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I HAVE WALDENSTROM MACROGLOBULINEMIA — WHY SHOULD I GET MY EYES CHECKED?

BY MAUREEN HANLEY, OD



Editor's Note: Dr. Maureen Hanley has been a long-standing faculty member at the New England College of Optometry. She is presently co-master of the Ocular Disease Principles Course. This is a one-year sequenced course in which she lectures on glaucoma, vascular disease, optic nerve abnormalities, pupils, cornea, cataracts, and visual fields.

After earning her Doctor of Optometry from the New England College of Optometry, Dr. Hanley completed a residency in hospital-based optometry at the West Roxbury VA Medical Center. Dr. Hanley has practiced at many clinical sites, most recently at the Uphams Corner Community Health Center and the Boston Healthcare for the Homeless. She spent the majority of her patient care experience as an attending optometrist in the VA Boston Healthcare System.

This article is dedicated to the memory of Alice Riginos. Alice edited the first article I wrote, "Waldenstrom and the Eye," in the January 2011 *IWMF Torch*. You can find it online at <https://www.iwmf.com/sites/default/files/docs/publications/Hanley.pdf>. In 2018 she asked me to write a follow-up article. I said I'd be happy to when I had some time during my busy schedule. Unfortunately, that never happened before her passing, but Alice: here it is.

I suggest reading that first article before this update just to re-familiarize yourself with all the terms and the basics of eye findings in Waldenstrom macroglobulinemia (WM).

Let us look at a few cases. These are all real-life patients.

Patient 1:

A 53-year-old white male was diagnosed with WM with a symptom of fatigue. His IgM was approximately 10,000 mg/dL, and serum viscosity (SV) was 9.0 centipoise (cp). His vision was fine, but he went for an eye examination because he knew there was some risk to his eyes with WM.

Upon presentation, his vision was very good at 20/20 in his right and left eye, but retinal hemorrhaging and cotton wool spots were noted in both eyes. Cotton wool spots are caused by lack of oxygen to the top part of the retina, the nerve fiber layer. They are named this because they look like fluffy cotton or fluffy wool. As the concentration of IgM increases, the blood gets thicker, and this creates a rise in the intravascular pressure within the retinal venous circulation. Impairment in the retinal circulation produced his hyperviscosity-related retinopathy.

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Figure 1. Right eye.

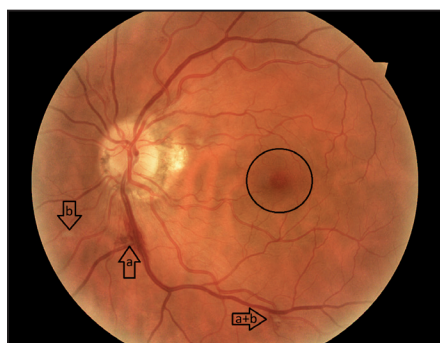


Figure 2. Left eye.

Note the retinal hemorrhaging (a) and cotton wool spots (b) in both eyes in Figures 1 and 2. The vision is still good because the macula region (the area in the black circle) is clear of retinopathy. The patient had retinal problems, but as he was asymptomatic, he was unaware of them.

Six weeks and five plasmapheresis treatments after Patient 1's first eye examination, his IgM had temporarily lowered to 2,600 mg/dL. You can see the large improvement in his retinal findings in Figures 3 and 4. Note that the diameter of the retinal veins (the darker colored vessels) are thinner and the amount of hemorrhaging is considerably less.

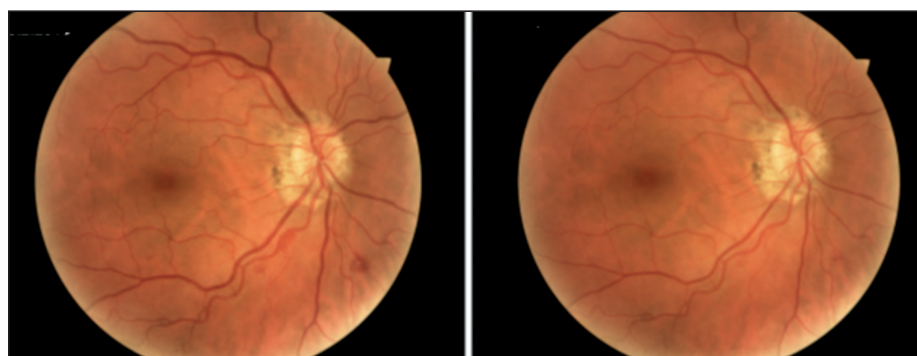


Figure 3. Right eye before plasmapheresis on left and six weeks after plasmapheresis on right.

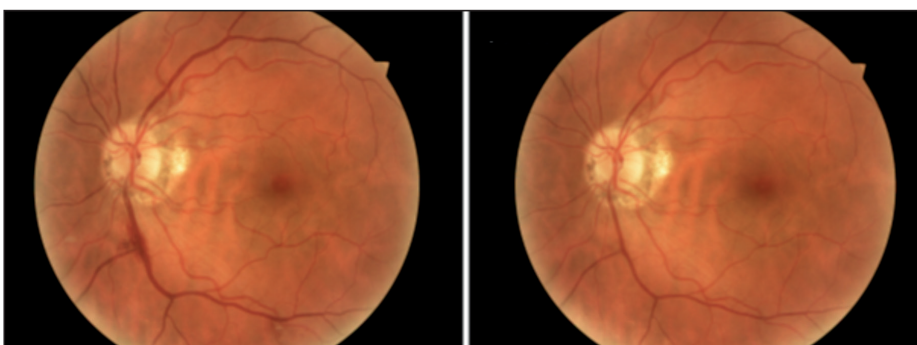


Figure 4. Left eye before plasmapheresis on left and six weeks after plasmapheresis on right.

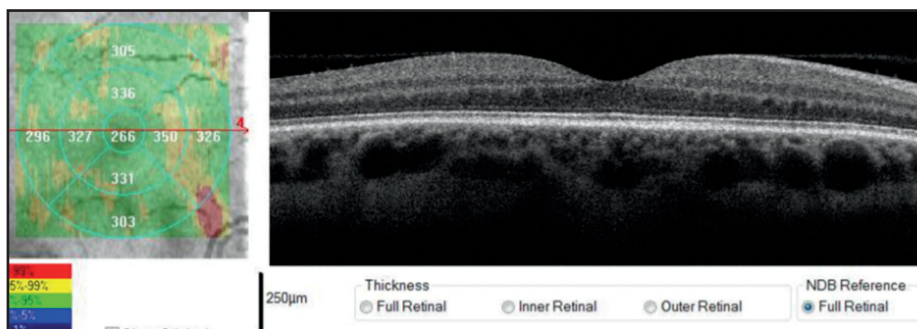


Figure 5. This is the OCT scan of Patient 1's macula. It has normal shape and contour.

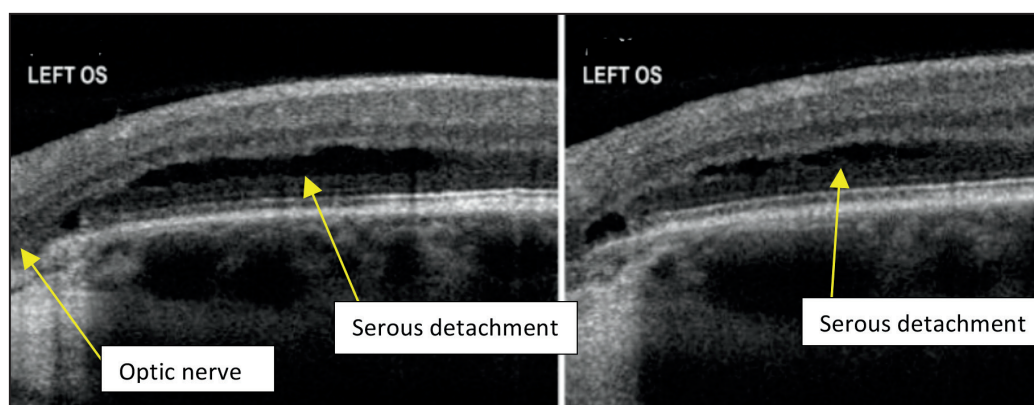


Figure 6. This is the OCT scan of Patient 1's optic nerve. The original left eye scan is on the left, and the one six weeks later is on the right.

Optical coherence tomography (OCT) is a non-invasive imaging test. OCT uses light waves to take cross-sectional pictures of your retina. It takes less than a minute per eye to get a wonderful image of the deep structures in the eye.

Although the OCT scan of the macula region in Figure 5 was fine at his first eye examination, the OCT scan of Patient 1's optic nerve in Figure 6 showed a serous detachment adjacent to the optic nerve, which was markedly improved after six weeks.

So we ask, what did this patient gain from having an eye examination? If he had not had treatment for WM, his eyes could have developed a full blown central retinal vein occlusion, possibly resulting in permanent vision loss. Lowering the serum viscosity decreased the stagnation of blood in the retinal vessels and allowed the hemorrhages to reabsorb before permanent damage could result.

Patient 2:

This 62-year-old white male with no prior diagnosis of WM went to his optometrist for a routine eye examination for a new pair of glasses. To the patient's surprise, upon dilating his eyes the optometrist saw hemorrhages in the periphery of his retinas as seen in Figures 7a and 7b. The optometrist was able to see the hemorrhages on the wide field Optomap—a camera used to image the peripheral retina. When an eye doctor sees peripheral retinal hemorrhaging, WM is not the first thing that comes to mind. Diabetes, anemia, and carotid issues are usually the primary causes for peripheral hemorrhaging in a 62-year-old male. The eye doctor called the patient's primary doctor to discuss the patient's findings, and routine tests were ordered to determine the cause.

These tests include checking blood pressure, a CBC with differential, fasting blood sugar levels, hemoglobin A1C, sedimentation rate, C reactive protein, a cholesterol panel, and usually a basic metabolic panel looking at renal, liver, heart, and bone function. If those come back normal, we think of a second line of testing, which usually includes inflammatory markers, coagulation markers, serum electrophoresis, and

possibly a carotid Doppler test. Which tests we order really depend on the patient. Certainly, each doctor may have a different order of testing or may order additional tests.

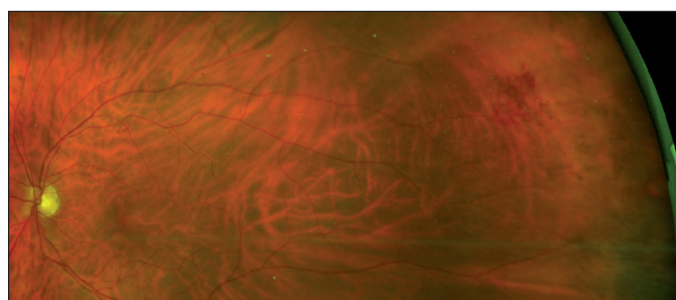


Figure 7a. Optomap of Patient 2 with hemorrhage in the far periphery.

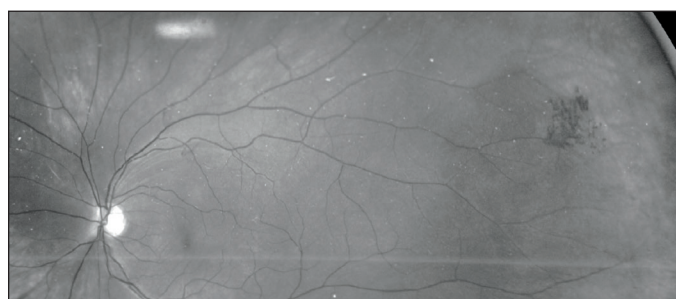


Figure 7b. Same patient but using a special autofluorescence filter.

Naturally we ask about trauma and if the patient is on any medications associated with retinal hemorrhaging, like interferon and anticoagulants. This patient had all these tests and they were normal—until the serum protein electrophoresis was performed, and it was discovered that the patient had an IgM of 5,600 mg/dL. After a bone marrow biopsy confirmed the diagnosis, the patient was treated for WM.

Going for an eye exam helped him get diagnosed and treated before more serious problems with hyperviscosity could occur.

Patients 1 and 2 both had high IgM and high serum viscosity. Normal serum viscosity (SV) is 1.4-1.8 cp. For reference, the SV of water is 1.

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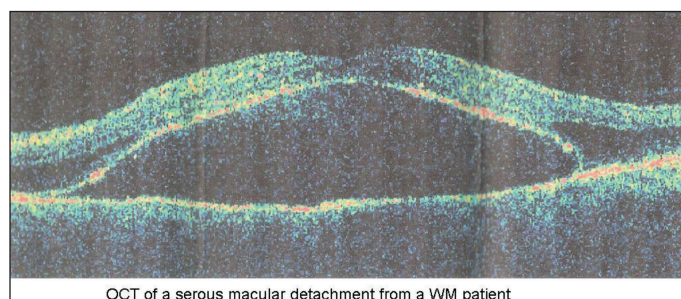


Figure 8. WM patient with WM maculopathy. Note how this does not look like the normal macula in Figure 5.

Marcel Menke (Menke et al., 2006) showed that retinopathy has been noted in patients with SV as low as 2.1 cp, but on average the peripheral retinal hemorrhages and dilated vessels were noted with a mean IgM 5,442 mg/dL and mean SV of 3.1 cp. Retinopathy in the posterior pole (the area where the macula and optic nerve rest) had a mean IgM of 8,515 mg/dL and a mean SV of 5.6 cp. The conclusion was: on average the higher your IgM, the greater your chances of having retinopathy.

In Menke's study the highest IgM reported without retinopathy was approximately 5,500 mg/dL.

All WM patients are different. There are patients who can have IgMs above 6,000 mg/dL, and we have not been able to detect retinopathy even with scleral depression of the peripheral retina.

You may ask, what has changed since 2011 when the first *Torch* article on WM and the eyes was written?

1. The basics are still the same, but ocular imaging has greatly improved, and OCT is now present in almost all eye care practitioners' offices. The image quality of these diagnostic tests has also greatly improved, though scleral depression is still the best way to see the most peripheral of retinal hemorrhages.

2. The maculopathy of WM can cause a serous detachment in the macula and lead to moderate or severe vision loss. Compared to ten years ago, many more cataract surgeons are doing OCT of the macula on their pre-op exams for cataract surgery. Certainly, every cataract patient with WM should have an OCT of the macula to make sure that vision loss is from the cataract and not from WM maculopathy. This maculopathy is very hard to detect unless you have an OCT, and occasionally it can occur with few or no hemorrhages.

It is my professional opinion that all WM patients with elevated IgM, certainly above 3,000 mg/dL, should have an OCT of the macular region, especially if they have unexplained visual acuity loss. The best way to treat WM maculopathy is to treat WM.

3. Bortezomib (Velcade), a proteasome inhibitor, was thought to be associated with meibomian gland dysfunction. Meibomian glands are located in the eyelids, and their openings or orifices are along the rims of the eyelids. The glands produce an oily/lipid substance that helps prevent evaporation of the eye's tear film. We now know that Velcade causes a

marked increase in chalazions (bumps on the eyelid caused by blocked meibomian glands) and blepharitis (inflammation of the eyelids). A study by Bonnie Sklar (Sklar et al., 2019) claims "the specific pathogenesis of blepharitis and chalazia secondary to proteasome inhibitor therapy is unknown, but is postulated to be related to inflammation. Bortezomib is a proteasome inhibitor that inhibits the ubiquitin [a small protein] proteasome pathway leading to the accumulation of pro-apoptotic molecules and thereby apoptosis [programmed death] of neoplastic cells. Accumulation of degraded proteins in the meibomian glands may lead to eyelid complications."

4. Some patients with WM retinopathy and/or WM maculopathy have been treated with anti-vascular endothelium growth factor (anti-VEGF) intra-vitreous injections, such as bevacizumab (Avastin). The literature shows mixed results; some patients have had fair results, but others have been totally refractory. Treating the WM itself remains the first-line treatment when it comes to WM-related retinopathy.

5. A retrospective study in Sweden by Kari Hemminki (Hemminki et al., 2016) confirmed that WM patients have a higher incidence of glaucoma (2.1 times) and cataracts (1.85 times), something that was always suspected but not actually confirmed.

6. Many WM patients also suffer from dry eye, and there are now many more treatments and diagnostic tests for this condition.

7. We also know a lot more about Bing Neel syndrome (occurring in about 1% of WM patients), a condition in which the WM cells invade the central nervous system (the brain and spinal cord). Eye doctors are more frequently watching for signs and symptoms of Bing Neel, including optic atrophy, facial nerve problems, eye movement problems, and neurological visual field defects.

As I am writing this, we are in the middle of a COVID-19 pandemic, and conjunctivitis can be a first sign of COVID-19, or the red eye can be "regular old" conjunctivitis. So, my last bit of advice is for everyone to stay safe and call your eye doctor if you have any ocular problems.

Hemminki, Kari, et al. "The Incidence of Senile Cataract and Glaucoma is Increased in Patients with Plasma Cell Dyscrasias: Etiologic Implications." *Scientific Reports*, vol. 6 28500. 22 Jun. 2016, doi:10.1038/srep28500

Menke, Marcel N. "Hyperviscosity-Related Retinopathy in Waldenstrom Macroglobulinemia." *Archives of Ophthalmology*, vol. 124, no. 11, 2006, p. 1601, doi:10.1001/archophth.124.11.1601.

Sklar, Bonnie A., et al. "Management and Outcomes of Proteasome Inhibitor Associated Chalazia and Blepharitis: A Case Series." *BMC Ophthalmology*, vol. 19(1) 110. 14 May. 2019, doi:10.1186/s12886-019-1118-x.

Forty-six additional references can be seen in this article's digital copy on the IWMF website's "Best of the Torch" page: <https://www.iwmf.com/library/best-iwmf-torch>

CEO'S CORNER

BY NEWTON GUERIN

Today, Tomorrow, and Beyond

At the IWMF, we take great pride in meeting head-on the opportunities and challenges that impact the lives of people dealing with WM. It has been almost a year since the IWMF Board of Trustees began a discussion and debate around organizational priorities. It was clear that much more could be done with additional resources and a renewed sense of focus and urgency. We needed to tell our story to all IWMF stakeholders: patients, caregivers, donors, volunteers, Board members, corporate partners, and the research and medical communities. We needed a plan!

That led to the creation of our “Compelling Intentions” (our version of a strategic plan) that spells out what we must do to move toward our vision of “A World Without WM.” It talks about big ideas, it’s simple to understand, it’s optimistic, and it focuses on the future.

During its recent June meeting, the IWMF Board examined and talked through our progress in bringing that plan to life. We looked at new and unexpected opportunities and challenges that are coming our way. Our “Compelling Intentions” provide guidance and direction and remind us that our ability and capacity to undertake these important goals is dependent on how nimble and tenacious we are. We must also demonstrate the courage necessary to navigate through these very difficult times. Just three months ago, none of us ever imagined the challenges we would face.

Being nimble has enabled us to deal with a variety of situations, problems, decisions, and technologies. Our biggest decision was to cancel our 25th Annual Ed Forum. The safety and health of our patients, caregivers, and Ed Forum faculty was our number one concern. The tenacity of our Ed Forum Committee has resulted in plans for a Virtual Ed Forum to take place August 27 and 28, 2020. Plans are also in the works for a series of webinars dealing with some of our most pressing topics. We have partnered with ON24, a virtual meeting platform vendor, to enable us to use new technology to deliver the same important information about the latest WM research, along with the most current updates about new therapy options. This virtual format will help us reach a much larger global audience than we have in the past.

COVID-19 has forced us to look at things differently. In several situations, that has allowed us to connect with stakeholders in ways that we haven’t before. Many of us have become much more familiar and comfortable with Zoom than



Newton Guerin

we ever thought. This includes your Board, which has been conducting its meetings virtually. To make sure that we stay connected as the IWMF community, support group leaders throughout the country are now engaging their members through meetings via Zoom. The results have been amazing!

The Board also reviewed and approved funding for two new Strategic Research Roadmap project grants. Our Roadmap has become a global effort, with IWMF international affiliates in Canada, Australia, and France now partnering with us to fund and expand our research efforts. Here’s how WMFC Board Chair Paul G. Kitchen described the importance of this partnership:

“The Board of the WMFC (Waldenström's Macroglobulinemia Foundation of Canada) is very pleased to support a research project that is focused on the Epigenomic Roadmap. The IWMF’s Grants Review Committee, comprised of some of the best WM researchers from all over the world, evaluated all the projects that were submitted to their annual Request for Proposals. The Canadian WM community wants to put every dollar of its research money to best possible use, so this year the Board has unanimously agreed to pledge \$200,000 to help complete a research project on the Epigenomic Roadmap. If the world WM community can work together and make the best possible decisions on supporting research, the cure will be found sooner.”

We are extremely appreciative of the support from Canada, Australia, and France and are in conversations with other international affiliates to encourage their participation as well. IWMF research has resulted in key discoveries that have led to novel therapies to treat WM. Our ultimate goal remains to find a cure for WM!

Donor confidence in the IWMF remains strong. Over 600 individual donors raised \$132,000 in 24 hours through the Giving Challenge in April. Support from our corporate and pharmaceutical partners has never been stronger, with almost \$400,000 this year alone in sponsorships to fund some of our most important programs, including: the 2020 Virtual Ed Forum, support groups, publications, and translations of publications into foreign languages. In addition, their support will fund the design and launch of our new website to better meet the needs of the WM community worldwide.

We are very proud of our top rating from Charity Navigator (the largest watchdog agency for nonprofits in the US). The IWMF achieved a Charity Navigator overall score of 95.59 on a scale of 100, and a 100 rating on accountability and transparency. This is the IWMF’s third consecutive 4-star rating from Charity Navigator. Fewer than 25% of the organizations reviewed by Charity Navigator have received

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this ranking three years in a row. This clearly reflects our strong commitment to good stewardship of our donor dollars.

As our Board works through its commitment to transition from operations to governance, I have taken on the responsibility for preparing this quarterly message from the IWMF leadership. I want to recognize and thank IWMF Board Chair Carl Harrington, who, over the last several years,

has delivered this message so eloquently himself in his role as chair.

Overall, we are now in a good place, and our future is very bright. Thank you for being part of our IWMF community.

I wish you and those you love good health!

– Newton Guerin

RESEARCH IS THE IWMF'S CONTINUING SUCCESS STORY

BY GLENN CANTOR, SCIENCE EDITOR

Editor's Note: As most people familiar with the IWMF know, research and education are two of the three main reasons for its existence. The IWMF's mission statement is: "Support and educate everyone affected by Waldenstrom's macroglobulinemia (WM) while advancing the search for a cure."

This is the first in a series of articles to introduce each research project currently being funded by the IWMF. The project summaries have been written by IWMF Research Committee Member and IWMF Torch Science Editor Glenn Cantor. The Foundation believes that it is important to educate our members about our research program because the projects that we are funding now will hopefully lead to a better understanding of the disease, better treatments for it, and a cure in our future. Two esteemed physicians associated with the IWMF offer their opinions in the accompanying sidebars about the importance of the Foundation's work in advancing the search for a cure.

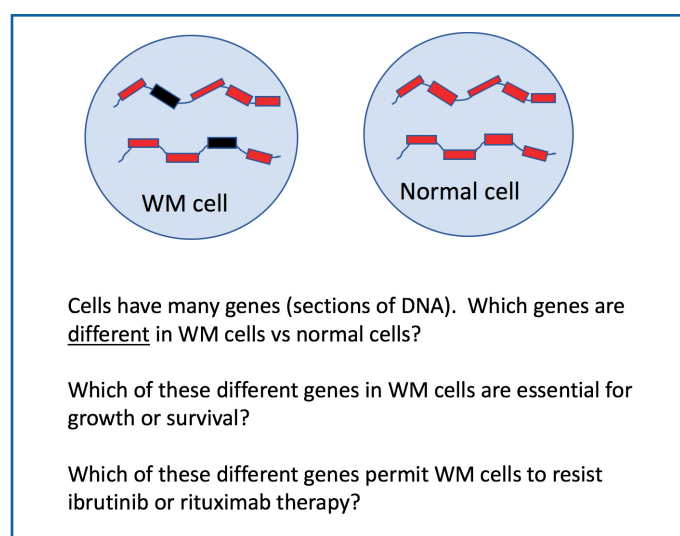
The first project is from Dr. Constantine Mitsiades of the Dana-Farber Cancer Institute, Harvard University:

CRISPR-based Functional Characterization of WM Cells: Insights into Therapeutic Vulnerabilities and Strategies to Overcome Resistance

Summary:

- This research takes advantage of new technologies, including the gene-editing tool CRISPR, to conduct a broad search to identify specific genes that allow WM cells to thrive.
- The key is to identify specific gene targets that cause death of WM cells, but do not alter normal body cells.
- This research will hopefully identify new, previously unsuspected molecular targets for WM therapy.

Many of the drugs used for WM target specific molecules in the WM cells. While the existing drugs provide benefit to many patients, there is clearly a need to identify additional targets and new drugs. Dr. Mitsiades and his group at Dana-Farber Cancer Institute at Harvard have proposed a fresh approach to



identify additional new drug targets. They propose to expand the prior work through a broader examination of numerous genes that could be involved in survival or proliferation of WM cells, including genes that have previously not been suspected. Identifying a new set of crucial genes in WM cells could lead to discovery of new drugs.

Dr. Mitsiades and his group propose to take advantage of several new technologies, including CRISPR, improved computational approaches, and new animal model techniques. The group has considerable experience using these technologies with a related cancer, multiple myeloma. In this new research, they propose to extend their experience to WM.

CRISPR technology is a tool for editing genomes. Dr. Mitsiades' team will use CRISPR for inactivating genes in WM cells grown in the laboratory. The CRISPR is targeted to specific genes by a sequence called "single guide RNA" (sgRNA). Dr. Mitsiades proposes to use a very large collection (termed a "library") of sgRNAs, each with a random sequence. In this way, the group can target many, if not all, of

Research, cont. on page 8

the genes in the WM cells. By using a large number of WM cells, each individual cell is only transfected with one or a few individual CRISPRs, each with unique sgRNA. When a sgRNA with a random sequence happens to target a gene in a WM cell, that gene is cut and inactivated. If that particular gene is essential for growth or survival of the WM cell, the WM cell dies. Using advanced molecular and computational techniques, investigators can identify the sgRNA sequences in the WM cells that died. From that knowledge, they can identify crucial genes. Some of these genes will be genes that are essential for any cell, and if a drug is targeted to these gene products, all of the cells in the body would die. Such a drug would probably be unacceptably toxic. The key to avoid toxicity is to identify specific gene targets that cause unique death of WM cells, but do not alter normal body cells. This is done by counter-screening the CRISPR library against a large panel of non-WM cells.

The *in vitro* CRISPR technology is not only useful for identifying genes that allow WM cells to thrive in the body, but also for identifying genes that allow WM cells to resist established therapies. For example, patients often develop resistance to ibrutinib or rituximab. In a second part of the research, Dr Mitsaides' group will attempt to use the CRISPR technology to identify novel genes that permit these resistant cells to survive. This could provide new targets for WM patients who become resistant to existing therapies.

Any genes identified will be further tested and validated in laboratory cells ("in vitro") using other methods. If successful, the genes then will be tested in a living animal system ("in vivo"). Mice will be implanted under the skin with human bone-forming cells, which grow into small nodules of bone and bone marrow. These human bone nodules have been shown to support the growth of other human cancers, including human multiple myeloma, in mice. The bone nodules will be injected with WM cells, which are either intact or have deletions of the genes identified by CRISPR. If the newly-identified genes are in fact important, the researchers predict that the WM cells in

the mouse model will either not grow, or will not be resistant to established therapies.

Successful completion of this project will hopefully identify new, previously unsuspected molecular targets for WM therapy. Drugs that inhibit these new targets may be already available for other types of cancers and could be re-purposed for WM patients. Alternatively, with new knowledge of novel molecular targets, drug discovery and development efforts could be initiated to generate new WM drugs.

The second project is from Drs. Marcel Spaargaren, Steven Pals, and Marie José Kersten from the Amsterdam UMC, University of Amsterdam, the Netherlands.

Towards a Rational Targeted Therapy for Waldenström's Macroglobulinemia by Kinome-Centered Loss-of-Adhesion and Synthetic Lethal Screens

Summary:

- One way that ibrutinib works is by dislodging WM cells from the bone marrow where they grow best.
- This research seeks to identify specific proteins that allow WM cells to be retained in the bone marrow.
- Identifying these proteins can help determine if existing drugs may be re-purposed to treat WM, or could lead to development of new drugs specific to WM.

Ibrutinib is a mainstay of treatment for many WM patients. Unfortunately, not all patients respond to ibrutinib, and sometimes those who respond initially develop resistance later. The IWMF-sponsored research of Dr. Marcel Spaargaren and his group at the University of Amsterdam, the Netherlands, seeks to identify new molecular targets in WM, which could lead to new drugs.

Dr. Spaargaren's group evaluates proteins called kinases, which are important in cell signaling and other key cellular processes. BTK, the target of ibrutinib, is one kinase, but there are more than 600 other kinases in the human body.



Dr. Marcel Spaargaren (back row, second from the left) and the research team

Dr. Spaargaren's group will evaluate if there are additional kinases that would make good drug targets for WM patients.

Researchers have found that WM cells grow best in the bone marrow. The bone marrow environment provides essential growth and survival factors for the WM cells. Dr. Spaargaren's group has hypothesized that one way that ibrutinib inhibits WM is by disrupting signals that allow WM cells to move into and then remain in the bone marrow. Upon disruption of these signals, the WM cells are dislodged from the bone marrow and move to the blood, where they are deprived of the essential growth and survival factors that they need, causing the WM cells to die. A major area of Dr. Spaargaren's research is to identify specific kinases that enable WM cells to remain in the protective bone marrow environment. These kinases could be good targets for novel WM drugs, either in combination with ibrutinib or in ibrutinib-resistant patients.

In related work, Dr. Spaargaren's group also seeks to identify molecular pathways that allow some of the ibrutinib-treated cells to survive. Cells that survive ibrutinib treatment may have developed alternative pathways that allow them to overcome the effects of ibrutinib. The investigators hypothesize that if key molecules in these alternative, compensatory pathways are inhibited at the same time as ibrutinib therapy, then ibrutinib would be more effective.

In previous IWMF-funded research, Dr. Spaargaren and his group identified a set of kinases with potential as new WM drug targets. In the present grant they will continue this work. They will first attempt to validate the targets recently identified in their previous IWMF work using lab-based cellular tests. They will also work to identify any new targets that emerge. Then, they will evaluate the role of these targets in living animals, using mouse tumor models. This will be done using WM cells in which the target kinase genes have been eliminated, or by using experimental drugs to inhibit the kinases. WM cells do not grow well in mice. Instead, Dr. Spaargaren's group will use a different in vivo system, in which mice are implanted under the skin with human bone-forming cells, which then grow into small nodules of bone and bone marrow. These human bone nodules have been shown to support the growth of other human cancers, including multiple myeloma, in mice. The group will attempt to use the same technique to grow WM cells in a living animal environment.

Identification of new molecular targets for WM patients is useful in several ways. First, there may be existing drugs (ideally, drugs that have been tested and are marketed already for other diseases) that inhibit the new molecular targets. In that case, the existing drugs could be re-purposed for WM patients and tested in clinical trials, as was done with BTK and ibrutinib. Alternatively, if drugs that inhibit the new targets do not exist, then the new targets could be the focus of drug discovery and development efforts. This

would be a longer-term effort, but one that may be fruitful for WM patients.

IWMF Board Member **Dr. Stephen Ansell, Mayo Clinic**, highlights the importance of IWMF-supported research:

"As patients with Waldenstrom's macroglobulinemia will know, WM is a unique disease. Particularly unique to this disease is the production of the IgM protein by the cancer cells and the presence of symptoms such as hyperviscosity that develop as a consequence of this protein, as well as the fact that the cancer cells typically grow in the bone marrow and replace the normal cells. Twenty years ago this was mainly all we knew about the disease. Since then, due in large part to funding provided by the IWMF, we have learned a tremendous amount about the genetics and biology of this disease. Research funded by the IWMF has allowed us to understand the mutations in genes that lead to the development of WM, to identify signaling pathways that are overactive in this disease, to determine which proteins present in the bone marrow promote the growth and survival of the cancer cells, and to identify some of the deficiencies in the immune system that prevent eradication of the cancer cells. This work has led to novel therapies to treat WM. While in the past, treatments for WM were borrowed from other diseases, they are now specifically approved for WM based on research supported by the IWMF. While we have gone from almost no knowledge regarding WM in the past to substantial knowledge of this disease at present, we are now poised to make additional breakthroughs that may potentially lead to a cure for WM patients. All this progress is directly due to funding provided by WM patients!"

Expressing similar sentiments, IWMF Board Advisor **Dr. Steven Treon, Dana-Farber Cancer Institute**, is expanding his relationship with the IWMF because he believes that *"the IWMF support has made some of the most pivotal discoveries in WM possible, including the genomics driving WM, and the development of drugs like ibrutinib, acalabrutinib, zanubrutinib, and tirabrutinib that target MYD88 signaling. These discoveries provide a real example of how basic scientific research is allowing us to make real gains on WM. I am honored to work with the IWMF Trustees and Scientific Advisory Committee to continue this progress, and to finding a cure for WM."*

THE RV LIFESTYLE IN A COVID-19 WORLD

BY WANDA HUSKINS



Wanda Huskins and Jeff Prupis

Editor's Note: Wanda wrote an article for the July 2017 Torch about her and her husband's life and travel full time in an RV. Now, however, with the coronavirus pandemic, this lifestyle has become difficult when non-essential businesses and camping areas are closed. Here is her update:

My husband Jeff and I, and two cats, had motored out of New York toward our great adventure. Taking different routes, we crossed the country multiple times, marveling at the new sights and expanding our memorable experiences. Frequently, and by design, our destinations focused on the vast National Park System. Camping in any of our national parks is truly liberating and offers a heightened sense of awe and wonder. As we also discovered, adventures and exploration do not stop at national borders. Traveling south of the border to Mexico and to the Great White North of Canada widened our perspective of the magnificence that the entire North American continent has to offer.

During our time on the road we never had a major issue. "Old Faithful," our 37-foot, class A diesel pusher RV, never let us down. Giving it proper maintenance and care, we skirted the common problems that others had warned about. Approximately one million people live full time in RVs, and we've enjoyed the company and tips of quite a few of them. Joining some of the numerous support groups online that assist fellow travelers in troubleshooting mechanical issues proved pivotal in avoiding or correcting them.

Beyond the importance of keeping our motor home operating safely, we ourselves had to be operating safely as well. Like many retirees enjoying this lifestyle, both my husband and I have health issues to manage. Our regular trips back to NY always included attending to our healthcare needs. While traveling, both of us made sure to have our routine labs done in a timely matter. We posted emergency numbers to our refrigerator wherever we were camped. Thankfully, trips to urgent care were rare. In addition to the precautions that

we took, our RV insurance covered us in the eventuality we needed to be airlifted to an emergency center.

As 2020 approached, we both started to think of the next phase of our lives. The original game plan was to travel full time for three to four years. Neither one of us wanted to give up traveling in our RV completely, but owning a home to enjoy during the winter months seemed a suitable compromise. Still, I'm not entirely sure that we would have felt the urgency to abandon our RV home if the SARS-CoV-2 virus had not emerged in the way it has.

The COVID-19 pandemic required us to rethink our lifestyle and vulnerability. With a home on wheels, natural disasters like hurricanes, fires, and floods could be easily avoided. But how could we travel away from a deadly virus consuming the country? In January, I began closely monitoring the reports, cases, and deaths from this virus. As a nurse and someone immunocompromised from WM, I was frightened for the first time since I was diagnosed. By February, I was taking precautions similar to those used when I was working in the hospital while undergoing chemo treatments during the 2009 H1N1 flu. Knowing Jeff is also at high risk, I instructed him on safety precautions because our avoidance of this virus was now dependent on one another's adherence to them.

*But how could we travel away from a **deadly virus** consuming the country?*

But if one of us became sick, following self-quarantine guidelines in another location of the house is not an option in a RV. In addition, it was becoming apparent that parks, public and private, were closing as non-essential businesses. Even in a self-contained RV, electricity, water, and dump sites are required after a week or so.

In the wake of this pandemic, our sporadic home search took on a more urgent call. Arizona had always been a draw for us in winter months, and in weighing our options, we decided to narrow our house search to the Grand Canyon State. Happily, we found RV parks still open to us while we searched for a house. But by March, we had noticed some parks were either closing or shutting down their community facilities such as pools, clubhouses, and showers. Many of our full time RV friends in different parts of the country experienced even more problems, from canceled reservations to lack of availability. Some of our friends opted to stay with family members, while others found long-term rental space for themselves and RV wherever they could. For us, finding an open park often

The RV Lifestyle, cont. on page 11

meant more crowded conditions not conducive to physical distancing. At one location, we found ourselves parked very closely between two RVs. The sound of unmasked coughing had me running inside and shutting our windows.

Toward mid-March we arrived in Tucson at a very accommodating RV park that balanced awareness of RVers' needs with safety needs. Tucson was also proving to be our preferred location for a home, and we were able to negotiate with the park owners to stay until we could close on a house.

Searching for a house during a pandemic is challenging, but we found it manageable. Much can be accomplished online, and while virtual house viewing is available, it's not ideal for purchasing a home. People understandably do not want to invite prospective buyers into their homes right now. Undeterred, we used real estate websites for listings, and on our own we drove to homes of interest. If they showed potential from the outside, we would call the agent for a look inside. With our now customary protocol of precautions, we felt safe entering homes with the agent. In late March, a listing jumped out at us and offered what we had been searching for—a home in a park-like setting beside the beautiful foothills of the Tucson Mountains and Saguaro National Park. The need to shelter in place could be enhanced by our love of parks and the outdoors.

As for the RV, it is tucked away in storage for now. We've

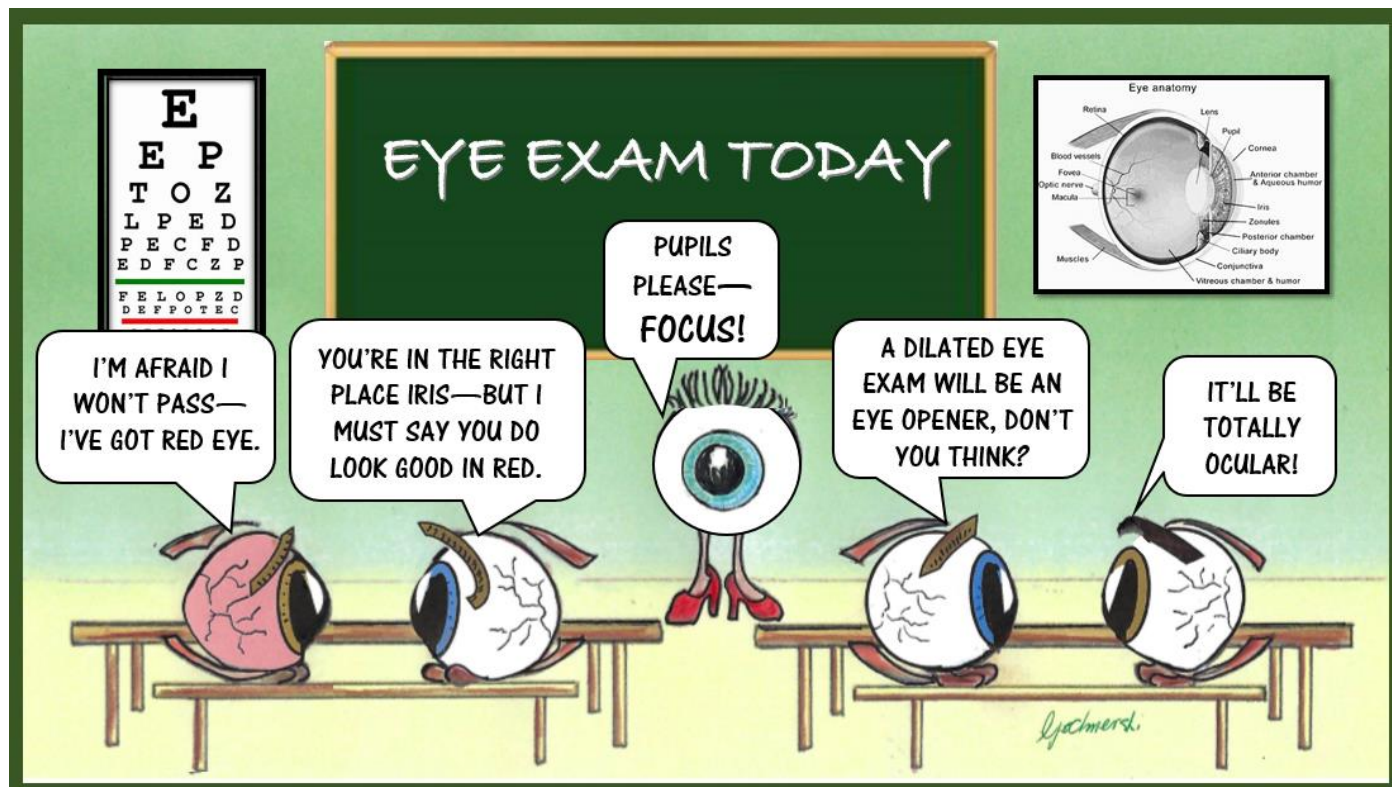
*We in the **WM community** need to be **vigilant**, as we are at particularly **high risk** from the effects of this virus.*

only briefly discussed future plans for RV travel. While we can envision short trips, we will wait out this pandemic before giving thought to longer trips. Personally, until there is a safe and effective vaccine, physical distancing is here to stay for us. With our annual NY trip indefinitely postponed, we will need to locate new healthcare providers, including an oncologist here in Tucson.

Our quarantine quarters are larger and more secure, but our COVID-19 uncertainties continue, as they do for all of us. We in the WM community need to be vigilant, as we are at particularly high risk from the effects of this virus. Having WM puts us at a distinct disadvantage, but our disease has already taught us to guard against infections and at times distance ourselves. I've learned to live with uncertainty, as COVID-19's path is uncertain, but with confidence in maintaining a safe environment, I've found solace in solitude as I "watch and wait" for a vaccine.

Stay safe, my Walden-friends!

Torch Toon by Linda Pochmerski



NOTE TO WMers: Get a dilated eye exam with a doctor who is knowledgeable examining a WM patient.



MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF RESEARCH COMMITTEE MEMBER

New BCL-2 Inhibitor to Enter Phase 1b/2 Clinical Trial for WM – Ascentage Pharma announced that it will begin a Phase 1b/2 clinical trial of its investigational drug APG-2575 as a single agent or in combination with ibrutinib (Imbruvica) or rituximab (Rituxan) for the treatment of WM. APG-2575 is a BCL-2 inhibitor in the same class as venetoclax (Venclexta). The trial is designated MAPLE-1 and is identified on www.clinicaltrials.gov as NCT04260217.

Phase 3 Study Will Compare Carfilzomib and Ibrutinib Combination to Ibrutinib Alone in WM Patients – A new Phase 3 study from the University of Ulm in Germany will compare the combination of carfilzomib (Kyprolis) and ibrutinib (Imbruvica) to ibrutinib alone in both treatment naïve and relapsed/refractory WM patients. Preliminary data have indicated that carfilzomib is able to overcome the inferior prognosis of solo ibrutinib in WM patients who are MYD88 wild-type (unmutated) or who have CXCR4 mutations. The primary objective of the trial is to test the efficacy and toxicity of the combination, as well as to investigate the rates of complete responses and very good partial responses after 12 months of combination treatment. Approximately 184 patients at 60 sites will be recruited. On www.clinicaltrials.gov, the identifier is NCT04263480.

US FDA Grants Fast Track Designation to Radiotherapeutic Drug Conjugate for LPL/WM – Cellectar Biosciences, Inc. announced that the US Food and Drug Administration (FDA) has granted Fast Track Designation for CLR 131 in lymphoplasmacytic lymphoma (LPL)/WM patients who have received two or more previous treatment regimens. CLR 131 is a small molecule, radiotherapeutic drug conjugate designed to deliver radiation directly and selectively to cancer cells. The Fast Track Designation is a result of the ongoing Phase 2 CLOVER-1 clinical trial of patients with relapsed/refractory B-cell malignancies, during which the four LPL/WM patients in the study achieved a 100% overall response rate. The identifier number on www.clinicaltrials.gov is NCT02952508.

Article Discusses Causes of Death Following LPL/WM Diagnosis – Data on cause-specific mortality after lymphoplasmacytic lymphoma (LPL)/WM diagnosis are lacking. A retrospective study from the National Institutes of Health, published in the *British Journal of Haematology*, looked at causes of death among 7,289 adults diagnosed with LPL/WM during 2000-2016 in 17 US population-based cancer registries. Based on 3,132 deaths, the 16-year cumulative mortality was 23.2% for lymphoma, 8.4% for non-lymphoma cancers, and 14.7% for non-cancer causes for patients less than 65 years old at diagnosis vs 33.4%, 11.2%,

and 48.7%, respectively, for those 75 years of age or more at diagnosis. Compared with the general population, patients with LPL/WM had a 20% higher risk of death due to non-cancer causes, most commonly from infectious, respiratory, and digestive diseases, but no excess mortality from cardiovascular diseases. Risks were highest for non-cancer causes within one year of diagnosis, declining thereafter. Myelodysplastic syndrome/acute myeloid leukemia deaths were notably increased, whereas solid tumor deaths were only elevated among those who survived 5 years or more after diagnosis.

CAR T-Cell Therapy Targeting CD20 Achieves Early Results in NHL Patients – Mustang Bio, Inc. announced that the first patient treated with its optimized MB-106 CAR T-cell therapy has achieved a complete response at the lowest starting dose in an ongoing Phase 1/2 clinical trial evaluating its safety and efficacy in relapsed or refractory B-cell non-Hodgkin's lymphomas (NHL). While most CAR T-cell therapies target CD19, MB-106 targets the CD20 antigen on the surface of B-cells. The trial is open to those with lymphoplasmacytic lymphoma (LPL), of which WM is the major subtype, and is being conducted at Fred Hutchinson Cancer Research Center, which helped develop the therapy. More information can be found on www.clinicaltrials.gov, using the identifier NCT03277729.

Early Results Discussed for New Non-Covalent Kinase Inhibitor in Phase 1a/b Dose Escalation Trial of CLL/SLL and NHL Patients – Early information was presented at the American Association for Cancer Research Virtual Annual Meeting I for the continuing Phase 1a/b dose escalation trial of CG-806 in patients with relapsed or refractory chronic lymphocytic leukemia/small cell lymphoma (CLL/SLL) or non-Hodgkin's lymphomas (NHL). CG-806 is an oral non-covalent kinase inhibitor that inhibits key clusters of related kinases (including BTK and ITK) that are involved in cancer signaling. Patients are dosed twice daily in 28-day cycles at six different dose levels to establish the recommended future Phase 2 trial dosing. Thus far there have been no adverse events from treatment and no evidence of bone marrow suppression.

Two Studies Discuss Higher Risk of COVID-19 Complications in Cancer Patients – According to two separate studies, cancer patients have a higher risk of death or other severe complications from COVID-19, compared with those without cancer. A Chinese study presented during the American Association for Cancer Research Virtual Annual Meeting I included 105 cancer patients and 536 non-cancer

Medical News Roundup, cont. on page 13

patients of the same age, all of whom had COVID-19. The study reported that cancer patients who developed the viral infection had nearly a threefold higher death rate than that of the general population; cancer patients were also more likely to experience severe events, such as being admitted to intensive care units and needing mechanical ventilation. Cancer patients at particularly high risk included those with blood or lung malignancies or with metastatic tumors. Another study, this one from Montefiore Medical Center in New York, identified 218 cancer patients treated for COVID-19 in its system between March 18 and April 8 and compared them with 1,090 age- and sex-matched non-cancer patients who contracted the viral illness. COVID-19 patients with cancer had double the fatality rate of those without cancer, at 28% and 14%, respectively. Of the 61 cancer patients who died, 25% had solid tumors and 37% had blood cancers. Fatality rates were elevated in all age cohorts in cancer patients and achieved statistical significance in patients aged 45-64 and older than 75.

BTK Inhibitors to Enter Clinical Trials for Treatment of Severely Ill COVID-19 Patients – In the search for drugs to treat coronavirus, several researchers, including Dr. Steven Treon at the Bing Center for WM at Dana-Farber Cancer Institute, are working from a growing consensus that BTK inhibitors might be able to rescue seriously ill COVID-19 patients from ventilators. Their hypothesis is that BTK inhibitors could help tame the out-of-control immune response to the virus that damages the lungs. Several clinical trials are looking into this possibility: BeiGene is launching a Phase 2 trial of COVID-19 patients in the US to test its candidate zanubrutinib (Brukinsa), AbbVie is sponsoring a Phase 2 trial of ibrutinib for COVID-19 patients in the US, and Astra Zeneca is opening two Phase 2 trials of acalabrutinib (Calquence) for COVID-19 patients, one in the US and the other in Europe.

Article Discusses Efficacy of BTK Inhibitor Therapy Following Disease Progression in CLL Patients on Venetoclax – An article published by Australian researchers in the journal *Blood* retrospectively evaluated 23 patients with relapsed/refractory chronic lymphocytic leukemia (CLL) who received a BTK inhibitor such as ibrutinib (Imbruvica) or zanubrutinib (Brukinsa) after stopping venetoclax (Venclexta) due to progressing disease. Median progression-free survival and median overall survival after BTK inhibitor initiation were 34 months and 42 months, respectively. BTK inhibitor therapy achieved durable benefit for patients with the BCL-2 Gly101Val mutation that causes venetoclax resistance. At a median follow-up of 33 months, 11 patients remain on BTK inhibitor therapy and 12 have ceased therapy due to disease progression (8 patients) or toxicity (4 patients). The authors concluded that BTK inhibitor therapy can provide disease

control of CLL after progression on venetoclax.

US FDA Approves Subcutaneous Formulation of the Monoclonal Antibody Daratumumab – The US Food and Drug Administration (FDA) has approved a subcutaneous formulation of daratumumab (Darzalex) for use in patients with multiple myeloma. The new formulation of daratumumab combined with a hyaluronidase is called Darzalex Faspro, and it can be given over approximately three to five minutes vs the typical two-hour administration of the intravenous drug. Daratumumab is an anti-CD38 monoclonal antibody currently in clinical trials for WM.

*The authors concluded that **BTK inhibitor therapy** can provide disease control of CLL after progression on **venetoclax**.*

Recommendations Available to Mitigate Biotin Interference with Certain Laboratory Tests – Individuals who regularly take more than 5,000 mcg of biotin supplementation per day to improve the condition of their hair, nails, and skin may have an excess amount of biotin in their blood that can interfere with some types of laboratory tests, including immunoassays for common tests such as troponin, thyroid hormones, parathyroid hormone, cortisol, follicle-stimulating hormone, luteinizing hormone, and vitamin D. The interference occurs because some immunoassays use biotin as part of the reagent mixture in the testing method; consequently, excess biotin may cause either falsely increased or falsely decreased test results, depending on the test. People who have consumed 5,000-10,000 mcg of biotin need to wait a minimum of eight hours after the last dose before having blood collected for laboratory tests. Waiting up to 72 hours may be required to prevent interference with some assays. Since biotin is cleared from the blood by the kidneys, people with kidney dysfunction or kidney disease may need to refrain from taking biotin for a longer period. The US Food and Drug Administration (FDA) recommends that consumers tell their healthcare practitioners if they take or plan to take biotin or a supplement containing biotin and alert their practitioners if they are concerned about test results and the possibility of biotin interference.

The following abstracts pertaining to WM were presented during the 2020 American Society of Clinical Oncology (ASCO) Virtual Scientific Program held on May 29-31:

Characteristics and Outcome of Patients with MYD88 Wild-Type Waldenström Macroglobulinemia – The Mayo Clinic discussed the characteristics and outcome of WM

Medical News Roundup, cont. on page 14

patients who are MYD88 wild-type and predominantly treated with non-BTK inhibitor therapies. Of 986 WM patients seen at Mayo between 1996 and 2018, MYD88 genotype data were available in 331 patients; 72 (22%) and 260 (78%) were MYD88 wild-type and MYD88 L265P, respectively. Pre-treatment bone marrow infiltration with lymphoplasmacytic cells and beta-2 microglobulin were lower in the wild-type patients, while other laboratory parameters were comparable between the two groups. Using the International Prognostic Scoring System for WM criteria, there were fewer wild-type patients in the high-risk group. Wild-type patients had a higher likelihood of transformation to an aggressive lymphoma, at 18%, vs 4% for MYD88 L265P patients. Among patients with treatment data available, the five-year overall survival was comparable between the two groups, at 85% in the wild-type and 82% in the MYD88 L265P cohorts.

*Three-year **progression-free** survival
[with single-agent zanubrutinib]
was **81%**, and **overall survival** was **85%**.*

Three-Year Follow-Up of Treatment-Naïve and Previously Treated Patients with Waldenström Macroglobulinemia (WM) Receiving Single-Agent Zanubrutinib – Researchers, primarily from Australia, presented data from a three-year follow-up of treatment naïve and previously treated WM patients who received single agent zanubrutinib (Brukinsa) in a Phase 1/2 clinical trial. Oral dosing was 160 mg twice daily or 320 mg once daily until disease progression or unacceptable toxicity. Between September 2014 and August 2018, 77 patients began treatment, and at a median follow-up of 32.7 months, 73% remain on treatment. Reasons for treatment discontinuation included adverse events in 13%, disease progression in 10.4%, and other in 3.9%. The overall response rate was 96%, and the very good partial response (VGPR)/complete response rate (CR) was 45%, with the VGPR and CR rates increasing over time: 22% at six months, 33% at 12 months, and 45% at 24 months. Three-year progression-free survival was 81%, and overall survival was 85%. The most commonly reported adverse events were upper respiratory tract infection, bruising, and cough. Adverse events that occurred less frequently were neutropenia, major hemorrhage, atrial fibrillation/flutter, and diarrhea.

ASPEN: Results of a Phase III Randomized Trial of Zanubrutinib Versus Ibrutinib for Patients with Waldenström Macroglobulinemia (WM) – Data resulting from the Phase 3 multi-center ASPEN study of zanubrutinib

(Brukinsa) vs ibrutinib (Imbruvica) in WM patients were also reported. In this trial, 201 patients with the MYD88 mutation were randomly assigned to receive either zanubrutinib at 160 mg twice daily or ibrutinib at 420 mg once daily. Patients with MYD88 mutations were assigned to a different group, reported separately below. At a median follow-up of 19.4 months, the rate of complete response/very good partial response was 28.4% for zanubrutinib vs 19.2% for ibrutinib. Rates of atrial fibrillation, bruising, diarrhea, peripheral edema, hemorrhage, muscle spasms, pneumonia, and adverse events leading to treatment discontinuation or death were lower with zanubrutinib; of particular note, the rate of atrial fibrillation was 2% in the zanubrutinib arm and 15.3% in the ibrutinib arm. However, the rate of neutropenia (low neutrophil count) was greater with zanubrutinib.

Updated Results of the ASPEN Trial from a Cohort of Patients with MYD88 Wild-Type (MYD88WT) Waldenström Macroglobulinemia (WM) – The Phase 3 ASPEN study referred to above also updated results for its cohort of WM patients who were MYD88 wild-type and received zanubrutinib (Brukinsa) at 160 mg twice daily until disease progression. In total 28 patients were included. With a median follow-up of 17.9 months, two patients discontinued zanubrutinib due to adverse events, and six patients experienced disease progression. The overall response rate was 80.8%, with a major response rate of 50%, including a very good partial response rate of 26.9%. Progression-free survival at 12 months was 72.4%. The most frequently reported adverse events were diarrhea, anemia, bruising, fever, and upper respiratory tract infection. Major hemorrhage was reported in two patients, and atrial fibrillation in one patient.

The author gratefully acknowledges the efforts of Grete Cooper, Peter DeNardis, Wanda Huskins, Pavel Illner, Meg Mangin, John Paasch, Colin Perrott, Howard Prestwich, Charles Schafer, Ron Ternoway, and others in disseminating news of interest to the IWMF Connect community. The author can be contacted at suenchas@bellsouth.net for questions or additional information.



IWMF DOC STAR: DR. TANYA SIDDIQI

AS TOLD TO RON TERNOWAY

In May of 2015, the leading minds in WM research met in New York. The conference—the first joint venture between the IWMF and the Leukemia & Lymphoma Society (LLS)—had the goal of identifying gaps in our knowledge of WM and prioritizing research projects to fill those gaps.

The outcome of this meeting was the Strategic Research Roadmap, which continues to be updated annually. One of those guiding this deployment of cutting-edge research is Dr. Tanya Siddiqi, hematologist and researcher from City of Hope National Medical Center (COH) in Duarte, CA.



Dr. Tanya Siddiqi

Born in Karachi, Pakistan, Siddiqi earned her medical degree at Aga Khan University Medical College in 2000. Packing her bags for America, she completed an internal medicine residency at University of Connecticut Health Center, Farmington, CT, followed by two fellowships: hematology and oncology at Beth Israel Deaconess Medical Center (Harvard Medical School, Boston) and hematopoietic stem cell transplantation at City of Hope.

She specializes in the diagnosis and treatment of blood cancers and is a supervising physician at COH's anti-coagulation clinic, which treats patients with blood clotting disorders due to their diseases or treatments. She is an associate clinical professor, Department of Hematology and Hematopoietic Cell Transplantation at City of Hope and director of the Chronic Lymphocytic Leukemia (CLL) Program at the Toni Stephenson Lymphoma Center.

In addition to her clinical practice, Dr. Siddiqi is principal investigator for a number of clinical trials evaluating the role of targeted therapies, including gene (CAR-T) therapy and other novel agents. Her continued work with the Strategic Research Roadmap group has enabled her to bring WM clinical trials to the West Coast, most notably a venetoclax clinical trial with Dr. Jorge Castillo and the Bing Center for WM in Boston and the ASPEN trial that compared zanubrutinib to ibrutinib.

Dr. Siddiqi sees great promise for CAR-T cell therapy: "CAR-T cell therapy is an amazing way to harness the body's own immune system to fight cancer. We have seen the greatest success in lymphoma, and the FDA has approved this therapy in aggressive diffuse large B-cell lymphoma. We are now

studying this therapy in CLL, and I also have a trial open here where we can treat any lymphoma patient, including WM, with COH-made CAR-T cells. If CAR-T cells work, they work extremely well, with the potential to lead to long-term remissions. So we think it's worth trying in all lymphomas, including WM."

She is delighted to be working at City of Hope. "The atmosphere here is collegial, friendly, and supportive. We see a lot of patients at COH, and I have been able to mold my career to see mostly CLL and WM patients and to conduct clinical trials for these diseases here."

Her advice to a newly diagnosed Waldenstrom's patient? "I reassure patients that there are many good treatment options available now for WM and that we have ongoing research to find a way to attain deeper and more durable remissions. Participating in trials is therefore important when treatment is indicated, because that is the only way newer and better therapies as well as combinations of novel therapies will get

*"...many **good treatment options**
available now for WM..."*

FDA approval, if they prove to be better than what's already available."

One WM patient who is also delighted that Dr. Siddiqi works at COH is Suzanne Rico. She was (eventually) diagnosed with WM and cryoglobulinemia two years ago when she lived in Maine, and she landed in the capable hands of Dr. Jorge Castillo. When Suzanne and her husband decided that a warmer climate—southern California—was required to diminish her cryoglobulinemia symptoms, Dr. Castillo recommended Dr. Siddiqi, a trusted friend and colleague who also specialized in treating WM.

And so it was—Suzanne was off to meet the new specialist. "I was nervous before our first appointment. The doctor-patient relationship is one of the most important and can be one of the most difficult to balance, at least for me. I want a doctor who will guide me medically, but who will also be responsive, kind, and not make me feel as if the clock is ticking on our appointment.

"Being a journalist, I thrive on information and need to understand all aspects of my disease and treatment. I needn't have worried: Not only did Dr. Siddiqi make me feel like I had her 100% attention, but her words were wise, straightforward, and uncomplicated. She welcomed my interest, respected my

IWMF Doc Star, cont. on page 16

need to know, and never gave the attitude of ‘just do what I tell you and don’t ask questions.’

“One thing that is special about Dr. Siddiqi is her bedside manner. She is warm and able to make my WM diagnosis feel more matter-of-fact than end-of-the-world. I so appreciate this reminder. Both she and City of Hope make me feel less like a victim and more like I have some control of my own health and future.

“Finding an intelligent, experienced doctor who chose her profession because she was called to it and who sees her patients not just as problems to be solved or diseases to outsmart, but as human beings who have hearts and souls as well as bodies, has been a gift. City of Hope is well-named because of doctors like Tanya Siddiqi.”

Rico is right about her doctor being called to her profession. Siddiqi was encouraged by her father to “choose subjects based on how good I am in them, not merely going for popular options. So I always veered towards biology-based options, choosing pre-med in our high school equivalent in Pakistan.”

On trying to find that elusive work-life balance: “It’s challenging because work is usually very demanding, between patients in clinic, inpatient service, clinical trials, conferences, and presentations. My husband is also a physician, and we try to spend good, quality time together as much as possible—long walks on the beach, eating out, watching movies, playing video games.

“The current lockdown and social distancing situation due to the COVID-19 pandemic has helped me slow down at work and spend more time with my husband and our parents. I am thankful for that, in a way.”

When asked for final thoughts, Siddiqi responded, “I have spoken at several IWMF patient education meetings in California and am always struck by how well-versed most of the patients are. The IWMF helps keep them informed so they can stay in some control of their treatment journey. I find this very impressive and am honored to be part of this group. Thank you.”

LEARNING A NEW VOCABULARY

BY CRAIG E. BURGESS

*What an exciting adventure
For a teacher who is sixty-five years
young:
Learning a new vocabulary
With new sounds that roll off my
tongue!
Macroglobulinemia,
With IgMs by the score,
Rituximab and Cytoxan
And so many, many more.*

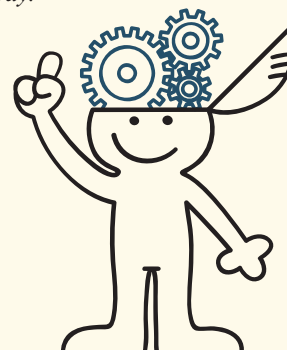
*Of course, there are medications
That have come to give me a thrill:
Dexamethasone and Claritin;
Prednisone and doses of Benadryl;
Allopurinol and Pepcid;
The list goes on and on...
I must remember when to take each
one
AND get refills when each is nearly
gone.*

*For a career foreign language teacher,
Familiar with pronunciation drills,
I now must RE-learn my English...
Before and after swallowing pills:
Five dexamethasone with breakfast,
Just two days, every three weeks;
One allopurinol, taken daily.
Their sounds now roll from my cheeks
As colleagues and many long-time friends
Just stare at me in disbelief.
"Where did you go on vacation?
Did you hit your head on some reef?"*

*As a reader of this crossword-like poem,
Containing many challenging terms,
Can YOU identify the world that I'm in?
Have I been invaded by computer
germs?*

*The answer, of course, to my query,
Lies imbedded in the medical field.
With the help of the vocabulary
mentioned,*

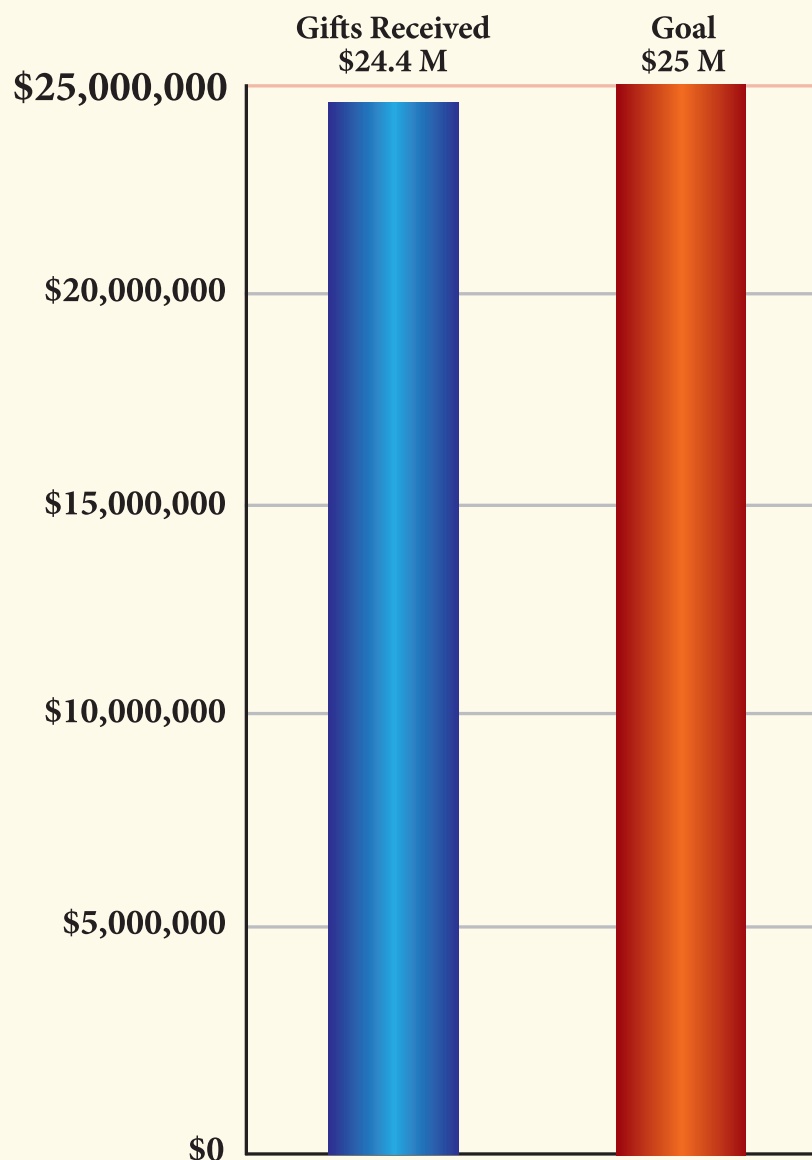
*Evil cancer cells may soon have to
yield
To the ongoing attack in treatment,
Designed to destroy and restore.
The most difficult task that now I must
face
Is one which will lead me to explore
The meanings and the functions of
these wonderful words,
More of which I'm encountering each
day:
It's the world of cancer chemotherapy
That is expanding my knowledge this
way.*



Your Legacy is Important

That's why you take time to plan and provide for the people and causes that mean the most to you.

Imagine a Cure Campaign Progress Report as of March 17, 2020



The Ben Rude Heritage Society for Legacy Gifts to the IWMF

The IWMF has a special club for those who name the IWMF as a beneficiary of their estate plan—the Ben Rude Heritage Society. No gift is too small for membership! If you have already made a provision for the IWMF in your will, trust, life insurance, or as a beneficiary of your IRA, please let us know, and we'll enroll you in the Ben Rude Heritage Society. You can remain anonymous if you prefer. Either way, we would like to say thank you and keep you in the loop with all things IWMF-related. For more information on estate gifts or to join the Ben Rude Heritage Society, contact Director of Development and Communications Jeremy Dictor at 941-927-4963 or JDictor@IWMF.com.

RESEARCH PARTNERS

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

The David and Janet Bingham Research Fund of the IWMF supports the following current research projects:

Factors Regulating Immunoglobulin-Producing B-Cells in Patients with WM- Part V

Targeting MYD88 Signaling in WM

The Elting Family Research Fund of the IWMF supports the following current research projects:

Anti-Tumor and Immune Microenvironment Responses Following a First-In-Human DNA Fusion Vaccine for Asymptomatic WM/LPL

Modulation of T-Cell Function by Metabolomic Signature of the Bone Marrow Microenvironment in WM

Non-Invasive Diagnostics and Monitoring of MRD (Minimal Residual Disease) and Clonal Evolution of WM

Novel Antibody-Targeted Interferons in Combinatorial Therapies for WM

Single-Cell Next-Generation Flow and Sequencing to Unravel the Pathogenesis of WM and to Design Genetically-Driven Human-Like Experimental Models

The K. Edward Jacobi Research Fund of the IWMF supports the following current research project:

From Biology to Treatment: Prognostic Factors, Bone Marrow Microenvironment, Genomic and Proteomic Profile of Light Chain Amyloidosis in WM

The Ed and Toni Saboe Research Fund of the IWMF supports the following current research project:

Anti-Tumor and Immune Microenvironment Responses Following a First-In-Human DNA Fusion Vaccine for Asymptomatic WM/LPL

The Carolyn Morris Research Fund of the IWMF supports current IWMF research

The Yang Family Research Fund of the IWMF supports the following current research project:

Targeting MYD88 Signaling in WM

NAMED GIFT FUNDS

For a commitment of \$10,000 per year for five years, or a lump sum of \$50,000 or more, you can establish a named fund at the IWMF in your own name or in the name of someone you wish to honor. This fund may support Member Services or Research or a combination of the two.

Baker Family Research Fund of the IWMF	Gary Green Research Fund of the IWMF	Gail Murdough Member Services and Research Fund of the IWMF
Yoshiko Button Member Services Fund of the IWMF	Dr. Robert Kyle Research Fund of the IWMF	Sesnowitz Family Research Fund of the IWMF
Friedlander-Scherer Family Research Fund of the IWMF	Lynn Martin and Carrie Wells Research Fund of the IWMF	Donald and Kathryn Wolgemuth Research Fund of the IWMF
Dr. Morie A. Gertz Research Fund of the IWMF	Dennis and Gail Mathisen Research Fund of the IWMF	

If you have discretionary giving power and would like to help move our research program forward in a special way, we invite you to join those listed above. For more information about Research Partners and Named Gift Fund opportunities and potential gifting options that might make that possible, please contact Director of Development and Communications Jeremy Dictor at JDictor@iwmf.com or 941-927-4963.

BEN RUDE HERITAGE SOCIETY ROSTER

* Deceased ◇ Founding Member

ANONYMOUS (4)	JAN HERGESHEIMER	PAUL AND JANICE RIPPAS
JEAN-MARC AUDIBERT*	SUZANNE L. HERMS	ROGER AND BARBARA ROBINETTE
BARBARA A. BACKER RN	ARLENE HINCHCLIFFE	MARGARET ROCKELMAN*
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PETER CARR	CHARLENE M. KYLE	JOHN AND DIANE TIPLADY
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A DOCTOR'S PERSPECTIVE ON MANAGING COVID-19

BY DR. SHIRLEY D'SA

It is a sunny Saturday afternoon in spring in London—well, a northwest suburb of London. I am at a newly fashioned desk space in the bay window of our living room, where there was once a sofa that we inherited from my late mum in the year of the London Olympics.

It has been the strangest two months on record. When news of the novel coronavirus in China began to emerge early in 2020, I felt a stab of concern, similar to that when SARS and MERS came on to the scene. What would this mean—was this a symptom of humankind's pushing the environmental envelope and getting too close to wild animals to enable cross-over of so-called “zoonotic” viruses to *Homo sapiens*? People would die for sure, but who and where?

And waves of unpleasant reality hit—first China, then Italy and Spain closer to home, and then the United Kingdom. By the time the news literally arrived on our doorstep, I was covering the plasma cell disorders service at UCLH, a large academic hospital in Central London. Updates from the Government, the National Health Service hierarchy, and Public Health England came thick and fast. Our hospital also had twice or thrice a day email updates about adapting our day-to-day practice, including converting intravenous to oral therapies, suspending stem cell transplants (except in a few cases), and suspending maintenance treatment like rituximab so as to limit journeys to hospitals and free up capacity for the likely tsunami of cases. The wards were emptied of “routine” planned treatments and there was segregation of possible and confirmed COVID-19 cases from non-COVID cases, although no one knew what symptoms really comprised a likely case. It was a steep but rapid learning curve.

We always wear masks to see patients with known respiratory symptoms or infections to protect vulnerable patients. Suddenly there was a degree of rationing of masks as supplies were in danger of running out. In the course of my ward cover spell, we had a flurry of COVID-19 positive cases. We had no sense of where the virus was being contracted. London is a busy and infinitely interconnected city with widespread use of public transport being the norm. Affected patients came from a spectrum of social, racial, and economic backgrounds.

*...the stance adopted was to assume everyone with a **lymphoma diagnosis** at any stage of their illness was **at risk**...*

Numbers seemed to build up rather quickly at first; it was difficult to test with certainty. In one case of a particularly feverish patient, the COVID-19 swab was negative twice while the patient deteriorated after recovering in other



Dr. Shirley D'Sa speaking at a WMUK meeting

ways from a stem cell transplant; yet she seemed to have all the hallmarks of the novel infection—increasing oxygen requirements, fluffy shadowing on her CT chest scan—until finally the third test was positive. I will always remember that brave lady, who was a nurse in the NHS before she retired. I could imagine her capably and cheerfully working in her role in the past, but now she was frightened. We all were to be honest. Sadly, although everything that could be done was done, including CPAP in the ICU, it proved hopeless and she succumbed, her family unable to visit due to stringent visiting restrictions.

Being a specialist in a completely novel scenario is a very strange and uncomfortable feeling. In other areas of my practice, I feel that I have done more than the “10,000 hours” needed and have a sense of useful experience (coupled with constant curiosity) upon which I can draw when faced with the care of patients with WM and related conditions. But now, here we were, staring into an abyss, about how to accurately diagnose this new version of an old virus (the range of symptoms is incredibly wide, and the tests not yet tried and tested), how to treat, who is vulnerable and needs “shielding” as per Government guidance. Should that include patients with WM who have never been treated (on watch and wait), patients who had chemotherapy many years ago and are stable, and what about MGUS?!

In the end the stance adopted was to assume everyone with a lymphoma diagnosis *at any stage* of their illness was at risk until proven otherwise. This meant that people were instructed to immediately and strictly self-isolate for 12 weeks. Letters from government agencies were sent out to “vulnerable” persons to inform as well as provide a “passport” for priority home delivery of provisions (this was the time of toilet paper stockpiling), but not everyone who was vulnerable got such a letter. Consequently many communications came from highly anxious patients about what they should do. People who were busy working suddenly had to stop if they were deemed vulnerable, and this was before the official lockdown was in place.

Managing COVID-19, cont. on page 21

Not long after I had been in contact with COVID cases and one of our junior doctors went off work with flu-like symptoms, I developed a tight, dry feeling in my throat—nothing else. Perhaps a slightly sniffling nose but no fever, no cough at all, let alone persistent cough...I was unsure about what to do. With staff self-isolating, it felt perverse to stay home while needs were ramping up in the health service. There were already media reports of struggling hospitals and doctors and nurses at the frontline dying from coronavirus. I felt useless, like a fraud, but was told in no uncertain terms that, as staff testing was not yet available, I had to self-isolate.

So I worked from home for a week. We learnt how to Zoom for meetings and use Microsoft Teams and other apps that enabled us to safely discuss confidential information, with or without video. It so happens that my sons were also required to use Microsoft Teams for on-line schooling, so I had an IT helpdesk at home, which was useful. We started doing telephone consultations with patients in lieu of face-to-face appointments and had to make executive decisions about how crucial it was to have blood testing for patients on watch-and-wait (we became comfortable with that quickly). But what about those on treatment? We soon made choices in discussion with patients, many of whom were understandably most uncomfortable about leaving their homes for a blood test, and London's cases were ramping up rapidly despite the early lockdown measures. We ended up continuing treatment (especially ibrutinib) without the "luxury" of blood tests, based on previous stability.

My own symptoms remained low-level and in fact seemed to improve, but the tightness in my throat was definitely different from anything I had before. Then my chest felt tighter, and I began to experience shortness of breath when I went for our daily walk in the quiet streets of our neighbourhood. After walking up a hill it took several minutes to catch my breath—it was a strange feeling. It occurred to me that perhaps it was a COVID-19 symptom, something that was affirmed by a colleague via email. So, I had to sit tight for another week until the symptoms subsided. As a doctor I had this compulsion to try and confirm a diagnosis properly, so I tried to make sense of it all. I felt fatigued and breathless on exertion but had no cough or fever—was this really coronavirus? Should I go back to work and be useful or not?

This feeling of uselessness bothered me greatly as I felt the health service crumbling around me. My colleagues quickly formed rosters to cover the dwindling number of routine and emergency inpatients in the non-COVID wards, as well as weekly shifts on the newly designated haematology COVID wards. Meanwhile, others were busy in the ICU, and a new temporary hospital dubbed the Nightingale Hospital (after nurse Florence) was opened at impressive speed in London's ExCeL exhibition centre to make thousands of extra beds available for mechanical ventilation of patients when capacity in the capital's ICUs had been exceeded.

Other specialist colleagues echoed my discomfort about our role in this pandemic. In time, I calmed myself by

Managing COVID-19, cont. on page 22

TORCHTOON Illustration by Linda Pochmerski



remembering that my day job is not on the frontline, and so I should ensure my efforts were directed at what I am best at doing—keeping a focus on the care of patients with WM through direct communication (with the help of the WMUK affiliate) and cutting through the massive surge in guidance documents in order to compose reader-friendly, relevant, and regularly updated documents for the WMUK website. This was very cathartic for me and a reminder that those not directly affected by COVID were still in need.

Around the same time, the IWWM10 Consensus Panel got together via email communication to finalise treatment guidelines for submission for publication. We were also able to exchange ideas and experience about emerging data from COVID-19 infections and how some treatments might actually prove protective due to favourable dampening down of the immune system in the event of an infection. The speed with which the panel worked was heartwarming, along with the rapid development of numerous trials across the globe for the treatment of COVID-19 patients. It was mind-blowing and impressive! The cooperation, which crossed institutional and national boundaries, was nothing short of remarkable.

On the home front, our family of five have all been working from home for the past six weeks. This took adjustment as we found corners in our home to work from, put our Broadband to the test (it has survived so far), and were blessed with three weeks of glorious spring weather with uncharacteristic unbroken sunshine that lifted the spirits and provided much needed solar energy! Final year school exams were cancelled, so history was made on that front too. The sixth member of the family, our cat Treasure, has been ambivalent about the non-stop attention—I promise you that cats do have a “when are you lot going off-to-work?” expression.

We have had many family quizzes that have been feisty affairs (not that we are competitive or anything) and have spent more time thinking about dinner menus and proper cooking. It has been lovely to have our social butterfly daughter to ourselves, and to her credit she has adapted well to this!

There is now talk of a relaxation of the lockdown—the concerns about the economy are head-to-head with fears of ongoing infections. The days that I do travel into Central London, it is eerily quiet. Only 1-2 people per carriage are on the Tube, streets are quiet, gone are the tourists queuing in front of Madame Tussauds at Baker Street (I usually have to dodge around them as I walk to work), and the restaurants are closed. There are orderly queues outside supermarkets with Xs taped at two meter intervals on the pavements.

It is unprecedented just how often the word “unprecedented” has been used to describe the situation the world finds itself in, simply because it is the most apt term. I am sure many people share my feeling of being in a dream or movie about a dystopian scenario. But there have been many silver linings. There has been a renewed and strengthened affection for our National Health Service launched after the end of the Second World War with the intention that “...the rich and the poor are treated alike, that poverty is not a disability, and wealth

is not advantaged.” (Aneurin Bevan, Minister for Health). It felt unreal when our Prime Minister was admitted to St. Thomas’s Hospital with COVID-19 infection and received treatment in the ICU.

I eventually had a nose and throat swab test when staff testing became possible, but this was more than four weeks after my symptoms had started, so it was unsurprisingly negative. The result simply means that I am not shedding the virus from my respiratory tract now. I am keen to avail of an antibody blood test when this is available. Some tests are approved, but my virology colleagues have warned that they remain imperfect with significant false positive and false negative results.

*But now there is a greater sense of **calm**,
and each day brings more **understanding**
about COVID-19...*

It is sobering to acknowledge how many people across the globe have been touched by anxiety, hardship, and grief. But now there is a greater sense of calm, and each day brings more understanding about COVID-19—and how to take the upper hand through testing and clinical trials. There is talk about resuming previous therapies that were suspended, but also discussions about whether some of our new ways of working should continue, such as telephone consultations. And there is the ecological footprint of the pandemic’s lockdown on the planet, where birds have become more audible, the sky bluer, and Venus shining brighter than ever before in the night sky.

FROM IWMF CONNECT: SUMMER 2020

BY JACOB WEINTRAUB, MD

This has been a most unusual and stressful time in our lives. Cancellation of the Ed Forum and almost every other live event we can think of has become routine. IWMF Connect discussion online has continued unabated, with many different subjects appearing and reappearing. Given the rapidly changing nature of the pandemic and issues related to it, we have chosen to limit our inclusion of the coronavirus discussion here. You are all invited to join IWMF Connect to participate or just “lurk” and absorb all the different experiences, observations, and opinions.

As always, there were links to articles and videos that involve aspects of life unique to our WM community or to items not directly related to our WM, but which are very relevant to our own feelings and experiences within our community.

*You are all invited to join **IWMF Connect** to participate...*

Lisa Wise, IWMF support group leader for Eastern Pennsylvania/Southern New Jersey, posted a link to an article in *The New York Times*. She has always dreamed of waking up to see the word “Waldenstrom” with a live link to the IWMF in *The Times*. This is a poignant story that she wrote about her husband’s experience with coronavirus, living in a household with a WM patient—herself. Her description of how she and her husband dealt with the issue of his infection and her cancer are instructive and spellbinding. She added that, thankfully, her husband is recovering beautifully, out of quarantine and getting stronger every day.

<https://www.nytimes.com/2020/04/13/well/family/virus-love-letter-husband-quarantine-cancer-lymphoma.html>

IWMF Connect Manager Peter DeNardis posted links to several items, including an article that is a reflection of a cancer patient’s experiences while living with an incurable cancer, entitled “That moment a cancer patient needs grounding.” This is a well-written reflection that uses a healthy mix of humor and reality.

https://thesouthern.com/opinion/columnists/column-kathychonez-that-moment-a-cancer-patient-needs-grounding/article_9950baec-9cff-507b-9e5c-4dc28b011b71.htm

Peter also included a link to a video from a television channel about a couple who initially met via an online dating app. She found out that he was just coming off a long journey with cancer, only to find herself being diagnosed with WM shortly afterward.

<https://www.wtnh.com/news/south-carolina-couple-finds-love-during-chemo/>

One additional post from Peter was to an article titled “10 Tips for a Life Worth Living With Chronic Illness.” Most of us have probably already adopted many of these practices, but Peter notes that the author did a nice job of hitting the “high notes” on some important steps to improve our quality of life. He also notes that just the fact we are part of Connect and the IWMF shows we’re well on our way to accomplishing these steps!

<https://themighty.com/2020/live-well-chronic-illness>

Finally, **Pat G** added a link about a woman with chronic lymphocytic leukemia (CLL), a “cousin” of our WM. Many of the issues she has dealt with are ones we all can relate to, and her message of hope in dealing with her leukemia and coronavirus resonates with us.

<https://www.cnn.com/2020/05/15/opinions/cancer-diagnosis-lockdown-coronavirus-beckett/index.html>

PORTS

One recurring theme is the issue of long-term intravenous access line placement. There are a variety of reasons for these lines, and this is reflected in the discussion. Ports appear to be the most frequently used. They are placed in the chest, usually below the collarbone, and can stay in place for a long time.

Lori P posted a scenario and question. She has finished six rounds of bendamustine and Rituxan due to Bing Neel syndrome. She then began maintenance Rituxan and monthly intravenous gamma globulin (IVIG) due to low IgG and multiple infections. Her veins have been damaged and are now difficult to access, and the infusion nurse and her oncologist have suggested placement of a port. She does not feel sick, and the days she goes for infusions are an unwelcome reminder that she has an illness. She says she is not in denial, but, since she feels so well, she is concerned that the presence of a port will be an unwelcome reminder of her illness, weighed against the painful process 1-2 times a month when the nurses are trying to find a vein. She also was concerned about infection risk. She asked for comments and thoughts from members of the group, and there were many answers to her query.

John S posted that his experience with a port is excellent. He also was concerned about the psychological effect of having one put in. However, he regretted having agonized in anticipation, since it made administering meds and doing blood testing very easy.

Sue H noted that her husband had a “Power Port” placed under his upper chest skin. This has been a godsend during all the blood transfusions, blood draws, and chemo infusions he’s had, although for a different cancer than WM. The port has not been a problem, and he never notices it except when

From IWMF Connect, cont. on page 24

it is accessed. It does have to be flushed every month, but it has been used at least monthly, so he has not needed to make any special trips to his infusion center.

Jim L had a different view. He has had a number of infusions of Rituxan and bortezomib (Velcade), then Rituxan maintenance. These were all done through a vein in his arm. He never has had any trouble, and his vein remains robust; however, he noted that this combination of treatments is not harmful to the veins, unlike bendamustine.

Janet M wrote that she had a port placed due to the issues of pain and access pointed out by Lori. Janet noted the downside is that a port is noticeable, like a raised bump, and you may not be able to wear some low-necked clothes. Janet puts a band aid over it when wearing a bathing suit. It was a bit bothersome at first due to the tubing, but she got used to it, and she would do it again if needed.

Christie A answered that she is an infusion and vascular access nurse with 25+ years' experience. She noted that a port lasts a long time and is low risk for infection as long as it is maintained carefully. A port is flushed monthly to every six weeks, and no dressing is needed.

Finally, **IWMF Trustee Dr. Tom Hoffmann** responded. He noted that ports do have a lower infection rate than other access lines. However, if an infection occurs, it is much worse. Septicemia and cardiac valve endocarditis are possible. But ports are great when needed. It is OK to leave a port in place forever if there is a high chance of additional therapies or prolonged need for blood draws. Any sign of infection, like red skin over the port or a fever, needs to be reported to your doctor immediately.

VEIN ACCESS

A corollary discussion developed relating to the use of veins, keeping veins accessible, and administration of some medications by subcutaneous injection.

As part of the discussion of ports, **Christie A** also added that she gives IVIG most days, and if a person's veins are not great, and he/she is going to continue getting infusions, she highly recommends a port. She knows many patients who had one placed and never regretted it.

However, **Peter DeNardis** answered that he has had over 50 IVIG treatments through peripheral veins monthly since 2017. His multiple IVIG infusions, blood draws, and recent hospital stays have made it quite the experience when it is needle time. Some draws are much better than others. He tries to stay hydrated and asked if there are other ways to help make one's veins more accessible. Might there be exercises that help? He also asked about subcutaneous gamma globulin. Have there been any issues with long-term treatment by this method of administration?

Julie T offered that in the past she has wrapped her arm in a heating blanket, which helped. She also found that a brisk walk with swinging her arms normally seemed to help pool blood in her arms. She then would hang down her arms just before the actual blood draw. She finally opted for a port, though. She only had a chemo regimen, not IVIG.

Paul L added that he had two years of biweekly transfusions, plus monthly IVIG. He uses an "industrial strength" heating pad, (Thermaphore Moist Heat) in order to get his arm super warm. He also hydrates.

Scott K posted that he had a severe allergic reaction to IVIG but has been told the latest subcutaneous product is much less likely to cause reactions. He was also told that since it is given at a lower dose and is more slowly absorbed, he may tolerate it better. He has had around 200 pheresis treatments, and his veins always have been excellent. Hydrating with water and non-sugared sports drinks the day before, along with simple moderate weight and repetition curls, works wonders for his vein size.

ZANUBRUTINIB

Although this treatment still is in clinical trials, it appears to have great promise, and some members of the group have posted notes about their own experiences.

Richard F stated that he recently found out about the zanubrutinib (Brukinsa) clinical trials that have opened in Boston, New Jersey, and Ohio. He sent a note to Dr. Castillo asking about the differences between this and ibrutinib (Imbruvica), which has a similar mode of action. Dr. Castillo answered that it is too soon to know what the differences in responses will be. He told Richard that zanubrutinib seems to be more potent and have fewer side effects than ibrutinib. Richard asked for reports from others who have been in one of the clinical trials.

Peter S answered that after six weeks on zanubrutinib, he feels very well. So far, he has had no adverse effects. He has gone back to work and remains cautiously optimistic about long-term effects.

Peter F added that he has been in a trial for 25 months and has been doing reasonably well. Blood testing has shown good results, and he remains fairly active. The only side effects are occasional petechiae. He has started to get dermatitis, but he does not know if that is related to the medication or not.

However, **Edna T** reported that she developed elevated blood pressure, dizziness, and stomach aches. Initial workup was completely negative for a major adverse event, and her doctors had her stop zanubrutinib and

her anticoagulant. Her doctors thought they had found evidence of internal bleeding; they did find a small benign tumor in her bladder, along with a bladder infection that she was advised was not completely unexpected since zanubrutinib can result in a person's being more susceptible to infections. She was treated with antibiotics and started feeling much better. She later reported that after a month in the trial, her IgM had decreased by 55%, for which she was grateful. Prior to the urinary tract infection, she was

feeling better than she had felt in years.

Again, this is just a small sample of what is posted online in IWMF Connect. If anyone has questions or would like 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

EDITED BY CHRIS STAY

PLEASE NOTE

Contact information for all support groups is available at
www.iwmf.com/get-support/us-and-international-support-groups.

Details of support group meetings and other upcoming events are posted on www.iwmf.com under **NEWS & EVENTS**. Please check there to confirm details of future events.

CALIFORNIA

Orange and San Diego Counties

This group had its second Zoom meeting on May 16. New connections were made (two members discovered that they live just blocks from each other), and WM stories were shared. Experience with WM ranged from 20 years on watch and wait without any treatment to someone who was very recently diagnosed and wanted to know how to seek a second opinion. For a while the group had two screens going during the meeting. Group Leader Julianne Flora-Tostado expressed her pleasure that the IWMF has given WMers and caregivers the ability to be supported with Zoom during this difficult time.

Julianne Flora-Tostado reporting

CONNECTICUT

On May 9, twenty-four WMers and caregivers from the Connecticut WM Support Group held their first two-hour Zoom meeting in the comfort of their homes, whether it was in CT or FL, VA or NY. In one case it was even from a car! Members shared personal updates and tips on managing during the COVID-19 pandemic. Special guest Newton Guerin, the new IWMF president and CEO, joined the group for a few minutes of interactive conversation. Newton updated the group on how the IWMF is continuing to work on WMers' behalf and shared news of education opportunities

that were currently being planned. Members want to continue using Zoom for the foreseeable future and were in favor of more frequent Zoom sessions being scheduled. Details will be listed on the IWMF website Events Calendar.

Bob Ulkus reporting

FLORIDA

Sarasota

The Sarasota group held its first virtual meeting on April 28 with seven in attendance. The group was joined by Lauren Walcott, MSW, manager of Patient & Community Outreach at the Leukemia & Lymphoma Society. Lauren educated the group about programs available to patients and caregivers.

Michelle Postek reporting

Tampa Bay

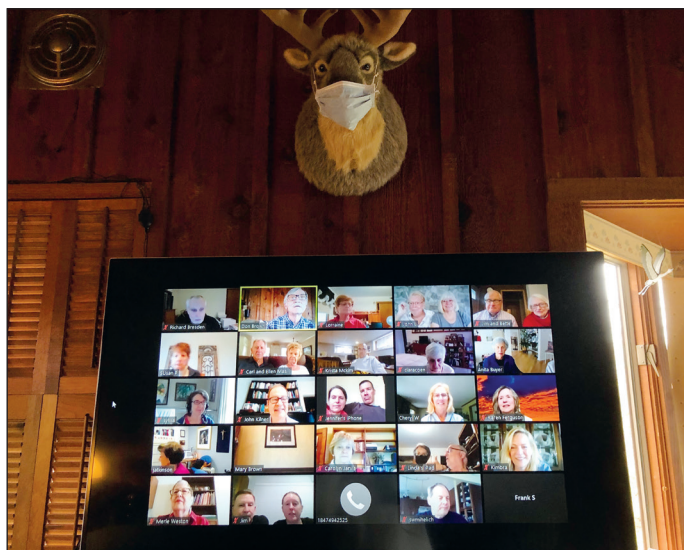
Ray Vance has started a support group for the Tampa Bay, FL, area. After being diagnosed, he spent three years looking for information on Waldenstrom's. He found the IWMF, but since the closest support group was two hours away, he decided to start a group in Tampa Bay. He says, "I felt there should be (a support group) here to help new patients and support those who need information, and as I no longer work and have the time to start a group, (I decided) I should." Before Ray retired, he owned and ran Able Pest control. A

Support Group News, cont. on page 26

Mason, he is a two-time past master, which means he ran the lodge of about 180 members. Two of his favorite things are playing with his grandson and going to parades with his Shriner brothers.



Dr. Janis Atkinson joined the Chicago Area/SE Wisconsin Zoom meeting.



The Chicago Area/SE Wisconsin Zoom meeting took place under the Brown's masked (faux) deer.

ILLINOIS

Chicago Area/SE Wisconsin

Thirty-five Zoom screens lit up Don and Mary Brown's large screen TV on April 25. The agenda included two videos from a local Chicago area TV station, one regarding how the coronavirus enters the body and a second showing how the body fights the virus with IgM and IgG molecules. Don also presented a short version of his new patient perspective that he and Mary had planned to present at the canceled IWFM Education Forum planned for June of this year. Dr. Janis Atkinson, laboratory medical director, Saint Francis Hospital, and vice president of Medical Affairs, ALVERNO Laboratories for AMITA Health, joined the meeting and answered questions. Dr. Atkinson has been very busy working COVID-19 issues for Illinois residents. She was able to help the group understand testing issues and new serology tests being developed locally. During the call, attendees raised questions and commented on their

experiences with ibrutinib and acalabrutinib relating to side effects and response. The response to the meeting was very much in favor of doing more Zoom meetings even after the pandemic subsides. The attendance and convenience made it very useful both for the presenter and attendees.

Don Brown reporting

EASTERN MASSACHUSETTS

The Eastern MA Support Group held two Zoom meetings in the spring of 2020. For our first meeting on March 22, we shared our stories with one another and then had a presentation from Larisa Patacchiola, MSW, LICSW, hematology/oncology clinical social worker from Dana-Farber Cancer Institute. Larisa's topic was "Dealing with Uncertainty," not only that of a rare blood cancer like WM, but also COVID-19. Larissa shared many strategies and offered a number of resources to participants.

The second Zoom meeting was on May 24, with 19 participants, including a member in Puerto Rico and several caregivers. This was more of a chat meeting, billed as a "tea party," though few people seemed to have brought tea or cookies. We caught up with and supported one another and had a chance to meet several new members who ordinarily live too far away to get to our meetings in Boston. After WM updates, we shared tips on keeping ourselves mentally and physically healthy during this stressful time. We also discussed dealing with appointments and medical issues in remote visits and what precautions folks were taking to stay safe during quarantine.

We plan to continue meeting via Zoom every few months until it is safe enough to resume in-person, and even after that, since the format seems to work well. We still need to work out the issue of virtual snacks!

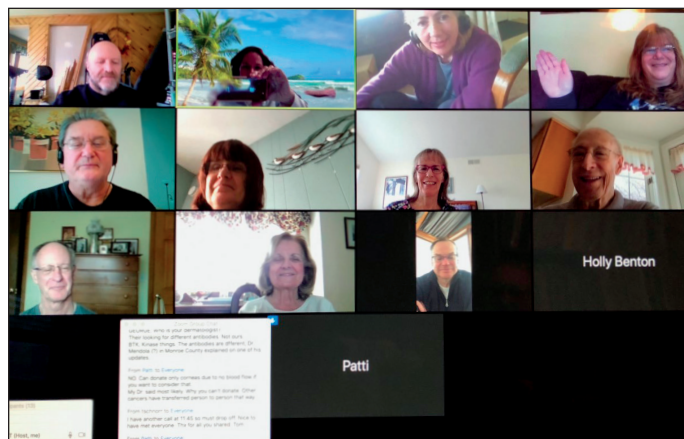
Eileen Sullivan reporting

NEW YORK

Western NY

On April 16 the support group of Western NY had its first virtual meeting, and a successful one at that! There were 19 participants, including seven members who joined for the first time. Several of these new attendees live a considerable distance from Rochester, making the drive to the usual luncheon meetings a challenge. The new members were quite interested in hearing the experiences and journeys of the regulars, and vice versa. The recent news that ibrutinib may be helpful in treating COVID-19 generated an interesting discussion. Also, members wondered whether or not it was important to continue to get lab work for telemedicine visits. If so, what is the safest way to accomplish that: going to a hospital, a small lab, or having it done at home? Technically, the meeting went well—a few people didn't have video; some

Support Group News, cont. on page 27



Smiling faces of Western NY WMers!

had to make adjustments for audio. The group found that it was important for all to mute when not speaking, otherwise background noise interfered. Participants were appreciative of the opportunity to see and talk with other members. It also provided time to de-stress. All agreed that the experience was worth doing again in the not-too-distant future.

Lynn Milliman reporting

OREGON & SOUTHWEST WASHINGTON

Our support group tried a new approach April 4, when it became obvious that in-person meetings were not going to happen for some time. Using Zoom, we “met” some old friends and welcomed a few new WMers. The advantage of Zoom calls, besides being so simple to use, is that they allow those who live farther from the meeting place to join the conversation, participate, and hear the speaker’s presentation. Most folks on the call joined by video, with a few calling in by phone. Our next virtual meeting is scheduled for June 13, and we’re hoping for an in-person meeting on September 13.

Cindy Jordan reporting

PENNSYLVANIA

Philadelphia

Who could ever have imagined what a treat it would be to have had 25 WMers gather together in the same room at the same time at the meeting on March 1? It was wonderful to be with each other in person at Lankenau Medical Center in Wynnewood, PA, to share stories, connect deeply, and support one another on their WM journeys. Each person offered a special touch in welcoming two newcomers to the group. Wise words of wisdom, along with much warmth and good humor, were shared in talking about life with this disease. It is always heartwarming to see the “WM family” rallying around newbies.

Our first Zoom meeting was held on March 22, when 22 WMers joined a virtual WM tea party. The world can feel a little intense right now, so we thought it might be lovely to take a break from the news and share a spot of tea with good friends. With “connecting” being the only agenda, it was an informal time to drop in, catch up, and see friendly, smiling faces. Folks were encouraged to bring their favorite tea and teacup (or coffee mug) to sip from, and easy Zoom instructions were provided in advance. Although remote meetings will never replace in-person meetings, it was helpful to use this supplemental resource to support one another virtually while this pandemic prevents meeting together in the same room. There is no better time to go virtual, and we look forward to more!

On May 3, fifty WMers enjoyed a lively, engaging, and informative conversation with Dr. Jorge Castillo, clinical director of the Bing Center for Waldenström’s Macroglobulinemia at Dana-Farber Cancer Institute. They had a plethora of pre-submitted questions answered, learned more about WM and COVID-19, and enjoyed seeing each other’s smiling faces.



The Philadelphia Support Group last held an in-person meeting on March 1.

Support Group News, cont. on page 28



The Philadelphia area's first Zoom meeting had a virtual tea party theme.

NOTE: Dr. Castillo's conversation can be seen at <https://tinyurl.com/ybjsc83f>. Use the password 9s#j0c.\$ to open (note a zero after the "j" in the password and a period before the "\$" sign.)

Lisa Wise reporting

TEXAS Denton

The Denton Area Support Group had its first Zoom meeting May 16. Thirteen members connected with the group, coming from the Denton and Dallas areas and from Oklahoma, with four first-time members, all recently diagnosed (one as recently as a week before the meeting). The meeting started with introductions, hearing from everyone about their WM



The Denton, TX Area WM Support Group met via Zoom in mid-May.

journey, which spurred lots of questions and discussion. Kelli Oldman, a dietitian/nutritionist affiliated with the Simmons Comprehensive Cancer Center at UT Southwestern Medical Center in Dallas, joined the group and provided great information about improving our diets, as well as giving tips and strategies for dealing with issues that can come up during treatment for WM. After the presentation, the group continued sharing and learned even more about the various paths WM can take, depending on the individual. Overall, the Zoom format worked well, with few technical difficulties. The next Zoom meeting will be in July.

Cathy Hartman, reporting

VIRGINIA Richmond

Margaret Long is the new support group leader for the Richmond area. She was diagnosed with WM in January of 2017. She says, "I volunteered to become a support group leader because I needed one! After coming home (from treatment), I was alone. All the time. The WM Facebook group became my literal lifeline, and I just wanted to extend that understanding and comfort to others near me who might also feel isolated." To recharge her batteries, Margaret loves to be around dogs and horses, specifically Connemara ponies, which she used to breed, raise, and train. She also has started a business doing custom longarm quilting.



Seventeen people joined the Seattle Area Support Group's first virtual meeting.

WASHINGTON

Northwest Washington/Seattle

The Seattle Area Support Group met in a Zoom meeting for the first time on May 6. It was fun to finally get together again, even virtually, with 17 members participating. We welcomed a couple visiting from Colorado and caught up on our news, including an interesting report from Janet McIntosh, who had been flying to Boston every month for a zanubrutinib study. That, of course, isn't possible now, but she is currently getting the drug by mail; she says that she and others on the study are very happy with the results. Perhaps with such ease of virtual connections, we will keep in touch more frequently with Zoom meetings.

Shirley Ganse reporting

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE



WMUK supporters took part in the 2.6 fundraising challenge.

UNITED KINGDOM

I am writing this from my garden office in leafy North London at a time when the UK is starting to take its first steps out of lockdown due the coronavirus pandemic. Early signs are that social isolation measures will remain in place for the foreseeable future here in the UK, and London is a strange mix of deserted public places, yet packed Tube trains, as people follow the latest advice and return to work. Here is a snapshot of how the coronavirus pandemic has impacted us in the UK and the work that we are doing at WMUK to help our community.

The UK government's approach since the start of the pandemic has been about protecting the National Health Service and ensuring there is capacity to deal with high numbers of people affected by COVID-19. Alongside the general instruction to everyone to stay at home, the government issued specific guidelines about "shielding" people who are "clinically extremely vulnerable," which includes people with WM. Shielding means not leaving the house, avoiding all gatherings of friends and family in private spaces, and avoiding contact with anyone showing symptoms of coronavirus. Those in the clinically extremely vulnerable category were contacted by letter or text by the health services; they could then register for support for day-to-day activities such as shopping. Shielding remains in place until the end of June, when it will be reviewed.

It has been a time of great anxiety and some confusion for WM patients and their families. Some patients did

not receive letters about shielding and found it difficult to self-register. Many of those who did register told us that they struggled to access the support they needed. The online forums and support groups have been places where people can discuss these concerns first-hand, and there has been a wonderful response from the WM community around supporting each other during this period of extended isolation.

At WMUK, over the last few weeks, we have received 50% more calls and emails from our community seeking help and advice about the impact of COVID-19 and WM. We have put in place new support and information initiatives to help, including a COVID-19 page on our new website <https://www.wmuk.org.uk/support/covid19> and a regular e-newsletter to keep the community up-to-date with latest developments in WM. We also launched a private WMUK Facebook Support Group.

WMUK Trustee and leading UK WM expert, Dr. Shirley D'Sa, from University College London Hospital, has been busy answering questions and writing helpful articles for the WM community. Her latest article "Viruses vs Science: how COVID-19 gives itself away" is available on our website (www.wmuk.org.uk/get-involved/news/viruses-vs-science-how-covid-19-gives-itself-away) and looks at the science behind the COVID-19 pandemic and what we know about the virus so far.

Like the IWMF, we have decided to postpone our annual Patient-Doctor Summit and reschedule it for spring 2021.

Rising to the challenge

It has been a challenging time for a small organisation like WMUK. Most of the big fundraising activities in the annual calendar have been cancelled, including the annual London Marathon, which raises millions of pounds for charities, and we saw an immediate fall in our income when the pandemic hit the UK. But WMUK is needed now, more than ever, and the WM community in the UK has been incredible in rising to the challenge to help support the charity and each other. On the date of the London Marathon (26 April), WMUK Home Heroes threw themselves into the national 2.6 fundraising challenge in their own homes and gardens. From supporter Bob Perry's heroic efforts climbing 2,610 garden steps in 50 minutes, to family marathon challenges and power walks on treadmills, to the "Where's Waldy" team taking on a whole host of innovative 2.6 challenges including: running 26.2 miles over a week, each day wearing a different colour of the rainbow, 26 burpees at 26 minutes past the hour for every hour awake in a day, performing

International Scene, cont. on page 30



Bob Perry met the challenge by climbing 2,610 garden steps in 50 minutes.

26.2 yoga sun salutations, and running 26.2 garden laps with cats, our amazing supporters raised an incredible £4,000 and still counting, to help support all those affected by WM.

I wish all our fellow IWMF affiliate organizations well and hope to see you in 2021!

Lindsey Bennister, chief executive WMUK, reporting

INDIA

WM India travelled to Kolkata to conduct our second support group meeting in the city on February 29. We had a wonderful meeting with Anil and Vasundhara Somani, and Rajat and Meena Saha, at the historic Calcutta Swimming Club. Rajat and Anil, both of whom have battled WM for a decade, shared their experiences and deep knowledge of the disease and its manifestations. They also spoke in-depth of their experiences of undergoing treatment, how the landscape has evolved, and how their lives have changed over time. As regional leaders, Rajat and Anil encouraged us along every step of the way when we first reached out to them about our plan to start an affiliate for India. They devoted a great amount of their time and shared their expertise to help us navigate our way as we were finding our feet. To eventually meet them in person at our first support group meeting in Kolkata in 2018 was a privilege. Vasundhara and Meena spoke of their experiences as caregivers and their personal journeys of supporting their spouses as they lived with WM. We had a special and fascinating discussion and did not realize how quickly time flew by!

After our meeting in Kolkata, India began gradually shutting down. By the end of March, the country was under total lockdown. The restrictions because of COVID-19 have been severe and touched almost every aspect of our lives. Our members conveyed to us that the lockdown led them to postpone their scheduled checkups by a few months while those undergoing treatment faced delays. Anecdotally, the supply of important drugs used to treat WM is in flux and may take until June to normalize. While those states badly impacted by COVID-19 have extended their lockdowns till the end of May, many states have begun to lift restrictions.

Closer to home in Bangalore, we were lucky to meet Jaya Mani, who herself had overcome WM for close to a decade. Unbeknownst to us, Jaya was the founder of a very popular boutique in the city and one that we loved and had visited several times before. What a fortunate coincidence it was! Over pasta and coffee, we shared stories of our journeys with WM and much more. In our continuous interactions with Anil, Rajat, and Jaya, we found comfort and kinship and would not have come this far if it were not for their guidance and wisdom.

We have been touched by many stories and lives in our journey of setting up WM India and supporting our members. While our purpose continues to be to support, inform, and encourage everyone diagnosed with this rare disease, we ourselves have grown and evolved because of our members. We are reminded, more so than ever, of the critical importance of doctors and caregivers in the lives of patients. But we are also deeply inspired by our patients and awestruck by their will and determination to overcome. We thank each and every one of you in India and around the world for how much we have learned from you and your continuing impact on us.

Saurabh Seroo, WM India, reporting



Left to Right - Anil and Vasundhara Somani, Saurabh and Rajini Seroo, and Meena and Rajat Saha, at the Calcutta Swimming Club, February 29, 2020.

CANADA

The new reality with COVID-19 has changed how we are all living. In these unprecedented times, Canadian WM patients have continued to support each other but are doing it differently. Face-to-face meetings had allowed us to mingle and socialize as we gave and got support. In the past few months, we have been able to continue supporting each other through virtual meetings. As one of the Toronto Support Group members, Ibrahim Abaza, said, "Now I have a WM family!" If you have not connected with a support group yet, consider joining a Zoom meeting! Please check our Facebook page or website www.wmfc.ca for dates and times. Here are some of our Canadian support group stories.

International Scene, cont. on page 31

Atlantic Canada

In Atlantic Canada, with the pandemic lockdown upon us, in an ever-changing world, we introduced bi-weekly Zoom meetings for our support group members in mid-March. They have been well attended by patients and caregivers. Topics discussed range from current treatments patients are undergoing, to the forever-changing protocols for appointments, blood collection, wearing PPE, to whether we are leaving our homes or not. It has helped to alleviate confusion and mental stress for members. Other topics have included dealing with self-isolation and how to stay connected to family and to what is important. The sessions typically last one hour, with 100% participation from those attending.

Jim Mason, co-leader, reporting

Toronto

On February 26, the Toronto Support Group met at ELLICSR: Health, Wellness & Cancer Survivorship Centre in Toronto General Hospital in downtown Toronto. After a few important announcements we watched part of the presentation that Dr. Steven Treon gave to the Montreal Support Group in November 2019, "Updates on the Genomics and Treatments of Waldenstrom's Macroglobulinemia." Attendees found it very valuable. It was attended by 20 members, and after the video members were free to ask questions and provide updates on their WM journey. The next scheduled meeting was to be on April 29 at the same location. Due to the COVID-19 situation, we decided to have a Zoom meeting instead. About twenty people joined the meeting. For many it was their first experience with Zoom, and it worked well. The meeting was moderated by Betty McPhee, WMFC Support Group Liaison, who did an excellent job of making sure everyone had a chance to speak and ask questions. Most of the time was spent discussing how everyone is keeping safe during these uncertain times, how they are handling doctor appointments, doing lab work, dealing with scheduled treatments, and what actions people are taking to stay mentally healthy as well. It was so well received that the attendees asked to have another Zoom meeting in a month.

Raffaella Mercurio, co-leader, reporting

Ottawa

The spread of COVID-19 has changed the way the world communicates and has introduced a whole new way of life. Virtual hugs, social distancing, self-isolation, and quarantine are now a part of everyday life, an unfortunate necessity to help flatten the curve.

The Ottawa WM Support Group meets six times a year – four regular meetings and two social meetings. Our last meeting was scheduled for April 23. Needless to say, with a state of emergency declared in Ontario, our plans fell through. One of our members had the brilliant idea of holding a meeting over Zoom. We were very fortunate that Paul Kitchen, board chair of the Waldenstrom's Macroglobulinemia Foundation of Canada, has a Zoom account that allows unlimited call

time. Using Zoom was a learning experience for several of our members, including myself. We had fifteen members participate, and we felt that it went quite well.

We learned several lessons from our first meeting: 1. Make sure everyone is logging in at the correct time—different time zones can cause confusion; 2. Sign on a few minutes early in case you run into technical issues; and 3. Most importantly, if you are not talking, keep your microphone muted. This eliminates extraneous noise from being transmitted. I would recommend any secure video conferencing application for times you are unable to meet face-to-face, and not just during the pandemic, but afterwards as well, such as any time that weather interferes with your normal meeting, or when multiple members cannot attend in person but can attend online. As I write this, we are in our ninth week of self-isolating and social distancing, and the Ontario premier has just extended the state of emergency once again. Our motto continues to be "Stay home. Stay safe." We must all remember that there is a light at the end of the tunnel, and that this will eventually be over.

Janet Parcher Cherry, support group leader, reporting

Vancouver

The Vancouver Support Group is doing well. Everyone is taking the restrictions seriously. We have a wonderful provincial health officer, Dr. Bonnie Henry, who urges us to be calm, be safe, and be kind. We are looking forward to our first Zoom meeting!

Catherine Schindell, support group leader, reporting

Montreal

On May 13, a meeting of the Montreal Support Group took place, thanks to Betty McPhee. Danielle Gagnon, Robert Perrault, Mark Seliskar, Lucie Martineau, Claude Gélinas, and I had a congenial and fruitful conversation. Although we are all fluent enough in English, Betty was kind enough to let us carry on in French. We all made a short narrative of our medical history and voiced our questions. As is probably the case with any support group, our stories are all entirely different, which makes the meeting even more illuminating. Lucie and Mark, having had substantial experience in consulting with the Dana-Farber Cancer Institute, shed light on the best way to proceed and what to expect. We have decided to meet again in the fall and, confinement or not, doing it on Zoom is the only realistic way of getting together, as only two of us are actually in the Montreal city area; one lives 100 km northwest, another 125 km southeast, and a third, 250 km northeast! Heartfelt thanks to Betty for bringing this promising group to life!

Paul Cadrin , co-leader, reporting

Calgary

Like it has for other support groups, COVID-19 has forced the cancellation of our regular quarterly meeting.

International Scene, cont. on page 32

Following in the footsteps of other Canadian support groups, we attempted our first Zoom meeting on May 14. We had 13 participants on Zoom, with one audio only. We realized that a couple of our members do not have computers, and a few live in the country where they must pay for time on the internet. We have now learned that the audio-only technique over a land line works very well, and we will be able to offer this service to these members for our next Zoom meeting.

Paul Kitchen, chair of the WM Foundation of Canada, was our guest speaker and provided our membership insight into the workings of the Canadian Foundation, along with a personal history of his journey with WM. One of the more interesting topics he touched on was his recent participation with the the IWWMF-LLS Strategic Research Roadmap Review Committee, in their recent grant review and project-awarding meeting for research in WM. As a result of this meeting and other discussions, the WMFC has agreed to participate financially with the IWWMF in some of its selected research projects. Our meeting included discussions about the effects of COVID-19 on WMers, as well as how to book private medical lab appointments for both our annual and oncology blood work tests for our immune compromised folks during these times. This was followed by a lengthy round table discussion with each

member updating the group with any changes in their WM history and upcoming treatment. Three of our members have had recent stem cell transplants, and the group was very interested in the process, results, and their individual recovery.

All in all, it was a terrific meeting, as we also welcomed two new members to our group. We are looking forward to the end of the COVID-19 restrictions and another Zoom meeting.

Cameron Fraser, co-leader, reporting

SPECIAL NOTE

WMFC would like to recognize the volunteer efforts of Sue Kitchen from Toronto, Stephanie Buchannan from Rothesay, NB, and Sandra Proctor from Quebec. They made masks during this COVID-19 season, which were distributed to 50 WM patients. This is how our WM community supports each other! Special thanks to all the support group leaders and co-leaders for everything they do to support patients and caregivers across the country!

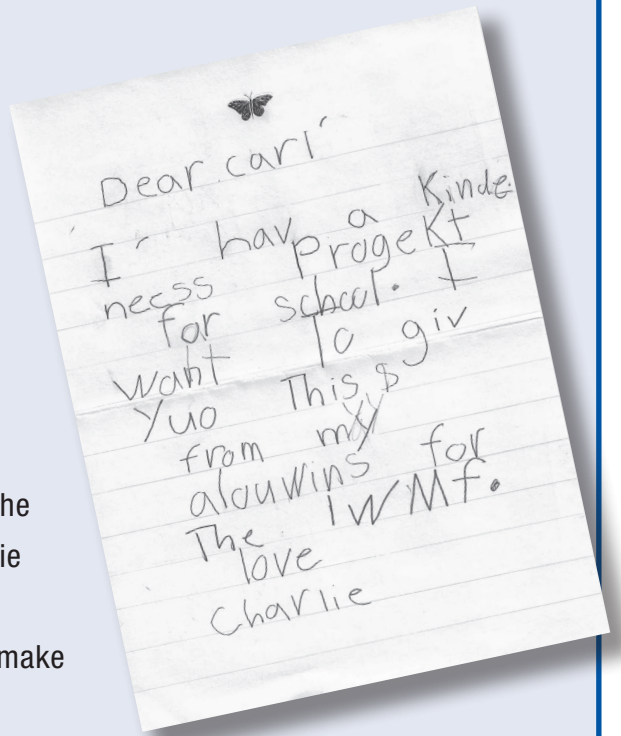
Betty McPhee, WMFC Canada, reporting

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

Never Too Young to Make a Difference

Five-year-old Charlie Atwood took his first steps into the world of philanthropy when he gifted the IWMF \$10. Charlie's kindergarten class was working on a "Kindness Project" for school, and Charlie decided that the IWMF was a worthy charitable cause. Perhaps he made a donation because he was impressed by the IWMF's support of cutting edge WM research, perhaps he made a donation because he was moved by the IWMF's vision and mission, or perhaps it is because Charlie's uncle happens to be Carl Harrington, chair of the IWMF Board of Trustees. We may never know why Charlie selected the IWMF to be a recipient of his hard-earned allowance, but we do know you are never too young to make a difference in this world.



"Charlie is the youngest donor ever to the IWMF* — and based on the size of his donation as a percentage of his net assets, he also might be one of the most generous donors to the IWMF," says proud uncle Carl Harrington. "Every gift to the IWMF impacts the lives of WMers around the globe. It is only with your support that we will be successful in our



Charlie Atwood and his father Mark

mission to support everyone affected by WM while advancing the search for a cure. I encourage WMers everywhere to reach out to their friends and family, and let them know what the IWMF means. Let them know that with the IWMF you are never alone."

*Note: As of the printing of this edition of the *Torch*, Charlie Atwood is no longer the youngest donor to the IWMF. That title now belongs to Carl Harrington's 2-month-old grandson, Miles.

BETWEEN MARCH 1, 2020, AND MAY 31, 2020, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

Ruth Bachner
Martha and Arthur Brody

Sandra Barker
Linda Yount

Sergio Bartolini
Maya and Hans Meyer

Judith Z. Clark of Meridian, ID
Deborah D. Wiking

Robert Cohen
Deborah Diaz
Roger Hickey

Ron Draftz
Angelique Draftz

Carol Ehlers
Otto E. Ehlers

Judy Flaxmayer
Ronald and Mary Flaxmayer

Stanleigh Goldberg
Anonymous
Anonymous
Lisa and Gary Berman
Judy and Richard Kepes
Avi Lebovic
Carol Lempert
Clare Loeb
Dresdner Robin
Shelby and Mikel Robinson
Beth Swartz and Family

Bernard F. Graham
Carlsen & Co Inc.

Jane Hughes
John Hughes

K. Edward Jacobi
Bernard Zablocki

Dudley Killam
Richard and Mary Wendt

Ann Lindsay
Margaret Stevenson Foundation

Patricia E. Lore
Joseph Lore

Dr. Lawrence Ludwig
Kristin and
Phil Ciocca Rence
Ed Fischer
Ruth Hattler
Joe Hessenthaler
Eileen and Bernie Mazis
Gene Noble
Peter Salm
Diane and Albert Schwab
Timi Wolov

Joseph and Mary Malunis
Gary Malunis

Peter Matessa
Carol Matessa

Barbara Matti
Larry and Carol Levin

Valerie Petelin
Joy Lynn Schnell

Robert Reinhard
Carol and
Michael Sesnowitz

Martin Rozenman
Eric Rozenman

Leslie Segal
Anne Lachs

Lt. Col. Arthur Sims
Blanche Kearney
Nevin and
Virginia Zimmerman

Dr. Michael J. Smith
Pernell W. Crockett

Rosemarie Snow
Maya and Hans Meyer

Richard Streicher
Anonymous
Susan Dashiff-Ellman
Joan Ginsberg
Helen Rosen

Alice Swift Riginos
Linda Erf Swift
Joel Ortega
Dr. Vasilis Riginos

Clare Thompson
Bruno and
Domenica Stanziale

Diane C. Treptow
Ron Treptow

Scott Trippel
Ryan O'Hare

Michael Veitengruber
Sheryl and Joel Breza
Jonathan Collier
Mary and
Anthony Krengielski
Rick and Joan Long

John E. Wheeler, Jr.
Bryan and Mary Gosselin

Jack Whelan
Thomas and
Carolyn Shyver

Marcia Wierda
Timothy and Sidney Hoesch
Betty TerHaar

BETWEEN MARCH 1, 2020, AND MAY 31, 2020, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

Leslie Allen's Birthday

Jamie Waggoner

Sandi Lee Bank's Birthday

Sandi Banks
Judie Blonder Doehrman
Ken Devore
Barb Eales
Janet Forney
Michael Kaplan
April Miller
Jen Olcovich
Daya Perkins
Marta Rodriguez

Bill Bass

A. Bruce and
Brenda Campbell

Toni Bodner

Eric Bodner

Simy Bami's Birthday

Simy Bami

Bill Burn's Birthday

Doug Boales
Michael Brookman
Jen Byberg
Brett Bye
Willie Escaba
Tim Fant
Arian Hormozi
Chris Johnston
Joy Liu
Mehmet Orun
Cathryn Reynolds
Mick Smith
Lawrence Snelly

Steven Clair's Birthday

Kathy Bucci
Donna Bucci
Steven Clair
Sarah Clair
Mary Clair
Monica Graham

Clara Coen's Birthday

Clara Coen
David Egeland

Donna M. Cutillo's Birthday

Julia Cleary
Jeanette Cohan
Donna M. Cutillo
Dr. Gary Gottlieb
Lorelei Paster

Chris Downs

Darren LaFrance

Martin Edelman

Carol Edelman

Laurence Elliott's Birthday

Anonymous
Larry Baker
Allison Claire
Carli Conners
Marcy Corson
Kyle Elliott
Brandon Farrow
Ken Krauter
Jim Lewis
Carole Lieberman
Roxanne Lorio Tini
Daniel McLaughlin
William Monach, Jr.
Bill Nichols
Thelma O'Neill

Pat Ruscio

Peter Schlemmer

Elise Shegal

Linda Sterling-Joseph

Suzy Truax

Jack Zoltak

Ed Goldberg

Anonymous
Amish and Arpana Shah

William Hall

Norma Hitson
Richard and Wendy Wallace

Wendy Hall's Birthday

Tony Elder
Amy Holland
Suzanne Johnson
Mindy Jordan
Vicki McMahan

Carl Harrington

Charlie Atwood

Miles Harrington

Carl Harrington and
Elly Levie
Maurice and Ruth Levie

Crystal Dawn Hitchcock's Birthday

Anonymous
Anonymous
Della Freedman
Danielle Garvin
Crystal Hitchcock
Lela Hitchcock
Susan Natter

Mel Horowitz's Birthday

Leslie Boyer
Fred Cole
Dorleen Ehrlich
Tricia Ellen
Liana Goguzad
Marie Miklic
Dan O'Donovan
John Ogden

Leslie Partington
Hugh Patience
Jody Malloy and Family
Bonnie and Mark Turpin

The IWMF

Laurie Barow
Gregory Bates
Mary Beth Elgass
Jan Hergesheimer
Ed Neiweem
Ariel Pertosoff
Jeffrey Schneider

The IWMF Home Office Staff

Steven M. Wit

The IWMF Volunteers

Christine and
Richard Harper

Annette Kocka's Birthday

Deb Vargo

Stanley Koustaal

Murilyn Koutstaal

Jane Loud's Birthday

Vicky Berger
Sandie Bock
Vicki Dennis
Patti Knapp
Jane Larson
Jane Loud
Nancy Loud
Robert McCamant
Jane Pardue
Debra Porter
Sue Pruitt
Sherrill Salisbury
Karen Shepard
Rayleen Stubbs
Deb Wallace

Denise Monk-Simmon's Birthday

Sherry Duda
Joe Hillmann
Stephen Hux
Denise Monk-Simmons
Michel Nonya
Belinda Perry
Marliz Radecker
Jody Richardson
Mike Tisdale

Maureen Murphy's Birthday

Julie Griffen
Duke Grimes

W. Thomas Myers

Sara Franklin

Angel Ogden's Birthday

Angel Ogden

Eunice Quast

Boston Scientific
Heidi Vlasak

Risa Rhodes's Birthday

Suzie Blackwell
Dawn Cardellio
Lori Faulkner
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