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IWWM7: PART 1

BY GUY SHERWOOD, M.D., IWMF TRUSTEE

The Seventh International Workshop on Waldenström's Macroglobulinemia (IWWM7) was held August 23-26, 2012, in Newport, Rhode Island, USA. This scientific conference for WM follows the previous conferences in Venice (2010), Stockholm (2008), Kos Island, Greece (2007), Paris (2004), Athens (2002), and Washington, D.C. (2000). For the IWMF readership, Dr. Guy Sherwood has prepared a summary of the lectures and presentations from IWWM7 that will soon be posted on iwmf.com in its entirety. Selected highlights from Dr. Sherwood's summary are included in the following article; for the complete summary please visit iwmf.com.



Zachary Hunter and Dr. Treon find a moment to relax at Newport. Their genomic study has set WM research in a new direction.

SELECT PAPERS FROM SESSIONS

“MYD88 $\text{L}_{265\text{p}}$ as a response marker in WM”

Zachary Hunter of the Dana-Farber Cancer Institute delivered a highly anticipated lecture on the recently identified somatic mutation ($\text{L}_{265\text{p}}$) in the MYD88 gene that has been found in 90% of WM patients. In order to determine the potential use of this important finding as a diagnostic test, an allele-specific (AS) polymerase chain reaction (PCR) assay was developed to permit quantitative assessments of the MYD88 $\text{L}_{265\text{p}}$ mutation. Using a series of very technical laboratory techniques, the AS-PCR assay was found to be

both sensitive and reliable. Furthermore, the AS-PCR assay was used in bone marrow biopsies of WM patients before and after treatment. Changes in the bone marrow infiltration levels and corresponding levels of MYD88 $\text{L}_{265\text{p}}$ mutations were compared. The high correlation between the bone marrow infiltration and MYD88 $\text{L}_{265\text{p}}$ mutation level suggests that the AS-PCR assay developed by Hunter and the rest of **Dr. Steven Treon's** team at Dana-Farber Cancer Center is indeed a sensitive (and inexpensive) laboratory test that allows accurate and quantitative detection of the MYD88 $\text{L}_{265\text{p}}$ mutation in WM.

Note: the whole genome sequencing that led to the identification of the MYD88 $\text{L}_{265\text{p}}$ mutation in WM was financed in part by the Research Fund of the IWMF.

Dr. Guang Yang of the Dana-Farber Cancer Institute lectured on the timely topic “**Targeting WM with MYD88 and IRAK inhibitors.**” The MYD88 $\text{L}_{265\text{p}}$ somatic mutation recently identified by Dr. Steven Treon was present in 90% of WM patients whose whole genome was sequenced. This specific genetic mutation is reported to cause the development of cancer (oncogenesis) in cell lines derived from patients with a subtype of diffuse large B cell lymphoma (DLBCL) by triggering the IRAK signaling pathway, among others. Dr. Yang and his colleagues have recently demonstrated that the MYD88 $\text{L}_{265\text{p}}$ mutation promotes survival of WM cancer cells.

New agents that could disrupt the oncogenic activity of the MYD88 $\text{L}_{265\text{p}}$ mutation or interrupt IRAK signaling were developed and evaluated by this sophisticated research team. Using

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cells from the bone marrow of WM patients with confirmed MYD88 $\text{L}_{265\text{p}}$ mutation and comparing them to healthy cells from non-WM volunteers, complex and highly technical laboratory assays were used to determine the efficacy of MYD88 inhibitory compounds or IRAK4 kinase inhibitors. A series of complicated experiments ensued. The results of these experiments showed that both inhibitors generated marked cell death (apoptosis) in the cells that contained the MYD88 $\text{L}_{265\text{p}}$ mutation in comparison to the healthy donor B-cells. A reduction in the IL-6 cytokine and corresponding reduction in IgM secretion was also noted in the WM cells. Further studies narrowed the list of the most potent inhibitors. This highly important basic research shows that the disruption of MYD88 pathway signaling leads to the loss of IRAK1 (and NF- κB and JAK/STAT) signaling and produces cell death (apoptosis) of WM cells with the MYD88 $\text{L}_{265\text{p}}$ mutation.

We now have several potential drug candidates that target the MYD88/IRAK4 signaling pathway in WM. Genetic drug therapy has indeed arrived at WM treatment!

An aside: These results illustrate why we have to continue to support young researchers and basic science!

Dr. Fred Hochberg of the Massachusetts General Hospital, Boston, MA, presented a lecture on **“Diagnosis and management of Bing Neel Syndrome.”** It is now clear that WM can affect all parts of the brain and central nervous system (CNS). This phenomenon is called Bing-Neel Syndrome (BNS). Dr. Hochberg, a neuro-oncologist, has aimed to better define Bing-Neel Syndrome as falling into two distinct categories: Group A whereby there is evidence of actual lymphoplasmacytoid (LMP) cells within the CNS or in the cerebrospinal fluid (CSF); and Group B which includes cases without apparent LMP cells but with the presence of the WM IgM antibody in the CNS.

Dr. Hochberg presented a review of 31 WM patients with Bing-Neel syndrome. He noted that a median of 36 months separated the diagnosis of WM and the subsequent diagnosis of BNS, although 26% of patients were diagnosed simultaneously. In the patients who were diagnosed with BNS, 9 patients had stable disease and 19 patients had progressive WM with BNS symptoms. Symptoms of BNS in WM patients range from memory deficits and behavioral changes to visual changes and cranial nerve sensory changes (numbness in specific facial areas for example). Of interest is the fact that 67%

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Please note the new address of the IWMF Business Office.



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of BNS patients experience symptoms related to the spinal cord as well as the lining of the brain itself (meninges, dura).

Dr. Hochberg is quick to point out that few WM patients have studies performed to diagnose BNS (for example, lumbar puncture to collect cerebrospinal fluid) and that many WM patients are diagnosed with BNS without proper distinction of other neurological conditions (for example, Parkinson's or dementia). Proper diagnostic criteria in the setting of a thorough patient history and physical exam and staging of WM include CSF collection and analysis (flow cytometry and/or immunohistochemistry and light chain quantification) as well as specific contrast-enhanced MRI of the entire CNS. Finally, Dr. Hochberg states that Bing-Neel is readily treatable in most cases with the appropriate selection of therapeutic modalities.

TREATMENT OPTIONS IN WM

Dr. Morie Gertz, Mayo Clinic, chaired a very informative debate session on four of the more controversial issues encountered in WM treatment.

1. "Should nucleoside analogues be used in young patients with WM?"

Speaking in the affirmative, **Dr. Enrica Morra** of Milan, Italy, a very experienced WM clinician and researcher, reminded the session attendees that the nucleoside analogues (NA) fludarabine (F) and cladribine (2-CdA) are very effective in both untreated and previously treated WM patients. The combination of NAs with rituximab (R) in studies using fludarabine and rituximab (FR) and FR plus cyclophosphamide (FCR) merit consideration in the treatment of WM as they produce rapid disease control with good quality of responses, even in previously treated WM patients. The associated side effects of NA-based therapies, however, which may include myelosuppression with increased infection rate, prolonged immunosuppression, stem cell damage, disease transformation to high grade B-cell non-Hodgkin's lymphoma, and development of second malignancies such as myelodysplastic syndromes (MDS) or acute myelogenous leukemia (AML), lead Dr. Morra to recommend avoiding these agents as first line treatment in younger patients and in patients considering future stem cell harvest for possible autologous stem cell transplant (ASCT). Dr. Morra repeated an assertion made earlier in the session by **Dr. Alesandra Tedeschi** that previous or concurrent treatment with alkylating agents (C, chlorambucil) may have a larger role to play in the development of transformation and secondary malignancies rather than the NA treatments themselves. Therefore, Dr. Morra concludes that nucleoside analogues can be used in young patients with WM after an accurate risk-benefit assessment. WM patients, including

young patients (those under 60 years) who have advanced or bulky disease requiring rapid control, as well as patients not eligible for stem cell transplant, may receive rituximab-NA based treatments. Shorter courses of therapy will reduce the myelosuppression and other side effects associated with use of NAs. In fact, Dr. Morra stressed that reduced duration NA-based therapies (FR, FCR, R-CdA) can be effective salvage treatment options for the carefully selected WM patient, including younger patients with adverse prognostic factors.

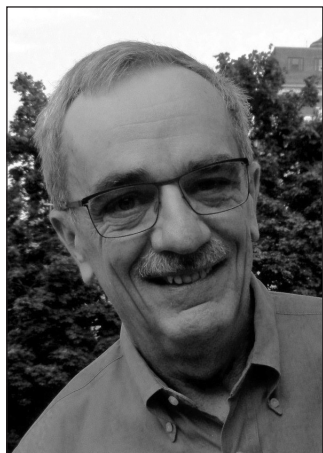
Dr. Xavier Leleu of Lille, France, countered that despite the effectiveness of NA-based therapies, there is a negative side to be weighed when selecting these therapies. On the negative side, Dr. Leleu listed the reduced ability to subsequently collect stem cells for ASCT after NA-based therapy, and the short and long term side effect toxicity profiles (particularly myelosuppression and neutropenias together with sustained depletion of both CD4+ and CD8+ T-lymphocytes resulting in opportunistic infections). These side effects are responsible for up to 5% of treatment-related mortality in NA-treated patients and may pose unnecessary hazards to the WM patient in need of treatment.

Furthermore, Dr. Leleu referenced the study he published from the Dana-Farber Cancer Institute showing a 7-fold increase in transformation to a more aggressive lymphoma and a 3-fold increase in the development of acute myelogenous leukemia (AML) and myelodysplasia (MDS) among WM patients who received NAs versus other therapies. Despite the observation that the median survival of patients who developed NA-related transformation (and were treated for transformed disease) was no different than from the WM patients who had not received NA-based salvage therapy, guidelines recommending nucleoside analogue therapy for WM patients were updated at the IWWM6 conference to reflect the increased risk of disease transformation and development of MDS and AML.

Dr. Leleu was careful to point out that despite the increased risks of NA-based therapies, these agents should still be considered in selected patients after a thorough risk versus benefit assessment. Nonetheless, he concludes, recent developments in the treatment of WM have given rise to equally effective and less toxic regimens such as DRC (dexamethasone + cyclophosphamide + rituximab) and R-Benda (rituximab + bendamustine) that should further limit the use of NA-based therapies in most if not all WM patients.



PRESIDENT'S CORNER



Happy New Year! As the new President of the IWMF, I'm honored that you have entrusted me with the leadership of the IWMF. Together we will work to fulfill the Foundation's vision:

Support everyone affected by Waldenstrom's macroglobulinemia while advancing the search for a cure.

The IWMF has a lot to celebrate as we start 2013. This is the fifteenth year since the Foundation was incorporated, and we step into the New Year as a strong organization, thanks to our previous leadership.

Our strength is evident in the results from the recent online membership survey. The IWMF's "report card" is displayed on page 7 of this issue. Just take a look to learn how nearly 500 WMers from around the world rated the IWMF. And thank you to everyone who completed this survey!

Important additions to the Board of Trustees were made in the second half of 2012. The October 2012 issue of the *Torch* introduced our new Secretary-Treasurer, Cynthia Ruhl, ending the hiatus of more than a year when we were without a Treasurer. This issue includes the Treasurer's Report for 2011. The management of the Foundation's money is in very capable hands, and reports from our Treasurer will be appearing regularly in the *Torch* and on the website.

Two great new members of the Board of Trustees were elected at the October meeting of the Board. Turn (or scroll) to page 13 to meet Marcia Klepac, the new head of IWMF support groups, and Michael Sesnowitz, the new head of IWMF fundraising.

At the very end of September the IWMF moved into a larger and more suitable office in Sarasota. As a result you are now better served at the same cost! Office Manager Sara McKinnie – now that the move is over – expresses her satisfaction on page 5.

The latter half of 2012 also saw the expansion of member services with additions to our website. A newly revised section Frequently Asked Questions (FAQs) and a new Glossary of Medical Terms were added to the IWMF website at www.iwmf.com. Information presented in these sections empowers you to make sure that you understand what your oncologist is telling you.

A very important new member service is the expanded Patient Database. The PDB is an Internet-secure record of the past medical and family history of Waldenstrom's macroglobulinemia patients and their test results. You can also enter your personal data and create graphs of your blood test records so you and your oncologist can spot trends – a very practical use of this new service. More details are explained in depth on page 10.

Looking ahead in 2013, we have the program already in place for an exciting Educational Forum scheduled for May 17-19 at the Westin Hotel in downtown San Diego, CA. We have the same great hotel rate for the three days before and three days after the conference, so why not turn it into a vacation? The IWMF website has more details, and on page 19 you will find some suggestions about the many attractions San Diego has to offer a visitor. Book your trip now!

In the opening lines I acknowledged the strengths of our previous leadership. And now I am pleased to announce a new award named in honor of Judith May, our President Emerita. The new Judith May Volunteer of the Year award will be presented for the first time at the San Diego Educational Forum. Your support group leader has all the information on how make a nomination. And thanks to everyone who donated in Judith's honor: tribute donations totaled an incredible \$56,984.

Finally, we can all share the excitement of the recent SEER study showing improved longevity for WM patients. Yes, we WMers are surviving longer! The article on page 9 is a summary of the epidemiological study of the database of WM patients covering the years 1988-2005. This study shows that WM patients diagnosed between 2000-2005 have a significant overall decrease in risk of death when compared to patients diagnosed between 1988-1995. And the benefit is even more striking for younger patients 50 years old and under. Details on page 9.

While we have a lot to celebrate, we also have a lot more to do. Since the IWMF is a volunteer-led and volunteer-funded organization, each and every WMer is critical to our success in conquering this disease. With a rare disease like WM, every person counts – especially you!

What can you do to help conquer WM? How about making New Year's resolutions to:

Give as generously as you possibly can to the IWMF. Give to both the Member Services Fund and to the Research Fund.

Check your charitable giving. Given the impact of WM on your life and the rarity of this disease, please make the IWMF one of the top three places on your list for charitable donations.

President's Corner, cont. on page 5



Be an advocate for the IWMF within the health care community.

When you visit your oncologist, ask your doctor or nurse if their practice has other WM patients. If so, ask them to recommend the IWMF to their patients. Not everyone with WM is aware of the IWMF.

Do your part to help out by "recruiting" your doctor as our ally. If your doctor is not on our mailing list, ask if he or she would like to be. Doctors on our mailing list will receive the *Torch* and other informative materials.

You can add your doctor to our mailing list by e-mailing his or her contact information to Julie Jakicic at office@iwmf.com or by calling her at 941-927-4963.

Ask your friends and family members to donate to the IWMF.

Have you told your friends and family about your disease? If so, ask them to help you find a cure by donating to the IWMF.

When I became President of the IWMF, my wife sent a letter to our friends and family asking them to donate. So far, more than 35 people have donated in my honor. Right now, the IWMF has roughly 2500

patient members. If each one of you were able to get 10 people to donate in your honor, we would have 25,000 new donations in 2013. For comparison's sake, right now we get about 4,000 donations a year. Help WMers everywhere by asking your friends and family to contribute. Ask today.

Get more involved.

Volunteer your time and skills to the IWMF. Ask your support group leader how you can help or call the IWMF office in Sarasota and tell us about your skills.

In particular, we need someone with video skills who can train at the San Diego Ed Forum with Michael Luttrell and take over production of the Ed Forum DVDs starting in 2014.

Set up a local fund raising event. See iwmf.com/donate/fundraising-events-and-activities.aspx to get started.

With each and every one of us pulling together, we'll have even more to celebrate at the end of 2013.

Stay well,

Carl

OUR NEW OFFICE: THE INSIDE SCOOP

BY SARA MCKINNIE

The IWMF Business Office moved to its new location in September. We now have twice the space for the same rent!

Everyone who has ever visited our old location will testify that it was beyond "cozy." Most visitors were amazed that so much production could have come from such a tiny place.

This past summer, a friend alerted me to two adjacent offices in an industrial park. Industrial square footage is significantly more affordable

than commercial office space. So, after researching what it would cost to combine the offices and move, I approached President Judith, who encouraged me to submit a proposal for the move to the Board. The Board was unanimously in favor, and we completed our move within one month. In fact, we were hauling boxes at about the same time that Hurricane Isaac was passing through! Coincidentally, within weeks of relocating, it was the office staff's pleasure to host your Board of Trustees at a retirement reception for Judith. It feels good to be proud of our workplace and to show it off.

Bringing offsite storage into our office is also a relief. We certainly won't miss hunting down archived files (or anything else there wasn't room for) in a hot metal building – especially during the summer months in Florida!

Thank you, members, for your support. Please do visit the IWMF Business Office at 6144 Clark Center Avenue if ever you are in Sarasota.



Clearly delighted with their new work space, the IWMF office staff from left to right: Danielle Bannister, Julie Jakicic, Gail La Bruno, and Sara McKinnie. The recent online survey confirmed that IWMF members appreciate the excellent services provided by the office.

than commercial office space. So, after researching what it would cost to combine the offices and move, I approached



THE IWMF GETS A GREAT REPORT CARD

BY CARL HARRINGTON, IWMF PRESIDENT

To understand how well we are doing in meeting your needs, the IWMF Board of Trustees authorized a membership survey. This survey was conducted at no cost to the IWMF via an online survey created by IWMF President Carl Harrington, who has experience conducting online research in his marketing consulting company. This survey was open to all WM patients, friends, and family who are on our e-mail list and was announced in a Constant Contact e-mail.

The extensive online survey measured many aspects of the IWMF, from overall satisfaction to specifics to interaction with the IWMF Office to how much you would be willing to pay for a room at the annual Educational Forum. Nearly 500 WMers from around the globe responded to the survey between October 24th and November 9th. This is an impressive response totaling more than eight times the number of respondents who took our last survey in 2009. Thank you to all who took the time to respond and help us understand what we're doing right and what we still need to work on.

And now the results are in, and the IWMF gets a great report card! We got 6 A's, 6 B's and 2 C's for an overall average of a strong B+. Interestingly, scores did not vary significantly by type of respondent (WMer, family member, or friend), by geography, by years since diagnosis, by age, or by any other measure.

Who answered the survey?

For those who just want to know, the survey respondents split as follows:

88% patients, 10% relatives, and 2% friends

56% male, 44% female

82% live in the US, 18% live in other countries, including 7% in Canada

Ages of respondents range from under 35 to over 85, but those 61-70 made up 43% of respondents.

Nearly 85% were between the ages of 55 and 80.

Within the 435 patients, there was a broad dispersion of years since diagnosis.

47% of respondents were diagnosed 7 or more years ago.

Long life to WMers!

OTHER KEY FINDINGS

What else did we learn?

Website

- Not surprisingly, most people (69% of those current members diagnosed in the last year) found the IWMF through our website, and most people first contacted us through our website. It's a good thing that we have such a strongly rated website.
- Overall, 90% of survey respondents have visited the IWMF website www.iwmf.com.
- Younger WMers visit the site frequently, but 83% of those over 75 have also visited.

Torch and Other Publications

- 98% of respondents read the *Torch* and they love it. The favorite features are Medical News Roundup and Doctor on Call.
- Many people who currently receive the *Torch* by mail would be willing to receive it electronically. The cost savings, particularly for international subscribers, would be significant if they opt to do so. Please do consider the electronic option.
- Many WMers are willing to pay more to receive physical copies of publications and the *Torch*. Others would prefer to receive them electronically or download them from our website. We'll consider both possibilities.

Fundraising

- WMers think the Fundraising Team is contacting them about the right number of times. However, they think direct mail is a very effective method to increase contributions. So you might hear from us by mail an extra time or two in the year ahead.

Educational Forum

- The 2014 Ed Forum will be in Florida. Respondents chose Tampa as their favorite site. We are looking at hotels in Tampa for May of 2014.

If you participated in the survey and gave a low score to some aspect of the Foundation, do not think that we're going to ignore you. We are going to evaluate every low score and all of the written comments you provided.

Thanks to everyone who took the time to fill out the online survey. Your input is critical to making the IWMF even better!

The IWMF Gets a Great, cont. on page 7



<i>IWMF 2012 Report Card</i>			
<i>Subject</i>	<i>Grade</i>	<i>Numerical Score (on a 10 point score)</i>	<i>Comments</i>
<i>IWMF Overall</i>	B+	8.92	Very strong score. Patients rate the IWMF a little higher than do relatives and friends. Congratulations to everyone associated with the IWMF. Now we'll work harder to do even better.
<i>The Torch</i>	A-	9.23	Outstanding score for our flagship service. We'll continue to publish three times a year, and we'll consider your suggestions for expanding content.
<i>IWMF Office</i>	A-	9.20	This score confirms what we already suspected: our office staff in Sarasota is outstanding! Ratings on individual questions range from 9.20 to 9.63!
<i>Research</i>	A-	9.15	Outstanding score but we need more \$\$ to fund the research requests we are receiving.
<i>Publications (booklets)</i>	A-	9.08	Very strong scores. WMers are split on how they want to receive the publications: online or in the mail (by far the more expensive alternative). We'll consider both.
<i>Introductory Info Pak</i>	A-	9.05	We changed the contents of the Info Pak last year. The score jumps to 9.42 among those who received an Info Pak in the last year.
<i>Website</i>	A-	9.01	Very strong scores ranging from 8.49 to 9.02 on individual components. We'll look to your ideas for ways to further improve.
<i>Ed Forum</i>	B+	8.78	59% of those responding have not been to an Ed Forum. If you're one of them, come to the San Diego Ed Forum in May 2013, from the 17th to the 19th, and you'll see what you've been missing.
<i>Ed Forum DVDs</i>	B	8.61	Only 45% of WMers have viewed an Ed Forum DVD either at a support group or at home. See our website if you want to purchase the DVD from the Philadelphia Ed Forum. Watching the DVDs is a great way to learn how the best minds in WM research assess the progress they're making towards better treatments and, ultimately, a cure.
<i>Lifeline</i>	B	8.54	Only 25% of WMers have ever used the Lifeline, but those who have are very satisfied.
<i>Fundraising</i>	B	8.51	Over 95% of respondents have given to the IWMF. Have you? Overall, this is a good rating for what some would view as a "necessary evil." Remember, we're an orphan disease. What each one of us does matters a lot.
<i>IWMF-Talk</i>	B	8.42	Only used by 26% of WMers. Those who use it are quite satisfied.
<i>Ed Forum Review</i>	B	8.40	While respondents were very satisfied with the Ed Forum DVDs, they ranked the <i>Ed Forum Review</i> somewhat lower. <i>The Review</i> includes summaries of all the major presentations from the most recent Educational Forum. It is the perfect companion for watching Ed Forum DVDs. We'll work to make the written summary even easier to understand.
<i>Support Groups</i>	C+	7.89	Only 51% of WMers have ever attended a support group meeting. To find the support group nearest you, contact the IWMF Business Office or look in the <i>Torch</i> . Your support group leader wants your help to develop dynamic agendas for the 2013 meetings.
<i>Facebook page</i>	C	7.28	We just launched our page. Not many WMers currently use Facebook, but we'll continue to improve our look. We expect that Facebook will become an increasingly useful tool for connecting WMers.



LIVING WITH WM

BY PENNI WISNER



Penny and her food processor: teaching healthy cooking at a recent UCSF Cancer Resource Center retreat.

As you read this article in January 2013, I will be celebrating my – wait now, let me count – 14th anniversary since diagnosis. That process, as with many WMers, began months before, when to “celebrate” turning 50, I took myself for my first physical in years and discovered my hemoglobin was below 10.

A year or two ago I participated in a research project studying post traumatic stress syndrome after lymphoma diagnoses. As I recounted those first terrifying weeks after

diagnosis, I felt tears well up. My reaction surprised me. I thought I was over all that.

So perhaps those feelings explain why I am only writing this story now that the deadline for submission is tomorrow. I have had the assignment for months. Maybe it is not just my usual procrastination. Therefore, I will pick up my story well after my initial diagnosis and treatment.

But living is a complicated business made even more complex with a history of cancer. Perhaps the easiest way to express the sea change that occurred back then is that now gaining weight means I am healthy. Each birthday is a triumph. And the physical, mental, and spiritual process of aging is a gift hard won.

I have never liked the label “cancer survivor” or the easy reference to dealing with cancer as a “battle.” Even in the very beginning, it was clear to me that these labels were not helpful. If I accepted them, then I would have to accept the rest of the claptrap swirling around every newly diagnosed patient – a miasma of positive thinking and quarts of green tea. Since I am mixing metaphors, I might as well continue: I have never been a “the glass is half full” kind of girl, and I do not particularly like green tea. Can you tell I am perhaps still angry?

In fact, my hematologist/oncologist remarked some years after my treatment that maybe I had done so well because I was so angry. The contrariness of my reactions later led me to lead a Waldenstrom’s support group in my area. I did not – and do not – want anyone to feel there is a “right way” to do cancer and another way might lead to failure. Later, applying a lesson learned only through my cancer journey, I asked for help and banded together with Cynthia Nicholson, folding the until-then separate Sacramento and Bay Area support groups into one.

In 2003, three and one-half years after completing a course of chemotherapy chased by Rituxan – Cytosan plus fludarabine

for three days every four weeks plus one (four-infusion) treatment with Rituxan – my IgM count descended into the normal range and the IgM spike disappeared. It has not yet (now that is a 1000-mile word) reappeared and my IgM, measured annually, has remained below 50. My doctor used to inquire as to whether I wanted to explore Rituxan maintenance, but I never heard a convincing argument for it.

Eventually, I have become accustomed to my “complete remission” status and even forget – in that deeply personal, intimate way – that I have had cancer. I do not get as anxious before my annual oncology appointment and view it as a convenient way to get all my blood work done, saving me a trip to a primary care doctor. I hope I do not appear cavalier. That distance has been many years in the making. I cannot forget that WM and its aftermath blasted my life and heart wide open. And life walked in.

I maintain my connection to our community by expressing my passion for cooking in the Cooks’ Happy Hour column and writing the Support Group News column. I am also listed with the IWmf and the LLS as available for peer support. But I prefer to focus my energy on my family and friends, my garden, my cookbook writing (the newest, *Hubert Keller’s Souvenirs: Stories and Recipes from My Life*, was published by Andrews McMeel 30 October 2012), and my work with individual clients as a kitchen coach. And I hope, soon after returning after a month in South Africa this winter, to adopt a dog. My previous dog, adopted just months before my diagnosis process began, gave me reason and purpose to force myself up after chemo treatments and out to the beach where both of us reveled in making fresh prints and then watching the waves erase them.

I have lived long and well with WM. My first oncologist retired, and I wonder when my current doctor will do the same. If, and when, WM recurs, I cannot predict how I will react. Most likely I will do as I did before: go sort of crazy. But then, I hope, I will have the smarts to return to our IWmf patient Educational Forums and the local support group. I might find comfort, too, in my greater knowledge and in research that has borne an abundant crop of choices well beyond what existed when I began treatment in 1999.

Maybe the greatest gift is this: That to live an unremarkable life is remarkable.

Penni herself is quite remarkable. Although achieving the response to treatment that most of us would envy, she has kept deep roots as a volunteer for the IWmf. In addition to her columns in the Torch and the other services she provides, Penni has only recently stepped down as support group leader for northern California after 10 years. We conclude with a quote from Socrates: The unexamined life is not worth living. Penni has taken the advice of the Athenian philosopher – she has examined the facets of her life with WM and is living the life worth living.



INCREASED LONGEVITY FOR WM PATIENTS

A recent study from the Washington University School of Medicine, the Yale University School of Medicine, and the Smilow Cancer Center, New Haven, CT, examines the incidence and survival of Waldenström's macroglobulinemia based on SEER (Surveillance, Epidemiology, and End Results) data released in 2008 and covering the years 1988 to 2005.¹

Over this defined span, 2,696 cases of WM were diagnosed, of which 1,659 were male and 1,037 were female. The incidence of our rare disease within the general population was 0.3 WM patients per 100,000 or 3 per 1,000,000. The median age at diagnosis was 73 (reflecting a range from 23 to 96), and 1,603 of those diagnosed were age 70 or older, while 1,093 were younger than 70.

For the entire cohort of 2,696 patients, there was a median overall survival of 65 months, and 52% had an overall survival of 5 years. However, for patients younger than 70, the overall survival rate was much improved at 71%. For patients older than 70, the prospects of 5-year survival declined to 39%.

When, however, the WM patients diagnosed between 1988 and 2005 were assessed by date of diagnosis within the years 1988-2005, there was, overall, a decreased risk of death. Simply translated, this indicates that as time goes forward – and assuming new drugs and improved treatment methods – we are living longer. For purposes of this study, the year of diagnosis was assessed at 5-year increments, and a 10% decrease in ‘hazard (or risk) of death’ was shown for each 5-year increase in year of diagnosis.

In other words, WMers diagnosed between 2000-2005 have overall a 20% decrease in hazard of death when compared with patients whose diagnosis was made between 1990-1995. And this benefit is greater in younger individuals. WM patients diagnosed at age 50 have a 30% *decrease* in hazard of death for each 5-year *increase* in year of diagnosis. For those patients aged 75 and over, this statistical benefit does not apply.

In conclusion, it can be said that WMers are surviving longer. The SEER-based study demonstrates a reduction in mortality, based on date of diagnosis, for the diagnostic period 1988-2005. And for younger individuals there are further improvements in survival; interestingly, this result is consistent with multiple myeloma.

Looking ahead to a comparable study in the future, even brighter results concerning survival may be anticipated. As the report states in closing, the improvement in outcomes of patients with WM is shown in this study for patients *without* “the full benefits of modern therapeutic agents such as rituximab, immunomodulatory drugs and proteasome inhibitors introduced recently for the treatment of patients with WM.” Because the use of these agents is far more prevalent today, the next SEER analysis should reflect usage of these agents to show increased survival.

Thanks to Peter DeNardis for bringing this report to IWMF-Talk.

¹ This summary is based on Sekhar, J., et al., “Waldenström macroglobulinemia: a Surveillance, Epidemiology, and End Result database review from 1988 to 2005.” *Leukemia & Lymphoma*, August 2012; 53(8): 1625-1626.

We Get Letters

We get letters, and, more frequently, we get mention in posts to IWMF-Talk. Yet what a surprise to receive a recent post from the land of Jan Waldenström!

In the last issue of the *Torch* I read an article about Rituxan written by Tom White, who was involved in the development of Rituxan and also has benefited by it himself. A strange coincidence! I really want to thank Tom White et.al. for this fantastic antibody, which suited me perfectly. My doctor says we know what to use the next time in my case.

It was also interesting reading about Emil Parente: living with WM for 32 years. It gives hope. I have “only” had WM for 18 years, so I hope to live many years more. But life is not predictable. My husband suddenly and unexpectedly died one year ago, when exercising at a gym. He was totally healthy with no problems at all.

Take care of your life!

Anne Odmark
Uppsala, Sweden



THE PATIENT DATABASE WANTS YOU!

The IWMF Patient Database team is proud to announce the improvements just completed to the Patient Database, a project supported by the Foundation for its members. If you haven't yet registered to use it or haven't visited it lately, now is the time to check it out.

As many of you may recall, an online Patient Database (PDB) was the vision of Ron Draftz, a WMer from Chicago who served the IWMF in many capacities through the years. Sadly, Ron passed away in 2011, but it was the heartfelt goal of the remaining members of the Patient Database team to continue his work and make it useful for WMers everywhere. In fact, we've followed through on his desire to ensure that the units of measure used for entering test data are reflective of each participant's country.

The IWMF Patient Database has been developed as a tool for the WM community to record and manage personalized medical history and test data, no matter where you are in the world – the data, in a sense, is stored “in the cloud” and can be accessed anywhere you have an Internet connection. The IWMF is unique within the orphan disease community in providing this type of tool for its membership. The PDB is truly the first and only of its kind, and we encourage the entire WM community to take full advantage of it.

Below you will find information about registering for the PDB, its new features, and a brief explanation of the three main modules (Patient History, Test Results, and View Data) and how to use them.

How to Register for the Patient Database

Those of you who used the older version of the PDB will still be able to use the same username and password as previously – the information you've already entered is there too.

If you are an IWMF member but have never used the database and want to register for the first time, go to www.iwmf.com/services/patient-database.aspx and click on the link provided to the IWMF Member Sign-In page. From that page, click to register and you will be taken to a page that explains what the PDB is all about. You should read it carefully and acknowledge that you understand the terms and conditions of its use. Once you've done that, you will be taken to a page for entering your contact information, including a username and password of your choice. Rest assured that your identity and those of others who enter their data are intended to remain confidential. Identities will be known only to the database managers who must be able to operate the database, verify membership, and supply lost usernames and passwords. Identities are not embedded in the database itself but are kept external to the database as a means of protecting confidentiality – this means that your name and contact information are not linked to your test results in the PDB itself. Your registration information will be processed by the PDB Team, and once this is completed you will receive an

e-mail confirmation instructing you to begin using the PDB. From that point on, anytime you want to enter information in the PDB, just go to the IWMF Member Sign-In page, log in with your chosen username and password, and proceed.

If you forget your username and password at some point, don't panic – and please don't register again to select new ones. It is very important that you keep the same username and password you originally chose when you registered; if you switch to new ones, the PDB will consider you to be a different user, and the history and test information you entered under your old username and password will not link up with information you enter under new ones. If you forget either one, there's a place on the IWMF Member Sign-In page for you to click to recover your original username and password from the database managers.

What's New in the Patient Database

If you haven't visited recently, you'll immediately notice that the PDB has been re-designed to have a *cleaner and more appealing look*.

New users and those who would like a refresher on using the PDB should take advantage of a very useful *tutorial feature* developed by the newest member of the PDB team, Brian DiCarlo. Brian is a fellow WMer, computer expert, and the PDB volunteer largely responsible for upgrading the “look and feel” of the PDB and for adding the newest features to it. Tutorials have been developed for each section of the PDB, and they are located in the About tab at the top of the IWMF Member Sign-In page. When you click on any of the tutorials, you will hear Brian's voice (and see his computer mouse!) lead you on a tour of that particular section. (Note: you must be logged into the PDB in order to use the tutorials for entering data and for reports and graphing.)

Also, and perhaps most importantly, *a new module called View Data* has been added to allow you to create charts and graphs of your own data that enable you to see trends in your test results and data history (see the section below for more about this new module).

Using the Patient Database

There are three main sections or modules to the PDB – Patient History, Test Results, and View Data – and several subsections.

The *Patient History module* captures your date of diagnosis, your nationality, your medical history, your family history, the signs and symptoms of your disease, and other useful information. This is the longest section, but you don't have to complete it in one session. Click on the Patient History tab at the top of the IWMF Member Sign-In page and then click Survey. If you want to exit the Survey, click the logout button on the top right of the page, and the PDB will save

The Patient Database, cont. on page 11



the information you've already completed. You can come back to it later. We recommend that you complete the Patient History Survey first if you haven't already done so.

The **Test Results module** has three subsections: CBC (Complete Blood Count), Chemical Panel, and Immunoglobulins. Click on the Test Results tab at the top of the IWMF Member Sign-In page and choose which subsection to enter. Each subsection will require you to have copies of your test results at hand, and we urge you to be careful when you enter this information. The PDB is set up to catch and alert you to major errors you might have made when entering your data but may not necessarily detect small errors. If you make an error during data entry, you can correct it then. You also have an option to edit or discard any previous test entries. Once you have completed the page, you can save it or discard it (if for some reason you decide not to use it).

One thing we strongly encourage you to do is to use the PDB on a regular basis. New users may find that they have to enter a large volume of data at the beginning, but those who go back to the PDB frequently (for example, to enter the results from their latest lab draw) will find it fast and easy. Of course, the best reason to use it regularly is to keep track of your own disease status.

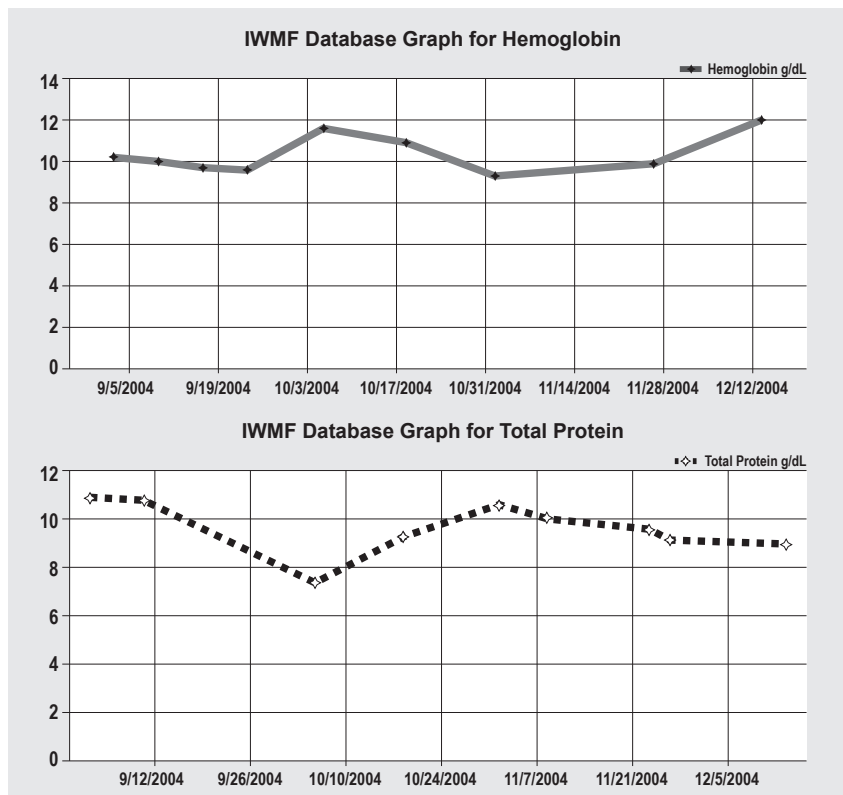
And that leads us to the newest and one of the best features of the PDB mentioned above – its ability to generate reports and graphs of your own test results over time. You can access these capabilities by going to the **View Data module** at the top of the IWMF Member Sign-In page. From there you can choose either Reports or Graphs. The Reports selection will generate a spreadsheet which you can print or save. The database can support generation of spreadsheets from Excel and other similar programs. Reports are based on information you entered from either the Patient History module or one of the Test Results subsections, and you can select data from one field or multiple fields to include in your report.

Let's use an example from actual results entered by a PDB team member. First, several lab draws over a period of time were entered in the CBC subsection of the Test Results module. It will help you to know that this patient was diagnosed in May 2004, had several plasmapheresis treatments in late September-early October, and began chemotherapy in late October. The following is a snapshot of the Excel spreadsheet report generated from the CBC data, and you can see the steady decreases in both hemoglobin and hematocrit after diagnosis, a brief bump upward after plasmapheresis, and another drop between plasmapheresis and the start

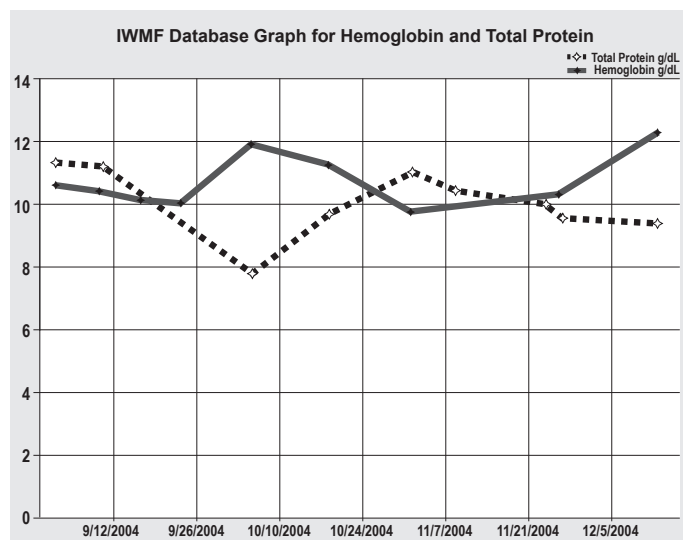
of chemotherapy. You will also notice an increase in both hemoglobin and hematocrit and a decrease in the WBC count after chemotherapy began (indicating a benefit from chemotherapy but with some toxicity to the WBCs):

Report Date	WBC	RBC	HgB	HCT	PLT
5/25/2004	6.8	3.78	11.3	33.4	198
5/26/2004	5.9	3.79	11.3	33.4	201
6/11/2004	6.7	3.66	10.6	31.6	271
9/2/2004	5.51	3.51	10.2	30.6	201
9/9/2004	5.49	3.21	10	30.2	200
9/16/2004	4.9	3	9.7	29.9	201
9/23/2004	5	2.9	9.6	28	199
10/5/2004	8.4	3.87	11.6	34.4	166
10/18/2004	5.8	3.69	10.9	32.7	257
11/1/2004	2.7	3.21	9.3	28.4	200
11/26/2004	3.5	3.32	9.9	29.7	248
12/13/2004	3.13	4.16	12	37.5	212

Your test information can also be used to automatically generate one or more graphs that you can print or save. When you choose the Graphs option from the View Data tab, you can select all data or data in a certain date range. For graphing, you can also choose one test field or multiple test fields to include. In the following example, this same WMer graphed total protein and hemoglobin over the period September-December 2004. This information can be graphed separately for each field, as in the following example:



Or the information can be combined in one graph with both fields, for an even more revealing representation:



You can easily see how useful this graphing function is. Looking at the above examples, note that in late September-early October this WMer's total protein briefly dropped

and hemoglobin bumped up. Again, that's because of plasmapheresis. After, plasmapheresis, you can also see that the total protein began to trend upward, along with a corresponding drop in hemoglobin. When chemotherapy was initiated in late October, total protein again started to decrease and hemoglobin slowly improved. This particular patient's test results show a very definite inverse relationship between hemoglobin and total protein. Trends are important in following your disease, as you've been told if you've ever attended an Ed Forum, participated in IWMF-Talk, or read the IWMF literature. A graph is a great visual representation of trends over time.

We sincerely hope that you will want to register for the PDB, use it regularly, and enjoy the new features – just go to www.iwmf.com/services/patient-database.aspx to do so. And if you need help or have problems, you can contact the PDB managers at database@iwmf.com.

From your Patient Database Team,

Peter DeNardis

Brian DiCarlo

Sue Herms

Tom Hoffmann

TREASURER'S REPORT FOR THE YEAR 2011

BY CYNTHIA RUHL, IWMF SECRETARY AND TREASURER

As the new Secretary and Treasurer of the IWMF, my first report will be for 2011 since the report for this year has not yet been published in the *Torch*. Our audited financial statements and tax returns are now available for your review on www.iwmf.com under Board Reports.

	2011	2010
Total revenue, gains, and other support	\$1,065,254	\$ 868,350
Research grant expenditures	\$ 718,545	\$ 916,885
Other member services	\$ 617,018	\$ 632,302
Change in net assets and administration	\$ (270,309)	\$(680,837)

Our future obligations on research grants awarded are \$1,161,250. These commitments require payments from 2012 to 2016, if the conditions of the grants are substantially met. It is obvious that if we want to continue to support the encouraging research being done, we must step up and contribute to our own future health and the health of our loved ones.

I assure you that 100% of every dollar donated to the Research Fund goes to research.

In 2011, 91% of every dollar donated to member services was spent on member services versus administration and fundraising. In my short time on the IWMF Board, I have been very impressed by the Board's sharp focus on careful custodianship of the funds that you as members entrust to the Foundation.

While a 22% increase in revenue for the combined funds is quite impressive in our current economic environment, our commitments resulted in a loss of net assets. Our overall cash reserves are a concern. At the end of 2010, our net assets were \$1,499,961. At the end of 2011, the net assets were \$1,229,652, reflecting the negative change in net assets of \$ (270,309).

Financial information for 2012 will be available after the annual audit is complete. The audit will be completed during the summer of 2013, and the information for 2012 will be posted on the website. The Treasurer's Report is published twice a year in the *Torch*.

Please do not hesitate to contact me concerning any questions about IWMF financial matters:

Cynthia Ruhl, Secretary/Treasurer
310-433-2247 or csruhl@hrmcps.com



IWMF WELCOMES TWO NEW TRUSTEES

At the October meeting of the IWMF Board of Trustees, Marcia Klepac and Michael Sesnowitz were elected Members of the Board. Each of the new trustees brings outstanding qualifications, and both express enthusiasm for their new responsibilities.



To her new role of Support Group Leader Coordinator, **Marcia Klepac** brings the experience of 4½ years as support group co-leader for the area encompassing western Pennsylvania, eastern Ohio, and West Virginia. (Readers of the *Torch* column Support Group News may have noticed the regularity with which Marcia and Glenn

Klepac are thanked for their gracious hospitality at recent support group meetings) Marcia is also a regular attendee at Ed Forums and she has participated in a panel on clinical trials.

When asked about her WM diagnosis, Marcia shared a personal recollection:

“You have MGUS.” This statement from my oncologist in 1995 gave me much hope because I had narrowly avoided a diagnosis of WM. Taking this as an opportunity to improve health habits, I continued to remain in the somewhat comforting state of MGUS for six years. Just months after my dad (also in the MGUS club) progressed to WM, I followed his path and converted to WM. One is never ready to face a cancer diagnosis, but I had six years to put my mind-body-spirit approach to health into action.

Today, in her 8th clinical trial and with good quality of life, Marcia is ready to take on her new role, and she looks “forward to working with support group leaders to promote connections with WM patients and their families through education, support, and friendship. I hope to foster the value of support group participation in achieving the best possible health outcome and overall quality of life.”



Michael Sesnowitz, now leading the Fundraising Team for the IWMF, holds a Ph.D. in Economics from the University of Pittsburgh and has pursued a long and very active career in academia. Since 2000 he is Professor of Economics at Virginia Commonwealth University and from 2000-2009 served as Dean of the School of Business, a position that entailed quite a lot of fundraising. In the course of his career, Michael

has served on eight nonprofit boards, including the Board of the Children’s Hospital in Richmond, VA, the Virginia Commonwealth University School of Business Foundation, and the Kent State University Foundation.

Commenting on the importance of fundraising for the IWMF, Michael recently said, “I hope to be able to help the IWMF increase the funds it raises to support patient services and WM research. I have been very impressed with what has been accomplished with so few resources. This is a very exciting time because the results of the research that the IWMF has funded have opened new avenues for exploration that promise far better treatments and, quite possibly, a cure. This will only happen if we all support the IWMF as generously as we can.”

Ed Forum 2012 DVDs

To order the Ed Forum 2012 DVDs, place your order at www.iwmf.com under *IWMF Library: Ed Forum DVDs*. Cost of the full set: \$14



MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWWMF TRUSTEE

Carfilzomib Dosing Established in Phase I Trial – A multi-center U.S. and Canadian Phase I study of carfilzomib in patients with relapsed or refractory multiple myeloma and lymphoma established its safety and tolerability in escalating doses. Carfilzomib is a next generation proteasome inhibitor in the same class as bortezomib (Velcade). Doses ranging from 1.2-27 mg/m² were administered intravenously on two consecutive days for three weeks of a four-week cycle. Single-agent dose escalation was followed by a dose-expansion phase that consisted of two dosing groups, carfilzomib or carfilzomib and dexamethasone combined. During dose expansion, carfilzomib was administered starting with 20 mg/m² during the first week and then escalated to 27 mg/m² thereafter. A maximum tolerated dose was not reached during dose escalation. Adverse events were primarily grade 1 or 2, with anemia and thrombocytopenia the main grade 3 or greater hematologic events. There were no grade 3 observations of peripheral neuropathy. At doses of 15-27 mg/m², there was evidence of therapeutic activity in patients with multiple myeloma and non-Hodgkin's lymphoma.

French Study Notes Unique Protein Expression Profile in WM – A multi-center French study compared the protein expression profile of WM cells with that of other lymphoproliferative disorders and demonstrated that WM is unique when compared to chronic lymphocytic leukemia and marginal zone lymphoma. In particular, the French researchers observed a major downregulation of the double strand repair protein Ku70 in WM cells and suggested that it may be relevant in the pathology of the disease.

Bortezomib Combined with SNS01-T in Pre-Clinical Study of Multiple Myeloma – Senesco Technologies, Inc. announced that the combination of bortezomib (Velcade) and the company's pre-clinical drug SNS01-T performed significantly better than either treatment alone in mouse models of multiple myeloma and resulted in 89% tumor inhibition. The company hypothesized that using SNS01-T could be a way to lower the dose and reduce the severity of treatment-related side effects of bortezomib. SNS01-T is based on the discovery of Factor 5A1, which is involved in the regulation of apoptosis (programmed cell death).

Mechanism of Everolimus Activity in WM Reported – Dr. Irene Ghobrial's research group at Dana-Farber Cancer Institute reported on the mechanisms of activity of the drug everolimus (Afinitor) in the treatment of WM. Everolimus is a TORC1 inhibitor with reported response rates of 30-70% as single agent therapy. According to this study, everolimus targeted mTOR-downstream signaling pathways and induced toxicity in primary WM cells, as well as in other IgM-secreting lymphoma cells. Everolimus showed activity against WM cells even in the context of the bone

marrow microenvironment where it affected migration, adhesion, and angiogenesis. Its activity was partially driven by microRNA155 and synergized with bortezomib and rituximab in targeting WM cells.

NCCN Clinical Practice Guidelines on WM/LPL Updated – The National Comprehensive Cancer Network has released its updated Clinical Practice Guidelines for Waldenstrom's Macroglobulinemia/Lymphoplasmacytic Lymphoma. These revised guidelines include the addition of regimens containing novel agents as primary and salvage therapy options, inclusion of the updated summary of response categories and criteria from the Sixth International Workshop on Waldenstrom's Macroglobulinemia, and a section on the management of peripheral neuropathy. The NCCN Clinical Practice Guidelines can be viewed on the IWWMF website at www.iwwmf.com/docs/NCCN_Guidelines_02_2013.pdf.

Chromosomal Abnormalities in WM Correlate with Prognosis – A joint study from the United Kingdom and France explored the cytogenetics of WM and examined the prognostic value of chromosomal abnormalities in an international randomized trial of 174 untreated patients. The main abnormalities were 6q deletions (30%), trisomy 18 (15%), 13q deletions (13%), 17p deletions (8%), trisomy 4 (8%) and 11q deletions (7%). Trisomy is the presence of three chromosomes rather than the normal two. Deletions of 6q and 11q, as well as trisomy 4, were significantly associated with adverse clinical parameters. Patients with 17p deletion had shorter progression-free survival and shorter disease-free survival. Although rare (less than 5%), trisomy 12 was associated with shorter progression-free survival.

Phase I Study Combines Interleukin-21 and Rituximab – A multi-center Phase I study of recombinant interleukin-21 and rituximab in relapsed and refractory low grade B-cell malignancies has been reported for 21 patients. One week after a lead-in rituximab dose, three groups of patients were treated with either 30, 100, or 150 µg/kg recombinant interleukin-21 weekly for four weeks, concurrent with four weekly doses of rituximab. The main treatment toxicities were nausea, vomiting, diarrhea, hypotension, edema, and low phosphate levels, mainly at the higher dosages. Clinical responses were seen in 42% of evaluable patients. Interleukin-21 is a cytokine expressed on activated T-cells.

Risks for Cardiovascular Disease Reported for Stem Cell Transplant Patients – To determine the risk for cardiovascular disease after either autologous or allogeneic stem cell transplant (SCT), investigators reviewed the records of 1,885 patients at City of Hope who underwent SCT for a hematologic malignancy and survived for at least one year. The median age at time of transplant was 44.4 years, and

Medical News Roundup, cont. on page 15



the indication for transplant was lymphoma, leukemia, or myeloma. At median follow-up of 5.9 years, new incidence of hypertension, diabetes, and dyslipidemia (abnormal lipid production) developed in 21.75%, 10.0%, and 30.8% of lymphoma, leukemia, and myeloma patients, respectively. These risk factors for cardiovascular disease appeared earlier in allogeneic vs. autologous SCT recipients. Other factors associated with risk among SCT recipients were older age and obesity at the time of transplant. Also, conditioning with chemotherapy plus total body irradiation was associated with an increased risk for these factors, as were treatment with anthracyclines and medications for graft vs. host disease.

Increased Risk of Melanoma in Transplant Recipients and Lymphoma Patients – A review published in the October issue of *Mayo Clinic Proceedings* determined that transplant recipients and lymphoma patients are far likelier than the average person to develop melanoma, a type of skin cancer, because their immune systems tend to be significantly depressed. Melanoma strikes roughly 1 in 50 people in the general population; the odds of developing melanoma are up to 2.5 times higher in people who have received a transplant or who have lymphoma. Melanoma also is likelier to be fatal in these patients. The take-home message of the review is that these patients should be very aware of any changes in their skin and that frequent sunscreen use is advisable.

Improving Survival for WM Patients Noted in Swedish Study – A Swedish population-based study of 1,555 LPL/WM patients diagnosed from 1980-2005 computed relative survival rates and determined that the survival of these patients has improved over time. The five-year relative survival rates were 0.57, 0.65, 0.74, 0.72, and 0.78 for patients diagnosed during the calendar periods 1980-1985, 1986-1990, 1991-1995, 1996-2000, and 2001-2005, respectively. Improvement in relative survival was found in all age groups and for LPL and WM separately. Patients with WM had lower excess mortality compared to LPL patients. Older age at diagnosis was associated with a poorer survival.

Phase II Trial Combines Bortezomib, Rituximab, Cyclophosphamide, and Dexamethasone – A Phase II clinical trial of combination bortezomib (Velcade), rituximab, cyclophosphamide, and dexamethasone as front-line therapy for low-grade non-Hodgkin's lymphoma (NHL) was conducted by the Division of Hematology and Oncology at Advocate Lutheran General Hospital in Illinois. Twelve patients were enrolled, with an overall response rate of 90%, including a complete response rate of 45%. One third of patients required dose reductions after a median of 6.5 cycles. No grade 3 or 4 peripheral neuropathy was observed. Although the number of patients in this study was small, the researchers suggest that this is promising as potential front-line therapy for low-grade NHL and warrants further study.

FDA Approves Faster Infusion Rate for Rituximab – The U.S. Food & Drug Administration has approved a faster 90-minute infusion for rituximab, starting at cycle 2 of therapy, for patients with non-Hodgkin's lymphoma. The faster infusion is indicated for patients who did not experience a grade 3 or 4 infusion-related reaction during cycle 1 of therapy. The infusion is not recommended for patients with clinically significant cardiovascular disease and high circulating lymphocyte counts. The faster infusion consists of 20% of the total dose given in the first 30 minutes and the remaining 80% of the dose administered over the subsequent 60 minutes.

TRU-016 Combined with Rituximab in Clinical Trial – Emergent BioSolutions, Inc. announced the initiation of a Phase Ib study of TRU-016 in combination with rituximab for patients with previously untreated chronic lymphocytic leukemia (CLL). TRU-016 is a humanized anti-CD37 monoclonal antibody in development for the treatment of B-cell malignancies. The study is enrolling approximately 24 previously treated CLL patients. The primary outcome measurement for the study will be overall response rate. Patients will receive TRU-016 and rituximab intravenously for six months. TRU-016 is also being evaluated in a Phase II trial in combination with bendamustine for patients with relapsed CLL and will be compared with bendamustine alone.

Retrospective Study Examines Efficacy of Bendamustine – The Rabin Medical Center in Israel performed a retrospective study of bendamustine in patients with indolent B-cell malignancies (including chronic lymphocytic leukemia) to evaluate the efficacy of therapy. The results included data from five trials of 1,343 patients. Trials varied in the type of lymphoid malignancy, the bendamustine regimen, and the control regimen, which included cyclophosphamide alone, CHOP, fludarabine, and chlorambucil. While bendamustine had no statistically significant effect on the overall survival of patients, progression-free survival was significantly improved. The risk of grade 3 or 4 adverse events was similar when bendamustine was compared to CHOP and fludarabine and higher when compared to chlorambucil, especially for patients with chronic lymphocytic leukemia.

The author gratefully acknowledges the efforts of Arlene Carsten, Peter DeNardis, Mike Dewhirst, John Paasch, Colin Perrott, and Wanda Huskins in disseminating news of interest to the IWMF-Talk community. The author can be contacted at suenchas@bellsouth.net for questions or additional information.



HOW MONTHLY GIVING CAN HELP THE IWmf AND YOU

BY L. DON BROWN, IWmf TRUSTEE, FUNDRAISING COMMITTEE

Many years ago I decided that paying monthly to my favorite charities was a more effective way to support those causes about which I cared deeply. It helps me manage my expenses throughout the year and keeps my focus on charities as a monthly priority. This also helps at the end of the year when I review my finances to decide what I can afford to give as a special year-end gift, knowing that my primary commitment to each charity has been met. In the same way regular giving helps the IWmf when you include us in your monthly budget so we can meet our regular expenses. We are starting the New Year with a new focus on regular giving which also helps us with our budgeting.

Please look at the seven giving levels below (for more detail, visit our website “Giving Overview” page; www.iwmf.com/docs/GivingCircles2010.pdf), think about where the IWmf fits in your giving priorities and see how much you can afford as a monthly gift. If your budget permits and you gave last year, try to move up a giving level! If at all possible, please make a multi-year gift up to 5 years. You can change or renew your commitment at any time by notifying our office.

Once you have made a decision, go to our website and click on the Give Now - Member Services button. After clicking on “Make a Member Services Gift,” fill out your personal information, scroll down to “Make a Gift,” click on “every Month” from the drop down menu, and fill out your credit card information. You will not have to write a monthly check using this one-time automatic process. Your gift will be

charged automatically every month with a receipt letter sent to you.

All of us on the Board of Trustees want to thank you for your continued support of the IWmf Member Services Fund. Without this fund, nothing happens. You might say it is the life blood of the IWmf family. Your generosity is much appreciated. If you have any questions please contact me at my e-mail address, ldonbrown@msn.com, or call me at 630-323-5894.

IWmf ANNUAL GIVING CIRCLES – MEMBER SERVICES FUND

- WMer (\$1-\$99)
- Circle of Friends (\$100 - \$299)

All “Giving Circles” below are recommended for the monthly giving option.

- Support Group Circle (\$300-\$499 annually; \$25-41 monthly)
- WM Family Circle (\$500-\$999 annually; \$42-83 monthly)
- Caregiver Circle (\$1000-\$2499 annually; \$84-208 monthly)
- President’s Circle (\$2500-\$4999 annually; \$209-416 monthly)
- Trustee Circle (\$5000 or greater annually; \$417 or greater monthly)

FROM IWmf-TALK

BY MITCH ORFUSS

A growing number of WMers – more than a thousand! – use IWmf-Talk for support and information from others with similar questions and experiences. This Internet forum creates a rich “town hall meeting place” that’s always available when you want it. As ever, the past few months were busy, with a wide range of topics discussed. What follows are some that generated the most conversation.

AGE AND TREATMENT

Shirley, age 79, is aware that the average age at diagnosis of WM is 62 and that IWmf-Talk readers range from young to very old. Shirley asked if there is an age when oncologists feel the advantages of treatment diminish because quality of life and life expectancy are greatly reduced. Also, many WM patients have other illnesses, and their oncologists have differing treatment opinions owing to inexperience with WM. Shirley said she is not ready to give up but wanted opinions about these practical and philosophical issues.

Hank Stupi replied that Shirley’s subject was a sensitive one but worthy of discussion because many of us are or will be in a similar situation. Putting himself in her shoes, Hank felt the choice for Shirley was clear: she should avail herself of the best doctors she can find and the best medical treatment available for her particular circumstances. Hank offered that he has found wisdom and spirituality in Eckhart Tolle’s book *A New Earth: Awakening to Your Life’s Purpose*.

Dr. Tom Hoffmann added that the important thing about treatment is not *chronological* age but *biological* age, which is measured by overall functional status. As a rule, the older you are, the less you can tolerate major treatment. However, older patients may do better than younger patients who also happen to have diabetes, vascular disease, and other comorbidities. Tom told his story of operating on the oldest individual at that time ever to undergo heart surgery. She

From IWmf-Talk, cont. on page 17



was 100 years old but sailed through the quadruple coronary bypass that Tom performed. She was very functional with no debilitating disease, lived alone, and was very spry. Every year she continued to go to the Florida beaches with her family and enjoy the ocean. She lived to be 108, and only in her final year required some assistance to function. On the other hand, there are people in their 50s and 60s who perhaps shouldn't be treated because of the cumulative toll of their physical problems.

SPEED OF INFUSIONS

Pete DeNardis shared interesting results of a study comparing the "standard" protocol of steadily increasing Rituxan infusion rates vs. a constant, slower infusion rate of no more than 200 mg/hr, which showed a statistical improvement over the standard protocol.

Hank Stupi replied that some folks are not bothered by Rituxan infusions, while others are extremely sensitive. From his observations, Hank is amazed at the number of patients who sail through Rituxan at the regular rate, as opposed to those like Hank, who react allergically when the dose hits 50-75 mg/hr. Hank personally has never exceeded 125 mg/hr and feels sure that if he were ever to start at a higher rate than 25, he'd be in big trouble. So, the constant rate of 200 mg cited in the study would, in Hank's opinion, be too fast for those who are so sensitive to Rituxan.

Renee Pailey Bain suggested that people who abandon Rituxan because of allergic reactions do not give the drug a chance to work and should try again at a slower rate. Like Hank, Renee requires a slow infusion to make it through Rituxan without a range of alarming reactions. Rituxan has been very effective for Renee's WM, and she feels that seven hours or more in the infusion room at 50-100 mg/hr is well worth it to avoid rigors, fevers, chest pressure, and other unpleasant reactions to Rituxan.

J.D. Turner has had 17 infusions of Rituxan since 2008 and has never been able to exceed 125 mg/hr. Only 3 of J.D.'s infusions have been without reactions. The good news is that Rituxan is working. His IgM decreased from 7000 to 1900 mg/dL. He found the reactions were worse with higher IgM. Premeds that help are ibuprofen, Solumedrol, (a steroid), and Benadryl. Because of rheumatoid arthritis, J.D. is also on prednisone.

Carl Graf offered that although it probably wouldn't work for everyone, he has a unique Rituxan protocol that he has used for 32 treatments. Carl's oncologist prescribes 100 mg/

hr the first day, at a slow, steady rate of 25 mg/hr. Typically at 90-100 minutes, Carl experiences chills and rigors. The infusion stops, he is given a shot of Demerol and another Benadryl pill, and according to the "rules" waits 30 minutes to resume. The rest of Carl's IV proceeds smoothly (at 25 mg/hr) until the full 100 mg dose has been administered. The next day he receives the balance of 650-680 mg with no problem, and likewise, the next three weekly treatments of 750-780 mg each with no problem. In Carl's case, it seems that once his body gets used to Rituxan on the first day of his first treatment, the remainder go smoothly.

BENDAMUSTINE

With her IgM above 4,900 mg/dL, **Sandra Adamson** took solo bendamustine, adding that Rituxan will be added when her IgM falls below 4000. According to Sandra's doctor, there is no data showing that "benda" alone benefits WM patients. Sandra asked those who have had single agent benda how long it took their IgM to come down. Sandra also wondered if anyone experienced shortness of breath.

Bernice Goll responded that her friend had solo benda for two rounds, and it decreased her IgM enough to add Rituxan safely to the mix. Adding Rituxan to the next round was even better. Bernice's friend is now on solo Rituxan for anti-MAG antibody treatment as much as to control IgM. Her only long-term effect was that the veins used for her IV became hard and were difficult to access later.

Many patients asked about the after effects of benda, either solo or in combination. **Neil Massoth** said he'd taken benda with Rituxan, and his only problem was mouth sores, which he attributed to benda. Neil's take-charge nurse recommended that he rinse with saline after eating something. After Neil followed this advice, he never had a mouth sore again.

Kenneth Leung wrote that he finished six rounds of benda + Rituxan, experienced no side effects during treatment, and his IgM decreased from 2190 to 713 mg/dL by the end. However, he started to suffer from rashes two weeks later and at the time of writing was still suffering. Kenneth's doctor said it was not a result of benda because the rash would have appeared during treatment.

Marilyn Bagel said that after her benda she was simply wiped out for three or four days – tired, feeling "punk," not much appetite.

From IWMF-Talk, cont. on page 18

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



BLOCKED EARS

Roger Bailey from New Zealand asked if anyone had problems with pressure blockage in the ears. Roger had experienced this on and off since an earlier bout of bronchitis. He didn't have an ENT appointment until much later, so it was some time before he found out via a biopsy of his lower nasal passages that there were malignant WM cells present. Roger had a recent appointment with his hematologist, who sent him for a bone marrow biopsy the next day, for PET and CAT scans two days later, and then a course of CVP. Roger was in shock from these sudden developments – especially since he'd been feeling fit and healthy apart from his ear problems.

Ginni Marshall replied that she too had ear issues but more like fluid with occasional pain. Ginni wondered what led to Roger's nasal biopsy. Her ENT did a head CT and said it looked good, but she had just finished an antibiotic. Ginni wondered if she and Roger had the same issue.

Bob Raymond was recently diagnosed with WM and had pressure in his ears for several years prior. He also experienced ringing in his ears and slight low frequency hearing loss but no vertigo. Since scans had not shown anything, his ENT diagnosed him with Meniere's disease. Bob had questioned this diagnosis for some time and is beginning to wonder if his symptoms are related to WM.

Julie Kansa also had similar ear symptoms. Prior to starting chemo, Julie had three rounds of plasmapheresis, which dropped her IgM from 5000 to 700 mg/dL. She then noticed there was no more roaring in her ears. She experienced a Rituxan flare which increased her IgM to around 3000, and the roaring came back. Julie's IgM at the time of writing was around 1300 and dropping, so she expected the roaring to diminish.

PCI-32765/IBRUTINIB

I, as your correspondent, typically stay out of this summary. However, several of you suggested that I include a section

about my personal experience with PCI-32765 (newly named ibrutinib) since my posting generated considerable discussion. Ibrutinib is a newer targeted treatment. As I understand it, ibrutinib works by interfering with the messages to the mutated cancer cell that instruct it to survive; the cancer cell dies without collateral damage to other cells. Best of all, this treatment comes in pill form. What brought me to ibrutinib was that, after success with ofatumumab (an antibody like Rituxan), I started developing enlarged lymph nodes, even though my bone marrow involvement was just 5%. This situation is rare. My doctor suggested four options. I chose the ibrutinib trial for three reasons: low toxicity; availability in pill form; and ability to shrink lymph nodes in chronic lymphocytic leukemia, a condition closely related to WM. Almost immediately I started feeling wonderful, my nodes appeared to shrink, my hemoglobin rose to 15.4 g/L, and my IgM fell to 420 mg/dL. I could not be happier so far.

These past few months, IWMF-Talk touched on too many other topics of interest to summarize, but they included blood pressure, CAL-101 (now GS-1101), dexamethasone, plasmapheresis, Velcade (dosing, side effects, subcutaneous administration), lorazepam, lymph nodes, medi-ports, sleep, weight loss, and the effects of high altitude on WM.

No matter what you want to talk about, there are dozens, if not hundreds, of experienced, interested, and generous fellow WM travelers who are happy to offer their points of view. So please consider using IWMF-Talk! Share your own story. Ask a question you'd like a reaction to. Respond to a fellow patient in search of information. Everyone benefits! Please don't forget that *we do not practice medicine on IWMF-Talk*. Each WM patient seems to have a one-of-a-kind variant of our common condition, and only your doctor, assisted by you and your family, is well informed enough about *you* to offer actual treatment advice.

Until the next *Torch*, I wish everyone the best of health.

HOW TO JOIN IWMF-TALK

Here are two ways to join:

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



COME TO THE ED FORUM!

The 2013 IWMF Educational Forum will be in beautiful, downtown San Diego on May 17-19. This is a great place and a great time of year in which to have an Ed Forum. Many of you may want to take advantage of this opportunity to come early or stay later and make this a vacation too!

We have negotiated a special room rate of \$129 per night at the Westin San Diego, which is convenient to local attractions, including the world-famous San Diego Zoo, Seaport Village, Little Italy, the Gaslamp District, Sea World, and Balboa Park and Museums. The Westin also offers free roundtrip airport shuttle service for your convenience. For more information about the hotel, see www.westinsandiego.com. For more information about San Diego, visit www.sandiego.org/what-to-do.aspx.

The inspiring theme for this year's Educational Forum is *Imagine a Cure*. Our agenda topics will include:

- More about the discovery and importance of the MYD88 mutation
- The newest developments in CD20 antibody therapy
- Novel treatments for indolent lymphomas
- An update on the building blocks of research – tissue bank, cell lines, and mouse models

- How to understand your blood tests
- The signs, symptoms, and complications of WM
- An explanation of chemotherapy and how it works
- The latest on relapsed WM therapies
- Stem cell transplantation and stem cell banking
- An update on WM cytokines and how WM cells communicate
- An overview of integrative/complementary medicine and its importance in wellness

And that's not all! We've listened to your requests and have added more breakout sessions this year on topics that matter to you, such as Velcade, Rituxan, plasmapheresis, and more. In these sessions, you will have an opportunity to talk with your fellow WMers, ask questions, and exchange ideas.

See the complete agenda at our website, www.iwmf.com. Don't delay, sign up soon, and take advantage of our special early registration rate of \$199, available until April 1, 2013. For more information, visit our website or call the IWMF office at 941-927-4963. We look forward to seeing you in San Diego!

SAN DIEGO PREVIEW

BY RONALD YEE, IWMF TRUSTEE

Rovin' Ron, our traveling Trustee, visited San Diego in advance of the May Ed Forum and filed this report from the field.

My anticipation while driving to the Philadelphia airport was great, knowing that I was returning to San Diego. San Diego has special significance for me because twelve years ago, when I was diagnosed with WM, I made a decision to take a vacation in California and check off one more item on my short list of things still not done. Little did I know that "things" would turn out so well, following many trials and tribulations and, finally, successful treatment. San Diego was then, and is now, a beautiful vacation destination, and I have fond memories of taking my family to the many attractions that San Diego offers.

After a long day at work, I flew out on Friday evening and arrived in time to have a late dinner in San Diego, at a well-known seafood restaurant overlooking the harbor. I had a total of six days to be in San Diego, and I had a loose schedule planned. Our visit began with a scenic tour of the historic lighthouse at Point Loma, overlooking the beautiful San Diego Bay with the skyline in the background. It is also the location for the U.S. Navy submarine fleet that patrols the

Pacific. The weather couldn't have been better – there was little humidity and beautiful bright sunshine. Leaving from the East Coast in late October, it was a welcome change from the rainy and cold weather that we left behind. Little did we know that the following few days would bring the advent of hurricane Sandy, and with her all of the devastation to the East Coast, which is home for us and for family members. There was little we could do – call home to confirm that friends and family were safe and that there was no damage to our home. We continued to enjoy our vacation while those back home struggled for up to fourteen days without electricity.

As the week progressed we spent leisurely days visiting Balboa Park, which is the main park in San Diego and contains approximately seven museums that are either free or low-cost venues. The park itself is beautiful, and many of the locals bring their families there on the weekend to enjoy the beauty of this natural setting.

We also had a rental car and drove out to Coronado Island to visit the famous Hotel Coronado. This historic location is filled with many nostalgic photographs of the famous people

San Diego Preview, cont. on page 20



who frequented the hotel. The interior of the hotel is lovely, and the view of the ocean from the dining decks is hard to compare.

We also spent a full day at the San Diego zoo. Unfortunately, my wife had a misstep the day before we planned to go to the zoo and strained her knee. She could barely walk, and I was concerned that she would not be able to hike through the San Diego zoo, which is quite hilly. Luckily I convinced her to rent one of the motorized scooters for the day, and we had a wonderful time touring the zoo and taking many photographs of their incredible collection, most notably their pandas! The zoo is wheelchair-friendly and she was able to see all of the exhibits. I had the harder job keeping up with her once she found out that there was a speed control on the motorized chair!

We also took in a tour of the Scripps Institute aquarium, which is located in La Jolla, just north of San Diego, as well as the wonderful shows at Sea World which features additional aquarium displays as well as their live performances. There are many fabulous restaurants to suit your tastes for any

cuisine in San Diego. During our visit we had continental, Thai, Southwest and, of course, my personal favorite, seafood! In a major city such as San Diego you can choose the price range of the restaurants, so there is no difficulty in matching your dining preferences with your budget.

The Westin Hotel for the Ed Forum is centrally located in the Gaslamp District. There are many shops and restaurants in the area, and a short distance away is the promenade along the waterfront with terrific views of the San Diego Bay. I was able to rent a car on the Internet for about \$25 a day. The extensive public transportation system in the city is also convenient for seeing the many attractions.

Even though I recently spent six days visiting this wonderful city, I look forward to the Ed Forum in May. An excellent program has been organized to update all of us on the latest advances in WM – and I will have another opportunity to take in San Diego!

I look forward to seeing you all in May!

COOKS' HAPPY HOUR

BY PENNI WISNER

What Was Bad Is Good Again

Here is how old I am. I've lived through The Era of the Bad Egg. Remember that? When I grew up, my father had two soft-boiled eggs for breakfast each working morning. And so, often, did my sisters and I. And then, the medical-nutrition complex discovered cholesterol and its relationship with heart disease. Now that the egg's intimate involvement was exposed, our love affair had to end.

Oh! You were thinking this column was about easy, delicious food made even more appealing by appearing in tandem with wine or cocktails? Trust me! I am getting to that. But first our beloved egg needs rehabilitation. After years in the wilderness – nearly 40 by last count – some farmers have rediscovered the old way of chicken and egg farming. The lucky chickens raised by these rebels are free to roam outdoors and eat whatever they can find while there. The farmers do not clip their chicks' beaks, feed them organic feed (in addition to those foraged insects), and use no antibiotics. Meanwhile, new laboratory tests have discovered that the cholesterol levels of these pasture-raised eggs are not as high as previously thought. And maybe eggs, at least in moderation, are not so bad after all.

Just in case you are beginning to suspect this is a column about quiche, it isn't. Quiche, a dish – a pie, actually – had its heyday at brunches throughout the 1970s and 1980s and then almost completely disappeared. But it is making a comeback now that the egg and its sidekick, free-range, heritage-breed

bacon, have been let out of dietary jail. We shall return to quiche on a later occasion.

We turn instead to deviled eggs, that perennial favorite we stopped making because it was too cliched not to mention unhealthy. Well, kiss all that goodbye. All your family and friends are waiting for you to make a batch. I made them for a birthday party I catered over Labor Day and made them for a San Francisco Professional Food Society event. These educational events – chocolate tastings, wine and cheese tastings (Yes, educational! For real!) – are followed by potlucks. You can imagine that the offerings are at a certain level. I suppose, to be authentically “deviled,” the eggs should have been assertively spiced with mustard and hot sauce. But I had discovered a jar of dried tomato tapenade – a mix of dried tomatoes (you remember how to make oven-dried tomatoes, right?), Kalamata olives, and spices.

The hardest part of making any kind of stuffed eggs is boiling and peeling them. You do not want to use fresh eggs. Plan ahead or make them when you discover or rediscover a dozen that have been in the refrigerator for a week or more. To cook your eggs, put them straight from the ‘fridge into a large saucepan, cover them with several inches of cold water, add a generous handful of salt, and a dollop of oil. This last might be an old wives' tale but why not use any trick that might help. Bring your pot to a boil, let simmer one minute, turn off the heat, and let the eggs sit another ten in the hot water.

Cooks' Happy Hour, cont. on page 21



Scoop them out and plunge them immediately into ice water.

When the eggs are cool, slide off their shells. Cut the eggs in half and spoon the yolks into a bowl. Now comes the best part of making stuffed eggs: open the refrigerator door again and see what you have that inspires you. Or go out in the garden and see what herbs are there. You can go for the classic preparation: mayonnaise, mustard, salt, pepper, and a pinch of cayenne or some hot sauce such as Tabasco. After mashing the yolks with the seasonings, spoon the filling back into the whites, top with a caper and a sprinkling of sweet or hot paprika.

But maybe you have some canned chipotles in adobo. If so, mince some of them and add them to your mix. Instead of mayonnaise, mash the yolks with Greek-style nonfat plain yogurt. Got some olive tapenade? Add a spoonful.

No tapenade, but you have some green olives? Mince them and fold them in. Now add some capers, some chopped cornichons, maybe a little diced shallot. Or go for a clean and brisk flavor profile with lemon zest and juice, fresh minced herbs, a tiny pinch of cayenne, and olive oil.

Increase the omega-3 count with freshly ground flax and chia seeds. Or whirl in some smoked salmon and garnish the top of each half with a thin slice. Do the same with some pancetta or bacon. Or anchovy! Why not? Dilute the animal protein but boost the total by mashing the yolks with some hummus or soft tofu. Every time you make them, they will be different.

But every time, watch eyes light up with delight at the sight of them.

Our motto: Eat Well to Stay Well

THE INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

BELGIAN SUPPORT GROUP

On November 10, 2012, forty participants, 22 patients and 18 caregivers, gathered in the welcoming General Hospital Sint-Jan in Bruges, Belgium, for the yearly Waldenstrom symposium. Again it was a day of hope and fear. There were familiar faces of patients who had attended in previous years, and there were many newly diagnosed patients. Would we get answers to our questions and help with our problems?

In the morning session Dr. Jan Van Droogenbroeck, a hematologist at the host hospital, explained in plain language what is wrong with our cells and leads to disease, which therapeutic options are possible, and what ultimately is decisive for the choice of treatment.

After lunch Dr. Liesbeth Schauvliege, a dynamic and committed young hematologist practising at the Municipal Hospital in Roeselare and St. Joseph Hospital in Izegem, lectured us about the treatment of relapse and maintenance currently in use in the Flemish part of Belgium. She emphasized the importance of evaluating the individual patient at the moment of relapse. There are no standard guidelines specific to treatment in relapse and for maintenance therapy. The reasons for this are that there are no reimbursable drugs and the lack of clinical trials. Undoubtedly a challenge for the patient group!

Drinks and cake after the meeting helped everybody relax. There was good conversation and newcomers discovered that meeting with fellow patients is encouraging and helps put our disease in perspective. Participants were more than satisfied and enthusiastic about the lectures of the presenting scientists.

The year 2013 will be the fifth anniversary for our WM support group and will warrant a celebration. Preparations

have already started and we are sure that, after this year's successful meeting, next year's will be a festive one.

Joanna Van Reyn reporting

CANADA: ALBERTA

In May of 2012, **Stu Boland** and **Cam Fraser** co-hosted the first Alberta Support Group meeting in Calgary, Canada. Fourteen people – a combination of patients and caregivers, including one who traveled 200 km from Brooks, Alberta – attended. The format was a “meet and greet,” during which each patient gave a brief history of his or her journey with WM. This was followed by a general discussion of the future direction of the support group. As most groups have witnessed, the group was amazed and delighted by the commonality experienced and the willingness to share concerns, resources, and advice on symptoms, hematologists, insurance issues, and the side effects of various treatments. All were comforted to meet others struggling with similar issues and questions.

The reception was so enthusiastic that the group met again in Calgary in September. This time 18 people attended, with one couple traveling all the way from Edmonton, 300 km away. Dr. Carolyn Owen, a hematologist and Assistant Professor in the Division of Hematology and Hematological Malignancies at the University of Calgary, was the speaker. Even though her presentation included much highly technical information, she presented it in such a way that each member could understand. Dr. Owen's particular clinical interests are low-grade lymphoma and chronic lymphocytic leukemia, for which she is the local principal investigator for several clinical trials. She is a member of a hematological research group, the goal of which is to improve the availability of

The International Scene, cont. on page 22



clinical trials in Calgary. She is hopeful that some of these trials will include WM patients.

As usual, the Q & A following the discussions was tremendously informative as attendees were able to ask questions specific to their conditions and treatments. The group hopes to expand awareness of its existence and to support and expand membership through Dr. Owen's network of contacts. Thanks to **Cam** and **Jane Fraser** for hosting the group in their recreation room. If attendance continues to grow, the search will be on for a larger venue for the next meeting planned for January. Stay tuned for more information.

FINNISH SUPPORT GROUP MEETING

"We started on Friday, October 5, with coffee, of course. After that, there was a lecture presented by Dr. Kari Remes, professor of clinical hematology at Turku University Hospital, which is the National Research Hospital for allogeneic stem cell transplants. Dr. Remes gave a thorough overview of Waldenstrom's macroglobulinemia, its symptoms and treatment options, and took time to answer all the questions from the audience."

The opportunity to hear an expert talk about our rare disease gives the newly diagnosed and the veterans of WM increased confidence in the various treatment regimes available to them. And having a chance to meet with other patients is also a boost. I wish I could have been there. Veikko, how was everybody doing? Were there any new members attending?

"Yes, there were two new members, both newly diagnosed. On Saturday morning, after a good and healthy breakfast, the twenty or so support group members met to report on their own WM symptoms and treatment and to catch up on personal news. How had they spent their summer? Who had new grandchildren? After lunch there was a presentation by a psychologist. Hannu Tonteri, who has worked with the Southwestern Finland Cancer Organization for some years, talked about the psychological ramifications of serious illness on a patient and also on people close to the patient. These themes were further explored in smaller groups."

Survival stories and support from our loved ones give us strength for the fight. With the increase of treatable cancers, education is also needed in the workplace so that there are ways to offer recovering patients or patients in remission tailored solutions to continue working. On this weekend in October, there was another support group in Hannu Tonteri's audience: the GIST (gastrointestinal stromal tumor) support group patients face many of the same challenges as WM patients do. But was it all serious work, no singing?

"On Saturday evening there was time for socializing. First there was a great dinner, and, after that, entertainment by local musicians. And yes, some sing-along type singing, too. The weekend wasn't so packed with programmed lectures as to have no time for relaxation. There even was time for long walks by the sea. Most memorable, though, was a parting

comment from a newbie, that the weekend had left them feeling renewed, literally, like a new person."

Next year the Finnish WM support group will have a regular one-day meeting somewhere in Southern Finland. The Finnish Cancer Organization is planning something a little different: a mini cruise to Tallinn, Estonia, is in the works for April 2013. Now that sounds interesting! I hope I will be able to attend. After all, I cannot ask Veikko Hoikkala to report on the stylish spring trends of Tallinn. Submitted by **Taina Lukkaroinen** and **Veikko Hoikkala**

WALDENSTRÖM FRANCE ASSOCIATION: ANNUAL MEETING 2012

On Saturday, September 29, 2012, the Waldenström France Association held its annual meeting at the Institution Robin which, as in the past, welcomed us in the beautiful city of Vienna (Isère), at the edge of the Rhone.

Attendees were a little less numerous than previous years despite the steady increase in *Waldenström France* members during the last year. We were happy to meet one another once more and to meet the newly diagnosed WMers, who were, by contrast, more numerous than in previous years. First-time attendees were warmly welcomed by our WM Family. The lunch, delicious as usual, allowed our conversations to continue.

Dr. Pierre Morel was our guest doctor, and he gave us a very interesting lecture. First he outlined the disease for the new participants, and then Dr. Morel spoke about more specific subjects such as the International Prognostic Scoring System for Waldenstrom's Macroglobulinemia (IPSSWM), which he himself has developed. He spoke of the use and limitations of this system. Then Dr. Morel spoke about particular complications, including peripheral neuropathy, cryoglobulinemia, bone pain, hyperviscosity, anemia, and cold agglutinins. All can cause pain or problems in daily life, and it is necessary to monitor them.

Dr. Morel then discussed the discovery of the mutation of the MYD88 gene found by Dr. Treon and his team, and how it will open new directions of research. The attendees asked many questions concerning all these points. Dr. Morel answered them at length.

Later, in a good gourmet restaurant, we had a fine dinner and a very friendly and cheerful evening. As usual, leaving each other was a bit difficult! Next year, our meeting will be held in Paris. **Nicole Bastin**, Waldenström France, reporting.

GERMAN WALDENSTRÖM MEETING

A meeting for German Waldenström patients and caregivers took place on September 1 and 2, 2012, in Darmstadt. The meeting was organized by the very active Leukaemia Patient Support Group Rhein-Main (LRHM) and attracted 63 participants from all parts of the country and from France.



We started the first day with lunch and then listened to a presentation by Dr. Karin Kolbe, head of the department of hematology, oncology, and pulmonology at Johannes Gutenberg University Medical School in Mainz, who spoke about the basics of Waldenström's and different treatment options including stem cell transplantation. Next, Dr. Mathias Rummel, professor of hematology and oncology at Justus-Liebig University Medical School in Giessen, answered all the questions that patients had sent in advance. It was a huge list, but no question went without reply. Discussions were lively, and after five hours of intense information and discussions, almost every patient and participant was exhausted but satisfied. We had dinner together and many friendships were formed. People communicated until late at night.

We started the second day with a session of Qi Gong. Mrs. Brigitte Metscher, a well-known movement therapist, encouraged everyone to take part. Participants were delighted to learn about several exercises that improve well being. Next, we had a session on psychological topics. Mrs. Sabine Sander, a psychotherapist and hypnotherapist, spoke about how to cope with the disease and what patients can do to help themselves. Patients' questions showed how emotional responses differ widely. An alternative session was offered to relatives in the form of a round table discussion and covered topics on how to cope with the burden of caregiving, not knowing what the beloved one is thinking or wanting, and

even dealing with bouts of aggression caused by feelings of helplessness.

At the end of our meeting, everyone agreed that the event was a big success. Participants appreciated that the meeting was held in German and noted that they do not take part in the international or European meetings because listening in English or even to simultaneous translations is too exhausting. In addition, the costs for traveling and accommodations for international meetings are too high. Darmstadt, with its central location in Germany, is easy to reach and the meeting hotel offers a low rate. Dr. Rummel's presentation with its exhaustive Q & A session was the most popular.

We again tried to start a German Waldenström group but were unsuccessful because, while everyone wants to be a member, few want to assume the obligations. We will therefore continue to function as a Waldenström working group under the leadership of the Leukaemia Patient Support Group Rhein-Main. Our next meeting will again be held in Darmstadt in the same hotel and will take place in the fall of 2014.

Lastly, we can report that on November 21, 2012, we celebrated the ten-year anniversary of Leukaemia Patient Support Group Rhein-Main (LHRM) in Bad Homburg with Dr. Mathias Rummel attending. **Anita Waldmann**, co-founder and chairwoman, LHRM, reporting

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

CALIFORNIA

Sacramento and Bay Area

Davell Hays, founder of the Sacramento/San Francisco Bay Area support group attended the November meeting at the Roseville Kaiser Hospital. Davell was a founding member of the IWMF who served on the first board of directors as treasurer with the first president, Arnie Smokler. She told us wonderful tales of deciding whom to award research grants to and of calling Dr. Kyle and Dr. Treon directly for advice. Davell was part of a pioneering group who had tandem stem-cell transplants as part of a clinical trial back in 1999 and 2000. Also present was **Eugene Turner** who participated in the same trial. Eugene told everyone about his extremely high IgM's, multiple hospitalizations, and rigorous early drug treatments before the stem-cell transplants rescued and revived him. Everyone, especially the newly diagnosed participants, were inspired to hear these stories and see that Davell and Eugene are still healthy. **Cynthia Nicholson**, who with Penni Wisner headed the group for ten years, also attended and continues to do well. After watching the veteran-patient panel DVD from the 2012 Philadelphia Patient Education Forum and enjoying finger foods brought by the participants, **Alyce**



Three 'generations' of leadership! From left to right: Davell Hays (founder of the Sacramento/San Francisco Bay Area support group and founding member of the IWMF who served as treasurer with the first president, Arnie Smokler), Alyce Rossow (current leader of the support group), and Cynthia Nicholson (who headed the group for ten years together with Penni Wisner).

Rossow and her husband, **Terry**, led a group discussion of everyone's progress with WM.

Support Group News, cont. on page 24





At the October meeting, from left to right: Dr. Jeff Matous, Eileen Parker, Megan Andersen, NP, Cindy Furst, and Roy Parker.

COLORADO & WYOMING

It was an overflow crowd of more than 50 in October 2012 when the area's support group met to hear from Dr. Jeffrey Matous and his nurse practitioner, Megan Andersen. Both are from the Colorado Blood Cancer Institute in Denver, and both had attended the August Newport, RI, IWWM7, the physician's workshop on WM. Ms. Andersen began the day's discussion with WM basics: its biology and diagnosis. Then Dr. Matous reviewed the latest and greatest WM information and treatments followed by an hour of terrific Q & A. Many of the very interested and enthusiastic group had traveled long distances to attend. One couple came down from Yellowstone National Park (12 hours), another couple drove in from western Nebraska (four hours), and still another couple arrived from western Colorado (five hours). Plus about six newly diagnosed patients were in the audience. The meeting was co-hosted by the Denver chapter of the Leukemia & Lymphoma Society. They helped advertise the event – discovering two new WMers – booked the room, and brought breakfast for all! What a great partnership. The next meeting is planned for Denver in January or February 2013. The format will be a share-and-discuss meeting with a viewing of one of the IWWMF Ed Forum talks from 2012.

ILLINOIS

Chicago Area/SE Wisconsin

Dave Benson, the IWWMF's Senior Development Officer, did a great job discussing estate planning with the group. He highlighted issues and concerns that come up as people review their investments, issues surrounding wills, trusts, and beneficiaries. The next meeting is planned for Saturday, 20 April 2013 when Dr. Stephanie A. Gregory of Rush University will bring us up-to-date on the latest Waldenstrom's treatments and help us better understand our rare disease. Dr. Gregory is well known in the Chicago area and has spoken at many national forums on WM including the Lymphoma Research Foundation workshops, the Waldenstrom's Patient-Physician Summit, and the IWWMF annual Educational Forum.

INDIANA

A smaller-than-usual group met in early November at the

Leukemia & Lymphoma Society offices in Indianapolis. Before watching one of the DVDs from the IWWMF 2012 Ed Forum, members shared their personal journeys with great compassion and support. Next the DVD of the panel discussion of veteran WMers Mitch Orfuss and Karen Lee Sobol discussing their experiences with clinical trials was viewed and made a particularly strong impression. Breakfast snacks were provided by Claire Kammen from LLS and were enjoyed by all. The group created a "progressive" mailing list for the Forum DVDs so that members could watch them and then forward the set to the next person on the list. Midwest winter weather tables further meetings until spring to protect the many members who travel from a distance to attend.

NEW YORK

New York City

In November the Weill-Cornell Medical Center graciously lent its beautifully appointed Board Room to the lucky New York metro-area support group. Despite an especially warm and gorgeous fall Sunday, there was an exceptional turnout. Even more notable was the presence of half a dozen brand-new or returning faces present, which mixed up the group dynamics nicely, like a well-orchestrated dinner party. The new folks asked almost all the questions, and the veterans responded with a wide range of comments that put emphasis on the words "information," "care," and "support," and left everyone feeling great about the future. The newbies were vocally grateful to scoop up all this experience and immediately saw the great benefit of participating in an IWWMF support group. All the members hope these new friends will return and become regulars in 2013.

Eastern NY/Western New England



Members of the Eastern New York support group.

In October Dr. Robert Fleming of Fleming Physical Therapy Consultants gave a great talk on WM symptom management through physical therapy. It was an unusual subject and very informative. Dr. Fleming focused in particular on the symptoms associated with weakness, imbalance during activities, and pain. He answered the participants' many

Support Group News, cont. on page 25





Dr. Robert Fleming demonstrates his method of computerized assessment of a client's balance.

questions and demonstrated a newer piece of technology that creates a computerized assessment of a client's balance, incorporating motion analysis. Recent group members **Sandy** and **Kent Solomon** invited the group to their home for a holiday party in early December. More than twenty attendees enjoyed good conversation, friendship, and, of course, a delectable variety of potluck dishes.

Rochester, Western and Central NY

In early November, group facilitator **Stephen French** wrote to say that it had been tough in Rochester, NY, for the last five days. Members of the group had just been informed that the DVD set of the Philadelphia Ed Forum had arrived, and they could sign up to view the disks. Then, on Tuesday, October 30, a combined hurricane and nor'easter called Sandy visited. Lights went out, trees fell blocking roads, and communications halted. Fortunately most cell phones still worked. Some folks had to move out of their cold houses while others did not dare leave the house unattended and just put on more clothes. Now that most power and communication systems are back online, the group will continue to work on their postponed plan to meet and share a meal in a local restaurant. It will be a celebration of both personal journeys – with WM as well as the storm.

EASTERN OHIO, WESTERN PENNSYLVANIA & WEST VIRGINIA

On September 23, new members **Vicki Marino** and **Peggy** and **Bill Kuehn** were warmly welcomed by seven regular members at the home of **Marcia** and **Glenn Klepac** for an afternoon of delicious potluck treats, group sharing, and review of 2012 Ed Forum highlights. Following lively conversations during drinks and hors d'oeuvres, group members shared

many important WM-related issues including maintenance Rituxan, bone marrow biopsy (BMB) experiences, and coping with relapse. Lots of tips for getting through a BMB with as little stress as possible were shared. Everyone relaxed after a tasty potluck to hear **Neal Makens**, retired pathologist and WMer, give a very informative review of several of the Ed Forum presentations. Neal graciously shared his medical expertise as technical questions came up in the discussion. The group anticipates a future meeting in the Cleveland area in order to more adequately cover our geographic area.

OREGON/SOUTHWEST WASHINGTON

The group enlisted John S. Allen, Ph.D. to discuss "Resilience in the Face of Chronic Illness" at the fall meeting. Dr. Allen offers clinical, health psychology, and wellness consulting services to individuals, families, and healthcare professionals in order to help people navigate major medical challenges. Before beginning his presentation, Dr. Allen asked the 25 members to take a quiet moment to think of three blessings. He referred to it as time to decompress. He then encouraged individuals to name their biggest challenges including dealing with fatigue, depression, anxiety, not knowing the future, friends' responses, and caregivers' needs. And he asked members to identify what gives them purpose during their coping process with WM. From this foundation, Dr. Allen led a discussion of ways to enhance one's life by engaging in life *today*, connecting to something bigger than oneself, playing, traveling, hiking, journaling, jotting down blessings, and most importantly, creativity. And not to forget humor: one couple's confession of loving to SKI (spend the kids' inheritance) brought general hilarity. In closing, Dr. Allen shared a quote from Rev. Dr. Forrest Church: "Want what you have (the blessings). Be what you are. Do what you can (giving)." The Oregon and Southwest Washington support group is a joint project of the IWFM and the Leukemia & Lymphoma Society. The group meets the fourth Saturday of January, April, July, and October each year, noon to 2:00 pm, at the Fairfield Inn & Suites, 6100 SW Meadows Road, Lake Oswego, OR.

SOUTH CAROLINA

The South Carolina support group holds "progressive" meetings, rotating the gathering spot around the state. The fall meeting in early November was held in Columbia at the Irmo Public Library. The members had a fun and informative "round-table" discussion covering current well being, treatments, and information recently learned. Of particular interest was support group member **Kathy Perrich's** talk on how helpful the LLS has been to her by providing financial assistance for out-of-pocket medical costs and reimbursement of travel costs associated with her annual visits to the Dana-Farber Cancer Institute. She has also received flight assistance from Mercy Medical Airlifts. All other WMs are encouraged to check out the LLS website to learn more about the services they provide (www.lls.org), as well as www.mercymedical.org. The Spring meeting location will most likely be Charleston at a date and time to be announced later.



2. “Should bendamustine + rituximab (R-Benda) be considered for frontline therapy in WM?”

The second debate topic was vigorously argued in the affirmative by Dr. Mathias Rummel of Giessen, Germany, the lead author of a recent landmark study in the use of R-Benda versus R-CHOP, the former gold standard treatment of indolent lymphomas. Dr. Rummel developed his argument by stating the following facts based on his study. Rituximab in combination with chemotherapy is considered first-line standard of care for WM patients. In a large multicenter, randomized, phase III study comparing R-Benda and R-CHOP as first-line treatment in indolent lymphoma entities including WM, R-Benda significantly outperformed R-CHOP. The median progression free survival (PFS) for the 19 WM patients randomized to R-CHOP was 35 months, while the median PFS for the 22 WM patients randomized to R-Benda was virtually double (and still has not yet been fully reached). At the time of study analysis, 4 relapses (18%) had occurred in the R-Benda patients versus the 11 relapses (58%) in the R-CHOP patients. The R-Benda regimen was better tolerated than R-CHOP, with no alopecia (hair loss) and with lower rates of myelosuppression, infections, and peripheral neuropathy. Dr. Rummel’s case for the use of rituximab + bendamustine as front-line therapy for WM was thus quite persuasive and supported by increasing data from clinicians who have been quick to jump on the “bendamustine bandwagon.”

However, the widely-respected Dr. Stephanie Gregory of Rush University Medical Center, Chicago, IL, countered Dr. Rummel’s assertions by reminding all the clinicians present at the conference that the mantra “Physician, do no harm” is central to medical care and that agents less toxic than bendamustine are indeed available for a hematological malignancy that is turning into a chronic disease for an ever-increasing number of WM patients. Dr. Gregory asserted that physicians must always take into consideration the age of the patient, their co-morbid conditions (for example, heart disease and high blood pressure), the aggressiveness of the disease, individual disease biology, and, of course, the patient’s preference and quality of life issues. Given that WM is an indolent lymphoma and given that the WM patient will likely need repeated courses of treatment over his or her lifetime, overtreatment and the subsequent accumulation of long term, treatment-related toxicities must now be considered more than ever before.

Dr. Gregory stated that she prefers single agent rituximab as the first choice of therapy and that she recognizes that not all WM patients respond to rituximab – some may indeed require more aggressive

therapy – but she believes that rituximab should be used before anything else if possible. Another reason Dr. Gregory advanced as to why R-Benda should not necessarily be used for frontline therapy is that the data specific to WM is scanty (only 8% of the 514 patients in the study referenced by Dr. Rummel had WM). Dr. Gregory stated that there is also no proof that increased quality and duration of response will translate into improved survival. She also pointed out that bendamustine is a very expensive drug (much cheaper in Europe, countered Dr. Rummel) and that long term safety data is lacking.

Finally, Dr. Gregory concluded by making a plea that physicians consider shorter courses of treatment (e.g. 3-4 rounds versus the standard 6 rounds) and avoid as much as possible overtreatment issues that are now beginning to plague those cancer survivors who are living longer.

3. “Should maintenance rituximab (MR) be used for rituximab responders in WM?”

The third debate session discussed the contentious issue of maintenance rituximab treatment. To the question **Dr. David Maloney** of the Fred Hutchinson Cancer Research Center, Seattle, WA, responded in the affirmative. He argued that, despite the lack of randomized studies, the accumulated available data supporting this treatment regimen is “compelling.” Dr. Maloney pointed out that WM patients have high levels of CD-20 antigens on tumor cells that are easily accessible to monoclonal antibody therapy with rituximab and that the efficacy and safety of rituximab treatment in WM patients have been the focus of many studies. Furthermore, many studies in other indolent CD20 positive B-cell lymphomas (in particular follicular NHL) have demonstrated that maintenance rituximab (MR) confers significant progression free survival (PFS) advantage in patients who previously received single agent rituximab treatment or rituximab-based combination treatment. The schedules evaluated, however, in these studies were not consistent; most patients were treated for two years and a few as long as five years. Improved PFS was noted in all trials, and in a few trials improved overall survival (OS) has been observed to date. Dr. Maloney cited **Dr. Steven Treon**’s retrospective study of WM patients who were initially treated with rituximab (or rituximab combination therapy) followed by maintenance rituximab and who had a significant improvement in median PFS (56.3 months in MR patients versus 28.6 months in non-MR patients) and median OS. WM patients in the study who received MR also reached lower IgM levels and



better hemoglobin levels. The most common side effects seen in WM patients who have followed a MR regimen were lower than normal immunoglobulin levels and more frequent respiratory infections. Dr. Maloney thus concluded that the use of MR in WM patients who respond to an initial course of single agent rituximab or rituximab combination therapy should be considered for maintenance rituximab.

Dr. Eva Kimby of the Karolinska Institute and University Hospital, Stockholm, Sweden, cautioned that the favorable results of maintenance rituximab (MR) in follicular lymphoma patients may not always be directly applicable to WM patients, despite Dr. Treon's smaller observational retrospective analysis of WM patients who did receive MR. There is also no optimum scheduling regimen known for MR – is it once every two or three months? Or six months? Or...? The prolonged B-cell depletion and overall serum immunoglobulin deficiency is a concern. In fact, there is an increased risk of bronchial and sinus infections, and some patients may develop late allergic reactions, as well as other long-term side effects to MR infusions. Dr. Kimby is quick to point out that newer and possibly safer oral therapies are emerging that may one day treat WM as a chronic disease and may lead to a higher quality of life for patients. Currently, however, clear evidence supporting the use of MR in WM is lacking, and until definite prospective randomized studies are performed we may never be truly assured of the benefit versus risk of MR therapy.

4. “Should autologous stem cell transplant (ASCT) be a front line option for WM?”

The final debate session focused on this always-controversial topic. **Dr. Bart Barlogie** of the University of Arkansas, Little Rock, AK, relied on his vast clinical experience in performing bone

marrow transplants to present arguments in favor of ASCT therapy in WM. From the outset Dr. Barlogie acknowledged that ASCT should not be used as front line therapy in WM, but he argued strongly, however, in favor of an increased role for ASCT in the salvage therapy of WM patients, particularly younger WM patients (Dr. Barlogie has transplanted patients up to the age of 79!). Dr. Barlogie lamented the fact that there are no established guidelines based on modern genetics for stratifying risk in WM patients with aggressive disease who may benefit from ASCT. He strongly encouraged all WM patients who could benefit in the future to harvest stem cells whenever possible. As is the case with the newer agents being used in the treatment of WM, ASCTs are becoming safer and treatment related mortality and morbidity compare favorably with many of the older established chemotherapeutic regimens while still providing very good and durable responses.

Dr. Jean-Paul Fermand from the Hôpital Saint Louis, Paris, France, disagreed. He stated that there is not enough evidence to suggest that ASCTs can produce superior outcomes compared to the standard rituximab + chemotherapy combination regimens. He did agree that ASCTs can be a very effective option for select WM patients in a salvage setting, particularly when rituximab is used in the pre-transplant phase and thereafter possibly as maintenance following ASCT.

Dr. Fermand echoed Dr. Barlogie's statements regarding the importance of stem cell harvest, the current inappropriateness of ASCT as an initial treatment option in the overwhelming majority of WM patients, and preserving the important option of ASCT in select qualified patients who have relapsed from initial front line treatments with less toxic therapies.

IWMF RECEIVES GIFT FROM GUTHRIE ESTATE

The IWMF recently received a generous gift, designated for research, from the estate of L. C. Guthrie, who passed away in June at the age of 84. In the letter to President Judith May announcing the gift, Maryann Guthrie, wife of “Les” Guthrie, wrote that her husband was diagnosed with Waldenstrom's macroglobulinemia in 1986 and received excellent care from Dr. Gary Shiller at UCLA. He attended a number of IWMF Educational Forums and benefited from the new treatments developed after his diagnosis.

Mrs. Guthrie ends with the following words: “My dear husband respected your organization and read your newsletter from cover to cover.”

The IWMF is very grateful to the Guthrie family for making this gift possible.



SINCE SEPTEMBER 2012, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

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May 17 - 19

San Diego, California

The 2013 Ed Forum will be held in downtown San Diego at the Westin Hotel. We've got a great rate at \$129 a night and that rate is good for 3 days before and 3 days after the meeting. Visit www.iwmf.com for program.