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DOCTOR ON CALL: STEPHEN M. ANSELL, MD, PhD

WHO NEEDS TREATMENT FOR WALDENSTROM'S MACROGLOBULINEMIA AND WHEN?



Dr. Stephen M. Ansell

Stephen M. Ansell is Professor of Medicine, Mayo Clinic College of Medicine, and a consultant in the Division of Hematology, Department of Internal Medicine, at Mayo Clinic, Rochester MN. Dr. Ansell received his medical degree at the University of Pretoria, South Africa, and subsequently completed his PhD at the same institution. He specialized in medical oncology before coming to the United States, where he completed a residency in Internal Medicine and a fellowship in Hematology and Oncology at Mayo Clinic.

In his clinical practice, Dr. Ansell's interests focus on non-Hodgkin lymphoma, Hodgkin's disease, and Waldenstrom's macroglobulinemia. His research concentrates on the biology of these diseases and on the development of new therapies. Funding for his research is received from the National Institutes of Health, the Leukemia & Lymphoma Society, and the International Waldenstrom's Macroglobulinemia Foundation.

Dr. Ansell is Chair of the Mayo Clinic Lymphoma Group as well as Chair of the Faculty Development and Recruitment for Hematology at Mayo Clinic. He has been honored with various awards during his training and career, including the Department of Medicine New Investigator at Mayo Clinic and Medical Honoree at the Lymphoma Research Foundation, Minnesota Chapter. Dr. Ansell has held memberships with organizations including the American Association for Cancer Research, the American Medical Association, the American Society of Clinical Oncology, and the Eastern Cooperative Oncology Group, and he has served on the editorial boards of the American Journal of Hematology, Journal of Clinical Oncology, Blood Cancer Journal, and Clinical Lymphoma and Myeloma. Dr. Ansell is the co-author of more than 234 articles in peer-reviewed journals.

Receiving a diagnosis of Waldenstrom's macroglobulinemia is life changing, and what to do next is often very confusing for the patient and for those offering support as well. The first issue is to try to understand the diagnosis you have received. At the simplest level, you learn that lymphoplasmacytic lymphoma cells are growing in your bone marrow and that these cancerous cells may be limiting the growth of healthy blood cells. You also are told that lymphoplasmacytic lymphoma produces a monoclonal IgM protein that can thicken your blood and clog your circulation.

Once you understand the diagnosis, you are assured that, although the disease is incurable, it can be managed successfully. You are then presented with a wide variety of treatment options. Treatment can be anything from a watchful-waiting observation approach, to treatment with chemotherapy in combination with rituximab, to possibly treatment with rituximab alone. Often, discussions related to the need for plasmapheresis also enter the conversation. All of this can be extremely confusing for patients, and a clear understanding of who should be treated and when treatment should be initiated is really important.

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Doctor on Call, cont. from page 1

Patients diagnosed with Waldenstrom's macroglobulinemia can present with a wide spectrum of findings. To illustrate the spectrum of presentation that I see among patients in my practice at Mayo Clinic, I will highlight two groups of patients on opposite ends of the symptom spectrum. The first group consists of patients diagnosed almost by accident when they undergo laboratory testing as part of an annual physical examination and are found to be mildly anemic. Follow-up testing to investigate the cause of their anemia often includes a serum protein electrophoresis test on the blood. A monoclonal IgM protein may be detected. The blood level, however, may show that the total serum IgM protein (that is, IgM present in the circulating blood) in these patients is actually only slightly higher than normal. When further testing, including a bone marrow biopsy, is done, the bone marrow does confirm low-level involvement by lymphoplasmacytic lymphoma. The presence of a serum IgM monoclonal protein and bone marrow involvement by lymphoplasmacytic lymphoma therefore confirms the diagnosis of Waldenstrom's macroglobulinemia. However, these patients often have no other symptoms and no other findings of significance. Patients in this group may not require immediate treatment.

In contrast, other patients can present with a far more complicated picture. Some patients in this second group can present with significant tiredness and nausea, sometimes with visual difficulties, confusion, sleepiness, and easy bleeding. Some patients can present with severe neuropathy, ankle ulcers, and possible organ compromise. Lab testing in such patients often shows the patients to be very anemic with low platelets, and there may be evidence of hyperviscosity (thickening of the blood due to high IgM levels). For such patients, bone marrow testing often shows much more extensive involvement by lymphoplasmacytic lymphoma, and a very high level of IgM in the blood is also identified. Patients in this second group also fit the diagnosis of Waldenstrom's macroglobulinemia but are far more ill than the first group of patients, and they need urgent treatment. Clearly, initial treatment of the two groups of patients will be quite different.

Overall the predominant decision regarding the optimal time to initiate treatment and the choice of treatment is determined by two main issues. The first is clinical symptoms associated with the extent of the disease and the second is complications related to deposition of the serum IgM. While it is tempting to consider treating everybody once the diagnosis is certain, it is important to note that some patients with very little disease at the time of diagnosis may remain without symptoms or complications for years. Immediately starting treatment in these patients would result in more side effects and toxicities and

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6144 Clark Center Avenue • Sarasota, FL 34238

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

E-mail: info@iwmf.com • Website: iwmf.com

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EDITOR

Alice Riginos

ASSOCIATE EDITOR

Sue Herms

SUPPORT GROUP NEWS

Penni Wisner

CULINARY EDITOR

Penni Wisner

INTERNATIONAL CORRESPONDENT

Annette Aburdene

IWMF-TALK CORRESPONDENT

Jacob Weintraub

SENIOR WRITER

Guy Sherwood, M.D.

CARTOONIST

Linda Pochmerski

FORMATTING & PRODUCTION

Sara McKinnie

TORCH ADVISORY PANEL

Carl Harrington, Robert Kyle,

Judith May, Guy Sherwood

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significantly more risks than observing the patients without initiating treatment. At the same time, a further goal of management is to monitor a patient under observation to avoid this patient becoming as ill as the patients in the second group outlined above.

The following are agreed-upon symptoms and clinical findings for starting treatment. The first set of symptoms is what are called ‘constitutional symptoms’ that would suggest that the disease is very active and progressing more rapidly. These include weight loss, fevers, and drenching sweats at night. Each of these is carefully defined – weight loss is significant when more than 10% of one’s body weight; fevers require the temperatures to be 101.5°F and higher; and night sweats need to be drenching to the point of soaking one’s clothing, requiring you to change your clothes or the bedding. Other evidence that the disease is very active and requires treatment is enlarging lymph nodes and an enlarging spleen or a decrease in blood counts because of involvement of the bone marrow. This would include blood counts with a low hemoglobin (less than 11g/dL) or low platelet count (less than 120,000/dL).

The second major factor contributing to a decision to initiate treatment is evidence for complications due to the serum IgM levels. These complications would include hyperviscosity, which usually presents with easy bleeding, confusion, visual changes, and also significant fatigue. Further symptoms associated with the serum monoclonal IgM can be peripheral neuropathy, protein deposition in the skin and organs resulting in systemic amyloidosis, and renal insufficiency.

What is notable, however, is that the absolute IgM level is on its own not usually a criterion to initiate treatment. Although high IgM levels are often associated with some of the symptoms listed above, and the IgM is expected to increase

over time if the disease slowly progresses, it is important to know that the IgM level itself may not necessarily require treatment. It is more important to consider these other factors at the time of initiating treatment.

The decision to select treatment based on the criteria above is often associated with what symptoms a patient has and how quickly a response is needed. In patients who have significant symptoms, treatment with chemotherapy plus rituximab is usually recommended. In our practice, the combination of dexamethasone, cyclophosphamide, and rituximab (DRC) is often selected. Treatment with bendamustine plus rituximab is an alternative if a more rapid response is needed. Additional choices could be treatment with a combination that would include bortezomib; however patients with neuropathy can have increased neuropathic symptoms with this agent. Some patients who have anemia secondary due to red cell breakdown or peripheral neuropathy due to IgM depositing in the nerves, could be treated just with rituximab alone. There are also other effective drugs to use in initial treatment. While these other treatment options are also reasonable, the combinations mentioned above are less toxic to bone marrow stem cells and allow for stem cell collection for future stem cell transplantation if necessary.

As outlined in this article, the choice of initial treatment for Waldenstrom’s macroglobulinemia and when to start treatment is often more complicated than simply noting changes in the blood test results. It is therefore very important to discuss all of the treatment options, as well as the decision to start treatment, with your treating physician and to be part of the decision-making process. Active participation in your care is a critical part of receiving good management of Waldenstrom’s macroglobulinemia and maintaining good quality of life.

IWMF Embraces Social Media Tools to Communicate with Members

To provide the latest news on advances in WM research and treatments and up-to-the minute information on our services to members, the IWMF will use both Facebook and Twitter.

“Like” us – facebook.com/waldenstroms.support

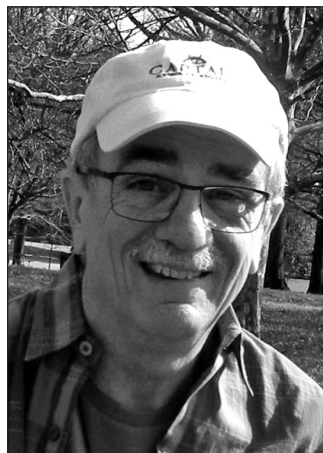
“Follow” us – twitter.com/wmiwmf

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 *Torch* editor Alice Riginos at ariginos@me.com



PRESIDENT'S CORNER



Living with cancer is often described as a journey, both for the patient and the caregiver. Before speaking about the next direction of the IWMF's continuing journey, let me share some personal news about a different, more literal kind of journey.

In December, our son, Sam, and his girlfriend, Bev, threw a big party for their friends. About 150 people

came, lured by the promise that they had a big announcement to make. Everyone thought that Sam and Bev were going to announce their engagement. But, no, instead they announced they were taking a leave of absence from their jobs, had bought a sailboat, and were leaving Troy, NY, where they live to travel the Great American Loop. What's that? It's a 6,000-mile circumnavigation route of the waterways of the eastern half of the United States. About a thousand people make this adventurous journey each year. They'll sail up canals and Lake Champlain to the St. Lawrence Seaway, through the Great Lakes to the Chicago River, down the Mississippi to the Gulf of Mexico. Then along the coastal waterway to Florida, across Florida, and finally back up the east coast to the Hudson River. Possible stops in Cuba and the Bahamas. It'll take them a year. And, yes, they're experienced sailors. Hey, they have three or four lessons under their belts. (Yikes!)

My wife and I, and Bev's folks, had been let in on the big news about the boat and the journey. But Sam surprised everyone, including Bev, by getting down on one knee and asking the big question. Fortunately, in front of all those people, she accepted! We're thrilled he'll have such a great partner in his journey through life. We know how important it is to make the commitment and to know you have the support of people who care.

No matter whether you're going on the Great American Loop or you're on a WM journey, the rules to be followed are the same.

Know where you're going

A good map is essential to any successful journey. At the IWMF, we're creating a Strategic Roadmap for WM Research in cooperation with the Leukemia & Lymphoma Society (LLS). On May 16-17, 2015, the leading minds in WM research will gather in New York City at Weill-Cornell to identify the critical gaps we have in understanding WM and reaching our ultimate goal of finding a cure. This meeting will result in a Strategic Research Roadmap for WM to guide us in investing your research dollars.

With this map in hand, we'll know how to chart our search for a cure!

Have a good crew

The IWMF is fortunate to have a great crew. From our outstanding Office staff (Sara, Lisa, Bobbie, and Alan) to our prestigious Scientific Advisory Committee chaired by Dr. Kyle, to our incredibly hard working Board of Trustees, Support Group Leaders, LIFELINE volunteers, Committee members, Imagine a Cure Advisory Board and, of course, our Torch team, the dedication and teamwork is incredible.

Today I want to pay special tribute to the WMers who participate in clinical trials. Without your courage and willingness to participate, the recent approval by the FDA of Imbruvica (ibrutinib), the first drug ever studied and approved for our orphan disease, would not have been possible. From the bottom of our hearts, all 7,000 WMers applaud you and thank you!

Thanks to these clinical trial participants and FDA approval, physicians can now prescribe Imbruvica for all WM patients, and many patients will be able to obtain better insurance coverage for its cost. With this major success, a greater awareness of WM, and continuing new scientific advances, the path to other approvals should be smoother and easier.

Meet friends and learn along the way

A great way to make a trip easier and more fun is to meet others on the same journey. It's amazing what you can learn from others in a similar situation . . . things that will make your own journey easier. In the case of WM, that means:

- Finding a way to come to the IWMF Educational Forum in Dallas, TX, from May 1-3, 2015, if you possibly can. We have a great line-up of speakers, but just as important are the connections you'll make with other WMers. You can register now at iwmf.com/news-and-events/iwmf-educational-forum. Come on, this is our **twentieth** Educational Forum. It's going to be so big that we could only hold it in Texas! If you haven't signed up yet, sign up today!

If you're in Europe and can't make it to Texas, consider attending the 2015 WMUK Ed Forum in Birmingham, UK, on May 11 or the Waldenström France Educational Forum in Toulouse on May 23.

- Attending your local IWMF support group meetings. We have forty-one support groups in the US and another twenty around the globe. You can find the support group nearest you at iwmf.com/get-support/us-and-international-support-groups.

Stay in touch

Another great way to get the most out of a journey is to stay

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in touch with others back home or with others who have experienced the same part of journey that you are facing right now. In our case, that means:

- Staying in touch with the latest developments in WM via the *Torch* and our new IWMF website. The new website launched in February. If you haven't visited it, please do. I think you'll find it easier to navigate than our old site. Plus, it will work on your cell phone or your tablet and other devices. One fun feature is that all of the pictures on the site are of fellow WMers. If you have pictures you think would be good additions to the site, send them to our webmaster, Barry Nelson, at BarryNelson@alum.MIT.edu. We'll be changing the photos periodically. We'd love to see you among us.
- Participating in IWMF-Talk, the on-line WM discussion group. If you are looking for support in navigating a tricky part of your WM journey, ask your fellow WM travelers. You can sign up for IWMF-Talk at iwmf.com/get-support/iwmf-talk-and-online-discussion-forums.

- Speaking with someone who's already been there will give you in-depth perspective on a particular issue on your WM journey. Use the IWMF LIFELINE and speak one-on-one with a fellow WMer about a specific issue such as experience with a particular drug, a particular side effect, or any one of a number of topics. See iwmf.com/get-support/lifeline-and-one-one-support for a description of LIFELINE, a complete list of topics, and the contact information for fellow WMers you can call for help. If you need a friend or advice, give one of our LIFELINE folks a call.

WM is a risky journey filled with situations you can't always control. Advance knowledge, commitment from your traveling partners, and a clear destination are essential. No matter where your WM voyage takes you, remember you're never alone. The IWMF and your fellow WMers are here to help. Call on us!

Best wishes for a safe WM journey,

Carl

INTRODUCING THREE NEW MEMBERS OF THE IWMF BOARD

At the November meeting of the IWMF Board of Trustees three new members were elected to the Board. Each comes with very strong credentials but from very different professions.

Barry Nelson is the new webmaster for the new IWMF website iwmf.com, a position he assumed late in 2014 after responding to an e-mail appeal from the IWMF for a volunteer, just as the website was entering its final phase of development. To the role of webmaster Barry brings his extensive expertise and cool professionalism drawn from a thirty-five year background in software design and engineering. Thanks to his skills and patience, the website was successfully launched on February 10.

Barry and his wife, Linda, reside in Newton, MA, where, weather permitting, he can be found daily on the cycling trails in the company of the Charles River Wheelmen and the CrackODawn cyclists, two of the organizations to which he also volunteers his time and computer savvy. For the past twenty years, Barry and Linda have participated in the Pan Mass Challenge ride in support of the Jimmy Fund at the Dana-Farber Cancer Institute.

Most recently Barry added two more non-profit and cultural groups to his volunteer list, "Anticipating," as he put it, "that the IWMF webmaster job would require less time after the website was launched."

Hopefully, by the time this issue of the *Torch* reaches you, the trails will be open after this most challenging winter in New England, and Barry will be off at the crack of dawn, cycling

on lovely spring mornings.

Gayle Backmeyer comes to the Board of the IWMF after a long and very active career in nursing, focusing primarily on women's health issues. Following certification as a RN, Gayle earned the degrees of BSN and RSN and also became a Certified Nurse Midwife. Active involvement with the IWMF began when she established the Indiana Support Group, and she continues today as its support group leader. As a member of the IWMF Board, Gayle will chair the newly created committees for the LIFELINE and for Clinical Trials.

In retirement Gayle has not slackened her pace of life. She volunteers for other non-profit organizations and the women's group at her church and is regularly found working out at the gym or practicing yoga. And for relaxation, she lists travel, reading, and attending plays and musicals as her favorite sorts of entertainment.

Eileen Frishman Lash is a retired CPA specializing in commercial taxation and comes to the IWMF with considerable experience in federal and multi-state tax compliance.

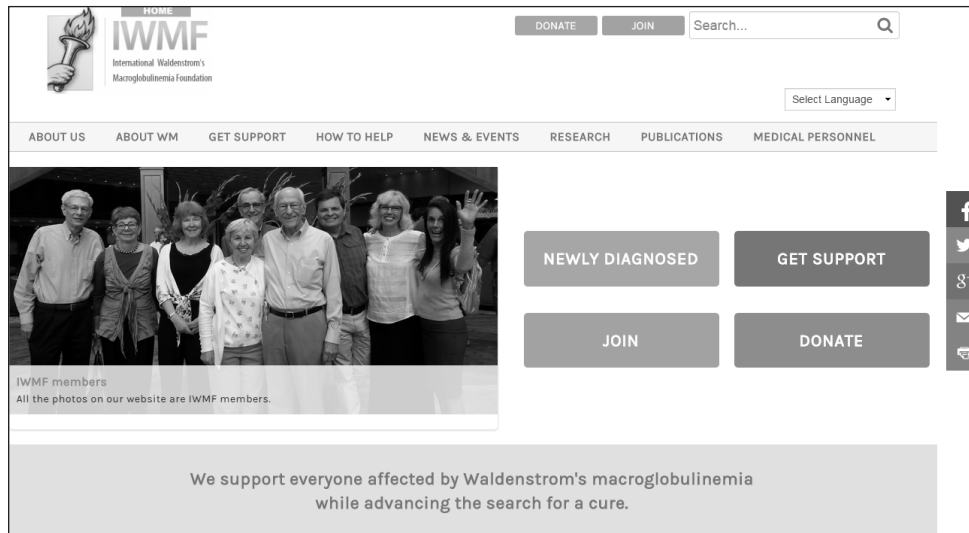
Eileen's earlier career training, however, was in education. She received a BS degree in Education from the City College of New York, followed by her MA in Education with a focus in educational psychology from the University of Connecticut. Following a career shift to accountancy, she acquired the MS in Accounting from the Pace University, Lubin School of Business.

With her new career, this native New Yorker moved west. For many years Eileen's professional base was Denver (where she

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HOME PAGE:



THE IWMF NEW WEBSITE – www.iwmf.com

BY BARRY NELSON, IWMF WEBMASTER

ELENA MALUNIS, VICE PRESIDENT FOR MEMBER SERVICES

PETER DeNARDIS, IWMF TRUSTEE

In February the IWMF introduced a new website that was specifically designed to better meet the needs of our members and friends. As the only not-for-profit foundation providing worldwide support to WM patients and their caregivers, we understand the need for easy access to information about WM in any language.

The website redesign project began in late 2013, when it became apparent that the previous website was no longer able, from a technical perspective, to meet the needs of the WM community worldwide. For example, people using smaller devices such as tablets and smartphones could not readily view our content. After we completed the initial design work in early 2014, it took several volunteers almost a year to redesign components, rewrite content, and develop new ways to provide content.

We built the website to accommodate your support needs in an easy-to-use and visually engaging manner, utilizing images of IWMF members who shared their photos with us so we can share them with you. If you have photos you would like to make available to us for possible inclusion on the website, please send them to: support@iwmf.com.

Now that the new website has been launched, the IWMF Board and a team of volunteers will remain committed to keeping the content fresh and current. Every effort will be made to revise content as needed and provide up to the minute information regarding WM- and IWMF-related news and events, the latest publications and documents regarding diagnosis and treatment, and new patient stories, videos, and photos.

To demonstrate the improvements in navigability and content of the website, let's travel together to destinations where some of the important improvements have been made. Get set with your desktop, laptop, tablet, or smartphone. First stop: the **HOME PAGE**.

HOME PAGE

The **HOME PAGE** now prominently displays two columns: **NEWS** and **EVENTS**.

The **NEWS** column enables our members to easily find the latest information that affects their wellbeing, support, and education.

The **EVENTS** column posts the details of upcoming meetings including Support Group Meetings, the IWMF Educational Forum, and country-specific educational forums of our Affiliates. Meetings are now displayed in a monthly calendar, making it easier for members to plan their personal schedules.

Across the top of the **HOME PAGE**, top menu items run in a horizontal band. Each top menu item accesses a major section of the website via a drop-down submenu.

Please visit the menus in order and “drop down” at each of them. Once there, you'll find updated content from the old website at each menu item, along with the special additions and improvements noted below.

ABOUT US

The IWMF currently has **INTERNATIONAL**

The IWMF New Website, cont. on page 7



AFFILIATES in ten countries providing information, education, and support to WM patients in these countries. Contact information is now accessible under **ABOUT US** for all IWMF International Affiliates.

ABOUT WM

The **ABOUT WM** section has been rewritten and re-organized to make it easier for both newly diagnosed and veteran WM patients to find information about their disease, including causes and risk factors, medical tests, and treatment options. Recent cutting-edge basic research into the biology and genetics of WM, including the MYD88 and CXCR4 mutations, is reviewed with some discussion of future directions for this research. Also covered is the use of translational research to convert basic research into treatments that are targeted to these pathways. A good example of the result of this translational work is the first drug, Imbruvica, specifically approved by the FDA for WM. Also covered is a promising new type of immunotherapy using the patient's own cells to recognize and destroy cancers.

GET SUPPORT

The **PHYSICIANS DIRECTORY** provides names and contact information of WM specialists and researchers knowledgeable about WM who have agreed to be included as a WM specialist resource available to patients and other physicians for consultation. This list was compiled for the new website by Dr. Robert A. Kyle, who personally contacted each doctor for their agreement and approval to be listed.

New! A simple drop-down menu now provides contact information regarding the **US AND INTERNATIONAL SUPPORT GROUPS**. With its International Affiliates, the IWMF has over fifty support groups, and finding a support group, whether within or outside the US, has never been easier! All a member needs to do is select the US state or the country of interest from a simple-to-use drop-down menu.

STORIES OF HOPE, personal stories of hope and survival, a very popular part of the “old” website, now includes new selections. In recognition of the fact that we are an international foundation, patient stories from Canada, Europe, and Australia have been included.

HOW TO HELP

Participate in **CLINICAL TRIALS**. Clinical trials are a final and crucial step on the path to developing better treatments for patients. A newly created webpage is here to help IWMF members understand clinical trials and locate trials that may be of interest.

PUBLICATIONS

The IWMF booklets in English, Spanish, and French

are available and can easily be downloaded and printed under **DOWNLOADABLE PUBLICATIONS**. New additions to our downloadable publications are the Fact Sheets on selected treatment options in English, French and Spanish.

New! In past issues the *Torch* has published articles focusing on specific aspects of our disease (including diagnosis, tests, management, and treatment) and many are written by leading WM specialists specifically for WM patients and caregivers. These articles in downloadable PDF format are collected in a new section of the website called **Best of the Torch**.

RESEARCH

The IWMF is funding research directed towards finding better treatments and ultimately a cure for WM. Specific information concerning the research projects previously receiving IWMF support as well as those currently funded is found under **RESEARCH**. Take the time to read over this list: these research projects are your hope for the future.

DONATE

Donating to the IWMF Research Fund and Membership Fund has also been simplified: a quick click on the orange **DONATE** button (found in the upper right hand corner of every page) takes you to your giving options. Note that PayPal has been added as a “way to give.”

And please remember that everything we do from the *Torch* to the website to research towards a cure is funded almost entirely by gifts from WMers like you.

SHARE

The IWMF is committed to providing WM-related information to patients and caregivers utilizing all the technology tools that are available, and that includes newer media tools such as Facebook and Twitter. IWMF members familiar with such tools will find the icons located on the right-hand side of each page useful for sharing vital information from the website in real time with family and friends, along with an easier mechanism for printing content from the website.

We conclude this brief tour of the new website in the expectation that you will come back often. News items, articles, events, and support group and affiliate information will be updated on a daily basis, and, if you don't find what you're looking for immediately, use the search box in the upper right hand corner of each page. You will surely find a wealth of new information each time you visit!

Comments and feedback about the website are welcome and should be sent to the webmaster at webmaster@iwmf.com.



IN THE TORCHLIGHT

MY FIFTEENTH ANNIVERSARY CELEBRATION

BY TOM HOFFMANN, MD

Doctor and surgeon Tom Hoffmann, member of the IWMMF Research Committee and a frequent voice of medical expertise on IWMMF-Talk, steps into the Torchlight having completed a significant number of years as a WM survivor. Dr. Hoffmann describes how a physician felt when the dreaded diagnosis of incurable cancer was his own.

I am celebrating the fifteenth anniversary of my diagnosis with Waldenström's macroglobulinemia. My celebration is for being alive and functional, not for having the disease.

I presented with numbness and tingling beginning in my feet, which slowly moved progressively up my legs, to thighs, also hands, then arms. The causation was elusive at first. I developed anemia and fatigue. After six months with no diagnosis, my neurologist, who is my friend as well as my doctor, called me one day and said, "Why don't you get a serum protein electrophoresis just to cover all the bases." He must have read a new article somewhere!! The SPEP was positive for an abnormal monoclonal antibody. The next step was the dreaded bone marrow biopsy.

My oncology friend, who taught me in medical school, said, "OK, but this is going to hurt." I said, "Just get it done, no anesthesia or drugs, please. I have patients waiting on me and I am sure this is a waste of time anyway!"

A couple of days after the bone marrow biopsy I visited the hospital pathology department and asked one of my pathology friends to look at the slides and tell me what he sees. He pulled the slides and offered to let me look at the specimen with him through the three-headed teaching microscope. As he was describing the pathology to me, another pathologist friend looked into the third head without knowing it was my tissue and said, "This poor bastard will be dead in a few years." Was he ever embarrassed when he found out whose sample he was looking at. I felt pretty low.

It was very hard to explain all this to my wife, a nurse, and we wept together. We have seen too many cancer patients and have watched some of the horrors that can befall them. I was only fifty years old. My son (the light of my life) was only seven years old, and the survival rate for WM at that time was quoted as three to five years. This was an extremely low point in my life.

I had unwittingly and certainly unwillingly become a cancer patient. Five bone marrow biopsies over the years. I was lucky to live in the same town as Dr. Bart Barlogie. The only problem was that as he is a "take no prisoners" type of guy. I think he put me through every test known to mankind. He wanted me to have CHOP or a transplant immediately. But I wouldn't give in to those options mainly because of the

things I learned on IWMMF-Talk, so we followed the lab work for one year as I educated myself and my neuropathy slowly progressed.

The neuropathy began to hinder my ability to operate. When my career as a surgeon was imperiled, I knew that something had to be done. In addition, I was always very fatigued and anemic and just couldn't keep up. Dr. Barlogie and I negotiated and settled on Rituxan, only because I wanted to keep working during the chemo. Operate in the morning and be infused in the afternoon.

Luckily, there were no side effects. Treatment began in early 2000, when Rituxan was a fairly new drug. We didn't know then what we do today about its side effects and effectiveness. At one appointment, I saw one of Dr. Barlogie's cohorts who was covering for him. He looked me square in the eye and bluntly told me that I would be dead in less than five years and it wouldn't be a pretty death. Thank you very much! I immediately scratched him off my list of good doctors and Christmas card recipients. I wanted to spit on him.

Dr. Barlogie decided to give me a double dose of the drug, so I received two infusions per week for four weeks. The proper number of infusions per course was still being worked out. My IgM was 1,800 on diagnosis and had climbed to 2,850 when Rituxan was started. My IgM spiked at 3,180 during treatment and then started to drop, falling to 2,160 at four months but then beginning to climb again. I had read that a certain green tea could be beneficial so I started brewing and drinking Essiac tea. The IgM level had climbed steadily from 2,160 to 2,540 but immediately started dropping again after the tea was started. It continued to fall in a relatively straight line to 1,000 at twenty-eight months after Rituxan. The curve then leveled a little but ultimately fell to 525 seven and one-half years after the Rituxan. It has been flat since then. What a beautiful curve! I still have the neuropathy, but it has regressed to just the soles of my feet. I am glad that I still have it because that keeps me wary of the disease.

About three years after my diagnosis, my father became ill. Nobody could figure out what was wrong with him. By that time I was pretty proficient with the WM scenario, and I was the one who diagnosed him with Waldenström's. Unfortunately, his bone marrow was 90% involved and acted very malignantly. He was extremely sick and in renal failure. He received CHOP-R, and a total remission followed, although multiple life threatening episodes ensued during the treatment. That remission lasted for three years. When WM returned, nothing would work. He passed in 2009 from a stroke, six years after diagnosis.

In the Torchlight, cont. on page 29



TORCH 'TOONS

They're back! Wally and Winnie Mouse, the charming Designer Mouse Models introduced in the 2013 Anniversary Issue of the *Torch*, will again grace our pages in 2015. Many thanks to their creator, cartoonist Linda Pochmerski.



Eager to learn all they can about WM, newbies Wally and Winnie are about to find out that the 2015 IWMF Educational Forum in Dallas-Fort Worth, Texas, will provide them the power of knowledge and the priceless support from survivors. But prior to entering, Winnie begins to squirm.

ED FORUM 2015: Y'ALL COME!

Winnie doesn't have to be nervous about attending an Ed Forum and neither do you! Everyone with an interest in WM is welcome, especially "newbies." There is still time to register, so go to iwmf.com to sign up online. The registration fee is only \$199 per person until April 1; after April 1, the registration fee will be \$250 and then \$275 at the door.

And, if you're like Wally, who is dressed and ready for the event, you might want to get in the "Texas spirit" and sign up for the optional Saturday Night Barbeque Buffet at the hotel for only \$18 per person, including beverage, tax, and service

charge. Wally knows a good deal when he gets a whiff! A cash bar will be available. The sign up deadline is April 25.

Don't forget to make your own hotel reservations at the Hilton DFW Lakes Executive Conference Center by calling Toll-Free 800-984-1344. Be sure to mention "IWMF" to obtain the special nightly room rate of \$127 plus tax, which is good until April 9.

At an Ed Forum you'll find that everyone is special, even those without tails!



MEDICAL NEWS ROUNDUP

BY SUE HERMS

Imbruvica Receives History-Making FDA Approval for WM

Marking a first for WM, Imbruvica (ibrutinib) received approval by the US Food and Drug Administration in January for treatment of all patients with the disease. Imbruvica, jointly developed by Pharmacyclics and Janssen Biotech, Inc., received Breakthrough Therapy Designation for WM in 2013; FDA approval was based on the results of single agent Imbruvica in daily doses of 420 mg in Phase I and Phase II trials of relapsed/refractory WM. Imbruvica is an oral inhibitor of Bruton's tyrosine kinase (BTK) and blocks signals that stimulate malignant B-cells to grow and divide uncontrollably. (See page 4 of this issue for IWMF President Carl Harrington's comments on this approval.)

Delisting of Blood Cancer Drugs in England May Impact WM Patients

Several blood cancer drugs were to be delisted in March from the Cancer Drugs Fund, which was set up in 2011 to give patients in England access to cancer treatments ruled too expensive for routine use on the National Health Service, the publicly funded healthcare system. Of particular interest to WM patients, the delisted drugs include bortezomib (Velcade) for the treatment of relapsed WM. However, patients already taking these drugs will be allowed to continue with them.

Ibrutinib Combined with Rituximab and Bendamustine in NHL

The Ohio State University discussed Phase I/Ib results of ibrutinib combined with rituximab and bendamustine for 48 patients with relapsed non-Hodgkin's lymphoma. Patients received the combination therapy for 6 cycles followed by ibrutinib alone until progression. The overall response rate was 72%, with 52% complete responses. Toxicities included lymphopenia (reduced lymphocytes), neutropenia (reduced neutrophils), thrombocytopenia (reduced platelets), and rash, but no dose-limiting toxicities were observed. Median progression-free survival had not yet been reached at the time of reporting. A Phase II trial of this combination is being considered.

French Study Looks at Lenalidomide in WM Patients

A multi-center French study presented by Dr. Xavier Leleu at the American Society of Hematology (ASH) annual meeting attempted to determine the maximum tolerated dose of single agent lenalidomide (Revlimid) for WM treatment. This Phase I/II dose escalation study of 17 relapsed/refractory WM patients established 15 mg/day for 21 days out of 28 as the maximum tolerated dose. The overall response was 36%; an initial IgM flare effect was observed in 5 patients. The most common adverse event was fatigue. The incidence of anemia with lenalidomide was a significant adverse event in a previous small study at Dana-Farber Cancer Institute that used a 25 mg/day dose. In this current study, anemia

occurred as a grade 3 event in 14% of WM patients who received 15 mg/day.

Final Results Released for Phase I/II Trial of Everolimus, Bortezomib, and Rituximab

Dr. Irene Ghobrial of Dana-Farber Cancer Institute discussed final results of a multi-center Phase I/II trial of everolimus (RAD001) in combination with bortezomib and rituximab (RVR therapy) in relapsed/refractory WM. Everolimus is an oral inhibitor of TORC1. The Phase I portion of the study evaluated the maximum tolerated dose, while the Phase II portion evaluated the depth of response to the combination. Patients received a total of 6 cycles followed by maintenance therapy with everolimus until progression. The study included 46 patients, 23 in each study phase. The everolimus dose was established at 10 mg daily, and the overall response rate was 91% in the Phase II study patients, with one complete response. The most common toxicities were fatigue, anemia, leukopenia (reduced white blood cells), neutropenia (reduced neutrophils), diarrhea, neuropathy, and pneumonitis/pulmonary infiltrates.

Oral Proteasome Inhibitor Oprozomib Evaluated in Relapsed WM

A multicenter Phase Ib/II study of single agent oprozomib, an oral proteasome inhibitor, was evaluated in 106 relapsed patients with hematological malignancies, including 36 with WM, and reported at ASH by the John Theurer Cancer Center in New Jersey. The maximum tolerated doses were established as 300 mg/day on 2 days of a 7-day cycle and 240 mg/day on 5 days of a 14-day cycle. The most common adverse effects in the WM patients were neutropenia (reduced neutrophils) and diarrhea. The overall response rate in the Phase II portion was 59%. Enrollment of patients on the 2/7 dosing schedule is continuing, and extended release oprozomib will be introduced to reduce gastrointestinal side effects.

Retrospective Study Looks at Autologous Stem Cell Transplant in WM/LPL

The European Society for Blood and Marrow Transplantation (EBMT) Lymphoma Working Party performed a retrospective study of 615 patients with WM/LPL (lymphoplasmacytic lymphoma) who had a first autologous stem cell transplant between 1995 and 2011 and were registered with the EBMT database. The median age at transplant was 53 years. With a median follow-up of 53 months, the 5-year overall survival was 65%, disease-free survival was 46%, incidence of relapse was 47%, and non-relapse mortality was 7%. Factors predicting for a favorable disease-free survival were female gender, transplantation in the rituximab era, and autologous transplantation in the first remission; however, even the outcome of patients undergoing transplant with advanced disease was still encouraging, with a disease-free survival

Medical News Roundup, cont. on page 11



of 40% and an overall survival of 63% at 5 years in this population.

Study Looks at Infections in WM/LPL Patients

A multi-center study reported at ASH by the University of Iceland identified all WM/LPL patients diagnosed from 1980-2005 in the nationwide Swedish Cancer and Patient registries to determine patterns of infectious morbidity. Compared to normal controls, WM/LPL patients had a 3.4-fold elevated risk of developing any infection. The most common bacterial infections included septicemia, endocarditis, pneumonia, meningitis, cellulitis, osteomyelitis, and pyelonephritis, while the most common viral infections were herpes zoster and influenza. The risk of infections was highest during the first year after diagnosis. Females had a significantly lower risk of infection compared to males, and increasing age was associated with a greater risk of infection. Interestingly, patients diagnosed in later years (1990-1999 and 2000-2004) had a greater risk of infection than patients diagnosed in 1980-1989.

Researchers Study Acquired Resistance to Ibrutinib in WM Cells

Mayo Clinic and Weill-Cornell Medical College looked at acquired *in vitro* resistance to ibrutinib in WM and mantle cell lymphoma. Despite the clinical success of ibrutinib, a high percentage of patients achieve only partial response and eventually acquire resistance to the drug. A mutation of cysteine to serine at position 481 in the Bruton's tyrosine kinase (BTK)-ibrutinib binding site has been reported to be one of the reasons for resistance. This study found that exposure of WM and mantle cell lymphoma cells to ibrutinib for prolonged periods of time resulted in outgrowth of clones that were resistant to apoptosis (programmed cell death). Analysis of these clones revealed no mutation at position 481 and suggested that the tumor cells can rely on a parallel survival pathway that includes activation of AKT and BCL-2.

Phase II Study Looks at Idelalisib in Refractory NHL

A multi-center study presented at ASH by the University of Washington School of Medicine in Seattle discussed results of a Phase II study of idelalisib (Zydelig) in indolent B-cell non-Hodgkin's lymphoma patients who were refractory to combination therapy with alkylating agents and rituximab. Idelalisib is an oral inhibitor of PI3K delta, which is over-expressed in several B-cell malignancies. Idelalisib at 150 mg twice a day was administered continuously or until disease progression or intolerance. Ten of the 125 patients in this trial had WM/LPL. The overall response rate for WM/LPL patients was 70% with no complete responses, while the duration of response was not yet reached at the time of reporting. The median progression-free survival was 22.2 months. Adverse events included diarrhea/colitis, fatigue, nausea, cough, fever, shortness of breath, rash, pneumonia, and pneumonitis. Elevations in the liver enzymes ALT and AST occurred in 14% of all patients. The results for WM/LPL patients were particularly promising, and idelalisib will

be evaluated in larger trials.

R-CyBor-D Phase II Results Released for Relapsed Low-Grade and Mantle Cell Lymphoma

Mayo Clinic and Princess Margaret Cancer Centre in Toronto, Canada, presented results of a Phase II trial of rituximab, cyclophosphamide, bortezomib, and dexamethasone (R-CyBor-D) in relapsed low-grade and mantle cell lymphoma. Twenty-one patients were enrolled; at a median follow-up of 32.8 months, 80% of the WM patients in this study achieved a partial response. Among patients who achieved a response, the median overall duration of response was 25.9 months; median progression-free survival and overall survival were 11.6 months and 54.8 months, respectively. Adverse events included leukopenia (decreased white blood cells), neutropenia (decreased neutrophils), thrombocytopenia (decreased platelets), anemia, peripheral neuropathy, and fatigue. Peripheral neuropathy was observed at a lower rate after a change in the bortezomib dosing schedule from twice weekly to once weekly.

German Study Compares Bendamustine-Rituximab to Fludarabine-Rituximab

The Study Group Indolent Lymphomas, Germany, reported 8-year follow-up results from a Phase III study of bendamustine plus rituximab (B-R) vs. fludarabine plus rituximab (F-R) in 219 patients with relapsed follicular, indolent, or mantle cell lymphoma. WM patient participation in each arm was 11-12%. The median observation time was 96 months. The overall response rate was significantly higher in the B-R arm than the F-R arm (83.5% vs. 52.5%, respectively), as were the median progression-free survival (34 months vs. 12 months) and overall survival (110 months vs. 49 months). Adverse effects in each arm were similar. Secondary cancers occurred in 14.9% of patients in the B-R arm vs. 15.2% in the F-R arm. An unplanned subanalysis showed that rituximab maintenance therapy significantly prolonged overall survival and progression-free survival in the small group of 40 patients who received maintenance compared to those who did not, although the numbers were too small to validate the conclusion.

PI3K Inhibitor Duvelisib Evaluated in Phase I Trial for Relapsed/Refractory NLH

A multi-center Phase I trial of duvelisib in patients with relapsed/refractory non-Hodgkin's lymphoma was reported at ASH by the Sarah Cannon Research Institute in Nashville. Duvelisib is a novel targeted inhibitor of PI3K delta and PI3K gamma. A total of 32 patients were enrolled. Clinical activity was observed at all doses of duvelisib evaluated (15 mg-75 mg/twice per day). The overall response rate was 65%, and the most common grade 3 or greater adverse events were elevations in liver enzymes, diarrhea, and transient neutropenia (reduced neutrophils). Additional trials are planned at the 25 mg/twice per day dosage of duvelisib, either as single agent therapy or in combination with rituximab.



RESEARCH UPDATE

BY GUY SHERWOOD, MD, VICE PRESIDENT FOR RESEARCH

The following update outlines the general directions in which research in Waldenström's macroglobulinemia is heading in early 2015, with a particular focus on research currently sponsored by the IWWMF.

Issues 15.4 (November 2014) and 16.1 (January 2015) of the *Torch* included the detailed summaries I prepared of the research projects presented at the IWWM8 Workshop in August of 2014. As reported, this research, both new and ongoing, is yielding results that are promising, even exciting.

The American Society of Hematology (ASH) held its fifty-sixth Annual Meeting and Exposition in the beautiful city of San Francisco, December 6-9, 2014. The ASH meetings are always very large occasions (over 20,000 attendees gathered in 2014 from all over the world) where cutting-edge developments in the field of hematology are shared with the medical community. As in past years, the IWWMF had an exposition booth to make Foundation publications available. President Carl Harrington, Office Manager Sara McKinnie, and I "passed the torch" by taking shifts at the booth. I also attended a number of scientific lectures relating to WM and viewed a number of research posters detailing some very interesting research endeavors.

Compared to the topics covered at IWWM8, the ASH conference had little in the way of new information about WM, with the exception of reports on developments in the emerging field of "immuno-oncology" which may have direct impact on future WM treatment. Adoptive T-cell therapy in particular received a lot of interest. A large standing-room-only scientific symposium reflected the current enthusiasm for this new and exciting change in the way oncologists might in the near future treat many types of hematological cancers, including WM.

We WM patients are very familiar with the targeted immunotherapy agent rituximab (Rituxan) that seeks out the CD-20 receptor on the surface of WM B-cells. The evolution of immunotherapy now seems to be geared toward engineering patients' own immune cells to recognize and attack the cancer cells and, harnessing the power of a patient's immune system, to rid the body of these uninvited guests. Impressive results from adoptive T-cell clinical trials in patients with advanced acute lymphoblastic leukemia (ALL) who had exhausted most remaining treatment options not only resulted in the disappearance of cancers for many patients, but several ALL patients have remained in complete remission for extended periods.

The Bingham Charitable Fund, a new IWWMF Research Partner (see page 16 of this issue), together with the Waldenström Macroglobulinemia Foundation of Canada (WMFC), is currently funding a research project in adoptive

T-cell therapy. Dr. Brad Nelson and Dr. Julie Nielsen of the British Columbia Cancer Agency are researching the newly identified MYD88 mutation as a potential target for adoptive T-cell therapy in WM. See issue 15.4 of the *Torch* (January 2015), pages 9-10 for further details.

Another interesting development in the field of hematological cancer in general and especially concerning WM and multiple myeloma, is the emerging interest in "precursor conditions." Precursor conditions are essentially early mutations in such conditions as, for example, IgM-MGUS and smoldering WM, which may lead to the development of aggressive WM in many instances. Whereas in the past many oncologists have relied on a "watch and wait" philosophy and elected not to treat WM patients until they become symptomatic, increasing evidence now points to possible advantages of earlier and more aggressive treatment. It is becoming uncomfortably clear that WM is a very complex disease and that a non-aggressive and "treat-later" approach may in fact lead to the emergence of resistant clones ("the strong survive" once again). This in turn, as the new line of thought goes, leads to more resistant disease as well as associated complications, reduced survival, and diminished quality of life.

Dr. Irene Ghobrial from the Dana-Farber Cancer Institute is an IWWMF-funded researcher who is hard at work collecting tissue samples from WM patients (the earlier the better!) and patients with the "WM precursor conditions." Her research lab is looking for genetic markers that may herald development to a more aggressive and hard-to-treat disease. Adriana Perilla Glen, Project Manager for Dr. Ghobrial's Waldenström Macroglobulinemia Tissue Bank and Blood Cancer Prevention of Progression Clinic (BCPC) will be at the upcoming 2015 IWWMF Educational Forum in Dallas to discuss this important research with interested WM'ers.

The IWWMF Board of Trustees recently approved a new research project from Dr. Steven Treon and Dr. Zachary Hunter at the Dana-Farber Cancer Institute. The new two-year research project "Identification of germline and somatic variants associated with predisposition to Waldenström's Macroglobulinemia (WM)" will seek to answer the questions raised by recent studies showing that mutations in the MYD88 gene alone do not appear to be sufficient to cause WM. Twenty-five percent of WM patients come from families with multiple cases of WM and other types of lymphoma. There remain important aspects of WM biology that elude us. As a result researchers believe that by studying WM predispositions they will be able to identify people at risk for WM, find new targets for WM therapies, and ultimately develop preventative interventions for people at high risk for developing WM. Drs. Treon and Hunter will be at the

Research Update, cont. on page 13



2015 IWMF Ed Forum and will undoubtedly provide us with interesting insights into the newest developments in the basic biology and genetics of WM.

Dr. Stephen Ansell from the Mayo Clinic (Rochester, MN) Division of Hematology submitted a new three-year research project proposal “Factors regulating immunoglobulin-producing-cells in patients with Waldenstrom’s macroglobulinemia.” This research project continues his fascinating research into the mystifying world of cytokines and cell-to-cell communication, particularly as it relates to IgM production. In his previous research project(s) Dr. Ansell sought to understand the mechanisms that result in increased serum levels of IgM and to determine which factors in the bone marrow microenvironment support malignant cell growth. He was able to determine that inhibition of the signaling pathway STAT5 led to significant reductions in IgM levels. Dr. Ansell also found that when STAT5 was activated using IL-21, PD-1 expression on the malignant cells was increased, suggesting that STAT5 may regulate PD-1 expression downstream. PD-1 (also known as CD279) is an acronym for Programmed cell Death protein 1. PD-1 plays an important role in down regulating the immune system by preventing the activation of T-cells, which in turn reduces

responses of an organism against its own cells and tissues and promotes a state of unresponsiveness of the immune system to substances or tissues that have the capacity to elicit an immune response. There exists little data on the role of PD-1 expression on malignant B-cells and the interaction between PD-1 and its ligands in the bone marrow, particularly in patients with WM. The consequences of abnormal cytokine signaling in WM that result in immune dysfunction form the basis of Dr. Ansell’s recently approved research project.

There are now 10 active IWMF-funded research projects ranging from the basic biology of WM, including the very complex cell-to-cell communication pathways, to the state-of-the-art genetic research at the most fundamental biological level (i.e. DNA and gene mutations).

The WM patient can anticipate continued breakthroughs in research leading to ever-improving treatment options. Combined with a newly found interest in WM on the part of the general scientific community and the continued important research currently sponsored by the IWMF (and others), the future is looking rosier all the time!

Donate and Participate!

THINKING ABOUT A CLINICAL TRIAL?

There are currently over 75 clinical trials that include WM patients!

If WMers had not participated in Phase I and Phase II clinical trials for Imbruvica, we would not have our first FDA-approved treatment for WM. If you need treatment, please consider the option of a clinical trial and discuss it with your hematologist-oncologist.

You can easily search for available trials yourself. Go to the website clinicaltrials.gov and enter “waldenstrom macroglobulinemia” in the “Search for Studies” box. Once you’ve clicked “Search” and your results appear, you can narrow your inquiry to actively recruiting trials by checking the boxes “Include only open studies” and “Exclude studies with unknown status.” Look for trials in your geographical area by clicking the tab “On a Map” and following the instructions.

Click on each clinical trial’s title in your search results to see a detailed explanation of the trial’s sponsor, purpose, outcome measures, eligibility requirements, locations, and contact information.



A JOURNEY TO HOPE

BY RON PAYNE



Ron at his desk

Former IWMF Trustee and support group founder Ron Payne presents the saga of his WM experience that led him to retreat literally to nature as a volunteer in the National Park Service. Now returned, he has stepped up to support the group he established.

Strange feelings appeared in my feet in the fall of 2000, as though wads of cardboard had been stuffed into my shoes. Uneven patterns of pressure on the soles of my feet as I walked became painful in a matter of weeks. Soon I could not sense just when my foot would touch the floor or pavement.

The podiatrist said I should stop wearing penny loafers and get a more substantial pair of shoes. I gave up the sloppy casual shoes, but instead of improvement, things only got worse. I began to have real difficulty walking and developed a rash-like pattern of tiny red spots on both ankles that looked like I was wearing a pair of light red socks. But I didn't realize it was a rash because it did not itch.

Realizing that I needed a more substantial diagnosis, not just sturdier shoes, I finally went to see my internist about increasing neuropathy. By then, I was using a cane to assure myself that I would not trip on the carpet or fail to lift my feet enough to negotiate thresholds or curbs. "There's a suspicious protein in your blood tests – Bence-Jones," the doctor said. "I want you to see an oncologist."

My wife was recently retired as a Hospice RN, and she had worked for the previous decade as a Certified Oncology RN. Although I knew nothing about a Bence-Jones protein, I certainly knew what an oncologist was, and I was shocked by the referral.

When I met the oncologist-in-solo-practice, he was pleasant enough. I was pleased when he said that he thought he knew what my internist suspected but also thought him mistaken. We would know for certain, he said, from a bone marrow biopsy. As I took out my pocket calendar to schedule this test, about which I knew nothing, the oncologist said, "No. I mean

I'll take the sample right now. Here's a gown. Disrobe, put it on, and hop up there on the exam table."

His nurse entered carrying what looked to me to be the largest syringe I'd ever seen attached to a hollow spike nail you could drive across the width of a 2x4. "You'll feel pressure as I insert this needle and press it into your pelvis," the now-not-so-seemingly-pleasant doctor said. "It may feel like I am extracting your toenails as I pull out the marrow," he continued. And did it! A light dressing, pants back on, I left his office with instructions to return later in the week.

The oncologist never did tell me what he thought my internist may have suspected when I returned for the results. What he did tell me took me several days to pronounce correctly and a week to learn how to spell it. W-a-l-d-e-n-s-t-r-ö-m's m-a-c-r-o-g-l-o-b-u-l-i-n-e-m-i-a. I left his office holding the pathologist's report informing me that 55% of my bone marrow was infiltrated with lymphocytic cells and that my IgM level was 685. He also provided me with a prescription for Leukeran (chlorambucil, a pill that I was to begin taking) and a page copied from a Merck Manual.

The copied page indicated that patients could expect to survive six to seven years, on the average, after diagnosis. The oncologist also added that I ought not take that dire prediction about survival too seriously, as the manual was somewhat out of date. Why, I wondered, did he give it to me if it was not accurate? However, reading that page from the manual caused me to focus more sharply on my future. And, after the initial scare, I also gathered some accurate information. For example, that Waldenström's was mostly a disease of older white men. Well, at least that was about right. It was late December and I had turned sixty in June. On the way home, my wife and I decided that I would retire as soon as possible and that in the future we would do only what we chose to, since it appeared that there was not all that much time left.

Retirement came in June 2001, and we located a new oncologist-hematologist near our retirement home. He said that while chlorambucil was a typical initial treatment, there were other options. He told me that he had had good responses from other patients with a relatively new treatment that he called a "monoclonal antibody" and that it was "off label" for Waldenström's disease. The new monoclonal antibody was, of course, Rituxan (rituximab). My new oncologist-hematologist asked if I wanted to give it a try. Why not? What did I know about "monoclonal antibodies" that were "off label"? I did know from information received from the IWMF that my IgM level was very near the normal range. Did I really need more treatment? This was beginning to be a very unusual disease. Could it be idiosyncratic, different, or possibly unique to each patient?

A Journey to Hope, cont. on page 15



I did know, too, what a bone marrow biopsy meant and did not look forward to another one, as requested by the new physician to confirm the diagnosis with his pathologist. A local anesthetic made this one a bit less traumatic.

I brought a full briefcase to my first Rituxan infusion, thinking that I'd have lots of time to read books and write on my laptop. Thanks to the 50 mg of Benadryl that I was given as a precaution against possible allergic reactions, I read and wrote very little. Instead I was afforded three-hour naps. I was somewhat embarrassed to enter the clinic treatment area and take my place on one of the many recliners – almost everyone else there was obviously really sick – and I came for a nap and a snack.

The next ominous experience occurred while attending the 2002 IWMF Ed Forum in Las Vegas. I was stricken with an almost disabling pain in my leg and was able to get through the weekend only with the help of Dr. Guy Sherwood, fellow patient, who provided me with sufficient painkiller. I knew Guy as he had phoned me, when he was recently diagnosed, to chat with another newly diagnosed WMer. This IWMF network was beginning to act like a family.

Back home from Las Vegas, an x-ray of my lower spine showed nothing, but an MRI revealed that a soft-tissue tumor had wrapped itself around my sacral spinal column. The tumor's location made surgery or radiation problematic, so my Rituxan provider and I opted for fludarabine treatment, assuming that the bone marrow infiltration had transformed into the soft-tissue tumor. Imagining the spinal tumor to be a serpentine entanglement, the meditation I had begun to accompany my infusions changed its focus. Through my mind's eye, my meditation focused on me standing victorious over a large dead snake, a universal symbol of evil. Within eight weeks of treatment with fludarabine and, I think, my meditative encouragement, the tumor had completely disappeared. To date it has not returned. The assumption that a lymphocytic cell transformation had taken place (the assumption which prompted our treatment option) was evidently correct. But who knows? Anecdotal examples do not a theory make.

At the advice of my original oncologist following his diagnosis of Waldenström's macroglobulinemia, I had contacted the IWMF in Sarasota and received a packet of information. This was the beginning of a steep but rapid learning curve. With invaluable information from the IWMF I also learned that the support groups nearest to my central Ohio residence were in Pittsburgh and Chicago. Not wanting to drive half a day to attend either group, I got Ohio-Indiana-Kentucky mailing addresses from Sara in Sarasota and established the West-Ohio-Eastern-Indiana-Northern-Kentucky group (WOEINKY for short) and led it for several years. On becoming an IWMF Trustee with responsibility for launching support groups, I turned over the WOEINKY leadership to others.

After the fludarabine treatment, I resumed a second series of Rituxan treatments. At my last bone marrow biopsy in late 2004, the pathologist determined that there were no lymphocytic cells in evidence and stated that I had "a complete response to treatment." By mid-2005 the "ankle-rash" was gone, as were almost all signs of peripheral neuropathy. I now see another oncologist annually, with blood tests at six-month intervals. My "hero oncologist" moved, making a continued relationship with him inconvenient. When I see the new doctor, I usually joke about coming in to help him with his boat payments. He grins.

Determined to fulfill our "bucket list," I served a couple of years as an IWMF Trustee and then re-directed our volunteer efforts to the AARP and the ACLU. An encounter with volunteers at Shenandoah National Park led us to yet another way to give our time. In 2008, we applied for and spent six winters as Volunteers in the Park at Big Bend National Park in southwest Texas. Three months in the Texas desert are a great way to spend a winter in Ohio!

The nomenclature itself was reason enough to work for the National Park Service: We were known as VIPs (no, not all that important, rather Volunteers in the Park). The volunteer position was work, thirty-two hours each week, which we could have split into sixteen each. But, after fifty-plus years of marriage, we're joined-at-the-hip and do few things apart, so we actually gave the Department of the Interior sixty-four hours a week for thirteen weeks each winter season. In exchange for our efforts, the Park Service gave us space to park our trailer, electricity, water, sewer access, and propane.

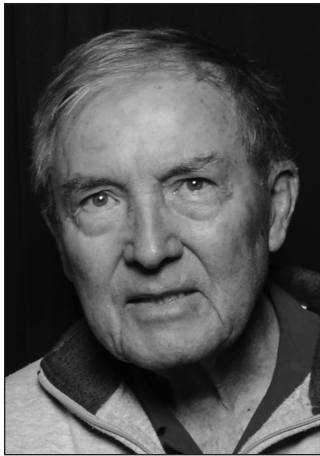
Three days each week, we managed a visitor center and book store, issuing permits and answering questions with an expertise that surprised us, the result of ten days of excellent classroom and in-the-field training that included an overnight river-raft trip down the Rio Grande. The final eight hours each week were spent on "special projects" that included hiking in uniform to be the "faces of the Park" to visitors, reclaiming a cactus-garden exhibit, demonstrating adobe-brick making, taking digital photo surveys of dozens of primitive grave-sites from pioneer days before 1944 when the Park was ranch land, and supplementing an oral history of the Park by conducting interviews with senior Hispanic men and women who had been ranchers and ranch-hands and who still live in southwest Texas. Interpreters assisted with our very limited Spanish, but our laptop keyboard skills served us well in the hours of transcribing the interviews to documents for the Park Archive.

But towing a 4-ton travel trailer across and back from Ohio to Texas with an F-150 and fuel prices at recent high levels became a physical and fiscal burden after six years, so we've retired from the National Park Service. An e-mail plea from Marcia Klepac, current Support Group Coordinator, prompted our return to being a part of the IWMF team by my resuming the leadership of the West Ohio Support Group, which we now call the WOWMERS.



A BIG BOOST TO THE RESEARCH FUND

THE BINGHAM CHARITABLE FUND GIVES \$500,000 TO THE IWMF



Dave Bingham

The Bingham, Dave and Jan as they like to be called, met in their native area of southeast England when Jan was 16 and Dave was 17 and were married in their early 20s. Dave's field of study in school was electronics, at a time when the integrated circuit was being invented. As Dave says, "You couldn't go wrong in electronics!"

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First of all, Dave feels that there are plenty of scammers, "bad guys," as he says, trying to take advantage of people. So the Bingham, Dave and Jan as they like to be called, met in their native area of southeast England when Jan was 16 and Dave was 17 and were married in their early 20s. Dave's field of study in school was electronics, at a time when the integrated circuit was being invented. As Dave says, "You couldn't go wrong in electronics!"

According to Tracy, Community Foundations find it easier to get responses from charities, and they tend to ask different questions and to dig deeper to learn about the various charities. The Community Foundation that the Bingham

The IWMF is very pleased to announce that David and Janet Bingham have become our latest Research Partners with the donation of a \$500,000 grant to support two exciting research projects. Research Partners are individuals or foundations committing to \$100,000 or more for research projects vetted and approved by our Scientific Advisory and Research Committees.

work with has four types of funds: donor-advised funds, endowment funds, designated funds, and bequest funds. Donors can be minimally involved or very involved. Over the years the Bingham, Dave and Jan as they like to be called, met in their native area of southeast England when Jan was 16 and Dave was 17 and were married in their early 20s. Dave's field of study in school was electronics, at a time when the integrated circuit was being invented. As Dave says, "You couldn't go wrong in electronics!"

Tracy began her process of vetting the IWMF by having numerous conversations with both Dave Benson, our Senior Development Officer, and Carl Harrington, our President. She discussed with them the various approved research projects that needed funding, narrowed down the number of projects, and took her research to the Bingham, Dave and Jan as they like to be called, met in their native area of southeast England when Jan was 16 and Dave was 17 and were married in their early 20s. Dave's field of study in school was electronics, at a time when the integrated circuit was being invented. As Dave says, "You couldn't go wrong in electronics!"

Through the Bingham Charitable Fund at the Community Foundation of Western Nevada, Dave and Jan Bingham decided to fund a \$500,000 grant to the IWMF, with 90% designated for Research and 10% for Member Services, payable over 5 years. Through the Bingham Charitable Fund's designation as a Research Partner, the Bingham, Dave and Jan as they like to be called, met in their native area of southeast England when Jan was 16 and Dave was 17 and were married in their early 20s. Dave's field of study in school was electronics, at a time when the integrated circuit was being invented. As Dave says, "You couldn't go wrong in electronics!"

The first project, co-funded with WMF Canada, was proposed to the IWMF by Dr. Brad Nelson and Dr. Julie Nielsen of the Deely Research Center, the British Columbia Cancer Agency, in Victoria, British Columbia. Drs. Nelson and Nielsen have found a way to generate highly specific killer T-cell responses against the MYD88 mutation, and they are performing the *in vitro* and mouse experiments that are necessary to prove the concept before launching a clinical trial. The project is funded for two years.

The second project supported by the Bingham, Dave and Jan as they like to be called, met in their native area of southeast England when Jan was 16 and Dave was 17 and were married in their early 20s. Dave's field of study in school was electronics, at a time when the integrated circuit was being invented. As Dave says, "You couldn't go wrong in electronics!"

By becoming a Research Partner, the Bingham Charitable Fund is supporting projects that will hopefully lead to breakthrough therapies and, eventually, a cure for WM. The Bingham, Dave and Jan as they like to be called, met in their native area of southeast England when Jan was 16 and Dave was 17 and were married in their early 20s. Dave's field of study in school was electronics, at a time when the integrated circuit was being invented. As Dave says, "You couldn't go wrong in electronics!"

A Big Boost, cont. on page 17

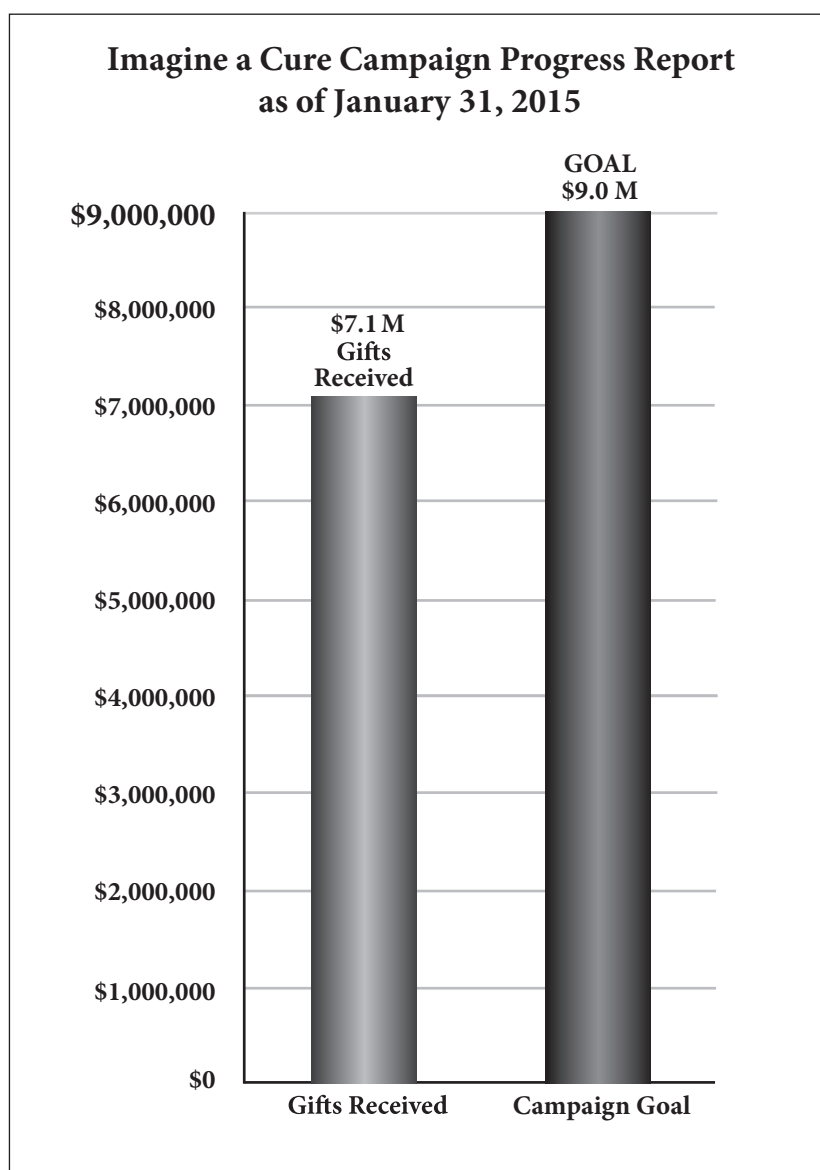


outcomes. Dave and Jan are indeed our partners in the true sense of the word since these research projects could not be conducted without their support. The Bingham and others who choose to become Research Partners will leave a lasting legacy with their donations.

Dave Bingham has stated, “As you get older, it’s important to look at where to give your money. Having a lot of money doesn’t necessarily improve the quality of life.” He adds that it is important to strike a balance. Once the family needs are taken care of, donors should do what they can to share their assets for the benefit of others. We are honored that the Bingham feel the IWWMF will be a good steward of their philanthropy and will make sure that their funds are used to support worthwhile projects.

While Dave has had Waldenstrom’s since 2006, his general health is “excellent – I can’t complain.” As has been noted in previous articles in the *Torch*, folks who give generously feel good about making donations to worthy causes. Perhaps this gift and pledge to the Imagine a Cure Campaign will continue to bring Dave and Jan good feelings and good health well into the future. All of us with WM will benefit from this research, none of which would be possible without the generosity of members like the Bingham.

If you or someone you know is interested in learning about making a multiple-year pledge, establishing a Named Gift Fund, or becoming a Research Partner, feel free to contact Dave Benson at Dave@dbenson.com or by telephone at 952-837-9980.



During the past 12 months commitments to the Imagine a Cure Campaign increased by \$2,360,000, bringing us to 79 percent of our goal. It was a very good year.

*If you are one of the donors who has helped bring us to this point, thank you for your generosity.
If you have not yet made your commitment to the campaign, we hope you will so do in 2015.*



COOKS' HAPPY HOUR

BY PENNI WISNER

Food writers like me pride themselves on offering seasonal food and recipe suggestions. But what are the seasons this year? As I write in mid February in Northern California, it is sunny, warm, and too terribly dry. In my garden, the rhubarb is growing, a pear tree is blooming, and the quince has begun pushing out new leaves. On the East Coast, once again, snow locks everyone indoors. What will it be like in April? Will the early spring crops – asparagus and watercress, for instance – be on their way to you? Or over completely?

Asparagus made its first appearance at the farmers market this morning. These early spears are thin; hopefully, they will fatten over the next few weeks. But, after so many months of none, I could not pass them up. “And what kind of potatoes do you want?” asked the young man behind the stand. Good upselling! I hadn’t planned on potatoes but his question reminded me of a favorite dish to make in the spring with fresh asparagus and small, new crop potatoes. Don’t think of potatoes as a spring offering? Think again and go in search of them.

Naturally, you have to cheat (the seasons) to make the dish. But you were not expecting purity I hope. Michael Chiarello taught me this combination of asparagus, tiny potatoes, and pasta when we worked on his big Tra Vigne cookbook. It is carbohydrate heaven. It is sauced with an asparagus-basil pesto. That’s the cheat. It is not basil season. So hopefully you have some in the freezer or you could buy a jar and brrrr it up with one bunch trimmed asparagus cooked until tender but still bright green, plus a handful of freshly grated Parmesan. To give the dish some textural contrast, first simmer the potatoes, halved if more than 1/2-inch in diameter, drain well, then sauté in olive oil until crispy, and salt well. Toss them with the hot pasta and asparagus pesto.

Today for a potluck, I turned the combination into a salad of fingerling potatoes, steamed romanesco, and steamed asparagus: In a bowl, toss steamed, small fingerling potatoes, halved lengthwise, with parsley pesto (Italian parsley, spring garlic, lemon juice and lemon zest, salt, pepper, and olive oil). Next, steam asparagus spears just until tender and cool in an ice water bath to stop the cooking. Drain and dry. Then, because romanesco is too beautiful to resist (Romanesco is that whorled, lime-green relative of cauliflower and is available at the same time as asparagus and new potatoes) cut

one into florets, steam them until tender, and then cool and drain as with the asparagus.

For the dressing, make a bright, strongly flavored lemon-anchovy vinaigrette: 4 to 6 anchovy fillets, 1 stalk green garlic, 1 tablespoon each Dijon mustard and mayonnaise, juice and zest of 1 lemon, 1 tablespoon red wine vinegar, 1/2 teaspoon sweet smoked Spanish paprika, salt and pepper to taste, and about 1/2 cup extra-virgin olive oil. Puree all that in a small food processor, and then taste and adjust the balance to your palate.

Toss the romanesco florets with some of the dressing in a bowl. Pile the potatoes in the middle of a platter and encircle with the florets. Arrange the asparagus on top and drizzle with more of the dressing. Lastly, sprinkle slivered, toasted almonds over all. Serve at room temperature. Hmmm. I see that this recipe has run on but you have three different vegetables that can be served separately or together.

And I did want to talk about watercress. It is now available year-round now but is traditionally available in spring and summer. It is crisp yet tender, peppery yet sweet, and who would guess such an innocent-looking green is such a nutritional powerhouse, even outperforming kale! For a quick and healthy snack, puree watercress with nonfat Greek-style yogurt, a little garlic, salt, pepper, and a little olive oil. Use the mixture as a dip for crudité or fill celery sticks with it. Or spread it on croutons and pave the tops with thinly sliced cucumbers. Use watercress anywhere you would use spinach or pea sprouts.

And, as we find our way to spring, I will leave you with a quick and versatile, no-cook soup or sauce for fish or baked potatoes (either white or sweet): simply puree defrosted green peas with a large bunch of watercress, some broth (chicken or vegetable or bean), and – if desired – a cooked potato or some drained, canned white beans or chick peas to add thickness. Season with lemon zest and juice, salt, and pepper and serve cold or heat just until warm. When serving as a soup, spoon a dollop of non-fat Greek yogurt on top of each bowlful and add a sprinkle of diced, fresh mint or minced fresh chives. To use as a sauce, pour a ladleful on warm plates, top with the fish, and then a dice of chives, parsley, or mint.

Our motto: Eat Well to Stay Well



FROM IWMF-TALK

BY JACOB WEINTRAUB, MD

Although this year's winter was particularly brutal in many parts of the country, the conversation on IWMF-Talk was very active and "warm." The highlight of the season was FDA approval of Imbruvica for the treatment of Waldenstrom's macroglobulinemia on January 29. Imbruvica is the first agent to be approved specifically for WM. This will be addressed elsewhere in the *Torch*. The approval certainly generated a lot of discussion about insurance coverage, including Medicare. Once again there were many human interest postings, not directly related to the treatment of Waldenstrom's but providing information and education about ancillary areas of interest to most of us. New members were welcomed, support was offered for those with issues, and congratulations were extended to many who are doing well.

HUMAN INTEREST ITEMS

IWMF-Talk Manager and IWMF Trustee **Peter DeNardis** posted several items not directly related to specific WM medical treatment or evaluation.

Pete posted a link to an article with the title "What your friends with cancer want you to know (but were afraid to say)." This article has many suggestions about things to say and ways to interact with people who have cancer. Interactions can include calling the person or members of his or her family to set up a date to come over to visit or to give help without waiting to be asked for it. Other suggestions are to "just listen," take pictures, and talk about other things going on in the world and life, not just the person's cancer. roadkillgoldfish.com/friends-cancer-want-know/ (A site of "common sense and other controversies with a sense of humor and a moral compass.")

Pete recommended an article on the website of the Kessler Institute for Rehabilitation, news-medical.net that provides some tips that hopefully would be of assistance to all those wonderful caregivers who selflessly tend to the needs of their loved ones.

One additional link from Pete was to an interesting article providing information about a book that can serve as a guide to help caregivers in their "heroic" role of tending to their chronically ill partners. It gives some

examples of very difficult situations for caregivers and some useful tips on how to negotiate such situations. well.blogs.nytimes.com/2012/4/09/caregiving-as-a-roller-coaster-ride-from-hell?r=1

Wanda H also posted multiple links to articles and other publications of interest to a more general audience. One link is to an article showing that, in general, cancer patients don't request unneeded tests. This conclusion was based on a survey of multiple oncologists, oncology fellows, and nurse practitioners immediately following visits with cancer patients. When there were requests for unnecessary tests, half were for imaging and the rest were for labs or genetic tests. drugs.com/news/cancer-patients-rarely-request-unneeded-tests-treatments-study-55619.html

This conclusion is reassuring considering that one of the ongoing discussions on IWMF-Talk is about various labs and imaging studies that are ordered by our hematologist-oncologists. IWMF-Talk participants also often discuss the need for studies that are requested by us, the WM patients. The study from *drugs.com* suggests that unnecessary studies are indeed requested but only by a small percent of patients.

Wanda also posted a link to an article from *KevinMD.com* about how patients can be medical educators. The article notes that the Mayo Clinic recently named a patient as its "visiting professor for 2015." This patient was designated an "e-patient – a patient who is equipped, engaged, empowered, and enabled to actively participate in his or her own care." In other words, the "e-patient" is the patient who comes to appointments well prepared with questions and with medical information. The e-patient for 2015 was selected by the Mayo Clinic residents to highlight the increasing importance placed on providers and patients working together. In the electronic era it is essential to educate medical students and residents to be prepared for patients who are informed, engaged, and expecting to participate in decisions about their care. kevinmd.com/blog/2015/01/patients-can-medical-educators.html

Jan H thanked Wanda for the article and commented on the similarity to all the participants on IWMF-Talk. She noted

From IWMF-Talk, cont. on page 20

HOW TO JOIN IWMF-TALK

Here are two ways to join:

1. Send a blank e-mail to: iwmf-talk-subscribe-request@lists.psu.edu
Make sure to enter the word "subscribe" as your subject, and do not sign or put anything in the message area (make sure you do not have any signature information in there). Also, do not put a "period" after "edu" or it will reject. Once approved you can post by sending e-mail to iwmf-talk@lists.psu.edu
2. Contact Peter DeNardis at pdenardis@comcast.net and provide your full name



there are many people who are willing to share information and help others with their problems. I suspect that most of us fall into this category in our interactions with our own medical provider, too. IWMF-Talk participants often report back that their own doctors are impressed with the knowledge and preparation that is brought to appointments.

One more link from Wanda is to an article in the *New York Times* by Susan Gubar, writing about her cancer experience. Gubar has a somewhat humorous approach to the unique terminology used in cancer centers. Although she does not have WM, her “snarky humor” – Wanda’s words – applies to situations many of us have encountered, and some of the terms she uses will bring a nod or a smile to most of us. well.blogs.nytimes.com/2015/01/22/living-with-cancer-coming-to-terms/

Many more links were posted to articles with human interest themes, related medical stories of general interest, and other topics, all of which provide valuable information or diversion.

IBRUTINIB/IMBRUVICA

Following the FDA approval of Imbruvica for WM treatment, there was considerable discussion about availability and insurance coverage, including coverage by Medicare. Some of the discussion was fairly detailed regarding specific costs, including the “donut hole.”

Linda A reported that the Leukemia & Lymphoma Society and the Chronic Disease Fund provide assistance in paying premiums and copays, although this is not insurance as such.

Anita L added that LLS assistance has been reduced to \$2500 this year because WM has apparently been reclassified from myeloma to lymphoma. Financial forms need to be filled out, but income limits are pretty high. Information is on the website lls.org.

David B noted that his drug plan with Blue Shield of California covers Imbruvica as per Medicare Part D.

There appears to be quite a variance in private coverages and supplemental coverages for Medicare. Many participants cautioned close attention to detail and filing, with possible need for appeal if insurance does not cover costs.

Further discussion again concerned side effects from this new treatment.

Gerri M repeated cautions from her pharmacist: Imbruvica should not be taken with grapefruit and products containing grapefruit. The pharmacist also cautioned about fish oil, which can pose a small risk of bleeding if her platelets are low. (Low platelets have been reported as an adverse effect of Imbruvica.) NSAID’s are to be avoided, too, for the same reason.

IWMF Trustee Sue Herms replied that, to the best of her knowledge, regular orange juice is allowed, but the full prescribing information sheet lists several antibiotics and antifungal medications that should not be used with ibrutinib.

Sue also reported a study that mentioned patients taking Imbruvica who developed nosebleeds while taking fish oil supplements. The fish oil was felt to interfere with platelet function because the nosebleeds stopped when the fish oil was discontinued. **Hank S** added that on the Dana-Farber clinical trial paperwork for Imbruvica, there were bold print warnings not to drink green tea and grapefruit juice and not to eat grapefruit, star fruit, and Seville oranges (used in marmalade).

There also were several reports of brittle fingernails and cracked skin from people taking ibrutinib. It is not clear whether winter weather or the medication is the cause. Reports came from several postings. **Vladimir N** reported his dermatologist prescribed Hylatopic Plus cream and this really works. One of the Dana-Farber staff recommended Hydrolatum which is available over the counter.

TRAVEL INSURANCE

Michael L contributed to an on-going discussion about travel insurance for persons with pre-existing conditions. Michael recommends Travel Guard (travelguard.com) following his extensive research. If a person signs up for coverage promptly after making travel reservations, the pre-existing condition limitation is waved with Travel Guard. Michael highly recommended that the purchaser read the policy closely before finalizing the purchase. Be sure to ask the company questions about any part that is confusing or not clear. He reported that this insurance would be considered supplemental to his own primary Kaiser insurance. Travel insurance may seem expensive, but, considering the cost of travel, it is cheap for providing peace of mind. Michael also suggested checking with our own insurance companies to see what coverage is provided when we are out of our home state or country.

SHINGLES

Kris S asked about shingles as a side effect of Rituxan treatment and whether most oncologists prescribe prophylactic medications such as acyclovir. Or is it better to wait and have a med prescribed for treatment after onset of shingles?

Ken W suggested that shingles is not an inevitable consequence of Rituxan treatment. However, he also suggested discussing the issue with one’s oncologist and obtaining a supply of acyclovir to start treatment if it appears a person is having an outbreak. **Hank S** reported his impression that shingles is **not** a common side effect of Rituxan. Hank has had quite a lot of Rituxan and has never had an antiviral prescribed to prevent shingles during solo Rituxan treatment. However, he did have prophylactic valacyclovir prescribed when he started Velcade treatment and continues today on valacyclovir, three years after the end of his Velcade treatment. **Lou B** commented that he participated in an early study on acyclovir back in 1987, before it was approved. Lou was not in the placebo group and



has continued taking acyclovir to this day. And he has never had shingles despite multiple treatments.

As **Anita L** indicated, shingles is a common side effect of any chemo that suppresses immunity, especially T-cell immunity. Anita got shingles after treatment with fludarabine in 2004 and has been on prophylactic valacyclovir ever since then. **Brad S's** oncologist prescribed acyclovir for him starting before Rituxan treatment and continued it for 3 months after finishing Rituxan treatment. Brad thinks his oncologist does this routinely for patients being treated with Rituxan.

The issue of the shingles vaccine was also discussed. **Kris S** began by asking whether the vaccine actually prevents shingles or results in a quicker response to treatment and a less severe case. **Ken M** reported that he received the shingles vaccine a couple of years ago and still got shingles after receiving the vaccine.

However, **Nancy R** stated that she asked her oncologist if she should get the shingles vaccine. His response was that this is a live virus vaccine and is contraindicated in people with a compromised immune system, so she definitely should not get the vaccine. Flu and pneumonia vaccines are not live vaccines and are recommended. **Dr. Jacob Weintraub** posted that this definitely is the correct recommendation. A person with a compromised immune system, such as a WM patient, should not receive live virus vaccines. Some people have received these vaccines and have tolerated them well, but the risk of complication is high. The list of live vaccines includes shingles, measles, the nasal flu vaccine, and others.

RITUXAN

Rituximab has become the “old standard,” and relevant postings are not so frequent as they once were. However, there is ofatumumab, a newer monoclonal antibody treatment that is humanized.

Ann posed this question: If so many people have problems with Rituxan, why is it still so widely prescribed? Why aren't more patients given ofatumumab? Are there legal reasons why it is not prescribed more often? **Hank S** posted that when he asked his oncologist about ofatumumab, the answer was a warning that Medicare wouldn't cover it unless a person absolutely could not tolerate Rituxan.

Dr. Jacob Weintraub wondered if the preference for Rituxan might have something to do with cost or safety. As a newer product, ofatumumab likely is more expensive than Rituxan. Also, Rituxan has been used longer and is more predictable in its effects and side effects. Insurance companies often want a patient to have exhausted all the more established treatments before authorizing use of a newer treatment. In addition, although some of the side effects of Rituxan are severe, they are manageable. Also, many people have posted good results with very few side effects from Rituxan. Some doctors may be waiting for more studies to be completed to document equivalence and safety for ofatumumab.

As the discussions continue, everyone is welcome to join and participate or just “lurk and learn.” The discussion topics cover the full range of medical and ancillary areas, too many to include in a column such as this.

If anyone would like to see more coverage of particular subject, I would welcome a note at: jweintraub922@gmail.com

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

ARGENTINA

MACROGLOBULINEMIA DE WALDENSTROM ARGENTINA: IWmf'S FIRST INTERNATIONAL AFFILIATE IN SOUTH AMERICA

The IWmf's first international affiliate in South America, Macroglobulinemia De Waldenström Argentina, was recently established in Buenos Aires, Argentina, under the leadership of Graciela Silvia Molina, MD. We hope for its success in reaching out and welcoming those in Buenos Aires touched by Waldenström's macroglobulinemia (WM). For further information about this support group, contact Dr. Molina at waldenströmmargentina@gmail.com

AUSTRALIA

PATIENT EDUCATIONAL MEETINGS

On February 18 a meeting for Sydney patients took place at Leukaemia Foundation Artamon. Current WMozzies topics were covered, and there was follow-up discussion from the previous meeting of “A practical guide to Waldenström's,” a 46-page document collated by Janelle Sullivan and distributed to all attendees.

On February 27 WMozzies participated in the Lymphoma Australia Education Day at Sydney University Concord Medical Education Centre with a break-out session for WM patients. The question and answer session was headed by bendamustine expert Professor Mathias Rummel and by

International Scene, cont. on page 22



principal investigator of the ibrutinib trial for WM patients in Sydney, Associate Professor Judith Trotman.

UPCOMING EVENT: MAY 23

The Lymphoma Foundation's Annual Blood Cancer Education conference will take place in the Parramatta district of Sydney with a special session for WM patients conducted by Dr. Constantine Tam, principal investigator of the ibrutinib trial for WM patients in Melbourne, as well as the ABT-199 clinical trial involving WMozzies patient and guitarist Colin Parrish.

WM PATIENT ADVOCACY

WMozzies are having their say to the Australian government on our need for access to the best WM treatments which are available in other countries.

11 February: Submission to Pharmaceutical Benefit Advisory Committee (PBAC) for Pharmaceutical Benefits Scheme (PBS) listing of Ribomustin (bendamustine). WMozzies feedback on completed submissions has been received from a wide cross-section of our members including all genders, thirty-year age span, and Eastern State domicile. The PBAC March 2015 meeting will be considering whether to recommend the funding of bendamustine. Bendamustine was approved in the US for B-lymphocyte cancers in 2008. In England, bendamustine is available and funded through the government-backed National Cancer Drugs Fund.

16 February: Survey by the Leukemia Foundation to assist their submission to the Senate Inquiry on availability of new, innovative, and specialist drugs in Australia. The Leukaemia Foundation received over 200 responses to the survey in the first three hours of opening.

27 February: Personal Submission to Australian Government Senate Inquiry into the availability of new, innovative, and specialist cancer drugs in Australia.

WMOZZIES WEBSITE

As with the IWMF recent launch of the new IWMF website, WMozzies are working to improve on the existing WMozzies website. WMozzies Advisory Group member Peter Carr has discovered previously undiscovered skills and now has the new WMozzies site in trial mode. A review panel of WMozzies has volunteered to review the site content and presentation prior to the launch of the new site in coming months.

WMOZZIES SUPPORT FROM THE LEUKAEMIA FOUNDATION OF AUSTRALIA (LFA)

The LFA continues to provide invaluable support for WMozzies. State-based WMozzies support group meetings are organised and hosted at LFA premises. The LFA also hosts quarterly WMozzies Australia-wide telephone forums. The LFA is currently assisting a WMozzies membership drive by contacting its database of WM patients, which is six times larger than the WMozzies mailing list, to invite them to join WMozzies. The LFA is also supporting WMozzies website development and creation of a donations website.

Andrew Warden, WMozzies, reporting.

BELGIUM

The Belgian Waldenstrom support group, CMP Vlanderen, is planning its next symposium for May 9. Information can be found at www.cmp-vlaanderen.be

Joanna Van Reyn, CMP Vlanderen, reporting.

FRANCE

The annual Patient Education Conference organized by the French association Waldenström France will take place on May 23 in Toulouse, at the Hotel Le Clocher de Rodez. Presenters will be Dr. Philippe Paux, General Practitioner, Dr. Loïc Ysebaert of the Department of Hematology and researcher at the Center for Research in Cancer, University of Toulouse, and Dr. Pierre Morel, Department of Hematology Clinic, Lens Cedex. Information can be found at portail.waldenstromfrance.org/journee-rencontre-des-patients-atteints-de-la-maladie-de-waldenstrom

Patrice Osterman, Waldenström France, reporting.

ITALY

As previously announced in the January issue of the *Torch*, the WM Patients Support Group of Italy (WM-IT) was established at the end of 2014 under the aegis of the Department of Hematology of the Niguarda Ca' Grande Hospital in Milan and the Associazione Malattie del Sangue (Association of Blood Diseases) ONLUS, with the guiding support of the President of the Associazione Malattie del Sangue ONLUS, Dr. Enrica Morra. Dr. Morra is also Advisor for the Hematological Scientific Research of the Ca' Granda Hospital, Scientific Coordinator of the Hematological Network in Lombardia, and recipient of the prestigious Jan

International Scene, cont. on page 23

WM-España: the IWMF's Most Recent International Affiliate

The establishment of the IWMF's most recent international affiliate, WM-España, was announced as this *Torch* went to press. WM-España is based in Navarra, Spain, under the leadership of Miguel Angel Berrueta. We hope for its success in reaching out and welcoming those in Spain touched by Waldenstrom's macroglobulinemia (WM). For further information about this support group, contact Miguel Berrueta at berruetadecora@gmail.com



Waldenström Award for her lifetime achievement in the research of Waldenström's macroglobulinemia, awarded at the recent workshop IWWM8 in London.

In the first months since its establishment, the Italian WM Patients Support Group has been quite active while in the process of defining the activities and services it will provide to WM patients, families, and caregivers within Italy.

THE E-MAIL LIST

The first step for our new organization was the creation of an e-mailing list (wm_it@googlegroups.com) aimed at sharing experiences and information among all members of the group (numbering approximately twenty persons at the outset). The mailing list is open to all. Contact information: to subscribe, simply communicate name and phone number by e-mail (wm_it@malattiedelsangue.org) or by telephone (Marco Balducci +39 339 78 03 373).

AWARENESS THANKS TO *EMATOS*

Further outreach and awareness of IW-IT is to be provided by support from the Associazione Malattie del Sangue (Association of Blood Diseases) ONLUS through their publication *Ematos*. A publication in magazine format, *Ematos* spreads information about medical issues in a language accessible to all. Beginning March 2015, *Ematos* will include as a regular feature a section wholly dedicated to the Italian WM Patients Support Group!

FIRST SUPPORT GROUP MEETING

On January 30 the first meeting of the Italian WM Patients Support Group was held at the Hospital of Niguarda

Hematology Department. The meeting opened with a presentation by Dr. Annamaria Frustaci, hematology specialist of Niguarda, together with Dr. Alessandra Tedeschi and Dr. Paola Picardi, who discussed the diagnosis, symptoms, and current therapeutic options for Waldenström's macroglobulinemia. Special emphasis was given to therapeutic combinations that include new "biological" drugs, for example rituximab (Rituxan) and ibrutinib (Imbruvica). Dr. Morra next provided an update on the use of ibrutinib in the US with excellent results in clinical trial. Recently the FDA approved the use of the drug for WM patients in the US, even for first-line treatment, while currently ibrutinib is authorized in Italy only as part of treatment protocols. It is anticipated that ibrutinib will also be available in Italy as a first-line treatment in about one year. Following the medical presentations, the meeting continued with discussion of the need of voluntary involvement of patients and families in supporting the group's activities, the aim of the group to address particularly the issues of wellness and lifestyle of WM patients in ways complementary to treatment protocols. Finally, the group discussed the project proposal developed by the Associazione Malattie del Sangue ONLUS to provide support and enrichment to future group activities.

FUTURE EVENT: JUNE 16

The next support group meeting of the Italian WM Patients Support Group will be on June 16 at 2:00 pm. Our special guest on this occasion will be Dr. Steven Treon, director of the Bing Center for Waldenström's Macroglobulinemia, the Dana-Farber Cancer Institute, Boston.

Ermanno Chiavaroli, WM-IT, reporting.

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

Please note: contact information for all support groups is found at iwmf.com under **GET SUPPORT – US AND INTERNATIONAL SUPPORT GROUPS**.

CALIFORNIA

Northern CA

In January the Sacramento/San Francisco Bay Area support group held a meeting in San Jose for the first time. This location drew some WMers who had not been able to travel to other meeting spots in Roseville and Vallejo. **Rose Crownover** asked her local oncologist, Dr. Thomas Chen, to join the meeting. Dr. Chen participated in the circle discussion of personal progress with WM, and members felt lucky to have Dr. Chen answer so many questions. The meeting took place in the Cancer CAREpoint office. Cancer CAREpoint is a local non-profit cancer organization which offers services to all types of cancers. However, they had never heard of the IWmf before!

Southern CA

The Southern California chapter of IWmf will participate in the 2015 Blood Cancer Conference sponsored by the Leukemia & Lymphoma Society (LLS) at the Anaheim Marriott near Disneyland in Orange County, CA, on Saturday, May 7. Six volunteers, WMers and family and friends, will man a booth from about 8 am to almost 5 pm. They will talk about the IWmf and its work and hand out literature provided by the IWmf office. LLS sponsors the annual Blood Cancer Conferences in the Los Angeles area, and they have all been very successful. During these events, numerous people sign up to be on the mailing list and make plans to come to future support group meetings. Every year the support group holds one or two Saturday afternoon meetings at a local hospital, most recently at the Hoag Hospital Cancer Center in Newport Beach. About 40 people attended last November when Dr. Tanya Siddiqi of the City of Hope Comprehensive Cancer

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Attendees at the recent support group meeting in San Jose: from left to right, John Justice, John Sherman, Rose Crownover, Alyce Rossow, Steve Tidd, Cindy Jordan, Sharon Leonard (behind her mother).

Center discussed the latest research and clinical advances in the combating and treatment of WM.

IDAHO

The 'around-the-kitchen-table' support group continues to meet on a quarterly basis plus frequent phone calls. The group is quite small in number with just five members: two WMers, two spouses, and the wife of a now deceased member. Mid January we all gathered to celebrate the sixtieth wedding anniversary of **Barb and Jerry Britschgi** at a party hosted by the children and grandchildren of the couple. See the photo of the Britschgi family taken by **Janet Corson Stanton**. All group members attended the festivities. In March **Marsha Stanger**, Janet Corson Stanton, and Barb Britschgi enjoyed the quarterly lunch at their favorite Mexican restaurant, sharing the latest *Torch* reports and their latest WM status reports. But, during the leisurely lunch, the members shared family news as well and highlights such as the anticipated arrivals of grandchildren, upcoming weddings, graduations, and more. WM has now been a part of their lives for many years: Janet was diagnosed in 2000 and Barb a year later.

ILLINOIS

Chicago Area/SE Wisconsin

The group plans to hold its first 2015 meeting on Saturday April 18 at Advocate Lutheran General Hospital in Park Ridge, IL, at 12:30 pm. The program will include remarks from recently retired Christine Winter, MD, FACP, who served as a hematologist/oncologist with Illinois Cancer Specialists, as an attending physician at Adventist Hinsdale and Bolingbrook Hospitals, and as an Assistant Professor and Consultant in Clinical Medicine and Hematology at Northwestern University Medical School, Chicago (1981-1991). The group eagerly anticipates an informal presentation regarding the treatment of WM patients and a lively Q & A.

Lots of new patients can look forward to discussion of the many new drugs available for WM treatment. Dr. Winter has served many WM patients from the Chicago area as well as from our support group. And soon it will be time for the group's famously fun and delicious annual summer picnic.

INDIANA

After a long winter without meetings, a good turnout is expected to hear Stacey Koleszar, patient director of the Indiana chapter of LLS, at the Saturday April 18 meeting. She will present an informative talk describing LLS patient resources and programs. The program will take place at the LLS building, 9075 North Meridian Street, Indianapolis IN 46260, Suite 150. The program will be followed by a general discussion with time for sharing and questions. Coffee and breakfast snacks will be served.

MAINE

To date, there's been no WM support group in the area and new co-leaders **Konnie Stinson** and **Carolyn Kauffunger** look forward to providing support and education. Konnie and Carolyn have been working to get the new group off the ground and are planning to host the meetings at the Cancer Community Center in South Portland. The IWMF support group is affiliated with the local office of the New England Cancer Specialists, and Konnie and Carolyn are excited about the forthcoming opportunities. Their target start date for a first meeting is summer 2015. Konnie's career in federal law enforcement brought her to Maine from California in 2001. Shortly thereafter she earned an RN degree and held nursing positions in the hospital, worker's compensation, and health insurance industries. The birth of her son in 2011 took her in yet another direction, this time as a stay-at-home mother. She is also an experienced WMer, having undergone two rounds

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*The sixtieth wedding anniversary of **Barb and Jerry Britschgi** was the occasion of a festive celebration, including all support group members, hosted by the children and grandchildren of the couple. Warmest congratulations to Barb and Jerry!*

of chemotherapy and an autologous stem-cell transplant since her diagnosis in the spring of 2013. In her spare time, Konnie takes full advantage of Maine's outdoor recreation opportunities, including running, paddleboarding, and skiing (see *Torch* 16.1 (January 2015) pages 11-12). She is excited to get the new support group off the ground and to facilitate an environment where her fellow Maine WMers can come for education and support.

NEW MEXICO

Ginny-Kay Massara is working on setting up a new group for the area. She plans on a meeting once good weather can be counted on. The first program will present DVDs of presentations from the IWMF Educational Forums for patients.

NEW YORK

New York City

The group is doubly lucky; first to have the magnificent Mahon Patient Resource Center, a gift of light, airy space, as the location for its bi-monthly meetings. The wonderful doctors and staff at Weill-Cornell Medical Center worked hard to make this happen. And second, the January meeting featured a guest visit from Dr. Richard Furman of Weill-Cornell. He was fulfilling a promise made in 2011 to return and update the group on the progress made since then. Dr. Furman gave a terrific talk about the biology of WM as it is currently understood, and then went on to discuss three promising drug targets under investigation: SYK (for which ACP-196 is being developed); BTK (which has already led to Imbruvica); and PI 3-kinase (idelalisib). Dr. Furman's talk was a wonderful, upbeat way to start 2015, and the group is very grateful for the care and support shown by Weill-Cornell.

OREGON/ SOUTHWEST WASHINGTON

It was an uncharacteristically sunny, dry day at the end of January; yet about 20 group members chose to celebrate the unusual weather by gathering to share their WM journeys with each other and to listen to Dr. Stephen Spurgeon of the Oregon Health and Science University (OHSU) and the WM physician for some of the folks in the room.

The meeting opened with

each patient telling the group when they were diagnosed, the treatments they've received, and how they are feeling now. After that sharing, Dr. Spurgeon reported news from the recent Annual Meeting of the American Society of Hematology. While there were no major breakthroughs to report, there were studies of new drug regimens to discuss as well as several open clinical trials at OHSU of next generation pathway inhibitors. The group is jointly supported by the IWMF and the LLS. The new LLS liaison, Kristin Sacco, who has replaced retiring Sue Sumpter, also attended the meeting.

VIRGINIA

Northern Virginia

The theme of our second Northern Virginia support group meeting at INOVA Life with Cancer Center in Fairfax, VA, was "Sharing Your Waldenstrom's Journey." Group member **Caral Mechling Bennett** convinced Suzanne Moore, Oncology Certified Nurse from Kaiser Permanente with twenty years of experience, to join the group for the afternoon and to act as a medical "sounding board." **Bonnie Beckett** kindly assisted with check-in. Sixteen members and caregivers attended and all openly discussed their WM diagnosis, symptoms, treatments, side effects, and hopes for the future. The personal experiences we heard during the ninety-minute period of sharing were quite varied, and many members jumped in to support one another in their stories. Several members expressed concern about finding a doctor who specializes in WM, and a number of members as well as the group leader encouraged them to seek a second opinion from a WM specialist by referring to the IWMF website for the list of doctor resources across the country. There was a strong interest in hearing more about a full range of current and upcoming therapies for our rare disease, including Imbruvica (ibrutinib). Our meeting was held shortly before the history-making news broke of the FDA's approval of ibrutinib specifically for WM patients.

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WASHINGTON

Seattle

A report from the first meeting after a long gap lasting years, planned for March 2015, will appear in a future issue of the *Torch*. Meanwhile, the new group leader, **Shirley Ganze**, introduces herself as follows: "I was diagnosed in October 2012 when I realized I was far more tired dancing Viennese Waltz and quickstep than usual. One week later I was diagnosed with WM with an IgM of almost 10,000. I immediately started on Rituxan, and in January 2013 a weekly Velcade (bortezomib) shot was added. By March 2013 I was back on the dance floor, but I continued with that drug regimen for another year. By November of 2014 my IgM was 241. For a year now I have been back fulltime into my passion for ballroom dancing, traveling, and checking activities off a bucket list: in November I did seven zip-lines over the rainforest canopy in Costa Rica and loved it! I am retired from being a museum consultant with a specialty in Chinese

ceramics. I cataloged collections, mounted exhibitions, and wrote a book on Chinese export porcelain. I taught seminars on Chinese art for the Smithsonian for years, and regularly lectured to their tour groups in China as the Study Tour Leader. One time I went back and forth to China three times in three months, two of them for the Smithsonian, the third when I traveled across the Silk Road in Central Asia. I never knew what time zone I was in. In 1998 I lived in Taiwan for an academic year studying Chinese. Currently, I still do some museum publication editing, but mainly I volunteer to help catalog collections at the Museum of History and Industry in Seattle, give community disaster preparation talks for the American Red Cross, and now work as the IWmf Pacific Northwest Support Group Leader. Last, but certainly not least, I enjoy three grandchildren, two of whom live near me. Life is good."

Change in Listing of Support Group Information

The newly launched *iwmf.com* maintains a comprehensive and continuously updated listing of contact information. Click on GET SUPPORT, then in the drop-down menu select **US AND INTERNATIONAL SUPPORT GROUPS** and then select the US state or foreign country of interest.

Because the details of these groups are subject to frequent change, **the quarterly *Torch* will no longer publish lists of US and international support groups, support group leaders, and contact information.** Refer instead to: *iwmf.com*-**GET SUPPORT-US AND INTERNATIONAL SUPPORT GROUPS** for the easy-to-find, up-to-the-minute information you are looking for.

If, however, you do not have ready access to an Internet-enabled device, you are always welcome to contact the IWmf Office for information via e-mail, telephone, or even postal mail.

WHAT IS THE IWmf LIFELINE?

The IWmf LIFELINE is a directory of volunteers available to WM patients and caregivers to speak about their personal experiences with specific drugs and treatments.

The LIFELINE is your link to reach out to someone who has the same diagnosis when you have questions or concerns about your disease. An international list is maintained as well as the list for volunteers within the US. Also included is a list of volunteers who speak languages other than English.

The current LIFELINE is printed below and also is accessible online at *iwmf.com* under GET SUPPORT. Since the LIFELINE is frequently updated, you are advised to check

the online listing for the most recent information. However, as a service to *Torch* readers, the LIFELINE will be published in the *Torch* twice each year, in the April and October issues.

Many WM patients and caregivers have used the LIFELINE over the years and have commented on the value of the one-on-one interaction with the LIFELINE volunteer and the sharing of experience. This is a great resource for our community and we encourage you to use it.

If you are interested in becoming a LIFELINE volunteer, please contact Gayle Backmeyer at divagayle@comcast.net



IWMF LIFELINE

Treatment

Treatment	Contact	E-mail	Telephone
2-CDA (Cladribine with Rituxan)	Bernard Swichkow	bswichkow@braae.com	305-670-1984
Bendamustine	Leslie Neustadt	lesbn96317@aol.com	518-374-8607
Bendamustine & Rituxan	Vicki Marino	Vlm4588@yahoo.com	330-393-4588
Bortezomib, Dexamethasone, & Rituxan (BDR)	Ron Linford	Rongl@aol.com	865-657-9895
CaRD (Carfilzomib, Rituxan, & Dexamethasone)	Mindy Caplan	mindycap@yahoo.com	504-309-2247
Chlorambucil			
Oral Cytosan	Lou Birenbaum	lbirenbaum@aol.com	314-961-5591
DRC (Dexamethasone, Rituxan, & Cytosan)	Alice Riginos	ariginos@me.com	202-342-1069
Everolimus (RAD001)	Larry Adam	admiralsiker@hotmail.com	608-774-3949 © 608-872-2263 608-754-3949
Fludarabine & Rituxan	Jerry Block	jblock35@comcast.net	301-460-9799
Ibrutinib (Imbruvica)	Mitch Orfuss Hank Stupi	morfuss@aol.com hstupi@hotmail.com	646-352-4476 804-758-4096
Ofatumumab	Rob Clark		518-298-2611
R-CVP	Allen Weinert	anweinert@gmail.com	760-704-1344
Lenalidomide	Chris Patterson	Christopher_patterson@dfci.harvard.edu	617-632-6285
Rituxan	Allen Weinert Mel Horowitz	anweinert@gmail.com wmcure@yahoo.com	760-704-1344 518-449-8817
Rituxan Maintenance	Sue Herms	suenchas@bellsouth.net	843-801-0989
Thalidomide	Mel Horowitz	wmcure@yahoo.com	518-449-8817
Velcade subcutaneous	Allen Weinert	anweinert@gmail.com	760-704-1344
Allogenic stem cell transplant	Eileen Sullivan	Ebsullivan27@gmail.com	617-625-6957
Autologous stem cell transplant	Scott Blazek	mandsblazek@aol.com	651-730-0061
IVIg	Ron Linford Peter DeNardis	rongl@aol.com pdenardis@comcast.net	865-657-9895 724-462-9458 © 412-624-1092
Plasmapheresis	Fred Bickle Fay Langer	Flb134@msn.com Fhlanger@gmail.com	805-492-4927 904-625-3135
Splenectomy	Kathleen Ugenti	Vugentil@optonline.net	631-470-0971



Other WM Issues

Issue	Contact	E-mail	Telephone
Amyloidosis	Leslie Neustadt	lesbn96317@aol.com	518-374-8607
Anemia due to WM	Marcia Klepac	marciaklep@hotmail.com	412-421-2437
Cryoglobulinemia	Fay Langer	fhlander@gmail.com	904-625-3135
MGUS	Mary Beth Nivens	mbnev@sbcglobal.net	203-375-7748
Newly diagnosed	Guy Sherwood	foxfiremedic@gmail.com	
Peripheral neuropathy	Gayle Backmeyer Tom Hoffman	divagayle@comcast.net thh97@msn.com	765-962-3746 501-868-8305
Watch & wait	Mel Horowitz Guy Lithwin Renee Paley-Bain Joel Rosenblit	wmcure@yahoo.com glithwin@sccoast.net paleybain@aol.com rosenblitj@gmail.com	518-449-8817 843-234-3310 203-744-7851 503-3657074
Young WM	Ryan Scofield Bob Bailey Scott Blazek	ryanscofield@gmail.com Bbailey@rune2e.com Laurabailey64@gmail.com mandsblazek@aol.com	312-576-9429 770-633-3536 770-361-4859 651-730-0061

US LIFELINE Specialty Topics

Topic	Contact	E-mail	Telephone
Affordable Care Act	www.ils.org		800-955-4572
Caregiving	Lynn Bickle	Flb134@msn.com	805-492-4927
Clinical Trials	Tom Hoffman	thh97@msn.com	501-868-8305
Hearing impaired TTY Facility	Betty McPhee	bjmcphoe@hotmail.com	647-348-7440
Military Veterans	Daniel Costigan Glenn Ross	dancostigan@hotmail.com GSR060647@aol.com	952-841-0174 305-808-4170 214-317-9494
Social Security Disability	Howard Prestwich	prestwichh@gmail.com	815-233-0915

International LIFELINE

Country	Contact	E-mail	Telephone
Arabic speaker	Sherine Elsawa	selsawa@niu.edu	815-753-7839
Australia	Peter Carr Andrew Warden	petercarr@iprimus.com.au Andrew.warden@bigpond.com	+61 75 552 90518 +61 75 552 90518
Belgian speaker	Joanna Van Reyn		+32 93 354660
Canada LIFELINE		http://wmfc.ca/local-support/canadian-lifeline-contacts/	



International LIFELINE

Country	Contact	E-mail	Telephone
Dutch speaker	Paul Theuns	pjtheuns@planet.nl	
Finnish speaker	Veikko Hoikkala	veikko.hoikkala@dnainternet.net	+35 85 500484864
French speaker	Patrice Ostermann	Pat.ostermann@orange.fr	+33 62 2347426 +33561712525
German speaker			
Japanese speaker	Tony Undo Otani (U.S.)	adyna@msn.com	562-924-0150
Spanish speakers (all in U.S.)	Peter Mitro Betty Beazley Leon Maya Brad Smith	stonehill@earthlink.net betsybeazley@gmail.com leonmaya55@gmail.com becandbrad@gmail.com	Ohio 216-591-1004 Florida 561-495-4299 510-527-5827 865-860-9216 808-694-9581
Sweden/Norway	Anne Odmark	Ag.odmark@gmail.com	+46 18 140513
UK LIFELINE		http://www.wmuk.org.uk/about-wm/links	

Introducing Three New Members, cont. from page 5

was also conveniently close to two of four grandchildren). Recently, however, she has moved to Doylestown, PA (a move bringing her closer to the other set of grandkids).

Eileen speaks enthusiastically of a passion for photography and for cycling, and says she is happiest when combining the two – cycling with camera at hand in surroundings to

inspire the photographer. Once the rigors of winter 2015 are over, Eileen and her husband will be headed for an energetic photographic vacation in Europe, from Berlin to Prague, on – you guessed it – wheels!

Eileen is excited to volunteer her skills to the IWFMF, her first venture into the non-profit arena.

In the Torchlight, cont. from page 8

During my early years as a WM patient, I discovered the IWFMF and attended the yearly Educational Forums. I was lucky enough to be sent to Paris and Athens to cover the IWWM Workshops. The IWFMF has been a blessing in my life and has helped many times over when making tough decisions. I have made many friends and am very grateful. I hope I haven't made too many enemies. I am also very sad as I reminiscence over the many friends I have met who are no longer with us.

I switched to EGCG capsules instead of Essiac since this seems to be the agent in green tea that is active. I don't know if it actually works, but my graph is pretty convincing to me.

Since EGCG is cheap, I refuse to stop it.

My son is now twenty-two, in medical school, and is all over the MYD88 issue, and I am still operating on people, albeit on a much slower schedule.

I don't know what the future brings but am thrilled to have made it this far. I have always refused to let this disease define my life and hope all who read this will do the same. Do not succumb to just being a cancer patient. Keep a positive attitude. Stay involved socially and enjoy life as best you can. I know that will be tough for some, but you have to try.

We are slowly whipping this disease.

A Journey to Hope, cont. from page 15

It is good to be back. I do hope that the Merck Manual has been updated! But now I have to learn how to pronounce and spell i-b-r-u-t-i-n-i-b. Even if I have no expectation of needing one of the new treatments, “complete response to treatment” way back in 2004 does not mean “cured.” There

is still not enough known about WM and its treatment to use such words with certainty. Whatever time and effort we can offer on the IWFMF team barely begins to measure up to the gratitude we want to express to the IWFMF for the knowledge, support, courage and hope it offered a very anxious “newbie” fourteen years ago.



**SINCE NOVEMBER 2014, THE FOLLOWING CONTRIBUTIONS TO THE
INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:**

Harry Abramoff
Kimiko Ise Abramoff

Rod Anderson
William Crawford

Jeff Atlin
Stuart Sinukoff

John Austin
Paula Austin

Edward Baer
Cindy Baer

Eric Birmingham
Joan Birmingham
Neal & Amy Foley

Bernie Bosley
Gregory & Marilyn
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Bruce Braaten
Kenneth Bergsma
Green Valley Recreation
Racquetball Club
Kenneth Jensen
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Theodore Evanish
Patricia Franks Evanish

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Mafalda Giustiniani
Simona & Michelle Cimato

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Eleanor Howenstine
Cathy Mack

Florence Huskins
Jeff Prupis & Wanda Huskins

Hal Johnstone
Bob & Judy Wagner

George H. Katz
Francine Varady

Lawrence Kelly
Sam & Doris Mathis

Terry Kilsby
Kevin Kilsby

Betty Klein's Brother
Malcolm & Judy Roseman

John Kovich
Paul & Nancy Berrigan

Michael Lesmister
Gay Lesmister

Alice Levine
Marvin Levine

Ronald Levy
Bernard Pasternack

Don Lindemann
Ellen Smith

Pearl Long
Wesley & Joan Crow

Sylvia Jean Luadtke
Gordy & Donna Best
Richard & Sharon Bosell
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Leonard & Wendy Dupre
Kent Eggleston & Carolyn Buth
Virgil & Janice Fedorenko
Frank & Karen Gagliardi
Clarence & Mary Ann Gervais
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Karen Hamre
Steve & Carol Hanson

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Adam & Julie Luadtke
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Mary Clare Mahoney
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Anne M. Mann
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Bob Martin
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Maryetta Mayer
Susan Allen
David & Carol Kratenstein
Bob & Dede Thompson
Adonna Yuse

George & Rita McDonnell
Anne Marie Vale

Dugger McNeil
Lea & Bill Hardman

Chuck Michel
Laurel & Emily Michel

Jeanne Milton
Marshall Milton

Ray Morgan
Larry & Dolores Johnson
Michael Morgan

Carolyn K. Morris
Maynard Morris

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Geoffrey William Mould

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Charles Murenbeeld

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Anita Y. Nelson
Helen Steadman

Peg Newberg
Marco & Karen Fiorello

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Donna Ooghe

Richard Owen
Frances Owen

Nathan Pettengill
Sarah Pettengill

Sharon Potesman
Ira & Sue Bernstein

George Prill
Adele Prill

Roberta Reed
Connie Reed

Lani Regis
Moshe & Eta Kwart

Bob Resnik
Sharon Resnik

Henry Rimmer Jr
Christina Rimmer

Carol Rodgers
Eugene Rodgers
Melissa Rodgers

Jackie Romanello
Tom Romanello

Susan Rubenstein
Ira & Sue Bernstein
Jeffrey Rubenstein

Ben Rude
Mikhail Souponitski &
Susan Gross

Max Samkoff
Bob & Judy Wagner

William M. Schieber
Susan E. Schieber

Alison Seidenberg
Seymour & Muriel Tinkleman

Ronald Shelffo
Tom & Charlotte Lockwood
Anne Shelffo
Philip & Camille Spletzer

Patricia Small
Daniel McGrath

Louise Smith
Robert & Shirley Losasso

Arnold Smokler
Fred & Lynn Bickle

Arnie & Bernie Smokler
John & Barbara Manousso

Burton A. Strnad
Steve & Susan Schnoll

Richard Swain
Charles Appler
Robert & Carol Swain

Gustavus F. Swift
Carl Harrington & Eleanor Levie
Michael & Carol Sesnowitz

Laurita Treat
Donald Treat

Charles Vassallo
Lucrezia Vassallo

Harry Wahl Sr
Harry & Kathi Wahl

Beulah Weinberger
Francis Cerniglia
Cohen Greve & Co. CPA, PC
Amy Cooper
Helen Gitlin
DeeDee Kramer
Ronald Margolies
Roni, Gary & Smoke Murillo
Howard Newman
Howard & Madlyn Steinhart

James H. Weir
Joyce Weir

Jim Werner
Ellen Werner

Milton Wirth
Robert Wirth

Joan Zeidner
William Zeidner

Jan Zimmerman
Brad Zimmerman

Albert Zucker
Jeffrey & Julie Kuhn & Family



**SINCE NOVEMBER 2014, THE FOLLOWING CONTRIBUTIONS TO THE
INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:**

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Ray Adamiec
All Caregivers
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Claire Anderson
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Keith Anderson
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Peg Bohanon
Elaine Bohanon
Kathleen Bohanon
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Ronald Branscome
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of Catherine Brotzman**
Catherine Brotzman
Kyle & Deborah Brunelle
Thad & Sylvia Raushi
**Chuck Caroselli &
Janet Livingston**
Mary Anne Callaghan
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Fred Warnick
Owen Crownover
Raymond Valadez &
Rose Crownover
Nancy Curtis
Robert Banzett
Dennis & Amy Daraghy
Daniel Odell
Julie Davidson
David Fullen
Lorraine DeLucia
David & Peg DeLucia
Pete DeNardis
John & Penelope Paasch
Andrew Warden
Caroline Dew
Marty Zumbrunnen &
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Jane Dobies
Karen Dobies
Joy Dulin
Michael & Jan Dulin
Michelle Elder
Brad Elder
Dr. Christos Emmanouilides
Fred & Lynn Bickle
FDA Approval of Imbruvica
Sue Herms
Cindy Furst
Hoyle Curtis
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Earl & Evelyn Furst
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Ray & Janet Furst
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Ray & Janet Furst

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Anita Nelson**
Helen Steadman
John Ganser
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Robert & Meryl Selig
Cynthia Gavin
Joyce Sullivan
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Larry Falzarano & Beth Hurley
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Ed Goldberg
Al Senter
Joe Green
Michael Williams
Nicole Williams
Richard & Karen Williams
Ryan Williams
Dr. Daren Grosman
Ronald & Elaine Levy
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Another BTK Inhibitor Under Development

Ono Pharmaceutical Co., Ltd. and Gilead Sciences, Inc. have entered into a license agreement for the development and commercialization of ONO-4059, another oral BTK inhibitor. Ono Pharmaceutical has presented Phase I preliminary data showing clinical activity in chronic lymphocytic leukemia (CLL) and non-Hodgkin's lymphoma. ONO-4059 is being developed as a single-agent therapy and in combination with approved and investigational agents, including combinations with several kinase inhibitors in Gilead's drug portfolio.

Two New Small Molecule Inhibitors Target B-Cell Pathways

Curis, Inc. and Aurigene Discovery Technologies are jointly developing an oral small molecule antagonist of PD-L1 and an oral small molecule inhibitor of IRAK4 and expect to file Investigational New Drug applications in 2015. IRAK4, in particular, is a downstream target of MYD88, which is dysregulated in WM and in a subset of diffuse large B-cell lymphoma.

New Monoclonal Antibody May Prevent Rituximab Resistance

BioInvent International, Cancer Research UK, Cancer Research Technology, and Leukaemia & Lymphoma Research are collaborating to fund a Phase I/II trial of BI-1206 in patients with chronic lymphocytic leukemia and non-Hodgkin's lymphoma. BI-1206 is a fully human anti-CD32b monoclonal antibody that, in addition to directly killing tumor

cells, is thought to work by maintaining CD20 on the cell membrane of B-cells, thus preventing them from becoming resistant to rituximab. This study will enroll between 50 and 60 patients who will receive either BI-1206 alone or in combination with rituximab and is expected to begin in the second half of 2015.

Positive Results Reported in Phase III Study of Gazyva

Genentech announced positive results from a Phase III study that evaluated Gazyva for patients with indolent non-Hodgkin's lymphoma who are refractory to rituximab-based therapy. This two-arm trial evaluated Gazyva plus bendamustine followed by Gazyva alone for up to two years, compared to bendamustine alone. The study of 413 patients showed that progression-free survival was significantly longer in the Gazyva arm. Gazyva (obinutuzumab) is an engineered monoclonal antibody targeting CD20 on B-cells. Gazyva is thought to have an increased ability to induce direct B-cell death and to improve antibody dependent cellular cytotoxicity (ADCC) when compared to rituximab. Gazyva continues to be investigated in a Phase III study comparing Gazyva plus chemotherapy to rituximab plus chemotherapy in previously untreated indolent NHL.

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