

## DOCTOR ON CALL: ROBERT A. KYLE

*With this issue the Torch begins a new series, Doctor on Call, in which a leading WM specialist discusses a specific aspect of the disease in an article written for the IWMF membership. The Torch is proud to introduce this series with an article by Dr. Robert A. Kyle, clinician and researcher, who has been "on call" for Waldenstrom's patients throughout a distinguished career that extends from the era of Dr. Jan Waldenström to the present.*

### **Monoclonal Gammopathy of Undetermined Significance (MGUS) and Smoldering Waldenstrom's Macroglobulinemia (SWM)**

*by Robert A. Kyle, M.D.  
Mayo Clinic, Rochester, MN*

Monoclonal gammopathy of undetermined significance (MGUS) is defined as a monoclonal (M) protein in the serum of 3 g/dL (grams per deciliter) or less, fewer than 10% plasma/lymphocytoid cells in the bone marrow, and no evidence of hypercalcemia, renal insufficiency, anemia, or bone lesions (CRAB) related to the plasma cell proliferative disorder. MGUS is found in 3% of the population 50 years of age or older and in 5% of persons older than 70 years. The M protein may be IgG (69%), IgA (11%), IgM (17%), or biclonal (two M-proteins) in 3%.

MGUS is more common in men than women (3.7% versus 2.9%). Patients with an IgG or an IgA MGUS progress to multiple myeloma and, less frequently, to light chain (AL) amyloidosis. Patients with an IgM MGUS progress to lymphoma, Waldenstrom's macroglobulinemia, chronic

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## **DR. GERTZ HONORED AT KOS WORKSHOP**

Dr. Morie A. Gertz of the Mayo Clinic, Rochester, MN, was honored as the first recipient of the Bob Kyle Award on the opening day of the scientific program at the Fourth International Workshop on WM held in June on Kos Island, Greece. The Bob Kyle Award, presented by colleagues and peers in the international circle of WM specialists, acknowledges Dr. Gertz' tireless effort devoted to the understanding of Waldenstrom's macroglobulinemia. Well-deserved, Dr. Gertz!

## ED FORUM COMING UP!

The annual Educational Forum, set for May 16-18 in Los Angeles, will bring together hundreds of patients and caregivers to hear about recent progress in understanding our disease from leading WM researchers and about treatment options from top clinicians. Among those reporting on medical research are Drs. Stephen Ansell, Irene Ghobrial, Linda Pilarski, and Steven Treon who are all supported by the IWMF Research Fund in their on-going projects.

A very special presentation this year will be the introduction of the new patient data base and demonstration of its value to patients and physicians when confronting the possible symptoms and courses of WM and comparing important similarities and differences among patients. We will have Dr. Guy Sherwood presenting on immunology to help us understand our own issues on this subject.

A number of sessions will also focus on the practical details of living with a long-term disease, from negotiating disability benefits to adopting a healthy lifestyle. Veteran Forum attendees and newly diagnosed patients alike will find topics of interest and benefit.

For registration information, along with more details about the program, visit the IWMF web site ([www.iwmf.com](http://www.iwmf.com)) and click on the "Education Forum" box at the top of the page.

Don't delay! The Educational Forum will surely sell out before the opening date, as it usually does.

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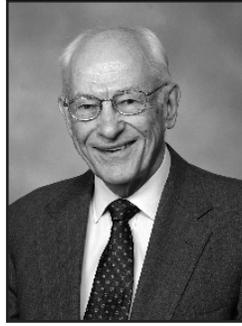
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## **CAREER HIGHLIGHTS: ROBERT A. KYLE, M.D.**



Dr. Kyle earned his medical degree from Northwestern University Medical School following his graduation from the North Dakota State School of Forestry and the University of North Dakota, Grand Forks. He did his residency training in internal medicine at Mayo Clinic—a first affiliation with the institution where he would earn his exemplary reputation as both clinical physician and medical researcher. Following his residency at Mayo Clinic, Dr. Kyle completed a fellowship at Tufts University under the mentorship of William Dameshek, M.D., and a postdoctoral research fellowship from the National Cancer Institute. He then joined Mayo Clinic in 1961. At Mayo Dr. Kyle served as the William H. Donner Professor of Medicine and Laboratory Medicine and as Section Head and Chairman of the Division of Hematology. At present he is Professor of Medicine, Laboratory Medicine, and Pathology at Mayo Clinic College of Medicine.

In 1963 Dr. Kyle performed the first bone marrow transplant at Mayo Clinic. In the course of his career he coined the terms “Monoclonal Gammopathy of Undetermined Significance” and “Smoldering Multiple Myeloma”, as well as “Idiopathic Bence Jones Proteinuria.” He is recognized for landmark contributions in the epidemiology of monoclonal gammopathy of undetermined significance. At the Mayo Clinic College of Medicine, moreover, his reputation is that of a tireless educator, having helped train over 200 practicing hematologists. He was also named Teacher of the Year in Internal Medicine. Judging from the warm blend of wit and wisdom he exhibits at the Ask the Doctor sessions of the IWMF Educational Forum, Dr. Kyle must have been a perennial favorite with the students at the College of Medicine.

Dr. Kyle’s research has been published extensively, including more than 750 peer-reviewed articles, and he has made a number of important contributions to the medical literature. He has been co-editor of four editions of *Neoplastic Diseases of the Blood* and co-editor of three editions of *Myeloma Biology and Management*.

*Career Highlights, cont. on page 13*



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## IWMF RESEARCH GRANT UPDATE: STEPHEN ANSELL

*The IWMF sponsors advanced research projects to understand the development and progression of WM and ways in which it can be controlled and cured. The IWMF Research Committee asks its*



*grantees to prepare summaries of their research grants periodically to inform members about those projects and the progress of their research efforts.*

*The following article by Dr. Stephen Ansell of the Mayo Clinic, Rochester, MN, provides a summary of his group's research on BLyS and other proteins that stimulate the production of monoclonal IgM from WM tumor cells. Controlling*

*IgM production may well control many of the autoimmune effects associated with WM and may ultimately lead to control of WM.*

*Tom Myers, Research Committee Chair*

### **The Monoclonal Protein in Waldenstrom Macroglobulinemia: “A Good Friend Gone Bad”**

*by Stephen Ansell, M.D., Ph.D.*

Waldenstrom macroglobulinemia (WM) is a B-cell malignancy characterized by the increased production of a monoclonal IgM protein (an antibody that usually protects against infection but is overproduced in WM) and an infiltrate of lymphoplasmacytic lymphoma B-lymphocytes (B-cells) in the bone marrow. Commonly patients have associated symptoms such as anemia, enlarged lymph nodes or an enlarged spleen, and hyperviscosity of the blood. While some patients may have few or no symptoms, at least initially, others may develop complications due to the infiltration of the cancerous B-cells in the bone marrow or secondary to the structural and flow characteristics of the monoclonal protein.

Symptoms at the time of diagnosis are due to the cancerous B-cells or the monoclonal protein the malignant cell produces. Symptoms related to the increased number of cancer cells are often non-specific, but many patients may present with fatigue and malaise owing to varying degrees of anemia. The anemia is usually due to the increase in the number of cancer cells in the bone marrow or is due to changes in factors that stimulate red cell production. The malignant B-cells of WM can infiltrate other organs and result in liver and spleen enlargement or in enlargement of the lymph nodes. Symptoms related to the monoclonal IgM protein are attributable to its characteristics in the circulation, its interaction with various body tissues when deposited, and its autoantibody activity.

## Effects of Increased Monoclonal IgM

The large size and increased concentration of the IgM in the blood leads to an increase in blood vessel resistance and increased blood viscosity. Serum hyperviscosity is a distinguishing feature of WM, but it is seen in fewer than 15% of patients at diagnosis. Hyperviscosity causes patients to feel sick and may result in bleeding, visual, neurologic, and cardiovascular problems. Heart failure may develop because of the expanded blood volume. Abnormalities in bleeding and clotting occur from the interaction of IgM with clotting factors in the blood. The circulating IgM may also precipitate at cooler temperatures and present as a condition called cryoglobulinemia. These patients may have Raynaud syndrome, joint pain, bleeding in the skin, and skin ulcers. Hyperviscosity is usually treated with plasmapheresis, but this only decreases the monoclonal protein temporarily.

IgM can be deposited in the kidney, intestine, and other organs. This may result in increased protein in the urine, diarrhea and poor absorption of food from the bowel, skin nodules, and other organ problems. The increased IgM can also be associated with primary amyloidosis. Amyloidosis develops because light chains from the monoclonal protein are deposited in various tissues in the body and occurs mainly in the heart, peripheral nerves, kidneys, soft tissues, liver, and lungs. Deposits of IgM result in impairment of the function of these organs.

The IgM protein can cause various autoimmune symptoms in WM. In some patients, the IgM reacts with red blood cells causing the cells to break down particularly at low temperatures resulting in a chronic immune hemolytic anemia. Other patients with WM present with or develop IgM-related peripheral neuropathy (nerve malfunction). The neuropathy develops when the monoclonal IgM interacts with various glycoproteins or glycolipids in the peripheral nerves. This most commonly results in loss of the myelin nerve sheath and subsequent loss of nerve function.

## Current Research

While other research groups have focused on what makes the malignant B-cells in WM survive and grow, our group is doing research predominantly on what regulates the production of the monoclonal protein. Although it is expected that treatments that kill the cancer cells will certainly suppress the IgM production, WM cells in many patients become resistant to treatment, and the symptoms related to the monoclonal protein then become an increasing problem. If therapies that permanently decreased the serum IgM were available, these would be very helpful in improving the quality of life of patients with WM.

Our research has investigated two facets of IgM production—namely what stimulates the cancer cell to make the

## PRESIDENT'S CORNER

by Judith May

For this edition of President's Corner I would like to share with you some recent information I've gleaned from resources available for cancer patients. I hope you find this useful.

### **Sixth Annual Cancer Survivorship Series: Living With, Through & Beyond Cancer**

A three-part telephone education workshop program presented by CancerCare in collaboration with the National Cancer Institute, the Lance Armstrong Foundation, the Intercultural Cancer Council, Living Beyond Breast Cancer, and the National Coalition for Cancer Survivorship.

This **free** series offers cancer survivors, their families, friends, and healthcare professionals practical information to help them cope with concerns and issues that arise after treatment ends.

Part I **April 22: The Importance of Communicating with Your Doctor About Follow-Up Care.**

Part II **May 13: Rediscovering Intimacy in Your Relationships Following Treatment**

Part III **June 24: Survivors Too: Family, Friends and Loved Ones**

All of the workshops take place from 1:30 to 2:30 pm Eastern Time.

These workshops are **free** – no phone charges apply, but pre-registration is required. To register simply go to the CancerCare web site [www.cancercare.org/TEW](http://www.cancercare.org/TEW)

### **Use of Vitamin and Mineral Supplements Among Cancer Patients**

Researchers have found that, while vitamin and mineral supplement use is widespread among cancer patients and survivors, up to 68% of physicians may not know when their patients are using them. The finding highlights the need for doctors to discuss supplement use with their cancer patients, and vice-versa.

Many cancer patients and survivors believe that vitamin supplements can reduce treatment side effects, decrease the chances of cancer recurrence, and improve their survival. However, studies addressing these topics are inconsistent or inconclusive—and many doctors worry that supplements can interact with cancer treatments or have other unintended consequences.

Drs. Christine M. Velicer and Cornelia M. Ulrich of the Fred Hutchinson Cancer Research Center wanted to investigate how widespread this problem might be. With funding from NIH's National Cancer Institute (NCI), the researchers analyzed 32 studies published between 1999 and 2006 that addressed vitamin and mineral supplement use among U.S. adult cancer patients and survivors. Their results were published in the February 1, 2008, issue of *Journal of Clinical Oncology*.

The researchers found extensive supplement use among cancer patients and survivors. In studies combining data from different types of cancer, 64-81% of survivors reported using some kind of vitamin or mineral supplements, and 26-77% reported taking multivitamins. Breast cancer survivors reported the highest use, with consumption of any vitamin or mineral supplements ranging from 67% to 87%, and multivitamin use ranging from 57% to 62%. In comparison, about half of all adults in the US take vitamin or mineral supplements, and about a third use multivitamins.

The researchers also found that between 14% and 32% of survivors started using supplements after their diagnosis. Women and people with higher levels of education were more likely to use supplements. Strikingly, the study found that 31-68% of cancer patients and survivors who use supplements may not discuss it with their doctors.

“Knowing about supplement use is crucial for doctors,” Ulrich explained. “Some vitamins, such as folic acid, may be involved in cancer progression while others, such as St. John's Wort, can interfere with chemotherapy. However, we really need more research to understand whether use of these supplements can be beneficial or do more harm than good.”

This study highlights the need for more research into how dietary supplements affect cancer treatment, survival and quality of life. To that end, NCI is currently conducting a number of clinical studies into different food components, many provided as dietary supplements, to determine their impact on cancer prevention and therapy. In the meantime, it's important for doctors and cancer patients to discuss any supplement use.

**Related link: Cancer Care.** Go to [www.cancer.gov](http://www.cancer.gov) and select 'Cancer Topics' and search 'nutrition'



# VOLUNTEERISM: A SOURCE OF GIVING

by Dick Weiland

When Alexis de Tocqueville wandered through the USA in the early 1800's he was struck by the drive of Americans "to help one another." The same is true today. Non-profit organizations in this country are dependent on the good will and support of the public. Among the most important of all resources available to an organization is the voluntary sharing of time and energy by its members. This is certainly the case for the IWWMF. Over the years we have had a terrific range of volunteer activities to raise funds and rouse friends. And we need even more help as we plan for the future while building on our past.

## A Review

Consider the many "**a-thons**." Our band of volunteers has raised funds by running, rowing, biking, driving, hiking, swimming, walking, or golfing. For example: **Bob Lynch's** Row-Bob-Row project of paddling up the coast of Florida, or **Barbara Backer's** walk over the Brooklyn Bridge, or **Peter Steele's** bike ride through the hills of Wales, or **Emily's** marathon that generated close to \$200K in 2006.

And let's not forget about "**special events**" such as **Lisa Lawton's** and **Nancy O'Soro's** 2007 annual fundraiser, "DJ, Dancing, Raffles, Laughter and Fun." Daughters of WM mothers have had benefits in bars on both coasts; **Heather Keaton** (daughter) and **Suzanne Machesney** (Mom) led an Avon fundraiser. Or what about **Laurie Ach** who has sponsored a "crafting for a cure" project and a jazz concert in the Chicago area?

Young family members, too, have done their part on behalf of a WM relative. **Jackie Romanello's** nephew selected Waldenstrom's as a sociology class project when he was assigned to choose a cause and learn about it. Prompted by this project, her nephew then went door-to-door and collected \$26.00 for WM research.

Recently, **Nancy Lambert** coordinated the Blue Tulip project: Nancy and eight others worked in four flower stores for five hours and raised almost \$800 for the IWWMF. And **Arlene Hinchcliffe** is currently planning to hold a special auction on a boat in Canada this coming fall.

"**Creative writing**" should not be omitted from our list of "things that help people." For example, **Carole Cohen's** Waliday Cards are still a big hit for WMers who want to send cards to friends or relatives on special occasions. Memorial and Tribute cards are also available through the office by contacting Sara. And, while we are in the writing realm, let's not forget those among us who have given proceeds from book royalties – for example, **K. Gordon Green** and

his book *Confessions of a Wooden Boat Lover*. By the way, Gordon also wrote over one hundred letters with a big dash of humor to generate funds for IWWMF research. And there are more—lots more—examples of creative use of writing for our cause.

## A Preview

We need help with future events. Practically every week we get requests for advice about some kind of "gig." WE NEED VOLUNTEERS TO SERVE AS A RESOURCE for folks considering special fundraising activities. A "resource person" could support, or critique, or recommend options, or comment on IRS regulations, etc., etc., in order to get projects off the ground. Could you help? If so, complete the questionnaire on page 31.

We need help to increase income from membership fees. The Member Services Fund is the life-blood (so to speak) of a non-profit such as ours. As you know, all operating expenses for the IWWMF are paid for from this source—and, as Jim Bunton has reported over the years, these expenses are under 12% of income, which is excellent when comparing the IWWMF to similar organizations. However, in 2007 we fell short of the goal set for income to the Member Services Fund. The Board has, accordingly, endorsed new strategies for FY '08. Consequently: WE NEED VOLUNTEERS WITH MARKETING SKILLS WHO THINK CREATIVELY to help us achieve the goal for 2008. Could you help? If so, complete the form on page 31.

We need help with the Research Fund. Last year about 30 of our members volunteered to contact other WMers to ask for funds. But a third of this group fell ill and were unable to follow through. Despite these challenges, the remaining volunteers, an intrepid group, raised over \$175,000 in cash or pledges in less than a year. We now need additions to the corps to do one or two jobs. The first is to help solicitors by opening the door to potential benefactors. The second is to actually call on donors to ask for a gift. Our mission is to raise \$1 million each year for the Research Fund. To this end we will be enlisting the services of a part-time professional fund-raiser who will depend on IWWMF volunteers to help contact benefactors with the potential to further our mission. SO WE NEED VOLUNTEERS WITH AN INTEREST IN SERVING AS A SOLICITOR OR AS A "PARTNER" IN THE PROCESS OF MAJOR GIFT SOLICITATION. Could you help? Want to hear more? If so, complete the form on page 31.

A heart-felt thanks to all those who have helped—and to those who are helping and those intending to help—to create a force of human fire-power with the potential to find the cause and the cure for WM.

# AMYLOIDOSIS

by Sue Herms

Amyloidosis is a group of diseases caused by the buildup of an abnormal protein, called amyloid, in various tissues and organs of the body. The amyloid protein forms fibers that may injure these body parts or interfere with their normal functioning, and the protein may be deposited in a localized area or systemically (throughout the body). There are approximately 25 different unrelated proteins that are known to form amyloid fibers in the human body.

The classification of amyloidosis can be confusing. Historically, the type of amyloidosis was based on whether it was primary (meaning that its cause was either unknown or associated with plasma cell disorders such as multiple myeloma or WM), secondary (indicating that it was associated with an inflammatory condition such as rheumatoid arthritis or Crohn's disease), familial (genetic), or localized. Examples of localized types of amyloidosis include those suspected of being associated with Alzheimer's disease, Parkinson's disease, and Huntington's disease, which affect only the brain. There are also amyloids that involve only the eye, the pituitary gland, the skin, or other specific locations.

As amyloid proteins were analyzed and became better understood, a newer classification was developed, based on the chemistry of the particular protein involved. Amyloidosis types are now more properly referred to by a capital letter designation which includes an "A" for amyloid followed by a capital letter abbreviation for the particular amyloid protein.

For instance, the primary amyloidosis associated with plasma cell disorders, such as multiple myeloma and Waldenstrom's, is now called AL amyloidosis, the "L" standing for light chain. In these disorders, the light chains (or their fragments), which are a portion of the antibodies secreted by the cancerous cells, may remain undissolved in the bloodstream and be deposited in one or more organs. There are two types of light chains, kappa and lambda. The most common light chain involved in AL amyloidosis is the lambda type, which is almost twice as likely to form amyloid as the kappa type of light chain. Most WM light chains, however, are of the kappa type, and amyloidosis is fortunately a fairly unusual complication of our disease.

AL amyloidosis tends to be systemic, and the organs most commonly involved are the kidneys, the heart, the gastrointestinal tract, the peripheral nerves, and the liver. Symptoms can vary widely, based on which organs have the protein deposits. Some symptoms may be fairly vague and generalized, such as weakness or fatigue, weight loss, shortness of breath, abnormal sensations in the feet, enlarged liver and/or spleen, bleeding under the skin, and anemia. Since

many of these symptoms are also frequently characteristic of the underlying plasma cell disease, amyloidosis is frequently not detected in its earlier stages. More specific symptoms might include swelling of the extremities, an enlarged tongue, carpal tunnel syndrome, food malabsorption, skin thickening, nail changes, bone fractures, unexplained congestive heart failure, and unexplained kidney failure.

If AL amyloidosis is suspected, bone marrow biopsy, serum protein electrophoresis, and immunofixation are necessary to determine the presence and significance of abnormal antibodies. Other tests can be performed to look for protein in the urine or abnormally high serum creatinine levels (indicators of kidney problems) and abnormalities of the lungs, heart, or bone. A high platelet count occurs in approximately 5-10% of patients, as does a high serum level of an enzyme called alkaline phosphatase, which is elevated in 25% of patients. A relatively simple and effective test for systemic amyloid requires a needle aspiration of fat just under the skin of the abdomen (fat pad aspiration) that is stained with a dye called Congo red. Biopsies of other suspected tissues (for either systemic or localized amyloidosis) may also be obtained and stained. If amyloid is present, it should be further characterized by immunofixation or biochemical means to determine its particular type, as the type of amyloid may determine its appropriate treatment.

Unfortunately, there is no known way to prevent or significantly reverse amyloidosis. Treatment involves slowing the progression of disease and reducing its harmful effects on certain organs. For AL amyloidosis due to multiple myeloma or WM, treatment obviously involves chemotherapy against the cancer, which may also include high-dose steroids. For patients with kidney involvement, hemodialysis may be indicated for progressing disease. Organ transplantation (heart and kidney) is another option, but, unless the associated disease is well managed, damage will occur in the transplanted organs as well. A promising avenue of investigation is the use of pharmaceuticals, such as Idox (a derivative of anthracycline), to help make the amyloid deposits soluble. Yet another promising treatment is the use of high-dose chemotherapy (usually melphalan) followed by stem cell transplantation.

## 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 Don Lindemann at 510-848-4069 or [torcheditor@gmail.com](mailto:torcheditor@gmail.com)

# MEDICAL NEWS ROUNDUP

by Sue Herms

**Cancer Drug NPI-0052 Combined with Bortezomib (Velcade)** – Nereus Pharmaceuticals presented pre-clinical study results for its cancer drug NPI-0052 combined with bortezomib (Velcade) and tested in tumor models for multiple myeloma, Waldenstrom's, and follicular lymphoma. NPI-0052 is a small molecule proteasome inhibitor that appears to have higher potency, faster onset, and longer duration of action than various other proteasome inhibitors tested. It also has both intravenous and oral availability.

**New Investigational Antibody Against CD22 Molecule** – The National Cancer Institute has put some of its resources behind an investigational lymphoma treatment under development at UC Davis. This treatment, called HB22.7, is an antibody to the CD22 molecule found on the surface of B-lymphocytes. By attaching to the CD22 molecule, the HB22.7 antibody is able to induce the death of B-lymphocytes.

**A New Protein Kinase Inhibitor Against Lymphomas** – Kinex Pharmaceuticals has begun Phase 1 testing of its drug KX2-391, which is a protein kinase inhibitor. It is being tested specifically in patients with solid tumors and lymphomas who have advanced disease that is resistant to conventional therapy. The drug targets a cell protein linked to the rapid growth and spread of cancer cells.

**National Cancer Institute Funds Agents Called Histone Deacetylase Inhibitors** – A research team at Virginia Commonwealth University Massey Cancer Center has received a renewal grant of almost \$1.3 million from the National Cancer Institute to improve the activity of a novel class of agents, called histone deacetylase inhibitors, in the treatment of leukemia and other blood cancers. Histone deacetylase inhibitors can trigger apoptosis, or programmed cell death, in tumor cells. The team has received approval to lead a trial of vorinostat, a histone deacetylase inhibitor, in combination with bortezomib (Velcade) in patients with lymphoma.

**Another Histone Deacetylase Inhibitor Tested in Phase 2 Clinical Trial** – Another histone deacetylase inhibitor, MGCD0103, is being tested in a Phase 2 clinical trial on patients with relapsed or resistant Hodgkin's and non-Hodgkin's lymphoma. The oral drug is being combined with an injectable drug called Vidaza. Both were developed by Pharmion Corporation and MethylGene Inc. Results so far have indicated an overall response rate of 38 percent, with the most common adverse events being pneumonia, thrombocytopenia, and fatigue. Dose modification was effective in controlling these events in many patients.

**Phase 1 Clinical Trial Results for Interleukin 21** – Zymogenetics Inc. presented interim results from a Phase 1 clinical trial of Interleukin 21 (IL-21) in combination with Rituxan in patients with relapsed low-grade B-cell lymphoma.

The Phase 1 data showed that the combination was well-tolerated, resulted in anti-lymphoma activity, and increased the ability of Rituxan to target and kill cancer cells.

**MT103 Targets CD19 Antigen on B-Cells** – Data from an ongoing Phase 1 clinical trial of a drug called MT103 showed potent activity in patients with late-stage non-Hodgkin's lymphoma. MT103 is an antibody targeting the CD19 antigen, which is uniquely expressed on B-cells. MT103 was developed by a partnership of Micromet Inc. and MedImmune Inc. and is entering Phase 2 trials for both acute and chronic lymphocytic leukemia.

**Disappointing Results for MyVax Personalized Immunotherapy** – In disappointing news from Genitope Corporation, its Phase 3 clinical trial of MyVax personalized immunotherapy for follicular lymphoma patients did not meet its primary endpoint. There was no statistically significant difference in progression-free survival of patients receiving MyVax compared to the control group.

**Congress Temporarily Retains Reimbursement for Bexxar and Zevalin** – The House of Representatives passed legislation that requires Medicare to retain its current system of reimbursement for the radioimmunotherapy drugs Bexxar and Zevalin through June 30, 2008. The legislation had previously passed the Senate. The legislation was in response to protest that the Centers for Medicare and Medicaid Services were proposing drastic cuts in reimbursements for these drugs.

**Rituxan Combined with Cytotoxic Agent Improves Activity** – Researchers from Wyeth Research have combined Rituxan with a potent cytotoxic agent called calicheamicin and tested the combination in mouse models of B-cell lymphomas. The combination vastly enhanced the activity of Rituxan in reducing growth and survival of the tumor cells.

**FDA Gives Approval to Use of Oral Fludarabine in the U.S.** – The FDA has granted Orphan Drug Designation to oral fludarabine phosphate tablets for the treatment of B-cell chronic lymphocytic leukemia. Xanthus Pharmaceuticals Inc. has been licensed to develop and commercialize oral fludarabine in the United States from Bayer Schering Pharma AG.

**Neupogen, Neulasta, and Granocyte May Cause Bone Loss** – Granulocyte colony-stimulating factor (G-CSF), a medication used to restore white blood cell counts after chemotherapy, has been implicated in bone loss and promoted tumor growth in bones in mouse models. Physicians who are treating patients with G-CSF should monitor their cancer patients' bone health with regular bone density scans and prescribe medications to prevent bone loss when needed. While G-CSF, commonly known as Neupogen, Neulasta, and Granocyte, had a strong effect in developing bone tumors in mice, so far no increase in bone tumors has been found in human patients.

# THE 4<sup>TH</sup> INTERNATIONAL WORKSHOP ON WM, Part 3: RESEARCH POSTERS

compiled by Guy Sherwood, M.D.  
edited by Sue Herms

At the Kos Workshop separate sessions were held for research on WM and on MM, acknowledging the fact that many of the speakers investigate both diseases and that some of the reported results pertain to both. While 30 research posters specific to WM were displayed, there was material relevant to WM in many of the more than 400 posters covering new research on MM. It is beyond the scope of this review article to extract all information relevant to WM from the large number of MM posters; the following overview is limited to the 30 posters specific to WM.

The information presented on research posters is directed to fellow researchers and is understandably complex. Nonetheless, brief and pithy comments are offered in an attempt to assist the *Torch* reader in discerning the overall direction of current scientific research regarding WM. Suffice to say that the major focus today in WM research (and this applies also to MM research) is on genetics and the micro-environment, familiarly known as the “neighborhood,” in the bone marrow where the WM cells interact with close neighbors including mast cells.

**Genomic mutations in the April/Taci/Traf pathway in Waldenstrom’s Macroglobulinemia (WM)** Z.R. Hunter, Bing Center for Waldenstrom's Macroglobulinemia, Dana-Farber Cancer Institute. Reduced levels of the immunoglobulins IgA and IgG (hypogammaglobulinemia) are common in patients with WM. Disease reduction or even attainment of a complete remission (CR) fails to improve IgA and IgG levels. A genetic link between WM and hypogammaglobulinemia was noted. Mutations in the Blys/April receptor Taci (TNFRSF13B) in 21% of patients studied correlated with IgG and IgA hypogammaglobulinemia.

**Deletions of chromosomes 6q and 13q, and trisomy 4 are the most common cytogenetic abnormalities in Waldenstrom's macroglobulinemia. Preliminary results of a multicentric study.** F. Nguyen-Khac, Hôpital Pitié Salpêtrière, Paris. Genetic abnormalities in WM are different than those reported in other B-cell malignancies (such as MM and CLL), confirming the originality of this disease.

**Re-evaluation of the t(9;14)(p13;q32)** R.G. Owen, HMDS Laboratory, Leeds Teaching Hospitals NHS Trust, Leeds, UK. The t(9;14)(p13;q32) gene abnormality (deregulates PAX5) is very rare in B cell lymphoma; it may be seen infrequently in patients with splenic marginal zone lymphoma (MZL).

**Pharmacogenomic in Waldenstrom’s macroglobulinemia (WM): hCNT1 expression as a possible predictive biomarker of clinical response at 2-CDA.** C. Rabascio, European Institute of Oncology, Milan. An interesting poster on a very exciting topic: pharmacogenomics demonstrates that the genetic expression of specific transporters and receptors molecules contributes to variable drug activity. Genetic factors influencing the clinical response to 2-CDA were studied. hCNT1 seems to be a gene involved in 2-CDA activity and its expression seems to correlate with clinical response. A lower hCNT1 expression in patients not achieving a complete or partial response suggests a possible relationship between reduced hCNT1 levels and a diminished clinical activity of 2-CDA.

**Transgenic mouse models of Waldenstrom’s macroglobulinemia.** S. Janz, Laboratory of Cancer Biology and Genetics, National Cancer Institute, National Institutes of Health, Bethesda, MD. New mouse strains with bone marrow IgM+ plasma cell neoplasms were developed by crossing IL-6, iMyc, and Bcl-XL transgenic mice with mice deficient in AID (activation induced cytidine deaminase); the AID-deficient offspring developed IgM+ tumors. This is the first step toward a new mouse model of human WM. The role of numerous biological factors involved in the natural history of WM (BLyS, del 6q21-22, bone marrow environment) can now be further evaluated.

**An animal model for Waldenstrom’s macroglobulinemia.** A.S. Tsingotjidou, Laboratory of Anatomy and Histology, Faculty of Veterinary Medicine, University of Thessaloniki, Greece. The aim of this IWMF-sponsored study is the establishment of a WM animal model. Cores of human bone obtained were implanted in the hip muscles of special immune-deficient mice and allowed to mature for eight to twelve weeks. WM cells were then transplanted either intramuscularly, intravenously, or a core bone marrow biopsy from WM patients was implanted to the opposite hip of animals carrying bone fragment from non WM individuals. Mice were followed for up to 6 months. Tumor progression was determined by monitoring human immunoglobulin M (IgM) levels and by histopathologic evaluation, including immunohistology for expression of human CD20 and IgM. All animals showed elevated levels of human IgM one month after the introduction of WM cells. However, only a small minority (10%) of mice injected intra-muscularly maintained elevated IgM beyond 5 months; in all the intravenously injected mice IgM gradually diminished over time; 60% of the mice implanted with the bone marrow core biopsies showed a steadily increasing level of IgM. The implantation of bone marrow biopsies from WM patients preserves the essential interaction of WM cells with the microenvironment and assures the creation of a successful WM animal model.

**Expression of the kappa myeloma antigen (KMA) on the cell surface of bone marrow aspirates from Waldenstrom's macroglobulinemia patients.** D.R. Jones, PacMab Ltd., Sydney, Australia. Bone marrow from WM patients was evaluated for the cell surface expression of kappa myeloma antigen (KMA), previously described in MM. KMA is a membrane associated kappa light chain present on malignant plasma cells. A murine monoclonal antibody (mKap) that recognizes KMA has been developed and has shown to be effective in MM. Phase I/II clinical trials for MM kappa patients in Australia are to begin in late 2007. Preliminary results demonstrate that KMA is expressed in some WM kappa patients. The chimeric monoclonal antibody mKap may be of use in the treatment of WM kappa patients.

**Immunophenotypic and molecular profile of Waldenstrom's macroglobulinemia (WM) and small lymphocytic lymphoma (SLL) PTS: report of a multicenter study.** D. Laszlo, European Institute of Oncology, Milan. Immunophenotypic studies of WM patients found that only 50% of them presented a typical immunophenotype profile.

**CXCR4 and VLA-4 interaction promotes adhesion of Waldenstrom's macroglobulinemia cells.** H. Ngo, Medical Oncology, Dana-Farber Cancer Institute. Adhesion of WM cells to the bone marrow microenvironment induces proliferation and resistance to therapy. Chemokines and adhesion molecules regulate the interaction of WM cells with their microenvironment. The CXCR4/SDF-1 pathway promotes adhesion of WM cells to the bone marrow microenvironment through its interaction with the adhesion molecule VLA-4.

**The CXCR4/SDF-1 axis regulates migration in Waldenstrom's macroglobulinemia.** H. Ngo, Medical Oncology, Dana Farber Cancer Institute. The continuous re-circulation of WM cells in the peripheral blood and the re-entrance into the bone marrow (homing and migration) is regulated by cytokines and chemokines. The CXCR4/SDF-1 pathway regulates migration in WM and therefore implies a potential role in homing.

**COX-2 expression in Waldenstrom's macroglobulinemia.** R.G. Owen, HMDS Laboratory, Leeds Teaching Hospitals NHS Trust, Leeds, UK. Cyclooxygenase-2 (COX-2) is the key enzyme involved in prostaglandin synthesis and it is expressed in many solid malignancies including colon, breast and lung cancers. COX-2 is extensively expressed in WM but appears to be confined to the plasma cell component of the disease. The significance of this is unclear at present but COX-2 inhibition may be of value in the treatment of WM.

**Serum soluble SYNDECAN-1 is increased in WM/LPL and SMZL.** M.C. Kyrtonis, Dept. of Internal Medicine, University of Athens Medical School, Greece. Syndecan-1

(CD138) is a transmembrane molecule expressed by most MM plasma cells that regulates adhesion, migration, and growth factor activity. Syndecan-1 can be shed from the surface of cells and circulate as a soluble factor (s-synd-1). A high level of syndecan-1 in the serum of MM patients is an indicator of poor prognosis. The elevated serum s-synd-1 levels found at diagnosis of WM reveals a role for this molecule in this disease.

**Differing serum cytokine levels in LPL and WM.** T. Tzenou, Dept. of Internal Medicine, University of Athens Medical School, Greece. The serum concentrations of selected cytokines (IL-6, IL-1, TNF, VEGF, TGF-beta-1, Blys) were evaluated in WM (and LPL) patients at diagnosis. Differences in cytokine levels between WM and LPL may reflect different biologic mechanisms of these similar diseases.

**Distinguishing IGM myeloma from WM.** S. Feyler, Faculty of Medicine, Department of Oncology and Hematology, Leeds University, UK. Elevated IgM levels usually occur in WM and are rare in patients with MM. Phenotypic and genotypic tests make it possible to make a clear distinction between IgM myeloma and WM.

**Regression of lymphoplasmacytic lymphoma after treatment of chronic hepatitis C.** T. Izumi, Tochigi Cancer Center, Utsunomiya, JAPAN. An association between (HCV) infection and B-cell lymphoma has been suggested and debated. A case report of a 76-year-old female hepatitis C virus (HCV) patient with WM who did not respond to CHOP but did very well when her HCV was treated with interferon-alpha (IFN) three times a week is presented. If HCV infection is causally linked to lymphoplasmacytic lymphoma, anti-viral treatment may be an effective therapy.

**Waldenstrom's macroglobulinemia of the stomach.** A.A. Mihas, Division of Gastroenterology, Hepatology and Nutrition, Virginia Commonwealth University School of Medicine, Richmond, Virginia. Gastrointestinal involvement in WM is exceedingly rare. Small-intestinal involvement in WM has been reported in less than 20 cases worldwide and the cases that are strictly limited to the stomach are less than five. Nonetheless, WM should be suspected in any GI lymphoma disease.

**Waldenstrom's macroglobulinemia (WM) in Japan. Results of a retrospective survey.** O. Tournilhac, Clermont-Ferrand University Hospital, France. WM seems infrequent in Japan, but lack of consistent reporting makes the determination of incidence difficult.

**Resveratrol exerts antiproliferative effect and induces apoptosis in Waldenstrom's Macroglobulinemia.** A.M. Roccaro, Bing Center for Waldenstrom's Macroglobulinemia, Harvard Medical School, Dana-Farber Cancer Institute,

Boston, MA. Resveratrol is synthesized by a wide variety of plant species including grapes. In vitro data demonstrates that resveratrol has significant antitumor activity in WM. Resveratrol induces significant cytotoxicity and inhibition of DNA synthesis. In contrast, resveratrol did not significantly affect proliferation of peripheral blood mononuclear cells from healthy donors. Clinical trials are pending.

**Simvastatin, an HMG-CoA inhibitor, induces in vitro antitumor activity in Waldenstrom's macroglobulinemia.**

A.S. Moreau, Bing Center for Waldenstrom Macroglobulinemia, Dana-Farber Cancer Institute. Low total cholesterol levels have been observed among WM patients; there also appears to be an inverse relationship between the IgM serum level and LDL cholesterol serum level. This study shows that simvastatin (Zocor) has significant antitumor activity in WM in vitro. Simvastatin induced-cytotoxicity was also noted to be enhanced by bortezomib (Velcade) or fludarabine. Clinical trials are pending.

**Protein kinase inhibitor, enzastaurin, induces in vitro and in vivo antitumor activity in Waldenstrom's macroglobulinemia.**

A.S. Moreau, Medical Oncology, Dana-Farber Cancer Institute, Boston, MA. The PKC $\beta$  pathway regulates cell survival and growth, as well as migration and homing in many B-cell malignancies. The PKC $\beta$  inhibitor enzastaurin has significant antitumor activity in WM in vitro and in vivo. Clinical trials are pending.

**Perifosine, an oral bioactive novel Akt inhibitor, induces in vitro and in vivo antitumor activity in Waldenstrom's macroglobulinemia.**

X. Leleu, Department of Medical Oncology, Dana-Farber Cancer Institute, Boston, MA. The PI3k/Akt pathway is a critical regulator of cell survival. Up-regulation of members of the PI3k/Akt pathway is noted in WM. Perifosine has significant antitumor activity in WM both in vitro and in vivo. Clinical trials are underway.

**The combination of perifosine with bortezomib and rituximab provides synergistic anti-tumor activity in Waldenstrom's macroglobulinemia.**

X. Leleu, Medical Oncology, Dana-Farber Cancer Institute and Harvard Medical School, Boston, MA. The combination of bortezomib (Velcade) + perifosine + Rituxan provides strong synergistic activity by targeting different signaling pathways activated in WM. Bortezomib (Velcade) + perifosine did not induce cytotoxicity in healthy-donor peripheral blood mononuclear cells or in hematopoietic stem cells.

**Phase II trial of perifosine (KRX-0401) in relapsed and/or refractory Waldenstrom's macroglobulinemia: preliminary results.**

I.M. Ghobrial, Dana Farber Cancer Institute, Boston, MA. The Akt pathway is up-regulated in patients with WM. The Akt inhibitor perifosine causes growth inhibition in models of WM. This phase II clinical trial aims to determine safety and activity of perifosine in

patients with relapsed/refractory WM. Perifosine appears to be well tolerated and shows activity in patients with relapsed WM. Updated data will be presented at the 2008 IWMF Educational Forum in Los Angeles CA.

**Cladribine(2-CDA) and rituximab combination treatment for patients with Waldenstrom's macroglobulinemia (WM) or small lymphocytic lymphoma (SLL): clinical preliminary reports of a multicenter study.**

D. Laszlo, European Institute of Oncology, Milan. Combinations of nucleoside analogues and rituximab are effective for treatment of WM. This study tested the efficacy of 2-CDA in combination with rituximab in the treatment of newly diagnosed/pretreated WM (or SLL) patients requiring treatment. The combination therapy consisted of rituximab on day 1 followed by 2-CDA (sc injection) for 5 consecutive days. Each cycle was administered monthly for 4 times. 21 WM patients were followed for a median of 12 months; 11 patients achieved CR/PR (30% of them presenting a molecular clearance in blood marrow); MR in 6 cases; SD in 1 case and PD/NR in 3 cases.

**Fludarabine, Cyclophosphamide and Rituximab (FCR) an effective regimen characterized by high incidence of delayed responses in Waldenstrom's macroglobulinemia.**

A. Tedeschi, Departments of Hematology, Niguarda Ca' Granda Hospital Milan, Italy. The FCR regimen is active and well tolerated in symptomatic WM patients, and even in previously heavily pre-treated patients. The high incidence and long lasting episodes of neutropenia did not cause major infection problems. Progressive delayed responses have also been observed in patients with longer follow-up.

**2-CDA-cyclophosphamide +/- rituximab for symptomatic WM.**

S.K. Thomas, University of Texas M.D. Anderson Cancer Center, Houston, TX. A retrospective analysis of this institution's experience with 47 previously untreated patients with symptomatic WM, treated with 2 consecutive 6-week courses of 2-CdA sc tid x 7d + cyclophosphamide (Cy) po bid x 7d (29 patients) alone or with rituximab q wk x 4 wk (18 patients). With 2-CdA-Cy, overall response rate (ORR) was 83%, including complete response (CR) in 4% (1 patient). With 2-CdA-Cy-Rit, ORR was comparable at 94%, including CR in 17% (3 patients). Median times to remission were similar at 2.3 (2-CdA-Cy) and 2.4 months (2-CdA-Cy-Rit); a trend towards longer duration of first remission (DOR) for patients treated with 2-CdA-Cy-Rit (58.6mos vs. 25.6mos) was noted. After only 2 courses of treatment with 2-CdA-Cy combinations, high response rates with little toxicity, long remission durations, longer time to need for re-treatment, and prolonged survival were obtained. When re-treated, second remissions were long as well. The use of limited 2-CdA-Cy based regimens as the treatment of choice for previously untreated patients with symptomatic WM is therefore supported at this institution.

*The 4<sup>th</sup> International, cont. from page 10*

**Autologous stem cell transplantation (ASCT) for patients with Waldenstrom's macroglobulinemia. An analysis of 201 cases from the European bone marrow transplant registry (EBMT).** C. Kyriakou, Lymphoma WP of the EBMT, United Kingdom. A retrospective multicentre study of 201 WM patients who underwent an ASCT; median age at transplant was 53 years (22-73); the median time from diagnosis to transplant was 18 months (3-239); median number of 2 (1- 10) treatments before ASCT. Various regimens were used. All patients but three successfully engrafted. With a median follow-up of 26 months (5-163), 112 (56%) patients are alive and free of disease, 73 (36%) patients have relapsed after a median of 14 months (1-110) post ASCT. Fifty-two patients died, 36 (18%) from disease progression and 16 (8%) from regimen toxicity. Non-relapse mortality was 6% at 1 year. Overall survival was 86% at 1 year, 75% at 3 years, and 61% at 5 years. The probability of relapse was 20% at 1 year, 38% at 3 years and 55% at 5 years with an estimated progression-free survival (PFS) of 74%, 54% and 33% at 1, 3, and 5 years, respectively. This study suggests that ASCT is a safe procedure that can achieve prolonged remissions in populations of heavily pre-treated patients.

**Hematopoietic stem cell transplantation (HSCT) in Waldenstrom's macroglobulinemia (WM), update of the French experience in 54 cases.** N. Dhedin, Hôpital Pitié Salpêtrière, Paris. Autologous HSCT produces high response rates and some long term responses while allogeneic HSCT performed after either myeloablative or reduced intensity conditioning (RIC-allo) regimens produce very long term disease control and may cure WM. The RIC-allo (in which cord blood was used on one patient) gives impressive results on disease control in a set of older patients, most of them heavily pretreated.

**Serum Free Light Chain is a marker of tumor burden and of prognostic impact in Waldenstrom's macroglobulinemia.** X. Leleu, Dana-Farber Cancer Institute, Boston, MA. The value of serum free light chain (sFLC) in WM was studied. The mean sFLC was significantly higher in WM as compared to IgM-MGUS. Elevated sFLC correlates with poor prognostic markers in WM, such as high serum 2M, anemia, thrombocytopenia and leucopenia. sFLC levels correlate well with the serum IgM level and serum viscosity, but not with bone marrow involvement. sFLC levels were clearly able to differentiate patients with WM and IgM MGUS.

*I do hope this coverage of the research and clinical highlights of the 4th International Workshop on Waldenstrom's macroglobulinemia is helpful. I realize that some of the science is quite complex and intimidating. However, one should not be left with a sense of bewilderment and hopelessness but rather with a positive outlook and, dare I say, elation on the*

*fantastic advances made in the basic biology of WM by world class researchers, many of them young and many of them supported in part by funds from IWMF. A word of caution is in order, however: what is the point of all this research and resultant novel drug development if we, the WM community, do not participate in the many clinical trials arising from this work?*

*After seven years of living with this disease and seven years of reading often very perplexing scientific articles, I feel more confident than ever that we shall see the day when the diagnosis of WM is no longer a threat to an individual's dreams and aspirations.*

*Donate and participate!*

*Guy Sherwood, M.D.*

## **BEN RUDE HERITAGE SOCIETY KICK-OFF**

*by Dick Weiland*

The Ben Rude Heritage Society will be inaugurated at the appreciation luncheon scheduled for May 17 during the 2008 Educational Forum in Los Angeles. Ben was the second president of the IWMF, and his wife, Laurie, is serving as the founding honorary chairperson of the Society. Laurie will be the mistress of ceremonies for the Saturday noon program.

So far seven people are to be recognized as founding members of the Ben Rude Heritage Society for including the IWMF in their estate planning. If you, too, intend to include the Foundation in your estate, please complete the **inquiry form** on page 16 and return it promptly in the enclosed envelope. Because of tight time considerations, you may also wish to call Dick Weiland (507-645-2633) or write him at [rjweiland@msn.com](mailto:rjweiland@msn.com) at your earliest convenience to see if you can join the founding members of the Ben Rude Heritage Society to be recognized in Los Angeles. Of course, if you wish to be an anonymous benefactor, your intentions will be respected. You should also note that there are restrictions with some estate planning tools, as determined by select states or by the IWMF. So be sure to contact your financial advisors.

# CAREGIVING IN WALDENSTROM'S MACROGLOBULINEMIA

by Connie Paul, Ph.D., ABPP

It's a beautiful winter day here in Tennessee today as I write this article on the topic of caregivers for the *Torch*. Ever since my husband, Bill, was diagnosed with WM in May 2005, our bookcase has a space dedicated for filing the *Torch* issues, with their familiar, bright blue covers, together with other references on WM. We both look forward to reading the next issue of the *Torch*, and my husband always asks me to return it to him to be filed for later use.

When I was first asked to write this article it was difficult to decide what specific aspect of caregiving to focus on. WM is a complex disease that may affect virtually every area of a person's life including physical health, cognitive functioning, social roles, psychological well-being, sense of self, family relationships, work and social environments. Caregivers for family and friends diagnosed with WM can be called upon to provide a wide scope of services ranging from, and not limited to, emotional support, personal care, and household responsibilities. Caregiving can also affect the physical and emotional health of the caregiver. It is not uncommon for caregivers, while providing care for a loved one, to neglect their own health. Stress for caregivers comes in the form of worry for a loved one, financial strains, time commitments, decreased social outlets/contacts, work demands, and changing roles.

The watch and wait time period recommended by the treatment team for some WMers adds another dimension to the caregiver role that is specific to WM. Sometimes it is hard to grasp that doing nothing, so to speak, is really doing something good and adaptive. It may seem strange to know that your loved one or friend has been diagnosed with a rare form of cancer and has been advised that the best course of action is simply to monitor the clinical course of the disease over time. What is a caregiver to do in such a situation?

The first step in providing the best support and care is to know the personality and propensities of your friend or loved one. It is never a good idea to deliver supportive and caring behavior without first knowing if what is offered will be well received and result in being truly helpful in the context of the situation. There is a vast range of possible interactions between patient and caregiver. The frequency and form of the contacts may vary according to the particular situation, but whatever form contacts may take, caregiving will be most effective when the caregiver knows the patient well.

Being well educated about the disease and treatment options is the next step for the caregiver. It is difficult to support and care for someone if your information and knowledge base about the disease are limited. The *Torch*, the annual IWMF Educational Forum, the IWMF support groups, and the

IWMF talk-list serve all provide a wealth of information and resources for learning about WM. Bill and I certainly know more about hematology than we did three years ago! I have enjoyed attending the last two Ed Forums, learning more and meeting new friends along the way. When Bill talks about something he has read recently or learned on the talk-list, it is good for me, too, to be able to join in and support him in a conversation about his new knowledge of WM.

A third step for caregivers is the role of "being there" during times of deliberation and decision making. An example would be when treatment options are being weighed. Never tell the person you care for what they should do and how they should do it. This leads to misunderstanding or confusion. A caregiver should allow a process of thinking out loud, weighing options, providing information, and asking questions for reflection. In this way the caregiver helps to find what is best for the individual. And then-and this is very important-once your loved one or friend determines a course of action and makes a decision, the role of a caregiver is to give support, to help with implementation of the decision, and to provide comfort. The goal becomes getting through the daily challenges together.

Yet another step for a caregiver is to keep one's own balance in the course of taking care of another. Strong coping skills, resiliency, respite, emotional support, self-care—all are as important for the caregiver as for the person diagnosed with WM. All things in nature seem to work better with balance.

At the 2007 Ed Forum in Atlanta I was pleased to be invited to present a talk on the topic of caregivers. I very much enjoyed meeting some of you, and I hope those who attended last year profited from the opportunity to meet each other and share aspects of being a WM caregiver.

This year I have been invited again to speak on the topic of the WM caregiver at the 2008 Ed Forum in Los Angeles. I look forward to seeing some of you again and meeting new attendees, too. I would appreciate your providing me with any specific topics you would like me to address during this year's WM caregiver presentation. I would be happy to incorporate your input. You can reach me at: TPAMember@Juno.com

I look forward to hearing from you!

## CORRECTION

The statement concerning predictors of positive responses to Rituxan therapy, printed on page 7 of the Winter 2008 *Torch* in the summary of Dr. D.M. Weber's presentation at the 4th International Workshop on WM, should be amended as follows: "Predictors of positive responses to Rituxan therapy include: a monoclonal protein *less* than 40 g/L, serum albumin *greater* than 35 g/L, hemoglobin greater than 10 g/dL, and a kappa light chain."

Outside of the laboratory and the classroom, Dr. Kyle has served his profession with distinction. For twelve years he was Chairman of the Myeloma Committee of the Eastern Cooperative Oncology Group. He hosted the IVth International Workshop on Multiple Myeloma and the VIIIth International Symposium on Amyloidosis, both in Rochester, MN. He served as Secretary-General of the International Society of Hematology. Currently he is on the Board of Directors and is Chairman of the Scientific Advisory Board of the International Myeloma Foundation. He is also Chairman of the Scientific Advisory Committee of the International Waldenström's Macroglobulinemia Foundation and President of the International Society of Amyloidosis. National and international acknowledgement of his professional status is seen in the designations of Master, American College of Physicians, and honorary membership in the Royal Society of Pathologists, London.

In his spare time, Dr. Kyle has become well known as a medical historian and philatelist with a specific interest in medicine and stamps.

In the course of his career, Dr. Kyle has received numerous prestigious awards. He has been recognized as the first recipient of the Robert A. Kyle Award for Waldenström's Macroglobulinemia Foundation, first recipient of the Robert A. Kyle Lifetime Achievement Award from the International Myeloma Foundation, Mayo Clinic's Henry S. Plummer Distinguished Internist Award, Mayo Clinic's Distinguished Clinician Award, and Mayo Clinic's Distinguished Alumni Award. In 2007 he was also recipient of the David Karnofsky Memorial Award from the American Society of Clinical Oncology.

To members of the IWMF, Dr. Robert Kyle is familiar as Chairman of the Scientific Advisory Committee and the popular moderator of the Ask the Doctor sessions at the annual Educational Forum. The highlights of Dr. Kyle's career make clear the debt of gratitude owed by the IWMF to this distinguished hematologist for his continuing service and guidance.

### IWMF E-BULLETINS

Occasionally we send e-bulletins via e-mail to our membership when there is a need to communicate between quarterly *Torch* issues. A significant number of e-bulletins are being returned to the office as "undeliverable" because members have changed their e-mail address. We would appreciate your notifying the IWMF Business Office whenever your contact information changes. You may do this by sending an e-mail to [tanyafraley@iwmf.com](mailto:tanyafraley@iwmf.com) or FAX to 941-927-4467.

**Phase 2 Study Underway for Rituxan Combined with Cytokine** – Berlex Oncology announced that a Phase 2 clinical study is underway to investigate the treatment of follicular lymphoma by combining Rituxan with a cytokine called sargramostim (Leukine). It is hoped that sargramostim will improve the efficacy of Rituxan by enhancing the immune system's action against tumor cells without increasing toxicity.

**Two Doses of Flu Vaccine Improve Its Effectiveness in Chemo Patients** – A study from M.D. Anderson Cancer Center suggests that a two-dose regimen of influenza vaccine would enhance its effectiveness in patients with lymphoma receiving chemotherapy. While one dose of the vaccine induced an immune system response in 42% of patients, a second dose improved the response to 71% of patients.

**Four-Year Follow-up Study of Rituxan and Favid** – A four-year follow-up study of results from a Phase 2 trial of follicular lymphoma patients treated with Rituxan and Favid (mitumprotimut-T) indicated an overall response rate of 63 percent. As late as 31 months after treatment, some patients were still converting to complete responses. Of previously untreated patients who responded to the initial therapy, 51 percent were still seeing response durations of four years following therapy.

**Mixed Safety Results Received on Humax-CD20** - Results were mixed in study results received on Humax (Ofatumumab)-CD20 in patients with chronic lymphocytic leukemia. It was hoped that many of the reactions/side effects frequently experienced by patients receiving Rituxan could be avoided by using the humanized anti-CD20 antibody Humax. While the treatment resulted in responses in 50 percent of patients, 27 of 32 patients completing the protocol reported side effects, including rigors, sweating, fatigue, and rashes. Although 92% of these effects were deemed to be mild, there were also reports of sinusitis, neutropenia, hepatitis, shingles, and pneumonia. It appears from the early data that substituting Humax will not alleviate some of the difficulties associated with Rituxan use.

**Smoking and Alcohol Consumption Affect Survival Rates of NHL Patients** – Findings reported in the International Journal of Cancer suggest that heavy tobacco smoking and alcohol consumption may be associated with poor survival among patients with non-Hodgkin's lymphoma. Compared with those who had never smoked, patients who smoked more than 20 cigarettes per day had a high risk of death and lower 5-year survival rates. At five years, 47% of the smokers had survived compared with 67% of the non-smokers. Similarly, patients who drank more than four drinks per day had a higher probability of death when compared with patients who drank less than two drinks per day.

*The author gratefully acknowledges the efforts of Arlene Carsten, Peter DeNardis, Mike Dewhirst, Gareth Evans, Howard Prestwich, and Bert Visheau in disseminating news of interest to the WM community.*

## AN INTERNATIONAL PERSPECTIVE

by Zed F

*Does the idea of living on a beautiful Mediterranean island hold a romantic fascination for you? How about Cyprus, the lush island in*



*Zed lands a big one! The author displays a swordfish 3 feet long and weighing over 30 pounds, caught off the coast of Zanzibar.*

*the eastern Mediterranean where sea-born Aphrodite first put foot on terra firma? When but recently informed of a blood disorder, IWMF member Zed F found himself relocated by his employer to this sunny isle where his local doctor's language was, literally, "Greek to him" and from where he had to fly into a Middle Eastern hotspot in order to*

*consult with the nearest WM expert. In his own words Zed shares his frustration in arriving at an accurate diagnosis, his transformation from shocked disbelief to personal advocacy, and—above all—his zest for living life to the fullest.*

As is the story for most Wallies, it all started with a routine physical in 2004. I was 43 and the time had come for the annual check-up, including a blood test to check for high levels of bad cholesterol, triglycerides, prostate antigens—standard tests for a healthy, active, young man. An executive in a multinational company, I had been living with my family for quite a few years in Geneva, but at that time we were preparing to move to my next assignment, on the Mediterranean island of Cyprus.

My test results were, as usual, fine, save for an elevated erythrocyte sedimentation rate of 48. My Swiss physician, dismissing the number as the probable result of a lingering infection, suggested I repeat the test one month later just to be on the safe side. He casually recommended that the test be repeated “anywhere in Cyprus” and that I not bother to fly all the way back to Switzerland. His records showed I was an exemplary patient without the faintest health issue or ailment to date, so there was absolutely no cause for concern.

By November we had moved to Limassol on the southern coast of Cyprus, and I visited one of the best local physicians, explained my situation, and redid the same test. This “overly thorough” physician ordered a serum protein electrophoresis, the results came back, and the saga began. A monoclonal paraprotein was detected in the gamma region. These dire words could have been uttered in Chinese for all I understood! The test was repeated in a different Limassol lab and the same verdict came back. Sitting in my physician’s office and listening to his words in Greek, which unfortunately I neither understand nor speak, I heard him mentioning the words “bone marrow” to a hematologist he was consulting by phone about my case. Those words were enough to send an electric chill down my spine, especially because I heard them quite often a few years earlier when my father was diagnosed and died of acute myelogenous leukemia.

Again, as most Wallies will admit, there came a period of disbelief, denial, fear, and depression. Suddenly the Internet was more than an online brokerage account, chat rooms, and an e-mail account. Medical sites were the order of the day, and oncology and hematology pages were more than a curiosity. And suddenly going to church on Sunday mornings seemed more than an obligation!

My new Limassol physician, who immediately understood the severity of the case, referred me to a young, US-educated oncologist/hematologist at the capital city of Nicosia, which is inland on Cyprus and to the north. With its medical centers and foreign embassies, Nicosia is much better equipped for major health issues than the seaside town of Limassol.

Leaving behind the friendliness of the general physician’s office in Limassol, we started visiting the Nicosia oncology center. The first priority was to identify the reason for the B cell abnormality and to recommend a course of action, if any. Following several weeks of commuting between Limassol and Nicosia, stressful and sometimes painful tests, the verdict came down: possibility of MGUS, maybe some kind of early stage lympho-proliferative disease, surely not multiple myeloma. My God-sent hematologist’s words came down like a blessing: “Nothing to do but regular monitoring, have a Merry Christmas, keep enjoying the daily glass of wine (he truly meant one glass!), and see you end of February.” What else could I ask for? Suddenly I had at least three months to live and organize my family and myself for the worst.

My scientific mind, however, was not totally at rest. Accordingly I flew to Beirut, Lebanon, where I visited two more oncologist/hematologists and a rheumatologist for good measure. The Nicosia diagnosis was confirmed. Beirut, I should add, with its various universities and medical centers, has always been the health Mecca of the Middle East. Doctors educated in the US and Europe practice there, and, despite the ravages of years of civil war, the city still provides the best health care one could ask for. And it’s only 20 minutes by plane away from Cyprus.

Christmas 2004 was spent as usual in Geneva. I paid a return visit to the physician’s office where it all started. He reviewed the whole file, confirmed the case, and agreed with the W&W approach. It was the first time I heard the words “we treat the patient not the numbers” (he said them in French though!).

A year went by as I continued traveling to the Nicosia oncology center for quarterly tests, the results of which continued to be “stable”. In between, I saw my doctor at home in Limassol, and, whenever business trips took me through Beirut and Geneva, I reported to doctors in both cities. All went well until the day my oncologist in Nicosia announced plans to return to the US for advanced training and referred me to another Nicosia-based oncologist. The new doctor reviewed my whole file, performed further “painful” tests, and—after more than a year of testing and consultations in Geneva, Nicosia, and Beirut—

## COOKS' HAPPY HOUR

by Penni Wisner and Nancy Lambert

Cynthia Nicholson, who facilitates our local IWMF support group with me, mentioned in a recent e-mail that she had made polenta fries for the first time. What a great idea for our column, I thought. When I mentioned it to Nancy, she said she'd love to know how to make them. We launched into a spirited conversation about all kinds of oven fries (perhaps we'll get to them in a future column) while Nancy started suggesting dips.

In its most humble guise, polenta is oatmeal's Northern Italian cousin, cornmeal mush. But you know those Italians . . . Which is why polenta shows up on haute cuisine restaurant menus enriched with crème fraîche or perhaps as a bed for sautéed greens and wild mushrooms. It's a classic companion for game. It can be made ahead. You don't need a recipe. And so it fits our definition of an interesting treat for a healthy Happy Hour snack.

Nancy recalls: "Polenta sounds like the cornmeal mush that I loved as a child. My mother let me smother it in butter and maple syrup. I no longer use just butter but make a lighter version—melted butter mixed with an equal amount of extra-virgin olive oil. I keep this mix in the refrigerator where it maintains a spread-able consistency and we don't worry about using too much butter. It would work for frying the polenta as well."

"Polenta" refers to the cooked dish as well as to the type of cornmeal: a sunny yellow, very coarse cornmeal. At the local market where I buy these ingredients in bulk, three grades of cornmeal are available: corn flour, cornmeal, and polenta.

You don't need a recipe to make polenta. Instead keep a simple ratio of dry to wet ingredients in your head: For a soft, almost pour-able, polenta to serve as a side dish, use 1 part dry to five or six parts liquid (water, stock, or milk). For a thicker polenta for making fries, use 1 part dry to three parts liquid. This translates to one cup polenta to three cups liquid to serve four. For added oomph, you might add fresh or dried herbs such as basil, thyme, and oregano, ground pepper, and, especially, some cheese, perhaps a little freshly grated Parmesan with a little Fontina and/or fresh goat cheese. Freshly grated nutmeg is another classic flavoring. Nancy adds, "I mix diced, roasted peppers—red or poblano—into my corn bread, so I guess (correct!) they could be mixed into the polenta as well."

Bring the liquid to a simmer and add salt to taste. Then slowly whisk in the polenta and cook over very low heat, whisking occasionally to prevent lumps and sticking, until the polenta grains taste very soft, about 15 minutes. Stir ingredients such as cheese and peppers in at the end of cooking, allowing the cheese to melt into the mixture.

Immediately scrape the polenta onto a board or parchment-lined baking sheet and spread it into an even layer. Let it sit until firm. It might take as little as 20 minutes, or, once cool, you can cover the polenta and refrigerate it for a day or so. Cut the firm polenta into fingers, perhaps 2 1/2 inches by 1/3 inch or so, or into small triangles. You can use the triangles as a base for canapés or to serve with roasted meats. You can also freeze the cut polenta for future use.

There are several methods to choose from to reheat and crisp the fries. If you deep fry, do it! Just fry in small batches. Or warm and toast the fries in a preheated, hot (500°F) oven. Or heat some olive oil in a skillet until hot and brown the polenta fries in the oil, turning as needed. Serve with the sun-dried tomato dipping oil we discussed in the last issue or sprinkle with Parmesan or other hard cheese. One of my favorite dips for polenta fries is a spicy aioli. I don't know how "healthy" it is (at least calorie-wise), but it tastes great: flavor purchased mayonnaise with pressed garlic, freshly grated lemon zest, and Tabasco or chili powder to taste.

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

*Penni (penniw@pacbell.net) and Nancy (lne3@aol.com) look forward to hearing your suggestions for healthy, fast, and easy snacks.*

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## TRIBUTE AND MEMORIAL GIVING CARDS NOW AVAILABLE

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IWMF has designed two personalized giving cards, created for your convenience and are available at no cost to you.

The **In Tribute** card is for those who wish to send a gift to IWMF to acknowledge a friend, family member, colleague or a special person on a special occasion, such as a wedding, birthday, anniversary, or holiday.

The **In Memory** card, serving you and your loved ones during difficult times, is to accompany a personalized condolence or *in memoriam* gift.

These cards may also be appropriate if you are participating in or coordinating an event to raise funds for IWMF. Please advise the IWMF business office if you would like a sample or supply of the cards. The names of donors to the IWMF, as well as the names of those honored or commemorated, are recognized in the *Torch*.

**Note to Canadian Members:** Similar cards for use in Canada for use in Canada can be obtained from Arlene Hinchcliffe at WMF Canada 905-337-2455 or [wafc@noco.ca](mailto:wafc@noco.ca)

### Celebrating the Successes of the Orphan Drug Act

The Orphan Drug Act has brought hope to the more than 25 million Americans who currently have one of 7,000 rare diseases or conditions. More than 300 treatments have been approved by FDA in the 25 years since this legislation went into effect. In the decade before the Act was passed, only 10 treatments had been developed for rare diseases.

The term "orphan drug" refers to a drug or biologic, such as a vaccine or blood product, that treats a rare disease or condition. A disease is rare if fewer than 200,000 people in the United States have it. This makes a diagnosis of Waldenstrom's macroglobulinemia one of the extremely rare cancers.

Like every other drug, orphan drugs must go through the FDA marketing approval process and be evaluated for safety and effectiveness for their intended use. However, there are certain short-cuts available for rare diseases and certain financial incentives available to those who will research and develop a drug approved for a rare disease. To date, more than 1,700 drugs and biologics have been designated as orphan drugs. However, there is not a single FDA-approved drug for our disease. Until there is, we will be treated with FDA-approved drugs for other lymphomas or myeloma. The solution lies in continuing to encourage and support WM research and to consider the clinical trials that become available seeking WM patients for their studies.

### Two New Resources from NCI

The National Cancer Institute is pleased to announce the availability of two resources: a DVD, *Understanding Cancer Clinical Trials*, and a booklet, *Taking Part in Cancer Treatment Research Studies*. These items incorporate and replace older materials.

To place orders call 1-800-4-CANCER or go to [www.cancer.gov](http://www.cancer.gov) and search 'NCI Publications Locator'

### IWMF Fundraising Initiatives

As the Board continues planning for enhanced services which include developing a revised and updated web site and expanding the number of research projects, we seek one million dollars annually to support these services and research projects. To achieve this goal we plan to hire a part-time fundraiser to solicit major gifts, as many comparable organizations have done to meet the competitive challenges of raising funds. Although IWMF has been largely member-supported in the past, we aim to attract gifts from foundations and other non-member sources where possible. The status of our fundraising efforts will be reported at the IWMF Educational Forum in May and in the following issue of the *Torch* for those who cannot attend the Forum.

Stay Well,

Judith

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## THE BEN RUDE HERITAGE SOCIETY INQUIRY FORM

**I would like to support IWMF in one of the following ways. Please contact me about:**

- A Bequest in my Will or making a Codicil
- A Life Estate or Real Estate Gift
- Other \_\_\_\_\_
- A Charitable Remainder Trust
- A Charitable Lead Trust
- A Gift Annuity
- Life Insurance

Signature \_\_\_\_\_

Name (please print) \_\_\_\_\_

Address/City/State/Zip \_\_\_\_\_

Telephone Number \_\_\_\_\_

E-mail Address \_\_\_\_\_

# TREASURER'S REPORT FOR THE YEAR 2007

*by James Bunton, Treasurer*

The finances of IWWMF are operated through two separate funds: the Research Fund and the Member Services Fund. The assets for these funds are kept separately as are the accounting records. The detailed financial statements are set out on our web site. For the sake of simplicity they are summarized as follows, with a comparison to last year, with amounts rounded to the nearest thousand.

<b>Research Fund</b>	<b><u>2007</u></b>	<b><u>2006</u></b>
Contributions received	\$ 901,000	\$ 582,000
Interest earned	<u>51,000</u>	<u>42,000</u>
	952,000	626,000
Research grants awarded	<u>38,000</u>	<u>1,797,000</u>
Increase or (decrease) in year	<b><u>\$914,000</u></b>	<b><u>\$(1,171,000)</u></b>

Contributions received during 2007 increased significantly over 2006 due to several large donations. Only one research grant was awarded in 2007 whereas in 2006 several were awarded, amounting to \$1,797,000, which was by far the largest amount ever awarded in one year. The details of these research projects were reported to members during 2006 and 2007. The total awarded by IWWMF to fund WM research since inception is over \$3 million.

As a result of the large increase in contributions in 2007 and the reduction in grants awarded, the deficit at the end of the last year of \$405,000 has been changed to a surplus of \$509,000 at the end of 2007. As well, a number of members have pledged, either orally or in writing, to make contributions over the next three years which in total amount to approximately \$529,000.

These are exciting times in WM research. The search for a cure is progressing quickly and IWWMF is fully involved in it. If you have not already done so, please consider making a five year pledge for research funding. Remember that no operating costs are charged to the Research Fund so every dollar pledged to research goes to research.

<b>Member Services Fund</b>	<b><u>2007</u></b>	<b><u>2006</u></b>
Contributions received	\$390,000	\$368,000
Member services and operating costs	<u>449,000</u>	<u>342,000</u>
Increase or (decrease) in year	<b><u>\$(59,000)</u></b>	<b><u>\$ 26,000</u></b>

Income in 2007 of \$390,000 is an increase of \$22,000 over 2006. However, expenses in 2007 amounted to \$449,000 which is an increase of \$107,000 over 2006. The result was a loss of \$59,000 for the year 2007. A significant expense in 2007 was the issuance of three new booklets: Healthy Living, Medical Tests, and Immunology. Operating and fundraising expenses in 2007 were only 12% of our total income; which means that 88% of all contributions went to help those with WM through member services or research towards ultimately finding a cure. This percentage compares favourably with other organizations similar to IWWMF.

The assets in the fund at the end of 2007 amounted to \$304,000 compared to \$363,000 at the end of 2006.

If you have any questions on IWWMF financial matters please do not hesitate to contact me directly at 416-621-7864 or [jbunton@sympatico.ca](mailto:jbunton@sympatico.ca).

lymphocytic leukemia, and, rarely, AL amyloidosis. The risk of progression is 1% per year for those with an IgG or an IgA MGUS and 1.5% per year for those with an IgM MGUS. The patient should realize that there is a 99% probability of not developing multiple myeloma, Waldenstrom's macroglobulinemia, etc. within the next year. However, the patient remains at this same risk for as long as he or she lives. Overall the risk of progression is 10% at 10 years, 21% at 20 years, and 26% at 25 years.

The median age at recognition of MGUS is 72 years. The rate of progression or death from plasma cell disorders is 6% at 10 years, 10% at 20 years, and 11% at 25 years, while the rate of death due to other diseases such as cardiovascular and cerebrovascular diseases and nonplasma cells cancer is 53% at 10 years, 72% at 20 years, and 76% at 25 years. Of the 70-year-old patients with MGUS only 20% are discovered during routine medical practice. The remaining 80% are found only if one performs electrophoresis upon a total population of 70-year-old persons. MGUS has been present for a median of 11 years in a 70-year-old person when it is discovered during routine clinical practice.

Risk factors for progression of MGUS to multiple myeloma or Waldenstrom's macroglobulinemia include the size of the M-protein when recognized. The risk of progression at 20 years was 14% when the M-protein value was 0.5 g/dL or less and 49% for those with an M protein of 2.5 g/dL. Patients with IgM or IgA monoclonal protein have an increased risk of progression as compared to patients with an IgG monoclonal protein. The presence of an abnormal free light chain (FLC) ratio is an additional risk factor. For example, patients with a serum M protein of 1.5 g/dL or more, IgA or IgM monoclonal protein, and an abnormal FLC ratio had a risk of progression at 20 years of 58%, compared to 5% when none of the risk factors were present.

IgM MGUS is defined as having a serum IgM monoclonal protein of less than 3 g/dL, bone marrow lymphoplasmacytic infiltration less than 10%, and no evidence of anemia, constitutional symptoms (fatigue, fever, night sweats, or weight loss), hyperviscosity, lymphadenopathy, or enlargement of the liver or spleen.

IgM MGUS was diagnosed in 213 Mayo Clinic patients who were residents of the 11 counties of Southeastern Minnesota. During long-term follow-up, 29 (14%) of these 213 patients progressed to symptomatic disease: 17 to non-Hodgkin lymphoma, 6 to Waldenstrom's macroglobulinemia, 3 to chronic lymphocytic leukemia, and 3 to AL amyloidosis. The relative risks were 15-, 262-, 6-, and 16-fold, respectively, when compared to a normal population. The overall risk of progression was approximately 1.5% per year. The level of serum M protein and the serum albumin value at diagnosis were the only independent predictors of progression.

Smoldering Waldenstrom's macroglobulinemia (SWM) is characterized by an IgM monoclonal protein of 3 g/dL or more and bone marrow lymphoplasmacytic infiltration of 10% or more with no evidence of anemia, constitutional symptoms, hyperviscosity, lymphadenopathy, or enlargement of the liver or spleen. Thus, MGUS and SWM are separated only by the size of the M protein and the degree of lymphoplasmacytic infiltration of the bone marrow. Both entities are asymptomatic. In a study from Italy, 35 (15%) of 217 patients with IgM MGUS and 45 (22%) of 201 patients with indolent (smoldering) Waldenstrom's macroglobulinemia progressed to symptomatic Waldenstrom's macroglobulinemia. The variables related to progression were the size of the initial M-protein value, hemoglobin level, and gender in both groups.

#### **A few questions for the doctor:**

*Is there a benefit to the patient and his doctor in identifying MGUS from the standpoint of monitoring and treatment?*

It is debatable whether the discovery of MGUS of the IgM type is of great value. Since MGUS is asymptomatic, it is discovered by chance. Treatment is not warranted unless the patient develops symptomatic disease.

*What are the key differences between MGUS and Smoldering WM patients?*

A MGUS patient is distinguished from a smoldering WM patient by the size of the M protein and the degree of bone marrow infiltration. A smoldering WM patient converts to WM upon the development of anemia, constitutional symptoms, hyperviscosity, lymphadenopathy, or hepatosplenomegaly.

*Once a patient is treated is the descriptor of Watch and Wait replaced by remission and relapse? Would that patient descriptor of remission and relapse also apply to one who has had only plasmapheresis?*

Following treatment, I think that "watch and wait" should be replaced by response (rather than remission) and relapse (evidence of progression of disease). Plasmapheresis is used only in patients with hyperviscosity. This lowers the IgM value and relieves the symptoms of hyperviscosity. I would not consider this to represent a response. I think that virtually every patient who has symptomatic hyperviscosity syndrome would also have other features of WM requiring therapy.

*What percentage of MGUS patients transform to WM versus MM?*

In our series of 1384 MGUS patients, 115 (8%) progressed to multiple myeloma, Waldenstrom's macroglobulinemia, or a related plasma cell disorder. Seventy-five of the 115 progressed to multiple myeloma, 19 to lymphoma,

10 to primary amyloidosis, 7 to Waldenstrom's macroglobulinemia, 3 to chronic lymphocytic leukemia, and 1 to plasmacytoma.

*Is it more likely that a MGUS patient with an IgM paraprotein will become a WM patient? Will a MGUS patient with IgG paraprotein more likely become a MM patient?*

Almost all IgM MGUS patients who progress will develop non-Hodgkin lymphoma (17 of 213), WM (6 of 213), chronic lymphocytic leukemia (3 of 213), or AL amyloidosis (3 of 213). A MGUS patient with IgG paraprotein may develop multiple myeloma or AL amyloidosis.

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Audio recordings of the WM sessions from the 2007 Lymphoma Research Foundation North American Educational Forum are now available. To access these presentations, follow these links:

**Dr. Irene Ghobrial - Novel Therapeutic Options in WM (52 minutes)**

[http://webcasts.lymphoma.org/2007EdForum3/IWMF\\_Ghobrial.mp3](http://webcasts.lymphoma.org/2007EdForum3/IWMF_Ghobrial.mp3)

**IWMF Patient Panel Discussion (47 minutes)**

[http://webcasts.lymphoma.org/2007EdForum3/IWMF\\_Patients\\_Perspective%20.mp3](http://webcasts.lymphoma.org/2007EdForum3/IWMF_Patients_Perspective%20.mp3)

In addition to the WM session, recordings of the other sessions at the LRF 2007 Ed Forum are available at no cost. Please contact the LRF Helpline directly at 1-800-500-9976.

pronounced a WM diagnosis. He insisted on immediate treatment. My whole "peaceful" existence suddenly came tumbling down. What happened to my beloved MGUS? My "treat the patient not the numbers"?

My scientific mind, however, refused to accept this hasty verdict and immediately kicked into action. Trips to Geneva and Beirut ensued, three new oncologist/hematologists were visited, two of them confirming that I have WM but advising that I remain on W&W as there had been no change in my status since a blood disorder was first discovered.

At that point I decided to drop my new oncologist in Nicosia and place my medical monitoring in the hands of a well-known hematologist practicing at the American University Hospital in Beirut. Quarterly blood test trips, results by fax or e-mail to Cyprus, and further trips a few weeks later for the physical check up and doctor's visit. It has been working very well for the past two years, save for the occasional disturbance due to the political or security situation in the country. And when travel is not permissible or possible, I have a blood test in Limassol just to be sure no major deviation is taking place. At the end of the day, I've learned to listen to my body whilst monitoring the critical WM parameters. And, above all, I've discovered the IWMF, its talk list and great members who have been both inspirational, educational, and supportive all along the way.

Three years have elapsed since that fateful day of initial diagnosis. Just for the record, in 2007 I traveled 150 days, visited dozens of countries both on business and on holiday, took a helicopter ride into an active volcano, went paragliding at the Indian Ocean island of La Reunion, sailed the Greek isles, went deep sea fishing, read multiple fantastic books, saw my daughter to university in the States, prepared my son for medical studies in the UK, and took mini-vacations with my wife, from Kyoto, Japan, to Burgundy, France, to Dubai, to the Greenbrier in West Virginia!

Two weeks ago I received an e-mail from Beirut with my latest test results: Hg of 14, B2M of 1.6, creatinine of 1.1 and IgM of 2400 down from 3000. A visit to my hematologist is due in one week's time, Beirut's security situation permitting. I hope I'll qualify for a few more quarters of W&W. I know that whilst my condition is somewhat stable today, one day I will face the music and move to treatment, or worse. Meanwhile, I'm taking advantage of every single day I'm still OK. Every new day is a blessing, a new glass of wine (or more!), a walk with the dog in the woods of the Mediterranean, and the enjoyment of the smell of wild thyme and oregano after the rain.

So a message to all new Wallies: life does not end on diagnosis. In a way, it only begins.

Greetings to all,

Zed

December 2007

## FROM IWMF-TALK

by Gareth Evans

**Katharine McCleary** wrote, “I use a library computer as we don’t have one and was spending a lot of time at the hospital.” That set me thinking that in this appearance as guest columnist I might begin by talking to our many readers of the *Torch* who don’t own computers. These days it is very easy at the library, in Internet cafes, or at a friend’s, to get access to a computer for a while. So it is possible for any of us to plug in to the amazing support service that IWMF-TALK provides to WM’ers around the world.

How would you do this? First you should create for yourself an e-mail address from one of the free services like Hotmail, Yahoo, or GMail. They all offer step-by-step instructions. And they provide so much free storage that you could keep every message from TALK for the next hundred years and still have room to spare. The information is stored remotely, so you’re not using up any capacity on your friend’s or a public computer. Once you have an e-mail address, follow the joining instructions at the foot of this page. Get a friend or grandkid to help if you’ve never used a computer before.

This will now allow you to put any questions you have about your WM to a thousand others, which includes people with a wide range of expertise and experience with every facet of this complicated condition. Even if you don’t have an urgent problem, there’s no better way to learn than by following the conversations that take place on TALK. You’ll also have access to the Archives, but, to protect members’ privacy, it is necessary to join TALK first.

What you will also find are friends and all the drama of the human condition. **Daniel** joined in December and proved himself an able and helpful researcher even before disclosing his wife’s situation. Martina, herself a critical care physician, was diagnosed in September 2007, aged only 40, after debilitating pain in the lower back progressed to the thighs. Her doctors recommended immediate treatment, complicated by the fact that she was pregnant. They decided on CHOP without rituximab, since various studies had shown its relative safety in pregnancy. We followed their progress until Daniel delighted us with the news that Oliver Dean arrived safely at the end of January, a bit early and a bit underweight, but mother and “just too cute” son are

doing well. We do also occasionally hear sad news from the other end of life, as when **Bertha Henriques** reported the peaceful passing, surrounded by family, of her 85-year-old father after a fifteen year history with WM. A good innings, as we international types from cricket playing nations would say, but **Bea Hollander** spoke for us all in writing, “You have my sincere sympathy on the loss of your Dad. God Bless you for all the care that you have given him.”

As usual we heard from many new members, some who had just been reading messages for a while and some newly diagnosed. **Andrea Dimond** asked, in regard to her mother, whether oncologists are “hesitant to start aggressive therapy for older people or does it mainly depend on the symptoms?” **Bea Hollander** replied that she was diagnosed 3 years ago, aged 75, and has remained on Watch & Wait, having already dealt with breast cancer and now thyroid cancer as well. Many younger patients would agree with her statement, “I strive now for quality and not quantity of time.” **Suzanne Maxson**’s husband, also over 70 at diagnosis, required Rituxan, chlorambucil, and Velcade treatment for kidney complications. “He’s doing well, and his age has never been an issue.” **Laura Elashewich**, now 73, wrote that she’s back on W&W after several successful WM treatments over the years. **Rajeev Goswami** wrote that his father in India, 74, has been receiving CHOP-R without side effects to date. I could also have added to the positive news that we have two members of the Australian Support Group in their mid-eighties recently successfully treated, one with rituximab and the other chlorambucil.

Cholesterol and statin drugs remained a popular subject of discussion. Statins are a class of drugs widely used to lower cholesterol, but WM patients usually return low cholesterol readings anyway. **Jeff Atlin** reported that his cholesterol numbers, low for years, had increased after successful treatment with R-CVP which lowered his IgM and raised his hemoglobin. Several members reported similar increases in cholesterol readings after successful WM treatment. Previously reported laboratory work by Dr. Treon’s team had shown that some statins may actually reduce IgM, as well as reducing cholesterol. Noting this paradox, **Steve Kirsch** advised that a clinical trial at Dana-Farber is now recruiting patients with a confirmed WM diagnosis but who do not meet the normal criteria for initiation of treatment and who

*From IWMF-Talk, cont. on page 21*

### HOW TO JOIN THE 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

are prepared to avoid grapefruit for the period of the trial. The trial drug is simvastatin (Zocor). Steve had to withdraw from the trial because of the need to pursue more aggressive treatment but not before reporting a drop in his IgM after the first week of simvastatin. Patients who have been treated with rituximab within the past three months are excluded from this trial.

**Ray Morgan** reported that he had been advised by Mayo Clinic to stop using Lipitor, another statin drug, since it may interfere with CD20 binding of rituximab. Daniel reposted the relevant abstract from the 2007 ASH conference that raised these concerns, but **Renee Paley-Bain** wrote that she had been successfully treated with rituximab on two occasions during the ten years she has been taking a statin drug. **Eddy Andersen**, however, had previously noted no positive effect on IgM from her eight years on simvastatin (it is perhaps worth noting also that her initial success with fludara+rituximab was not repeated on subsequent use). The discussion and diverse experiences of listmembers reinforced the need to pursue such complex questions in clinical trials under expert supervision. We look forward to the results of the Dana-Farber trial answering some of these questions.

The briskest discussion was prompted by **Steve Kirsch's** enticing subject line "WM research projects: Low hanging fruit." Perhaps not surprising since Steve was inviting us to help spend his foundation's money! He wrote, "I'm trying to prioritize the WM research projects which could make a significant contribution to patient outcomes within 12 months." Steve went on to nominate two possibilities, using drugs like AMD3100 to mobilize WM cells into the bloodstream to increase their susceptibility to rituximab and a WM clinical trial for ofatumumab, one of the next generation humanized CD20 mAbs. "It could be a better Rituxan," Steve concluded, before calling for comments and suggestions. Among the thirty responses, some did venture alternative projects, but **Tom Hoffmann** questioned the rationale. Most discussion led by **Colin Perrot** and **Peter DeNardis** centered on the mechanics of funding and supervising research grants. These are of course questions that our Foundation has grappled with for many years. **Ron Draftz** summarized the rigorous procedures followed by our Research Committee and pointed members to the impressive current and past research funded by our IWMF donations detailed under "Research" at the [www.iwmf.com](http://www.iwmf.com) website. Despite the controversy generated, most would agree with **Gordon Green** who wrote, "We all admire your efforts, Steve. Good luck in your search!"

*Gareth Evans, support group leader for Australia, contributes regularly to IWMF Talk. The Torch thanks Gareth for agreeing to serve as guest editor and writing from IWMF-Talk at short notice for this issue.*

## SUPPORT GROUP NEWS

*edited by Penni Wisner*

### ARIZONA

*Tucson*

The small group of seven to ten members has discovered a meeting format they very much enjoy. The group meets every other month—November, January, and March—for lunch when the facilitator, **Jackie Smith**, is in residence. The most recent venue, a Denny's restaurant, was a great success.

### CALIFORNIA

*Los Angeles*

In January, Dr. James Berenson of the Institute for Myeloma & Bone Cancer Research in West Hollywood spoke to about 30 members of the Los Angeles support group. One interesting point he made was to make sure to include a blood test for iron and a bone density scan as part of a medical work up. Several group members have volunteered to help at the upcoming Ed Forum in Los Angeles. A future meeting concentrating on the importance of diet and nutrition in WM is in the planning stages.

*Orange County*

Because the 2008 IWMF Ed Forum takes place next door in Los Angeles, the Orange County group will not have a spring meeting. **Marty Glassman** and **Emil Parente** are working on lining up a guest speaker for the fall meeting in October.

*Sacramento and Bay Area*

The press deadline was too close to include a report of the most recent meeting (March 29) when John Haluck, an attorney and blood cancer survivor, discussed "Cancer and the Law." The event was cosponsored by the IWMF and the Leukemia & Lymphoma Society. There will be a general meeting in late June. Dr. Steven Treon of the Dana-Farber Cancer Institute will speak to the group on November 1, 2008. **Gene Elvee**, a fairly new, but no less treasured, member, just passed away at the end of February.

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### 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 used by the leaders to share their experiences and ideas for facilitating our IWMF support groups. Please e-mail Support Group Coordinator Karen Pindzola at [kpindzola@yahoo.com](mailto:kpindzola@yahoo.com) if you would like to participate.

## COLORADO & WYOMING

Sixty-five people attended the Rocky Mountain support group "Visit with Dr. Steve Treon" on February 9 at Presbyterian St. Luke's Hospital in Denver. The Leukemia & Lymphoma Society cosponsored the event that combined WM and MM (45 WM patients and caregivers plus about 20 multiple myeloma patients/caregivers). A wonderful breakfast sponsored by Millennium Group kicked off the day. Thanks again to them. The event was extremely successful! Many thanks to Dr. Treon and Chris Patterson for an exceptional event. Dr. Treon began with a review of the Bing Center for WM at the Dana-Farber Cancer Institute. They have about 600 WM patients and currently treat about 300. Dr. Treon said that in the US 2000-4000 new cases of WM are diagnosed each year. In noting some of the effects of WM, Dr. Treon listed lower hematocrit, platelets, and white blood counts, more fatigue, higher IgM, greater serum viscosity, and, frequently, damage to the nerves. Most WM patients also have lower IgA and IgG, which tends to cause high incidence of sinus issues and respiratory problems. In the last year researchers have made progress in understanding familial connections in WM, as well as environmental causes of WM cell growth. This will help them design solutions to discourage cell growth and keep the WM under control for longer periods. Dr. Treon summarized the last year's clinical trial progress by saying that single-drug regimens had been effective—yielding about 30 to 70% response rate depending on the drug. But combination drug regimens were proving to be even more effective with 60 to 80% response rates. He also offered to consult with local oncologists to assist in making the optimum treatment choice for each patient and reminded the group that, with WM, we treat the symptoms, not the numbers.

## FLORIDA

### *Fort Lauderdale Area*

The group was so pleased to host Dr. Steven Treon on March 22. At press time in February, there were already 70 reservations for the event. His exciting and inspiring program was followed by a Q&A led by Dr. Treon and Dr. Daren Grosman, Director of the Leukemia and Lymphoma Program at the Memorial Cancer Center in Pembroke Pines, Florida. The local Millennium Pharmaceutical representative arranged for a complimentary lunch for all attendees. **Charlie Koch** and **Theo Vagionis**, co-leaders of the group, promised a write up would be available after the meeting.

### *Southwest Florida*

Dr. Steven Treon received an enthusiastic reception from a capacity crowd on Saturday, March 1, 2008 in Sarasota.

### *Tallahassee*

Meetings are tentatively scheduled for April 25, June 27, and October 31, 2008.

## EASTERN IDAHO

The Eastern Idaho support group is a very small group of four patients (one of whom has progressed to a form of MDS so WM has become a minor issue for him). Severe winter weather and poor road conditions prevented the last get together. Leader **Barb Britschgi** telephones the members on a frequent basis to relay news. The Britschgis plan to travel in Australia throughout the spring so there are no current plans for another meeting.

## ILLINOIS

The Chicago area support group had a good year in 2007. Breakout sessions at the three meetings focused on separate topics including caregiver support, treatment options, and Ed Forum videos. Marnie McHale, Program Director at Wellness House, a cancer patient support facility in Hinsdale, Illinois, was the guest speaker for the year. The 2008 series of meetings kicks off on Saturday, May 3, in Chicago with Dr. Morie Gertz, a well-known WM expert from the Mayo Clinic. Plans are currently in process. For details contact **Don Brown** at [Ldonbrown@msn.com](mailto:Ldonbrown@msn.com)

## GEORGIA

On February 16 the Georgia support group met at the Wellness Center in Atlanta. The meeting opened with a discussion and update from each of the members regarding their health. Then the group watched the popular Ask the Doctor DVD from last year's IWFM Ed Forum. Even though some attendees had been at the Forum, they appreciated the review.

## MICHIGAN

The group met in Saginaw, Michigan, in October 2007. Everyone brought a dish to share for a pot luck lunch. **Gail Xuereb**, a member of the Michigan support group, and her daughter, Suzanne, had attended the IWFM Ed Forum in Atlanta the previous April and they shared some of what they had learned. Much of the time members enjoyed catching up with each other. The spring meeting is planned for April or May, probably in the Royal Oak area.

## MINNESOTA & WESTERN WISCONSIN

Featured speaker at the January 12 meeting was Dr. Karen Lawson from the Complementary and Integrative Medicine division at the University of MN Center for Spirituality and Healing. The next meeting date is May 17. We will be joined by Dr. Alice Shapiro of the Park Nicollet Institute for a discussion about nutrition. We are also planning our summer picnic for July 12.

## NEW YORK

### *Eastern New York/Western New England*

A very spirited, open, and fruitful set of discussions about "Caring Partners" occupied the January meeting agenda. The support group met at the Capital Region's Gilda's Club and divided themselves into two groups with the patients in one

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room and their partners in another. Members **Tom and Kay Zolezzi** very thoughtfully facilitated these two groups. The annual luncheon outing took place mid March and in May the group plans a community meeting with Dr. Irene Ghobrial of the Dana-Farber Cancer Institute. The meeting will be co-sponsored by the Leukemia and Lymphoma Society. As of press time the date had not yet been confirmed. July 19 is the tentative date of the annual summer picnic. The group was recently saddened by the passing of two longtime member-patients, **Priscilla Merriman** and **Joe Grasso**. Memorial donations were made to IWWMF.

### OREGON/SOUTHWEST WASHINGTON

Current meeting plans are for May 3, July 26, and October 25, 2008.

### PENNSYLVANIA

#### *Harrisburg*

Light refreshments were shared by the southeastern PA group on February 10. Thanks again to **Kate and Don Wolgemuth**. The conversation revolved around recent treatments and current health issues. Not all those in attendance are talk list members, so there was some discussion of late-onset neutropenia after Rituxan treatment, as well as some other concerns mentioned on the IWWMF talk list. **Rita Ziats** had been in contact with a newly diagnosed patient who was relieved to be able to talk to someone who had personal experience with WM. **Terrie Eshleman** mentioned that the American Cancer Society has a Cancer Survivorship Celebration on April 15th. Lilly Oncology is providing art materials, and Terrie has been asked to be one of the “working” artists for the day. She plans to have IWWMF information and New Patient Packets to hand out to patients from cancer treatment centers throughout Lancaster County. Patients need to register to attend. The next scheduled meeting will be May 11, from 2 to 4 pm at Messiah Village. Contact Terrie about the April 15 event and future meetings.

#### *Philadelphia*

In February the Philadelphia support group had a great meeting with one of our local oncologists as the guest speaker. Dr. Edward Statdmuer, the oncologist of one of our members and Director of the Multiple Myeloma Program at the University of PA, gave an overview of Waldenström’s in a down-to-earth presentation that newbies could understand and veterans could learn from. He covered all aspects of WM including what it is, how it is monitored, and what treatments are used. Twenty-one people attended and, as usual, the Pindzola’s little white dog, Heidi.

### SOUTH CAROLINA

The next meeting of the South Carolina WM support group will be Saturday, April 5, in Aiken, South Carolina. The meeting will be an informal lunch meeting from noon to 2:30 pm. During this past year a few WM patients have

been newly diagnosed in South Carolina. The get together is a great opportunity for new patients and caregivers to meet others dealing with WM and to share information. For details, contact the coordinators for the SC WM support group, **John and Paula Austin** at [jhaustin@bellsouth.net](mailto:jhaustin@bellsouth.net).

### TENNESSEE

Both groups plan to meet during late April at the usual meeting places and times. The groups thank the Memphis Center for Women & Families and the Nashville Airport Marriott for providing meeting spaces at a reduced or no-fee basis. The two Tennessee groups usually draw about half the potential attendance, often with varying attendees. They enjoy the more intimate atmosphere and are flourishing.

#### *West Tennessee, Eastern Arkansas, and Northern Mississippi*

A small attendance at the January meeting provided a warm, supportive environment for a sharing-and-caring session. Even with only four attendees, the meeting managed to be lively and interesting.

#### *Central Tennessee*

December’s small, intimate group led to more personal conversations and more opportunities to get to know others better.

### TEXAS

#### *Dallas and Northern Texas*

The north Texas WM support group meets at Baylor University Medical Center in Dallas. The center provides a great meeting room with audio-visual support, coffee, tea, and parking passes. The cafeteria is adjacent and attendees can bring their lunch into the meeting room. The January meeting featured a presentation by Kristin Ringo, a registered and licensed dietitian at Baylor. She talked about Power Foods for Fighting Cancer. The early spring meeting was March 15. The speaker, a physical therapist from Baylor, spoke about peripheral neuropathy and its management. In addition to the guest speakers, the group always takes time to give updates and share WM experiences.

#### *Houston*

Dr. Irene Ghobrial gave a wonderful program in November 2007. The next program will be on April 27 with Dr. Maria Scouros, head of the Houston Cancer Institute, discussing new advances in treatment options and diagnostic tests including PET scans. The meeting will be on Sunday, April 27, at 3 pm, at 21 Briar Hollow Lane, Houston 77027, inside I-610 Loop in Uptown. Doors open for refreshments at 2:30 pm. Everyone living in or visiting the Houston area is welcome to attend. There is no participation fee and there is plenty of free parking at the door. The location is also wheelchair accessible. For more information, call **Barbara and John Manouso** at 713-840-0828.

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**WASHINGTON**

The Waldenstrom's Macroglobulinemia support group-northwest (WMSG-NW) is headquartered in the Seattle area, currently with 167 members, not counting spouses and caregivers (as of Feb. 2008). Meetings are held three or four times a year, usually at the home of **Peggy and Bob Horton** in Auburn, WA. The group draws from a wide area including Washington, Oregon, Alaska, and British Columbia. Leader Peg Horton and co-leader **Deloris Morriscal** keep their group vibrant through frequent and detailed contact by e-mail, regular mail, and telephone. Meetings are recorded and minutes written up that include everyone's contributions. These are then distributed to all the members, providing invaluable information, especially for those who could not attend. There are no dues or membership fees. Voluntary contributions have covered our operating expenses. The last meeting of 2007 was in November and the next meeting will be held Saturday, April 5 at noon at the Hortons'. Everyone brings whatever food they want to share with the group, creating the most incredible potlucks! In fact, the gatherings can seem more a party than a meeting, with lots of laughter and good humor. Meeting dates, directions to the Hortons' house, and other pertinent information will be distributed a few weeks before each meeting. For more information, contact **Peg Horton** [peggy.horton@comcast.net](mailto:peggy.horton@comcast.net) or **Deloris Morriscal** [delmorr@comcast.net](mailto:delmorr@comcast.net)

**WASHINGTON D.C./METROPOLITAN AREA**

Veteran WM'ers described their wide-ranging symptoms, treatments, and their generally optimistic outlook at the February gathering. It seemed to dispel some of the anxiety of newly-diagnosed members. The group also discussed concerns and issues gleaned from the IWWMF-Talk. The next meeting is scheduled for May 25.

**INTERNATIONAL SUPPORT GROUPS**

**FINLAND**

The WM support group in Finland is now two years old and establishing activities. Because of the long distances patients must travel to a central location, the group has met just once a year. The most recent meeting took place in Tampere in the middle part of the country. The participation doubled since the first meeting; there were a good 20 patients including several caregivers at the October 2007 meeting. From its inception the group has enjoyed great support from the National Cancer Association of Finland, which provides a meeting-room and lunch. Our guest-speaker was Dr Petri Oivanen, the leading hematologist at Tampere University Hospital. He also treats patients privately from all over Finland. The National Cancer Association also sponsored the very first publication about WM in the Finnish language. The booklets arrived just in mid February. They give WM information for patients, especially for those newly diagnosed.

If you can't get to a local support meeting, use our IWWMF Telephone Lifeline to call a WM veteran.

The lifeline is seeking volunteers who speak a language other than English. If you would like to volunteer, please contact the IWWMF business office at 941-927-4963 or [info@iwwmf.com](mailto:info@iwwmf.com).

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# VOLUNTEER FUNDRAISING QUESTIONNAIRE

Please consider helping us help others by selecting a volunteer task you are interested in or would like to hear more about

## An "a-thon" (biking, walking, running, etc.)

\_\_\_\_\_ I would like to serve as a resource person for those considering an "a-thon."

\_\_\_\_\_ I would like to help market an "a-thon."

\_\_\_\_\_ I would like to do an "a-thon" but would like some information.

\_\_\_\_\_ I would like to help finance an "a-thon."

\_\_\_\_\_ Other: \_\_\_\_\_

## An event or activity (golf, auction, sales, book royalties, dinner/luncheon, etc)

\_\_\_\_\_ I would like to serve as a resource person for those considering an event.

\_\_\_\_\_ I would like to help market an event or activity.

\_\_\_\_\_ I would like to do an event but need some information.

\_\_\_\_\_ I would like to help finance an event.

\_\_\_\_\_ Other: \_\_\_\_\_

## Member Services Fund

\_\_\_\_\_ I would like to help manage or coordinate this fund.

\_\_\_\_\_ I would like to help write appeal letters for the fiscal year.

\_\_\_\_\_ I would like to help with special e-mail letters for the annual program.

\_\_\_\_\_ I would like to help finance the annual program with a matching gift.

\_\_\_\_\_ Other: \_\_\_\_\_

## Research Fund

\_\_\_\_\_ I would like to serve as a solicitor for the IWWMF research fund volunteer corps.

\_\_\_\_\_ I would like to serve as a "door opener" or "partner" for the solicitors.

\_\_\_\_\_ I would like to serve as a special resource for IWWMF estate planning donors.

\_\_\_\_\_ I would like to hear more about volunteering as a solicitor or a "partner" by

a) \_\_\_\_\_ attending the 5/17/08 volunteer workshop-dinner at no cost to me/us on Saturday, May 17th in LA, or

b) \_\_\_\_\_ inviting Dick Weiland to call or write me at the addresses listed below.

## Other

I would like to: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

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

Address: \_\_\_\_\_

E-mail: \_\_\_\_\_ Phone: \_\_\_\_\_

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**PAGE 32**

*IWMF Research Grant, cont. from page 3*

monoclonal protein and what controls how much is produced. To answer the first question we have looked at proteins in the bone marrow and lymph nodes and have shown that B-lymphocyte stimulator (BLyS) and interleukin-6 (IL-6) increase IgM production (and also support the cancer cell growth). We have found that IL-6 is controlled by another protein, called Rantes (also known as CCL5), and that Rantes levels are very high in the blood of patients with WM. Similarly, we have found that BLyS levels are increased in the blood of some WM patients, but this is largely controlled by differences in the BLyS gene.

To answer the second question and understand why some patients have high IgM levels and others do not, we are looking at the control of genes involved in the development of plasma cells from B-lymphocytes. As part of this research, we are measuring small RNA fragments (called microRNAs) that may have a role in controlling these genes and are measuring their presence in WM compared to normal cells and other B-cell malignancies. Our hope is that this research will allow us to identify what drives the IgM production in WM and provide us with additional therapeutic targets in the future.

Mayo Clinic, Rochester, MN

*Stephen Ansell went to medical school at the University of Pretoria in South Africa. He subsequently obtained a Ph.D. from the University of Pretoria and then trained in general internal medicine and oncology. He came to Mayo Clinic for further training in hematology and oncology in 1994 and joined the staff of the Mayo Clinic in the Division of Hematology in January 2000. He is currently an associate professor and his clinical and research focus is on B-cell malignancies.*

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