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IWWM5: REPORT FROM STOCKHOLM

BY GUY SHERWOOD, M.D.

The Fifth International Workshop on Waldenström's Macroglobulinemia (IWWM5) was held in the beautiful and historic city of Stockholm, Sweden, from October 15 to 18. More than 150 physicians, researchers, pharmaceutical representatives, and others attended this exciting meeting. Organized by Dr. Eva Kimby of Sweden and Dr. Steven Treon from the United States, this three-day conference highlighted the amazing growth in new scientific knowledge of WM. Since the first IWWM was held in Bethesda, MD, in 2000, there has been a steady and continuous increase in the number of investigators working in this field. I attended IWWM4 in Kos, Greece, in the summer of 2007 and heard then all the recent developments. Nonetheless in Stockholm I was amazed and very encouraged by the tremendous progress that has been made in WM research in the one short year between international workshops.

Over the course of three very busy days, world leaders in WM basic and clinical research presented formal lectures, debated and discussed areas of scientific controversy, identified gaps in knowledge as well as clinical challenges, and informally attempted to prioritize future research directions. The nights were just as busy and exciting because the conference organizers selected beautiful historic venues for the evening dinner events. The formal opening ceremonies were held at the famous Vasa Museum where Dr. Veronique Leblond (France) was announced as the recipient of the prestigious Robert A. Kyle Award for her contribution to the understanding of Waldenström's macroglobulinemia (Dr. Leblond was, unfortunately, unable to attend due to a family emergency). The awe-inspiring Nobel Museum was the venue for the reception honoring the recipients of the Young Investigator Awards and for the display of their research results in poster format. At the closing ceremony, held at the beautiful Nobel Hall within the Stockholm City Hall, our very own president, Judith May, accepted a Waldenström Award on behalf of the IWMF in recognition of the IWMF's outstanding contributions to WM patient education and advocacy, as well as support of research.

The IWMF Executive Committee has asked me to summarize and explain in layperson-friendly language the more than 58 lectures given by researchers at the conference, as well as the 8 poster presentations of the Young Investigator Award recipients. The initial idea was to publish this summary in the next two issues of the *Torch*; it soon became evident, however, that the sheer size of this summary would overwhelm the *Torch* newsletter and increase the printing and postage costs, which are high as it is. A smaller, more concise document would be economical but would require considerable editing, with the result that a wealth of information would be lost—hardly serving the purpose of educating our membership. Therefore, you can expect to have a full



IWWM5 organizers Dr. Eva Kimby and Dr. Steven Treon in Nobel Hall with recipients of the Waldenström Awards. From L to R: Dr. Kimby (Sweden, Co-Chair); Dr. Meletios Dimopoulos (Greece); Dr. Giampaolo Merlini (Italy); Dr. Pierre Morel (France); Judith May (USA, IWMF President); Dr. Deborah Dunsire (USA, Millenium Pharmaceuticals Inc.); Dr. Sol Baber (USA, Celgene Corporation); Dr. Treon (USA, Co-Chair)

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IWMF5: Report From Stockholm, cont. from page 1

summary of all the IWMF5 presentations and posters, along with a glossary of medical and research terms, available for viewing and downloading on the IWMF website (www.iwmf.com) within the month of January.

In the next *Torch* I will be writing a short article about my personal impressions of the state of WM research, as one who has not only a deep interest in the scientific aspect of this research but also, and perhaps more importantly, a personal perspective in terms of what it all means for me as an eight-year WM survivor. Without spoiling the surprise or diminishing anyone's sense of anticipation, I can tell you that I have never been more positive and more encouraged by the new developments in WM research and treatment.

Donate and participate!

(visit www.wmworkshop.org for further information on IWMF5)

NEW ANTI-CD20 MONOCLONAL ANTIBODIES

BY SUE HERMS

A previous article in the Fall 2008 *Torch* entitled "Rituximab – How It Works and Why Resistance Occurs" dealt with the mechanisms that may explain how rituximab affects our B-cells and why some patients show no response to it, either initially or at retreatment.

The current article will explore some of the new anti-CD20 antibodies and the strategies used to re-engineer them in order to make them more effective – in other words, "new and improved" versions of rituximab. During this discussion you may find it helpful to refer to the previous article mentioned above.

New Anti-CD20, cont. on page 3



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HAVE YOUR SAY

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

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

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.

NEW SPARKLE FOR THE TORCH

The fall issue of the *Torch* assumed a bright and bold new appearance due to the masthead prepared for us by graphic designer **Ken Edmondson**. The son of IWMF members **Charley and Fran Edmondson**, Ken operates his own design consulting business, Edmondson Design (www.edmondsondesign.com), which specializes in helping companies establish their own brand identities.

Many thanks to Ken for volunteering his talents to the IWMF in designing the masthead and suggesting stylistic details to enhance the appearance of our *Torch*.

Several new anti-CD20 antibodies are undergoing pre-clinical and clinical evaluations. These include modifications that permit better binding to the CD20 antigen on B-cells, better activation of antibody-dependent cellular cytotoxicity and/or complement-dependent cytotoxicity, and more effective direct apoptosis (death) of the B-cell by interfering with its structure or protein expression.

Many of us are familiar with some of the infusion-related side effects of rituximab that include fever, nausea, headache, chills, itching, and/or rash. One explanation for these adverse reactions is that the human immune system recognizes the mouse part of rituximab as foreign, thereby causing such inflammatory effects. An obvious solution to this problem would be to generate rituximab and similar antibodies directly from humans, but this is not easy, primarily because it is not considered ethical to introduce such antigens to humans in order to produce antibodies. Various approaches to overcome this problem have been tried since the late 1980s. One approach involves using just a few amino acids of the mouse antibody, while another approach genetically alters mice to produce more human-like antibodies. Unfortunately, there are reports that these newer “humanized” antibodies are still generating side effects, although some of them claim to be less toxic than rituximab. It is likely that there are other mechanisms in play that account for infusion problems, such as the body’s generalized response to the rapid destruction of circulating B-cells, which causes the release of cytokines (small proteins secreted by cells that regulate immunity, inflammation, and cell growth).

In spite of the excitement generated by these new anti-CD20 antibodies, their place in treatment therapies will depend not only on their safety profile but, more importantly, on whether they can demonstrate a therapeutic efficiency greatly superior to rituximab. Developers of these drugs will face increasing competition as well as greater oversight from regulators and payers. Right now, Roche dominates the market because rituximab is the leading treatment for non-Hodgkin’s lymphoma (NHL) and posted double digit growth (21%) in Europe and the U.S. for early 2008, with increasing use in Japan. Rituximab sales are also benefiting from its increased use as maintenance therapy for follicular lymphoma.

The following are anti-CD20 antibodies that have reached the clinical trials stage and have the potential to enter the market in the not-too-distant future.

Ofatumumab (HuMax-CD20)

The humanized product furthest along in clinical development is ofatumumab (HuMax-CD20), co-developed by Genmab and GlaxoSmithKline. Ofatumumab binds to a different epitope (an antigenic area recognized by an antibody) of the CD20 antigen on B-cells than rituximab and provokes a stronger complement-dependent cytotoxicity (CDC) response. Recall from the earlier article on rituximab that complement is a system of proteins that circulate in the blood and form a series

of enzymes that can directly attack the B-cell membrane or target it for destruction by the body’s own effector cells (macrophages, neutrophils, natural killer cells).

Ofatumumab is currently in Phase 3 trials for follicular lymphoma patients who are refractory (not responding) to combination rituximab/chemotherapy or to maintenance rituximab. Approximately 80 patients will receive one infusion of 300 mg followed by seven weekly infusions of 1000 mg. Disease status will be assessed every three months for two years. Other clinical trials of ofatumumab are combining it with CHOP or chlorambucil, and there are plans to initiate protocols for both retreatment and maintenance therapy. The antibody is also being tested in patients with chronic lymphocytic leukemia (CLL).

GA101

Genentech, Biogen Idec, and GlycArt (a Roche subsidiary) are co-developing humanized GA101, which claims to enhance B-cell death by two methods. First, the structure of the molecule was modified so that it could more effectively cause direct apoptosis of the B-cell. GA101 also binds more strongly to the Fc receptor site on the body’s effector cells. This improved binding leads to a 10-100 fold increase in antibody-dependent cellular cytotoxicity (ADCC). The ADCC mechanism occurs after the CD20 antibody attaches to the B-cell and attracts effector cells that bind and release proteins and enzymes to break up and degrade the structure of the B-cell.

In cell lines and animal models, it was reported that GA101 was significantly more potent than rituximab, causing more complete and longer responses. GA101 is currently in Phase 1/2 clinical trials for NHL and CLL. GlycArt and Roche planned to provide an update on Phase 1 data for GA101 at the American Society of Hematology meeting in December 2008.

AME-133v

AME-133v was developed by Applied Molecular Evolution, a subsidiary of Eli Lilly. The engineering of this drug has resulted in better binding of the antibody to the Fc receptor of effector cells, and AME-133v is claimed to produce a 10-fold killing of human B-cells that is improved by 10-fold when compared to rituximab.

The previous *Torch* article on rituximab discussed the Fc receptor on the body’s effector cells that binds to rituximab and other anti-CD20 antibodies and how the genetic code for this receptor varies among individuals. People who have two valine amino acids at a certain gene sequence (the FcRIIIa site) for this receptor have effector cells that will bind to rituximab more effectively than people who have two phenylalanine amino acids at this position or who have one valine and one phenylalanine. The structure of valine seems to confer a better locking mechanism for the effector cell



when it attaches to rituximab. AME-133v has been modified so that it attaches more effectively than rituximab to the effector cells of those individuals who do not have the more beneficial two valines at this position.

This antibody is in an ongoing Phase 1/2 clinical trial for NHL. Preliminary results of the Phase 1 portion of the study involved 16 patients who did not respond to initial treatment with rituximab. Of these patients, four achieved either a partial or complete response.

Veltuzumab (hA20, previously called Immu-106)

Veltuzumab is a humanized antibody made by Immunomedics. A major advantage of this drug is that it is being tested as a subcutaneous shot rather than an intravenous infusion – if successful, this method of administration would probably reduce many adverse side effects typically associated with intravenous infusions. The major difference between veltuzumab and rituximab is the substitution of one amino acid which is claimed to provide slightly improved binding to effector cells; otherwise the methods of action and effectiveness of veltuzumab appear to be quite similar to rituximab.

The first studies administered the drug intravenously at the outset, but it was found that lower doses were effective; hence the current effort to test the drug subcutaneously. Patients are being recruited for a Phase 1/2 trial for both NHL and CLL. The study is hoping for 72 patients and is a dose escalation study, with doses from 40mg to 80mg to 160mg. This compares to the standard dose of 375mg/m² for rituximab. Patients will receive the injections once a week for four weeks.

PRO131921

This humanized antibody produced by Genentech is in a Phase 1/2 trial for patients with relapsed or refractory indolent NHL who have been previously treated with a rituximab-containing therapy. This trial will first assess the safety of escalating doses of the drug to determine the maximum tolerable dose and then divide the patients into different groups, with each group receiving different doses for four weekly infusions. The groups will be tracked for 48 weeks following the start of treatment to assess their disease status.

PRO131921 exhibits a 30-fold better binding to the FcRIIIa receptor site in patients without two valines and enhanced antibody-dependent cellular cytotoxicity.

Ocrelizumab

Ocrelizumab is another humanized antibody being developed by Genentech, Roche, and Biogen Idec and shows more potent antibody-dependent cellular cytotoxicity. While it has been evaluated in Europe for recurring indolent NHL, no results have been published. Current clinical trials are evaluating its use for rheumatoid arthritis, lupus, and relapsing multiple sclerosis. It appears to show fewer infusion-related side effects, hence its targeted use for such autoimmune diseases where repeated infusions are necessary to achieve an on-going therapeutic response for long periods of time.

STOCKHOLM PATIENT FORUM ON WALDENSTROM'S MACROGLOBULINEMIA OCTOBER 19, 2008

**BY ROY PARKER, VICE PRESIDENT FOR ADMINISTRATION AND
CHAIR OF THE INTERNATIONAL RELATIONS COMMITTEE**

The more than 100 patients and their family members who attended the first European Patient Forum in Stockholm on Sunday, October 19, included residents of Sweden, Norway, Finland, Iceland, the Netherlands, Belgium, France, the United Kingdom, Ireland, and Albania. Planned as an adjunct to the Fifth International Workshop on Waldenstrom's Macroglobulinemia (IWWM5) held October 15-18, the program featured presentations by physicians and researchers from Sweden and the United States and by a panel of three patients, also from the United States.



Dinner in Nobel Hall

Many Forum participants arrived on Saturday, October 18, and enjoyed the opportunities and adventures of sightseeing in Stockholm. On Saturday evening the Forum participants were invited to attend the wonderful dinner and closing ceremonies of IWWM5 at the Nobel Hall, known for its beautiful gold terrazzo tiles and works of art. Speeches by medical dignitaries from around the world followed dinner, and a chorus of Swedish folk singers provided a cappella musical entertainment. The

Stockholm Patient Forum, cont. on page 5



highlight of the evening was the presentation of the Jan Gosta Waldenström Awards. Six splendid medals were presented. Three prominent doctors, Pierre Morel, (France) Giampaolo Merlini (Italy), and Meletios Dimopoulos (Greece) received awards for their outstanding research into our disease. Two pharmaceutical firms were honored for their work to provide better drugs, and Dr. Deborah Dunsire, President and CEO of Millennium Pharmaceuticals Inc., and Dr. Sol Barer, President and CEO of the Celgene Corporation, received these awards. The sixth award was given to the IWWMF in recognition of the patient support and care we provide. The medal was accepted on behalf of the Board of Trustees and foundation members by Judith May, President.



Judith May (IWWMF) accepting award at Nobel Hall

At the conclusion of the dinner, Dr. Jan Waldenström's family surprised Dr. Steven Treon by presenting him with a medal which had been first given to Dr. Waldenström many years ago by the Dana-Farber Cancer Institute in Boston for his research efforts and for the discovery of our disease. The medal will make a full circle upon its return to Boston with Dr. Treon!

The formal program of the Patient Forum began on Sunday morning when Dr. Marvin Stone from Baylor University, Dr. Robert Kyle from the Mayo Clinic, and Dr. Eva Kimby from the Karolinska Institute in Stockholm made illustrated presentations about Waldenström's disease morphology, treatments, and clinical trials. After a short break for refreshments, Dr. Steven Treon provided a summary of the latest information on research efforts and offered an overview and summary of potential new



Doctors Kyle, Kimby, and Treon at the "Ask the Doctor" session

drugs and research initiatives. Dr. Treon also shared some of the consensus recommendations that will likely be forthcoming from the just-concluded IWWM5.

Following the formal presentations, patients enjoyed an "Ask the Doctor" session for more than one hour. Afterwards several attendees remarked that, in their opinion, most European doctors would never have been so frank with their patients, and all appreciated the opportunity to ask questions of such outstanding physicians.

After lunch, three patient members of the IWWMF from the United States, Karen Lee Sobol, Ed Saltzman, and Dr. Guy Sherwood, formed a panel to discuss their own experiences with WM, their treatments, and their observations about clinical trial participation. A question and answer session followed with the Forum attendees.



IWWMF Patient Panel participants Dr. Guy Sherwood, Karen Sobol, and Edward Saltzman



Dr. Guy Sherwood (IWWMF), Nicole Bastin (France) and IWWMF French members in their breakout session

One highlight of the day came when the Forum participants broke into small group sessions with IWWMF facilitators: a French group with Guy Sherwood; a United Kingdom group with Tom Myers, IWWMF Vice President for Research; and a Nordic group with Judith May. These groups discussed their own operation and how they thought the IWWMF could be of help to them. They were primarily interested in how to locate, attract, and keep new members. They also spoke of ways the IWWMF could provide advice and greater support to European members.

Suggestions and recommendations included:

1. New publications and translations of our existing publications into major European languages.
2. Support for the creation of national or regional talk lists (two already exist, in the UK and France) and the development of a Nordic talk list as soon as feasible. There was also discussion of a talk list for Germany.
3. Cooperation and coordination of services with European nonprofit WM patient service organizations such as the CKP (MM & WM Patient Association) in the Netherlands (represented at the Forum by Marlies Oom, Paul Theuns and Siebe

Stockholm Patient Forum, cont. on page 6





Siebe Homminga (the Netherlands) at the "Ask the Doctor" session

Homminga) and similar organizations elsewhere in Europe, including the DLH (Deutsche Leukämia & Lymphom-Hilfe, the German leukemia-lymphoma support organization) in Germany.

4. Preparation for sale of DVDs of the Forum's complete program of events and transactions.

All suggestions and recommendations will be discussed by the IWWMF Board.

To wrap up a most informative and wonderful day there was a discussion on "looking forward" by the entire group, whose members also expressed their thanks and great appreciation for the planning and execution of this special event. They told the IWWMF representatives how informative the day was and that they were looking forward to the possibility of doing another forum bringing

patients and doctors into contact at IWWM6, scheduled for 2010 in Venice.

Attendees enthusiastically promised to promote more group meetings in their home countries and publicize the 2010 forum in Venice. Many took our literature to bring back to their own personal doctors along with numerous notes transcribed during the sessions. Patients were extremely pleased knowing they would provide their doctors with the most up to date information on Waldenstrom's.

The success of this day offering European WM patients the chance to engage with WM specialists is representative of what the IWWMF stands for in its efforts to provide information and help to patients.

The author expresses his thanks to Judith May, Tom Myers, and Guy Sherwood for contributing to this article and to the success of the first European Patient Forum.



Tom Meyers (Vice President for Research, IWWMF), Dr. Robert Kyle (Mayo Clinic), and Dr. Eva Kimby (Karolinska Institute)



5th International Workshop on Waldenstrom's Macroglobulinemia organizers and volunteers at closing ceremonies



Judith May (President, IWWMF) speaking with Forum patients

PRESIDENT'S CORNER: DECEMBER 2008

BY JUDITH MAY

The month of November has brought changes. Two hard-working and much-liked members of the Board of Trustees left us during the month. Both were long-time WM patients.



DAVE LIVELY (1948 – 2008)

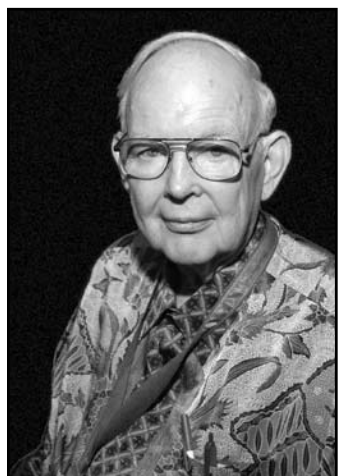
Dave Lively was diagnosed with WM over 20 years ago and had come close to death several times. But he had always turned the corner and come back, robust and cheerful, to tell patients what his latest escape was like and to counsel them to never give up hope and to keep on fishing. Dave joined the Board in 2005 and was Chair of the IWMF Fundraising Committee. He helped shape the IWMF fundraising campaign for the past three years, was a major player at our Ed Forums and on IWMF-Talk, and he went fishing. Dave touched many people with his kindness and caring, often writing to new patients to give them hope and encouragement. He inspired people with his enthusiasm for life and his courageous approach to living with and overcoming WM.

Dave earned a degree in history from the University of Wyoming and worked in the insurance field. However, he also had a colorful career as a cowboy and as a copper miner, and this let him live the outdoor life he loved and enjoy his favorite activities including fishing, hunting, collecting Indian artifacts, skiing, and walking with his dog, Wolff.

Over the past year and a half Dave was in declining health, and finally the damage was overwhelming. He could not rebound, and he left us on November 7. We will always remember Dave for his love and passion for fishing and the outdoor life, and he will continue to be in our thoughts. A paragraph from an essay Dave wrote for the *Torch* and IWMF-Talk at the end of 2006 follows:

“Above all, most of us have survived another year with an uncertain prognosis in an uncertain disease with uncertain treatment regimens and uncertain results. We have tingled, itched, staggered, coughed and passed out, but we have also rowed, hiked, run, walked, and biked many miles in the face of our difficulties with a courage and spirit that shows that we are still full of life and still capable of holding our place on this planet with strong hearts and minds.”

Go in peace, Dave.



JIM BERG (1930-2008)

Jim Berg lived with Waldenstrom's for many years and joined the IWMF Board of Trustees in 2000. Jim was a quiet man of wit and special intellectual skills. He served as Secretary for the Board of Trustees and was our publications editor and special projects writer. These titles do not reveal his true worth or talents. Jim was exceptional in his ability to understand technical presentations, especially at the annual Patient Education Forums, and translate them into detailed and understandable summary reports for those who could not attend or could not understand the technical language.

Jim was a scholar, attending Harvard as an undergraduate and pursuing graduate work in theology and Byzantine history at the Lutheran Theological Seminary at Philadelphia and the University of Pennsylvania. For most of his professional career he taught ancient and medieval history at Wilkes University, while his love of radio led him to develop the Wilkes FM radio station. Jim retired from Wilkes University as Professor Emeritus of History in 2002 and thereafter served on a number of boards of charitable organizations. He was very active with

the AARP volunteer tax program, acting as their tech person as well as the preparer who handled the complicated returns.

Jim was a gentleman, unfailingly courteous, with a wonderful wry sense of humor. He kept up a constant search for new information, sharing his findings, and simplifying the technical so that we might understand what hopes the new developments offered. We are enriched in being beneficiaries of Jim's talent and generosity, and we will miss him greatly.

Jim's professionalism and wisdom helped to shape the IWMF Board, and we are less without Jim Berg.

President's Corner, cont. on page 8



As I write this article, shortly after Thanksgiving, we give thanks for the contributions of Dave Lively and Jim Berg, for the ways in which they helped patients and guided the IWMF Board of Trustees to where we are today. We thank you both and give you leave to go in peace.

IWMF AWARDS

The IWMF Board is delighted to have been recognized by two of our closest collaborators. In September, at the Lymphoma Research Foundation's Educational Forum in San Francisco, the IWMF was given an award in recognition of our collaborative efforts as partners in lymphoma issues. President Suzanne Bliss presented the award to Judith May, who received it on behalf of the IWMF membership.

In October, at the Fifth International Workshop on Waldenström's Macroglobulinemia in Stockholm, the closing ceremony included presentation of the Waldenström Awards to three physician-researchers, two CEOs of pharmaceutical firms, and one to the IWMF for our continued support and education of WM patients and advocacy on their behalf.

Both awards are now in the IWMF headquarters in Sarasota, FL. We are so proud to have received these awards and recognize that the credit belongs to our members who make all of the Board activities possible through your volunteerism and contributions. In truth, these awards are yours. Congratulations.

Stay well through the New Year and fish on!

Judith



Judith May receives award from the Lymphoma Research Foundation. To her left, Karen Van Rassel, Executive Director, Lymphoma Foundation Canada, and Sue Bliss, President, LRF.

IWMF RESEARCH GRANT UPDATE: IRENE M. GHOBRIAL

An important line of research supported by the IWMF is the testing of blood and tissue samples from patients undergoing clinical trials of novel drugs found promising in the laboratory. Such tests may lead to an understanding of the mechanisms by which the trial agents work. Dr. Irene Ghobrial here reports on recent testing at the Dana-Farber Cancer Institute of three novel therapies with differing modes of operation—perifosine, RAD001 (Everolimus), and bortezomib (Velcade) in combination with rituximab (Rituxan). Dr. Ghobrial received support from the IWMF in her study of the blood and tissue samples tested in the perifosine trial. When tested in a clinical trial, none of the three drugs offered the promise of curing WM. Yet all may have an important role in the treatment and management of WM in the years ahead.

Tom Myers, Vice President for Research



NOVEL THERAPEUTIC AGENTS IN WALDENSTROM'S MACROGLOBULINEMIA

BY IRENE M. GHOBRIAL, M.D.

For Waldenström's macroglobulinemia (WM), a distinct low grade B-cell lymphoma characterized by the presence of lymphoplasmacytic cells in bone marrow and a serum monoclonal IgM protein¹⁻³, there is no standard therapy, and there are, to date, no FDA-approved therapeutic agents specific for the treatment of WM⁴. Most treatment options in use for WM were originally derived from treatments for other lymphoproliferative diseases, including multiple myeloma (MM) and chronic lymphocytic leukemia (CLL)⁵. There is, therefore, a need to develop novel therapeutic agents that are based on their activity in WM, both preclinically (that is, in the laboratory) and clinically (when administered to WM patients).

At the Dana-Farber Cancer Institute we have tested multiple agents in the preclinical or laboratory setting. Of these novel agents, three—perifosine, RAD001, and bortezomib—have advanced to clinical trials. Recently we completed a Phase 2 clinical trial of single agent perifosine, a Phase 2 clinical trial of single agent RAD001, and a Phase 2 clinical trial of the combination of bortezomib and rituximab. These three clinical trials were restricted to patients with relapsed or relapsed/refractory WM. The results of the trials are summarized below.

IWMF Research Grant, cont. on page 9



In our preclinical studies, the Akt inhibitor perifosine (KRX-0401, produced by Keryx Biopharmaceuticals Inc.) showed promise as an agent that both inhibits the proliferation and promotes the killing of WM cells⁸. These studies have shown that the activity of the protein Akt, found in B-cells and known as a survival protein, is increased in patients with WM when compared to normal B cells and that perifosine has the effect of limiting the activity of Akt and thus reducing the number of WM cells.

Based on these preclinical studies, we initiated a Phase 2 trial of single agent perifosine in patients with relapsed or relapsed/refractory disease, that is, only patients who had at least one previous therapy for WM and whose disease was relapsed or refractory were eligible. All patients received 150 mg of oral perifosine daily for 28 days per cycle until either experiencing progression of WM or excessive toxicity from the regimen. The trial enrolled patients from 10/06 to 11/07, with 37 patients (27 men and 10 women; median age 65 years, range 44 – 82) treated. Of these patients 65% were relapsed and 35% were relapsed and refractory to prior therapy, and the median number of prior treatments per patient was 3 (range 1 - 5), with 35% of the patients having more than 3 lines of prior therapy. The response of 36 patients has now been evaluated, and the overall response rate is found to be 36%. Partial response (50% reduction in IgM) occurred in 2 (6%) patients; the duration of response was 9+ and 18+ months. Minimal response (25% reduction in IgM) was recorded in 11 (30%) patients; the median duration of response was 7 months, ranging from 2 to 21+ months. Stable disease resulted for 21 (58%) patients (that is, their status did not worsen), while progressive disease occurred in 2 (6%) patients at 2 and 4 months.

Gastrointestinal toxicities (nausea, vomiting and diarrhea), experienced by 36% of the patients receiving perifosine, were the most common adverse effects in the trial using this drug as a single agent. Anemia (9%) and leucopenia (low white cells 9%) also occurred. While arthritis occurred in 9% of the patients and was considered likely to be related to therapy (especially in rapidly responding patients), it was reversible by appropriate treatment as well as by dose reduction. As of August 2008, the duration of progression-free survival and time to progression are similar at a median of 10.7 months. We conclude, therefore, that treatment with perifosine as a single agent offers a prolonged time to progression in relapsed or refractory WM, a promising response rate of 36%, stabilization of disease in 58% of patients, and manageable toxicity, together with the convenience of oral administration.

The trial using RAD001 (Everolimus, produced by Novartis) was based on data from laboratory studies that demonstrated increased activity of the PI3K/mTOR pathway in WM. RAD001 (shown to be an inhibitor of mTOR pathways) was studied in vitro for WM and showed significant cytotoxicity in WM cells lines, specifically when combined with bortezomib (unpublished data). A Phase 2 trial of single agent RAD001 was initiated for WM patients with relapsed or relapsed/refractory disease. All patients received daily RAD001 at 10 mgs and were allowed to continue therapy until progression of disease or excessive toxicity. This study was conducted in a collaborative effort between Dana-Farber and Mayo Clinic College of Medicine. The data in this report come from patients participating at Dana-Farber, where 19 patients (15 men and 4 women) have been treated to date, all having symptomatic disease and requiring therapy. The median IgM level of the patients at the outset of the trial was 3330 mg/dL (range: 1010 - 7410). The median follow-up on the patients taking RAD001 was 8 months (range 3 - 22 months). Currently 18 patients can be evaluated for response. The best responses to RAD001 were as follows: partial remission in 8 patients (44%), minimal response in 5 patients (28%), giving an overall response rate (PR+MR) of 72%. In 4 patients (22%) progressive disease followed treatment, and in 1 patient (6%) stable disease resulted. The median duration of response has not been reached (the range is 3 to 22+ months). Patients tolerated RAD001 therapy well; toxicities were not significant. Instances of thrombocytopenia (low platelets), pneumonia, hyperglycemia, and mucositis (inflammation of the digestive tract, including the oral cavity) were limited to single patients. Nail cracking, diarrhea, and fatigue were also observed. Toxicities attributable to the regimen otherwise proved manageable with appropriate care, and RAD001 was generally well-tolerated. Future studies combining this agent with rituximab and bortezomib are currently being planned.

Previous clinical studies have demonstrated the efficacy of the proteasome inhibitor bortezomib (Velcade, produced by Millennium Inc.) as a single agent in patients with WM. At Dana-Farber we performed preclinical studies that showed synergistic activity of bortezomib with the anti-CD20 antibody rituximab (Rituxan) in WM cell lines and in patient samples. The Phase 2 study aimed to determine the safety and activity of bortezomib when administered weekly in combination with rituximab for patients with relapsed/refractory WM. For all patients, bortezomib was administered once a week at 1.6 mg/m² in 6 cycles of 4 weeks each. On cycles 1 and 4 rituximab was administered at 375 mg/m² once a week for 4 consecutive weeks.

Thirty-seven patients (26 men and 11 women, median age 62 years, range 42 – 73) have been treated to date in this trial. All had symptomatic disease and required therapy. The median number of prior treatments for this patient group was 3 (range 1 - 5), including prior bortezomib and prior rituximab for some patients. The median IgM at baseline (the point at which each



patient entered the trial) was 3540 mg/dL (range 700 - 10,800). The median follow-up is 12 months (range 4 - 24 months). Thirty-five patients can currently be evaluated for response. Complete remission and near-complete remission occurred in 2 patients (6%), partial remission in 17 (48%), and in 10 (29%) there was minimal response. Progressive disease resulted in 1 patient (3%), and in 5 patients (14%) stable disease was the outcome. The patients who achieved response did so rapidly for the most part, within 3 months of therapy (2-7 months). A rituximab flare occurred in only 6 patients (20%). The median duration of response has not been reached (5 - 26+ months). Patients tolerated therapy well without significant toxicities. Overall 12 patients (32%) developed peripheral neuropathy. In 10 of these patients the resulting neuropathy was not severe in degree; significant peripheral neuropathy occurred in only 2 patients at cycle 6 and completely resolved in one of these patients within one month after stopping therapy. Other toxicities included neutropenia (low neutrophils) in 3 patients, anemia and hyponatremia (low salt) in 1 patient, and thrombocytopenia (low platelets) in 1 patient. Severe pneumonia and viral infection occurred in 1 patient. In conclusion, the combination of weekly bortezomib and rituximab was well tolerated and demonstrated encouraging activity, with CR+ PR + MR in 83% of patients with relapsed WM who were evaluated. No significant peripheral neuropathy has been observed to date with this regimen. Studies using the combination of bortezomib and rituximab in newly diagnosed patients are ongoing.

Other continuing studies at Dana-Farber include upfront therapy with weekly bortezomib and rituximab for newly-diagnosed WM patients, as well as the Phase 2 trial of Enzastaurin in relapsed/refractory WM. Future studies will include the use of RAD001 in combination with rituximab or in combination with bortezomib and rituximab, as well as the single agent study of LBH589 (a histone deacetylase inhibitor produced by Novartis Inc.) in relapsed/refractory WM.

In summary, multiple targeted agents are currently being tested in WM in the preclinical and clinical setting. It is expected that future combinations of these novel agents will lead to high overall responses with minimal long-term toxicities compared to traditional chemotherapeutic agents, resulting in improvement in the quality of life and survival of patients with this disease.

Department of Medical Oncology, Dana-Farber Cancer Institute

In the three years since Dr. Ghobrial joined the Department of Medical Oncology at Dana-Farber Cancer Institute she has become familiar to IWMF members, whether speaking at the annual Education Forums or visiting with and speaking to IWMF support groups or receiving patients at the Dana-Farber clinic. Dr. Ghobrial earned her M.D. in 1995 from the Cairo University School of Medicine, Egypt. Following an internship at the Cairo University Hospitals, she completed her residency in Internal Medicine at Wayne State University. Further training in the subspecialty of Hematology/Oncology followed at Mayo Clinic College of Medicine. In 2005 Dr. Ghobrial assumed her current position at Dana-Farber. Dr. Ghobrial is also Instructor in Medicine, Harvard University.

Dr. Ghobrial's research at Dana-Farber is supported in part by the Kirsch Laboratory for WM, the National Institutes of Health, and the IWMF research program.

References:

1. Ghobrial IM, Gertz MA, Fonseca R. Waldenstrom macroglobulinaemia. *Lancet Oncol.* 2003;4:679-685.
2. Dimopoulos MA, Kyle RA, Anagnostopoulos A, Treon SP. Diagnosis and management of Waldenstrom's macroglobulinemia. *J Clin Oncol.* 2005;23:1564-1577.
3. Treon SP, Dimopoulos M, Kyle RA. Defining Waldenstrom's macroglobulinemia. *Semin Oncol.* 2003;30:107-109.
4. Treon SP, Gertz MA, Dimopoulos M, et al. Update on treatment recommendations from the Third International Workshop on Waldenstrom's macroglobulinemia. *Blood.* 2006;107:3442-3446.
5. Vijay A, Gertz MA. Waldenstrom Macroglobulinemia. *Blood.* 2007.
6. Moreau AS, Jia X, Ngo HT, et al. Protein kinase C inhibitor enzastaurin induces in vitro and in vivo antitumor activity in Waldenstrom macroglobulinemia. *Blood.* 2007;109:4964-4972.
7. Roccaro AM, Leleu X, Sacco A, et al. Dual targeting of the proteasome regulates survival and homing in Waldenstrom's Macroglobulinemia. *Blood.* 2008.
8. Leleu X, Jia, X, Moreau, AS, Hatjiharisi, E, Ngo, H, O'Sullivan, G, et al. Perifosine, an Oral Bioactive Novel Akt Inhibitor, Induces In Vitro and In Vivo Antitumor Activity in Waldenstrom Macroglobulinemia. *Blood.* 2006;108:Abstract 2488.



STAND UP TO CANCER

BY BILL PAUL, TREASURER AND SUPPORT GROUP LEADER

On September 5 at the Kodak Theater in Hollywood, IWMF Stood Up To Cancer. So did Katie Couric, Brian Williams and Charlie Gibson. So did Patrick Swayze, Jennifer Aniston, James Taylor, Sheryl Crow, Marge & Homer Simpson, Lance Armstrong and about 50 other celebrities from various fields. Joining them were over 200 representatives from 75 advocacy groups, including IWMF. The event was strictly by invitation only, and IWMF received four tickets. That's pretty strong representation for such a small group ... four of the 200 were us: Bill Paul, Kathie Cohen, Marty Glassman, and Connie Paul. It was a long day. We enjoyed a luncheon at 12:30 pm catered by Wolfgang Puck. It was buffet style, featuring prime rib, various salads, side items and desserts, and accompanied by Cleavage Creek Wine. Yes, Cleavage Creek was featured because 10% of the sales proceeds are donated to breast cancer research. The bottles have pictures of breast cancer survivors. It's very good. The wine, that is. And the pictures.

After the luncheon we were escorted to our seats in the theater for the rehearsal. We were not seated together, but were scattered throughout the audience to show full support for all forms of cancer. One of the organizers, Noreen Fraser, informed us that we would be announced by foundation name, and to stand up and cheer, clap, whatever felt right. Alas, that didn't happen. I suspect the producers decided there was no time to do that during a one hour show.

That might lead us to conclude that the whole thing was a waste of time. After all, we didn't return from Hollywood with a large check made payable to IWMF. We didn't get our Foundation name called out on national television. However, we did learn a lot, and we did educate others a lot. Almost all of our IWMF business cards were handed out, and nearly all of the other pins, brochures, and copies of the *Torch*. People listened to us, and we listened to them.

We spoke to a 25-year old who was with a gorgeous Saint Bernard. We wanted to pet the dog, but she was wearing a sign saying "Please don't pet me, I'm working". It turns out the girl is still struggling with her chemotherapy, and sometimes just falls down without warning. She had previously been paralyzed from the waist down, so this is an improvement. When she falls, the dog lies down beside her so she can use the dog's "saddle" to help her get up again. In the theater I sat next to a 22-year old who just had a mastectomy and was scheduled to start chemotherapy on Monday, September 8. I asked her if she was frightened, and she said no, that she has learned a lot and made many new friends. I reminded her of the Gilda Radner quote that says something about this being a terrific club... the only problem is, you have to have cancer to be a member. She laughed. I hope she does okay.

At 4:45 pm. we shuffled back into the theater and took our seats again. Hopefully you already know what happened next, because you were watching it. Patrick Swayze started things off, right below where we were sitting. We almost lost half the female audience members wanting to jump over the balcony. As you know, James Taylor and Sheryl Crow sang "Fire and Rain". Homer Simpson, Charles Barkley, and Brad Garrett dramatized the importance of a colonoscopy and a rectal examination. However, no celebrity endorsed a bone marrow biopsy. Maybe next time.

Okay, so no one wrote a check for \$25 million to IWMF. No one even mentioned the Foundation on television. Waste of time? Not a chance. The money raised at this event will be used to fund all forms of cancer. The American Association for Cancer Research, the largest scientific organization in the world, will decide where the money goes. Seventy percent of the funds will be given to research "dream teams" working together to help stop our collective disease. Twenty percent will be awarded to "outside the box" research groups who have innovative thoughts and ideas but have no hope of being funded elsewhere. The final ten percent will be used to continue the initiative of the Stand Up To Cancer group.

Hopefully some of our WM researchers will fall into one of these groups that will receive funding. And we're not completely anonymous. As mentioned, we spoke with a number of people who were interested in WM. The IWMF will be listed at www.standup2cancer.org as a source of support, and possibly as advocates as well. People will find us. Some of those in attendance have already asked how to find us. A few IWMF members have sent e-mail messages to the office commenting that the show has strengthened their resolve even more to support IWMF.

We considered the afternoon to be a rousing success. We hope you will agree.



EUROPE-WIDE CONFERENCE ON WALDENSTROM'S AND MULTIPLE MYELOMA IN MAASTRICHT, THE NETHERLANDS

BY ROY PARKER, VICE PRESIDENT FOR ADMINISTRATION

Organized by the European Myeloma Platform and the MM & WM Patient Association of the Netherlands (CKP: Contactgroep Kahler en Waldenström Patiënten), a symposium “No Policy Without Patients” was held in Maastricht on October 30-31 in celebration of the CKP’s 25th anniversary. Participants came from seventeen European countries and represented a range

of target groups, including organizations for MM and WM patients, healthcare professionals, politicians, policymakers, and spokespersons for industry. Their purpose was to discuss the current role of the respective organizations in the treatment of MM and WM, with focus on the need for European patient networks and on the role of patient organizations both in spreading adequate and current information about available treatments and in making medication and treatment available to every patient. The IWMMF was represented by Roy Parker, Vice President of Administration and Chair of the International Relations Committee, who participated at the invitation of L. van Ginneken-Noordman, Vice Chair of the CKP and Marlies Oom of the EWM (European Waldenström’s Macroglobulinemia) Network.

Prof. dr. E. Borst of the Netherlands and Prof. dr. B. van Camp of Belgium co-chaired the first day of this two-day conference. Dr. Borst is the patron of the European Cancer Coalition and former Minister of Health for the Netherlands. Dr. van Camp is a hematologist at University Hospital, Brussels, and chairman of the Medical Advisory Board of the European Myeloma Platform.



Mr. Andre Poort (CKP, the Netherlands) welcomes participants to the Symposium

Summary of Day 1. The main goal of the Maastricht conference was to make patient organizations more effective in partnership with all the involved target groups and to make these organizations more effective in voicing their concerns

and needs within their home countries and throughout Europe. A secondary goal was to prioritize access to treatment and care for all patients with rare diseases.

Presenters discussed how patient organizations stimulate contact between patients and the optimum way to disseminate the latest information about MM and WM to their patient bases. The attendees spoke at length about the need to inform patients of the development and introduction of new drugs and treatments and of clinical trials. The EMEA, a European agency, is similar to the FDA in the United States. However, when the EMEA authorizes a new drug it does not mean that this drug is immediately available in all European countries. Each of the European Union countries has its own rules with respect to providing the drug to the patient. Reimbursement by insurance companies, guidelines for treatment, information to the patient, implementation of risk management plans—all vary from country to country.

Several speakers observed that Europeans do not have access to as many new drugs and treatments as do patients in the USA. They also discussed the fact that in the USA more intensive research is directed toward the treatment and cure for MM and WM than in Europe and that it takes longer for the drug approval process in the European Union. The aim of the proposed platform, once established, is to address such problems through cooperation between all patient organizations and the target groups represented at the Maastricht symposium.

Summary of Day 2. The conference convened with twenty-five representatives of the target groups in “round table format” to discuss and review the previous day’s presentations and select the most important and pressing issues in order to formulate goals and a plan of action preliminary to drafting a document with recommendations on the future role of patient organizations in the formulation of health policies at national and European levels.



Professor Dr. P. Huijgens (Free University of Amsterdam, the Netherlands) speaking on the “Democracy of Patient Advocacy”.

Europe-Wide Conference, cont. on page 13



After the conclusion of the Maastricht conference, a plan for accomplishment of these goals will be presented for approval to each of the participating patient organizations. Once approved, the European Myeloma Platform will work in cooperation with all relevant parties and through the European Organization for Rare Diseases (EURODIS) to accomplish these goals.

Following the second day's agenda, participants split into three different breakout groups to discuss what they felt were the most important results of the symposium:

1. An action plan to establish working relations with clinical trial sponsors.
2. An action plan to engage in dialogue with regulatory bodies.
3. An action plan to tackle inequities in access to treatments, drug pricing, and reimbursement for patients.

At the end of the conference, the attendees agreed to work with their organizations and others to:

1. Create an awareness program to sensitize politicians and government officials about the problems facing patients with rare diseases.
2. Bring public attention to rare cancer diseases by initiating a Europe-wide "Rare Cancer Disease Day."
3. Establish a unified European network for MM and WM to achieve these goals.



Back row, L to R: Roy C. Parker (Vice President, IWMF, USA); Paul Theuns (the Netherlands); Jeroen van Ginneken (the Netherlands). Front row: Lia van Ginneken-Noordman (Vice Chair, MM & WM Patients Association [CKP], the Netherlands); Eileen Parker (IWMF, USA); Marlies Oom (European WM Network)

Many of those attending lauded the IWMF for its extensive patient services, publications, and awareness programs. They also expressed the hope of cooperating with the IWMF in setting up such programs in their own countries. The IWMF will continue to cooperate with these organizations and offer our support where requested.

INTERNATIONAL NEWS

BY ROY PARKER, VICE PRESIDENT FOR ADMINISTRATION

FOCUS ON A SISTER ORGANIZATION IN THE NETHERLANDS

The Dutch MM & WM Patient Association (CKP: Contactgroep Kahler en Waldenström Patiënten) is celebrating the 25th anniversary of its founding. With more than 1500 members, 250 of whom are WM patients and approximately 900 are MM patients, the CKP is a volunteer organization comparable to the IWMF. The CKP has contacts with national and international patient organizations and medical cancer specialists to keep up to date on new treatments and clinical trials.

The main aim of the CKP is to support the interests of WM and MM patients through a) the organization of patient support group meetings b) the distribution of information about the disease c) patient advocacy and d) stimulation of research. In addition to direct contributions, the CKP also receives funding from the Dutch government and from the profits of the football "tote" and national lotteries (as do many other organizations in the fields of health care, culture, sports, and nature conservancy).

The CKP holds general meetings once a year with medical specialists reporting on the latest developments concerning WM. Twice a year regional meetings are held, giving patients a chance to hear guest speakers and exchange experiences with each other. The CKP has a web site, telephone contacts, a digital forum for different groups (including patients, partners, children of partners, patients under 55). The CKP publishes a quarterly magazine, a patient information book on WM for doctors, and participates with a booth at the appropriate information markets. The CKP encourages research via a separately funded foundation.

The CKP can be contacted @ www.ewmnetwork.eu or www.waldenstrom.eu

AUSTRALIAN MEMBER DONATES NEW IWMF BANNER

The IWMF is the proud owner of a large banner (approximately 3' X 4') , suitable for hanging. This banner was donated by our Australian member, **Anja McGifford**, whose company, Artelina, produced it for us.

International News, cont. on page 14



The banner is decorated with the IWMF logo in blue on white satin, with a border of blue fringe enhancing the banner on three sides. The banner was displayed at the IWMF's Patient Forum in Stockholm and received a very positive reaction. (See the photographs on page 5) The foundation will hang this splendid banner at future forums, meetings, and medical conferences.

The IWMF is grateful to Ms. McGifford and congratulates her on the tenth anniversary of Artelina (www.artelina.com).

EUROPEAN WALDENSTRÖM NETWORK

BY MARLIES OOM, CKP, THE NETHERLANDS

The EWM Network was created in 2008 at the initiative of the MM & WM Patient Association (CKP) of the Netherlands. The EWM Network does not focus on the concerns of individual members but is intended to be an umbrella organization for European Waldenström patient support groups. This umbrella provides WM patients representation at the European level and gives a stronger voice to WM patients in European institutions and organizations, including the European Organisation for Rare Diseases (EURORDIS), the European Cancer Patient Coalition (ECPC), and the European Medicines Agency (EMA).

Because WM is a rare disease, in most European countries there is little experience with the organization of WM patient support groups. It is our expectation that the European patient support groups, both those currently in existence and those formed in the future, will cooperate, together with the IWMF, to jointly address matters concerning WM at the European governmental level.

For more information: www.ewmnetwork.eu or www.waldenstrom.eu or contact Marlies Oom moom@planet.nl

THE IWMF IN FINLAND

BY VEIKKO HOIKKALA

Finland is the eastern-most of the Scandinavian countries, with vast Russia lying just to our east. Our geographical position between east and west has played a significant role in our history. While our land area is rather large, our population is only 5 million.

By unofficial estimate, there are 100-200 WM patients in Finland. This means that until recently this disease has been almost unknown, and among oncologists in our country there are only a few who have a deeper knowledge of WM. The level of medical care is high in Finland, but, as mentioned, the small number of patients means that the oncologists have limited experience in treatment. There are no clinical trials for WM in our country. Public medical care, on the other hand, is well organized and provides a high quality of treatment for every citizen. Normally Finns do not have private insurance; we pay these costs with our rather high income tax.

Support group activities for WM patients have been available here for approximately three years. While the initial action came from Finnish members of the IWMF, our national Cancer Association played the most important role in establishing a support group. WM patients initially contacted the Cancer Association to inquire about patient services. In response the Cancer Association began to collect the names of WM patients by contacting healthcare professionals. Naturally the Internet and cancer magazines were also used to develop contacts. Finally the very first support group meeting took place in Tampere, in October of 2006, with 15 participants. The Cancer Association did all the practical work— sending invitations, booking a good meeting place, taking care to invite good guest speakers, and so forth. For the first meeting the Association even paid the traveling costs for all participants. Since then we have had meetings in 2007 and 2008. The latest took place November 18 in Tampere, and the number of participants this time was already 31, mainly patients but some caregivers as well. We intend to continue to meet once a year. For 2009 we are planning to have a meeting over one weekend in a country hotel owned by the Cancer Association.

In addition, earlier this year we saw the first Finnish information booklet about WM printed. The booklet was circulated among our support group members and was also distributed to the cancer departments of big hospitals and to doctors in order that they pass it on to patients, especially to the newly diagnosed.

Furthermore, 2 members of our support group will be trained by the Association to be “official” contact and support persons for WM patients. The Association will cover all the costs of training, which takes place over two weekends.

All told, these support group activities have been very much welcomed by WM patients. Most of them had never before met any other person with this disease and now there is an opportunity to share experiences and encourage one another.



IWMF INTERNATIONAL TALK LISTS

BY ROY PARKER, VICE PRESIDENT FOR ADMINISTRATION

NEW TALK LIST FOR NORDIC COUNTRIES

At the recent Stockholm Patient Forum attendees from the Scandinavian and Nordic Countries expressed a desire to communicate with each other and asked the IWMF to organize and establish a new talk list for their region. The language of the talk list is English.

The new talk list is now in operation and can be accessed by following directions:

To subscribe:

To subscribe to IWMF-TALK-NORDIC, send e-mail to:

iwmf-talk-nordic-subscribe-request@lists.psu.edu

Type the word “subscribe” in the subject area and leave the message area blank. Then follow the instructions in the confirmation e-mail you will receive from lists.psu.edu.

Sending e-mails:

All messages that you wish to send to fellow list members should be addressed to:

iwmf-talk-nordic@lists.psu.edu

(be sure to use ‘dashes’ and ‘dots’ in the appropriate places)

Viewing archives and managing your account:

To visit the archives once you are registered with IWMF-TALK-Nordic:

<http://lists.psu.edu/archives/iwmf-talk-nordic.html>

TALK LIST FOR FRANCE

For information:

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

Contact: Nicole Bastin *nicbastin@yahoo.fr*

TALK LIST FOR THE UNITED KINGDOM

To subscribe:

Send e-mail to: *raltman@btinternet.com*

TALK LIST FOR GERMANY

The talk list in the German language for Waldenstrom patients and support givers is maintained and operated by the DLH (Deutsche Leukämia & Lymphoma-Hilfe), the German Leukemia & Lymphoma Patients’ Association, an organization similar to the IWMF.

For information:

[http://www.leukaemie-hilfe.de/foren.html?&tx_mmforum_pi1\[action\]=list_topic&tx_mmforum_pi1\[ffid\]=14](http://www.leukaemie-hilfe.de/foren.html?&tx_mmforum_pi1[action]=list_topic&tx_mmforum_pi1[ffid]=14)

Cut and paste the above link into the address bar of your internet browser and click the ‘enter’ key; or alternatively type the above link and click the ‘enter’ key and you will be taken to the site.

HOW TO JOIN THE IWMF-TALK

Here are two ways to join:

1. Send a blank e-mail to: *iwmf-talk-subscribe-request@lists.psu.edu*

Make sure to enter the word subscribe as your subject, and do not sign or put anything in the message area (make sure you do not have any signature information in there). Also, do not put a “period” after “edu” or it will reject. Once approved you can post by sending e-mail to *iwmf-talk@lists.psu.edu*

2. Contact Peter DeNardis at *pdenardis@comcast.net* and provide your full name



YOUR IRA AND THE EASE OF GIVING

BY DICK WEILAND

Aristotle reminded us several thousand years ago that the act of giving may itself be “easy” to do. What is tough to do is to give in spite of, or perhaps because of, current economic conditions.

You may be thinking that the financial marketplace in recent months has not been treating you as it has in the past, especially as we leave the 2008 calendar year behind and consider the tax implications of April 15. But this may be the best possible time to reflect on IWMF philanthropic investment opportunities for 2009.

Thanks to legislation enacted in October 2008, you may realize extra benefits by making a gift of your IRA withdrawal to the IWMF before the end of the year. The Tax Relief Act of 2008 permits an IRA owner 70 ½ or older to make a direct transfer to charity. The transfer may be up to \$100,000 in one year and this IRA rollover is relatively easy to do.

To qualify for benefits under the 2008 legislation:

- You must be 70 ½ or older.
- Your transfer of funds must meet Minimum Distribution Rules (MDR).
- You must transfer your funds directly from your IRA accounts to IWMF; it cannot pass through the hands of the donor.

The following also apply:

- You and your spouse may each transfer up to \$100,000 from individual IRA accounts.
- You must make an outright gift; in other words, life-income gifts such as charitable gift annuities or charitable remainder trusts do not qualify.
- Your state laws might affect gift benefits.

Check things out with your tax adviser, or give Dick Weiland a call at 507-645-2633. I can put you in touch with Dave Benson, IWMF’s special resource person for this kind of planning. There may be special tax benefits since you make the gift directly from your IRA rather than making a charitable gift from regular income.

So start planning for 2009. Use the Ben Rude Heritage Society Inquiry Form below, insert IRA after the “Other” line, and then submit in the enclosed envelope. See how easy it is so far?



THE BEN RUDE HERITAGE SOCIETY INQUIRY FORM

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

- | | | |
|-------------------------------------------------------------------|-------------------------------------------------------|-----------------------------------------|
| <input type="checkbox"/> A Bequest in my Will or making a Codicil | <input type="checkbox"/> A Charitable Remainder Trust | <input type="checkbox"/> A Gift Annuity |
| <input type="checkbox"/> A Life Estate or Real Estate Gift | <input type="checkbox"/> A Charitable Lead Trust | <input type="checkbox"/> Life Insurance |
| <input type="checkbox"/> Other _____ | | |

Signature

Name (please print)

Address/City/State/Zip

Telephone Number

E-mail Address



COOKS' HAPPY HOUR

BY PENNI WISNER AND NANCY LAMBERT

It is January now, that notorious season of good intentions and new beginnings. Maybe one of your resolutions was to eat a healthier diet. So why not start at breakfast? Jan Jones of Ottawa, Canada, sent along "Effie Taylor's Favorite Breakfast Oatmeal." Effie, age 89, a good cook, and a WMer, still drives and travels, and created her oatmeal recipe out of a concern for increasing the protein content of her diet.

Okay, oatmeal may not qualify as a "snack", but I had a weight trainer who ate oatmeal for supper and it's a great idea to have on hand for a midnight raid on the fridge. Place 2 tablespoons/20 grams raisins in a microwaveable, 2-cup measuring container. Add ¼ cup water. Let stand overnight to soften raisins. In the morning, add 2 tablespoons/12 grams wheat germ, 2 tablespoons/19 grams flax seed, ½ cup old-fashioned rolled oats, spices to taste such as cinnamon, ginger, cloves, nutmeg, and a pinch of salt. Add ¾ cup more water and stir well. Microwave on high for 2 minutes or more. Let stand 1 to 2 minutes before serving. Serves 1 to 2. The calorie count of Effie's oatmeal is about 350 for the whole batch, 170 per person, and 200 with 1/3 cup nonfat milk.

I know, I know, we promised not to count calories, didn't we? Recently, I have had my come-uppance around calorie counting; I was convinced, as a life-long food person, I knew it all. But then, this summer I grew curious to learn just how much I was eating. . . That curiosity led directly to a nearly 20-pound weight loss.

Effie's notes include storing the flax seed and wheat germ in the refrigerator or freezer and grinding the flax seed in small amounts to maintain its nutrient value. A coffee grinder dedicated to grinding spices works well. I find it easier to weigh than measure, so I included ingredient weights in Effie's recipe. Plus I make a large batch of the cereal, refrigerate leftovers, and reheat with milk and fruit. You can also make the cereal with steel-cut oats and whole flax seed, simply adding them to the raisins with all the water the night before. The flax seeds swell, soften, and add a great textural contrast. And you don't have to grind them. In the morning, you may need to add extra water to cook the cereal, but it needs only brief cooking.

For a Happy Hour snack you will want to make in batches to keep on hand, I hope you will try these Herbed Nuts I've adapted from a recipe in *The Casual Vineyard Table* by Carolyn Wente and Kimball Jones (Ten Speed Press 2003). I serve them on their own before dinner parties, eat them by the handful as a snack, and toss them into salad.

Start with 2 pounds of raw nuts. I buy 1-pound bags of walnut and pecan halves, and whole, unblanched almonds. Put them in a large bowl and preheat the oven to 375 degrees. Finely chop masses of fresh herbs including rosemary (less of this), thyme (more of this), sage, oregano, marjoram—basically, whatever you have in your garden or you can find at the store. It might seem like overkill, but I add as much as a cup of chopped herbs to 2 pounds nuts.

To the nuts, add the herbs, 1/3 cup each of maple syrup (preferably grade B which has a stronger flavor than A) and canola or safflower oil, and salt to taste. Toss very well and spread on a large, rimmed baking sheet. Toast in the oven, stirring and tossing every 5 minutes, until the nuts are browned and fragrant, about 15 minutes. Be careful as the pecans, if you use them, will burn before the others. Scrape the nuts into a clean bowl to cool and taste for salt, adding more if needed. Store in sealed containers for up to several weeks or freeze. Now, about all those crumbled bits of now toasted herbs that remain after the nuts have gone. They have amazing flavor and I often think I like them even better than the nuts. But I have not gone so far as to try a batch of toasted herbs. Instead, the leftover herbs make a delicious crumble to add to salads, risotto, or to top melted cheese sandwiches or perhaps a potato gratin.

Our motto: Eat Well to Stay Well

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



FROM IWMF-TALK

BY MITCH ORFUSS

IWMF-Talk was as active, exciting, and varied as ever in late summer and fall, with questions and comments across a wide range of concerns related to the care and management of WM. As usual, the IWMF-Talk postings proved to be an invaluable source of tips on managing irritating or worrisome conditions that may accompany WM, be they side effects of the disease itself or of a particular treatment. What follows is a representative sample from the topics that generated the largest volume of ongoing discussion.

Maintenance Rituxan

Arno Muller reminds us that no one knows who will and won't respond to Rituxan; that all drugs have side effects; that we don't know who may have a long remission from one treatment or short remissions from multiple treatments; or who will and won't show resistance to Rituxan over time. Arno also raised cost issues: specifically, he asks, "Who is paying for maintenance Rituxan?"

Bill Block was interested in what may be an evolving view of maintenance Rituxan—that it appears to be gaining in usage and favor. **Betty McPhee**, citing her own case, reminds us that the final verdict is not in on the merits of maintenance Rituxan.

More Discussion on the Rituxan Topic

Daryl writes that he has had two different sets of Rituxan infusions, both weekly x 8 weeks. The first delivered a 4-year remission, the second was earlier this year and so length of remission remains to be seen. **Renee Paley Bain** asks if less Rituxan could actually be more effective and suggests that this might be the case. Renee, like Daryl, had two sets of infusions: 4 in 2001 giving her a 3-year remission, and 2 in 2004 that have, remarkably, worked for 4 1/2 years and counting. **Charles Schaefer** reports that a 4x4 Rituxan treatment some years ago brought his IgM to below 1,000. His next treatment was 2 weekly infusions in late 2007 as his IgM was climbing beyond 2,000 and then 2 more in April 2008, by which time his IgM had risen to 2,900. For Charles a reduced dosage of Rituxan proved unsuccessful.

Ron Draftz reminds us that all drugs take their toll and the more the drug, the greater the potential toll. Ron brought two points to our attention: Dr. Abonour's CHOP investigations showed that those who were treated aggressively lived shorter lives than those treated less aggressively; and Dr. Gertz's inference that in order to live a normal lifestyle it is not necessary to treat heavily in search of a complete remission. A heavier, more intense regimen does not necessarily increase the time span to next treatment, so we should not fault the patient who prefers one Rituxan regimen over another.

IWMF-Talk and Age

This issue turned out to generate just a short discussion string but is worth mentioning. The question was asked whether

we would benefit from "list segmentation" by having two versions of IWMF-Talk—one targeted to the interests of traditional "older" posters, and another for the increasingly large number of "younger" posters, who frequently seem to have more aggressive disease. Consensus seemed quickly to converge around continuing the way it's done now, with one IWMF-Talk for all interested participants irrespective of age.

Sinusitis

Bob Kalish writes that he uses non-iodized salt and warm water in a Nielmed bottle to combat his sinusitis. **Shirley Shepard** successfully used sinus irrigation (Nielmeds in particular) a few years ago but had to stop when it suddenly and unaccountably caused her excruciating head pain. **Steve Kirsch** offers that he has had a tough time with sinusitis since diagnosis. Steve's doctors explained that the bug is deep in the sinuses, where it is hard to get to and culture. So the doctors resorted to trying their favorite antibiotics like Levaquin and Augmentin. Steve warns not to expect a quick fix, and in fact he is still uncertain of what finally alleviated his symptoms. Others, including **Mike Hilt**, **Jeffrey Minot**, and **Lon Tanner**, write about persistent, hacking coughs with phlegm. **Jane Schlosberg** keeps her chronic sinusitis at bay simply by drinking plenty of fluids. **Ken Warner** recommends saline spray to break up the mucus and ponaris oil to moisturize.

Rosacea

Peter DeNardis says that he suffered a mild case for years before diagnosis that required no treatment, but it flared up after fludarabine/Cytosan/Rituxan combo treatment three years ago. Pete's dermatologist could not confirm that his rosacea was caused by WM. **Lon Tanner** has had this condition for thirty years and also suffered a flare after treatment with Rituxan. Like Pete's, Lon's dermatologist could not assert a connection between rosacea and WM. **Ron Draftz** also developed rosacea after fludarabine x 2, and his dermatologist believes WM was causal. **Vicki Hoorman's** mother-in-law is being treated for rosacea following her fourth treatment with cladribine and Rituxan. **Bea Hollander** also got rosacea after diagnosis in 2005 and has had no treatment. Bea found that her rosacea cleared after she stopped eating chocolate (so for all us chocophiles, let's hope this is true only for poor Bea!).

Itching

Kathryn Kramer's husband began itching on his arms and shoulders after treatment with chemo and prednisone. Topical creams like fluocinonide gel did not help. **Arlene Carsten** suggests 25mg hydroxyzine. **Neil Massoth** offered that prescription Lidoderm patches work well for him. Your IWMF-Talk correspondent frequently awakens in the middle of the night with intense itching on his ankles and lower legs. My doctor recommended 1% hydrocortisone cream.



SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

As Dr. Steven Treon of Dana-Farber Cancer Institute travels to speak to our support groups, he will be inviting us all to the the Third International Patient and Physician Summit on Waldenstrom's Macroglobulinemia and Tenth Anniversary Gala of the Bing Center for WM. The event will be held May 1-3, 2009, in Boston, just a few days post the IWMF patient education forum in Memphis. Log onto www.wmprogram.com for registration. You might also want to check out Dr. Treon's new web site: www.stevenptreon.com Questions? Contact Christopher Patterson at christopher_patterson@dfci.harvard.edu.

Please note: contact information for all support groups is printed on pages 22 & 23.

IWMF CHAPTERS--USA

CALIFORNIA

Los Angeles, Orange County

Dr. Stephen Forman, Chief of Hematology and Head of the Bone Marrow Transplant Unit at the City of Hope Hospital, was our guest speaker in November. Dr. Forman broke his presentation into two parts. In the first, he presented a wide array of general information, including defining Waldenstrom's, how it develops, and similarities between WM and other B-cell disorders. His approach gave the 55 attendees a common understanding of WM. In the latter half, Dr. Forman responded to questions from the floor. He responded to specific issues while placing them in a wider context. Some areas covered included: the importance of recognizing that an individual patient may respond differently to the same treatment, at the same or different dosages, as well as with variations in treatment sequencing; information about clinical trials of several new drugs and initial results; how plasmapheresis works and when to use it with WM patients; and much more. For more information, see Dr. Forman's web site: www.cityofhope.org/directory/people/forman-stephen.

Sacramento and Bay Area

The Bay Area was indeed fortunate that the Lymphoma Research Foundation held their annual patient education conference in San Francisco this fall. Even better, Dr. Treon flew in for the Waldenstrom's breakout session. The group welcomed him with a large turnout and many eager questions. It was perhaps the best presentation any had heard yet from Dr. Treon, and all left uplifted and hopeful for more good news as his research progresses. The first meeting of 2009 will be Sunday, 1 March.

COLORADO & WYOMING

Megan Andersen, nurse practitioner for the Rocky Mt. Cancer Center and Dr. Jeffrey Matous, was the guest speaker for the group's early November meeting. She works with about 15 local Waldenstrom's patients. She reviewed the biology of WM, the standard tests, what each showed, typical issues and

how to test for each, and some treatments. She managed to make all the technical information easy to understand and was open to lots of questions. An excellent crowd of about 30 people, including five new WM patients and a college student observer, turned out. The group partnered with Lynn Callaway of the Denver Leukemia & Lymphoma Society (LLS). During the very lively interactive meeting, group members reviewed recent WM experiences, new patients asked many questions, and issues that were previously unclear were clarified. It was a packed 2 hours!

Dr. Steven Treon is expected for the next meeting in Denver in February (exact date to be determined).

FLORIDA

Tampa

The next meeting of the Tampa area support group will be on Saturday, February 28, at 1:00 pm in Spring Hill, FL. If you plan to attend, please e-mail group leader **Linda Rothenberg**.

ILLINOIS

The Chicago area support group held their last meeting of 2008 in October. After having great formal presentations from Dr. Morie Gertz of Mayo Clinic and Dr. Treon earlier this year, a fine group of 32 patients (including eight first-time attendees), families, and friends had a wonderful time sharing stories and discussing each other's concerns in a very informal but productive atmosphere. The first meeting of 2009 will most likely be in either February or May.

MICHIGAN

Everyone at the October meeting in Lansing had an opportunity to share their experiences of Waldenstrom's and the treatment options they had found most effective. The group chose to watch a DVD from an IWMF patient education forum that discussed new treatment possibilities and the results of clinical trials. The next meeting is planned for late April or May.

EASTERN OHIO, WESTERN PENNSYLVANIA & WEST VIRGINIA

Despite the wintry November weather and scheduled Steelers game, ten support group members gathered at the home of **Marcia and Glenn Klepac** in Pittsburgh to focus on the whole person (mind, body, spirit) approach to health. Dr. Betsy O'Neil, Medical Director of the Integrative Medicine Center at Allegheny General Hospital, presented an overview of integrative medicine. She addressed lifestyle factors and appropriate alternative therapies that can be incorporated into conventional care for people living with cancer. Dr. O'Neil's personable approach encouraged an active discussion. During the pot-luck dinner members shared their Waldenstrom's

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stories including treatment, experiences with the health care system, and lifestyle issues. A winter meeting will be planned, weather permitting.

NEW YORK

Albany

Georgia Decker, the immediate past-president of the Oncology Nursing Society and respected nutritionist, spoke to the eastern NY/western NE support group at the fall meeting. Her topic was "Complementary and Alternative Medical Therapies." Much to the group's delight, she answered many, many general and very specific questions. Other subjects of discussion included the April patient education forum in TN and the patient database. Tentative plans were made for 2009 programs: January 24 (DVD from 2008 Forum), March 21 annual restaurant gathering, May 21 LLS-sponsored luncheon and speaker, August annual picnic, September 26, and November 14.

PENNSYLVANIA

Central and Southeast PA and Northern MD

The group discovered their petty cash on hand outweighed current needs and so it was decided to send \$100 in honor of Jim Berg to the IWMF research fund. Also at the fall meeting **Kate and Don Wolgemuth** and **Rita Ziats** provided delicious refreshments while **Roberta Neal** gave quick overviews of the talks she attended at the Los Angeles IWMF patient education forum. She also discussed her testing and treatment in Little Rock for a study being done there. Many questions were asked and fielded, and this provided for a lively discussion among all the group as they shared their most recent Waldenstrom's experiences and treatments. The next meeting will be on Sunday, February 15, 2:00 pm at the Messiah Village Board Room.

Philadelphia

The Philadelphia area support group has been meeting every other month in a comfortable room at Bryn Mawr Hospital for over eight years now. Fifteen to twenty people attend. Some members date their participation from the inception of the group, some have passed away, and there are always newly diagnosed WMers in attendance. The group hosts occasional speakers, perhaps a doctor, nutritionist, or attorney, but mostly the group meets to share their Waldenstrom's stories and support each other. Someone always brings a snack and there is always time for informal chitchat. The Pindzola's little dog, Heidi, loves to come for the handouts and the attention. **Karen Pindzola** has recently been sending out minutes of the meetings to let people know what was discussed, and this seems to be appreciated.

SOUTH CAROLINA

On Saturday, February 14, bring your Valentine for an informal lunch meeting with other Waldenstrom's patients and caregivers to exchange information about our respective experiences with WM and to discuss the latest progress

and activities in WM research and treatments. The South Carolina support group will meet in Aiken, South Carolina, noon to 2:30. Both newly diagnosed and veteran WMers are encouraged to attend. For details, call or e-mail support group coordinators **John and Paula Austin**.

TEXAS

Dallas & Northern Texas

The November meeting of the group was held in conjunction with the Workshop on Complementary Methods for Health and Relaxation which was given by Baylor University Medical Center in Dallas. The next meeting is scheduled for January 17 at 10:30 am, Baylor University Medical Center, Truett Hospital, Lower Level, Room 7. A speaker from the Leukemia and Lymphoma Society will be making a presentation on the programs provided by that organization. We will have lunch during the meeting. Lunch is available from the Baylor Cafeteria, which is adjacent to the meeting room.

VIRGINIA

On a lovely, sunny day in October, the central Virginia group met to share with each other their progress—or lack of progress—in their personal journeys through doctors' offices, treatments, and times of watch-and-wait. They all gathered round to support a newly diagnosed patient and worried together over friends who were unwell at the time and unable to join in the fellowship.



First row, L to R: George King, Kathy James, Phyllis and Jim Swint, kneeling Ms. Muller. Second row: Helen Garrett, Brent James, Ursula Muller, Greg Robertson, Nancy Stupi. Third row: Howard Garrett, Bob Zehner, Arno Muller and Hank Stupi



Out-going Northwest Support Group founder Peg Horton receives plaque from the new group leader Malcolm Brewer.

WASHINGTON

Leadership of the group officially passed from **Peggy Horton** to **Malcom Brewer** in October when the members met to give Peggy a rousing thank you and a plaque to honor her for her effective and gracious leadership. They also gave

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Malcolm a warm welcome as the new leader and offered each other their ongoing mutual support.

WASHINGTON D.C./METROPOLITAN AREA

In November the group lost a valued member with the death of **Morris Gordon**.

Dr. Treon gave his exciting presentation to the group in December. Meetings in 2009 are tentatively scheduled for February and May.

IWMF CHAPTERS—INTERNATIONAL

CANADA

Toronto

The “Scramble Fore Waldenstrom’s Golf Tournament”, the first of two fall fundraising events, was held on September 13 in memory of **Brenda Robinson** who lost her courageous battle with Waldenstrom’s on July 17, 2008. With this annual event, her son Brett has raised over \$22,000 in the past five years in support of his mother. The group extends its sincere sympathy to Brett and his family and a huge thank you for all the support and awareness given to the Waldenstrom’s Macroglobulinemia Foundation.

The second event was the Waldenstrom’s Macroglobulinemia Foundation of Canada Fundraising Gala held on Saturday, September 27, at the Bata Shoe Museum in Toronto. The evening was a resounding success with 126 guests enjoying the evening reception. The event surpassed its goal of \$20,000 by raising \$32,095. The children of group leader **Arlene Hinchcliffe**, Rebecca, Christopher, and James, organized the fundraiser in memory of their grandfather, **Nick Carrick**, who lost his battle with Waldenstrom’s in 1998.

Arlene is working to reschedule Dr. Treon’s visit for the spring.

FINLAND

Taina Lukkaroinen reported that the third annual meeting of the Finnish National WM group attracted 30 people, patients and caregivers among them, to the Hotel Scandic in Tampere City when it met in November. This shows a definite increase from previous years and there is a reason for this: Finnish patient activist **Veikko Hoikkala** has put his considerable management experience to good use in creating a contact network for Finnish WM patients, modeled in part on the IWMF. Hoikkala himself also praises the ready cooperation of the national Finnish Cancer Association, Suomen syöpäpotilaat ry. This umbrella organization is supported by government funding and by a well-organized program of fund-raising. It provides an infrastructure and funding for patient activities.

Once the update of this national organization’s web site is complete early in 2009, its entry page will include links to cancer patient groups, including the Finnish WM group. This news was brought to the WM group by **Riikka Koskinen**,

the parent organization’s research psychologist, who was this year’s guest speaker. While previous guest speakers have provided medical and scientific information, on this occasion the theme was coping with cancer and the uncertainties of WM. Riikka Koskinen also informed the group that training is now available for support volunteers, and there was immediate interest among the attendees.

In Finland new WM patients get information from their physicians, who often direct their patients to the national cancer patients’ website. Now patients may also receive information in booklet form from their doctor, since one of the accomplishments of the WM group in 2008 was to publish and print a booklet on WM in the Finnish language. The booklet is also available for downloading on the cancer patients’ web site. Patients are encouraged to copy the booklet free of charge and to leave copies at the offices and waiting rooms of their health professionals. The medical consultant on the booklet was Tampere haematologist Dr. Petri Oivanen.

In October Dr. Oivanen was also among the Finnish specialists attending the Fifth International Workshop on WM in Stockholm. Since several of the patients at the November support group meeting had also attended the IWMF Patient Forum in Stockholm, news of international research was discussed at the meeting. The program of the Fifth International Workshop on WM was circulated.

One interesting feature of these Finnish patient get-togethers is the round of introductions where each patient gives the year of diagnosis and any treatments undertaken. This sparks conversation and helps new patients see the advantages of being well informed about their illness and current developments in treatments. It also gets the new patients quickly socialized into the group as it is so wonderful to find other people who actually know what Waldenström’s disease is! An e-mail list was once again updated since continuing conversations result from contacts at our meetings.

Veikko Hoikkala’s suggestion of an intensive, two-day WM seminar in 2009 at a Finnish cancer patients’ facility in southeast Finland was greeted with enthusiasm. The Finnish Waldenström’s patients have good things to look forward to!



Veikko Hoikkala and Riikka Koskinen at a meeting of the Finnish WM group in November.



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Jeff & Julie Kuhn

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Norma Bishop & Ted Raspin

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Laura Applebaum & Patrick Hamilton
Zeev & Marsha Greenberg
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In honor of Mickey Zimmerman:
The Fuchs Family



MEDICAL NEWS ROUNDUP

BY SUE HERMS

Transplant Mortality Study in the United Kingdom Analyzes Lymphoplasmacytic Lymphoma Patients – The Department of Haematology at Leeds Teaching Hospitals in the United Kingdom released results of a retrospective analysis of lymphoplasmacytic lymphoma patients who had either autologous or allogeneic transplants from 1984-2003. Nine autologous transplant patients had a transplant-related mortality rate at 12 months of 0%. Median follow-up of 44 months showed a 4 year disease free survival of 43% and overall survival of 73%. Nine allogeneic transplant patients had a transplant-related mortality rate of 44%. Median follow-up of 32 months showed a 4 year disease free survival of 44% and overall survival of 56%.

Mini-Allo Transplants in Follicular Lymphoma – A study of 47 follicular lymphoma patients at M.D. Anderson Cancer Center in Texas provided some of the first long-term data on the effectiveness and toxicity of nonmyeloablative allogeneic transplants. The reduced intensity (also called mini-allo) transplants in this study used less toxic doses of chemotherapy (fludarabine/cyclophosphamide/rituximab) for the conditioning regimen. The principle behind mini-allo transplants relies on graft vs. lymphoma effect to induce the transplanted cells to attack the patient's lymphoma cells and produce a response, with less risk of transplant-related mortality. Follow-up ranged from 19-94 months. The investigators estimated a survival rate of 85% and a progression-free survival rate of 83%. However, it was noted that the patients in this particular study were relatively young, had not previously been treated heavily for their disease, and had responded to previous therapies.

Comparison of Infection Rates in Mini-Allo and Traditional Allo Transplants – Meanwhile, a study by the Division of Hematology, Oncology and Transplantation at the University of Minnesota compared mini-allo transplants to the more traditional allogeneic transplants. They specifically evaluated the impact of these two transplant types on the development of post-transplant infections. Seventy six relapsed lymphoma patients received the mini-allo procedure, while 65 received the traditional allo procedure. Before engraftment by the transplanted stem cells, the mini-allo set had a 53% lower rate of bacterial infection, whereas after engraftment, the rate of bacterial infection was similar in the two groups. Early invasive fungal and viral infections were also less frequent in mini-allo patients. The researchers concluded that while early infections were substantially fewer in the mini-allo group, the frequency of later infections was approximately similar between the two groups. This was primarily attributed to delayed immune system recovery with both types of transplants.

Drug Given to Mini-Allo Transplant Patients Improves Overall Survival – A study by the Dana-Farber Cancer Institute and the Department of Medicine at Cambridge Hospital in Massachusetts suggested that mini-allo patients who received sirolimus to help prevent graft vs. host disease also showed improved overall survival by reducing the rate of their disease progression. Sirolimus is also known as rapamycin and is used to prevent rejection in organ transplantation. It is marketed under the trade name Rapamune by Wyeth. Sirolimus has also shown activity against certain lymphoma subtypes. Of the 190 patients in this study, the

overall survival rate for sirolimus-treated patients was 66% vs. 38% for non-sirolimus-treated patients.

Agencies Crack Down on Bogus Cancer Cures – The Federal Trade Commission (FTC) in the U.S. is cracking down on companies and individuals who deceptively advertise that their products cure or treat cancer while offering either no proof or quoting false clinical evidence in support of their claims. The products include essiac teas and other herbal mixtures, laetrile, black salve, and mushroom extracts. As part of this crackdown, the U.S. Food and Drug Administration sent warning letters to 23 companies in the U.S. and two individuals outside the U.S. The Competition Bureau in Canada also sent similar warning letters to companies in Canada. Those in the U.S. seeking additional information on false cancer cures can go to www.ftc.gov/opa/2008/09/boguscures.shtm.

New Technique for Identifying Proteins in Tumor Cells – Researchers at Cambridge Research & Instrumentation Inc. in Massachusetts have demonstrated a new instrument that makes it possible to detect and quantify multiple different and clinically important proteins in a single tumor sample using conventional staining. Currently, pathologists usually need a separate tissue slice for each protein they want to examine. The new process is fast and automated—up to 180 tumors from different patients can be analyzed in an hour by computer. The technology is designed to be used by pathologists to reveal new data that can help researchers develop targeted therapies and to enable physicians to personalize treatments for individual patients.

Vaccination of NHL patients with Dendritic Cells – A study from the C. Gandini Bone Marrow Transplantation Unit in Milan, Italy, reported the results of vaccination of 18 relapsed non-Hodgkin lymphoma patients with dendritic cells loaded with their killed tumor cells. Dendritic cells are specialized cells of the immune system that recognize foreign antigens and present the antigens to B- and T-cells to initiate an immune response. The vaccination induced both B- and T-cell activity against the tumor cells, with 6 patients achieving either a partial or a complete response, 8 patients with stable disease, and 4 patients with progressive disease.

Genmab to Begin Trials with Ofatumumab in CLL and Follicular Lymphoma – Genmab has announced plans to begin four studies of ofatumumab, a human anti-CD20 antibody, in chronic lymphocytic leukemia and follicular lymphoma. In this Japanese study, patients initially will be randomized to receive ofatumumab in combination with chlorambucil, compared to chlorambucil alone. Those receiving the combination therapy will receive one 300 mg infusion of ofatumumab, one 1000 mg infusion a week later, and 11 monthly 1000 mg infusions thereafter. They will be evaluated for disease status for a total of 5 years. Additional studies will explore ofatumumab as a sole treatment, as retreatment therapy, and as maintenance therapy.

Tobacco Plants Used to Produce NHL Vaccine – Bayer AG recently announced the opening of a production facility that will use tobacco plants to manufacture biopharmaceutical vaccines for cancer. The tobacco plants are being used to produce proteins that target tumor cells in non-Hodgkin's lymphoma. The technology exploits the tobacco plant's vulnerability to a virus that only attacks the plant. The

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researchers altered the virus, adding specific antibody-producing genes from a patient's cancer cells. Then they infected the tobacco plants with the gene-carrying virus, turning the plants into a factory for manufacturing the antibodies. The plant-based approach is very fast, yielding vaccine within a week. A human clinical trial resulted in immune responses in more than 70% of the patients who were given the subcutaneously administered vaccine.

Mega Dosing of Vitamin C May Reduce Effectiveness of Anti-Cancer Drugs – Experiments on cell cultures and mouse models suggest that high amounts of Vitamin C from supplements may actually reduce the effect of anti-cancer drugs, according to a study at Memorial Sloan-Kettering Cancer Center in New York. The study tested a wide range of chemotherapy drugs, some that rely on the free radical method and some that work by other means, on leukemia and lymphoma cells. In cell cultures, between 30-70 percent fewer Vitamin C pre-treated cancer cells were killed, depending on the drug. What the researchers found was that Vitamin C was revitalizing the cells' mitochondria, which are the energy-producing powerhouses of cells. By restoring the mitochondria in the cancer cell, the Vitamin C was actually helping the cell to live longer. Vitamin C is good for normal tissue because it protects the mitochondria and extends cell life, but that is not the desired outcome for tumor cells. The study did say that cancer patients should stick to a healthy diet that includes Vitamin C but not dose themselves with large amounts of over-the-counter Vitamin C supplements.

Genentech Begins Clinical Study of Apoptotic Antibody Called Apomab – Genentech has initiated a Phase 2 clinical study of its fully human antibody, apomab, used to treat non-Hodgkin's lymphoma. Apomab binds to and activates an important receptor, called proapoptotic death receptor 5 (PARA), which is found on the surface of various types of cancer cells. This binding appears to directly induce cell apoptosis (death).

Another Apoptotic Antibody in Phase 2 Study for Multiple Myeloma – Another fully human apoptotic antibody, called mapatumumab, is in Phase 2 clinical development as a single agent and in combination with chemotherapies such as bortezomib (Velcade) for multiple myeloma. This particular antibody targets TRAIL-R1, which is a tumor necrosis factor involved in apoptosis regulation. The trial is being sponsored by Human Genome Sciences.

Biovest Asking for Accelerated Approval of Biovax for Follicular Lymphoma – Biovest International updated clinical reporting of its anti-cancer vaccine, Biovax ID, in Phase 3 trials for treatment of follicular lymphoma. Based on encouraging trial results, Biovax now believes that it would be unethical to withhold Biovax ID from the control patients in the study and is asking for accelerated approval from the FDA. Biovest also has a distribution agreement to supply Biovax ID in France, Germany, Italy, Greece, Spain and the UK, with sales expected to begin in the first quarter of 2009. This distribution is being allowed to patients with CLL, MM, and NHL under a special program, pending formal approval of the drug by the European Medicines Agency.

Rituximab Plus Epratuzumab Evaluated for NHL – A multicenter trial involving Weill Cornell Medical College and New York Presbyterian Hospital evaluated rituximab plus epratuzumab (anti-CD22) in patients with relapsed or refractory indolent non-Hodgkin's lymphoma. Twenty two of 41 patients (54%) had a response to this treatment, with some responses that continued for more than four years.

Geron Corporation Testing Telomerase Inhibitor in Multiple Myeloma – Geron Corporation has enrolled the first multiple myeloma patient in a Phase 1 clinical trial of its telomerase inhibitor drug GRN163L in combination with other treatments. The drug is being administered intravenously in combination with bortezomib (Velcade) with or without dexamethasone. A Phase 1 trial of GRN163L alone was previously initiated. Telomerase is an enzyme expressed in a wide range of malignant tumors and is essential for the indefinite capacity of tumor cells to grow.

NHL Decreasing in Developed Countries – The upward trend in the incidence and mortality of non-Hodgkin's lymphoma (NHL) seen during the latter part of the 20th century has now started to level off or decline in Europe and other developed countries. In the European Union, NHL mortality declined from 4.3 per 100,000 to 4.1 in men and from 2.7 per 100,000 to 2.5 in women. Similar reductions were observed for the U.S. and Japan. In most countries studied, NHL incidence reached a peak between 1995 to 1999 and then began to level off or decline. Advances in treatment for some types of lymphoma may have had some role in these declines. The findings were published in the October 15 issue of the International Journal of Cancer.

Use of Revlimid for Multiple Myeloma at Risk in Great Britain – The National Institute of Health and Clinical Excellence in Great Britain has issued draft guidelines which say that the drug lenalidomide (Revlimid) is not cost effective for the treatment of multiple myeloma and dispute the estimate of its effectiveness in extending life expectancy. Charities are now calling for drug companies and the Department of Health to broker a deal so that Revlimid can be used—a deal similar to that currently in place for Velcade. They are hoping that Celgene, the maker of Revlimid, will agree to a discount or offer one or two free courses of treatment in order to determine which patients will respond.

Treanda Approved by FDA for NHL – The FDA has approved Cephalon's injectable Treanda for treatment of those patients with recurring NHL whose cancer is spreading despite treatment with Rituxan. The approval was based on a 100-patient study in which three out of four patients saw their cancer diminish or disappear after taking the drug. The FDA previously approved Treanda in March for treatment of chronic lymphocytic leukemia (CLL).

Orphan Drug Status Declared for CD74 Antibody – Immunomedics, Inc. announced that the FDA has granted orphan drug designation to milatuzumab for the treatment of multiple myeloma. This antibody targets the overexpression of CD74 in CLL, MM, and NHL. The company has initiated Phase 1-2 studies to evaluate its therapeutic potential.

Genome of Cancer Patient Decoded – Scientists at Washington University School of Medicine in St. Louis and the University of Washington in Seattle have decoded the complete DNA of a cancer patient and identified 10 gene mutations that appeared crucial to the development of the woman's acute myeloid leukemia (AML). The sequencing technique was described in the journal Nature and could be applied to other cancers. The researchers took two samples from the woman, one from healthy skin cells and the other from bone marrow tissue with cancerous cells. By comparing the two samples, they were able to discover which mutations were involved in her disease. Of the ten documented mutations only two were previously known to be linked to AML.

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More Evidence for Effectiveness of Radioimmunotherapy for Indolent B-Cell Lymphomas – Evidence is accumulating for the important role that radioimmunotherapy (RIT) can play in the treatment of B-cell lymphomas, particularly indolent ones. Studies by the Fred Hutchinson Cancer Research Center and the University of Washington have demonstrated that upfront RIT, administered either alone or with chemotherapy to previously untreated patients produces overall response rates of 90-100%, complete response rates of 60-95%, and durable remissions. RIT includes drugs such as Bexxar and Zevalin. Despite this evidence, RIT remains under-utilized in the U.S. and other countries. The reasons may include logistic issues involved in transfer of care from the hematologist/oncologist to the nuclear medicine physician, concerns about Medicare reimbursement, and concerns about delayed effects

such as marrow damage and secondary malignancies.

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This issue of the Medical News Roundup does not include information presented at the recent Fifth International Workshop on Waldenström's Macroglobulinemia in Stockholm. A separate article by Dr. Guy Sherwood covering this important information will appear in the spring 2009 Torch. Dr. Sherwood's complete summary of the program of papers and posters presented at IWWW5 will be available on the IWMF website early in 2009.

ADMINISTRATIVE MATTERS

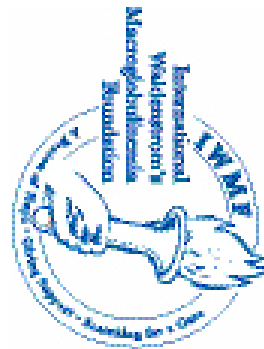
BY ROY PARKER

Recently **Bill Beazley**, whose wife, IWMF member **Betsy Beazley**, is a volunteer on the Lifeline for Spanish translation, generously sent us a wireless keyboard, laser printer, and a spare cartridge. We appreciate his donation of such useful office equipment. Everyone can be certain that the office put this equipment to good use as soon as it was received. Thanks, Bill, for your contribution to the IWMF.

The DVDs from the 2008 IWMF Ed Forum in Los Angeles are currently in duplication and the IWMF office expects to ship the first week of January. This should come as good news for all those waiting to see these fine presentations!

If you haven't ordered DVD's, you can do so by following the instructions at: <http://www.iwmf.com/Publications.htm>.

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