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## PRESIDENT'S CORNER



*Judith May, President*

### Trustee Deaths

I sadly report to you the recent deaths of two IWMF Trustees.

Elinor Howenstine, who passed away in February, was an active member of the Board since 2004. Elinor developed and led the Awareness Project and provided valuable guidance to the Board in the areas of finance and investment where she had long experience.

Former Trustee Bob Bent passed away in January. Bob served on the Board for three years and always gave very generously of his time and expertise in the years that followed. He remained active on the Research Committee until very recently.

We mourn the loss of these two fine and remarkable people. You may read more about their lives on pages 5-6.

### IWMF Status

Every member recently received a letter from me regarding the Foundation's finances for 2011. Any amount you can contribute will help. You should know that we have pared down wherever we could to reduce costs. This year you may find significant sessions from the Ed Forum recorded on YouTube rather than DVDs. We encourage members who so wish to sign up to receive publications electronically in order to reduce printing and mailing costs. We will do what we must do to contain costs. With your help we will come through this.

### Fundraising employee

Many of you have already met Dave Benson, a professional fundraiser who has been on contract with the IWMF for several years. Dave has been very effective in fundraising for us and has helped the IWMF by offering advice and assistance to members. His outreach has established pledges and planned estate gifts that will benefit the IWMF in years to come.

IRS rules require the IWMF to register in every state where we send e-mail or postal letters to members asking for contributions. A recent change in the rules requires that we must also register (and pay registration fees for) each solicitor we contract with in every state where we conduct fundraising. For the past three years Dave has been on contract with us. The cost to register Dave now under the new rules would come close to \$20,000 per year, depending on how many states he visits as a solicitor. However, if Dave becomes an employee of the IWMF, he does not have to be registered separately from the IWMF and we save those funds that would otherwise be spent on registration fees.

The Board voted at our meeting in February to change Dave's status to that of an IWMF employee, and he has agreed. Dave is now employed by the IWMF one-quarter time. He has voluntarily lowered his salary to subsidize the IWMF's cost of the employer's share of payments for social security, Medicare, and state taxes. Dave has great professional abilities and experience for this work. We are very fortunate to have him helping us.



*IWMF Trustee Elinor Howenstine on the occasion of her 75th birthday. An appreciation of her life is found on page 5.*

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*President's Corner, cont. from page 1*

## Bill Paul

There has been a change in Bill Paul's status following a six-month period when we worked together towards a transition in the office of president. During this time Bill has had reoccurring eye problems and has already gone through two surgeries with another one coming up. The time he is able to spend at the computer or reading is limited. In addition, Bill has a business to run and he found that he does not have the time necessary to fulfill the duties of president. While he has stepped back from the position of Executive Vice President, he will continue as Secretary-Treasurer. I will continue as President for the foreseeable future.

## Volunteers

As the IWMF has grown so the workload of the Board has also grown. At present there are several opportunities open for new trustees. If you feel a strong commitment to the continued development of the IWMF and have 5 to 10 hours a week that you can give to Board work, I encourage you to send your resumé with cover letter to Sara McKinnie at our office in Sarasota. [IWMF, 3932D Swift Road, Sarasota, FL 34231] We are especially in need of a person experienced in the area of fundraising or marketing to join our 4-member Fundraising Team. While we need only a few new trustees at the moment, we would like to maintain a file of potential trustees for future use. On the other hand, you might be more interested in volunteering for an occasional assignment on a project when we need help, and we encourage you to propose your resumé with your skills and interests so you can be matched to a volunteer project.

## Ed Forum

We continue with plans for the next Ed Forum, to take place in Minneapolis, MN, at the Radisson Hotel, June 24 - 26, 2011. The IWMF website has the Ed Forum agenda and other details. The link is right on our home page at [www.iwmf.com](http://www.iwmf.com). We know you will enjoy the many fine speakers who will present this year. We hope you are planning to attend. A team of eight physicians from the Mayo Clinic will hold a special two-hour team session on Saturday, June 25, and will cover such topics as: Genetic Studies in WM; Development of WM Cell Lines; Epidemiology of WM; IgM Effects on the Kidneys; Clinical Trials at Mayo; and Research Integration. We will also have updated research reports from Dr. Stephen Ansell, Dr. Irene Ghobrial, Dr. Steven Treon, as well as a number of presenters new to the Ed Forum. The Early Bird registration fee has been extended until the end of April. Don't miss it.

Stay well,

Judith



The IWMF *Torch* is a publication of:

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This publication is designed to provide information about the disease Waldenström's macroglobulinemia. It is distributed as a member service by the International Waldenström's Macroglobulinemia Foundation, Inc., to those who seek information on Waldenström's macroglobulinemia with the understanding that the Foundation is not engaged in rendering medical advice or other professional medical services.

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## 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 Alice Riginos at 202-342-1069 or [ariginos@sy-thetis.org](mailto:ariginos@sy-thetis.org)

IWMF is a 501(c)(3) tax exempt non-profit organization Fed ID #54-1784426. Waldenström's macroglobulinemia is coded 273.3 in the International Classification of Diseases (ICD) of the World Health Organization.

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# ASH 2010 HIGHLIGHTS

BY SUE HERMS, IWWMF TRUSTEE

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Clinicians, researchers, and representatives from pharmaceutical companies, cancer organizations, and associated industries attended the 52<sup>nd</sup> Annual Meeting of the American Society of Hematology (ASH) in Orlando, Florida, on December 4-7, 2010. The IWWMF manned an information booth and was represented at ASH by Dr. Robert Kyle, Bill and Connie Paul, Tom Myers, Sara McKinnie, and Sue Herms.

This article discusses some of the themes and highlights of the meeting, as well as several of the more outstanding research abstracts and reports that are of special interest in WM. Two topics in particular stand out as contributors to our basic understanding of and treatment for lymphomas and multiple myeloma: the role of the tumor microenvironment in the development and growth of cancer cells and the importance of epigenetics in cancer development. A better understanding of these concepts is in turn leading to the discovery of more and better-targeted cancer therapies that are less toxic to other cells.

## The Tumor Microenvironment

The tumor microenvironment is the “stew” of normal cells, molecules, and blood vessels surrounding a tumor cell. Cancer research in the past focused on the characteristics of tumor cells; however, recent studies suggest that the tumor microenvironment plays a critical role in cancer growth by protecting and nourishing cancer cells as well as enhancing their ability to resist drug therapies. A promising new area of cancer therapeutics is to target these components of the tumor microenvironment in addition to the tumor cells themselves.

Dr. Irene Ghobrial of Dana-Farber Cancer Institute presented an interesting discussion of multiple myeloma cells and their environment at a mini-symposium, sponsored by the Leukemia & Lymphoma Society, which preceded the formal ASH meeting. Multiple myeloma cells, under the influence of various signaling molecules called chemokines, adhere to certain niches (areas) in the bone marrow, increase their blood supply, and proliferate; at a critical point the myeloma cells leave the bone marrow (mobilize) and travel through the bloodstream to “home” to other bone marrow sites in a process called trafficking. One of the chemokines that influences myeloma cells is called CXCR4. Dr. Ghobrial has done some preliminary work with a mobilizing agent called AMD3100 (also called plerixafor or Mozobil) that inhibits CXCR4, thereby disrupting the usual adhesion and homing process and forcing myeloma cells to move into the bloodstream and stay there longer. The theory is that AMD3100, in combination with a therapeutic agent targeted against the myeloma cells, will better sensitize and expose these circulating myeloma cells to the effects of the therapeutic agent, making it more effective. To test this hypothesis, Dr. Ghobrial is currently conducting a Phase I/II trial of AMD3100 combined with bortezomib (Velcade) for multiple myeloma patients.

Dr. Ghobrial also talked about other chemokines that regulate adhesion, mobilization, and homing of myeloma cells in the bone marrow and the potential for targeting several of these molecules as a way to control myeloma growth in the

bone marrow. Since WM is also primarily a tumor of the bone marrow, there is certain to be applicability for using some of these same (or similar) molecular targets in the WM microenvironment in order to enhance the effect of therapeutic agents.

Along this same line, several abstracts were presented at ASH that specifically dealt with the interaction of WM cells and their microenvironment, including a few examples discussed below.

A poster abstract presented by Azab et al. of the Dana-Farber Cancer Institute discussed the role of receptor tyrosine kinases (RTKs), which are key regulators of the development and progression of many types of cancer. This study characterized the RTK called Eph-B2 receptor and how it affects the interaction of WM cells with their bone marrow environment. The Eph-B2 receptor was highly activated in all WM patient samples, with a 5-fold increase in WM cells compared to a normal control. Moreover, blocking this receptor inhibited the adhesion of the WM cells to bone marrow endothelial cells (cells that are involved in maintaining an adequate blood vessel supply). This blocking or inhibition of the Eph-B2 signaling receptor may provide a basis for further studies to explore Eph-B2 as a novel therapeutic target in WM.

Elsawa et al. from the Mayo Clinic in Rochester identified a pathway that is involved in uncontrolled immunoglobulin secretion by malignant cells in B-cell/plasma cell cancers, including WM. The cytokine interleukin-6 (IL6) has been shown to promote immunoglobulin secretion, but the mechanisms involved have remained elusive. This study identified a pathway, induced by the chemokine receptor CCL5, which increases IL6 expression in WM bone marrow stromal cells; knockdown of this receptor led to significantly reduced IL6 activity. Further analysis identified a protein called GL12 as the mediator of this CCL5-IL6 interaction. The importance of this phenomenon was also confirmed in other B-cell/plasma cell abnormalities such as MGUS and multiple myeloma. Therefore, therapies targeting this signaling axis in the tumor microenvironment might prove effective in controlling immunoglobulin secretion in patients with these diseases.

Fulciniti et al. presented a study describing the transcription factor Sp1, which activates key elements controlling cell differentiation and growth and which affects the growth and survival of tumor cells. WM cells expressed increased Sp1 activity; moreover, adhesion of WM cells to bone marrow stromal cells further induced Sp1 activity. Based on these observations, this joint study by Dana-Farber Cancer Institute and the University of Catanzaro in Italy investigated a small molecule agent called terameprocol (TMP), which disrupts the action of Sp1. TMP significantly inhibited WM cell growth and was able to overcome the protective effects of bone marrow stromal cells, providing a rationale for clinical development of TMP alone and in combination with conventional and novel therapeutic WM agents.

*ASH 2010 Highlights, cont. on page 4*





Jiang et al. from the Dana-Farber Cancer Institute also examined the possible contribution by monocytes to the growth and survival of WM cells in the bone marrow. This is based on the observation that macrophage-derived inflammatory factors are elevated in WM. Monocytes from the peripheral blood of 8 untreated WM patients and 6 healthy donors were isolated and analyzed by gene expression profiling. Fifteen genes from this study were validated as being over-expressed in WM patients in comparison to the healthy age-matched donors. These genes affect pathways involving innate immunity, inflammation, and apoptosis and provide a distinct microenvironmental signature that can be used to develop new targets for therapy of WM.

### Epigenetics

Epigenetics is the study of chemical markers that modify genes but are not part of DNA itself. These modifications are superimposed on our genes to tell them whether they should be active or inactive. While every cell in the body has the same DNA, some cells are specialized for certain functions, such as heart cells, brain cells, nerve cells, skin cells, etc. These cells are specialized because different sets of genes are turned on or off at certain points in cell development, leading to differences in the types and amounts of proteins produced and thus determining how the cells look and behave. For a long time, it was believed that cancers are caused only by mutations in the cell DNA; however, we now know that cancer can be caused by epigenetic changes as well. Changing the epigenetic chemical markers can switch genes involved in cell growth on or off, allowing the abnormal expression of some genes or the silencing of others. If these changes occur at the wrong time or in the wrong cell, they can convert normal cells into tumor cells that grow out of control [for a more comprehensive discussion of epigenetics, see the article entitled “Epigenetics – Looking at Cancer Development and Treatment in a New Way” in the *Torch* volume 11.3, July 2010].

Because of increased emphasis on the importance of epigenetics in cancer development, a discussion entitled “Epigenetic Regulation in Lymphoid Malignancies” was presented at two morning sessions of ASH. Our current understanding is that every individual patient’s tumor cells harbor many abnormally expressed or silenced genes which affect virtually every cell signaling pathway. While a detailed explanation of the various epigenetic mechanisms is beyond the scope of this article (and in some cases are still not well understood), these mechanisms include histone modifications, DNA methylation, nucleosome remodeling, and small non-coding RNAs called micro-RNAs. Because multiple cell signaling pathways are involved in tumor growth and development, it is anticipated that combinations of therapies will be needed to target these multiply dysregulated mechanisms. At this time, the FDA has approved four epigenetic therapies for various cancers: Vidaza (azacitidine), Dacogen (decitabine), Zolinza (vorinostat), and Istodax (romidepsin). Many more are in clinical and preclinical development.

Critical needs for improved epigenetic therapies include a more precise determination of how they work so that we can identify the subsets of patients who will achieve the best disease response. We need to define how resistance

to treatment emerges when treatment fails so that we can prevent resistance. We need effective combinations of epigenetic drugs or epigenetic drugs in combination with other treatments to increase their activity. In order to achieve the potential of epigenetic therapy, a significant research effort will be needed.

Several abstracts at ASH dealt with research into the specific epigenetics of WM and epigenetic-based treatments. A couple of these are presented below.

Ghobrial et al. presented study results of an epigenetic drug called panobinostat (LBH589) in patients with relapsed or refractory WM. Of the 27 patients enrolled to date, all had received prior rituximab therapy. Minimal response or better was achieved in 60% of the patients, while 36% achieved stable disease and 4% showed progression. The median percent decrease in IgM was approximately 37%. Responses were prompt, with the median time to first response at two cycles, out of a total of six cycles administered. The major toxicities were anemia, thrombocytopenia, diarrhea, and fatigue, and 20% of patients had asymptomatic pulmonary infiltrates. During the study, the starting dose of 30 mg three times a week was amended to 25 mg in order to reduce toxicity. Dr. Ghobrial is evaluating plans to combine panobinostat with rituximab (Rituxan) or bortezomib (Velcade).

Another poster from Zu et al. of the Dana-Farber Cancer Institute discussed the epigenetic drugs 5-azacitidine and 5-aza-2'-deoxycytidine, which are used to treat myelodysplasia, and their potential use as therapeutic treatments for WM. Of the two drugs, 5-azacitidine was found to be more potent in WM cell lines and in patient WM cells, and appeared to work primarily through the genes FASN and SCD1, which code for enzymes essential for lipogenesis (the conversion of non-fat materials into fats).

### Other ASH Highlights

A multi-center study by Furman et al. reported on a Phase II trial of ofatumumab in 15 WM patients. Ofatumumab is a fully humanized monoclonal antibody that targets a different portion of the CD20 surface molecule than rituximab and is approved for the treatment of fludarabine- and alemtuzumab (Campath)-resistant chronic lymphocytic leukemia. This study was performed to examine IgM flare, toxicity, and response data. Patients received 300 mg during week 1 and 1000 mg during weeks 2-4; interim results were available for 14 patients. Of these patients, three achieved a partial response and three a minor response. The most common side effects included infusion-related events and infections. Less common but more serious were neutropenia, hemolytic anemia, and IgM flare. The study concluded that ofatumumab shows clinical activity in WM, and it has been amended to increase the dose to 2000 mg and allow a second cycle of therapy for patients who do not attain partial response after cycle 1.

The European Myeloma Network performed a Phase II study of weekly bortezomib, low-dose dexamethasone, and rituximab (BDR therapy) in previously untreated WM patients. In order to prevent the IgM flare frequently seen with rituximab, one monthly course of single agent bortezomib was first administered at the standard dose of



## Elinor Howenstine

July 13, 1932 - February 20, 2011

The IWMF Board is saddened by the loss of Trustee Elinor Howenstine who passed away at home in Larkspur, California, on February 20, 2011, surrounded by family and friends. Born on July 13, 1932 in Lima, Ohio, Elinor is survived by five siblings: Dr. James Howenstine, Louise Whiteford, Virginia Robison, John Howenstine, Sr., Thomas Howenstine, and many loving nieces and nephews. Diagnosed with Waldenstrom's macroglobulinemia in 2000, she served on the Board of Trustees of the IWMF from 2004 until the time of her death.

Elinor was one of the strongest supporters of the IWMF Research Program, and she also diligently worked to help the foundation reach out to newly diagnosed patients through the Awareness Project, which she started and led. She was an active member of the Finance and Investment Committees, providing professional guidance from her career in investment management.

Elinor earned a B.A. from Ohio State University in 1954 and began her career working for the U.S. Department of State in Paris. She then moved on to World Airways, later to the Joseph Magnin Company, and finally to the San Francisco-based investment management firm of Dodge & Cox Funds. In 1973 Elinor was elected one of the first female stockholders (partners) at Dodge & Cox. She retired from the firm in 1997 after 30 years.

When nearing retirement, Elinor assumed guardianship of her niece Lara Howenstine and raised her into adulthood. She also supported nieces and nephews through medical, photography, law, and architecture schools. A lifelong world traveler, in between chemo treatments she snorkeled through the waters of Fiji and savored gnocchi with shaved truffles in Rome. Known to slip on a fun necklace and "Jackie-O" sunglasses, hop into her cherry-red 1974 BMW and cruise to the wine country for the weekend, Elinor had a keen eye for all things beautiful. Through her support of the San Francisco Symphony, SFMOMA, and the San Francisco Ballet, she helped to ensure that others could also enjoy the cultural life of San Francisco. And she was also an avid fan of the Ohio State Buckeyes, the SF Giants, and the 49ers.

The Howenstine family has asked that Elinor be remembered through donations to the IWMF. A memorial service will be held at 1:30 pm on April 9, 2011, at the Lark Theater, 549 Magnolia Avenue, Larkspur, California. Telephone: 415-924-5111.

In her lasting legacy, Elinor reminds us all that we should never give up and should always find the fun in our life's endeavors.



*Elinor Howenstine*

### *ASH 2010 Highlights, cont. from page 4*

1.3 mg/m<sup>2</sup> twice weekly. For courses 2-5, bortezomib was administered weekly at a dose of 1.6 mg/m<sup>2</sup>, followed by administration of dexamethasone (40 mg) and rituximab (375 mg/m<sup>2</sup>) during the second and fifth courses. Bortezomib was administered weekly in the later courses to reduce peripheral neuropathy. During treatment, valacyclovir prophylaxis for shingles was prescribed. Of the 54 patients evaluable for a response, complete response was seen in 4%, partial response in 61%, minor response in 15%, stable disease in 9%, and progressive disease in 11%. The IgM flare phenomenon was not observed in any patients, and the dose of bortezomib was reduced in 30% of patients, primarily because of peripheral neuropathy. So far, this is the largest trial evaluating the role of a bortezomib-containing regimen in the frontline treatment of WM. An update on response, toxicity, and time to progression will be presented later.

McMillin et al. from Dana-Farber Cancer Institute investigated a novel drug called MLN4924 for preclinical activity in multiple myeloma and WM. Cell lines and mice engrafted with multiple myeloma and WM cells were studied for both effectiveness and toxicity of this drug. MLN4924 has some similarities to bortezomib, in that it acts on protein degradation pathways, but appears to be a more targeted approach. Cell lines showed a rapid, tumor-selective effect. MLN4924 was also tested in a series of combinations with dexamethasone, doxorubicin, and bortezomib and showed additional activity. The animal safety studies demonstrated that MLN4924 was tolerated at doses up to 60 mg/kg twice daily for one week. Studies with this drug are continuing.

An abstract by Kahl et al. of a multi-center Phase I study of the drug CAL-101 presented data on its effectiveness and

*ASH 2010 Highlights, cont. on page 31*



## Robert Demo Bent

December 22, 1928 - January 2, 2011

The IWMF Board regrets to inform you of the death of former Trustee Robert D. Bent, Ph.D., Professor Emeritus of Physics at Indiana University, Bloomington, Indiana, who passed away January 2, 2011. Bob served on the IWMF Board of Trustees from 2002 to 2005 and thereafter remained active on the IWMF Research Committee until only recently. His participation in the Research Committee's review and follow-up procedures was always professional and greatly valued. Bob was a soft-spoken gentleman, very accomplished, highly intelligent, and a joy to work with.

Robert Bent received his A.B. in physics in 1950 from Oberlin College and his Ph.D. in physics from Rice University in 1954. After three post-doctoral years at Columbia University, he came to Indiana University-Bloomington to join the Physics Department, instructing in the classroom and conducting research in nuclear physics. He soon joined a new research venture, helping to develop the Indiana University Cyclotron Facility, where much of his physics research took place. He was a Fellow of the American Physical Society, a member of Sigma Xi, and a Guggenheim Fellow in 1962-63 when he worked in Oxford, England. Bob's publications in the field of physics include more than 60 articles in professional journals.

Over his many years of teaching Bob became interested in the field of energy use, sustainability, and the environment, and he developed courses in that area. Even after he retired from the Physics Department and the Cyclotron following a career of thirty-eight years, he continued to teach an environmental physics course. During this time he also taught a course in energy and environment at the Collins Living and Learning Center at Indiana University. At the IU Institute for Advanced Study he facilitated a faculty seminar on energy, the environment, and sustainability, which resulted in the publication of *Energy, Science, Policy, and the Pursuit of Sustainability* (Island Press). He was appointed to the Sustainability Commission of the City of Bloomington when it was first created, and his interest in that area continued all the rest of his life.

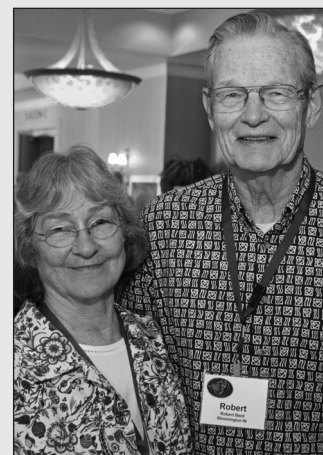
Life in Bloomington afforded many opportunities for participation in two of his passions: music and tennis. A cellist from childhood, he enjoyed playing in string quartets, small ensembles, and orchestras. He played in both the first and the fortieth concert seasons of the Bloomington Symphony Orchestra and kept up his playing until a few months before his death. He had an uncommonly sophisticated taste in music, enjoyed listening as well as playing, and always had an astute and interesting opinion on what he heard. His beloved cello teacher, Elizabeth Mulchy, who is 103 years old, survives him.

Another lifelong activity was the game of tennis. Largely self-taught, Bob learned the game playing with his brother, a cousin, and neighborhood friends. He played on his high school and Oberlin College Varsity teams. In later years he continued to play even after losing his sight in one eye due to WM. Bob and his many friends enjoyed tournaments and social tennis in Bloomington for decades, and many deep and lasting friendships were formed on the courts.

During his early college years, his family and a few close family friends built a beautiful log cabin in the north woods of Minnesota. Using no power tools, they did everything in the traditional Scandinavian log-building style, resulting in a vacation home that has been used by the family for more than 60 years. This beautiful place was a place of joy and renewal for him and all his family. This adventure is recorded in *The Cabin Book*, which he created from letters, pictures, family memoirs, and with the help of his brother and other family members.

Bob is survived by his wife of 54 years, Mary Keating Bent, daughter Usa Scott and her husband Perry Scott of Indianapolis; sons Jason and Alan, and their wives Erica Duke and Amanda, of Anchorage and Fairbanks, Alaska. Six grandchildren brought joy and pleasure to his life: Aaron Scott, Brian Scott, Jack Henry Bent, Lucca Duke, Alice Bent and Aster Bent. He is also survived by brother Henry A. Bent and his wife, Anne; by a niece, Elizabeth Bent Weberg and husband Rolf; by many other nieces and nephews, cousins and relatives-in-law, and by many friends and colleagues.

A Memorial Service will be held later this spring at the Unitarian Universalist Church, of which Bob was a member.



Former IWMF Trustee Bob Bent  
and his wife Mary at the  
Memphis Ed Forum.





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# TREASURER'S REPORT FOR THE YEAR 2010

BY BILL PAUL, IWMF SECRETARY AND TREASURER

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The finances of IWMF are operated through two separate funds: the Research Fund and the Member Services Fund. The assets of these funds are kept separately as are the accounting records. For the sake of simplicity they are summarized as follows, with a comparison to last year. Amounts are rounded to the nearest thousand.

<b>Research Fund</b>	<b>2010</b>	<b>2009</b>
Contributions Received	\$ 424,000	\$ 365,000
Interest Income	18,000	17,000
	<u>442,000</u>	<u>382,000</u>
Research Grants Awarded	<u>1,542,000</u>	<u>588,000</u>
Increase (Decrease) for Year	<b><u>(1,100,000)</u></b>	<b><u>(206,000)</u></b>

Contributions during 2010 were approximately 15% higher than during 2009. The amount in the checking accounts and CDs on December 31, 2010 was \$1,190,000. Research Grants of approximately \$1,500,000 are payable in 6-month increments and most are multi-year grants going forward for three or more years. Keep in mind that these grants are not payable currently but are due over a period of time between now and 2014. While we hope and anticipate that we will receive substantial contributions this year and the years ahead, we will need to be diligent about not awarding further grants until we know the contribution level for 2011. It should also be pointed out that we have pledges of over \$800,000 from our membership, almost exclusively in the form of Estate Gifts. When matured, these gifts will assist greatly in overcoming this deficit. Obviously, it is also at some unknown future date that these estate gifts will actually be received as cash.

<b>Member Services Fund</b>	<b>2010</b>	<b>2009</b>
Contributions Received	\$ 433,000	\$ 625,000
Member Services and Operating Costs	<u>607,000</u>	<u>525,000</u>
Increase or (Decrease) for Year	<b><u>\$(174,000)</u></b>	<b><u>\$ 100,000</u></b>

Income for 2010 was significantly lower than for 2009. The Member Services Fund showed a serious deficit at year end, with a shortfall of \$174,000. With your help, and with

reduced spending, we can turn this around in 2011 and hope to be able to report a larger cushion of assets once again. One factor that changed our 2009 income total was the receipt of two large estate gifts. Similar gifts were not received in 2010, and that, along with increased expenses, contributed to our overall deficit. As of December 31, 2010, the Member Services Fund had assets in our checking account and CDs with a combined value of \$258,000, compared with \$400,000 at the end of 2009. This is a disturbing trend. As recently as a year ago, we had cash and CDs sufficient to support our office for approximately nine months, even if no further contributions were received. That cushion is now down to approximately three months of anticipated expenses.

## OBSERVATIONS AND OUTLOOK

As your Treasurer, I am charged with reporting the facts of our financial situation. As a member of your Board of Trustees, I wish to join others in sharing my concern for our current financial situation. As you can see, both our Research Fund and our Member Services Fund are struggling. For a number of years during this troubling economy, you, our members, have come through and have helped us maintain a solid financial footing. As you will hear from others, we now need you more than ever to continue or to increase your giving.

I should point out that, even in this less than stellar year, your Foundation has always met its obligations. IWMF has never missed making a payment to a grant recipient. The Foundation has never fallen behind on office operating expenses such as rent, telephone, etc. We meet our obligations, thanks to your contributions. Indeed, during 2010 we added even more research grants and hope to be able to add even more in 2011, with your help.

Every nickel IWMF collects is used to the advantage of you, our member. Whether it is supporting research grants to help find a cure or paying for postage to get Info Paks mailed around the globe, the Board has your best interests in mind when considering and approving expenses. The money you find the time to give now will come back to you, we are confident of that.

As always, if you have any questions on IWMF financial matters please do not hesitate to contact me directly at 901-767-6630 or [billpaul1@juno.com](mailto:billpaul1@juno.com).



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# A GREAT “ANYTIME” GIFT IDEA FOR WMERS AND FOR THE IWMF

BY L. DON BROWN AND CARL HARRINGTON  
IWMF TRUSTEES AND FUNDRAISING COMMITTEE MEMBERS

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Most people come to a point in their lives when they find they have enough stuff. When someone asks what you want for a birthday, an anniversary, Father’s Day, Mother’s Day, Christmas, Hanukkah, retirement or any other special event, do you have a long list? Or do you have to struggle to come up with something? The next time you’re asked this question, how about suggesting a donation to the IWMF in your honor instead? This gift will be contributing to the future health of everyone with WM.

To make it easy, we’ve posted the draft letter below on the IWMF website at <http://www.iwmf.com/docs/AnytimeGift.doc>

Just e-mail it to your computer-savvy friends and relatives, or print it and give it to your family members and friends. Either way, it’s a great way to give to the IWMF and WMers everywhere.

If you don’t use a computer, call Julie Jakicic at the IWMF office (941-927-4963) and Julie will create a prototype with you that is customized for your occasion. She’ll mail you a master copy that you can use to make as many copies as you’ll need. It’s that easy.

Dear \_\_\_\_\_

Over the years, some of my favorite gifts have come from you, but now I have reached a stage in life when I really don’t need more things. What I want instead is to help cure Waldenstrom’s macroglobulinemia (WM), a disease that [complete as appropriate: I have/someone else in the family has/a friend has]. Therefore, instead of a gift for [Christmas/my birthday/my anniversary/or other special occasion], would you consider giving a gift to the IWMF (International Waldenstrom’s Macroglobulinemia Foundation)? More information at [www.iwmf.com](http://www.iwmf.com)

IWMF is the trail-blazing organization that is funding research for better treatment and a cure for WM and providing essential support to those with this disease. Please consider making a gift “in tribute” to the IWMF in my name. Gifts to the IWMF can be easily made online or by mail.

Mail: Go to [www.iwmf.com/docs/HonorCard.pdf](http://www.iwmf.com/docs/HonorCard.pdf), print out the form and mail with your donation. Please make your check payable to IWMF and mail it to the IWMF Business Office at 3932 Swift Road, #D, Sarasota FL 34231.

Online: Go to [www.iwmf.com/donate/tormgift.aspx](http://www.iwmf.com/donate/tormgift.aspx) and make your donation online. From this page, click on “Make a Member Services Gift.” Then, on the next page, enter the required information. When you click the arrow in the “My Gift is” box, you can select “In Honor Of” and fill in my name and address \_\_\_\_\_

In the special section that appears. You can even include a personal message if you would like. Try it; it’s easy.

Thank you for helping to find a cure and for giving me a gift you know I’ll love!

Sincerely,

Thanks in advance for sharing this great “anytime” gift idea with your friends and relatives!





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# RESEARCH UPDATE: A SUMMARY OF RECENT PROGRESS ON IWMF SPONSORED RESEARCH

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BY TOM MYERS, IWMF VICE PRESIDENT FOR RESEARCH

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## COMPREHENSIVE STUDIES INTO THE GENETIC BASIS AND PATHOGENESIS OF WM

**Dr. Steven Treon, Bing Center for WM, DFCI**

This major study was completed at the end of 2010. The genetic investigation revealed that there are three distinct cohorts of WM based on familial clusterings. The three cohorts, identified by clinical and genetic differences, are:

Sporadic: The patient has WM, but the family members have no other B-cell disorders.

Familial: The patient has WM and only WM is present in other family members.

Familial Mixed B-cell Disorders: The patient has WM and other family members have various B-cell disorders.

These studies identified genetic patterns that would predict patients who might have more aggressive disease characteristics. Of great importance was the identification of distinct microRNA and methylation dysregulation, which represent novel targets for the treatment of WM.

Dr. Treon was recently awarded an IWMF grant of \$227,800 in support of a new project to study the whole genomic sequence of several WM patients with the aim of learning more about the genetic alterations that lead to the disease and its classification into one of the three subtypes.

## FACTORS REGULATING IGM-PRODUCING B-CELLS IN PATIENTS WITH WM

**Dr. Stephen Ansell, Mayo Clinic**

The project has shown that BlyS (B-Lymphocyte Stimulator) is important in stimulating the production of IgM in WM patients. As the work progressed, it was found that the protein cytokine IL-6 (Interleukin-6), as well as other cytokines, collaborates with BlyS in stimulating the IgM production. Dr. Ansell has proposed a mechanism by which the cytokines interact to stimulate the production of IgM. This information will enable the development of an optimum treatment approach to prevent the growth of the malignant cell producing the excess IgM. This project will continue through October 2011.

## HEPCIDIN AS A KEY REGULATOR OF ANEMIA IN WM

**Dr. Rafael Fonseca and Travis Henry, Ph.D., Mayo Clinic Arizona**

This recently completed project showed that WM patients with lowered hemoglobin levels had higher concentrations of hepcidin (a 25 amino acid peptide). Hepcidin regulates iron metabolism by binding to the iron exporter ferroportin resulting in degradation of the compound. This in turn reduces the release of iron into the red cells causing iron deficiency anemia. As iron is important in the transport of

oxygen by hemoglobin, an iron deficiency means that less oxygen is transported in the blood. In studies on WM patients the scientists found elevated hepcidin levels and also elevated IL-6 concentrations. It has been shown that IL-6 stimulates the production of hepcidin. The scientists propose that the malignant plasma cells increase the production of IL-6 and this in turn stimulates hepcidin generation. Future studies aimed at reducing anemia may seek out agents to control hepcidin concentrations.

## DEVELOPMENT OF A TRANSGENIC MOUSE MODEL

**Dr. Siegfried Janz, University of Iowa**

Many researchers have recommended that a transgenic mouse be developed to further their research on WM. 'Transgenic' means that the mouse has been genetically engineered to have the genes required to develop a disease, in this case WM. The first report on this project is very promising. Engineered mice did develop B-lymphocyte tumors, some of which were similar to WM tumors. Further work is now required to speed up the development of the tumors and to insure that they are IgM-producing.

## DEVELOPMENT OF A WM CELL LINE

**Dr. Asher Chanan-Khan, Roswell Park Cancer Institute; Dr. Stephen Ansell, Mayo Clinic; Dr. Irene Ghobrial, Dana-Farber Cancer Institute; Suning Chen-Jiangen, Institute of Hematology, China**

At a WM workshop sponsored by the Leukemia & Lymphoma Society in October 2008 the attending scientists indicated that their studies of WM were impeded by the lack of a representative WM cell line. Although several cell lines for WM had been reported in the literature, all of them had changed with time and there was some question as to whether they represented the disease. LLS and IWMF published a Request for Proposal to develop a stable representative cell line. As a result the four scientists listed above were selected to each independently develop such a cell line. The projects are funded by LLS and IWMF and were started in the late summer of 2010.

Mid-term reports have been received from three of the project leaders and the results are varied. Dr. Ansell has cells from 4 patients that have remained viable and are proliferating since the start of the project. He also started developing a cell line on his own and has one patient whose cells have been proliferating for over a year.

Dr. Ghobrial is taking a two-pronged approach in attempting to develop cell lines from both mice and humans infected with WM. The initial work was done with mice, and several

*Research Update, cont. on page 10*



animals demonstrated the ability to secrete IgM. More work is required to characterize the diseases exhibited by the mice. Samples of human cells are being collected for the development of a human cell line.

Dr. Chen's report demonstrates the difficulty researchers experience in trying to develop cell lines. Twenty-one patients contributed cells initially. Six patients had hyperviscosity and insufficient material was obtained to start cell lines. Nine of the remaining 15 cell lines died in the first three

months of the study. Currently cells from the remaining 6 patients are alive and proliferating. Dr. Chen plans to recruit another 8 to 15 patients for cell line development.

Dr. Asher-Khan has not reported yet. He has a cell line that he has been maintaining for a long period of time.

Much more work will be required by the principal investigators to demonstrate that the cell lines can remain stable and proliferate.

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## SIXTH INTERNATIONAL WORKSHOP: PART II

BY GUY SHERWOOD, M.D., IWMF TRUSTEE

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*In a report written for the IWMF on the Sixth International Workshop on WM, Dr. Sherwood reviews the presentations included in the Workshop's fifteen sessions spread over three days in October 2010. Dr. Sherwood's report is written for the lay reader with an interest in the most recent research directed toward understanding and treating the disease Waldenström's macroglobulinemia. This detailed and informative report is available in its entirety on the IWMF website under IWMF Library, International Workshop Proceedings, [www.iwmf.com/iwmf-library](http://www.iwmf.com/iwmf-library)*

*A portion of this report, an overview of Workshop Sessions I through VI, was published in the Torch volume 12.1, January 2011, pages 7-10. Coverage continues in this issue in a second part that consists of Dr. Sherwood's lively summary of Session XI and his Conclusion, focusing on what he deems "the take away messages from IWMF-6." The complete report at [www.iwmf.com/iwmf-library/](http://www.iwmf.com/iwmf-library/) covers many more topics relevant to the latest WM research.*

The Sixth International Workshop on Waldenström's Macroglobulinemia (IWMF-6) was held October 6-10 in Venice, Italy. This premier scientific conference for WM, organized by Dr. Giampaolo Merlini, Dr. Enrica Morra, and Dr. Steven Treon, was attended by close to 200 individuals from all over the world. The 3-day workshop consisted of 15 lecture sessions and a total of 80 presentations from over 90 speakers, including 14 young investigators, 5 special guest presentations, 5 debates, and 2 consensus panel discussions.

### SUMMARY OF SESSION XI

This session featured a series of five debates on treatment challenges in WM between world-renowned WM experts in a "Yes versus No" format. Following a brief introduction by the moderator, **Dr. Nikhil Munshi**, Dana-Farber Cancer Institute, the debates proceeded as follows.

#### FIRST DEBATE: "Is there a role for nucleoside analogue therapy in WM?"

**Dr. Enrica Morra**, Department of Hematology, Niguarda Ca' Granda Hospital, Milan, Italy, argued that nucleoside

analogues (NAs) do indeed have a role in WM therapy given their record of efficacy as single agents or in combinations, with good responses and long duration of responses, even in heavily pre-treated WM patients.

**Dr. Xavier Leleu**, formerly of the DFCI and now at Hôpital Huriez-CHRU, Lille, France, argued that the risk of myelosuppression, together with the risk of stem cell damage (and hence difficulty in possible future stem cell harvest) and risk of transformation (4-7% according to a study published earlier by Dr. Leleu), should give great pause to clinicians considering the use of NAs in the treatment of WM. Both debaters agreed that the use of NAs should be limited in younger WM patients, that consideration be given to reduction of doses or cycles in order to minimize the associated side effects of these very effective agents, and that clinicians should be allowed to consider their use in limited, yet appropriate, circumstances. Both debaters also agreed that the use of NAs in WM should be limited to clinicians very familiar with the potential hazards of these agents.

#### SECOND DEBATE: "Should the combination bendamustine + rituximab (B-R) be considered the standard as frontline therapy in WM?"

**Dr. Mathias Rummel**, Clinic of the Justus-Liebig University, Giessen, Germany, who had previously presented the very favorable results of a German clinical trial on B-R in WM, argued that the outcome of the Phase III randomized clinical trial had indeed resulted in the change to B-R as standard treatment in WM versus the previous choice of R-CHOP. B-R use in WM improved virtually all parameters, with fewer side effects attributable to therapy.

**Dr. Véronique Leblond**, Groupe Hospitalier Pitié Salpêtrière, Paris, France, had the unenviable task of arguing the opposing view. She focused her arguments on the relatively low numbers of WM patients studied and the relative paucity of data in the optimal dosing schedule as well as in the use of B-R in patients older than 70. She suggested that patients

*Sixth International Workshop, cont. on page 11*



preferred oral therapy versus the B-R intravenous therapy and that the cost of B-R was quite high. Unfortunately for Dr. Leblond, who was admittedly finding it difficult to argue against B-R in support of R-CHOP, it appeared that most of the audience sided with Dr. Rummel.

**THIRD DEBATE: “Should maintenance rituximab (MRx) be used for rituximab responders in WM?”**

Beginning debate on this controversial topic, **Dr. Ranjana Advani**, Stanford Advanced Medicine Cancer Center, Stanford University, argued that Dr. Treon’s recent retrospective study on MRx and WM, coupled with the large trial in follicular lymphoma showing definite advantages to MRx, clearly indicated the positive benefits of MRx in WM.

However, **Dr. Eva Kimby**, Karolinska Institute, Stockholm, Sweden, pointed out that there is no completed Phase II or Phase III trial in MRx and WM. Furthermore, long-term use of rituximab results in immune compromise, leads to an increased incidence in infections, and may impair vaccination efficacy. Dr. Kimby went on to ask why bother with MRx when WM patients have access to many efficacious options after relapse. Dr. Advani countered by stating that rituximab has never been fully evaluated in a randomized Phase III clinical trial and is nonetheless used as single agent and in combinations without any hesitation in the treatment of WM. Dr. Advani also brought up the often ignored quality of life issues that WM patients face every day and argued that these issues should not always hold second place to absolute scientific validation, particularly in terms of rigorous Phase III randomized clinical trials that are so difficult to do in WM given the relatively small number of patients. The questions and comments from the audience certainly mirrored the ongoing controversial nature of the MRx debate.

**FOURTH DEBATE: “Should autologous stem cell transplant (ASCT) be a frontline option for WM?”**

**Dr. Charalampia Kyriakou** of the Royal Free Hampstead Trust in the UK, a recognized expert in transplants and WM, argued in the affirmative. Once again, due to the low numbers of WM patients involved in Phase III trials, it is difficult to interpret data on the use of ASCTs in WM. Furthermore, ASCTs have been used as “last resort” for many WM patients, leading to a bias in the outcomes. Not only do high risk WM patients have a very poor prognosis, but the duration of response for most non-ASCT treatments is lower than with ASCTs (66-82 months). Dr. Kyriakou also noted that newer ASCT protocols have high efficacy, reduced toxicity, lead to prolonged survival, and favor quality of life issues for the WM patient. It is better to go early in ASCT than as last resort, and young WM patients should definitely consider harvesting stem cells in the event that an ASCT is chosen as treatment.

**Dr. Jean-Paul Fermand**, Hôpital Saint-Louis, Paris, France, did not disagree that ASCT was an efficacious option for

WM patients but did argue against using it as a frontline option, preferring to reserve it for second line treatment for the young relapsed high-risk patient. He did state that WM patients should choose stem-cell sparing frontline treatments such as his preferred RCD (rituximab, cyclophosphamide, dexamethasone) combination to preserve the option of an ASCT in the future. Dr. Fermand also questioned if ASCTs might eventually be replaced by lower intensity non-myeloablative allogenic transplants in the near future.

**FIFTH DEBATE: “Should allogenic transplant represent a standard of care option in WM?”**

Two of the most respected experts in transplants and WM clashed over this topic. **Dr. David Maloney** of the Fred Hutchinson Cancer Center in Seattle, Washington, remarked that in autologous transplants the efficacy of the treatment is due to the high dose chemotherapy given prior to the stem cell infusion and that it is very difficult to completely “sanitize” the bone marrow of a WM patient prior to stem cell infusion. This contrasts to the newer “mini-allo” or low-intensity non-myeloablative allogenic transplants used in ever increasing frequency where the chemotherapy regimen is reduced and the donor stem cells produce a graft versus tumor effect that may actually lead to a complete eradication of the disease – a cure. Furthermore, the mini-allo transplants are less toxic and can be used in older patients. Dr. Maloney did go on to say that the conventional allogenic transplants were no better than ASCTs.

**Dr. Bart Barlogie**, Myeloma Institute for Research and Therapy, University of Arkansas, refused to limit himself to any single option in the treatment of WM, preferring to use the most appropriate treatment for the individual patient. However, for the sake of the debate, Dr. Barlogie did refer to his considerable experience in autologous and allogenic transplants in both WM and MM. He reiterated that the data do demonstrate a higher mortality in allogenic transplants compared to ASCTs without any apparent increase in length of remission. He did not disagree that low-intensity non-myeloablative allogenic transplants may hold considerable promise, but he maintained that the protocols for these mini-allo transplants still need considerable refinement and are not quite ready for “prime time” yet. Dr. Barlogie finally alluded to the current WM treatment recommendations that list ASCTs as second line options and agreed that allogenic transplants still remain an option to be used in a clinical trial setting.

**CONCLUSION AND THANKS TO THE ORGANIZERS**

The amount of information presented at these meetings can be overwhelming. Having attended a few of these conferences, I usually am struck by a few presentations that stand out from the rest because of importance or sheer “wow” factor. In no particular order of significance, here are the “take home messages” from Venice as I see it.





(Items 1-5 of the list below are accompanied by Dr. Sherwood's summary of the pertinent presentation referenced by Session number)

1. **Dr. Roger Owen** from the UK presented a very convincing argument regarding the need for more frequent bone marrow biopsies (BMBs). Given that we have more and more newer targeted therapies that are so specific to certain pathways (and as a result such therapies generally result in fewer side effects), it is imperative to get BMBs prior to starting any new treatment and sometimes even during the actual course of a treatment plan in order to assess the response exactly. Measuring serum IgM levels exclusively is a fool's errand.

SUMMARY OF DR. OWEN'S PAPER FROM SESSION X: This session focused on the – at times controversial – response assessment in WM. As is appropriate in the opinion of this writer, the session began with a presentation by **Dr. Roger Owen**, St. James Institute of Oncology, Leeds, UK. Dr. Owen cautioned that the usual method of assessing response to WM treatment by serial measurements of serum IgM levels is no longer appropriate and can lead to false assumptions given the newer targeted therapies now being developed and used in WM. Specifically, Dr. Owen pointed out that: changes in IgM do not always result in the improvement of symptoms; responses to some drugs (alkylating agents, purine analogues and monoclonal antibodies) are typically slow whereas responses to other drugs (Velcade) can be rapid; great bone marrow responses may be seen in patients with small reductions in IgM due to the selective depletion of B cells and persistence of the plasma cell component of the disease; and, finally, rapid drops in serum IgM levels may be seen with poor bone marrow and lymph node responses in some patients treated with bortezomib (Velcade). Dr. Owen concluded his presentation by suggesting that the assessment of residual bone marrow disease by flow cytometry is a highly effective way to define response independent of IgM levels. In other words, more bone marrow biopsies should be performed in order to truly evaluate ongoing therapy and end-of-therapy response.

2. **Dr. Mathias Rummel** from Germany presented a well-executed Phase III randomized trial comparing the standard R-CHOP versus bendamustine and rituximab (B-R) for WM. It is clear that R-Benda is the new standard: better results, far fewer side effects.

SUMMARY OF DR. RUMMEL'S REPORT FROM SESSION VIII: Dr. Mathias Rummel reported for the German study group on indolent

lymphomas in a multicenter, randomized Phase III study comparing a maximum of 6 cycles of bendamustine plus rituximab (B-R) versus R-CHOP as first-line treatment in various indolent lymphomas including WM. The current standard of care for first-line treatment in patients with advanced indolent lymphoma and WM is rituximab plus chemotherapy (such as R-CHOP). At a median follow-up of 35 months, median progression free survival (PFS) was significantly prolonged with B-R compared with R-CHOP. Decreases in IgM levels were better with B-R, as were increases in hemoglobin levels. The median PFS for 22 WM patients randomized to B-R was not yet reached at time of presentation, whereas the median PFS for 19 WM patients randomized to R-CHOP was 35 months. Four relapses (18%) have occurred in the B-R group and 11 relapses (58%) in the R-CHOP group as of time of the presentation. The B-R regimen was better tolerated than R-CHOP with far less toxicity. The author concluded that B-R should be considered the new standard of care for treatment in WM. Of interest was the well-received announcement that this group is now undertaking a rituximab maintenance study.

3. **Dr. Andy Rawstron**, colleague of Dr. Owen at Saint James Institute of Oncology, Leeds, UK, delivered a fascinating yet quite sobering lecture on the progression of disease in indolent lymphomas. Drawing predominantly on his experience with CLL, he noted that over time normal B-cells are replaced with abnormal B-cells, even in the setting of an asymptomatic disease state. These findings, which Dr. Rawstron plans to study in detail in WM, give pause to individuals who prefer to watch and wait for extended periods of time without a periodic and accurate gauging of the status of their disease. Ignore appropriate periodic bone marrow biopsies at your own peril. (More on Dr. Rawstron's lecture, *Torch* 12.1, page 10.)
4. **Dr. Guang Yang**, monoclonal antibody “expert” from the prolific research department at the Bing Center for Waldenstrom's Macroglobulinemia, Dana-Farber Cancer Institute, Harvard University, presented a stunning report on the new monoclonal antibody GA101, basically a “super rituximab” that is able to overcome unfavorable genetics that play a large role in treatment failure with rituximab. One can only hope that clinical trials with GA101 in WM are soon to begin and that WM patients line up to participate in this trial testing a very exciting new option in the treatment of WM.

SUMMARY OF DR. YANG'S REPORT FROM SESSION VII: Dr. Guang Yang presented

*Sixth International Workshop, cont. on page 13*





fascinating research on the new anti-CD20 monoclonal antibody (MAb) GA101. This novel humanized anti-CD20 MAb appears to be 2-3 times more effective than rituximab in WM and may be of particular benefit for WM patients with “unfavorable” genetics with respect to FcγRIIIA CD-20 receptor polymorphisms. Future research and clinical trials using this exciting new monoclonal antibody in WM will hopefully be forthcoming in the very near future.

5. **Dr. Fred Hochberg**, relative newcomer to the WM research community but a very experienced and distinguished clinician in neuro-oncology at Massachusetts General Hospital, Boston, has truly started to unravel some of the mysteries of Bing-Neel Syndrome (BNS), a devastating complication seen in ever-increasing frequency in WM patients. I believe that BNS poses a serious threat to WM patients as we push the survival curve beyond 15 and even 25 years!

**SUMMARY OF DR. HOCHBERG’S LECTURE FROM SESSION XV:** The last lecture of the Workshop was presented by **Dr. Fred Hochberg** on the very interesting and worrisome Bing-Neel syndrome (BNS). Although WM produces peripheral neurologic complications in over half of patients, rarely do we see involvement of structures in the brain and spinal cord. Dr. Hochberg and his colleagues reviewed their clinical experiences with BNS together with cases reported by others to accumulate 31 examples of BNS. They subsequently classified these cases as either Group A with evidence of lymphoplasmacytoid (LMP) cells within the central nervous system or Group B with LMP cells absent but symptoms and/or signs explained by an autoimmune mechanism. Of the patients studied, 61% had BNS in the setting of progressive WM when BNS developed subsequent to a diagnosis of WM; a median of 36 months separated a diagnosis of BNS from the initial diagnosis of WM. However, 26% of the patients reviewed had coincident occurrence of BNS and WM at diagnosis. Neurologic symptoms attributable to BNS include cortical dysfunction (memory deficits and behavioral changes), visual field deficits, optic nerve lesions, cranial nerve sensation changes, and amnesia. Spinal cord changes were noted in 67% of the BNS WM patients studied. The treatment of WM in the setting of BNS does offer some hope as 42% of responders sustained a response from 6 months to 4 years while three non-responding patients succumbed within 8 months. Dr. Hochberg commented that BNS may be both over-diagnosed and under-diagnosed, and in order to increase the accuracy

of BNS diagnoses he proposed a registry for WM BNS using criteria provided for the diagnosis of BNS Group A and Group B. These proposed criteria would include cerebrospinal fluid (CSF) flow cytometry and/or immunohistochemistry and light chain quantification, and contrast-enhanced MRI of the central nervous system and the spine.

6. Session XII was devoted to the young investigators who presented their research at the Venice IWWM-6 conference. The promise of better futures for WM patients worldwide is in their hands. These bright individuals must be supported and encouraged to continue their amazing research in WM. We are seeing more and more young (and nervous) investigators present at conferences, and the sophistication of their work is only eclipsed by the obvious interest they have in the pursuit of their research. The IWWMF is proud to help sponsor these young investigators: is there a better investment in the future and prolonged health of WM patients?
7. One of the many statements made, echoed by numerous WM experts at the Venice conference, is the increasing evidence that aggressive treatment for WM may be a better overall strategy than more timid approaches as it results in more complete responses (CR) or very good partial responses (VGPR), and these translate into improved overall survival.

\* \* \*

The success of the Sixth International Workshop on WM is, to no small degree, thanks to the tireless efforts of Dr. Steven Treon, WM researcher and clinician extraordinaire, and of Christopher Patterson and the entire team at the Bing Center for WM, DFCI. The IWWMF is proud to have been a sponsor of this event.

As a trustee of the IWWMF, and as a 10 year+ WM patient, I am very grateful for the incredible amount of work and dedication that everybody involved demonstrated on behalf of WM patients and caregivers worldwide. I very much look forward to IWWM-7 to be held in 2012 in Newport, Rhode Island, USA, and I anticipate many more years of fruitful cooperation between the IWWMF and their close friends at the Bing Center for WM, DFCI. Well done!

Donate and participate.

*Dr. Guy Sherwood is a Member of the IWWMF Board of Trustees, Chair of the IWWMF International Committee, and Member of the IWWMF Research Committee.*

Further information about IWWM-6 is available at:

[www.wmsummit.org/wmwkshop/Venice-2010/Overview.htm](http://www.wmsummit.org/wmwkshop/Venice-2010/Overview.htm)

Workshop abstracts can be accessed at:

[www.wmsummit.org/wmwkshop/Venice-2010/Abstracts.htm](http://www.wmsummit.org/wmwkshop/Venice-2010/Abstracts.htm)



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# RETIREMENT WITH WALDENSTROM'S

BY NORMAN L. THOMPSON, M.D.

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*Tom Thompson (Dr. Norman L. Thompson) was raised in a small rural community in south central Nebraska. Immediately following high school graduation – and the realization that “college at that time would not end successfully” – Tom and*

*Sami the poodle, Patty and Norman L. “Tom” Thompson.*



*four friends enlisted together in the U.S. Air Force. This step launched his four-year career as an aircraft engine mechanic. The year following his discharge from the Air Force was spent at a Buick-Pontiac dealership. At this point in his life prospects for success as a college*

*student seemed brighter, and Tom enrolled in a pre-med program. Three years later he was accepted at the University of Nebraska College of Medicine from which he was graduated in 1967. After a year of internship and another year of general surgery he set off on a thirty-year career of solo family practice that he describes as “fully enjoyable.” In this personal account Tom recalls how a diagnosis of WM in 1997 led him and his wife Patty to another change in direction and to a new life in retirement.*

Since diagnosis in 1997: I am both a physician and a Waldenstrom's 'watch and wait' patient. It is my practice to undergo a complete physical every December, but in 1997 this happened a bit early. During that summer I spent a week in Nebraska 'out on the farm' with three friends whom I have known since first grade. I thought I had started my annual bout of "hay-fever" type allergies aggravated by hanging out in the fields, but the symptoms (usually responsive to prednisone burst and steroid nasal spray) remained unresponsive and lingered. This condition prompted me to run a full metabolic panel, combined blood count (CBC), and so forth in September rather than waiting until December. All was well except for serum globulin. This was one point above high normal.

I filed my results under my desk calendar thinking, "Oh, it's a fluke." Three days later, still nagged by the result, I realized that if the test result came from my patient, I as physician would follow up with the next step. Consequently, I ordered both serum protein electrophoresis and immunofixation electrophoresis. The result: an M-spike. A bone marrow biopsy followed. The BMB showed lymphoplasmacytoid lymphoma, aka WM. CT scan of the chest and abdomen with contrast – even though a doctor I pronounced this 'yuck' – was normal. My oncologist suggested immediate chemotherapy with CHOP and three-year survival or a second opinion with Dr. Alan Saven at the Scripps Clinic in La Jolla, California.

I gathered up lab reports, slides, and scans and visited Dr. Saven who discussed 'watch and wait' and suggested return visits every three months.

I next had the good fortune to have lunch with Rafael Fonseca while attending the annual IWMF Ed Forum in Chicago with Patty. Dr. Fonseca is an oncologist and research scientist at Mayo Clinic in Scottsdale, Arizona, and limits his practice to patients with multiple myeloma and WM, along with full-time research. In the care of Dr. Fonseca, I have now graduated to an annual visit. Diagnosis is smoldering Waldenstrom's.

I was 61 years old at diagnosis and had contemplated (but not promised myself) retirement at age 65. My wife (then my office manager) and I decided to marry and begin planning retirement, having come to the realization that the stress of maintaining a solo family practice was exacting a toll on both of us. That toll – two malpractice suits (both dropped), the increasing encroachment of bureaucratic paperwork, decreasing revenue, increasing overhead (you get the picture!) was just the short list of stressors. On October 1, 2002, when I was 65, we left our thirty-three year old solo practice in the hands of a young and ambitious internist, sold my Harley, sold our houseboat, and decided to see what life would be after working all our lives.

Our retrospection tells us the diagnosis may have been one of those "blessings in disguise" as our life now belongs to us and no one else. We have the time to pursue hobbies, take naps, eat healthy, sleep well and late, and say "NO" and mean it. Yes, we ponder expenses, Medicare and its changes, and the 'what ifs' of the disease. However, the good outweighs the bad, moment by moment.

My colleagues bet good money I would come back to work after three or four months of retirement. They lost. I continue with a regular exercise routine (one I have had all my life) plus we share a pool and tennis courts with great neighbors. There is a nearby park with two small lakes and easy access to the irrigation canals where I ride my bike or recumbent trike (20,000 miles since retirement) and avoid the hazards of street riding. Still the mechanic after all these years, I build and fly remote control airplanes. Recently I exchanged the Smart Car (self-customized!) for a custom red-and-black topped Mini Cooper. Our grandchild, now two years old, is another great source of enjoyment.

I visit Dr. Rafael Fonseca here in Arizona every summer and hope for, and even expect, a 'high five' after every visit. We have not lost sight of 'watch and wait.'

Perhaps my wife Patty and I appear strange to outsiders who question our laid-back lifestyle after retirement. But we are not Pollyanna-ish about "our disease" (it is a partnership of sorts). We maintain a thankful attitude for each day and will take the future as it comes.



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# FROM IWMF-TALK

BY MITCH ORFUSS

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During an especially cold winter between 2010 and 2011, TALK took a turn toward the science of WM, cutting across a wide swath of topics. What follows are some of those TALK-topics generating the most online discussion.

## NEUROPATHY – WHOLE-BODY AND OTHERWISE

For many of us, PN (peripheral neuropathy) is a familiar devil affecting feet, legs and even hands. **Bret Blakeslee** asked about full-body neuropathy: if full-bodied is so unusual in cases of WM, is the cause of this neuropathy something other than Waldenstrom's? Bret was hoping to hear back from the medically trained readers of TALK. Several "admittedly not medically trained" voices replied. **Colin Perrott** wrote that, backing off from Waldenstrom's as "devil of all trades," a search for "whole body neuropathy" returns a topic entitled "small fiber neuropathy" which affects the skin and is thus widespread. Now you have to divert around all sorts of naturopathic trenches. But beyond comes the information that small fiber neuropathy has many causes. **Scott K** offered a reply after visiting his neurologist, having had a burning sensation on the legs and torso. (Scott also gets it on his arms and face from time to time but not as often) He has been complaining about this with no satisfactory answers till his neurologist said that Scott's affliction is, just as Colin provided, "small fiber neuropathy." Scott was told that this burning sensation was most likely caused by a small protein that wears down and erodes the myelin sheath encasing the small nerve fibers below the skin. Of the several different types of neuropathy, the small fiber one is apparently a better one to have. My experience before being diagnosed with WM was itchiness almost everywhere, most intense peripherally but nearly universal. **Gregg Robertson** countered that for him the direct cause seems to be WM; as the WM was brought under control, his itching subsided. **Sue Pruce** offered that she has PN mostly in her feet and lower legs. Sue was then being treated with BDR (Velcade, dexamethasone, and Rituxan). Her skin, especially on the lower half of her body, is very sensitive. Sue sometimes feels she has flu, with "achy skin", and gets what she calls "the Velcade aches" two days after treatment. That intense "achiness" then subsides and she is left with a feeling of skin sensitivity. Sue asked if that would be considered full-body neuropathy? If so, Sue infers that it is related more to her treatment regimen than to WM itself. **Colin Perrott** then replied that Sue needs to search the term "small fiber neuropathy" to find information about the situation she describes. Colin believes that Velcade was the culprit in Sue's case, suggested a consideration of dose-reduction, and provided links to articles for Sue.

## BONE-MARROW BIOPSY (BMB)

The accuracy of any one bone marrow biopsy has long been debated on TALK since this procedure is the defining test for presence of WM. **Ron Draftz** offered this: a patient needs to consider cellularity (% volume occupied by cells in marrow) along with infiltration (% tumor cells) to estimate "tumor

burden." For example, someone with 100% cellularity, instead of the 50%-or-less cellularity common to 60+ years old patients, would have twice the tumor burden of a patient with 50% cellularity for the same infiltration %. So: non-homogeneous cellularity also affects tumor burden, though it does not affect the infiltration estimate (which is based on a cellular type ratio). Key is to consider both cellularity and infiltration in assessing total tumor burden and the accuracy of those independent estimates. We must recognize that infiltration % is an estimate that normally should be reported as a range rather than a single value. Some pathologists use a quick count of total cells versus tumor cells to obtain a better semi-quantitative number for the reported infiltration rate. **Dr. Tom Hoffmann** answered that, in reality, "disease burden" is rarely used in our disease to determine treatment because this disease is best treated by symptoms and non-tumor labs (for example, hematocrit). Certainly, people with higher burdens tend to get treated earlier, but that may also be related to presence of symptoms. The only place tumor burden is useful is when using bone marrow to decide whether a treatment is working. Sooner or later we will be able to determine burden by some non-invasive type of scan. For now, the single-puncture BMB will remain the gold standard.

## CHOLESTEROL LEVEL

**Carol "dacamar"** asked if anyone has information about how WM affects cholesterol measurement. Carol thought she had read in the past that the measured lab values may not be accurate in cases of WM. **Sue Pruce** then added that she would also be interested in this because her total cholesterol has always been in the 120's, yet her recent value was 263 with HDL 75 and LDL 163. She had received 6 cycles of BDR and wondered if her values were so high due to the chemo or perhaps due to the WM. **Chaz** in Cleveland said he has a history of borderline high cholesterol, and occasionally higher spikes, but levels are normal since having blood drawn for WM. **Dr. Jacob Weintraub** replied that the observation about WM and low cholesterol has been known and discussed on TALK for several years. In fact, he continued, Dr. Treon even ran at least one clinical trial using a statin drug but results weren't good enough to consider use of statin drugs as a regular WM treatment. Jacob noted other discussions about whether low cholesterol measurement represents a true lowering of cholesterol or just the elevated IgM interfering with the lab test to give an artificially low reading. Jacob has been inclined just to accept his extremely low cholesterol as a small benefit of our unusual disease. **Eunice Johnson** said the question about WM and cholesterol levels resonated with her as well. When diagnosed in 2004, Eunice's total number was 175, while it had been around 230 since 1988. After her treatments ended in 2008, her total cholesterol was 330, but it later it fell to around 225. Eunice finally recalled a posting by **Daniel Hachigian**, who said this topic has not been fully resolved. Daniel referenced Dr. Ghobrial, who said

*From IWMF-Talk, cont. on page 16*





that IgM can interfere with HDL cholesterol and bilirubin readings. But only one out of the five samples studied was inaccurate. **Stuart Usdan** wrote that his entire WM journey began because of cholesterol! Stuart had a history of high cholesterol and when it was time to be tested his total cholesterol had dropped from 240 to 110 in a little over a year. Stuart sensed strongly that something was wrong. He was retested a few weeks later and found that it had dropped further. Given diet, exercise and family history, he knew this was a mistake. Stuart's IgM at the time was up to a very high 12,000. None of the oncologists Stuart saw were sure why this happens, but they were all familiar with the cholesterol phenomenon in WM.

### MOUTH SORES

**Michael Luttrell** noted that quite a few TALK writers have mentioned mouth sores, mainly in regard to treatments with bendamustine or other pathway inhibitors. At the time Michael was not in treatment but seemed to be the victim of multiple episodes of mouth sores, which he believes were canker sores turning to oral herpes. Michael's first herpes infection erupted five years prior and was particularly pervasive. Subsequent episodes were less so but still uncomfortable to painful and lasted from several weeks to a couple of months. Acyclovir seemed to have no effect. Michael used a topical, Zilactin B, for temporary relief; nothing else seems to do much good. So he asked if readers would weigh in on drugs prescribed for treatments of this condition so he could discuss them with his own doctors. **David Sellers** offered that he too suffers from canker sores during times of stress and so knows how painful they are. Two prescriptions which helped are: Viscous Lidocaine 2%, which eases the pain, and dexamethasone oral solution 0.5 mg per 5ml, which also eases the pain and, he thinks, promotes faster healing.

### RITUXAN AND JOINT OR BONE PAIN

**Lois Smith** writes that when taking single Rituxan she had severe bone pain during the first infusion. At Lois' most recent treatment her vein collapsed as the pain started, and because the nurses present could not find a replacement vein they threw away most of the infusion – down the drain. Because of this Lois' doctor did not consider that she had had a full infusion, calling the little bit that first day a "taste." The next week Lois had no pain receiving Rituxan and no collapsing vein. Lois wonders out loud whether others who experience bone pain from infusions could be given the same "week-ahead-of-the-actual-infusion taste" as she received. She also asks whether the producers of Rituxan could

package a "taster dose." Lois' doctor told her that her body had gotten used to that little bit and therefore "recognized" the next week's infusion, which did not cause a painful bone reaction to the normal dose. **Robert Reeber** replied that Lois had made an astute observation and wondered if Biogen-Idec and Genentech would forgo their \$8K income for each infusion to run an expensive trial on a much cheaper "tasting" dose. Unfortunately, Robert continued, we are in the hands of a complex regulatory and profit-motivated environment. One might think the oncologist, if he or she knew enough or would work with an immunologist who was knowledgeable, would try such a small trial on 5 to 10 patients. But then, again, the doctor would have to get releases from all the patients to limit their personal liabilities and also from their hospital committees. **Anita Lawson** replied that she works for a specialty pharmacy and infusion company and knows that the cost of Rituxan is \$583 for 100 mg (for her that translates to getting about \$3500 worth.) What the facility bills to insurance is, she continued, another matter. Anita got IV Benadryl and decadron as pre-meds, and the hospital billed her insurance company \$23,000 for everything. Reimbursement is about \$5200. It's all the intermediate steps that drive up the cost, not necessarily the drug itself (although it is pricey). **Pat O'Brien** reported that her husband **Steve** completed a 4-infusion protocol on November 26 (second series this year) and two weeks later had severe spinal pain that ultimately ended him up in the ER. CT scans, X-rays, and other tests suggested severe spinal arthritis. Since Pat's husband had had no prior back pain, she asked if there is a possibility that Rituxan itself could have been the initiating factor. There was no speculation from the experienced supervisors there that this would be a possibility.

### BENDAMUSTINE – SINGLE AGENT AND IN COMBINATIONS

Bendamustine is getting a lot of buzz recently. **Anita Lawson** wrote that she recently learned that her 3-year course of Rituxan maintenance had evidently lost its effectiveness (her IgM has risen from 1800 in August 2010 to 3000). A CT scan showed enlarged lymph nodes and she was becoming mildly symptomatic; so her oncologist recommended treatment – bendamustine + Rituxan – before her condition worsened. Though Anita was not especially looking forward to her fourth treatment protocol, it was nevertheless encouraging for her to hear about such wonderful results for bendamustine, especially the absence of side effects. **Malcolm Walpole**

From IWMF-Talk, cont. on page 17

### 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](mailto: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](mailto:iwmf-talk@lists.psu.edu)

2. Contact Peter DeNardis at [pdenardis@comcast.net](mailto:pdenardis@comcast.net) and provide your full name





seconded the vote for bendamustine to treat WM. He'd had 8 cycles finishing in Feb 2010 and progressed well since then. Malcolm's HgB, which was ~7 when he started, is now 14.4, the highest it has been for 15 years; and his other blood fractions were improving. His IgM reached its lowest level in 15 years. Side effects were extremely mild. Malcolm's oncologist has said he will use it a second, and possibly a third, time if it remains effective. If Malcolm gets the reported 60 months' remission each time, he says he shall be a very happy (and old!) man! **Veikko Hoikkala**, our support group contact for Finland, wrote that because he had encountered very uncomfortable side effects with rituximab his doctor decided to try ofatumumab (Arzerra) as a replacement. Results were encouraging: IgM down from 2800 to 180...HgB from 10 up to 14.8...CRP down from 40 to 1 – all this in about 2 months. Bendamustine was prescribed because it is less toxic than CHOP. Veikko experienced no side effects with this combo. **Mike Dewhirst** added that leading edge clinicians believe that the bendamustine + Rituxan/CD20-antibody combo is rapidly becoming the new “norm,” with better response rates and lower toxicities. And the goal of treatment seems to be shifting to lifelong management of our disease. **Ron Ternoway** chimed in that there is a Phase III clinical trial underway with either bendamustine or bendamustine and ofatumumab in 45 centers worldwide. **Ann Betts** lives in the

UK and wrote that she too is being treated with bendamustine and so far it appears to be doing her some good. Ann has to pay for it out of pocket since her National Health Service refuses. She is charged the equivalent of US \$1,200 for 150 mg, i.e., more than she has seen quoted. On top of this charge there are other costs for accommodations, saline, and more. However, it was a matter of bendamustine or nothing for Ann, after she'd become resistant to Velcade. And, unfortunately, Rituxan alone had not worked for Ann either – as a solo agent or in combination with Velcade. Ann found bendamustine easy to tolerate, with little in the way of side effects apart from some itching and queasiness the first couple of rounds.

Other “TALK Topics” over the long winter months revolved around such considerations as itching, low platelets, osteoporosis, tinnitus, chronic cough, resting heartbeat, hair loss, peripheral neuropathy, paraprotein levels...you get the drift! TALK readers are insatiable consumers of every aspect of the WM experience, and this summary never does adequate justice. As always, of course, “caveat emptor” as you read TALK or the *Torch* summary. TALK is not for the practice of medicine – but for opinions and support.

I wish you the best of health until next time.

## Losses from the circle of IWMF-TALK participants touch us all

Two recent deaths evoked special comments among the TALK postings.

**Nancy Lambert**, co-editor of the *Torch* column *Cooks Happy Hour*, former support group leader in eastern Pennsylvania, creative fund-raiser for the IWMF, and frequent TALK participant, passed away in early January. In tribute to Nancy's warm and generous spirit **Linda Jane** wrote the following:

“When I was diagnosed in July of 2008, I contacted LLS for more information about WM. They assured me that I would be contacted through their “first connection” program. With the limited number of people with WM, I thought I would have to wait a long time. I received a call within 24 hours. Nancy was my first connection through LLS and she had such kind words for me, giving me hope. We had many conversations and the first thing she suggested was getting on this chat group. I was so blessed to get those rays of hope from such a kind person. I am thankful for the opportunity to learn so much from her. I continue to have hope and pray that I will live a long time with the same kind of dignity and grace that she shared with me.”

Over the recent years **Daniel Hachigian** has been a regular and valuable participant in IWMF-TALK. When his wife **Martina Kreutzer**, physician and former member of the IWMF Research Committee, was diagnosed with WM, Daniel rose to the challenge and focused his energy and education on cracking the riddles of our disease with the hope of saving, or at least prolonging, the life of Martina. He generously shared the information he gathered and presented it in his frequent posts with insight and clarity. And when Martina's death was made known, many voices on TALK blended their condolences with gratitude to Daniel. **Gerri McDonald** spoke for all of us when she wrote:

“I can hardly express how shocked and saddened I am to hear of Martina's death. Daniel has been such a faithful and helpful contributor to our talk-list, but there was never any doubt that his primary concern was finding new information that would help his wife, Martina. Through Daniel, we came to care deeply about both of them and their young family. Please extend my deepest condolences to Daniel. And my thanks... because of his dedication to Martina he's provided all of us with much new information and understanding about WM. I consider him to be one of this list's primary authorities on scientific matters. I hope he knows that we love him as a part of our ‘family’.”



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# COOKS HAPPY HOUR

BY PENNI WISNER

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Even in sunny CALIFORNIA, we've had the heat going full blast. Not that there's a competition for cold weather going on. The sun, however, peeked out today after a week of downpours and lit up my abandoned garden. I gave up (for now) when snails took all of two days to mow down the early February lettuce starts. And the dog, curious about the smells from fresh compost, dug up the few rows of seeds I'd gotten around to planting.

However, all is not entirely lost. Garlic and shallots, planted in another rainstorm last October, have grown and so far have survived the various animal threats. Garlic, like the human baby, is a nine-month crop; it won't be until summer that I can harvest and discover what, if anything, I have out there. Meanwhile, I depend on farmers markets for seasonal produce. At this time of year that includes lots of alliums: chives, green garlic, spring onions, and leeks, plus new crops of radishes, and freshly dug potatoes. Soon, we will have asparagus, too. All of these are juicy, sweeter versions of their later season selves.

Green – or spring – garlic is immature garlic and looks very like young leeks or green onions. Its appearance gives rise to one of the very easiest Cooks Happy Hour snacks ever. And one that you and your guests will fall on with gusto. Unless you happen to be one of those unhappy people who are sensitive to garlic. Actually, the dish can be done all year round but is prettier this time of year simply because you can use the greens of green garlic (as long as they are not dried out or tough) as well as the white and pale green parts.

So, forthwith: Take a 6 to 8-ounce log of fresh goat cheese and put it in a deep dish. Finely slice 1 – or more! – stalks green garlic into very thin rounds. Put them with about 1/2 cup olive oil in a small saucepan and place over medium heat. Cook the garlic until it softens. Pour the mixture hot over the goat cheese and serve immediately with crackers or flatbread. If all you have are garlic cloves, do not despair. Simply chop a bunch of them very finely and add to the olive oil. Cook

them until they have turned pale gold and are very tender. Be careful not to overcook and burn the garlic as it becomes decidedly unpleasant. If you have fresh chives or scallions, finely slice them and add to the olive oil for the last minute or so of cooking. You can also add fresh herbs – a little minced rosemary, chopped parsley, oregano, thyme, or mint – at the last minute as well. And I will since I do have those in the garden, most likely because they thrive on neglect.

You can also dispense with the cooking part altogether and mash the goat cheese with the green garlic, salt and pepper to taste, a splash of olive oil for smoothness, a pinch of freshly grated lemon zest, and whatever fresh herbs you have on hand. I particularly like chives, parsley, thyme, oregano, mint, tarragon, etc, etc. I don't think there's one I don't like. Plus using different herbs gives you a new flavor every time you make this.

You can also vary this concoction by using a blend of goat cheese and Greek-style nonfat, plain yogurt. Or sour cream – or even crème fraîche for luxury. Or use ricotta, alone or in a mix with yogurt. If you are counting calories, use low-fat and non-fat versions of sour cream, ricotta, and yogurt.

Keep a vat – or perhaps all you need is a small container – full of this herb-cheese spread to make instant hors d'oeuvres by spreading it on crackers, flatbread, and toast. You can also run the topped toasts under the boiler until the cheese melts if you'd prefer something warm. This makes an outstanding accompaniment to soup and salad. Or steam those freshly dug potatoes and toss them while warm with some of the herb-cheese mix. Or oven-roast the fresh asparagus spears and serve them with your herb-cheese. And don't forget those radishes. Use the herb-cheese as a dip for them, or cut them in half and sauté them quickly and toss with the cheese. Or grate them finely and mix them into the cheese.

*Our motto: Eat Well to Stay Well*

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# MEDICAL NEWS ROUNDUP

BY SUE HERMS

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**Humanized Anti-CD40 Antibody in Preclinical Testing** – CD40 is a surface antigen highly expressed in various B-cell malignancies and represents a target for immunotherapy by an anti-CD40 antibody. A study from Christian-Albrechts-Universität in Germany reported the development of a humanized anti-CD40 antibody that has significantly enhanced anti-tumor activity through the mechanism of antibody-dependent cell-mediated cytotoxicity (ADCC). This antibody was compared to rituximab in B-cell lymphoma,

leukemia, and multiple myeloma cell lines and was superior in enhancing ADCC activity.

**Phase II Trial Results Presented for Combination Rituximab and Epratuzumab** – The Cancer and Leukemia Group B presented Phase II clinical trial results of combination rituximab and epratuzumab (anti-CD22) therapy for follicular lymphoma. This therapy was used as frontline

*Medical News Roundup, cont. on page 19*



treatment for 60 patients. Both rituximab and epratuzumab were administered in a series of 8 doses over 9 months. Fifty-three patients completed therapy, with an overall response rate of 84%, including 33% complete responses. Most toxicities were minor and included fatigue, nodal pain, and itching, while major toxicities included thrombosis, shortness of breath, and pulmonary problems.

**Study Identifies Rate for Rituximab-Associated Hepatitis B Virus Reactivation** – Rituximab use has been associated with hepatitis B virus (HBV) reactivation; however, the scope of this association has remained largely undefined. Northwestern University reported the results of a comprehensive literature search of published rituximab-associated HBV infections. One hundred eighty-three cases were identified; the median time from last treatment to HBV reactivation was 3 months. Compared to non-rituximab treated patients, this study identified a more than 5-fold increased rate of rituximab-associated HBV reactivation.

**Anti-CD19 Antibody Tested in Phase I Trial** – MorphoSys AG and Xencor, Inc., have announced Phase I testing of their monoclonal anti-CD19 antibody MOR208 in chronic lymphocytic leukemia patients. CD19 is highly expressed in non-Hodgkin's lymphomas and B-cell leukemias. In preclinical studies, MOR208 was well tolerated at various dose levels, elicited immediate and sustained B-cell depletion, and showed strong anti-tumor potency.

**Another New Anti-CD20 Antibody Reported in Preclinical Studies** – A report from the Netherlands discussed HuMab-7D8, a monoclonal antibody directed against a different portion (epitope) of the CD20 molecule than rituximab. This new antibody more efficiently killed cells with low CD20 expression than rituximab and may represent a way to treat patients who do not respond well to rituximab therapy.

**Phase III Trial Compares Bendamustine-Rituximab with Fludarabine-Rituximab** – The Study Group Indolent Lymphomas, Germany, presented its final Phase III trial results of bendamustine-rituximab (B-R) compared to fludarabine-rituximab (F-R) in patients with relapsed follicular, indolent, or mantle cell lymphoma. Progression-free survival was 30.4 months in the B-R group vs. 11.2 months in the F-R arm. Overall response rate was also significantly higher with B-R than with F-R, 82% vs. 49%, respectively. Overall survival was similar between the two arms. A median of 6 cycles of chemotherapy was given. No significant differences were observed between groups in the rates of hair loss, mouth sores, allergic reactions, peripheral neuropathy, or infectious episodes. The incidences of neutropenia and leukopenia were somewhat less in the B-R group.

**Incidence of Excess New Cancers Reported in Multiple Myeloma Patients Treated with Lenalidomide** – Researchers at the American Society of Hematology meeting reported an excess of new cancers in multiple myeloma patients treated with lenalidomide (Revlimid). This secondary malignancy statistic emerged in a study of three randomized trials that

otherwise demonstrated clinical advantages for lenalidomide maintenance therapy in myeloma. Researchers intend to closely monitor this situation to see if further studies will confirm these observations, possibly altering the risk-benefit ratio for using lenalidomide in myeloma.

**Rituximab May Reduce Incidence of Graft-vs.-Host Disease in Allogeneic Transplants** – Approximately half of patients who receive an allogeneic stem cell transplant for leukemia or lymphoma develop the complication of graft-vs.-host disease (GVHD), which can be life threatening. GVHD develops because of genetic differences between the donor and the recipient, leading donor immune cells to recognize recipient cells as foreign and attack them. Current attempts to reduce GVHD development and severity include immunosuppressants and T-cell depletion. The Dana Farber Cancer Institute presented a new approach that focuses on prophylactic rituximab to deplete B-cells. Rituximab use reduced the incidence of GVHD to 44.6%, lower than has been seen historically. The incidence of chronic GVHD that required treatment with corticosteroids was only 31.2%, a substantial reduction from historical levels of nearly 100%.

**Treatment of Asymptomatic Follicular Lymphoma with Rituximab May Improve Progression-Free Survival** – For the past three decades, the standard for patients with asymptomatic, advanced-stage follicular lymphoma has been a watch and wait approach. Researchers funded by Cancer Research UK randomized a total of 462 patients with asymptomatic follicular lymphoma to one of three treatment arms: 186 underwent watch and wait, 84 received rituximab once a week for four weeks, and 192 received rituximab once a week for four weeks followed by maintenance rituximab therapy that was given every two months for two years. The primary endpoints of the study were time to initiation of new therapy and overall effect on quality of life. Three years into the trial, a decision was made to discontinue the second arm of the study as evidence of the efficacy of rituximab maintenance therapy became apparent, and additional patients were enrolled either in arm 1 or arm 3. With a median follow-up of 34 months, the study found that fewer patients required a new therapy in both rituximab-containing arms; at three years of follow-up, 49% of patients in the watch and wait arm had not required new therapy, whereas 80% of patients in the second arm and 91% of patients in the maintenance arm had not required new therapy. At this time, 96% of patients in the study remain alive, and there is no difference in overall survival among the arms. The study demonstrated that treating asymptomatic patients with rituximab can significantly prolong the time until a patient may require chemotherapy.

**Additional Information on BiovaxID Vaccine for Follicular Lymphoma Presented at ASH.** Biovest International, Inc., presented Phase III clinical trial results of BiovaxID, a personalized cancer vaccine for follicular lymphoma patients. In the study, patients who received BiovaxID demonstrated





an average of 13.6 months of additional disease-free survival (duration of remission) compared to patients who received a non-specific control vaccine. The data, reported at ASH 2010, demonstrate that the improved disease-free survival depends upon a specific variant of the tumor-derived protein fragment present on each patient's BiovaxID vaccine. In lymphoma, this protein variant is either of the IgM or IgG type. Approximately half of the patients in the Phase III trial had tumor cells bearing the IgM protein and half the IgG protein. New analysis revealed that patients receiving the vaccine manufactured with the IgM isotype experienced a dramatic disease-free survival benefit of over two years, while patients receiving the vaccine manufactured with the IgG isotype did not.

**Companies Developing "Generic" Rituximab** – Rituximab had worldwide sales of about \$5.6 billion in 2009 for all indications, including non-Hodgkin's lymphoma. Its patent protection expires in the U.S. in 2018 and elsewhere in the world in 2013; consequently, several companies are announcing plans to develop "generic" versions of rituximab. Although no generic monoclonal antibodies have been approved in Europe or the U.S., the U.S. health care reform law passed last year gives the FDA authority to approve copies of biological drugs. Companies will have to submit their products to human trials, although they will usually be less extensive than those needed for the approval of a branded antibody. Among companies developing generic forms of rituximab are Teva Pharmaceutical Industries Ltd. of Jerusalem, Dr. Reddy's Laboratories Ltd. of India, Novartis AG's Sandoz, and Spectrum Pharmaceuticals, Inc.

**Rituximab Maintenance Approved for Advanced Follicular Lymphoma in Europe and the U.S.** – Both Europe and the U.S. have approved rituximab as a maintenance therapy for patients with advanced follicular lymphoma who respond to initial treatment with rituximab plus chemotherapy. This latest approval was based on data from a Phase III PRIMA trial, sponsored by the Groupe d'Etude des Lymphomes de l'Adulte, which enrolled 1,217 patients with previously untreated advanced follicular lymphoma. Rituximab maintenance was given every two months for a period of two years; maintenance treatment nearly doubled the length of

time of progression free survival compared to those patients who were under observation only.

**Phase II Trial Reports on Bendamustine, Rituximab, and Bortezomib Therapy** – A multi-center U.S. study reported on Phase II results of the activity and tolerability of bendamustine, rituximab, and bortezomib in patients with relapsed indolent and mantle cell non-Hodgkin's lymphoma. Six 28-day cycles were planned. Of the patients evaluable, 83% achieved an objective response. With a median follow-up of 24 months, progression free survival was 47%. Common toxic events were nausea, neuropathy, fatigue, constipation, and fever.

**Proposed Legislation Will Deal with Cancer Drug Shortage in U.S.** – New proposed legislation in the U.S. will require prescription drug manufacturers to give early notification to the U.S. Food and Drug Administration of any incident that would likely result in a drug shortage. Ongoing shortages, the worst in recent years, currently affect around 150 drugs that are deemed medically necessary, including many chemotherapy, anesthetic, and analgesic agents. Oncology has been hit hardest, and the shortages are placing cancer patients at risk. Among the cancer drugs in short supply are carboplatin, cisplatin, doxorubicin, etoposide, leucovorin, nitrogen mustard, and vincristine.

**Subcutaneous Rituximab to Be Assessed in Phase III Trial** – Halozyne Therapeutics, Inc., and Roche announced that the first patient has enrolled in a Phase III trial using subcutaneous rituximab and Enhance, a recombinant human hyaluronidase enzyme, for follicular lymphoma. If successful, this technology will allow patients to receive rituximab in less than 10 minutes via a simple subcutaneous injection at their physician's office. It is hoped that offering this treatment outside of the IV infusion center or hospital setting could reduce costs.

*The author gratefully acknowledges the efforts of Arlene Carsten, Peter DeNardis, Mike Dewhirst, Gareth Evans, Daniel Hachigian, John Paasch, Colin Perrott, Howard Prestwich, and Bert Visheau in disseminating news of interest to the IWMF-Talk community.*

### What is the Telephone & E-mail Network?

The concept of putting WM patients in touch with each other originated with IWMF Founder Arnie Smokler.

When you were newly diagnosed and first made contact with IWMF, you may have received a list of telephone numbers and e-mail addresses of other WM survivors and caregivers in your area. Today, the Telephone & E-mail Network remains a valuable resource, providing comfort and reassurance, especially for those who do not have Internet access. Additionally, this method of networking is useful in the formation of support groups.

The membership/giving form enclosed with your newsletter has boxes to check if you wish to participate. The same opportunity to sign up is available when you join or renew your membership online at [iwmf.com](http://iwmf.com).

Participation means you are willing to share your e-mail address and telephone number with other WMers nearby. Members who indicate they do not wish to share their contact information will not appear on the Telephone & E-mail Network list.

The Telephone & E-mail Network list for your area is available upon request from the IWMF business office.





# FIRST WMUK LONDON SEMINAR: A GREAT SUCCESS

BY ROGER BROWN, PATIENT REPRESENTATIVE, WMUK

*Dr. Shirley D'Sa of University College Hospital, London, conference organiser and speaker.*



speaker worked to a brief by seminar organiser Dr. Shirley D'Sa of University College Hospital, London, and kept in order by Rita Flatley, specialist neutropenia nurse at the Brompton Hospital.

The keynote talk was given by IWMF International Committee Chair Dr. Guy Sherwood, outlining IWMF achievements and latest updates from the October Venice Workshop and setting the friendly, optimistic mood of the day. Dr. Roger Owen from Leeds followed with a masterly demystification of WM whilst Dr. Shirley D'Sa outlined the growth in interest in WM, current therapies, and the detailed treatment algorithm used at London's University College Hospital WM clinic. She strongly encouraged similar approaches throughout the country. After a quick buffet networking lunch, veteran patient Roger Brown put forth his view, stressing the need to be informed about treatment options, keeping records, being positive and living life to the full.

Dr. Michael Lunn from the National Hospital for Neurology brought to life basic biochemistry and physics of neuropathy and its treatment – often overlooked by Doctors whilst treating the core problems of WM. Dr. Saul Berkovitz of the Royal London Hospital for Integrated Medicine explained the even more elusive causes of the fatigue which from so many suffer and gave us numerous coping strategies.

The Royal College of Pathologists hosted the United Kingdom's largest ever meeting of WM patients, carers and specialist doctors organised by WMUK at the end of January with 120 delegates and a waiting list of 40.

With people travelling from as far as Hong Kong, the day aimed to pack in as much as possible with 8 speakers, follow up questions and a panel discussion – and did not disappoint. Each



*Dr. Guy Sherwood introducing the work of the IWMF to the packed audience at the Royal College of pathologists.*

Dr. Chara Kyriacou from Northwick Park gave an impressive resume of the huge amount of data from the European Bone Marrow Transplant programme – 424 allogenic bone marrow transplants alone – and outlined the rising success rates of both auto and allo transplants. Last but not least was Dr. Rebecca Auer of Barts, London, who gave an uplifting summary of emerging therapies including panobinostat and ofatumumab. Slide presentations from all speakers are on the new WMUK website [www.wmuk.org.uk](http://www.wmuk.org.uk).

This occasion was also the launch event of WMUK, the UK point of contact for WM, a charitable collaboration of patients, carers and WM doctors dedicated to raising the UK profile of WM and helping the estimated 3500 UK sufferers. WMUK is committed to working closely with the IWMF, the European WM organisation, and the UK support group. Two key aims are to speed the patient path from diagnosis to WM specialist and to ensure early treatments do not prejudice later therapies such as transplants.

The event was made possible by a generous grant by the IWMF who supplied copies of their popular publications for the IWMF stand and helped publicise the event. Thanks also to the Binding Site who provide immunoglobulin assay products. Present as well was the UK Lymphoma Association launching their excellent WM fact sheet on WM, also available via the WMUK site. The overwhelming response to the seminar shows the appetite for more knowledge in the UK and planning for the next event has already started.

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*At the IWMF display of publications Guy Sherwood talks to the delegates.*



*Photos courtesy of Roger Brown.*



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# SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

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*Please note: contact information for all support groups is printed on pages 26-27.*

## IWMF CHAPTERS – USA

### CALIFORNIA

#### *Sacramento and Bay Area*

Twenty attended the January meeting including several first timers. **Penni Wisner** gave a great talk on nutrition for WMers, including lots of information about ingredients (good and bad) in “manufactured” food. The main message was “Read the labels” when buying food. Even a simple ingredient like salt often has ingredients added like sugar or anti-caking agents such as magnesium oxide. Members were happy to see Penni again. She was our group leader for ten years. Penni has a website ([www.penniwisner.com](http://www.penniwisner.com)) which many might find useful. There are healthy recipes such as “Chocolate, Cherry, Walnut No-Knead Sourdough Bread” (to strengthen the mind-body connection!). Penni also writes cookbooks with famous chefs. The formal presentation was followed by a break for great snacks including member **Eugene Turner’s** gluten-free carrot cake and Penni’s celery root, apple, and walnut salad. The next meeting is planned for April with a report on the WM Patient-Physician Summit in Orlando, Florida from **Beverly Bloss** who will have attended.

### COLORADO & WYOMING

The group turned out in force (70!) for a meeting in February co-sponsored with the Leukemia & Lymphoma Society which graciously provided refreshments, sweets, and healthy munchies. Lynn Callaway, Patient Services Manager at LLS, was instrumental in the success of the meeting. The group filled the theater provided by the Colorado Blood Cancer Institute at Presbyterian St. Luke’s Hospital to capacity. **Dr. Jeffery V. Matous**, who attended the Sixth International Workshop on WM (Venice, Italy, October 2010), reported on

the event: “I attempted to review an immense body of data to a very enthusiastic and knowledgeable WM audience. I summarized what I felt were the most germane and interesting presentations.” A long Q & A followed. At the meeting’s conclusion, one attendee said, “I’m more optimistic than even before.” The Colorado & Wyoming group is exploring the creation of smaller, regional groups, specifically: one in Colorado Springs (south of Denver) and a second in the northern Colorado/Wyoming region. The next meetings will be in late spring or possibly in July subsequent to the IWMF’s Minneapolis Educational Forum in June 2011.

### FLORIDA

#### *Southwest Florida*

The very first meeting of the group was held some years ago in a small health club in Sarasota. Group leaders **Herb** and **Marge Kallman** mailed 75 postcards, made many phone calls, and sent e-mails. Fifteen people attended that initial meeting. The next year the group rented the meeting room at the Hampton Inn in Sarasota for 100 people. Sara McKinnie from the IWMF office was very helpful in organizing the meeting and Dr. Steven Treon was the speaker that year. The very successful format has been repeated every year since. In 2011 the group met, without Dr. Treon, in March and enjoyed the sharing of personal stories.

### GEORGIA

Dr. Leonard Heffner from the Winship Cancer Institute of Emory University spoke at the group’s February meeting at the Wellness Center in Sandy Spring. Dr. Heffner discussed the latest treatments and research presented at the International WM Venice Workshop.

*Support Group News, cont. on page 23*

*Dr. Jeffrey Matous reports on IWWM-6 to the Colorado support group.*





## ILLINOIS

### *Chicago Area/SE Wisconsin*

Dr. Stephanie Gregory will speak on new and emerging treatment options on Saturday April 9 at 12:30 pm at Advocate Lutheran General Hospital in Park Ridge. Dr. Gregory is a scheduled speaker at the 4th International Patient and Physicians Summit on Waldenstrom's in Orlando, Florida, in March. The group, especially those who cannot attend the March meeting in person, feels very fortunate to hear firsthand from Dr. Gregory and to have her answer questions afterwards.

## INDIANA

**Gayle Backmeyer** announced that Indiana is working on starting a support group. Co-sponsored by the LLS, meetings will take place in the Society's building in Indianapolis. The first meeting will hopefully take place in the early spring and will focus on learning what members most want to have as the focus of the group.

## NORTHEAST KANSAS & NORTHWEST MISSOURI

The newly formed Kansas City area support group – covering northeast Kansas and northwest Missouri – started meeting in August 2010. They meet every other month at the Kansas University Medical Center's West Campus in Westwood, KS, a suburb of Kansas City. About 20 people have attended each of the three meetings. The nutritionist's presentation at the January meeting sparked lively discussion. The spring meeting was planned for March 26.

## NEW YORK

### *New York City*

At the most recent meeting, the first with **Mitch Orfuss** as the leader-facilitator cum referee (depending on need), there was non-stop discussion of the pros and cons of the clinical trials for CAL101, RAD, and ofatumumab. Mitch described the scene as "like 'High Noon' between DFCI and Cornell-Weill. Kidding. Sort of." Demonstrating the power of questioning, one attendee, agonizing over a decision about which of the three

trials to volunteer for, picked everyone's brains in ways that all present felt was both illuminating and, in a weird way, fun.

### *Northeastern New York/Western New England*

In February, members gathered for their first meeting following a new format: presentation-lunch break-discussion. They began by viewing the Las Vegas IWMF Patient Educational Forum DVD of Dr. Joseph Mikhael's excellent "Rituxan Monotherapy" presentation. After a break for lunch and conversation, **Mel Horowitz** handed out the results of an 11-question, totally unscientific survey sent to our members (33 responded, 28 had had Rituxan, 24 said it was successful). Much discussion ensued; almost everyone attending had had Rituxan and felt that it had been successful, and they added personal stories, knowledge, and questions. Several felt that, when they needed treatment again, they would like to consider ofatumumab. This generated a discussion of the potential expense and concerns about a recent Medicare ruling that seems to indicate that "off label" drug usage will not be covered. There was general agreement that this format resulted in an informative and stimulating session. The next gathering is purely social: the annual "pig out" luncheon, March 26, at a Chinese buffet.

## NORTH CAROLINA

On an exceptionally sunny and warm day in the western North Carolina mountains at Hendersonville, Dr. Kenneth Benjamin, Pharmacy Clinical Coordinator at Pardee Memorial Hospital, provided informative commentary on "Managing Your Medications." Fifteen WM survivors and caregivers, including one new member who had learned of the group through the *Torch*, enjoyed the presentation, which included an in-depth description of Rituxan and its mechanism for destroying malignant B-cells. Dr. Benjamin graciously provided, on a private basis, drug-interaction analysis for prescription medications. As is the group's custom following the program, **Don Nolan** led a discussion during which

*Support Group News, cont. on page 24*

*The northeastern New York/Western New England support group gathered in February.*



individual experiences were shared. After the meeting, most of the group enjoyed lunch together. Don Nolan generously provided the lunch to honor a fraternity brother who, upon hearing his college friend was diagnosed with WM, had made donations to Dana-Farber. As interest dictates, the support group will rotate future meetings between Hendersonville and central North Carolina.

## PENNSYLVANIA

### Harrisburg Area

Old and new friends shared an afternoon of conversation in the boardroom of Messiah Village in Mechanicsburg. Laughter and expressions of happiness to be in each other's company again punctuated the animated conversation. After everyone had shared personal concerns, the group embraced memories of **Nancy Lambert** who recently passed. Nancy had organized the group in 2003; the convenient meeting location was entirely due to her efforts. She also started the annual potluck picnic and she and Larry were always most gracious hosts. The loss of her laugh and wit was deeply felt. **Rita Ziats** and her two sisters provided snacks and Valentine chocolates that lifted the group's spirits. The next meeting is planned for Sunday 15 May (the third Sunday of May due to Mother's Day falling on the second Sunday, our usual meeting date). Other meetings this year will be on the second Sunday of the month in August, probably a picnic, and then again back at Messiah Village for November.

## SOUTH CAROLINA

The group will hold its next meeting in late May or early June in the Florence area (date and location to be announced later). Several newly diagnosed WMers have attended the last few meetings and the leaders, **John** and **Paula Austin**, continue to encourage new members to join.

## TEXAS

### Dallas & Northern Texas

The NTWMSG held its January 15 meeting at Baylor University Medical Center in Dallas. Guest speaker Jane

Beeson of the LLS North Texas/Oklahoma Chapter shared information about LLS and its resources for patients and families. Of particular interest was the wealth of available educational materials and the LLS's financial aid programs. Additionally, Jane generously provided delicious baked goodies for the group to enjoy. Several group members attended the February 26 Lone Star Blood Conference sponsored by the LLS and shared their notes. Larry Anderson, M.D., Ph.D., Assistant Professor of Internal Medicine at the University of Texas Southwestern Medical Center in Dallas, presented the educational talk at the March meeting. He discussed "Lab Tests, Results, and What They Mean for the WM Patient," a topic of much interest and discussion within the group. The document 'Blood Tests,' authored by **Barb Hauser** for the IWFMF, was a handout at the meeting. The group greatly enjoyed the opportunity for a better understanding of how their lab values relate to diagnosis and treatment options. Both meetings concluded with a "Caring & Sharing" period.

## THE INTERNATIONAL SCENE

### FRANCE

The annual meeting of Waldenström France will be held on 24 September, 2011, in Paris, at the *Plateforme Maladies Rares*, Hôpital Broussais, 102, rue Didot, 75014. The speaker will be Dr. Véronique Leblond, an important figure in the field of French hematology and a member of the IWFMF Scientific Advisory Committee. For program details and registration information, please contact [waldenstromfrance@live.fr](mailto:waldenstromfrance@live.fr) or phone +33 (0)490 870 930.

### UNITED KINGDOM

In addition to the first UK WM Forum held in London in February, the UK WM support group has launched its website [www.wmsupportgroup.org.uk](http://www.wmsupportgroup.org.uk). It went live on 10 January 2011. The hope is that the site becomes a central point for information for members, newly diagnosed WMers,

*Support Group News, cont. on page 25*

*The Harrisburg support group meets regularly in the Messiah Village boardroom.*





and other interested parties including doctors who can employ the site as a medium to inform WMers of on-going research projects and clinical trials as well as other related information. The support group's telephone contact number has changed to +44 (0)20 8326 3286 and the e-mail to [info@wmsupportgroup.org.uk](mailto:info@wmsupportgroup.org.uk).

### AUSTRALIA

The newly appointed support group leader for Australia, **Colin Perrott**, filed this report. Colin succeeds **Gareth Evans**, founder of the Australian group called "WMozzies." Colin reports: The Ed Forum in Las Vegas turned out to be catalyst for change in Australia (Oz). There, I had the chance to meet three WMers from Australia: **Peter Carr** (Queensland), **Harry Doorn** (NSW) and **Peter Marfleet** (Victoria). This doubled the number of my Aussie WM contacts. **Andrew Warden** (NSW) was at Los Angeles and also **Jan Jones** who now lives in Ottawa but who spent earlier years in South Australia. My wife Ann and I live mostly in Washington State but we're Australian by birth. The reason why I identify strongly with the Australian WM community is simple. I felt the frustration and torment of years prior to diagnosis while living in Oz. A small population is spread over a vast land. Medical and social support is not easy to find when your ailment is exceptionally rare – such as it is for WM. Exactly the need seen by Gareth and Ben Rude years ago! Could we improve things?

Discussions and another meeting with the two Peters, consultation with Gareth – then action followed. The flagship for Australian efforts to support patients and families touched by blood cancers is the Leukaemia Foundation. Its services range from transporting patients to therapy points and providing "family" accommodation nearby, to providing educational support centrally and at regional oncology units throughout the country, and to sponsoring research. As their slogan they have "Vision to Cure, Mission to Care." The two Peters applied action to fuzzy thoughts about ways to improve patient support in Australia and also to strengthen the ties with the IWMF far away. Andrew joined the team. We found receptive people. The Leukaemia Foundation is now a formal member of IWMF. Now there is an infrastructure by which to reach and support patients and hopefully inform the professions in Australia.

### SUPPORT GROUP LEADERS TALK LIST

This list is only for support group leaders to use in communicating with each other about support group issues. It is designed for the leaders to share their experiences and ideas for facilitating our IWMF support groups. Contact Cindy Furst at [cindyfurst@msn.com](mailto:cindyfurst@msn.com) if you would like to participate.

An excerpt from the forthcoming "Lymphoma News" in Australia:

If you would like to find out more about Waldenstrom's macroglobulinemia, please don't hesitate to contact the Leukaemia Foundation for more in-depth information on the disease and its treatments. Other handy resources are as follows:

- International Waldenstrom's Macroglobulinemia Foundation (IWMF): [www.iwmf.com](http://www.iwmf.com)
- [www.wmozzies.com](http://www.wmozzies.com) is a wonderful Australian site which includes a 'talk list' or 'forum' which enables WM patients to talk, ask questions and discuss symptoms and treatments with fellow patients.

The Leukaemia Foundation is currently seeking feedback to determine whether patients or their family and friends would benefit from support meetings, (at this stage based in Brisbane) to enable WM patients to get together face to face to learn, share and discuss aspects of their journey. If this would be of interest to you, or you would like to see an Australian wide telephone forum developed, we would like to hear from you. Please contact support coordinator Nicole Douglas, at [ndouglas@leukaemia.org.au](mailto:ndouglas@leukaemia.org.au) or (07) 3259 1000.

During the year, I began building a new website [www.wmozzies.com](http://www.wmozzies.com). This attempts to provide a patient and doctors "grab bag" of information. The concept I am following is to provide access to solid information but keep the site as simple as possible. Many patients do not know how to explore virtual cities. Most doctors don't have time to spare. In Australia there are issued treatment guidelines that fail to recognize information that has come available in the last decade. Others cement precipitous reaction to a point-in-time extreme of research excitement – such as the dangers of encountering IgM flare even in patients whose need for treatment is perhaps borderline. Ongoing educational effort is needed in this regard. It is not simple and will never really be finished.

Finally, let me thank Gareth Evans who created and led the WMozzies support group and has helped many people along the way. As is the course of things, Gareth has faced health challenges this year – and rose to the occasion of course. He has now stepped aside but remains Founder of the group. The new leadership team is small and hopefully will grow to include members from each state and major region. This and the involvement of the Leukaemia Foundation will offer patients, caregivers, and professionals active support with physical reach across the nation.

Finally, I admit readily to copying several ideas from our WM friends in Canada, including the format of the WMozzies logo.

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**WMozzies**



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# THE LIFELINE

If you can't get to a local support group meeting, use our IWMF Telephone and Email Lifeline to call a WM veteran. The Lifeline provides telephone numbers and email addresses of IWMF volunteers who will answer questions about their first-hand experience with specific treatments for WM.

*\*The Lifeline is seeking volunteers who speak a language other than English. If you would like to volunteer, please contact the IWMF business office at 941-927-4963 or info@iwmf.com.*

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**In honor of Wanda Huskins:**

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**In honor of Bob Zehner:**

Tom McElwee

*ASH 2010 Highlights, cont. from page 5*

toxicity in patients with hematologic malignancies, including relapsed or refractory non-Hodgkin's lymphoma. CAL-101 inhibits the PI3K pathway, which plays a key role in B-cell proliferation and survival. This drug was administered orally once or twice a day in 28-day cycles for up to 12 cycles. The response rate in indolent non-Hodgkin's lymphoma patients was 62%, and median duration of response had not been reached at the time of reporting. Most toxicities were low-grade and included neutropenia, thrombocytopenia, and elevated liver enzymes.

A multi-center Phase I trial from Fowler et al. reported results on the Btk inhibitor PCI-32765 for patients with relapsed or refractory B-cell malignancies. Btk (Bruton's tyrosine kinase) is a downstream mediator of B-cell receptor signaling, and PCI-32765 is an orally available small molecule inhibitor of this mediator. Of 47 patients enrolled in the trial, 20 achieved a response, including 3 complete responses and 17 partial responses; toxicities were reported in 9 patients and included neutropenia, hypersensitivity reactions, small bowel obstruction, anemia, and exacerbation of chronic obstructive pulmonary disease. Further studies of this drug are contemplated, alone and in combination with other therapies.

A French retrospective study from the Pitié-Salpêtrière Hospital examined the role of two treatments for peripheral neuropathy (PN) in WM patients who had anti-MAG (myelin-associated glycoprotein) antibodies. Sixty one patients were analyzed, none of whom had criteria for treatment except symptomatic or evolving PN. All patients underwent neurological, biological (anti-MAG antibodies, serum IgM) and electrophysiological examination before and after each treatment. Treatment with chlorambucil was administered to 45 patients, while rituximab, either alone or in combination therapy, was given to 16. Rituximab alone or in combination was associated with a higher response rate than chlorambucil, and most patients who relapsed after chlorambucil treatment still responded favorably to subsequent rituximab therapy. With a median follow-up of 96 months, 15 patients treated with chlorambucil relapsed, while only one patient treated with rituximab relapsed. A low IgM level was associated with a better response to treatment.

*If you have questions about ASH 2010 or would like to have an electronic file of ASH 2010 abstracts on WM, please contact the author at [suenchas@bellsouth.net](mailto:suenchas@bellsouth.net).*



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