



INSIDE THIS ISSUE

Peripheral Neuropathy
in IgM-MGUS
and Waldenstrom
Macroglobulinemia.... 1

President's Corner..... 5

2019 Ed Forum and the
WM Revolution..... 7

IWMF DOC STAR:
Dr. Richard Furman .. 15

IWMF Connect:
Summer 2019 17

Living Life to the
Fullest..... 19

Wally and Winnie,
Model Mice 21

Medical News
Roundup 21

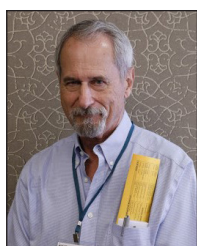
Cooks' Happy Hour ... 25

Support
Group News 26

International Scene.... 30

PERIPHERAL NEUROPATHY IN IGM-MGUS AND WALDENSTROM MACROGLOBULINEMIA

BY TOM HOFFMANN, MD,
IWMF VICE PRESIDENT FOR RESEARCH

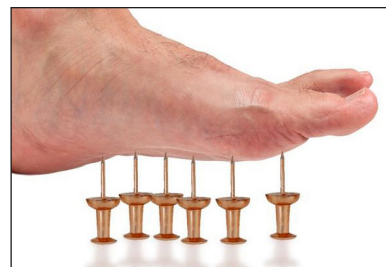


Dr. Tom Hoffmann

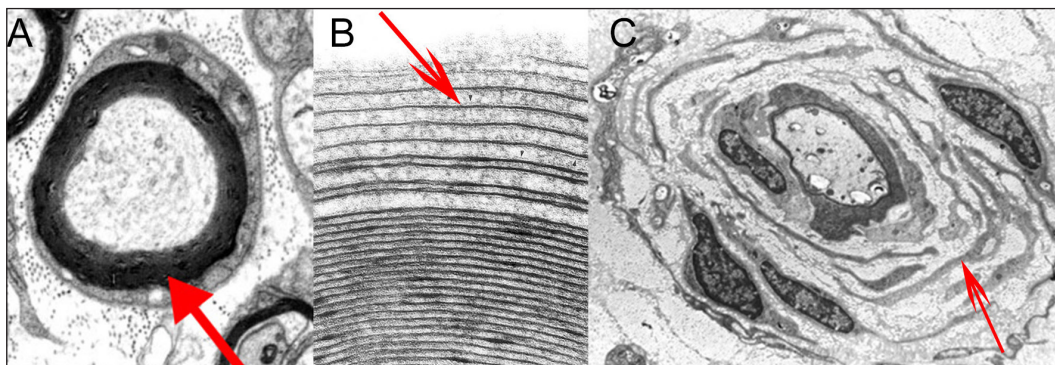
Peripheral neuropathy (PN) is a common disease in the general population and in the Waldenstrom community. It is defined as a diseased or degenerative state of the peripheral nerves in which nerve fibers are damaged. Peripheral nerves are all the nerves in the body that are not in the brain or spinal cord. They are divided into three categories: sensory, motor, and autonomic. Sensory nerves carry information from the body to the spinal cord and brain by an electrochemical signal. These signals are perceived as taste, smell, touch, sight, and hearing. Special sensors in the skin and deep inside the body help people identify if an object is sharp,

rough, or smooth, if it's hot or cold, or if a body part is still or in motion. Sensory nerve damage can result in tingling, numbness, pain, and extreme sensitivity to touch. Motor nerves carry information from the brain and spinal cord to muscle fibers throughout the body to enable movement. Autonomic nerves regulate bodily functions such as temperature, heart rate, blood pressure, digestion, respiration, urination, and many others.

Peripheral neuropathy affects 3-4% of the general US population, increasing to 8% with advancing age, and affects at least thirty million people. A myriad of diseases, cancers, and medications can attack nerves, resulting in a neuropathy. This makes it very difficult to determine the cause.



Peripheral neuropathy can
feel like walking on pins.



Peripheral nerve with myelin sheath stained black. A: Normal nerve with thick myelin sheath.
B: Enlargement showing mild delamination secondary to neuropathic IgM.
C: Progression to totally destroyed and broken myelin sheath.

OFFICERS & TRUSTEES

FOUNDER

Arnold Smokler

PRESIDENT EMERITA

Judith May

PRESIDENT

Carl Harrington

SECRETARY-TREASURER

Beverly Docteur

VICE PRESIDENTS

Elena Malunis

Michael Sesnowitz

Tom Hoffmann, MD

BOARD OF TRUSTEES

Stephen Ansell, MD

Ron Branscome

Peter DeNardis

Marlyn Friedlander

Shirley Ganse

Robert A. Kyle, MD

Barry Nelson

Linda Nelson

Lisa Wise

IWMF SCIENTIFIC

ADVISORY COMMITTEE

Stephen Ansell, MD, Chairman
Mayo Clinic

Bart Barlogie, MD
Mount Sinai Hospital

James R. Berenson, MD
Institute for Myeloma & Bone Cancer
Research

Morton Coleman, MD
Weill Cornell Medical College

Meletios A. Dimopoulos, MD
School of Medicine
University of Athens Greece

Stanley Frankel, MD
Columbia University

Morie Gertz, MD
Mayo Clinic

Irene Ghobrial, MD
Dana-Farber Cancer Institute

Eva Kimby, MD
Karolinska Institute, Sweden

Robert A. Kyle, MD
Mayo Clinic

Véronique Leblond, MD
Hôpital Pitié Salpêtrière, France

Gwen Nichols, MD
Leukemia & Lymphoma Society

Roger Owen, MD
St. James's Institute of Oncology
United Kingdom

Lia Palomba, MD
Memorial Sloan Kettering Cancer Center

Surinder Sahota, PhD
University of Southampton, United Kingdom

Sheeba Thomas, MD
MD Anderson Cancer Center

Steven Treon, MD
Dana-Farber Cancer Institute

Brian Van Ness, PhD
University of Minnesota

Peripheral Neuropathy, cont. from page 1

Monoclonal gammopathy of unknown significance (MGUS) is present in 3.2% of the general population over fifty years old and increases to 9% by age 90. The major immunoglobulins present in MGUS patients and their incidence are IgA (12%), IgM (15%), and IgG (70%). PN is reported in 30-50% of IgM MGUS patients and up to 47% of WM patients. PN is reported by 25% of newly diagnosed WM patients as their presenting symptom at diagnosis. The clinical spectrum spans from distal paresthesias (abnormal skin sensations in the extremities) and mild gait imbalance to more severe sensory ataxia (loss of coordination), with falls and a varying degree of both sensory and motor deficits in the extremities.

IgM MGUS and WM Neuropathy Etiology

Myelin composes the peripheral nerve cell sheath, which is the insulation covering that protects the nerve, and is made by Schwann cells. Patients with PN caused by IgM MGUS or WM typically manifest symptoms associated with dysfunction or loss of large myelinated nerve fibers. This occurs because of specific IgM monoclonal proteins that attack peripheral nerves, causing demyelination of the nerves and neuropathy that ultimately lead to nerve death. If you have PN caused by monoclonal IgM, you have one of these anti-myelin IgMs, although not all of them have been delineated yet. Anti-MAG is the most prevalent in WM PN patients. Myelin-associated glycoprotein (MAG) is a special type of glycoprotein that plays a role in a signaling cascade that "turns on" the Schwann cells, leading to normal myelin production and healthy peripheral nerve activity. Anti-MAG IgM blocks MAG, resulting in loss of myelin production and destruction of the nerve sheath. Patients with anti-MAG can develop a neuropathic tremor that may respond to currently approved WM therapies. Anti-MAG and anti-sulfoglucuronyl paragloboside (SGPG) are the major two glycoproteins that induce PN (50% and 25%, respectively). GM1, GM2, GD1A, GT1B, and GQ1B are other targets that result in PN—GM1 and GM2 induce motor neuropathy. All of these can be tested by a blood sample.

Peripheral Neuropathy, cont. on page 3



The **IWMF Torch** is a publication of:

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

EDITOR
Shirley Ganse

ASSOCIATE EDITOR
Sue Herms

SUPPORT GROUP NEWS
Penni Wisner

IWMF DOC STAR EDITOR
Ron Ternoway

IWMF CONNECT
Jacob Weintraub, MD

**INTERNATIONAL
CORRESPONDENT**
Annette Aburdene

CULINARY EDITOR
Penni Wisner

CARTOONIST
Linda Pochmerski

**FORMATTING &
PRODUCTION**
Sara McKinnie

PHOTOGRAPHER
Tom Shyver

TORCH ADVISORY PANEL
Carl Harrington
Robert Kyle, MD

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

Polyneuropathies are rarely a presenting feature in WM, as anti-MAG or anti-SGPG are seen in 75% of neuropathy cases. Polyneuropathies can attack both sensory and motor nerves. Polyneuropathy can be associated with an anti-MAG antibody, and it is a demyelinating, slowly progressing, sensory or sensorimotor ataxic neuropathy. Other rare polyneuropathies are POEMS syndrome (Polyneuropathy, Organomegaly, Endocrinopathy, Monoclonal protein, Skin changes); anti-GM1; anti-GM2; amyloidosis; CIDP (Chronic Inflammatory Demyelinating Polyneuropathy); cryoglobulinemia; and CANOMAD (Chronic Ataxic Neuropathy with Ophthalmoplegia, M protein, cold Agglutinins, and Disialosyl antibodies).

IgM MGUS and WM Neuropathy Symptoms

These include one or more of the following:

- Paresthesias, including numbness; burning, stabbing, lancing, boring, shooting pains; and pins and needles or tingling sensations. Many of these are worse at night.
- Sensitivity to touch or temperature.
- Loss of reflexes.
- Sensory neuropathy that is symmetrical and begins in the toes.
- Progression of symptoms up the legs, then the arms.
- Feeling like a sock is rolled up under your foot, or a feeling that you are wearing a tight, invisible glove or sock.
- Impaired balance, particularly in the dark.
- Distal extremity weakness.
- Motor damage – muscle weakness, cramps, spasms, twitching, muscle shrinking.
- Dizziness, especially when getting up from a bed or a chair.
- Loss of co-ordination and proprioception (the ability to sense stimuli arising within the body regarding position, motion, and equilibrium).
- Fatigue.
- Ataxia and tremors.

Nerve Destruction

As discussed previously, the IgM associated with anti-MAG and similar antibodies destroys the myelin covering of the nerve. Think of the myelin as the insulation covering of an electric cord. As the myelin insulation is destroyed, the nerve is exposed and dies. This is similar to the copper wire in an electrical cord that shorts out when the insulated wall has been stripped away. Which nerve in the body becomes demyelinated first? Of course, it would be the longest nerve in the body, as it has more myelin for the anti-MAG IgM to attack. That nerve is the one that goes from the spinal column to the toe. It is approximately four feet long, depending on

*Which **nerve** in the body becomes **demyelinated** first?*

your height. Breaks in the sheath will happen more quickly in that nerve. The neuropathy creeps up your leg as the disease progresses. The other leg will show symptoms at that same time because it is the same length. Once the PN is far enough up the legs, it begins to cause symptoms in the second longest nerves, in the arms. This type of PN is also called DADS (Distal Acquired Demyelinating Symmetric).

Some WM PN patients state that their PN began in the wrist, or the arm, or a rib, and so on. In order for that to happen, the patient has to have two diseases. Any nerve in the body that has had damage or is being damaged by a second disease will deteriorate faster into PN than a normal nerve. In the examples above, those patients must have had asymptomatic carpal tunnel syndrome, nerve impingement in the neck, or shingles in an intercostal nerve, previously or concurrently.

PN Workup

Determination of the cause of PN can be long and tedious. There are many other diseases, cancers, and drugs, more prevalent than IgM-MGUS or WM, which can cause PN:

- Diseases – diabetes, degenerative joint disease, infections in nerves, shingles, spinal cord injuries, poor circulation, hypothyroidism, surgery, radiation therapy, amyloidosis, renal failure, inflammatory disease, heavy metal poisoning, prior chemotherapy, physical injury, alcohol abuse, low vitamin B-12, some autoimmune diseases, HIV, sarcoidosis, Lyme disease, hepatitis, cryoglobulinemia, and cold agglutinins.
- Common cancers – breast, lung, other B-cell lymphomas, ovarian, testicular, multiple myeloma, any cancer that presses on a nerve.
- Chemotherapy drugs – cisplatin, carboplatin, cytosine, tacrolimus, Taxol, Taxotere, Jevtana.
- WM therapy drugs – immunomodulatory drugs (IMiDs) such as Thalomid, Revlimid, Pomalyst; proteasome inhibitors such as Velcade, Kyprolis, Ninlaro.
- Other drugs – amiodarone, Flagyl, HIV medications, Antabuse, interferon, and others.

Considerable testing may be required to make the diagnosis.

Neurological tests may be used to help determine the nerve problem. Nerve conduction studies (NCS) and electromyography (EMG) are used to help define the neuropathy. Negative testing may not mean that you don't have PN, since early in the disease these tests cannot pick it

Peripheral Neuropathy, cont. on page 4

up. CT and MRI scans can discern nerve impingement, Bing-Neel syndrome, and masses that compress nerves.

Many people may have more than one disease, drug, or cancer that results in PN. That makes it difficult to come to a conclusion.

More Specific Tests for PN from IgM MGUS and WM

- Cerebrospinal fluid shows an elevated protein level (IgM) in 80% of demyelinating PN (>1 g/L).
- Anti-MAG IgM antibody testing.
- Anti-SGPG IgM antibody testing.
- WM neuropathy is mostly associated with IgM kappa light chains.
- If the diagnosis is unclear after a peripheral PN workup, multiple plasmaphereses should be considered. Plasmapheresis can be diagnostic and therapeutic. It will lower the IgM level considerably, although temporarily. Having three or four of these at two-to-three week intervals should temporarily improve the PN. If so, one has PN from IgM MGUS or WM.
- A sural nerve biopsy is also a definitive test. This is performed at the ankle. Sural nerve biopsies will cause a permanent sensory deficit on the lateral side of the foot and a 10-20% risk of post-biopsy pain. The biopsy will show IgM and an immune system protein called complement deposited on the myelin sheath and delamination (separation) of the sheath.
- Fat and skin biopsies are usually non-diagnostic, except, for example, in the case of fat pad biopsies and amyloidosis.

*PN is a **quality of life** issue.*

PN Medications

PN is a quality of life issue. Medications are used to allow the patient to remain functional, mobile, free of pain, and enjoy life. Over-the-counter medications are used to treat the minor symptoms of neuropathy. Escalation to prescription drugs is tailored by one's doctor to fit each patient's situation. Some of the drugs may also help with depression, hypertension, and degenerative joint disease.

- Non-narcotic pain relievers – Tylenol, Motrin, Mobic
- COX-2 inhibitors – Celebrex
- Narcotics for pain
- Ultram/tramadol

- Tricyclic antidepressants – Pamelor (nortriptyline), Elavil (amitriptyline), Cymbalta (duloxetine)
- Topical medications and/or lidocaine patches
- Alpha 2 adrenergic agonists – Clonidine (blood pressure medication)
- Anti-seizure medications – Neurontin (gabapentin), Lyrica (pregabalin)

Waldenstrom Treatment for PN

The only way to decrease the progression of PN due to monoclonal IgM in WM patients relies on lowering the IgM level. If the PN becomes a quality of life issue, consideration should be given to WM treatment. Early treatment intervention may prevent debilitating neuropathy. Nerve regrowth after treatment may take up to two years to resolve neuropathy. Neuropathy is permanent after two years if not treated, but treatment may still prevent its worsening.

Local treatments with nerve blocks or a transcutaneous electrical nerve stimulation (TENS unit) may be of value. Steroids are used only in those with inflammatory or autoimmune neuropathy like CIDP. IVIG is rarely used now as it is only 15-20% effective, has only short term benefit, and costs approximately \$10,000 per course.

The first drug tested to lower IgM for WM PN was Rituxan in the early 2000s. It has been the mainstay treatment for WM PN when there are no other WM problems, due to its safety profile. However, it only has a 30-50% improvement rate. Combination therapies of other drugs with Rituxan are now the preferred first-line treatment of many indolent lymphomas, including Waldenstrom. It is logical to extrapolate conclusions from WM treatment results when treating WM PN. Many times those drugs are used with Rituxan for its synergy.

Mantras for PN from IgM MGUS and WM

- Quality of life is paramount.
- The presence of mild neuropathy alone is not a justification for WM treatment, but steady progression with accumulating disability or loss of quality of life should prompt action.
- Most WMers with neuropathy have relatively low IgM levels and predominant IgM kappa light chains.
- Drugs that induce neuropathy should not be used.
- The treatment goal for WM PN should be to use standardized treatment protocols. Perhaps those with non-improving WM PN after treatment, or those with anti-MAG, cryoglobulin, or amyloidosis should continue on treatment to lower the IgM as much as possible. Even if the IgM does not go back to normal, a significant improvement can be gained. Rituxan maintenance may help. Newer

Peripheral Neuropathy, cont. on page 5

drugs, such as ibrutinib and venetoclax, lower the IgM considerably and may end up becoming the best therapies for PN.

- Rituxan alone may not give adequate relief.
- Nerve regrowth and function may take up to two years to return to normal.
- Stability, rather than improvement, is the likely outcome of treatment in someone with chronic neuropathy (> two years).
- Supportive treatment is helpful – orthotics, balance training, occupational and physical rehab.
- Medication usage and exercise help maintain quality of life.

Peripheral neuropathy can be a daunting problem and a huge quality of life issue. All patients with IgM-MGUS or WM

*All patients with **IgM-MGUS** or **WM** should be aware of the symptoms of PN and **report** them to their physicians.*

should be aware of the symptoms of PN and report them to their physicians. If symptoms progress, their severity and effect on daily activities should be discussed at each visit. Your physician may not be aware of the fact that PN is a complication of WM. If so, provide a printed copy of this article or other medical information on PN related to WM to increase his or her knowledge on the subject. Ask for (insist upon) a neurology consult or a second opinion when the symptoms have become more than just a minor nuisance.

PRESIDENT'S CORNER

BY CARL HARRINGTON

The theme of the 2019 IWMF Educational Forum in Philadelphia was Imagine a Cure: The WM Revolution. And the meeting was, well, revolutionary! Here are a few highlights:



- We had an extremely successful meeting with over 360 attendees and an overall rating of 4.83 out of 5. This is the fourth straight year that attendees rated the Ed Forum a 4.8 or better! It's really hard to do better than that!
- The Walk for Waldenstrom's was a huge success, and we even had good weather! We had 14 teams who have raised over \$30,000 so far, well above our goal of \$20,000. And if you haven't given yet, you still can at <https://www.mightycause.com/event/2019-Walk-For-Waldenstroms> or mail a check to the IWMF Office, 6144 Clark Center Ave., Sarasota, FL 34238, attention Jeremy Dictor. The Walk for WM campaign doesn't close until July 31. Let's push our record higher. Donate today!
- The Support Group Leaders Workshop that preceded the Ed Forum was wildly successful with record attendance, including representatives from our affiliates in Australia, Canada, China, Italy, Finland, Scandinavia (Sweden, Norway and

Denmark), and the UK. Kudos to Trustee Lisa Wise for this outstanding session.

- For the very first time we posted Facebook Live videos. These videos ranged from activities at the office preparing for the Ed Forum, to breakout sessions at the Ed Forum for caregivers and for understanding your blood tests, to shots from the Walk for WM. These Facebook Live sessions gave those who couldn't attend a sense of what was going on.
- For the first time, we had WM Great Debates that were informative and fun. Be sure to watch the videos of Dr. Stadtmayer vs. Dr. Castillo on Limited Duration Treatment vs. Continuous Pill and Dr. Coleman vs. Dr. Ansell on Rituxan Maintenance vs. No Maintenance. Important topics covered in a revolutionary way!
- Perhaps, best of all, for the very first time, we provided a LIVE presentation to all WMers around the world. This revolutionary "real time" presentation from Dr. Steven Treon of Dana-Farber Cancer Institute, entitled "Breaking News from the Front: IWWM-10 & the IWMF-LLS Strategic Research Roadmap Summit," was viewed live from the Ed Forum on the IWMF You Tube channel and the IWMF Facebook page. Almost 2000 people have viewed this session so far. If you missed it, it's available here:

President's Corner, cont. on page 6

<https://www.youtube.com/watch?v=IDZevlO5Drw>.

Of course, this presentation and all of the presentations will be available on the IWWMF website. Look for the details in an IWWMF e-NEWS. This live presentation and the Facebook Live postings were made possible by support from Pharmacyclics LLC and Janssen Biotech, Inc.

Getting back to The WM Revolution theme of the Ed Forum, this was a nod to the critical role that Philadelphia played in the American Revolution, but it was also focused on the absolute revolution that has occurred and is occurring in the understanding and treatment of WM. Now I have to admit that I was a history major in college and planned to be a high school history teacher. So, you'll all be happy to know that I've prepared a 20-page dissertation on the role of Philadelphia in the American Revolution. But at my wife's insistence, I've cut it down to 3 points:

1. In 1775 Philadelphia, the City of Brotherly Love, was the largest and most important city in North America.
2. The Declaration of Independence was written and signed right here.
3. Philadelphia was the capital of the United States from 1790-1800, when the capital moved to Washington, DC.

So how does this connect to the WM Revolution?

The Declaration of Independence includes these stirring words: "We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are **Life, Liberty and the pursuit of Happiness.**"

Similarly, the Preamble of the US Constitution includes this phrase: "...secure the blessings of liberty to **ourselves and our posterity...**"

Let me focus on our rights as WMers to life, liberty, and the pursuit of happiness, and how we provide these rights to ourselves and to posterity. To bring our theme to life, we had "Ben Franklin" attend our opening reception and dinner.

The WM Revolution: Number of Members

First, let's start with the revolution in the number of IWWMF members. The IWWMF was founded in 1994 with 21 members and incorporated in 1998, so the IWWMF is a bit younger than the US. As an aside, many of us have children, furniture, and clothing older than the IWWMF.

Today we have over 21,000 members from over 80 countries. Think of that another way: for every founding member there are now 1,000 members! For comparison, the US grew about 80 times from the four million people in the first census in 1790 to about 325 million today. We've grown by 1,000 times in about a tenth of the time.

Today we have over **21,000** members
from over **80** countries.

More members mean more power, more resources, more clout, and more chances we'll find a cure.



The WM Revolution: Life (Expectancy)

In 1994, no one had any idea what life expectancy was for someone diagnosed with WM. When I was first diagnosed with WM in July of 2006, I was very, very worried about my future. At the time, the posted survival rate was three to five years. That later grew to six to ten years but now, I'm hearing Dr. Treon talking about 16 to 20 years from the date of diagnosis. That's 16+ years! Or if you look at it another way, with an average age of diagnosis around 65, that would put most WMers at the average life span for Americans. And these treatments are better, with fewer side effects and deeper, longer remissions.

The WM Revolution: Liberty to Choose Treatments

In 1994, we had four treatments. Now it's hard to count, but we have at least 36, including ibrutinib, the first and only drug approved by the FDA for WM.

Liberty Provided by "Revolutionary" Treatments Coming

When you watch the tapes of the presentations from the Ed Forum, be on the lookout for mention of revolutionary new treatments such as venetoclax and acalabutinib, among others. Having so many new drugs in the pipeline is truly revolutionary and will give future WMers the liberty to pick and choose among good treatment options.

Liberty Provided by IWWMF Sponsored Research & Patient Support

Since 1999, the IWWMF has funded over \$14 million in WM research for over 45 specific projects. Every single one of those dollars has come from WM patients, family, and friends.



The WM Revolution: Pursuit of Happiness

IWMF support, which I'm going to liken to the pursuit of happiness, also occurs 24/7 during every revolution of our planet. We now have affiliates in 18 countries outside of the US. We have over 65 support groups globally, and our materials are translated into seven languages and available free on our website. Whenever you need help, the IWMF is there to help you.

Those are just a few examples of The WM Revolution. When you're talking with some of the long-term WM veterans on IWMF Connect or at your local support group, ask them how things are different now. They'll tell you there's been a revolution in our understanding of WM and a revolution in the services we offer. But we won't stop our revolution until we get to a cure.



The WM Revolution: Secure the Blessings of Liberty to Ourselves and Our Posterity

Now recalling the words in the US Constitution, we ask, "How do we secure blessings to ourselves and our future WMers?" Our options and successes today began with those 21 people who first started the IWMF. What can you do to keep it going and build a better future for WMers everywhere?

Keep on giving! Make the IWMF one of your top three charities. You and previous WMers have made possible everything we've been able to accomplish so far. Keep donating your time and your expertise to help your fellow WMers. Keep participating in clinical trials. If we all work together, we can and will get closer to a cure!

I hope to see many of you at our next IWMF Educational Forum, June 5-7, 2020, at the Hyatt Regency Lake Washington in Renton, WA (near Seattle). If you thought the Philadelphia Ed Forum was a sterling experience, you won't want to miss our silver anniversary 25th Educational Forum in 2020. Mark your calendar now!

2019 ED FORUM AND THE WM REVOLUTION

BY PETER DENARDIS, IWMF TRUSTEE AND IWMF CONNECT MANAGER

For the past 24 years, WMers from around the world have looked forward to the chance to attend or read about the annual IWMF Educational Forum. The Forum provides a unique opportunity for patients, caregivers, researchers, and medical professionals to get together and share information about and experiences with WM.

The 2019 Educational Forum participants came with the desire to learn more about treatment options and new treatments under development and for the opportunity to connect and re-connect with fellow attendees.

Since the Ed Forum took place in Philadelphia, PA, the theme this year was "Imagine a Cure: The WM Revolution!"

Throughout the weekend of June 7-9, one could feel a growing atmosphere of optimism, as presenters provided encouragement, inspiration, and information regarding promising results with existing and upcoming treatments.

WMers came from 32 of the 50 states in the US and from seven countries outside the US (Canada, Italy, UK, Sweden, Finland, Australia, and China), with one-third being "first timers" at an Ed Forum.

THURSDAY, JUNE 6 – SUPPORT GROUP LEADERS WORKSHOP

Even though the 2019 Ed Forum didn't "officially" begin

2019 Ed Forum, cont. on page 8



until Friday, one could already sense the excitement in the air on Thursday when walking into the Doubletree Philadelphia Center City Hotel in the downtown area. First-timers and previous attendees mingled in anticipation and, behind-the-scenes, IWMF staff and volunteers were hard at work preparing the registration desk, meeting rooms, and big bags stuffed with information.

Around noon, the Support Group Leaders Workshop got underway, led by Lisa Wise, chair of the US Support Groups Committee. During the workshop, support group leaders and affiliate leaders from around the world introduced themselves and shared brief stories about the groups that they lead. After that session, Larisa Patacchiola, Dana-Farber Cancer Institute's WM social worker, shared helpful tips on how best to facilitate support group meetings. Members of the IWMF office staff also were on hand to introduce themselves and provide guidance on the services they can provide.



The support group leaders and affiliate leaders came away energized and ready to go back to their hometowns to provide improved experiences for their meeting attendees.

As the day went on, more attendees arrived, and evening descended upon the fair city of Philadelphia. While the support group leaders dined at a nearby Italian restaurant, groups of Waldenfriends, old and new, could be seen gathering in the

lobby to walk to a local restaurant for dinner and for drinks to toast to each other's health!

FRIDAY, JUNE 7 – THE ED FORUM OFFICIALLY BEGINS!

Friday's activities began with a continental breakfast for all attendees, followed by a special Early Bird Session for newly diagnosed patients and those wishing to brush up a bit on the basics of WM.



Basic Training for WMers – Dr. Jeffrey Matous

The first presentation was by Dr. Jeffrey Matous from the Colorado Blood Cancer Institute. Dr. Matous has the unique ability to present medical and scientific details in such a manner that any non-science person can easily understand. His presentation topic was aptly titled “Basic Training for WMers,” and covered what WM is, what symptoms one can expect with it, how it is diagnosed and monitored, and when treatment is appropriate.

Patient Perspective – Pete DeNardis

Dr. Matous's session was to have been followed by a patient perspective from Don and Mary Brown, but unfortunately, Don and Mary could not make it because of health issues (one tends to forget that WMers do get sick from time to time!). Not to worry though...Don and Mary will be doing their presentation next year at the IWMF's 25th Annual Ed Forum. Pete DeNardis, IWMF Trustee, filled in at the last minute, appearing on stage in his “treatment uniform” of a wildly colored Hawaiian shirt. He polished and updated a presentation he gave a few of years ago and



provided heartfelt, personal reflections and his perspective on how best to approach living with WM.

Welcome by President Carl Harrington

At 11am, President Carl Harrington officially kicked off the Ed Forum, providing interesting statistics on the history of the IWMMF and information regarding what to expect throughout the weekend. He also announced that next year's Ed Forum will be June 5-7 at the Hyatt Regency Lake Washington in Renton, Washington (near Seattle).



The Power of Choice: Current Treatment Options – Dr. Edward Stadtmauer

The first presentation of the general session was by Dr. Edward Stadtmauer from the University of Pennsylvania, who discussed current treatment options for WM. He provided a very helpful summary of the primary options that are currently in use for WMers, including solo Rituxan, ibrutinib, ibrutinib + Rituxan, bendamustine + Rituxan, and bortezomib + dexamethasone + Rituxan.

During the ensuing question and answer session, someone asked about using Rituxan versus newer anti-CD20 antibodies, like obinutuzumab and ofatumumab, and Dr. Stadtmauer stated that both are effective alternatives to rituximab.

At that point, a mad dash for the buffet lunch ensued, with a great selection of food options for all.

The Revolution in WM Treatment: What's on the Horizon – Dr. Jorge Castillo

Dr. Castillo from Dana-Farber Cancer Institute (DFCI) had graciously agreed to give this presentation in place of Dr. Furman, who unfortunately had to cancel due to an illness in his family. Dr. Castillo arrived from Boston with about 10 minutes to spare before his talk was to begin, and as he took the stage, he received a discernibly loud round of applause, as many patients in the audience were under his care and very appreciative for all he does for them.

Dr. Castillo presented information regarding novel agents that we can expect to be available for WMers in the near future: ixazomib, acalabrutinib, zanubrutinib, venetoclax, ulocuplumab, LY321496, umbralisib, and daratumumab.



Rare Complications of WM – Dr. Jorge Castillo

For the next presentation, Dr. Castillo discussed a variety of rare complications that can occur in WM and common treatments that are used for them. Among the complications he discussed were: Bing Neel syndrome, amyloidosis, hyperviscosity, cold agglutinin disease, cryoglobulinemia, and transformation to aggressive lymphoma.

Breakout Sessions

At this point, there was a break in the action to allow folks to have time to get to their selection of the breakout session they wished to attend. The breakout sessions for Friday were:

- Oral Treatments (Dr. Jorge Castillo)
- Understanding Your Blood Tests (Dr. Jeffrey Matous)
- Tips to Help Caregivers (Dr. Julianne Flora-Tostado)
- A Deeper Dive into the Genomics of WM (Dr. Zachary Hunter)
- Cancer Fatigue (Colleen Erb, RN)

Each of the breakout sessions was very well attended and well-received, with the presenters being quite knowledgeable about their topics and helpful to patients.

President's Reception and Welcome Dinner

With the breakout sessions over and the weather cooperating, the President's Reception took place outdoors on a fifth floor hotel roof, and "Ben Franklin" was on hand to greet and talk to folks on the outdoor patio.

The President's Reception was followed by a Welcome Dinner and Awards Presentations. Carl Harrington again welcomed





International Attendees' Dinner

The IWMF's 2019 Educational Forum in Philadelphia was pleased to welcome leaders from seven of the IWMF's 18 global affiliates. They attended the Support Group Leaders Workshop, held the day before the Forum started, where workshop participants (including 20 US support group leaders) shared experiences in coordinating and managing support groups. International attendees included Andrew Warden from Australia (WMozzies), Betty McPhee and Paul Kitchen from Canada (WMFC), Roger Yao from China (WM-CHINA), Ann Vitia from Finland (Waldenstrom Finland), Claudia Begnoni from Italy (WMFI), Owe Solven from Sweden (WM-Scandinavia), and Lindsey Bennister from the UK (WMUK).

IWMF President Carl Harrington and Vice President for Member Services and Chair of the International Committee Elena Malunis hosted a dinner one evening for the international attendees, where they enjoyed meeting each other. Their feedback about their experiences at the Forum included appreciation for learning so much about WM at such a comprehensive and well-organized meeting and being able to see in person many of the top hematologist-oncologists that they have read so much about.

At the Ed Forum, Andrew Warden was recognized with the IWMF Judith May Volunteer Award for his leadership in providing support to WM patients across Australia and for his effort on the WhiMSICAL Registry, the first worldwide registry of WM patient medical data for research use.

The IWMF looks forward to seeing more affiliate representatives at future Ed Forums, as everyone enjoys meeting them and learning about the worldwide impact of the IWMF.



all in attendance and then announced the winner of the Judith May Volunteer Award—Andrew Warden, leader of Australia’s WMozzies. Laurie Rude-Betts discussed the importance of the Ben Rude Heritage Society, established in honor of the IWMF’s second president, Ben Rude. She recognized two of the newest members of the Ben Rude Heritage Society, Barry and Linda Nelson (who also happen to be trustees of the IWMF).



SATURDAY, JUNE 8 – A COUPLE OF FIRSTS – A LIVESTREAM AND DEBATES

Saturday at an Ed Forum is usually the day when attendees get together for breakfast at “hosted” tables, or they get together with new and old friends to chat and discuss the previous day’s sessions. The hosted tables this year included Young WMers, Caregivers, Newly Diagnosed, Watch and Wait, WhiMSICAL, and IWMF Connect/Facebook. Folks were obviously enjoying the company of their Waldenfriends and were glad for the opportunity to have a bit of friendly discussion on topics and questions near and dear to their hearts. Then began the morning sessions.

Immunotherapy: Making the Immune System Target WM – Dr. Stephen Ansell

Dr. Ansell from the Mayo Clinic provided an engaging talk,

utilizing creative metaphors to help explain complex biologic and scientific concepts, along with healthy doses of humor. He discussed various ways to help turn on the immune cells in the body so that they can target and kill WM cells. One way to do this is through chimeric antigen receptor (CAR) T-cell therapy, and Dr. Ansell discussed its possible applicability for WM patients and some potential toxicities that could occur with its use.



During the Q&A, questions were asked regarding the role of natural killer cells in WM (there are not enough of them in the body to be effectively focused on WM), the financial toxicity of CAR T-cell therapy (upwards of \$500,000 USD for treatment), and whether there are supplements one can take to stimulate the immune system. Dr. Ansell’s response to the latter was to be careful when using supplements, as you could be making it more difficult for treatments to work or you could even be stimulating the malignant cells! He did say, though, that you should try to improve your overall health but always discuss any such plans with your medical professionals.

Fact or Fiction: Nutrition and Cancer Myths – Stacy Kennedy, RD

Stacy Kennedy from DFCI is a returning presenter and once again provided a lively and very informative discussion about various aspects of nutrition and cancer. Her exhaustive knowledge of the topic and the energy she brings to the presentation make for a very engaging session. Among the concepts she covered were nutrition and its impact on survivorship, symptom management, weight management, energy levels, the immune system, and overall wellness. She also provided handy tips and guidelines for nutrition and physical activity. Ms. Kennedy took the time to cover aspects of some myths regarding alkaline diets, coffee enemas, detox diets, and superfoods (none of them are very helpful!). Interestingly, she suggested that several small meals throughout the day rather than two or three big meals may be the healthier way to go.



Breakout Sessions

Next on the agenda were several breakout sessions, with interesting choices that made it difficult to decide which to attend. As on Friday, each of the sessions was very well attended. While these sessions were not videotaped, slides for most of them will be available on the IWMF website soon. The topics were:

- Sharing Circle for Caregivers (Dr. Julianne Flora-Tostado)
- Peripheral Neuropathy (Dr. Tom Hoffmann)
- Complementary and Integrative Therapies and Myths (Stacy Kennedy, RD)
- Palliative Care and Supportive Oncology (Dr. Susan McInnes)
- The Financial Side of Cancer (Dr. Heather Klusaritz)



Lunch

At this point, folks were ready for a break for food to help build up their energy levels after having taken in so much information during the morning sessions. Lunch also included reports from the IWMF Board of Trustees, as the Ed Forum also happens to be the annual meeting of the IWMF membership. It's good to get to know the leadership of the IWMF and what has transpired over the past year. Thanks to generous donations, much progress has been and continues to be made in both Member Services and Research.

Breaking News from the Front: IWMF10 and IWMF-LLS Strategic Research Roadmap – Dr. Steven Treon

The afternoon sessions began with a “first ever” from the IWMF Ed Forum—livestreaming of a presentation. Anyone around the world was able to watch Dr. Treon's presentation live on either YouTube or Facebook. There were about 300 concurrent users that day. There's always a heightened level of excitement when Dr. Treon steps up to the podium because of the time and attention he's given to WM over his career and his compassion towards WM patients. In fact, through his efforts as principal investigator and the efforts of others involved in the seminal Phase II clinical trial of ibrutinib, it

became the first treatment approved specifically for WM.

Dr. Treon began his presentation with a discussion about the difficulty of achieving complete responses (CR) in WM patients, and that, in most cases, the focus is on extending disease control for as long as possible, while CR still does remain an ultimate objective (along with a cure, of course). He also discussed various toxicities associated with commonly used treatments such as rituximab, fludarabine, bendamustine, and bortezomib. This was followed by an explanation of the MYD88 and CXCR4 mutations and their importance in helping to determine the best treatment protocol for an individual patient. Dr. Treon then discussed other novel agents that are undergoing trials right now, such as venetoclax, ERK inhibitors, acalabrutinib, and zanubrutinib.

He also mentioned a comprehensive new effort called The 300 Project, where his research team at DFCI plans to sequence 300 symptomatic untreated WM patients (funded by the IWMF). His talk was followed by questions from the audience, including whether to ask your doctor to prescribe ibrutinib and what is the most exciting new BTK inhibitor that is coming up soon (the response was that each has its own good and bad points, and all are comparable). Dr. Treon did mention a trial using dasatinib, for which Dunkin Donuts has actually provided a breakthrough grant. To a question about mutations that eventually cause treatment resistance, Dr. Treon said that these mutations are present before treatment and can survive and become predominant as therapy proceeds over time, thus the need for additional types of treatments.

NOTE: While the IWMF will be providing slides and videos of all presentations on its website in a couple of weeks, you can view Dr. Treon's presentation and the Q&A here:

<https://www.youtube.com/watch?v=IDZevlO5Drw>

Another first for an IWMF Ed Forum was the Great Debates sessions, where two topics of interest were debated by top doctors/researchers, with Carl Harrington moderating and refereeing. He even got into character with a referee uniform and a yellow penalty flag in his pocket!

Rituxan Maintenance vs. No Maintenance – Dr. Morton Coleman and Dr. Stephen Ansell

Dr. Ansell presented the case for no maintenance, while Dr. Coleman from Weill Cornell Medical College presented the case for the utility of Rituxan maintenance.

Limited Treatment Duration vs. Continuous Pill – Dr. Edward Stadtmauer and Dr. Jorge Castillo

Dr. Castillo presented the case for taking a continuous pill, while Dr. Stadtmauer presented the case for the benefit of limited duration treatments.

The debates provided compelling arguments on both sides of each issue. Yet, it became apparent that what really mattered



for each of the debated issues was which would be the best option for an individual patient's particular health situation. As with any treatment decision, careful attention to the patient's history, symptoms, and well-being will draw out the best option.

It should be noted that the debates were spirited, with the doctors obviously also having fun with this part of the program, interjecting humor while discussing serious issues. And, to their credit, President Carl had to throw his yellow penalty flag only twice!

Following the last session, a group of WMers got together in the lobby (about 50 in total!) to go on an evening leisure walk that took them through Love Park (with a photo opportunity at the LOVE statue), and onward to the Rocky statue and steps at the Philadelphia Museum of Art, where several WMers took the challenge of running up the steps. Incidentally, a group of local folks sitting on the steps cheered us on as we did it!



SUNDAY, JUNE 9 – THE ED FORUM FINALE

Sunday morning began with the early morning “Walk for Waldenstrom’s” (now in its third year), where Waldenfriends got together to share stories, breathe some fresh air, see the sights of the city, and, for many, walk to raise money for the IWMF. This year, 75 people took part in the walk, and the efforts of many of the walkers led to donations to the IWMF totaling \$30,000! The 5K walk wound through several sites of historic significance—Independence Hall, the Liberty



Bell, and the IWMF's president's house (ok...it's first lady Elly's house too!). This year, we had perfect weather for the event, and we look forward to another amazing turnout next year in Seattle!

Take Home Messages about WM – Dr. Morie Gertz

Dr. Morie Gertz of Mayo Clinic provided a wrap-up for the entire weekend, focusing on “take home messages” about WM and treatment options. Dr. Gertz always makes sure to kick off his talk on a humorous note, and this year was no exception.



Ask the Doctor Panel

Dr. Gertz's informative wrap-up was followed by one of the highlights of the entire Ed Forum—the Ask the Doctor Panel. IWMF Facebook members, IWMF Connect online discussion group members, and those in attendance at the Ed Forum submitted questions in advance to the panel of physicians. The panel this year included Dr. Steven Treon, Dr. Stephen Ansell, Dr. Morie Gertz, and Dr. Morton Coleman. Moderating the session was IWMF VP for Research Dr. Tom Hoffmann. While the session was about 1.5 hours in length, there still wasn't sufficient time to address all the questions, as more than 50 were submitted.

The questions were quite insightful and again displayed the depth to which WM patients and caregivers go to get a strong understanding of their disease. The responses by the panelists were also well thought out and helpful. We encourage you to view the Ed Forum videos when they become available on the IWMF website to hear all the questions and answers.

At this point, the 2019 IWMF Ed Forum was officially over, and attendees gathered together to say final goodbyes (or perhaps “see you next year”) to new and old Waldenfriends.

2019 Ed Forum, cont. on page 14



For many, this becomes a bittersweet moment, as we return to our day-to-day challenges and activities outside of WM. It gives one pause, as one realizes that the past weekend truly was a unique experience—energizing, supportive, educational, and providing a boost of hope in our WM journey.

THE ED FORUM EXPERIENCE

A few things that became quite evident as the weekend progressed:

- The doctors who presented at the Forum gave of their time throughout the weekend; they were not paid to speak. They are truly to be commended, and the IWMF community is fortunate to have such dedicated and caring individuals looking out for our best interests.
- After every session, and, in fact throughout the weekend, one could see patients approaching the presenters, clinicians, and researchers to pose their own personal questions. Each medical professional made sure he or she was available and engaged with patients and caregivers.
- About one-third of the attendees were “first timers” and had special ribbons on their name tags to designate that. The “veteran” attendees always went out of their way to welcome the new folks and to talk to them...a very supportive atmosphere.
- Each year, although the city changes, the hotel changes, and each venue has its own different layouts and elevator issues, the overriding factor is that the IWMF manages to put together an agenda of highly qualified professionals dedicated to passing along their knowledge and experience

to patients and caregivers in “layman’s terms” (no small feat given the intricacies of working with the immune system) and does its best to ensure a supportive atmosphere with ample opportunities for patients and caregivers to get together and provide assistance to each other.

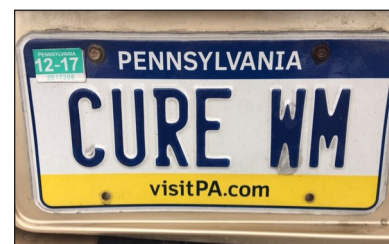
- It takes a village to pull off an Ed Forum, or something like that! The hard work and dedication of the Ed Forum Committee over the past year in organizing the event, and Sara McKinnie’s efforts to coordinate and direct volunteers to help run the registration desk and perform other duties made the weekend a fantastic experience for all attendees. If you’re planning on attending next year and would like to help, contact Sara McKinnie at sara@iwmf.com.
- Throughout the weekend, patients and caregivers could be seen huddled together sharing concerns and experiences, asking for help and advice, and exchanging hugs and handshakes in appreciation for the comfort provided. Truly a unique gathering of what can best be described as Waldenfriends for life!

Be sure to mark your calendars now for the 2020 Ed Forum in Renton, WA (near Seattle) to be held in the Hyatt Regency Lake Washington Hotel on June 5-7, 2020. Incidentally, that will be the 25th IWMF Educational Forum! Check your January 2020 IWMF Torch magazine and the IWMF website in early January for details.

Videos and slides of all 2019 general session presentations are now, or will soon appear, on the IWMF website at:

<https://www.iwmf.com/library/media-library/educational-forum-multimedia>.

And you can view photos from throughout the weekend at <https://tinyurl.com/iwmf2019photos>.



To see additional moments, go to the back cover!



IWMF DOC STAR: DR. RICHARD FURMAN

EDITED BY RON TERNOWAY

Q: How many hematologists does it take to find a tapeworm?

A: Only one, if his name is Richard Furman, the Morton Coleman, MD, Distinguished Professor of Medicine at Weill Cornell Medical Center in New York, NY.

David Sellers was diagnosed with Waldenstrom's macroglobulinemia (WM) in 2001, and has been a patient of Dr. Furman's for the past ten years. He is one of the first WM patients world-wide to have been prescribed ibrutinib, as participant in a clinical trial led by Furman.

Soon after meeting with Dr. Furman, a routine CT scan showed several cysts in David's liver, which the radiologist reported as possible echinococcal cysts. Echinococcus is an infection caused by a parasite, usually acquired from eating contaminated food. The parasite is very rare in the US, so Sellers may have acquired it on one of his overseas vacations.

Dr. Furman did further tests and research, then consulted with the head of the Infectious Diseases Department at Weill Cornell, who confirmed the diagnosis. The parasite had set up shop in David's liver and was fervently reproducing, causing the cysts to grow ever larger. Left untreated, the infection could have been fatal. Dr. Furman first administered a drug that killed the parasite, then referred Sellers to a surgeon with experience in removing echinococcal cysts.

"It was not a pleasant ordeal, but I fully recovered," David said. "I believe that Dr. Furman saved my life by taking the lead in researching and treating this infection. And it had nothing to do with my cancer.

"When I need treatment, Dr. Furman always discusses the pros and cons of the various options with me, listens to my concerns, and answers my questions. Together we come to a decision. Thankfully, so far we have been able to avoid treatments that might permanently damage my bone marrow.

"I feel that Dr. Furman has given my life back to me more than once. I have nothing but the utmost respect for him, and I feel very fortunate that he is my doctor. Nowadays, I think he may indeed be able to reach our shared goal of giving me a normal life span. What more could I possibly ask of a physician?"

Richard Furman grew up in South Orange, NJ, the middle child with two sisters. All three siblings went into medicine, his older sister becoming an infectious disease physician and his younger sister a cardiologist. "I like to say that I always wanted to be a physician, and that my sisters decided to become physicians later," he says.

While neither of his parents were physicians, his grandfather was one of the "old-fashioned" family practitioners, who took care of all of his patients as best he could, 24 hours a



Before David's consultation – Left to right: Mitch Orfuss, NYC SGL; Dr. Richard Furman; David Sellers, ibrutinib pioneer and patient of Dr. Furman; and Emilee Thomas, assistant to Dr. Furman

day, seven days a week. "He was my role model for what a physician should be."

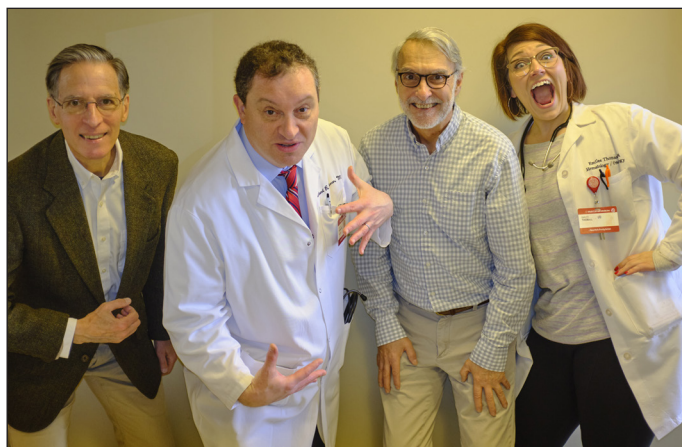
Furman received a BA in biology from Dartmouth College in Hanover, NH, and his MD from Mount Sinai School of Medicine in New York. His residency in internal medicine was at the University of Pennsylvania and fellowship in hematology and oncology at Weill Cornell Medical College.

He began working in bench-top research in immunology during college and continued through medical school. He then focused on immune aspects of chronic lymphocytic leukemia (CLL) at Mount Sinai School of Medicine. "After spending three years in the laboratory, I decided that I missed caring for patients and moved back to Weill Cornell Medical College to pursue clinical research in CLL and Waldenstrom's."

Furman cites his most important influences as his grandfather, his research mentor Lloyd Mayer, and his clinical mentor Morton Coleman. "All three of these people demonstrated to me how gratifying and important caring for patients is. They also demonstrated the need to listen to the patient, to educate the patient, and to provide always for all of the patient's needs. Dr. Coleman started me on my clinical research career, demonstrating how fascinating it could be and how great an impact it could have for patients."

When asked to identify his greatest professional reward and greatest professional challenge, Dr. Furman responds: "My greatest professional reward is knowing that after many failed attempts, I have a very large series of patients who are alive and well because of the novel agents I was involved in developing. I have a patient who was on his way to hospice in 2010, but stopped to see me at his wife's insistence, and is still alive and doing extremely well.

IWMF Doc Star, cont. on page 16



After David's consultation

"My greatest challenge is trying to prevent the anxiety patients experience associated with incurable malignancies that is often exacerbated by a watch-and-wait approach. My goal is always to achieve, or re-establish, normalcy for my patients. To allow them to proceed with their lives. Many patients cannot understand the idea behind delaying therapy, and this anxiety begins to overwhelm their lives."

"My goal is always to achieve, or re-establish, normalcy for my patients. To allow them to proceed with their lives."

Furman is a member of the WM Clinical Trials Group, and also director of the Waldenström's Macroglobulinemia Research Consortium (WRC), consisting of investigators from five institutions (Weill Cornell, Columbia, Ohio State University, Roswell Park Cancer Institute, and the Mayo Clinic) collaborating on clinical trials and translational research projects in WM. The WRC is currently exploring several projects to improve the efficacy and tolerability of ibrutinib therapy by combining it with daratumumab. It has also recently collaborated with the Bing Center for WM at Dana-Farber Cancer Institute on the clinical trial investigation of venetoclax for WM. WRC's future plans involve more trials of safer, better tolerated, and more effective drugs.

Furman was co-chair of the 5th International Patient and Physician Summit on WM in New York City, October 2018.

He also devotes a great deal of time to programs aimed at improving Weill Cornell Medicine—medical school and hospital—such as serving on the Faculty Council and being the quality assurance chair for the Division of Hematology and Oncology.

Furman is candid about the old work-life balance question: "I don't really achieve any sort of a work-life balance. I have a phenomenal wife who is an obstetrician-gynecologist, and we have two amazing children, 17 (son) and 14 (daughter), who understand how important it is to care for others and society at large. Most of our leisure time is spent watching my daughter compete in travel soccer, but we otherwise just enjoy each other."

Final words on the contributions of our devoted Doc Star from Mitch Orfuss, 17-year WM survivor and IWMF support group leader for New York City: "In 2009 I first invited Dr. Furman to speak to the New York WM Support Group, and he gave what was for me a transformative presentation. He had a vision of low-toxicity treatment for this incurable disease, available in the short term, and I found his philosophy and support for it most persuasive. He discussed new drugs that were under investigation at the time which were starting to show incredible promise—more targeted to the precise biology of WM, yet at the same time less toxic—which sounded nearly too good to be true. That day was the first time I'd learned about the potential of PCI-32765, which became ibrutinib.

"The 'Furman Strategy' was to drive WM into a very good remission while keeping the patient's bone marrow and DNA stronger and healthier for the long run or until the cure came along—whichever came first; it hardly mattered. No need to win the battle but lose the war to cumulative toxicity from drugs that knocked back the disease more than was necessary. Instead, we could battle our foe to a respectful draw while staying healthy for the kill shot when research brought it along.

"Rick Furman was first to envision and deploy what was to me a sensible, novel strategy, and to believe it was not a pipe dream, but here on the doorstep. Because of his inspiration and brilliance as a researcher and as a clinician, I volunteered to become a test pilot for ibrutinib and have remained one of Furman's most admiring and grateful acolytes for more than a decade. I seek out every word he says. Thank you, Dr. Furman, for your immeasurable contribution to WM and, more selfishly, to me!"

IWMF CONNECT: SUMMER 2019

BY JACOB WEINTRAUB, MD

The 2019 IWMF Educational Forum has ended, but IWMF Connect continues, as it did throughout the Ed Forum with posts by “Secret Wallie” that shared the excitement of the sessions and the fellowship of the attendees. As always, there were multiple links to human interest articles, scientific studies, and other important subjects. Many issues were discussed, and even old topics were presented with new twists or were reminders of information we may have forgotten.

GENERAL INTEREST

IWMF Connect Manager and IWMF Trustee Peter DeNardis posted several links of general interest. He also noted that there are several Stories of Hope about fellow WMers on the IWMF website. As an example, Pete posted a link to the story of Gunnar Armansson, who was diagnosed at 38 years of age and had never considered a need for medical attention until he almost passed out 14 years ago.

<https://www.iwmf.com/get-support/patient-stories/iceland-gunnar-%C3%A1rmansson-%E2%80%9Cdiagnosed-age-38-running-became-my-lifeline%E2%80%9D>

Another link from Pete was to an article entitled “Work can be a refuge from cancer.” Many of us are not quite ready for retirement when we are diagnosed with cancer, and this article discusses how balancing the doctor and treatment schedules with work schedules can be daunting at times. It also provides some useful insights into workforce accommodations available to patients and caregivers in the US by way of the Americans with Disabilities Act (ADA) and the Family and Medical Leave Act (FMLA). On a personal note, I was a beneficiary of FMLA. During my recent hospitalization at Mayo Clinic and week-long stay in Rochester, my daughter used FMLA to stay with me. She knew she was guaranteed to have her job waiting for her, along with privacy protection from a prying supervisor who wanted more details than my daughter cared to give out.

<https://www.columbusceo.com/business/20190218/work-can-be-refuge-from-cancer>

Peter also posted links to an article and a video about how to talk to patients who have cancer. This is a piece about a 14-year-old girl with acute lymphoblastic leukemia who has had multiple relapses and treatments. She provides a list of “rules” for what people should and should not say, in an honest, engaging, and straightforward way, and with a healthy dose of humor sprinkled throughout. As Pete says, she “nails it.” He also adds that “This girl is amazing...can we make her an honorary Waldenfriend?” The article is here:

<https://www.wral.com/how-to-talk-to-kids-about-cancer-a-raleigh-teen-sets-some-ground-rules-in-video-that-s-racking-up-views/18275219/>

You can watch the video here:

<https://www.youtube.com/watch?v=5FwfbGYxDqg>

Wanda H also posted links to articles of interest, including an article in *Cure* entitled “No Donuts, No Job” about job loss with cancer. This article deals with work situations and loss in people with cancer and how to address various issues and enlist help from family and friends.

<https://www.curetoday.com/community/ryan-hamner/2019/04/no-donuts-no-job>

Wanda added a link to an article in *Lymphoma Today* called “The Joy of a New Oncologist,” which discusses how to choose a new oncologist when your doctor retires or leaves practice. There are some good suggestions and observations about characteristics that are desirable in an oncologist.

<https://lymphomanewstoday.com/2019/02/08/joy-new-oncologist-research-developments/>

Finally, **Julianne F** posted a link to “Tackling Cancer Anxiety,” an article published in the *New York Times*. Julianne comments that no matter how often she deals with periodic blood tests, CT scans, and mammograms, they always trigger a huge wave of “scanxiety,” and I think this is true for most of us. She adds that the author is witty and right on target. Reading this essay gave her some new terms and a chuckle or two.

<https://www.nytimes.com/2018/11/15/well/live/tackling-cancer-anxiety.html>

BATTLING CANCER

One of the discussions that tends to recur is about how we describe our relationship with our disease and how we refer to our status and treatments. Pete posted a link to an article entitled “With Alex Trebek’s announcement comes unease over the words ‘fight’ and ‘win’ applied to cancer.” Pete commented that Alex Trebek vowed he would “fight and beat” his cancer, regardless of the odds. The article was in the *Chicago Tribune* and presented one person’s opinion regarding “war” and “battle” metaphors. There is a feeling expressed with these metaphors that, if one “fights” and still dies despite treatment, one is somehow weak. The author suggests we need new terminology.

<https://www.chicagotribune.com/lifestyles/stevens/ct-life-stevens-thursday-alex-trebek-cancer-language-0307-story.html>

Beth G commented that she has said to several friends that she is not “fighting” cancer, she is accepting reality and taking every action she can to take care of herself one day at a time.

Julianne F agrees with the author that the words we use can more correctly reflect hope, kindness, and gratitude for when one is fortunate and honor for those who don’t happen to have

From IWMF Connect, cont. on page 18

cells that respond to treatment.

In a similar line, Peter later posted another link to an article titled “I Have Cancer. Please Don’t Call Me a Survivor.”

<https://www.medpagetoday.com/special-reports/apatientjourney/79229>

Amy D suggested she will call herself a cancer survivor when we start hearing the terms diabetes survivor, heart disease survivor, and other similar terms.

However, **Steven D** noted that he has seen the terms heart attack and stroke survivor.

Nick M posted that if you’re alive today, then you are a survivor. He is a seven-year pancreatic cancer survivor, and his wife was diagnosed 18 months ago with WM. Even though there is no known cure yet for WM, he considers everyone on IWMF Connect to be a survivor.

Ed K posted that he has had multiple cancers, including kidney cancer for which cryoablation was used. He also had surgery for skin cancer. Now he has WM and has had many transfusions, a very high IgM resulting in the loss of vision in his right eye, and multiple chemo regimens. Finally, he needed a stem cell transplant. He definitely feels like a cancer survivor.

Finally, on a personal note I added my own perspective to the discussion. I grew up in an era when having a diagnosis of cancer meant you were going to die. My mother died from cancer at age 43, and even into the 1970s when I was in training to be a physician, cancer almost universally had a terrible prognosis. I think “cancer survivor” arose out of that mindset, though current medical knowledge and treatment modalities no longer make this true. I have had WM for 18 years without treatment and had not considered myself a “survivor.” However, in the last year, I was diagnosed with another cancer that looked aggressive and advanced. With hormone treatment and then surgery, the cancer looks to be gone completely. After DaVinci robotic surgery, I had a lot of bruising and feel like I truly have been through a battle and consider myself a “survivor,” at least with regard to the new cancer. Although I still feel the same about my WM, I agree with Ed that any of us easily could consider himself or herself a survivor of a battle, even with WM.

IMMUNIZATIONS

This is a subject that recurs in many different forms. However, with the recent increase in measles cases, the discussion has taken on a very timely note.

Larry P had questions regarding measles. He has WM, and his wife had a blood test that showed lack of immunity to measles despite having had a vaccine in the early 1960s. With pending airline travels, her doctor recommended she be vaccinated for measles, but this is a live virus vaccine. He wanted to know if there is any risk to him from the vaccine if he doesn’t have evidence of immunity on blood testing.

Karen R asked about potential exposure to a friend who cares for a 4-year-old grandchild who may not have received measles immunization. Should Karen stop contact with her friend?

Dr. Tom Hoffman, IWMF Trustee, replied that due to the immunodeficiency related to WM, we should never receive a live virus vaccine. He also suggested that Larry avoid being around his wife for 3-5 days after she receives her vaccine.

I posted that I agreed with Dr. Hoffman’s note, though I indicated that the risk of contracting measles from the vaccine is very low. However, to be absolutely safe, Larry should avoid being around his wife for a few days. I added that if a person was born before 1957, it is assumed that he or she has had measles and is immune. I also added that if a person with WM thinks he or she has been exposed to measles, there is a measles immune globulin that can be given, but it needs to be given within six days of exposure.

Eileen P suggested that Karen should ask her friend about the immunization status of the grandchild and explain her own situation. The friend should know that since Karen is immunocompromised and cannot receive the measles vaccine, it would be dangerous to contract measles. Eileen also suggested it would be prudent to have a titer done to see if there is any evidence of immunity.

Larry P asked what a “titer” is, and **Sue H** replied that an antibody titer is a blood test that measures the amount of antibody that a person’s body produces to protect against a specific disease-causing organism. In this case, the test would be for an IgG antibody against measles. The IgG is produced as a result of previous measles infection or vaccination.

Meg M added a list of live vaccines, including combined MMR (measles, mumps, and rubella), varicella (chicken pox), the “old” zoster vaccine for shingles (Zostavax)—but not the new shingles vaccine called Shingrix. In addition, the yellow fever vaccine and the oral typhoid vaccine are live but are used mainly for travel in certain areas.

From IWMF Connect, cont. on page 19

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

There was some additional discussion about the new shingles vaccine, Shingrix. **Barbara G** posted that her oncologist wants her to get the Shingrix vaccine, but not yet. On further questioning, she said that she has been treated with bendamustine and Rituxan, and her doctor thinks she has not yet recovered sufficiently from the treatment to generate enough antibodies from the vaccine. She is currently taking the antiviral acyclovir. She was started on this after having a case of shingles despite having had the Zostavax vaccine three years before.

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 welcomed. If you have any questions or wish to see more from our discussions on a particular topic, please let me know and I will try to include those discussions in a future column. The summer presents fresh opportunities for adventure and travel, and I wish you all continued good health.

LIVING LIFE TO THE FULLEST

BY LIZ ELTING



Left to right, back: Liz Elting, Joanne Elting (Everett's wife), Everett Elting, Michael Burlant (Liz's husband); left to right, front: Zachary and Jason Burlant

My dad was diagnosed with Waldenstrom's macroglobulinemia in 2011.

It's going to be a familiar story to anyone reading this, no doubt, united as we all are by our experience with loved ones suffering from this illness, or by our own affliction. We only found out because he was hospitalized for something entirely unrelated.

You need to know something about my dad: he's not a complainer. He doesn't believe in it. It's admirable in the best circumstances, but in the worst, it can mean it's hard to know when something is wrong. My dad had already survived multiple bouts of skin cancer, and since he's never been one to make a fuss about how he's feeling, even those weren't always the quickest to be diagnosed. To say he's resilient would be an understatement. He's the sort of man who, even in the frigid weather of Canada, would never wear a coat, as though it were a sign of weakness or a mark against his pride. He couldn't control it, so why worry? And he has maintained an active lifestyle well into his senior years and to this day, which even younger men would envy.

And that, it turned out, was the key to discovering his illness.

My father has always been athletic and a sports lover; he was an avid tennis player throughout most of his life. And he was good, too. I still think about watching him move up and down the court with the fancy footwork of someone 20 years his junior, in fluid motion with every step deliberate and considered. I think about how he'd serve the ball with all the force of a major league power hitter, an audible “thwap” ringing out at racket strike. But the human body can only take so much, and every single step, however considered, was a blow to his knees. So much so, in fact, that over the years he needed no less than four knee surgeries.

Like I said, he's just not a complainer.

By 2011, the damage was so great that his tennis days were over, and he needed a complete knee replacement. Now,

hearing that your lifelong pastime is over with is hard enough, but once his surgeons got in there, they discovered something terribly wrong with his blood. It's a common refrain in the WM community — since the disease moves

slowly and tends to have nonspecific symptoms like fatigue, weakness, and weight loss that are relatively common (especially among older patients), it can be slow to detect. And some of the symptoms can easily be mistaken for a sign of something else. That's especially true when you're as much of a trooper as my dad and as reluctant to seek help. It took something as dramatic as wrecking his knee to discover the



Liz Elting and her father Everett

Living Life to the Fullest, cont. on page 20

indolent illness spreading throughout his blood by degrees.

His diagnosis didn't come easily; initially, we believed he had a more common type of lymphoma. But with his diagnosis of Waldenstrom's came a five-year prognosis, and we prepared for the worst. I'm forever thankful that the worst never came, and he's long since outlived his initial prognosis—a feat that was only achieved thanks to the incredible strides in research made possible by the IWFMF. Just as much as the research the IWFMF supports, I'm grateful for the support I've found here and the support I've in turn been able to offer.

If there's anything I've learned from my dad over the course of my life, it's perspective. From childhood lessons on independence, self-reliance, and positivity to his lifelong commitment to fitness and health to his chin-up response to his diagnosis, he's always had an attitude that, while easily mistaken for "always look on the bright side of life," is much richer than that. It's an attitude of what I'll call "optimistic resignation." There are things that you can control and things that you can't; nobody lives forever, and that gives you a certain kind of freedom to live the way you want. After all, the worst that can happen is you die, and that is going to happen eventually anyway. Your fate, in short, is what you make of the circumstances you're given. Wealthy or poor, healthy or sick, your life is ultimately your own.

It's that attitude and good fortune that have seen my father spend his illness, not at hospitals waiting to die, but on months-long world-spanning cruises, seeing the world in new and exciting ways and making the best of the time he has. It's been inspiring to see, and it's why I participate in the IWFMF the way I do.

At the end of the day, we are the captains of our fate; we live and we die by our own decisions, and the mark we leave on the world is ours to choose. It's why I, after learning of the IWFMF in early 2017 (a full six years after my father's diagnosis and a year after his life was supposed to be over) began donating \$500,000 a year to its work and why I continue to do so. My life's fortune does nobody any good sitting in a vault accruing interest, and I already have every comfort in life I could ask for. The money I give is a fraction of what my father has given me in my life, and it was the upbringing he offered that made my success



Liz Elting

possible. I'm proud to be able to support the IWFMF's work, the same way I work with the American Heart Association's Go Red for Women campaign in support of women's cardiac health. The goal isn't just philanthropy as an abstract good; it's to participate meaningfully in something that affects not only my father, but countless others.

What I hope to do, more than anything, is to help people see that WM isn't a death sentence. That has been the greatest lesson my dad has taught me these last few years. You can look at it as a sword dangling over your head or as a daily reminder to live your life on your own terms.

By supporting research that helps doctors identify and treat WM, we—you and I, together—can make those years as meaningful as possible, allowing those with WM to live their lives on their own terms. Most don't realize it until it's taken away, but good health is such a big thing. Being able to wake up in the morning and manage your daily routine is profound. It's something that a disease can make difficult to impossible without the right care. Not everyone has my dad's energy or outlook, but the right treatment can make the illness recede into the background for years on end.

One day, sometime after my dad's knee replacement, my son—then just ten years old—wanted his grandfather to join him out on the tennis court. By then, we knew about his cancer, and he was under explicit instructions to put tennis behind him as it could damage his new knee. My father, then in his late 70s, could have been seen as the archetypal frail old man—reeling from a cancer diagnosis, limping about after knee surgery, restrained and confined by the physical limitations of his body and doctors' orders. But instead, he got right out on the court and hit the ball with his grandson for a while. After all, what was the worst that could happen? Was it going to kill him? That ship, he figured, had already sailed, and besides, how many more chances was he going to have to do this? In watching my dad, I've seen how death sentences can even be freeing, if you want them to be.

Ultimately, that's been the best lesson he's taught me: to remember that we only get one go-round in this world and to spend it living, loving, and doing good. The IWFMF makes it possible for so many to live their own lives, not under the sword of WM, but in the liberating light of life.



Everett Elting and his grandson Jason



Note To WMers: Get a dilated eye exam with a doctor who is knowledgeable examining a WM patient. If you have any sudden changes in vision, call your eye care provider immediately.

As for Winnie, one day she will see that Eye Care doesn't have extra wide parking!



MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF RESEARCH COMMITTEE MEMBER

Mayo Clinic Study at ASCO Compared Outcomes of Three Different Frontline Therapy Regimens for WM –

A study from the Mayo Clinic, presented during the 2019 ASCO Annual Meeting, compared outcomes from three commonly-used frontline therapy regimens in WM. The three regimens were bendamustine and rituximab (R-Benda); dexamethasone, rituximab, and cyclophosphamide (DRC); and bortezomib, dexamethasone, and rituximab (BDR). The study included 172 patients treated at Mayo Clinic between 2000 and 2018. Baseline characteristics were similar among the three groups. Moderate to severe peripheral neuropathy requiring treatment discontinuation was encountered in 13% of patients treated with BDR; otherwise, the toxicity profile across the three groups was comparable. The overall response rates, major response rates, event-free survival, and overall survival with frontline R-Benda were superior in comparison to frontline DRC or BDR therapies; there were no significant differences in clinical outcomes with DRC versus BDR.

Retrospective Study Presented at ASCO by Mayo Clinic Supports Maintenance Rituximab Treatment in WM –

Another abstract from the Mayo Clinic discussed during the 2019 ASCO Annual Meeting was a retrospective study of

WM patients treated with maintenance rituximab (Rituxan) between January 2000 and June 2018. Of 776 patients with active WM treated during this period, 42 patients received maintenance following rituximab-based frontline therapy and were matched with a control group of 84 patients treated with rituximab-based frontline therapy but without maintenance. Patients in the maintenance rituximab group showed a trend toward longer time-to-next-therapy (8.8 years) versus the control group (5.8 years) and a longer overall survival (not reached) versus the control group (10.1 years). Maintenance was administered most commonly on a schedule of every 2 months for a median duration of 1.9 years. Infections were reported in 31% of patients during maintenance therapy, and 12% discontinued maintenance due to toxicity. The researchers concluded that, despite the limitations of a retrospective study and the relatively high rate of infections, the data add to the body of literature supporting maintenance rituximab.

Pilot Study Evaluated TP53 Mutations in WM – A pilot study in the United Kingdom, published in the *British Journal of Haematology*, evaluated the incidence and clinical

Medical News Roundup, cont. on page 22

*In current practice, the prevalence and significance of **TP53 mutations** in WM are largely unknown, and TP53 testing is **not routinely** performed in WM patients.*

significance of mutations of the TP53 gene in WM. In current practice, the prevalence and significance of TP53 mutations in WM are largely unknown, and TP53 testing is not routinely performed in WM patients. However, in chronic lymphocytic leukemia patients, small TP53 mutated subclones can expand over time, leading to a more aggressive disease course and increased resistance to chemoimmunotherapy. In this study, 14 WM patients were examined at diagnosis and at subsequent intervals for the presence of TP53 mutations, using DNA from their bone marrow, peripheral blood, and saliva and analyzed by next generation sequencing. Four patients (29%) were identified with mutations in TP53 subsequent to diagnosis. Two of the four were negative for the MYD88 L265P mutation, and both became refractory to therapy with BTK inhibitors, such as ibrutinib. Because of the small study size, the researchers could not conclude whether TP53 mutations were a contributing factor to BTK therapy resistance; however, they suggest that TP53 gene testing be performed at diagnosis and prior to each line of therapy and that further studies are desirable to clarify the incidence and significance of acquired TP53 mutations in WM. Because these mutations were detected in peripheral blood, liquid biopsies could be used, enabling regular monitoring without the need for repetitive bone marrow biopsies. This study was partially funded by WMUK, the United Kingdom affiliate of the IWMMF.

Phase I Trial Results Presented at ASCO for Novel DNA Vaccine in Smoldering WM – A Phase I trial of a novel DNA vaccine used in patients with smoldering WM was presented by the University of Texas MD Anderson Cancer Center and the City of Hope in California during the 2019 ASCO Annual Meeting. The abstract discussed the safety results for this idiosyncratic vaccine, which is targeted to the DNA of the IgM on the surface of each patient's WM cells. The goal of the study is to lengthen the smoldering phase of WM by generating an immune response against the WM cells. Nine smoldering WM patients received three vaccinations at four-week intervals. With a median follow-up of 26.5 months, seven patients have stable disease, and two progressed to symptomatic WM. Adverse events included leukopenia (low white blood cell count), nausea, anemia, increased creatinine, and fatigue. Results are underway to determine whether tumor-specific immune responses in these patients were generated from the vaccine, but the trial is no longer recruiting patients.

ASCO Abstract Presented Data on Cause-Specific Mortality in LPL/WM – An abstract presented by the National Cancer Institute and the US Food and Drug Administration at the 2019 ASCO Annual Meeting discussed cause-specific mortality in lymphoplasmacytic lymphoma (LPL) and WM patients. The study identified 6,659 LPL/WM patients within 17 US-based population cancer registries from 2000 to 2015. Of 2,826 deaths within this period, 43%, 13%, and 42% were due to lymphoma, cancers other than lymphoma, and non-cancer causes, respectively. The most common non-cancer causes of death were infectious, respiratory, and digestive diseases. Of note, cumulative mortality from non-cancer causes (23.7%) exceeded that from lymphoma (22.9%) beginning nine years after LPL/WM diagnosis.

*The aims of the study are to **characterize** the clinical, biologic, and molecular events of each disease and **clarify** the processes involved in disease progression.*

Observational Trial Available for LPL/WM Patients at NIH – The National Institutes of Health (NIH) has been operating an observational study on the biology of several diseases, including lymphoplasmacytic lymphoma (LPL)/WM. The study, called “Natural History Study of Monoclonal B Cell Lymphocytosis (MBL), Chronic Lymphocytic Leukemia/Small Lymphocytic Lymphoma (CLL/SLL), Lymphoplasmacytic Lymphoma (LPL)/Waldenstrom Macroglobulinemia (WM),” is listed on www.clinicaltrials.gov as NCT00923507. The aims of the study are to characterize the clinical, biologic, and molecular events of each disease and clarify the processes involved in disease progression. The trial intends to enroll 550 participants, who are followed every 6-12 months for the first two years and every 12-24 months thereafter in the NIH clinic. When required, patients have blood draws and may undergo additional testing, including bone marrow biopsy and aspiration, lymph node biopsy, X-rays, and CT, PET, and MRI scans. Clinical information will be collected and stored in a central databank for analysis. If their cancer requires treatment at some point, patients will be taken off the study, and treatment options will be discussed with them. If no NIH trial protocols for treatment are available, patients will be returned to the care of their local physicians.

Collaboration Formed to Advance the Development of New CXCR4 Antagonist for Treatment of WM – X4

Medical News Roundup, cont. on page 23

Pharmaceuticals and the Leukemia & Lymphoma Society (LLS) have announced a collaboration to accelerate the development of a small molecule oral antagonist of CXCR4 called mavorixafor (X4P-001) for the treatment of WM. About 30-40% of WM patients express CXCR4 gene mutations in their cancer cells. Mavorixafor was selected for LLS's Therapy Acceleration Program to speed the development of new therapies for blood cancers. Under the collaboration, X4 Pharmaceuticals will conduct a multi-national Phase I/II clinical trial of WM patients to evaluate the safety and assess the preliminary anti-tumor activity of mavorixafor in combination with ibrutinib (Imbruvica) and is expected to begin the trial later this year.

Immune Globulin Shortages Occurring in the US – At press time, a shortage of certain immune globulin products is being reported in the US. Immune globulin, also called gamma globulin, is a biological product composed primarily of purified immunoglobulin G (IgG) prepared from plasma collected from a large number of normal individuals who have been carefully screened to be sure they are healthy and do not harbor certain infectious diseases. It is administered either intravenously or subcutaneously to people who have been identified as immunosuppressed in an effort to boost the immune system. A list of current immune globulin products in short supply can be found on the US Food and Drug Administration website at <https://www.fda.gov/vaccines-blood-biologics/safety-availability-biologics/cber-regulated-products-current-shortages>.

Health Canada Has Approved Truxima Biosimilar for Rituximab – Health Canada has granted approval to Truxima, a biosimilar for rituximab (Rituxan), for the treatment of patients with non-Hodgkin's lymphoma, chronic lymphocytic leukemia, and rheumatoid arthritis. Truxima is manufactured by Teva Pharmaceutical Industries and was previously approved by the European Commission in 2017 and the US Food and Drug Administration in 2018. 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 somewhat lower than those for the original products.

FDA Has Placed Partial Hold on Clinical Trials of Venetoclax in Multiple Myeloma – The US Food and Drug Administration (FDA) has placed a partial hold on clinical trials designed to evaluate venetoclax (Venclexta) for the treatment of multiple myeloma. The decision came after a review of the ongoing Phase III BELLINI trial, which included patients with relapsed or refractory myeloma and showed a higher proportion of deaths among those patients treated with a combination therapy that included venetoclax (21.1%) versus those not treated with venetoclax (11.3%).

Most of the deaths in the venetoclax group were associated with infection. The partial hold means that no new patients should be enrolled in studies of venetoclax for multiple myeloma until additional analyses of the trial data are completed. The hold does not affect the use of venetoclax for indications other than multiple myeloma.

*Acalabrutinib is the **first BTK inhibitor** to show **benefit** as single agent therapy over standard-of-care combination treatments for relapsed/refractory CLL.*

Acalabrutinib Monotherapy Improved Progression-Free Survival Compared to Combination Therapies in Relapsed/Refractory CLL – Treatment with single agent acalabrutinib (Calquence) significantly improved progression-free survival among relapsed/refractory chronic lymphocytic leukemia (CLL) patients when compared to rituximab (Rituxan) in combination with either idelalisib (Zydelig) or bendamustine (Treanda). This conclusion was the result of the Phase III ASCEND trial, which evaluated acalabrutinib in 310 CLL patients. Acalabrutinib is the first BTK inhibitor to show benefit as single agent therapy over standard-of-care combination treatments for relapsed/refractory CLL.

Phase II Trial Results Reported for Duvelisib in Indolent NHL – Results have been reported in the *Journal of Clinical Oncology* for the Phase II DYNAMO clinical trial of the oral PI3K gamma inhibitor duvelisib (Copiktra) in patients with refractory indolent non-Hodgkin's lymphoma (NHL). Treatment in this trial consisted of twice-daily 25 mg doses of duvelisib in 28-day cycles until progression, unacceptable toxicity, or death and was administered to 129 patients with either follicular lymphoma, small lymphocytic lymphoma, or marginal zone lymphoma. With a median follow-up of approximately 32 months, the overall response rates were 42%, 68%, and 39%, respectively, for the three lymphoma types. The median time-to-response was 1.87 months, and the median duration of response was 10 months. The most commonly occurring adverse events were diarrhea, nausea, neutropenia (low neutrophil count), fatigue, and cough.

Single Agent Umbralisib Therapy Discussed in Phase II Study of Marginal Zone Lymphoma – A Phase II multi-center study, reported by the University of Texas MD Anderson Cancer Center during the 2019 American Association for Cancer Research (AACR) Annual Meeting, shared interim findings for single agent umbralisib in patients

with relapsed marginal zone lymphoma (MZL). The UNITY-NHL trial enrolled 69 MZL patients, who received 800 mg of umbralisib once daily. The overall response rate was 55%, and progression-free survival after one year was 71%. The most common adverse events were diarrhea, nausea, fatigue, headache, cough, and decreased appetite. A trial of single agent umbralisib for relapsed/refractory WM is recruiting patients and is listed on www.clinicaltrials.gov as NCT03364231. Umbralisib is a next generation oral PI3K delta inhibitor also known as TGR-1202.

*Umbralisib is a **next generation** oral PI3K delta inhibitor also known as TGR-1202.*

Preliminary Results Presented for Phase I Trial of IRAK4 Inhibitor to Treat Relapsed/Refractory NHL – Preliminary safety results were presented at the 2019 ASCO Annual Meeting for a multi-center Phase I clinical trial of CA-4948, an oral IRAK4 inhibitor, in patients with relapsed/refractory non-Hodgkin's lymphoma (NHL). The study includes one WM patient of the 13 enrolled and receiving treatment. Adverse events reported were fatigue, conjunctivitis, constipation, neutropenia (low neutrophil count), and leukopenia (low white blood cell count). One case of disease progression has occurred. Preliminary pharmacological data showed on-target reduction in NF-kappaB-associated factors. The trial is listed on www.clinicaltrials.gov as NCT03328078.

Phase I Chinese Study Discussed PI3K Delta Inhibitor in Relapsed/Refractory B-Cell Malignancies – Researchers from China discussed a Phase I study of the oral PI3K delta inhibitor YY-20394 in patients with relapsed or refractory B-cell malignancies during the 2019 ASCO Annual Meeting. The study of 22 patients includes one patient with lymphoplasmacytic lymphoma (LPL). The overall response rate was 68%, and adverse events included elevated LDH levels, pneumonia, elevated uric acid levels, neutropenia (low neutrophil count), lymphocytosis (high lymphocyte count), leukocytosis (high white blood cell count), and leukopenia (low white blood cell count). The trial is identified on www.clinicaltrials.gov as NCT03757000.

Results Discussed for Phase I Triple Combination Therapy in CLL and NHL – An article in *Lancet Haematology* discussed results of a multi-center Phase I

study of ublituximab, umbralisib, and ibrutinib (Imbruvica) in 46 patients with chronic lymphocytic leukemia (CLL) or non-Hodgkin's lymphoma (NHL). Of 44 evaluable patients, 84% achieved an overall response. The most common adverse events were diarrhea, fatigue, infusion-related reactions, dizziness, nausea and cough. Ublituximab, also called TG-1101, is a monoclonal antibody that targets a unique part of the CD20 antigen and has been bioengineered to deliver enhanced activity and potency. Umbralisib is a next generation oral PI3K delta inhibitor also known as TGR-1202. Both ublituximab and umbralisib were developed by TG Therapeutics.

New Oral Kinase Inhibitor to Begin Phase I Trial in CLL and NHL – Aptose Biosciences Inc. announced that it has been granted approval by the US Food and Drug Administration to initiate a Phase I clinical trial of its oral drug CG-806 in patients with chronic lymphocytic leukemia (CLL) or non-Hodgkin's lymphoma (NHL). CG-806 is a pan-FLT3/pan-BTK inhibitor and has demonstrated inhibition of both wild-type and C481S-mutated forms of the BTK enzyme—the C481S mutation being the most common cause of acquired resistance to BTK inhibitors such as ibrutinib (Imbruvica). This trial is expected to begin recruiting in the second quarter of 2019, and the trial identifier on www.clinicaltrials.gov is NCT03893682.

New Monoclonal Antibody Approved by FDA for Phase I Study in Lymphoma Patients – I-Mab Biopharma has received approval from the US Food and Drug Administration (FDA) to begin a Phase I/Ib clinical trial of its investigational drug TJC4, alone and in combination therapies, as a treatment for solid tumors and lymphoma, and the trial is expected to launch across multiple sites in the US in the second quarter of 2019. TJC4 is a monoclonal antibody that targets part of the CD47 protein, which can be produced by several types of cancer cells to suppress the ability of the body's own macrophages to engulf the cancer cells and subsequently prime the T-cells of the immune system. Previous agents targeting CD47 have had off-target effects against red blood cells and platelets, but I-Mab claims that TJC4 has a lower risk of this type of toxicity. At press time, the clinical trial was not yet listed on www.clinicaltrials.gov.

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.

COOKS' HAPPY HOUR

BY PENNI WISNER

My hope is that you will indulge me as I expound, once again, on Middle Eastern cooking. About six months ago I visited a favorite shop, Oaktown Spice Shop in the East Bay (<https://oaktownspiceshop.com>). And there, after buying an assortment of dried chiles, I noticed a recipe for sweet and smoky beet burgers in Louisa Shafia's *The New Persian Kitchen* (Ten Speed Press). It looked intriguing, but I left the book and forgot the idea.

Forgot, that is, until I was back in the shop for a fresh supply of chiles and a favorite blend, chile limon (a blend of Aleppo chile, coriander, sea salt, lime juice powder, and smoked paprika). It tastes amazing on corn on the cob and we roast winter squash with it for tacos mixed with roasted mushrooms, onions, and poblano chiles. But I digress.

There, again, lay the book. It again fell open to the beet burgers. The recipe was too complicated to just remember (I will not go into details about my current brain function), and, yes, I could have photographed the page, but there were other delights such as a radish, rhubarb, and strawberry salad. I think I have mentioned before that rhubarb in San Francisco produces for at least nine months out of 12.



This time, the book came home with me. And the burgers are well worth trying and then making regularly. They have a wonderful, deep mineral red color and a satisfying, “meaty” flavor. I’ve recently tried both the Impossible Burger and the Beyond Burger and cannot really recommend them. But then I’ve never appreciated soy masquerades. These beet burgers are small, about 3.5 oz each, but they are filling. As I read the recipe, I remembered the Faux Gras recipe I wrote about some time ago. It, too, combined lentils, onion, and walnuts. But the burgers add beets and smoky paprika while the Faux Gras added well-browned mushrooms.

Start by cooking some green lentils in plenty of salted water until tender. Take ½ cup of them and rinse and drain them. Set aside. Save the rest for soup or salad. You will also need 2 cups of cooked and cooled short-grain brown rice or white sushi rice. These are sticky and, together with the lentils and 1 egg, will hold the burgers together. Now you are ready to prepare the burgers themselves.

Start by slicing a large, yellow onion. Sauté it in a little canola, olive, or grapeseed oil in a large skillet over medium-high heat until well cooked and browned. Lower the heat and add about 1 cup of raw, grated beets (about 5.5 oz before trimming and peeling) along with 3 fat crushed cloves garlic, 1 cup walnuts, ½ cup golden raisins, and 2 teaspoons sweet, smoked paprika. Cook, stirring often, to give the beets a chance to soften a bit and the nuts to toast, about ten minutes.

Scrape the contents of the pan into a food processor and pulse until the mixture turns chunky. Turn out into a large bowl (do not wash the food processor; you will need it again) and add the lentils, 2 teaspoons salt, and 1 teaspoon pepper. Process the cooked rice and egg until it forms a coarse puree, and then scrape it into the bowl with the lentil mixture. Knead the mixture with your hands until evenly mixed.

Divide the mixture into 8 even portions (about 3.5 oz each). Wet a counter or smooth work surface (or work on aluminum foil or plastic wrap) and shape each portion into a patty. Work with wet hands, dropping the patty onto the wet surface and then turning it between your hands, and then patting it down, until each is round and about one inch thick.

To cook, heat a heavy skillet over medium-high heat and add a little oil. Cook the burgers, without moving them, until browned on the bottom, 3 to 5 minutes. Peek to see how fast they brown so you do not burn them. Turn them over, lower the heat, cover the pan, and cook until heated through and browned on the second side, about 5 minutes.

Serve hot on a toasted bun with sliced tomato and cucumber for crunch and a sauce for richness—perhaps aioli or Greek yogurt. But my vote goes to labne (also spelled labneh, a strained, very creamy yogurt cheese), seasoned with salt, pepper, some minced fresh herbs, a splash of olive oil, and perhaps a pressed garlic clove and minced green olives. You could flavor Greek yogurt the same way. (You can try making your own labne by letting plain kefir or yogurt drip through several layers of cheesecloth until you have a creamy cheese. Do this in the refrigerator so it does not get too sour.)

For a cocktail snack, shape the mixture into walnut-size balls and roll them in hot oil in a skillet until browned all over. Then use toothpicks to dip the balls in the sauce.

Our motto: Eat Well to Stay Well

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER



Drs. Julianne and John Flora-Tostado – John is a WMer diagnosed in 2015.

PLEASE NOTE

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

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

CALIFORNIA

Orange and San Diego Counties

Dr. Julianne Flora-Tostado is the new support group leader for Orange and San Diego Counties. She is a licensed counseling psychologist (PhD) with over 40 years of training and experience. After 23 years at a non-profit counseling children and families, her current private practice focuses on individual adults. She learned about Waldenstrom's and the IWMF after her husband John was diagnosed in 2015. In 2017 Dr. Flora-Tostado started leading breakout sessions for caregivers at the annual IWMF Educational Forums. There, she says, "I have been touched by how newly diagnosed members are so deeply reassured as they hear from the kind, long-time survivors who share their experiences. I'm hoping the same generous atmosphere will develop once I'm able to get sharing meetings set up here in Orange and San Diego Counties."



WM breakout room at the LLS-sponsored Rocky Mt. Blood Cancer Conference

COLORADO AND SOUTHERN WYOMING

The Rocky Mountain Blood Cancer Conference, sponsored by the Leukemia & Lymphoma Society (LLS), took place on a beautiful spring day in early May. This is its ninth year, and almost every year it includes a special breakout session for Waldenstrom's because our champion, Dr. Jeffrey Matous of the Colorado Blood Cancer Institute, pushes for it. The turnout for the conference is huge, almost 300, including 34 (and five newcomers) for the WM breakout session and support group meeting.

The conference kicked off with LLS staff, then a keynote speaker, Dan Shapiro from Penn State College of Medicine. He described his very funny perspective on life with cancer and how it changes your viewpoint on, well, everything! It was uplifting and started the day on a great note. After this came the specific cancer breakout sessions. WM group members discussed the IWMF, the Ed Forum, and all the many tools, videos, and booklets the IWMF offers to the WM patient. Most of the new people had already been viewing the many videos from expert doctors. During the session, Megan Anderson, Certified Nurse Practitioner (NP-C) at Colorado Blood Cancer Institute, gave a WM update. She sees mostly WMs and is in Dr. Matous's practice. Megan created an easy-to-understand presentation, focusing on essential information for newly diagnosed patients and those currently in treatment, and what to expect in the future. After the presentation and a lively Q&A, the discussions continued over lunch provided by the LLS. In the afternoon, attendees could pick from cancer-related topics such as: "What to Eat for Optimum Wellness," "Exercise is Key for the Cancer Patient," "Balancing Work and Cancer," and "Managing Your Emotions with a Cancer Diagnosis." It was a full day with lots of new information, lots of new WM connections, and lots of support!

Support Group News, cont. on page 27

FLORIDA

Southern Florida

The group held well-attended meetings in January and March. Since several members planned to attend the June Ed Forum, the group decided this would stand in for a summer meeting. A local meeting is now planned for September.

ILLINOIS

Chicago Area/SE Wisconsin

Dr. Shuo Ma, a hematologist-oncologist at Northwestern Memorial Hospital and an assistant professor in the Department of Medicine, spoke at the early May meeting at Elmhurst Hospital in the western suburbs of Chicago. Five new families were among the 47 who attended to hear about new treatment options for Waldenstrom's. Dr. Ma was featured in the January 2019 *IWMF Torch* as "IWMF Doc Star." The group was thankful that she took time out of her busy family and professional schedule. The summer picnic plans are being worked on with details to be announced in June.



Dr. Shuo Ma at Elmhurst Hospital at the May meeting



Chicago Area Support Group members in May

INDIANA

Following a long, cold winter, the Indiana group met in late March. Even after a rash of last-minute cancellations due to illness, 15 members showed up. They enjoyed coffee, juice, fruit, yogurt, and bagels, all provided by the Leukemia & Lymphoma Society (LLS). Everyone was glad to see old friends and anxious to hear updates. The sharing was active with all members participating. There were announcements about the upcoming annual IWMF Ed Forum and the IWMF's new member services specialist. The group was encouraged to check the IWMF website section Stories of Hope as well as updated educational material. The meeting concluded with



*Indiana Support Group members having another fun get together
Leader Gayle Backmeyer is on the right.*

one of the members sharing his experience with a "functional medicine" physician. The group expressed interest in learning more about this subject.

MICHIGAN

The area's support group meeting was held on a beautiful, sunny day in May in the outpatient center of the Heart Institute of Providence Park Hospital in Novi. Seventeen members attended, shared their stories, and updated the group on their experiences since the last meeting. Jenn Goldman led the group on a discussion of mental health issues including sadness, anxiety, depression, adjustment disorder, acute stress disorder/PTSD, sources of support, and self-care. Jenn, a WM patient diagnosed in 2015 and a member of the group, has an MA in psychology from Wayne State University. She has done research on stress and health. The group actively engaged in the discussion and shared many experiences. Since it was Cinco de Mayo, the snacks and goodies were Mexican-themed. Plans have begun to hold the next meeting in Clarkston, Michigan, in August. Details to come once the venue has been secured.



Dr. Jeremiah Moore, specialty pharmacist from Wilmot Cancer Center, and several support group members

NEW YORK

Rochester, Western and Central NY

The group met in mid-March at Casa Italiana on the Nazareth College of Rochester. A fantastic turnout of 16 followed

Support Group News, cont. on page 28

the group's usual format: spending time catching up with one another and welcoming a new member who had driven two hours in order to attend. In addition to sharing stories of treatment and progress, Dr. Jeremiah Moore, specialty pharmacist from Wilmot Cancer Center, gave a very informative presentation on the medications being used to treat WM and how they work. He also provided information on how to investigate getting financial assistance to help pay for some of the more expensive therapies such as ibrutinib. His presentation was much appreciated by all.



North Carolina Support Group

NORTH CAROLINA

The North Carolina Support Group's first meeting in 2019 was on March 30 at the home of Support Group Leaders Carl and Susan Stoel. There were a few returning participants along with a few new patients. We shared stories, watched a video from the 2018 Ed Forum (Ask the Doctors) and enjoyed an array of refreshments. Although the May meeting was a small group, it was productive, exhilarating, and uplifting. One person brought his guitar. Members sang and even created a new song. Unfortunately, no one recorded it. We are in the planning stages for an upcoming group support meeting in Greensboro, NC.

EASTERN OHIO, WESTERN PENNSYLVANIA, AND WEST VIRGINIA

A refreshing spring day in early April was the perfect time to reconvene after the weather-related winter hiatus. Three new members were warmly welcomed to the potluck meal and informal sharing meeting at the home of Marcia and Glenn Klepac in Pittsburgh, PA. The agenda began with lunch (a mix of creative healthy food selections plus irresistible desserts). During the meal, conversation flowed, allowing time for all to catch up with one another and to get acquainted with newcomers. Continuing on to the sharing circle, new members openly participated, relating their personal stories and inspiring the listeners with their "take control" approach

to WM. The lively discussion covered the WM landscape of diagnosis, treatment options, and side effects, including chronic pain. WM as a treatable disease was emphasized, as was remaining mindful of the psychological issues that relate to living with a chronic disease. All enjoyed the uplifting afternoon of friendship, support, and good food.

SOUTHWEST OHIO AND NORTHERN KENTUCKY

Hematologist-oncologist Dr. Manish Sheth presented an excellent talk on WM, with informative and easily understood slides, at the Kettering Medical Center. He spoke with each of the small and grateful group, answering questions both before and after his 35-minute presentation. He currently has 55 patients with WM.



Dr. Manish Sheth presenting at the May meeting



*Support group members after the February meeting
Co-leaders Marie Navarro (third from the left) and Joel Rosenblit
(sixth from the left), Presenter Dr. Alex Speers (fourth from right)*

OREGON AND SOUTHWEST WASHINGTON

After the usual introductions and health status reports, the group was treated to a delightful and informative presentation by Dr. Alex Speers, a naturopathic physician who works in a Portland cancer clinic. Dr. Speers specializes in complementary care for cancer patients before, during, and after conventional cancer treatment. The goal of his practice is to enable patients to become active participants in their own cancer treatments by providing options from the world of natural medicine that can aid in reducing side effects, thereby enhancing quality of life and improving outcomes. Naturopathic medicine is a distinct primary health care profession that includes modern and traditional scientific and empirical methods. Dr. Speers works in concert with the patient's oncologist before recommending specific natural remedies. Although unfamiliar with Waldenstrom's

Support Group News, cont. on page 29

prior to the meeting, Dr. Speers extensively researched the disease so he could provide complementary naturopathic options for the various WM treatments that could help cope with side effects. Members left the meeting fully armed with information on possible naturopathic therapies to discuss with their health care providers. Furthering our exploration into complementary and alternative treatments, our upcoming June meeting will include a presentation on the therapeutic use of cannabis and holistic care planning for cancer pain.



Philadelphia's smiling gang of fun and fabulous WMers!
(photo courtesy of Eleanor Levie)

PENNSYLVANIA

Philadelphia

After hibernating since the 4th Annual "Chili in Philly" gathering in November, Philly WMers came out twice already in 2019 to reconnect after a long winter. Every time the group comes together, an uplifting dose of inspiration is shared around the circle. Members leave encouraged, empowered, and inspired by fellow Waldenfriends.

On March 10, special guest speaker Dr. David H. Vesole, hematologist-oncologist at Hackensack University Medical Center, presented "Report from the Frontlines of WM Care" at the Annenberg Conference Center in Lankenau



Presenter Dr. Adam Cohen (l) with David Boyer (r), inspiring WMer and greenhouse owner who lovingly gifts plants to all group members. (photo courtesy of Eleanor Levie)

Medical Center in Wynnwood, PA. Forty-two patients and caregivers were in attendance and enjoyed time snacking and catching up before the formal presentation began. The generous snack volunteers brought a plethora of healthy goodies, and the buffet was overflowing with enticing offerings. Members enjoyed hearing Dr. Vesole's presentation on trends in WM care, treatment, and management. As always, folks arrived with complex questions to pose and enlightening comments to share. Dr. Vesole was generous with his time, answering numerous questions before returning to his home in New Jersey.

In early May, 42 WM patients and caregivers were engaged and energized by esteemed guest speaker Dr. Adam D. Cohen, who shared a highly informative and interesting presentation on "Exciting Advancements in WM Treatment." Dr. Cohen is the director of Myeloma Immunotherapy and assistant professor of Medicine at the Hospital of the University of Pennsylvania. His areas of clinical expertise include: Waldenstrom's, multiple myeloma, amyloidosis, monoclonal gammopathies, and POEMS syndrome. He has published widely, most recently in the *Journal of Clinical Investigation* discussing CAR-T cells and multiple myeloma. Dr. Cohen's experience and expertise in WM shone through with many members commenting on the clear, concise, comprehensive, and understandable manner in which he presented highly complex concepts. Dr. Cohen offered an exciting overview of what is coming next in WM treatment, including a look at acalabrutinib, zanubrutinib, venetoclax, newer immunotherapies (such as daratumumab), and CAR-T cell therapy. Dr. Cohen addressed multiple queries throughout his enlightening talk. Although the day was gray and pouring rain outdoors, the spirit was upbeat and sunny indoors as old friends mingled and new friends connected over a bountiful snack buffet, thanks to generous snack volunteers! Everyone left with a huge smile and a beautiful green citronella plant, courtesy of members Linda and David Boyer, who own a greenhouse.



Linda Boyer carries tray full of citronella plants into the meeting room for all to take home and enjoy.

SOUTH CAROLINA

Fifteen WMers, family, and friends attended the March meeting at the American Cancer Society Hope Lodge in Charleston. Eight attendees were WMers; two were in attendance for the first time; and two for the second time. They appreciated hearing the experiences of fellow WMers

during the round-table discussion. Sue Herms was present and provided context and insight as various issues came up. The next meeting will be in the fall, date and location to be determined, probably in the Columbia area.

TEXAS

Houston

In May, Dr. Barbara and John Manoussos hosted the group in their home in Houston's Uptown-Galleria. Together they watched Dr. Steven Treon's 2017 Ed Forum presentation on upcoming therapies and enjoyed a generous buffet.

WASHINGTON

Seattle Area

A gorgeous spring day in late March saw 20 people, two of them newly diagnosed, attend the Seattle area support group meeting at the Kirkland Library. While plans had been made to view one of Dr. Jorge Castillo's videos, everyone found that just exchanging information and learning from each other was the most useful way to spend the afternoon. Two members came all the way from the Port Angeles area and



Houston Support Group members at meeting hosted by Co-leaders Dr. Barbara and John Manoussos at their home in Houston

indicated an interest in starting a group on Kitsap Peninsula, since about a dozen WMers live across Puget Sound. We also appreciated a beautiful array of snacks thanks to Linda Pochmerski!

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

AUSTRALIA

Melbourne, Victoria – Patient Education Session

WMozzies attended a presentation by Professor Mathias Rummel from Germany on March 25 at Monash Hospital, Clayton Campus, organised by Lymphoma Australia. The main topics covered were:

- Current frontline and relapsed treatments
- What is new
- Your questions answered

Professor Rummel is listed on the IWMF directory of WM physicians. The video of the session lasting one hour and forty minutes is available at <https://www.youtube.com/watch?v=EigpcELS3r8&feature=youtu.be>



Professor Mathias Rummel in Melbourne session with WMozzies Andrew Warden (l) and Patrick Devine (r).

Brisbane, Queensland – Patient Meeting

On March 30 a coffee, cake, and chat for people with Lymphoma and Waldenström's, organised by The Leukaemia Foundation, was held at Jo-Jo's Cafe in West End, Brisbane. There were 16 attendees with a WMozzies first timer who

had never met anyone with WM before and another who had travelled 80 miles to attend.

Sydney, New South Wales – Patient Education Session

The session topic in Sydney on May 7 covered when cancer becomes aggressive and when options for treatment need to be considered. The program, organized by Lymphoma Australia, had haematologists and clinical specialists from The Australasian Leukaemia and Lymphoma Group speaking on:

- Immunotherapy
- Targeted therapies
- Clinical trials
- CAR-T Australian experience

Andrew Warden, WMOZZies, reporting

CANADA

On April 13, the Waldenström's Macroglobulinemia Foundation of Canada (WMFC) hosted an Educational Forum in Toronto at the Grand Suites Hotel. The day turned



Dr. Jane Estell, pathologist-haematologist at Concord Cancer Centre, a speaker at Sydney session

International Scene, cont. on page 31



Dr. Stephen Ansell addressing the Toronto Ed Forum

out to be a great success with about 95 attendees, many newly diagnosed and many family members, who came to learn more about this rare disease. The day started off with opening remarks from Arlene Hinchcliffe, WMFC President. In a very special moment, Carl Harrington presented an award to Arlene for her 20 years of outstanding dedication, service, and leadership to the Canadian WM community. The roster of stellar speakers included Dr. Jeffrey Matous (“WM Basic Training For Patients”), Dr. Steven Treon (“Breaking News From The Front”), Dr. Stephen Ansell (“Immunotherapy—Getting The Immune System To Target WM”), Dr. Ruben Carrasco (“WMFC Sponsored Research—Engineering A Mouse Model Of LPL/WM”), Dr. Jorge Castillo (“New Treatment Options For WM”), and finally Dr. Christine Chen (“Navigating Treatment Options For WM In Canada”). The morning and afternoon sessions concluded with Ask the Doctor panels moderated by J.A. Clancy. Many attendees came especially for these sessions, giving them an opportunity to ask their own burning questions. Sarah Khan, community engagement manager for the Ontario region, came to represent the Leukemia & Lymphoma Society of



Arlene Hinchcliffe, WMFC President, accepting her award from Carl Harrington



Ask the Doc Panel. From left to right J.A. Clancy (WMFC Board member), Dr. Steven Treon, Dr. Jeffrey Matous, and Dr. Jorge Castillo

Canada and hosted an information table. The entire day was a time for all WM patients and their families to be encouraged, informed, and learn that they are not alone!

The Toronto Ed Forum presentations can be found at www.wmfc.ca.

Betty McPhee, WMFC, reporting

INDIA

After months of consultation and interviews with different agencies across the country, we successfully found a wonderful organization to help us design and build our website and give Waldenstrom India a presence on the Internet. The design of the prototype is in its final stage with development set to begin shortly. We hope that our web presence helps us attract patients who are newly diagnosed and those who are further along in their journey but unaware of our support group, so that together we can share our experiences and knowledge and support one another.

At the time of publication, members and affiliates of the IWMF and Waldenstrom India are encouraged to visit our website at www.wmindia.org.

Saurabh Seroo, WM India, reporting

UNITED KINGDOM

WMUK Regional Meeting in Bournemouth

In April, WMUK supported a regional support group meeting on the south coast of England, in Bournemouth, the second meeting in this part of the UK. It was a popular event, attended by 45 people, including patients, caregivers, clinicians, specialist nurses, and members of other charities who work in the field of support for people with cancer. It was organized by WM patient Bob Perry, who set up the support group and runs it.

The meeting was hosted at The Grove, the only hotel in the UK that offers cancer patients and caregivers a holiday facility where they can come for a short break.

The afternoon consisted of presentations and discussions, and an opportunity to meet others, along with refreshments. Speakers included:

- Dr. Helen McCarthy, consultant haematologist from The Royal Bournemouth and Christchurch Hospital Trust and WMUK Trustee, who provided information about WM, stages of disease, treatment options, and new developments in WM treatment.
- Rupinder Bancil – administration officer, WMUK, who gave an overview of the developments at WMUK, including the annual Doctor-Patient Summit in July 2019.
- Margie Mangles, apheresis specialist nurse, The Royal Bournemouth and Christchurch Hospital Trust, who talked about the process of stem cell and plasma exchanges; what is involved in separation and removal of blood components; and how the

treatment is likely to impact the patient during and after treatment.

- A representative from Wessex Cancer Trust, Bournemouth Cancer Centre, provided information about how the local center can support patients and their families throughout their treatment journey, help them to combat isolation, and encourage better mental and physical health.

The meeting was very well received and oversubscribed, with a mixed audience of both newly diagnosed and experienced WMers. Delegates particularly enjoyed the Q&A sessions with the panel of experts, as well as having contact with the specialist nurses and seeing the transplantation process they may go through at some stage in their treatment. More time will be built in at future meetings for networking and making connections with other delegates.

Lindsey Bennister, WMUK, reporting

Lindsey Bennister Named CEO of WMUK

Lindsey Bennister has worked in the UK voluntary sector for 30 years and has enjoyed a 15 year career in senior leadership roles in the cancer world. She has a special interest in rare and less common cancers and is a trustee of Cancer 52 (a UK alliance of rare and less common cancer organizations) and St. Luke's Hospice in the UK.

She has a track record of supporting patients and their families, setting up research programs, and campaigning for improved health services and treatments. Joining Sarcoma UK (bone and soft tissue cancer) in 2010 as its first chief executive, she implemented a strategy to seek answers through research, support the sarcoma community, and build resources for the future, establishing Sarcoma UK as a leading and respected national charity. Her work included setting up a national specialist nurse-led support line for patients; a patient-led online forum; and a network of support groups. She also worked internationally with other patient organizations and health professional groups.

As the new CEO, she says "I have been so impressed by the achievements of WMUK, in particular the strong and unique partnership between patients, carers and health professionals, all working together to improve lives. I am delighted to join WMUK as its first chief executive and am very much looking forward to meeting the WM worldwide community at the IWMF Educational Forum in June in Philadelphia."

Ms. Bennister is a Fellow of the Royal Society for Arts, Manufactures and Commerce (RSA) and a graduate of Harvard Business School's Social Enterprise program.

BETWEEN MARCH 1, 2019 AND MAY 31, 2019, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

David Richard Ahmann

Anne M. Ahmann

Marvin Arenson

Diane and Ivan Arenson

Jacob Block

David Fisher

John Fried

Stanley Green

Allen Weitzner

"The Poker Group"

William A. Cameron

Alicia and Joe Kessler

Patsy Christopher

The Dibb Family

Al and Joyce Hornish

Dawn Sprecher

Carole Cohen

Marc D. Finkelstein

Donald Louis Colavecchio

Power Design, Inc.

Carole Corman Beatty

Liferay Foundation

Paul and Missy Huffman

Elizabeth M. Egan

Bernard A. Egan Foundation, Inc.

Carol Ehlers

Otto Ehlers

Oscar Eisenberg

Bonnie and Mike Eisenman

Suzanne and Norman Horn

Melissa and Barry Lieber

David John Fullen

Richard and Nancy Chagnot

Kevin O'Brien

Paul and Jane Reagan

William A. Gagliardi

The Knowles Family

Ronald Kriesel

Helen Elaine Hansen

Barry Hansen

Merwin Harrington

Anonymous

Elena and Gary Malunis

Dr. Charles Hess

John and Valerie Barry

Marilyn S. Hopkins

Jim Reed

Stanley Kemp

Noah and Phyllis Fields

Patricia E Lore

Joseph M. Lore

Martin McMorro

Jim Reed

Boyd Nelson

Helen Steadman

Peg Newberg

Karen Fiorello

Voula Pappas

Katherine L. Bennett

James Paxton

Lois and Gene Angell

Eleanore Beckman

Barbara Canova

Ann Jean Duke

Richard and Sharon Ericson

Genevieve Honomichl

Richard and June Malliet

Garnet Maxwell

Patricia Sands

Lawrence and Glenna Utberg

A. Roger and Darlene Witke

Valerie Petelin

John M. Modders

Frances Prior

Anonymous

Claude Lauderbach

John and Darlene

Lauderbach

Bill and Peggy Lobb

Stephen H. Prior

Anonymous

Carl Roeder

Richard M. Abernathy

Susan and Bob Bolling

Kent and Melanie Brown

Pamela A. Campbell

First Central Presbyterian Church

Dian Graves

Owen Foundation

Glen and Carol Hall

Laura and Lee Henson

Peter and Cathy Lauve

Thomas and Vicki Madden

Susan Pittman

Lavern Roeder

Angie Roeder

Daniel Roeder

Matthew Roeder

Sarah Roeder

Nancy and Dick Roeder, Jim Roeder and

Ruth Roeder

Phyllis (Shifrin) Rosen

Lawrence and Eleanore Zaiden

Joseph Stanley Surman, Sr.

The Clink Family

Christopher and Allie Frank

Nicholas and Leteefa Grippo

Dominick and Alexandra

Termini

Scott Trippel

Frank Bergonzi and Azelis Americas

Jannifer Mowery and Ribelin Sales (Azelis)

Julie Biggerstaff

Morgan Thermal Ceramics

Evans Fantasy Football League and

Families

Ryan, Jessica and Sophie O'hare

Marcia Wierda

Sidney and Timothy Hoesch

BETWEEN MARCH 1, 2019 AND MAY 31, 2019, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

Doris Ballmer

Patricia C. Sirls

Bonnie Beckett's Birthday

Anonymous

Bonnie Beckett

David Faul

John Hardin

Mark Johnson

Gloria Kirby

Sarah Nolan

Daniel Tancredi

Dominique Blandine's Birthday

Anonymous

Dominique Blandine

Joe Chazen

Elisabeth Dixon

Ken Dixon

Teresa Zumbach Favero

Dominique Blandine's

Birthday (cont.)

Devonna Dee Kee

Diane Kornya

Angie Mack

Bill Malone

Kawanne Pernermon

Seth Schermer

Lemma Senbet

Dominique Blandine Smith

Gina Smith

Gloria Weissman

Toni Bodner

Eric Bodner

Ron Branscome's Walk for Waldenstrom's

Ronald W. Branscome

Ron Branscome's Walk for Waldenstrom's (cont.)

Nick G. Calamos, Jr.

Don & Mary Brown

Clara Cpen

Irene Campana

James and Irene Campana

Dr. Carla Casulo

Lynn C. Milliman

Clara Coen's Birthday

Anonymous

Mary Baim

Clara Coen

Sylvie Cohen

David Egeland

Sandra Escala

Mary Abbott Hess

BETWEEN MARCH 1, 2019 AND MAY 31, 2019, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

Clara Coen's Birthday (cont.)

Jill Niland
Monique Tranchevent
Judy Wise

Mark Davidson's Birthday

Louis Bondurant
Kasan Carla Callahan
Clyde Davidson
Mark Davidson
Elizabeth Grindon
Terri Huber
Sissy Kayser
Dot Louie
Jane Overall

Peter DeNardis

Anonymous
Elly Bresz
Jennifer Killam

Pete's 2019 Walk for Waldenstrom's

Nicole Baleno
Michael Bartko
Maureen M. Beal
James Borowski
Elysa Braunstein
Jean D. Brock
Marie Carter
Michelle Cheney
Charles and Diane Creed
Peter L. DeNardis
Diane Drazdzinski
Linda Evans
Mary Frederickson
Robert Goga
Catherine Gustaitis
Linda Haberman
Suzanne L. Herms
Patricia Jacobs
James Karabetos
Yvonne Keafer
David and Penny Kirby
Claudia Barron Klos and Raymond Klos
James Lambert
Karen M Lorenzini
Shari and Ron Manges
Sarah Matthews
Karly R. McCutcheon
Eileen McLaughlin
Ray McMullen
Lynn and Tom Milliman
Kathy L. Moonan
Margaret J. Nicholas
John Paasch
Sara E. Richard
William D. Rupp
Sandra L. Stimmier
Kathy Tosh
James K. Vesco
Thurman D. Wingrove

Beverly Docteur

Carl Harrington

Sandy Hevey Ferrante's Birthday

Anonymous
Missy Kohlhepp
Dianne Limoges
Gayle Nidoh

Karen Fiorello's Walk for Waldenstrom's Macroglobulinemia

Karen Fiorello

Julianne Flora-Tostado's Walk With Us!

Ware B. Flora
Debra Friedman
Ellen and Steven Rose
Janet Sonne
J Flora-Tostado

Shirley Ganse's A Walk for WM!

Jane E. Ballard
Judi L. Chandless
Terri L. Morin-Dilts
Lynn M. DuPaul
Shirley H. Ganse
Suzanne L. Herms
Janet McIntosh
Audrey H. Miller
Jeffery D. Stolz
Tara Stolz
Ronald Ternoway

Dr. Morie Gertz

Mr. and Mrs. Wayne Holimon

Ed Goldberg

Anonymous
Geoffery Engel
Erica Goldberg
Claire Tess Perez

Dr. Andre Goy

Wanda Huskins

David Handelman

Matthew J. Handelman

Carl Harrington's 2019 Walk for Waldenstrom's

Barbara Adler
James F. Anderson
Lori M. Atkin
Phyllis Barsky
Bonnie A. Beckett
Sydney Boisbrun
Judith Crown
Morris D. Edwards
Bonnie Sedlmayr-Emerson
Francine Fielding
Linda Garfield
Marcie Handler
David Harari
Carl T. Harrington
Samuel L. Harrington
Suzanne L. Herms
John P. Jenkinson
Arnold Kalman
Roy K. Langhans
Aaron Levie
Eleanor Levie
R. Thomas Lutz
Sammie and Dan Moshenberg
Ruth N. Reber
Ed and Rebecca Schulman
Bernard E. Sherr
Eileen R. Sherr
Mark Tarses
Robin and John Tucker
Samuel B. Wechsler

Tony Hasler's Birthday

Todd Dean
Melissa Elmes
Lea Frost
Jack Hasler
Loie Hasler
Tony Hasler
Pamela King

Tony Hasler's Birthday (cont.)

David Lawton
Chris Maple
Alicen Moser
Susan Dorris-Moser
Amy Nelson
Nicola Royan
Katherine Terrell

Sue Herms

Jennifer Killam

Sue Herms' Help the IWFM with Your Support

Amy Brewster
Carl Harrington
Neal Makens
John Paasch
Andrew D. Warden

Dr. Tom Hoffmann

David B. Kirby, Jr.

Marcia & Jack Honaker Fundraiser for Waldenstrom's

Marcia Bradberry
Kara Camalier
Elizabeth Dick
Mary B. Dilworth
Brock and Midge Estes
Angie Foltz
Anthony L. Hancox
Drew Honaker
Gary and Pam Kelley
Josh and Tricia Maxfield
Paige McCarthy
Kevin Rauckman
The Turner Family

Jack Honaker

Sarah Fitori

Larry Horowitz's Birthday

Becca Betancourt
Christine Chassen
Cheryl Lassoff Doran
Larry Horowitz
Tom Hunsinger
Stephen Kohn
Marlene Lassoff
Esther Rouder
Wendy Rouder
Cheryl Smith

Melvyn Horowitz

Jody Malloy

IWMF/Cancer Care Workshop

Jeff and Janice Atkinson

IWMF

Andrea J. Bensusan
David W. Brauer
Glenn H. Cantor
Bruce Fox
Francine Fox
Pamela P. Freyd
Jamie Gorman
Christine Mateer
Barbara Schwartz
Carmen A. Tostado
Robert W. Ulkus
Martin Vanderlaan
Rita Wagner

Christine Jasiewicz's Birthday

Dolores Ricco

Russ Kocka

Edward M. Dean

BETWEEN MARCH 1, 2019 AND MAY 31, 2019, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

Nett M. Kocka's Birthday

Meg Cyr Mangin
Diane Schaffel

Stanley Koutstaal

Murilyn Koutstaal

Cathy Lark-Townsend's Birthday

Kathy Eno
Nancy Simmons
Kathleen Wilmoth

Anita Lawson's Walking for a Cure

Cathy N. Hartman
Anita Lawson
Melanie Terwoord
Anastasia Vassos

Janet Livingston

Bob and Marysue Livingston

Kathy Gregory Lollar's Birthday

Meredith Brooks
Billie Gregory
Kathy Gregory Lollar
Linda Loudenback
Tammy Stallcup
Raul Villanueva

Jane Loud's Walk for Waldenstrom

Anonymous
Mitzi Lucco-Baron
Laura Barr
Patti Knapp
Jane Larson
Nancy Loud
Cordy Mack
Barbara Martin
Debra Porter
Sue Pruitt
Jean Rizzo
Sherrill Salisbury
Vickie Selleck
Barbara Sirvis
Rayleen Stubbs
Donna Tauro
Carol Xavier

Meg Cyr Mangin's Birthday

Anonymous
Lillian Arleque
Lisa Beeby
Susan Chastan
Lee Ann Fausnaugh
Judy Foust
Pat Jacobs
Melinda Mangin
Tom Mangin
Ted Meyer
Cathy Miller
Claudia Muir
Dianne Schumacher
Deborah and Douglas Troxel

Judith May

Lois Ezell

Monica Morin's Birthday

Lora Fults
Michele Graval
Rachel Montoya
Garrett Morin
G. I. Riepma
Brandon Sims
Rachel Wrangham

Claudia Muir's 5k Walk for Waldenstrom's

James Bryant

Claudia Muir's 5k Walk for Waldenstrom's (cont.)

Amy Donovan
Kate Fleming
Christine L. Forber
Anne Godfrey
Ivan Hodes
Brian M. Loughrey
Rachel Peterson
Louise Williams

Maureen Murphy's Birthday

John Manis
Pamela Tourangeau

W. Thomas Myers

Jean K. Myers
Rebecca Spencer
Sara Franklin

Linda P. Nelson's WM Walk for 2019

Linda P. Nelson

Angel Ogden's Birthday

Ruthie M. Batrez
Vickie Meyer
Angel Ogden

John Paasch

Jennifer Killam

Dr. Jonas Paludo

IWMF Minnesota/Wisconsin Support Group

Jennifer Patten's Birthday

Kathy Coffman-Cuoio
Christina Lords
Jennifer Patten
Steve Reidy
LeeAnn Smith
Tiffany Sandusky Szymanski

James A Paxton

Maureen K. Lyons

Dr. Robert Pohlmeier

Ann Kallam

Alice Riginos

Dr. Vasilis Riginos

Barbara Shuman

Linda J. Kallish

Jay Singer

Helene and Howard Scott

Bradstreet Walter Smith

Anonymous

Michael J. Smith, PhD

Anonymous

Bradstreet Walter Smith

The LSL Fund

Cinda Spavins Walking for IWMF 2019

Patricia Adams
Tim Avery
Laurie Bluff
Jane and Dan Brannegan
Sharon L. DePerry
Kieran Dignam
Linda Francis
Diane E. Guigli
Jenn and Luca Holme
Kenneth R. Milner
Martha H. Murtiashaw
James Rashford
Robin Rashford
Shauwen L. Sokol
James C. Spavins

Cinda Spavins Walking for IWMF 2019 (cont.)

Suzanne G. Starr
Linda R. Sylvester
Peter H. Thompson

Dr. Edward Stadtmauer

Carl Harrington

Julie Steffen's IWMF Walk

Suzanne L. Herms

Maureen Sullivan

Joseph Hauswirth

Charles Thorsen

Margaret Thorsen

Dr. Steven Treon

Keith Coplen

James D. Turner

Michelle Harper

Bob Ulkus' CT for a Cure 2019

Christine A. Forber
James Lambert

Ray Valadez

Rose Crownover

Elaine Van Bloom

Fred and Dolores Pernerstorfer

Verjaardagsinzamelingsactie van Winny

Bobby Maxwell

Dr. Christopher N. Vaughn

Ron and Mary Jane Branscome

Mary Wendel

Lauren Wendel and Chris Dougherty

Lisa Wise and Carl Harrington

Barbara Schwartz

Lisa Wise's Philly Brings the Love!

Philly WM Support Group

Lisa Wise



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

Non Profit Org
US Postage
PAID
Manasota, FL
Permit No. 133

Memories from IWMF Ed Forum 2019



For the whole scoop, see pages 7-14!

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

