



ISSUE 19.4

IWMF TORCH

October 2018

INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION

INSIDE THIS ISSUE

President's Corner:
20th Anniversary 1

Making the Music Even
Louder: What the
Next Five Years Could
Bring..... 3

IWMF Member
Services: Reaching
New Heights 5

IgM MGUS, Smoldering
Waldenstrom's
Macroglobulinemia,
and Waldenstrom's
Macroglobulinemia..... 6

IWMF Online
Discussions – WSMG-
Net to IWMF-Talk to
IWMF Connect..... 8

Living with WM for
20+ Years 11

IWMF Doc Star:
Jorge J. Castillo 13

From IWMF Connect:
Summer 2018..... 15

Twenty Years of Giving:
How Your Support Has
Made a Difference ... 17

Medical News
Roundup 19

You Can Limit
Death's Financial
Costs, if Not the
Emotional Ones 23

Cooks' Happy Hour ... 24

Support
Group News 26

International Scene..... 30

PRESIDENT'S CORNER: 20TH ANNIVERSARY

BY CARL HARRINGTON

It was twenty years ago today

Our non-profit started leading the way.

We've been building up our skills and style

Raising hopes that really make us smile.

So let me introduce to you

The help you've known for all these years:

The Waldenfriends' One & Only Big Hearts Band.*

*Apologies to all you Beatles fans who remember the real words to "Sgt. Pepper's Lonely Hearts Club Band."

As you can see in this 20th anniversary *IWMF Torch*, we're celebrating! It was 20 years ago that Arnie Smokler, the founder of the IWMF, led a newly-elected first Board of Trustees in the incorporation of the IWMF as a private, non-profit 501(c)(3). During the following 20 years—under the stellar leadership of former IWMF Presidents Ben Rude and Judith May and during the six years of my presidency—the IWMF has grown exponentially.

So why did I open with a variation of a Beatles hit? Well, because the whole history of the IWMF is about how an incredible group of WM patients and caregivers has banded together to help each other understand, live with, and sometimes even thrive with a rare and incurable cancer. This ever-changing IWMF band is dedicated to making sure no one feels alone after they are diagnosed with WM and that everyone gets the education and support to help them partner with their doctor in choosing the best treatment. No Lonely Hearts Club Band at the IWMF!

Throughout the past 20 years, WMers have always given each other the time and the help they need. This "pay it forward" attitude makes the world a better, safer, and less lonely place for the next generation of WMers.

We've made incredible progress in the last 20 years, but things have really accelerated in the five years since we issued the 15th anniversary *IWMF Torch*. All of this progress has occurred because of dedicated WM volunteers and supporters like you. Even if you're not a "numbers person," just let these numbers wash over you and notice the enormous progress.

- In 2013, we had 6,307 members in 64 countries. We now have over 16,000 people in our database from 76 countries. Almost 10,000 more in a very short time!
- In 2013, we had invested over \$6,300,000 in WM research during the 14 years since research was first sponsored by the IWMF in 1999. As of today, we've invested nearly \$14,000,000—more than twice as much. In other words, we've invested more in the last five years than we did in the first 13! In fact, in the last three years, we've invested over \$5,600,000 in new research that will bring us closer to a cure. All of this money has come from WMers and their friends and families. People just like you.
- In 2013, we had 219 attendees at our Educational Forum in San Diego. In 2018, there were a record-breaking 373 attendees. The thirst for knowledge thrives!



President's Corner, cont. on page 2

OFFICERS & TRUSTEES

FOUNDER

Arnold Smokler

PRESIDENT EMERITA

Judith May

PRESIDENT

Carl Harrington

SECRETARY-TREASURER

Beverly Docteur

VICE PRESIDENTS

Elena Malunis

Michael Sesnowitz

Guy Sherwood, MD

BOARD OF TRUSTEES

Stephen Ansell, MD

Peter DeNardis

Marlyn Friedlander

Sue Herms

Tom Hoffmann, MD

Marcia Klepac

Robert A. Kyle, MD

Barry Nelson

Linda Nelson

Lisa Wise

BUSINESS OFFICE

Jennifer Silva, Operations Manager

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

Lisa 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

President's Corner, cont. from page 1

- In 2013, we provided our information in English. Today our website is translated into over 100 languages. And most of our publications are available in seven languages: English, Spanish, French, German, Italian, traditional Chinese, and simplified Chinese.
- In 2013, we had affiliates or contacts in a few countries. Now we have affiliates in 18 countries. Nearly half the world's population lives in those 20 countries. That's really making the "International" in our name come to life.
- In 2013, we weren't doing newfangled things like webinars or using social media platforms like Facebook. But this year our WM webinar with our partner CancerCare reached 1,500 WMers around the globe. For perspective, this is the largest single webinar CancerCare has ever done. And they do webinars for very common cancers such as breast, prostate, and lung cancer. Can you believe that? More people at the webinar for our little disease that makes up only 1.5% of all blood cancers than for those huge diseases. WMers really know how to band together!

I could go on listing examples of what we've accomplished together. If past IWMF Presidents Arnie Smokler and Ben Rude were around today, they would be so proud! And we owe them, as well as past President Judith May and all of the IWMF Board members and volunteers since 1998, a huge debt of gratitude. Without them, we would each be part of a Lonely Hearts Club Band instead of sharing in a vibrant, caring, and supportive community that is dedicated to supporting everyone with WM while we advance the search for a cure.

Let's band together and make the music even louder!

Your faithful bandleader,

Carl Harrington



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.

EDITORS

Alice Riginos

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

TORCH ADVISORY PANEL

Carl Harrington

Robert Kyle, Judith May

Guy Sherwood

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.

MAKING THE MUSIC EVEN LOUDER: WHAT THE NEXT FIVE YEARS COULD BRING

BY ALICE RIGINOS

When the editors of the *IWMF Torch* read the first draft of President's Corner, we knew we had a page one article worthy of the 20th anniversary issue! It was very inspiring to read the list of accomplishments achieved over the past five years by the energetic and dedicated IWMF volunteers following their bandleader. How, I wondered, did their bandleader envision "making the music even louder" in the next five years?

I put this question to Carl, and he responded in a wide-ranging conversation covering the four directions that the IWMF Board sees as promising over the next five years. All of these directions are focused on realizing the simple but compelling vision of the IWMF: "To support everyone affected by Waldenström's macroglobulinemia while we advance the search for a cure." Here are four highlights from our conversation.

1. Research

"Thanks to our partnership with the Leukemia & Lymphoma Society (LLS) we have a robust plan for research in place for the next years," Carl began, referring enthusiastically to the IWMF-LLS Strategic Research Roadmap, the agreement set up in 2013-14 aiming at a cure for WM. "To be sure," he added, "from our earliest years the IWMF prioritized a research program, directed by the vice president for Research and supported by contributions from our members. The Research Roadmap, however, placed the IWMF, a small and relatively new cancer organization, in partnership with the LLS, the third largest cancer organization in the US. Roughly 125-200 times larger than the IWMF!"

I agreed that it was a lucky day for the IWMF in 2015 when Dr. Lee Greenberger, Chief Scientific Officer of the LLS, agreed to collaborate with the IWMF in efforts to expedite a cure for WM!

At this point in our conversation, one might say that Carl had assumed the role of bandleader and was increasing the tempo, so eager was he to outline for our readers the plan underlying the IWMF-LLS Strategic Research Roadmap. It is, as Carl described it, straightforward: first, to identify the gaps in understanding that were holding back progress toward a cure for WM and then to identify and fund the best global research to fill those gaps. The plan calls for leading WM researchers and clinicians to review the research proposals submitted for funding at an annual meeting or summit to be held in New York City each year. Since the initial summit meeting held in NYC, the four research gaps have been refined at two additional meetings in 2016 and 2017.

The gaps are:

- Signaling – What pathways do WM cells use for communication?
- Immunology/immunotherapy – How can we better use our own immune system to fight WM?
- Tumor microenvironment – How does the bone marrow/tumor environment affect WM cells?
- "Omics" – What else can we learn about genomics, epigenomics, and mutations in WM cells?

You can read more about the Roadmap in Carl's July 2015 *IWMF Torch* article at https://www.iwmf.com/sites/default/files/docs/Torch_16.3_July2015.pdf

Without missing a beat, Carl continued to explain how the Roadmap is running so far. "Each year the IWMF circulates a Request for Proposals (RFP) in the WM research community. Starting with the first RFP in the fall of 2015, we have issued three RFPs and have now funded **ten Roadmap research projects**. These are not just ordinary research projects; each one is for a total of \$400,000 over two years. This has enabled us to attract the leading minds in lymphoma and WM to tackle our disease. So far, we have been successful in expanding the group of scientists working on our disease. Of the ten projects, eight are researchers we've never funded before, seven are at institutions we've never funded before, and four are international (Italy, Spain, the Netherlands, and Germany)."

This research has helped enhance interest in WM. We are all benefitting, as there are now more treatments with fewer side effects and deeper, longer remissions. Carl says the IWMF Scientific Advisory Committee (SAC) and the Research Committee expect the rate of progress to accelerate. Be on the lookout for new drugs like venetoclax, acalabrutinib, zanubrutinib, ulocuplumab, ixazomib, daratumumab, oprozomib, obinutuzumab, carfilzomib and tirabrutinib. Some of these and other drugs in the pipeline may make a big difference in the lives of WMers.

2. Growth in the number of IWMF partners and the depth of our partnerships

As a small, volunteer-led and volunteer-funded organization, the IWMF simply doesn't have the resources to do everything. While the Roadmap is a great

Making the Music, cont. on page 4

example of a partnership, the IWmf has established strong relationships with a number of other non-profits. A continuing aim for the future is to find partners who can provide services and expertise for WMers that the IWmf just does not have or cannot develop. Using the Roadmap as an example, the LLS has provided scientific leadership and meeting coordination, shared the costs of the summits, and provided \$625,000 in research funding.

Carl gave further examples of how partnerships increase the IWmf's outreach, including the free *CancerCare* webinars (last one of which attracted over 1,500 attendees); the advocacy work where we partner with the Lymphoma Research Foundation (LRF), LLS, and the National Organization for Rare Disorders (NORD); the LLS Patient Registry; the Lymphoma Coalition Global Lymphoma Patient Survey; and Triage Cancer. The partner listing on our website gives more information about what services these and our other partners offer. See <https://www.iwmf.com/about-us/partners>

3. Expansion of Member Services and international outreach

The IWmf is expanding its Member Services in so many ways that Carl directed me to Elena Malunis, the IWmf vice president for Member Services and chair of the International Committee. The article by Shirley Ganse on page 5 describes the great new services and the international expansion the IWmf is experiencing under Elena's direction. Make use of all of them!

4. Increasing funds for research: the importance of volunteerism and prospects for expansion of IWmf membership

Carl concluded his view of future directions for the IWmf with an example of one asset that can provide the Foundation with significant savings. IWmf expenditures have doubled, he noted, from \$1 million to \$2 million per year since the Roadmap and other research projects were initiated. One approach to limiting the IWmf's expenses is to have volunteers perform services which otherwise would require salaried workers. Volunteerism has always been a part of the IWmf culture. In 2017 alone, 200 WMers worked over 35,000 hours to support the IWmf. That's the equivalent of 17 full-time positions! No wonder we're able to get so much done!

Our conversation moved further into the future with the IWmf President looking into the third decade of the IWmf and my asking Carl if it is possible to double the IWmf membership by adding 16,000 more members.

His reply: it **is** possible. One of our pharmaceutical partners estimates that the number of WM patients globally is 30,000. We know that most of our members are either WM patients themselves or members of a patient's family. If the estimate of 30,000 patients is reasonable, it is not far-fetched to believe that, as the IWmf's global outreach expands, another 16,000 WMers would become IWmf members.

You can help yourself by asking your friends and family to donate to the IWmf and become members. And, Carl added, with the potential of doubling membership comes the possibility of increasing annual giving to \$3 million!

And this, he said, is also possible! The IWmf is now employing new and better ways to share information, such as webinars and Facebook, and to attract new members in all directions of the globe.

In closing our conversation Carl then returned to the imagery of his page one article, President's Corner. Urging every WMer "to make the music even louder" and become more active in the "WM Band," the president provided the following recommendations:

- Pick up your "instrument"—whether it's your pen, your phone, or your Internet connection and support us financially with a donation, a pledge, and by naming the IWmf in your estate plan. Contact Jason Watkins at: jwatkins@iwmf.com to find out how.
- Ask your friends and family to support the IWmf and become members. At the very least, tell them what you want for holidays is not more things but a donation to the IWmf!
- Volunteer your talents.
- Share your hard-earned knowledge about WM, what's worked for you and what hasn't on IWmf Connect, on Facebook, at support group meetings, on LIFELINE, or by telling your Story of Hope.
- Participate in the LLS Patient Registry, WhiMSICAL, and surveys when they request information.
- Update your contact information to make sure we have your email address, your mailing address, your date of birth, your date of diagnosis. Contact Jennifer Silva, the IWmf Operations Manager, at jsilva@iwmf.com

We are on target for our third decade. Let's make the music even louder!

IWMF MEMBER SERVICES: REACHING NEW HEIGHTS

BY SHIRLEY GANSE

As a Waldenström's macroglobulinemia (WM) patient or caregiver, how often have you checked www.iwmf.com for information? Have you consulted the Physician Directory or used LIFELINE? Are you a support group member or a WMer and website user who lives in a country other than the US? Have you attended an Ed Forum or viewed a video from one? If you said "yes" to any of these, you have made use of the varied services offered by the IWMF. All together, they are referred to as Member Services and form the largest part of the IWMF's mission to you, the WM-related recipient.

In the 20 years since the IWMF's founding, its Member Services program has become the support system that many WMers turn to when the need arises. Its offerings and reach have extended exponentially in the last ten years, thanks to the Member Services "team" that includes Board Trustees Elena Malunis, who is Vice President for Member Services, Linda Nelson, Barry Nelson, Marcia Klepac, Sara McKinnie, Lisa Wise, and Peter DeNardis.

IWMF Educational Forum

Known as the Ed Forum, this yearly meeting, held in various cities around the country, is the pre-eminent patients' and caregivers' educational meeting about WM. In April 1996, IWMF founder Arnie Smoker arranged the first patient conference in Arlington, VA, which was attended by 75 people. By early 1998, when the organization became known officially as the IWMF, the conferences were called Educational Forums and had become an annual event. Attendance at Ed Forums has steadily grown, and in May of this year the number who came to the Ed Forum in Rosemont, IL, reached an all-time high of 373. New sessions, such as one for the needs of the newly diagnosed, and breakout sessions on specific, and changing, topics of interest are offered each year. Updates on treatments and research from leading experts on WM, as well as the Ask the Doctor question and answer session, find intense interest from their audiences. The success of the Forum's ability to fill the on-going need for up-to-date WM information and to provide opportunities to network with fellow WMers is reflected in the attendance level and in the consistent overall favorable response ratings for the meeting.

Physician Directory

The Physician Directory is a resource based on the realization that people often asked the IWMF for names of physicians who were well-versed in treating WM. As WM is a rare disease, that can make it hard to determine which doctors to contact for the best skill set and most current information.

So Elena Malunis and fellow Board Trustees Dr. Robert Kyle and Dr. Guy Sherwood spent much time planning the list, contacting hematologist-oncologists, and adding those with WM experience who agreed to consult with patients and their doctors.

As the IWMF's reach has continued to expand worldwide, and since the original list contained only US doctors, recommendations for WM doctors from other countries have also been added. Of the 18 international affiliates, 14 now have representation in the Directory; this number will be expanded as Member Services continues to work at identifying physicians with the WM expertise to consult with patients and other physicians. Currently, the Physician Directory is the most-used link on the IWMF website.

The IWMF Website

The IWMF website is the basic resource upon which many depend for access of information. The site in 2012 had good information, but more, and more easily accessible, information was needed. It took at least a year to reorganize it, salvage what was needed, and add more resources. As international expansion began, the Member Services team felt that the information also needed to be available in local languages in other countries. With the help of IWMF Webmaster Barry Nelson, Google Translate was used for this function.

A very useful sidelight of the reorganized website is the ability to track its usage and what areas are most visited, information that informs any changes in the future. A website redesign is now needed, and it will be addressed as resources allow.

International Affiliates

Ten years ago the IWMF had little international focus, and consequently the "I" in IWMF seemed to have little basis in fact. So an expansion of its international approach was needed. The IWMF called the then existing entities in six or seven European countries "support groups," but that was not an appropriate name for them. Realistically, they had little to do with the IWMF, for there had been no formal agreement and they did not necessarily function as support groups do in the US. With a recognition that these groups outside the US provide tremendous support to WMers in their respective countries—and thereby help the IWMF fulfill its mission of "support to all," the IWMF decided it should focus on providing them with help and guidance. These international groups were then identified as affiliates of the IWMF. With the organization of the international program, the IWMF also created an Affiliate Agreement for new country affiliates so

IWMF Member Services, cont. on page 6

that expectations are understood on both sides and all are treated equally.

It's difficult to create and sustain groups in countries outside the US, because unlike in the US, many have no infrastructure for the support of a rare disease group, so it takes a while to get established. Sometimes it required a personal contact, from Malunis or others, and much can depend on the background of an affiliate's leader or whether the group has a local institutional connection. So each country has its own way of creating an entity that can support its WM patients, with the collaboration and help of the IWMF.

With the number of international affiliates now 18, a website in over 100 languages, and publications translated into seven languages, the "I" in IWMF can truly reflect its international reach.

Publications

With the increase in the number of international affiliates, it became clear that while the IWMF had excellent publications about WM and treatments, they were of little help to those people who don't know English. The IWMF worked with the affiliates to find ways to get some IWMF publications translated. It started with France, then Italy when the new affiliate was created there; the affiliate in Argentina helped with Spanish, and Taiwan and China followed. Most IWMF publications are now available in seven languages in addition to English. This effort continues when a new publication is developed or existing publications are updated.

In recent years fact sheets have been developed. These are shorter informational pieces for a quick read instead of the

longer publications. Several IWMF trustees have written simpler descriptions of terms, treatments, and drugs, and nine fact sheets are now available, eight of them available in seven different languages. The Publications Committee also wrote a new Frequently Asked Questions (FAQ) booklet and had several patients read it before publication to be sure it was direct and easy to understand. It is also available in seven languages and is now the number one requested booklet.

IWMF Connect, LIFELINE, and Support Groups

Other Member Services have seen tremendous progress in recent years as well. IWMF Connect, the online forum which evolved from IWMF-Talk, has had its content separated into topics accessed with hashtags, and it has a new technology base. LIFELINE, which provides one-on-one telephone and email support from volunteers, now offers more topics and more volunteers to take calls, including in Spanish, French, Arabic, and Japanese. In the US, the number of support groups has increased to 34; these provide much-needed support and education in small group settings.

All those involved in Member Services—dedicated office staff, Board Trustees, and many volunteers—work hard to make its programs increasingly better for more people in the US and worldwide. In the 20 years since the IWMF's creation, its focus on service has greatly extended Arnie Smokler's vision of providing support for WMers. The IWMF, which also added an emphasis on supporting research to find a cure, reflects this approach in its vision and mission, reaching out to people everywhere who need support in their WM journey.

IgM MGUS, SMOLDERING WALDENSTROM'S MACROGLOBULINEMIA, AND WALDENSTROM'S MACROGLOBULINEMIA

BY ROBERT A. KYLE, MD

Robert A. Kyle, MD, of Mayo Clinic Rochester, our "Doctor on Call" for this issue of the IWMF Torch, needs little in the way of introduction to our membership. Dr. Kyle has been a supporter of the IWMF since its earliest days, serving as Chair of our Scientific Advisory Committee from the time the Committee was established until 2017 and continuing to serve as IWMF Board advisor. Many reading this issue are sure to recall Dr. Kyle's engagement in lively discussions from the podium as he moderated a panel of WM experts at IWMF Educational Forums. Earlier this year, we celebrated Dr. Kyle's 90th birthday in the April 2018 issue of the IWMF Torch.

Dr. Kyle's status today as a preeminent expert in WM is rooted in his personal friendship with Dr. Jan Waldenström and supported by his long career as a researcher and clinician at Mayo Clinic. In this article, entitled "IgM MGUS, Smoldering Waldenstrom's Macroglobulinemia, and Waldenstrom's Macroglobulinemia," Dr. Kyle reports the most recent research on the status of the so-called "precursor conditions" to WM and their relationship to the development of active disease.

IgM MGUS, cont. on page 7



Dr. Robert A. Kyle at the bow of the Norwegian Bliss traveling through the Panama Canal, May 2018

Although the term “monoclonal gammopathy of undetermined significance” (MGUS) was introduced in 1978, efforts in the area had begun a half century before by Theodor Svedberg and his graduate student, Arne Tiselius. They demonstrated that certain proteins in the blood could be separated on the basis of their electric charge, but it was not

until 1951 that Tiselius and Henry Kunkel developed a practical laboratory technique for electrophoresis of the serum. Before this approach, electrophoresis required the effort of one technician for an entire day to examine the serum of one patient. This, of course, was impractical for general usage.

In 1944, Jan Waldenström described two patients that we recognize today as having “Waldenström’s macroglobulinemia.” Even more importantly, he described the concept of *monoclonal* and *polyclonal* gammopathies in 1961. This was fundamental because the former can be associated with a malignant or serious condition (multiple myeloma, Waldenström’s macroglobulinemia, AL (light chain) amyloidosis) or a potentially malignant condition (MGUS), compared to a *polyclonal* gammopathy, which is secondary to an inflammatory process such as a rheumatic disorder or liver disease and does not progress to a malignancy.

MGUS occurs in older persons, with 98% being 40 years of age or greater. Its frequency increases with age. About 3% of a normal population 50 years of age or older have MGUS, and approximately 5% of normal people greater than 70 years of age have it. However, we have seen MGUS in two teenagers and several persons in their 20s in a large normal population. MGUS is recognized at an average age of about 72 years, and slightly more than one-half of those affected are male. Almost 4% of men and 3% of women above 50 years of age have a MGUS. The rate in men is similar to women who are a decade older, suggesting that women “age” more slowly than men. In people older than 85 years of age, the prevalence was almost 9% of men and 7% of women. The incidence of MGUS is twice as high in African Americans. The size of the monoclonal protein does not increase with advancing age. The frequency of MGUS is not greater in those who seek medical care frequently than in those who infrequently see a physician.

The immunoglobulin type is IgG in about 70%, IgA in 12%, IgM in 15%, and biclonal (two monoclonal proteins) in 3%

of persons. The size of the M-spike in the serum protein electrophoretic pattern is less than 1.0 g/dL in 60% and greater than 2.0 g/dL in only 5% of persons. The light chain type is kappa in about 60% of individuals and lambda in the remainder. The level of uninvolved immunoglobulins (IgG or IgA) is reduced in about one-third of persons with an IgM monoclonal gammopathy. Approximately one-third of patients with MGUS have an abnormal kappa to lambda free light chain ratio. Examination of the urine reveals a monoclonal light chain (kappa or lambda) in about 30% of persons. The amount of urinary light chain is modest, with the majority of patients having less than 150 mg in a 24 hour urine specimen. Examination of the bone marrow, if done, usually contains less than 5% monoclonal plasma cells or lymphocytes, and must be less than 10% to qualify as a MGUS.

During long-term follow-up of more than 1,000 persons with MGUS, the risk of developing multiple myeloma was increased 24-fold, lymphoma with an IgM monoclonal protein was increased 1.6-fold, AL amyloidosis nearly 9-fold, WM 47.5-fold, and chronic lymphocytic leukemia 0.6-fold when compared to a normal population. These conditions developed in about 10% of patients with MGUS, which is six times higher than one would expect in a normal population. The risk of progression of MGUS was approximately 10% at 10 years, almost 20% at 20 years, 28% at 30 years, and 36% at 35 years if one excludes death from heart disease, stroke, or other malignancies such as cancer of the breast, prostate, lung, colon, or kidney. However, if one includes death from these conditions, only 10% of patients with MGUS overall developed multiple myeloma, lymphoma, AL amyloidosis, or WM. The rest died of conditions unrelated to these disorders. Sex, age at diagnosis, or duration of follow-up did not play a role in progression of MGUS. The M-protein disappeared during follow-up in 5% of this large series, but in the majority of persons, treatment with corticosteroids for a condition unrelated to the plasma cell disorder was responsible. The overall survival of patients with MGUS was shorter than that of a comparable normal population.

We estimate that an MGUS, when discovered “accidentally” in clinical practice, has likely been present for at least a decade.

In this discussion, we will emphasize IgM, which accounts for approximately 15% of all monoclonal gammopathies. IgM MGUS is characterized by the presence of a serum IgM monoclonal protein less than 3 g/dL; a bone marrow, if done, containing fewer than 10% lymphoplasmacytic cells; the absence of symptomatic anemia, enlargement of lymph nodes, liver or spleen; and no hyperviscosity of the blood. In addition, there are no constitutional symptoms such as unexplained fatigue, fever, night sweats, or weight loss. MGUS is completely asymptomatic and is usually found when the physician is examining the patient’s blood for an unrelated condition.

The risk of progression among patients with IgM MGUS is almost 11 times that of a normal, comparable population. The risk of progression to non-Hodgkin's lymphoma is increased 10.5-fold, AL amyloidosis 13-fold, and WM 288-fold. The risk of progression among patients with IgM MGUS is about 2% per year for the first 10 years and then approximately 1% per year thereafter.

The initial concentration of the monoclonal protein and the serum free light chain ratio are the most important risk factors for progression.

Patients with IgM MGUS who have an abnormal free light chain ratio and a serum M-protein level greater than or equal to 1.5 g/dL have a risk of progression at 20 years of 55%, compared to 41% of patients with one of these risk factors and only 20% of patients with neither risk factor. The risk of progression was higher when there was a reduced concentration of both uninvolved immunoglobulins (IgG or IgA).

It is likely that virtually all patients who have WM have had an initial IgM MGUS followed by smoldering Waldenstrom's macroglobulinemia (see discussion of smoldering disease below), but these intermediate conditions are often not recognized in clinical practice.

"Smoldering Waldenstrom's macroglobulinemia" (SWM) is characterized by an IgM monoclonal protein greater than or equal to 3 g/dL and/or bone marrow lymphoplasmacytic infiltration greater than or equal to 10%. These patients have no symptomatic anemia or enlargement of the liver or spleen related to the IgM protein. There is no hyperviscosity, and patients have no constitutional symptoms such as unexplained fatigue, weight loss, or night sweats.

In contrast to IgM MGUS, 90% of patients with SWM progress to symptomatic WM requiring therapy and 10% to AL amyloidosis. The likelihood of progression is 6% at one year, almost 40% at three years, and 60% at five years of follow-up. The major risk factor for progression is the number of lymphoplasmacytic cells in the bone marrow, the size of the serum M-protein, and the hemoglobin value at diagnosis. At ten years follow-up, 70% of patients with a serum M-spike greater than or equal to 3 g/dL and bone marrow containing greater than or equal to 10% monoclonal lymphoplasmacytic cells progressed to symptomatic WM, compared to 50% in those with an M-protein less than or equal to 3 g/dL and a bone marrow containing greater than or equal to 10% lymphoplasmacytic cells. The risk of progression of IgM MGUS is about 1.5% per year, compared to 12% per year for patients with smoldering disease.

The diagnosis of "active WM" requires the presence of symptoms such as anemia, enlargement of the liver or spleen, hyperviscosity, or constitutional symptoms; the presence of a monoclonal IgM protein of any size; and a bone marrow containing 10% or more cells with lymphocytoid or plasmacytoid features (lymphoplasmacytic lymphoma). The lymphoplasmacytic infiltration has the same morphologic features as IgM MGUS and SWM.

Patients with smoldering disease should be observed closely without therapy. The history and physical examination as well as determination of the hemoglobin and serum M-protein should be reevaluated at 3-12 months initially, depending on the clinical and laboratory findings. At this time, the consensus is that patients should not be treated until active WM develops.

IWMF ONLINE DISCUSSIONS – WSMG-NET TO IWMF-TALK TO IWMF CONNECT

REFLECTIONS ON A VITAL RESOURCE FOR SUPPORT AND INFORMATION

BY PETER DENARDIS, IWMF TRUSTEE AND IWMF CONNECT LIST MANAGER

Someone recently asked me how long it's been that I've had the role of List Manager for the IWMF's online discussion list, IWMF Connect. My response was "Honestly, I'm not sure." I have been doing it for such a long span of time that I no longer recalled the exact day that I officially took over as "List Mom" of the IWMF online discussion list.

So I did a bit of investigating on the various platforms the IWMF has used over the years—first with *ACOR.org* (and briefly at *Delphi.com*), then with *lists.psu.edu*, and finally with *groups.io*. That exercise led me to re-visit many email exchanges that have occurred over the years and to re-read

poignant messages from noted list members, along with the occasional differing views of opinions.

Ultimately, I did find the information I was looking for, as my "official" role as List Manager was given to me by then IWMF President Judith May on March 22, 2007. Actually, I was initially approached by Ron Draftz a few months earlier to consider serving as a "backup" to then List Manager Eddy Anderson, as I was one of the more engaged participants and had a background in information technology.

IWMF Online Discussions, cont. on page 9

At the time, Eddy, who was endearingly referred to by list members as the “Talk-List Mom,” was experiencing significant health issues and could no longer serve in the role that she had held since 2000. (Sadly, Eddy passed away on January 9, 2009.)



Some of you might find it interesting to know that the original list, WSMG-NET (hosted by ACOR, Association of Cancer Online Resources), was set up by Dr. Arnold (Arnie) Smokler, the founder of the IWMF, on February 1, 1997. Shortly thereafter, the name was changed to IWMF-Talk when the name of IWMF was officially adopted by the organization later in 1997. The first message sent by Arnie to each of the 22 members at the time was:



Those were the very early days of the IWMF and of the online discussion list. Given the small number of members, there wasn't much activity on the list, and, in an attempt to keep them engaged and active in communicating with each other, Arnie would send out a humorous message from time to time. In fact, the very next message he sent is pictured on page 10.

Over time, as personal computers became more popular and affordable, as features and functionality of the Internet continued to evolve, and as word spread about the IWMF, the membership began to grow. Five years later, at the end of 2002, there were 100 members. By 2007, when I took over as List Manager (I hadn't quite earned the title of “List Mom” yet), membership had grown to 500 members. Today, 21 years after Arnie's original email message, we now have 2,100 members. And that continues to grow and expand.

Of course, as technology evolves, so does the IWMF. Over the past few years, we've also established a presence on the popular social media tool for online engagement called Facebook, where we have a community of 2,200 members on the private WM Support Facebook group and another 2,200

Subject: The Waldenstrom's Macroglobulinemia Online Discussion List

From: "Dr. Arnold Smokler" <asmokler@EROLS.COM>

Reply-To: WSMG-NET: The Waldenstrom's Macroglobulinemia Online Discussion List" <WSMG-NET@LISTSERV.MEDINFO.ORG>

Date: Sun, 2 Feb 1997 07:58:26 -0500

Content-Type: text/plain

Parts/Attachments: text/plain (31 lines)

The WM online discussion list is up & running. To subscribe send a message to:

listserv@medinfo.org

Nothing in the Subject field.

In the body type:

subscribe WSMG-NET your first name your last name.

Once subscribed you can send messages to the list by addressing the message to WSMG-NET@listserv.medinfo.org

Please note:

WSMG-NET is not a mistake.

Questions and/or problems send messages to me at asmokler@erols.com

Arnie

```
*****
* Dr. Arnold Smokler, Pharmacologist - Computer Scientist *
* Chair, Waldenstrom's Macroglobulinemia Support Group    *
* WM Home Page: http://www.erols.com/asmokler/wmsg.htm *
* Phone: 703-321-8888 Fax: 703-321-8920                    *
* WMSG Annual Conference: April 18-20, 1997                 *
*****
```

Subject: Psych HotLine

From: "Dr. Arnold Smokler" <asmokler@EROLS.COM>

Reply-To: WSMG-NET: The Waldenstrom's Macroglobulinemia Online Discussion List" <WSMG-NET@LISTSERV.MEDINFO.ORG>

Date: Sun, 2 Feb 1997 20:30:28 -0500

Content-Type: text/plain

Parts/Attachments:  text/plain (32 lines)

```
>From: Joseph <postbmt@ix.netcom.com>
>Subject: Psych HotLine
>
>Picked this up from the Orange County Register:....
>
>Ring...Ring...Ring....
>Welcome to the Psychiatric Hotline!
>If you are obsessive-compulsive, please press 1 repeatedly.....
>
>If you are co-dependent, please ask someone to press 2.
>
>If you have multiple personalities, please press 3,4,5, and 6.
>
>If you are schizophrenic, a little voice will tell you which number to
>pressssssss.
>
>If you are manic-depressive, it does not matter which number you press.
>No one will answer.
>
>If you are paranoid, we know who you are and what you want. Just stay on
>the line so we can trace your call.
>
>
>
>
*****
* Dr. Arnold Smokler, Pharmacologist - Computer Scientist *
* Chair, Waldenstrom's Macroglobulinemia Support Group *
* WM Home Page: http://www.erols.com/asmokler/wmsg.htm *
* Phone: 703-321-8888 Fax: 703-321-8920 *
* WMSG Annual Conference: April 18-20, 1997 *
*****
```

followers of our official IWMF Facebook page. We continue to keep a watchful eye on new technologies and mechanisms as they emerge, since they help ensure that we are able to fulfill the IWMF's mission to "support everyone affected by Waldenstrom's macroglobulinemia while advancing the search for a cure." From the very beginning, the intent and focus of the online discussion platforms has been to provide a mechanism for patients and caregivers to share information and provide comfort and support to each other. In recent years, that evolution has included sharing and discussing abstracts and details regarding recently published scientific journal articles pertinent to WM patients and caregivers, which are made available online in IWMF Connect.

In the early days, when a few list members had the same first name, they would number themselves (Ron 1, Ron 2, Ron 3, Ron 4) to distinguish one from the other, and we always knew which one was which based on writing style. We had the emergence of sub-groups like the Over 10K Club (for those with IgM values over 10,000 mg/dL), the WM Tumor group, the CAD (cold agglutinin disease) group, the CAM (complementary and alternative medicines) group,

the WM Humor group, the WM Science group, and others that have come and gone over the years. We've welcomed each patient and caregiver facing a new diagnosis with open arms, comforting words, and suggestions regarding possible treatments and doctors to seek out. We've shared notable happy life moments (birth of children and grandchildren, their high school and college graduations, and their weddings; retirement from work; and those exciting moments of achieving remissions), and shared and grieved together over each relapse and each loss of loved ones that we've come to know so well via the list. We've also celebrated the giving life forces who graced us with their presence as volunteers and supporters in the WM community but left us all too soon—folks like Arnie Smokler, Ben Rude, Eddy Anderson, Dave Lively, Sybil Whitman, Raphael Altman, Roy Parker, Ron Draftz, Ron Yee, and many others like them.

In the end, whether participating in the online communities as frequent or casual posters, or as habitual lurkers, we all find value and take heart in the messages shared therein and invariably become a loving, caring extended family of

IWMF Online Discussions, cont. on page 11



people all dealing with the enormity of a very rare disease that still is incurable (but we're getting closer!). No matter what part of the world we come from, we are able to share our joys, our sorrows, our pains, our questions, our advice, and our compassion. The true value of such mechanisms is the "virtual hugs" we extend to each other via our words and the useful advice given from a battle-tested fellow patient and caregiver experience.

As I like to say in my tag line in my emails: "*Vino, Amore, Salute - cos'altro c'è?*" (Wine, Love, Health - what else is there?)—well, there's hugging...there's always hugging.

If you're a member of IWMF Connect or one of the Facebook groups, you're to be commended and part of a loving and caring family. If you're not a member yet, why not consider joining us in sharing and receiving knowledge about how best to deal with WM, and yes, even in sharing and receiving a much-needed virtual hug from time to time?

Here's how you can join us:

IWMF Connect: Go to <https://groups.io/g/iwmfconnect> and click the "Sign Up" icon (in the upper right corner). Also, for more details about using Connect, go to the IWMF website at: <https://www.iwmf.com/get-support/iwmf-connect-and-online-discussion-forums>.

The official IWMF Facebook page: Go to <https://www.facebook.com/waldenstroms.support/> and "Like" the page.

The WM Support Facebook Group (closed group): <https://www.facebook.com/groups/wmsupportgroup> and click the "Join Group" button.

If you need further assistance, contact Pete DeNardis at pdnardis@gmail.com, or fill out the "Contact Us" form on the IWMF website at: <https://www.iwmf.com/about-us/contact-us>.

LIVING WITH WM FOR 20+ YEARS



Peg Horton, 23-year WM survivor

PEG HORTON, PORT ORCHARD, WA

Finding out I had Waldenstrom's (WM) kind of snuck up on me in 1996. My neurologist changed her diagnosis of inflammatory large vessel disease to WM. When I asked her to spell it and what was it, she said, "It's like leukemia, but it's not." So when I visited an oncologist (I didn't know what one was then), I told

him, "Wow! For a while I thought I had cancer!"

He said, "You DO have cancer, and you've probably had WM for at least a year." When my husband Bob and I went to the library and read in a small paragraph that life expectancy was 1-3 years, we went home, and I bravely started telling friends and relatives good bye. I was 55.

I re-examined my thoughts on life after death, spiritual existence, guardian angels. I thought back to what events and memories mattered the most throughout my life—running in sand dunes at the ocean, playing mud pies in my grandma's back yard, singing, dancing, painting with acrylics—and later, giving birth to and raising my three daughters, teaching them the joy of music and singing in four-part harmony. I retired from real estate when we left Tucson to move to Seattle in 1990 and began taking care of grandchildren. A year after my WM diagnosis I drove solo (except for my little dog) from Seattle back to Tucson in our 24-foot, Class C motor home, visiting friends and family along the way. Great experience but a huge challenge.

Bob and I first met Arnold Smokler at a WM conference in Virginia (IWMF didn't exist at the time). He sent me a lot of information on WM and asked me to start a support group in Seattle. I started WMSG-NW with just four members in 1998, and Deloris Morrical as my secretary and friend. I led the group for a total of 13 years (with a two-year hiatus led by Malcom Brewer) before passing the baton to Shirley Ganse.

Living with WM, cont. on page 12

My last chemo and Rituxan treatment was in 2004 when my IgM reached nearly 6000. My IgM counts have gone down continually since then (IgM 507, August 6, 2018). I get a check-up every six months.

WM rarely crosses my mind these days. At 78 years old, I've once again started thinking more about life after death and where my spirit goes, especially when dealing with the normal aches and pains that come with age. I treasure each day more and more. In July, 2017 I had deep brain stimulation surgery (DBS) to help curtail Essential Tremor. Rougher than any chemo I ever went through, but well worth it. I was able to resume my acrylic painting which had all but ceased until the surgery. Ironically, many of the friends and family I said

good-bye to 23 years ago have gone to their maker.

JOSEPH HARVATH, TACOMA, WA

In July 1997 I took early retirement with a plan to sail from Seattle to the South Pacific. It had been my dream for many years. I had been feeling sluggish and seemed to fatigue easily, but I chalked it up to aging. My diagnosis, a byproduct of a routine physical, came as a complete surprise.

I had lived the kind of

life good health and independence allow. Having WM was a shock to my ego and my belief that I could do anything I set my mind to. It forced me to alter my ambitious retirement plan. Early on, the biggest adjustment was accepting the fact that I am not in control of my destiny and that God has a purpose for my life even in the midst of challenges.

I never considered WM a death sentence even though for years it was estimated patients live an average of five years post-diagnosis. After diagnosis my first thoughts were gratefulness for the life I had been given and all I had experienced. While I was surprised to discover that it might end sooner than I had imagined, I was at peace with the possibility.



Joseph Harvath, 21-year WM survivor

In the 21 years since my diagnosis, there have been a few seasons characterized by long periods of decline, eventually necessitating treatment, followed by very, very slow improvement. During these dips, when my energy was sapped, my vision threatened, and a simple cold could become a major illness, it was difficult to remain upbeat and optimistic, especially when it appeared the treatment wasn't working. Some days (weeks, months) I just slogged through.

During these tough times I questioned my value to my home life, my wife, my friends, and my community. It was then, and still is, immensely helpful to continue to enjoy the company of good friends, nurture my spiritual life, and acknowledge my blessings.

I remember one particular time when I was receiving chemo in a group infusion room. Someone suggested we all share our names and a little about why we were there. One man had an autoimmune disease that was causing his body to destroy his blood vessels. I thought I had it bad until I heard his story. Surprisingly, he thought the exact same thing about me! It made me realize the strength that comes from "owning" your own disease. Mine had some definite drawbacks, but I had already begun to accept these realities and was learning how to live with them. A good friend's second-grader once explained a significant disappointment in her life this way: "You get what you get and don't throw a fit." It's good advice at any age and applies well to my life with WM.

I remain especially grateful for the medical professionals who have guided my care with the goal of preserving my quality of life, for those who have bravely tried the chemotherapies that have led to advances in disease care and consequently my recoveries, and to those who have shared both their struggles and successes. All have been a source of strength and encouragement.

If you are in a difficult place, facing fatigue and uncertainty, and perhaps not quickly getting the treatment results hoped for, don't despair! Your value and contribution to those closest to you is not dependent upon your physical wellbeing.

It may take time, but periods of good health are possible with WM. My experience has shown me over time that you can still be blessed with a rich and rewarding life.



IWMF DOC STAR: JORGE J. CASTILLO

EDITED BY RON TERNOWAY



Dr. Jorge Castillo, Dana-Farber Cancer Institute, Boston

Dr. Jorge J. Castillo has been the clinical leader at the Bing Center for Waldenström's Macroglobulinemia (WM) at the Dana-Farber Cancer Institute in Boston, MA, since 2013, where, with nurse practitioner Toni Dubeau, he provides clinical care for more than 1,000 WM patients annually.

While he has been a practicing doctor for two decades, his informal

training began some 40 years ago, at the tender age of five years, in the Peruvian seaside city of Chimbote. "My father is a cardiologist, an outstanding clinician with the best bedside manners I have seen. I was exposed to the doctor's lifestyle since I was little, so being interrupted during family time or woken up in the middle of the night was common. Not once did I hear my father complain. So, I pretty much said that I wanted to be a doctor since I was five."

"My mother is a great teacher, always simplifying concepts and ensuring they are well understood. She gave up her career to raise my sister and me. I think my style of taking care of patients is a combination of both my parents.

"When I was 14, we got our first computer, and I was so impressed by it that I changed my mind and wanted to become a systems engineer. My parents supported me, of course. It was a later conversation with my paternal grandmother that put me back on track. She spoke to me about the nobility that comes with being a doctor and the opportunity of positively affecting people's lives in a one-of-a-kind manner. That was it. I was going to be a doctor, and off I went to Mexico City to medical school."

Castillo received his medical degree in 1996. He completed his internal medicine residency in Framingham, MA, where he was also the chief medical resident. He then pursued training in hematology and oncology at Brown University in Providence, RI.

From 2008 to 2013 Castillo was a faculty member at Brown University Medical School, responsible for clinical care, clinical research, and teaching. His research focused on factors associated with increased risk of developing blood cancers. Using meta-analytical methods, he identified smoking as a risk factor for Hodgkin lymphoma; red blood cell transfusion as a risk factor for chronic lymphocytic leukemia; and an in-

creased risk of blood cancers in individuals with diabetes. His work has been published in nearly a dozen medical journals.

Dr. Castillo has secured research grants to study novel non-chemotherapeutic agents for the treatment of WM. Based on Bing Center research, ibrutinib (Imbruvica) was the first drug ever approved by the US Food and Drug Administration for the treatment of WM. Dr. Castillo is currently running ground-breaking clinical trials evaluating novel agents such as venetoclax, daratumumab, ulocuplumab, and zanubrutinib. His epidemiological research showed that patients with WM have longer survival than previously thought, but with a higher risk of developing second cancers. He has also studied rare clinical presentations in WM patients, including rituximab intolerance, pleural effusions, meningeal involvement by WM (Bing-Neel syndrome), and hyperviscosity. Dr. Castillo has plans to create a national clinical trials group for WM.

He serves as a member of a number of national and international committees, including the National Comprehensive Cancer Network and the International Workshops for WM. In this capacity, Dr. Castillo has helped formulate diagnosis and therapeutic guidelines for WM patients.

Teaching is one of Dr. Castillo's favorite activities. Throughout the year, he has a busy schedule of invited lectures to physicians and to patients within the US and abroad, especially Europe and Latin America. He works closely with the IWMF and the Lymphoma Research Foundation to provide education to patients via in-person presentations, teleconferences, and printed informational material.

He has been a speaker at the 2016 and 2018 IWMF Educational Forums. His June 2018 CancerCare webinar, "Progress in the Treatment of Waldenström's Macroglobulinemia," with Dr. Morie Gertz of Mayo Clinic Rochester and International Waldenström's Macroglobulinemia Foundation (IWMF) President Carl Harrington, drew over 1000 international participants. See:

https://www.cancercare.org/connect_workshops/652-progress_treatment_waldenstrom's_macroglobulinemia_2018-06-27

Dr. Castillo also enjoys mentoring colleagues, fellows, residents, and medical students, including colleagues from his native land of Peru. His mentees have presented their research at national and international meetings and published their findings in high-impact journals. He is proud to see his students go on to do meaningful research, and he is always happy to help with study design, statistical support, or constructive criticism of protocols and manuscripts. His work with Peruvian colleagues has been fruitful, with close to 20 publications in the last five years.

IWMF Doc Star, cont. on page 14

And then there is his position at the Bing Center, taking care of all those patients at one of the leading WM clinical and research centers in the world. When asked how he puts the disease in perspective for a newly diagnosed WM patient, Dr. Castillo replies, “Get to know your disease and find a good medical team. This disease is quirky and affects different patients in different ways. In fact, a patient once told me that each and every patient has a different version of this disease, and that pretty much sums it up. So, know your disease, know your numbers, and know your symptoms.

“However, the disease should not take over your life. There should be time to live and enjoy your family and your loved ones. A good medical team is key for making the right diagnosis and at the time of treatment. It is important that patients are not treated too early nor too late. The intensity of treatment should not be too high, that is, too toxic; or too low, that is, ineffective. Reaching that balance is important and is only achieved through common sense, experience, and years of dedication.”

Paul Kitchen, a WM support group leader in New Brunswick, Canada, met Dr. Castillo in 2014 after receiving a tentative diagnosis of lymphoplasmacytic lymphoma from his local doctor following a bone marrow biopsy. Kitchen was pretty certain he had WM, as his mother had died from it some 30 years previously. As his symptoms worsened and his hemoglobin plunged, his hematologist suggested a second opinion, and at Paul’s request began the process with the Bing Center.

Trans-border shipping is never without its challenges, and Kitchen got to Boston before his bone marrow biopsy slides. Not a problem for Dr. Castillo, reported Paul. “I was treated with amazing respect, warmth, and understanding. Dr. Castillo conducted a series of blood tests and said I had all the characteristics of WM. He assured us he would have my slides read as soon as he received them. Dr. Castillo answered every question my wife and I posed and seemed to have all the time in the world for us.

“Dr. Castillo was compassionate and caring and put us at ease. His relaxed, reassuring manner and his confidence that I still had a lot of living to do greatly comforted me, because I knew what I had, and that I was in very good hands.”

Dr. Castillo arranged for the proposed treatment to be administered in Kitchen’s local hospital. Once treatment started, Paul stayed in touch with Dr. Castillo every three months and had blood results sent to him every week during chemotherapy. “He gave me his pager number and his email. On several occasions I emailed Dr. Castillo a question, and each time within a few hours I received a thoughtful and helpful personal response.”

After initial treatment, Dr. Castillo recommended a two-year maintenance program; again, he set the protocol to be

administered by Paul’s local hematologist. Kitchen now sees Dr. Castillo annually and sends him blood tests quarterly. “As a Canadian patient within the Canadian system but needing the expertise of a WM specialist, I was treated as well as I could have imagined. I was fortunate to be able to get a world leader in WM to take me on and support me through my journey while collaborating with my physician at home.”

And how does this “world leader in WM” find balance in his life? With family, of course.

“Achieving work-life balance is definitely difficult, although not impossible. I am lucky enough to have married a smart, beautiful, and hardworking woman. My wife is also a physician, a diabetologist. Our conversations are interesting, since she sees a disease that affects millions of people while I see a disease that affects thousands. She talks about global health initiatives while I focus on the genomic abnormalities inside the patient’s cell.

“We have two children, Sofia who is six and Jorge who is four. We decided that we wanted to raise them ourselves without a nanny. We both are foreign, so we don’t have family nearby, and we both have very busy schedules, so we have to compromise. My wife and I support each other. We sit down and review our schedules often and make sure that one of us is here when the other one is traveling, for example.

“When one of us is away, then the other one has to take care of the kids, get them dressed, cook for them, take them to and pick them up from school, and drive them to their activities.

“We also have to make sure on-call weekends do not overlap. And whenever there is a conflict, we can always use the visit of our parents or siblings for a little bit of help. I think my wife and I have achieved a nice balance at the moment, but this needs constant work and supervision. We make sure there is also space for quality time, such as family game night once a week and having meals without electronic devices in hand.

“Despite our busy work life, we have time to be a family. We all enjoy swimming and playing tennis. We love to watch movies and read books. Particularly, I love traveling and eating good food. So, I combine these activities when I am away giving lectures or attending conferences. We have family trips throughout the year. We have traveled to many places in the United States and abroad as well. I am amazed at how well my kids travel and also how adventurous they are when it comes to food. I have seen them eat Peruvian ceviche with the same gusto as Lebanese tabbouleh or Swedish pickled herring.”

On the 20th Anniversary of the IWMF, a final observation from Dr. Castillo: “I really would like to thank the IWMF for the opportunity of letting the WM community know a little more about me, as a person and as a physician. I am truly impressed by how this Foundation, composed, supported, and

run by patients, is leading the way toward better understanding of the biology of the disease and to improving treatments.

“I believe the work of the IWMF has a deep positive impact on patients’ lives and, for that, it should be highly commended. I have not seen anything like it.”

FROM IWMF CONNECT: SUMMER 2018

BY JACOB WEINTRAUB, MD

Now that the summer is over, we can enjoy the fall as well as the ongoing discussions on IWMF Connect. I am privileged to have been editing this column for the past several years, I hope bringing some useful information to the readers and stimulating further discussion. I also feel grateful to be able to participate in this 20th anniversary issue. As always a multitude of links are posted. Some are links to human interest articles, some are links to informational items about WM-related educational events, and others are links to the newest research about the many treatment options with which we now are blessed. The ongoing support for new members, the sharing of experiences, and suggestions for questions to ask our own physicians are always a major part of the day-to-day discussions.

HUMAN INTEREST/ARTICLES

IWMF Connect Manager and IWMF Trustee **Peter DeNardis** posted several links of general interest, including an article titled “I Couldn’t Find Joy in Exercising After Cancer, Until I Did it in the Dark.” This is an exercise activity where a DJ plays various tunes for an hour while attendees dance “as if no one is watching” in a room with low light. The article gives one person’s experience with this activity:

<https://www.self.com/story/exercising-after-cancer-no-lights-no-lycra>

Diane S then posted that this article spoke to her soul. It should all be about our “happy places.”

Pat J also reported her experience. When no one is home, she closes the drapes, turns up the radio, and dances her housekeeping away. She learned to dance from a friend and has loved it from the day she learned. She said we should all keep on dancing. Baz Lurman has a song that has this sentence in it: “Dance like no one’s looking.”

Pete also gave us a link to an article from *The Inquirer* titled “Barbara Bush and the Problem with ‘Comfort Care.’” The article points out that it should not have to be either a comfort care or a hospice decision and that both should be provided when needed to appropriately treat patients in certain situations.

<http://www.philly.com/philly/health/barbara-bush-and-the-problem-with-comfort-care-20180424.html>

Wanda H also posted links to items of interest, including one to “Cure Talks Cancer.” This is an audio podcast titled “Support Groups: A Saving Grace.” In the podcast, the benefits of joining a support group are discussed by a survivor, a caregiver, and a social worker. This was a very familiar topic and presentation by each participant, but a message that bears repeating: https://www.curetoday.com/podcasts/support-groups-a-saving-grace?utm_medium=email&utm_campaign=CURE%20Extra%20eNews%20%20Un-sponsored%20%207-21-18&utm_content=CURE%20Extra%20eNews%20%20Un-sponsored%20%207-21-18+CID_4779ac47d804416b787a0af2ec4e70a3&utm_source=CM%20CURE&utm_term=Support%20Groups%20A%20Saving%20Grace

She also added a link to another podcast, this one titled “Career After Cancer,” about managing our professional work life, which can be challenging for those us with cancer. This is particularly relevant, since more of us with WM seem to be having the diagnosis made earlier than previously.

<http://www.curetoday.com/podcasts/career-after-cancer>

Finally, Wanda posted this link to an article titled “Don’t Let Lymphoma Stop you from Living.” This is a lesson that we all can learn and one that can help us find ways to participate in activities that renew our love for life.

<https://lymphomanewstoday.com/2018/07/02/dont-let-lymphoma-stop-you-from-living-activities/?amp>

SLEEP

Meg M also posted an article of interest. This was “Insomnia in Cancer Patients: Interventions That May Help.” This article investigates two non-pharmacologic approaches that may be beneficial for those of us with insomnia: acupuncture and cognitive behavioral therapy. One physician involved suggests these may have longer lasting remediation than pharmacologic treatments.

https://www.medscape.com/viewarticle/896879?nlid=122677_4503&src=wnl_dne_180521_mscpedit&uac=67391MX&impID=1637815&faf=1

Separately from Meg’s posting, there was additional discussion about sleep or lack thereof.

From IWMF Connect, cont. on page 16

Art M asked if anyone has used melatonin as a sleep aid. He noted the warnings on the label say not to use melatonin if you have an autoimmune disease, but wondered if this would apply to WM.

Pavel I offered that he has been using melatonin for about ten years, using 5 or 10 mg nightly. He has had no apparent side effect and thinks it is helping. As far as he knows, the melatonin has not had any effect on his WM. He added that WM is not an autoimmune disease.

Donna R posted that she noticed the warnings are for autoimmune and lymphoproliferative disorders. She asked her rheumatologist, and he recommended she not take melatonin, but she had an acute vasculitis problem in the past.

Wanda H told Donna that her observation was a good one. Wanda had thought of melatonin as a natural sleep product that has been sold for quite some time and can be purchased anywhere. She even has seen the product sold as gummy bears. Wanda thinks the melatonin she took may have interacted with one of her current meds, possibly her Cymbalta. She blacked out once while driving but fortunately was not injured.

Others reported taking Benadryl for sleep or taking “PM” which includes acetaminophen and diphenhydramine (Benadryl) with varying effects.

ITCHING

This is an ongoing issue appearing on IWMF Connect.

Bonnie B reported she suffers terribly in reaction to mosquito, spider, and other bites and has random itchy skin. She has (monoclonal gammopathy of uncertain significance) MGUS, not WM. She has been following a website with research focused on follicular lymphoma, but often relevant to WM. She found an article which cites a physician’s report that itching may be the most common of all B-cell manifestations associated with follicular lymphoma. The itching is probably related to a paraneoplastic syndrome with a release of several chemical substances in the body. WM is a B-cell lymphoma.

Cheryl F indicated that severe, whole body itching, along with a raised rash on her back was the very first symptom she had. She saw a dermatologist who ruled out all the other dermatological causes and then focused on possible blood cancer as the cause. The dermatologist told Cheryl that approximately one out of ten patients with itching of undetermined origin ends up being diagnosed with a blood cancer. The itching did not subside until multiple treatments reduced her IgM to below 400.

Marilyn S also reported that her husband had very itchy skin in his legs and arms for a couple of years before his WM diagnosis. Although they attributed it to dry skin, perhaps this, too, was an early manifestation of his WM.

Others added comments about itching in general and remedies.

Andi S reported itching since being diagnosed. This is primarily on the scalp. It comes and goes and is very aggravating. However, treatment has not yet been sought.

Marilyn B reported she has itching with a rash. She has small red dots, at times so bad that her scratching causes bleeding. It is particularly intense on her scalp. She has been to a dermatologist who has explored a multitude of possible causes, and when nothing could be diagnosed, the final conclusion was that the rash is somehow related to her WM. None of the topical remedies has helped. She also has had an allergy evaluation, but that was negative too.

Joel C did report that he has been to dermatologists and an allergist, and none of them related the itching to WM. He has had a “modicum” of relief from cortisone and anti-itching creams and topical Benadryl spray.

Dr. Tom Hoffmann added that 8% of people have chronic itching; however, 8% of the population does not have WM. There is good evidence that pruritis (itching) can be caused by lymphoma and WM.

IMBRUVICA SIDE EFFECTS

Discussion continues about all the various aspects of Imbruvica treatment, from cost, to effectiveness, to side effects. Many different perspectives and experiences are reported. There are even some political discussions about cost and availability of Imbruvica in this country and around the world.

Larry P asked if anyone has been experiencing cramps in various parts of the body. He has been taking Imbruvica for two and a half years and for the last couple of months is experiencing cramps on a daily basis. These occur in his back or neck or fingers and toes. He wasn’t sure if this is related to his Imbruvica or if he should look elsewhere.

Ron T answered that he has been taking Imbruvica for three and a half years and the cramps come and go. They occur in his feet, calves and hands, and generally occur weekly. He tries to stay hydrated and drinks pickle juice or tonic water that contains quinine, which helps relieve the cramps. He definitely feels these are drug related.

Beth C also reported that she has periodic “terrible” cramps in her feet and calves. However, her cramps started before her diagnosis and treatment. She has now been taking Imbruvica for six months, and the frequency has not changed. If she feels them coming on she usually is able to walk them off. If this is at bedtime, she takes a muscle relaxer, but that makes her very tired the next morning, so she doesn’t take them very often.

Eileen K added that she has been taking Imbruvica since

January. Her IgM has decreased significantly, but she has had an onset of neck pain. She feels that her feet are tight and that wakes her up at least once a night to walk it out for ten minutes. However, this started before Imbruvica was prescribed.

Finally, **Joanne B** added that all these events happen to her, but she is not taking any medications at this time.

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. I wish you all continued good health.

TWENTY YEARS OF GIVING: HOW YOUR SUPPORT HAS MADE A DIFFERENCE

There is much to celebrate about the IWMF’s 20-year history. Founded in 1998, the IWMF grew out of a support group of 21 WMers formed by Arnold Smokler in 1994. Today we have over 10,000 members worldwide. In 1999, the IWMF began raising money to support services for our membership and to support research that would lead to better treatments and, eventually, a cure.

The table to the right shows how our fundraising has progressed over time, increasing from just under \$50,000 in 1999 to over \$2.6 million last year. In total, we have raised over \$20 million to implement our vision to “support everyone affected by Waldenstrom’s macroglobulinemia while advancing the search for a cure.”

How have the funds raised in the past been used, and how will funds raised in the future be employed to improve the lives of those affected by Waldenstrom’s macroglobulinemia?

Readers of the *IWMF Torch* are likely to be familiar with the membership services provided by the IWMF. Over 2,000 of our members participate in IWMF Connect, the online forum that has helped educate so many of us. Over 300 people attend the Educational Forum each year, and thousands more view the outstanding presentations by world class researchers and clinicians when their video and slide presentations are posted on the IWMF website. Many have taken advantage of LIFELINE, learning about treatments directly from those who have experienced them. Thousands have read our publications, learning about the immune system and treatment options, how to decipher medical tests, and much more. Thousands of our members have participated in support groups, networking with other WMers who are eager to share experiences. And thousands more take advantage of the information on our website, finding the names and contact information of WM experts who can provide second opinions, reading Stories of Hope, downloading publications including the *IWMF Torch*, viewing video presentations and webcasts, and reviewing the research projects funded by the IWMF.

Having used our services, you know how valuable they are. We need your continued financial support to provide these essential services in the future.

IWMF Revenue History

Year	Revenue
1999	\$ 49,637
2000	\$ 139,447
2001	\$ 316,154
2002	\$ 451,941
2003	\$ 605,266
2004	\$ 562,701
2005	\$ 1,030,411
2006	\$ 997,382
2007	\$ 1,350,412
2008	\$ 958,735
2009	\$ 1,003,106
2010	\$ 888,562
2011	\$ 1,034,522
2012	\$ 1,050,217
2013	\$ 1,414,226
2014	\$ 1,695,012
2015	\$ 2,019,227
2016	\$ 2,656,361
2017	\$ 2,604,173
Total	\$20,827,492

While many of our members are well acquainted with the impact of our services because they use them directly, fewer are likely to know the impact of the almost \$14 million the IWMF has committed to funding 45 WM research projects. IWMF-funded research has enhanced our understanding

Twenty Years of Giving, cont. on page 19

RESEARCH PARTNERS

For a commitment of \$50,000 per year for a minimum of two years, or a lump sum of \$100,000 or more, you can become a Research Partner supporting a specific IWmf research project approved by our Scientific Advisory and Research Committees. Research Partners will have an opportunity to be kept informed of the progress of the research project and will be formally acknowledged by the investigators in their report of the project as well as in any resulting publications. We generally have 4 to 6 research projects underway with new projects under consideration throughout the year.

David and Janet Bingham Research Partners Fund of the IWmf

Elting Family Research Partners Fund of the IWmf

Robert Douglas Hawkins Research Partners Fund of the IWmf

Michael and Rosalie Larsen Research Partners Fund of the IWmf

Carolyn K. Morris Research Partners Fund of the IWmf

K. Edward Jacobi Research Partners Fund of the IWmf

Marcia Wierda Memorial Research Partners Fund of the IWmf

NAMED GIFT FUNDS

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

Baker Family Research Fund of the IWmf

Yoshiko Button Member Services Fund and Research Fund of the IWmf

Friedlander-Scherer Family Research Fund of the IWmf

Dr. Morie A. Gertz Research Fund of the IWmf

Gary Green Research Fund of the IWmf

Dr. Robert Kyle Research Fund of the IWmf

Lynn Martin and Carrie Wells Research Fund of the IWmf

Dennis and Gail Mathisen Research Fund of the IWmf

Gail Murdough Member Services Fund and Research Fund of the IWmf

Sesnowitz Family Research Fund of the IWmf

Donald and Kathryn Wolgemuth Research Fund of the IWmf

If you have discretionary giving power and would like to help move our research program forward in a special way we invite you to join those listed above. For more information about Research Partners and Named Gift Fund opportunities and potential gifting options that might make that possible, please contact Dave Benson, IWmf Senior Development Officer, at (952) 837-9980 or dbenson@iwmf.com

of the biology of WM, improving our knowledge of (a) the mutations, and their genetic basis, found in WM patients, (b) signaling pathways that allow WM cells to survive, and (c) the bone marrow and tumor microenvironment that support cell growth and drug resistance. To see important research projects currently underway, please visit:

<https://www.iwmf.com/research/current-research-recipient>.

To see the results of past research projects please visit:

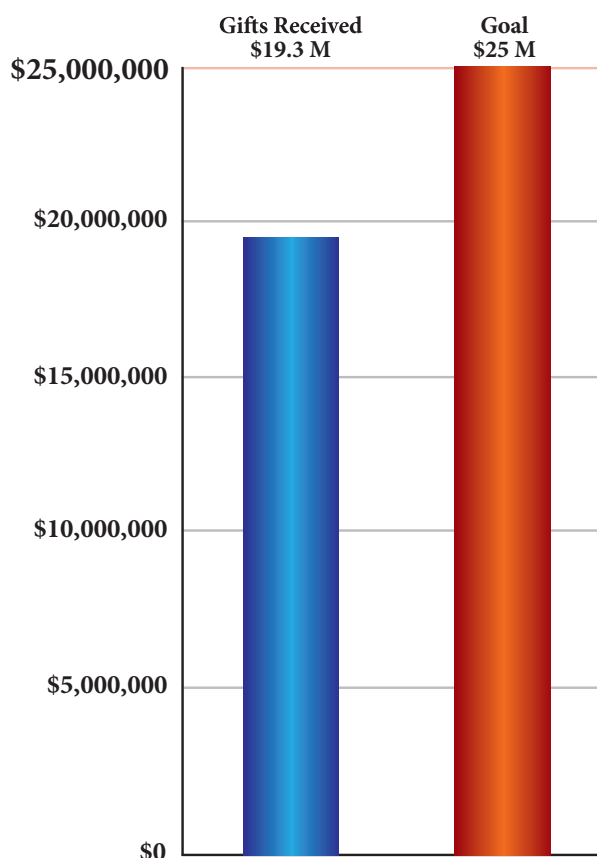
<https://www.iwmf.com/research/past-research-recipient>.

In 1998 there were only four treatments for WM, and mean survival was 3-5 years. Today there are more than 30 treatment options, and mean survival is 12-16 years. Research has made a huge difference in both the length and quality of our lives. But we are not yet where we need to be.

Ibrutinib, considered by many a wonder drug for the treatment of WM, does not work for everyone. Readers of IWMF Connect know that some patients, for whom the drug may be effective, cannot tolerate its side effects. We need to continue to support research that will lead to better treatments, with fewer and less severe side effects—research that will eventually lead to a cure. This is why we developed, together with the Leukemia & Lymphoma Society (LLS), the Strategic Research Roadmap. It will continue to guide our research funding to those areas most likely to get us to the finish line.

How does the Roadmap work? Each year a number of the best WM researchers participate in a meeting sponsored jointly by the LLS and the IWMF to review progress-to-date and decide on the most important areas that need to be addressed. The IWMF then issues a Request for Proposals (RFP) that is posted on our website and sent to the best researchers around the world. The chair of our Scientific Advisory Committee, Stephen Ansell, MD, PhD, of Mayo Clinic, convenes a review group of international researchers who are qualified to evaluate the proposals received. This review process mimics that used by the National Institutes of Health (NIH) to evaluate proposals for NIH funding. The results of the review

Imagine a Cure Campaign Progress Report as of August 31, 2018



process are sent to the IWMF Board of Trustees for approval of as many well-ranked projects as funding will allow. The more projects we fund, the more progress is made.

We need your sustained support if we are to continue to progress toward a cure. Please use the attached donation envelope, or go to:

<https://www.iwmf.com/how-you-can-help/support-member-services-and-research> to make an online donation.

MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF TRUSTEE AND RESEARCH COMMITTEE MEMBER

FDA Approves Ibrutinib and Rituximab Combination Therapy for WM – AbbVie announced that the US Food and Drug Administration (FDA) has approved the combination of ibrutinib (Imbruvica) plus rituximab (Rituxan) for the treatment of WM. This represents the only chemotherapy-free combination treatment specifically indicated for the disease. The approval was granted because of results from the Phase III iNNOVATE clinical trial of 150 relapsed/refractory

and treatment naïve WM patients, reported during the 2018 American Society of Clinical Oncology (ASCO) Annual Meeting and published in the *New England Journal of Medicine*. At 30 months, the progression-free survival rate for the combination arm was 82% versus 28% for the rituximab plus placebo arm. The most common adverse reactions were

Medical News Roundup, cont. on page 20

bruising, musculoskeletal pain, hemorrhage, diarrhea, rash, arthralgia (joint pain), nausea, and hypertension (high blood pressure). In this trial, ibrutinib was dosed continuously at 420 mg daily until disease progression or unacceptable toxicity, and intravenous rituximab was dosed at 375 mg/m² once weekly for four consecutive weeks, followed after a three-month interval by a second four-weekly rituximab course. Ibrutinib was administered prior to rituximab when dosed on the same day.

Zanubrutinib Granted Fast Track Designation for WM by the FDA – BeiGene, Ltd. announced that its BTK inhibitor zanubrutinib (BGB-3111) has been granted Fast Track designation by the US Food and Drug Administration (FDA) for the treatment of patients with WM. In the first half of 2019, BeiGene is preparing to submit a New Drug Application to pursue accelerated approval of the drug based on data from its Phase I study in WM (see below). The Fast Track program is intended to expedite or facilitate the process for reviewing new drugs that are used to treat a serious or life-threatening disease or condition for which there is no effective treatment.

Phase I Trial Results Reported for Zanubrutinib in WM – Results from the Phase I trial of the BTK inhibitor zanubrutinib mentioned above were presented during the 23rd Congress of the European Hematology Association in June. The trial, conducted in Australia, New Zealand, the US, Italy, and South Korea, enrolled 67 WM patients, of whom 51 were evaluable for efficacy (12 treatment naïve and 39 relapsed/refractory). The overall response rate was 92%, with a major response rate of 80%. The 12-month progression-free survival was estimated at 91% and median time to response was 88 days. While the presence of the MYD88 L265P mutation appeared to be associated with depth of response, significant activity was also observed in patients with wild-type MYD88. Atrial fibrillation was experienced by 6% of patients. The most frequent adverse events were bruising and bleeding under the skin, upper respiratory tract infections, constipation, and diarrhea. A Phase III trial comparing zanubrutinib to ibrutinib in WM patients has completed enrollment.

Update Presented on Phase II Trial of Venetoclax in Relapsed/Refractory WM – An update on the Phase II clinical trial of venetoclax in 30 relapsed/refractory WM patients was presented by Dana-Farber Cancer Institute during the 23rd Congress of the European Hematology Association. Treatment protocol was initially 200 mg daily on days 1-7, then ramped up to 400 mg daily on days 8-14 and 800 mg daily thereafter. The MYD88 L265P mutation was detected in all patients, and CXCR4 mutations in 53%. At six months, median serum IgM declined from 3,563 mg/dL to 1,640 mg/dL, median bone marrow involvement declined from 35% to 5%, and median hemoglobin increased from 10.6 g/dL to 12.6 g/dL. The overall response rate was 80%, and the major response rate was 53%; the major response rate was not statistically

different based on prior BTK inhibitor exposure or CXCR4 mutation status. Adverse effects included neutropenia (low neutrophil count), anemia, back pain, constipation, diarrhea, headache, upper respiratory infections, nausea, and rash. There was one incidence of laboratory tumor lysis syndrome, but no clinical symptoms of the syndrome occurred. There were no instances of IgM flare.

Phase II Trial of Acalabrutinib for WM Reported at ASCO Annual Meeting – The Phase II study of the BTK inhibitor acalabrutinib for both treatment naïve and relapsed/refractory WM was reported during the 2018 ASCO Annual Meeting in June. Acalabrutinib achieved an overall response rate in excess of 90% and a major response rate of approximately 80%. At two years, progression-free survival was 90% in treatment naïve patients and 82% in relapsed/refractory patients. Of the 106 patients, atrial fibrillation occurred in approximately 5%, and hypertension (high blood pressure) in approximately 3%. Bleeding events were reported in over 50% of patients, although no patient discontinued treatment due to a bleeding episode. The most commonly reported side effect was headache.

Results Reported for Ibrutinib in Front-Line Therapy for WM Patients – The *Journal of Clinical Oncology* published information from a study of ibrutinib (Imbruvica) in 30 symptomatic, treatment naïve WM patients conducted at Dana-Farber Cancer Institute. All patients were assessed for MYD88 and CXCR4 mutation status—100% had the MYD88 mutation, and 47% carried a mutation in CXCR4. After treatment, median serum IgM declined from 4,370 mg/dL to 1,513 mg/dL, bone marrow involvement declined from 65% to 20%, and hemoglobin rose from 10.3 g/dL to 13.9 g/dL. Overall and major response rates for all patients were 100% and 83%, respectively. Rates of major and very good partial responses were higher and time to major responses more rapid in patients with wild-type CXCR4 versus those with CXCR4 mutations. With a median follow-up of 14.6 months, two patients, both with CXCR4 mutations, progressed. The 18-month, estimated progression-free survival was 92%. Treatment-related toxicities included joint pain, bruising, neutropenia (low neutrophil count), upper respiratory tract infections, urinary tract infections, atrial fibrillation, and hypertension (high blood pressure).

Multicenter Study Looks at Front-Line Treatment and Outcomes in European WM Patients – A multicenter study on behalf of the European Consortium for Waldenstrom's Macroglobulinemia, published in *Lancet Haematology*, looked at treatment and outcomes in European patients with WM. Physicians in ten countries submitted electronic medical records for review and analysis of 454 WM patients who received front-line treatment after January 1, 2000, and before January 1, 2014. The most frequent reasons for treatment were anemia (72% of patients) and constitutional symptoms such as

recurrent fevers, night sweats, weight loss, and fatigue (58% of patients). In the front-line setting, 43% of patients received single agent therapy (most commonly chlorambucil), 36% received a combination of chemotherapy and immunotherapy (most commonly R-CHOP), and 21% received other combination regimens (most commonly bortezomib and rituximab). After front-line treatment, median progression-free survival was 29 months and ten-year overall survival was 69%. Progression-free survival was shortened in patients treated with single agent therapy compared to those treated with a combination therapy. Constitutional symptoms (excluding fatigue) were associated with worsened overall survival.

Phase IIa Trial Results Reported for Cerdulatinib in Lymphoma – Results of a multi-center Phase IIa study to confirm the safety and efficacy of cerdulatinib were presented during the 2018 ASCO Annual Meeting. The drug is an oral inhibitor of the kinases SYK, JAK1, JAK3, and TYK2. Of the 99 patients enrolled with relapsed/refractory B- and T-cell lymphomas, four had WM. Responses typically occurred after two cycles of treatment, and partial responses of more than seven months were achieved with the WM patients who had previously relapsed on BTK inhibitor therapy. The most common adverse events were diarrhea, fatigue, and nausea. The study is still accruing patients, and the trial identifier number on www.clinicaltrials.gov is NCT01994382.

Mayo Clinic Discusses Predictors for Progression of Smoldering WM – A study presented at the 2018 ASCO Annual Meeting by Mayo Clinic discussed predictors of disease progression in patients with smoldering WM (SWM). Patients with WM seen at Mayo Clinic from 1996-2013 were included, and time-to-progression was defined as the interval from diagnosis of SWM to initiation of WM-directed therapy or development of light chain amyloidosis or transformation to more aggressive lymphoma. Of 823 patients with WM, 143 were characterized with smoldering disease. After a median follow-up of 9.5 years, 110 patients progressed, approximately half within five years of diagnosis. Of these patients, 107 required therapy for WM and three developed amyloidosis. The most significant predictors of shorter time-to-progression at diagnosis were hemoglobin equal to or less than 12.3 g/dL and beta-2 microglobulin equal to or greater than 2.7 micrograms/mL.

Phase II Trial in the UK to Investigate Rituximab and Pembrolizumab in Relapsed/Refractory WM – University College London anticipates opening a Phase II clinical trial in October 2018 to investigate the safety and efficacy of rituximab (Rituxan) plus pembrolizumab (Keytruda) in relapsed/refractory WM. Enrollment is estimated at 42 participants, and the trial identifier number on www.clinicaltrials.gov is NCT03630042. Pembrolizumab is an immunotherapy drug that targets PD-1 and is administered intravenously.

Phase II Study in Europe to Open for Combination of Bortezomib, Rituximab, and Ibrutinib as First-Line Therapy for WM Patients – A Phase II trial conducted under the auspices of the European Consortium for Waldenstrom's Macroglobulinemia will look at the efficacy of combination bortezomib (Velcade), rituximab (Rituxan), and ibrutinib (Imbruvica) for first-line treatment of WM patients. The trial will enroll 53 participants and is anticipated to begin in November 2018. The trial identifier number on www.clinicaltrials.gov is NCT03620903.

Pacritinib Clinical Trial Began Enrollment in September – At press time, the University of Michigan Rogel Cancer Center was planning to start a Phase I clinical trial in September of pacritinib for several lymphoproliferative disorders, including WM/LPL. The study will enroll 26 relapsed/refractory participants who will be dosed at 200 mg twice daily. Pacritinib is an oral inhibitor of Janus kinase 2 (JAK2). The trial identifier number on www.clinicaltrials.gov is NCT03601819.

TG Therapeutics Announces Phase II Data for Umbralisib in Relapsed/Refractory CLL – TG Therapeutics, Inc. announced data at the 2018 ASCO Annual Meeting from its Phase II study evaluating umbralisib (TGR-1202), a PI3K delta inhibitor, in patients with relapsed/refractory chronic lymphocytic leukemia who were intolerant to BTK inhibitors or other PI3K delta inhibitors. Umbralisib demonstrated a favorable safety profile in these patients, and only 13% discontinued treatment due to an adverse event. Median progression-free survival had not been reached at a median follow-up of 9.5 months. A Phase II trial of umbralisib in relapsed/refractory WM and marginal zone lymphoma is currently recruiting patients, and its trial identifier number on www.clinicaltrials.gov is NCT03364231.

Cancer Survivors with Chronic Fatigue May Benefit from Bright Light Therapy – A study from the Northwestern University Feinberg School of Medicine in Chicago suggested that cancer survivors who suffer from chronic fatigue may sleep better when they wake up to bright white light. For the month-long study, 44 cancer survivors were randomized to receive light box therapy every morning for 30 minutes with either bright white light or dim red light. Following treatment, 86% of people exposed to bright white light showed improvements in sleep quality, total sleep time, and wake time, while 79% of people exposed to dim light still had poor sleep quality. It was theorized that bright white light helps cancer survivors reset their internal clocks, or circadian rhythms, so that they can more easily rest at night and wake during the day. Participants in the study had blood malignancies, breast tumors, and gynecological cancers. When researchers checked back with participants three weeks after stopping light therapy, improvements in sleep quality associated with bright white light had disappeared.

suggesting that ongoing therapy may be need for sustained improvement in sleep. The study was published in the *Journal of Clinical Sleep Medicine*.

Risk Factors Discussed for Development of Atrial Fibrillation on Ibrutinib Therapy – Northwestern University researchers discussed the risk factors for developing atrial fibrillation (AF) while on ibrutinib therapy during the 2018 ASCO Annual Meeting. Patient charts were retrospectively reviewed to include patients treated with ibrutinib for any indication between July 2012 and July 2016. Those with existing AF were excluded. Of the 168 patients included, 13.1% had WM. In all patients, the incidence of AF was 11.9% after a median of 153 days of treatment. The incidence of AF on ibrutinib was higher in older patients and in patients with coronary artery disease, heart failure, and moderate/severe mitral regurgitation. The authors suggested that patients with these risk factors should be counseled on the risk of AF and monitored closely. An echocardiogram to evaluate for structural heart disease prior to initiating ibrutinib therapy should be considered.

Cleveland Clinic Study Looks at Management of Atrial Fibrillation in Patients on Ibrutinib – The Cleveland Clinic retrospectively looked at the management of atrial fibrillation (AF) in patients on ibrutinib (Imbruvica) and reported its results in the open access journal *Cureus*. These researchers studied the records of Cleveland Clinic patients over a three-year period from February 2014 to February 2017, identifying 43 patients during that period who started ibrutinib therapy. Of these, ten had AF prior to treatment, and four developed AF while on ibrutinib. From their study of the various ways in which AF was managed in these patients, the researchers concluded that ibrutinib could be safely given in the presence of AF and that beta blockers were the preferred agents for heart rate control because ibrutinib has interactions with many other rate and rhythm control agents. When AF was uncontrolled, ibrutinib was temporarily held and then cautiously restarted. Due to the small study population, the researchers were unable to determine whether interventions such as cardioversion or ablation would be helpful.

Biosimilars Approved by FDA for Neulasta and Neupogen – Two biosimilar products for the treatment of neutropenia (low neutrophil count) caused by chemotherapy have been approved by the US Food and Drug Administration (FDA). They are Fulphila, a biosimilar for Neulasta (pegfilgrastim), and Nivestym, a biosimilar for Neupogen (filgrastim). A biosimilar is an almost identical equivalent to an original biologic product that is manufactured by a different company. It is an officially approved version of the original “innovator” product and can be manufactured when the original product’s patent expires. List prices for biosimilars have generally been lower than those for the original drugs, although not dramatically so.

Obinutuzumab and Bendamustine Combination Compared to Bendamustine Alone in Rituximab-Refractory Indolent NHL – The *Journal of Clinical Oncology* published an updated analysis of the Phase III GADOLIN study of obinutuzumab (GA101) and bendamustine in 413 patients with rituximab-refractory indolent non-Hodgkin’s lymphoma. One WM patient was included in this study, in which patients received treatment with either obinutuzumab and bendamustine or bendamustine alone. Patients who did not progress after treatment received maintenance obinutuzumab for up to two years. Progression-free survival and overall survival were prolonged in patients treated with the combination, compared to solo bendamustine. Adverse events included neutropenia (low neutrophil count), thrombocytopenia (low platelet count), anemia, and infusion-related reactions.

Venetoclax Approved by FDA for Relapsed CLL/SLL Patients with or without a 17p Gene Deletion – Venetoclax (Venclexta) has been approved by the US Food and Drug Administration (FDA) for the treatment of patients with chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL), with or without a 17p gene deletion, who have received at least one prior therapy. The drug had previously been approved in 2016 only for relapsed/refractory CLL/SLL patients with the deletion. This expanded approval was based on the Phase III MURANO clinical trial of 389 patients who received venetoclax in combination with rituximab (Rituxan). The trial compared venetoclax/rituximab to bendamustine/rituximab in CLL patients who had received at least one prior line of therapy. The overall response rate was 92% in the venetoclax/rituximab arm, and progression-free survival was not reached at 23 months of follow-up; the bendamustine/rituximab arm had an overall response rate of 72% and a progression-free survival of 18.1 months.

Early Phase II Results Released for Ibrutinib and Venetoclax Combination in Previously Untreated CLL/SLL – Meanwhile, early Phase II CAPTIVATE trial results were announced at the 2018 ASCO Annual Meeting for the combination of ibrutinib (Imbruvica) and venetoclax (Venclexta) in previously untreated patients with chronic lymphocytic leukemia/small lymphocytic lymphoma. After six cycles of the combination, 77% of the first 30 patients achieved responses with no detectable minimal residual disease (MRD). Of the first 14 patients to complete the combination for 12 cycles, approximately 90% achieved responses with no detectable MRD. In this study, patients received single agent ibrutinib for three 28-day cycles before initiating venetoclax with dosage ramp-up to 400 mg daily. The trial is designed to evaluate if remission with undetectable minimal residual disease can provide these patients a “treatment holiday”—a period of time when they

can stop therapy. The most common adverse effects were diarrhea, fatigue, nausea, headache, upper respiratory tract infections, and arthralgia (joint pain).

Combination of Venetoclax, Bendamustine, and Rituximab Studied in Phase I Trial of Relapsed/Refractory NHL –

The combination of venetoclax (Venclexta), bendamustine, and rituximab (Rituxan) was tolerable and produced long-lasting responses in patients with relapsed or refractory non-Hodgkin's lymphoma (NHL), according to results from a Phase I trial published in *Annals of Oncology*. The multicenter dose-escalation trial enrolled 60 patients with follicular lymphoma, diffuse large B-cell lymphoma, and marginal zone lymphoma. The overall response rate for all patients

was 65%, with a median duration of response of 38.3 months and a median progression-free survival of 10.7 months. The most prevalent side effects were nausea, neutropenia (low neutrophil count), diarrhea, and thrombocytopenia (low platelet count). The recommended dose of venetoclax was established at 800 mg daily.

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.

YOU CAN LIMIT DEATH'S FINANCIAL COSTS, IF NOT THE EMOTIONAL ONES

BY WARREN KOZAK



*The author's late wife, Dr. Lisa Jane Krenzel
Photo courtesy of Warren Kozak*

*Dr. Lisa Jane Krenzel was a New York internist for 30 years. She was diagnosed with WM in January 2014 at the age of 56. Dr. Krenzel became an active member of support groups and the IWMF, offering medical advice to other patients, even when she was dealing with her own illness. In 2016, she was diagnosed with amyloidosis and she passed away on January 1, 2018 leaving her husband, Warren Kozak, and their 19 year old daughter, Claire. Four months after Dr. Krenzel's death, her husband, a journalist and author, wrote this informative OpEd in the print edition of the April 28, 2018 **Wall Street Journal** to help others dealing with loss.*

THE TRANSFER OF ASSETS WHEN A SPOUSE DIES CAN BE FAIRLY SIMPLE—IF YOU LEARN FROM MY MISTAKES.

I pride myself on keeping meticulous financial records. But since my wife died on January 1, I discovered I had made some real rookie mistakes that led to hours of extra work and substantial fees. The transfer of assets between spouses can be fairly simple—if you learn from my mistakes.

Dr. Lisa Jane Krenzel and I shared everything throughout our marriage. Like many couples, we split responsibilities. I paid the bills and made investments. She took care of our health insurance, plus the house. We maintained individual checking and savings accounts, as well as separate retirement accounts from various jobs throughout our careers. What went wrong?

- **Issue One:** When we opened those checking and savings accounts, we never named beneficiaries. I had assumed, incorrectly, that our accounts would simply transfer to the other in case of death. The banker who opened the accounts never suggested otherwise. With a named beneficiary, her accounts would have simply been folded into mine. Instead, I had to hire a lawyer—at \$465 an hour—to petition the court to name me as the executor of her estate. I needed this power to transfer her accounts. Filing cost in New York City for the necessary document was \$1,286. The running bill for the lawyer stands at \$7,402.00, and I expect it to rise. I also needed the documents for the companies that managed her

You Can Limit, cont. on page 24

retirement accounts and a mutual fund, because, as at the bank, we never named a beneficiary. By the way, this paperwork also required signature guarantees or a notary seal, which can take up an afternoon.

- **Issue Two:** The highly charged question of funeral and burial. Last summer, when I was told Lisa would not survive this illness, I tried to raise the issue of burial with her. She refused to have the conversation, but I quietly went ahead and purchased a plot of graves in the cemetery in Wisconsin where my parents, grandparents and great-grandparents are buried. This was something I actually did right.

We had to employ two funeral homes—one in New York and one in Wisconsin—and her body had to make the journey out there. All told, I spent \$46,359 to cover funeral expenses, graves, transportation, a headstone, and a basic casket.

I noticed something interesting in this process. All of my fellow baby boomer friends I have since asked have so far refused to deal with the issue. They wince when I even raise the question. Hear me: You don't want to have to make this decision at the time someone close to you dies. You simply are not thinking straight.

- **Issue Three:** Our health insurance plan covered the long hospital stays and doctors' visits. However, shortly after Lisa died, I still received bills, even though our deductibles and co-pays had long since been covered. I paid them immediately, which was a mistake. I was incorrectly billed and I have been fighting the hospitals and insurance company since January to get a refund, even though everyone agrees the bills were incorrect.

Before you pay any medical bills, make a simple call and determine their legitimacy. Mistakes are constant: The systems are so complicated, even people in these offices don't always understand the intricacies.

- **Issue Four:** Lisa had two life-insurance policies—one through her work and the other we purchased privately. The former was handled quickly and efficiently by her job and a check arrived almost immediately. Although the insurance company sent me a check for her private policy soon after her death, it took three months of constant calls and emails to determine a refund of the premium I had already paid for three months past her death. I kept getting wrong information from the company, because the people I dealt with didn't understand it themselves.
- **Issue Five:** Over the course of Lisa's working life—from her first job at a fast-food restaurant to medicine—she paid more than \$100,000 to Social Security. Since she died at 60, and our 19-year-old daughter is one year past the age of receiving a monthly benefit, all this money has simply disappeared into the lockbox in Washington. Nothing you can do about this one.

Finally, there is the major psychological trauma of grief. I think most people believe death will never intrude on their lives and when it does, we will be so old and decrepit that it won't much matter. Trust me on this—even when it's been expected for a while, it still shocks deeply. There is absolutely no way you can prepare yourself for the shattering heartbreak of loss. When it did come to me, I found the support of friends, family and faith to be invaluable. Amazingly, that cost nothing.

COOKS' HAPPY HOUR

BY PENNI WISNER

Theme and Variations: Ratatouille

A friend and I cook with some regularity for a weekly group of volunteers at our sports club at Aquatic Park in San Francisco. While we make dinner in the cookshack, they maintain our fleet of old, wooden rowboats.

On the night that inspired this column, my pal had made a big potful of ratatouille. We cook vegetarian meals with meat or



fish as a side dish for those who cannot do without. But this night, we bulked up the ratatouille with extra protein in the form of beans and pasta and did not worry about providing any meat.

And that is the beauty of a dish like ratatouille, which is really just a vegetable stew from Provence. It includes a list of vegetables you could easily guess: tomatoes, onion, eggplant, zucchini, sweet bell peppers, garlic, and herbs. You could stop reading here and just go into the kitchen and make it now. I've told you just about everything you need to know.

But hang in here with me for a minute. Perhaps you want more specifics: How much of each? Which herbs? How are

Cooks' Happy Hour, cont. on page 25

the vegetables prepared? How long to cook the dish? Here's the thing. If you need hard and fast rules, prepare to be frustrated. Because of the simplicity of the ingredients and our year-round food supply, you can make ratatouille in any season, but, I think, it may be best when the abundance of vegetables in farmers markets peaks in late summer and fall.

Begin with equal amounts of tomatoes, eggplant, and zucchini. If you use canned tomatoes, you won't need to peel them. Or, if you cook garden-ripe tomatoes separately and whirl them in a blender so the skins disintegrate, you won't have to peel them. Do you see what I mean about there being no rules? Think of onions, peppers, garlic, and herbs as seasonings so you can adjust these to taste. The more onions, the sweeter the dish. The classic recipe calls for green bell peppers. But I don't like them much, so I use red bell peppers.

If you are a lazy cook like me, you will (maybe) peel the eggplant. Then, once all the vegetables are chopped into approximately the same size pieces, you will toss everything into the pot with olive oil to cook at a slow simmer on top of the stove or in a slow oven until everything has melted into a fragrant, rich stew.

But there is another school of thought. If you attend that school, the vegetables will be cooked separately, each until lightly browned, and then combined to cook together to allow the flavors to meld. In this second case, peel the eggplant and slice it into rounds about ½-inch thick. Salt them and leave them in a colander to drain while you prepare the rest of the ingredients. Cut the zucchini into ½-inch cubes. You can salt it, too, if you want. I've been using my garden zucchini which is an Italian, meaty variety with less water than the common, smooth-skinned green zucchini. It does not (in my opinion, anyway!) need salting.

Slice your onions (half as much by weight as eggplant) very thinly or roughly chop them. Cook them in olive oil in a large pot over medium heat until very soft. It's fine with me if they get a little brown around the edges but that is not part of the "formal" recipe. Add a bay leaf or two and whole, peeled garlic cloves while the onions are cooking. The number depends on how much you like garlic and how many vegetables you are cooking. If you must chop your garlic, please do, but the dish will cook for long enough that the sweet garlic flavor of whole cloves will permeate the entire stew. And anyone who loves garlic will be delighted to mash a whole clove onto their bread during dinner.

Cut your red (or green!) peppers into ½-inch cubes. Rinse your salted vegetables and spread them on a clean kitchen towel. Cover with another towel and press down firmly to squeeze out moisture. Scrape your onions into a large bowl, add more oil to the pan and start cooking the eggplant, in batches if necessary, until lightly browned. As it is cooked, add it to the onions in the bowl. Repeat with the zucchini and peppers.

Now for the tomatoes. If you peel them, chop them and put them in a large pot with all the vegetables, place over medium heat, bring to a simmer, and cook for about 20 minutes. Make sure to stir well every few minutes so the stew does not scorch.

If you don't peel the tomatoes, cut them in half, squeeze out the juice sacs and seeds into a strainer suspended over a bowl. Cook the tomatoes, cut side down, in the skillet in more olive oil until browned. Remove to a cutting board and chop them fine. Meanwhile, cook the juices at a simmer until thick. Add the tomatoes and reduced juices to the large pot with the rest of the cooked vegetables, and cook as above.

As for herbs, add them to the pot when you are cooking all the vegetables together. You can stay as simple as adding a handful of finely chopped, flat-leaf parsley. Or add oregano, marjoram, and thyme. Right now in California, fennel flowers are in full bloom. A scattering of golden fennel pollen would be a pretty and delicious addition right before serving. And no, the pollen is not just an affectation. You, too, can buy it in tins if you do not collect your own. I did that once. Just once. Taste the ratatouille and adjust with salt and pepper. If you have salted the eggplant or the zucchini, you may not need much. Add a few spoonfuls of water or wine if the dish threatens to scorch. If you can, make the ratatouille a day or so ahead of time. The flavor develops even more with a little age. (Hmmm, age is becoming a potentially sore subject as I have just hit a big number.)

Here are some variations: add a couple of anchovies to the onions, letting them melt into the mass as the onions cook. Add halved, pitted black olives to the stew for the last few minutes of cooking so their flavor permeates the dish. Add cooked white beans as we did, including the bean cooking liquid (or the liquid from the can, tasting first!). You could cook pasta, such as penne, and add it to the ratatouille. If you like spice (yes, please), add a dried hot chile, chile flakes, a pinch of cayenne, or perhaps hot, smoked paprika. You might also pass a small dish of Aleppo pepper at table. While we are talking about additions at table, think about grated parmesan or pecorino and perhaps a dish of pesto.

If you cut your vegetables very small, then you can pile the stew on croutons as an appetizer or first course. To serve the ratatouille cold, as a luncheon salad, add splashes of red wine vinegar or balsamic. To turn ratatouille into a brunch dish, bring it to a simmer in a large skillet, make hollows in the surface of the stew and crack an egg into each. Cover the pan and simmer gently a few minutes until the eggs have set. You might recognize this variation as a close relative of the Middle Eastern shakshuka. It has different spicing (such as cumin and preserved lemon) and more sweet red peppers. In whatever guise you serve your ratatouille, make sure to include crusty bread.

Our motto: Eat Well to Stay Well

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

Please note!

Contact information for all support groups is found on www.iwmf.com under GET SUPPORT. Details of support group meetings and other upcoming events are posted under EVENTS. Please check there to confirm details of future events.



San Diego Support Group at University of California San Diego Moores Cancer Center with Dr. Caitlin Costello, center, in white coat

CALIFORNIA

San Diego Area

The San Diego Area Support Group in March welcomed Caitlin Costello, MD, assistant professor of medicine, Blood and Marrow Transplantation Program, University of California San Diego Moores Cancer Center. Dr. Costello's presentation, "Waldenstrom's and Me," was appreciated by all 25 members in attendance, from a newly diagnosed member to one who was diagnosed in 1994. Following the presentation there was time to meet and greet and share some snacks.

In June, 18 members of the group met to hear speaker Marin Xavier, MD, hematologist-oncologist at Scripps Mercy Hospital and Scripps Mercy Cancer Center. His very informative presentation, "Novel Ibrutinib Combinations: Lessons Learned from the CLL Studies," gave the group additional optimism because the FDA has approved venetoclax for other blood cancers. There was also plenty of time for questions, socializing, sharing of stories, and refreshments.

CONNECTICUT

The primary focus of the May meeting at the Westport library was to discuss each patient's personal WM situation, including medical and alternative therapies being used or contemplated. This resulted in a very lively and informative discussion among the 20 or so members and filled the entire

meeting duration. Several patients in attendance were newly diagnosed and new to these support group meetings. It seemed that they, in particular, learned a lot and appreciated hearing each person's very individual story. After the meeting, some of the participants reconvened at a local restaurant for dinner to continue discussions and get to know each other better. All in all, it was a very productive day. The fall meeting is planned as a lunch on Saturday, November 10, at a conference room at the Westfarms Mall in Farmington, CT. More information regarding this meeting will be forthcoming in October.

FLORIDA

Southwest Florida

The Leukemia & Lymphoma Society provided refreshments and lunch for the summer meeting of the South Florida Support Group. It took place in the new multi-media auditorium that had just opened at Memorial Hospital West, home to the group's meetings for the past 12 years. An LLS intern first provided information about LLS support programs, and the group then watched Dr. Morie Gertz's May 2018 IWMF Ed Forum presentation on "Unusual Conditions in WM." After a lunch break, Dr. Daren Grosman of Memorial led a lively Q&A session.



Cheryl and Steve Wyatt with baby granddaughter Elizabeth at the Chicago area meeting

ILLINOIS

Chicago Area/SE Wisconsin

The Chicago Area Support Group, including SE Wisconsin, celebrated its tenth annual summer event during a gathering with hors d'oeuvres and beverages at the home of Don and Mary Brown on Saturday, August 25. It was the first time Don and Mary have hosted the event. Don shared his recent experience with Dr. Ansell at Mayo Clinic in Rochester, MN.

Support Group News, cont. on page 27



Don Brown, daughter Melissa, grandson Charlie, and 2012 Chicago WM Marathon Runner Ryan Schofield

Many others shared key WM experiences, including six first timers. Thirty of the 36 who had planned to attend actually came. Several were unable to attend due to illness/respiratory issues common to WMers. Although the day turned a humid 87 degrees, almost everyone stayed outside enjoying the final days of a sunny summer. During the close of our fellowship, everyone agreed that sharing WM stories is very helpful and comforting. We are not alone, and are thankful for the symphony of medical and spiritual help available to so many of us, especially in major metropolitan areas like Chicago.

We are planning our next educational meeting at Lutheran General Hospital in Park Ridge on Saturday, November 3, at 12:30 p.m. Our guest speaker will be Dr. Janis Atkinson, wife of fellow patient Jeff Atkinson. Janis is vice president medical affairs at Presence Health, Presence Saint Francis Hospital in Evanston. She will give a presentation on pathology and medical testing for WM. We are thankful for the support from both Janis and Jeff. Contact Don Brown at Ldonbrown@msn.com if you have any questions.

INDIANA

June found many Indiana Support Group members on vacation, but an enthusiastic and interested smaller group gathered in Indianapolis to hear Janell Foust discuss household remedies for common side effects such as nausea, loss of appetite, and insomnia. Janell Foust is an herbalist who studied at Dominion Herbal College and is studying for a Doctorate in Natural Healing at Trinity College. She also is a yoga instructor, reiki master, and the owner and founder of Lavender & Roses Herbary and Florals, an herb shop in Richmond, IN. She gave each participant a set of handouts covering her important points. The early fall meeting was a gathering of many as vacations were coming to an end. Sharing of symptoms and treatment helped fortify two new members and provided opportunities for all to catch up with each other. As usual, everyone enjoyed coffee and breakfast snacks.



Indiana Support Group at the Indianapolis LLS office.

The Indiana WM support group met at the LLS office in Indianapolis Saturday, September 22 for group sharing. Twenty one WMers and support people gathered together to discuss symptoms, treatments, and challenges. It was a lively exchange enjoyed by all. It was the first time attendance by one patient and second time for two others. We had five old timers who have been with the group since our first meeting October 29, 2011. There was coffee, juice, bagels, and Snickers on the table. The meeting was enjoyed by all.

MICHIGAN

A large group of 24 gathered on a beautiful day to hear J. Christine Ye, MD, give an excellent review of Waldenstrom's: how it is diagnosed, tests and lab results, and treatment modalities. Dr. Ye is clinical assistant professor at the University of Michigan Comprehensive Cancer Center in the Division of Hematology/Oncology. The group enjoyed light refreshments and peppered Dr. Ye with questions. Several newcomers shared their experiences. The next meeting is planned for early November when the focus will be on sharing WM journeys and learning from each other's experiences.

EASTERN OHIO, WESTERN PENNSYLVANIA, & WEST VIRGINIA

On a beautiful summer afternoon in July, members met at the home of Marcia and Glenn Klepac in Pittsburgh, PA, for an informal meeting and picnic potluck. It was a special treat to have founding co-leaders, Shari Hall (current co-leader) and Bob Shaffrey, present representing the longevity of our group, approximately 21 years! Incredible advances in the understanding and treatment of WM have been made during this period with much hope for further progress. Members shared their WM stories of successes and challenges illustrating the evolution of treatments from more than two decades ago to the present. New treatments on the horizon were discussed, providing more seeds of hope. Following the spirited discussion, participants reconvened to the patio for

sandwiches, salads and desserts, including Shari's flourless blueberry pie with homemade ice cream. The group looks forward to a fall meeting in the Cleveland area.



Oregon/SW Washington Support Group Leaders Joel Rosenblit, Marie Navarro, and Cindy Jordan welcome Dr. Jorge Castillo to Portland.

OREGON/SOUTHWEST WASHINGTON

Earlier this year, Cindy Jordan took over as the area's support group administrator and joins Marie Navarro and Joel Rosenblit as a co-leader. Carol Auger, who was the administrator for many years, appreciated passing the reins (and data files!) to Cindy in January 2018. The job entails keeping track of members' contact information and sending email blasts to the membership, tasks that take minimal time thanks to modern technology. Cindy continues: "My husband and I moved to Eugene, OR, in early 2017 (yes, another California ex-pat) and were pleased to find a thriving support group in Portland. I was diagnosed in 2010 and was on "watch-and-wait" until August 2016, when I underwent six (cyclophosphamide/dexamethasone/rituximab) CDR treatments. Now in remission, I have a caring oncologist here in Eugene who trained under Dr. Kyle. Becoming more involved in this support group has further increased my awareness of how our disease manifests itself so differently in each individual and of the tremendous benefits we receive due to the single-minded disease focus of the IWMF"

The June meeting was a full house of 35 attendees at the Oregon Health & Science Hospital (OHSU) South Waterfront campus in Portland. Presenters included a trio of experts—two from the WM field and one from the field of exercise oncology. Dr. Stephen Spurgeon, OHSU associate professor of medicine, spoke first, followed by Dr. Kerri Winters-Stone, OHSU research professor, and, lastly, by Dr. Jorge Castillo of Dana-Farber Cancer Institute who traveled from Boston for the day. Dr. Spurgeon, who treats many of the group's members, spoke about OHSU's unique classification as a cancer research institute. He also provided an overview of the progression of WM. Dr. Winters-Stone discussed her research into the role exercise plays as a low-cost, accessible, enjoyable

tool that can help a cancer patient heal faster, stronger, and better. Dr. Castillo reviewed guidelines for when to initiate therapy for WM and discussed the latest pharmaceutical developments in blood cancer treatment. All three doctors generously answered questions from our members. The group very much appreciates the assistance received from Dr. Spurgeon's staff and OHSU's event coordinator. Both were instrumental in making the arrangements for presenters and meeting space. At the close, some members took the opportunity to ride the tram up to the main OHSU campus for great views of Portland and beyond.



Susquehanna Valley Support Group July meeting



Susquehanna Valley Support Group – Support is social too.

PENNSYLVANIA

South Central Pennsylvania/ Susquehanna

The July meeting was once again a potluck picnic held at the Brethren Village near Lititz, PA. This meeting is always informal, with both patients and caregivers socializing and discussing treatment results and options in small groups while sharing the wonderful food that members bring. Several of the members have been attending these picnics since the first one held at Nancy and Larry Lambert's home in 2003. We all still miss Nancy's leadership. The next meeting will be the second Sunday in November. Details about the speaker will be announced when confirmed.

Philadelphia

Twenty-four members met on June 3 and celebrated the news that Philadelphia will host the IWMF's 2019 Ed Forum

Support Group News, cont. on page 29



Memphis Support Group members at IWMF Ed Form 2018

from June 7-9, 2019! Group members are already looking forward to introducing their vibrant, fun, and fabulous center city to all their fellow WMers! Three new members joined at this meeting, where they were welcomed by Carl Harrington's wise words: "We fully appreciate that this may not be a club you ever wanted to join, but one we hope you'll come to cherish over time. The very first thing you should know is that you are not alone. The IWMF is always by your side." During introductions of the newbies, several questions and issues came up that led to a most meaningful, moving, and rich exchange. The new members wanted to hear more about three specific topics: 1) How to cope with the normal anxiety arising from living with "watch and wait," 2) How to live a full, joyful, hopeful, and engaged life with a cancer diagnosis lurking in the back of your mind, and 3) Strategies for sharing your diagnosis of WM with family, friends, and work colleagues...or choosing not to share your news. The discussion was extremely informative and helpful, with WMers who have lived with the disease for decades sharing words of wisdom. The conversation continued long past the "official" meeting end time as folks continued to hang out, enjoying chatting in small groups and munching on goodies from the snack table. All refreshments were provided by the wonderful group of "snack volunteer" members who generously bring an assortment of healthy bites to share at each meeting. Priceless!

TENNESSEE

W. Tennessee, E. Arkansas, N. Mississippi

Things have been uneventful over the summer—a good thing when dealing with WM. Group members appear to be stable, whether in treatment, in remission, or still with no treatment. Six were able to attend the IWMF's Educational Forum in Rosemont (Chicago) last May, and as usual, learned a great deal while meeting many fellow patients. Members are already making plans for Philadelphia in 2019!

WASHINGTON STATE

Seattle Area

Fourteen members and caregivers met at the Renton Public Library on the afternoon of Sunday, August 26. The planned program was to watch Dr. Jorge Castillo's presentation on new WM treatments from the Chicago Ed Forum. However, with some relatively newly diagnosed people as well as those who were attending for the first time, we found that we were totally absorbed in each others' stories and never got around to watching the video. It turned out to be a most useful meeting of exchanging experiences, and some even stayed to talk after the main meeting adjourned. We look forward to our yearly Seattle Cancer Care Alliance (SCCA)-sponsored main meeting in Seattle in early November.

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE



Crowded auditorium at the Concord Haematology Clinical Research Symposium, Sydney, Australia

AUSTRALIA

Meetings for WMozzies organised by Leukaemia Foundation of Australia

The Leukaemia Foundation Blood Cancer Conference, held at Melbourne Convention Centre on September 8 with 450 in attendance, had a separate session for WMozzies. Professor Judith Trotman was the keynote speaker for the Waldenström's macroglobulinemia session, which included a question and answer segment.

WhiMSICAL database presentations

WhiMSICAL: Waldenström's Macroglobulinemia Study in CART-WHEEL was presented to an audience of 160 by WMozzies leader Andrew Warden and Dr. Ibrahim Tohidi-Esfahani, WhiMSICAL principal investigator. The presentation was at the Concord Haematology Clinical Research Symposium on August 9 in the Medical Education Centre, University of Sydney, Concord Hospital Campus. Andrew covered his role as a patient investigator, and Ibrahim highlighted



Judith May and Michael visiting Concord Cancer Centre with WhiMSICAL Principal Investigators Professor Judith Trotman and Dr Ibrahim Tohidi-Esfahani, Sydney, Australia

International Scene, cont. on page 31



WhiMSICAL Investigators at Cancer Institute of NSW Innovations Conference, Sydney, Australia

the principal research findings and identified the new developments in the WhiMSICAL study. At the symposium, Professor Judith Trotman also announced the new facilities for the Haematology Clinical Research Unit. This was of particular interest to the WMozzies attending who are in the ibrutinib and BGB-3111 clinical trials at the research unit.

WhiMSICAL: A Global WM Registry for the Patient's Voice was presented at the Cancer Institute of New South Wales 2018 Innovations Conference. The presentation by Andrew Warden was on the importance of the role of patient investigator in the WhiMSICAL study. Andrew spoke of the important part that the IWMF had in the creation of the WhiMSICAL database. In 2006, the late Ron Draftz invited Andrew as international representative on his IWMF patient database team. Other team members were Peter DeNardis, Sue Herms, and Tom Hoffmann. They initiated Andrew in his current role as Australian WhiMSICAL patient investigator. The other WhiMSICAL IWMF patient investigators are Peter DeNardis, Carl Harrington, and Elena Malunis. The importance of the patient voice in WhiMSICAL was highlighted. Professor Christian Buske, European Consortium WM coordinator, said about WhiMSICAL: "patient voice, your experience... data provides the patient voice so instrumental in informing and driving medical research to focus on the priorities of patients."

IWMF affiliation with WMozzies

As the IWMF celebrates its 20th anniversary of incorporation, WMozzies celebrates its long affiliation with the Foundation. Gareth Evans, an Australian member of the IWMF, established WMozzies as an email group in 2003. In 2004, IWMF President Ben Rude announced that the IWMF would organize and fund the first meeting of WM patients in Australia. On Ben's death in early 2005, Judith May became President and confirmed that the IWMF would hold the planned April 2005 meeting in memory of Ben. Sixty-seven people attended the meeting in Sydney to hear the world's top three WM experts, Drs. Morie Gertz, Robert Kyle, and Steven Treon. In October 2015, IWMF President Emerita Judith May visited Sydney and spoke to the Sydney WMozzies support group meeting. She told us how successive IWMF Presidents Smokler, Rude, May, and Harrington's personal passion and energy have been so important to the successful growth of the IWMF. It was an inspiring message. Since then WMozzies' initial membership of 100 has grown to 200, from 10% to 20% of the Australian WM population. WMozzies are greatly indebted to Ben Rude and Judith May in the establishment of WMozzies. The benefits of WMozzies affiliation are greatly appreciated and highly valued by the membership throughout Australia.

Andrew Warden, WMozzies, reporting

International Scene, cont. on page 32



WMUK London Summit at the Royal Society of Medicine on July 1

UNITED KINGDOM

Our London summit at the Royal Society of Medicine on July 1 was well supported with 130 attendees and a wide range of topics, including a potential role for CAR-T therapy in WM from Dr. Claire Roddie of University College Hospital. The UK is setting up six CAR-T centers, and although attention is focused on aggressive lymphomas, progress to wider use seems inevitable. I went to the European Haematology Association meeting in Stockholm as part of the European WM network team and can report that the CAR-T sessions were queuing out of the door. The few WM presentations were also well attended. In London, we collected a further 60 spit tube samples for biobanking for DNA analysis. Thanks to Janssen, BeiGene, and the Binding Site for their support.

At the summit we announced substantial changes to improve our support for patients and clinicians. Will Franks agreed to take over as WMUK Chair, Eric Low, ex-CEO of Myeloma UK, has agreed to join the WMUK board, and I will deal with external links to pharma, government, international, and other charities. We have also appointed Rupinder Bancil to take over daily administration from me and hope to have a new website by the autumn.

The Rory Morrison Registry, under Dr. Joshua Bomszyk, winner of the Rory Morrison 2018 WMUK doctor award presented at the summit, is rapidly expanding. Sixteen

UK centers are now collecting data, and 700 patients are projected to be included soon. As part of our contribution to IWWM10 in New York in October, the Registry will be presenting posters and a detailed first report on findings so far. One further step achieved is gathering patient-reported health input online via automated emailing, probably a first in the UK. Those wishing to sign up should email registry@wmuk.org.uk.

On the treatment front, some 180 patients are now benefiting from ibrutinib, and we finally secured permanent National Health Service (NHS) use of bendamustine + rituximab as first line treatment. We are currently pressing the NHS to try to do the same for relapsed patients and for ibrutinib + rituximab.

Externally, we are working closely with Lymphoma Action and hope to have more breakout WM sessions like the one run by Joshua Bomszyk at their Manchester meeting and with the Blood Cancer Alliance over September's national *Make Blood Cancer Visible* event.

Roger Brown, WMUK, reporting from Cocktail Lounge, The Shard (at 1,106 ft. the highest building in Western Europe)

International Scene, cont. on page 33

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



Dr. Joshua Bomsztyk and Ben Jefferies with spit tubes collected for DNA sampling in London

CANADA

On Sunday, June 10, the Nova Scotia and New Brunswick Support Group held a lunch meeting hosted by Ted and Janet Moore in Truro, Nova Scotia. The semi-annual meeting had 24 patients and caregivers in attendance, including three first-timers. The agenda consisted of a summary of the 2018 IWMF Educational Forum, held in Chicago, from member Paul Kitchen; a presentation on CAR-T therapy

from member Charles Schafer; an update on planning for the upcoming WMFC 2018 Educational Forum, October 27, 2018, in Halifax, Nova Scotia; and the ever popular sharing and discussion of our own individual journeys with WM.

Jim Mason (SG co-leader) and Betty McPhee, WMFC, reporting

BETWEEN JUNE 1, 2018 AND AUGUST 31, 2018, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

Eddy Andersen

Robert Andersen

Gail Arcari

Anonymous
Judith and Harlen Chapman
Marcia Comer
Louise Day Cook
Middlesex County Blue Star
Mothers-CT3
Jean Parker
Joan and Franklin Spector
Bob and Barbara Ulkus

Edward Baer

Cindy Baer

Stephen Beebe

Richard Beebe

Mark Biase

Marcia Biase
Linda, Michael and
Brendan Connors
The DeBartolo Family
Maureen and Jack Donnan
Kate and David Foley
and Wright
Marie Gardyne
Gretchen Romilly
Edward and Carolyn Shea
Nancy and Brian Southworth
Nancy and Mark Traut
Elizabeth and Steven Wayne

Scott Blazek

Peg Bohanon
Earl Nolting
Phyllis Stanchfield

Allan Bosswick

Marcia Bosswick

Will Bridges

Suzanne Bridges

Richard T. Cannone

Richard M. Cannone

Dr. Ira Chidel

Jerry and Harriet Block

Walter Dere

Laura Dere

Elizabeth M. Egan

Bernard A. Egan Foundation

Theodore Evanish

Patricia Franks Evanish

Bradley Fariello

Albert Fariello

Richard Fusco

Janet Fusco

Robert Gerhardy

Louis and Lois Andrews
Larry and Mary Grinstead
A. Patrick McEvoy
Celeste Roberts

Brig Savinder Nath Gulati

Sneh Gulati

John Haverstick

B&F Partners
The St. Ours Family

Tommy Horton

Helen Horton

Dr. Lisa Jane Krenzel

Jo Carole and
Ronald S. Lauder
Jordan and Tom Saunders

Dr. Edward Lerchin

Mary E. Bahnline
Betty Blase
Dr. Henry and Janice Citron
Dr. Alissa Citron and
Dr. Jeffrey Lupovitch
Dr. Matthew and Marcy Citron
Jacqueline S. DeYoung
Brina and Doug Drobnis
Stephen Field
Eleanor and Daniel Fogel
Barbara Fox
Peggy Frank
Carol Gallant
Dorothy Harwood
Dennis and Herma Heyza
Nancy Ackerman and
David Hirsch
Madeline Lan
Ruth M. Lerchin
Joanne Levitan, M.D.
Paul and Lynn Lieberman
Edward and
Jolanta Malinowski
Karen Diane Rosender
Marc Shulman
Daniel and Sherry Stewart
Michal Tamuz
Vicki and Joel Tarnopol
Barbara and David Weiss

Michael Carl Lesmister

Gay Lesmister

William S. McIlrath

Pauline McIlrath

Peyton F. McLamb Jr.

Emily McLamb

Andree Miller

Richard Miller

Boyd Nelson

Helen Steadman

A. Edward Ooghe

Donna Ooghe

Nancy O'Soro

Gregory and Mary Ann Afarian
The Aiello Family
Edward and Janet Annaian
Anonymous
Jack and Janice Azarian
and Family
John and Violet Dagdigan
Joseph and Kathleen DeMita
Mr. and Mrs. Larry Duhamel
James and Millicent Gard
Alan and Cathy Greene
Elizabeth and
Charles Kochakian
Janet O'Soro
Paul and Laurie Ricciardi
William and
Catherine Sutherland
Dina and Jonathan Yorke

Paul the Tent Maker

Stephen Sherman

Gary Peters

Bridget Balbier
David and Nancy Bayless
Ronald R. and
Cathy J. Brogan
Holly Brownnewell
Arlene and Denny Bruderly
Linda S. Buttermore
John and Carol Denny
Michael F. and Linda L. Dillion
Richard and
Constance Franklin
Scott and Christa Garman
The Imoberstegs
Michael and Jane Johnson
Paul W. and Sandra K. Kilmer

Gary Peters (cont.)

Theodore and Holli Majestic
William and
Michele McCallum
Curt and Beverly Mosher
Philip C. Neitz
Mrs. Emma A. Neitz
Frank and Ruth Pickell
Kenneth and Rita Schoeni
Glynn and Cheryl Steinke
The Alliance Elks 467
Monday Morning Golfers
and Old Coots

Mattie Lois Peterson

Margaret Eldridge

Edward Petschl

Linda Petschl

Karen Pindzola

Robert and Alice Katin
J. Ander and Kathy Pindzola

Roselle Poisner

Alan Poisner

Peter A. Rocchio

Anthony Rocchio

Estelle Roodman

Stanford Roodman

Raquel Sanudo

Melvin Goldberg

Mari Ellen Stoddard

Judy Workman

Robert E. Swisher

Nita Patridge Swisher

John Vander Heide

Babbie Cameron

John E. "Jack" Wheeler

Bryan and Mary Gosselin

Marcia Wierda

Paetyn Bentley
Betty Lou Ter Haar

Ron Yee

Robert and Alice Katin

Harold Zfaney

June Zfaney

Jan Zimmerman

Antoinette Zimmerman

BETWEEN JUNE 1, 2018 AND AUGUST 31, 2018, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

Brooke Aiken's Birthday

Kim Aiken
Sharon Beavers
Kimberly Bishop
Marti Brauer
Maryellen Connelly
Maeve Curley
Ms. Brenda Hunt
Sarah Le
Mary Lile
Julie Medlin
Cheryl Nelson

Brooke Aiken's Birthday (cont.)

Casey Novak

All the First-Time Donors Who Responded to My Match Challenge and Those Who Signed Up With AmazonSmile

Edward Goldberg

David Bernier

Tammy Bernier

Lawrence Bonney's Birthday

Eric Bonney
Carole Bonney
Tabitha Bonney Rozeboom
Chris Hopkins
Margaret McCreadie Helton
Rhonda Rosa
Tim Rozeboom

Don and Mary Brown

Jack Tieman
Angelique Draftz

Tom Cardas: Cycling 2 x 200km Challenge

Anonymous
Bonnie Beckett
Maciej Dluzynski
Christopher and
Deirdre Edgerton
Paul Eustace
Rafal Fracz
Carl Harrington
Dara Hogan
Ewelina Jachimowicz

BETWEEN JUNE 1, 2018 AND AUGUST 31, 2018, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

Tom Cardas: Cycling 2 x 200km Challenge (cont.)

Tamara Lewis
Margaret and Tom Mangin
Frank J Manning
David May
Rafal Obora
Grzegorz Pelikan
Miloslav Strecnasky
Slawomir Trebacz
Mr. Clodagh Wheelan

Cheri Chadima

Rachel DeNicola

Ev Ciaston

Annette Ciotola

Lisa Davies' Birthday

Linda Davies
Jennifer Worrell

Joyce Kleinhenn Deaton's Birthday

Thomas Berryman
Roger Hill
Ann Minnette
Patti Nollman
Pamela Powell

Pete DeNardis

Gerri and Michael McDonald

Dr. M. Emran

James Terwoord

James Euzukonis' Birthday

Carin Bennett-Rizzo
Jason Cronin
Jill Da Silva
Nadene Elizabeth
Mr. and Mrs. A. Euzukonis
Jason Euzukonis
Mark Flaherty
Domini Gardner
Chris Gunderson
Nikhil Jain
Cindy Jan
Karen Prime
Laryssa Rod
Erica Roopenian
Trish Steele
The Venzas
Kelly Watts
Tina Woolston

John Finley

Robert and Gloria Sliwinski

Stanley Fisher

Jodi, Brian, Joseph Barlow,
Emily Fisher, Lilly Jane and
Sophie Lynch

Scott Foerster

AT&T

Thomas Fuller

Phyllis Gayle Decker

Dr. Richard Furman

Elena and Gary Malunis

Pat Getz's Birthday

Jerry Bober
Michael Burgan
Teri Caputo
Lois Greenberg
John Hasse
Joan Kessler
Meg Lenzer

Pat Getz's Birthday (cont.)

Paul Schmitt
Jim Terr
Pete White
Karyn Zoldan

Edward Goldberg

Steven Chess
Ms. Sandra Loebmann

Gary Green

Norma and William Green

Olivia Griffin's Birthday

Ann Loomis
Karen Tharpe

David Handelman

Matthew Handelman

Carl Harrington

David and Penny Kirby

Sam Harrington

Maurice and Ruth Levie

Nancy Hess

Joe Brohas

David C. Hill

David Hill, PhD

Jack Honaker

The Fitori Family
Amanda, Drew, Chloe and
Owen Honaker

Roderic Hood

Eleanor Hood

Patricia James' Birthday

Kendra Bagsby
Rosemary Fletcher-Perkins
Beverly Griffin
Gena Hall
Francis Jackson
Larry James
Patricia James
Keisha Kirkpatrick
Beverly Logan
Manuelita Tayao
Angela Van Zandt
Calvin Walker
Pat Wilkerson

Josh Jones' Birthday

Grace Cummin
Josh Jones
Louisa Jones
Katie Kennedy
Lori Passoni

Arnold Kalnitz's Birthday

Shirley Kalnitz
Joanne Kalnitz and
Marshall Sorkin

Dr. Steven Krause

Jerry and Karen Eisman

Doug Kresse

Carol Kresse

Martin Loughlin

Martin and Geraldine Loughlin

Susan Covet Matthews

Jacqueline Rivera

Ilene Medovich

The Linda Theiben Trust

Martha Nicolaides

Alegria Smith

Katie Parson's Birthday

Brian Davis
Salome Gutierrez
Roxanne Parson
Susan Parsons
KaBoujee Xyooj

Julie Raimondi's Birthday

Lisa Kurtz

Alice Riginos

Dr. Vasilis Riginos
Linda Erf Swift

Robbi Rucker's Birthday

Anonymous
Carla Becker
Emily Feder
Becca Feder
Karen Feder
Michael Goldstein
Shelle Goldstein
Tracy Gordon
Larry Herzberg
Richard Johnson
Joshua Martin
Robbi and Steve Rucker
Jeremy Rucker
Robbi Rucker
Sandi Swerdloff
Victoria Van Zandt
Avery Walsh
Eva Wilson

Susan Schmitz Sandeen's Birthday

Peggy Diamond
Melissa Perotti
Barbara Perotti
Sabrina Sandeen
Patti Schmitz
Stacie Spell
Linda Wilkins
Lyn Willerton
Susie Winchester

Laura Schaefer's Birthday

Colleen Eagen
Nica Jadoch
Elizabeth Kirby
Kathy McIntyre Schafer
Mary Przybylak
Milagros Ray
Enid Rivera

Jenni Schaf-Caira's Birthday

Barb Anderson
Kelly Archambault
Chad Armstrong
Donna Brace Lemacher
Justin Caira
Lexi Caira
Denise Caira
Jessica Caira
Dawn Caira Klauer
Chuck Caira
Bryan Cron
Sandy Gaeth
Peggy Gould
Sherry Grundman
Cindy Hoiland Eggert
Gregory Holley
Amy Hopkins
Joan Judy
Norma Latzke

Jenni Schaf-Caira's Birthday (cont.)

Brianna Mallmann
Felica McWilliams
Froschmayer
Gina Meller
Tony Meyer
Justine Najmabadi
Maggie Perkins Smoot
Debbie Purfuerst
Anthony Rehm
Debbie Roth-Cohenet
Kathy Schaf
Nick Schaf
Mary Kay Smith Wolf
Diane Sonnheim
Marj Tell
Ken Williams

Karen Schange

Dr. Stephen J. Schange

Jack Sprinkle

Jack and Victoria Sprinkle

James W. Squires

Anonymous

Estelle Sugarman

Jay, Lisa, Josh, and
Sarah Sugarman

Maureen Sullivan

Joseph Hauswirth

Norman L. Thompson, MD

Patricia Thompson

The IWMF Torch!

Marilee Morris and
David Skolnick

Alexiss Turner's Birthday

Allison Hurd

Elaine Van Bloom

Fred and
Dolores Pernerstorfer

Rick Volkers

Mary Dabros Powell

Wheaton Franciscan

Infusion Pharmacy

Anonymous

Dennis Wiggins

Dennis Wiggins

Dr. Patrick Williams

Terry Tatro

Lisa Wise

Anonymous

Don and Kate Wolgemuth

Fredrick L. Browne

Rudy Zunich

Pauline Zunich



International Waldenstrom's
Macroglobulinemia Foundation

6144 Clark Center Avenue
Sarasota, FL 34238

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

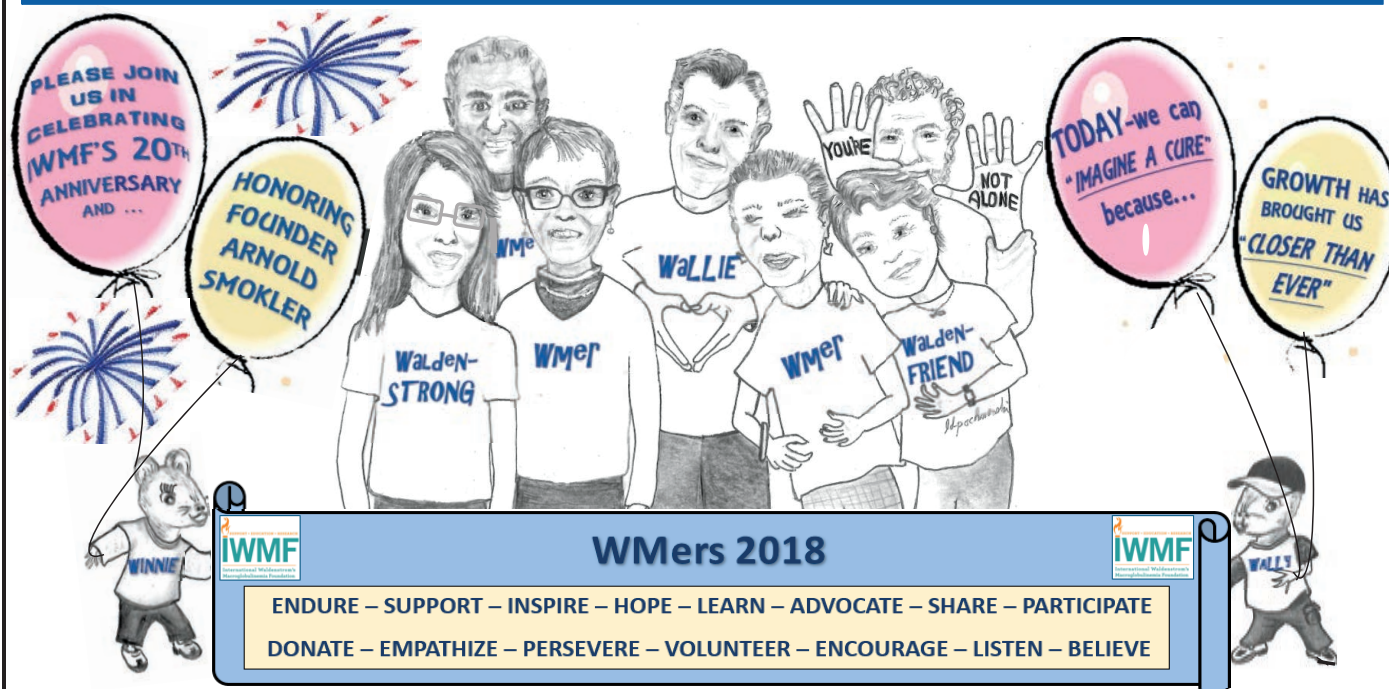
E-mail: info@iwmf.com • www.iwmf.com

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

Founder Arnie Smokler's objective 20 years ago remains the same today – support for WM patients.



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

