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INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION

INSIDE THIS ISSUE

DOCTOR ON CALL: NEAL MAKENS, MD

Dr. Neal Makens

Neal Makens, MD, completed his medical training in 1969 at St. Louis University, St. Louis MO, followed by an internship in internal medicine and a residency in anatomic and clinical pathology, both at Naval Medical Center, San Diego CA. From 1974-81, Dr. Makens served as a staff pathologist and later as the Head of the Laboratory Department, Naval Hospital, Camp Pendelton CA. From 1981-88 he served at Naval Medical Center, Portsmouth VA, first as a staff pathologist and subsequently as Laboratory Director and Chairman of the Department of Pathology. In 1988, Dr. Makens retired from the United States Navy with the rank of Captain.

For the next fifteen years he was affiliated with Robinson Memorial Hospital in Ravenna OH, where he worked both as a staff pathologist and as Director of the Laboratory Department. He retired from practice in 2003.

Dr. Makens is an emeritus Fellow of the American Society of Clinical Pathologists and the College of American Pathologists. He is currently a member of the IWMF Research Committee.

SERUM FREE LIGHT CHAIN TESTING AND WALDENSTRÖM MACROGLOBULINEMIA

Introduction

Antibodies (immunoglobulins) are proteins produced by plasma cells (and to a limited extent by their immediate B-lymphocyte precursors) in response to antigens, which are foreign substances from microbes and other sources. A basic immunoglobulin (Ig) molecule is composed of 2 identical longer chains of amino acids called *heavy chains* and 2 identical shorter chains of amino acids called *light chains*. The resulting structure has a roughly Y-shaped configuration in which each arm of the Y is formed by an entire light chain bound to about half of a heavy chain (see diagram). Each tip of the arms of the Y constitutes an antigen binding site; the stem of the Y, consisting of the bound "lower" halves of the heavy chains, can attach to the surface of an immune cell or to an immune system protein such as complement.

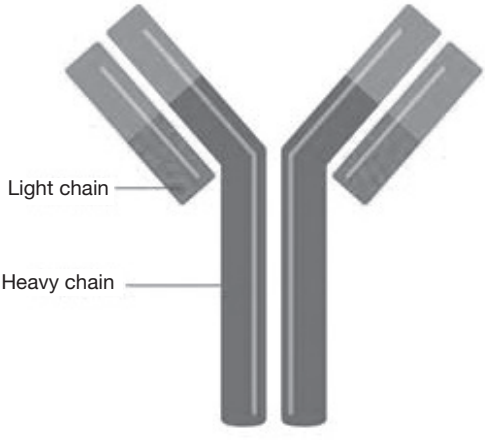

Diagram of Immunoglobulin (Antibody) Molecule

The light chains can be either of two types designated by the Greek letters *kappa* **(κ)** or *lambda* **(λ)**. Intact immunoglobulin (Ig) molecules can be any of five types, each determined by the type of heavy chain that it contains (**γ** = gamma in IgG, **α** = alpha in IgA, **μ** = mu in IgM, **δ** = delta in IgD, or **ε** = epsilon in IgE). A heavy chain may be paired with either of the two light chain types, but any given Ig molecule will contain only **κ** or only **λ** light chains. Likewise, the

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heavy chains in an individual Ig molecule will be of only one type. In the plasma, IgG is a "monomer", a single unit that contains two identical light chains and two identical heavy chains. IgM is usually a "pentamer" that contains 5 of these units arranged radially like the spokes of a wheel, with the Y "stems" directed inward.

Free light chains

Plasma cells normally produce more light chains than heavy chains and more **κ** light chains than **λ** light chains. These excess light chains are not joined to heavy chains and they circulate in the blood as *free* light chains (FLCs). FLCs of **κ** type usually exist as monomers (single units), whereas **λ** free light chains are usually in pairs called dimers. Most FLCs are small enough to pass through the glomeruli, the blood filtering structures of the kidney, and are subsequently reabsorbed and metabolized in the proximal renal (kidney) tubules through which the fluid filtered by the glomeruli passes. **λ** FLC dimers are twice as large as **κ** FLC monomers, and the **λ** FLCs therefore are filtered through the glomeruli more slowly. (The half-life of **λ** FLCs in the blood stream is about 5-6 hours, which is about twice the **κ** FLC half-life.) The result is that the *serum concentration of* **λ** *FLCs is typically higher* than that of **κ** FLCs (**κ/λ** = 3:5).

It is important to distinguish between the measurement of *total* light chains in the blood and *free* light chains. Total light chain tests measure both free light chains and those light chains that are bound to heavy chains in intact Ig molecules without distinguishing between them. In contrast to the FLC ratio, the *total* **κ/λ** light chain ratio in serum is approximately 2:1.

Since FLC absorption and metabolism in the proximal tubules of the kidney normally far exceed the FLC synthesis rate, FLCs do not appear in the urine in more than trace amounts unless they are markedly overproduced. In multiple myeloma, however, monoclonal free light chain levels can be hundreds of times higher than normal. (In WM, the range of values is not as extreme as in myeloma.) When abnormal amounts of free light chain ("Bence Jones" protein) are present in urine, they are normally detected by urine protein electrophoresis (uPEP) and immunofixation electrophoresis (IFE). The *urine* FLC ratio by the Freelite test (see below) has been found to be less sensitive than IFE on a 24 hour urine. Consequently, *urine* FLC testing is not recommended for screening or monitoring.

The serum free light chain measurement, in contrast, is more sensitive in detecting low levels of free light chains in the blood than the traditional serum protein tests (PEP or SPEP – protein electrophoresis and IFE – immunofixation electrophoresis). The

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SUPPORT • EDUCATION • RESEARCH
IWMF
International Waldenstrom's Macroglobulinemia Foundation

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first commercially useful test for monitoring serum free light chains (sFLC) was developed by The Binding Site, Inc., Birmingham UK, and is known by the trade name of "Freelite™". It uses polyclonal sheep antibodies directed against antigenic sites in the light chain that are hidden in *intact* Ig molecules, but exposed in *free* light chains. The reference (normal) ranges for this test are given below and are those most commonly cited:

Serum Free Light Chain Reference Ranges:

κ: 3.3–19.4 mg/L

λ: 5.7–26.3 mg/L

κ/λ ratio: 0.26 –1.65

In addition to the above test, the Siemens company has developed a monoclonal antibody sFLC test that is currently available in Europe, but not in the United States. Patients who are being monitored should be followed with only one type of test, preferably performed by the same laboratory, in order to maintain the continuity of test results from one office visit to the next.

κ/λ *ratios that are increased above normal are considered as presumptive evidence of a* **κ** *monoclonal gammopathy* (a disorder in which Ig molecules are produced by a single abnormal clone of lymphoid cells), while *ratios that are decreased are interpreted as evidence of a* **λ** *monoclonal gammopathy*. However, it must be kept in mind that patients with polyclonal hypergammaglobulinemia (a broad elevation of many different Igs due to infections, autoimmune diseases, and other chronic inflammatory conditions) can have elevations of both light chain classes, and the **κ/λ** ratio can sometimes be slightly abnormal even though no monoclonal process is present. There can also be lot-to-lot variations in reagents and other technical problems that could affect the test results. In the presence of renal disease, the **κ/λ** ratio may also be altered, usually in an upward direction, due to a slower than normal rate of renal clearance of **κ** monomers. *It has been recommended that FLC test results in patients with renal impairment be evaluated using a different reference range for the* **κ/λ** *ratio: 0.37–3.1.* For these reasons, serum light chain individual **κ** and **λ** values and **κ/λ** ratio test values that are slightly outside of their reference ranges should be interpreted cautiously.

The **κ/λ** ratio should be interpreted together with the individual **κ** and **λ** values and not be considered in isolation:

- If one of the light chain measurements were elevated and the serum light chain ratio were significantly elevated, then a monoclonal gammopathy (in our case, IgM-MGUS or WM) would be likely.
- If both light chain values were elevated and the ratio were normal or borderline, then a polyclonal gammopathy due to a chronic inflammatory condition or kidney impairment would be suspected. (In rare cases, a biclonal gammopathy with one **κ** and one **λ** clone could also produce this pattern.)
- If both individual light chain values were low and the ratio were normal, bone marrow failure would be suspected.
- If all values were within the normal ranges, a monoclonal gammopathy could still be possible if the monoclonal cells were producing only an intact monoclonal Ig without a detectable increase in monoclonal free light chain. (This should be evident by PEP and IFE, however.)

Serum free light chains and Waldenström macroglobulinemia (WM)

Serum FLC (sFLC) testing is recommended as part of the initial workup for all MGUS (monoclonal gammopathy of undetermined significance) patients. The sFLC **κ/λ** ratio value is one of the 3 major risk factors used in stratifying MGUS patients into 4 groups for risk of progression to one of the plasma cell-related malignancies. sFLC testing is also recommended for *screening/diagnostic evaluation* for multiple myeloma (in its various forms), light chain (AL) amyloidosis, and a related condition known as light chain deposition disease (LCDD). It is recommended for ongoing *monitoring* of patients with oligosecretory multiple myeloma (in which the amount of secreted monoclonal protein is very low), light chain myeloma, light chain (AL) amyloidosis, and LCDD. It is also recommended for *verifying complete remission* in multiple myeloma, and may have a broader role in determining the response to treatment in myeloma.

Because FLCs have a substantially shorter half-life in the blood (up to 6 hours) than IgM (4-5 days), it has been hypothesized that sFLC testing might provide more rapid indications of changes in the course of WM that would facilitate monitoring of the disease. In 2011, Leleu and colleagues noted (in a study of sFLC monitoring of patients treated with bortezomib and rituximab) that sFLC analysis showed promising results as a sensitive marker of WM tumor measurement that correlated well with IgM and M-spike measurements, showed a more rapid change in test results in patients who responded to treatment, and also provided an earlier indication of disease progression (by about 1 month) than the results observed with traditional IgM or M-spike measurements. The article ended with a comment that the authors proposed to study sFLC measurement in future large, prospective trials to confirm whether or not early determination of sFLC would help in decision-making during the course of therapy. Kyrtsonis and colleagues in 2012 reported that the level of the involved (monoclonal) FLC and the FLC **κ/λ** ratio correlated with time to first treatment and adverse survival in WM. To date, however, there have been relatively few FLC studies in WM. As a consequence, the status of sFLC testing in WM remains

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uncertain. In review articles on WM in 2015 by Drs. Gertz and Treon, sFLC testing was included in lists of tests that may be ordered as part of the *initial workup* for WM. However, at the present time, it has not been recommended for *ongoing monitoring* of patients with WM who can be followed with conventional testing.

Screening for AL amyloidosis and LCDD

It has been recommended that MGUS (monoclonal gammopathy of undetermined significance) patients whose baseline **κ/λ** ratio is abnormal and whose involved (monoclonal) FLC is elevated be monitored periodically for the development of heart or kidney damage due to amyloidosis or a related condition, light chain deposition disease. The recommended tests are serum NT-proBNP, which is a sensitive indicator of cardiac injury, and urine albumin (or microalbumin) to detect renal injury at an early stage. Such monitoring has also been recommended for selected WM patients. Signs and symptoms of amyloidosis can develop insidiously. Many of these (such as peripheral neuropathy, constipation or diarrhea, feeling lightheaded upon standing, peripheral edema, etc.) may also be seen with other diseases, so the diagnosis requires the demonstration by biopsy of one or more sites or by abdominal fat aspiration (at medical centers skilled in its detection by this technique). The need for such testing increases with additional risk factors, such as the presence of **λ** light chain as a monoclonal component of IgM gammopathy. It has been recommended that WM patients with peripheral neuropathy be considered for evaluation for amyloidosis, particularly if they have an IgM**λ** monoclonal protein. (While most WM patients have **κ** monoclonal light chain, the majority of patients with light chain amyloidosis have **λ** light chain. The ratio of **λ** to **κ** monoclonal light chain involvement is nearly 4:1.) For a fuller discussion of amyloidosis in WM, see Dr. Merlini's previous article in the April 2013 edition of the *Torch* newsletter. *iwmf.com/sites/default/files/docs/publications/Merlini.pdf*

Kidney injury from WM may involve infiltration by lymphoplasmacytic WM cells, deposition of intact IgM in glomerular capillaries, cryoglobulin injury, or deposition of monoclonal light chains. Light chain deposition disease always involves the kidney. The liver is the organ next most commonly involved, but numerous other organs can be involved as well. It typically presents with hypertension (high blood pressure), protein in the urine, and microscopic blood in the urine. There are microscopic and clinical differences between LCDD and light chain amyloidosis. At least half of the patients with LCDD have multiple myeloma, but LCDD can occur by itself, in association with MGUS, and occasionally in WM patients. Treatment is aimed at lowering the monoclonal light chain to the maximum extent possible, which would be monitored by sFLC analysis and other tests.

Conclusion

My personal opinion is that it would be reasonable to order sFLC testing at the time of initial diagnostic evaluation to establish a baseline for future reference. At present, however, it is not considered necessary for determining response to therapy or for routine monitoring for most patients with WM. It could be useful for selected patients who are being evaluated for light chain amyloidosis or light chain deposition disease as well as those who already have either of those conditions.

For those of you who are having periodic FLC testing:

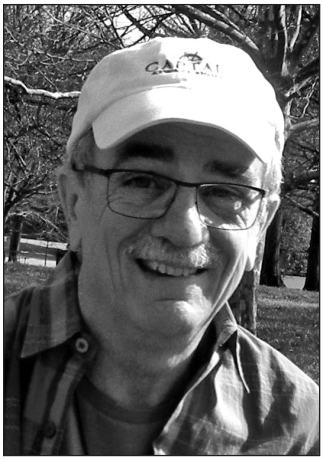
A rising involved (monoclonal) individual kappa or lambda light chain level well above the normal range associated with a rising ratio of the involved FLC/uninvolved FLC suggests that your WM is producing more monoclonal protein and may be proliferating. The reverse suggests that you are responding to treatment. These values may precede changes in your IgM by several weeks. The trend is important. They need to be correlated over time with the level of your M-spike by PEP and IgM by nephelometry, hemoglobin, platelet count, white count, kidney function tests, bone marrow findings, your general level of energy for daily tasks, the status of other illnesses that you may have, and your oncologist's impression of the status of your WM.

The future:

Over the last few years, articles have been appearing in the literature that evaluate a newer test developed by the same company that developed the sFLC test (The Binding Site). The new test is known generically as the heavy/light chain (HLC) test and is known by the trade name of "Hevylite™". The HLC test uses antibodies that target junctional binding sites between the constant regions of heavy and light chains of Ig molecules, thereby measuring heavy/light chain pairs. Thus, there is simultaneous measurement both of a particular type of heavy chain (gamma, alpha, or mu) and the **κ** or **λ** light chains that are associated with that heavy chain. For example, in a case of IgM**κ** WM, the level of IgM**κ** would be increased, while the level of IgM**λ** might be normal or decreased. It may be that the HLC test could serve as a way to monitor the level of the M-spike. Some studies have evaluated both sFLC and HLC testing to see if the combination offers advantages over HLC alone. At the present time, only the IgG and IgA HLC tests are approved for use in the United States. In Europe, the IgM HLC test is also available. Before the HLC test is recommended for use in the diagnosis and monitoring of WM patients, additional prospective studies will be needed.

A select bibliography for Serum Free Light Chain Testing and Waldenström Macroglobulinemia *is found on page 31.*

PRESIDENT'S CORNER



In kindergarten we all learned to "play nice with others." Later on we were told, "To be successful, be a team player." Today doesn't it feel as if the world is dividing more and more into little groups looking only after their own interests and not cooperating with anyone else? In US politics this election year, it seems to be true in spades. No one appears to agree with anyone else on anything, and so nothing gets done. On the global stage, war used to mean two opposing sides such as the Allies vs. the Axis. Today in Syria it's hard to keep track of the number of ever-increasing factions in that conflict.

Happily, politicking and fractionalizing are disappearing in the world of WM. Our world is coalescing, converging, and cooperating more than ever. Let me give you four examples of the growing cooperation within the world of WM.

1. **More WM research proposals**

   As I write this, we are receiving proposals in response to the Request for Proposals (RFP) from the IWMF-LLS Strategic Research Roadmap Initiative. The good news is that we are getting more research proposals than ever before; the proposals are coming from new researchers, from new institutions, and from new countries – new in the sense of never having previously applied for IWMF grants. And, perhaps even more important, we are receiving more proposals that involve collaborating researchers from different institutions. In other words, more people are interested in working on our little orphan disease, and they are working together to try to earn the dollars you have donated to fund their research. That ought to make you smile!

2. **An even bigger and better Strategic Research Roadmap Conference for 2016**

   The second Strategic Research Roadmap Conference is scheduled for May 20-21 in New York. This meeting will involve more researchers, including more from the international arena, and more pharmaceutical companies. The spirit of cooperation established at the first Conference in May of 2015 is alive and growing. That's worth noting with pride.

3. **A great line-up of speakers for the IWMF Educational Forum**

   Coursing through the entire Ed Forum weekend will be a series of presentations to cover the four pillars of the IWMF-LLS Strategic Research Roadmap: the Tumor Microenvironment; Immunotherapy; Genomics and Epigenomics; and Cell Signaling.

   - Dr. Stephen Ansell from Mayo Clinic will kick off the meeting by presenting an overview of the Roadmap and then covering the Tumor Microenvironment. Dr. Ansell serves as Scientific Co-Chair of the Strategic Research Roadmap Conference.
   - Dr. Edward Stadtmauer from the University of Pennsylvania will cover Immunotherapy with a presentation on killer T-cells.
   - Dr. Zachary Hunter from Dana-Farber and Dr. Ari Melnick from Weill-Cornell will cover "Omics" in separate presentations: Dr. Hunter on Genomics and WM and Dr. Melnick on Epigenomics and WM.
   - Dr. Steven Treon from Dana-Farber, who is the other Scientific Co-Chair of the Strategic Research Roadmap Conference, will speak about Cell Signaling and the exciting progress being made in his laboratory.
   - Dr. Morton Coleman from Weill-Cornell will wrap things up on Sunday with a look at the Future of Indolent Lymphoma Research.

   The above are only the presentations related to the Strategic Research Roadmap. For more information about the Educational Forum, visit the IWMF website to see the full agenda and to register now.

4. **2016 IWWM9/IWMF International Doctor-Patient Forum for WM patients and their caregivers hosted by the IWMF on Sunday, October 9**

   The 2016 IWWM9/IWMF International Doctor-Patient Forum for WM patients and their caregivers is a great learning opportunity linked to the 9th International Workshop on Waldenstrom's Macroglobulinemia (IWWM9). The International Workshops are organized by the Bing Center for Waldenstrom's Macroglobulinemia at Dana-Farber Cancer Institute and are held on alternate years. IWWM9 is planned for October 6-8 in Amsterdam, the Netherlands. Over 200 of the world's leading physicians and researchers in WM will attend and present their most recent research and share results with one another. Attendance at the Workshops is by invitation only and limited to the medical community.

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However, as in past years, an International Doctor-Patient Forum will be held on the day after the conclusion of the Workshop.

The IWMF is proud to be hosting the 2016 International Doctor-Patient Forum for WM patients and their caregivers on Sunday, October 9, from 9:30 am to 5:00 pm. We will be working with Chris Patterson of the Bing Center (Chris is Secretariat of the IWWM9). If you are located in Europe, or are planning a trip to Europe, mark your calendar and plan to attend. See also p. 13 of this issue.

More information, including how to register, can be found on the IWWM9 website at:
wmworkshop.org/patients

5. Coming in 2016: Publication of an updated version of the IWMF booklet *Treatment Options* based on the Consensus Panel Reports from IWWM8.

One important outcome of the International Workshops is the establishment of Consensus Panels. The name 'consensus panel' as used here refers to a relatively small number of WM researchers appointed to confer jointly at a Workshop in order to determine the current status of a variety of topics important to the diagnosis and care of WM patients. The deliberations of a Consensus Panel begin during the course of an International Workshop and continue after the Workshop concludes. The results are published at a later date.

The reports of Consensus Panels from IWWM8 (held two years ago in London) will be released in the first half of 2016. These reports will provide guidelines to inform local hematologists and oncologists globally on the state-of-the-art best practices in WM, including diagnosis, treatment recommendations, peripheral neuropathy, and Bing-Neel syndrome, among others. Now that's cooperation we can all benefit from!

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By now I hope you recognize that in the world of WM a powerful, strong team is working together in your best interests. We're making huge strides because there is collaboration. And there is healthy competition among researchers vying for our attention and investment. Let's keep that going and growing and let's fulfill our vision of "supporting everyone while we advance the search for a cure." If we all pull together, almost anything is possible.

Let me close with other good news. We've strengthened our Board of Trustees through the additions of Wanda Huskins, RN, and Dr. Stephen Ansell. Wanda will serve as Chair of our Clinical Trial Committee and our LIFELINE Committee. Dr. Ansell, who also serves on our Scientific Advisory Committee (SAC), will greatly strengthen our scientific capabilities. See page 7 for introductions to Wanda and Steve.

Stay well,

Carl

Have Your Say

The *Torch* welcomes letters, articles, or suggestions for articles. If you have something you'd like to share with your fellow WMers, please contact *Torch* editor Alice Riginos at *ariginos@me.com*

MEET THE NEW TRUSTEES

BY SUE HERMS, IWMF TRUSTEE

The IWMF has added two new Trustees to its Board, and both will be familiar to the many WMers who attend the IWMF Educational Forum or follow IWMF-Talk. The Board and the IWMF membership are fortunate to be on the receiving end of the special talents offered by these two Trustees, Dr. Stephen Ansell and Wanda Huskins.

Dr. Stephen Ansell

Dr. Stephen Ansell, MD, PhD

Dr. Stephen Ansell is a Professor of Medicine in the Hematology Department of the Mayo Clinic in Rochester MN. Those who have attended the past several Educational Forums will recognize Dr. Ansell as a presenter, especially for his unique and memorable take on "How B-Cells Talk to Each Other." WMers who will be attending this year's Ed Forum in Providence on June 10-12 will have the opportunity to hear him give the opening presentation, "An Overview of the Strategic Research Roadmap and the Bone Marrow/Tumor Microenvironment."

Dr. Ansell received his medical degree from the University of Pretoria in South Africa, where he met his future wife, Ingrid. He completed his residency in internal medicine at the Mayo Graduate School of Medicine and at the University of Pretoria and earned a PhD in Medical Science from the University of Pretoria. While in South Africa, he became interested in lymphoma, which also led him to study WM. Upon completing a fellowship in Hematology at Mayo Clinic, Dr. Ansell was offered a position there.

Dr. Ansell splits his working hours almost evenly between his research and his clinical practice, with a small amount of time devoted to teaching. While he says that juggling these work duties is "always a challenge," he adds that "it helps to be able to delegate some of the work" to team members.

His research laboratory at Mayo focuses on B-cell lymphomas and biologic therapies for these cancers. Current strategies being developed include the use of novel antibodies and cytokines, the use of targeted therapies, and the inhibition of B-cell signaling through receptors that promote the survival of malignant B-cells.

Dr. and Mrs. Ansell have two children, although they are now "empty-nesters." Their daughter Kerryn is graduating this spring with an undergraduate degree in psychology and hopes to become a clinical psychologist. Their son Bradley is a sophomore majoring in mechanical engineering. Mrs. Ansell volunteers in music ministry at their church, and Dr. Ansell keeps busy in his spare time playing soccer, traveling, and reading. When he travels, his favorite places include "anywhere warm," which is perhaps understandable considering the cold winters in Minnesota!

In addition to his new role as Board Trustee, Dr. Ansell is a member of the IWMF Scientific Advisory Committee. Dr. Ansell says that "substantial progress has been made in [WM] in the last five years. That progress has included understanding the biology and the development of new therapies. I am hopeful that further development will result in a cure for patients with WM." He adds that he hopes to be able to "help identify the best research" to support achievement of this goal.

Wanda Huskins

Wanda Huskins, RN

Wanda Huskins is well known to members of IWMF-Talk as a frequent poster of links to articles and blogs to help people deal with the psychological and social issues surrounding the diagnosis and management of cancer. She comes by this interest honestly, given the focus of her nursing career.

Wanda became a registered nurse at Columbia Presbyterian Hospital and went on to receive a Bachelor's Degree in Psychology from New York Institute of Technology. She first worked at St. Vincent's Hospital on its adolescent unit, eventually leading therapeutic groups, doing individual therapy, and facilitating family sessions. At St. Luke's Roosevelt Hospital, Wanda was involved with leading therapeutic groups, individual therapy, and cognitive behavioral therapy for adults. At the New York Psychiatric Institute, she followed protocols for clinical research as an assistant head nurse. Her current position at her local hospital in Suffern, NY, involves working with the chemically dependent who also have mental health issues and chronic conditions that require close monitoring.

Wanda was diagnosed with WM in November 2008 at the age of 54. Despite her then 34 years of nursing, she had never heard of WM, let alone met a patient with it. Learning that she had a rare and incurable cancer generated her desire "to locate others facing such a daunting disease. The IWMF came to the rescue, providing me with the learning tools and

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THE LONG AND WINDING ROAD: MY WM STORY

BY EILEEN SULLIVAN

Eileen Sullivan

Eileen Sullivan's WM story reveals a courageous and determined woman who has met with a succession of daunting challenges from our disease. During her 20 years of travel down the "long and winding road of WM," Eileen moved along slowly for the first 8 years, and then her pace accelerated. Major challenges along the way included treatment in a trial for Rituxan and fludarabine that initially brought rapid success only to be followed by resurgent IgM and failure, a "rogue WM" that turned up in unexpected places and responded to radiation, and finally treatment with CHOP and then an allogeneic stem cell transplantation. When a 7-year break from WM came next, Eileen believed she was cured. But not so: her Waldenstrom's recurred. Facing this "new bend in the road," Eileen has recently finished a regimen combining Rituxan, everolimus, and Velcade.

It's been over 20 years since that summer when my hands hurt so badly that I went to see a rheumatologist. Blood tests were ordered; a high SED rate sent me to a hematologist. More blood work and the dreaded bone marrow biopsy led to the diagnosis of *smoldering* WM. I was 45 years old at the time, and my IgM was about 1300, so no treatment was needed right away. Even today, as a long-time member of the New England Support Group, I'm always amazed when I hear a new patient's story of diagnosis. Is there any other cancer that comes with as many weird presentations as WM?

My long and winding "walk with Waldenstrom's" started with 8 years of "watch & worry" (during which time the hand pain disappeared as suddenly as it had arrived). In those early years, the main concern was anemia, but my hemoglobin never dropped to a level requiring treatment. I did *try* not to worry during those years, but, as it turns out, that's not my specialty. Finding the IWMF on the Internet was a gift. I received the amazing packet of information from founder Arnie Smokler, and that was empowering. IWMF-Talk was in its infancy at that time, but I found that participating caused me more worry than not belonging, so I didn't use it for years – not until treatment was imminent. By that time the list had grown into a vibrant community.

At age 53, things changed abruptly and dramatically. I lost 10 pounds in a month. I suddenly started to have intense night sweats again (after finally finishing menopause – not fair!), coupled with crashing white counts, worsening anemia, IgM over 4000, lymph node involvement, and a beta-2 microglobulin level of 5.6. It was time to treat.

I consulted with Dr. Steven Treon at Dana-Farber Cancer Institute and entered a clinical trial of Rituxan plus fludarabine. The other option offered was R-CHOP, but I didn't want to come out of the "cancer closet" at work by losing my hair. I never wanted people to look at me and think, "Cancer – you poor thing." I was working in five elementary schools at the time, supporting teachers in science and social studies. I was afraid they would stop asking for help. As things turned out, however, I might have been better off with R-CHOP. But there's no such thing as time travel – you can't go back and change the past.

I responded immediately to the Rituxan – IgM dropping several thousand points quickly – and no flare. Shortly after the treatment concluded, however, my IgM began to climb rapidly. My T-cells had crashed owing to fludarabine. At first Dr. Treon thought it was a fluke but no such luck. My T-cells never recovered, and my WM seemed to go a bit rogue, later turning up in strange places outside the bone marrow. At one point they found a few cells of diffuse large B-cell lymphoma (DFBCL) in a mass in my thigh. For years the low level of T-cells caused trouble for me until my eventual stem cell transplant in 2006. Thanks to acyclovir, shingles and cold sores were kept at bay.

In the next few years following treatment and before the transplant, WM popped up in my breast tissue, my sacrum, and my thigh. More treatment followed, now R-CHOP with methotrexate added. Radiation was needed for the sacral mass and the leg. Treatment with R-CHOP was tricky, as each round put me in the hospital for a week with neutropenic fever, likely a result of the bone marrow suppression from fludarabine. Eventually the nurse told me to have a suitcase ready to go to the hospital as soon as the fever started to spike. Timing was quite predictable.

I recall sitting in my hospital bed after my fourth round of R-CHOP when one of my oncologists stopped by. I had recently had a PET scan, in the course of which they scanned my lower body as well as the trunk. The radiologist had commented, "For some reason, your doctor wants us to scan your legs and feet as well." Strangely, the doctor didn't recall later having asked to include legs and feet, but she was happy that they were scanned because my right heel was full of cancer, along with the bottom of my foot! Biopsy confirmed WM cells in the foot, results that sealed the deal for a transplant. Interestingly, at that point, my IgM was normal, with no evidence of disease in the bone marrow. If it hadn't been for the PET scan, we might not have known that cancer had spread to a new area.

The Long and Winding, cont. on page 9

The Long and Winding, cont. from page 8

Dr. Treon had raised the possibility of a bone marrow transplant. My doctor now advocated the transplant option. Her comment was, "We can continue to 'spot-weld' you with radiation, but that's probably not a great long-term solution." At that point, I guess my disease would more properly have been classified as lymphoplasmacytic lymphoma since my IgM was then within normal limits.

I was very fortunate to be treated at Dana-Farber and Brigham and Women's Hospital by Dr. Peter Mauch, the radiation oncologist who literally "wrote the book" on radiation oncology. Dr. Mauch said that cancer in the foot is extremely rare and that radiation in that spot can be problematic. He made the call to do a short course of radiation just prior to the transplant. In the meantime I prepared to take a year off work.

An autologous transplant of my own stem cells was not possible because my bone marrow was too depleted. In addition, given the wandering nature of my WM, there was no way to be sure that I was "clean enough" to use my own stem cells. It must be determined that a patient's WM is almost gone before an autologous transplant is undertaken. In the meantime, we found 3 perfect sibling matches (2 sisters and a brother). Mike was selected to be my donor because both of my sisters had had children and therefore had been exposed to "foreign" DNA. Apparently Mike has very powerful stem cells because I was in great shape for 8 years following transplantation.

The transplant was not easy, but I think my husband was more scared than I was. Perhaps I was just too "out of it" to be scared. I have pretty vague memories of the month I spent in the hospital. Eventually I had to learn to give myself Aranesp and Neupogen injections to boost red cells and neutrophils. I'm not sure why I found it so scary to learn. I made my husband learn to do the injections at first. Later on, in preparation for my eventual stem cell transplant, my brother needed to give himself Neupogen to prep his stem cells for collection. He ended up going to a doctor-friend's house before work for each shot. He never did learn to give himself an injection.

My husband's colleagues from work were an amazing support – they kept asking what they could do to help. In the end they came over to the house and cleaned for hours, including behind the stove and refrigerator, finding dirt in places we didn't even know existed. They carted carloads of random stuff to Goodwill and took the car in for sorely needed detailing. Other friends did spring cleaning in the garden and planted flowers so that I would have something to enjoy in the summer months.

My husband, a teacher, had the summer off to be home with me. Perfect timing. The first few months were tough. Several of my sisters flew to Boston for visits and fussed over me, cooking foods that I was allowed to eat and could stomach and then freezing portions. The treatment and radiation caused problems: loss of taste, weight loss, and a few return trips to the hospital when fevers arose. But we got through it. I ate a lot of soup and drank lots of milk shakes. Unfortunately I couldn't taste any sweetness for months, so there wasn't much fun in being allowed to eat as much ice cream as I wanted. Eventually I began to feel better and had energy to do things, though I still wasn't allowed to return to work in a school district full of germy children. I started making soup and bread for the local homeless shelter, and my husband was able to deliver it for me. I found that my love of cooking was a big help in getting through a few more months of isolation.

Following the transplant, I was closely monitored by an amazing team at Dana-Farber. I thought I was cured.

Seven years later, just as we were about to reduce the frequency of my follow-up visits and scans to yearly events, a small M-spike popped up on my blood work, putting me back in treatment. I entered a trial of Rituxan, everolimus, and Velcade with Dr. Irene Ghobrial at Dana-Farber. It was tough. The digestive problems and neuropathy were nasty. I am still weaning myself off Neurontin for the neuropathy. My sister Peggy and I both call Neurontin the "stupid drug" because it severely impairs memory. Years ago a neurologist told me that you could fool your brain into thinking it was still getting the same level of medication if you reduce your dose very, very gradually. His idea seems to be working. I'm down to the smallest possible pill and hope to stretch the time between doses gradually and to be weaned from Neurontin completely in a few months.

Eileen Sullivan, Greenwich, England, summer 2014; standing on the Prime Meridian, one foot in each hemisphere.

The Long and Winding, cont. on page 10

The Long and Winding, cont. from page 9

I survived that treatment regimen, and it worked. Next came the "transplant booster." They called brother Mike back to Boston from Michigan to donate lymphocytes for what's called a donor lymphocyte infusion. No Neupogen shots this time for the donor, just a few hours hooked up to the big machine that filters out whatever cells they need from your blood and then gives you back what's left. They infused some of the collected cells and put another bag on ice, just in case. The return to treatment prompted me to take a slightly early retirement, though I will be going back to fill in for a few months this spring.

Throughout this journey I continue to work, garden, cook, and travel a bit. I also sing with a local chorus where I met a young post-doc who works at Dana-Farber. Small world – it turns out that her lab was working with a grant from the IWMF!

Living next door to Boston with its amazing medical resources has helped us navigate this winding road. My husband is my partner and has been my support for the whole journey, saying at each new twist, "We'll figure this out just as we've done for every other problem that's popped up." I'm so fortunate to have been able to work with amazing doctors and nurses over the past 20 plus years. My incredible primary care doctor, Dr. Rachel Berger, doesn't hesitate to pick up the phone and call me every once in a while. I do think that, once you get the "big C" on your medical record as a middle-aged woman, doctors take you a bit more seriously.

The IWMF Ed Forums and Support Groups have been a wonderful resource over the years, as have the Lymphoma Research Foundation workshops that come to Boston every few years. I find it incredible that our group of patients has become so instrumental in shaping the course of research for our strange cancer.

TREASURER'S REPORT

BY CYNTHIA RUHL, IWMF TREASURER

The finances of the IWMF are accounted for through two separate funds. The Research Fund is used solely to provide research grants for projects that our Research Committee has reviewed and recommended. Our Member Services Fund provides for all of our outstanding services for members, including the Educational Forum, the website, and the *Torch*. Both funds are critically important to the work of the IWMF.

The following is a summary of the financial results for 2015. The amounts are rounded to the nearest thousand and have not yet been audited. We are expecting the audited financial statements to be completed by the time of the Educational Forum in June, and they will be posted on the website when available. However, I wanted to share with you the outstanding financial results of the IWMF for 2015.

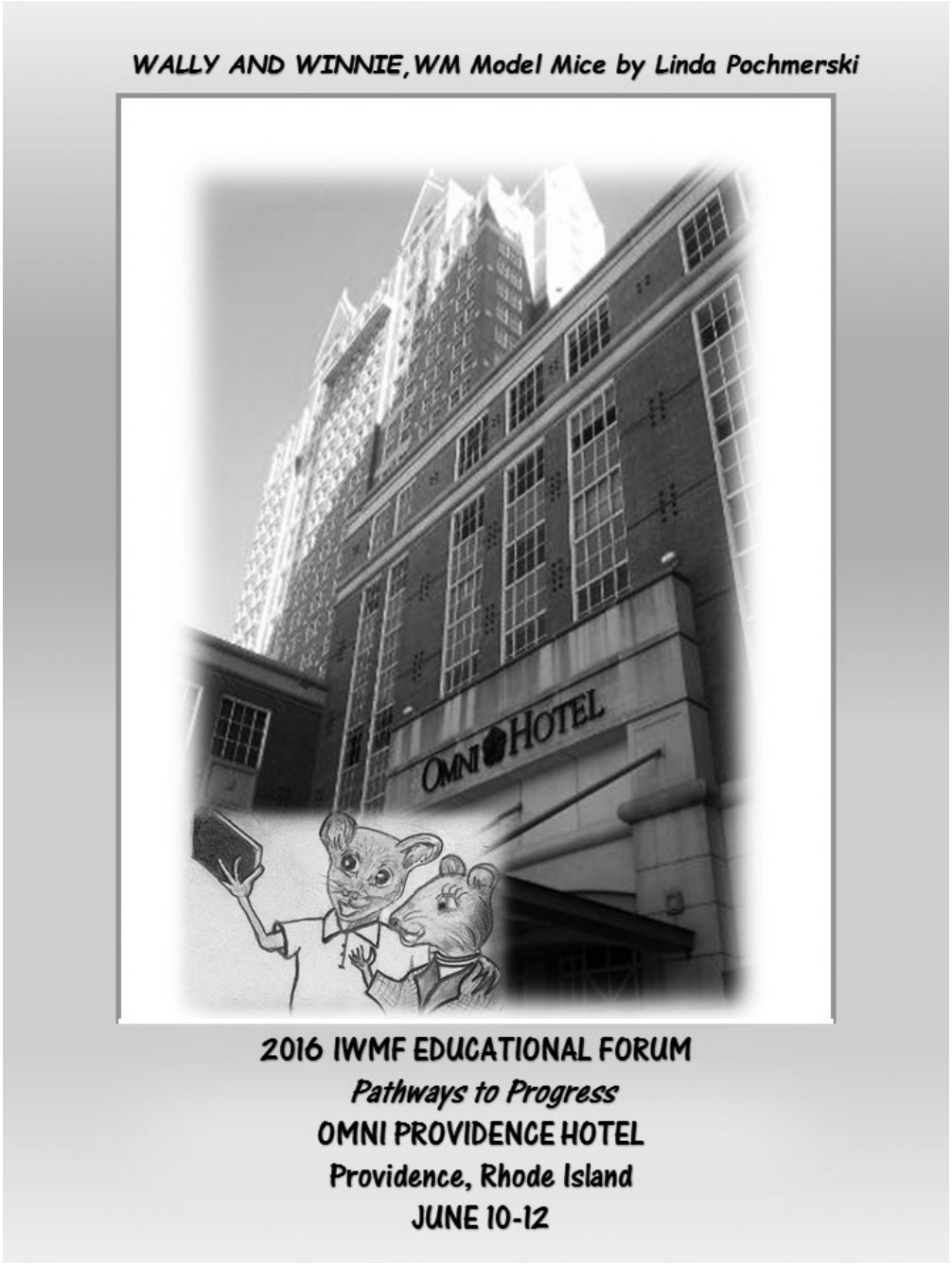
As a result of your generous support in 2015 we were able to publish the *Torch* four times, update some of our literature, upgrade the IWMF website, have the annual Educational Forum, and fund new research grants!

At the end of December 2015, our cash reserves for the Research Fund were $1,094,000 and for the Member Services Fund were $837,000.

I can assure you that the Board does its very best to make certain that every dollar given is wisely spent on serving you, our members. Also, all donations to the Research Fund go directly 100% to research. Thank you for your continued support.

	Research	Member Services	Total
Revenue	$ 1,005,000	$ 1,014,000	$ 2,019,000
Expenditures	$ 644,000	$ 717,000	$ 1,361,000
Net Income	$ 361,000	$ 297,000	$ 658,000

FOCUSING ON THE ED FORUM



Join Wally and Winnie to take your own Ed Forum "selfie" in front of the Omni Providence Hotel on June 10-12!

You can register online for the 2016 IWMF Ed Forum in historic downtown Providence, RI, from our website at *iwmf.com/news-and-events/iwmf-educational-forum*. Registration is only $199 through May 1 and increases to $250 on May 2 and to $275 at the door.

Reserve your room at the Omni for our special rate of $145 plus tax per night, which is good until May 20. You can also make your room reservation online from our website or call the hotel at 401-598-8000 or Toll-Free 800-843-6664 and mention the code "060516INTWALDEN".

The theme for this year's Ed Forum is *Imagine a Cure: Pathways to Progress*, and you'll hear all about our new Strategic Research Roadmap for WM. And there's a session on Friday morning for the newly diagnosed/first timers too! You should indicate on your registration form if you plan to attend this session.

WMers everywhere will be as excited about his special weekend of education, camaraderie, and support as our model mice Wally and Winnie!

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

AUSTRALIA

WMOZZIES GO TO CIRQUE DU SOLEIL

Through IWMF President Emerita **Judith May**, WMozzies was recently contacted by a WM patient from Las Vegas, **Armand Thomas**. He was visiting Australia in his capacity as Stage Manager of Cirque du Soleil's show *Quidam*. They were performing in a number of Australian cities including Wollongong and Newcastle. **Andrew Warden** put him in touch with Dr. Judith Trotman at Concord Hospital as he had some concerns. Dr. Trotman assured him that he should have no problems while in Australia. Armand then kindly offered complimentary tickets to any WMozzies who would like to attend a Cirque du Soleil performance. **Michael van Ewijk** took up his offer as he lives close to Wollongong. He and a friend went to the spectacular performance on December 30. Armand asked Michael to wait at the end of the show so they could meet and have a chat. The chat turned into a tour of the backstage area to meet some of the performers and look through the costume and make-up rooms. The logistics of putting on such a show and then packing up and moving to the next city was as amazing as the show itself. **Margaret Sim**, another Sydney WMozzies member, also was treated to complimentary tickets at the final performance of the *Quidam* Australian tour by Cirque du Soleil. See also page 14.

WMOZZIES EDUCATION AND SUPPORT MEETINGS

The Leukaemia Foundation has released early details of the 2016 WMozzies meeting program where WMozzies can come along to share experiences and exchange information in an informal, supportive environment organized by the Leukaemia Foundation. The first such meeting for 2016 took place in Sydney on March 15.

Leukaemia Foundation's Phone Forums are also being held to give WMozzies around Australia a chance to share experiences and talk to others from their home or location of choice. At the Phone Forum on March 9 the Guest Speaker was Dr. Simon He who spoke on the "latest in clinical trials for WM patients" including treatments such as ABT-199 (venetoclax), ibrutinib, and the BGB-3111 trials.

WMOZZIES IN CLINICAL TRIALS

At Concord Cancer Centre in Sydney, 4 WMozzies are in the Imbruvica/ibrutinib trial and one in the BGB-3111 clinical trial. In Melbourne, WMozzies have been involved in clinical trials with ABT-199 and BGB-3111. The principal investigators in the Imbruvica/ibrutinib clinical trials in Sydney and Melbourne were co-presenters of the poster of initial results of the international, multicentre, open-label Phase III sub-study (iNNOVATE). The oral and poster abstracts were presented at the American Society of Hematology meeting in December at Orlando FL.

Andrew Warden, WMozzies, reporting.

The Leeds University DNA team: left to right, Dr. Reuben Tooze, Dr. Gina Doody, Jenny Shrimpton (WMUK postgraduate research fellow), Dr. Roger Owen.

UNITED KINGDOM

At the time of writing we still await an outcome of our 'scoping' meeting for Imbruvica/ibrutinib in relapsed WM from NICE, the England health gatekeeper. At the meeting, Dr. Roger Owen with WMUK and Janssen, and supported by the Lymphoma Association and other charities, presented an urgent case for its full assessment for funding in 2016. This has been slow, as it was licensed by the European Medicines Agency on July 10, 2015, and is already funded in several EU countries.

WMUK also made its submission to the England Cancer Drugs Fund consultation, along with the newly formed Blood Cancers Coalition of which WMUK is a member. We pointed out the previous unfair treatment for rare and blood cancers and asked for more heed to be taken of clinical specialists actually treating WM and listening to the patient voice, as well as limited trials data. The revised fund, which comes into operation in April, is designed to speed up the adoption of innovative treatments, but many blood cancer charities feel it will remain under-resourced.

UK WM doctors are making rapid headway on the development of a trials hub, to co-ordinate and encourage more trials to be held in the UK, where we have lagged behind other European countries despite having an excellent recruitment record. WMUK has made its first staged payment to Dr. Roger Owen's WM DNA analysis team at Leeds University. We are also developing a strategy on DNA testing to see how doctors can be supported in the move towards personalised medicine.

After some test runs and modifications, the Rory Morrison Registry now has some 150 sets of patient data already entered and is being rolled out to other hospital centres. The plan is to ensure that the Registry also provides additional data from 'real' clinical situations to assess the effectiveness of new

International Scene, cont. on page 13

International Scene, cont. from page 12

drugs aiming at funding by the UK Health Service. The WM biobank at University College Hospital in London, supported jointly by WMUK and the IWMF, is now fully functional, and the first progress report was recently approved by the IWMF.

The encouragement of specialist centres for WM is moving ahead and was boosted by the move of WM patients at London's Royal Free Hospital to University College Hospital (UCLH), creating one of the largest specialist WM clinics outside the USA and run by Dr. Shirley D'Sa and Dr. Derralynn Hughes. UCLH is also the only UK hospital to run joint clinics to deal with WM-related neuropathy, an under-investigated problem area.

WMUK is exhibiting at the joint British Society of Haematology and International Society of Haematology meeting in Glasgow, April 18-21, where there is an international WM session for the first time. Among other things, doctors will be invited to take part in a revamped WM treatment survey on our stand.

On the patient front, the "Bake for Rory" event at the BBC raised over £2000 despite running out of cake, and there are to be more improvements to the website *wmuk.org.uk*

Bookings are being taken online for the annual UK Doctor-Patient Meeting this year in the attractive Georgian city of Bath on Sunday, May 15th. All are welcome. Details are at: *wmuk.org.uk/events/doctor-patient-meeting-15th-may-2016*

Roger Brown, WMUK, reporting from Queen Elizabeth's Hunting Lodge, Epping Forest.

IWWM9 PLANNED FOR AMSTERDAM, OCTOBER 6-8

Since 2000 the International Workshops on Waldenstrom's Macroglobulinemia have been held on alternate years in different international locations. In 2016 IWWM9, the 9th in the series of Workshops, will take place in Amsterdam, the Netherlands, on October 6-8. The organizers for this Workshop are Dr. M. J. Kersten (University of Amsterdam, the Netherlands), Dr. Monique Minnema (University of Utrecht, the Netherlands), Dr. Steven T. Pals (University of Amsterdam, the Netherlands) and Dr. Steven P. Treon (Dana-Farber Cancer Institute). The IWMF, a supporter of the Workshops since 2000, is proud once again to continue its support in 2016.

Attendance at the Workshops is by invitation and limited to members of the medical and research community actively involved worldwide in WM research. In 2016 more than 200 attendees will gather to present their very latest research results and current analyses of treatment regimens. Major advancements in understanding WM are likely to come from these sessions, which tend to be lively and sometimes provocative. The January 2017 issue of the *Torch* will include coverage of the proceedings.

IWWM9/IWMF INTERNATIONAL DOCTOR-PATIENT FORUM, OCTOBER 9

IWMF and IWWM9 are pleased to announce their joint sponsorship of the IWWM9/IWMF International Doctor-Patient Forum to take place on Sunday, October 9, from 9:30 am to 5:00 pm. The venue is the Koepelkerk Conference Hall at the Renaissance Hotel in Amsterdam. [Please note: Sunday, October 9, is the day after the closure of IWWM9.]

The International Doctor-Patient Forum is open to all WM patients and their caregivers. The 2016 Forum will be conducted in English. Complimentary refreshments and lunch will be served. No registration fee is required. However, because the seating capacity of the Koepelkerk Conference Hall is limited and can only accommodate 300 people, REGISTRATION is MANDATORY.

Please register early at *wmworkshop.org/patients* to ensure that a place is reserved for you. Last minute registration will also be available at the door on October 9 from 8:00 am to 9:30 am, pending availability.

The agenda for the 2016 IWWM9/IWMF International Doctor-Patient Forum will be available on *iwmf.com* when it is finalized later this year. For further information, contact the IWMF at *admin@iwmf.com* or the IWWM9 Secretariat at *cpatterson1@partners.org*

IN THE TORCHLIGHT

BY ARMAND THOMAS

Armand Thomas on tour with the Cirque du Soleil.

Barely one year ago the January 2015 issue of the Torch *featured a moving account by Armand Thomas of his near-fatal bout with Guillian-Barré syndrome in his sixth year of "living with Waldenström." At that time he was unable to continue his work on the production side of the Cirque du Soleil. He had recently mounted two displays in Las Vegas of his photographs taken on his earlier days of travel in the near and far East. There was wistfulness to his words. When, one wondered, would the passionate photographer and traveler be on the go once more? The answer: Sooner than we might have imagined!*

I wolfed down my dinner in catering, flipped into my blacks, and dashed to the stage to check on presets – hopping over cables in the darkness and climbing a ladder to the upper deck. Sixty minutes to showtime!

I switched on lamps, nudged a prop in place, and bent down to pick up a strip of white confetti fallen during the previous performance.

And I paused, looking out into the vast empty theater, rolling up the little piece of paper between my fingers.

And thought: My my, how time has passed, how things have changed, how far I've come.

Barely two years ago, I couldn't place one foot in front of another, couldn't lift my foot high to slip into a sandal, much less bend down to pick anything off the floor.

I was paralyzed by Guillian-Barré syndrome. It came on quickly and struck me down hard. I was in my sixth year with Waldenström, suffering another of its autoimmune setbacks.

I had to take a long leave from work with Cirque du Soleil in Las Vegas. I had a lot of treatments and a lot of therapy. I wondered if I'd ever recuperate enough to walk again normally, to sit and stand without a shooting sciatic pain – I wondered if my days of travel were over, if my passions for street photography and bike riding, managing big stage productions, and taking long hikes in the canyons were over.

When you're in the clutches of a struggle, you never know, you just bear down and hope. And you thank the heavens for loving support and modern medicine.

Yes, lucky me, I've made it back. GBS can be devastating, and it has left its mark on me: I now have neuropathy in both feet, an atrophied calf muscle and highly diminished flexibility. When I lamented this to my neurologist, he scolded me: "You're lucky it was just that!"

In other words, get on with your life.

So I did. I returned to work 5 months after the onset, and made it back to spin class within10 months. Last September, I embarked on a five-month gig with a Cirque touring show, visiting South Korea, Australia, and New Zealand. During a break between stops, I traveled to Laos, filling my senses with wonder while never taking anything for granted. (pssst: visit my photo website *www.armandthomas.com*)

In Australia, I made contact with WMozzie leader Andrew Warden and invited fellow WMers to the *Quidam*. It's always so touching and humbling to meet members of our peculiar family. Wherever we're from, whoever we are, there's a bond that connects us. Here's hoping my little story provides both enjoyment and resolve to us all, whatever comes our way.

February 2016
Christchurch, New Zealand

In the Torchlight *is a column for sharing the personal stories of Wallies of all ages to illustrate spirit and strength in the face of adversity. Our pages are full of stories of awards, accomplishments, successful treatments, new adventures, strength of character. Won't you share yours with the* Torch*? Let us hear from you at: ariginos@me.com*

COOKS' HAPPY HOUR

BY PENNI WISNER

Spring must be coming. The calendar says so. That means asparagus and peas and tiny new potatoes, freshly dug. Soon thereafter, there will be zucchini. There is always zucchini.

Silvena Rowe, the London chef, in her cookbook, *Orient Express, Fast Food from the Eastern Mediterranean*, has an intriguing recipe for a zucchini-chile "pesto" that I would call a relish. She serves it with duck rillettes, but I hesitate here as I fear duck, especially duck cooked in lots of fat, might not quite fit our definition of healthy.

Before I get totally distracted by the prospects of unctuous duck rillettes, I should return to the zucchini relish. To add flavor, start by cutting a pound of zucchini lengthwise into slices about 1/3 inch thick. Brush them with olive oil, and grill on both sides until browned. Make sure to oil the grate well so the vegetables do not stick. You'll want a medium fire.

Once cooked (You can cook the slices inside on a grill pan if the weather doesn't invite grilling.), let the slices cool a little, and then cut into small dice. Put them in a bowl and toss them with 1 or 2 finely chopped jalapenos, a small handful of toasted and roughly chopped pine nuts (or almonds), minced garlic to taste, an ounce of freshly grated Parmesan, a large handful of finely chopped fresh basil (or mint or a mix of the two), and a good splash of olive oil. Season lightly with salt and pepper and taste. Adjust the flavors with more salt and pepper as needed. This would taste great with a simple omelette or with grilled, sautéed, or steamed fish or chicken.

Now, if you are still thinking of duck, you can buy it at specialty groceries. Or you can make Rowe's lighter version, marinating the duck legs and thighs overnight in yogurt and lots of spices such as coriander, fennel, cinnamon, cumin, za'atar, black pepper, and lots of fresh orange zest. Brown the duck in an oven-going skillet over medium heat. Add about 1/2 cup chicken broth or water, cover with a tight-fitting lid, and bake at 300° F until the meat is ready to fall off the bone, about 1 1/2 hours. Remove the lid and cook another half hour to concentrate the liquids. Cool and shred the meat, discarding the skin. Serve the rillettes on toasted or grilled bread, lightly brushed with olive oil, and topped with a spoonful of the zucchini relish.

I mentioned peas earlier. When fresh and tender, they make one of the easiest and best snacks or hors d'oeuvre ever. Just put out a bowl of them, unshelled, and let everyone shell their own. Once you get tired of that, you can make a pea pesto. I did discuss pea pesto in Spring 2010 but I don't expect you to remember and am amazed I do. You need tender, young peas, barely cooked and still bright green; basil; Parmesan; garlic; toasted pine nuts (or pistachios); olive oil; and salt and pepper pureed together in a blender or food processor until smooth (that's the way I like mine, but stop sooner if you prefer more texture). If the fresh basil looks tired or seems too expensive, buy a jar of prepared pesto, and whir a big spoonful of the sauce with the cooked peas. Taste and adjust the flavors with more sauce, salt, pepper, and lemon zest, if you like.

Potatoes, small, tender, new potatoes may not seem seasonal, but they are. Like fresh corn, their sugars begin turning to starch after harvesting. Go to the farmers market and look for marble-sized potatoes. Steam them, carve out a little of the flesh from the top, and stuff them with your zucchini relish or your pea pesto. (Eat the extra flesh as a cook's snack.) If you want to make the potatoes a little richer, mix the relish or pesto with a little Greek-style yogurt, fresh goat cheese, ricotta, or feta. Serve a platter of the warm, stuffed potatoes with a glass of chilled, good-quality dry vermouth.

Oh dear! I meant to chat with you about seeds – flax, chia, sunflower, pepita, hemp, and watermelon (yes, watermelon). To eat, not to grow. But this is what happens when ideas confront Spring's promises. Stay tuned and if you have ideas and ways you enjoy these super seeds, let me know and I'll incorporate them into a future column.

Our motto: Eat Well to Stay Well

COUNT THE MANY RETURNS FROM YOUR DONATIONS

During 2015 the IWMF received gifts from more than 2,200 donors. The average gift was $885 with donations totaling approximately $2,000,000. These gifts will enable us to continue to provide the vital member services upon which so many of us rely, as well as begin to fund the Strategic Research Roadmap that was developed jointly with LLS. We are most grateful to our donors for their generosity.

The outstanding WM researchers and clinicians who participated in the development of the Strategic Research Roadmap identified four areas that require exploration if additional progress in treating our disease is to be made. Because this research will require significant additional funding, your Fundraising Committee is looking for ways to increase donations to the IWMF. To help us better understand what motivates donors, we interviewed three of our members who made a recent gift to the IWMF. Each shared with us their thoughts about what they received in return for donations to the IWMF.

Meryl Selig

Meryl Selig was diagnosed with WM in 2009 and spent six years on watch and wait until chronic anemia led to treatment with bortezomib, dexamethasone, and Rituxan (BDR), which she successfully completed in January 2015 at the Stanford Cancer Center. Meryl feels particularly indebted to the team at Stanford now that she is in full remission, and she and her husband Rob continue to support them. When asked what motivated her to donate to the IWMF, Meryl mentioned two things: the reliable and timely information in the *Torch* and IWMF's support of cutting edge research. She indicated that most of her insights into WM have come from articles in the *Torch*. Her mission is to stay on top of the most recent developments in WM research and treatments and she finds the *Torch* to be the best source of such information.

Meryl is thrilled with the progress that has resulted from research supported by the IWMF and wants to help fund future research projects that will emanate from the Roadmap. She said that she and Rob want to give more to the IWMF and are having conversations about making a 5-year pledge this year, recognizing that multi-year research projects require multi-year funding. She is most excited by the bench-to-clinic funding, and she feels that this is the best time to get involved and to step-up fundraising because of the many recent research advances. She wants funding to help future patients, not just current WM patients, and feels that "the IWMF is on the edge of making a huge difference, and that this is a great time to build on the successes that we are having."

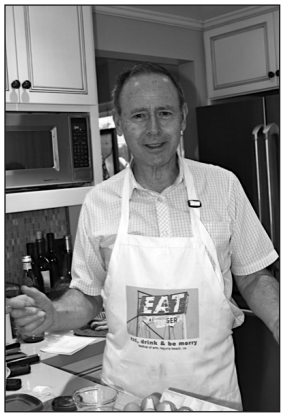
After being treated, Meryl gained a more personal experience of what WM patients go through and has greater compassion for them, understanding that everyone experiences the disease and responds to treatments differently. "When the disease touches you, you have a whole different level of connection, and this connection is a more compelling reason to get involved with the IWMF." From her reading of the *Torch*, Meryl feels that the WM community is a "tight community, really a family, and we need to band together." She said that it is heartening for all of us that so many advancements are happening in the WM field, specifically noting the development of the BTK inhibitor ibutinib and the research that is continuing on this and other signaling pathways. She said that this is the time to rally because there is so much momentum in the treatment of blood cancers.

Beverly Bloss

Beverly Bloss was a nurse for many years at Kaiser-Permanente, and seeing so much illness she thought she had become pretty knowledgeable about the diseases that people deal with. But when she was diagnosed with an orphan disease, she soon discovered that she did not know enough to be a participant in her own treatment. "At the time, I didn't know about the IWMF. I first found out about it when I took myself to a Lymphoma Research Foundation session about WM that I'd heard about. Dr. Treon was speaking there, so I lucked into a meeting with an expert right away. I approached Dr. Treon after his wonderful presentation. We talked and he asked me about cancer in my family. After I answered that there's a lot of cancer in my family, he suggested I might participate in a familial study. I did participate and, through that, my brother learned that he has MGUS, something we had not imagined."

Dr. Treon also told her about the IWMF, and "when I got in touch, I immediately found out how personal – and *personable* – an organization it is. I'm involved with many charities, but IWMF is different. It's the one I feel closest to. It gives patients so much – I hear lots of personal stories about how others think through their struggle with WM, and that inspires me. There is so much learning! Support groups! The wonderful *Torch*! Recipes! Information about clinical trials! I realized quickly that I need more than just my oncologist to

deal effectively with this rare disease. And the IWMF gives me everything I could ever need. That's why I give generously to the IWMF and have decided to include more for IWMF in my estate planning. I have nothing but glowing praise for how it's helped me, and I have to do all I can to keep the organization thriving. We all do!"



John Flora-Tostado

Dr. John Flora-Tostado, a retired psychologist in California, is a relatively new member of the IWMF, having been diagnosed with WM in mid-December 2015. At the beginning of January he visited the IWMF website *(iwmf.com)* at the suggestion of a friend whose spouse had had WM. She also shared one of the IWMF educational booklets with him. Upon visiting the website he submitted an online membership form and made a donation to the IWMF. John was impressed with the IWMF website and immediately understood through his previous participation with various professional organizations just how hard it is to create an attractive, user-friendly site. He also knew the amount of money it would take to make the website a success, even with the help of committed volunteers. In reviewing the booklet he was struck with the overall quality of the piece and the hard work that had gone into creating it. He felt that it was natural to give in recognition of the labor involved from volunteers providing services to those affected by WM. "Someone has to do the work," he stated. "The website was very easy to use. I was impressed with the accuracy and depth of the information contained in the booklet. I know it takes a lot of volunteers and money to support and maintain these kinds of efforts and if those of us who benefit don't support the IWMF, who will?"

Meryl, Beverly, and John are just three of the more than 2,200 individuals who donate to the IWMF every year. Some of our donors are motivated by the progress resulting from IWMF supported research, knowing that every dollar donated to research is used to fund a promising research proposal. Others are motivated by the support services provided at no charge to anyone affected by WM. For some it is the website or publications, for others it is IWMF-Talk. For still others it is the Ed Forum, or the support groups, or the LIFELINE. Whatever the motivation, all of our donors have one goal and intention in common: they want to ensure that the IWMF can continue to achieve its vision to "Support everyone affected by Waldenstrom's macroglobulinemia while advancing the search for a cure." If you are one of the more than 2,200 individuals who donated to the IWMF in 2015, thank you so much for helping us realize our vision. If you are not yet participating, won't you please consider making a gift this year?

It is easy to contribute to the IWMF using any of the convinient options listed below.
We appreciate any and all donations!

Visit **iwmf.com** to give securely **online.**

Mail your gift using the **enclosed envelope**.

Call (941) 927-4963 between 9-5 EST Monday through Friday to make your donation over the phone.

FROM IWMF-TALK

BY JACOB WEINTRAUB, MD

We made it through another winter! And now thoughts turn to the upcoming Ed Forum in Providence, Rhode Island, June 10-12. IWMF-Talk has been busy, as always, with a variety of topics, many of which will be reviewed in greater depth at the Ed Forum. A number of new members have joined, bringing their questions for the "veterans" of the forum. Personal experience and support and suggestions for solutions are the mainstays of our discussions. However, there also are personal interest reports and links to stories that bring a perspective from the larger community of oncology patients. Questions and reports of Imbruvica/ibrutinib treatment are ongoing and appear regularly. Issues about vision are another continuing concern. To be sure, questions and concerns about other treatments recur, but Imbruvica/ibrutinib seems to consistently generate the most interest.

ARTICLES OF HUMAN INTEREST

IWMF-Talk Manager and Trustee **Peter DeNardis** posted several items of general interest for all readers.

On an amusing note, but not directly related to WM, Pete cited an article from the online journal *PLOS ONE* entitled "Pigeons spot cancer as well as human experts" by John Bohannon (18 November 2015). A team led by a pathologist at the University of California Davis and a psychologist from the University of Iowa found that pigeons have excellent visual systems and can be trained to recognize breast cancer cells on slides made from biopsies, with as much as 80% accuracy. Using data from multiple birds, the accuracy rose to 99%, on a par with trained human experts and even more accurate than a computer doing automatic image analysis. Pete compared this avian ability to the "canary in the coal mine" as an early warning signal.
journals.plos.org/plosone/article?id=10.1371/journal.pone.0141357

Another link from Pete is to an article from the website of *The Guardian*. The article "How Do You Tell Your Children You Have Cancer?" covers a subject that many people in this group have confronted. Written by Ranjana Srivastava, MD, it recounts how one of her patients, a mother with young children, decided to address the issue of telling her children. This situation resonated with the doctor who herself had been diagnosed with cancer when she had children at home. Pete observed that, although every patient's situation is different (and how we choose to deal with our own diagnosis is different), it helps to get perspective on how others face this issue. *theguardian.com/society/2015/nov/29/how-do-you-tell-your-children-you-have-cancer*

Wanda H posted a link to a thoughtful and well-written article on the subject of living with a chronic illness. It is an op-ed piece from the *LA Times* by Adam Baer with the title "The Pressure to Say You're OK." The author discusses the pressure on those living with chronic illness to try to conceal the gravity of their situation. This article presents the possibility that recovering from a medical problem today doesn't mean what "our outdated dictionaries" say it does when they speak of successful treatments. One must consider the "mysterious late effects from treatments and additional medical problems caused by the first ones" that often have more impact that previously acknowledged. Wanda felt the last sentence is particularly strong in meaning for us: "There's power in understanding that good health is necessarily temporary, a subjective goal, while uncertain health is permanent." *latimes.com/opinion/op-ed/la-oe-1209-baer-sickness-upbeat-notes-20151209-story.html*

Ginger H thanked Wanda for this post and also pointed out a link within the article that led to another relevant article titled "How not to say the wrong thing" which is about talking to a person with cancer or another serious diagnosis.

Finally Wanda posted a link to an article in the *Business Insider* about IBM Watson and personalized healthcare for cancer. The article titled "How personalized healthcare is revolutionizing how we fight cancer" describes how IBM Watson Health is utilizing the computer Watson to look at genetic sequencing and translate this into potential treatment options to guide further decisions. In one example Watson was able to read and combine one patient's data from such different sources as a chest x-ray, EKG, and physician notes. Some leading cancer centers are collaborating with IBM, and Wanda wondered if one day Watson might be used for WM. *businessinsider.com/sc/ibm-watson-and-personalized-healthcare-for-cancer-2016-1*

From IWMF-Talk, cont. on page 19

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

From IWMF-Talk, cont. from page 18

IMBRUVICA/IBRUTINIB

As this new medication continues to be used more and more, a multitude of reports has come in to IWMF-Talk concerning both improvement and questions about potential side effects.

Sharon reported that she had no previous treatment before her doctor started her on Imbruvica/ibrutinib. She asked if it wouldn't be easier to go on with infusions for other treatments and be done with treatment instead of taking pills every day. Her doctor replied that Imbruvica definitely would be easier on her. She has been taking Imbruvica since June 2015. Blood tests are coming soon. However, she did report the med is expensive, with her first prescription costing $3005 out of pocket for a 30-day supply. If she were in the hospital receiving infusions of another med, her Medicare would cover the cost.

Dudley K suggested that Sharon's doctor should be able to assist her with her Medicare plan by putting in a treatment code for the Imbruvica prescription to reduce her out of pocket cost to less than $3005.

*[**Editor's Note**: There are resources available to help with prescription costs through the manufacturer, the Leukemia & Lymphoma Society, and the Patient Access Network Foundation. For information regarding qualification and application, see* Torch *16.3 (July 2015) pages 6 and 7.]*

Julie T reported fatigue from her WM. Initially she responded to B-12 injections, however with increasing IgM she now is having symptoms of dizziness, pain near her joints, and shortness of breath. She has approval to start Imbruvica/ibrutinib but is concerned about reports of increased blood pressure and other side effects, including atrial fibrillation and bleeding. She wondered if it wouldn't be better to start solo Rituxan.

Hank S suggested that our online discussion is skewed in that we are more likely to hear from people who have had problems with treatment, regardless of treatment type. Hank has been taking Imbruvica/ibrutinib for some time and has done well, with minimal side effects and excellent response. He prefers this to the potential side effects of some of the other available treatments.

Anita L reported she has been on Imbruvica/ibrutinib for 2 years now, with very few side effects, and they proved to be transient. Previously she had been treated multiple times with fludarabine, R-CVP, Velcade, and bendamustine, and she is now thrilled to take 3 pills a day. All the previous treatments had significant side effects with less than full effectiveness.

Ron T reported that he is a 14-month Imbruvica/ibrutinib user. He has gone from being transfusion-dependent to having a normal hemoglobin level. Ron has had minimal and very manageable side effects. His blood pressure, for example, was normal at the start of treatment and now is in the high-normal range. He also reported the ease of taking pills once a day compared to prior treatments. As he is in a clinical trial, the cost of the med is not an issue for him. Ron recently celebrated his 42nd wedding anniversary, and his daughter commented on "how nice it is to have you back."

Some members on Imbruvica/ibrutinib have reported a rise in blood pressure (BP) at varying degrees of severity. This issue was raised initially by **Thomas P.** He has been on it for 4 months, and in the last 2-3 weeks his BP has been spiking into the range of 150 to 180 over 80 to 90. Prior to this, his BP was normal-high at 130/75 and at the start of treatment it was 120/60. His IgM has fallen from 7200 to 2900 since the start of treatment.

Ron T noted that pre-Imbruvica/ibrutinib his blood pressure was 110/60 or lower and now averages around 140/90. He has not been able to find out anything online about hypertension associated with Imbruvica, but he has written to the manufacturer and will share the response.

Colin P reported a potential mechanism that explains increased blood pressure while on Imbruvica. It involves inhibition of the pathway BMX/ETK, which the drug affects in addition to BTK. This inhibition can also down regulate VEGF, which is involved in the growth and regulation of blood vessels, causing hypertension in 30-80% of patients. He cited several references.

VISION

Most of us know that hyperviscosity is a major threat to our vision, but there are many questions that arise with respect to vision and the need for evaluation and treatment.

Peter F asked if anyone has had any visual or eye problems due to WM. He has experienced some deterioration in one of his eyes over the past few months. He also noted symptoms other than vision, including ringing in his ears (some possible residue from labyrinthitis) and occasional fatigue. His IgM is around 1000 (US; 10 Australian).

Dudley K suggested that Peter should let his WM oncologist know as soon as possible and suggested a visit to an ophthalmologist if that has not been done. Dudley also referenced an article on the IWMF website from a previous *Torch* that could be helpful (see below for *Torch* reference).

Penny J suggested that some eye problems could be unrelated to WM. She has had dry eyes, probably from allergies, whose onset predates her WM diagnosis. She uses Restasis and patanol. She also has some blurriness, but her retinologist is not sure that this is related to her WM.

Ginger H reported that extensive retinal bleeding led her to a retinal specialist and then to a hematologist who diagnosed her WM and started treatment. Ginger suggested that early intervention is important since damage can be permanent. Fortunately, as her IgM came down and her viscosity decreased, her eyes improved.

From IWMF-Talk, cont. on page 20

From IWMF-Talk, cont. from page 21

Hank S reported that during a dilated eye exam his ophthalmologist noted some deterioration of the optic nerve in his left eye. Further evaluation showed cupping, and more recently a visual field test showed some worsening of vision in his left eye. His intraocular pressure is normal, but there is still concern for glaucoma, so this will continue to be monitored. When Hank mentioned the issue to Dr. Jorge Castillo at Dana-Farber, Dr. Castillo replied that WM patients are permitted to have other health problems beside WM, and glaucoma does not appear to be common among WM patients.

Robert S added that his right eye has had worsening myopia in the last year. Diabetes and cataracts have been suspected, and he was found to have a cataract. He will be scheduled for surgery in the near future.

Finally **Dr. Maureen Hanley**, who holds a degree in optometry, suggests that myopia is common in nuclear sclerotic cataracts and at low IgM, and in general, a person should not be expecting retinal changes. However, a person can get vascular changes with diabetes. She suggested an OCT (optical coherence tomography) of the macula before one considers cataract surgery to be sure it is only the cataract causing the vision problems.

Dr. Hanley, our resident authority on WM and eye issues, regularly monitors the IWMF-Talk discussions and offers comments regarding the eye problems presented. Her frequently cited article, "WM and the Eye," can be found online at *iwmf.com/sites/default/files/docs/publications/Hanley.pdf*

IWMF-Talk MANAGER

Finally, IWMF-Talk Manager and Trustee **Peter DeNardis** posted a year-end reflection noting that this is the first time in over seven years of being manager of our online forum that he has included his personal observations. Pete noted the growth of IWMF-Talk to over 1800 registered members and also pointed out the great variability in degree of participation and topics over the year. He has seen very helpful new insights to old problems, the emergence of new treatments, especially Imbruvica/ibrutinib, and the increasing longevity of members. He also spoke of the loss of some very caring individuals. Pete himself was diagnosed almost 13 years ago, and he spoke of his fears at the time of diagnosis. He is grateful, however, for all that he has experienced in the interval from diagnosis to the present, including being there to give his daughter in marriage in 2015. As always, Pete pledged to raise an extra glass of wine in honor of all his friends in this group and of those who have come before us. I would personally like to thank Pete for his outstanding management of this large forum and wish him many more years of good health. I, too, will raise an extra glass of wine in his honor and to all the exceptional members of this forum.

Meet the New Trustees, cont. from page 7

contacts I needed to better understand WM. I soon joined IWMF-Talk and found it offered the ongoing peer support to further my knowledge on living with the disease." Wanda also says that seven years post-diagnosis (the last four not in treatment) she has "learned the importance of being part of this WM community."

As Wanda points out, "Despite being fearful of some of the information that would come my way, I knew that knowledge would ultimately be empowering for me and alleviate the anxiety I was experiencing. I know this is true for many of us." Wanda also believes that "with so many new discoveries and treatments, one continues to have opportunities to learn and make better choices." Part of Wanda's new Trustee duties will keep her very involved in this area, as she has agreed to become Chair of LIFELINE and Chair of the Clinical Trial Committee.

Wanda and her husband Jeff will shortly be entering a new chapter in life. Wanda is preparing to retire in June, at which point they plan to travel full-time with their two cats in an RV motor home throughout North America. Wanda hopes that she will be able to meet some of her fellow WMers during her travels. In addition to her Board duties, she is on the upcoming Ed Forum agenda as moderator for a breakout session entitled "Psychosocial Aspects of a Cancer Diagnosis."

MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF TRUSTEE AND RESEARCH COMMITTEE MEMBER

Dana-Farber Cancer Institute to Open Clinical Trial for Venetoclax (ABT-199) for WM – Dana-Farber Cancer Institute plans to open a Phase II clinical trial of oral venetoclax (ABT-199) in patients with relapsed or refractory WM. Venetoclax is a small molecule inhibitor of the BCL-2 protein and was developed by Genentech in partnership with AbbVie. On *clinicaltrials.gov* the trial identifier is NCT02677324.

Venetoclax (ABT-199) Receives Important Approvals for Use in CLL – Meanwhile, Genentech announced that the US Food and Drug Administration has accepted a New Drug Application and granted Priority Review for venetoclax (ABT-199) for the treatment of patients with chronic lymphocytic leukemia (CLL) who have received at least one prior therapy. In a separate development, a Marketing Authorization Application has been validated by the European Medicines Agency (EMA) for venetoclax for patients with CLL who harbor a 17p deletion or TP53 mutation. Both agencies acted on data from a Phase II study of venetoclax that elicited responses in nearly 80% of patients with relapsed/refractory CLL who had the 17p deletion, a type of CLL that is difficult to treat. The most common adverse events were fever, low red blood cell count, pneumonia, and low white blood cell count.

French Researchers to Begin Trial of Unique Protein Expression in WM Patients – A new study from Central Hospital, Nancy, France, proposes to explore the mechanism whereby a protein called Ku70 is under-expressed in WM patients, compared to other lymphoid malignancies and to normal B-cells. The trial identifier on *clinicaltrials.gov* is NCT02640287.

Phase I Trial Is Recruiting Lymphoma and Multiple Myeloma Patients to Test Novel Monoclonal Antibodies – A Phase I clinical trial is recruiting lymphoma and multiple myeloma patients to investigate the safety and dosing of nivolumab (Opdivo) alone or in combination with ipilimumab and lirilumab. Nivolumab is a monoclonal antibody that targets the programmed death receptor (PD-1) on T-cells. By blocking this receptor, the body's T-cells are reinvigorated to potentially target and attack cancer cells. The monoclonal antibody ipilimumab targets CTLA-4, improving the function of cytotoxic T-cells, while the monoclonal antibody lirilumab targets KIR2DL1/2L3, facilitating the activation of natural killer cells. The trial identifier on *clinicaltrials.gov* is NCT01592370.

Immune Checkpoint Inhibitor to Enter Clinical Trial Testing for Blood Cancers – AstraZeneca and Celgene Corporation recently announced that they will initiate the FUSION clinical development program for the anti-PDL1 immune checkpoint inhibitor called durvalumab for a range of blood cancers including multiple myeloma, non-Hodgkin's lymphoma, and myelodysplastic syndrome. By blocking PDL1, durvalumab can counter the ability of cancer cells to avoid detection by the body's immune system. FUSION will initially comprise four clinical trials of the drug alone or in combination therapy with other agents.

Acerta Sponsors Phase I/II Trial for Patients with B-Cell Malignancies – Acerta Pharma is sponsoring a Phase I/II proof-of-concept trial of the combination of ACP-196 and ACP-319 in patients with B-cell malignancies. ACP-196 is a novel BTK inhibitor in the same drug class as ibrutinib (Imbruvica), while ACP-319 targets P13K delta, an enzyme involved in cell growth, proliferation, and survival. On *clinicaltrials.gov* the trial identifier is NCT02328014.

Dana-Farber Cancer Institute Is Conducting Phase II Trial of Imprime PGG and Rituxan in Indolent NHL Dana-Farber Cancer Institute is conducting a Phase II clinical trial of Rituxan and intravenous B-glucan (Imprime) PGG in relapsed indolent non-Hodgkin's lymphoma (NHL). B-glucan PGG is a yeast-derived product that primes the body's monocytes and macrophages to re-direct their killing ability toward tumor cells. The trial identifier on *clinicaltrials.gov* is NCT02086175.

Study Discusses BCR Receptor Signaling in WM – Joint research by Memorial Sloan Kettering Cancer Center and the Bing Center at Dana-Farber Cancer Institute investigated chronic active signaling of the B-cell receptor (BCR) in WM patients. The use of flow cytometry in primary WM cells as compared to normal B-cells supported the presence of chronic active BCR signaling in WM and the classification of WM samples into two groups: one with "high" signaling and one with "healthy-like" signaling, the latter corresponding to patients with more indolent disease. It was unclear whether this active BCR signaling was antigen-dependent or not. The authors concluded that, from a therapeutic perspective, there is a need for BCR-directed therapies in WM, especially in patients with more aggressive disease. This research was published in February in the journal *Leukemia*.

Research Looks at Clinical Efficacy of Ibrutinib and Idelalisib in WM – A study reported by the University of Amsterdam, The Netherlands, and published in the journal *Haematologica* investigated the molecular and cellular mechanisms underlying the clinical efficacy of ibrutinib (Imbruvica) and idelalisib (Zydelig) in WM patients. At clinically relevant concentrations, their data showed that WM cells express a signaling competent B-cell receptor (BCR) and that both ibrutinib and idelalisib inhibit BCR signaling, whereas they did not affect CXCL12/CXCR4 signaling. Their data also indicate that ibrutinib and idelalisib do not directly kill WM cells, but rather result in mobilization of WM cells

Medical News Roundup, cont. on page 22

Medical News Roundup, cont. from page 21

from their protective niches in the lymphoid organs into the circulation, depriving the WM cells of essential growth and survival factors in their microenvironment and resulting in disease regression.

Retrospective Study Presents Information on Bing-Neel Syndrome – A multi-center retrospective study appearing in the *British Journal of Haematology* in December presented information on a rare complication in WM patients called Bing-Neel syndrome (BNS), in which the WM cells colonize the central nervous system. In the 34 patients involved, the median time from WM diagnosis to BNS diagnosis was three years. Patients presented with variable clinical features including limb motor deficits, change in mental status, and cranial nerve palsies. The diagnosis was made by using a combination of cerebrospinal fluid cytology, flow cytometry and detection of the MYD88 L265P mutation, and magnetic resonance imaging (MRI). The estimated 3-year overall survival rate was 59%. Of the survivors, 40% have evidence of disease persistence. A worse outcome was associated with age older than 65 years, platelet count lower than 100,000, and treatment for WM prior to BNS diagnosis. Exposure to rituximab for treatment of BNS was associated with a better outcome.

Additional Phase I Trial Data Released on New BTK Inhibitor – More data from a Phase I study of the BTK inhibitor ONO/GS-4059 in relapsed/refractory B-cell malignancies was recently published in the journal *Blood*. The study included 90 patients from centers across the United Kingdom and France and was initiated in January 2012. Patients included those with chronic lymphocytic leukemia (CLL), mantle cell lymphoma, and diffuse large B-cell lymphoma. The treatment was most successful for CLL patients, whose response rate was 96%, with 21 out of 25 patients remaining on treatment three years later. ONO/GS-4059 was well tolerated with 75% of adverse events being grade 1 or 2; grade 3 and 4 adverse events were mainly hematological and resolved spontaneously during ongoing therapy. No clinically significant diarrhea, cardiac dysrhythmias, or arthralgia (joint pain) were observed, and the maximum tolerated dose was not reached in the CLL cohort. The researchers plan to test this drug in combination with other agents in a trial that will open in the United Kingdom. This drug is manufactured by Ono Pharmaceuticals.

Retrospective Study Compares Two Stem Cell Mobilization Therapies in Multiple Myeloma – A retrospective study from Memorial Sloan Kettering Cancer Center compared two regimens for stem cell mobilization prior to transplantation in multiple myeloma patients. The study, reported in January in the journal *Bone Marrow Transplantation*, compared the most widely used regimen, cyclophosphamide plus G-CSF, to plerixafor plus G-CSF, which is a newer regimen whose use has been limited, due mostly to price concerns. In this study, 112 patients received the plerixafor regimen, which was associated with a higher success rate of stem cell collection and fewer toxicities than the cyclophosphamide regimen

Medical News Roundup, cont. on page 23

We Get Letters

Recently the Torch *received a letter from Robert Feragen, an IWMF member, describing the assistance provided to him by articles in the* Torch *during difficult times he has experienced as a WM patient. Receiving such a letter is very rewarding for the all-volunteer staff responsible for writing and producing the newsletter. It is clear that our regular columns Medical News Roundup and From IWMF-Talk have been very helpful to Mr. Feragen – who, incidentally, provides a terrific example of a spirited individual confronting the challenges of our disease and continuing to live a productive and rewarding life.*

The *Torch* newsletter has been an enormous help to me since my diagnosis and during the period from 2009 when I first began treatment with Rituxan. The experience of other patients helped me assess my own experience. In 2014 because of persistent reactions, my oncologist would no longer prescribe Rituxan infusions. For most of a year, until 2014, I went without treatment. With the FDA about to approve Imbruvica for Waldenstrom's, my doctor prescribed it for me and I took my first daily dose on November 4, 2014.

The results were an impressive immediate lowering of IgM, which was at 3700. By July 1, 2015, in five decreasing readings of 1700, 472, 310, and 241, the IgM number is now within the normal range. Although I am nearly 91 years old, this oral medication has given me new life and energy.

During this time I completed the editing of a 77-page book of my poetry and prose which I published myself for family and friends.

I watch the *Torch* carefully for reports of other patients taking Imbruvica to get some notion of the possible long-term effects as well as the successes.

Robert Feragen

given to 111 patients. In addition, no plerixafor patients were hospitalized for complications, compared to 13 patients in the cyclophosphamide arm. The greater efficacy and reduced complications in the plerixafor patients resulted in reduced costs to the institution.

Cases of Pneumonitis Reported for CLL Patients on Ibrutinib – A letter written to the editor in the December issue of the journal *Blood* from the Abramson Cancer Center of the University of Pennsylvania reported four cases of relapsed/refractory chronic lymphocytic leukemia (CLL) patients who developed pneumonitis (inflammation of lung tissue), while on ibrutinib (Imbruvica) therapy, the first series of cases of this reported toxicity. The findings from this report suggest that any respiratory illness while in treatment should be taken seriously and evaluated and that management strategies could include dose interruption and/or drug discontinuation along with initiation of steroid therapy in severe cases.

MD Anderson Cancer Center Presents Phase I Study Results of Novel Therapy in Multiple Myeloma and Lymphoma – Results of a multicenter Phase I study of the novel investigational drug pevonedistat (MLN4924) for patients with relapsed/refractory multiple myeloma or lymphoma were reported by the University of Texas MD Anderson Cancer Center and published in the journal *Clinical Cancer Research*. The intravenous drug is a novel inhibitor of NEDD8-activating enzyme, which is part of the cellular proteasome system, and is manufactured by Millenium Pharmaceuticals. Two dosing schedules were used. Of the 44 patients enrolled, three achieved a partial response and 30 achieved stable disease. Common adverse events included fatigue and nausea, and grade 3 or greater events included anemia, neutropenia (reduced neutrophils), and pneumonia. While the drug used alone showed modest activity, the researchers expect greater activity when given in combination with standard therapy.

Italian Researchers Report Outcomes of Combination Lenalidomide/Rituximab in Indolent Lymphoma – A multicenter Phase II Italian study reported by Fondazione Italiana Linfomi reported final outcomes for the safety and efficacy of lenalidomide combined with rituximab in recurrent indolent non-follicular lymphoma. Of the 39 patients enrolled, 13 had a diagnosis of lymphoplasmacytic lymphoma (LPL). Patients received oral doses of lenalidomide at 20 mg once daily on days 1-21 and rituximab at 375 mg/m^2 on day 14 of each 28-day course. Patients received up to 6 courses. The response rate for LPL patients was 46%, and estimated remission duration at two years was 100%. Toxicities were mild, predictable, and manageable.

Blinatumomab Antibody Tested in Phase I Trial for Relapsed/Refractory NHL – A Phase I dose-escalation trial of blinatumomab for relapsed/refractory non-Hodgkin's lymphoma (NHL) has been reported in the *Journal of Clinical Oncology*. Of 76 heavily pretreated patients, the overall response rate was 69% at the maximum tolerated dose of 60 μg/m^2/day, with 37% complete responses and 31% partial responses. The median response duration was 404 days, and 12 patients had long-term remissions of more than one year. However, Grade 3 adverse events occurred in 90% of patients, grade 4 in 66%, and grade 5 in 4%; the most common adverse events included lymphopenia (reduced lymphocytes), fever, increased C-reaction protein level, and others. Blinatumomab is a bispecific T-cell engager (BiTE) antibody that targets both the CD3c subunit of the T-cell receptor complex and the B-cell antigen CD19.

Oral Proteasome Inhibitor Ixazomib Accepted for Priority Review in Canada for Multiple Myeloma – Takeda Pharmaceutical's new drug ixazomib has been accepted for Priority Review by Health Canada for relapsed/refractory multiple myeloma; if approved, it will be the first oral proteasome inhibitor available in Canada. This decision was primarily based on results from the Phase III clinical trial program called TOURMALINE. Ixazomib was granted Orphan Drug designation for multiple myeloma in both the US and Europe in 2011 and for light chain (AL) amyloidosis in 2012. It also received Breakthrough Therapy status by the US Food and Drug Administration in 2014 for relapsed/refractory AL amyloidosis.

Novel Monoclonal Antibody Treatment Reported for Light Chain (AL) Amyloidosis – The Mayo Clinic reported a Phase I/II multicenter study of intravenous NEOD001 in 27 patients with light chain (AL) amyloidosis and persistent organ dysfunction who had received at least one prior therapy. This type of amyloidosis is caused by the accumulation of misfolded proteins, inducing the dysfunction of vital organs such as the heart and kidneys. NEOD001 is a monoclonal antibody that targets these misfolded proteins. The recommended dosing from this study was determined as 24 mg/kg every 28 days. The most frequent adverse events were fatigue, upper respiratory tract infection, cough, and shortness of breath. Of 14 cardiac-evaluable AL amyloidosis patients, 57% met the criteria for cardiac response and 43% had stable disease; of 15 renal-evaluable patients, 60% met the criteria for renal response and 40% had stable disease.

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

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

Please note!

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

Details of support group meetings and other upcoming events are posted on *iwmf.com* under EVENTS. Please check the website for up-to-date details of local meetings.

CALIFORNIA

Sacramento and Bay Area

The very knowledgeable Dr. Michaela Liedtke of Stanford Medical Center was the guest speaker for the group's February meeting. The medical center hosted the large and enthusiastic audience in the second floor conference room. Dr. Liedtke is involved with the drug trials for ibrutinib (Imbruvica) at Stanford Medical Center. After her presentation "Principles of Clinical Trials" she remained to answer the many, many questions engendered by her talk. Many of the group's members brought finger food to share.

Dr. Michaela Liedtke speaking to the northern California support group at the Stanford Medical Center.

Southern CA

The region has a new support group leader: **Marla Chao**. She replaces **Sid Bursten** and **Marty Glassman**.

COLORADO & WYOMING

February 20 was a sunny, beautiful, and warm day in Colorado – 64° F! – when the group gathered to meet a new WM expert, Dr. Dan Sherbenou, at the University of Colorado Cancer Center. Recently arrived from the University of California San Francisco (UCSF) with strong credentials in cutting-edge cancer treatment research, he gives the CO center a new focus on WM. (Dr. Sherbenou was originally from Colorado.) His nurses, who have worked with many of us previously, suggested he come to our meeting! We had 24 people in attendance including two first-timers. Dr. Sherbenou discussed his views on diagnosing, treating, and managing

Dr. Dan Sherbenou (on the right) with Connie Deffert and Rudy Bettmann from Florence CO.

WM. The group peppered him with questions, giving him an even greater opportunity to engage with WM patients. The Colorado chapter of Leukemia & Lymphoma (LLS) provided the food and beverages catered by Panera Bread. The group spent the entire morning in the new facility. Members had ample opportunity to meet others from their towns or who were taking the same drugs or had the same symptoms. The group received reminders of upcoming events, including the April Rocky Mountain Blood Cancer Conference put on by LLS and the June 2016 IWMF Ed Forum in Providence, RI. IWMF booklets, DVDs, *Torch* issues – all were available for members – and for our new doctor.

IDAHO

In Idaho, WMers are stretched pretty thin on the ground. So family and friends provide whatever support is needed. For **Janet Corson Stanton**, her family has been her support group. The title of her story might be: It's So Hard to Get a Correct Diagnosis. Here are her own words: "I was diagnosed with WM in 2000. It was a diagnosis that took my family by surprise. They always considered me 'healthy as a horse' whatever that means. I have lived in Idaho for many decades, but all my family of origin lived on the East Coast. When diagnosed, I was 51 years old. One of my sisters is a publisher and writer. Her help to me was finding books and articles that focused on healing by meditation and visualization. She also decided that she needed to visit me more often; for several years she came three or four times a year for a support visit. My other sister worked for a scientific information company and was able to find pages and pages of articles on WM and NHL. I devoured them with eagerness to learn of my options. I found the IWMF online and was delighted to have more "family" to learn from. What a great resource YOU are! Your histories and stories kept me going for many weeks

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and brought me the latest on treatment options. I was treated with cladribine (2CdA) in 2000, but I developed generalized chicken pox, shingles, and paralysis of my right arm and right diaphragm from the shingles. Then I was treated with four weekly infusions of Rituxan. In 2001 I was declared in remission and decided to do a stem cell harvest and freeze the cells for later use. For support, I asked my 82-year-old mother to come west and accompany me on that journey. The nearest facility was in Utah; we roomed together in the doctors' residence apartment for the days during the harvest. During the procedure I developed allergies to both stem cell stimulations, which meant taking Benadryl every 4 hours. Eventually, I had to abandon my idea. Throughout, I was so glad that my mother was with me! I was in remission until 2006 when I developed a MALT tumor in my stomach in November. I had 2 'lumps' removed that were 'odd but not malignant.' My stomach MALT did NOT respond to the triple antibiotic treatment that works in 78% of the cases. I needed Rituxan weekly infusions for eight weeks. After that I went on Rituxan maintenance for 2 years, ending in August 2009. Since then I have had two masses removed; they both were marginal zone lymphomas. This changed my original diagnosis to MZL. I have seen Dr. Treon twice: once in 2001 and a second time in 2012. He confirms that MZL is most likely the primary diagnosis. I am negative for the WM genetic transformation. Throughout the years, I have often thought of how much friends and family offer to the newly diagnosed. With their help we 'keep on trucking' as we said in the 70s! I know mine did much for my spirit and survival."

ILLINOIS

Chicago Area/SE Wisconsin

The group's program committee thanks **Arline Tufano** for over 10 years of dedicated support. She will be leaving the committee but still plans to attend when time permits. Taking her place will be **Greg Ligman** who works in the medical field and has been attending meetings since 2014. Welcome Greg! On a sad note, WMer **Carol Kowaleski**'s husband **Bill Kowaleski** passed away on December 31, 2015. Carol is also on the program committee, and she and her husband have been consistent supporters of the group. Bill's friendly face and engaging personality will be greatly missed; he was one of the group's main greeters. We plan to start the New Year on an exciting note. So much has happened and is happening with expanding treatment options that the program committee felt it is time to bring back Dr. Sho Ma in April. She is very involved with Waldenstrom's at Chicago's well-known Northwestern University Feinberg School of Medicine.

NEW YORK

New York City

In January the group had the rare opportunity to welcome three newly diagnosed patients and caregivers. Getting to know them, listening to them spill out their fears and confusion, and then responding optimistically to their lost-in-the-unexpected-fog questions occupied nearly all the meeting time. However, it was well spent: it was gratifying to see the clouds start to lift in just two hours. Strangers who walked in nervous and uncertain walked out with a palpable sense of relief and with ideas for a preferred path forward based on the group's experiences. All three newbies promised to return and expressed gratitude to the IWMF for clearing a helpful path for them through the availability of local support groups.

Eastern NY/Western New England

In February the group hosted an excellent meeting with oncology nurse and nutritionist Georgia Decker as our presenter. Georgia is a very popular presenter with the group as this is the third time she has joined us. A check of her past visits revealed that she has made a presentation every four years. This time she brought along a student nurse practitioner, Linda Daton, as a bonus. As usual, the meeting was held at the ACS Hope Club in Latham, NY. We gathered in a very comfortable living room area for an informal and very valuable discussion. Georgia spoke of cancer as becoming a "chronic illness" and of the role of an anti-inflammatory nutrition plan. Several group members prepared questions for her before the meeting. The handouts she provided also increased our understanding. Several members of the group have had good progress with treatments including Imbruvica and bendamustine. They report having much more energy, improved blood counts, and an IgM nearing, or in, the normal range! Other topics covered included the "paleo diet" and some of the non-traditional treatments being considered by some members. After the wonderful session with Georgia, the group moved to the kitchen and lunch. This was followed by firming up plans for the annual restaurant outing and topics for the late May/early June meeting program.

PENNSYLVANIA

Philadelphia

Who can turn down Cowboy KickAss Vegetarian Chili, warm corn bread, and hot apple cider on a chilly November Sunday afternoon? (Keep an eye on the Cooks' Happy Hour for **Lisa Wise's** chili recipe once the calendar clicks around again to cold weather.) Twenty-four members of the Philadelphia support group gathered at the home of leader Lisa Wise to celebrate the season and share their WM stories around a roaring fire. It was a very meaningful way to spend quality time together connecting and sharing experiences. During the past several meetings of 2015, the group benefited greatly from hearing presentations from local leading WM physician experts. These meetings have been well-attended and highly informative with lively and engaging Q & A sessions. However, for the aforementioned chili event, the format changed in order to bring everyone together in the warmth of a home setting, to have a chance to re-connect, to hear an update from each person, and to get to know each other further. As several new members have joined recently, it was

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a nice opportunity to welcome them to the group. Spread across the four annual meetings, the group has found a formula that works: a healthy balance of formal presentations and personal sharing to create the right mix of both learning and support and to meet all of the members' needs. The many interesting themes explored ranged from the challenges of living with a compromised immune system, to managing shingles, coping with difficult feelings, fatigue and energy management, choosing to share (or not) a WM diagnosis with others, balancing the equation of living life fully and living with WM, and more. Lots of food for thought to chew on, not to mention the chocolate-blueberry biscotti. A topic for a future meeting emerged from the general discussion: "what are the things that help WMers and caregivers feel better?" Perhaps exercise, nutrition, acupuncture, movement, mindfulness meditation, hobbies, mustard-packet collections on the night table (for night-time leg cramps!), etc.

SOUTH CAROLINA

A good showing of people from around the state attended the winter-spring South Carolina meeting in Myrtle Beach on February 27. Since several people are now taking Imbruvica/ibrutinib, it was a hot topic. One member, who has been on "wait and watch" for 18 years, had recently started ibrutinib. Several new members benefited from the insight of the veteran WMers present. To make the most of the get-together, a number of the group enjoyed dinner out following the meeting, and some who had traveled from other parts of the state stayed overnight to enjoy the weekend in Myrtle Beach.

TENNESSEE

W. Tennessee, E. Arkansas, N. Mississippi

The Memphis area group continues to grow and thrive. It has moved to a new meeting space at Saint Francis Hospital in Memphis, allowing for more room and greater accessibility for those with mobility problems. In January 11 patients and caregivers engaged in lively discussions on a number of topics, ranging from IVIg to successful and not-so-successful treatments, to arranging travel for appointments using private corporate jets (corpangelnetwork.org). On May 7 an oncologist is scheduled as our speaker, and group members are already preparing questions. This group can now boast approximately 20 members (if everyone is able to attend) and the goal is to meet that number in attendees. Meanwhile, the group (all together and individually) wishes happiness and good health to all WM warriors around the world.

TEXAS

Houston

In mid December, a group of old friends and new met to bring the group up to date on their state of health and any current treatments (or not). In addition, Mayo Clinic's Dr. Morie Gertz's presentation from the 2015 Dallas IWMF Ed Forum played on the large screen. All the while, refreshments and social conversation were enjoyed. The next meeting date is Saturday, April 9. The meeting starts at 10 am and will be held at the Manousso's home, 21 Briar Hollow Lane, Houston 77027.

WASHINGTON

The best-laid plans sometimes do not work out. In January the Pacific Northwest group met in the south of the county at the Federal Way Library to accommodate 3 folks who were going to come for the first time. However, they could not come and only those from way up north did attend. Naturally, the next meeting will be in the north. However, 6 members did show up, doubling the number who attended the meeting before last. All enjoyed learning the multifaceted nature of WM from each other. During the discussion, a topic of interest to all was identified – the financial aspects of WM management. The search for a well-versed speaker from the area is ongoing. In November the group met in downtown Seattle at the University of Washington Medicine South Lake Union Campus. It was hosted by Seattle Cancer Care Alliance's (SCAA) Waldenstrom's Macroglobulinemia program, in collaboration with the IWMF. The special guest was Sheeba Thomas, MD, from the University of Texas MD Anderson Cancer Center in Houston. Dr. Thomas and Dr. Ed Libby of SCCA gave talks on recent WM research and held an extensive question and answer session, always a popular part of the program with WMers.

This meeting concluded in a novel way when Certified Laughter Leader Teresa Verde led a session on "Laughter as Exercise". As support group leader **Shirley Ganse** summed up the experience, "You might call it forced laughter to start, feeling really funny (strange) at first, but then it became very funny (ha, ha) because we felt and sounded so silly. By the time we were done, we could feel exactly where our stomach muscles were! And we all left with smiles on our faces."

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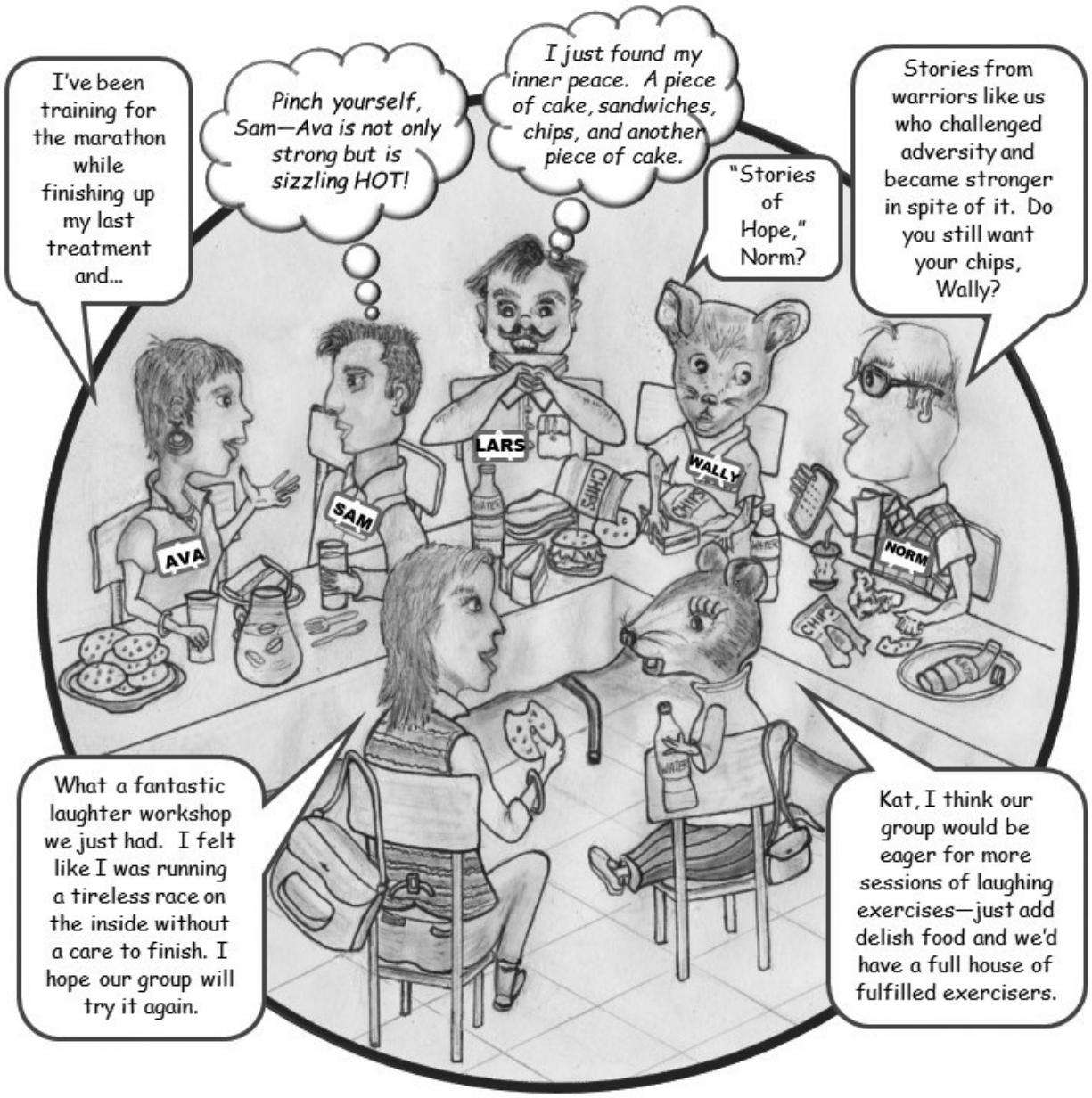
The session on "Laughter as Exercise" led by a Certified Laughter Leader at a meeting of the Washington Support Group inspired the cartoon below where Winnie and Wally and the other members of their support group chat cheerfully, each buoyed up by a good laugh shared together.

WALLY AND WINNIE, WM Model Mice by Linda Pochmerski



SUPPORT GROUPS

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FUND RAISING IS GREAT FUN

BY GAIL ARCARI, CO-LEADER OF THE CONNECTICUT SUPPORT GROUP

Kudos to Ed Goldberg's IWMF fundraising efforts as described in the January 2016 *Torch*. I was thrilled to learn of someone who, despite his health issues, is so dedicated to raising funds in innovative ways. His success explains why I saw so many donations in Ed's honor in the *Torch*, an observation that piqued my curiosity.

I have always been interested in donating to find a cure for WM. Soon after being diagnosed in 2012, I pledged to give regularly each month something to the Research and Member Services Funds automatically from my credit card. I find it better to give a regular monthly amount than to wait for a good financial month to give a larger amount. As a new member, I donated to the IWMF for each of my children to become a member. They have followed suit and continue to give generously.

In 2014 I became active in the Leukemia and Lymphoma Society (LLS) and began attending support group meetings. Subsequently I became a co-leader of the IWMF Connecticut support group. One of our members said she was going to be a team captain for the Light the Night Walk organized by the LLS. At this evening fundraiser held across the nation, LLS supporters carry lit Chinese lanterns. In support of her efforts, I started asking for donations by knocking on the doors of my neighbors in Covenant Village of Cromwell, my retirement community. I told them that I had Waldenstrom's macroglobulinemia and that I was going to walk to raise money for LLS. People were so generous. It was fun and easy. We had a chance to visit and talk. Only a few people said no. One person told me that she gave all her money to one charity that benefitted her great-grandson. Others were concerned about the economy. When asking for a donation, I always asked if it was comfortable for them to do so. I also posted on Facebook. Altogether I raised $777 from over 35 contributors.

When 2015 rolled around, I thought, "Why don't I ask for donations for IWMF as well as LLS?" So if someone was writing a check, I asked him or her to make it out to IWMF in honor of me. I filled out the donation envelope and photocopied it to give to donors to fill in the rest. In 2015 I had 16 donors to IWMF and raised $665. I left one envelope with a neighbor, and a month later he gave me a check for $100. You never know who is going to be generous. Don't be afraid to ask.

At every Connecticut support group meeting I always encourage members to pledge a monthly or annual amount to IWMF. This is so important for research funds, for it is the basis of knowing how much grant money to give out.

Let's make the donation pages in the next *Torch* cover 4 pages!

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International Waldenstrom's Macroglobulinemia Foundation

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