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## DOCTOR ON CALL: TODD LEVINE, M.D. WALDENSTROM'S AND PERIPHERAL NEUROPATHY



Todd Levine, M.D., at the  
2009 IWMF Ed Forum in Memphis.

### What is PN and what causes its symptoms?

Peripheral neuropathy is a broad term used to describe any disease that damages nerves of the peripheral nervous system. The nervous system is divided into two parts. The central nervous system includes the brain and the spinal cord, while the nerves that travel between the spinal cord and the skin and muscles comprise the peripheral nervous system.

There are, literally, thousands of causes for peripheral neuropathies, and despite the most intensive investigations 50% percent of all cases of peripheral neuropathy have no clear cause. The term *idiopathic* describes such cases. Twenty-five percent of peripheral neuropathy cases are caused by diabetes. Five to 10% of peripheral neuropathy cases are caused by excessive alcohol use. This leaves a balance of 15 to 20% to other causes. Vitamin deficiencies, such as B12, and chemotherapies can also cause peripheral

neuropathies. In rare cases a patient may have a cancer, such as WM, which can cause or be related to peripheral neuropathies. In our survey of 119 WM patients, 48% developed a peripheral neuropathy. This was in contrast to neuropathy being found in 19% of age-matched controls.

### What are the signs and symptoms of PN?

Peripheral neuropathies can cause symptoms that are directly related to the type of nerve that is damaged. The most common type of nerve to be damaged is the sensory nerve. Patients with damage to their sensory nerves will experience numbness, tingling, pain, burning, stabbing, or shooting sensations. This is because the sensory nerves are designed to transmit this type of information, and, when damaged, they will give off abnormal electrical discharges mimicking these sensations even when nothing is stimulating them.

Alternatively, if the motor nerves are damaged, then patients will experience muscle weakness. And in many cases both the motor and sensory nerves are damaged together. This can also lead to problems with balance.

When damage occurs to peripheral nerves, the symptoms will relate directly to the damaged nerves. The most common place where these symptoms are first experienced is in the toes and feet. This is because the nerves located in the toes and feet are the longest nerves in our body. They begin in the spinal cord and extend all the way down to the toes.

If the neuropathy spreads from the feet, it then typically moves up the ankles and calves – and, if it becomes severe enough, neuropathy can begin to involve the hands. It is unusual to have symptoms that are worse in the hands or arms than in the feet. If the symptoms are more pronounced in the hands compared to the feet, it raises the possibility of another cause for the

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*Doctor on Call, cont. from page 1*

symptoms. There are many other causes of numbness, pain, or weakness in addition to peripheral neuropathy. Other potential causes include pinched nerves around the spinal cord (called radiculopathy), pinched nerves in the arms such as carpal tunnel, orthopedic issues such as plantar fasciitis or spinal stenosis, or vascular insufficiency. All can cause symptoms that are similar to peripheral neuropathy. It is, therefore, important to see a doctor who understands how to diagnose and treat peripheral neuropathy because many of these mimics of peripheral neuropathy are actually more treatable than PN.

### How is PN diagnosed?

If you have symptoms that are mentioned above, then you need to see a physician who can take your history, perform an examination, and determine if you have PN. However, because there are so many conditions that can have similar symptoms, there are only a few ways to determine for sure if you have peripheral neuropathy. The most common way is to do the test called Nerve Conduction Study (NCS).

This test uses electrical impulses to activate your nerves and study the way in which the nerves carry these impulses. For most patients, this test can detect whether there is damage to the peripheral nerves. If a neuropathy is suspected and the NCS is negative, then that result suggests that only the smallest nerves may be damaged. The nerves carrying information about sensations are too small to detect with NCS. In this case a small, relatively painless punch biopsy of your skin can be done to actually look at these small nerves under a microscope and see if they appear damaged. The technique of examining these small fibers involves using an antibody to stain for the small fibers and then counting the number of nerve fibers per millimeter of skin. This technique is only available in a few specialized centers, but samples from any location can be shipped to the centers that perform Epidermal Nerve Fiber Counting.

Once you are diagnosed with PN, the focus switches to see if a cause can be determined. This is traditionally done through an extensive series of blood tests to look for the known treatable causes of peripheral neuropathy. If the blood tests do not give a specific answer and the neuropathy is aggressive, some patients will undergo a biopsy of a large nerve. In this way pathologists can study the nerve and see if the biopsy determines a specific cause for the neuropathy.

*Doctor on Call, cont. on page 3*



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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.

In many cases no specific test can answer the question as to what caused the neuropathy. In some of these cases the neuropathy can be attributed to other diseases or conditions that a person has, such as diabetes, heavy alcohol consumption, or a cancer known to be associated with PN. In the case of Waldenstrom's, we know that 48% of WM patients will develop neuropathy associated with WM. But keep in mind that neuropathy in a WM patient may be due to a number of reasons, including those listed above, and that it therefore can still be difficult to diagnose whether the PN is from WM. The only way to be certain is to test to see if the abnormal antibodies that directly attack the peripheral nerves are in your blood. There are several IgM antibodies that have been associated in this way, such as anti-MAG (Myelin Associated Glycoprotein) or sulfatide (a sulfur-containing lipid [fat] associated with the myelin layer). In our study of 119 patients with WM only 5% had antibodies to MAG and only 4% had antibodies to sulfatide. So it is important to rule out other causes of PN even if you have WM.

### How is Peripheral Neuropathy treated?

The treatments for PN are directed at their underlying cause. So if the patient has diabetes, the best treatment is to control blood sugar, follow an appropriate diet, and exercise. If a patient has a vitamin deficiency then this can be corrected.

If the PN is caused by one of the abnormal proteins in the blood, then lowering the level of the antibody in the blood will treat the PN. The antibody level can be lowered using chemotherapy or by directly removing the antibodies through plasmapheresis. These treatments may lower the level of the IgM; however, plasmapheresis is both time consuming and expensive and its effect is of short duration. Moreover, most patients with peripheral neuropathies have relatively mild symptoms that do not progress to severe neuropathies, and there is not much evidence to show that starting therapy with chemotherapy or plasmapheresis for a mild neuropathy will delay the progression to a more severe neuropathy. Most cases of PN associated with abnormal antibodies are mild and remain that way. So it is rarely worth the risk of aggressive therapy early on. Such decisions should be discussed with a doctor familiar with these types of neuropathies, in other words with a neurologist who specializes in diseases of the peripheral nerves.

Even if there is no specific treatment for the underlying cause of the neuropathy, there are many treatments available that reduce the pain and the symptoms of PN. Such treatments are very commonly used in all forms of neuropathy and include amitriptyline, gabapentin, pregabalin and duloxetine. These agents can reduce the symptoms of PN by up to 50%. If the pain is uncontrollable even when these drugs are taken, then many patients will use narcotic medications such as oxycodone or methadone to reduce their pain. In these cases it is preferable to be followed by a pain specialist who can track the medications and their side effects. The key thing

to keep in mind is that even without specific therapy for the cause of the neuropathy doctors should be able to improve your quality of life.

### Which treatments for WM are known to cause PN?

This is a complicated subject since we know WM can cause PN, but we also know that some of the treatments for WM also cause or intensify PN symptoms. Several chemotherapy drugs including Vincristine, Velcade, Thalidomide, and Revlimid can cause PN. In most cases the likelihood that PN will develop during treatment is increased if there is even a mild PN before treatment. Further, if the drugs are the cause of the PN then the symptoms of PN tend to develop during the months of treatment. If symptoms of PN develop during chemotherapy it is important to notify your doctor immediately since stopping the chemotherapy can stop the progression of the PN or even reverse the symptoms. The decision to use the agents that cause PN has to be balanced against the need to treat Waldenstrom's and should be discussed with your doctor.

Peripheral neuropathy associated with Waldenstrom's is a complex disorder, and there are many people with WM who suffer from neuropathy. The following are steps that will help formulate a treatment plan for the WM patient with neuropathy. Note, however, that the same steps are recommended to the patient who is experiencing neuropathy but who does not have WM.

- 1) Establish that PN is the accurate cause of the symptoms.
- 2) Establish whether WM is the likely cause for the PN or if there are other causes.
- 3) Direct therapy based on the severity of symptoms, i.e. in cases of severe neuropathy related to WM patients need aggressive therapy to reduce antibody levels; in cases of mild PN symptomatic therapy may be all that is required.
- 4) Follow routinely with a neurologist familiar with disorders of the peripheral nervous system.

These steps will help ensure that everything that can be done will be done to treat your PN.

*Dr. Levine is at present Assistant Professor of Clinical Neurology at the University of Arizona and in private practice with Phoenix Neurological Associates in Phoenix. He is board-certified by the American Board of Psychiatry and Neurology (1998) and the American Board of Electrodiagnostic Medicine (2000). He is currently Co-Director of the Samaritan Peripheral Neuropathy Center, Co-Director of the Samaritan ALS Clinic, and Director of the Department of Neurophysiology at the Good Samaritan Hospital in Phoenix.*

*After earning his medical degree from Duke University School of Medicine in Durham, NC, he completed his internship in internal medicine at the Jewish Hospital of St. Louis,*



MO. Designated chief resident during his residency in the Neurology Department at Washington University School of Medicine in St. Louis, he subsequently received a fellowship in neuromuscular diseases from the same institution.

Dr. Levine is also a Fellow of the American Association for Electrodiagnostic Medicine and has published widely within the field of neurology. A dynamic lecturer, he is a frequent speaker at the IWMF Educational Forums.

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## PRESIDENT'S CORNER

BY JUDITH MAY

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Judith May, President

When you receive this issue of the *Torch* it will be spring, the season of renewal. But, even though it is February as I write this, the Board of Trustees is experiencing an early spring. Why? Because of the wonderful renewal of faith in the IWMF that you have shown by your contributions to continue your membership and to support our research. To the Board, this was an affirmation that we are on the right track with the services we provide and the research we fund. We deeply appreciate the donations you made at a time of continued economic stress for many of us. Thank you.

I am happy to see all the survey forms that come in daily after my second request that members complete the form so we can know what is working well for you and what you feel we should add or change. Soon we will begin a comprehensive analysis of your responses, and I will report the results to you in the *Torch*. Please! If you have not yet sent in your survey form, the time to do so is now.

### VOLUNTEERS

Once again I am calling for volunteers. We are looking for volunteers with specific knowledge and experience in these fields: finance, fundraising, scientific writing and editing, and computer technology. If you have skills and experience in these areas and are willing to contribute to the IWMF effort as a volunteer, please send your resumé to our office: Sara McKinnie, Office Manager, 3932D Swift Road, Sarasota, FL 34231, or e-mail to: [info@iwmf.com](mailto:info@iwmf.com)

### EDUCATIONAL FORUM

I want to encourage all those who have not yet registered to please consider attending this year's Ed Forum. We have a new format for the conference this year, with a number of plenary sessions beginning at 9:30 am on Friday, April 9. Please note that this new format would require most attendees to arrive on Thursday, April 8. The full day planned for Friday is followed by a second full day on Saturday and half a day on Sunday. The final agenda can be found on our website, and you will be glad to see that many of our familiar WM experts will be presenting once again, as will be new presenters you have not met before. Our breakouts will include two experts who work in Social Security Disability and Medicare to answer the questions that I'm sure many of you have. In addition, Dr. Steven Treon's group will once again set up a blood drawing room, and you will have an opportunity to contribute to research by donating your blood.

I hope your plans for attending the Ed Forum will include staying for the Business Meeting, which is always on Sunday, 11:00 am until noon. The Board of Trustees gives their annual report to the members at this meeting, and it is a time when we encourage members to speak out and tell us what they think about the Foundation's services, our research program, and our future direction.

### BIG NEWS

I am happy to announce that Bill Paul, our current IWMF Secretary-Treasurer, was elected to the new post of Executive Vice President at a Board Meeting several weeks ago. As Executive Vice President, Bill will be my successor to the position of President after a period of time during which the two of us will work together to ensure a smooth transition. Bill has been a member of the Board for two years and has proven to be a dedicated Trustee, skilled not only in financial issues but also in communications and in managing people. He has a very clear vision of the Board's responsibilities and sharp logic behind his opinions, while always being open to the opinions of others. Bill has an easy diplomacy in dealing with others, whether they are IWMF members, physicians, staff, or Trustees. As the Executive Vice President, Bill will have oversight of the office and staff to ensure that work is handled effectively and efficiently, will share the workload of the President during a training period, and will succeed to President in the near future.

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*President's Corner, cont. on page 5*





I have thoroughly enjoyed my 12 years on the Board and five years as President of the IWFM. And I won't be going far away. As I move to emerita status, I will continue to be there, to support Bill whenever needed. And I will continue to be involved with the Board in ways that I can contribute to the work of the Foundation while living part-time in Mexico. I will be seeing you at all Ed Forums. You will find a photo and career details about Bill Paul in the article that follows.

The IWFM membership is a terrific group of people. We are a foundation of patients and caregivers who have sustained our grass roots idea that people helping people is the best

way to face adversity. The Board of Trustees is a wonderful, hard-working group of very dedicated people. We have accomplished so much with your help and will continue to do so with everyone doing what they can do best, by volunteering, donating, and giving the Board their thoughts for the future of the organization.

See you in Las Vegas!

Stay well,

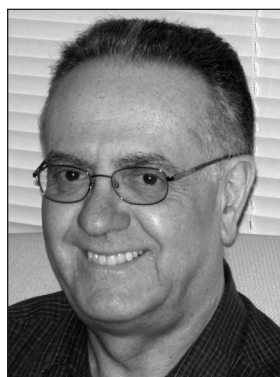
Judith

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## INTRODUCING BILL PAUL

BY JUDITH MAY, IWFM PRESIDENT

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Bill Paul,  
Executive Vice President

*The following is a little background information on newly appointed IWFM Executive Vice President Bill Paul, who will become the next IWFM President.*

Bill was employed by the IRS from 1972-1982 in various positions from tax examiner to statistical analyst, to trainer for IRS employees on tax changes and Unit Supervisor for 25 employees. In 1982 Bill opened his own tax services business in Memphis, Tennessee, and continues to own and operate the business today. In addition, he has worked with the Tennessee Psychological Association since 1997, providing financial services and investment reports. Bill also is the business administrator for a local organization, the Memphis Center for Women & Families, and spends volunteer hours assisting the Pastor of St. Michael's Catholic Church in Memphis. He is also on the finance committee of St. Michael's.

Bill's awards and achievements include the 1978 IRS Superior Performance Award for service that best exemplifies the mission of the IRS. In 2004 he received a Certificate of Recognition for Extensive Service to the Tennessee Psychological Association.

Included among Bill's professional affiliations are: the National Society of Professional Accountants, the American Association of Certified Tax Professionals, and the National Federation of Independent Business.

As a businessman, Bill has considerable experience with finance and management. As a volunteer, not only does Bill work long hours assisting the IWFM Board of Trustees in his current position of Secretary-Treasurer, but he is also the support group leader for the Memphis and Nashville groups. His compassion for people led him to volunteer through his church, visiting those in nursing homes, hospitals, and at home in hospice situations.

His free time (scarce as it is!) Bill likes to spend with his wife, psychologist Connie Paul, at their vacation home in the Arkansas River Valley, on a mountain where the foothills of the Ozark and Ouachita Mountains meet. Here Bill and Connie enjoy hiking mountain trails, swimming, entertaining, and reading and relaxing while enjoying sunsets and sunrises from their mountain.



Hotel Molino Stucky Hilton

### EXCITING NEWS ON THE INTERNATIONAL FRONT!

Mark your calendar for the Second IWFM International Patient Forum being planned for Sunday, October 10, 2010 at the Hotel Molino Stucky Hilton in Venice, Italy. This special event is being coordinated with the Bing Center, Dana-Farber Cancer Institute at Harvard University, to coincide with the 6th International Workshop on Waldenström's Macroglobulinemia. More details will be available at [iwfm.com](http://iwfm.com) and special announcements will follow as the program develops.



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# TREASURER'S REPORT FOR THE YEAR 2009

BY BILL PAUL, 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><u>2009</u></b>	<b><u>2008</u></b>
Contributions Received	\$ 365,000	\$ 519,000
Interest Income	<u>17,000</u>	<u>46,000</u>
	382,000	565,000
Research Grants Awarded	<u>588,000</u>	<u>60,000</u>
Increase (Decrease) for Year	<b><u>\$(206,000)</u></b>	<b><u>\$ 505,000</u></b>

Contributions during 2009 were approximately 30% lower than during 2008. However, the amount in the checking accounts and CDs on December 31, 2009 was \$1,660,000. With Research Grants Payable of \$854,000 on December 31, 2009, the Research Fund is still in a healthy financial position. We expect more Research Fund requests during 2010, and we anticipate those requests with enthusiasm as we search for a cure for WM. 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 more than suffice to overcome any temporary deficit.

<b>Member Services Fund</b>	<b><u>2009</u></b>	<b><u>2008</u></b>
Contributions Received	\$ 625,000	\$ 393,000
Member Services and Operating Costs	<u>525,000</u>	<u>414,000</u>
Increase or (Decrease) for Year	<b><u>\$ 100,000</u></b>	<b><u>\$( 21,000)</u></b>

Income for 2009 was significantly greater than for 2008. The Member Services Fund showed a profit at year's end, an improvement of \$121,000 over 2008. Last year at this time we requested your help to turn our \$21,000 deficit into a profit, and you responded. With your help this can continue in 2010, and we can report a profit on a continuing basis. Overall, the Fund is in a relatively healthy position, with net assets in our checking account and CDs having a combined value of \$384,000, compared with \$284,000 at the end of 2008. Thanks to your help, your Foundation is alive and well – and indeed thriving even in difficult times.

## IWMF, THE ECONOMY, AND YOUR MONEY

It seems appropriate to mention the safety of your money when donating to the IWMF. I would like to reassure you that the Board of Trustees is very concerned about the safety of your money. During these troubling times with an unsteady stock market, not a penny has been lost due to poor investment decisions by the IWMF Board. The financial situation of the IWMF is very healthy.

The world economy has been truly concerning, and the IWMF is financially challenged as are all donation-dependent organizations. Please know that by donating to IWMF you are contributing to an organization that has very low administrative costs and helps patients, families and friends directly. The monies donated have an immediate impact on the Educational Forums, the *Torch*, the website, IWMF-Talk, e-mail alerts, and our many other member services. This is not a time to stop giving, whether you designate your contributions to the Research Fund or leave designation to the discretion of the Board. Either way, your donations are helping to save lives and to improve the quality of lives.

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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# RESEARCH UPDATE: THE IMMUNE RESPONSE TO WM IMPLICATIONS FOR IMMUNOTHERAPY

BY TOM MYERS AND GUY SHERWOOD, M.D.

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*The Waldenstrom's Macroglobulinemia Foundation of Canada, the Canadian branch of the IWMM, is proud to be the principal sponsor of an important research initiative led by Brad Nelson, Ph.D., of the Trev and Joyce Deeley Research Center in Victoria, British Columbia. The research project, recently approved by the IWMM Scientific Advisory Committee, outlines the very first step toward immune-based therapy for WM. Below Tom Myers, IWMM Vice President for Research, and Guy Sherwood, M.D., IWMM Trustee and member of the Research Committee, explain how the project directed by Dr. Nelson offers hope of eventual disease control in WM through immunotherapy.*

Waldenstrom's macroglobulinemia (WM) is an indolent non-Hodgkin lymphoma cancer characterized by bone marrow infiltration of malignant B cells and the production of large amounts of serum IgM. Currently there is no known cure for the cancer, but recent results using immune based therapies for lymphomas give hope that a cure may be developed using this approach.

Dr. Nelson and his fellow scientists at the Deeley Research Center are interested in the development of strategies that could be used for future immune-based treatments for WM. Their proposed study will evaluate the use of a vaccine targeting the WM cell idotype (an idotype is a unique rearranged mutated version of the surface immunoglobulin that is specific to all cells within a WM patient's tumor – essentially an ID tag) together with multiple other recently discovered vaccine targets found only in lymphoma-specific mutations. A vaccine that targets multiple sites on a cancer cell will provide higher response rates and disease control compared to a vaccine that simply targets the tumor cell idotype.

Furthermore, Dr. Nelson and his team will evaluate the feasibility of combining vaccine-based therapy with adoptive T-cell therapy – a much-discussed topic at the recent 2009 American Society of Hematology meeting in New Orleans. The scientists plan to isolate "tumor reactive T-cells," cells that have demonstrated an affinity for WM cells bearing the idotype targets as well as the other identified lymphoma-specific mutations from patients with WM. Such T-cells (usually not present in sufficient numbers in the typically immune-compromised WM patient) can be removed from the patient, expanded exponentially in vitro, and then re-infused into the patient in much greater numbers with the expectation that they will eliminate all residual tumor cells. Such high concentrations of T-cells cannot always develop normally in a patient because of the cancer and its treatments. This will be the first study to investigate the immune response as a potential therapeutic agent for vaccine and/or adoptive T-cell based therapy in WM.

In summary, this project aims to: identify in a series of WM patients the unique tumor cell idotype as well as the recently discovered multiple other lymphoma-cell specific mutations; identify and isolate a population of the reactive T-cells that recognizes the particular target(s); and finally assess these cells for reproducibility and growth, relevance for immune-based therapy, ease of functionality, and targeted cytotoxic potential.

Dr. Nelson and his team are well respected in the field of immunology and the research they are embarking on has the potential to result in new and effective treatment for those afflicted with WM. On behalf of all members of the IWMM, we express our gratitude to the WMFC for so generously undertaking to support this important advance in WM research.

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## HIGHLIGHTS OF ASH 2009

BY GUY SHERWOOD, M.D., IWMM TRUSTEE

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The fifty-first Annual Meeting of the American Society of Hematology (ASH) was held on December 5-8, 2009, in New Orleans, Louisiana. Attending physicians, researchers, and associated industry and cancer-organization related personnel were estimated to number at least 23,000. The IWMM had an information booth, and Tom Myers, Bill and Connie Paul, Sara McKinnie, and myself also attended to represent our Foundation and staff the booth.

This article outlines my personal highlights of the ASH Annual Meeting, a summary of information that struck me as most important from all the lectures and posters I managed to hear and see during the four intense days of ASH. In upcoming issues of the *Torch* I will write about specific talks and reports that have particular importance to WM'ers.

A series of presentations regarding the manipulation of the individual immune system was perhaps the most important

*Highlights of ASH 2009, cont. on page 8*



event I attended. The research presented indicates that, in the very near future, lymphoma and other hematological cancer patients will have some of their circulating immune system cells harvested (much like a stem cell harvest) and that these harvested cells (predominantly T-cells) will, in turn, be grown in the lab, amplified in numbers and in their cancer fighting capabilities, and returned to the patient to assist in the treatment of the patient's cancer. This process is already being done to great effect in bone marrow transplant patients, and it is expected that similar techniques can be used to boost patient response to immunotherapeutic drugs like rituximab. Perhaps we can envision the day when we not only receive an infusion of rituximab but also an infusion of large numbers of killer T-cells to increase the effectiveness of the monoclonal antibody treatment.

Speaking of monoclonal antibodies, it is now quite clear that the addition of rituximab to many combinations of "traditional" chemotherapeutic agents – cyclophosphamide, fludarabine, bortezomib, CHOP – significantly enhances rate of response and survival. The trial results of a new drug, ofatumumab (GlaxoSmithKline), that works in manner similar to the anti-CD20 monoclonal antibody rituximab (Rituxan, Genentech/Roche), were reported at the meeting as an example of monoclonal antibodies used in immunotherapy for lymphoma. The trial in previously untreated patients with chronic lymphocytic leukemia (CLL) showed that ofatumumab given in combination with fludarabine and cyclophosphamide was "highly active." One researcher commented that ofatumumab monotherapy was not a viable treatment option in patients with follicular lymphoma unresponsive to rituximab. In 116 patients who failed to achieve at least a partial response to rituximab – used either alone or with chemotherapy – objective responses occurred in only 11% of those taking ofatumumab. The same researcher noted, however, that the response was higher – 22% – in a subgroup of patients who had failed rituximab monotherapy. A clinical trial with ofatumumab in WM is currently underway. Yet another agent, GA 101 from Genentech, has been dubbed "son of rituximab" and is being investigated in relapsed/refractory CLL.

In the case of patients with indolent lymphoma (such as WM) whose disease has progressed after treatment with rituximab, another study indicated that long-term survival can still be achieved if the patients are switched to the radioimmunoconjugate Bexxar (Iodine-131 tositumomab). Median overall survival was 6.7 years after receiving Bexxar.

In the area of cancer vaccines, a new protocol for treating low-grade B-cell lymphomas with Rituxan (rituximab) and tumor-specific vaccination was presented that appears to increase response rates and time to progression over Rituxan alone. In a clinical trial of patients with follicular B-cell non-Hodgkin's lymphoma, Rituxan followed by vaccination with an antibody directed against a lymphoma-specific tumor

idiotype resulted in a 64% overall response rate compared with Rituxan alone. The use of rituximab followed by vaccination may change the natural course of the disease and is obviously very attractive for the patient as it does not include chemotherapy.

Insofar as the traditional chemotherapeutic regimens are concerned, results from a Phase III study demonstrated that the combination of rituximab and bendamustine (Treanda) in the first-line treatment of patients with advanced follicular and indolent lymphomas resulted in better outcomes than the "gold standard" of R-CHOP (rituximab plus cyclophosphamide, doxorubicin, vincristine [*Oncovin*] and prednisone). Bendamustine is an old drug that was used more than thirty years ago in Germany. This new study used first-line treatment with bendamustine in B-cell non-Hodgkin's lymphoma, and the results showed improved progression-free survival and tolerability. These new data for bendamustine have already impacted clinical practice in NHL, including WM.

Of interest to some WM'ers is the relationship between cholesterol, the use of cholesterol-lowering drugs (statins in particular) and lymphomas. In New Orleans researchers reported that patients who are already taking statins to reduce cholesterol at time of diagnosis with CLL may be less likely to need treatment for the cancer. The researchers believe that lipid biology is important in CLL progression. Whether this applies to WM remains to be seen.

There were some interesting presentations in the area of complementary/integrative medicine. The medical director of the Center for Integrative Therapies at the Dana-Farber Cancer Institute reflected that a patient once told him: "I may be receiving the best therapy in the world, but you are not treating me as a whole human being." Current data on integrative approaches as they pertain to children, survivorship, and supplements was presented at ASH (as is the case at virtually all cancer conferences nowadays).

Finally, of great interest to me, and perhaps to some of you, a small randomized clinical trial showed that employing a simple acupressure technique significantly reduced the proportion of patients who reported severe pain during bone marrow aspiration and biopsy. The technique involved use of suction cups to apply pressure to the large intestine 4 (LI4) acupoint near the space between the thumb and forefinger. Patients treated with acupressure were 89% less likely to find the bone marrow procedure severely painful compared with patients who had sham acupressure. Bonus observation: this works with dental pain as well!

In the next issue of the *Torch*, look for reports from the 2009 ASH conference in New Orleans that are more technical and in greater depth.





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# MEDICAL NEWS ROUNDUP

BY SUE HERMS

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**The Leukemia & Lymphoma Society Increases Benefit for WM Patients** – The Leukemia & Lymphoma Society has announced that, effective February 1, 2010, patients with WM and multiple myeloma will be able to receive up to \$10,000 in support to help offset the costs of prescription drug co-pays and other insurance related expenses. This increase is retroactive for expenses incurred from July 1, 2009 through June 30, 2010, and is available to new and currently approved patients. Patients, caregivers, and healthcare professionals may submit applications online at [www.lls.org/copay](http://www.lls.org/copay). Applications can also be submitted by calling 877-557-2672. Eligibility will be determined by medical and financial need.

**United Kingdom Study Highlights Importance of T-Cell Response in Lymphoma** – An important factor in cancer progression is the ability of tumor cells to evade recognition by the body's immune system. A multi-center study in the United Kingdom identified a defect in T-cells of patients with follicular lymphoma and diffuse large B-cell lymphoma, called T-cell immunologic synapse dysfunction, which suppresses T-cell numbers and activity by reducing the expression of certain T-cell proteins. This defect is induced after short-term contact with tumor cells. The study also demonstrated that lenalidomide (Revlimid) was able to repair this defect. These results highlight the importance of identifying treatments for repairing T-cell responses in lymphoma.

**Stanford University Reports on Side Effects of Rituximab Treatment Following Autologous Stem Cell Transplant** – Rituximab has been administered after autologous stem cell transplantation for B-cell lymphomas with the goal of eradicating any residual disease that may be present. Stanford University School of Medicine researchers previously reported that two courses of rituximab after transplantation had encouraging clinical outcomes; however, neutropenia (abnormally low numbers of neutrophils) occurred in 52% of treated patients. The researchers determined that the Fc $\gamma$ RIIIa gene polymorphism on the patients' effector cells (macrophages, neutrophils) predicted the occurrence of the neutropenia. Those who had the amino acid valine at position 158 of this polymorphism correlated with a higher incidence of neutropenia. Testing for this polymorphism in transplant patients should be able to identify a high-risk population for neutropenia following rituximab treatment.

**Second Generation Oral Proteasome Inhibitor Begins Phase I Trial** – Millennium Pharmaceuticals has initiated a Phase I clinical trial in multiple myeloma patients for an oral formulation of MLN9708, a second-generation proteasome inhibitor. Millennium developed bortezomib (Velcade), currently FDA-approved for the treatment of multiple myeloma and relapsed mantle cell lymphoma and increasingly used for the treatment of WM.

**Results Reported for Phase II Study of Perifosine in WM** – Dana-Farber Cancer Institute recently reported results from a Phase II study of oral perifosine in 37 relapsed/refractory WM patients. A minimal response was achieved in 35% of patients, while 54% showed stable disease. The median progression-free survival was 12.6 months. The most common adverse events were cytopenias, gastrointestinal symptoms, and arthritis flare.

**Multi-Center Study Investigates Anti-Interleukin 6 Monoclonal Antibody in Multiple Myeloma** – A multi-center study reported in *Clinical Cancer Research* has investigated the anti-multiple myeloma activity of monoclonal antibody 1339, a fully humanized anti-interleukin 6 antibody, alone and in combination with other multiple myeloma treatment agents. When tested on cell lines and in mouse models of multiple myeloma, the antibody significantly inhibited the growth of multiple myeloma cells. It also enhanced the action of dexamethasone, bortezomib, lenalidomide, and perifosine.

**Pomalidomide/Dexamethasone Combination Benefits Patients with Relapsed Multiple Myeloma** – Combination pomalidomide (a newer immunomodulatory agent) and dexamethasone therapy has demonstrated a response rate of 63% in a Phase II trial in patients with relapsed multiple myeloma. Researchers at Mayo Clinic have treated an additional group of patients who were resistant/refractory to lenalidomide, a drug in the same class as pomalidomide. Both pomalidomide and dexamethasone were administered orally. Twenty six percent of patients in this trial had a partial response, while 53% had stable disease. With a median follow-up of four months, 65% remain progression free. Pom/dex appears to offer benefit to patients who have relapsed after other previous therapies.

**Vitamin D Shortage May Adversely Impact Survival in Lymphoma** – A shortage of vitamin D may adversely impact survival in lymphoma patients, says a report presented at the recent December meeting of the American Society of Hematology. From 2002 to 2008, researchers analyzed blood samples from 374 newly diagnosed patients with diffuse large B-cell lymphoma. Half of these patients were deficient in vitamin D at the start of treatment. During follow-up, these vitamin D-deficient patients were twice as likely to die. All patients received standard treatment, and the researchers accounted for differences between groups in age and other factors that might bias the comparison. While the minimum healthy blood levels of vitamin D have traditionally been defined at 25-30 ng/ml, others suggest that the level should be 40 ng/ml. More study is needed before supplementation of vitamin D is routinely ordered for lymphoma patients. Although fortified foods provide some vitamin D, these may

*Medical News Roundup, cont. on page 10*



be inadequate to maintain ideal levels. Vitamin D is primarily manufactured in the skin by exposure to ultraviolet B radiation from the sun. The vitamin can be stored, but during winter months in temperate zones the supply dwindles.

**Treanda More Effective and Less Toxic than CHOP in NHL** – Cephalon's Treanda, also known as bendamustine, was significantly more effective and less toxic than standard CHOP (cyclophosphamide, hydroxydoxorubicin, Oncovin, prednisone) chemotherapy as an initial treatment for non-Hodgkin's lymphoma. Both treatments were tested in combination with rituximab in patients with follicular, indolent, and mantle cell lymphomas. The primary goal of the 4 ½ year Phase III study was progression-free survival. Patients given Treanda had a median progression-free survival of 54.9 months compared with 34.8 months with CHOP. In addition, 39.6% of Treanda patients achieved complete response vs. 30% with CHOP. There was a significantly lower incidence of leukopenia (decreased white blood cells), as well as fewer infections and no hair loss in Treanda patients. This particular study used a lower dose of bendamustine than the approved dosage in the U.S., which may account for the better toxicity profile.

**New Small Molecule Inhibitor Blocks BCL-2 Proteins in Malignant B-Lymphocytes** – The Bcl-2 family of proteins is critical to the life and death of malignant B-lymphocytes. Interfering with their activity by using small-molecule inhibitors is being explored as a new therapeutic strategy for treating B-cell tumors. Wayne State University School of Medicine evaluated TW-37, a small molecule inhibitor, against a spectrum of human B-cell lymphoma lines, fresh patient samples, and mouse models. TW-37 was able to block several Bcl-2 proteins, causing apoptosis (cell death).

**United Kingdom Trial to Investigate Anti-CD19 Monoclonal Antibody in Leukemia and Lymphoma** – The charitable organization, Cancer Research UK, and its development and commercialization arm, Cancer Research Technology, are to undertake a Phase I clinical trial of an investigational monoclonal antibody developed by Merck. The antibody, DI-B4, binds to the CD19 protein found on the surface of B-cells. It is hoped that this antibody will help those patients with leukemia and lymphoma who do not respond to existing therapies. The trial will be held at several hospitals in the United Kingdom.

**ImmunoGen Reports Results from Another Anti-CD 19 Monoclonal Antibody** – Meanwhile, ImmunoGen, Inc. announced initial clinical findings of its anti-CD19 antibody called SAR3419. The study found that 17 of 27 (63%) patients with non-Hodgkin's lymphoma experienced a reduction in tumor size. Included were patients refractory to rituximab treatment. The maximum tolerated dose was determined as 160 mg/m<sup>2</sup> once every three weeks. A Phase I study is also underway to assess weekly dosing of SAR3419.

**UCLA Reports on Misregulation of Protein in B-Cell Lymphoma** – A group at UCLA has reported in the *American Journal of Pathology* that misregulation of the protein SPAK may contribute to B-cell lymphoma development. SPAK is a protein that regulates response to cellular stress, and SPAK expression is inhibited in B-cell tumors. This silencing of SPAK protects the cancerous B-cells from environmental stresses that would induce cell death in normal cells.

**Flu Shots May Not Be Effective in Certain Patients Being Treated with Rituximab** – According to a new study by the University Medical Center Groningen in the Netherlands, the flu shot does not protect arthritis patients who are being treated with rituximab. In patients vaccinated within two months after treatment with rituximab, the drug inhibited the formation of antibodies against the flu because of B-cell depletion. Although this study began before H1N1 (swine) flu emerged, the effects on that vaccine are expected to be similar.

**New Blood Test May Detect Incipient Graft vs. Host Disease in Allogeneic Stem Cell Transplant Patients** – A new blood test, developed and reported by the University of Michigan, could discern whether a patient who has undergone allogeneic stem cell transplant will develop serious graft vs. host disease (GVHD). GVHD occurs when the newly transplanted stem cells develop into immune cells that attack tissues in the recipient's body. Frequently, a skin rash can be the first symptom of GVHD. Current testing to confirm if a rash is due to GVHD is done by tissue sampling. The new blood test detects increased elafin levels in the blood, which may indicate the onset of GVHD and predict its severity.

**Possible New Treatment Reported for Graft vs. Host Disease in Transplantation** – A report in the February edition of the *Journal of Leukocyte Biology* outlines the use of an anti-inflammatory agent called ATL146e to significantly improve the likelihood of success for allogeneic bone marrow transplants. Graft vs. host disease (GVHD), a situation in which the donor marrow attacks the recipient's cells, can be a serious and life-threatening complication of transplantation. In mouse models treated with ATL146e, the severity of GVHD was reduced, leading to a decrease in tissue damage and an increase in survival.

**Biovax ID Lymphoma Vaccine Granted FDA Orphan Drug Designation** – Biovest International announced that the U.S. FDA has granted Orphan Drug Designation for BiovaxID, a personalized follicular lymphoma vaccine. With Orphan Drug Designation, Biovest has a seven-year period of market exclusivity for BiovaxID, as well as eligibility for tax credits, grant funding for research and development, and reduced filing fees for marketing applications.

**French Study Reports Results of Allogeneic Stem Cell Transplantation in WM Patients** – A retrospective analysis by the Société Française de Greffe de Moelle et de Thérapie



Cellulaire examined the long-term outcome of allogeneic stem cell transplantation (SCT) in WM by studying the records of 24 patients. Median age at the time of transplantation was 48 years, and patients had previously received a median of three lines of therapy beforehand. The overall response rate after transplantation was 92%, with a complete response rate of 50%. After a median follow-up of 64 months, the 5-year overall survival rate was 67% and the progression-free survival rate was 58%. The authors concluded that allogeneic SCT yields a high rate of complete remissions and is potentially curative in poor-risk WM.

**United Kingdom Cancer Survivors to Receive Additional Support and Services** – The United Kingdom Department of Health and Macmillan Cancer Support have jointly announced that cancer survivors in the UK will receive additional support and services under a plan, called the National Cancer Survivorship Initiative, to be put in place by 2012. Cancer survivors will have a personalized assessment and care plan, support to self-manage their condition, information on the long-term effects of living with and beyond cancer, and access to specialists for complications that can occur after cancer. Pilot studies for this program are being established in 38 sites around the country.

**Australian Study Reports on Significance of Persistent Cytopenias Following Fludarabine Treatment** – The Peter MacCallum Cancer Centre and the University of Melbourne in Australia reported on the presence and significance of prolonged cytopenias (low hemoglobin, neutrophils, and/or platelet counts) after completion of treatment with fludarabine-based therapy. The study included 61 patients and noted that persistent cytopenias were found in 43% of patients. These cytopenias, while unrelated to disease status, were associated with important rates of infection and transfusion requirements. Persistent cytopenias also predicted worse overall survival. Increasing age appeared to increase the risk of persistent cytopenias while dose intensity did not appear to be a factor.

**New Proteasome Inhibitor Tested by Dana-Farber Cancer Institute** – Dana-Farber Cancer Institute has conducted studies on WM cells with a new proteasome inhibitor called ONX0912. Since a significant fraction of patients relapse after bortezomib treatment, this newer inhibitor of chymotrypsin-like activity of the proteasome may represent a valid anti-tumor therapy in WM because it induces apoptosis (cell death) and reduces expression of several proteins produced by bone marrow cells and implicated in WM cell growth.

**Bayer Tests NHL Vaccine Developed from Tobacco Plants** – Bayer has begun a Phase I study with a personalized vaccine for non-Hodgkin's lymphoma patients developed from tobacco plants. The company uses tobacco plants in order to produce a high yield of idiotype (tumor-specific) vaccines for treatment of B-cell lymphomas. In this process, the tobacco plant is not genetically modified; instead, the

blueprint for the required product is inserted temporarily into the plant by a species of bacteria and distributed throughout the plant cells. The vaccine is subsequently extracted from the plant's leaves in a pure form and is used to stimulate an immune response against the cancerous cells when injected into the patient. In this study, 20 patients will each be given six subcutaneous injections of the vaccine over a six-month period. The clinical study will be performed at the University of Texas Southwestern Medical Center in Dallas.

**Mayo Clinic Reports on Phase I Trial of Rituximab and Interleukin-12** – Mayo Clinic conducted a Phase I trial of interleukin-12 (IL-12) in combination with rituximab for non-Hodgkin's lymphoma. IL-12 facilitates the T-cell response, enhancing the killing activity of natural killer cells and inducing the secretion of interferon. Objective responses occurred in 29 of the 43 patients (69%) in the study, with several complete responses. The optimal dose of IL-12 was determined to be 300 ng/kg administered subcutaneously twice weekly.

**German Drug Company Is Conducting Phase I Trial of New Drug for Lymphomas** – 4SC AG, a German drug discovery and development company focused on autoimmune and cancer conditions, announced a Phase I study evaluating 4SC-205, an oral Eg5 kinesin spindle protein inhibitor, in patients with solid tumors and lymphomas. Eg5 kinesin spindle protein is important for proper cell division – its inhibition leads to cell cycle arrest and apoptosis (cell death). Since the expression of Eg5 is confined to actively dividing cells, it is hoped that the drug will have an acceptable toxicity profile.

**Dana-Farber Plans Study of New Oral Drug Called Panobinostat in WM Patients** – Dana-Farber Cancer Institute is currently recruiting patients for a Phase II study of panobinostat (LBH-589) in relapsed/refractory WM. Panobinostat is an oral drug, developed by Novartis, that is being tested in multiple myeloma and several types of leukemia and lymphoma. It inhibits the enzyme histone deacetylase, leading to apoptosis (death) of malignant cells via multiple pathways.

**New Fusion Protein of Anti-CD20 Antibody and Interferon Improves Rituximab Efficacy** – In an effort to improve the outcome of rituximab therapies and overcome rituximab resistance, UCLA researchers have constructed a fusion protein consisting of an anti-CD20 antibody and mouse or human interferon alpha. Efficacy was established in mouse models of lymphoma and may represent a useful strategy for treatment of B-cell malignancies.

*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.*





## Letter to the Editor

*Each issue of the Torch invites readers to “Have your say” by sending letters, articles, or suggestions for articles to the editor of the newsletter. Recently the Torch received a letter from Raphael Altman, an IWMF member in England, outlining what he perceived to be disinterest in IWMF publications and in the medical community at large concerning the rare occurrence of tumors in WM. This letter is printed in full below. The response which follows was written by Dr. Robert A. Kyle, IWMF Trustee and Chairman of the IWMF Scientific Advisory Committee.*

*Alice Riginos  
Torch Editor*

Dear Editor,

I am addressing the topic: WM, Tumors, and the IWMF.

I have surveyed IWMF-Talk and found that of 1,000 members, 10 have solid tumors. That's 1%. Eight of these ten have enough abnormal IgM to be diagnosed WM but not enough to be a problem. Steven Treon states, “Most cases of LPL are WM, with less than 5% of cases made up of IgA, IgG and non-secreting LPL.” (All WM patients have underlying LPL) People reporting on IWMF-Talk have had tumors on the spine, in the foot, in the mouth – it seems like they can appear anywhere.

A word about words. Many doctors appear to be satisfied with the term ‘solid tumor’ to describe this phenomenon. Others suggest alternative terms such as ‘mass’ or even ‘aggregations of lymph tissue cells.’ What we decide to call the condition is less important than the implications of having it.

I have observed that there is currently no mention of it on the IWMF website. Nor is it mentioned in the ‘Introduction to WM’ or ‘For the newly diagnosed’ or ‘When to treat’ type of articles that have appeared in the *Torch* or in similarly-titled talks given at the annual Educational Forum. I believe this is an omission that stands to be corrected.

Firstly, the simple acknowledgement of a form of the disease affecting probably 1+% of patients would seem to be reasonable. Secondly, particular observations – and even suggested treatments? – relating to this section of patients might then have a greater chance of appearing on the WM radar. Thirdly, patients who might only monitor their IgM as a disease indicator would be less likely to make the mistake of thinking that good IgM readings alone are necessarily an indicator that all is well, when they could have indolent tumors quietly growing undetected.

For example: my first tumour (6 cm), inside the spinal column, was spotted because at diagnosis I presented with some back pain and was scanned. My second tumour (12 cm), on the outside of the spine, was missed, possibly for as long as 2 years, because my IgM counts continued to be fine and dandy. (It was eventually spotted because I started to experience a similar, albeit mild, back pain)

Risks of extra exposure to radiation notwithstanding, the dominant view among those on IWMF-Talk with tumors appears to be to scan at diagnosis and/or whenever unexplained pains might warrant scanning. Once someone has had a tumor, occasional scanning to pick up anything untoward could be considered.

As to the science of what is going on with these patients (let alone why this happens to particular individuals) there appears to be not a great deal available on the subject, presumably (and understandably) because researchers and clinicians are concentrating on the issues of elevated IgM which afflict the vast majority of patients.

Accepting the caveat that there are areas where the clear distinction between B-cells and plasma cells becomes less clear and where it even becomes unclear as to which cells are proliferative and which are IgM secreting, nevertheless in his paper ‘Pathological findings in WM’ Dr. Roger Owen writes “The dominant component is comprised of B-cells which are considered to be the proliferative fraction ... the second cellular component comprises plasma cells which are responsible for the production of IgM.” Elsewhere he states: “The clinical features of WM will likely form a continuous spectrum with the high IgM / hyperviscosity patients at one end and the patients with bulky lymph node disease (and tumors? – RA) and low IgM at the other.”

Raphael Altman

England

### RESPONSE

Mr. Altman has raised an important point about Waldenstrom's macroglobulinemia. When one mentions “solid tumors,” the hematologist/oncologist thinks first of cancer of the lung, colon, prostate, breast, etc., while Mr. Altman is referring to a mass which consists of malignant lymphocytes and plasma cells that are identical to those seen in the bone marrow of patients with WM. The bone marrow, lymph nodes and spleen are the usual sites of WM, but in a small number of patients (approximately 5%), masses or tumors of the malignant lymphocytes and plasma cells are found outside the bone marrow and the lymph nodes.

*Letter to the Editor, cont. on page 13*





The most critical site is involvement of the spine in which a tumor consisting of malignant lymphocytes and plasma cells compresses the spinal cord. The patient usually presents with back pain and may have numbness, tingling and weakness of the lower extremities as well as difficulties in bowel or bladder function. This is a “medical emergency” and the patient must have an MRI or a CT scan of the spine immediately to localize the tumor. Radiation therapy and dexamethasone are the usual therapy. I do not recommend routine MRI or CT scans of the spine of patients with WM, but if the patient has any symptoms suggesting the presence of a tumor compressing the cord, immediate evaluation is essential. As Mr. Altman pointed out, this can occur without any change in the M spike or IgM levels.

Malignant lymphocytes and plasma cells may involve the lung and appear as an infiltrate or a mass on the chest x-ray. The pleura may also be infiltrated by malignant lymphocytes and plasma cells and produce pleural effusion (fluid around the lungs). In addition, the lymph nodes in the chest may be enlarged and produce local symptoms. A tumor of lymphocytes and plasma cells may involve the orbit (socket of the eye) and produce prominence and reduced movement of the eye. Tumors consisting of lymphocytes and plasma cells may involve the gastrointestinal tract. The kidney

is frequently infiltrated by malignant lymphocytes and plasma cells, but they rarely produce any symptoms or kidney problems. The retroperitoneal lymph nodes are frequently enlarged and there may also be masses (tumors) consisting of lymphocytes and plasma cells in this area. The skin may be involved by papules or nodules consisting of the malignant lymphocytes and plasma cells. Rarely, lymphocytes and plasma cells may involve the meninges (membranes covering the brain). In that setting, one sees malignant lymphocytes and plasma cells in the cerebrospinal fluid.

In summary, the patient must report new symptoms or signs to their physician so that they can be appropriately evaluated. It is not necessary to routinely search for masses or tumors because one does not treat unless the patient is symptomatic or about to develop symptoms from the tumor. These complications from the growth of lymphocytes and plasma cells in an unexpected area must be evaluated carefully. It is important to keep in mind that these tumors may appear without a change in the serum M spike, IgM value, hemoglobin or other features of WM.

Robert A. Kyle, M.D.

Mayo Clinic, Rochester MN

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## COOKS' HAPPY HOUR

BY PENNI WISNER AND NANCY LAMBERT

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*Penni and Nancy are poised beside their processors and blenders, ready to pass a happy hour pureeing seasonal green vegetables and herbs full of vitamins and minerals.*

### Theme and Variations: Herb and Vegetable Pestos

You may think I have lost my seasonal frame of mind since I want to discuss pesto in February when the only basil available is from someone's greenhouse or indoor plant or from some politically-incorrect, thousand-mile distance from your house. But pesto, that unctuous, fragrant, addictive green sauce of basil, garlic, pine nuts, Parmesan, and olive oil, has developed a benign sort of multiple-personality disorder. No longer willing to be pinned down and confined to summer, pesto happily mixes it up and incorporates, oh, just about anything you'd like. But especially this time of year, pesto lends itself to thick, flavorful, vitamin-and-mineral-packed sauces based on winter greens.

Just to make sure you understand the lack of limits, you can make “pesto” of fresh or frozen green peas, lima beans, and edamame (soy beans). Oh, by the way, don't forget herbs such as cilantro and just about any kind of nut you can lay your

hands on. These pestos make delicious snacks smeared on crackers and croutons spread first, if you like, with a thin layer of cheese such as cream cheese. Choose low-fat if your New Year's resolution remains in effect.

Let's begin with a few basics. We do not intend to make a smooth puree appropriate for a fine restaurant. Instead, we plan to make rustic purees – no less delicious or beautiful than their more sophisticated cousins. You need a good food processor or powerful blender. And no matter whether your pesto will be based on greens or beans, you will need garlic, lemon, salt, freshly ground pepper, toasted nuts, chili flakes if you like heat, and extra-virgin olive oil.

For an emerald-toned pesto of greens, start with a pile of just about any winter green except red chard. Color, not flavor, is the problem with red chard. You can use mustard greens, too, but I would only add mustard greens to a mix, not make a whole batch with straight mustard. I often use a mix of greens – collards, dinosaur kale, green chard – that add up to about a pound. While a big pot of water comes to a boil,

*Cooks' Happy Hour, cont. on page 14*



strip the leaves off any tough stems. Reserve the stems for another use or compost them. Put a bowl of ice water in the sink. Now, salt the boiling water and quickly blanch the leaves, stirring them into the water so they cook evenly. Even collards need hardly more than a minute! Spinach requires a minimal dunking.

As soon as they are done, drain the greens and dump them into the ice water to stop the cooking. When they are cool enough to handle, gather the leaves into handfuls and squeeze out as much water as you can. Rough chop the leaves and set aside.

In a food processor, chop about 3 fat garlic cloves with a large pinch of salt. If you have roasted garlic, so much the better for you. Add the greens and process until they are finely chopped. Add the zest of a small lemon (out here in California, we have aromatic Meyer lemons and I use the zest of a large one), a good pinch of chili flake, freshly ground pepper to taste (start with 1/4 teaspoon and work up), and a large handful of toasted pine nuts. Pistachios would be excellent, too; if they are salted, don't add salt when chopping the garlic. Process until smooth, and then, with the machine running, add about 1/2 cup olive oil. The texture should be thick but loose. Taste, add a squeeze of lemon to brighten the flavors, blend it in, and then taste again. Adjust the flavors with salt, pepper, more chili flake perhaps, and lemon.

This wintry pesto tastes amazing on pasta, especially when tossed with roasted squash and freshly grated Parmesan cheese. Or use it as a topping for baked potatoes or sweet potatoes, polenta fries, or Alice's roasted potatoes. It keeps several days in the fridge or freeze it in ice cube trays and add a cube or two to tomato sauce or soups.

Talking of frozen pesto reminds me that now is a great time to be using up your supply of frozen basil pesto from last summer. Didn't make any? Then plan to this summer when big bunches of basil perfume the whole farmers' market. The method is the same as above; you are just using basil instead

of winter greens. Most recipes don't call for blanching basil for pesto but it's worth taking the time. Giving the basil a quick dunk helps preserve its color. The ingredients are nearly identical, too. Just omit the lemon and chili flake and pulse a handful of grated Parmesan into your pesto. To make an even more versatile basil puree, I often simply process blanched basil with olive oil and freeze that. Then, of course, I need to remember to label it correctly.

If you do have some frozen pesto or maybe a jar of it lurking in your fridge, then make some protein-rich pesto with edamame, baby lima beans (not dried beans!), or a spring pesto of basil and green peas, fresh fava beans, or asparagus. If your soy beans or peas have been frozen, just defrost them and go about your pesto making—pureeing the peas or shelled soy beans with garlic, lemon zest, basil pesto, salt, pepper, olive oil, and perhaps a little vegetable broth or chicken broth to loosen the puree. Baby limas need a few minutes cooking before you process them. For an asparagus pesto, trim the spears and blanch them just until tender in plenty of boiling salted water so they retain their color. Plunge them in ice water to stop the cooking, drain them well, and then process them with the rest of your ingredients.

You can make all sorts of herbal pestos, too. Instead of basil try a combination of cilantro and parsley and use it as a topping for burgers (beef, poultry, fish, or vegetarian—they all taste better with a dose of pesto) or steamed or grilled fish. Or add some fresh mint to your pesto. Mix it up with different nuts, too. Just toast them first to bring out their flavor.

On the menu for Happy Hour tonight, we have grilled (or roasted or broiled, your choice) mushroom caps stuffed with pesto. Sip your drink of choice and watch the sunset.

***Our motto: Eat Well to Stay Well***

*Surely you have a favorite snack that is healthy, fast, and easy? Penni (penniw@pacbell.net) and Nancy (llne3@aol.com) would like to hear from you!*

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## **THE BEN RUDE HERITAGE SOCIETY ENROLLMENT**

BY DICK WEILAND, VICE PRESIDENT FOR FUNDRAISING

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At the IWMF Board meeting on February 5, 2010, after three years of careful study the Board of Trustees approved comprehensive policies for planned giving and procedures to govern estate planning for the Foundation.

You will now be able to take advantage of more gifting opportunities so feel free to check the items of interest to you and your family on the form on page 15. Send your completed enrollment form in the enclosed envelope, and either Dick Weiland or Dave Benson will contact you with helpful information. If you are concerned that the rules of an individual state may restrict some philanthropic investment options for you, Dick and Dave can provide you with the answers.





# THE BEN RUDE HERITAGE SOCIETY ENROLLMENT

BY DICK WEILAND, VICE PRESIDENT FOR FUNDRAISING

*Significant resources have been generated for IWMF through the Ben Rude Heritage Society by legacy gifts. More and more members and friends are asking about the Society so we thought we would reproduce the enrollment form here and cordially invite you to become a member of the Ben Rude Heritage Society. We are confident your legacy will prove to be an inspiration to others. We hope also that you will consider providing information about your legacy by completing the form below so we have a full understanding of your wishes. Use the enclosed envelope to facilitate your response. If possible, please attach supporting documentation. Thank you.*

## **LEGACY GIFT**

I/We have arranged a legacy gift for the benefit of IWMF through my/our:

☐ Will      ☐ IRA/Retirement-Plan Beneficiary Designation      ☐ Trust      ☐ Charitable Remainder Trust

☐ Other (please specify): \_\_\_\_\_

Additional Information: \_\_\_\_\_

## **DESIGNATION**

This gift is to be used for the following purpose: **(please check one)**

☐ IWMF's Greatest Need      ☐ Research Fund      ☐ Dr. Kyle Endowment Fund      ☐ Fellowship Stipend Fund

☐ Other Named or Designated Fund: \_\_\_\_\_

## **GIFT DETAILS**

As of this date, the value of my/our gift is: the sum of \$ \_\_\_\_\_ or \_\_\_\_\_% of my/our estate or other gift plan, with the current value of the IWMF portion estimated at \$ \_\_\_\_\_. I/we understand that my/our estate **is not** legally bound by this statement of gift value.

## **RECEIPT OF GIFT**

This gift will be received by IWMF after the life of:

☐ The First Donor      ☐ The Surviving Donor/Spouse      ☐ Other Individual(s): \_\_\_\_\_

☐ Other Contingencies or Stipulations such as: \_\_\_\_\_

## **BEN RUDE HERITAGE SOCIETY HONOR ROLL LISTING:**

Name(s): \_\_\_\_\_

☐ Please enroll me/us in the Ben Rude Heritage Society using the Honor Roll listing above.

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Please note that all information will remain confidential to IWMF. For further information about the Ben Rude Heritage Society, please contact Dick Weiland at [rjweiland@msn.com](mailto:rjweiland@msn.com) or 507.645.2633



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# FROM IWMF-TALK

BY MITCH ORFUSS

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Several prominent threads ran through the comments on IWMF-Talk during the past three months. Recurrent discussion of sinusitis and gamma globulin therapy may well reflect the impact of the rough weather in much of North America this winter. Some also felt that pain in the joints, particularly the knee, might be aggravated by the cold. Many worry that WM may lead to another form of cancer and report their vigilance when a breast lump is detected. A possible cause-effect relationship between Rituxan and swollen legs is aired. And some thoughts on using Port-a-Cath are shared.

Speaking of sinusitis, respiratory infections, sore joints – doesn't a stay at the JW Marriott Resort and Spa in Las Vegas sound like just the ticket? The dry and warm desert climate sure seems appealing as this goes to press in March. Here's hoping many of you will enjoy the Nevada climate in April when you attend the Educational Forum with its multi presentations by WM experts. And the TALK will certainly flow when you meet your IWMF-Talk friends in person!

## PERSISTENT SINUSITIS

**Sandy Scheibe** asked if anyone experiences persistent sinusitis that does not respond to antibiotics, and, if so, what treatment(s) have been helpful. **Sylvia Cury** replied that chronic sinusitis happens because of low IgA and IgG, and, when it becomes worse with high fever, she needs IV antibiotics plus IVIg immunoglobulin.

**Everett Drugge** said he was given Augmentin for ten days by his ENT doctor and takes vitamin D supplements regularly. His sinusitis finally settled down but is a constant threat with cold weather where he lives as his IgA is less than 5 and IgG is about 40. This happens to Everett regularly – more so after his Rituxan treatments.

**Dr. Guy Sherwood** weighed in by saying that there are many "recipes" for sinusitis. Septra is one of Guy's favorites. It is inexpensive and works well for most patients. Guy reminds us that nothing works for viral sinus infections, which account for about 90% of all sinusitis. More important, says Guy, is prevention. Regular saline nasal wash (be it by neti pot or his favorite "squeeze" bottle) is a godsend. Sometimes Guy does nasal washes four times daily. If infections are too frequent, it may be time for IVIg. If sinusitis doesn't respond to antibiotics (sometimes it takes 3-6 weeks of antibiotics), one must worry

about fungal infections. In this case, time to visit the ENT for an evaluation. Do not jump to antibiotics too quickly – unless you are really sick or are especially immune-compromised. Guy usually waits a week before starting antibiotics himself. Most times he gets by without meds. Sinusitis is by far the most frequent problem for WM'ers, he says. Pollution and environmental allergies, which are increasing, do not help.

**Hank Stupi** added that a few years ago his oncologist at the time prescribed once daily Bactrim to prevent infections. Within weeks Hank's creatinine skyrocketed and did not come down until he stopped the Bactrim. Hank recommends caution about continued use of Bactrim if there are kidney issues.

## GAMMA GLOBULIN THERAPY

**Dr. Jacob Weintraub** writes that people with WM usually have low IgG and IgA, even before treatment. The abnormality that results in WM cells also interferes with normal production of IgG and IgA. Jacob had not had any treatment and his IgM had not gone over 1000 until last year, when IgG was only 275 and IgA 8. The body's complex immune system does not depend entirely on antibodies – the primary function of IgG and normal IgM. Some people have very few infections despite low IgG, and some have multiple on-going infections. Monthly gamma globulin (IVIg) infusions afford the body a new set of antibodies drawn from other people, but the level must be maintained monthly. Most WM patients who have received IVIg had it because of on-going, recurrent infections, and most have derived significant benefit from the monthly infusions, especially in winter. This solution is not perfect, but it really helps a lot of people.

**Daniel Hachig** agreed with Jacob, adding a few other comments: "Rituxan," he said, "doesn't significantly affect the IgA and IgG levels, despite B cell depletion. IgA and IgG are produced by differentiated B-cells known as plasma cells. Mature plasma cells don't normally express CD20, the target of Rituxan, so they are still around following Rituxan treatment and can generate antibodies. About 60% of WM patients have low IgA or IgG and about 50% are low in both. Significantly, these low levels don't seem to correlate with increased risk of infection, as studied by Dr. Treon's lab.

*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





If one is an MGUS patient, these low levels do correlate with increased chance of progression to WM.”

**Dr. Tom Hoffmann** wrote that Rituxan has a long-term effect on all our immunoglobulins. Rituxan kills all memory B cells, and, although it does not kill current plasma cells, it does prevent the formation of new plasma cells. All Ig’s typically decrease after Rituxan, and for many patients Ig’s may never return to their pre-Rituxan levels.

**Michael Toms** wrote that he has received IVIg infusions once a month for four years. Gone are the sinus infections, shingles, sore throats, infected skin lesions (e.g., a cat scratch), “sniffles” – and more – that Michael suffered all his life. He now sees what a “normal” immune system is like. The changes occurred after the first infusion. If he notices the start of a sore throat, a “scratchy” feeling that, in the past, used to be the harbinger of a full bore cold with bronchial involvement, he now deals with it by the “donated” IgG within 48 hours and calls the results “amazing.”

**Ann Fried** adds that her fiancé, age 74, has been receiving IgG infusions every 6 weeks for more than 3 years. Prior to that he had been getting repeated bronchial infections the last of which morphed into pneumonia. These repeated infections are what led his primary care physician to have his IgM level checked, leading to the WM diagnosis. Since his IgG infusions he has no longer had infections or side effects from the infusions themselves. He is pre-medicated with Benadryl, Decadron, and Tylenol.

**Bob Reeber** wrote that his hematologist indicated that the long-term prognosis from gamma globulin infusions (or IVIg) does not justify them. Other hematologists believe differently.

**Everett Drugge** said that IVIg infusions are very expensive. Everett suggested that *WebMD* gives good information on these proteins. He personally has not had infusions of IgG and does not think that IgA is available – so one may not be able to do much about low IgA except supplement with vitamin D to keep respiratory problems at bay.

#### RITUXAN ONCE MORE

**Ralph Applegate** asked for advice about whether plasmapheresis after treatment will diminish rituximab’s effect. After his last rituximab, Ralph’s WBC went down to 4.0, his SV went up to 5.0, his IgM went up to 11,180, his HgB fell to 8.3, and his platelets dropped to 170. **Bob Reeber** replied that in his understanding plasmapheresis is used to bring IgM down to prevent problems owing to hyperviscosity. Bob offered that, since Ralph has high IgM, there could be a flare as additional monoclonal IgM is released into the blood stream from some action of the Rituxan. Bob’s IgM reached 2500 mg/DL from 2000 with flare, a roughly 25% increase, that was caused by Bob’s first series of treatments. In his case his lipid panel also increased significantly requiring separate treatment.

#### SWOLLEN LEGS AND FEET

**Edna Talbert** reported that she’d started suffering from swollen legs and feet after flying for ten hours just two days after maintenance Rituxan. Edna’s legs “blew up” and never went down. **Dr. Tom Hoffmann** replied that Edna’s history of so-called blowing up right after a long plane ride is much more indicative of acute thrombophlebitis with subsequent chronic post-phlebotic syndrome. Tom asked if Edna is on blood thinners and had she had a venogram? Even a negative venogram, Tom suggested, would not rule out this scenario. It sounded to Dr. Tom as if Edna’s current Rituxan treatment was appropriate and not the cause of her leg problem.

**Arno Muller** wrote that he remembers a couple of years back taking some antibiotic during his prostate cancer treatment and reading a caution about the antibiotic affecting tendons and joints. Arno’s right foot got plantar fasciitis and he took painkillers and stopped playing tennis for a couple of months.

#### MAMMOGRAMS AND SELF-EXAMS

**Ellen Bresnick** wrote that her oncologist wanted her to have a lump removed from her breast – a lump that she was pretty sure was benign (and it was). Ellen’s oncologist felt strongly that WM patients are pre-disposed to other cancers. Ellen listened and did as she was told, which gave her tremendous peace of mind.

**James Mahood** observed that though having breast cancer (or any cancer) is a tragedy, he was unaware of any scientific or medical relationship between other cancers and WM – a medical, physiological, or genetic relationship. James asked if any other TALK readers thought there is such a relationship.

**Eve Cushing** responded that in her view it was psychological.

**Fay Langer** (our cryo patient), who has had three cancers other than WM, said that her oncologists believe that the cause of her WM is radiation that was administered thirty years ago to treat her first breast cancer. **Sandy Patton**, who is on watch and wait, added that she also had a lump removed that was fortunately benign, and the doctor felt that it was related to her WM. **Joanne Slate’s** oncologist felt the same way when she had what turned out to be a benign lump removed in November.

#### KNEE PAIN

**Laurie Fraser** wondered if any TALK readers feel knee pain in the cold weather. Laurie has had WM for 8 years and most winters she seldom feels cold in her knees. This past winter it was uncomfortable most of the time and hurt a lot. Laurie made a knee blanket for her car to put over her knees while driving – even in a warm car. Laurie also uses a blanket on her knees while watching TV. The discomfort had become so bad she began thinking of wearing ski silks or long johns to keep her knees warmer.



**Bob Reeber** said that he doesn't have knee pain or at least not more than the occasional ache. He does, though, have weaker knees, which he'd noticed when the weather became colder. When working outside he uses kneepads to help protect the knees. Whether his weaker knees come from WM or statin-related cholesterol treatment is hard to say. "I do know," says Bob, "that since I have gone on Niaspan, red yeast rice and green tea extract, my knees have been better. Part of it probably is owed to reduced muscle strength with age: "If you don't use it you lose it."

**Gerry Wergland** said she does not have knee pain yet but has experienced severe back pain (not WM related). Gerry's PCP prescribed a Lidoderm Lidocaine patch 5% and that worked immediately to ease the pain, where Tylenol and Advil did not. The patch was 10cm x 14cm and may come in other sizes. They can be easily cut with scissors. The only downside is that they can be left on no longer than 12 hours in a 24-hour period.

**Sandra Adamson** added that she is experiencing knee ache for the first time. Sandra said that she has been receiving IVIg infusions for the past five months and notices that following an infusion her knees feel much better.

**Bob Kallish** cautioned that not every ache and pain can be blamed on WM. Bob said we get older and wiser but crankier.

## PORT-A-CATH

**Steve Baylus** asked if anyone would share experiences with a Port-a-Cath. His oncologist had suggested it as a possibility after having enduring arm pain following two Treanda infusions. **Dr. Tom Hoffmann** replied that the advice to get a Port-a-Cath must be tempered with the reason for the arm pain and the planned number of infusions left to go. Steve clarified that he believes his arm pain was from the Treanda infusions, which were painful even during the infusion. Steve was at that point scheduled for four more monthly infusions.

**Sarah** offered that she had a port-a-cath for about a month to six weeks when she first began treatment. It was used for plasmapheresis prior to CRP (Cytoxan/Rituxan/prednisone). Sarah did not like the cath: she was aware of its presence in her body, it was physically uncomfortable, and she was unable to swim which along with yoga is how she manages. She noticed that the veins in her hands suffered from the IV. Sarah advises that if one's treatments are painful or harmful to the veins and are scheduled to be long term, the cath might be a good choice, if one's doctor concurs.

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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 21-22.*

### IWMF CHAPTERS – USA

#### ARIZONA

In March, approximately 50 people attended a session on WM at the Lymphoma Research Foundation (LRF) Regional Workshop in Scottsdale, AZ. Dr. Joseph Mikhael of the Mayo Clinic gave a two-part presentation and answered many questions. IWMF partnered with the LRF to coordinate this special session and attendees were treated to a delicious breakfast and lunch.

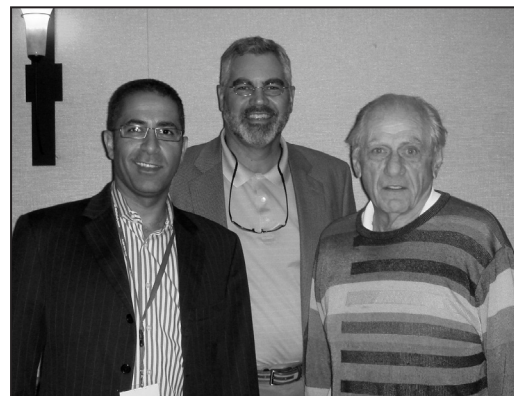
#### CALIFORNIA

*Orange County*

"Real Life WM experiences" will be the theme of the Saturday 24 April 2010 meeting from 2 to 5 pm held at the Hoag Cancer Center conference room. This will be an opportunity for each attendee to share his/her experience with WM, provide support to others, and hopefully learn something of benefit from the exchange. In addition, members who attended this year's IWMF Ed Forum, April 9-11, in Las Vegas, will share their "best of" recollections.

*Sacramento and Bay Area*

After ten and eight years, respectively, **Penni Wisner** and **Cynthia Nicholson** are stepping down from their facilitation of the Northern



From left to right: Dr. Joseph Mikhael of the Mayo Clinic and IWMF member John Dethloff with Ed Nadel, AZ support group leader.

*Support Group News, cont. on page 19*



California group. Where did all that time go?! They are both well but need to focus on their respective businesses: kitchen coaching and graphic design. **Alyce** and **Terry Rossow** will take over as leaders. The next meeting is planned for 23 May at the usual spot, Kaiser Permanente in Vallejo.

### GEORGIA

The Georgia Waldenstrom's support group met on Saturday 27 February at 1 pm. The guest speaker was Ms. Tiffany Barrett, MS, RD, LD, Clinical Dietitian Specialist, hematology-oncology department at Emory's Winship Cancer Institute. The meeting was held at the Sandy Springs Wellness Community Center. The center is located at 5775 Peachtree Dunwoody Road, Sandy Springs, GA, <http://www.thewellnesscommunity-atlanta.org>.

### ILLINOIS

The Chicago area support group, including SE Wisconsin, had its first potluck dinner on Saturday 13 February. Although originally planned for smaller groups of 8 to 10 to meet and eat in several locations, due to cancellations the whole group very much enjoyed **Patricia** and **Chris Madden's** wonderful hospitality at their home. **Sara Thran's** brainstorm brought together a new-member couple with some veteran WMers. The group looks forward to the next meeting planned for Saturday afternoon 24 April at Lutheran General Hospital in Park Ridge, IL. Plans include showing a video on the new treatment drug bendamustine.

### NEW ENGLAND

#### Boston

The New England Waldenstrom's macroglobulinemia support group met in February at the Jimmy Fund Auditorium of the Dana-Farber Cancer Institute in Boston. A good crowd of thirty people braved a cold but clear night to hear Zachary Hunter give a presentation on the results to date of his study of familial Waldenstrom's macroglobulinemia. For the past seven years, Zachary has been working with Drs. Treon and Ghobrial in the Waldenstrom's program at DFCL. He has gathered and analyzed measurements from 482 individuals representing 148 families. Zachary was able to divide the families into three groups: those with just the patient having WM, the second group having 2 or more cases of WM, and the third group having just the patient with WM and other family members having some other B-cell disorder.



Zachary Hunter at the podium answering questions from the audience on his work.

Zachary also described the results of comparative gene analysis between people with WM and a group of healthy donors. He was able to identify certain genes that were more up-regulated in the WM patients. These findings may help to better understand our disease. Zachary will be speaking at the 2010 IWMF Educational Forum in April. That would be a great opportunity to hear a more complete explanation of his work to date, to ask questions, or discuss participating in the familial study. **John Paasch** of the Boston group and his brother have joined the familial study and have wagered (not the Las Vegas kind!) that the more participants Zachary can enlist, the more all WMers will benefit.



Friends and foodies: members of the Eastern New York / Western New England support group. Left to Right: standing are Jonathan Oseas, Karen Cadden, Ron Goss, Sissy Horowitz, Doug Jones, Tom Zolezzi, Kay Zolezzi; seated are Pam Fox, Frank Ferro, and Mel Horowitz.

### NEW YORK

#### Eastern New York/Western New England

A cheerful and colorful group met at the end of January at the wonderful Latham, NY, Gilda's Club. The cold northeastern winter temperatures and lack of snow failed to dampen anyone's spirits. **Doug Jones** reviewed the impressive Brooklyn LRF Educational Forum that he and his wife Kim attended. Several members talked about their continued "watch and wait" status or their current treatments. There was great interest in **Tom Zolezzi's** report of his good results in the enzastaurin trial. After the lunch break, which included **Karen Cadden's** excellent tabbouleh, the group watched the "Understanding Your Blood Tests" DVD from the 2009 Forum and discussed plans for attending the 2010 Las Vegas Forum. While this issue of the *Torch* progressed through its production schedule and headed to mailboxes in late March, the group met again to enjoy limitless Chinese food, great friendship, and conversation in a private room at the Capital Buffet in Colonie, NY. How many trips can one person make to the many temptingly tasty and unique food selections? Members are mum on the subject. The next gathering is planned for Saturday 22 May when this food-first group will – among other discussions – plan their annual August picnic!

Support Group News, cont. on page 20





### NEVADA

The Las Vegas, NV, WM support group met in early January at the newly refurbished Southern Nevada Leukemia and Lymphoma Society office conference room. Thanks to LLS, the group now (finally) has a lovely place for quarterly meetings. At the end of the same month, several members met for lunch at a local restaurant, sharing lots of information over a good meal. The next meeting takes place at the Las Vegas Ed Forum: a 12:30 pm lunch at the Promenade Cafe, JW Marriott, on 9 April. Future meetings will be held at the LLS office from 1 to 3 pm on 9 July and 12 November.

### WESTERN OHIO, EASTERN INDIANA, & NORTHERN KENTUCKY

Unfortunately, the January meeting was cancelled. But the next meeting is scheduled for 17 April, following close on the heels of the Las Vegas forum.

### PENNSYLVANIA

*Central and Southeast PA and Northern MD*

Light snacks and chocolate brought by **Rita Ziats** and her sisters rewarded group members who ventured out in the less than lovely weather on Valentine's Day. Due to the recent storms and several members' winter residency in Florida, the group was smaller than usual. A general discussion of current treatments provided the reassuring news that most were doing well, which is always a joy to hear. The group delights not

### 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.

only in treats and chocolate: laughter is always on the agenda. In fact, the group hoped to have a certified "laugh counselor" speak (?) at the next meeting, 16 May 2 pm, at Messiah Village. **Dr. Jim Yaeger** often sends the group home laughing by telling several jokes at the end of meetings. A recent story focused on a timely topic: diet. A doctor put a patient on a diet in order to lose 10 pounds. He was to eat normally for two days and then skip the third day, and then repeat for one month. On his follow-up visit, the patient had lost 25 pounds and looked terrible. When answering the doctor's questions, the patient said that, no, he hadn't had trouble following the diet, but the skipping on the third day not only wore him out, but he had also worn out a pair of shoes!

### SOUTH CAROLINA

The South Carolina support group plans to hold its next meeting in the early summer in the Charleston area. A fall meeting will be held in Florence.

### WASHINGTON D.C./METROPOLITAN AREA

In March, Dr. Mary McMaster of the National Cancer Institute, Genetic Epidemiology Branch, spoke to the group about her work on the familial aspects of WM. And Dr. Ashraf Badros of the Greenebaum Cancer Center, University of Maryland, has confirmed that he will be the speaker for the following meeting on Sunday 16 May at 2:30 pm at Holy Cross Hospital, in Education room 2, on the first floor. More meetings are planned for 12 September and 14 November.

## IWMF CHAPTERS – INTERNATIONAL

### IRELAND

Anne Staples, the group leader, is planning the next meeting for 25 April 2010.





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# THE LIFELINE

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If you can't get to a local support group meeting, use our IWMF Telephone and E-mail Lifeline to call a WM veteran. The Lifeline provides telephone numbers and e-mail 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](mailto:info@iwmf.com).*

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## REQUEST FOR TELEPHONE AND E-MAIL LIFELINE VOLUNTEERS

Recently, the office has heard from patients who have questions about perifosine and ofatumumab. If you have experience with perifosine and/or ofatumumab and would be willing to answer questions and share experiences about these treatments, we would appreciate hearing from you and to publish your contact information in the Lifeline that appears in each issue of the *Torch* and at the IWMF website. The Telephone and E-mail Lifeline is a valuable resource for putting patients in touch with each other so that they may discuss WM disease-specific issues.



# THE LIFELINE

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Eye Care Center West



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Carol Scott  
James & Carol Shiner  
Colleen & Gary Smith  
Douglas & Karen Storrs

**In honor of Marilyn Oliver:**  
David & Lynn Eikenberry

**In honor of James Ortoleva's Birthday:**  
Louise Stiller

**In honor of John Osborne:**  
Jean Osborne

**In honor of Joseph Palermo:**  
John & Mary Palermo  
Robert Palermo

**In honor of Mike Pennington:**  
Karen Blocksom

**In honor of Karen Pindzola:**  
Lauren Courtney

**In honor of Anna Mae Quitter:**  
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**In honor of Colin Rainford:**  
Angie Hall

**In honor of David & Diana Raushi:**  
Thad & Sylvia Raushi

**In honor of Thad & Sylvia Raushi:**  
Kyle & Deborah Brunelle

**In honor of Alice Riginos:**  
Corinna Riginos  
Vasilis Riginos  
Eleanor Swift

**In honor of Alyce Rossow:**  
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**In honor of Susan Rubenstein:**  
Christine & J.B. Bakalar  
Rubenstein Family Philanthropic Fund of the  
Jewish Federation of Metropolitan Chicago

**In honor of Roda Salvador:**  
Chris Duggan  
Delores Larrier

**In honor of Fritz Shaw:**  
Karen Fitzgerald

**In honor of Ronald & Ann Shelffo's  
50th Wedding Anniversary:**  
Larry & Regina Albard  
Irene Alexander  
Ray & Marie Anel  
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Mary E. Beres  
Cecile & Martin Bradshaw  
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Andrew & Beatrice Schultz  
Eleanor Secord  
Barbara & Art Shaw  
Mary & James Souza  
Philip Spletzer  
Dorothy Stix  
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Marjorie Towle  
Eileen Vici  
Howard Watkins  
Carole & Phil Woods  
Marie Zagone

**In honor of Norm Thompson, M.D.:**  
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Mark Petersen & Krystal Burge

**In honor of Tom Thompson:**  
Robert Reder

**In honor of Nancy Tucker:**  
Glenn Tucker

**In honor of Rudy Weber:**  
Anna Weber

**In honor of Richard Wieland:**  
Dr. Bob Kolasa & Loie Lenarz

**In honor of JoAnn Wiele:**  
Joyce Hagemann

**In honor of Marcia Wierda:**  
Rick Costen  
Evelyn Hamberg

**In honor of Chris Wiman & Danielle Chapman:**  
Bill & Gayle Harnes  
Brent & Christine Harnes

**In honor of Bob Zehner:**  
Tom McElwee





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## THE LAST WORD

BY SARA MCKINNIE

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*From left to right: Julie Jakicik, Sara McKinnie, Jordan Lanier-Nall*

### MEET THE IWMF OFFICE STAFF

The IWMF Business Office is located in Sarasota, Florida, and is responsible for coordinating a wide variety of administrative and support services. Three skilled and capable ladies work part-time to keep up with a growing workload and keep things running.

**Office Assistant Julie Jakicik** has experience in office administration, project management and computer information technologies. She has excellent secretarial and organizational skills and is fluent in Excel, PowerPoint and desktop publishing

applications. Julie joined IWMF in 2009 and handles the fulfillment of literature requests and newly diagnosed patient information packages. She also manages purchasing and inventory of office supplies, addresses computer software and hardware issues and assists in maintenance of the IWMF website. Julie Jakicik – Office Assistant = [office@iwmf.com](mailto:office@iwmf.com)

**Bookkeeper Jordan Lanier-Nall** has degrees in both accounting and finance and also an impressive background working with other non profits. Jordan's prior experience includes working on financial audits, cash flow analysis, investment instruments and development of investment policies. She manages the IWMF membership database and the processing of all donations received by IWMF. Jordan Lanier-Nall – Bookkeeping, Accounting = [admin@iwmf.com](mailto:admin@iwmf.com)

**Office Manager Sara McKinnie** was hired by IWMF founder, Arnie Smokler in 1997. Sara reports to the Board of Trustees and oversees most member services operations, including the *Torch* newsletter production. Specific support activities include preparation, analysis, and negotiation involved with IWMF operations. She also plans conferences and meetings and focuses on membership outreach by facilitating IWMF's growing support group network worldwide. Sara McKinnie – Admin, Member Services = [info@iwmf.com](mailto:info@iwmf.com)