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## DOCTOR ON CALL: MORIE A. GERTZ, MD, MACP WALDENSTRÖM MACROGLOBULINEMIA: WHAT YOU NEED TO KNOW TO CONTROL YOUR DESTINY



Morie A. Gertz, MD

*Dr. Morie A. Gertz is the Roland Seidler, Jr., Professor of Medicine at Mayo Clinic. Recently he completed an 8-year term as Chair, Department of Internal Medicine, which has over 700 faculty members.*

*At the Eighth International Workshop on Waldenström's Macroglobulinemia in 2014, Dr. Gertz was awarded the Jan Waldenström Medal for Medical and Scientific Achievements in Waldenström's Macroglobulinemia. His most recent publication concerning Waldenström's macroglobulinemia is "Waldenström macroglobulinemia: 2017 update on diagnosis, risk stratification, and management," American Journal of Hematology Volume 92, No. 2, February 2017, pages 209-17.*

*Dr. Gertz has given significant support to the International Waldenström's Macroglobulinemia Foundation since its establishment, serving on the IWMF Scientific Advisory Committee, speaking frequently at the annual IWMF Educational Forums, and writing articles for the Torch which target our readership comprised of patients with Waldenström's macroglobulinemia and their caretakers. All articles written by Dr. Morie A. Gertz for the Torch can be found on the IWMF website, [iwmf.com/MEDIA\\_LIBRARY/BEST\\_OF\\_THE\\_TORCH](http://iwmf.com/MEDIA_LIBRARY/BEST_OF_THE_TORCH).*

### INTRODUCTION

Waldenström macroglobulinemia is a rare form of malignant lymphoma in which the malignant cells produce an abnormal protein that is known as IgM. Most commonly, patients are seen because of the progressive development of anemia (a low blood cell count), resulting in fatigue. This is a disorder that has a premalignant phase that is referred to as IgM MGUS. Patients with IgM MGUS will not necessarily develop Waldenström macroglobulinemia but will need life-long monitoring because there is a continual risk that the precursor condition, MGUS, will evolve into overt Waldenström macroglobulinemia. Studies have clearly demonstrated that outcomes and survival for Waldenström macroglobulinemia are making major strides due to better understanding of the biology of the disease and improved therapies that have a low side effect profile.

Waldenström macroglobulinemia is a very rare disorder seen only in about four per million persons per year. This disorder is age-dependent and is quite rare under the age of 40. Typically, patients present between the ages of 60 and 70. For reasons that are unclear, Waldenström macroglobulinemia is twice as common in men as in women and is twice as common in whites compared to blacks. A positive family history of Waldenström macroglobulinemia or other forms of lymphoma can be found in 4.3% of patients. The average age at diagnosis for Caucasians is 73 years compared to 63 years for African-Americans. The IgM protein found in Waldenström macroglobulinemia is useful in the diagnosis when this diagnosis is suspected and is particularly beneficial in monitoring those patients who are on "watch and wait" or who are being treated.

*Doctor on Call, cont. on page 2*

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*Doctor on Call, cont. from page 1*

However, the abnormal IgM in Waldenström macroglobulinemia also causes unique problems that are not seen in other patients with lymphoma.

Of the problems directly related to the IgM protein, the two most frequently seen are peripheral neuropathy and hyperviscosity syndrome. Peripheral neuropathy most commonly manifests itself with numbness in the soles of the feet, and into the ankles. Hyperviscosity syndrome, rare but unique to Waldenström macroglobulinemia, occurs when extremely high levels of the IgM protein cause thickening of the blood which, if extreme, can cause problems with bleeding, most typically in the gums or nose.

The typical evaluation of a patient with Waldenström macroglobulinemia will include measurement of the level of the IgM protein, blood counts, and blood chemistries, including liver and kidney function. A bone marrow biopsy is required to make the diagnosis of Waldenström macroglobulinemia in all patients. A biopsy of the bone marrow, however, is *not* required for patients with IgM MGUS if no other feature of Waldenström macroglobulinemia is present. An experienced provider is generally able to determine whether a bone marrow biopsy is required or not. Many patients, as part of Waldenström macroglobulinemia staging, have some form of imaging, either in the form of CT scanning of the chest and abdomen or PET CT scanning. If a bone marrow biopsy is performed, it is particularly important that MYD88-L256P analysis is performed since this is a powerful marker of Waldenström macroglobulinemia. Additional blood tests that are warranted specifically for patients with Waldenström macroglobulinemia include measurement of the blood LDH and the  $\beta 2$  microglobulin, the latter important in the staging of Waldenström macroglobulinemia.

MYD88 appears to be a defining mutation in Waldenström macroglobulinemia and, depending on the laboratory, is seen from 67% to 90% of patients. The presence (or not) of the MYD88 mutation is at times important in making therapeutic decisions.

## SHOULD I BE TREATED?

The most common question patients ask me is how they should be treated. This is not the most important question. A far more important question is: "Should I be treated?" I continue to see patients in my practice who are receiving chemotherapy treatment when, in my opinion, continued "watch and wait" was appropriate. The rarity of the disease means many providers have very limited experience with this disorder and often will make decisions based on the IgM level in a patient who is otherwise completely free of symptoms.

*Doctor on Call, cont. on page 3*



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It is my policy not to treat patients who are asymptomatic. The most frustrating thing that I find is when practitioners tell patients that there is a specific threshold of IgM above which treatment is required. Thirty-five years of experience have shown me that every patient is an individual, and generalizations of IgM therapy thresholds in patients who are otherwise completely well cannot be justified. Therefore, the first questions you should have for your provider are: “Why do I need treatment? What problems am I currently having?” or “Are there imminent issues that warrant preemptive treatment?” The latter is rare.

In my practice, I have followed patients without treatment who slowly evolve in levels of IgM from 3000 to 8000 (and, rarely, 10,000) before treatment was required. These patients have very slowly progressive lymphoma; and with correct monitoring, delayed therapy is appropriate because it allows patients to take advantage of new breakthroughs as the therapeutic landscape of Waldenström macroglobulinemia is continuously changing.

The converse is also true. Patients can have very low levels of IgM under 1000 yet absolutely require therapy due to extensive involvement of the bone marrow, liver, spleen, and lymph nodes. Therefore, a high IgM does not justify therapy, and a low IgM does not mean that therapy is not required. The rule of thumb is that the IgM level is not the factor to determine which patients require intervention.

IgM MGUS is far more common than Waldenström macroglobulinemia. A monoclonal IgM protein will be found on routine screening in 1 person out of 600 over the age of 50. This relatively common protein abnormality, however, requires life-long monitoring because these patients are at risk for developing Waldenström macroglobulinemia.

In cancer, it is common to ask, “What stage am I?” A staging system does exist for Waldenström macroglobulinemia. There are five components to the staging system, and they include age, hemoglobin level, platelet count,  $\beta 2$  microglobulin level, and the level of the IgM protein. These can all be used to determine the stage. The question “Am I in remission?” is common. Usually, responses are defined by reductions in the level of the IgM protein. A bone marrow biopsy is generally not required to assess response. It is accepted that a 25% decline in the IgM represents a minor response, a 50% decline represents a partial response or objective response, and a 90% reduction in the IgM is a very good partial response. Because Waldenström macroglobulinemia is a very slowly progressive disease with excellent treatment alternatives and a very long survival, patients live to develop other common problems as we age. In fact 23% of WM patients who die do so of causes unrelated to Waldenström macroglobulinemia; and after the age of 75, 40% of patients die of causes unrelated to Waldenström macroglobulinemia. Patients with Waldenström macroglobulinemia do have a higher risk of second cancers compared with the general population,

particularly large cell lymphoma and bone marrow damage referred to as myelodysplasia.

## WHAT ARE THE TREATMENT OPTIONS FOR WALDENSTRÖM MACROGLOBULINEMIA?

Another major error that I see in my practice occurs with patients who are treated only with rituximab (Rituxan) for their Waldenström macroglobulinemia. Using rituximab alone is a decidedly inferior regimen for the treatment of Waldenström macroglobulinemia, and virtually all trials now underway use more than rituximab for the treatment with a nearly doubling of response rates. There is general consensus among Waldenström macroglobulinemia experts that if therapy is truly necessary, rituximab alone appears to be insufficient to assure that a significant proportion of patients will achieve long-term disease control.

Overall, rituximab produces responses in less than half of the patients who receive it. Every combination regimen containing rituximab reports responses in excess of 80%, and analysis of multiple trials has confirmed that the response rate is greater with combination therapy than with rituximab alone. Oddly enough, there are very few factors that actually predict how well a patient will respond to a combination regimen. Although the majority of patients will respond, there appears to be no relationship to age, bone marrow results, IgM level, or  $\beta 2$  microglobulin.

Ofatumumab is a second monoclonal antibody that has been used in Waldenström macroglobulinemia. However, it is unclear whether it offers advantages to rituximab, and it is unclear that it is safe in patients who have had severe allergic reactions to rituximab.

There are many combination chemotherapy regimens that include rituximab. Two very traditional but very effective regimens include R-CVP (cyclophosphamide, vincristine, and prednisone) and R-CHOP (cyclophosphamide, doxorubicin, vincristine, and prednisone). These produce response rates of 90% and have the advantage that all practicing providers are familiar with these regimens; this familiarity and experience reduces the complication rates seen in patients because of the ability of providers to recognize and intervene with dosage modifications before problems occur. The Mayo mSMART guidelines for Waldenström macroglobulinemia (*mSMART.org*) list rituximab, cyclophosphamide, and dexamethasone as a potential first-line regimen for the treatment of Waldenström macroglobulinemia.

Bortezomib is also known to have high levels of activity when combined with rituximab in the treatment of patients with Waldenström macroglobulinemia. Bortezomib can be given weekly as an injection under the skin. Response rates are comparable to R-CHOP and R-CVP, but it does have a disadvantage in that it can produce nerve damage in the feet that is potentially irreversible; and for that reason, despite its



high level of effectiveness, I tend not to use it as first-line treatment.

Bortezomib falls into the class of proteasome inhibitors active in all forms of lymphoma. The proteasome inhibitor, carfilzomib, does not cause damage to the nerves in one's feet but does produce a response rate of 87% and is well tolerated. An oral proteasome inhibitor, ixazomib, is currently undergoing diagnostic testing for its utility as a pill to treat Waldenström macroglobulinemia.

There are a number of drugs under development, most of which require participation in a clinical trial but show clear-cut promise, including everolimus, perifosine, and panobinostat. A good resource for the availability of new agents for the treatment of Waldenström macroglobulinemia can be found on the Internet at *ClinicalTrials.gov*. Participation in clinical trials is important. Participation virtually ensures you will be seeing someone with expertise in the disease, and there is pre-specified monitoring to ensure best outcomes with lowest side effect profiles.

For patients unable or unwilling (shame on you) to participate in a clinical trial, the Mayo Clinic mSMART guidelines at *mSMART.org* recommend rituximab and bendamustine as the choice for treatment for newly diagnosed Waldenström macroglobulinemia. Bendamustine, in experienced hands, has remarkably low toxicity and is easy to administer in patients up to the age of 90. It does affect the normal blood count, so a dose modification with the first few cycles is often required, and close monitoring of the blood counts is warranted to ensure that excessive suppression of normal healthy blood counts does not occur. However, combining rituximab with bendamustine has been reported to produce response rates of 83% with very low side effects.

### **IBRUTINIB**

Because its use is growing rapidly, ibrutinib (Imbruvica) warrants separate discussion. In the first trial of 63 patients with previously treated Waldenström macroglobulinemia, a response rate of 73% was seen, with the side effects primarily being reductions in the normal white blood cell and platelet counts. Responses occurred quickly, averaging four weeks. However, significant side effects that are not seen with other forms of chemotherapy, including diarrhea, bleeding, and atrial fibrillation (an irregular heart rate that puts a patient at risk of stroke) have been reported. Atrial fibrillation was seen in 10.7% of patients and frequently required hospitalization.

There is a limited amount of information on the use of ibrutinib in newly diagnosed Waldenström macroglobulinemia,

but these studies are underway. A trial of 31 patients with Waldenström macroglobulinemia who had previously been treated with rituximab was recently reported. The follow-up is very short for a Waldenström macroglobulinemia population, so the most reliable information is on response rate. With this oral treatment, the overall response rate was 90%, of which 71% were responses that reduced the IgM by >50%. Unfortunately, 65% of patients experienced significant adverse side effects, including reduction of the white count, high blood pressure, anemia, low platelets, and diarrhea. However, only two patients had to discontinue treatment due to side effects. This second trial, with its high response rate, is an exciting new development, and ibrutinib is considered an important second-line therapy for patients with Waldenström macroglobulinemia.

### **WHAT CAN I DO FOR MYSELF?**

There is increasing evidence that patients who are fit (as opposed to frail) do better with treatment. Patients can tolerate their therapy with lower complication rates and this, hopefully, will translate into better outcomes. Therefore, daily activity in the form of walking, as briskly as is physically possible without the risk of falls, is strongly encouraged.

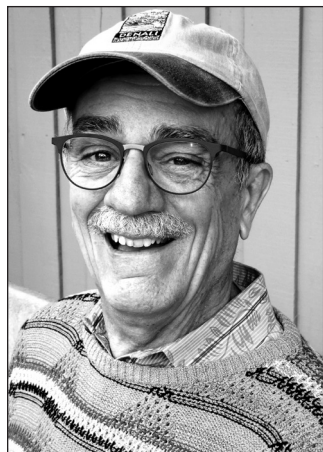
There is increasing evidence that obesity is linked with cancer. At this time, 50% of the US population qualifies as obese. Therefore, attention to diet (reducing total calories and fat) is important for overall health, and maintaining a normal weight contributes to being fit.

Many patients ask about sugar and cancer. There is no evidence that sugar feeds cancer. However, consumption of sugar is calories wasted and has little nutritive value. Sugar raises insulin levels; this contributes to the deposition of fat in the body and merely adds to the total caloric intake in a day. Many people look at sugar as a natural food. In fact, it did not exist in the human diet before the Fifteenth Century and then only existed in the island nations of Southeast Asia until sugar cane was imported into the West Indies. Humans are not well adapted for high levels of sugar. I notice that people are reluctant to consider artificial sweeteners because they represent a chemical. I suspect that artificial sweeteners are no more unnatural than sugar is in the diet, and sugar produces far more harm in the long run. In any case, there is no single dietary culprit. Eating right, maintaining normal body weight, and maintaining aerobic activity are important for improving your outcomes with Waldenström macroglobulinemia.

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## PRESIDENT'S CORNER

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Do you know what the theme of this year's IWMF Educational Forum in Phoenix, Arizona, is? It's *Imagine a Cure: Mapping Our Future*.

I don't know about you but, throughout my life, I always had a general map in mind of where I wanted to go and what I wanted to do. Getting cancer, especially a rare cancer like Waldenstrom's macroglobulinemia, was

definitely not on my map. I bet it wasn't on yours either.

But now that we're in this together, let's map-out our future. You've been hearing a lot about the IWMF-LLS (Leukemia & Lymphoma Society) Strategic Research Roadmap. The purpose of this roadmap is to enable us to focus our limited resources on the best possible research to help us reach our ultimate goal of a cure. As part of the Roadmap, we asked preeminent researchers in the world to respond to our second RFP (Request for Proposal). The proposals had to be submitted by February 17. I'm happy to report that we received 17 proposals from around the globe including 6 ½ from the US and 10 ½ from research centers in Australia, France, Greece, Italy, Slovakia, Slovenia, the Netherlands, Spain, and the UK. Of course, you guessed it. The ½ means that a proposal is jointly submitted by a US and a European institution.

Such an overwhelming response to our RFP is testament to the fact that our rare, small disease is now on the map of the largest and best cancer researchers in the world. In other words, the best minds in the world are competing for your dollars, to help find a cure for your disease.

The next step on the Strategic Research Roadmap is the scientific review and ranking of the applications, which will be completed in the spring. Announcement of the recipients of the new awards will be in June 2017. Funding for approved proposals is expected to be available from July 2017. We hope to fund three new research projects but will fund more if we have enough money. So if you can make a further contribution or increase your donation, please do so. It's up

to us ... no one else will do it. So, go check your sofa, your car seats, and your heart, and give as much as you can. All of us will benefit.

In addition, thanks to a generous donor, we issued a second RFP, focused on amyloidosis in WM. I'm delighted to say that we received 5 proposals on this specific topic. Progress of this research will follow the same timeline as the IWMF-LLS Strategic Research Roadmap.

While we're moving ahead on research, we're also improving the roadmap for Member Services. I was thrilled that 823 WMers, from around the world, were able to participate in the January 11 CancerCare Education webcast titled *Advances in the Treatment of Waldenstrom's Macroglobulinemia* (WM). If you weren't able to attend the workshop – by Dr. Stephen Ansell of the Mayo Clinic and Dr. Jorge Castillo of Dana-Farber Cancer Institute – it is available online at [cancercare.org/connect\\_workshops/562-advances\\_treatment\\_waldenstroms\\_macroglobulinemia\\_2017-01-11](http://cancercare.org/connect_workshops/562-advances_treatment_waldenstroms_macroglobulinemia_2017-01-11)

You can also find it on telephone replay 24 hours a day, 7 days a week. Just call 1-800-625-5288 and give the code #36548736.

In addition to CancerCare, LLS, LRF (Lymphoma Research Foundation) and our other long-term partners, we have new alliances with AACR (American Association for Cancer Research), Lab Tests Online, Triage Cancer, National Comprehensive Cancer Network (NCCN) and Cancer Connect. Please visit our website [iwmf.com/about-us/partners](http://iwmf.com/about-us/partners) to learn how to use the resources our partners provide. We work with these organizations to ensure you have access to services we cannot afford to provide alone.

Let me finish by urging you to attend our 22nd Educational Forum, in Phoenix, Arizona, May 19-21, 2017. You can read more about it on pages 17-19.

As Tim Cahill, the founding editor of *Outside* magazine writes, "A journey is best measured in friends, rather than miles." Remember, with the IWMF, you are never alone on your journey. Come to Phoenix and make some new friends. It's the ultimate WM road trip.

Stay well,  
Carl

### 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](mailto:ariginos@me.com)

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## NEW MEMBERS ON THE IWMF BOARD OF TRUSTEES

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Dr. Linda Nelson

with CLL and WM in the 1950's. Possibly another sibling shared this diagnosis. This family history led Linda to suspect that she, too, might share a blood disorder. Her suspicion was confirmed at the Dana-Farber Cancer Institute where she was diagnosed with MYDD MGUS+.

As Trustee of the IWMF, Linda joins her husband, Barry Nelson, who since 2015 serves as our Webmaster. The Nelsons met in college and have been married for 42 years. They have one son, now engaged to be married and currently living in Seattle, writing software for Amazon.

As many of you may know, the Nelsons have for the past 24 years shared an enthusiasm for biking, both as a sport

**Dr. Linda Nelson** comes to the IWMF Board following an extremely active career in the field of pediatric dentistry. This past July, Linda retired from Harvard School of Dental Medicine where from 1996-2016 she was a member of the faculty and also held many administrative positions. Linda's commitment to the IWMF grows out of very personal reasons: her mother and one sibling were diagnosed

and for charitable causes. They ride a tandem bike that can be easily packed in two suitcases for long distance travel. A special European trip is planned for this summer. Perhaps Linda will "send a postcard" to the *Torch* covering some of the highlights!



Beverly Docteur

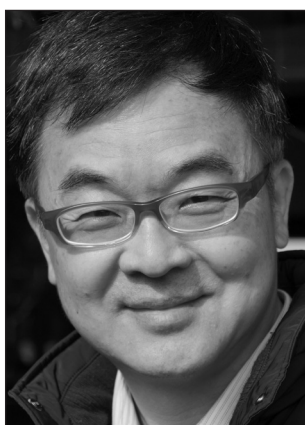
**Beverly Docteur**, the newly elected Secretary-Treasurer of the IWMF, has over thirty years experience in the world of finance. Her background covers top positions in both the for-profit and non-profit areas. For the past fifteen years Beverly was Chief Financial Officer for two non-profit organizations. Her experience will be of great help in managing the financial areas of IWMF.

Beverly is also very generous with her volunteer service to philanthropic organizations in the communities near Binghamton, NY, where she and her husband, Jerry, reside. Their two adult children are identical twins, one living in Texas and the other in Rhode Island. Between them there are six grandchildren, four boys and two girls. Great times, as Beverly reports, are had when they all get together on vacation!

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## INTRODUCING DR. JYH-SENG WANG

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Dr. Jyh-Seng Wang

Group – Taiwan. His interest in the disease Waldenstrom's macroglobulinemia developed when a family member was diagnosed with WM. Finding that physicians gave conflicting opinions in the management of this rare disease, Dr. Wang realized the difficulties faced by a newly diagnosed patient

Congratulations are due to Dr. Jyh-Seng Wang on the publication of his article "An Introduction to Waldenstrom Macroglobulinemia" in the *Taiwan Medical Journal*, volume 60.2 (February 2017).

Dr. Wang, Chairman of the Department of Pathology and Lab Medicine at the Kaohsiung Veterans General Hospital in Kaohsiung, Taiwan, is the Affiliate Leader of IWMF Support

and his or her family in understanding WM. When he found the online IWMF publications available in English and four other European languages, he saw that they are extremely useful in providing WM patients, as well as their doctors, information essential for the management of WM.

Since then Dr. Wang has made it his mission to circulate information about this disease in Chinese. His first step was to ensure that the IWMF publications are available in the two forms of Chinese, both Traditional Chinese and Simplified Chinese. With help from colleagues, Dr. Wang translated the entire bibliography of IWMF publications available under the three headings Booklets, Treatment Guides, and Fact Sheets (see [iwmf.com](http://iwmf.com) PUBLICATIONS).



Cover of *Taiwan Medical Journal*, volume 60.2 (February 2017).

*Introducing Dr. Jyh-Seng Wang, cont. on page 7*

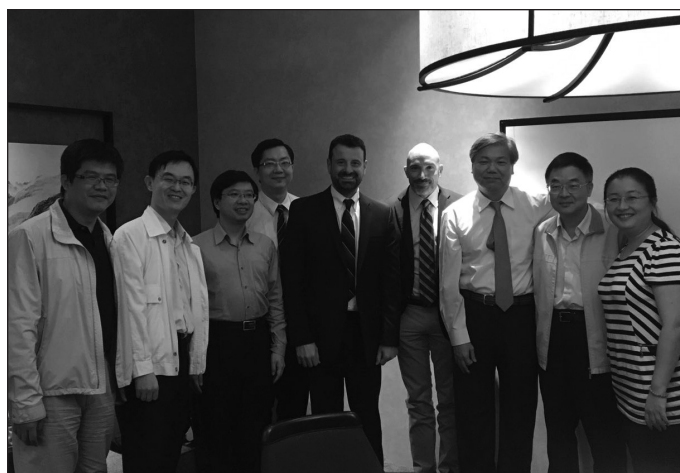
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With the publication of “An Introduction to Waldenström Macroglobulinemia” in the prestigious *Taiwan Medical Journal*, Dr. Wang now addresses information concerning the disease to a Chinese readership of medical professionals.

Born and raised in Luangprabang, Laos, Dr. Wang received his PhD degree from the Institute of Clinical Medicine, National Wang-Ming University, Taipei. Since 1994 he is Associate Professor at National Wang-Ming University. Together with colleagues, Dr. Wang has published more than 100 articles in medical journals including the *New England Journal of Medicine*, the *Lancet*, and the *American Journal of Surgical Pathology*.

In April of 2015, under the leadership of Dr. Wang, the IWFM Support Group – Taiwan was established. With so much time and energy spent on translation of the IWFM publications, it is not surprising that Dr. Wang has not yet organized regular meetings of IWFM Support Group – Taiwan. He has, however, enlisted colleagues with an array of specialties (hematologist, hematopathologist, nephrologist, ophthalmologist and social worker) who have pledged to be members of the support group. Furthermore, Dr. Wang has established a Facebook page especially for WM patients and their caregivers, and, as of now, more than 200 people have visited the page. A number of WM caregivers correspond with Dr. Wang via Facebook. Other WM caregivers from Taipei, Hong-Kong, and China reach out to him by e-mail. Dr. Wang is certainly



*Dr. Jyh-Seng Wang (second from right) and Dr. Yu Ming-Sun, Chief of Haematology-Oncology section of Kaohsiung Veterans General Hospital (third from right) met Dr. Steven Treon when visiting Taiwan.*

to be applauded for all that he has done on behalf of those of the WM community who are Chinese speakers!

In closing, Dr. Wang wishes to express his gratitude to Dr. Steven Treon, Dr. Jorge Castillo, and Chris Patterson of the Bing Center for Waldenström's Macroglobulinemia, Dana-Farber Cancer Institute, Boston MA, and to Dr. Yu Ming-Sun, Chief of Haematology-Oncology section of Kaohsiung Veterans General Hospital, for their generous assistance.

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## A WALK IN THE GARDEN OF DR. WALDENSTRÖM

BY ALICE RIGINOS, PHD, TORCH EDITOR

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*Alice at work in Samos.*

*The following is an account by your Torch Editor of her experience, now in its fourteenth year, of living with Waldenström macroglobulinemia. Much of what I say here refers to the first year following my diagnosis and is written in the hope of encouraging those who have recently received a diagnosis of the same cancer to take heart and believe that they may yet live long and full years.*

The Garden of Dr. Waldenström. The title is, as you may have recognized at first glance, a deliberate reference to the “Garden Talk,” the presentations by Dr. Morie A. Gertz of the Mayo Clinic delivered over the years at IWFM Educational Forums and subsequently seen by thousands of WMers on disc (included in Info Paks for newly diagnosed patients or shown in IWFM Support Group meetings) and online at *iwmf.com*. In the Garden Talk, delivered with the intensity of a great teacher and the sarcasm of a great humorist, Dr. Gertz develops a metaphor to compare the growth of the incurable disease Waldenström macroglobulinemia in the bone marrow of a patient to the invasive growth of weeds that overtake

*A Walk in the Garden, cont. on page 8*

a garden if left untended. Metaphorically, WM is the weed that imperils the growth of our erythrocytes and leucocytes and platelets, the cells essential for sustaining life that are compared to “flowers” flourishing in a healthy bone marrow.

The metaphor further suggests that, as the experienced gardener can restore the vigor of the garden by the judicious use of chemical weed killers, so the expert physician can employ drugs to combat the WM cells in the bone marrow as they multiply and threaten the survival of cells essential for life to continue. Dr. Gertz’s metaphor offers us reassurance and encouragement when we consider that the expertly tended blooms survive year after year: in the care of a WM specialist experienced in the use of the “weed killers” (that is, one experienced in determining *when, which, and how much* of the available chemotherapeutic drugs are required by the symptoms of a specific patient), we patients can live through alternating cycles of growth and then destruction of our WM cells.

During my own walk, now moving toward fourteen years, within the Waldenström Garden, it has been a stroke of good fortune that for thirteen and a half of those years the Gardener is Dr. Gertz. This article is written in appreciation for his care and concern that have enabled me to live what is, and has been, a very good life within the limits of the Garden.

Waldenström’s macroglobulinemia is aptly labeled a “wily disease.” It manifests itself in different ways in different patients. This is, perhaps, one reason why we patients read the personal reports in IWmf-Talk, or on *iwmf.com*, or in the *Torch*, with such interest. We look to glimpse some insight to our own status from the accounts of other WMers. We may find a sense of relief when we read of a course of disease similar to our own, be it years of “watch and wait” or the successful outcome of the treatment that we are currently following. We feel anguish in reading the reports of those of us facing an insurmountable turn of the disease. We never cease to wonder to ourselves “How will things go?” referring to our own case as time moves forward.

On December 3, 2003, I became aware that my life had taken a new direction. This is the date on which I first entered the door of the *hematologist* I was referred to when blood test results at my annual physical showed, for the second year in a row, a decline in hemoglobin level. On that cold December day I was stunned to see the word “oncology” joined to “hematology” following the name of Dr. Bruce R. Kressel, the *hematologist* to whom I had been referred in Washington, DC. I was 62 years old.

In 2002 I had retired from the faculty of Howard University where I had taught for twenty-six years in the Department of Classics. One course I taught over the years was Classical Mythology. It is well known that myths of all cultures share certain comparable components, and often our own experiences in real life seem to have a mythic element. At the door of my new doctor I experienced a *liminal* moment. From the Latin word *limen*, meaning ‘*threshold*,’ a liminal moment

occurs when the hero (or heroine, as the case may be) takes the decisive action that will alter forever the future direction of his or her life. Think of Theseus entering the labyrinth of the Minotaur, for example. As I crossed the threshold into Dr. Kressel’s office, moving from one existential state to another, life, as I had known it for 62 years, came to an end. In fact, I was already well along a pathway in the Garden.

A change of state was certainly apparent when I stepped over the threshold again two hours later. A bit of bone and a scoop of marrow lighter, more blood drawn, and the words of my new doctor in my ears: “Schedule a skeletal x-ray, come back in one week, *and bring your husband*.” The shock of my altered existence was such that I could not tell my husband the full details of this appointment for 24 hours.

In the narratives shared among WM patients (the WM mythology, if you will) a report of how WM was diagnosed frequently entails stories of misdiagnosis and its consequences (remember, this disease is wily). In my own case, Dr. Kressel scored 100. A week later, my husband Vasilis Riginos in tow, I crossed the now-familiar threshold. We were given the correct diagnosis: a very rare and incurable blood disease with an unfamiliar name that was difficult to retain. Further, we were told that I had an IgM level of 8981 (a statistic that meant little to me then), hemoglobin level of 9.6, and that I needed treatment right now.

Dr. Kressel outlined the treatment options that were currently recommended for WM: the monoclonal antibody Rituxan; a nucleoside analogue such as fludarabine; or an alkylating agent such as cyclophosphamide. I cannot claim that these names were “Greek to me.” After all, I could read Greek! But I had no background to translate this alien terminology, much less to participate in selecting one treatment from the three options. And, moreover, the need to make a decision among three alternatives has a scary mythic precedent: think of King Oedipus of Thebes who arrived at a “place where three roads meet” and had to make a choice between the three alternatives to continue on his way. Oedipus made a very poor choice indeed and wound up slaying his father and with other dire consequences concerning his mother!

The need to make a treatment decision among three unknown alternatives that confronted us on 10 December 2003 was actually overwhelming. The doctor suggested the following: we return in one week and he in the meantime would call one of the centers known to treat WM patients, report my blood and biopsy results, and seek a recommendation. When we returned on December 17, Dr. Kressel had been as good as his word: he had called Mayo Clinic Rochester and spoken with Dr. Morie Gertz. The recommendation: 4 rounds of Rituxan. I began treatment the following week.

The suggestion that I should consult in person with an oncologist experienced in the treatment of Waldenström’s also came from Dr. Kressel, who referred me to a lymphoma



specialist at The Johns Hopkins University Kimmel Cancer Center in Baltimore. It was not possible to make an appointment with this doctor until the middle of January, and, by then, I had completed the four weeks of rituximab. To this day I remember well that visit. It was an extremely cold and gray January morning when Vasilis drove me to Baltimore. Following a physical examination, the “lymphoma specialist” seated me opposite him and looked me straight in the eye and began a lengthy exposition of the disease I was going to live with as long as I might be alive. My recollection is that I hardly blinked an eye while I listened with riveted attention in the attempt to absorb and mentally organize this stream of valuable information. Vasilis, too, was intent on retention of the details. The doctor generously held his schedule in abeyance that afternoon in order to give this new patient what, in his estimation, was needed for her survival. I think we were in the examination room with him for a full 60 minutes. There were dark looks aplenty from occupants of the waiting room when we finally came out.

We hardly spoke on the return drive home. The visit to the specialist in early 2004 was an important event along the way to becoming initiated to our new prospects as patient and, yes, caregiver. The lymphoma specialist was certainly well informed about WM. But when asked if there were many WM patients currently followed at the Hopkins Center he replied, “I have several WM patients.” In retrospect, I think he had not had much hands-on experience caring for WM patients.

My first treatment went well in December 2003-January 2004. I had no trouble with the administration of the drug rituximab then (and none in the 20 infusions that have since followed, both solo and in combination with other drugs). In 2003-2004 Rituxan was a new and miraculous drug. The flare phenomenon was unknown, a number of patients reported major responses of IgM lowered by 50% and more. Some patients, as I was now reading on IWMF-Talk, were even enjoying years of inactive disease (“watch and wait”) following treatment with solo rituximab. While the months of early 2004 passed by, my IgM declined very slowly and my hemoglobin level, with Procrit as a booster, hovered below 10 g/dL. By April I did not know what to make of my status. And I was feeling restless thinking about the summer!

At this point, a follow-up visit to the lymphoma specialist in Baltimore was suggested. We did follow up but were not encouraged when he said that, because Rituxan failed to significantly reduce my WM involvement, further treatment was now necessary. He recommended fludarabine and was ready to confer with Dr. Kressel on a “comprehensive program.” I then became balky and said I would not agree to further treatment. I’m not quite sure why I felt this way. Today we are aware of serious possible negative consequences of fludarabine exposure, but in 2004 fludarabine was frequently prescribed to treat WM.

Soon after this Vasilis had an appointment with his primary

care doctor. It was the practice of this physician to ask his patients about the health of the other family members. When hearing of all that had happened in the past five months, he said at once and emphatically, “She needs to see a WM expert. Take her to Boston. Or Rochester. Or Houston. But take her to a doctor with plenty of experience treating WM.” Vasilis understood that his doctor was speaking very seriously. And by this time I was aware that many other WM patients periodically went to certain cancer centers for consultation. Why did I choose Mayo Clinic? Well, Dr. Kressel had called there for advice, plus travel to Rochester could take me through Chicago where I grew up and where I still had family to visit. I telephoned Mayo Clinic, Rochester, and self-referred an appointment in the Department of Hematology. I requested an appointment with Dr. Gertz.

It should also be noted that I had made an effort to learn something about this wily disease during the five months since diagnosis. Here is what I wrote to my local oncologist on April 28, 2004, to inform him that I would *not* be following the recommendation of the lymphoma expert to begin treatment right away with fludarabine:

In the meantime, having spent these past 3 months attempting to grasp what I can about Waldenström’s as a disease – from Internet postings, from medical organizations, from the materials available through the International Waldenström’s Macroglobulinemia Foundation (printed publications and taped lectures given by WM specialists, Dr. Treon and Dr. Gertz), and from the talk list voices of other patients—I have learned that hardly any two cases of WM involve the same physical responses to a high level of IgM and hyperviscosity. The more I learn, the more complex it seems. **And instead of knowledge allaying anxiety, my anxiety seems to be on the rise.** For this reason I have decided to seek yet another outside opinion. I have been able to make an appointment with Dr. Morie Gertz for May 11.

So there we were in Rochester, MN, on an early afternoon in the month of May 2004, seated in an examination room of the Mayo Clinic Hematology Department with an appointment to see Dr. Morie Gertz. In the morning blood had been drawn, a CT scan taken, an electrocardiogram administered, and paperwork completed. The correspondence from Mayo Clinic prior to the appointment said to bring pertinent records. I had along a tote bag stuffed with printouts.

The hematology examination rooms at Mayo, Rochester, are rather small. When Dr. Gertz burst in with a smile and extended a hand of welcome, he appeared larger than his surroundings. Seated at his desk, he first fired questions in rapid succession and then produced the results from the morning’s blood tests. Good news there: at five months since completion, the rituximab treatment was at last showing results. IgM was down, the hemoglobin up. Acceptable ranges. And then,

before my relief could be thoroughly appreciated, there I was on the table for a thorough examination from ears to toes (based on knee-jerk response from a whack on the patella, lower extremities were declared to show no indication of neuropathy – a possible symptom which had not yet occurred to me in my five-month long life as a WM patient). During the course of the examination, Dr. Gertz kept up his line of inquiry with many questions based on what he was observing from my physical condition.

Then, and this is the climactic moment that has followed each annual physical examination since that day, Dr. Gertz seated himself at his desk and, looking straight at the wall, began to dictate the record of my visit, a detailed synthesis of all that I had reported combined with his own observations to sum up the present status of the patient's disease. It was quite a feat of data assimilation and integration. In conclusion, he issued the directive for the patient's care in the year ahead: observation by local oncologist and blood tests every three months. No further treatment necessary at present.

Dictation concluded, the doctor spun around in his chair and asked if there was "anything further." There was. I had not yet broached the question of being well enough to travel, a question of importance for both Vasilis and myself. Hearing my concern, Dr. Gertz at last put his hands on the jumble of paper records I had brought along. Rumbling quickly through them, he extracted a sheet with lab results from the annual physical examination of 2000, gave it a cursory glance, and declared, "Three years before diagnosis you certainly had Waldenström's macroglobulinemia and you did whatever you wanted. There is no reason not to continue as before." A quick handshake, and the WM specialist was out the door and off to the next patient.

Once we were out of the office, palpable relief flooded over the patient and her companion: no treatment for the present and no restriction on activities. I did not mind so much that a bone marrow biopsy was scheduled at Mayo Clinic before I returned home. The important thing was that I now had a sense of confidence. I now had a WM specialist who could be called upon when needed. In the metaphor of the Garden, I was in the care of a good Gardener.

When the flowers in the Garden are in bloom, we may walk in good health. Inevitably, however, we succumb to the "weeds" in our blood. It is at this time that we require the guidance of a Gardener in the selection of the drug or drugs among those available and in the administration of the drugs selected. The aim is to allow us a longer time in the Garden. The Gardener experienced in the treatment of patients with Waldenström's macroglobulinemia is best qualified to make the selection of the drugs and give the instructions for their application.

In my own years in the Garden, the "weeds" have threatened my well being five times, and each time drugs were selected to kill off enough of the weed to allow the "flowers" to reassert themselves and to bloom once more. In the first

two instances, Rituxan administered alone was moderately successful in controlling the weeds for a span of two years. For the third treatment, cyclophosphamide together with Rituxan and dexamethasone were sent against the weeds. A gap of three years elapsed, and then the same drugs were used a second time. Again the flowers blossomed, this time for two years.

The fifth treatment applied to the resurgent weeds was the most effective in terms of results: IgM from 7660 to 581, a 92% reduction in the weeds accomplished by only four infusions of BR (bendamustine and Rituxan). This time, however, there were serious after effects following treatment (bacterial infections, shingles), and caution was required over the ten months that followed until my immune system was at an acceptable (translate acceptable as "safe") level. This is where I find myself now: the Garden is in bloom and I am walking there vigorously once again.

Life (that is, normal, everyday life) is suspended during each round of treatment. We are impatient for treatment to be over and to return to our own daily rhythms of life. No promises can be made concerning outcome of treatment. However, it is certain that the possibility for success increases greatly if you are in the care of the experienced doctor who has calculated the optimum treatment for your present status. And I hasten to add that the local oncologist plays a very significant role. Your "good" local oncologist is the one who makes a correct diagnosis, who monitors your condition on a routine basis, who consults comfortably with the expert in questions of care, and who supervises and manages treatment when necessary, sharing with you the schedule and details of each drug administered. For all the years of my life in WM, my local oncologist (and the very model of a responsible local oncologist) has been Bruce R. Kressel, MD, FACP, first in his private practice and more recently at The Sidney Kimmel Cancer Center, Sibley Memorial Hospital, Washington, DC. It was, after all, a stroke of good fortune that it was the threshold to his office that I crossed so long ago.

Approaching a conclusion, I note that for over thirteen years the WM I live with has been steadily active at a fairly high level of IgM, with intervals of approximately two years between treatments (the exception: the three years following the first DCR treatment, marked also by a high energy level). Anemia is the symptom driving retreatment, manifesting itself above the IgM level of 5000. When I look back over the years spent in the Garden, there are so many experiences shared with Vasilis and our two daughters (not to mention with other family members and friends), that I am ever so grateful to have been alive to experience. We have watched our two daughters become mature young women, each completing graduate studies and now pursuing challenging and rewarding careers. With enormous satisfaction I have seen my daughters become loving mothers – the first of our

three grandsons arriving the year of my diagnosis and his two cousins coming more recently.

Did I ask my expert about travel that first afternoon at Mayo Clinic? It might seem that we have never stopped traveling. In 2006 one daughter moved her family to Australia where she, a marine biologist, began her career as a university professor. Three trips to Australia have followed for her parents, each trip highlighted by time at the Great Barrier Reef. In 2008 the marriage of our second daughter was celebrated in Chennai, India, with family members and friends coming from many, many corners of the world. The wedding occasioned travel to India (two trips: a tour of southern India to serve as introduction to the land of our future son-in-law and then the wedding a year later). Two years later found us traveling in Kenya visiting our pair of ecologists at the Mpala Research Centre in Laikipia, the region west of Mt. Kenya.

And then there is Samos. For many summers, beginning when the children were small, we have spent time in Greece, specifically on Samos, the beautiful eastern Aegean island where Vasilis' parents were born (also the birth place of the goddess Hera, if you enjoy a mythic reference). My concern in 2004: would I now be able to travel to Samos? And spend time there as in previous years? The answer then was yes, and yes for all but two summers when treatment coincided with summer months. And many summers since 2004 there have been grandchildren visiting with their parents: happy days that already become happy memories.

My life all these years had many high spots and highlights. That I am so very fortunate in having a treatable cancer and excellent medical care was brought, literally, home to me while watching my brother, six years my junior, move from diagnosis of a very aggressive cancer of the esophagus to dependency on rough chemo administered every other week for three years until his death on the very last day of 2014. He was my "baby brother." My arms were among the first to hold him when he came home from the hospital, so new and perfect. It was hard to see him in his 60s taking such difficult treatment that held no hope for the quality of life that I was experiencing.

Finally, I will add that my WM life has benefited from the enormous support that the IWMF offers to cancer patients. It has been very satisfying to be your *Torch* editor since 2008. Together with the terrific *Torch* Team, we have, to date, produced more than 30 issues of the IWMF newsletter. Many of these issues were edited in Samos! And in Kenya . . . in Australia . . . in India . . .

\* \* \* \*

*Some data of possible interest: I have had 2 bone marrow biopsies; no plasmapheresis; no transfusion; no hospitalization; no Rituxan flare; no maintenance Rituxan; no sinus infection; no stem cell collection; no genetic testing. In 2012 I was diagnosed with atrial fibrillation.*



## IWMF DOC STAR: MADHAV DHODAPKAR

EDITED BY RON TERNOWAY



*Dr. Madhav Dhodapkar.*

from all over India, Madhav graduated from the All India Institute of Medical Sciences in New Delhi, an experience

As a boy growing up in Indore, India, Madhav Dhodapkar needed to look no further than across the table for inspiration for his future calling. His mother and father were both doctors, and as Madhav grew, so did his appreciation that "medicine is one of the most rewarding professions one can pursue."

One of only 35 students chosen annually from thousands of applicants

he describes as, "Invigorating – an opportunity for lifelong friendships with some very bright folks."

Next step – halfway around the world for a fellowship in hematology and medical oncology at the renowned Mayo Clinic in Rochester, MN. Then it was off to Little Rock, AR, for a stint at the exceptional Myeloma Institute under Dr. Bart Barlogie.

Dr. Dhodapkar moved on to the Rockefeller Institute in New York in 1998, in his opinion "one of the greatest research institutions in the world". He worked closely with Dr. Ralph Steinman, later winner of the 2011 Nobel Prize in Medicine, while also serving on the faculty of Memorial Sloan Kettering Cancer Center in New York City.

2008 found Dr. Dhodapkar in New Haven, CT, where he is currently the Arthur H. and Isabel Bunker Professor of Medicine and Immunobiology, and Chief, Section of Hematology at Yale University.

*IWMF Doc Star, cont. on page 12*



Dr. Dhodapkar was recently awarded an IWMF Strategic Research Roadmap grant for his project *Origins and Immunotherapy of Macroglobulinemia*. In this research, Dr. Dhodapkar will first develop a much-needed model for Waldenstrom macroglobulinemia (WM). Such models are necessary to better understand how WM originates and how to improve current therapies such as ibrutinib. He will also explore new approaches to harness the properties of the immune system, specifically T-cells against the MYD88 mutation found in WM cells.

Dr. Dhodapkar has received several awards for his research, including the Damon Runyon / Eli Lilly Clinical Investigator Award, Cancer Research Institute Investigator Award, NIH Director's Transformative Research Award, NCI Outstanding Investigator Award, as well as awards from New York Community Trust, Irma T. Hirsch Foundation, American Society of Clinical Oncology, and election to the American Society of Clinical Investigation.

Dr. Dhodapkar's greatest professional satisfaction, however, is his clinical work. "My patients – the opportunity and *privilege* to be part of their care and their life – their courage is a daily inspiration."

Asked what advice he gives to the blood cancer patients he cares for, he urges them to "take the long view – cancer therapy is more like a marathon than a sprint – it does not matter what happens in the next 100 meters."

He appreciates that while we have made significant progress in the understanding of blood cancers, much more remains to be done. He believes that major success in blood cancers will come from our ability to harness the immune system, not just to treat but to prevent cancer in patients.

When he's not in the lab, clinic, or classroom, Dr. Dhodapkar treasures time with his loving wife, Kavita, whom he met while at Mayo, and their children, Rahul and Meera. He has the greatest admiration for his mate, who is also a professor at Yale and a practicing pediatric oncologist. "It is much harder to take care of children with cancer," he says, with typical understatement.

He finds opportunities for reading non-fiction – among his favorite authors is Jared Diamond of *Guns, Germs and Steel* fame. Dr. Dhodapkar enjoys a game of tennis and took advantage of his time in New York to regularly attend the US Open in Flushing Meadows, particularly enjoying day passes for the early rounds.

He also has a musical side, learning the Tabla, or Indian drums, at an early age, and being sufficiently proficient – no surprise – to be featured on the radio in India. He still plays regularly.

Dr. Dhodapkar will be speaking at the upcoming IWMF Educational Forum in Phoenix on the topic of *Immunotherapy – The Newest Treatment Route*.

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## FROM IWMF-TALK

BY JACOB WEINTRAUB, MD

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With winter now over, we start looking toward warmer days and the 2017 Ed Forum in Phoenix, May 19-21 (see pages 17-19). Throughout the winter, discussion continued on many subjects, but ibrutinib (Imbruvica) still seems to dominate. Members want to discuss all aspects concerning this drug, from genetic markers, treatment efficacy, and possible adverse effects to use as a first line med. I will focus on a few aspects and urge you all to read the online discussions to get a full measure of the information exchange.

Other significant topics recently discussed include Bing Neel syndrome, cataracts, and lymph nodes.

### HUMAN INTEREST/ARTICLES

As always, there were postings of many interesting and helpful items. Here are links to articles of human interest, support issues, and relevant topics, not only to our cancer but also to people with cancer in general.

IWMF-Talk Manager and Trustee **Peter DeNardis** posted a link to a "wonderful story" from a caregiver. Pete also suggested that we all give a big hug to our caregivers.

[http://www.njtvonline.org/programs/pbs-newshour/how-caring-for-a-dying-husband-made-life-worth-living\\_clip/](http://www.njtvonline.org/programs/pbs-newshour/how-caring-for-a-dying-husband-made-life-worth-living_clip/)

Another post from Pete links to an article on yoga for improving health-related quality of life, including mental health and cancer-related symptoms in women diagnosed with breast cancer. While the cancer discussed is not WM, many of us with WM deal with pain due to our disease and issues with the side effects of treatment. Perhaps yoga can be of benefit to us also.

<http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD010802.pub2/full>

Pete also posted a link to an "Inspiring Story of Hope from Bob Lynch-Row Bob Row." Bob has been enjoying his favorite sport, slide seat rowing, for many years, both as a hobby and to help him deal with his treatments. Many of you will remember that years ago Bob rowed as a fund-raiser for IWMF.

<http://www.iwmf.com/get-support/patient-stories/bob-lynch-still-rowing-after-21-years-wm>

*From IWMF-Talk, cont. on page 13*

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IWMF-Talk editor **Jacob Weintraub, MD**, wrote that he remembered the Doctor Patient Summit in 2001 when he was newly diagnosed. In addition to the other eye-opening events he experienced and the exceptional people he met, Jacob saw promotions for Bob Lynch's long distance row to raise funds for WM. The "Row Bob Row" website was available to follow Bob's progress as he went along. It was impressive to see how much stamina Bob had, and Jacob felt very optimistic regarding his own prognosis, especially compared to what he was led to believe at the time of diagnosis.

**Wanda H** posted several items with links. One is to an article titled "Things You Find Out When You Have Cancer..." This article comes from the United Kingdom and includes experiences that most of us share, including reactions to what others say to us when they find out we have cancer and some of the thoughts that go through our minds as we deal with our diagnosis and associated issues.

[http://www.huffingtonpost.co.uk/annie-levy/things-you-find-out-when-\\_b\\_12981448.html](http://www.huffingtonpost.co.uk/annie-levy/things-you-find-out-when-_b_12981448.html)

Wanda also posted a link to an article listing five books destigmatizing cancer. Unfortunately, there are no WM authors, but, as Wanda pointed out, the cancer experience can be both unique and universal, and one might find much that overlaps and strikes a chord in these books. One of these books is "When Breath Becomes Air" by Paul Kalanithi, a neurosurgery resident who is diagnosed with lung cancer. This is a very thought-provoking book, and the other books appear to be similar.

<http://www.signature-reads.com/201701/authors-on-illness-5-books-destigmatizing-cancer/?cdi=4268D3208ADA19BD E0534FD66B0AC727&ref=PRH24BB520913>

One other recommendation from Wanda is to an online resource center that offers caregivers of all ages support.

<http://www.curetoday.com/articles/the-caregiver-space-reaches-caregivers-of-all-ages?p=2>

## **IBRUTINIB/IMBRUVICA**

Much discussion concerned the question "When is the best time of day to take Imbruvica?" The initial question was posed by **Michael K**, who was about to start treatment and asked if bedtime is the best time to take Imbruvica.

**Mitch O** suggested that it would be best to take it at the time of day when Michael would be least likely to forget or to be away from the pills. One doctor suggested to Mitch that bedtime would be the best time to reduce GI side effects. Mitch, however, decided to take it as soon as he wakes up, and this has become a habit with him.

**Vlad N** also suggested taking the medication first thing on awakening in the morning. However, if a person wanted to change times, he or she should do it gradually, **not** take 3 pills at night and then 3 again the next morning. He raised the question of taking the med on an empty stomach. He did not think that was necessary.

**Ginger N** reported that she began by taking ibrutinib at night, but it disturbed her sleep. She switched to a morning schedule by taking a night dosage as usual and then skipping a dosage next the day. The following day she then began taking her pills in the morning. She now takes ibrutinib with breakfast, and this helps with some intestinal side effects she was having. Ginger also added an alarm to her cellphone in case she forgets to take her pills, and so far she has not missed a dose.

**Colin P** noted that pharmacological studies have shown that the presence of ingested food can affect absorption and serum levels. Ibrutinib seems to be better absorbed with food.

However, **Dr. Tom Hoffmann** cautioned about trying to affect the serum level by taking the med at a certain time in relation to meals. A person might be getting too much medicine, or too little, without realizing it. Potential adverse effects are "not inconsequential" and tend to be dose- dependent in clinical studies. He recommended taking Imbruvica the way a person's physician instructs him or her to take it in relation to meals. Tom thinks that taking it on an empty stomach would be best because this gives constant levels as compared to taking it with or after meals.

For a very good discussion of ibrutinib, see the article by Dr. Jeffrey Matous, "Ibrutinib in WM," *IWMF Torch*, issue 17.3 (September 2016) pages 1-4 and now online at [iwmf.com/MEDIA\\_LIBRARY/BEST\\_OF\\_THE\\_TORCH](http://iwmf.com/MEDIA_LIBRARY/BEST_OF_THE_TORCH)

## **CATARACTS AND SURGERY**

**Barbara S** asked if any WMers have had cataract surgery while on ibrutinib. She has been on the med for two years and has stopped twice for surgeries. Barbara is doing very well on ibrutinib, with normalization of IgM and lymph nodes. She was under the impression that she was not a candidate for lens implant because of her WM.

Optometrist **Maureen Hanley, OD**, responded that if a person has cataract surgery, that person should have a lens implant. Without the implant, it will be very difficult to see and will require very thick glasses. Having WM does not mean a person cannot have an implant.

**Robert S** reported that he had bilateral cataract surgery and lens implants, with the surgeries done three months apart. So far his vision has been normal, and he has had no complications.

**Gerri M** added that she had her first cataract surgery in November. She had a lens implant and had no complications. She discussed Imbruvica concerns with her ophthalmologist. He was confident that there would be no problems, and there were not. Gerri suggested that if Barbara (or her ophthalmologist) has concerns, she might want to consult with her oncologist.

## LYMPH NODES

Although enlarged lymph nodes are not a common manifestation of WM, they do occur, and this is a periodic subject of discussion.

**Andrea H** reported her IgM levels have been in the normal range, but recently she found a swollen lymph node above her collarbone. Andrea has a biopsy scheduled but asked if anyone else has had enlarged nodes. **Wanda H** added that she hoped infection was ruled out before scheduling the biopsy for Andrea. Wanda indicated that Andrea's oncologist would need the pathology report to make certain the enlarged node is WM and not something else that would require different treatment. Wanda has had an unsuccessful CT-guided node aspiration, after which she had several nodes removed surgically for a diagnostic pathologic report.

**Susan F** reported she had a swollen lymph node due to swollen gums. She also had a fever. When the fever went away, the lymph node shrank back to normal. She had further lab testing for infection, but results were negative.

However, **Donna O** stated that she developed a large lymph node on her neck. It was removed, and the biopsy showed she had transformed to diffuse large B cell lymphoma (DLBCL). A PET/CT scan revealed over 20 enlarged nodes in her neck, abdomen and kidneys. Following treatment, Donna is now in remission from her DLBCL but still has active WM. She has started on Imbruvica and is feeling better,

## BING-NEEL

Bing-Neel occurs when there is infiltration of WM cells into the central nervous system (CNS), a WM condition that is very rare. Recently there was considerable discussion about Bing-Neel. The article "The Bing-Neel Journey of Julie Davidson" in the *Torch*, issue 17.3 (September 2016) pages 8-11 generated some additional discussion about this subject.

**Michael D** posted a question about his mother who was diagnosed with Bing-Neel in October 2015. Her symptoms were rapid onset of dementia and altered gait. She has received treatment and her cerebral spinal fluid (CSF) results have shown improvement. However, clinically, she is still having considerable difficulty. He wondered about an adverse CNS effect from the Rituxan she received. Has anyone had a similar experience?

**Julie D** added that she has yet to speak with any two persons whose manifestations of Bing-Neel are similar. Julie is the IWMF LIFELINE contact for Bing-Neel and feels that this disorder is just beginning to get attention from the WM medical community. She also noted the uptick in patients identified as having Bing-Neel. Julie now communicates with

a small group and has references and articles to share. Within the group she has circulated e-mail addresses for Bing-Neel patients and caregivers.

**Kris S** was pleased with the startup of a support group for WM patients with Bing-Neel. When she was first diagnosed with WM, she felt all alone. Now she takes great comfort from meeting others with the same diagnosis.

**Grete C** and **Pavel I** posted a link to an article titled "Guideline for the diagnosis, treatment and response criteria for Bing Neel syndrome."

[haematologica.org/content/102/1/43](http://haematologica.org/content/102/1/43)

## MEMBERS WHO RECENTLY PASSED AWAY

Finally, the IWMF-Talk family marked the passing of two long time members, **Billie Evans** and **Peter Sissman**. Peter was a participant on IWMF-Talk for many years and usually provided some uplifting information in his postings. Billie, too, was a long-time contributor to IWMF-Talk. She offered support and spoke frankly about her own experiences. Many members on IWMF-Talk shared memories of these two members of our community and offered condolences to the families.

**JULIE D** offered this meditation from John Donne as a reflection of our feelings of loss at the death of our members:

*No man is an island,  
Entire of itself;  
Every man is a piece of the continent,  
A part of the main.  
If a clod be washed away by the sea,  
Europe is the less.  
As well as if a promontory were.  
As well as if a manor of thy friend's  
Or of thine own were:  
Any man's death diminishes me,  
Because I am involved in mankind,  
And therefore never send to know for whom the bell tolls;  
It tolls for thee.*

\* \* \*

In closing, I note once more that everyone is invited to participate, offer support, report experiences, and seek advice. The IWMF-Talk community is very welcoming and supportive for a large circle of WMers.

*Editor's note: this is the last issue of the Torch to include a column called "From IWMF-Talk," a title that has appeared continuously in each issue of the IWMF newsletter. A change is coming soon, very soon!*



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## PETE'S VALENTINE'S DAY 2017

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Everyone knows Peter DeNardis. And to know him is, indeed, to love him.

Everyone who reads the *Torch* and who follows IWMF-Talk knows Pete in his many roles. He's the IWMF-Talk Manager who daily scans the listings of the most recent reports on cancer research and helpful articles about living with cancer, selects whatever is particularly pertinent for those affected by Waldenstrom's macroglobulinemia, and sends them on to us. Pete's the IWMF-Talk Manager who gently intervenes when the discussion oversteps the boundaries he has set. He's the fun-loving Pete who adopts the pen name of Secret Wallie to send daily reports of the Ed Forum doings. How many glasses of red wine have we all clinked together when Pete lifts his glass in a toast? Quite a few!

It was, then, a cold wind that blew on January 10 when Pete made the announcement to IWMF-Talk that his WM had resurfaced after an interval of 7 years during which Pete dared to hope that he no longer harbored lymphoplasmacytic lymphoma cells in his system. Pete the WM survivor reminded the "old-timers" on the list that in late 2009 "I was experiencing rising IgM, hemolytic anemia, cold agglutinin disease, hypogammaglobulinemia, and an LPL tumor (pre-sacral mass at the base of my spine)." We who are "old-timers" to IWMF-Talk did remember Pete's candid reporting at that time and Pete's firm belief that, by sharing the difficult times, a Wallie helps others who have comparable symptoms. In 2010 Pete's successful treatment included Cytosan, dexamethasone, and radiation for the tumor. From 2010 through the end of 2016 he was in the clear.

In the January 10, 2017, announcement Pete reported that a routine PET scan taken November 3 showed a "spot" near the sciatic nerve on the right side. Surgery followed on December 16 and revealed more involvement of the sciatic nerve than was expected: the mass around the nerve could not be surgically removed in its entirety. The pathology report that followed on January 6 revealed that the mass was actually comprised of lymphoplasmacytic lymphoma tumor cells, CD20 positive, and 35% MYD88 expression. This clinched the diagnosis: Waldenstrom's macroglobulinemia.

Following the January 10 announcement, Pete had 12 rounds of daily radiation of 24 rads to the right sciatic nerve area in the lower buttocks to try to rid him of the rest of the LPL tumor that remained after surgery. By the second week in February it was time for a bone marrow biopsy "just to be sure of what's taking place." And so we come to Pete's account of Valentine's Day 2017, a day on which Peter and Terri DeNardis celebrated the holiday in a manner most unusual, yet one to confirm the value of love and devotion. The excerpt that follows is in Pete's voice, regaling readers with details of his 2017 Valentine's Day's BMB.



*During the 12 days of radiation therapy Pete walked daily 1.5 miles from the bus stop near his office to the Hillman Cancer Center in Pittsburgh, Pennsylvania. One morning was particularly beautiful.*

*All photos courtesy of Peter DeNardis*

"I had a Valentine's Day breakfast at a local restaurant with my wife, Terri; first song we heard after we sat down was Johnny Cash's "Ring of Fire" – a love song of sorts and a bit prescient of what was about to happen!

We arrived at the facility at 9:45 for a 10:30 appointment, and I had a sample kit to take an extra collection for the research study at Dana-Farber Cancer Institute. The instructions for the collection were conflicting, so the nursing staff had to call DFCI for clarification. This took a bit of time, which delayed the start.

At 11 I met the physician's assistant who would do my BMB. When I was asked two days ahead of time whether I would need anti-anxiety meds or Dilaudid, I responded Dilaudid would be OK, if possible. Yet, when I arrived this day they didn't have either ready; they said I could ask for Dilaudid if I wanted. We decided to go without as they were going to use



*The tubes lined up for blood draw before the bone marrow biopsy. One sample of bone marrow was kept for analysis and a second sample was drawn and sent to Dr. Irene Ghobrial's Tissue Bank Study at DFCI.*

*Pete's Valentine's Day, cont. on page 16*

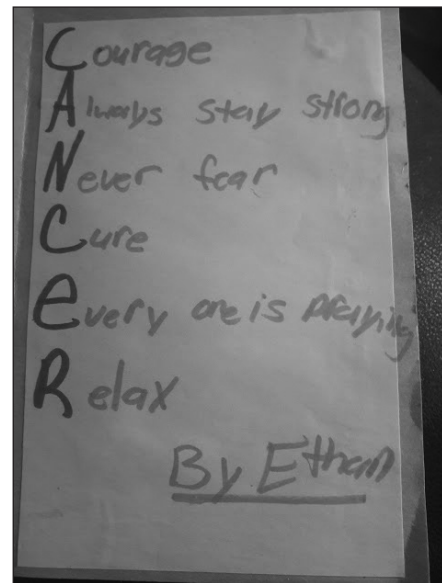
numbing medication, lidocaine, with a needle inserted under the skin to numb the skin around the area they would be working on, and then further insertion near the hipbone to numb the area where the extraction would occur.

I lay on my side, they inserted the needle, and I could feel light tapping and pressure. The assistant said I was the last biopsy of the day – the fifth one, so there was no rush to get done (good thing, too!). As the doctor (Did I mention that she was visibly pregnant and was due in a few months? A nice thing to see on Valentine's day to be sure – and I thought, perhaps erroneously, a good omen) continued to work on my hip, I could tell she was having some difficulty. She said that she would keep trying, but if she could not get through the bone, as my bones were very hard, she would have to consider other alternatives. She continued applying pressure to the needle and twisting it to drive it into the bone, but no luck. She decided to call for another doctor who was “also good at doing extractions” and have her assist. The original doctor said she'd done around 1,000 BMBs and in only two other cases did she have such a problem (lucky me!).

Then I felt cramping pressure as the new person hit the bone and got through it. They extracted a small piece of the bone for analysis and then worked a bit harder to try to get some “aspirate” or marrow. When she was extracting the marrow, I felt strong cramping inside my bone. As luck would have it, I got an extra “cramp jolt” as I had volunteered to have a second batch of marrow extracted to be sent to Dr. Ghobrial's tissue bank study (funded incidentally by the IWmf). When it was all over, they applied pressure to stop the bleeding and had me remain lying down for a half hour. I could tell that they had worked quite hard, as they did their best to clean up my backside, and I did notice a bit of blood spatter on the bottom of doctor #1's lab coat.

After a half hour or so, I attempted to stand, and found that my left leg would not support my weight at all – it felt very weak. They said it was due to the lidocaine, and that in a few cases it does happen that the lidocaine travels a bit and may impact the sciatic nerve, causing the weakness. I was moved to an infusion chair and stayed there, flexing my leg for two hours to get some strength back. I was finally able to put pressure on the leg and have it hold my weight somewhat – still not normal, but much better. So, I was released to go home, and my wife wheeled me in a wheelchair down to our car.

While I was having my BMB, Terri was in the waiting area, and a volunteer was walking around handing out roses for Valentine's Day, provided by the LLS. Another volunteer was handing out greeting cards made by local school kids, specifically designed for cancer patients – what wonderful gestures. My special card had an acrostic written in marker inside that said: **C**ancer, **A**lways stay strong, **N**ever fear, **C**ure, **E**very one is praying, **R**elax (by Ethan). One could almost sense that Ethan may have gone through some sort of cancer experience himself, either as a patient or as a family member.



*Valentine's card made by local school student was delivered by volunteers at cancer center on day of BMB when Pete was dealing with unusual complications.*

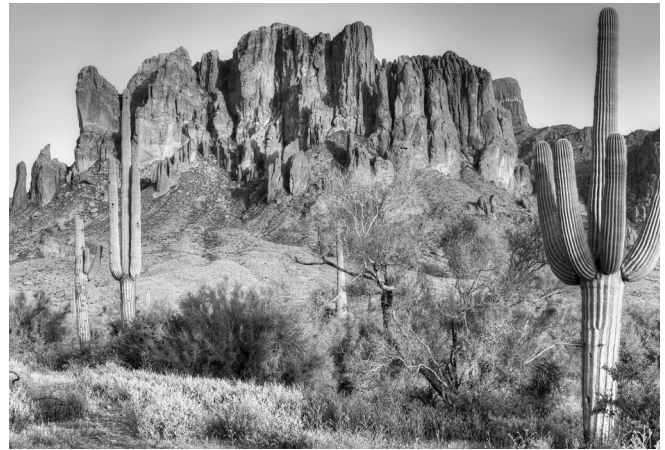
I decided to take the next day off from work (actually, I'd be working from home) due to the pain and weakness in hip and leg – not easy to take public transportation and walk back and forth in such a state.

When Terri and I got into our car, the song playing was Jimmy Buffett's “Margaritaville” – perhaps fate's way of saying the hard part is over, time to relax and get back to enjoying life again!”

*Editor's note: Pete's service to WMers extends way beyond his role as IWmf-Talk Manager. He has served on the IWmf Board of Trustees since 2008, has been involved in updating the IWmf website twice, and is a member of the Publications Committee, the Information Technology Committee, the Ed Forum Committee, the Judith May Volunteer of the Year Award Committee, and the Patient Database Team.*



*The “Circle of Care” monument at the entrance to the Hillman Cancer Center consists of six bronze figures representing three generations of caregivers - past, present and future. These larger-than-life figures are encircled by a ribbon, which signifies the continuity of care patients receive at the Hillman Center.*



**Can you hear the cacti calling?  
Come join us in Phoenix, Arizona!**

## **2017 IWWMF EDUCATIONAL FORUM MAY 19-21, 2017**

**By Lisa Wise and Lu Kleppinger, Educational Forum Committee**

As we enter our second decade of the highly successful Educational Forums for WMers and caregivers, we invite you to join us in Phoenix, AZ, on May 19-21, 2017. This year's theme is *Imagine a Cure: Mapping Our Future!* We hope that YOU will map your own route to Arizona and join us for fun in the sun!

Walking into an Ed Forum conjures feelings of excitement, anticipation, and solidarity. For many of us, it is the one and only time all year long that we are surrounded by folks who are travelling along the same path...living, coping, and thriving with their diagnosis of WM. It is an incredible opportunity to hear WM world experts share cutting-edge research and explore new treatment options. It is a special time to reconnect with old WM friends and make some special new ones.

**We hope this quick sneak peek of the itinerary helps you decide to register TODAY!**

### **GET BACK TO BASICS WITH THE ABCs of WM!**

Whether you are newly diagnosed with WM or a longtime experienced veteran, it is always great to get back to the basics! This exciting new session (added last year to great success!) covers "The ABCs of WM" and is OPEN TO EVERYONE. This information-packed Friday morning session, led by Jeffrey Matous, MD, of the Colorado Blood Cancer Institute, will explain what WM is, what causes it, and how it is diagnosed and monitored. This session is enjoyed over a delightful continental breakfast and promises to be an excellent way to hear about what may lie ahead on your WM path and offer you the opportunity to ask questions in a smaller, more intimate setting. IWWMF Trustee Peter DeNardis will also be on hand to share his accumulated wisdom from a patient's perspective of being newly diagnosed.

### **MEET WORLD-CLASS EXPERTS!**

Carl Harrington, our fearless IWWMF President (and extremely entertaining speaker!), will kick off our Ed Forum and set the stage by assuring us all that "We are NOT ALONE" in our WM journeys – we are part of a special family, the IWWMF.

**Continued on page 18.**



We are privileged to have many expert WM physicians and researchers addressing the latest hot topics for our rare disease. Here is a sneak peek of some of the presentations:

- ***The Map of Current Treatment Options for WM***  
*Craig Reeder, MD, Mayo Clinic, Phoenix/Scottsdale*
- ***The Genetic Drivers of WM***  
*Zachary Hunter, PhD, Dana-Farber Cancer Institute, Boston*
- ***Meet a Young Investigator***  
*Jonas Paludo, MD, Mayo Clinic, Rochester*
- ***Immunotherapy – The Newest Treatment Route***  
*Madhav Dhodapkar, MD, Yale University, New Haven*
- ***Genomic-Based Treatment Advances for WM***  
*Steven Treon, MD, PhD, Dana-Farber Cancer Institute, Boston*
- ***Overview of the IWMM-LLS Strategic Research Roadmap – Our Track for the Future***  
*Stephen Ansell, MD, PhD, Mayo Clinic, Rochester*
- ***Self-Management During Your WM Journey***  
*Toni Dubeau, RN, NP, Dana-Farber Cancer Institute, Boston*
- ***Clinical Trial News: What New Treatments are Coming Down the Road?***  
*Edward Libby, MD, Seattle Cancer Care Alliance*
- ***The Patient Perspective on Clinical Trials***  
*Ron Ternoway, Support Group Leader from Nova Scotia*
- ***The Burning Questions About WM***  
*Morie Gertz, MD, FACP, Mayo Clinic, Rochester*

#### **HAVE A BURNING QUESTION?**

Got something on your mind? Want to ask a specific question? Don't miss the ever-popular "Ask the Doctor" Panel discussion on Sunday morning, moderated by engaging IWMM Trustee Dr. Guy Sherwood. YOUR questions are addressed during this very lively and fun exchange! *Always* promises to be entertaining...

#### **NEED AN EXCUSE TO DRESS UP?**

Join us at the President's Reception on Friday evening, followed by the Welcome Dinner and President's Address. Guaranteed fun at a festive and elegant sit-down dinner with all your favorite WM buddies.

#### **DO YOU PREFER SMALL GROUPS?**

We've got you covered! Smaller, themed "Breakout Sessions" are scheduled throughout the Forum. These informal meetings provide an opportunity to ask your questions and get firsthand information about a variety of topics of keen interest to WMers. These breakout sessions, along with a variety of hosted "meet and greet breakfast tables," offer encouragement and camaraderie in a smaller setting. They enhance our sense of community and allow you to have your voice heard in a more intimate setting.

#### **WANT TO EXERCISE FOR A GOOD CAUSE?**

Pack your sneakers and get ready for the "Walk for Waldenstrom's," a 5K fundraiser on Sunday morning to benefit the work of the IWMM for WMers everywhere! To read more about how you can participate, see <http://www.iwmm.com/fundraise> and click on the Walk for Waldenstrom's button.

#### **CALLING ALL SUPPORT GROUP LEADERS!**

Don't miss this unique opportunity to connect with other Support Group Leaders, strengthen your leadership skills, and get some fresh new ideas to jazz up your meetings! All Support Group Leaders are invited and encouraged to attend a half-day workshop on Thursday, May 18, led by Marcia Klepac, the IWMM's Support Group Coordinator.

Continued on page 19.

### STAY & PLAY IN A GREAT HOTEL!

Renaissance Phoenix Downtown Hotel

100 North 1st Street, Phoenix, Arizona 85004

[www.marriott.com/hotels/travel/phxbd-renaissance-phoenix-downtown-hotel](http://www.marriott.com/hotels/travel/phxbd-renaissance-phoenix-downtown-hotel)

602-333-5126 • Toll-Free 800-468-3571

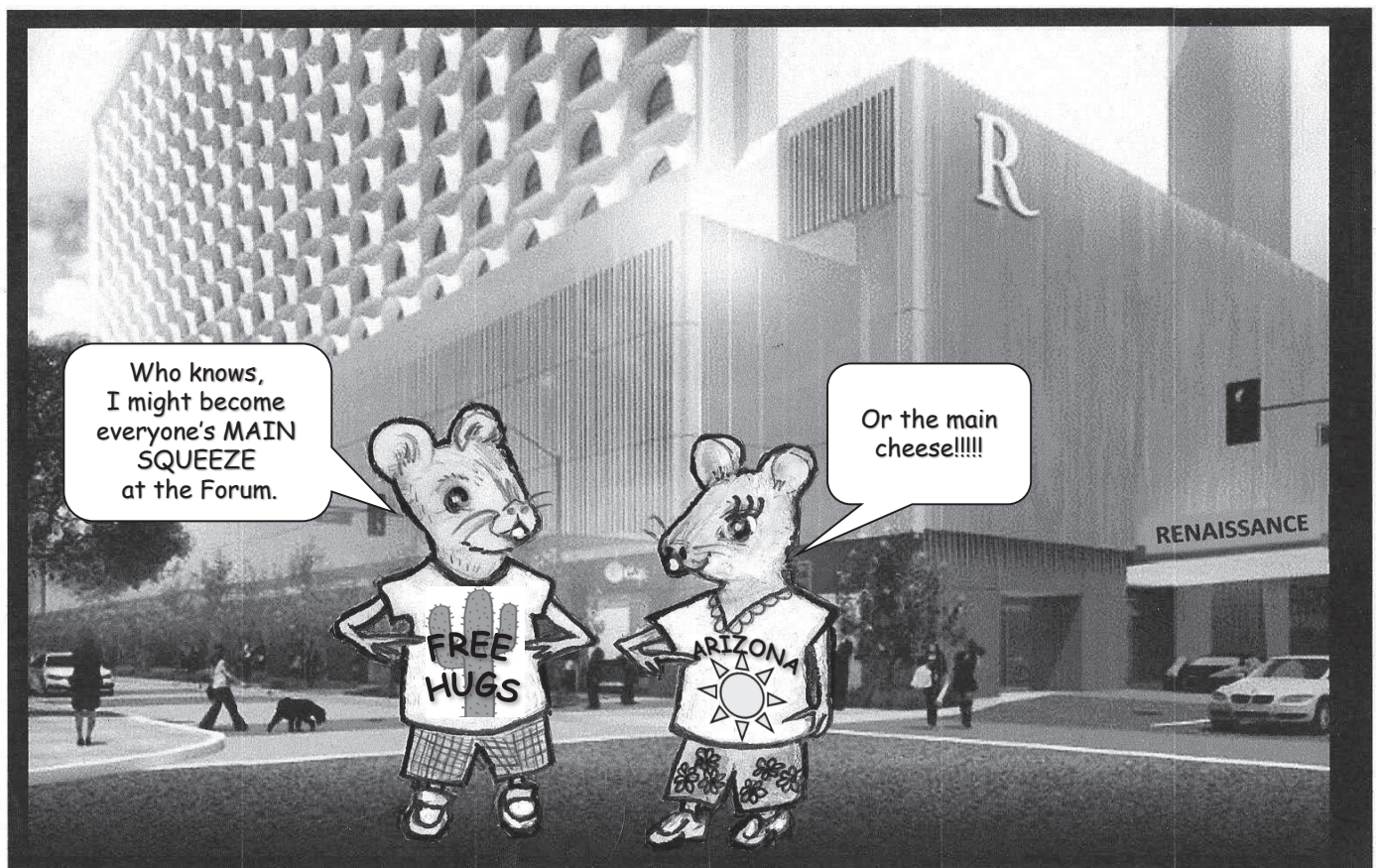
Don't forget to make your own hotel reservations! The Renaissance Phoenix Downtown Hotel enjoys a central location near downtown restaurants and attractions, the Phoenix Art Museum, Arizona Science Center, Orpheum Theatre, Heard Museum, historic St. Mary's Basilica, Chase Field (home of the Arizona Diamondbacks) and much more! Phoenix Sky Harbor International Airport is just 4 miles away, and light rail transportation to local venues is available nearby. Come early and stay later to enjoy all the sights!

Please note: our negotiated room rate of \$144/night is available to you for three days before and after the event for a limited number of rooms. Have some fun in the sun (but wear your sunscreen!)

**Register online at [www.iwmf.com](http://www.iwmf.com)**

**See you in Phoenix!**

*WALLY and WINNIE in Phoenix, Arizona, by Linda Pochmerski*



*Like so many other positive acts, it turns out that hugging boosts our immune system—plus it just plain feels good. Feel free to hug it out with friends at the Ed Forum. That's a wrap!*

# MAJOR GIFTS TO THE IWMF

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

## Research Partners

David & Janet Bingham Research Partners Fund of the IWMF

Robert Douglas Hawkins Research Partners Fund of the IWMF

Michael & Rosalie Larsen Research Partners Fund of the IWMF

Carolyn K. Morris Research Partners Fund of the IWMF

K. Edward Jacobi Research Partner Fund of the IWMF

Marcia Wierda Memorial Research Partner Fund of the IWMF

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

## Named Gift Funds

Baker Family Research Fund of the IWMF

Dr. Morie A. Gertz Research Fund of the IWMF

Gary Green Research Fund of the IWMF

Samuel Schneider Research Fund of the IWMF

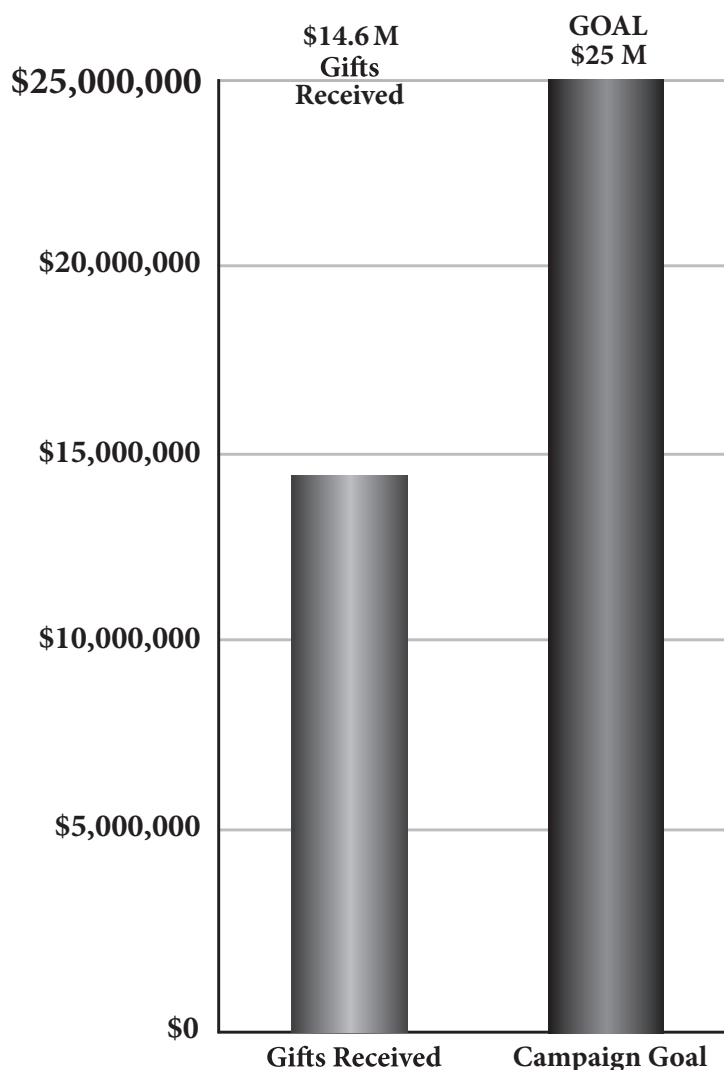
Lynn Martin & Carrie Wells Research Fund of the IWMF

Gail Murdough Member Services/Research Fund of the IWMF

Sesnowitz Family Research Fund of the IWMF

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

## Imagine a Cure Campaign Progress Report as of February 28, 2017





# Create a *Legacy*

## GIFTS TO THE IWMF



*IWMF members Paul and Janet Rippas accept their award from Society Chairman Laurie Rude-Betts at the 2016 Ed Forum.*

Every day, the IWMF touches the lives of many people.

Our resources, built through the generosity of supporters like you, permit us to continue our work today and in the future. If you are looking for a way to leave a lasting legacy, it's easier than you might think to make a significant impact through a planned gift to the IWMF.

While gifts of cash and checks are always appreciated, gifts to the IWMF can be made in many other ways. And you can make a gift without affecting your current lifestyle by using your assets during your lifetime

and leaving what remains to help further our mission.

You may join the Ben Rude Heritage Society by naming the IWMF as a beneficiary of any of the following assets:

- Retirement accounts such as an IRA, 401(k) or 403(b)
- Life insurance policies
- Commercial annuities or investment accounts

For an even simpler way of giving, you could name the IWMF as a "payable on death" beneficiary of your savings or investment accounts.

When you name the IWMF as a beneficiary on any of your accounts or assets, you can potentially reduce taxes for your family and your estate. You can also reduce your estate administration costs. Best of all, when you give to the IWMF, your values, your ideals, and your legacy last forever. Call or e-mail Dave Benson, Senior Development Officer, at 952-837-9980 or [dave@dbenson.com](mailto:dave@dbenson.com) for more ideas on ways to endow your legacy by becoming a member of the IWMF's Ben Rude Heritage Society.

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## MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF TRUSTEE AND RESEARCH COMMITTEE MEMBER

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**First Biosimilar Monoclonal Antibody for Cancer Treatment Receives Marketing Authorization in the European Union** – Celltrion Healthcare, a South Korean company, announced that the European Commission has approved its drug Truxima, a biosimilar rituximab, for all indications that reference rituximab (Rituxan or Mabthera) in the European Union. A biosimilar is an almost identical copy of an original biological drug manufactured by a different company, is an officially approved version of the original drug, and can be manufactured when the original drug's patent expires. Much like generic medications, biosimilars have the potential to offer cost savings for healthcare systems. Truxima is the first biosimilar monoclonal antibody authorized by the European Commission for the treatment of

cancers, including diffuse large B-cell lymphoma, follicular lymphoma, and chronic lymphocytic leukemia, and is also approved for a few autoimmune conditions, including rheumatoid arthritis. The drug targets the same CD20 antigen on B-cells as rituximab and has gone through preclinical and clinical testing to determine that it is comparable to rituximab. Mundipharma has distribution rights to the drug in the UK, Germany, Italy, Ireland, Belgium, Luxembourg, and the Netherlands. Truxima is not yet approved in the US and Canada, although Celltrion Healthcare is preparing for a US Food and Drug Administration filing and has selected Teva as its distribution partner in the US and Canada.

*Medical News Roundup, cont. on page 22*

**Phase III Trial of BGB-3111 Announced for WM Patients** – BeiGene, Ltd. has announced that it plans to initiate a global, randomized Phase III trial of its BTK inhibitor BGB-3111 in patients with WM. The study is designed to determine whether the responses with BGB-3111, particularly complete or very good partial responses, are superior to those of ibrutinib (Imbruvica). Approximately 170 patients are expected to be enrolled at clinical sites in North America, Europe, Australia, and New Zealand. The study will enroll relapsed/refractory or treatment-naïve WM patients who are not appropriate candidates for chemoimmunotherapy. At the time of enrollment, patients will be tested for MYD88 mutational status and accordingly assigned to one of three experimental arms: 1) Arm A will enroll approximately 75 patients with the MYD88 mutation who will receive BGB-3111 at 160 mg twice daily; 2) Arm B will enroll approximately 75 patients with the MYD88 mutation who will receive ibrutinib at 420 mg once daily and 3) Arm C will enroll 15-20 patients with wild-type MYD88 who will receive BGB-3111 at 160 mg twice daily. The clinical trial identifier number on <http://www.clinicaltrials.gov> is NCT03053440.

**Study Looks at Ibrutinib as Treatment Choice for Rituximab Refractory WM Patients** – A substudy of the multicenter iNOVATE Phase III clinical trial on the use of ibrutinib (Imbruvica) in WM reported preliminary results from treatment of 31 WM patients who had rituximab-refractory disease. Refractory disease was defined as either 1) relapse less than 12 months since the last rituximab dose or 2) failure to achieve at least a minor response. At a median follow up of 18.1 months, the proportion of patients with an overall response to ibrutinib was 90%, with 71% achieving a major response. The estimated 18 month progression-free survival rate was 86%, and the estimated 18 month overall survival rate was 97%. Common grade 3 or worse (moderate to severe) side effects included neutropenia (low neutrophils), high blood pressure, anemia, thrombocytopenia (low platelets), diarrhea, and infections. The authors concluded that ibrutinib is a potential treatment choice for patients with rituximab-refractory WM.

**Journal Article Discusses Practical Approaches to Chemotherapy-Induced Neuropathy Pain** – Chemotherapy-induced peripheral neuropathy (CIPN) pain was discussed by Mayo Clinic physicians in the Cancer Network's online journal *Oncology*. For many patients, control of pain requires opioids; however, use of opioids in this setting has become problematic, given the new CDC guidelines instructing practitioners to reduce their use. There are no proven drugs to prevent CIPN, and while omega-3 fatty acids have shown some promise in this regard, only one small trial has been done. Emerging data support the idea that a moderate-intensity walking and resistance exercise program protects against CIPN and may help repair damaged nerves after CIPN develops. For treatment of established CIPN, the decision to reduce chemotherapy dosing or discontinue it should be

made with consideration of the severity of symptoms. When patients experience pain that requires additional intervention, the authors of this article urge oncologists to first use the only drug with proven benefit, duloxetine (Cymbalta), and to not routinely prescribe drugs such as gabapentin (Neurontin) and pregabalin (Lyrica), which have not been demonstrated to work for CIPN in clinical trials even though they work for other types of neuropathic pain and may show some effectiveness in selected individuals. The authors suggest some efficacy for the combination of nortriptyline and gabapentin, as well as topical agents such as BAK (baclofen, amitriptyline, and ketamine), low-concentration menthol, and topical gabapentin. The authors suggest that it is important to have a sequence of drugs to try, since the number of people who benefit from each pain medication is only about 1 in 3. It is also important to give each drug for at least 2 weeks to fully evaluate it before moving on. For intractable pain, neuromodulation therapy, which disrupts pain signals, is another option to be considered. Neuromodulation techniques include spinal cord stimulation, "scrambler" therapy, and acupuncture. While spinal cord stimulation can be effective, it is invasive and expensive. "Scrambler" therapy involves the use of electrodes placed around the area of pain and incorporates a device to deliver non-pain low-current electrical signals through cutaneous nerves to the pain site. Acupuncture has demonstrated benefit in some patients, but the evidence for its effectiveness is still inconclusive. The link to the complete article is <http://tinyurl.com/PNApproach>

**Preliminary Results Announced for Phase I/II Trial of Acalabrutinib in CLL** – AstraZeneca announced preliminary results from its Phase I/II clinical trial of acalabrutinib (also known as ACP-196) in chronic lymphocytic leukemia (CLL) patients who were intolerant to ibrutinib (Imbruvica) or who had transformed to a more aggressive B-cell malignancy (Richter's transformation). The ibrutinib-intolerant group included 33 patients and resulted in a 79% overall response rate with acalabrutinib. The median progression-free survival had not yet been reached, with 81% of responding patients achieving a response duration of more than 12 months. The most common adverse effects included diarrhea, headache, cough, increased weight, and nausea. The transformation group included 29 patients, who achieved an overall response rate of 38%. The median progression-free survival was 2.1 months, and the median duration of response was 5.2 months. The most common adverse events were headache, diarrhea, anemia, fatigue, joint pain, and back pain. Acalabrutinib is a BTK inhibitor that demonstrated fewer off-target effects in pre-clinical studies and is being studied in a range of B-cell cancers, including WM.

**Phase I Results Reported for Venetoclax in Relapsed/Refractory NHL** – An article published in the *Journal of Clinical Oncology* detailed findings of a Phase I clinical trial of venetoclax in 106 patients with relapsed or refractory non-

Hodgkin's lymphoma (NHL), including 4 patients with WM. Oral dosing of venetoclax was once daily at 200 to 1200 mg in this dose-escalation and safety phase. Treatment emergent adverse events were reported in 103 patients, a majority of which were mild to moderate. The most common moderate to severe adverse events, reported in 59 patients, included anemia, neutropenia (low neutrophils), and thrombocytopenia (low platelets). The overall response rate was 44%, and the response rate for WM was 100%, although none of the WM responses were complete ones. Given that tumor lysis syndrome was seen in earlier studies of chronic lymphocytic leukemia patients on venetoclax, its incidence was closely monitored in the study. Tumor lysis syndrome is a group of metabolic abnormalities that can occur as a complication during cancer treatment when large amounts of tumor cells are killed at the same time, releasing their contents into the bloodstream. Clinical tumor lysis syndrome was not observed here, although laboratory evidence of it was documented in 3 patients who were treated for it and continued venetoclax on schedule. Venetoclax is a small molecule inhibitor of BCL2 that blocks an important protein in the B-cell pathway, thereby leading to programmed cell death.

**Combination of Venetoclax and Rituximab Studied in Phase Ib Study of CLL** – Meanwhile the combination of venetoclax and rituximab is being studied in relapsed or refractory chronic lymphocytic leukemia (CLL). This Phase Ib dose-escalation trial enrolled 49 patients. Venetoclax was dosed daily at 200-600 mg, with monthly rituximab dosing. Grade 3-4 (moderate to severe) adverse effects occurred in 76% of patients; the most common were neutropenia (low neutrophils), thrombocytopenia (low platelets), anemia, febrile neutropenia, leukopenia (low white blood cell count), fever, lower respiratory tract infections, and pneumonia. Clinical tumor lysis syndrome occurred in 2 patients, resulting in one death. After enhancing tumor lysis syndrome prophylaxis, the syndrome did not occur. The maximum tolerated dose was not identified, but the recommended dose of venetoclax for Phase II studies is 400 mg. Overall 86% of patients achieved a response, including a complete response in 51%. Patients are still receiving therapy, and follow up is ongoing.

**Multicenter Study Discusses Once-Weekly Ofatumumab for Untreated or Relapsed WM** – A multicenter Phase II study of once-weekly ofatumumab in untreated or relapsed WM was reported in *The Lancet*. A total of 37 WM patients were enrolled, 15 in Group A and 22 in Group B. For cycle 1, Group A patients received ofatumumab 300 mg during week 1 followed by 1000 mg during weeks 2-4, and Group B patients received ofatumumab 300 mg during week 1 followed by 2000 mg during weeks 2-5. Patients in both groups with stable disease or a minor response after 16 weeks were eligible to receive a redosing cycle of 300 mg during week 1 and 2000 mg during weeks 2-5. Patients responding to cycle 1 or the redosing cycle who developed disease progression within 36 months could receive cycle 2

of ofatumumab 300 mg during week 1 and 2000 mg during weeks 2-5. Fifty one percent of patients achieved an overall response after cycle 1, and 59% achieved an overall response after the redosing cycle. Thirteen patients received treatment cycle 2, and 77% of these patients achieved a response. All patients had at least one adverse event – the most common moderate to severe events were infusion reactions, chest pain, hemolysis, and neutropenia (low neutrophils). Two patients in Group B experienced an IgM flare.

*The following are summaries of selected abstracts about treatments and survival trends in WM patients presented at the 2016 ASH Annual Meeting on December 3-6, 2016, in San Diego, CA. These and other ASH abstracts can be viewed online by going to <https://ash.confex.com/ash/2016/webprogram/start.html>. For a specific abstract search, type the abstract number in the Search box; for a general search of all abstracts related to WM, type "Waldenstrom macroglobulinemia" in the Search box.*

**Survival Trends in Young Patients with Waldenstrom Macroglobulinemia: Over 5 Decades of Experience, Abstract #1810** – This Mayo Clinic retrospective analysis reviewed all 1,181 WM patients seen consecutively at the Mayo Clinic from 1960-2013, with 140 patients  $\leq$  50 years of age at diagnosis selected for and compared to a control cohort of patients 65 years or older at diagnosis. The patients were divided into 3 groups based on the timing of therapy initiation: 1960-1977, 1978-1995, and 1996-2013. Younger patients were more likely to present with adenopathy (enlarged lymph nodes) and splenomegaly (enlarged spleen), have higher IgM levels, and hyperviscosity symptoms. At the time of analysis, 91% of the deaths for the younger cases were WM-related, compared to 58% in the control group. Younger patients had a better overall survival with a median disease-specific survival (DSS) of 15.6 years vs. 11 years for the older patients. Among the young patients, there was no difference in the median DSS across the 3 time periods; however, the median DSS for the control group improved over the same 3 time periods. The incorporation of rituximab to the previously existing treatment regimens and the transition to non-chlorambucil-based regimens have resulted in substantial survival gains in the older WM population over the past 5 decades; however such improvement outcome was not observed in the younger patients. The majority of younger patients, despite a protracted disease course, succumb to their disease.

**Survivorship in WM: Identification of Factors Associated with Survival of More Than a Decade and with Early WM-Related Death, Abstract #2954** – This multicenter study from Greece analyzed WM patients from the database of the Greek Myeloma Study Group who were symptomatic, requiring therapy. For the first part of the analysis, 292 patients with at least 10 years of follow up (diagnosed before 2006) were



divided into 2 groups: patients who survived for 10 years or more following treatment initiation (34.5% of the total) and patients who died from WM within 3 years of treatment (13% of the total). Those with survival of 10 years or more were younger, had lower levels of beta-2-microglobulin, had less anemia or thrombocytopenia (low platelets), higher levels of serum albumin, lower levels of LDH, and less splenomegaly (enlarged spleen). The study evaluated the presence of these same clinical characteristics in patients with survival of less than 3 years who started therapy between 2006 and 2012 and thus had less follow up. The incidence of WM-related death within 3 years was 10%, similar to that observed in the era before 2006. The clinical characteristics of these patients were also similar to those in the previous era. Based on their analysis, the authors suggest that a simple staging system using just age, beta-2-microglobulin, and serum albumin can predict patients with shorter or longer survival.

**Ixazomib, Dexamethasone and Rituximab in Previously Untreated Patients with WM, Abstract #2956** – Ixazomib is an orally administered proteasome inhibitor that has demonstrated limited neuropathy in multiple myeloma patients but has not been previously evaluated in WM. During each cycle ixazomib was administered at 4 mg on days 1, 8, and 15, while dexamethasone at 20 mg was given on days 1, 8, and 15 and rituximab at 375 mg/m<sup>2</sup> was given on day 1. There were six 4-week cycles of induction therapy followed by six 8-week cycles of maintenance. Rituximab was withheld for the first 2 cycles to minimize risk of IgM flare. Prophylaxis to prevent shingles and proton pump inhibitors were administered throughout therapy. All 26 previously untreated WM patients in the study were positive for the MYD88 L265P gene mutation, and CXCR4 mutations were identified in 15 patients. The overall response rate was 88%, with a major response rate of 50%, and the median time to response was 8 weeks. Major responses for patients with CXCR4 mutations were less than those with wild-type CXCR4 (47% vs. 64%), and the median time to response was slower in CXCR4-mutated patients. There was one case of progressive neuropathy in part due to worsening of diabetic neuropathy.

**Bortezomib, Dexamethasone and Rituximab in Newly Diagnosed Patients with Waldenström's Macroglobulinemia: Final Analysis of a Phase 2 Study After a Minimum Follow Up of 6 Years, Abstract #2957** – In this multicenter European study of 59 newly diagnosed WM patients requiring treatment, BDR treatment consisted of a single 21-day cycle of IV bortezomib alone (1.3 mg/m<sup>2</sup> on days 1, 4, 8, and 11), followed by weekly IV bortezomib (1.6 mg/m<sup>2</sup> on days 1, 8, 15, and 22) for 4 additional 35-day cycles, and with IV dexamethasone (40 mg) and IV rituximab (375 mg/m<sup>2</sup>) on cycles 2 and 5, for a total treatment duration of 23 weeks. The overall response rate was 85%. After the 6-year follow up, median progression-free survival was 43

months and median duration of response for patients with at least a partial response was 64.5 months. Overall survival at 7 years was 66%. No patient developed myelodysplasia, and transformation to high grade lymphoma occurred in 3 patients who had received chemoimmunotherapy after BDR treatment.

**Clinical Presentation and Outcome of Patients with Myeloid Differentiation Factor 88 Gene (MYD88) Wild-Type Waldenstrom Macroglobulinemia, Abstract #2960** – There has been a paucity of clinical and outcome data on WM patients with wild type MYD88. A recent small study reported an older age for WM patients with wild type MYD88 and an unexpectedly higher mortality rate than patients with mutated MYD88. Consequently Mayo Clinic researchers retrospectively evaluated their WM patients diagnosed between 2007 and 2014 and performed AS-PCR on archived bone marrow samples to determine MYD88 status. From the cohort of 171 patients with known MYD88 status, 40 wild type MYD88 patients were identified. All patients required therapy. At diagnosis, the median age of these patients was comparable to those of the mutated MYD88 cohort of 131 patients. Familial WM was identified in 10% of patients; 64% presented with constitutional symptoms at diagnosis. Symptoms included fatigue, weight loss, night sweats, dizziness, shortness of breath, bleeding, headache, and hyperviscosity syndrome. Splenomegaly (enlarged spleen) and lymphadenopathy (enlarged lymph nodes) were observed in 20% and 27%, respectively. Thirteen percent of patients had AL amyloidosis, and transformation to a higher grade lymphoma was noted in 23%, almost half of whom had received previous therapy with a nucleoside analog or chlorambucil. Median overall survival for wild type MYD88 patients was 8.5 years, with no statistically significant difference in overall survival evident between this cohort and the mutated MYD88 cohort.

**Bendamustine and Rituximab Versus Dexamethasone, Rituximab and Cyclophosphamide in Patients with Waldenstrom Macroglobulinemia (WM), Abstract #2968** – Bendamustine/rituximab (BR) and dexamethasone/rituximab/cyclophosphamide (DRC) combination therapies are both acceptable treatment options for WM in the frontline and relapsed settings. No direct comparison between the two has previously been reported. This retrospective study by Mayo Clinic researchers analyzed records of Mayo Clinic WM patients, both relapsed/refractory and treatment naïve, who received either BR or DRC therapy from 2007 to 2014. Although both regimens show comparable toxicities, the BR regimen overall showed a trend for superior progression-free survival in WM patients, both in the relapsed/refractory and treatment naïve settings. MYD88 L265P mutational status did not appear to impact the activity of either treatment. The authors suggest that randomized prospective studies are needed to confirm these findings.

**Lower Doses of Bendamustine Are Not Associated with Lower Response Rates in Previously Untreated Patients with Waldenström Macroglobulinemia, Abstract #2969** – The Bing Center for WM at Dana-Farber Cancer Institute presented this retrospective study by searching its database of previously untreated WM patients who received bendamustine and rituximab between 2008 and 2015. A total of 48 patients were included, and based on total bendamustine dose, these patients were divided into 3 groups: 90 mg/m<sup>2</sup> on days 1 and 2 for 6 cycles; 90 mg/m<sup>2</sup> on days 1 and 2 for 4 cycles; and 70 mg/m<sup>2</sup> on days 1 and 2 for 4 cycles. There was no difference in age, hemoglobin levels, platelet counts, serum IgM levels, beta-2-microglobulin levels, or IPSSWM scores among the three groups. The rates of major responses were 95% in the first group, 89% in the second group, and 90% in the third group. The rates of deep response were 55% in the first group, 44% in the second group, and 50% in the third group. The conclusion suggested that receiving a lower total bendamustine dose does not negatively impact the attainment of major and deep responses to therapy in previously untreated WM patients.

**The High Risk for Symptomatic Hyperviscosity in Patients with High Serum IgM Levels Can Be Used to Support Initiation of Treatment in Waldenström Macroglobulinemia, Abstract #2983** – Another retrospective study from the Bing Center looked at hyperviscosity in WM patients. Current consensus panel guidelines recommend initiating treatment only for symptomatic hyperviscosity rather than a specified serum IgM level. However, many clinicians treat an elevated IgM in the absence of hyperviscosity-related findings to prevent this condition from developing. In this study 112 cases of hyperviscosity syndrome (HVS) were identified from 1992-2016, and the incidence of HVS in patients with serum IgM levels of 3000-3999, 4000-4999, 5000-5999, 6000-6999, and  $\geq 7,000$  mg/dL was 3%, 22%, 30%, 61%, and 79%, respectively. No symptomatic HVS was observed in patients with a serum IgM  $< 3000$  mg/dL. HVS patients with a serum IgM level  $\geq 6,000$  mg/dL were also significantly more anemic and thrombocytopenic and were more likely to receive plasmapheresis than those at lower levels. The study authors concluded that patients with a serum IgM  $\geq 6,000$  mg/dL are at a significantly increased risk for developing symptomatic HVS and that this IgM level may reasonably be considered as a criterion for treatment initiation.

**Comparative Effectiveness of Rituximab-Based Immunochemotherapy in Waldenström's Macroglobulinemia (WM), Abstract #2986** – This joint study from Brown University and Dana-Farber Cancer Institute pointed out that the effect of rituximab alone or in combination with chemotherapy on overall survival in WM has not been demonstrated in clinical trials even though over 80% of WM patients in the US are now treated with it. Using the Surveillance, Epidemiology and End Results (SEER) registry data from 1999-2013 and Medicare data, 1,310 WM patients were identified as having received treatment with or without rituximab. Rituximab therapy was more frequently used in patients with metropolitan residence, diagnosis after 2003, and baseline neuropathy. A comparative analysis showed that overall survival was significantly better for patients who received rituximab as part of their therapy, compared with those who did not. Toxicity of single-agent rituximab was lower compared with combination regimens, without a difference in survival, thus confirming its utility as a treatment option for older patients who do not have a strong indication for cytotoxic therapy.

**Prospective, Multicenter Clinical Trial of Everolimus as Primary Therapy in Waldenström Macroglobulinemia (WMCTG 09-214), Abstract #4487** – Everolimus, an oral inhibitor of mTOR, which is a component of the PI3K/AKT pro-survival signaling pathway triggered by MYD88 and CXCR4 activating mutations, was evaluated in 33 symptomatic, previously untreated WM patients. The study dose was 10 mg/day until progression or unacceptable toxicity. The overall and major response rates were 72.7% and 60.6%, respectively. Among genotyped patients, non-responders were associated with wild-type MYD88 and mutated CXCR4 status. Median time to response was 4 weeks. Discordance between serum IgM levels and bone marrow disease burden was common. The median time to progression was 21 months, and for major responders was 33 months. Discontinuation of everolimus led to rapid serum IgM rebound in 7 patients. Toxicity led to treatment discontinuation in 27% of patients, including 18% for pneumonitis. The conclusion was that the risks and benefits of everolimus should be carefully weighed against other frontline treatment options for WM.

*The author gratefully acknowledges the efforts of Peter DeNardis, Wanda Huskins, Pavel Illner, John Paasch, Colin Perrott, Howard Prestwich, Charles Schafer, Ron Ternoway, and others in disseminating news of interest to the IWFM-Talk community. The author can be contacted at [suenchas@bellsouth.net](mailto:suenchas@bellsouth.net) for questions or additional information.*

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# COOKS' HAPPY HOUR

BY PENNI WISNER

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## **All the Seeds You Want to Know (and maybe a few nuts)**

I planned to write about this subject over a year ago, maybe two (you know that funny thing about time). Now it seems almost everywhere you look in the grocery store (including – or especially – the snack aisle), products trumpet their inclusion of small but nutritionally mighty seeds.

Please do not accuse me of trendiness or California hippy-dippy eating habits (although my love of avocado toast could be one of the main reasons I moved out here in the early 1980s), but some of my favorite foods now include seeds and nuts. For many years, a favorite, easily portable lunch was coffee yogurt, sliced banana, and toasted sunflower seeds. Now I bake seeds and nuts into bread, mix them into oatmeal, sprinkle them on yogurt and soups for crunch, and especially add them to salads (green, leafy ones as well as pasta and bean salads) and vegetables (Hey! I live in CA; remember we eat a lot of salad here, year 'round) and even coat fish in a seed coating before cooking.

Flax seeds by now have become old hat, but they are as delicious as ever with their nutty flavor (I often mix flax with sesame seeds) and contain loads of omega-3s, lignans to regulate hormone levels, and fiber. Like chia seeds (high in minerals and fiber), they absorb water, getting fat and sticky and turning the liquid into a gel. For vegans or for anyone wishing to cut down on egg consumption, these qualities make chia and flax great additions to baked goods and puddings.

The super seed category includes our old friends sunflower and pumpkin seeds. Sunflower seeds contain Vitamin E and magnesium while pumpkin seeds have zinc and iron. Their size makes them perhaps the most satisfying of the bunch, but they are still small enough that you don't have to do any chopping before cooking with them (unless you are making a pumpkin seed sauce). Returning to the tiny seeds, you run into sesame seeds (toasted sesame, ground to a paste, is otherwise known as tahini and it makes a fabulous dressing mixed with lemon and miso) which contain copper and magnesium. One of the newest members of this community is hemp, a protein source for vegans. It has a soft texture and a bland taste (can you tell it's not my favorite?) but mixes well with others, adding an extra dose of Vitamin E and antioxidants. Then, there are watermelon seeds! They, too, are a good source of magnesium, zinc, and protein.

Something to remember about all these seeds is that they are just that: seeds! That means they have a high oil content

wrapped in a protective coat. They need to be stored at cool room temperature and used up relatively quickly to avoid spoilage. As you read this, it will be spring, and then summer. Consider keeping your nut and seed supplies in the freezer.

You may have noticed snack packages of sprouted seeds. Sprouting is an appetizing way of saying "germination." When you eat a raw sprout, you are eating a living plant. Sprouting makes the nutrients, locked away in the seeds, nuts, grains, or legumes, easier to digest and thus more nutritionally available.

You could try making a "super seed granola" by mixing seeds and rolled oats together with a little oil and salt (and/or maple syrup) and baking the mix in a medium oven or in a skillet over low heat, stirring regularly, until fragrant and lightly toasted. (The lazy cook's solution to this is to buy your nuts and seeds already toasted.) You might also just toss a mix of toasted seeds together in a bowl with some roughly chopped, toasted almonds and/or cashews and some spices such as the Mediterranean spice sumac, coriander, fennel, and perhaps some dried herbs such as thyme and oregano. Keep experimenting until you come up with your own house blend.

Last week I found myself eating oatmeal for supper, a wonderfully comforting retreat from the day. If I had followed David Tanis's advice (which I often do as he is one of my favorite New York Times food columnists), I might have had savory oatmeal: A bowl of creamy cracked oats, surrounded by sautéed greens with garlic, and garnished with a toasted seed blend and a big spoonful of yogurt. Actually, that sounds like an equally good breakfast to me.

Also involving greens, seeds, and nuts, is a kale salad a friend recently made. You prepare the kale as for any raw kale salad but perhaps cut the leaves a little more finely. Then cut romaine the same way and add it to the kale in a big bowl. Make a dressing of fresh lemon juice, pressed garlic, salt, pepper, and untoasted sesame oil. Toss the greens with the dressing and then add generous handfuls of toasted sesame seeds and roughly chopped cashews. Try making it as a "goodbye to winter" salad just as the tender spring greens take over farmers' markets. It could well make you nostalgic for those times of year when there are no greens except bunches of firm, sturdy kale and chard.

*Our motto: Eat Well to Stay Well*



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# INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE AND JAMES CAMPBELL

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## BELGIUM

The symposia organized by CMP, the Flanders support group, are always well-attended and very interesting, and the symposium that took place in spring 2016 was no exception. A number of regional events followed in the autumn. When I say “well-attended,” our friends at the IWFM might wonder what I mean. So I’d like to point out that 161 attendees, from a country as small as Belgium, is quite an achievement.

Divided by an (imaginary) language barrier, between the Dutch-speaking north and the French-speaking south, Belgium even has a third language: a small German-speaking community still exists in the east of the country. However, the CMP’s activities take place only in the Dutch-speaking north: the regions of Antwerp, Limburg, Flemish Brabant and East and West Flanders, that account for about 6.7 million people, roughly 60% of the total population.

On September 24 the **West Flanders region** took on a challenging, yet rather obvious topic: *With the End Of Life in Sight*. At New Year everyone wishes you good health. But who remembers or has the courage to wish someone a good death? Fifty percent of people would like to die at home, in a familiar environment, and we all have the right to live a life of the highest possible quality in the period leading up to this unavoidable event.

About 40 people attended the meeting, held in Ostend. Niek Vervaeck, a family doctor and also Team Physician-Palliative Home Care, opened the morning session. Palliative care addresses the physical, spiritual, and emotional needs of patients and caregivers.

Niek described a novel approach to the delicate relationship between the professional caregiver, in this case a palliative doctor, and the patient. He said “The doctor might find it helpful to work with the concept of *ICE*: an acronym for *Ideas, Concerns and Expectations*.” The examples he gave:

**Ideas:** What do you see when you look towards the end of your life?

**Concerns:** What do you worry about? What would you like or not like to happen?

**Expectations:** What do you expect from the hospital? From your family?

He ended with the words of Cicely Saunders, one of the founders of the hospice movement:

*You matter because you are you, and you matter to the end of your life. We will do all we can, not only to help you die peacefully, but also to live until you die.*

After lunch, it was the turn of Dr. Frank Declercq, coordinator of Leifarts in Ostend. First, though, what is a *Leifarts*? Arts is Dutch for doctor, and a *Leifarts* is a doctor who has extensively

studied the issue of euthanasia and fully understands the possibilities and politics of palliative care in Flanders (and Brussels – the seat of Belgian government). *Leif* stands for *Life End Information Forum*. It is an open initiative of people and organizations aiming for a dignified life for all, with respect for the will of the patient.

There was some discussion about palliative care in this afternoon session, but mainly it was about patients’ rights, especially the combination of euthanasia and one’s last will: what documents are required and how they should be completed. The day concluded with fellow patients supporting each other through sharing stories and experiences.

Twenty-one people from the **Flemish Brabant region** came together on September 27, in Leuven. No speaker had been invited, as regional representatives had chosen to discuss this specific issue with only attendees present: *What are the most frequent problems with which patients, partners and caregivers must contend?*

Amongst others, they looked at the following sub-topics: fatigue, memory problems, side effects of medication, lack of time during consultations with physicians, additional/complementary treatments, and relationship problems. There wasn’t enough time to answer every question, but we aim to do so during the next regional meetings.

The regional representatives of **East Flanders** brought their members together on October 15 at the AZ Sint-Lucas in Ghent (AZ literally translates as Academisch Ziekenhuis; in the UK, a University Hospital). The theme of the day was *Mental Fortitude*.

Both the date and the theme proved a hit and resonated with the National Week of Resilience, which ended the same day. Mental fortitude is the ability to stand up for yourself, to respond appropriately, to be resilient. The ability to live life positively through all the stress and setbacks. To be the one in control of your illness and your life, and to stay very close to each other through the good and the bad.

In times of crises we need to process one thing at a time, thoroughly and consciously. And remember: daydreaming has positive effects!

What might help you?

- Attention to breathing.
- Enjoyable distractions; taking time for creativity.
- Monitoring your sleep.
- A balanced diet.
- Meaningful relationships.

*International Scene, cont. on page 28*

Forty-five enthusiastic participants listened attentively to an engrossing presentation by Els Van Poucke, oncopychologist and onco-coach at the welcoming hospital. Her talk was followed by a Q & A session.

While enjoying some tasty soup and sandwiches, the participants got to know each other and shared experiences as patients and caregivers.

Working together with two organizations, the *LVV*: patients with lymph node cancer and *LOTUZ*: patients who have undergone allogeneic stem-cell transplantation, the **Antwerp region** chose *transplantation* as the central theme for their meeting.

Held on November 12 at the Middelheim Hospital in Wilrijk, a municipal district of Antwerp, the event welcomed two specialist doctors: Dr. Lemmens of the St. Augustinus Hospital in Wilrijk, and Prof. Dr. Zachée of the Stuivenberg Hospital in Antwerp. Doctor Lemmens discussed autologous SCT (stem cell transplant) and Prof. Zachée allogeneic SCT.

Almost 80 attendees learned more about:

- what stem cells are.
- when SCT is appropriate.
- SCT methods.
- who can get a transplant.
- the difference between autologous and allogeneic SCT and the advantages and disadvantages of both.
- the side-effects of chemotherapy (possibly-heavy) and of the transplant itself.

The meeting was appreciated tremendously. Everyone came to a similar conclusion: it is vital to discuss SCT thoroughly with your treating physician.

As is usual, in the fifth region, **Limburg**, the CMP representative worked together with *Wildgroei*, a contact group for various blood cancers. Wildgroei and the Limburg CMP region organize about eight meetings per year, and they are always well supported. Different activities were organized, including a presentation by a clinical biologist/microbiologist about infections that are dangerous to a patient with reduced immunity, and how to avoid them.

I wonder if anyone, anywhere in the IWFM, has ever attended a lecture called *Weep and Laugh*? A doctor/humorist took us on an emotional journey of the humor and tears in medicine.

Right now, all the regions are looking forward to our symposium, in Hasselt, on March 25!

**Joanna Van Reyn, CMP Vlaanderen, reporting.**

## **FINLAND**

The Finnish Waldenström's Macroglobulinemia Patients' Group held its annual meeting, in October 2016, at Hotel Vantaa in Tikkurila, near Helsinki. The venue is within easy reach for those of us from Southern Finland, but also close



*At the far right, Veikko Hoikkala, founder and leader of the Finnish WM support group. Speaker of the day, Pasi Koivunen, stands second from the right. Those with questions and comments for Mr. Koivunen quickly formed a line to his left at the conclusion of his presentation.*

to the airport and commuter trains so that newbies from farther afield were able to attend. Those of us who've been attending these occasions for some years now were glad to see each other once again; happy to chat about the state of our remission or about some of the new treatment options available. It was also nice to meet with the family members of the WM patients!

These meetings are equally meaningful to the newly diagnosed; what they see is a group of active, positive-thinking people with WM, who are leading ordinary lives. Usually there's a hematologist guest speaker to give us an update on the latest WM studies.

This year was an exception in that we did not have a guest hematologist, as there are not that many Finnish experts in this field and none were available on that particular weekend. We did get something else though: four for the "price" of one! Pasi Koivunen: teacher, personal trainer, motivational speaker and psychologist who coaches the Finnish National Biathlon team.

If anyone present had doubts about the value of what was to come, those doubts were quickly dispelled. At the age of 82, Pasi Koivunen is a vibrant example of vitality and spirit triumphing over challenging life-long health problems. Anything and everything that he had to tell us was valuable, tried and tested, especially when he hypnotized us, for he is also a licensed practicing hypnotist! He guided us through exercises in self-hypnosis and autosuggestion and stayed with us during lunch-table conversations and the afternoon coffee break to teach us more.

Later in the afternoon there was a moderated group discussion for members of the WM group, an opportunity to discuss treatment options and personal experiences. Soon after the event ended, the Finnish WM Facebook site had several positive comments about this year's meeting; it seems we

all came away feeling healthier and stronger. These annual meetings are sponsored by the Finnish Cancer Patients' Organization.

**Footnote:**

On the 14th and 15th of January 2017, Kaisa Makarainen of the Finnish women's biathlon team won two gold medals in the World Cup round held in Germany!

**Taina Lukkaroinen reporting.**

## **WM SCANDINAVIA**

### **FIRST WM SCANDINAVIA MEETING HELD 15 DECEMBER 2017.**

The WM Scandinavia Facebook group numbered around 60 members last December. At our first ever meeting, 40 participants gathered for a day of lectures, sharing experiences, and making new friends. The day started with a brunch where we got to know each other, creating a positive and open atmosphere that lasted the whole day.



*From left to right: Susanne Öhrn (WM Scandinavia), Dr. Eva Kimby, Tone Hansen (Chair, Norwegian Blood Cancer Association) and Christian Pedersen (Swedish Blood Cancer Association).*

The program opened with welcome speeches from **Susanne Öhrn** (WM Scandinavia group leader), **Christian Pedersen** (Swedish Blood Cancer Association), and **Tone Hansen** (Chair of the Norwegian Blood Cancer Association).

This was followed by short presentations where participants introduced themselves and their personal situations. Some had long-term experience of WM and many different treatments, others had just begun their WM journey. This really helped to break the ice and bring everyone into warm and open contact with each other. In planning the day, we had reserved time for patients and caregivers to exchange experiences, which was appreciated very much.

**Professor Eva Kimby** gave a very interesting lecture about WM in general, about different treatment approaches and medications, and provided an update on new research. Eva's lecture was so exciting and interesting that, unusually for

almost any event, no one had noticed that we'd run over lunchtime. We broke for a (quick) lunch as we all wanted to get back to Eva's lecture. At the end of her talk, Eva opened the floor to a valuable Q & A session. Unfortunately, her colleague, Doctor Lena Brandefors, had caught a cold, so Eva had to answer all the questions herself.

The Chairman of the Norwegian Blood Cancer Association, Tone Hansen, gave a very vivid and inspiring presentation. She focused on the psychological aspects of living with WM, and what we can all do to feel a little better by working on our mindset and how we communicate about our condition.

The day ended with a summary of the meeting. All participants – patients, carers and experts alike – were extremely positive about the day.

Many thanks to all who helped make this day possible: the IWFMF, the Swedish and Norwegian Blood Cancer Associations, Lyle (Danish Lymphoma and Leukemia Association), ABF Stockholm and the Janssen Pharmaceutical Company.



*Swedish WM specialist Dr. Eva Kimby spoke to a full lecture hall during the inaugural meeting of WM Scandinavia.*

## **SCANDINAVIA IN SHORT**

Scandinavia is actually 3 different countries: the Kingdoms of Sweden, Norway and Denmark. Sweden's population recently topped the 10 million mark; Norway and Denmark have about 5 million inhabitants each. Sometimes people use the term "Nordic countries" which includes Finland, Iceland and the Faroe Islands.

The languages of Sweden, Norway and Denmark are quite similar, especially the written. However, it can be hard to understand the different dialects, both between countries and within countries. The difference is similar to that between a Scottish or Irish accent and an American accent. Most inhabitants of all three countries can understand each other, especially when you tune in to regional melodies, but certain words are totally different.



When it comes to WM it is probably not a coincidence that our disease was discovered by a Swedish doctor. Recently, Professor Eva Kimby reported that the risk of contracting WM is much higher in Sweden than in any other country. “Luckily,” however, as far as I know, Denmark and Norway have similar risk levels as the rest of the world.

Scandinavians do not just share their languages: we also share a common history (we have been a part of each other’s lands from time to time) and the same goes for Finland’s 5 million citizens. Although their main language, Finnish, is completely different from the other three Scandinavian languages, for around 300,000 citizens Swedish is their mother tongue. In earlier times, for over 600 years, Finland was a part of Sweden.

WM is a rare disease, and very few people have even heard of it, let alone experienced it. So it can feel quite lonely out there. Being able to share knowledge and experiences is informative and valuable; giving and receiving comfort and understanding – in one’s own language – is crucial to managing WM as well as possible.

Most patients are older when get their WM diagnosis. They might not have studied English at school, as younger generations do, so it is vital that they have a forum where they can participate in their own language. But even those of us who grew up with English in school find it difficult sometimes to understand medical terminology. Even the most “elementary” blood test results can be quite challenging to comprehend. Moreover, it is difficult to really express your real feelings in a foreign language – try it for yourself. Remember how you felt when you got your WM diagnosis, then try to formulate those feelings in French or German or any other language you learned in school – not very easy, right?

I started the WM Facebook group in May 2016 and to date we have 69 members, mostly from Sweden. Our aim for 2017 is to make more patients aware of the group and the help and information we can provide. We are delighted to be networking with the Scandinavian cancer organizations: we need their networks if we are to reach all Scandinavian WM patients, But we also need their administrative and economic help, as we hope to provide regular events – following the success of the first Scandinavian WM Conference.

**Susanne Öhrn reporting.**

## AUSTRALIA

### CONTINUATION OF WhiMSICAL STUDY

The WhiMSICAL study empowering patients internationally to contribute patient-derived data for observational research was successfully launched in June 2016. The focus for 2016 has been on Project 100 with recruitment predominantly from



*Dr. Steven Treon with WhiMSICAL Study Principal Investigators.*

Australia and New Zealand. Already over 60 are in the study. This participation has confirmed the project’s feasibility.

WhiMSICAL Study conference papers have been presented at both national and international venues, obtaining international endorsement. WhiMSICAL is now established as an innovative form of medical observational research, with a continuously expanding WM dataset. The study has collected patient-derived (de-identified) medical data – medical history, disease-related symptoms, pathology results and treatments. Data has been entered by participants using an ethically approved, privacy-protected, online questionnaire following informed consent.

A detailed update on the status-quo of the WMozzies WhiMSICAL CART-WHEEL research study was published in the January 2017 issue of the *Torch* (volume 18.1) page 27.

Further WhiMSICAL enhancements are planned for 2017, including the collection and analysis of data from 1,000 recruited participants, thus providing more meaningful clinical data. International participation will also allow a validation study comparing WhiMSICAL data with those collected from large registries, such as the Dana-Farber Cancer Institute.

### WMozzies meetings in 2017

**March meeting:** The first meeting in 2017 for WMozzies was a non-speaker meeting held on 15 March 2017. The venue at the Sydney harbour-side Kirribilli Club was chosen to ensure a friendly and relaxed atmosphere. WMozzies were encouraged to come along, share experiences and exchange information in an informal, supportive and friendly environment.

**November meeting:** Planning is under way for an October / November meeting for WMozzies to be held at the Sydney International Convention Centre, concurrent with the 2017 meeting of the Haematology Society of Australia and New Zealand.

**Andrew Warden reporting.**

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# SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

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## Please note!

Contact information for all support groups is found on *iwmf.com* under GET SUPPORT.

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

## CALIFORNIA

### Northern CA

The most recent meeting was held at Kaiser Roseville Hospital on Saturday, 11 February. Some travelled two to three hours just to talk to others with this rare disease. The group of fourteen watched the informative DVD of the “Ask the Doctor” session recorded last May at the IWMF Ed Forum in Providence. All members were encouraged to attend the Forum this May, especially since it will be so close – in Phoenix. Many are planning to go; some for the first time ever! After a break for some yummy refreshments, there was a lively sharing session. Several first-timers really needed to be reassured that WM does not usually cause mortality in five years. Discussion topics included how useful a second opinion from a doctor who has seen many WM patients can be. It was nice to have a former leader of our group, **Cynthia Nicholson**, doing so well after fourteen years of living with Waldenström’s.



*Members of the Northern California Support Group at their February meeting.*

### Southern CA

Dr. Lauren Pinter-Brown, Clinical Professor of Medicine in the Division of Hematology/Oncology at UC Irvine School of Medicine, spoke at the November 2016 meeting. She discussed the latest WM treatments and spent a generous amount of time answering many questions. The next SoCal group meeting will take place in Spring 2017. A separate San Diego support group is in the planning stages and will be led by **Kathy Battle**. Kathy can be reached at [kkbattle@aol.com](mailto:kkbattle@aol.com). Area members and friends are welcome to attend any meetings that are convenient.

## CONNECTICUT

In May, 2016, **Bob Ulkus**, co-leader of the CT WM group, attended the Lymphoma Research Foundation’s Lymphoma Workshop held at the Needham Sheraton in Needham, MA. He wrote up his impressions for *The B Cell*, a twice-yearly newsletter created by his wife, Barbara. Bob recently signed on as one of the CT WM support leaders. The CT group consists of 15-20 WMers and caregivers who meet at different locations across the state in the spring and fall. Bob was a participant in the recent IDR clinical trial at Dana-Farber Cancer Institute. The support group held its semi-annual meeting at Covenant Village of Cromwell. Three newcomers joined and shared their stories. Others caught up with one another and learned much from the experiences of others. Because several members were taking Imbruvica, there was a great deal of interest in comparing symptoms. The time flew by. **Bob Hammond** made a wonderful Power Point presentation on the cost of Imbruvica with help from Patient Access Network Foundation (PANF) and the Leukemia & Lymphoma Society’s (LLS) co-pay assistance program for those on Medicare. Plans are afoot for Madhav Dhodapkar, MD, Chief of Hematology at Yale University, to speak at the spring meeting, probably in June 2017. He was one of the recipients of the 2015 IWMF-LLS Strategic Research Roadmap grants. His presentation is entitled: “Origins and Immunotherapy of Macroglobulinemia.”

## IDAHO

The small group of five continues its commitment to casual, “kitchen table” oriented meetings, more or less on a quarterly basis. This past season was unusually busy, as the individual members immersed themselves in community volunteer activities. These vary from providing free tax preparation through the AARP to approved applicants; knitting and sewing clothing for Court Appointed Special Advocate (CASA) clients, nursing homes, and local hospitals; to screening children for visual problem referrals through a Rotary Club program; plus volunteering with the local arts council, symphony, and as lay ministers for their church. When the group gathered, participants realized that discussions of their individual community support efforts dominated the conversation. They are so enthusiastic about their various activities that they want to encourage others to also get involved with their local communities if they are not already serving. The group is sure that these efforts help preserve their mental health.

## ILLINOIS

### Chicago Area/SE Wisconsin

Over the last fifteen years many wonderful doctors have

*Support Group News, cont. on page 32*

spoken to the Chicago Area Support Group. None have been more well-received than Dr. Steven Treon from the Dana-Farber Cancer Institute, Dr. Stephanie Gregory from Rush University Medical Center in Chicago, and Dr. Robert Kyle from Mayo Clinic Rochester. The group has been very fortunate to have all three make presentations, including Dr. Kyle through the first IWMF video conference in 2009. Dr. Gregory, who lives in the Chicago area, has spoken several times, and now Dr. Treon has agreed to come for a second time. He will be flying to Chicago to speak on Saturday, 10 June, 2017, at a new meeting location. For more than fifteen years we have met at Lutheran General Hospital in Park Ridge. But, due to construction at this facility, the Elmhurst Memorial Hospital (rebuilt at a new location in 2011) has agreed to host our June meeting in a state-of-the-art conference room. The group expects to see a great turnout for this rare opportunity. Dr. Treon has spent many years of his clinical and research activities supporting Waldenstrom's and has championed significant research including the relatively new drug ibrutinib.

### MICHIGAN

The next support group meeting for Michigan is planned for 22 April from 2 to 4 pm at Providence Park Outpatient Center Heart Institute, rooms B and C. The building is located in front of the Providence Park Hospital at Grand River Avenue and Beck Road. Follow signs for parking for Heart Institute. It is the same location as previous meetings, just a room change. The topic for the meeting will be "Sharing Experiences." Please call **Jan Wheeker**, the group facilitator, with any questions at 734.718.9437. Or e-mail at [dwheeker@comcast.net](mailto:dwheeker@comcast.net)

### MINNESOTA & WESTERN WISCONSIN

It had been more than two years since the group last met. But new group leader, **Eunice Quast**, arranged a meeting for November of last year. The group of twenty WMers and caregivers met at Fairview Hospital in Edina, MN, to reconnect and welcome new members. After sharing experiences, feelings, and concerns, there was time for validation and support (and snacks). Members refocused on the group's priorities and parted re-energized. Afterwards, one new member stated, "Being with others who have this rarity and sharing how long some of them have had it, makes you realize it's a long-term disease." The next meeting is planned for Saturday, 8 April at Fairview Hospital. Dr. Prashant Kapoor, a WM specialist at Mayo Clinic Rochester, will be speaking on new and novel treatments.

### NEW YORK

*New York City*

The New York Metro-Area group met on cold February 5 – Super Bowl Sunday, a few hours before the big game. One former regular returned to the fold, and one newly diagnosed patient joined the group for the first time. The focus was on

serving and supporting the newbie, who arrived calmer than most, perhaps because he'd done some upfront homework with the IWMF and was more prepared than most to believe that if you have to be on the receiving end of a cancer diagnosis, Waldenstrom's is one of the indolent conditions you'd prefer to deal with. By the end of the group discussion, it seemed that the new member would continue to return and benefit from the rich and varied experiences of the long-term members.

*Rochester, Western, and Central NY*

A May meeting is being planned to accommodate the return of the snowbirds. The special guest speaker will be Carla Casulo, MD, Assistant Professor of Medicine, UR Medical Center, Rochester, NY. Her specialty is hematologic oncology.

### SOUTH CAROLINA

The South Carolina support group held its spring meeting on a March Saturday afternoon in Charleston. The lively discussion group took place at the American Cancer Society's "Hope Lodge" at the corner of Ashley and Calhoun Streets.



*Barbara and John Manoussou, Leaders of the Houston Support Group, were on hand to welcome 50 IWMF members to the Lymphoma Research Foundation's November 2016 conference in Houston.*

### TEXAS

*Houston*

**Dr. Barbara and John Manoussou**, Houston Support Group Leaders, welcomed over fifty members to the Lymphoma Research Foundation's November 2016 conference in Houston. Kudos to the LRF for an incredible breakfast and lunch. The lecturers were outstanding and generous with their time and answers. Dr. Sheeba Thomas from M.D. Anderson gave a very informative presentation for a Waldenstrom's breakout session that answered questions for the novice or experienced patient. Afterwards, Dr. Thomas answered all questions (and there were many) with patience and depth. The group met again in March when Dr. Jorge Castillo of Dana-Farber visited and made a presentation.



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