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## DOCTOR ON CALL: DR. MORIE A. GERTZ



Dr. Morie A. Gertz

*In the following article written for the Torch readership, Dr. Morie Gertz discusses amyloidosis in WM. This rare complication of our disease is linked to the abnormally high level of the IgM protein found in the bloodstream of WM patients. While Dr. Gertz here limits his discussion to IgM-associated amyloidosis, the reader should understand that amyloid deposits can develop from a significant number of proteins in addition to IgM and can afflict patients in many diseases other than WM. The symptoms in such cases, however, are the same as those described below when the disease is IgM-related.*

### IgM-ASSOCIATED AMYLOIDOSIS

In Waldenström macroglobulinemia, the symptoms in virtually all patients are derived from the growth of the malignant Waldenström cells in the bone marrow, lymph nodes, liver, and spleen. The growth of these malignant cells is responsible for the most common findings in Waldenström's: anemia leading to fatigue, lymph gland enlargement, and enlargement of the liver and spleen, sometimes associated with weight loss. The monoclonal IgM, which is a hallmark of Waldenström macroglobulinemia, does not play a role in producing symptoms in most patients. The IgM is a useful measure of a patient's course as it indicates a response to treatment when declining, or stability when showing slight variations, or, when rising, evidence of progressive disease.

In rare instances, the IgM protein itself is responsible for symptoms. When the IgM level is very high, the blood can become syrupy and thick, and this is the hyperviscosity syndrome that requires plasma exchange. When the IgM binds to a nerve, it can cause damage to the nerve, leading to numbness, tingling, and weakness in the feet and lower legs. This is so-called peripheral neuropathy. Occasionally, the IgM protein leads to amyloidosis, the subject of this review.

All proteins, including the Waldenström's protein, are biodegradable and recyclable. The life of the IgM protein in the circulation is roughly 6 weeks. After 6 weeks, the protein goes to the recycling center of the human body, is degraded, and then the breakdown products are used for

the production of new IgM protein. Occasionally, the IgM protein misfolds and, therefore, becomes non-recyclable and non-biodegradable. As a consequence, it can build up in the circulation and deposit in the tissues, causing organs to malfunction.

When the IgM protein misfolds and is no longer amenable to the recycling processes of the human body, it is carried in the blood to different tissues in the body and deposited there. It is now referred to as an amyloid deposit. Amyloid typically deposits in the tissue of the heart, liver, kidney, nerve, and lung. In each of these organs, the deposits of amyloid can cause those organs to malfunction.

When depositing in the kidney, amyloid causes the kidney to leak protein into the urine with resultant swelling in the lower extremities, a rise in the serum cholesterol, and eventual damage to the purifying function of the kidney. When amyloid deposits into the heart, it causes the heart to function poorly and become less efficient. The resultant impairment of heart function leads to exertional fatigue, shortness of breath, and ultimately heart failure. Deposits in the nerve can resemble

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*Doctor on Call, cont. from page 1*

IgM-associated neuropathy with numbness and tingling, burning, and lower extremity weakness. Deposits in the lung can cause shortness of breath and interfere with oxygen flow from the atmosphere into the bloodstream. Amyloid deposits in the liver can cause enlargement of the liver with the resultant loss of appetite, fatigue, weight loss, and distaste for specific foods.

Amyloid deposits are never normally found in the body. Their presence always indicates an abnormal process. The disorder is rare. It affects 8 out of one million people yearly. In the case of IgM-associated amyloid, the protein is produced by the Waldenström cell and, although it can affect anyone, the majority of patients are over age 60 with an average age at diagnosis of 67. Two-thirds of the patients we see are men. Although amyloid is an abnormal protein, diet and the amount of protein eaten play no role in the development of the disease; and no links have been found with stress, occupation, or environmental exposure. It is not infectious or contagious. The reasons why the amyloid protein cannot be broken down by the body are not well understood, but research studies are underway at Mayo Clinic to try and understand what is unique about the amyloid protein that prevents it from being removed by the body. The symptoms of amyloid include swelling, weakness, weight loss, shortness of breath, diarrhea, easy bruising of the face or eyelids, tongue enlargement, and dizziness upon standing. Some of these symptoms are also seen in Waldenström macroglobulinemia, and caution is required to distinguish the two disorders.

Amyloid needs to be treated because it can irreversibly damage the heart and the kidney. Patients who develop severe kidney damage from amyloid may require dialysis treatment for support. Patients whose hearts become involved can have serious problems related to the reduced pumping action of their heart resulting in fatigue and loss of energy. The most common symptom of heart amyloid is shortness of breath with the slightest physical activity. It is difficult to climb stairs, and blood pressure often will fall. This needs to be distinguished from the fatigue and shortness of breath associated with Waldenström, which are usually due to anemia.

The diagnosis of amyloidosis is fundamentally different from the diagnosis of Waldenström macroglobulinemia. While the diagnosis of Waldenström is based on bone marrow findings or the size of the IgM protein, neither are predictors for the presence of amyloid. The first suspicions of amyloidosis are based on symptoms, and then specialized biopsies and specialized staining techniques are required to confirm a diagnosis. Most patients with Waldenström need not be concerned with the possibility of

*Doctor on Call, cont. on page 10*



The IWMF *Torch* is a publication of:

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3932D Swift Road • Sarasota, FL 34231-6541

Telephone 941-927-4963 • Fax 941-927-4467

E-mail: [info@iwmf.com](mailto:info@iwmf.com) • Website: [www.iwmf.com](http://www.iwmf.com)

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### HAVE YOUR SAY

The *Torch* welcomes letters, articles or suggestions for articles.

If you have something you'd like to share with your fellow WMers, please contact Alice Riginos at 202-342-1069 or [ariginos@sy-thetis.org](mailto:ariginos@sy-thetis.org)

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

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## PRESIDENT'S CORNER

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Judith May, President

### **A Word of Thanks**

Our letter in February informing you of the need for foundation resources was quickly answered by many of you. We are deeply grateful for your commitment and support. Your quick actions have ensured the future of the many services provided by the IWMF. I promise you that we will continue to bring you important educational information and patient services and that we will continue to search for a cure. I also promise you that we will do our very best to keep our costs down. Thank you for your loyalty and all you do to maintain a stable and effective IWMF.

### **ONS Annual Congress**

In April we had the wonderful opportunity to have a booth at the Oncology Nursing Society's Annual Congress in Boston. These are the compassionate and efficient nurses most of you have met in your WM journey who administer the IV chemotherapy and care for you while you are in treatment. Since WM is such a rare disease, we thought it would be a good idea to create awareness of the IWMF among the nurses and to encourage them to take some of our publications back to their treatment rooms to give to WM patients.

Our office manager, Sara McKinnie, very capably and efficiently trots to various conferences during the year and sets up an IWMF information booth with our literature. In Boston, she was assisted by volunteers John Paasch and Jack Whelan. During the two days of the conference they spoke with over 200 oncology nurses who had treated WM patients but had never heard of IWMF. Many nurses took publications with them and others took the order forms to complete and return later. Forms have been coming to the office in the mail and by FAX. We have found this to be an excellent way to get WM materials into the hands of nurses and patients who do not yet know about the IWMF. When you require treatment, it would be another way to build awareness if you could please take a *Torch* newsletter, or other publication you may have, and leave it at the treatment facility for other WM patients.

### **NIH News**

News from the National Institutes of Health shows increased interest in rare diseases. As WM is on the rare disease list, this is a significant development. I will monitor news of their efforts and report back periodically. You will see two relevant items with the title "NIH News" on pages 13-14 of this issue.

### **Ed Forum**

Soon I will be off to the 2011 Educational Forum in Minneapolis, and by the time you read this issue of the *Torch* it will all be over. I do hope to see many of you there. It is one of the few times during the year when the Board of Trustees and members meet one another and talk, and we enjoy this very much.

As summer approaches, I wish you all time to relax and enjoy the beauty around us during this wonderful season.

Stay well,  
Judith

### **We Get E-mails**

I just received the latest *Torch* and my wife commented at how many people past and present have done so much to keep IWMF going. She has a rare condition and there is nothing even comparable to the resources so many have put together over the years regarding WM. I don't know any of the officers and trustees, but you are a great and wonderful group of people. Thank you so much for your time and work . . . and especially now when the economy is not the greatest. You are special people.

paul k



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# MEDICAL NEWS ROUNDUP

BY SUE HERMS

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**New WM Cell Line Announced by Mayo Clinic** – Researchers from the Mayo Clinic have described the establishment of a new WM cell line, MWCL-1, which should be important in understanding the mechanisms driving the development and progression of WM. Genetic analysis of the cell line has confirmed a clonal relationship between this cell line and the original tumor, and the cell line exhibits a morphology comprised of small B-lymphocytes and larger lymphoplasmacytic and plasma cells, along with the typical markers of WM tumors. The cell line retains the ability to secrete high amounts of IgM protein in the absence of an external stimulus. The establishment of new and improved WM cell lines is being funded by a joint grant award from the Leukemia & Lymphoma Society and the IWWMF.

**Serum Free Light Chain Measurement Evaluated in WM** – The Dana-Farber Cancer Institute and Service des Maladies du Sang, Hôpital Huriez, France, examined the role of serum free light chains in studying the response and progression of 48 WM patients, either untreated or relapsed/refractory, and prospectively treated in a bortezomib/rituximab trial. Serum free light chain response occurred in 79% of patients vs. 60% by M-spike criteria, and the median time to response was shorter when measured with serum free light chain. Progression using serum free light chain measurement correlated well to progression using M-spike; however the median time to progression was more rapidly detected by serum free light chain. The study also confirmed a flare by serum free light chain measurement in post-rituximab therapy. The study concluded that serum free light chain may be a useful marker for tumor measurement, demonstrating earlier response to therapy and earlier detection of disease progression, compared to IgM or M-spike measurements.

**Milatumuzumab in Clinical Trials for Hematologic Malignancies** – Milatumuzumab is a humanized monoclonal antibody targeting tumors that express the CD74 antigen and is being studied in early clinical trials for the treatment of multiple myeloma, non-Hodgkin's lymphoma and chronic lymphocytic leukemia. It has received orphan drug designation from the FDA in the United States.

**Canada Invests in National Cord Blood Bank for Blood and Immune Disorders** – Canada is progressing with the establishment of a national cord blood bank that can be used to treat a variety of blood and immune disorders. Cord blood remains in the umbilical cord and placenta after birth and is a rich source of stem cells. Health ministers representing the Canadian provincial and territorial governments (with the exception of Quebec, which has its own program) announced that they will invest \$36 million to set up the bank; an additional \$12 million will come from public fundraising. Once the system is up and running, parents will be asked to donate their newborns' cord blood to the public bank, which will be open to any Canadian patient in need.

**New Monoclonal Antibody Enhances Rituximab Activity** – Antibody-dependent cell-mediated cytotoxicity (ADCC), largely mediated by the body's natural killer cells, is thought to play an important role in the effectiveness of rituximab therapy. A joint study conducted by Stanford University, Centre Hospitalier Universitaire de Rennes in France, Johns Hopkins University School of Medicine, and Duke University Medical Center reported on a new monoclonal antibody which, when administered after rituximab, enhanced rituximab's effectiveness by improving the ADCC activity of natural killer cells. This study used animal models of lymphoma.

**New Small Molecule Drug Shows Positive Results in Clinical Trials for CLL** – Advancell, a biopharmaceutical company, announced positive results from a Phase I/II clinical trial conducted with Acadra (acadesine) in chronic lymphocytic leukemia (CLL) patients resistant to current therapies. The company also announced promising pre-clinical results for this drug in multiple myeloma, mantle cell lymphoma, and other lymphoproliferative disorders. Acadra is an intravenous small molecule treatment that induces apoptosis in B-cells. Acadra did not induce bone marrow suppression at any of the doses tested, and no grade 3 or 4 adverse events occurred in this trial.

**Pre-Clinical Data Released for New Combination Therapy in B-Cell Cancers** – ImmunoGen disclosed pre-clinical data for the company's novel IMG529, an anti-CD37 targeting antibody combined with a potent cancer cell killing agent called DM1. This combined therapy is a candidate for the treatment of B-cell malignancies including non-Hodgkin's lymphoma and chronic lymphocytic leukemia. The prevalence of CD37 is comparable to that of CD20 in key B-cell malignancy subtypes. In pre-clinical testing, this new agent appeared to be superior to rituximab in causing cell death.

**Australian Researchers Correlate Bone Marrow Pathology and Clinical Findings in WM** – An Australian study from the Royal Melbourne Hospital, the University of Melbourne, and the Peter MacCallum Cancer Centre discussed the correlation between bone marrow histopathology and clinical findings in WM. Eighty newly diagnosed, untreated WM cases were examined. Serum monoclonal IgM concentration was related to the plasma cell burden in the bone marrow but not the B-lymphocyte infiltrate. Overall, lymphoplasmacytic disease burden weakly correlated with severity of anemia.

**New HDAC Inhibitor Begins Phase I Clinical Study in Hematologic Cancers** – 4SC, a drug discovery and development company, announced that the first patient has been treated in a Phase I trial with 4SC-202, a selective histone deacetylase (HDAC) inhibitor which interferes with mitosis (cell division). This trial will evaluate the safety and effectiveness of this oral medication in patients with

*Medical News Roundup, cont. on page 5*



several advanced hematologic conditions, including chronic lymphocytic leukemia, multiple myeloma, myelodysplastic syndrome, and lymphomas. Different dosing schedules will be evaluated.

**Rituximab Evaluated in Central Nervous System Lymphoma** – A joint study from Oregon Health & Science University, Oregon State University, and Portland Veterans Administration Medical Center evaluated the effect of rituximab therapy in animal models of central nervous system lymphoma when delivery of rituximab to the brain was optimized with a substance called BBBD to help it cross the blood-brain barrier. Using this method, rituximab was effective at decreasing tumor volume and improving survival and warrants further study in human central nervous system lymphoma.

**Bortezomib Substituted for Vincristine in R-CVP Treatment Regimen** – Memorial Sloan-Kettering Cancer Center and New York University Langone Medical Center reported on the safety and effectiveness of substituting bortezomib for vincristine in the R-CVP regimen (rituximab, cyclophosphamide, vincristine, and prednisone) in patients with relapsed/refractory indolent and mantle cell lymphoma. This Phase I trial enrolled 57 patients. Bortezomib was administered either weekly or twice weekly. Both schedules of the bortezomib substitution regimen were well tolerated with toxicities of grade 1 or grade 2. Overall response rates for the patients on the weekly and twice-weekly bortezomib schedules were 46% and 64%, respectively.

**Swedish Study Reports on Humoral Immunity in MM, MGUS, and WM Patients** – A multi-center Swedish group investigated the humoral (antibody-mediated) immunity to 24 different disease-causing bacteria and viruses in elderly patients with multiple myeloma (MM), monoclonal gammopathy of undetermined significance (MGUS), and WM, compared to age-matched controls. Multiple myeloma patients displayed the most depressed humoral immunity, although significantly decreased antibody levels were also evident in patients with WM and MGUS, particularly against *Staphylococcus aureus*, *Streptococcus pneumoniae*, and varicella virus. Conversely, immunity was retained for *Haemophilus influenzae* type b and certain herpes viruses in all study groups.

**Dana-Farber Studies FGFR3 Inhibitor Called Dovitinib** – A protein called fibroblast growth factor receptor 3 (FGFR3) has been identified as playing a major role in several types of cancer. Dana-Farber Cancer Institute studied this protein in WM cells, which were shown to over-express it. Dovitinib, an inhibitor of FGFR3, was tested as a therapeutic target in WM cells, and it decreased WM cell survival, increased apoptosis, and induced cell cycle arrest. Dovitinib also had an additive effect with other drugs.

**Dana-Farber Examines Incidence of Other Malignancies in WM Patients and Family Members** – Dana-Farber Cancer Institute examined the incidence of other malignancies in 924 WM patients and their family members. A total of 225

(24.3%) WM patients had an additional malignancy, with 63% predating the WM diagnosis. The most common additional malignancies were prostate, breast, non-melanoma skin, hematologic (blood), melanoma, lung, and thyroid. Among hematologic malignancies, all 13 cases of diffuse large B-cell lymphoma and 4 cases of acute myeloid leukemia were diagnosed after WM and were therapy-related. An increased incidence of myeloid leukemias was reported among kin of WM patients with a familial history of WM.

**Italian Study Reports Incidence of Second Cancers in WM Patients** – Another study, by Fondazione Istituto di Picerca e Cura a Carattere Scientifico Policlinico San Matteo in Italy, reported an increased incidence of second cancers in 230 WM patients and compared the incidence with that of an age- and sex-matched population control. Twenty-two patients (10%) developed solid cancers and 10 (4%) developed second hematologic malignancies. The overall risk of second cancer in WM was 1.69 times higher than expected. WM patients were at increased risk for diffuse large B-cell lymphoma, myelodysplastic syndrome/acute myeloid leukemia, and brain cancer. The sample size did not allow firm conclusions about the effect of therapy on the development of second cancers.

**Bendamustine Therapy Evaluated in WM** – Dana-Farber Cancer Institute evaluated treatment outcome for 30 relapsed/refractory WM patients who were subsequently treated with bendamustine-containing therapy. Treatment consisted of bendamustine and rituximab or, for rituximab-intolerant patients, bendamustine alone or bendamustine and ofatumumab. Each cycle was four weeks, and the median number of treatment cycles was five. At best response, median serum IgM declined from 3980 to 698 mg/dL, and hematocrit rose from 31.9% to 36.6%. Overall response rate was 83.3%, and the median estimated progression-free survival for all patients was 13.2 months. Overall, therapy was well tolerated. Prolonged bone marrow suppression was more common in patients who received prior nucleoside analog treatment.

**New Oral Drug Enters Phase II Clinical Trial for B-Cell Malignancies** – Based upon encouraging data from a Phase I study, Pharmacyclics has initiated a Phase II clinical trial of oral PCI-32765 in patients with chronic lymphocytic leukemia, mantle cell lymphoma, and diffuse large B-cell lymphoma. PCI-32765 is a Btk (Bruton's tyrosine kinase) inhibitor. Pharmacyclics has observed considerable activity of this drug in multiple B-cell malignancies, with a relatively benign safety profile and no evidence of cumulative toxicity. PCI-32765 is also being studied in combination with other therapies.

*The author gratefully acknowledges the efforts of Arlene Carsten, Peter DeNardis, Mike Dewhirst, Gareth Evans, John Paasch, Colin Perrott, Howard Prestwich, and Bert Visheau in disseminating news of interest to the IWMF-Talk community. The author can be contacted at [suenchas@bellsouth.net](mailto:suenchas@bellsouth.net) for questions or additional information.*



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# 5 WAYS TO GIVE TO THE IWMF AFTER YOU MAKE A GIFT

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

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If you've already given as much as you can to the IWMF but wish you could do more, here are 5 ways you can give without spending more money.

**1. Do all of your Internet shopping at [www.GoodShop.com](http://www.GoodShop.com)**

When you shop on the Internet, just add one step and the IWMF will get 1-5% of what you spend at **no** additional cost to you. All you have to do is go to [www.Goodshop.com](http://www.Goodshop.com), select the IWMF as the charity you want to support, and then shop as usual. It's that simple. There's no additional cost to you.

To really make this pay off for the IWMF, ask all of your Internet-savvy friends and family to shop for the IWMF, too. Imagine what the IWMF can earn with thousands of people shopping!

**2. Do all of your Internet searching at [www.GoodSearch.com](http://www.GoodSearch.com)**

Every time you do a search on the Internet you could be contributing to the IWMF. All you have to do is search with [www.GoodSearch.com](http://www.GoodSearch.com) instead of Google, Yahoo, Bing, or whatever you use. You'll get great quality results but you'll be donating to the IWMF each time. How easy is that? Again, share this idea with your Internet-savvy friends and family. With thousands of people searching, the IWMF can benefit from a new source of revenue.

**3. Instead of more gifts you don't need, ask your friends and family to contribute to the IWMF through an honorarium in your name.**

See the article in the last issue of the *Torch* (12.2 page 8) or go to the IWMF website at [www.iwmf.com/docs/AnytimeGift.doc](http://www.iwmf.com/docs/AnytimeGift.doc). You'll see exactly how to ask your friends and family to contribute to the IWMF in your honor the next time you anticipate receiving any gifts for holidays or other special occasions.

**4. Ask your doctor to refer any other WM patients he may be seeing to the IWMF.**

You know the tremendous value the IWMF offers. You remember how important the information and support from the IWMF were to you when you were first diagnosed – and still are today. You can make sure everyone else in need shares in the benefits of the IWMF.

Ask your doctor to tell his other WM patients about the IWMF. All your doctor needs to do is tell them to call our office in Sarasota (call Julie Jakicic at 941-927-4963) or visit online at [www.iwmf.com](http://www.iwmf.com). If your doctor wants more information to give out to patients, just call Julie and she'll send a supply of our brochures. Thanks for helping others learn about the IWMF.

**5. Change your subscription to the *Torch* so you receive it electronically instead of in the mail.**

The *Torch* is a fabulous source of information about what's new about the IWMF and the progress we're making in finding a cure and better treatments for WM. But while it's wonderful to get the *Torch* in the mail, printing and mailing our newsletter costs the IWMF nearly \$50,000 a year. For every hard copy we send out, it costs about \$2.25. So, with four issues every year, you can save the IWMF \$9.00 a year just by switching to electronic delivery. Your "donation" will be even greater if you are an international member since postage is so costly.

We'll send you an e-mail and a link to the *Torch* each time a new issue comes out, and you will receive it even faster than you do now by mail. And you don't have to worry about losing your copy. If you do, just print another or print the articles that are of special interest you. Get your copy of the *Torch* via the Internet and help the IWMF save funds for other critical activities.

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**How many of these easy giving opportunities will you do?**



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# ON TO THE SUMMIT: MY RECENT VISIT TO FLORIDA

BY RONALD YEE, IWMF TRUSTEE

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I began my trip to Florida with great anticipation knowing that, in the space of four days, I would visit the IWMF business office in Sarasota and also attend the Fourth International Patient and Physician Summit on WM. The Summit was to be held at the Buena Vista Palace Hotel in Orlando. It had been a long, cold winter in the northeast punctuated by frequent snowstorms which tested my old bones, but that is another story!

As I serve as a board member for the IWMF, there was business to take care of at the office and a visit was in order. As always, the office was alive with activity, and on the morning of my arrival Sara McKinnie was packing IWMF literature for distribution at the Summit. My timing couldn't have been better, or so I was told, as I was volunteered to load boxes of literature into a local WM support group leader's car who was giving Sara a ride to Orlando! The balance of the literature, however, got loaded into my rental car for the ride back to Orlando with delivery to the Summit registration desk!

Over the years, I have never ceased to be amazed at how many services the IWMF provides from such an austere office. It is a credit to the office staff of the IWMF that so much is accomplished with limited resources. My thanks to Sara, Julie, and Jordan!

Friday morning was sunny and warm as I arrived at the Summit. It was great to see some old friends volunteering at the registration desk. I received my registration package and was impressed by the lineup of speakers, some of whom I had not previously heard present on WM. The Summit was dedicated to Elinor Howenstine, a fellow IWMF board member, advocate and major benefactor in the search for a cure for WM who recently passed away. We will all miss Elinor.

The Summit was opened by Dr. Steven Treon of the Dana-Farber Cancer Institute, Bing Center for Waldenstrom's Macroglobulinemia. Dr. Treon has been a key player in the field of WM research and was the driving force in the organization of the Fourth International Patient and Physicians Summit on WM.

The Summit was comprised of 7 major sessions which included the following topics:

- Diagnosis of WM – Chaired by Dr. Robert Kyle, this session covered the general diagnosis, symptoms, and prognostic factors related to WM. Included in this session were the topics of neuropathy and amyloidosis.
- Predispositions to WM – Chaired by Dr. Mary McMaster, this session covered the topics of familial predisposition, associated malignancies, MGUS and its significance. Of particular interest

were the recent advances in genetic sequencing studies reported by Zachary Hunter of the DFCI, which are thought to be key to the understanding of the cause and potential treatment for WM. His work is partially funded by the IWMF through grants to the Bing Center for Waldenstrom's Macroglobulinemia, DFCI.

- Genetic Insights and Therapeutic Targets in WM – Chaired by Dr. Owen O'Connor, this session continued to describe the work in gene expression and MicroRNA work at the DFCI that are revealing evidence of common genetic defects in WM patients.
- Treatment of WM: Indications, Response Assessment, Novel Options – Chaired by Dr. Roger Owen, this session began with a discussion on the reasons for treatment, the assessment of responses, and the challenges of treatment. The session was punctuated by presentations by Dr. Stephanie Gregory on new and emerging treatments and by Dr. Mathias Rummel on his experience using bendamustine for the treatment of WM.
- Treatment Strategies in WM – Chaired by Dr. Mathias Rummel, this session provided details on treatment with novel agents, Rituxan maintenance, stem cell transplants, and treatment of neurological complications.
- Treatment Challenges in WM – Chaired by Dr. Marvin Stone, this session was delivered in a novel manner, in a debate format. It must be mentioned that Dr. Stone opened the session with a disclaimer that the presenters might not subscribe to the position that they had been assigned to defend. Debate topics included:
  - a. The use of nucleoside analogue therapy?
  - b. Should bendamustine-rituximab be considered front line therapy?
  - c. Should bortezomib be considered a frontline therapy?
  - d. Should rituximab maintenance be considered for rituximab responders?
  - e. Should autologous stem cell transplant be a frontline option for WM?
- Case Presentations in WM – Chaired by Dr Robert Kyle, this session was a set of case presentations

*On to the Summit, cont. on page 8*



that Dr. Kyle selected from his many years of clinical experience in treating WM.

The sessions were full of information, and it is always difficult for the attendee of many of these patient forums to absorb all of the information presented. It was not all work, however, as there were optional dinner events each night held at the Buena Vista Palace Hotel where patients and physicians got to know each other and to build lasting friendships. We even got to have photos with the Disney characters!

The most important message that I can give from the Summit is that we as a WM community are blessed with a very dedicated and hard working group of researchers, physicians, and support personnel, searching for the answers to this very rare and at times perplexing disease. The connections which I have made over the years with patients and physician researchers cannot be compared. Please continue to support the IWMF as we push ahead to fund valuable research and to provide patient education and support!

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## OUTREACH AT ITS BEST: IWMF AT THE ONS ANNUAL CONGRESS

BY JACK WHELAN, IWMF VOLUNTEER

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The primary goals set out in the Mission Statement of the IWMF are to offer support and encouragement to those with an interest in the disease WM, to provide information that addresses patients' concerns, and to support research for a cure. In fulfilling the goals of providing support and encouragement and of sharing information, I think that outreach or, more popularly, *reaching out* to WM patients, caregivers, and medical professionals plays a particularly worthwhile role for the IWMF. Recently I had the chance to play an active part in *reaching out*. Having participated in a variety of clinical trials and treatments over the past several years, I've developed close friendly relationships with several oncology nurses at the Dana-Farber Cancer Institute. It's no secret, I love 'em all! So when Sara McKinnie, office manager at our IWMF office in Sarasota, called to ask if I'd be willing to volunteer for 'booth duty' at the 36<sup>th</sup> Annual Congress of the Oncology Nursing Society (ONS) in Boston (close to home for me), I jumped at the opportunity. The Annual Congress is one of the largest educational events

for oncology nurses. Over 4000 nurse professionals from across the country attend this four-day conference. For more info, check out [www.ons.org](http://www.ons.org)

The IWMF volunteer team working the exhibit hall along with 275 exhibitors included Sara McKinnie, my dear friend and WM fighter (and retired rocket scientist) John Paasch, and myself. While I wondered what 'hook' we'd use to get any of the very targeted audience of nurses to stop and chat, Sara calmly said, "Just ask, 'Do you have any Waldenstrom's patients?'" I thought that was a great way to qualify a good lead. It worked flawlessly. Their eyes would light up, a bright smile would emerge as the most interested nurses would say, "Yes, we have one in treatment." This was a pleasant surprise. I imagined all the good work previously done by the IWMF and other volunteers. These nurses knew something about Waldenstrom's macroglobulinemia. They were keenly interested. They asked great questions and wanted to learn more about the IWMF and its programs.

John and I had plenty of opportunity for some inside jokes. Just as oncology nurses frequently ask us (when they zap that patient wrist bracelet before a blood draw or an infusion), with a smile we'd ask them, "What's your date of birth?" while we scanned the bar code on their ONS badge. You have to be a hematology patient or nurse to get it. Joking aside, our volunteer coterie conducted engaging Q&A discussions with these nursing professionals. At last count, I think we got close to 200 oncology nurses who expressed interest in the IWMF. Without doubt, these nursing professionals will appreciate the valuable literature and booklets supplied at no charge from the IWMF. Sharing this information with their nurses also directly benefits present and recently diagnosed WM patients. This is outreach at its best!

In conclusion, I'd like to take this little opportunity to say thanks to Sara and the entire IWMF team who work so hard on our behalf.



The IWMF Team at the ONS Congress: office manager Sara McKinnie with volunteers Jack Whelan (left) and John Paasch (right).





Jack Whelan

## Meet Jack: Volunteerism At Its Best

*The Torch asked Jack Whelan to accompany his coverage of volunteer duty at the ONS congress with a few details about volunteering for the IWMF and participating as a WM patient in clinical trials. His reply outlined such spirited volunteerism that it seemed only appropriate to cast a little ‘torchlight’ on Mr. Whelan.*

A few weeks after diagnosis about four years ago, at the suggestion of Dr. Ghobrial, Jack attended his first IWMF Ed Forum. He volunteered his skills as a hobbyist photographer to take candid photograph shots working alongside Ron Draftz. Soon Jack will participate in and take candid photos at his fifth Ed Forum, in Minneapolis this June. If you’ve attended any of these Ed Forums, there’s a good chance that Jack has shot you at least once and your photo has been added to the IWMF’s photo library.

Jack has participated in a few clinical trials including the bortezomib and rituximab (Velcade/Rituxan) study, the enzastaurin study, the RAD001 (everolimus) study and currently is participating in the LBH589 study at the Dana-Farber Cancer Institute. Recent blood chemistry test results from the LBH589 clinical trial are very encouraging. There has been a meaningful improvement and Jack now has his best overall numbers since diagnosis.

Jack manages a small research firm in Boston that does institutional investment research for leading mutual funds and hedge funds focusing on tech stocks. He and his wife Jan live in Andover, MA; they have three “grown” daughters, and the youngest is a repeating marathon runner and Team in Training Leader and fundraiser for the Leukemia & Lymphoma Society. Volunteerism “runs” in this family!

And Jack and Jan are soon to be grandparents of twin girls – a nice double dividend.

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## COOKS HAPPY HOUR

BY PENNI WISNER

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*Penni’s up for summer flavors! Her processor is pulsing and sending forth the potent scents of pureed pestos. Capers, olives, pine nuts, lemon zest, Turkish pepper, Spanish paprika are blended in varying combinations and proportions with marjoram as the underlying flavor. Plus Penni the pro shares her culinary savoir-faire with advice about the vinegar we buy and equipment for our kitchens.*

Yes, I know the year is half gone. That fact makes me contemplate those year-end, ten-best lists. As in books and music, they are endemic in the food world. But now that we have progressed along the avenues of time, what do you remember of those lists? Me? Nothing. It occurs to me that you only know the best of the past because it has become a necessary part of the present.

And that brings me to one of my favorite recipes from 2010 that I now cannot live without. At least for long. It is an herb pesto. Yes, I remember, we discussed them before. But the flavors in this one were new to me and might be to you. It appears in *Local Flavors* by Deborah Madison, a cookbook published in 2002 but new to me in 2010. It remains fantastically current to anyone interested in buying, cooking,

and eating local, seasonal foods. And what better time to do that than the summer? (Disclaimer: Deborah and I teach a 4-day cooking class together at Rancho La Puerta. The first was in October 2010, the second April 2011.)

I tried the Marjoram Pesto with Capers and Olives last summer when I was staying at the house of a friend who happened to have a prolific pot of marjoram. And I liked it so well, a marjoram plant immediately went in my garden. It is only now – the beginning of summer 2011 – getting big enough to make this pesto. But it is worth the wait. (Is this too big a build up?) Deborah says it is good with beets. I agree. Remember those roasted beets from two years ago? And the big roasted onions? Slice them both, slather them with marjoram pesto and enjoy the sunset. Love deviled eggs? You might like them even more if you add a dab of pesto. Or just smear it over toasted bread. No, better yet, grilled bread. Have we talked about that? No? Brush both sides of good, crusty bread with olive oil and toast on the grill. Topped with the pesto and a couple of fresh, grilled sardines and accompanied by a glass of rosé–peace might spontaneously break out.

*Cooks Happy Hour, cont. on page 10*



I've taken a few liberties with Deborah's recipe: She uses a mortar and pestle. I'm lazy and use a food processor. I also use fewer pine nuts in order to have a more herbal finished flavor, add lemon zest, and Turkish red pepper (Aleppo). It has a rounded, sweet, sunny heat. A medium-hot Spanish paprika or the Spanish piment d'Espelette would also be great. Remove the crusts from a slice of country bread and soak it in 2 tablespoons red wine vinegar. (Vinegar digression: Do you taste your vinegar? Try it. If it does not taste good – tart, sure, but also full of flavor – then go shopping. A good source would be, perhaps, one made by a local winery from good red wine. I bought one from Preston Winery in Dry Creek, Sonoma County. It has amazing flavor – deep and winery. Delicious. That's the kind you want for this recipe.)

Drop 1/4 cup (a good handful) of marjoram leaves in a food processor with a fat garlic clove, the zest of half a lemon, a good pinch of Aleppo pepper, and perhaps a half teaspoon of salt. Start pulsing and scraping down the sides, as needed, while you add the leaves from a bunch of parsley, 1/4 cup (another good handful or more) pine nuts, 3 tablespoons drained capers, and 2 tablespoons pitted green olives.

(Do not substitute black olives. The color will make you sorry you did.) Process until everything is evenly chopped and you have a coarse puree. Now add the bread (which should have sopped up all the vinegar) and enough olive oil, 1/4 to 1/2 cup, to make a chunky, thick puree. Taste for seasoning and add salt, pepper, and maybe another splash of vinegar if you like.

I've used a mix of oregano and marjoram and used only oregano, too, but always with the parsley. Hopefully, this early in the season, the zucchini in your garden are just beginning to bear and so you remain excited. Trim the ends from small ones and cut them, lengthwise, into thin ribbons with your handheld mandoline. (What? Don't have one? We must have a serious talk. It has become one of my most essential tools. The big deal, fancy mandolines I fell for have all gone to gadget heaven. But the handheld I keep close at hand.) Toss them with your marjoram pesto. Serve it next to an omelette for a terrific breakfast, lunch, or, hey, why not, supper with that glass of rosé and those grilled sardines.

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

*Thanks, Penni, for this tantalizing Happy Hour suggestion.*

amyloidosis. However, for patients whose symptoms include numbness in their feet, unexplained weight loss, leaking of protein into the urine, or evidence of heart malfunction, amyloidosis should be suspected as the cause. Biopsy of the bone marrow, skin, or the fat can be used to demonstrate amyloid deposits.

The prognosis of amyloid is dependent on the extent of heart involvement and generally is a more serious condition than Waldenström's macroglobulinemia. The typical evaluation of a patient with amyloid includes measurements of proteins that reflect the efficiency of heart function, as well as ultrasound of the heart.

The treatment of amyloidosis is different from Waldenström. A biopsy is always required to establish the diagnosis. It cannot be done with x-rays or scans. There is no smoldering phase of amyloidosis; and at diagnosis, virtually all patients require some form of therapy. Watch and wait does not apply to most patients with amyloidosis. For a subset of patients, high-dose chemotherapy and autologous stem cell transplant is an appropriate technique. For others, more traditional chemotherapy akin to that used in Waldenström macroglobulinemia is appropriate. One specific regimen

cannot be recommended and evaluation of therapy options has to be done in consultation with a physician experienced in the management of amyloidosis.

The treatment is usually designed to limit production of the amyloid protein. Measurements of the light chain in the blood are performed on a regular basis to assess the impact of therapy. As in all patients with Waldenström, the IgM level is measured on a serialized basis as well. Supportive care is important. Well-balanced nutrition is important for the body's energy supply. Specialized diets may be required, and dietary restrictions are common. Sufficient sleep is essential. Strenuous activities need to be avoided, although activity is beneficial. In general, amyloid does not increase the risk of getting infections, but direct exposure to people with known infections is not recommended. If there are questions about the diagnosis or treatment, your healthcare provider or amyloid specialists at Mayo Clinic would be happy to perform an evaluation.

*Dr. Morie Gertz is Chair, Department of Internal Medicine at Mayo Clinic, Rochester, MN. He is a good friend to the IWMF, serving on the Scientific Advisory Committee and enthusiastically participating in IWMF Educational Forums.*



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# FROM IWMF-TALK

BY MITCH ORFUSS

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During an especially long winter between 2010 and 2011, TALK took a noticeable turn toward the science of WM. How could it not, with all the research that's been underway to understand the fundamental biology of WM so that new drugs can be invented and tested? Beyond the science, however, TALK discussion cut its usual wide swath across topics of broad interest to more than 1,000 readers. What follows are some of the TALK-topics generating sustained online discussion as winter 2011 melted into spring.

## Role of IVIG – a dilemma?

**Paul Smith**, who is currently receiving Rituxan on a maintenance schedule, wrote that he had started monthly IVIG infusions last April and that within a month his elevated IgG level alleviated the chronic sinus issue he was experiencing for a year. When Paul visited Dr. Treon in September for his annual follow-up visit, Dr. Treon highly recommended reducing IVIG treatments to once a quarter to avoid reducing the effectiveness of the Rituxan. So far, Paul has not experienced significant sinus issues with the reduced IVIG schedule but feels he is rolling the dice. Paul asked whether anyone on both Rituxan maintenance and IVIG is on the same schedule he is and what their experiences have been.

**Bob Reeber** replied to Paul that he had been off Rituxan since July 2009 after long-term treatment following a bad sinus infection from February 2008. His IgG was 200 or less in Fall of 2009. By February 2010 he had chest congestion, sinus problems, and partial hearing loss. In March of 2010 Bob had the first of four IgG infusions. A week after, his sinuses were clear, hearing normal, chest clear. With the next three IgG infusions his IgG level reached 1059 mg/DL. In July 2010 it was still 629. By October 2010 his IgG was 394. Meanwhile IgM remained stable in the 400 - 500 range and his free light chain ratio also approached normal. In January Bob's IgG was still 294.

**Ron Draftz** then asked whether Dr. Treon gave a rationale for IgG infusions reducing the effectiveness of Rituxan treatments. Ron was unable to find any published papers discussing interference of IgG and wondered if Dr. Treon was expressing an opinion or if the suggestion that IVIG interferes with Rituxan is based on clinical or lab experiments.

**Colin Perrott** quickly found an article about the role of IVIG for transplant patients suggesting that if receiving IVIG improves Rituxan efficacy for transplant patients, there is no reason it shouldn't do the same for everyone. Ron went on to infer that if such a protocol were developed for IVIG, we should remember that IVIG increases serum viscosity and, taken soon after or in conjunction with Rituxan, could lead to a rise in serum viscosity (SV) due to the Rituxan flare added to the IVIG bump in SV. Ron referenced **John Paasch's** observation that using plasmapheresis (PP) and dropping

existing IgG levels by half immediately prior to receiving Rituxan might actually reduce the efficacy of Rituxan. Dr. Treon recommends the use of PP prior to Rituxan infusions to reduce IgM flare and improve the efficacy of Rituxan for those with high IgM levels. But if IgG does improve the efficacy of Rituxan, we have a dilemma about the value of PP that would lower the IgG level.

As she read Ron's post, **Eunice Johnson** had a random thought: What about using gamma globulin instead of IVIG? In 2002, before her diagnosis, Eunice did not have time for (nor want) the full hepatitis series before taking a two-month visit to China. The travel nurse in the county health department suggested instead that Eunice receive gamma globulin purported to give a certain level of protection against viral infections for 2 - 3 months. She did and had neither side effects nor problem with hepatitis. Can this (she asked) be a comparable and less expensive alternative to the IVIG infusions for WM patients?

## Peripheral Neuropathy (PN) and IVIG

**Scott Keddal** asked if IVIG treatment can cause peripheral neuropathy. Though Scott did not find a study or medical reference to confirm this, he wondered whether anyone could report on this and say whether he or she had been told that it results from IVIG? **Billie Evans** replied that, on the contrary, IVIG is a treatment for PN and gives some improvement in about 12% of cases. Billie says she is among the 2% who have an IgM flare after IVIG. The flare, she says, caused her multifocal motor neuropathy to advance quickly and severely damaged her nerves and muscles. Billie's suggestion is to have IgM tested prior to first IVIG and monitor it afterwards. If there is an unexpected rise in IgM, you may entertain the possibility of a flare and contact Dr. Treon who has researched such flares, which can last more than six months.

**Lon Tanner** wrote of PN in his right foot – not pain as much as no feeling. Lon had this for two years before WM was diagnosed in October 2007. By October 2009 his primary care physician diagnosed Lon as diabetic as well. Lon asked how to tell if the PN was from WM or diabetes, or did it not matter? **Dr. Guy Sherwood** replied that it matters very much whether PN is driven by diabetes or WM. Treatment is different for each. Diabetes, Guy warns, is serious business. Keep sugar level under control. Moderate exercise is the best "pill" for diabetes. Walking or swimming are good – exercise is a must.

## Bone Marrow Biopsy (BMB) as "The Gold Standard"

As a generally fear-inspiring, anxiety-producing procedure, BMB is a topic that TALK returns to frequently, and the last three months were no different. **Dr. Jacob Weintraub** wrote that while he believes that BMB remains the "gold standard"

*From IWMF-Talk, cont. on page 12*



for diagnosis, his impression is that the WM experts do not rely on the estimated infiltration percent but look instead at the whole picture when deciding on treatment. Information from the BMB, continues Dr. Jacob, is used together with lab results and clinical evaluation in order to decide how to proceed.

**Dr. Guy Sherwood** took up the question of even distribution of WM cells in the bone marrow and wondered if the exact percentage truly matters. “What we want to know,” wrote Dr. Guy, “is whether there has been a change in histology or a definite (but what is “definite”?), unexpected increase in infiltration after treatment. Exact “infiltration” rate is very subjective. Pathologist # 1 may say ‘looks like 50%’ whereas pathologist # 2 may say ‘hmmm, looks like 55%’ and pathologist # 3 says ‘time for lunch.’ Bone marrow biopsies are definitely the gold standard if you ask the experts – no question there.”

Ron Draftz commented on the fact that whether or not BMB’s are the gold standard for disease identity and status, they also happen to be all we have. Pathologists, Ron continued, don’t need a representative sample to determine which types of tumor cells are present but they certainly do need a representative sampling to determine the response from a drug in trial or the progression of disease for a patient. We have come to accept changes in IgM levels as the measure of our response to treatment, except that IgM concentrations do not necessarily reflect the reduction of tumor burden for some drugs such as Velcade. Ron wondered how many other drugs also produce reductions in IgM levels with no reduction in tumor burden? **Malcolm Walpole** added that BMBs are 100% specific but probably only 20-50% sensitive. A negative biopsy means only that the particular sample was negative. It does not mean you do not have WM. A positive sample definitely indicates one does have WM! To make an informed diagnosis, clinicians need a lot more information such as an immunoglobulin profile, serum viscosity – if symptomatic – the complete blood count, a CT scan to see if adenopathy or splenomegaly are present. Doing multiple BMBs on the same occasion may help but, equally, may not.

Guy then offered the prediction that as we develop better and better targeted drugs, with fewer unwanted side-effects, bone marrow biopsies will gain more importance because we will need actual tumor cells to evaluate targets, changes and mutations of targets, and of course tumor cells in order to develop our own personal WM vaccines. “Once again, I do

not feel that percent-infiltration is that terribly important as a stand-alone measurement. It is simply a piece of information that one can look at with a certain degree of healthy skepticism and correlate with other disease markers (IgM, hemoglobin, platelets, B-2). Maybe what we need are better BMB techniques. The engineers need to develop effective, quick and painless BMB instruments and techniques.” Failing that, Guy said he insists on sedation!

**Bendamustine (Treanda): Single agent and in combination, frequency, mechanics, dosing**

**Anita Lawson** wrote that she is currently on bendamustine plus Rituxan and her oncologist decided on 28-day intervals. Because of gastrointestinal side effects and fatigue, that schedule allows her a couple of weeks of feeling better between treatments. Bendamustine is administered before Rituxan on day-1. Anita gets Zofran, Pepcid, Benadryl and dexamethasone as premeds on day-1, and Zofran and decadron on day-2 when only bendamustine is infused. The good news for her (as she hopes would be the case for all) is that *just one round of bendamustine* reduced her IgM in half, and her M-spike from 1.9 to 0.9. “This stuff really works!” she said enthusiastically.

**Nancy Herring** added that her bendamustine plus Rituxan treatment frequency was also every 28 days, from January to July 2010. She said she had waited to post because she wanted to be conservative. Nancy feels that her previous R-CHOP was not effective since within 20 months she found herself back on chemo with B + R. Results from bendamustine plus Rituxan were outstanding: her IgM in July was down in the 200’s. By October her IgM count had dropped further, and in January 2011 it was even lower, at 112! Since then Nancy reports that her mood is up, she sleeps better, and her strength returned. She feels she is doing wonderfully well, with anemia under control and all blood work results again within normal parameters.

**Neil Massoth** described his experience: Neil had bendamustine plus Rituxan on day-1 and solo-bendamustine on day-2. Six total treatments. Prior treatment history included Rituxan at least five times, once with fludarabine (because Rituxan was becoming less effective). Following bendamustine, Neil’s IgM is lower than it has been in nine years (he’s had WM for 13 years) and is holding steady.

From IWMF-Talk, cont. on page 13

**HOW TO JOIN IWMF-TALK**

Here are two ways to join:

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



When he finished treatment, Neil's IgM was 606 and at the time of posting it was down to 566. Hemoglobin normal. IgG remains very low (as is his WBC level but this had been Neil's experience for 12 years). Neil experienced no side effects from bendamustine other than some mouth sores; a nurse suggested rinsing with saline for 5 days after treatment, which solved that minor problem. Neil again feels wonderful (age 70) and is back to playing racquetball.

### Stem Cell Transplant (SCT)

**Scott Keddal** posted that his objective is to be ready for a relapse and then to utilize autologous stem cell transplant to provide a reasonably long life of good quality while new treatments are being developed. In short, Scott is trying to develop incremental periods of good quality of life while more solutions become available without utilizing chemo that may well result in some serious side effects. He asked for intelligent feedback on this. **Dr. Tom Hoffmann** wrote that the role of transplant is yet to be defined in our disease. If you look at the survival statistics from studies others have quoted, they look pretty scary to Tom for allogeneic (outside donor) transplants. In autologous transplants only 68.5% are alive, and only 40% of them are progression-free at 5 years. **Peter DeNardis** added that over a year ago he made the decision to collect his stem cells at a time when his BMB showed only 3% involvement. At the time Pete had been treated for some serious autoimmune and WM-related complications. He did in fact go through the stem cell collection process, utilizing high-dose Cytoxan (alkylating agent) and Neupogen to coax those stem cells out of his marrow. Pete's cells are now safely banked – but at what cost (he asked rhetorically) given the need for high-dose Cytoxan?

Among the many other TALK topics of shorter duration between winter and spring were Rituxan flare, dog bites, elevated platelets, flu vaccine, anemia, eye exams, atrial fibrillation, genetics, co-morbidity scoring, irregularity, pain, and neutropenia.

Even a list of that breadth fails to exhaust the amazing range of what TALK readers seek as a community to explore. As always, it's key for us to remember that no one is licensed to practice medicine on TALK and that no one's individual experience, no matter how encouraging or passionately presented, should be mistaken for advice. What's good for the goose may not be good for the gander, however interesting for us to know about. While there are members of the medical profession, including Drs. Tom, Guy, Jacob, and Neal, who offer their opinions *gratis*, these good doctors have not examined you and have not read your lab reports. They cannot act in place of your oncologist, and they do not intend to.

What TALK readers seem to me to marvel at most is the speed and range of well-meaning responses when a query is posed to the group – currently more than 1,000 readers. When a fellow patient responds, we feel a little less alone, a little less frightened, a little more hopeful and connected. Much experience, information, and support is shared and drawn upon, and isn't it great that it's there! Of course not everything will be interesting or appropriate for everyone, but it's a wonderful gift we give each other in support of the vast majority of readers on any given day, precisely at the moment they most need relevant input. But in the last analysis we are well advised to make medical decisions with the doctors we trust. Only they know us in ways that other patients cannot.

Best of health to all.

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## RECENT NIH NEWS

### THE PROMISE AND PAYOFF OF RARE DISEASES RESEARCH

BY DR. FRANCIS S. COLLINS, DIRECTOR OF THE NIH

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*Francis S. Collins, M.D., Ph.D., Director of the National Institutes of Health, led the successful effort to complete the Human Genome Project, a complex multidisciplinary scientific enterprise to map and sequence human DNA. He spoke recently with NIH MedlinePlus magazine about the increasing promise of genetics research to the investigation and diagnosis of rare diseases.*

#### Why should we focus on rare diseases when they affect so few people?

If you or your family were affected, it wouldn't be rare for you. And the study of rare diseases has taught us more than most people realize. Furthermore, the opportunities to capitalize on what we have learned so far have never been greater. If you

care at all about biology and about understanding medicine, rare diseases are critical.

#### How many rare diseases are there?

Altogether, rare diseases affect almost 25 million Americans. Worldwide, there are more than 6,000 that have an impact on people.

#### How much progress has there been toward understanding rare diseases?

The good news is that we have learned a lot about the molecular basis of many of those that are caused by single genes that have gone awry. The bad news is that treatments are available for fewer than 200 of them at the present time.

*Recent NIH News, cont. on page 14*

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**How much does the mapping of the human genome help?**

The Human Genome Project has provided many of the tools that have made it possible to reach our current understanding about the molecular causes of disease. But, I think it's fair to say that most of what we've learned from the genome project has not yet been applied. We want to accelerate that process. And that's one of my goals.

**What is the state of the art of genetics and disease now?**

The ability to identify the molecular basis of a disease, even a very rare one, has progressed rapidly. The challenge now is to develop clinical interventions in fewer than the 20 to 30 years it takes through traditional research methods.

**Have you an example of a disease on which there has been substantial progress?**

It has been just eight years since the cause of progeria, a rare childhood disease that causes rapid aging, was discovered in my lab. And we now have kids in clinical trials, some of them for more than two years. We were lucky here because the gene involved turned out to be one that we knew a lot about. And we were particularly lucky because that information suggested use of a drug that was developed for an entirely different reason; a "repurposing," if you will. That will happen from time to time, and we should not miss such opportunities.

**What does the research future hold?**

The challenge is to cross the gulf between the molecular understanding we now have of thousands of diseases and develop treatments for them. And this is where NIH can play a critical role in supporting the necessary translational research.

**NIH RESEARCHERS CREATE COMPREHENSIVE COLLECTION OF APPROVED DRUGS TO IDENTIFY NEW THERAPIES FOR RARE AND NEGLECTED DISEASES**

**Bethesda, Maryland:** Researchers have begun screening the first definitive collection of thousands of approved drugs for clinical use against rare and neglected diseases. They are hunting for additional uses of the drugs, hoping to find off-label therapies for some of the 6,000 rare diseases that afflict 25 million Americans. The effort is coordinated by the National Institutes of Health's Chemical Genomics Center, and on the list is Waldenstrom's macroglobulinemia. "This is a critical step to explore the full potential of these drugs for new applications," said NIH Director Francis S. Collins, M.D., Ph.D. **"The hope is that this process may identify some potential new treatments for rare and neglected diseases."** Needless to say, this may take some time before we begin to have results.

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## SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

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*Please note: contact information for all support groups is printed on pages 18-19.*

### IWMF CHAPTERS – USA

#### CALIFORNIA

##### *Monterey*

After much effort and great help from **Judy White Ryan, Sandy Skillicorn** put together Monterey's first support group meeting in April at the Monterey Library Solarium. Demonstrating a need for a local group, 14 people showed up, maxing out the room. Members got acquainted and shared resources such as books including *AntiCancer* by David Servan-Schrieber. Plans are afoot for another meeting in mid-July in Capitola.

##### *Sacramento and Bay Area*

Eleven members of the San Francisco and Sacramento support group met in May at the usual location at the Kaiser Vallejo Hospital to view the DVD of the "Ask the Doctor" session from the 2010 IWMF Ed Forum in Las Vegas. Most of the participants had never been to an IWMF Ed Forum. The DVD gave a flavor of what the forums are like and allowed viewers to "meet" doctors Kyle, Treon, Nichols and Gertz. An informative discussion of each person's progress in WM followed. Old-timers' stories were most helpful to those

more newly diagnosed or considering new treatments. And then, in an effort to reach more members living in the Central Valley and Sierra Foothills, an additional meeting was held at the Kaiser Roseville Hospital in June. The DVD of the talk known as "The Garden" was shown, in which Dr. Morie Gertz gives a very clear overview of WM. A roundtable discussion followed, allowing all present to air their particular concerns.

#### COLORADO & WYOMING

On 9 April, the Rocky Mountain IWMF support group had another great opportunity to get together and to learn about WM specifically, non-Hodgkin's lymphomas generally, as well as about 25 other related topics, all presented by various medical experts for the Rocky Mountain Blood Cancer Conference. The event was coordinated by the Leukemia & Lymphoma Society's Denver chapter. The IWMF had a table at the event and about 20 support group members attended. Participants could sign up for three different sessions throughout the day, as well as hear the keynote speaker, Dr. Wendy Harpham, speak about "Hope and Happiness after Cancer." Dr. Harpham, who has lived with chronic indolent

*Support Group News, cont. on page 15*





From left to right: Roy Parker, Cindy Furst, Lynn Callaway (LLS patient services manager), and Bill Bass – all in front of the IWMF table during the kick off of the one day Rocky Mt. Blood Cancer Conference.

lymphoma for many years, has written a number of books on cancer survivorship. The group met during lunch and talked about our WM issues and especially what we learned during the day’s presentations. About 5 from the group plan to attend the upcoming IWMF Ed Forum in Minneapolis. Three newly diagnosed patients came and were delighted to be able to ask lots of questions and learn so much. The Denver group enjoys an excellent working relationship with the LLS Patient Services Manager, Lynn Callaway, and continues to benefit from her help and support for most meetings throughout the year. The next meeting is planned for the July or August, following the Ed Forum.

### GEORGIA

The Cancer Support Community Center, which is affiliated with Northside Hospital in Atlanta, has been extremely generous to the Atlanta group for years, allowing it to meet in their facility without charge. Recently their center was upgraded with technology that permitted Dr. Leonard Heffner, Jr., of Emory University’s Winship Cancer Institute to show his presentation on large flat-screen TVs. Dr. Heffner updated our group on treatment regimens and the October 2010 International Workshop on Waldenström’s Macroglobulinemia held in Venice. The Cancer Support Community Center is part of the Cancer Support Community, a national organization that might be of help to WM groups in other parts of the country. [www.thewellnesscommunity.org](http://www.thewellnesscommunity.org)

### IDAHO

Just before the start of summer, the group met for lunch at a local restaurant. Since the members are few in number, they

### SUPPORT GROUP LEADERS TALK LIST

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

prefer a “kitchen table” approach: informal meetings and personal contact by telephone and informal get-togethers as often as possible. They are fortunate that one of their number is a nurse practitioner who can, and often does, “decode” the alphabet soup of terms encountered in the medical literature and test reports.

### ILLINOIS

#### Chicago Area/SE Wisconsin

Spring was in the air for the first meeting of 2011. Over 60 people attended our April meeting to hear two local doctors, Dr. Stephanie Gregory, Professor of Medicine and Director of the Section of Hematology at Rush University Medical Center/Rush University, Chicago, IL, and Dr. Christine Winter, hematology/oncology consultant and attending physician at Hinsdale Hospital, and Assistant Professor of Clinical Medicine and Consultant in hematology and oncology at Northwestern University Medical School, Chicago. Dr. Gregory gave a great presentation on Waldenstrom’s – including how it fits into the larger group of lymphomas – and treatment options. Both doctors stayed for an hour-long question and answer period which was particularly helpful for the 22 first-time patients and caregivers, including a couple who had traveled from Kentucky. Two members participated by Internet conference from southern Illinois. The group felt fortunate and thankful to spend such a rich afternoon with two of the best WM doctors in the Chicago area. The next meeting will focus on fellowship and good food. The annual picnic will be held in the western suburbs of Chicago on Saturday 20 August in the afternoon.



Drs. Christine Winter (left) and Stephanie Gregory (right) address the Chicago area support group. In the wings (far left) Ron Draftz, chair of the Chicago area support group program committee.

### INDIANA

This new group held its first meeting in April at the Leukemia & Lymphoma Society offices in Indianapolis. Twenty-four attended and all were excited by the formation of this new





*Dr. Guy Sherwood spoke to the 24 attendees at the inaugural meeting of the Indiana support group.*

Indiana group. Their plan is to meet quarterly. **Dr. Guy Sherwood** gave an informative and stimulating presentation: “What I learned in Venice” (at the Sixth International Workshop on Waldenström’s Macroglobulinemia). **Gayle Backmeyer**, an RN, and her best friend, **Janet Gray**, an RN clinical nurse specialist in mental health, are co-facilitators. The entire group extends their thanks to **Robert Nall**, who initiated the group’s formation.

### NEW ENGLAND

#### *Boston*

In April the Lymphoma Research Foundation held one of its terrific one-day workshops in the greater Boston area. These tremendously popular events attract a large crowd; this one numbered about 300. The early morning featured general presentation topics such as clinical trials. In the late morning the large group broke into break-out sessions focused on individual lymphomas, including Waldenström’s. The IWMF was represented by group member **John Paasch**, who was there throughout the workshop to answer questions about WM and the IWMF and to man the table full of IWMF booklets

and other useful publications. Dr. Steven Treon of the Dana-Farber Cancer Institute gave his ever exciting, always up-to-the-minute presentation to a group of almost 50 WM patients and caregivers. A particularly exciting bit of news was the preliminary results of a genome-wide survey of WM patients’ cells. DFCI has been looking at cells of WM patients and cells from healthy individuals in a research project that is co-sponsored by the IWMF. Dr. Treon shared that they have seen the same genetic mutation in the first small cohort of patient WM cells. While there is still much more validation work to be done, including looking at samples from more patients, the possibility of a commonality among some WM patients (and that we may not be ‘all different’ after all) could help focus future research efforts. Dr. Treon answered questions both during and after his presentation and also took time after ‘the afterwards’ to discuss WM with individual patients and caregivers. After the break-out sessions everyone returned to the main lecture hall for lunch, followed by more presentations that were beneficial to the entire group.

### NEW YORK

#### *New York City*

There was a smaller-than-usual turnout for the mid-May meeting, probably due to inclement weather, but those who were there participated in a lively two-hour discussion, most of which seemed to be about bendamustine, solo and in combination with other drugs. Some had been treated with it already, others were curious to know how it went and explore its potential for their next treatment. The prevailing sentiment was that there seem to be many more good-to-potentially-excellent options today for WM than were available even a few years ago. Bendamustine (Treanda); ofatumumab for the Rituxan non-responders; CAL101; and others. The competition (our word) between Dana-Farber and Weill Cornell (to name two warrior institutions) to develop



*Dr. Treon at the Lymphoma Research Foundation's workshop in April. As always, his presentation generated intense interest from members of the audience.*



new treatments was applauded by all, and participants left the discussion with what appeared to be optimistic smiles.

#### *Eastern NY/Western New England*

About two dozen members gathered at the Dragon Buffet at the end of March for the group's annual "beat the winter blues" all-you-can-eat event. The excellent food fueled lively conversation about a variety of topics (some even included WM!). The annual picnic is coming up in August and plans are afoot to host a speaker for the September meeting.

### OREGON/SOUTHWEST WASHINGTON

On a beautiful, warm, sunny day in April, 26 group members gathered at the Fairfield Inn & Suites in Lake Oswego, just South of Portland, OR. Several newcomers as well as a couple who returned after some time away were warmly welcomed by the regulars. Members **Rowland** and **Tobbie Leep** shared their impressions and news from the Bing Center's Patient & Physician Summit held in March in Orlando, FL. A lively discussion followed, with many comments and questions. Patients and caregivers alike were encouraged by hearing of the growth in understanding of WM and the ever-increasing options for WM treatment. The active and lively group partners with the local LLS chapter which helps to arrange speakers, sponsors the meeting room, provides lunch, and helps with publicity.

### PENNSYLVANIA

#### *Philadelphia*

The group celebrated its tenth anniversary in April. It was a good excuse to have a delicious carrot cake with "10 Years" written on the top. The meeting was spent sharing WM experiences and welcoming a new member whose story interested all those present. In June the guest speaker was Dr. Ander Pindzola, son of support group leader **Karen Pindzola** and husband **Dan**. Dr. Pindzola is a hematopathologist at York Hospital in York, PA. Dr. Pindzola explained the role of the

pathologist in diagnosing and following Waldenstrom's. He also showed slides describing WM at the cellular level, so now we all understand what our WM looks like under a microscope.

### SOUTH CAROLINA

The South Carolina support group held its summer meeting at the Florence County Library in late June. Newly diagnosed and veteran WMers and caregivers from around the state exchanged information about their respective experiences with WM. The next support group meeting will be held in late fall in the Greenwood area. The exact date and location have yet to be decided.

### TEXAS

#### *Dallas & Northern Texas*

This past spring, the Northern Texas group met as usual at Baylor University Medical Center in Dallas to view the DVD of Dr. Steven Treon's presentation "Latest Developments in Waldenstrom's Macroglobulinemia" from the IWMF 2010 Ed Forum. Even when Dr. Treon is not personally presenting, his message inspires confidence in the progress towards understanding WM. The meeting concluded with a 'caring and sharing' period during which patients and caregivers had the opportunity to update and discuss topics specific to their disease and lives. There will be no meeting during the summer months. The next meeting will be Saturday 17 September at Baylor.

### WASHINGTON

**Peg Horton** and husband, **Bob**, returned to the Seattle area and took up the reins again as the area support group leaders. They hosted a "get-acquainted" potluck lunch and meeting in March at their home in Port Orchard. With lots of good food to share, the spirited conversation among the 17 attendees covered the usual health updates, questions, and concerns.

## THE INTERNATIONAL SCENE

### FRANCE

The annual meeting of Waldenström France will be held on Saturday 24 September in Paris, at the *Plateforme des Maladies Rares*, Hôpital Broussais, 102, rue Didot, 75014. The speaker will be Dr. Véronique Leblond, an important figure in the field of French hematology and a member of the IWMF Scientific Advisory Committee. In addition, two clinical psychologists from the Psychology and Cancer Group will give presentations in the afternoon intended for caregivers and WM family members. For program details and registration information, please contact [waldenstromfrance@live.fr](mailto:waldenstromfrance@live.fr) or phone +33 (0)490 870 930. The volunteers for the French group can also be congratulated for the work they do translating materials such as the *Torch* into French and posting them on the Waldenström France website.



Heidi gave her sniff of approval! The Pindzolas' little white dog is a regular attendee of the Philadelphia support group meetings and was first in line when the tenth anniversary cake was served.



# IWMF SUPPORT GROUP CHAPTER LISTINGS

## ALABAMA

Mal Roseman  
770-392-1255  
malroseman@comcast.net

LaJune & Troy Mitchell  
205-678-7960  
landtmitchell@bellsouth.net

## ARIZONA

### Phoenix

John Dethloff  
623-388-7152  
jdethloff1@cox.net

Ed Nadel  
480-502-5045  
enadeL63@aol.com

## ARKANSAS

### Eastern

Bill Paul  
901-767-6630  
Billpaul1@juno.com

## CALIFORNIA

### Monterey

(May – October)  
Sandy Skillicorn  
831-277-5274  
jLsLs@aol.com

### Orange County

Emil Parente  
949-388-9666  
pnepar@cox.net

Marty Glassman  
949-458-7147  
mglassman@cox.net

### Sacramento/

### San Francisco Bay Area

Alyce & Terry Rossow  
925-447-8881  
Rossow@ieee.org

## COLORADO

Bill Bass  
303-753-0070  
303-808-5734 cell  
basswilliam9@gmail.com

Cindy Furst  
970-667-5343  
970-227-4686 cell  
cindyfurst@gmail.com

Roy Parker  
303-470-6699  
roypar@gmail.com.

## CONNECTICUT

Francoise Lampe  
203-431-1455  
wmfgL@sbcglobal.net

Bob Hammond  
203-426-2772  
Rhamm17@aol.com

Linda McIntosh  
860-460-6445  
lynmac47@aol.com

## DELAWARE

Karen Pindzola  
717-845-5937  
karenpindzola@yahoo.com

## FLORIDA

### Ft. Lauderdale Area

Charlie Koch  
954-476-8726  
bonnie143@bellsouth.net

Phil Lewis  
561-630-3931  
philancier@gmail.com

### West Coast

Herb Kallman  
239-466-6911  
margerina@aol.com

### Tampa

Rita & John O'Brien  
813-654-4986  
promo1rita@verizon.net

## GEORGIA

### Atlanta

Mal & Judy Roseman  
770-392-1255  
malroseman@comcast.net

## HAWAII

### (Nov. – Apr.)

Sandy Skillicorn  
808-891-2882  
jLsLs@aol.com

## IDAHO

### Eastern

Barbara Britschgi  
208-522-2130  
cbrits@cableone.net

### Western

Judy Clark  
208-888-0346  
jzclark@cableone.net

## ILLINOIS

### Chicago

Don Brown  
630-323-5894  
Ldonbrown@msn.com

## INDIANA

Gayle Backmeyer  
divagayle@comcast.net  
765-962-3746

## KANSAS

### Eastern

Karen & Joe Davis  
785-266-0121  
karenjdavis@gmail.com

## KENTUCKY

Marion Petry  
mLpetry123@earthlink.net  
937-438-8850

## MARYLAND

Catherine Naylor  
301-229-0319  
catherinenaylor@verizon.net

## MASSACHUSETTS

### Boston

Lynne & Joe Mara  
781-749-0204  
jmara@nordicgroupusa.com

Judy Christensen  
781-335-5698

## MICHIGAN

Peter & Barbra Boyse  
989-415-9936  
peterdboyse45@charter.net

## MINNESOTA

### Minneapolis/St. Paul

Michelle Blazek  
651-730-0061  
mandsblazek@aol.com

## MISSISSIPPI

Bill Paul  
901-767-6630  
billpaul1@juno.com

## MISSOURI

### Northwestern (KC Area)

Karen & Joe Davis  
785-266-0121  
karenjdavis@gmail.com

## MONTANA

Barbara Britschgi  
208-522-2130  
cbrits@cableone.net

### Regional Contact:

Cindy Furst  
970-667-5343  
970-227-4686 cell  
cindyfurst@gmail.com

## NEVADA

### Eastern

Gerri McDonald  
801-484-0360  
gerri-sLc@comcast.net

### Las Vegas

Robin Grenz  
702-657-3860  
Rgrenz1@cox.net

## NEW ENGLAND

### Boston

Lynne & Joe Mara  
781-749-0204  
jmara@nordicgroupusa.com

Judy Christensen  
781-335-5698

### Western MA, VT & CT

Mel Horowitz  
518-449-8817  
wmcure@yahoo.com

## NEW MEXICO

### Regional Contact:

Bill Bilbro  
575-642-4987  
wbilbro@gmail.com

## NEW YORK

### NE New York/

### Western New England

Mel Horowitz  
518-449-8817  
wmcure@yahoo.com

### New York City

Mitch Orfuss  
646-352-4476  
morfuss@aol.com

### Syracuse/Rochester/Buffalo and surrounding areas

Stephen E. French, Sr.  
585-621-3317  
sfrench@rochester.rr.com

## NORTH CAROLINA

### Western/Central

Don Nolan  
828-692-1114  
nondolan@aol.com

Tim Brown  
336-642-4402  
tbrown23838@yahoo.com

### Northeastern

Bob Zehner  
804-796-3571  
bobnbetsz@comcast.net

## NORTH DAKOTA

### Regional Contact:

Cindy Furst  
970-667-5343  
970-227-4686 cell  
cindyfurst@gmail.com

## EASTERN OHIO

Shariann Hall  
330-533-4921  
shari19@juno.com  
  
Marcia Klepac  
412-421-2437  
marciaklep@hotmail.com

## WESTERN OHIO

Marion Petry  
mLpetry123@earthlink.net  
937-438-8850

## OKLAHOMA

### Western

### Regional Contact:

Bill Bilbro  
575-642-4987  
wbilbro@gmail.com

## OREGON/ SW WASHINGTON

Joan Berglund  
503-668-5037  
jboanberglund@gmail.com



# IWMF SUPPORT GROUP CHAPTER LISTINGS

**OREGON/  
SW WASHINGTON (cont.)**  
Jules Auger  
503-746-7990  
j.auger@comcast.net

**PENNSYLVANIA  
Philadelphia**  
Karen Pindzola  
717-845-5937  
karenpindzola@yahoo.com

**Harrisburg, Central and  
Southeast PA and Northern MD**  
Terrie Eshleman  
717-665-7393  
tmes74@ptd.net

**W. PENN, E. OH, WV**  
Shariann Hall  
330-533-4921  
shari19@juno.com

Marcia Klepac  
412-421-2437  
marciaklep@hotmail.com

**RHODE ISLAND**  
Linda McIntosh  
860-460-6445  
lynmac47@aol.com

**SOUTH CAROLINA**  
John & Paula Austin  
803-644-6002  
jhaustin@bellsouth.net

**SOUTH DAKOTA  
Regional Contact**  
Cindy Furst  
970-667-5343  
970-227-4686 cell  
cindyfurst@gmail.com

**TENNESSEE  
Central & Western**  
Bill Paul  
901-767-6630  
Billpaul1@juno.com

**Eastern**  
Regional Contact:  
Myrna Daniel  
423-837-3537  
mdmermer@yahoo.com

**TEXAS  
Dallas**  
John Knutson  
972-726-7790  
johnknutson@tx.rr.com  
  
Steve Pine  
214-244-5515  
iwmf4steve@verizon.net

**TEXAS (cont.)  
Houston**  
Barbara & John Manoussou  
713-840-0828  
wm@manoussou.us

**Western**  
Regional Contact:  
Bill Bilbro  
575-642-4987  
wbilbro@gmail.com

**UTAH**  
Gerri McDonald  
801-484-0360 or 801-232-5811  
gerri-sLc@comcast.net

**VIRGINIA**  
Bob Zehner  
804-796-3571  
bobnbetsz@comcast.net

**WASHINGTON  
Northwest (Seattle Area)**  
Peg Horton  
360-874-6906  
peggyhorton@q.com  
  
**Southwest (Portland Area)**  
Joan Berglund  
503-668-5037  
jbjoanberglund@gmail.com

**WASHINGTON D.C.,  
NORTHERN VA**  
Catherine Naylor  
301-229-0319  
catherinenaylor@verizon.net

**WISCONSIN  
Northwest WI**  
Michelle Blazek  
651-730-0061  
mandsblazek@aol.com

**Southeast WI**  
Don Brown  
630-323-5894  
ldonbrown@msn.com

**WYOMING**  
Bill Bass  
303-753-0070  
303-808-5734 cell  
basswilliam9@gmail.com

**Regional Contact:**  
Cindy Furst  
970-667-5343  
970-227-4686 cell  
cindyfurst@gmail.com

## INTERNATIONAL SUPPORT GROUPS AND CONTACTS

**AUSTRALIA**  
Colin Perrott  
colin@wmozzies.com  
www.wmozzies.com

**BELGIUM**  
Joanna Van Reyn  
+32 9 335 46 60  
joanna.vanreyn@cmp-vlaanderen.be

**CANADA  
Alberta**  
Cam Fraser  
403-281-8278  
cmfraser@shaw.ca  
  
Stu Boland  
403-281-0271  
stu\_boland@hotmail.com

**Montreal**  
Regional Contact:  
Sandra Proctor  
450-672-4336  
sandra.proctor@sympatico.ca

**Nova Scotia**  
Susan Gagnon  
902-446-9533  
suemarg3x3@hotmail.com

**Ottawa**  
Janet Cherry  
613-596-1413  
janet.parcher.cherry@sympatico.ca

**CANADA (cont.)  
Toronto**  
Arlene Hinchcliffe  
905-337-2450  
wmfc@noco.ca  
  
**Vancouver**  
Charlene Kornaga  
250-474-7011  
dennischarlene.kornaga@shaw.ca

**DENMARK**  
Steffen Stello  
+45 3582 7707  
Mobile: +45 2123 7707  
snejka@mail.dk

**EUROPEAN WM NETWORK**  
Marlies Oom, secretary  
+31 73 5217643  
secretary@ewmnetwork.eu

**FINLAND**  
Veikko Hoikkala  
+35 8500 48 4864  
veikko.hoikkala@dnainternet.net

**FRANCE**  
Michel Houche  
+33 (0)490 870 930  
houchemichel@wanadoo.fr

**GERMANY  
Regional Contact:**  
Dr. Rolf Pelzing  
rolf.pelzing@t-online.de

**GREECE**  
Alexia Kapralou  
+30 210 6858574  
kapralou\_alexia@hotmail.com

**INDIA  
Regional Contact:**  
Anil and Vasundhara Somani  
+91 98300 49300  
asomani@vsnl.com

**Mumbai & Western India**  
Sanjeev Kharwadkar  
91-98210-69769  
92-22-6691-9957  
swkharwadkar@yahoo.co.in

**IRELAND**  
Anne Staples  
annehstaples@yahoo.ie  
+35 353 9158825

**ISRAEL**  
Moshe Kwart  
+97 254 2270527  
m.kwart@tehitlot.com

**JAPAN  
Regional Contact:**  
Sanjeev Kharwadkar  
+81 03-6712-1887  
+81 090-9971-4541 mobile  
swkharwadkar@yahoo.co.in

**NEW ZEALAND**  
Michael Goldschmidt  
+03 384 5399  
goldschm@paradise.net.nz

**UNITED KINGDOM**  
Nigel Pardoe & Cheryl Luckie  
+44 0208 3263286  
info@wmsupportgroup.org.uk  
wmsupportgroup.org.uk

**Patient Representative:**  
Roger Brown  
+44 1285 650107  
info@wmuk.org.uk  
www.wmuk.org.uk

**Sussex**  
Mike Dewhirst  
mkdewhirst@yahoo.co.uk

**Birmingham & West Midlands**  
Geoffrey Willsher  
+44 0121429 1038  
willsher.s@btinternet.com



# THE LIFELINE

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

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

## TREATMENTS

### ALLOGENEIC STEM CELL TRANSPLANTS

Eileen Sullivan ..... 617-625-6957  
[esullivan27@comcast.net](mailto:esullivan27@comcast.net)

### 2-CdA (CLADRIBINE) WITH RITUXAN

Bernard Swichkow ..... 305-670-1984  
[theswichkows@aol.com](mailto:theswichkows@aol.com)  
 Brent Wingett ..... 805-466-2345  
[bwingett@charter.net](mailto:bwingett@charter.net)

### BORTEZOMIB DEXAMETHASONE & RITUXIMAB (BDR)

Joe Gallo ..... 941-493-1809  
[galljocon@verizon.net](mailto:galljocon@verizon.net)  
 Ron Linford ..... 865-657-9895  
[rongl@aol.com](mailto:rongl@aol.com)

### CHLORAMBUCIL

Janice Stein ..... 415-346-6620  
[janicemstein@aol.com](mailto:janicemstein@aol.com)

### CRYOGLOBULINEMIA

Fay Langer ..... 904-625-3135  
[fhlanger@gmail.com](mailto:fhlanger@gmail.com)

### FLUDARABINE with cyclophosphamide (Cytosan)

Penni Wisner ..... 415-552-6579  
[penniw@pacbell.net](mailto:penniw@pacbell.net)

### FLUDARABINE with Rituxan

Marty Kopin ..... 310-390-1546  
[mkopin@yahoo.com](mailto:mkopin@yahoo.com)  
 Jerry Block ..... 301-460-9799  
[jblock35@comcast.net](mailto:jblock35@comcast.net)  
 Eileen Sullivan ..... 617-625-6957  
[esullivan27@comcast.net](mailto:esullivan27@comcast.net)

### ORAL CYTOXAN

Lou Birenbaum ..... 314-961-5591  
[lbirenbaum@aol.com](mailto:lbirenbaum@aol.com)

### PLASMAPHERESIS

Fred Bickle ..... 805-492-4927  
[Flb134@msn.com](mailto:Flb134@msn.com)  
 John Borchert ..... 440-449-1662  
[gdvibes@sbcglobal.net](mailto:gdvibes@sbcglobal.net)

### RAD 001

Tom Howenstine ..... 419-542-8921  
[Howen978@verizon.net](mailto:Howen978@verizon.net)

### R-CVP

Allen Weinert ..... 360-683-3495  
[anweinert@gmail.com](mailto:anweinert@gmail.com)

### (revlimed) LENALIDOMIDE

Christopher Patterson ..... 617-632-6285  
[christopher\\_patterson@dfci.harvard.edu](mailto:christopher_patterson@dfci.harvard.edu)

### RITUXAN

James Townsend ..... 352-376-3664  
 Allen Weinert ..... 360-683-3495  
[anweinert@gmail.com](mailto:anweinert@gmail.com)

### SPLENECTOMY

Kathleen Ugenti ..... 631-470-0971  
 Patricia McCue ..... 239-348-3456 winter  
 802-468-5779 summer

### STEM CELL TRANSPLANT

Howard Donley ..... 307-587-3397  
[donleyh@tctwest.net](mailto:donleyh@tctwest.net)

### THALIDOMIDE

Mel Horowitz ..... 518-449-8817  
[wmcure@yahoo.com](mailto:wmcure@yahoo.com)

### VELCADE

Jeff Atlin ..... 905-707-5640  
[jeffatlin@hotmail.com](mailto:jeffatlin@hotmail.com)

## SPECIALTY TOPICS

### CAREGIVING

Lynn Bickle ..... 805-492-4927  
[Flb134@msn.com](mailto:Flb134@msn.com)  
 Brad Alexander ..... 972-529-2002

### CLINICAL TRIALS

Tom Hoffmann ..... 501-868-8305  
[Thh97@msn.com](mailto:Thh97@msn.com)  
 Guy Sherwood ..... 765-282-4377  
[guysherwood@comcast.net](mailto:guysherwood@comcast.net)

### HEARING IMPAIRED TTY FACILITY

Betty McPhee ..... 647-348-7440  
[bjmcphee@hotmail.com](mailto:bjmcphee@hotmail.com)

### NEWLY DIAGNOSED

Guy Sherwood ..... 765-282-4377  
[guysherwood@comcast.net](mailto:guysherwood@comcast.net)  
 Sallie Moore ..... 516-795-3746  
[Smoore6042@aol.com](mailto:Smoore6042@aol.com)

### SOCIAL SECURITY DISABILITY

Howard Prestwich ..... 815-233-0915  
[prestwic@mwci.net](mailto:prestwic@mwci.net)

### WATCH AND WAIT

Mel Horowitz ..... 518-449-8817  
[wmcure@yahoo.com](mailto:wmcure@yahoo.com)  
 Renee Paley-Bain ..... 203-744-7851  
[paleybain@aol.com](mailto:paleybain@aol.com)

### YOUNG WM

Nobby Riedy ..... 650-879-9104  
[knobby@wildspaces.net](mailto:knobby@wildspaces.net)  
 Bob Bailey ..... 770-664-8213  
[Laurabailey64@gmail.com](mailto:Laurabailey64@gmail.com)  
 John Borchert ..... 440-449-1662  
[gdvibes@sbcglobal.net](mailto:gdvibes@sbcglobal.net)

## INTERNATIONAL

### AUSTRALIA

Colin Perrott  
[Wmozzies-owner@yahoogroups.com](mailto:Wmozzies-owner@yahoogroups.com)  
[www.wmozzies.com](http://www.wmozzies.com)

### BELGIUM

Joanna Van Reyn ..... +32 9 335 46 60  
[joanna.vanreyn@cmp-vlaanderen.be](mailto:joanna.vanreyn@cmp-vlaanderen.be)

### DUTCH SPEAKER

Lia van Ginneken-Noordman ..... 00-31-(0)70-3475520  
[Ginneken.noordman@wxs.nl](mailto:Ginneken.noordman@wxs.nl)

### EUROPEAN WM NETWORK

Marlies Oom, secretary ..... +31 73 5217643  
[secretary@ewmnetwork.eu](mailto:secretary@ewmnetwork.eu)

### FINNISH SPEAKER

Veikko Hoikkala  
[veikko.hoikkala@dnainternet.net](mailto:veikko.hoikkala@dnainternet.net)

### FRENCH SPEAKER

Guy Sherwood ..... 765-282-4377  
[guysherwood@comcast.net](mailto:guysherwood@comcast.net)  
 Sybil Whitman ..... 506-450-3970  
[hcouture@nbnet.nb.ca](mailto:hcouture@nbnet.nb.ca)



# THE LIFELINE

## FRENCH LANGUAGE TALK LIST

<http://sympa.medicalistes.org/wws/info/waldenstrom>

## GERMAN SPEAKER

Roy Parker (Colorado, USA) ..... 303-470-6699  
*roypar@gmail.com*

Sybil Whitman (New Brunswick, CANADA) .... 506-450-3970  
*hcouture@nbnet.nb.ca*

## GERMAN LANGUAGE TALK LIST

[http://www.leukaemie-hilfe.de/foren.html?&tx\\_mmforum\\_pi1\(action\)=list\\_topic&tx\\_mmforum\\_pi1\(fid\)=14](http://www.leukaemie-hilfe.de/foren.html?&tx_mmforum_pi1(action)=list_topic&tx_mmforum_pi1(fid)=14)

## SPANISH SPEAKER

Peter Mitro ..... 440-247-3460  
*stonehill@earthlink.net*

Betsy Beazley ..... 510-527-5827  
*betsybeazley@gmail.com*

## SPANISH SPEAKER (cont.)

Gladys Mendieta ..... 215-860-9216  
*Gladysmendieta@aol.com*

Leon Maya ..... 865-694-9581  
*veraleon@comcast.net*

## SPANISH LANGUAGE TALK LIST

[iwmf-talk-espanol-subscribe-request@lists.psu.edu](mailto:iwmf-talk-espanol-subscribe-request@lists.psu.edu)

## SWEDEN/NORWAY

Anne Odmark ..... +46 18-14 05 13  
*ag.odmark@gmail.com*

## NORDIC COUNTRIES TALK LIST

[iwmf-talk-nordic-subscribe-rquest@lists.psu.edu](mailto:iwmf-talk-nordic-subscribe-rquest@lists.psu.edu)

## UNITED KINGDOM LIFELINE

### 2Cda (CLADRIBINE)

Roger Brown ..... +44 01285 650107  
*Rogerbrown961@btinternet.com*

### FLUDARABINE

Ken Rideout ..... +44 1278 782108  
*ken@4rosetree.fs.co.uk*

### FLUDARABINE AND RITUXIMAB

Mike Dewhirst  
*dewhirst\_6@hotmail.com*

### OPHTHALMOLOGY

Terry Betts ..... +44 01992 583643  
*tjb-planning@freeuk.com*

### PLASMAPHERESIS

Roger Brown ..... +44 1285 650107  
*Rogerbrown961@btinternet.com*

### RITUXAN

Nigel Pardoe ..... +44 0208 326 3270  
*pardoe@aol.com*

### WALDENSTROM'S MACROGLOBULINEMIA

### UK CANCER SUPPORT

Roger Brown ..... +44 1285 650107  
*info@wmuk.org.uk*  
*www.wmuk.org.uk*

### UK SUPPORT GROUP ONLINE FORUM

Raphael Altman  
*raltman@btinternet.com*

## CANADA LIFELINE

### CLINICAL TRIALS

Rod Anderson (Cobourg, ON) ..... 905-372-2410  
*rod@rodmer.com*

### TTY- HEARING IMPAIRED

Betty McPhee (Toronto, ON)  
*bjmcphree@hotmail.com*  
*Fluent in American Sign Language*

### NEWLY DIAGNOSED

Jeff Atlin (Toronto, ON) ..... 905-707-5640  
*jeffatlin@hotmail.com*

Rod Anderson (Cobourg, ON) ..... 905-372-2410  
*rod@rodmer.com*

### WAIT & WATCH

Jim Bunton (Toronto, ON) ..... 416-621-7864  
*jbunton@sympatico.ca*  
 Debbie Irwin (Toronto, ON)  
*Debbie.Irwin@Mecglobal.com*

### CVP/RITUXAN

Betty McPhee (Toronto, ON) ..... 647-348-7440  
*bjmcphree@hotmail.com*

Ritwik Ray (Toronto, ON) ..... 416-693-0910  
*ritwik@rogers.com*

Rod Anderson (Cobourg, ON) ..... 905-372-2410  
*rod@rodmer.com*

Debbie Irwin (Toronto, ON)  
*Debbie.Irwin@Mecglobal.com*

### FLUDARABINE

Jeff Atlin (Toronto, ON) ..... 905-707-5640  
*jeffatlin@hotmail.com*

Gary Dvorkin (Mississauga, ON)  
*annawill@sympatico.ca*

Bert Visheau (Hamilton, ON)  
*visheau@mcmaster.ca*

### RITUXAN

Rod Anderson (Cobourg, ON) ..... 905-372-2410  
*rod@rodmer.com*

Gary Dvorkin (Mississauga, ON)  
*annawill@sympatico.ca*

Susan Gagnon (Halifax, NS)  
*suemarg3x3@hotmail.com*

Bert Visheau (Hamilton, ON)  
*visheau@mcmaster.ca*

### STEM CELL TRANSPLANT

Sybil Whitman ..... 506-450-3970  
*hcouture@nbnet.nb.ca*

### VELCADE

Jeff Atlin (Toronto, ON) ..... 905-707-5640  
*jeffatlin@hotmail.com*

Rod Anderson (Cobourg, ON) ..... 905-372-2410  
*rod@rodmer.com*

### VETERANS

Bert Visheau (Hamilton, ON)  
*visheau@mcmaster.ca*



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Terry Crews

**In honor of Richard Beckman:**

Linda & Bob Kallish

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**In honor of Mindy S. Caplan – Happy Mother's Day:**

Mike & Anna Caplan

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International Waldenstrom's  
Macroglobulinemia Foundation  
3932D Swift Road  
Sarasota, FL 34231-6541

Telephone 941-927-4963 • Fax 941-927-4467  
E-mail: [info@iwmf.com](mailto:info@iwmf.com) • [www.iwmf.com](http://www.iwmf.com)  
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## IWMF MISSION STATEMENT

To offer means of mutual support and encouragement for those with Waldenstrom's macroglobulinemia, their family members, and others with an interest in the disease

To provide information and educational programs that address patients' concerns

To promote and support research leading to a cure