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DOCTOR ON CALL: MELETIOS A. DIMOPOULOS, M.D. TREATMENT CHOICES FOR NEWLY DIAGNOSED SYMPTOMATIC PATIENTS WITH WALDENSTRÖM'S MACROGLOBULINEMIA



Dr. Meletios Dimopoulos at the podium of the Third International Patient & Physician Summit on WM, May 2009 in Boston. Photo courtesy of the Bing Center, Dana-Farber Cancer Institute.

IWMF Scientific Advisory Committee Member Dr. Meletios Dimopoulos writes for the Torch a detailed outline of the treatment options available to the Waldenström's macroglobulinemia patient who is symptomatic at the time of diagnosis. Dr. Dimopoulos' overview concludes with a summary of the consensus panel recommendations that were formulated following the Fifth International Workshop on Waldenström's Macroglobulinemia in Stockholm, October 2008.

Waldenström's macroglobulinemia (WM) is a disorder of the B-lymphocytes characterized by infiltration of the bone marrow by lymphoplasmacytic cells that secrete a monoclonal IgM immunoglobulin. Symptoms and signs of the disease are the result of reduced hemopoiesis due to infiltration of the bone marrow, organomegaly (such as lymphadenopathy or splenomegaly) due to infiltration of these organs by monoclonal lymphoplasmatic cells, or a result of the monoclonal IgM and its properties, such as neuropathy, hyperviscosity, cold-agglutinin related anemia, cryoglobulinemia.

Many patients who are diagnosed with WM do not require immediate treatment. The decision to initiate therapy is based on specific criteria that include the presence of at least one of the following: disease related anemia with a hemoglobin level less than 10 g/L, platelet count less than $100 \times 10^9/L$, bulky adenopathy or organomegaly, symptomatic hyperviscosity, severe neuropathy, amyloidosis, cryoglobulinemia, cold-agglutinin disease, or evidence of disease transformation to a more aggressive lymphoma. Serum monoclonal protein levels alone are not an indication for initiation of therapy; however, rapidly increasing IgM may be an indication for treatment.

Asymptomatic patients should be observed without treatment. Some asymptomatic patients with low levels of b2-microglobulin and a hemoglobin level 12 g/L may have a very indolent course with a long lasting period not requiring therapy.

When, however, the criteria for treatment initiation are met, several factors associated with the patient and the characteristics of the disease should be taken into account in order to make the appropriate treatment choices. Over the years since the Second International Workshop on Waldenström's Macroglobulinemia (Athens 2002) treatment options have been increased because several novel agents have been added to the therapeutic armamentarium.

Conventional chemotherapy is an option for some patients. Rituximab has been used for the treatment of WM for approximately a decade. Thalidomide and bortezomib (Velcade) have also been used increasingly over the last years. Factors that should be evaluated before the selection

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Treatment Choices, cont. from page 1

of treatment include the patient's age and functional status, candidacy for autologous stem cell transplantation, disease related complications, aggressiveness of the disease, and probability of short-term and long-term toxicities.

Rituximab (mabthera, Rituxan) is a chimeric human/mouse antibody directed against the CD20 antigen that is almost always present on the surface of WM cells. Rituximab is not associated with complications from chemotherapy because it does not cause neutropenia, thrombocytopenia, or anemia and is not stem cell toxic. Thus, it can be combined with other drugs without increasing toxicity. As a single agent and at a standard schedule, rituximab induces responses in about one third of previously untreated patients. A more extended schedule of rituximab (4 weekly infusions followed by another round of 4 weekly infusions 12 weeks later) may be associated with higher response rates and longer duration of response. Maintenance treatment with rituximab has not been explored in the context of clinical trials. Rituximab may also be used for the treatment of IgM-related neuropathies when symptomatic treatment is not sufficient, and rituximab is an effective treatment for cold-agglutinin anemia. Responses after rituximab may be slow, and very high levels of baseline serum monoclonal protein may be associated with lower response to single agent rituximab. Following initiation of rituximab, a transient increase in serum IgM levels (IgM flare) has been reported in up to 50% of patients 3 to 4 weeks after initiation of therapy. This flare, which may persist for up to 4 months, does not indicate treatment failure but may necessitate plasmapheresis to reduce hyperviscosity in some patients with high IgM levels.

Combinations of rituximab with chemotherapy, such as cyclophosphamide, nucleoside analogs, and dexamethasone, have shown synergistic activity. Combination of rituximab with cyclophosphamide-based therapy such as R-CHOP (rituximab, cyclophosphamide, doxorubicin, vincristine and prednisone) or the less toxic DRC (dexamethasone, rituximab and cyclophosphamide) are effective regimens for symptomatic patients. DRC is a relatively non-toxic regimen that was associated with an objective response in 83% of patients, including 7% who achieved a complete response and 67% who achieved a partial response, while 90% of the patients are progression-free at 2 years. This regimen is not associated with significant hematologic toxicity and does not always cause hair loss.

Treatment Choices, cont. on page 3



The IWMF *Torch* is a publication of:

International Waldenström's Macroglobulinemia Foundation

3932D Swift Road • Sarasota, FL 34231-6541

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

E-mail: info@iwmf.com • Website: www.iwmf.com

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

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HAVE YOUR SAY

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

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

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

In another study, rituximab added to combination chemotherapy (CHOP) was compared to CHOP alone and resulted in significantly more responses (91% vs 60%) and a significantly longer time to disease relapse. R-CHOP may be preferable when rapid control of the disease is needed.

Nucleoside analogs, such as fludarabine, cladribine and pentostatin, are active drugs, both for newly diagnosed as well as for patients with relapsing disease. Rituximab can be combined with nucleoside analogs resulting in high response rates. The combination of rituximab with fludarabine and cyclophosphamide (FCR) is very effective although toxic, mainly due to hematologic toxicity and prolonged immunosuppression. As an upfront treatment, response rates may exceed 90%. Such regimens may be particularly useful when rapid disease control is required because of hyperviscosity, bulky lymphadenopathy or splenomegaly, symptomatic cryoglobulinemia etc. However, nucleoside analogs are stem cell toxic and may not be an appropriate first choice for patients who are candidates for autologous stem cell transplantation. There may be an increased incidence of transformation of WM to a more aggressive lymphoma and development of myelodysplastic syndromes or secondary acute myelogenous leukemia in WM patients treated with nucleoside analogue-containing therapy.

Bortezomib (Velcade) is a reversible proteasome inhibitor: it blocks the function of intracellular “disposal” machinery, thus altering the function of many different signaling pathways, and increases the intracellular workload, finally leading cancer cells to apoptosis. Bortezomib as a single agent showed significant activity when initially evaluated in patients who had relapsed or refractory disease. As a single agent, bortezomib also had significant activity in newly diagnosed patients. As an upfront treatment, bortezomib has been combined with dexamethasone and rituximab, resulting in rapid (median 1.5 months) responses in 91% of patients, including complete response in 9% and partial response in 61%. Bortezomib is associated with the development of peripheral neuropathy, resulting in paresthesias and numbness, mainly of the lower limbs. However, this is a reversible complication, and most patients will improve after dose reduction or when they discontinue treatment. Bortezomib can reduce the levels of serum IgM rapidly, and thus it is useful for patients who present with symptoms and signs of hyperviscosity and who require immediate reduction of IgM. Further studies are needed to fully establish the safety and activity of bortezomib-based regimens in WM. A study by the European Myeloma Network using bortezomib on a weekly basis with rituximab is ongoing.

Thalidomide and lenalidomide are immunomodulatory drugs (IMiDs) with a wide spectrum of activity: they have antiangiogenic properties, they modulate immune response, and they may have direct anticancer activity. Thalidomide as a single agent has shown some activity in WM patients.

In vitro data indicated a synergistic effect of rituximab with the IMiDs, resulting in the increase of rituximab activity through enhancement of antibody dependent cell mediated cytotoxicity. In a trial where thalidomide was given in combination with rituximab a partial response or better was achieved in 72% of patients with a median time to progression of 35 months, and it was relatively non-toxic. Thalidomide is associated with the development of peripheral neuropathy, and thus dose reduction of thalidomide was required in all patients. Optimal thalidomide dosing and schedule remain subject to further investigation, but lower dose may be associated with a lower risk for neuroparesthesias while allowing for more prolonged administration. The combination of rituximab with lenalidomide is still under investigation; a pilot trial showed that unexpected anemia may complicate this regimen.

The role of transplantation in the initial management of patients with WM is still under investigation. Autologous transplantation may be considered for young, fit patients with features of high-risk disease. Allogeneic transplantation is associated with very high rates of toxicity and mortality, thus it is only considered in the context of clinical trials or in young patients with relapsed disease and limited treatment options.

Alemtuzumab, a monoclonal anti-CD52 antibody, has shown activity in patients with relapsed WM, but there are no data in patients with previously unrated disease. Other drugs, such as perifosine, are under investigation in patients with relapsed or refractory disease. PI3K/Akt/mTOR pathway inhibitors, PKC pathway inhibitors, NF- κ B signaling pathway inhibitors, tyrosine kinases, and histone deacetylase inhibitors are under study, but it will take several years before these new drugs will be evaluated for the upfront treatment of WM.

Recently, as part of the Fourth International Workshop on Waldenström's Macroglobulinemia, a consensus panel provided specific recommendations for the upfront treatment of patients with symptomatic WM. According to these recommendations, rituximab-based therapies are considered the preferred initial treatment for most patients with WM. Regimens such as R-CHOP or DRC should be considered in patients who are (or may be in the future) transplant candidates since these regimens are not stem cell toxic. DRC is less toxic, and can be considered especially for patients for whom anthracyclines are contraindicated, as in the case of preexisting cardiac dysfunction. Rituximab with thalidomide can also be a choice for some patients and is also appropriate initial therapy for patients who in the future may be candidates for autologous transplantation. When patients present with significant cytopenias (and especially thrombocytopenia), regimens with low myelotoxic potential such as DRC or rituximab with thalidomide may be preferable. The combination of rituximab with a



nucleoside analogue (fludarabine or pentostatin), with or without cyclophosphamide, is very effective; however, due to potential short and long term toxicities such combinations should be considered for patients with features of advanced disease. These regimens may not be appropriate for young patients who are candidates for autologous transplantation. For certain patients (for example those with low risk disease, significant comorbidities, or low IgM levels), rituximab or chlorambucil as single agent may be considered.

In conclusion, treatment options for patients with WM are increasing and in the majority of patients the disease can be controlled for a number of years.

Meletios A. Dimopoulos is currently Professor and Chairman of the Department of Clinical Therapeutics, the University of Athens School of Medicine, Athens, Greece. He received his medical degree from the University of Athens in 1985 and then completed a residency in internal medicine at the Royal Victoria Hospital, McGill University, Montreal, Canada, followed by a fellowship at the University of Texas M.D.

Anderson Cancer Center, Houston, Texas. Dr. Dimopoulos is the author of more than 350 publications in refereed journals. He served as Associate Editor of the European Journal of Internal Medicine from 2001-2007, as Editorial Board Member of the Journal of Clinical Oncology from 2005-2008, and at present is Associate Editor of Current Hematologic Malignancy Reports. He is journal reviewer for the New England Journal of Medicine, Blood, the Journal of Clinical Oncology, Haematologica, and the Journal of Haematology, among others. In addition to his service on the IWMF Scientific Advisory Committee, Dr. Dimopoulos is a member of the scientific advisory boards of the Multiple Myeloma Research Foundation, the International Myeloma Foundation, and the European Myeloma Network. He organized the Eleventh International Myeloma Workshop and the Fourth International Workshop on Waldenström's Macroglobulinemia, both held on Kos Island, Greece, in 2007. Dr. Dimopoulos is a recipient of the Robert A. Kyle Award in recognition of his outstanding contributions to the study of Waldenström's macroglobulinemia.

TREASURER'S REPORT AS OF JUNE 30, 2009

BY BILL PAUL, TREASURER

The finances of IWMF are operated through two separate funds: the Research Fund and the Operating Fund.

The Research Fund accounts for all contributions received for research and is charged only for funds to be expended on approved research projects.

The Operating Fund accounts for contributions from members and others that are not designated for research, such as membership contributions. This fund is charged with all member services expenses and all operating expenses, none of which are charged to the Research Fund.

The following is a summary of the financial results for the first six months of 2009:

	Research	Operating	Total
Income	\$107,000	\$300,000	\$407,000
Expenses	1,000	299,000	300,000
Net Income	<u>\$106,000</u>	<u>\$ 1,000</u>	<u>\$107,000</u>

Income in the Research Fund was nearly \$100,000 short compared to the same period in 2008. However, the Research Fund is still in a healthy position due to the fact that we have few research projects outstanding for the first six months of 2009. Our current Research Fund bank and CD balance is \$1,500,000, while we have research grants payable of only \$400,000, leaving us with a surplus of over \$1,000,000 to apply to future grant requests.

The six-month profit for the Operating Fund, while quite modest, is actually quite an accomplishment considering current economic conditions. In fact, if we can continue this trend for the rest of the year, it will be the first profitable year for the Operating Fund in the past three years.

Many thanks for your support in the past, and thank you in advance for your generosity in the future. IWMF needs our support now more than ever. Please continue to contribute.

If you have any questions, feel free to contact me at 901-767-6630 or Billpaul1@Juno.com.



PRESIDENT'S CORNER

BY JUDITH MAY



Judith May, President

About Our Foundation

We have been struggling along with our original website for the last nine years, and I am now happy to say that very soon we will have a totally renovated site. The new website will feature updates, expanded sections, and much more information than the current site. Following several months of writing text, we expect that by the end of November we may very well be online

with the new version. While rethinking our website and reassessing the information it provides, it seemed opportune to contemplate the services we offer our members, and, in fact, our whole *raison d'être* – or reason for being.

As a foundation, we have continuously worked to help those diagnosed with WM in many ways. Each person diagnosed with WM, and also friends and family members of patients, should have information that will empower them at their level of need, at their own pace, and in their own way. The IWMF was founded and developed by those who saw this need as a crucially important mission. We have also worked diligently toward the hoped-for cure through developing the IWMF research program and fundraising program. We are firmly rooted in this mission. This has been our continuous role since the very beginning. We see our foundation's principal products as educational, informational, and providing

communication services for members, and we dedicate our research grants to the furthering of knowledge about WM.

Our all-volunteer Board of Trustees is responsible for directing and managing the IWMF programs, and we are directly accountable for the work that we do. Over time the foundation has grown in function and membership and also in our collaborations with other organizations for mutual benefit. We consider and debate new directions and changes as a Board, but we also realize it is important to know whether our efforts are having their desired impact. We also need to know if, from the perspective of our members, their needs are effectively met.

We do receive, and are very thankful for, the letters and e-mails of appreciation from many of you. We also talk with many of you at the Ed Forums and at the Annual Business Meeting each year to hear what you think of IWMF's services for members. However, we would like to reach out to all members, and so we kindly ask that each of you take the time to complete the questionnaire enclosed with this newsletter so we can know what the broader spectrum of patients, friends, and family members think of IWMF programs. You will notice that the questions have rating numbers you can select for each service, but there is also space for commenting. We welcome your comments. As we grow and evolve, we want to be sure that we are walking the same path and delivering the services you need. So, let the ideas flow to help light the way with your knowledge and wisdom.

Stay Well,

Judith

FUNDRAISING: A PRIORITY FOR EVERYONE

BY DICK WEILAND, VICE PRESIDENT FOR FUNDRAISING

The IWMF may be a small not-for-profit foundation, but we have an ambitious agenda to provide extensive membership services for patients with Waldenstrom's macroglobulinemia and for their families, as well as to fund research towards improved treatments and a cure for this disease. Membership fees cover many, but not all, of our expenses. Our fundraising program includes the Research Fund, the Fellowship Stipend Fund, and the newly established Kyle Endowment Fund, all of which support on-going WM research. The Ben Rude Heritage Society encourages long range planning to fund all activities of the IWMF. Monetary gifts and pledges to these named funds are sought and are always welcome.

Articles in past issues of the *Torch* have showcased another

important way that has been used to spread the word about our foundation as well as to raise funds. IWMF volunteers have organized "a-thons" encouraging contributions from folks to sponsor a particular activity. Marathons, walkathons, bikathons – volunteers have raised funds by running, rowing, biking, driving, hiking, swimming, walking, or golfing. Recent initiatives include the bike-riding **Randalls** in California who not so long ago generated about \$15,000. And this season we are all cheering on racing driver **James Hinchcliffe**, son of **Arlene Hinchcliffe**, who has pledged five dollars to the Waldenstrom's Macroglobulinemia Foundation of Canada for every lap he leads throughout his entire 2009 car racing campaign.

Fundraising, cont. on page 6



Finally, there are numerous examples of personal initiatives undertaken because someone wishes "to do something" to benefit the IWFM, often honoring someone near and dear. This sweet story will surely leave you smiling. Perhaps it will also inspire you.

From the UK **Alison Brown**, the wife of **Roger Brown**, sends this:

"I belong to Lyndsey's Get Fit In Time Ladies Gym in our small town of Cirencester in England. No men, no mirrors, just lovely ladies doing 30 minute circuit

training. We are very friendly and spend as much time chatting as keeping fit. Twice a year Lyndsey holds a raffle to raise money for causes dear to her members' hearts. Generous people provide raffle prizes such as wine or chocolates (that's why we all need to go to the gym!) and we buy tickets. I told Lyndsey in conversation once about Roger's illness, and she said the next raffle would be in his honour. So we raised £90 for IWFM – and I won a large box of chocolates."



THE BEN RUDE HERITAGE SOCIETY ENROLLMENT

BY DICK WEILAND, VICE PRESIDENT FOR FUNDRAISING

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

LEGACY GIFT

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

- ☐ Will ☐ IRA/Retirement-Plan Beneficiary Designation ☐ Trust ☐ Charitable Remainder Trust
☐ Other (please specify): _____

Additional Information: _____

DESIGNATION

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

- ☐ IWFM's Greatest Need ☐ Research Fund ☐ Dr. Kyle Endowment Fund ☐ Fellowship Stipend Fund
☐ Other Named or Designated Fund: _____

GIFT DETAILS

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

RECEIPT OF GIFT

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

- ☐ The First Donor ☐ The Surviving Donor/Spouse ☐ Other Individual(s): _____
☐ Other Contingencies or Stipulations such as: _____

BEN RUDE HERITAGE SOCIETY HONOR ROLL LISTING:

Name(s): _____

- ☐ Please enroll me/us in the Ben Rude Heritage Society using the Honor Roll listing above.
☐ Please do not list my/our name(s) in the Honor Roll and _____ in all other publications.
☐ Typically, IWFM recognizes Heritage Society membership with a recognition piece.
Check here if you prefer not to receive this token of appreciation.

Donor Signature: _____ Date of Birth: _____ Date: _____

Donor Signature: _____ Date of Birth: _____ Date: _____

Please note that all information will remain confidential to IWFM. For further information about the Ben Rude Heritage Society, please contact Dick Weiland at rjweiland@msn.com or 507.645.2633



MEDICAL NEWS ROUNDUP

BY SUE HERMS

Subcutaneous Injections of Veltuzumab Tested in NHL and CLL Patients – Immunomedics, Inc. announced that subcutaneous injections of low doses of veltuzumab in patients with non-Hodgkin's lymphoma (NHL) or chronic lymphocytic leukemia (CLL) produced a slow and efficient delivery of this second generation anti-CD20 antibody. The injections of veltuzumab were given two weeks apart for a total of four doses. Patients received the drug at one of three dose levels: 80, 160, or 320 mg. The injections were well tolerated with only transient, mild adverse effects. The NHL patients had a 53% response (27% of which were a complete response); these findings were similar to the previously reported Phase I/II results using the intravenous formulation. For CLL there were no responses, but 50% of patients had stable disease for more than 12 weeks. An adequate dosing schedule for CLL patients has yet to be determined.

New Histone Deacetylase Inhibitor Investigated in NHL and CLL Cell Lines – Northwestern University and the Robert H. Lurie Comprehensive Cancer Center in Chicago, along with Pharmacyclics Inc., investigated a broad spectrum histone deacetylase (HDAC) inhibitor called PCI-24781, alone and combined with bortezomib (Velcade) in Hodgkin's lymphoma and NHL cell lines and in CLL cells. PCI-24781 induced dose-dependent apoptosis (programmed cell death) in all cell lines, with strong synergistic apoptosis when combined with bortezomib. This investigational drug significantly down-regulates several of the genes involved in the NF-kappa B pathway.

FDA Committee Gives Preliminary Approval to Arzerra for CLL Patients – The U.S. Food and Drug Administration's Oncologic Drugs Advisory Committee voted that Arzerra (ofatumumab) data are reasonably likely to predict clinical benefit for patients with CLL whose disease is refractory to fludarabine and alemtuzumab (Campath). While current treatments for CLL can provide prolonged remissions, some patients will progress rapidly and relapse, highlighting the need for new therapies. Arzerra, manufactured by GlaxoSmithKline and Genmab, is a monoclonal antibody that targets the CD20 molecule on B-cells, but at a different part of the molecule than rituximab. Arzerra is still in clinical trials and has not yet been approved for use in any country.

Use of Short-Term Rituximab Maintenance in Follicular Lymphoma Results in Increased Event-Free Survival – The Swiss Group for Clinical Cancer Research and the Istituto Europea di Oncologia in Milan, Italy, recently published a study on short-term rituximab maintenance treatment in follicular lymphoma (FL). Between 1998 and 2002, chemotherapy-naïve or pre-treated FL patients received four weekly doses of rituximab; those responding or with stable disease were randomly assigned to either no further treatment (observation only) or to four additional doses of rituximab

given at two-month intervals (consolidation therapy). At a median follow up of almost nine years, the event-free survival was 13 months for the observation arm and 24 months for the consolidation arm. No long-term toxicity from treatment was observed.

Another European Study Reports on Safety of Long-Term Rituximab Maintenance – A cooperative group of researchers from Switzerland, Italy, Brazil, Macedonia, and South Africa recently published in the Journal of Clinical Oncology its study on the safety of long-term rituximab maintenance therapy in 270 follicular lymphoma patients. All patients first received four weekly doses of rituximab; responding patients were randomly assigned to either a short maintenance regimen or to prolonged maintenance (five years or until disease progression or unacceptable toxicity). At this point, the median duration of prolonged maintenance has been 23.7 months. So far, the study has no evidence for increased toxicity due to prolonged maintenance and concludes that maintenance therapy beyond two years is feasible, although patients in this study are still being followed. Close follow up of patients on prolonged maintenance therapy is necessary.

Roswell Park Cancer Institute Tests Combination Obatoclax and Bortezomib – Investigators from Roswell Park Cancer Institute combined two drugs, obatoclax and bortezomib, that target molecular pathways that play an important role in acquired resistance to standard therapies of rituximab and chemotherapy in NHL. Obatoclax is an investigational drug designed to kill cancer cells by blocking a protein (Bcl-2) that usually prevents cell death, while bortezomib is a proteasome inhibitor that disrupts the growth and survival of cancer cells. When used in combination on lymphoma cell lines and tumor cells derived from patients, the drugs demonstrated synergistic action.

Results from Study of Bortezomib, Dexamethasone, and Rituximab Therapy – The Bing Center for Waldenström's Macroglobulinemia at Dana-Farber Cancer Institute has reported on the activity of bortezomib, dexamethasone, and rituximab (BDR therapy) in patients with symptomatic, untreated WM. Patients received four consecutive cycles for induction therapy and then four more cycles, each given three months apart, for maintenance therapy. Bone marrow disease involvement declined from 55% to 10%, serum IgM levels declined from 4,830 to 1,115 mg/dL, and hematocrit increased from 29.8% to 38.2% at best response. The overall response rates and major response rates were 96% and 3%, with three complete responses. Responses occurred at a median of 1.4 months, and with a median follow up of 22.8 months, 18 of 23 patients remained free of disease progression. Peripheral neuropathy was the most common toxicity, and four of the first seven treated patients developed

Medical News Roundup, cont. on page 8



shingles, resulting in the institution of prophylactic antiviral therapy for all patients.

Dana-Farber Reports on Weekly Bortezomib in Combination with Rituximab – The Dana-Farber Cancer Institute also reported on a Phase II study of six cycles of weekly bortezomib in combination with rituximab in patients with relapsed/refractory WM. Thirty seven patients have been treated to date, with 35 patients evaluable for response. Most patients achieved response rapidly, within three months of therapy, and rituximab flare occurred in only six patients. A response rate of 83% was achieved. At 24 months of follow up, 8 of 35 patients have shown relapsed disease. No significant peripheral neuropathy was observed to date with this regimen. Toxicities included neutropenia, anemia, and thrombocytopenia, as well as shingles.

FDG-PET Scans Used in Study to Determine WM Tumor Burden and Prognosis – The Dana-Farber Cancer Institute has suggested the need for more sensitive tools to determine tumor burden and prognosis in WM. The use of FDG-PET scans has not been previously studied in WM but has been an effective diagnostic and prognostic tool for other low-grade lymphomas. FDG-PET stands for fluorodeoxyglucose-positron emission tomography. Fluorodeoxyglucose is a radioactive tracer that mimics glucose and is used to detect metabolically active cancer lesions. This study included patients enrolled in a Phase II trial of bortezomib and rituximab. Over 60% of WM patients demonstrated FDG-PET active disease before treatment, with the majority showing no disease after therapy. This correlated with the 67.9% response rate. The study concluded that FDG-PET scans may prove an effective tool in the diagnosis and prognosis of WM.

Minor Responses to Rituximab Therapy Compare Favorably to Objective Responses – The Eastern Cooperative Oncology Group reported on long-lasting responses after four doses of rituximab in WM. Uniform response criteria define an objective response to treatment as a 50% reduction in IgM and a minor response as a 25% reduction in IgM. Clinicians who treat patients that achieve a minor response are left uncertain as to whether the response is adequate and patients should be monitored for progression or whether they should be considered treatment failures and treated with an alternative regimen. In this study, 69 patients were treated with a single four-week course of rituximab and were monitored with no further therapy until progression. There was no difference in overall or progression free survival between patients who achieved an objective response when compared to those who achieved a minor response. There was also no difference between the two response categories by age, time from diagnosis to treatment, number of bone marrow lymphoplasmacytes, hemoglobin level, creatinine, IgM level, or M-spike. The pre-treatment level of IgM did not predict overall survival, progression-free survival, time to progression, or response rate.

United Kingdom Approves Revlimid for Multiple Myeloma Patients – The UK National Institute for Health and Clinical Excellence (NICE) has reviewed its decision on the clinical and cost effectiveness of lenalidomide (Revlimid) in multiple myeloma patients. Initially, NICE had rejected lenalidomide, but after the manufacturer (Celgene) agreed to fund treatment beyond the 26th cycle for patients who have received two or more previous therapies, NICE determined that this brought the treatment into acceptable parameters of cost effectiveness.

National Cancer Institute Identifies Several Genetic Polymorphisms Implicated in Familial WM and CLL – The National Cancer Institute is examining the role of genetic variation underlying susceptibility to the development of familial lymphoid malignancies. This particular study analyzed 1,536 single nucleotide polymorphisms in 152 genes involved in apoptosis, DNA repair, immune response, and oxidative stress pathways among a sample of familial cases including patients with CLL, WM and Hodgkin's lymphoma. The study confirmed a polymorphism in the IL10 promoter is associated with both CLL and WM, as well as polymorphisms in TNFSF10. This data further support the close association of WM and CLL.

Two Anti-CD40 Antibodies Used in Phase I Study for NHL and MM – Stanford University Medical Center is testing two antibodies targeting CD40 in multiple myeloma (MM) and NHL patients. The antibodies are SGN-40 and HCD122. In WM, CD40 expression is a common feature of bone marrow-infiltrating lymphoplasmacytic cells, and preclinical evidence suggests that CD40 signaling is functionally important for WM growth and survival. Phase I data suggest that both agents are well tolerated and have early evidence of clinical activity in relapsed and refractory NHL and MM. These observations support the testing of CD40-targeted agents in WM.

Bone Marrow Responses Evaluated in Fludarabine Therapy – St. James's Institute of Oncology in Leeds, UK, used bone marrow flow cytometry and immunohistochemistry to evaluate response to fludarabine therapy in patients with WM. Responses in serum IgM were typically delayed with a median time to maximum response of six months following the completion of therapy. In contrast, bone marrow responses occurred promptly in responding patients, such that there were no detectable clonal B-cells at the end of therapy in 55% of patients. Persistent monoclonal plasma cells were, however, readily identified by CD138 immunohistochemistry, explaining the persistence of serum IgM in these patients. This simple observation has significant implications for the assessment of responses in WM.

Genomic Sequencing Performed on Multiple Myeloma Patients – The sequencing of the first three multiple myeloma (MM) whole genomes has been completed by U.S. scientists,



and these genomes should be available online to researchers within the next several months. The DNA analysis from more than 50 patient samples was conducted as part of the Multiple Myeloma Genomics Initiative. Overall, more than 250 patient samples have been collected and additional MM genomes are being sequenced. It is hoped that this genomic sequencing will pave the way toward personalized treatment for MM patients.

Mozobil for Autologous Transplant Approved for Marketing in Europe – Genzyme Corporation announced that the European Commission has granted marketing authorization for its Mozobil product, providing another option for patients with lymphoma and multiple myeloma who require an autologous stem cell transplant. Mozobil is combined with granulocyte-colony stimulating factor (G-CSF) to enhance mobilization of stem cells into the bloodstream for collection and subsequent transplantation. The product has been granted orphan drug status in the European Union and the United States. For many patients, the stem cell collection process can take three to four hours over multiple days to complete. Even then, some patients are not able to mobilize enough cells, and a transplant is not possible. In Phase III studies, Mozobil in combination with G-CSF increased the number of patients achieving the targeted stem cell levels in fewer sessions. Mozobil was approved for use in the U.S. in 2008, and Genzyme has filed applications for its approval in Argentina, Australia, Brazil, Israel, and Singapore.

Embryonic Stem Cells Manipulated to Produce White Blood Cells – The University of Wisconsin-Madison has

been able to transform embryonic stem cells into progenitors of white blood cells and into several types of mature white blood and immune cells. The technique works equally well with stem cells grown from an embryo and with adult pluripotent stem cells, which are derived from adult cells that have been converted until they resemble embryonic stem cells. This technique allows the production of large quantities of cells in a Petri dish that can be more exactly tailored to the task at hand, without requiring a constant supply of bone marrow cells from donors. Researchers have found a recipe of biologic signaling molecules that cause the embryonic cells to move through a process of specialization into osteoclasts, eosinophils, dendritic cells, Langerhans cells, and neutrophils. Researchers hope to be able to take cells from patients with a disease of the blood system and explore the cause and treatment of that specific disease. They eventually hope to be able to produce hematopoietic stem cells that can be used in bone marrow transplants.

BiovaxID Available for Compassionate Use in Europe – Biovest International announced that BiovaxID, its therapeutic anticancer vaccine, is available on a compassionate-use basis in Europe. BiovaxID will be supplied by Idis Limited to European healthcare professionals for the treatment of follicular NHL and potentially for other B-cell blood cancers such as CLL, mantle cell lymphoma, and multiple myeloma.

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

MANAGING FATIGUE, ONE STEP AT A TIME

BY WENDY HARPHAM, M.D. – A LYMPHOMA SURVIVOR

“Do you want to go?” my husband, Ted, asks without a smidgen of pressure. I’ve gone to day-long volleyball tournaments before, so I know I’ll feel rotten halfway through and even worse after it’s over. Without hesitating, I answer, “Of course!”

I’m like a Lexus with a one-gallon tank: Wherever I go and whatever I do, I run out of gas while others (even my 81 year-old mother) are still going strong. It’s more than just being sleepy; I am headachy and irritable. By mid-afternoon, my IQ seems to be slipping 10 points per hour.

Unless I catch some ZZZs – in my car, on the bleachers, anywhere – word block is followed by thought block. Contributions to conversations peter out, my tongue weighted down by the accumulation of responses clinging to its tip. If I keep pushing past my limits, I get flustered easily and appear angry when I’m not. It’s hard to think, act or be like the real me.

I used to be an MD – a Mommy/Doctor. Multitasking was a way of life. After my diagnosis of lymphoma in 1990, I traded my energy for my survival. The various courses of radiation, chemo- and immunotherapy that bought me remissions cost me my stamina.

As a physician-survivor, I tackled my fatigue the same way I approached other challenges: I read the available literature and consulted with experts. Changes in my diet, sleep and exercise routine helped, as did joining a support group. But my frustration and disappointment continued until I explored the emotional impact of my invisible wound and found healthy responses.

Now, if others assert, “You say you’re tired, but you look great!” or “I’m tired, too, and I’ve never had cancer,” I remind myself that post-cancer fatigue is real and different than the tiredness that healthy people feel at the end of a long

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day. When I nap in the afternoon (which is almost every day) or tuck in early at night, I mutter my mantra, “Sleeping is not wasting time!” Getting enough rest is one element of healing under my control. If nothing else, I make fewer mistakes and act more like myself (a good thing for everyone).

A cardinal rule keeps me from overdrawing my energy account: I say “no” when the stakes of muddle-headedness are high. I never ever drive when I’m tired, no matter how much inconvenience it causes or what I have to miss. I decline elegant dinners if I need rest in order to ramp up the wattage later that evening when I take the microphone for a public lecture.

On most afternoons and evenings that I feel tired and headachy, I could feel better. I could choose to rest more and do less. But I’d rather feel under par and write another chapter. I’d rather massage my scalp while watching my girls’ volleyball match or reviewing vocabulary words with my son. What’s the point of surviving if I’m not living my life?

I’m confident (after checking with my physicians) that the headachy irritability won’t increase my chance of cancer recurrence or other significant medical problems. As long

as I respect my limits and don’t risk hurting myself or others – physically or emotionally – the choice is mine. Doing or declining is a constant balancing act: discomforts, mistakes and grumpiness versus the pleasures.

If I think about it, I miss working and go-go-going all day long. But honestly, I’m so focused on all the opportunities still open to me that I rarely think about what I’ve lost. I feel well enough – not perfect, maybe not even good, but well enough – to live and love this life I have.

So Ted drives; I relax. At the tournament, my spirited cheers disappear in the roar of the crowd, but they shout to the world, “I’m here.”

Reprinted from CURE Magazine, spring 2007, with the permission of the author, Wendy Harpham, M.D.

Dr. Harpham is a lymphoma survivor who spoke at one of our early Ed Forums. She has written many books which can be found at her website www.wendyharpham.com and her blog on healthy survivorship at <http://wendyharpham.typepad.com/>. Two books by Dr. Harpham of special interest are: *Happiness in a Storm* and her latest book, *Only 10 Seconds to Care*.

LIFE AFTER STEM CELL TRANSPLANTATION: AN INTERNATIONAL PERSPECTIVE

BY COLIN PARRISH



Susan and Colin Parrish with the other members of *Takin’ Time*, Fourth of July performance 2009.

Athlete, educator, musician: Colin Parrish writes from Australia to share the good news of a successful stem cell transplantation after more than a decade of chemotherapeutic treatment and to tell of the happy turn his post-transplant life has taken.

At an early age I had been a keen sport person, and during my twenties played a good standard of rugby football both in England, where I grew up, and in Australia, where I migrated to in 1981. But the knocks were taking too long to get over by the time I reached 33 years of age, and so I took up the challenge of running marathons for the next 11 years, completing my 14th marathon at the age of 44 in a time of 3 hours and 17 minutes. But only twelve months before I had finished in a time of 2 hours and 54 minutes, 23 minutes quicker, and I reckoned I simply had to be getting a little too old to run any more competitive times! 1995 proved to be a struggle for me in achieving any longer distance runs so I decided to abandon

the marathon that year and instead chose to make a blood donation to the Red Cross, which I had used to do quite regularly when I was younger. To my surprise I was told, upon checking in for my appointment, that they weren’t able to take a blood donation from me because I was anaemic; my Hgb was a below-normal 11.8.

The rest, as they say, is history. The diagnosis of WM – which I found difficult to say initially! – was quite a shock. I went through the usual period of asking the question “why me?” I was fit, healthy, didn’t smoke or drink alcohol excessively, ate healthy foods and had always reckoned I was going to live to be 100 years old!

As a senior school year level co-ordinator, I had often spoken to my students about managing their studies and their lives during their final year of schooling. I stressed the importance of being able to deal with any kind of ‘challenge’ in their lives, and one of my favourite quotes was from Martin Luther King who said: “The measure of a man (woman) is not where

Life After Stem Cell, cont. on page 11



he stands in moments of comfort and security, but where he stands in moments of challenge and adversity.” I had always been prepared to step outside of my own comfort zone because I believe that you cannot discover your own potential as a human being until you have. That was one reason I kept running my marathons. In 1995 I was then well and truly outside of my comfort zone.

My initial IgM reading was around 4200. It would have been easy to have allowed the diagnosis to overwhelm me, but I decided instead to find out as much as I could about WM. It was to the newly established IWmf that I turned after I discovered their website on the Internet. My attitude became one of “why not me?” I tried hard not to feel sorry for myself and began the usual journey of treatment commencing with oral chlorambucil, which had some impact on the IgM level for about 18 months. We then chose to try oral Cytosan (cyclophosphamide here), which became my treatment option for the next 5 years or so, putting me into a sort of remission several times, with my IgM level falling to 1400 at one stage. We tried Rituxan (mabthera in Australia) and I remember getting a bad reaction to it with a very high fever – chills, the works! The initial treatments had a moderate effect on my IgM level bringing it down to around 3500 from the 5000 it had reached prior to that.

But by 2003 my oncologist felt that intravenous chemotherapy involving the mix of Rituxan, Cytosan, and fludarabine in combination, spread over four months, was our next option. It worked exceedingly well, and I enjoyed a remission of 18 months, during which time my IgM fell to 1700 and my Hgb climbed to 15 at one stage. I felt OK and, to all intents, I was able to live a ‘normal’ life.

It was during this period – in a sort of remission – that we decided to undergo a stem cell harvest at the Peter MacCallum Cancer Institute in Melbourne. Often, after chemotherapy involving fludarabine, the stem cells are damaged to such an extent that only insufficient numbers can be harvested for a future autologous stem cell transplant. I was asked to participate in a Phase II trial involving a new drug called Stemgen, in conjunction with Neupogen, and the result in March of 2005 was a yield of roughly 1.8 times the required number of stem cells for a successful transplant.

By July of 2007 my IgM had climbed again into the 4000 range, and so I underwent another 4 month course involving the FCR regimen, during which I contracted shingles and suffered a complete loss of neutrophils (neutropenia) which required hospitalisation for a week. This was all in preparation for an autologous stem cell transplant (SCT) that would happen in the new year – 2008.

I knew that it wouldn’t be an easy ride. I still had our dear friend Dave Lively’s e-mail, in which he describes being told that he had this “incurable disease called Walden’s Mountain or something,” filed away as a reminder of Dave’s incredible strength of mind that enabled him to live a fulfilling life whilst

he had WM. Having come this far I felt a SCT would give me a better chance of a long-term remission. I had to undergo a full cardiac and pulmonary check, as well as a dental check, to ensure a minimal risk of infection or cardiac arrest following the high dose chemotherapy they would administer.

The transplant proved to be a very rough ride for me, as I have described before on the IWmf-TALK. I lost all of my hair for the first time, and it took 6 months before it started to grow back. I wonder if they had given me a higher dose of chemo than normal to ensure a better outcome? I spent two periods in intensive care and really did wonder a few times if I had made the correct decision. It took me three months or so before I felt close to ‘normal’ and my blood counts were improving slowly. But my IgM level has remained a rock bottom 200 – which I believe is well within the ‘normal’ range for a healthy individual – and a bone marrow biopsy last year showed no presence of the illness. So does that mean I am ‘free’ of WM? I don’t believe so, but I have entered a phase in my life when I am enjoying being free from periodic treatments. I have made the decision to only teach part-time (2 days a week) and have removed myself from the frenetic life that I once experienced. I eat healthy food and take a few ‘alternative medicines’ and I drink plenty of tea – not just green tea.

Most importantly to me, I re-married and have a wonderful relationship with my wife. How long this remission will continue remains to be seen, but I have already come 14 years with this illness and expect to be around for a good few more years yet. I’ll be turning 60 next January. My dad turned 90 this June. I still have a lot of good ‘living’ to do.

I know this illness behaves quite erratically in many of us, but one unchallengeable mantra for dealing with this illness is to *remove* yourself – in as much as it is possible to – from the things that cause you stress and make you unhappy. Use your mind to remain positive. I am reminded of an Australian survivor of the Thredbo Mountain disaster, Stuart Diver. He survived for 36 hours alongside the body of his newly wed wife beneath a crushed ski lodge. When asked how he kept himself from giving up, he replied, “I never let a negative thought remain in my head for more than ten seconds.” You can check out his story on Google.

If you feel inclined, you can visit our website: www.takintime.com.au.

“Takin’ Time” is the name we have given to our music band. It reflects our philosophy that we must take the time to . . . smell the roses . . . tell the ones that are important to us that you love them . . . find the time to help those less fortunate than you might be.

On July 4, 2009, we played at an American Independence Day celebration as a fund-raiser for a local hospital!

Best wishes to Susan and Colin Parrish. May they keep on takin’ time and livin’ well.



COOKS' HAPPY HOUR

BY PENNI WISNER AND NANCY LAMBERT

Easy, Quick Pickles

As this column goes to print, in the middle of harvest abundance, perhaps, you, too, are thinking: “Vegetables!? Just what else can I do with them?” We have an answer and it happens to be an ideal nibble for Nancy’s evening rendezvous with the sunset: bright-tasting, easy, homemade pickles of cucumber, carrot, radish, cauliflower, asparagus, green bean, red onion, whole garlic cloves, sweet and hot peppers. You may have noticed that humble pickles are – yes, believe it – trendy. Restaurateurs make their own as a way to distinguish themselves and home cooks flock to pickling and preserving workshops. So jump on the bandwagon and make a batch. It will take less time than an episode of *Julia and Jacques Cooking at Home*.

These fresh, quick pickles have many advantages: they can be prepared in a few minutes and keep several weeks in the fridge; they are not particularly “pickle-y”, but instead taste fresh and vibrant; the flavors can be adjusted to suit your palate; they are naturally fat-free and salt and sugar content can be adjusted to suit your palate and/or dietary requirements. Plus they make great snacks on their own or as a welcome change from crudités and as condiments with sandwiches, burgers, and roasted meats and fish.

Pickles mystified me until my CSA (Community-Supported Agriculture) box contained two six-pound bags of carrots. I thought pickles would be hard to make. Didn’t they involve fermentation? Complicated brines? Well, yes and no. I turned for help to my favorite vegetable cookbook, *Vegetarian Cooking for Everyone* by Deborah Madison. I adapted her recipe for Pickled Carrots and Garlic with Cumin as my jumping off place. You barely cook the vegetables and don’t boil the pickling brine.

Start with equal amounts vinegar and water. Distilled white vinegar is the classic pickling vinegar but other vinegars add different flavors. For instance, Deborah Madison’s recipe recommends apple cider vinegar for the carrots to enhance their natural sweetness. But I tend to use whatever I’ve got, except balsamic and red wine vinegar. The former because it is too sweet and the latter because it would change the color of the pickle. If I were pickling beets (delicious done at home, perhaps not so terrific from a can if you were raised on them as I was), red wine would be fine.

Season the pickling brine with a pinch each of salt and sugar and whatever herb and spice flavors you’d like to add to your pickles. If you want pickled garlic, add more. If you want it as a flavoring (that’s me), add less. Got dill? Terrific, use the whole bunch in your cucumber pickles. Don’t have dill? No problem, substitute fennel fronds, chervil, and/or tarragon. Beginning to get the idea? Let’s start with carrots.

Peel a pound or more of carrots and cut them into matchsticks. Crush several garlic cloves and peel them. Bring a large pot of water to a boil and salt it. While the water comes to a boil, put equal amounts water and vinegar in a bowl, maybe a cup of each. Add a pinch of salt, a large pinch of sugar, maybe 10 peppercorns, a generous teaspoon of cumin seeds, and a bay leaf. If you want a little spice (yes, please), add a pinch of chili flakes or a sliced fresh jalapeno or Serrano chile. Stir until the sugar and salt dissolve.

Plunge the carrots and garlic into the boiling water very briefly. You just want to take the raw edge off them, not cook them, in order to have crisp pickles. Depending on the size of your carrot pieces, they may need as few as 10 seconds. Drain the carrots and garlic and immediately put them in the pickling mix. There should be enough liquid to just cover the carrots. If you don’t have enough, add equal amounts of vinegar and water until you do.

The above method has become my habit with variations. Cauliflower makes a terrific pickle. Cut it into florets, cook *very* briefly, and include coriander in the pickling mix. I keep a jar of pickled, thickly sliced red onions in the fridge for burgers, and turkey, chicken, and cheese sandwiches. For the red onions I like to add a cinnamon stick, allspice berries, and star anise and omit the cumin. To extract the most flavor from these hard spices, bash them up a bit and then simmer them in the brine for several minutes. Add the raw onion to the hot brine. I also use more sugar, about ¼ cup for a pound of onions.

A several-pound bag of Kirby cucumbers (small, knobby, and meaty), the kind you pickle, necessarily introduced me to homemade cucumber pickles. For these I combined and adapted two recipes from *The America’s Test Kitchen Family Cookbook*. But the recipe is really just another variation of the method already outlined. For a pound or so of cucumbers, cut into lengthwise wedges, simmer together 1 ½ cups each vinegar and water with mustard, coriander, and fennel seeds; chili flakes; about 10 peppercorns, 4 allspice berries; 1 bay leaf, and 2 crushed garlic cloves. Put the cucumbers, a thinly sliced red onion, and a big handful of dill in a bowl and pour in the hot brine. Stir and let cool on the counter. Then cover and refrigerate.

Whatever vegetable you use for your pickles, do them the day before you plan to serve them so they have a chance to develop flavor. Store them in the fridge and they’ll keep several weeks. But since they are so easy to make, you can prepare small batches every week, trying a new seasonal vegetable each time: perhaps trimmed asparagus spears, sliced beets (maybe add strips of orange zest to these), or bell

Cooks’ Happy Hour, cont. on page 13



pepper strips (don't blanch these, just cut them into strips and plunk them directly in the cool brine).

Is there a junior cook in your life? What fun a grandkid or younger friend will have helping to turn any of those vegetables so abundant at harvest time into pickles! Healthy snacks, good not only at sunset but also to nibble round the clock.

Our motto: Eat Well to Stay Well

Penni (penni@pacbell.net) and Nancy (Lne3@AOL.COM) eagerly await your suggestions for healthy, fast, and easy snacks.

FROM IWMF-TALK

BY MITCH ORFUSS

IWMF-TALK had a rollicking spring and summer, with an exceptionally wide range of topics raised. Following are those receiving the greatest TALK space.

Hydration

For a long time **Duane Trechessett** has felt that the only cure for cancer is its prevention. He has listened long enough to know that what many of us have in common is a history of strenuous athletics. Since dehydration causes complicated exchanges within, Duane could imagine a point where, after so much dehydration, our body chemistry "invites" WM. Yet researchers insist on finding a "cure." Duane asks, could there be a connection between dehydration and WM? **Ken Warner** offered a strategy that gets around the "I do not drink enough water" problem – he just drinks a large glass or two of his special "rehydrating" fluid every afternoon. Generally, no problems yet, he claims.

In older people, says **Colin Perrott**, the kidneys are less able to regulate the excretion of water and to concentrate urine as needed. Therefore, more water may be lost in urine. Also, older people often do not drink enough water, especially on hot days – partly because they tend to be less thirsty. When a person becomes dehydrated, the brain releases an anti-diuretic hormone signaling the kidneys to retain more water by making and excreting less urine. In effect, psychological distresses are shuttered down. Positive stimulation to drink can be essential. Sports drinks are formulated to achieve such an effect.

Dr. Jacob Weintraub adds that although the sports drink industry would have us all think that their drinks are wonderful and necessary, the real answer is that most people (other than the marathoners and other world class athletes) need water replacement more than they need the electrolytes and that the earlier products all had too much sugar in them and not appropriate amounts of other electrolytes. Most people can hydrate with just extra water and with whatever else we eat during the day. The normal adult diet has more than enough salt and other nutrients to make electrolyte solutions unnecessary as long as you are not over-hydrating with gallons of water.

Consequences of a Rituxan flare

Lou Birenbaum writes that he had blurred and dimmed vision in 2004, noticed a day or two after the 3rd of 4 Rituxan infusions. Lou told his oncologist about the vision impairment, and the doctor prescribed several days of prednisone. That seemed to reverse it. When the same thing happened again in July following the 3rd of 4 infusions, Lou's oncologist recommended seeing a neurological ophthalmologist and did not prescribe prednisone. The rationale was that he wanted to try to determine the cause of the impairment rather than again treat with prednisone. After two MRIs and two spinal taps, the ophthalmologist found an abnormality in the optic nerve but could not determine the cause. The vision impairment gradually lessened over the following 6-8 months but did not completely go away. Same problem again in March 2009, following a Rituxan infusion. Lou again asked his oncologist to prescribe prednisone, which this time did not seem to bring any improvement in vision but created digestive problems. Prednisone, combined with overindulgence in pepadew cocktail peppers, gave Lou the absolute worst abdominal gas he had ever experienced, painful enough to keep him in bed for two days. Lou will never use prednisone again, or at least will never combine prednisone with peppers! To this day, vision in Lou's left eye is blurry. Lou believes the vision distortion was due not to a Rituxan flare but to an allergic response to Rituxan. Neither of his doctors agrees. But the same distortion at the same time relative to his Rituxan infusions convinces Lou that it was an allergic response.

Dr. Guy Sherwood wrote that it is impossible to predict who may or may not get a Rituxan flare – but who wants to risk losing sight in one eye or worse? Guy safely drives his car to work daily but still wears his seatbelt. "In Stockholm," Guy recalls, "Dr. Marvin Stone, a super-experienced hematologist/oncologist and WM-treating physician, recommended keeping your IgM below 3000-4000 with plasmapheresis, mostly because of possible retinal damage." Perhaps a little aggressive for some, but Guy does not pretend to have the same degree of clinical experience and agrees with Dr. Stone that prevention is better than dealing with a disaster. Guy never liked "walking around" with high IgM. He had 30 plasmapheresis

From IWMF-Talk, cont. on page 14



treatments in 2001-2002 until IgM finally dropped below the 3000-4000 level.

Green Tea

Daniel Hachig wrote that the *Journal of Clinical Oncology* has published results of the Mayo Clinic's Phase I study of green tea extract in CLL patients. Results show that at 2000 mg twice per day, 11 of 12 patients (92%) with palpable lymphadenopathy experienced at least a 50% reduction in all nodal areas. Daniel alluded to a couple of other convincing papers recently published showing that green tea extract (rich in the polyphenol egcg), some other flavinoids (but not resveratrol!) and vitamin C (at higher doses) are competitive with bortezomib (Velcade) – that is, if you're taking Velcade, stay away from green tea. Even a couple of Snapples can, he says, have an impact.

Sed rate

After her husband's doctor said he may have temporal arteritis (AT) and would require a blood test to confirm the diagnosis, **Diane Tiplady**, the caregiver to her husband, wondered whether her husband's WM would affect this test. **Dr. Jacob Weintraub** responded that sed rate (ESR: erythrocyte sedimentation rate) is almost always abnormal in WM patients because it is a function of the way IgM interferes with the testing itself and does not necessarily represent increased inflammation. **Ron Draftz** responded to Diane that a comment on IWMF-TALK about temporal arteritis a few days earlier had sent him to do a search for information. Ron learned that treatment is started before testing precisely to prevent permanent vision loss, which is such a significant threat that treatment is used whenever there is even the suspicion of TA. Sed rate, however, will not be diagnostic of TA for those who have an elevated IgM since the IgM will cause agglomeration of the red blood cells leading to an elevated sed rate. The usual diagnostic testing for TA is biopsy. Ron ended by asking that if the symptom that gives rise to a suspicion of TA is a vision problem, is it possible that the problem is hyperviscosity and not TA?

Mouth Sores

Connie Mansfield asked for suggestions to soothe or heal dry mouth/sore throat/mouth sores due to treatment. Connie said she has a script for nystatin. She also uses a baking soda and salt solution in water, but this is not much help so far. Connie, not wanting to use over the counter products, would

like something more natural. **Ken Warner** warned against using commercial toothpaste because it usually contains sodium laurel sulfate, a foaming agent that removes protective surface cells from the sore and lets one's natural digestive juices in the mouth attack the cells in the open wound. **Tom Howenstine** came across debacterol and found it effective in healing mouth sores quickly. "It's not for the faint of heart, but it does work. Most dentists have a supplier who handles it. You might need to have a dentist numb your mouth and apply it, but it can be self-administered."

Fay Langer had mouth sores this winter during Rituxan/Fludara treatment. She was first given Gelclair, which is an oral gel packaged in dosage packs. This was better than nothing, but didn't do much. Then Fay was given a prescription mouth rinse, Peridex (a 12% chlorohexidine rinse), which did the trick. Directions were to rinse twice daily, as needed. Fay was warned not to overdo it – it can cause teeth to turn blue. **Maureen Hanley** said she used Peridex in the past when very sick and it worked wonders on gums and mouth. She adds that it does not permanently change the tooth color but that one has to be careful not to drink water just after using since it stains the teeth slightly brown (this can be reversed by a professional dental cleaning).

Spleen

Joanne Pavia responded to **Neil's** question about the spleen by saying she was helped by a splenectomy after 3 ½ years of symptoms and moderate improvement with other treatments (Rituxan, fludarabine). With those treatments, Joanne's somewhat enlarged spleen decreased in size, but last summer and early fall it started to enlarge very rapidly with worsening anemia (which she has had throughout those 3 ½ years, sometimes necessitating transfusions). Fevers, occasional night sweats, fatigue and mental fog also increased. After the splenectomy last November Joanne's counts have returned to normal – first time since diagnosis. She now has, for the first time, a number of hours each day when she feels like she did before WM. This has thrilled her! **Bill Paul** had his spleen removed over 30 years ago due to its rupture in injuries from an auto accident. Other than a PneumoVac vaccine every five to ten years, Bill has no restrictions or medications, and it has not caused problems.

Paul Listen writes that his spleen is enlarged, and it isn't clear whether it's affecting his hemoglobin. Paul asks if a Coombs

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HOW TO JOIN IWMF-TALK

Here are two ways to join:

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

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



HIGHLIGHTS OF THE RECENT PATIENT & PHYSICIAN SUMMIT SPONSORED BY THE BING CENTER, DANA-FARBER CANCER INSTITUTE



Photos courtesy of the Bing Center, DFCI



test would determine that. He had one about a year ago at a point when his oncologist was looking for causes of anemia other than bone marrow involvement. Iron malabsorption was finally determined to be a factor, which has been linked with gluten intolerance. At the time of writing Paul had gone gluten-free for a month, and his serum ferritin started taking off “like gangbusters.”

Dr. Tom Hoffman replied that many times the diagnosis of hypersplenism is a diagnosis of exclusion, since there is no direct test. Tom said that if all other identifiable problems are negative after testing and the spleen is large and HgB is dropping, it is appropriate to try medication such as steroids. If that doesn't work, splenectomy is in order. Results, says Tom, are high but not 100%.

Velcade

Elinor Howenstine wrote that she had run into problems with her cornea, specifically “cornea melt” (progressive thinning of the cornea) after being treated with Velcade and asked if anyone else on Velcade experienced any corneal problem.

Dr. Guy Sherwood replied that he'd had Velcade in 2005 – a terrible experience with neuropathy. Guy didn't like Velcade, it spooked him, but he realized that many people have done well with it. As a result he just considers it very toxic, perhaps one of the most toxic “new” regimens out there. Guy looks forward to the “new and improved” second-generation Velcade that has apparently much-reduced neurotoxicity. Guy visits his ophthalmologist every year since diagnosis. He actually has very good vision apart from getting old (Guy's words!) and requiring weak reading glasses. A yearly exam is an absolute necessity, he believes, for WM patients.

Daniel Hachig replied – with the greatest respect, admiration, and appreciation for Guy – that newer dosing schedules for

Velcade show a completely different experience from the old bi-weekly dosing. There are now two good studies (Drs. Rohatiner's and Ghobrial's) that show practically no PN at 1.6 mg/m² once a week dosing, with efficacy just as good as the “conventional” schedule. Daniel thinks the statistical results bode well for themselves, so he would urge caution about being overly influenced by less recent anecdotal experience.

Renee Paley Bain had minimal Velcade, and her mental state is, in her words, just plain foggy, akin to not getting enough sleep. Renee has plenty of physical energy. “I go for moderately vigorous bike rides with no problem.” It's just that “her brain feels like it's turned to oatmeal” and she isn't sure if it's the Velcade or not.

Colin Perott offers that in clinical trials the most common side effects associated with Velcade are asthenic conditions (fatigue, malaise, weakness), nausea, diarrhea, decreased appetite, constipation, low platelet count, peripheral neuropathy (numbness, tingling and/or pain in the hands, arms, feet, or legs), fever, vomiting, and anemia. The most commonly reported serious side effects, he says, are fever, pneumonia, diarrhea, vomiting, dehydration, and nausea. Velcade may cause low blood pressure leading to tiredness, dizziness, fainting, or blurred vision. Following Velcade, one may also experience vomiting and/or diarrhea.

Other discussion points

There were many other discussion topics over the summer quarter, including job discrimination, Rituxan maintenance, neuropathy, mega-doses of vitamins, rouleaux, hemoglobin, R-CHOP, Treanda, stem-cell transplant, and more. For the full monty, we respectfully suggest you tune in online – at least from time to time.

DEFINITIONS OF POST-TREATMENT RESULTS

In case you are interested in the definitions for the results of treatment therapy, below are the scientific standards used for all WM treatment protocols:

MR – Minor Response: A 25% reduction in IgM monoclonal protein and no evidence of increase in signs or symptoms of WM.

PR – Partial Response: A 50% or greater decrease in IgM monoclonal protein, and 50% or greater decrease in enlarged liver, spleen and lymph nodes and no new symptoms.

CR – Complete Response: Serum and urine IgM immunofixation are negative, resolution of any enlargement of liver, spleen and lymph nodes, no malignant cells in the bone marrow, and no signs or symptoms of WM.

Progression: A 25% increase in IgM monoclonal protein or development of symptoms, or physical findings of enlargement of liver, spleen or lymph nodes.

In low-grade non-Hodgkin Lymphomas, such as WM, when treatment becomes necessary, it is usually continued to the point of “best response” – or, as good as it is going to get with the treatment used – whether that is a PR or CR. At this point the disease is often “quiet” and the patient feels well again. Until there is progression, no further treatment is needed, and in this situation can last a long time.



SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

Please note: contact information for all support groups is printed on pages 20-21.

IWMF CHAPTERS--USA

CALIFORNIA

Los Angeles

The Los Angeles WM support group met on August 22 to watch the Ed Forum DVD and catch up on everyone's status. About 20 people attended, including a few first-timers. They were all delighted with the news that UCLA Medical Center is going to have special programs for WMers.

Sacramento and Bay Area

A general meeting took place in June, but the fall is packed with visits by WM experts. In October Dr. Morie Gertz of the Mayo Clinic, Rochester, will be the WM featured speaker at the Lymphoma Research Foundation's weekend conference in San Francisco. Then Dr. Steven Treon of the Dana-Farber Cancer Institute will speak with the group at the Vallejo Kaiser Permanente in November.

COLORADO & WYOMING

The group hosted its summer meeting at the Denver University United Methodist Church, thanks to member and co-leader

Bill Bass. As thanks for its hospitality, the hat was passed and all donations went to the church. Many newly diagnosed patients and their families swelled the crowd to about 25. Individuals shared not just their WM experiences,



From left to right: Roy Parker, Cindy Furst, Eileen Parker, and Bill Bass at the recent Colorado-Wyoming support group meeting.

including clinical trial results, but their doctor contact information as well – in case anyone wanted an alternative. The Leukemia and Lymphoma Society (LLS), which provided snacks and coffee, brought the group up to date on current educational opportunities. Plans for the fall meeting are well in hand: on November 21, the featured speaker will be Dr. Martha Lacy of the Mayo Clinic, Rochester.

FLORIDA

Southwest Florida

Dr. Treon continues his tour of IWMF support groups with a visit to Sarasota in February.

EASTERN IDAHO

The Eastern Idaho WM Support Group is still alive and functioning after the loss of three members in the last two

years. But this is a story about friendship and living well. **Janet Corson-Stanton** and **Barb Britschgi** met in the early 1980's at the Eastern Idaho Health Department. Janet, a public health nurse, and Barb, the public health dental hygienist, covered eight counties from Montana to the north, Wyoming to the east, the Sawtooth Mountains to the west, and SE Idaho to the south. They did a lot of traveling! When Janet's family grew to include two boys, she moved to a home just few houses away from Barb's family, which included six children. Over the years, they watched their families grow and celebrated family milestones together. When, in 2000, Janet was diagnosed with WM, Barb had never heard of it. Then, when she received the same diagnosis eighteen months later, she knew where to turn: to Janet!! Since they had different oncologists, they combined their knowledge. And



A meeting of the eastern Idaho support group: Janet Corson-Stanton on the left and Barb Britschgi on the right.

by then, Janet had attended two IWMF annual conferences. The "group" began with the two sharing and caring around their kitchen tables. Now the two women continue their meetings and their celebrations of life: Janet and Glen's eldest son's wedding and Barb's and husband Jerry's 80th birthdays. Janet and Barb encourage small support groups that may be struggling to keep in contact with one another even if it is just a phone call or the kitchen table cup of coffee since it is quite different to share concerns with someone who has been there versus friends and family, no matter how much they care.

GEORGIA

For Dr. Treon's visit on October 10 the group has invited both the North and South Carolina groups to attend. Dr. Leonard Heffner, a hematologist at Emory Winship Cancer Institute, where the meeting will be held, will also be present.

ILLINOIS

The IWMF Chicago area support group held its first summer meeting and picnic on Saturday, August 15, at the gazebo in Ty Warner Park of Westmont, Illinois, on a very nice sunny day. This became a special time for those attending to share stories and to get to know families within our local WM support group. **Don Brown**, the group's leader, made his famous brats soaked in beer and special burgers. Thanks to our

Support Group News, cont. on page 18





*Under the gazebo:
Chicago area WMers enjoying those brats!*

grandchildren. The next meeting is planned for October 24 at the usual location, the Lutheran General Hospital, Park Ridge, Illinois.

MICHIGAN

On the technical cutting edge – thanks to member **Fred Van Hartesveldt** – the group met in May with Dr. Irene Ghobrial of the Dana-Farber Cancer Institute via video conferencing. The group of about 20 was able to have a question-and-answer session with Dr. Ghobrial as well. The next meeting is planned for October.

MINNESOTA & WESTERN WISCONSIN

The Minnesota & Western Wisconsin support group held its third annual summer picnic on the weekend after the Fourth of July. A dozen people spent a lovely afternoon enjoying one another's company and favorite recipes. Anyone walking past would have thought the party must be a family reunion. On November 14 Dr. Stephen Ansell of the Mayo Clinic will speak on WM at an LRF Regional Workshop in Bloomington, MN. For information, call 800-500-9976.

NEW ENGLAND

Boston

Because the Dana-Farber WM Patient & Physician Summit was held in May, the New England support group meeting was slipped to June. Dr. Treon presented to almost 50 patients and caregivers. Thanks to DFCI, the Bing Center, and to Chris Patterson for getting the function room and providing treats for the group. Once again this fall, **Joe Mara**, the group facilitator, participated in the Dana-Farber Cancer Institute's Jimmy Fund walk to raise money for cancer research. This is another in a long series of events that Joe has been involved in

picnic committee, **Ron Draftz**, **Arline Tufano**, **Hugh Edfors**, and their spouses for all the help in preparation. We had no time for games although the "Spray Water Park" was popular with the



The day at Ty Warner Park was fun for families. Shown here: Melissa Tieman with her daughter, Cassidy Brown, and Cooper the Golden. Melissa and Cassidy are, respectively, the daughter and granddaughter of Chicago area support group leader Don Brown.

to raise money for research in our disease. The next meeting is planned for mid October with hopes for a guest speaker.

NEVADA

Robin Grenz reports that the group has grown to about a dozen members. Hopes and plans for a recent meeting were dashed when the speaker moved away. It happens all too often. She hopes to arrange another meeting soon. Meanwhile, the group interacts via e-mail.

NEW YORK

Eastern NY/Western New England

On August 14 members enjoyed the annual summer picnic at the beautiful home of **Kay and Tom Zolezzi** in Delmar, NY. As the weather was perfect, the group spent the day in their beautiful back yard, enjoying the pool and the gorgeous garden (with many of the plants well marked). There was plenty of delicious food to share, and the conversation, as usual, covered a wide range of interests and topics, even, occasionally, WM. At the late September gathering (at Gilda's Club in Latham, NY) recently diagnosed members were welcomed. The next meeting is planned for November 14.

EASTERN OHIO, WESTERN PENNSYLVANIA, & WEST VIRGINIA

With renewed spirit and hope following the Ed Forum and Boston WM Summit, group members gathered to hear highlights from conference attendees. Members shared their stories with the intent of helping a new WMer struggling with the treatment decision process. All were inspired by a member's remarkable recovery from life-threatening chemotherapy-related problems. Great fellowship and delicious food contributions for the potluck dinner at the home of **Marcia and Glenn Klepac** created a supportive atmosphere.

OREGON/SOUTHWEST WASHINGTON

The October meeting shifted to late September so the group could hear a presentation by Dr. Morie Gertz.

PENNSYLVANIA

*Central and Southeast Pennsylvania
and Northern Maryland*

The annual potluck picnic was held at **Nancy and Larry Lambert's** home, as it has been since they started the group

Support Group News, cont. on page 19

SUPPORT GROUP LEADERS TALK LIST

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



in 2003. Good company and good food (including meat or vegetarian subs, coleslaw, herbed nuts – from Nancy’s Cooks’ Happy Hour column – brownies, and chocolate cupcakes) were shared along with caring concern and encouragement. The group discussed ideas for fund raising. The favorite ideas were a yard or tag sale, selling tickets to a dinner with food and location donated, or a “bake” sale offering just one or two very special items. As some members spend the colder months in Florida, the actual event will not be held until 2010. The winter meetings will be held on Sunday November 8 and February 8 at the Messiah Village Board Room, from 2-4 pm.



From the potluck picnic held at the home of Nancy and Larry Lambert in August. Nancy co-authors the Cooks’ Happy Hour columns.

Philadelphia

Through the magic of technology, Dr. Irene Ghobrial met with the group in August via Web conferencing. Everything went quite smoothly; both sides could hear each other and see each other well. Dr. Ghobrial gave her talk showing her Power Point slides on the screen, and then members were able to ask questions which Dr. Ghobrial answered. The 22



The Philadelphia support group at a recent meeting. Seated at center is support group leader Karen Pindzola with her little white dog, Heidi.

attendees talked enthusiastically about the possibilities of having more such speakers in future and sharing speakers with other support groups. Group member **Ron Yee** and **Joe Massanelli**, the technical person from the local hospital, spent a lot of time setting everything up, as did **Jack Whelan** and **John Paasch** on Dr. Ghobrial’s end in Boston.

SOUTH CAROLINA

Sue Herms, IWMF Trustee and Medical News Editor for the *Torch*, gave an enlightening talk about rituximab and the “new and improved” versions of the drug that are on the horizon. The next meeting will be held in Greenwood, SC, on Saturday, December 12.

TENNESSEE

W. Tennessee, E. Arkansas, N. Mississippi

This summer the group met at its usual meeting place, Memphis Center For Women & Families. There were nine patients and caregivers in attendance. Discussion topics included brief coverage of the 2009 IWMF Education Forum, and then the rest of the meeting was devoted to comparing anecdotes on treatments and results and to welcoming a new member.

Central Tennessee

The Nashville area support group has not been as active in recent months but did meet in August at the Nashville Airport Marriott Hotel. Attendance was small, but spirited, with a discussion of the events of the IWMF Education Forum.

TEXAS

Dallas & Northern Texas

The North Texas WM support group’s September meeting featured its first Web-based video conference. Dr. Ghobrial gave her presentation “Update on WM.” The group greatly appreciates the support of Baylor University Medical Center, Dallas, which provided the meeting room and video conferencing support, and we thank **Jack Whelan**, who arranged the video conferencing for Dr. Ghobrial in Boston. And many thanks again to Dr. Ghobrial for her dedication to finding better treatments and a cure for WM and for giving up part of her Saturday to do the video conference.

WASHINGTON

The Washington group enjoyed a successful and well-attended summer potluck in July at the new home of **Bob and Peg Horton**. The group demonstrated resourcefulness in finding the Horton’s gravel road in the woods – a road that neither Mapquest nor GPS has yet discovered! The group also took advantage of the Lymphoma Research Foundation’s Seattle workshop in September, which included two sessions on WM presented by Dr. Damian Green of the Fred Hutchinson Cancer Research Center. The next support group meeting is scheduled for November 14.



IWMF SUPPORT GROUP CHAPTER LISTINGS

ALABAMA

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

ARIZONA

Phoenix
Ed Nadel
480-502-5045
enadel63@aol.com

ARKANSAS

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

CALIFORNIA

Los Angeles
Kathie Coen
310-454-7127
kdcoen@roadrunner.com

Orange County

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

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

Sacramento

Cynthia Nicholson
916-851-9003
cyn.nicholson@att.net

Santa Barbara

Ceci Menchen
805-687-1736
cici@menchen.sbcoxmail.com

San Francisco

Penni Wisner
415-552-6579
penniw@pacbell.net

COLORADO

Bill Bass
303-753-0070
303-808-5734 cell
wmbass@ix.netcom.com

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

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

CONNECTICUT

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

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

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

DELAWARE

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

FLORIDA

Ft. Lauderdale Area
Charlie Koch
954-476-8726
bonnie143@bellsouth.net

Theo Vagionis
954-564-9262
wesport2@msn.com

Tallahassee

James O'Neill
850-656-5586
jmotlo@comcast.net

West Coast

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

Tampa

Linda Rothenberg
352-688-0316
A1pets@tampabay.rr.com

GEORGIA

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

HAWAII

(Nov. - Apr.)
Sandy Skillicorn
808-891-2882
jLsLs@aol.com

IDAHO

Eastern
Barbara Britschgi
208-522-2130
cbrits@cablone.net

Western

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

ILLINOIS

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

MARYLAND

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

MASSACHUSETTS

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

Judy Christensen
781-335-5698

MICHIGAN

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

MINNESOTA

Minneapolis/St. Paul
Michelle Blazek
651-730-0061
mandsblazek@aol.com

MISSISSIPPI

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

MISSOURI

Nancy Gerhardy
417-889-2461
gerhardy2000@yahoo.com

MONTANA

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

Regional Contact:

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

NEBRASKA

Regional Contact:

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

NEVADA

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

Las Vegas

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

NEW ENGLAND

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

Judy Christensen
781-335-5698

Western MA, VT & CT

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

NEW MEXICO

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

NEW YORK

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

New York City

Neil Massoth
201-444-6253
nmassoth@aol.com

NORTH CAROLINA

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

Don Nolan

828-692-1114
nondolan@aol.com

NORTH DAKOTA

Regional Contact:

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

EASTERN OHIO

Shariann Hall
330-533-4921
shari19@juno.com

Marcia Klepac

412-421-2437
marciaklep@hotmail.com

OKLAHOMA

Western

Regional Contact:

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

OREGON

Joan Berglund
503-668-5037
rjbergie@verizon.net

PENNSYLVANIA

Philadelphia

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

Harrisburg

Terrie Eshleman
717-665-7393
tmes74@ptd.net

W. PENN, E. OH, WV

Shariann Hall
330-533-4921
shari19@juno.com

Marcia Klepac

412-421-2437
marciaklep@hotmail.com

RHODE ISLAND

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



IWMF SUPPORT GROUP CHAPTER LISTINGS

SOUTH CAROLINA

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

SOUTH DAKOTA

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

TENNESSEE

Central & Western

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

Eastern

Regional Contact:
Myrna Daniel
706-539-2866
mdmermer@yahoo.com

TEXAS

Dallas
Jerry Fleming
972-867-2030
NTWMSG@verizon.net

Houston

Barbara & John Manoussou
713-840-0828
wm@manoussou.us

Western

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

UTAH

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

VIRGINIA

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

WASHINGTON

Malcolm Brewer
206-772-7430
clanbrewer@gmail.com

Kristen Jenson
425-483-6605
Kristen@jensonfamily.org

WASHINGTON D.C., NORTHERN VA

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

WISCONSIN

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

WYOMING

Bill Bass
303-753-0070
303-808-5734 cell
wmbass@ix.netcom.com

Regional Contact:

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

INTERNATIONAL SUPPORT GROUPS AND CONTACTS

AUSTRALIA

Gareth Evans
WMozzies-owner@yahooogroups.com

BELGIUM

Joanna Van Reyn
+032 (0) 5033
Joanna.van.reyn@telenet.be

CANADA

Alberta

Cam Fraser
403-281-8278
cmfraser@shaw.ca

Stu Boland
403-281-0271
stu_boland@hotmail.com

Nova Scotia

Susan Gagnon
902-446-9533
Suemar3@hotmail.com

Montreal

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

Ottawa

Terry Cherry
613-596-1413
terry@tccherry.com

Toronto

Arlene Hinchcliffe
905-337-2450
wmfc@noco.ca

Vancouver

Charlene Kornaga
604-487-1100
dennischarlene.kornaga@shaw.ca

DENMARK

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

FINLAND

Veikko Hoikkala
+35 8500 48 4864
veikko.hoikkala@finnforest.com

FRANCE

Nicole Bastin
+02.54.37.89.52
nicbastin@aol.com

GERMANY

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

GREECE

Alexia Kapralou
+30 210 6858574
kapralou_alexia@hotmail.com

INDIA

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

Mumbai & Western India

Sanjeev Kharwadkar
91-98210-69769
92-22-6691-9957
swkharwadkar@yahoo.co.in

IRELAND

Anne Staples
annehstaples@yahoo.ie
+35 353 9158825

ISRAEL

Moshe Kwart
+97 254 2270527
m.kwart@tehilot.com

JAPAN

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

THE NETHERLANDS

Regional Contact:
Marlies Oom
+31 (0) 73.52.17.643
moom@planet.nl

NEW ZEALAND

Sally Simson
+64 3 338 3072
russall@paradise.net.nz

UNITED KINGDOM

Nigel Pardoe & Cheryl Luckie
+44 020 8579 8120
info@septemberservices.com
cheryl.luckie@septemberservices.com

Sussex

Mike Dewhirst
+44 1323 841735
mkdewhirst@yahoo.co.uk

Birmingham & West Midlands

Geoffrey Willsher
+44 0121429 1038
willsher.s@btinternet.com



THE LIFELINE

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

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

TREATMENTS

2-CdA

Norm Spector858-454-6313
nspector@san.rr.com

2-CdA WITH RITUXAN

Bernard Swichkow305-670-1984
theswichkows@aol.com

CRYOGLOBULINEMIA

Fay Langer904-625-3135
fhlander@gmail.com

FLUDARABINE

Peg Horton360-874-6906
peggyhorton@q.com

FLUDARABINE with cyclophosphamide (Cytosan)

Penni Wisner415-552-6579
penniw@pacbell.net

FLUDARABINE with Rituxan

Marty Kopin310-390-1546
mkopin@yahoo.com

Jerry Block301-460-9799
jblock35@comcast.net

ORAL CYTOXAN

Lou Birenbaum314-961-5591
lbirenbaum@aol.com

PLASMAPHERESIS

Fred Bickle805-492-4927
Flb134@msn.com

RITUXAN

Charles Vassallo201-947-6977
cvassallo@nj.rr.com

James Townsend352-376-3664

Allen Weinert603-863-5347
anweinert@gmail.com 760-568-2918

SPLENECTOMY

Kathleen Ugenti631-470-0971

Patricia McCue239-348-3456 winter
802-468-5779 summer

STEM CELL TRANSPLANT

Howard Donley307-587-3397
donleyh@tctwest.net

Sybil Whitman506-450-3970
hcouture@nbnnet.co.com

THALIDOMIDE

Mel Horowitz518-449-8817
wmcure@yahoo.com

VELCADE

Jeff Atlin905-731-7756
jeffatlin@hotmail.com

SPECIALTY TOPICS

CAREGIVING

Lynn Bickle805-492-4927
Flb134@msn.com

Brad Alexander972-529-2002

CLINICAL TRIALS

Tom Hoffmann501-868-8305
Thh97c@msn.com

Guy Sherwood765-282-4377
guysherwood@comcast.net

HEARING IMPAIRED TTY FACILITY

Betty McPhee905-775-3413
bjmcphee@hotmail.com

LATEST RESEARCH

Bert Visheau905-528-1789
visheau@mcmaster.ca

NEWLY DIAGNOSED

Guy Sherwood765-282-4377
guysherwood@comcast.net

Norm Spector858-454-6313
nspectoe@san.rr.com

Sallie Moore516-795-3746
Smooore6042@aol.com

SOCIAL SECURITY DISABILITY

Howard Prestwich815-233-0915
prestwic@mwci.net

VETERANS

Jerry Fleming972-867-2030
ntwmsg@verizon.net

WATCH AND WAIT

Mel Horowitz518-449-8817
wmcure@yahoo.com

Renee Paley-Bain203-744-7851
paleybain@aol.com



THE LIFELINE

YOUNG WM

Nobby Riedy650-879-9104
knobby@wildspaces.net

Bob Bailey770-664-8213
Laurabailey64@gmail.com

INTERNATIONAL

BELGIUM

Joanna Van Reyn +32 (0) 50 33 35 48
Joanna.van.reyn@telenet.be

DUTCH SPEAKER

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

FRENCH SPEAKER

Guy Sherwood765-282-4377
guysherwood@comcast.net

Sybil Whitman506-450-3970
hcouture@nbnet.nb.ca

FRENCH LANGUAGE TALK LIST

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

GERMAN SPEAKER

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

Sybil Whitman506-450-3970
(New Brunswick, CANADA)
hcouture@nbnet.nb.ca

GERMAN LANGUAGE TALK LIST

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

SPANISH SPEAKER

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

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

Gladys Mendieta215-860-9216
Gladysmendieta@aol.com

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

SPANISH LANGUAGE TALK LIST

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

SWEDEN/NORWAY

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

NORDIC COUNTRIES TALK LIST

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

UNITED KINGDOM LIFELINE

2Cda

Roger Brown+44 01285 650107
Rogerbrown961@btinternet.com

FLUDARABINE

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

FLUDARABINE AND RITUXIMAB

Mike Dewhirst+44 1323 841735
dewhirst_6@hotmail.com

OPHTHALMOLOGY

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

PLASMAPHERESIS

Roger Brown+44 1285 650107
Rogerbrown961@btinternet.com

RITUXAN

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

UK SUPPORT GROUP ONLINE FORUM

Raphael Altman
raltman@btinternet.com



THE LIFELINE

CANADA LIFELINE

CLINICAL TRIALS

Jan Jones (Ottawa, ON) 613-722-2385
janellejones@rogers.com

Terry Cherry (Ottawa, ON)
terrence.cherry@sympatico.ca

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

TTY-HEARING IMPAIRED

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

NEWLY DIAGNOSED

Jeff Atlin (Toronto, ON) 905-707-5640
jeffatlin@hotmail.com 905-731-7756

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

Terry Cherry (Ottawa, ON)
terrence.cherry@sympatico.ca

Stu Boland (Calgary, AB)
stu_boland@hotmail.com

WAIT & WATCH

Stu Boland
stu_boland@hotmail.com

Jim Bunton (Toronto, ON) 416-621-7864
jbunton@sympatico.ca

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

2CDA/RITUXAN

Terry Cherry (Ottawa, ON)
terrence.cherry@sympatico.ca

CVP/RITUXAN

Betty McPhee (Bradford, ON) 905-775-3413
bjmcphree@hotmail.com

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

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

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

FLUDARABINE

Jeff Atlin (Toronto, ON) 905-707-5640
jeffatlin@hotmail.com 905-731-7756

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

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

FLUDARABINE/RITUXAN

Bill Gee (Toronto, ON)
wgee@sympatico.ca

RITUXAN

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

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

Susan Gagnon (Halifax, NS)
suemar3@hotmail.com

Terry Cherry (Ottawa, ON)
terrence.cherry@sympatico.ca

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

STEM CELL TRANSPLANT

Olga Anderson (Perth, ON)
olga.anderson@sympatico.ca

VELCADE

Jeff Atlin (Toronto, ON) 905-707-5640
jeffatlin@hotmail.com 905-731-7756

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

VETERANS

Terry Cherry (Ottawa, ON)
terrence.cherry@sympatico.ca

Jan Jones (Ottawa, ON) 613-722-2385
janellejones@rogers.com

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



**SINCE JUNE 2009, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S
MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:**

In memory of Eddy Anderson:
Guy & Faith Sherwood

In memory of Edward Baer:
Benjamin & Cynthia Baer

**In memory of Jim Berg and in
honor of all those who have
helped me through the past
few difficult months:**
Frances Berg

In memory of Jim Berg:
Guy & Faith Sherwood

**In memory of
Murray Bromberg and Sharon:**
Carole Cohen

In memory of Dr. Blythe Brown:
Ray & Vida O'Neil
Marina Skulsky

**In memory of
Michael Coleman-Smith:**
Friends & Family

In memory of Steven David:
Patricia David

In memory of Walter H. Dere:
Laura Dere

**In memory of
Frances Garrett Frye:**
Margaret Groff

**In memory of
Mary Katherine Geldmacher:**
Jim & Louise Thompson

In memory of H. Kay Goldstein:
Michael L. Poss

In memory of Mary Gross:
Raymund & Mary Gross
Gary & Jill Ladwig

In memory of Henry Hoffmann:
Jackie & Carolyn Bosshardt
Linda Hoffman
Paula Mizell
Gene & Sandra Patton
Lynn & Polly Polk
Guy & Faith Sherwood
Lauren Wendel

In memory of Janet Kelly:
Robert Kelly

**In memory of
Frances Robison King:**
Bruce Baker & Rhonda Ligon
Rebecca Brand
William Burton
John & Elizabeth Butterworth
Doris Carter
Donald & Rebecca Chumney
The Board of Directors and
Staff of Circle Center
Adult Day Services
Bryant & Margaret Clarke
Bo & Margaret Dale
Amy Dalton

**In memory of
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Gary & Ormonde Wilkinson
"Bee" Elizabeth Lee Wright

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Brian & Jill Koch
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Faye Koch
Harold & Thelma Millen

**In memory of
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Ed & Patti Lawson & Family
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In memory of Steve Levinson:
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In memory of Marsha Lipman:
Fred Lipman

In memory of Dave Lively:
Jeff & Lisa Rosen
Guy & Faith Sherwood

In memory of Dan Lotts:
Julieann Wexler

In memory of Jim Lowery:
The Rothenberg Family

In memory of Norma J. Michel:
E. Elizabeth Williams

In memory of Gene Mickle:
Bruce & Nadine Byers

In memory of Cecelia Nardelli:
The Rothenberg Family

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Edna Salzberg
Susan Salzberg
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The Wireline Competition
Bureau, FCC
The Wireline Competition
Bureau Front Office
Your Friends at Politico

In memory of Dave Schick:
Barbara Elmhirst
Nigel & Trudine Wilson

**In memory of
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Alden Halloran

In memory of Jackie Smith:
Van & Dolores Crouter
Ken & Edy Deault
Samuel & Patricia Duncan
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Evelyn O. Speinle
Smith Living Trust
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Carol Martin
Gladys Normand
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Locust Hill Country Club

In memory of Doris Sullivan:
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**In memory of
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Ethan & Ashley Busald
Jane Keller
Charles & Honi Kibler
Jesse Portugal
Michael & Johnny Smith
Sherry Tenhundfeld

In memory of Linda Wooters:
Jerry & Beverly Fleming



**SINCE JUNE 2009, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S
MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:**

**In honor of Rosemary Aiello's
75th Birthday:**

Hank & Harriet Fuld

In honor of Keith Anderson:

Richard & Susanne Twomey

In honor of Alve Asquini:

Sandra Borsos

In honor of Jeff Atlin:

Eve Atlin

In honor of Scott Blazek:

Ann Jackson

In honor of Maria Colosi:

Tom Colosi

In honor of Jeff Eickhoff:

Robert & Tara Vincent

**In honor of Marilyn Filler's
Special Birthday:**

Jerry & Marian Michaels

In honor of Stanley Fisher:

Karen Dianda

In honor of John Flanzer:

Alison Mandeville

**In honor of
Joseph & Helen Friedman:**

Lori Ann Stevens-Hogue

In honor of Dr. Richard Furman:

Linda Irving

In honor of Joe Gallo:

Eljay Bowron

In honor of Christopher Hinchcliffe:

United Family Martial Arts

In honor of James Hinchcliffe:

Ian Miller (*Racing for WM*)

In honor of Wanda Huskins:

Vicki Canet

In honor of Catherine James:

Brent James

In honor of Cyrus Karper:

John & Blanche Brais

In honor of Robert Kelson:

Ann Marie Kelson

Richard Kelson

Cheryl Mulhall

**In honor of Richard Lovely's
50th birthday:**

Peter & Janet Atwater

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The Caola's

Scott & Dawn Cohen

Dennis Lynch

Mark & Trish MacIntyre

Randy & Mary Reardon

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In honor of Tom Lovely:

James & Mary Conroy

Matt & Becky Gabriele

T. G. & Mary Whitten

In honor of Juan Jose Martinez:

Ana Wendelken & Berenfeld, Spritzer,

Shechter & Sheer

In honor of Dr. Mary McMaster:

Mindy Caplan

In honor of Marilyn Miller's Birthday:

Marcia Lockwood

Mary Zukowski

In honor of Robert Murenbeeld:

Walter Murenbeeld

**In honor of the birth
of Samuel Boyd Nelson:**

Mr. & Mrs. Vance A. Nelson

In honor of Mike Pennington:

Karen Blocksom

In honor of Anna Mae Quitter:

Janine Quitter

In honor of Joseph Ricci:

Denise Clark

In honor of Judith Salzberg:

Erroll & Elizabeth Segall

In honor of Dave Schenck:

Angie & Mary Cable

In honor of William Sears:

Gary & Belinda Lavergne

In honor of Donald Smith:

Kathleen Patrona

In honor of Hank Stupi:

Paul & June Canter

In honor of Carl Unger:

Megan Andersen

Beverly Coombs

John Coombs

Bill Crabtree

Dennis Lower

Amanda Seitz

Colista Strand

Nadine Unger

In honor of Ubaldo Vitali:

Jennifer Bernbaum

Peter & Helena Hollitscher

Val Iacovantuno

Ralph & Nicole Wagner

WEB CONFERENCING: A GREAT VALUE FOR THE IWMF AND FAMILIES

BY DON BROWN, IWMF TRUSTEE

Seeing and hearing is believing that the IWMF has joined the information technology age to benefit its membership! Two technically savvy Bostonians, John Paasch and Jack Whelan, spent hours of preparation to support Don Brown's and Ron Draftz's IWMF Chicago area support group meeting on May 9. Dr. Irene Ghobrial had accepted Don's invitation to visit and speak in the Chicago area, but everyone wanted to see if we could save both time and travel expenses for the well-known Waldenstrom's expert from the Dana-Farber Cancer Institute in Boston. The solution came with the decision to attempt a real-time presentation via Internet between Boston and Chicago.

This passionate group of WM patients spent many hours of testing and discussing Web conferencing options. After settling on the WebEx conferencing service, our concerns centered on using the secure corporate Internet and phone access at both the Lutheran General Hospital auditorium (Chicago area) and the Dana-Farber conference room (Boston). After several tests, we became confident that laptops at either end of the conference would support the Internet voice and data call using a simple Internet connection. We wanted to make sure that we would simultaneously hear and see Dr. Ghobrial while also watching her detailed slides, all on the large projection screen in the auditorium. WebEx enabled

Web Conferencing, cont. on page 27



all three connections with the computer in the auditorium connected to the auditorium audio system and large video screen. We did not need a phone line even though we used our cell phones and landlines as a backup during testing. A portable microphone connection to the computer in the auditorium enabled attendees to come up and ask questions to Dr. Ghobrial in Boston while those in the auditorium were watching and hearing her response.

Everyone was very pleased with the entire session and had the feeling that Dr. Ghobrial was actually with us. The highlight of the session was probably a special appearance of Dr. Ghobrial's young daughter, Tiana, on camera. She was able to spend the day with Mommy while many WM patients were benefiting from Mom's Internet "virtual" presence. The IWMF was not only "green" and cost effective since no travel was involved, but we were also promoting family values and WM education simultaneously! Thanks to Jack, John, Dr. Ghobrial, and Tiana for making the total conference a resounding success from every perspective.

Subsequently, the Michigan, Philadelphia, and Texas support groups have also used a similar means to bring expert knowledge to their IWMF support group members. Web conferencing service, moreover, offers the potential to make presentations to a number of support groups simultaneously, including international groups, while providing high quality educational value for IWMF members consistent with our fundamental goals to provide hope, outreach, support and research.

The IWMF Board of Trustees is considering using WebEx as a permanent conferencing tool for support group meetings as well as for Board and committee meetings. This capability will enable us not only to further curtail administrative expenses but also to create opportunities for the WM community to become better acquainted while reducing support group speaker expenses. We thank all of those who volunteered to make these ground breaking events happen and thus to enhance IWMF services.

THE LAST WORD

BY SARA MCKINNIE

Office Manager Sara McKinnie has the last word in our newsletter; a space devoted to disseminating specific news bulletins about the many IWMF services managed by the office, soliciting member participation in IWMF activities, and asking your help in keeping up-to-date and accurate the various lists of services printed in each issue of the Torch.

STRATEGIC PLANNING SURVEY

In her 'President's Corner' in this issue of the *Torch*, Judith May discusses the importance of the Strategic Planning Survey inserted in your copies of the *Torch* received in the mail. Judith and the Board of Trustees urge all members of

the IWMF to take the time to complete this survey and return it to the IWMF office.

Members who choose to receive their newsletter electronically (and we do thank those who have elected to do so, thereby saving the foundation significant postage costs) will find the Strategic Planning Survey available at our website, www.iwmf.com.

The IWMF Board of Trustees looks forward to receiving your important input. You can print out the survey, fill it out, and then mail or fax it to the IWMF Business Office.

The Last Word, cont. on page 28

MARK YOUR CALENDAR FOR THE 2010 EDUCATIONAL FORUM IN LAS VEGAS!

The IWMF Board is pleased to announce that our 2010 Educational Forum will be held over the weekend of April 9-11 in Las Vegas, Nevada. We are currently working hard to develop a program that, in keeping with past Ed Forums, will provide something for everyone, no matter what your previous experience or knowledge about WM.

The Ed Forum will be held at the Alexis Park Resort, which offers a tranquil meeting environment but is located just minutes away from all the excitement on the famous Las Vegas "Strip." We have secured a special rate of \$89/night for mini-suites in low-rise buildings set amidst 16 acres of gardens and pools. For reservations call 800-582-2228 (in the Continental United States) or 702-796-3322 from elsewhere and mention that you are with the IWMF Educational Forum. The special rate is valid for up to 3 days before or after the Ed Forum. For more information about the hotel, see the website, www.alexispark.com.

As we finalize the program, additional details will be provided in future mailings and on our website, www.iwmf.com.





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

Telephone 941-927-4963 • Fax 941-927-4467
E-mail: info@iwmf.com • www.iwmf.com
IWMF is a 501(c)(3) tax exempt non-profit organization
Fed ID #54-1784426

The Last Word, cont. from page 27

TELEPHONE AND E-MAIL LIFELINE LIST

We want to hear from those of you who are volunteers participating in the IWMF Telephone and E-mail Lifeline. We are interested to learn how many of you receive calls or e-mails with questions about specific treatments and/or specialty topics. Also, please check the Lifeline List in this newsletter to be sure your contact information is printed correctly. Because the Telephone and E-mail Lifeline List is published at the IWMF website and in each issue of the *Torch*, it is important that this information is kept current. Please also let us know if you no longer wish to participate so that we can remove your name. Send your feedback to Sara McKinnie at the Business Office info@iwmf.com or 941-927-4963. Thank you so much for your involvement in this valuable resource for other WMers who have questions and concerns regarding WM.

FOLLOWING UP WITH AWARENESS PROJECT VOLUNTEERS

Please let us know if you are active in the Volunteer Awareness Project that involves taking IWMF publications and literature to your doctors' offices and contacting other local hospitals and oncology centers in your area.

The Board of Trustees would like to hear about your experiences helping to elevate awareness about IWMF. Please contact the IWMF Business Office and share with us information about the specific healthcare institutions you have visited and report any progress you have made. Please send the names and addresses of the contacts you have made to the IWMF Business Office so that these contacts can be added to the IWMF physicians' mailing list. The goal is to spread the word about IWMF, to find more WM patients and more doctors who treat WM patients, and, ultimately, to increase our membership.

If you are not currently participating but are interested in getting involved in this worthwhile project, please contact IWMF Trustee Elinor Howenstine at 415-927-1536 or e-mail Laraellie@aol.com

