonal antibodies and to determine the safety and efficacy of subcutaneous vs. intravenous administration. The combination was well tolerated in the trial, with an overall response rate in rituximab-sensitive patients of 78% and in rituximab-refractory patients of 40%. The combination induced the expansion, activation, and modulation of natural killer cells and CD8+ T cells.

US FDA Approves Umbralisib for Both Relapsed/Refractory Marginal Zone Lymphoma and Follicular Lymphoma – The US Food and Drug Administration (FDA) has granted accelerated approval to umbralisib (Ukoniq), an

Medical News Roundup, cont. on page 14

oral PI3K inhibitor, for the treatment of relapsed/refractory marginal zone lymphoma and follicular lymphoma. Approval was based on the clinical trial designated UTX-TGR-205, in which patients with marginal zone lymphoma or follicular lymphoma achieved overall response rates of 49% and 43%, respectively. Serious adverse reactions occurred in 18% of patients, most often from diarrhea-colitis and infections. The prescribing information includes warnings for adverse reactions including infections, neutropenia (low neutrophil count), diarrhea-colitis, liver toxicity, and severe skin rashes. The recommended umbralisib dose is 800 mg taken once daily with food.

The author gratefully acknowledges the efforts of Glenn Cantor, Grete Cooper, Steven De Cenzo, Peter DeNardis, Julianne Flora-Tostado, Tom Hoffmann, Pavel Illner, Meg Mangin, Colin Perrott, Howard Prestwich, Richard Savoy, Charles Schafer, Ron Ternoway, 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.*

DON'T DUMP IT – DONATE IT

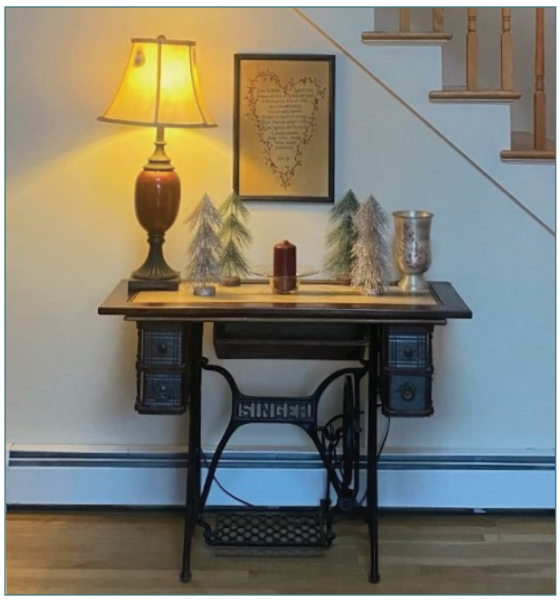
By Barbara Ulkus, Connecticut Support Group

When the pandemic hit and my husband Bob and I were sheltered in place, we decided to use the opportunity to take stock of our belongings, which included an abundance of well-loved, but unused, old furniture that had found a home in our basement. In other words, we would rid ourselves of our "treasures" and purge our stuff.

There in the dark corner sat an old dresser with a loose drawer, the rocking chair I used on many nights to calm my firstborn many years ago, and Bob's parents' dining room and kitchen tables and chairs. And nearby, covered with a sheet, was his great-grandmother Hannah's 1900s Singer sewing machine with a metal foot pedal. After a few moments of reminiscing and traveling down memory lane, we got to work finding the items a good home. We recalled the charming and quaint gift and furniture repurposing shop a few miles down the road, appropriately named Over AndOver Barntique (in Andover, CT) and gave them a call.

Within the week, the shop owners arrived at our home and loaded the furniture into the back of their pickup. As they were leaving, they mentioned their donation program: you donate furniture and they refinish the piece, sell it in their shop, and then donate a portion of the sale to the charity of your choice! As Wendy, the owner, says, "This is a feel-good program which enables a piece of furniture to live on, all the while avoiding the landfill, making another family happy, and generating funds to give back to the charity of one's choice." Of course, the charity of our choice was an easy one, our favorite—the IWMF.

Months later, I received an email from Wendy suggesting I check out a few photos she recently posted on the shop's Facebook page. Remember great-grandmother's sewing machine? The photo that was posted on the shop's page was of Hannah's dusty old sewing machine now transformed into a beautiful piece of furniture. It was repurposed into an entry way desk and purchased by a gentleman as an early Christmas gift to his wife. He also matched the amount of Over AndOver's donation to the IWMF! A win-win for all!



Repurposed: an antique sewing machine cabinet turned into a desk

In response, I posted the following comment on the shop's Facebook page in response: "Wow! This gorgeous restoration/repurpose of my husband's great-grandmother, Hannah's, sewing machine brings us much joy and pride. As a young bride, Hannah emigrated from Sweden to America with her husband and raised their family in CT. My husband remembers visiting her each Friday as a young child, sharing her warmth and love, a tiny teacup of coffee (with a little cube of sugar), and Swedish pastries (quite the treat for a youngster). I hope the gentleman's wife enjoys this gift, knowing it was once the precious possession of a lovely woman in a loving home."

Thank you to all who contribute to the IWMF, an organization near and dear to our hearts. Check out the Andover shop's updated website donation page, which now features this story and a nod to the IWMF at *https://www.overandoverct.com/donationprogram*. If you are ever in eastern Connecticut, pop into the shop, say hi to Wendy, and explore all the nooks and crannies filled with creative designs and furniture that have been loved over and over!

FROM IWMF CONNECT: SUMMER 2021

By Jacob Weintraub, MD

Now that summer weather is here, we are spending more time outdoors, but discussion on IWMF Connect continues unabated.

Subjects vary and span all aspects of our WM, including the ongoing coronavirus pandemic. I have not included discussion of coronavirus because of the rapidly changing nature of the science, and restrictions and information relative to WM are still somewhat limited. I strongly urge you all to join the group to follow developments and understand how they may affect those of us with WM.

We have personal interest items, ongoing discussions about current treatment—especially ibrutinib use and withdrawal—the use of antivirals, and medications for peripheral neuropathy (PN). You'll also find many links to current research articles, presentations at conferences, and support group meetings.

You are all invited to join IWMF Connect to participate or just "lurk" and absorb all the different experiences, observances, and opinions.

PERSONAL INTEREST

Chair of the Board of the IWMF and former IWMF Connect Manager Peter DeNardis continues to be active in the discussion. Peter has posted some links to very relevant personal interest and informational articles.

One link he posted is to an article about survivorship, with a story about a patient who had both male breast cancer and WM. This is a very moving article and includes many aspects of cancer treatment that we can relate to.

https://conquer-magazine.com/issues/2021/vol-7-no-1-february-2021/1514-my-story-male-breast-cancer-and-waldenstroem-s-macroglobulinemia

IWMF Connect Manager Julianne Flora-Tostado posted a link to a podcast, as well as an actual article about Kevin Tracey, MD. He was inspired by a patient's illness to study further, leading to the eventual discovery of monoclonal antibodies, something with which we are all very familiar, even if we haven't personally used them. Julianne's post was on May 14, 2021, if you want to look it up in the Connect archive.

https://www.medpagetoday.com/podcasts/anamnesis/92468

Dorrie I posted an article from the website 3 Quarks Daily about a nonscientist's adventure in studying immunology. It is titled "Accidental Adventures in Immunology." Though the author's immunologic condition isn't clear, her presentation on learning about B cells and T cells and other aspects of our immune system strikes a familiar note to some of us about how difficult it has been to learn fully about our WM and our immune system.

https://3quarksdaily.com/3quarksdaily/2021/02/accidental-adventures-in-immunology.html

Pavel I posted an article about "Change in Health Behaviors Affect Quality of Life in Lymphoma Survivors," by Andrea S. Blevins, PhD, MBA. We don't have a link, but the whole article was posted on May 21, 2021, so it can be viewed in the Connect archives. Pavel's comment was that if you read this article, you will discover that after you have been diagnosed you should quit smoking and start drinking to feel better. This is a prospective study of 2805 adult patients within nine months of a lymphoma diagnosis. There was a three-year follow up. Smoking at baseline and after three years was associated with significantly lower quality of life compared with people who never smoked. However, baseline "moderate" alcohol consumption (about 2.1 drinks per week) was associated with higher quality of life when compared with people who never use alcohol. The questionnaire used was "The Functional Assessment of Cancer Therapy-General Scale" (FACT-G, version 4).

*You are all invited to join **IWMF Connect** or just "lurk" and **absorb** all the different **experiences**, observances, and opinions.*

IBRUTINIB AND WITHDRAWAL

Lawrence F asked about coming off ibrutinib (Imbruvica). He had to stop taking it recently. A few days afterward, he became very sick with a high fever, dizziness, and feeling lightheaded. He had night sweats and decreased appetite. He asked if anyone else has had a similar problem.

Anita L posted that this has been reported to happen in about 15% of people who discontinue ibrutinib.

IWMF Trustee Tom Hoffmann posted that he does not think a person should quit ibrutinib "cold turkey." It can cause the side effects Lawrence has had. In some cases, an IgM flare can happen in addition to the side effects. Most do not have such severe side effects, but others do. It would be better to taper the medication, if possible, and taking steroids will help.

Richard S also answered. He said that, unfortunately, if a person is scheduled to have a colonoscopy or other

From IWMF Connect, cont. on page 16

procedure, or if a person has to stop due to an adverse effect like atrial fibrillation, it might not be possible to taper. A short course of steroid has been reported to help with the withdrawal symptoms.

Cathy H also reported on withdrawal symptoms. She was experiencing an irregular heart rhythm, and her local oncologist suggested she stop ibrutinib. The irregular rhythm abated, but on the third day, withdrawal symptoms started, with severe headaches, nausea, chills, body aches, and loss of taste and smell. It was completely debilitating. Her oncologist prescribed prednisone, but this provided little relief. On day seven, she resumed ibrutinib, and this relieved symptoms almost immediately. However, she had an IgM spike, and it took almost six months to get back to her previous IgM level.

SHINGLES AND PAIN TREATMENT

Shingles is a common problem for us. There are a multitude of treatments, antivirals for immediate treatment and then other modalities for those of us who have ongoing pain. This thread encompassed both of these aspects.

Jan B asked about gabapentin (Neurontin). She is taking that for shingles and was having a problem with dosage. She was initially prescribed 600 mg three times a day, but she was very disoriented, hands shook, and balance was off. When the dose was decreased, the adverse effects diminished, but at the end of the day, the pain from her shingles became worse. When she returned to the original dose, the adverse effects weren't quite as bad as before, but she still had shaking and twitching. She asked if others had similar problems.

Burka replied that after having a case of shingles despite having been vaccinated, gabapentin was prescribed, 100 mg three times a day. The dose reported by Jan is high, and Burka was not surprised Jan is having side effects. The antiviral acyclovir (Zovirax) was prescribed for her, as well as amitriptyline (Elavil) at bedtime to help sleep.

Eileen S also replied that she felt Jan's dose is fairly high, though Eileen knows how painful shingles can be. Eileen felt that taking an antiviral was at least as important as a medication for pain, which is what the gabapentin is for. She also suggested pregabalin (Lyrica) for pain. This medication is used often for nerve pain.

Beth C reported that she is taking gabapentin 600 mg, but only twice a day. However, it is for restless leg syndrome. She does not have shaking but does have to slow down for balance. It makes her feel like she is walking through soup. She tried the timed-release gabapentin, but it had a stimulating effect.

Tom Hoffmann added that gabapentin is most commonly taken as 300 mg four times daily. It can be prescribed up to 3,600 mg daily. Some people get a high or other side effects, but it has a very safe profile for the vast majority of patients at all levels.

Everett D posted that he takes he takes only gabapentin 100 mg at bedtime as suggested by his physician. This helps him get a restful night's sleep.

Lea H also suggested amitriptyline. She was prescribed this medication for back pain, and it not only helped the pain, but stopped her restless legs syndrome as well. She did have gastrointestinal side effects, including vomiting.

Finally, **Jan B** added that she had been taking valacyclovir (Valtrex) when the shingles was first diagnosed. She is not taking it currently. She only had a few blisters on her chest and back, mostly just red blotches on her arm where the majority of her pain is now. Even at her current dose of gabapentin, she has pain almost constantly, so changing to Lyrica might be a good idea and she will discuss it with her physician.

A parallel discussion then evolved around treatment of shingles and the shingles vaccine.

Dan W posted that he is now taking Valtrex 250 mg and has been for the last 2-3 years. He had treatment for his WM about a year ago. He asked how long can he keep taking Valtrex? Are there any side effects or long-term issues? What are his chances of getting shingles again if he stops it?

***Shingles** is a common problem for [WMers]. There are a multitude of **treatments**, antivirals for immediate treatment, and then other modalities for those of us who have **ongoing** pain.*

Anita L responded that she has been taking Valtrex for at least 12 years with no side effects. She had shingles in 2004 after her first treatment, which was fludarabine. She also suffered post-herpetic neuralgia for about a year. This was not fun! Valtrex was started in 2007.

Jan B posed the question about whether taking Valtrex prophylactically stops us from getting shingles, or does it just lessen the severity if we get shingles? She is currently suffering through her third shingles outbreak. Should she ask her doctor about taking Valtrex on a regular basis, since her immune system has been continuously compromised for the last three years? Her physician has never given her the okay to get the shingles vaccine.

Pat G added that she has never had shingles nor the vaccine, despite WM treatments. However, when she started taking venetoclax (Venclexta) she was told she would need to receive acyclovir for the rest of her life.

From IWMF Connect, cont. on page 17

From IWMF Connect, cont. from page 16

She called the manufacturer, who confirmed the need to take the prophylaxis even if she received the vaccine. She now has been taking Valtrex for three years without side effects.

Steven D posted that both medications [acyclovir and valacyclovir] are reported to be equally effective. He also said that the current vaccine, Shingrix, is different from the old vaccine, which we were advised not to take. Shingrix is not a live virus vaccine and is usually recommended for everyone.

In response to another question, **Sue Herms**, associate editor of the *Torch* and member of the IWMF Research Committee, said that she does not know of any studies specific to WM patients evaluating immune response to the Shingrix vaccine. She added that the original Shingrix trials showed an effectiveness of about 91-97%, depending on age. Older people, over age 80, have effectiveness at the lower end. However, these were participants with apparently intact immune systems. A subsequent study looked at patients with leukemia, lymphoma, and multiple myeloma, with about a third being in treatment at the time of the study. Overall effectiveness was around 87%, fairly close to the original study. There may be additional studies going on, so we will have to watch for this in the future. She also feels that our immune response to this vaccine will cover a spectrum, depending on our age, current or previous treatment, comorbidities, and type of treatment.

FAREWELL

Peter DeNardis posted news of the passing of another IWMF Connect member. Ann Tygart was diagnosed in 2009 and died recently from another, unrelated cancer. A message from her daughter said Ann wanted everyone to know that IWMF Connect provided invaluable information to her over the years and a chance to talk with others who have WM. Her daughter also was very appreciative of the help the group provided Ann over the years. Ann was a frequent contributor to our discussion list, always ready with kind and encouraging words and willing to share her experiences with the rest of us. She will be missed.

So, again, this is just a small sample of what is posted online in IWMF Connect. Everyone is welcome to join and participate, or just read the posts and benefit from the support and information. If anyone has any questions or wishes to see more on a particular topic, please contact me at *jmw003@aol.com*, and I will try to include those discussions in a future column. I wish you all continued good health.

SUPPORT GROUP NEWS

PLEASE NOTE

Contact information for all support groups is available at *https://iwmf.com/us-and-international-support-groups/*.

Details of support group meetings and other upcoming events are posted at *https://iwmf.com/events-calendar/*. Please check there to confirm details of future events.

CALIFORNIA

Monterey Bay

The Monterey Bay Support Group met on Zoom on April 18 for discussion. We sure have plenty to share! We seem to be merging with the South San Jose group, which is wonderful, but nothing is official yet. We will meet again the third Sunday in July. Maybe I'll find a speaker; you all are quite inspirational in that area. I like the Zoom platform for support, but I do think occasional meet-ups for socialization are important and on the horizon.

Suzie Shook reporting

CONNECTICUT

On Saturday, May 15, 2021, the Connecticut WM Support Group held our spring support meeting in the comfort of our homes. Twenty-four WMers and caregivers joined in a lively two-and-a-half-hour session filled with member health updates, announcements, and two guest speakers.

Dr. Nicholas Edgerton led a discussion on naturopathic medicine and acupuncture. His presentation was informative and offered insight on the value of natural healing, and

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the use of acupuncture in treatment. He answered many questions about naturopathic care, including evaluative tests, nutritional supplements, and how to develop a plan to address health needs, goals, and dietary choices. He shared his vision about the evolution of naturopathic medicine in our healthcare system. (Currently, 22 states, the District of Columbia, and the United States territories of Puerto Rico and the United States Virgin Islands have licensing or registration laws for naturopathic doctors.)

Prior to Dr. Edgerton's presentation, we were treated to a virtual visit from our own IWMF Board of Trustees Chair Peter DeNardis. Peter updated us on the latest IWMF news and participated in a lively discussion with us.

Despite the pandemic that changed our lives in 2020, our support group consensus is that the IWMF rose to the challenge and provided timely medical and educational information and offered continued support with new technologies applications, live educational webcasts, and resources. Thank you, IWMF! We look forward to our next virtual gathering in the fall. Details will be listed on the IWMF event calendar.

Bob Ulkus reporting

FLORIDA

Sarasota

The Sarasota Support Group met on May 14. We had an engaging conversation about WM treatment experiences and discussed how members are coping with the pandemic. We look forward to our next meeting, date TBD.

Michelle Postek reporting

South Florida

On April 10, the South Florida Support Group participated in a Zoom meeting program sponsored by the Leukemia & Lymphoma Society (LLS) and Memorial Cancer Institute as a virtual education program for patients and their families. The highlight of the meeting was a presentation by Dr. Steven Treon of the Dana-Farber Cancer Institute, followed by questions. Dr. Daren Grosman of the Memorial Cancer Institute participated. The impact of COVID-19 and the vaccine was also discussed.

Charlie Koch reporting

INDIANA

In Memoriam: Support Group Leader Sue Pruce

When the Indiana Support Group held its first meeting on July 16, 2011, Sue Pruce and her husband Frank were a part of that group. Sue was a nurse and an active contributor to the group.

Sue Pruce

She shared openly and cared deeply for WM patients and caregivers. Even when she was in the hospital during her transformation to diffuse large B cell lymphoma, we discussed announcing her struggles to the support group and she said, "Gayle, I am an open book." She surely was, never holding back her personal story if it would help another. She suggested for our next support group meeting to explore asking a WM physician to speak about transformation. Sue felt that WMers needed to know.

Sue became Indiana's support group leader in the fall of 2020 and led us into the COVID era of learning to meet through Zoom. We appreciated her dedicated work and her caring approach to all she did. Sue will be deeply missed. Thank you to Sue for all her contributions.

On June 17, Dr. Shayna Sarosiek, WM specialist from Dana-Farber, will present a Zoom program on Waldenstrom transformation. Indiana will be joined by the West Pennsylvania, Eastern Ohio, and Western Virginia Support Groups. Much information and conversation on the topic is anticipated, as well as the variety of Waldenstrom's questions asked during the question-and-answer period. Following the hour with Dr. Sarosiek, we will have our time of caring and sharing. The Indiana Support Group meets every three months, and while caring and sharing is a most popular meeting, we enjoy a speaker too. We look forward to learning a lot from Dr. Sarosiek.

Gayle Backmeyer reporting

Eastern Massachusetts Support Group

MASSACHUSETTS

Eastern Massachusetts

The Eastern Massachusetts Support Group has decided to hold Zoom meetings every two months until we can meet occasionally in person once again. Members who live farther from Boston have been able to join in, many for the first time, so the Zoom format has been helpful.

Recent meetings took place in February and April and consisted of members sharing their updates and questions

Support Group News, cont. on page 19

Michigan Support Group

with one another. At our April meeting, we discussed trying an evening meeting rather than our typical Sunday afternoon times. We also discussed inviting occasional speakers for future meetings.

Eileen Sullivan reporting

MICHIGAN

The Michigan Support Group of 12 met via Zoom to discuss progress and problems of living with WM and managing lives around COVID. Three new members to the group made the conversation very interesting, as we learned where members are in their journeys with WM. Jennifer Goldman shared several newer articles with the group from Cancer Care and the National Center for Biotechnology Information. She also shared the website *www.ciitizen.com/LLS/* for obtaining a voucher for free testing for antibody levels following vaccination for COVID. The group determined they want to meet about every 2-4 months via Zoom for now. Janice and Jennifer need to investigate venues for eventual in-person meetings that would allow all members to feel safe.

Janice Wheeker and Jennifer Goldman reporting

NEW YORK

New York City

Greetings from the New York Metro Area Support Group! We've been experimenting with much more frequent meetings on Zoom of 40 to 80 minutes' duration. We meet every third Sunday and every third Wednesday in between, so we're getting together to support one another every 10 or 11 days. The group is enjoying the more frequent meetings and making what appears to be excellent use of this experimental change of pace. We typically draw a group of between eight and a dozen participants. I know such a meeting schedule may not be ideal for all support groups but we are getting a lot out of getting together more often. The closeness generated by increased continuity has, so far, been a good change, and we will continue this way as long as the feedback is positive. Wishing the best to our fellow support groups as we continue through the age of COVID!

Mitchell Orfuss reporting

OREGON/SOUTHWEST WASHINGTON

On Saturday, April 17, 13 members of the Oregon/SW Washington Support Group were privileged to have the opportunity to hear Kerri Winters-Stone, PhD, and her research associate Kimi Daniel speak about their research work at Oregon Health and Science University (OHSU). Kerri is a research professor at OHSU school of nursing who focuses on using exercise to improve health and survival rates in cancer patients. Her studies are with breast cancer patients due to the large number of available study candidates. Her findings, however, cross over to individuals with any type of cancer.

Kimi led the group in a 20-minute basic exercise program that had everyone moving in front of their Zoom screens. Used daily, the immediate goal is for patients to avoid inactivity, even if the exercise is as little as 20 minutes a day. The long-term goal is total fitness for disease prevention: aerobic, resistance, flexibility. Both women strongly emphasized the vital importance of just moving and following a regimen that promotes gains in strength over time.

Kerri also provided tips on dealing with neuropathy and referenced studies which suggest that exercise may delay or lessen neuropathy during a course of treatment. The presentation was recorded and made available to all IWMF members.

Cindy Jordan reporting

Support Group News, cont. on page 20

PENNSYLVANIA

Philadelphia

Dr. Shayna Sarosiek

Forty-four WMers attended the Philly Support Group meeting on Sunday, February 21, and enjoyed a lively conversation with Dr. Shayna Sarosiek, Dana-Farber Cancer Institute's newest clinical addition. Our group benefited greatly from her highly informative COVID vaccine update and the helpful clarity of her message. We look forward to hearing more about DFCI's exciting research regarding WM and antibodies and the potential efficacy of the COVID vaccine.

Special thanks to Co-Leader Andrea Bensusan for leading an engaging group discussion about the ways we WMers are coping with the pandemic and being socially distant this past year. Many terrific ideas, fascinating hobbies, and helpful strategies were shared. Special thanks to Elly Levie and Carl Harrington for sharing their fabulous slides with us from their recent travels to Denmark to visit the newest addition to their beautiful family. We all felt a HUGE HYGGE HUG from their fun slide show!

The Leukemia & Lymphoma Society and the IWMF partnered again! On Wednesday, April 7, LLS hosted a patient education program for over 50 attendees on new treatments in Waldenstrom's macroglobulinemia with Dr. Edward A. Stadtmauer, section chief of Hematologic Malignancies, Penn Medicine. This event featured a wonderful panel of WM patients and caregivers—all fun friends from Philly's IWMF support group! Bravo to Roy Langhans, Jim and Bette Ortoleva, and Judie and Laurence Elliott for sharing their experiences with WM.

On Sunday, April 11, 38 WMers participated in "Step into Spring," with renowned nutrition, wellness, and fitness expert Stacy Kennedy, MPH, RD. This phenomenal meeting, "WM and Wellness," covered: What is the best eating plan for WMers? Can nutrition and exercise help reduce fatigue? How much is too much sugar? Can we go back safely to the gym? The program included a lively Q&A and group sharing with WMers from across Pennsylvania, New Jersey, Washington DC, Maryland, and Virginia! Enjoy the video here: *https://us02web.zoom.us/rec/play/HZyrNWYoPXtv4aF5VSbqLoO6D8Kzx-R8CqunM_d2pMPjr28zllanZ9wltpn13z1EzXvdrYkTvP8uWAQn.U2yfGtGeTjHD4WLJ?continueMode=true* (Passcode: Uik^d34S)

Retired IWMF Board Chair Carl Harrington with grandson Miles

Lisa Wise and Andrea Bensusan reporting

Western Pennsylvania, Eastern Ohio & West Virginia

At the end of February, twenty members enthusiastically gathered on Zoom for a winter get-together to share their WM updates. It was a delight to welcome five new attendees who joined in the discussion, contributing to the spirit of group support. Peter DeNardis, support group member and newly elected chair of the IWMF Board, highlighted recent IWMF initiatives. The expansion of IWMF services is quite impressive!

The support group reconvened again on Zoom in April with ten members attending. Participants shared a wide range of WM experiences, ranging from watch-and-wait status, treatment anticipation, and remission with various therapies. Many expressed the personal benefit of consulting with a WM expert as a key part of their care. We had an engaging discussion about life after COVID vaccination that reflected concerns about our degree of immune protection and hope for a return to meaningful activities safely.

Marcia Klepac reporting

TEXAS

Dallas & Northern Texas

The Denton Area and Dallas Support Groups met jointly via Zoom on March 20 for a conversation with Dr. Ankit Kansagra from UT Southwestern Medical Center. Dr. Kansagra updated the group about his ongoing research for WM and promising treatments, now and in the near future. He then spent significant time responding to questions from the group. The SG leaders received very positive comments from members about his knowledge of WM and his obvious passion for his research and work with WM patients.

Twenty WM patients and caregivers joined the meeting with two very recently diagnosed WMers attending. Time at the beginning and end of the presentation offered members opportunities for updates and to respond to specific questions from our newest members. Support group leaders agreed that the joint meeting via Zoom was a productive way to bring together WMers from Austin, Dallas, Fort Worth, the Denton Area, and Oklahoma for a special program without some having to drive long distances to attend.

Cathy Hartman and Steve Pine reporting

Support Group News, cont. on page 21

Support Group News, cont. from page 20

Houston

The Houston chapter of the IWMF has had two outstanding speakers within two months. On March 13, Dr. Shayna Sarosiek, the newest associate at Dana-Farber with Dr. Jorge Castillo, spoke on the promising research of Dr. Steven Treon's team. Fourteen families joined the presentation on WM updates on therapies and new ideas on treatment. She was wonderful!

On Tuesday, April 27, neurologist and nutritionist Dr. Madhureeta Achari enthralled the group of 18 on a Zoom meeting with information on "Food for Thought: The Essential Nutrition for Optimal Health." Her talk was quite interesting and very well received. Co-Leaders Dr. Barbara (caregiver) and John Manousso (WMer) will hold the next Zoom Houston Support Group meeting with a medical provider TBA for Thursday, June 24, at 7pm. For more information, call (713) 557-1010 or email *WM@manousso.us*.

Dr. Madhureeta Achari

Barbara Manousso reporting

WASHINGTON

Seattle Area

Ten members of the Seattle Area Support Group met on Zoom on March 25, and as usual, we enjoyed sharing information and support. We were happy to welcome Betty Walters, in Kodiak, AK, as she could not find an Alaska support group to join. Next time, we are looking forward to meeting and hearing from Dr. Mary Kwok, hematologist-oncologist, who has joined Seattle Cancer Care Alliance. We are sorry to hear that Dr. Ed Libby is retiring, for he has been a great support to us over the years. Thank you, Dr. Libby! The meeting will be on June 30 from 6 to 8pm, and for many of us, we will be sharing information as well as enjoying our dinners too. A virtual picnic!

Shirley Ganse reporting

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

AUSTRALIA

BioGene applies to the TGA to have zanubrutinib listed as a subsidised therapy

In July 2020, the Therapeutic Goods Administration (TGA) accepted the first two zanubrutinib applications for evaluation. The applications were for patients with mantle cell lymphoma (MCL) who have received at least one prior therapy and patients with WM who have received at least one prior therapy or in first-line treatment for patients unsuitable for chemo-immunotherapy. Consequently, in March 2021, BioGene requested the inclusion of these two applications in the Pharmaceutical Benefits Scheme (PBS).

Both relapsed and refractory MCL and WM are rare and incurable diseases. Given the current treatment situation, a significant unmet clinical need exists for effective and well-tolerated therapies for patients with these two conditions.

Efficacy of COVID-19 vaccination in people with Waldenström macroglobulinemia and follicular lymphoma - COVAX-lymphoma study

This research study will collect information on how well people living with follicular lymphoma (FL) or WM respond to the COVID-19 vaccination. The study aims to see what kind of immune response patients with FL and WM have to the COVID-19 vaccine, compared to people who do not have these disorders. Forty patients have been recruited to receive the Pfizer COVID-19 vaccination. Blood samples will be taken at the first vaccination and the second vaccination after three weeks. Further blood samples will be taken at three months and six months. The study is being conducted at Concord Repatriation General Hospital in Sydney and is jointly funded by Concord and the IWMF.

Patient-entered data in WhiMSICAL Registry published in leading haematology journal

The WhiMSICAL registry, built through a patient-clinician investigation partnership, is a global database for WM patients to enter their own data. Results of the WhiMISCAL study have just been published in the prestigious *American Journal of Hematology*. Highlights of the study so far include:

- Little consistency in first-line therapy choice globally, with 46 different types of therapy given.
- USA patients commence their first therapy almost three times faster than the rest of the world.
- First-line bendamustine/rituximab has outperformed the Bruton tyrosine kinase inhibitors (e.g. ibrutinib, zanubrutinib) and rituximab alone in time-to-next-treatment. The findings are preliminary, however, without

Internationa Scene, cont. on page 22

exact matching of the groups. More participants and longer follow-up of existing participants are needed to confirm these exciting preliminary results.

- Patients on BTK inhibitors report better quality of life scores than those who recently received other treatments.

More patients on WhiMSICAL are needed to strengthen these results.

Michael van Ewijk reporting

Kathy Fulham and Peter Freese - OZ First COVAX-lymphoma study participants. They are both WM patients, and both are on the WMozzies Committee.

CANADA

Canadian SG meeting highlights

A Canadian support group leaders' meeting was held on March 30. Daniel Zlatin provided important information on how to post and market meetings for our website as well as membership list updates and considerations for in-person/hybrid meetings after COVID.

At our national Zoom meeting held on April 7, Ron Ternoway from Atlantic Canada and Joe Lewicki from British Columbia each gave a brief summary of their experiences in clinical trials. Ron spoke about his current experience on the LOXO-305 (pirtobrutinib) trial, and Joe spoke about his experiences on three separate clinical trials. Their talk was very encouraging for all WMers to seriously consider clinical trials for treatment options.

Special thanks to Lisa Dickie (Southwestern Ontario) for participating as a panelist on the IWMF Fatigue Support Session. Her personal story dealing with fatigue was very helpful and much appreciated.

New support group leaders

Elsebeth Hansen-Kriening and Vivian Kachanoski (both from Winnipeg) have volunteered to start a new support group for Manitoba and Saskatchewan. Go to our website (*www.wmfc.ca*) for updates on this exciting news. Other new support group co-leaders are Brenda Rogers (British Columbia), Murray Shaw (Eastern Ontario), and Margaret Seliskar (Toronto/Southern Ontario).

Atlantic Canada Support Group

We will continue to have "sharing" Zoom meetings every six weeks until the pandemic is in the rear-view mirror. We discuss local COVID updates, current challenges in our health system, clinical trials, and drug updates, as well as summaries from those who have attended the most recent IWMF/WMFC webinars and/or presentations. The meetings are lively with lots of great discussion and very appreciated by those who attend. On May 12, 15 people attended the support group Zoom meeting—13 "Bluenosers" (residents of Nova Scotia) and Paul and Liz Kitchen from New Brunswick.

Paul Kitchen has made great strides in his Walk for WM to support WMFC Research Month. His efforts have received international publicity. The moral and financial support he received has been quite impressive.

Jim Mason and Ron Ternoway reporting

British Columbia Support Group

The newly tagged BC (formerly Vancouver) Support Group has been meeting monthly on Zoom for the last year. We have a tight-knit group of "veteran" WMers who meet each month. We have been checking in with each other, sharing our stories, and growing closer doing so. We genuinely look forward to seeing each other. As we hold our meetings on Zoom, we can expand our reach to those in all of BC, thus the name change. The last few months our numbers have been growing, and we are welcoming new members, those newly diagnosed and those who have lived with WM for years. It is a lively bunch who share encouragement, support, and a lot of laughs. Our plan is to continue to meet monthly.

Brenda Rogers reporting

Eastern Ontario Support Group

The Eastern Ontario (formerly Ottawa) Support Group met in February and April by Zoom. We are so fortunate to have the technology to keep in touch with each other. On the other hand, it would be nice to be face-to-face with our group! That, too, will come. In Ontario we experienced a "Stay at Home Emergency Order." The updating of the WMFC membership list will, hopefully, encourage other WMers to participate in our support group. Finally, you can read about new Co-Leader Murray Shaw on the IWMF Stories of Hope.

Janet Parcher Cherry reporting

Toronto/Southern Ontario Support Group

The Toronto/Southern Ontario Support Group Zoom meeting held on April 23 was a "sharing" meeting with 37 participants, ten of whom were new! Margaret Seliskar was introduced and welcomed as a third co-leader. Dr. Christine Chen from Princess Margaret Hospital joined the session and provided some recent updates regarding BTK inhibitors (ibrutinib, zanubrutinib, and acalabrutinib). Of particular interest was

International Scene, cont. on page 23

International Scene, cont. from page 22

First meeting of the China WM workshop

that zanubrutinib is now approved for WM in Canada. She also gave a brief update on her research (partially funded by WMFC) which may provide a blood test in lieu of a bone marrow biopsy. A lively Q & A followed her presentation, which was moderated by Margaret.

Betty McPhee reporting

CHINA

Establishment of China's WM workshop
Representatives from 55 hospitals and institutes in China attended this first meeting and witnessed establishment of China's WM workshop on March 20, 2021, in Tianjin, China.

China's WM workshop is jointly led by Prof. Yi Shuhua from Hematology Hospital of Chinese Academy of Medical Sciences and Prof. Li Jian from Peking Union Medical College Hospital. Prof. Qiu Lugui, Prof. Li Jianyong, Prof. Ma Jun, Prof. Zhao Weili, and Dr. Steven Treon serve as advisors.

Roger Yao, from China's WM support group, and Hong Fei, from House086 patient group, joined China's WM workshop as special guests. In this meeting, Roger, as the founder of China's WM support group, introduced its history and the main concerns of WM patients. Roger appreciated this milestone event in WM in China, stating that the WM support group will collaborate with hematologists and institutes to promote WM education and caring activities.

Roger Yao reporting

NEW ZEALAND

Our WM-NZ attendance numbers for the second IWMF global affiliates Zoom meeting doubled in size to two, with Duncan Kay joining me at the meeting on April 29. Duncan has agreed to be the assistant affiliate leader, for which I am very grateful. We have been working together for some time now, and he brings expertise in areas I do not have.

New Zealand has a good percentage of patients enrolled with WhiMSICAL (the Australian worldwide data registry for WM), so it was good to see the presentation by Professor Judith Trotman and Dr. Ibrahim Tohidi-Esfahani of the WhiMSICAL group. I sent out the recruitment and presentation flyers to the NZ list and since then have used the Zoom licence, given by the IWMF for our affiliate's use, for two one-on-one meetings, helping one person to update and another to join WhiMSICAL.

Matthew Eby, support person for Leukaemia & Blood Cancer NZ in the South Island except Southland, organised the first Zoom meeting for our NZ WMers. We are grateful, as with only 39 members at the time, we are very few and mostly not living near others. For those of us who were able to join Matt, the meeting was productive. We introduced ourselves and discussion led the way. Great to put faces to people. It was almost like meeting in person, except for the lack of travel worries, being safe in our homes, and we could grab a coffee or tea and sit in our comfortable chairs. Our WM-NZ has since climbed to 43 patients, and Matt intends to hold another meeting soon.

Leukaemia & Blood Cancer NZ has also arranged for Auckland haematologist Dr. Samar Issa to give a webinar on WM later this year.

Lea Hullett reporting

Internationa Scene, cont. on page 24

UNITED KINGDOM

WMUK has had a busy quarter, with new Chief Executive Jane Nicholson starting in March. Jane's previous experience at the Clatterbridge Cancer Charity has already been invaluable in pushing forward the charity's work in supporting people living with WM in the UK.

Patient support survey results
In early May, we asked our community to tell us how we can improve our services. We had brilliant feedback from patients and family members about the types of information and support that they need. From this feedback, we are proud to announce our pledge to our community:

- We will create a one-stop website to help you easily find the information and support services you need;
- We will produce information that is both detailed and easily digested about the topics that concern you most;
- We will continue to create a supportive and positive community, where you can meet and talk with others in similar situations and get the support you need.

This pledge will inform all our work over the next year.

New support services
In February, we launched our popular virtual support groups. Since then, our new patient support manager, Bob Perry, has expanded the range of groups to cater to parents living with WM and to carers. We also have a series of regional-based groups springing up virtually.

In tandem with our support groups, Bob has been busy scheduling webinars with expert consultants. Covering subjects as diverse as cardiology, COVID-19, and mental health, the webinars aim to give patients, family members, and friends an opportunity to hear directly from experts. If you have missed a webinar, or want to watch it again, you can find the recordings on our website at: *https://www.wmuk.org.uk/support/finding-support/wmuk-webinars*.

Find and register for upcoming webinars and support groups at: *https://www.wmuk.org.uk/get-involved/whats-on*.

Fundraising
We have some brilliant fundraisers currently raising money on our behalf, from Ken, who is jumping out of an airplane, to Kate, who is running 100 km in a month, and to Michael, who is cycling in memory of his mum.

In October, we have three brave fundraisers taking on the virtual London Marathon—running 26.2 miles in one day!

A huge thank you to every donor and fundraiser supporting the charity; we really could not do what we do without you.

COVID-19 update
As of May 2021, the UK has lessened lockdown restrictions. People from different households can now meet inside, and shops and services are reopening after many months of closure. The vaccination programme continues to roll out, and many WM patients are reporting that they have had their second vaccine dose. However, despite this, there is still a sense of caution about returning to normal routines.

WMUK continues to monitor the situation alongside our WM experts to provide the most accurate and up to date advice and information on the vaccine and virus. To read more, see: *https://www.wmuk.org.uk/support/Waldenstroms/covid19*

Patient outreach
The charity is focussed on reaching as many UK patients as we can. Currently we know there are about 3,000 patients who possibly are not aware of our services and might be looking for expert information or personal support. We are working on reaching out to haematology departments across the country to provide packs and leaflets to ensure every patient knows we are here for them.

Patient-Doctor Summit 2021
After last year's event was cancelled due to COVID-19, we are excited to announce that the summit will be back in 2021. The event will be held entirely online and although the information will be focussed on the UK, anyone is welcome to join. The date is Saturday, 13 November 2021.

More details will be forthcoming over the next months, but in the meantime please register your interest by emailing us: *info@wmuk.org.uk*.

Kat Tucker reporting

BETWEEN APRIL 1, 2021, AND JUNE 1, 2021, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

Patricia Burdick
Lester Burdick

Lee Ann Fausnaugh
Jamie & Matt Bertram
Bob & Sherry Dunning
Brian Rapp
Don & Peggy Wenneman

John P. Flanzer
Mrs. Gloria Flanzer

H. Anne Jack
Alison Greif
R. William Jack

Christine MacKeown
E. Valerie MacKeown

Alfred Mathurin
Diane Mathurin

W. Thomas Myers, Jr.
Bob & Rebecca Spencer

Valerie Petelin
Chris and Terri Haws

Linda Pochmerski
Carl Harrington

Rocco J. Policastro
Josephine Policastro

Susan Pruce
Gayle and John Backmeyer
Kristine Mangano
Katie Stell
Jessica Wegmann
Ashley Zichelli

Ralph G. Richard
Katharine Richard

Scott Trippel
Ryan & Jessica O'Hare

Ann Tygart
Susan Hill
Leola Keiser
Stephen and Mary Zafer

Marcia Wierda
Timothy and Sidney Hoesch
Betty TerHaar

Diane Yedwab
Steve and Alyce Pine

PLANNING AHEAD – IDEAS FOR GIVING IN 2021

This past year was filled with difficult choices, but your determination to support our mission through charitable giving was unwavering. Thanks to your donations, the IWMF's commitment to supporting everyone affected by WM while advancing the search for a cure has only strengthened in the face of the global pandemic. COVID has impacted almost every aspect of our lives—our priorities, our plans, and for many, to whom and how we give. In the United States, Congress has extended some of the COVID relief tax changes into 2021. The IWMF has compiled the following information to help you with your tax planning and to offer some ideas for you to consider if you are thinking about making a gift in 2021.

2021 GIVING INCENTIVES

The CARES Act passed in 2020 included several charitable tax provisions to encourage giving. Congress has extended these provisions for 2021, including:

- A deduction for charitable donors who do not itemize when filing their tax returns. If you do not itemize but make a cash gift to charity, you will be allowed to take a special tax deduction, up to $300 ($600 for joint filers), to reduce your tax liability.
- An increase in the deduction limit up to 100% of a donor's annual income for cash gifts (previously the deduction was capped at 60% of annual income). If you make a gift, you will be able to deduct more this year.

DONOR ADVISED FUNDS

If you have a Donor Advised Fund (DAF) and wish to help us this year, you can make a gift from your DAF to support our work without affecting your personal financial security.

DONATING APPRECIATED ASSETS

If you itemize, appreciated non-cash assets held more than one year may offer an additional tax benefit compared to donating cash. You can claim a deduction for the fair market value of an asset, and it is possible to eliminate the capital gains tax you would otherwise incur if you sold the asset and donated the cash.

CHARITABLE BEQUESTS AND PLANNED GIVING

Many of our friends are updating their estate plans. If you would like to support the IWMF with a charitable bequest, we can help.

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 a 401k or IRA), or a life income agreement such as a Charitable Remainder Trust. There is no minimum requirement to join the Ben Rude Heritage Society, and these planned gifts represent an important component of the IWMF's financial future.

Please contact Jeremy Dictor, IWMF director of Development and Communications, at *JDictor@IWMF.com* or call our offices at 941-927-4963 for a free estate planning guide. We can provide you with a copy of our bequest language to assist you with creating and updating your plans.

IMAGINE A CURE: A WORLD WITHOUT WM

2021 EDUCATIONAL FORUM UPDATE

GET READY FOR ED FORUM MONTH!

With the uncertainty of the COVID-19 pandemic, the IWMF Scientific Advisory Committee recommended moving the in-person event in St. Louis to April 2023 and going completely virtual this year. Now you can attend all Ed Forum sessions from the comfort of your home! Plus, all of October will be Ed Forum Month, so you can enjoy informative sessions throughout the month.

Earlier this year, the IWMF surveyed the full IWMF community to learn what Ed Forum topics would be most important, and your 2021 Ed Forum Planning Committee is designing an educational program with sessions to address the most popular topics within three specific categories: disease information, treatment options, and coping/getting support.

Ed Forum Month kicks off with two half-day workshops leading up to the two-day Ed Forum, October 28 and 29. An "Understanding WM" workshop on Wednesday, October 6, will deliver basics on diagnosis, symptoms, treatment guidelines, blood and bone marrow tests used to help diagnose WM, understanding basic science, and WM genomics.

A "WM and Self-Care" workshop on Wednesday, October 13, will cover the impact of cancer-related fatigue on quality of life, how to manage fatigue, finding balance in dealing with the stress of medical uncertainty, and tips to strengthen and protect the immune system.

As always, a faculty of leading WM healthcare professionals will deliver accurate and current science to help you better understand WM and learn about the latest breakthroughs in WM treatments and care. A preliminary agenda for both workshops and the Ed Forum are available at the Ed Forum page on the IWMF website, *https://iwmf.com/iwmf-educational-forum/*, and Ed Forum Month registration details will be announced shortly.

WALK FOR WALDENSTROM'S

Walk with us toward a world without WM

Join us for the

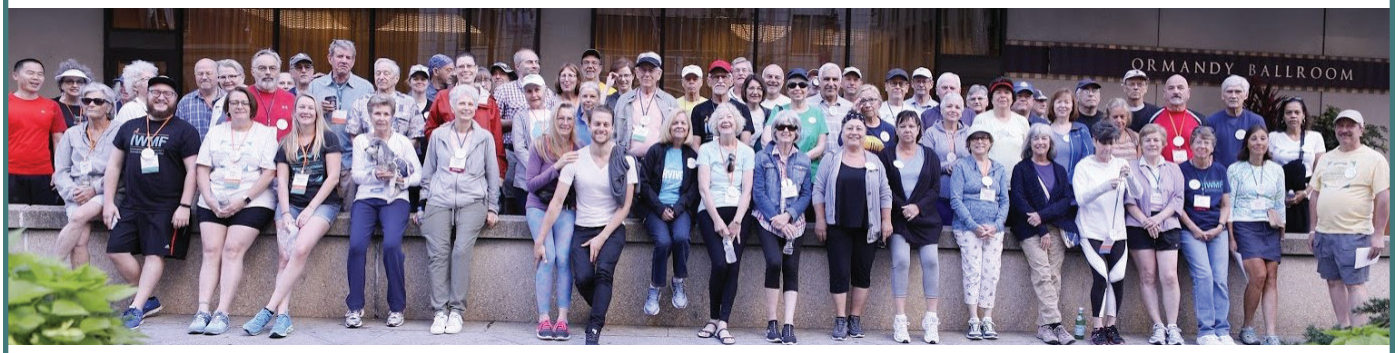
2021 *Virtual* WALK FOR WALDENSTROM'S

and walk with us toward a world without WM!

OCTOBER 29, 2021

There is no fee to register or attend.

Visit ***www.IWMF.com*** for more information or contact Jeremy Dictor (*JDictor@IWMF.com* / 941-927-4963)



Walk for Waldenstrom's participants at the 2019 Ed Forum in Philadelphia

International Waldenstrom's
Macroglobulinemia Foundation

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