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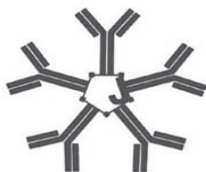
Dr. Shirley D'Sa

HYPERVISCOSITY SYNDROME

CAUSE OF HYPERVISCOSITY SYNDROME

Patients with Waldenström's macroglobulinemia produce an IgM monoclonal protein, a fact that sets this disease apart from other types of non-Hodgkin lymphoma and provides a host of unique clinical challenges. The presence of IgM in the blood provides a 'tumor marker' that can be followed during the course of treatment to gauge the involvement of disease in the bone marrow. However, the presence of IgM within the blood stream may exert damaging effects on the functioning of the body due to its physical, chemical, or immunological properties.

Whole blood comprises red and white blood cells and platelets which are suspended in plasma, a tissue fluid that consists of water, important salts, and proteins, each of which has specific properties. The thickness or viscosity of the blood is determined by the number and size of the blood cells, as well as by the protein constituents of the plasma. An increase in the viscosity of the blood is an important complication encountered in Waldenström's macroglobulinemia. Increased viscosity results from the physical presence of the IgM paraprotein in the bloodstream. This protein is large, owing to its tendency to circulate in clusters of five, known as pentamers.



*IgM pentameric structure
(5 IgM molecules joined together)*

As the level of the IgM protein increases, so does the viscosity of the blood, but the relationship between the two is not linear. As a result, the viscosity of the blood may rise sharply even when there is only a modest elevation in the IgM level. As the viscosity rises, the flow of blood within the vessels slows down, reducing the delivery of oxygen and cellular nutrients to the tissues. The result is an impairment of tissue functions, and in this situation a variety of symptoms occur. This condition is termed the hyperviscosity syndrome (HVS). The incidence of HVS in Waldenström's macroglobulinemia is 10-30%. (1)

SYMPTOMS OF HVS

The symptoms of a raised blood viscosity result from sluggish flow of blood through the blood vessels. When occurring in the cerebral system, this may result in fuzzy-headedness, headaches, blurred vision, double vision, poor concentration and thinking, and, in severe cases, even reduced levels of consciousness. The risk of stroke is also higher under these circumstances.

Sluggish blood flow through the lungs may result in breathing difficulty. While such difficulty may initially occur on exertion, for example walking upstairs or uphill; when the blood flow is more severely impaired, breathing difficulty may happen even at rest.

Impaired flow through the coronary circulation may lead to chest pains due to angina in a patient prone to this problem. In patients with underlying heart problems, the development of 'heart failure' may occur, where the heart muscle struggles to pump effectively due to inadequate delivery of oxygen as a result of poor blood flow. The exertion of pumping more viscous blood through the circulation adds to the stress on the heart muscle. Patients with poor leg circulation characterized by pain when walking that improves with rest (such intermittent pain is known as claudication) may find this problem markedly worse in the setting of hyperviscosity.

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Doctor on Call, cont. from page 1

All the above symptoms may be aggravated by the presence of anemia, which often co-exists with HVS since both problems are more common when the disease is burdensome within the body. Correction of HVS by plasmapheresis is usually needed in advance of a blood transfusion to avert a steep and dangerous rise in blood viscosity.

Another consequence of HVS may be a bleeding tendency resulting from the high shear force of blood flow in the smallest blood vessels or capillaries that causes them to rupture. Nosebleeds or bleeding in the gums, back of the eye (the retina), or the skin may result. It is most important to report any bleeding symptoms to your medical team so that appropriate assessments and investigations can be carried out.



Photo of the retina showing hemorrhages secondary to HVS

DIAGNOSIS OF HVS

The symptoms of HVS can develop gradually as the IgM protein rises. As a result, the onset of symptoms may not be noticed until the situation is severe and may take both the patient and doctor by surprise. If the symptoms described above begin to develop, the possibility of HVS should be considered. (2) The possibility of HVS is greater when the M protein exceeds 4000 mg/dL. The onset of symptoms also depends on the condition of the blood vessel system.

As people get older, their blood vessels become more rigid and may have a reduced diameter due to the depositing of fats such as cholesterol, akin to the “furring up” of a water pipe due to calcium deposition. A patient has an increased chance of developing the symptoms of HVS at lower levels of IgM if his blood vessels are rigid and have a fatty deposit.

The first assessment is a physical examination for signs of a tendency to bleed – bruises on the skin, blood blisters in the mouth or the back of the eye. It is important to view the retina at the back of the eye using an instrument known as an ophthalmoscope. Classical changes include sausage-shaped blood vessels and small bleeds on the retina. It is also important to assess the functioning of vital organs, primarily the heart and lungs.

Blood tests should be carried out to measure the levels of hemoglobin, the IgM protein, and plasma viscosity (PV), as well as the other routine tests of kidney and liver function. The PV is a test carried out in specialized laboratories. Normal plasma viscosity lies between 1.4 and 1.8 cp. As the IgM value rises, the PV level tends to rise according to a logarithmic scale. Typically, a PV of 3.0 cp or less is not associated with symptoms. In most cases, subtle symptoms tend to arise when the PV reaches 4.0 cp. When the PV exceeds 5.0 cp, most, but not all, patients experience some symptoms, and 5.0 cp is regarded as being a critical level by most doctors for taking action to lower the plasma viscosity. However, symptoms can occur at a lower level of PV, and in this case symptoms should take precedence over the measured value of PV.

Doctor on Call, cont. on page 28



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PRESIDENT'S CORNER



Judith May, President

Happy New Year to all. Did you make a New Year's Resolution? We did, and it is: **to contain costs.**

It should come as no surprise that I begin my first column in 2012 with comments on the financial shape of the IWMF, a topic I have addressed in the three previous issues of the *Torch*. Due to the current economic outlook, it is necessary and important that the IWMF Board of Trustees remains focused on adjusting spending to fit with contributions projected for the coming year and into the future. We are determined to tighten our belts as necessary to keep the Foundation financially stable. We are equally determined to continue all Foundation services and to keep you informed of developments. The following is an overview of our 2011 financial status and plans for 2012.

In April of 2011 I wrote of a special appeal I had made earlier, when it was clear that the Membership Fund did not have assets to see us through the year. In June I thanked you, the membership, for your rapid response to the appeal. I pledged at that time that the IWMF would practice even tighter stewardship of the funds you so generously donated. Yet as the year went forward our finances remained precarious, and in the October *Torch* I felt it necessary to remind you of the importance of the Membership Services Fund by itemizing the services that you receive as members of the IWMF. I also emphasized the importance of the Research Fund to the Foundation's mission. And in the same column I noted that there would be more appeals to your generosity coming in the last quarter of 2011 during our annual end-of-year campaign.

Although the final income figures for the end of 2011 are not available as this issue of the *Torch* goes to press at the end of December, we, the Officers and Board Members, are pleased to report that, following the initial appeal, the e-mails regarding fundraising, and the special incentive of a matching fund (already matched! see page 4), contributions as of November 30, 2011, total \$546,718 for the Membership Services Fund and \$236,281 for the Research Fund, with yet another month to go in 2011. Once again you have come through, and there are adequate funds to sustain the Foundation in 2012.

Moreover, thanks to several estate gifts soon to be finalized, the Research Fund's "Five-in-Five" campaign is going to end with resounding success, and our goal of \$5 million dollars in five years will soon be met. Since 2007 contributions to the "Five-in-Five" campaign have been incorporated into the Research Fund and applied directly to the research projects currently supported by the IWMF. For these past five years your contributions have been driving forward important research that has added to our knowledge of all aspects of WM. Our deeper understanding of the disease opens the way to our final goal, a cure for WM. We need to continue our support of the best WM research.

However, as gratifying as our successes may be, the condition of the economy in the US, in Europe – indeed in the world – is hardly stable. With this in mind, the IWMF Board is determined to adhere to a budget in 2012 that will fall well within the contributions that come to us this year. Furthermore, we are committed to putting aside an amount each year to build a safety cushion that will ensure our ability to continue our programs and services into the future, even if the economy continues to be disappointing.

The 2012 budget was reviewed and discussed by the Board over the past several months. A provisional budget has been approved pending the end of year final accounting of contributions and other income. The final budget for 2012 will be frugal and will contain reductions in funding for nearly all Foundation expenditures. We will be challenged, but it is crucial that our spending be reduced and that a portion of income be put aside with a view to future stability.

Our Fundraising Team has provided excellent professional guidance to form our development program, and the program is working well. Our Fundraising Team leader, Trustee Carl Harrington, is now IWMF's Vice-President for Fundraising and a member of the Board's Executive Committee.

With development of a financial base in mind, the Board of Trustees will work continuously to contain costs each and every year and to keep us on a steady financial track. Ideas proposed for cost containment include:

Reducing printing and postage costs by limiting publications. IWMF booklets: revision of booklets due for updating and reprinting will be postponed for the time being. The *Torch*: in 2012 the IWMF newsletter may circulate in three issues instead of four. The proposed measures will go far towards reducing printing and postage costs. The *Torch* Team and editor Alice Riginos will see to it that each issue you receive is just as full of valuable and interesting articles as ever. We also encourage members to voluntarily elect to receive IWMF publications electronically, further reducing production and mailing expense. (See details printed on the back cover)

President's Corner, cont. on page 4



Holding down staff costs by putting a cap on work hours. The current staff of four in the office, all of whom work part-time, will continue to take care of member requests and mailings and to generate data regarding membership, contributions, and other activities of the Foundation. However, more of the analytical reports will be prepared by individual trustees. This will increase the workload for trustees but will save on labor costs. The office staff has already cooperated in finding ways to decrease operating costs for the office.

Limiting Ed Forum costs by seeking more grants from pharmaceutical firms and other corporate grant programs, booking in less expensive hotels, and inspiring more of you to attend the Ed Forum.

Delaying further website development costs by placing a hold for now on incremental value-added developments for the IWMF website until funding is available.

Seeking more support through our growing partnerships with other non-profit organizations to share and co-fund areas of mutual interest.

Curtailling IWMF Board expenses by using teleconferencing and reducing face-to-face meetings.

In all of the Board's deliberations we are reviewing our established programs and services "with the eyes of surgeons," keeping these programs and services alive while cutting whatever is expendable. You will notice that there is one thing we are not cutting back on and that is funding critical research in our search for a cure. Just as a reminder, 100 percent of all research contributions are dedicated to fulfilling this mission of the IWMF.

Finally, of course, we always are looking for volunteers to fill certain niches.

Please call or e-mail our Sara McKinnie at our office (941-927-4963, or info@iwmf.com) with your interests and skills, and we will look for a match where you could be the most helpful. Currently we need volunteers for support group leaders in various locations, fundraising assistance, and a legal advisor.

We are making plans for the 2012 IWMF Patient Educational Forum to be held in **Philadelphia**, June 1-3. We do hope you will plan to attend! Specific details will be forthcoming as we confirm speakers. Be sure to mark the dates on your calendar now: **June 1-3, 2012.**

We are very grateful for your continued support of the IWMF and trust that you understand and will agree with our changes to live within our budget.

Have a healthy and happy New Year.
Judith

MATCHING GIFT FUND SUCCESS

We are thrilled to announce that our 2011 matching grant challenge for the Membership Services Fund has been met thanks to the generosity of the WM community. As you may remember, we originally had a pledge of \$50,000 to match your gifts. More WMers soon stepped forward to add to the pledge amount, and in the end we had a total of over \$80,000 in the matching gift fund. Contributions came in to match the pledged amount, and we were able to qualify for every single dollar in the matching fund. The IWMF received a total of \$160,045 for Membership Services! Thanks go to everyone who pledged and contributed.

Of course, we all know that there is still much to do to accomplish the IWMF vision: *Support everyone affected by Waldenstrom's macroglobulinemia while advancing the search for a cure.* We hope some of you will be inspired by the article on page 5 about the new Ben Rude Society members and consider joining them with a generous legacy gift from your estate for the IWMF. See page 6 for more details or call Dave Benson at 952-837-9980 to discuss a matching gift or an estate gift.

Thank you for your support and best wishes for a happy and healthy 2012!

The IWMF Fund Raising Team,
L. Don Brown, Carl Harrington, Dave Benson, Dick Weiland, and Julie Jakicic



NEW INDUCTEES IN THE BEN RUDE HERITAGE SOCIETY

BY CARL HARRINGTON, VICE PRESIDENT FOR FUND RAISING

In honor of the second president of the IWMF, the Ben Rude Heritage Society was established in 2008 by Laurie Rude-Betts to keep Ben's leadership and legacy alive. Currently there are twenty-six members of the Society. All have made provisions for the IWMF through bequests, gift annuities, trusts, insurance policies, or similarly planned gifts. In 2008 the Society received over a quarter of a million dollars. Three short years later, that number has risen to \$1,034,074. We have crossed the million-dollar mark!

Three new inductees in the Ben Rude Heritage Society were honored in June at the Ed Forum in Minneapolis. One of them, who chose to remain anonymous, has named the IWMF as the beneficiary of her IRA.

The second new inductee is Ric Moore. Ric joins his mother, Eleanor Moore, and his sister, Lesley Moore Bradstreet, as members of the Society. At the 2010 Ed Forum in Las Vegas, as many of you will remember, Eleanor and Leslie were welcomed into the Ben Rude Heritage Society. The story of the Moore family's generosity to the IWMF is as follows. Eleanor Moore and her husband owned farmland in Nebraska where they raised their family. Upon retirement they placed one of the farms in a charitable remainder trust set up to provide income to the two senior Moores for their joint lives. At that time they named several local charities as eventual beneficiaries, but over the years the charities they had identified ceased to exist. Needing to identify new charitable beneficiaries, Eleanor asked her two children, Lesley and Ric, to choose a charity or charities that they thought would be worthy of support. Lesley has been a close friend of Cindy Furst, one of our Trustees, from the time that they pledged a sorority at Northwest Missouri State University. Because of their deep friendship, Lesley opted to direct half of the trust to the IWMF. Since the last Ed Forum, when Eleanor and Lesley were honored, Ric Moore, a high school math teacher and tennis coach, decided that he would recommend directing the other half of the trust to the IWMF. So this year we thank the entire Moore family for their generosity to IWMF and their pledge to the importance of friendship. Thanks as well to Cindy for her help in making this gift possible.

The third new member is our own Senior Development Officer, Dave Benson, whom many of you have come to know. Dave has made a gift naming the IWMF as one of



At the 2011 Ed Forum, President Judith May presented the IWMF award for outstanding service to Dave Benson.

his beneficiaries of a testamentary charitable remainder trust. His gift is in memory of his best friend, Dave Hetland, who died from pulmonary hypertension, another orphan disease. The death of his friend has also motivated Dave to work on behalf of the IWMF. Dave Benson has been an integral part of the IWMF since 2008, and it is with his help, and yours, that the IWMF is able to provide new and veteran patients, caregivers, and families the services and research funding we all so very much appreciate. To Dave, many thanks for your work with the IWMF and your estate gift!

The roster of members in the Ben Rude Heritage Society reflects a cross section of our membership. Few members are what you would call wealthy and most have family members to provide for, but they all have set a priority on providing a portion of their estate for the Foundation after they pass away. They have made these provisions knowing that the need will continue for support for the newly diagnosed and their families and for additional research to identify improved treatments and to search for a cure for our disease. If any of you are thinking about your personal estate planning and can find a way to donate some of your resources to enable the IWMF to continue serving members and supporting research, please contact Dave Benson.

Dave can be reached at 952-837-9980 and dave@dbenson.com.

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 *Torch* editor Alice Riginos at ariginos@sy-thetis.org





THE BEN RUDE HERITAGE SOCIETY ENROLLMENT

The International Waldenström Macroglobulinemia Foundation (IWMF) cordially invites you to become a member of the Ben Rude Heritage Society. Your legacy is an inspiration to others. Please indicate below your acceptance of enrollment in the Ben Rude Heritage Society. We hope also that you will consider providing information about your legacy so that we have a full understanding of your wishes. If possible, please attach supporting documentation. Thank you.

LEGACY GIFT

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

____ Will ____ IRA/retirement-plan beneficiary designation

____ Trust ____ Charitable remainder trust

____ Other _____

Additional information: _____

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

☐ IWMF's greatest need ☐ Research Fund ☐ Dr. Kyle Endowment Fund

☐ Other Named or Designated Fund _____

GIFT DETAILS

As of this date, the value of my/our gift is:

the sum of \$ _____ or _____% of my/our estate or other gift plan,

with the current value of the IWMF portion estimated at \$ _____.

I/we understand that my/our estate **is not** legally bound by this statement of gift value.

RECEIPT OF GIFT

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

____ the first donor ____ the surviving donor/spouse

____ other individual(s) _____

____ other contingencies or stipulations such as: _____

BEN RUDE HERITAGE SOCIETY HONOR ROLL LISTING:

Name(s) _____

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

____ Please do not list my/our name(s) in the Honor Roll and ____ in all other publications.

____ Typically, IWMF recognizes Heritage Society membership with a recognition piece. Check here if you prefer not to receive this token of appreciation.

(Note: All information will remain confidential to IWMF)

____ Donor Signature ____ Date of Birth ____ Date

____ Donor Signature ____ Date of Birth ____ Date

*For further information about the Ben Rude Heritage Society, please contact
Dave Benson at 952.837.9980 or dave@dbenson.com*

Please mail completed enrollment form to: IWMF Business Office, 3932D Swift Road, Sarasota, FL 34231



SURVIVORSHIP IN CANCER PART 2: CANCER FATIGUE

BY GUY SHERWOOD, M.D., IWMF TRUSTEE

While the cancer survivorship experience encompasses many different physical and emotional ordeals, virtually all survivors – irrespective of the cancer – would place cancer related fatigue (CRF) high on the list of constant challenges.

I was diagnosed with WM in early 2001 at the relatively young age of 40, and I remember vividly the very difficult phone call I made to my father to inform him of my illness. My father, who is well educated but certainly not someone with any medical training to speak of, made a most prescient remark: “Guy, the hardest thing you will have to deal with is the fatigue and loss of energy.” At first I dismissed his comments – my father had never experienced a serious illness like cancer and was after all a corporate lawyer, not a health care professional. Over the past 10 years, however, I can absolutely affirm that Dad was quite right and that fatigue has indeed been the single most difficult part of the cancer survivorship experience for me personally. One that I deal with virtually every single day.

INTRODUCTION

Cancer-related fatigue (CRF) is a highly prevalent, disabling, and distressing symptom experienced by both active cancer patients and long-term cancer survivors. In survey after survey cancer patients and survivors describe CRF as “overwhelming” or “all-encompassing” and rate CRF as more distressing than any other cancer or treatment-related symptom, including pain.

CRF often begins pre-diagnosis and treatment and often persists for years after discontinuation of cancer treatment, throughout survivorship to end of life. More than 90% of patients will experience CRF at some point in their disease course.

CRF is associated with decreases in physical, psychological, and social functioning: all important aspects of the much overlooked Quality of Life (QOL) metric. Not only is CRF under-treated, but health-care professionals often do not fully understand the significant degree of distress and functional loss that it may engender. Many patients are hesitant to discuss CRF with their physicians in order to avoid being labeled as a “complainer.” Perhaps the single most important barrier to the recognition and management of CRF is the fact that fatigue is subjective, not life-threatening, and that we tend to view CRF as an inevitable consequence of illness.

DEFINITION

The National Consortium of Cancer Centers defines cancer-related fatigue as an unusual, persistent, subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning. The National Comprehensive Cancer Network defines CRF as a distressing, persistent, and subjective sense of tiredness or exhaustion related to cancer

or cancer treatment that is not proportional to recent activity and interferes with usual functioning. What is now clear to many health care professionals is that CRF has a notably different quality and severity from ordinary fatigue, has an adverse impact on function, and is unrelieved by rest or sleep.

DIAGNOSIS AND CLINICAL FEATURES OF CRF

CRF is characterized principally by decreased energy levels and an increased need for rest disproportionate to any recent change in activity level. It is often associated with other symptoms: generalized weakness, diminished mental concentration, insomnia or hypersomnia (too much sleep), treatment noncompliance, emotional lability (having emotions that tend to change quickly and spontaneously – “mood swings”), and emotional and spiritual distress for both the patient and his or her family members.

According to the International Classification of Disease (ICD)-10, a physician may make a diagnosis of CRF provided that the patient has a known malignancy and experiences daily persistence of the symptom for more than 2 weeks, as well as 6 of the following 11 symptoms: diminished energy, increased need for rest, limb heaviness, diminished ability to concentrate, decreased interest in engaging in normal activities, sleep disorder, inertia, emotional lability due to fatigue, perceived problems with short term memory, and malaise following exercise and exceeding several hours. The physician must also be fairly certain that the underlying cause of CRF is cancer or its treatment.

ETIOLOGY AND RISK FACTORS

There appear to be multiple causes and risk factors for CRF. The differences in occurrence and severity of CRF from patient to patient do not appear to be related to demographic variables such as gender, age, marital status, and employment status; nonetheless, among cancer patients fatigue is associated with the duration of both disease-free survival and overall survival.

CRF is more prevalent and severe during chemotherapy administration. As noted earlier, CRF is experienced by up to 90% of patients during chemotherapy: symptoms are generally most intense during the first three days following chemotherapy administration and subsequently improve slowly over the next few weeks.

The underlying biological mechanisms involved in CRF are not well understood. Abnormalities in biochemical and physiological systems have been implicated in CRF and affect both central and peripheral systems. Central mediated fatigue originates in the central nervous system and appears to disrupt normal transmission of nerve impulses; muscle and related tissue fatigue is a peripheral manifestation of CRF.

Survivorship in Cancer Part 2, cont. on page 8



The most readily identifiable causes of CRF may be related to: anemia; bone marrow suppression; mood disorders; coexisting symptoms such as pain or sleep abnormalities; serum electrolyte abnormalities (low or high potassium or calcium, for example); cardiopulmonary, liver, or kidney dysfunction; hypothyroidism; low sex hormone levels (menopause or andropause); adrenal insufficiency; infection; malnutrition; debility; skeletal muscle atrophy or weakness; and the adverse effects of medications. Sleep and rest abnormalities may represent one of the more common symptoms in CRF patients.

Patients with immune system cancers, of which WM is an example, may be especially prone to abnormalities in cytokine (biological response modifiers) levels. As is well known in WM biology, cytokines are released by the WM tumor in response to treatments. We are already quite familiar with the administration of biological response modifiers (interferon, for example) for therapeutic purposes and the onset of severe fatigue. Pro-inflammatory cytokines such as interleukin-1 β (IL-1 β), interleukin-6 (IL-6), and tumor necrosis factor α (TNF- α) have been implicated.

Indeed, treatment with antibodies directed at pro-inflammatory cytokines appears to reduce fatigue in patients with rheumatoid arthritis (an auto-immune disease with symptoms similar to WM). Reduced levels of immune system natural killer cells and natural killer cell activity have been associated with increased CRF symptoms (author's note: as someone who has experienced zero levels of natural killer cells and immune system cells during stem cell transplant, I can certainly attest to the indescribable feeling of fatigue one experiences with a white blood cell count of "0"!).

Elevated levels of circulating cytokines and their receptors (most notably IL-6) have been observed at initial diagnosis and disease progression. These biological response modifiers may result in worsening anemia when erythropoiesis (production of red blood cells) is suppressed. The cytokine tumor necrosis factor (TNF), frequently implicated in WM pathophysiology, has been associated with abnormalities in central nervous system function, particularly transmission of nerve impulses. Interferon(s) can engender neurological fatigue, the condition known as neurasthenia. Cytokines such as interleukins, interferon- γ , leukemia inhibitory factor, and, in particular, tumor necrosis factor can function as cachectins, resulting in cachexia, a condition of marked tissue wasting and weight loss. The IL-6 cytokine has been associated with depression, with fatigue as a major component. Other symptoms such as anorexia, fever, infection – all of which certainly can contribute to fatigue – have been associated with abnormalities in cytokine regulation.

Given the incredible advances in molecular and genetic technology, researchers are now able to identify genes that influence the development of CRF. Cancer-related fatigue symptoms are quite likely to be controlled by a number of

gene polymorphisms (gene variations and mutations). Genes responsible for the production of cytokines in particular can have more than one effect on fatigue symptoms. Some researchers suggest as well that certain genes that control depression and/or pain may contribute to CRF.

EVALUATION OF THE PATIENT WITH CRF

The National Comprehensive Cancer Network recommends that every patient be screened for cancer-related fatigue. Although there is currently no consensus concerning the optimal method or frequency of screening for CRF, fatigue should be assessed quantitatively on a 0 to 10 scale (no fatigue to worst fatigue imaginable). Individual patients with a severity of more than 4 should be further evaluated by a comprehensive history and physical examination addressing cancer treatment history, coexisting medical problems that may amplify CRF, and other associated symptoms. It is obviously important to determine whether disease progression or recurrence could be among the principal causes of fatigue. Fatigue frequently occurs in association with pain, depression and anxiety, shortness of breath, insomnia, as well as other symptoms.

Medications can often intensify fatigue. The patient's medication profile needs to be reviewed in order to identify specific classes of medications (including over-the-counter medications and "natural" supplements) as side-effect profiles may worsen fatigue. Medications such as opioid analgesics (e.g. morphine), sedative-hypnotic agents, benzodiazepines, and anxiolytics often contribute to fatigue symptoms. Antidepressants, anti-nausea, antihistamines, and anticonvulsant medications also have the potential to produce daytime sleepiness and fatigue. Some cardiac and blood pressure medications (beta-blockers, for example) may contribute to fatigue. Corticosteroids (such as prednisone and dexamethasone) may contribute to fatigue by disrupting sleep and when used for extended periods of time may cause proximal muscle weakness and in some cases tissue wasting.

PHARMACOLOGIC AND NON-PHARMACOLOGIC INTERVENTIONS

CRF typically has several different causes in any one patient; therefore the treatment plan must be multidimensional and individually tailored. Given that it is unlike any other fatigue that patients with cancer have experienced, its unpredictability and intractability to self-management strategies may contribute to the frustrations patients often associate with CRF. Frank and open discussions between the patient, family, and health-care team will lead to a treatment plan that may properly address the experience of fatigue and its effects on daily life.

Balancing rest with physical activity plus optimization of the patient's nutritional status coupled with soul-restoring distractions such as listening to music, spending time in natural environments, and other beneficial activities are

Survivorship in Cancer Part 2, cont. on page 9



simple and effective strategies that can often mitigate the unpleasant experiences that accompany fatigue.

Physical inactivity and resultant deconditioning is very common among cancer patients. Exercise improves aerobic capacity, prevents muscle loss and deconditioning, and can produce beneficial effects on sleep, mood, and the immune system – all the while boosting the patient's morale. Whereas many cancer patients are simply too tired to be active, and in some cases too demoralized, a structured rehabilitation program can result in significant and sustained improvements in fatigue, particularly in patients who have completed treatment and are in survivorship mode. Rehabilitation programs comprising a structured combination of intensive exercise, physical training, group sports and activities, and other physical modalities such as yoga and massage are very successful in not only improving symptoms of fatigue but also improving quality of life. Cancer survivorship centers often offer therapeutic rehabilitation programs during the course of several weeks of inpatient rehabilitation when necessary.

A wide range of pharmacologic and non-pharmacologic interventions has shown initial promise in reducing CRF symptoms. Non-pharmacologic interventions for fatigue during and after cancer treatment can be quite helpful. There is increasing evidence to support the efficacy of selected complementary therapies such as acupuncture, yoga, Tai Chi, Qigong, assisted relaxation, mindfulness-based stress reduction, massage, healing touch and Reiki, reflexology, and even aromatherapy in the management of CRF.

The following are found to improve fatigue symptoms in cancer patients: educational interventions and psychological support to optimize exercise activity levels and sleep or rest; coaching to enhance motivation, self-care, and active coping; praise and encouragement to promote self-efficacy and augment feelings of control. Cognitive-behavioral therapy designed to improve sleep quality is particularly helpful in the treatment of CRF.

The judicious use of medications can serve as a useful adjunct in the treatment of CRF. Methylphenidate (Ritalin), a central nervous system (CNS) stimulant, has been used most extensively to treat fatigue in cancer patients. Numerous well-designed clinical trials have examined the efficacy of methylphenidate in alleviating CRF. Modafinil (Provigil), used to treat excessive sleepiness caused by narcolepsy, has successfully been used in breast cancer survivors who reported less fatigue even after a two-year duration of CRF.

Antidepressants have not consistently been shown to alleviate CRF in depressed cancer patients. Studies using antidepressants in cancer patients revealed improved depression scores but no change in fatigue levels.

The nutritional supplement L-carnitine (biologically active form of carnitine) is used widely in the body building community as a number of studies have demonstrated that

oral carnitine reduces fat mass, increases muscle mass, and reduces fatigue. Regular supplementation of L-carnitine has been shown to contribute to increased energy metabolism and improved neurotransmitter function in selected populations, particularly the elderly. A small number of targeted studies have also shown some benefit in CRF.

The perennially controversial (it seems) topic of the treatment of anemia with erythropoiesis-stimulating agents (Procrit or Epogen, Aranesp) has been studied extensively in CRF with mixed results and thus unclear resultant recommendations. Systematic reviews and meta-analyses of multiple clinical studies suggest that patients receiving recombinant erythropoiesis-stimulating agents (ESAs) to correct anemia (hemoglobin less than 10 g/dL) may experience increased vigor and diminished fatigue. There is, however, limited evidence that ESAs improve fatigue when the anemia is less severe. The risks associated with the use of these agents, which include an increased risk of thrombotic events (blood clots), hypertension, pure red cell aplasia (diminished bone marrow production), and decreased disease control and survival outcomes in selected cancers, must be considered in an objective manner.

Despite the moderately promising treatments currently available for CRF, it is clear that further randomized clinical trials are needed to identify and study newer interventions that can be most effective in treating CRF in specific subpopulations (such as stem cell transplant recipients, older adults, cancer survivors, and those at the end of life).

CONCLUSION AND FUTURE DIRECTIONS

Cancer-related fatigue continues to be the most common symptom experienced by cancer patients in treatment and by cancer survivors. Continued scientific investigations delineating the pathophysiology and etiology of CRF have resulted in improved interventions that can be used in reducing this most vexing of symptoms. Careful observation and examination of patients, particularly in identifying and treating coexisting medical conditions that may be contributing to fatigue symptoms (including deconditioning, impaired sleep quality, mood disturbances, and cardiovascular or endocrine disease), are absolutely essential to improve quality of life, not only for cancer patients and survivors but also for their family and loved ones.

In a recent comprehensive oncology nurses' study (thank goodness for nurses!) the most frequently quoted coping strategies used by cancer patients afflicted with CRF were to "learn to live with fatigue" and to "rely on willpower to overcome the feeling." It appears that patients in this study pushed themselves to do things – "where there is a will there is a way."

I am an eleven-year WM survivor. I have undergone numerous treatments in the past and will undoubtedly require



more treatments in the future if I am to break the world record for longevity in WM. My father was right: cancer-related fatigue is my biggest cancer-related complaint. My various and numerous coping strategies for living with fatigue have included, but were not limited to, increased exercise, modifying my diet by eating “healthy” foods (like chocolate and red wine), planning ahead to ensure enough energy for things that are important to me, sleeping more, laughing more, enjoying music, meditation, cutting back on some activities while increasing the more pleasant and rewarding activities, and relying more on family and friends. Perhaps

the most effective coping strategy for me, one that has not been discussed in this brief article, is my volunteer activity in cancer patients’ organizations such as the IWMF. I have had the good fortune to meet so many vibrant and life-loving individuals in this organization who have always lifted my spirits despite the all-too-often periods of bone weary fatigue that threatened to ruin my day.

Playing with my beautiful one-year old granddaughter also helps a great deal.

REACHING FOR A DIFFERENT BRANCH: KAREN LEE SOBOL’S JOURNEY FROM WALDENSTROM’S MACROGLOBULINEMIA TO RECOVERY

REVIEWED BY WANDA HUSKINS



Karen Lee Sobol

Twelve Weeks – An Artist's Story of Cancer, Healing, and Hope by Karen Lee Sobol is a riveting personal account of the author’s cancer quest that has resulted in an enduring recovery. Karen Lee describes the disturbing medical symptoms leading to her eventual diagnosis of Waldenstrom’s macroglobulinemia and her choice of the treatment that led to her status, even today, as cancer-free. Her cancer story is a personal narrative that is

both unique and exceptional. *Twelve Weeks* offers for the first time a vivid portrait of Waldenstrom’s macroglobulinemia, a rare, mysterious cancer allegedly without a cure. Karen Lee’s cancer memoir becomes even more dramatic as she enters into a clinical trial for frontline treatment. This decision evokes a heroic and pioneering spirit, but she calls it simply “reaching for a different branch.” The “different branch” turned out to be a new monoclonal antibody called alemtuzumab offered to her in a clinical trial by her oncologist, Dr. Steven Treon at the Dana-Farber Cancer Institute. For Karen Lee, enrolling in this twelve-week study was her branch back to health. The achievement of a complete response (CR) at the end of the clinical trial meant that there was no detectable cancer found in her body. In the case of a cancer deemed without cure, Karen Lee’s successful treatment challenges the very concept of WM as “incurable” and may have ushered in a new era of forecasting a cure for this cancer. *Twelve Weeks* will

offer inspiration to all people facing the daunting challenges arising from a diagnosis of incurable cancer and hopefully enable them to consider different treatment options, including clinical trials.

Karen Lee creates a retrospective of her world prior to a life-altering diagnosis of WM. In 2004 at age 56 she is an accomplished artist living a comfortable and conventional life in Boston with husband Bill and daughter Sara. Healthy eating and exercise to stay trim and fit come naturally to Karen Lee. She is, as she says others would describe her, “the healthiest person we know.” Probably cancer, her own that is, would not have intruded on her thoughts or plans. But odd symptoms did begin to appear. Uncharacteristically she began to experience shortness of breath, joint pain and stiffness, and leg cramping. Inevitably symptoms would abate only to flare again with intensity. Eventually Karen Lee found herself with escalating leg pain and immobility. Initially her doctor seemed unalarmed and offered her reassurance that there was nothing wrong. Karen Lee continued to live her life, albeit more slowly, keeping up with the hectic pace of social and family obligations. Finally, towards the end of 2004, blood work results offered the first clue that something could be seriously wrong. The CRP (c-reactive protein) level and the ESR (erythrocyte sedimentation rate) were elevated and suggested an inflammatory condition. Despite a thorough rheumatological work up this unsolved medical riddle continued. And, as is all too often the case with this disease, testing led to more testing. Eventually CT scans were done followed by an endoscopy, and then an endoscopy with a biopsy. Karen Lee finally learned that her diagnosis was lymphoma. A bone marrow biopsy further defined

Reaching for a Different Branch, cont. on page 11



it as Waldenstrom's macroglobulinemia. Her blistering description upon learning of her diagnosis will cause every cancer survivor to relive those unraveling moments of fear that followed their own shocking diagnosis.

Distressed, confused, and in the throes of an immobilizing panic, Karen Lee's mind attempted to incorporate the implications of having this disease. Family, friends, and her own inner strength and intelligence propelled her forward. The Internet would eventually become her partner in navigating this new and terrifying terrain. She is reassured that "for now" she does not require treatment and can continue all of her normal activities under "watchful waiting." But this "watch and wait" approach was short lived, and in less than five months intervention became necessary. Karen Lee consulted and listened intensely to the knowledgeable individuals in her life, even a neighbor who was a Nobel Prize contender (fearing long-term results, he dissuaded her from treatment with fludarabine). Ultimately she landed at the door of the Dana-Farber Cancer Institute to consult with a highly respected expert in WM, Dr. Steven Treon.

The reader is next invited to step into a multilayered landscape of cancer treatment care portrayed with the depth and texture one finds in the artistic depictions by Karen Lee that illustrate the book. Her artwork itself demonstrates openness and creativity in using different media to complete a project. Yet while ill Karen Lee seems to suspend her actual artistic work and to channel her creativity into a new project: battling cancer. She relied on many approaches to creatively recapture her health. Included in her palette were holistic treatments like yoga, meditation, herbal drinks from a practitioner who encouraged Eastern medicine, and positive visualization and thinking. These non-traditional ways of contending with cancer enabled her to participate actively in her treatment and served to reinforce her faith and confidence in Dr. Treon's scientific approach. Karen Lee became convinced that she would overcome this disease.

The author's very dynamic decision, however, to embrace a clinical trial deserves more attention and wider discussion. Critical analysis of the thought process leading to this bold determination would be of interest to readers who, like Karen Lee, find themselves on the verge of a critical decision about a potentially risky treatment for themselves. Enrolling in the alemtuzumab trial was, to use her metaphor, most definitely a "different branch." But the author does not share with her readers the introspection that led her to reach for it.

Karen Lee started the alemtuzumab (Campath) trial on September 21, 2005. In *Twelve Days* she captures an unsettling image of that first infusion. Her heightened emotions make her particularly sensitive to her surroundings. The reader succumbs to her unease and fear of the unknown. While there is no certain predictor of how an individual will react to a medication, least of all to a research drug, Karen Lee was well informed about all possible outcomes before signing

consents for the trial. Like other monoclonal antibodies, alemtuzumab comes with a high risk for an allergic reaction, particularly during the initial infusions. The rigors Karen Lee experienced, while uncomfortable, were not unusual and were promptly treated. As her course of treatments continued for weeks, fatigue became a steady companion – but so, too, was her husband Bill, who was frequently the one at her side during those long days of infusions.

For Karen Lee the infusion room was never a comfortable arena for socializing with others. Like many she preferred her privacy but remained hyper-vigilant and vulnerable to all that was going on in this most unnatural of settings. Later in her treatments she did find herself opening up and engaging in brief conversations with others. She mentions a breast cancer survivor who had relapsed and was receiving a harsher treatment. Despite fatigue this woman had to go into work after her infusions. During these short exchanges Karen Lee was put in touch with the hardships of others. Interactions of this kind can be healthy for the cancer patient as they deflect us from our own self-involvement.

Karen Lee discusses her laboratory findings infrequently, but we do learn that midway through her twelve weeks there was a significant drop in her M-spike and IgM. The "Mighty Team," as Dr. Treon refers to his staff, received this news with excitement. It meant that Karen Lee had already achieved a major response to alemtuzumab. And Karen Lee's mood picks up with this very welcome news. She is buoyant in her optimism and concludes she is on the right path to wellness. Continuing with her holistic approach, she finishes out the twelve weeks with alemtuzumab, convinced that this integrated approach is outsmarting her cancer.

However, finishing the trial did not eliminate the possibility of adverse effects occurring from the monoclonal antibody. Just when she thought her immune system was no longer under assault and was on the road to recovery, Karen Lee was stricken with a rapidly rising rash. A late consequence of this drug, the rash ultimately covered most of her body and was very painful. She landed back in the infusion room, this time for steroids. Even then recovery from this rash was disappointingly slow. Still, at long last when the results were all in, Karen Lee had her victory: a complete recovery.

Despite Karen Lee's success in this trial, it seems fair to mention that she was the only participant to achieve a CR. Whether or not a CR could have been achieved with another monoclonal antibody, such as Rituxan, is uncertain. Karen Lee seems unconcerned with speculating about "what if" and remains steadfast in the conviction that her efforts, the medication, and Dr. Treon's "Mighty Team" combined to produce the creative force behind these lasting results.

Karen Lee's CR has lasted for over five years. Many cancers use the five-year mark to indicate that an individual is cured



of his cancer. But WM remains marked as an incurable lymphoma. However, the many scientific strides made over recent years lead one to feel very optimistic about future trends. With improving survival rates and increasing breakthroughs in research, we may indeed be moving towards the day when we hear WM declared curable. This will only happen with continued contributions to research and participation in clinical trials. Truly, Karen Lee is to be applauded for promoting this cause.

For those with WM as well as for those who have a loved one with the disease, *Twelve Weeks* will offer a much-needed message of hope and encouragement and will empower them to consider – as Karen Lee did – many available approaches. “Watchful waiters” will take comfort in Karen Lee’s tale knowing that research and breakthroughs are moving apace while they continue to enjoy good health and to benefit from scientific advancements. In fact, a wider audience of folks

with all types of blood cancers, or indeed anyone diagnosed with an incurable cancer, will undoubtedly adopt a more life-affirming perspective after reading *Twelve Weeks*.

Wanda Huskins lives in New York and works full time as a registered nurse specializing in Behavioral Health. She was diagnosed with WM in 2008 and is currently on maintenance Rituxan. She is also enrolled in Dr. Treon’s Familial Studies and his WM Genome Research program. She can be reached at lymphomation@yahoo.com.

Twelve Weeks – An Artist’s Story of Cancer, Healing and Hope by Karen Lee Sobol is available at amazon.com in paper cover and as e-Book.

For more information, visit twelveweeks-thebook.com or Facebook *Twelve Weeks – An Artist’s Story of Cancer, Healing and Hope*

MEDICAL NEWS ROUNDUP

BY SUE HERMS

Rituximab Treatment Blocks Immune Response to Flu Vaccination – A multi-center Norwegian study investigated whether lymphoma patients undergoing rituximab-containing treatment regimens or having received such regimens within the last six months were able to mount a protective immune response to the H1N1 influenza virus vaccine during the 2009 swine flu pandemic. Contrary to the control group, where 82% responded to the vaccine, none of the 67 lymphoma patients who recently received rituximab achieved protective antibody titers. The authors suggested that physicians who care for such patients should be aware that their patients may fail to respond not only to the influenza vaccine, but also to other common vaccines.

Biovest Receives Orphan Drug Designation for BiovaxID in WM – Biovest International, Inc., recently obtained Orphan Drug designation from the U.S. Food & Drug Administration for BiovaxID to cover the treatment of WM. BiovaxID is a personalized, patient-specific therapeutic cancer vaccine designed to stimulate the patient’s own immune system to recognize and destroy cancerous B-cells that may remain in the body or may arise after the patient has been treated with chemotherapy. This advances Biovest’s plans to develop and commercialize Biovax ID for the treatment of multiple subtypes of B-cell lymphoma. With Orphan Drug Status, Biovest gains seven years of market exclusivity, thereby offering competitive protection from similar drugs of the same class. Orphan Drug status also allows Biovest to receive potential tax credit benefits and potential grant funding for research and development. The requisite filing fees for marketing applications are also significantly reduced.

BiovaxID has already received Orphan Drug designation for follicular lymphoma and mantle cell lymphoma.

Fatty Acids in Fish Oil Supplements May Impair Action of Chemotherapy – Researchers at University Medical Center Utrecht, the Netherlands, have discovered that certain fatty acids, including those found in commercially-produced fish oil supplements, can cause tumor cells to acquire resistance to a broad spectrum of chemotherapies. The fatty acids, which include omega-3 and omega-6, appear to provide protection to the cancer cells against the effects of chemotherapy. The researchers suggest that, while awaiting the results of confirmatory research, patients undergoing chemotherapy should not use fish oil supplements.

Mayo Clinic Review Concludes that Autologous Transplantation Is Effective and Underutilized in WM – The Division of Hematology at the Mayo Clinic in Rochester, MN, recently published a report that reviewed the literature on autologous and allogeneic transplants for WM and concluded that autologous transplant is effective and underutilized in the management of WM. The report also concluded that allogeneic transplant should still be considered investigational and used only in the context of a clinical trial or when other chemotherapeutic options have been exhausted.

Clinical Trial for Btk Inhibitor Advances – Avila Therapeutics, Inc., announced that it has completed 28 days of dosing of the first cohort of patients in its Phase Ib clinical trial of AVL-292 and is now advancing to the second dose cohort. The trial is being conducted in patients with

Medical News Roundup, cont. on page 13



B-cell malignancies including WM, other non-Hodgkin's lymphomas, and chronic lymphocytic leukemia. AVL-292 is an orally available inhibitor of Bruton's tyrosine kinase (Btk). AVL-292 demonstrated a favorable profile in completed Phase 1a studies.

New Monoclonal Antibody to Boost T-Cell Function Tested in Follicular Lymphoma Patients – A Phase I/II clinical trial at UCLA and the Mayo Clinic will evaluate a monoclonal antibody treatment called anti-CTLA-4 for follicular lymphoma. This therapy is targeted toward a negative T-cell regulatory molecule, cytotoxic T-lymphocyte antigen 4. The premise of this approach is to reverse the lack of responsiveness of T-cells to the cancer cells and boost their number and function, thus enhancing their anti-tumor effects. The study will recruit up to 36 patients who have relapsing or resistant disease.

PIM Kinases May Be Another Treatment Approach for Lymphoma – Researchers at the Spanish National Cancer Research Centre in Madrid have investigated PIM serine/threonine kinase expression in multiple B-cell lymphoma types and have discovered that it is frequently over-expressed in mantle cell lymphoma, diffuse large B-cell lymphoma, follicular lymphoma, marginal zone lymphoma, and chronic lymphocytic leukemia. Inhibition of these PIM kinases induced changes in apoptosis and cell growth and may be another approach to treatment.

Glutamine Explored For Alleviation of Peripheral Neuropathy in Multiple Myeloma Patients – Case Western Reserve University is exploring the use of glutamine in multiple myeloma patients who have painful symptoms of peripheral neuropathy caused by treatments. Glutamine can be bought over the counter at drug stores and has been reported to alleviate neuropathy symptoms in colon and breast cancer patients. The study will enroll 60 patients – half the group will receive glutamine and the other half a placebo.

Case Western Reserve Produces Cells in Animal Models That Replenish Myelin Coating on Nerves – Scientists at Case Western Reserve University have found a way to rapidly produce pure populations of cells that grow into the protective myelin coating on nerves in mice. Their process may open the door to research and potential treatments for demyelinating diseases. The scientists are using pluripotent epiblast stem cells, which can make any cell type in the body. Adding certain proteins, growth factors, and thyroid hormone causes the stem cells to develop into cells that produce myelin.

Antibody Fusion Protein Is Being Evaluated in Phase I Study – An antibody fusion protein called moxetumomab pasudotox is being evaluated in Phase I trials in patients with chronic lymphocytic leukemia, B-cell lymphomas, and childhood acute lymphoblastic leukemia. Antibody fusion proteins contain a protein toxin fused to an antibody. The antibody binds to an antigen on a target cell and brings the toxin into the cell interior, where it causes cell death.

Moxetumomab pasudotox is composed of an anti-CD22 monoclonal antibody fused to a fragment of toxin from the *Pseudomonas* bacterium.

New Anti-CD19 Monoclonal Antibody Tested in B-Cell Lymphoma – SAR3419 is a new anti-CD19 humanized monoclonal antibody used as single agent therapy in Phase I trials conducted for refractory-relapsed B-cell lymphoma. Two different dosing schedules were tested, and activity was reported in both schedules with a notable lack of significant hematological toxicity.

Small Molecule Drug Targets p53 Protein – Cylene Pharmaceuticals, Inc., has completed pre-clinical studies on its small molecule drug CX-5461, which inhibits RNA polymerase (Pol I) and thus activates the p53 protein. Upon activation, the p53 protein functions as a tumor suppressor by causing cancerous cells to self-destruct. CX-5461 is being tested as an agent for patients with leukemia, lymphoma, multiple myeloma, and some types of solid tumors. Targeting of p53 through Pol I kills cancer cells without damaging DNA.

Certain Generic Cancer Drugs in Short Supply in the U.S. – Several recent news articles have called attention to the short supply in the U.S. of several essential generic chemotherapy drugs, including vincristine, methotrexate, leucovorin, cytarabine, doxorubicin, bleomycin, and paclitaxel. These shortages have caused serious concerns about safety, cost, and availability of lifesaving treatments. In a survey from the Institute for Safe Medication Practices, 25% of clinicians indicated that an error had occurred at their site because of drug shortages. Many of these errors were attributed to inexperience with alternative products. The shortages have increased the already escalating costs of cancer care because brand-name substitutes for generic drugs can add substantial cost. A gray market for essential drugs – an unofficial alternative market of drugs obtained by vendors outside the usual distribution networks – has grown rapidly, with unregulated vendors charging markups of up to 3000% for cancer drugs. A report published in the *New England Journal of Medicine* analyzed the main drivers of these drug shortages and concluded that they are economic in nature. If manufacturers don't make enough profit, they are reluctant to continue making generic drugs. Also, oncology practices that administer chemotherapy drugs have had their Medicare and Medicaid reimbursement rates cut to the point that the reimbursement is less than the cost of administering certain generic drugs.

FDA Approves First Cord Blood Product for Stem Cell Transplant – The U.S. Food and Drug Administration has approved the first cord blood product, called Hemacord, with indications for cord blood stem cell transplant procedures in patients with blood malignancies such as leukemia and lymphoma. Currently the primary reason cord blood is harvested and stored is for parents trying to ensure that their



child will have cord blood available if the child develops a medical condition requiring a stem cell transplant. It is hoped that FDA approval of this product will encourage the donation of cord blood to public cord blood banks and increase the pool of donor stem cells available to the general public. Hemacord is manufactured by the New York Blood Center.

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

BRINGING DOCTORS AND PATIENTS CLOSER IN LONDON 2012: THIRD INTERNATIONAL WM PATIENT FORUM

Registration is open for the Third International Patient Forum, to be held in London on Sunday, 11 March 2012, at the Royal Society of Medicine. This event, generously supported by the IWmf and the European WM network and jointly hosted by WMUK, builds on the Stockholm and Venice Forums.

Already there are bookings from the USA, Greece, France, Norway, Germany, Finland, Belgium, the Netherlands, and the UK, but there are still places available at the prestigious central venue, close to Oxford Street. Organizer Roger Brown advises you not to leave your registration to the last minute as the 2011 domestic meeting was oversubscribed months in advance.

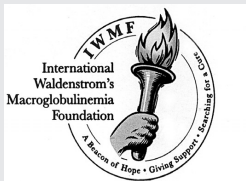
Main presentations (scheduled to date and subject to change):

KEYNOTE ADDRESS – Dr. Steven Treon (Boston, USA)
UNDERSTANDING WM – Dr. Eva Kimby (Stockholm, Sweden)
RITUXIMAB (MABTHERA) AND WM – Dr. Pierre Morel (Lens, France)
NERVE PROBLEMS AND WM – Dr. Michael Lunn - (London)
DIAGNOSIS AND PROGNOSIS – Dr. Roger Owen (Leeds)
INITIAL TREATMENT – Dr. Shirley D'Sa (London)
STEM CELL TRANSPLANTATION – Dr. Chara Kyriacou (London)
TREATMENT OF RELAPSE – Dr. Rebecca Auer (London)
WM IN THE NETHERLANDS – Dr. Pierre Wijermans (The Hague, Netherlands)
THE ROLE OF THE IWmf – Dr. Guy Sherwood (USA, IWmf International Chairman)

New for this Forum! Apart from the always-popular *Ask the Doctor* panel with 10 specialists, an innovation is *Ask the Doctor Lite*. Between sessions WM experts will be available at stands where participants will be able to directly seek one-to-one advice and discuss topics. Planned stations include: *diagnosis and prognosis, supportive care and survivorship, IgM-related problems, initial treatment, treatment after relapse, and stem cell transplantation*. Cancer support charities and other organizations will staff other stations, and there will also be a 'Patient Tales' wall of WM experiences to share and compare.

On Saturday there is an optional group tour of the Olympic Site and a dinner for doctors, patients, and carers in the evening. We invite you to take a long weekend in London.

The cost is £35, €40, US\$55 and includes lunch and refreshments. Registrations can be made online at www.wmuk.org.uk where you can find more details about the Forum, hotel information (including discounted rates), and activities on the Saturday. UK residents can also register by post and cheque. Enquiries and problems with registration should be sent to Roger Brown at info@wmuk.org.uk



THE INTERNATIONAL SCENE

A WORD FROM THE IWMF INTERNATIONAL COMMITTEE CHAIR

As one can readily discern from this issue of the *Torch*, there is no shortage of enthusiasm amongst the WM patient community outside of North America.

The past few years have seen an explosion of activity within support groups all over the world. This marked increase in international WM patient support organizations is due in some small way to an initiative set by the IWMF Board of Trustees a few years ago regarding the development of international support groups. One must state, however, that the principal movers and shakers of this rapidly expanding international scene are the volunteers themselves who have worked tirelessly to broaden the availability of WM patient support in their respective countries and regions.

The Waldenström's macroglobulinemia community in Australia (WMozzies) continues to grow under the stewardship of dedicated volunteers. The WM community in New Zealand is similarly moving ahead despite considerable geographic and demographic limitations.

As one can read on page 14, London, England, will be the site of the 2012 Third International WM Patient Forum. This WM patient and physician meeting has been organized entirely at the local level by volunteers in the UK, the IWMF assisting only when needed and providing a portion of the funds necessary to host this event. The Third International WM Patient Forum promises to be even better than the London WMUK patient seminar held in January 2011!

The European WM network (EWMn) is a dynamic group of energetic and committed volunteers from numerous countries in Europe who have done some truly remarkable work in only a few short years – witness the initiative with EURORDIS and NORD to create the online WM community (IWMF is actively involved in this) and its considerable financial support of the upcoming 2012 London patient forum. The EWMn represents such varied countries as Belgium, Finland, Greece, amongst others.

Speaking of Greece, online information on WM is now available for the first time in the Greek language, thanks to the initiative of the IWMF support leader in Athens (see the report on page 18).

Elsewhere in Europe, autumn 2011 was a particularly busy season for meetings of WM organizations – September in France, October in Finland, and November in Belgium. At its Paris meeting, Waldenström France for the first time donated funds as an organization to help support IWMF-funded research. This donation is directed to on-going research conducted in Lille, France, by Dr. Xavier Leleu, an alumnus of the Dana-Farber Cancer Institute.

A brief return to North America: one cannot forget the WM Foundation of Canada. It is an extremely well-organized and administered volunteer organization, and perhaps it can provide a model for individual countries to organize their own support groups outside of the US. The WMF Canada is the principal financial supporter of the IWMF-approved WM vaccine project since its inception two years ago.

The IWMF is an active member of the Lymphoma Coalition, a worldwide network of lymphoma groups. One of my goals as the IWMF International Committee Chair is, with the help and networking opportunities available through our participation in the Lymphoma Coalition, to finally breach one day the Spanish and Latino threshold. The IWMF would indeed like to be able to assist individuals and organizations in these regions in developing much-needed WM support groups.

The international scene is truly alive and well. I am convinced that in the future the international patient organizations, together with the IWMF, will continue to thrive and expand and bring much needed support to WM patients all over the world.

Guy Sherwood, Member, IWMF Board of Trustees and Chair, IWMF International Committee

ONLINE MACROGLOBULINEMIA COMMUNITY IN FIVE LANGUAGES

In October 2011 the launch of the Waldenström Macroglobulinemia (WM) Community, a part of the Rare Diseases Communities project, was announced. The WM Community is accessible in English at:

<http://www.rarediseasecommunities.org/en/community/waldenstrm-macroglobulinemia>

The Rare Disease Communities project is an outcome of the strategic partnership signed in 2009 between EURORDIS, the European Rare Disease Organization, and NORD, the National Organization for Rare Disorders. At this moment fourteen different rare disease communities participate in this online project.

The partnership of EURORDIS and NORD ensures that international collaboration will be fostered amongst patient groups and that the voice of patients will be protected from commercial interests. You can find the participating rare disease communities at:

www.rarediseasecommunities.org and/or www.rareconnect.org

The main idea behind the project is to create an online social network for patients and caregivers living with rare diseases in order to enable the sharing of experiences and increase access to quality information. International patient organizations collaborate to develop these communities along with EURORDIS and NORD. Patient organizations play a key

The International Scene, cont. on page 16



role in governing and communicating with their respective communities, recruiting forum moderators, and providing sources of information to patients and their families.

The website is split into three sections: What, Meet, and Learn. The “What” section features patient stories and blog-style updates from patients and representatives of patient organizations. The “Meet” section is a forum moderated by volunteers and offering human translation services across 5 languages: English, French, Spanish, Italian, and German. Since patients and families are spread thinly across the globe and some countries do not as yet have patient organizations for WM, it is vital to create a space where information can be shared with the best possible translation. Finally, the “Learn” section is a resource of information in the form of frequently asked questions (FAQs), documents, recently published news and scientific articles, upcoming events, and contact information for patient organizations.

After registering, users can upload their story on living with the disease through a link on their profile page. The story is then automatically added to the “What” section and is translated into all of the platform’s languages. Users can also participate in forum discussions or post their own questions. If a user sees a message on the forum that is not in his language (French, German, Italian, Spanish, or English), he can request that a translation be made. Within a few hours, the message is translated and uploaded automatically to the website. The user who requested the translation also receives the translated content by e-mail.

Invited by EURORDIS and NORD, members of the European WM network (www.ewmnetwork.eu) helped to create this website and act as moderators of the forum. **We need more moderators (English, French, German, Italian, or Spanish speaking) to help to expand the online WM community.** If you are interested in becoming a moderator of the online WM community and want to know what it implies, please contact Marlies Oom: secretary@ewmnetwork.eu

The project is financed by the European Commission, the French Telethon (AFM), the French Federation of Pharmaceuticals (LEEM), and a diverse array of corporate partners. These organizations play no role in the operation of the participating communities.

More information:

EURORDIS: Robert Pleticha, robert.pleticha@eurordis.org

NORD: Alexandra Freitas, afreitas@rarediseases.org

Moderator (English speaking): Phil Manning, drumphil@me.com

Moderator (French speaking): Joanna Van Reyn, joanna.van.reyn@telenet.be

Marlies Oom reporting.

BELGIUM: SIXTH ANNUAL SYMPOSIUM

In the capital of the European Union on November 18, 2011, nearly 40 interested people came together at the Universitair Ziekenhuis Brussel (familiarily known as UZ Brussel) to attend the sixth symposium on WM. Attendees included patients, partners, and caregivers. Hematologist Dr. Fabienne Trullemans, who is affiliated with UZ Brussel, began with a very clear exposition of WM, the signs and symptoms, diagnosis and treatment. While all present welcomed information about the current therapeutic arsenal available to treat the disease, the newly diagnosed in particular were reassured to learn of the many options. After lunch the audience heard a very interesting presentation from a lawyer working at the research department of the Flemish League against Cancer speaking on ‘The cost of care for hematologic disease for the patient.’

Everyone departed from the event satisfied and with positive feelings, ready to be back next year for the seventh symposium. One indication of the sixth symposium’s success is that attendance was higher than expected. Perhaps the number is low compared to American standards, but our contact group, CWP-Vlaanderen, a subdivision of CMP-Vlaanderen (contact group for patients with MM), includes only patients coming from the Dutch speaking part of Belgium (a region of nearly 13,500 km²). Our support group, however, is open to friends supporting each other, sharing experiences, warmly welcoming the newly diagnosed, and joining together with great joy at the annual symposium or the regional contact opportunities throughout the year.

Joanna Van Reyn reporting.

FINLAND: FIFTH ANNUAL SEMINAR FOR THE FINNISH WM GROUP

The fifth annual seminar of the Finnish WM group was held on October 8, 2011, at the Scandic Hotel Salpaus of Lahti, Finland.

If you have ever watched International Ski Federation Nordic events on a sports channel, you may have seen a silhouette of three hills used for ski jumping that dominate the skyline of a city. The city you see is Lahti, situated on the shores of a sheltered bay of Vesijärvi lake. (Finns cannot be blamed for hyperbole: the name of the city, Lahti, translates to Bay, and the name of the lake, Vesijärvi, translates to Water Lake!)

Lahti’s location is central for WM group members from southern Finland. It’s easy to come for a day’s seminar by road or rail, and this year there were about thirty people attending. In five years of seminars, the faces and voices have become familiar, and it was with especial warmth that we met again. We were greeted at the start by our active organizer and contact person, Veikko Hoikkala, who hails from Lahti. We also met the Finnish Cancer Patients’ contact person, Inka Talvitie, who keeps us in touch via our Finnish WM website.



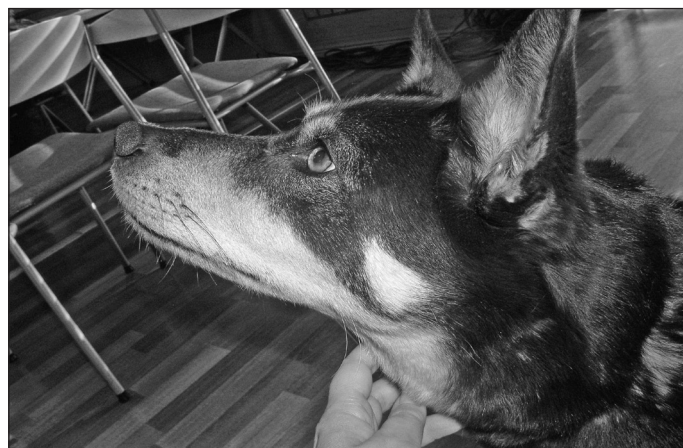


From left to right: Finnish WM group contact person Veikko Hoikkala, Finnish Cancer Patients' association Patient Group Organizer Inka Talvitie with Dr. Tuomo Honkanen, whose presentation was met by enthusiastic applause and some polite barking.

Our annual meetings have become a source of support and strength for newly diagnosed patients. They may attend for the first time to try to come to grips with all the unknowns of their situation. When long-time members introduce themselves and talk of treatments, remissions, and relapses in a matter of fact way, it becomes clear that life goes on and information is available.

During lunch a group of ladies, some newly diagnosed and some veterans, noticed that their discussion turned to gender specific issues. Various symptoms, side effects of treatments, and other practical considerations do bring extra challenges equally to a busy working mom, a busy menopausal teacher, and a few active retirees. It was an eye-opening chat!

The more information we have, the easier it is to communicate with our doctors. Learning the vocabulary and the terminology for bringing our concerns to our scheduled appointments and for asking about new treatment options are just some of the benefits that we gain from having a specialist



Sippan, the purebred Lapponian Herder (a type of dog used by the Lapps for herding their reindeer) who gave his top accolade to Dr. Honkanen.

present at each of our seminars. This is something that newly diagnosed WM patients appreciate from the start.

Our specialist at the Lahti seminar was Dr. Tuomo Honkanen, Department Head and Haematologist at the Päijät-Häme Central Hospital. Dr. Honkanen presented a concise talk, starting with WM from a diagnostic point of view. He then focused on symptoms, indications for treatment, and current treatment protocols. Time was also provided for questions and answers. His long experience with WM patients brought depth to the discussion of some of the new treatment options such as bendamustine and ofatumumab. The applause after his presentation was heartfelt.

And only when the audience burst into applause did it became evident that a member from Turku had brought not only his wife to the seminar but also his best friend, Sippan, a purebred Lapponian Herder. Sippan joined the applause with a few appreciative barks! During the day's programs he had been very quiet and attentive and had all but gone unnoticed. Once noticed, he received a lot of positive attention.

And of course we all decided that we *will* meet again in 2012! Maybe we'll even go back to that lovely island in Turku where we had our seminar in 2009.

Taina Lukkaroinen reporting.

FRANCE: WALDENSTRÖM FRANCE IN PARIS

Saturday, September 24, 2011, at the Hôpital Broussais, "Plateforme Maladies Rares." Greetings of welcome fill the air, hugs and kisses follow as friends meet one another. It is beautiful weather for the annual meeting of our association, Waldenström France.

A quick lunch and then we can circulate and speak with our acquaintances from prior meetings and can meet at last face-to-face with friends we know only through our talklist. We are so pleased to have Dr. Guy Sherwood with us on this special day.

Dr. Véronique Leblond comes walking through the courtyard of the hospital and finds a group of patients ready and eager to hear her speak. In another room a session called "give the floor to caregivers" is underway, led by two psychologists.

Here we go! For more than two hours our guest speaker holds the attention of the attendees, two hours that fly by without our noticing! Dr. Leblond already knows a number of those present, and those who are meeting with her for the first time will certainly be inclined to visit her for a second opinion! Her lecture is detailed and very clear, touching on the many available WM treatments. A "questions-answers" session follows, and Dr. Leblond replies to questions with full and complete explanations drawn from her vast experience. As always, her great kindness is evident. Diane Ibled, a psychologist with whom Dr. Leblond works frequently, is also present and tries to analyze the doctor-patient relationship in some of the examples patients describe.

The International Scene, cont. on page 18





Members of Waldenström France in the conference room at the Hôpital Broussais listen attentively to Dr. Guy Sherwood. At the keyboard, Nicole Bastin, volunteer extraordinaire.

On this occasion Dr. Guy Sherwood “wears several hats.” As trustee of the IWMF, he introduces us to all the activities of the Foundation to help and support WM patients as well as its educational mission to enable every patient to manage his disease by being informed concerning treatments, clinical studies, and research. As a “doctor-reporter” at the important scientific meetings where new research on Waldenström’s macroglobulinemia is reported, Dr. Sherwood speaks to us about the most recent International Workshop on WM sponsored by the Dana-Farber Cancer Institute, held in Venice October 2010, and the very encouraging new research that was presented there. Finally, Dr. Guy speaks as a patient living for more than ten years with WM when he narrates for us the very powerful story, illustrated with photos and graphics, of one phase in the history of his disease: the autologous stem cell transplant which he underwent five years ago. Based on this experience he has embraced the following belief: *One cannot be a good doctor if he himself has not been ill.*



From left to right: Dr. Xavier Leleu (Dana-Farber alumnus working now as oncologist and principal investigator of the IWMF-funded research project in Lille, France), Dr. Véronique Leblond (highly regarded French oncologist specializing in WM and a member of the IWMF Scientific Advisory Committee), Dr. Guy Sherwood, and Michael Houche (President of Waldenström France). Representing the IWMF, Dr. Sherwood received a check from President Houche on behalf of Waldenström France to support the research of Dr. Leleu.

And then, a pleasant surprise at the last minute! Dr. Xavier Leleu appears for a brief moment to sign the contract for the two-year grant he was awarded by the IWMF in support of the research he directs in his laboratory at Lille. Dr. Leleu takes the opportunity to remind us that, when we invited him two years ago to the meeting in Vienna (France) before our association Waldenström France was established, he indicated how very important it is for researchers to know that patients are interested in their work. The check that our president, Michel Houche, presents today to Dr. Sherwood for the IWMF on behalf of Waldenström France in support of Dr. Leleu’s research proves that he had indeed been heard.

We conclude our day by dining all together and prolonging the evening as much as possible. Leaving one another is difficult! We will meet again, in person, next year but on the talklist ... tomorrow!

Nicole Bastin reporting.

GREECE: TORCHBEARERS OF TODAY

The Greek WM group met in October at the home of Ivi and Byron Riginos in Kifissia, a northern suburb of Athens. Present were Alexia Karpalou, IWMF support group leader for Greece, member Evi Galazidou, and as guest Alice Riginos, *Torch* editor. You may have guessed that there is a connection between Alice and the host and hostess – and this is true, they are my wonderful sister- and brother-in-law. Sometimes, possibly more often in a small country like Greece, the small world of WM overlaps with the small world of personal acquaintances. Such was the case when Evi was diagnosed with WM six years ago; Evi and Byron are friends since their teenage years, and now Ivi is the caring friend who sits with Evi in the infusion room. Alexia, as it turns out, is a close friend of Riginos cousins. When the Greek WM group met over delicious *mezedakia* prepared by Ivi, we spent the evening in animated conversation about attempts to advance the cause of WM in Greece.

Alexia and Evi make an impressive team. Alexia is by profession a biologist affiliated with a major hospital in Athens, Evi is a lawyer now retired from private practice. For several years they attempted to form an active support group in Greece, but their effort met with only limited success for a number of reasons. Individual patients do contact Alexia (for the most part they find her from the IWMF website), and while she is very diligent in meeting with them individually and maintaining steady contact, it has not been possible to establish a group that meets with some regularity.

Subsequently Evi and Alexia turned to a volunteer cancer organization called *AgaliaZo* (www.agaliazo.gr) and are now working with it in different capacities, always having in mind to spread information about WM. Established in 1976 and with offices in three cities (Athens, Patras, and Heracleion), *AgaliaZo* is a member of ECPC (European Cancer Patient Coalition) and IAPO (International Alliance of Patients

The International Scene, cont. on page 19



Organization), participates in the Rare Disease Communities project, and has a scientific committee of sixteen medical professionals. Evi was recently elected president of the board of directors. Alexia, on the other hand, has assumed responsibility for preparing information about lymphoma for dissemination via website entries and the publication of pamphlets. The website of *AgaliaZo* offers information for ten types of cancer in seven languages in addition to Greek. While the website section for lymphoma is still under development, Alexia's priorities are evident when one sees that a separate section for Waldenström macroglobulinemia is already up and running and provides an excellent introduction to WM prepared by Alexia. Such information is not available elsewhere in Greek; via the website this current coverage of WM is also accessible to readers of English, French, German, Italian, Portuguese, Russian, and Spanish. "Bravo" to Alexia and Evi for their determination to bring help and support to the WM community in their own country and beyond.

Alice Riginos reporting.

NZ WALDO'S HOLD SECOND ANNUAL MEETING

Seven of the Waldo's in New Zealand and four of their supporters met November 5-7 at Palmerston North for our second (and for what we hope will be an annual) get together.

This time we were well informed by Dr. Bart Baker, Clinical Haematologist at the Palmerston North Public Hospital. The general discussion went very well with Dr. Baker giving an excellent address on the latest known facts



Dr. Bart Baker addresses the NZ Waldo patients assembled in Palmerston North.

about Waldenström's as a condition and its treatment. He elaborated as well on the whys and wherefores of when and how treatment is approached in different ways in different patients. Dr. Baker built this address around questions Waldo patients were invited to forward to him in writing some three weeks prior to the meeting.

In the evening some of us met for an excellent meal at one of the many top class restaurants in Palmerston North.

It was a great opportunity to meet up, but, due to the cost and the distances involved, very few attended, which was a pity.

Michael Goldschmidt reporting.

COOKS' HAPPY HOUR

BY PENNI WISNER

The holidays have come and gone. Perhaps we have enjoyed to excess those wonderful seasonal sweets and hearty dishes that are part of our own family's tradition. Resolutions recently made, primarily dietary, are still to be kept. The days ahead look bleak indeed. But here's Penni to the rescue! She's ready to go with a slew of unusual suggestions to please the most jaded January palate, nearly all with a vegetable base and in brilliant, enticing colors. Those resolutions are going to be positively enjoyable after all. Let's take a brisk walk to market and stock up with Penni!

THE UNDERCOVER REPORT

Once again, the year starts over and so do we. Or that is our intention. (Maybe I should just speak for myself here.) But our favorite rituals sustain us year in and year out. Hopefully, one of yours is nibbles with cocktails or wine.

I've often spent time in my Happy Hour discussing ideas for foods that need some kind of support during their transport from hand to mouth. I've spent far less time discussing the actual transport vehicles. So let's do it now.

And we'll begin with what used to be a late fall or winter seasonal vegetable but is now grown year round by Vegetable Specialties here in California: endive. (Pronunciation cue: we are discussing "ohn-deeve" and not "ohn-dive" with a long "i".) The former is Belgian-style endive, the slim, tight, very pale green (and now sometimes red) member of the chicory family. Like sparkling wine (just because the holidays are over, it's not time to stop drinking sparkling wines) which ferments twice, once in a tank and a second time in the bottle, endive grows twice: once in the field and then again in a cold, dark, controlled environment. (I went for a tour and you can, too, by visiting www.endive.com to make arrangements.)

When you separate the heads into leaves, each one takes the role of a single-calorie "chip" for dipping (make your dip from nonfat yogurt, crushed garlic, salt, pepper, and herbs and maintain your virtue) or stuffing. You could make a very pretty presentation by arranging the leaves in a circle on a platter and filling them with a tiny dice of mixed vegetables

Cooks' Happy Hour, cont. on page 20



(carrots, celery, bell pepper, etc) blanched very quickly and then marinated in spices, herbs, and olive oil.

Another idea for low-to-no calorie “beds” is radish. Except in the coldest regions, radishes grow nearly year round and they are making a comeback in the farmers markets here. My favorite is the watermelon radish; my pet name for it is Christmas radish, because it has a pale green outer band surrounding a white band and a brilliantly red interior. Slice it thin on your handheld mandolin (you got one in your stocking didn't you?) and spread the slices with your dip.

And if you are not sick of making stuffing – or your family would not allow you to try anything other than the old-familiar – make up a small batch from some more unusual grains such as couscous, quinoa, freeka (a green wheat) combined with chopped nuts, spices, and herbs (and a little diced bacon if you just can't help yourself). Fill raw mushroom caps, especially button mushrooms (white or brown) or baby portobellos (after scraping out the gills). Then brush them with olive oil and bake at 350° until tender.

Another virtuous option is to open a jar of pickled peppadew peppers. They are about an inch or a little more in diameter and just beg to be stuffed with one of your dips or stuffings. Check the jar's label and choose mild or hot peppers.

And let's not forget the ubiquitous (this time of year) hard winter squashes and pumpkins. Did you know you could eat the skin of most of those squashes once they are cooked? I didn't either until recently. Cut the squash (peeled or not, your choice) into

slices or wedges. Sprinkle them with spices – ras el hanout? dukka? baharat? *Plenty*, the fabulous new vegetable cookbook from the London chef and author, Yotam Ottolenghi, has you make up a mix of ground cardamom and allspice mixed with olive oil and salt to brush on the squash before baking. You serve the slices at room temperature with a scattering of little triangles of fresh lime; thinly sliced, fresh, hot pepper; and a sauce of Greek-style yogurt mixed with tahini, lime juice, and salt. Or, another Ottolenghi idea, top the squash or pumpkin slices with a stuffing-like mix of breadcrumbs, finely grated cheese, herbs and lemon zest, and olive oil. Bake until tender in a hot oven and serve warm.

But man does not live by vegetables alone and this woman could and would live by bread alone. Bread in all its guises including flatbreads and crackers. But maybe you don't want to deal with rising a loaf. How about batter breads? A whole-wheat, date-nut bread would be proud to be covered with goat cheese or cream cheese and taste delicious, too. Or try adding some mashed, roasted squash to a quick bread recipe, stir in some pumpkin and sunflower seeds, and then sprinkle more seeds on top of the loaf before baking. Batter breads can taste and feel very like yeasted bread. For example, you could make brown soda bread. (Find the recipe on www.epicurious.com. The recipe uses some butter, which is not “authentic” so you can leave it out if you choose.) Fresh, warm bread spread with your dip? Or just some good, unsalted butter? Break out the wine, quick!

Our motto: Eat Well to Stay Well

FUNDING WHILE FEASTING

Dining out tonight? Do you want to do more for the IWMF? We have just the fare for you! Now whenever you dine out you can donate up to 6% of your restaurant bill to the IWMF, at no extra cost to you. Introducing *GoodDining.com*. Here is what you do:

- Go to www.GoodDining.com, a new service from *GoodSearch.com* and *GoodShop.com*, designate the IWMF as your charity, sign up for an account, and put one or more credit cards on file. The site, of course, is secure.
- Whenever you dine out at a participating restaurant and use a registered credit card, 2.5% of the amount you charge to your credit card will be automatically donated to the IWMF. You do not have to do anything other than have a valid e-mail address, agree to receive e-mails from *GoodDining.com*, and keep your credit card registration current.

- If you spend more than \$750 in a year, you'll become a VIP – Very Important Philanthropist – and 5% of your spending will go to the IWMF. Care to write a restaurant review? If you do, the IWMF will receive an extra 1% for a total of 6%.

No need to show an ID card, memorize a membership number, or carry any coupons at participating restaurants, bars, or clubs. Your privacy will be respected. Simply use your registered credit card when you settle your bill. The IWMF will automatically receive your donation.

How do you know which restaurants are participating? That's easy. Just go to www.GoodDining.com and open your account. You can search for restaurants by:

- Distance from your house
- Member ratings
- Average entrée price
- Neighborhood

Funding While Feasting, cont. on page 21



- Day of the week when donations are available (most but not all restaurants offer the donation whenever they are open for business)

Thousands and thousands of restaurants nationwide are already participating. Some restaurants even allow you to make a reservation right from the *GoodDining.com* site.

What an easy way to give to the IWMF. It takes less than 5 minutes to register and you're done! No need to search to find out if a restaurant is participating. If it is, the IWMF will automatically get a donation. If the restaurant is not participating, the IWMF receives no extra benefit. But you can also search and choose restaurants that are participating in this program and thank them with your business.

But don't stop there, tell your children, tell your brothers and sisters, tell your cousins, tell your nieces and nephews, tell your friends. Tell anyone who dines out a lot to register. Stop for a minute and think, who would help the IWMF by joining this program?

Call them and ask them to join *GoodDining.com* today.

Best wishes for a happy and healthy 2012 filled with good dining!

The IWMF Fund Raising Team,
L. Don Brown, Carl Harrington, Dave Benson, Dick Weiland,
and Julie Jakicic



SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

Please note: contact information for all support groups is printed on pages 24-25.

CALIFORNIA

Monterey

All the animated discussion and the potluck lunch made the time fly by at the September meeting. Topics included how to find doctors with WM expertise, members' treatment experiences, and establishing other WM support groups in the state – one attendee had come from Lake Tahoe and another from Paso Robles. **Wendy and John Justice** will host the next meeting, also a potluck, Sunday 15 January, at their home in Capitola.

Sacramento and Bay Area

In November, eleven members attended the second meeting in Roseville at the new Kaiser facility there to watch excerpts from the 2011 IWMF Educational Forum DVDs. After viewing the presentation by Dr. Stephanie Gregory from Rush University Medical Center, "New and Emerging Treatment Options for Indolent Lymphoma," the group broke for some light refreshments and a circle discussion about personal progress in dealing with WM. Several of the attendees have been living with WM for decades. The next meeting is planned for the spring at the Kaiser in Vallejo.

COLORADO & WYOMING

On a beautiful fall day in October, the group met as they have for many years in the basement of the University Park United Methodist Church. This central location is convenient for residents of Denver and cities to the north and south. With 32 attendees, the potluck breakfast buffet was generous and delicious. The speaker, Dr. Teri Simoneau of the Colorado Blood Cancer Institute, gave a fascinating talk about "chemo brain." It sparked a lively and enthusiastic discussion and comforted all who had received chemo and complained of "not remembering lately." Six new members were introduced, including two who had found the group through the Leukemia



At the recent support group meeting in Colorado, from left to right are Dave and Shara Stills from Fort Collins, speaker of the day Dr. Teri Simoneau of the Colorado Blood Cancer Institute, and Molly O'Connell of Centennial. Patients come to our meetings from many directions, some driving 2-3 hours to attend.

& Lymphoma Society. The LLS had announced the meeting in the monthly newsletter – another instance where the close association between our organizations is a benefit to patients. More experienced WMers offered to help the new members with issues in their cities, suggested doctors, and shared similar experiences to make them feel that they were not alone on their WM journeys. Those interested in Dr. Simoneau's slide set on chemo brain, please contact Cindy Furst at cindyfurst@gmail.com for an electronic copy. The next gathering is planned for early in 2012 to watch one of the DVD presentations from the June 2011 Ed Forum.

FLORIDA

Ft. Lauderdale Area

Dr. Steven Treon of Dana-Farber Cancer Institute will be the

Support Group News, cont. on page 22



featured speaker at the Saturday 14 January winter support group meeting. Held in conjunction with the Leukemia & Lymphoma Society, the day extends from 10 am to 4 pm. Several other speakers will fill out the agenda of the conference. Lunch is included. Please be in touch with the group's leaders for more details.

Southwest Florida

On Saturday 3 March the Southwest Florida area support group will meet at Doctors Hospital of Sarasota on Bee Ridge Road in Sarasota. Dr. Steven Treon of the Dana-Farber Cancer Institute will be the featured speaker. There will be plenty of time for questions from the audience and refreshments will be served. Please RSVP to **Herb** and **Marge Kallman**, 239-466-6911, margerina@aol.com

Tampa

Support group leader **Rita O'Brien** announces the first meet-and-greet for the area on Saturday January 21 at 1:00 pm. The meeting will be at her home, 6115 Kingbird Manor Drive, Lithia, FL 33547. RSVP: 813-654-4986 or promo1rita@verizon.net. Rita will have the DVDs of the June 2011 Ed Forum available to watch on the spot or to borrow, as well as lots of literature supplied by the IWMF office. Patients, family members, and friends are welcome.

GEORGIA

A group of twenty watched a DVD from the IWMF Minneapolis Ed Forum at the fall meeting. One new member diagnosed just one month earlier was happy to meet and speak to so many fellow WMers and to learn how much is happening on the research front. As usual, members compared health notes and exchanged e-mail addresses and telephone numbers in order to stay in close touch.

ILLINOIS

Chicago Area/SE Wisconsin

The Chicago area support group had an active year ending with a meeting on October 22. This was the first meeting without faithful friend and super volunteer Ron Draftz, who was remembered during the introductory time. During the meeting the group broke into two: one for caregivers only led by **Carolyn Hyser**, **Germaine Draftz**, and **Mary Brown**; and a second for patients who viewed Dr. Treon's presentation



Chicago area support group leader Don Brown is delighted to greet his new grandson, Jackson Louis Tieman. Congratulations to Jackson's parents, Melissa and Aaron Tieman.

from the recently released 2011 Education Forum DVD set. As a result of the discussions and presentations, one patient changed his treatment plan. Others found comfort in their ability to share their stories with an understanding group. Shortly after the meeting **Mary** and **Don Brown** celebrated the arrival of a new grandson. "Everyone is happy and healthy!" reports Don. The next support group meeting is planned for Saturday 21 April.

INDIANA

The LLS hosted the just-before-Halloween meeting, providing pastries, coffee, and seasonal treats. Sixteen attendees introduced themselves and shared their current status and concerns. One member had an autologous bone marrow transplant at the end of August, and the group celebrated his continued recovery and presence at the meeting. Dr. Treon's presentation, "Advances in the Genetics and Treatment of Waldenstrom's Macroglobulinemia," from the IWMF Educational Forum 2011 held in Minneapolis provided the educational program. An electronic snafu nearly torpedoed the program, but, with the able help of **David Chance**, the projector and speakers were both soon working. The next meeting is planned for Saturday 31 March with Dr. Rafat Abonour, Director of Indiana University Simon Cancer Center, scheduled to speak on stem cell transplant. The group decided not to meet during the winter months due to potentially bad roads.

MICHIGAN

The Michigan group held their summer meeting in June under the capable leadership of charter member **Lorraine Alkon**. The group discussed their current health issues and the treatments they have experienced. Family needs and holidays interfered with plans for a fall meeting. But with hope and good intentions, plans for a meeting will be reinvigorated in the new year!

EASTERN NEW YORK/WESTERN NEW ENGLAND

Neurologist Dr. Sheldon Staunton, a member of the Schenectady Neurological Consultants and affiliated with Sunnyview Rehabilitation Hospital, spoke with a sense of humor and a great deal of experience and wisdom for almost ninety minutes, including numerous questions. He volunteered to come back another time, and the group members all agreed to accept his offer. At the November meeting held at the ACS Hope Club in Latham, NY, the group watched with interest the first four doctors' presentations of the Mayo Clinic report at the IWMF Forum. The next two programs are a meeting with speaker in February and, in April, the annual restaurant feast.

OREGON/SOUTHWEST WASHINGTON

On a sunny, bright October Saturday, about 55 members of the group met in Lake Oswego, OR, to hear Dr. Steven Treon's presentation on the latest developments in the WM realm. Dr. Treon was eloquent in his description of the disease and the available treatment options, as well as the research currently underway for the development of new drugs. Dr. Treon continues to amaze with his ability to make so much of this difficult-to-understand medical and scientific terminology come alive and be accessible (and even understandable) to a lay





The meeting of the Dallas support group drew a large and enthusiastic number of participants to hear Dr. Marvin Stone.

audience. The news that he reported is very encouraging about both the progress in understanding the genetic background of WM and how that understanding supports the development of new, more specifically targeted treatments. While meetings are usually very participatory, informative, and supportive, this session was particularly lively and full. Attendees asked many questions to clarify how the news might apply to their own situations. Many members of the group left the meeting encouraged by the progress the physicians and researchers are making and feeling more hopeful and grateful for their efforts. The Oregon-SW Washington support group meets at the Fairfield Inn & Suites, 6100 SW Meadows Road, Lake Oswego, OR (just off I-5 Exit 292). Future meeting dates are: Saturday 28 January; Saturday 28 April; Saturday 28 July; and Saturday 27 October. The speaker for the January meeting will be a local oncologist. The local LLS chapter provides the meeting place and luncheon, and its Patient Services Coordinator, Sue Sumpter, works with **Joan Berglund**, the IWMF group leader, to arrange speakers, keep up contact lists, and share resources.

PENNSYLVANIA

Philadelphia

Sixteen people and four-footed, tail-wagging mascot, Heidi, attended the October meeting. This round-robin, sharing meeting generated so much enthusiastic conversation that the two hours flew by. Two members of the IWMF Board of Trustees, **Ron Yee** and **Carl Harrington**, attended the meeting and updated the group on the Board's activities, particularly in the areas of fundraising and research. And then at the December meeting, attendees watched presentations by Drs. Steven Treon and Stephen Ansell from the 2011 Ed Forum DVDs. Both discussed new developments toward the cure for Waldenstrom's, a topic in which everyone is particularly interested. The meetings, as always, concluded with time for casual chit chat and enjoying the yummy refreshments brought in by one of the group members.

SOUTH CAROLINA

The group got a jump on the holiday season and met in early December in Greenwood at the Greenwood County Library. Over holiday goodies, the newly diagnosed and veterans shared their WM experiences with each other. The next support group meeting will be held in late spring. For

information about the South Carolina support group, please contact support group leaders John and Paula Austin at jhaustin@bellsouth.net.

TEXAS

Dallas & Northern Texas

Dr. Marvin J. Stone, Baylor University Medical Center, Dallas, was the guest speaker for the early fall meeting. The November meeting featured a viewing of selections from the most recent Ed Forum DVD, followed by lunch and caring-and-sharing by the members. Special thanks go to Dr. Stone for his on-going support of the group and to Pam Carnevale, Manager of the Cvetko Patient Education Center at Baylor's Charles A. Sammons Cancer Center, for her continued help facilitating the group and for arranging educational speakers.

Houston

Don and Kathy Knop have volunteered to become the new support group leaders in Houston. The city has been their home since 1971. Don was diagnosed with Waldenstrom's in late 2008 and, after successful treatment in early 2009, continues to do well. He retired in early 2011 after more than 40 years as a business economist in the energy industry. He remains active in industry and economic professional organizations and serves as a director of Peoples Trust Federal Credit Union and of Signal Hill Financial. Kathy also retired several



Kathy and Don Knop are the new support group leaders in Houston.

years ago after working in retail management and gas contract analysis. Together they like to exercise and travel, especially mountain hiking. Don enjoys classical music, wine, and history, while Kathy enjoys keeping up on health and nutrition, genealogy, and her American Association of University Women (AAUW) book group. Kathy and Don have two married daughters, a nine-year-old granddaughter, and a geriatric tuxedo cat named Molly Marie.



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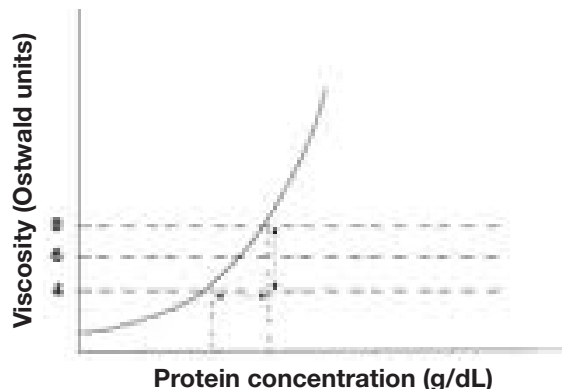
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[Editor's note: Your laboratory may test serum viscosity (SV) rather than plasma viscosity. Whereas plasma is the complete liquid portion of the blood, serum is plasma without clotting factors. Serum viscosity and plasma viscosity are roughly equal, and the measurements discussed by Dr. D'Sa in this paragraph apply to serum viscosity as well.]



Relationship between serum viscosity and IgM level

TREATMENT OF HVS: PLASMAPHERESIS

Established hyperviscosity syndrome is a medical emergency that should be managed actively and promptly. Effective treatment relies on the physical removal of the IgM protein from the blood stream by a technique called plasma exchange or plasmapheresis. (3)



Apheresis machine in action

Plasmapheresis consists of connecting the patient to an apheresis machine via two separate veins so that the blood can be circulated through the machine and the IgM protein physically removed via one vein before the blood plus albumin and saline is returned through the other vein. If the veins are not in good enough

condition to be cannulated such that free flow of blood occurs, the insertion of a central venous catheter may be needed for the procedure. In the case of Waldenström's patients, because 70 to 80% of the IgM protein is contained within the intravascular space, a single plasmapheresis session can result in significant clinical improvement and a reduction in serum viscosity by 50% or more. (4)

In the acute setting, this procedure is carried out as an inpatient treatment, but it can also be performed as an outpatient procedure. Daily or alternate day single plasma volume exchanges are used initially until symptoms are relieved. Later, plasmapheresis may be repeated less frequently (such as once per week) as needed for control of symptoms. It is important for chemotherapy to be considered in parallel with

the plasmapheresis so that the production of the IgM protein can be lowered definitively.

When should plasma exchange be used? This decision should be made on an individual-case basis, since the symptomatic threshold varies from patient to patient. Generally speaking, plasmapheresis is indicated for the following conditions:

- Symptomatic patients regardless of their plasma viscosity level
- Asymptomatic WM patients with plasma viscosity > 5.5 cp (this is an arbitrary cut-off used at our center)
- Patients who have had a previous heart attack or stroke or suffer from circulatory disorders such as poor circulation in the legs (such patients may need plasma exchange irrespective of the PV level)
- In patients with anemia that requires transfusion – prior plasmapheresis may be needed to 'make room' for the transfused blood

Special circumstances where plasmapheresis may be called for include the following:

- When surgery is required, for reasons unconnected to Waldenström's. In some patients with a high IgM level who need surgery, I consider the need for plasmapheresis to aid healing and recovery post operatively, even if they are not otherwise receiving chemotherapy and are on a 'watch and wait' schedule. Plasmapheresis in this context improves the flow of blood at the site of the operation and is also likely to lower the risk of developing a deep vein thrombosis during or after surgery.
- In an emergency situation in which a patient is experiencing life-threatening effects of a raised blood viscosity and access to plasmapheresis is not immediately available. An improvement in blood flow may be achieved by a therapeutic venesection (removal of 250-300 mls of blood from a vein), with simultaneous replacement of normal saline or packed red cells, depending on the degree of anemia that is present. This maneuver can be carried out pending plasmapheresis to improve flow of blood to vital organs.
- The phenomenon of IgM flare. A rise in the level of IgM following treatment with rituximab is well recognised and does not represent failure of treatment. A flare is more likely to occur if rituximab is administered when the IgM level is 4000 mg/dl or above and may last several weeks. It is preferable to prevent this phenomenon in the first place by administering other chemotherapy agents that start to lower the IgM level before rituximab is commenced. However, if the IgM flare does occur, then some sessions of



plasmapheresis may be needed to lower the PV in the short term until the treatment effect becomes established and the IgM level begins to decline.

COMPLICATIONS OF PLASMAPHERESIS

Plasmapheresis is generally well tolerated, but 12-40% of patients may experience complications during the procedure. The most commonly experienced complications are as follows:

- **Allergic reaction.** Allergic reactions are rare because few people react to infusions of albumin, the fluid that is administered as part of the exchange process following removal of the patient's plasma. Should symptoms such as a rapid pulse rate, falling or rising blood pressure, skin rashes, or breathing difficulties occur during plasmapheresis, then the administration of an anti-histamine and corticosteroids is routinely carried out.
- **Viral infection.** Since albumin solution is a virally inactivated blood product, the chance of infection by a blood-borne virus is extremely small.
- **Excessive fluid in the circulatory system.** Owing to the fluid shifts that occur during plasmapheresis, an imbalance may occur, leading to fluid overload and breathlessness. This can be managed effectively by altering the flow dynamics on the apheresis machine or the administration of a diuretic to increase urine output. This balances out the fluid shifts and offloads the excessive fluid.
- **Mineral imbalance.** Similarly, imbalances in certain minerals, calcium and magnesium for example, may occur resulting in symptoms such as muscle cramps, twitching, and tetany (muscular spasms). This can be easily managed by the replacement of the mineral by intravenous infusion. The levels of these minerals and plasma proteins as well as kidney and liver function are closely monitored during and after the procedure.
- **Reduction in platelet count.** The platelet count may fall as a result of plasmapheresis due to removal of platelets as a side effect of the procedure. If platelets fall to a critical level, then a platelet transfusion may be needed. This is not a common occurrence; typically the reduction is modest, with spontaneous resolution over time.
- **Medication removed from the blood stream.** Some medications can be removed from the blood stream by plasmapheresis, especially if they are bound to plasma proteins. It is important to administer such drugs after completion of the procedure to avoid this problem.

CONCLUSION

The hyperviscosity syndrome is an important complication for some patients with Waldenström's macroglobulinemia. It can be easily identified if the symptoms and signs of the disorder are sought and effectively managed using plasmapheresis when indicated. Concomitant chemotherapy may also be important and is usually considered so that the root cause of the problem of IgM production by the lymphoma cells is addressed. Complications of plasmapheresis may occur but are not severe in most cases. The technique can dramatically reduce the symptoms and signs of HVS, reduce clinical risk, and improve wellbeing.

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Dr. D'Sa has worked with patients and colleagues to set up an not-for-profit organization called WMUK (www.wmuk.org.uk), which seeks to bring health professionals and patients closer together in the fight against the rare form of B-cell lymphoma, Waldenström's macroglobulinemia, including the organization of patient seminars for patients from across the UK and beyond. She is a member of the WM Guidelines Writing Group under the auspices of the British Committee for Standards in Haematology.



SINCE SEPTEMBER 2011, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

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In memory of Olga Anderson:

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In memory of Anne Betts:

Terry Betts

In memory of Herbert Bisol:

Iris Park & Rick Kelleher

In memory of Arlou Brahm:

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Audrey Thompson

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Theodore Wadanole
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Louis & Eileen Vogt

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Tom & Anna Mae Quitter

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Bev Anderson

In honor of Tina Ann:

Ingrid Larson

In honor of Deanna Ball:

Mary Lee Ball

In honor of Scott Blazek:

Nick Blazek

In honor of Tom Bommarito:

Debbie & Steve Salek

In honor of Jim Bunton:

John A. Wilson

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In honor of Beverly Dibilio:

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Tuan Nguyen and Heather Weiland Le

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Joel Pollack

In honor of Marci Heller:

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Christy Heron

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In honor of

Trisha Hood's 60th Birthday:

Helen Dickens & Alan Molk
Bonnie Flueger
Judith Haynes
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Thomas Reaster

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Joanne Rifzis

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Eric & Cheryl Terpsma

In honor of Marcia Wierda:

Evelyn Hamberg
Kenneth Wierda



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