IWMF TORCH

April 2019

Issue 20.2

International Waldenstrom's Macroglobulinemia Foundation

INSIDE THIS ISSUE

FOOD, FITNESS, AND CANCER

BY STACY KENNEDY, MPH, RD, CSO, LDN

Stacy Kennedy

Stacy Kennedy is a board-certified specialist in nutrition through the Academy of Nutrition and Dietetics and an American College of Sports Medicine-certified fitness specialist with over 20 years of experience. She is a senior clinician at the Dana-Farber Cancer Institute/ Brigham & Women's Hospital, Harvard Medical School Teaching Affiliates in Boston, MA; adjunct faculty at Simmons College; and co-founder of her private practice, Wellness Guides, LLC. She also serves as a consultant and advisory board member for health and wellness-focused companies. Stacy is a sought-after international speaker, regularly featured in TV, film, radio, print, podcasts, online, and social media. She has a BS in nutrition science and dietetics from Indiana University and a master of public health (MPH) from the University of North Carolina at Chapel Hill. She lives in Wellesley, MA, with her husband, two sons, and three dogs and enjoys running, yoga, cooking, and gardening.

Nutrition and exercise play a powerful role in the prevention, treatment, and survivorship of cancer. Together, they boost energy levels, support the immune system, and provide symptom and weight management, ultimately contributing to overall health and wellness.

Nutrition

The key starting point to a healthy diet is creating a balanced plate. This means filling 50% of your plate with fruits and vegetables, 25% with lean protein, and 25% with whole grains. Include a variety of brightly colored fruits and vegetables to obtain essential nutrients that are important for the immune system. For example, cruciferous vegetables, such as broccoli, cauliflower, and kale, contain potent phytochemicals that promote natural liver detoxification and immune support. Protein is essential for energy and immune function. It also helps to prevent muscle and weight loss during treatment. Consider choosing lean and plant-based protein sources, such as eggs, fish, chicken, hummus, nuts, seeds, and beans. Finally, whole grains and starchy vegetables make up the remainder of our balanced plate. Choose quinoa, brown rice, or sweet potatoes instead of refined grains like white rice and breads.

The key starting point to a ***healthy diet*** *is creating a* ***balanced plate****.*

Food can also help manage treatment side effects. Here are some simple tips to ease symptoms:

- Eat 6-8 smaller meals throughout the day to help manage lack of appetite, getting full quickly, or sustaining energy levels.

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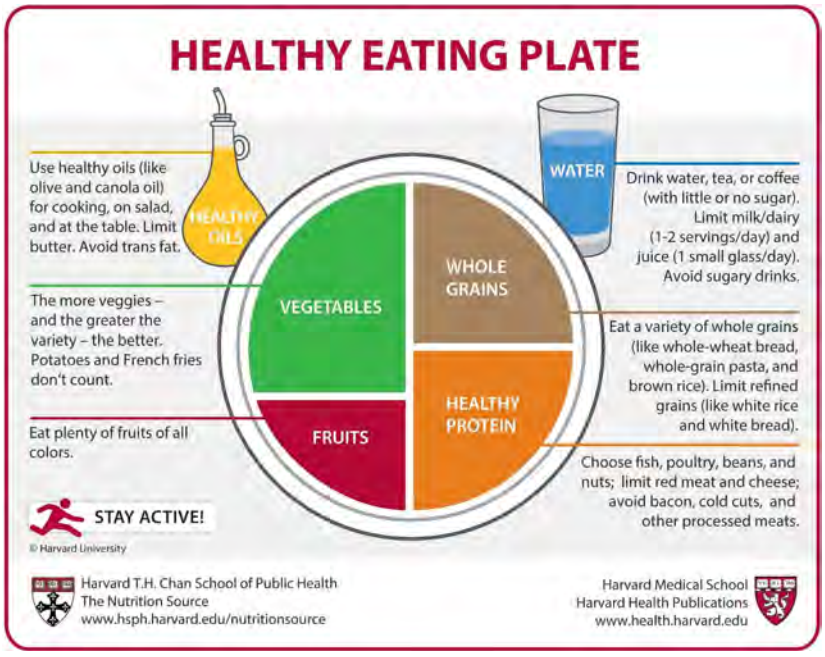

Healthy Eating Plate, from the Harvard University T.H. Chan School of Public Health

- Steep fresh lemon and ginger in hot water for nausea. Include easy-to-digest foods like toast, crackers, potatoes, soups, and smoothies.
- Alleviate constipation with hydration, senna tea, adequate fiber intake, and gentle walking or activity. Try warm beverages and foods like herbal tea, hot water with lemon, oatmeal, and vegetable, lentil, or bean soups.

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SUPPORT • EDUCATION • RESEARCH
IWMF
International Waldenstrom's Macroglobulinemia Foundation

The *IWMF Torch* is a publication of:
International Waldenstrom's Macroglobulinemia Foundation
6144 Clark Center Avenue • Sarasota, FL 34238
Telephone 941-927-4963 • Fax 941-927-4467
E-mail: *info@iwmf.com* • Website: *www.iwmf.com*

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

EDITOR
Shirley Ganse

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SUPPORT GROUP NEWS
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IWMF DOC STAR EDITOR
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PHOTOGRAPHY
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FORMATTING & PRODUCTION
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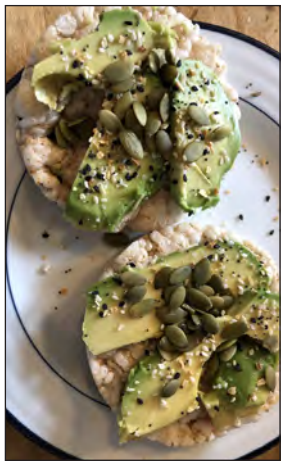
***TORCH* ADVISORY PANEL**
Carl Harrington
Robert Kyle, MD

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

- Prevent electrolyte depletion and nutrient malabsorption from diarrhea by hydrating with electrolytes and achieving the right balance of dietary fiber in foods.
- Avoid concentrated sweets, lactose, spicy foods, extreme food temperatures, and excess caffeine when experiencing heartburn or diarrhea. Bland foods rich in carbohydrates with sodium can help, such as a baked potato with sea salt.
- Snack on tart, sour foods like cherries or citrus to combat taste changes. Hydrate with natural flavors, such as adding fresh fruits and herbs to water; season foods with spices and herbs and avoid contact with metal utensils and packaging.
- To ease peripheral neuropathy, speak with your doctor and dietitian about a B-vitamin supplement (B6 and/or B12). Include colorful fruits and vegetables and healthy fats like those found in nuts, seeds, avocados, and olives to provide natural anti-inflammatory compounds. Be sure to stay well hydrated with electrolytes.



Healthy snack of avocado and seeds on rice cake

Exercise

Physical activity can help reduce the risk of developing cancer. According to the National Cancer Institute, exercise can also play a role in preventing future cancers and may impact quality of life after cancer. Many of us think that physical activity should include running, long gym workouts, or a kickboxing class. However, 30 minutes of walking every day can reduce treatment side effects and promote cancer survivorship. Movement therapies such as qigong, tai chi, and yoga may be helpful in relieving tired muscles and reducing stress. Remember to start slowly, pace yourself, and celebrate small accomplishments. Not only does exercise provide a physical benefit, it establishes social connections, helps fight anxiety, and it can elevate your mood. Explore the various types of physical activity and choose something that fits your lifestyle.

Nutrition Myths and Cancer: Fact or Fiction?

A healthy, balanced diet may seem impossible to achieve with the countless myths regarding food and the development of cancer. Let's take a closer look at some of them:

Myth: All meat causes cancer.
Truth: A large amount of red meat in your diet may raise the risk of getting cancer. Limit servings to less than 18 oz per week. Processed meats, such as hot dogs, bacon, and salami should be consumed less than once a week because of their link with colorectal and breast cancer.

There is no proven, direct link between ***sugar*** *and* ***cancer risk.***

Myth: Fresh fruit and vegetables are healthier than frozen fruit and vegetables.
Truth: Frozen fruit and vegetables are just as healthy as fresh.

Myth: Sugar causes cancer.
Truth: There is no proven, direct link between sugar and cancer risk. However, large amounts of refined sugar can lead to obesity, which increases cancer risk. Limit added sugars to less than 25 grams a day for women and less than 36 grams a day for men.

Myth: All carbohydrates are bad.
Truth: Different carbohydrates have different effects on our body. Stick to lower glycemic foods, like starchy vegetables and whole grains. Avoid higher glycemic foods like cakes, cookies, and candy. *(Editor's note: Glycemic refers to a food's ability to affect blood glucose levels.)*

Myth: Organic foods prevent cancer.
Truth: While experts agree that consuming a variety of fruits and vegetables is healthy, the consensus about consuming organic continues to emerge. According to the National Comprehensive Cancer Network, there is limited evidence to suggest that eating organic foods can reduce your cancer risk. A recent study observed a reduction in the risk of non-Hodgkin lymphoma among women who "usually/always" ate organic foods. These results were compared to women who reported "never" eating organic foods. Look for locally sourced produce, meat, dairy, and eggs in your community; they may have less pesticide compared to store bought items, even without the organic stamp of approval.

Myth: Superfoods such as chia seeds, seaweed, and acai have powerful cancer-fighting properties you can't get with your average fruit or veggie.
Truth: Unfortunately, there is little research to support the overstated claims we often hear associated with these foods. All fruits, veggies, herbs, and spices are "super" for a variety of reasons. Many super foods can be found in one's own local produce and other ingredients unique to the locale. "Superfoods" can be a part of a well-balanced diet to offer new and interesting flavors and options for plant-based foods.

Should I Be Taking Supplements?

Many patients ask if they should take vitamin and mineral supplements during treatment. Taking a "food first" approach is recommended. This means trying to get as many nutrients

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from food as possible. The National Cancer Institute, American Cancer Society, and American Society of Clinical Oncology discourage the use of high dose antioxidants such as vitamins C, E, and carotenes, in pill or supplement form, during radiation and chemotherapy, as they may reduce treatment effectiveness. However, eating foods rich in antioxidants like blueberries, oranges, spinach, and sweet potatoes do not pose any risk during treatment; they provide important nutrients in an ideal dose and form.

If you're concerned, micronutrient deficiencies in magnesium or iron, for example, can be detected through blood tests. Talk to your physician and registered dietitian to discuss a safe approach for correcting deficiencies.

Another popular interest is the benefit of probiotics. Probiotics are healthy bacteria that can improve upon the gut flora that live inside our digestive system. They can be found naturally in foods like Greek yogurt, kefir, and fermented foods, but also in supplement form. While probiotics can provide gastrointestinal benefits, like helping control diarrhea, they are not necessary for everyone. Consult your physician or registered dietitian before adding probiotics into your diet.

Click on the following links for further information:

"A Prescription for Healthy Living: How Diet and Exercise Can Help Cancer Patients"
blog.dana-farber.org/insight/2018/09/prescription-healthy-living-diet-exercise-can-help-cancer-patients/

"What Is a Balanced Diet?"
blog.dana-farber.org/insight/2019/02/what-is-a-balanced-diet/

"Exercise as Part of Cancer Treatment"
https://www.health.harvard.edu/blog/exercise-as-part-of-cancer-treatment-2018061314035

"More Evidence of Exercise for Cancer Prevention"
www.aicr.org/cancer-research-update/2016/05_18/cru-More-Evidence-of-Exercise-for-Cancer-Prevention.html

"Debunking Common Nutrition Myths [Infographic]"
blog.dana-farber.org/insight/2014/04/debunking-common-nutrition-myths/

"Does Sugar Cause Cancer?"
blog.dana-farber.org/insight/2015/05/does-sugar-cause-cancer/

"Nutrition for Cancer Survivors"
www.nccn.org/patients/resources/life_after_cancer/nutrition.aspx

"Human Health Implications of Organic Food and Organic Agriculture: a Comprehensive Review"
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5658984/

PRESIDENT'S CORNER

BY CARL HARRINGTON

The Cost of Treating Our Disease

Recently, someone posted the following thought on IWMF Connect: "This is where I think the IWMF is ignoring the elephant in the room. They talk about finding a cure (or better treatments). But of what value is a better treatment or cure if it can't be accessed by the patient. The cost of the drugs that are currently available is blocking access for many with WM. If the IWMF is serious about finding more effective treatments or a cure, they need to get involved in addressing the issue of access and affordability."

Since affordability and access are huge issues for all of us, I wanted to share and expand upon the response I sent on IWMF Connect, so everyone can know what the IWMF is doing and what you personally can do.

The cost of drugs is a real concern to all of us. There's even a fancy term used in the health care industry about this, called "financial toxicity." The concern is that cost will get in the way of patients and their doctors choosing the best treatment for their disease.

While financial toxicity is a new and significant phenomenon in the US, it is also of concern in other countries. However, outside of the US the issue can become access to newer treatments rather than their cost to the patient. That's because most health care systems outside of the US won't allow new drugs to be used until they meet a "benefit vs. cost" criterion. What that means is that WMers outside of the US may not have access to the same novel drugs as WMers in the US do. Since health care systems differ by country, approvals need

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to be made on a country-by-country basis to give WMers in those countries access to the newest drugs. Or said another way, there isn't one room and one elephant. Rather, a series of rooms and elephants are hindering accessibility and affordability of the drugs we need. Those rooms and elephants are the differing health care systems found around the world.

I wish we could wave a magic wand and give every WMer worldwide immediate access to the best WM drugs available at an affordable cost. To make that possible, we would have to change the healthcare system of every country in the world.

What the IWMF Is Doing to Remove Barriers to Drug Accessibility

The IWMF and its partners are involved in the issue of treatment access and affordability. Let me give you six examples of actions we have taken, or are taking, to address financial toxicity.

1. By now, you have all seen our welcome e-News piece of a **50%** increase in the reimbursement available to WM patients through the Leukemia & Lymphoma Society (LLS) Co-Pay Assistance Program. In the past, this program had a limit of $5,000 for WM. In 2019, that will increase to $7,500. To see how to qualify, go to *https://www.lls.org/support/financial-support/co-pay-assistance-program*. Our partners at LLS want WMers to understand that insurance premiums and other drugs—such as anti-nausea or anti-diarrhea drugs—prescribed by your doctor to help in your treatment are covered too. There are income limits for this program, which you'll see in the details. The limits are five times the federal poverty guidelines, or about $82,000 for a couple. If you have questions about this program, you should contact LLS directly at the email and phone number listed on its site. Only WMers in the US or US territories qualify for this program. Note that this program has limited funding and opens and closes as LLS obtains outside funding. Check the LLS website regularly to see if funding is available.
2. Last year, Pharmacyclics-Janssen announced a new tablet form of Imbruvica (ibrutinib) that would replace the existing capsules. As part of a new pricing strategy, this change would have increased the monthly cost for WMers on 140 mg or 280 mg by up to $500 a month. Fortunately, we and other patient advocate organizations were able to persuade them to rescind the decision to discontinue the capsules. If you don't remember this, see the IWMF News piece at *https://www.iwmf.com/news-and-events/news/update-regarding-new-imbruvicaibrutinib-formulation.*
3. We have a section on the IWMF website called Financial Assistance at *https://www.iwmf.com/get-support/financial-assistance.* Within this, you'll find the newest information we just posted from LLS. It's a 35-page document called *Cancer and Your Finances*. Take a look if you have questions. *http://www.lls.org/sites/default/files/file_assets/PS79%20CAYF%20Booklet_2018.pdf*
4. If you want to get a second opinion or participate in a clinical trial but are concerned about travel costs, check to see if you qualify for the LLS Patient Travel Assistance Program. This program will allow WMers from certain parts of the US to qualify for two $500 travel allowances over the course of a year. For details and restrictions, see *http://www.lls.org/support/financial-support/patient-travel-assistance-program.*
5. While the examples above are focused on the US, the IWMF also worked closely with our affiliates in Canada (WMFC) and the UK (WMUK) in their efforts to get ibrutinib approved as a therapy in those countries.
6. Finally, at the 2019 IWMF Educational Forum on June 7-9, we will have a breakout session entitled "The Financial Side of Cancer: How Do I Afford My Treatment?" If you can't make it to the Ed Forum in Philadelphia, you'll be able to see the slides from the session posted on our website after the Forum.

I hope this information helps you and other WMers.

In total, our ***volunteers*** *worked* ***over 35,000 hours*** *last year to help us deliver our vision to "****support everyone affected by WM*** *while we advance the* ***search for a cure****."*

What You Can Do

Whenever I hear WMers say things like the IWMF ought to do x or y or z, I'm both gratified and concerned. I'm gratified because most people seem to think the IWMF is a powerful organization capable of almost anything. That's nice to hear! I'm concerned, however, because this is unrealistic and often comes with the intimation that the IWMF is some big, impersonal, bureaucratic institution that is out of touch with WM patients. That worries me because the IWMF is made up of patients and people closely connected to them. I'm a patient; everyone on the IWMF Board of Trustees (except Dr. Kyle and Dr. Ansell) is a patient or caregiver; all of our support group leaders, our LIFELINE volunteers, the *IWMF Torch* staff who created this great issue you're reading, and the folks who create our website and run our research program and the rest of our member services programs are all patients, caregivers, friends, and relatives of WMers, as well

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as volunteers. In total, our volunteers worked over 35,000 hours last year to help us deliver our vision to "support everyone affected by WM while we advance the search for a cure." Those 35,000 hours are about 2½ times the hours our dedicated and hard working paid staff put in. Volunteers are how we get so much done. Not to mention, practically all of our funding comes from patients and their friends and families. If we have more funding, we can do even more.

Finally, the part about what can you do? If you live in the US, you can call or write to your senators and representatives. Hold them accountable! Visit the advocacy page on our website *https://www.iwmf.com/how-you-can-help/advocate.* Since we are so small in the scheme of things for the folks in Washington, we partner with the National Organization for Rare Disorders (NORD), the Lymphoma Research Foundation (LRF), and the Leukemia & Lymphoma Society on advocacy issues. We tried doing advocacy on our own and found we just didn't have the resources. Every time NORD sends a position paper to Congress, the IWMF is one of the hundreds of organizations who sign on as supporters. That's how we leverage our collective clout. But please raise your voice and tell your representatives your story! If you're outside of the US, coordinate your actions with your IWMF affiliate leader.

Why the IWMF Will Keep Working Toward Better Treatments and a Cure

The task of reforming the world's healthcare system is a formidable one that we will continue to work on with our partners. However, we will place greater resources into finding better treatments and ultimately a cure. Why?

- The IWMF is the only organization focused on this goal. For our partners, WM is one of many diseases in their portfolio. For us, WM is our only focus. We are the only global organization dedicated solely to WM patients and caregivers and their needs. If we don't keep pushing ahead in the search for better treatments and a cure, no one else will step into the breach.
- WM is the same disease worldwide. Healthcare systems may vary. WM does not. Any progress we make in understanding WM and moving toward a cure will help every single WMer in the world, no matter what health care system they are in. When the world gets its act together about providing equal and affordable access for all, we'll be there with the best possible treatments and maybe a cure, or something tantamount to a cure, for WM.

Remember the IWMF starts with the letter "I"—as in "What can *I* do?"—and follows with the letter "W" for "What can *we* do?" Together we can go far in making lives better for WMers and their families. With the IWMF, you are never alone!

Stay well,

Carl Harrington

AMBITION, DEVOTION, AND MAKING A DIFFERENCE

BY LISA MARIE KAISER, 2016 YOUNG INVESTIGATOR AWARD RECIPIENT

I feel lucky to share my story with you, the WM community that is my everyday motivation. I didn't choose a straight path into science; my unusual career combines my passion about driving change and my authentic interest in science. Growing up in a small town in south Germany, I learned early about the importance of science and the "nobles" in research—because Lindau, on Lake Constance, is the place where, since 1951, the annual Nobel Laureate meeting has taken place.

Becoming a scientist wasn´t just something I was drawn to; the decision came after extensive soul-searching, and it was my own and honest wish. Starting as a lab technician and working as a lab manager for many years, I felt that the laboratory, as the place of ideas and research, always was my home. But at some point I wanted to know more, to dig deeper, to understand and to concentrate on pure science. So I left my position (which broke my heart) and started to study medical

Lisa Marie Kaiser at her workplace, the Institute for Experimental Tumor Research

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science, only possible with a loving family and a supportive mentor. I succeeded with an outstanding performance and was allowed to start my PhD at the University of Ulm directly after my undergraduate studies without doing a master's degree. It was a great honor, given only to the best graduates.

My workplace, where I continue to work on my PhD, is the Institute for Experimental Tumor Research, which belongs to the University Hospital Ulm and the Comprehensive Cancer Center Ulm (CCCU), in Germany. Its primary goal is to promote translational and clinical research in hematology and oncology. Translational in this context means that discoveries in basic research are translated into clinical applications.

The medical director, my supervisor Professor Dr. Christian Buske, coordinates the European Consortium for Waldenström's Macroglobulinemia and the National Marginal Zone Lymphoma Register (MZoL Register). Our lab consists of roughly 20 people, and I am the only one who works on WM; it's certainly not a given to have the opportunity to work on WM in a leukemia research lab.

The primary focus of our group's work is the investigation of tumorigenesis, or the origin, of acute leukemia. Another focus is clinical research and the initiation and coordination of multicenter randomized trials involving indolent B-cell lymphomas (notably WM and marginal zone lymphoma).

Currently, several clinical trials have been initiated with the goal of improving ibrutinib therapy to provide the best possible treatment to all patients. Within the Consortium, I am the responsible scientist for the coordination of a biobank to foster translational research within the network. For more information about the Consortium, go to *http://www.ecwm.eu/home/__zur-Startseite.html*.

When I received the Young Investigator Award in 2016, I was overwhelmed by the support WM patients give to young scientists. The IWWM-9 conference in Amsterdam was my first conference, and I gave my first little poster talk with a heartbeat that was about to explode. I met for the first time other young scientists and physicians who work on WM and I met you—the patients who stand behind us and support us. When talking for the first time with Elena Malunis (a member of the IWMF Board of Trustees), I instantly knew that we were connected. While traveling back to Germany, I made my decision: I wanted to continue to do research on WM, and I wanted to help patients who suffer from WM.

In my spare time, I translated fact sheets written by the IWMF into German to help German patients understand better about their disease. Meanwhile I was working in the lab and studying at the same time.

I am a person who sees beauty in the small and very special things, and a person of strength who is willing to fight for the worth of those things, two aspects that explain why I am especially interested in WM, a very special disease. I am different in my choice of career, and I want to make a difference for the people suffering from WM. So "difference" is one of my key words.

In my current work, I am focusing on a small peptide (a tiny protein) that might have the ability to change future treatments. Thanks to tremendous progress in identifying the genetic characterization of Waldenström's, one of the main genetic characters that defines WM and shapes sensitivity to the drug ibrutinib is CXCR4, a signaling protein that is expressed on the surface of the cell. Our work focuses on a novel CXCR4 blocking peptide called EPI-X4 (endogenous peptide inhibitor of CXCR4) that is generated naturally in the human body.

When I received the ***Young Investigator Award*** *in 2016, I was overwhelmed by the* ***support WM patients*** *give to* ***young scientists****.*

Finding this peptide was a long journey. We had to screen a peptide library of human hemofiltrate (a waste product from patients who undergo dialysis) containing more than one million peptides in order to find that special one. Now with this little diamond in our hands, we tried to find out what it is doing in our body, where it is generated, and why and how it can help patients in the future. By using modern-day technology called RNA-seq and mass spectrometry, we shed light on the inner cell processes of a WM cell when treated with EPI-X4. Interestingly, with this small peptide we have been able to alter the metabolism of cancer cells, which is their Achilles heel.

We are also working on improving the activity of the endogenous EPI-X4 and creating more potent derivatives that are more stable and have a significant impact on certain pathways that are important for cancer cells to survive. Altogether, our data show the potential of a new peptide, generated in our body, which might help to get one step closer to a cure. This work was funded by the IWMF through the IWMF-LLS Strategic Research Roadmap Initiative, and I am immensely thankful for the great support.

For the future, I am interested in the physiological function of EPI-X4 and understanding how it may have an impact on inflammation and immunity. Moreover, it may be possible to specifically alter EPI-X4 production in vivo to treat various diseases. The great potential of this peptide lies in the

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possibility that it can be produced anywhere in our bodies. Optimized EPI-X4 derivatives are of interest for the treatment of a variety of CXCR4-associated diseases like WM. The peptide could improve therapeutic effects with a lower risk of toxicity compared to existing CXCR4 blockers. Thus, these agents have a great potential for clinical development.

My strong curiosity is not just limited to medicine and molecular biology. There are many things that light my fire, in particular classical literature, philosophy, and Homeric and other epics that tell the myths of the ancient Greeks and Romans. I enjoy seeking true human values in the decadent and contrary world of the Greek gods, as well as finding meaning in Nietzsche's wise and beautiful words that go right to the heart to inform a moral and thinking mind.

Goethe has said, *Das ist nicht erdacht, das ist erwandert*, basically meaning "That is not conceived, I've hiked it." I am not just hiding in old books thinking of the world, but I have also seen it with my own eyes, visiting many countries like Africa, Asia, and America with a backpack and a low budget. I've hiked it, learning from other cultures, meeting people, hearing their stories, and feeling life in its purest form.

Lisa Marie Kaiser with her grandmother and role model, Hildegard Kaiser

Difference, ambition, and devotion are my key players. They will lead my way in academia, and I hope to achieve my goal one day to become a professor.

I am devoted to science, and I've simply discovered a way to do more of what matters. I want you to know that there are highly ambitious people around the world who are working restlessly and passionately to make a change for you.

GET READY FOR A PHABULOUS TIME IN PHILLY!

BY LISA WISE & LU KLEPPINGER, EDUCATIONAL FORUM COMMITTEE MEMBERS

Thinking about attending the Ed Forum from June 7-9 in Philadelphia but haven't hit that registration button yet? Here are a few "only in Philly moments" to whet your appetite and give you a taste of our historic and exciting city. As Philly-ophiles, we could not be more excited to welcome all WMers to this great city! Here are seven reasons why you won't want to miss the 2019 Ed Forum!

REASON #1: Are you a **Rocky fan**? Head over to the Philadelphia Art Museum and **grab a cool selfie with the famous statue of the Champ**. Still in training for a jog up those famous steps? Start your program with Stacy Kennedy of Dana-Farber Cancer Institute (DFCI), who will be teaching us all about "Nutrition, Exercise, and WM: The Art of Self Care." Be sure to check out Dr. Jeffrey Matous of the Colorado Blood Cancer Institute for his primer on "Basic Training for WMers"—he will be a KNOCKOUT!

REASON #2: Philly's newest **Museum of the American Revolution** is the buzz of the town, and its tagline is: *"You don't know the half of it!"* If you enjoy two sides to every story, join the "Great Debates in WM." The first debate features Dr. Morton Coleman of Weill Cornell Medicine taking on Dr. Stephen Ansell of the Mayo Clinic on the topic

Elfreth's Alley, historic street in Philadelphia, dating to 1702

"Rituxan Maintenance or Not." The second debate pits Dr. Edward Stadtmauer of the University of Pennsylvania against Dr. Jorge Castillo of DFCI on the topic "Limited Duration Treatment vs. Continuous Pill." Then go find President Carl and a few other locals and ask them all to agree upon the best cheesesteak in town. Enjoy the show!

REASON #3: Seeing all those **coins in production at The U.S. Mint** might make you think about all the medical

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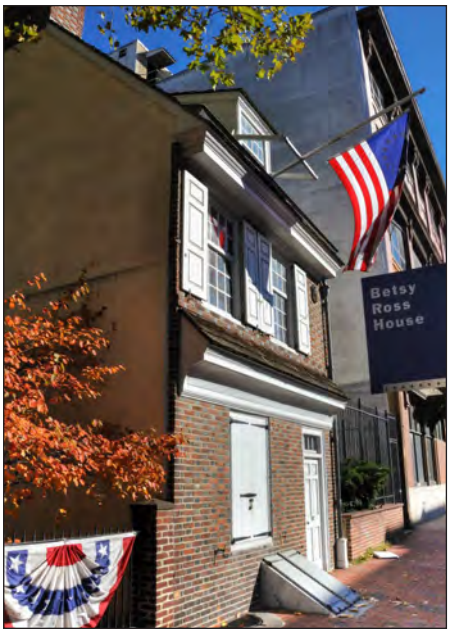
Sights to Visit in Philly!



Betsy Ross House

Philadelphia City Hall

Robert Indiana sculpture in "Love Park" (John F. Kennedy Plaza)

bills stacked up on your desk back home. Come learn about "The Financial Side of Cancer: How Do I Afford My Treatment?" with Dr. Heather Klusaritz of the University of Pennsylvania.

REASON #4: Feeling hungry? Stroll through the **delicious scents and bustling sounds of Reading Terminal** and grab a delectable bite or two along the way. Room for more? We've got you covered! All meals at the Ed Forum will offer healthy buffets. Enjoy mingling at the President's Reception over hors d'oeuvres and be sure to choose your favorite entree selection for the Welcome Dinner on Friday night when registering for the Ed Forum. Saturday night is dinner on your own so gather some old and new Waldenfriends together and enjoy the city's vibrant dining scene within walking distance of the hotel!

REASON #5: Not to rub it in, but…**The Philadelphia Eagles** are the 2018 Superbowl Champions. Think Philly's winning that title was rare? Keep the theme going and check out the presentation by Dr. Jorge Castillo of DFCI on "Rare Complications in WM."

REASON #6: Calling all science whizzes! **The Franklin Institute** is one of the premier science museums in the world and the center of science education and research in Philadelphia. Go check out the exciting exhibits and then enjoy "A Deeper Dive into the Genomics of WM" with research scientist Dr. Zachary Hunter of DFCI.

REASON #7: Can't make it to Philly in person? We'll come to you! Don't miss this historic moment! **Streaming LIVE from Philadelphia… Dr. Steven Treon** of DFCI presenting on "Breaking News from the Front: IWWM-10 & the IWMF-LLS Strategic Research Roadmap Summit." The Tenth International Workshop for Waldenstrom Macroglobulinemia (IWWM-10) was held in New York City in October 2018. It was the most comprehensive meeting to date, with hundreds of physicians from around the globe in attendance. This meeting reflected the continued growth in investigators working on the genetic basis, pathogenesis, and clinical treatments of WM. It continues its mission to help foster discoveries and collaborations leading to more effective treatments and ultimately a cure for WM.

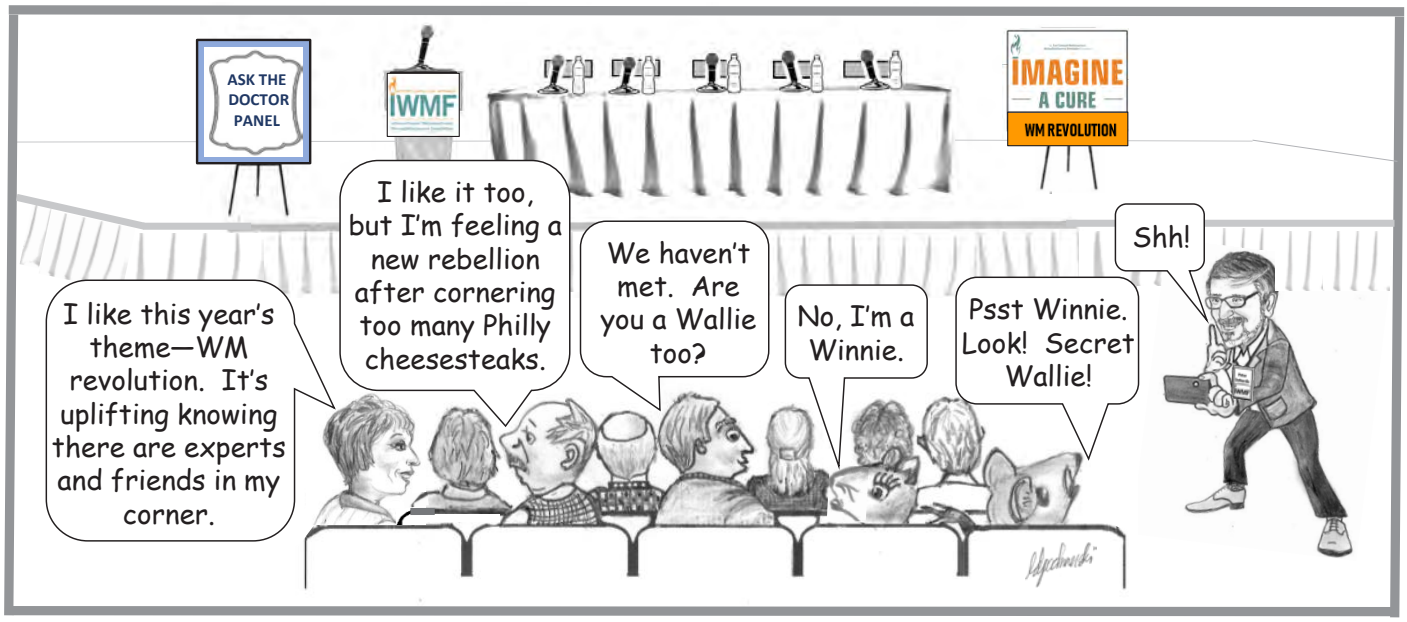
See you in Philly! Come be a part of history in the making. Don't miss the chance to celebrate the progress and JOIN the WM Revolution!

24th Annual IWMF Educational Forum
June 7-9, 2019
DoubleTree by Hilton Philadelphia
Center City Hotel
237 South Broad Street, Philadelphia, PA 19107

**** Important: Ed Forum space is limited and we may sell out early***

Register today and JOIN US in Philadelphia!
https://www.iwmf.com/news-and-events/iwmf-educational-forum

Wally and Winnie, WM Model Mice, attending the 2019 Ed Forum in Philadelphia by Linda Pochmerski



As the attendees wait for the Ask the Doctor Panel to get underway, Wally almost exposes Secret Wallie, (the anonymous IWMF Connect blogger) while taking snapshots for the Forum album.

Walk for Waldenstrom's and Walk from Anywhere!

On Sunday, June 9, at 6:30am at the IWMF Ed Forum in Philadelphia, patients, caregivers, and health care professionals will take part in a 5K walk through some of downtown Philly's most historic areas. They will be sharing their life experiences and their ways of dealing with WM. Many will also be walking to help raise money that will be used by the IWMF as it fulfills its mission to support everyone affected by WM while advancing the search for a cure.

Walk for Waldenstrom's 2018 - Rosemont, IL

Help them reach their goal by donating on behalf of one of the participating walkers or by joining the team and fundraising to help find a cure for WM!

This year, you don't have to be at the Ed Forum to participate as a walker. You can walk from anywhere! Just choose a local route and set up a fundraising page on our website or on Facebook. Encourage your friends and family to support a cause you care about.

Visit the following website to donate or create your own fundraiser for the IWMF today:

https://www.mightycause.com/event/2019-Walk-For-Waldenstroms

Questions? Contact Jeremy Dictor, IWMF Development Manager, at *JDictor@IWMF.com* or 941-927-4963

PENNY WISE: FROM POCKET CHANGE TO INTERNATIONAL IMPACT

By Jeremy Dictor, IWMF Development Manager

On the top shelf in the back of a storage closet at the home offices of the IWMF sits a small metal cashbox. Once used as the preeminent means for storing IWMF donations, the cashbox now rests unused. Twenty years of organizational and financial growth have rendered it inadequate—still, it remains as a dusty reminder of how far we have come. Not only has our financial support grown exponentially over the last two decades, but so too have the various ways of contributing to the IWMF.

In the beginning, the IWMF could accept only cash or checks as charitable donations. Today, donors can gift securities, donate through *www.iwmf.com*, create planned gifts through the Ben Rude Heritage Society, donate real estate, and, of course, donate with cash or a check. In recent years, WMers have begun to donate through donor-advised funds or by making a qualified charitable distribution from their IRA. Through our knowledgeable and dedicated fundraising team, our organization now helps WMers make charitable decisions that benefit both the donor and the IWMF. Some WMers have even begun fundraising themselves! Through various crowdfunding platforms and social media outlets, people around the world are creating birthday fundraisers for the IWMF, sponsoring 5K races, cycling events, and so much more.

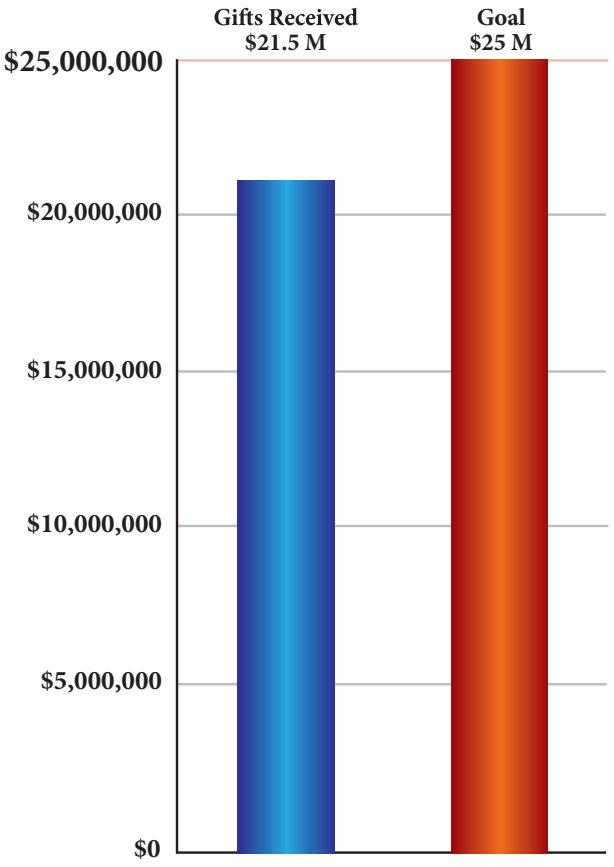
Twenty years ago, we were limited in our treatment options for WM; today we have many options, including an FDA-approved drug therapy. Twenty years ago we had one support group; today, along with our international affiliates, we have over 60. Twenty years ago, the IWMF had 21 dedicated members who banded together to raise almost $50,000 for the WM community. In 2018, with over 10,000 members around the world, dozens of philanthropic foundations, corporate contributions, and grants from pharmaceutical companies, the IWMF raised more than $2.5 million. Your support over the last two decades has empowered the IWMF to dedicate nearly $14 million to WM-specific research. This research has brought about better treatment options for WMers that have led to deeper, longer lasting remissions with fewer side effects. Each gift brings us closer than ever to a cure. No matter how you give, please continue to give.

None of this would be possible without you.

Join the Ben Rude Heritage Society today.
Leave a legacy.

Contact Jason Watkins:
***JWatkins@IWMF.com* / 912-215-2215**

Imagine a Cure Campaign Progress Report as of February 28, 2019



MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF RESEARCH COMMITTEE MEMBER

Bortezomib May Overcome Treatment Resistance in WM Patients with CXCR4 Mutations – Approximately 40% of WM patients have mutations in the gene CXCR4 that may negatively impact response to certain treatments, such as ibrutinib, ixazomib, and everolimus. According to a letter written by Dana-Farber Cancer Institute and published in the journal *Blood*, the use of bortezomib (Velcade)-based combinations may help to overcome treatment resistance in patients with WM who have CXCR4 mutations. The researchers compared the effects of treatment with the combination of bortezomib and rituximab in both treatment naïve and relapsed/refractory WM patients based on their CXCR4 mutation status and found no significant difference in progression-free survival or overall survival when comparing the patients who were CXCR4 mutated to those who were CXCR4 wild type (unmutated). The researchers recommend that their results be confirmed in a prospective clinical trial of WM patients with CXCR4 mutations.

Study Identifies Two High-Risk Genetic Loci Associated with Susceptibility to WM in Families – A multicenter study reported by the National Cancer Institute in the journal *Nature Communications* discussed a genome-wide study of WM/LPL (lymphoplasmacytic lymphoma) to identify the association between inherited genetic variants and the risk of developing WM/LPL. Although the somatic driver mutation MYD88 L265P occurs in most cases of WM, germline (inherited) MYD88 mutations have not been observed, and no predisposing germline mutations have been conclusively reported to date. This study was conducted on 530 unrelated WM/LPL cases and 4362 controls of European ancestry and identified two high-risk gene loci associated with WM/LPL. One locus was at chromosome location 6p25.3 and the other at chromosome 14q32.13, and both were observed at a low frequency among controls, while occurring in excess in affected cases within families. Additional functional and epidemiological studies will be needed to clarify the underlying biological mechanisms and to identify additional susceptibility genetic loci that may influence disease risk.

Ibrutinib Dose Reductions Do Not Significantly Impact Progression-Free Survival in WM – Ibrutinib (Imbruvica) dose reductions are sometimes needed in WM patients to manage toxicity; however, data have been lacking about whether these reductions affect progression-free survival. For this study, 217 WM patients being treated with ibrutinib were evaluated. All patients were initiated on ibrutinib at 420 mg once daily. Older WM patients, patients with higher International Prognostic Scoring System scores, and patients who achieved major responses with ibrutinib were more likely to need a dose reduction while on treatment, according to findings presented by Dana-Farber Cancer Institute during the 2018 ASH Annual Meeting in December. At a median follow-up of more than two years, 27% required a dose reduction; of those who did, 78% were reduced to 280 mg daily, 21% to 140 mg daily, and 2% to 140 mg every other day. Among the reasons listed for dose reductions were cytopenias (low blood cell counts), cardiac arrhythmia, musculoskeletal discomfort, constitutional symptoms (fevers, weight loss, night sweats, fatigue), and skin changes/rash. Overall, patients with mutated MYD88 and those who attained a major response had better progression-free survival. However, those who had a dose reduction in ibrutinib experienced no significant difference in progression-free survival compared with those whose dose was not reduced.

*An abstract from Mayo Clinic presented during the **2018 ASH Annual Meeting** reported on the impact that the depth of response to treatment has on **progression-free** and **overall survival** in WM.*

Depth of Response to Treatment Affects Progression-Free and Overall Survival in WM – An abstract from Mayo Clinic presented during the 2018 ASH Annual Meeting reported on the impact that the depth of response to treatment has on progression-free and overall survival in WM. A total of 181 WM patients consecutively treated at Mayo Clinic between January 1998 and December 2016 were reviewed for response to therapy and disease burden. The treatments included bendamustine and rituximab (Benda-R); dexamethasone, rituximab, and cyclophosphamide (DRC); bortezomib, dexamethasone, and rituximab (BDR); and high-dose chemotherapy followed by autologous stem cell transplant. According to this study, the median overall survival was longer in patients who achieved at least a partial response, and a trend towards a longer overall survival was also seen when deeper responses were achieved with frontline therapy. Among patients achieving a partial response or a very good partial response, those with a normal free light chain ratio after treatment demonstrated a longer progression-free survival and longer time-to-next-treatment.

Retrospective Study Identifies Risk Factors for Progression of Smoldering WM to Symptomatic Disease – A multi-institutional study presented during the 2018 ASH Annual Meeting attempted to determine which patients with smoldering

Medical News Roundup, cont. on page 13

(asymptomatic) WM were at the highest risk of progression to symptomatic disease. This retrospective study looked at clinical data from all WM patients diagnosed and followed up at Dana-Farber Cancer Institute from 1982 to the end of 2014. Only patients with asymptomatic disease at the time of diagnosis were included to identify the risk factors for disease progression, resulting in a study set of 439 patients. During the 35-year study period and with a median follow-up of 7.8 years, 317 patients (72.2%) progressed to symptomatic WM. The median time to progression was 3.9 years. The following were all identified as independent predictors of disease progression: bone marrow infiltration percentage equal to or greater than 70%; serum IgM equal to or greater than 4,500 mg/dL; albumin less than 3.5 g/dL; and beta 2-microglobulin equal to or greater than 4.0 mg/dL. Using these factors and a proportional hazards model that the researchers developed, three distinct risk groups were identified—a high-risk group with a median time to progression of 1.9 years, an intermediate-risk group with a median time to progression of 4.6 years, and a low-risk group with a median time to progression of 8.1 years. The authors indicated that they intend to provide this model as an open access web application for oncologists to use in their practices.

CD13 Surface Marker May Aid in the Diagnosis of WM/LPL – The diagnosis of WM/LPL (lymphoplasmacytic lymphoma) has largely remained one of exclusion from other B-cell lymphomas, especially marginal zone lymphoma, because these other lymphomas can fulfill similar diagnostic criteria. Although the presence of the MYD88 L265P mutation is an important aid in the diagnostic criteria for WM/LPL, testing for the mutation is not available everywhere. A group of French researchers published a study in the *British Journal of Haematology* suggesting that a surface marker called CD13 is more frequent in WM/LPL than in other B-cell lymphomas and has been described on normal and malignant plasma cells. In this study, CD13 expression was assessed by means of flow cytometry testing in 1037 B-cell lymphoma patients and was found to be significantly more expressed in WM/LPL. The authors suggest that testing for CD13 expression in flow cytometry panels, which are widely available, could help to discriminate WM/LPL from other B-cell lymphomas, especially in situations where MYD88 L265P testing is not available.

US FDA Approves Biosimilar for Rituximab – The US Food and Drug Administration (FDA) has approved a biosimilar for rituximab (Rituxan) as a single agent or in combination therapy for the treatment of adult patients with CD20-positive, B-cell non-Hodgkin's lymphoma. The biosimilar, called Truxima, was developed by Celltrion and Teva Pharmaceuticals. A biosimilar is an almost identical equivalent to an original biologic product that is manufactured by a different company—it is an officially approved version of the original "innovator" product and can be manufactured when the original product's patent expires. List prices for biosimilars have generally been lower than those for the original products, although not dramatically so. Truxima's approval is based on data that included extensive structural and functional characterization, animal study data, human pharmacokinetic data, clinical immunogenicity data, and data from two randomized, double-blinded trials of Truxima in follicular lymphoma, which showed no clinical meaningful differences between it and rituximab. The most common adverse events in Truxima trials were infusion reactions, fever, lymphopenia (low lymphocyte count), chills, infection, and weakness. Similar to rituximab, the Truxima label contains a boxed warning regarding increased risks of fatal infusion reactions, severe skin and mouth reactions, hepatitis B reactivation, and a rare and serious brain infection called progressive multifocal leukoencephalopathy. Truxima and another rituximab biosimilar called Rixathon have already been approved by the European Medicines Agency.

*Patients with **hematologic malignancies** treated with anticancer immunosuppressive therapies are at **increased risk** of developing **shingles** (herpes zoster).*

Article Reports Efficacy of Shingrix Vaccine in Patients with Hematological Cancers – Patients with hematologic malignancies treated with anticancer immunosuppressive therapies are at increased risk of developing shingles (herpes zoster). An article in the *Journal of Infectious Diseases* discussed a clinical trial abstract reporting on the safety and efficacy of the new Shingrix vaccine to prevent shingles in adults with hematologic malignancies. The Phase III clinical trial compared 259 patients who were on anticancer therapy or had just completed it and vaccinated with Shingrix to 256 similar patients vaccinated with a placebo instead. At the end of the study, the Shingrix vaccine had reduced the incidence of shingles by 87% overall in patients with hematological malignancies, and the occurrence of adverse events was similar between the study groups; however, vaccine efficacy appeared to be less in patients with chronic lymphocytic leukemia and B-cell non-Hodgkin's lymphoma. The US Centers for Disease Control reports that the most common side effects of the vaccine since its introduction to the public have been fever, chills, body aches and pains, and swelling and redness in the arm receiving the shot.

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Shortage of Shingrix Vaccine in US Continues – Meanwhile, a US shortage of the Shingrix vaccine is projected to continue through 2019. The efficacy rate of the new vaccine (as much as 97% in healthy adults between 50 and 69 years old and 91% in healthy adults 70 years and older) has led more doctors to prescribe it, causing an unprecedented demand by health care providers and patients. GlaxoSmithKline, the manufacturer, has increased production, but the vaccine takes six to nine months to produce. Shingrix is given in two doses, with the second dose to follow two-to-six months after the first dose.

Alert Issued for the Use of Tap Water in Neti Pots – The US Centers for Disease Control (CDC) has sent an alert about the use of neti pots, which are containers designed to rise debris or mucus from the nasal cavity in order to treat symptoms of nasal allergies, sinus problems, or colds. Recently a neti pot user died from a brain-eating amoeba infection after using a neti pot with tap water filtered by a Brita water purifier. Although this type of brain infection is rare, neti pot users are warned not to use tap water directly. Sterile water is recommended instead, and tap water can be used only if it has been passed through a special filter or boiled for three to five minutes, then left to cool until lukewarm. Most bottled "spring" water is not considered sterile, so it should not be used unless similarly treated first. Also, the irrigation device should be rinsed after each use with sterile or previously boiled and cooled water and left open to air-dry.

US FDA Updates Warnings for Fluoroquinolone Antibiotic Use – The US Food and Drug Administration (FDA) has updated its warnings for oral and injectable fluoroquinolone antibiotics due to disabling side effects. The antibiotics include ciprofloxacin (Cipro), gemifloxacin (Factive), levofloxacin (Levaquin), moxifloxacin (Avelox), norfloxacin (Noroxin), and ofloxacin (Floxin). These antibiotics have been associated with disabling and potential permanent side effects on the tendons, muscles, joints, nerves, and central nervous system. The FDA recommends that health professionals should not prescribe systemic fluoroquinolones to patients who have other treatment options for acute bacterial sinusitis, acute bacterial exacerbation of chronic bronchitis, and uncomplicated urinary tract infections because the risks outweigh the benefits in these patients.

Clinical Trial Expands for New BTK Inhibitor Vecabrutinib – Sunesis Pharmaceuticals has opened a new dosing cohort in a Phase Ib/II clinical trial of its BTK inhibitor vecabrutinib in patients with relapsed/refractory chronic lymphocytic leukemia (CLL) and other B-cell malignancies. The new 100 mg twice daily dosing schedule was added based on the safety profile of a lower dosing schedule reported during the 2018 ASH Annual Meeting. The company is positioning vecabrutinib as a potential treatment option for patients who are resistant to ibrutinib (Imbruvica) because it retains its activity in the presence of the BTK C481S mutation, the most common one seen in ibrutinib-resistant CLL patients. Vecabrutinib also inhibits IL2-inducible T-cell kinase (ITK), which may improve T-cell function. The most common adverse events in the lower dosing schedule cohort, which included two WM patients, were anemia, neutropenia (low neutrophil count), and night sweats. It is anticipated that the target dose level for vecabrutinib will likely be between 100 mg and 300 mg twice daily. The trial identifier number on *www.clinicaltrials.gov* is NCT03037645.

Clinical Trial Opens for New BTK Inhibitor LOXO-305 – A Phase I/II clinical trial of a different BTK inhibitor called LOXO-305 is beginning to recruit patients with relapsed/refractory chronic lymphocytic leukemia, small lymphocytic lymphoma, and non-Hodgkin's lymphoma. The drug's manufacturer, Loxo Oncology, has specifically designed its drug to address acquired resistance to ibrutinib (Imbruvica) and to avoid some of the off-target effects of ibrutinib use. In Phase I, patients will receive ascending doses of LOXO-305 to determine the maximum dose tolerated by patients, and a recommended dose for further testing. Researchers will also assess safety, look for preliminary indicators of anti-tumor activity, and determine how the medicine behaves from the moment it is administered to the point it is completely eliminated from the body. In Phase II, researchers will enroll patients in one of six groups. Group 1 will include CLL/SLL patients who failed a prior BTK inhibitor and have a C481 mutation. Group 2 will include CLL/SLL patients who failed a prior BTK inhibitor but do not have a C481 mutation. Groups 3 and 4 will include NHL patients (particularly those with WM, mantle cell lymphoma, or marginal zone lymphoma) who failed a prior BTK inhibitor and either have or don't have a C481 mutation. Group 5 will include patients intolerant to a prior BTK inhibitor, and Group 6 will include those who failed a prior BTK inhibitor but with unknown C481 mutation status or who do not otherwise meet the criteria appropriate for Groups 1-5. The trial identifier number on *www.clinicaltrials.gov* is NCT03740529.

BeiGene's BTK Inhibitor Zanubrutinib Receives Breakthrough Therapy Designation for Mantle Cell Lymphoma – The Chinese company BeiGene has received breakthrough therapy designation from the Food and Drug Administration (FDA) for its BTK inhibitor zanubrutinib in adults with mantle cell lymphoma who have received at least one prior therapy. Breakthrough therapy designation allows the FDA to grant priority review to drug candidates if preliminary clinical trials indicate that the therapy may offer substantial treatment advantages over existing options for patients with serious or life-threatening diseases. Zanubrutinib is designed to maximize BTK occupancy and minimize the off-target effects seen with ibrutinib (Imbruvica); the drug is currently in a head-to-head Phase III study comparing it to ibrutinib in WM patients.

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Interim Results Published for Phase I Trial of Bispecific Monoclonal Antibody in Relapsed/Refractory NHL – Interim results from a Phase I clinical trial of the monoclonal antibody mosunetuzumab in relapsed/refractory B-cell non-Hodgkin's lymphoma (NHL) were reported in the journal *Blood*. Mosunetuzumab is a bispecific antibody that redirects the body's own T-cells to kill malignant B-cells by binding to CD3 on T-cells and to CD20 on B-cells. Among the 98 patients enrolled, anti-tumor activity was achieved at doses equal to or greater than 1.2 mg, and objective responses were observed in 41% of patients who received this dose. The most frequently reported adverse event was cytokine release syndrome and primarily occurred with the first dose. Cytokine release syndrome is caused by a large, rapid release of cytokines into the blood from immune cells affected by the immunotherapy. Signs and symptoms of cytokine release syndrome include fever, nausea, headache, rash, rapid heartbeat, low blood pressure, and trouble breathing. Most patients have a mild reaction, but sometimes the reaction may be severe or life threatening.

Ibrutinib Combined with Nivolumab in Phase I/IIa Study of B-Cell Cancers – The combination of ibrutinib (Imbruvica) plus nivolumab (Opdivo) was studied in 144 patients at Memorial Sloan Kettering Cancer Center with relapsed/refractory chronic lymphocytic leukemia (CLL), small lymphocytic lymphoma (SLL), follicular lymphoma, diffuse large B-cell lymphoma (DLBCL), and Richter's transformation and reported in *The Lancet Haematology* journal. Overall responses in this Phase I/IIa clinical trial were 61% in CLL/SLL, 33% in follicular lymphoma, 36% in DLBCL, and 65% in Richter's transformation. The most common adverse events were diarrhea, neutropenia (low neutrophil count), and fatigue. Nivolumab is an immune-checkpoint inhibitor that enhances the ability of the body's own T-cells to attack cancer.

Nivolumab is an ***immune-checkpoint inhibitor*** *that enhances the ability of the body's own T-cells to* ***attack cancer****.*

Monoclonal Antibody BI-1206 Receives Orphan Drug Designation for Mantle Cell Lymphoma – BioInvent International has been granted orphan drug designation by the US Food and Drug Administration (FDA) for its monoclonal antibody BI-1206 for the treatment of mantle cell lymphoma. The company is currently conducting a Phase I/IIa study of BI-1206 in combination with rituximab in patients with relapsed or refractory indolent B-cell non-Hodgkin's lymphomas across sites in Europe and the US. BI-1206 is a monoclonal antibody that selectively binds to the protein FcgRIIB, also called CD32b, on B-cells. By blocking this protein, BI-1206 is expected to recruit the body's own immune cells to attack the cancer cells and improve the activity of rituximab and other anti-CD20 monoclonal antibodies.

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.*

DR. MELETIOS DIMOPOULOS: IWMF DOC STAR

AS TOLD TO RON TERNOWAY

Dr. Meletios Dimopoulos

Many years before most of us had ever heard of Waldenstrom's macroglobulinemia (WM), Dr. Meletios (Thanos) Dimopoulos was awarded the Robert A. Kyle Award for WM at the Second International Workshop on WM (IWWM-2) in his hometown of Athens, Greece. The year was 2003. Five years later, Dimopoulos added a Jan Gösta Waldenström Lifetime Achievement Award for his contributions to the understanding of this rare malady.

Flash forward to 2018, where Dimopoulos, as chief investigator for the iNNOVATE clinical trial, delivered the exciting results that led to US Food and Drug Administration (FDA) approval for the combination therapy of rituximab and

Dr. Meletios Dimopoulos, cont. on page 16

ibrutinib for WM. To see a video of his presentation on the trial results, go to *https://vimeo.com/275371905*.

Currently Dimopoulos is professor of hematology and oncology, chair of the Department of Clinical Therapeutics, National and Kapodistrian University of Athens School of Medicine, as well as rector (president) at the university. He obtained his medical degree at the University of Athens, completed his residency at the Royal Victoria Hospital in Montreal, Canada, and pursued a fellowship in hematology and oncology at the University of Texas MD Anderson Cancer Center in Houston, TX.

Dimopoulos is a dedicated teacher and researcher, who has written more than 50 chapters in medical textbooks, and he appears as author in more than 900 peer-reviewed journal articles. He is a member of the International Waldenstrom's Macroglobulinemia Foundation (IWMF) Scientific Advisory Committee. In the past 25 years he has directed more than 130 clinical trials.

*"During my **medical education** I also became fascinated by **research**."*

Born in Paris while his family was living and working there, Dimopoulos moved to Athens a few years later, where he completed primary and secondary school. "I was interested in becoming a physician since I was in primary school," he said, "I never wanted to be anything else. During my medical education I also became fascinated by research. I had the opportunity to work and to collaborate with great physicians and researchers who reinforced my decision to become a clinical researcher in the fields of oncology and hematology."

Dimopoulos developed a particular interest in WM during his fellowship at MD Anderson with Dr. Raymond Alexanian. While on the faculty there, he was intrigued by the unique characteristics of the disease, by its natural history, and especially by the treatment of WM.

In 1993 Alexanian and Dimopoulos published the first studies on the use of purine nucleoside analogs such as cladribine and fludarabine, which showed very impressive results. Around the same time he had the opportunity to meet with Dr. Jan Waldenström himself and to discuss with him Dimopoulos's views on the diagnosis and treatment of WM. His contact with Waldenström inspired him to intensify his WM research, and upon returning to the University of Athens he began a WM patient database which has now grown to be a source of priceless data.

Dimopoulos's subsequent research focused on WM therapies, many of which are still in use today. From rituximab to thalidomide to bortezomib, and combinations such as DRC (dexamethasone, rituximab, and cyclophosphamide), BDR (bortezomib, dexamethasone, and rituximab), and most recently IR (ibrutinib and rituximab), Dimopoulos has dedicated more than two decades to understanding and treating WM. "During these years I was blessed to have many collaborators and friends from Greece, Europe, and the USA who have built a strong and dedicated community fighting this disease," he said.

"I have witnessed and feel lucky that I have contributed to the change in the outlook of WM therapies and the development of many new drugs and combinations which have improved patients' lives. I witness the results of this research every day in my practice in the Department of Clinical Therapeutics, especially when I see my patients, some of whom I have been treating for more than 25 years.

"We are living in interesting times and we witness improvements in every aspect of the disease—in the diagnosis, in the treatment, and in the management of the complications of WM. I am very optimistic for the future because the strongest prognostic factor is the dedication of researchers, physicians, and the WM patient community to fight and win the war against cancer."

Dr. Dimopoulos concludes: "Like every physician I have a very tight schedule and very limited free time, with many working hours in the clinic as well as my responsibilities as rector of the oldest and largest university in Greece. However, being in the clinic, caring for patients, and doing clinical research is what I like best, and it never feels like 'work.'"

Dr. Efstahios Kastritis, associate professor of clinical therapeutics and medical oncology at the University of Athens, reflects on his long association with our Doc Star: "Professor Dimopoulos has been my mentor for many years and has introduced me to clinical research and Waldenstrom's; he has made working with him an exciting experience. Every day I admire how he approaches the patients, the disease, and the research with uncompromising passion and devotion. I can only say I am blessed to work with him."

The final words on Dr. Dimopoulos are from Dr. Steven Treon, director of the Bing Center for Waldenstrom's Macroglobulinemia: "Dr. Dimopoulos is a true giant in the field of Waldenstrom's. He has impacted every aspect of care for WM patients, including the development of every modern-day drug that we use to treat WM. He is deeply devoted to his patients, passionate about research, and a gifted teacher and mentor."

FROM IWMF CONNECT: SPRING 2019

By Jacob Weintraub, MD

With winter ending, our thoughts turn to spring and the upcoming IWMF Ed Forum in Philadelphia. However, whatever the season, discussion continues online unabated. As always, new and old topics are discussed. Newly diagnosed people join to ask questions or just absorb the information exchanged. Long-time members have questions about new treatments or symptoms they have not previously encountered. Venetoclax and ibrutinib are the newest treatments that were discussed, but rituximab, bendamustine, and bortezomib (Velcade) also have been discussed. Anxiety in relation to treatment or maybe just to having the diagnosis of WM was also of concern, as was the need for taking special precautions while traveling. Finally, many links are posted to all different types of articles. Some are human-interest stories, some are clinical studies, and others are informational articles, but all are very relevant to our disease.

GENERAL INTEREST

Peter DeNardis, IWMF Trustee and IWMF Connect Manager, posted several links of general interest. One was titled "When Cancer Meets the Internet: Dr. Google doesn't always know what's best." Pete commented that the advice in this article, published in the *New York Times* recently, is something that we all are too well aware of. That's why we gravitate to reliable sources like IWMF and IWMF Connect.
https://www.nytimes.com/2019/01/21/well/live/when-cancer-meets-the-internet.html/

Pete posted an article about how we view our disease. He commented that he often pondered how best to note the anniversary of his own diagnosis without feeling morbid or even guilty in some respects. He felt this article might put us in the right frame of mind for how best to approach this date when it comes up.
https://lymphomanewstoday.com/2019/01/11/lymphoma-diagnosis-anniversary-celebrate/?amp

Pete posted a link to one more article about a caregiver and how she deals with the enormity of cancer, especially one that is incurable and recurs. Many of her insights are true for both the caregiver and the "cared-for."
https://www.curetoday.com/community/diana-martin/2019/01/coping-with-caregiver-pstd

He also posted several links to articles with stories of people with WM. These stories are about diagnosis, treatment, and coping. These can be found on the IWMF website at
https://www.iwmf.com/get-support/stories-hope

Wanda H also posted links to articles of interest. The first one is from a CancerCare blog and it is titled "For Individuals Diagnosed With a Rare Cancer" and explores the challenges individuals face when diagnosed with a rare cancer such as ours.
https://www.cancercare.org/blog/for-individuals-diagnosed-with-a-rare-cancer

Wanda also posted a link to an article titled "Modern myths about cancer: from 'chemicals' in food to wifi." This is a topic that comes up for discussion in the online group, especially about what might have caused our WM. I found this article to be very objective in assessing some of the more common perceived risks.
https://www.theguardian.com/science/2018/aug/20/modern-myths-about-cancer-from-chemicals-in-food-to-wifi

Ron T posted an opinion piece from the *Globe and Mail*, a well-known Canadian news source. This is titled "Don't fall prey to the cult of wellness" and written by a Scottish doctor. Ron commented that listening to his body about when to drink water, how much food to eat, and how often to exercise feels right. He does not wear a Fitbit or Apple watch. He especially liked the ending statement: "Wellness is meant to be good for us—not complicated, not expensive, and not making us slaves of self-absorption."
https://theglobeandmail.com/opinion/article-dont-fall-prey-to-the-cult-of-wellness/

ANXIETY

Anxiety was a new subject presented to the group.

Bruce J is a caregiver for two WM patients but has a friend with CLL who is taking ibrutinib. The friend has severe anxiety attacks and wondered if this could be related to the ibrutinib.

Elle posted that she doesn't have severe anxiety attacks since starting ibrutinib, but she does feel more nervous than before she started. Her doctor prescribed lorazepam, and she takes one occasionally, which does help.

Andrea V commented that whether it is from aging, WM, post-chemo side effects, ibrutinib, or all of these, anxiety attacks have become more prevalent for her. At this time, these have not been severe enough to warrant medication. She finds relief with walking, exercising, and minimizing contact with people.

Christine F added some comments about anxiety in general. She suggested adding facing our mortality to the list of anxiety-producing events. She finds that she is more emotional in general, both in feeling love or gratitude. She cries more easily, but mainly tears of joy for being alive another day.

Beth G noted she used to love people and parties, social and business related. She was very used to crowds, business events, and meeting new people. Last year she started to get

From IWMF Connect, cont. on page 18

dizzy at an event and had to leave early. Her hematologist did not think it was related to her WM. She is now taking ibrutinib but feels the problem is better only because she has curtailed her activities, and she plans to leave an event early, if necessary. She feels the dizziness coming on if she gets excited or deeply engrossed in a conversation and then leaves early. At home, she is more sensitive to loud sounds and the family's lively conversations. She finds that walking, meditating, and hot baths with lavender and chamomile all help. However, she still prefers not to be around people so much. Her oncologist thinks it's anxiety, but she feels she may just be getting more sensitive with age.

Ed G reported he started having anxiety issues a year or so prior to diagnosis. He's been on ibrutinib for almost two years now. He's not sure if it is the medication, the stress of having a second round of cancer, the WM itself, or something else, but his anxiety does seem to be more intense as he ages. His doctor has him on a low dose of Xanax, and this helps. He also finds himself wanting less and less to be around other people, and loud noises really get to him.

IBRUTINIB (IMBRUVICA) AND BLEEDING

Although this topic has been discussed a lot in the past, it recurs frequently because WM patients are started on this medication frequently.

Renee C asked if anyone has experienced little red marks on the skin as a side effect of ibrutinib and should we be concerned. Her boyfriend has been on this for three months and has these marks.

Beth G added her experience. She has had red bumps, something like mosquito bites since starting ibrutinib. They generally show up after a hot shower or bath and usually are tender. Sometimes they are quite large on her ankle, bottom of her foot, knee, and joints. They usually last 48 hours and then fade. Her doctor felt that as her IgM goes down, these bumps would stop, and they have reduced.

John P added that when he was diagnosed with WM, his platelet count was very low, 10,000. He had little red dots on his feet. He has been on and off and on ibrutinib since 2014. He has not noticed these red dots while taking the medication, but his platelet count has risen to over 200,000. He does bruise easily on his arms and hands but does not have prolonged bleeding.

Dr. Tom Hoffmann, IWMF Trustee, added that small red bumps that appear while taking ibrutinib could be from several things. They are most likely petechiae from the drug interfering with the platelets. They are not a serious problem but could be a harbinger of inability to form clots and a possible increase in bleeding problems. Nothing can be done except lower the dosage of the drug or stop the drug, but the bumps are not necessarily an indication for stopping the drug. They should be shown to your doctor. In response to John's post, Tom posted that platelet counts only tell the quantity of platelets. The count does not say anything about how well the platelets work. Ibrutinib affects their quality, so that none of the platelets function normally.

TRAVEL

This is a subject that comes up periodically and generates a lot of good information and sharing of experiences. The last time it was discussed, there even was a comment from a certified airline pilot.

Marilyn S posed a question about precautions when traveling. Her husband has completed treatment, and they want to travel. They note the usual precautions of handwashing, clean food and water, and sanitizing "every surface in sight" but were looking for other hints.

Linda C noted that her husband ended up with pneumonia while on a cruise. More recently, they took a trip to South America, rounding Cape Horn. Again, her husband got sick, this time with a sinus infection. He was taking ibrutinib plus monthly intravenous gamma globulin (IVIG). They brought amoxicillin with them, and she recommends bringing your own medications in case you get sick.

Dan W uses a nasal spray with sesame oil that keeps a protective layer on the inside of his nose. This also helps keep the nose lining moist. He also recommends travel insurance and suggests that a person should know where the best care facilities are located on the itinerary.

Beth G has a very low IgG. Her doctor has recommended IVIG treatment, too. She has not had any infections for the first time in 20 years. She is very careful with hand washing, staying away from sick people, and avoiding small closed rooms with people who may have something contagious. She wipes down surfaces, especially on planes, with antibacterial wipes, and wears a mask. She opens doors with her sweater or fabric, if possible, and does not touch her eyes or mouth with her fingers until she washes her hands.

Marilyn added that her husband was in the hospital this past summer and saw an infectious disease expert. This expert said that three feet is a good distance to stay away from an active cougher or sneezer. Little children are viral "time bombs," which limits contact with her grandchildren. Marilyn has asked to be moved to a different table in a restaurant because someone at the next table was coughing. They try to be as proactive as they can.

Finally, here is a reprint of one comment from the prior discussion a few years ago: **Lydia M** reported on this topic as a certified airline pilot. She stated that there is no difference between airlines in their air recirculation systems, nor is there a significant difference between airplanes. Air on airplanes is much better than most people are led to believe. The problem

From IWMF Connect, cont. on page 19

From IWMF Connect, cont. from page 18

with air travel has more to do with contact with dirty surfaces and close proximity to other people.

I would add that some recent articles show that people sitting in aisle seats on airplanes are more likely to be exposed to infectious agents. Window seats seem to be more protected from people walking in the aisle who might be ill.

As always, the discussions and links here represent only a small portion of the wide range of topics discussed. Everyone is invited to join the group. We hope you will participate, but just "lurking" and reading on the sidelines also is welcome. If you have any questions or wish to see more about our discussions on a particular topic, please let me know, and I will try to include those discussions in a future column. I wish you all continued good health.

COOKS' HAPPY HOUR

BY PENNI WISNER

Spring onions

Just a week or so ago, spring onions and spring garlic made their first appearance at Northern California farmers' markets. (They announced spring even if the weather is the coldest it has been all winter.) Need I remind you to smash minced spring garlic into fresh goat cheese to make one of the season's great snacks?

The sight of those first spring onions reminded me that my mom used to love raw scallions and ate them whole as a snack. I put them raw into salads all the time but never thought, and still don't think, I would eat one from root to green tip. I also remember descriptions in novels of people biting into raw onions as they might an apple. Those must have been spring onions.

Spring onions—red, yellow, and white, and of all shapes from the flattish rounds of cippolini onions to the long, tapered bulbs of red and white ones—are sweeter and crunchier than their brothers and sisters that have been in storage all winter. Please buy them by the bunch(es), bring them home, and start cooking. If you make stews, turn them into spring celebrations by using radishes, turnips, and lots of chunks of spring onions. And don't ignore baby leeks (they are in the onion family after all), chives which are just coming up in the garden, and the scallions, year-round workhorses of Asian kitchens.

Since April can trick you and turn chilly, perhaps soups are still in order. Try a very simple lentil soup: slice a whole bunch of red or white spring onions, including the green tops. Reserve the tops and cook the rest in a soup pot in a little oil until softened. If you have spring garlic, mince it and add a couple pressed cloves of garlic. Cook a minute or two, then add a pound of red lentils (for a sunny look to the finished soup), some salt, and two quarts of vegetable or chicken stock. Bring to a simmer and cook until the lentils are completely soft. Puree the soup with an immersion blender or in a countertop blender. Taste for seasoning and add a spoonful of apple cider vinegar. Serve the soup with the sliced green tops from the onions.

Now this reminds me of a soup I had years ago in New York City (follow the bouncing thought threads here!). It, too, was a lentil soup. But it had an added element: a puree of roasted eggplant seasoned with herbs. Lentils and roasted eggplant—warming and satisfying.

Returning to onions: softly scrambled eggs on toast with a sprinkling of fresh, snipped chives is another early spring delight. Don't just serve it for breakfast; it makes a great appetizer on small toast squares or a soul-restoring supper on an English muffin. (Does your local bakery make English muffins? They are worth searching for.)

While on the subject of eggs, make a spring frittata with lots of onion, garlic, and ricotta. Cook thinly sliced yellow or red onions until soft in a nonstick omelet pan. Add thinly sliced spring garlic and cook another minute. In a bowl, beat eggs just to break them up, season with salt and pepper, and stir in some thinly sliced scallion greens. Pour egg mixture over the onions in the pan and stir to distribute the eggs evenly. Dot with spoonfuls of fresh ricotta. Cover and cook over low heat until the frittata is puffed and cooked through.

Cooks' Happy Hour, cont. on page 20

Cooks' Happy Hour, cont. from page 19

Since we are discussing using spring onions copiously, have you tried David Chang's ginger scallion sauce? He published it in his *Momofuku* cookbook, written with Peter Meehan. I love it mixed into a bowl of warm short grain brown rice for breakfast. Or, do the same for supper, adding a fried egg to the bowl of rice. It is also terrific as a sauce for noodles of all types. Or serve it with shrimp, scallops, crab, and chicken. Oh, and pork, and vegetables: oh, just about everything.

Thinly slice one or two bunches of scallions, both white and green parts, and put them in a bowl with ½ cup finely minced ginger, and ¼ cup neutral-tasting oil, a small splash of soy sauce, a smaller splash of sherry vinegar, and a large pinch of salt. Taste for seasoning. Cover and refrigerate for at least 15 minutes or up to several days. Toss with hot noodles and serve warm or at room temperature.

I always like the option of adding a little spice (or a lot). You can, too. Add a half teaspoon or more of chile flakes to your sauce. Or a little Chinese chili sauce, or chili oil. You could add a little brightness with freshly grated orange or lemon zest, a little funk with a couple tablespoons of minced fermented black beans, and/or a toasty note with a little toasted sesame oil. Try the sauce once without any embellishments and then go where your culinary inspiration takes you.

Scallions (green onions)

Our motto: Eat Well to Stay Well

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

Monterey Bay Support Group – left to right: Tom Rollins, Lee Wilkinson, Vicki Leisses, Mary Schumacher, Cheryl Darling (Mary's daughter), John Justice, Mary Jo (Frank's wife), Frank Warren, and Support Group Leader Suzie Shook

Northern California – Attendees enjoyed refreshments and discussion after Bonnie Andersen's presentation.

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

CALIFORNIA

Monterey Bay

The Monterey Bay IWMF Support Group met in January at the Sutter Maternity and Surgery Center in Santa Cruz. Nine were in attendance, seven WMers and two supporters. They watched and discussed Dr. Jorge J. Castillo's recent video presentation, "What are the best front-line therapies

Support Group News, cont. on page 21

for WM?" available on YouTube at *https://www.youtube.com/watch?v=mT3YSc_HQ4Q*. He is an oncologist at Dana-Farber Cancer Institute and assistant professor of medicine at Harvard School of Medicine.

Northern California

Twenty-two WMers met at the Kaiser Foundation Hospital in Vallejo at the end of January. Member Bonnie Andersen shared what she learned at the 5th International Patient and Physician Summit in New York City last October. In addition, the group had a good discussion about how they personally are dealing with WM.

Sarasota – Every patient and caregiver had a few minutes to share highlights of their personal WM journey as we went around the circle at the Sarasota Support Group Meeting.

FLORIDA

Sarasota

The day offered perfect beach weather—a sunny and sparkling 85 degrees with clear blue skies outside—but nothing could match the warm, welcoming, upbeat, and bright atmosphere at Sarasota's special WM support group meeting. Thirty people gathered on February 11 for a fabulous meeting featuring IWMF President Carl Harrington presenting a highly informative and entertaining "President's Update on the IWMF." The slide presentation offered insights into the plethora of free member services offered and the extensive, impressive research being funded by the IWMF, illustrating that "the sun never sets on IWMF research and member services."

Thirty people entered the Sarasota Support Group meeting as strangers but left as new friends. Lisa Wise, IWMF Board member, ran the first meeting, and this new group's co-leaders are already planning the next meeting.

Carl Harrington attended the first Sarasota Support Group meeting and shared a few inspirational thoughts about his own WM journey.

Following Carl's presentation, Lisa Wise, IWMF Board member, facilitated a group sharing experience where each patient and caregiver was warmly invited to offer a two-minute overview of his or her WM experience. The members enjoyed a lively and heartfelt group discussion. Since Sarasota does not currently have an on-going IWMF support group, it was encouraging to identify future leadership at this meeting. Lisa will be mentoring a new volunteer to take over the support group leader role. Plans for a second meeting are already in the works. Since this meeting was held in Sarasota, where the IWMF office is located, the entire office staff attended in order to witness firsthand what a support group meeting experience offers members. The staff deeply enjoyed being an integral part of this meaningful and moving group experience, and their support and assistance in making this meeting possible was invaluable. The newest member of the IWMF staff is Michelle Postek, and in her role as the new member services specialist, she had this to say about attending the meeting: "It was a privilege being present for the beginning of a safe, supportive space for IWMF members in the Sarasota area. I observed that IWMF support group leaders have experienced their own struggles and triumphs with WM and can truly walk beside group members on their own journeys. I felt inspired sitting amongst members and caring partners and am honored for this opportunity to work with an incredible organization." It is exciting to add Sarasota

Support Group News, cont. on page 22

to the list of US WM support groups. Welcome aboard, Sarasota!

In January, Dr. Daren Grosman spoke to the group.

Southern Florida Support Group – Twenty-five patients and caregivers attended Dr Grosman's presentation.

Southern Florida

The Southern Florida IWMF Support Group held its first meeting of 2019 at Memorial Hospital West in Pembroke Pines on Saturday, January 26. It was a traditional interactive meeting with patients and caregivers exchanging thoughts, and, as usual, Dr. Daren Grosman was available to answer questions from those attending. Lunch was provided, courtesy of the Leukemia & Lymphoma Society (LLS). Despite severe inclement weather, 25 patients and caregivers attended, including one patient whose WM diagnosis was more than 25 years ago. Topics included available supplemental funding from LLS, some specific questions from patients regarding their treatment, when to start WM treatment, treatment for increasing neuropathy symptoms, and advances in availability of treatments in pill form.

The second meeting of the year was part of the LLS Florida Blood Cancer Conference on Saturday, March 30, at the Marriott Harbor Beach Resort and Spa. Attendance was free for all patients and caregivers. After a delicious lunch provided by LLS, members attended afternoon breakout sessions. For the past three years, a special highlight of the conference has been the presentations and Q&A sessions with Dr. Steven Treon of Dana-Farber Cancer Institute. A number of the Southern Florida Support Group members plan to attend the IWMF Educational Forum in Philadelphia in June; they will be featured at the next meeting in September.

ILLINOIS

Chicago Area/SE Wisconsin

Dr. Shuo Ma will be the featured speaker at the first meeting of 2019. It is planned for Saturday, May 4, 1:00pm, at Elmhurst Hospital on the west side of Chicago in Elmhurst, Illinois. This will be Dr. Ma's third time speaking to the group; her last presentation for the members was three years ago. She was honored as "IWMF Doc Star" in the January 2019 *Torch* and spoke at the 2018 IWMF Educational Forum for the first time. She practices at Northwestern Memorial Hospital in Chicago and is known for her WM expertise, research, and caring nature for patients.

New York, Rochester, Western and Central - Dr. Carla Casulo is surrounded by members of the support group on January 10, 2019, at Nazareth College in Rochester, NY.

NEW YORK

Rochester, Western and Central NY

Despite the wintry weather, January 10 marked the group's largest turnout yet. Seventeen attendees, including three new members, gathered for lunch and heartfelt discussion on the beautiful Nazareth College Campus in Rochester, NY. Dr. Carla Casulo, hematologist and oncologist from the University of Rochester Wilmot Cancer Center, joined the group for an informal question-and-answer format meeting. This was the second time Dr. Casulo graciously gave of her time to lend support to the group. The meeting began with introductions and a sharing of questions for Dr. Casulo to address. She

Support Group News, cont. on page 23

responded to queries on a range of topics including when to treat, types of treatments, symptoms, side effects, and even mental health issues associated with cancer diagnosis. It was a very productive meeting. Everyone seemed quite impressed and appreciative of Dr. Casulo's knowledge and attention to detail. All left with a smile, looking forward to the next meeting.

EASTERN OHIO, WESTERN PENNSYLVANIA, AND WEST VIRGINIA

In festive holiday spirit, members gathered at the Hilton Garden Inn Akron for an early December meeting and luncheon. This lovely setting, decked out in holiday decor, provided the perfect venue for enjoying each other's company over a delicious lunch of healthy salad choices, sandwiches, and an irresistible selection of holiday cookies. Guest speaker Kris Austin, chief marketing officer at The Gathering Place in Beachwood, OH, highlighted key services of this cancer-caring community to support emotional, nutritional, and physical wellness, in addition to education and information resource assistance. Kris guided group members into relaxation mode with short meditative exercises that all agreed would make good additions to their cancer survivorship toolkits. In leading the group sharing, Shari Hall, support group co-leader, expressed her deep gratitude to the IWMF, including founder Arnie Smokler, the leaders and volunteers who continue to offer valuable member services, and research that contributes to exciting treatment advances and much hope for the future. Shari has recently surpassed her 25th anniversary with WM! Members appreciated hearing each other's WM updates with many stories of treatment successes, including a positive venetoclax trial experience by one member. The group looks forward to this special time of sharing at each meeting. In closing, everyone expressed holiday wishes and thoughts of good health until they meet again in the spring.

TEXAS

Houston

The group met at the end of January at the home of Dr. Barbara and John Manousso. It was a lovely group with the addition of a newly diagnosed WMer and partner. Members offered them ideas for navigating WM, as each attendee shared his or her journey since the last meeting. The group watched the DVD of Mayo Clinic's Dr. Morie Gertz's 2018 IWMF Ed Forum presentation. The information was clear and appreciated by all attendees. The next meeting is planned for Saturday, May 4, at 10:00am, 21 Briar Hollow Lane, Houston, TX, in the Uptown-Galleria area.

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

A WM update meeting was held in Sydney on February 21 at Concord Cancer Center. At the podium is Dr. Nicole Wong Doo, clinical and laboratory haematologist at Concord Hospital.

AUSTRALIA

WM Update Meeting in Sydney

A WM update meeting organised by the Leukaemia Foundation was attended by 28 participants on February 21 at Concord Cancer Centre. Professor Judith Trotman and Drs. Ibrahim Tohidi-Esfahani and Nicole Wong Doo delivered presentations covering:

- General WM knowledge update, including overview of current treatment options, familial risk, testing required, and when to start treatment;
- Highlights of the 10th International Workshop on Waldenstrom's Macroglobulinemia, October 2018, New York, including updates on new treatments;
- Latest on WhiMSICAL with inclusion of the Quality of Life Questionnaire; and
- "Ask the Doctor Q & A session" with questions pre-submitted as well as from audience.

New Newsletter for Australia and New Zealand

The first issue of the WM Australia and New Zealand newsletter was published in December 2018. The second edition will be named "Beacon" as selected by a poll of WMozzies. The new name avoids confusion with the *IWMF Torch* publication.

Andrew Warden, WMozzies, reporting

International Scene, cont. on page 24

CHINA

On December 20, 2018, the first WM educational meeting was held in Renji Hospital, Shanghai, China, for WM patients and caregivers.

More than 30 WM patients and caregivers attended this meeting. They came from different cities in China; some took long flights and high-speed trains to get to Shanghai. It was the first time in China that a number of WMers gathered together for an educational meeting organized by a WM support group.

Dr. Hou Jian, director of the hematology department and consultant to China's Waldenstrom's Macroglobulinemia Support Group (CWMSG), and his colleagues, Dr. Huang Honghui, Dr. Wang Ting, and nursing supervisor Ms. Cai Yongmei, contributed their time to this meeting.

The educational program started with "The Standard Treatment for Malignant Lymphoma and Its Overall Management" by Dr. Huang Honghui and was followed by Dr. Hou Jian's topic of "Waldenstrom's Macroglobulinemia Treatment and Its Follow-up Observation." Then Roger Yao, as China's support group leader, gave a brief introduction about the development of CWMSG and its outlook for the future. Dr. Wang Ting talked about "General Side Effects of Treatment," which drew great attention from those who suffered during and/or after treatment. The educational program ended on the topic of maintenance of venous catheters by Ms. Cai Yongmei.

Finally, a question-and-answer session was held, which allowed WMers to seek face-to-face second opinions from WM experts at Renji hospital. After the meeting, patients and caregivers gathered together and continued to discuss other WM topics, such as how to deal with depression, how to find second opinions, and how to appeal to the government for a WM medical insurance policy.

CWMSG later shared a video of this meeting on its website *www.huashijuqiu.com* and WECHAT official account (WM_Together), so that WMers who were not able to attend this meeting could have a chance to watch online. Many WMers appreciated the effort by the WM support group and its volunteers and thanked the IWMF for sharing information and contributing educational publications.

In early March, China's Institute of Hematology (*http://www.chinablood.com.cn*), on its WECHAT official account, acknowledged and forwarded our publication of "Frequently Asked Questions" from our own WECHAT account, which means that our support group has been recognized by the most professional hematological institute in China. WECHAT is a social media platform similar to Twitter in the US.

On our WECHAT account, we now have more than 500 followers online to "like" our sharing, stories, and articles, especially those from the IWMF. We even received a small number of donations because readers, mainly WMers, thought those articles were helpful for themselves or for their family members.

Thank you to the IWMF for its support, without which our small support group would not have reached where we are today.

Roger Yao, CWMSG, reporting

Attendees at the first WM educational meeting in Shanghai, China

Dr. Hou Jian, hematologist, and Roger Yao, CWMSG leader, at the first Shanghai WM educational meeting

BETWEEN DECEMBER 1, 2018 AND FEBRUARY 28, 2019, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

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Employees at Western Michigan Fleet Parts, Inc.
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Ed Wubbens
Robert and Susan Morris

Ron Yee
Vince and Susie Santa Maria
Donald H. and Kathryn R. Wolgemuth

Jan Zimmerman
Anonymous

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*

BETWEEN DECEMBER 1, 2018 AND FEBRUARY 28, 2019, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

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Kris Campoli
Pat Campoli
Tara Farley-Wyckoff
Kelly Hunter Sterner

Pat Campoli's Birthday (cont.)
Beth Joliceur
Bob Mayo
Sharon Nosal
MaryAnn Remington
Mary Anne Vautrin Dunham

Dr. Jorge Castillo
Bonnie MacMaster Andersen
Jayne McMellen

Kate Larocca Chahmirzadi's Birthday
Karen Bradshaw Zagorski
Kelly Carlson
Manou Chahmirzadi
Heather Cunningham
Jon Cunningham
Jamie Faber
Christie Hurta
Jeanne Jankowski
Bob Larocca
Kris Luedtke
Colleen Puttin
Karen Temple Vavra

Maria Colossi
Vivienne Fontaine and Yvonne Eaton

Amy & Dennis Daraghy
Anonymous

Mark Davey
James and Patricia Davey

Joyce K. Deaton
Derek Croft

Peter DeNardis
David B. Kirby, Jr.

Caroline Dew
Martha A. Zumbrunnen

Glen Durmas
Charlotte P. Doss

Lynda Cyr Dvorachek
Lynda Cyr Dvorachek
Michaeline Grogan
Meg Cyr Mangin
Sarah Pielhop
Sue Schultz

Jon Dwinell
Daniel and Sandra Dahl

Marty Edleman
Carol Edleman

Hubert C. Edfors
Anonymous

Carol Ehlers
Otto Ehlers

Dr. Christos Emmanouilides
Fred and Lynn Bickle

Carol Van Fossen
E. Jane Van Fossen

Bruce Fox's Giving Tuesday Fundraiser
Gene Carney
Shelley Cices
Bruce Fox
Francine Fox
Iris Rifkin-Gainer

Dr. Mathew Frank
Meryl and Robert Selig

Wayne Games' Birthday
Debbie Burmeister

Shirley Ganse
Anonymous

John E. Ganser
Jennifer Ganser

Nadjas Geburtstags-Spendenaktion
Marjan Burgers

Dr. Morie Gertz
Phil Cacioppo
William J. Hannaford

Deanna Gilman
Arthur and Ellen Pincus

Sara McKinnie
Phil Cacioppo

Ann Peterson's Birthday
George Gathy
Faith Peterson
Larry Peterson

Ed Goldberg
Katherine and George Coutrakon
Geoffery Engel, M.D.
Marcy Traxler

James Van Guilder
National United Brokers
Craig Sussillo
Jim and Kim Weilbacher

Christopher Hanneman-Rawlings
Anonymous

Carl Harrington
Lesley Wiessmann-Cook and James Cook
Morry, Dawn and Micah Edwards
Eiseman Construction Company, Inc.
Sam Harrington
Maurice and Ruth Levie
David L. Skolnick

Carl Harrington's Birthday
Shirley Banker
Carolyn Handler
Benjamin Levie
Elly Levie
Elena and Gary Malunis
Sammie and Dan Moshenberg
Bill and Connie Paul
Bryna Sherr
Marc Silver
Barbara Spiller
Bonnie Tarses
Mark Tarses
Gail Terp
Sue Herms
David and Penny Kirby

Bill Hicks' Giving Tuesday Fundraiser
Amberly Bland
Bill Hicks
Kimberly Keeling
Rose Macey
Pam Morrison
Leslie Shakespeare

Bill and Kris Howanski
Elizabeth Howanski

Bill Howanski
Kristine Howanski

Jane Hughes
John Hughes

Dr. Zachary Hunter
Anita Nelson

Joe Janda
Anonymous

Jenny Benak's Birthday
Jenny Benak
Benjamin Horseman
Lori Wheeler

Thomas K. Jewell
Jim and Holly Jewell

Nadine Knowles' Birthday
Charles J. Beikman
Christina Huete-Clarke

Nadine Knowles' Giving Tuesday Fundraiser
George Evanson
Frank Hoff
Nadine Knowles
Anne Marie Maltese

Dr. Steven Krause
Karen and Jerry Eisman

Dr. Robert Kyle
Phil Cacioppo
Roy Langhans

Terry LaBarge
Patty LaBarge

Michael Lasalandra's Birthday
Barry Gilbert
Stephen Kurkjian
Frank Lasalandra
Michael Lasalandra
Cosmo Macero
James J. O'Brien

Donald LaTorre
Donald and Joan LaTorre

Edwina Franzen Ledel's Birthday
Joanne Burnett
Kelly Chambers
Tracey Murray

Denise Lewis
Linda Adamany

Ruth Lizotte
Marie McCabe
Barbara and David ONeil

Kathy Lollar's Birthday
Nancy Madonna

Margaret E. Long's Giving Tuesday Fundraiser
Joyce Anderson
Ann Borowiec
Fran Borowiec
Nancy Bullough
Sally Dully
Emily Eaton
Eileen Felton
Judy Gallman
Margaret E. Long
Joe Walshe

Tamara Lubliner
Erin, Aaron, Ethan and Reyes

BETWEEN DECEMBER 1, 2018 AND FEBRUARY 28, 2019, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

Olivia Matthews' Giving Tuesday Fundraiser
Karen Lattanzi Mathews
Olivia Mathews
Patrick Mulligan
Ashley Occhipinti
John Richard

Carol Martin
Carol Martin

Ginny-Kay Massara's Birthday
Shirley Atkinson
Jeff Danska
Virginia Lamkin
MaryAnn Lange-Pecastaing
Woody Massara
Ronald Pyle
Diane Reuler
Sue Ann Voris
Marla Voss
Paula Voss

Lori Mattson's Birthday
Nik Mattson
Marn Sandum

Judith May
W. Thomas and Karen Myers

Judy A. McCoy
Richard and Carrie Hill

Gerri McDonald
Patricia C. Sirls

Carol Mudgett's Birthday
Barbara Choyke
Edie Vandenabeele-yee

Claudia Muir
Noelle Soroka

William Thomas Myers, Jr.
Sara Franklin
Rebecca Spencer

Lynda Paxton Nielsen's Giving Tuesday Fundraiser
Lynda Paxton Nielsen

Majorie Oberlander
Sarita and Bill Hart

Peter and Ann Odell
Anonymous

Polly Oldberg's Giving Tuesday Fundraiser
Barbara Levins
Julie Minnix
Vanda Monkman

Lia Palomba MD
Joel H. Charkow

Kathy Cross Pemberton's Birthday
Shelly Capps
Jeri-Lynn Cross
Mandee Hallgarten
Lynn Harrison

Eunice Quast
Heidi Vlasak

Thad and Sylvia Raushi
Anonymous

David and Diana Raushi
Thaddeus and Sylvia Raushi

Renate's Birthday
Deborah Chiu
Russ Darbon
Andrea Miller
Renate Miller-Fouts
Deborah Rude
Terri Sheahan Olivio

Cynthia Robyn's Birthday
Nancy Bellon

Tom Rousher
The Rousher Family

Jeff Sandberg's Giving Tuesday Fundraiser
Daniel Duimstra
Jeffrey and Ashley Sanberg

Pam Sarles' Birthday
Caroline Arter
Shannon Chembless
Liz Low

Giulia Adamo Savery
Antonella Marotti

William Scaring
Carole Scaring

Karen Schange
Stephen Schange

Debbie Schwagler's Birthday
Julie Cycon Stuewe
David Gohn
Ron Mikulski
Debbie Schwagler

Ryan Scofield
Diane McKim

Barbara Sherman
Barbara Sherman

Cindy Shubert's Birthday
Chelsea Augustine
Joe Lair
Cindy Shubert
Ed Shubert

Jennifer Silva's Giving Tuesday Fundraiser
Karin Braunsberger
Rosemary Mullarkey
Jennifer Silva
Len Silva
Nancy Silva

Michael Smith and Gina Odell
Anonymous

Bradstreet Walter Smith
Anonymous

Max Smith-Stern's Hanukkah gift
Donald Stern

Deborah Steinmiller
Richard B. Weinstein

Carl Stoel
The Duncan Family
The Irving Family
Carl and Susan Stoel

Dr. Carl and Susan Stoel
Jeff, Molly and Caleb Sims

Maureen Sullivan
Joseph Hauswirth

Katie Susag Bauer's Birthday
Michael Cook
Amy Maynard
Constance Peterson
John Susag

Lee Talisman
Jon and Alisa Talisman

Norman L. Thompson, MD
Dr. Normal L. and Mrs. Patricia Thompson

Peg Thornton's Birthday
Anonymous
Tracey Lapierre
Peg Thornton

Nancy Tucker
Anonymous

James D. Turner
Michelle Harper

Dr. Steven Treon
Anita Nelson

Ray Valentine
Cindy Anders

Daryll Wartluft
Todd Wartluft

Aaron Weldy
Dr. George H. Kates

Lisa Weldy
Mort and Judy Weldy

Marcia Wierda
Mill Creek Construction LLC

Diana Wilkinson
Anonymous

Ric Williams
Karen Williams

Verjaardagsinzamelingsactie van Winny
Berrie Vereijken

Patty Vorbach Caroleo's Birthday
Linda Carlson
Lisa Centaro
Elaine Dalton
Kathy Halligan
Gerard Iacovano
Gina Le
Jim Piccolo
Maria Vinci

Merle Weston's Giving Tuesday Fundraiser
Reuben Lewy
Merle Weston

Lisa Wise
Roy K. Langhans

Dr. Clive Zent
Daniel S. Marder and
Mary Elizabeth Reinhardt

Mary Jo Zervas' Birthday
Anonymous
Lisa Grisolia
Kelley Nordin
Heather Nordin Kring
Joshua O'Brien
Jim Plavouth
Laura Puckett
Anonymous
Sandra Zarodnansky

SUPPORT • EDUCATION • RESEARCH
IWMF
International Waldenstrom's Macroglobulinemia Foundation

6144 Clark Center Avenue
Sarasota, FL 34238

Telephone 941-927-4963 · Fax 941-927-4467
E-mail: info@iwmf.com · www.iwmf.com
IWMF is a 501(c)(3) tax exempt non-profit organization
Fed ID #54-1784426

This issue of the IWMF Torch *was made possible by Pharmacyclics LLC and Janssen Biotech, Inc.*